Approved: 4-2-09
Date

MINUTES OF THE HOUSE HEALTH AND HUMAN SERVICES COMMITTEE

The meeting was called to order by Chairman Brenda Landwehr at 1:30 p.m. on March 5, 2009, in Room 784 of the Docking State Office Building.

All committee members were present.

Committee staff present:
Norm Furse, Office of the Revisor of Statutes
Melissa Calderwood, Kansas Legislative Research Department
Reed Holwegner, Kansas Legislative Research Department
Janet Grace, Committee Assistant

Conferees appearing before the Committee:
Mary Lou Davis, Board of Cosmetology (Attachment 1)
Representative Lana Gordon, (Attachments 2, 3, 4, 5)
Porscha Waggle, (Attachment 6)
Linda Kenney, Bureau of Family Health, Kansas Department of Health and Environment (Attachment 7)
Charlotte Buchanan, Kansas Diabetic Association (Attachment 8)
Catherine Mangiaracina, Registered Dietitian (Attachment 9)
Melissa Rodriguez, Parent of a PKU child (Attachment 10)
Dr. Brenda Issa, Pediatric PKU Clinic KU-Wichita (Attachment 11)
Marlee Carpenter, Kansas Association of Health Plans (Attachment 12)
Bill Sneed, American's Health Insurance Plans (Attachment 13)

Others attending:
See attached list.

Chairman Landwehr called the meeting to order.

HB 2243-Cosmetology board fees.was passed from the Health and Human Services Committee to Appropriations and it pertained fees. HB 2359 - Cosmetology board written renewal examination information booklet. HB 2359 is **HB 2243** without the fees.

Hearing on **HB 2359 - Cosmetology board written renewal examination information booklet**.

Mary Lou Davis, Board of Cosmetology, provided the committee with the provision from **HB 2243** and the costs for practitioner renewal and monthly notice reminders with on-line renewal implementation. (Attachment 1)

Representative Crum moved to report **HB 2359** favorably and place on the consent calendar. Representative Morrison seconded the motion. The motion carried.

Hearing on **HB 2344 - Insurance coverage for special dietary formulas**.

Representative Gordon provided proponent testimony for **HB 2344** (Attachments 2, 3, 4, 5). The issue is the need for children to obtain special elemental formulas to sustain life. Insurance companies will pay for the formula during hospital stays, but they will not while the child is at home. This legislation is patterned after that in several other states that are requiring insurance companies to cover special dietary formulas essential to life. 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.

Melissa Calderwood, Legislative Research, provided background information on the bill and answered the committee's questions. It is commonly considered an insurance mandate. Melissa is searching for states other than Illinois that have this type of bill. There are an estimated 16 children in Kansas with this disorder, an estimated 1 in every 10,000 is diagnosed each year.

Dick Carter offered to answer any questions for the proponents-written testimony from Charlotte Buchanan, Catherine Mangiaracina, Melissa Rodriguez, and Dr. Brenda Issa.

Porscha Waggle, parent who was the impetus for this bill, provided proponent testimony for **HB2344**. (Attachment 6) The formula is an amino acid-based elemental formula. Her attachment contains the symptoms of Eosinphilic Gastrointestinal Disorder (EGID) and the need for insurance companies to cover the cost of formulas when not in the hospital. Ms. Waggle answered questions from the committee pertaining to the costs of the formula, and why the insurance company will not pay for the formula (it is a food) that is vital for 16 children in Kansas with this disease. There are several other diseases that such legislation will help. Other states are considering similar legislation.

Lasanna Waggle, mother of Porscha Waggle, provided proponent testimony for this bill. (No written testimony)

Beverly Bernadi, owner of Bernadi Dance Studio, provided proponent testimony for this bill. (No written testimony)

Representative Morrison informed the committee that 32 states are considering and/or have this bill in place. He urged the committee to do the same.

Linda Kenney, Bureau of Family Health, Kansas Department of Health and Environment (KDHE. discussed the screening that started July, 2008. (Attachment 7) KDHE now screens for all 25 metabolic disorders including PKU, though not for EGID. Two years ago the cost of formulas increased as did the number of people on them. They asked the legislature for additional funding, which they received from the Children's Initiative Fund. Ms. Kenney discussed with the committee the side effects if the formula was not provided which include retardation, a nursing home care, and eventually death.

Written testimony in support of **HB 2344** was provided by: Charlotte Buchanan, Kansas Diabetic Association (Attachment 8)
Catherine Mangiaracina, Registered Dietitian, **HB 2344** (Attachment 9)
Melissa Rodriguez, parent of a PKU child (Attachment 10)
Dr. Brenda Issa, Pediatric PKU Clinic KU-Wichita (Attachment 11)

Marlee Carpenter, Executive Director of the Kansas Association of Health Plans (KAHP), provided opponent testimony for **HB 2344** (Attachment 12). KAHP opposes this bill and reviews it as a mandate requiring health insurance reimbursement for dietary formulas. Every health insurance mandate is brought to the legislature with good intention, but as additional mandates have been enacted, health insurance companies have become limited in the types of lower costs plans they can offer. Mandates place additional requirements upon health insurance companies in Kansas and limit their ability to offer new, innovative, and lower costs health insurance products for Kansas citizens.

Bill Sneed, Legislative Counsel for America's Health Insurance Plans (AHIP) spoke in opposition of this legislation which 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. (Attachment 13) AHIP is uncertain why this mandate is needed. Two years ago, AHIP, along with others worked with the KDHE regarding additional funding for newborn screening. It was AHIP's understanding that there was necessary funding for dietary formulas for eligible individuals. There are two different coverages for in-the-hospital and outside-the-hospital which is covered by a drug coverage; price is the issue. It is a food, not a medically prescribed formula. This is for the state to address not private industry to address, one answer would to have KDHE buy the formula in bulk and provide it to the families that need it. Insurance companies reject a formula for a diagnosed problem based on pricing, the committee feels this is an issue, it is then an overall health issue that the state should spend tax dollars (KDHE) to take care of. The Committee asked Mr. Sneed to explain why some diagnoses should be paid by the state and others should be under private industry. Industry contends that it should be provided for by the state-by price.

Representative Morrison read a letter from Sandy Praeger, Insurance Commissioner, about the word "formula" to better clarify the issue discussed today. Formula is a food, not a prescription. There needs to be a distinction between food and medically-prescribed formulas.

The Chairman closed the hearing on **HB 2344**.

The next meeting is scheduled for March 10, 2009.

The meeting was adjourned at 3:00 p.m.

HOUSE HEALTH & HUMAN SERVICES COMMITTEE

DATE: 3-5-09

NAME	REPRESENTING
Kara Neill	St. Francis CMN - #2344
Marla Carpenter	KAHP
Jim Gaertner	Polsinelli
DICK CARTER	KS DIETETIC ASSN
Gary Robbins	Ks Optometric Assn
Ks. Mary Lou Davis	Ks. Bd of Cosmetology
Joe Mosimann	Hein Law
Bill Sneed	AHIP
Michelle Butler	Cap. Strategies
Samuel Forbes	UHG

Please use black ink

House Committee on Health and Human Services
March 5, 2009

Testimony by Mary Lou Davis, Executive Director

Madam Chair and Members of the Committee:

On-Line Renewal

House Bill 2243 revises one provision within K.S.A. 65-1904. The Board's request for statutory revision would allow the agency to implement on-line renewals for practitioners in the cosmetology professions.

Currently, K.S.A. 65-1904 requires the Board send licensure renewal packets to cosmetology, nail technology, esthetic and electrology practitioners. The Board currently licenses over 21,000 practitioners in these professions.

