

Thank you, Mr. Chairman and members of the committee, my name is Mary Murray. I am from Idaho Falls and the President of the Idaho Down Syndrome Council.

I am here to present on Bill 1270, the Down Syndrome Diagnosis Information Act.

I want to begin with the background of how this piece of legislation was started. In 2020, the three regional Down syndrome organizations in Idaho came together to form the Idaho Down Syndrome Council to provide a connection across the state. Through the council, we collaborate on projects and tasks that impact the Down syndrome and Disability communities. For the past two years, we have been working on this bill and we are so grateful and excited that it has brought us here today.

As you heard from Chairman Martin, the goal of Bill 1270 is to ensure that parents receiving a Down syndrome diagnosis are provided timely, accurate, and complete information.

Research shows that a parent's experience of receiving a diagnosis of Down syndrome for their baby is very impactful. Often, the memory of **fear or hope** stays with the parent for a lifetime. The ultimate goal of this act is to help change the way Down syndrome is perceived in Idaho. In 2021 we conducted a survey of about 70 families and found that 68% percent of the families who responded had a negative diagnosis experience. Too many Idahoans have started their journey with Down syndrome feeling terrified and isolated because they were not given accurate information and resources at diagnosis. We want to create a culture of optimism and support by providing information and assistance when a diagnosis is delivered.

I have a beautiful son, Eli, who has Down syndrome, and our journey with him started as one of immense fear and sadness. At our 20 week ultrasound, our medical provider saw many health issues and the first thing she said to me was **that she suspected chromosomal issues and that we needed further testing as we only had one week left to abort in Idaho.** *Those words were powerful and have stayed with me and will for the rest of my life.* We did pursue further testing as we wanted as much information about our baby so we could prepare. When the official diagnosis of Down syndrome came back from the testing, our medical provider called me on the phone and said that our baby had Down syndrome and that was the extent of the information given. We were left with so many questions and such fear.

I am a very strong supporter of the medical community. Eli had surgery at 3 hours old and then several more throughout the first two years of his life. We are so grateful to those doctors and nurses for literally saving his life so that he can now thrive and enjoy popcorn, music, snuggling, reading, and playing with his friends at 7 years old. He brings so much joy to so many people and reminds me daily of the true importance of life.

We want to assist the medical community in providing the best experience possible for **ALL** parents receiving a Down syndrome diagnosis for their baby, pre or post-natal. Our goal is to provide parents with a well-thought-out information sheet. We have already drafted information that we wish we had been provided at the time of diagnosis and hope to work in collaboration with the Department to make this become a reality. This handout contains accurate information, positive pictures, as well as local, state, and national resources available. We hope to share this information along with helpful and supportive ways to give a diagnosis with providers. We are here to help and support the medical community which in turn will help and support the parents receiving the diagnosis.

Everyone I have ever met, who has a child with Down syndrome is so grateful for their son or daughter and is so thankful they get to raise them. There is a disconnect between getting the news that your baby has Down syndrome and then actually raising and loving that same child. We want to close that gap and help parents to feel support, love, and hope from the very beginning.

Thank you for allowing me to present today and I respectfully request you support Bill 1270 and send it to the floor with a DO PASS recommendation.

I am happy to stand for any questions you may have at this time.

(Thank Idaho Council on Developmental Disabilities in appropriate)