

Approved: February 19, 2008

Date

MINUTES OF THE HOUSE INSURANCE AND FINANCIAL INSTITUTIONS COMMITTEE

The meeting was called to order by Chairman Clark Shultz at 3:35 P.M. on February 18, 2008 in Room 527-S of the Capitol.

All members were present except:

Representative Tom Burroughs- excused

Committee staff present:

Melissa Calderwood, Kansas Legislative Research Department

Terri Weber, Kansas Legislative Research Department

Bruce Kinzie, Revisor of Statutes Office

Ken Wilke, Revisor of Statutes Office

Sue Fowler, Committee Secretary

Conferees appearing before the committee:

Representative Lana Gordon, District #52

Linda Kenney, Kansas Department of Health & Environment, Bureau of Family Health

Porscha Waggle, Self

Heidi Dawson, Self

Kim Johnson, Self

Leslie Seidel, Self

Jessica Seidel, Self

Others attending:

See attached list.

Hearing on:

HB 2769 **Insurance coverage for special dietary formulas**

Melissa Calderwood, Legislative Research Department, provided a brief overview on **HB 2769**.

Proponents:

Representative Lana Gordon, District #52, (Attachment #1), presented testimony before the committee in support of **HB 2769**.

Linda Kenney, Kansas Department of Health & Environment, Bureau of Family Health, (Attachment #2), gave testimony before the committee in support of **HB 2769**.

Porscha Waggle, Self, (Attachment #3), appeared before the committee in support of **HB 2769**.

Heidi Dawson, Self, (Attachment #4), presented testimony before the committee in support of **HB 2769**.

Kim Johnson, Self, (Attachment #5), gave testimony before the committee in support of **HB 2769**.

Leslie Seidel, Self, (Attachment #6), appeared before the committee in support of **HB 2769**.

Jessica Seidel, Self, (Attachment #7), presented testimony before the committee in support of **HB 2769**.

Opponents:

William W. Sneed, Americans Health Insurance Plans, (Attachment #8), presented written testimony in opposition to **HB 2769**.

Larrie Ann Lower, Kansas Association of Health Plans, (Attachment #9), presented written testimony in opposition to **HB 2769**.

Hearing closed on **HB 2769**.

CONTINUATION SHEET

MINUTES OF THE House Insurance and Financial Institutions Committee at 3:30 P.M. on February 18, 2008 in Room 527-S of the Capitol.

Discussion and action on:

HB 2688 **Enacting the property and casualty actuarial opinion letter law**

Representative Dillmore moved **HB 2688** favorable for passage and place on Consent Calendar. Seconded by Representative Colyer. Representative Peck raised questions concerning placing **HB 2688** on the Consent Calendar. Representative Anthony Brown made a substitute motion to favorably pass **HB 2688**. Seconded by Representative Coyler. Motion carried.

Representative Grant moved without objection to accept the February 11, 2008, February 12, 2008 and February 13, 2008 minutes.

Next meeting will be Tuesday, February 19, 2008, 3:30 PM, in Room 527-S.

Meeting adjourned at 4:50 PM.

STATE OF KANSAS

LANA GORDON
REPRESENTATIVE, FIFTY-SECOND DISTRICT
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TOPEKA
HOUSE OF
REPRESENTATIVES

COMMITTEE ASSIGNMENTS

CHAIR: ECONOMIC DEVELOPMENT AND TOURISM
MEMBER: COMMERCE AND LABOR
EDUCATION BUDGET
JOINT COMMITTEE ON ECONOMIC DEVELOPMENT
ARTS & CULTURAL RESOURCES

Chairman Shultz and Members of the House Insurance and Financial Institutions:

I am here today to testify in favor of HB2769. My constituent, Porscha Waggle, brought a matter to me concerning her son who has a condition for which he requires a special elemental formula to sustain his life.

Porscha had been trying to work with her health insurance company to have coverage for this formula as prescribed by his doctor. After they refused coverage, we contacted the Insurance Commissioner's office to see if there was any intervention that they could do. Because of what was in her contract, the insurance company said that they were unable to help. Therefore, we decided to introduce the bill that is in front of you today.

It seems it is a sad situation, that the insurance company will cover costs of formula when the child is going through costly treatments while hospitalized; but not when he is being cared for at home. Furthermore, if this formula is doctor prescribed, there should be coverage allowed.

Porscha shared with me that she is trying to do her best to set a good example to her children by staying in the workforce rather than relying on the welfare system with which she would have her son, Christian's formula covered. It is a shame that insurance companies are more willing to cover in hospital care rather than less expensive out-patient care. (Seems this issue is similar to placing persons in nursing homes rather than in their private homes.)

The Legislation in front of you today is patterned after that in several other states that are requiring insurance companies to cover special dietary formulas essential to life. To me, it seems that needing this type of formula prescribed by a physician is no different than someone needing insulin or other prescription drugs which would be covered by insurance.

As much as I dislike mandates, sometimes we do things because they are the right thing to do.

You will hear from my constituent and others regarding their experiences.

I would appreciate your support of HB 2769. Thank you for allowing me to come before you today.

Lana Gordon

House Insurance
Date: 2-18-08
Attachment # 1



February 18, 2008

Committee on Insurance and Financial Institutions
Kansas House of Representatives
Topeka, Kansas 66612

Dear Mr. Chairman and Members of the Committee:

The Children's Milk Allergy and GastroIntestinal Coalition (Children's MAGIC) strongly encourages the Committee on Insurance and Financial Institutions to favorably support House Bill 2769.

Children's MAGIC, a 501(c)(4) non-profit organization is dedicated to promoting healthcare coverage and reimbursement for amino acid-based elemental formulas for children who are unable to consume a natural life-sustaining diet due to various allergies and diseases. We have been involved in dozens of states, assisting parents and educating legislators about the medical importance of amino acid-based elemental formulas for those who use them, as well as the financial and emotional struggle of the families who lack proper coverage.

I am writing to you to express the support of our organization in regards to House Bill 2769 and I strongly hope that you will pass favorable consideration upon this legislation. To that end, I wish to provide you with information and statistics we have calculated regarding prevalence and usage, the importance of amino acid-based elemental formulas and why legislation like House Bill 2769 is vitally needed.

Based on the expert advice of medical professionals as well as verified statistics from a number of state health offices, we have found that the number of those who rely on these formulas is very low, while the medical necessity for such elemental formulas is very high.

According to Dr. Robert Wood, MD, Professor of Pediatrics and International Health and the Director of Pediatric Allergy and Immunology at Johns Hopkins University School of Medicine, 1-2% of the 2.5% of children who have a milk allergy, require an amino acid-based elemental formula. Dr. Wood has stated that the highest estimate would be 10% of the 2.5%. Mathematically, this statistic is equivalent to range of 0.025% to 0.050% (or our midrange estimate of 0.0375%). Dr. Wood's highest estimate would be equivalent to 0.25%.

Another dually verifiable method we have used to calculate an estimate of how many in Kansas could need amino acid-based elemental formulas, is based off actual usage data from state WIC (Special Supplemental Nutrition for Women, Infants and Children) departments, which provides coverage for amino acid-based elemental formulas.

Data from the Kansas Department of Health and Environment, Division of WIC and Nutrition Services showed that on average, twenty six (26) of the 18,673 infants and children on WIC were

issued amino acid-based elemental formulas, equivalent to 0.001366 (0.1366%). This data is quite similar to numbers we have calculated off WIC data from other states like Maryland (0.1086%) and Virginia (0.0649%)

The Maryland Office of WIC Programs showed that ninety two (92) of the 84,716 infants and children on WIC received amino acid-based elemental formulas, or 0.1086%. Data from the Virginia Department of Health's Division of WIC and Community Nutrition Services, sixty eight (68) of the 104,812 infants and children on WIC received amino acid-based elemental formulas, or 0.0649%.

All the computational methods illustrate that the percentage of children and infants using amino acid-based elemental formulas is very small and within tenths and hundredths of a percent. Our intent is to extrapolate these multiple methods to provide prevalence projections for Kansas.

According to the United States Census' 2006 American Community Survey, there are 194,702 children under five years old in Kansas. Based on Dr. Wood's methodology, between 49 and 97 children under five years old in Kansas would require amino acid-based elemental formulas. His maximum prediction (0.1%) would be 195 children under five.

Based on the Kansas-specific WIC data, ninety-one children under five could potentially require amino acid-based elemental formulas. Projections off the Maryland and Virginia WIC statistics show a range of 127 to 211 children under the age of five.

Legislation like House Bill 2769 does not affect the entire population needing formulas. The projected numbers above are estimations of the total prevalence in the state. As mentioned, a certain percentage of the population receives coverage for amino acid-based elemental formulas as a result of WIC and/or Medicaid. In addition, there is sadly but inherently a certain amount of the population who are uninsured.

House Bill 2769 only affects those who have private insurance. According to the Kaiser Foundation, 64% of Kansans are covered by employer or individual-based private insurance plans. Among children 18 and under, 65% of the population is covered by such private plans. 26% have Medicaid, while 7% are uninsured.

Thus, the prevalence statistics calculated remain true, but the actual population affected by HB2769 is much smaller. Adjusted to account for only those with private insurance, the estimates would be as follows: Dr. Wood's range 32-63 (127 highest estimate), Kansas WIC projection 60, Maryland WIC projection 137 and Virginia WIC projection 82. The spread of these projections is relatively small and indicates a strong likelihood of accuracy.

For children suffering from conditions outlined in HB2769, amino acid-based elemental formulas are a dire source of life sustaining nutritional intake. We have heard many heart wrenching tales from families of children who must rely on these formulas as their only source of nutrition. The sadder story though, and the need for legislation like HB2769, stems from the lack of access to coverage and reimbursement, among those who do have private insurance. From what we have encountered time and time again, not just in Kansas, but throughout the nation, is that private insurers generally will not provide coverage and/or reimbursement for amino acid-based

elemental formulas when consumed orally, despite this being the medically preferred and without any doubt simplest and least costly method.

Amino acid-based elemental formulas are extremely costly. We have calculated that on average they cost \$5,075 a year. That is nine percent of a median family income in Kansas! This of course does not take into account any of the costs for frequent and necessary trips to pediatricians, allergists, gastroenterologists and other medical professionals.

Medically, the impact amino acid-based elemental formulas have on children is remarkable. From countless stories we have heard, the child's health drastically improves. The need for trips to the emergency room decreases (which also lessens the strain and cost of healthcare). Healthier infants grow into healthier children and healthier adults. The long term benefits are immeasurable.

The cost of amino acid-based elemental formulas however wrecks financial hardship upon those who need them. Insurers deny claims for a variety of reasons. Many state that only provide coverage for enteral (tube) feeding, while others claim that amino acid-based elemental formulas are "foods" or "not really" prescriptions... even though they are not accessible to the general public and generally require a doctor's supervision.

Parents are forced to wrangle with a terrible decision: submit their children to surgery and enteral (tube feeding) intake and receive coverage by their insurer, or take the formulas orally, like any 'normal' child, but be forced to pay out of pocket. Even worse, when facing the financial crush of the costs, some families consider taking their child off (which results in deteriorating health and then eventually forces the need for enteral feeding). We have heard cases of families nearing bankruptcy and considering 'paper divorces,' so they would be eligible for public health programs like WIC and Medicaid which do provide coverage.