Each licensure renewal packet expense is $1.89; this is an annual expense of approximately $20,412. Should this legislation be enacted, the Board will continue to send renewal notices to practitioners. However the cost would be reduced to $0.48 per practitioner, thus potentially reducing the Board's annual expense to approximately $5,184.

Both the practitioner and agency will benefit with this law revision. The practitioner who renews on-line will more timely receive their license and the Board will have a cost savings as well as more efficiency in work processes.

Please note there is no restriction in law that will negate the implementation of on-line renewals for cosmetology, tanning and body art facilities. Currently the Board licenses over 4,600 facilities. The Board does send courtesy notices for these annual renewals and will continue this practice.

Monthly expense related to practitioner renewal

900 renewal packets	Law booklets	x	.80	$ 720	
	Envelope/label	x	.11	$ 99	
	Renewal exams	x	.05	$ 45	
	Postage	x	.93	$ 837	
			$1.89	$ 1,701 per month	$20,412 per year

Monthly notice reminders with on-line renewal implementation

900 renewal notices	Envelope/label	x	.04	$ 36	
	Renewal exam/letter	x	.10	$ 90	
	Postage	x	.34	$ 306	
			.48	$ 432 per month	$5,184 per year

HEALTH AND HUMAN SERVICES
DATE: 03/05/09
ATTACHMENT: 1

Representative Lana Gordon
District 52

300 SW 10th, Room 142W
Topeka, KS 66612

785/296-7652
gordon@house.state.ks.us

March 5, 2009

Dear Health Committee Members:

I am here today to testify in favor of HB2344. Last year, my constituent, Porscha Waggle, brought a matter to me concerning her son who has a condition (eosinophilic disorders) 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.

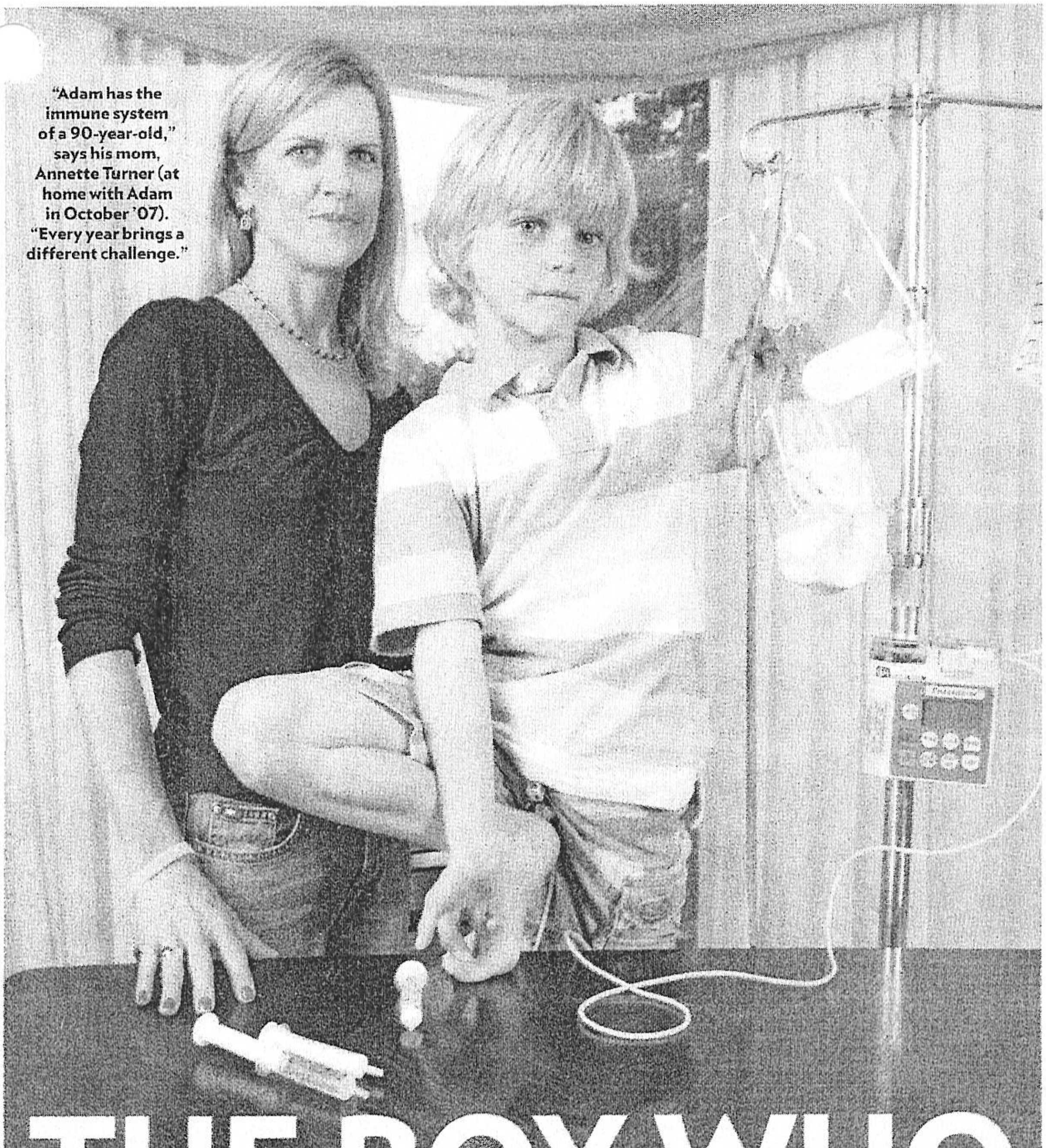
Porscha shared with me that she is trying to do her best to set a good example to her children by staying in the workforce rather than relying on the welfare system with which she would have her son, Christian's formula covered. It is a shame that insurance companies are more willing to cover in hospital 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 2344. Thank you for allowing me to come before you today.

HEALTH AND HUMAN SERVICES
DATE: 03/05/09
ATTACHMENT: 2



"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

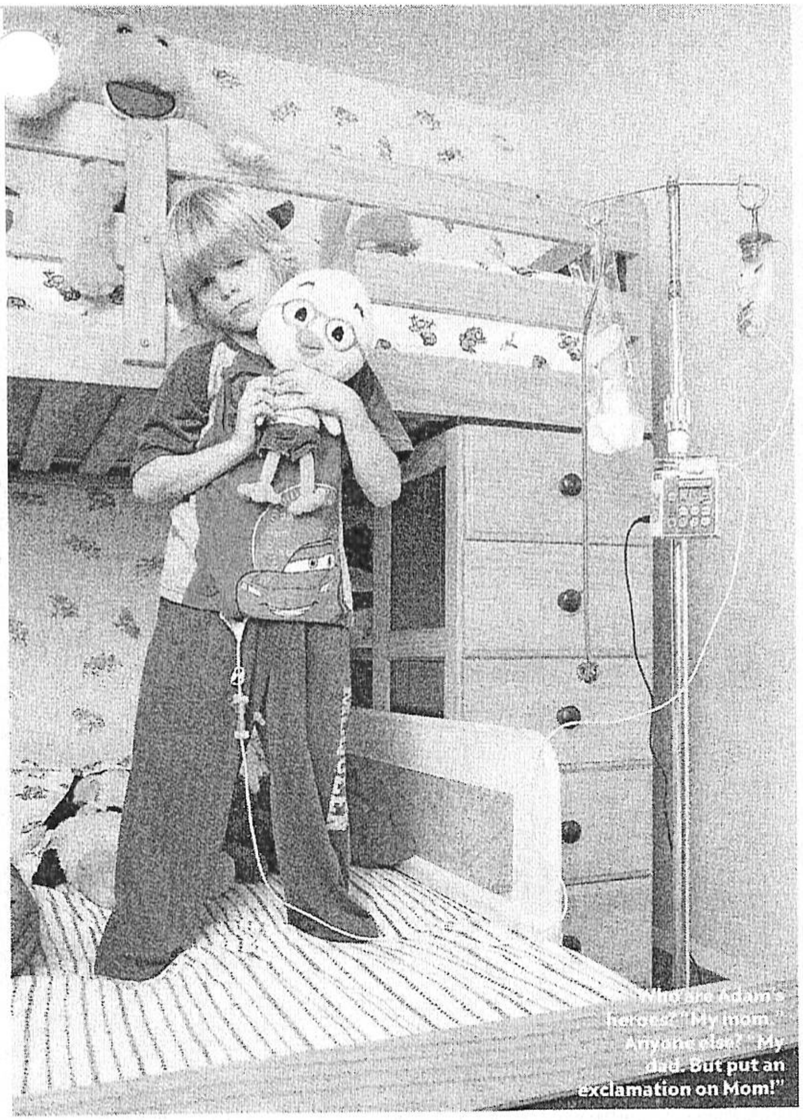
Mealtimes used to be torture for Adam Turner, who is allergic to nearly every kind of food. But this feisty second-grader has a huge appetite for life

