



February 8, 2023

The Honorable Tina Liebling

Chair, Minnesota House Health Finance and Policy

477 State Office Building

St. Paul, MN 55155

Dear Chair Liebling,

The Epilepsy Foundation of Minnesota (EFMN) serves people with epilepsy and seizures across Minnesota. Epilepsy is a neurological condition that is defined as having more than one unprovoked seizures. One in 26 people will develop epilepsy in their lifetime, and 1 in 10 will have a seizure in their lifetime. We are writing today to express our support for HF 384, which helps expand access to care for rare disease diagnosis and treatment.

Of the 55,000 people living with active epilepsy in Minnesota, a significant number have a rare form of epilepsy. These forms of epilepsy often affect children, who may have hundreds of seizures a day. Rare epilepsies are often difficult to diagnose and treat due to medical complexity. This legislation will make sure that individuals with a rare disease, including a rare epilepsy, will have access to a provider that is knowledgeable about their disease. This can reduce the length of the diagnostic odyssey, ensuring timely and relevant care.

We know that finding a diagnosis and starting a treatment plan early can be life-changing for a family. We know that on average, it takes seven years for people with a rare disease to get a diagnosis in the U.S., and that is too long for the people we serve.

Please support HF 384, and expand access to care for rare disease diagnosis and treatment.

Sincerely,

A handwritten signature in blue ink, appearing to read "Glen Lloyd". The signature is fluid and cursive, with a large loop at the end.

Glen Lloyd
Executive Director
Epilepsy Foundation of Minnesota