

2011 SENATE HUMAN SERVICES

SB 2212

2011 SENATE STANDING COMMITTEE MINUTES

Senate Human Services Committee
Red River Room, State Capitol

SB 2212
1-17-2011
Job Number 12962

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

To provide for a state department of health study of department programs for catastrophic diseases.

Minutes:

Attachments included.

Senator Judy Lee opened the hearing on SB 2212. She introduced the bill and explained that it was supposed to be the one concerning diseases that have dramatic impact on the finances and the general health and well being of ND citizens, particularly children.

She spoke about this one in conjunction with SB 2153.

She thought doing individual disease legislation was not a good way to run the government. This bill is the effort after visiting with the Department of Health and other stakeholders in this issue. It would be a mandatory study and it would be quite broad. They would like the study group to determine how they are going to limit it. She said it was important to understand that she wasn't trying to open up broad state support for every kind of illness. They are talking about a fairly narrow window, but with the idea that, if a situation comes up, there will be a process in place.

The good news is that there are more newborn screenings than there used to be, but some of the syndromes or conditions are not discovered until the child is older. She said they don't want to eliminate those children from consideration for these unique circumstances.

There is an appropriation because the parties involved with the discussion feel that this is going to require hiring an expert consultant.

Senator Dick Dever asked about the rationale behind the number 60,000. Was that what the department felt they could do the study for?

Senator Judy Lee replied that the dept. recommended that as a figure that would be a maximum figure for a consultant.

Heather Zietz presented supporting testimony. Attachment #1

There was no opposing testimony.

Dan Ulmer, BCBS, said they encourage these types of studies.

Senator Spencer Berry asked why BC is in favor of this study.

Mr. Ulmer replied that it's always good to look at how things are done in the legislature and to address these types of issues.

Senator Judy Lee said that in the past there had been situations where BCBS has been supporting the cost of some of the products that were needed and other carriers were not. There wasn't a consistency to the way these situations were being addressed.

The hearing on SB 2212 was closed.

Senator Tim Mathern stated that he supported the bill but was concerned that they weren't really addressing the issues that were brought to their attention on SB 2153.

Senator Judy Lee said they tried to leave the subject of the study broad enough so the study group can look at what supports are appropriate. She didn't see it as limiting. It would be up to the stakeholders involved in the study to determine what the study should include and what kind of support services would be available. She personally thought they would be opening a whole new area if they provide services beyond what is currently covered in legislation for one individual without having looked at what kinds of additional services might be required by other individuals with other conditions who are covered by other specific laws dealing with specific diseases.

Senator Tim Mathern pointed out that passing this bill as is does not respond to the immediate request of SB 2153 of changing the law to spend those available monies so they can be used in other areas. It would not be in this bill.

Senator Spencer Berry moved a **Do Pass**.

Seconded by **Senator Tim Mathern**.

Roll call vote 5-0-0. **Motion carried**.

Carrier is **Senator Judy Lee**.

Attachment #2 – additional information.

Date: 1-17-2011

Roll Call Vote # 1

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. 2212

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. Mathern

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

Total (Yes) 5 No 0

Absent 0

Floor Assignment Sen. J. Lee

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

REPORT OF STANDING COMMITTEE

SB 2212: Human Services Committee (Sen. J. Lee, Chairman) recommends **DO PASS**
(5 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2212 was placed on the
Eleventh order on the calendar.

2011 SENATE APPROPRIATIONS

SB 2212

2011 SENATE STANDING COMMITTEE MINUTES

Senate Appropriations Committee Harvest Room, State Capitol

SB 2212
January-24-2011
Audio not available

Conference Committee

Committee Clerk Signature *Alice Delzer*

Explanation or reason for introduction of bill/resolution:

A BILL for an Act to provide for a State Department of Health study for catastrophic diseases

Minutes:

No testimony provided in this Bill

V. Chair Bowman called the committee to order on SB 2212 at 1100 am on January 24, 2011. All committee members were present except Chairman Holmberg. Sheila M. Sandness, Legislative Council and Joe Morrissette, OMB were also present.

Senator Judy Lee, District 13, introduced the Bill and stated what this Bill calls for is how we can address these catastrophic diseases and provide a study for providing services to individuals with catastrophic diseases, such as inherited metabolic diseases and provide the sum of \$60,000 to the DOH for the purpose of performing the study of catastrophic diseases. We discussed the language in the bill, and left the umbrella large, so the study group could make determinations regarding this bill, because we don't know all the answers. The DOH agrees there needs to be a program. It is a one-time expenditure. We need to figure out a better way to help these families concerned and this bill would provide a vehicle through which someone can get help for their child. These diseases, which I call "orphan diseases" are very expensive, and there isn't anyone with expertise to pull it out so the staff of DOH came up with the idea for a study for catastrophic diseases. Two years ago when the bill was first introduced, there was only one child in the state of ND that had Russell Silver disease, now there may be 2 or 3.

