

Approved: 3-26-97
Date

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE.

The meeting was called to order by Chair Sandy Praeger at 10:00 a.m. on March 19, 1997 in Room 526-S of the Capitol.

All members were present except:

Committee staff present: Emalene Correll, Legislative Research Department
Norman Furse, Revisor of Statutes
Jo Ann Bunten, Committee Secretary

Conferees appearing before the committee:

State Representative Terry Presta
Donna Makings, Natoma
Cassie Lauver, Director, Div. of Health/Children, Youth & Families, KDHE
Katherine Loomis, Kansas City
Denise Ferrer, Topeka
Mark Stueve, Topeka

Others attending: See attached list

Hearing on HB 2255 - Reimbursement, medically necessary food treatment product

State Representative Terry Presta appeared before the Committee in support of HB 2255 which would require the Department of Health and Environment to provide reimbursement for the costs of purchasing a medically necessary food treatment product for diagnosed cases of hypothyroidism, galactosemia, phenylketonuria (PKU), and other genetic diseases in children younger than 18 years of age. Representative Presta noted that the bill would allow for the reimbursement from the state of up to \$1,500.00 per child per year to parents of children with PKU, and that this reimbursement will prevent or minimize the chance that any child with PKU will not be able to live a normal productive life for lack of a proper diet. (Attachment 1) Committee discussion related to mandated insurance coverage, the number of children diagnosed with PKU, removal of child from home if not on the prescribed diet, and consideration of a means testing. It was noted that diagnosed cases of maple syrup urine disease was included as an amendment to the bill by the House Committee, and amended further by the House Committee of the Whole to authorize the Department of Health and Environment to purchase food treatment products for distribution to diagnosed cases in an amount not to exceed \$1,500 per year per diagnosed case age 18 or younger.

Donna Makings, of Natoma and mother of a PKU son, testified in support of HB 2255. Ms. Makings noted in her written testimony the need to raise the age limit to 30 of those persons receiving reimbursement for the purchase of the necessary diet for PKU. (Attachment 2)

Cassie Lauver, Director of the Division of Health, Bureau for Children, Youth and Families, provided information to the Committee on HB 2255. Ms. Lauver noted in her written testimony that last year KDHE spent approximately \$160,000 for formula on contract, and based on the language in the bill, 68 individuals could potentially qualify for the food treatment product at an additional cost of \$102,000 per year. (Attachment 3)

Parents with children with PKU appearing before the Committee in support of HB 2255 and submitting written testimony were Katherine Loomis, (Attachment 4), Denise Ferrer, (Attachment 5), and Mark Stueve, (Attachment 6).

There were no opponents to HB 2255.

Action on HB 2129 - Licensed masters level psychologists practice requirements

Staff briefed the Committee on proposed amendments to HB 2129 as shown in a balloon of the bill as well as amendments adopted previously by the Committee. (Attachment 7 and 8)

CONTINUATION SHEET

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE, Room 526-S
Statehouse, at 10:00 a.m. on March 19, 1997.

After Committee discussion Senator Jones made a motion the Committee adopt the amendments shown in the balloon of the bill as well as technical clean-up of language in the bill as suggested by staff, seconded by Senator Steineger. The motion carried.

Senator Salmans made a motion the Committee recommend **HB 2129 as amended** favorably for passage, seconded by Senator Steineger. The motion carried.



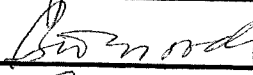
Adjournment

The meeting was adjourned at 11:00 a.m.

The next meeting is scheduled for March 20, 1997.

SENATE PUBLIC HEALTH AND WELFARE COMMITTEE GUEST LIST

DATE: 3-19-97

NAME	REPRESENTING
Terry Presta	123rd District
Cheryl H. Kinderknecht, PhD	. BSRB
MaryAnn Gabel	BSRB
Sheila Hoque	Southern Leav. Co. Leadership
Steve Gumm	" " "
	" " "
Joe Seaman	" " "
Jay Anderson	" " "
	" " "
Gayle Bunnels	" " "
Susan Guy	" " "
Janne Shore	BSRB Mother of PKU child
	So. Le. Co. Leadership
Earl L. D. Macey	S. Leav. Co. Leadership
Connie Puttkoff	So. Leav. Co. Leadership
Karen Walters	" " " "
Janet Angell	" " " "
KEITH R LANDIS	CHRISTIAN-SCIENCE COMMITTEE ON PARLIAMATION FOR KANSAS
Lisa Meyer	HS Governmental Consulting

SENATE PUBLIC HEALTH AND WELFARE COMMITTEE
GUEST LIST

DATE: 3-19-97

NAME	REPRESENTING
Susan M. Baker	Hein + Weir
LARRY BUENING	B'D OF HEALING ARTS



TOPEKA

HOUSE OF
REPRESENTATIVES

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

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 Chair Praeger for scheduling this hearing and I ask for your favorable consideration upon her working of the bill.

