

September 8, 2025

The Honorable Susan Collins (ME)
Chair
Committee on Appropriations
U.S. Senate
Washington, DC 20510

The Honorable Patty Murray (WA)
Vice-Chair
Committee on Appropriations
U.S. Senate
Washington, DC 20510

The Honorable Tom Cole (OK-4)
Chair
Committee on Appropriations
U.S. House of Representatives
Washington, DC 20515

The Honorable Rosa DeLauro (CT-3)
Ranking Member
Committee on Appropriations
U.S. House of Representatives
Washington, DC 20515

Dear Chair Collins, Chair Cole, Vice Chair Murray, and Ranking Member DeLauro:

The undersigned epilepsy-related organizations thank you for your past support of research, public health, and health care programs that help increase understanding and treatment of the epilepsies as well as support people with the epilepsies in their day-to-day lives. As you work on the FY 2026 appropriations bills, we urge you to continue this commitment by providing robust funding as outlined below for programs at the Department of Health and Human Services, Department of Defense, and Department of Veterans Affairs that are vital for the epilepsy community.

For background, there are nearly 3.4 million people including 456,000 children and teenagers living with active epilepsy in the United States.¹ There are hundreds of epilepsies, which are disorders of the brain characterized by abnormal nerve cell signaling. This causes seizures, uncontrolled bursts of electrical activities that change sensations, behaviors, awareness, and muscle movements. Epilepsy is a complex spectrum disease that can affect infants, children, young adults, seniors, military service members, Veterans and anyone suffering from traumatic brain injury (TBI). The epilepsies are comprised of an ever-growing number of rare epilepsies.

Due to this vast spectrum, there are many different types of seizures and varying levels of seizure control. Furthermore, the challenges of the epilepsies extend far beyond seizures to include cognitive, behavioral, and psychiatric mood disorders, as well as mobility, gastrointestinal, and respiratory issues.² People with epilepsy have a three times higher risk of early death than the general population, and each year, more than 6,000 people die from causes including Sudden Unexpected Death in Epilepsy (SUDEP), continuous seizures, and accidents.³ Every year, 1 in 1,000 people with epilepsy die from SUDEP and this

¹ Kobau R., Luncheon C., Greenlund K. (2024). 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.* 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 Ho, N.T., Kroner, B., et al. (2018). Comorbidities of rare epilepsies: Results from the rare epilepsy network. *The Journal of Pediatrics*, 203, 249-258. <https://doi.org/10.1016/j.jpeds.2018.07.055>.

³ Devinsky, O., Spruill, T., Thurman, D., & Friedman, D. (2016). Recognizing and preventing epilepsy-related mortality: A call for action. *Neurology*, 86(8), 779-786. <https://doi.org/10.1212/WNL.0000000000002253>.

number increases drastically to 1 in 150 for people whose seizures are not controlled by treatment.⁴ As SUDEP is prevalent in children and young adults, it is second to only stroke as the leading cause of potential years of life lost.⁵ Mortality rates with epilepsy as an underlying or contributing cause of death are higher in older age groups, among males (than females), among non-Hispanic Black or non-Hispanic American Indian/Alaska Native persons (than non-Hispanic White persons), among those living in the West and Midwest of the U.S. (compared with the Northeast), and in non-metro counties (compared to urban regions).⁶

Despite major advances in science over the past several decades, the overall impact on the lives of people living with epilepsy remains largely unchanged. Epilepsy and/or seizures impose an annual economic healthcare burden of at least \$54 Billion in the U.S.⁷ A vast number of people with epilepsy—more than 30% of adults and 20-25% of children—don't respond to treatment.⁸ This number is much higher for people with rare, genetic epilepsies. Death from SUDEP and other epilepsy-related causes remains a constant risk for people with the epilepsies. There has been no decrease in premature deaths, especially among children with epilepsies. There are no biomarkers for the vast majority of the epilepsies and few effective technologies exist to track real-time data from patients living with epilepsy. Therefore, clinicians are unable to predict which drugs will be effective for a given patient, which side effects a patient is likely to experience when taking a drug, or what a patient's future might look like.

