

**FISCAL NOTE**  
**Requested by Legislative Council**  
**02/03/2017**

Amendment to: HB 1187

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2015-2017 Biennium		2017-2019 Biennium		2019-2021 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
<b>Revenues</b>						
<b>Expenditures</b>			\$31,200		\$40,032	
<b>Appropriations</b>			\$31,200		\$40,032	

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2015-2017 Biennium	2017-2019 Biennium	2019-2021 Biennium
<b>Counties</b>			
<b>Cities</b>			
<b>School Districts</b>			
<b>Townships</b>			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

The Engrossed Bill amends NDCC relating to the medical food program for phenylketonuria (PKU) or maple syrup urine disease (MSUD) by extending metabolic food & low-protein modified food products to males with PKU and MSUD under age 26 & to offer for sale at cost, medical food to males age 26 & over.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

The engrossed bill will result in additional males being covered under the program up to age twenty-six. For the 2017-2019 biennium we estimated there would be 5 additional males added to the program and 6 males added for the 2019-2021 biennium.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*
- B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

For the 2017 – 2019 biennium the average monthly costs per individual on the program is estimated to be \$260 multiplied by 5 individual resulting in a biennial cost of \$31,200.

For the 2019-2021 biennium the average monthly cost per individual on the program is estimated to be \$278 based on an estimated 7% increase in formula costs multiplied by 6 individuals resulting in a biennial cost of \$40,032.

As there is no identified funding source the costs would need to be covered by the general fund.

- C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation or a part of the appropriation is included in the executive budget or relates to a continuing appropriation.*

The amount is not reflected in the DoH's appropriation. Therefore, an appropriation would be necessary.

**Name:** Brenda M Weisz

**Agency:** Department of Health

**Telephone:** 328-4542

**Date Prepared:** 02/06/2017

**FISCAL NOTE**  
**Requested by Legislative Council**  
**01/09/2017**

Bill/Resolution No.: HB 1187

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2015-2017 Biennium		2017-2019 Biennium		2019-2021 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
<b>Revenues</b>						
<b>Expenditures</b>			\$243,360		\$273,552	
<b>Appropriations</b>			\$243,360		\$273,552	

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2015-2017 Biennium	2017-2019 Biennium	2019-2021 Biennium
<b>Counties</b>			
<b>Cities</b>			
<b>School Districts</b>			
<b>Townships</b>			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

The Bill amends NDCC relating to the medical food program for phenylketonuria (PKU) or maple syrup urine disease (MSUD) and eliminates the age limits and the sale of medical food at cost for individuals served by the Health Department.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

The bill will result in additional individuals being covered under the program by removing the age limits and sale of medical food at cost. Data indicates that one baby each year is born with PKU and one baby born every 20 years with MSUD. For the 2017-2019 biennium we estimated there would 39 individuals added to the program and 41 individuals added for the 2019-2021 biennium.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*
- B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

For the 2017 – 2019 biennium the average monthly costs per individual on the program is estimated to be \$260 multiplied by 39 individual resulting in a biennial cost of \$243,360.

For the 2019-2021 biennium the average monthly cost per individual on the program is estimated to be \$278 based on an estimated 7% increase in formula costs multiplied by 41 individuals resulting in a biennial cost of \$273,552.

As there is no identified funding source the costs would need to be covered by the general fund.

- C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation or a part of the appropriation is included in the executive budget or relates to a continuing appropriation.*

The amount is not reflected in the Governor's budget and an appropriation would be necessary.

**Name:** Brenda M Weisz

**Agency:** Department of Health

**Telephone:** 328-4542

**Date Prepared:** 01/13/2017

**2017 HOUSE HUMAN SERVICES**

**HB 1187**

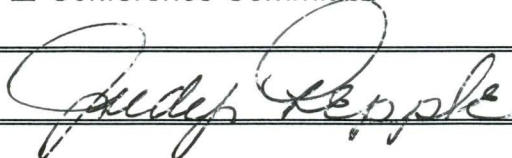
# 2017 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee  
Fort Union Room, State Capitol

HB 1187  
1/17/2017  
26977

- Subcommittee  
 Conference Committee

Committee Clerk Signature



## Explanation or reason for introduction of bill/resolution:

Relating to the medical food program for phenylketonuria or maple syrup urine disease.

## Minutes:

1, 2, 3

Chairman Weisz: Called the committee to order.  
Chairman Weisz: Opened the hearing on HB 1187

Rep. Lois Delmar to introduce HB 1187  
(Attachment 1)

Chairman Weisz: How many would this effect if you make this change?

Rep. Delmar: I don't know, but the health care people can tell you more. It is a very low number. It is one of those things that is preventative and it means you can pay now or pay a lot more later.

Chairman Weisz: Do you remember the rationale at the time as to why we limited it to 21 and 45?

Rep. Delmar: We decided there were limited resources at that time, so we tried to cover the most vulnerable. Really people are vulnerable no matter what stage of life they are in. Some of these foods are very expensive and if insurance doesn't pick it up, they can end up costly a great portion of their income to cover it.

Representative Westlind: Can you explain what this is?

Rep. Delmar: It is diagnosed at various stages of life, but it is best if diagnosed at birth, so they can be treated with food without the protein. They can't metabolize protein and it leads to a long list of disabilities if left untreated. Emotional, physical, and intellectual implications.

Chairman Weisz: You can't have protein, so you need very specialized foods.

Vice Chairman Rohr: So this bill basically now opens it up to everyone. They used to have to pay for the food and supplements and now we will pay for everything. I believe what this would do is allow the insurance companies to pay for it.

Chairman Weisz: Further questions from the committee?

Representative Skroch: On line 19 it says, "The department". Which department are you referring to?

Rep Delmar: Human Services Dept. It looks like the fiscal note says 39 individuals.

Representative Skroch: If insurance is being billed for it then why does the department need to be reimbursed?

