



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 opposition of HB 2987 in relation to newborn screening.

Each state or territory operates its own Newborn Screening Program (NBS) or contracts with another state to screen their newborn population. All states have laws that require newborn screening, but the conditions screened for may vary by state. The process for adding conditions to state NBS panels varies by state, but can involve, legislation, regulation and/or advisory committees. NBS programs involve much more than the test itself; every state program includes screening, follow-up, diagnosis, management, evaluation and education.

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. The secondary disorders are not actively sought by NBS but are revealed in the course of screening for the core conditions.

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.

In 2019 Oregon HB 2563 created the Northwest Regional Newborn Bloodspot Screening Advisory Board to provide recommendations, information, and advocacy to guide the Newborn Bloodspot Screening Program with strategic planning and recommendations on operational changes and recommendations on a process for the addition or removal of disorders from the Oregon panel. I am currently a member of this advisory board for Oregon. Stage 1 of the

procedure for disorder evaluation is its addition to the RUSP. Disorders that have been reviewed by the SACHDNC and have been added to RUSP will be reviewed for further evaluation. Oregon currently screens for 33 of the 35 RUSP disorders. The Board has recommended that SMA and X-Ald recently added to the RUSP be approved for addition to the Oregon panel.

Several conditions listed in HB 2987 have not made the RUSP and March of Dimes opposes the passage of this bill.

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