House Bill 2769 creates an equitable, common sense policy for amino acid-based elemental formulas. The current system denies the best method of treatment for those who have insurance, while at the same time public programs do provide coverage. This is a basic contradiction in logic and it hurts average middle class Kansan families the most.

Eight states throughout the nation have adopted legislation similar to HB2769. In addition to Kansas, there are currently seven other state legislatures that are reviewing similar bills.

HB2769 would fix the current problem and improve the lives of the children and families suffering.

I hope that you consider passing favorable judgment on this serious matter and join me in advocating for these children and families whose needless suffering can be curtailed.

Sincerely,



Jason Eberstein
Children's MAGIC



DEPARTMENT OF HEALTH
AND ENVIRONMENT

*Kathleen Sebelius, Governor
Roderick L. Bremby, Secretary*

www.kdheks.gov

**Testimony on HB 2769
Insurance Coverage for Special Dietary Formulas.**

**Presented to
House Insurance and Financial Institutions Committee**

**By
Linda Kenney
Director Bureau of Family Health**

February 18, 2008

Chairman Shultz and members of the committee, my name is Linda Kenney, Director of the Bureau of Family Health at Kansas Department of Health and Environment, and I am here to testify in support of HB 2769 which proposes to mandate insurance coverage of special dietary formulas in Kansas.

Prior to FY 2007, our Children with Special Health Care Needs (CSHCN) program covered the full cost of metabolic formula for Phenylketoneuria (PKU) and Maple Syrup Urine Disease (MSUD) for non-Medicaid eligible individuals and those whose insurance denied coverage of this medically-necessary formula. Due to statutory changes to KSA 65-180, starting in FY 2007, a sliding fee scale was implemented. Currently, when CSHCN makes formula purchases for families, the families may be required to reimburse KDHE for all or part of the formula cost.

The financial impact of purchasing treatment formula on non-covered families is substantial as well as the financial impact even for those families who receive assistance on a sliding fee scale from KDHE. Families who pay full cost for the formula can expect to pay \$8,000 to \$10,000 per year. Yet, families cannot do without the necessary formula as it may cause death or brain damage resulting in mental retardation or other severe neurological complications.

At the present time, CSHCN has approximately 20 out of 60 enrolled clients with no coverage from their insurance companies. We do not know which of these are covered under ERISA plans and therefore not subject to this proposed mandatory law. Although we would expect

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House Insurance
Date: 2-18-08
Attachment # 2

passage of this bill to decrease CSHCN expenditures over time, we cannot predict the extent of the decrease since this is dependent upon client factors such as severity of the condition, compliance with regimen, type of formula prescribed or tolerated. Beginning July 1, 2008, we will begin screening for the 29 conditions recommended for all State programs. The cost of metabolic formula is expected to increase with expanded newborn screening and these cost estimates have been built into the budget request for SFY 09.

Many states do mandate insurance coverage of metabolic formulas, some with age or other restrictions such as California's where insurance is required to cover costs of food and formula to the extent that the expenses exceed the cost of a "normal" diet. The most complete listing we found of state laws can be found at: <http://www.pkunews.org/rights/lobby6.htm>. It appears that about 40 states do mandate some type of coverage although there are generally restrictions. In May of 1994, the American Academy of Pediatrics Committee on Nutrition issued a statement supporting reimbursement by insurance carriers for medical formulas used for treatment of inborn errors of metabolism. The AAP updated and reissued its policy statement in May of 2003, again urging insurance carriers to cover medical foods.

Thank you for the opportunity to appear before the committee today. I will now stand for questions.

Oral Testimony Supporting HB 2769

Porscha Waggle
7410 SW 22nd Ct
Topeka, KS 66614
785-213-9894

Good afternoon ladies and gentlemen. I want to thank you for allowing me the privilege and honor of addressing you today regarding Amino Acid-Based Elemental Formula, an issue that is very near and dear to my heart. My two year old son Christian has a rare disease, the umbrella term is called Eosinophilic Gastrointestinal Disorder, Christians' specific diagnosis is Eosinophilic Gastroenteritis, Eosinophilic Esophagitis. EGID's are characterized by having above normal amounts of eosinophils, a type of white blood cell, in one or more specific places anywhere in the digestive system. EGID is further subdivided into organ-specific diagnosis. For example, Eosinophilic Gastritis means eosinophils infiltrating the stomach. "itis" means inflammation. Christian was born prematurely March 22, 2005 with severe jaundice. As the mother of a newborn I was extremely concerned. If I had only known that jaundice was a picnic compared with what my baby would suffer in the future. Visits to the Doctor, the ER, hospital admissions, and surgeries are Christians' life. It was on one of the hospital admissions that I first heard the words Eosinophilic Gastrointestinal Disorder . I never realized that three words could change mine and my sons life forever. . His little body is in pain on a daily basis.

Symptoms of EGID vary widely, but they include:

- Nausea or Vomiting
- Diarrhea
- Failure to thrive (poor growth or weight loss)
- Abdominal or chest pain
- Reflux that does not respond to usual therapy
- Dysphagia (Difficulty swallowing)
- Food impactions (food gets stuck in the throat)
- Gastroparesis (Delayed emptying of the stomach)
- Anorexia (poor appetite)
- Bloating
- Anemia
- Blood in the stool
- Malnutrition and
- Difficulty sleeping Not the life I am sure that you or anyone wants to live, much less a two year old little boy. There is no "cure" for EGID, but treatment can help alleviate symptoms and prevent further damage to the gastrointestinal (GI) tract. Treatment of eosinophilic disorders will vary based on the location of the eosinophils, severity of

symptoms, and other medical problems the child may have. In most cases, dietary measures can improve problems related to the underlying eosinophilic disease. Dietary measures begin with an "Elimination" diet. An elimination diet means strictly avoiding all foods to which the patient has tested positive on allergy testing. Skin and patch testing are used to guide elimination diets, but it only takes one false negative food for the diet to "fail". To more simply explain this, food introduced into an intestinal tract that has

high eosinophil counts causes an attack reaction. The body literally attacks itself trying to destroy the foreign invader. That foreign invader can be something as simple as a cookie and glass of milk. Sometimes a stricter diet – an elemental diet – Elemental diet means No protein, either in its whole or incomplete (pre-digested or hydrolyzed) form is allowed. Special elemental formulas are made of amino acids (the building blocks of proteins), fats, sugars, vitamins and minerals. Amino acids do not cause allergic reactions but whole or partial proteins can.

Children and adults who rely in part, or completely, on an elemental amino acid based formula may have a difficult time drinking enough of the formula. To maintain proper nutrition, some require tube feedings directly into the stomach (enteral feeds). In the most severe cases, nutrition is administered directly into the blood stream (parenteral feeds). My son is one of the children that are on the elemental diet. Christian also has a feeding tube. The feeding tube administers the elemental diet, otherwise known as Ele Care. This diet was not prescribed as a band-aid to his disease. The Ele Care was prescribed to keep my son alive. Yes, it must be prescribed by a physician. Without the administration of Ele Care on a daily basis (given at home) Christian would have been hospitalized to receive his nutrition. Ele Care is a medically covered expense when he is a hospital inpatient. Christian spent over 15 weeks in the hospital last year. He should not be forced to be placed in the hospital to receive nutrition. He is a little boy that loves to pretend he is a Power Ranger, and play with his puppy (named Ranger). He loves to dance, sing, play with play-doh, and spend time playing with his brother and cousins. To rob him of what little bit of normalcy he has in his life is not fair. If Ele Care is a medically covered expense as a hospital inpatient, why does BCBS deny him coverage upon discharge? Christian as I stated spent 15 weeks in the hospital as an inpatient in 2007, that is just a small glimpse into what his life is truly like. He has numerous Dr and ER visits (locally). He must ride in a car for 20 (10 to and 10 from). hours to see his specialist in Cincinnati, Ohio. He has been coped, poked and prodded and put under general anesthesia more in two years than I have been in 23 years. He is so used to having injections and IV's that he volunteers his hand. No child should be so used to having needles penetrate their skin that it is common place. Since being placed on Ele Care and having his feeding tube, Christian has flourished. He has put on weight, has had less Dr and ER visits (which saves BCBS a lot of money), and most importantly is being an ornery little boy. I want to acknowledge BCBS, and their position. However, how can Ele Care be a covered expense while in the hospital, yet non-covered upon release? Furthermore, it is in the financial best interest to cover Ele Care on an outpatient basis. I recognize that insurance companies have powerful lobbyist, and Christian only has me to be his advocate. I am a single Mom trying my best to raise both of my "special needs"

sons. Yes, I have another son Anthony, he is four years old and has autism. I could sit back, receive state assistance and be financially in a more comfortable position. All of Christians' medical needs would be covered. However, what lesson would that teach my sons? I want them to learn by being their role model that hard work is what will bring you success in life. I want to lead by example that the easy road is not the best road. I stand before you as a Mom that could possibly lose her son without this life saving formula. I stand before you begging that you pass this legislation so that my son can continue to flourish in his home, not the inside of a hospital. Christian will never eat birthday cake and ice cream at his or anyone's birthday party. Christian will never be allowed to go to Chuck E. Cheese and eat pizza. He will never be able to wake up Christmas morning and have Christmas candy in his stocking. He will never know the joy of eating a chocolate Easter bunny, a peanut butter and jelly sandwich or a hot dog at a ball game. All of those things, I have accepted. What I cannot accept is that my son must grow up within the walls of a hospital to receive life sustaining nutrition. Please do not allow private insurance companies to deny my child or the others like him in Kansas the one medically prescribed food item that he can have. Please pass

Bill number

HB 2769.

Again, thank you for allowing me the honor and privilege to address you this afternoon.

Amino Acid-Based Elemental Formulas Estimated Cost For One Year



Average Cost of Elemental Formula's Per Year: **\$5,075**

Although Christian goes through \$18,000 a year
Average cost of "Regular" Formula Per Year: \$2,175.00

Average Cost of Breast Feeding Per Year: \$0.00

Average Expenditures for a Family of 4 Earning the Median Income That Purchases an Elemental Formula

Housing	\$23,621.00	42%
Health Care and Other Insurance	\$8,533.00	15%
Food	\$7,472.00	14%
Miscellaneous	\$7,662.00	14%
Elemental Formula	\$5,075.00	9%
Personal Taxes	\$2,838.00	5%
Median U.S. Income	\$55,201.00	

Amino Acid Based Elemental Formula and "regular" formula pricing based on data from a national pharmacies chain. Quantity needed based on Ross Laboratory's estimate of 14,500 ounces of formula needed per year. From www.kidsource.com . Chart based on data obtained from the U.S. Census Bureau; <http://www.census.gov/compendia/statab/tables/06s0670.xls>

Christian goes through 18,250 ounces of formula a month.

The Number of Children Affected

Amino acid-based elemental formulas provide the proper life sustaining nutrition for children and infants with severe multiple food allergies and related conditions. Children who require amino acid-based elemental formulas are statistically small in numbers.

