NATIONAL PLAN FOR EPILEPSY ACT

RECOMMENDATION

Co-sponsor and pass the **National Plan for Epilepsy Act (S. 494 and H.R. 1189)** 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

Sources: 1. Hesdorffer DC, Logroscino G, Benn EK, Katri N, Cascino G, Hauser WA. Estimating risk for developing epilepsy: a population-based study in Rochester, Minnesota. Neurology. 2011 Jan 4;76(1):23-7. doi: 10.1212/WNL.0b013e318204a36a. PMID: 21205691; PMCID: PMC3032191. 2. Zack MM, Kobau R. National and state estimates of the numbers of adults and children with active epilepsy — United States, 2015. MMWR. 2017;66:821–825. DOI: 10.15585/mmwr.mm6631a1. 3. Moura LMVR, Karakis I, Zack MM, Tian N, Kobau R, Howard D. Drivers of US health care spending for persons with seizures and/or epilepsies, 2010-2018. Epilepsia. 2022 Aug;63(8):2144-2154. doi: 10.1111/epi.17305. Epub 2022 May 29. PMID: 35583854; PMCID: PMC10969856. 4. Chen Z, Brodie MJ, Liew D, Kwan P. Treatment Outcomes in Patients With Newly Diagnosed Epilepsy Treated With Established and New Antiepileptic Drugs: A 30-Year Longitudinal Cohort Study. JAMA Neurol. 2018 Mar 1;75(3):279-286. doi: 10.1001/jamaneurol.2017.3949. Erratum in: JAMA Neurol. 2018 Mar 1;75(3):384. doi: 10.1001/jamaneurol.2018.0018. PMID: 29279892; PMCID: PMC5885858. 5. Trinka E, Rainer LJ, Granbichler CA, Zimmermann G, Leitinger M. Mortality, and life expectancy in Epilepsy and Status epilepticus-current trends and future aspects. Front Epidemiol. 2023 Feb 23;3:1081757. doi: 10.3389/fepid.2023.1081757. PMID: 38455899; PMCID: PMC10910932.

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:

HR 1189 - House of Representatives:
Rep. Murphy, M.D. (NC-3)
McLean Piner, mclean.piner@mail.house.gov
Rep. Costa (CA-21)
Wade Roberge, wade.roberge@mail.house.gov

S 494 - Senate:
Sen. Schmitt (MO)
Peter Dudziak, Peter_Dudziak@schmitt.senate.gov
Sen. Klobuchar (MN)
Ruth McDonald, Ruth_McDonald@klobuchar.senate.gov