To continue and expedite progress towards better understanding, treating, and supporting people with the epilepsies, we urge the following investments in the FY 2026 federal budget:

Subcommittee on Labor, Health and Human Services, Education and Related Agencies

- **\$12 Million for the Centers for Disease Control & Prevention (CDC)'s National Center for Chronic Disease Prevention and Health Promotion's Epilepsy program.** This program provides national data on epilepsy burden and prevalence, supports seizure recognition and seizure first aid training for key parts of the community like school personnel and law enforcement; and helps train primary care and behavioral health providers about epilepsy to improve health outcomes particularly in rural and underserved communities. It also funds key epidemiological studies that have profound impact on our understanding of epilepsy mortality and its prevention. As the *only* public health program specifically related to epilepsy with a national scope and community programs that examine, test, and share strategies to improve the lives of

⁴ 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](https://doi.org/10.1212/WNL.0000000000005762).

⁵ *Ibid.*

⁶ Tian, N., Kobau, R., Friedman, D., Liu, Y., Eke, P., & Greenlund, K.J. (2024). Mortality and mortality disparities among people with epilepsy in the United States, 2011-2021. *Epilepsy Behav.*, 155, 109770. [doi:10.1016/j.yebeh.2024.109770](https://doi.org/10.1016/j.yebeh.2024.109770).

⁷ Moura, L.M.V.R., Karakis, I., Zack, M.M., Tian, N., Kobau, R., & Howard, D. (2022). Drivers of U.S. health care spending for persons with seizures and/or epilepsies, 2010–2018. *Epilepsia*, 63(8), 2144–2154. [doi:10.1111/epi.17305](https://doi.org/10.1111/epi.17305).

⁸ Chen, Z. et al. (2018). Treatment Outcomes in Patients with Newly Diagnosed Epilepsy Treated With Established and New Antiepileptic Drugs A 30-Year Longitudinal Cohort Study. *JAMA Neurology*, 75(3), 279-286. [doi: 10.1001/jamaneurol.2017.3949](https://doi.org/10.1001/jamaneurol.2017.3949).

people with epilepsy and their families, it is vital that funding for this program continue. *In FY 2025, the CDC Epilepsy Program was funded at \$11.5 Million.*

- **\$1 Million for the National Institutes of Health (NIH) to establish a Pediatric-Onset Epilepsies Network.** Supporting establishment of a National Plan for Epilepsy and creating an infrastructure to understand the pediatric diagnoses by cause and coordinate research across institutions is critical to maximize the potential for scientific progress in the era of precision medicine. This network would create a collaborative, multidisciplinary research model to enroll patients from many hospitals in the same system to enable cooperative research studies, accelerate the development of knowledge about the epilepsies, and rapidly advance therapeutic options and their implementation to improve treatments and healthcare outcomes. *In FY 2024, under the heading of 'Pediatric-Onset Epilepsies Research,' NIH was encouraged to continue to enable cooperative research studies, accelerate the development of knowledge about epilepsies, and rapidly advance therapeutic options and their implementation to improve treatments and healthcare outcomes. In FY 2025, NIH was directed to provide a report on key findings and planned actions, however the report was not adopted as part of the FY 2025 Continuing Resolution.*
- **At least \$51.3 Billion for the National Institutes of Health (NIH).** Within NIH, several institutes fund epilepsy-related research which has helped better understand, diagnose and treat epilepsy—perhaps most notably, the National Institute of Neurological Disorders and Stroke (NINDS). In FY 2022, the NIH funded about \$226 million in epilepsy research—but the epilepsy community is *very* concerned with how the significant cuts to the NIH's funding in FY 2024 and FY 2025 are starting to impede epilepsy research and progress. In FY 2024, the NINDS received a 4.4% decrease in appropriations which forced the payline being reduced from the 14th percentile in 2023 to the 11th percentile in 2024. There are many critical epilepsy-related initiatives at the NIH including the Epilepsy Therapy Screening Program, Centers Without Walls (CWoW) for Collaborative Research in the Epilepsies, the Interagency Collaborative to Advance Research in Epilepsy (ICARE), and Curing the Epilepsies. We support the continuation of Section 224 of the FY 2024 Appropriations Act in the final appropriations bills since it prohibits changes to NIH Facilities and Administrative cost reimbursements. The proposal to cap and cut indirect costs would have immediate and harmful impacts on research. We oppose efforts to restructure the NIH through the appropriations process because it lacks transparency and does not allow for stakeholder input, data review, and congressional hearings. *In FY 2025, the NIH was funded at \$48 Billion.*
- **At least \$680 Million for the BRAIN Initiative.** The BRAIN Initiative brings together federal and non-federal partners with a common goal of accelerating the development of innovative neurotechnologies and producing a revolutionary new dynamic picture of the brain that shows how individual cells and complex neural circuits interact in both time and space. Several projects relevant to epilepsy are funded through the BRAIN Initiative that aim to better understand, measure, and monitor how the brain generates neural activity and are working to develop new technologies and devices to measure brain activity, predict seizure onset, and deliver therapeutic stimulation to limit seizure activity. For example, in current work supported by the BRAIN Initiative, investigators are using an implantable brain device to treat Lennox- Gastaut Syndrome, a devastating form of childhood onset epilepsy characterized by cognitive dysfunction and very frequent generalized onset seizures that often lead to injury. *In FY 2025, the BRAIN Initiative was funded at \$321 Million—\$359 Million less than the \$680 Million it received in FY 2023.*

