Approved: March 5, 1997

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES.

The meeting was called to order by Chairperson Carlos Mayans, at 1:30 p.m. on February 20, 1997 in Room 423-S-of the State Capitol.

All members were present.

Committee staff present: Emalene Correll, Legislative Research Department
Norman Furse, Revisor of Statutes
Lois Hedrick, Committee Secretary

Conferees appearing before the committee:
Shelly Krestline, Grants Manager, Kansas Council on Developmental Disabilities, Topeka
Barry Feaker, Topeka Rescue Mission
Marg Roberts, Executive Director, Let's Help, Topeka
Representative Bill Reardon
Representative Terry Presta
Cassie Lauver, Director, Kansas Division of Health/Bureau for Children, Youth and Families
Denise Ferrer, Topeka
Katherine Loomis, Kansas City
Pam Hart, Shawnee
Robin Stone, Plains
Donna Makings, Natoma

Others attending: See Guest List (Exhibit 1).

Chairperson Mayans opened the hearing on **HB 2249 - contribution assistance program for the homeless and hungry.**

Chairperson Mayans stated that he sponsored the bill because of welfare reform, which will impact many by disqualifying them from state assistance. Chairperson Mayans distributed a copy of an article from the Wichita Eagle wherein Governor Graves indicated that focus must be placed on charitable giving. Chairman Mayans indicated the tax credit in this bill is a step in the right direction to interest citizens in contributing to those in need (see testimony, Exhibit 2).

Shelly Krestline. Kansas Council on Developmental Disabilities, testified that the bill will provide an additional incentive to taxpayers to support organizations who serve the homeless and needy (see Exhibit 3). Representative Wells questioned Ms. Krestline about her statement on advocating developmentally disabled to have choices in their lives, when they do not work or have income to support themselves. Ms. Krestline stated that even small daily choices are needed for the disabled (to match those the non-disabled have) and this bill would in time surely avail some services to those who really need them.

Barry Feaker, Topeka Rescue Mission, testified that the bill offers motivation for taxpayers to provide more help to the homeless and hungry (see Exhibit 4). A question was directed to Mr. Feaker by Representative Vining, asking, after being overwhelmed with the number of apparently able-bodied persons in Washington, D.C. begging for money, if the Rescue Mission questioned those who come for help as to their ability to take care of themselves. Mr. Feaker stated his organization's mission is to help people develop responsibility for themselves and places close limits on the assistance that is given.

Chairperson Mayans noted that Marg Roberts, Executive Director of Let's Help, Topeka, had written testimony supporting the bill (see Exhibit 5).

Representative Freeborn asked if **HB 2249** could be worked as a tax bill, and the Chairperson said that because of the large number of tax bills, this bill was referred to this committee as a health issue. With respect to the fiscal note provided by the Budget Division that the $500 deduction may reduce receipts some $6.1 million in fiscal year 1998, Chairperson Mayans stated there is no way to fairly estimate the impact on the state. Representative Geringer, saying the tax credit is dollar for dollar, stated the bill would be of great help.

Emalene Correll asked if a technical amendment would be in order to bring the varying definitions of "community service organizations" the same as the one beginning on page 4. Representative Geringer moved, seconded by Representative Henry, that **HB 2249** be passed favorably. Representative Wells moved a substitute motion, seconded by Representative Vining, that the bill be passed without recommendation. After discussion of the substitute motion, a vote was called and the substitute motion failed.

Representative Morrison moved, seconded by Representative Henry, in a substitute motion, that **HB 2249** be passed to include a technical amendment to define "community service organizations" the same wherever it appears in the bill. The motion carried. Then, on motion of Representative Morrison, seconded by Representative Henry, the committee voted to pass **HB 2249**, as amended.

Chairperson Mayans then opened the hearing on **HB 2255 - reimbursement, medically necessary food treatment product.**

Representative Bill Reardon, stating that this bill is the only bill he is co-sponsoring this year, testified that the bill is a compassionate one. He has first-hand knowledge of PKU from a young neighbor, named Garrett, from whom he learned the severity of the metabolic disorder and its potential devastation.

Representative Terry Presta, a co-sponsor of the bill, described the bill's provisions. With respect to Section 1(e) of the bill, she stated they do not want to cap that area to a single product but to include others required by those with metabolic disorders (see written testimony, Exhibit 6). She indicated there may be a need to include other conditions, like someone who is pregnant and has the PKU disorder. Representative Geringer asked how many are afflicted now. Representative Presta answered that we don't know exactly. The fiscal note based the fiscal year 1998 reimbursement of $102,000 on 68 children. Representative Gilmore questioned why the state should reimburse costs for PKU, when other diseases (such as diabetes) causes expenses for insulin, needles and other medical supplies.

Cassie Lauver, Kansas Department of Health and Environment, described the Bureau of Children, Youth and Families program to purchase the medically necessary formula for PKU patients, its cost benefits, and the impact **HB 2255** would have on the Bureau. She said estimating 1 for every 13,000 (of 37,000 born each year) having PKU, one new PKU patient would be born every one to two years. That was the formula used to arrive at 68 in the fiscal note. The food product cost is usually not reimbursed by insurance or Medicaid. Ms. Lauver stated there may be other food protein products for metabolic disorders that could be purchased by the state and be authorized by this bill. (See testimony, Exhibit 7.)

Shelly Krestline also testified in support of the bill, urging its passage (see Exhibit 8).

Denise Ferrer, of Topeka, described the situation of her daughter who was born with but not diagnosed PKU until years later. Ms. Ferrer told of the financial burdens caused by the disease (see Exhibit 9).

Katherine Loomis, of Kansas City, described the importance of **HB 2255** to her family, and families like hers, in the care of a PKU child (see Exhibit 10).

Pam Hart, of Shawnee, a mother of two PKU children, testified in strong support of the bill and how important the reimbursement is for those families with PKU children (see Exhibit 11).

Robin Stone, of Plains, who has a daughter with Maple Syrup Urine Disease, described the experiences her family has faced in caring for the only MSUD victim in Kansas. She asked that the bill be amended to include all other children with metabolic diseases, including MSUD (see Exhibit 12).

Donna Makings, of Natoma, spoke eloquently on the daily requirements of handling a PKU child; the costs; the dietary requirements before and during pregnancy; the possibility of adding the requirement to this bill for testing for MSUD at birth (like other tests now required); and the need to authorize KDHE to also contract for and sell low-protein modified foods to MSUD persons as well as those with PKU. (See testimony, Exhibit 13.)

Chairperson Mayans directed attention to the written testimonies of the following: Cathy Fox-Bacon, RD, LD, and Leona Therou, M.D., KUMC (Exhibit 14); Carol Greene, M.D., The Children's Hospital, University of Colorado Health Sciences Center (Exhibit 15); H. E. Wiltse, M.D., Department of Pediatrics, University of Nebraska Medical Center (Exhibit 16); Laurie Bernstein, Nutritionist, University of Colorado Health Sciences Center (Exhibit 17); Cecelia Currin (Exhibit 18); Nina Colson (Exhibit 19); and Kristi Hoffman (Exhibit 20).

There being no others present to testify on the bill, the hearing was closed. Chairperson Mayans called for action on **HB 2255**.

Representative Henry suggested amending the bill's title to delete reference to "insurance." After discussion, Representative Henry moved, seconded by Representative Freeborn, that the title of **HB 2255** be amended by deleting "concerning insurance." The motion carried.

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES, Room 423-S of the State Capitol, at 1:30 p.m. on February 20, 1997.

Representative Geringer moved that **HB 2255** be passed as amended. Representative Powell then made a substitute motion, seconded by Representative Henry, that **HB 2255** be further amended in subsection (e), line 5, page 2,by adding a new sentence that reads,"In addition to diagnosed cases under this section, diagnosed cases of maple syrup urine disease shall be included as a diagnosed case under this subsection." The motion carried.

Representative Geringer moved, seconded by Representative Henry, that **HB 2255** be passed, as amended. The motion carried unanimously.

Chairperson Mayans noted that **HB 2278 (Restrictions on persons operating, working or volunteering in adult care homes)** was withdrawn from this committee and referred to the House Federal and State Affairs Committee.

The meeting was adjourned at 3:20 p.m.

The next meeting is scheduled for March 5, 1997.

HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES COMMITTEE GUEST LIST
FEBRUARY 20, 1997

NAME	REPRESENTING
Alan & Robin Stone	Plains, KS
Daniel Fenner	Topeka
Donna Mallings	Natoma
Jeanne Shove	Topeka
Barry Teaford	Topeka
Jim Hart	Shawnee, KS
Pam Hart	Shawnee
Brian Quinby	Topeka
Judy K. Martin	KC Mo
Jerry Martin	Kansas City
Kathie Loomis	KS City, KS
Garrett Loomis	Kansas City KS
Mike Saragusa	Kansas City, KS.
Steven Dowell	Independence, KS.
Rayanne Dowell	Independence KS.
Shelley Kreitzer	KCDD

HOUSE HEALTH/HUMAN SERVICES
Attachment 1
2 - 20 - 97

STATE OF KANSAS

CARLOS MAYANS
REPRESENTATIVE, 100TH DISTRICT
SEDGWICK COUNTY
1842 N. VALLEYVIEW
WICHITA, KS 67212
316-722-0286

STATE CAPITOL—115-S
TOPEKA, KANSAS 66612-1504
913-296-7616
TOLL FREE (DURING SESSION) 1-800-432-3924

TOPEKA

HOUSE OF
REPRESENTATIVES

COMMITTEE ASSIGNMENTS
CHAIRMAN: HEALTH & HUMAN SERVICES
MEMBER: JUDICIARY
JOINT COMMITTEE ON HEALTH CARE REFORM
LEGISLATION OVERSIGHT
SRS TRANSITION OVERSIGHT
UTILITIES

February 20, 1997

My Esteemed Colleagues:

HB 2249 is a personal invitation to use the strength of our economy in order to shape a society that better protects the dignity and basic rights of our brothers and sisters.

The impetus for this legislation is the current welfare reform guidelines that affect those that are poor, homeless, and living on the edge. The hungry and the homeless are in our churches, in our service agencies, in our shelters, and on our streets.

This legislation will provide a tax credit against the liability of an individual imposed under Kansas Income Tax. This credit will not exceed $500 a year and would be available to any individual that contributes to any non-profit organization that provides 70% of its resources towards helping the homeless and hungry. Corporate contributions will also be allowed.

As leaders in our communities, we are challenged to speak for the voiceless, to defend the defenseless; and to assess life styles, policies and social institutions in terms of their impact on the poor.

This legislation is a response to that challenge.

Respectfully submitted,

CARLOS MAYANS
State Representative
100th District

HOUSE HEALTH/HUMAN SERVICES
Attachment 2-1
2-20-97

Graves says United Way is vital to reform

■ Governor says agency promotes tradition of giving, advantages of cooperative efforts.

By Anita Schrodt
The Wichita Eagle

It will be the United Way that people turn to to serve the people who "fall through the cracks" of welfare reform, Gov. Bill Graves said Tuesday night.

He sang the praises of the United Way approach to charitable services and charitable giving at the 74th annual dinner, held at Beech Activity Center, of United Way of the Plains.

"There are going to be significant critical changes in how we manage the population of the country and the state," he said about welfare reform. "And United Way is clearly going to be a critical component in managing welfare reform."

Graves, a former United Way fundraising volunteer himself, cited two other significant accomplishments of United Way:

■ Maintaining the "American tradition of giving. We must focus on teaching the next generation of Americans the importance of charitable giving in their lives."

■ Setting an example for what can be achieved through a spirit of unity and cooperation.

The United Way is "the only way," he said. "If you want an example of the non-united way, just check out the Kansas Legislature to see how things are going."

Tuesday night's dinner kicked off the 75th anniversary celebration of the United Way of the Plains, which funds 38 agencies and their services throughout Sedgwick County and parts of south-central Kansas. The local United Way began as the Wichita Community Chest in 1922.

Among the several awards presented Tuesday night were the Capt. Laurie Green Award for outstanding loaned executive to Jason Gillig of Martin K. Eby Construction; the Aaron Joel Smith Award for youth volunteerism to Jaclyn McCaleb, a senior at Metro-Boulevard High School; and the John E. Rees II Memorial Award, recognizing law firms for volunteerism and sense of community, to the law firm of Fleeson, Gooing, Coulson and Kitch.

Three companies were honored for having the highest corporate gift per capita for companies of their size: Baird Kurtz and Dobson; Fleeson, Gooing, Coulson and Kitch; and Cargill Cares, which includes Excel Corp., Cargill Flour Milling, Cargill Oilseeds Processing and Cargill Grains Division.

Anita Schrodt writes about non-profit and charitable activities. She can be reached at 268-6290.

2-2

Kansas Council on Developmental Disabilities

BILL GRAVES, Governor
TOM ROSE, Chairperson
JANE RHYS, Executive Director

Docking State Off. Bldg., Room 141, 915 Harrison
Topeka, KS 66612-1570
Phone (913) 296-2608, FAX (913) 296-2861

"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

COMMITTEE ON HEALTH AND HUMAN SERVICES
2/20/97

Testimony in Regard to H. B. 2249 AN ACT RELATING TO TAX CREDITS FOR DONATIONS MADE TO ORGANIZATIONS SERVING THE HOMELESS AND HUNGRY.

Mr. Chairman, Members of the Committee, I am appearing today on behalf of the Kansas Council on Developmental Disabilities in support of H.B. 2249, relating to tax credits for donations made to organizations serving the homeless and hungry.

The Kansas Council is a federally mandated, federally funded council composed of individuals who are appointed by the Governor. At least half of the membership are persons with developmental disabilities or their immediate relatives. We also have representatives of the major agencies who provide services for individuals with developmental disabilities. Our mission is to advocate for individuals with developmental disabilities to see that they have choices regarding their participation in society just as you and I have choices.

Organizations dedicated to alleviating the plight of the homeless and hungry typically operate on a shoe-string budget and depend on private donations for their existence. Many of these service agencies provide more than a meal and a bed for the evening and take a holistic approach in assisting persons to get back on their feet and plan for their futures. H.B. 2249 will provide an additional incentive to taxpayers to support these greatly needed organizations. The Kansas Council on Developmental Disabilities urges your support of this bill. Thank you for the opportunity to testify, and I would be happy to stand for questions.

Shelly Krestine, Grants Manager
Kansas Council on Developmental Disabilities
Docking State Office Building, Room 141
915 SW Harrison
Topeka KS 66612
(913)296-2608
krestine@idir.net

HOUSE HEALTH/HUMAN SERVICES
Attachment 3
2 - 20 - 97

TOPEKA RESCUE MISSION
600 N KANSAS AVE
FAITH WITH ITS SLEEVES ROLLED UP
PO BOX 8350
TOPEKA KS 66608-0350
(913) 354-1744

HOUSE BILL No. 2249

Testimony of Barry Feaker, Topeka Rescue Mission, Inc.

Changes to the welfare system will certainly have a major impact on community service organizations. Time limits on benefits and work requirements alone will drive many current recipients to these organizations. More people will be hungry and homeless because they will be unable to meet the requirements or the deadlines for benefits.

Time limits alone do not ensure that current recipients of assistance will be gainfully employed by the deadline, nor do work requirements enable people unqualified by education or training to find work.

We view these changes as threatening to the very existence of many community service organizations as people who cannot meet assistance requirements go to these organizations urgently in need of food and shelter and long-term solutions to their immediate problems.

Community service organizations are going to be forced to develop new programs to return their new clients to a productive life. The alternatives for the organizations is to smother under the demands of a growing clientele or to "dump" these people on the street to support themselves by whatever means they can devise. If they are to help prevent a worsening "street people" problem, community service organizations will need substantial additional funding. It has been said that the savings to the welfare system are showing up as added costs to community services organizations.

Community service organizations such as the Topeka Rescue Mission, Inc. which in 1996 provided 111,881 meals (33,000 more than in 1995) and 35,742 nights' lodging are supported entirely by private donations. With government cutbacks being the order of the day, there is no reason to expect that support base to change. In order to realize the additional funding we need, our supporters who are taxpayers must be motivated to pick up a higher percentage of assistance costs than they have traditionally done.

The "contribution assistance program for the homeless and hungry" section of House Bill 2249 offers motivation for taxpayers to provide more help in this area that is reverting to the private sector. In many instances it will make it possible for our supporters of limited means to help even more generously.

Although this section of the bill will not solve the problems of community service organizations such as the Topeka Rescue Mission, we believe it will be of very significant assistance, and we applaud the humanitarian motivation of the legislature in addressing this very urgent situation.

Let's Help
NEIGHBORS HELPING NEIGHBORS
PO Box 2492, Topeka, KS 66601-2492

February 20, 1997

Representative Carlos Mayans
Representative, 100th District
Sedgwick County

Dear Representative Mayans:

I am writing in regards to House Bill 2249.

I, personally have been in the business of working with poor people for over 25 years. Let's Help, Inc., is committed to enabling each individual to become self sufficient.

Any legislation which would effectively enhance the efforts to assist the homeless and hungry would be welcomed by Let's Help, Inc., and I would think any other 501 (c) 3 agency which has a similar mission.

Let's Help, Inc. resources are at the present time stretched to the limit and we are continually seeing increased needs in all of our programs. Our lunch program, alone had an increase of over 1,500 meals in 1996.

