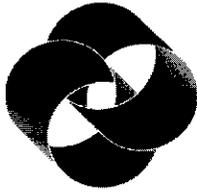


SENATE PUBLIC HEALTH, WELFARE & SAFETY

EXHIBIT NO. 4

DATE: 1-31-05

BILL NO. SB 275



Shodair Children's Hospital

Psychiatric Services for Children and Adolescents
Medical Genetic Services

Testimony and Exhibits For Senate Bill 275

Submitted by

Mona Jamison ✓

On Behalf of Shodair Children's Hospital

January 31, 2005

Case Statement for Increased State Funding of Medical Genetic Services

1. The need for genetic services has increased steadily in Montana over the past twelve years, while state funding for those services has decreased.

- From 1992 through 2004, numbers of clinical genetic patients increased by 24 %.
- During the same time period, demand for cytogenetic laboratory services increased 175%. (Cytogenetic laboratory services include testing for risk of and treatment for various types of cancer.)
- Between 1992 and 2004, state-supported funding for genetic services in Montana decreased by 10% from \$554,340 in 1992, to \$500,000 in 2005. This decrease is in actual dollars and not adjusted for inflation.
- When inflation is taken into consideration, the decrease in state funding from 1994 to 2004 amounts to 101.69%. (Source: *Global Financial Data, Economic History Services, and the U.S. Bureau of Labor Statistics.*)
- Seventy cents in 1991 is now worth one dollar and twenty seven cents

2. To ensure that Montanans continue to receive these services, Shodair Children's Hospital has supplemented the funding provided by the state with funds from its charitable foundation.

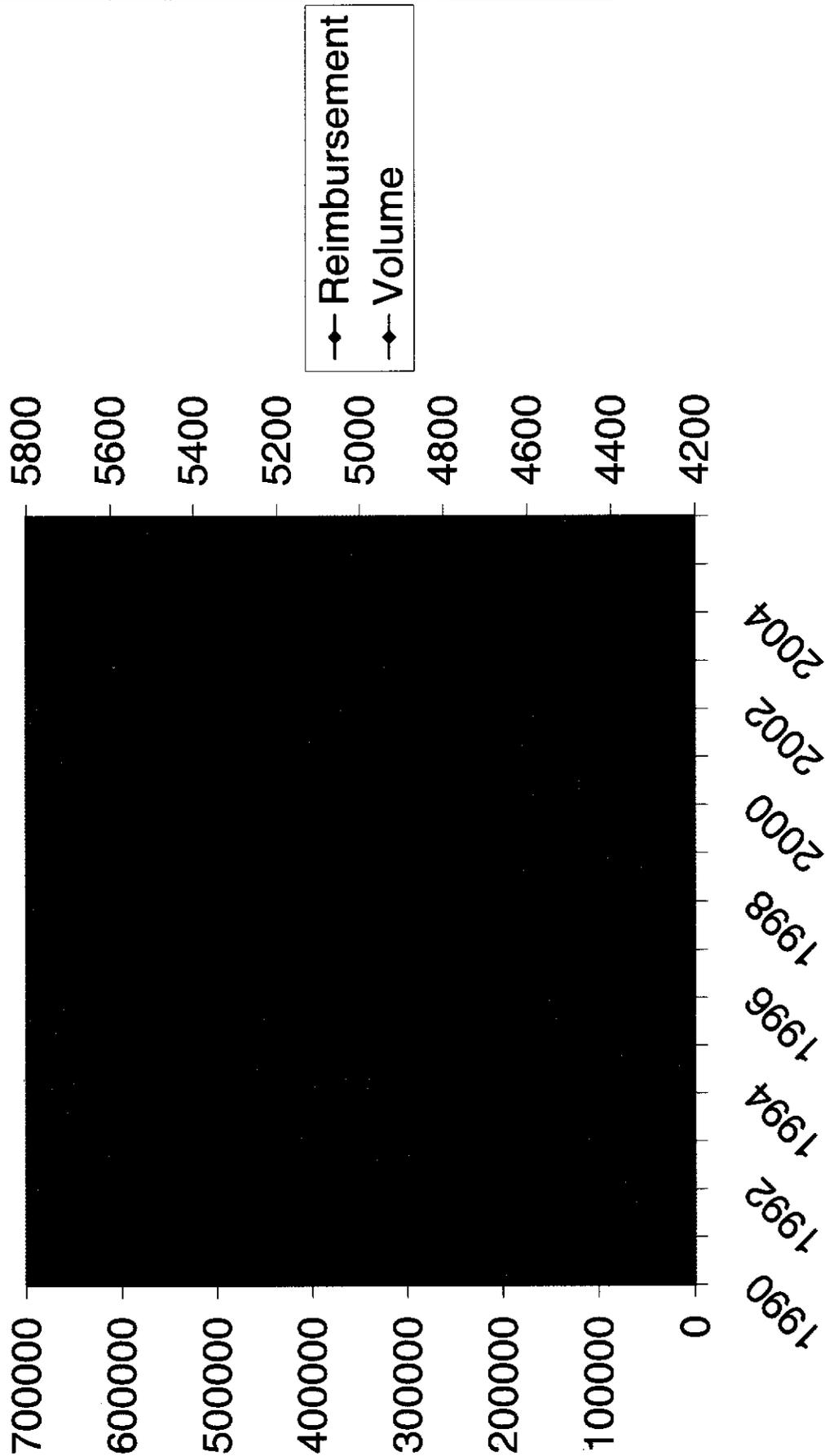
- Shodair Children's Hospital maintains a charitable foundation to raise money to support the overall operation and services of the hospital.
- Since 1994, Shodair's Foundation (the Montana Children's Foundation) has provided \$868,254 to ensure that patients needing medical genetic services receive them.
- The average annual funding provided by Shodair's foundation to support the needs of genetics patients in Montana is \$86,800 per year over the past ten years.

