

Empowering Epilepsy

Change The Conversation

May 12, 2025

Chairman Romanchuk, Vice Chair Huffman, Ranking Member Liston, and members of the Senate Medicaid Committee, thank you for the opportunity to testify today on House Bill 96. Empowering Epilepsy is providing this testimony to express support for House Bill 96, regarding the Medicaid payment for the Vagus Nerve Stimulator, a much needed medical device for many people living with drug resistant epilepsy, for which Brain Surgery is not considered as a successful option.

Empowering Epilepsy, based in Beachwood, Ohio, is a nonprofit 501(c)3 public charity organization that connects people with epilepsy to experts and peers for education, care, and friendship. We anchor a caring community that empowers our members and their loved ones to better understand and manage their treatment plan throughout their epilepsy journey.

I am the Founder and Executive Director of Empowering Epilepsy. Creating the organization in 2014, my goal was to help others receive the assistance and services I so desperately needed, but could never find when I was growing up with drug resistant epilepsy. People assume we are fine when we are not having a seizure, yet there is so much more to epilepsy than “just the seizures.”

People with epilepsy are dealing with unpredictable seizures, and debilitating medication side effects, which affect our lives every day. I had a difficult time succeeding in school and work, had issues with friends who stopped coming around once they saw me have a seizure, and was dealing with ongoing anxiety and chronic depression because I never knew when a seizure would take place. In 1993, I was able to have a left mesial temporal lobectomy, and have been seizure free, so far for 32 years. Brain surgery for epilepsy is not an option for everyone, though. It all depends on where seizures are starting in a person’s brain. VNS could be considered the next option.

The most scary part of epilepsy, that I personally learned more about back in 1992, when a former boyfriend of mine suddenly and unexpectedly passed away, is that epilepsy can kill. I know all of you are very familiar with SIDS - Sudden Infant Death Syndrome, but I want to educate you more about SUDEP - Sudden Unexpected Death in Epilepsy. SUDEP occurs when an otherwise healthy person with epilepsy dies, and there is no connection to any other cause of death, such as an accident, illness, injury, or drowning. Empowering Epilepsy has lost 17 members of our community to epilepsy, that we know of, since we began in 2014. VNS can help reduce seizures and save lives.

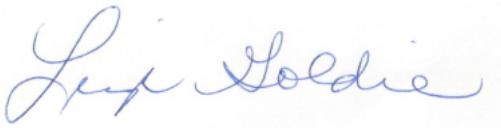
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Vagus Nerve Stimulation is one of currently 4 potential options that I know of to help better control seizures for people living with drug resistant epilepsy. While these options don't always cure epilepsy, they can help reduce seizures significantly, reduce their risk of death, and improve quality of life.

According to the Centers for Disease Control and Prevention, 53% of adults living with uncontrolled seizures live in households earning less than \$25,000 per year. Many people living with drug resistant epilepsy rely on Medicaid to receive the appropriate diagnosis related healthcare. VNS should be an accepted potential option. We need your help now to consider Vagus Nerve Stimulation as an approved potential treatment option for people with drug resistant epilepsy who are Medicaid recipients in Ohio. Your vote on this could literally save someone's life.

Thank you for your time and consideration.

Sincerely,

A handwritten signature in blue ink that reads "Leigh Goldie". The signature is fluid and cursive, with the first name "Leigh" and last name "Goldie" clearly distinguishable.

Leigh Goldie, M.Ed.
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