State Laws

State	Diet Coverage		Disorders		Limitations	
	Formula	Foods	PKU	Others	\$	Age
Alaska	yes	no	yes	no	no	no
Connecticut	yes	yes	yes	IEM	no	yes*
Florida**	yes	yes	yes	AA & OA	\$2,500 (for food)	24
Maine	yes	yes	yes	IEM	\$3,000 (for food)	no
Maryland	yes	yes	yes	IMD	no	no
Massachusetts	yes	yes	yes	AA & OA	\$2,500 (for food)	no
Minnesota	yes	yes***	yes	no	no	no
Montana	yes	no	yes	no	no	no
New Hampshire	yes	yes	yes	AA & OA	\$1,800 (for food)	no
New York	yes	no	yes	MSUD, Gal, HSU	no	no
South Dakota	yes	no	yes	no	no	no
Tennessee	yes	yes	yes	no	no	no
Texas	yes	no	yes	Heritable Diseases	no	no
Washington	yes	no	yes	no	no	no
*Infants, children and pregnant women only						
**Only available with special rider and increased premium on insurance						
***Not specified in statute but the law has been interpreted by the Minnesota Depts. of Commerce and Health to cover foods.						

Miss. Wyoming
Arizona - Iowa
Missouri
Mississippi
Illinois
Colorado
New Mexico

STATE LAWS THAT REQUIRE INSURANCE

COVERAGE FOR DIETS

State	Diet Coverage		Disorders		Limitations	
	Formula	Foods	PKU	Others	\$	A
ARKANSAS -	yes	no				
Alaska	yes	no	yes	no	no	r
CALIFORNIA						
Connecticut	yes	yes	yes	TEM	no	r
Florida**	yes	yes	yes	AA & OA	\$2,500 (for food)	r
KENTUCKY -	"MEDICAL FOODS FOR PKU MAY NOT BE EXCLUDED"					
Maine	yes	yes	yes	TEM	\$3,000 (for food)	r
KANSAS -	PENDING					
Maryland	yes	yes	yes	IMD	no	r
Massachusetts	yes	yes	yes	AA & OA	\$2,500 (for food)	r
Minnesota	yes	? yes***	yes	no	no	r
Montana	yes	no	yes	no	no	r
New Hampshire	yes	yes	yes	AA & OA	\$1,800 (for food)	r
New York	yes	no	yes	MSUD, Gal, HSU	no	r
PENNSYLVANIA -	PENDING					
NORTH DAKOTA -	PENDING					
South Dakota	yes	no	yes	no	no	r
Tennessee	yes	no	yes	no	no	r
Texas	yes	no	yes	"Heritable Diseases"	no	r
UTAH -	MUST INCLUDE COVERAGE IN BASIC SERVICES PROVIDED BY HMO					
Washington	yes	no	yes	no	no	r

*Infants, children and pregnant women only

** Only available with special rider and increased premium on insurance

*** Not specified in statute but the law has been interpreted by the Minnesota Depts. of Commerce and Health to cover foods



GARDEN MEDICAL CLINIC, P.A.

603 NORTH FIFTH
GARDEN CITY, KS 67846
OFFICE (316) 275-3700
KANSAS WATS 1-800-344-3402

February 24, 1997

INTERNAL MEDICINE

David F. Beggs, M.D. - Oncology*
Frank W. Hansen, M.D. - Pulmonology
Abel S. Cruzado, M.D.
Ann L. Polich, M.D.*

FAMILY PRACTICE

Michael D. Jackson, M.D.*
Eric R. Oppliger, D.O.*
Terry R. Hunsberger, D.O.*

FAMILY MEDICINE

Traci L. Ivey, M.D.

GENERAL SURGERY

Zeferino J. Arroyo, M.D.*

THORACIC AND GENERAL SURGERY

Robert E. Miller, M.D.*

INTERNAL MEDICINE/PEDIATRICS

Mark S. Simmons, M.D.*

PEDIATRICS

Stephen C. Meyers, M.D.*
James T. Zauche, M.D.*
Michael W. Shull, D.O.*

UROLOGY

Sheldon D. Roberts, M.D.*

OTOLARYNGOLOGY

Patrick N. Monaghan, M.D.*

NEUROLOGY

Ahmad A. Anouti, M.D.

ORTHOPAEDIC SURGERY

Gary M. Kramer, M.D.

