MICROFILM DIVIDER

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

ROLL NUMBER

DESCRIPTION

4034

2007 SENATE HUMAN SERVICES

SCR 4034

2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. 4034

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 3-21-07

Recorder Job Number: 5364

Committee Clerk Signature Mary K Monson

Minutes:

Senator Judy Lee called the committee to order.

Roll was taken and all members were present.

Senator Judy Lee opened the public hearing on SCR 4034.

Senator Carolyn Nelson from District 21 introduced the resolution. This resolution is to bring awareness to Smith-Lemli-Opitz Syndrome known as SLOS. See attachment #1. She introduced Mrs. Gretchen Noah.

Gretchen Noah: Her first impression was that this would just be a token bill and not accomplish much. SLOS children typically have profound mental retardation. Their son is mild and can walk and talk. She and her husband have felt it is their job to raise awareness and funds for the foundation. Raising awareness can help families who are seeking a diagnosis for their own child. Studying rare diseases helps to gain insight into related diseases. SLOS is related to autism. Her son's mild case could drive treatment studies for children with autism. If this syndrome is diagnosed early, dcotors can significantly alter the progression of the disease by giving the children cholesterol. The size the children will grow to can be changed, their behaviors can be improved if they diagnose it early. She feels the support groups for families affected by disorders such as SLOS are very important. It communicates to the families that

they are important and their children are important. Spurred on by their son having SLOS, they have raised $40,000.00 for SLOS Foundation. She was frustrated that it took so long because no one knew about the syndrome. It took 2 years to get a diagnosis. She asked her geneticist why pediatricians don't know the warning signs for children with syndromes and ADHD and autism, etc. He said it is that they are not educated in it. She raised $21,000.00 and they are hosting a conference that will train social service professionals, medical professionals, how to recognize the warning signs of the whole gamut of special needs and conditions. The conference is April 23 – 24 in Fargo. The conference is titled "Hearing the Hoofbeats and Thinking Zebras." See attachment A and attachment #2. It has been well received and is long overdue. She made note that if you are not in the state system, you have no idea what programs the state has available. She said her experience with getting on the state program was very favorable. They got on immediately. Some of their friends had long waits in other states. The support her family has received has been much appreciated.

Senator Lee made mention that the rare syndromes need to find a voice. If the families band together they can be heard.

Gretchen Noah: A syndrome is considered rare if fewer than 100,000 people have it. The people who have these rare syndromes do need to be heard.

Senator Heckaman: How does Markie take his medication? Shots? Liquid?

Gretchen: He takes liquid cholesterol, cherry flavored. He was off it for three weeks to be part of a study being done in Oregon and he started showing some self abusive behaviors and tantrums. As soon as he went back on the medication the behaviors leveled out.

Senator Mathern from District 11 testified in support of SCR 4034. See attachment # 3.

Senator Dever asked whether the House Appropriations Committee had acted on SB 2326 yet.

Senator Mathern said SB 2326 had not yet been acted on.

More testimony in favor? None

Opposed? None

Neutral? None

Senator Warner made a do pass motion on SCR 4034.

Senator Dever seconded the motion.

Roll Call Vote: Yes 6 No 0 Absent 0

Carrier: Warner

Date: 3-21-07

Roll Call Vote #: 1

2007 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SCR 4034

Senate **HUMAN SERVICES** Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass

Motion Made By Sen. Warner Seconded By Sen. Dever

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee, Chairman	✓		Senator Joan Heckaman	✓	
Senator Robert Erbele, V. Chair	✓		Senator Jim Pomeroy	✓	
Senator Dick Dever 2	✓		Senator John M. Warner 1	✓	

Total (Yes) 6 No 0

Absent 0

Floor Assignment Senator Warner

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

REPORT OF STANDING COMMITTEE

SCR 4034: Human Services Committee (Sen. J. Lee, Chairman) recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SCR 4034 was placed on the Eleventh order on the calendar.

2007 HOUSE HUMAN SERVICES

SCR 4034

2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SCR 4034

House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: March 29, 2007

Recorder Job Number: 5613

Committee Clerk Signature Judy Schock

Minutes:

Chairman Price: We will open the hearing on SCR 4034.