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,

Photographs by RACHEL WATSON

HEALTH AND HUMAN SERVICES
DATE: 03/05/09
ATTACHMENT: 3



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

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 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."

B-2

BlueCross BlueShield of Kansas

1133 SW Topeka Boulevard
Topeka, Kansas 66629-0001

www.bcbsks.com

Premier Blue

JAN 17 AM 9:56

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

HEALTH AND HUMAN SERVICES
DATE: 03/05/09
ATTACHMENT: 4

(1)

Pediatric
Associates
Of Topeka, P.A.

3500 SW Sixth Ave., Topeka, Kansas 66606 (785) 235-0335
Business Office (785) 235-0104

Dennis M. Cooley, M.D., F.A.A.P.
David J. Nichols, D.O., F.A.A.P
Greggory J. Van Sickle, M.D., F.A.A.P
Tara Pridgett, M.D., F.A.A.P.
Rendi Kersting, ARNP
Debra Mackey, ARNP

February 27, 2008

RE: Christian Ramirez
DOB: 032205

To Whom It May Concern:

The above named child is a patient of mine with the diagnosis of eosinophilic esophagitis and eosinophilic gastroenteritis with delayed stomach emptying. He has had extensive evaluations by numerous pediatric gastroenterologists throughout the country. He needs to be on Elecare formula 28-30 cans per month. This is his sole source of nutrition.

Sincerely,

Dennis M Cooley

Dennis M. Cooley, MD, FAAP

DMC/bjc

HEALTH AND HUMAN SERVICES
DATE: 03/05/09
ATTACHMENT: 5

GORDON

Written and Verbal Testimony

From:
Porscha Waggle
7410 SW 22nd Ct
Topeka, KS 66614

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 three year old son Christian has a rare disease, the umbrella term is called Eosinphilic Gastrointestinal Disorder . Since I was here last year, Christian has further been diagnosed with a terminal Mitochondrial disease Complex I, III, and IV. Nutrition is imperative to the longevity of life, it is paramount with the diseases that Christian has.

Symptoms of EGID vary widely, but include
Nausea or Vomiting
Diarrhea
Failure to thrive
Abdominal or chest pain
Reflux
Difficulty Swallowing
Food Implications
Gastroparesis
Anorexia
Bloating
Anemia
Blood in Stools
Malnutrition
Difficulty Sleeping

Not the life I am sure that you or anyone wants to live, much less a three year old little boy. There is no "CURE" for EGID, but treatment in the form of an elemental diet can help alleviate symptoms and prevent further damage to the gastrointestinal tract.

Children and adults who rely in part, or completely, on elemental amino acid bases formula may have a difficult time drinking enough formula, to maintain proper nutrition, some require tube feedings directly into the stomach. In the most serve cases nutrition is administered directly into the blood stream. My son is on of the child that are on the elemental diet. Christian also has a feeding tube in his stomach. The feeding tube administers the elemental diet, otherwise knows as Elecare or Neocate. This diet was not prescribed as a band-aid to his disease. The Elecare was prescribed to keep my son alive. Yes, it must be prescribed by a physician. Without the administration of Elecare on a daily basis. Christian would have to be hospitalized to receive this nutrition. Elecare is a MEDICALLY COVERED EXPENSIVE WHILE IN THE HOSPITAL. He should not be forced to be placed in the hospital to receive his nutrition. He is a little boy who loves to pretend he is a power ranger, and play with his dog. 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 or normalcy he has in his life is not fair. If Elecare is a medically covered expense as a hospital inpatient, why does BCBS deny him coverage upon discharge? Since being placed on Elecare and having his feeding tube, Christian has flourished. He has put on some weight, has had less Dr and ER visits. and most importantly is being a little boy.

HEALTH AND HUMAN SERVICES
DATE: 03/05/09
ATTACHMENT: 6

I do want to acknowledge BCBS and their position. However, how can Elecare be a covered expense while in the hospital, yet non covered upon release? Furthermore, it is in the financial best interest to cover Elecare 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 five years old and has autism. I could sit back, receive ***state*** assistance and be financially in a more comfortable position. All of Christian's medical needs would be covered, including the Elecare. 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 knows in her heart what the future looks like for my son. A life of scopes, surgeries, doctor appointments, ER visits, therapy sessions, hospital stays, medications that do not cure, and physical pain. I feel helpless and hopeless some days. But all I have to do is see the fight in Christian and I can do anything. I can hold Christian when he cries in pain, I can assure him that the pain will subside, and I can try to bring sunshine and more fight into his heart. What I cannot do is to stop the muscle loss, his slow loss of daily activities, the future of a wheel chair and the loss of his life. I nor Christian signed up for this life. No parent of a special needs child got into a line and said, "Yeah, this sounds like fun, sign me up." For every difficult moment with a child with special needs comes strength and love. I trust that there is a bigger reason than myself or my child can understand while on this earth that children must suffer. I have been given the strength to fight for Christian and other children like him. I will never stop fighting. Without fight there is no hope, without hope there is no joy. Childhood is meant to be joyous. I stand before you begging that you pass this legislation so that my son can continue to flourish in his home and not inside the walls of a hospital. Begging that my son receive the needed Elecare so that he may stay with our family for a longer period of time. Christian will probably not attend his senior prom. He does not know the simple joys of birthday cake, pizza or a cheeseburger. 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 they can have. Please pass HB2344.

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

Porscha Waggle

Written Testimony
Marc E Rothenberg, MD, PhD
Cincinnati Children's Hospital Medical Center

Madam Chair and Members of the Committee, My name is March 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 2344, 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 the 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, eosiniphilis respond to food and flood 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 the 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, and elimination diet is prescribed where eliminate all positive allergy foods from their diet. In some cases, this involved removing many common foods from the child's diet, without leaving adequate source of sustainable nutrition. Many of these children require the addition of an amino acid-bases 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 diagnostic measure to determine which food are causing the disorder. An elemental diet is composed of no proteins, which means no food since all food have some protein.

Elemental formula are composed of man-made synthetic amino-acids. These formulas allow the body to heal and the 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 is no other option for that patient. These formulas are medically necessary and coverage for them shouldn't be dependent on a 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 though an enteral tube.

