

November 7, 2022

President Joseph R. Biden  
The White House  
1600 Pennsylvania Avenue, NW  
Washington, D.C. 20500

Dear President Biden:

We applaud your leadership in improving health outcomes and advancing breakthroughs in research that can save lives, improve the quality of life for patients, and save millions of dollars in health expenditures. As part of your leadership efforts in launching transformative health initiatives such as ARPA-H and the Cancer Moonshot, **we respectfully request that you increase federal investment in the vast array of epilepsies that together are among the most common conditions affecting the brain and range in impact from profoundly debilitating to manageable with therapy.** With government investment, we can make critical gains in the understanding of these various epilepsies, develop more effective and targeted therapies, and establish new, transformative models of patient care. **An excellent way to highlight the importance of addressing epilepsies would be to issue a presidential proclamation declaring November National Epilepsy Awareness Month and bring further public attention to this disease that has a profound effect on Americans everywhere.**

One in 26 people will develop a form of epilepsy in their lifetime<sup>1</sup> and 3.4 million Americans currently live with active epilepsy, including 470,000 children and teenagers.<sup>2</sup> The epilepsies can be deadly, with one out of every 1,000 people dying from sudden unexpected death in epilepsy (SUDEP).<sup>3</sup> Delayed recognition of seizures and inadequate or delayed treatment increase a person's risk of subsequent seizures, brain damage, disability, and death. The idiopathic epilepsies are some of the most burdensome neurological disorders in the US, based on a recent survey.<sup>4</sup> Moreover, epilepsies together impose an annual economic burden of \$28 billion on the country,<sup>5</sup> yet only half of a percent of the more than \$42 billion the NIH spends on medical research each year, goes to epilepsy.<sup>6</sup>

At the fundamental level, epilepsies 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. It is important to note that epilepsy is a spectrum disease that may affect infants, children, young adults, seniors, wounded warfighters and veterans, and anyone suffering from traumatic brain injury. The epilepsies are comprised of many diagnoses, including an ever-growing number of rare epilepsies. Due to this vast spectrum,

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<sup>1</sup> Hesdorffer et al., Estimating risk for developing epilepsy. A population-based study in Rochester, Minnesota Neurology 2011;76:23–27

<sup>2</sup> Zack MM and Kobau R, National and State Estimates of the Numbers of Adults and Children with Active Epilepsy — United States, 2015 MMWR Morb Mortal Wkly Rep 2017;66:821-825

<sup>3</sup> CDC, <https://www.cdc.gov/epilepsy/communications/features/sudep.htm>.

<sup>4</sup> GBD 2017 US Neurological Disorders Collaborators, Burden of Neurological Disorders Across the US From 1990-2017 A Global Burden of Disease Study, JAMA Neurol. 2021;78(2):165-176.

<sup>5</sup> Examining the Economic Impact and Implications of Epilepsy, Amer J Managed Care 2020 A948

<sup>6</sup> <https://report.nih.gov/funding/categorical-spending#/>; <https://www.nih.gov/about-nih/what-we-do/budget>

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.<sup>7</sup>

Despite major advances in science over the past several decades, and valuable support from the NIH, the overall impact on the lives of people living with epilepsy remains largely unchanged. A vast number of patients (more than 30% of adults and 20-25% of children) don't respond to treatment.<sup>8</sup> This number is much higher for patients with rare, genetic 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 to track real-time data from patients living with epilepsy. 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. As Executive Vice Chancellor and Provost at the University of California, San Francisco, and esteemed epilepsies researcher and neurologist, Dr. Dan Lowenstein has stated - "For the vast majority of my patients, I can't tell them why this happened; I can't tell them with any certainty if we have a treatment that will work; and I can't tell them what their future might hold."

Funding for research of the epilepsies is disproportionately low compared to other health conditions, including other major neurological disorders. This funding 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 account for 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 World Health Organization (WHO). This staggering rate shows the need for quality federal investment to better understand the root causes of the disease and its progression, and then convert the knowledge acquired into therapies that will improve the quality of life for those impacted by the epilepsies.

We deeply appreciate your Administration's efforts to prioritize access to innovation and eliminate disparate health outcomes across disease states. We commend the establishment of ARPA-H and your commitment to encouraging the development of breakthrough areas of health and medicine and transformative new therapies. By investing strategically in epilepsy research, new therapies and data surveillance through agencies such as ARPA-H, NIH, CDC, and the VA, we can drive forward innovative approaches backed by robust science to elevate the level of care people with epilepsy receive. Collaborative efforts across government will also be key to addressing the challenges related to understanding the epilepsies through increased data tracking and translating that data into solutions to help patients and save lives.