3. Patients often decline needed services because they are unable to pay for them—leaving them without important healthcare information. Shodair Children's Hospital encourages all patients to be seen regardless of their ability to pay.

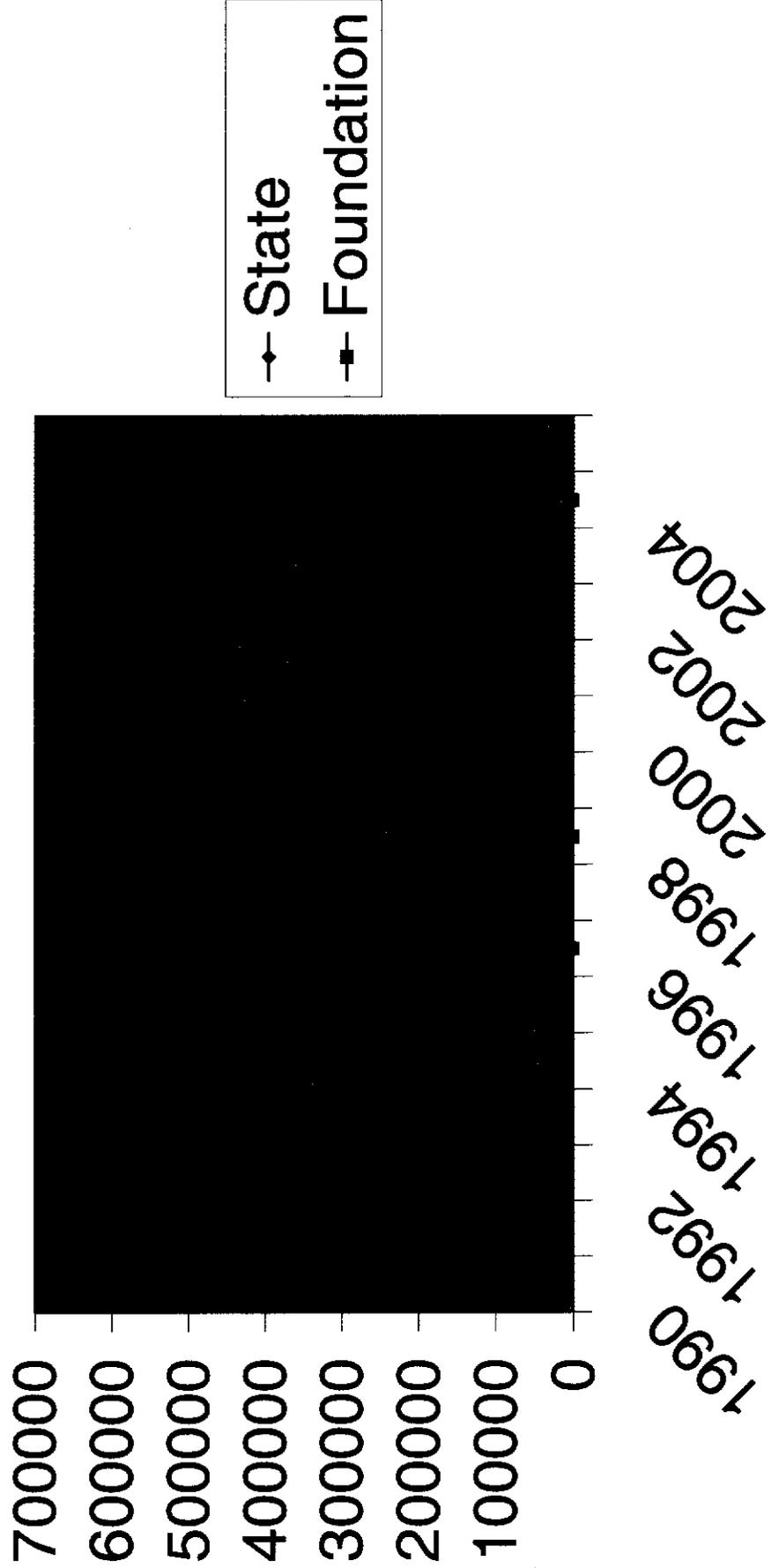
- Third party reimbursement for genetic services, even when available, is often extremely limited. In 2004, reimbursement from all third party payers—including Medicare, Medicaid, and other insurance—was only 50% of billed charges.
- Patients often forego the testing because of lack of Medicaid reimbursement. Medicaid does not reimburse for tests that cannot be performed in Montana and must be sent out of state to a Medicaid non-participating laboratory.
- When patients attempt to have services pre-authorized with insurers and receive denials, they often cancel or do not keep scheduled appointments. When they are not seen after referrals, lack of diagnosis, appropriate treatment, and follow-up can cause long term health problems for patients.
- In 2004, Shodair Children's Hospital provided more than \$13,000 in charity services for patients needing medical genetic services.

