MICROFILM DIVIDER

OMB/RECORDS MANAGEMENT DIVISION
SFN 2053 (2/85) 5M

GREAT SEAL 1889 STATE OF NORTH DAKOTA

ROLL NUMBER

DESCRIPTION

2395

2005 SENATE HUMAN SERVICES

SB 2395

2005 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2395

Senate Human Services Committee

☐ Conference Committee

Hearing Date February 2, 2005

Tape Number	Side A	Side B	Meter #
1	X		0.0 - end
		X	0.0 - 360
2	X		6,125 - end
		X	0.0 - 4800
Committee Clerk Signature	Cathy		

Minutes:

Senator Judy Lee, Chairman of the Senate Human Services Committee opened the hearing on SB 2395 relating to a department of human services treatment program for children with Russell Silver syndrome and to income eligibility for Russell Silver syndrome treatment services.

All members of the committee were present.

Senator Judy Lee of District 13 cosponsor of SB 2395 introduced the bill stating it will address the help needed for the cost of the growth hormone that is required to treat this rare and unique disease is very expensive.

Representative Dwight Wrangham of District 8, cosponsor of SB 2395 testified his involvement with this bill because of his constituents and the serious problems of the people who are caught in this situation.

Heather and Derek Zietz testified as parents of a child with Russell Silver Syndrome (RSS) in support of SB 2395 (See attached testimony).

Senator Lee reminded the committee that because Laikyn will be turning three years old and she will then will not be eligible for Medicaid under the current benefits.

Senator Lee asked about when and the process of the diagnosis of RSS in Laikyn.

Derek Zietz stated the Bismarck doctors felt this might be the problem but the actual diagnosis happened when she was about 15 months old and weighed 10 pounds.

Senator Richard Brown asked what exactly is RSS.

Derek Zietz explained that for some odd reason a child is growth insufficient, their bodies just will not grow, they are not interested in food and to do not feel hungar. She will be starting growth hormone injections in February which will help her grow through puberty.

In the world there are approximately 400 cases of RSS with maybe 300 in the United States.

Wendy Graff testified in support of the Zietz family and in the passing of SB 2395. She is an early interventionist in occupational therapy with BACEF Early Intervention Birth to Three Program. She has worked with Laikyn, who has come a long away developmentally put continues to have major medical concerns and needs further treatment. It is vital the state supports the diet and growth treatment for children with RSS. The state can invest now in the treatment that is necessary in order to prevent modifications and assistance later of these victims of this disease.

Roxane Romanick, employee of the Bismarck Public Schools and specialist with the Bismarck Early childhood Education Program testified in support of SB 2395 (See attached testimony).

Candy Zietz, grandmother of Laikyn testified in support of SB 2395 sharing the history of having a granddaughter and the difficult and stressful time of having a RSS child in the family. As Laikyn approaches her third birthday, the family is concerned about the financial burden of the hormone injections she will require.

The committee asked what the will be the cost of the hormone injections.

Derek Zietz answered that injections could range from $20,000.00 to $50,000.00 a year depending on the type prescribed. Food and feeding supplies costs about $850.00 - $950.00 a month. He also questioned the amount of the Fiscal Note on the bill.

Discussion was held in regards to the support group called Magic Foundation that has been very helpful and pays the expenses for one doctor consultation of up to $650.00. The Katie Becket waiver was also explained to the Committee (See attached) that allows children to stay and be treated at home with medical coverage instead of being in an institution.

Theresa Larson from the Protection Advocacy Project testified in support of SB 2395. She stated that the Katie Becket Waiver is being considered for North Dakota.

Senator Lee asked for opposing testimony of SB 2395 and not hearing any asked for testimony in a neutral testimony of the bill.

Tamara Gallup-Millner, Director of the Children's Special Health Services unit of the Medical Services Division in the Department of Human Services provided information related to SB 2395 (See attached). She explained the Fiscal Note of the bill stating that formula was the only food included and defined the pharmacy price of the hormone replacement treatment. The fiscal note was difficult to develop because of all the variables and the different medical needs of children that would be required. Of course there would be the private insurance variable.

Senator John Warner asked what the role of insurance companies would be in this process.

Tamera Gallup-Millner answered there are different companies who each have different criteria and benefit schedules.

Rod St.. Aubyn representing the North Dakota Blue Cross Blue Shield testified that this was the first of this he has heard of this and that is why he was present at the hearing. He stated the family's policy is copay and has reached the out of pocket maximum, so Medicaid would cover the remaining expenses under the SB 2395. If the bill is not passed these expenses will be the responsibility of the family.

Discussion was held as the other children who have rare diseases and how those will be addressed in the future.

Tape 1, Side B

Discussion continued about the possible benefits of hormonal treatment for other childhood diseases and if nutritional treatments are covered the same way.

Senator Lee gave great credit to the Zietz family and the unconditional love and care of Laikyn as sadly many children are not so fortunate.

Senator Lee closed the hearing on SB 2395.

Tape 2, Side A, 6125 - end

Senator Judy Lee opened the committee work on SB 2395.

Discussion was held in regards to the BCBS coverage of nutritional feeding. According to the medical management staff, the nutritional feeding most be the sole source and in reality the primary source of nutrition and uses a standard 80% copay.

Tape 2, Side B, 0.0 - 4800

Telephone conference call was made to **Dr. Ted Kleindman** of Fargo, North Dakota who shared medical information of the symptoms and treatment of RSS. In years past, insurance companies did not cover treatment with growth hormones because the children did not meet the criteria because they did not test for abnormal levels of growth hormones. As technologies advance, more and more people become eligible for very expensive treatments that are covered by the government. Hormonal treatment should be approached very cautiously and should only be considered for very rare diseases or this could become out of control and be very expensive program for the government. He stated that hormone treatment will range from $15, 000.00 to $20,000.00 a year with the length of treatment being variable.

The fiscal note was discussed and that it reflects that way the bill is presently written. It needs to be fine tuned in order to pass through appropriations. The committee discussed concerns of specifically naming the disease in the bill and opening things up for every child with a disease. They would really like to do something to help maybe during the interim while a study is conducted. They will ask the department to create a better estimate for the fiscal note and also what it would mean for the state to the last provider of funding. There also needs to be better definition of the disease to be identified in the bill and that maybe research of federal law could be of help.

Senator Lee made a telephone call to Theresa Larson at the Protection Advocacy Project regarding the Katie Becket Wavier. The connection was made with **Bruce Murry**, attorney with the department explained that the waiver is for a child who has significant health needs and looks only at the kid's income for eligibility for services. It is a state match with the federal government. The bill could be drafted as to the eligibility of the child based on the parent's or the child's income.

Senator Lee asked if they could help and develop an amendment by the Monday to meet the crunch time line.

Bruce Murry answered that they would do that and check other resources to develop want the committee is looking for. They will develop two versions that be a study and one describing some criteria of serious health conditions.

Senator Lee will contact Tamera Gallup-Millner to rewrite the fiscal note with the state being the payee as the last resort and the insurance companies being the primary payee.

Committee work ended on SB ~~2341.~~ 2395

2005 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2395

Senate Human Services Committee

☐ Conference Committee

Hearing Date February 7 2005

Tape Number	Side A	Side B	Meter #
1	x		00-1000
Committee Clerk Signature Cathy Dinius			

Minutes:

Chairman Lee reopened the discussion on SB 2395. All members were present.

Dave Boeck and Bruce Murry from Protection and Advocacy were present to explain the amendment which was distributed. See attachment 1 which is the broad language of the Katie Beckett waiver. There was also a waiver that covered a narrower focus which deals with children with specific diseases. (Attachment 2)

Murry: It's my understanding, that PKU and Maple Syrup funding are state funds at this point.

Chairman Lee: Beyond the insurance, we want to make sure that the state will be the provider of last resort, if we did something at all. So insurance does need to be a component.

The children with Russell Silver Syndrome and some of these other conditions aren't necessarily going to be requiring nursing home or even home and community based care; they're not going to be disabled, there're just going to be very tiny. So, that's part of the rub here, is that it's not, they growth hormone and the nutritional product that is provided will assist them in growing to a normal stature. They aren't mentally retarded as a result of this disease; which PKU and MSU diseases would result in mental retardation. That's important because we're looking at being compassionate to the family but also recognizing that there's isn't an offset in deduction in state expense because they're not going to be cared for by the state for their lives.

Murry: I thing that's important for the existing waiver that the state has, but this bill, I pulled out the language from the SSI disability criteria and from nursing home screenability and it looks to me like a child with Russell Silver Syndrome will readily fit into these two categories so that she would quality.

Chairman Lee: They're covered under the statute that addresses conditions that are screened at birth. Because both of those conditions, children are screened and this is not. It's not an easy condition to determine. I've had emails from other families and may be the only other ones in the state with ABC disease; and I don't think the state should be practicing medicine, so I don't want to get involved with a diagnosis and treatment choices. But if we're going to be doing something, I think the committee is trying to see if there's a way without an enormous fiscal note, that we can address the need of these families who have other conditions than Russell Silver (who are limited in number).

Bruce Murry explained the Katie Beckett waiver and Dave Boeck said he thought this child would fit the criteria. But the other diseases that were mentioned, but the narrower version might not work.

Chairman Lee: What we learned, and this child has good insurance coverage, we're not looking at a huge annual expenditure for the family but it increases after the age of three, because she goes off Medicaid. But some of these other families have significant financial commitment to provide what's needed.

Dave Boeck mentioned that some states put a number on the number of cases allowed. We probably need someone from Human Services to tell us. Bruce Murry said it was their hope to move some of the kids with PKU and MSU to Medicaid eligibility to try to save the state some general funds there to offset bringing some new children in.

Chairman Lee thanked both men for giving the committee additional information and asked them to get together with Denise Feist and with the family and with Human Services before this afternoon, because the committee would like to more this forward to the Appropriations Committee.

Chairman Lee closed the discussion on SB 2395

2005 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2395

Senate Human Services Committee

☐ Conference Committee

Hearing Date February 7, 2005

Tape Number	Side A	Side B	Meter #
3	X		1,136-2100
Committee Clerk Signature	Cathy Menard		JH

Minutes:

Chairman Lee opened the meeting to discuss SB 2395. All Senators were present.

Bruce Murray offered amendments for the committee's consideration. See attachment.

Chairman Lee- Will this have any impact on reimbursement that we already have for the PKU, Russell Silver syndrome kids?

Bruce- It would leave the state funding for those children in place and unaffected.

Chairman Lee- Will this cover other chronic health diseases that don't have mental retardation?

Bruce- The Department does have the authority to seek waivers currently. If the family opportunity act opens up, the department may limit it to fifteen participants. It may not address children with other conditions.

Chairman Lee- A child with Russell Silver Syndrome, does not require hospitalization or nursing facility care.

Bruce- That child would be covered under the state funding language. We are trying to get the small group of children that need the help the most.

Chairman Lee- There may be time to do some additional work with this in Senate Appropriations before we send it to the House, we want something to work out.

Action taken:

Senator Dever made a Do Pass recommendation with an emergency clause for the amendment. Seconded by Senator Brown. The amendment passed unanimously, 5-0-0.

Senator Warner made a Do Pass as Amended recommendation to re-refer it to Appropriations. Seconded by Senator Brown. The bill as amended passed unanimously, 5-0-0, with an emergency clause. Senator Warner is the carrier of the bill.

Chairman Lee closed the hearing on SB 2395.

FISCAL NOTE

Requested by Legislative Council
03/22/2005

Amendment to: Reengrossed SB 2395

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.*

	2003-2005 Biennium		2005-2007 Biennium		2007-2009 Biennium	
	General Fund	**Other Funds**	**General Fund**	**Other Funds**	**General Fund**	**Other Funds**
Revenues	$0	$0	$0	$106,766	$0	$415,921
Expenditures	$13,926	$0	$210,343	$106,766	$241,869	$415,921
Appropriations	$13,926	$0	$60,343	$106,766	$0	$0

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

2003-2005 Biennium			2005-2007 Biennium			2007-2009 Biennium		
Counties	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**
$0	$0	$0	$0	$0	$0	$0	$0	$0

2. **Narrative:** *Identify the aspects of the measure which cause fiscal impact and include any comments relevant to your analysis.*

This bill would create and enact a new section to chapter 50-10 of the NDCC relating to department of human services treatment program for children with Russell-Silver syndrome; would amend and reenact subsection 12 of section 50-10-06 of the NDCC relating to income eligibility for Russell-Silver syndrome treatment services; would direct the department to apply for a medicaid waiver to provide in-home services for children with extraordinary medical needs who would otherwise require hospitalization or nursing facility care; would provide for a legislative council study; would provide for a report to the legislative council; would provide an appropriation of $150,000 out of general funds and would declare an emergency.

This affects the department's regular appropriations.

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.*

There are no revenues available for Russel-Silver syndrome under this bill as all available federal funds have been dedicated to other services. For estimated costs under the medicaid waiver, federal revenue of $106,766 would be available under Title XIX for 2005-2007.

   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 2003 - 2005 the expenditures would be for 3 months of costs associated with the known case of Russel Silver syndrome in the state.

For 2005-2007 section 2 of this bill would limit payment to $50,000 per child per biennium for individuals through age 18 who have been diagnosed with Russell-Silver syndrome; however section 6 of this bill limits any appropriation from the general fund to $150,000 for providing Russell-Silver syndrome services. Under Section 3 the Department estimates that a waiver would take 12 months to write, submit and receive approval from the federal government with an estimated 3 individuals qualifying for this waiver at a cost of $167,109.

For 2007-2009 expenditures would potentially increase to $657,790.

C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, of the effect on the biennial appropriation for each agency and fund affected and any amounts included in the executive budget. Indicate the relationship between the amounts shown for expenditures and appropriations.*

For 2003 - 2005 an appropriation of $13,926 would be needed all general funds as the federal funds are projected to be expended.

For 2005-2007 appropriations for medical assistance grants need to be increased by $167,109 in total for those individuals that may qualify under the Medicaid waiver.

