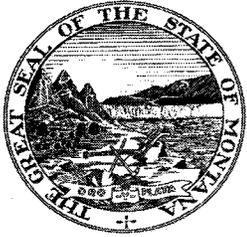


DEPARTMENT OF
PUBLIC HEALTH AND HUMAN SERVICES



BRIAN SCHWEITZER
GOVERNOR

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STATE OF MONTANA

www.dphhs.mt.gov

**DPHHS Testimony for SB 162
House Human Services Committee**

Representative Stoker, members of the committee, I am Jo Ann Dotson, chief of the Family and Community Health Bureau within the Department of Public Health and Human Services. We developed and strongly support SB 162, which moves Montana's public health newborn screening into the 21st century. This bill and the associated funding in HB 2 is an investment in the health of all babies born in Montana, and their families. This bill increases the potential for more babies to have a chance for as normal and healthy a life due to early detection and effective intervention of metabolic and endocrine disorders.

Babies are important and precious everywhere, and we want to be sure that babies in Montana are protected and cared for. With newborn screening technology widely available today and with treatment options more clearly defined, Montana has the opportunity to prevent serious disabilities and premature death with relatively little monetary investment. Montana is one of only five states in the nation who still screen for fewer than ten conditions, and every other state around us – Wyoming, Utah, Idaho, North and South Dakota screen for 27 or more conditions.

One of the many sequela of some of the undiagnosed or untreated conditions is mental retardation. National data collected by the Centers for Disease Control and Prevention (CDC) demonstrate that the lifetime cost to society for a person with mental retardation in the United States is \$1.1 million (adjusted to 2006 values). Not just PKU, but most of the metabolic disorders included in the nationally recommended newborn screening panel result in mental retardation if not managed adequately.

Important points re this bill:

- ◆ This bill allows us to create a long term follow up program including endocrine, metabolic, nutritional and other experts needed to effectively serve these kids.
- ◆ Expanding the panel of tests without developing a sound follow up program is not recommended, and is not good public health practice.
- ◆ The expanded panel of tests will actually be in ARM 37.57.301
- ◆ Funding to support the follow up program is in the budget bill.
- ◆ Creation of this new program removes the role from the genetics program. It was put there 20 years ago when there were limited treatments or intervention identified for many of the conditions. Genetic counseling continues to be an important part of services provided to families, but is, by no means, all they need.

Newborn screening must include adequate follow-up in order for the screening results to have the desired impact on health outcomes. We must have appropriate medical consultation for babies' primary care providers and families. We must track the babies with critical values from their screenings to be sure that the proper diagnostic tests are made as soon as possible and treatment begun. We must monitor the effectiveness of the services provided to families, and assure that the system of care is working for children and families in Montana.

We ask you to send a clear message that we are serious about preventing morbidity and providing early intervention for all babies born in Montana. Vote do pass on SB 162.

My name is Jill Hansen-Twardoski and I am here to testify IN FAVOR of SB-162. My son Derek will be 3 in May, and I am here because of him.

Having a child with a disease like cystic fibrosis is unimaginably hard. Barely a waking hour has gone by since my son's diagnosis that I haven't thought about it. CF is a terrible disease: there is no known cure and the average life expectancy is just 37. My son can't digest most foods, he is susceptible to lung infections by bacteria that exist everywhere (like in standing water and dirt), and he is most likely sterile. He does chest therapy and breathing treatments from 1½ to 5 hours a day. There are no support groups for families with CF, because of the risk of cross contamination. The closest pediatric pulmonologist, who we see every three months, is based in Great Falls—250 miles from our home in Hamilton.

When Derek was born, he was at the 50th percentile in weight and height; that is he was a perfectly average sized newborn. He breastfed well but didn't gain weight like he should. When he started daycare at three months old, he began to have a persistent cough and permanent nasal congestion. At a time where most kids are sleeping through the night, he was breastfeeding for up to three hours each night. As first time parents my husband and I were concerned and took him to our family practice clinic six times in three months, or about every other week. We knew something wasn't right. Finally after Derek got pneumonia and had a respiration rate at nearly four times average, we were recommended to follow up with a pediatrician. She diagnosed cystic fibrosis immediately. Derek was eight months old.

By this time he was seven pounds lighter and four inches shorter than average. His failure to thrive in combination with his lung problems was a textbook case of CF. What we learned after Derek's diagnosis is that my husband and I both unknowingly carried the CF gene. One in every thirty one Americans carries a CF gene and one in every three thousand babies is born with CF. I know that's only three or four babies a year in Montana but the health issues for kids with CF are

bad enough without being exacerbated by a late diagnosis. You can google article after article supporting this point. Children with CF who do not have an early diagnosis are shorter, have more hospitalizations, and are not as healthy as those who get immediate treatment.

