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☞ Details: Legislation requiring insurance companies to cover medically necessary treatment for phenylketonuria (PKU)

(FORM UPDATED: 08/11/2010)

WISCONSIN STATE LEGISLATURE ... PUBLIC HEARING - COMMITTEE RECORDS

1995-96

(session year)

Assembly

(Assembly, Senate or Joint)

Committee on Insurance, Securities and Corporate Policy...

COMMITTEE NOTICES ...

- Committee Reports ... **CR**
- Executive Sessions ... **ES**
- Public Hearings ... **PH**

INFORMATION COLLECTED BY COMMITTEE FOR AND AGAINST PROPOSAL

- Appointments ... **Appt** (w/Record of Comm. Proceedings)
- Clearinghouse Rules ... **CRule** (w/Record of Comm. Proceedings)
- Hearing Records ... bills and resolutions (w/Record of Comm. Proceedings)
 - (**ab** = Assembly Bill) (**ar** = Assembly Resolution) (**ajr** = Assembly Joint Resolution)
 - (**sb** = Senate Bill) (**sr** = Senate Resolution) (**sjr** = Senate Joint Resolution)
- Miscellaneous ... **Misc**

Dave Plombon

STATE REPRESENTATIVE



68TH ASSEMBLY DISTRICT

TO: All Legislators

SEP 20 1995

FROM: Rep. Dave Plombon

DATE: September 21, 1995

Re: Extended deadline for co-sponsorship of LRB 3069/2 requiring insurance companies to cover medically necessary formulas and foods for people with PKU.

Due to increased interest in LRB 3069/2, the deadline for co-sponsorship has been pushed back to Friday, September 29th. If you are interested in signing onto this bill, please call 6-9192.

Darry - Talk to Ins Co about this one -

Analysis by the Legislative Reference Bureau

This bill requires every health insurance policy (called "disability insurance policy" in the statutes), including health care plans offered by health maintenance organizations, preferred provider plans and the state, and every self-insured health plan of the state or a county, city, village, town or school district, to provide coverage of any special medical formulas, specially formulated foods or other products that are prescribed by a physician as medically necessary for the treatment of an infant or child with coverage under the policy or plan who has any of a number of diseases specified in the bill, including phenylketonuria (PKU). Every such policy or plan must also provide coverage of any special medical formulas, specially formulated foods or other products that are prescribed by a physician for a pregnant woman with coverage under the policy or plan who has PKU for the protection of the fetus. Specifically excluded from the requirement are health insurance policies that cover only certain specified diseases, health care plans offered by limited service health organizations, medicare replacement or supplement policies and long-term care insurance policies.

For further information see the ***state and local*** fiscal estimate, which will be printed as an appendix to this bill.

Health Ins.

Kelly -

Tasha Weber BC/BS

258-3347
414 226-5264

FAX 258-3359

Madison office: P. O. Box 8953, Madison, WI 53708-8953 ■ 608/266-9172

Legislative Hotline: To leave a message or find out legislative information, call toll-free 1-800-362-9472

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Cheryl Evans
Rt. 1 Box 121A
Boyd, WI 54724

NOV 08 1995

November 5, 1995

Dear Representative Albers:

I have two children, Garrett 6 and Brittany 4 months, who suffer from a rare genetic disease called Phenylketonuria (PKU). They are unable to metabolize phenylalanine, an amino-acid found in most foods. The treatment consists of specially made medical foods which are quite costly; at present my insurance company does not cover this much needed prescription food.

The outcome, if this strict diet isn't followed, is mental retardation or other serious medical problems.

