

# Insurance Market Issues Workgroup

---

**Tuesday, July 10, 2012**

9:00 a.m.

Room 445 Capitol Building

---

## ENCLOSURES

**Emailed comments regarding selection of Essential Health Benefits Package**

<u>Topic</u>	<u>Number of Responses Enclosed</u>
Acupuncture . . . . .	8
Autism . . . . .	55
Cochlear Implants . . . . .	12
Elemental Formula . . . . .	35
PKU . . . . .	27
Other . . . . .	21

These include suggestions to:

- include diabetes testing and treatment
- cover part-time workers
- cover dental care, including pediatric dental, and basic dental
- provide care and medications for chronic illnesses
- include free vaccinations, cancer screenings, annual physicals, birth control, emergency care, prenatal and delivery care, and screenings appropriate to age, gender, and ethnicity
- cover those with preexisting conditions
- include a full blood panel in conjunction with an annual doctor's visit
- provide consumers with cost and quality data related to plans, providers, and hospitals
- choose an affordable plan (less than \$75/month)
- eliminate the confusion among workers and departments regarding Medicaid disability
- adopt the FEHBP BCBS Basic and Standard options
- cover "E.R. visits with no monetary limits" and "one or two specialist visits a year"
- ensure that "individuals exiting Medicaid and entering the individual market do not face a 'benefit cliff,' which could have the unintended consequence of creating an incentive to stay on Medicaid"



*For further information, please contact Mark Andrews, Cathy Dupont, or RuthAnne Frost at 801-538-1032.*

Prepared by the Office of Legislative Research and General Counsel



---

**From:** Elaine Lu <elaine@luhealthcenter.com>  
**Sent:** Monday, July 02, 2012 1:34 PM  
**To:** Lori Rammell  
**Subject:** Determination of an Essential Health Benefits Package

Dear Mr James Dunnigan;

I have been a health care professional for 39 yrs in the state of Utah.

As a health care professional I would encourage your task force to include the procedure of acupuncture to be a covered benefit under that package when performed by qualified, licensed professionals.

Acupuncture has been a useful adjunct to the treatment of numerous problems such as both acute and chronic pain syndromes, anxiety/depression, post traumatic stress disorders, and even some things such as allergies. The NIH has approved its use for such problems as infertility. Again, I think that it is essential that it be performed by qualified licensed health professionals such as licensed acupuncturists, and medical doctors. It is also a cost effective means of treatment for many illnesses. It is much less costly than procedures such as epidural injections and nerve blocks. It should be considered an intervention to be utilized prior to some more expensive interventions when the safety of the patient allows for such a series of treatments.

Acupuncture is safe as a medical procedure, and has been utilized in Asia for approximately 3000 yrs. It is now recognized world wide as an effective treatment, and when performed by qualified health professionals is extremely safe compared to more invasive procedures.

Thank you for your consideration of this proposal. I would welcome any comments or ideas you may have as well.

Sincerely

Elaine T. Lu PT, MHED, ATP

---

**From:** Bette M.L. Arcaris <chimerican@hotmail.com>  
**Sent:** Monday, July 02, 2012 11:24 AM  
**To:** Lori Rammell  
**Subject:** Comment and statement of health benefits using Acupuncture

To Whom It May Concern:

I would like to take this time and leave my personal opinions and statements about the benefits of Acupuncture. Since I was at the age of 12 years old I have suffered from various things such as depression, anxiety, ADD, and Fibromyalgia amongst other things. Now at the age of 30 by using Acupuncture it has helped with me so much with pain, my adult ADD, depression and anxiety that I do not rely on Western based medications. My body works quite differently than most and I do not respond well to Western based medications. Acupuncture and Chinese herbs have been the only thing to help me and I believe that without Eastern medicine I would not be here today.

I strongly feel that health insurance should offer Acupuncture into their benefits. Chinese medicine has been around for thousands of years and has been more beneficial in my life and I know in others' lives as well. Also Acupuncture costs less than even going to a doctor for a general check up. If insurance covered Acupuncture it would benefit both the patient as well as the insurance company.

Thank you,

Bette Arcaris

---

**From:** Tyehao Lu <tyehao@luhealthcenter.com>  
**Sent:** Monday, July 02, 2012 10:59 AM  
**To:** Lori Rammell  
**Subject:** Comments and Statements for Utah's Essential Health Benefits to include Acupuncture  
**Attachments:** AAAOM\_EHB\_Economic\_Evaluatio.pdf; AAAOM\_EHB\_Letter\_to\_HHS-FINA.pdf;  
AAAOM\_EHB\_Support\_Letters-FI.pdf

To Whom It May Concern:

I am writing in behalf of my self as a Licensed Acupuncturist and for the Utah Acupuncture and Oriental Medicine Association. I am writing in support for acupuncture to be designated as an essential health benefit in the state of Utah.

Acupuncture in Utah has grown and is utilized widely in Utah. It was first regulated in Utah in 1983 from that time until now there are more than 100 Licensed Acupuncturists licensed within the state. There has been an increase of people utilizing acupuncture for many different health conditions ranging from chronic pain to cancer treatments. There are even hospitals in Utah that are now using acupuncture. Such places that have utilized acupuncture include Huntsman Cancer Center, Veterans Memorial, and reports of Primary Children's uses some acupuncture.

Acupuncture is also low cost compared to traditional Western medicine procedures. It can be a stand alone therapy, but also complimentary to conventional treatments. Acupuncture is a scientific proven therapy with modern research to back it up. There are many MDs/DOs who are practicing or including acupuncture as part of their practice. The NIH and WHO also have researched acupuncture to be effective for many health conditions. As a Licensed Acupuncturist in the state I highly recommend acupuncture to be included in the essential health benefits package. It will benefit the public and will also help lower health care costs. By including acupuncture the public people will have greater access to acupuncture treatments and will help people regain their health and wellness.

I am attaching some statements that were given by our national association to the HHS about acupuncture and its economic evaluation and why it should be included within the essential health benefits.

Please let me know if you have any questions or if you want to discuss more about acupuncture and EHB. Thank you very much.

Sincerely,  
Tyehao Lu, L.Ac, MAOM

--  
Tyehao Lu, L.Ac, MAOM  
Master Lu's Health Center  
3220 South State Street  
Salt Lake City, UT 84115  
[www.luhealthcenter.com](http://www.luhealthcenter.com)  
(801) 463-1101



AAAOM. ONE VOICE. ONE MEDICINE. ONE WORLD.

AAAOM  
全美中醫公會

IN HEALTHCARE REFORM

American Association of Acupuncture & Oriental Medicine

P.O. Box 162340 • 909 22nd Street, Sacramento, CA 95816 • Tel: 866-455-7999 or 916-443-4770 www.aaaomonline.org

## Economic Evaluation in Acupuncture: Past and Future

by Michael Jabbour, LAc, MS, Michael T. Sapko, MD, PhD, David W. Miller, MD, LAc, Lucas M. Weiss, MS, and Matthew Gross, MD

**Key Words (MeSH):** acupuncture, acupuncture therapy, complementary therapies, costs and cost analysis, cost-benefit analysis, evidence-based medicine, quality-adjusted life years, quality of life

### Acupuncture's Place in U.S. Healthcare

The National Center for Complementary and Alternative Medicine (NCCAM) defines complementary and alternative medicine (CAM) as "a group of diverse medical and health care systems, practices, and products that are not generally considered to be part of conventional medicine."<sup>1</sup> Nearly 40% of United States citizens use some form of CAM each year<sup>2</sup> and according to the 2007 National Health Interview Survey (NHIS) there were 354 million visits to CAM providers and 835 million CAM purchases. The 2007 out-of-pocket expenditure for CAM in United States was nearly 34 billion dollars.<sup>2</sup> Visits to a health care practitioner of any kind totaled \$61.5 billion, of which, \$11.9 billion was spent on CAM providers such as acupuncturists and chiropractors. Over 3.1 million adults visited an acupuncturist in 2007, a figure that has risen sharply over the past decade; in 1997 there were 27<sup>2</sup> visits to an acupuncturist per 1,000 adults compared to 79.2 visits in 2007.<sup>3</sup> This is due, in part, to successful efforts at regulation and licensing acupuncturists, a movement toward standardization of acupuncture delivery, and increased referrals by MD/DO physicians.<sup>4,5</sup>

### Making Medical Decisions Depends on Perspective

Factors involved in a patient's decision to seek CAM treatments in general and acupuncture specifically are varied and complex.<sup>6</sup> They include a desire to participate in one's own care, dissatisfaction with or ineffectiveness of conventional therapy, a desire to avoid side effects or complications of conventional therapy, and belief in a holistic versus reductionist view of health and disease.<sup>3,6</sup> While reasons that patients choose acupuncture vary, the decision to pay for most or all of the costs without reimbursement strongly suggests that acupuncture is perceived as both valuable and beneficial to consumers.

An insurance company's decision to cover acupuncture (or any treatment) is based on different factors. Insurance companies and health management organizations (HMO) must balance their overall costs with the need to attract and keep customers. The strategies used to determine premium rates and selection of benefits are not publicized but are based on market analyses, actuarial tables, and negotiations with large and medium corporations. Oddly enough, overall patient health may not be the primary determining factor. When this decision process is applied to acupuncture, some insurance companies have determined that paying for visits to an acupuncturist represents a good investment.

Health programs operated on a national level, so called state health programs (not to be confused with individual states within the United States), base funding decisions on a different set of factors. One of the major incentives of federally-operated health care systems is to keep citizens healthy and functional. As national systems operate with a finite pool of resources, maintaining the health of the citizenry must be achieved at a reasonable cost. To achieve this goal, administrators of state health programs rely on economic evaluations of treatments to determine what services should and can be covered. Implicit in this evaluation is the effectiveness of treatment—ineffective treatments are not considered in a cost analysis. Each effective treatment needs to be weighed against its expense. For example, if each citizen has a colonoscopy every month for their entire lives, deaths from colon cancer could be virtually eliminated; however, the direct and indirect costs of this colon cancer screening would be exorbitant and would leave few resources for any other medical intervention. Thus decisions about resource allocation on a national level must balance effective treatments with relative cost.

## Acupuncture Reimbursement by Some Western Countries

Government attitudes toward reimbursement for acupuncture vary. In the United Kingdom, acupuncture is available through the federally funded National Health Service (NHS).<sup>7</sup> Patients obtain acupuncture referrals from their general practitioner and about one million people receive acupuncture treatments through the NHS each year. In France, acupuncture is not covered by the federal health care system but its costs are tax deductible, similar to dental care which is tax-deductible for those above the age of 14 and not yet retired.<sup>8</sup> While coverage varies by territory, Health Canada does not cover acupuncture beyond an initial visit; however, many supplemental insurance companies in Canada do cover treatment. A similar situation exists in the United States with an increasing number of health insurance companies covering some of the cost of acupuncture. Medicare does not currently reimburse for acupuncture treatments.

## Performing Economic Evaluations

There are various ways to perform economic evaluations and each method of economic evaluation has advantages and disadvantages.<sup>9</sup> Also, there is significant variation in terminology and definitions across economic papers which complicates both interpretation and generalizability across different populations.<sup>10</sup> The challenges that acupuncture researchers face in conducting clinical trials also exist for those conducting economic evaluations. Many of these challenges, however, exist for researchers in mainstream medicine as well, and efforts are underway to standardize economic evaluations so that they are of maximal usefulness to health policy decision makers.<sup>11</sup>

The simplest form of economic evaluation is the cost-identification study (CIS). A CIS simply defines the economic outcomes of a particular intervention. A CIS can be a useful tool for framing a larger economic evaluation but rarely serves as a complete cost analysis for a treatment. There are three types of full economic evaluations used in health care economics: namely cost-effectiveness analyses (CEA), cost-benefit analyses (CBA), and cost-utility analyses (CUA). A primer on economic evaluation, particularly as it relates to CAM, is provided by Herman et al.<sup>12</sup>

The National Institute for Health and Clinical Excellence (NICE) is an organization responsible for providing health care guidance to the UK's NHS. NICE states a preference for cost effectiveness studies, specifically CUA, to be reported in terms of a metric called a quality-adjusted life-year (QALY; Table 1). The generally accepted definition of a QALY is how NICE defines it: "a measure of a person's length of life weighted by a valuation of their health-related quality of life (HRQL) over that period." A QALY is the arithmetic product of life expectancy and quality of life. A year of perfect health is worth 1, death is scored as zero, and health states that are considered worse than death may be assigned a negative value. Determining a patient's HRQL can be done with several valid, reliable, and patient-friendly questionnaires such as Short Form (SF-36)<sup>13</sup> and EuroQoL Five Dimensions (EQ-5D is preferred by NICE).<sup>14</sup> In practical terms, one of these questionnaires is completed prior to, during, and after treatment to assess HRQL as perceived by patients. In this way, any change in HRQL that arises from the treatment can be quantified and compared to the effect of a second treatment.

Table 1 - Key Points of a Quality-Adjusted Life-Year or QALY

<p>QALY is the arithmetic product of life expectancy and quality of life</p> <ul style="list-style-type: none"> <li>• A year of perfect health is worth 1</li> <li>• Death is rated as zero</li> <li>• Health states that are considered worse than death may be assigned a value less than zero</li> </ul>	<p>Treatment A provides five years in health state 0.80</p> <p>Treatment B provides five years in health state 0.40</p> <p>Treatment A = (5)(0.80) = 4 QALYs</p> <p>Treatment B = (5)(0.40) = 2 QALYs</p> <p>In five years, Treatment A provides an additional 2 QALYs over Treatment B</p>
<p>There are several instruments used to assess QALY like EuroQoL (EQ-5D) and the Short-Form 36 (SF-36)</p> <p>QALY is a useful measure for comparing the health benefits of treatments in terms of cost per QALY</p> <p>Commonly used figures for cost per QALY are \$50,000/QALY in the US and £30,000/QALY in the UK<sup>55</sup></p> <p>QALYs can be used in costutility studies to define a costutility ratio</p>	
<p>Cost-Utility Ratio</p> $\frac{\text{Cost of Treatment A} - \text{Cost of Treatment B}}{\text{Number of QALYs from Treatment A} - \text{Number of QALYs from Treatment B}}$	

The other part of a CUA is to determine the costs for the treatment. For a basic analysis, an accounting of most costs is straightforward. Costs of acupuncture might include a measurement of the combined costs of the acupuncturist's time, needles, and herbs while the same analysis applied to conventional medicine could include costs of physician's time, diagnostic tests, test interpretation, medications and/or surgery. In addition to direct and indirect costs, proper economic evaluations of acupuncture should attempt to include intangible costs such as pain and suffering. Intangible costs can be more difficult to quantify than direct and indirect costs, but these costs can be particularly important to capture when studying acupuncture interventions.

## Economic Analysis in Acupuncture

Determining health outcomes in terms of QALYs has several major advantages, especially for the field of acupuncture. QALYs and CUA are becoming the standard means of discussing health outcomes as laid out by NICE. This metric provides health care policy makers with a tool to determine the **value** of a particular treatment. By constructing acupuncture trials in terms of QALYs, insurance companies and federal organizations have useful information in an easily comparable format. HRQL questionnaires provide specific benefits of acupuncture since they offer a scientifically reliable way of quantifying effects of treatment.<sup>13</sup> This provides a solution for not only some of the barriers to acupuncture research in general<sup>15</sup>, but also the hurdles that acupuncture faces as it seeks to justify costs alongside other forms of health care.

Perhaps the clearest example of how a demonstration of cost utility affects health care policy decisions at a national level comes from a series of studies performed in Germany, specifically the Acupuncture Randomized Trials (ART),<sup>16-18</sup> the Acupuncture in Routine Care (ARC) studies,<sup>19</sup> and the German Acupuncture trials (GERAC).<sup>20-23</sup> These large clinical trials not only demonstrated the benefit of acupuncture in various disease states, but showed them to have an acceptable cost-utility in terms of cost per QALY as long as the rate of an acupuncture session does not exceed €35 (roughly \$50).<sup>24</sup> In April 2006, Germany's social health insurance funds began normal reimbursements for acupuncture treatment of chronic low back pain and osteoarthritis of the knee.

## Effectiveness of Acupuncture

Any discussion of the economic impact of an intervention, especially when considering it for inclusion/exclusion in a national health system, must begin by demonstrating that intervention's benefits to health. According to NCCAM, CAM includes therapies that have not yet been shown to be safe or effective in large, scientific trials. NCCAM acknowledges, however, that there are different amounts and levels of scientific evidence to support various CAM therapies. While it is true that acupuncture has not yet been demonstrated in Western scientific literature as effective in the treatment of all medical diseases and disorders, extensive research has demonstrated the benefits of acupuncture for various illnesses. Systematic reviews of the use of acupuncture have shown a significant benefit in many medical conditions including neck disorders,<sup>25</sup> migraine,<sup>26</sup> tension headache,<sup>27</sup> and postoperative nausea and vomiting<sup>28</sup> among others. Apart from these disease states, hundreds of small studies in the literature have shown acupuncture's benefit. As acupuncture researchers continue the current trend of performing high quality clinical trials, other roles for acupuncture, as adjunct or replacement for conventional health care, will likely emerge.

## Methods

Searches were conducted between May and August 2009 using the search terms: complementary alternative medicine, complementary, alternative, acupuncture, cost-effective, and economic. Searches were conducted on Medline, PubMed, and Web of Science. Some relevant studies were found by alternate methods including NIH and NHS documents on CAM and through the bibliographies of published studies. Acupuncture treatments that involved needling, electroacupuncture, laser acupuncture, and/or acupressure were considered. In some studies, acupuncture needling may have been administered with adjunctive interventions such as moxabustion, cupping, life skills education, etc. For purposes of evaluating the status of economic evaluation in the literature, the definition of cost studies in this study was fairly broad. All acupuncture studies that discussed cost, regardless of payer perspective or type of economic analysis, were included. Studies that did not discuss cost were excluded.

## Results

### The Value of Acupuncture

Superficially, the cost of acupuncture should be relatively low when compared to conventional medicine. Modern conventional medicine is based on the results of numerous diagnostic tests, branded pharmaceuticals, and surgical and non-surgical procedures, which are often expensive. In contrast, the cost of acupuncture treatment supplies is relatively small and typically included in the overhead costs of the acupuncturist's practice. While there may be notable exceptions,<sup>29</sup> most acupuncture practitioners spend nearly an hour with each patient per visit. Since the average time that an MD/DO physician spends with patients is less than 20 minutes<sup>30, 31</sup> the relative costs of acupuncture treatment time must be considered.

Economic studies of acupuncture date back to the mid-1990s (Table 2). They have included CIS, CBA, CUA and CEA evaluations and have covered a wide range of disease states or symptoms. In one of the earliest studies of acupuncture economics, Paul Downey reported results of 50 consecutive patients who presented for a surgery and, if suitable for acupuncture treatment based on a physician's determination and their willingness to try the therapy, were given acupuncture.<sup>32</sup> The conditions treated varied widely since consecutive patients were enrolled, regardless of diagnosis. Eighty percent of the participants reported symptom improvement and over half rated their symptom relief as good or excellent. Ten cases had a complete resolution of symptoms. Downey then asked the question, "What other treatment would have been offered to this patient if I had not used acupuncture?" He determined that the cost savings were on the order of £12 per patient in the study. The study is admirable, in that acupuncture was studied in a way that is similar to the way that acupuncture is practiced: unrestricted and based on the acupuncturists' assessment. No limitations were placed on which acupuncture points were used or what components of acupuncture could be used in the trial. It also compared acupuncture to conventional care across many different diagnoses. As an economic evaluation, however, the Downey study is of limited usefulness for several reasons, not the least of which is its lack of randomization. All participants were asked if they wished to participate, which introduces a selection bias to the group.

In the late 1990s, Steven Lindall followed 65 patients with pain, mostly of musculoskeletal origin, and offered them acupuncture for pain control as an alternative to outpatient referral.<sup>33</sup> Over three quarters of the participants responded to acupuncture treatment, and, based on these results, the author determined that UK's NHS saved approximately £232 per patient. This study was small and not controlled, but it was one of the earliest indications that acupuncture may offer a cost savings over traditional therapies. Also not included in the estimation of conventional care was the cost of medications, often a considerable expense when dealing with pain management issues.

Table 2 – Cost Studies and Economic Evaluations in Acupuncture

Study	Disease/Symptom	Cost Analysis	Study Design	Participants	Cost outcome of acupuncture
Ballegaard 1999 <sup>34</sup>	Angina	CBA	Open, Prospective	105 patients	Cost savings over 5 years were \$32,000 per patient
Ballegaard 2004 <sup>35</sup>	Angina	CBA	Retrospective, Nonrandomized	168 consecutive patients who had clinical angina and proven ischemia	Cost savings over 3 years were \$36,000 for surgical and \$22,000 for nonsurgical patients
Branco 1999 <sup>36</sup>	Carpal Tunnel	CEA	Open treatment, not controlled	36 hands in 31 patients	Average cost savings of \$11,000 per patient
Downey 1995 <sup>32</sup>	Various	CBA	Case studies	50 consecutive patients	Cost savings of £12 per patient over 50 patients
Humaidan 2004 <sup>46</sup>	Oocyte Retrieval	CEA	Randomized, Prospective	200 patients	Cost savings of €1.35 per patient
Liguori 2000 <sup>32</sup>	Migraine	CEA	Randomized, Prospective	120 patients	Cost savings of 1,332,000 Italian Liras (obsolete) per patient; Roughly 700 Euros
Lindall 1999 <sup>33</sup>	Various	CIS	Not random or controlled	65 patients	Cost savings of £232 per patient
Naeser 2002 <sup>53</sup>	Carpal Tunnel	CEA	Double-blind, placebo controlled RCT	11 patients who failed standard medical/surgical treatment	Approximately \$4,000 cost savings per patient
Paterson 2003 <sup>54</sup>	Dyspepsia	CEA	RCT, Open	60 people with dyspepsia for not less than 2 weeks	Increased cost of £11.61 per patient over 6 months
Ratcliffe 2006 <sup>40</sup>	Back Pain	CUA	Pragmatic, RCT	241 adults with non-specific low back pain of 1 to 12 months duration in 2:1 ratio of acupuncture to control	ICER of 0.012 QALY (1 yr) ICER of 0.027 QALY (2 yr) £4241 per QALY (SF-36) £3598 per QALY (EQ-5D)
Reinhold 2008 <sup>43</sup>	Arthritis	CUA	RCT	489 patients to receive immediate or delayed acupuncture	ICER of €17,845 per QALY gained
Spira 2008 <sup>45</sup>	Various	CBA-CEA	Case studies, Open	500 patients	Cost savings of \$3,956 per avoidance 1 hospital day
Willich 2006 <sup>41</sup>	Neck Pain	CUA	RCT	3,451 patients; 1,753 acupuncture, 1,698 control	ICER of €12,469 per QALY gained
Witt 2006 <sup>44</sup>	Back Pain	CUA	Both RCT and nonrandomized	11,630 patients; 1,549 randomized to acu, 1,544 randomized to ctrl; 8,537 not randomized	ICER of €10,526 per QALY gained
Witt 2008 <sup>38</sup>	Headache	CUA	RCT	3182 patients 1613 acupuncture; 1569 controls	ICER of €11 657 per QALY gained
Witt 2008 <sup>44</sup>	Dysmenorrhea	CUA	Both RCT and nonrandomized	649 women; 201 randomized	ICER of €3,011 per QALY gained
Witt 2009 <sup>42</sup>	Allergic Rhinitis	CUA	RCT, open	981 patients	ICER = €17,377 per QALY €10,155 for women €44,871 for men
Wonderling 2004 <sup>37</sup>	Headache	CUA	RCT	401 patients	0.021 QALY for one year, £9180 per QALY gained

Abbreviations: CBA – Cost-benefit analysis; CEA – Cost-effectiveness analysis; CIS – Cost-identification study; CUA – Cost-utility study; EQ-5D – EuroQoL 5 Dimensions; ICER – incremental cost-effectiveness ratio; RCT – Randomized, controlled trial; SF-36 – Short Form 36; QALY – quality-adjusted life-year

In that same decade, Ballegaard and colleagues performed an open, prospective study on 105 patients with angina pectoris.<sup>34</sup> Seventy-three patients were candidates for invasive treatment while the others were excluded from invasive treatment for various health reasons. A cost savings of around \$30,000 was calculated for each patient enrolled in the study. This cost savings was mainly attributed to a reduction in hospitalization and surgery. The Ballegaard study in 1999 is important since it is the first full economic evaluation of acupuncture including not only measure of cost and benefit, but also HRQL measures. In 2004, Ballegaard and coworkers reported results from cardiac patients that were too ill to undergo conventional interventions, and, again, acupuncture (combined with stress management techniques, lifestyle adjustments and Chinese health philosophy) was effective and saved tens of thousands of dollars on average.<sup>35</sup>

Around the same time, Branco and colleagues showed that needle or laser acupuncture not only provided effective pain relief to patients with carpal tunnel syndrome (in 33/36 hands), but, resulted in a cost savings of around \$10,000 per case, which combines cost estimates of approximately \$5,000 for those that do not need surgery and \$20,000 for those patients that do require surgical release of the carpal tunnel.<sup>36</sup>

Headache, whether of migraine or tension-type, is also effectively treated with acupuncture and has been the focus of several cost-effectiveness studies. Vickers, Wonderling, and coauthors performed a randomized, controlled trial looking at the use of acupuncture on chronic headache, mostly migraine-type.<sup>37</sup> The trial randomly assigned 401 patients to receive either acupuncture or conventional care over a three month period. Patients in the acupuncture group could receive up to 12 acupuncture visits over that three month period. The main outcomes were headache score and HRQL as assessed by SF-36. At twelve months, the headache score was lower in the acupuncture group versus standard care, and patients undergoing acupuncture treatment experienced 22 fewer days of headache per year than subjects in the control group. Acupuncture-treated subjects used 15% less medication, took 15% fewer sick days from work, and consulted a general practitioner 25% less often than controls.

During the first year of this study, acupuncture led to a mean increase of 0.021 QALYs translating to a base-case estimate of nearly £9180 per QALY gained. The cost per QALY is the amount that would be required to achieve a year of perfect health. Commonly used figures for the maximum acceptable cost per QALY are \$50,000/QALY in the US and £30,000/QALY in the UK.<sup>38</sup> While the cost of acupuncture was slightly more than conventional treatment, Wonderling et al. suggest that if medical decision makers are willing to pay up to £30,000 per QALY (and perhaps less) then acupuncture is a cost effective intervention for chronic headache.<sup>37</sup> Similar results were obtained by Witt and coauthors.<sup>38</sup> This analysis examined outcomes of over three thousand patients and found that while the cost of acupuncture does exceed conventional care, the incremental cost-effectiveness ratio of acupuncture treatment was nearly €12,000 per QALY gained.

Low back pain is another symptom in which the scientific literature supports the use of acupuncture.<sup>39,19</sup> Ratcliffe and colleagues performed a full CEA of a randomized, controlled trial including 241 adults with non-specific low back pain.<sup>40</sup> In this study, two thirds of participants received individualized acupuncture (along with traditional Chinese medicine) and the rest received usual care. As with chronic headache, acupuncture was slightly more expensive than the usual care group, however the mean incremental health gain was 0.012 QALYs at one year and 0.027 QALYS at two years with a base case estimate of £4241 per QALY gained. The authors concluded that acupuncture provides a modest health benefit for a minor extra cost in persistent low back pain.<sup>40</sup> This work was echoed by Witt and colleagues who studied over 11,000 patients with back pain.<sup>19</sup> It is interesting to note that many participants refused to be randomized fearing they may be assigned to the group not receiving acupuncture, thus a portion of the participants were not randomized. Considering only those subjects that were randomized, back function was significantly better in the acupuncture group versus control and HRQL was rated higher in the randomized acupuncture arm. Results from non-randomized subjects were similar. Based on these results, the incremental cost-effectiveness ratio was €10,526 per QALY.

Acupuncture appears to be cost-effective in neck pain as well. Willich and colleagues randomized nearly 3,500 patients with neck pain of over six months duration to receive acupuncture or delayed acupuncture treatment for three months (control group).<sup>41</sup> They used a HRQL scale, SF-36, at baseline and at intervals. Subjects were not restricted from accessing the German health system for primary care during this period. As with other disease states, acupuncture was more expensive than not performing acupuncture due to the cost of the treatments themselves; the incremental cost-effectiveness ratio (ICER) was €12,469 per QALY gained. This same group looked at allergic rhinitis<sup>42</sup> and found acupuncture to be cost effective in women (€10,155 per QALY), but less so for men (€44,871 per QALY). This gender specificity was also seen when this group considered the cost effectiveness of osteoarthritis of the knee.<sup>43</sup> Reinhold and colleagues concluded that acupuncture is both effective and cost effective, though more so for women. In a study of women with dysmenorrhea, this same group found a good clinical benefit for acupuncture and an exceptionally low ICER of €3,011 per QALY.<sup>44</sup> It should be noted that acupuncture is primarily performed by physicians in Germany. Physician-performed acupuncture may raise the overall cost of the intervention compared to countries in which acupuncture is performed by licensed, non-physician practitioners.

A particularly intriguing study performed by Commander Alan Spira demonstrates the effectiveness and cost-benefit of acupuncture within the United States military.<sup>45</sup> Spira studied 500 sailors that were deployed to Iraq in 2006-7, and all care was performed by board-certified physicians and/or board-certified acupuncturists depending on the treatment arm of the study. Patients were offered acupuncture instead of or in addition to conventional medical care. Acupuncture was delivered as some combination of needle acupuncture, electroacupuncture, moxibustion and other treatments common to traditional Chinese medicine. A total of 435 acupuncture treatments were administered to 132 patients for a variety of acute and chronic illnesses and injuries. Orthopedic complaints were by far the most common symptom treated and usually ailments of the back or spine.

Treatment outcomes were divided into three categories: significant improvement, improvement, or no improvement. Significant improvement was defined as a patient requiring fewer than three treatments, or one who experienced a greater than 50% decrease in symptoms based on a subjective measure. Less than 20% of patients receiving acupuncture experienced no benefit at all across all ailments treated, while over half of individuals reported significant benefit from acupuncture treatment. Also interesting in this study was the high acceptance rate of acupuncture as a treatment modality among US service personnel. This is especially true among patients who faced daily use of pain or anti-inflammatory drugs.

What makes this study so compelling, beyond the general effectiveness of acupuncture in overseas military personnel, is the discussion of cost. In Spira's study, the cost of raw materials used in acupuncture was nominal—about 10 cents per single-use, sterile acupuncture needle. The cost of long-term analgesics, whether ibuprofen or COX-2 inhibitors, outweighs the acupuncture costs considerably. When added to the costs associated with treating side effects of medicinal therapy, the cost benefit ratio is largely in favor of acupuncture. Spira found that if one hospital day was avoided by the use of acupuncture, the cost savings would be \$3,956 per patient. Unfortunately, this evaluation does not include the cost of the acupuncturist's time which, in effect, overestimates the cost savings.

Care must be taken, however, to draw proper conclusions from the collected data. Humaidan and Stener-Victorin examined the role of electroacupuncture as a replacement for conventional medical analgesia in oocyte retrieval, a part of *in vitro* fertilization.<sup>46</sup> Patients in both trial arms received paracervical nerve blocks. The authors conclude that electroacupuncture provided cost superiority over conventional analgesia. A careful examination of the study shows that patients undergoing electroacupuncture experienced significantly more pain immediately after the ovum retrieval than those receiving drugs. The cost savings of acupuncture was roughly €1.35 per patient. Overstating the effects of a treatment, whether direct benefits or cost, undermines the scientific validity of the endeavor and the field as a whole.

Many studies that have performed economic evaluations of acupuncture were designed to assess acupuncture as an adjunct to conventional therapy. While acupuncture has been shown to be cost-effective under these conditions, it is possible that when evaluated as an alternative to more costly interventions, the increased benefit for acupuncture in terms of cost may become more obvious. Bonafede and coworkers recently published a study in which they examined insurance claims data of 1,688 eligible acupuncture users and compared them with every 18th non-eligible user (16,282 subjects). Acupuncture was found to be a statistically significant substitute for primary care, outpatient services, pathology, surgery and medications to treat gastrointestinal disorders.<sup>47</sup> The conclusion made by the authors is that acupuncture is an economical substitute for some medical services and pharmaceuticals. It also suggests that spending on acupuncture may be offset by reductions in other medical costs. It is precisely questions such as these that can be answered through careful clinical trial design and economic evaluation.

## Conclusions

Both conventional medicine and CAM are being called upon to demonstrate benefit and justify costs.<sup>48</sup> In this "justify or die" climate of modern medicine, acupuncture researchers face several hurdles in conducting cost analysis work in CAM<sup>12</sup> that are indicative of challenges in CAM research in general.<sup>15</sup> While it is impossible to place a value on human life, there are ways to determine how much a particular treatment costs and psychometric instruments to estimate health and well-being. Acupuncture patients have traditionally paid for treatments and other services mostly out-of-pocket; however, as the United States moves toward a federally-supported system of health care, discretionary spending for health care may fall as the overall tax burden increases. Therefore it is incumbent upon all fields of health care, especially CAM providers and acupuncturists, to justify their role in health care delivery.

This economic justification does not need to be exceedingly difficult, nor must it conflict with the traditions or practice of acupuncture. Just as clinical trials in acupuncture have improved over the last two decades, so have economic evaluations of acupuncture. While there are many hurdles to performing solid clinical and economic studies of acupuncture, researchers have identified many vehicles to overcoming these challenges.<sup>49,15</sup> With each high quality clinical trial performed in acupuncture, an economic evaluation should be performed in tandem. One straightforward enhancement that can be made to future clinical trials in acupuncture is the simple inclusion of a HRQL questionnaire like SF-36 or EQ-5D. These measures are negligibly more difficult to implement and score than tasks already performed in any other high quality clinical trial. For acupuncture studies, it is useful to include not only the costs of treatment but also indirect costs and intangible costs as outlined by Herman et al.<sup>12</sup> In order to make generalizations from studies it is necessary to obtain results from heterogeneous, randomized, matched populations. While there are some technical considerations in studies on acupuncture, it is certainly possible to design studies that accommodate these issues.<sup>50, 51</sup>

Other countries, including Western European countries, have managed to integrate acupuncture into the existing conventional system of medicine. In fact, some nations are providing reimbursements through state health programs. This trend toward greater and more widespread reimbursement is likely to continue as more and better economic evaluations in acupuncture are performed. Acupuncture is a safe and effective modality when performed by qualified practitioners and has the capacity to offer cost-effective treatment to society even when compared to conventional medicine; however, a common language must be adopted, one that decision makers understand.

## Acknowledgments

The authors wish to thank Patricia M. Herman, ND, PhD, Richard Harris, PhD, Rosa Schnyer, DAOM, LAc, Steven Schram, DC, LAc, PhD, and Bill Reddy, LAc for their careful review and thoughtful consideration of this manuscript. Thanks are also due to Rhonda Wilbur, LAc, MS for her work as contributor.

This work was supported by the Acupuncture Society of New York Research Team and the American Association of Acupuncture and Oriental Medicine National Government Affairs Committee, including Misha R. Cohen, OMD, PhD and Sydney Dugan.

## References

1. NCCAM. What Is Complementary and Alternative Medicine? National Center for Complementary and Alternative Medicine. [Online] [Cited: August 24, 2009.] <http://nccam.nih.gov/health/whatiscam/>.
2. Nahin, RL, Barnes, PM, Stussman, BJ, Bloom, B. Costs of Complementary and Alternative Medicine (CAM) and Frequency of Visits to CAM Practitioners: United States, 2007. National Health Statistics Reports. Hyattsville, MD 2009. no. 18.
3. Wolsko PM, Eisenberg DM, Davis RB, Ettner SL, Phillips RS. Insurance coverage, medical conditions, and visits to alternative medicine providers: Results of a national survey. *Arch Intern Med.* 2002 162(3):281-7.
4. Astin JA, Marie A, Pelletier KR, Hansen E, Haskell WL. A review of the incorporation of complementary and alternative medicine by mainstream physicians. *Arch Intern Med.* 1998;158(21):2303-10
5. Wahner-Roedler DL, Vincent A, Elkin PL, Loehrer LL, Cha SS, Bauer BA. Physicians' attitudes toward complementary and alternative medicine and their knowledge of specific therapies: a survey at an academic medical center. *Evid Based Complement Alternat Med.* 2006;3(4):495-501.
6. Astin, JA. Why patients use alternative medicine: results of a national study. *JAMA.* 1998;279(19):1548-53.
7. National Health Service. Who can use acupuncture. [Online] [Cited: August 18, 2009.] <http://www.nhs.uk/Conditions/Acupuncture/Pages/Who-can-use-it.aspx>.
8. Centre des Liaisons Européennes et Internationales de Sécurité Sociale. Le régime saint-marinais de sécurité sociale. le CLEISS. [Online] [Cited: August 18, 2009.] [http://www.cleiss.fr/docs/regimes/regime\\_sanmarin.html](http://www.cleiss.fr/docs/regimes/regime_sanmarin.html).
9. Hutubessy R, Chisholm, D and Edejer, TT. Generalized cost-effectiveness analysis for national-level priority-setting in the health sector. *Cost Eff Resour Alloc.* 2003;1(1):8.
10. Sculpher MJ, Pang FS, Manca A, et al. Generalisability in economic evaluation studies in healthcare: a review and case studies. *Health Technol Assess.* 2004;8(49):iii-iv, 1-192.
11. Murray CJ, Evans DB, Acharya A, Baltussen RM. Development of WHO guidelines on generalized cost-effectiveness analysis. *Health Econ.* 2000;9(3):235-51. Review
12. Herman, PM, Craig, BM and Caspi, O. Is complementary and alternative medicine (CAM) cost-effective? A systematic review. *BMC Complement Altern Med.* 2005;5:11.
13. Brazier JE, Harper R, Jones NM, et al. Validating the SF-36 health survey questionnaire: new outcome measure for primary care. *BMJ.* 1992;305(6846):160-4.
14. EuroQol Group. EQ-5D. [Online] [Cited: August 25, 2009.] <http://www.euroqol.org/>.
15. Nahin, RL and Straus, SE. Research into complementary and alternative medicine: problems and potential. *BMJ.* 2001;322(7279):161-4.
16. Linde K, Streng A, Jürgens S, et al. Acupuncture for patients with migraine: a randomized controlled trial. *JAMA.* 2005;293(17):2118-25.
17. Melchart D, Streng A, Hoppe A, et al. Acupuncture in patients with tension-type headache: randomized controlled trial. *BMJ.* 2005 Aug 13;331(7513):376-82.
18. Witt C, Brinkhaus B, Jena S, et al. Acupuncture in patients with osteoarthritis of the knee: a randomized trial. *Lancet.* 2005;366(9480):136-43.
19. Witt CM, Jena S, Selim D, Brinkhaus B, Reinhold T, Wruck K, et al. Pragmatic randomized trial evaluating the clinical and economic effectiveness of acupuncture for chronic low back pain. *Am J Epidemiol.* 2006;164(5):487-96.
20. Endres HG, Böwing G, Diener HC, et al. Acupuncture for tension-type headache: a multicentre, sham-controlled, patient-and observer-blinded, randomised trial. *J Headache Pain.* 2007;8(5):306-14.
21. Haake M, Müller HH, Schade-Brittinger C, et al. German Acupuncture Trials (GERAC) for chronic low back pain: randomized, multicenter, blinded, parallel-group trial with 3 groups. *Arch Intern Med.* 2007;167(17):1892-8.
22. Diener HC, Kronfeld K, Boewing G, et al. Efficacy of acupuncture for the prophylaxis of migraine: a multicentre randomised controlled clinical trial. *Lancet Neurol.* 2006;5(4):310-6.
23. Acupuncture and knee osteoarthritis: a three-armed randomized trial. Scharf, HP, et al. 1, 2006, *Ann Intern Med*, Vol. 145, pp. 12-20.
24. Cummings, M. Modellvorhaben Akupunktur - a summary of the ART, ARC and GERAC trials *Acupunct Med.* 2009;27(1):26-30.
25. Trinh KV, Graham N, Gross AR, et al. Acupuncture for neck disorders. *Cochrane Database Syst Rev.* 2006;3:CD004870.
26. Linde K, Allais G, Brinkhaus B, Manheimer E, Vickers A, White AR. Acupuncture for migraine prophylaxis. *Cochrane Database Syst Rev.* 2009;(1):CD001218.
27. Linde K, Allais G, Brinkhaus B, Manheimer E, Vickers A, White AR. Acupuncture for tension-type headache. *Cochrane Database Syst Rev.* 2009;(1):CD007587.
28. Ezzo J, Richardson MA, Vickers A, et al. Acupuncture-point stimulation for chemotherapy-induced nausea or vomiting. *Cochrane Database Syst Rev.* 2006;(2):CD002285.
29. Teig S, Peacock S, Stevens L, Tordoff K, Maguire E, Watson P. An audit of self acupuncture for chronic musculoskeletal pain. *Acupunct Med.* 2006;24(2):80-6.
30. Gilchrist V, Miller RS, Gillanders WR, et al. Does family practice at residency teaching sites reflect community practice? *J Fam Pract.* 1993 Dec;37(6):555-63.
31. Mechanic, D, McAlpine, DD and Rosenthal, M. Are patients' office visits with physicians getting shorter? *N Engl J Med.* 2001;344:198-204.
32. Downey, P. Acupuncture in the normal general practice consultation: an assessment of clinical and cost effectiveness. *BMJ.* 1995;13:45-7.
33. Lindall, S. Is Acupuncture for Pain Relief in General Practice Cost-Effective? *Acupuncture in Medicine.* 1999;17:97-100.
34. Ballegaard S, Johannessen A, Karpatschof B, Nyboe J. Addition of Acupuncture and Self-Care Education in the Treatment of Patients with Severe Angina Pectoris May be Cost Beneficial: An Open, Prospective Study. *J Altern Complement Med.* 1999;5:405-13.
35. Ballegaard S, Borg E, Karpatschof B, Nyboe J, Johannessen A. Long-Term Effects of Integrated Rehabilitation in Patients with advanced angina pectoris: a nonrandomized comparative study. *J Altern Complement Med.* 2004;10(5):777-83.
36. Branco K, Naeser MA. Carpal tunnel syndrome: clinical outcome after low-level laser acupuncture, microamps transcutaneous electrical nerve stimulation, and other alternative therapies--an open protocol study. *J Altern Complement Med.* 1999;5(1):5-26.
37. Wonderling D, Vickers AJ, Grieve R, McCahey R. Cost effectiveness analysis of a randomised trial of acupuncture for chronic headache in primary care. *BMJ.* 2004;328(7442):747.
38. Witt CM, Reinhold T, Jena S, Brinkhaus B, Willich SN. Cost-effectiveness of acupuncture treatment in patients with headache. *Cephalalgia.* 2008;28(4):334-45.
39. MacPherson H, Thorpe L, Thomas K, Campbell M. Acupuncture for low back pain: traditional diagnosis and treatment of 148 patients in a clinical trial. *Complement Ther Med.* 2004;12(1):38-44.
40. Ratcliffe J, Thomas KJ, MacPherson H, Brazier J. A randomised controlled trial of acupuncture care for persistent low back pain: cost effectiveness analysis. *BMJ.* 2006;333(7569):626.
41. Willich SN, Reinhold T, Selim D, Jena S, Brinkhaus B, Witt CM. Cost-effectiveness of acupuncture treatment in patients with chronic neck pain. *Pain.* 2006;125(1-2):107-13.
42. Witt CM, Reinhold T, Jena S, Brinkhaus B, Willich SN. Cost-effectiveness of acupuncture in women and men with allergic rhinitis: a randomized controlled study in usual care. *Am J Epidemiol.* 2009;169(5):562-71.
43. Reinhold T, Witt CM, Jena S, Brinkhaus B, Willich SN. Quality of life and cost-effectiveness of acupuncture treatment in patients with osteoarthritis pain. *Eur J Health Econ.* 2008;9(3):209-19.
44. Witt CM, Reinhold T, Brinkhaus B, Roll S, Jena S, Willich SN. Acupuncture in patients with dysmenorrhea: a randomized study on clinical effectiveness and cost-effectiveness in usual care. *Am J Obstet Gynecol.* 2008;198(2):166.e1-8.
45. Spira, A. Acupuncture: a useful tool for health care in an operational medicine environment. *Mil Med.* 2008;173(7):629-34.
46. Humaidan, F and Stener-Victorin, E. Pain relief during oocyte retrieval with a new short duration electro-acupuncture technique--an alternative to conventional analgesic methods. *Hum Reprod.* 2004;19(6):1367-72.
47. Bonafede M, Dick A, Noyes K, Klein JD, Brown T. The effect of acupuncture utilization on healthcare utilization. *Med Care.* 2008;46(1):41-8.
48. Kernick, DP. The impact of health economics on healthcare delivery. A primary care perspective. *Pharmacoeconomics.* 2000;18(4):311-5.
49. White, A, Trinh, K, Hammerschlag, R. Performing systematic reviews of clinical trials of acupuncture: problems and solutions. *Clinical Acupuncture and Oriental Medicine.* 2002;3:26-31.
50. Sherman, KJ and Cherkin, DC. Challenges of acupuncture research: study design considerations. *Clinical Acupuncture and Oriental Medicine,* 2003;3:200-6.
51. White A, Cummings M, Barlas P, et al. Defining an adequate dose of acupuncture using a neurophysiological approach—a narrative review of the literature. *Acupunct Med.* 2008;26(2):111-20.
52. Liguori A, Petti F, Bangrazi A, et al. Comparison of pharmacological treatment versus acupuncture treatment for migraine without aura—analysis of socio-medical parameters. *J Tradit Chin Med.* 2000;20:231-40.
53. Naeser MA, Hahn KA, Lieberman BE, Branco KF. Carpal tunnel syndrome pain treated with low-level laser and microamperes transcutaneous electric nerve stimulation: A controlled study. *Arch Phys Med Rehabil.* 2002;83(7):978-88.
54. Paterson C, Ewings P, Brazier JE, Britten N. Treating dyspepsia with acupuncture and homeopathy: reflections on a pilot study by researchers, practitioners and participants. *Complement Ther Med.* 2003;11(2):78-84.
55. Eichler HG, Kong SX, Gerth WC, Mavros P, Jönsson B. Use of cost-effectiveness analysis in health-care resource allocation decision-making: how are cost-effectiveness thresholds expected to emerge? *Value Health.* 2004;7(5):518-28.

---

Michael Jabbour earned his Master's of Science Degree from Touro College in Traditional Acupuncture and Oriental Medicine. In addition to acupuncture research and Chinese medical text translation, he is an active speaker on issues of technology, medicine, and politics pertaining to traditional Chinese medicine. Mr. Jabbour is one of the founding directors of the New York State Acupuncture Coalition and the current president of the Acupuncture Society of New York (ASNY). He maintains a private practice in acupuncture and herbology in midtown Manhattan.

---

Michael Todd Sapko received his PhD (neuroscience) and MD degrees from the University of Maryland in completion of a dual MD/PhD physician scientist training program. He has completed research fellowships from the Howard Hughes Medical Institute, National Institute of Mental Health, and National Institute of Neurological Disorders and Stroke. In 2006, Dr. Sapko completed an internship in Internal Medicine at Mercy Medical Center in Baltimore, Maryland and is currently a medical and research consultant in private practice.

---

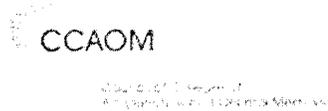
Dr. David W. Miller, MD, LAc received his undergraduate degree in Theoretical Mathematics from Vassar College, his MD from the Brown University School of Medicine, and completed his internship and residency in Pediatrics at the University of Chicago. He is currently an instructor at the Pacific College of Oriental Medicine in Chicago and is in private practice with East-West Integrated Medicine. Dr. Miller is also president of the Illinois Acupuncture Federation and a Board member of the Illinois Association for Acupuncture and Oriental Medicine.

---

Lucas M. Weiss received an MS from Swedish Institute in Acupuncture. His focus is classical Chinese medicine and Chinese medical text translation. Mr. Weiss is currently enrolled at Columbia University, earning an MA in Chinese History.

---

Matthew F. Gross earned an MD degree from the University of Illinois at Chicago and completed residencies in Pediatrics at University of California San Diego Hospital and Pediatric Critical Care Fellowship at Children's Hospital and Health Center in San Diego. He is board certified in pediatrics and pediatric critical care. Dr. Gross is active in both clinical and research endeavors. He is currently the director of the Pediatric Critical Care Division at Riverside County Regional Medical Center.



American Association of Acupuncture  
and Oriental Medicine  
PO Box 96503 PMB 93504  
Washington, D.C. 20090-6503  
866-455-7999 | info@aaaomonline.org

January 31, 2012

The Honorable Secretary Kathleen Sebelius  
U.S. Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Ave., SW – Room 120F  
Washington, DC 20201

Re: Essential Health Benefits Bulletin Released December 16, 2011

Dear Secretary Sebelius:

On behalf of the acupuncture and Oriental medicine (AOM) community, the American Association of Acupuncture and Oriental Medicine (AAAOM), the Council of Colleges of Acupuncture and Oriental Medicine (CCAOM) and the National Certification Commission for Acupuncture and Oriental Medicine (NCCAOM<sup>®</sup>) appreciate the opportunity to comment on the Essential Health Benefits Bulletin released by the United States Department of Health and Human Services (HHS) on December 16, 2011.

The AAAOM, formed in 1981, is the sole professional organization for licensed acupuncturists in the United States (US); representing the interests of individual practitioners, their small businesses, physicians, health care professionals, patients and state professional associations. Enclosed is the AAAOM position statement and rationale<sup>1</sup> **in support of the designation of acupuncture services as an essential health benefit.** This position paper is endorsed by the CCAOM<sup>2</sup>, an organization representing 51 AOM colleges approved by the Accreditation Commission for Acupuncture and Oriental Medicine (ACAOM), the national accrediting agency recognized by the US Department of Education for AOM colleges; and the NCCAOM<sup>®3</sup>, the nationally recognized certification body in the US, representing over 17,000 licensed acupuncturists that have acquired Diplomate status. Collectively, our organizations represent the interests of over 29,000 licensed acupuncturists and nearly 6,000 students, as well as the millions of patients who seek out acupuncture services.

Since the start of its regulation in 1974, patient utilization of acupuncture as part of their overall health care has risen considerably every year<sup>4</sup>; between the 2002 and 2007 National Health Interview Surveys<sup>5</sup>, acupuncture use among adults increased by approximately 1 million people. Acupuncture continues to spark significant public demand as a result of high patient satisfaction, positive clinical outcomes, physician

referrals and cost-effectiveness<sup>6</sup>. Acupuncture has been found to be highly effective in several medical conditions, including the management of chronic pain<sup>7,8</sup>, increasing conception rates in couples experiencing infertility<sup>9</sup>, in controlling chemotherapy-induced nausea and vomiting<sup>7,10</sup> and in the treatment of migraine headaches<sup>11,12</sup>, to name a few. Acupuncture is a low-tech, non-invasive and cost-effective system of care with an excellent record of success and unparalleled safety record. The practice of acupuncture is standardized, licensed and currently regulated in 44 states, plus the District of Columbia; with legislation pending in five of the six remaining states.

For a particular service to be eligible for inclusion as an Essential Health Benefit (EHB), the Institute of Medicine (IOM) criteria state that it must (1) be safe, (2) be medically effective, (3) demonstrate meaningful improvement, (4) be a medical service and (5) be cost effective. As documented in the enclosed position statement by the AAAOM, acupuncture fits all of the above criteria for an eligible EHB service, and has demonstrated meaningful improvement in outcomes over current effective services and treatments for conditions in at least five of the ten general categories of health care outlined by HHS and IOM. Additionally of note, acupuncture delivery of care models improve access to care for a diversity of cultures within the US.

The Affordable Care Act (ACA), and its provisions establishing state health exchanges and prohibiting discrimination against licensed health care providers<sup>13</sup>, holds tremendous potential to improve the lives of Americans and to reduce health care costs by providing services that are both effective and focused on preventive care. The inclusion of acupuncture services within this purview is pivotal to achieving the stated goals of the ACA. In addition, the ACA's emphasis on patient choice and access to care, as elucidated in section 2706 on non-discrimination<sup>13</sup>, will benefit the most vulnerable, who historically cannot afford or access proper health care. The undersigned support HHS's determination to engage the states in establishing their own benchmarks under the ACA. Furthermore, we strongly encourage the setting of a default national benchmark plan that includes acupuncture as an essential health care service. Considering the existing variability in each state, one way to ensure a high level of uniform quality of care is to base the default benchmark plan for state exchanges on the Federal Employee Health Benefits (FEHB) program.

Federal health benefits, especially the FEHB program (the largest employer-sponsored health insurance program in the world), are cited as consumer friendly and cost-efficient, and are often held up as a model of the good employee coverage that should be available to all Americans. All federal employee health plans include coverage for some acupuncture services; evidencing support by the US government for acupuncture as an accepted and standard treatment of care. This recognition points to one of the many

reasons that acupuncture services should be considered by HHS to be part of the defined EHB.

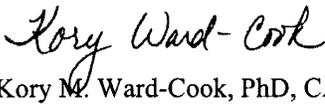
Since AAAOM's position paper was first published weeks ago, tens of thousands of acupuncture patients across the US have expressed a desire to send comments to HHS urging support for inclusion of acupuncture services as part of the EHB. On behalf of those patients who have benefited from acupuncture services and have yet to provide comments and share their compelling stories, we request that HHS extend its public comment period. Given the substantive complexity of this critical issue, we feel the current response deadline is unreasonably short for all citizen stakeholders throughout the country to have an adequate opportunity to comment.

Our organizations welcome the chance to work with HHS on including acupuncture services in the EHB package and stand ready to educate and assist in the implementation of the state health exchanges. On behalf of the AOM profession and the patients it services, we thank you for the opportunity to comment on this important matter.

Sincerely,

  
Jeannie Kang, MS, LAc  
President, AAAOM

  
Lixin Huang, MS  
President, CCAOM

  
Kory M. Ward-Cook, PhD, CAE  
Chief Executive Officer, NCCAOM

CC: Herb Schultz, Regional Director of Region IX, HHS  
Representative Judy Chu

---

<sup>1</sup> The PDF is accessible online at [aaaomonline.org](http://aaaomonline.org) or <http://goo.gl/SkuBq> [ENCLOSED]

<sup>2</sup> Council of Colleges of Acupuncture and Oriental Medicine: [ccaom.org](http://ccaom.org)

<sup>3</sup> National Certification Commission for Acupuncture and Oriental Medicine: [nccaom.org](http://nccaom.org)

<sup>4</sup> Barnes P. & Bloom B. (2008, December 10). Complementary and alternative medicine use among adults and children: United States, 2007. *National Center for Complementary and Alternative Medicine*. Retrieved January 27, 2012, from <http://nccam.nih.gov/news/2008/nhsr12.pdf>

<sup>5</sup> Barnes P.M., Powell-Griner E., McFann K. & Nahin R.L. (2004). Complementary and alternative medicine use among adults: United States, 2002. *CDC Advance Data Report #343*.

<sup>6</sup> Jabbour, M., Sapko, M.T., Miller, D.W., Weiss, L.M. & Gross, M. (2009). Economic evaluation in acupuncture: Past and future. *American Acupuncturist*, 49, 11. [ENCLOSED]

---

<sup>7</sup> Ezzo J., Vickers A.J., Richardson M.A., Allen C., Dibble S.L., Issell B.,...Zhang, G. (2006). Acupuncture-point stimulation for chemotherapy-induced nausea and vomiting. *Cochrane Database Syst Rev*, (2)..