Name:	Brenda Weisz	**Agency:**	Human Services
Phone Number:	328-2397	**Date Prepared:**	03/23/2005

FISCAL NOTE

Requested by Legislative Council
03/07/2005

Amendment to: Reengrossed
SB 2395

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.*

	2003-2005 Biennium		2005-2007 Biennium		2007-2009 Biennium	
	General Fund	**Other Funds**	**General Fund**	**Other Funds**	**General Fund**	**Other Funds**
Revenues	$0	$0	$0	$106,766	$0	$415,921
Expenditures	$13,926	$0	$194,030	$106,766	$241,869	$415,921
Appropriations	$13,926	$0	$59,030	$106,766		

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

2003-2005 Biennium			2005-2007 Biennium			2007-2009 Biennium		
Counties	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**
$0	$0	$0	$0	$0	$0	$0	$0	$0

2. **Narrative:** *Identify the aspects of the measure which cause fiscal impact and include any comments relevant to your analysis.*

This bill would create and enact a new section to chapter 50-10 of the NDCC relating to department of human services treatment program for children with Russell Silver syndrome; the bill would also amend and reenact subsection 12 of section 50-10-06 of the NDCC relating to income eligibility for Russell Silver syndrome treatment services; to direct the Department to apply for a Medicaid waiver to provide in-home services for children with extraordinary medical needs who would otherwise require hospitalization or nursing facility care; to provide for a legislative council study; to provide an appropriation of $135,000 out of general funds and declare an emergency.

This affects the department's regular appropriations.

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.*

There are no revenues available for Russel Silver syndrome under this bill as all available federal funds have been dedicated to other services. For estimated costs under the medicaid waiver, federal revenue would be available under Title XIX.

   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 2003 - 2005 the expenditures would be for 3 months of costs associated with the known case of Russel Silver syndrome in the state.

For 2005-2007 the potential expenditures would include the amount covered for the known case of Russel Silver syndrome after insurance and an estimate of an additional case being diagnosed - $133,687. Under Section 3 the Department estimates that a waiver would take 12 months to write, submit and receive approval from the federal government with an estimated 3 individuals qualifying for this waiver at a cost of $167,109.

For 2007-2009 expenditures would potentially increase to $657,790.

C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, of the effect on the biennial appropriation for each agency and fund affected and any amounts included in the executive budget. Indicate the relationship between the amounts shown for expenditures and appropriations.*

For 2003 - 2005 an appropriation of $13,926 would be needed all general funds as the federal funds are projected to be expended.

For 2005-2007 appropriations for medical assistance grants need to be increased by $165,796 in total for those individuals that may qualify under the Medicaid waiver.

Name:	Brenda Weisz	**Agency:**	Human Services
Phone Number:	328-2397	**Date Prepared:**	03/08/2005

FISCAL NOTE

Requested by Legislative Council
02/16/2005

Amendment to: Engrossed SB 2395

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.*

	2003-2005 Biennium		2005-2007 Biennium		2007-2009 Biennium	
	General Fund	**Other Funds**	**General Fund**	**Other Funds**	**General Fund**	**Other Funds**
Revenues	$0	$0	$0	$106,766	$0	$415,921
Expenditures	$13,926	$0	$194,030	$106,766	$241,869	$415,921
Appropriations	$13,926	$0	$59,030	$106,766		

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

2003-2005 Biennium			2005-2007 Biennium			2007-2009 Biennium		
Counties	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**
$0	$0	$0	$0	$0	$0	$0	$0	$0

2. **Narrative:** *Identify the aspects of the measure which cause fiscal impact and include any comments relevant to your analysis.*

This bill would create and enact a new section to chapter 50-10 of the NDCC relating to department of human services treatment program for children with Russell Silver syndrome; the bill would also amend and reenact subsection 12 of section 50-10-06 of the NDCC relating to income eligibility for Russell Silver syndrome treatment services; to direct the Department to apply for a Medicaid waiver to provide in-home services for children with extraordinary medical needs who would otherwise require hospitalization or nursing facility care; to provide for a legislative council study; to provide an appropriation of $135,000 out of general funds and declare an emergency.

This affects the department's regular appropriations.

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.*

There are no revenues available for Russel Silver syndrome under this bill as all available federal funds have been dedicated to other services. For estimated costs under the medicaid waiver, federal revenue would be available under Title XIX.

   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 2003 - 2005 the expenditures would be for 3 months of costs associated with the known case of Russel Silver syndrome in the state.

For 2005-2007 the potential expenditures would include the amount covered for the known case of Russel Silver syndrome after insurance and an estimate of an additional case being diagnosed - $133,687. Under Section 3 the Department estimates that a waiver would take 12 months to write, submit and receive approval from the federal government with an estimated 3 individuals qualifying for this waiver at a cost of $167,109.

For 2007-2009 expenditures would potentially increase to $657,790.

C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, of the effect on the biennial appropriation for each agency and fund affected and any amounts included in the executive budget. Indicate the relationship between the amounts shown for expenditures and appropriations.*

For 2003 - 2005 an appropriation of $13,926 would be needed all general funds as the federal funds are projected to be expended.

For 2005-2007 appropriations for medical assistance grants need to be increased by $165,796 in total for those individuals that may qualify under the Medicaid waiver.

Name:	Brenda Weisz	**Agency:**	Human Services
Phone Number:	328-2397	**Date Prepared:**	02/16/2005

FISCAL NOTE

Requested by Legislative Council
02/14/2005

REVISION

Amendment to: SB 2395

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.*

	2003-2005 Biennium		2005-2007 Biennium		2007-2009 Biennium	
	General Fund	**Other Funds**	**General Fund**	**Other Funds**	**General Fund**	**Other Funds**
Revenues	$0	$0	$0	$106,766	$0	$415,921
Expenditures	$13,926	$0	$194,030	$106,766	$241,869	$415,921
Appropriations	$13,926	$0	$194,030	$106,766		

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

2003-2005 Biennium			2005-2007 Biennium			2007-2009 Biennium		
Counties	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**
$0	$0	$0	$0	$0	$0	$0	$0	$0

2. **Narrative:** *Identify the aspects of the measure which cause fiscal impact and include any comments relevant to your analysis.*

This bill would create and enact a new section to chapter 50-10 of the NDCC relating to department of human services treatment program for children with Russell Silver syndrome; the bill would also amend and reenact subsection 12 of section 50-10-06 of the NDCC relating to income eligibility for Russell Silver syndrome treatment services; to direct the Department to apply for a Medicaid waiver to provide in-home services for children with extraordinary medical needs who would otherwise require hospitalization or nursing facility care; to provide for a legislative council study and declare an emergency.

This affects the department's regular appropriations.

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.*

There are no revenues available for Russel Silver syndrome under this bill as all available federal funds have been dedicated to other services. For estimated costs under the medicaid waiver, federal revenue would be available under Title XIX.

   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 2003 - 2005 the expenditures would be for 3 months of costs associated with the known case of Russel Silver syndrome in the state.

For 2005-2007 the potential expenditures would include the amount covered for the known case of Russel Silver syndrome after insurance and an estimate of an additional case being diagnosed - $133,687. Under Section 3 the Department estimates that a waiver would take 12 months to write, submit and receive approval from the federal government with an estimated 3 individuals qualifying for this waiver at a cost of $167,109.

For 2007-2009 expenditures would potentially increase to $657,790.

C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, of the effect on the biennial appropriation for each agency and fund affected and any amounts included in the executive budget. Indicate the relationship between the amounts shown for expenditures and appropriations.*

For 2003 - 2005 an appropriation of $13,926 would be needed all general funds as the federal funds are projected to be expended.

For 2005-2007 appropriations for medical assistance grants need to be increased by $300,796 in total.

Name:	Brenda M. Weisz	**Agency:**	DHS
Phone Number:	328-2397	**Date Prepared:**	02/14/2005

FISCAL NOTE

Requested by Legislative Council
02/09/2005

Amendment to: SB 2395

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.*

	2003-2005 Biennium		2005-2007 Biennium		2007-2009 Biennium	
	General Fund	**Other Funds**	**General Fund**	**Other Funds**	**General Fund**	**Other Funds**
Revenues	$0	$0	$0	$213,532	$0	$415,921
Expenditures	$13,926	$0	$254,373	$213,532	$241,869	$415,921
Appropriations	$13,926	$0	$254,373	$213,532		

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

2003-2005 Biennium			2005-2007 Biennium			2007-2009 Biennium		
Counties	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**
$0	$0	$0	$0	$0	$0	$0	$0	$0

2. **Narrative:** *Identify the aspects of the measure which cause fiscal impact and include any comments relevant to your analysis.*

This bill would create and enact a new section to chapter 50-10 of the NDCC relating to department of human services treatment program for children with Russell Silver syndrome; the bill would also amend and reenact subsection 12 of section 50-10-06 of the NDCC relating to income eligibility for Russell Silver syndrome treatment services; to direct the Department to apply for a Medicaid waiver to provide in-home services for children with extraordinary medical needs who would otherwise require hospitalization or nursing facility care; to provide for a legislative council study and declare an emergency.

This affects the department's regular appropriations.

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.*

There are no revenues available for Russel Silver syndrome under this bill as all available federal funds have been dedicated to other services. For estimated costs under the medicaid waiver, federal revenue would be available under Title XIX.

   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 2003 - 2005 the expenditures would be for 3 months of costs associated with the known case of Russel Silver syndrome in the state.

For 2005-2007 the potential expenditures would include the amount covered for the known case of Russel Silver syndrome after insurance and an estimate of an additional case being diagnosed - $133,687. Under Section 3 the Department estimates that a waiver would take 12 months to write, submit and receive approval from the federal government with an estimated 3 individuals qualifying for this waiver at a cost of $334,218.

For 2007-2009 expenditures would potentially increase to $657,790.

C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, of the effect on the biennial appropriation for each agency and fund affected and any amounts included in the executive budget. Indicate the relationship between the amounts shown for expenditures and appropriations.*

For 2003 - 2005 an appropriation of $13,926 would be needed all general funds as the federal funds are projected to be expended.

For 2005-2007 appropriations for medical assistance grants need to be increased by $467,905 in total.

Name:	Brenda M. Weisz	**Agency:**	DHS
Phone Number:	328-2397	**Date Prepared:**	02/10/2005

FISCAL NOTE

Requested by Legislative Council
01/25/2005

Bill/Resolution No.: SB 2395

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.*

	2003-2005 Biennium		**2005-2007 Biennium**		**2007-2009 Biennium**	
	General Fund	**Other Funds**	**General Fund**	**Other Funds**	**General Fund**	**Other Funds**
Revenues	$0	$0	$0	$0	$0	$0
Expenditures	$0	$0	$557,030	$0	$657,790	$0
Appropriations	$0	$0	$557,030	$0	$657,790	$0

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

2003-2005 Biennium			**2005-2007 Biennium**			**2007-2009 Biennium**		
Counties	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**	**Counties**	**Cities**	**School Districts**
$0	$0	$0	$0	$0	$0	$0	$0	$0

2. **Narrative:** *Identify the aspects of the measure which cause fiscal impact and include any comments relevant to your analysis.*

This bill would create and enact a new section to chapter 50-10 of the NDCC relating to department of human services treatment program for children with Russell Silver syndrome; the bill would also amend and reenact subsection 12 of section 50-10-06 of the NDCC relating to income eligibility for Russell Silver syndrome treatment services.

This affects the department's regular approptians.

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.*

There are no revenues available for this bill as all available federal funds have been dedicated to services.

   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 2005-2007 the potential expenditures would be $557,030 - all general funds. For 2007-2009 expenditures would potentially increase to $657,790.

   C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, of the effect on the biennial appropriation for each agency and fund affected and any amounts included in the executive budget. Indicate the relationship between the amounts shown for expenditures and appropriations.*

For 2005-2007 appropriations for medical assistance grants need to be increased by $557,030 - all general funds.

Name:	Brenda Weisz	**Agency:**	Human Services
Phone Number:	325-2397	**Date Prepared:**	02/01/2005

Date: 2-7-05
Roll Call Vote #: 1

2005 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2395

Senate **Human Services** Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass amendment

Motion Made By Sen Dever Seconded By Sen Brown

Senators	Yes	No	Senators	Yes	No
Sen. Judy Lee - Chairman	✓		Sen. John Warner	✓	
Sen. Dick Dever - Vice Chairman	✓				
Sen. Richard Brown	✓				
Sen. Stanley Lyson	✓				

Total (Yes) 5 No 0

Absent 0

Floor Assignment

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

Date: 2-7-05
Roll Call Vote #: 2

2005 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2395

Senate **Human Services** Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass as am

Motion Made By Sen. Warner Seconded By Sen. ~~Dever~~ Brown

Senators	Yes	No	Senators	Yes	No
Sen. Judy Lee - Chairman	✓		Sen. John Warner	✓	
Sen. Dick Dever - Vice Chairman	✓				
Sen. Richard Brown	✓				
Sen. Stanley Lyson	✓				

Total (Yes) 5 No 0

Absent

Floor Assignment Sen. Warner

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

rerefer
emergency clause

REPORT OF STANDING COMMITTEE (410)
February 10, 2005 12:44 p.m.

Module No: SR-27-2395
Carrier: Warner
Insert LC: 50785.0101 Title: .0200

REPORT OF STANDING COMMITTEE

SB 2395: Human Services Committee (Sen. J. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (5 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2395 was rereferred to the **Appropriations Committee.**

Page 1, line 3, remove the first "and"

Page 1, line 4, after "treatment" insert "and"

Page 1, line 5, after "services" insert "; to direct the department of human services to apply for a medical waiver; to provide for a legislative council study; and to declare an emergency"

Page 1, line 21, after the underscored period insert "The parent of an individual receiving services under this section shall obtain any readily available employer-based health insurance, and that insurance must be the primary payer before payment under this program. There may be no recipient liability connected with this program.

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 shall require an applicant to demonstrate a chronic physical condition that results in prolonged dependency on medical care for which daily skilled nursing intervention is medically necessary. The department shall require an applicant to demonstrate a condition that is life-threatening, requires frequent administration of time-consuming medically necessary daily treatments, or requires the use of complex medical equipment or services such as a ventilator, dialysis machine, enteral or parenteral nutrition support, or continuous oxygen. The department may limit the waiver to fifteen participants and may prioritize applicants by degree of need.

SECTION 4. LEGISLATIVE COUNCIL STUDY - CHILD 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 legislative council may assign portions of this study to appropriate interim committees. 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. EMERGENCY. This Act is declared to be an emergency measure."

Renumber accordingly

2005 SENATE APPROPRIATIONS

SB 2395

2005 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2395

Senate Appropriations Committee

☐ Conference Committee

Hearing Date 02/11/05

Tape Number	Side A	Side B	Meter #
1		x	780
Committee Clerk Signature			

Minutes: **Chairman Holmberg** opened meeting on SB 2395.