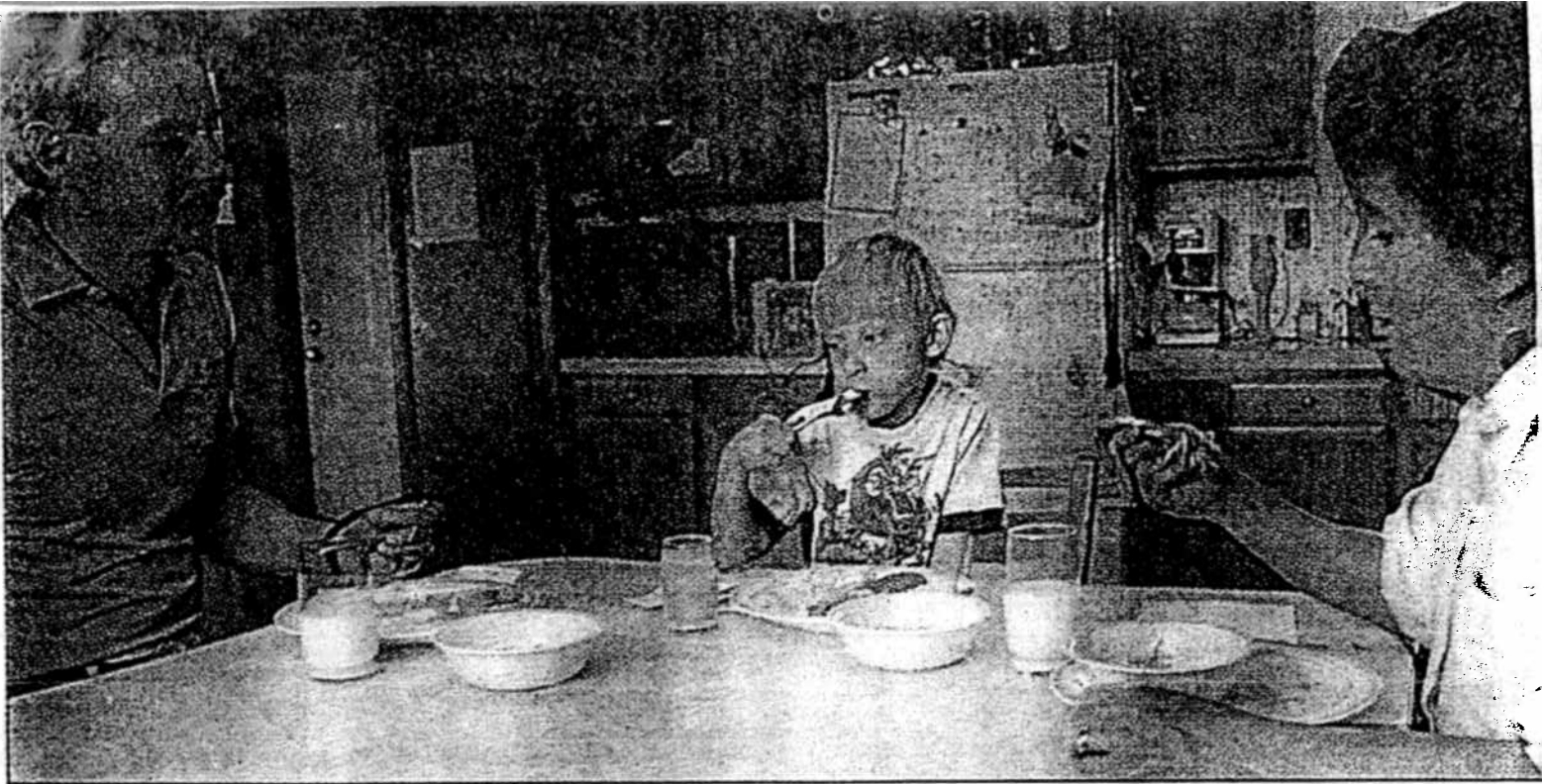
I implore you to support Assembly Bill 620 "Garrett's Bill" authored by Dave Plombon. Please consider holding a public hearing on this matter, my family and other PKU families would greatly appreciate it.

Thank you so much for your time.

Sincerely,

Cheryl Evans and family

Cheryl, Darwin, Garrett, and Brittany Evans



Staff photo by Brian Pault

Darwin and Cheryl Evans of Boyd try to make foods appealing for their son Garrett, 5, despite his disease that requires special food.

Family fights for son's special food

State cuts could take away needed funding

By Janean Marti
Chippewa Falls News Bureau

BOYD — Hot dogs with all the fixings. Sizzling golden french fries from McDonald's. These are a few of Garrett Evans' favorite things.

But Garrett hasn't had a hot dog since he traded a Tater Tot to a child for one bite two years ago while his parents weren't looking.

And if he has one order of those golden french fries, he faces the rest of the day eating specially made low-protein food that, truth be told, doesn't pack quite the flavor punch of regular food but is ludicrously expensive.

While most 5-year-olds are learning their ABCs, Garrett's life is ruled by the letters PKU.

