Recommendation

Appropriate $11,500,000 within the Centers for Disease Control and Prevention (CDC)’s National Center for Chronic Disease Prevention and Health Promotion’s Epilepsy program to direct and support activities that improve quality of life and care for people affected by epilepsy.

BACKGROUND: The Institute of Medicine’s (IOM) report on epilepsy, Epilepsy Across the Spectrum: Promoting Health and Understanding, identifies the Epilepsy Foundation and the CDC as leaders in addressing many of its national recommendations. 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.” Continued and increased funding for the CDC epilepsy program is critical to meeting this goal—as it is the only public health program specifically related to epilepsy that offers a national scope and local community programs. The Epilepsy Foundation, supported by a cooperative agreement with CDC, has:

- Provided education and/or direct training on epilepsy to more than 81,487 law enforcement and first responders, 57,511 school nurses and 407,649 students and teachers;
- Delivered evidence-based self-management training to people with epilepsy so that they can take control of their health, better cope with day-to-day challenges and reduce healthcare utilization and healthcare costs;
- Reached underserved populations through:
  - Project ECHO, a tele-mentoring process between an epilepsy specialist and primary care providers, in Ohio, Indiana, West Virginia and Kentucky;
  - An advanced practice provider model with family nurse practitioners and physicians assistants;
  - Delivery of signature programs through local Epilepsy Foundation offices;
  - Training community health workers in Texas and Illinois; and
  - Outreach to behavioral health professionals in rural settings.

ABOUT EPILEPSY

Epilepsy is a disease or disorder of the brain which causes reoccurring seizures. Epilepsy is made up of many different types of seizures or syndromes, affects people throughout the lifespan, and can have many different causes and associated conditions.

3.4 million Americans live with active epilepsy. While some are able to gain seizure control, 30-40% 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.

| FY 2019 | $8,500,000 |
| FY 2020 ADMINISTRATION | $0* |
| FY 2020 REQUEST | $11,500,000 |

* The Administration proposes an America’s Health Block Grant that would eliminate the Epilepsy program

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