Senator Carolyn Nelson, District 21 Fargo: I am sorry I could not bring the main focus for this resolution with me today. He is a cute little boy about three years old. See attached testimony. This is about a disease that years ago we didn't know any thing about. In1980 we probably had 4 kids diagnosed with autism in the Fargo public schools. This disease is one they are just now starting to study because 80% of the pregnancies are carrying fetuses that have this disorder in the miscarriage, or still born. A number of the children who are actually born don't make it past the age of 1 or 2. Markie is now 3. The Mother knew something wasn't right, and went to many doctors, and was persistent. You will see in the material I handed out to you, there are not many in ND. We know of 4 in the state. There could be more, people don't always see doctors. This disease blocks the ability to process cholesterol. They are trying things out with Markie. There is a liquid that looks like a cough syrup that he takes daily for cholesterol. They think there are only about 500 in the US living with this. Many die early. They are looking to what can be done genetically to fix this. That is what we are asking you to look at today. This is a resolution to bring awareness and education.

Chairman Price: Just curious is this disease passed onto males or both genders?

Senator Nelson: It sounded like most of them were males.

Representative Conrad: I move a do pass consent to the calendar, seconded by

Representative Schneider. The vote was taken with 8 yeas, 0 nays, and 4 absent.

Representative Schneider will carry the bill to the floor.

Date: 3/29
Roll Call Vote #: 1

2007 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. "Click here to type Bill/Resolution No."

House HUMAN SERVICES SCR 4034 Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass Consent Calendar

Motion Made By Rep. Conrad Seconded By Rep. Schneider

Representatives	Yes	No	Representatives	Yes	No
Clara Sue Price – Chairman	✓		Kari L Conrad	✓	
Vonnie Pietsch – Vice Chairman	✓		Lee Kaldor		
Chuck Damschen	✓		Louise Potter	✓	
Patrick R. Hatlestad			Jasper Schneider	✓	
Curt Hofstad	✓				
Todd Porter					
Gerry Uglem	✓				
Robin Weisz					

Total (Yes) "Click here to type Yes Vote" 8 No "Click here to type No Vote" 0

Absent 4

Floor Assignment Rep. Schneider

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

REPORT OF STANDING COMMITTEE

SCR 4034: Human Services Committee (Rep. Price, Chairman) recommends **DO PASS** and **BE PLACED ON THE CONSENT CALENDAR** (8 YEAS, 0 NAYS, 4 ABSENT AND NOT VOTING). SCR 4034 was placed on the Tenth order on the calendar.

2007 TESTIMONY

SCR 4034

#1

SENATE

NORTH DAKOTA LEGISLATIVE ASSEMBLY

SENATOR CAROLYN NELSON
District 21
1 Second Street South, #5-402
Fargo, ND 58103-1959
cnelson@nd.gov

STATE CAPITOL
600 EAST BOULEVARD
BISMARCK, ND 58505-0360

Assistant Minority Leader
COMMITTEES:
Judiciary
Government and Veterans Affairs

SCR 4034

This is a resolution to bring awareness to Smith-Lemli-Opitz Syndrome, known as SLOS. The syndrome was first described by geneticists David Smith, Luc Lemli and John Opitz in 1964 but it wasn't until 30 years later that scientists discovered the cause.

SLOS blocks the body's ability to make or process cholesterol. The disorder affects 1 in about 40,000 births and is most common in whites of European ancestry.

This resolution is intended to raise awareness of the disease and I'm very happy to introduce the mother of an SLOS child, Mrs. Gretchen Noah. Gretchen and Mark Noah are parents of Markie, a sweet, cute, rambunctious 3 year old. Gretchen is here today to talk to you about Markie, his medical situation, and her dreams for him.

SCR 4034

Senator Carolyn Nelson

A concurrent resolution to bring awareness to SLOS Disease (Smith-Lemli-Opitz syndrome).

This resolution was brought about from the family of Markie Noah, a 3 year old boy Fargo boy who was diagnosed with SLOS disease in the spring of 2006.

SLOS blocks the body's ability to make or process cholesterol. It can cause serious birth defects, or death in severe cases. It has no cure.

SLOS is characterized by distinctive physical features - a small head, upturned nose, droopy eyelids, cleft palate, short thumbs, low-set ears, a single palm crease and webbing between the second and third toes - as well as mental retardation or learning disabilities, and behavioral problems.

Infants with SLOS have weak muscle tone, experience feeding difficulties, and grow more slowly than other children. A majority of the patients have autistic characteristics.

The diagnostic rate is 1 in about 50,000 and only about 500 people in the United States are living with the disorder.

Researchers believe that there are no people with SLOS disease who live independently, except for Markie. Markie has a mild case of the disease which is allowing researchers to learn more about him and his disease.