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<sup>7</sup> <https://www.sciencedirect.com/science/article/abs/pii/S0022347618309600>

<sup>8</sup> 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, <https://www.epilepsy.com/treatment/medicines/drug-resistant-epilepsy#:~:text=Studies%20suggest%20that%20epilepsy%20fails,20%2D25%25%20of%20children.>

Thank you for your consideration. The community is unified in our commitment to improving the lives of people with the epilepsies, and we welcome the opportunity to collaborate with you to fully utilize available tools, while also developing new ones, to treat epilepsies. It is imperative that as a nation we do more to better understand the epilepsies, in addition to bringing forward improved therapies. We strongly encourage you to increase federal investment and resources in the epilepsies, proportionate to its high personal and economic costs, and to proclaim November National Epilepsy Awareness Month.

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:

**Organizations**

- Alliance to Cure Cavernous Malformation
- American Academy of Neurology (AAN)
- American Epilepsy Society (AES)
- Angelman Syndrome Foundation
- CACNA1A Foundation, Inc.
- Child Neurology Foundation (CNF)
- Coalition to Cure CHD2
- COMBINEDBrain
- CSNK2B Foundation
- CURE Epilepsy
- Cure Sanfilippo Foundation
- CureSHANK

**Individuals**

- Sasha Alick-Lindstrom, MD, FAAN, FAES, FACNS,  
 Department of Neurology, University of Texas  
 Southwestern Medical Center
- Orly Avitzur, MD, MBA, FAAN, President, American  
 Academy of Neurology
- Carl Bazil, MD, PhD, Professor of Neurology, Columbia  
 University
- Peggy Beem Jelley, President & CEO, Epilepsy  
 Association of Western and Central Pennsylvania
- Elinor Ben-Menachem, MD, PhD, Professor of  
 Neurology, Goteborg University
- Anne T. Berg, PhD, Adjunct Professor, Neurology,  
 Northwestern University
- Madison Berl, PhD Pediatric Neuropsychologist,  
 Children’s National Hospital, Associate Professor,  
 George Washington University

Danny Did Epilepsy Foundation	Terry Jo Bichell, PhD, MPH, Director, COMBINEDBrain
DEE-P Connections	
Doose Syndrome Epilepsy Alliance	Andria Bilan, CEO, Josh Provides Epilepsy Assistance Foundation
Dravet Syndrome Foundation	Geraldine Bliss, President, CureSHANK
Dup15q Alliance	Chere Chapman, CEO, Ardea Outcomes
Empowering Epilepsy	Angel Chewning, Pediatric Epilepsy Advocate
Empowering People's Independence	Michele Collins, CEO, Hope for ULD
Epilepsy Advocacy Network	Gabrielle Conecker, President & Co-founder, International SCN8A Alliance
Epilepsy Alliance America	
Epilepsy Alliance Louisiana	Elizabeth Coulter, Director, Louie's Howe
Epilepsy Association of Western and Central Pennsylvania	Hina Dave, MD, Associate Professor, University of Texas Health Sciences Center Houston
Epilepsy Foundation (National)	Beth Lewin Dean, MPA, MBA, CEO, CURE Epilepsy
Epilepsy Foundation Alabama	Kamil Detyniecki, MD, Associate Professor of Neurology, University of Miami
Epilepsy Foundation Alaska	Yssa DeWoody, PhD, Cofounder/Director of Research, Ring14 USA
Epilepsy Foundation Arizona	
Epilepsy Foundation Arkansas	Bree DiVentura, MBA, Executive Director, Epilepsy Study Consortium, Inc.
Epilepsy Foundation Colorado & Wyoming	Tracy Dixon-Salazar, PhD, Executive Director, Lennox- Gastaut Syndrome (LGS) Foundation
Epilepsy Foundation East Tennessee	
Epilepsy Foundation Florida	Elizabeth Donner, MD, FRCPC
Epilepsy Foundation Georgia	Mary Duffy, Executive Director, Danny Did Epilepsy Foundation
Epilepsy Foundation Greater Orange County California	R. Edward Faught, MD
Epilepsy Foundation Greater Southern Illinois	Nathan Fountain, MD, Professor of Neurology
Epilepsy Foundation Hawaii	Jacqueline A. French, Chief Medical and Innovation Officer, Epilepsy Foundation; Professor of Neurology, NYU Langone Health
Epilepsy Foundation Indiana	