Senator Christmann asked if this is what Senator Dever was addressing on the floor.

Senator Lee: Yes, that was the only child at the time. Now there are 2 children, and a third has applied. That is exactly what we are talking about. There are about 6 or 7 children with PKU disease,

Senator Christmann: We thought there was only one child with it, now there are two or three. Shouldn't we look at what other states are doing in regards to this matter?

Judy Lee: I would anticipate that would be part of the study to see what other states are doing also. We need to look at the outcome, not only for the sake of the welfare of the child

but also we are saving a lot of money if you look at it from a fiscal point of view. It is more cost effective to treat it then to have these children develop mental disorders or other consequences of this disease and then there is the need to take care of them.

Senator Kilzer: Is the term "catastrophic" defined someplace in code?

Senator Lee: No, it is not. We wrestled with the word, we are trying to leave it open enough to recognize what the committee needs to do in this study. We went back to the original form, and came up with the term catastrophic.

Senator Kilzer: I am very concerned about the term, catastrophic, there are so many conditions that are catastrophic. Hundreds would qualify; bone diseases, all of the heart defects that babies are born with, all the congenital heart conditions, we are talking about tremendous numbers. It will take me some time to define them all, but you almost have to define what your restrictions are, like inherited conditions, genes and chromosomes, everything from Turner Syndrome, Down's Syndrome, whatever you define will probably be broadened a lot.

Judy Lee: We are open to have a new definition. I would look forward to redefining it with this committee, if they so desire to work with us regarding this matter.

Senator Warner had questions regarding special services provided to the children through the DOH, whether federal government gets involved or private insurance pays for the services. He also asked about children's coverage after they are 3 years old.

Tammy Gallup-Millner, Children's Special Health Services Division Director, DOH stated those have not been defined yet. We don't know the outcome of some of these issues concerning metabolic food and the federal government. We knew that birth to 3 year olds often had access to Medicaid, included serving children with the risk, and we were finding at age 3 they might not qualify. Our division through a small treatment program, is currently servicing families, where there may or may not be state support.

Senator Christmann asked about how people are paying for the formulas concerning the metabolic problem and what other states are doing regarding this issue. He was told there is little information available regarding this matter. She stated she knows there are some states that are providing aid to some people.

Senator Erbele: Do you have a number for us of all the kids we are paying for?

Tammy Gallup-Millner: We are serving 23 with metabolic; there are 7 inactive we could serve. It is a life-long diet. We have two more families, but only one has asked for assistance, and then we have one inquiry that has come in.

V. Chair Bowman closed the hearing on SB 2212.

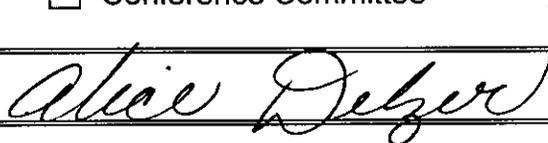
2011 SENATE STANDING COMMITTEE MINUTES

Senate Appropriations Committee Harvest Room, State Capitol

SB 2212
02-17-2011
Job # 14672 (Meter 13.34)

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

A SUBCOMMITTEE HEARING ON SB 2012 (SEVERAL BILLS WERE DISCUSSED AND ACTION WAS TAKEN BY THE SUBCOMMITTEE)

Minutes:

You may make reference to "attached testimony."

Senator Kilzer states he would like to go through the nine "stand alone" bills.

Senator Fischer, Chairman opened the subcommittee hearing in reference to the Department of Human Services. Senator Kilzer, Senator Erbele, Senator Warner were also present. Lori Laschkewitsch, OMB and Roxanne Woeste, Legislative Council were also present.

The bills that this subcommittee is assigned to are: 2029, 2043, 2163, 2212, 2240, 2264, 2298, 2334, 2357.

Senator Fischer states that we will now talk about SB 2212.

Senator Kilzer states that this is the one that we had trouble with the definition of "catastrophic". I don't think it was ever resolved. I think it could be a moderately severe injury to an inherited condition. It is very broad. \$60, 000 wouldn't scratch the surface in accomplishing what would it be like. **I recommend a DO NOT PASS.**

Senator Warner states that he would like to **resist the motion**. My understanding of "catastrophic" is that it has nothing to do with the disease. It has to do with the financial mechanisms that the family would have. A collision, of a lack of insurance coverage, plus an extraordinarily high cost, that causes a catastrophe, not any particular characteristic of the disease. We have out of great compassion, on occasion, approached these diseases, one at a time. I think we need to be looking for, systematically, taking a more intellectual look at what constitutes the criteria for when the state should intervene and provide coverage. I think the disease, as devastating as it is to an individual, is not the focus of this. It is the collision of the lack of insurance coverage plus the extraordinary costs that are entailed. So I would **resist the motion for a DO NOT PASS.**

Senator Kilzer states that "disease" is the noun and the "catastrophic" is the adjective that modifies it. So it says, "catastrophic diseases". Even if you do shift it over to how it affects the families, you are still going to have to put some "defining limits" and that is not present here.