<sup>8</sup> Hopton A. & MacPherson H. (2010, March-April). Acupuncture for chronic pain: Is acupuncture more than an effective placebo? A systematic review of pooled data from meta-analyses. *Pain Pract*, 10(2):94-102.

<sup>9</sup> Franconi G., Manni L., Aloe L., Mazzilli F., Giambalvo Dal Ben G., Lenzi A., & Fabbri A.J. (2011, April). Acupuncture in clinical and experimental reproductive medicine: a review. *Endocrinol Invest*, 34(4), 307-311.

<sup>10</sup> Chao L.F., Zhang A.L., Liu H.E., Cheng M.H., Lam H.B. & Lo S.K. (2009, November). The efficacy of acupoint stimulation for the management of therapy-related adverse events in patients with breast cancer: a systematic review. *Breast Cancer Res Treat*, 18(2), 255-267.

<sup>11</sup> Linde K., Allais G., Brinkhaus B., Manheimer E., Vickers A. & White A.R. (2009, January). Acupuncture for migraine prophylaxis. *Cochrane Database Syst Rev*. 21;(1)..

<sup>12</sup> Li Y., Zheng H., Witt C.M., Roll S., Yu S.G., Yan J.,...Liang F.R. (2012, January).Acupuncture for migraine prophylaxis: A randomized controlled trial. *Canadian Medical Association Journal*.

<sup>13</sup> Section 2706. Non-discrimination in health care. *Patient Protection and Affordable Care Act* (Enrolled Bill [Final as Passed Both House and Senate])\_Retrieved January 30, 2012, from <http://www.gpo.gov/fdsys/pkg/BILLS-111hr3590enr/pdf/BILLS-111hr3590enr.pdf>

**Congress of the United States**  
**Washington, DC 20515**

January 18, 2012

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Ave., SW  
Washington, DC 20201

Dear Secretary Sebelius,

Thank you for your work on pushing forward the implementation of the Patient Protection and Affordable Care Act (PPACA). The Essential Health Bulletin (the Bulletin) is a first step in the right direction in defining the essential health benefits. I would like to comment on the Bulletin as you look to finalize essential health benefits guidance.

Under the Department of Health and Human Service's intended approach to the essential health benefits, states will select an existing health plan to serve as the "benchmark" for services included in their health plans. The Bulletin says that states will have ability to choose between four different health insurance plans as a benchmark for their health insurance plans including: 1) one of the three largest federal employee health plan options; 2) one of the three largest small group plans in the state; 3) one of the three largest state employee health plans; and 4) the largest HMO plan offered in the state's commercial market. It should go further in ensuring that states offer the most comprehensive coverage in their state exchanges.

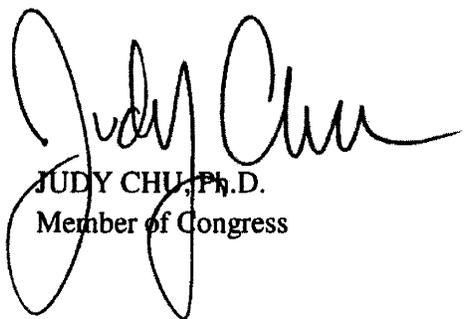
In order to allow for the best possible health plans available, states should be required to use one of the three largest federal health plans and along with another largely used local plan. The principle behind healthcare reform is to set high-quality minimum standards that will be accessible to everyone through the state exchanges. Given the variability in every state, the one way to ensure a uniform high stand is to require one of the benchmarks for state exchanges to be based on the Federal Employee Health Benefits (FEHB) program. Federal health benefits, especially the FEHB program, are cited as being consumer friendly and being cost-efficient. FEHB covers nine million people and is currently the largest employer sponsored health insurance program in the world. Federal employee health plans are often held up as a model of the good employee coverage that should be available to all Americans. In fact, some legislators suggested during the debate on health reform for all Americans to have access to the FEHB.

All federal employee health plans include some coverage for acupuncture proving that acupuncture is widely recognized as an accepted and standard treatment. Therefore it should be included as a part of the defined Essential Health Benefits. As you are already aware, I am a strong advocate for the inclusion of acupuncture in the essential health benefits. Acupuncture is one of the most cost-effective treatments available for chronic ailments and it has developed a tremendous following. In certain medical situations, from end of life care to chemotherapy to child birth, it can replace pain medications and surgeries saving costs and resources with no side effects to patients. Additionally acupuncture is effective, is non-invasive, has minimal side effects and is efficient.

Acupuncture is also very cost effective. For example, carpal tunnel syndrome (CTS), a common ailment that frequently forces workers to lose time from work, can be effectively treated with acupuncture. One case of CTS in 2002 without surgical intervention would cost an estimated \$5,246 versus an estimated \$1,000 in acupuncture treatments (based on 15 visits at \$65 per visit). This is a cost-savings of approximately \$4,000. There are also few side effects and there is no risk of interaction with other medicines as may occur with other types of treatments.

As you make the final determination about essential health benefits coverage under the PPACA, I ask you to revisit the use of benchmarks and require all states use of one of the top three federal health plans for the state and another widely used local plan as the benchmarks for states health insurance plans. I also urge you to include acupuncture as part of the essential health benefits. I appreciate the attention you and your staff has paid to this issues to date, and should you have any questions, please do not hesitate to contact my staff Moh Sharma at 202-225-5464 or moh.sharma@mail.house.gov  
Thank you for your consideration.

Sincerely,



JUDY CHU, Ph.D.  
Member of Congress

CC: Herb Schultz, Regional Director of Region IX, HHS



4380 Harlan, Suite 203 Wheat Ridge, CO 80033  
303-572-8744 Fax 303-422-1377  
Email: [info@acucol.com](mailto:info@acucol.com)

January 28, 2012

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Dear Secretary Sebelius,

On behalf of the Acupuncture Association of Colorado, I fully endorse and fully support the American Association of Acupuncture and Oriental Medicine's position and rationale on the designation of acupuncture services as an Essential Health Benefit.

Acupuncture is an incredibly effective and cost efficient way to serve the citizens of this great country. And with over 800 active Licensed Acupuncturists in the state of Colorado, the Acupuncture Association of Colorado feels strongly about supporting the HHS's intended approach of having states select an existing health plan to serve as the benchmark for services in each state's health plan.

With this letter, the Acupuncture Association of Colorado respectfully asks to include acupuncture as an Essential Health Benefit service.

Sincerely,

Greg Shim, L.Ac., M.Ed., MTCM, Dipl. OM.  
President



January 27, 2012

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Ave., SW  
Washington, DC 20201

Dear Secretary Sebelius,

I am writing to you as the president of Acupuncture Society of New York (ASNY) in response to the HHS call for comments on EHB inclusion issued on Dec 16, 2011. In NY, acupuncture has been recognized through licensure since 1975 and the Acupuncture Society of New York (ASNY) has represented the interests of nearly 3000 licensed acupuncturists in NY since 1991.

My comments are in regards to the Department of Health and Human Service's proposed approach to the determination of the essential health benefits packages, in which states will select an existing health plan to serve as the "benchmark" for services included in their health plans. The Bulletin says that states will have ability to choose between four different health insurance plans as a benchmark for their health insurance plans including: 1) one of the three largest federal employee health plan options; 2) one of the three largest small group plans in the state; 3) one of the three largest state employee health plans; and 4) the largest HMO plan offered in the state's commercial market. It should go further in ensuring that states offer the most comprehensive coverage in their state exchanges.

In order to allow for the best possible health plans available, ASNY recommends that one of the benchmarks for state exchanges to be based on the Federal Employee Health Benefits (FEHB) program. Federal health benefits, especially the FEHB program, are cited as being consumer friendly and being cost-efficient.

FEHB covers nine million people and is currently the largest employer sponsored health insurance program in the world. Federal employee health plans are often held up as a model of the good employee coverage that should be available to all Americans. In fact, some legislators suggested during the debate on health reform for all Americans to have access to the FEHB.

Our national organization, the AAAOM has written a position paper and rationale on this issue and it is attached along with an economic analysis. Acupuncture is one of the most cost-effective treatments available for chronic ailments and it has developed a tremendous following. In some medical situations, from end of life care to chemotherapy to childbirth, it can reduce or replace pain medications and surgeries saving costs and resources with no adverse effects to patients.

Thank you for your consideration.

Sincerely,



James Shinol

ASNY President



## American Traditional Chinese Medicine Society

美国中医药针灸学会

14 East 34<sup>th</sup> St, 5<sup>th</sup> Fl, New York, NY 10016, USA Tel 212 689-1773 Fax 212 689-1898

Date: January 29, 2012

To: The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independent Ave., SW  
Washington, DC 20201

Dear Secretary Sebelius,

On behalf of American Traditional Chinese Medicine Society (ATCMS), I am writing to you in response to HHS call for comments on EHB inclusion issued on Dec 16, 2011. In NY, acupuncture has been recognized through licensure since 1975 and the American Traditional Chinese Medicine Society has represented the interests of 700 licensed acupuncturists in the Great New York area since 2007.

My comments are in regards to the Department of Health and Human Services' proposed approach to the determination of the essential health benefits packages, in which states will select an existing health plan to serve as the "benchmark" for services included in their health plans. The Bulletin says that states will have ability to choose between four different health insurance plans as a benchmark for their health insurance plans including: 1) one of the three largest federal employee health plan options; 2) one of the three largest small group plans in the state; 3) one of the three largest state employee health plans, and 4) the largest HMO plan offered in the state's commercial market. It should go further in ensuring that states offer the most comprehensive coverage in their state exchange.

In order to allow for the best possible health plans available, ATCMS recommends that one of the benchmarks for state exchanges to be based on the Federal Employee Health Benefits (FEHB). Federal health benefits, especially the FEHB program, are cited as being consumer friendly and being cost-efficient. FEHB covers nine million people and is currently the largest employer sponsored health insurance program in the world. Federal employee health plans are often held up as a model of the good employee coverage that should be available to all Americans. In fact, some legislators suggested during the debate on health reform for all Americans to have access to the FEHB.

Acupuncture is one of the most cost-effective treatments available for chronic ailments and it has developed a tremendous following. In some medical situations, from end of life care to chemotherapy to childbirth, it can reduce or replace pain medications and surgeries saving costs and resources with no adverse effects to patients.

Thank you for your consideration!

Sincerely,

Ling Zheng, L.Ac.  
Secretary-in-General  
American Traditional Chinese Medicine Society (ATCMS)  
Email: [lingzheng62@yahoo.com](mailto:lingzheng62@yahoo.com)

---

[www.ATCMS.org](http://www.ATCMS.org) [AmerianTCMSociety@gmail.com](mailto:AmerianTCMSociety@gmail.com)

*The Most Active TCM Society in the East of America*



## Acupuncture Society of Virginia

January 27, 2012

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Ave., SW  
Washington, DC 20201

Dear Secretary Sebelius,

Thank you for your work on pushing forward the implementation of the Patient Protection and Affordable Care Act (PPACA). The Essential Health Bulletin (the Bulletin) is a first step in the right direction in defining the essential health benefits. I would like to comment on the Bulletin as you look to finalize essential health benefits guidance.

Under the Department of Health and Human Service's intended approach to the essential health benefits, states will select an existing health plan to serve as the "benchmark" for services included in their health plans. The Bulletin says that states will have ability to choose between four different health insurance plans as a benchmark for their health insurance plans including: 1) one of the three largest federal employee health plan options; 2) one of the three largest small group plans in the state; 3) one of the three largest state employee health plans; and 4) the largest HMO plan offered in the state's commercial market. It should go further in ensuring that states offer the most comprehensive coverage in their state exchanges.

In order to allow for the best possible health plans available, states should be required to use one of the three largest federal health plans and along with another largely used local plan. The principle behind healthcare reform is to set high-quality minimum standards that will be accessible to everyone through the state exchanges. Given the variability in every state, the one way to ensure a uniform high stand is to require one of the benchmarks for state exchanges to be based on the Federal Employee Health Benefits (FEHB) program. Federal health benefits, especially the FEHB program, are cited as being consumer friendly and being cost-efficient. FEHB covers nine million people and is currently the largest employer sponsored health insurance program in the world. Federal employee health plans are often held up as a model of the good employee coverage that should be available to all Americans. In fact, some legislators suggested during the debate on health reform for all Americans to have access to the FEHB.

All federal employee health plans include some coverage for acupuncture proving that acupuncture is widely recognized as an accepted and standard treatment. Therefore it should be included as a part of the defined Essential Health Benefits. As you are already aware, I am a strong advocate for the inclusion of acupuncture in the essential health benefits. Acupuncture is one of the most cost-effective treatments available for chronic ailments and it has developed a tremendous following. In certain medical situations, from end of life care to chemotherapy to childbirth, it can replace pain medications and surgeries saving costs and resources with no side effects to patients. Additionally acupuncture is effective, minimally-invasive, has few negative side effects and efficient.

Acupuncture is also very cost effective. For example, carpal tunnel syndrome (CTS), a common ailment that frequently forces workers to lose time from work, can be effectively treated with acupuncture. One case of CTS in 2002 without surgical intervention would cost an estimated \$5,246 versus an estimated \$1,000 in acupuncture treatments (based on 15 visits at \$65 per visit). This is a cost-savings of approximately \$4,000. There are also few side effects and there is no risk of interaction with other medicines as may occur with other types of treatments.

As you make the final determination about essential health benefits coverage under the PPACA, I ask you to revisit the use of benchmarks and require all states use of one of the top three federal health plans for the state and another widely used local plan as the benchmarks for states health insurance plans. I also urge you to include acupuncture as part of the essential health benefits. I appreciate the attention you and your staff has paid to this issues to date, and should you have any questions, please do not hesitate to contact Sarah Shupe L.Ac., ASVA Secretary 703-217-7124 or [mail@acusova.com](mailto:mail@acusova.com).

Thank you for your consideration.

Sincerely,

cc: Herb Schultz, Regional Director of Region IX, HHS



**NCAAOM**  
**4822 Six Forks Rd., Ste 202 Raleigh, NC 27609**  
**Phone (919) 788-1568 Fax (919) 788-1569**  
**GINNA BROWNING, LAc, Dipl. OM**  
**NCAAOM President**

January 25, 2012

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Ave., SW  
Washington, DC 20201

Dear Secretary Sebelius,

As President of the North Carolina Association of Acupuncture and Oriental Medicine (NCAAOM), I am writing to you primarily on behalf of our members, but also on behalf of our patients. The NCAAOM represents the interests of over four hundred licensed acupuncturists in the state of North Carolina where acupuncture has been recognized as a licensed healthcare profession since 1993. As such, we also stand for the tens of thousands of patients who have used or would like to use our services as a health sustaining and health improving resource.

This letter is in response to the HHS call for comments regarding the establishment of the Essential Health Benefits plan. The position of the NCAAOM is to support a federal benchmark plan that includes acupuncture. Currently *all* federal employee health plans include some coverage for acupuncture; this clearly indicates that our federal government recognizes that acupuncture is a beneficial treatment. Therefore acupuncture must be included as a part of the defined Essential Health Benefits.

The principle behind healthcare reform is to set high-quality minimum standards that are accessible to everyone via the state exchanges. Given the variability in every state, the one way to ensure a uniform high standard is to require one of the benchmarks for state exchanges to be based on the Federal Employee Health Benefits (FEHB) program. Federal health benefits, especially the FEHB program, are cited as being consumer friendly and being health-cost efficient. FEHB covers nine million people and is currently the largest employer sponsored health insurance program in the world. Federal employee health plans are often held up as a model of good employee coverage that should be available to all Americans.

The NCAAOM endorses the position and rationale of the American Association of Acupuncture and Oriental Medicine (AAAOM). The AAAOM supports designating acupuncture as an Essential Healthcare Benefit (EHB) because:

- *acupuncture is safely and effectively practiced nationally by state licensed and regulated healthcare professionals, trained in institutions accredited by a US Department of Education recognized accreditor;*
- *acupuncture has proven to be a cost and comparatively-effective medical treatment for commonly occurring illnesses as enumerated by the World Health Organization (WHO) and the National Institutes of Health (NIH);*

- *acupuncture is an important aspect of integrative medical care whereby thousands of trained licensed acupuncturists and physicians are practicing acupuncture in clinics, hospitals, universities, veteran care facilities, and military establishments;*
- *acupuncture reimbursement is available through federal, state, and private third party payers for licensed acupuncturists and physicians;*
- *acupuncture has an unparalleled safety record, with far fewer side effects than conventional therapies such as drugs and surgery;*
- *acupuncture is in public demand and there is an established need for increased patient access to care; and*
- *acupuncture meets the EHB criteria and could service, at minimum, five of the EHB categories of care.*

As you make the final determination about essential health benefits coverage under the PPACA, I ask you to revisit the use of benchmarks and require that all states use one of the top three federal health plans along with another widely used local plan as the benchmarks for their state's health insurance plans. I also urge you to include acupuncture as part of the essential health benefits.

Thank you for your consideration.

Sincerely,  
Ginna Browning, L.Ac., M.S.  
President, NCAAM



**New Jersey Association of Acupuncture and Oriental Medicine**

January 26, 2012

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Dear Secretary Sebelius,

I write to you today on behalf of the New Jersey Association of Acupuncture and Oriental Medicine (NJAAOM) representing the patients and practitioners of New Jersey in response to the December 16, 2011 HHS call for comments and your work towards implementing the Patient Protection and Affordable Care Act (PPACA).

Acupuncture is a licensed independent healthcare profession recognized by statute in New Jersey since 1983. Since that time, tens of thousands of New Jersey's almost nine million citizens have benefitted from the medical care we offer. Many insurance companies in New Jersey, including the State employees' benefit program, include acupuncture coverage. That said, countless other New Jersey citizens who remain uninsured or underinsured, do not have access to acupuncture services.

The NJAAOM endorses and supports the American Association of Acupuncture and Oriental Medicine (AAAOM) position and rationale on the designation of acupuncture services as an Essential Health Benefit. Furthermore, we support the HHS intended approach that will have states select an existing health plan to serve as the "benchmark" for services in their health plans.

The NJAAOM firmly supports patient choice and unencumbered access to all licensed healthcare providers. The inclusion of acupuncture as an Essential Health Benefit will be the inclusion of an effective and cost reducing therapy that will benefit countless citizens. As such, we respectfully submit this letter and ask that acupuncture be specifically included as an Essential Health Benefit service.

Sincerely yours,

Candace Sarges M.Ac, L.Ac., Dipl. O.M.  
President

300 Madison Avenue, Suite 102, Madison NJ 07940  
www.njaaom.net (973) 660-0110



January 27, 2012

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Avenue, SW  
Washington DC 20201

Dear Secretary Sebelius,

As President of the New Mexico Society for Acupuncture and Asian Medicine (NMSAAM), I am writing this letter in response to HSS call for comments on December 16, 2011. Our organization represents the current 640 licensed Doctors of Oriental Medicine in the state of New Mexico. Practitioners of Acupuncture and Oriental Medicine have enjoyed licensure within New Mexico's healthcare system since 1979. We write to you to respectfully request that Acupuncture be included in the Patient Protection and Affordable Care Act as an Essential Health Benefit.

Acupuncture is covered under all state based insurance plans in New Mexico. Since 1991, we have had nondiscrimination laws in statute, which has allowed our profession to grow and prosper, bringing much needed care to our medically underserved state. We believe that providing Acupuncture as an Essential Health Benefit will help to bring relief to countless other patients who still have no access to the health benefits our service provides.

This clinically proven, minimally invasive medical intervention serves a minimum of five of the EHB categories of care and should be widely available to the public. As Sec. 2076 of the act clearly states, people should have the right to choose quality care provided by a licensed professional in their state without discrimination.

NMSAAM strongly endorses and supports the American Association of Acupuncture and Oriental Medicine (AAAOM) position and rationale on the designation of acupuncture services as an Essential Health Benefit. We also support the HHS intended approach that will have states select an existing health plan to serve as the "benchmark" which includes Acupuncture.

Respectfully,

Eric Raymond Buckley  
Doctor of Oriental Medicine  
President, New Mexico Society of Acupuncture and Asian Medicine

PO Box 91353, Albuquerque, NM 87199  
[www.nmsaam.org](http://www.nmsaam.org)



28 January 2012

U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington D.C., 20201

To Whom It May Concern:

This letter is written to respond to the Department of Health and Human Services (HHS) December 16, 2011 call for comments. The Oregon Association of Acupuncture and Oriental Medicine (OAAOM) supports the American Association of Acupuncture and Oriental Medicine (AAAOM) position that 1) Acupuncture should be included as an Essential Health benefit (EHB) by HHS under the Affordable Care Act, and, 2) if states are asked to formulate their own packages, they should be specifically directed by HHS to include acupuncture in their Essential Health Benefits Package.

The OAAOM is Oregon's non-profit professional acupuncture association, representing acupuncturists and patients of acupuncture. There are currently 1,225 acupuncturists in Oregon licensed through the Oregon Board of Medical Examiners. Acupuncture has been recognized as an independent licensed healthcare profession in Oregon law since 1983. Numerous insurance companies and managed care organizations cover acupuncture in Oregon. Licensed Acupuncturists in the state work in urban centers and rural settings, in private practice and in integrated healthcare settings. Countless numbers of Oregonians benefit from acupuncture treatment for a broad range of health complaints. Perhaps most significantly, thousands of Oregonians, often through recommendation of medical providers, access acupuncture treatment as a safe, effective therapy for chronic pain.

The OAAOM firmly supports patient choice in health care and unencumbered access to all licensed healthcare providers. The AAAOM Position Paper effectively presents the importance of and the rationale for inclusion of acupuncture as an Essential Health Benefit. Inclusion of acupuncture as an EHB will ensure that patients can continue to access this highly effective medical intervention, despite potential income barriers.

Thank you for your thoughtful consideration.

Sincerely,

Laura E. Ocker, MAcOM, LAc  
President

OAAOM - PO Box 14615 - Portland, OR 97293-0615 - (503) 893-5993 - [info@oaaom.com](mailto:info@oaaom.com)



**South Carolina Oriental Medicine Association**  
1901 Laurens Road, Suite E, Greenville, SC 29607  
Phone: (864) 370-1140 Email: info@sc-oma.org  
<http://www.sc-oma.org>

January 26, 2012

Dear HHS Secretary Kathleen Sebelius,

As President and Founder of the South Carolina Oriental Medicine Association (SC-OMA), which represents the interests of the more than seventy licensed acupuncturists practicing in the state of South Carolina, I'm responding to the Department of Health and Human Service's December 16, 2011 call for comments regarding the scope of Essential Health Benefits (EHB) in the Affordable Care Act (ACA). Specifically, I'm writing on behalf of SC-OMA and all South Carolina acupuncturists to ask that acupuncture be included in the Affordable Care Act as an Essential Health Benefit.

Acupuncture, which has been recognized as a licensed healthcare profession in law since 2005, is a proven, safe and cost-effective component of integrative healthcare for commonly-occurring illnesses, a statement supported by both the World Health Organization and the National Institute of Health.

This clinically-proven and minimally-invasive treatment option is actively sought after by the public at-large. Fair and comprehensive healthcare absolutely necessitates patient choice and access to acupuncture—as the ACA's non-discrimination provisions clearly dictate. Acupuncture meets the EHB criteria and services and, at minimum, serves five of the EHB categories of care and therefore should be available to the public.

I support a federal benchmark for acupuncture based on the federal care plan, and I wholeheartedly endorse the American Association of Acupuncture and Oriental Medicine's (AAAOM's) position and rationale regarding the designation of acupuncture as an EHB. I've included a copy of the AAAOM's position statement and economic evaluation of acupuncture for your review.

Again, please allow me to reiterate on behalf of SC-OMA and South Carolina acupuncturists that acupuncture should be included as an EHB in the ACA. Please feel free to contact me with any questions you may have. Thank you for your time.

Sincerely,

Marina Ponton, DAOM  
President, South Carolina Oriental Medicine Association



January 24, 2012

To Whom It May Concern:

I am writing on behalf of the Texas Association of Acupuncture and Oriental Medicine (TAAOM). The TAAOM is a private sector entity and one of the primary organized bodies of licensed acupuncturists in the state of Texas. As of the fall of 2011, statistics reflect that Texas has over a 1000 licensed acupuncturists with the vast majority of them actively practicing within its borders. Licensed acupuncturists in Texas are required to meet stringent educational requirements and pass nationally recognized examinations of competency. Patients are turning to acupuncture more frequently, and it is rapidly becoming a mainstream option for a broad range of needed healthcare. Consequently, this correspondence is being sent to support a federal benchmark based on a health plan which includes acupuncture. In this regard, the TAAOM is in support of the position recently expressed by the American Association of Acupuncture and Oriental Medicine (AAAOM).

Acupuncturists have been practicing in Texas for more than a century, and in 1993 the Texas State Board of Acupuncture Examiners was established to license acupuncturists as part of the formal recognition and regulation of these dedicated healthcare professionals. The Texas State Board of Acupuncture Examiners works in conjunction with the Texas Medical Board in licensing acupuncturists and overseeing their practice. The Texas Insurance Code also contains provisions to prevent insurance carriers from discriminating against licensed acupuncturists so that insured patients can seek out affordable care from qualified and licensed practitioners. The Texas State Board of Acupuncture Examiners is currently involved in an ongoing effort to educate clinicians and carriers on the broad scope of acupuncture care that is authorized and the appropriate billing codes to be used in order to avoid unnecessary disputes. A position paper is expected to soon be promulgated.

Patient choice and access to acupuncture treatment remain essential linchpins in the evolving healthcare environment. The need for preventative care and minimally invasive treatment options remain important to the citizens of Texas, and the cost-effectiveness of acupuncture promises to bring some measure of relief to a fiscally threatened health care system. Non-discrimination language is a vital component in any health care plan so that acupuncture will remain a reasonable and cost-effective alternative for patients in need. The TAAOM endorses the AAAOM's position on making acupuncture an essential health benefit. Acupuncture and a patient's ability to choose acupuncture should be considered an integral part of any comprehensive healthcare package. We hope you will agree and act accordingly.

Best Regards,

John Paul Liang  
President, Texas Association of Acupuncture and Oriental Medicine

**United Alliance of NYS Licensed Acupuncturists**

纽约州执照针灸医师联合公会

---

41-25 Kissena Blvd, Suite 101E, Flushing, NY 11355 Tel: 212-966-2201  
web :www.acupunctureny.org email:UANYSLA@yahoo.com fax: 212-334-9347

January 29, 2012

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Ave., SW  
Washington, DC 20201

Dear Secretary Sebelius,

I am writing to you as the president of the United Alliance of NYS Licensed Acupuncturists (UANYSLA) and as an Executive Committee Member of both the World Federation of Acupuncture-Moxibustion Societies and the World Federation of Chinese Medicine Societies which are both NGOs in official relationship with the World Health Organization in response to the HHS call for comments on EHB inclusion issued on Dec 16, 2011.

In New York State, acupuncture has been recognized through licensure since 1975. In addition, Acupuncture and Moxibustion of traditional Chinese medicine with a history of over two thousand years of continuous practice, was inscribed in 2010 on the Representative List of the Intangible Cultural Heritage of Humanity by UNESCO, and it is currently widely practiced in China, other regions of Asia, Europe and the Americas.

My comments are in regards to the Department of Health and Human Service's proposed approach to the determination of the essential health benefits packages, in which states will select an existing health plan to serve as the "benchmark" for services included in their health plans. The Bulletin says that states will have the ability to choose between four different health insurance plans as a benchmark for their health insurance plans including: 1) one of the three largest federal employee health plan options; 2) one of the three largest small group plans in the state; 3) one of the three largest state employee health plans; and 4) the largest HMO plan offered in the state's commercial market. It should go further in ensuring that states offer the most comprehensive coverage in their state exchanges.

In order to allow for the best possible health plans available, UANYSLA recommends that one of the benchmarks for state exchanges be based on the Federal Employee Health Benefits (FEHB) program. Federal health benefits, especially the FEHB program, are cited as being consumer friendly and being cost-efficient. FEHB covers nine million people and is currently the largest employer sponsored health insurance program in the world. Federal employee health plans are

**United Alliance of NYS Licensed Acupuncturists**

纽约州执照针灸医师联合公会

---

41-25 Kissena Blvd, Suite 101E, Flushing, NY 11355 Tel: 212-966-2201  
web :[www.acupunctureny.org](http://www.acupunctureny.org) email:[UANYSLA@yahoo.com](mailto:UANYSLA@yahoo.com) fax: 212-334-9347

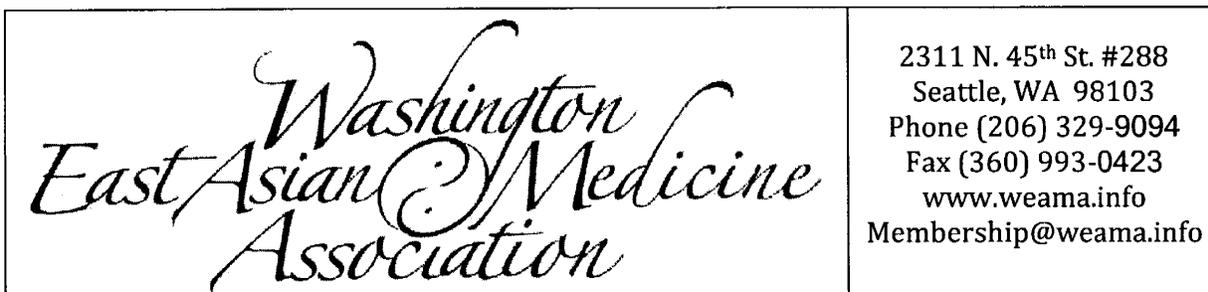
often held up as a model of the good employee coverage that should be available to all Americans. In fact, some legislators suggested during the debate on health reform for all Americans to have access to the FEHB.

Acupuncture is one of the safest and cost-effective treatments available for chronic ailments and it has developed a tremendous following. In some medical situations, from end of life care to chemotherapy to childbirth, it can reduce or replace pain medications and surgeries saving costs and resources with no adverse effects to patients.

Thank you for your consideration.

Sincerely,

Rong Sheng Lin, PhD, OMD,LAc.  
President of UANYSLA  
Executive Committee Member,  
World Federation of Acupuncture-Moxibustion Societies,  
World Federation of Chinese Medicine Societies  
NGOs in official relationship with the World Health Organization



January 28, 2012

The Honorable Kathleen Sebelius, Secretary  
Department of Health and Human Services  
200 Independence Avenue NW  
Washington DC 20201

Dear Secretary Sibelius:

I am writing to you as president of the Washington East Asian Medicine Association (WEAMA) in response to the Department's December 16, 2011 call for comments on determining what elements should be included as "Essential Health Benefits" under the Patient Protection and Affordable Care Act (PPACA).

WEAMA and its predecessor organizations have represented the interests of acupuncturists in Washington State since it began licensing practitioners in 1985. There are presently over 1,200 licensed East Asian Medicine Practitioners/acupuncturists practicing here.

Washington is unusual among states, in that almost all health insurers include acupuncture as a covered benefit. As a result our citizens have reasonably priced access to effective health care, insurers benefit from valuable and cost-effective treatments for their clients, and patients can choose the style of medicine they find most effective.

We believe the non-discrimination clause of the PPACA describes the benefits we enjoy here, and we support your expanding those benefits nationwide. For these reasons we support a benchmark that specifically includes acupuncture as an Essential Health Benefit. The Federal Employee Health Benefits program is frequently cited as another model for patient choice and access for all licensed healthcare providers.

WEAMA endorses and supports the American Association of Acupuncture and Oriental Medicine's position on designating acupuncture as an Essential Health Benefit. It has submitted a paper to you supporting inclusion, which we support.

Including acupuncture as an Essential Health Benefit assures that an effective and cost-reducing therapy will be available to benefit countless citizens of our Nation. We respectfully ask that acupuncture be specifically included as an Essential Health Benefit.

Sincerely,

Curtis Eschels, M.Ac., EAMP  
President



January 27, 2012

To;  
U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

The Wisconsin Society of Certified Acupuncturists Inc.(WISCA) represents the interests of the acupuncturists in the State of Wisconsin. In Wisconsin, acupuncture has been a state certified medical profession since 1989. Acupuncturists have long provided quality health care to the people of Wisconsin. It is important that in this era when acupuncture is provided in some of our top hospitals and to our veterans through the VA medical system, that this system of medicine be an easily available choice for all citizens.

In response to the call for comments by Health And Human Services, WISCA endorses and supports the position of the American Association of Acupuncture and Oriental Medicine, in calling for the inclusion of Acupuncture into the Essential Health Benefits to be included into the Affordable Care Act.

Sincerely,

Cassandra Wind, CAC; MSOM  
President of Wisconsin Society of Certified Acupuncturists  
13620 W. Capitol Drive Suite E  
Brookfield, WI 53005  
262-790-1713

<b>WISCA, INC.</b>	
13620 W. Capitol Dr.	info@acupuncturewisconsin.org
Ste E	www.acupuncturewisconsin.org
Brookfield, WI 53005	
(262) 709-1713	



January 28, 2012

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Bret Moldenhauer  
President:  
Tennessee Acupuncture Council  
325 Market Street Suite 203  
Chattanooga, TN 37402

Dear Secretary Sebelius,

On behalf of the Tennessee Acupuncture Council, I fully endorse and fully support the American Association of Acupuncture and Oriental Medicine's position and rationale on the designation of acupuncture services as an Essential Health Benefit.

Acupuncture is one of the most cost-effective treatments available for chronic ailments and it has developed a tremendous following in some medical situations. From end of life care to chemotherapy to childbirth, it can reduce or replace pain medications and surgeries saving costs and resources with no adverse effects to patients.

Since 2003, Tennessee has made legal and available acupuncture services for the citizens of our state. In Tennessee, acupuncture is considered a branch of medicine which falls directly under the Tennessee Board of Medical Examiners. We are considered a primary care provider and do not require any referral from a medical doctor.

Two of Tennessee's largest teaching hospitals, Vanderbilt Medical Center and the University of Tennessee College of Medicine, have hospital privileges for the acupuncture scope of practice. The Vanderbilt Center for Integrative Medicine is employing acupuncture in a multi-disciplinary approach in treating chronic pain while the University of Tennessee College of Medicine has elective acupuncture clinical training available for second and third year residents.

The Tennessee Acupuncture Council endorses the position of the NCCAOM to support a federal benchmark plan that includes acupuncture. Currently all federal employee health plans include some coverage for acupuncture; this clearly indicates that our federal government recognizes that acupuncture is a beneficial treatment. Having that said, shouldn't all American citizens share equally?

Thank you for your consideration.

Sincerely,

Bret Moldenhauer D. Ac, L.Ac.  
President:  
Tennessee Acupuncture Council

1996



2012



CALIFORNIA  
S T A T E  
O R I E N T A L  
M E D I C A L  
A S S O C I A T I O N

703 Market Street, Suite 250  
San Francisco, CA 94103-2100

Toll-free:  
800.477.4564 [voice/fax]

International:  
415.357.1940 [voice/fax]

info@csomaonline.org [email]  
csomaonline.org [web]

January 27, 2012  
Re: Acupuncture & Essential Health Benefits

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Ave., SW  
Washington, DC 20201

Dear Madam Secretary:

The California State Oriental Medical Association (CSOMA) is California's largest English-language professional association of licensed acupuncturists. CSOMA has represented many of the more than 10,000 acupuncture and Oriental medical providers across the state for more than two decades.

This letter is our response to the Department of Health and Human Services' call for comments regarding its December 16, 2011, Essential Health Benefits (EHB) bulletin.

On behalf of CSOMA's membership and Board of Directors, please note that CSOMA strongly supports the inclusion of acupuncture as an Essential Health Benefit (EHB). Accordingly, we note:

- Acupuncture offers a proven, safe, and cost-effective approach to promoting wellness and treating illness.
- Acupuncture has been a part of health care in California since the mid-1800's and has been a state-recognized health care profession since 1976.
- Acupuncture meets the criteria for EHB services and offers significant value in at least five of the required categories of EHB care.
- HHS should specifically instruct and require states to include access to acupuncture services as part of their EHB mix.

CSOMA supports the EHB position statement produced by our national counterpart—the American Association of Acupuncture and Oriental Medicine (AAAOM).

Sincerely,

William F. Mosca, LAc  
Executive Director & CEO

cc: American Association of Acupuncture and Oriental Medicine



OREGON COLLEGE *of* ORIENTAL MEDICINE  
Office of the President

January 25, 2012

U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

To Whom It May Concern:

This letter is written to respond to the Department of Health and Human Services (HHS) Dec. 16, 2011, call for comments. Oregon College of Oriental Medicine (OCOM) supports the AAAOM position that 1) Acupuncture should be included as an Essential Health Benefit (EHB) by HHS under the Affordable Care Act, and, 2) if states are asked to formulate their own packages, they should be specifically directed by HHS to include acupuncture in their Essential Health Benefits Package.

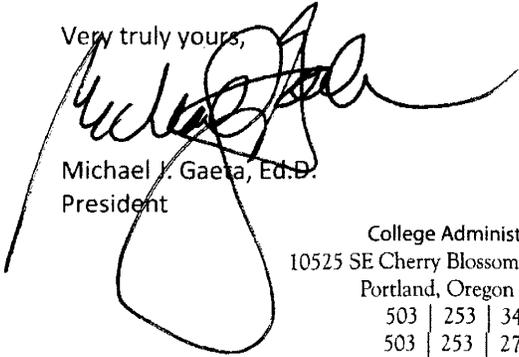
OCOM is one of the oldest and best regarded colleges of Acupuncture and Oriental Medicine in the United States. Since OCOM's inception in 1983, the College has graduated over 1,000 masters students who, as licensed acupuncturists, have provided an estimated 10,000,000+ individual patient treatments throughout the world. OCOM graduates currently practice in 37 states nationwide. OCOM's students under clinical supervision provide 24,000+ treatments to patients in College clinics annually.

OCOM administration, faculty and students actively work with the Oregon Association for Acupuncture and Oriental Medicine (OAAOM) to provide research support for the association's public education and health care public policy efforts. Acupuncture has been recognized as a licensed healthcare profession in Oregon law since 1983.

AAAOM's position paper effectively presents the importance of and rationale for inclusion of acupuncture as an Essential Health Benefit. Clearly, based on well-accepted medical research, Acupuncture provides relatively low cost yet effective medical treatment for many chronic and complex conditions, and especially provides health services to low income individuals and senior citizens who otherwise may not have access to adequate care. Inclusion of acupuncture as an EHB will ensure that patients can continue to choose and have access to this effective medicine.

Thank you for your thoughtful consideration of these comments.

Very truly yours,

  
Michael J. Gaeta, Ed.D.  
President

College Administration  
10525 SE Cherry Blossom Drive  
Portland, Oregon 97216  
503 | 253 | 3443   
503 | 253 | 2701   
[www.ocom.edu](http://www.ocom.edu)

Acupuncture & Herbal Clinic  
10541 SE Cherry Blossom Drive  
Portland, Oregon 97216  
 503 | 253 | 3443  
 503 | 251 | 2092  
[www.ocom.edu](http://www.ocom.edu)

T 512-454-1188  
F 512-454-7001  
4701 West Gate Blvd.  
Austin, TX 78745

www.aoma.edu

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Ave., SW  
Washington, DC 20201

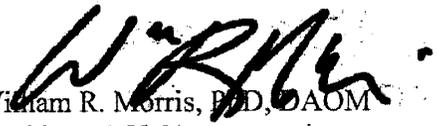
RE: Support for the AAAOM position paper on EHB

Dear Secretary Sebelius,

As President of AOMA Graduate School of Integrative Medicine, I write to you on behalf of our community including students, faculty, staff and patients. More than 40,000 patient visits are seen per year through internships and our professional clinics. These include partnerships with the Seton hospital network and People's Clinic. AOMA is both regionally and programmatically accredited, with more than 200 students in a four entry-level program leading to licensure.

Sovereign nations throughout Asia provide acupuncture in their national healthcare plans, including: China, Japan and Korea. There large-scale studies demonstrating lowered cost of care acupuncture (1-3); such data as this led to the inclusion of acupuncture in the national healthcare plans for certain European nations such as Germany.

Given the safety and efficacy of acupuncture with wide spread public interest and potential for lowering cost of care, it appears that inclusion of acupuncture as an Essential Health Benefit is in the interest of American and its citizens. For these reasons and on behalf of the AOMA community, I endorse the American Association of Acupuncture and Oriental Medicine, call for the inclusion of Acupuncture into the Essential Health Benefits language of the Affordable Care Act.



William R. Morris, PhD, AAOM  
President, AOMA

1. Witt CM, Reinhold T, Jena S, Brinkhaus B, Willich SN. Cost-effectiveness of acupuncture treatment in patients with headache. Cephalalgia. 2008 Apr;28(4):334-45.
2. Ratcliffe J, Thomas KJ, MacPherson H, Brazier J. A randomised controlled trial of acupuncture care for persistent low back pain: cost effectiveness analysis. Bmj. 2006 Sep 23;333(7569):626.
3. Haake M, Muller H-H, Schade-Brittinger C, Basler HD, Schafer H, Maier C, et al. German Acupuncture Trials (GERAC) for Chronic Low Back Pain: Randomized, Multicenter, Blinded, Parallel-Group Trial With 3 Groups. Arch Intern Med. 2007 September 24, 2007;167(17):1892-8



6685 Doubletree Ave. • Columbus, Ohio 43229  
ph 614.825.6255 • fax 614.825.6279 • info@aiam.edu

Dear Secretary Sebelius:

On behalf of the American Institute of Alternative Medicine, I appreciate the opportunity to comment on the Essential Health Benefits Bulletin released by the United States Department of Health and Human Services (HHS) on December 16, 2011.

I co-own the American Institute of Alternative Medicine (AIAM). It is a multi-purpose educational institution and Acupuncture is one of our programs. Since we started our first cohort in 2001, after then-governor George Voinovich legalized the practice of Acupuncture in the State of Ohio, I have personally witnessed the use of acupuncture by many in our Faculty and Intern clinics. It is simply astonishing to see the health benefits that acupuncture yields.

Acupuncture is safe, cost-effective, and has great results for a variety of human ailments. It has been used for thousands of years on billions of people because it works. It should be included as an essential health benefit.

I urge that acupuncture services be included in the in the EHB package.

Thank you,

D. M. Sater  
Chief Executive Officer

**[www.aiam.edu](http://www.aiam.edu)**



FINGER LAKES SCHOOL OF  
**ACUPUNCTURE  
& ORIENTAL MEDICINE**  
of New York Chiropractic College

*Academic Excellence*

January 30, 2012

*Professional Success*

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
200 Independence Ave., SW  
Washington, DC 20201

RE: Support for the AAAOM position paper on EHB

Dear Secretary Sebelius:

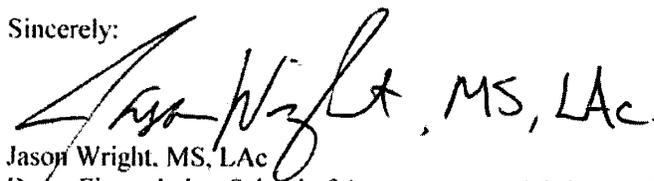
This letter is written to respond to the Department of Health and Human Services (HHS) December 16, 2011 call for comments on Essential Health Benefits. As Dean of the Finger Lakes School of Acupuncture and Oriental Medicine (FLSAOM) of New York Chiropractic College, I write to you on behalf of our community including students, faculty, staff and patients. FLSAOM supports the American Association of Acupuncture and Oriental Medicine (AAAOM) position that 1) acupuncture should be included as an Essential Health Benefit by HHS under the Affordable Care Act, and 2) if states are asked to formulate their own packages, they should be specifically directed by HHS to include acupuncture in their EHB Package.

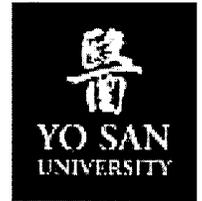
FLSAOM is an accredited acupuncture program within the regionally accredited New York Chiropractic College (NYCC). FLSAOM operates clinics throughout the upstate New York region, including providing services within the Veteran's Administration Hospital system. Founded in 1919, NYCC is recognized as a leading institution for the education and training of integrative and natural healthcare professionals and academicians. In 2003, in recognition of the importance of acupuncture in healthcare, NYCC began offering Master of Science degree programs in Acupuncture and Oriental Medicine and opened the Seneca Falls Health Center, a 19,400 square-foot multidisciplinary, integrated healthcare facility.

The position paper of the AAAOM effectively presents the rationale for, and importance of, inclusion of acupuncture as an Essential Health Benefit. Accepted medical research supports acupuncture as a safe, affordable, and effective medical treatment for a wide array of chronic and complex conditions. With strong public interest and the potential for lowering cost of care, it appears that inclusion of acupuncture as an EHB is in the interest of the American public. For these reasons and on behalf of the FLSAOM community, I endorse the AAAOM's call for the inclusion of acupuncture into the Essential Health Benefits language of the Affordable Care Act.

Thank you for your consideration of these comments.

Sincerely:

  
Jason Wright, MS, LAc  
Dean, Finger Lakes School of Acupuncture and Oriental Medicine of NYCC



January 30, 2012

U. S. Department of Health and Human Services  
200 Independence Avenue. S.W.  
Washington, D. C. 20201  
[EssentialHealthBenefits@cms.hhs.gov](mailto:EssentialHealthBenefits@cms.hhs.gov)

Dear Department Directors and Managers,

This letter is written to respond to the Department of Health and Human Services (HHS) December 15, 2011 call for comments. Yo San University of Traditional Chinese Medicine (YSU) supports the AAAOM position that acupuncture should be included as an Essential Health Benefit (EHB) by HHS under the Affordable Care Act. WE also HHS encourage states to formulate their own packages that include acupuncture in their EHB packages.

Since the founding of Yo San University in 1989 over 300 individuals have graduated and achieved state licensure as acupuncturists. Those graduates have provided approximately one million treatments in areas that cover our entire country. Our own students provide over 21,000 treatments to patients in our on campus and community externship sites each year.

The Yo San University administration, faculty and students are also actively involved in research which adds to the evidence based nature of Traditional Chinese Medicine and acupuncture. We also engage in significant public education efforts to inform diverse individuals and groups regarding wellness and the potential benefits of acupuncture.

The perspective presented in the AAAOM position paper highlights the importance and rationale for inclusion of acupuncture as an Essential Health Benefit. That position is based on well-accepted medical research and demonstrates that acupuncture provides low cost, yet effective medical treatment for many chronic and complex conditions. It has been shown that acupuncture especially provides health services to low income individuals and senior citizens who otherwise may not have access to adequate care. Inclusion of acupuncture as an EHB will ensure that patients can continue to choose and have access to this effective medicine.

Thanks for your consideration.

Sincerely,

Lawrence J, Ryan, Ph.D.  
President

CC: [ehb@aaaomonline.org](mailto:ehb@aaaomonline.org)



January 30, 2012

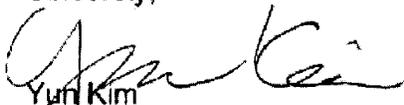
The Honorable Secretary Kathleen Sebelius  
US Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Ave, SW Room 12F  
Washington, DC 2021

Dear Secretary Kathleen Sebelius,

I, on behalf of the students, staff, and faculty, of Emperor's College of Traditional Oriental Medicine, am writing to endorse AAAOM's position on designating acupuncture as an Essential Healthcare Benefit (EHB) under the Affordable Care Act. I am also attaching letters from our College constituents in support of the AAAOM's position.

Emperor's College, founded in 1983, is one of the oldest and most distinguished Oriental medical schools in the country, with over 1,000 alumni practicing nationwide. Our teaching clinic provides over 15,000 acupuncture treatments a year. We also provide acupuncture services at three externship sites in greater Los Angeles: UCLA Health and Wellness Center, Providence/ St. Joseph's Medical Center, and Venice Family Clinic. We strongly believe that acupuncture should be an EHB under the Affordable Care Act. Thank you for your consideration.

Sincerely,

  
Yun Kim  
CEO



Northwestern  
Health Sciences University

January 30, 2012

The Honorable Kathleen Sebelius  
U. S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

To Whom It May Concern:

This letter is in response to the HHS call for comments regarding the establishment of the Essential Health Benefits plan.

As Dean of the College of Acupuncture and Oriental Medicine (CAOM) at Northwestern Health Sciences University, I am submitting this letter on behalf of our college in support of 1) the inclusion of acupuncture services as an Essential Health Benefit (EHB) under the Affordable Care Act and, 2) if states are asked to formulate their own packages, that they should be directed by HHS to include acupuncture services in their respective EHB packages.

Northwestern Health Sciences University, founded in 1941, now offers diverse academic programs in acupuncture and Oriental medicine, chiropractic and massage therapy as well as having a strong clinical research program. From an original 3 students to just under 1,000, Northwestern has grown in size, scope, and influence and produces a high-quality, science-based education that prepares practitioners for the ever-growing field of natural health care. Our 125 CAOM students, in particular, have the opportunity to complete in-patient clinical internships at four local area hospitals, demonstrating both the acceptance of acupuncture by the medical profession, as well as its importance as an Essential Health Benefit.

I have reviewed and support the American Association of Acupuncture and Oriental Medicine (AAAOM) position and rationale paper. This position paper has also been endorsed by the Council of Colleges of Acupuncture and Oriental Medicine (CCAOM) and the National Certification Commission for Acupuncture and Oriental Medicine (NCCAOM).

Thank you for your consideration of these comments.

Sincerely

A handwritten signature in black ink, appearing to read 'Mark S. McKenzie, L.Ac.'.

Mark S. McKenzie, L.Ac.  
Dean, College of Acupuncture and Oriental Medicine  
Northwestern Health Sciences University



**FIVE BRANCHES UNIVERSITY**  
*Graduate School of Traditional Chinese Medicine*

Santa Cruz Campus  
 200 Seventh Avenue  
 Santa Cruz  
 California  
 95062

January 27, 2012

US Dept of Health and Human Services  
 200 Independence Avenue, SW  
 Washington, DC 20201

(831) 476-9424  
 Fax (831) 476-8928  
 Clinic (831) 476-8211

To Whom It May Concern

On behalf of our Board, our 60 staff, 200 faculty and 500 students, Five Branches University supports

1. Including acupuncture as an Essential Health Benefit (EHB) by the HHS under the Affordable Care Act
2. For HHS to guide and direct states to include acupuncture in their Essential Health Benefits
3. offers Nationally accredited

■  
 San Jose Campus  
 3031 Tisch Way  
 Suite 507  
 San Jose  
 California  
 95128  
 (408) 260-0208

Founded in 1984, Five Branches University has campuses in Santa Cruz and San Jose, California and offers Nationally accredited Master's and Doctoral program in Traditional Chinese Medicine which includes acupuncture.

We have over 1500 graduates who practice throughout the US and who treat approximately 15,000 patients a day with acupuncture. These patients appreciate integrative medicine, using Western medicine for emergencies, and relying on acupuncture for regular health care.

For a particular service to be eligible, the IOM criteria state that it must (1) be safe, (2) be medically effective, (3) demonstrate meaningful improvement, (4) be a medical service, and (5) be cost effective.<sup>1</sup>

Fax (408) 261-3166  
 Clinic (408) 260-8868

Acupuncture fits all of the criteria for an eligible EHB service, and has demonstrated meaningful improvement in outcomes over current effective services and treatments.

Yours truly,

\_\_\_\_\_  
 Ron Zaidman, President & CEO

www.fivebranches.edu

<sup>1</sup> Section 1302(b)(2) of the Affordable Care Act.



# Pacific College of Oriental Medicine

January 30, 2012

U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

To Whom It May Concern:

This letter is written to respond to the Department of Health and Human Services (HHS) December 16, 2011, call for comments. Pacific College of Oriental Medicine (PCOM) supports the AAAOM position that 1) Acupuncture should be included as an Essential Health Benefit (EHB) by HHS under the Affordable Care Act, and 2) if states are asked to formulate their own packages, they should be specifically directed by HHS to include acupuncture in the Essential Health Benefits Package.

PCOM administration, faculty and students actively work with the California State Oriental Medicine Association (CSOMA) to provide research support for the association's public education and health care public policy efforts. Acupuncture has been recognized as a licensed healthcare profession in California law since 1975.

AAAOM's position paper effectively presents the importance of and rationale for inclusion of acupuncture as an Essential Health Benefit. Clearly, based on well-accepted medical research, Acupuncture provides relatively low cost yet effective medical treatment for many chronic and complex conditions, and especially provides health services to low income individuals and senior citizens who otherwise may not have access to adequate care. Inclusion of acupuncture as an EHB will ensure that patients can continue to choose and have access to this effective medicine.

Thank you for your thoughtful consideration of these comments.

Very truly yours,

Stacy Gomes, Ed.D  
VP Academic Affairs

 Academy for  
Five Element Acupuncture

January 27, 2012

To Whom It May Concern,

My name is Misti Oxford-Pickeral and I am the Executive Director of Academy for Five Element Acupuncture in Gainesville, Florida. I am writing in response to the Department of Health and Human Services (HHS) December 16, 2011, call for comments. Academy for Five Element Acupuncture (AFEA) supports the AAAOM position that 1) acupuncture should be included as an Essential Health Benefit (EHB) by HHS under the Affordable Care Act, and 2) if states are given the charge of formulating their own packages, they should be specifically directed by HHS to include acupuncture.

Since 1989, AFEA has been educating acupuncture practitioners in the Five Element tradition. Based on our alumni demographics, AFEA represents the interests of acupuncturists in the state of Florida and all over the nation. Currently, we have over 75 students enrolled and since 1991, AFEA has graduated over 350 students. Each year, our students, under clinical supervision, provide over 2000 treatments to patients in our clinic.

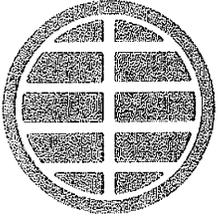
Acupuncture is proven to be an affordable and effective treatment modality, not only for the promotion of health, but also the treatment of chronic and complex conditions. Acupuncture is experiencing an unprecedented period of growth in the United States with more and more people actively choosing acupuncture as an important part of their health care regimen. Protecting and promoting the ability of patients to choose and have access to comprehensive health care, including acupuncture, is critical - as the Affordable Care Act's non-discrimination provisions clearly dictate.

Given the importance of this issue, I encourage you to extend the period for commentary for one month. AFEA supports a federal benchmark for acupuncture based on the federal care plan, and we support the AAAOM's position and rationale regarding the designation of acupuncture as an Essential Health Benefit.

Thank you for your time and consideration.

Sincerely,

Misti Oxford-Pickeral, M.Ac., AP  
Executive Director



January 31, 2012

U.S. Department of Health & Human Services  
200 Independence Avenue, SW  
Washington DC, 20201

Acupuncture &  
Integrative Medicine  
College, Berkeley

Re: Acupuncture in Essential Health Benefits

2550 Shattuck Avenue  
Berkeley, CA 94704-2724

To Whom This May Concern,

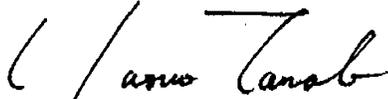
510-666-8248  
www.aimc.edu

The Acupuncture & Integrative Medicine College, Berkeley (AIMC Berkeley) supports the position of the AAAOM that acupuncture be included as and Essential Health Benefit under the Affordable Care Act, and that states should be directed by HHS to include acupuncture in their Essential Health Benefits Packages.

