Recommendation
Provide robust funding for the CDC’s Safe Motherhood/Infant Health Program in Fiscal Year (FY) 2023 in order to support and help expand the SUID and SDY Case Registry.

BACKGROUND
SUDEP is the sudden, unexpected death of someone with epilepsy, who was otherwise healthy. It is the leading cause of death in people with uncontrolled seizures. Each year, it is thought that more than 1 in 1,000 people with epilepsy die from SUDEP and this number increases drastically to 1 in 150 for people whose epilepsy is not controlled by treatment. But there are deficiencies and inconsistencies with how SUDEP-related deaths are tracked. While some strides are being made, the exact cause(s) of SUDEP are not known.

Building on child death review programs at the National Center for Fatality Review and Prevention Case’s Reporting System, the Sudden Unexpected Infant Death (SUID) portion was initiated in 2009 and in 2015, the Sudden Death in the Young (SDY) Case Registry component was added to include children and adolescents. A joint collaboration of the Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH), the SDY Case Registry increases the understanding of the prevalence, causes, and risk factors for infants, children, and young adults up to age 20, who die suddenly and unexpectedly including from SUDEP—informing strategies to prevent future deaths.

The registry has grown over the years and is now present in 22 states and jurisdictions. However, this is capturing less than half of these deaths nationwide. Increased investment in the CDC’s Safe Motherhood/Infant Health Program—where the Registry is housed—would allow more states to participate and in turn, yield more data to improve understanding and prevention.

 ABOUT THE EPILEPSIES
Epilepsy is a disease or disorder of the brain which causes reoccurring seizures. It is a spectrum disease comprised of many diagnoses including an ever-growing number of rare epilepsies. There are many different types of seizures and varying levels of seizure control.

3.4 million Americans live with active epilepsy including 470,000 children and teenagers. Thirty to forty percent of people with epilepsy live with uncontrolled seizures despite available treatments. Delayed recognition of seizures and inadequate treatment increase a person’s risk of subsequent seizures, brain damage, disability, and death. Epilepsy imposes an annual economic burden of $19.4 billion on the country.