Prevalence

The majority of children on amino acid-based elemental formulas are those who experience severe multiple food allergies. These children represent approximately 80 percent of those who use these formulas. It is important to note that the vast majority of these children outgrow their allergies and their need for the formulas within 18 to 24 months.

The other 20 percent of these children have eosinophilic gastrointestinal disorders. These are rare disorders that occur when eosinophils, a type of white blood cell, are found in above-normal amounts in the gastrointestinal tract. These cells cause extensive inflammation and damage. Food allergens have been identified as an important cause of this disorder. Dr. Marc Rothenberg, the leading expert on eosinophilic disorders estimates that 1 out of every 10,000 children has an eosinophilic disorder.

Children With Milk And Soy Allergy	55,421	.0027% Of Total U.S. Children's Population
27 out of every 10,000 Children have both a Milk and a Soy Allergy		
1 out of every 10,000 Children have an Eosinophilic Disorder		
3 out of every 1,000 Children		

Combining this prevalence data leads us to the estimated 0.3 percent, or 3 in 1000 children could have a condition that requires amino acid based elemental formulas. However two things should be noted:

- Having both milk and soy allergies alone does not require the use of amino acid based elemental formulas – however this serves as a good indicator of other conditions.
- This figure (3 out of 1,000) actually double counts children who have BOTH multiple food allergies and an eosinophilic disorder which is highly common.

Thus, less than 0.3% of children require amino acid-based elemental formulas.

Total population and total children's population provided by the U.S. Census. "Children" refers to age 5 and under. Number of Children with a milk allergy from Annals of Allergy Asthma and Immunology, Volume 96, March 2006, Page 22. Approximate Number of Children with Milk and Soy Allergies (11%) from Zeiger RF, Sampson HA, Bock SA, Soy allergy in infants and children with IgE-mediated cow milk allergy. *J Pediatr.* 1999; 134:614-622.

The Argument

	<i>What The Problem Is</i>	<i>How It Will Be Fixed</i>
<u>Medically Wise</u>	<p>Unnecessary procedures and operations are often required for an insurer to cover amino acid-based elemental formulas.</p> <p>Even if required or recommended by a licensed health care professional, insurers will not provide coverage or reimbursement if taken orally.</p>	<p>By covering amino acid-based elemental formulas regardless of delivery method, medical professionals will avoid unnecessary procedures.</p>
<u>Fiscally Sound</u>	<p>Those in the middle and working class are unable to afford the high cost of amino acid-based elemental formulas, even when they have private health care insurance.</p>	<p>Insurers should be required to cover the cost of amino acid-based elemental formulas when required or recommended by a licensed health care professional.</p>
<u>Logically Best</u>	<p>Many invasive tests and operations are performed multiple times by multiple doctors and specialists in an attempt to reach a diagnosis.</p>	<p>Insurers should be required to cover the cost of amino acid-based elemental formulas for testing purposes when used with an "elimination diet" when required or recommended by a licensed health care professional.</p>

Below is an example of an insurer's policy on the issue. For coverage, they require an infant or child to undergo an often unnecessary, complicated and expensive medical procedure. Aetna's specifies that their policy will only be changed by state mandate.

The text below was taken in September 2007, directly out of a widely available Aetna Clinical Policy Bulletin available at http://www.aetna.com/cpb/medical/data/1_99/0061.html



Clinical Policy Bulletin: Nutritional Support

Number: 0061
(Replaces CPB 144)
Policy

Notes:

- I. For members with such plan benefit, specific nutritional support is considered to be a medical item *only* when it is administered enterally (i.e., by feeding tube) or parenterally (i.e., by intravenous administration) where the member has either (a) a **permanent*** non-function or disease of the structures that normally permit food to reach the small bowel; or (b) disease of the small bowel which impairs digestion and absorption of an oral diet, either of which requires enteral or parenteral feedings to provide sufficient nutrients to maintain weight and strength commensurate with the member's overall health status. Note: Not all benefit plans cover nutritional support even in the circumstances stated above. Please check benefit plan descriptions.
- II. **Aetna does not cover nutritional support that is taken orally (i.e., by mouth), unless mandated by state law.** Oral nutrition is not considered a medical item. See section on Special Medical Foods below.

[...]

Infant Formula

Note: Infant formulas are only covered if administered via the tube-feeding route and the criteria for coverage of enteral feedings are met. **Infant formulas given orally are not covered.**

[...]

II. Special Medical Foods Taken Orally

Note: **Aetna covers special medical foods only when mandated by state law.**

[...]

Aetna does not cover food supplements, specialized infant formulas, banked breast milk, vitamins and/or minerals taken orally (i.e., by mouth).

Food supplements, specialized infant formulas (e.g., Nutramigen, Elecare, and Neocate), lactose-free foods, vitamins and/or minerals may be used to replace intolerable foods, for lactose intolerance, to supplement a deficient diet, or to provide alternative nutrition in the presence of such conditions as hypoglycemia, allergies, obesity, and gastrointestinal disorders. Food supplements, lactose-free foods, specialized infant formulas, vitamins and/or minerals taken orally are **not covered, even if they are required to maintain weight or strength.**

Most Aetna plans do not specifically include coverage of infant formulas when taken orally. In the absence of a specific inclusion or state mandate, specialized infant formulas are not covered.

Law Governing Amino Acid-Based Elemental Formulas

CHAPTER I--FOOD AND DRUG ADMINISTRATION,
DEPARTMENT OF HEALTH AND HUMAN SERVICES
(CONTINUED)

PART 107--INFANT FORMULA--Table of Contents

Subpart C--Exempt Infant Formulas

Sec. 107.50 Terms and conditions.

(c) Infant formulas not generally available at the retail level. (1)

These exempt infant formulas are not generally found on retail shelves for general consumer purchase. Such formulas typically are prescribed by a physician, and must be requested from a pharmacist or are distributed directly to institutions such as hospitals, clinics, and State or Federal agencies.

Such formulas are also generally represented and labeled solely to provide dietary management for specific diseases or conditions that are

Parent Testimony Example #1

Testimony before the Washington State Senate Committee on Health & Long Term Care

Madam Chair and Members of the Committee, I thank you very much for the opportunity to speak to you today regarding Senate Bill 5874 – this is extremely important legislation to me and my family, and the Food Education Allergy Support Team of Seattle and its members. My husband and I adopted our daughter Katie at birth. We were so excited to have this beautiful baby. We thought everything was going to be perfect but then Katie started to cry. She cried about twenty hours a day and wouldn't eat. We took her to the emergency room but they couldn't figure out what was wrong with her. The doctors at the hospital gave her some very strong pain medication and she finally ate. I couldn't believe it – they had to drug my little baby just to feed her. We were in and out of the pediatrician's office and the ER and no one could figure out what was wrong with her. She wasn't growing. She cried all the time and still she wouldn't eat. We tried lots of different medicines. We tried store bought soy formula. We tried the “mostly hypoallergenic” specialized formulas. This went on for two months. I felt so powerless – I knew my baby was hurting, and I couldn't figure out how to fix it.

Finally, I took Katie to see an allergist. It turned out that Katie had a severe intolerance to milk AND soy. The allergist suggested that we try a special kind of formula available only from a pharmacy called an amino acid-based elemental formula; this formula was different than what we have been trying because it contained only amino acids instead of “complete proteins.” Within two days, Katie stopped crying and started to eat. She became a healthy growing baby. This life changing formula is very expensive. Katie's formula cost around \$800 a month - no small expense. I called our health insurance company and they said that they didn't cover baby formula.

At this point I was extremely frustrated and very upset; there was only one feeding option for my daughter that wouldn't make her hurt and we couldn't afford it.

I called our insurance company multiple times. Our allergist and pediatrician wrote letters, explaining that we'd tried ALL other options for feeding Katie, and had failed them all and that this was the only thing she was able to tolerate and that it was medically necessary. The insurance company replied that they would cover her formula if we had her fitted for tube feeding. This was ridiculous – Katie was drinking the formula just fine from a bottle, and thriving on it. There was no reason to subject her to a needless surgery, a hospital stay, and the likely complications.

Our allergist wrote back, saying that it was not appropriate to schedule Katie for surgery when she was able to take the formula by mouth.

I fought and fought with our insurance company, and finally got in touch with a sympathetic person there who decided to make an exception in their coverage policy for us. Katie's formula eventually did get covered. She was on the formula for 18 months – gradually transitioning off it as she gained more table foods. The vast majority – over

Parent Testimony Example #1 (continued)

80% -- of those on these formulas for allergies out grow the need for them in about 18 months to 2 years.

I don't know what we would have done without this formula.

Elemental formula is the last option for the sickest of the sick food allergic and intolerant kids. Very few children need it – our doctor suggests that less than ½ a percent of all the children in Washington State need the formula, but for those that do, it's literally a lifesaver, providing life sustaining nutrition when there are absolutely NO other options.

Families in our state cannot afford to pay for these formulas out of pocket. The kids who are on these formulas are on them because of severe medical conditions that preclude them from getting adequate nutrition from other sources. It needs to be accessible to those with private health insurance just as it is for those on Medicaid; that's right – Medicaid in Washington State covers elemental formulas for those in the program regardless of how the formula is taken.

Many doctors have told me anecdotally that kids on these formulas get healthier – resulting in fewer doctor and emergency room visits which they believe is actually an overall reduction in their medical bills despite the cost of the formulas. I think it's obvious to anyone that when children have far fewer doctors visits, diagnostic tests, emergency room visits, and hospitalizations their medical bills are reduced.

I can tell you that this has certainly been the case with my daughter. Until we got her onto elemental formula, we had endless pediatrician visits and several trips to the emergency room and one hospitalization. And since she began formula she has been extremely healthy and has only had well-baby visits to the pediatrician!

This legislation is extremely important. If insurers are willing to cover the expensive and invasive tube feeding option they should also be required to cover the less invasive non surgical option of oral feeding. This legislation provides a nutritional safety-net for the worst of the worst sick children who have no other options.

Thank you so much for taking the time to consider this bill.

I fully support this legislation and I hope that you will to. I'd be happy to answer any questions that you might have.

Parent Testimony Example #2

Testimony before the Health Care Availability and Access Committee

My name is Ralph and my 3 year old son Bobby has an extremely rare condition called eosinophilic esophagitis. For our family it has been a long and hard journey to realize that there is only one way to keep him alive and happy; that way is with EO28 - an amino acid based elemental formula. Without it, he is considered to be on a downward spiral, an effect doctors call Failure to Thrive. EO28 is fondly referred to at our house by Bobby, as "spider juice", after his beloved hero "Spiderman." The doctors at Children's Memorial Hospital have said our biggest challenge would be to have him drink the formula orally. Dr. Smith said to do whatever we can to avoid the feeding tube. So, along came "spider juice" that helps Bobby become strong.

One year ago Bobby weighed 24 pounds and was considered a failure to thrive. Today, he weighs 39 pounds and is a very active four year old boy.