PODIATRY

Curtis C. Pedersen, D.P.M.

PHYSICAL THERAPY

Eddie V. Pearson, R.P.T.

AUDIOLOGY

Kim M. Hendricks, M.A., CCC-A

ADMINISTRATOR

* DIPLOMATE OF THE RESPECTIVE
AMERICAN BOARD

Representative Terry Presta
State Office Bldg.
800 S.W. Jackson
Topeka, KS 66612-1227

Dear Mr. Presta:

I would like to commend you for your work on the Bill regarding helping families pay for supplemental diets for metabolic disorders such as PKU and maple syrup urine disease. This is a significant cost to these families that is not covered by insurance or by State Medicaid. We do have some very unusual patients out here in Southwest Kansas with very unique metabolic needs. I was just notified last week of a new PKU baby in our District. I would hope that this Bill could be passed through the House and on to the Senate and be funded appropriately.

Thank you for your time and consideration in this matter.

Sincerely,

Stephen C. Meyers, M.D., F.A.A.P.
Chairman of Governor's Commission
for Children with Special
Health Care Needs

SCM/ds

1-4

March 17, 1997



Representative Terry Presta
House of Representatives
Topeka, KS

FAX (913) 298-7517

Dear Representative Presta,

I am writing this letter in support of HB No. 2255.

I, Sechin Cho, M.D., am a Board Certified Medical Geneticist and Pediatrician, who is specialized in Inborn Metabolic Disorders including PKU and Maple Syrup Urine Disease.

To have a successful Newborn Genetic Disease Screening Program, it takes a multi-disciplinary team involving newborn screenings, confirmation of diagnosis, and comprehensive treatment and follow-up systems. Low protein food along with disease-specific special formula will help the patients with PKU and other inborn metabolic disorders to grow and develop normally. Without these specially designed low protein foods, optimal treatment for these rare disorders is so often difficult and does not achieve the intended goals.

I thank you and your colleague for the endeavor to improve the outcome of the children with rare inborn metabolic disorders.

Sincerely Yours,

A handwritten signature in black ink that reads "Sechin Cho".

Sechin Cho, M.D.
Professor and Director
Genetic Services

SC/jb

Genetic Services

Wesley Medical Center • University of Kansas School of Medicine-Wichita • 550 N. Hillside • Wichita, KS 67214 • (316) 688-2362 • FAX 688-7859

1-5

Donna Makings
707 West Avenue
Natoma, KS 67651-9741
913-885-4434

Senate Committee of Public Health and Welfare
Committee Hearing HB#2255
March 19, 1997

Dear Senators,

I am a mother of a nine year old PKU son. PKU is a daily challenge for not only my son but also for the rest of the family. The very strict and very costly diet is, at times, over whelming. However; our story is much like all the other stories you have heard today so I would like to inform you of some PKU facts.

PKU (Phenylketonuria) is the inability of the body to break-down one of the 22 amino acids in protein called phenylalanine (phe). The phenylalanine builds up in the blood stream and is deposited in the brain causing severe and permanent brain damage.

PKU is a relatively new treatable disorder. Until the early 60's there was no way of detecting PKU. The first indications of PKU at that time was after the irreversible brain damage had begun.

Kansas began mandatory newborn screening in 1965. Any PKU person born before that time most likely ended up being institutionalized due to the seriousness of the disorder and lack of treatment.

The first test for PKU was a simple urine test. This test was later replaced with the Guthrie blotter paper blood test. It is a law in all 50 states all newborns must be screened for PKU.

PKU is treatable entirely with diet. When treatment was first begun in the early 60's many mistakes were made. In the beginning children were taken completely off of all protein. This resulted in little or no growth for the PKU person and in a few instances even death. Even the PKU person must have a certain amount of protein to grow normally.

Another mistake that was made in the early days of treatment was to take the child off the low protein diet at age 6 or 8. At that time it was common belief the brain was fully developed and was no longer at risk. This is why the older PKU persons do not maintain as strict of a low protein diet, they were allowed to go off the diet at an early age. Once off the diet and a taste for "real" food is developed it is very hard to return to the diet. However; they now know being off diet can cause behavior problems, lose of cognitive functions, some may develop neurological problems, mental illness and psychological disorders. Dietary treatment is now mandatory for life.

There is an average of 3 PKU persons born each year in Kansas. If you would look at the enclosed PKU age break-down you will find there are years there are no recorded PKU births Kansas. You will also find there are years showing more than 3 PKU births in Kansas, this figure is not totally accurate in that

Senate Public Health & Welfare
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PKU persons moving to Kansas from out of state are also shown on this break-down.

