

Dear Senator Lieber, representative Nosee and Members of the JWM Subcommittee on Human Services,

On behalf of the 1 in 40 Oregonians who carry the gene for Spinal Muscular Atrophy, I urge you to amend HB 5024, Section 6, to include funding to implement Spinal Muscular Atrophy's inclusion on the Oregon Newborn Bloodspot Screening, as was unanimously approved by OHA's Newborn Bloodspot Screening Advisory Board in February of 2020. Thirty three other states have already done so. Oregon must be next to save the lives of babies with SMA.

While the necessary legwork has been completed, funding is the final hurdle. HB 5024 has the power to add that funding. This cannot wait until the next legislative session or lives will be lost.

Spinal Muscular Atrophy is the number one cause of genetic infant death. SMA is a congenital condition with devastating degenerative symptoms similar to ALS and Polio, but it affects babies shortly after birth. My husband and I searched blindly for three years before our daughter's diagnosis of SMA and subsequent treatment. During that time, our daughter suffered irreparable damage to her nervous system, which will limit her physical abilities for the rest of her life. We consider ourselves fortunate that she has a relatively mild version of this deadly and cruel disease, which gave us the time to find the right specialists to ensure her life expectancy was not affected.

Most SMA parents aren't so fortunate, as the survival rate to 2 years of age is currently only 8 percent due to late diagnosis. While treatments can ensure 100 percent of babies survive, these highly specialized drugs must be administered within 2 months of age to be fully effective. Adding SMA to the newborn Bloodspot Screening will ensure no more Oregon babies or families suffer needlessly, as caregivers struggle to figure out why their newborn is slowly dying.

It is unconscionable to stand by and allow Oregon babies to suffer and die due only to this committee's inaction. Please do what is right for Oregon and for the 1 in 40 of your own constituents and family members who unknowingly carry the gene for Spinal Muscular Atrophy. Amend this bill to provide OHA the necessary funding to add SMA to Oregon's newborn screening today.