Words can not express how elated we were after he started taking the formula – he changed almost instantly. All of this happiness was shattered by our insurance company denying our claim multiple times for the sole reason that he was able to drink it and did not have a feeding tube in place.

We spend around \$1,000 a month on his formula and this is an extreme hardship. We have to think twice about even spending \$14.00 dollars on a school year book for my older son or purchasing routine products like we did before. We are worried that we wont have anything saved for our boys college fund because my son is taking his only source of nourishment orally, instead of by feeding tube. I distinctly remember Dr. Smith telling me to persuade Bobby in anyway I could to take the EO28 orally or else we have to surgically insert a feeding tube.

As Bobby grows, his body's demand for EO28 will increase along with our monthly expenses to feed him.

My frustration level with my insurance company has reached an all time high. Numerous parts of our file have been lost or end up in the wrong department even after an Aetna customer service representative has given me the name, address and department to send the paperwork to I have followed up on claims and questions only to be told nothing because again key documents have been lost or transferred to a different department and subsequently lost again.

I ask all of you sitting here before me today, if this was your child's only source of nourishment to stay alive and your insurance company basically asked you to put him through an unnecessary operation, which would hinder every aspect of a vivacious four year old boy's life.....what would you choose?

Parent Testimony Example #3

Statement before the Health Care Availability and Access Committee

I am currently employed here in Springfield by the State – I am here today to speak on behalf of my family. My statement is not in any way affiliated with my employment with the State.

My son, Jake, was born 2 ½ months premature. After bringing him home from the hospital, we experienced a lot of stress. He cried a hurtful cry day and night. The doctor kept saying that he was just colicky. After trying 3 different formulas, we were recommended to a specialist. He diagnosed Jake as being protein intolerant and also with having reflux. He prescribed an amino acid based elemental formula for him. Within 3 days, we saw a major difference in our baby's behavior. He didn't seem to be in pain any longer and he was finally sleeping more than 2 hours at a time. Our stress level eased also. We missed out on the first 3 months of his life and we can no longer get that back or look back at it with happy memories.

Our stress came back due to the cost of this medically required formula. Our insurance denied coverage because they said that it was available over the counter and that our son was thriving. I have issues with this. For one, it was not readily available. We had to ask the pharmacy for it. In turn, they had to know which doctor prescribed it. These formulas are not available to anyone that wants them. They had to special order the formula and it cost more to get it from them then it did to buy it from the company that produces it. We eventually bought it off of EBAY. I was not comfortable with this because of safety issues but we had no choice, we could not afford it – our son had to have it - and this was the cheapest route. Since Jake was able to be on the formula, he eventually outgrew his intolerance like most with intolerances and allergies and he was off the formula by the time he was six months old. I believe that if he had not had this formula, the stress on his body would have been so severe and he would have gotten sicker with even more complications. I don't believe a baby can thrive when each day he is in pain. Now we have a beautiful, healthy, one year old boy who we can enjoy.

I strongly support House Bill 1560 and I urge you to do the same

Doctor Testimony Example (Oral)

Testimony of Dr. Alan Stillerman
Minnesota House Health and Human Services Committee

Thank you. Mr. Chair and Members, I thank you for allowing me to testify on this matter that certain severe medical problems require the presentation of elemental amino acid building blocks of protein be administered in term, in order to prevent severe life threatening anaphylactic allergic reactions, in others to assist in the digestive and absorptive problems.

The wrong formula can be and has been life threatening. The correct formula is life saving.

The root of administration for many patients is interior. If a patients going to a have a life threatening anaphylactic reaction to milk or cow's milk or cow's milk or soy, to give them a nasogastric tube, it's not going to save that patient. It's only for some patients who might need additional formula administration who might benefit from a nasogastric tube.

The requirement from insurance companies that patients be malnourished before insurance coverage is also nonsensical. Patients [that] are going to die from an anaphylactic reaction are going to die before they're malnourished.

So in conversations with the healthcare plans of Minnesota, we've come to an agreement on the coverage and I would like to support it and request your support in this issue.

In summary, the solution to the problem today is the correct solution, it is elemental.

Doctor Testimony Example (Written)

Marc E. Rothenberg, MD, PhD
Director of Allergy & Immunology Division
Cincinnati Children's Hospital Medical Center



Statement For the Illinois General Assembly House Health Care Availability and Access Committee

Madam Chair and Members of the Committee, My name is Marc Rothenberg and I am the Director of the Allergy & Immunology Division at Cincinnati Children's Hospital Medical Center and I strongly offer my support of House Bill 1560, requiring insurance companies to provide coverage for amino acid-based elemental formulas regardless of delivery method when recommend by a licensed health care provider.

I would like to provide you with information about a group of disorders and why elemental amino acid-based formulas are medically necessary for the diagnosis and treatment of these disorders.

Eosinophilic gastrointestinal disorders are relatively new and are estimated to afflict 1 in 10,000 children. Eosinophils are white blood cells that are normally associated with fighting parasitic infections. Rarely, eosinophils respond to food and food areas of the Gastrointestinal tract. They then release toxins that cause tissue damage. Symptoms include difficulty swallowing, abdominal pain, malnutrition, failure to grow, uncontrolled reflux, nausea, vomiting, food impactions where food actually gets stuck in the esophagus, difficulty sleeping, and diarrhea. These gastrointestinal disorders are diagnosed by an invasive procedure called endoscopy, and tissue samples are taken from various regions and analyzed for the presence of abundant eosinophils.

There are no medications to cure these disorders, but some medications, such as steroids, can alleviate the symptoms. The best treatment is to remove the triggers, food, that attracted these white blood cells to the GI tract.

About half of the children with these disorders also have food allergies. For some children, an elimination diet is prescribed where they eliminate all positive allergy foods from their diet. In some cases, this involves removing many common foods from the child's diet, without leaving adequate sources for sustainable nutrition. Many of these children require the addition of an amino acid-based formula to their very restricted diet in order to maintain health.

For other children, it is necessary to use an elemental diet in order to sustain life or as a diagnostic measure to determine which foods are causing the disorder. An elemental diet is composed of no proteins, which means no foods since all foods have some protein.

Doctor Testimony Example (Written) (continued)

Elemental formulas are composed of man-made synthetic amino acids. These formulas allow the body to heal and then foods can be introduced one at a time to determine which ones were causing the disorder.

Some children cannot drink enough of the amino acid formulas and require tube insertion. Other children can drink the formula orally.

When an amino-acid formula is prescribed, it is because there are no other options for that patient. These formulas are medically necessary and coverage for them shouldn't be dependent on diagnosis or delivery method. As a medical professional I see no reason why insurance companies will cover the tube feeding method only and not the oral method – oral is inherently much cheaper as it requires no surgery or maintenance and it's significantly less invasive on the patient.

Many insurance companies will only provide coverage for these expensive formulas if the patient is diagnosed with a metabolic disorder, or if the formula is fed only through an enteral tube.

Children who need these amino acid-based elemental formulas and are using these formula tend to heal quickly and become healthier in not just the short term but the long term. Amino acid-based elemental formulas are medical treatments and should be treated as such.

I strongly offer my support for House Bill 1560.

Dr. Marc Rothenberg, M.D.



CHRISTIAN'S TIME LINE

March 14th, 2005 Christian's older brother Anthony was diagnosed with autism, at the time of the diagnose it was just myself and Anthony. Anthony & Christian's father did not except the diagnose to well.

March 22nd, 2005 Christian made his appearance into the world 5 ½ weeks early. Due to the face that myself was under a lot of stress because my other son Anthony was just diagnosed with autism. The stress put my into pre-term labor.

March 23rd, 2005 Christian's jaundice levels started to climb at this point the was separated from myself and was put into a isolate with special lights.

March 30th, 2005 Christian came home but on a jaundice blanket to help with his levels to go down.

During all of April 2005 Christian was weighed daily at the breastfeeding clinic because he was not holding his body weight. At this time everyday he would also have a jaundice test done. And also everyday I went into the breastfeeding clinic because Christian was not wanting to breastfeed. At this time he I had to finger feed him with a feeding tube.

April 1st, 2005 Christian was put back in the hospital because his jaundice levels were to high to be at home.

April 4th, 2005 Christian came home for the 2nd time. This time from being in the hospital

for jaundice levels.

April 17th, 2005 Christian was put into the hospital for Apnea here in Topeka, KS

April 19th, 2005 Christian was discharged from the hospital and put on a apnea monitor.

April 27th, 2005 Christian was admitted to KU Medical Center in Kansas City, KS for his apnea, where they found at this time his right lung diaphragm was half paralyzed. At this time he had undergone 5 spinal taps, MRI, EEG, EKG, Reflux testing, blood work, culture tests.

May 2nd, 2005 Christian was transferred from KU Medical Center to Children's Mercy Hospital in Kansas City, MO

May 3rd, 2005 Christian was finally discharged and still on his apnea machine but was put on reflux med

May 5th, 2005 Christian's feeding tube (NG Tube) came out finally

June 2005 At the doctors every week for weight checks and stool cultures

July 1st, 2005 Anthony and Christian's father left, stated he could not handle all the pressure and I was a single mom now. One son with autism and one son with something wrong but no diagnose yet.

July 2005 At the doctors every week for weight checks and stool culture, he was getting more fussy, crying all the time

August 2005 Christian was seen at least 10 times this month because of his diarrhea, lost of appetite , poor weight gain

September 2005 Christian was admitted to St Francis Health Center by his PC doctor to do a intake/out take study. At this time he was put on Golightly, something to thicken up my breast milk

October 2005 His diarrhea was getting out of control going about 15-20 times a day, nothing was helping

November 2005 Diarrhea slowed down but his weight was not where it should be, and his pains were picking up again

December 2005 Finally met with GI specialist at Children's Mercy Hospital in Kansas City, MO. At this time he was put on allergy med to help

January 2006 Christian under went his first of many scopes to see exactly what was going

on.

January 2006 Christian was diagnosed with a rare disease called Eosinophilic Gastroenteritis. I was told at this time there was no cause so no cure. But trial and error.

February 2006 Christian started to get healthier (what I thought)

July 2006 Christian started having blood in stools and weight loss

August 2006 Christian's blood count was dropping, they started him a 5 different meds daily. Which was not working at this time

September 2006 Christian was admitted for the first of very many admits. At this time he under went a scope, blood work, stool cultures, MRI, X-rays, Meckles Scan, Camera Pill Study. Found his bleeding but could not find the cause. Also had a PICC line put in for IV access which was a surgery he had to under go.

October 2006, Christian was in the ER twice for fluids

November 2006, over thanksgiving Christian was admitted. He started with a stomach virus which took it's toll on the little guy. At this time he under went X-rays' blood work, stool cultures, he had a PICC line put in which was surgery.

December 2006, Christian was in the ER once for IV fluids

January 2nd, 2007 Christian was admitted to Children's Mercy Hospital in KC, MO where he under went another scope, another surgery (PICC Line), more blood work, more stool culture, no answers, changed of med. This time he was put on a med that cost everything I basically had.