Sen. Judy Lee District 13 appeared in support of SB 2395. This bill involves a young girl with Russell Silver Syndrome, she is the only diagnosed child with this disease in ND. She will be three years old in April, this is important because Medicaid goes away when a child turns three. Growth hormone should be administered at three years old. We are asking to pay the assistance to the growth hormone. We have included in our amendments for a mandatory study resolution. Sen. Lee also asked for the Katie Becket waiver.

Sen. Fischer Could you explain the fiscal note.

Sen. Lee maximum of three children with out insurance, this is significantly lower than the original fiscal note. I am sorry I do not have it with me as of yet.

Sen. Tallackson (1325) The other funds should that be federal.

Sen. Lee Title nineteen a waiver says that other funds will support the families.

Sen. Krauter: If the waiver is approved, then we would not need any fiscal dollars right?

Sen. Lee It would make a significant difference

Brenda Wies, CFO Department of Human Services, appeared in support of SB 2395. She answered Sen. Krauter's previous question regarding the need for a fiscal note. Ms. Wies stated that there would be a fiscal note.

Dave Zentner, Director Department of Human Services, appeared in support of SB 2395.

Sen. Mathern Brenda I am wondering if this bill were to pass how many months would there before there is a waiver in the mail?

Mr. Zentner: Couple months.

Ms. Wies stated to the committee that without medical insurance it would be $111,406.

Sen Kilzer: In the previous biennium, how are we doing are we running short or do we have enough money. Do most third party payers pay 80% of the cost of special treatment modalities.

Tammy Galletmelner, Director Children Health Services criteria for food may not be covered, until you know special circumstances of the child it is hard to tell what will be covered and what will not be.

Sen. Fischer: What is the PKU number

Ms. Galletmelner 21 People

Sen. Andrist: When a family moves into the state is their a waiver coverage.

Ms. Galletmelner: That has not been an issue.

Sen. Mathern (2333) This will bill wouldn't authorize you do decline eligibility if you think its a manageable move, they could show up tomorrow and you would have to approve it right.

Ms. Galletmelner: That is correct.

No further questions were asked of Ms. Galletmelner.

2005 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2395

Senate Appropriations Committee

☐ Conference Committee

Hearing Date 02/11/05

Tape Number	Side A	Side B	Meter #
2		x	5,840-end
Committee Clerk Signature			

Minutes: **Chairman Holmberg** opened discussion of SB 2395.

Sen. Fischer explained amendment. Explaining Medicaid waiver. Sen. Fischer motioned for an appropriation section to appropriate 135, for the bill. A voice vote was taken, amendment was accepted**. A Do Pass As Amended** motion was made by Sen. Andrist, seconded by Sen Bowman. Vote was taken 14 to 0 with 1 absent and not voting. Sen Wardner will be carrying the bill.

Chairman Holmberg closed discussion of SB 2395.

Date 2-14-05
Roll Call Vote #: 1

2005 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. SB 2395

Senate SENATE APPROPRIATIONS Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do PASS as Amended

Motion Made By A Seconded By Fl B.

Senators	Yes	No	Senators	Yes	No
CHAIRMAN HOLMBERG	✓		SENATOR KRAUTER	✓	
VICE CHAIRMAN BOWMAN	✓		SENATOR LINDAAS	✓	
VICE CHAIRMAN GRINDBERG	✓		SENATOR MATHERN	✓	
SENATOR ANDRIST	✓		SENATOR ROBINSON	✓	
SENATOR CHRISTMANN	✓		SEN. TALLACKSON	✓	
SENATOR FISCHER	✓				
SENATOR KILZER	✓				
SENATOR KRINGSTAD	✓				
SENATOR SCHOBINGER	✓				
SENATOR THANE					

Total (Yes) 14 No 0

Absent 1

Floor Assignment HMS Wardner

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

REPORT OF STANDING COMMITTEE (410)
February 15, 2005 10:53 a.m.

Module No: SR-30-2923
Carrier: Wardner
Insert LC: 50785.0201 Title: .0300

REPORT OF STANDING COMMITTEE

SB 2395, as engrossed: Appropriations Committee (Sen. Holmberg, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (14 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). Engrossed SB 2395 was placed on the Sixth order on the calendar.

Page 1, line 6, after the semicolon insert "to provide an appropriation;"

Page 2, after line 19, insert:

> "**SECTION 5. APPROPRIATION.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of $135,000, or so much of the sum as may be necessary, to the department of human services for the purpose of providing Russell-Silver syndrome treatment services, for the biennium beginning July 1, 2005, and ending June 30, 2007."

Renumber accordingly

STATEMENT OF PURPOSE OF AMENDMENT:

This amendment adds a section to the bill providing a $135,000 general fund appropriation to the Department of Human Services for providing Russell-Silver syndrome treatment services.

2005 HOUSE HUMAN SERVICES

SB 2395

2005 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. **SB 2395**

House Human Services Committee

☐ Conference Committee

Hearing Date **February 28, 2005**

Tape Number	Side A	Side B	Meter #
2	X		**22**
Committee Clerk Signature	Jamie Stein		

Minutes:

REP. CLARA SUE PRICE, CHAIRPERSON Called the committee hearing to order.

SEN. JUDY LEE, DIST. 13, WEST FARGO Introduced the bill. She stated she introduced the bill at the request of someone who had a little girl with Russell-Silver Syndrome, which is an extremely unusual and rare condition. This young lady is the only diagnosed case in North Dakota. There is a possibility of one other child. At the age of three, medicaid will pay, so they have been able to get some assistance with the cost of the medication she requires. In order to grow up to be a normal sized young lady, her parents will give you more information about that, she needs to have human growth hormones, beginning when she is three.

Congress is discussing a bill which may also provide some additional relief for families throughout the country. It is a treatable condition, but the treatments are very costly. We are also calling for a study because, we just didn't have the time to property word this, so we are including the children that can benefit from this special care, when there are extra ordinary costs.

Insurance would be the first provider, the state would be the payor of last resort. There is a study resolution HCR 3054, which calls for a study of this. We ask that the study part of this be in harmony with HCR 3054.

REP. DWIGHT WRANGHAM, DIST. 8 Co-sponsor of the bill. We have those who are affected by this bill here to talk to you today. As I look at this legislation, from my perspective as a legislator, I recall so many bills, and we wonder will it really make a difference, this bill will.

SEN. DICK DEVER, DIST. 32 Testified in support of the bill. See attached written testimony.

HEATHER ZIETZ, PARENT OF CHILD WITH RUSSELL SILVER SYNDROME

Testified in support of the bill. See attached written testimony.

Mr. Zietz also testified stating they have been through a lot this past three years, but nothing like their child has been through. It seems like for every step forward, she takes three steps back.

ROXANE ROMANICK, BISMARCK Testified in support of the bill. See attached written testimony.

Ms. Romanick also submitted written testimony from Blair Aasland.

CANDACE ZIETZ, LAIKYN'S GRANDMOTHER Testified in support of the bill.

Gave a brief history of how Laikyn's disease was discovered and what the family went through in the meantime. She needed constant care and was sick a lot. She related the financial burden the family went through.

BRUCE MURRAY, STAFF ATTORNEY WITH THE NORTH DAKOTA PROTECTION AND ADVOCACY PROJECT. Testified in support of the bill.

He stated the Protection and Advocacy staff helped draft some of the language in the bill.

ROBERT WENTZ, PEDIATRICIAN IN BISMARCK Testified in support of the bill. See attached written testimony.

JENNIFER RESTEMAYER, BISMARCK Testified in support of the bill. See attached written testimony.

LINDA SCHATZ, MANDAN, ND Testified in support of the bill. See attached written testimony.

TAMARA GALLUP-MILLNER, DIRECTOR OF CHILDREN'S SPECIAL HEALTH SERVICES UNIT Testified in support of the bill. See attached written testimony.

REP. POTTER Do you have any idea what other states do for these extraordinary diseases, are they generally covered or not covered?

TAMARA GALLUP-MILLNER I have not explored that issue. We think it would be fair to say that other states have applied for help for these children.

With no further testimony, the committee hearing was closed.

2005 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. **SB 2395**

House Human Services Committee

☐ Conference Committee

Hearing Date **2 March 2005**

Tape Number	Side A	Side B	Meter #
1		X	2395 - end
2	X		0 - 597
Committee Clerk Signature	Jan Prindle		

Minutes:

Chairman Price opened discussion of SB 2395

Rep. Nelson: Your subcommittee of Representatives Pietsch, Potter and myself worked with Tamara Gallup-Miller from the department on the concerns that they had on this bill. Their biggest problem was they thought it was all encompassing. We tried to define on line 17, the medical food definition. What we decided to go with was "Medical food means a food that 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." We decided to go with that definition for this exercise because as you will see later in the proposed amendments that we sunset this bill after this biennium. The other change on line 18 further defines growth hormone treatments so doesn't include more than the payment for the hormones we deleted the word "treatment" in that line and through the whole section we deleted that line. On the second page in the study section we added the language that was in the resolution SCR 3054 to include the cost/benefit of CHAN coverage. So we are looking at the insurance aspects during the interim so next legislative session we can make a better decision. We felt very uncomfortable of creating legislation for one individual and understanding the need for it we decided to go that route but we added the sunset clause as well. We are trying to limit the exposure of the department in this legislative session.

Chairman Price: Did you take any discussion on the proposed amendment from P&A? Protection and Advocacy put some amendments in on the Senate that there is some concern that those amendments may hinder the application for a waiver.

Rep. Nelson: We never talked about that.

Chairman Price: (Read from testimony of Bruce Murry, P&A.)

Rep. Nelson: We overlooked that.

Rep. Devlin: We also talked about changing employer based health insurance on line 23.

Rep. Nelson: We visited about that and I guess the question was when we are requiring parents to pay to obtain insurance it would have a very high deductible that might kick them out of this program. Some may be very expensive. It's very specific in this legislation that "they shall obtain." The reason we didn't go down that road because of the sunset clause I don't think we're talking about more than one family in this biennium so we decided that was better left alone at this time.

Rep. Devlin: Does employer based mean employer paid? What about the CHAN?

Chairman Price: My concern is that they require CHAN to be primary. If this waiver goes through that would be secondary. It's possible that we would be using more state dollars through the premium tax offset of the assessment to the insurance companies than we might be able to use if we get the waiver? CHAN costs us too. It's not a free program. We might be dollars ahead to go with the waiver and forget it.

Rep. Porter: We probably didn't read those two lines correctly when we were looking at it. It talks about if there is insurance available through the employer that they obtain that. It's not like we're telling them to go out and get insurance. My question is regards to the escalation of this act. The individual will be five years old when this expires and if nothing happens with the study, do we want to put this family through this again in 2007? Or do we want this to move forward to when she is 14 or 15 years old.

Rep. Nelson: That's a good point. What we are opening up here is a box that we might have a hard time closing. Maybe we shouldn't close it. The expiration date is July 31, 2007, so there wouldn't be a gap in coverage but we would have to continue to revisit this. We're assuming the interim committee will forward legislation that addresses some of the other cases that were referred to in testimony. We didn't feel comfortable including that in this bill at this time. It needs to go through that study process to see where the state of ND is going to end up with that.

Rep. Porter: We are talking about one specific disease. If we don't put the expiration date on it and the study shows something that is stop gap or bigger than life itself then the 2007 legislature can open this up and take it out. That will give that family some assurance that they have a treatment modality for their daughter for now. We have bought two years of time for their daughter.

Rep. Nelson: We don't care if the sunset clause comes off. Ms. Milner said they identified possibly eight other cases of this in the state. Just understand that there may be some exposure in several other cases if we don't limit this.

Rep. Porter: If it is possible that there are more then $135,000 isn't enough money to cover it and the Department is going to have to go to the emergency budget section to get money to cover this during the next biennium.

Rep. Nelson: That hormone treatment is very expensive. For 4-5 year olds it is $12,000 per year and as they get older it goes up to almost $40,000 for those treatments. There is some significant exposure.

Rep. Potter: I don't have any particular ownership for the sunset clause. It seemed to me that Tamara felt more comfortable having a sunset. She was uncomfortable with this whole thing because it's an unknown situation.

Chairman Price: Rep. Kaldor, back in your days as an appropriation committee member...can't we insert a section that says the department of human services shall report to the legislative council on the status of the waiver, the number of children that applied, the budget thing. Just the fact that the funding is going to expire but if they have to report the status of the waiver application and the reaction to this program we would have something to trigger us in the interim.

Rep. Porter: If the waiver kicks in there is a potentially large amount of money available.

Rep. Kaldor: I think part of the problem is that this demonstrates a much bigger problem. There are many, many others out there that differ that are just as dramatic and there is no question we are opening a door that we don't know what will come of it. How do they approach a waiver?

Chair Price: Probably on all three. It's an 1115 waiver but the groups involved are calling it the Katy Beckett waiver because that's where it originated from.

Rep. Damschen: I like the sunset clause just because of all the unknowns that exist. The political reality to have a sunset clause and extend it, it looks better than cutting something short.

Chair Price: My comment on that is I don't want to smell that PKU food again. I don't want these families to feel they have to come back to prove their case all over again.

Rep. Damschen: I'm not disagreeing with the concept of helping or having compassion for what they're going through. I'm just looking at all the unknowns. In light of putting them through what they are going through and we end up with something we can't handle.

Chairman Chair: In the case of the PKU for those of who weren't here, if the children don't get the right kind of food they are guaranteed to be mentally retarded. There is no way around it. That is definitely a cost benefit to the state to keep them out of institutions.

Rep. Potter: With removing the sunset clause and putting what ever it's called you were discussing, does that make it to where once we have the study and they look at all these extraordinary medical situations does that make it that in two years that does bring that situation back to where we're looking at the possibility of adding those on to this or where does that stand? I don't have a problem with that. From what Tamara was talking about there are others out there that are just as bad as this and we just haven't heard about them. In my view if we do for these few how fair is it to not come back and look at the others that are comparable? It seems like the fair thing to do.

Chair Price: We are looking at two separate issues. One is the study and we want to keep that separate. I want to make sure we come back and revisit if the waiver has been applied for, has it been received, if it has been received what are we going to do. We have to take a look at it.

Rep. Kaldor: One thing about leaving the language as it is rather than having the sunset I think it does put pressure on the Department to get the waiver. I just get the feeling they would rather not deal with it. I don't think there is anyone in the chamber that would deny that little girl help but it's a pretty big issue.

Rep. Nelson: I move we strike Section 6 in the proposed amendment (attached), add the P & A proposed amendments as well as on page 2, line 1 and page 2, line 5, add the status report, and the waiver application and the appropriation status.

Rep. Porter: I Second.

A voice vote was taken. The amendment carried.

