2011 SENATE HUMAN SERVICES

SB 2153

2011 SENATE STANDING COMMITTEE MINUTES

Senate Human Services Committee
Red River Room, State Capitol

SB 2153
1-17-2011
Job Number 12966

☐ Conference Committee

Committee Clerk Signature

Explanation or reason for introduction of bill/resolution:

Relating to the food program for individuals with metabolic diseases.

Minutes:

Includes written testimony

Senator Lee opened the hearing on SB 2153 which includes a fiscal note.

Senator Judy Lee, District 13, prime sponsor introduced SB 2153. She explained that she mistakenly carried around the wrong draft for this particular issue. SB 2153 is not the one that should be considered. She was unable to withdraw it because of procedural issues. SB 2212 is the actual bill which deals with metabolic foods. She said we already are supporting the needs of children who at birth are screened for a variety of conditions. The problem is that it is not good to legislate by disease. We need to make sure we recognize what the states responsibilities might be and help the families, with those children, deal with those conditions.

The goal continues to be providing the services that our constituents and our citizens need, particularly those affecting our children, who are discovered during the screening at birth. She asked the committee for a do not pass recommendation on SB 2153 and to instead consider SB 2212. This is a very complicated issue.

Heather Zietz, parent, supports SB 2153 and SB 2012. (Attached Testimony #1).

Dan Ulmer, representing Blue Cross Blue Shield of ND, opposes SB 2163. (Attached Testimony #2).

Senator Tim Mathern asked about mandates being paid by the state and why it would be a problem for the insurance companies?

Dan Ulmer stated that it is not a problem for them but for the state. It would take place in 2014, so they have to pay for it in the meantime.

Senator Spencer Berry stated that now 40 diseases are screened for and it will likely become much higher. He asked if there were any numbers as to what impact this has on BC/BS.

Dan Ulmer did not have any numbers but had recently been told that there have been very few people that have taken advantage of this, mainly because a lot is funded through other sources.

Senator Berry asked if it might be premature, based on time line of the current PPACA, the idea that a lot of these things are being slowly implemented and that full implementation will be 2014.

Dan Ulmer stated "exactly". He said that is what SB 2212 is about. Their task at Blue Cross is to comply fully with PPACA. The biggest piece of this reform is with 'insurers". It was not with consumers.

The hearing on SB 2153 was closed.

Senator Berry moved a **DO NOT PASS.**

Senator Uglem seconded the motion.

Discussion:

Senator Mathern stated that this disease is already in statute in SB 2212 which most likely will pass. Possibly make some minor changes until the other study comes back.

Senator Lee was reluctant to expand any services until after the study is done.

Senator Berry concurred with **Senator Lee.**

Senator Uglem agreed with Senator Lee that it is very hard, once you have provided services, to take them away.

Senator Dever pointed out that this bill may not be the vehicle to address their needs.

Roll call vote 4-1-0. Motion carried.

Carrier is Senator Lee.

FISCAL NOTE

Requested by Legislative Council
01/07/2011

Bill/Resolution No.: SB 2153

1A. **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.*

	2009-2011 Biennium		2011-2013 Biennium		2013-2015 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures			$79,391		$210,762	
Appropriations			$79,391		$210,762	

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

2009-2011 Biennium			2011-2013 Biennium			2013-2015 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts

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

This bill allows the department to provide medical food and low-protein modified food products for individuals with metabolic diseases for which the department determines the provision of these food items will lead to a significant reduction in mortality, morbidity, and associated disabilities.

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.*

SB 2153 addresses the state Department of Health's food program for individuals with metabolic diseases. Currently, medical food and low-protein modified food products are provided without regard to income to individuals with phenylketonuria and maple syrup urine disease. Section 3, a new section to chapter 25-17, allows the department to administer a program to provide medical food and low-protein modified food products for individuals with metabolic diseases for which the department determines the provision of these food items will lead to a significant reduction in mortality, morbidity, and associated disabilities. The health council is to adopt rules specifying which metabolic diseases are to be covered.