January 18th, 2007 Christian was discharged from Children's Mercy in Kansas City, MO

January 21st, 2007 Christian was admitted again to Children's Mercy in Kansas City, MO for more blood in stools, weight loss. At this time he was labeled as a FTT child. He under went more blood work, more stool cultures, another surgery (PICC Line)

February 1st, 2007 Christian was discharged from Children's Mercy in Kansas City, MO

February 10th, 2007 Christian was admitted to Children's Mercy in Kansas City, MO for dehydration yet again. Weight loss. At this time they stopped all his meds and changed them all around hoping this would work.

February 18th, 2007 Christian was discharged from Children's Mercy in Kansas City, MO

March 27th, 2007 Christian spiked a 104 temp and could not even walk, he was so

dehydrated they could not even get a IV in him. He was then sent to Children's Mercy in Kansas City, MO where he was admitted. They did stool culture, blood work, x-rays. And changed his meds again.

April 2007, on the phone with the doctors none stop. I was not wanting Christian in the hospital again but wanting some answers. Some answers to find out what is causing my son's disease to flare up.

April 29th 2007 Traveled to Cincinnati, OH

April 30th, 2007 Christian under went a scope, stool cultures, blood work at Cincinnati Children's Hospital where they have the US leading doctors in his disease. At this time he was not only diagnosed with EGE, he was diagnosed with EE, EGE, EC, IBS, Eczema.

April 31st, 2007 Christian under went allergy testing where he was poked 72 times and also had a patch test done.

May 2nd, 2007 Christian's diet would change now he is NO sugar, High Fat, High Calorie, Low Fiber Diet.

May 3rd, 2007 Reading of the patch testing showed he was allergic to soy

May 4th, 2007 Arrived back home in Topeka from Cincinnati, OH

May 7th, 2007 Christian started vomiting again, starting having diarrhea, crying all the time

May 11th, 2007 Christian was taken off ALL dairy products and put on a expensive formula called Elecare which is \$50 a can, and which he goes through 5 cans almost 6 cans a week.

May 17th, 2007 Christian started having blood in his stool and went to see PC doctor because Christian's GI doctors are not helping to much at this point. Christian's PC doctor said his weight is down. And we wanted to watch him

May 22nd, 2007 Christian is seen at the doctor for one of the scariest things he has been tested (blood work) for and that is junior arthritis. Christian at night can not walk almost ,he screams that his knees and wrists hurt. All he can do is lay on the bed and cry.

May 25th, 2007 Which is today I called Christian's PC doctor and stated we need his blood work back and that someone has to do something with Christian because his legs are killing him. He can not walk at times he needs help. And I am still waiting on the phone call

June 20th, 2007 Christian has a appointment with a arthritis specialist in Kansas City, MO

July 26th-August 9th, 2007 Christian was admitted to Children's Mercy Hospital for dehydration, not wanting to eat or drink anything, stomach pains, diarrhea, fever. At this time of the 2 weeks stay he had a NG Tube (Feeding Tube) placed in his nose for us to provide his formula to him.

November 9th, 2007 Spent 6 hours in the er with the croup

November 13th, 2007 Christian under went yet again another surgery this time to remove his NG feeding tube and put in a more permeant feeding tube (Gtube).

November 2007, 2 ER visit for blockages in his bowels.

December 11th, 2007 Christian was diagnosed with pneumonia. And placed on some new meds. Spent 6 hours in the ER

December 13th, 2007 Christian had to have his skin around his feeding tube burned off

December 28th, 2007 Christian yet again had to endure having his skin around his feeding tube burned off.

January 15th, 2008 Diagnosed with PICA and under went X-rays and CT Scan

January 18th, 2008 Another ER visit this time was admitted to hospital for 1 ½ days

January 31st, 2008 Christian underwent another surgery, this time was to change his feeding tube to a low profile tube, rescope and cleaned out bowels.

Christian is also having new signs of yet another problem which would be Sensory Disorder. Which is another disorder he can get from his other disease.

All of these appointments, hospital stays, phone calls, picking up the meds. I have had to do myself as a single mother.. I have learned so much from being a single mom. It's VERY hard but I love it! I have learned to see the world for what it truly is and I thank my boys for helping me learn so much and teaching me.

Christian was diagnosed at the age of 10 months with these rare disease. I have included copies of what the disease is. What it can do to him, and what his future looks like. Christian most likely will spend the rest of his life and out of hospitals. He will be have surgery to put a feeding tube into his stomach. Because his body is not holding weight again. He also is being considered for surgery to have a port which is a IV under the screen put in. Christian did not ask for this, but he is holding up very well. He is the most loving little kid. He is as we call him the kissing bandit, he loves giving kisses and hugs. Christian has a hard future ahead of him not only for himself but also being a little brother to Anthony and having to deal with a brother having autism. Christian will have to at

some point step into the role of being a big little brother. And that is so much to ask of someone so small. Everyday Christian goes through at least 10-15 diapers which is double the normal amount of diapers for his age. Because of his diarrhea, Christian has to take meds daily. He has to be fed his formula through a NG tube because he will not take it. Christian has been in the hospital so much that when he sees even a push pin he tries to poke himself (acting like he is giving himself a IV). A 2 year old should not know how to do that and should not even be trying to do it to himself. Christian is the light of my world along with his brother. I am having to sell my house right now and it might foreclose because I have to get my older son Anthony into a different school district for his autism. This is not what I wanted to do. But my son's deserve the best and for being a single mom I am trying. But right now money is getting so tight because of Christian and his medical bills. I would be lost without my family. When Christian and I are in the hospital my parents watch my son Anthony for me. And one day when Christian was in the hospital I called to talk to Anthony and I told him "Hi Anthony it's Mommy." He then replied with "Anthony no Mommy." which broke heart. To hear your own son say that is enough to crumble your heart into a million pieces. Everyday with Christian I have to watch every sneeze, every cough because even a cold can put him into the hospital. And a GI bug can do some serious damage to him. I have to have him on a special diet because of his disease. So I have to watch everything he does. He is not able to be a normal child. He is sort of living in a bubble. . If you have never had a little one in the hospital it is the hardest thing you will have to go through. Seeing your child hooked up to IV's, Heart Monitors, watching them come and draw blood. Or watching your child not understand that he can't eat and watching your child hide in the bathroom from anyone. From the nurses, from the doctors, from even yourself. The hospital is our second home basically. If I could have picked somewhere to have a second home it would not be a hospital. All the nurses know us by first names, which should not happen. But seeing my son sometimes just screaming and crying because he is in pain and I knowing that I can not help him. I feel so useless sometimes. I just want him healthy and I know that probably won't happen. I know he can get better because he has for a short period of time. But right after about a month of getting better he is back in the hospital. As you can see from Christian's pictures he is such a handsome little guy, his eyes are so bright and his smile is so big. But try seeing that face when he is sick and in the hospital. Not knowing the future is what is hard for myself, I do not know when I wake up in the morning if I am going to end up with my son in the ER or admitted to the hospital or be able to tuck him into his own bed. I wish I knew the future for me son but as the doctors say they do not even know what the future holds for Christian.

Thank You

Porscha Waggle



Kansas Insurance Department
Sandy Praeger, Commissioner of Insurance

January 11, 2008

MS PORSCHA WAGGLE
7410 SW 22ND CT
TOPEKA KS 66614

Re: BLUE CROSS AND BLUE SHIELD OF KANSAS, INC.
Department File No.: 0108CA141075

Dear MS PORSCHA WAGGLE:

I have received your recent insurance related inquiry and have asked my Consumer Assistance Division to investigate the matter you brought to our attention. We will contact the insurance company and request a written report. As soon as we have received a response and have had a chance to review the response, we will contact you. This process usually takes about 30 to 45 days.

Please understand, we will conduct an informal investigation regarding your inquiry; however, my staff at the Kansas Insurance Department cannot act as your attorney, cannot file a private action on your behalf and cannot provide you legal advice. Any private action that you may have will need to be filed within the applicable statute of limitations. To make sure that you are aware of all of your rights and that those rights are protected, you should contact and consult with your attorney.

If we can be of further assistance in the meantime, or if you want to provide any additional information, please do not hesitate to contact the Consumer Representative listed below who has been assigned to your case. Please refer to your Department File Number when you call.

Karen Larsen
Topeka office - 785-296-7829 or 800-432-2484

I hope that we are able to be of assistance to you.

Sincerely,

Sandy Praeger
Commissioner of Insurance

-----FOR INTERNAL USE ONLY-----

File No.: 141075
First Name: PORSCHA
Last Name: WAGGLE
Rep: KLL
Doc: A-1



Kansas Insurance Department

Sandy Praeger, Commissioner of Insurance

January 28, 2008

Ms. Porscha Waggle
7410 SW 22nd Court
Topeka, Kansas 66614

Re: Company: Blue Cross Blue Shield of Kansas
Department File No.: 0108CA141075

Dear Ms. Waggle:

We have been in contact with the above captioned company regarding your complaint.

As indicated in the Company's reply, it appears a duplicate inquiry was received by the Company on the day prior to receiving your complaint filed and sent by our office. As such, the Company provided our office with a copy of their response dated January 16, 2007 and addressed to you. A copy of this letter has been enclosed for your review.


From the information provided by you and the Company, it appears that the Company has acted in accordance with the terms set forth in your policy. As reflected in the Exclusions section of the policy, "Benefits are not provided for:

- 13). any food item, including breast milk, formulas and other nutritional products"

Since the Kansas Insurance Department is limited to ensuring compliance with policy language and state law, it does not appear that there is any further action that we can take on your behalf regarding this matter.

If we can be of assistance to you on any other insurance related matter in the future, please feel free to contact this office.

Sincerely,


Karen Larsen
Life and Health Unit
Consumer Assistance Division

Enclosure

cc: Senator Pat Roberts



**BlueCross
BlueShield
of Kansas**

1133 SW Topeka Boulevard
Topeka, Kansas 66629-0001

www.bcbsks.com

JAN 17 AM 9:56

Premier Blue

January 16, 2008

KAREN LARSEN
CONSUMER ASSISTANCE DIVISION
KANSAS INSURANCE DEPARTMENT
420 SW 9TH ST
TOPEKA KS 66612 1678

CONSUMER: Porscha Waggle
DEPT. FILE NO.: 0108CA141075
ID# XSA878433691
NAIC# 70729
INQUIRY# 200801508046

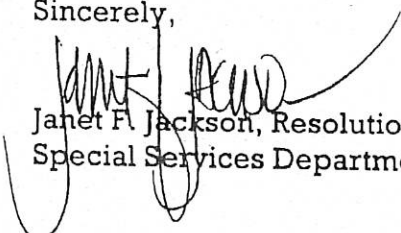
Dear Ms. Larsen:

This letter is in response to your inquiry filed on behalf of Ms. Porscha Waggle regarding the ineligibility of formula for her son, Christian.

Ms. Waggle sent us a duplicate inquiry that we received the day prior to receiving your inquiry. The enclosed response that was sent today to Ms. Waggle is included in my response.

If you have any questions regarding this letter, please contact me at 291-4375, extension 3581.