Rep. Porter: I move **a Do Pass as Amended and Rerefer to Appropriations.**

Rep. Uglem: I second.

A roll call vote was taken.

Yes: 12 No: 1 Absent: 0

Rep. Nelson will carry the bill

2005 HOUSE STANDING COMMITTEE MINUTES

BILL NO. SB 2395

House Human Services Committee

☐ Conference Committee

Hearing Date March 15, 2005

Tape Number	Side A	Side B	Meter #
1	X		0-10.7
Committee Clerk Signature			

Minutes:

Rep. Clara Sue Price, Chairperson Called the committee hearing to order.

Rep. Nelson: (0.3) Yesterday we met with the parties, the Zietz's as well as the Protection Advocacy people, as well as the department and we came to an agreement to; first of all in the definition section 2 you find growth hormone treatment as to include the hormone to include the hormone as well as the treatment. One outer state physician visit per year to obtain expert consultation for the management of Russell-Silver syndrome, appropriate in state visit physical visits and travel associated with physical visits for the child and one parent. Also in the medical foods definition to include the equipment that is needed, in some cases, to administer that food. We did also put a limit of $50,000 per child per biennium to limit the exposure of the state in the case of more. There is confusion on how many cases might pop up with the passage of this bill.

What the state is going to be exposed to is the out of pocket portion of their insurance coverage, which is $2600 and then the travel to Laikyn will be going to Chicago for one of her visits and that consultation is free, the travel expenses because the family is providing. Evidently Heather is going to the workshop as well. She will also need a follow-up visit to New York so that would be included in this bill. We would have enough funding if it was matched out for three children, or three cases with the remainder of the money that could appear we could pick up a forth or possible a fifth child depending on what the costs are. I think it will get us through the biennium. It certainly does meet what the Zietz family is expecting. We did raise the appropriation from $135,000 to $150,000 so that would be covered. I would like to further amend on section 2 the 3 line in the first section of the first sentence it talks about the state agency shall provide payment of a maximum of $50,000 per child per biennium for medical, food and growth hormone treatment at no cost to the individual under the age of 18. I would suggest that we overstrike the word under in that sentence and replace it with through age 18. That should not have any impact on this occurrence, but I understand. As I understand if Medicaid covers through age 18 so it just mirror's Medicaid payments.

Rep. Nelson made a motion to accept the amendments. Seconded by **Rep. Potter.**

Rep. Weisz: (3.5) The way I read the language self employed would not constitute to use your insurance to cover before this kicks in? You only have to have insurance that is available for certain employer units.

Rep. Porter: (3.8) It is our intention that any insurance coverage would be utilized. In the original bill readily available employer base felt insurance, was the language. We did not ask for that change. I am not sure why it was changed.

Rep. Pietsch: (4.2) If you have insurance already you don't drop what you have. Be it bank depositors, self employed groups, union or whatever. If they don't have insurance now, they will not be able to get any insurance for that child now for medical reasons.

Chairman Price: Because any one could loose their job I don't see how you could possible write it in saying you would have to keep your insurance.

Rep. Porter:(5.3) The other safety valve in there is limited to $50,000.

Chairman Price: The reason we haven't specified that they have to go for CHAN is it may cost the state more to have them on CHAN than this program.

Voice vote - Carried

Any further amendments.

Motion Made By Rep. Nelson Do Pass As amend Seconded By Rep. Potter

Discussion:

Rep. Nelson:(6.6) I think this time we have got what we intended. Laikyn will be able to go through her treatment. The family will get some assistance. The questions that came up, is there a number of other cases like hers out there. We tried to address that as well as we could with the funding mechanisms that we have. I don't think we will see the potential of 8 cases that we have heard about. We put some limits as far as each individual case addressing the one that came before us so the family is satisfied now. We have some room for other cases and that is all we can do at this stage of the game.

Rep. Potter:(7.6) The study that is attached to this will also bring interesting things and who knows what we will find.

Rep. Weisz: (8.) There are a whole lot of them. The bill will determine that they may not be able to get the care they need.

Rep. Pietsch: We understand completely what this does and it was covered quite well in earlier discussions.

Chairman Price: (9.0) There are allot of things that Laikyn requires that are not prescription type things just for daily maintenance. Allot of the over the counter drugs and things they also pick up out of their own pocket above and beyond the deductible.

Rep. Nelson: (9.) This bill was brought to us over one case. Any time you develop a policy for one person or entity you do open some flood gates. I don't know how we could do much more to help this family.

Do Pass As Amended and Re-referred to appropriations:

10 Yes 1 No 1 Absent Carrier: Rep. Nelson

(10.6)

50785.0301
Title.

Prepared by the Legislative Council staff for
Representative Nelson
March 2, 2005

PROPOSED AMENDMENTS TO REENGROSSED SENATE BILL NO. 2395

Page 1, line 6, after the second semicolon insert "to provide an expiration date;"

Page 1, line 17, after "food" insert ", as defined under section 25-17-00.1,"

Page 1, line 18, remove "treatment"

Page 1, line 20, remove "treatment"

Page 1, line 22, remove "treatment"

Page 2, line 13, remove "**CHILD**"

Page 2, line 16, after "institutionalization" insert "; 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" and remove "The legislative council may assign"

Page 2, line 17, remove "portions of this study to appropriate interim committees."

Page 2, line 23, remove "treatment"

Page 2, after line 24, insert:

"**SECTION 6. EXPIRATION DATE.** Sections 1 and 2 of this Act are effective through July 31, 2007, and after that date are ineffective."

Renumber accordingly

Date: 3-2-05 **Roll Call Vote #:**

2005 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2395

House Human Services **Committee**

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass as Amd Rerf App

Motion Made By Porter Seconded By Uglem

Representatives	Yes	No	Representatives	Yes	No
Chairman C.S.**Price**	—		Rep.L. **Kaldor**	—	
V Chrm.G. **Kreidt**	—		Rep.L. **Potter**	—	
Rep. V. **Pietsch**	—		Rep.S. **Sandvig**	—	
Rep.J.O. **Nelson**	—				
Rep.W.R. **Devlin**	—				
Rep.T. **Porter**	—				
Rep.G. **Uglem**	—				
Rep C. **Damschen**	—				
Rep.R. **Weisz**		—			

Total ( ) 11 **No** 1

Absent 0

Floor Assignment Carrier - Rep Nelson

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

REPORT OF STANDING COMMITTEE (410)
March 3, 2005 2:58 p.m.

Module No: HR-39-4104
Carrier: Nelson
Insert LC: 50785.0302 Title: .0400

REPORT OF STANDING COMMITTEE

SB 2395, as reengrossed: **Human Services Committee (Rep. Price, Chairman)** recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (11 YEAS, 1 NAY, 0 ABSENT AND NOT VOTING). Reengrossed SB 2395 was placed on the Sixth order on the calendar.

Page 1, line 6, after the first semicolon insert "to provide for a report to the legislative council;"

Page 1, line 17, after "food" insert ", as defined in section 25-17-00.1,"

Page 1, line 18, remove "treatment"

Rep Price

Page 1, line 20, remove "treatment"

Page 1, line 22, remove "treatment"

Page 2, line 1, remove "There may be no"

Page 2, remove line 2

Page 2, line 5, remove "The department shall"

Page 2, remove lines 6 through 10

Page 2, line 11, remove "machine, enteral or parenteral nutrition support, or continuous oxygen."

Page 2, line 13, remove "**CHILD**"

Page 2, line 16, after "institutionalization" insert "; 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" and remove "The legislative council may assign"

Page 2, line 17, remove "portions of this study to appropriate interim committees."

Page 2, after line 19, insert:

"**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."

Page 2, line 23, remove "treatment"

Renumber accordingly

Date: 3/15/05 **Roll Call Vote #:** 1

2005 HOUSE STANDING COMMITTEE ROLL CAll
BILL/RESOLUTION NO. SB 2395

House **Human Services** **Committee**

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass as Amd - Re Ref to Approp

Motion Made By **Rep.** Nelson Seconded By **Rep** Patter

Representatives	Yes	No	Representatives	Yes	No
Chairman C.S. **Price**	✓		Rep.L. **Kaldor**	✓	
V Chrm.G. **Kreidt**	✓		Rep.L. **Potter**	✓	
Rep. V. **Pietsch**	✓		Rep.S. **Sandvig**	AB	
Rep.J.O. **Nelson**	✓				
Rep.W.R. **Devlin**	✓				
Rep.T. **Porter**	✓				
Rep.G. **Uglem**	✓				
Rep C. **Damschen**	✓				
Rep.R. **Weisz**		✓			

Total **Yes** 10 **No** 1

Absent 1

Floor Assignment **Rep.** Nelson

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

REPORT OF STANDING COMMITTEE

SB 2395, as reengrossed: Human Services Committee (Rep. Price, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (10 YEAS, 1 NAY, 1 ABSENT AND NOT VOTING). Reengrossed SB 2395 was placed on the Sixth order on the calendar.

In lieu of the amendments adopted by the House as printed on pages 901 and 902 of the House Journal, Reengrossed Senate Bill No. 2395 is amended as follows:

Page 1, line 6, after the first semicolon insert "to provide for a report to the legislative council;"

Page 1, line 17, after "Services" insert "- Definitions", after the boldfaced underscored period insert "1.", and after "provide" insert "payment of a maximum of fifty thousand dollars per child per biennium for"

Page 1, line 18, remove "coverage for" and replace "under" with "through"

Page 1, line 20, remove "treatment"

Page 1, line 22, remove "treatment"

Page 1, line 23, remove "readily available employer-based" and after "insurance" insert "available to the parent on a group basis or through an employer or union"

Page 2, line 1, replace "There may be no" with:

"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."

Page 2, remove line 2

Page 2, line 5, remove "The department shall"

Page 2, remove lines 6 through 10

Page 2, line 11, remove "machine, enteral or parenteral nutrition support, or continuous oxygen."

Page 2, line 13, remove "**CHILD**"

Page 2, line 16, after "institutionalization" insert "; 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" and remove "The legislative council may assign"

Page 2, line 17, remove "portions of this study to appropriate interim committees."

Page 2, after line 19, insert:

"**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."

Page 2, line 21, replace "$135,000" with "$150,000"

Page 2, line 23, remove "treatment"

Renumber accordingly

2005 HOUSE APPROPRIATIONS

SB 2395

2005 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB2395
Russell Silver Syndrome

House Appropriations Full Committee

☐ Conference Committee

Hearing Date March 23, 2005

Tape Number	Side A	Side B	Meter #
1	X		#3.4 - #18.0
Committee Clerk Signature	Chris Alexander		

Minutes:

Rep. Ken Svedjan, Chairman opened the discussion on SB2395.

Rep. Price explained is a disease that is difficult to diagnose and is very rare. If this little girl does not get the proper amount of nutrients needed from the proper food, her growth hormones will not function properly and her body would not develop equally on both sides and there would be many other physical problems caused by this as she grows. This family is covered by Blue Cross and Blue shield for some of their expenses and they have been covered through Medicaid, but the Medicaid coverage stops when she turns the age of 3. Other things covered in this bill would include the special medical food and all the medical equipment needed to administer the medication and the injections needed for the growth hormones. Twice a year through puberty this child needs to see a specialist who is located in New York and Chicago so there are travel expenses involved here as well. The recipient liability would be $2800 before this bill would become effective. Each child would be covered up to $50,000 to cover those expenses not covered by their insurance. This bill allows for 3 children to be covered, even though we currently only have this one case reported.

Rep. Ken Svedjan, Chairman commented that there is only one child currently identified with this disease, but the bill's fiscal impact is based on 3 children. Rep Svedjan asked Rep Price to discuss the new fiscal note

Rep Price answered that this was correct and that the new fiscal note would be set at $150,000 maximum. The fiscal notes for this bill have been at varying amounts as we have struggled to identify all the needs that are involved with this disease.

Rep. Francis J. Wald explained the conditions of a child he knew in Dickinson and asked if this child could be covered under this bill as well.

Rep Price answered that many families have e-mailed us concerning their specific ailments, but none have requested to be covered under this bill. A study is attached to this bill that would allow us to gather information on other diseases out there and residents of North Dakota with special health needs so we can begin to put a policy together that would deal with these issues. This particular child in Dickinson would not be covered under this bill since this specifies a certain disease.

Rep. Mike Timm, Vice Chairman asked why the original bill has an appropriation and the amendments do not reference that.

Rep Price answered that section 6 of the second engrossment with house amendments states that there is an appropriation of $150,000 out of general funds for the 2005-07 biennium.

Rep. Bob Skarphol confirmed that new version of the bill does state the correct amendment.

Rep. Keith Kempenich commented that the outcomes of this are unclear and asked what the study will do (meter Tape #1, side A, #11.1)

Rep Prices commented that this study will allow us to look at the overall issues and plan accordingly for the future policy on this instead of dealing with one specific case at a time.

Rep. Ken Svedjan, Chairman clarified that Blue Cross and Blue Shield covers some of this cost, but the Medicaid coverage stops at age 3.

Rep Price answered that this was correct.

Rep. Ken Svedjan, Chairman asked how the committee arrived at the $50,000 cost per child

Rep Price explained that the committee estimated high so that the families in the future that do not have as much insurance would still be covered.

Rep. Jeff Delzer asked if the committee changed the recipient liability

Rep Price answered no

Rep. Jeff Delzer asked how much is currently being spent on section one in Humans Services.

Rep Price answered that this was not discussed in committee

Rep. Jeff Delzer asked what the prognosis was for the child past the age of 18

Rep Price answered that the bulk of the problems with this disease happen between the ages of 13-16. We put the age of 18 on the bill to be consistent with Medicaid and the others.

Rep. Keith Kempenich asked if this bill could still be changed to cover the child mentioned by Rep Wald.

Rep. Ken Svedjan, Chairman commented that the study to be done will discuss all the health requests received and then make a policy for dealing with these issues in the future.

Rep Price answered that this was correct and that by then we would have a better understanding regarding the types of waivers that we would be eligible for.

Rep. Francis J. Wald commented that the study would be great, but asked what would happen to these other families in need who have immediate concerns. Could this bill be held to deal with this child.

Rep. Ken Svedjan, Chairman answered that several diseases could be identified to be covered by this bill, but is that what we want to do with this bill.

Rep Price commented that there are 19,500 children under the age of 18 who have special health care needs.

Rep. Alon C. Wieland moved a Do Pass motion on SB2395.

Rep. James Kerzman seconded

Rep. Ken Svedjan, Chairman called for a roll call vote on the Do Pass motion for SB2395. Motion carried with a vote of 22 yeas, 0 neas and 1 absence. Rep Nelson will carry the bill to the house floor.

