

February 23<sup>rd</sup>, 2021

## Minnesota Council on Disability Support of HF 626

Chair Stephenson and Committee Members of Commerce Finance & Policy,

The Minnesota Council on Disability would like to express our support for **HF 626** – a bill to require unrestricted service access to the diagnoses and treatment of rare disease.

Many disabilities are conditions of rare diseases so this bill would have a positive impact on the disability community. Disabled Minnesotans with rare diseases often have diagnostic odysseys, waiting for an average of 6 years from the onset of symptoms for an accurate diagnosis. Misdiagnosis and incorrect treatment are frequent in rare diseases. During the diagnostic odyssey, Minnesotans with disabilities suffer from loss of quality of life, disease progression, incorrect treatment, and sometimes irreversible complications. At the same time, unnecessary consultations cause substantial costs for the individual and healthcare systems. Therefore, there is an urgent need to improve rare disease diagnosis.

Under most Minnesota-based health insurance policies, Minnesotans with rare diseases must first see doctors and specialists within their insurance network before being referred to see an out-of-network specialist. Due to the nature of rare diseases, few doctors may be aware of the disease, much less able to treat the condition. This requires a person with a rare disease to see many doctors and can be both a time and financial burden on a person with a rare disease. In many cases, a Minnesotan with a rare disease knows exactly which specialist they need to see, especially if there is a limited number of specialists who can accurately diagnose and treat the condition. Passing HF 626 will allow people with rare diseases to see rare disease specialists right away, regardless if they are in-network or not, would save time, and reduce the financial burden on the person with the rare disease. Anything that helps lower or remove barriers for Minnesotans with a disability, particularly those with rare diseases, will improve their quality of life and allow them to stay connected to their communities.

Thank you for your support for HF 626,

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