03/15/22

Minnesota House of Representatives
75 Rev. Dr. Martin Luther King Jr Boulevard
St. Paul, MN 55155

Dear Members of the House Health Finance and Policy Committee,

On behalf of The Epilepsy Foundation, we urge you to support HF 3958, which would ensure Medicaid coverage for seizure detection devices. Scientific evidence strongly supports that prompt attention during or shortly after convulsive seizures can be lifesaving in many cases, and seizure detection devices will ensure people with epilepsy are able to receive that attention as soon as possible. Not only that, ensuring Medicaid coverage for these devices means that they will be able to be used by people regardless of income, which can otherwise be a serious barrier to care.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of at least 3.4 million Americans living with epilepsy and seizures. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition that produces reoccurring seizures- which are caused by disturbances in the electrical activity of the brain and affect a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy, and 1 in 10 people will experience a seizure at some point in their lifetime. Epilepsy is the 4th most common neurological disorder in the United States, and it is estimated that 150,000 new cases are diagnosed annually. In Minnesota alone, there are 53,700 people living with active epilepsy.

Epilepsy is associated with substantially higher rates of mortality than experienced in the population as a whole, with Sudden Unexpected Death in Epilepsy (SUDEP) being the most common cause of epilepsy-related deaths. SUDEP applies to a sudden death in someone known to have epilepsy, in the absence of another cause for the death, and people with epilepsy succumb to sudden death at a rate over 20 times higher than the general population. The cause of SUDEP is not yet known and when an autopsy is conducted, no other cause of death is found. The majority of SUDEP cases occur during the night when the individual is sleeping, which often means there are no witnesses or caregivers present to provide aid to prevent an early death. Tragically, more than 1,000 Americans die each year from SUDEP, and it occurs more often in people with uncontrolled or frequent seizures. One out of 150 people with uncontrolled seizures may die from SUDEP. These sudden deaths are the leading cause of death in children and young adults with uncontrolled seizures.

The devices mentioned in this bill can detect seizure activity and notify a family member or caregiver immediately to help ensure that an appropriate medical response can be provided. Providing Medicaid coverage for these devices will ensure that everyone who needs it will have a device to be able to
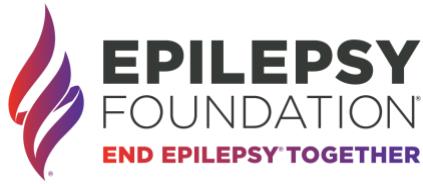
recognize and intervene during a seizure as soon as it becomes medically necessary. These devices will save lives every day all across Minnesota. The Epilepsy Foundation urges you to support HF 3958. Please do not hesitate to contact Dominique Brown, Senior Manager, State Relations and Public Policy if you have any questions or concerns. For questions about SUDEP, please reach out to Alison Kukla, Senior Manager, Programs and Partnerships at akukla@efa.org.

Sincerely,

Laura Thrall
President & CEO
Epilepsy Foundation