Recent changes would make it appear that our resources will be extended even further, thus making it more difficult to meet the needs of persons, who are not able to feed or shelter their families. Again, any action which would assist those in need would be helpful.

Enclosed is pamphlet, which describes the services provided by Let's Help, Inc.

Sincerely,

Marg Roberts
Executive Director
Let's Help, Inc.

LET'S HELP is a non-denominational, non-profit organization which provides a comprehensive range of services.

COMPREHENSIVE EMERGENCY SERVICES

- Free Lunch program provides balanced meals five days a week and two Saturdays each month for an average of 300 persons a day. 84,820 meals were served in 1995.
- Food Bank supplies emergency groceries to feed a family for three to five days. $1,196,800 worth of food was donated in 1995.
- Clothing Bank has free clothing and household items for people. An average of 1104 families are assisted each month.
- Emergency Services are provided to individuals and families depending on their immediate needs. Emergency services include rent assistance, utility bill payment, medical and transportation assistance. Additional services are also available depending on particular and unique emergency needs.

  Applicants for emergency services are carefully screened to ensure that there is no unnecessary duplication of services between agencies in Shawnee County.

- Self Help programming is provided to ensure that individuals utilizing the diverse services offered at Let's Help are able to achieve economic and personal independence.

  Let's Help staff works closely with individuals; a personalized plan is designed, and close contact is kept on the progress and problems for each family.

- Let's Help is committed to working with individuals and families in the program so that the cycle of social dependence is broken and self sufficiency is attained.

HEARTLAND SHARE is a self-help program dedicated to concerns surrounding human dignity and potential. Heartland SHARE seeks to awaken a sense of unity through which neighbors begin to help each other. Working together, participant's achievement build and continually reinforce a solid sense of community, productivity, stability and self worth.
Heartland SHARE is for everybody. Anyone can become a participant by contributing $13.00 plus tax or $13.00 in food stamps, for each package of food ordered and by donating two hours of volunteer service.
For more information about Heartland SHARE and how you can participate call 913-234-6208.

COMMODITY PROGRAMS

- TEFAP distributed over 110,608 pounds of food to 11,486 people during 1995.
- CSFP provided food to 16,674 mothers, children and elderly persons last year.

HARVESTERS PROGRAM

- Provided 575,125 lbs. of food to 59 affiliate non-profit agencies.

EDUCATION PROGRAMS

- Adult Literacy Program provides instruction in math, reading, computer literacy and GED preparation. A variety of learning techniques including small group instruction, individual, self-paced activities and computer assisted instruction is used. Each student has an individual learning plan.
- Employment/Job Training provides a variety of options for changing jobs and gaining employment. Assistance with resume, applications, cover letters and interviewing is provided. Training for some entry level jobs is arranged.
- Even Start Family Literacy program is located at Quincy Elementary School. The program includes adult education, early childhood education, parent and child interaction time, parent support group and h visits.
- Older Kansans Employment Program provides special support for finding employment for people over 55 years of age.
- Children's Hour Program provides preschool children ages 3, 4 & 5 with structured learning experiences.
- Volunteers are the backbone of Let's Help. They are involved in every component of Let's Help, and are vital to the operation of the agency.

We have been blessed with the resources needed to continue to provide quality programs and services to people in need, while maintaining low administrative costs (4%). The commitment of volunteers and charitable gifts have made this possible.

LET'S HELP needs your help. For twenty six years LET'S HELP has been reaching out to people who need a helping hand. The first day we opened we served five people. Today, we touch thousands of lives. The commitment of volunteers and charitable gifts has made this possible.

Yes, I want to help LET'S HELP provide assistance to all those who need a helping hand.
Please sign me up as a volunteer:

Name _____

Address _____

Phone _____

Donations may be sent to Let's Help at P.O. Box 2492, Topeka, Kansas 66601

For more information, please call 232-4357.

Let's Help

SHARING OUR BLESSINGS WITH ONE ANOTHER

When a family lives from paycheck to paycheck, it is sometimes faced with choosing between repairing the car so Mom and Dad can get to work or paying the electricity bill. A little help at the right time can make all the difference in the world. It can save needless deprivation, worry and despair.

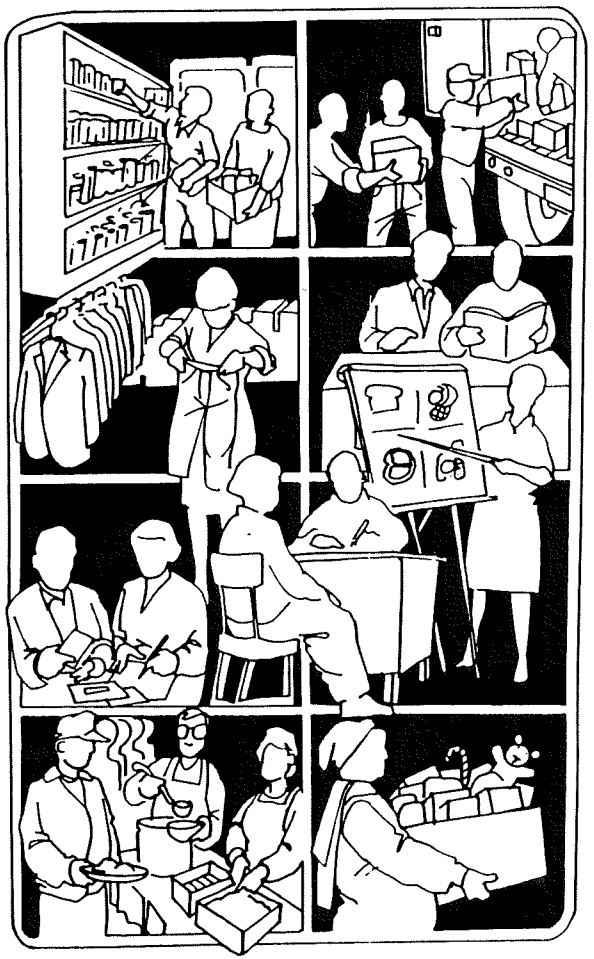
53

Let's Help
302 Van Buren
Topeka, KS 66603

Neighbors helping Neighbors: Building a Better Community

Member Agency **United Way** of Greater Topeka

120-C



Let's Help

NEIGHBORS HELPING NEIGHBORS

Designated the 181st
"Point of Light"
by President George Bush, June 28, 1990

STATE OF KANSAS

TERRY PRESTA
REPRESENTATIVE, 123RD DISTRICT
FINNEY COUNTY
P.O. BOX 1709
GARDEN CITY, KANSAS 67846
(316) 275-7564

STATE CAPITOL, ROOM 171-W
TOPEKA, KS 66612-1504
(913) 296-7660

TOPEKA

HOUSE OF
REPRESENTATIVES

COMMITTEE ASSIGNMENTS
VICE-CHAIR: TOURISM
MEMBER: JUDICIARY
TAXATION

My 16 month old daughter Haleigh and Kennedy Brunson both attend the same day care sitter in Garden City. In my unbiased opinion, they are both playful, vibrant, beautiful little toddlers. However, I learned last year that Kennedy has a metabolic disorder that my daughter does not. Kennedy has PKU, a disorder that will not allow her body to digest proteins like the rest of us. Undetected and untreated, PKU **will** result in severe brain damage and mental retardation.

Treatment consists of any PKU child following a strict low protein diet consisting of specially manufactured foods, for the rest of their lives. These foods are very expensive, costing up to 10 times more than the foods we buy. (Which most of us do not consider cheap.)

HB 2255 would allow for the reimbursement from the State of up to $1,500.00/child per year to parents of children with PKU. This reimbursement will prevent or minimize the chance that any child with PKU will not be able to live a normal productive live for lack of a proper diet.

I believe we have both a moral and financial interest in seeing that any potential tragedy's are averted. And thereby fulfilling the promise of the Declaration of Independence where our founding fathers declared all of us equal and that we all have, "certain unalienable rights among them are life liberty and the pursuit of happiness."

I want to thank Chairman Mayans for scheduling this hearing and I ask for your favorable consideration upon his working of the bill.

State of Kansas

Bill Graves Governor

Department of Health and Environment

James J. O'Connell, Secretary

Testimony presented to

House Health and Human Services Committee

by

The Kansas Department of Health and Environment

House Bill 2255

The amendment to this bill would require that KDHE reimburse the purchaser of new food treatment products (in addition to the traditional pku formulas) for costs up to $1500/year per diagnosed child 18 years old or younger, at 100% of the product cost.

Currently KDHE provides medically necessary formula by prescription for these children through a state contract. In addition, KDHE is supportive of families' desires for new products such as our addition of phenylade drink mix to the contract during the last fiscal year.