Senator Fischer asks Roxanne, when this was written, did you have a definition of how you see that sentence structure was intended by the author. She will be here in a little while. It appears **Senator Warner** and **Senator Kilzer**, seem to have a definition issue over "catastrophic diseases" and you say, Senator Warner, when you signed onto this, you felt it was though "catastrophic diseases", such as inherited metabolic diseases, that is a catastrophic disease and that would be the metabolic disease, that would be the ones that were studied.

Senator Warner states that when I signed on, it had to do more with the financial situation of the family. A disease, which could not be covered by insurance, and at the same time, would have a devastating effect on the finances of the family.

Senator Kilzer states that there would be room in the Health Dept. budget, when we get it after "crossover", if we would want to put it in there.

Senator Warner states he would be amenable to that.

Senator Fischer states at least we can address it at that time.

There is a **second by Senator Erbele for a DO NOT PASS.**

Senator Warner states if we fail to pass the bill, it's gone.

Senator Fischer asks about amending the motion. Is it at \$60,000 or \$30,000?

Roxanne Woeste states that bill, as introduced in Appropriations, is \$60,000.

Senator Kilzer states, "No, he does not have an amendment".

Senator Fischer states that we will have to take a vote as DO NOT PASS and leave the money in it.

Roll is called and vote is taken Yea: 3; Nay: 1.

Motion for DO NOT PASS is carried.

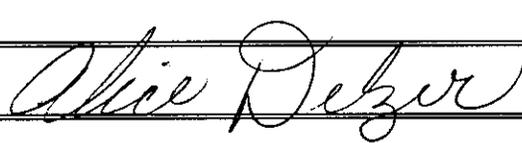
2011 SENATE STANDING COMMITTEE MINUTES

Senate Appropriations Committee Harvest Room, State Capitol

SB 2212
02-17-2011
Job # 14716 (Meter 50.06 – 59.27)

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

A ROLL CALL VOTE on the Bill to provide for a State Department of Health study for catastrophic diseases.

Minutes:

You may make reference to "attached testimony."

Chairman Holmberg called the committee to order on Thursday, February 17, 2011. Lori Laschkewitsch, OMB and Roxanne Woeste, Legislative Council were present.

There was discussion on several bills and when the committee will be taking action on the bills that are left to pass out of committee.

JOB #14716 INCLUDES THE ROLL CALL VOTES ON THE FOLLOWING BILLS: SB 2345, 2159, 2029, 2299, 2298, 2212, 2334, 2357.

Chairman Holmberg called the committee to order regarding SB 2212. 2212 is \$60,000 for a health study of catastrophic diseases. How did your subcommittee react to 2212?

Senator Warner: The subcommittee voted 3 to 1 DO NOT PASS. I am not making the motion.

Senator Kilzer Moved a DO NOT PASS ON SB 2212. Seconded by V. Chair Bowman.

Senator Kilzer: This is a funding bill for \$60,000.00 for the Department of Health to make a study of catastrophic diseases. My difficulty with it was not particularly the funding but the definition of catastrophic diseases, which can be very wide. Diseases is the noun and catastrophic is the adjective, as I mentioned this morning, and until there is more specifics I think this would be not a very good use of money. It's poorly defined.

Senator Warner: My understanding when I signed on to this that these were diseases which cause catastrophes within families and that was the collision of the lack of insurability plus the disease which headed up normally a large cost, some are metabolic diseases, some are genetic diseases but they are diseases which have a hard time finding a funding source for their remending. That's part of the problem as exactly address by Senator Kilzer is that they are very difficult to define and we have been approaching these in a very piece-meal fashion. You might call them poster child diseases. If you have an attractive charismatic young child

who has this disease that gets funded, if it is a less attractive child or disease it really struggles so we've funding things like maple syrup disease and Russel Silver Syndrome. This just instructs the department, it doesn't give them much. It would instruct the department to come up with some guidelines and try to figure out what kind of perimeters we should be using, so we have some guidelines to go by as we are approached by individual heart breaking cases. I would resist a Do Not Pass. I think this is a worthy topic for study and I think that it's not a partisan issue but a matter of coming up with good public policy.

V. Chair Grindberg: Maybe the subcommittee can give me a recollection of the sponsor's motivation. Was there something that occurred during the interim that led Senator Lee to put this bill in? I would think, truly, is a situation the sponsors think it is important, obviously, but why couldn't the department help do this without a bill? It goes on in Subsection 2, it says the department's report to the legislative management must include proposed legislation. I don't know why it couldn't be performed now without having the bill.

