

November 13, 2023

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 Kay Granger (TX-12)
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 Granger, 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 work to finalize the FY 2024 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 3.4 million people including 470,000 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 Zack, M.M. & Kobau, R. (2017). National and State Estimates of the Numbers of Adults and Children with Active Epilepsy — United States, 2015. *Morbidity and Mortality Weekly Report (MMWR)*, 66(31), 821-825. <http://dx.doi.org/10.15585/mmwr.mm6631a1>.

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 reiterate our recommendations outlined in our letter from May 16, 2023, and urge the following investments in the final FY 2024 federal budget:

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

- **At least \$11.5 Million for the Centers for Disease Control & Prevention (CDC)'s National Center for Chronic Disease Prevention and Health Promotion's Epilepsy program.** 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 2023, the House recommended \$13 Million for this program and the Senate recommended \$12.5 Million—with \$11.5 Million being included in the omnibus.*
- **\$5 Million for the CDC's National Neurological Conditions Surveillance System (NNCSS) and language included in the Senate LHHS bill for the CDC to report to the Committee within 120**

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.

days of enactment on current gaps in surveillance data of people living with epilepsies and on the feasibility, cost, and timing of case reporting epilepsy through the addition of the disease to the NNCSS. For context, 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 2023, NNCSS was funded at \$5 Million but did not specify the epilepsies.*

- **At least \$110.5 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—informing strategies to prevent future deaths. *In FY 2023, the House recommended \$143 Million and the Senate recommended \$164 Million—with \$108 Million being included in the omnibus.*
- **Language included in the Senate LHHS bill encouraging the NIH 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, as well as for NINDS to prepare and submit a report on progress and incorporate key findings and planned actions resulting from convenings of the Curing the Epilepsies conference to better facilitate implementation of translational research.** This Consortium would be a first step toward establishing a generalizable proof of principle mechanism 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 patient outcomes. Both NINDS and NCATS leadership have been consulted on this Consortium. *This is a new request for FY 24.*
- **Increased investment in the NIH, rejecting proposed cuts to this vital agency.** The NIH is the largest government funder of epilepsy-related research and in FY 2022, invested \$226 million in epilepsy-related research. The NIH supports several critical projects and programs including NINDS Centers without Walls, Curing the Epilepsies, the HEAL Initiative, the recently announced Community-Engaged Health Equity Research in Neuroscience Initiative and the BRAIN Initiative. Cuts to the NIH would completely stifle our progress in understanding and better treating the epilepsies.

Subcommittee on Defense

- **At least \$12 Million for the Epilepsy Research Program, \$175 Million for the Traumatic Brain Injury and Psychological Health Research Program and at least \$10 Million for the Tuberculous Sclerosis Complex (TSC) Program, all within the Department of Defense’s Congressionally Directed Medical Research Programs (CDMRP).** Veterans can acquire epilepsy and seizure disorders through a variety of means. Traumatic Brain Injury (TBI)— the leading form of injury or

head trauma in service people, can cause seizures to start happening, leading to a diagnosis of Post-Traumatic Epilepsy (PTE). Tuberosus sclerosis complex (TSC) is a rare genetic disorder that causes non-malignant tumors in many different organs. The aspects of TSC that most strongly impact quality of life are generally associated with the brain: seizures, developmental delay, intellectual disability, and autism. These three important programs within the CDMRP fund research to better understand the incidence of PTE following a traumatic brain injury (TBI), understand TSC and in turn, improve patient care and outcomes. *In FY 2023, the Epilepsy Research Program received \$12 Million, the Traumatic Brain Injury and Psychological Health received \$175 Million and the TSC Research Program received \$8 Million.*

Subcommittee on Military Construction, Veterans Affairs and Related Agencies

- **At least \$21 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 2022, the VA ECoE treated 81,019 unique veterans with epilepsy or seizures and 6,383 with conversion disorder with 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. Access to electroencephalograms (EEGs), the gold standard test for diagnosing and treating epilepsy, is insufficient at many VA Hospitals and medical centers resulting in expensive community transfers. Additional funding will help further expand ECoE telehealth and Tele-EEG programs, extending the expertise of VA epileptologists to ensure that Veterans nationwide receive equitable care. *In FY 23, the VA ECoE received approximately \$19 Million.*

Once again, 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 works to complete the FY 2024 budget. For additional information or if you have any questions, please contact Laura Weidner at lweidner@efa.org or Liz Powell at lpowell@G2Gconsulting.com, or any of our community members.

Sincerely,

5p Minus Syndrome
Alliance to Cure Cavemous Malformation
BDSRA Foundation
BPAN Warriors
CACNA1A Foundation, Inc.
CFC International
Coalition to Cure CHD2
CSNK2A1 Foundation
CSNK2B Foundation
CURE Epilepsy
Cure KCNH1 Foundation
CureSHANK
Danny Did Foundation
DEE-P Connections
Dravet Syndrome Foundation

Dup15q Alliance
Empowering Epilepsy
Epilepsies Action Network
Epilepsy Alliance America
Epilepsy Foundation
FAM177A1 Research Fund
FamilieSCN2A Foundation
Glut1 Deficiency Foundation
GRIN2B Foundation
HardyHandz Foundation
Hope for HIE
Hope for Hypothalamic Hamartomas
International Foundation for CDKL5 Research
International SCN8A Alliance
KCNQ2 Cure Alliance
Koolen-de Vries Syndrome Foundation
Lennox-Gastaut Syndrome (LGS) Foundation
NORSE Institute
Pediatric Epilepsy Surgery Alliance
Phelan-McDermid Syndrome Foundation
PPP3CA Hope Foundation
Project 8p
Rare Epilepsy Network (REN) Coordinating Committee
RASopathies Network
Ring14 USA
Saving Grace Epilepsy Foundation
SHINE Syndrome Foundation
SNAP25 Foundation
South Carolina Advocates For Epilepsy (S.A.F.E.)
STXBP1 Foundation
SynGAP Research Fund
Tatton Brown Rahman Syndrome Community
TBC1D24 Foundation
TESS Research Foundation for SLC13A5 Epilepsy
The Charlie Foundation
The Cute Syndrome Foundation
The SPATA Foundation
TSC Alliance
When The Trumpet Sounds

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. 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