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

I strongly offer my support for House Bill 2344
Dr Marc Rothenberg, M.D

Dear Representatives of the Kansas Legislator,

I am writing you today to urge you to please pass House Bill 2344, which deals with Kansas Insurance paying for Elecare/Neocate Formula for children with life threatening diseases. My god son Christian Ramirez has EGID) and Mitochondrial Disorder, and has been on Elecare/Neocate for two years. Christian Ramirez is a little boy who is almost 4 years old and has had to endure more pain and sickness than any of us can imagine. Christian has been sick since he was born and has been in and out of the hospital ever since. His family has had to spend countless hours in the hospital, at doctors appts or on the phone with them updating how he is doing. About a year and half ago the doctors said Christian was no longer able to eat food and was to only have Elecare/Neocate Formula to provide him nutrition. How devastating news to a parent that their child is no longer able to eat food, no longer able to have his own birthday cake, no longer able to just enjoy a piece of pizza or some ice cream. On top of the devastating news the parents learn that the average cost of formula per month is about $1300 and will only go up as the child grows. On top of the huge medical bills and travel, they now have to come up with a huge amount of money a month to just feed their child. Ever since Christian has been on Elecare/Neocate Formula he has had fair less hospital stays and his EGID disease has been under better control.

I am asking you to please pass Bill 2344 to help Kansas families with very sick children who just want to feed their children and can not afford too. Many people will argue that this is the same as insurance not paying for babies formula but its not. Elecare is something that a doctor prescribes and the only thing that is helping keep these children stay out of the hospital for repeated stays. Covering Elecare/Neocate Formula would pay for itself by just keeping a child out of the hospital for one visit a year. Another argument is that the children could go on Medicare and that the formula would be paid for under that. At a time when our country is in such deficit I don't see why anyone would urge someone to go on Medicare when they don't need too. These families don't want the tax payer to pay for their child's health care or to rely on the government for assistance. Most of the families wish to stay on their own private insurance but it makes it very hard when the only way you can feed your sick child is to spend $16,000 a year on life saving formula, and that's not including all the other medical expenses and travel they must also pay. Please help these families who so desperately need this formula covered under their private insurance plan. These families have already gone through so much and should not have to worry how they will come up with an extra $1300 a month just to feed their sick child. I urge you to please pass House Bill 2344.

Thanks,
Jill Burkhart

6-5

1904 SW Edgewater Ter
Topeka, KS 66604

I am writing in support of Kansas Bill Mandating Elemental Formula.

Elemental formulas are a primary treatment option for Eosinophilic Disorders.
There use helps to relieve the suffering and symptoms patients with these disorders have including chest pain, choking, shortness of breath, nausea, vomitting, searing reflux, and failure to thrive. Treatment with these amino acid formulas helps to allow the body to heal, provide nutrition, and help patients getter better faster. Their use helps to reduce costly hospital admissions and reduces other medical costs. It helps to give those afflicted a chance to get back to a quality of life. Whether someone drinks it orally (taste is quite awful) or has it by tube fed, the formula is the same.
In esoinophilic disorders, in a small limited subset of patients, this is their only choice to live except costly and riskier intravenous nutrition. Many use this to heal and start to retrial foods back into their life.
My daughter is now eating a limited diet after the short term use of elemental formula.
She was so ill, she was in a wheelchair and could no go to school at 15 yrs old. She was in severe pain and short of breath. Prior to that she had been an honor student and could rollerskate for 12hrs a day on a competetivie level.

Thank you

Vivian Sarubbi RN
Public Health Nurse.

To whom it may concern,

My son Aidan-Michael has an EGID called 'Eosinophilic Gastroenteritis'. Aidan has had difficulty receiving nutrition due to being allergic.

These formulas are necessary for my son.

I'd like to communicate my support for 'HOUSE BILL NUMBER 2344'.

Imagine not being able to feed your child normal food, coupled with going into financial ruin due to the cost of the elemental formula he/ she requires for survival and relief of wasting.

My best regards,

John Dodge

Written Testimony Supporting HB 2344

I am writing you today on behalf of House Bill 2344. This bill is something that is close to my heart and I also take deep pride in supporting. My nephew Christian Ramirez is but one of the many children that this bill will help.

My nephew Christian Ramirez might appear to you as a normal healthy 3 (almost 4) year old boy. But the inside his poor little body is worn out and tired. His body has to fight daily to hold on to all of it's nutrition. Not the normal nutrition you and I get to indulge in, Christian gets his nutrition by a formula called Elecare. Elecare is administered through a feeding tube in his stomach. Christian does not know a different life, his "normal" is having to be fed formula through a tube. This is not a baby formula you can just go pick up at the grocery store. The formula he is fed has to be ordered directly from the manufacturer. Even without the middleman the formula is extremely expensive. This formula is also not covered by his BCBS insurance (unless the child is hospitalized).

For Christian not to receive this formula. is like telling a cancer patient "no, you cannot have your chemo or radiation". Or telling a diabetic, "no, you cannot have your insulin". There is not difference, life saving medical treatment is life saving medical treatment. The formula is keeping these children alive and thriving and most importantly, out of the hospital. Christian's journey through this life has, is, and will be a long hard battle. Our family recognizes that the day will come when we have to say goodbye to Christian and let his little body be at peace. Please do not make the time we have with him be in a hospital room. Your support of this legislation, will allow Christian and those children to spend their childhood at home.

Thank You
Patsy Waggle

Ellyn Kodruff
2937 Bayberry Drive
Buffalo Grove, Illinois 60089
(847) 793-0071

Madam Chair and Members of the Committee, **I am here today to testify in support of House Bill 2344** – 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 years. Her esophagus and stomach are finally healing and her gastrointestinal system has stopped bleeding -- more importantly her biopsies have come back with drastically reduced levels of eosinophils. A high level of eosinophils in your blood can cause damage to your organs – Jori's level of eosinophils have gone from a dangerous level of 39% to a now normal level of 7%. Our daughter has lived for over 4 years 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.

I would like to thank Rep. Ryg for authoring the bill. It means so much to me and all those who are in our situation. Thank you for your leadership on this issue.

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. Our doctor ordered her diet to be 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, she was in-fact 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.

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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 want 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 logically, they are willing to pay for the surgery, the hospital cost, the complications, the maintenance, and on top of all that – the formula. But they have refused to cover 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's 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 now creates a healthier adult which I'm sure would cut down on future medical bills.

It's difficult for me to put into words what our family has gone through. We didn't and some times still don't know how we're going to feed Jori. She has no safe foods and absolutely has to be on an elemental diet. We have taken out personal loans in order to care for our daughter. And still, we fight each week to find the resources to feed our young 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 and emotional agony but our daughter is healthier and thriving and we are so happy for that.

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

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.

Written Testimony Supporting HB 2344

Thank you for letting me write to you today and for you to allow me to show my support in Kansas House Bill 2344. This House Bill is in honor of my nephew Christian Ramirez. Christian is the youngest grandchild (of 4 grandsons) in our family. However, for being the youngest he has had to endure more then all 4 of the grandsons will ever have to endure.

Since Christian's birth he has been a fighter and he still refuses to give up. Without the life saving nutrition from the Elecare Formula, no amount of fight inside of him would be enough to survive. Our entire family knows without Elecare, Christian would be spending most of his days in the hospital or possibly not even be here today.

Christian suffers from EGID, which has damaged his GI tract. Due to the damage he has to be fed 53 ounces a day of Elecare Formula through a feeding tube in his stomach. The one thing that comes to mind when you think formula is nutrition. Then I think of how Blue Cross & Blue Shield of Kansas chooses not to give Christian the life saving nutrition when he is not hospitalized.. Yet, when he is hospitalized BCBS will pay for the formula. I do not understand the logic. Having Christian at home is less expensive for everyone. This is not a life Christian has choosen for himself. That being said he should not be forced to spend his 4 year old days inside hospital walls, when he can be at home.

One last item I would like to bring to your attention, BCBS of KS will cover all of Christian's feeding supplies, and they covered his feeding tube surgery yet, will not cover what goes through that feeding tube that is keeping him alive. So please help me stand up for these sick children (there are many more like Christian). They do not deserve to grow up in a hospital to receive the nutrition that they need to survive.