We have medical consultants associated with this program, and we utilize their expertise regarding quality assurance of products - that the treatment products are meeting the nutritional needs of the child. The consultants are cautious about new products until sufficient data are available to assure meeting the quality desired as well as the appropriateness.

KDHE has contracted for the treatment products because contracting is a more cost effective strategy than paying 100% of the cost. We will continue to work with our consultants and families to assure the availability of the widest range of treatment products possible at the most cost effective rate.

Last year KDHE spent approximately $160,000. for formula on contract. Based on the language of this amendment, 68 individuals could potentially qualify for the additional food treatment product. At $1500 per year per person, the additional cost totals $102,000. per year. The formula now provided by contract is medically necessary and additional funding must be provided to support this new cost in order to avoid funds for the formula becoming inadequate.

Testimony Presented by: Cassie Lauver
Director
Division of Health/Bureau for Children, Youth and Families
Date: February 20, 1997

HOUSE HEALTH/HUMAN SERVICES
Attachment 7
2 - 20 - 97

Bureau for Children, Youth and Families, 900 SW Jackson Street
Landon State Office Building, 10th Floor, Topeka, KS 66612

Telephone: (913) 291-3368
Fax Number: (913) 296-8626

Kansas Council on Developmental Disabilities

BILL GRAVES, Governor
TOM ROSE, Chairperson
JANE RHYS, Executive Director

Docking State Off. Bldg., Room 141, 915 Harrison
Topeka, KS 66612-1570
Phone (913) 296-2608, FAX (913) 296-2861

"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

COMMITTEE ON HEALTH AND HUMAN SERVICES
2/20/97

Testimony in Regard to H. B.2255 AN ACT RELATING TO COST REIMBURSEMENT FOR NECESSARY FOOD TREATMENT PRODUCTS.

Mr. Chairman, Members of the Committee, I am appearing today on behalf of the Kansas Council on Developmental Disabilities in support of H.B.2255, relating to cost reimbursement for necessary food treatment products.

The Kansas Council is a federally mandated, federally funded council composed of individuals who are appointed by the Governor. At least half of the membership are persons with developmental disabilities or their immediate relatives. We also have representatives of the major agencies who provide services for individuals with developmental disabilities. Our mission is to advocate for individuals with developmental disabilities to see that they have choices regarding their participation in society just as you and I have choices.

We support this bill as it will provide funds to purchase food treatments essential to the health and survival of children. Making an investment in a child's life and using tax dollars to prevent life-long disabilities is a responsible and fiscally-sound approach. Providing the maximum of lifetime benefits through this reimbursement program (18 years @ $1,500 per year) is $27,000. Compare this cost to just one year of institutional care ($128,115) or community-based care ($29,198) for persons with mental retardation and/or developmental disabilities, and you will soon realize the cost savings. A multitude of quality of life issues for the child would also be impacted by this legislation.

The Kansas Council on Developmental Disabilities urges your support of this bill Thank you for your time, and I would be happy to stand for questions.

Shelly Krestine, Grants Manager
Kansas Council on Developmental Disabilities
(913)296-2608 or krestine@idir.net

House Committee of Health & Human Services
Committee Hearing on HB#2255
Topeka, KS 66612
February 20, 1997

Hello, my name is Denise Ferrer and I am here today to tell you what having a child with untreated PKU is like and the importance of the PKU diet. My daughter, Angie, is seven years old and was born with PKU.

PKU is an inherited metabolic disorder that, when left untreated, causes mental retardation and hinders the development of the brain and nervous system. The brain damage that occurs when the child is not placed on the special low-protein diet at birth is irreversible. Untreated PKU also causes severe vomiting, diarrhea, frequent irritability, hyperactivity, severe eczema or skin rash, and convulsions.

My daughter was left untreated, in fact she just started the special diet in October of 1996. Angie now has irreversible brain damage. She is a slow learner and has been labeled mentally retarded. Angie should be in second grade, however, she was held back in kindergarten. She is now in first grade in a special education class.

Angie becomes very irritable. If she does not get her way she is unable to control her temper. She flies into a rage and becomes mean and won't listen. She is uncontrollable at school kicking over tables, chairs and kicking other children.

Because Angie is hyperactive (an effect caused by untreated PKU), she was misdiagnosed as ADHD (Attention Deficit Hyperactivity Disorder). Because of her hyperactivity she was placed on ritalin. Angie cannot sit still, much less sit still long enough to learn or be taught anything.

Angie has been misdiagnosed as autistic because of the effects of untreated PKU. There are times she seems to slip off into her own little world. She repeats the same phrase over and over again (much like Dustin Hoffman in "Rain Man").

Her speech is impaired. She talks like a two or three year old, has trouble putting words in the proper order in sentences and confuses he and she regularly.

Untreated PKU has caused Angie to have poor motor skills. She was late learning to sit up and walk. She also had great difficulty negotiating stairs when she was younger. She still has difficulty holding on to things today.

Angie has also suffered from severe eczema which required the advice of a dermatologist and prescription medicine in an attempt to control it and give her some relief. Angie's eczema is better now that we have her on the low protein diet. She has had times when she was covered from head to toe with eczema and it was so severe she looked like she had been burned badly on her legs.

At night Angie is unable to control her urine. She has to wear diapers when she goes to bed so she does not wet her bed every night.

With all of Angie's problems caused from untreated PKU I am forced to stay home to give Angie the care she requires. Because I am unable to work, our family is limited to living on my husbands income of $17,415 a year. SSI pays us $484 a month for Angie. I also receive $97 a month child support for my older child. My husband pays $1,752 a year in child support. This money supports a family of four. If my husband works overtime to try to get ahead it affects Angie's SSI for up to two months when we have nothing. We have no insurance because we are unable to afford it.

It is extremely hard for us to afford the very expensive low protein modified foods our daughter is now required to eat. We had to wait until our income tax check came back so we could order Angie more special foods. We do not know how we will continue to provide her the foods she needs for her diet.

Angie is seven years old, she cannot write her name, she does not know her colors, numbers, or ABC's. Angie does not know her address or telephone number like other children her age. She cannot get dressed without help. We do not know if Angie will ever be able to take care of herself.

This is why I am here today to ask you to vote yes to HB#2255. I know first hand both the effects of PKU and the hardship of not being able to afford the expensive food. It is families like ours that cannot afford insurance and cannot afford the very expensive low-protein modified foods required for the PKU diet that will benefit so greatly from this bill.

Katherine Loomis

1010 N. Washington Blvd. Kansas City, KS 66102

(913) 621-1856

House Committee of Health and Human Services

Re: Testimony

HB#2255

February 20, 1997

It is my pleasure that I am allowed to present to you my perspective regarding HB#2255. Kansas Statute 65-180 is literally the foundation of my son's opportunity to life and livelihood. It has allowed me a parent's daily appreciation of life and joy watching him thrive. I am, and will be forever, grateful to the people and legislators of Kansas for mandating the infant screening in 1965 that identified him as Phenylketonuric, thereby, instigating lifesaving dietary treatment.

My son's name is Garrett. His first word was "boo." He was running by the time he was eight months old! He has been a Cub Scout for four years. He is crossing over to the Boy Scouts this Saturday having achieved the highest rank in Cub Scouts, the Arrow of Light. He turned eleven years old this past January and attends the fifth grade at Monticello Trails Middle School. The grades he earns are mostly A's (a B here or there). He wants to be a bugler for the Boy Scouts. He's bright and funny and wonderful. He has PKU.

PKU stands for Phenylketonuria. This is a genetic disorder involving the digestion of protein. When we eat we consume protein. Nearly all food has protein. Protein consists of 22 amino acids. Eight of those are considered essential amino acids. One of those essential amino acids is called phenylalinine. As you and I metabolize phenylalinine, ("phe" as we PKU people call it), it travels through our livers where it attracts an enzyme called phenylhydrolace. This, now complex molecule, is called tyrosine. Very basically, tyrosine is responsible for delivering and producing oxygen, hydrogen and water to our brains. Phenylketonurics do not produce normal levels of phenylhydrolace in their livers. Therefore, no tyrosine is produced. Subsequently, their brains do not get oxygen, hydrogen and water by this metabolic system. Consequently, the phenylalinine rots, if you will; it remains raw in the bloodstream until it breaks down. This complicates matters further, as damage is also caused by the toxins created from the unnatural states of the phenylalinine in the bodies of Phenylketonurics. A very strict diet is prescribed and followed to prevent the catastrophic, physical and mental illnesses associated to high levels of phenylalinine.

Summarily, high levels of phenylalinine in the blood system creates two problems: Oxygen, hydrogen, and water are not delivered to the brain and the phenylalinine breaks down and poisons the body. The results are grave. Drastic reduction of IQ levels, dangerous seizures, severe eczema, incapacitation and ultimately, institutionalization.

