NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

March 4, 2025

The Honorable Jeff Backer, Chair
Health Finance and Policy Committee
Minnesota House of Representatives
658 Cedar St
Saint Paul, MN 55155

Re: NORD Supports House File 1501 – Minnesota Rare Disease Advisory Council Funding

Dear Representative Backer and Members of the Health Finance and Policy Committee,

The National Organization for Rare Disorders® (NORD) writes today in support of House File 2501, legislation that will provide funding to support operations of Minnesota's Rare Disease Advisory Council (RDAC). **These resources will be invaluable for the Council as they continue their work to fulfill its existing statutory mandates.**

NORD is a federation of non-profits and health organizations dedicated to improving the health and well-being of people living with rare diseases. We have over 330 member organizations which represent patients and caregivers living with one of the over 10,000 known rare diseases. For over 40 years, NORD has been at the forefront of advocacy for policies and programs such as the creation of state Rare Disease Advisory Councils that aim to improve the health and well-being of individuals living with rare diseases and their families. Through Project RDAC, NORD is working to establish an effective RDAC in every state in the country. To date, there are 30 Councils nationwide.

Minnesota's Rare Disease Advisory Council was established in 2019 to represent rare disease patient communities in the state. Originally housed at the University of Minnesota, the council transitioned to a state agency in 2022. In the 2023 legislative session, the Council's base operational budget was established, but only a portion of the budget was established as an ongoing appropriation with the remaining amount being a one-time appropriation. **The workload associated with a high functioning RDAC necessitates funding – particularly in Minnesota, the only RDAC to be a state agency**.

In its current form, HF 1501, appropriates $342,000 in both FY2026 and FY2027 for the Council. Minnesota is a leader among Rare Disease Advisory Councils, advising MDH, DHS, and other state agencies on best practices for treating patients with rare diseases. Adequate funding will allow the Council to help identify more efficient ways to improve care for the rare disease community, saving money and ensuring that Minnesota's most vulnerable populations receive appropriate care.

The value of a high-functioning RDAC cannot be understated. People living with rare diseases face many challenges, including delays in obtaining an accurate diagnosis, finding a health care provider with expertise in their condition, and a lack of affordable access to therapies and medications used to treat rare diseases. This Council provides Minnesota's rare community with a much-needed forum to put these challenges before stakeholders in the best position to find solutions and ensure Minnesota's rare disease patients and families are living the most fulfilling and healthy life possible.

I hope you consider NORD a resource for you as this bill moves through the legislative process. I look forward to working with you and your staff to improve the lives of rare disease patients and families living in Minnesota.

Sincerely,

Lindsey Viscarra
State Policy Manager, Western Region
National Organization for Rare Disorders®

CC:
Leah Barber, Director of Grassroots Advocacy
Erica Barnes, Executive Director, Minnesota Rare Disease Advisory Council