Rep. Delmar: Maybe there are some that don't have insurance. I really don't know the answer to that question.

Chairman Weisz: Further questions from the committee?

Senator Kreun

I am before you to support HB 1187. You have a pretty good overview of the medical needs that this requires. Technically it requires that all through their life. The change that I view is necessary and if you look on line 16 and 17 it is the miracle food originally at no cost to males under age 22 and females under 45. We changed that to individuals diagnosed with these diseases. From my experience of 13 years of dealing with children and young adults our society has changed a great deal. Chairman Weisz, you brought that up as the reason was probably childbearing nutrition. Our society has changed over a period of time and childbearing is very important, but now we have child rearing. The male aspect has been far more prevalent in the last 10 or 12 years than it has in the past. This is an ongoing life illness that requires good nutrition and also as Rep. Delmar indicated there are severe repercussions if we don't follow through with this. My understanding is that as we get older the repercussions could be less, but they don't go away. It becomes more important if we are going to rear children as a family it is more important that we have an equal portion. More men than women now. Requires good nutrition all of their life. I would urge you to support HB 1187

Chairman Weisz: Questions

Representative P. Anderson: On the back page on line 3, why do they leave in the ages and they are taken out everywhere else. Is there a reason for that?

Senator Kreun: There is a difference between the two foods. If you look at one it is a low protein modified food product. That is not quite as extreme as the other one. The other one is medical food. This is just a low protein. If you would prefer, I have an amendment to fix that. I did anticipate that question and I would leave it up to this group to determine if that is a need.

Representative P. Anderson: It says for people that are receiving medical assistance. So, if they are on Medicaid do we still have an age limit?

Senator Kreun: I don't know if there is an age limit on the particular portion of it. That goes back to the question about government programs. If the government program is available, then they would utilize that program for the food programs that are available especially if they qualify for that financially. My understanding is that there are a couple of food programs for the younger age kids that are on this type of diet.

Vice Chairman Rohr: Not an agency bill so how was it brought forth?

Senator Kreun: Rep. Delmar brought this forward. I looked at it closely and decided both male and female should have the same opportunities at any age.

Representative McWilliams: What is a medical food?

Senator Kreun: A very specific food put together in only a couple places in the US. Each diet is specifically made for that individual. It is not something you can go home and blend and put in the mixer and design yourself. I am sure the parent and child coming up can give you more information.

Chairman Weisz: Further questions from the committee?  
Thank you Senator.

Chairman Weisz: Is there further testimony in support of HB 1187?

S. Mullane, parent of a child with PKU  
(Attachment # 2)  
16:54

Chairman Weisz: Are there any questions from the committee?  
24:00

Representative Kiefert: Are there people now without knowledge of the fact that they have this disease?

S. Mullane: No, every infant born now is tested within 10 days of their life. Oldest person living now is 57 years old and in an institution. They don't live very long after they are institutionalized.

Chairman Weisz: Further questions from the committee?

Vice Chairman Rohr: Can you tell us if your insurance gave you any help?

S. Mullane: When he was first born we were denied by Tricare. That was our insurance at the time in the military. Now we have federal blue cross and what they cover is only what is left when we go to medical visits. We go once every 6 months in Fargo and there is a huge team of doctors we see. They bill the insurance and whatever is left after our copays, ND



Blue Cross picks up the rest of that. Right now ND is paying for my son's formula which is the medical formula. He has the low protein foods and we have been having to buy that before, but now ND is providing some support for low protein foods. That is also very expensive. For an example, a loaf of bread is \$12.50. A package of noodles is \$8.75. Without ND's support we would probably have filed bankruptcy and we would be living....I don't know where.

Chairman Weisz: Further questions from the committee.

Chase Mullane: I have PKU.  
(Attachment 3)  
27:30

30:44

Chairman Weisz: Are there questions from the committee?

Representative Westlind: Can you describe your daily diet? Do you eat fruits and vegetables?

C. Mullane: Basically what my diet consists of is fruits, vegetables, and grains, but even grains are limited. Like one slice of bread would be about 3 grams of protein, so if I ate 4 slices of bread I wouldn't be able to eat much the rest of the day. It is pretty severe. The slice of bread with 3 – 4 grams of protein is compared to a slice of bread with 0 grams of protein that I can eat.

Chairman Weisz: Are there further questions for Chase?

Chairman Weisz: Is there any further testimony in support of HB 1187?

Tammy Johnson, program administrator with the ND Dept. of Health  
I oversee the medical formula program. I would just like to take a couple of minutes to clarify some of the questions that some of you had. The medical formula or the medical food Chase and any male can receive it through their 21<sup>st</sup> birthday. It stops when they turn 22. The females are the same way until they turn 45. The ND Dept. Health Children's Special Health Services is the division that oversees that and the way that the bill is written we are the first payer. It does reflect that insurances can pay for it, but often times those families come to us first and we don't have any way to make sure that insurance is paying the coverage that they should. We are told at times that Blue Cross Blue Shield may pay up to \$3000, but we don't get that feedback from the families. So there is some insurance coverage, but it would be up to the family then to make sure that the bills when they order formula are submitted to the insurance company. This is a life long diet and when this coverage was set up in the beginning it was to cover women until they were done with child bearing. There were a couple other questions. Is there something else that I can specifically answer?

Chairman Weisz: Do you have any data that shows if some of these go off of the program? Do you have any statistics of the results of that?

Tammy: Once they are off the program we don't track it anymore. They can still order the formula through us at cost, so they are not paying what they would through a pharmacy, but they get it at cost. Once they have transitioned off the program we don't track them any longer.

Chairman Weisz: Do you have any idea how many are ordering through you?

Tammy: About 20 – 25 a year. It stays pretty steady, because you have some babies born. Now we have about 1 -2 born in a year. When we are looking at the projection of how many people will be coming on to the program there was a time when weren't tracking those statistics so we used the formula of one child born per year. That would be 27 individuals possibly with PKU, 2 individuals with MSUD, and then folks that have transitioned off the program since 1996. That's how we came up with the numbers.