There are currently 56 PKU persons receiving formula (medically necessary food) from the State of Kansas. The ages of these persons range from newborn to age 38. There are only 55 PKU persons currently on diet to age 30, not the 90 estimated by SHS in preparing their fiscal note.

Not all PKU persons drinking formula are eating the low protein modified foods. One reason for this is the expense is too great. Another common reason these persons do not eat the modified foods is because they have tasted "real" food and it is very hard to acquire a taste for the low protein modified foods.

Other points to keep in mind are, infants do not eat very much, if any, solid foods. Young children will not eat as much as the older children.

It is essential for PKU women of child bearing age to maintain an acceptable blood phe level if she is planning on having healthy children. This level must be obtained and maintained for some time before becoming pregnant. It is also essential the blood phe levels remain in an acceptable range during the complete pregnancy.

If blood phe levels are not maintained in acceptable levels before and during pregnancy the unborn child will suffer severe birth defects. Some of the birth defects caused by too high of blood phe levels are reduced brain size of the infant (microcephaly), defects of the heart structure (congenital heart disorders), developmental disabilities, and even fetal loss (spontaneous abortion or miscarriage).

The low protein modified foods persons with PKU must eat are not just food you can go to the grocery store and pick up. These very expensive foods (costing up to 10 times the amount of the food it is designed to replace) can be purchased from only three companies in the entire United States and can take up to 3 weeks for delivery. These low protein modified foods are the medically necessary treatment provided to prevent catastrophic physical and mental illness as well as irreversible brain damage.

Very few people are financially stable enough at age 18 to be able to afford the \$2,000 to \$3,000 needed a year to purchase low protein modified foods. This is an age young people start out on their own with very little. When my son goes off to college he will most likely have to hold down a part-time job, or two, to make ends meet. I pray my son will never have to make a choice between paying utility bills or rent or being able to purchase his low protein modified foods.

I hope you understand just how vital the low protein diet is to the PKU person and the importance of maintaining this diet for life. I hope, too, you will see both the benefit and the need of raising the age limit to age 30.

Thank you for your time and your considerations.

Sincerely,

Donna Makings

Donna Makings

FORMULA SHS USED IN ESTIMATING FISCAL NOTE

TO AGE 18

PKU

(It is estimated there are 3 PKU births per year in Kansas.)

$$18 \times 3 = \underline{54 \text{ PKU}} \text{ Persons up to 18}$$

$$54 \times \$1,500. \text{ per person} = \$81,000.$$

GALACTOSEMIA

(already provided for by state statute 65-180)

$$13 \times \$1,500. \text{ per person} = \$19,500.$$

MAPLE SYRUP URINE DISEASE

(Is being picked up in HB#2255)

$$1 \times \$1,500. \text{ per person} = \underline{\$1,500.}$$

$$\underline{\$102,000. \text{ total}}$$

TO AGE 30

PKU

$$30 \times 3 = \underline{90 \text{ PKU}} \text{ persons up to 30}$$

$$90 \times \$1,500. \text{ per person} = \$135,000.$$

GALACTOSEMIA

$$18 \times \$1,500. \text{ per person} = \$27,000.$$

MSUD

$$2 \times \$1,500. \text{ per person} = \underline{\$3,000.}$$

$$\underline{\$165,000. \text{ total}}$$

Please note:

There are currently 56 PKU persons (newborn to age 38) receiving formula in Kansas.

There are only 42 PKU persons (newborn to age 18).

It will take at least 10 to 15 years for these numbers to become more accurate due to the fact all PKU persons are now kept on diet for life.

The difference between the projected number of 90 PKU persons to age 30 and the actual number of 55 is 35 (there is one drinking formula that is over 30)wx. In dollars this translates to $(35 \times \$1,500. =) \underline{\$52,500.}$

We need to make sure to add enough to what we have to allow for the estimated 3 PKU births per year (\$4,500. increase per year until we reach the actual projected numbers of PKU persons).

