NORD®
National Organization
for Rare Disorders

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November 14, 2024

The Honorable Tim Walz
Office of the Governor
Attn: Chris Schmitter
130 State Capitol
75 Rev. Dr. Martin Luther King Jr. Blvd.
St. Paul, MN 55155

RE: Support for funding for Minnesota's Rare Disease Advisory Council (RDAC)

Dear Governor Walz,

On behalf of the 1-in-10 individuals in Minnesota living with one of the more than 10,000 known rare diseases, I am writing in strong support of the Minnesota Rare Disease Advisory Council (RDAC) Fiscal Year 2025 budget request of $668,000 to be established as their ongoing base operating budget. This funding is vital to support the critical work that the Council is doing in the state of Minnesota to assist people impacted by rare diseases.

In the United States, any condition that affects fewer than 200,000 Americans is considered rare. There are more than 30 million people in the United States living with a rare disease, across a broad spectrum of medical conditions. Individuals with rare diseases often face inequities in diagnosis, care management, and treatment far beyond that which are experienced by individuals living with common diseases.

As you know, the Minnesota Rare Disease Advisory Council is a strong advocate for the rare disease community, growing from a truly grassroots organization to a state agency which has assisted countless families, medical professionals, and public officials understand and address the unique barriers to care that individuals with rare diseases encounter trying to manage their complex health condition. Increased funding for the Minnesota RDAC would enable sustained advocacy, enhanced collaboration between the RDAC and other stakeholders in the rare disease community and state government, and ensure that the resources necessary for the RDAC to carry on its essential work are within reach.

The Minnesota RDAC is nationally recognized and is considered by NORD to be a model for the other 29 RDACs that exist across the country. Under Erica Barnes' leadership, the MN RDAC was one of the first Councils to be created and has provided guidance and mentorship to other state advocates throughout the process of RDAC creation and implementation. In addition, the legislative progress and policy influence that Minnesota's RDAC has achieved has set the standard for all other states. The Minnesota Legislature and Executive branch should be proud of the innovation and progress that is being done through their state agency and provide the funded vital to continue its great work.

NORD urges your support for this important funding request. We join Minnesota's rare disease community in thanking you for your commitment to providing a voice for those living with rare diseases and their caregivers.

Sincerely,

Lindsey

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