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for the

House Energy and Commerce Health Subcommittee

Re: The National Plan for Epilepsy Act, H.R. 1189, Witness Testimony

September 15, 2026

Chairmen Guthrie and Griffith and Ranking Members Palone and DeGette, I am honored to share testimony today on behalf of the 1 in 26 Americans who will develop epilepsy in their lifetime, as well as those who care for them.

I am Co-Founder of Decoding Developmental Epilepsies, which includes both disease-specific and broad-based epilepsy organizations (the International SCN8A Alliance[1], DEE-P Connections and The Inchstone Project[2]), and serve on the leadership team for the Epilepsies Action Network, a coalition of organizations advocating for policies like the National Plan for Epilepsy that will improve outcomes for people with epilepsy. But most importantly, I am a mom of a child with a rare and catastrophic epilepsy.

First, I 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 for people with the epilepsies. I would like to share information on the vast impact of this neurological disease and my family's journey, in order to illuminate the challenges for the committee and the public. I hope this will encourage you to support and pass the National Plan for Epilepsy Act (H.R. 1189) to improve the lives of the millions of Americans living with epilepsy, make care more affordable, reduce the significant economic burden of epilepsy on our country, and ensure healthcare providers have the knowledge and resources to deliver safer, faster, more effective, and cost-efficient care.

Epilepsy is a disorder of the brain characterized by abnormal nerve cell signaling that leads to seizures—uncontrolled bursts of electrical activity that often impact behavior, awareness, and muscle movements. Epilepsy can affect people of any age (e.g., infants, school-aged children, service members after suffering a TBI, adults, and seniors) and is often lifelong. There are multiple types of seizures, many underlying causes of epilepsy, and with the rise of genetic testing, an ever-growing number of rare and genetic epilepsies. 1 in 10 people will experience a seizure at some point in their lifetime and 1 in 26 people will be diagnosed with epilepsy. In the United States, nearly 3.4 million people are living with epilepsy, of which 456,000 are children

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[1] Conecker G, Hecker J, Hammer MF. Patient leadership and partnerships accelerate therapies for SCN8A and other developmental and epileptic encephalopathies. Ther Adv Rare Dis. 2025 Feb 20;6:26330040241252449. doi: 10.1177/26330040241252449. PMID: 39989508; PMCID: PMC11843689.

[2] Hecker J, Conecker G, Chapman C, Hommer R, Ludwig NN, Sevinc G, Te S, Wojnaroski M, Downs J, Berg AT. Patient-advocate-led global coalition adapting fit-for-purpose outcomes measures to assure meaningful inclusion of DEEs in clinical trials. Ther Adv Rare Dis. 2024 Jun 22;18:26330040241249762. doi: 10.1177/26330040241249762. Erratum in: Ther Adv Rare Dis. 2024 Oct 4;5:26330040241277869. doi: 10.1177/26330040241277869. PMID: 38911512; PMCID: PMC11193340.

or teenagers.[3] Of the more than 500 neurological conditions and disorders, epilepsy is the fourth most prevalent.

To start, I'd like to share my family's story, and then I will address the larger epilepsy challenges and opportunities for Congress to consider as you discuss The National Plan for Epilepsy Act (H.R. 1189).

Elliott, my first, was born in late 2012. Within days, we noticed that he was making strange movements, which turned out to be a very severe type of seizure. These seizures were dismissed by the pediatrician for months before we received a referral to a neurologist. Our diagnostic odyssey, with more than a dozen doctors and invasive interventions along the way—spinal taps, skin biopsies, MRIs, EEGs, and more—lasted a year and a half. During that time, Elliott had hundreds of seizures and was hospitalized many times, never receiving care that was in line with his ultimate diagnosis. Tragically, this delay is not unusual; it is the status quo. Families across the country face the same maze of misdiagnoses, fragmented care, and "throw spaghetti at the wall" treatments. No child should suffer preventable harm because our health care system is not designed to recognize or respond to the many forms of epilepsy. A National Plan could address this gap in understanding and awareness.

In 2014, Elliott was finally diagnosed with SCN8A-Related Disorder as a result of genetic testing. At the time, little was known about this disorder as it was newly discovered. More than 10 years later, despite knowing that there are many more people living with SCN8A, it falls upon small, caregiver-led groups like the one I started with other SCN8A caregivers—the International SCN8A Alliance—to find, track and monitor those living with this disorder. In addition to caring for loved ones who require 24/7 care, caregivers are also left to lead organizations in order to provide support, education and resources to families and clinicians, all while asking their families, friends and neighbors to help finance—on bake sales and lemonade stands—the science to search for a cure.

Every day I fear the loss of my child. Children with SCN8A are dying at an alarming rate. We know of roughly 800 people in the United States who have SCN8A, though many are yet to be identified via genetic testing. The mortality rate for SCN8A is between 5-10%; many children die before their 5th birthday. Parents whose children have rare epilepsies—which have been associated with more than a thousand genes to date—live with this fear every minute of every day.

Elliott is now 13 years old, and his development remains intensely slow. He is still working on head control and is exclusively fed through a tube that goes to his small intestine. He cannot grasp a toy and has severe vision impairment that means he cannot see my face. He cannot tell me if he feels happy or sad, cold or hot, hungry or full. When he cries or screams, I can only guess why and try to comfort him. I often cannot. He has never said he loves me or given me a hug. I know Elliott better than anyone else in the world and have learned to read his sounds and body language to best carry out his wishes.