Sincerely,

Duane Bo Waggle

My three year old son has a rare disorder that does not allow his body to tolerate any food proteins. Until we were able to get an accurate diagnosis for him, he was a miserable little boy who was not growing or developing properly. He hurt too much to be able to sleep, his weight was not even on the growth chart, and he was delayed in cognitive development in several areas.

Food proteins cause his body to react with inflammation. All food has some protein. After being diagnosed, he was put on an elemental formula that has the proteins totally broken down into amino acids. This allows his body to take in nutrition without triggering inflammation. His diet consists totally of elemental formula (which is nutritionally complete) and water or ice.

Since he started on an elemental formula diet, he has gained weight and is now at the 50th percentile for weight and height. He is happy and pain free for the first time in his life. He sleeps all night long. His speech and cognitive development have made great gains.

David's formula costs about $2000 a month. We have five children and normally have to budget very carefully to make ends meet. We have no way to afford elemental formula, out of pocket, long term.

I respectfully request that you pass Kansas HB 2344 for insurance coverage of Amino Acid based elemental formula.

Thank you,

Kara Hanna

My dream when I entered college was to become a lawyer, a judge and then a United State Congresswoman. However, life had grander things in store for me. Those things were to become a Mom and most importantly to become a Grandma. I was born to be a Grandma.

I have four little beautiful boys in my life; Jonathan age 8 (healthy as can be), Anthony age 5 (he has autism), Alec age 5 (he has a disease called Sphereosytosis) and Christian age 3 (he has two life threatening illnesses). Explaining the love and devotion I have to these four boys is like trying to explain the thrill of the sound of thunder to one that cannot hear, or the beauty of a sunset to one that cannot see. There truly are no adequate words. They are the loves of my life.

Christian is the sweetest, kindest, and strongest of the four boys. He smiles when I know he wants to cry. He gives kisses when I know he would rather lash out. And most importantly he fights when every odd is stacked against him.

This bill is not for an experimental treatment. This bill allows Christian and other children like him to receive a formula to live. Christian's life is not the normal life of a three year old. When I take him and his brother and cousins to the grocery store, they are wanting pudding, ice cream and chocolate bars. Christian hangs his head and says, "I can't have those, can I Grandma?". The answer never changes, the answer is always no. So, we scour the store on an adventure looking for that special thing Christian can have on his limited food trials. We will pretend that we are all Indian Jones looking for Christians treasure. Many boxes are read (yes, every ingredient must be read), many boxes are put back on the shelf until we find that treasure. Without Elecare there would be no adventures, there would just be hospital walls.

I understand that Elecare and other formulas like it are expensive. However, from a fiscal stand point BCBS of Kansas will save money by covering the formula outside of the hospital. Christians formula costs $49.31 per day. You can barely get an aspirin inside of a hospital for that amount of money. Christian spent four days in the hospital at a cost of $22,000.00. Forget the cruelty of forcing a child to be hospitalized to receive life saving nutrition. From just a dollar and cents stand point, this bill makes perfect fiscal sense.

As I stated, Christian fights with all odds stacked against him. The present odds of this bill passing are against him. He needs your voice, your vote to stand up for him and other children like him. You took an oath to your office. The good people of Kansas entrusted you to protect us, to put our best interest before that of big companies. I was born to be a Grandma, were you truly born to lead and fight for your fellow Kansans?

Thank you,
Rossanna Waggle
2400 SW Valleybrook LN
Topeka, KS 66614

To Whom It May Concern,

My son has eosinophilic esophagitis and was diagnosed last summer. (2008). However we have been dealing with gastro issues two years prior to diagnosis. Due to serious food allergies, Ryan, was not gaining any weight and only put weight on after supplementing his limited foods with elecare. Currently he is receiving ONLY elecare formula due to the food allergies, and has gained significant weight on the formula only.

Without this formula he was well below weight as compared to children his age. He was below the 4th persentile meaning 96% of children his age weighed more than he. Once on this formula for 5 weeks (without other foods present) he has gained 2 pounds and now he is in the 10th percentile. (Now only 90% of kids his age weigh more than him.) He also has more energy and we can see he is continues to grow.

We support the bill to insure that insurance companies can cover this medical necessity for children and adults alike. If our little ones do not gain the necessary weight or get the appropriate nutrition, they will suffer and will in turn have other medical issues arise. Without the formula and with continued eating of some foods, these children have damage done the the esophagus creating more medical problems.

Thanks you for planning on passing this bill.

Brandy Jones
bwmisspriss@yahoo.com
mom to Ryan, 3 year old with EE (eosinophilic esophagitis)

Dear legislstors,

I am writing in support of Kansas House Bill 2344. My husband and I, both native Kansans, have two children with eosinophilic esophagitis. This is a disease in which their bodies reject most food. We rely on amino acid formulas to nourish our youngest daughter, who cannot eat any food. The cost of these formulas are astronomical. We pay $2,000 a month for just one child. We are a middle-income family, and the cost of the formula is a strain on our budget. The insurance company pays for other treatments like medicine, but they are often reluctant to pay for a treatment that is as simple as an amino acid formula. This bill would make a difference in the lives of those who rely on the formula to survive.

The insurance companies are making record profits, so covering this formula for the minimal number of families who need it wouldn't be a stretch for them but would make a huge difference in the lives of the families. Thank you for supporting this bill.

Sincerely,
Renee Martin-Kratzer
reneemk@gmail.com

Dear Lawmakers,

My son Asher, now 5, sufferers from eosinophilic esophagitis, which is a severe form of food allergy. He is allergic to nearly all foods. Elemental formula is his primary source of nutrition and the only thing which keeps him alive. However, it is not covered by my insurance and it costs $1,200/month. I recently lost my job and I still need to spend the $1,200/month to feed my son.

Asher's doctor has confirmed that the elemental formula is medically necessary for Asher. Like insulin for diabetes is also medically necessary. Why is elemental formula not covered under insurance? How can insurance companies cover the cost of viagra for men yet deny coverage to keep a child alive by feeding him elemental formula?

As a parent, I beg you to support this bill.

Sincerely,
Elizabeth Ruben

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My name is Sharon Goldin, and I have 3 boys with extensive medical conditions. All 3 boys have a primary diagnosis of Mitochondrial cytopathy. As a result of their disorder, 2 of the boys Jake, (14) and Clayton (10) are g-tube dependent. They rely on an amino acid-based elemental formula called Elecare. The reason they must use Elecare versus other formulas is that they have eosoniphilic gastroenteritis and gastroparesis and they are unable to digest and break down whole proteins. In addition, they are allergic to almost all foods. They do not have typical allergic reactions, like hives or welts. They have severe GI and internal reactions. They develop stomach pain, diarrhea, vomiting (although Clay is unable to throw up do to significant stomach surgeries he has undergone).

Clayton's first diagnosis, back when he was 3 months of age was eosoniphilic gastroenteritis. He has been on elemental formula since he was 3 months of age and received his first g-tube at the age of 18 months. Up until the age of 3 Clayton ate nothing but the elemental formula. From the ages of 3-10 he ate a very limited diet, always supplemented by formula. Starting again last May he became 100% g-tube dependent and dependent on the elemental formula. His stomach is unable to process any other formula.

Jake, was first diagnosed with an eosinophilic disorder at the age of 13 when he weighted 54 pounds. He had a g-tube placed in June of 2006 and was placed on Elecare formula and now currently weighs 90 pounds. Prior to his g-tube and being placed on Elecare Jake had constant stomach pain, and in fact missed almost 80 days of school in 2006 due to constant GI problems. Since he started on the Elecare he has thrived and is currently on the honor roll in his freshman year of high school.

