

NATIONAL PLAN FOR EPILEPSY ACT

RECOMMENDATION

Co-sponsor and pass the National Plan for Epilepsy Act to support the development of a comprehensive strategy to prevent, diagnose, treat and cure epilepsy and improve the wellbeing of people with epilepsy and their families.

BACKGROUND

Epilepsy is the fourth most common neurological disorder. It is a spectrum disease comprised of many diagnoses and an ever-growing number of rare epilepsies. Despite scientific advances, the everyday lives of people living with epilepsy can be challenging or even profoundly debilitating and financially devastating on individuals and families.

More than 30% of adults and 20-25% of children with epilepsy do not respond to current treatments. There are no biomarkers for the vast majority of the epilepsies and few effective technologies to track real-time patient data. Clinicians cannot predict drug efficacy, adverse side effects or long-term prognosis for any given person with epilepsy.

As a result, people with epilepsy can face difficulties in many areas of life, including education, employment, transportation, and more. These issues are further complicated by barriers that people with epilepsy face in accessing care and participating in research. Epilepsy can be fatal, with 1 in 1,000 people with epilepsy dying from Sudden Unexpected Death in Epilepsy (SUDEP) every year.

More significant investment and coordination is needed to advance understanding of the epilepsies, develop more effective and targeted therapies, and establish new, transformative models of care.

By directing the Secretary of Health and Human Services to establish and maintain a National Plan for Epilepsy, this bill will enable necessary federal coordination to ensure a unified approach that facilitates better outcomes for people with epilepsy and prioritizes development of more effective epilepsy treatments.

The Secretary would establish and rely on an Advisory Council of relevant federal government departments and agencies and community representatives including people with epilepsy, family members, health care providers, researchers and epilepsy organizations.

The legislation would require public meetings of the Advisory Council, reports from both the Advisory Council and the Secretary with recommendations for priority actions and an annual assessment by the Secretary on progress.



1 IN 26 people develop epilepsy at some point in their lives.

3.4 MILLION people living with active epilepsy in the U.S.

\$54 BILLION economic impact of the epilepsies and seizures in the U.S.

30% of people do not respond to epilepsy medications.

2-3X higher risk of premature death than the general population.

“For the vast majority of my patients, I can’t tell them why this happened; I can’t tell them with any certainty if we have a treatment that will work; and I can’t tell them what their future might hold.”

– Dr. Dan Lowenstein, Executive Vice Chancellor and Provost at the University of California, San Francisco

ABOUT THE EPILEPSIES

Nearly 3.4 million people including 456,000 children live with active epilepsy in the U.S. Epilepsy causes reoccurring and unprovoked seizures and affects people of all ages and members of the military and Veterans.

There are hundreds of epilepsies that span from types that can be managed with medication or surgery to those that are complex and rare with no effective treatments.

Delayed recognition of seizures and inadequate treatment increase a person's risk of subsequent seizures, brain damage, disability and death.

To cosponsor the National Plan for Epilepsy, please reach out to:

House of Representatives:

Rep. Murphy, M.D. (NC-3)

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Rep. Costa (CA-21)

Kit Devine, kit.devine@mail.house.gov

Senate:

Sen. Schmitt (MO)

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Sen. Klobuchar (MN)