**PKU AGE BREAKDOWN FROM THE FILES OF KDHE
SPEC HLTH SVCS**

<u>YEAR</u>	<u>AGE</u>	<u>CITY</u>	<u>TOTAL</u>
'96	1	*Salina, *Wichita, *Kansas City, *Shawnee Mission	4
'95	2	*Great Bend, *Garden City, *Independence	3
'94	3	*Shawnee Mission, *Junction City, *Topeka, *Kechi	4
'93	4	*Independence, *Dwight	2
'92	5	*Arkansas City, *Independence, *Ensign	3
'91	6	*Hutchinson	1
'90	7	*Lawrence, *Overland Park	2
'89	8	*Princeton, *Topeka	2
'88	9	*Natoma, *Wichita, *Wichita	3
'87	10	*Hutchinson, Wichita?	1
'86	11	*Basehor, *Olathe, *Shawnee Mission, *Wichita, *Wichita, Wichita?	5
'85	12	*Marion, *Wichita	2
'84	13	*Wichita	1
'83	14	*Topeka, Emporia?	1
'82	15	*Esbon, *Lawrence, *Wichita, Wichita?, Overland Park?	3
'81	16	*Lenexa, *Wichita	2
'80	17	NONE ON RECORD	0
'79	18	*Chapman, *Kansas City, *Manhattan, Andover?	3
'78	19	*Emporia, *Wichita, *Wichita	3
'77	20	*Hutchinson, *Junction City, *Topeka	3
'76	21	NONE ON RECORD	0

'75	22	Garnett?, Lawrence?, Overland Park?, Wichita?	0
'74	23	Bonner Springs?	0
'73	24	*Overland Park, Wichita?	1
'72	25	*Coldwater, Lawrence?, Manhattan?, Topeka?	1
'71	26	*Overland Park	0
'70	27	South Haven?	0
'69	28	*Lenexa, *Olathe, *Shawnee Mission, *Wichita, Dennis (may start formula again but not food)	4
'68	29	NONE ON RECORD	0
'67	30	NONE ON RECORD	0
	...		
'59	38	*Topeka	

* Currently receiving formula from KDHE SPEC HLTH SVCS

? No current update, safe to presume not on diet or have moved out of state.

56 PKU persons receiving formula from KDHE SPEC HLTH SVCS to date

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

State of Kansas

Bill Graves



Governor

Department of Health and Environment

James J. O'Connell, Secretary

March 19, 1997

Testimony presented to

Senate Public Health and Welfare

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: March 19, 1997

Senate Public Health & Welfare

Date: 3-19-97

Attachment No. 3

Katherine Loomis

1010 N. Washington Blvd. Kansas City, KS 66102
(913) 621-1856

Senate Committee of Public Health and Welfare

Re: Testimony

HB#2255

March 19, 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 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 now a Boy Scout 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 in Shawnee, Kansas. 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 phenylalanine. As you and I metabolize phenylalanine, ("phe" as we PKU people call it), it travels through our livers where it attracts an enzyme called phenylhydrolase. This, now a 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

Testimony Katherine Loomis 1

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levels of phenylhydrolase in their livers. Therefore, no tyrosine is produced. Subsequently, their brains do not get oxygen, hydrogen and water by this metabolic system. Consequently, the phenylalanine 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 phenylalanine 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 phenylalanine.

Summarily, high levels of phenylalanine in the blood system creates two problems: Oxygen, hydrogen, and water are not delivered to the brain and the phenylalanine 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 (formula) 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.

Keeping track of every milligram of phenylalanine consumed is another fascinating aspect of our daily lives. It is

imperative to constantly evaluate and monitor the daily intake of protein and phenylalanine. Fruit and vegetables each contain different amounts of phenylalanine. Apples and carrots have lower amounts of phenylalanine, while bananas and corn on the cob have more. The formula removes the phenylalanine from the protein allowing ingestion of the other necessary amino acids protein offers without the phenylalanine. The other required amino acids of protein are thus available to phenylketonurics through the formula. The medically necessary food products grow-up with the children. As they become older, their nutritional needs change. Two-thirds of the total daily requirement of protein Garrett gets, he gets from this formula. Only one-third of his total protein intake is attained through the consumption of fruit, vegetables and low-protein modified foods. He has one-third the food allowance you have on a daily basis. What you will eat for *lunch* today probably has 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.

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 an 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 more than \$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 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.

4-4

Decreases in IQ levels of phenylketonurics occur within five weeks of consistently high levels of phenylalanine. 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 doctors’ 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 phenylalanine, are constant worries in addition to maintaining his daily diet. We are forever and constantly tending the physical and monetary demands of this condition.

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 hurdle for a young child. We see within society, each individual striving to find comfort in believing themselves 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 set 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.

In regards to the age limit set upon this bill, I urge you to consider that an eighteen-year-old will be facing entry-level wages or his family will be incurring college expenses. To encourage phenylketonurics to remain steadfast to the prescribed diet, please reconsider and deem a more appropriate age limit, if one is required within the

letters of this bill.

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 taken the time and interest to produce the low-protein modified foods 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.

Senate Committee of Public Health and Welfare
Committee Hearing HB#2255
Topeka, KS 66612

March 19, 1997

Dear Senators:

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

PKU is an inherited metabolic disorder that, when left untreated, results in 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, and convulsions.

My daughter was left untreated until age seven. 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 affect 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.