- 4. Genetics is part of a comprehensive system of healthcare that can save healthcare dollars by assisting in accurate, early diagnosis and treatment recommendations.**
- Staff at Shodair work with obstetricians, neonatologists, pediatricians, oncologists, internists, family practitioners and a variety of other specialists to provide a comprehensive, integrated approach to patient care.
 - Genetic counseling and testing enable healthcare professionals to identify risk for many types of cancer, including breast and colon cancer. Identifying increased risk allows for early diagnosis and treatment. Equally important, early identification of reduced risk can prevent costly medical and surgical procedures.
 - Example, early diagnosis of the genetic condition Marfan Syndrome can allow increased surveillance and treatment to prevent life-threatening heart problems.
- 5. Genetic services provide a critical link for patients and families to other healthcare, educational, and support services.**
- Shodair's genetics staff works with a network of healthcare professionals from around Montana to provide resources for patients: Speech therapists, physical and occupational therapists, support groups, and public health nurses are among the many other healthcare providers with whom Shodair staff interacts to assist patients.
 - Shodair's genetic staff also works with schools—either directly or through patients' families—to help teachers understand learning disorders and other special needs of children with genetic conditions.
- 6. As it is throughout the nation, cancer genetics is an emerging need in Montana. Patients can now make important treatment decisions based on genetic information.**
- Genetic counseling and testing enable earlier diagnosis of cancers—when they are most treatable.
 - Genetic characterization of leukemia is vital to diagnosis, prognosis, and treatment of the disease.
 - Example: A specialized tissue test performed at Shodair—known as *her2neu*—identifies changes in breast cancers which respond well to the drug Herceptin. This is important, because other kinds of breast cancer do not respond to this drug, which is costly and often has major side effects for patients who take it.
- 7. Shodair Children's Hospital is providing genetic services in locations throughout Montana.**
- A physician geneticist and genetic counselor travel to over 70 clinics throughout the state each year. Monthly clinics are held in Billings, Missoula, and Great Falls. Four to six clinics per year take place in Kalispell, Bozeman, and Butte. Clinics are also held at least once a year in Wolf Point, Browning, Sidney, and Miles City.
 - With telemedicine technology, patients can be seen almost immediately for emergencies or if they are unable to travel. Shodair has access to over 100 telemedicine sites throughout Montana.
 - Montana healthcare professionals have access to Shodair's genetic staff 24 hours a day for consultations via a toll-free 800 number.