Senator Kilzer: No one from the Health Department appeared in front of the subcommittee.

V. Chair Grindberg: Conceivably then, it could happen on it's own. \$60,000 is not a lot of money in the Department of Health's budget.

Senator Warner: We were talking about that this morning. I think this is maybe the 4th bill that we have said that on in Health. I am not dis or agreeing with you at all.

Chairman Holmberg: We really have a couple of options. We have a motion, we will pass it. We could pass it and then this issue is behind us. We could bring it up again when we have the Health Department budget and question them if this is a good idea and on the face of it with some intergrate language it is maybe something that needs to be done or if that motion fails that we have before us we could amend the money and pass it like we've done a couple of other areas.

Senator Wardner: One thing I know it would be studied if we made it a study; turned over to Legislative Council and said "You shall study" and that would get the job done. So if you want it studied somebody would have to do the work and bring it to a committee.

Chairman Holmberg: Are you offering that as something we should think about before we vote on the motion which is DO NOT PASS.

Senator Wardner: Yes, I am and we could amend it and make a study out of it. We would just remove section 2 and go forward.

Chairman Holmberg: If you just pass it the way it was it would be the Department of Health that would do the study and then the question is "should they be the ones that do the study or should it be Legislative Management?"

Senator Kilzer: They would also have to do the defining because I don't think catastrophic disease is restricted enough.

Chairman Holmberg: We have a motion, we have second. So the motion is DO NOT PASS ON SB 2212. Would you call the roll on that motion?

A ROLL CALL VOTE WAS TAKEN ON A DO NOT PASS ON SB 2212. YEA: 8; NAY: 5; ABSENT: 0. MOTION CARRIED. Senator Kilzer will carry the Bill.

The hearing was closed on SB 2212. (Meter 59.27)

Date: 2-17-11
Roll Call Vote # 1

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2312

Senate Senate Appropriations 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 Kilzer Seconded By Bowman

Senators	Yes	No	Senators	Yes	No
Chairman Holmberg	✓		Senator Warner		✓
Senator Bowman	✓		Senator O'Connell		✓
Senator Grindberg	✓		Senator Robinson		✓
Senator Christmann	✓				
Senator Wardner	✓				
Senator Kilzer	✓				
Senator Fischer	✓				
Senator Krebsbach		✓			
Senator Erbele		✓			
Senator Wanzek		✓			

Total (Yes) 8 No 5

Absent 0

Floor Assignment Kilzer

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

REPORT OF STANDING COMMITTEE

SB 2212: Appropriations Committee (Sen. Holmberg, Chairman) recommends DO NOT PASS (8 YEAS, 5 NAYS, 0 ABSENT AND NOT VOTING). SB 2212 was placed on the Eleventh order on the calendar.

2011 TESTIMONY

SB 2212

#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

SB 2212

#2

From: Jennifer Restemayer [mailto:jennmarie@bis.midco.net]
Sent: Wednesday, January 12, 2011 7:37 AM
To: Lee, Judy E.
Subject: SB 2067 ~ Sorry, I forgot the picture the first time :)

Senator Lee,

I am writing to you today in regard to Senate Bill 2067. I would like to let you know that I fully support the changes to the North Dakota Century Code to include Genetic Diseases.

I am the mother of a child with a progressive and degenerative genetic disorder. My daughter Allison was diagnosed with Mucopolysaccharidosis (MPS) type 1 just before her second birthday. I will never forget sitting in the Doctors office and being handed a photocopy of the Physicians Desk Reference page on Hurler Syndrome (or MPS 1) and reading that she would be bedridden by the age of 8 and dead by the age of 10.

We were fortunate that a treatment for her disorder was FDA approved shortly after Allison's diagnosis, and we were able to start that treatment within weeks of approval. Allison is affected by her disorder, the damage that was done before she was able to start treatment will never be undone, however, she has a much better quality of life and many complications of her disease that have not yet touched her because she was able to start treatment at age 2. Allison will celebrate her 10th birthday on Feb 5, 2011. I can only imagine the possibilities for the babies able to start treatment shortly after birth.

It is so important for us to remember that the earlier children with genetic and metabolic disorders are diagnosed and can start treatment, the better their quality of life will be. Rare diseases and genetic disorders are becoming less and less rare, so unfortunately there will be more children affected by them. Our children in the state of North Dakota deserve every chance we can give them to grow up healthy and strong. With the changes to the North Dakota Century Code, we can ensure that as newborn screening tools become available for more genetic disorders, we can request that our wonderful state start to screen for them. We can give this population of children the best chance for a great life!

Thank you for your time.

Jennifer Restemayer
2217 E Capitol Ave
Bismarck, ND
(701) 471-8714

