



Alone we are rare. Together we are strong.®

April 1, 2025

The Honorable Melissa Wiklund
Chair, Health and Human Services Committee
Minnesota State Senate
2107 Minnesota Senate Building
Saint Paul, MN 55155

Re: NORD Supports Senate File 2037 – Minnesota Rare Disease Advisory Council Funding

Dear Chair Wiklund and Members of the Senate Health and Human Services Committee,

The National Organization for Rare Disorders® (NORD) writes today in support of Senate File 2037, legislation that will provide funding to support operations of Minnesota's Rare Disease Advisory Council (RDAC). **These resources will be invaluable for the Council to fulfill its existing statutory mandates.**

With a more than 40-year history, NORD is the leading and longest-standing patient advocacy organization for the estimated 1-in-10 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. 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, SF 2037, 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.

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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, NORD

Erica Barnes, Executive Director, Minnesota Rare Disease Advisory Council