

Feb 23, 2021

The Honorable Zack Stephenson  
Chair, Minnesota House Commerce Finance and Policy Committee  
509 State Office Building  
St. Paul, MN 55155

Dear Chair Stephenson,

The Epilepsy Foundation of Minnesota (EFMN) serves people with epilepsy and seizures across Minnesota. Our programs educate, connect, and empower individuals and families throughout their epilepsy journey. We are writing today to express our support for HF 626 which helps expand access to care for rare disease diagnosis and treatment.

Of the 65 million people living with epilepsy worldwide, 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 difficult to diagnose and treat because they are so uncommon.

One of the largest challenges an individual with a rare epilepsy faces is the lack of doctor awareness of the disease. Insurance adds yet another level of complexity to a family's journey to find a diagnosis and access appropriate treatment options, resulting in delays and inaccurate diagnosis and treatment. This legislation will make sure that individuals with a rare disease have access to a provider that is knowledgeable about their disease.

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 that is too long for the people we serve.

We urge you and your members to support HF 626 and to expand access to care for rare disease diagnosis and treatment.

Sincerely,

Heather Besonen

Associate Executive Director, Mission & Strategy  
Epilepsy Foundation of Minnesota