Complying with the prescribed treatment of medically necessary food and low-protein modified foods allow Phenylketonurics normal growth and development. Very generally, the PKU diet restrictions include, but are not limited to: no red meat; no poultry; no fish; no pork; no seafood; no eggs; no dairy products; many non-dairy products (as most replace the dairy protein with soy protein); no nuts; no seeds; very small amounts of grain.

"What else is there?" everyone exclaims. Fruit, vegetables, and very expensive, medically necessary food and low-protein modified foods is the only answer. Fruit and vegetables, each contain different amounts of phenylalinine. Apples and carrots have lower amounts of phenylalinine, while bananas and corn on the cob have more. The medically necessary food products grow-up with the children. As they become older, their nutritional needs change. The formula removes the phenylalinine from the protein allowing ingestion of the other necessary amino acids protein offers without the phenylalinine. The other required amino acids of protein are thus available to Phenylketonurics through the formula. Two-thirds of the total daily requirement of protein Garrett gets, he gets from this formula. Thirty-three percent of the total protein intake, he has to attain through fruit, vegetables and low-protein modified foods. He has one-third the food allowance you have on a daily basis. What you ate for *lunch* today was probably more than Garrett's daily allotment of protein from food. Children growing from infants to adolescents, into and through adulthood do not outgrow this condition-- PKU is a lifetime disorder, a very expensive one.

update

Over the past several years, scientists have created some wonderful products. They may seem rather plain and basic to you, but they are essential to the compliance of the diet prescribed for Phenylketonuria. PKU people should have these products available to them every day. (See included price sheet, please.) For instance, everyday flour for baking is not allowed in this diet. Can you imagine telling your son or daughter they will

never get to eat holiday sugar cookies or their own birthday cake? If the child sneaks those things, everybody s in trouble! What is life in America without bread and biscuits? How about pancakes? Flour, plain ordinary flour, for Garrett costs over $15.00 for four pounds! This flour combined with other diet-friendly ingredients, each loaf of bread costs over $6.00. Pancakes are more than a dollar a piece!

It is too often that I have had to refuse Garrett basic staples, begging him to fill up on apples and carrots. This diet is unreasonably expensive. I am absolutely certain that most , if not nearly all of the families with metabolic disorders worry about affording these modified foods. When I am able to buy them for Garrett, it is due to scrimping, my doing without lunch and postponing new shoes for him. I know that people like me are out there, because I am out there every day. Without this bill, my son and others do not get today's prescribed treatment. HB#2255 is today's version of the 1965 Statute.

Every day I pray for him, and for me. My nightmares are of "no way out" signs and the elimination of the assistance the State of Kansas provides Garrett. I do not have health insurance now. I'm am finally, once again, in a position to afford health insurance for Garrett and me. As it stands now the insurance company my employer has chosen as our provider absolutely, will not cover any PKU treatment or related illnesses. (Quite frankly, I am not sure they will cover Garrett at all based on my prior experiences. Their actuaries apparently have no data regarding his medical future by which to calculate their risk and premium factors; the oldest, treated PKU person is no older than 32 years.) Even if PKU families all had insurance coverage, which they don't, people face losing their insurance coverage due to losing a job, changing jobs and divorce. We hear every day that millions of Americans are completely without health insurance.

We have to make sure constant, appropriate treatment is available. Doing so provides an incredibly successful medical treatment that allows people with metabolic disorders a chance to develop to their potential-- mentally, physically and emotionally. The time it will take to switch from one coverage to another will be devastating to them. Insurance may be the answer to finally, equalizing our medical, financial bills in the future, but it is certainly not responsible and stable enough to provide constant, competent coverage for my son's scientific, medical treatment now.

Decreases in IQ levels of Phenylketonurics occur within five weeks of consistently high levels of phenylalinine. Unless the formula and related foods are available to us, you will see an increase of PKU children not getting the proper treatment. It is far more expensive per child to institutionalize them than to provide them medically necessary food and low-protein foods to keep them healthy. In fact, when Garrett was diagnosed as a newborn, the doctor and nutritionist discussed, right in front of me, whether or not to pull him off of breast milk "cold turkey". This swiftly initiated me to the cold-hearted facts of science. I was threatened, then, that Garrett "is a state case." If I "do not follow doctor's orders, he will be taken away" from me. That fear was deeply instilled in this new mother's heart. Yet, the prescribed diet is so costly that it is not affordable. What is a mother to do?

Trouble comes out of nowhere! His first birthday cake caught fire while it was baking. Rice flour, I learned very quickly, does not tolerate oven temperatures of 350 F. Fever, because it raises the "phe" level in the blood, peer pressure and NutraSweet, which contains huge amounts of phenylalinine, are constant worries in addition to maintaining his daily diet.

On the other hand, Garrett has come to realize that everyone, at some time in their life, will face a special diet, be it glasses, insulin, low cholesterol, a cane, sign language. Facing the fact that there really is no "normal" in reality is an incredible hurtle for a young child. We see within society, each individual striving to find comfort in believing themself normal. Our place in society is certainly affected by the actions and reactions of others. Their reaction to Garrett's difference etches his emotional and spiritual being; thus his life and livelihood. Intolerance and degradation will not free him. Acceptance and consideration sets him free to offer all of his wonderful energy to the world. The low-protein modified foods not only guaranty his health's safety, it allows him to fit in, just a little bit more.

Even though I was raised squarely and fairly, trained to consider others and mind all of my manners, I was never so impressed by the magnitude of self-control and social tolerance as I have been seeing my son cope with PKU every day. The sacrifices each of us make in our lives so that others may simply take their turn living their own lives is crucial to individual opportunity.

The PKU diet is blatant at best. Garrett is unable to approach any social function, a day at school, or an overnight camp-out without being required to divulge details about his condition and the restrictions of his diet. He, and in fact, his entire family and circle of close friends, approach these circumstances as opportunities to teach people, genuinely curious about the simple malfunction of an incredibly complicated system, about differences and integrity. We approach them confidently, intelligently, honestly, and without self-pity. People are not only fascinated at the miracle of it all-- nature's glitch and science's solution--they, voluntarily, make themselves available to Garrett. The birthday host will call to plan the menu to include things Garrett may have. Cub Scouts bring treats they can all share.

Our lives are based upon a medical miracle, but with it comes much responsibility. We have become educators teaching tolerance for issues we could not control nor change.

There are many defects in the nature of our human-state. Garrett, his family and community are very fortunate, and know it. With the compliance to the specific diet we have opportunity that others with worse conditions do not. I appeal to you, that the success of dietary control for metabolic disorders is why HB#2255 is so important. The prescribed dietary treatment for metabolic disorders relieves these children, their families and the State of Kansas from the physical horrors of brain damage, severe seizures, IQs of less than forty, total incapacitation and the emotional and financial costs of institutionalization, or worse. Not only the formula is medically necessary , but so are the modified staples: flour, bread, pasta, etc.

Thirty-two years ago there came a means of diagnosis and a foundation to a treatment. Medical research has had a chance, these past thirty-two years, to analyze and determine more complete medical instructions. Subsequently, medical research teams have had time to produce the modified food staples crucial to the more specific instructions to maintaining normal growth and development. Today, doctors prescribe a specific treatment that entails both the formula and low-protein modified foods. I need your help to afford them.

Please, vote yes for House Bill No. 2255.

HART

February 18, 1997

TO THE KANSAS LEGISLATORS

My name is Pam Hart and I am the mother of two children with PKU...Deanna is almost 3 years and Lucas is 5 months. I also have a daughter, Monica, who is 7 years old and does not have PKU. It came as a shock when my husband and I found out that Deanna was diagnosed with PKU since both sides of our families have never recalled an ancestor who was retarded (which is what would have happened to any person born with PKU prior to the newborn screening tests initiated in the early 1960's). We knew we had another 25% chance of having a child with PKU when we became pregnant again. However, my husband and I felt sure that Deanna was our "genetic fluke" and it wouldn't happen again. It turns out Lucas was positive for PKU and we now have two children to raise with a serious metabolic disorder.

We, as most other parents, want the best for our children. Yet, we face a challenge that most other parents never do...that is if we don't have our children follow a strict low protein diet every day then mental retardation would certainly occur in a matter of months. This is especially the case in the first 2 to 3 years of life since the young and undeveloped brain is vulnerable and at its most risk. Yet, even after successfully monitoring the diet past the early preschool years, it does not stop there for the parents. We then enter the school age years where we deal with children eating meals away from home whether it be at a friend's house or school. Then there's the teenage years when peer pressure and the desire to be "one of the group" sets in. And of course, young adulthood when children leave for college or their first apartment and we as parents hope and pray that we taught them well with the management of their diet. Studies are currently reporting that neurological problems can occur at any stage of a PKU person's life if the diet is not strictly followed and controlled. It is no longer a common practise to take a child off the diet after a certain age. It is a DIET FOR LIFE.