Dr. Forbes Porter, a researcher with the national institute of health, is studying mutations in Markie's genes and how his cells synthesize cholesterol. Treating the learning and behavior problems associated with SLOS could involve trying to change brain chemistry.

Dr. Porter stated that through his research with Markie, the outcome could impact thousands of lives, including SLOS patients as well as other children with more common disorders, such as autism.

According to Dr. Porter, about 80 percent of SLOS pregnancies never survive to a full term. More than half of the children with the syndrome must be tube-fed for several years.

The disorder affects 1 in up to 40,000 births and is most common in whites of European ancestry.

The resolution will raise awareness of the disease so that mothers can get test to see if their unborn child has the disease so that they may receive early treatment. The added awareness will also aid other children so that they may be properly diagnosed with the disease so that they can live a better quality of life.

In August of 2006, Markie's family hosted a walkathon, which raised over $40,000 for SLOS disease awareness.

Nelson, Carolyn C.

From: Jayne Brown [jbrown@medicine.nodak.edu]
Sent: Monday, March 19, 2007 3:54 PM
To: Mathern, Tim; Nelson, Carolyn C.; Fiebiger, Tom D.; Flakoll, Tim; Mathern, Tim; Pomeroy, Jim R.
Subject: SLOS resolution and state genetics plan

Hello,
On behalf of the Division of Medical Genetics, located at the School of Medicine & Health Sciences at UND, I would like to state we have four confirmed cases of Smith-Lemli-Opitz Syndrome diagnosed since 1983. We have three patients with a last known address within North Dakota and one in Minnesota. For your information, John T. Martsolf, MD is the only geneticist in North Dakota, therefore the statistics concerning patients seen in North Dakota by a geneticist would be maintained in our office.
Unfortunately, we cannot account for the number of North Dakotan residents seen for genetic appointments outside of North Dakota.

I would also like to inform you of a conference we are putting on April 23 & 24, 2007 in Fargo. Monday morning we will have Dr. Susan Sparks talk about Smith-Lemli-Opitz Syndrome, following this we will focus on North Dakota newborn screening by utilizing a panel discussion and then the emergency treatment of metabolic disorders with Dr. Cheryl Greenberg. We will follow Tuesday with Dr. Bryan Hall talking about dysmorphic features, Dr. Martsolf will talk about the process of making a referral for genetic services, as well as a parents discuss their process through the diagnostic system. For more information about the conference you may visit our web site at www.medicine.nodak.edu/genetics.

We are currently in the final stages of writing a State Genetics as recommended by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services. The goal of the state genetics plan is to write a working plan to address the genetic needs of the North Dakota citizens.

As genetics is integrated into public health, all public health programs need to be strengthened. This requires a commitment to sharing resources to address and identify gaps and encompass integration of population-based screening, genetic risk assessment, health promotion and disease prevention strategies within chronic disease, cancer, environmental health and other programs. To foster the integration, many states have developed state genetics plans. The _intent_ of a state genetics plan is to enhance genetics into public health and health care practices. The health status of North Dakotans should be optimized by using genetic/birth defect services. Genetic medicine should also improve public health care and social services systems within the state.
Therefore, we would love to have legislators input and invite you to join us April 22 at the Ramada Plaza from 5:00-6:30.

I look forward in hearing from each of you regarding your interest.

Sincerely,
Jayne Brown

--
Jayne Brown
Human Service Information Coordinator
Division of Medical Genetics
UND School of Medicine & Health Services PO Box 9037 Grand Forks, ND 58202-9037
(701) 777-4277

Conference Goals

Upon completion the learner will be able to:

- Describe the signs, symptoms and current issues concerning Smith-Lemli-Opitz Syndrome (SLOS).
- Identify metabolic disorders detected with ND newborn screening.
- Identify and manage emergency care for specific metabolic diseases.
- Facilitate and strengthen relationships between the health care professionals and the family support professionals.
- Identify resources available for families.
- Identify legislative impacts on healthcare related to genetics & newborn screening.
- Recognize families' struggles through the process of finding the diagnosis.
- Identify services available through the North Dakota Genetics Program.
- Recognize the diagnostic approach with a child who has dysmorphic features.

Continuing Medical Education

This activity has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint sponsorship of the University of North Dakota School of Medicine and Health Sciences and Dakota Medical Foundation. The University of North Dakota School of Medicine and Health Sciences is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

The University of North Dakota School of Medicine and Health Sciences designates this education activity for a maximum of 14 Category 1 Credit(s)™ toward the AMA Physician's Recognition Award. Physicians should claim credit commensurate with the extent of their participation in the activity.

