House Bill 3107
Requires birthing facilities to add testing via NewBorn Screening for SMA, Spinal Muscle Atrophy
My name is Kathy Oullette and I fully support adding SMA (Spinal Muscle Atrophy) to Oregon's NewBorn Screening program

I am a grandmother of a SMA1 child. Our grandson, Lincoln was born in Oregon on October 10, 2019.
The treatment that ultimately saved his life was FDA approved in May 2019, just 5 months earlier.

Unfortunately many medical professionals did not detect early signs of concern until our Lincoln's 2 month checkup.
When a neurologist was assigned, an SMA test was suggested, only to discover the FREE test onsite was expired.
More waiting and anguish with now a large concern for the life of our child. It was the first mention of SMA which can be a death sentence by age 2.

After a new SMA test was received, taken and submitted, ANOTHER MONTH would go by before the heartbreaking SMA1 diagnosis was received.
This #1 genetic cause of death was not included in Oregon's NBS test at the time. Today 34 other states (and growing) support SMA detection via NBS.
Lincoln would have to wait to receive a SMA diagnosis 4+ months after his birth, in late February 2020.

Now the fast track, TREATMENT plans were defined by a team of professionals along with Lincoln's parents.
All moved mountains to obtain his LIFE SAVING treatment on March 4th 2020 (just one week later).
Lincoln was the FIRST infant treated with gene therapy 'Zolgensma' at Doernbecher Children's Hospital.

Today, over a year later, Lincoln is able to sit unassisted for limited time. He is off his feeding tube and improving with oral foods. He is saying words, kicking his legs, attempting rolls, demonstrating increased head control and getting stronger everyday.
Lincoln will need increased care throughout his lifetime due to a "LATE DIAGNOSIS" which the cost of care far exceeds the cost of testing each newborn for this disease.

No parent should have to endure the suffering of knowing something is wrong and having to WAIT in pain when early detection would have confirmed a path of action.
Each child is unique, however it is unknown what Lincoln could be achieving 'now' if NBS for SMA had been in place.
Many SMA treated infants demonstrate ability to accomplish early milestones once thought impossible with TYPE 1 infants through early diagnosis and treatment.

Please implement life saving NewBorn Screening for SMA in our state to ensure others do not have to endure what our family experienced.
Find a way to close this gap in our healthcare options in Oregon. Your family, Members of the House and other Oregonians are not immune from this terrible disease.
You likely know someone or will know someone who has had SMA touch their life. It's the most common rare disease no one has heard about. That is our story.

Again, I fully support this need and as a lifetime Oregonian, let's catch up with other states and federal guidelines for early detection for one of the most common rare diseases.

Thank you.