



CDC EPILEPSY PROGRAM

Labor, Health and Human Services, Education and Related Agencies Appropriations Bill | FY 2022

Recommendation

Provide \$13 Million for the Centers for Disease Control & Prevention (CDC)'s National Center for Chronic Disease Prevention and Health Promotion's Epilepsy program in Fiscal Year (FY) 2022.

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 to eliminate stigma, improve awareness and education and better connect people with the epilepsies to health and community services. The CDC Epilepsy program is the only public health program specifically related to epilepsy with a national scope and community programs. Focus areas requiring continued and increased investment include:

- In FY 20, **481** law enforcement and first responders, **5,033** school nurses, **214,702** school personnel, and **4,071** students have been trained on seizure recognition and seizure first aid. On-demand training modules are being developed to scale up training of these key, frontline community members.
- **10,000** people have been certified in seizure first aid, though more focus is needed on rural and ethnically and racially diverse communities as nearly **40%** of persons diagnosed with epilepsy are African American or Hispanic and many people with epilepsy in those communities have poorer health outcomes.
- To improve care in rural and underserved communities, Project ECHO has educated more than **400** healthcare providers about managing epilepsy, though more focus is needed on management of severe, drug-resistant epilepsy and quality of care improvement methods.
- **60** community health workers in Texas and Illinois have been trained to implement self-management programs resulting in improved health outcomes for people with epilepsy. More funding could scale up this evidence-based training in other states.
- By screening and addressing barriers to medication adherence, an Epilepsy Learning Healthcare System is reducing healthcare utilization and costs.
- Mental health screenings have been implemented and people with epilepsy are being connected to self-management programs that prevent and decrease depression since people with epilepsy at increased risk for depression and anxiety.

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.

FY 2021

\$10.5 Million

1 in 26 people

in the U.S. will develop epilepsy at some point in their lifetime

25%

of the general public say they would be nervous around a person with epilepsy

FOR MORE INFORMATION, CONTACT:

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