September 29, 2026

The Honorable Mike Johnson
Speaker
U.S. House of Representatives
H-232, The Capitol
Washington, DC 20515

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
H-204, The Capitol
Washington, DC 20515

The Honorable John Thune
Majority Leader
U.S. Senate
S-230, The Capitol
Washington, DC 20510

The Honorable Chuck Schumer
Minority Leader
U.S. Senate
S-221, The Capitol
Washington, DC 20510

Dear Speaker Johnson, Minority Leader Jeffries, Majority Leader Thune, and Minority Leader Schumer:

The undersigned 190 organizations strongly support the National Plan for Epilepsy Act (S. 494/H.R. 1189) and **respectfully urge that Congress work together to pass this important, bipartisan, and zero cost legislation before the end of the year.** We were delighted to see the Senate pass S. 494 with amendment by unanimous consent on August 4th and the House Energy & Commerce Committee include H.R. 1189 in a September 15th hearing. This progress is monumental and shows Congress's widespread support of the legislation. Passage this year is necessary to improve the lives of the nearly 3.4 million Americans living with epilepsy, make care more affordable, reduce the significant economic burden of epilepsy on our country, and ensure healthcare providers have the knowledge and resources to deliver safer, faster, more effective, and cost-efficient care.

<u>About Epilepsy</u>
Epilepsy is a neurological disorder characterized by a predisposition of the brain to produce seizures, which are sudden abnormal bursts of electrical energy that disrupt brain functions. It can affect people at any age and is often lifelong. There are multiple types of seizures and many underlying causes of epilepsy, including an ever-growing number of rare epilepsies. Many of these are severe and medically complex, causing relentless seizures, developmental and cognitive impairment, loss of independence, significant caregiver burden, and, for some, life-threatening complications and premature death. In addition to seizures, epilepsy can also cause fatigue, learning and memory problems, mood or behavior changes, anxiety, or difficulty

concentrating, all of which can significantly impact daily life and the ability to work. Nearly 3.4 million Americans live with epilepsy.[1]

The Need for a National Plan for Epilepsy

The goals of the National Plan for Epilepsy align with Congress's commitment to making healthcare more accessible, effective, and affordable by closing gaps between scientific progress and clinical care and equipping physicians and other healthcare providers to deliver earlier diagnosis, more informed treatment, and better outcomes for people with epilepsy.

Despite scientific advances, epilepsy can still be profoundly disabling, dangerous, and financially devastating for individuals, families, and our country. For families caring for children or adults with severe epilepsy and lifelong disabilities, the impact can be even greater - requiring around-the-clock care and forcing caregivers to reduce work hours or leave the workforce altogether to keep their loved ones safe. Timely access to effective treatment is critical as uncontrolled seizures can lead to injury, permanent disability, and death. People with epilepsy face an increased risk of premature death from Sudden Unexpected Death in Epilepsy (SUDEP), prolonged seizures, injuries, drowning, and other epilepsy-related complications. The annual risk of SUDEP alone rises from about 1 in 1,000 people with epilepsy to as high as 1 in 150 when seizures are not controlled.[2]

The annual U.S. economic healthcare burden of epilepsy or seizures is $54 billion.[3] Lack of effective treatments for one third of all adults and a quarter of all children[4] adds to the burden and cost of epilepsy. Adults with epilepsy are more likely than those without epilepsy to struggle to pay medical bills, be

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[1] Kobau R, Luncheon C, Greenlund K. 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;157:109852. doi: https://doi.org/10.1016/j.yebeh.2024.109852.; Data Research Center. 2022 National Survey of Children's Health. Accessed February 2, 2024. https://www.childhealthdata.org/browse/survey/results?q=10071&r=1.

[2] Thurman, D.J., Hesdorffer, D.C. & French, J. (2014). Sudden unexpected death in epilepsy: Assessing the public health burden. *Epilepsia, 55(10),* 1479-1485. https://doi.org/10.1111/epi.12666. Keller, A.E., Whitney, R., et al. (2018). Incidence of sudden unexpected death in epilepsy in children is similar to adults. *Neurology, 91(2),* e107-e111. DOI: 10.1212/WNL.0000000000005762.

[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.

[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.

unable to afford prescription medications, and skip doses to save money.[5] Direct, epilepsy-related medical costs associated with uncontrolled epilepsy are 2 to 10 times higher than costs associated with controlled epilepsy.[6]

Epilepsy care also places significant demands on an already strained health care workforce. Epileptologists and other clinicians caring for people with epilepsy must manage complex, often lifelong conditions that require substantial care coordination, medication management, patient and family counseling, and collaboration across multiple specialties. At the same time, workforce shortages, administrative burdens, and reimbursement structures that do not always adequately recognize the complexity and ongoing nature of epilepsy care can limit healthcare providers' capacity to meet growing patient needs. Physicians and advanced practice providers often lack the tools to predict which treatment—if any—will work, who is most likely to experience harmful side effects, and/or how an individual's epilepsy will progress, making better research, data, and clinical guidance essential. Prior authorization requirements further strain practices by consuming valuable clinician and staff time and can delay patients' access to necessary medications, diagnostic testing, and treatments. Addressing these challenges is essential to ensuring that people with epilepsy have timely access to high-quality, specialized care.