A large part of the mission of AIMC Berkeley is to help facilitate the integration of acupuncture and traditional medicines in to mainstream healthcare. Patients clearly benefit from the effectiveness and relative low cost of acupuncture, as outlined in the AAAOM's position paper. Including acupuncture as an Essential Health Benefit will ensure that most patients will be able to choose and have access to this effective medicine.

Thanks for your thoughtful consideration.

Sincerely,

  
Yasuo Tanaka  
CEO/President

January 30, 2012

U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

To Whom It May Concern:

This letter is to respond to the Department of Health and Human Services December 16, 2011 call for comments. Southwest Acupuncture College supports the AAAOM position that

- 1) Acupuncture should be included as an Essential Health Benefit (EHB) by HHS under the Affordable Care Act (ACA), and
- 2) if states are asked to formulate their own packages, they should be specifically directed by HHS to include acupuncture in the Essential Health Benefits Package.

Southwest Acupuncture College is one of the oldest and most respected colleges of Acupuncture and Oriental medicine in the United States. We have colleges in Santa Fe and Albuquerque, New Mexico, and Boulder, Colorado. Since our inception in 1983, we have graduated over 1100 students who as licensed acupuncturists and Doctors of Oriental Medicine, have performed millions of acupuncture treatments throughout the world. Our graduates currently practice in almost every state. Our student clinics provide 16,000+ treatments to patients annually.

The AAAOM position paper cogently presents the importance and rationale for including acupuncture as an Essential Health Benefit. Acupuncture provides relatively low cost yet effective medical treatment for many chronic and complex conditions. Lack of insurance coverage provides a barrier to patient choice and access. Inclusion of these services meets the ACA standard for a medical benefit as well as the non-discrimination clause, and can ensure that patients can choose to have access to this effective medicine.

Thank you for your thoughtful consideration of these comments.

Sincerely,



Dr. Anthony Abbate, D.O.M.  
President

**ALBUQUERQUE CAMPUS**

7801 Academy, NE †Albuquerque, NM 87109  
Phone 505.888.8898 †Fax 505.888.1380

**BOULDER CAMPUS**

6620 Gunpark Drive †Boulder, CO 80301  
Phone 303.581.9955 †Fax 303.581.9944

---

**From:** dr.frosty@comcast.net  
**Sent:** Tuesday, June 19, 2012 5:22 PM  
**To:** Lori Rammell  
**Subject:** comments from Ogden on hearing from Marianne Frost-Higgins MS, LAc

I would like to propose that acupuncture be included in the insurance plans. It is cost effective for the insurance companies to offer acupuncture for acute and chronic pain conditions, rather than simply prescribe opiates and narcotics that risk addiction. Acupuncture is also very effective in treating drug and alcohol withdrawal, obesity, asthma and a wide range of other chronic conditions. The acupuncture should be covered only if it is provided by LICENSED acupuncturists, who have thousands of hours of training, as opposed to Chiropractors who have lobbied DOPL to allow them to practice acupuncture in this state with only 100-200 hours of training. Acupuncture is a drug-free therapy that works, and since there are so many hundreds of thousands of people dying in this country every year from prescription drug use, it should be made available to everyone.

I am a licensed acupuncturist, but cannot provide acupuncture for PEHP, the states employee health insurance plan. PEHP will only cover acupuncture if it is performed by an MD or a Chiropractor, both of whom have negligible training in this therapy. This is absurd, and points to the fact that lobbyists have too much power to determine healthcare choices in this state. Let's put the people first, not the lobbyists.

---

**From:** Joyce Polster <joyce2polster@gmail.com>  
**Sent:** Monday, June 25, 2012 7:05 PM  
**To:** Lori Rammell  
**Subject:** Acupuncture

I think is is a low cost alternative (vrs surgery) to chronic pain and should be included in Health care plans up to 6 visits and then a review as to its benefits. Personally, I have had relief from chronic tail bone pain which was ongoing for 9 years. After 3 treatments I can say my chronic pain is gone...knock on wood., I don't think it is a 'cure all' for everything and have issues that most acupuncture practices. also deal with non scientific 'drugs' not regulated that have no science back up as far as claims. Please support acupuncture as being included in Utah health plans given number of treatments restrictions.. Thank you, Joyce Polster Carbon county

--  
*Joyce*

---

**From:** Clark and Barbara Warren <cpwnbarb@emerytelcom.net>  
**Sent:** Tuesday, June 26, 2012 2:34 PM  
**To:** Lori Rammell  
**Subject:** Solicited Public Input re:health care benefits

I am writing in reference to the solicited public input Re: what I would like to see included in health care benefits.

I am a strong advocate for acupuncture and I will explain why. About two and a half years ago I suffered severe trauma to my right leg and for a year and a half, I was faithful in seeing Doctors, going to the local hospital wellness center and finally being sent to a neurologist in Provo where I was diagnosed with trauma related neuropathy. I was told there was no cure for my neuropathy and I was given some pain eliminating types of therapy to try and some other things to try to help with the pain and I was also given pain prescriptions to help with the pain at night which was terrible and to continue using a cane to help with walking.

***I was referred to a highly recommended acupuncturist whom I contacted and started treatment with about 10 months ago. I no longer use my cane, walk easily and I am almost pain free. I occasionally use a pain pill. I visit monthly with the acupuncturist and the treatments have helped me greatly.***

*Sincerely,  
Barbara R. Warren  
1556 Mountain States Rd  
Price, UT 84501*

[cpwnbarb@emerytelcom.net](mailto:cpwnbarb@emerytelcom.net)

---

**From:** MARK MONTGOMERY <healingarts@beyondbb.com>  
**Sent:** Tuesday, June 19, 2012 2:34 PM  
**To:** Lori Rammell  
**Subject:** Comments for the Insurance Market Issues Workgroup

To: The honorable members of the Insurance Market Issues Workgroup

Ladies and gentlemen,  
Thank you for taking the time to read my comments.

Below you will find excerpts from reports produced by Kaiser Permanente of Northwest detailing their conclusions on the efficacy of including CAM (complementary and alternative medicine) components, especially acupuncture, into existing and newly structured insurance programs. I hope this information will convince you of the cost-effectiveness of doing something similar here in Utah.

Again, thank you for considering my comments.

Mark Montgomery, Licensed Acupuncturist, President, Utah Association for Acupuncture and Oriental Medicine

*2) According to a recent study proposal published by researchers from the Kaiser Permanente Center for Health Research in Portland, Oregon, with researchers from the Department of Family and Community Medicine at the University of Arizona, "there is a high potential for acupuncture and chiropractic care to provide safe and effective treatment for chronic pain." The authors further state, that "Americans seek CAM treatments far more often for chronic musculoskeletal pain (CMP) than for any other condition. Among CAM treatments for CMP, acupuncture and chiropractic care are among those with the highest acceptance by physician groups and the best evidence to support their use. Further, recent alarming increases in delivery of opioid treatment and surgical interventions for chronic pain-despite their high costs, potential adverse effects, and modest efficacy-suggests the need to evaluate real world outcomes associated with promising non-pharmacological/non-surgical CAM treatments for CMP, which are often well accepted by patients and increasingly used in the community."*[i]

---

[i] DeBar LL, Elder C, Ritenbaug C, Aickin M, Deyo R, Meenan R, Dickerson J, Webster JA, Yarborough BJ. (2011). Acupuncture and chiropractic care for chronic pain in an integrated health plan: a mixed methods study. BMC Complementary and Alternative Medicine 2011, 11:118. Full text retrieved June 10, 2012 from <http://www.biomedcentral.com/1472-6882/11/118>

3) A study published in 2011 by researchers from the Kaiser Permanente Northwest Center for Health Research suggests that group acupuncture clinics within conventional managed care networks may be a feasible model of care and an effective strategy to address chronic pain. The study found that “*chronic pain patients who received acupuncture at KPNW were generally satisfied with the care received and reported improvements in quality of life and pain control.*” Some patients expressed initial reservations about group acupuncture treatments, but once they actually received group acupuncture, they generally responded favorably.<sup>[i]</sup>

---

[i] McCuaig S, Elder C, McMullen C, Weih J. (2011). Feasibility of Group Acupuncture Clinics at a Health Maintenance Organization. *Medical Acupuncture*. Vol 23(2). Link to abstract 6/10/2012 <http://online.liebertpub.com/doi/abs/10.1089/acu.2011.0789>

---

**From:** Lynne Morgan <sunnysaspen@gmail.com>  
**Sent:** Monday, June 18, 2012 8:53 AM  
**To:** Lori Rammell  
**Subject:** Acupuncture as an EHB

Hello,

I would like to express an interest in including Acupuncture, as one of Utah's Essential Health Benefits. I am currently working at the VA hospital in Salt Lake City, treating or soldiers and Veterans with Acupuncture, in a full time clinic. The response has been so well recieved , that I have now created a situation in which I have a wait list of 120 patients, that I can not treat for 4-5 months.

If I were able to suggest to patients that they could seek treatment in the community, and it would be a covered benefit, then that would be a wonderful oppotunity.

I realize that this population has different benefits, but it is an example of the demand that is out there. Acupuncture has been wonderful for reducing chronic and acute pain, anxiety, depression, insomnia, and many, many other health issues.

I hope to be able to attend the various meetings tomorrow regarding EHB, but if not, I hope that you take this into consideration.

Thank you for your time,

Lynne Morgan, RN., L.AC,  
Holistic Medicine department,  
VHA, Salt Lake City, Utah  
801-582-1582 Ext. 2651

--  
lynne



---

**From:** Sarah Daugherty <sarahdorotea@yahoo.com>  
**Sent:** Tuesday, July 03, 2012 1:41 AM  
**To:** Lori Rammell  
**Subject:** Autism therapies MUST be included in insurance packages!

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My 3 year old, Cohen, will be turning 4 in August. He still does not speak. If you are a parent you know how wonderful it is to hear your child's first words. To hear them start to share the things that interest them and tell you funny stories. I don't get to share any of those things with my son. My husband works over 80 hours a week as a chef to provide for us and everything we have goes towards his therapies. But with my husband only making 35K a year we cannot afford much since most of the intensive treatment options cost close to his annual income. Parents NEED this help to help our children!!!!

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Sarah Sargent  
1737 s 300 e  
Salt Lake City, UT 84115  
801-809-3581

---

**From:** Nancy Winn <nhwinn@gmail.com>  
**Sent:** Monday, July 02, 2012 4:04 PM  
**To:** Lori Rammell  
**Subject:** Autism coverage for our Utah autistic community

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Nancy Winn  
4360 S Bench Creek Rd  
Kamas, UT 84036-9653

---

**From:** brittany recalde <brittanyrecalde@gmail.com>  
**Sent:** Sunday, July 01, 2012 11:42 PM  
**To:** Lori Rammell  
**Subject:** Autism benefit coverage

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My husband and I paid out of pocket for these treatments. We took out a second mortgage on our home at a time when our home was worth more. We are now backwards like so many others in our home. We can barely pay our bills and are just scraping by paycheck to paycheck.... The good news is, our daughter benefited incredibly from her treatment. She went from being in special ed classrooms to a regular classroom with 2 years of applied behavior analysis. We took the risk by spending the money we didn't have to pay for her treatment. It paid off for us!!!! It worked! Our daughter is thriving in a regular classroom, with regular friends, doing regular class work. Let's talk now about how much we saved the state over her life time. I believe the studies show that each child that can make these kind of improvements will save the state 3.1 million in disability supports that she would have needed. Your welcome! Unfortunately, I'm still on huge debt for it.....

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being. (funny, I just read the canned message below, it's pretty much what I just said)

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,  
Brittany Recalde  
1066 milky way  
Sandy, UT 84094

Sent from my iPhone

---

**From:** Katrena Lee <ldyvixenne@yahoo.com>  
**Sent:** Sunday, July 01, 2012 11:06 PM  
**To:** Lori Rammell  
**Subject:** essential benefits package

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Katrena Lee  
3178 E 4650 N  
Liberty UT, 84310

---

**From:** Mike Ainsworth <michael.b.ainsworth@gmail.com>  
**Sent:** Sunday, July 01, 2012 10:43 PM  
**To:** Lori Rammell  
**Cc:** Angela Ainsworth  
**Subject:** Autism Insurance Reform

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My son Keith has PDD, an Autism spectrum disorder. We will begin ABA therapy with him this fall and expect to spend approx 30k out-of-pocket this year. This will completely deplete our savings and put us one more hardship away from bankruptcy. For the majority of the families we have met who are struggling with ASD, this treatment is not even an option.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care,

therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Michael Ainsworth  
4756 Farview Lane  
South Jordan, UT. 84095.

-Mike

Sent from my iPhone. Please pardon any typographical errors.

---

**From:** Jerrald Engelson <jhengelson@yahoo.com>  
**Sent:** Monday, July 02, 2012 12:01 AM  
**To:** Lori Rammell  
**Subject:** evidence-based treatment for autism

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My stepson, Jason, is a wonderful, outgoing boy, who although his IQ has been measured at 49, has much to give. With proper treatment, he can learn to become a productive member of society. Supporting people like Jason is a sound investment. Many can learn to hold jobs, pay taxes and otherwise contribute to society.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Jerry Engelson  
13728 S. Manas Way  
Herriman, UT 84096

---

**From:** Gail Johnson <gajohnson@interlinebrands.com>  
**Sent:** Monday, July 02, 2012 12:07 PM  
**To:** Lori Rammell  
**Subject:** Essential Benefits Package

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

**Gail Johnson**  
**Branch Sales Manager/ West Regional Team Lead**  
**Barnett Pro Contractors**  
**Cell 801-502-4011**  
**Fax 856-505-1632**  
**Counter 801-478-1599**  
**Counter fax 801-975-6518**  
<http://www.ebarnett.com/>

Ready To **Organize** Your Shop & Trucks...?  
Ready To **Reduce** Your Inventory Costs...?  
Want to get your trucks to \$1000. per day in sales...?  
**Ask ME How.....**

---

**From:** C <twizzlerr@yahoo.com>  
**Sent:** Monday, July 02, 2012 12:18 PM  
**To:** Lori Rammell  
**Subject:** Essential Autism Project

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I have 2 teenage daughters with Autism. They had no treatments or school accommodations available to them. If they had such treatments, they would function much better, and be better equipped to be on their own as they reach adulthood. As it is now, I believe my oldest will rely on me for the rest of my life; and I worry about what she will do when I am gone. My youngest functions a little better; I believe if I get her set up in a home in an area with good neighbors, she will be ok when I am gone, barring any tragic events in her life. These girls will probably cost society a lot more as adults than the treatments would have cost as children.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,  
Cheryl Harrison  
9270 Solena Way  
Sandy, UT, 84093

---

**From:** Brownmama <brownmomtracy@yahoo.com>  
**Sent:** Sunday, July 01, 2012 10:30 PM  
**To:** Lori Rammell  
**Subject:** Utah Healthcare

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My daughter is 12 YRS old and has Phelan Mcdermid Syndrome, which causes Autism. She has received special care and services since she was 2 1/2 YRS old. It is my hope and desire that you will heed this information when designing a healthcare exemption for our state!

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Tracy L Brown  
PO Box 421  
Santaquin UT, 84655

---

**From:** Debbie Joplin <debbie\_joplin@hotmail.com>  
**Sent:** Sunday, July 01, 2012 10:16 PM  
**To:** Lori Rammell  
**Subject:** Essential Benefits Packate for Utah

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Debbie Joplin  
9488 Wasatch Downs Circle  
South Jordan, UT 84095

---

**From:** Paul Carbone <Paul.Carbone@hsc.utah.edu>  
**Sent:** Sunday, July 01, 2012 9:38 PM  
**To:** Lori Rammell  
**Subject:** essential benefits package input  
**Attachments:** state\_insurance\_ASD.pdf

Dear members of the Health System Task Force,

I would like to ask that you include one of the essential benefits that was passed within the Affordable Care Act:

"Mental health and substance use disorder services, including behavioral health treatment"

The last four words were specifically added to the law to address the issue of autism in the United States. As you know, autism spectrum disorders are common brain-based disorders and Utah has the highest prevalence of these conditions, according to the Centers for Disease Control and Prevention. Autism can be effectively addressed with the use of a specialized type of behavioral therapy, known as Applied Behavioral Analysis. There are now 31 states that have autism insurance mandates that cover these treatments – Utah is not one of them. There are a few things that are known about autism insurance laws that have passed in other states: (1) They do not significantly increase the cost of premiums and (2) they are very effective in decreasing health care related costs to families. I have attached a research article about these mandates for your review. I would be happy to discuss any questions you may have. I am a member of the American Academy of Pediatrics Autism Subcommittee. Our subcommittee has recommended these treatments for children with autism spectrum disorders. Recently, the health care plan for federal employees includes a benefit for Applied Behavioral Analysis because it has been studied and deemed to be a medical treatment for a neurologically based disorder.

Respectfully,

Paul Carbone

**Paul Carbone, MD**

Assistant Professor of Pediatrics

University of Utah, Department of Pediatrics

Phone Numbers:

Neurobehavior HOME Program – 801.581.5515

Child Development Clinic – 801.584.8510

Administrative Office – 801.585.1017



UNIVERSITY OF UTAH  
SCHOOL OF MEDICINE

**CONFIDENTIALITY:** The information in this email and any attachments is confidential. If you are not the intended recipient, you may not and must not read, print, forward, use, or disseminate the information contained herein. If you are not the intended recipient of this message, please reply to the sender and include this message and then delete this message from your inbox and your archive and/or discarded messages files.

**URGENT OR EMERGENCY SITUATIONS:** Emails should not be used for urgent or emergency situations. Risks of using email for healthcare communications include, but are not limited to, delay in receipt or response, unintended disclosure and/or email not reaching intended recipient due to incorrect addressing, unintended forwarding, and third party interception or alteration. University Health Care cannot guarantee that your email will be read or that you will receive a response. If an email requires a response and a response is not received in a reasonable amount of time, it is the patient's responsibility to follow up as needed or appropriate.

## State Insurance Parity Legislation for Autism Services and Family Financial Burden

*Susan Parish, Kathleen Thomas, Roderick Rose, Mona Kilany, and Robert McConville*

### Abstract

We examined the association between states' legislative mandates that private insurance cover autism services and the health care–related financial burden reported by families of children with autism. Child and family data were drawn from the National Survey of Children with Special Health Care Needs ( $N = 2,082$  children with autism). State policy characteristics were taken from public sources. The 3 outcomes were whether a family had any out-of-pocket health care expenditures during the past year for their child with autism, the expenditure amount, and expenditures as a proportion of family income. We modeled the association between states' autism service mandates and families' financial burden, adjusting for child-, family-, and state-level characteristics. Overall, 78% of families with a child with autism reported having any health care expenditures for their child for the prior 12 months. Among these families, 54% reported expenditures of more than \$500, with 34% spending more than 3% of their income. Families living in states that enacted legislation mandating coverage of autism services were 28% less likely to report spending more than \$500 for their children's health care costs, net of child and family characteristics. Families living in states that enacted parity legislation mandating coverage of autism services were 29% less likely to report spending more than \$500 for their children's health care costs, net of child and family characteristics. This study offers preliminary evidence in support of advocates' arguments that requiring private insurers to cover autism services will reduce families' financial burdens associated with their children's health care expenses.

**Key Words:** *autism; family financial burden; state insurance parity*

The evidence that children with autism, whose care needs are complex, require greater health care and ancillary services than other children is extensive (Ganz, 2007; Gurney, McPheeters, & Davis, 2006; Kogan et al., 2008; Mandell, Cao, Ittenbach, & Pinto-Martin, 2006). These substantially elevated health care needs translate into high costs borne by the health care system—both the public Medicaid system that is jointly funded by the states and the federal government (Ganz, 2007; Krauss, Gulley, Sciegaj, & Wells, 2003; Mandell et al., 2006) and, to a lesser extent, even, private insurers (Leslie & Martin, 2007). However, families bear high costs for their children with autism, and families' costs of care for their children with autism are disproportionately higher than those of families raising children with other disabilities or health conditions (Fujiura, Roccoforte, & Braddock, 1994; Jarbrink,

2007; Jarbrink, Fombonne, & Knapp, 2003; Kogan et al., 2008; Wang & Leslie, 2010).

Private insurers have borne more limited health care costs associated with treating children with autism because of patterns of exclusion, in which services that are explicitly intended to treat autism are either limited or denied by a diagnostic exclusion for autism. Peele, Lave, and Kelleher (2002) found pervasive exclusion of care among a wide range of private insurers.

To address both gaps in the receipt of adequate health care and the financial burden borne by families, advocates have pushed for state legislation mandating the coverage of health care and ancillary services for children with autism (Autism Speaks, 2007). The intent of these legislative mandates has been to directly tackle the exclusion of autism services. As of June 2011, 26 states had

enacted some form of insurance reform legislation. This legislation has taken different forms. Parity laws require private health insurers to provide coverage for services required for autism equal to that provided for other kinds of needs. Other legislative mandates require coverage of certain services (e.g., diagnostic, behavioral support) up to prescribed limits.

Little research has examined the impact of these private insurance mandates for autism services. What research has been conducted to date has examined the effect of autism insurance mandates on private insurance premiums. The few studies along this line have found that legislative mandates thus far have not been associated with the catastrophic costs predicted by opponents of the legislation (Bouder, Spielman, & Mandell, 2009; Reinke, 2008).

What remains wholly unclear is the extent to which these state mandates have been effective in reducing the financial burden borne by families of children with autism. Our aim in this study was therefore to examine the association between state legislative mandates for private insurers and the financial burden of families raising children with autism. We hypothesized that compared with families living in states without such legislative mandates, families of children with autism living in states that passed legislation mandating coverage of autism services would report less financial burden, net of individual and family characteristics, the severity of the child's condition, and the relative wealth of their state of residence. We tested this hypothesis using data from the 2005–2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) and state legislation mandating coverage of autism services.

## Method

We took several steps in conducting these analyses. First, we matched individual-level data to state-level data; second, we imputed missing individual-level data using multiple imputation; and third, we subjected the data to multilevel analysis.

## Data Sources and Sample

Individual and family data were obtained from the 2005–2006 wave of the NS-CSHCN (Blumberg et al., 2008). The NS-CSHCN was a random-digit-dialed telephone survey representative of the U.S. noninstitutionalized, civilian population of chil-

dren younger than age 18 conducted by the National Center for Health Statistics. A complete description of the survey methodology and sample are available elsewhere (Blumberg et al., 2008; Maternal and Child Health Bureau, 2007). At least 750 interviews were conducted in every state and the District of Columbia, making population estimates obtained from the NS-CSHCN representative at the state level (Blumberg et al., 2008). The parent or guardian who was interviewed was identified as the person most knowledgeable about the child's health care. The population investigated in this study consisted of children with autism only. On the basis of responses to the question "To the best of your knowledge, does [your child] currently have autism or autism spectrum disorder, that is, ASD?" we determined that 2,123 children with autism were sampled in the NS-CSHCN. The final sample of children with autism, which was adjusted for nonresponse on the dependent variables ( $n = 41$ ), included 2,082 families.

Legislation on health insurance was identified from the literature and a Lexis-Nexis search on *autism* and *insurance*. The legislation was collected from the offices of state insurance commissioners (Bunce & Prikazsky, 2006; Bunce, Wieske, & Prikazsky, 2006; Bunce, Wieske, & Siedlick, 2007; Crosby, Moore, & Broderick, 2004; National Alliance on Mental Illness, 2007). State median income values for families with children younger than age 18 were obtained from the Annie E. Casey Foundation (2008). The proportion of people in each state living in areas classified as nonmetropolitan was obtained from the U.S. Census Bureau (2006, 2010).

## Measures

**Dependent variables.** We adapted two binary dependent variables from questions in the NS-CSHCN asking families to report the level of out-of-pocket expenses associated with their child's medical care over the 12 months before their interview. A variety of health-related needs specifically for the child with autism were considered. Copayments, medications, special foods, and durable equipment were considered eligible out-of-pocket expenses. However, insurance premiums, deductibles, and reimbursable costs were excluded.

The first dependent variable classified families into two categories: those with any eligible out-of-pocket expenses versus those without ( $N = 2,082$ ).

The second dependent variable, reported only among those having out-of-pocket expenses, contrasted families spending more than \$500 on annual eligible expenses (high) with those spending less than \$250 (low). There were 1,280 families with a valid response for this variable, a net loss of 802 families indicating that they did not have any out-of-pocket expenses ( $n = 398$ ) or that their level of expense was between \$250 and \$500 ( $n = 404$ ). We compared extremes of expenditures to assess important rather than simply statistical impacts of the legislation.

**State independent variables for children with autism.** States were classified according to whether they had (a) no legislation; (b) parity legislation, which required coverage of autism services at the same level as other covered health insurance services; or (c) any other type of insurance mandate implemented by 2005. Most states had no legislation; four states (California, Maine, New Hampshire, Virginia) had parity legislation; five states (Iowa, Indiana, Kansas, Kentucky, Tennessee) had other types of mandates. We note that the status of legislation we analyzed was what was in effect in 2005; these mandates have subsequently evolved in some states.

**State covariates.** To control for confounding effects of the legislation at the state level and reduce state-level variance, we included two state-level covariates. The first was a proxy indicator of state wealth, measured as median income for families with children younger than age 18 in 2005, measured in tens of thousands of dollars. The second was the percentage of families living in nonmetropolitan areas.

**Individual covariates.** To promote an estimate of the policy effect unconfounded by common correlates of the financial burden of families with children with special health care needs, we examined several child and family characteristics for inclusion in the model. Because of the relatively small within-state sample sizes (an average of 33 children per state for any out-of-pocket costs and an average of 18 for absolute costs of more than \$500), our final selection of individual-level covariates was parsimonious. Therefore, of the available child and family characteristics obtained from the NS-CSHCN, and on the basis of the literature on financial burdens experienced by families with children with autism, the final models included these four variables: income relative to the federal poverty level (less than 200%); child's minority

status (children reported as being Black, Hispanic, Asian, multiracial, Native American, Aleut, or Pacific Islander); the severity of the child's condition (mild or moderate vs. severe); and an indicator of health insurance status (no public or private insurance).

### **Analytic Strategy: Hierarchical Generalized Linear Models**

The two dependent variables were binary and therefore best examined using logistic regression. Because the independent variable, type of legislation, was a state-level variable, with the children in the sample nested within the 50 states and the District of Columbia, we used multilevel regression techniques (Raudenbush & Bryk, 2002). These approaches account for the commonalities between individuals in a state and adjust the variance or standard error of the legislation variable and state covariates accordingly to reflect the higher uncertainty associated with having fewer observations at that level. Multilevel models that enable estimation of parameters for binomial outcomes are referred to as *hierarchical generalized linear models* (Raudenbush & Bryk, 2002).

Each type of legislation has the potential to explain residual variance between states, once the individual and state covariates are controlled. The proportion of state-level variance explained by legislation was estimated by taking the difference between the state-level variance parameter estimate in the full model and the model with all individual- and state-level covariates but not the policy variables (Table 1; Raudenbush & Bryk, 2002).

**Missing data.** To reduce the potential bias from deletion of records with missing values (ranging from 3 to 136), we imputed data using SAS Proc MI. We combined the individual logistic hierarchical linear modeling results from 15 imputed datasets, using the methods suggested by Rubin (Graham, 2009; Rose & Fraser, 2008; Rubin, 1987; Schafer, 1997).

**Weighting and variance adjustment.** Mplus modeling program (Muthén & Muthén, 2010) accommodates the adjustment to standard errors from multilevel clustered data and handles the complex sampling weights of the stratified random sample according to the specification in the NS-CSHCN (the U.S. Census estimates for the age, sex, race, and ethnicity of the population; Blumberg

**Table 1**  
*Multinomial Multilevel Logistic Regression Predicting Measures of Family Financial Burden*

Variables	Any out-of-pocket costs <sup>a</sup> ( <i>N</i> = 2,082; OR CI 95%)	Absolute costs >\$500 <sup>b</sup> ( <i>N</i> = 1,280; OR CI 95%)
<b>Individual, family, and state level</b>		
Intercept (conditional mean for reference conditions)	12.06 [9.21, 15.79]***	3.96 [3.13, 5.03]***
Income <200% of federal poverty level	0.20 [0.14, 0.27]***	0.30 [0.23, 0.39]***
Race or ethnicity: Minority	0.38 [0.30, 0.48]***	0.88 [0.54, 1.45]
Child's condition or problem is severe	1.00 [0.83, 1.19]	2.36 [1.71, 3.26]***
Child has neither private nor public health insurance	3.35 [1.47, 7.65]**	0.68 [0.35, 1.32]
<b>State</b>		
Median income for families with children <18 years (\$1000s) <sup>c</sup>	1.03 [0.92, 1.16]	1.16 [1.02, 1.33]*
Proportion of nonmetropolitan population <sup>c</sup>	0.99 [0.99, 1.00]**	1.01 [1.00, 1.02]**
<b>State policy</b>		
State insurance: Other mandate	0.87 [0.69, 1.09]	0.72 [0.56, 0.94]*
State insurance: Parity legislation	0.72 [0.56, 0.92]*	0.71 [0.55, 0.92]*
<b>Variance components<sup>d</sup></b>		
Variance of random intercept	0.09	0.17
Proportion of variance explained by state policy	0.08	0.07

<sup>a</sup>Reference outcome is all families that do not have out-of-pocket costs.

<sup>b</sup>Reference outcome if families' out-of-pocket costs <\$250.

<sup>c</sup>Variable is mean centered.

<sup>d</sup>Proportion of variance explained is the difference in state-level variance between models with and without the policy variables.

\**p* < .05. \*\**p* < .01. \*\*\**p* < .001.

et al., 2008; Carle, 2009). Mplus does not allow for further adjustment to the standard error usually conducted on complex survey data, and we identified no software that performed all three adjustments. Because we used a software that fully adjusts for complex survey data but not for the multilevel aspects of the data, the standard errors for state-level variables were not sufficiently inflated to account for the independence of only 51 observations at this level, a critical factor for the validity of inferences in light of the salience of the state-level policy variables to this investigation.

## Results

Table 2 contains a description of the sample, including individual and family characteristics, state characteristics, and dependent variables. Among families of children with autism, 78% reported having any health care expenditures for their child. Of families with out-of-pocket costs, 21% had a burden of between \$1 and

\$249, 24% had a burden of between \$250 and \$500, and 55% had a burden in excess of \$500.

Table 3 presents the percentage of families of children with autism within each state that reported any expenditures, annual expenditures between \$250 and \$500, and annual expenditures of more than \$500. Table 3 also includes the state rankings for each state on each of these characteristics and the type of legislation in each state. States are listed in order by their ranking on the percentage of their population of families with high (more than \$500) annual expenditures for their children with autism.

The proportion of each state's population of families raising children with autism that had any health expenditures for their child ranged from 52% in the District of Columbia to 96% in Nevada. The proportion of families that reported spending \$250–\$500 ranged considerably (2% in Oklahoma to 35% in Colorado), as did the proportion of families that reported spending more than \$500

Table 2  
*Description of the Sample of Children with Autism (N = 2,082) and State-Level Measures of Income and Insurance Eligibility Thresholds*

Variables	Statistic
<b>Child and family (N [%])</b>	
Income <200% federal poverty level	794 (43)
Gender: Female	410 (21)
Race or ethnicity: Minority	514 (30)
Child's age	9.7 (6.8)
Highest grade level among parents: Did not graduate high school	92 (6)
Child's condition or problem is severe	564 (29)
Child's health care needs are not stable	269 (14)
Parent is single mother	556 (30)
Child has public health insurance	903 (47)
Child is uninsured	73 (3)
<b>State variables</b>	
Proportion (and <i>SD</i> ) of median income for families with children <18 yr (\$10,000s)	5.37 (0.98)
Proportion (and <i>SD</i> ) of nonmetropolitan population	0.27 (0.18)
State insurance: Other mandate ( <i>M</i> )	0.10
State insurance: Parity legislation ( <i>M</i> )	0.08
<b>Dependent variables (N [%])</b>	
Had out-of-pocket costs	1,685 (78)
Among those having out-of-pocket costs	
Had out-of-pocket costs between \$1 and \$249	346 (21)
Had out-of-pocket costs between \$250 and \$500	405 (24)
Had out-of-pocket costs more than \$500	934 (55)

*Note.* Percentages reported in the table are weighted.

(18% in Rhode Island to 60% in Massachusetts, Missouri, and Utah). The results of the multilevel logistic regression models are reported in Table 1. In the second column, parity legislation was significantly associated with lowered odds of having out-of-pocket costs among families of children with autism (OR [9+] = .72,  $p < .05$ ). The state insurance legislation variables explained 8% of state-level variance. In the third column, both other mandates (OR = .72,  $p < .05$ ) and parity legislation (OR = .71,  $p < .05$ ) were significantly associated with reduced odds of having out-of-pocket costs in excess of \$500 per year. The policy variables explained 7% of the state-level variance.

### Discussion

Consistent with research reported elsewhere, we found significant state-level variability in the level

of financial burden reported by families of children with autism (Shattuck & Parish, 2008). This state-level variability persisted after controlling for characteristics of the family and the individual child, including impairment and whether the child was insured. The important contribution of this study is that after controlling for these covariates, we found a significant association between state legislative mandates requiring private insurers to cover autism services and families' financial burden. Net of family and individual characteristics, families living in states with legislative mandates were less likely to have any financial costs and were less likely to have high financial costs.

A consideration of the limitations of this study is warranted to fairly assess these findings. First, the analyses are correlational, and we cannot infer causality between state programs and family

Table 3  
*Percentage of Families of Children with Autism with Financial Burden by State and State Rankings*

State	Type of legislation in 2005	Any out-of-pocket spending		Annual spending of \$200–\$500		Annual spending of >\$500	
		% of families	Rank	% of families	Rank	% of families	Rank
Massachusetts	None	81	19	16	32	60	1
Utah	None	94	4	18	27	60	2
Missouri	None	82	15	20	22	60	3
Maryland	None	95	2	18	26	59	4
Delaware	None	86	8	8	48	56	5
Connecticut	None	86	10	26	7	56	6
Illinois	None	87	7	20	25	55	7
Michigan	None	79	23	12	44	53	8
New Jersey	None	89	6	24	13	53	9
New Mexico	None	73	38	5	50	51	10
Iowa	Other	95	3	27	5	51	11
Minnesota	None	78	25	16	31	51	12
Ohio	None	84	11	17	29	51	13
North Carolina	None	81	17	24	14	49	14
Hawaii	None	75	30	5	49	47	15
West Virginia	None	81	18	20	24	47	16
Nevada	None	96	1	22	17	47	17
Montana	None	77	27	20	23	46	18
Virginia	Parity	73	36	14	38	45	19
New Hampshire	Parity	83	14	25	8	44	20
Arkansas	None	83	14	25	8	44	21
Florida	None	79	24	14	40	43	22
Wisconsin	None	80	20	9	46	43	23
Oregon	None	72	40	15	33	43	24
South Carolina	None	78	26	12	43	42	25
Vermont	None	73	32	14	39	42	26
North Dakota	None	86	9	24	11	41	27
Alaska	None	73	34	13	41	41	28
Indiana	Other	79	22	22	16	39	29
Tennessee	Other	73	35	11	45	39	30
Oklahoma	None	69	43	2	51	39	31
Louisiana	None	72	39	31	3	37	32
Washington	None	73	33	14	36	37	33
California	Parity	82	16	24	12	37	34
Idaho	None	76	28	23	15	36	35
South Dakota	None	66	45	21	21	36	36
Kansas	Other	80	21	25	9	36	37
Arizona	None	65	46	14	35	36	38
Nebraska	None	70	42	8	47	36	39
Kentucky	Other	59	48	12	42	35	40
Wyoming	None	76	29	21	20	34	41
Colorado	None	92	5	35	1	33	42

Table 3  
*Continued*

State	Type of legislation in 2005	Any out-of-pocket spending		Annual spending of \$200–\$500		Annual spending of >\$500	
		% of families	Rank	% of families	Rank	% of families	Rank
New York	None	72	41	15	34	32	43
District of Columbia	None	52	51	14	37	31	44
Pennsylvania	None	74	31	18	28	29	45
Alabama	None	83	12	28	4	29	46
Georgia	None	55	50	24	10	29	47
Texas	None	73	37	32	2	29	48
Maine	Parity	66	44	22	18	27	49
Mississippi	None	56	49	21	19	25	50
Rhode Island	None	62	47	26	6	18	51

financial expenditures. As such, the results must be interpreted tentatively. Further study could fruitfully examine whether families' financial burden actually declined after implementation of these state legislative mandates, which would provide more robust evidence of the causal link between mandates and family burden. Second, the ordinal measures of household income and families' expenditures cannot fully capture the level of nuance that would be ideal to inform policymakers. Third, we were unable to model parental employment because the NS-CSHCN did not measure it. However, parental employment is strongly associated with insurance status (DeNavas-Walt, 2006) and financial burden (Parish, Seltzer, Greenberg, & Floyd, 2004). Fourth, the specification of autism mandates varies across states, and modeling the effects of the unique program characteristics in each was beyond the scope of this study. Finally, these findings offer preliminary evidence of the relationship between a novel legislative approach and family financial burden. Further research is necessary to understand the long-term effects of these legislative mandates as well as how specific features reduce or increase family financial burden.

Several important strengths offset the study's limitations. First, the sampling design of the NS-CSHCN resulted in a representative sample of children with autism from each state. Second, the use of multilevel regression enabled us to simultaneously examine both individual-level and state-level public health program characteristics that are correlated with families' out-of-pocket spending for their children with autism. As far as we know, this

study is the first to analyze the relationship between state legislative mandates for autism services and the financial burden experienced by families raising children with autism.

We cannot infer causality from this study. However, we speculate that families living in states that have implemented mandates may experience a direct reduction in the health care costs they incur to meet the care needs of their children with autism. The results presented here provide initial tentative evidence that families may be able to share the costs of their child's care with private insurers in states with such legislative mandates. In light of the existing evidence of modest costs of implementing these legislative mandates (Bouder et al., 2009) and high costs to families, policymakers should be encouraged to further support initiatives that reduce the financial burden borne by families of children with autism.

## References

- Annie E. Casey Foundation. (2008). Median family (with child) income: 2005. *KIDS COUNT 2008 data book online*. Available at <http://datacenter.kidscount.org/databook/2008/Default.aspx>
- Autism Speaks. (2007). *Arguments in support of private insurance coverage of autism-related services*. Available at [http://dhhs.nv.gov/autism/TaskForce/2008/ATF\\_Report\\_08/Appendix%20E.pdf](http://dhhs.nv.gov/autism/TaskForce/2008/ATF_Report_08/Appendix%20E.pdf)
- Blumberg, S. J., Welch, E. M., Chowdhury, S. R., Upchurch, H. L., Parker, E. K., & Skalland, B. J. (2008). Design and operation of the National Survey of Children with Special

- Health Care Needs, 2005–2006. *Vital Health Statistics*, 1(45), 1–188.
- Bouder, J. N., Spielman, S., & Mandell, D. S. (2009). Brief report: Quantifying the impact of autism coverage on private insurance premiums. *Journal of Autism and Developmental Disorders*, 39, 953–957.
- Bunce, V., & Prikazsky, V. (2006). *Trends in state mandated benefits: 2006*. Alexandria, VA: Council for Affordable Health Insurance.
- Bunce, V., Wieske, J., & Prikazsky, V. (2006). *Health insurance mandates in the states*. Alexandria, VA: Council for Affordable Health Insurance.
- Bunce, V., Wieske, J., & Siedlick, L. (2007). *Health insurance mandates in the states*. Alexandria, VA: Council for Affordable Health Insurance.
- Carle, A. C. (2009). Fitting multilevel models in complex survey data with design weights: Recommendations. *BMC Medical Research Methodology*, 9, 49.
- Crosby, M., Moore, N., & Broderick, C. (2004). *State parity update*. Washington, DC: American Academy of Child and Adolescent Psychiatry.
- DeNavas-Walt, C. (2006). *Income, poverty, and health insurance coverage in the United States: 2005* (Report No. P60-231). Washington, DC: U.S. Census Bureau.
- Fujiura, G. T., Roccoforte, J. A., & Braddock, D. (1994). Costs of family care for adults with mental retardation and related developmental disabilities. *American Journal of Mental Retardation*, 99, 250–261.
- Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatric and Adolescent Medicine*, 161, 343–349.
- Graham, J. W. (2009). Missing data analysis: Making it work in the real world. *Annual Review of Psychology*, 60, 549–576.
- Gurney, J. G., McPheeters, M. L., & Davis, M. M. (2006). Parental report of health conditions and health care use among children with and without autism: National Survey of Children's Health. *Archives of Pediatric and Adolescent Medicine*, 160, 825–830.
- Jarbrink, K. (2007). The economic consequences of autistic spectrum disorder among children in a Swedish municipality. *Autism*, 11, 453–463.
- Jarbrink, K., Fombonne, E., & Knapp, M. (2003). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: A pilot study. *Journal of Autism Developmental Disorders*, 33, 395–402.
- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*, 122, e1149–e1158.
- Krauss, M. W., Gulley, S., Sciegaj, M., & Wells, N. (2003). Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation*, 41, 329–339.
- Leslie, D. L., & Martin, A. (2007). Health care expenditures associated with autism spectrum disorders. *Archives of Pediatric and Adolescent Medicine*, 161, 350–355.
- Mandell, D. S., Cao, J., Ittenbach, R., & Pinto-Martin, J. (2006). Medicaid expenditures for children with autistic spectrum disorders: 1994 to 1999. *Journal of Autism and Developmental Disorders*, 36, 475–485.
- Maternal and Child Health Bureau. (2007). *The national survey of children with special health care needs: Chartbook 2005–2006*. Rockville, MD: Author.
- Muthén, L. K., and Muthén, B. O. (2010). *Mplus* (6th ed.) [Modeling program]. Los Angeles, CA: Author. Available at <http://www.statmodel.com/>
- National Alliance on Mental Illness. (2007). *State mental health parity laws 2007*. Available at <http://www.nami.org/Template.cfm?Section=Parity1&Template=/ContentManagement/ContentDisplay.cfm&ContentID=45313>
- Parish, S. L., Seltzer, M. M., Greenberg, J. S., & Floyd, F. (2004). Economic implications of caregiving at midlife: Comparing parents with and without children who have developmental disabilities. *Mental Retardation*, 42, 413–426.
- Peele, P. B., Lave, J. R., & Kelleher, K. J. (2002). Exclusions and limitations in children's behavioral health care coverage. *Psychiatric Services*, 53, 591–594.
- Raudenbush, S., & Bryk, A. (2002). *Hierarchical linear models: Applications and data analysis methods* (2nd ed.). Thousand Oaks, CA: Sage.
- Reinke, T. (2008). States increasingly mandate special autism services. Insurers are being handed some treatment responsibility for this complex disorder, but some say that it is an educational, not medical, task. *Managed Care*, 17, 35–36, 39.

- Rose, R., & Fraser, M. (2008). A simplified framework for using multiple imputation in social work research. *Social Work Research, 32*, 171–178.
- Rubin, D. B. (1987). *Multiple imputation for nonresponse in surveys*. New York, NY: Wiley.
- Schafer, J. (1997). *Analysis of incomplete multivariate data*. Boca Raton, FL: Chapman & Hall/CRC.
- Shattuck, P. T., & Parish, S. L. (2008). Multilevel analysis of financial burden in families of children with special health care needs. *Pediatrics, 122*, 13–18. doi:10.1542/10.1542/peds.2006-3308
- U.S. Census Bureau Population Division. (2006). *Annual estimates of the population for counties: April 1, 2000 to July 1, 2005 (CO-EST2005-01-04)*. Washington, DC: Author.
- U.S. Census Bureau Population Division. (2010). *Metropolitan and micropolitan statistical areas and components, December 2009, with codes*. Washington, DC: U.S. Census Bureau.
- Wang, L., & Leslie, D. L. (2010). Health care expenditure for children with autism spectrum

disorders in Medicaid. *Journal of the American Academy of Child and Adolescent Psychiatry, 49*, 1165–1171.

Received 6/20/11, first decision 9/15/11, accepted 11/22/11.

Editor-in-Charge: Glenn Fujiura

Support for this study was provided by the Maternal and Child Health Bureau of the Health Resources and Services Administration (No. R40MC17158).

**Authors:**

**Susan L. Parish** (e-mail: slp@brandeis.edu), Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University, 415 South Street, MS 035, Waltham, MA 02454, USA; **Kathleen Thomas**, Cecil G. Sheps Center for Health Services Research; **Roderick Rose**, University of North Carolina; **Mona Kilany** and **Robert McConville**, University of North Carolina at Chapel Hill.

---

**From:** Cheryl Smith <smithfam29@msn.com>  
**Sent:** Sunday, July 01, 2012 8:43 PM  
**To:** Lori Rammell  
**Subject:** Fwd: Health System input

Sorry, I did not put my address and phone.

Cheryl C. Smith  
1687 Ensign Place  
SLC, UT 84121  
(801) 944-1729  
*Cheryl C. Smith*



[www.autismcouncilofutah.org](http://www.autismcouncilofutah.org)

Begin forwarded message:

**From:** Cheryl Smith <smithfam29@msn.com>  
**Date:** July 1, 2012 8:41:41 PM MDT  
**To:** [LRammell@Le.Utah.gov](mailto:LRammell@Le.Utah.gov)  
**Subject:** Health System input

Dear Utah Health System Task Force:

I am the parent of a child with autism, as well as the President of the Autism Council of Utah.

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left

untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Children with autism, including my son, Carson, will greatly benefit from early interventions. Pay now, or pay later. Do not jump over dollars to save pennies now.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

*Cheryl C. Smith*  
*President*



[www.autismcouncilofutah.org](http://www.autismcouncilofutah.org)

---

**From:** Holli Murphy <hhmurphy@gmail.com>  
**Sent:** Thursday, June 28, 2012 2:47 PM  
**To:** Lori Rammell  
**Subject:** Please Include Autism Treatment in Utah's Definition of the Affordable Health Care Act

Our son was diagnosed with an autism spectrum disorder at age 2 1/2. We are luckier than many in that our insurance covers some of our speech, occupational, and physical therapy needs. However, it does not cover the therapy that has been the most beneficial to him, DIR (Developmental, Individual Difference, Relationship-based Model) or Floortime therapy. We have been paying \$500-\$1000 a month for his therapies and would buy more therapy if we could afford it. We designed an at home Floortime program and trained family and volunteers to perform the therapy with our son and he has made progress, but would have done so much better had professionals been administering the therapy. I know that other families have had similarly good results with ABA (Applied Behavior Analysis) therapy. These therapies are not experimental and have been proven to give children with autism spectrum disorders the foundation they need to learn as other children would intuitively. Two years later our son is attending a mainstream preschool half of the week and a special needs preschool half of the week along with continued Floortime, occupational therapy, and social skills groups. We anticipate that next year he will thrive in mainstream kindergarten and may not need any special education services. Early intervention is the key to helping children with autism spectrum disorders. It makes a huge difference for their future ability to be self reliant. We are blessed that we have been able to provide the services that our son needs, but so many other families cannot and the results are devastating, both to the families and to the community. Please help give these children a future by including autism treatment in Utah's definition of the Affordable Health Care Act.

Thank you,  
Holli Murphy  
633 Rose Bud Ct.  
Saratoga Springs, UT 84045

---

**From:** CAROL S WATTS <linawatts@msn.com>  
**Sent:** Thursday, June 28, 2012 2:59 PM  
**To:** Lori Rammell  
**Subject:** Autism health benefits

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Carol S. Watts  
820 Three Fountains Drive, #134  
Murray, Utah 84107

---

**From:** Ari & Diana Bruening <adbruening@gmail.com>  
**Sent:** Thursday, June 28, 2012 3:24 PM  
**To:** Lori Rammell  
**Subject:** Utah insurance - please include autism coverage!!!

To Whom it May Concern at the Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My nephew Eli has autism, as well as several of the children in the neighborhood. It breaks my heart to see them not be able to get the care they so desperately need and deserve. I don't understand why it's ok to say that speech therapy or physical therapy is covered if the problem is caused by certain birth defects, but not by others, including autism. It's our duty to make sure the children in our state don't go without this essential treatment.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Thank you for taking the time to make sure our Utah health coverage is what it needs to be,

Diana Bruening  
4637 Lumina Dr.  
South Jordan, UT 84095  
801-302-9658

---

**From:** Carol Ann Wiley <carolannwiley2002@yahoo.com>  
**Sent:** Thursday, June 28, 2012 3:37 PM  
**To:** Lori Rammell  
**Subject:** Autism awareness

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

We have numerous friends and family members who deal with autistic children every day. We have seen the benefits of treatment. These can cost thousands of dollars out of pocket for these families. Please give autism the respect and care that it needs!

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,  
CarolAnn Wiley  
1223 Trimble Lane  
West Jordan UT 84088

---

**From:** Sanda R. Flint <sflint@Strongandhanni.com>  
**Sent:** Thursday, June 28, 2012 3:50 PM  
**To:** Lori Rammell  
**Subject:** Inclusion of Autism health benefits

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Sanda R. Flint, CP  
STRONG & HANNI  
9350 South 150 East, Suite 820  
Sandy, UT 84070  
Telephone: (801) 532-7080  
Facsimile: (801) 596-1508  
E-mail: [sflint@strongandhanni.com](mailto:sflint@strongandhanni.com)  
Website: [www.strongandhanni.com](http://www.strongandhanni.com)



**CONFIDENTIALITY NOTICE:** This transmission is intended for the sole use of the individual or entity to whom it is addressed and may contain information that is confidential, attorney-client privileged, or otherwise exempt, by law, from disclosure. Any dissemination, distribution, copying, or taking of any action in reliance on the contents of this transmission, by someone other than the intended addressee or its authorized agent is strictly prohibited. If you have received this transmission in error, please notify the law firm of Strong & Hanni immediately at the telephone number listed above, or by reply to this transmission.

---

**From:** Carma Harper <charper@Strongandhanni.com>  
**Sent:** Thursday, June 28, 2012 2:46 PM  
**To:** Lori Rammell  
**Cc:** Sariah Sanchez  
**Subject:** Utah Health system Task Force

Dear Utah Health System Task Force;

I am writing because I know several people with children and family members who are autistic. They struggle everyday financially and mentally trying to teach their children the correct social skills, along with the educational learning skills that it takes to function in our day to day lives. Often medications are extremely expensive,, causing either both parents to work outside the home, which does not allow enough time to work with the family member who needs the special attention or one parent to work two jobs leaving the other parent home on a daily basis to struggle with the emotional turmoil that goes along with the disease, illness, mental illness or however you want to qualify "AUTISM". It seems to me that it is very important to teach and educate these children, family members and others who need to deal with this on the daily basis, so that the autistic person can live useful and productive lives, not relying on the system for support. Autism should be treated like any other illness, and should be covered as any other illness by the insurance carriers. It is truly terrifying to know that we as human beings, parents and grandparents (even insurance adjustors fit in there somewhere) put so little value on someone's well being and a families future by causing a family with specific needs, who are struggling everyday, dealing with this disease, illness and working so hard to be able educate, teach, and correctly be able to medically treat their family members in the specific way that they need to be medically treated. SHAME on us and our society for not taking more value in their future and their medical needs and their quality of life now and for the future.

I feel pretty confident when I say, that the families of the autistic members more than likely DID NOT wake up one day and say, "lets have an autistic child, so we can struggle every day we live and breathe, and not be able to insure our child or be able to obtain the correct medical care they need because they are "AUTISTIC".

We put people in jail for being cruel to animals and other people, yet the insurance industry is being just as mean and cruel and nothing happens to them. I always thought that people with autism qualified as a "protected class." Autism is an awful disability to struggle with, especially with no resources available to you.

Carma J. Harper, CP  
Certified Paralegal  
5812 S. 4050 W.  
Roy, Utah 84067  
(801) 323-2029

This email message has been delivered safely and archived online by Mimecast. For more information please visit <http://www.mimecast.com>

---

**From:** Eva Bell <evie.bell@live.com>  
**Sent:** Thursday, June 28, 2012 1:51 PM  
**To:** Lori Rammell

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I personally have a child with Autism and she would definitely not be where she is today without the early intervention treatments and care she has been given. Most of this care has been covered by me out of pocket. This expense has severely limited the things we can do for our other children and has caused a hardship for our family. There are many, many families with children with Autism in the same or worse situation. Many of these children do not get the early intervention services needed. I would hope that this would change with the new essential benefits package.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Evamarie Bell  
659 Christopher Street  
Stansbury Park, UT 84074

---

**From:** Jon Owen <vorpaljon@gmail.com>  
**Sent:** Thursday, June 28, 2012 11:53 AM  
**To:** Lori Rammell  
**Subject:** essential benefits package

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Our son Benjamin is five years old and has autism. You can read about him and our experiences in my [blog](#). After lots of research, my wife and I concluded that the best way to help our son was to enroll him in the Pingree School where he has access to ABA therapy and other evidence-based treatments. We've refinanced our house in order to be able to afford the almost \$30,000 in tuition. It's the sort of thing that health insurance should cover, and does in most states.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Jon Owen  
275 Virginia Street  
Salt Lake City, UT 84103

--

<http://happytrbl.blogspot.com>

---

**From:** Sherrie Janicki <sherjanicki@comcast.net>  
**Sent:** Thursday, June 28, 2012 9:16 PM  
**To:** Lori Rammell  
**Subject:** Inclusion of Autism Health Benefits

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Sherrie Janicki  
2381 Brook Lane  
Sandy, UT 84092

---

**From:** Melanie Lutz <m.b.lutz@comcast.net>  
**Sent:** Thursday, June 28, 2012 8:45 PM  
**To:** Lori Rammell  
**Subject:** Autism Benefits

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

We are desperately trying to get my son into an ABA program that is low cost at the moment. There isn't much options for us right now.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Melanie Lutz  
1382 S 875 W  
Woods Cross, UT 84087

---

**From:** mikevo@comcast.net  
**Sent:** Friday, June 29, 2012 11:21 AM  
**To:** Lori Rammell  
**Subject:** Treatment for Autism

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Mike Van Orden  
11492 Jordan Bend Road  
South Jordan, UT 84047

---

**From:** Chase Ames <comes@Strongandhanni.com>  
**Sent:** Friday, June 29, 2012 1:55 PM  
**To:** Lori Rammell  
**Subject:** Autism Health Care

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Chase Ames  
Bountiful, Utah

This email message has been delivered safely and archived online by Mimecast. For more information please visit <http://www.mimecast.com>

---

**From:** herelt@comcast.net  
**Sent:** Saturday, June 30, 2012 5:41 PM  
**To:** Lori Rammell  
**Subject:** the Utah Essential Benefits Package

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My son, 6, has been diagnosed with mild to moderate autism. He doesn't verbally communicate with me at all. My employer (UPS) and my current healthcare (or lack) provider, United Healthcare, DO NOT cover autism related claims. I make too much money to apply for states assistance on his behalf. I cannot afford the therapy that he needs and provide him with his basic life essentials, like food, and a place to live, and clothing.

