Dear President Biden:

As a community of clinicians, researchers, and thought leaders collaborating on many fronts alongside people with the epilepsies, family members, caregivers, and advocates, to improve epilepsy healthcare and outcomes, we respectfully request increased federal investment for research into the epilepsies, as part of your FY 2025 budget proposal. Collectively, the epilepsies are among the most common conditions affecting the brain and range in impact from profoundly debilitating to manageable with therapy. More significant government investment is needed to advance understanding of these various epilepsies, develop more effective and targeted therapies, and establish new, transformative models of patient care.

One in 26 people will develop a form of epilepsy in their lifetime and 3.4 million Americans currently live with active epilepsy, including 470,000 children and teenagers. The epilepsies can be deadly, with one out of every 1,000 people dying from sudden unexpected death in epilepsy (SUDEP). Delayed recognition of seizures and inadequate or delayed treatment increases a person’s risk of subsequent seizures, brain damage, disability, and death. Moreover, the epilepsies that lack a definitive biological cause are some of the most burdensome neurological disorders in the US, based on a recent survey.

Epilepsy is a spectrum disease that affects infants, children, young people, working adults, seniors, wounded warfighters, veterans, and persons impacted by traumatic brain injury. At the fundamental level, epilepsies are disorders of the brain characterized by abnormal nerve cell signaling. This causes seizures, which are driven by uncontrolled bursts of electrical activity that change sensations, behaviors, awareness, and muscle movements. The epilepsies consist of many diagnoses, including 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 health challenges of the epilepsies extend far beyond seizures to include cognitive, behavioral, and psychiatric mood disorders, as well as mobility, gastrointestinal, and respiratory issues.

We deeply appreciate your administration’s efforts to prioritize access to innovation and eliminate disparate health outcomes across disease states, especially for epilepsies and other neurological disorders. This is exemplified by the U.S. Department of Health and Human Services’ statements

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1 Hesdorffer et al., Estimating risk for developing epilepsy. A population-based study in Rochester, Minnesota Neurology 2011;76:23–27
5 https://www.sciencedirect.com/science/article/abs/pii/S0022347618309600
of support for the World Health Organization (WHO) Intersectoral Global Action Plan (IGAP) that was unanimously approved in May 2022. IGAP envisions a future where “brain health is valued and protected across the life course; neurological disorders are prevented, diagnosed and treated; premature mortality and morbidity are avoided; and people affected by neurological disorders have equal rights, opportunities, respect, and autonomy.” Your administration’s commitment to encouraging the development of breakthrough areas of medicine and transformative new therapies is commendable and can position the U.S. to realize the vision outlined in the IGAP. By investing strategically in epilepsy research, new therapies, and data surveillance through agencies such as ARPA-H, AHRQ, NIH, CDC, CMS, HRSA, FDA, DoD, and the VA, we can drive forward innovative approaches backed by robust science to elevate the level of healthcare for people with the epilepsies. Collaborative efforts across government will also be key to addressing the challenges related to increasing data tracking and translating data into solutions to help people with the epilepsies and save lives.

Recent research developments have pushed the envelope on multiple fronts. There is now a more robust understanding of the genetic underpinnings of a growing number of epilepsies. The use of rapid genome sequencing to diagnose genetic epilepsies has enabled precision medicine in the clinical care of infants with new-onset epilepsy, with implications for the wider population. Other notable breakthroughs in the last year include the development of a novel seizure mitigation therapy using stem cells that has progressed to clinical testing in people with epilepsy and the creation of an electronic medical record model to predict seizures and minimize invasive procedures.

Despite these advances and valuable support from the NIH over several decades, the everyday lives of people living with epilepsy remain largely unchanged. A vast number of patients (more than 30% of adults and 20-25% of children) don’t respond to treatment. This number is much higher for patients with rare, genetic epilepsies. For example, nearly 60% of tuberous sclerosis complex (TSC) patients with focal seizures exhibit drug resistance, while a small-scale study of patients with mutations of the SCN8A gene, demonstrated nearly 90% being unresponsive to treatment. There has been no decrease in premature deaths due to the epilepsies, especially

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6 https://iris.who.int/bitstream/handle/10665/371495/9789240076624-eng.pdf?sequence=1
7 http://epilepsygenetics.net/2023/05/10/five-novel-concepts-in-epilepsy-genetics-you-need-to-know-in-2023/
10 https://classic.clinicaltrials.gov/ct2/show/NCT05135091
12 Chen 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,
among children. There are no biomarkers for the vast majority of the epilepsies and few effective technologies to track real-time data from patients. Clinicians cannot predict drug efficacy, adverse side effects or long-term prognosis for any given patient. These intractable issues are further complicated by barriers that patients face in accessing care and participating in research. As the Chief of the Dell Children’s Comprehensive Epilepsy Center, Dr. Dave Clarke has stated, “There are still huge swaths of the population affected by the epilepsies that have no access, no voice and are unheard and not part of the research community. You have these vast differences in care.”