Rep. Ken Svedjan, Chairman closed the discussion on SB2395.

Date: **March 23, 2005**
Roll Call Vote #: 1

2005 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. SB2395

House Appropriations - Full Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken **DO PASS**

Motion Made By **Rep Wieland** Seconded By **Rep Kerzman**

Representatives	Yes	No	Representatives	Yes	No
Rep. Ken Svedjan, Chairman	X		Rep. Bob Skarphol	X	
Rep. Mike Timm, Vice Chairman	X		Rep. David Monson	X	
Rep. Bob Martinson	X		Rep. Eliot Glassheim	AB	
Rep. Tom Brusegaard	X		Rep. Jeff Delzer	X	
Rep. Earl Rennerfeldt	X		Rep. Chet Pollert	X	
Rep. Francis J. Wald	X		Rep. Larry Bellew	X	
Rep. Ole Aarsvold	X		Rep. Alon C. Wieland	X	
Rep. Pam Gulleson	X		Rep. James Kerzman	X	
Rep. Ron Carlisle	X		Rep. Ralph Metcalf	X	
Rep. Keith Kempenich	X				
Rep. Blair Thoreson	X				
Rep. Joe Kroeber	X				
Rep. Clark Williams	X				
Rep. Al Carlson	X				

Total Yes 22 No 0

Absent 1

Floor Assignment **Rep Nelson**

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

REPORT OF STANDING COMMITTEE

SB 2395, as reengrossed: Appropriations Committee (Rep. Svedjan, Chairman) recommends **DO PASS** (22 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). Reengrossed SB 2395 was placed on the Fourteenth order on the calendar.

2005 TESTIMONY

SB 2395

Attachment 1

Testimony
SB 2395 – Russell Silver's Syndrome
Senate Human Services Committee
Chair – Senator Judy Lee
February 2, 2005

Senator Judy Lee and members of the Committee, my name is Heather Zietz and I am the parent of a child with Russell Silver's Syndrome. I am here today in support of SB 2395.

Russell Silver's Syndrome (RSS) is an extremely rare growth disorder. Dr. Madeleine Harbison diagnosed my daughter Laikyn, with the disorder. She is the Assistant Professor of Pediatrics at Mt. Sinai Hospital in New York City. She is one of few Doctors who specialize in Russell Silver's Syndrome. We have tried several times to find a doctor in ND who had experience with RSS and have come up with no one. We tried Bismarck and Fargo, and no one had even heard of RSS. We were also directed by the Department of Human Services to try Mayo Clinic. Again, we couldn't find a doctor that specialized in RSS or even one that had experience with RSS. My husband Derek and I met Dr. Harbison in Chicago about 2 years ago. At that time she told us that our daughter looked as though she was starving and we needed to take immediate action with her growth. From that day on Laikyn has been doing wonderful with the food and medications that she was given.

In April, my daughter will lose her Medicaid coverage. She doesn't qualify for Developmental Disabilities services's because she doesn't

meet the criteria for being "Mentally Retarded." In our state there are a lot of other children including Laikyn who need services who are not considered "Mentally Retarded". By understanding the importance of aggressively feeding these children with RSS, no matter what it takes, we are able to avoid the malnutrition and low blood sugars that in the past has so negatively affected their growth and development. With the resent U.S. Food and Drug Administration's approval of growth hormone for the treatment of the growth failure associated with being small for gestational age, these young children can start the first grade with normal height if treated early, as stated by Dr. Harbison. With the proper medical food and growth hormone therapy treatments, my daughter will have the opportunity to grow and develop just like a typical child does. She needs these treatments so she can better her life in the future. Through these treatments, she will have the chance to catch-up to her expected developmental stages later in life.

Currently, our family has a health care plan through Blue Cross Blue Shield. My daughter is also covered under this plan. Medicaid wouldn't even be our family's primary insurance. Starting in April, our family's recipient liability (RL) would roughly be $2,800 a month. I had Jackie Vetter from Medicaid figure out our recipient liability. I provided all of you documentation of how much my RL would be. It is attached to the back of this testimony.

Because of the way our current system works, some kids fall through the cracks based on eligibility and screening criteria that are currently in place. I understand the need to have screening and eligibility criteria

in place, but sometimes the same criteria prevents services from being offered or delivered to those who desperately need them. When the opportunity for "prevention" presents itself, as a mom, I must act. Our family is asking for your help. By passing Senate Bill 2395 you are helping to assure that the opportunity my daughter has, isn't missed.

Thank you for your time and attention this morning, I will try and answer any questions that you may have.

Sincerely,

Heather Zietz

Attachment 1A

Burleigh County Social Services

The Provident Building•415 E. Rosser Avenue, Suite 113•Bismarck, ND 58501-4058•Telephone:701-222-6622•Fax:701-222-6644•701-222-6476

January 31, 2005

To Whom It May Concern:

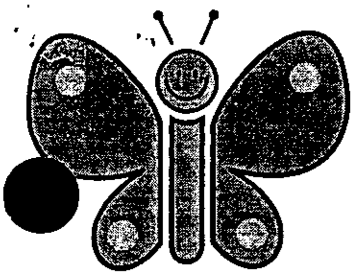
Per my conversation with Heather Zietz regarding continuing Medicaid coverage for Laikyn, it appears the family would no longer be eligible for Medicaid due to their income when Laikyn is no longer screened for and receiving home and community based services. Their monthly gross income is approximately $3300 a month and medically needy income limit for a household of three is $666. This means they would have a few thousand dollar a month recipient liability. Their income also exceeds the poverty level income guideline.

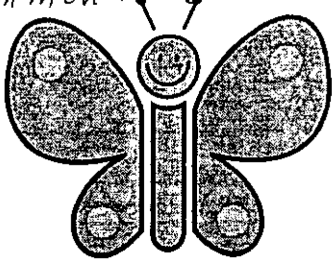
Sincerely,

Jackie Vetter

Jackie Vetter
HSPA IV

Attachment 1B





Heavens Very Special Child

A meeting was held quite far from earth.
"It's time again for another birth",
said the angels to the lord above.
"This special child will need much love".
her progress may seem very slow,
Accomplishments she may not show.
and she'll require extra care
From the folks she meets way down there.
So lets be careful where she's sent,
we want her life to be content.
Please, lord, find her parents who
will do a special job for you.
They will not realize right away
the leading role they're asked to play.
But with this child sent from above
comes stronger faith and richer love.
And soon they'll know the privilege given
in caring for this gift from heaven.
Their precious charge, so meek and mild
Is Heavens Very Special Child.

THE MAGIC FOUNDATION

Russell-Silver Syndrome

- INTRODUCTION
- PDF Brochure

INTRODUCTION

In 1953 and 1954, Drs. Silver and Russell independently described groups of small-for-gestational-age [SGA] children whose pregnancies had been complicated by intrauterine growth retardation [IUGR]. Their common findings were short stature without catch-up growth, normal head size for age, a distinctive triangular face, low-set ears and incurving fifth fingers. These two groups of patients are now considered to have had variations of the same disorder that we now call Russell-Silver Syndrome [RSS] in the U.S. and Silver-Russell Syndrome [SRS] in Europe.

One interesting and important aspect of the Russell-Silver syndrome is its variation in phenotype. In this context, a phenotype is all the physical characteristics and abnormalities found in an individual patient that are attributed specifically to RSS. Some individuals with RSS have many traits, thus a severe phenotype, while others have very few traits, thus a mild phenotype.

When first described, RSS was NOT thought to be a genetic disorder because it recurred within families rarely, and when it did recur, its pattern of transmission failed to follow a consistent genetic mode of inheritance. More recent understandings of genetic mechanisms have led scientists to conclude that RSS is genetic, but its genetics are not simple. Scientists now believe that the RSS phenotype is associated with more than one genotype.

A genotype is the status of a specific gene at a specific location on a specific chromosome. Therefore, an abnormal genotype means there has been a specific alteration, such as a deletion, duplication, insertion, substitution or imprinting error within the code of a specific gene located at a specific site in an individual's genetic code.

Since our genotype is responsible for our phenotype, abnormal genotypes result in abnormal phenotypes. If we assume several genotypes for RSS, then we should not be surprised at a variety of phenotypes. We view this as one reason for the marked variability within the group of patients considered to have RSS. But deciding which child should be considered to have RSS is not always easy. When more is known about the genetics of RSS, we will find that some patients were incorrectly included while others were incorrectly excluded.

How is RSS Diagnosed?

The diagnosis of RSS is still a judgment call on a physician's part because there is no definitive laboratory test that can answer yes or no in a specific case. Doctors generally base their diagnosis on characteristic, clinical findings that make up the RSS phenotype. It is easy to diagnose the "textbook" RSS phenotype. An SGA child, however, who lacks catch-up growth, has low weight-for-height, normal head size for age, and few, if any, features that make him look different, is much more difficult to classify.

What is the Typical RSS Phenotype?

The RSS phenotype includes a number of physical and developmental characteristics. One of these, asymmetry, is unique to RSS, while others, like low birth weight and length, are shared by RSS and SGA children in general.

Characteristics Considered to Distinguish RSS Children From Other SGA Children:

- body asymmetry -LARGE side is "normal" side
- inadequate catch-up growth in first 2 years
- persistently low weight-for-height
- lack of interest in eating
- lack of muscle mass and/or poor muscle tone
- broad forehead
- large head size for body size
- hypoplastic (underdeveloped) chin & midface
- downturned corners of mouth & thin upper lip
- high-arched palate
- small, crowded teeth
- low-set, posteriorly rotated &/or prominent ears
- unusually, high-pitched voice in early years
- clinodactly (inward curving) of the 5th finger
- syndactyly (webbing) of the 2nd and 3rd toes
- hypospadius - abnormal opening of the penis
- cryptorchidism - undescended testicles
- café-au-lait (coffee-with-milk) birth marks
- dimples in the posterior shoulders and hips
- narrow, flat feet · scoliosis - curved spine, associated with spinal asymmetry and accentuated by a short leg

Characteristics of SGA Patients in General That Are Seen More

Often in RSS Patients:

- fasting hypoglycemia & mild metabolic acidosis
- generalized intestinal movement abnormalities:
  a) esophageal reflux resulting in movement of food up from stomach into food tube
  b) delayed stomach emptying resulting in vomiting or frequent spitting up
  c) slow movement of the small intestine &/or large intestine (constipation)
- blue sclera (bluish tinge in white of eye)
- late closure of the anterior fontanel (soft spot)
- frequent ear infections or chronic fluid in ears
- congenital absence of the second premolars
- delay of gross and fine motor development
- delay of speech and oral motor development
- kidney abnormalities
- delayed bone age early, later fast advancement
- early pubic hair and underarm odor (adrenarche)
- early puberty or rarely true precocious puberty
- classical or neurosecretory growth hormone deficiency
- ADD and specific learning disabilities

Links

Child's Site with RSS
coltongeorge.com

What Should I Do If I Think My SGA Child Has RSS?

- Have your child's diagnosis confirmed by a doctor who is familiar with RSS-SGA patients.
- Make sure your child is measured carefully & frequently. KEEP YOUR OWN RECORDS. Find an endocrinologist who knows how to treat SGA children's growth failure and discuss the options.
- Find a pediatrician who is willing to learn from experts about RSS-SGA children, and will coordinate care and opinions with consulting specialists.
- Get adequate calories into your child. Insufficient nutrition & low blood sugar damage the developing brain and compound the growth failure.
- Take necessary measures to prevent hypoglycemia in young RSS children. Pay special attention to the night when everyone is asleep, anytime your child is ill or not eating normally, and when your child is unusually active or stressed.

- **Know clues that hypoglycemia is occurring**:

a) waking to feed at night past early infancy
b) excessive sweating
c) extreme crankiness improved by feeding
d) difficulty waking up in the morning
e) ketones in the urine

- **Prevent hypoglycemia by:**

a) feeding frequently during the day & night
b) keeping snacks with you at all time
c) feeding through gastrostomy tube

d) adding glucose polymer in infant's, & cornstarch in child's, bed- & night-time feeding
e) keeping glucose gel with you at all times
f) making prior arrangements with your doctor and local ER to start IV glucose if feeding is impossible
g) having urine ketone sticks at home

· Treat your child his age not his size. Arrange safe, age-appropriate activities; buy age-appropriate clothes; and expect age-appropriate behavior and responsibility.

· Watch your child's psychosocial and motor development. All states have developmental evaluation & intervention services for children less than 3. These programs are based on the child's needs not parental income. For children over 3 years, the school district becomes responsible for providing these services. Take advantage of this; intervention can make a world of difference for your child!

· Seek appropriate consultation for recurrent ear infections, hypospadius, undescended testicles, leg length discrepancies, etc.
But remember:
a) Only emergency surgery should be done until the child is gaining weight well.
b) A young SGA child should NEVER be fasted or kept NPO for more than 4 hours for ANY reason without glucose-running IV.
c) For surgery, IV glucose should be given during the procedure and continued in the recovery room.

Why Does My Child Have RSS?

It is not your fault! You could have done nothing to prevent it! RSS occurs through complicated genetic mechanisms and could never be caused by what you as parents did or did not do.

What Can I Expect Regarding My Child's Cognitive Abilities?

An infant with RSS is generally born with normal intelligence. Learning disabilities and Attention Deficit Disorder (ADD) appear to be increased in incidence in RSS. Autism and similar disorders like pervasive developmental disorder (PDD) may also be increased. It is unclear whether these problems just appear to be increased in RSS, are innate to RSS, or
are acquired through early malnutrition and hypoglycemia, both of which are preventable.

Where can I meet other RSS families?

Coping with the time-consuming special attention and services necessary to care for an RSS-SGA child can be overwhelming, especially if you try to face it alone. Good physicians often have no experience with routine needs of RSS-SGA children. Day-to-day challenges such as feeding, formulas, fitting clothes, school issues and peer pressures can be less stressful if you are in contact with other families who "have been there and done that." Making connections between families with similar issues and facilitating sharing of information and experience is a major goal of the MAGIC Foundation's RSS Division. We can put you in touch with other people who have had, and have solved, problems similar to yours.

What Treatments are Available for RSS?