I wonder everyday if there was a way to get him the therapy that he needs, would he talk to me? would potty training be easier? would he understand what I say, not just how I say it? I wonder a lot of things about his life. I wonder what will happen to him when his father and I are gone? Who will watch out for him and protect him? The government? Why would they bother to take care of him when he's an adult and it's so expensive (as much as \$3 million dollars) when they wouldn't bother to help him out now when it's such a small amount? (just \$0.44 - \$0.83 per member per month) --- Do I think that the Utah Health System Task Force is going to do anything to help my son? NO. Do I hope that you will do something to help another child and another family? YES. As long as I breathe I will always have hope. If I don't there is nothing left and the insurance companies don't pay on suicides.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Helen Rebecca Felt Jarrell

3660 American Drive  
West Valley City, UT 84119

---

**From:** G. Blake Hoopes <g.blake.hoopes@gmail.com>  
**Sent:** Sunday, July 01, 2012 1:47 AM  
**To:** Lori Rammell  
**Subject:** Autism

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

G. Blake Hoopes  
4759 South 1300 East Apt. A2  
Holladay, UT 84117

---

**From:** melyssa smith <melyssasmith1@gmail.com>  
**Sent:** Thursday, June 28, 2012 6:23 AM  
**To:** Lori Rammell  
**Subject:** Utah family with Autsim

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

We have three children and our two sons ages 2 and 4 are both on the spectrum. We NEED these treatments covered in Utah! Our four year old has been getting ABA therapy at The Pingree School for Children with Autism and has done so much this year, including learning to communicate better AND being almost potty trained. The school has been amazing and yet we've basically ruined ourselves financially paying to send him there. PLEASE, PLEASE give our little boys a chance at a better life! They deserve this coverage!! We are looking to leave the state to move to a place that covers these curtail treatments for our boys. Help all of Utah out and help our boys!

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Melyssa Smith  
1014 Allington Drive  
North Salt Lake City, UT 84054

---

**From:** Eliece Simonson <private\_8\_69@yahoo.com>  
**Sent:** Wednesday, June 27, 2012 10:18 PM  
**To:** Lori Rammell  
**Subject:** Autism

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Eliece Simonson  
571 West 200 North  
Smithfield, UT 84335

Eliece Simonson  
*Independent Beauty Consultant with MARY KAY*

---

**From:** H Salls <zailth@hotmail.com>  
**Sent:** Wednesday, June 27, 2012 9:08 PM  
**To:** Lori Rammell  
**Subject:** Autism Support!

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Heather Salls  
3577 Kingsburg Cove #11  
Magna, UT 84044

---

**From:** Heather Cannon <heathercan@gmail.com>  
**Sent:** Wednesday, June 27, 2012 8:45 PM  
**To:** Lori Rammell  
**Subject:** Autism - Essential Benefits Package

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I am the parent of 3 darling boys who have all been diagnosed with autism. My oldest is 7 and my youngest are 5 year old twins. Autism is more than deficits in social function, more than than difficulties with speech. Children with autism also commonly have sensory processing disorder, planning deficits, executive function impairments to just name a few. An average family with a child or children on the autism spectrum find it necessary to take their child to specialists such as an ABA practitioner, speech therapist, occupational therapist, physical therapist to name just a few. Each provider gives our children an opportunity to function better and to gain independence but it's never free and the costs for one child's services alone can be monumental. It is simply inexcusable to deny coverage of the services that are essential to their future, essential to OUR future as a community.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Heather Cannon  
6153 Vinecrest Drive  
Murray, UT 84121

--  
*"Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society."*

---

**From:** Gloria Sanchez <sanchezrgloria@gmail.com>  
**Sent:** Wednesday, June 27, 2012 7:56 PM  
**To:** Lori Rammell  
**Subject:** Inclusion of Autism Health Benefits

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Gloria Sanchez  
14663 CULROSS LN  
DRAPER, UT 84020

---

**From:** Chris Gerlisky <gerlisky@msn.com>  
**Sent:** Wednesday, June 27, 2012 7:52 PM  
**To:** Lori Rammell  
**Subject:** Autism treatment needed

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I have an 8 year old daughter that is "in the Autism Spectrum" she has multiple problems. We've been kicked out of schools, daycares, and, we were even asked to leave church once when she was younger. I was the main breadwinner and insurance holder for our family. When I lost my job, we lost everything. My husband makes \$9.40 an hour. Our cars were repossessed, we lost our home, we have no insurance and one of her meds alone is \$186.00 per month. That doesn't include the \$150.00 visit to the doctor every month for her prescription or her other medications. I pawned my wedding ring one month to pay her bills. As her mother, it kills me to see her struggle and be unable to help her. We are virtual prisoners in the trailer we rent because she cannot control herself in public. As a result, I can't look for another job because I can't afford the daycare nor can I find one to accept her unmedicated. We have no family in this state. We are virtually afloat on our own; struggling as a family to survive day to day.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Janice Gerlisky  
106 E Flinders Way  
Tooele UT 84074  
(435) 882 1000 cell

---

**From:** Sherry M. Hunter <sherry.m.hunter@gmail.com>  
**Sent:** Wednesday, June 27, 2012 7:37 PM  
**To:** Lori Rammell  
**Subject:** Autism Benefits!

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Sherry Hunter  
397 North 2420 West  
Provo, UT 84601



*~Just because somebody doesn't love you the way you want them to, doesn't mean they don't love you with all they have.~*

<http://andthesearethedaysofourlives.blogspot.com/>  
<https://www.facebook.com/sherrymarie1966>

---

**From:** S Enderton <senderton@ymail.com>  
**Sent:** Wednesday, June 27, 2012 7:35 PM  
**To:** Lori Rammell  
**Subject:** Autism coverage

It is essential that treatment for autism be included in Utah's health benefits. Treatment not only helps the people directly affected by autism but also the state as a whole. Our schools have to deal with IEP's for all kids with special needs. The special needs that schools provide would be greatly reduced if the kids received treatment. The cost of treatment for autism is much less than the social costs of dealing with untreated autistic children. Currently 34 states and the District of Columbia have laws related to autism and insurance coverage. Those states have recognized how essential autism insurance coverage is for their citizens. It is time for the State of Utah to join the states that have mandated coverage for autism. Without autism coverage, Utah will not be able to attract many employers or some of the best employees because they will want to locate in a state that has autism coverage.

---

**From:** Lindsey Roecker <lindseyj.roecker@gmail.com>  
**Sent:** Wednesday, June 27, 2012 7:05 PM  
**To:** Lori Rammell

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

[Insert personal experience here, if desired.]

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Lindsey Roecker  
477 E 2650 N  
North Logan, UT 84341

---

**From:** Susan <sjum@comcast.net>  
**Sent:** Wednesday, June 27, 2012 6:48 PM  
**To:** Lori Rammell

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My 6 year old daughter has been involved with many therapies since she was diagnosed at age 2 1/2. For 2 years she had over 30 hours therapy a week. Some of this therapy included ABA therapy, sensory processing therapy, food therapy and more. She went from 6 1/2 hr tantrum days and no communication skills to being mainstreamed in school and able to participate and excel in every 'typical' environment we place her in. She participates in typical soccer and piano, already accomplishing 2 recitals at age 6! She is bright, very advanced and we can all enjoy her amazing abilities even more thanks to the therapies that have helped put some of her 'puzzle' together for all of us. However the insurance I pay for now, Altius does not cover Autism treatment and I have had to pay for everything out of my pocket. Currently I am covering therapy for my daughter anxiety.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Susan Jumonville  
3119 S. 1115 W.  
Syracuse, UT 84010

---

**From:** katherine scott <scottkat14@gmail.com>  
**Sent:** Wednesday, June 27, 2012 6:36 PM  
**To:** Lori Rammell  
**Subject:** evidence-based treatment for autism

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Katherine Scott  
Executive Board President  
Utah Association for Intellectual Disabilities  
1622 W. Russett Ave. West Valley City, Utah, 84119

---

**From:** Michelle Hilton <michelleiz@yahoo.com>  
**Sent:** Thursday, June 28, 2012 8:16 AM  
**To:** Lori Rammell  
**Subject:** Autism Coverage

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My son was recently accepted into the PEHP Autism Pilot Program. While this is a great opportunity for him and for us, our out of pocket costs will still be \$6,000 per year. This will still be very hard for us to come up with. We will need to get outside help to make this work. At least we have a chance of providing this very important therapy for our son. Without it, we would never have even been able to consider it. These kids deserve a chance. They are so smart and have so much potential, but are extremely limited without extensive therapy at a young age. All children should be able to have access to insurance coverage for whatever disability they have.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Michelle Hilton  
4566 Kestrel Way  
Eagle Mountain, UT 84005

---

**From:** Deb Moeller <debmoeller73@gmail.com>  
**Sent:** Thursday, June 28, 2012 9:18 AM  
**To:** Lori Rammell  
**Subject:** Utah Essential Benefits Package

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning; only 2% of children who are left untreated can make the same achievement. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I have two children with autism. My son, who is 8, has severe autism—he cannot talk, he is not toilet-trained, he is a risk to himself if he is not closely supervised at all times. However, thanks to evidence-based behavioral therapy early in his life, which cost our family more than \$25,000 out of pocket, he is now able to sit calmly in his classroom and work on academic skills. His teachers this past year were constantly surprised by his knowledge and intellectual development.

Including evidence-based treatment for autism in the essential benefits package is relatively inexpensive (\$0.44 – \$0.83 per member per month). The average cost of caring for an untreated individual with autism over his or her life span will cost as much as \$3 million dollars - most of which will be incurred in the later part of their lives. My son, without intervention, would have been one of these individuals. As an adult, the only setting that would provide safety for him and those around him would have been a residential institution. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults who are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

My daughter, who is 5, also is unable to talk, although her language has developed significantly in the past two years. Thanks to various kinds of interventions, we anticipate that within about five years, she should be able to participate in a mainstream classroom setting. We think she will be able to go to college, hold down a job, have a family, and do all the things a typical child can look forward to doing as an adult.

Currently 31 states require insurance companies to cover the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect taxpayers from the expense of a large population of untreated individuals with autism. I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,  
Deborah Moeller  
620 E Pico Street  
Sandy, UT 84070  
801.419.9663

---

**From:** Debbie (Comcast) <debdanderson@comcast.net>  
**Sent:** Thursday, June 28, 2012 9:25 AM  
**To:** Lori Rammell  
**Subject:** Essential Benefits Package: Evidence-Based Treatment for Autism

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Our deceptively charming six-year-old child with autism has made remarkable progress with multiple therapies, including evidence-based Applied Behavior Analysis (ABA treatment), speech therapy, and occupational therapy. He is just starting to have intelligible speech, improved eye contact, and progress with motor skills and social skills. He is funny, sweet, and also quite gifted in some areas...his math and memory abilities continuously knock our socks off. Still, without autism treatment, no one would ever know of his amazing skills, personality, wit, charm, or potential. All this has come at a great cost, however. As you know, none of these treatments are covered by insurance, and all of our resources go to our son's therapies and schooling. I have had to give up my job/career in order to work with him, facilitate his daily therapies, etc. This has created a great financial hardship for our family, but nothing is more important.

During the school year, I drive 100 miles/day, 5 days a week, in order to take our son back and forth to a school for children with autism.

With his speech disability, we didn't think we would ever get to hear our boy say "I love you," but now that it happens every night. Despite all of the hardships, I can tell you that truly rocks a mom and dad's world.

Sometimes I contrast our experience with my young niece's experience with cancer. She is just a bit younger than my son. Almost all of her intense cancer treatments are, of course, covered by insurance. Most people would be outraged if insurance did NOT cover her treatments. She has the support of the community. All of the neighbors rally around. Is autism any less important to treat?

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Debbie Anderson  
1967 Rocklin Drive

Sandy, UT 84092

---

**From:** Burton, Courtney <Courtney.Burton@supervalu.com>  
**Sent:** Thursday, June 28, 2012 10:03 AM  
**To:** Lori Rammell

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I have a son with Aspergers Syndrome. He is 10 years old, and was diagnosed at the age of 7, although his struggles started at the age of 4. Currently he is going into the 5<sup>th</sup> grade, yet because of behavioral problems stemming from sensory issues, he is only on a 2<sup>nd</sup> grade level for reading, and 3<sup>rd</sup> grade level for Math. He is a very bright kid, but his meltdowns have impeded his learning, and the school he attends struggles daily to just have him present in the classroom. With evidence based approval, ABA therapy, we could work on his issues and get him up to speed so he could live a mostly normal life, and become a productive citizen that will give back to society when he grows up. I am a single Mom to 2 young boys, and paying for therapy on my own is not even remotely possible. I have insurance, but unfortunately the therapy my son desperately needs is not covered. Instead of therapies to cure his issues, I resort to medications to try and handle him. Although, we've been through 10 different meds in 2 years. His body gets used to them, and they slowly become ineffective. Secondly, these newer medications are MUCH more costly than ABA therapy, and the risk of long term effects honestly frightens me.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 32 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Courtney Burton  
1037 Allington Dr.  
North Salt Lake, Utah 84054

---

**From:** Stephanie Childs <dncngqueen@gmail.com>  
**Sent:** Thursday, June 28, 2012 11:30 AM  
**To:** Lori Rammell  
**Subject:** Utah Healthcare

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I have four children and two of them have autism. This affects our entire family and everything we do. Because we have never qualified for assistance- I have had to learn and do most treatments myself. I am happy to do this for my children and am grateful that I have the ability but not every family does and it gets harder the older the children become. I have seen the progression in my own children with pro-active and persistent intervention therapy but I have also seen the lack of it when resources aren't available to others. Autism doesn't just affect the person diagnosed. It changes their parents' marriage, their siblings' opportunities and the communities in which they live. Schools are not equipped to handle the large amounts of children diagnosed with autism but they are sitting in the classrooms just the same. When families are able to meet the needs of their own children through the mentioned treatments, less strain is put on our school and communities. Enabling parents to raise their children and give them what they need is all I ask for. You have the power to give many parents the hope they are searching for- hope that their child will one day speak to them, look them in the eye or at the very least; not shutter from a loving embrace. These children and their families are amazing. Given the right tools, the walls of autism can be broken down piece by piece. Therapy is a part of the puzzle and without it, our children are incomplete and wandering.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Stephanie Childs  
3450 W Willow Trail Loop

Lehi, UT 84043

--  
happiness is a must but sanity is always optional.

---

**From:** Jessi Runia <jessirunia@hotmail.com>  
**Sent:** Sunday, July 01, 2012 1:02 PM  
**To:** Lori Rammell  
**Subject:** Autism Benefits

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I have a 7 (almost 8) year old daughter that we STRONGLY believe has Aspergers. I say believe because we have not yet gotten her assessed. Our health benefits don't cover this and it's expensive. We are trying to save up enough money so she can get the help she needs but it's a lot of money. She qualified for an IEP under the autism umbrella at her school (just more evidence for us). If we had the chance to get my daughter the help she needs I would take it in a heart beat. She is amazing and I think with just a bit of treatment will be able to do so many amazing things in this world. Why not give these kids a fighting chance.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Jessica Runia  
264 Bubblingbrook Ln  
Draper, Utah 84020

---

**From:** Ashli Crookston <ashli.crookston@gmail.com>  
**Sent:** Wednesday, June 27, 2012 6:01 PM  
**To:** Lori Rammell

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My nephew has been involved in various treatments and programs for Autistic children over the last few years. He has gone from not being able to say more than a few words to being in a normal classroom for most of the school day, learning to read, and even making friends. These programs have made an enormous impact in his life and in the lives of my family members.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Ashli Crookston  
212 S. 3475 W.  
Layton, UT 84041

---

**From:** Heidi Bitton <heidbitt@aol.com>  
**Sent:** Wednesday, June 27, 2012 5:50 PM  
**To:** Lori Rammell  
**Subject:** From Heidi Bitton, Democratic candidate, House District 29

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Children with ASD grow up to be adults with ASD. My children with ASD deserve a chance, as do the rest of Utah Autism families. We should not have to go bankrupt trying to do it ourselves, or move out of the state because it's not available to us here. My Charlie was diagnose PDD-NOS when he was 8, and our insurance will not cover anything. My 17 year old will be a senior this coming fall, and there are no resources to help him unless we travel to the University of Utah and pay out of pocket for everything. Is this the legacy you want Utah to be known for? We are already last in the nation for education. Let's not be last in the nation for ASD insurance reform that covers ALL diagnosed, with NO age cap.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Heidi Bitton  
Candidate, Utah House of Representatives, District 29  
2813 W North Plain City Rd  
Ogden, UT 84404

Heidi Bitton  
[heidbitt@aol.com](mailto:heidbitt@aol.com)

I don't care how much you know, until I know how much you care.

---

**From:** Shelli Preece <pandanvic@hotmail.com>  
**Sent:** Wednesday, June 27, 2012 4:47 PM  
**To:** Lori Rammell  
**Subject:** Autism essentials benefit package

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Shelli Preece  
164 Ross Drive  
Clearfield, Utah 84015

---

**From:** stephanie roach <violinstephanie@live.com>  
**Sent:** Wednesday, June 27, 2012 4:55 PM  
**To:** Lori Rammell  
**Subject:** Insurance Reform

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My son received intensive evidence-based treatment when he was 4 years old. As a result, he is now in 3rd grade in a mainstream setting and is doing well both academically and socially. When he was in preschool at the age of 3, before the treatment, 90% of the time the teacher spent with him was attempting to get him to pay attention or stop having a tantrum. School went from an experience filled with anguish for everyone involved: my son, his teachers, and us as his parents; to an experience that for the last 2 years has been positive and hopeful.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the latter part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Stephanie Roach  
7549 S 6670 W  
West Jordan, UT 84081

---

**From:** Ivan Garcia <gus\_ivan@yahoo.com>  
**Sent:** Wednesday, June 27, 2012 3:46 PM  
**To:** Lori Rammell  
**Subject:** Essential Autism Package

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

My beautiful 6 year old son, Parker, has had limited exposure to this specific treatment as my own insurance does not cover it in any meaningful way. I do what I can to take advantage of the limited hours of treatment I can afford to allow him to continue to progress. As a child with high functioning autism, he is truly in a position to take advantage of these treatments to allow him to grow into an independent and tax paying citizen of the future, but without your help I fear I will not be able to get him enough of the treatment that would benefit him.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Gus Ivan Garcia  
8183 Old Factory Drive.  
West Jordan, UT. 84088

---

**From:** Jen Crocker <hukajen@yahoo.com>  
**Sent:** Wednesday, June 27, 2012 4:06 PM  
**To:** Lori Rammell  
**Subject:** Comments

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

At the age of 2 we noticed there was something different with my son, he didn't talk and if he did pick up a new word it was quickly forgotten within a few days, as well as the need to touch just about everything. At the age of 3 he was diagnosed with PDD-NOS and Sensory Processing Disorder, now at the age of 4 and after a barrage of schools, doctors and therapists he can finally say 2 word sentences and sit in a chair for 45 minutes straight. Without evidence based treatments it frightens me to think where he would be today and I am very proud to say that after all of our hard work he will be mainstreamed into regular preschool and kindergarten classes starting next school year. We still have a long road ahead of us and it has not been easy by any means, we don't want to free load or abuse services that are not needed, we just want to be the best parents that we possibly can be and give him a chance to be a successful adult.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,  
Jen and Jeremy Crocker

---

**From:** F.A.A.S.T. <faastutah@gmail.com>  
**Sent:** Wednesday, June 27, 2012 4:30 PM  
**To:** Lori Rammell  
**Subject:** Utah Essential Benefits Package

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I don't think that I need to belabor anyone with our story of autism. The struggles we face are not all that different from my friends who have children who also have an ASD, they are trying, they are frustrating and often stretch our family budget further than permissible. I will be the first to say that we don't expect a handout, we don't expect a free lunch, but we do expect equality for our child who certainly did not ask to have autism. Would you expect anything else?

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely

James S. Vaughan  
Families of Autism and Asperger's Standing Together (F.A.A.S.T.)

<http://faastutah.weebly.com>

"Look up, get up and don't ever give up."

Michael Irvin, HOF Induction Speech, 2007

---

**From:** Stoll, Robert <StollR@aetna.com>  
**Sent:** Tuesday, July 03, 2012 10:09 AM  
**To:** Lori Rammell  
**Subject:** smart states will cover Autism treatment

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Robert Stoll  
1011 Millcreek Way,  
SLC, UT 84106

This e-mail may contain confidential or privileged information. If you think you have received this e-mail in error, please advise the sender by reply e-mail and then delete this e-mail immediately. Thank you. Aetna

---

**From:** Brandon Bosworth <bgbosworth@aol.com>  
**Sent:** Tuesday, July 03, 2012 8:56 AM  
**To:** Lori Rammell  
**Subject:** Inclusion of Autism health benefits

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Brandon Bosworth

---

**From:** Lisa F. Smith <lisafsmith@hotmail.com>  
**Sent:** Monday, July 02, 2012 9:33 AM  
**To:** Lori Rammell

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I am a mother of 5 children ages 4-14. Currently 2 of my children have been diagnosed with autism and 1 that is suspected of having autism. My other 2 children are currently being watched for signs of autism. The treatment that they need in order to be functional in society is expensive and not covered by our insurance (Altius). I have spoken with Dr. Ghandi in Farmington who says our insurance is the worst in the state for children diagnosed with autism. They are unable to receive social skills training, counseling, and dire treatment that would make them functional in society. Because of this the psychological issues associated with being ostracized and unable to understand and socially interact with others has taken its toll. My 9 year old daughter, Saedra, is suicidal. She has a plan that involves kitchen knives and runs away frequently stating that she "has no friends and wants to die." Instead of being a contribution to society she is a financial burden to society and financially we are unable to afford the help that she needs. Autism is not a choice. It is a physical and mental disability that impairs speech, cognitive reasoning, social functioning, physical mobility, and emotional stability. Without treatment Saedra may be successful in her attempts to end her life. Drugs and counseling will not address the issue that she is socially dysfunctional and that she needs that training in order to be successful in life. She will be unable to hold a job for a long period of time and will consistently have mental and emotional issues if not helped at a young age. There isn't time left for Utah congress to decide whether this is an important issue that needs to be taken care of. 1 in every 47 should be significant enough proof that it is an issue that needs to be dealt with and provided for. As these children with autism become untreated adults the consequences for society will be dire. Now is the time to act. Please help us and our children be successful rather than dependent.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Lisa Smith  
678 N Colonial Ave  
Layton, Utah 84041

---

**From:** Kimberly Jensen <kcjensen419@msn.com>  
**Sent:** Monday, July 02, 2012 9:03 AM  
**To:** Lori Rammell  
**Subject:** Support Autism

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

I have a 14 year old son with autism and I worry about his long-term care and providing him a quality of life. When he was diagnosed, I did not know one other child with autism and was lost it finding treatment options for him that were not "snake oil" or promises of "cures." We nearly mortgaged our home to finance unproven treatments to cure him. Instead we blazed our own trail and with the help of the State of Washington (where we lived at the time) were able to provide him much needed early intervention treatments at no cost. We moved to Utah and were shocked at the how little the state offered in services for our son. He remains on the waiting list for services with DSPD. If he had Down's Syndrome, he would have the services, because it is "medically proven."

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Kimberly Jensen  
2186 Cherry Meadows Lane  
Layton, UT 84040

---

**From:** Michalene Winkelspecht <mewinky8@gmail.com>  
**Sent:** Tuesday, July 03, 2012 3:55 PM  
**To:** Lori Rammell  
**Subject:** Autism Health Care

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptoms.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Michalene Winkelspecht

1565 Durocher Lane

Tooele, Utah 84074

---

**From:** Petersen, Brigitta A <bapetersen@graniteschools.org>  
**Sent:** Tuesday, July 03, 2012 4:14 PM  
**To:** Lori Rammell  
**Subject:** Insurance support for autism

Dear Utah Health System Task Force:

I am writing to ask you to please include evidence-based treatment for autism in the essential benefits package for Utah. Currently, Utah leads the nation in autism prevalence rates with 1 in every 47 children having some form of autism spectrum disorder. With treatment, 47% of children with autism can achieve normal intellectual functioning as opposed to just 2% of children who are left untreated. With treatment, 80-90% of children receiving evidence-based treatment show significant improvement of their autism symptom.

Including evidence based treatment for autism in the essential benefits package is relatively inexpensive - just \$0.44 - \$0.83 per member per month. The average cost of caring for an untreated individual with autism over their life span is as much as \$3 million dollars - most of which will be incurred in the later part of their lives. Providing coverage to treat autism in the early years of a person's life can save millions of dollars and result in independent adults that are able to contribute to the society in which they live rather than rely on others for their livelihood and well-being.

Currently there are 31 states with legislation requiring coverage for the treatment of autism. Aside from the basic humanity of caring for the children in Utah affected by autism, the state of Utah has an obligation to protect tax-payers from the expense of a large population of untreated individuals with autism. As a concerned Utah resident, I urge you to include evidence-based treatment for autism including behavioral health treatment, pharmaceutical care, psychiatric care, psychological care, therapeutic care (including occupational and speech therapy) and medical care.

Sincerely,

Brigitta Petersen  
4985 Atwood Blvd.  
Murray, UT 84107

**Brigitta Petersen**  
**Whittier Elementary School**  
**K-2 Special Education Autism Unit**



---

**From:** Rebecca Bowers <becca\_bowers@hotmail.com>  
**Sent:** Monday, July 02, 2012 11:21 PM  
**To:** Stewart Barlow; Rebecca; Lori Rammell  
**Subject:** Health Care

Stewart Barlow, MD

We are writing this letter to help you understand the great benefit and blessing that having a cochlear implant has brought to our children. We have two children who lost their hearing within the first few months after birth for reasons we don't know. We were able to get bilateral cochlear implants for both of my children before the age of 3. My children are now 4 and 6 years old and are doing awesome with their cochlear implants. My son is starting 1st grade in a mainstreamed school and is starting the school year knowing how to read. My husband and I are just so floored with his progress. My daughter who is 4 is picking up language left and right from her older siblings. Our kids are doing so wonderful! And we know that without the cochlear implants their progress would be extremely slower.

We can not express enough how important it has been for our children to get bilateral cochlear implants. We know that insurance company's claim that the cochlear implants are cosmetic, but they are not, they are a necessity! You can teach one child to talk but you can not teach everyone to sign. Our kids love their cochlear implants, and it gives them so much more opportunity than they would have otherwise. Our kids love to be able to be included, involved, and to simply know what's going on without having an interpreter. They can be independent and they know it and love it. We hope that this letter will help give you insight on cochlear implants, and the need for insurance coverage for them. Our two deaf children can talk today because of receiving cochlear implants. Please understand this is not a "cosmetic" procedure and is a vital necessity to allow children with hearing loss the same opportunities of others.

Thank you for your time,

Joshua and Rebecca Bowers

---

**From:** Clough Shelton <clough.shelton@hsc.utah.edu>  
**Sent:** Monday, July 02, 2012 3:04 PM  
**To:** Lori Rammell  
**Subject:** mandatory minimum health care coverage  
**Attachments:** 2012-07-02 TWIMC- Mandat Min.pdf

Please find attached a letter by me advocating insurance coverage for cochlear implants.

Thanks  
Clough

Typos courtesy of Dragon voice recognition software



Faculty

CLOUGH SHELTON, M.D.  
Professor and Chief  
Otolaryngology/Neurotology  
801-585-5450

BRANDON G. BENTZ, M.D.  
Associate Professor  
Head and Neck Oncology  
801-585-1626

LUKE O. BUCHMANN, M.D.  
Assistant Professor  
Head and Neck Oncology  
801-585-7143

J. FREDRIK GRIMMER, M.D.  
Assistant Professor  
Pediatric Otolaryngology  
801-587-3888

RICHARD K. GURJEL, M.D.  
Assistant Professor  
Otolaryngology/Neurotology  
801-585-1280

JASON P. HUNT, M.D.  
Assistant Professor  
Head and Neck Oncology  
801-587-3888

KATHERINE A. KENDALL, M.D.  
Associate Professor  
Laryngology & Swallow  
801-585-1260

JEREMY D. MEIER, M.D.  
Assistant Professor  
Pediatric Otolaryngology  
801-585-7143

STEVEN R. MOBLEY, M.D.  
Associate Professor  
Facial Plastic &  
Reconstructive Surgery  
801-585-5223

HARLAN R. MUNTZ, M.D.  
Professor  
Pediatric Otolaryngology  
801-662-5666

RICHARD R. ORLANDI, M.D.  
Professor  
Rhinitis and Sinus Surgery  
801-581-7515

ALBERT H. PARK, M.D.  
Professor  
Pediatric Otolaryngology  
801-581-7515

MARSHALL E. SMITH, M.D.  
Professor  
Laryngology  
Pediatric Otolaryngology  
801-662-5663

MICHAEL H. STEVENS, M.D.  
Adjunct Professor  
Otolaryngology -  
Smell & Taste Disorders  
801-585-1626

YONG WANG, Ph.D.  
Assistant Professor  
Research  
801-587-3846

P. DANIEL WARD, M.D.  
Assistant Professor (Clinical)  
Otolaryngology - Facial Plastics  
801-585-6580

KEVIN F. WILSON, M.D.  
Assistant Professor (Clinical)  
Otolaryngology - Allergy  
801-585-6580

July 2, 2012

Re: Mandatory Minimum Health Benefits for the on-line Health Exchange.

To Whom It May Concern:

I am writing to support the inclusion of cochlear implant coverage in the mandatory minimum health benefits. Cochlear implants are a medical prosthesis that is proven effective at rehabilitating deafness. They are standard therapy that is used for both children and adults.

Deafness is the number one birth defect in the United States. One would certainly expect health insurance coverage to cover treatment of a birth defect.

Deafness is an expensive disability. In 1995, the difference of educating a deaf child [K-12] in a residential deaf school versus a mainstream school was \$386,000. This data is from the State of Maryland, Department of Education Budget, 1995. This figure is now much larger. Also, in 2000 the estimated lifetime cost of deafness for congenitally deaf child was \$1,020,000. This encompasses decreased wages and earnings, social security insurance, and education costs.

For a deafened adult, a cochlear implant can make the difference in gainful employment and communicating with family and friends. For a deaf child, it can make the difference on whether one can learn to speak or not, which makes a huge difference in someone's earning potentials and quality of life. Mandatory coverage of cochlear implants is a small cost given the expense of deafness. By mandating cochlear implant coverage, the State of Utah would likely decrease its educational costs and also improve its tax revenue.

In biblical times, making a deaf person hear was called a miracle. Too often in Utah, it is called "not a covered benefit". As an ear surgeon, cochlear implantation is one of the most gratifying procedures that I do. It makes a huge difference for the patient, a lifetime of difference. I urge the Legislature to include cochlear implant coverage as part of the mandatory minimum health benefits.

Please do not hesitate to contact me if I can provide further information.

Sincerely,  
  
Clough Shelton, MD, FACS

Professor and Chief  
C. Charles Hetzel Jr., MD and Alice Barker Hetzel  
Presidential Endowed Chair in Otolaryngology  
CS: sc

All Correspondence to:

University of Utah School of Medicine  
50 North Medical Drive 3C120  
Salt Lake City, Utah 84132  
Fax 801-585-6744

Primary Children's Medical Center  
100 North Mario Capecchi Drive, Suite 4500  
Salt Lake City, Utah 84113  
Fax 801-587-3945

---

**From:** Louie Yilling <Louie.Yilling@medel.com>  
**Sent:** Thursday, June 28, 2012 7:42 AM  
**To:** Lori Rammell  
**Cc:** Clough Shelton; Gary Makowski; Richard Collette; Pat Macy  
**Subject:** RE: Cochlear Implants = excellent investment of taxpayer dollars  
**Attachments:** Cochlear Implant Significant Findings.pdf; Cochlear Implant life-changing benefits for Children.pdf

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

Hello –

We respectfully request that you consider cochlear implants as part of the "essential benefits" package, or bare minimum of health benefits mandatory for all policies sold on Utah's online health exchange.

The economic and social benefits of cochlear implants are long well established, we cannot more eloquently state this than the attached articles which we submit and ask that you review and consider. The economics add up to millions (adjusting figures in the attached articles for inflation) per individual in increased earnings potential and lower medical bills, and also benefits others as well thru better awareness of the now-hearing individual for safety precautions. The tremendous human side of the ability to hear could not be fully explained or measured - - to hear the voices of your loved ones, attend the same schools and pursue the same career opportunities as everyone else, relish the sounds of nature, etc – to fully participate in the world as we know it = priceless.

But with all the information available in the attached and in the public domain, we think the most compelling reason from the perspective of the State of Utah to ensure every child that can benefit from cochlear implants receives one is that that child will be able to have a more productive life, earning higher wages, and be able to pay more taxes. Many are quick to criticize but few are slow to appreciate the tightrope governments must walk to try to provide so much for so many in need with limited funds. *I myself have a daughter who mentally incompetent and is completely unable to care for herself - - but fortunately she at least will have some assistance by our state government (North Carolina) to supplement provisions my wife and I have made for her care after we are gone. I know Utah has similar provisions for your citizens as well. Nothing can be done about those who are mentally incompetent, they will always need the love and support of others. But many deaf children can be enabled to hear with cochlear implants.* By enabling a deaf child to fully participate in our hearing-dominant world, you would enable someone who might otherwise be drawing from public funds to be positioned to instead now contribute to public funds thru higher earnings potential and taxable wages.

Please be sure the sound and irrefutable benefits of the life-changing technology of cochlear implants is available to all children of Utah as an "essential benefit" in your healthcare packages.

Best regards,

Louie Yilling  
Director of Finance  
MED-EL Corporation  
Phone: 919-314-3028

**COCHLEAR IMPLANT  
OUTLINE OF SIGNIFICANT FINDINGS  
November 2000**

**INTRODUCTION**

Severe to profound hearing impairment affects millions of Americans. Unlike many clinical conditions, severe to profound hearing loss largely impacts the social welfare system rather than the medical care system. To function in a hearing society, hearing-impaired persons with this level of loss require specialized education, social services, and other resources.

Severe to profound hearing loss is expected to cost society an average of \$297,000 over the lifetime of an individual. Lifetime costs for those with pre-lingual onset of deafness exceeds \$1 million. The particularly high costs associated with pre-lingual onset suggest interventions aimed at children, such as medical intervention, may have a substantial payback. Medical technologies, such as the cochlear implant, have proven to be cost effective; however, while this device is not appropriate for all hearing-impaired individuals, implantation of this auditory prosthesis is extremely low among those who could benefit. Reimbursement rates for cochlear implants are extremely low (particularly under the Medicare and Medicaid programs) relative to the costs of implantation and pose a serious constraint on access for this population.

**CLASSIFICATION OF HEARING LOSS**

Complete audiometric evaluations are required to determine the functional status of a patient, including his or her response to speech presented at various loudness levels. An audiometric screening typically examines hearing thresholds (the lowest loudness level at which sound can be detected) across frequencies. Frequency, measured in Hertz (Hz) or cycles per second, is perceived as pitch. Intensity, measured in decibels (dB), is perceived as loudness. Decibel levels are used to classify the hearing impairment of patients. Typically, a patient who responds to all the tones or frequencies at a level between 0 and 20 dB is considered to have normal hearing. Patients whose auditory sensitivity is reduced and who can only detect tones at 21 dB or above are classified as hearing impaired in the categories ranging between mild and profound, depending on the loudness levels at which they respond. Using audiometric results, severe to profound hearing loss is commonly considered the inability to detect a sound at 70 decibels or greater in the better ear.

Classification	Mild	Moderate	Moderate-Severe	Severe	Profound
Intensity or Loudness	21 - 40 dB	41 - 60 dB	61 - 70 dB	71 - 89 dB	90+ dB

**SOCIETAL IMPACT OF SEVERE TO PROFOUND HEARING IMPAIRMENT**

➤ **AGE**

The severely to profoundly hearing impaired population is divided into five age cohorts, each representing life stages associated with the use of different types of economic resources. The five cohorts and their distribution by age include:

1. Prelingual (0 - 2 years) 11%
2. Prevocational (3 - 17 years) 1%
3. Early Working Age (18 - 44 years) 16%
4. Later Working Age (45 - 64 years) 34%
5. Retirement Age (65+ years) 38%

Source: Project HOPE calculations from the 1990-91 *National Health Interview Survey* and U.S. Census, 1991

➤ **EDUCATION LEVEL**

Of the severely to profoundly hearing impaired population, about 44% do not graduate from high school, compared to approximately 19% in the general population. 46% of the severely to profoundly hearing-impaired students graduate from high school and attend college, compared with 59% of the general population. Only 5% of the hearing impaired students graduate from college, compared with 13% of the general population.

Educational Level	Severely to Profoundly Hearing Impaired	US Population
Did not Graduate High School	44%	19%
High School Grad; Some College	46%	59%
College Graduate	5%	13%
Post-College	5%	9%

Source: Project HOPE calculations from the 1990-91 *National Health Interview Survey*

➤ **INCOME LEVEL**

Statistical data indicates that most of the severely to profoundly hearing impaired population are, on average, poorer than other Americans. More than half (53%) of the severely to profoundly hearing impaired population have family incomes of less than \$25,000 as compared to 36% of the general population.

Income Level	Severely to Profoundly Hearing Impaired	US Population
< \$10,000	15%	10%
\$10,000 - \$24,999	38%	26%
\$25,000 - \$49,999	33%	36%
\$50,000+	14%	29%

Source: Project HOPE calculations from the 1990-91 *National Health Interview Survey*

➤ **LABOR FORCE**

Many of the working-age adults in the severely to profoundly hearing impaired population are not in the labor force. Specifically, 42% of those with severe to profound hearing impairment between the ages of 18-44 years are *not* working compared to 18% of the general population.

Pop. in the Labor Force by Age	Severely to Profoundly Hearing Impaired	US Population
18-44 yrs	58%	82%
45-64 yrs	46%	73%
65-79 yrs	11%	16%
80+ yrs	2%	3%

Source: Project HOPE calculations from the 1990-91 *National Health Interview Survey*

➤ **INSURANCE COVERAGE**

While most of the severely to profoundly hearing impaired population have health insurance coverage, many in this population are covered exclusively under public insurance programs such as Medicare and Medicaid. Despite the relatively high overall insurance coverage rate of this population, many are covered by public payers with reimbursement rates that are substantially lower than that of the private payers.

Coverage Type	Severely to Profoundly Hearing Impaired	US Population
No Insurance	6%	14%
Public Only (Medicaid, Medicare)	31%	13%
Public/Private	40%	12%
Private Only	23%	61%

Source: Project HOPE calculations from the 1990-91 *National Health Interview Survey*

## ECONOMICS OF SEVERE TO PROFOUND HEARING IMPAIRMENT

### ➤ LIFETIME COSTS OF DEAFNESS BY AGE OF ONSET

Severe to profound hearing loss is expected to cost society an average of \$297,000 over the lifetime of an individual. Costs include both direct medical and nonmedical costs and indirect productivity losses associated with hearing loss.

Direct medical costs for the hearing impaired include the costs of diagnosis, periodic medical visits to assess the physical status of the ear as well as audiological evaluation of hearing and fitting of hearing aids, costs associated with other assistive devices and visits to a medical doctor for concomitant middle ear problems. Direct nonmedical costs include costs associated with special education and rehabilitation (including services of speech and language pathologists, educational audiologists, and vocational rehabilitationists).

Age of Onset	Lifetime Costs*
0-2 yrs	\$1,020,000
3-17 yrs	\$919,000
18-44 yrs	\$453,000
45-64 yrs	\$253,000
65+	\$43,000
All	\$297,000

Source: Project HOPE calculations from the 1990-91 *National Health Interview Survey* and U.S. Census, 1991 \*All costs are inflated to 1998 dollars using the Urban Consumer Price Index

Persons who experience severe to profound hearing loss before retirement are expected to earn only 50-70% of their non-hearing impaired peers and lose between \$220,000 and \$440,000 in earnings over their working life, depending on when their hearing loss occurs.

Cost Component	Percentage of Costs
Vocational Rehabilitation	1%
Assistive Devices, Medical Costs, and Other	11%
Special Education	21%
Lost Productivity	67%

Most of these losses (67%) are due to reduced work productivity and opportunity, although the use of special education resources among children contributes an additional 21%. About 60% of the special educational costs are for educating children in more intensive instructional settings, such as self-contained classrooms, with the remainder for supplemental services provided to students not in residential or day schools, such as speech/language therapy or sign language interpreters. Unlike many clinical conditions, severe to profound hearing loss largely impacts the social welfare system rather than the medical care system.

The magnitude of loss is directly related to age of onset, with persons experiencing severe to profound hearing loss in childhood incurring the largest expected costs. The expected lifetime cost of deafness for a child with prelingual onset **exceeds \$1 million**. By contrast, societal losses for persons who acquire their hearing loss later in life are expected to average \$43,000.

➤ **Lifetime Cost Comparison of Severe to Profound Deafness and Other Conditions**

The magnitude of difference between the lifetime costs of deafness and other conditions is so large, it warrants review.

Condition	Lifetime Costs
Severe to Profound Hearing Impairment	\$ 297,000
Schizophrenia	\$ 295,000
Epilepsy (noninstitutionalized with frequent seizures)	\$ 172,900
Rheumatoid Arthritis (25-year cost for young women)	\$ 130,500
Stroke	\$ 129,200
Near-Drowning	\$ 98,500
Accidents with Firearms	\$ 89,100

➤ **EDUCATIONAL RESOURCES**

An estimated 84 - 90% of deaf children are taught outside of traditional mainstream classes. These children may visit a resource room for a part of the school day, attend a self-contained classroom specifically for the disabled in a public school, or be enrolled in day or residential education in a school for the deaf. Costs range from \$6,100 per year for a resource room to \$53,200 for placement in a residential facility. In addition to more instructive assistance, rehabilitative support services, such as speech and language therapy, itinerant special education, interpretation, or vocational therapy, are typically required. Technological equipment may also be needed to enhance communication, such as closed caption decoders, telephone amplifiers, and improved sound systems in public venues (such as visual smoke alarms and computers).

The additional **annual** costs of educating a deaf child in a more intensive instructional setting alone have been estimated at \$18,800 for the State of Texas and \$20,600 for the State of California.

According to the National Longitudinal Transition Study (NLTS), a nationally-represented sample of secondary special education students, 80% of children age 13-17 who are not in residential facilities receive auditory training or speech/language therapy. The average time spent for these services was 174 hours annually. Approximately 57% of children age 3-17 used the resources of a tutor, reader, or sign language interpreter. Children making use of these services received, on average, 860 service hours per year, or 22 hours per week.

Hearing aid use varies among age groups, with a high proportion of severely to profoundly hearing impaired who are age 3 to 17 and the elderly using hearing aids (75 - 78%).

In studies comparing educational costs for specific disabilities, deafness is among the most costly, ranking just below the costs for educating the multiply disabled.

On the average, deaf students graduate from high school with language and academic achievement below that of a fourth grade student.

## Cost of Education Resources, Vocational Rehabilitation and Assistive Learning Devices

Component	Average Estimate (Median Cost)
Cost of residential school (per year)	\$53,200
Cost of day school (per year)	\$28,200
Cost of self-contained classroom (per year)	\$14,500
Cost of resource room (per year)	\$ 6,100
Regular-mainstream education (per year)	\$ 5,030
Cost of Vocational Rehabilitation	
Age - Youth	\$ 2,187
Age - 18 - 44	\$ 2,033
Age - 45 - 64	\$ 1,515
Cost of audiologist follow up exams	\$ 100
Comprehensive audiometric exam (MD)	\$ 235
Cost of diagnosis	\$ 880
Cost of periodic hearing aid evaluation	\$ 216
Cost of TTD/TTY (per device)	\$ 285
Cost of telephone amplifier (per device)	\$ 25
Cost of FM system (per device)	\$ 700
Cost of hearing aids (binaural)	\$ 4,000

Source: Department of Education's Office of Special Education and Rehabilitation Services; *Annual Report to Congress on the Implementation of Individuals with Disabilities Education Act, 1997.*

## THE COCHLEAR IMPLANT

### ➤ BACKGROUND

#### What is a cochlear implant?

A cochlear implant is an electronic device, comprised of internal and external components, that provides useful hearing and improved communication ability to individuals who are severely to profoundly hearing impaired and gain little or no benefit from hearing aids. At the present time, it is the *only* medical intervention that restores aspects of hearing for severely to profoundly hearing impaired individuals.

#### How does the cochlear implant differ from a hearing aid?

A hearing aid picks up sounds, makes them louder, and delivers the amplified sounds to the ear. The cochlear implant takes over the job normally done by the ear, particularly the cochlea, or inner ear.

#### How does the cochlear implant work?

- A microphone in a headpiece worn behind the ear picks up sound.
- The sound is converted into an electrical signal that is sent to a speech processor, a small unit that can be worn on a belt or behind the ear.
- A tiny computer chip in the unit converts the signal into an electrical code.
- The coded signal is transmitted to a tiny device that has been surgically implanted under the skin.
- The device decodes the signal and sends it down electrodes (very thin wires) threaded in to the cochlea.
- These signals in turn stimulate the auditory nerve.

### Number of cochlear implants performed annually

Approximately 3,000 implants were performed in the United States during 1999.

### Cost of implant

Total treatment costs, including cost of the implant device and required professional services, range from \$29,000 to \$60,000. According to 1997 data, total costs for a child were \$43,000, including the approximate \$20,000 cost of purchasing the cochlear implant device from a manufacturer.

## ➤ BARRIERS TO ACCESSING COCHLEAR IMPLANTS

### Lack of Professional Education

Many primary care physicians may be unaware of the availability and performance of the technology resulting in lack of patient referrals to appropriate specialists.

### Lack of Consumer Awareness

Potential candidates may be unaware of the technology.

### Social and Ethical Issues

Some members of the deaf community have argued against cochlear implants, especially for children born deaf.

### Financial Reimbursement

Low levels of insurance reimbursement for the device and associated professional services, especially from Medicare and Medicaid, does not adequately cover the costs of surgery and rehabilitation, resulting in a strong disincentive for hospitals to provide cochlear implantation.

## ➤ FINANCIAL REIMBURSEMENT

Insurance reimbursement that does not cover the costs of physicians, audiologists and hospitals limits access to cochlear implants. Differences between costs and reimbursements are particularly noticeable for Medicare and Medicaid. This is especially noteworthy since approximately 30% of severely to profoundly deaf individuals in the U.S. are covered *only* by public health insurance.

### Physician

On average, otolaryngologists (ear, nose, and throat specialists) spend three hours performing each implant surgery. Additionally, they spend an average of four hours before and after each surgical procedure in activities that are not reimbursed by insurance. The average hourly income of otolaryngologists, is approximately \$207 before professional expenses and \$93 after expenses. (Source: American Medical Association.)

When all of the hours physicians spend related to a cochlear implant surgery are taken into account (reimbursable and unreimbursable), private insurance reimburses on average, \$333 per hour; Medicare, \$192 per hour; and Medicaid, \$156 per hour.

### Otolaryngologist Reimbursement

Service	Estimated Avg. Hourly Income		Median Insurance Reimbursement		
	Before Expenses	After Expenses	*Private	*Medicare	*Medicaid
Implantation Surgery	\$207	\$93	\$333/hr	\$192/hr	\$156/hr

	Reimbursement Per Surgery (Based on Mean Averages)	\$2,422	\$1,332	\$1,013
--	---	---------	---------	---------

\*Includes unreimbursed time spent by physician before and after surgery

**Findings:**

- Private insurance reimbursement appears to cover physicians' estimated time costs in most cases.
- Medicare reimbursement is substantially lower than average private reimbursement, but may still be adequate enough to cover the cost of a surgeon's time.
- Medicaid reimbursement is lower on average than Medicare, and even the average rate may be insufficient to cover the time costs of most surgeons. Medicaid reimbursement rates for cochlear implant surgery varies widely across the country. The range of reimbursement rates for 33 Medicaid agencies varies from \$600 to approximately \$2,200, while 11 agencies report payment levels of less than \$1,000. Three Medicaid agencies report that implant surgery is not covered for children, while 11 agencies report that it is not covered for adults. In many states, reimbursement is so low that it provides a financial *disincentive* to almost all physicians performing this surgical procedure for Medicaid patients.

**Audiologist**

Audiologists perform a variety of procedures to evaluate candidates for cochlear implants before surgery and to try to achieve optimal performance during "aural rehabilitation" after surgery. Aural rehabilitation involves programming the device and teaching the patient how to use it. This is the most time-consuming of the procedures performed by audiologists, and is critical to the successful use of the implant. Varying estimates indicate average audiologists' salaries plus practice expenses range from \$40 - \$46 per hour. For aural rehabilitation, private insurance reimburses, on average, \$78 per hour; Medicare, \$52 per hour; and Medicaid, \$38 per hour.

**Audiologist Reimbursement**

Service	Estimated Avg. Hourly Income		Median Insurance Reimbursement		
	Not Including Expenses	Including Expenses	*Private	*Medicare	*Medicaid
Aural rehabilitation after surgery	\$20 - \$23	\$40 - \$46	\$78/hr	\$52/hr	\$38/hr

\*Excludes unreimbursed time spent by audiologist before and after surgery

**Findings:**

- On average, audiologists spend 8 additional hours before *and* after surgery on behalf of each patient in activities that are not reimbursed by insurance at all.
- For most audiologists, Medicare and Medicaid payment rates for aural rehabilitation are too low to cover the costs of this process. It is doubtful that reimbursement rates for other services performed by audiologists are high enough to offset this financial disincentive, especially in view of the additional, unreimbursed hours spent on behalf of each patient.

## Hospital

On average, hospitals report they pay \$20,850 to purchase cochlear implant systems from manufacturers. Private insurance reimburses an average of \$18,000 for the device. Medicare pays approximately \$14,500 if the surgery is performed on an outpatient basis and less than \$9,000 for the device plus other hospital costs if the surgery is performed on an inpatient basis. Medicaid reimbursement for the device cannot be adequately summarized with an average figure because of widely varying approaches to payment (only 8 of 44 state Medicaid agencies reported using a set fee to reimburse hospitals for purchase of a cochlear implant device).

### Hospital Reimbursement

Service	Median Purchase Cost	Median Insurance Reimbursement		
		Private	Medicare	Medicaid
Cochlear Implant System	\$20,850	\$18,000	\$14,500 (Part B, Outpatient Surgery) <\$9,000 (Part A, Inpatient Surgery)	*Varies greatly

\*There are numerous types of Medicaid Reimbursement Policies across the country for the cochlear implant device. The following table illustrates the numerous policies.

### Types and Prevalence of Medicaid Reimbursement Policies for the Cochlear Implant Device

Category	Number of States	Comments
DRG (no separate payment for device)	12	4 states report amounts ranging from \$10,500 to approximately \$50,000. No amounts reported for 8 states
Fee Schedule	8	All states report amounts ranging from approximately \$13,200 to \$18,500 Mean: \$15,060
Per-diem (no separate payment for device)	6	3 states report amounts ranging from approximately \$300 to \$900 No amounts reported for 3 states
Full invoice (cost) or full invoice plus markup	6	5 states report full invoice or cost reimbursed 1 state reports full invoice plus a markup
Case by case payment review	3	
No Medicaid fee for service	3	
Less than 100% of invoice	2	Fractions are about 80% and about 50%. In the latter case, agency will reimburse for either the device or the procedure, but not for both
Percent of charges	2	1 state reports 90% of charges 1 state did not report percentage
No payment for device	1	
No policy	1	
No agency response	7	

Source: Rand Health, May 2000

### **Findings:**

- Although device reimbursement is substantially higher with private payers, it still often fails to cover hospital costs for cochlear implant systems.
- Under Medicare reimbursement, hospitals typically lose about \$6,000 for each device purchased for outpatient surgery and more than \$10,000 for each inpatient surgery.
- Medicaid reimbursement varies widely across the country. In 18 states, accounting for 44% of the national Medicaid enrollment, the reimbursement is low enough to penalize hospitals financially for allowing access to cochlear implant surgery. For almost all of these 18 states, potential losses to hospital for the device range from approximately \$5,000 to \$20,000 per implant provided to a Medicaid enrollee.

### **SUMMARY**

Severe to profound hearing loss is expected to cost society an average of \$297,000 over the lifetime of an individual. Lifetime costs for those with pre-lingual onset of deafness will exceed \$1 million.

The cochlear implant offers significant economic benefits and costs savings, especially in children. The savings in special-education costs alone have been estimated to exceed the total cost of the cochlear implant by at least \$30,000 and as much as \$200,000 per child.

Studies have shown that profoundly deaf children who had more than two years experience with a cochlear implant were able to move out of special education into a mainstream setting at twice the rate of their age-matched peers without a cochlear implant.

Approximately 30% of severely to profoundly deaf individuals in the United States are covered only by public health insurance, such as Medicare and Medicaid.

Average reimbursement rates for the cochlear implant and related professional services are overall lower for Medicare than for private insurance and much lower for Medicaid than for Medicare. Additionally, Medicaid payment rates differ substantially across the country with the extent of any losses ranging from \$5,000 per device to up to approximately \$20,000 (in per-diem and no-reimbursement states).

Under Medicare, hospitals currently lose on average about \$6,000 and more than \$10,000 per outpatient and inpatient surgery, respectively on the device alone.

While private payers may be adequately reimbursing physicians and audiologists for services, hospitals are not receiving adequate reimbursement from private payers for the implant device.

Audiologists and physicians comment extensively that much of their unreimbursed time involves dealing with private and public insurers who do not know what cochlear implants are, understand why serving cochlear implant patients is so costly or why it might be appropriate to cover, authorize or reimburse a procedure. Substantially expanding access might increase awareness regarding these issues and decrease the amount of time professional providers spend dealing with insurance matters.

It appears that many physicians and audiologists are making financial sacrifices to care for the 3,000 individuals currently receiving cochlear implants each year. If cochlear implants are to be made accessible to larger numbers of qualified candidates, financial disincentives, created by

insurance reimbursement levels, need to be investigated. Changes in various aspects of Medicare and Medicaid payment policies are needed, particularly in the areas of reimbursement for the implant surgery, aural rehabilitation after surgery, and for purchase of the device.

# Cost-Utility Analysis of the Cochlear Implant in Children

André K. Cheng, MD, PhD

Haya R. Rubin, MD, PhD

Neil R. Powe, MD, MPH, MBA

Nancy K. Mellon, MS

Howard W. Francis, MD

John K. Niparko, MD

IMPAIRMENT OF HAIR CELL FUNCTION induces profound deafness in approximately 0.3% of children younger than 5 years.<sup>1,2</sup> Cochlear implants may affect the auditory rehabilitation of an estimated 200 000 US children with profound deafness who fail to benefit from conventional hearing aids. Rising health care costs, due in part to advances such as the cochlear implant, have led to pressures that discourage the use of cost-increasing technology. Two thirds of US health care plans cited "no timely cost-effectiveness data" as a barrier to reimbursement.<sup>3</sup> Policymakers, third-party payers, and pediatricians have called for more cost-effectiveness data on pediatric cochlear implantation.

Conversely, costs associated with profound deafness are already substantial. The expected lifetime cost to society for a child with prelingual onset of profound deafness exceeds US \$1 million, largely because of special education and reduced work productivity.<sup>4</sup> Cochlear implantation may result in a net savings to society if benefits translate into reduced educational costs and increased earnings.

A recent multicenter study of the cochlear implant in postlingually deaf adults reported a reasonable cost-utility of \$14 670 per quality-adjusted life-year (QALY) using the Health Utility Index (HUI).<sup>5</sup> Published cost-

**Context** Barriers to the use of cochlear implants in children with profound deafness include device costs, difficulty assessing benefit, and lack of data to compare the implant with other medical interventions.