The regimen we were placed on was extreme, due to the level of damage and infection in Derek's lungs and his position on the growth chart—or I should say OFF the chart. The black line is the 50th percentile, or average height and weight for a baby boy. The orange line follows Derek's actual measurements. We gave him percussions and multiple nebulized breathing treatments every four hours around the clock. He was instantly placed on two antibiotics (one was Cipro, what they give to people with anthrax and the other was Tobi, which bills out over \$3,000 a month), a bronchodilator, a mucus thinner (which costs almost \$2,000 a month), enzymes, and extra vitamin supplements. He was already infected with a bacteria in his lungs that took eight months to get rid of. His oral antibiotics made him throw up and the nebulized antibiotics took an extra hour an a half every day. We administered chest therapy three or four times a day where we had to beat on our baby's chest to physically loosen clogged mucus from his lungs.

CF has affected every decision my husband and I have made in the past two years. First of all, I gave up breastfeeding so he could have both an extra calorie formula and a special easy-to-digest formula which was much more expensive than the regular stuff. Second, my husband was in the middle of changing jobs and suddenly it didn't matter where he wanted his career to go, all that mattered was where we could get the best health insurance. Third, I quit my senior-level accounting job to stay home and care for our boy. And finally, our family's everyday routine completely revolves around fitting in his therapies and being constantly vigilant about germs.

The problem in Montana is that what happened to Derek and to us could happen to anyone. My husband and I are responsible, college-educated parents with health insurance and our son was literally starving to death for eight months under a doctor's constant care. The suffering he went

through is unconscionable and it is your responsibility to protect future Montanans from this unnecessary pain. Family doctors and nurse practitioners, especially in small towns, need more help diagnosing diseases like CF.