Cost figures were determined based on the following:

- An incidence of inborn errors of metabolism requiring metabolic food of 1/1,500 births - 6 new clients per year based on 8,974 resident births in 2009.
- Formula cost estimates were derived by averaging company costs for one low-priced and one high-priced formula used for two different metabolic disorders.
- Formula cost estimates were based on amounts needed for clients with ages ranging from infancy through 18 years (adulthood).
- A 7% increase in formula costs per year was included based on average cost increases for nine types of formula purchased by CSHS for the metabolic food program during the 2007-2009 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 2011-2013 biennium, expenditures are projected at $79,391 with an increase to $210,762 for the 2013-2015 biennium.

The original cost of $25,283 for State Fiscal Year 2011 was obtained by adding the average company cost per year of two different metabolic formulas - one for LCHAD, a low-priced formula ($9,238) and one for OTC, a high-priced formula ($41,327) and dividing by 2 to get a yearly average.

The estimated number of new clients per year is 6, one for each age range identified below. The amount of formula required varies by age. Projections assume the incidence of inborn errors of metabolism requiring metabolic food is 1/1,500 births. North Dakota 2009 resident births were 8,974. The number of clients for each new fiscal year increases by 6 -- the original number from the previous fiscal year plus an additional 6 clients for the next year and each subsequent year thereafter.

Infancy
1-3 Years
4-8 Years
9-13 Years
14-18 Years - Female
14-18 Years - Male

2011-13 Biennium:

Beginning cost for SFY 2011 is $25,283.
The cost per child for SFY 2011 is $4,214 ($25,283/6).
The percentage of price increase for formula was derived by averaging costs for 9 types of formula currently purchased by CSHS for the metabolic food program, which was 7% for the 2007-2009 biennium.
A 7% increase in the cost of formula for SFY 2012 would be $1,770 ($25,283 x 7%)
$25,283 + 1,770 = $27,053
The cost per child for SFY 2012 is $4,509 ($27,053/6).
SFY 2012 adds another 6 children for a total of 12 children served.
SFY 2012 budget would be $54,108 ($4,509 x 12).
Total for 2011-13 Biennium is $79,391 ($25,283 + $54,108).

2013-15 Biennium:

A 7% increase in the cost of formula for SFY 2013 would be $3,788 ($54,108 x 7%)
$54,108 + $3,788 = $57,896.
The cost per child for SFY 2013 is $4,825 ($57,896/12).
SFY 2013 adds another 6 children for a total of 18 children served.
SFY 2013 budget would be $86,850 ($4,825 x 18).
A 7% increase in the cost of formula for SFY 2014 would be $6,080 ($86,850 x 7%)
$86,850 + $6,080 = $92,930.
The cost per child for SFY 2014 is $5,163 ($92,930/18).
SFY 2014 adds another 6 children for a total of 24 children served.
SFY 2014 budget would be $123,912 ($5,163 x 24).
Total for 2013-15 Biennium is $210,762 ($86,850 + $123,912).

Above costs do not include prescribed low protein food of $1,200 - $3,500 per year beginning in the toddler years.

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 is also included in the executive budget or relates to a* *continuing appropriation.*

Funding for this project is not included in the Department's appropriaiton bill (HB 1004). The Department will need an appropriation for thses funds to carry out this project.

Name:	Kathy J. Albin	Agency:	Health
Phone Number:	328.4542	**Date Prepared:**	01/14/2011

Date: 1-17-2011

Roll Call Vote # 1

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. 2153

Senate **HUMAN SERVICES** Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken: ☐ Do Pass ☒ Do Not Pass ☐ Amended ☐ Adopt Amendment

☐ Rerefer to Appropriations ☐ Reconsider

Motion Made By **Sen.** Berry Seconded By **Sen.** Uglem

Senators	Yes	No	Senators	Yes	No
Sen. Judy Lee, Chairman	✓		**Sen. Tim Mathern**		✓
Sen. Gerald Uglem, V. Chair	✓				
Sen. Dick Dever	✓				
Sen. Spencer Berry	✓				

Total (Yes) 4 No 1

Absent 0

Floor Assignment Sen. J. Lee

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

REPORT OF STANDING COMMITTEE

SB 2153: Human Services Committee (Sen. J. Lee, Chairman) recommends **DO NOT PASS** (4 YEAS, 1 NAYS, 0 ABSENT AND NOT VOTING). SB 2153 was placed on the Eleventh order on the calendar.