Funding for epilepsies research is disproportionately low compared to other health conditions, including other major neurological disorders. For context, $24.5 billion in direct U.S. healthcare spending is attributable to epilepsy or seizures, with the total healthcare burden being at least $54 billion. However, only half of a percent of the more than $42 billion the NIH spends on medical research each year, goes to epilepsy. This disparity has worsened since 2007 and cannot be explained by differences in the incidence or the overall impact of these diseases on Americans. Another significant challenge to understanding the epilepsies and developing new therapies is the lack of comprehensive, timely, representative data. The nation has insufficient surveillance data on the spectrum of the epilepsies, which could contribute to some of the disparity in funding that the epilepsies receive. The cause of the disease is unknown in about 50% of cases, according to the WHO. This underscores the need for federal investment to better understand the root causes of the disease and its progression, and facilitate translation of acquired knowledge into therapies that can improve the quality of life for those impacted by the epilepsies.

This past year, considerable progress was made in raising the profile of the epilepsies, including the establishment of the Congressional Epilepsy Caucus. Our community is united and continues to work collaboratively to improve the lives of people with the epilepsies. We welcome the opportunity to collaborate with government partners to facilitate better outcomes and prioritize development of more effective treatments. Given the high incidence of the epilepsies in the U.S., it is nearly impossible to pass through daily life without encountering persons directly impacted by these disorders. The epilepsies, therefore, merit greater, more strategic investment and attention proportionate to their high personal and economic costs. Moreover, research advances in brain health can catalyze breakthroughs across the wider spectrum of health, which aligns with the priorities of your administration, particularly in improving access to and the quality of care, promoting health equity, bettering understanding of rare diseases, and fostering an innovation ecosystem.

As part of your administration’s forthcoming budget proposal, we strongly encourage you to strategically augment federal investment in the epilepsies including: 1) programs with a high potential for translational payoff that can lead to better health outcomes for people living with the epilepsies and 2) existing funding streams at NIH, CDC, HRSA, VA and DoD to support research needed to further understand the epilepsies. Thank you for your consideration.

Sincerely,

M. Scott Copeland  
Co-Founder, Epilepsies Action Network  
Principal, RST Development, LLC  
CEO, Z-Pop Media, LLC

Jillian Copeland, MS  
Co-Founder, Epilepsies Action Network  
Founder, Main Street  
Owner & Operator, The Soulfull Café  
Founder, The Diener School

Joined By:

- Alliance to Cure Cavernous Malformation
- American Epilepsy Society (AES)
- Angelman Syndrome Foundation
- Association of University Centers on Disabilities
- ASXL Rare Research Endowment Foundation
- BAND Foundation
- BDSRA Foundation
- Boston Children’s Hospital Epilepsy Center
- Bubba's Light
- CACNA1A Foundation
- Cardio Facio Cutaneous International
- Chelsea’s Hope Lafora Children Research Fund
- Child Neurology Foundation (CNF)
- Children's National Comprehensive Pediatric Epilepsy Program
- Coalition to Cure CHD2
- COMBINEDBrain

