



RE: [HF 3676](#) Rare Advisory Council move to the Minnesota Council on Disability
ATTN: Minnesota House Health Finance and Policy Committee
Date: February 23rd, 2022

Chair Liebling and Members of the Committee,

The Minnesota Council on Disability urges you to support HF 3676 which would relocate the Rare Disease Advisory Committee (RDAC) to the Minnesota Council on Disability (MCD). We believe a formal partnership between RDAC and MCD will be mutually beneficial for both organizations. MCD is an independent state agency with a statutory authority to take policy positions, advise state agencies, and advocate to the state legislature. Currently, RDAC is unable to take independent policy positions or consult directly with elected officials. This comes at a detriment to the rare disease community, because it prevents RDAC from taking a holistic approach to rare disease advocacy.

Not all disabilities are rare diseases, but many rare diseases manifest themselves as disabilities. Rare diseases are protected under the Americans with Disabilities Act and the Minnesota Human Rights Act. The work of RDAC and MCD overlap considerably, and we believe we will be stronger and more effective advocates together. Moving to MCD also allows RDAC to take policy positions which benefits the rare disease community by advocating in all aspects of the lives of Minnesotans with rare diseases. At this time, RDAC is limited to clinical and academic research; however, Minnesotans with rare diseases also face barriers and adversity in education, employment, healthcare, human services, transportation, and more. Living with a rare disease is more than just doctor visits and experimental treatments. It is a lived experience that impacts all aspects of the lives of Minnesotans with rare diseases and their loved ones.

MCD's Council has voted to support this move. By moving to, and partnering with, the Minnesota Council on Disability, the Minnesota Rare Disease Advisory Council will be able to better serve holistically Minnesotans with rare diseases.

We advise the members of this committee to vote in favor of this legislation.

Sincerely,

Trevor Turner
Public Policy Director
Minnesota Council on Disability