Parents of PKU children and adult PKU people are asking that the State of Kansas help us with the physician-ordered diet by providing reimbursement for the cost of low protein food. By having this service available, diet compliance would most certainly remain high and these young children and adults would lead healthly and productive lives.

6618 Ambassador ♦ Shawnee, KS 66217 ♦ 913-962-1178

The word DIET is loosely used in our society and often means a person is following a "low-fat" diet, or a "low-sodium" diet or a "low-cholesterol" diet. Usually this means that a person is picking and choosing a variety of foods that they can continue to eat but eliminating a few items that are not part of the diet plan. But the diet for PKU children and adults is very restrictive and not just eliminating a few items from their meals. It means no meat, nuts, seeds, dairy products, eggs, bread, poultry and peanut butter. We have to measure, count and/or weigh every food item consumed by the child. We have to daily record the amount and type of food and write it in a diet book. We have to routinely stick fingers or heels of feet to draw blood and to send these blood samples to clinic labs. And yet, as parents we do this because we know we are responsible for the future of our children's lives.

As parents of two PKU children, we know that low protein foods have to be purchased and that this is not an option. The cost will only rise as our children grow and their appetites increase. I also have to make a decision as a mother and the main manager of their diets. Do I take an outside job so we can afford the costs of these special foods and therefore expect a caregiver to correctly monitor their snacks and meals? Or do I stay home and continue to be in charge of their diets yet due to a limited income not be able to afford an adequate supply of low protein food?

We as parents of two children with PKU strongly ask that the State of Kansas pass House Bill #2255. By passing this bill you are taking an active role in the lives of approximately 53 citizens. Enabling these people to obtain low protein foods and then reimbursing them for the cost will greatly effect diet compliance and therefore their quality of life.

We ask that the State of Kansas assume this role and help keep PKU children and adults healthy and productive.

Sincerely,

Pam Hart

House Committee on Health and Human Services
Capital Building
Topeka, KS

Our daughter, Libby, was born on December 10, 1985, at Southwest Medical Center in Liberal, KS. Shortly after bringing her home, we suspected that she was not well, so we checked back into Southwest Medical Center. During the five day stay there, she was treated only for an infection. Seeing that she wasn't receiving the treatment that she needed, my husband and I requested to be dismissed so that we could take her to Wesley Medical Center in Wichita.

While at Wesley's Infant Intensive Care Unit, she continued for days going through many different tests, becoming much weaker, but yet fighting to stay alive. Six more days passed until finally through the help of Dr. Cho and his medical staff, a diagnosis was made that our precious child has Maple Syrup Urine Disease. By this time, she was suffering from numerous complications. Her brain was swelling and she was having seizures.

Immediately, her treatment was put into effect, and we as first time parents, had an enormous load of information and instructions dumped onto our laps, trying to grasp and understand what we could about this strangely named disease that we had never heard of.

Maple Syrup Urine Disease or (MSUD), is a rare disease with a national incidence of 1 in 250,000 in the United States. (Libby is the only treated MSUD patient in the state of Kansas). MSUD is an inherited disorder of protein metabolism. Children with MSUD do not have a functioning enzyme to process or breakdown a group of three amino acids called the Branched Chain Amino Acids or (BCAA's). They are leucine, isoleucine and valine. The BCAA's are found in all food proteins.

All Children need a certain amount of BCAA's for normal growth and tissue repair. In most people, any extra BCAA's are broken down and eventually used by the body in different ways. But with MSUD, extra BCAA's are not broken down, and can build up in the blood, spinal fluid and urine, producing a sweet maple smell, thus giving Maple Syrup Urine Disease its name. Left untreated, the extra BCAA's can interfere with normal brain development causing mental retardation, physical difficulties and death.

The earlier an infant is diagnosed and treated, the less risk there will be of permanent damage. Many states have a newborn screening program which checks a baby's blood during its first days of life to see if the infant has MSUD. The infant with MSUD can then be put on a carefully controlled diet and must have close medical supervision. (Today, KS does not have this newborn screening program.)

The diet centers around a synthetic formula which the child must drink every day. It provides most of the protein necessary for normal growth and development without those three offending amino acids.

We have had to purchase Libby's formula through a pharmacy for the past eleven years. During this time, we have had several struggles with the Insurance Company concerning this product. They have argued with us claiming her formula is not a prescribed medication, therefore declining to help cover a part of the cost.

Three years ago, we were confronted with this situation again. I contacted many of the state and national legislators by letter concerning this matter. It was then, Secretary of State Bill Graves, who took it upon himself to help us. Through his efforts, our insurance company began again to cover part of the cost for her formula.

Families are responsible for the daily care and diet of a child with MSUD. It is a real challenge!

Information on nutrition, low protein recipes and low protein food products are increasing. These help improve the care of the child by giving them a wider variety of foods to choose from. These foods are much needed, and are very expensive.

I feel that it is important for all of us to support House Bill #2255, and include all metabolic diseases. Each child needing medically necessary foods will have the opportunity to receive all the dietary treatment they need to maintain a happy and healthy life.

MSUD is a disease that cannot be cured. It is of vital importance that these children have early diagnosis, as with an MSUD newborn screening program. And, only with strict dietary management can these children lead a normal, healthy and productive life.

I hope that when you make your decision on this Bill, you will remember our daughter, Libby, and all the other children with metabolic diseases and support House Bill #2255.

Thank you for your time.

Robin Stone

12-2

House Committee on Health & Human Services
Committee Hearing HB#2255
Topeka, KS 66612
February 20, 1997

Like most PKU parents, I had never heard of PKU until my son was born with it in 1988. When bringing children into the world there is a certain understood responsibility. Parents know it is their responsibility to raise their children to the best of their ability to be productive members of society. However, parents of PKU children have the added responsibility of knowing their child's IQ depends entirely on how well they manage a very strict low-protein diet.

Everything a PKU child eats is carefully weighed or measured and recorded. Once the food and food amounts have been recorded a running total is kept to make sure the child's daily intake amount is **exactly** the prescribed amount allowed for his (or her) individual diet.

Going to restaurants involves packing a pre-measured meal for your PKU child. If the restaurant has a good salad bar you take your scales and weigh the exact amount of allowed food for your child. A trip to a restaurant requires much preparation and never on a last minute invitation.

School meals are weighed and measured and packed everyday. The special medically necessary food (formula) is measured and put in a thermos. This is done every school day without exception.

School parties present yet another challenge. Usually the teacher will call ahead of time to let us know there is going to be a birthday party or special event where food or treats will be served. We can plan our child's diet to include a special treat, usually one brought from home.

The special low-protein modified food products that are used to supplement the PKU diet are very expensive. Most of these products do not have a very pleasing taste. These low-protein modified foods substitute such foods as bread, pasta, spaghetti and jello.

The high cost of these special food products make it very difficult to buy a variety of food for our child's PKU diet. I ordered 2 cans of bread machine mix (1 can makes 4 loaves of bread at $15.25 a can) and 3 boxes of cream-filled wafers (12 cookies per box at $3.20 a box). The total of this order (with $7.50 shipping and handling) was $47.60! I received what amounts to 8 loaves of bread and 36 cookies.

Not being able to provide your child a good variety of food choices because the cost limits what you can purchase is a feeling that is hard to describe. There have been times we could afford only the minimum amount of modified food products. I believe the PKU families need help providing a good variety of modified food products for the health and well-being of their children (no matter what their age).

Under no circumstances can any changes be made to the provision of medically necessary food (formula) now being provided to a PKU person regardless of age. The cost of this formula would make it impossible for a lot of families in Kansas to provide the needed amount for their child to remain healthy. There is no question to the fact PKU persons **must** have the formula for life to remain healthy.

In a few years my son will be going off to college. He will have to hold down one or two part-time jobs to make ends meat. As a parent, I would like to have the comfort of knowing he will **never** have to choose between paying the electric bill or rent or buying his low-protein modified foods.

As for putting an age cap on the provision of low-protein modified foods, the state has somewhat over-estimated the cost of picking up these food products. Currently there are 53 PKU persons on diet, not the projected 68, a difference of 15 persons at $1,500 per person. There are 5 children under age one, these babies would eat little, if any, of the modified foods. There are 12 children ages 1 to 6 and it is questionable the children in this age group would eat $1,500 worth of modified foods. There are 12 PKU kids ages 7 to 12 who are probably real close to the $1,500 amount. PKU kids ages 13 to 17 are undoubtedly eating the full amount of modified foods not to mention any and all other foods allowed by their diet. There are 15 PKU persons over age 18 in Kansas.

Of the 15 PKU persons over age 18 in Kansas you have women of child bearing age. Women with PKU **must** follow the strict low-protein diet before and during pregnancy to insure the health of their unborn child. PKU women not on diet before and during pregnancy subject their unborn child to several types of PKU related birth defects.

