

February 11, 2025

The Honorable Greg Murphy, M.D.
U.S. House of Representatives
407 Cannon House Office Building
Washington, DC 20515

The Honorable Jim Costa
U.S. House of Representatives
2081 Rayburn House Office Building
Washington, DC 20515

The Honorable Eric Schmitt
U.S. Senate
387 Russell Senate Office Building
Washington, DC 20510

The Honorable Amy Klobuchar
U.S. Senate
425 Dirksen Senate Office Building
Washington, DC 20510

Dear Representative Murphy, Representative Costa, Senator Schmitt, and Senator Klobuchar:

The undersigned organizations are writing to express our strong support for the National Plan for Epilepsy Act (H.R. 1189/S. 494). We appreciate your leadership on this critical piece of legislation, as well as initiating the Epilepsy Caucus and supporting so many other issues important to the epilepsy community.

The fourth most common neurological disorder, epilepsy is a disease or disorder of the brain that causes reoccurring and unprovoked seizures. It is a spectrum disease comprised of many diagnoses and an ever-growing number of rare epilepsies. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime¹ and nearly 3.4 million people including 456,000 children live with active epilepsy.² Epilepsy affects people of all ages and members of the military and veterans.

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. The annual economic health care burden of epilepsy or seizures is \$54 billion in the U.S.³ More than 30% of adults and 20-

¹ Hesdorffer DC, Logroscino G, Benn EK, et al. Estimating risk for developing epilepsy: a population-based study in Rochester, Minnesota. *Neurology*. 2011 Jan;76(1):23-27.

² Kobau R., Luncheon C., Greenlund, KJ. About 1.5 million community-dwelling US adults with active epilepsy reported uncontrolled seizures in the past 12 months, and seizure control varied by annual family income-National Health Interview Survey, United States 2021 and 2022. *Epilepsy Behav.* 2024 Aug; 157:109852.; Data Research Center. 2022 National Survey of Children's Health. Accessed February 2, <https://www.childhealthdata.org/browse/survey/results?q=10071&r=1>.

³ Moura, L.M.V.R., Karakis, I., Zack, M.M., Tian, N., Kobau, R. & Howard, D. (2022). Drivers of US health care spending for persons with seizures and/or epilepsies, 2010-2018. *Epilepsia*, 63(8), 2144-2154.

25% of children with epilepsy do not respond to current treatments.⁴ 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, and transportation. These issues are further complicated by barriers that people with epilepsy face in accessing care and participating in research.

Delayed recognition of seizures and inadequate treatment increase a person's risk of subsequent seizures, brain damage, disability, and sadly, even early death. Each year, 1 in 1,000 people with epilepsy die from Sudden Unexpected Death in Epilepsy (SUDEP).⁵ That number dramatically increases to 1 in 150 for people whose seizures are not controlled.⁶

The undersigned organizations representing the entire epilepsy community are united in believing that more significant investment and coordination by the federal government is needed to advance understanding of the epilepsies, develop more effective and targeted therapies, and establish new and transformative models of care in order to improve the lives of people with epilepsy and their families. We are grateful to you for your leadership of these goals and strongly support the National Plan for Epilepsy Act.

This bill, which is modeled on national plans for Alzheimer's and Parkinson's Disease that became law, would direct the Secretary of Health and Human Services (HHS) to establish and maintain a National Plan for Epilepsy. The plan would enable necessary federal coordination to ensure a unified approach that would facilitate better outcomes for people with epilepsy and prioritize development of more effective 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, their 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.

⁴ Kwan, P & Brodie, MJ. Early identification of refractory epilepsy. *N Engl J Med.* 2000;342(5):314-319.; Chen, Z., Brodie, M.J. et al. Treatment outcomes in patients with newly diagnosed epilepsy treated with established and new antiepileptic drugs: A 30-year longitudinal cohort study. *JAMA Neurol.* 2018;75(3):279-286.

⁵ Thurman D.J., Hesdorffer D.C., French J.A. (2014). Sudden unexpected death in epilepsy: Assessing the public health burden. *Epilepsia*, 55(10), 1479-1485.

⁶ Tomson, T., Nashef, L. & Ryvlin, P. (2008). Sudden unexpected death in epilepsy: Current knowledge and future directions. *The Lancet Neurology*, 7(11), 1021-1031.

Thank you again for your leadership of the National Plan for Epilepsy Act. The epilepsy community stands with you in support of this legislation. Should you have any questions, please do not hesitate to contact Katie Collins, Vice President, G2G Consulting, kcollins@g2gconsulting.com, or Roxanne Yaghoubi, Senior Director, Federal Relations & Policy, Epilepsy Foundation of America, ryaghoubi@efa.org.

Sincerely,

American Academy of Neurology

American Epilepsy Society

Angelman Syndrome Foundation

BDSRA Foundation

CACNA1A Foundation

Care and Cure Institute

CFC International

Child Neurology Foundation

Coalition to Cure CHD2

COMBINEDBrain, Inc.

CSNK2A1 Foundation

CSNK2B Foundation

Cure CLCN6, Inc.

CURE Epilepsy

CureSHANK

Developmental and Epileptic Encephalopathy Project/DEE-P Connections

Dravet Syndrome Foundation

Dup15q Alliance

Empowering Epilepsy

Epilepsies Action Network (EAN)

Epilepsy Advocacy Network

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 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
Hope for HIE
Hope for ULD
International Foundation for CDKL5 Research
International SCN8A Alliance
Joanna Sophia Foundation
JoshProvides Epilepsy Assistance Foundation, Inc.
KCNQ2 Cure Alliance
KCNT1 Epilepsy Foundation
Koolen-de Vries Syndrome Foundation
KPTN Alliance
Lennox-Gastaut Syndrome (LGS) Foundation
My Kool Brother
National Association of Epilepsy Centers
NORSE Institute
Partners Against Mortality in Epilepsy (PAME)
Pediatric Epilepsy Research Consortium
Phelan-McDermid Syndrome Foundation
PPP3CA Hope Foundation
PVNH Support & Awareness
Rare Epilepsy Network (REN) Coordinating Committee
Rea of Hope for a Cure Foundation
SNAP25 Foundation
Sociedad Puertorriqueña de Epilepsia
South Carolina Advocates for Epilepsy
STXBP1 Foundation
SynGAP Research Fund, dba curesyngap1
Tatton Brown Rahman Syndrome Community
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
YWHAG Research Foundation