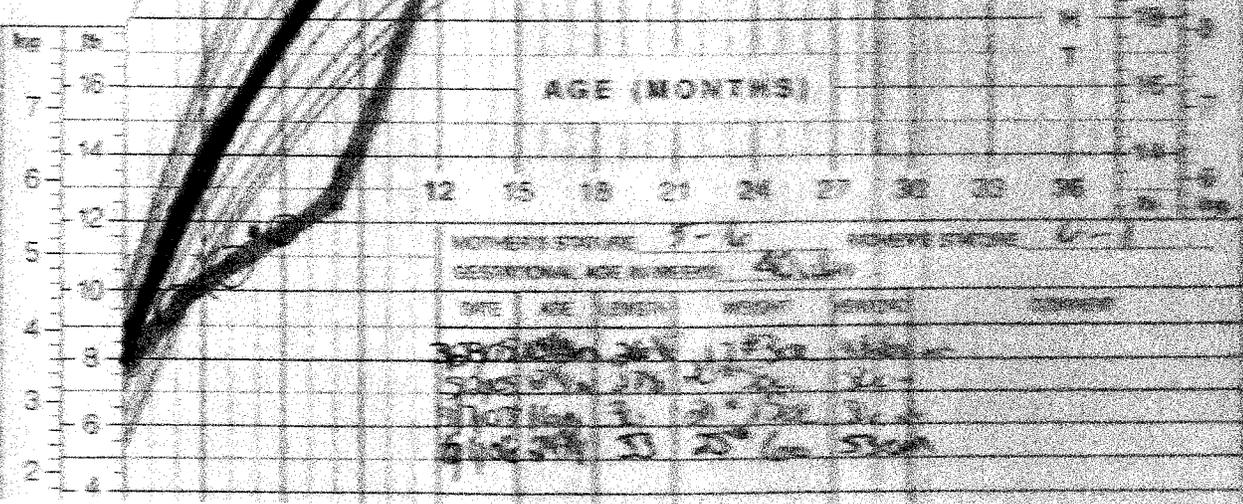
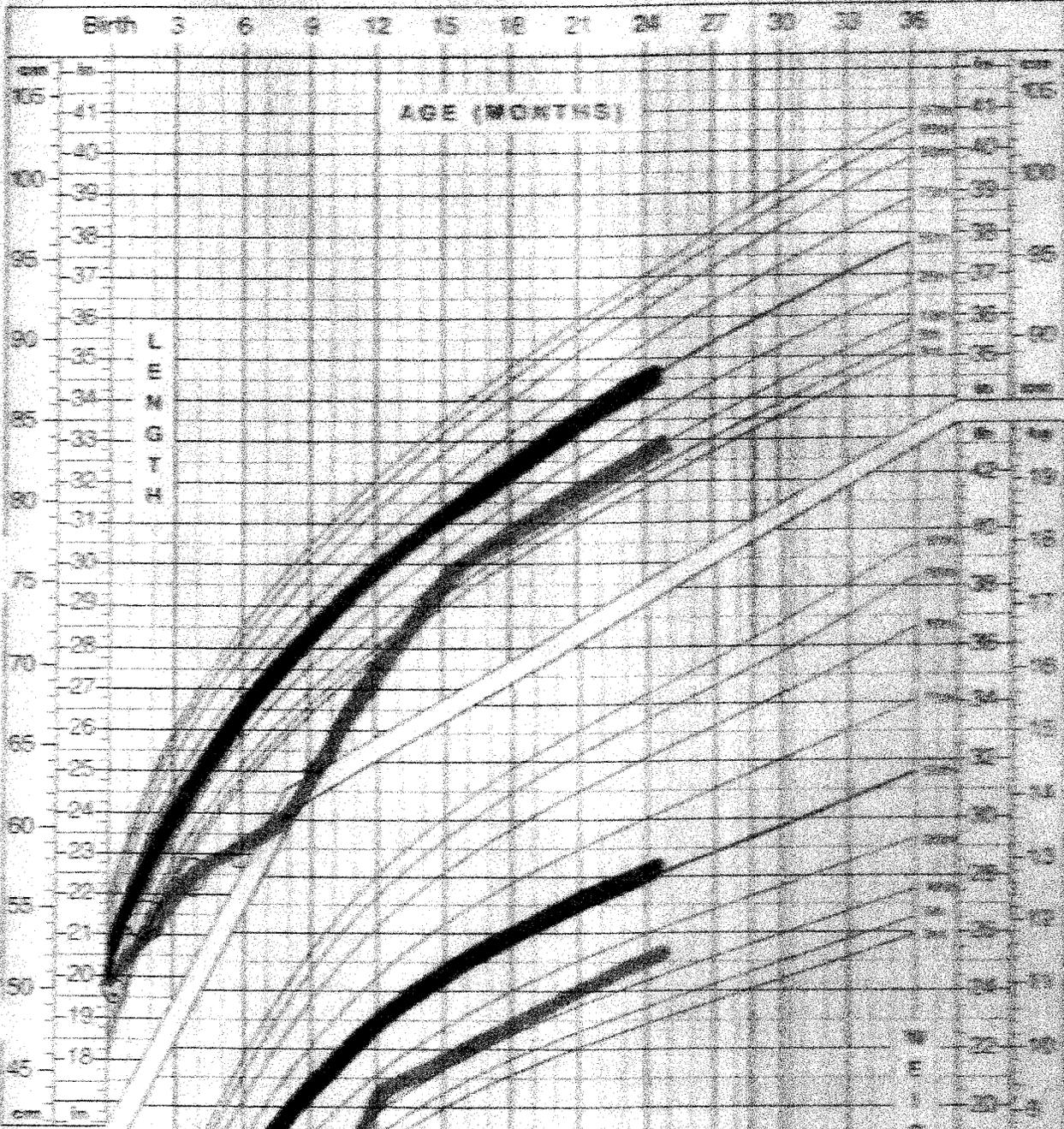
In conclusion, I can't emphasize enough what a difference an early diagnosis would have made for Derek's health. This is not the face of a healthy eight month old boy. But with his breathing treatments and digestive enzymes, and even though he has CF, he is a very healthy two year old. I know there will be a cure for CF in Derek's lifetime, and my family raises a lot of money each year for the Cystic Fibrosis Foundation. But medical research is slow and we need to take action RIGHT NOW to protect our most precious resource—the next generation of Montanans. Every child born in Montana needs to be screened for CF.

It hasn't been easy for me to write this speech and relive the terrible and needless suffering that Derek went through. But I am here because I think our story can make a difference. Each of you has the opportunity to make a difference to future parents just like me and get kids like Derek off to a much better start in life. The newborn screening program MUST be expanded. So it costs \$10 per baby to screen for CF? Don't you think I would've paid a thousand or a million times that to not watch my son starve?

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BOYS: BIRTH TO 36 MONTHS
CDC US GROWTH CHARTS*

Name: Derek Twardowski Record # 159273



MOTHER'S STORAGE: 3-4 MOTHER'S STORAGE: 0-1
 GESTATIONAL AGE IN WEEKS: 42
 DATE: 3/28/08 AGE: 24 WEIGHT: 13.5 LENGTH: 85
 SEX: M RACE: W ETHNICITY: W
 OCCASION: 1 VISIT: 1 PROVIDER: Dr. [unclear]

Vertical text on the right side of the chart, including medical notes and administrative information, is mostly illegible due to the image quality and orientation.