PKU is short for phenylketonuria — a disease in which the body cannot metabolize the amino acid phenylalanine. Since all proteins contain phenylalanine, Garrett cannot eat meat or dairy products or just about any food that a 5-year-old would like to eat. If he consumes more than a minute amount of protein in a day, he risks brain damage and mental retardation.

Garrett takes a lot of this in stride — he has been known to turn down a plate of chocolate cookies offered by a well-meaning relative who wasn't aware of his diet restrictions. And he happily shares his special chips and crack-

Costly Food

Here are the costs of some of the low-protein food items that Garrett Evans eats:

- Bread, one 10-inch loaf, \$5.
- Macaroni, 8-oz. box, \$8.50.
- Baking mix, 14-oz. box, \$8.
- Peanut butter flavoring, one pint, \$20.
- Six cans of formula (two week supply), \$91.

ers with a visitor, pushing them shyly across the kitchen table in a silent offering of friendship and welcome.

Parents Darwin and Cheryl Evans take it in stride too and have learned to cook creatively for Garrett. Cheryl rolls, cuts and bakes special crackers and "chips"; she whips up concoctions using artificial cheese or artificial peanut butter flavoring.

If the family is eating fish, Cheryl will fix a special potato dish, shaping it like a fish so Garrett doesn't feel left out. She has, in essence, become a chef for her little boy, cooking five to 12 hours a week just for Garrett.

Some of the assistance the Evanses used to receive to help pay for special foods has been taken away.

And the Evanses fear that more cuts could be coming, including elimination of the program that provides them with some of the

basic, low-protein foods Garrett must eat. If the basic food stuffs are no longer free, then they could not afford to buy the cheese substitute or artificial chocolate flavoring that the boy loves to mix in his formula "milk" because the straight formula tastes so bad.

"We don't know what will happen if they cut the funds," said Darwin Evans, who attends the Chippewa Valley Technical College and drives school buses for the Stanley-Boyd school district.

The state distributes eight different special food items to PKU sufferers, including noodles, pastas, baking mix and formula, said Elizabeth Suckow, a pediatric dietitian with Marshfield Clinic who is assigned to Garrett's case. The money for the special foods comes from a newborn baby testing fee that all new parents pay. All newborns are tested for PKU.

All the rest of the foods, such as the peanut butter flavoring that costs \$20 a pint, that the Evanses want to use to give Garrett a varied and tasty diet must be purchased by the family.

"People with PKU have to have the formula. And it is very, very expensive. They can't live without it and develop normally. If Garrett did not have his special food, he would become slower or remain at the mental state he is," Suckow said.

A person with PKU can consume regular food items but not enough in one day to keep an active 5-year-old satisfied. For instance, if Garrett were to eat regular bread, he could eat only one-sixth of a slice a day, Suckow said.

See GARRETT, Page 2

Rare diseases carry little clout

GARRETT
from Page 1

"When your child is saying, 'I'm hungry,' and you can only give them one-sixth slice of bread, that won't fill them up," Suckow said.

The Evanses' fear that budget cuts could eliminate all state help is a realistic one, Suckow said. "The funding will not necessarily end, but they have a right to be worried."

The state changed the way it assists funding for children with PKU, said Wynne Cook, care coordinator with the Chippewa County Public Health Department.

Cook has worked with the Evanses in the For U program for special health needs children, which helps find resources for families with children with special health-care needs.

Budget cuts may affect certain programs, including the Women, Infants and Children program, which provides assistance for children and infants up to 5 years of age, Cook said.

"I don't want people to think we are whining and want to get something for nothing," Cheryl Evans explains.

"We don't want people to think we are lazy and don't want to cook for him," she said.

The family weighs and measures all Garrett's food, figuring out how much protein each foodstuff has so they can carefully control his protein intake to a maximum number of grams per day.

"The Evanses have done beautifully," Suckow said. "They have been excellent parents. They work on measuring his foods. They continually try to come up with creative ideas for Garrett's meals."

Cheryl Evans has worked as a nursing assistant for Clark County for 12 years, and her group health insurance has paid for Garrett's medical costs unrelated to PKU. State grant money pays for the monthly \$75 to \$100 blood tests Garrett must undergo.

But if the state cuts funding for special foods altogether, the Evanses say they could never afford to feed Garrett at the cost of \$2,000 a year for his formula and another \$2,000 a year for the other food items.

To compound their fear, Cheryl is expecting another child in July. Since PKU is an inherited condition, the new baby also could be affected.

