



Make today a breakthrough.

January 14, 2021

Representative Rob Nosse, Co-Chair
Senator Kate Lieber, Co-Chair
Subcommittee on Human Services
Joint Committee on Ways and Means
900 Court St. NE, Room H-178
Salem OR 97301

Senator Lieber, Representative Nosse, and Members of the Subcommittee:

On behalf of Oregon residents with spinal muscular atrophy (SMA), **Cure SMA asks that the Subcommittee add funding in the 2021-2023 State Budget for the Oregon Health Authority (OHA) to implement newborn screening of SMA.**

SMA is a progressive neurodegenerative disease that robs individuals of physical strength, taking away their ability to walk, eat, and breathe. SMA impacts 1 in 11,000 births in the United States. In Oregon, more than 83,800 residents are carriers of the SMA genetic mutation.ⁱ If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA, regardless of race, ethnicity, and gender.

With three effective U.S. Food and Drug Administration-approved SMA treatments and advances in SMA care, individuals with SMA are achieving unprecedented milestones and stopping or slowing the degenerative course of the disease. However, these dramatic outcomes are only possible with early diagnosis and access to these life-saving treatments. Newborn screening is the most effective and efficient way for babies with SMA to access timely treatments and available supports.

Cure SMA and families with SMA throughout Oregon have been pushing for and waiting for implementation of newborn screening of SMA since July 2018, when the federal government recommended that states add SMA to their newborn screening programs.ⁱⁱ Currently, 33 states, including Utah, Washington, and Wyoming, screen for SMA. Oregon does not currently screen for SMA. However, in February 2020, Oregon took an important step forward when your state's Northwest Regional Newborn Bloodspot Screening Advisory Board unanimously approved adding SMA to the list of screened conditions. OHA accepted the advisory board's recommendation, pending funding during the 2021 legislative session.ⁱⁱⁱ

This joint subcommittee is key in ensuring Oregon newborns are screened for SMA, the most common genetic cause of infant death. We ask that you add the resources the Oregon State Public Health Laboratory needs to complete implementation of SMA as soon as possible. Based on Oregon's SMA incidence and birth rate, it is very likely that 10 babies in your state have been born with SMA in the 30 months since the federal recommendation and 3 babies in the 11 months since the advisory committee's unanimous vote.^{iv} With further delay, Oregon infants born with SMA and their families will experience the frustration of delayed diagnosis and missed opportunities for better outcomes. Due to the degenerative nature of the condition, infants with SMA type 1 lose 90% of the motor neurons needed for strength and development by six months of age. Once those neurons are lost, they can never be regenerated.^v

Newborn screening funds must be approved during the 2021 legislature so that Oregon parents of infants born with SMA receive a diagnosis shortly after birth and can make timely decisions about treatment and care. Thank you for considering the views of Cure SMA and Oregon individuals and families with a connection to SMA. Please do not hesitate to contact Cure SMA if you have questions or need additional information related to our request. Cure SMA can be reached through Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,



Kenneth Hobby
President



Mary Schroth, M.D.
Chief Medical Director



Jill Jarecki, PhD
Chief Scientific Officer

Cc: *Senator Sara Gelser*
Senator Tim Knopp
Representative Wlnsvey Campos
Representative Cedric Hayden
Representative Duane Stark
Representative Anna Williams

ⁱ Cure SMA Oregon State Fact Sheet, 2020, https://www.curesma.org/wp-content/uploads/2020/09/SMA-State-Fact-Sheet_Aug2020_OR_v2.pdf

ⁱⁱ HHS Secretary Azar SMA Approval Letter, July 2018, https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/reports-recommendations/final-sign-azar-response-sma.pdf?utm_source=Daily%20on%20Healthcare%20070518_07/05/2018&utm_medium=email&utm_campaign=WEX_Daily%20on%20Healthcare

ⁱⁱⁱ Oregon Health Authority Northwest Regional Newborn Bloodspot Screening Advisory Board, February 4, 2020, https://www.oregon.gov/oha/PH/LABORATORYSERVICES/NEWBORNSCREENING/Documents/20200204_NWRNBSAdvisoryBoard_Meeting%20Summary.pdf

^{iv} COVID-19 National Public Health Emergency Declaration, March 13, 2020, <https://www.whitehouse.gov/presidential-actions/proclamation-declaring-national-emergency-concerning-novel-coronavirus-disease-covid-19-outbreak/>

^v Treatments for SMA, Cure SMA, 2020, <https://www.curesma.org/treatment/>