To be honest for many years I never worried about the cost of formula as I did have insurance coverage from the time Clay was 18 months until this January, when we switched to United HealthCare. Despite my boys being 100% g-tube dependent and the fact that it is medically necessary, the boys have been denied formula coverage. As such I pay more than $1,500 a month to provide the formula for my boys. As a single mother of 3 boys, all with a chronic and potentially fatal medical conditions, this places an additional burden on my family and severe financial hardship, despite the fact that I work, earn a good living, and have medical insurance. I know many insurers will cover the formula if the kids are g-tube fed, well my boys are g-tube fed and it is still not covered. My boys are g-tube dependent as their body cannot absorb the nutrients any other way.

However, just because a child is g-tube dependent, it should not be the determining factor for formula coverage. If it was not medically necessary for my boys to have g-tube, I would not have put them through the procedures just to get formula coverage. No one should have to go thru a surgical procedure SOLELY to ensure that they get their child's sole source of nutrition covered.

In our case without the formula my boys may not be alive. They cannot exist without the formula as it is the sole source of their nutrition.

My boys have been through so much in their short lives. It is bad when you have a 10 year old child who walks into the hospital and can tell the nurse his exact diagnosis, where to place his IV and exactly what he is allergic to, including latex. Clayton has been scoped so many times in 10 short years I have lost count. He has undergone 2 major stomach surgeries.

About ½ my income the last 3 years has gone to cover my boy's medical expense – almost $45,000 a year, granted not all for formula, but also for medications, co-pays, feeding supplies, and the like.

Without mandated insurance coverage for formula many families will sufferer financially, and this will result in bankruptcy, severe financial hardship and kids suffering because their parents are unable to pay for the formula that sustains their lives. Without their elemental formula my boys and others like them would thrive and would be much sicker and thus place a more severe financial burden on the insurance companies. While Elemental formula will not CURE my kids underlying mitochondrial disorder, it has allowed them to grow and be much healthier and have a much better quality of life. Elemental formulas are medically necessary for many children and insurance companies should have to cover their costs no matter whether a child drinks them or is g-tube fed. It is not a supplement or food, it is medically necessary to sustain the lives of my boys...

I strongly support this legislation. Please act quickly, and pass this legislation so that I and other Maryland families will never have to endure this horrible ordeal again or go bankrupt trying to take car of our children.

To Whom it May Concern:

It is with strong support of HOUSE BILL 2344, that I urge you to consider the absolute need for your support of this bill as well!

I write to you today as a mother of 4 children suffering from Eosinophilic Diseases. This disease has caused significant mental, physical, emotional, and financial down fall for our family. It is completely devastating, as you can imagine. I cannot stress how absolutely imperative it is that you realize and consider the need for Formula coverage in this state. Although 2 of my children require special amino acid based formulas, Neocate Jr and Elecare, one of my children is completely life dependent on it.

A few short months ago our youngest son was diagnosed as "Failure To Thrive" as he was less than HALF of the size he should have been for his age at 12 months. Upon such diagnosis, it was discovered that he had Eosinophilic Esophagitis, triggered by multiple severe food allergies. My son could NO LONGER EAT! Food was hurting him, causing him to "lose his battle" with his disease! My son did not function as he should, he lacked energy, stamina, and over all quality of life. Due to the Amino Acid based formula, Elecare, my son is now thriving! He has DOUBLED in size, he has hit all of his "mile stones" that he was lacking, but more importantly has a quality of life he had yet to experience! He is now a happy healthy little boy, normal in EVERY way, with exception to the fact....he cannot have food. Our hope is that one day, with research and a lot of faith that he will have a "normal" food diet and be able to enjoy the simple things like a birthday cake or a sucker, but for now.....we count on Elecare Formula.

Our older son is on a very restricted diet, one that does not always allow total balance and nutrition. He suffers from Eosinophilic Esophagitis as well as Eosinophilic Gastroenteritis. He MUST have Neocate Jr in his diet if he is to remain healthy and continue to grow. Without it, his health will deteriorate significantly.

I ask you to consider what life would be like without food, without basic proper nutrition? I ask you to consider the daily battle this must be? If something so simple, that is readily available, such as Amino Acid Based formula's, can help these children, why are we fighting for it? The answer to all of these questions is quite simple....

Formula coverage, whether orally taken or tube fed, is necessary! I cannot stress enough how important it is that you support this Bill on behalf of all of the families with a story like mine. I urge you to do the right thing and make our daily battle a little less by supporting and passing House Bill 2344.

Best Regards,

Stephanie A. Bocanegra, mother of

McKenna, 9 yrs, Eosinophilic Esophagitis

Noah, 6 yrs, Eosinophilic Esophagitis and Eosinophilic GastroEnteritis....Neocate Jr.
Olivia, 2 1/2 yrs, Eosinophilic Esophagitis
Ethan, 1 1/2 yrs, Eosinophilic Esophagitis...Elecare dependent

Dear Representative,

Thursday you will be asked to vote on HB 2344. I am writing to ask that you vote in favor of this bill. Legislation requiring insurance companies to provide coverage for medically necessary amino acid based formulas is important to me because I have two children with eosinophilic esophagitis. The sole treatment for their condition is an elemental diet of Neocate One Plus. Pharmaceutical treatments are available for the condition, however they are not appropriate for all patients and they do not always eliminate the need for an elemental formula.

Insurance companies typically exclude coverage for these formulas, which are designated as medical foods, indicating that they do not pay for food under their plans. However, these formulas are not food as you and I know it. They must be lab created. The FDA's definition of a medical food reads as "a food which is formulated to be consumed or administered enterally under the supervision of a physician and which is intended for the specific dietary management of a disease or condition for which distinctive nutritional requirements, based on recognized scientific principles, are established by medical evaluation." There is no way that a parent could go to the grocery store and purchase the ingredients to make an elemental formula at home.

The cost of an elemental formula is beyond the reach of most families. When purchased directly from the manufacturer, which is cheaper than purchasing from a pharmacy or medical store, the cost to purchase the amount of formula that is prescribed to my two boys is $1840 for a 30 day period.. That is an annual cost of $22,080. When insurance companies refuse to pay for elemental formula that is medically necessary, families are forced to make tough decisions. Many will purchase their child's formula through online auctions, taking the chance that they are purchasing something other than the real thing. Other families will forego the medically necessary treatment which will lower the quality of, and sometimes endanger, the life of their child because they simply cannot afford the expensive treatment despite the purchase of medical insurance for their family. Please ensure that the children who need these medically necessary elemental formulas will have access to them by voting for the passage of this bill and encouraging your fellow Representatives to do the same.

Thank you for taking the time to hear my plea for assistance on this matter.

Sincerely,

Kendra Tiedemann

Dear Representative,

Thursday you will be asked to vote on HB 2344. I am writing to ask that you vote in favor of this bill. Legislation requiring insurance companies to provide coverage for medically necessary amino acid based formulas is important to me because I have two children with eosinophilic esophagitis. The sole treatment for their condition is an elemental diet of Neocate One Plus. Pharmaceutical treatments are available for the condition, however they are not appropriate for all patients and they do not always eliminate the need for an elemental formula.

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The cost of an elemental formula is beyond the reach of most families. When purchased directly from the manufacturer, which is cheaper than purchasing from a pharmacy or medical store, the cost to purchase the amount of formula that is prescribed to my two boys is $1840 for a 30 day period.. That is an annual cost of $22,080. When insurance companies refuse to pay for elemental formula that is medically necessary, families are forced to make tough decisions. Many will purchase their child's formula through online auctions, taking the chance that they are purchasing something other than the real thing. Other families will forego the medically necessary treatment which will lower the quality of, and sometimes endanger, the life of their child because they simply cannot afford the expensive treatment despite the purchase of medical insurance for their family. Please ensure that the children who need these medically necessary elemental formulas will have access to them by voting for the passage of this bill and encouraging your fellow Representatives to do the same.