Sincerely,


Janet F. Jackson, Resolution Specialist
Special Services Department



**BlueCross
BlueShield
of Kansas**

1133 SW Topeka Boulevard
Topeka, Kansas 66629-0001

www.bcbsks.com

PremierBlue

January 16, 2008

PORSCHA WAGGLE
7410 SW 22ND CT
TOPEKA KS 66614

RE: Elecare formula
ID# XSA878433691
INQUIRY# 200801416181

Dear Ms. Waggle:

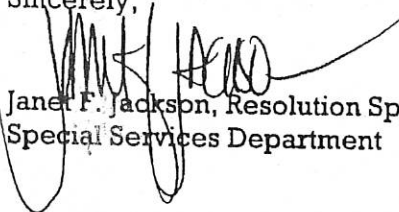
Thank you for sharing your letter that you have forwarded to the media and the government officials regarding Christian's need for Elecare formula.

As we previously indicated to you, formula is an exclusion of the Blue Cross and Blue Shield of Kansas benefits. Our health insurance plans do not provide coverage for every medical service, procedure, and piece of equipment or drug that a health care provider may use to prevent, diagnose or treat a particular problem.

Blue Cross and Blue Shield of Kansas does not deliver health care; we finance it for our members. Our coverage contains certain restrictions designed to help keep premiums affordable. Some of these restrictions are specific contract exclusions, such as the formula that Christian uses. Our cost containment programs save substantial amounts of money for our members.

We appreciate the opportunity to provide you with this explanation. It is not our intent to minimize Christian's health care needs. I hope you can understand the obligation we have to all of our policyholders to pay only what the contract stipulates. To do otherwise would inflate the cost of health insurance for all of our members.

Sincerely,


Janet F. Jackson, Resolution Specialist
Special Services Department

1. **Contracting Pharmacies** -- The allowable charge for a covered Prescription Drug is as provided for in the Contracting Pharmacy Agreement. The allowable charge minus the Copay will be paid directly to the Pharmacy.
2. **Non-Contracting Pharmacies** -- The allowable charge is the lower of: the Pharmacy's actual charge for the Covered Prescription Drug or the maximum amount allowable had the order been filled by a Contracting Pharmacy. You are responsible for the Copay and difference, if any, between the allowable charge and the actual charge.

Benefits for services received from a Non-Contracting Pharmacy will be paid to the Insured. Such benefits are personal to that Insured and cannot be assigned to any other person or entity.

NOTE: If You obtain a Prescription Drug from a Contracting Pharmacy and do not, at that time, notify the Pharmacy that You are eligible for Prescription Drug benefits through this program the Prescription will be considered as having been provided by a Non-Contracting Pharmacy. The charge will be processed according to the guidelines that apply to Non-Contracting Pharmacies and You will be responsible for any amount that is above the allowable charge for a Contracting Pharmacy.

F. Exclusions

Benefits are not provided for:

1. Charges to administer or inject any drug.
2. Prescription Drugs that are administered or entirely used up at the time and place ordered.
3. Prescription Drugs for which normally (in professional practice) there is no charge.
4. Prescription Drugs for other than human use.
5. Contraceptive devices; therapeutic devices; artificial appliances; hypodermic needles; syringes or similar devices. This exclusion applies regardless of the intended use.
6. Prescription Drugs purchased from an institutional pharmacy for use while the Insured is an Inpatient in that institution.
7. Charges for delivering any drugs.
8. Prescription Drugs obtained for use in connection with drug addiction.
9. A drug approved for experimental use.
10. The Company has the right to deny benefits for any drug prescribed or dispensed in a manner that does not agree with normal medical or pharmaceutical practice.
11. Drugs, supplies, and equipment used in intravenous treatment. This exclusion does not apply to drugs which require prior authorization, as set forth in Section D.
12. Coverage for allergy antigens under any circumstances.
- * 13. Any food item, including breast milk, formulas and other nutritional products.
14. Coverage for total parenteral nutrition.
15. Drugs available in the equivalent dose over-the-counter which do not require a Prescription Order by Federal or State law.
16. Charges for services that are not listed as covered services.
17. Services for injuries or diseases related to Your job to the extent You are covered or are required to be covered by a worker's compensation law. If You enter into a settlement giving up Your right to recover past or future medical benefits under a worker's compensation law, the Company will not pay past or future medical benefits that are the subject of or related to that settlement.

In addition, if You are covered by a worker's compensation program which limits benefits if other than specified providers of health services are used, and You receive services from a provider not specified by the program, the Company will not pay balances of charges from such non-specified providers after Your benefits under the program are exhausted.

"Adam has the immune system of a 90-year-old," says his mom, Annette Turner (at home with Adam in October '07). "Every year brings a different challenge."

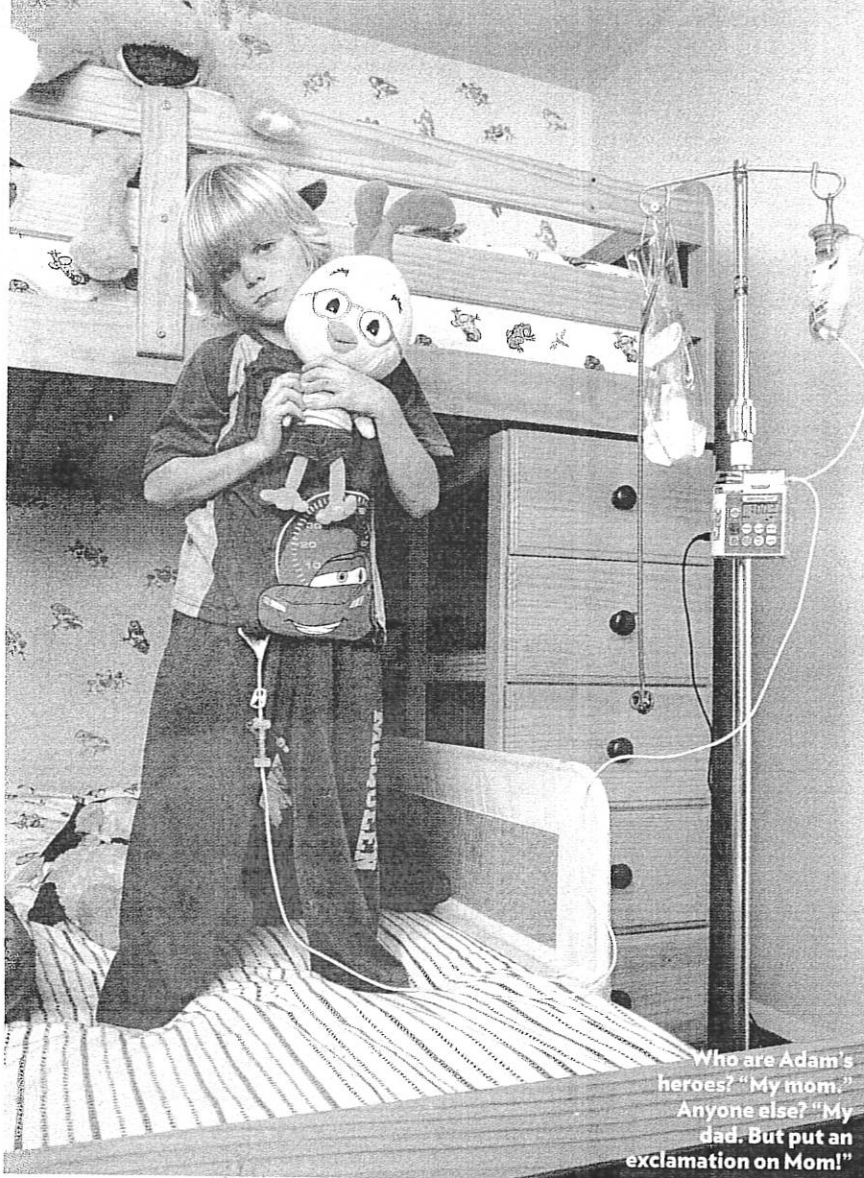


THE BOY WHO COULDN'T EAT

Mealtimes used to be torture for Adam Turner, who is allergic to nearly every kind of food. But this feisty second-grader has a huge appetite for life

BY JILL SMOLOWE

On Adam Turner's 7th birthday, he blew out the candles on a soccer cake, then looked on as his friends devoured their slices. Last year he insisted on opening an electronic lunch account at school,



Who are Adam's heroes? "My mom." Anyone else? "My dad. But put an exclamation on Mom!"

“ Sometimes, I wish food would go away”

—ANNETTE TURNER, ADAM'S MOM

spoon-feed himself ice chips from a cereal bowl. She soon began hating food herself. “I didn’t put anything in my mouth in front of him for about six months,” she says. After dropping 15 lbs., Annette forced herself to eat in front of Adam—which brought new challenges. In mall food courts he’d inhale and say, “Ah, french fries.” At dinner, he’d climb into his mom’s lap to touch and smell—but not eat—her food. Adam now says he finds watching people eat “boring.”

If Adam’s diet is severely restricted, his life is anything but. “We’re adrenaline addicts; we love adventure,” Annette says. Since infancy, Adam has logged thousands of miles on bikes and motorcycles, strapped to his dad’s back. He also surfs, plays soccer and baseball and goes on family trips. “We’ve hooked up feeding bags in parking lots and on highways,” Annette says. Adds Mike: “We don’t make a big deal, so he doesn’t.” That low-key approach extends to Adam’s school, where few people, classmates included, are aware of his condition. Sometimes at lunch he strays from his approved diet and experiments with hamburgers and cookies—then pays for it with gastrointestinal discomfort. “You would never know,” says cafeteria manager Beverly Frederick.

Adam prefers it that way. At 7, he just wants to be like other kids. Still, he’s aware of the toll his disability takes on his family. “One day he said, ‘Mom, did you really want a kid that has all these diseases?’” Annette says. “He tries to be tough, but he’s got a big heart.” The limited body of existing EE research indicates a normal life span for Adam, but Annette takes no day for granted. “What I’ve done with Adam in seven years is more than some mothers do in a lifetime,” she says. “I try to squeeze every minute out of every day.”

of starting on formula, Adam began to vomit, had trouble breathing and suffered his first skin eruption. Doctors diagnosed a milk-protein allergy and, to give Adam’s GI tract a rest, inserted a feeding tube that ran from his nose to his stomach. The tube, part of which had to be taped to his face, was clumsy and easily dislodged, and Annette often had to wrestle it back into place. Still, she says, “we thought, No biggie.”

But the worst was yet to come. After being introduced to mashed bananas, rice cereal and other baby foods, Adam began to lose weight, plagued by up to 12 bouts of diarrhea a day. This time, tests revealed EE, which, says Dr. Liacouras, “can be one food or it can be all food.” In Adam’s case, skin-prick testing proved him allergic to all foods, except carrots and pears—a discovery

that tortured Annette. “To find I’d been basically poisoning him while feeding him...” she says, tearing up. “That was the most painful thing.” Adam was 2½ when his reluctant parents agreed to have a device surgically implanted so that formula could be pumped directly into his stomach.

Adam quickly gained weight, and began to sleep better—a peace that eluded his parents, awakened up to 10 times a night by an alarm that signaled when Adam’s feeding tube was tangled. “It was worse than having a newborn,” recalls Adam’s dad, Mike Rubin, 56. Desperate, Mike, a health-care administrator, and Annette, a corporate controller, leaned on disability insurance to bring in night nurses.

