

November 22, 2024

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

The Honorable Susan Collins (ME)
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 Murray, Chair Cole, Vice Chair Collins, 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 complete work on the FY 2025 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 Epilepsy can also be fatal. Sudden Unexpected Death in Epilepsy (SUDEP) is the sudden, unexpected death of someone with epilepsy, who was otherwise healthy. Every year, 1 in 1,000 people with epilepsy die from SUDEP and this number increases drastically to 1 in 150 for people whose seizures are not

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](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>.

controlled by treatment.³ Alarming, the mortality rate increased 47% from 2005 to 2014 overall and this increase was about two times higher among the non-Hispanic Black population.⁴

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.⁵ A vast number of people with epilepsy—more than 30% of adults and 20-25% of children—don't respond to treatment.⁶ 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 final FY 2025 federal budget:

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

- **\$12.5 Million for the Centers for Disease Control & Prevention (CDC)'s National Center for Chronic Disease Prevention and Health Promotion's Epilepsy program and report language encouraging the CDC to enhance surveillance and epidemiologic studies of the epilepsies.** The CDC Epilepsy program is the only public health program specifically related to epilepsy with a national scope and community programs. This funding supports seizure recognition and seizure first aid training for key parts of the community like school personnel; training primary care and behavioral health providers about epilepsy to improve health outcomes particularly in rural and underserved communities; and addressing health disparities by providing mini-grants to increase awareness and connect people with epilepsy to services, as well as partnerships with medical associations representing and serving racial and ethnic minorities. *In FY 2024, the CDC Epilepsy Program was funded at \$11.5 Million.*
- **\$10 Million for the National Institutes of Health (NIH) to establish a Pediatric-Onset Epilepsies Network.** Creating an infrastructure to understand the pediatric diagnoses by cause and coordinate research across institutions is critical to maximize the potential for scientific progress

³ 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).

⁴ Greenlund, S. F., Croft, J. B., & Kobau, R. (2017). Epilepsy by the Numbers: Epilepsy deaths by age, race/ethnicity, and gender in the United States significantly increased from 2005 to 2014. *Epilepsy & behavior : E&B*, 69, 28–30. <https://doi.org/10.1016/j.yebeh.2017.01.016>.

⁵ 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.

⁶ 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.

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.*

- **At least \$48.9 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 about the significant cut to the NIH's funding in FY 2024 and the negative impact that will have on epilepsy research and progress. 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. ARPA-H is an exciting, promising new entity but for the NIH and ARPA-H to be maximally successful, any funding for ARPA-H should supplement, not supplant the essential foundational investment in the NIH. *In FY 2024, the NIH was funded at \$47.081 Billion—which was a \$378 Million cut from the previous year.*
- **At least \$680.4 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. One such activity is the work around Electrocortical Stimulation (ECS), which has been used for functional mapping for decades to identify areas of the brain that are critical for speech and language prior to epilepsy or tumor surgery. It is also used to modulate neural activity in directly treating epilepsy or pain. *In FY 2024, the BRAIN Initiative was funded at \$402 Million—which was a \$278 Million cut from the previous year.*
- **\$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 2024, NNCSS was funded at \$5 Million and within 120 days, required the CDC to produce a report on the current gaps in surveillance data of people living with epilepsy and on the feasibility, cost, and timing of potentially adding epilepsies to the NNCSS.*

- **\$116.5 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. More investment will enable more states to participate, yielding more data and understanding—informed strategies to prevent future deaths. *In FY 2024, the Safe Motherhood and Infant Health Program was funded at \$110.5 Million.*

Subcommittee on Defense

Within the Congressionally Directed Medical Research Programs (CDMRPs):

- **\$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.
- **\$8 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.

In FY 2024, the Epilepsy Research Program received \$12 Million, the TSC Program received \$8 Million and the TBI and Psychological Health Program received \$175 Million.

Subcommittee on Military Construction, Veterans Affairs and Related Agencies

- **At least \$26.8 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 2023, the VA ECoE treated 86,414 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; continue growing the VA Mind Brain Program to train clinicians in neurobehavioral therapy to deliver whole-person care for veterans dealing with PNES and other neurological disorders; and open additional sites to reach more veterans with epilepsy. *In FY 2024, the VA ECoE was funded at \$25 Million.*

Thank you for the opportunity to provide input on research and programs that are critical to the epilepsy community and effective, cost-efficient use of federal spending as Congress completes work on the FY 2025 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,

Alliance to Cure Cavernous Malformation
American Clinical Neurophysiology Society
ASXL Rare Research Endowment Foundation
BDSRA Foundation
Bubba's Light
CACNA1A 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 Association of Western and Central PA
Epilepsy Foundation of America
Epilepsy Leadership Council (ELC)
Epilepsy Reach Foundation
Epilepsy Services Foundation, Inc.

Epilepsy Support Network of Orange County
FAM177A1 RESEARCH FUND
Finding Hope for FRRS1L
GABA-A Alliance
Glut1 Deficiency Foundation
GRIN2B Foundation
HNRNP Family Foundation
Hope for HIE
Hope for Hypothalamic Hamartomas
International Foundation for CDKL5 Research
International SCN8A Alliance
Jordan's Guardian Angels
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
NORSE Institute
NR2F1 Foundation
PCDH19 Alliance
Pediatric Epilepsy Research Consortium
Pediatric Epilepsy Surgery Alliance
Phelan-McDermid Syndrome Foundation
PPP3CA Hope Foundation
PURA Syndrome Foundation
Purple Peace 4 Epilepsy
Rare Epilepsy Network (REN) Coordinating Committee
Ring14 USA
SLC6A1 Connect
SMC1A Foundation
South Carolina Advocates For Epilepsy
STXBP1 Foundation
SynGAP Research Fund
TESS Research Foundation for SLC13A5 Epilepsy
The Anita Kaufmann Foundation
The Baker Gordon Syndrome Foundation
The Charlie Foundation for Ketogenic Therapies
The Cute Syndrome Foundation
The FamilieSCN2A 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

CC:

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

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

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

Sen. Kyrsten Sinema (AZ), Chair, Senate Appropriations Subcommittee on Military Construction, Veterans Affairs and Related Agencies

Sen. Jon Tester (MT), Chair, Senate Appropriations Subcommittee on Defense

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