

FISCAL YEAR 2021 LABOR, HHS, AND EDUCATION APPROPRIATIONS BILL

Centers for Disease Control and Prevention | Chronic Disease Prevention and Health Promotion

Recommendation

Appropriate \$11.5 Million 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 **81,531** law enforcement and first responders, **58,543** school nurses and **419,541** 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 2020

\$9.5 Million

FY 2020 ADMINISTRATION

\$0*

FY 2021 REQUEST

\$11.5 Million

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

FOR MORE INFORMATION, CONTACT:

LAURA WEIDNER Vice President, Government Relations & Advocacy, Epilepsy Foundation | 301.918.3766 | weidner@efa.org or
AMY SOUDERS Principal & Director, Cornerstone Government Affairs | 202.448.9500 | asouders@cgagroup.com



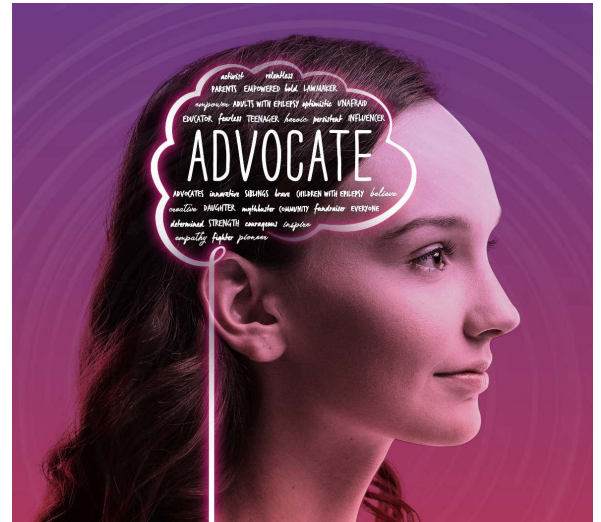
IMPACT OF THE CDC EPILEPSY FUNDING

“AS A YOUNG ADULT LIVING WITH EPILEPSY, THERE ARE MANY CHALLENGES THAT I FACE EVERY DAY, EVEN WITH SEIZURE FREEDOM. EPILEPSY ISN'T JUST ABOUT SEIZURES; IT'S ALSO ABOUT THE REMNANTS IT LEAVES BEHIND. OUR EMOTIONAL HEALTH IS JUST AS IMPORTANT. THE CDC EPILEPSY FUNDING PROVIDES SERVICES TO GIVE HOPE TO ELIMINATE THE STIGMA AND GIVE ADVOCATES LIKE ME, A VOICE.”

- Lyndsey Crunk, Kentucky

“AS A PARENT OF A YOUNG ADULT LIVING WITH EPILEPSY, CDC FUNDING IS VITAL. THE LACK OF AWARENESS AND EDUCATION OF THE GENERAL POPULATION ONLY EXACERBATES THE STIGMA. AS AN ADVOCATE, THE WORK WE HAVE DONE AND CONTINUE TO DO MUST BE MET WITH VIGILANCE IN FUNDING. FUNDING CREATES MORE HOPE THAT FAMILIES LIKE MINE AREN'T ALONE IN THE BATTLE OF EPILEPSY.”

-Cyndi Crunk, Kentucky



“AFTER TRAINING COMMUNITY HEALTH WORKERS IN OUR AREA WITH FUNDING FROM THE CDC, PARTICIPANTS WITH EPILEPSY EXPERIENCED THE GREATEST IMPROVEMENT IN THESE AREAS: IMPLEMENTING ACTIVITIES TO MANAGE STRESS, AND DETERMINING THE BEST WAYS TO SUPPORT MEDICATION ADHERENCE.”

- Epilepsy Foundation of Greater Chicago