Angie has been misdiagnosed as autistic because of affects 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. She has trouble putting words in the proper order in sentences. She 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 with

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holding on to things today.

Angie has also suffered from severe eczema which required the advice of a dermatologist. In an attempt to control the severe eczema and give her some relieve, prescription medicine had to be prescribed. Angie's eczema is better now she is 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 of four 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. If my husband works overtime to try to get ahead it effects 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 now is 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 required for her diet and pay our bills.

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 for your support of HB#2255. I know first hand, both the affects of PKU and the hardships of not being able to afford the expensive low protein modified foods. 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.

Denise Ferrer
1035 S.E. Lime Street
Topeka, KS 66607

March 19, 1997

Senate Committee of Public Health and Welfare
State of Kansas

Dear Committee Members, Senators, and Guests.

Thank you for this opportunity to testify before this committee, in favor of HB 2255.

My name is Mark Stueve, I currently reside at 2006 SW Washburn Terrace, Topeka, Kansas 66604-3135. My children and I have resided in Topeka since 1983.

I served as a sergeant in the USMC, including a tour in Viet Nam during 1969, and in the Kansas National Guard.

I have a Bachelor of Science degree from Kansas State in Construction Science, and have twenty years of experience in commercial construction, throughout the United States.

I am currently a law student at Washburn, and expect to obtain my Juris Doctor degree in May of this year.

I am a parent of three children, two with PKU -- Amy, age 19, and Joshua, age 13. (Ryan, age 16, does not have PKU). Both Amy and Josh have benefitted greatly from the restrictive PKU diet.

On the other hand, when not on the diet, their performance in school has progressively deteriorated. For children with PKU who are under six years of age, the diet is absolutely essential in order to avoid retardation!

Years ago, conventional thinking held that a special diet need only be maintained until approximately age six, because the brain is essentially developed at that age. We now know that deterioration of the brain results whatever the age of an affected person who is not on the "special" diet.

We recommend that special low-protein modified foods be made available for life for persons with PKU. This is especially important for women during childbearing age, because with proper diet the effects of the mother's PKU upon her child can be negated.

Amy was on the PKU special diet (in Iowa) from birth until age 6, when we moved to Topeka. She is trying to get re-adjusted to the special restrictive diet after being off it for many years. She has been struggling somewhat in college, but knows she will do better when she can get completely back on the diet.

Most college students I know, Amy and myself included, subsist on student loans or other borrowed money. College would be out of the question for Amy if she had to pay for the specially formulated medical supplements.

Josh has been off the diet since age 6. He was doing very poorly in school until he went back on the diet last fall. He adjusted more readily than Amy to the formula, and although he still requires more help than a "non-PKU" student, his grades have improved, and he has an improved outlook toward the future.

We now know that PKU persons must take regular blood tests and carefully monitor their levels of phenylalanine. Proper treatment requires a continuing and coordinated effort by: the afflicted child, peers, parents, extended family, school officials, medical personnel and government authorities. The family already bears a tremendous burden, without the extra expense of medical product and medical treatment, and should not be placed in a position where a choice must be made between medical product or treatment and other necessities.

PKU is permanent, but it is rare, and although the treatment is cumbersome and stressful, it is effective. We are fortunate to have the modern miracles of science and technology to bring to bear on the problem. The primary burden is being shouldered by responsible parents, who are, at times, overwhelmed by management of their PKU child's special needs. These needs are in addition to all of the other "ordinary" problems of parenting.

I don't have statistics to prove what I am going to say next. My conviction is that the difficulties involved with management of PKU are a source of stress and conflict and a contributing factor leading to divorce of PKU parents. (I feel this was true in my own case.) I feel that, without the continuing and coordinated effort currently being supported by the state, we would see a higher incidence of divorce among PKU parents. This would leave the problem in the hands of more single parents.

Although we have become conditioned to living in a society where divorce is common-place (fifty percent of first marriages end in divorce, and sixty percent of repeat attempts), I submit that PKU children are among those who most need the traditional two-parent family support.

We hope the State of Kansas will continue to support the treatment of PKU and pass this very important and vital legislation. Please vote YES on HB 2255!

Thank you for your consideration.

Mark Stueve

senator

HOUSE BILL No. 2129

By Committee on Appropriations

1-29

10 AN ACT concerning licensed masters level psychologists; practice
11 requirements; amending K.S.A. 1996 Supp. 74-5362 and 74-5363 and
12 repealing the existing sections; also repealing K.S.A. 74-5363, as
13 amended by section 124 of chapter 229 of the 1996 Session Laws of
14 Kansas.