For RSS and non-RSS/SGA patients, the prospect for a normal life with a normal adult height is closer than ever before. By understanding the importance of aggressively feeding these children, no matter what it takes, we are able to avoid the malnutrition and low blood sugar that in the past has so negatively affected their growth and development. With the recent U. S. Food and Drug Administration's approval of growth hormone for the treatment of the growth failure associated with being born small-for-gestational age, these young children can start the first grade with a normal height if treated early. By taking medications to postpone puberty, called LHRH analogues [LHRHa], the older children can recover growth potential lost in-utero, in infancy and in early childhood. By continuing growth hormone until growth is finished, the teenagers have a better growth spurt during puberty. The figures comparing the average growth of a large sample of untreated, European RSS children to examples of currently treated RSS children are available from MAGIC.

The RSS Division of MAGIC has information on current therapy and ongoing research involving RSS and SGA children. Please contact us if you have questions about treatment options for your child, difficulty arranging medical care for your child, or if you are interested in learning more about ongoing research in the field.

Contributing Medical Specialist

Madeleine D. Harbison, M.D.
New York, New York

Attachment 2

Testimony
SB 2395
Senate Human Services Committee
Senator Lee, Chairperson
January 20, 2005

Senator Lee and members of the Senate Human Services committee, I am Roxane Romanick and am employed with Bismarck Public Schools. More specifically I work as an experienced parent specialist with the Bismarck Early Childhood Education Program. I am in support of Senate Bill 2395.

The most significant role for me in my job is to provide informational and emotional support to families who have children that receive Early Intervention services. These services are provided to children, age birth to 3, who meet the criteria of "developmental delay". Because it's my job to provide information and support to families, I am very familiar with the ramifications of "turning 3" for families.

One of these ramifications is the need for re-determination of eligibility for continued Developmental Disabilities Case Management, which allows persons with mental retardation and developmental disabilities to be screened for the home and community based waiver. Eligibility requirements change at the age of 3. Children who are not found eligible can no longer access case management services, services that are included under the home and community based waiver, or have access to the income and asset disregard for medical assistance. Children can continue to access medical assistance, but at the cost of huge recipient liabilities that most families cannot afford.

SB 2395 is a result of the Zeitz family advocating for the needs of their daughter. This is a family that has explored many avenues to make sure that their daughter receives the best health care treatment that she can get. They also have a solid understanding of what her health care costs will mean for their family and also what preventive care will mean for her in the long run. I am in support of their efforts to advocate for her needs.

Thank you for your time.

Roxane Romanick
701-527-4645
romanick@bis.midco.net

Attachment 3

TESTIMONY BEFORE THE SENATE HUMAN SERVICES COMMITTEE
REGARDING SENATE BILL 2395
FEBRUARY 2, 2005

Chairman Lee and members of the committee, I am Tamara Gallup-Millner, director of the Children's Special Health Services (CSHS) unit, which is located in the Medical Services Division in the Department of Human Services. I'm here to provide information related to SB 2395.

Work done in the CSHS unit focuses on children with special health care needs and their families. Children and youth included in this population have chronic conditions of some kind and a need for health and related services generally beyond those needed by most children. In North Dakota, about 12.4% or 19,500 children under age 18 are estimated to have a special health care need based on the definition I've just described.

Families we work with in CSHS report that having a child with special health care needs has a financial impact on their family. Some families do not have insurance, but more often, the health care coverage they do have does not meet all of their child's needs. The care that is required can become a cumulative burden when expenses are incurred year after year. Many families we hear from share the need that gave impetus to this bill.

If passed, SB 2395 would require CSHS to provide medical food and coverage for growth hormone treatment at no cost to individuals under age eighteen who have been diagnosed with Russell Silver Syndrome, regardless of income.

While I recognize the importance of services for all children with special health care needs and their families, including children with Russell Silver Syndrome, there are also important implications that merit attention as this bill is considered.

1. Eliminating the income eligibility requirement for treatment services through CSHS is setting a precedent that certain conditions receive prefferential treatment. Families that have children with asthma, diabetes, cerebral palsy, cleft lip and palate, hearing loss, cystic fibrosis, etc., would need to meet the eligibility criteria at 185% of the federal poverty level, while those with Russell Silver Syndrome would not. Is this fair to other families that have children with high medical expenses? The Legislature mandated the eligibility level currently used for CSHS treatment services in 2001.

2. Definitions for "medical food" and "coverage for growth hormone treatment" have not been included in the bill. These terms could be very narrowly or very broadly interpreted. For example, does the term "medical food" mean that a typical infant formula like Similac be provided, just because its concentration has been adjusted to provide more calories in order to promote adequate growth? Similac is a formula many well babies routinely use in the first year of life. Or, does "medical food" imply coverage of various formulas that are used as the primary source of nutrition for children if they require tube feedings in order to increase caloric intake? Does "coverage for growth hormone treatment" literally mean only the medication used for hormone replacement or does it include office visits, lab, x-rays, etc. needed for monitoring whether the medication is actually achieving the desired results? Legislative intent needs to be clear so that expectations about covered services are well understood.

3. <u>Use of private insurance coverage is not addressed</u>. The vast majority of children CSHS serves have a source of health care coverage. Usually, CSHS is a secondary payer and takes a gap-filling role. Using this approach, we have been able to spread available resources to help more children. Currently, CSHS limits reimbursement for diagnostic and/or treatment services in a one-year period to $20,000 per child regardless of the number of eligible conditions a child may have. When benefits are coordinated with other payers, the limit rarely becomes an issue for eligible families. It's unclear in SB 2395 whether private insurance can be used if it is available. If it is not to be used, CSHS would be sole payer for all of the defined services for these children, which would increase the fiscal impact.

4. <u>Impact on the CSHS unit's current services and programs is possible</u>. Although considered rare, the incidence of this syndrome is truly not known. Its unclear how many children might receive medical food and coverage for growth hormone treatment. Unless additional funding is made available, CSHS will need to redirect current resources to meet service needs of children with Russell Silver Syndrome. Although not a certainty, this could lead to elimination of other services that currently are provided.

5. <u>Characteristics of Russell Silver Syndrome vary widely.</u> Some individuals have many of the documented traits associated with this syndrome, while others have very few. Required treatment may vary based on each individual's specific medical needs which may or may not be consistent with services that are included in this bill.

This concludes my testimony. I would be happy to respond to any questions you may have.

Attachment 1

PROPOSED AMENDMENTS TO SENATE BILL 2395

On page 1, line 4, after the word “syndrome” remove the word “and”.

On page 1, line 5, after the word “treatment” insert “and”.

On page 1, line 5, after the word “services” insert “to provide for a legislative council study and to direct the department of human services to apply for a medicaid waiver”

On page 1, line 12, after “eligibility.” insert “The child’s parents shall obtain any readily available employer-based health insurance for the child and that insurance shall be the primary payer before payment is available under this program. There shall be no recipient liability connected with this program.”

On page 1, line 21, insert, “SECTION 3. 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 shall require applicants to demonstrate a chronic physical condition that results in prolonged dependency on medical care for which daily skilled nursing intervention is medically necessary. The department shall require applicants to demonstrate a condition that is life threatening, requires frequent administration of time-consuming medically necessary daily treatments, or requires complex medical equipment such as a ventilator, dialysis machines, enteral or parenteral nutrition support, or continuous oxygen. The department may limit the waiver to fifteen participants. The department may prioritize applicants by degree of need.

SECTION 4. The Legislative Council shall study issues relating to medicaid and other public funding for the extraordinary health care needs of children who live in an institution or are at risk of institutionalization. The Legislative Council may assign portions of this study to appropriate interim committees. The Legislative Council shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the Sixtieth Legislative Assembly.”

Lee, Judy E.

TO: The Honorable Judy Lee, Chairman of the Senate Human Services Committee

Attached are three attachments.

The first is not in bill draft form. It is a draft to show how a full "Katie Beckett" waiver would look. This would cover many more children than those with phenylketonuria, maple syrup urine disease, and Russell-Silver Syndrome. I think most of them are already receiving Medicaid dollars for care in a hospital, nursing home, or ICF-MR.

The second shows the "Katie Beckett" waiver narrowed to cover only those with phenylketonuria, maple syrup urine disease, and Russell-Silver Syndrome.

The third shows bill draft language amending SB 2395 to include a study.

David Boeck

-----Original Message-----
From: Lee, Judy E. [mailto:jlee@state.nd.us]
Sent: Sunday, February 06, 2005 2:01 PM
To: Murry, Bruce D.; Boeck, David E.
Subject: Russell Silver, etc.

Bruce and David - Can you meet with the Human Services committee on Monday? We have to get that bill out that day, because it has a fiscal note and Monday is the deadline. The committee is going to meet at 8 a.m. on Monday for 30 minutes before the first hearing. If that doesn't give you enough time, how about after the session at about 2:30-3 p.m.?

Attachment 1

[Broad language for Katie Beckett waiver]

Children with Extraordinary Medical Needs. The department shall provide medical coverage for children who have extraordinary medical needs.

1. A child shall be eligible for this program if
   a. The child satisfies the medical criteria for disability established under federal law for the supplemental security income program;
   b. The child is less than 19 years old;
   c. The child would be eligible for the Medicaid program if not for parental income and resources;
   d. The child would live at home though medically eligible for or at risk of requiring hospital or nursing home level of care without this coverage;
   e. The child's physician states that the quality and quantity of services and supports that the child will receive are sufficient to meet the needs of the child in the home; and
   f. There is a reasonable expectation that the cost for the child to live at home will not exceed the cost for the child to live in a hospital or nursing home.
2. The state agency shall seek federal funds for this program to the maximum extent available through a waiver to the Medicaid program.

3. The child's parents shall obtain any readily available employer-based health insurance for the child and that insurance shall be the primary payer before payment is available under this program. There shall be no recipient liability connected with this program.

4. The department shall provide coverage for the child's medical needs, functional needs, social needs, and home/environmental needs as determined by a care team that includes the parents. This coverage includes medically necessary and specifically prescribed therapies, enteral and parenteral nutrition, and assistive technology devices and services.

Attachment 2

Children with Extraordinary Medical Needs. The department shall provide medical coverage for children who have extraordinary medical needs.

1. A child shall be eligible for this program if
   a. The child has phenylketonuria, maple syrup urine disease, or Russell-Silver Syndrome;
   b. The child is less than 19 years old;
   c. The child would be eligible for the Medicaid program if not for parental income and resources;
   d. The child would live at home though medically eligible for or at risk of requiring hospital or nursing home level of care without this coverage;
   e. The child's physician states that the quality and quantity of services and supports that the child will receive are sufficient to meet the needs of the child in the home; and
   f. There is a reasonable expectation that the cost for the child to live at home will not exceed the cost for the child to live in a hospital or nursing home.
2. The state agency shall seek federal funds for this program to the maximum extent available through a waiver to the Medicaid program.
3. The child's parents shall obtain any readily available employer-based health insurance for the child and that insurance shall be the primary

payer before payment is available under this program. There shall be no recipient liability connected with this program.

4. The department shall provide coverage for treatment services for Russell-Silver Syndrome, phenylketonuria, or maple syrup urine disease.

Attachment 3

PROPOSED AMENDMENTS TO SENATE BILL 2395

On page 1, line 4, after the word "syndrome" remove the word "and".

On page 1, line 5, after the word "treatment" insert "and".

On page 1, line 5, after the word "services" insert "to provide for a legislative council study"

On page 1, line 21, insert, "SECTION 3. The Legislative Council shall study issues relating to medicaid and other public funding for the extraordinary health care needs of children who live in an institution or are at risk of institutionalization. The Legislative Council may assign portions of this study to appropriate interim committees. The Legislative Council shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the Sixtieth Legislative Assembly."

1

Testimony on SB 2395
House Human Services Committee
Senator Dick Dever

Madam Chair, members of the committee, for the record, I am Dick Dever, Senator from District 32 here in Bismarck. Every bill that comes before the legislature is important to someone. This bill is important to me, and I believe, to every member of the Senate Human Services Committee. It was suggested to me that I use for my testimony this morning, the speech that I delivered on the floor of the Senate in consideration of this bill. With your indulgence, I would like to do that.

"Mr. President, it's just not fair! They brought that little girl into our committee a couple of weeks ago and she stole my heart! Now I'm supposed to make an objective decision!

‘I have given this a lot of thought. I'd like to give you three objective reasons to support this bill.

‘The first reason is because this could happen to anybody. It is not a matter of life choices. It is not a matter of genetics. It just happens. According to one doctor, it happens only once in 100,000 births. You can't explain why it happened to this little girl.

‘The second reason to support this bill is because the doctors say that the treatment will work. With the hormone treatment and nutritional considerations, when she is 14 or 15 years old she will be the same size as other girls her age. Without the treatment, the doctor told us that she will sound like a 14 or 15 year old, but she will look like a two year old.

‘The third reason is because her parents have demonstrated to us the commitment they have for their little girl that will virtually guarantee the success of this treatment. After she was born, the doctor didn't know what he was dealing with, but he knew enough to know that he needed to install a plug in her tummy to provide the nutrition that she desperately needed.

‘Her parents talked about feeding her a little at a time through that plug, slowly enough that she wouldn't expel it - - around the clock.

‘Her mother told us that her little girl was a very "lucky" little girl. I think a better word might be "blessed". God "blessed" that little girl when he chose her parents. If I was to ask one more thing of those young parents, it would only be that they bring their precious little girl back up to see us every couple of years so we can see how she is doing.

‘You can feel good about this bill. You can do something good for a very deserving family. Vote green!!"

2

Testimony
SB 2395- Russell Silver Syndrome
House Human Services Committee
Chair- Clara Sue Price
February 28, 2005

Representative Clara Sue Price and members of the committee, My name is Heather Zietz and I am the parent of a child with Russell Silver Syndrome. I am here today in support of SB 2395.

Russell Silver Syndrome (RSS) is an extremely rare growth disorder. Dr. Madeleine Harbison diagnosed my daughter Laikyn, with this disorder. She is the Assistant Professor of Pediatrics at Mt. Sinai Hospital in New York City. She is one of few Doctors who specialize in RSS. We have tried several times to find a doctor in North Dakota who had experience with RSS and have come up with no one. We tried Bismarck and Fargo, and no one had even heard of RSS. We were also directed by the department of Human Services to try Mayo Clinic. Again, we were unable to find a doctor that specialized in RSS or even one that had experience with RSS. My husband Derek and I met Dr. Harbison in Chicago about 2 years ago. At that time she told us that our daughter looked as though she were starving and we needed to take immediate action with her growth. From that day on, Laikyn has been doing wonderful with the food and medications that she was given.

In April, my daughter will lose her Medicaid coverage. She doesn't qualify for Developmental Disabilities Service's because she doesn't meet the criteria for being "Mentally Retarded". In our state there are a lot of other children including Laikyn who need services who are not considered "Mentally Retarded".