But that did little to ease Annette’s anguish at meals as she watched Adam

On the next following pages you will have recent parent stories of their children dealing with Eosinophilic Disease and Amino Acid Based Elemental Formulas, you might also see a few of them that have helped their own state get legislation on this matter.

Supporting Bill HB 2769, this mother also helped passed legislation in Illinois in her home state.

March 20, 2007

Ellyn Kodroff
2937 Bayberry Dr.
Buffalo Grove, IL 60089
847-793-0071

Madam Chair and Members of the Committee, **I am here today to testify in support of House Bill 1560** – this legislation is extremely important and I trust that you will agree.

My daughter Jori has finally begun to thrive again: In the last 9 months she has gained 15 pounds and grown 3 inches after not growing at all for 4 full years. Her esophagus and stomach are finally healing and her gastrointestinal system has stopped bleeding and more importantly her biopsies have come back with drastically lower levels of eosinophils. The high level of eosinophils in her blood – which could cause damage to her organs - have gone from a dangerous level of 39% to a now normal level of 7%. She survived for over 4 years living with constant pain, reflux, nausea, and intense head aches and now she is feeling better and improving. The only reason she has improved is because of amino acid based elemental formulas.

Jori was diagnosed with an eosinophilic disorder at age 10. Through testing we learned Jori was allergic to 44 foods. During that first year the disease worsened and progressed to her esophagus. On doctors orders her diet was restricted to red meat, potatoes, and a couple fruits and vegetables. She was put on 2 different kinds of strong steroids and other medications. Our daughter was extremely sick and allergic to just about everything. After 3 years of trying different medications and treatments Jori was no better, infact worse.

At this point under a doctors order we eliminated all “normal” foods from her diet and began giving her an amino acid based elemental formula. This formula was and still is her only source of nutrition.

After beginning the formula Jori drastically improved and we were even able to take her off one of her steroids. Because the formula, Neocate Jr., allows her body to heal naturally doctors are optimistic that we will soon be able to try and introduce normal foods into her current diet of only formula.

During this process our family has been facing severe hardship mainly because of one reason. Amino acid based elemental formulas are highly specialized and subsequently are extremely expensive -- costing our family over \$1,200 per month.

When we filed a claim for her medically required formula I was denied and told by my insurer that they would only cover the cost of the formula if Jori was taking it through a

feeding tube. (I have attached the letter from Blue Cross Blue Shield to the back of my testimony which I believe you have been given a copy of) My daughter is 14 years old and thankfully is completely capable of drinking the formula just like you and I would drink a soda. To feed Jori through a feeding tube would require an unnecessary surgical procedure, a hospital stay, strong pain medication, and constant maintenance. Not to mention the strong possibility of infection and changing her quality of life more then it already is. My daughter has been through so much – bi weekly blood tests and biopsies – constant trips to multiple doctors – and severe pain and discomfort – neither my husband nor I wanted to put Jori through what would be an elective surgical procedure just to gain coverage. I was appalled to learn that had our family qualified for state sponsored health care like Medicaid Jori's formula would be completely covered no matter which way she ingested it.

Our insurer was telling us that they would only cover the formula if she had the surgery. So they were willing to pay for the surgery, the hospital cost, the complications, the maintenance, and the formula – but not the formula by itself even after numerous doctors had written to them explaining that it was a medical necessity and that she didn't need the surgery. I'm not an expert on medical costs but I think for our family it is obviously cheaper on our insurance company to cover the formula when taken orally then if we had elected to put Jori through an operation. It seems to me that by agreeing to pay for the oral delivery of the formula, they would actually be saving money. Not to mention providing her with the formula creates a healthier adult as she grows which I'm sure would cut down on future medical bills as well.

It is difficult for me to put into words what our family has gone through. We didn't know how we were going to feed Jori. She has no safe foods and absolutely had to be on an elemental diet. We literally go week to week not knowing if we are going to be able to get the formula for her. We have taken out personal loans in order to care for our daughter.

We still have not received coverage —our most recent appeal was denied two weeks ago for the same reasons I mentioned earlier. My family is still experiencing financial hardship but our daughter is healthier and thriving and we are so happy for that.

Without this formula Jori will not thrive, she will not feel well; and there is a good possibility that her disease could attack her organs making her much sicker. Amino acid based elemental formulas has made Jori better – and insurance companies should be required to cover them regardless of how they are taken when they are medically necessary.

I strongly support this legislation. Please act quickly, and pass this legislation so that I and other Illinois families will never have to endure this horrible ordeal again.

I appreciate the opportunity to tell you our story.

Parent Testimony Supporting Bill HB 2769

Since Ethan was able to eat he has always had horrid bowel movements and stomach cramping. I cannot remember when he did not get stomach aches. The doctors explained it away as too much orange juice or too many vegetables. Ethan loves vegetables and eats all imaginable and he is a fruit lover. So often the doctor would say to give more grains to stabilize the stomach. As he grew and had several ear infections he got tubes and the ear infections continued. I thought maybe he had allergies so I got him tested and the skin prick tests came back showing nothing. But he continued to have stuffiness and drainage in his nasal passage way so I took him to the eye doctor to see if there was any odd swelling there. The eye doctor said to get him to an ENT. My doctor for two years stated he would grow and the ear infections would stop. When I changed doctors the new doctor immediately sent us to an ENT and the ENT schedule surgery for two weeks later stating Ethan had horribly huge adenoids and had a horrid case of congestive sleep apnea. At the time of his surgery his ears were full of fluid and infected and his adenoids were huge. He got tubes in his ears when they took out the tonsils and adenoids. The ENT at that time also started treating the other area we were complaining about which was a discomfort at his throat and in his stomach - she he was treated for Acid Reflux. Prior to and on our one year visit we said the medication was not working so they changed the medication and scheduled us for an upper GI. The upper GI tests were read by the ENT and he felt he had acid reflux and to be patient for the med's to work. The individual who performed the barium upper GI test asked us if Ethan's stomach was on backwards as it was taking a long time for fluid to process form his esophagus to his stomach. Our ENT said that was normal. We called the ENT in two months and complained again and he sent us back to our primary. By this time he was vomiting full meals at least 4 times a week and still always complaining of chest & stomach pain so we pushed the doctor to refer us to a GI and after two months were diagnosed with EE. After diagnosed the doctor at KUMC put us on medications but Ethan was still cramping and rather miserable. So I contacted Dr Putnum in Cincinnati and we went there 6 mnths later and Ethan is on a treatment plan. Ethan has Eosinophils in his esophagus, stomach, duodenum, small intestines. He is lactose intolerant and cannot have peanuts. But his EOS is not food allergy related so it is more up in the air of what causes his problems.

Kimberly Johnson

University of Kansas

Energy Balance Laboratory

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Written Testimony for Bill HB-2769

My name is Erin Crapser. I live in Overland Park, KS. I am the mother of a beautiful 14-year-old young lady, Morgan, who has Eosinophilic Enteropathy or EE. This disease is life altering, to say the least. My daughter lived in constant pain her whole life. Mysterious bouts of pain that due to a developmental disability she couldn't exactly locate for us. Chronic constipation, bowel impactions, joint pain, headaches even seizures were on her list of symptoms. In January 2007 she began to have trouble swallowing and began telling us very specifically that the pain was in her throat, chest and stomach. She was 12 when we received the EE diagnosis. EE is when the gastrointestinal system thinks food is a parasite and attacks by producing a white blood cell, called an eosinophils, to destroy the enemy. Instead these cells overproduce in the GI tract reeking havoc leading to the symptoms listed above. Left on its own with a constant source of fuel, food, the cells can cause serious and potentially permanent damage to the GI system.

The best treatment for a person with this disease is to go on a special hypoallergenic formula. This nutrition can maintain the person without triggering the EE process. My child was very ill and was ready and willing to do anything, we were able to get the formula easily and quickly because we have health insurance, but also have Medicaid as a secondary, since Morgan has a developmental disability. We were told insurance rarely paid, but they knew Medicaid would pay after a denial from the insurance company. At this point we were able to focus on helping our daughter get better and adjust to life without any food. We didn't have to stress about how to pay the \$2000.00 a month it was going to cost to heal her.

My first point is a money issue. How many families with insurance and Medicaid are forced to rely on Medicaid to pay for this formula, I do not know the number, but I am sure there are quite a few. These are people that pay large health insurance premiums, taxes and have coverage. Wouldn't it be better if the State didn't have to pick up the cost

of the formula? Medicaid is the payer of last resort and thank God they are, but should they have to be in this situation?

Insurance companies have many responses as to why they don't cover it, a big one is it is not a covered service. In our legalistic society we like to split hairs over wording in policies and completely ignore the intention with which they were written. "Medical food" in my mind is the same as medicine. Without this formula, my daughter could never heal; there is absolutely nothing else she can consume that would heal her esophagus and small intestine. She could consume only water and she would begin to heal, this is obviously not a valid option, she would become ill in different ways and would die without hospitalization. A five day hospital stay would cost the insurance company 15K-20K, just a little less than a years worth of formula. Interestingly enough the insurance would cover the cost of the formula while she was hospitalized. Formula is the only option, it is certainly not an easy treatment to live with, but it is the only way for her to live.

I think insurance companies should be required to cover these formulas when they are clearly the only treatment option for a disease. The burden of these expenses frequently drives families to second mortgages, second jobs, bankruptcy and eventually some even give up and quit their jobs and go on public assistance so that the formula will be covered by Medicaid. I think that insurance companies have taken advantage of gaps in the law and interpret the policies so that they don't have to pay. Now that we know this gap exists, you have the opportunity to fill in this gap and protect the people who need this formula to live.

Thank you for listening,

Erin Crapser

9638 West 116th cir
Overland Park, KS 66210

From: <JDDancer5368@aol.com>
To: <Gordon@house.state.ks.us>
Date: Sunday - February 17, 2008 7:21 PM
Subject: Heidi Dawson Speech

Oral Testimony Supporting HB 2769

Good afternoon, My name is Heide Dawson. I am a mother of 16 year old girl with Eosinophilic Gastrointestinal disorder. I thought about bringing her today so she herself could share her story. She could have told you about how this chronic condition has ravaged her body, left her with scars, indescribable pain, weeks and weeks of hospitalizations, emergency room visits, home health visits and sometimes weekly clinic appointments. She could tell you how her childhood was stolen with the progression of the disease, unable to attend school, no summer camp, no school dances, how she had to give up playing in orchestra because she was too weak to lift her violin. She would tell you that living in a food focused society, when your body rejects all food proteins is very difficult and isolating. I didn't bring her to speak to you, because the issue in front of us today is not that of EGID but instead the refusal of insurance companies to pay for the formula that is a physician prescribed treatment. My husband and I want to spare her of carrying the burden that my story of formula cost would put on her. We don't want her to know the financial burden that the cost of her formula has had on our family. We want her to concentrate on the fact that at the moment she is in remission. She is strong enough to attend school four hours a day, she is relishing in the joy of real food for the first time in years. She knows that these precious things could be ripped from her at any moment.