Representative Seibel: If the family has to buy the medical formula at retail price, how much would it cost? I am sure it varies depending on the formula.

Tammy: It varies due to the formula. The numbers that we used in our fiscal note is an average number. I believe the number is \$260/month so that is an average number with people with PKU and MSDU. The average user of that formula probably uses about 2 cases a month, so that can be anywhere from \$500 or \$600 a month or more. Some of the formula is more expensive than others. We don't make the decision about what formula they use. That is made through their metabolic team.

Representative Seibel: So the \$278 for the next biennium, is that the cost or the retail?

Tammy: That would be the cost. That is what we pay for it.

Vice Chairman Rohr: Through research, what has changed in the treatment of PKU? Are we getting smarter? Do we have better treatment protocols?

Tammy: They do have a better management of diet and there are changes in the formula. What we are looking at now, some of those formulas that are being requested are more expensive, but they have a lesser calorie count. Often times some individuals with PKU have a difficult issue with managing their weight. They are trying to keep their weight down and those formulas tend to be more expensive than the traditional ones. Their team manages that for them.

Representative Devlin: About 20 – 27 are the average of people that are on the program, but the fiscal note is for 39. Is that for the people that have transitioned off before because of age that would be coming back on or is there something else that I am missing?

Tammy: We average between 20 and 27 every year for the people that are continually on the medical food. Those numbers that we came up with are those people that have transitioned off or those people that were born once they started doing the heel stick test. That started in 1964 , so we are assuming there was probably a baby a year born during that

time. We don't have those statistics so those 39 people coming back on are potential people that have PKU or MSUD or they have transitioned off of the formula program.

Representative Devlin: Tell me how many other states cover this the way ND does and how many other states have looked at making this change?

Tammy: I don't have those numbers, but as Mrs. Mullane had referred to there are very few states that cover the way that ND does. The other thing is that we could do a bit more research, but around our state there aren't that many. We can still provide that formula if they go to college, but if they take up residence in another state, we can no longer provide that.

Chairman Weisz: Is there further testimony in support?  
Is there any opposition to HB 1187?

Closed hearing.

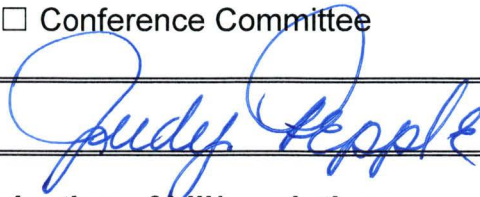
# 2017 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee  
Fort Union Room, State Capitol

HB 1187  
1/31/2017  
27684

- Subcommittee  
 Conference Committee

Committee Clerk Signature



## Explanation or reason for introduction of bill/resolution:

Relating to the medical food program for phenylketonuria or maple syrup urine disease

## Minutes:

1

Chairman Weisz: Called committee to order

We will start out with HB 1187.

Representative Devlin: Do you have something for us?

Representative Devlin: Passing out an amendment put together by Rep. Delmore, but she couldn't be here today. (Attachment 1)

Chairman Weisz: It moves the age of the male to 25 and leaves everything else alone. Are there any questions from the committee?

Representative Skroch: We were looking at the data of being able to help them afford this, but as I look at this it is increasing the age.

Chairman Weisz: The original bill took away the age limits, but this amendment increased the current age from 21 to 25. At least it gives those males a chance to get through college, get established before they are responsible for paying for this on their own. It is an increase from current law, but a decrease from the bill that was put forth.

Representative Devlin: I moved to accept the amendments to HB 1187

Representative Seibel: second

Chairman Weisz: any discussion on the amendments?

For the committee, I had some discussion with the department. I was concerned that the insurance wasn't the primary. That we didn't go to the insurance first. There are a lot of complications with that since the state purchase the medical formula at way cheaper than the person can buy and because many insurance companies, of course, dictate where it has

to go through they felt it was going to cost them more to try to do that than what it is costing to just give them the product. Currently with Wic they said for example that Wic will provide 9 cans. I don't know if that is a week or a month, but they need 10. So the state provides the 10<sup>th</sup> can for a lot less cost than what the other 9 cans cost because they go through a pharmacy. Wic doesn't get them through the state.

Representative McWilliams: After the age of 26 can they still buy the food from the state at cost?

Chairman Weisz: Yes, they can. Anyone can purchase the product from the state for cost for the rest of their life.

Chairman Weisz: further questions on the amendment? Seeing none we will have a voice vote on the amendment.

Voice vote taken on the amendments on HB 1187.

Chairman Weisz: Motion carried. Are there any more amendments? If not I will entertain a motion.

Vice Chairman Rohr: I move a do pass as amended on HB 1187

Representative McWilliams: second

Chairman Weisz: Discussion on the bill?

Seeing none, the clerk will call the roll for a do pass as amended on HB 1187.

Roll call taken    yes 14    No 0    Absent 0

Motion carried. Do I have a volunteer to carry it?

Vice Chairman Rohr will carry it. Thank you.

Adjourned.

*Done 1/31/17  
191*

PROPOSED AMENDMENTS TO HOUSE BILL NO. 1187

Page 1, line 16, remove the overstrike over "~~males under age~~"

Page 1, line 16, after "~~twenty-two~~" insert "twenty-six"

Page 1, line 16, remove the overstrike over "~~and females under~~"

Page 1, line 17, remove the overstrike over "~~age forty five who are~~"

Page 1, line 17, remove "individuals"

Page 1, line 18, remove "age or"

Page 1, line 22, remove the overstrike over "~~Offer for sale at cost medical food to females age  
forty five and over and to males age~~"

Page 1, line 23, after "~~twenty-two~~" insert "twenty-six"

Page 1, line 23, remove the overstrike over "~~and over who are diagnosed with phenylketonuria  
or maple syrup urine~~"

Page 2, remove the overstrike over lines 1 and 2

Page 2, line 3, remove the overstrike over "6."

