



Chair Prusak, Vice Chair Hayden, Vice Chair Salinas and Committee Members:

My name is Joanne Rogovoy. I am the Director of Maternal and Infant Health for the March of Dimes-Oregon. I submit this testimony in support of HB 3107 -1 in relation to newborn screening of Spinal Muscular Atrophy. (SMA)

Newborn screening efforts took root in the 1960's with the development of a screening test to detect PKU in newborns 24-48 hours after birth. In February 2003, at the federal level the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) was formed to advise the HHS Secretary on newborn screening. SACHDNC worked closely with the American College of Medical Genetics (ACMG) as progress was made toward developing a recommended uniform screening panel (RUSP) as an equitable process for adding additional conditions to state panels. In September 2005, SACHDNC recommended the RUSP to the HHS Secretary as the nation's newborn screening standard. Today there are 35 core conditions on the RUSP and 26 secondary conditions. Oregon currently is screening for 33 of the core conditions on the RUSP.

SMA was recently added to the RUSP as was X-linked Adrenoleukodystrophy (X-ALD). Neither of which are currently screened for at birth in Oregon. The Northwest Newborn Bloodspot Screening Advisory Board was created by HB 2563 in the 2019 legislative session to provide recommendations, information and advocacy to the Oregon Newborn Screening Program. The advisory board of which I am a member recommended the addition of SMA and X-ALD to the state panel. Disorders on the RUSP are chosen based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments.

The March of Dimes recommends all states screen for all conditions on the RUSP and refrain from adding tests that have not yet been added to the RUSP. Scientific advances may allow some conditions to be identified through testing before they meet the criteria for inclusion on the RUSP. Once a disorder is added to the RUSP March of Dimes will actively advocate for its inclusion on state panels.

March of Dimes supports HB 3107-1 and requests that X-ALD be added to this legislation.

March of Dimes-Oregon
4931 SW 76th Avenue #347
Portland, Oregon 97225