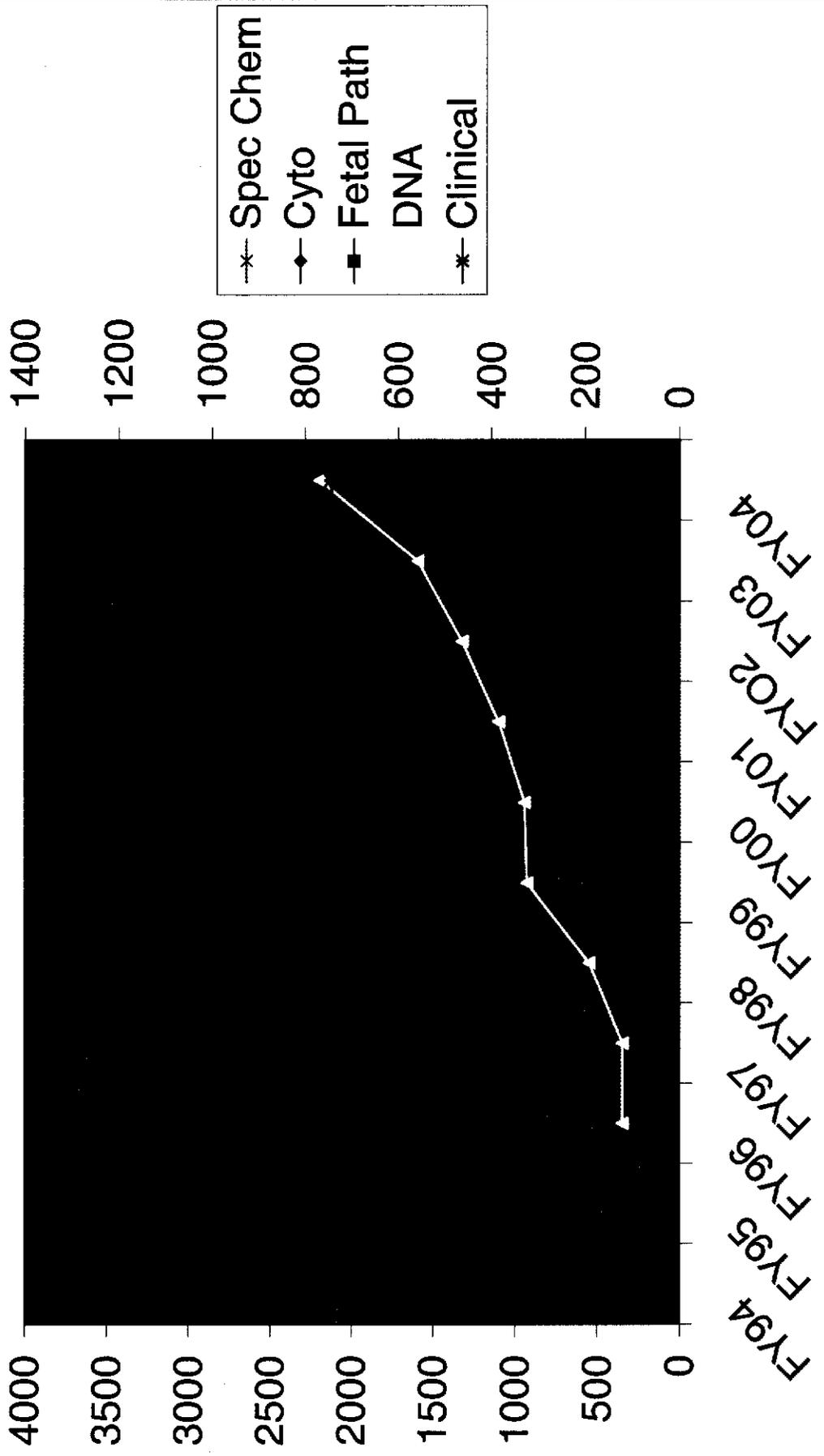
Genetics Reimbursement and Volume

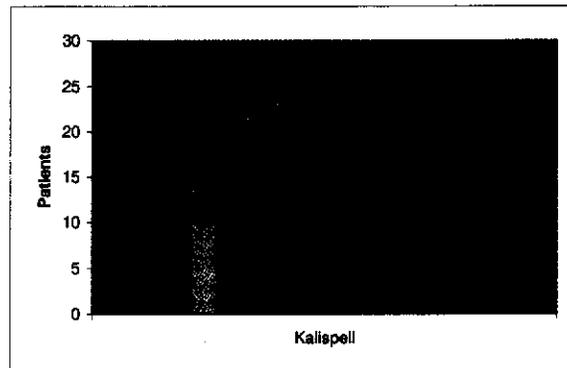
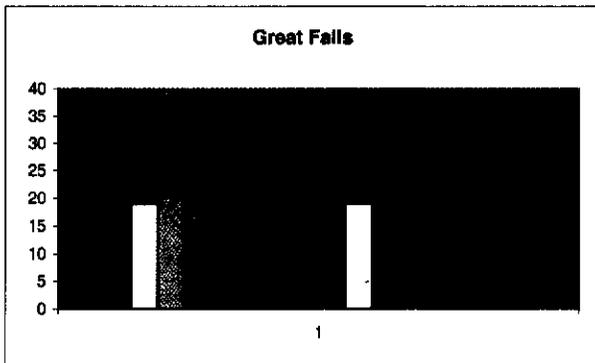
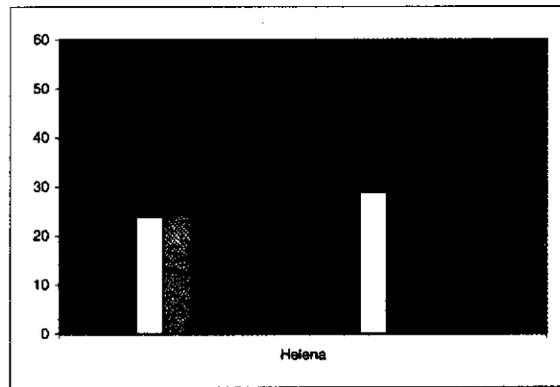