Page 2, line 5, overstrike "twenty-two" and insert immediately thereafter "twenty-six"

Renumber accordingly

Date: 1-31-17  
Roll Call Vote #: 1

2017 HOUSE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. HB 1187

House Human Services Committee

Subcommittee

Amendment LC# or Description: 17.0639.01002

Recommendation:  Adopt Amendment  
 Do Pass     Do Not Pass     Without Committee Recommendation  
 As Amended     Rerefer to Appropriations  
 Place on Consent Calendar  
Other Actions:  Reconsider     \_\_\_\_\_

Motion Made By Rep. Devlin Seconded By Rep. Seibel

Representatives	Yes	No	Representatives	Yes	No
Chairman Weisz			Rep. P. Anderson		
Vice Chairman Rohr			Rep. Schneider		
Rep. B. Anderson					
Rep. D. Anderson					
Rep. Damschen					
Rep. Devlin					
Rep. Kiefert					
Rep. McWilliams					
Rep. Porter					
Rep. Seibel					
Rep. Skroch					
Rep. Westlind					

*voice to adopt the amendment - Carried*

Total (Yes) \_\_\_\_\_ No \_\_\_\_\_

Absent \_\_\_\_\_

Floor Assignment \_\_\_\_\_

If the vote is on an amendment, briefly indicate intent:

Date: 1-31-17  
Roll Call Vote #: 2

2017 HOUSE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. HB 1187

House Human Services Committee

Subcommittee

Amendment LC# or Description: \_\_\_\_\_

Recommendation:  Adopt Amendment  
 Do Pass  Do Not Pass  Without Committee Recommendation  
 As Amended  Rerefer to Appropriations  
 Place on Consent Calendar  
Other Actions:  Reconsider  \_\_\_\_\_

Motion Made By Dee Dee Lohr Seconded By Rep. McWilliams

Representatives	Yes	No	Representatives	Yes	No
Chairman Weisz	✓		Rep. P. Anderson	✓	
Vice Chairman Rohr	✓		Rep. Schneider	✓	
Rep. B. Anderson	✓				
Rep. D. Anderson	✓				
Rep. Damschen	✓				
Rep. Devlin	✓				
Rep. Kiefert	✓				
Rep. McWilliams	✓				
Rep. Porter	✓				
Rep. Seibel	✓				
Rep. Skroch	✓				
Rep. Westlind	✓				

Total (Yes) 14 No 0

Absent \_\_\_\_\_

Floor Assignment Rep. Lohr

If the vote is on an amendment, briefly indicate intent:



REPORT OF STANDING COMMITTEE

HB 1187: Human Services Committee (Rep. Weisz, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (14 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). HB 1187 was placed on the Sixth order on the calendar.

Page 1, line 16, remove the overstrike over "~~males under age~~"

Page 1, line 16, after "~~twenty-two~~" insert "twenty-six"

Page 1, line 16, remove the overstrike over "~~and females under~~"

Page 1, line 17, remove the overstrike over "~~age forty five who are~~"

Page 1, line 17, remove "individuals"

Page 1, line 18, remove "age or"

Page 1, line 22, remove the overstrike over "~~Offer for sale at cost medical food to females age forty five and over and to males age~~"

Page 1, line 23, after "~~twenty-two~~" insert "twenty-six"

Page 1, line 23, remove the overstrike over "~~and over who are diagnosed with phenylketonuria or maple syrup urine~~"

Page 2, remove the overstrike over lines 1 and 2

Page 2, line 3, remove the overstrike over "6:"

Page 2, line 5, overstrike "twenty-two" and insert immediately thereafter "twenty-six"

Re-number accordingly

**2017 SENATE HUMAN SERVICES**

**HB 1187**

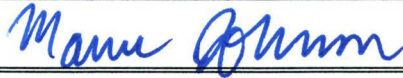
# 2017 SENATE STANDING COMMITTEE MINUTES

Human Services Committee  
Red River Room, State Capitol

HB 1187  
3/1/2017  
Job Number 28580

- Subcommittee  
 Conference Committee

Committee Clerk Signature



## Explanation or reason for introduction of bill/resolution:

A bill relating to the medical food program for phenylketonuria or maple syrup urine disease.

## Minutes:

2 Attachments

**Chair J. Lee:** Brought the public hearing to order. All members were present.

**Rep. Lois Delmore, District 43 (0:37-2:20) Introduced the bill, testified in favor.** This bill would provide testing for infants and later provide increased access to specialty foods for individuals diagnosed with phenylketonuria (PKU). Milk, eggs, cheese, soybeans etc. must be avoided by people with PKU. This bill helps provide food at little or no cost for specific individuals diagnosed with PKU. The bill would cover males up to 26, we've covered women through child bearing years, because it proves cost effective.

**Senator Kreun, District 42, testified in favor. Please see attachment #1 for amendment.** Stated that since society is changing and males aren't necessarily the breadwinners anymore, the ages provided for should be the same, so that there isn't a cessation of coverage that would make members of the family ill.

My thought on this bill was that both be the same, if you look on page 1 line, 16 "at no cost – individuals diagnosed," there's no age limit. When we testified in front of the House, they were going to change on page 2, they still have line 4: females under the age of 45, males under 22; I have an amendment here, to match that first portion on page one, line 16.

**V-Chair Larsen:** If a person has this PKU, does the food get covered by Medicaid? It turns into like a medicine?

**Senator Kreun:** We have other people who can verify this, there are certain portions that are paid for by insurances. We would be the secondary provider at that time. This is a lifelong condition, there's only one or two places in USA that prepare this food, because it's for individual use only. What I'm saying is some people hit 44, won't be able to pay, end up with deficiency, it's a lot cheaper to serve it in the beginning than the end.