- **\$164 Million for the CDC's Safe Motherhood and Infant Health Program in order to support and help expand the Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry.** A joint collaboration of the CDC and National Institutes of Health (NIH), this case registry increases the understanding of the prevalence, causes, and risk factors for various infant, childhood, and young adult deaths up to age 20 including from SUDEP. Expanded investment will enable more states to participate, yielding robust data essential to understanding the true burden of epilepsy mortality, its risk factors, and how to prevent future deaths. *In FY 2024, the Safe Motherhood and Infant Health Program was funded at \$110.5 Million.*
- **\$5 Million for the CDC's National Neurological Conditions System (NNCSS) demonstration projects plus \$5 million to expand the system to the epilepsies.** The NNCSS is an integrated system that uses state-of-the-art data sources, tools, and analytic methods to track the epidemiology of neurological conditions to increase understanding and catalyze research into causes, diagnosis, and treatment. Congress authorized the NNCSS in 2016 through the 21st Century Cures Act and funding was first appropriated for the NNCSS in FY 2019. Since then, the CDC has been working on demonstration projects for Multiple Sclerosis and Parkinson's Disease with the plans of adding other neurological conditions. There is significant need for ongoing and improved data and surveillance related to the epilepsies and the NNCSS could be an integral part of the solution. *In FY 2025, NNCSS was funded at \$5 Million.*

Subcommittee on Defense

The Congressionally Directed Medical Research Programs (CDMRP) originated in 1992 to investigate new biomedical research approaches for conditions disproportionately affecting military members, veterans, their families, and the public. As part of the FY 25 Continuing Resolution, CDMRP funding was cut by \$859 million or 57%. This cut was not done equally across the board, and all three of the epilepsy-related research programs saw their funding completely eliminated. While some conditions are now eligible to compete for peer-reviewed funding, the significant funding decrease and lack of funding dedicated to specific conditions will impede our understanding of epilepsy and disrupt the health and readiness of our warfighters. In FY 2026, we ask that funding for the epilepsy-related programs within the CDMRP be restored to:

