



RE: [HF 384](#) Rare disease diagnoses and treatment unrestricted services access required
ATTN: Minnesota House Health Finance and Policy Committee
Date: February 8th, 2023

Chair Liebling and Members of the Committee,

The Minnesota Council on Disability urges you to support HF 384 which would reduce or eliminate the diagnostic odyssey that many people with rare diseases face to get treatment from a specialist. We believe that people with rare diseases should be able to get diagnosis, treatments, and care as quickly as possible to improve their health outcomes, costs, and emotional burden.

It takes the average person with a rare disease seven to nine years from the onset of symptoms to get a formal diagnosis, largely due to bureaucratic hurdles placed on in-network insurance policies. 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 a specialist that is out-of-network. Due to the nature of rare diseases, there are likely few doctors who 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 and their families.

In many cases, a person with a rare disease knows exactly which specialist they need to see, especially if there are limited number of specialists who can accurately diagnose and treat the disease. Updating Minnesota law to require health insurance plans to 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.

The Minnesota Council Disability supports HF 384 because Rare Diseases are protected under the Americans with Disabilities Act and the Minnesota Human Rights Act. Not all disabilities are due to a rare disease, but many rare diseases manifest themselves as disabilities. This legislation supports the choice of Minnesotans with rare diseases to get the treated by the doctors they want in the hospitals they prefer. We advise the members of this committee to vote in favor of this legislation.

Sincerely,

Trevor Turner
Public Policy Director
Minnesota Council on Disability