The Evanses' dream is that state laws would be changed to mandate that insurance companies pay for medically necessary foods as is the law in 15 other states.

Cheryl's insurer, Blue Cross-Blue Shield of Wisconsin, has denied coverage for Garrett's special food costs, even though his pediatrician, Sharon Mabe of the Marshfield Clinic, has written a prescription indicating that the special foods are a medical necessity to prevent Garrett from permanent brain damage.

Some insurance companies do provide coverage for the special foods and others do not, Suckow said. She

"As a society we are better off paying for these foods than caring for Garrett if he incurs permanent brain damage"
—Thomas Starr, attorney

likens PKU patients needing special foods to diabetic patients who need insulin.

On behalf of the Evanses, attorney Thomas Starr has filed an appeal with Blue Cross-Blue Shield seeking payment for the special foods.

"Cheryl's insurance policy provides coverage for prescription leg-end drugs and certain non-legged drugs and supplies as approved by Blue Cross-Blue Shield when used in medical treatment," Starr said.

"My argument is that the special foods are a medical supply. The foods are not an experimental treatment but a proven and effective treatment used for 20 years."

Client confidentiality laws prohibit Blue Cross-Blue Shield United of Wisconsin spokesman Tom Luljak from discussing the Evanses' case. But Luljak said the general policy of the company is not to pay for food products with the exception of those used in intravenous feedings or certain tube feedings.

"(Food products) are over-the-counter products and do not need a prescription. It is our policy not to pay for any over-the-counter products," Luljak said.

The policy was developed based on industry standards, and most insurance companies do not pay for over-the-counter food products, even if they do cost more than non-specialty food items, Luljak said.

For instance, insurance companies do not pay for low-sugar products that some diabetics are required to eat, Luljak said.

"If you open the door to (paying for some specialty food products), then do you do that for everyone who has special dietary needs?" Luljak said.

State Rep. Dave Plombon, D-Stanley, helped the Evanses get assistance from the University of Wisconsin Hospitals when some of the funding for the PKU program was cut.

Plombon is mulling over drafting legislation that would mandate that insurance companies pay for the low-

protein foods, but he would prefer to work out the problem through the state insurance commissioner.

"This is why you buy health insurance — for unanticipated things like this. I find it appalling that the insurance company does not cover this," Plombon said. "These foods are budget busters for these families."

Insurance is supposed to protect the person against unforeseen circumstances like this. That is why we all pay insurance premiums.

Garrett Evans' case is another example of the health-care crisis in this country," Plombon said.

Many residents housed in state institutions for the developmentally disabled at state expense were born with PKU but before state-mandated testing and the discovery that low-protein foods could keep the condition under control.

Suckow said many residents at the Northern Wisconsin Center for the Developmentally Disabled were impaired by PKU. Cheryl Evans cares for twin brothers at the nursing home where she works who are mentally impaired because they have PKU.

"As a society we are better off paying for these foods than caring for Garrett if he incurs permanent brain damage," Starr said.

If Blue Cross-Blue Shield denies the Evanses' appeal, they could take the insurance company to court.

"But an appeal trial costs money. I don't know if they can afford to fight an insurance company in court," Starr said.

The Evanses face a political problem because only one in 15,000 people are born with PKU, meaning

there are few people but there lobbying for insurance coverage for PKU special food items, Starr said. Other specialized illness groups, such as people with kidney disease who needed dialysis, have successfully lobbied for insurance coverage, but groups with very rare diseases often don't have that kind of clout, Starr said.