By understanding the importance of aggressively feeding these children with RSS, no matter what it takes, we are able to avoid the malnutrition and low blood sugars that in the past have so negatively affected their growth and development. With the recent Food and Drug Administration's approval of growth hormone for the treatment of the growth failure associated with being small for gestational age, these young children can start the first grade with normal height if treated early, as stated by Dr. Harbison. With the proper medical food and growth hormone therapy treatments, my daughter will have the opportunity to grow and develop just like a typical child does. She needs these treatments so she can better her life in the future. Through these treatments, she will have the chance to catch-up to her expected developmental stages later in life.

Currently, our family has a health care plan through Blue Cross Blue Shield. My daughter is also covered under this plan. Medicaid won't even be Laikyns primary insurance. Staring in April, our family's recipient liability (RL) would roughly be $2,800 a month. I had Jackie Vetter from Medicaid figure out our RL. I have provided all of you documentation of how much our RL would be. It is attached to the back of this testimony.

Because of the way our current system works, some kids fall through the cracks based on eligibility and screening criteria that are currently in place. I understand the need to have screening and eligibility criteria in place, but sometimes the same criteria prevents services from being offered or delivered to those who desperately need them. When the opportunity for "prevention" present itself, as a mom, I must act. Our family is asking for your help. By passing SB 2395 you are helping to assure that the opportunity my daughter has, isn't missed.

Thank you for your time and attention this morning, I will try and answer any questions that you may have

Sincerely,

Heather Zietz

The MAGIC Foundation®

Russell-Silver Syndrome

In 1953 and 1954, respectively, Dr. H. K. Silver and Dr. A. Russell independently described a special group of IUGR (Intrauterine Growth Retardation) children with short stature along with a small triangular face, low-set ears, incurved fifth fingers, and other characteristics. Their independent and varied findings were eventually determined to be a variation of the same syndrome. (A syndrome is a group of physical signs and symptoms which make up a specific disease or disorder.) As a result, the syndrome received its name.

Russell-Silver Syndrome (RSS) is also known as Silver-Russell Syndrome, Silver Syndrome, and Russell Syndrome.

One of the interesting and at the same time unsettling aspects of this syndrome is the very wide variation of its characteristics. Some individuals with RSS have many of the documented traits, while others have very few. Mental retardation is not characteristic of this disorder.

Almost, without exception, every RSS individual has:

- Low birth weight (Intrauterine Growth Retardation)
- Decreased birth length
- Triangular shaped face (lessens with age)
- Scaphocephaly (long narrow head) at birth
- Normal head size appearing large because of reduced body length and weight
- Postnatal growth retardation
- Poor appetite in early years
- Fifth finger clinodactyly (incurving)

Common characteristics:

- Hypoglycemia (low blood sugar) in infancy and early childhood (2-3 years)
- Asymmetry (unequal in length or size)
- Late closure of the fontanel (soft spot)
- Broad forehead
- Hypoplastic mandible (small chin)
- Downturned corners of the mouth
- Thin upper lip
- Crowding of teeth
- Microdontia (small teeth)
- Unusual, high-pitched voice (usually disappears in later years)
- Abnormal ears (low-set, small, and/or prominent)
- Syndactyly of the toes (fused or webbed - degree of fusing varies)
- Hypospadius (abnormal location of urethral opening)

- Cryptorchidism (undescended testicles)
- Delayed bone age
- Weak muscle tone
- Developmental delays

Rarer traits:

- Hydrocephalus
- Blue sclerae (a blue tinge in the whites of the eye)
- High-arched palate
- Congenital absence of the second premolars
- Frequent ear infections or chronic fluid in the ear (can result in temporary hearing loss)
- Migraine headaches
- Scoliosis (often due to asymmetry)
- Vertebral abnormalities
- Renal abnormalities
- Reflux
- Precocious (earlier than usual) puberty
- Growth hormone deficiency
- Cafe-au-lait spots (flattened, irregularly spaced oval spots which are usually the color of cream and coffee)
- High energy
- ADD
- Passing out spells

What To Do If You Suspect Russell-Silver Syndrome:

1. Consult a Geneticist to confirm or rule-out the diagnosis of RSS.
2. See a Pediatric Endocrinologist who will evaluate and follow the patient to determine what physical abnormalities need treatment. The rarity of this syndrome makes it difficult to find physicians familiar with RSS and treatment options. Some of the actions taken by the Pediatric Endocrinologist might include:

- Examining the patient's growth curve
- Documenting daily caloric and nutritional intake
- Measuring for asymmetry
- Examining male genitals for hypospadius and/or cryptorchidism
- Taking a bone x-ray to determine the bone age versus chronological age
- Testing for growth hormone deficiency
- Testing for hypoglycemia (A commom characteristic of hypoglycemia is excessive sweating on the head & upper trunks)

3. Contact other RSS families. The Endocrinologist often only treats the physical problems. However, the syndrome poses many more concerns for families than can be addressed entirely by physicians. Day to day challenges, such as feeding techniques, finding clothes to fit, learning difficulties, etc., may be made less stressful and eased or eliminated by contacting other families of RSS. Any medical treatments discussed by other RSS families should be discussed with your doctor.

Treatments

Currently, there are various methods used by physicians and professionals to treat problems resulting from RSS. However, limited knowledge about RSS and the relatively recent use of several of these treatments often makes it difficult to determine their effectiveness and, consequently, recommend them or verify concrete results. It is very important you consult with a qualified professional before agreeing to any of the following:

- **Diet Change** - Hypoglycemia treatment, increase caloric intake, improve growth
- **Periactin** - Antihistamine used as an appetite stimulant
- **Feeding Pump** - Increase caloric intake
- **Recombinant Growth Hormone** - Used to increase growth velocity and final height
- **Gastrostomy** - Increase caloric intake
- **Ear Tubes** - Improve fluid drainage from ears
- **Lupron** - Attempt to delay puberty
- **Speech Therapy**
- **Remedial Reading**
- **Physical Therapy**
- **Occupational Therapy**
- **Shoe Lifts** – Asymmetry
- **Limb Lengthening Surgery** - Leg asymmetry
- **Corrective Surgery** - Various physical abnormalities

Long Term Effects of RSS and Quality of Life

The diagnosis of RSS does not mean a reduced quality of life. A person with RSS typically lives a normal life. However, their short stature may pose some challenges not encountered by average- sized individuals.

The early years are often the most difficult. For instance, poor eating; developmental delays; weak muscle tone; learning disabilities; asymmetry; and other traits cause concern and require intervention. This will be time-consuming, stressful, and create uncertainty. However, the extra effort and caring will pay off over time. Typically, the triangular-shaped face will lessen; muscle tone will strengthen; motor coordination will develop; appetite will improve; speech will become clear; learning will occur; and RSS infants will become healthy and happy adults.

It is recognized the severity with which an individual is affected by RSS varies. Certain traits can create more difficult obstacles to overcome than others.

Why does my child have RSS?

There is no known etiology (the study of all factors that may be involved in the development of a disease) of RSS. Most cases of RSS occur sporadically with no previous family history. However, there are rare occurrences where RSS is present in more than one member of a family. Research is continuing in an attempt to locate the source of RSS. There are several findings which indicate a possible location on a specific chromosome. However, there is no confirmation yet.

It is extremely important you realize nothing you did before or during your pregnancy caused your child to have RSS. Most parents have trouble releasing

themselves from guilt. This is common. However, please try to ease your stress by understanding you are not responsible for the existence of RSS in your child.

Contributing Medical Specialist
Dr. Marilyn Cowger
Pediatric Endocrinologist

The MAGIC Foundation is a national nonprofit organization created to provide support services for the families of children afflicted with a wide variety of chronic and/or critical disorders, syndromes and diseases that affect a child's growth. Some of the diagnoses are quite common while others are very rare.

MAGIC continues and develops through membership fees, corporate sponsorship, private donations and fundraising.

"Not an illusion or magical, but the caring for children and their families"

* * * * Dedicated to the growth and overall development of children * * * *

MAGIC Foundation
1327 N. Harlem Avenue – Oak Park, IL 60302
Tel: 708-383-0808 Fax 708-383-0899

3

Testimony
SB 2395
House Human Services Committee
Rep. Price, Chairperson
February 28, 2005

Madam Chair Price and members of the House Human Services committee, I am Roxane Romanick. I am in support of Senate Bill 2395. I am here today in support of the families whose lives are impacted by this bill. Because of my job with Bismarck Public Schools and more specifically as an experienced parent specialist with the Bismarck Early Childhood Education Program, I am acutely aware of the gaps in services that some families face.

The most significant role for me in my job is to provide informational and emotional support to families who have children that receive Early Intervention services. These services are provided to children, age birth to 3, who meet the criteria of "developmental delay". Because it's my job to provide information and support to families, I am very familiar with the ramifications of "turning 3" for families.

One of these ramifications is the need for re-determination of eligibility for continued Developmental Disabilities Case Management, which allows persons with mental retardation and developmental disabilities to be screened for the home and community based waiver. Eligibility requirements change at the age of 3. Children who are not found eligible can no longer access case management services, services that are included under the home and community based waiver, or have access to the income and asset disregard for medical assistance. Children can continue to access medical assistance, but at the cost of huge recipient liabilities that most families cannot afford.

SB 2395 is a result of the Zeitz family advocating for the needs of their daughter. This is a family that has explored many avenues to make sure that their daughter receives the best health care treatment that she can get. They also have a solid understanding of what her health care costs will mean for their family and also what preventive care will mean for her in the long run. I am in support of their efforts to advocate for her needs.

SB 2395 amazes me and I am very pleased to be amazed. Over the course of the past year, I have been to many meetings in hopes that we could find some answers for the families that were losing Medical Assistance and for whom the loss would have a significant impact. I don't think that we left a stone unturned in state government. The stone that we did leave unturned however was turning to you, our legislators, and asking for help. That was until the day Heather and Derek decided to ask. Thanks to the Zeitz's and thanks to the insight of the sponsors of this bill, it appears that maybe with your support in the House of Representatives, this will be the one stone that provides the initiative that's needed to put a Medicaid waiver for children with special health care needs in place.

Thank you for your time.

Roxane Romanick
616 Crescent Ln.
Bismarck, ND 58501
701-527-4645
romanick@bis.midco.net

#5

TESTIMONY – PROTECTION AND ADVOCACY PROJECT
SB 2395 – HOUSE HUMAN SERVICES COMMITTEE
HONORABLE CLARA SUE PRICE, CHAIRMAN
February 28, 2005 11:00 a.m.

Chairman Price, and members of the House Judiciary Committee, I am Bruce Murry, a staff attorney for the North Dakota Protection and Advocacy Project (P&A).

P&A strongly supports Senate Bill 2395, and each of its key features. First, SB 2395 includes children with Russell Silver Syndrome along with those with PKU and MSU Syndromes for state funded assistance with extraordinary health care needs. This is appropriate as the expenses families face for those conditions are very analogous.

P&A supports the second key feature creating a Medicaid waiver for a small number of children with extraordinary health care needs. This waiver might serve some children with PKU and RSS, about 20%, with Medicaid funding rather than pure state funds. P&A was pleased to participate in drafting some of the language to accomplish this purpose. However, parents and persons knowledgeable of Medicaid waivers have indicated some of P&A's suggested language might create barriers to approval of the waiver, or cause the waiver to omit some of the children for whom it was drafted. Proposed amendments are attached to remedy these problems. The contents of these provisions are either included in federal authorizing law, or would be more appropriate within the Medicaid waiver application itself.

Third, P&A supports a study of special health care needs of children. As stated by Senator Judy Lee, this should be done in harmony with HCR 3054.

Thank you for your consideration, and I suggest your favorable recommendation for SB 2395.

PROPOSED AMENDMENTS TO SENATE BILL 2395
Protection and Advocacy Project

On page 2, line 1, remove "There may be no recipient liability connected with this program."

On page 2, line 5, remove "The department shall require an applicant to demonstrate a chronic physical condition that results in prolonged dependency on medical care for which daily skilled nursing intervention is medically necessary. The department shall require an applicant to demonstrate a condition that is life-threatening, requires frequent administration of time-consuming medically necessary daily treatments, or requires the use of complex medical equipment or services such as a ventilator, dialysis machine, enteral or parenteral nutrition support, or continuous oxygen."

#4

2/28/05
last ins

Senate Bill 2395

Madam Chair and Committee Members, thank you for the opportunity to provide written testimony on Senate Bill 2395.

My name is Blair Aasland and my wife Nicole and daughters Kaitlyn and Ellie live in Fargo. Katie has just turned 3 years old and Ellie is 19 months. They, of course, are very special little girls to us. They are also special in another way; they are among the few in North Dakota with Mitochondrial disease. This disease is a rare genetic disorder which affects the amount of energy for the body to use. A useful analogy is to think of an eight-cylinder car running on only six cylinders.

Mitochondrial disorders differ from other genetic disorders affecting the muscles in a number of ways. Most significantly, although mitochondrial disease can present as a "pure myopathy," meaning that only the skeletal or heart muscles are affected, it more often causes problems in many different organ systems, including the nervous, visual, renal, digestive and circulatory systems. Despite the fact mitochondrial diseases can be so variable and affect so many organ systems, a few symptoms are common to many of these disorders. These include muscle weakness, muscle cramps, extreme fatigue, gastrointestinal problems, droopy eyelids, eye muscle paralysis, retinal degeneration with vision loss, seizures, ataxia (loss of balance and coordination) and learning delays. This is a progressive and degenerative disease with no known cures. At present, there are many more unknowns than proven treatments for these patients.

Kaitlyn recently turned three and her last day on Medicaid is Monday, February 28th. She is currently prescribed two seizure medications and a supplement. These are covered by insurance and the remainder picked up by Medicaid. She is also on four "over the counter" supplements, paid out of pocket. The saving grace for us was the fact that Medicaid picked up the amount not covered by insurance on the prescribed medications. This benefit is ending because Katie has done so well over the past year and has achieved a lot of her goals. Therefore, she is ineligible for services. Keep in mind this is a degenerative disease and she could regress at any time, not just within the first three years of her life. Also, there is not a Mitochondrial expert in Fargo so trips to the Mayo clinic in Rochester and to St. Paul Children's' clinic occur every six months. Once again, ineligible for services and thus reimbursement for the trip is no longer available to us.