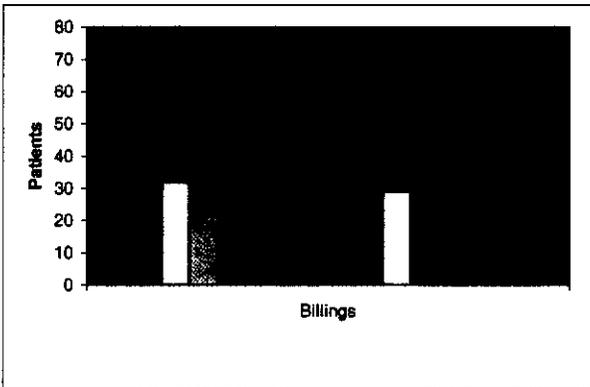
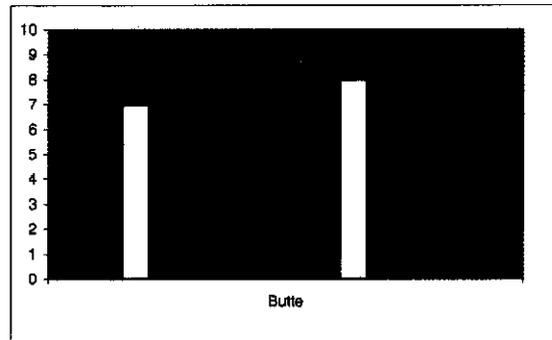
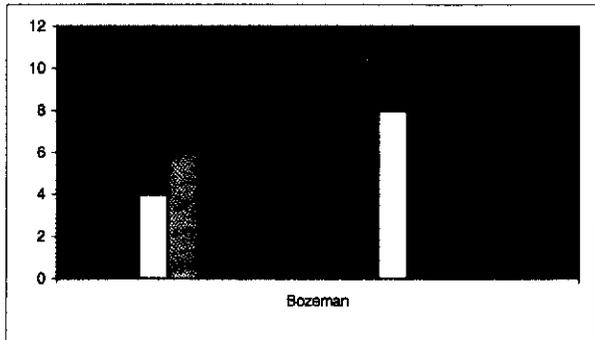
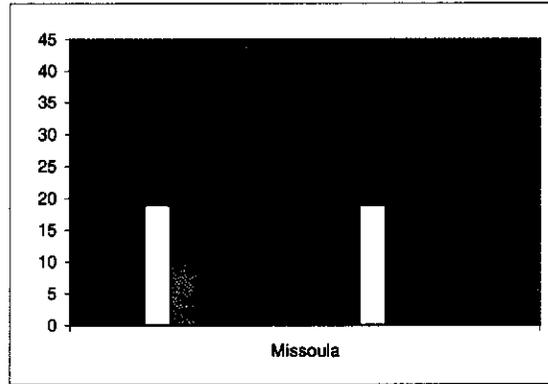
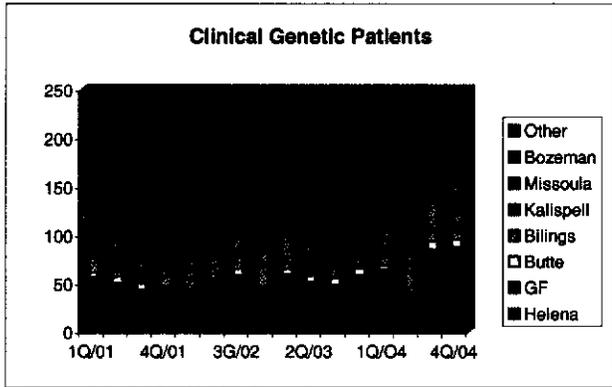