Would it surprise you if I told you that we consider our family very lucky? We do consider ourselves lucky. Lucky in that my daughter has knowledgeable and caring physicians at Children's Mercy Hospital who are researching and treating this newly recognised disorder. Lucky that we have a good insurance policy provided to us from my husband's employer. Our insurance covers all of our daughter's numerous hospital stays and also covers her formula when she is inpatient. She was 100% covered for the Gastro-jejunum tube surgery that was approved as a life saving procedure, she is 100% covered for all tubing and feeding bags and pumps needed to deliver her formula. She is 0% covered for the formula that goes through that pump, tubing and GJ tube. This makes no sense whatsoever, obviously the insurance company agreed with the treatment,

why house Insurance
Date: 2-18-08
Attachment # 4

else would they approve the surgery?

Our denial of coverage letter told us that our policy does not cover medical food. They call it medical food. I call it life sustaining treatment. To me, calling a special medical formula that has all proteins broken down, food. Is like calling Insulin for a diabetic child a pancreatic supplement. We all agree that denying a person with diabetes, coverage of life sustaining insulin and a way to deliver that insulin would be utterly reprehensible, yet that was the case until states began to mandate the coverage of diabetes treatment. Children with advanced Eosinophilic disorders also have a life sustaining treatment, long term elimination of all food proteins, replaced with a amino acid based formula.

The results of denial of coverage for our family has been financially devastating. For us the cost of formula has ranged from \$350 to \$1700 a month. We

have been through our entire savings, our children's college funds, and have maxed out loans from our 401 K. There have been times when we have had to discuss whether or not to make our mortgage payment to pay for formula. These are choices that no family should face. When you add the cost of formula to the fact that I am unable to work full time, so I can care for my special needs child, you have a recipe for bankruptcy.

I implore you to consider Bill #2769 and trust that you will help protect the fragile families of Kansas that have struggled with the diagnosis of EGID. That you will insist that insurance policies cover formula as life sustaining physician prescribed treatment.

*****Ideas to please picky eaters. Watch video on AOL Living.
(<http://living.aol.com/video/how-to-please-your-picky-eater/rachel-campos-duffy/2050827?NCID=aolcmp00300000002598>)

Oral Testimony In Support of House Bill 2769

Kim Johnson
Kansas City

Hello my name is Kim Johnson, I'm the mother of Ethan Johnson, age 10.

Ethan has EGID! Ethan does not have food allergies he has food intolerance.

My fear is that one day Ethan may have to have formula as his primary nutrient intake. My insurance will not cover formula. However my insurance does cover prothesis so individuals who need to walk can walk. Those who need formula need it to survive. Without the formula they will slowly suffer from malnutrition and die.

In closing it is important to note:

- Formula is not a diet the child chooses to have – it is prescribed
- If insurance does not cover formula they will spend more dollars for treatment of malnutrition and other conditions related to an individual not receiving the needed nutrients to live

Thank you and I hope you take into consideration this is a rare disease and the few children who have it will not break the banks of the insurance companies to cover their needs as again these needs are prescribed by a specialist treating eosinophilic disorders.

Thank you for allowing me to speak with you about this very important bill. I hope that you will support this bill and these children with their needs and health care needs.

Oral Testimony Supporting HB 2769

Good afternoon- my name is Leslie Seidel and I am proud to say that I am the mother of an amazing 11 year old daughter with Eosinophilic Gastroenteritis. Jessica has been on elemental formula for the past 5 years and would not be here today if it weren't for the formula. It has been her sole source of nutrition since she was 6 years old.

I am here today as one of the lucky ones. At this point in time we have formula coverage from our insurance company, but it did not come without a fight and a lot of emotional and financial stress.

When the decision was made by Jessica's doctors to have her stop consuming all food she began by trying to drink the elemental formula. At that time our insurance company denied payment based on the fact that she was able to drink it instead of it needing it to be delivered through a feeding tube and stating that it was supplemental nutrition. That is when we filed our 1st appeal and had the first letter of medical necessity written by Jessica's GI doctor sent to the insurance company.

While we were waiting for an insurance decision to be made, Jessica continued to loose weight and she became very malnourished. She was unable to consume enough formula orally to sustain her and she had a feeding tube placed into her stomach and we began delivering her formula with a pump directly into her stomach. We thought that insurance would now start paying for the formula, but we were once again denied coverage. We were told that there were many formulas available at the local grocery store that didn't require prescriptions. They refused to believe that Jessica could only tolerate the elemental formula Neocate 1+ which did require a prescription. We filed a 2nd appeal and had additional letters of medical necessity written, but we were again denied coverage.

After 6 months and being denied coverage of her elemental formula 4 times, it was starting to take a toll on our family. In addition to the huge financial strain, \$15 hundred a month for formula, and constantly fighting with the insurance company for coverage we were also trying to deal with the emotional aspects of helping a 6 year old child understand that she could not longer eat her favorite foods or have ice cream and cake at her birthday parties. That sleepovers at friend's houses were no longer an option because she was hooked up to a feeding pump 24 hours a day.

100% of our focus and attention should have been on helping our daughter deal with the major life changing challenges she was facing, not on fighting for insurance coverage for an elemental formula that she needed to keep her alive.

Our frustration finally grew to the point that my husband went to the human resources department at his company and asked for their help in fighting the insurance battle. We were very fortunate that they agreed to help.

After almost 8 months of both financial and emotional stress, our insurance company finally agreed to add elemental formula coverage to our benefits.

Your child's health and emotional well being should be a parent's main concern, not trying to figure out how to pay for a formula that they need to survive. We are asking that you move forward with Bill #2769 and allow parents to focus their attention on their ill child not on fighting an insurance battle.

We are one of the lucky ones, but it did not come without financial and emotional sacrifices.

Please make it a requirement for insurance companies to cover life saving elemental formulas.

Than you~

Oral Testimony Supporting HB 2769

Hello- My name is Jessica Seidel. I was diagnosed with Eosinophilic Gastroenteritis when I was 2. At age 6 every time I ate I would vomit, have severe diarrhea and be in horrible pain. I lost so much weight I was malnourished and very ill. That is when the doctors made the decision to put me on the elemental formula Neocate 1+. I stopped consuming all food and my sole source of nutrition was the formula. It was the only thing that was keeping me alive.

At first my parent's insurance company refused to pay for the formula saying it was considered supplemental nutrition. My parents had to file several appeals and many notes of medical necessity were written by doctors before the insurance company finally agreed to pay. Please consider moving forward with Bill #2769 requiring insurance companies to pay for elemental formula so that parents can spend their time helping their kids get better; not worrying about how to pay for the formula that is keeping them alive.

For many kids, including myself, elemental formula is not a supplement, it's what keeps us alive. We're asking insurance companies to be required to pay for life saving elemental formulas.

Thank you

Polsinelli

Shalton | Flanigan | Suelthaus PC

Memorandum

TO: THE HONORABLE CLARK SHULTZ, CHAIRMAN
HOUSE INSURANCE AND FINANCIAL INSTITUTIONS COMMITTEE

FROM: WILLIAM W. SNEED, LEGISLATIVE COUNSEL
AMERICA'S HEALTH INSURANCE PLANS

RE: H.B. 2769

DATE: FEBRUARY 18, 2008

Mr. Chairman, Members of the Committee: My name is Bill Sneed and I am Legislative Counsel for America's Health Insurance Plans ("AHIP"). AHIP is a trade association representing nearly 1,300 member companies providing health insurance coverage to more than two million Americans. Our member companies offer medical expense insurance, long-term care insurance, disability income insurance, dental insurance, supplemental insurance, stop-loss insurance and reinsurance to consumers, employers and public purchasers. Please accept this testimony as our opposition to H.B. 2769.

As we read the bill, the proponents of this legislation would mandate that all accident and health group and individual policies would be required to pay for special dietary formulas, including the treatment for phenylketonuria and amino acid based elemental formulas ordered by a physician. Since we were not approached by the proponents of the bill, we are uncertain why this mandate is needed.

Last year our organization, along with many others, worked with the Kansas Department of Health and Environment regarding additional funding for newborn screening. It was our understanding that there was necessary funding for dietary formulas for eligible individuals. We can only assume that this is not being brought by individuals who are eligible for KDHE provided formulas, but for individuals who do not qualify and have insurance. We would simply argue that if that is the case, these individuals should bear the responsibility of the costs associated with the formulas and not the entire insurance marketplace.

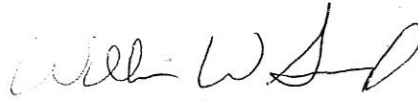
In an era when we are trying to reduce the cost of health insurance programs, we contend this bill is unnecessary and unwarranted. Thus, we would respectfully request that the Committee act unfavorably on H.B. 2769.

House Insurance
Date: 2-18-08
Attachment # 8

555 Kansas Avenue, Suite 101
Topeka, KS 66603-3443
Telephone: (785) 233-1446
Facsimile: (785) 223-1939

We are available for questions at your convenience.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Will W. Sneed". The signature is written in a cursive style with a large, stylized "W" and "S".

William W. Sneed

WWS:kjb

Larrie Ann Lower
Attorney at Law
212 SW 8th Avenue Suite 201
Topeka, KS 66603
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Kansas Association of Health Plans
Written testimony before the
House Insurance and Financial Institutions Committee
HB 2769
February 18, 2008

Mister Chairman and members of the Committee. Thank you for allowing me to submit testimony today. I am Larrie Ann Lower, Executive Director of the Kansas Association of Health Plans (KAHP).

The KAHP is a nonprofit association dedicated to providing the public information on managed care health plans. Members of the KAHP are Kansas licensed health maintenance organizations, preferred provider organizations and other entities that are associated with managed care. KAHP members serve most all Kansans enrolled in private health insurance. KAHP members also serve the Kansans enrolled in HealthWave and Medicaid managed care. We appreciate the opportunity to provide comment on HB 2769.

The KAHP appears today in opposition to HB 2769. This bill would require health plans to reimburse for special dietary formulas and amino-acid based elemental formulas. This bill is another example hard choices health plans must make when offering health insurance to Kansas individuals, families and employers.

In addition, this bill does not meet the requirements set forth in statute requiring a cost impact report be performed prior to the legislature considering a mandate bill (KSA 40-2248) and other legislation requiring the testing of any new mandate first on the state employees health plan in order to help determine its cost impact commonly called the "test track" legislation (KSA 40-2249a). As I mentioned last year, many bills have been introduced requiring increased mental health coverage, mandating hearing aids, clinical trials, colon cancer screening, autism, bariatric surgery, wigs and telemedicine coverage. All of these bills, including HB 2769, are proposals demanding that private health plans and your constituents who pay the insurance premiums pay for more services or providers. If you determine that this particular mandate is wise and more important than the others, we ask that you require the proponents to follow current law and submit a cost impact study and agree to test track the requirement first on the state employees' health plan to help protect your constituents and our policyholders from unwise and uneconomical state mandates. Thank you and I'll be happy to answer any questions you may have.