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American Academy of Neurology	Epilepsy Foundation Nebraska	Hope for HIE
American Epilepsy Society	Epilepsy Foundation Nevada	Hope for ULD
Angelman Syndrome Foundation	Epilepsy Foundation New England	International Foundation for CDKL5 Research
BDSRA Foundation	Epilepsy Foundation New Jersey	International SCN8A Alliance
CACNA1A Foundation	Epilepsy Foundation New Mexico	Joanna Sophia Foundation
Care and Cure Institute	Epilepsy Foundation North Carolina	Josh Provides Epilepsy Assistance Foundation, Inc.
CFC International	Epilepsy Foundation North Carolina	KCNQ2 Cure Alliance
Child Neurology Foundation	Epilepsy Foundation North Dakota	KCNT1 Epilepsy Foundation
Coalition to Cure CHD2	Epilepsy Foundation of America	Koolen-de Vries Syndrome Foundation
COMBINEDBrain Inc	Epilepsy Foundation of Delaware	KPTN Alliance
CSNK2A1 Foundation	Epilepsy Foundation of Georgia	Lennox-Gastaut Syndrome (LGS) Foundation
CSNK2B Foundation	Epilepsy Foundation of Greater Chicago	My Kool Brother
Cure CLCN6, Inc.	Epilepsy Foundation of Greater Southern Illinois	National Association of Epilepsy Centers
CURE Epilepsy	Epilepsy Foundation of Hawaii	NORSE Institute
CureSHANK	Epilepsy Foundation of Kentuckiana	Partners Against Mortality in Epilepsy (PAME)
DEE-P Connections	Epilepsy Foundation of Michigan	Pediatric Epilepsy Research Consortium
Dravet Syndrome Foundation	Epilepsy Foundation of Minnesota	Phelan-McDermid Syndrome Foundation
Dup15q Alliance	Epilepsy Foundation of Missouri and Kansas	PPP3CA Hope Foundation
Empowering Epilepsy	Epilepsy Foundation of Northeastern New York, Inc.	PVNH Support & Awareness
Epilepsies Action Network (EAN)	Epilepsy Foundation of Northern California	Rare Epilepsy Network (REN) Coordinating Comm.
Epilepsy Alliance America	Epilepsy Foundation of San Diego County	Rea of Hope for a Cure Foundation
Epilepsy Alliance Louisiana	Epilepsy Foundation of Texas	SNAP25 Foundation
Epilepsy Alliance North Carolina	Epilepsy Foundation of Virginia	Sociedad Puertorriqueña de Epilepsia
Epilepsy Alliance Ohio	Epilepsy Foundation of Wisconsin	South Carolina Advocates For Epilepsy
Epilepsy Association of Western and Central PA	Epilepsy Foundation Ohio	STXBP1 Foundation
Epilepsy Foundation Alabama	Epilepsy Foundation Oklahoma	SynGAP Reseach Fund, dba CURE SYNGAP1
Epilepsy Foundation Alaska	Epilepsy Foundation Oregon	Tatton Brown Rahman Syndrome Community
Epilepsy Foundation Arizona	Epilepsy Foundation South Carolina	The Charlie Foundation for Ketogenic Therapies
Epilepsy Foundation Arkansas	Epilepsy Foundation South Dakota	The Danny Did Epilepsy Foundation
Epilepsy Foundation Central & South Texas	Epilepsy Foundation Utah	The Epilepsy Foundation of Metro NY
Epilepsy Foundation Eastern Pennsylvania	Epilepsy Foundation Washington	The Familiescn2A Foundation Inc
Epilepsy Foundation Florida	Epilepsy Foundation West Virginia	The LCC Foundation
Epilepsy Foundation Greater Orange County	Epilepsy Services of New Jersey	The MED13L Foundation
Epilepsy Foundation Indiana	Epilepsy Wellness Advocates	The Rory Belle Foundation
Epilepsy Foundation Iowa	Fairfax County Parents Association	The Sturge-Weber Foundation
Epilepsy Foundation Long Island	FAM177A1 Research Fund	Tough Genes
Epilepsy Foundation Los Angeles	Foundation for Angelman Syndrome Therapeutics	TSC Alliance
Epilepsy Foundation Louisiana	GABA-A Alliance	Valley Children's Healthcare
Epilepsy Foundation Maryland	Glut1 Deficiency Foundation	YWHAG Research Foundation
Epilepsy Foundation Metro D.C.	GNB1 Advocacy Group, Inc	
Epilepsy Foundation Mississippi	GRIN2B Foundation	
Epilepsy Foundation Montana	HardyHandz Foundation	
	Henry's Heroes Foundation	

FOR MORE INFORMATION, CONTACT:

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