Genetics State and Foundation Funding



Genetics Volume





April 21, 1988

Ray Hoffman, Fiscal Analyst
Department of Health & Environmental Services
Cogswell Building
Helena, Mt 59620

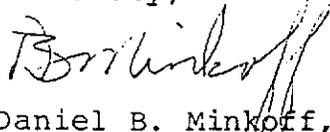
Re: Interim Financial Report
Montana Genetics Program

Dear Mr. Hoffman:

Enclosed please find the above-referenced report for the quarter ending March 31, 1988. Total expenditures as of March 31, 1988 were \$400,798.55. The Hospital's request for funds of \$65,000.00 is reflected in the quarter ending 3/31/88 column on page 2 of the report.

Should you have any questions concerning the enclosures and/or the above request, please contact me.

Sincerely,



Daniel B. Minkoff, C.P.A.
Controller

Enclosures

cc: John M. Opitz, M.D.
Jack Casey, Administrator

DBM:sc

MONTANA GENETICS PROGRAM
 HB 716 (1987 MONTANA LEGISLATURE)
 INTERIM FINANCIAL REPORT
 FOR PERIODS AS INDICATED

	QUARTER ENDING			YEAR TO DATE
	9/30/87	12/31/87	3/31/88	
) IN-HOUSE CLINICAL GENETICS PROGRAM				
PERSONNEL	\$19,389.76	\$20,468.67	\$22,116.29	\$61,974.72
TRAVEL	387.36	416.55	372.44	1,176.35
SUPPLIES	1,863.23	1,611.85	2,832.05	6,307.13
EDUCATION	100.00	40.00	0.00	140.00
LIBRARY USE	552.54	168.50	458.46	1,179.50
TOTAL	\$22,292.89	\$22,705.57	\$25,779.24	\$70,777.70
) GENETIC FIELD CLINIC PROGRAM				
PERSONNEL	\$17,799.36	\$18,789.78	\$20,302.26	\$56,891.40
TRAVEL	762.87	820.35	733.49	2,316.71
SUPPLIES	1,918.22	1,659.42	2,915.61	6,493.25
EDUCATION	100.00	0.00	0.00	100.00
LIBRARY USE	476.54	145.32	395.41	1,017.27
TOTAL	\$21,056.99	\$21,414.87	\$24,346.77	\$66,818.63
) FETAL GENETIC PATHOLOGY PROGRAM				
PERSONNEL	\$19,702.03	\$20,798.31	\$22,472.48	\$62,972.82
TRAVEL	197.53	212.41	189.91	599.85
SUPPLIES	2,082.48	1,801.51	3,165.29	7,049.28
EDUCATION	100.00	0.00	0.00	100.00
LIBRARY USE	476.54	145.32	395.41	1,017.27
TOTAL	\$22,558.58	\$22,957.55	\$26,223.09	\$71,739.22
) INFORMATION AND LIBRARY SERVICES				
PERSONNEL	\$15,729.67	\$16,604.92	\$17,941.53	\$50,276.12
SUBSCRIPTIONS, ETC.	2,850.63	869.31	2,365.30	6,085.24
TRAVEL	254.24	273.39	244.44	772.07
SUPPLIES	966.23	1,078.32	1,666.22	3,710.77
EQUIPMENT	1,495.80	5,031.00	0.00	6,526.80
CONSULTANTS	130.00	0.00	0.00	130.00
EDUCATION	0.00	0.00	0.00	0.00
TOTAL	\$21,426.57	\$23,856.94	\$22,217.49	\$67,501.00

MONTANA GENETICS PROGRAM
 HB 716 (1987 MONTANA LEGISLATURE)
 INTERIM FINANCIAL REPORT
 FOR PERIODS AS INDICATED

	QUARTER ENDING			YEAR TO DATE
	9/30/87	12/31/87	3/31/88	
CYTOGENETICS AND CELL BIOLOGY				
PERSONNEL	\$31,212.25	\$33,428.06	\$34,968.00	\$99,608.31
TRAVEL	1,063.15	182.97	0.00	1,246.12
SUPPLIES	4,207.63	5,689.10	12,306.83	22,203.56
LIBRARY USE	423.48	129.15	351.38	904.01
TOTAL	\$36,906.51	\$39,429.28	\$47,626.21	\$123,962.00
TOTAL EXPENDITURES	\$124,241.54	\$130,364.21	\$146,192.80	\$400,798.55
LESS: HOSPITAL MATCHING FUNDS	86,053.39	38,552.36	81,192.80	205,798.55
NET GRANT REQUEST	\$38,188.15	\$91,811.85	\$65,000.00	\$195,000.00

ChiariPeople of MT.
5649 Roundup Road
Billings, MT 59105

Phone: 406 252-7343
Julie: 406 208-4720
Jade: 406 208-4883

ChiariPeople of MONTANA

January 27, 2005

To Whom It May Concern,

Mr. Chairman, Members of the Committee:

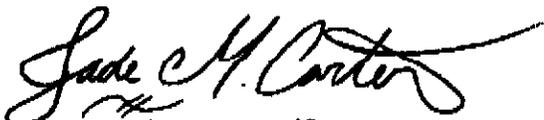
My name is Jade Carter, I am a Montana native, born in Billings. I spent a good share of my childhood suffering from strange symptoms that no doctor could seem to put a name on. By the time I was in my early teens, I had developed excruciating headaches that could not be controlled by regular pain-relievers or even prescribed medications. My mother suffered the exact same symptoms as me; she too went undiagnosed, or misdiagnosed all her life. When I was 15, my mother was diagnosed with a disease called Chiari [Brain] Malformation. It was then that we began to wonder if I had the same thing...

My health grew worse, and my High School, Skyview, put me on their "handicapped" list, even though we still had no diagnosis. My grades began to drop, I was missing so much school; falling down, blacking out, I could not even think my head hurt so bad.

I went to so many doctors, they could find nothing wrong with me. Finally, in Oct. of 2003, one of our local Neurologists, considered the top of his field, diagnosed me as needing Psychiatric treatment. We knew that wasn't the case, but no one would even listen. Finally we were put in touch with Shodair Childrens Hospital in Helena, and directed to their Genetics Dept. Those folks knew what Chiari was, and that it wasn't a "psychiatric" problem. They sent a team of specialists down to meet us, as traveling is a nightmare for us. We met Dr. Reynolds, a Medical Geneticist, and Cindy Hudson, a Genetic Counselor at a clinic in Billings in Nov. 2003. They asked alot of questions, and came to the conclusion that I needed to see a specialist. They assisted us in getting to a team of experts in New York, and are we glad we listened to them!

As it turns out, I did have a Chiari Malformation, but one that was hard to detect without a diagnostic tool called Cine MRI; this is not available in Mt. When you have Chiari, your Cerebellum is too large for your skull, and the brain presses into the brainstem and spinal cord, causing blockage of the CSF, Cerebrospinal Fluid. I was getting no fluid to my brain, and this pressure caused a condition known as Syringomyelia, cysts in my spinal cord, to form. I underwent a brain decompression and laminectomy of the C-1 vertebrae in April of 2004. I feel so much better, am living a much more normal and active life. I don't know where I would be if Shodair's Genetics team had not stepped into my life..... The Genetic staff at Shodair helped save my life. For people like me with rare Genetic disorders and diseases, they provide diagnosis, support, resources and hope. I strongly urge you to support Senate Bill 275, to expand and support Montana's Medical Genetics services. We would be lost without them.

