cure SMA

Make today a breakthrough.

April 22, 2019

Senator Laurie Monnes Anderson
Chari, Senate Health Committee
Oregon State Senate
900 Court St. NW, S-211
Salem, Oregon 97301

Dear Senator Monnes Anderson:

On behalf of the largest nonprofit organization dedicated to finding a cure for spinal muscular atrophy (SMA), we ask you to move quickly to add SMA to Oregon’s newborn screening panel.

SMA is the most common genetic cause of death in infants in the United States, affecting approximately 1 in 11,000 newborns. The condition is caused by a mutation in the survival motor neuron gene 1 (*SMN1*). In a healthy person, this gene produces a protein that is critical to the function of the nerves that control our muscles. Without it, those nerve cells cannot properly function and eventually die, leading to debilitating and often fatal muscle weakness, taking away the ability to walk, eat and breathe. Without treatment, SMA Type I, the most common and severe form of the condition, results in death or permanent ventilation before two years of age. While other forms of SMA are not as severe, they all cause profound loss of muscle function and ability.

Newborn screening is particularly important to treating SMA. The FDA approved treatment, SPINRAZA, must be administered as soon as possible to be most effective. In fact, in clinical trials of SPINRAZA, pre-symptomatic infants with the genetic markers causing SMA are reaching age-appropriate developmental milestones. To date, none of the infants treated before showing symptoms have died. We expect the FDA to approve another treatment this spring, but it too must be administered quickly to achieve the best possible health outcomes.

Given the importance of newborn screening in effectively treating SMA, Health and Human Services Secretary Alex Azar added SMA to the Recommended Uniform Screening Panel in July of 2018. Twenty other states have approved adding SMA to their newborn screening program, and five states have already begun testing.

For further information, please contact Jaimie Vickery, Vice President of Policy and Advocacy for Cure SMA at 202-841-4001 or at jaimie.vickery@curesma.org. We look forward to working with you to ensure the best possible health outcomes for Oregon's newborns and their families.

Sincerely,

K.A. Hobby	Jill Jarecki	Mary Schroth	Jaimie Vickery
Kenneth Hobby President	Jill Jarecki, PhD Chief Scientific Officer	Mary Schroth, M.D. Chief Medical Officer	Jaimie Vickery, MPP Vice President, Advocacy and Policy