The year and a half Katie was on Medicaid was certainly appreciated and was such a stress reliever. My youngest daughter Ellie will soon be on the same "over the counter" medications as Katie and like her sister will lose Medicaid services at the age of three, barring any major medical setbacks. This will place a tremendous amount of financial stress on our family. I truly hope that my children's' disease continues to stay at bay. But the reality of this disease is that this is truly a degenerative disease and my daughters will continue to regress.

Please consider my family and other families in North Dakota in our situation. We depend on Medicaid benefits financially, and also for the peace of mind it offers us.

Blair Aasland

1009 7th St S

Fargo, ND 58103

701-793-4799 or 701-298-3674

#6

Testimony in Support of SB 2395

Robert M. Wentz, MD, MPH

My name is Robert Wentz. I am a pediatrician who recently had to take a disability retirement because of the effects of a genetic disorder known as Fabry disease. In addition to practicing general pediatrics, I worked for the State Department of Health for 16 years and served as State Health Officer for eight years. I currently serve as part time Medical Director for Children's Special Health Services but am not appearing today in that capacity. I am appearing on behalf of myself as well as providing you with written testimony on behalf of Mrs. Jennifer Restameyer, who is unable to attend this hearing.. Jennifer has a daughter, Allison, to whom I provided some care prior to my retirement. Allison has a genetic condition called mucopolysaccharidesosis Type I (MPS I) which is in the same category of metabolic disorders ("lysosomal storage diseases") as the Fabry disease which affects me. Jennifer recently appeared before this committee regarding HCR 3054 and described the problems she has encountered in obtaining services for her daughter. MPS I has been added to the "List of Eligible Conditions" for Children's Special Health Services (CSHS) but it is subject to the financial means test of 185% of poverty level and the $20,000 annual maximum expenditure which applies to other CSHS eligible condtions.

Jennifer and I wish to make certain that the committee is aware that there are a number of families in North Dakota with children with special health needs and that we need to be equitable in providing assistance to these children and their families.

Unfortunately, the state lacks a system of care for these children and families are forced to deal with a patchwork of agencies and services in trying to obtain care for their children. Many children are covered, to some extent, by private health insurance, but coverages vary depending on the type of policy. Other children may be eligible for Medicaid, Healthy Steps or the Caring for Children program, but certain parts of their care may not be covered. Children who have conditions which are on the "List of Eligible Conditions" for the CSHS program may be eligible for diagnostic evaluation and for treatment services if the family income does not exceed 185% of the poverty level. CSHS often serves in a "gap-filling" role with other health coverage.

Providing assistance for Russell-Silver dwarfism is a good thing, but there are a number of other children with special health needs who need and deserve this type of assistance also. Do we have the courage to help them?

Thank you

Robert M. Wentz, MD, MPH
8401 Briardale Dr., Bismarck, ND
(701) 258-1749

#7

SB 2395

Madam Chair and Committee Members, I would like to thank you for the opportunity to speak today in support of a Medicaid waiver for children with Exceptional Health Care Needs, and for a study to identify the gaps in the state's system for providing services to children with special health care needs. My testimony today is very similar to the testimony I provided in regards to HCR3054.

My name is Jennifer Restemayer, and I would like to tell you a little about my four year old daughter Allison. Allison is a very bright and active child. She amazes me every day with her unique personality, persistence and curiosity. In November of 2002, Allison took a hard fall and we brought her to the walk in clinic to make sure she was OK. At the conclusion of this visit, the Doctor at the walk in clinic sent us home with a photocopy of the PDR that described something called Mucopolysaccharidosis (MPS) or Hurler syndrome. The prognosis said children with MPS1 or Hurler Syndrome are typically bedridden by eight and dead by ten. We had never heard of Hurler Syndrome or MPS until that day. My husband and I were so scared of this disorder, we couldn't even consider the possibility that Allison could be affected by it. We started the testing process...just to rule it out so we could go on with our lives. January 8th 2003, just weeks before her second birthday, Allison was officially diagnosed with MPS 1.

MPS I is an inherited lysosomal storage disorder caused by the deficiency of an enzyme called alpha-L-iduronidase. This enzyme is required for the breakdown of certain substances in the body known as glycosaminoglycans(GAGS). Without sufficient quantities of this enzyme, GAGs accumulate in virtually all organs of the body, causing progressive damage. The incidence of MPS is about one in 100,000 births. Though many patients with this disease may have the same enzyme deficiency, patients with this disease have a wide range of symptoms and experience variable degrees of disease severity. Allison has been affected by MPS in many different ways. She has corneal clouding, a mild to moderate hearing loss, Mitral valve thickening and an irregular heartbeat, she also has many orthopaedic problems and is at a very high risk for developmental delay. All of this needs to be monitored very closely. We take Allison to Fairview in Minneapolis every 6 months to monitor her conditions.

Allison qualified for Early Intervention services by her diagnosis. She was able to start therapies shortly after she was diagnosed. Speech Therapy and PT/OT have been wonderful for Allison! However, at age three children have to undergo developmental testing and basically have to have a diagnosis of Mental Retardation to qualify for continued services. Allison scored within the "normal" range for all areas tested. While we were thrilled with her test results, we also knew that this opened up whole new area of problems. We needed Allison to continue to get her therapies! MPS is progressive and degenerative. The typical MPS child STOPS developing, usually as a toddler, and then starts to regress! We need help to keep her on track as long as we possibly can! We worked closely with the Early Intervention team and did find a way for her to continue therapies, but because she was no longer eligible for MR-DD services, she was no longer able to be screened for the Home and Community Based waiver which allowed us to access the income and asset disregard so that she could get Medicaid. Without the Medicaid Waiver it is increasingly difficult for our family to financially provide for Allison's ongoing medical needs.

Financially, Allison's diagnosis has brought up many concerns for my family. She is on a new treatment called Aldurazyme, which consists of an IV infusion once a week, for life. This infusion is a synthetic version of the enzyme Allison is missing. It was approved by the FDA on April 30th, 2003. Unfortunately, the cost of Aldurazyme is very high; it is $565.00 per vial. The dosage is based on weight; Allison is 34lbs and requires three vials for a cost of $1,695.00 per infusion. As Allison grows and gains weight, she will require more vials of Aldurazyme and our weekly bill will increase. Our total weekly bills including the Doctor's visit, supplies, the I.V. infusion center and the Aldurazyme, total $2,130.50 per week, or $110,786.00 per year.

I have searched and searched for a program within our state to assist our family with the cost of the many medical bills as well as the cost of additional out of pocket expenses that are not covered by our primary insurance. I have found that any family can receive medicaid, but with a recipient liability. Our recipient liability was estimated at $2,900.00/month. We can not afford to pay that every month before Medicaid kicks in and starts to help. I have talked to many people who work in the Department of Human Services and I have been told that IF my husband and I were to get a divorce, my children and I would qualify for Medicaid based on my income. It has also been suggested that we move our family to Minnesota because there a Medicaid waiver for children with exceptional medical needs. My husband and I have had very serious conversations about what we will do when our savings runs out and we can no longer handle the medical bills and the out of pocket expenses that our insurance does not cover. This is an ongoing source of stress for us.

A study to identify the children that are falling into the "GAP" in our states current system is a very necessary tool to help find a way to serve these children. A Medicaid Waiver would give families like mine hope for the best possible outcome for their child, and a sense of security knowing they will be able to provide the Medical care and treatment their child needs.

Please consider helping our families care for these wonderful children, and assist us in making sure they have all treatments necessary to ensure the best future they can possible have.

Thank you for your time,
Jennifer Restemayer
2217 E. Capitol Ave
Bismarck, ND 58501
(701)222-0493

#8

Testimony
SB 2395
House Human Services Committee
Rep. Price, Chairperson
February 28, 2005

Madam Chair Price and Committee Members,

I am writing to you in support of SB 2395. Children with special health care needs that do not fall under the DD/MR classification deserve the same level of care and support as those children. I am specifically interested in the Legislative Council Study of Child Health Care Needs.

As a parent of a special health care needs child, I understand only too well the sacrifices that must be made to meet that child's needs. Our son has a very rare primary immune deficiency that affects only a handful of people worldwide. We are in the process of completely identifying our son's diagnosis and the potential treatments. The diagnoses that we are looking at are potentially fatal without treatment. Our son's NK cells do not function at all. These are the body's innate ability to fight viral infections and tumor cells. He is at increased risk of developing cancer or lymphoma due to this defect also.

There are many issues that face families of special health care needs children. Families incur many expenses to meet these needs that do not qualify for insurance reimbursement such as nutritional and vitamin supplements, out of town/state travel to larger tertiary centers to receive appropriate treatment, loss of wages to provide care to an ill child, there is also the fear that you may loose your job due to absenteeism to care for that child. FMLA is a wonderful program, but it is unpaid and most families can't afford the loss of income so it becomes a balancing act to work and meet the child's needs.

There are also issues that families face in regards to their primary care insurance. Your primary care insurance may have a lifetime cap that means your child will run out of insurance during childhood. There is also the possibility that your employer can change your plan at any time and decrease your benefits.

Caring for these special needs children is a full time job to meet their medical issues along with just being their parent. It is another job to coordinate the care, from appointments to tracking the bills and what has been reimbursed, what hasn't been covered and why not. There are many days that you spend on hold to the various agencies/facilities to accomplish this coordination of care.

Many families of special needs children sacrifice other things to provide for their child's needs including the inability to take a vacation due to the medical issues, needing to access retirement funds to pay for extraordinary medical bills, changing employment or work schedules. These families are trying to provide a stable environment for these special needs children along with holding the other family members together. These illnesses affect the whole family unit and other children in the family. There can be a loss of extracurricular activities for the other children also.

Our family has made many sacrifices to meet our son's needs. My husband works during the week and I commute to Fargo for a weekend status position as a nurse so that our son doesn't have to be in a day care setting. We have had to borrow money from our retirement to pay for the unexpected bills we incurred last year prior to being serviced by IDEA Part C. The financial support that we have received has alleviated a lot of the financial stress in regards to Jacob's care for the present. We are quite worried about what will happen to us next year when we no longer have that support. The support we have received has not only been financial, but there has been a tremendous emotional support associated with this program that has facilitated our son's care and the whole care of our family.

I encourage you to support this bill along with HB3054 to study the gaps in our system and to meet the needs of children with special health care needs.

Sincerely,
Linda Schatz
1207 23rd St. SE
Mandan, ND 58554
lmschatz@bis.midco.net

#9

TESTIMONY BEFORE THE HOUSE HUMAN SERVICES COMMITTEE
REGARDING SENATE BILL 2395

FEBRUARY 28, 2005

Chairman Price and members of the committee, I am Tamara Gallup-Millner, director of the Children's Special Health Services (CSHS) unit, which is located in the Medical Services Division in the Department of Human Services. I'm here to provide information related to SB 2395.

Work done in the CSHS unit focuses on children with special health care needs and their families. Children and youth included in this population have chronic conditions of some kind and a need for health and related services generally beyond those needed by most children. In North Dakota, about 12.4% or 19,500 children under age 18 are estimated to have a special health care need based on the definition I've just described.

Families we work with in CSHS report that having a child with special health care needs has a financial impact on their family. Some families do not have insurance, but more often, the health care coverage they do have does not meet all of their child's needs. The care that is required can become a cumulative burden when expenses are incurred year after year. Many families we hear from share the need that gave impetus to this bill.

If passed, Section 1 and 2 of SB 2395 would require CSHS to provide medical food and coverage for growth hormone treatment at no cost to individuals under age eighteen who have been diagnosed with Russell Silver Syndrome, regardless of income.

While I recognize the importance of services for all children with special health care needs and their families, including children with Russell Silver Syndrome, there are also important implications that merit attention as this bill is considered.

1. Eliminating the income eligibility requirement for treatment services through CSHS is setting a precedent that certain conditions receive prefferential treatment. Families that have children with asthma, diabetes, cerebral palsy, cleft lip and palate, hearing loss, cystic fibrosis, etc., would need to meet the eligibility criteria at 185% of the federal poverty level, while those with Russell Silver Syndrome would not. The Legislature mandated the eligibility level currently used for CSHS treatment services in 2001.

2. Definitions for "medical food" and "coverage for growth hormone treatment" have not been included in the bill. These terms could be very narrowly or very broadly interpreted. For example, does the term "medical food" mean that a typical infant formula like Similac be provided, just because its concentration has been adjusted to provide more calories in order to promote adequate growth? Similac is a formula many well babies routinely use in the first year of life. Or, does "medical food" imply coverage of various formulas that are used as the primary source of nutrition for children if they require tube feedings in order to increase caloric intake? Does "coverage for growth hormone treatment" literally mean only the medication used for hormone replacement or does it include office visits, lab, x-rays, etc. needed for monitoring whether the medication is actually achieving the desired results? A clear understanding regarding the scope of covered services that are expected for children with Russell Silver Syndrome would be helpful.

3. Impact on the CSHS unit's current services and programs is possible. Although considered rare, the incidence of this syndrome is truly not known. There is currently no effective system in place to identify individuals with Russell Silver Syndrome so some caution is needed when determining the number of children in North Dakota who might receive services through this program. Projections regarding insurance status of children who would potentially be served must also be made with care. Although we did our best fiscal estimate based on information available at the time, it is unknown whether the appropriation included in this bill will be enough to meet service needs of children with Russell Silver Syndrome in the state. If more children with this syndrome are identified than projected, CSHS may need to redirect resources to this program that are currently budgeted for other services.

4. Characteristics of Russell Silver Syndrome vary widely. Some individuals have many of the documented traits associated with this syndrome, while others have very few. Required treatment may vary based on each individual's specific medical needs which may or may not be consistent with services that are included in this bill.

Section 3 directs the Department to apply for a Medicaid waiver to provide in-home services to children with extraordinary medical needs. The Department will need to determine what type of waiver would best meet the needs of the children. It could be a 1915 home and community waiver or an 1115 demonstration waiver. Based on previous experience, we estimate it will take at least a year to prepare, submit and receive approval for this type of waiver.

The fiscal note anticipates that three individuals who are not currently on the Medicaid program will take advantage of the waiver. We do recognize that a gap may exist for children who may no longer qualify for the Developmentally Disabled waiver and are not eligible for the Elderly and Disabled waiver because of the age limitation. The costs for those individuals are not included in the Executive budget.

Section 4 asks the Legislative Council to consider studying issues relating to children with extraordinary health care needs. The Department agrees that a study of this nature would be useful in determining the direction the state should follow regarding the delivery of services to this segment of our population. We would encourage SB 2395 and HCR 3054 be looked at together as both pieces of legislation address studies for children with special health care needs.

This concludes my testimony. I would be happy to respond to any questions you may have.