- CSNK2A1 Foundation
- CSNK2B Foundation
- CTNNB1 Connect & Cure
- CURE Epilepsy
- Cure KCNH1 Foundation
- Cure Sanfilippo Foundation
- CureDRPLA
- CureGRIN Foundation
- CureSHANK
- Danny Did Epilepsy Foundation
- DEE-P Connections
- Dell Children's Comprehensive Epilepsy Center
- Doose Syndrome Epilepsy Alliance
- Dravet Syndrome Foundation
- Dup15q Alliance
- Empowering Epilepsy
- Empowering People’s Independence
- Epilepsies Action Network (EAN)
Epilepsy Advocacy Network
Epilepsy Alliance America
Epilepsy Alliance Louisiana
Epilepsy Association of Western and Central Pennsylvania
Epilepsy Foundation (National)
Epilepsy Foundation Alabama
Epilepsy Foundation Alaska
Epilepsy Foundation Arizona
Epilepsy Foundation Arkansas
Epilepsy Foundation Central & South Texas
Epilepsy Foundation East Tennessee
Epilepsy Foundation Eastern Pennsylvania
Epilepsy Foundation Florida
Epilepsy Foundation Indiana
Epilepsy Foundation Iowa
Epilepsy Foundation Los Angeles
Epilepsy Foundation Louisiana
Epilepsy Foundation Maryland
Epilepsy Foundation Metro DC
Epilepsy Foundation Metro New York
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 Northern California
Epilepsy Foundation of Colorado & Wyoming
Epilepsy Foundation of Connecticut
Epilepsy Foundation of Delaware
Epilepsy Foundation of Georgia
Epilepsy Foundation of Greater Chicago
Epilepsy Foundation of Greater Orange County California
Epilepsy Foundation of Greater Southern Illinois
Epilepsy Foundation of Hawaii
Epilepsy Foundation of Kentuckiana
Epilepsy Foundation of Minnesota
Epilepsy Foundation of Missouri & Kansas
Epilepsy Foundation of Northeastern New York
Epilepsy Foundation of Virginia
Epilepsy Foundation of Wisconsin
Epilepsy Foundation Ohio
Epilepsy Foundation Oklahoma
Epilepsy Foundation Oregon
Epilepsy Foundation San Diego County
Epilepsy Foundation South Carolina
Epilepsy Foundation South Dakota
Epilepsy Foundation Southeast Tennessee
Epilepsy Foundation Texas
Epilepsy Foundation Utah
Epilepsy Foundation Washington
Epilepsy Foundation West Virginia
Epilepsy Leadership Council (ELC)
Epilepsy Learning Healthcare System
Epilepsy Services Foundation
Epilepsy Services of New Jersey
Epilepsy Support Network of Orange County
FACES (Finding a Cure for Epilepsy and Seizures)
FAM177A1 Research Fund
FamilieSCN2A Foundation
Global Organization of Health Education (GOHE)
Glut1 Deficiency Foundation
GRIN2B Foundation
HNRNP Family Foundation
Hope for HIE
Hope for Hypothalamic Hamartomas
Hope for ULD
Idaho Comprehensive Epilepsy
International Foundation for CDKL5 Research
International SCN8A Alliance
Jordan's Guardian Angels
Josh Provides Epilepsy Assistance Foundation
KCNQ2 Cure Alliance
KCNT1 Epilepsy Foundation
KIF1A.ORG
Koolen-de Vries Syndrome Foundation
KPTN Alliance
Lennox-Gastaut Syndrome (LGS) Foundation
Louie's Huwe
Malan Syndrome Foundation
Mid-Atlantic Epilepsy and Sleep Center
My Epilepsy Story (MES)
My Kool Brother
National Association of Epilepsy Centers (NAEC)
NORSE Institute
NR2F1 Foundation
NYU Langone Comprehensive Epilepsy Center
Orphan Disease Center
Partners Against Mortality in Epilepsy (PAME)
PCDH19 Alliance
Pediatric Epilepsy Learning Healthcare System (PELHS)
Pediatric Epilepsy Research Consortium
Pediatric Epilepsy Surgery Alliance
Phelan-McDermid Syndrome Foundation
PPP3CA Hope Foundation
Project 8p Foundation
Project Alive
Purple Point Neurodiagnostics
PVNH Support & Awareness
Rare Epilepsy Network (REN) Coordinating Committee
RASopathies Network
Ring14 USA
ROW Foundation
SATB2 Gene Foundation
Seattle Children’s Hospital Epilepsy Program
SLC6A1 Connect
SMC1A FOUNDATION
SNAP25 Foundation
Sociedad Puertorriqueña de Epilepsia
South Carolina Advocates for Epilepsy
STXBPI Foundation
SynGAP Research Fund
Tatton Brown Rahman Syndrome Community
Tbc1d24 Foundation
Telethon Kids Institute
TESS Research Foundation
The Cameron Boyce Foundation
The CASK Gene Foundation
The Charlie Foundation for Ketogenic Therapies
The Coelho Center for Disability Law, Policy and Innovation
The Connected Parent
The Cute Syndrome Foundation
The DESSH Foundation
The Epilepsy Study Consortium (TESC)
The Global Foundation for Peroxisomal Disorders
The Inchstone Project
The MED13L Foundation
The Rory Belle Foundation
The Schinzel-Giedion Syndrome Foundation
The SPATA Foundation
The Sturge-Weber Foundation
THG1L Families
TSC Alliance
YWHAG Research Foundation