This conference has also been approved for 13 contact hours by the North Dakota State Board of Social Work Examiners (www.ndbswe.com).

Conference Schedule

Monday, April 23, 2007

8:00- 8:30	Registration and continental breakfast
8:30- 8:45	Welcome and Opening Remarks
8:45- 9:30	Spectrum of Smith-Lemli-Opitz (SLOS), Dr. Susan Sparks
9:30-10:15	Neurological features and functioning in SLOS. Dr. Susan Sparks
10:15-10:45	Break (in exhibit area)
10:45-11:30	New SLOS Research, Dr. Sparks
11:30-12:30	Lunch with Markie Noah
12:30-2:00	Newborn Screening Panel Discussion, including Cystic Fibrosis.
2:00-2:15	Break (in exhibit area)
2:15-4:00	Continuation of Newborn Screening Panel Discussion
4:00-4:15	Break (in exhibit area)
4:15-5:15	Adventures in Metabolic Nutrition. Dr. Cathy Breedon
5:15-6:15	Social Hour (no host)
6:15-8:30	Dinner with Dr. Cheryl Greenberg (Practical Approach to Emergency Treatment of Metabolic Disorders.)

Tuesday, April 24, 2007

8:00-8:30	Continental Breakfast
8:30-9:30	Diagnostic approach with a child who has dysmorphic features. Dr. Bryan Hall
9:30-9:45	Break (in exhibit area)
9:45-10:45	Referral to a Clinical Geneticist? Now What? Dr. John Martsolf
10:45-11:30	Legislative impacts to genetic healthcare. Donene Feist
11:30-12:15	Family resources for the health care professionals. Panel Discussion
12:15-12:30	Break: Pick up Box Lunch
12:30-2:00	Parent Panel: Parents' perspectives on the diagnostic process.
2:00	Closing Remarks

Sponsored by:

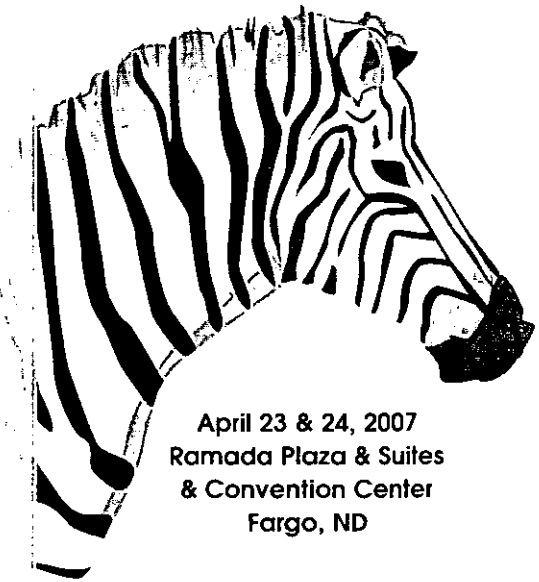
UND School of Medicine & Health Sciences
Division of Medical Genetics &
Dakota Medical Foundation

A

Hearing Hoofbeats and Thinking ZEBRAS

"Look for the ordinary but remember the rare."

Screening, Testing & Management of Children with Genetic Disorders



April 23 & 24, 2007
Ramada Plaza & Suites
& Convention Center
Fargo, ND

The University of North Dakota
School of Medicine
& Health Sciences

DMF
DAKOTA MEDICAL FOUNDATION
YOUR HEALTH IS OUR FOUNDATION

DIVISION OF MEDICAL GENETICS
SCHOOL OF MEDICINE AND HEALTH SCIENCES ROOM 5910
501 North Columbia Road Stop 9037
GRAND FORKS, NORTH DAKOTA 58202-9037

UND

NON-PROFIT ORG
U.S. POSTAGE PAID
Grand Forks, ND
58201
PERMIT #10

Hearing Hoofbeats and Thinking ZEBRAS

Screening, Testing & Management of Children with Genetic Disorders

Conference Fees

Early Bird Registration (prior to Feb. 28, 2007)	$70.00
Registration (Deadline March 28, 2007)	$90.00
Student Registration (valid student ID required)	$25.00

Scholarships available for UND Medical Students

Continuing education credit will be given only to those who attend all sessions and complete required documentation.

Payment Method

Please submit payment with your registration.