**Chair J. Lee:** I have performed the blood test on newborns for PKU diagnosis. There is a breakdown in the ability to metabolize food, very quickly it becomes a problem. As a result

of buildup of the ketones, the infant has intellectual disabilities; we end up providing supports for them, if they get the special food, they develop normally. That's the deal here, investing in the food, instead of services for intellectually disabled children.

**Senator Kreun:** That's exactly what I'm saying. The fiscal note is only \$50,000 a year. With the amendments we'll have to clean up that. It was supposedly the right number.

**Chair J. Lee:** If you want these both the same, then your amendment ends up saying, provides low protein modified food products as medically necessary as determined by a qualified health care provider, individuals 26--

**Senator Kreun:** That can be taken out, it should just say individuals.

**Chair J. Lee:** We'll have to rework the amendment. It should be the same as the front page.

### **No opposition**

**Tammie Johnson, Program Administrator ND Department of Health (DoH), Division of Children's Special Health Services (12:25-16:20) testified neutral, please see attachment # 2.**

**Senator Piepkorn:** How is this condition diagnosed?

**Ms. Johnson:** With a newborn test, heel poke, that simple test is completed and sent into a lab.

**Senator Anderson:** We have an amendment; those 4 additional years would mean that there's 5 additional individuals. Is that a good average? One ages out each year? For each year we add we can add one individual? What is their life expectancy? Do you have numbers about what we can expect if we open it up?

**Ms. Johnson:** We came up with that number based on number of males that aged out of the program or would age out during the biennium, we don't have a way of knowing how many people for certain out there over those age ranges; we didn't keep those statistics. Statistically, there is 1 child born every year with PKU. One child in every 10,000-15,000 births. MSUD is higher 1 in 185,000 births, we expect someone with MSUD to be about 1 in every 20 years. We average that with births in North Dakota.

**Senator Anderson:** When you were in the House, what did you discuss relative to the funding? Was the perception that you had enough money in the budget? You're talking about and additional \$30,000 for 5 individuals.

**Ms. Johnson:** When we spoke to the House, and they had no age requirements, that fiscal note was larger, about \$200,000 to include the additional people that would come on. The \$30,000 would just be for the added 5 individuals, we took the average of 260 a month time 5 times 24 months. That's how we came up with that figure.

**Chair J. Lee:** Did the original bill have unlimited ages throughout?

**Ms. Johnson:** Yes, they had unlimited ages throughout. The males currently receive until they turn 22; and females until 45 because of that childbearing age. We do know that women of childbearing age, that are planning to have children have a high risk of having a child with severe impairments if they're not currently on the right diet. It wasn't trying to pick women over men, it was based on ability to have children and affecting that child.

**Chair J. Lee:** Senator Kreun, your amendment would leave the regardless of income parts with the age restriction on, but those that are on Medicaid, that would be regardless of age is that what your goal was?

**Senator Kreun:** Yes.

**Chair J. Lee:** We would need a new fiscal note.

**Senator Kreun:** The 45 year range for the female that's usually past child bearing years.

**Ms. Johnson:** That's not the case anymore.

**Senator Kreun:** That's my point; society has changed. With a dynamic family, it should be relatively equal because all you're looking at childbearing age difference; what about the family being taken care of. If you're looking at it for the benefit of the child, I think we ought to look at the whole family.

**Chair J. Lee:** As she said, if that woman who gets pregnant doesn't have appropriate food, significant developmental issues happen to the child.

**Senator Anderson:** We don't give prenatal vitamins to men, just women.

**Senator Piepkorn:** What can you eat?

**Ms. Johnson:** Many of the foods are low protein, not all fruits and vegetables, there's a special flour for making their own bread, it is very difficult, but the diet is a very important part, as well as the formula, they have to do both to have an optimal outcome, that's basically their diet. They work with dietician for their whole life. When the discussion was going on about the coverage of Medicaid, and North Dakota Medicaid doesn't cover these formulas, even though they are a medical food, they do not cover any of them. The medical assistance with the low protein foods, if they receive medical assistance, and they're under those age ranges that we have, we will order those foods for them they get them at no cost, but they have to be eligible for Medicaid. Medicaid does not pay for formula or low-protein foods.

**Chair J. Lee:** So they could get them at cost?

**Ms. Johnson:** If they were over age?

**Chair J. Lee:** They have to qualify for medical assistance in order to get low protein food, but Medicaid doesn't pay for it. So the Department pays for it?

**Ms. Johnson:** The Medicaid requirement for us is so that we pay for the low protein foods, they have to meet those low income guidelines, but the formula that they have to take daily, that isn't covered by Medicaid, so Children Special Health Services, or the Department for Health provides formula to everybody regardless of income.

**Chair J. Lee:** Closed the Public Hearing.

# 2017 SENATE STANDING COMMITTEE MINUTES

Human Services Committee  
Red River Room, State Capitol

HB 1187  
3/7/2017  
Job Number 28825

- Subcommittee  
 Conference Committee

Committee Clerk Signature



## Explanation or reason for introduction of bill/resolution:

A bill relating to the medical food program for phenylketonuria or maple syrup urine disease.

## Minutes:

No attachments

**Chair J. Lee:** Brought the hearing for committee action on HB 1187. All members were present.

**Senator Anderson:** We need to make incremental changes, if we're going to change this thing. The way it came to us is an incremental change. If we remove the limits altogether, the actuarial study and fiscal note have to be redone. I disagree with Senator Kreun, there is a difference between women and women. This is one of the cases where it comes to the top.

**Senator Kreun:** What is your suggestion then?

**Senator Anderson:** We should leave it like it is.

**V-Chair Larsen:** The change to 26 is to stay in line with the socialized medicine I'm ok with that. I wouldn't support it after that. It's \$250 a year, is what they're saying.

