

May 27, 2021

House Committee on Health Care
Oregon State Legislature
900 Court Street NE
Portland OR 97301

RE: Informational Hearing on Northwest Regional Newborn Bloodspot Screening (NWRNBS) Program

Chair Prusak, Vice Chairs Hayden and Salinas, and Members of the Committee on Health Care:

It is a privilege to be here to speak to the work of the Newborn Bloodspot Screening Program. I would like to share my perspective on the work of the NWRNBS Program as a member of the Advisory Board, as a retired professional having worked to assure effective systems of care for children with special healthcare needs and their families in Oregon, and, most importantly to me, as a parent of a child (now adult) born with a life shortening genetic condition of which few medical practitioners had training or experience at the time. I am currently fulfilling my role as Co-Chair of the Board and thus work closely with the Program Chair. I participate in planning for Board activities and priorities presented to the Board at their meetings.

Background

- **Who comprises the Advisory Board of the NWRNBS Program?** The Advisory Board was formed in 2019 under HB2563. The board membership is comprised of a representation of key stakeholders including healthcare professionals involved in the health and wellbeing of pregnant women and their infants, family members of people with special health care needs, and community based providers.
- **What is the Advisory Board's charge?** The board exists to provide advocacy, advice, recommendations and technical information based on members' respective areas of expertise relative to the implementation of the Newborn Bloodspot Screening (NBS) Program. The NBS Program is conceptualized and operationalized as a coordinated public health system that relies on providers, parents and the public health laboratory.

- Our charge, as a Board, is to assist the NBS Program with strategic planning and the development of policies, priorities and services related to the newborn bloodspot screening system.
- The goal is to improve health outcomes for all infants and their families via implementation of an efficient and effective newborn screening program.

Work to Date of the NWRNBS Board

- The NWRNBS Board was formed in 2019 under HB 2563. It addressed itself to:
 - adopting a charter, including a commitment to consensus-based decision making,
 - approving a protocol and criteria for recommending addition of disorders to the screening test panel, and
 - agreement on findings and recommendations for changes to improve the timeliness of newborn screening.
- During 2020, the NWRNBS Board met twice to use our new protocol to evaluate and recommend the addition of two new disorders to the screening protocol – specifically Spinal Muscular Atrophy (SMA) and X-linked Adrenoleukodystrophy (X-ALD).
- Our future work include:
 - conducting strategic visioning,
 - planning for the program
 - addressing program sustainability, and
 - achievement of its mission over the long term.
- We also have on our list of future work screening education for providers and families, and evaluating the equity of newborn bloodspot screening testing reimbursement.

The work of the NWRNBS Program is a critical component of Oregon’s comprehensive system of care addressing the health and well-being of children and their families by assuring the earliest identification of special health needs of newborns with treatable conditions.

Thank you,

Marilyn Sue Hartzell