



February 22, 2022

**RE: HF626 and HF3676**

Dear Chair Lieblich and members of the House Health Finance and Policy Committee,

The Minnesota Consortium for Citizens with Disabilities (MNCCD) is a broad coalition of over 30 advocacy and provider organizations along with individual members, working to change public policy to improve the lives of people with disabilities. MNCCD would like to express our support of HF 626, rare disease diagnosis and treatment unrestricted services access required and HF 3676, the bill to move the Rare Disease Advisory Council from the University of Minnesota to the Minnesota Council on Disability. We would like to thank Representative Reyer for authoring this important legislation.

#### **HF 626 – Rare Disease Access**

Rare diseases are often complex, chronic, progressive, degenerative, and life-threatening. Although rare diseases can affect any biological system and have a myriad of root causes, the effects on life and functioning are often similar. To have a rare disease is often to have a condition that goes undiagnosed for years. This delay can result in profound impacts for quality of life. Once diagnosed, there might be few experts who have experience in treating any one rare disease, and specialists for any one complex condition may be spread across multiple health systems. It is important patients with a rare disease aren't restricted in accessing the appropriate providers who can help to diagnose their condition and provide treatment and management of their condition.

#### **HF 3676 – Rare Disease Advisory Council moved from the University of Minnesota to the Minnesota Council on Disabilities**

Through grassroots advocacy led by patients and families the Rare Disease Advisory Council was created by the passage of HF 684/SF 973 in 2019. Moving the Rare Disease Advisory Council to the Minnesota Council on Disability will allow the council to fulfill the intent of the stakeholders who brought forward the original legislation to have a statewide council that advises government and is directly involved with policy efforts impacting the rare disease community.

We support these bills because they align with our policy principles of individual empowerment, choice and access to needed services. MNCCD asks that you please vote yes for both HF 626 and HF 3676.

Sincerely,

Maren Hulden and Melissa Haley  
*MNCCD Policy Committee Co-Chairs*