

February 11, 2025

Dear Chair Jon Hoffman, Ranking Member Jordan Rasmusson, and members of the Senate Human Services Committee,

The Minnesota Rare Disease Advisory Council (RDAC) **expresses strong support of SF 1175** which establishes a presumptive disability determination process for medical assistance eligibility for infants with a positive newborn screening or a compassionate care allowance determination. This legislation is an essential step toward ensuring timely access to necessary medical care for some of our most vulnerable children. RDAC is an executive branch state agency whose mission is to improve diagnosis and care for the 1 in 10 Minnesotans living with a rare disease.

One of the greatest challenges affecting the health, survival, and well-being of individuals with rare diseases and their families is the long road to diagnosis. Delays in diagnosis can lead to inappropriate disease management, disease progression, and missed opportunities for early intervention. Many patients with rare diseases are misdiagnosed two to three times due to symptom overlap with more common conditions, often resulting in ineffective or even harmful treatments. For children with a rare disease, shortening the diagnostic journey could be the key to a longer, healthier life. Currently, delays in disability determinations can leave infants and children with severe or life-threatening conditions without access to critical medical services. By aligning presumptive eligibility with a positive newborn screening result or a compassionate care allowance determination, this bill ensures that infants with urgent medical needs receive immediate access to care, reducing barriers and preventing adverse health outcomes.

This policy will have profound impacts by:

- **Providing Immediate Access to Care:** Infants who test positive for congenital or heritable disorders often require urgent medical intervention. Presumptive eligibility ensures they receive timely delivery of care without unnecessary delays. These children would otherwise qualify for disability services, this just streamlines the access to care.
- **Improving Health Outcomes:** Early intervention is critical for infants diagnosed with severe conditions. By facilitating prompt access to medical assistance, we can improve survival rates and long-term health outcomes.
- **Enhancing Healthcare Efficiency:** Streamlining the eligibility process reduces administrative burdens on hospitals and healthcare providers, allowing them to focus on patient care rather than bureaucratic hurdles.

The importance of early diagnosis is underscored by recent research from the EveryLife Foundation for Rare Diseases, which found that early rare disease diagnosis could save as much as \$500,000 per patient in medical costs and productivity losses. Their report, "The Cost of Delayed Diagnosis in Rare Disease<sup>1</sup>," highlights the avoidable costs associated with several rare diseases. The study emphasizes the significant benefits of early intervention in states that have instituted newborn screenings. Eliminating the often months- or years-long diagnostic odyssey experienced by people with rare diseases not only saves money but also ensures patients receive optimal, life-saving interventions at the earliest possible stage.

Sincerely,



Erica Barnes  
Executive Director  
Minnesota Rare Disease Advisory Council