Maple Syrup Urine Disease (MSUD) is also a metabolic disorder affecting 1:250,000 newborns a year. At present time Kansas has only one case of MSUD and it is an 11 year old little girl.

MSUD, like PKU, is an inability to break down certain amino acids in protein. Each disorder involves different amino acids. MSUD is treated by diet much like PKU with medically necessary food (formula) and low-protein modified foods. By changing lines 20 and 41 of State Statue 65-180 to read "including the following inborn metabolic disorders, but not limited to" this would allow Kansas to cover MSUD diets also.

The projected 10 year birth rate of MSUD is 2. However, no MSUD patients have been born in the 11 years since the birth of the one little girl in Kansas with MSUD.

The way the state statue is written now, medically necessary food (formula) is provided only to those diseases Kansas screens for in newborns at only a few days of life. It may not be practical to mandate MSUD newborn screening but at the same time it makes no good sense for the state not to provide the medically necessary foods required by the MSUD diet.

According to the state lab., newborn screening is possible. There are two ways of screening for MSUD. The Agar method would cost the state approximately 50¢ per test. The Micro titer method would be higher and cost the state 55¢ per test. This would be an annual cost to the state of $25,000. Neither testing method would require additional staff.

I am asking for your support on providing low-protein modified foods to both PKU and MSUD persons in the state of Kansas. These are not foods that can be bought at the grocery store but rather very expensive foods that must be ordered. To my knowledge, there are only four companies in the United States that provided these food products.

Thank You!

Donna Makings

Donna Makings
707 West Avenue
Natoma, KS 67651
(913)885-4434

FOOD COST COMPARISON

FOOD	REGULAR	LOW-PROTEIN
Spaghetti (16 oz)	$1.25	$5.00
Flour (1 pound)	$0.18	$7.08
Crackers (16 oz)	$0.79	$15.85
Cream Filled Wafers	$0.49	$2.95
Jell-o (3 oz)	$0.55	$1.27
Tomato Sauce (4 oz)	$0.25	$4.07

shipping & handling
$5.00 to $25.00
per order

On-diet Numbers

2-13-97-Kids active on SHS with PKU

Under 1 year of age	5
1-6 years of age	12
7-12 years of age	12
13-17 years of age	8
18 years and older	15

MSUD (Maple Syrup Urine Disease) newborn testing:

Two testing methods -

1.) Agar method
approx. 50¢ per test (high end)
or $25,000.00 annually

2.) Micro titer method
approx 55¢ per test

neither testing method would require additional staff.

1 in 250,000 births

(Michigan did 140,000 test with 0 showing positive.)

WHAT PKU MOMS HAVE TO SAY...

There isn't any question about the importance of diet to an individual with PKU, however, for most middle-income Americans it is very difficult to afford the diet. We want our son to like his special foods and to remain on the diet for life because of his health. The more affordable and accessible that the diet is than the more encouraged the children are because that allows them more choices, still only a fraction of choices of non-PKU diets. We want our son to grow up enjoying life, and we want to be able to provide him with good nutrition and choices however this will be limited to him unless we get some assistance, not from lack of love or desire, but money!

Andrew's mom

I think all states should be like Kansas and provide formula for PKU people. I also believe all insurance companies should allow people to purchase low protein foods on a plan similar to the way prescription medicine is purchased. We will be getting insurance (medical) next month. It is very difficult for us because both my husband and myself are self employed, so insurance is very very expensive for us.

Morgan's mom

The cost of low protein products are so high that there is a limit on what is purchased. The diet is so strict that if the cost was not so high or if there was help with it, then we could offer more foods to our children. A PKU mom

I'm really grateful we don't have to pay for formula. I wish we could get help on the food. It is very expensive. Bret's mom

In the 18 years our daughter has needed lo-protein food it has never been covered by insurance. And I'll have to admit during some financially tight times we were not able to order all that Melissa needed for her special diet. We even requested help from a local children's fund but was denied because all children have to eat and food was not a benefit of their program.
On the positive note, we have always been grateful to the Kansas PKU Fund for covering the doctor visits and lab expenses along with providing the lo-protein formula for the last 18 years. This has been a tremendous help and very much appreciated. It has helped our daughter grow into a very pleasant, beautiful, honor roll student who is and absolute joy to have around! Melissa's mom

We've recently started to get new insurance and have run into a hurdle with PKU. We've had several insurance companies not want to write PKU. At this time we think we have found a good policy but they were very leery and we had to provide records showing she's the healthiest of the family. A PKU mom

We have had a difficult time providing the special diet foods for our son because they are so expensive. It is very heart-breaking knowing that your son could have better but you are unable to provide it for him. If the state did not provide the special formula I honestly don't know how we would ever be able to provide it for him. Most insurance companies do not want to touch PKU with a 10 foot pole even though we have never found one that would cover the special diet food or medically necessary formula.
It is a very helpless feeling knowing you can't afford the special diet food your son needs to keep healthy, I hope something can be done to help relieve the financial burden of such expensive foods that are so vital to the health and well-being of these PKU kids. Nathan's mom

February 20, 1997

PKU is an inherited metabolic disorder, which if untreated, results in mental retardation, neurologic and behavior problems. The treatment is dietary and consists of specialized formulas and products that are low in phenylalanine, an amino acid present in protein foods. If PKU is diagnosed in early infancy and treated with the prescribed low-protein diet, mental retardation can be prevented.

In the past, dietary treatment was discontinued after the age of six, because the brain is fully developed. However, we now know due to current research that if diet is discontinued, and the phenylalanine level in the serum is high, children and adults can exhibit behavior problems, lose congnitive function, and some may develop neurological problems. Dietary treatment is therefore recommended for life.

It is important that the state continue to support the comprehensive program for the diagnosis and treatment for PKU.

Cathy Fox-Bacon, RD, LD

Cathy Fox-Bacon, RD, LD

Leona Therou, M.D.

Leona Therou, M.D.

HOUSE HEALTH/HUMAN SERVICES
Attachment 14
2 - 20 - 97

The Children's Hospital

February 18, 1997

To Whom This May Concern:

1056 East 19th Avenue
Denver, Colorado 80218
(303) 861-8888

I am writing to you as the metabolic director of The Inherited Metabolic Diseases Clinic at The Children's Hospital in Denver, CO. I urge you to support this bill that will provide coverage for low protein modified medical food products for individuals with Phenylketonurea (PKU) and other inborn errors of metabolism.

For these conditions, the medical treatment is based upon an artificial diet. The diet consists of the daily consumption of medically prescribed formulas(medical foods) and low protein modified food products. Since very few foods are naturally low in or devoid of protein, it is important that the low protein modified food products be used in addition to the formulae. Regular bread, pasta and rice have so much protein that a child with PKU might, without these modified products, be restricted to one slice of bread or a 1/4 cup of rice in a day. Unfortunately, the costs of these products continue to be of paramount concern to our families. As an example, the cost to simply bake a loaf of bread for these children costs over $7.50; ready made low protein bread costs even more. Without recognition of the usefulness of these products in our medical treatment, we invite preventable and irreversible damage to a child's growth and development.

It is my opinion as a physician treating PKU and other metabolic disorders, that it is unreasonable to expect that each family can be expected or required to provide out-of-pocket, these costly products that clearly protect the physical and mental health of our children. Proper medical use of these products will improve outcome in PKU and other metabolic disorders, thereby decreasing burden on families and on the community.

I thank you for your attention and hope you will support this bill, and with your vote support children and families with PKU and other inborn errors of metabolism in Kansas.

Sincerely,

Carol L. Greene M.D.
Director, IMD Clinic

HOUSE HEALTH/HUMAN SERVICES
Attachment 15
2 - 20 - 97

University of Nebraska Medical Center
Nebraska's Health Science Center

Department of Pediatrics
600 South 42nd Street
Box 982165
Omaha, NE 68198-2165
(402) 559-6009
Hearing Impaired:
(402) 559-4222 TTY/TDD
Fax: (402) 559-5137

February 11, 1997

Donna Makings
707 West Avenue
Natoma, KS 67651

Fax #913-885-4434

Dear Ms. Makings:

I am a specialist in pediatric metabolism and am involved in the care of many children with phenylketonuria. It is imperative that each person with this condition maintain a carefully supervised and severely restricted low-protein diet supplemented with a low-phenylalanine formula and appropriate low-protein medical foods. These items are used only under the direction of a metabolic nutritionist working with a physician specialist. Without this treatment, severe brain damage will result early in life. If treatment is interrupted during adolescence or adult life, the usual result is progressive neurologic disability.

All jurisdictions within the USA have mandated screening tests for early diagnosis of phenylketonuria in order to assure that every child with this condition can have the benefit of treatment. We must not permit any child to suffer neurologic impairment because family finances are inadequate to pay the cost of the special formula and special medical foods, or because of arbitrary exclusion of these items from insurance coverage.