2011 TESTIMONY

SB 2153

#1

Testimony
Senate Human Service Committee
Chair- Senator Judy Lee
January 17, 2011

Good morning Senator Lee and members of the committee. My name is Heather Zietz. I am here today as a parent in support of senate bill 2153. 2212

I am here today because of what you all did for my daughter Laikyn 6 years ago. She is the child with Russell Silver Syndrome. Six years ago you passed a senate bill to provide feeding supplies and Growth Hormone therapy to any child diagnosed with RSS. As you can see by looking at my daughter the bill you passed has worked very well. Laikyn no longer needs feeding supplies because she was able to remove her feeding tube that she has had since birth in July. She still receives GH shots daily to help her grow height wise, which she has done very well since the last time you saw her.

I am here today to ask you to revise the RSS bill just a little. I am not here to ask for more money, just a more productive way to use it. Six years ago we didn't realize the medical needs that Laikyn would now need. As she has gotten older we have experienced different issues. She now needs OT, PT and speech that is not covered in the bill. She no longer has a feeding tube so when she gets sick we will no longer be able to treat her at home like before. She will now need to go to the hospital for IV therapy to keep her blood sugars up, which is also not covered in the bill. She was seeing a Dr. here in Bismarck for her asymmetry and bone issues but that got to be too expensive and we now travel to MN to see Drs. at Shriners hospital to help cover those costs. She has had a lot of other medical expenses that we never saw coming 6 years ago that are all due to RSS.

What I am asking is that the bill be modified to cover all RSS related medical costs up to the $50,000 per child per biennium. My suggestions would not add any money to the bill just utilize the money better to help those with RSS. Once the money is all used then that's it, the parents will be left to cover the remaining costs. By changing the uses for the money these children will be able to get the full benefit of the treatment until the treatment plan is done. Most RSS kids are done with treatment by the age of 16.

To my knowledge since the bill passed 6 years ago, I believe only 1 child has applied for the services that this bill offers so it would not cost the state any more money. This would just be a better way to make what you already did great. Our family is forever grateful to you all for your help already. Laikyns situation is so rare and we all want to give her the best health management as possible.

Thank you for taking the time to listen to me and I hope to have your support in this matter. I will try and answer any question at this time.

Fifty-ninth Legislative Assembly of North Dakota
In Regular Session Commencing Tuesday, January 4, 2005

SENATE BILL NO. 2395
(Senators J. Lee, Cook)
(Representatives R. Kelsch, Wrangham)

AN ACT to create and enact a new section to chapter 50-10 of the North Dakota Century Code, relating to a department of human services treatment program for children with Russell-Silver syndrome; to amend and reenact subsection 12 of section 50-10-06 of the North Dakota Century Code, relating to income eligibility for Russell-Silver syndrome treatment and services; to direct the department of human services to apply for a medical waiver; to provide for a legislative council study; to provide for a report to the legislative council; to provide an appropriation; and to declare an emergency.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. AMENDMENT. Subsection 12 of section 50-10-06 of the North Dakota Century Code is amended and reenacted as follows:

12. Establish eligibility criteria for services under this chapter at one hundred eighty-five percent of the poverty line, except for criteria relating to Russell-Silver syndrome, phenylketonuria, or maple syrup urine disease treatment services for which income is not to be considered when determining eligibility. For purposes of this chapter, "poverty line" has the same meaning as defined in section 50-29-01.

SECTION 2. A new section to chapter 50-10 of the North Dakota Century Code is created and enacted as follows:

Russell-Silver syndrome - Services - Definitions.