- **\$12 million for the Epilepsy Research Program (ERP).** Service members and veterans can acquire epilepsy through a variety of means but often times, Traumatic Brain Injury (TBI) causes seizures to start happening—leading to a diagnosis of Post-Traumatic Epilepsy (PTE). The ERP was initiated in 2015 to better understand the genesis and progression of PTE in order to better treat and prevent it. Focus areas of the ERP that require robust investment include identifying biomarkers or mechanisms of PTE; epidemiological characterization of PTE following TBI; and longitudinal studies of the evolution of PTE and understanding and improving the quality of life of individuals with PTE, their families, and/or caregivers.
- **\$10 Million for the Tuberous Sclerosis Complex (TSC) Program.** Since FY2002, the TSC Research Program has supported projects that pave the way to treatments for individuals with TSC and related disorders like epilepsy, autism, cancer and diabetes. A hallmark achievement is research that examined the role TSC genes play in cell growth and proliferation – specifically in controlling the mammalian Target of Rapamycin (mTOR) signaling pathway in cells – which rapidly led to clinical trials, resulting in the first FDA-approved drug specifically to treat TSC. Continued funding

is essential to accelerate the development of new therapeutic agents, understand the biology underlying the wide variation in severity among individuals with TSC, advance gene therapy, identify potential biomarkers that can be applied to newborn screening and develop tools to translate basic scientific discoveries into clinical treatments.

- **\$175 million for the Traumatic Brain Injury (TBI) and Psychological Health Research (TBIPHRP) Program.** The TBIPHRP supports research focused on understanding of risk, protective, and biological factors contributing to an individual's vulnerability to, response to, and long-term outcomes of psychological health conditions and/or TBI, and factors that influence treatment engagement, follow-up care, and improvement of long-term outcomes for those affected by these conditions.

Subcommittee on Military Construction, Veterans Affairs and Related Agencies

- **At least \$29.2 Million for the VA Epilepsy Centers of Excellence (ECoE).** Recognizing the need, Congress passed a law in 2008 directing the Secretary of Veterans Affairs (VA) to establish ECoE within the VA. There are now 4 regions with 19 VA hospitals that provide specialty care and state-of-the-art diagnostic and therapeutic services to our nation's veterans with epilepsy and seizure disorders. In FY 2024, the Veteran's Health Administration (VHA) treated 90,073 unique veterans with epilepsy or seizures. To reach the over 404,000 Veterans with definite/probable epilepsy and seizures receiving care in VA, there is an acute need to expand access to specialized epilepsy care. With a funding increase in FY 2023, the VA ECoEs were able to welcome two new sites in Birmingham, Alabama and Chicago, Illinois. With even more investment, the VA ECoEs could continue growing the Tele-EEG program, providing remote monitoring and reaching more veterans, particularly those in rural and underserved communities. *In FY 2025, the VA ECoE was funded at \$26.8 Million.*

Thank you for the opportunity to provide input on research and programs that are critical to the epilepsy community and effective, cost-efficient uses of federal spending as Congress works on the FY 2026 budget. For additional information or if you have any questions, please contact Laura Weidner at lweidner@efa.org or Katie Collins at kcollins@G2Gconsulting.com, or any of our community members.

Sincerely,

National Organizations

Alliance to Cure Cavernous Malformation
Alternating Hemiplegia of Childhood Foundation
American Clinical Neurophysiology Society
Angels of Epilepsy, Inc.
ASXL Rare Research Endowment Foundation
BDSRA Foundation
Bubba's Light
CACNA1A Foundation
CFC International
Child Neurology Foundation
Coalition to Cure CHD2
CRELD1 Warriors
Cri du Chat Research Foundation