**Objective** To determine the quality of life and cost consequences for deaf children who receive a cochlear implant.

**Design** Cost-utility analysis using preintervention, postintervention, and cross-sectional surveys conducted from July 1998 to May 2000.

**Setting** Hearing clinic at a US academic medical center.

**Participants** Parents of 78 profoundly deaf children (average age, 7.5 years) who received cochlear implants.

**Main Outcome Measures** Direct and total cost to society per quality-adjusted life-year (QALY) using the time-trade-off (TTO), visual analog scale (VAS), and Health Utilities Index—Mark III (HUI), discounting costs and benefits 3% annually. Parents rated their child's health state at the time of the survey and immediately before and 1 year before implantation.

**Results** Recipients had an average of 1.9 years of implant use. Mean VAS scores increased by 0.27, from 0.59 before implantation to 0.86 at survey. In a subset of participants, TTO scores increased by 0.22, from 0.75 to 0.97 (n=40) and HUI scores increased by 0.39, from 0.25 to 0.64 (n=22). Quality-of-life scores were no different 1 year before and immediately before implantation. Discounted direct costs were \$60 228, yielding \$9029 per QALY using the TTO, \$7500 per QALY using the VAS, and \$5197 per QALY using the HUI. Including indirect costs such as reduced educational expenses, the cochlear implant provided a savings of \$53 198 per child.

**Conclusions** Cochlear implants in profoundly deaf children have a positive effect on quality of life at reasonable direct costs and appear to result in a net savings to society.

JAMA. 2000;284:850-856

www.jama.com

utility ratios of pediatric cochlear implantation have been limited by using hypothetically estimated utilities<sup>6-9</sup> or visual analog scale (VAS) scores obtained from adult patients.<sup>10-12</sup> Empirical data are necessary, and utilities from adult patients may not capture the impact of issues unique to childhood deafness, including development and language acquisition.

We conducted a cost-utility analysis of the cochlear implant in children from the societal perspective using 3 different instruments to measure quality of life.

## METHODS

### Study Design

We conducted preintervention, postintervention, and cross-sectional surveys of parents of profoundly deaf children (average hearing loss  $\geq 90$  dB for both

**Author Affiliations:** Departments of Otolaryngology-Head and Neck Surgery (Drs Cheng, Francis, and Niparko and Ms Mellon), Medicine (Drs Rubin and Powe), Health Policy and Management (Drs Rubin and Powe), and Epidemiology (Dr Powe), Johns Hopkins University, Baltimore, Md.

**Corresponding Author and Reprints:** John K. Niparko, MD, Department of Otolaryngology, Division of Otolaryngology Neurotology, Johns Hopkins University, 601 N. Carolina St, Baltimore, MD 21287-0910 (e-mail: jnipark@jhmi.edu).

ears) each of whom have received or will receive a cochlear implant. The institutional review board of The Johns Hopkins Hospital approved the study. All participants gave informed consent. The VAS was mailed to parents of each child who received an implant at The Listening Center at Johns Hopkins. The HUI, appropriate only for children aged 5 years or older, was mailed to families of school-aged children who responded to the VAS. The time-trade-off (TTO), which is more demanding in time and emotions, was conducted as parental interviews during routine appointments, following standardized protocols with visual aids.<sup>13</sup>

To assess potential selection or recruitment bias, we compared sociodemographic and audiological characteristics and VAS scores of all participants (n=78) with subgroups that also completed the TTO (n=40) or HUI (n=22). We also compared these characteristics of study participants with characteristics of parents of children who had received an implant but who did not participate.

#### Measurement of Health Utility

Each parent rated his/her child's health state at survey, immediately before and 1 year before the implantation using the VAS and TTO instruments, and at survey and before implantation using the HUI.

The VAS is presented as a vertical 10-cm "feeling thermometer" with grid marks from 0 (death) to 100 (perfect health); respondents mark a number corresponding to perceived quality of life. In the TTO,<sup>14</sup> respondents are offered 2 alternatives. Alternative 1 is current health state (deaf without cochlear implant) for time *t* (rest of life expectancy). Alternative 2 is perfect health for time *x*. The *x* is then varied until the respondent is indifferent between the 2 alternatives, at which point health utility is expressed as *x/t*.

The HUI,<sup>15</sup> a population-based health utility instrument, postulates the domains of health as hearing, speech, vision, emotion, pain, ambulation, dexterity, cognition, and self-care. Respondents are mapped into 1 of 972 000

health states depending on their functional capacity based on a 15-question survey. For example, deafness without other comorbidities would generate a score of approximately 0.61 because in the derivation of the HUI, 532 nondeaf adults representing the general population rated the state of being deaf as 0.61 using the standard gamble.

Mean group VAS scores can also be transformed into TTO scores by a power function. Several investigators, in mapping the relationship between VAS and TTO scores obtained from individuals who completed both, found concordance in the formula  $TTO = 1 - (1 - VAS)^b$ , with *b* ranging from 1.55<sup>16</sup> to 1.61<sup>17</sup> to 1.81.<sup>18</sup> Transformed scores using these coefficients can be compared with empirically obtained TTO scores as another means of evaluating the validity of the TTO assessments.

Because of the possibility of recall bias in retrospective assessment of quality of life before the implantation, we also administered the instruments to parents of deaf children who were eligible but had not received an implant. Parents rated their children's health state at the time of the survey and 1 year ago. We also retested a small group of patients to assess test-retest reliability. For those who completed multiple instruments, Pearson correlations were calculated.

#### Measurement of Costs

Direct medical costs were estimated using the Medicare resource-based relative-value scale (RBRVS) for inpatient and outpatient preoperative, operative, and postoperative services covered by the Physician Fee Schedule,<sup>19</sup> average Medicare blended payment for hospital costs,<sup>20</sup> wholesale cost of the device, average cost per surgery of complications and device failure, processor upgrade costs, and patient-borne costs of warranty, loss or damage insurance, and batteries.

Wholesale device cost was used because this aspect of Medicare reimbursement is substantially below cost (Health Care Financing Administra-

tion Common Procedure Coding System code L8614, \$14 500 for outpatient surgery; diagnosis related group [DRG], 49; \$11 000 global fee for inpatient surgery).<sup>19,20</sup> Device, warranty, and battery costs were estimated as the average between the most common implants currently used at The Listening Center: Nucleus-24 (Cochlear Corp, Englewood, Colo) and Clarion (Advanced Bionics, Sylmar, Calif). An internal device failure rate of 0.2% was calculated based on observed failure rates in all children worldwide with the Nucleus-22 for over 5 years, the Nucleus-24 for over 1 year, and the Clarion for over 2 years (P. Parker, BA, Cochlear Corp, oral communication, October 1999; J. Grant, BA, Advanced Bionics, oral communication, October 1999). Because our observed complication rates have been lower than reported figures, we derived the costs of complications from a previous study of 2751 patients<sup>21</sup> to obtain more conservative and stable estimates.

Indirect costs included time off from work, travel expenses, change in educational costs, and change in future earnings. For time off from work, we estimated 4 hours per visit and a weighted-average salary based on employment status and sex. We used the parents' work until their children would be aged 18 years and then used the recipient's work; 3 days off were given at time of surgery. Change in educational costs was based on differences in school placement before and after receiving the implant as previously described.<sup>22</sup> Change in future earnings took into account differences in school placement and nondeaf and deaf employment rates and wages.<sup>1,4,23</sup>

#### Measurement of Life-Years

We used a life table to estimate remaining average life expectancy.<sup>24</sup> We assumed the cochlear implant would not alter life expectancy and that the implant would be used for the remainder of life.

### Calculation of the Cost-Utility Ratio

By definition,

$$\begin{aligned} \text{Cost-Utility} &= \frac{\text{Costs (in US\$)}}{\Delta (\text{QALYs})} \\ &= \frac{\text{Costs (in US\$)}}{\Delta (\text{Life-years} \times \text{Health Utility})} \end{aligned}$$

Health utility is the numerical valuation of one's quality of life on a linear scale from 0.00 (death) to 1.00 (perfect health). Both costs and benefits are discounted at the recommended 3% rate to express future expenses and earnings in today's dollars.<sup>25</sup>

We calculated cost-utility using 3 different utility instruments. To explore the effect of potential recall bias, we also calculated cost-utility using cross-sectional comparisons of preimplanta-

tion at-survey ratings of candidates with after implantation at-survey ratings of recipients.

### Sensitivity Analysis

We performed 1-way sensitivity analysis for both direct and total costs, varying the covariates about their ranges to test the robustness of the cost-utility analysis.

## RESULTS

### Study Population

Response rates were 78 (74%) of 105 eligible families for the VAS, 40 (77%) of 52 for the TTO, and 22 (73%) of 30 for the HUI. The 78 children had an average age of 7.5 years and had used their implants for an average of 1.9 years.

There was no significant difference in characteristics among the VAS, TTO, and HUI subgroups, nor between the recipient and candidate cohorts, in VAS scores or sociodemographic and audiological characteristics (TABLE 1). There were also no significant differences between recipients whose parents participated in the study and those who did not.

### Measurement of Health Utility

Mean VAS scores (n=78; age 7.5 years with 1.9 years of implant use) increased 0.27 on a scale from 0 to 1, from an immediately before implantation score of 0.59 to a postimplantation score of 0.86 (FIGURE and TABLE 2). Twenty-six respondents repeated the VAS a second time (average time, 9.6 months); test-retest correlation was 0.62. The mean (SD) retest response was slightly lower than the original response ( $\Delta$ , 0.02 [0.18]).

Mean TTO scores (n=40; age 7.4 years with 1.7 years of implant use) increased 0.22. The 1-year-before implantation score was 0.75, followed by an immediately before implantation score of 0.75 and an at-survey score of 0.97. When asked, the 40 TTO respondents reported that their 1-year-before and their immediately before VAS scores did not differ.

Mean VAS scores were transformed into TTO scores by the power function described in the "Methods." Transforming the VAS scores (0.59 preimplantation to 0.86 postimplantation) yielded scores of 0.75 to 0.95 ( $\Delta$ , 0.20), 0.76 to 0.96 ( $\Delta$ , 0.20), or 0.80 to 0.97 ( $\Delta$ , 0.17), respectively. This agreed with TTO results of 0.75 to 0.97 ( $\Delta$ , 0.22).

HUI scores (n=22; age 10.0 years with 2.8 years of implant use) increased 0.39, from 0.25 before implantation to 0.64 at survey. Of the 9 health domains, hearing and speech were solely responsible for the significant overall improvement in utility (Table 2).

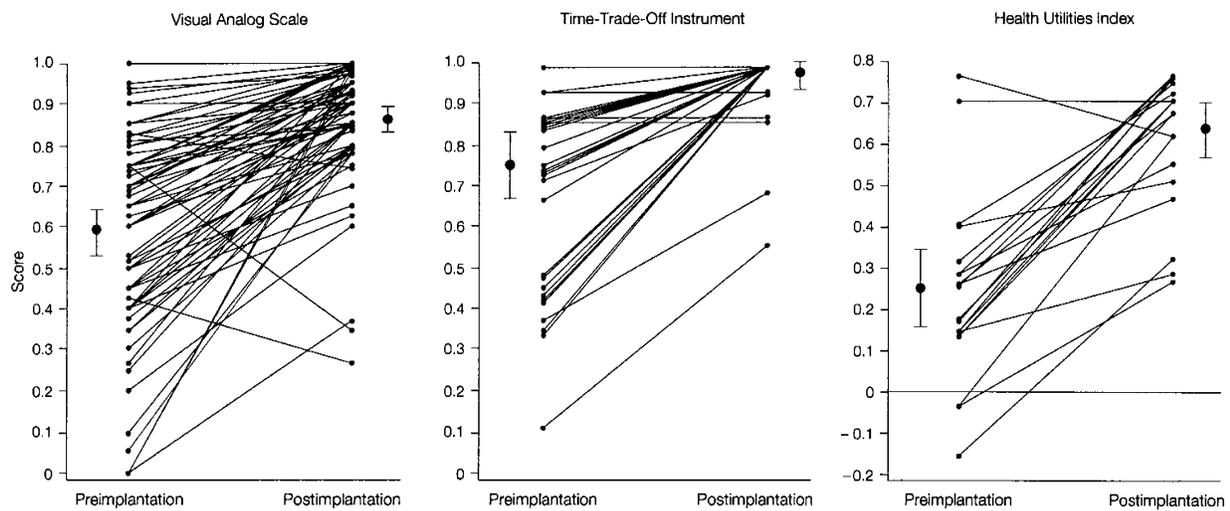
Ninety-two percent of parents perceived an improvement in quality of life in terms of VAS scores; 4% no change (n=3, representing 2 scores of 100 to 100; 1 of 90 to 90); and 4% a decrease (n=3). Of those with decreased scores, one patient required reimplantation, a

**Table 1.** Characteristics of Recipient Cohort\*

Characteristic	VAS (n = 78)	TTO (n = 40)	HUI (n = 22)
Current age, y, mean (SD)	7.5 (4.5)	7.4 (5.3)	10.0 (4.9)
Cochlear implant use, y, mean (SD)	1.9 (2.0)	1.7 (1.7)	2.8 (2.8)
Age at implantation, y, mean (SD)	5.7 (4.2)	6.1 (4.7)	6.4 (4.7)
Age at onset of deafness, y			
Prelingual (<3)	93	90	91
Perilingual (3-5)	3	10	9
Postlingual (>5)	4	0	0
Duration of deafness, y, mean (SD)	4.5 (3.6)	4.3 (4.3)	5.4 (3.9)
Origin of deafness, %			
Congenital	73	63	67
Meningitis	18	25	25
Progressive	9	13	8
Female child	46	44	40
Female parent	89	90	87
Parent age, y, mean (SD)	38.3 (6.1)	39.8 (5.2)	39.2 (5.0)
Parent race			
White	86	90	93
Black	5	2	0
Asian	2	0	0
Other	7	8	7
Parent education			
High school or less	18	22	13
Some college	23	20	24
College degree	29	34	26
Graduate degree	30	24	27
VAS scores			
Preimplantation mean (SD)†	0.59 (0.24)	0.58 (0.21)	0.69 (0.19)
Postimplantation mean (SD)	0.86 (0.14)	0.87 (0.12)	0.91 (0.08)
$\Delta$ mean (SD)	0.27 (0.23)	0.29 (0.18)	0.22 (0.17)

\*VAS indicates visual analog scale; TTO, time-trade-off; HUI, Health Utilities Index—Mark III. Data are presented as percentages unless otherwise indicated. Among the VAS, TTO, and HUI subgroups, there were no significant differences (ie,  $P < .05$ ) in any of the above characteristics, with statistical testing conducted by unpaired  $t$  tests for means or  $\chi^2$  test for proportions. Parent characteristics represent the responding parent.

†Preimplantation indicates surveys taken immediately before implantation.

**Figure.** Retrospective Health Utility Scores From Parents of Children With Cochlear Implants

The mean change in utility (postintervention–preintervention scores) was 0.27 for the visual analog scale, 0.22 for the time-trade-off instrument, and 0.39 for the Health Utilities Index. Mean scores (95% confidence intervals) are indicated by data points and error bars.

second patient had difficulty in rehabilitation, and third patient is doing well in language acquisition. Ninety-five percent of HUI scores improved and 5% decreased ( $n=1$ ); the one decreased HUI score correlated with a decreased VAS score. Seventy-eight percent of TTO scores improved and 22% had no change, reflecting the fact that a significant decrement in quality of life must generally occur before respondents are willing to trade-off years of life.

Pearson correlations were moderate between changes in VAS and TTO scores ( $n=40$ ;  $R, 0.57$ ), VAS and HUI ( $n=22$ ;  $R, 0.44$ ), and TTO and HUI ( $n=15$ ;  $R, 0.48$ ).

### Measurement of Costs

Using fiscal year 1999 data, lifetime direct medical costs of the implantation and associated services were \$60 228 at a 3% discount rate and \$51 900 at a 5% rate (TABLE 3). Five percent were preoperative costs; 9%, operative costs; 32%, device costs; and 55%, postoperative costs. Indirect costs were a reduction of \$113 426 at a 3% discount rate and a reduction of \$82 374 at a 5% rate, largely because of educational savings (TABLE 4) and increased future earnings. Combining all costs, cochlear implantation would

**Table 2.** Health Utility Scores Using 3 Different Instruments\*

Instrument	No. of Children Tested	Preimplantation Score	Postimplantation Score	$\Delta$
Visual analog scale	78	0.59 (0.53 to 0.64)	0.86 (0.83 to 0.89)	0.27 (0.22 to 0.32)
Time-trade-off	40	0.75 (0.67 to 0.83)	0.97 (0.93 to 1.00)	0.22 (0.15 to 0.28)
Health Utilities Index	22	0.25 (0.16 to 0.34)	0.64 (0.57 to 0.70)	0.39 (0.31 to 0.46)
Hearing		0.65 (0.61 to 0.68)	0.86 (0.83 to 0.89)	0.22 (0.17 to 0.26)
Speech		0.80 (0.75 to 0.84)	0.93 (0.91 to 0.94)	0.13 (0.09 to 0.17)
Emotion		0.96 (0.93 to 1.00)	0.99 (0.99 to 1.00)	0.03 (0.00 to 0.06)
Cognition		0.94 (0.91 to 0.98)	0.97 (0.95 to 0.99)	0.03 (–0.01 to 0.06)
Ambulation		0.98 (0.94 to 1.00)	0.99 (0.98 to 1.00)	0.01 (–0.01 to 0.04)
Vision		0.98 (0.95 to 1.00)	0.98 (0.94 to 1.00)	0.00 (–0.01 to 0.00)
Pain		1.00 (0.99 to 1.00)	1.00 (0.99 to 1.00)	0.00 (–0.01 to 0.00)
Dexterity		0.99 (0.97 to 1.00)	0.99 (0.97 to 1.00)	0.00 (0.00 to 0.00)

\*Data reported as mean (95% confidence interval). Preimplantation indicates surveys taken immediately before implantation.

save \$53 198 per child at a 3% discount rate and \$30 474 at a 5% rate.

### Measurement of Life-Years

The average age at implantation in our cohort was 5.7 years. With 54% males and 46% females, we projected an average life expectancy of 78 years and therefore 73 years of implant use.

### Cost-Utility Ratios

Direct medical cost per QALY was \$9029 per QALY using the TTO, \$7500 per QALY using the VAS, and \$5197 per

QALY using the HUI (TABLE 5). Before discounting, changes in utility were assumed to remain stable for the remainder of life. Differences between the preimplantation at-survey scores of candidates and the after implantation at-survey scores of recipients reflect similar improvements in utility, resulting in cross-sectional cost-utility ratios of \$10 131 per QALY using the TTO, \$8809 per QALY using the VAS, and \$5957 per QALY using the HUI (Table 5). Total cost per QALY, after incorporating indirect costs, was less than \$0.

**Table 3.** Lifetime Costs of Pediatric Cochlear Implantation (1999 US Dollars)\*

Variables	No. of Years	Costs, US \$
<b>Direct costs</b>		
Preoperative costs	1	2863
<b>Operative costs</b>		
Cochlear implant device	1	19 153
Hospital and surgery charges	1	4612
Medical complications, if any	1	710
Total operative	1	24 475
<b>Postoperative costs</b>		
Audiology follow-up	1-73	5148
Rehabilitation follow-up	1-2	8984
Device failure, if any	1-73	1007
Loss or damage insurance	1-73	4013
Extended warranty, external	4-73	7341
Special batteries	2-73	1293
Processor upgrade	2-73	5104
Total postoperative	2-73	32 890
<b>Total Direct Costs</b>		<b>60 228</b>
<b>Indirect costs</b>		
Time off from work†	1-73	4623
Travel expenses	1-73	4830
Parking expenses‡	1-73	589
Change in educational costs	1-13	-65 558
Change in future earnings§	14-73	-55 574
Special equipment	1-73	-1012
<b>Total Indirect Costs</b>		<b>-113 426</b>
<b>Total Costs</b>		<b>-53 198</b>

\*Assumes average age at implantation 5.7 years, 73 remaining years of life, and 3% discount rate. Negative numbers represent savings due to cochlear implantation. Criteria for cost estimates are available on request.

†Assumes time off from work as 4 hours per visit and 2080 work hours per year. Average parent salary based on employment (of the 40 participants 30% had full-time jobs, 18% had part-time jobs, 52% homemakers, and 0% were unemployed). By sex, full-time salary was \$35 345 for men and \$25 862 for women.<sup>23</sup> Homemaker salary estimated as median professional housekeeper salary of \$17 449<sup>41</sup>; part-time salary estimated as average of full-time and homemaker salaries. Parent's salary was deducted until the recipients became 18 years old, then recipient's projected salary was deducted.

‡Parking costs per visit were \$5; travel expenses per visit were calculated as round-trip miles between home city and Baltimore, Md (n = 69; 94 miles) multiplied by standard reimbursement rate of \$0.31/mile.<sup>26</sup>

§Differences between nondeaf and deaf employment rates and wages, tabulated by age groups 18-44, 45-64, and 65 years or older, suggest a lifetime earning gap of \$421 768 (\$148 198 after discounting).<sup>1,4,23</sup> Increased earning potential was based on 75% of those attending mainstream classes to attain the average nondeaf employment profile and the rest of the cohort to remain at the average deaf employment profile.

**Table 4.** Educational Placement and Costs\*

Placement	Cost per Year, US\$†	Percentage of Patients (n = 44)		
		Preimplantation	Postimplantation	Change
Mainstream class with hearing peers	6680	13‡	63	50
Partial mainstream	13 521	4	5	1
Self-contained class with deaf peers	15 801	71	27	-44
State school for the deaf, day student	31 728	13	5	-8
State school, residential student	45 948	0	0	0
Average cost per year, \$		16 753	10 737	-6016

\*Average current age 6.6 years, with 2.3 years implant experience. Negative numbers represent savings due to cochlear implantation. Preimplantation indicates surveys taken immediately before implantation.

†From the 1995 budget of the Maryland Department of Education as previously described,<sup>22</sup> inflated to 1999 dollars using the Consumer Price Index for All Urban Consumers.<sup>27</sup>

‡Consistent with 10% for deaf children without cochlear implants in 2 national surveys.<sup>28,29</sup>

### Sensitivity Analysis

Varying relevant covariates about their ranges still generated consistently favorable cost-utility results (TABLE 6).

### COMMENT

This analysis suggests that the cochlear implant is highly cost-effective in children, with a net expected savings of \$53 198 over a child's lifetime. Considering only direct medical costs yields cost-utility ratios of \$9029 per QALY using the TTO, \$7500 per QALY using the VAS, and \$5197 per QALY using the HUI. For public policy, cost-utility analysis is useful because its measure of benefit—the QALY—incorporates the dimensions of both quantity and quality of life, permitting comparison of all interventions on a uniform scale. Medical interventions with a cost-utility less than \$20 000 to \$25 000 per QALY are generally considered to represent acceptable value for money, ie, cost-effective.<sup>30,31</sup> The cost-utility of pediatric cochlear implantation compares favorably with many other procedures that use implants, including (inflated to 1999 dollars<sup>32</sup>) the defibrillator implant, which costs \$34 836 per QALY<sup>33</sup>; knee replacement, \$59 292/QALY<sup>34</sup>; and adult cochlear implantation, \$11 125 per QALY,<sup>35</sup> using the VAS; \$16 061 per QALY<sup>5</sup> using the HUI. Previous pediatric cochlear implant studies, all postulating hypothetical or adult utilities and performed in England or Australia, reported cost-utility ratios ranging from less than \$0 to \$25 942 per QALY,<sup>6-12</sup> generally including educational savings but being inconsistent in treatment of other costs. To our knowledge, this is the first cost-utility study of pediatric cochlear implantation that uses US cost data or directly elicits utilities from recipients or their parents.

Of the 7 empirical adult studies, 4 used the VAS, 2 used the HUI, and 1 used the Quality of Well-being Scale.<sup>36</sup> This is the first cochlear implant study to use the TTO. The TTO elicited robust gains in utility, but the scores were consistent with transformed VAS scores using established power functions de-

scribed in the literature. The preoperative baseline TTO score may be considered conservative compared with an average standard gamble score (generally similar to TTO) of 0.61 for being deaf obtained in the derivation of the population-based HUI. The TTO and standard gamble scores for being deaf from the general population may therefore require further assessment. Comparing benefits to direct costs, all 3 instruments yielded favorable results, ranging from \$5197 to \$9029 per QALY. This convergence of results provides confidence that the true cost-utility lies within or close to this range. Varying other covariates in a sensitiv-

ity analysis confirms the robustness of this analysis.

Several limitations of our study deserve comment. Recall bias, inherent in any retrospective study, may have caused overestimation of utility gains. However, recall bias in cochlear implant patients' preoperative utilities may be less substantial. Patients revisit the state of being deaf when the processor is removed daily for bathing and sleeping, when the battery power is exhausted, and when equipment failure is experienced. Patients and their families probably appreciate the communication and sensory difficulties of profound deafness even many years after

cochlear implantation. Consistent with this, candidates similar in key characteristics generated prospective preoperative scores nearly identical to recipients' retrospective preoperative scores.

Parental proxy bias also may have caused overestimation of utility gains.<sup>37,38</sup> We thought it necessary and desirable to use hearing parents as proxies because average age of those at the time they received their implants was younger than 5 years and as young as 1 year, greater than 90% of deaf children are born to hearing parents, and parents must make this decision. However, future longitudinal assessments that include self-reported

**Table 5.** Cost-Utility of the Cochlear Implant in Children Using Direct Medical Costs\*

	Cochlear Implant Recipients						Cochlear Implant Candidates		
	No. of Children Surveyed	Preimplantation†	Postimplantation	Gain in Utility†	Gain in QALYs†	Cost-Utility Cost per QALY, US \$†	No. of Children Surveyed	At Survey	Cost-Utility Cost per QALY, US \$‡
TTO	40	0.75	0.97	0.22	6.54	9209	32	0.77	10 131
VAS	78	0.59	0.86	0.27	8.03	7500	48	0.63	8809
HUI	22	0.25	0.64	0.39	11.59	5197	12	0.30	5957

\*Assumes average age at implantation 5.7 years, 73 remaining years of life, direct medical costs of \$60 228, and 3% discount rate. QALY indicates quality-adjusted life-year; TTO, time-trade-off; VAS, visual analog scale; and HUI, Health Utilities Index—Mark III.

†Determined retrospectively, based on recipients' preimplantation (immediately before implantation) and postimplantation utilities.

‡Determined cross-sectionally, based on candidates' preimplantation utilities and recipients' postimplantation utilities.

**Table 6.** Sensitivity Analysis Using Time-Trade-Off Instrument\*

Variables	Base Estimate	Range of Estimate (Best Case to Worst)	Direct Costs, US \$, Cost-Utility Cost per QALY (Base Case, 9209)	Total Costs, US \$, Savings to Society (Base Case, -53 198)
Gain in health utility	0.22	0.39 to 0.10	5196 to 20 278	...
Implant use, y	73	90 to 40	8966 to 10 719	-52 467 to -39 169
Discount rate, %	3	0 to 5	4987 to 10 912	-131 066 to -29 474
Direct medical costs, US \$	60 228	31 856 to 99 678†	4871 to 15 241	-84 263 to -16 441
Cochlear implant device	19 153	14 027 to 37 016‡	8425 to 11 940	-58 324 to -35 335
Surgery	4612	3000 to 10 000	8963 to 10 033	-54 810 to -47 810
Audiology and rehabilitation, US \$	14 133	7381 to 17 067§	6755 to 10 770	-59 950 to -50 264
Warranty and insurance, US \$	11 354	0 to 11 354	7473 to 9209	-64 552 to -53 198
Frequency of processor upgrades	2	0 to 6	6755 to 10 770	-58 302 to -42 990
Time off from work, hours per visit	4	0 to 8	...	-57 821 to -48 982
Salary, parent taking time off, US \$	21 209	0 to 100 000	...	-57 821 to -38 547
Travel distance, miles	47	5 to 200	...	-56 353 to -48 056
Additional children mainstreamed, %	50	70 to 30	...	-85 449 to -45 667
Gain in future earnings, US \$	-55 574	-148 198 to 0¶	...	-145 822 to 2376
Special living equipment, US \$	-1012	-38 374 to 0#	...	-90 560 to -52 186

\*All costs and benefits discounted at 3% per year. Negative numbers indicate savings; ellipses, no change; and QALY, quality-adjusted life-year.

†Minimum costs represent preoperative evaluation, operative costs, and 1 year of audiology and rehabilitation only; maximum costs represent summing maximum estimates of all direct costs.

‡Range of reported device costs in a recent multicenter study.<sup>5</sup>

§Length of rehabilitation therapy depends on age, school, and preoperative hearing; base case represents median length of 1.5 years, with a range of 1 to 2 years.

||Two lifetime processor upgrades consistent with observation that approximately one third with 10 years' implant use have upgraded (The Listening Center, unpublished data, 2000); provided is range of 0% to 100% of recipients upgrading every 10 years.

¶\$148 198 represents discounted lifetime earnings gap between average nondeaf and deaf individual.<sup>1,4,23</sup>

#\$38 374 represents discounted savings in special living equipment estimated in a previous study.<sup>6</sup>

ratings from the older children would be informative.

This study is also subject to potential selection bias, only representing deaf children who have received or will receive an implant at a large tertiary care center. It does not include those who did not receive implants for ideological, medical, or insurance-related reasons, nor does it address the controversy within the deaf community about adverse effects on deaf culture.<sup>39</sup> However, ability to pay has no bearing on candidacy at The Listening Center, which we currently regard as "no substantial growth in speech sound recognition and age-appropriate verbal language abilities despite continued use of powerful hearing aids, fit for both ears."<sup>40</sup> We also demonstrated no recruitment

bias among the VAS, TTO, and HUI subgroups by comparing key characteristics. Our cohort had higher socioeconomic status than the general population, but utilities were similar across strata of parent educational level.

Our estimates of indirect costs are probably conservative. In our cohort, with average implant experience of 2.3 years, 63% attended mainstream school classes, compared with 75% with at least 4 years' experience in a previous study.<sup>22</sup> Of those in mainstream classes, we only assumed that 75% (instead of 100%) would attain the average nondeaf employment profile. The rest of the cohort is assumed to remain at the average deaf employment profile, a probable underestimation of earnings. One study

estimated a savings of \$38 374 in special living equipment after implantation<sup>6</sup>; we only included the commonly used telephone text device.

In summary, direct medical cost ranged from \$5197 to \$9207 per QALY using 3 utility instruments and total cost per QALY was less than \$0. The cochlear implant is extremely cost-effective, generating important health benefits in children at reasonable direct costs and providing a net savings to society.

**Funding/Support:** This work was supported in part by a training grant from the National Institute on Deafness and Other Communication Disorders (Dr Cheng) and grants from the Deafness Research Foundation (Drs Cheng and Niparko), the Advisory Board Foundation (Drs Cheng and Niparko), and the Sidmore Family Foundation (Drs Rubin and Niparko).

**Acknowledgment:** We thank Conan Dickson, MPH, Colleen Lee, MHS, Kanwal Minhas, MBA, and Alan Murphy, MHS, for their assistance in providing cost data.

## REFERENCES

- Reis R. Prevalence and characteristics of persons with hearing trouble: United States, 1990-1991. *Vital Health Stat 10*. 1994;1.
- Blanchfield B, Dunbar J, Feldman J, Gardner E. *The Severely to Profoundly Hearing Impaired Population in the United States: Prevalence and Demographics*. Bethesda, Md: Project HOPE Center for Health Affairs; 1999.
- Steiner CA, Powe NR, Anderson GF. The review process used by US health care plans to evaluate new medical technology for coverage. *J Gen Intern Med*. 1996;11:294-302.
- Mohr P, Feldman J, Dunbar J, et al. The societal costs of severe to profound hearing loss in the United States. *Int J Tech Assess*. In press.
- Palmer CS, Niparko JK, Wyatt JR, Rothman M, de Lissovoy G. A prospective study of the cost-utility of the multichannel cochlear implant. *Arch Otolaryngol Head Neck Surg*. 1999;125:1221-1228.
- Hutton J, Polit C, Seeger T. Cost-effectiveness of cochlear implantation of children: a preliminary model for the UK. *Adv Otorhinolaryngol*. 1995;50:201-206.
- Lea AR. *Cochlear Implants*. Canberra: Australian Institute of Health; 1991. Health Care Technology Series No. 6.
- Lea AR, Hailey DM. The cochlear implant: a technology for the profoundly deaf. *Med Prog Technol*. 1995;21:47-52.
- Carter R, Hailey D. Economic evaluation of the cochlear implant. *Int J Tech Assess*. 1999;15:520-530.
- Summerfield AQ, Marshall DH. *Cochlear Implantation in the UK 1990-1994*. London, England: MRC-INR, HMSO; 1995.
- Summerfield AQ, Marshall DH, Archbold S. Cost-effectiveness considerations in pediatric cochlear implantation. *Am J Otol*. 1997;18:S166-S168.
- O'Neill C, O'Donoghue GM, Archbold SM, Normand C. A cost-utility analysis of pediatric cochlear implantation. *Laryngoscope*. 2000;110:156-160.
- Gudex C. *Time Trade-off User Manual: Props and Self-Completion Methods*. York, England: Centre for Health Economics, University of York; 1994.
- Torrance GW, Thomas WH, Sackett DL. A utility maximization model for evaluation of health care programs. *Health Serv Res*. 1972;7:118-133.
- Feeny D, Furlong W, Barr RD, Torrance GW, Rosenbaum P, Weitzman S. A comprehensive multi-attribute system for classifying the health status of survivors of childhood cancer. *J Clin Oncol*. 1992;10:923-928.
- Stiggelbout A, Eijkemans M, Kiebert G, Kievit J, Leer J, De Haes H. The "utility" of the visual analog scale in medical decision making and technology assessment. *Int J Tech Assess*. 1996;12:291-298.
- Torrance GW. Toward a utility theory foundation for health status index models. *Health Serv Res*. 1976;11:349-369.
- Loomes G. *Disparities Between Health State Measures: An Explanation and Some Implications*. York, England: Dept of Economics, University of York; 1988.
- Smith SL, Gallagher PE. *Medicare RBRVS: The Physician's Guide*, 1999. Chicago, Ill: American Medical Association; 1999.
- American Medical Association. *Health Care Financing Administration Common Procedure Coding System*. Chicago, Ill: American Medical Association; 2000.
- Wyatt JR, Niparko JK, Rothman M, deLissovoy G. Cost utility of the multichannel cochlear implants in 258 profoundly deaf individuals. *Laryngoscope*. 1996;106:816-821.
- Francis HW, Koch ME, Wyatt JR, Niparko JK. Trends in educational placement and cost-benefit considerations in children with cochlear implants. *Arch Otolaryngol Head Neck Surg*. 1999;125:499-505.
- US Department of Commerce, Bureau of the Census. *Income 1998*. Available at: <http://www.census.gov/hhes/income98>. Accessed May 1, 2000.
- US Department of Commerce, Bureau of the Census. *Statistical Abstract of the United States, Expectation of Life and Expected Deaths*. Washington, DC: US Government Printing Office; 1992.
- Gold MR, Siegel JE, Russell LB, Weinstein MC. *Cost-effectiveness in Health and Medicine*. New York, NY: Oxford University Press; 1996.
- US Department of the Treasury, Internal Revenue Service. *Form 2106, Unreimbursed Employee Business Expenses*. Washington, DC: US Dept of Treasury, Internal Revenue Service; 1999.
- US Department of Labor, Bureau of Labor Statistics. *Consumer Price Index for All Urban Consumers*. Washington, DC: US Dept of Labor, Bureau of Statistics; 2000.
- 1997-98 Annual Survey of Deaf and Hard-of-Hearing Youth. Washington, DC: Gallaudet Research Institute; 1999.
- US Department of Education, Office of Special Education and Rehabilitative Services. *Annual Report to Congress on the Implementation of Individuals With Disabilities Education Act, 1997*. Washington, DC: US Dept of Education; 1997.
- Azimi NA, Welch HG. The effectiveness of cost-effectiveness analysis in containing costs. *J Gen Intern Med*. 1998;13:664-669.
- Kind P, Gudex CM. Measuring health status in the community: a comparison of methods. *J Epidemiol Community Health*. 1994;48:86-91.
- US Department of Labor, Bureau of Labor Statistics. *Consumer Price Index for All Urban Consumers: Medical Care Component*. Washington, DC: US Dept of Labor; 2000.
- Larsen G, Manolis A, Sonnenberg F, et al. Cost-effectiveness of the implantable cardioverter-defibrillator: effect of improved battery life and comparison with amiodarone therapy. *J Am Coll Cardiol*. 1992;19:1323-1334.
- Drewett R, Minns R, Sibly T. Measuring outcome of total knee replacement using quality of life indices. *Ann R Coll Surg Engl*. 1992;74:286-289.
- Wyatt J, Niparko J. Evaluating the cost effectiveness of hearing rehabilitation. In: Cummings C, Frederickson J, Harker L, Krause C, Schuller D, eds. *Otolaryngology-Head and Neck Surgery Update*. 2nd ed. St Louis, Mo: Mosby Yearbook; 1995:112-125.
- Cheng AK, Niparko JK. Cost-utility of the cochlear implant in adults: a meta-analysis. *Arch Otolaryngol Head Neck Surg*. 1999;125:1214-1218.
- Theunissen NC, Vogels TG, Koopman HM, et al. The proxy problem: child report versus parent report in health-related quality of life research. *Qual Life Res*. 1998;7:387-397.
- Achenbach TM, McConaughy SH, Howell CT. Child/adolescent behavioral and emotional problems: implications of cross-informant correlations for situational specificity. *Psychol Bull*. 1987;101:213-232.
- Lane H, Bahan B. Ethics of cochlear implantation in young children: a review and reply from a Deaf-World perspective. *Otolaryngol Head Neck Surg*. 1998;119:297-313.
- NIH Consensus Development Panel. Cochlear implants in adults and children. *JAMA*. 1995;274:1955-1961.
- Healthcare salary data Web site. Available at: <http://www.wageweb.com/health1.htm>. Accessed May 1, 2000.

---

**From:** Stephanie Clegg <sc1@ssummit.org>  
**Sent:** Wednesday, June 27, 2012 6:02 PM  
**To:** Lori Rammell  
**Subject:** Health insurance coverage

To Whom It May Concern:

My name is Stephanie Clegg and I am writing to plead for you to include cochlear implants in the minimal health care coverage for all policies sold in Utah's health exchange. I am the mother of a four year-old daughter that has severe to profound hearing loss in both ears. What that means is that without hearing aids, she can only hear very loud things like motorcycles and lawn mowers. With hearing aids she can hear almost everything. However, she cannot hear all speech sounds such as s, th and f.

A year ago she qualified for a cochlear implant, based on the criteria of audiologists, speech therapists, and surgeons. Yet our insurance company denied her multiple times, stating that she could hear an average of 10 – 5 decibels more than their criteria.

Unfortunately my daughter's hearing continued to deteriorate and eventually met the insurance companies criteria. Thankfully my daughter just received her implant two days ago, however I hate to think about what progress she could have made this past school year had she received her cochlear when she originally qualified.

My daughter will be entering Kindergarten in the fall, with the speech development of a two year-old. Hopefully, she will soon catch up to her peers and the average person will not notice any speech delays. I feel that we lost a year of growth and opportunities for my child and that is difficult to accept simply because some individuals that have never met her have previously set certain criteria without possible exceptions.

Cochlear implants are just one of medicine's amazing new advancements and when a hearing-impaired individual qualifies for an implant and has the opportunity to hear please do not deny them that opportunity.

Sincerely,

Stephanie Clegg  
Art Teacher - South Summit High School  
UAEA President - Elect  
[sc1@ssummit.org](mailto:sc1@ssummit.org)

---

**From:** Scrap-n-Craft <scrap-n-craft@comcast.net>  
**Sent:** Tuesday, July 03, 2012 11:22 AM  
**To:** Stewart Barlow; Lori Rammell  
**Subject:** Setting Utah's Health Minimums {Hearing Impaired Children}

Dear Task Force Members,

First, thank you for allowing public comment. Second, may I tell you a little about my experience with health care and how impactful it has been for our family.

For 7 years we as parents were told that we should implant our daughter, and we kindly accepted their info and discussed it and as she got older we talked about it. However, we did not want to implant our daughter unless it was the only right thing to do...and we did not foresee that until last summer. In the last few years it has become standard to implant babies who are deaf, when our daughter was born this was not the case. Without going into the full story, let me say that the decision to have cochlear implant surgery was not made lightly, and it was not made without Savanna. Savanna had a big role in whether or not we were going to follow through past the information stage. We were doing this for several reasons, but mainly because it because it was now right for Savanna.

Do we see anything wrong with Savanna being deaf? NO. Absolutely NOT! We love Savanna however she is a very social child, and if you knew her you would attest to this, we made this decision after very careful consideration, we did not take this lightly.

This is from a letter that was sent on behalf of my daughter (response to an insurance denial): "Savanna has had to struggle against great odds. I began teaching her when she was 3. Imagine a 3 year old with no language. That's the student that entered preschool when Savanna entered. If you have children or grandchildren, think of the treasured first words, the terrible twos as they begin to assert themselves and show understanding of language and put together their sentences. What trauma for a family and child to be deprived so early, and have to spend years trying to make up for what is missed. The expertise of my colleagues is helping her, BUT let me caution you, all the educational expertise in deafness can never do for a child what hearing the language around them does. What children at 4 or 5 have fully ingrained in their language development, 20 years ago I was still trying to teach to the high school students. Today, I'm finding the deaf children with cochlear implants are starting to reach that same achievement by 4 to 6 {years of age}, that the hearing 4 and 5 years olds peers have. It's astounding. The cochlear implant is today's standard of care and medical necessity. Please, for the sake of Savanna, give her the chance she deserves to live the life that her hearing peers take for granted."

Implanting Savanna is what was right for her, and it was the right time. We only want the best for her...not for anyone but for her. My husband and I have a deep love for the deaf community, we respect the deaf community and we respect the right for anyone asl or lsl (listening & spoken language) to choose what is best for them or their child and we ask for that same respect. Again, we did not come to this decision lightly...this took over 6 1/2 years, and it was only made after speaking to Savanna and taking her to see what is involved and to try to make sure she fully understands (as well as a 7 year old can) what the pros and cons are. There is absolutely nothing wrong with her being deaf. Savanna will always be deaf...now will she be aided? YES. But, at any time she can take those aids off and she will be deaf.

Since being implanted last December and having it turned on in January Savanna has made drastic enough language and listening improvements that we were able to decide at the end of May to move her from the Utah Schools for the Deaf & Blind in Salt Lake to her home school in Heber City. This will be great socially, but it will also reduce her daily travel time from 2 1/2 hours to a matter of a few minutes.

Savanna's life has forever been changed because she is able to hear with 2 ears, not just partially with one ear.

Everyone is talking about Obama Care/Affordable Care Act and how it will play into healthcare changes in our state. How can we make it more affordable? Accessible? Regardless of what the outcome is of the PPACA we will end up with some changes whether it is federal or state run, there are important messages about hearing loss that insurance companies, doctors, and the government need to consider when designing minimum standards.

There is an urgent need to provide hearing aids and services that are appropriate for each individual. Individuals with profound hearing impairment may benefit from a cochlear implant (CI). Each individual's needs should be evaluated and decided based on their needs, some may need one or two hearing aids, one or two cochlear implants or one of each. No one plan will work for every individual. The medical teams that have been involved in determining eligibility here in Utah have been quite good at making sure that they are doing their very best to determine and meet the needs of Utahns who are in need of hearing devices.

**IT IS MANDATORY FOR INSURANCE TO COVER HEARING DEVICES (hearing aids as well as cochlear implants).**

With cochlear implants, though, the fact is that they work and, in the vast majority of cases, save society money in the long run by enabling our children to be hearing, speaking fully functioning members of society who do not need to rely on special services, such as interpreters, to communicate in the work place or with the rest of the world.

Some label cochlear implants as "optional" which is misleading: "optional" services are medically necessary for those who use them. Most states cover the optional services that have previously been targeted for elimination in Utah.

Health insurance coverage for cochlear implant services has improved greatly in recent years, with the majority of commercial health plans and managed care organizations now providing some level of benefits for the procedure and related services, including programming and aural rehabilitation. The increase in coverage is largely due to increased education regarding the costs and outcomes of cochlear implantation, and federal and state laws (such as the Americans with Disabilities Act) prohibiting exclusionary insurance policies that deprive cochlear implant candidates from the only opportunity to alleviate their hearing loss.

Because cochlear implants are recognized as standard treatment for severe-to-profound nerve deafness, most insurance companies cover them. In 2004, Medicare, Medicaid, the Veteran's Administration and other public health care plans cover cochlear implants. In 2004, more than 90 percent of all commercial health plans cover cochlear implants. Cochlear implant centers usually take the responsibility of obtaining prior authorization from the appropriate insurance company before proceeding with surgery. Federal law requires that all state Medicaid agencies provide coverage for cochlear implants for children under 21 years old, and most provide benefits for adults as well. Vocational rehabilitation, maternal and children's health services, and other combined federal-state programs also often provide benefits.

The costs of cochlear implants vary widely depending on a number of factors, including the duration and extent of a patient's hearing loss prior to surgery. The average cost for the entire procedure, including the post-operative aural rehabilitation process, exceeds \$40,000. However, cochlear implantation consistently ranks among the most cost-effective medical procedures ever reported, according to research completed by the Johns Hopkins University and the University of California-San Diego. These studies indicate that cochlear implantation can result in a net savings of more than \$53,000 per child versus the more than \$1 million average expected lifetime cost of a child who has profound hearing loss prior to language development.

Adults who have severe to profound hearing loss in both ears and have benefited only minimally from hearing aids may qualify as candidates for cochlear implantation. Children as young as 12 months of age with profound hearing loss in both ears and who demonstrate little progress in the development of auditory skills may also be considered candidates for some implant devices. It is very important that the implant recipient (and the family, in the case of a young child) have an understanding of cochlear implants and realistic expectations regarding the use of the device.

As with any medical procedure, the results of implantation cannot be predicted prior to surgery and recipients may experience a wide range of outcomes. For individuals who lost their hearing after learning to speak, the perception of speech and sounds after implantation may initially seem quite different from what they remember. After using the cochlear implant for several months or more, these individuals often report that they perceive speech to be more natural or closer to their memory of familiar sounds.

While many factors affect outcomes for both children and adults, typically, the younger a child who was born deaf is implanted, the greater the benefit achieved in the areas of speech perception and speech and language development. A predictive factor for implant performance for adults who are deaf is the length of time between the onset of deafness and implantation; those with the shortest duration of deafness tend to experience better outcomes.

Among the professionals who may work as part of the cochlear implant team are audiologists, speech-language pathologists, educators, surgeons, medical specialists, psychologists and counselors. There are many pieces to cochlear implant devices, there are not as many with hearing aids, but all pieces of these devices need to be included in medical coverage. From batteries to cords to replacement of devices, all these need to be taken into account when implementing these in the minimum standards for health care.

Coverage for hearing aids and cochlear implants is crucial. This isn't about being fair or nice. Sure, we want companies and the government to be fair and nice, but we are realistic—many decisions are made because they are a cost effective way of dealing with a medical condition or illness. We don't want to be throwing money around for experimental or wasted use. Coverage of cochlear implants SAVES society and insurance companies money— and lots of it.<sup>1</sup> As parents, of course, our reasons for wanting coverage are deeper and more about wanting the best for our kids— but in this case, it's in perfect alignment with cost saving measures.

The world operates as a hearing world. As much as we try, we cannot (for example) make the entire world handicap accessible. We've all seen wheelchairs at amusement parks or national forests. It's great that there are paths and various things which make bathrooms, restaurants and scenic overlooks approachable to all. But not ALL areas are approachable. If you want to hike the Appalachian trail, and you use a wheelchair, it's unlikely it will happen. So back to the hearing world. Even in the best of circumstances with a child who uses sign language, even if her entire family is fluent in sign language and her teachers teach with it, eventually she will have to go to college and get a job. Not every single scenario of learning and employment can be accompanied by an interpreter. So, when a child goes from being deaf to being hearing with a cochlear implant, the world becomes a place which is much more accessible. How would you like to go to first Communion or a Baptism and not know what the priest or Priesthood holder was really saying? Would you like to go to a grocery store and have people turn to you and say something, but know that you would never be able to get it?

More than that, it's about psychological health. Studies<sup>2</sup> show that implanted children are more likely to have normal self-esteem.

Cochlear implants, hearing aids and glasses all should be part of basic health insurance coverage. Children can't function well in school if they can't hear or see well. Adults' can function better in a job with optimal hearing and vision. That both hearing aids and glasses are not included in most health insurance plans is absurd. That some insurance plans still won't cover cochlear implants is arbitrary and unacceptable. Part of health insurance reform should be determining what is standard of care and who makes that determination. Currently, these decisions are made by medical "experts" who work exclusively for the insurance companies. I have encountered these people too many times.

According to [www.medterms.com](http://www.medterms.com), "standard of care" is defined as "A diagnostic and treatment process that a clinician should follow for a certain type of patient, illness, or clinical circumstance." Healthcare reform should include a definition of standard of care that comprises not just that which is necessary for survival but also to preserve quality of life and, as Amy has described, a treatment that will enable society as a whole to save money in the long term even if it is costly in the short term. Those making these decisions need to truly be experts. It is not sufficient to use one person to make all medical decisions because, as any physician will readily admit, it is impossible for one physician to be an

expert in every field of medicine. Any true health care reform has to include overhauling the system of who gets to make the decisions, and it should include true experts in each field who receive no benefit from denying care.

It's no longer a question of efficacy— we know that cochlear implants work. Even studies about background noise with kids who have perfect hearing show that anything which reduces the amount of information a child hears can stunt their learning and language in school and in the home.

For parents who are fighting with insurance companies about any aspect of the cochlear implant, I tell them to keep this axiom in mind: NEVER GIVE UP. Basically, if you pursue all avenues, you are very likely to win. The persistent parent will usually get what they need for their child. I guess it's a "squeaky wheel" truth! As one parent shared, "We fought for over a year for Elliot's 2nd cochlear implant on his left, non-implanted ear. When he had been implanted, as a baby, no one was implanting small children with two, and even one was sometimes a challenge. By the time he was 3 we were considering the idea and it had been done in a few children. It was intuitive to us that a 2nd ear would be better, but we were also armed with several studies indicating that it was beneficial for localizing sound and better hearing in noise.<sup>3,4</sup> Since they refused 3 times, we were able to go to the state of Georgia's Insurance Commissioner's office, which quickly overturned their denials! The worst part of that process was the waiting... because insurance companies love to use up as much time as possible in the hopes that you'll "give up." (At least that's my assumption.) The other part that was aggravating was simply getting the message to them that we were not speaking about hearing aids, that we had reams and réams of data, and that we expected a reasonable response. Most of their responses didn't really make sense. But we also had help from the Let Them Hear Foundation, which gives pro bono assistance to families who need help fighting insurance regarding hearing health. In the end, within a week of having received the good news, we received ironic news from a Blue Cross Blue Shield of GA Vice President— that ALL the Wellpoint companies had changed their policy to include bilateral cochlear implants. We believe that our case, along with many others, helped sway them toward this reformation of their policy. We then had NO trouble whatsoever in early implantation for our youngest son, even though he was below the "recommended age" for FDA approval of a CI. I tend to believe that there is a giant red sign on our file which says "don't mess with these parents— it will get expensive!" Oliver was implanted at 6 and 11 months and insurance was a breeze. Whew."

Insurance companies are like a lot of other companies, in that they have to consider costs. No doubt they are dealing in a monopoly-style method, currently, which means they can all deny certain kinds of procedures because they don't have to worry that we'll leave. Cochlear implants work and in the vast majority of cases they save society money in the long run by enabling our children to be hearing, speaking fully functioning members of society who do not need to rely on special services, such as interpreters, to communicate in the work place or with the rest of the world.

<sup>1</sup>Cheng A K; Rubin H R; Powe N R; Mellon N K; Francis H W; Niparko J K. "Cost-utility analysis of the cochlear implant in children." JAMA : The Journal of the American Medical Association 2000;284(7):850-6.

<sup>2</sup>Percy-Smith, Lone; Cayé-Thomasen, Per; Gudman, Mette; Jensen, Jørgen Hedegaard; Thomsen, Jens. "Self-esteem and social well-being of children with cochlear implant compared to normal-hearing children." International Journal of Pediatric Otorhinolaryngology 2008 72, 1113-1120.

<sup>3</sup><http://www.sciencedaily.com/releases/2009/09/090915100951.htm>

<sup>4</sup><http://www.classroomhearing.org/acoustics.html>

I want to thank the Health System Reform Task Force for allowing and asking for public input. As a parent of two hard of hearing/deaf children I appreciate it when I am asked to share my thoughts. Please take into consideration that although there can be a great expense with hearing aids and cochlear implants, the amount saved overall is well worth the investment.

Thanks you again,

Anissa Wardell

---

\*This message contains confidential information and is intended only for the individual named. If you are not the named addressee you should not disseminate, distribute or copy this e-mail. Please notify the sender immediately by e-mail if you have received this e-mail by mistake and delete this e-mail from your system. E-mail transmission cannot be guaranteed to be secure or error-free as information could be intercepted, corrupted, lost, destroyed, arrive late or incomplete, or contain viruses. The sender therefore does not accept liability for any errors or omissions in the contents of this message, which arise as a result of e-mail transmission. If verification is required please request a hard-copy version.

---

**From:** Amber Rasmussen <arasmussen1@gmail.com>  
**Sent:** Tuesday, July 03, 2012 9:33 AM  
**To:** Stewart Barlow; Lori Rammell  
**Subject:** cochlear implant coverage support letters  
**Attachments:** SelectMed Appeal Board.docx

----- Forwarded message -----

**From:** **Rachal Green** <rachalgreen@live.com>  
**Date:** Wed, May 23, 2012 at 9:27 PM  
**Subject:** Letter  
**To:** [arasmussen1@gmail.com](mailto:arasmussen1@gmail.com)

Amber,

Good luck tomorrow!!! Thank you for this opportunity. If you need anything at all, even if its me coming down there with you, please do not hesitate to ask. I would be more than happy to do everything I can to help. I am very passionate about this!! I attached a word document, as well as put it in the body of the email. Thanks again!! Let me know if I need to change anything.

Rachal Green

Dear: SelectMed Appeals Board:

I am writing this letter to you as a mother, like Amber Rasmussen, who has had the courage to plead for the life of her child with a hearing loss. I too have a son who was born with a hearing loss. My son Cooper had a severe-profound hearing loss when he was born in 2001. He had his first cochlear implant when he was 18 months old, and his second surgery when he was six to be bilaterally implanted. While the decision to put my child at risks for surgery was a challenging one, it is one I would do many times over. This decision has 100% changed the course of his life to one which will provide him with the same opportunities as his hearing peers.

Cooper's audiograms prior to his implantation were bleak to say the least, he was scoring in the 95db levels which are about the same sound as a jet plane, and these were sounds he was just barely registering. His audiograms now show he hears sounds between 0-10 db!! This is considered "normal" hearing. He hears better than most older adults. Cooper is now 11, he is in the 5<sup>th</sup> grade in a mainstream school setting. His favorite subjects are math and recess of course, he plays keeper for competition soccer and tumbles among many other hobbies. His report cards are exceptional and consist of mostly B+ & A's. His teachers year after year have commented on how he excels in school above his typical peers.

