NORD®

February 20, 2025
The Honorable Dan Bronoske
Chair, House Health Care and Wellness Committee
504 15th Ave SW, House Hearing Room A
Olympia, WA 98501

Dear Chair Bronoske and Members of the Health Care and Wellness Committee,

On behalf of the one-in-ten Americans living with one of the over 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for the opportunity to provide comments on House Bill 1697 (HB 1697).

With a more than 40-year history, NORD is the leading and longest-standing patient advocacy group for the more than 30 million Americans living with a rare disease. An independent 501(c)(3) nonprofit, NORD is dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 355 patient organization members, is committed to improving the health and well-being of people with rare diseases by driving advances in care, research, and policy. NORD believes that all individuals with a rare disease should have access to high quality, affordable health care that is best suited to meet their medical needs.

HB 1697, if passed, would direct the Washington Board of Health to evaluate conditions that appear on the Recommended Uniform Screening Panel (RUSP) for addition to the state newborn screening panel within 12 months of the condition's addition to the RUSP. It would also require the Board of Health to complete and consider a feasibility review to identify costs to screen for the condition, federal funding available to aid implementation of screening, recommendations for changes to the fee charged for screening, and a timeline for adding the condition to the newborn screening panel. Should the Board find the condition suitable for addition to the newborn screening panel, the bill would direct them to begin rulemaking to add the condition to the state panel within 12 months of their determination. NORD urges you to support HB 1697 and advance the bill favorably out of the Health Care and Wellness Committee.

Newborn screening is a vital public health program with a long history of successful operation in the United States, improving the health of many children through timely diagnosis and treatment. Today, nearly 4 million newborns across the country are screened each year for a number of rare conditions that can cause permanent disability or death in the absence of early detection and treatment. Babies born with these serious conditions typically appear healthy at birth, so screening is critical to ensure newborns who need it receive early care, treatment, or intervention as early as possible. Over 14,000 babies are found to have a serious rare disorder through newborn screening each year. In many cases, these early diagnoses are lifesaving and as science progresses, an increasing number of conditions are being added to the screening panel, helping to save additional lives.

Newborn screening programs are operated at the state level, and the specific conditions on each state's newborn screening panel vary across the country. To guide state newborn screening programs, the Health Resources and Services Administration's (HRSA) Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) maintains a list of conditions recommended for screening called the Recommended Uniform Screening Panel (RUSP). To be added to the RUSP, a condition must meet all of the following criteria: 1) be a serious medical condition; 2) have a clear and well-described case definition; 3) have a screening process that has high analytical validity; 4) have a screening process that is clinically useful; 5) have well-defined treatment protocols; and 6) have data available demonstrating that population-based screening works well to find newborns with the given condition.[1] Washington currently screens for 35 of the 38 conditions on the RUSP, but does not have a defined timeline for when conditions added to the RUSP must be added to the state's newborn screening panel.

By not screening newborns for all conditions on the RUSP, the state risks missing critical information about newborn Washingtonians' health, and children with conditions that are not on the newborn screening panel can suffer preventable, irreversible health complications as a result. NORD strongly supports the timely addition of RUSP conditions to state newborn screening panels and the process laid out in HB 1697. We encourage Members of the Committee to support this legislation and advance it out of Committee.

Once again, on behalf of the Washington rare disease community, we thank you for the opportunity to provide comments on HB 1697. For any questions, please feel free to contact Allison Herrity at aherrity@rarediseases.org.

Sincerely,

Allison Herrity, MPH
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National Organization for Rare Disorders

CC: Leah Barber, Director of Grassroots Advocacy, NORD