OHIO HOUSE OF REPRESENTATIVES

Representatives Bride Rose Sweeney & Thomas F. Patton
Sponsor Testimony on H.B. 229 (SUDEP Awareness) – Health Provider Services Committee
October 10, 2023

Chairman Cutrona, Vice Chair Gross, Ranking Member Somani, and members of the Health Provider Services Committee, thank you for the opportunity to testify on House Bill 229 – the Brenna Brossard SUDEP Awareness Act.

SUDEP stands for Sudden Unexpected Death in Epilepsy, which is the sudden, unexpected death of someone with epilepsy, who was otherwise healthy. SUDEP occurs when the brain sends a faulty signal to the heart to stop beating or lungs to stop breathing. It can happen with or without evidence of a seizure. It is the leading cause of death in people with uncontrolled seizures. According to the Epilepsy Foundation, more than 1 in 1,000 people with epilepsy die from SUDEP each year – a statistic that is likely very underreported. Because the risk factors for SUDEP can be mitigated, at-risk individuals and their families should be informed.

On January 30, 2022, in the middle of the night, a healthy and active 25-year-old young woman named Brenna passed away suddenly during an epileptic seizure. Stunned by their horrible loss, Brenna's parents met with the Epilepsy Association of Cleveland. It was only then that they learned about SUDEP for the very first time. Despite over two decades of doctor visits with epilepsy specialists, they were never previously informed about SUDEP, nor the steps that can be taken to reduce the risk of this tragic occurrence. It is because of their efforts – and the efforts of other families whose lives have been forever changed – that this legislation is before you today.

House Bill 229 would apply to health care practitioners entrusted with the primary responsibility for the treatment or care of a patient diagnosed with epilepsy, other than treatment during an emergency. Very simply, those individuals would be required to give patients written information (such as a pamphlet) developed by the Director of Health that includes:

1. Current, evidence-based information about sudden unexpected death in epilepsy risk factors and conditions; and
2. Contact information for nonprofit organizations that provide information and support services for epilepsy conditions.

Once this information has been reviewed by one or more professional nonprofit organizations with expertise in neurology and epilepsy, the Department of Health would share this information on its website and ensure that it is accessible for all recipients. Finally, the Director would also provide guidance to healthcare practitioners to assist them in determining whether a patient is at an elevated risk for SUDEP.

Greater awareness around this issue will help save the lives of more Ohioans who are currently living with epilepsy and at risk for SUDEP. We commend the Brossard family for honoring Brenna’s memory through their advocacy, and we look forward to answering any questions you may have.