Thank you for taking the time to hear my plea for assistance on this matter.

Sincerely,

Kendra Tiedemann

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To Whom it May Concern:

I write today in support of House Bill 2344. As a father of 4 children suffering from EGID's, 2 requiring Amino Acid Based Formula's, I urge you consider the significance of this bill.

Although 2 of my children require formula, one is completely dependent on it as he is not allowed ANY food as it is like poison to him. Elecare Formula has saved my son from a life of constant pain, sickness, and failure to thrive. Elecare has allowed him to grow and meet milestones he had yet to make. He is a healthy normal child now, with exception to the fact, he cannot have food.

Your support and passing of House Bill 2344 will ensure quality of life for children that suffer from disease and illness like mine. It will ensure availability to families that cannot afford it any other way. Formula coverage for children, both orally taken and tube fed, is necessary and should not be questioned. These families deserve the health and nutrition that House Bill 2344 will provide.

Respectfully,

Michael Bocanegra
Father of 4 EGID children, 2 on Amino Acid Based Formula's, one dependent.

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KANSAS
DEPARTMENT OF HEALTH
AND ENVIRONMENT

Kathleen Sebelius, Governor
Roderick L. Bremby, Secretary

www.kdheks.gov

Testimony on HB 2344
Insurance Coverage for Special Dietary Formulas

Presented to
House Health and Human Services Committee

By
Linda Kenney
Director, Bureau of Family Health

March 5, 2009

Chairman Landwehr and members of the House Health and Human Services Committee, my name is Linda Kenney, Director of the Bureau of Family Health at the Kansas Department of Health and Environment. Thank you for the opportunity to provide written testimony on HB 2344 which would mandate insurance coverage of special dietary formulas in Kansas.

While our Children with Special Health Care Needs (CSHCN) program has never covered eosinophilic formulas, from the late 1960's through 2006, CSHCN has covered the full cost of metabolic formulas for newborns identified through our State screening program. CSHCN covered formulas for Phenylketonuria (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 on families of purchasing treatment formula is considerable. Families who pay full cost for the formula can pay $8,000 to $10,000 per year or more. Even those who receive assistance on a sliding fee scale from KDHE may experience significant financial burden. However, the costs of doing without formula are significant: brain damage, mental retardation, severe neurological complications and even death.

At the present time, CSHCN has approximately 20 out of 63 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. Even though we would expect

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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 initiated screening for the 29 conditions recommended for all State programs. The cost of metabolic formula is expected to increase with this expansion.

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 age or other 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 again for the opportunity to provide this information to the committee.

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KANSAS DIETETIC ASSOCIATION

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Written Statement to the
House Committee on Health and Human Services
In support of
House Bill 2344
March 5, 2009

Chair Landwehr, and members of the committee: I write to you today as the state policy representative for the Kansas Dietetic Association. Part of my role as a registered dietitian is to provide nutritional therapy to patients with Phenylketourina (PKU). PKU is the most common genetic disorder affecting 1 in 13,000 births. It is a rare metabolic disorder lacking the enzyme to breakdown an amino acid called Phenylalanine (PHE), which is found in all foods that contain protein. Too much PHE intake causes high blood PHE levels, resulting in mental retardation, microcephaly, delayed speech, seizures, eczema and behavioral abnormalities. At present, our clinic follows 37 patients living in Kansas who are diagnosed with PKU. We have seen 5 newly diagnosed infants in the past 6 years.

The only treatment for PKU is following a very specialize lifelong diet consisting of PHE free formulas and low protein foods. These formulas must be prescribed and supervised by a physician. Registered dietitians work closely with the prescribing physician to calculate proper formula amount for each Individual patient. PKU patients need this required formula to ensure proper growth and development while avoiding complications (listed above).

Some Insurance companies have denied coverage for treatment stating that nutritional supplements are not covered. However, the same insurers may cover tube feedings, which are often used in a hospital setting and could also be classified as a nutrition supplement. At this time, PHE free formulas are the primary and most effective treatment for PKU. Any alternative to the PKU nutrition formula would be considered mismanagement of the disease.

There are many other states have enacted similar legislation to cover a medical drink beverage (often called formula). Formula cost can range from $300-800 per month depending on the formula amount and type. This cost does not include the special low protein foods also needed for diet variety and normalcy. Many times, this cost causes a financial burden to the patient and could result in decreased nutrition therapy compliance.

As a registered dietitian, I support HB 2344 because specialized PKU formulas are medically necessary and should be coverage by insurance. I am available to answer questions regarding this matter.

Charlotte Buchanan RD, LD, CNSD
KU School of Medicine – Wichita
620 N. Carriage Parkway
Wichita, Kansas 67208
316-962-7386
buchrd@cox.net

Terry Koch-Menge, MBA, RD, LD, Executive Director, 8921 Quail Ridge, Lenexa, KS 66220-3445
Phone/Fax: 913-742-8365 Email: kda_exec@dietetics.com

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Written Statement by Catherine Fox Mangiaracina
House Committee on Health and Human Services
In support of House Bill 2344
March 5, 2009

Chair Landwehr, and members of the committee, the state of Kansas recently initiated the New Born Screening Program. This program identifies infants with disorders that require specialized formula. These formulas have been designed and formulated to treat a specific disorder. One of the most common examples is that of phenlyketonuria, or PKU. Prior to newborn screenings, these infants and children were damaged by a regular diet of baby formula or breast milk. These children were severely cognitively impaired and were sent to state institutions. We are now identifying more and more infants with other life threatening disorders that also require specialized formula.

Because these disorders are rare, the formula can be very costly to a family. These special formulas can not be given to any infant. They are very specialized and could cause serious medical problems if given to a normal, developing child.

By supporting this bill, families can be assured that if their child is identified by newborn screening, help and support are available.
Families should not have to go into debt because they have a special needs child. But rather, insurance companies should provide for basic medical care of these infants and children. I have work with special needs children for over 30 years and have seen many families suffer because they did not have money to buy specialized formulas for their infant and children.

Please support House Bill 2344.

Catherine Fox Mangiaracina

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House Committee on Health and Human Services

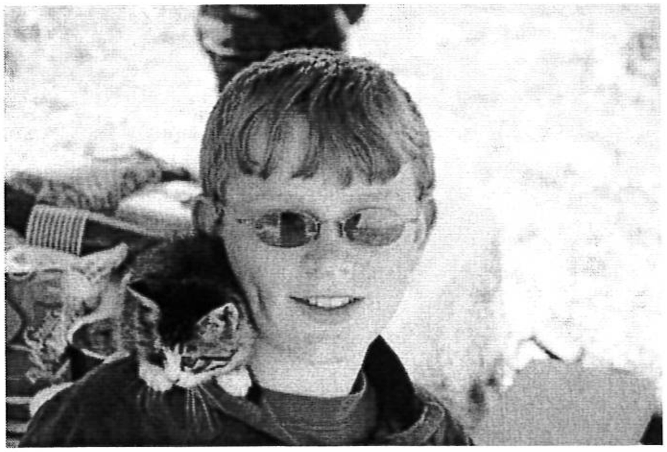
Written Statement by Melissa Rodriguez

Supporting HB 2344

March 5, 2008

Good afternoon Chair Landwehr and members of the committee. My name is Melissa Rodriguez, my husband and I have a 14 year old son that has PKU his name is Dusty. Up until March of 2006 our son was able to obtain his medically necessary formula (Phenyl-Ade) paid for through Special Health Services through the state of Kansas, in September of 2006 a hearing for HB 2971 halted this assistance. The Phenyl-Ade costs $620.00 for 1 box that contains 4 cannisters, one canister lasts our son for 3 days. Some insurance companies cover the formula, however others do not, one of these insurance plans includes the State of Kansas insurance. As you can well imagine paying 100% for this formula creates a hardship for families that deal with PKU on a daily basis. The low protein food that is required for these individuals is also very costly and like the formula may or may not be covered by insurance, and again creates yet another hardship for these families. My family and I are in support of HB 2344 that would make it possible for these families to actually feel like they can provide for their child, without this formula a child would not grow and develop normally resulting in more costs for the government and the ultimate cost for the children and families directly impacted.