Hotel Reservation Information

The conference hotel is:

Ramada Plaza & Suites & Conference Center
1635 42 Street SW
Fargo, ND 58103
(701) 277-9000

To reserve a hotel room, please call the Ramada directly and reference the conference to secure the group rate.

Exhibitors

If your organization would like to exhibit at the conference, please contact Jayne Brown at (701) 777-4276 or email her at jbrown@medicine.nodak.edu.

Who should Attend:

Health and Human Services Professionals (ie. MD, PA, NP, nurses, OT/PT, speech/language, social workers)

A special Thank You goes out to our Genetic Advisory Committee for your support and assistance.

Thank you to Cullen Children's Foundation for being a Commercial Sponsor.

Presenters

Cathy Breedon, Ph.D., Clinical Nutrition Specialist at MeritCare Medical Center.

Cheryl Greenberg, M.D., Head of the Department of Pediatrics and Child Health; Medical Director, Child Health Program; Director of the Metabolic Service; clinical geneticist with the Program in Genetics and Metabolism; and Professor in the Departments of Pediatrics and Child Health, Biochemistry, and Medical Genetics at the University of Manitoba.

Bryan Hall, M.D., Former Chief of Genetics and Dysmorphology at the University of Kentucky.

John T. Martsolf, M.D., Professor of Pediatrics and Director of Division of Medical Genetics at UND School of Medicine and Health Sciences.

Susan Sparks, M.D., Ph.D., Pediatrician, Clinical Geneticist, and Clinical Biochemical Geneticist at the Children's National Medical Center (CNMC) in Washington, DC.

Newborn Screening Panel:

Barb Schweitzer, RN, BSN, (moderator), Director of the North Dakota Newborn Screening Program, North Dakota Department of Health.

Sara Copeland, M.D., Assistant Professor, University of Iowa, School of Medicine, Department of Pediatrics. Dr. Copeland is also a consultant for the North Dakota Newborn Screening Program.

Alan Kenien, M.D., Pediatric Endocrinologist at MeritCare Medical Clinic. He also is a consultant for the ND Newborn Screening Program.

Stephen Tinguely, M.D., Chair of Pediatrics University of North Dakota School of Medicine and Health Sciences. Pediatrician, Meritcare Health Systems and co-director of MeritCare Cystic Fibrosis Program.

Family Resource Panel:

Pat Conway, Ph.D., LCSW, (moderator); Director of Family-to-Family, Professor at the Center for Rural Health of the University of North Dakota (UND) School of Medicine and Health Sciences.

Donene Feist, Executive Director and a parent activist of the North Dakota Chapter of Family Voices.

Tammy Gallup-Millner, RN, MPA, Director of the Children's Special Health Services unit, Medical Services Division, Department of Human Services.

Parent Panel:

Gretchen Noah, (moderator), Parent of a child with Smith-Lemli-Opitz Syndrome and lay advocate for Smith-Lemli-Opitz Syndrome Parent Group.

Phil & Dianna Hansen; Parents of three children, one with scoliosis and a chromosome disorder.

Jane & Stephen Nelson, M.D., Dr. Nelson and his wife have four children, one who was diagnosed with Cornelia de Lange Syndrome.

Scott & Robyn Throlson, First-time parents of a child with Primary Carnitine Deficiency.

Janette Venaas-Gilbraith, parent of two children, one with cerbral palsy.

Visit www.medicine.nodak.edu/genetics or www.marknoah.com for conference updates.

Hearing Hoofbeats and Thinking ZEBRAS~
Screening, Testing & Management
of Children with Genetic Disorders
Ramada Inn, Fargo, ND
April 23 & 24, 2007

Registration Type:

- ○ Early Bird Registration (prior to Feb. 28, 2007) $70.00
- ○ Registration (Deadline March 28, 2007) $90.00
- ○ Student Registration (valid student ID required) $25.00

Please check your Monday dinner preference: ○ Greek Lemon Chicken ○ Pork Loin Dijonnaise

Name: _____ Title: _____

Organization: _____

Address: _____ City: _____ State: ____ Zip: ____

Phone: _____ Fax: _____ E-mail: _____

Special Needs/Requests: _____

Name (as you would like it to appear on your badge): _____

Scholarships available to UND Medical Students

Payment Information:

Make checks payable to Division of Medical Genetics. Send the registration form and payment to Attn: Jayne Brown, Pediatrics/Division of Medical Genetics, School of Medicine and Health Sciences Room 5910, 501 N. Columbia Road Stop 9037, Grand Forks, ND 58202-9037