**Chair J. Lee:** No, it's way more than that. It's thousands of dollars.

**Chair J. Lee:** Its \$31,200. Its 260 multiplied by 5...

**Senator Anderson:** it's \$250 for the diet you would be on.

**V-Chair Larsen:** At 26 years you should get a job to pay for your diet.

**Senator Kreun:** I respect the conversation, but it's way more money than what you're talking about, it's thousands of dollars a year. There's only 2 places in in the country you can buy the formula from. A loaf of bread is \$30. My point is our society isn't male/female society any more. What we do for one, why not do for the other? We just passed a bill for some women's thing on the floor. I would vote to next session to eliminate that. Why would we do these

things when our society is blending together as far as responsibilities go in the family? You mentioned prenatal vitamins, why do we do that? What if they never get pregnant?

**Senator Kreun:** Why do we do that? It's just as good a deal if the male parent is the one taking care of the kids. If he's not capable of doing it, how are they going to make the money to supply that? I would amend it to 45 and make it equal.

**Senator Anderson:** We're not giving them the food or the formulary to protect the mother. It's for the potential child.

**Chair J. Lee:** It costs a lot of money to care for a child who is born with PKU that is not cared for properly, it will end up with intellectual difficulties that cost us a million dollars.

**Senator Kreun:** If that mother goes to work, and the father has that, we're going to be taking care of the father just as well.

**Chair J. Lee:** It has to do with the physiology of the thing. It doesn't have to do with gender equality. It has to do with the fetal health of the child, that's why it goes to 45.

**Senator Kreun:** I understand that aspect but there are other aspects in our changing society that will require the same care.

**Chair J. Lee:** I'm very glad to see that too.

**Senator Heckaman:** I move do pass.

**V-Chair Larsen:** Second.

**A roll call vote was taken.**

**Motion passes 4-2-1.**

**Senator Heckaman will carry.**

**Vote was held for Senator Piepkorn. He recorded his vote on Job Number 28882.**

**Final vote was 5-2-0.**

**Chair J. Lee:** Closed the hearing.



Date: 3/7 2017

Roll Call Vote #: 1

2017 SENATE STANDING COMMITTEE  
ROLL CALL VOTES

BILL/RESOLUTION NO. 1187

Senate Human Services Committee

Subcommittee

Amendment LC# or Description: \_\_\_\_\_

Recommendation:  Adopt Amendment  
 Do Pass     Do Not Pass     Without Committee Recommendation  
 As Amended     Rerefer to Appropriations  
 Place on Consent Calendar

Other Actions:  Reconsider     \_\_\_\_\_

Motion Made By Sen Heckaman Seconded By Sen. Larsen

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee (Chairman)	X		Senator Joan Heckaman	X	
Senator Oley Larsen (Vice-Chair)		X	Senator Merrill Piepkorn	X	
Senator Howard C. Anderson, Jr.	X				
Senator David A. Clemens	X				
Senator Curt Kreun		X			

Total (Yes) 5 No 2

Absent 0

Floor Assignment Sen. Heckaman

If the vote is on an amendment, briefly indicate intent:

**REPORT OF STANDING COMMITTEE**

**HB 1187, as engrossed: Human Services Committee (Sen. J. Lee, Chairman)**  
recommends **DO PASS** (5 YEAS, 2 NAYS, 0 ABSENT AND NOT VOTING).  
Engrossed HB 1187 was placed on the Fourteenth order on the calendar.

**2017 TESTIMONY**

**HB 1187**

A.H. 1 HB 1187  
1-17-17

Chairman Weisz and Members of the House Human Services Committee-

For the record, I am Rep. Lois Delmore from District 43 in Grand Forks.

I am here today to introduce House Bill 1187 on medical food programs for individuals with PKU.

When I was a freshman legislator, I became aware of PKU and was asked to co-sponsor a bill to provide testing for infants and provisions for speciality foods which are critical to these individuals. Early diagnosis and a lifetime diet with very limited intake of protein are essential to people diagnosed with PKU. Today I am here to ask that you provide this access to all individuals diagnosed with PKU.

Milk, eggs, cheese, nuts, soybeans, beans, chicken, beef, pork, fish, potatoes, and the list goes on, must all be avoided by people with PKU.

HB 1187 provides food at no cost for all individuals diagnosed with PKU.

Preventative treatment can help these individuals live quality lives.

There are others here to testify today on this bill who are far more knowledgeable on PKU than I am.

I would be happy to answer any questions I can, and would urge your favorable consideration of House Bill 1187. Thank you, Mr. Chairman.

1-19-17  
A.H. Z  
HB 1187

Respectable committee members:

This bill means a great deal and is very personal to me. You see my son Chase has PKU. Let me give you a brief summary about this disease.

- \* PKU is a metabolic disease in which the body cannot process a part of protein called Phenylalanine. If left untreated, PKU can lead to severe and progressive mental retardation.
- \* 1 in 19,000 people is born with PKU.
- \* In order to remain healthy, individuals with PKU are limited to a highly restrictive low-protein diet and must consume a liquid medical formula every day for the rest of their lives.
- \* Living with PKU is difficult. The specially manufactured low protein food and medical formula are extremely expensive. The average family cannot afford them without assistance.
- \* This restrictive diet proves challenging for teens and adults. There are social and educational difficulties that come with PKU.
- \* Women with PKU face dilemma in planning a pregnancy. Infants of mothers with high phenylalanine levels exhibit mental retardation, heart defects, and growth retardation.
- \* There are estimated 20,000 people in the US with a metabolic disease.
- \* If a person discontinues diet at an early age they will experience and average IQ drop of about 12 points, and will continue to drop as long as they are off diet.
- \* Adults not on diet will experience depression, impulse control disorder, phobias, epilepsy, tremors and pareses.

