



Dear Chair Stephenson and Members of the House Commerce Finance and Policy Committee,

The Minnesota Consortium for Citizen's with Disabilities (MNCCD) would like to express our support of HF 626, rare disease diagnosis and treatment unrestricted services access required, and we wish to thank Rep. Reyer for authoring this important legislation. MNCCD is a broad-based coalition of advocacy and provider organizations working to change public policy to improve the lives of people with disabilities through building awareness, providing education, and engaging in the community.

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. That 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 that 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.

We ask for your support of HF 626.

Sincerely,

Maren Hulden
Public Policy Co-Chair

Melissa Haley
Public Policy Co-Chair