15
16 *Be it enacted by the Legislature of the State of Kansas:*

17 Section 1. K.S.A. 1996 Supp. 74-5362 is hereby amended to read as
18 follows: 74-5362. Any person who is licensed under the provisions of this
19 act as a licensed masters level psychologist shall have the right to practice
20 only in a licensed community mental health center or one of its contracted
21 affiliates in any federal, state, county or municipal agency, or other po-
22 litical subdivision, ~~in a contracted affiliate or for a contractor of a fed-~~
23 ~~eral, state, county or municipal agency, or other political subdivision, in~~
24 a duly chartered educational institution, in a medical care facility licensed
25 under K.S.A. 65-425 et seq. and amendments thereto or in a psychiatric
26 hospital licensed under K.S.A. 75-3307b and amendments thereto, ~~or for~~
27 ~~a contractor of such educational institution, medical care facility~~
28 ~~or psychiatric hospital,~~ insofar as such practice is part of the duties of
29 such person's paid position and is performed solely on behalf of the em-
30 ployer, so long as such practice is under the direction of a person licensed
31 to practice medicine and surgery or a person licensed to provide mental
32 health services as an independent practitioner and whose licensure allows
33 for the diagnosis and treatment of psychological disorders. ~~Such licensed~~
34 ~~person~~ may use the title licensed masters level psychologist and the ab-
35 breviation LMLP but may not use the title licensed psychologist or psy-
36 chologist.

37 Sec. 2. K.S.A. 1996 Supp. 74-5363 is hereby amended to read as
38 follows: 74-5363. (a) Any person who desires to be licensed under this
39 act shall apply to the board in writing, on forms prepared and furnished
40 by the board. Each application shall contain appropriate documentation
41 of the particular qualifications required by the board and shall be accom-
42 panied by the required fee.

(b) The board shall license as a licensed masters level psychologist

Proposed Amendment LMLP

Employment limitations

A licensed masters level psychologist

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1 any applicant for licensure who pays the fee prescribed by the board
2 under K.S.A. 74-5365 and amendments thereto, which shall not be re-
3 funded, who has satisfied the board as to such applicant's training and
4 who complies with the provisions of this subsection (b). An applicant for
5 licensure also shall submit evidence verified under oath and satisfactory
6 to the board that such applicant:

7 (1) Is at least 21 years of age;

8 (2) has satisfied the board that the applicant is a person who merits
9 public trust;

10 (3) has received at least a master's degree in clinical psychology based
11 on a program of studies in psychology from an educational institution
12 having a graduate program in psychology consistent with state universities
13 of Kansas; or has received at least a master's degree in psychology and
14 during such master's or post-master's coursework completed a minimum
15 of 12 semester hours or its equivalent in psychological foundation courses
16 such as, but not limited to, philosophy of psychology, psychology of per-
17 ception, learning theory, history of psychology, motivation, and statistics
18 and 24 semester hours or its equivalent in professional core courses such
19 as, but not limited to, two courses in psychological testing, psychopa-
20 thology, two courses in psychotherapy, personality theories, developmen-
21 tal psychology, research methods, social psychology; or has passed com-
22 prehensive examinations or equivalent final examinations in a doctoral
23 program in psychology and during such graduate program completed a
24 minimum of 12 semester hours or its equivalent in psychological foun-
25 dation courses such as, but not limited to, philosophy of psychology, psy-
26 chology of perception, learning theory, history of psychology, motivation,
27 and statistics and 24 semester hours or its equivalent in professional core
28 courses such as, but not limited to, two courses in psychological testing,
29 psychopathology, two courses in psychotherapy, personality theories, de-
30 velopmental psychology, research methods, social psychology;

31 (4) has completed 750 clock hours of academically supervised prac-
32 ticum in the master's degree program or 1,500 clock hours of postgrad-
33 uate supervised work experience;

34 (5) has completed 2,000 clock hours of postgraduate work experience
35 under the supervision of a licensed psychologist or a currently licensed
36 master's level psychologist with three years' experience;

37 (6) for applicants on and after January 1, 1997, has passed an exam-
38 ination approved by the board with a minimum score set by the board by
39 rules and regulations at 10 percentage points below the score set by the
40 board for licensed psychologists; and

41 ~~(7) is in the employ of a Kansas licensed community mental health~~
42 ~~center, or one of its contracted affiliates, or a federal, state, county or~~
43 ~~municipal agency, or other political subdivision, or a contracted affiliate~~