The National Plan for Epilepsy Act, which is modeled on the successful national plans for Alzheimer's and Parkinson's Disease, would direct the Secretary of Health and Human Services (HHS) to establish and maintain a National Plan for Epilepsy. The Secretary would review existing epilepsy programs and provide recommendations to Congress, strengthening federal coordination and advancing a unified approach to the prevention, diagnosis, treatment, and ultimately, cure of epilepsy. This coordinated approach would help improve affordability and quality of life for people with epilepsy while reducing burdens on health care providers. To inform this work, the Secretary would regularly convene and solicit input from relevant federal agencies and key stakeholders, including patient advocates and subject matter experts.

Conclusion

The undersigned organizations are united in our support of the National Plan for Epilepsy Act and urge Congress work together to pass this important, bipartisan legislation before the end of the year. Should you have any

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[5] Tian, N., Kobau, R., Zack, M.M., & Greenlund, K.J. Barriers to and disparities in access to healthcare among adults ≥ 18 years with epilepsy – United States, 2015 and 2017. Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report. May 27, 2022; 71(21): 697-702.

[6] Begley, C.E. & Durgin, T.L. (2015). The direct cost of epilepsy to the United States: A systematic review of the estimates. *Epilepsia, 56*(9), 1376-87. Retrieved from https://onlinelibrary.wiley.com/doi/full/10.1111/epi.13084.

questions, please do not hesitate to contact Roxanne Yaghoubi, Senior Director, Federal Relations & Policy, Epilepsy Foundation of America, ryaghoubi@efa.org or Katie Collins, Vice President, G2G Consulting, kcollins@g2gconsulting.com.

Sincerely,

16p11.2 Genetic Foundation
Alternating Hemiplegia of Childhood Foundation
American Academy of Neurology (AAN)
American Association on Health and Disability
American Brain Coalition (ABC)
American Clinical Neurophysiology Society (ACNS)
American Epilepsy Society (AES)
American Pharmacists Association (APhA)
Angelman Syndrome Foundation
ASXL Rare Research Endowment Foundation
Autism Science Foundation
BAND Foundation
BDSRA Foundation
CACNA1A Foundation
Care & Cure Institute
CASK Gene Foundation
CASK Warriors Foundation
CFC International
CHAMP1 Research Foundation
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
CureGRIN Foundation
Cure NDD
CureSHANK
CURE SYNGAP1
Developmental and Epileptic Encephalopathy Project/DEE-P Connections
DLG4 SHINE Foundation
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 Center of Northwest Ohio
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 Colorado & Wyoming
Epilepsy Foundation of Connecticut
Epilepsy Foundation of Delaware
Epilepsy Foundation of East Tennessee
Epilepsy Foundation of Georgia
Epilepsy Foundation of Greater Chicago
Epilepsy Foundation of Greater Southern Illinois
Epilepsy Foundation of Hawaii
Epilepsy Foundation of Idaho
Epilepsy Foundation of Kentuckiana
Epilepsy Foundation of Metropolitan New York
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 Southeast Tennessee
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 Reach Foundation
Epilepsy Services of New Jersey
Epilepsy Wellness Advocates
Fairfax County Parents Association
FAM177A1 Research Fund
FamilieSCN2A Foundation
Finding Hope for Frizzle (FRRS1L)
Foundation for Angelman Syndrome Therapeutics (FAST)
GABA-A Alliance
GLUT1 Deficiency Foundation
GNB1 Advocacy Group, Inc.
GRIN2B Foundation
HardyHandz Foundation
Henry's Heroes Foundation
Hidden Truths Project
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
Lakeshore Foundation
Landon's Legacy Foundation
Lennox-Gastaut Syndrome (LGS) Foundation
Little Friends of Epilepsy
MEF2C Family Foundation
My Epilepsy Story
My Kool Brother
National Association of Epilepsy Centers (NAEC)
National Health Council (NHC)
NORSE Institute
Ogden C.A.R.E.S
OPHN1 Foundation
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
Rare Remy Foundation for DHX30
RASopathies Network
Rea of Hope for a Cure Foundation
ReNU Syndrome United
Ring14 USA INC
Ring 20 USA
SCAMP5 Foundation
Schinzel-Giedion Syndrome Foundation
SETD1B Research Foundation
SLC6A1 Connect
SMC1A Foundation
SNAP25 Foundation
Sociedad Puertorriqueña de Epilepsia
South Carolina Advocates for Epilepsy
SSADH Association
STXBP1 Foundation
SynGAP Research Fund, dba curesyngap1
SynGAP1 Foundation
Tatton Brown Rahman Syndrome Community
TBC1D24 Foundation
TESS Research Foundation
The Charlie Foundation for Ketogenic Therapies

The Cute Syndrome Foundation
The Danny Did Epilepsy Foundation
The DESSH Foundation
The DNM1L Foundation
The Famliescn2A 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
ZTTK SON-Shine Foundation

CC: House Energy & Commerce Committee
Rep. Jim Costa (CA-21)
Rep. Greg Murphy, M.D. (NC-3)
Sen. Eric Schmitt (MO)
Sen. Amy Klobuchar (MN)