Epilepsy Foundation Iowa	Daniel Friedman, MD, MSc, Professor of Neurology, New York University Grossman School of Medicine
Epilepsy Foundation Kentuckiana	
Epilepsy Foundation Los Angeles	Brandy Fureman, PhD, Chief Outcomes Officer, Epilepsy Foundation
Epilepsy Foundation Louisiana	Alicia Gajewsky, Program Manager, Epilepsy Foundation of Wisconsin
Epilepsy Foundation Maryland	
Epilepsy Foundation Metro DC	Michael Gelfand, MD, PhD, Associate Professor of Clinical Neurology, University of Pennsylvania
Epilepsy Foundation Metro New York	Patricia A. Gibson, MSSW DHL ACSW, Director, Epilepsy Information Service of Wake Forest University School of Medicine
Epilepsy Foundation Minnesota	
Epilepsy Foundation Mississippi	Barry E. Gidal, PharmD, FAES
Epilepsy Foundation Missouri & Kansas	Leigh Goldie, Executive Director, Empowering Epilepsy
Epilepsy Foundation Montana	J. Michael Graglia, Managing Director, SynGAP Research Fund
Epilepsy Foundation Nebraska	
Epilepsy Foundation Nevada	Brandi Green, Program Director, Epilepsy Foundation of East Tennessee
Epilepsy Foundation New England	Kristie Griess, CEO, Visionary Founder, Warrior Mom
Epilepsy Foundation New Jersey	Zachary Grinspan, MD, MS, Principal Investigator, Pediatric Epilepsy Learning Healthcare System
Epilepsy Foundation New Mexico	
Epilepsy Foundation North Carolina	Jill Hawkins, Founder & President, FAM177A1 Research Fund
Epilepsy Foundation North Dakota	JayEtta Hecker, Executive Director and Co-founder, DEE-P Connections
Epilepsy Foundation Northern California	
Epilepsy Foundation Ohio	Rachel Heilmann, President & Co-founder, The Rory Belle Foundation
Epilepsy Foundation Oklahoma	Susan T. Herman, MD, President, National Association of Epilepsy Centers
Epilepsy Foundation Oregon	
Epilepsy Foundation San Diego County	Lawrence J. Hirsch, MD, Professor of Neurology, Yale University
Epilepsy Foundation South Carolina	Kristina Hone, MBA, Founder/CEO, The CASK Gene Foundation
Epilepsy Foundation South Dakota	

Epilepsy Foundation Utah	Veronica Hood, PhD, Scientific Director, Dravet Syndrome Foundation
Epilepsy Foundation Washington	
Epilepsy Foundation West Virginia	Chunhui Hu, MD, Attending Doctor, Pediatric Neurologist, Fudan University
Epilepsy Leadership Council (ELC)	Heather Jackson, Founder/President, Doose Syndrome Epilepsy Alliance
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Epilepsy Services Foundation	Charuta Joshi, MD, MBBS, FAES, CSCN
Epilepsy Services of New Jersey	Peter Kaplan, MD
Epilepsy Support Network of Orange County	Siddharth Kapoor, MD, Neurologist
FAM177A1 Research Fund	Reena Kartha, PhD, Assistant Professor, University of Minnesota
Glut1 Deficiency Foundation	Sudha Kilaru Kessler, MD, Associate Professor of Neurology and Pediatrics, Children's Hospital of Philadelphia, Perelman School of Medicine
GRIN2B Foundation	
Hope for HIE	Pavel Klein, Director, Mid-Atlantic Epilepsy and Sleep Center
Hope for ULD	
Idaho Comprehensive Epilepsy, PLLC	Gregory Krauss, Professor of Neurology, Johns Hopkins University
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International SCN8A Alliance	
Josh Provides Epilepsy Assistance Foundation	Gardiner Lapham, Trustee, The BAND Foundation
KCNQ2 Cure Alliance	Elinor LaTouche, Executive Director, Epilepsy Foundation of Metro New York
KCNT1 Epilepsy Foundation	
Koolen-de Vries Syndrome Foundation	Connie Lee, Psy.D., CEO, Alliance to Cure Cavernous Malformation
KPTN Alliance	Kevin Lind, President & CEO, Longboard Pharmaceuticals, Inc.
Lennox-Gastaut Syndrome (LGS) Foundation	
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Malan Syndrome Foundation	Laura Lubbers, PhD, Chief Scientific Officer, CURE Epilepsy

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National Association of Epilepsy Centers (NAEC)	
NORSE Institute	
Partners Against Mortality in Epilepsy (PAME)	Debra McGrath, Executive Director/Co-founder, Epilepsy Foundation of Kentuckiana
Pediatric Epilepsy Learning Healthcare System (PELHS)	Kimford J. Meador, MD, Professor of Neurology, Stanford University
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SATB2 Gene Foundation	
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SNAP25 Foundation	Janna Moore, Executive Director, Epilepsy Support Network of Orange County
Sociedad Puertriqueña de Epilepsia	
South Carolina Advocates for Epilepsy	Angie Nelson, Executive Director, Epilepsy Advocacy Network
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SynGAP Research Fund	
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The CASK Gene Foundation	
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The FamilieSCN2A Foundation	
The Global Foundation for Peroxisomal Disorders	Christy Polk, Treasurer, Epilepsy Foundation of Missouri and Kansas
The NR2F1 Foundation	
The Rory Belle Foundation	Carlos Quesada, CEO, Epilepsy Foundation of Northern California
The Schinzel-Giedion Syndrome Foundation	Alex Ramirez, Director, Sociedad Puertrriqueña de Epilepsia
TSC Alliance	Charlene Son Rigby, President & Co-founder, STXBP1 Foundation
	Kari Rosbeck, President & CEO, TSC Alliance
	Denise Scott, President, CSNK2B Foundation
	Scotty Sims, Director, KCNQ2 Cure Alliance
	Jeff Sinsebox, President, Empowering People's Independence
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