Recommendation: Appropriate $9,500,000 within the Centers for Disease Control and Prevention (CDC), Chronic Disease Prevention and Health Promotion for the Epilepsy program to direct and support activities that improve quality of life for people affected by epilepsy.

Background: In the United States, 5.1 million people have had a diagnosis of epilepsy or a seizure disorder. Advances in medical treatment have allowed some individuals with epilepsy to control their condition. However, between one-third to one-half of people with epilepsy have uncontrolled seizures. Of the 3.4 million people in the United States with active epilepsy, at least one-third of them are not receiving the appropriate level of care to manage their condition. Among older children and adults, epilepsy remains a formidable barrier to normal life, affecting school participation and educational opportunities, employment and overall well-being.

Epilepsy accounts for $19.4 billion in direct costs (medical) and indirect costs (lost or reduced earnings and productivity) each year. Delayed recognition of seizures and inadequate treatment, which may result from lack of specialty care, increases a person's risk of subsequent seizures, brain damage, disability, and death. Epilepsy is a widely recognized health condition, but one that is poorly understood, often leading to stigma in the workplace and in schools.

Justification: The Epilepsy Foundation supports continued investment in the CDC’s epilepsy program, which is the only public health program for people with epilepsy that offers a national scope and local community programs. The Department of Health and Human Services initiative, Healthy People 2020, includes the goal to “increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care,” which can only be accomplished through the CDC epilepsy program. The Epilepsy Foundation, supported by a cooperative agreement with CDC, has provided education and/or direct training to more than 80,606 law enforcement and first responders, 56,385 school nurses and 390,524 students and teachers.

The Institute of Medicine (IOM) released its report on epilepsy: *Epilepsy Across the Spectrum: Promoting Health and Understanding.* In this report, the IOM identified the Epilepsy Foundation and the CDC as leaders in addressing many of its national recommendations. Key consideration and needs identified by the IOM include improved education of health professionals, delivery and coordination of community services, increased public awareness, and better health care outcomes through patient self-management tools. These recommendations can be best achieved through support of CDC work with the Epilepsy Foundation to expand use of model education and awareness programs, increase evaluative research on epilepsy programs, and increased epidemiological and prevention research.
Proposed FY 2019 Report Language: Epilepsy—Approximately, 3,400,000 individuals in the United States have epilepsy and, while new cases are most common among young children, the onset of epilepsy can occur at any age. The Committee has included an increase of $1,000,000 from last year’s level for CDC to expand telehealth and educational training programs for rural and underserved areas that reach school nurses, child care personnel, first responders, and care providers for seniors, to recognize and respond appropriately to seizures caused by epilepsy or result from trauma and other acute chronic illness.

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