While you may be wondering what my child's success has to do with Colton Rasmussen, it has everything to do with him. These successes my child has accomplished in his short life are the result of his cochlear implants. Cochlear implants allow for children and adults to experience the majority of the hearing world. It provides them to hear their peers and teachers in school, to hear their coaches, and parents as they are guided in life. It allows hearing the sounds we so easily take for granted such as the humming from the refrigerator or a dripping faucet. It allows for them to excel and succeed in the school setting providing them with a competitive

chance at becoming gainfully employed, options to attend the university of their dreams and to be the self sufficient individuals they deserve.

As sure as my son Cooper could sit before you this day and carry on a full verbal conversation, as clear as Amber Rasmussen is speaking to you now, without the help whatsoever of a sign language interpreter. I believe Colton would do the same in 10 years if given this opportunity to hear. This one decision is the fork in the road for this young boy, answering yes to this, will take him down a path of endless opportunities and successes starting a chain reaction of opening so many doors for him.

I urge you to approve this funding for the Rasmussen's and sweet Colton. The cost associated to it now, is mere pennies in comparison to the impact it will have upon his future. It is truly a life altering decision for this young child.

Thank you for your time and consideration.

Sincerely

Rachal Green

801-336-8849

Dear: SelectMed Appeals Board:

I am writing this letter to you as a mother, like Amber Rasmussen, who has had the courage to plead for the life of her child with a hearing loss. I too have a son who was born with a hearing loss. My son Cooper had a severe-profound hearing loss when he was born in 2001. He had his first cochlear implant when he was 18 months old, and his second surgery when he was six to be bilaterally implanted. While the decision to put my child at risks for surgery was a challenging one, it is one I would do many times over. This decision has 100% changed the course of his life to one which will provide him with the same opportunities as his hearing peers.

Cooper's audiograms prior to his implantation were bleak to say the least, he was scoring in the 95db levels which are about the same sound as a jet plane, and these were sounds he was just barely registering. His audiograms now show he hears sounds between 0-10 db!! This is considered "normal" hearing. He hears better than most older adults. Cooper is now 11, he is in the 5<sup>th</sup> grade in a mainstream school setting. His favorite subjects are math and recess of course, he plays keeper for competition soccer and tumbles among many other hobbies. His report cards are exceptional and consist of mostly B+ & A's. His teachers year after year have commented on how he excels in school above his typical peers.

While you may be wondering what my child's success has to do with Colton Rasmussen, it has everything to do with him. These successes my child has accomplished in his short life are the result of his cochlear implants. Cochlear implants allow for children and adults to experience the majority of the hearing world. It provides them to hear their peers and teachers in school, to hear their coaches, and parents as they are guided in life. It allows hearing the sounds we so easily take for granted such as the humming from the refrigerator or a dripping faucet. It allows for them to excel and succeed in the school setting providing them with a competitive chance at becoming gainfully employed, options to attend the university of their dreams and to be the self sufficient individuals they deserve.

As sure as my son Cooper could sit before you this day and carry on a full verbal conversation, as clear as Amber Rasmussen is speaking to you now, without the help whatsoever of a sign language interpreter. I believe Colton would do the same in 10 years if given this opportunity to hear. This one decision is the fork in the road for this young boy, answering yes to this, will take him down a path of endless opportunities and successes starting a chain reaction of opening so many doors for him.

I urge you to approve this funding for the Rasmussen's and sweet Colton. The cost associated to it now, is mere pennies in comparison to the impact it will have upon his future. It is truly a life altering decision for this young child.

Thank you for your time and consideration.

Sincerely

Rachal Green  
801-336-8849

---

**From:** Amber Rasmussen <arasmussen1@gmail.com>  
**Sent:** Tuesday, July 03, 2012 9:31 AM  
**To:** Stewart Barlow; Lori Rammell  
**Subject:** cochlear implant coverage support letters  
**Attachments:** Letter for Colton.docx

May 22, 2012

To Whom It May Concern:

I am writing this letter to share my experience I have had as a mother of a profoundly deaf daughter who has benefited immensely since the activation of her bilateral cochlear implants March of this year. The short version of our experience is that our daughter was born with a moderate to severe hearing loss in 2009. She had some benefit from hearing aids but never really started talking even though we made every effort in teaching her and having therapy weekly. In February of this year a routine hearing test was done and we found that her hearing had dropped to the severe and profound levels. With no hesitation I asked if she was eligible for cochlear implants as I am an advocate for this medical miracle and as her parents we decided in the beginning that our daughter was going to speak and this was the only route that would still make that possible. My husband and I then pushed for the soonest date we could to get her in for surgery. She had surgery on March 26, 2012 and was activated April 11, 2012.

These few weeks since her activation our daughter has made astronomical progress in her speech and sound awareness; she can hear! It is such a wonderful sight to see her point to her ears when she hears something and try her hardest to repeat what we say. She is a child that wants to communicate and knows without those magnets on her head she can't hear us.

I will never forget that my daughter is deaf, but I know that without the option of cochlear implants our daughter would live a very different life than the rest of our family. We have four other children, none of which have hearing loss. Our extended family is hearing; she belongs to a hearing family. I am so grateful that there is a device that "fixed" her hearing. I am also so grateful that with some money out of our pocket we were able to have this done for her, what a blessing.

I believe that cochlear implant surgery should not be considered an elective surgery or only partially covered; individuals have the right to hear just like a person who has lost a leg can get a prosthesis leg if they choose. Parents have the right to make that choice for their children and give them the opportunity to hear...to hear everything. The opportunity should not be taken away by the insurance company because the family can't afford it. Please give Colton Rasmussen this same opportunity without drowning his parents in a sea of debt.

Loss of vision separates you from things. Loss of hearing separates you from people – Helen Keller

Sincerely,

Megan Brimhall

---

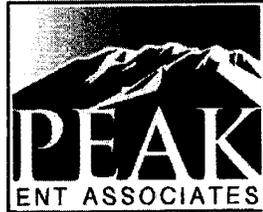
**From:** D. Spencer Darley <spencerdarley@gmail.com>  
**Sent:** Tuesday, July 03, 2012 2:42 PM  
**To:** Lori Rammell  
**Subject:** Utah Essential Benefits  
**Attachments:** cochlear letter for legislature.pdf; Baha letter for legislature.pdf

To whom it may concern,

Thank you for allowing me to comment regarding the Utah Essential Benefits. I have attached two letters addressing two surgical modalities which are standard of care for specific types of hearing loss which help the hearing impaired citizens of the state. They are cochlear implants and oseointegrated implants. If you have any further questions or concerns I am at your service. My contact information is below.

Sincerely,

D. Spencer Darley, MD  
Director Hearing and Balance Center, Peak ENT associates  
1055 North 300 West #401  
Provo, Utah 84604  
801 357-7499  
801 357-5980 (fax)



Ear, Nose, & Throat  
Head & Neck Surgery  
Facial Plastic Surgery  
Audiology  
Allergy

July 1, 2012

To the Utah State Legislature:

Thank you for the opportunity to comment on Utah's Essential Benefits package as part of the ongoing discussion for our state's provision of health benefits under national health care reform.

I would like to provide input on the cochlear implant. A cochlear implant is a treatment that enables children and adults who are deaf to hear sounds of speech, music and the environment in their daily lives. Without this intervention, adults and children with severe to profound hearing loss many experience significant consequences, such as delays in the development of spoken language, reduced academic performance and reduced occupational success. The reduction in disability and the societal benefits of this technology make it one of the most cost effective treatments in all of modern medicine.

I would like to offer the following comments regarding the efficacy, reliability, quality, and cost-effectiveness of cochlear implants for your consideration:

#### **Efficacy - Benefits of Cochlear Implantation**

It is well documented that unilateral cochlear implantation provides significant and substantial benefits to adults and children with severe to profound hearing loss as compared to a hearing aid. Available in the U.S. commercial market place for close to 30 years for adults<sup>1</sup> and 15 years<sup>2</sup> for children, it is fair to say that cochlear implantation as a treatment modality has come to be considered the "standard of care" for those individuals meeting its indications. The transition into bilateral implantation has naturally evolved as did the practice of unilateral hearing aid fitting to bilateral fittings over 20 years ago. The recognition of binaural hearing advantages is not disputed, and individuals meeting indications for treatment of mild to moderately severe bilateral hearing disability are routinely fitted with bilateral hearing aids. A review of over 100 articles specifically addressing the use of bilateral implants was completed last year (Sammeth, Carol A, Bundy, Sean M, Miller, Douglas A; Bimodal hearing or bilateral cochlear implants: a review of the research literature; Seminars in Hearing 32(1):3-31 2011). In this review, the psychoacoustic benefits of binaural hearing (e.g., squelch effect, binaural summation and head-shadow effect) are well supported.(did you attach this?)

#### **Overview of Therapeutic Efficacy**

In December 1984, the cochlear implant was approved in the United States by the Food and Drug Administration (FDA) to be implanted in adults<sup>1</sup> (18 years of age and older). In 1990, the FDA lowered the approval age to two years of age<sup>2</sup>, then in 1998 to 18 months<sup>3</sup>, and finally in 2000 to 12 months<sup>4</sup>.

Overall, the published clinical evidence demonstrates many improvements in both clinical outcome measures and health-related quality of life associated with cochlear implants in patients with severe to profound sensorineural hearing loss. The attached bibliography highlights the body of evidence associated with both unilateral and bilateral cochlear implants.

Regarding evaluation of cochlear implant safety and health outcomes evidence, it is considered accepted study design to use within subject controls where patients serve as their own controls. Large scale randomized controlled studies are impractical given the afflicted, very small patient populations, and also considered unnecessary because the natural history of deafness is well characterized. Within subject controlled research protocols have been the basis for FDA approvals across all three U.S. manufacturers, and it is also accepted by clinicians as a framework for researching long term outcomes and benefits amongst various hearing loss patient subgroups. The published evidence for this small patient population has also been further expanded by the medical community through prospective and retrospective case series reviews.

In adult patients with sensorineural hearing loss, the unilateral cochlear implant evidence shows substantial gains in speech recognition scores post-implant compared with pre-implant scores on tests such as multi-syllable tests and open-set sentence tests (e.g., Hearing in Noise Test or HINT sentences), with or without use of hearing aids. Unilateral implants have also demonstrated improvements in quality of life including psychosocial benefits (overcoming feelings of isolation) and ability to more effectively communicate in society (use communication means such as telephone and interact better within groups).

Research on predictive factors of clinical benefit including use of modeling has demonstrated a likely correlation between pre-implant residual hearing / duration of deafness and the post-operative cochlear implant outcomes (Tyler & Summerfield, 1996; Rubinstein, 1999<sup>5</sup>).

### **Bilateral Implantation**

Bilateral cochlear implants have enabled improvements in speech recognition when compared with unilateral, particularly for speech in noise. It allows for a range of technical benefits including localization. The use of bilateral implants is now considered accepted medical practice (Balkany et al, 2008<sup>6</sup>).

Studies show that bilateral implantation offers superior outcomes to unilateral implantation in realistic, every day conditions, which include the need to localize sounds and hear in noisy environments. Published evidence also indicates that there are no statistically significant differences in benefit between older adults (> 65 year of age) and younger adults as a result of cochlear implantation (Sprinzl and Reichelmann 2010<sup>7</sup>). Published data indicate that speech perception benefit is independent of age at implantation (e.g., Cambron 2006, Chatelin et al. 2004, Haensel et al. 2005, Orabi et al. 2005, Nakajima et al. 2000, Vermeire et al. 2005<sup>8,9,10,11</sup>). Similarly, quality-of-life measures show no difference between elderly cochlear implant users and younger cochlear implant users (e.g., Horn et al. 1991, Kelsall et al. 1995, Vermeire et al. 2005).

In the AHRQ's recent draft *Technology Assessment on the Effectiveness of Cochlear Implants in Adults with Sensorineural Hearing Loss*, the authors' review of preoperative patient characteristics as potential modifying factors found no significant difference in improvements in health outcomes when looking at

older (~65 years) versus younger (<65 years) patients (see Table D.7 in AHRQ Technology Assessment). Further, results for several different speech perception tests in an elderly group (n=34, range=65 to 80 years of age) were found to have significant to highly significant differences from pre-implant to post-implant performance. Further, these speech perception results were compared to those of a younger group, and no statistically significant difference was found in the test scores between the older and younger groups. (Orabi et al. 2006)

While the benefits of unilateral CI are well accepted, the implantation of a single device does not provide normal (binaural) hearing to an individual with severe bilateral hearing loss. Binaural hearing provides certain auditory effects that assist in localizing sound and understanding speech in a noise environment. The auditory benefits enabled by binaural hearing include addressing "head shadow," "binaural summation," and "binaural squelch" (Gantz, 2002). Head shadow is the barrier the head creates between sounds emitted from one direction and the contralateral ear. Head shadow dampens noise reaching the contralateral ear and delivers a more intelligible signal to noise ratio (SNR) or "speech-to-noise" ratio. Head shadow is believed to permit a bilateral CI user the flexibility to hear with the ear having the better signal-to-noise ratio (SNR). This shadowing or attenuating effect works best for high frequency sounds.

With binaural hearing, each ear receives both unique and redundant information (acoustical representation) that is processed in the brain. The processing of this redundant information, "binaural summation," improves hearing threshold and increases sensitivity to small differences in sound frequency and intensity. Binaural summation can lead to improved speech perception in both quiet and noise. The third effect of binaural hearing is "binaural squelch." With two ears, the brain uses cues to separate sounds coming from different locations. Optimal sound localization requires the ability to detect differences in time and amplitude between signals reaching both ears (Tyler, 2003).

The following table summarizes the current labeling for adult use of the three devices available in the U.S. today:

<b>Dimension</b>	<b>AB</b>	<b>Cochlear</b>	<b>MedEl</b>
Age	≥ 18 years old		
Type of HL	Bilateral sensorineural hearing loss		
Audiometric Criteria	Severe-to-profound HL	Moderate-to-profound HL	Severe-to-profound HL
Speech Perception Criteria	≤50% correct HINT sentences with HA	≤50% on open set sentences with HA and ≤60% best aided	≤40% correct HINT sentences best aided
Last updated	2002	2000	2001

The following table summarizes the current labeling for pediatric use of the three devices available in the U.S. today:

<b>Dimension</b>	<b>AB</b>	<b>Cochlear</b>	<b>MedEl</b>
Age	≥12 months old		
Type of HL	Bilateral sensorineural hearing loss		
Audiometric Criteria	Profound HL	<b>Younger children:</b> Profound HL  <b>Older children:</b> Severe to profound HL	Profound HL
Speech Perception Criteria	<b>Younger children:</b> <4 years: Limited benefit from appropriate binaural hearing aids; failure to reach developmentally appropriate auditory milestones; <20% correct MLNT or LNT; 3 month hearing aid trial  <b>Older children:</b> ≥4 years: ≤30% correct HINT-C; 6 month hearing aid trial  <b>Hearing aid trial:</b> 12-23 months old: 3 month trial; 2-17 years: 6 month trial	<b>Younger children:</b> 12-24 months: Limited benefit from appropriate binaural hearing aids; lack of progress in development of simple auditory skills with appropriate amplification & intensive aural habilitation  <b>Older children:</b> 2+ years: <30% correct MLNT or LNT  <b>Hearing aid trial:</b> 3-6 month trial if no previous hearing aid experience	<b>Younger children:</b> Lack of progress in development of auditory skills with appropriate amplification & intensive aural habilitation  <b>Older children:</b> <20% correct MLNT or LNT  <b>Hearing aid trial:</b> 3-6 month trial if no previous hearing aid experience
Last updated	2002	2005	2003

## **Value of Cochlear Implants - Children**

In the January 2009 publication from the National Institute for Health and Clinical Excellence, Section 4.3.10, “the Appraisal Committee heard from clinical specialists that it was important that the auditory nerve was provided with stimulation early in the child’s development because it became less sensitive to stimulation as the child became older. Hence, failure to stimulate the auditory nerve early impaired the development of central pathways necessary for the appreciation and understanding of sound. The Committee was persuaded on the basis of consultee comments that the potential benefits of bilateral auditory stimulation would apply to both prelingual and post lingual children with severe to profound deafness because neurosensory development continues after the development of language.”

### **Spoken Language Development**

Use of a cochlear implant has a significant impact on the linguistic competence of profoundly hearing-impaired children. Although the cochlear implant does not allow for hearing of the same quality as that experienced by persons without hearing loss, it nonetheless has revolutionized the experience of spoken language acquisition for deaf children. Children who are implanted early and receive an appropriate follow-up habilitation program are more likely to have speech and auditory skills approaching that of their hearing peers. Please see references x through y in appendix.

**Social and emotional benefits:** The greatest changes in the social emotional dimension take place one year after implantation. Five years after implantation, two thirds of children were judged to be as independent as their age peers.

Results show that the prevalence of psychosocial difficulties was 3.7 times greater compared with a group of hearing children. In the group of children with additional disabilities, the prevalence was 3 times greater compared with children without additional disabilities. If sign language and/or oral language abilities are good, the children do not have a substantially higher level of psychosocial difficulties than do hearing children. This study documents the importance of communication-no matter the modality or degree of hearing loss-for the psychosocial well-being of hearing-impaired children.

**Bilateral:** The study showed that prelingually deaf children's ability to develop complex expressive and receptive spoken language after early bilateral implantation appears promising. The majority of the children achieved expressive and receptive language skills within the normative range.

### **Age at the time of Cochlear Implantation**

The age at which a child receives a cochlear implant has been demonstrated to impact speech perception, speech production, and other language skills. Over time the definition of an “early implant” has changed from age 3 to 5 years to 12 to 18 months. Children who are deaf at birth and implanted under 18 months are generally able to achieve the best language outcomes. The language outcomes for teens with more than 10 years of CI experience reflects the role of early exposure sound in later spoken language development. Please see references in appendix.

### ***Use of spoken language at home and at school***

The consistent use of a rich spoken language communication mode at home and at school was shown to have a strong effect on the listening, speech and language outcome for CI children. Children exposed to spoken language had a higher likelihood of scoring high in all tests of spoken language. Please see references in the appendix

Three publications which we would like to specifically point out are:

- 1) Stacey, Paula C, Fortnum, Heather M, Barton, Garry R, Summerfield, A Quentin; Hearing-impaired children in the United Kingdom, I: Auditory performance, communication skills, educational achievements, quality of life, and cochlear implantation; *Ear Hear* 27(2):161-186 Apr 2006 pointed out that benefits for those implanted 5 years of age and under include: enhanced auditory receptive skills and evidence of the emergence of aural/oral communicative modes; useful levels of ability in spoken language; enhanced scholastic achievement (reading, writing, mathematics); enhanced social versatility and robustness; successful transition to secondary school; enhanced educational qualifications; enhanced opportunities in further education and employment; and enhanced social independence and quality of life in adulthood.
- 2) In another article by *J Robert, Niparko, John K, Rothman, Margaret L, deLissovoy, Gregory; Cost Utility of the Multichannel Cochlear Implant in 258 Profoundly Deaf Individuals; Laryngoscope* 106(7): 816-821 Jul 1996, concluded that auditory perception is critical – tests of selective visual attention reveal deficits in deaf children and suggest that auditory input affects the development of attention skills. Profoundly deaf children who receive a cochlear implant demonstrate improved visual attention skills that eventually match those of age-matched peers.
- 3) A study published in the *Int J Pediatr Otorhinolaryngol*. 2008 Jul;72(7):1023-8. Epub 2008 Apr 22. Cochlear implant candidacy in the United States: prevalence in children 12 months to 6 years of age; Bradham T, Jones J.:

#### **Objectives:**

Pediatric cochlear implantation has been demonstrated to be effective for children as well as cost-effective for society. A goal of Healthy People 2010, a program started in January 2000 by the United States Department of Health and Human Services to promote nationwide health and disease is to increase the number of people who are deaf or significantly hard of hearing to begin to use a cochlear implant system. NIDCDs Healthy Hearing Progress Reports from 1999 reported that only 2 out of every 1000 adults who are deaf or hard of hearing received a cochlear implant. There were two main objectives for the Bradham, et al study: (1) to estimate the number of children between the ages of 12 months and 6 years of age with severe to profound bilateral hearing loss who could benefit from a cochlear implant, and (2) to determine if the number of children projected to be candidates received this medical care.

#### **Methods:**

Using the 2000 US Census Data from children 12 months to 6 years, the number of children with severe to profound bilateral hearing loss was calculated. Children who would be considered "neurologically devastated" and children with absent eighth nerves were excluded from the calculations.

**Results:**

Based on the total population of children in the US aged 12 months to 6 years of slightly over 231 million, 15,219 children presented with severe to profound hearing loss. Taking into account some exclusions, 12,816 children would be considered cochlear implant candidates. Based on the number of children who were implanted in 2000, approximately 55% of the projected number of candidates received a cochlear implant.

**Conclusion:**

Even though the estimates do not reflect a direct measure of actual candidates in the targeted age groups, the population who could benefit from this technology is still being significantly underserved in the United States. With a continued shortage of qualified personnel to serve these children, insufficient reimbursement rates, and disparities in implantation rates based on ethnicity and socioeconomic status, the question remains can we truly meet the needs of these children?

**Number of Persons Affected**

According to the U.S. Food and Drug Administration (FDA), as of December 2010, approximately 219,000 people worldwide have received cochlear implants; in the United States, roughly 42,600 adults and 28,400 children are recipients – NIH Publication No. 11-4798 (2011-03-01) “Cochlear Implants.” National Institute on Deafness and Other Communication Disorders.)

**Cost-Effectiveness and Quality of Life**

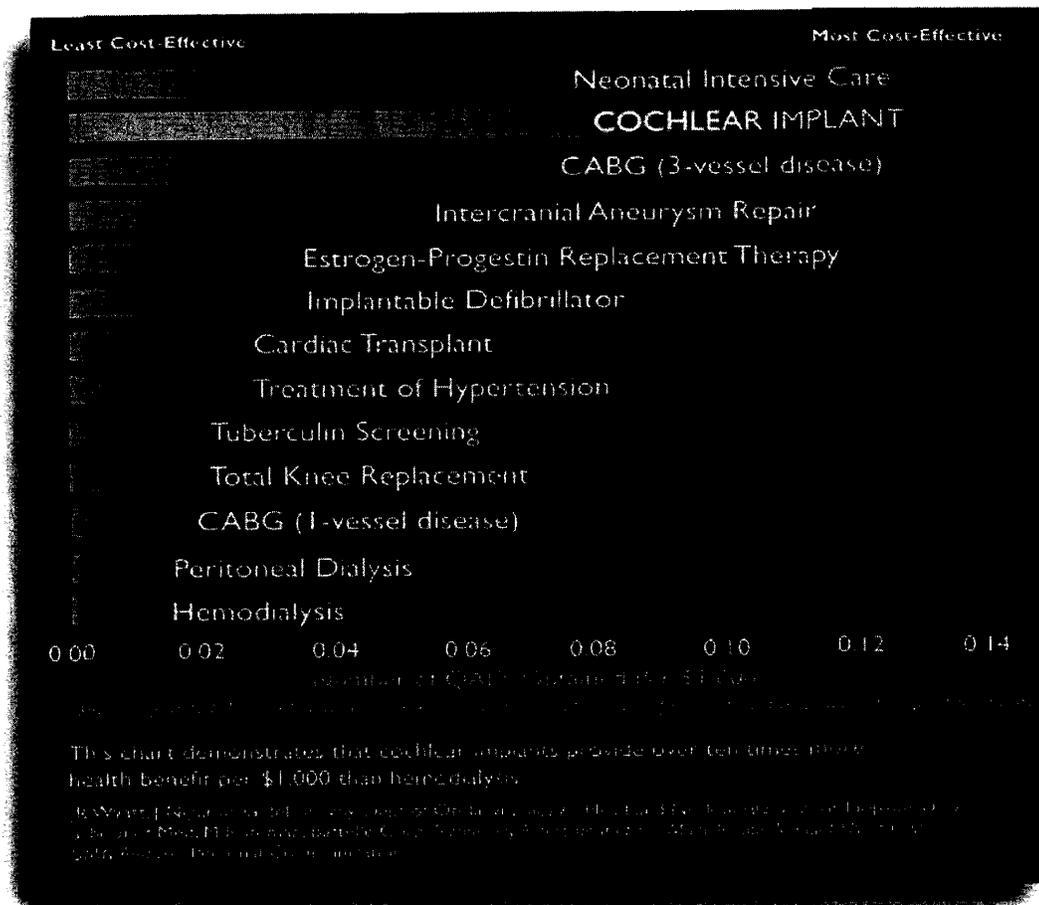
Well known and recognized experts in the field have studied and addressed the quality of life improvements associated with the quality-of-life improvements and cost-effectiveness associated with cochlear implantation as summarized below:

The article by Wyatt, J Robert, Niparko, John K, Rothman, Margaret L, deLissovoy, Gregory; *Cost Effectiveness of the Multichannel Cochlear Implant*; *AJO* 16(1):52-62 Jan 1995 states that “cost utility analysis is a widely used method of medical technology assessment that permits the cost effectiveness comparisons between medical interventions by determining the cost per quality adjusted life year (QALY) they provide. The cost per QALY for the cochlear implant was determined using clinical cost data and a health utility outcome model based on the established communication gains attained with the device. Cochlear implantation costs approximately \$15,600 per QALY provided. Sensitivity analysis, a technique that systematically varies the assumptions underlying the calculations, suggests a range for the true value of between \$12,000 and \$30,000. The conclusions of this analysis are most sensitive to four factors: the health utility increase, the length of implant use, and two of the largest costs (device and surgical costs). This compares favorably with other medical interventions, such as coronary artery bypass grafting, the defibrillator, and cardiac transplantation. This analysis indicates that the cochlear implant lies well within the cost effectiveness range currently accepted by the American Medical system.”

Implant recipients report a variety of improvements in their quality of life, and available studies support assertions of improved vocational, social and psychological function. Cost effectiveness in children is also influenced by the degree to which the costs involved in the education of profoundly hearing impaired

children can be decreased by the cochlear implant. Education in a school for the deaf costs approximately \$29,000 per child per year, more than double the cost of a public education of a hearing child.

The primary use of cost utility analyses is to compare the cost effectiveness of various health technologies. One comparative measure is the result of a study that systematically reviewed 293 analyses of medical interventions and determined that the average cost per life/year provided was \$17,000. Cochlear implantation appears to rate extremely favorably within the range of cost effectiveness accepted by the American medical system.



The United Kingdom Cochlear Implant Study Group published an article on the Criteria of candidacy for unilateral cochlear implantation in postlingually deafened adults II: cost-effectiveness analysis; *Ear Hear* 25(4):336-360 Aug 2004. The objective of this article was to estimate the cost-effectiveness of unilateral cochlear implantation for postlingually deafened adults. It was determined that cochlear implantation was a cost-effective intervention for the majority of subjects, including the group given implants when older than 70 years of age. These authors (Carter & Hailey, 1999; Cheng & Niparko, 1999; Francis, Chee, Yeagle, Cheng & Niparko 2002; Palmer, Niparko, Wyatt Rothman & de Lissovoy, 1999; Summerfield & Marshall, 1995; Summerfield, Marshall, Barton & Bloor 2002; Wyatt, Niparko, Rothman and de Lissovoy 1995; Wyatt, Niparko, Rothman & deLissovoy 1996) concluded that the provision of cochlear implantation represents good value for money in relation to reimbursement costs in the United States and acceptable value for money in relation to total health care costs in the United Kingdom.

According to The National Institute for Health and Clinical Excellence (NICE) in their January 2009 report Section 4.3.5, “the Appraisal Committee concluded that for many people deafness would have a significant adverse impact on their quality of life, and that it was appropriate to consider cochlear implants as a means of reducing this impact.”

The Appraisal Committee also stated that in their examination of the cost-effectiveness of unilateral cochlear implantation concluded, “that unilateral cochlear implantation for adults and children with severe to profound deafness who did not derive adequate benefit from acoustic hearing aids, would be a cost-effective use of National Health Services (NHS) resources.”

### **CMS Coverage of Cochlear Implants**

The Centers for Medicare and Medicaid Services (CMS) issued a national coverage decision on April 5, 2005 for coverage of cochlear implants. According to the Medicare National Coverage Determinations Manual, Chapter 1, Part 1 (Sections 10 – 80.12), “cochlear implantation may be covered for treatment of bilateral pre or post linguistic, sensorineural, moderate-to-profound hearing loss in individuals who demonstrate limited benefit from amplification. Limited benefit from amplification is defined by test scores of less than or equal to 40% correct in the best-aided listening condition on tape-recorded test of open-set cognition. Medicare coverage is provided to patients who meet the following guidelines:

- Diagnosis of bilateral moderate to profound sensorineural hearing impairment with limited benefit from appropriate hearing (or vibrotactile) aides;
- Cognitive ability to use auditory clues and a willingness to undergo an extended program of rehabilitation;
- Freedom from middle ear infection, an accessible cochlear lumen that is structurally suited to implantation, and freedom from lesions in the auditory nerve and acoustic areas of the central nervous system;
- No contraindications to surgery; and
- The device must be used in accordance with Food and Drug Administration (FDA)-approved labeling.”

### **Coverage Cochlear Implants**

Cochlear implantation is covered by Medicare, Medicaid and the vast majority of private commercial insurers in the United States.

### **Safety of cochlear implants**

Relative to many other surgical or medical procedures cochlear implantation is extremely safe; in the largest reported series, no deaths occurred, and the incidence of significant morbidity is less than 0.05%.

The FDA has determined that cochlear implants are a safe and effective treatment of sensorineural hearing loss in children and adults. Cochlear implant internal devices are warranted for ten (10) years for potential device failure. On average, cochlear implants have at least a 99% success rate at one year, and a minimum of 97% at four years. This information shows that cochlear implants are one of the most reliable implantable devices with low failure rates. The reliability of each device is available for review on each manufacturer’s respective website.

<http://www.medel.com/int/show/index/id/280/titel/Outstanding+Reliability+Data?PHPSESSID=leffdd98eogq17anjv2thjt275>

[http://www.advancedbionics.com/content/dam/ab/Global/en\\_ce/documents/candidate/AB\\_Technology\\_Reliability\\_Report\\_2011.pdf](http://www.advancedbionics.com/content/dam/ab/Global/en_ce/documents/candidate/AB_Technology_Reliability_Report_2011.pdf)

<http://professionals.cochlearamericas.com/sites/default/files/resources/Nucleus%20Implant%20Reliability%20Report%20FUN2012%20ISS3%20AUG2011.pdf>

### **Conclusion**

Again, I appreciate the opportunity to comment for this process. I would like to emphasize the fact that the gift of hearing provides adults and children with severe profound hearing loss to experience an improved quality of life and an opportunity to contribute as fully independent members of society. We now live in a day and age where there is a hearing solution for nearly every kind of hearing loss. To deny these standard of care services to appropriately selected patients is unconscionable. Please support our deaf community by assuring them basic coverage of cochlear implants.

Sincerely,

A handwritten signature in black ink, appearing to read "Darley", with a long, sweeping horizontal line extending to the right.

DAVID SPENCER DARLEY, M.D.

Director of Hearing and Balance Center, Peak ENT Associates

## REFERENCES

### *References for Spoken Language Development Section*

- Geers AE, Sedey AL. Language and verbal reasoning skills in adolescents with 10 or more years of cochlear implant experience. *Ear Hear*. 2011 Feb;32(1 Suppl):39S-48S.
- Niparko JK, Tobey EA, Thal DJ, Eisenberg LS, Wang NY, Quittner AL, Fink NE. Spoken language development in children following cochlear implantation. *JAMA*. 2010 Apr 21;303(15):1498-506.
- Geers AE. *Adv Otorhinolaryngol*. 2006;64:50-65. Factors influencing spoken language outcomes in children following early cochlear implantation.
- Geers AE, Nicholas JG, Sedey AL. Language skills of children with early cochlear implantation. *Ear Hear*. 2003 Feb;24(1 Suppl):46S-58S.
- Eisenberg LS, Johnson KC, Martinez AS, Cokely CG, Tobey EA, Quittner AL, Fink NE, Wang NY, Niparko JK. Speech recognition at 1-year follow-up in the childhood development after cochlear implantation study: Methods and preliminary findings. *Audiol Neurootol*. 2006;11(4):259-68. Epub 2006 May 12.
- Uhler K, Yoshinaga-Itano C, Gabbard SA, Rothpletz AM, Jenkins H. Longitudinal infant speech perception in young cochlear implant users. *J Am Acad Audiol*. 2011 Mar;22(3):129-42.
- Geers A, Tobey E, Moog J, Brenner C. Long-term outcomes of cochlear implantation in the preschool years. *Int J Audiol* 208;47 suppl 2):S21-S30.
- van Besouw RM, Grasmeyer ML, Hamilton ME, Baumann SE. *Int J Audiol*. 2011 May;50(5):340-8. Epub 2011 Feb 2. Music activities and responses of young cochlear implant recipients.
- Huttunen K, Välimaa T. Parents' views on changes in their child's communication and linguistic and socioemotional development after cochlear implantation. *J Deaf Stud Deaf Educ*. 2010 Fall;15(4):383-404. Epub 2010 Jul 2.
- Fagan MK, Pisoni DB. *J Deaf Stud Deaf Educ*. 2010 Spring;15(2):149-61. Epub 2010 Feb 3. Hearing experience and receptive vocabulary development in deaf children with cochlear implants.
- Nicholas JG, Geers AE. Will they catch up? The role of age at cochlear implantation in the spoken language development of children with severe to profound hearing loss. *J Speech Lang Hear Res*. 2007 Aug;50(4):1048-62.
- Tait ME, Nikolopoulos TP, Lutman ME. Age at implantation and development of vocal and auditory preverbal skills in implanted deaf children. *Int J Pediatr Otorhinolaryngol*. 2007 Apr;71(4):603-10. Epub 2007 Jan 18.
- Rance G, Barker EJ. Speech and language outcomes in children with auditory neuropathy/dys-synchrony managed with either cochlear implants or hearing aids. *Int J Audiol*. 2009;48(6):313-20.

- Nott P, Cowan R, Brown PM, Wigglesworth G. Early language development in children with profound hearing loss fitted with a device at a young age: part II--content of the first lexicon. *Ear Hear.* 2009 Oct;30(5):541-51.

#### ***References for Age at the time of Cochlear Implantation***

- Uhler K, Yoshinaga-Itano C, Gabbard SA, Rothpletz AM, Jenkins H. Longitudinal infant speech perception in young cochlear implant users. *J Am Acad Audiol.* 2011 Mar;22(3):129-42.
- Dettman SJ, Pinder D, Briggs RJ, Dowell RC, Leigh JR. Communication development in children who receive the cochlear implant younger than 12 months. *Ear Hear.* 2007; 28(2)(suppl):11S-18S.
- Geers A, Tobey E, Moog J, Brenner C. Long-term outcomes of cochlear implantation in the preschool years. *Int J Audiol* 208;47 suppl 2):S21-S30.
- Colletti L, Mandalà M, Zocante L, Shannon RV, Colletti V. Infants versus older children fitted with cochlear implants: performance over 10 years. *Int J Pediatr Otorhinolaryngol.* 2011 Apr;75(4):504-9. Epub 2011 Jan 31.
- Niparko JK, Tobey EA, Thal DJ, Eisenberg LS, Wang NY, Quittner AL, Fink NE. Spoken language development in children following cochlear implantation. *JAMA.* 2010 Apr 21;303(15):1498-506.
- Moog JS, Geers AE. Early educational placement and later language outcomes for children with cochlear implants. *Otol Neurotol.* 2010 Oct;31(8):1315-9.
- Lee KY, van Hasselt CA. Spoken word recognition in children with cochlear implants: a five-year study on speakers of a tonal language. *Ear Hear.* 2005 Aug;26(4 Suppl):30S-7S.
- Holt RF, Svirsky MA. An exploratory look at pediatric cochlear implantation: is earliest always best? *Ear Hear.* 2008 Aug;29(4):492-511.
- Nikolopoulos TP, Dyar D, Archbold S, O'Donoghue GM. Development of spoken language grammar following cochlear implantation in prelingually deaf children. *Arch Otolaryngol Head Neck Surg.* 2004 May;130(5):629-33.
- Hammes DM, Novak MA, Rotz LA, Willis M, Edmondson DM, Thomas JF. Early identification and cochlear implantation: critical factors for spoken language development. *Ann Otol Rhinol Laryngol Suppl.* 2002 May;189:74-8.
- Tait ME, Nikolopoulos TP, Lutman ME. Age at implantation and development of vocal and auditory preverbal skills in implanted deaf children. *Int J Pediatr Otorhinolaryngol.* 2007 Apr;71(4):603-10. Epub 2007 Jan 18.

- Ertmer DJ, Young NM, Nathani S. Profiles of vocal development in young cochlear implant recipients. *J Speech Lang Hear Res.* 2007 Apr;50(2):393-407.
- Kirk KI, Miyamoto RT, Lento CL, Ying E, O'Neill T, Fears B. Effects of age at implantation in young children. *Ann Otol Rhinol Laryngol Suppl.* 2002 May;189:69-73.
- Low WK, bin Iskandar MF, Sarepaka GK. Outcome of early cochlear implantation. *Ann Acad Med Singapore.* 2008 Dec;37(12 Suppl):49-3.
- Wie OB. Language development in children after receiving bilateral cochlear implants between 5 and 18 months. *Int J Pediatr Otorhinolaryngol.* 2010 Nov;74(11):1258-66. Epub 2010 Aug 25.

***References for Use of spoken language at home and at school***

- Moog JS, Geers AE. Early educational placement and later language outcomes for children with cochlear implants. *Otol Neurotol.* 2010 Oct;31(8):1315-9.
- Kirk KI, Miyamoto RT, Lento CL, Ying E, O'Neill T, Fears B. Effects of age at implantation in young children. *Ann Otol Rhinol Laryngol Suppl.* 2002 May;189:69-73.
- Geers AE, Nicholas JG, Sedey AL. Language skills of children with early cochlear implantation. *Ear Hear.* 2003 Feb;24(1 Suppl):46S-58S.
- Percy-Smith L, Cayé-Thomasen P, Breinegaard N, Jensen JH. Parental mode of communication is essential for speech and language outcomes in cochlear implanted children. *Acta Otolaryngol.* 2010 Jun;130(6):708-15.



Ear, Nose, & Throat  
Head & Neck Surgery  
Facial Plastic Surgery  
Audiology  
Allergy

July 1, 2012

To the Utah State Legislature:

Thank you for this opportunity to express my concern regarding minimal coverage in the Utah Essential Benefits package. I would specifically direct my comments to osseointegrated implants (also known as bone anchored auditory implants or Baha), which provide direct cochlear stimulation for patients with significant hearing loss. Currently, the state and many private insurers have either limited benefits or do not provide benefit coverage for this important surgical intervention for both children and adults.

As an otolaryngologist fellowship-trained in otology and neurotology I can testify that this device has become the standard of care treatment option for patients with single-sided deafness, conductive hearing loss, and mixed hearing loss. For appropriately selected patients, no adequate alternative medical solution exists. This implant has been approved by the FDA since 1996 for use in adults. Moreover, it has also been approved for the use in children over the age of five since 1999. With appropriately selected patients, this device provides excellent outcomes, has been proven by countless medical trials, and has been in use since the 1970s. Medicare has clarified that the auditory osseointegrated implant is not a hearing aid and has covered the medical device and related surgery since 2005. Utah currently does not meet this minimal medical coverage standards set by the federal government.

I currently have about a dozen patients who would benefit from this device who have had a life changing event known as sudden deafness, where they instantaneously go deaf in one of their ears. This can be a traumatic experience. Having lost perception of sound in one ear they lose the ability of locate sound, understand speech in noise, and hear sound from their deaf side in general due to sound head shadow effect. The loss can lead to significant impairments in productivity in work with impairments of communication often leading to disability, depression, and social isolation. Clinical studies have shown significant improvements in productivity and functional hearing with use of this simple device. Therefore it is very cost effective for the state of Utah to provide these services in order to keep its citizens working and productive.

It is worth pointing out that during my training in Syracuse, New York and my fellowship in Sarasota, Florida, I performed approximately 75 of these procedures over a six year period. In these regions it was standard of care treatment for patients with very specific indications and generally covered by the majority of insurance providers. This procedure is now accepted interventions that is covered by not only Medicare and Medicaid, but also Aetna, United Healthcare, Veterans Association, Group Health, High Mark, and select Blue Cross Blue Shield policies.

It appears that there is a regional disparity in coverage in the Rocky Mountain Region and specifically here in Utah. It is my feeling that we cannot discriminate in our medical policies against adults and children with hearing difficulties in this region if it is being actively provided in other regions around the country. This is unfortunate because Utah has been a leader in multiple other, cutting-edge medical technologies and high quality healthcare provisions. We are unfortunately behind the curve in providing these important treatments

to restore hearing. It is unconscionable to allow our state to become known as one that provides poorly for its citizens with hearing loss.

I would urge the Utah State Legislature to evaluate and change the exclusion of auditory osseointegrated implants for cochlear stimulation in adults and children to provide parity in health coverage for people with hearing loss in Utah. It would be my pleasure to meet with you and discuss my own experiences, as an expert in hearing restoration, regarding the use, treatment, and outcomes regarding this device. I have also attached an appendix which gives a more detailed overview and background of auditory osseointegrated devices for your convenience.

I also have several patients who would be happy to meet with you and give you their perspective and what it would mean to them to have the procedure performed, or to bring in patients who have had the procedure and what it means to them to have their hearing restored.

Sincerely,

A handwritten signature in black ink, appearing to read "Darley", with a long, sweeping flourish extending to the right.

DAVID SPENCER DARLEY, M.D.

Director of Hearing and Balance Center, Peak ENT Associates

## Auditory Osseointegrated Devices

### Background on Auditory Osseointegrated Devices

- Auditory osseointegrated devices (also called bone anchored auditory implants or Baha) were first implanted in Europe in 1977. The bone-anchored hearing device was approved by the FDA for mixed/conductive hearing loss in 1996, for pediatric use in children age 5 and older in 1999 (younger children can use the device without surgery on a Softband), for bilateral fittings in 2001, and for Single-Sided Deafness (SSD) in 2002.
- The bone-anchored hearing device operates using technologies and mechanisms that are distinctly different from those utilized by both air- and bone-conduction conventional hearing aids. The implant requires surgical placement and is one of several prosthetic auditory devices that are covered by Medicare. These devices include cochlear implants, auditory brainstem implants, and osseointegrated implants.
- By using direct bone transmission (via the bones in the head), Baha allows sound to bypass the damaged, non-functioning middle ear and delivers a signal to a functioning cochlea, where the sound information can then be transmitted to the brain. Baha also provides an option for individuals with single-sided deafness, those who need the benefit provided by bilateral hearing.
- In November 2005, CMS published language covering auditory osseointegrated implants for all FDA approved indications. At the time it decided to cover, CMS changed its rule: "The definition of hearing aids has been modified to exclude certain implantable devices from the category of hearing aids.... Medicare will pay for auditory osseointegrated devices." This established this intervention as a complete system (implant and external processor).
- The auditory osseointegrated device consists of three parts: a titanium implant, an abutment, and a sound processor. The system provides sensitive hearing in a variety of previously untreatable conditions affecting the ear canal, middle ear and mastoid.
- The CMS designation and decision to cover as a prosthetic was based on how the device works to bypass abnormalities of the auditory periphery and the fact that the auditory osseointegrated device enabled prosthetic hearing for individuals who are not candidates for conventional amplification.
- Most large private insurers cover auditory osseointegrated implants as a medical device including Aetna, United Healthcare, VA, Highmark BCBS, Excellus BCBS, Wellmark BCBS, and a number of the other Blues. A number of smaller insurance plans also cover the implant as a prosthetic device. These insurers have all thoroughly evaluated the device and determined it is not a hearing aid and therefore should be provided as a medical device for children and adults who need access to sensitive hearing.

---

**From:** Abigail Wright <abigail.rose.wright@gmail.com>  
**Sent:** Tuesday, July 03, 2012 2:08 PM  
**To:** Stewart Barlow; Lori Rammell  
**Cc:** jeff@jwright.biz  
**Subject:** Cochlear Implant Coverage/ Insurance Minimums

Good Afternoon,

I am a mother of a 2 year old boy who was born profoundly deaf, but who hears and is learning to talk thanks to bilateral cochlear implants.

I will briefly give you the background on the struggle that we faced with our insurance coverage when trying to provide the best possible care and life for our son, Alexander.

When we found out that Alexander was profoundly deaf (2 weeks after his birth), it was shocking and devastating for us. There was no history of hearing loss in either maternal or paternal families, and Alexander was born full term with no complications during the pregnancy. We immediately began looking at our options as parents of a deaf child. I cannot fully express to you how overwhelming it was to face raising a deaf child when I had never personally known anyone who is deaf. I wondered how we would communicate, how he would fit into society, how he would learn to read, what would his life be like? Suddenly I began noticing deaf individuals around us... they were working at fast food drive throughs handing us our food. I just want to clarify that I have no negative feelings toward the deaf ASL community, but we had very high hopes and dreams for our son. We didn't want him to just get by in life by making minimum wage working at a fast food restaurant, but to be going to college at an ivy league school and contributing to society in some exceptional way.

My husband and I are both very proactive, action oriented people. We immediately began researching cochlear implants and weighing the choice as to whether we should have Alexander implanted, or if we should sign with him. We believe it is in Alexander's best interest to have every opportunity available to him in life. That includes having this basic sense of hearing. We sought out specialists in Utah and even traveled to the University of Iowa to meet with one of the top cochlear implant surgeons in the country. Our only hold up was insurance coverage... We were dismayed to find out that we were facing an uphill battle to try to provide the best outcome for our son. In other parts of the U.S. (and world) it is becoming more and more common to implant children as young as 6 months, so that the children can catch up as quickly as possible. Don't forget, babies begin hearing and learning in utero... We tried for approval to go out of network for cochlear implants to have the surgery done earlier and were denied. We decided not to fight that battle after being denied several times. The new plan was to wait until Alexander was 12 months old and have him implanted here in Utah by Dr. Clough Shelton. As time went on and we got further in the process, we realized our insurance really didn't even cover ONE implant, let alone two.

Our story is a bit of a unique situation in that my husband owns his own business and provides health insurance coverage to his employees and of course our family. I had inquired with our health insurance provider (Select Health) about the cochlear implant coverage when Alexander was about 2.5 months old. As the coverage is not spelled out in the member benefits guide, I called a representative (as directed in the benefits guide). I specifically asked about the \$35,000 lifetime coverage for cochlear implants. The representative assured me that that lifetime coverage was only for surgery related costs, and that the actual devices were billed under Durable Medical Equipment. To give you an estimate, the cost per ear for surgery and the device is approximately \$70,000. To have both ears implanted (bilateral) we were looking at a cost of about \$140,000, with Select

Health's coverage being A LIFETIME MAXIMUM OF \$35,000. To provide our son with the best possible outcome we were looking at an out of pocket expense of \$105,000! Long story short, we fought tooth and nail for coverage. I wrote letters, we hired an attorney, we went through the appeals process and went before the grievance committee. I could not believe how unjust this was and was not about to give up on giving my son the best possible care. Two days before Alexander's scheduled surgery date Select Health reversed their previous denials and granted us authorization for the surgery. Select Health gave us the reason that they did this as the fact that we relied on what their representative had told me on the phone to make decisions regarding our health insurance provider. We had the opportunity to change providers, but did not because of what we were told about this issue that was very important to us. My feeling is that they did not want to set a precedent for coverage on this particular issue. Utah is SO far behind in the standard of care regarding hearing loss, and appears to have gone backwards even in the time since we waged our battle for Alexander. Please, please make bilateral cochlear implants a minimum standard of care! I know that almost every family that has dealt with hearing loss in Utah has been affected by the lack of insurance coverage. Most people don't have \$105,000 just waiting to be used for an unforeseen condition- particularly families with newborns as they are usually just starting out. Additionally, not all families are as vocal or know that they can make appeals to their insurance companies. Their children will not get the best possible care and outcomes without this amazing technology being available to them.

Alexander has been hearing for about 14 months now and his progress has been nothing short of amazing. I feel like I have the privilege of witnessing a miracle every time he surprises me with a new word, new linguistic sound, or acknowledges that he hears an environmental sound. These experiences literally bring tears to my eyes. When I first found out that Alexander was deaf I thought of all the simple sounds that I take for granted every day- the sound of a car in the street, birds singing, footsteps, the wind... sounds I thought Alexander would never hear. A few months back Alexander acknowledged that he heard the wind blowing; even after Alexander was implanted I never thought this would be a sound that he would really be able to hear- I was wrong. Alexander receives lots of therapy and he is steadily catching up to his peers in his speech and comprehension. He loves to hear; he knows the difference between silence and the world of sound and his choice even at such a young age is to be able to hear. He is so proud of himself when he recognizes a sound- the microwave beeping, our dogs barking, the doorbell, the toaster... His face lights up and he proudly points to his ear and tries to say "I hear that," then pointing to whatever made the noise. My worries as a parent are far from over, but as I have seen the amount of progress that Alexander has made in just over a year, I no longer wonder if he will make it in the hearing world. I know that Alexander will catch up and surpass his peers, he just has to work a little bit harder.

I am attaching a link to a youtube video that we made when Alexander's implants were activated. Some of the video clips were taken just days after his activation, and you can see the enthusiasm and how much he already loved to hear everything and learn the words for everything. Please take a few minutes to watch- it really gives you an idea of the delight a child has at having to opportunity to enter the hearing world.

[http://www.youtube.com/watch?v=NNanhix6lko&feature=BFa&list=ULiCyHHc3\\_9Oc](http://www.youtube.com/watch?v=NNanhix6lko&feature=BFa&list=ULiCyHHc3_9Oc)

The technology to essentially restore the lost sense of hearing is available and can make a world of difference in a child's life, but unfortunately it is out of reach for many families due to the lack of adequate insurance coverage. Please, please take into consideration what a huge impact bilateral cochlear implant coverage can make in a person's life. Believe me, cochlear implants are not "cosmetic"- no one would choose to wear a hearing device with a magnet hooked to the back of their head- it's about giving that person every opportunity to maximize their contribution to society. Let's face it, the vast majority of the world are not going to learn sign language, and this isolates people with hearing loss to a very small community.

Thank you for your time and consideration.

Sincerely,

Abigail Wright

---

**From:** Heather Sutton <heatherjsutton@msn.com>  
**Sent:** Tuesday, July 03, 2012 4:49 PM  
**To:** Stewart Barlow; Lori Rammell  
**Subject:** Minimum Health Insurance Coverage and Hearing Aids

Dear Legislators,

Please see my attached letter regarding the proposed minimum health insurance plan mandated by the state of Utah. My letter is written to address the need for coverage of hearing aids, implantable hearing devices, and audiology services. Thank you for your time and consideration.

Sincerely,

Heather Sutton

Heather has a file to share with you on SkyDrive. To view it, click the link below.



Hearing Aid Letter.docx

---

**From:** Brian Loe <deannaloe@gmail.com>  
**Sent:** Tuesday, July 03, 2012 4:58 PM  
**To:** Lori Rammell  
**Subject:** Coverage for Hearing Impaired Children  
**Attachments:** legislature letter.docx

To Who it May Concern,

We believe that the minimum healthcare coverage should include costs that cover hearing devices such as; hearing aids, baha's, cochlear implants ( CI's), and whatever hearing device is needed to help an individual hear as correctly as possible. We have new medical advancements to help one's senses that do not work well or at all available today that are covered in the minimum healthcare. For example, vision is covered, but helping an individual who is deaf or hard of hearing is many times classified as cosmetic and not covered by healthcare. There is a large gap between what private insurance companies will cover, what is expected out of pocket, or they may not even help cover costs at all. In order to get Cochlear Implants or other hearing devices many people have to get on Medicare to pay for the costs or bridge the gap of coverage, that is if they qualify for it.

For example, our son Mason Loe was born severely deaf and within months he was profoundly deaf. While he was a newborn we choose to help him have more opportunities to succeed in life by choosing the listening and spoken language route. This route requires the aid of hearing devices. When Mason was 3 months old he was fitted with loner hearing aids through a state program for low income families, because insurance would not cover the costs. He used them for a trial period and failed to respond to sounds, let alone speech. Because he did not benefit from hearing aids the next step was to do more testing to see if he was a candidate for receiving cochlear implants. To be a CI's candidate must pass certain physical and mental capabilities, and have support group if it is for a child. This is determined through tests and specialists' observations that are certified in cochlear implants .

When our son, Mason, qualified for implants we new he needed to get them as soon as possible to best help him. Unfortunately our private insurance only covered a small portion of the costs for CI's and classified them as cosmetic. This forced us to get our son on Medicare to pay for the huge remainder of his surgery; this was a long hard process, with many denials at first due to incorrect calculating on their part. If my husband had a better paying full time job and was not going to school we would have not qualified nor been able to afford the costs of the surgery and appointments that go along with it on our own nor had the help of Medicare. Which situation we have seen other families struggle with getting any help with the coverage they are desperately in need of. Because of Medicaid our son was able to receive the surgery when he was 13 months old and is blessed with the priceless opportunity to hear with his bilateral CI's. He loves to hear, speak, communicate with many people and enjoy sounds. He is almost 3 years old and has been caught up with hearing children his age for about the last 6 months. Mason tests higher than the average child his age in his understanding of language and vocabulary. The main area we are focusing on his now his articulation and we go to therapy for that every other week . He is doing remarkable and will be attending a mainstream preschool when he is barely 3 years old, which is unheard of. His success is due to his receiving hearing aids, CI's, audiology appointments, and speech therapy at such a young and critical age. Watching our son and his success because he can hear is a everyday and modern day miracle and possibility due to advanced medical technology.

Please consider helping more qualifying deaf people hear who choose to have the opportunity to hear through hearing devices, like our son, have a brighter future. Being deaf or hard of hearing is a medical condition. It affects one of our most used senses, which also protects us from danger. Some deaf people who use Sign Language as their main means to communicate can succeed, but the truth is it is a small percentage that even get pass a second graders reading level, graduate high school, or advance in college. Therefore a high percentage of those in the deaf community have to live on government programs and can not pay into private healthcare companies. So, by helping those who qualify and choose to hear well with hearing devices we can help them have more chances to be independent and therefore contributing more to society.

We hope that you will pick a healthcare plan that includes covering the costs of hearing devices and make a impactful decision that will better our society as a whole and give our children more windows of opportunity to communicate well with many people not just a small elect group. These children can do it with your help. I see it everyday with my son and am so very thankful that he was able to receive CI's to make so many things possible for him. But this is not the end, he will need ongoing appointments to make sure he is hearing well and the CI equipment is functioning properly. Please make minimum healthcare cover hearing devices, audiology and speech therapy appointments possible.