Thank you for your time,
Melissa, Tom, Dusty Rodriguez and Family
1603 7th Ave.
Dodge City, KS. 67801
620-408-5108



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Written Statement to the

House Committee on Health and Human Services

in support of

House Bill 2344

March 5, 2009

Chair Landwehr, and members of the committee:

This is a statement regarding House Bill 2344 and the requirement it would make on insurance companies to cover the payment of medical formulas as it would other prescription medications. As a physician who cares for children and adults with phenylketonuria (PKU), I am writing in support of this Bill. I have worked with many patients and their families who have struggled to pay for this medical treatment. It is a financial burden on the family, which could become an increased financial burden on society in the future. In some cases, the implications of a person with a certain medical diagnosis not taking his/her prescription medication may be detrimental. If ever there was an example of such a diagnosis, PKU is it. Over the past several years, I have seen many patients who did not comply with his/her medical treatment and the outcome is always less than optimal. Typically, the reason for noncompliance is financial. These patients always end up requiring more time and resources in the long term due to the problems that may manifest if inadequate treatment is an issue.

As you know, PKU is a genetic metabolic disorder of protein metabolism that affects 1:19,000 infants in the United States. This disorder is due to a defect in the enzyme responsible for the metabolism of phenylalanine, which is an essential amino acid. As a consequence of not being able to utilize or breakdown phenylalanine, blood and tissue concentration of phenylalanine are greatly elevated resulting in an accumulation of toxic phenylalanine metabolites. If left untreated, a person with PKU suffers irreversible and progressive brain damage. Manifestations also include: profound mental retardation, neurological, cognitive, and psychological disorders. High phenylalanine levels can lead to: learning disabilities, behavioral disturbances, lowered IQ, impaired attention, depression, anxiety, phobias, irritability, difficulty remembering things in the short term, slowed processing of information, delayed speech, slowed reaction time, and difficulty in decision making, problem solving, and planning.

PKU and other inborn errors of metabolism require medical treatment with a special prescription formula and a very specific diet. At this time, the standard of care and the only effective treatment available for PKU is strict dietary control of phenylalanine intake. This is accomplished by restricting high-protein foods such as meats and dairy products while simultaneously allowing low protein medical foods, fruits and vegetables, and minimal quantities of low-protein grains. This stringent diet restricts consumption of natural or whole protein. The majority of the patient's daily protein intake must therefore come from phenylalanine-free medical foods in the form of formulas, drink mixes, capsules etc., which provide all the other essential and non-essential amino acids. Without these amino acid-based products, a patient with PKU would experience malnutrition. On the other hand if a patient follows a 'regular' diet, he/she will develop irreversible profound mental retardation and the other manifestations listed above.

Like any other medication if compliance with the medication is an issue, the outcome is not optimum. When a medication cost as much or close to the amount that a family takes home in a year, compliance is always an issue. When a family is unable to afford a treatment, they are less likely to comply and all of the manifestations listed above are the potential outcomes.

We are not asking insurance companies to pay for an experimental treatment or even to pay for a medication where the benefits are not known. The treatment for PKU has been proven and with appropriate treatment these patients have the potential to become productive members of society as opposed to becoming a burden on society. With the appropriate treatment these people are able to live healthy and productive lives.

As required in all 50 states PKU is screened for at birth, due to the fact that if it is diagnosed early, the treatment will prevent profound mental retardation. It is not enough just to diagnose this. We must

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support these patients and families in dealing with this diagnosis. It is our responsibility to provide these children a chance to be successful. They deserve a chance at life just like any other member of society. They should not be discriminated against just because the treatment for their illness is a 'dietary supplement' or is in the form of a formula. Currently, this medical treatment is the only option for treatment of PKU. I cannot think of a diagnosis where if appropriately treated the outcome is so much better than if left untreated.

In clinic today I saw a newborn and her parents in consultation for the baby's newly diagnosed PKU. This is a young family just starting out in life with a healthy 6 year-old boy and now a newborn girl with a diagnosis of PKU. They are now trying to educate themselves about PKU and all the questions and implications that go along with this diagnosis. Where did it come from? Why our family? No one in our family has this diagnosis, why our little girl? Is my little girl going to be retarded? The list goes on and on. After discussing the inheritance pattern and why treatment is so important, I then discussed with them how the medical treatment is effective and how if treated early, their child will be able to live up to her full potential. They were obviously relieved to know that this was diagnosed early and that they will be able to provide treatment for their child. Sometimes it is much more difficult to explain to families why the treatment for PKU is not always covered by insurance companies. To a young family, it seems obvious that they will do whatever they can for their newborn to have the best life possible. Getting a grasp on the diagnosis is only one hurdle, now they have to try to understand why insurance companies do not feel that the treatment for PKU is as important as for other illnesses.

Thanks for taking the time to consider another point of view and for supporting these patients and their families. We should applaud the few insurance companies who – after carefully considering the facts – do decide to provide payment for the medical treatment of PKU.

Sincerely,

Brenda Issa, MD
Assistant Professor
Pediatric PKU Clinic
University of Kansas – School of Medicine – Wichita
Pediatric Faculty Clinic

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Kansas Association of Health Plans

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March 5, 2009

HB 2344
Before the House Health and Human Services Committee
Marlee Carpenter, Executive Director

Chairman Landwehr and members of the Committee;

I am Marlee Carpenter, 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 the majority of 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 comments to this committee.

KAHP is here today to oppose HB 2344, a mandate requiring health insurance reimbursement for dietary formulas. KAHP members are dedicated to providing low costs health insurance to Kansas citizens. Each additional coverage or provider mandate that is enacted, the cost of health insurance is increased and health insurance plan's ability to provide new, innovative and lower cost health insurance products is restricted.

There is much debate around the cost of health insurance mandates. While actuaries, insurers, and health economists agree that virtually all mandates increase the cost of health insurance, the magnitude of their effects has been subject to debate. The Council for Aforadable Health Insurance estimates that mandated benefits currently increases the cost of basic health coverage from a little less than 20% to more than 50%, depending on the state and its mandates.

Every health insurance mandate is brought to the legislature with good intention, but as additional mandates have been enacted, health insurance companies have become limited in the types of lower costs plans they can offer. Mandates place additional requirements upon health insurance companies in Kansas and limit their ability to offer new, innovative and lower costs health insurance products.

The KAHP requests that as you look at newly proposed health insurance mandates that you consider the impact they will have on the health insurance market and ability to offer cost effective insurance products to Kansas citizens.

Thank you for your time and I will be happy to answer any questions.

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Polsinelli Shughart PC

Memorandum

TO: THE HONORABLE BRENDA LANDWEHR, CHAIR
HOUSE HEALTH AND HUMAN SERVICES COMMITTEE

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

RE: H.B. 2344

DATE: MARCH 5, 2009

Madam Chair, 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. 2344.

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.

Two years ago 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 disfavorably on H.B. 2344. We are available for questions at your convenience.

Respectfully submitted,

William W. Sneed

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