1. The state agency shall provide payment of a maximum of fifty thousand dollars per child per biennium for medical food and growth hormone treatment at no cost to individuals through age eighteen who have been diagnosed with Russell-Silver syndrome, regardless of income. If the state agency provides an individual with services under this section, the state agency may seek reimbursement from any governmental program that provides coverage to that individual for the services provided by the department. The parent of an individual receiving services under this section shall obtain any health insurance available to the parent on a group basis or through an employer or union, and that insurance must be the primary payer before payment under this program.

2. For purposes of this section:

    a. "Growth hormone treatment" means a drug prescribed by a physician or other licensed practitioner for the long-term treatment of growth failure, the supplies necessary to administer the drug, one out-of-state physician visit per year to obtain expert consultation for the management of Russell-Silver syndrome, appropriate in-state physician visits, and the travel expenses associated with physician visits for the child and one parent.

    b. "Medical food" means a formula that is intended for the dietary treatment of a disease or condition for which nutritional requirements are established by medical evaluation and is formulated to be consumed or administered under the direction of a physician as well as any medical procedure and supplies necessary for assimilation of the formula.

SECTION 3. MEDICAID WAIVER - IN-HOME SERVICES. The department shall apply for a medicaid waiver to provide in-home services to children with extraordinary medical needs who would otherwise require hospitalization or nursing facility care. The department may limit the waiver to fifteen participants and may prioritize applicants by degree of need.

SECTION 4. LEGISLATIVE COUNCIL STUDY - HEALTH CARE NEEDS. The legislative council shall consider studying, during the 2005-06 interim, issues relating to medicaid and other public funding for the extraordinary health care needs of children who live in an institution or who are at risk of institutionalization; the comprehensive health association of North Dakota program provided for under chapter 26.1-08, including contracting for a cost-benefit analysis of this program; and the state programs providing services to children with special health care needs to determine whether the programs are effective in meeting these special health care needs, whether there are gaps in the state's system for providing services to children with special health care needs, and whether there are significant unmet special health care needs of children which should be addressed. The legislative council shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the sixtieth legislative assembly.

SECTION 5. REPORT TO LEGISLATIVE COUNCIL. During the 2005-06 interim, the department shall report to the legislative council regarding the status of the medicaid waiver to provide in-home services under section 3 of this Act, the number of applications the department receives for the in-home services, and the status of the program's appropriation.

SECTION 6. APPROPRIATION. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of $150,000, or so much of the sum as may be necessary, to the department of human services for the purpose of providing Russell-Silver syndrome services, for the biennium beginning July 1, 2005, and ending June 30, 2007.

SECTION 7. EMERGENCY. This Act is declared to be an emergency measure.

President of the Senate   Speaker of the House

Secretary of the Senate   Chief Clerk of the House

This certifies that the within bill originated in the Senate of the Fifty-ninth Legislative Assembly of North Dakota and is known on the records of that body as Senate Bill No. 2395 and that two-thirds of the members-elect of the Senate voted in favor of said law.

Vote: Yeas 46 Nays 0 Absent 1

President of the Senate   Secretary of the Senate

This certifies that two-thirds of the members-elect of the House of Representatives voted in favor of said law.

Vote: Yeas 90 Nays 3 Absent 1

Speaker of the House   Chief Clerk of the House

Received by the Governor at ________ M. on ________________________________, 2005.

Approved at ________ M. on ____, 2005.

Governor

Filed in this office this ____________ day of ________________________________, 2005,

at ___ o'clock ______ M.

Secretary of State

#2

Testimony on SB 2153

Senate Human Services Committee 1/17/11

Madam Chair and members of the committee I'm Dan Ulmer representing Blue Cross Blue Shield of North Dakota and we oppose SB2153.

We fully appreciate the importance and the expense involved in making sure that folks with metabolic disorders have access to and can afford the specialized foods they need in order to survive and thrive. And even though we have very few folks who have taken advantage of this we have been funding these specialized foods ever since 26.1-36-09.7 became law.

In order to fully appreciate our opposition to this bill I believe it's important to gain an understanding of how PPACA (the recently passed federal law known as the Patient Protection and Affordable Care Act) affects mandates.