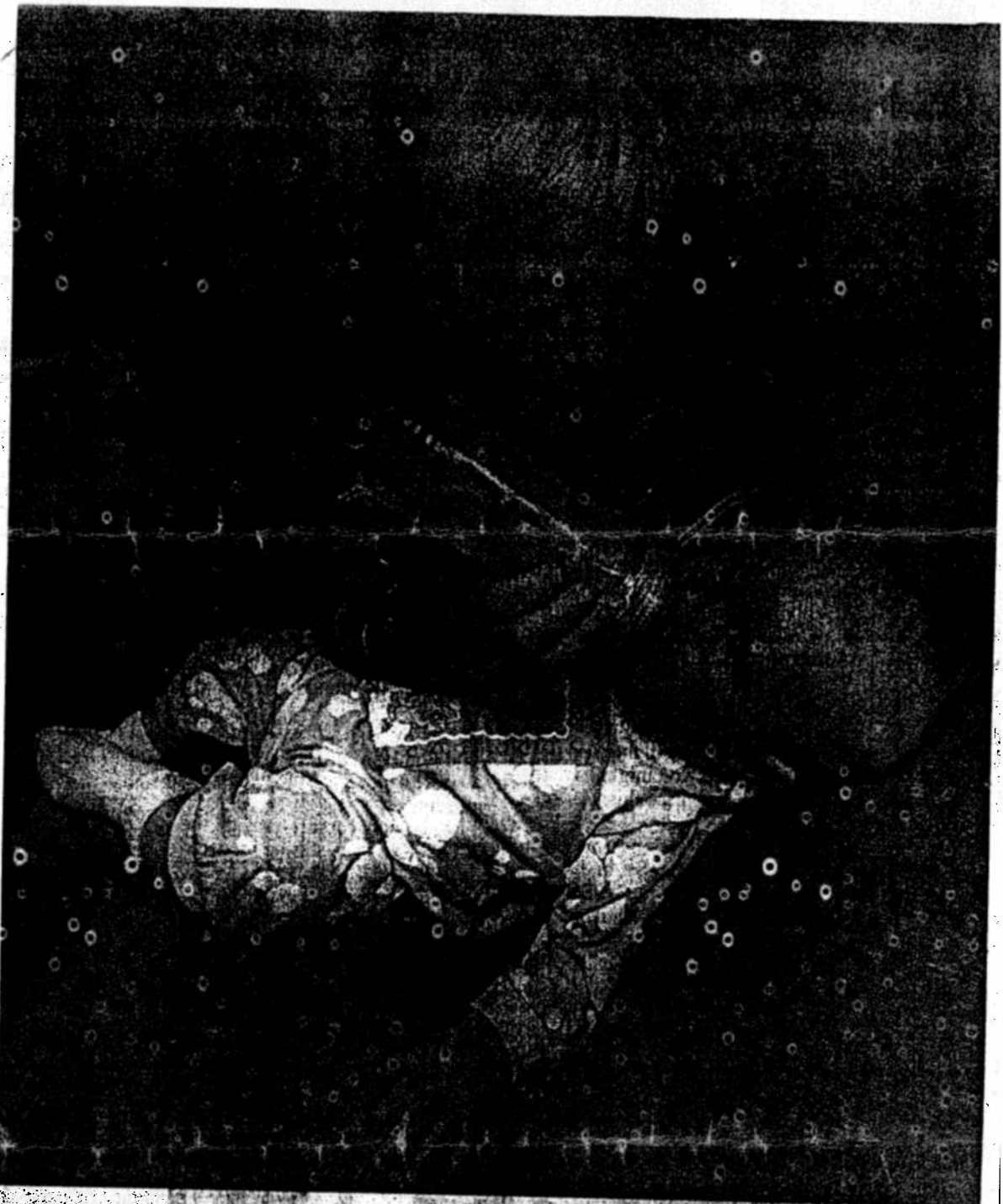
The Evanses also wish all food manufacturers were required to accurately label foods, including the amount of protein contained in each serving of a product.

But most of all, they just want their son to continue to grow and develop into a happy, healthy adult.

"Children with PKU can be perfectly normal children if their protein level is controlled. If your child is going to be a genius, he will be a genius even if he has PKU if his special dietary needs are met," Suckow said.

It is sometimes frustrating — all the measuring, reading labels, special cooking and cautioning day-care providers, relatives and teachers about the dangers to Garrett if he eats something with too much protein, the Evanses say. When they go on a camping vacation or to visit relatives, they must mail food ahead to make sure it is available for Garrett.

But Cheryl Evans says nothing is as frustrating as worrying that someday they might not be able to afford to feed Garrett.



Oct 05

Garrett Evans, 6, and his three-month-old sister Brittany must eat special foods because of a disease that won't allow them to eat meat or dairy products.

Staff photo by Jeff Thompson

Matter of life and diet

Proposed law would make insurance pay tab for special foods needed by disease victims

By Janean Martl
Chippewa Falls News Bureau

CHIPPEWA FALLS — Six-year-old Garrett Evans would rather show visitors his new swingset than sit indoors and talk about a legislative bill named after him.

As a matter of fact, Garrett doesn't pay too much attention to talk about new legislation introduced by state Rep. David Plombon, D-Stanley, that could

help Garrett and other children with diseases that require special foods.