7-2

7-3

1 ~~Contractor of a federal, state, county or municipal agency, or other po-~~
 2 ~~litical subdivision, or a duly chartered educational institution, or a medical~~
 3 ~~care facility licensed under K.S.A. 65-425 et seq. and amendments thereto~~
 4 ~~or a psychiatric hospital licensed under K.S.A. 75-3307b and amendments~~
 5 ~~thereto, or a contractor of such educational institution, medical~~
 6 ~~care facility or psychiatric hospital, and whose practice, in any such~~
 7 ~~employment, is a part of the duties of such applicant's paid position and~~
 8 ~~is performed solely on behalf of the employer.~~

9 (c) The board shall adopt rules and regulations establishing the cri-
 10 teria which an educational institution shall satisfy in meeting the require-
 11 ments established under item (3) of subsection (b). The board may send
 12 a questionnaire developed by the board to any educational institution for
 13 which the board does not have sufficient information to determine
 14 whether the educational institution meets the requirements of item (3)
 15 of subsection (b) and rules and regulations adopted under this section.
 16 The questionnaire providing the necessary information shall be com-
 17 pleted and returned to the board in order for the educational institution
 18 to be considered for approval. The board may contract with investigative
 19 agencies, commissions or consultants to assist the board in obtaining in-
 20 formation about educational institutions. In entering such contracts the
 21 authority to approve educational institutions shall remain solely with the
 22 board.

23 Sec. 3. K.S.A. 1996 Supp. 74-5362 and 74-5363 are hereby repealed.

24 Sec. 4. On July 1, 1997, K.S.A. 74-5363, as amended by section 124
 25 of chapter 229 of the 1996 Session Laws of Kansas, is hereby repealed.

26 Sec. 5. This act shall take effect and be in force from and after its
 27 publication in the Kansas register.

See attached Sec. 3.

Sec. 4. Amendment to K.S.A. 1996 Supp.
 74-5366 deleting employment requirement for
 renewal of license previously adopted by
 committee.

And by renumbering sections accordingly and
 changing the repealer and title accordingly.

Sec. 3. K.S.A. 1996 Supp. 74-5361 is hereby amended to read as follows: 74-5361. As used in this act:

(a) "Practice of psychology" shall have the meaning ascribed thereto in K.S.A. 74-5302 and amendments thereto.

(b) "Board" means the behavioral sciences regulatory board created by K.S.A. 74-7501 and amendments thereto.

(c) "Licensed masters level psychologist" means a person licensed by the board under the provisions of this act.

(d) "Masters level psychology" means the practice of psychology pursuant to the restrictions set out in K.S.A. 74-5362 and ~~74-5363~~ and amendments thereto.

Proposed Amendment to HB 2129

Sec. 3. K.S.A. 65-2895 is hereby amended to read as follows:
65-2895. (a) There is hereby created a designation of institutional license which may be issued by the board to a person who is a graduate of an accredited school of the healing arts or a school which has been in operation for not less than 15 years and the graduates of which have been licensed in another state or states which have standards similar to Kansas and who is employed by the department of social and rehabilitation services, employed by any institution within the department of corrections or employed pursuant to a contract entered into by the department of social and rehabilitation services or the department of corrections with a third party. An applicant for an institutional license shall pass an examination in the basic sciences approved by the board. The institutional license shall confer upon the holder the right and privilege to practice that branch of the healing arts in which the holder of the institutional license is proficient and shall obligate the holder to comply with all requirements of such license. The practice privileges of institutional license holders are restricted as follows: The institutional license shall be valid only during the period in which the holder is: (1) Employed by the department of social and rehabilitation services, employed by any institution within the department of corrections or employed pursuant to a contract entered into by the department of social and rehabilitation services or the department of corrections with a third party, and only within the institution to which the holder is assigned; or (2) employed to provide mental health services in the employ of a

Kansas licensed community mental health center, or one of its contracted affiliates, or a federal, state, county or municipal agency, or other political subdivision, or a contractor of a federal, state, county or municipal agency, or other political subdivision, or a duly chartered educational institution, or a medical care facility licensed under K.S.A. 65-425 et seq. and amendments thereto, or a contractor of such educational institution, medical care facility or psychiatric hospital, and whose practice, in any such employment, is limited to providing mental health services, is a part of the duties of such licensee's paid position and is performed solely on behalf of the employer.

(b) An institutional license shall be valid for a period of two years after the date of issuance and may be renewed if the applicant for renewal is eligible to obtain an institutional license under this section, has successfully completed the examination required under subsection (a)(3) of K.S.A. 65-2873 and amendments thereto and has submitted evidence of satisfactory completion of a program of continuing education required by the board. The board shall require each applicant for renewal of an institutional license under this section to submit evidence of satisfactory completion of a program of continuing education required by the board of licensees of the branch of the healing arts in which the applicant is proficient.

(c) This section shall be a part of and supplemental to the Kansas healing arts act.

And by amending the repealer and title accordingly.