American Academy of Neurology
American Epilepsy Society
Angelman Syndrome Foundation
BAND Foundation
BDSRA Foundation
CACNA1A Foundation
Care and Cure Institute
CASK Gene Foundation
CFC International
Child Neurology Foundation
Coalition to Cure CHD2
COMBINEDBrain, Inc.
CSNK2A1 Foundation
CSNK2B Foundation
CTNNB1 Connect & Cure
Cure CLCN6, Inc.
CURE Epilepsy
Cure GABA-A Variants
CureSHANK
DEE-P Connections
Dravet Syndrome Foundation
Dup15q Alliance
Empowering Epilepsy
Epilepsies Action Network (EAN)
Epilepsy Advocacy Network
Epilepsy Agency of the Big Bend
Epilepsy Alliance America
Epilepsy Alliance Louisiana
Epilepsy Alliance North Carolina
Epilepsy Alliance Ohio
Epilepsy Association of Western and Central PA
Epilepsy Foundation Alabama
Epilepsy Foundation Alaska
Epilepsy Foundation Arizona
Epilepsy Foundation Arkansas
Epilepsy Foundation Central & South Texas
Epilepsy Foundation Eastern Pennsylvania
Epilepsy Foundation Florida
Epilepsy Foundation Greater Orange County
Epilepsy Foundation Indiana
Epilepsy Foundation Iowa
Epilepsy Foundation Long Island
Epilepsy Foundation Los Angeles
Epilepsy Foundation Louisiana
Epilepsy Foundation Maryland
Epilepsy Foundation Metro D.C.
Epilepsy Foundation Mississippi
Epilepsy Foundation Montana
Epilepsy Foundation Nebraska
Epilepsy Foundation Nevada
Epilepsy Foundation New England
Epilepsy Foundation New Jersey
Epilepsy Foundation New Mexico
Epilepsy Foundation North Carolina
Epilepsy Foundation North Dakota
Epilepsy Foundation of America
Epilepsy Foundation of Delaware
Epilepsy Foundation of Georgia
Epilepsy Foundation of Greater Chicago
Epilepsy Foundation of Greater Southern Illinois
Epilepsy Foundation of Hawaii
Epilepsy Foundation of Kentuckiana
Epilepsy Foundation of Michigan
Epilepsy Foundation of Minnesota
Epilepsy Foundation of Missouri and Kansas
Epilepsy Foundation of Northeastern New York, Inc.
Epilepsy Foundation of Northern California
Epilepsy Foundation of San Diego County
Epilepsy Foundation of Texas
Epilepsy Foundation of Virginia
Epilepsy Foundation of Wisconsin
Epilepsy Foundation Ohio
Epilepsy Foundation Oklahoma
Epilepsy Foundation Oregon
Epilepsy Foundation South Carolina
Epilepsy Foundation South Dakota
Epilepsy Foundation Utah
Epilepsy Foundation Washington
Epilepsy Foundation West Virginia
Epilepsy Learning Healthcare System
Epilepsy Services of New Jersey
Epilepsy Wellness Advocates
Fairfax County Parents Association
FAM177A1 Research Fund
Foundation for Angelman Syndrome Therapeutics
GABA-A Alliance
Glut1 Deficiency Foundation
GNB1 Advocacy Group, Inc.
GRIN2B Foundation
HardyHandz Foundation
Henry's Heroes Foundation
HNRNP Family Foundation
Hope for HIE
Hope for ULD
International Foundation for CDKL5 Research
International SCN8A Alliance
Joanna Sophia Foundation
Joey's Song
JoshProvides Epilepsy Assistance Foundation, Inc.
KCNQ2 Cure Alliance
KCNT1 Epilepsy Foundation
KIF1A
Koolen-de Vries Syndrome Foundation
KPTN Alliance
Lennox-Gastaut Syndrome (LGS) Foundation
Little Friends of Epilepsy
My Epilepsy Story
My Kool Brother
National Association of Epilepsy Centers
NORSE Institute
Partners Against Mortality in Epilepsy (PAME)
Paul's Purple Warriors
Pediatric Epilepsy Research Consortium
Pediatric Epilepsy Surgery Alliance
Phelan-McDermid Syndrome Foundation
PPP3CA Hope Foundation
Project CASK, Inc.
PURA Syndrome Foundation
PVNH Support & Awareness
Rare Epilepsy Network (REN) Coordinating Committee
RASopathies Network
Rea of Hope for a Cure Foundation
Ring14 USA
SLC6A1 Connect
SNAP25 Foundation
Sociedad Puertorriqueña de Epilepsia
South Carolina Advocates For Epilepsy
STXBP1 Foundation
SynGAP Reseach Fund, dba Cure SYNGAP1
SynGAP1 Foundation
Tatton Brown Rahman Syndrome Community
TBC1D24 Foundation
TESS Research Foundation
The Charlie Foundation for Ketogenic Therapies
The Danny Did Epilepsy Foundation
The Epilepsy Foundation of Metro NY
The FamilieSCN2A Foundation, Inc.
The LCC Foundation
The MED13L Foundation
The Rory Belle Foundation
The Sturge-Weber Foundation
Tough Genes
TSC Alliance
Valley Children's Healthcare
v-ATPase Alliance
What the EF
Young Adults with Epilepsy
YWHAG Research Foundation

FOR MORE INFORMATION, CONTACT:

Katie Collins, Vice President, G2G Consulting for Epilepsies Action Network at kcollins@g2gconsulting.com
Roxanne Yaghoubi, Senior Director, Federal Relations & Policy, Epilepsy Foundation of America at ryaghoubi@efa.org