MINNESOTA
RARE DISEASE ADVISORY COUNCIL

April 9, 2025

Senate Human Services Committee
Chair John Hoffman and Ranking Member Jordan Rasmusson
Minnesota Senate
95 University Ave W.
Saint Paul, MN 55155

Chair Hoffman and Ranking Member Rasmusson,

The Minnesota Rare Disease Advisory Council strongly urges the committee to include SF1175 ,which would establish temporary presumptive eligibility for Medicaid based on a child receiving a positive newborn screen while awating a final disability determination, in the Human Services Committee Omnibus.

The majority of rare diseases are genetic in origin and are of pediatric onset. The complexity and heterogeneity of rare diseases combined with their low prevalence leads to extreme difficulties in establishing a diagnosis for practitioners, with the results being an average delay of 7-8 years to diagnosis[1]. And for some rare diseases **once a child experiences symptom onset they are ineligible for treatment**. For example, the State of Minnesota screens for a rare condition called Krabbe disease. This is a devastating disorder for which the only treatment is a bone marrow transplant. But the transplant must be done before 30 days of life to have a chance for success. In these cases, identification through newborn infant screening is the only effective diagnostic pathway. Even under the Compassionate Allowance referral program (which is only available for some diseases on the newborn screen) the time to a disability determination without electronic records is between 19-44 days. This timeline means that a child identified with Krabbe through newborn screening would be at risk of losing a chance for the only known treatment while awaiting a disability determination.

In addition to the human cost of missing the window to treat these diseases, healthcare cost utilization for rare, complex diseases often exceeds that even of more common diseases and is a financial strain on our Medicaid programs.[2,] The healthcare utilization costs for untreated children with rare diseases can be staggering.[3]

Newborn infant screening is one of the most successful public health initiatives in the US, saving countless lives and averting significant healthcare costs.. In Minnesota in 2023, 347 newborns were identified with a heritable or congenital disorder through newborn screening, the majority of which required urgent intervention. Due to the rigor of adding a disease to the newborn screening panel and the criterion a disease must meet, the MNRDAC believes that a positive newborn screen is a strong proxy for identifying children who will qualify for Medicaid through a disability determination and should be used to expediate access to treatments.

We thank the committee for your ongoing work to support people with disabilities across Minnesota**. However, rare disease patients—who are very much part of this community—face continued and significant barriers to diagnosis and treatment**. The omission for SF1175 leaves major gaps in our state's disability infrastructure. We urge you to recognize the real, human impact of this omissions and to support and SF 1175/HF 1502. Minnesota can and should continue to lead in supporting the most vulnerable among us.

Thank you for your leadership and consideration.

Erica Barnes

Erica Barnes, Executive Director

[1] ShireReport-1.pdf (globalgenes.org)

[2] NIH Study Suggests People with Rare Diseases Face Significantly Higher Health Care Costs | National Center for Advancing Translational Sciences

[3] Medicaid covers sick or dying children. But it takes 'going to battle' to get it | STAT