Sincerely,

Mason's parents, Deanna and Brian Loe

---

**From:** Melinda Clark <mindykimballclark@gmail.com>  
**Sent:** Tuesday, July 03, 2012 5:00 PM  
**To:** Stewart Barlow; Lori Rammell  
**Subject:** Hearing device coverage  
**Attachments:** April-May 2012 001.JPG

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

Hi there! I just wanted to let you know how important it has been in my daughters life to have Cochlear Implants and was hoping you would take this into consideration when making decisions. She is 3 almost 4. She was born profoundly deaf, she could not hear anything, not even with hearing aids. She got her first implant at age 1 and is now testing within normal limits in some areas as her hearing peers. When she had access to sound it was like she was a completely different baby, in a good way! She would get excited about things where before she would just sit there, not much emotion. Our insurance paid for one, they actually won't even do that any more. She received one for her other ear when she was 2, that was a major battle with the insurance company. Most people have no clue that she is even deaf unless they see her implants. We usually bling them out with stickers and jewels so they are noticeable because I like to educate people on what they are. She will be able to function in society as a normal person because of this. If she only had access to sign language she would need help her whole life. I wanted to write more but I know you needed these by 5pm. I would be happy to even come down and show you how great she is doing. All deaf babies should have access to sound, or at least have a choice to. Thanks for taking the time to read this!

Sincerely,  
Melinda Clark  
Mother of Taylor Ann Clark  
801-414-4939



---

**From:** deborahsbruner@comcast.net  
**Sent:** Saturday, June 30, 2012 7:14 AM  
**To:** Lori Rammell  
**Cc:** deborahsbruner@comcast.net  
**Subject:** Health insurance plans - a plead for inclusion

Hi,

I was told that Utah lawmakers are looking for public input for Utah's "essential benefits" package and know that you are accepting comments. Items on this list will be included in all health insurance plans sold in Utah. We need to be sure elemental formula makes it onto this list.

I am one of many (although rare) who have an eosinophilic- GI related disease. I am fortunate in that I am only allergic to environmental things. However, many of those with these diseases are allergic to just about all foods and require elemental formula. As you may know, the price of this formula each month can be greater than the total monthly mortgage and car payments combined.

Please do everything in your power to consider elemental formula an essential benefit for those diagnosed with an eosinophilic disorder. This is what keeps these patients alive!

Many thanks for reading, and for all your efforts,

Deb Bruner  
Philadelphia PA

---

**From:** Seth & Sarah Metcalf <sametcalf@gmail.com>  
**Sent:** Wednesday, June 27, 2012 3:38 PM  
**To:** Lori Rammell  
**Subject:** Elemental formula - essential benefit

To Whom it May Concern,

I'm writing to encourage that elemental formula be added as an essential benefit for those who have been diagnosed with an eosinophilic gastrointestinal disorder. I am a Utah mother of two young sons with eosinophilic disorders that require elemental formula to live healthy lives. Removing all foods from their diet and putting them on a 100% amino acid-based elemental formula was not something we were excited to do, but we were incredibly grateful it was something our doctors could prescribe to combat the pain, vomiting, diarrhea, and weight loss of our sons. This formula does not compare to store-bought formulas in composition or price, it would cost our family approximately \$1800 per month to purchase this formula out of pocket. We have had to resort to Medicaid to ensure our children will have this formula covered. I have been involved in working on legislation for several years in Utah to seek insurance coverage of elemental formula, this is incredibly important to my family and many others throughout Utah.

Thank you,

Sarah Metcalf  
Provo, UT

---

**From:** Karen Deutsch <karen@allaboardfl.com>  
**Sent:** Friday, June 29, 2012 9:17 AM  
**To:** Lori Rammell  
**Subject:** Elemental Formula

Dear Utah Lawmakers,

Please include elemental formula as an essential benefit for those diagnosed with an eosinophilic disorder. My son has an eosinophilic disorder and elemental formula is "food" for children with some eosinophilic disorders as they cannot eat. Denying them access to elemental formula is denying someone access to food necessary to live.

Thank you for your time and consideration,

Karen Deutsch

**Karen A. Deutsch, M.S. CCC-SLP**  
Director, Speech-Language Pathologist

ALLAboard Therapy LLC  
576 Riverside Drive  
Coral Springs, FL 33071  
phone: 954-341-0090  
fax: 888-577-1487  
email: [karen@allaboardfl.com](mailto:karen@allaboardfl.com)  
[www.allaboardfl.com](http://www.allaboardfl.com)

Note: This email may contain material that is CONFIDENTIAL under Florida Statutes and is intended to be delivered to only the named recipient(s). Unauthorized dissemination of this information may be a violation of criminal statutes. If this information is received by anyone other than the recipient(s), the recipient(s) should immediately notify All Aboard Therapy, LLC at the email, address or telephone number shown on this page and obtain instruction as to the disposal thereof. Under no circumstances should this material be read, retained or copied by anyone other than the named recipient.

---

**From:** Dianne <dicarp2@aol.com>  
**Sent:** Wednesday, June 27, 2012 2:33 PM  
**To:** Lori Rammell  
**Subject:** Elemental Formula need for EE children

To Whom This May Concern:

I am writing to enforce the critical support needed for families with a member suffering from any Eosinophilic disorder. I cannot emphasize the importance of insurance benefit for an elemental formula for basic nutritional needs. Please, Please mandate that all elemental formula is covered as a benefit for any patient of an Eosinophilic Disorder.

To summarize why I think it is so important:

My son was diagnosed at 9 months old with Eosinophilic Esophagitis Disorder. Until that point, any nursing, formula or basic baby food would cause him severe pain, vomiting and poor nutrition. It was a terribly difficult road until he received his diagnosis and a real solution and treatment became available. His physician gave us a few samples of the elemental formula and stopped ALL foods or formula or nursing immediately. For the first time in his nine months, he had his formula without vomiting or crying in severe pain. In a short time, he dramatically improved. However, I battled the insurance company for an additional one month for coverage of his elemental formula even though the state of Arizona mandated coverage. During that time, I had to pay out of pocket ~\$1800.00 for his formula which was absolutely not affordable. So, I had no choice but to return to over the counter formula since I had stopped nursing. This time, my son was even more ill. His vomiting and pain landed him in the hospital. I cried every time I would feed him. I was stuck with a horrible dilemma that with the non elemental formula he will get worse and cry with severe pain and without it he will die. I didn't feel my son anything but water for 1-2 days until I finally received my next pay check and didn't pay my mortgage to pay for his formula. I didn't know what to do next. My son was suffering and his problem can be solved, but the only treatment was out of reach because of the cost - even though the state mandated it. After fighting a long battle with my insurance company, it has been covered. My son is now almost 4 years old and still drinks elemental formula for his primary nutrition. If you met him, you would never know anything was wrong with him. My co-pay is still \$250.00 per month, while expensive, much more affordable. Now I know most people cannot afford this critical treatment and nutritional support without insurance coverage. I am a health care provider myself with a good income and there is no way possible that I can afford the out of pocket cost for this prescription elemental formula. In addition to the formula, most EE children have expensive medications and regular biopsy's which create additional health care expenses. Please Please recognize how important this coverage is for these patients....it is truly a matter of life or death. Don't let other families suffer with the battle of the insurance companies for non coverage of the formula.

Sincerely,

Dianne Carpenter, PT, DPT  
Goodyear, Arizona

---

**From:** Vicki McGinley <[vickimcginley@yahoo.com](mailto:vickimcginley@yahoo.com)>  
**Sent:** Wednesday, June 27, 2012 1:33 PM  
**To:** Lori Rammell  
**Subject:** essential benefits package

June 27, 2012

I am writing this letter regarding support for Utah to set the course for elemental formula to be included in the essential benefits package. I greatly appreciate you taking the time out of your busy schedule to read my letter. I have just finished doing a presentation for my graduate nursing class on the disease which my son also has- eosinophilic esophagitis, and many children are limited to only drinking extremely expensive elemental formula for their daily nutrition intake. It is unfortunate that children with dietary disorders are becoming more and more common, though we do not know why. In my research I was surprised to find that Eosinophilic Esophagitis was not officially established as a disease until recently and in an article from 2009, the physician author writes “there has been a dramatic increase in the diagnosis of EE over the last couple years, due to increased awareness and an actual increase in prevalence” Before this patients were misdiagnosed as having gastric reflux disease as many of the symptoms are similar. (Lambrosa, 2009) Also, in the past the estimate for the number of people that have the disease when it was first named in 2007 (Rothenberg, Franciosi & DeBrosse, 2011) was 1 in every 10,000 people, the current estimate is now one in every 1,000 people. (Rothenberg, Franciosi & DeBrosse, 2011) Most patients with the disease are not diagnosed “If a patient has long term upper GI symptoms and allergies, this should be considered” (Rothenberg, Franciosi & DeBrosse, 2011). Recent studies have shown it may be more prevalent than Crohns disease or cystic Fibrosis. (Eosinophilic Information, 2011). Great sites for further information are “Cured” at [www.curedfoundation.org](http://www.curedfoundation.org) where there is even an area where a mother writes how she drank her sons neocate (elemental formula) for a week to see what it would be like, and Apfed or American partnership for eosinophilic disorders: <http://apfed.org>

Again, I thank you very much for your time and would appreciate your consideration of elemental formula to be included in the essential benefits category.

Sincerely,

Victoria McGinley, BA, RN, BSN

811 East Fitzsimmons Road Oak Creek, WI 53154

- “Eosinophilic Information”, (n.d.) Retrieved from [http://www.njpaeos.org/eosinophilic\\_esophagitis.html](http://www.njpaeos.org/eosinophilic_esophagitis.html)
- Lambroza, A., (2009). Retrieved from [http://www.lambroza.com/eosinophilic\\_esophagitis-.htm](http://www.lambroza.com/eosinophilic_esophagitis-.htm)
- Rothenberg, M., Franciosi, J & DeBrosse, C., (2011). Retrieved from <http://www.cincinnatichildrens.org/news/release/2011/eosinophilic-esophagitis-study-6-3-2011>

Vicki McGinley,  
B.A.,R.N.,B.S.N.

[www.3gifts.org](http://www.3gifts.org)

---

**From:** tcr611@gmail.com on behalf of Tom Riccio <tcr61@comcast.net>  
**Sent:** Tuesday, June 26, 2012 8:37 PM  
**To:** Lori Rammell  
**Subject:** EOS - Insurance coverage for elemental formula

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

To whom it may concern,

I am writing on behalf of all patients and families of those patients who have EOS. When a loved one is diagnosed with EOS it is hard enough to cope with the reality your daily life has dramatically changed forever. When they are prescribed elemental formula to heal their esophagus and are told it is not covered by insurance it can also be a financial bankruptcy for the family.

When my son was diagnosed with EOS and put on Elemental Formula (his formula was EO28) by his specialist at Children's Hospital (Chicago, Illinois) we were told that it would not be covered by insurance because it was "food." Yes, it was his calorie intake for the next seven weeks but it was hardly food. It was pre-digested amino acids that gave him calories to survive. It was prescribed by a Doctor and the only way you can buy the Elemental Formula. It was also a very real financial hardship for a married couple with two boys under 5. See, the EO28 came in a case of 32 juice box size containers and cost \$1,200.00 to \$1,400.00 per case. My son drank three box containers a day for seven weeks straight and was only allowed one Life Saver per day. Five cases later and at a cost of over \$6,000.00 we wondered why this isn't covered by insurance. And we still wonder why because it is very far from food.

That is why I'm writing you and asking you to make sure Elemental Formula is covered by insurance in the state of Utah. I do not want to see any other families face the financial hardships we dealt with. Elemental Formula is medicine to heal the esophagus. EOS is a Disease ~

Thank you for your time,

Tom & Paige Riccio  
Granby, Colorado  
2 sons with EOS

---

**From:** chadrhinehart@bellsouth.net  
**Sent:** Tuesday, June 26, 2012 4:33 PM  
**To:** Lori Rammell  
**Subject:** Elemental Formula

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

To Whom it May Concern,

I am a mother of a child with an Eosinophilic Disorder. He is only 4 years old and is on a feeding tube that requires elemental formula. This formula is a necessity for my son's survival. Without this formula my son would not receive enough nutritional support from the few foods he can eat. This formula is like medicine for these kids and therefore should be covered under health insurance plans. The formula is very expensive (apx. \$50 a can) and my son takes almost an entire can per day. This formula is used to treat a medical condition and it is saving my son's life! Please help it save lives in your state.

Sincerely,  
Leslie Rhinehart  
South Carolina

*Sent from my Verizon Wireless 4G LTE DROID*

---

**From:** Hepsi Pena <motas333@hotmail.com>  
**Sent:** Wednesday, June 27, 2012 5:33 AM  
**To:** Lori Rammell  
**Subject:** Health Care Essentials Benefit

Hello,  
I am writing in support of having Elemental Formula covered as an Essential Benefit. For those of us with children suffering with gastrointestinal diseases that require our children to consume their nutrition from elemental formula, the coverage is a necessity. No family feeds their children filet mignon every day, but the cost of elemental formula is just as expensive. Without the elemental formula our kids would die. Please include elemental formulas in the Essential Benefits. Thank you. Hepsi Pena

---

**From:** teachermorgan@yahoo.com  
**Sent:** Tuesday, June 26, 2012 2:56 PM  
**To:** Lori Rammell  
**Subject:** Elemental formula is essential

PLEASE support the concept that elemental formula. Is a necessary benefit for the unfortunate patients diagnosed with eosinophilic esophagitis.

This diagnosis can bankrupt families without the support.

My son has the disease and the support is vital.

SINCERELY,

Margaret Morgan

*Sent from my Verizon Wireless Phone*

---

**From:** ancylusgirl@hotmail.com  
**Sent:** Tuesday, June 26, 2012 2:47 PM  
**To:** Lori Rammell  
**Subject:** Elemental formula

Please include this in the state law that all children may eat. It is also used in Tube Feeding...at hospitals  
Sent from my HTC Inspire™ 4G on AT&T

---

**From:** Bob & Mary K. Baird <pz5c8xba2323@cox.net>  
**Sent:** Monday, June 25, 2012 1:02 PM  
**To:** Lori Rammell  
**Cc:** ba2323@cox.net  
**Subject:** EoE - Eosinophilic Disorder

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

Please know it is imperative that elemental formula should be considered an essential benefit for those diagnosed with an eosinophilic disorder.

This disease is becoming more actively diagnosed today. We need to understand the critical needs of the families involved with EoE. The expenses alone are astronomical and can bankrupt a family quickly. Please read about EoE and help us make it an essential benefit..... we ask you, please.

*Mary Kay and Bob Baird*

---

**From:** Brittney Castine <brittneycastine@gmail.com>  
**Sent:** Monday, June 25, 2012 12:32 PM  
**To:** Lori Rammell  
**Subject:** Elemental Formula Added to Essential Benefit Health Care

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

Hello,

As a sufferer of Eosinophilic Esophagitis, and as a woman not knowing if this is hereditary (studies haven't proven otherwise,) please make elemental formula considered as an essential benefit for those diagnosed with an eosinophilic disorder."

Thank you,  
Brittney Castine

---

**From:** jennifer smialek <jsmialek@live.com>  
**Sent:** Tuesday, June 26, 2012 8:18 AM  
**To:** Lori Rammell  
**Subject:** ELEMENTAL FORMULA

Dear Representative Rammell-

It is imperative for children who are diagnosed with an Eosinophilic Disorder to survive with Elemental Formula, this is usually all that these children's bodies can consume to give them some type of nutrition, and until a cure is found it is so important that ELEMENTAL FORMULA be considered an essential benefit. Please help us by making sure this happens.

Thank you for your time.

Sincerely,  
Jennifer Smialek

---

**From:** Gwpagan@aol.com  
**Sent:** Monday, June 25, 2012 3:05 PM  
**To:** Lori Rammell  
**Subject:** (no subject)

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

Elemental formula should be considered an essential benefit for those diagnosed with an eosinophilic disorder like my precious grandson, Oliver. Please do not consider this formula as anything but a pharmaceutical therapy as he cannot eat any food at all.

Thank you.  
Gail Pagan

---

**From:** Heidi McKinsey <heidichadcarlee@gmail.com>  
**Sent:** Monday, June 25, 2012 7:20 PM  
**To:** Lori Rammell  
**Subject:** Elemental formula

To Whom it may concern,

Elemental formula is essential for the health and well being of children and adults suffering from eosinophilic related illnesses. Some of these individual are unable to tolerate any other foods and rely solely on these formulas for sustenance. Others use elemental formulas as a supplement to get adequate daily calories while doing food reintroduction trials. Many of these children are failure to thrive because of the feeding intolerance's associated with the pain and discomfort of these disorders so the extra calories and nutrients provided by elemental formulas are needed to mind and body growth and development. These formulas are very expensive and can put a large financial strain of families who rely on them. Please consider adding insurance coverage of elemental formulas to Utah's Essential Benefits package and give those with eosinophilic related disorders the nutrition they need to live and grow as others around them.

Thank you,  
Heidi McKinsey  
mother of a 2 year old with Eosinophilic Esophagitis from Felton, PA

---

**From:** Jessica Young <jey\_76@yahoo.com>  
**Sent:** Monday, June 25, 2012 7:39 PM  
**To:** Lori Rammell  
**Subject:** Fw: CALL TO ACTION

Please consider mandating health insurance coverage for medically necessary elemental formula. This formula is so expensive, and such a burden on a family's finances when it's not covered by insurance. For an example, our medical supply company charges about \$1,500 per month for my daughter's elemental formula, which is her sole source of nutrition.

Thanks for your consideration,  
Jessica Young

----- Forwarded Message -----

**From:** American Partnership For Eosinophilic Disorders <[email@apfed.org](mailto:email@apfed.org)>  
**To:** jey\_76 <jey\_76@yahoo.com>  
**Sent:** Monday, June 25, 2012 3:04 PM  
**Subject:** CALL TO ACTION



## American Partnership for Eosinophilic Disorders

*Connecting the Eosinophilic Community*

### Eos Advocates in Utah Need Our Help

Utah lawmakers are looking for public input for Utah's "essential benefits" package. Items on this list will be included in the insurance plans sold in Utah. We need to be sure elemental formula makes it onto this list.

Comments are accepted through July 3 and should be sent to [LRammell@Le.Utah.gov](mailto:LRammell@Le.Utah.gov).

Let them know that "elemental formula should be considered an essential benefit for those diagnosed with eosinophilic disorders."

If you have family, friends, or neighbors that would be willing to write a quick note, please pass this on to get coverage for elemental formula.

<http://www.sltrib.com/sltrib/news/54325054-78/utah-health-state-benefits.html.csp>



American Partnership For Eosinophilic Disorders

[www.apfed.org](http://www.apfed.org)

PO Box 29545

Atlanta, GA 30359

[mail@apfed.org](mailto:mail@apfed.org)

Phone: (713)493-7749

If you want to be removed from our email list, please notify us at [mail@apfed.org](mailto:mail@apfed.org) or members may select to receive just our newsletter by notifying us at [mail@apfed.org](mailto:mail@apfed.org)

---

**From:** Lutspa@aol.com  
**Sent:** Monday, June 25, 2012 7:57 PM  
**To:** Lori Rammell  
**Subject:** Support elemental formula as essential benefit for health insurance plans

To Whom It May Concern,

I understand that Utah lawmakers are looking for public input for Utah's "essential benefits" package. Items on this list will be included in all health insurance plans sold in Utah. Elemental formula should be considered an essential benefit for those diagnosed with an eosinophilic disorder.

My son, as well as many other children (and adults too) have eosinophilic disorder. Can you imagine what it would be like if you could not eat regular food and needed elemental formula for your survival? Please support elemental formula as part of Utah's essential benefits package!

Thanks,  
Diane Luteran (parent of child with eosinophilic disorder)

---

**From:** Dominique <dominiquepl99@yahoo.com>  
**Sent:** Monday, June 25, 2012 8:34 PM  
**To:** Lori Rammell  
**Subject:** Elemental formula essential for children with eosinophilic disorders

Dear Sir or Madame:

Please make sure that elemental formula is included in your health care plan benefits. My child suffers from eosinophilic esophagitis, and he has (over the years) used elemental formula both exclusively and as a supplement to his restricted diet. I am happy to state that he has grown so much because of the nourishment he receives from the formula, and I hope other children with eosinophilic disorders can also benefit.

Thank you for reading my letter.

Sincerely,  
Dominique & Robert Lamaute

---

**From:** Janet Marciniak <jmarciniak.ct@gmail.com>  
**Sent:** Monday, June 25, 2012 11:45 PM  
**To:** Lori Rammell  
**Subject:** Utah's essential benefit package

I feel that elemental formula should be considered an essential benefit for those diagnosed with an eosinophilic disorder. My son is now 22, and after having this disease since he was born, and having it in remission for 4 years, it is back. If he needs to go on formula only, which is frequently necessary to let the gut heal, the cost is prohibitive, particularly given his size, 6'3" and the calories it would take to sustain him. According to the most recent survey conducted by APFED, American Partnership For Eosinophilic Disorders, the cost of formula for a year is as follows:

Less than \$500- 49.4%  
\$501 to 1000- 7.1%  
\$1001-2000- 13.5%  
\$2001-5000- 18.4%  
\$5011-10,000- 8.6%  
More than \$10,000- 3%

Janet Marciniak  
29 Wayne Street  
Norwich, CT. 06360

---

**From:** jennherman@cox.net  
**Sent:** Tuesday, June 26, 2012 3:10 AM  
**To:** Lori Rammell  
**Subject:** Health Insurance plan: adding elemental formula

I am writing to highly encourage you to please consider elemental formula an essential benefit for those diagnosed with an eosinophilic disorder. This is a very costly formula and I have personally know families who have had to sell their own house to cover this expense for one child. For some children, it is needed on a temporary basis, but for many, it is long-term. Please consider adding this to the insurance as covered. Thank you.

Jennifer Herman  
P.O. Box 567  
Waddell, AZ 85355

---

**From:** Tina L. Suhocki <tsuhocki@tbccpa.com>  
**Sent:** Tuesday, June 26, 2012 4:52 AM  
**To:** Lori Rammell

Ms. Lori Rammell,

I am writing to you on behalf of the many patients that suffer with Eosinophilic Gastrointestinal Disease. I know all too well the devastating effects of this disease, as I have a seven year-old son that suffers from Eosinophilic Esophagitis. And, although I am not a Utah resident (we reside in New York State), I understand that the Utah Legislature is currently contemplating public opinion in regards to an essential health benefits package for health insurance coverage for your constituents.

Although no one knows the true cause of Eosinophilic Diseases, they are thought to be food allergy related. As such, many live with very limited diets and rely on a prescription formula to meet their daily nutritional needs. Not having access to this formula would be detrimental to the lives of those with these diseases. We happen to be very fortunate, in that we reside in a state that mandates health insurance plans cover this formula. If we were not so fortunate, it would cost our family approximately \$800 a month to sustain our son. That is what many pay for a mortgage payment each month! I urge you to carefully consider the implications of not including this coverage in whatever health plan you ultimately decide on. It literally could mean the difference between life and death.

Thank you for your time and consideration.

Sincerely,

*Tina L. Suhocki*  
**(518) 577-3332**  
**tsuhocki@tbccpa.com**

To ensure compliance with requirements imposed by the IRS, we inform you that any U.S. federal tax advice contained in this communication (including any attachments) is not intended or written to be used, and cannot be used, for the purpose of (1) avoiding penalties under the Internal Revenue Service Code or (2) promoting, marketing, or recommending to another party any transaction or matter addressed herein.

NOTICE: This electronic message and any attachments are the confidential information and property of the sender. The information in this email and any attachments may only be used by the person to whom it is addressed. Any intercepting, copying, accessing, distributing or disclosing of this email or any attachments by any other person is prohibited. The sender takes no responsibility for any unauthorized reliance on this email or any attachments or for the presence of any viruses.

This email message has been delivered safely and archived online by Mimecast. For more information please visit <http://www.mimecast.com>

---

**From:** Rod Crawford <rcrawfor@tampabay.rr.com>  
**Sent:** Tuesday, June 26, 2012 5:12 AM  
**To:** Lori Rammell  
**Subject:** EoE

Unless you have experienced food allergies its hard to understand how difficult it is to cope with them. Imagine not being able too swallow any food. It doesn't take long to get weak.

I urge you to add elemental diet food to your covered list of conditions.

Sincerely,

Roderick Crawford

*Sent from my Verizon Wireless 4G LTE DROID*

---

**From:** Kathy Gasior <Gasiork@mc-mc.com>  
**Sent:** Tuesday, June 26, 2012 5:28 AM  
**To:** Lori Rammell  
**Subject:** Elemental Formula for Eosinphilic Disorder

Dear L. Rammell,

Help the helpless, especially a child.

My son is now 20 and is in remission, so do you your part and make this part of your health care coverage.

Mrs. K. Gasior  
28040 Kingswood Court  
Warren, MI. 48092



---

**From:** Boxer Family <mmboxer5@aol.com>  
**Sent:** Tuesday, June 26, 2012 5:45 AM  
**To:** Lori Rammell  
**Subject:** Insurance and elemental formula

To Whom it May Concern:

I am writing you to inform you of the importance of including elemental formula under insurance coverage- whether it be taken by mouth or by a feeding tube. My 13 year-old son cannot eat foods because of food allergies that cause eosinophils to attack his esophagus and cause it to fibrose. This diagnosis is very hard on a family. Everything in our world revolves around food. It is also very expensive. Our cost was \$45 a day. Families facing this diagnosis should not have to fight insurances to cover the formula. Nobody would choose this if they had the choice. It is a medical necessity- the only thing they are allowed to consume sometimes as is the case with my son. Please help support these families in their fight against food. Without your help, this could financially bond many families or even make it impossible to give them what their child medically needs. Thanks for your consideration.

Sincerely,  
Michelle Boxer and Family

---

**From:** Jeremy Morton <Jeremy.Morton@LMH.ORG>  
**Sent:** Tuesday, June 26, 2012 6:17 AM  
**To:** Lori Rammell

To Whom it may concern:

My name is Jeremy Morton and I am contacting you regarding the upcoming decision for Utah on what is necessary for your essential benefits to be included in your healthcare insurance plan.

My son Cole, like many other infants, children and young adults, suffers from an **Eosinophilic disorder** called Eosinophilic Esophagitis. These disorders limit the number of foods which are tolerated or safe. The only source of nourishment for some sufferers of these disorders is elemental formula. Some children and young adults must receive a continuous infusion of these formulas directly into their stomach because they cannot tolerate any food.

It is essential that your plan allows coverage for these elemental formulas. They are expensive and as I've mentioned are a large part or in some cases the only component of limited diets which are safe for people with these disorders. There are, in many cases, no alternatives to adequately nourish these young people.

Thank you for your time.

Very sincerely,

Jeremy Morton  
De Soto, KS

LMH Confidentiality Notice: This e-mail message, including any attachments, is for the sole use of the intended recipient(s) and may contain confidential and privileged information. Any unauthorized review, use, disclosure or distribution is prohibited. If you are not the intended recipient, please contact the sender by reply e-mail and destroy all copies of the original message.

---

**From:** St. Clair, Linda <Linda.St.Clair@transamerica.com>  
**Sent:** Tuesday, June 26, 2012 6:46 AM  
**To:** Lori Rammell  
**Subject:** elemental formula

It is very important that there is insurance benefits for families that have kids with EE. My little friend Ryan needs these and it is a great expense to his parents. There are more and more kids being diagnosed with this disease and I feel there should be some sort of relief for these families. Please consider giving them the elemental benefits package. These formulas are SO.....important to these kids surviving.

Sincerely Yours,

Linda St.Clair ☺  
Advertising Compliance Coordinator  
610-648-4784

---

**From:** Victoria DeLano <eosalabama@gmail.com>  
**Sent:** Tuesday, June 26, 2012 7:00 AM  
**To:** Lori Rammell  
**Subject:** Essential Benefits in Utah

To Whom It May Concern:

As Utah reviews its list for essential benefits, I am writing to you on behalf of the members of the American Partnership for Eosinophilic Disorders (APFED). Many of the families who live with these orphan diseases rely on amino acid-based elemental formulas as their only effective means of treatment for these devastating illnesses. However, insurance companies in Utah are not currently covering the expense of this much needed treatment that has been shown in published research to be effective in over 90% of patients. It is the position of APFED that elemental formula should be considered an essential benefit for those diagnosed with an eosinophilic gastrointestinal disorder.

Respectfully,

Victoria DeLano  
Board Member  
APFED

--

American Partnership For Eosinophilic Disorders  
PO Box 29545  
Atlanta, GA 30359  
[www.apfed.orgmail@apfed.org](mailto:www.apfed.orgmail@apfed.org)  
Phone: (713)493-7749

The American Partnership for Eosinophilic Disorders is a non-profit advocacy organization for those living with eosinophilic esophagitis, eosinophilic gastroenteritis, eosinophilic colitis, hypereosinophilic syndrome, and other eosinophilic disorders. We are a resource for patients, their families, physicians and the medical community.

APFED provides accurate, up-to-date information on eosinophilic disorders and related problems. Our goals are to increase awareness, educate patients and physicians, increase funding for research and provide support for the eosinophilic community.

#### Confidentiality Notice

This e-mail message (including any attachments) is for the sole use of the intended recipient(s) and may contain confidential and privileged information. If the reader of this message is not the intended recipient, you are hereby notified that any dissemination, distribution or copying of this message (including any attachments) is strictly prohibited.

If you have received this message in error, please contact the sender by reply e-mail message and destroy all copies of the original message (including attachments).

---

**From:** SUSAN SCHIESSL <schiesm@msn.com>  
**Sent:** Tuesday, June 26, 2012 8:08 AM  
**To:** Lori Rammell  
**Subject:** Eosinophilic Disorder

As a parent of a child with eosinophilic disorder we urge you to consider elemental formula as an essential benefit for those diagnosed with an eosinophilic disorder.

Thank You,

Susan Schiessl

---

**From:** Melissa Miller <rn051370@me.com>  
**Sent:** Tuesday, June 26, 2012 8:25 AM  
**To:** Lori Rammell  
**Subject:** Please pay for all elemental feeding for our children

Good morning. I am mother residing on Dallas Texas with my husband and two boys. My middle son is seventeen today and we will be celebrating quietly as h tries to accommodate his Eosiniphilic esophagitis and his psychological battle of a chronic disease. We are patients at Cincinnati Children's Hospital, center for Eosiniphilic disorders (cced) because so little is known about this autoimmune chronic disease. Please please become educated on the disease and why it is necessary to approve all claims for elemental feeding as a supplement or as a primary nutrition. Our kids have an immune system that is allergic to food!!!! All cases are different. The food each child(and adult) can eat is different. Please understand how expensive it is to buy an amino acid based formula for our children because it is all they can have to survive. Please visit:

[www.apfed.org](http://www.apfed.org)

[www.curedfoundation.org](http://www.curedfoundation.org)

[www.rarediseases.org](http://www.rarediseases.org)

There are other sites, too. Please help us give our kids the food they need.

Respectfully,

Mrs. Melissa Miller, RN

1305 Wheatberry lane

Allen, TX. 75002

260-438-2662

[rn051370@me.com](mailto:rn051370@me.com)

Sent from my iPhone

---

**From:** Rebecca Stewart <rebeccastewart1@cox.net>  
**Sent:** Tuesday, June 26, 2012 8:27 AM  
**To:** Lori Rammell  
**Subject:** Elemental formula keeps my son alive

To whom it may concern,

My son, Adam, is nine years old and survives by drinking a specially designed elemental formula. He was diagnosed as a baby with EGID (an eosinophilic gastrointestinal disorder). His body attacks itself when he tries to eat food, even one bite, and the symptoms lasts for days and days, even weeks. It is not an allergy as many are quick to think because that is what they know.

My son cannot tolerate food because when he tries to eat food, the eosinophils from his bone marrow confuse food with a parasite, so to speak, and attack his GI system. He suffers from a host of symptoms including malnutrition if he tries to eat food. This happens because his body isn't absorbing the nutrition from the food. If my son did not have elemental formula, he would not thrive. The formula is NOT a baby formula, rather, it is a specially designed, all-amino acid based MEDICAL FOOD for impaired GI systems that is referred to as formula.

We fight to get my son to grow even with his severely restricted diet and the formula. Children call him midget because he is so small for his age. The one blessing we have with all the struggles we face is our safety net, THE FORMULA! He drinks it 8 times a day and that is his nutrition. The formula is their only source of real nutrition that their bodies can tolerate. These children NEED THIS FORMULA TO SURVIVE! Please include formula coverage (specially designed medical food in the form of formula) as an essential benefit in health insurance coverage. Please, for the sake for families who watch their children suffer 24/7!

Respectfully,  
Rebecca Stewart

---

**From:** Scott Toner <scottsclubshop@yahoo.com>  
**Sent:** Tuesday, June 26, 2012 1:41 PM  
**To:** Lori Rammell  
**Subject:** Eosinophilic disorders

I have eosinophilic disorder and lucky for me I don't need the formula that some people with this disease need to have that formula is essential to people with eosinophilic disorders and should be put into all health insurance policies thank you for your time.

Sent from my iPhone

---

**From:** Jeff Schwartz <jeff.schwartz@alumni.utexas.net>  
**Sent:** Saturday, June 23, 2012 9:10 PM  
**To:** Lori Rammell  
**Subject:** Include Elemental Formula coverage in Utah's Essential Benefits  
**Attachments:** Jacob's story.pdf

I am writing in response to the Salt Lake Tribune article - [What should Utah's 'bare minimum' health plan cover?](#)

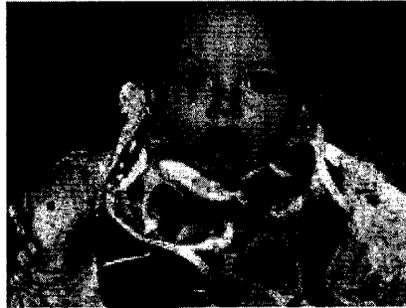
**I urge you to include coverage of elemental formula for those diagnosed with Eosinophilic disorders as an essential benefit.**

Residents within the state of Utah have been working on legislation seeking coverage of elemental formula for multiple years. Elemental formula should be considered an essential benefit for those diagnosed with Eosinophilic disorders.

My family has been personally impacted by the lack of elemental formula coverage in our state - Washington. Jacob my youngest son was diagnosed with Eosinophilic Gastritis at the age of 6 months. He went from a healthy and happy infant at 3 months to a frail and malnourished infant at 6 months.



**3 months  
14lbs 2oz**



**6 months  
13lbs 15oz**

Elecare - an elemental formula - saved his life! Jacob orally took Elecare as his primary source of nutrition for 3 years during which he has grown into a young and thriving young boy. Elemental formula is expensive – like most medicines – and is out of reach for many middle class families.

I urge you to include elemental formula coverage as an essential benefit to help save the lives of children like Jacob.

Please find attached a more complete story of our struggle with Eosinophilic Gastritis. Jacob's elemental formula saved his life. Our doctors were unable to explain why he recovered - to me I believe that the elemental formula allowed Jacob's body to calm down enough and reset allowing him to enter into remission. I can only hope that soon elemental formulas are more widely covered allowing more families to be as blessed as we are.

Thank you for your thoughtful consideration on this matter,

Jeff Schwartz

Jacob Cole Schwartz was born a healthy baby boy in September 2007. The first 3 months of his life were uneventful and very similar to his older brother Samuel (born July 2004). This all changed in December 2007 when Jacob began excessively spitting up after nursing. His pediatrician assured us on multiple occasions that he, like some kids, just spit up a lot and not to worry.

By February 2008, my wife and I became concerned with how much of the day Jacob slept and how he seemed thinner. While dealing with Jacob's daily needs and problems, we failed to see the small changes that occurred every day. At Jacob's 6 month checkup we received the worst possible news – Jacob was failing to thrive and that without immediate medical attention he was in danger of dying.



**3 months  
14lbs 2oz**



**6 months  
13lbs 15oz**

Our lives stood still at that moment – I took leave from work and everything we did evolved around Jacob. Luckily, we were able to see one of the best local Pediatric Gastroenterologists, Dr. Jane Todaro. She was able to get us into Children's Hospital, Seattle for an endoscopy. Watching Jacob's frail body go limp when they put him under still brings tears to my eyes. It was this procedure that officially diagnosed Jacob with an extremely rare disease named Eosinophilic Gastritis.

This diagnosis meant our lives would now be very different. Our number one concern was this confirmed that food and environmental factors were causing Jacob's body to destroy itself. If left untreated, the inner lining in his stomach would be torn apart. Secondly, Jacob would not eat food like normal children. Third, without immediate hospitalization to stabilize his nutrition, he would die. And finally, there was no chance for a cure – research was being done but the disease had only first been diagnosed in 1970 and research had only seriously begun 10 years ago.

That evening we were admitted to Swedish Hospital, Seattle under Dr. Todaro's care. We spent a week in the hospital where Jacob was fed an Amnio Acid based formula through a feeding tube and slowly transitioned to a bottle. With daily oral ingestion of Elecare - the taste of Amnio Acid based formulas are barely tolerable - Jacob began to regain weight and start to recover.

Within four weeks of treatment on Elecare, Jacob was able to remain awake for more than three hour stretches and started to smile again.

With Elecare as his primary source of nutrition, we were able to start food trials with Jacob. The American Academy of Pediatrics recommends new food introduction to last for 2-3 days to watch for

adverse food allergies. Given Jacob’s diagnosis, the only true way to know if he would react to a new food was through endoscopy – as a result our food trial last 3 weeks at a minimum. Jacob had to eat one food – with no contamination – at least 3 times a day for 3 weeks. Only after this period could we consider a food successful. Each food in Jacob’s diet was painstakingly scrutinized and trialed. A successful food trial took 3 weeks, but a negative trial could take 6 weeks or more before another food could be trialed. After a negative food trial Jacob would drink only Elecare for 3+ weeks for his system to recover.

Dr. Todaro was not sure if Jacob’s reactions were due to only food or if there was an environmental trigger. We scrutinized and agonized over every single thing we did never knowing if we were making his condition worse. Our family made drastic changes in our daily lives to make them as predictable as possible. The kitchen was effectively split in half – Jacob’s equipment and the rest of the family’s. Food was prepared separately. Dishes were washed separately. All food was stored separately. Jacob’s ingredients were bought strictly organic – again we never could predict what small difference would cause a reaction. We made all our meals at home – very few restaurants could cater to Jacob’s extreme allergies. As a family we adopted Jacob’s diet and we ate chicken and rice for most meals – including breakfast.

During a food trial, we monitored how he felt, his stool, mood, sleep patterns, temperature; you name it we worried about it. Given that Jacob was only 6 months old, he could not tell us if his stomach hurt. We spent many sleepless nights holding Jacob upright and remained awake with him as we failed another food trial.

After a lot of work, we successfully brought 15 foods into his diet over 2 ½ years. The unsuccessful list of foods was 2-3 times longer than the successful list.

Jacob’s Diet 6 months to 3 years	
6 mo.	
8 mo.	   
1 yr.	    
2 yr.	            
3 yr.	                

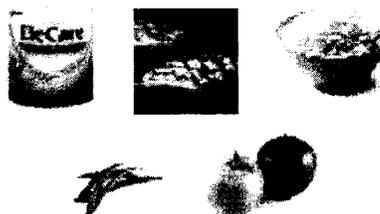
The above chart is a complete accounting of food that Jacob could eat through age 3. Jacob’s primary source of nutrition remained Elecare as eating enough of his “safe foods” to successfully meet his dietary needs was difficult. Our goal was to discover a list of foods which would allow Jacob to have a complete balanced diet and eventually wean him off Elecare. Jacob worked the hardest and continued

to try new foods even though we knew he understood that 3 out of every 4 foods we tried would make him sick for up to 6 weeks.

As a comparison, normally progressing children by the age of 1 are encouraged to try a wide range of foods.



**Normally progressing 1 year olds food selection**



**Jacob's 1 year food selection**

We luckily had a lot of support. I have a stable job with good health benefits, my wife is a stay at home mother, supportive family (though they live out of state), and wonderful friends. Even with all of this support we maintained insane levels of stress. Though we were blessed, many are worse off than we were.

Jacob was growing again and thriving. He was enrolled in a wide range of therapies to help gain skills that he missed from his abnormal infancy. This included: Feeding Therapy to learn how to properly chew and swallow, Speech Therapy to learn how to use his tongue appropriately, Physical therapy to strengthen his core due to inactivity when he was sleeping all the time, and Occupational therapy to adapt him to his sensory world due to the inability to introduce texture through food.

One aspect of being blessed was my strong health insurance. Up through 2009 our health insurance covered the weekly therapies' plus our full supply of Elecare (11-14 cans a month). Jacob consumed \$800 of Elecare a month through a bottle – the taste was so disgusting that his bottle was the only way he would drink this formula.

On November 2<sup>nd</sup>, 2010 we received a letter from our insurance provider informing us that on November 8<sup>th</sup> 2010 our coverage of Elecare would be terminated. We had 6 days to appeal or forfeit our right of appeal.

Our appeal and further rebuttal were rejected for the following reason:

“The reviewer concluded that although this formula may be considered a medical food, it is available to be obtained without a prescription; therefore, this is considered an over-the-counter (OTC) nutritional supplement formula. There is no provision under the Plan to allow coverage for this formula.”

The truly frustrating part about our insurance coverage was if Jacob had an eternal feeding tube his necessary Elecare would be covered with no out of pocket expenses.

I still feel my family is blessed because we had savings that allowed us to purchase Jacob's necessary Elecare without insurance coverage – about \$800 a month. This was not easy – but is not an option for most middle income families.

March 2011 changed our lives forever. January through February 2011 we began to aggressively trial foods. To our surprise, Jacob successfully trialed Eggs, Wheat, and Milk – we were told to never expect to add these foods to his diet. Even our Doctors were overjoyed!

At an appointment in March 2011 we received our miracle – Dr. Muir declared him cured for the present! We clarified with Dr. Muir because we were always told that there was no cure for Eosinophilic Gastritis. She confirmed there is no known cure that this was a miracle. Later that night Jacob at the age of 3 ½ was able to order anything he wanted from the restaurant of his choice. He chose Red Robin, Redmond where he got Strawberry Lemonade, corn dog (dipped in ranch), and French fries with ketchup. We were able to see something that we never thought possible – Jacob eating like a typical child savoring every bite.

It is hard to believe but that was only a little over a year ago. Even with Jacob's miraculous cure, all we can do was take life one day at a time and count our blessings.



**Jacob 4 1/2 years old**

Jacob is now a healthy, growing, engaging boy. We live with a constant uneasiness that this may all change. We were once told Jacob's disease was incurable and any hormonal shift in his body may return us to where we were. We are living with the knowledge that someday we may need amino acid-based formula and have to rebuild his diet from scratch once again.

On that day, 1 year and 3 months ago, my wife and I vowed that we were going to ensure that no family had to make a choice between saving their child's life and financial stability. I believe we are truly blessed in many ways. There are many other families far less fortunate than ours.

Jacob's amino acid-based formula saved his life. Our doctors were unable to explain why he recovered - to me I believe that the amino acid-based formula allowed Jacob's body to calm down enough to heal which allowed him to enter into remission. I can only hope that amino acid-based formulas will be more widely covered and allow more families to be as blessed as we are.

---

**From:** Alan Veteri <al\_veteri@hotmail.com>  
**Sent:** Monday, June 25, 2012 11:32 AM  
**To:** Lori Rammell  
**Subject:** Elemental Formula is an "Essential Benefit"

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

After suffering from an Eosinophilic disorder for more than 40 years, I am acutely aware that elemental nutrition formulas are the safest and most effective treatment option for patients with these conditions.

They also place a heavy financial burden on families when insurance doesn't cover them as medical treatment.

Sufferers of eosinophilic conditions deserve to have their best treatment option covered by health insurance.

Elemental formulas should be considered an essential benefit for those diagnosed with eosinophilic disorders.

Thank you,  
Alan Veteri

---

**From:** Jenny Black <jennyblack\_@hotmail.com>  
**Sent:** Friday, June 22, 2012 12:45 PM  
**To:** Lori Rammell  
**Subject:** essential benefits--elemental formula

I am a mom of two daughters with eosinophilic gastritis and colitis. In this disease white blood cells called eosinophils react against the protein found in food and proliferate causing inflammation and malabsorption and malnutrition. They became very sick from this illness. Their treatment included eliminating most foods from their diet and taking an elemental formula. This has saved their lives. However, in Utah elemental formula is not covered in many insurance plans for this disease. Many states require insurance to cover it and many insurance companies do without being required to because it is more cost effective to do so.

For years we have been working legislatively in Utah to get elemental formula coverage for individuals with eosinophilic diseases. This is a life saving treatment for many individuals with this disease. It makes these individuals healthier and less prone to needing more costly procedures. Please consider making elemental formula coverage for persons with Eosinophilic diseases part of the "essential benefits" for Utah.

Sincerely,

Jennifer Hunt

---

**From:** Amy Anderson <amyand13@yahoo.com>  
**Sent:** Thursday, June 21, 2012 7:48 PM  
**To:** Lori Rammell  
**Subject:** Essential Benefits Healthcare

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

To Whom it may concern,

I am writing to ask that Elemental Formula be listed under the Essential Benefits for insurance companies in Utah. This is a form of treatment for those who suffer from Eosinophilic disease. There are several people in Utah who suffer from this disease who find it difficult to get adequate treatment as many insurance companies do not cover this necessary treatment.

Thank you for your time and consideration.

Amy Anderson



---

**From:** emilie.wilkinson@comcast.net  
**Sent:** Monday, July 02, 2012 11:00 AM  
**To:** Lori Rammell  
**Attachments:** PKU letter.docx

July 2, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included.

I am the aunt of two beautiful boys, ages 2 and 4, who have PKU. PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives.

I love my nephews with all my heart. It is very important to me that they and other children like them have all the opportunities that other children in our communities have. Without proper insurance coverage of medical foods, I worry that as they grow up, they will face difficult decisions, regarding the costs of their medical food. I don't want them to have to choose between their formula and college, or between low-protein foods and starting a family.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

Sincerely,  
Emilie Wilkinson  
2908 Pika Drive  
West Valley City, UT 84128

801-455-5389

[emilie.wilkinson@comcast.net](mailto:emilie.wilkinson@comcast.net)

July 2, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included.

I am the aunt of two beautiful boys, ages 2 and 4, who have PKU. PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives.

I love my nephews with all my heart. It is very important to me that they and other children like them have all the opportunities that other children in our communities have. Without proper insurance coverage of medical foods, I worry that as they grow up, they will face difficult decisions, regarding the costs of their medical food. I don't want them to have to choose between their formula and college, or between low-protein foods and starting a family.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

Sincerely,  
Emilie Wilkinson  
2908 Pika Drive

West Valley City, UT 84128  
801-455-5389  
emilie.wilkinson@comcast.net

---

**From:** DAN L RICHINS <drqw717@msn.com>  
**Sent:** Monday, July 02, 2012 10:30 AM  
**To:** Lori Rammell  
**Subject:** Health Care Benefits

July 2, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am a grandfather of two darling children who are leading perfectly normal lives thanks to insurance coverage. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk. Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Dan Richins  
4806 Marabow Circle  
Holladay, Utah 84117  
[drqw717@msn.com](mailto:drqw717@msn.com)

---

**From:** Denise Richins <ndsr55@msn.com>  
**Sent:** Monday, July 02, 2012 10:20 AM  
**To:** Lori Rammell  
**Subject:** Health benefit bill  
**Attachments:** PKU.wpd

Attached is a letter regarding health benefits. Please read. Thank you

Denise Richins  
4806 Marabow Circle  
Holladay, Utah 84117  
[ndsr55@msn.com](mailto:ndsr55@msn.com)

July 2, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am a grandmother of two darling children who are leading perfectly normal lives thanks to insurance coverage. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk. Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Denise Richins  
4806 Marabow Circle  
Holladay, Utah 84117  
ndsr55@msn.com

June 19, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am an aunt to two beautiful little boys who both have PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,



Allison Trease  
7646 So. 2920 West  
West Jordan, Utah 84084  
atrease1@yahoo.com

July 1, 2012

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder. PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Wendy Turgeon  
9216 Mount Airey Drive  
Eagle Mountain UT, 84005

---

**From:** Wendy Turgeon <wendytrgn@yahoo.com>  
**Sent:** Sunday, July 01, 2012 11:57 PM  
**To:** Lori Rammell  
**Subject:** Essential Health Benefits  
**Attachments:** July 1.docx

July 1, 2012

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder. PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Wendy Turgeon  
9216 Mount Airey Drive  
Eagle Mountain UT, 84005

---

**From:** Marie Richardson <mariebabyj2@gmail.com>  
**Sent:** Sunday, July 01, 2012 4:03 PM  
**To:** Lori Rammell  
**Subject:** PKU medical foods

July 1, 2012

Office of Legislative Research and General Counsel

ATTN: Insurance Market Issues Workgroup

210 House Building

Utah State Capitol Complex

Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am a friend to someone who has two boys with PKU.

We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization.

Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

**Marie Richardson**  
**1062w Jerusalem Dr. Taylorsville, Ut 84123**  
**[mariebabyj2@gmail.com](mailto:mariebabyj2@gmail.com)**

---

**From:** alicia\_rogers@comcast.net  
**Sent:** Sunday, July 01, 2012 1:20 PM  
**To:** Lori Rammell  
**Subject:** ATTN: Insurance Market Issues Workgroup  
**Attachments:** July 1.docx

Read attached letter regarding the selection of a small group health plan for the Essential Health Benefits.

Alicia Rogers

July 1, 2012

Office of Legislative Research and General Counsel

ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives.

**Don't put these lives at risk.**

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,  
**Alicia Rogers**  
247 S. 1100 E. Salt Lake City, UT 84102  
[Alicia\\_rogers@comcast.net](mailto:Alicia_rogers@comcast.net)

---

**From:** Brian Ericson <brian@moosefoo.com>  
**Sent:** Sunday, July 01, 2012 12:59 PM  
**To:** Lori Rammell  
**Subject:** Selection of a small group health plan for the Essential Health Benefits  
**Attachments:** Brian PKU letter.odt

Please read my attached letter before choosing a Essential Health Benefits Plan.

-- Thanks!

Brian Ericson

[www.Moosefoo.com](http://www.Moosefoo.com)

June 19, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am the uncle to Jackson and Sawyer Tye, two cute little boys with PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk. Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely  
Brian Ericson  
4528 Heritage Drive, Eagle Mountain Utah, 84005  
Brian@moosefoo.com

---

**From:** RODNEY G TYE Owner <rod\_tye@q.com>  
**Sent:** Saturday, June 30, 2012 3:07 PM  
**To:** Lori Rammell  
**Subject:** Insurance for people with PKU

June 30,2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building Utah State Capitol Complex  
Salt Lake City UT 84114-5210

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical food is included. I have two grandsons with PKU. They are amazing little boys, so bright and doing so well. We love them so much. Without their medical food my grandson will be mentally handicapped. As a grandparent we will do all that we can to make sure this does not happen but there is only so much we can do. Please ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein food every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical food, children with PKU can lead normal and healthy lives. Please don't put these lives at risk!

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health benefit by selecting one of the three small group plans as the benchmark plan.

Thank you for any help you can give us it means so much to us.  
Sincerely,

Ann Tye  
1279 Marinwood Ave.  
Salt Lake City Ut 84123  
[Rod\\_Tye@q.com](mailto:Rod_Tye@q.com)

---

**From:** Matt Tye <mtyehammer@hotmail.com>  
**Sent:** Saturday, June 30, 2012 2:28 PM  
**To:** Lori Rammell  
**Attachments:** DSC01518.JPG

June 19, 2012

Office of Legislative Research and General Counsel ATTN: Insurance Market Issues Workgroup 210 House Building Utah State Capitol Complex  
Salt Lake City, UT 84114-5210 Re: Selection of a small group health plan for the Essential Health Benefits Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am The uncle of two of the cutest little boys in the world! We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Matt Tye,  
1279 Marinwood Ave.  
Taylorsville Ut. 84123

---

**From:** JoEllen Kunz <rjkunz@greatharvest.com>  
**Sent:** Friday, June 29, 2012 11:02 PM  
**To:** Lori Rammell  
**Subject:** PKU coverage in Essential Health Benefits.

June 29, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included.

I am a friend of two beautiful kids with PKU . We must ensure that everyone with PKU has the access and coverage they need to treat this disorder. PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk. Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

JoEllen Kunz

---

**From:** Kirsten Ericson <kirstiebethtye@yahoo.com>  
**Sent:** Thursday, June 28, 2012 7:39 PM  
**To:** Lori Rammell  
**Subject:** Selection of a small group health plan for the Essential Health Benefits  
**Attachments:** PKU Letter.doc

Please help my nephews by choosing one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included.

We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

I have attached a letter concerning this issue.

Sincerely,  
Kirsten Ericson

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am the aunt of Jackson and Sawyer Tye. They both have PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods.

However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,  
**Kirsten Ericson**  
4528 Heritage Dr. Eagle Mountain, UT 84005  
Kirstiebethtye@yahoo.com

---

**From:** Shelly T <ny3538@yahoo.com>  
**Sent:** Thursday, June 28, 2012 10:52 PM  
**To:** Lori Rammell  
**Subject:** Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am an aunt to two boys that have PKU . We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the bench mark plan.

Sincerely,

Michelle Jackman  
4736 Kootenai Ct.  
Riverton, UT 84096  
[ny3538@yahoo.com](mailto:ny3538@yahoo.com)

---

**From:** Tom Jackman <jackman\_tom@hotmail.com>  
**Sent:** Thursday, June 28, 2012 10:57 PM  
**To:** Lori Rammell  
**Subject:** Selection of small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am an Uncle to two boys that have PKU . We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the bench mark plan.

Sincerely,

Thomas Jackman  
4736 Kootenai Ct.  
Riverton, UT 84096  
[ny3538@yahoo.com](mailto:ny3538@yahoo.com)

---

**From:** Shannan Ellig <sellig@davidlaw.com>  
**Sent:** Monday, June 25, 2012 10:47 AM  
**To:** Lori Rammell  
**Subject:** PKU Essential Health Benefits  
**Attachments:** pku letter\_0001.pdf

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

Thank you for your time and consideration.  
Shannan Ellig

June 25, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am mother with a child with PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder. PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk. Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,



Shannan Ellig  
2880 Majestic Isle Drive  
Clermont, FL 34711  
[Shannanellig2@yahoo.com](mailto:Shannanellig2@yahoo.com)

---

**From:** Sara Tye <family.tye@gmail.com>  
**Sent:** Thursday, June 28, 2012 12:37 PM  
**To:** Lori Rammell  
**Subject:** Essential Health Benefits

Office of Legislative Research and General Counsel

ATTN: Insurance Market Issues Workgroup

210 House Building Utah State Capitol Complex

Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am the mother of 2 wonderful boys with PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk. Please consider viewing "My PKU Life" (11 1/2 minutes) on YouTube for additional information.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Sara Tye

8146 Marcy Brook Place  
Magna, UT 84044

[family.tye@gmail.com](mailto:family.tye@gmail.com)

---

**From:** lucie miller <mach.miller@yahoo.com>  
**Sent:** Saturday, June 23, 2012 1:07 PM  
**To:** Lori Rammell  
**Subject:** ATTN: Insurance Market Issues Workgroup 210 House Building Utah State Capitol Complex

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am a mother of a 2-year-old daughter Zoe who was diagnosed with Classic PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Lucie Miller  
1769 Alpine drive, apt.B  
Vail, CO 81657

email: [mach.miller@yahoo.com](mailto:mach.miller@yahoo.com)

---

**From:** Kate Alford <kda08@yahoo.com>  
**Sent:** Tuesday, June 19, 2012 5:34 PM  
**To:** Lori Rammell

June 19, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup

210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am a friend of someone who's 1 year old daughter has PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Kate Dunstan  
1988 S 600 E  
SLC, UT 84105  
[kda08@yahoo.com](mailto:kda08@yahoo.com)

---

**From:** Oliver, Amy <amy@go-ipad.org>  
**Sent:** Tuesday, June 19, 2012 10:29 PM  
**To:** Lori Rammell  
**Subject:** comments for the Insurance Market Issues Workgroup  
**Attachments:** Insurance Market Issues Workgroup letter 6.19.12.pdf

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

Ms. Rammell,

Attached please find my comments for the Insurance Market Issues Workgroup regarding the selection of the essential health benefits benchmark plan.