I can't begin to tell you how this disease has turn my family's world upside down. I know families that have filed for bankruptcy, had to live in their cars to be able to afford the cost of just feeding their child with PKU. Since Chase's birth we had to make many sacrifices, we had to uproot our family which included 2 older siblings and move to a new state. My husband had to give up his military career and take a lower position in a new state; I also had to quit my job. Finding a place to live and new jobs was a hectic and scary time for us as we had to learn how to deal with this disease, PKU, and worry about how we were going to afford it. Long story short we moved to ND. This was one of the only states that offered support for families with children who had PKU. We moved here and we were welcomed. It has meant everything to us to have exceptional care, exceptional doctors, and overall it's been the best place for my husband and I to raise our family. I have learned how to be an advocate for my son and have tried to teach him to be one for himself. And so we find ourselves here asking you for help.

The laws in place now were worked on by excellent people, but more needs to be done. This disease does not go away, people do not outgrow it. It is a lifelong disease that needs to have lifelong treatment. As it stands today, my son will lose his support at the age of 21. This will be a life threatening event for my son.

Everything negative or life threatening to people with PKU basically evolves around 2 simple factors: Diet and Formula (metabolic foods). The ability to be able to afford or have access to these imperative factors for life can either keep my son healthy and productive member of society or it can cause him to be institutionalized in a mental health facility. I'm sure you are aware of companies charging exuberant amounts of money for medical treatments no matter what it may be. The same is true for people with PKU.

**The costs of treating an individual with untreated PKU can be up to 13 times the cost of providing proper treatment. Screening and lifelong care for people with PKU will result in a net gain to taxpayers and a cost-savings to the government. (PKU Alliance)**

*\*Average yearly cost for treatment of PKU = \$15,000(medical food and medical visits)*

*\*Average cost of untreated PKU patients= \$ 60,000 to \$200,000(inpatient mental health facilities or treatment centers)*

A person treated with PKU lives normal life. They work and pay taxes, raise families and live productive lives. A person who is not treated have severe brain damage, can't work, and require costly care. I urge the members of this committee to support this bill to ensure that Chase and others like him will become productive members of North Dakota.

Thank you for your time,

Sherry Mullane

2

A.H. 3  
HB 1187  
1-17-17

Hello, my name is Chase Mullane. I'm 18 and a senior at Grand Forks Central High School, with plans to attend a technical college in the spring pursuing a degree in HVAC. I have Phenylketonuria. I would like to explain my hardships with living with it and how North Dakota has helped and supported me.

Firstly, North Dakota providing me with the money to be able to afford my formula and other metabolic foods has got me to the point I am today, there is no doubt that without the support I have received from this state I would not be the same person standing in front of you. But this may come to an end shortly unless this committee decides to support this bill, as it is written now I will only get support until I reach the age of 21, changing this bill would give me a chance to be able to stay in North Dakota to grow to be a productive tax paying citizen. And in the future when I'm able to start a family I will not have to worry about the needs of my children or their future as the chances of my child having PKU can be up to 50%.

Secondly, some of the hardships I have experienced have been from being bullied to peer pressure to learning how to deal with staying on diet. The very strict diet I have and the formula I drink is basically my life line. I know that if I don't stay on diet I face a chance of becoming mentally retarded and have irreversible brain damage. Because of my PKU I have also been diagnosed with other disabilities that have made school more challenging for me than for a kid who does not have PKU. I have had to learn how to be an advocate for myself at a young age which has helped me deal with these hardships.

If this bill doesn't get passed it will negatively effect me for the rest of my life. When a person with PKU strays or goes off diet they suffer Irreversible brain damage that can lead to retardation. And that's not all, they can also experience the following, seizures, memory loss, loss of balance, short attention span, vomiting and speech problems. As you can see if my metabolic needs are not met I will slowly neurologically and physically deteriorate. Which means my

chances at finishing school are low due to the cost of my formula and physical side effects of leaving my strict diet. This will lead to not having a job that will pay me enough to be able to afford formula, this would be a terrible fate. I have seen in person the people that have decided to go off diet and how nonfunctional they have become compared to their old on diet selves.

This bill is going to decide my future for the best or for the worst, I cannot express how important this is me. Please consider letting me continue living a healthy lifestyle and staying in the great state of North Dakota, by supporting me for life.

Thank you

Chase Mullane



Att. 1 HB1187  
1-31-17

17.0639.01002  
Title.

Prepared by the Legislative Council staff for  
Representative Delmore  
January 30, 2017

PROPOSED AMENDMENTS TO HOUSE BILL NO. 1187

Page 1, line 16, remove the overstrike over "~~males under age~~"

Page 1, line 16, after "~~twenty-two~~" insert "twenty-six"

Page 1, line 16, remove the overstrike over "~~and females under~~"

Page 1, line 17, remove the overstrike over "~~age forty-five who are~~"

Page 1, line 17, remove "individuals"

Page 1, line 18, remove "age or"

Page 1, line 22, remove the overstrike over "~~Offer for sale at cost medical food to females age  
forty-five and over and to males age~~"

Page 1, line 23, after "~~twenty-two~~" insert "twenty-six"

Page 1, line 23, remove the overstrike over "~~and over who are diagnosed with phenylketonuria  
or maple syrup urine~~"

Page 2, remove the overstrike over lines 1 and 2

Page 2, line 3, remove the overstrike over "~~6.~~"

Page 2, line 5, overstrike "twenty-two" and insert immediately thereafter "twenty-six"

Renumber accordingly

17.0639.01001  
Title.

Prepared by the Legislative Council staff for  
Senator Kreun

January 16, 2017

HB 1187  
Attache #1  
3/1  
Pg. 1

PROPOSED AMENDMENTS TO HOUSE BILL NO. 1187

Page 2, line 4, overstrike "females under age forty-five and males under age"

Page 2, line 5, overstrike "twenty-two" and insert immediately thereafter "individuals"

Renumber accordingly

HB 1187  
Attach #2  
3/1  
Pg. 1

**Testimony  
House Bill 1187  
Senate Human Services Committee  
Wednesday, March 1, 2017  
North Dakota Department of Health**

Good afternoon, Chairman Lee and members of the Senate Human Services Committee. My name is Tammie Johnson, and I am a Program Administrator for the North Dakota Department of Health (NDDoH), Division of Children's Special Health Services (CSHS). I am here today to provide information about House Bill 1187.