Sincerely,



Jade Michel Carter, age 18



January 24, 2005

Mr. Chairman, Members of the Committee:

My name is Dana Avison. I'm from Polson.

Our son, Christian, has a genetic condition called Jacobson syndrome. In technical terms, it means he is missing a small piece of chromosome # 11. What it means to us is that he has a serious heart defect, hearing loss, speech loss and learning disabilities.

We were first referred to the genetics program at Shodair children's hospital in November 1999 when Christian was one year old. We now live in Polson and are followed by the genetics staff in Missoula. The genetics laboratory at Shodair diagnosed his condition. More important, the counseling staff helped us to understand this condition. They told us what to watch for, connected us with other families in a support group and provided countless resources to us.

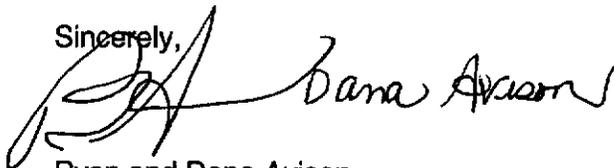
They have organized a connection for us with the School for the Deaf and Blind in Great Falls.

On a personal level, they were also instrumental in supporting our family while Dana was completing nursing school. The doctor and counselor even wrote a letter to my nursing instructors explaining my short term inability to complete course work.

Christian is now five and in kindergarten. He only has about five words, but he has over fifty signs and communicates well.

The staff from Shodair has been with us each step of the way as Christian grows up, offering expertise, support and resources. This program is vital to Montana families. We urge you to support the continuation and expansion of this program through Senate Bill 275.

Sincerely,

A handwritten signature in cursive script that reads "Dana Avison". The signature is written in black ink and is positioned to the right of the word "Sincerely,".

Ryan and Dana Avison

January 27, 2005

Mr. Chairman, Members of the Committee:

My name is Brian Arneson and I live in Billings, Montana. I am writing in support of Senate Bill 275 on behalf of my daughter, Ashley, currently age four.

I had my colon removed three years ago when I was 31. After a routine physical, my internist referred me for a colonoscopy because my mother had colon cancer at a young age. The results of the test were awful—I had a condition called **Familial Adenomatous Polyposis**—which carries a 100% likelihood of contracting colon cancer if left untreated. At the time, Ashley was only eleven months old. My first concern was for her and whether she would also become a victim of this inherited disease and cancer.

I contacted the genetic department at Shodair in regards to testing Ashley for a genetic predisposition for colon cancer. They counseled me about the testing, and I learned that familial testing is much more accurate when testing someone who is already afflicted with the disease. At that point, I was tested. Shodair's clinical team coordinated the testing and I learned that I was positive for a mutation in the gene associated with this type of familial colon cancer. Now we were able to test Ashley, and because I had been tested, we knew the results would be 100% accurate.

You can imagine our relief when Ashley tested negative. She can look forward to a bright future. Additionally, she won't need the yearly colonoscopies that typically start at age 11 for young people at risk, in absence of genetic testing.

Shodair gave us peace of mind and helped us make good health care decisions. They provide a great service to Montanans. On Ashley's behalf, I urge you to support Senate Bill 275.

Sincerely,

A handwritten signature in cursive script that reads "Brian Arneson". The signature is written in black ink and is positioned above the printed name.

Brian Arneson

January 24, 2005

Mr. Chairman, Members of the Committee:

My Name is Brandi Moore. I live in Kalispell.

My family has a history of colon cancer. My aunt was diagnosed with colon cancer at age 47. My mother does not have colon cancer, but she has colon polyps at a young age. I was referred to Shodair Hospital's genetics program by my oncologist, Dr. Goodman in Kalispell because of the strong family history and because an MRI showed an unusual spot on my brain.

The geneticist (physician) and counselor first saw me in a clinic in Kalispell in May of 2004. They reviewed hereditary risk in cancers and suggested that we start the process of identifying our families risk with my aunt. My aunt tested positive for a mutation in the gene responsible for the inherited cancer syndrome Hereditary Nonpolyposis Colon Cancer (HNPCC). This information was critical. In addition to colon cancer, she now has a 60% risk of uterine cancer and a 12% risk of ovarian cancer. She is now considering surgical options to prevent additional cancers.

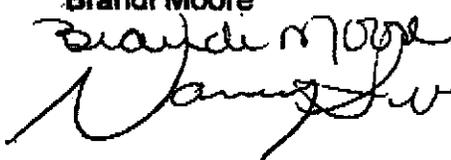
Next we tested my mom, who does not have cancer, but is also positive for the gene. Knowing this information, she can make health care decisions that will allow her to live a longer, healthier life.