Thanks,

Amy Oliver

Amy Oliver, President  
**Intermountain PKU and Allied Disorders Association**  
P.O. Box 9762  
Salt Lake City, UT 84109  
[amy@go-ipad.org](mailto:amy@go-ipad.org)



## Intermountain PKU and Allied Disorders Association

June 19, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

Thank you for the opportunity to testify to the Workgroup today. I appreciate the Workgroup's willingness to include the public in the process of selecting Essential Health Benefits. I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included.

I am the mother of two young children, Claire (5) and Seth (3), who have PKU, and we must ensure they have the access and coverage they need to treat this disorder. I am also the President of the Intermountain PKU and Allied Disorders Association (IPAD), a local non-profit in Salt Lake City that is dedicated to serving people in Utah who suffer from PKU and other metabolic disorders.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods, so my children have been able to obtain treatment for their PKU and they are developing normally like any other child. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

IPAD recently conducted a survey of its members and they were uniform in reporting that it is a financial hardship for their family to pay for medical formula and medical food. Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan so families have access to, and coverage for, this critical treatment.

If I can provide additional information or answer any questions, please feel free to contact me.

Sincerely,

A handwritten signature in black ink, appearing to read "Amy J. Orver", is written over a faint, larger version of the same signature.

Amy J. Orver  
President, Intermountain PKU and Allied Disorders Association  
Salt Lake City, Utah  
801-560-1946  
[amy@go-ipad.org](mailto:amy@go-ipad.org)

---

**From:** Shelly Lund <shellyclund76@yahoo.com>  
**Sent:** Wednesday, June 20, 2012 11:31 AM  
**To:** Lori Rammell  
**Subject:** PKU insurance law changes

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

June 20, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am a close friend of a family with 2 children with PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,  
Jared, Shelly, Austin, Ashley, & Hunter Lund

891 E. 860 S. / P.O. Box 803  
New Harmony, Utah 84757  
shellyclund76@yahoo.com

---

**From:** Heidi Maxfield <heidimaxfield@hotmail.com>  
**Sent:** Tuesday, June 19, 2012 2:21 PM  
**To:** Lori Rammell  
**Subject:** Benchmark Health Plan Feedback  
**Attachments:** Benchmark health plan letter june 2012.docx

To Whom it May Concern,

Please see the attached letter regarding the Benchmark Health Plan.

Kind regards,  
Heidi Maxfield

June 19, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am a mother to a darling five-year old boy with pheynylketonuria (PKU). We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage. Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk. Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,  
Heidi Maxfield  
7757 S. Plum Creek Lane  
Sandy, UT 84093  
heidiannmaxfield@yahoo.com

---

**From:** jreeder5@comcast.net  
**Sent:** Tuesday, June 19, 2012 7:53 AM  
**To:** Lori Rammell  
**Subject:** Essential Health Benefits  
**Attachments:** June 19 PKU.doc

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

June 19, 2012

Office of Legislative Research and General Counsel

ATTN: Insurance Market Issues Workgroup

210 House Building

Utah State Capitol Complex

Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am the father to two children with PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical

formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Joel Reeder

151 East 500 South

Farmington, UT 84025

[jreeder5@comcast.net](mailto:jreeder5@comcast.net)

---

**From:** Brian Jensen <summit90@earthlink.net>  
**Sent:** Tuesday, June 19, 2012 8:31 AM  
**To:** Lori Rammell  
**Subject:** PKU - Insurance

June 19, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am [connection to PKU]. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization.

Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Char Jensen  
89 E 100 N  
Springville, UT 84663

June 19, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am the loving father of a beautiful daughter who has the genetic disorder PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Kyle Post  
1876 North 2145 West  
Lehi, UT 84043  
kyleairpost@yahoo.com

---

**From:** Kourtney Post <kourtneypost@gmail.com>  
**Sent:** Tuesday, June 19, 2012 9:15 AM  
**To:** Lori Rammell  
**Subject:** Selection of a small group health plan for the Essential Health Benefits

June 19, 2012

Office of Legislative Research and General Counsel

ATTN: Insurance Market Issues Workgroup

210 House Building

Utah State Capitol Complex

Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am the mother of an 11 month old baby girl with PKU. Without coverage for her medical formula, we would not be able to afford the cost of caring for her. Please, we must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods.

However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization.

Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Kourtney Post

1876 N 2145 W

Lehi, UT 84043

[kourtneypost@gmail.com](mailto:kourtneypost@gmail.com)

June 19, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am the parent of a child with PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Julianne Christensen  
183 S. 950 W.  
Layton, Ut. 84041  
jhchristensen@wsd.net

---

**From:** Wade Post <wadepost@hotmail.com>  
**Sent:** Tuesday, June 19, 2012 10:50 AM  
**To:** Lori Rammell  
**Subject:** Selection of a small group health plan for the Essential Health Benefits

June 19,

2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am the uncle of a little PKU baby, Avery Post. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Wade M. Post  
1913 Lexis Lane #104

Nampa, ID 83686  
(208) 724-2696  
wadepost@hotmail.com

---

**From:** Krista Viau <Krista.Viau@hsc.utah.edu>  
**Sent:** Tuesday, June 19, 2012 11:31 AM  
**To:** Lori Rammell  
**Subject:** Select a small group health plan  
**Attachments:** Coverage of Medical Formula.pdf

Dear Insurance Market Issues Workgroup,

I am writing to request the State of Utah choose a small group health care plan to select as its benchmark plan for Essential Health Benefits. Please see the attached letter. Thank you for your consideration.

**Krista Viau, MS, RD, CSP**  
Metabolic Dietitian  
Division of Medical Genetics  
University of Utah

Clinic: (801) 585-2457  
Office: (801) 587-9590  
Fax: (801) 587-7690  
[krista.viau@hsc.utah.edu](mailto:krista.viau@hsc.utah.edu)

June 19, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am a metabolic dietitian working with patients diagnosed with PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,



Krista Viau, MS, RD, CSP  
50 North Medical Drive  
School of Medicine, Room 2C412  
Salt Lake City, UT 84132  
[Krista.viau@hsc.utah.edu](mailto:Krista.viau@hsc.utah.edu)

---

**From:** Brian Jensen <summit90@earthlink.net>  
**Sent:** Tuesday, June 19, 2012 12:11 PM  
**To:** Lori Rammell  
**Subject:** Fwd: PKU - Insurance

June 19, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am an aunt to two beautiful nieces living with PKU. We must ensure that everyone with PKU has the access and coverage they need to treat this disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life a mental retardation and costly institutionalization.

Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,

Char Jensen  
89 E 100 N  
Springville, UT 84663

July 2, 2012

Office of Legislative Research and General Counsel  
ATTN: Insurance Market Issues Workgroup  
210 House Building  
Utah State Capitol Complex  
Salt Lake City, UT 84114-5210

Re: Selection of a small group health plan for the Essential Health Benefits

Dear Insurance Market Issues Workgroup:

I am writing to ask you to select one of the three small group health plans as Utah's benchmark plan for the Essential Health Benefits so that the state mandated coverage for medical foods is included. I am a metabolic dietitian caring for individuals with inborn errors of metabolism. We must ensure that everyone with PKU and other amino acid and urea cycle disorders has the access and coverage they need to treat their disorder.

PKU is a rare genetic disorder that is detected at birth through the State's newborn screening program. In order to remain healthy, children and adults with PKU must drink a medical formula and eat special low-protein foods every day for the rest of their lives. Utah has a state law that requires insurance coverage for these very expensive formulas and low-protein foods. However, unless medical foods are included as an essential health benefit, we risk losing that coverage.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with medical foods, children with PKU can lead normal and healthy lives. Don't put these lives at risk.

Please ensure that medical foods for the treatment of PKU and other inborn errors of metabolism are included as an Essential Health Benefit by selecting one of the three small group plans as the benchmark plan.

Sincerely,



Sharon L. Ernst, MPH, RD, CSP, CD  
1701 Northshore Court  
Park City, UT 84098  
nutrislep@comcast.net

---

**From:** mandykix@aol.com  
**Sent:** Saturday, June 23, 2012 8:02 PM  
**To:** Lori Rammell  
**Subject:** health care

June 23, 2012

To Whom It May Concern:

I read the story on KSL.com stating that the State is taking public comments on health care. I have not had health insurance in two years and neither has my husband, our 3 children are on SSI Disability, but the state kicks them off Medicaid more often than they are on, for the past 8 months they have been completely uninsured (although we get SSI still). The problem in Utah is the cuts to government departments have left confusion among workers and departments that aren't sure if they are responsible for what. A personal example of this is my children. They all have classic autism, severe asthma, ADHD, and more—the rules say if you are on SSI Disability you are on Disability Medicaid, but that isn't the case. I have talked with countless workers at Work Force Services and they tell me there is NO difference in Utah, but if you appeal, suddenly there is a difference in income requirements and the kids qualify for Disability Medicaid and so the kids are back on. When the kids were kicked off in November and December (each kid came off at a different time), we received no explanation and no one at Work Force services seemed to know why either. Now honestly I would love to be off all programs, but with autism not covered in Utah SSI is my only option and this has been repeatedly stated from both insurance vendors and the state. I would love to find affordable health care for my family. I don't mind paying copays and deductibles, but insurance companies need to quit denying coverage for illnesses. For example, my daughter Bella fell and broke her leg we had insurance at this time with a major insurance company in Utah, they denied all medical bills for her broken leg stating if she didn't have autism she MIGHT not have fallen and broken her leg. I spent months on the phone to the insurance companies, the call center knew me by voice, the doctors didn't believe her autism had anything to do with the broken leg, and yet I still couldn't get her leg covered.

If I had to make a list of MUST COVERS it would include:

1. Well check/Yearly Physical appointments for both children and adults as recommended
2. Basic Prescription medicine (tier the copays on Meds)
3. Vaccinations for children and for adult boosters
4. Emergency or Instant Care appointments for emergencies (like broken legs, kidney stones)
5. DENTAL
  - a. Yearly screenings
  - b. Tiered system for dental work (cavities, caps, bridges)
6. Vision Screening for children yearly or every other year

Thanks for your time,  
Mandy Bogart

1286 N 1725 W  
Layton, UT 84041  
801-499-3696



---

**From:** Michelle McOmber <michelle@utahmed.org>  
**Sent:** Friday, June 29, 2012 1:05 PM  
**To:** Jim Dunnigan; Wayne Niederhauser; Lori Rammell  
**Cc:** Casey Hill  
**Subject:** UMA Essential Benefits Package Comments Attached  
**Attachments:** Final Board Approved - June 28 2012 Statement on Essential Benefits Plan.docx

Thanks for giving us the opportunity to comment. Our comments are attached.

Michelle S. McOmber, MBA, CAE  
CEO



### Utah Medical Association

310 E 4500 S, Suite 500  
Salt Lake City, UT 84107  
(801) 747-3500 work  
(801) 403-6390 cell  
(801) 747-3501 fax  
email: [michelle@utahmed.org](mailto:michelle@utahmed.org)

This is a private and confidential email message for the sole use of the intended recipient. It may contain legally protected and privileged information. Any unauthorized review, use, disclosure or distribution is prohibited. If you have received this communication in error, do not use, disclose or copy any of the contents. Please immediately notify the sender by reply email or calling 801-747-3500, so that our address record can be corrected, and delete all copies from your system. Thank you.



## **The Utah Medical Association - Policy Statement on Essential Benefits – JUNE 2012**

### **Basis**

The Utah Medical Association (UMA) Interpretation of “Essential” aims to maximize patient choice of health plans and their respective benefits packages. This includes support of the role of health savings accounts (HSAs).

### **Defining essential**

We believe that “essential” in the context of an essential benefit package should align with existing federal guidelines regarding types of health insurance coverage (e.g. Title 26 of the U.S. Tax Code and Federal Employees Health Benefits Program (FEHBP) regulations). These existing regulations have reflected the reality that patients define “essential” benefits differently, based on their health care needs and budgetary restrictions. At the same time, they make clear that health insurance should provide coverage for hospital care, surgical and medical care, and catastrophic coverage of medical expenses, as defined by Title 26, Section 9832 of the U.S. Code. Section 9832 incorporates by reference Section 213 of Title 26 (Medical, dental, etc., expenses), under which “medical care” means amounts paid for the “diagnosis, cure, mitigation, treatment, or prevention of disease, or for the purpose of affecting any structure or function of the body,” and for transportation primarily for and essential to medical care.

The UMA would like to suggest that the State use the existing FEHBP as a reference when considering if a given plan would provide meaningful (“essential”) coverage. All FEHBP plans cover basic hospital, physician, surgical and emergency care, even though the Program does not require a standard benefit package. FEHBP follows existing evidence-based guidelines for preventive care for children and adults. FEHBP plans are also required to cover additional benefits including child immunizations, prescription drugs, mental health services (with parity of coverage with medical care coverage), and a catastrophic limit for out-of-pocket costs. It is important to note that even with these requirements; FEHBP is able to offer high-deductible health plans coupled with HSAs, as well as consumer-driven health plans, to its enrollees.

### **Importance of patient choice and flexibility**

It is imperative that the definition of “essential” in the context of an essential benefit package, which will include the general categories of services outlined in the ACA, does not preclude patients from being offered a range of health plan options from which to choose, or further impede private market innovation in product development, benefit packages, and purchasing arrangements.

### **The prudent physician standard**

The UMA wants to strongly emphasize that when looking at medical necessity, health insurers in coverage determinations should look at covering health care services or products that a prudent physician would provide to a patient for the purpose of preventing, diagnosing or treating an illness, injury, disease or its symptoms in a manner that is (a) clinically appropriate in terms of type, frequency, extent, site, and duration; and (b) not primarily for the economic benefit of the

health plans and purchasers or for the convenience of the patient, treating physician, or other health care provider.”

The “prudent physician” standard of medical necessity ensures that physicians are able to use their expertise and exercise discretion, consistent with good medical care, in determining the medical necessity for care to be provided each individual patient.

### **Decisions should be driven by quality and effectiveness**

In advising physicians and in its efforts with health plans, the UMA has historically opposed definitions of medical necessity that emphasize cost and resource utilization above quality and clinical effectiveness. Such definitions of medical necessity interfere with the patient-physician relationship and prevent patients from getting the medical care they need. Health plans should develop formal protocols as to their methodology for determining "medical necessity," including distinctions between those instances where in house medical expertise is considered sufficient and those where outside consultation is considered necessary.

UMA believes that rather than striving for a “balance” among the 10 essential care categories, there should be efforts to ensure parity and choice in terms of access and coverage among the ten categories listed.

In ensuring parity among these categories, such factors as out-of-pocket costs and benefit limits must be considered. A “prudent physician” standard could even be applied in this arena, as physicians, with their training and expertise, have the unique ability to help ensure that patients get the right care at the right time, and in the right place.

The “prudent physician” standard could only be strengthened by results of comparative effectiveness research (CER), which has the potential to have a profoundly positive impact on the quality of the information available to physicians and patients. CER can help foster the delivery of patient-centered care, by enhancing—not dictating—physician clinical decision-making.

### **Non-Discrimination, patient responsibility and other critical factors**

It is critical for patients to become active partners in their health care, and through a strong physician-patient relationship, physicians and patients should jointly participate in making value-based health care decisions. The coverage of essential benefits should be consistent with the goals of patient-centered care, which is ultimately based on evidence and factors relevant to each individual patient. Physicians should have easy access to and consider the best available evidence at the point of decision-making, to ensure that the chosen intervention is maximally effective in reducing morbidity and mortality. Clinical information about health conditions, treatment options, and potential outcomes could then be discussed with the patient. Age and disability have to be taken into consideration by the "prudent physician" in deciding what is medically necessary.

### **Age appropriate care**

Essential benefits, like any other health insurance benefit, need to be age-appropriate. Individuals within each age group should have a wide variety of coverage options from which to choose, which could include coverage options more comprehensive than the essential benefits package.

### **Disabilities and high risk pools**

Individuals with congenital or acquired disabilities should have access to appropriate and affordable medical care throughout their lives, and benefits deemed to be essential for them may go beyond those of patients without disabilities. To address those with additional health care needs, there may be a role for high-risk pools. The UMA is also cognizant that individuals with disabilities have unique health needs and supports their access to adequate and affordable medical care.

### **Unique care for women**

The UMA supports the coverage by health plans of care, services, treatments, and interventions uniquely for women

### **The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program and appeals process**

The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program can be used as a model for moving forward in taking into account the health care needs of diverse segments of the population. Under EPSDT, if a medical treatment or service will help the child even when the state Medicaid program doesn't specifically cover the treatment, it can be authorized (by the Medicaid medical director) on an individual basis.

The UMA believes that it is absolutely vital for an appeals process to be established through the state department of insurance or another state agency regarding the coverage of essential benefits to ensure fair and non-discriminatory practices in a timely fashion.

### **Updating the essential benefit package**

In order to assess whether and how enrollees are facing difficulty in accessing needed services for reasons of cost or coverage, the state should establish a process such as a hotline or a website to collect data on problems from patients, physicians, hospitals, and other stakeholders. Also, especially early on in the implementation, the state should conduct surveys of patients, physicians, hospitals and other stakeholders as a useful review and improvement tool. It will also be important for the state to enlist the assistance of patient groups such as AARP and Voices for Utah's Children, as well as the UMA and physician specialty societies that provide services covered as essential benefits to patients, to assess the experiences of enrollees regarding the essential benefits package. With the end goal of analyzing and updating the essential benefits package on an ongoing basis.

### **Establishment of an advisory committee**

The UMA strongly recommends that the state should consider convening an essential benefits advisory committee to be comprised of physicians, patients, and other stakeholders. Physician (especially those in clinical practice) and patient representation on this committee should be central and significant.

## **Conclusions**

The UMA appreciates this opportunity to provide input to the Task Force Committee and we offer our assistance to the Committee as it develops its recommendations to the legislature.

1. The best definition of "essential" is found in the Federal Employees Health Benefits Program.
2. Patients should have a range of benefit levels to choose from. The patient has a good idea about what is "essential" to them.
3. Health Savings Accounts (HSA's) should be an option for any essential benefit plan offered.
4. The "Prudent Physician Standard" coupled with comparative effectiveness research (CER) is the best standard to use in determining appropriate coverage and care.
5. Certain populations (Women, those with disabilities, aged) have unique essential needs that should be addressed through unique plans and in some cases through high risk pools.
6. The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program can be used as a model for moving forward in taking into account the health care needs of diverse segments of the population.
7. There must be an established process for reviewing and updating the list of essential benefits on an ongoing basis.

Footnote: The UMA testimony on essential benefits closely aligns with AMA comments to the IOM on essential benefits and the adoption of resolutions proposed by delegates, including Utah delegates to the AMA House of Delegates.

---

**From:** Janida Emerson <Janida@auch.org>  
**Sent:** Monday, July 02, 2012 3:00 PM  
**To:** Lori Rammell  
**Subject:** Insurance Market Issues Workgroup: AUCH Comments on EHB Benchmark Selection  
**Attachments:** AUCH EHB Benchmark Selection Comments.pdf

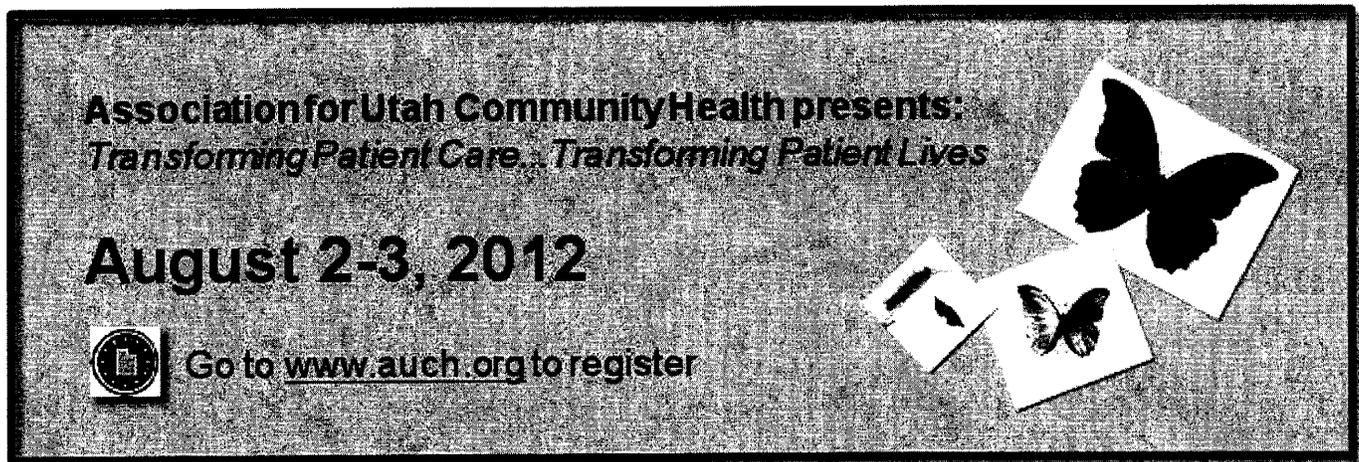
Ms. Rammell,

Thank you for the opportunity to comment on the State's selection of an essential health benefits benchmark. Attached you will find our comments.

Hope you have a nice holiday! Thank you for your time.

Janida

Janida Emerson  
Policy and Public Affairs Coordinator  
Association for Utah Community Health  
860 East 4500 South, Suite 206  
Salt Lake city, Utah 84107  
801-716-4611 Direct  
801-974-5563 Fax  
[janida@auch.org](mailto:janida@auch.org)



**Association for Utah Community Health presents:**  
*Transforming Patient Care... Transforming Patient Lives*

**August 2-3, 2012**

 Go to [www.auch.org](http://www.auch.org) to register

The advertisement features a dark, textured background. On the right side, there are three white squares, each containing a black silhouette of a butterfly in various poses. The text is in a mix of bold, sans-serif and italicized serif fonts.

This email and any attachments to it may be confidential and are intended solely for the use of the individual to whom it is addressed. If you have received this message by mistake, you may not copy it or disclose its contents to anyone; please let us know by email reply and delete it from your system. AUCH cannot guarantee that this message is free from viruses or other defects.



**Association for  
Utah Community Health**  
Supporting Health Care for the Underserved

**Bear Lake Community  
Health Center, Inc.**

July 2, 2012

**Carbon Medical Services  
Association, Inc.**

Thank you for the opportunity to comment on the State of Utah's selection of an Essential Health Benefits (EHB) benchmark. The Association for Utah Community Health and its member organizations would like to take this opportunity to comment on what we believe to be the best EHB benchmark for our patients.

**Community Health  
Centers, Inc.**

**Enterprise Valley Medical  
Clinic**

**Background**

AUCH has been the Federally-recognized State Primary Care Association in Utah since 1985. As a private, not-for-profit 501(c)(3) corporation, AUCH has sixteen organizational members, including the eleven Health Resources and Services Administration's Bureau of Primary Health Care (BPHC)-funded grantees (FQHCs) in Utah, and the three Health Clinics of Utah. Together these organizations provide a medical home to more than 150,000 patients, many of whom are uninsured and will qualify for expansions in coverage under the Affordable Care Act (ACA).

**Family Healthcare**

**Green River Medical  
Center**

**Health Clinics of Utah**

**Utah should select either the Federal Employee Health Plan (FEHBP) Blue Cross Blue Shield (BCBS) Basic or Standard options for its EHB benchmark plan**

**Health Choice  
Network of Utah**

**Midtown Community  
Health Center**

We believe that the best balance of consumers' needs for comprehensive coverage and affordability is best demonstrated in the FEHBP BCBS Basic and Standard options. The FEHBP BCBS Basic and Standard options come the closest to ensuring coverage for all ten categories of services set forth in the ACA. Furthermore, we believe that the FEHBP BCBS Basic and Standard options provide coverage consistent with the Mental Health Parity and Addiction Equity Act (MHPAEA).

**Mountainlands Family  
Health Center**

**Odyssey House**

**Planned Parenthood  
Association of Utah**

Guidance from the Department of Health and Human Services (HHS) indicates that if states select a benchmark plan missing one or more of the 10 mandated benefit categories, the State must supplement the missing categories using benefits from any of the other benchmark options. Both the FEHBP BCBS Basic and Standard options include coverage for benefit categories that many of the other benchmark plans do not include, such as pediatric oral services and pediatric vision care. By selecting the FEHBP BCBS Basic or Standard options as the EHB benchmark, Utah will ensure that its benchmark requires a minimal amount of adjustment to comply with the ACA and this will facilitate the State's ability to quickly implement health reform measures.

**Urban Indian Center of  
Salt Lake**

**Utah Navajo Health  
System, Inc.**

**Wasatch Homeless  
Health Care, Inc.**

HHS guidance also indicates that any benchmark selected will have to be consistent with the MHPAEA, and that coverage for mental health and substance abuse disorders is often limited in the small group markets. After analyzing the benchmark options before the State, we believe that the FEHBP BCBS Basic and Standard options provide mental health and substance abuse benefits more consistent with the MHPAEA than the other benchmark options.

Finally, in choosing an EHB benchmark, we ask the State to take special consideration of those individuals who will likely “churn” between Medicaid and the individual market. The State’s selection of an EHB benchmark should ensure that individuals exiting Medicaid and entering the individual market do not face a “benefit cliff”, which could have the unintended consequence of creating an incentive to stay on Medicaid. We believe that the FEHBP BCBS Basic or Standard options will smooth the transition from the Medicaid market to the individual market—and offer the best opportunity to ensure continuity of care for affected individuals.

Thank you for this opportunity to comment on the State’s selection of an EHB benchmark plan. We look forward to continuing our partnership with the community on the implementation of health reform in Utah.

Sincerely,

A handwritten signature in black ink, appearing to read 'APR', is centered on the page.

Alan Pruhs, Executive Director  
Association for Utah Community Health

---

**From:** Lisa Dahlstrom <lisa.dahlstrom@hsc.utah.edu>  
**Sent:** Saturday, June 30, 2012 9:04 PM  
**To:** Lori Rammell  
**Subject:** Utah's "essential benefits package"

Although I was unable to attend the recent hearing regarding Utah's State Insurance Exchange and the "essential benefits" package, I would like you to consider my written comments regarding this package.

I am an audiologist at the University of Utah Hospital. In my position I provide services for diagnosis, treatment and rehabilitation for individuals with hearing problems, vestibular problems and many other medical conditions which are inter-related with hearing problems. At the present time, many of the tests that are performed are considered non-covered services by insurance companies. I feel that this is preventing us from providing comprehensive medical care for many individuals.

Some examples of medical conditions and treatments that can directly be affected by audiometric testing results includes: acoustic neuromas, otitis media, Meniere's disease, otosclerosis, cholesteotoma, chemotherapy for cancer treatment, cochlear implants, Bell's palsy.

Many of these conditions have the potential to be life-threatening. Insurance plans that do not cover audiometric testing can make undue hardship for people with financial difficulties to obtain the medical care they need.

Please consider including audiometric testing and hearing services as an essential insurance benefit.

Sincerely,

Lisa Dahlstrom  
Audiologist  
University of Utah ENT  
50 N Medical Dr. 3C120  
Salt Lake City, UT 84132  
(801)581-8743

---

**From:** Tina Hose <tkhose@msn.com>  
**Sent:** Tuesday, June 19, 2012 11:47 AM  
**To:** Lori Rammell  
**Subject:** Utah Health Insurance Exchange Comment

Thank you for the opportunity to briefly comment on what I would like to see available for others with a chronic illness, specifically diabetes.

I am on an insulin pump (diabetic for 44 years, on the pump for six years) and since being on the pump, my A1C has been at target or better. I see my diabetes physician assistant/diabetes educator (whose agency is not covered by my insurance plan, hence I self pay) four times a year to check in on my record of daily blood sugar readings (8-10 finger sticks/per day), adjust the pump's insulin delivery and answer any other questions I have about the maintenance of my health. That individual is caring, encouraging, and well educated on the the current treatments, complications, etc. of diabetes.

For diabetics: ensure that they have affordable quarterly access to endocrinologists who specialize in diabetes care and affordable, regular access to Diabetes Educators; that where patients are able to understand and have support for an insulin pump they can receive one; that the cost of insulin is affordable and that blood glucose testing strips that feed the pump the patients' glucose readings, are covered and affordable as well.

I have been very fortunate to be able to afford my care and medication costs so far, even with the annual premium increases since my retirement.

Please ensure affordable access to the medications, technology and health care teams, so critical to well managed diabetes.

Thank you.  
Tina Hose  
1864 Berkeley Street  
Salt Lake City, Utah 84108  
801-582-0467

---

**From:** Kris Baker <kristy.baker@comcast.net>  
**Sent:** Monday, June 18, 2012 1:11 PM  
**To:** Lori Rammell  
**Subject:** Suggestions for "bare minimum" healthcare package

Regular doctor's visits, preventive care (including complete blood panels), as well as emergency care.

Why?

Our daughter, uninsured at age 22 after she aged off our FEHBP plan, got sick.

Because she was uninsured, she got only minimal care from doctors at IHC "instacare" who kept treating her for pneumonia.

It wasn't until I went in and signed that I would cover the expenses, that she was referred to another doctor who took one look at her, and could see she was in distress.

By the next afternoon, she had been diagnosed with end-stage renal failure -- and so near-death, that she spent several days in ICU at high expense..

Medicare and Medicaid (thank God for them!) stepped in and took care of her dialysis and our transplant surgeries.

We'll never know what caused it, only that due to no insurance, it progressed to a point where she was near death at diagnosis.

If the wonderful Affordable Care Act had been in place when our daughter got sick, she'd have had coverage.

Don't take that away from Utah children.

Kris Baker  
Layton, Utah

---

**From:** Sandy Lee <kneedeep350@gmail.com>  
**Sent:** Monday, June 18, 2012 1:31 PM  
**To:** Lori Rammell  
**Subject:** Health Reform

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

I am taking a moment to share my concerns regarding Utah's Health Reform Initiatives and what should be included in the "essential benefits" package for individuals and small businesses. First, let me begin by sharing my story. After being an employee of the State of Utah and Valley Mental Health for nearly 30 years, I was included in a reduction in force and was forced to retire. As a state employee, I had excellent medical benefits, which I very much appreciated and valued.

Since my retirement, my husband and I applied for individual health insurance with Select Health, of which I had been a member of this insurance group for a number of years. My husband and I are healthy, eat right, exercise and get yearly physicals and follow our doctors orders. When my husband was turning 50 years old, he had a colonoscopy, which was what the doctor ordered. Because he had four benign polyps, he was denied insurance coverage. Because I have a family history of diabetes, my doctor prescribed medication to help manage pre-diabetic and I too was denied. Apparently, if you answer yes to any of the insurance companies questions, you are denied.

Select Health graciously offered us the high cost plan, HIP Utah, also administered by Select Health because we were deemed a "high risk". Neither I or my husband have ever been high utilizers of any medical benefits. I can't afford the high cost of this plan and am upset that we were denied. I am in favor of President Obama's health plan and am looking forward to the day when I can reapply to Select Health and they will have to take me with my existing conditions, which I am not diabetic and my husband does not have cancer. It's about time that the "little person" have rights and not the all powerful insurance industry. I encourage those who are making decisions for the citizens of Utah to make insurance benefits accessible and cost effective. I only wish I could attend your open door hearing on Tuesday, June 19, 2012. Thank you.

Sincerely,  
Sandra Lee  
8525 Daneborg Dr  
SLC, UT 84121  
801-971-4810

---

**From:** Kris Baker <kristy.baker@comcast.net>  
**Sent:** Monday, June 18, 2012 2:21 PM  
**To:** Lori Rammell  
**Subject:** Re: Suggestions for "bare minimum" healthcare package

Thank you, Lori

I guess my bottom line is this: "bare minimum" insurance coverage should include a full blood panel in conjunction with an annual doctor's visit.

It would have caught our daughter's problem much earlier.

----- Original Message -----

**From:** "Lori Rammell" <LRAMMELL@le.utah.gov>  
**To:** "Kris Baker" <kristy.baker@comcast.net>  
**Sent:** Monday, June 18, 2012 1:15 PM  
**Subject:** RE: Suggestions for "bare minimum" healthcare package

Ms. Baker,  
Thank you for your interest in the Insurance Market Issues Workgroup. We received your recommendation and will make sure it is forwarded to the members of the workgroup.

Lori Rammell  
Legislative Secretary  
801-538-1032

-----Original Message-----

**From:** Kris Baker [<mailto:kristy.baker@comcast.net>]  
**Sent:** Monday, June 18, 2012 1:11 PM  
**To:** Lori Rammell  
**Subject:** Suggestions for "bare minimum" healthcare package

Regular doctor's visits, preventive care (including complete blood panels), as well as emergency care.

Why?

Our daughter, uninsured at age 22 after she aged off our FEHBP plan, got sick.

Because she was uninsured, she got only minimal care from doctors at IHC "instacare" who kept treating her for pneumonia.

It wasn't until I went in and signed that I would cover the expenses, that she was referred to another doctor who took one look at her, and could see she was in distress.

By the next afternoon, she had been diagnosed with end-stage renal failure -- and so near-death, that she spent several days in ICU at high expense..

Medicare and Medicaid (thank God for them!) stepped in and took care of her dialysis and our transplant surgeries.

We'll never know what caused it, only that due to no insurance, it progressed to a point where she was near death at diagnosis.

If the wonderful Affordable Care Act had been in place when our daughter got sick, she'd have had coverage.

Don't take that away from Utah children.

Kris Baker  
Layton, Utah

---

**From:** Johnson, Cara D <cara.johnson@optum.com>  
**Sent:** Tuesday, June 19, 2012 9:49 AM  
**To:** Lori Rammell  
**Subject:** Regarding Health Care Reform

I would like to see dental covered as basic care, as folks are not going to the dentist due to the recession. Uncared, dental issues, can lead to heart disease. So it is extremely important to have coverage for dental care. Also I would like to see autism spectrum disease and Alzheimer's , completely covered. As there is an epidemic. With out covered care, it could be catastrophic. Also preventative all the way, free screening for mammograms, pap smears. We must have early detection, or the cost of health care will increase. Please share my comments with the Health Insurance Reform Task Meeting.

Sincerely

**Cara Johnson Account Manager**  
Ingenix OptumInsight \*2525 Lake Park Blvd \* Salt Lake City , UT 84120  
Tel 801 982 3269 Fax 866-333-4170 [cara.johnson@optum.com](mailto:cara.johnson@optum.com) [www.shopingenix.com](http://www.shopingenix.com)

This e-mail, including attachments, may include confidential and/or proprietary information, and may be used only by the person or entity to which it is addressed. If the reader of this e-mail is not the intended recipient or his or her authorized agent, the reader is hereby notified that any dissemination, distribution or copying of this e-mail is prohibited. If you have received this e-mail in error, please notify the sender by replying to this message and delete this e-mail immediately.

---

**From:** Holbrook, Vaughn <Vaughn.Holbrook@regence.com>  
**Sent:** Tuesday, June 19, 2012 10:44 AM  
**To:** Lori Rammell  
**Subject:** Written Comment - Regence BCBS: Determination of an Essential Health Benefits Package

Please accept our written comment for the Public Hearing: Determination of an Essential Health Benefits Package.

Regence BlueCross BlueShield of Utah supports an Essential Health Benefit package that sets a floor for health plans in Utah and keeps health insurance affordable and accessible for all Utahans. It's also important consumers be provided with cost and quality data related to health benefit plans, providers, and hospitals offered in plan networks to help them make informed health care decisions. Regence appreciates the opportunity to comment and looks forward to continued involvement in the process of defining an affordable Essential Health Benefit plan.

Regards,

D. Vaughn Holbrook  
Regence BlueCross BlueShield of Utah  
W: 801.333.5202  
M: 801.400.2362

**\*IMPORTANT NOTICE:** This communication, including any attachment, contains information that may be confidential or privileged, and is intended solely for the entity or individual to whom it is addressed. If you are not the intended recipient, you should delete this message and are hereby notified that any disclosure, copying, or distribution of this message is strictly prohibited. Nothing in this email, including any attachment, is intended to be a legally binding signature.

\*

---

**From:** Kathryn Fitzgerald <klrfitzgerald@gmail.com>  
**Sent:** Tuesday, June 19, 2012 11:36 AM  
**To:** Lori Rammell  
**Subject:** minimum mandatory health benefits

To the Task Force:

I believe the following are among the most basic health care necessities:

Free vaccinations for all diseases as recommended by the American Medical Association

Free cancer screenings as recommended by the American Cancer Society.

Free preventative annual physical examinations for children under 18.

Free birth control including all prescription and mechanical forms.

Free pre-natal and delivery care.

Free emergency treatment for accidents, including dental treatment.

Free sight and hearing examinations for children, free glasses and hearing aids for children.

Coverage of all pre-existing conditions.

Transferability of all coverage from employer to employer; maintenance of insurance when unemployed.

No upper lifetime monetary limits on health care.

All necessary treatment for chronic conditions such as heart disease, diabetes and cancer.

Free physical therapy as recommended by physician.

Kathryn Fitzgerald  
1385 Butler Ave.  
Salt Lake City, UT 84102

---

**From:** Linda Johnson <gostalinda73@gmail.com>  
**Sent:** Tuesday, June 19, 2012 1:56 PM  
**To:** Lori Rammell  
**Subject:** Health Care Requirements Comment

I think it is essential to provide basic care and basic medications for chronic and longterm illness. At the rate health care costs are escalating, these expenses are onerous for poor and moderate income families.

It has become clear in the medical literature that exposure to the kind of air pollution in the Wasatch Valley is implicated in diseases such as asthma and other respiratory problems, heart disease and circulatory problems, and developmental disease such as autism. In Utah the rate of autism is 1 child in 47, whereas in the United States the average rate is 1 in 115. [Autism is one example out of many available. I believe I don't need to send you 1000 words, let alone 1000 pages to prove my point, but if desired I can provide same; please let me know if you want detailed testimony.]

As the State allows and even encourages polluting industries to locate here, the side effects should be covered by the State's insurance planning.

Thank you for considering covering autism and other chronic disease in the State's insurance plan. It will set a good example for other states' decisions and serve our people well.

Linda Johnson  
1356 E 4500 S, SLC 84117  
801-277-4499

---

**From:** Gene Fitzgerald <gfitzger@sisna.com>  
**Sent:** Tuesday, June 19, 2012 1:56 PM  
**To:** Lori Rammell  
**Subject:** health care

First, I would like to say that it would be good to have 1) a dental plan coverage(not in the affordable health care act) 2) continue children staying on parents' plan until 26 (the University plan allows this already), 3) get rid of the existing conditions clauses that health insurance companies use to the detriment of the public all the time 4) find a way to fund those who are not insured at all-- you could consider following the Massachusetts plan and require that everyone buy health insurance coverage, it was, after all, Mitt Romney's plan for the state which he still supports 5) find coverage for part time workers--another dodge by companies who hire part time workers for whom they do not need to offer or provide coverage.

Just a few of my thoughts-- it will be interesting to see if any of these even get discussed to say nothing of being implemented.

Gene Fitzgerald

[gfitzger@sisna.com](mailto:gfitzger@sisna.com)  
[gfitzgerald@mail.hum.utah.edu](mailto:gfitzgerald@mail.hum.utah.edu)  
Professor Emeritus of Russian  
(University of Utah)  
1385 Butler Ave  
Salt Lake City, UT 84102-1803

---

**From:** Lincoln Nehring <lincoln@utahchildren.org>  
**Sent:** Tuesday, June 19, 2012 1:34 PM  
**To:** Lori Rammell  
**Subject:** Essential Health Benefit Comments

Thank you for giving me a few moments to talk speak about EHBs and what Voice's for Utah Children believes is the right course for Utah's kids.

### **A Plan that Covers the Most Categories Will Make the Best Benchmark Plan**

Most of the media coverage has described today's hearing as an effort to define what benefits will be covered by health plans beginning in 2014. That is a bit of misnomer. What we really are talking about today is what the actuarial baseline will be for health plans in our state.

The guidance provided by the United States Department of Health and Human Services requires that plans cover 10 broad categories of services. However, HHS gives plans flexibility in determining exactly what benefits are offered in each category. HHS simply insists that the benefit package offered in each category is actuarial equivalent to what the benchmark plan offers in a respective category. Given the flexibility plans have in designing what benefits they will offer in each category, there is no need to discuss what specific services should be included at this meeting. Rather, today should be a discussion about what the actuarial bar plans must meet should be.

The sooner the state defines what that actuarial bar is; the sooner plans can begin to design their benefit packages to meet that bar.

Unfortunately, of the benchmark plans we are considering today, most do not offer benefits in each of 10 categories required by the ACA. Utah's largest small group plans and largest non-Medicaid HMO plan generally do not offer mental health, substance abuse, or pediatric dental services, for example. If the state chooses one of these plans as our benchmark, there is great uncertainty what the actuarial bar health plans must meet will be in those categories.

As a result, Voices for Utah Children, encourages the state to choose clarity and select a benchmark plan that currently covers the most required categories. The potential benchmark plans that come closest to this goal are the three largest federal employee health benefit plans, and PEHP's Traditional and Star plans.

These five plans provide the most clarity about what the actuarial bar plans must meet in all 10 categories of benefits. This clarity will allow insurers to quickly get to the hard work of designing plans.

### **Small Group Plan and Pediatric Dental Services**

Because Utah's small group plans or HMO plans do not offer pediatric dental services, if we choose one of these plans as our benchmark, we must choose another plan to benchmark dental service to. The federal government allows the state to choose between: (1) The Federal Employees Dental and Vision Insurance Program dental plan with the largest national enrollment; or, (2) Utah's CHIP program.

In this scenario, we encourage the state to adopt the Federal Employee plan as our benchmark. Over the last 18 months, Utah's CHIP dental benefit has been redesigned and redesigned again. It is unclear whether even its current form it provides the best and most cost-effective care. The Federal Employee pediatric dental benefit has been more stable and predictable over the last few years.

Lincoln Nehring, JD

Senior Health Policy Analyst  
Voice for Utah Children  
747 E. South Temple, Ste. 100  
Salt Lake City, UT 84102  
801-364-1182 (o)  
801-364-1186 (f)



---

**From:** George Stoddard <stoddard.george@gmail.com>  
**Sent:** Tuesday, June 19, 2012 4:54 PM  
**To:** Lori Rammell  
**Subject:** Benchmark comment

How does this impact Medicare coverage?

George Stoddard

Sent from my iPad

---

**From:** PJ <pjluvzu2@gmail.com>  
**Sent:** Tuesday, June 19, 2012 5:50 PM  
**To:** Lori Rammell  
**Subject:** Healthcare Plan Comments

Any basic healthcare plan should include dental care. Poor dental healthcare can cause a myriad of other health problems that can cause an increase to healthcare costs. A basic plan should also cover mental healthcare. We all know that poor mental health can interfere with one's ability to be productive in life which sometimes results in crime, thus incurring increased costs to the state. The state saves money in the long run by enabling those in need of counseling and possibly therapy to receive care.

Sincerely,

PJ Steiner  
Saratoga Springs, UT

---

**From:** Carla G. Hundley <cghundley@orem.org>  
**Sent:** Wednesday, June 20, 2012 9:14 AM  
**To:** Lori Rammell  
**Subject:** Federal Health reform

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

I would like to ask that coverage for Diabetes be included in this reform issue. I've had type 1 Diabetes for 22 years and without insurance coverage, I would not be in as good health as I am, or be able to afford the items I need to control my disease.

People with Diabetes should not be denied insurance just because they require it's use more often than people without the disease. It's a very expensive disease not only for the cost of medicine, but it can cost a person it's value of life with the complications it can cause if not controlled.

Thank you for you attention to this note.

Carla Hundley  
654 West 600 North  
Orem, Utah 84057

---

**From:** CHRISTINA SUMMERS <chrstnsummers@msn.com>  
**Sent:** Tuesday, June 19, 2012 8:43 PM  
**To:** Lori Rammell  
**Subject:** Comment on Minimum Health care guidelines for Utah

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

I am the target consumer for this legislation. I am a 35 year old self-employed single female with no insurance. I am healthy, I don't use the insurance if I had it, except for emergencies (broken arms, whatever). I am waiting for an affordable plan (affordable means under \$75 per month, OK...) that will cover an ER visit, with no monetary limits, I could even accept a nice hefty deductible/ER copay, and one or two specialist visits a year. I have not found any plan that covers any of this for less than \$150 per month. I can self insure for that. Please, listen to my two cents, and thank-you for giving me a voice.

---

**From:** Diane Forster-Burke <dfburke@westminstercollege.edu>  
**Sent:** Wednesday, June 20, 2012 10:00 AM  
**To:** Lori Rammell  
**Subject:** Basic Benefits discussion

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

Hello,  
I was unable to attend the meetings yesterday and wanted to give my input nonetheless. I have read the article in the Salt Lake Tribune and agree with all of the benefits listed in the 2nd to last paragraph. I would hope that under "prevention and wellness" that all screenings appropriate to age, gender and ethnicity would be included. I would also add that family planning should be covered as this saves a lot of money in the long run. I am a registered nurse with a masters in nursing and a nursing professor. Thank you for your time. Diane Forster-Burke

---

**From:** Deborah Turner <deborahturner@utah.gov>  
**Sent:** Tuesday, July 03, 2012 12:00 PM  
**To:** Lori Rammell  
**Cc:** David Patton; Michael Hales; Robert Rolfs  
**Subject:** Utah Department of Health - Testimony to the Insurance Market Issues Workgroup  
**Attachments:** Testimony to the Health Reform Taskforce.docx

Dear Rep. Dunnigan:

The Utah Department of Health would like to submit written testimony regarding the Determination of an Essential Health Benefits Package for Utah. Please find it attached to this e-mail. If you have any questions, please contact Deborah Turner at 801-538-6983.

Deborah Turner  
Utah Department of Health  
288 North 1460 West  
Salt Lake City, Utah 84114  
(801) 538-6983  
(801) 558-6764

Testimony to the Health Reform Task Force  
Insurance Market Issues Workgroup  
Hearing on Essential Health Benefits Package  
by  
The Utah Department of Health

The Insurance Market Issues Workgroup convened a hearing on June 19, 2012 to gather public opinion regarding which of the 10 potential benchmark plans should be selected by Utah as a benchmark or reference plan for the state.

The Utah Department of Health (UDOH) supports the inclusion of “items and services”<sup>1</sup> in Utah’s benchmark Essential Health Benefits package that support the areas of maternal and newborn care, prevention and wellness services, and chronic disease management as outlined in the 10 statutorily defined benefit categories.

Specifically, these items and services should include:

- All immunizations recommended by the Advisory Committee on Immunization Practices<sup>2</sup>
- All clinical preventive services recommended by the U.S. Preventive Services Task Force<sup>3</sup>
- Systems and resources to manage chronic diseases
- Services including guaranteed maternity coverage; eliminating pre-existing coverage exclusions for women who are pregnant, have had a previous cesarean, or are the victims of domestic violence; ensuring direct access to ob-gyns; and providing access to vital preventive screenings including mammography and Pap tests.
- Services outline and endorsed by the American Academy of Pediatrics in its “Bright Futures” materials, including “Bright Futures Guidelines”<sup>4</sup>
- Facilitated coordination of care of individuals and families through a “medical home” concept

UDOH manages a wide variety of maternal and child health, chronic disease management, and prevention programs. These programs interact with local health departments, public and private health care providers in program and service development, implementation and outcomes data collection. The data collected from these programs demonstrates the value of preventive services in improving the health of Utah residents while reducing costs.

These programs provide and support access to:

- Services that promote healthy weight management prevent high blood pressure, high blood cholesterol and diabetes, breast, cervical and colon cancer screening, tobacco cessation programs, and programs to help people with chronic diseases such as arthritis and diabetes manage their conditions and reduce complications due to poor management.
- Maternal and child health programs and services that include promotion of dental health for children and adults, prenatal care, pregnancy planning, injury prevention, breastfeeding, programs to prevent premature births, teen suicide, maternal, infant and child mortality,

smoking among youth and pregnant women, programs to support services for children and youth with special health care needs, newborn screening and many other services.

Many of the costs attributed to the health conditions listed above can be managed through prevention and chronic disease management programs. Utah costs associated with chronic conditions are currently an enormous burden to the health care system:

- Utah's adult obesity rate has more than doubled since 1990, with medical costs associated with obesity estimated at \$393 million for 2008, part of an estimated \$147 billion in the United States.
- Each year more than 1,200 Utah smokers will die from tobacco-related causes. Utah spends \$663 million every year on smoking-related medical expenses and lost productivity.
- In 2009, 2,543 Utah deaths were attributable to cancer. The financial costs of cancer are also substantial, with an overall annual cost estimated at \$228.1 billion in 2009.<sup>5</sup>
- In Utah, nearly 5,000 (4,957) babies were born prematurely in 2010. Medical costs are estimated to average \$51,600 per premature baby, amounting to \$255.8 million for Utah. Of the \$51,600, the breakdown is 65% for medical costs, 7% for delivery, 2% for Early Intervention services, 4% for special education services and 22% for lost household and labor market productivity.<sup>6</sup>

Two additional benefit categories that should be mentioned are mental health and substance abuse disorder services, including behavioral health treatment and prescription drugs. The Department has worked with other state and local agencies to develop programs that help health care providers and patients to recognize the signs of prescription drug misuse and abuse. Attention to this issue by policymakers as the Utah basic plan is developed is critical.

Health data tools developed with the cooperation of the health care community including local and public health, are now available to enable health care providers to better manage the preventive programs described in this testimony. Among these programs are the Utah Statewide Immunization Information System (USIIS) "a statewide information immunization system that contains immunization histories for Utah residents of all ages.. and provides easy access to reliable immunization histories for new and current patients,"<sup>7</sup> and the Utah cHIE which "provides a safe, secure place for patients to share medical information with healthcare professionals. With patient consent, healthcare professionals have access to their patients' health information including medications, allergies, immunizations, lab test results, imaging reports, and other aspects of their medical history .... With access to patients' medical story, healthcare professionals can make the best possible decisions for quality treatment and patients can get the best possible care."<sup>8</sup> These are just two data programs that have been initiated through joint public and private sector efforts to increase access to preventive care and improve patient outcomes.

The mission of the Utah Department of Health is to protect the public's health through preventing avoidable illness, injury, disability, and premature death; assuring access to affordable, quality health

care; and promoting healthy lifestyles. Promoting the inclusion of “items and services” in Utah’s benchmark Essential Health Benefits package supports this mission.

Footnotes:

1. Centers for Medicare and Medicaid, Center for Consumer Information and Insurance Oversight, Essential Benefits Bulletin, December 16, 2011, Page 1. “Section 1302(b)(1) provides that EHB include items and services within the following 10 benefit categories: (1) ambulatory patient services, (2) emergency services (3) hospitalization, (4) maternity and newborn care, (5) mental health and substance use disorder services, including behavioral health treatment, (6) prescription drugs, (7) rehabilitative and habilitative services and devices, (8) laboratory services, (9) preventive and wellness services and chronic disease management, and (10) pediatric services, including oral and vision care.”
2. Advisory Committee on Immunization Practices (ACIP): consists of 15 experts in fields associated with immunization, who have been selected by the Secretary of the U. S. Department of Health and Human Services to provide advice and guidance to the Secretary, the Assistant Secretary for Health, and the Centers for Disease Control and Prevention (CDC) on the control of vaccine-preventable diseases. The Committee develops written recommendations for the routine administration of vaccines to children and adults in the civilian population; recommendations include age for vaccine administration, number of doses and dosing interval, and precautions and contraindications. (CDC Website: <http://www.cdc.gov/vaccines/recs/ACIP/#about>).
3. U.S. Preventive Services Task Force (USPSTF) is an independent panel of non-Federal experts in prevention and evidence-based medicine and is composed of primary care providers (such as internists, pediatricians, family physicians, gynecologists/obstetricians, nurses, and health behavior. The USPSTF conducts scientific evidence reviews of a broad range of clinical preventive health care services (such as screening, counseling, and preventive medications) and develops recommendations for primary care clinicians and health systems. The USPSTF has developed a list of preventive service relevant for implementing the Affordable Care Act. This list can be found at: <http://www.uspreventiveservicestaskforce.org/uspstf/uspsabrecs.htm>
4. American Academy of Pediatrics: “Bright Futures is a national health promotion and disease prevention initiative that addresses children's health needs in the context of family and community. In addition to use in pediatric practice, many states implement Bright Futures principles, guidelines and tools to strengthen the connections between state and local programs, pediatric primary care, families, and local communities. Whether you are a health care or public health professional, a parent, or a child advocate, Bright Futures offers many different resources for your use in improving and maintaining the health of all children and adolescents.” <http://brightfutures.aap.org/>
5. Health Innovations Report: A report from Gov. Gary R. Herbert’s 2011 Health Summit, Wellness, Page 12.
6. March of Dimes Prematurity Campaign: “In 2003, the March of Dimes launched the [Prematurity Campaign](#) to address the crisis and help families have full-term, healthy babies. We’re funding lifesaving [research](#) and speaking out for [legislation](#) that improves care for moms and babies. Worldwide, 13 million babies are born prematurely each year. In 2008, we expanded the campaign” [globally](#). [http://www.marchofdimes.com/prematurity/21198\\_10734.asp](http://www.marchofdimes.com/prematurity/21198_10734.asp)

7. The Utah Department of Health USIIS Website – About US: <http://www.usiis.org/aboutUSIIS.shtml> “The Utah Statewide Immunization Information System (USIIS) is a statewide information immunization system that contains immunization histories for Utah residents of all ages. USIIS is a free, confidential, web-based information system that contains immunization histories for Utah residents of all ages. USIIS is designed to help health care providers track immunization information for patient care. It consolidates immunizations from all providers into one centralized record. Only authorized users, such as health care providers, schools, and public programs have access to USIIS. USIIS complies with HIPAA and state law to protect patient privacy. All providers and users must sign confidentiality agreements before they are given access to USIIS.”
  
8. myCHIE Website: <http://mychie.org/>: “The Utah Health Information Network (UHIN) has initiated the Clinical Health Information Exchange (cHIE) to improve the quality of healthcare in Utah and to give patients more control over their health information. The cHIE provides authorized medical professionals a way to share and view patient information in a secure electronic manner. Since 1993, UHIN members have come together for the common goal of reducing healthcare costs and improving the quality of care through the use of electronic data interchange (EDI). By exchanging information electronically rather than by phone, fax or surface mail, information can get to those who need it quickly, safely, economically and efficiently. Utah Health Information Network (UHIN) is a broad-based coalition of Utah healthcare insurers, providers, and other interested parties, including the Utah State government.

---

**From:** Cathy Allison <redofreedom@hotmail.com>  
**Sent:** Monday, July 02, 2012 11:43 PM  
**To:** Lori Rammell

kids need this . with all they go through and all we as mom s and dads do it is the kides who need to get it .  
if you can not get it the state should help some ways .