Garrett has phenylketonuria, or PKU, a genetic disease in which the body cannot metabolize the amino acid phenylalanine.

Because all proteins contain phenylalanine, Garrett cannot eat meat or dairy products or just about any food that a typical 6-year-old eats.

The problem for Garrett's parents,

Darwin and Cheryl Evans, is that the special foods that Garrett's doctor says Garrett, and his 3-month-old sister, Brittany, need to eat to prevent mental retardation are incredibly expensive.

The special bread Garrett eats costs \$5 a loaf; an 8-ounce box of noodles, \$8.50; a two-week supply of formula for Brittany, \$91.

Garrett, Brittany and others with PKU

See 5000 Page 2A

Issue is fairness, family says

tening to a special interest who has a vested financial interest in seeing that this does not pass.

The bill has been referred to the Committee on Insurance, Securities and Corporate Policy

she said. Other diseases or conditions covered in the proposed legislation include tyrosinemia, homocystinuria, maple syrup urine disease, propionic acidemia and methylmalonic acidemia.

"You just can't buy this food off the shelf. We are trying to give these children some sort of quality of life," Plombon said. "I'm hopeful my colleagues will look at the necessity of the bill instead of its-

"The insurance companies have avoided covering this type of condition because they know it is expensive. —Dave Plombon, legislator

insurance companies have avoided covering this type of condition because they know it is expensive. The idea they would cover my medication for a heart condition but not cover medically necessary food for a child is unbelievable."

Darwin said his children need the special food to live, terming it a "medical necessity."

"I thought that was what insurance was for — for covering things like this," Darwin said.

Half the states mandate insurance coverage for certain types of conditions, including PKU, that require medically necessary foods, Plombon said.

The Evanses say families with PKU children and other conditions requiring special foods are rallying around Plombon's bill. It is much cheaper for insurance companies to pay for the special foodstuffs than to pay to house people who are developmentally disabled in special care institutions, Cheryl said.

"Would they want to pay the costs of institutional care instead?"

FOOD from Page 1

must have the special "milk" formula to develop normal intelligence. And because the expensive formula tastes so bad, Garrett begs his mom to add the special artificial chocolate flavoring to the formula.

"This formula makes me gag just mixing it up," Darwin said.

Trouble is, Cheryl said, the family cannot afford to buy the chocolate formula and the company that provides Cheryl's health insurance coverage will not pay for even the basic special foods, such as bread, let alone the "luxury" special food items, like the chocolate or peanut butter flavoring.

Plombon's bill would require every health insurance policy to provide coverage of any special medical formulas, especially formulated by a physician as medically necessary for the treatment of an infant or child who has one of a number of diseases, including PKU.

Earlier this year a spokesman for Blue Cross-Blue Shield United of Wisconsin, Cheryl's insurance carrier, said the general policy of the company is not to pay for food products with the exception of those used in intravenous feedings or certain tube feedings. To do so, Tom Luljak said, could open the door to paying for foodstuffs for every person with special dietary needs.

Diseases included in Plombon's bill "require very expensive medically necessary food" that can break the budget of the average family, Plombon said.

The bill for Garrett's special foods is \$2,000 to \$4,000 a year.

"You take that off the top of an income of \$20,000, which is the median income in my district, and that is a big bite for families. It puts a lot of strain on families," Plombon said.

"The important issue is that the

November 9, 1995

Darwin and Cheryl Evans
Rt. 1 Box 121A
Boyd, WI 54726

Dear Mr. and Mrs. Evans:

Thank you for sharing your story with me. It is important for legislators to be reminded of the real stories behind the legislation that is proposed in the legislature.

I will send a notice to you to let you know when a hearing is scheduled, and if you are able to come to Madison, you may wish to testify.

Best wishes to your family.

Sincerely,

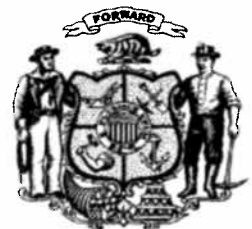
Sheryl K. Albers
State Representative
50th Assembly District

c: Representative Dave Plombon

What bill?
Pit bill #



WISCONSIN STATE LEGISLATURE



11/9/95

Rep. Cheryl Alben
P.O. Box 8952
Madison WI 53708

Cheryl:

Am writing in regard to
"Harrett's Bill", and to ask you to
please support the Assembly Bill

A B-620 and also to hold a
public hearing in that regard.