This whole process for our family began in May of 2004. Despite my high risk, I unfortunately have not been tested yet. Shodair's staff has worked actively with my insurance company on the testing, but at this point they have denied it. At this point, the genetics staff at Shodair are recommending a uterine biopsy and a colonoscopy, procedures which are more invasive, riskier and much more costly than the test. I am still working with the staff on funds for the testing.

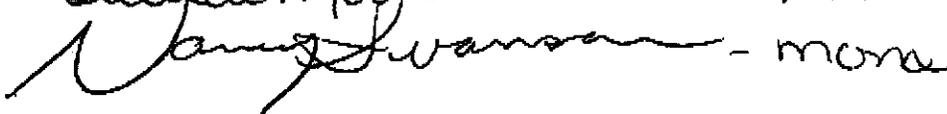
The staff at Shodair has been available to be for both counseling and testing. Their services have changed the lives of my family.

I urge you to support SB 275 to continue and expand their services

Sincerely
Brandi Moore



Carol Jeffries - Aunt

 - mom

January 29, 2005

Re: Senate Bill 275

Mr. Chairman, Members of the Committee:

My name is Rebecca Norton. I live in Whitefish. I wish I could be there in person to testify before you on this important issue. Thank you for considering my opinion as a patient, and also as a health care provider myself.

The Montana Genetics Program at Shodair Hospital has provided services that were vital to me and my family. That's why I'm writing to you today to ask your support for Senate Bill 275 which provides additional funding and clarification language for the program.

I first came into contact with Shodair's genetic counselors in November of 2002. My great-grandmother, grandmother, mother and sister were all diagnosed with breast cancer at an early age. During the course of her treatment in 2001, my older sister was tested for the gene associated with breast cancer. This came back positive, and increased my own risk of being a carrier. Not only does the gene increase breast cancer risk (87% chance by 70 yrs of age), but it also is associated with an increased risk in colon cancer (17%), and ovarian cancer (29%).

I decided to have genetic testing to see if I carried the gene at that time. Shodair provided counseling to explain the risk, coordinated testing, and helped me to sort through the results. The services provided by Shodair helped me immensely—not only with giving me the test kit, but explaining about the emotional and financial considerations if I tested positive. They also referred me to other resource people to talk to. Surprisingly, I do not have the gene. It's changed my life knowing that. I am thankful that we have that service here, not only for myself, but for all the women of our state.

My second encounter with Shodair's genetics program came in November of 2003 following the loss of our baby half way through our pregnancy. Our daughter, Annabelle Marie, died in my womb at 5 months, and I went through an induced labor and delivery. We got to hold her, and see her, which has been helpful with the intense grief that comes with losing a child. As I was 45 at the time, and this was my first child, we wanted to know why the baby had died, and if it was a cause related to my age or our genetics. The counselors met with us in our own town, which was very helpful, and explained that the laboratory at Shodair was able to diagnose a condition called Turner Syndrome, a chromosome abnormality. We were shocked and sad to hear that 95% of babies with this diagnosis die before they are born. They were also able to explain to us that the likelihood of recurrence of this condition was very low, and that it was not related to my age, or our genetic histories.

I cannot imagine going through this excruciatingly painful experience without the support of the professionals at Shodair for testing and counseling. If our baby had lived, they would be who we would turn to for guidance on how to deal with rare disabilities as well.

I urge your continued support of this program. It is vital to health care in this rural state. Thank you for your good work on behalf of the citizens of Montana, and if I can single out my own Senator, thanks to Dan Weinberg for hearing my heart in this testimony.

Rebecca Norton, OTR
530 Scott Avenue
Whitefish, MT 59937

January 31, 2005

To the Chairperson and Members of the Public Health, Welfare, and Safety Committee,

Please support Senate Bill 275, which will increase by 30 cents each year the fee on disability and health insurance policies purchased by each Montana resident. This would be the first increase in ten years.

Cancer runs in my family. Both my maternal grandmother and aunt died of ovarian cancer. My mother has battled through breast cancer, and two rounds of ovarian cancer. She has a mutation in the BRCA2 gene, nucleotide 7253 deletion AA. My husband and I had discussed my options and I was giving serious consideration to having preventative, prophylactic surgery and reconstructive breast surgery. My insurance company would have paid for all the expenses of the surgeries.

Thanks to Dr. Johnson, Director of Medical Genetics at Shodair Hospital, and Katherine Berry, M.S., Genetics Counselor, I had genetic testing for the BRCA1/BRCA2 genes and, thankfully, I do not carry the 7253 del AA mutation. This information resulted in a net savings of thousands of dollars for the insurance company. I have peace of mind as I continue to care for my husband and our four sons, and to volunteer in my community.

The support, education and professional guidance given by Dr. Johnson and Counselor Berry were tremendous. I urge you to vote in favor of SB 275, so that other Montanans may live with peace of mind.

Thank you for your time and efforts.

Sincerely,

Mary A. Matelich

Mary Matelich

Attorney at Law

3916 13th Ave. So.

Great Falls, MT 59405

(406)727-5803

matelich3@bresnan.net