As a physician involved in the on-going care of a child with phenylketonuria residing in Kansas, I want to add my support to your efforts to bring about legislation that will help to assure that the health care needs of persons with phenylketonuria can be met.

Sincerely,

H.E. Wiltse, MD
Professor
Department of Pediatrics

HEW/pdd3

HOUSE HEALTH/HUMAN SERVICES
Attachment 16
2 - 20 - 97

The Children's Hospital

February,18,1997

To Whom This May Concern:

1056 East 19th Avenue
Denver, Colorado 80218

(303) 861-8888

I am a metabolic nutritionist working with children and adults with inherited metabolic disorders. Some of these diseases result in mental retardation and neurological deterioration when a very strict diet is not begun at birth and well-maintained. Special Formulated medical foods are critical in this diet management along with the use of low protein foods. Without these low protein foods the diet is both extremely difficult, very limiting and can lead to patient non compliance due to a lack of variety. The costs of these foods prohibit most families from using them.

The low protein medical therapy consists of expensive low protein items, such as low protein bread, pasta, baking mix, rice and jello. These products are only available through mail order by three U.S. companies specializing in metabolic diseases. An example of the cost of dietary supplements includes over $7.50 for a loaf of low protein bread and $5.25 for a single box of low protein spaghetti (plus $5.00 shipping and handling). The child suffers from the inability to pay for the low protein products, but we as taxpayers, may bear the burden of supporting this child or adult in a home for the mentally handicapped several years later.

Due to the low incidence rate of these rare metabolic diseases, the number of individuals and associated costs are far less than the cost for caring for a mentally retarded child. Passage of this bill would alleviate this most unfortunate problem, thus allowing our families to properly focus on the effective medical treatment of our children.

These products are a part of the treatment, not just food. I ask you to support this bill. Everyone deserves the right to be able to eat a bowl of spaghetti.

Laurie Bernstein

Laurie Bernstein MS,RD., FADA
Nutritionist, IMD Clinic
Instructor, Department of Pediatrics
University of Colorado Health Sciences Center
Denver, CO

HOUSE HEALTH/HUMAN SERVICES
Attachment 17
2 - 20 - 97

February 13, 1997

To whom it may concern

Having grown up with PKU as a child, and growing into a responsible mother of two girls, ages three years, and five months old, I have to say "I don't know what I would have done without our low protein foods. The low protein foods is very filling for me now, and as I was a child. When I was in school, and was only allowed to eat small amounts of vegetables throughout the day We had to carefully measure vegetables out. It was nice to have the vegetables as much as we could, and still rely on the low protein foods to satisfy us.

I can't imagine how 'unlucky"I might have been growing up without my diet food. I commend you for working hard for PKU children under eighteen, However, as a PKU mom of two, I also want to stress how very important this food is to PKU adults as well.

As a pregnant mom without PKU gains weight, her baby also gains adequate weight. However, a PKU mom struggles to gain weight and fights tooth and nail to gain appropriate weight so her un born child may have a good chance at life, and is born with a decent birth weight. This food is very helpful to PKU moms because of the correct nutrients it provides their unborn child, and supplies many calories for the mother and baby to allow them mother to gain weight appropriately. Because of the high calories this food offers, it satisfies the mother and baby good. This is why is is so critical that we, as adults with PKU, as well as children with PKU receive low protein food. Because of the cost of this food, many people can't afford to buy this food. But obviously are in desperate need of it. I feel like help should be given to the PKU children and adults to purchase the food they need to have to take this important step to help provide these PKU patients with the adequate help they need to ensure a healthy well-being for both present and future generations.

Sincerely,
Cecelia L. Currin
Cecelia Currin

HOUSE HEALTH/HUMAN SERVICES
Attachment 18
2 - 20 - 97

February 17, 1997

To Whom it May Concern:

I am writing this letter in regard to the importance of receiving PKU food and formula for those with Phenylketonuria. I would like to stress that being a pregnant PKU mother, it is very important to receive low-protein food and formula. Without the proper diet foods for my medical problem, my baby would be at extremely high risk of abnormalities such as retardation, and endanger the development of my growing baby. It is so important for mothers with PKU to receive the proper food and the PKU formula over the age of 18.

It is just as important for a child with Phenylketonuria to follow the low-protein diet. PKU is an inherited condition some children have that makes it impossible for their bodies to properly use Phenylalanine, and amino acid found in some foods. If the condition is not treated, the brain does not develop normally. The only treatment that has been discovered for this condition is through a diet low in phenylalanine. Normal foods are not as filling for the child, and the formula helps in receiving the proper vitamins that are so very essential in that of a growing child as well as that of a growing fetus. The aim of a child with Phenylketonuria or a pregnant mother of Phenylketonuria is always to maintain serum phenylalanine levels that will allow the fullest development of intellectual potential while supplying adequate protein and calories for growth and prevention of hunger both for the PKU child, or the pregnant PKU mother.

One of the concerns of adults with PKU is the high cost of the low-protein foods that are necessary to maintain a healthy diet for patients with PKU. I feel that medical aid should automatically be provided for these patients with Phnylketonuria to ensure the well being of themselves and their children. It should not always be such a constant battle to get the assistance that is needed to medically and physically protect the unborn babies, children, and adults in our society that need constant medical attention for a healthy, secure, and successful life.

In conclusion, I am confident that you will make the right decision to supply the adults, parents, and children with the proper diet food and formula they so desperately need to become successful, healthy, and confident intellectuals in todays society.

Sincerely,

Nina Colson
PKU Mother

Dear Kansas Legislators,

I am a 25 year old woman who has been treated since birth for the genetic disorder, Phenylketonuria (PKU). I graduated from Manhattan High School and Kansas State University with a degree in Elementary Education. I am now married and work at a bank as a teller/bookkeeper. I tell you these accomplishments because I know I am a very fortunate person. I am the youngest of five children in my family and three of us have PKU. Unfortunately, my two other sisters, one eleven years older and the other five years older were not diagnosed until I was born and the damage from the disorder was already done. My oldest sister never made it past junior high and now works in a sheltered workshop. My middle sister graduated from high school through special education. After completing courses & training at a sheltered workshop, she is now able to hold down a job as a dishwasher at a restaurant. I am very thankful for being diagnosed right at birth as having PKU, because I <u>really</u> know what I could have been like. I am also fortunate to have been born in a state that has provided the formula I've needed to get my daily protein.

I was put on a restricted diet as soon as I was diagnosed with PKU. The restriction is from phenylanine (Phe) which is an amino acid in all protein. I was born lacking the enzyme to break down this amino acid. The phe that is not broken down builds up in the blood stream and causes brain damage. I have always had to watch what I eat but when I was younger I had to watch it more closely because of how rapidly my brain was growing. In order to keep my blood phe level at the level it needed to be for me to develop properly, I had to count the phe in all the foods I ate, including special product foods. I ate special bread, pasta and cookies as well as the daily requirement of protein supplement formula.

Recent research has found that it is best for people with PKU, male or female, to always stay on the diet and to keep phe levels as low as possible. When levels are kept low people tend to function better in relationships and in being able to work more effectively and efficiently. As this new research shows, I need to get back to keeping my levels lower so I can function better. The old idea that the diet only benefits when you are a child is no longer correct. This has been seen in adults who were only treated for PKU in their childhood.

Since high school, I have not been as strict with the diet, although I still don't eat meat, milk, eggs, cheese or nuts. I also haven't used special products since I was in grade school, except the formula supplement. Now that I am married I am looking at the possibility of having children. In order for me to do that I need to have levels as low as when I was a child, in fact probably lower. This needs to be done so the child I am carrying will develop properly in my womb. After speaking to my doctor about this I went home and changed my eating habits to get my phe down, as I did this I realized that it would be impossible for me to get my level down that low without using special products.

My purpose in letting you know all this about myself and PKU, is that untreated PKU has some very severe results. I would also like to let you know that being treated for PKU can cost a lot of money. The state of Kansas does pay for the formula and for that I am hankful. But, people with PKU or their parents must purchase special product foods to keep phe levels as low as possible so they can reach their full potential. I am concerned for the children whose families do not have the money to buy the special foods. I know state funding for these products would be expensive, but if these children don't get the products they need, in the long run it will be much more expensive to the state because of the long term damage that can be done. Untreated PKU and unproperly treated PKU results in unproductive or less productive citizens of Kansas, which will probably cost the state more then the treatment for PKU with these products. I hope the information I have given you will help you to understand the need for special food products in a PKU persons life.

Sincerely,

Kristi M. Hoffman

HOUSE HEALTH/HUMAN SERVICES
Attachment 20
2 - 20 - 97