CSNK2A1 Foundation
CSNK2B Foundation
CTNNB1 Connect & Cure
CURE Epilepsy
Cure GABA-A
Cure KCNH1 Foundation
CureSHANK
Danny Did Foundation
Developmental and Epileptic Encephalopathy Project (DEE-P Connections)
Dravet Syndrome Foundation
Dup15q Alliance
DYNC1H1 Association
Empowering Epilepsy
Epilepsies Action Network (EAN)
Epilepsy Alliance America
Epilepsy Foundation of America
Epilepsy Leadership Council (ELC)
Epilepsy Services Foundation, Inc.
FACES – Finding a Cure for Epilepsy and Seizures
FAM177A1 RESEARCH FUND
Finding Hope for FRRS1L
GABA-A Alliance
Glut1 Deficiency Foundation
GNB1 Advocacy Group, Inc.
GRIN2B Foundation
Hidden Truths Project
HNRNP Family Foundation
Hope for HIE
Hope for Hypothalamic Hamartomas
Hope for ULD
International Foundation for CDKL5 Research
International SCN8A Alliance
Jordan's Guardian Angels
JoshProvides Epilepsy Assistance Foundation, Inc.
KARES Foundation
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
NR2F1 Foundation
Partners Against Mortality in Epilepsy (PAME)
PCDH19 Alliance
Pediatric Epilepsy Research Consortium
Pediatric Epilepsy Surgery Alliance

Phelan-McDermid Syndrome Foundation
PPP3CA Hope Foundation
PRISMS
Project 8p Foundation
Project CASK
PURA Syndrome Foundation
Purple Peace 4 Epilepsy
Rare Epilepsy Network (REN) Coordinating Committee
RARE Hope
Ring14 USA
SLC6A1 Connect
SMC1A Foundation
STXBP1 Foundation
SynGAP Research Fund
TESS Research Foundation for SLC13A5 Epilepsy
The Anita Kaufmann Foundation
The Baker-Gordon Syndrome Foundation
The Charlie Foundation
The Cute Syndrome Foundation
The FamilieSCN2A Foundation
The LCC Foundation
The MED13L Foundation
The Rory Belle Foundation
The SPATA Foundation
The Sturge-Weber Foundation
THG1L
TSC Alliance
v-ATPase Alliance
Yellow for Yiannis IRF2BPL Foundation
YWHAG Research Foundation

Regional, State, Or Local Organizations

Cure DHDDS
Empowering People's Independence
EPIC Family of Human Services Agencies
Epilepsy Agency of the Big Bend
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 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 Middle Tennessee
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 Northeastern New York
Epilepsy Foundation of Colorado & Wyoming
Epilepsy Foundation of Connecticut
Epilepsy Foundation of Delaware
Epilepsy Foundation of East TN
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 Michigan
Epilepsy Foundation of Minnesota
Epilepsy Foundation of Missouri and Kansas
Epilepsy Foundation of Northern California
Epilepsy Foundation of Southeast Tennessee
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 Texas - Houston/Dallas-Fort Worth/West Texas
Epilepsy Foundation Utah
Epilepsy Foundation Washington
Epilepsy Foundation West Virginia
Epilepsy Information Service of Wake Forest School of Medicine
Epilepsy Reach Foundation
Epilepsy Support Network of Orange County
Families of SCAMP5
South Carolina Advocates For Epilepsy

The Epilepsy Center of Northwest Ohio
The Epilepsy Foundation of Metro New York

CC:

Sen. Tammy Baldwin (WI), Ranking Member, Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Sen. John Boozman (AR), Chair, Senate Appropriations Subcommittee on Military Construction, Veterans Affairs and Related Agencies

Sen. Shelley Moore Capito (WV), Chair, Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Sen. Chris Coons (DE), Ranking Member, Senate Appropriations Subcommittee on Defense

Sen. Mitch McConnell (KY), Chair, Senate Appropriations Subcommittee on Defense

Sen. Jon Ossoff (GA), Ranking Member, Senate Appropriations Subcommittee on Military Construction, Veterans Affairs and Related Agencies

Rep. Robert Aderholt (AL-4), Chair, House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Rep. Ken Calvert (CA-41), Chair, House Appropriations Subcommittee on Defense

Rep. John Carter (TX-31), Chair, House Appropriations Subcommittee on Military Construction, Veterans Affairs and Related Agencies

Rep. Betty McCollum (MN-4), Ranking Member, House Appropriations Subcommittee on Defense

Rep. Debbie Wasserman Schultz (FL-25), Ranking Member, House Appropriations Subcommittee on Military Construction, Veterans Affairs and Related Agencies