Optimal management of Phenylketonuria (PKU) and Maple Syrup Urine Disease (MSUD) includes a lifelong diet of medical food (formula) and low-protein modified food products. Currently, NDCC 25-17-03 requires the NDDoH to:

- Provide medical food at no cost to males under age twenty-two and females under age forty-five who are diagnosed with phenylketonuria or maple syrup urine disease, regardless of income.
- Offer for sale at cost, medical food to males age twenty-two and over and females age forty-five and over who are diagnosed with PKU or MSUD, regardless of income.
- Provide low-protein modified food products, if medically necessary as determined by a qualified health care provider, to males under age twenty-two and females under age forty-five who are receiving medical assistance and are diagnosed with PKU or MSUD.

CSHS has managed this Metabolic Food Program since 2001. The formula provided by CSHS is purchased from a small number of medical food companies. The division maintains an inventory of frequently ordered formulas, which assures timely access for individuals served through the program. To date, twenty-eight individuals have received metabolic formula and/or low-protein food products through CSHS during the 2015-2017 biennium.

The NDDoH would like to provide information regarding the following sections of HB 1187:

- Section 1, Part 4, 5 and 6 – The proposed changes would expand the program to include provision of medical food (formula) at no cost to males

1187  
#2  
3/1  
Pg.2

with PKU or MSUD under age twenty-six, regardless of income. Low-protein modified food products would also be available for males under age twenty-six who are receiving medical assistance (Medicaid). Lastly, medical food would be offered for sale at cost, to males age twenty-six and over who are diagnosed with PKU or MSUD, regardless of income.

The fiscal note for this bill totals \$31,200, which is the estimated cost to expand the Metabolic Food Program to include five additional males between age twenty-two and twenty-six during the 2017-2019 biennium. Average formula costs for individuals served through the Metabolic Food Program during the current biennium were compiled. Costs per individual averaged \$260/month. Based on the incidence of PKU and MSUD, the department estimated there would be five additional males between ages twenty-two and twenty-six with PKU and MSUD that could potentially order formula.

Without an appropriation to cover the costs of the additional formula, CSHS would have to utilize general funds from within the division (e.g., catastrophic relief). This would impact other programming and decrease services and/or assistance needed throughout the department.

This concludes my testimony. I am happy to answer any questions you may have.

## NDLA, S HMS - Johnson, Marne

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**Sent:** Lee, Judy E.  
Friday, March 03, 2017 7:48 PM  
**To:** -Grp-NDLA Senate Human Services; NDLA, S HMS - Johnson, Marne; NDLA, Intern 02 -  
Arendt, Ian  
**Subject:** FW: Clarification after Hearing on HB 1187


Copies for books, please

Senator Judy Lee  
1822 Brentwood Court  
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**From:** Johnson, Tammie M.  
**Sent:** Friday, March 3, 2017 2:17 PM  
**To:** Lee, Judy E. <jlee@nd.gov>  
**Cc:** Lelm, Tamara G.  
**Subject:** Clarification after Hearing on HB 1187


Senator Lee,

 the hearing on HB 1187 on Wednesday, March 1, 2017, I thought it important to provide some clarifying information regarding coverage of medical food (formula) and low-protein modified food products.

There are several references to metabolic food and food products in North Dakota Century Code (NDCC). The first is **Chapter 25-17 Testing and Treatment of Newborns**. Section 25-17-03 Treatment for positive diagnosis – Registry of cases, parts 4-6 address requirements for the ND Department of Health regarding provision of medical food and low-protein modified food products. Specifics regarding this were included in the testimony provided by Children’s Special Health Services (CSHS) staff during the hearing.

The second reference is in **Chapter 26.1-36 Accident and Health Insurance. Section 26.1-36-09.7 Foods and food products for inherited metabolic diseases** includes the following requirements for health insurance policies or contracts regarding medical foods and low-protein modified food products:

- 3. This section applies to any covered individual born after December 31, 1962. This section does not require coverage in excess of three thousand dollars per year total for low-protein modified food products or medical food for an individual with an inherited metabolic disease of amino acid or organic acid.*
- 4. This section does not require medical benefits coverage for low-protein modified food products or medical food for an individual to the extent those benefits are available to that individual under a state department of health or department of human services program.*

The ND Department of Health is the primary payer for metabolic food (formula) for the population identified in NDCC Chapter 25-17 (Section 25-17-03) currently served through the Metabolic Food Program administered by CSHS. Health  is not a payer of metabolic formula for individuals served through this program because “medical benefits coverage is available through a state department of health program”.

Although some state Medicaid programs cover special formulas needed to treat various metabolic disorders, ND Medicaid does not. ND Medicaid's policy on Enteral Nutrition indicates nutritional supplementation coverage through Medicaid is considered optional by CMS. ND Medicaid Policy indicates, that "Nutritionally complete formula, for special metabolic needs, **excludes** inherited disease of metabolism." This exclusion includes PKU and MSUD. ND Medicaid does not reimburse CSHS for the costs of providing formula or low-protein food products to Medicaid-eligible individuals.

In order to receive low-protein modified food products from CSHS, individuals must be Medicaid eligible. CSHS pays for and provides these products, without reimbursement by insurance or Medicaid. Individuals with PKU and MSUD who are not Medicaid-eligible are likely paying out-of-pocket or using their private health insurance for coverage of these specific types of food products.

If you have any further questions, please don't hesitate to contact me.

*Tammie Johnson, LSW*  
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