A major piece of PPACA mandates that everyone become insured...it's called the individual mandate. The question then becomes 'what's insured', i.e what essential benefits will have to be included to be considered insured? These essential benefits are presently in the process of being defined by a committee of the Institute of Medicine (IOM). It's our understanding that this committee had its first round of meetings last week (see attached).

The rub in this discussion is that we don't know what will be considered an essential benefit and in particular we aren't sure if PKU and other metabolic disorders will be included. – Under PPACA if the benefit is not considered essential and is still mandated by a state then the state , not insurers, will have to pay the costs of the mandate.

As you know North Dakota has over 20 mandates from mental health to PKU and once the essential benefits for PPACA get defined the legislature is going to have to determine whether or not they want to keep and fund or remove any of the existing mandates.

SB2153 appears to expand the metabolic disorders that insurers would have to fund. It seems that there are conflicting definitions :' inherited metabolic disorders'(p.4 line 5 thru 7) and 'inherited metabolic disease of amino organic acid'(p4 lines 24 thru 27).

The first definition is very broad and includes amino acid disorders, organic acidemias, urea cycle disorders, fatti acid oxidation disorders, mitochondrial disorders, peroxisomal disorders, lysosomal storage disorders, purine and pyrimidine disorders, and metal metabolism disorders. The bill then removes Maple Syrup and PKU disorders and thus we think significantly increases our financial exposure by not only mandating coverage for the specific agent/food but also requiring us to pay for genetic testing.

We are left to wonder if this expansion is intended or if we are only required to continue paying for what we already cover-i.e.-inherited metabolic disease of amino acid or organic acid. If the bill expands what we have to pay for we are fully opposed and if not we believe that it's important for the legislature to understand the implications of mandating insurers to cover benefits that go beyond PPACA's definition of essential benefits.

Madam chair and members of the committee I would be happy to answer any questions.

Dan Ulmer AVP Government Relations

BCBSND-

Dan Ulmer

[redacted]**n:** Haltmeyer, Kris [Kris.Haltmeyer@BCBSA.COM]
t: Friday, January 14, 2011 5:37 PM
To: CRC@LMS.BCBS.COM
Subject: IOM First Committee Meeting on Determination of Essential Health Benefits
Attachments: Highmark_ EHB Testimony_FINAL.pdf

Importance: High

SUBJECT: IOM First Committee Meeting on Determination of Essential Health Benefits

[redacted]

DATE: January 14, 2011

TO: Health Reform Implementation Task Force
Congressional Relations Coordinators
State Relations Coordinators
Exchange Workgroup

FROM: Kris Haltmeyer
Executive Director, Legislative and Regulatory Policy

The Institute of Medicine (IOM) Committee on the Determination of Essential Health Benefits held its first meeting on January 12-14. This was the first of four public meetings that we expect to be held by this committee.

The main charge for this committee is to make recommendations to HHS on the criteria, methods and process for determining and updating the essential health benefits package. This committee will not define specific service elements of the benefit package.

[redacted]

Dr. Calega, Vice President of Medical Management and Policy at Highmark Blue Cross and Blue Shield, presented as part of an insurer panel on behalf of BCBSA. Her comments underscored the need that any definition of essential benefits must assure affordability and preserve an insurer's ability to utilize medical necessity and other management tools. She also stated that the process for identifying and updating essential health benefits must be based upon evidence-based research and marketbased input. Her full testimony is attached.

Many speakers on Thursday highlighted the need for affordability and to minimize disruption in the individual and small group markets. In addition, several speakers argued that medical necessity should be separate from any determination of essential health benefits. On Friday, numerous patient advocate groups made presentations to the committee arguing for a broad definition of essential health benefits.

Presentations from speakers during the public sessions can be found at the following website under "Other Meeting Resources" on the right hand side of the page: http://www.iom.edu/Activities/HealthServices/EssentialHealthBenefits/2011-JAN-12.aspx

BCBSA will send out a more detailed summary of the IOM meeting next week. If you have any questions or concerns, you can reach me at kris.haltmeyer@bcbsa.com or (202) 626-4814.

Attachments:

Highmark Testimony before IOM Essential Health Benefits Committee