As a grandmother of Harrett and
Brittany, I have close contact with
them, a constant reminder of their
special needs. A lot of "Help" is
needed to carry on. Thank You!

Sincerely,

Grandma Smith

Helenette A. Smith
3011 Apple Ave., Rm 46
Chippewa Falls, Wisconsin
54729

18:20 11/09/95 EAU CLAIRE



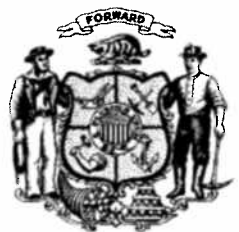
Rep. George Allen, Chair

P. O. Box 8952

State Capitol
Madison, Wisconsin 53708



WISCONSIN STATE LEGISLATURE



PKU Briefing Paper

Phenylketonuria (PKU) is an inherited enzyme defect found in most population groups with incidence in the USA of about 1 in 16,000 live births. As a result, phenylalanine, an amino acid used by the body to make protein, accumulates in the blood. If untreated, this disorder produces mental retardation, which is usually severe, extreme hyperactivity, psychosis, sometimes seizures, and hair and skin changes.

Newborns are screened within the first few days of life. If abnormally high levels of phenylalanine are present, a confirmatory test is performed and treatment is begun.

Treatment consists of restricting the phenylalanine intake in order not to exceed the minimum requirement to allow normal growth and development. In this way, the mental retardation and other changes can be prevented. Periodic monitoring of phenylalanine levels are required particularly in the first year of life. Many physicians are now recommending that treatment should continue throughout life in order to avoid subtle changes in IQ and behavioral problems. The phenylalanine restriction involves the use of a metabolic formula, as a low phenylalanine milk substitute, and, in some cases, there is also a need for low protein foods made from wheat starch and cornstarch.

Apart from PKU, there are numerous other conditions that also require dietary treatment. There are at least 26 abnormalities of amino acid metabolism in addition to PKU which are treated by dietary restriction of various amino acids or proteins. Some examples of these include maple syrup urine disease, homocystinemia, lysine intolerance, which all produce various forms of mental retardation, skeletal and neurological problems.

There are also abnormalities of carbohydrates metabolism, such as galactosemia, glycogen storage disease and fructose intolerance which produce various problems such as liver damage, mental retardation and hypoglycemia. Dietary modifications or restrictions in certain types of carbohydrate intake are required for these conditions.

The foods, formulae and special diets needed to treat all of the above conditions are available without a physician's prescription. They all represent types of modified diet and replace what would otherwise be considered a normal food intake. In this respect, they are really no different from the special diets that are required in multiple other medical conditions. For example:

1. Obesity, which requires a special weight reducing diet of limited caloric intake while at the same time providing adequate nutrition.
2. Diabetes, requiring special carbohydrate limitations.
3. Hypertension and congestive heart failure which may require special diets that are low in sodium content.
4. Chronic kidney failure, requiring diets containing restricted amounts of sodium, potassium and protein.
5. Malabsorption syndromes secondary to gluten sensitivity, requiring gluten free diets.
6. Hyperlipidemias, including high cholesterol, requiring low fat and low cholesterol diets.
7. Irritable bowel syndrome or diverticulitis, requiring high fiber diets.
8. Gout, requiring diets that avoid food high in purine content.
9. Certain forms of resistant epilepsy that may require ketogenic diets that are low in carbohydrate and high in fat in order to produce a state of ketosis which reduces seizure activity.
10. Cystic Fibrosis requiring high caloric with high protein and fat intake, vitamin and salt supplements. In the case of infants with C.F. and pancreatic insufficiency, formulae containing special types of protein and fat are used instead of whole milk.
11. Food allergies requiring dietary modification, or avoidance.
12. Coronary artery disease and other forms of arteriosclerosis requiring reduced fat intake.

The modified diet required for PKU is no different from the dietary treatment of all the above conditions. In general, special foods replace or substitute for the food that would normally be eaten by the individual and do not represent a "medication" in any sense of the word. These foods are available without a physician's prescription.

Mandating coverage for the modified diet required by individuals with PKU would logically result in coverage being expected for the diet modifications required for all of the conditions mentioned above and any special food products (such as low salt, low fat, etc.) that were part of that diet. This expectation would be both unreasonable and prohibitive when applied to the provision of health insurance benefits.