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[3] 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.; 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.

Elliott brings us so much joy but make no mistake, this life is grueling. My husband, John, had to quit his job as a university professor 12 years ago to become Elliott's primary caregiver. Instead of using his PhD to teach the next generation, he spends his days ordering supplies and medications, preparing feedings, managing my son's bowels, cleaning supplies and equipment, and, among many other things, ensuring that Elliott is well positioned so he doesn't aspirate and end up sedated and intubated with yet another pneumonia.

Without a second income, our family has had to rely on our community to keep us afloat. Luckily, we have also been able to access Medicaid to help our family avoid bankruptcy and access critical medications and equipment. Without access to Medicaid, many families fall into even further financial peril. Families like mine live this reality every day—juggling financial challenges, living with limited support at home for the care of their complex children and fighting to keep their children alive—but the burden should not also fall on us to navigate a system that leaves us without guidance, data, or coordinated care. The National Plan is essential to ensure that no family faces this journey without the support they need.

Despite having a diagnosis of the disorder that plagues my son, our treatment odyssey continues. Elliott has tried and failed nearly every approved anti-seizure medication on the market. Even with four anti-seizure medications (plus about a dozen other medications administered at ten different times throughout the day), he continues to seize.

The reality is that nearly every treatment decision for those with epilepsy is still a guess. This uncertainty is unacceptable. Our foundation led a massive effort to develop and publish guidelines on how to best diagnose and treat children with SCN8A, a time-consuming and expensive effort that required massive buy-in from around the globe. Caregiver-led foundations are forced to do this because there are currently no standardized ways of tracking the number of people with epilepsy, their care or their outcomes. We need to harness the incredible scientific prowess and leadership in this country to build next generation treatments that will change the future for people living with epilepsy. A National Plan will help ensure that critical research does not sit stagnant, but is better coordinated, translated into clinical practice, and used to drive continued innovation and improved outcomes for people with epilepsy.

The very disturbing truth is that we have known about epilepsy for thousands of years. There is incredible work being done in epilepsy yet very little is translating into improved quality of life and outcomes for those living with the condition. At least one-third of adults and a quarter of children with epilepsy cannot get control of their seizures with currently available treatments.[4] Despite the staggering prevalence, epilepsy remains one of the least systematically tracked and strategically coordinated neurological conditions in the United States. The absence of a National Plan is a policy, health and economic failure we can no longer afford.

For the vast majority of the epilepsies, there are no biomarkers, and relatively few studies systematically capture and incorporate the experiences of people living with epilepsy to inform research and care. Beyond seizures, those with epilepsy can also experience cognitive,

[4] Kwan, P & Brodie, MJ. Early identification of refractory epilepsy. *N Engl J Med*. 2000;342(5):314-319.; Chen, Z., Brodie, M.J. 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.

behavioral, and psychiatric mood disorders, as well as mobility, gastrointestinal, and respiratory issues.[5] People with epilepsy face an increased risk of premature death from Sudden Unexpected Death in Epilepsy (SUDEP), prolonged seizures, injuries, drowning, and other epilepsy-related complications. The annual risk of SUDEP alone rises from about 1 in 1,000 people with epilepsy to as high as 1 in 150 when seizures are not controlled.[6] Many of these deaths are preventable. A National Plan, with coordinated federal leadership in partnership with the community, would foster earlier diagnosis, improve treatment guidance, and save lives.

In addition to impact on quality of life, epilepsy is an expensive disease for the individual, family, and our country. Epilepsy and/or seizures impose an annual economic healthcare burden of at least $54 billion.[7] Adults with epilepsy are more likely than those without epilepsy to struggle to pay medical bills, be unable to afford prescription medications, and skip doses to save money.[8] Direct, epilepsy-related medical costs associated with uncontrolled epilepsy are 2 to 10 times higher than costs associated with controlled epilepsy.[9]

Epilepsy care places significant demands on an already strained health care workforce. Epileptologists and other clinicians caring for people with epilepsy must manage complex, often lifelong conditions that require substantial care coordination, medication management, patient and family counseling, and collaboration across multiple specialties. At the same time, workforce shortages, administrative burdens, and reimbursement structures that do not always adequately recognize the complexity and ongoing nature of epilepsy care can limit healthcare providers' capacity to meet growing patient needs. Physicians and advanced practice providers often lack the tools to predict which treatment, if any, will work, who is most likely to experience harmful side effects, and/or how an individual's epilepsy will progress, making better research, data, and clinical guidance essential. Prior authorization requirements further strain practices by consuming valuable clinician and staff time and can delay patients' access to necessary medications, diagnostic testing, and life-saving treatments. Restrictions on access to telehealth can create additional barriers for patients who cannot drive because of their seizures, live far from an epilepsy center, or need to reach specialists with expertise in rare or complex forms of epilepsy, particularly when that expertise is located across state lines. Addressing these challenges is essential to ensuring that people with epilepsy have timely access to high-quality, specialized care. Without a national strategy, clinicians are forced to operate without the data, tools, and coordinated infrastructure needed to deliver modern epilepsy care.

The goals of the National Plan for Epilepsy Act align with Congress' commitment to making healthcare more accessible, effective, and affordable by closing gaps between scientific progress and clinical care and equipping physicians and other healthcare providers to deliver earlier

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[5] Zhou Y, Kobau R, Pastula DM, Greenlund KJ. Comorbidity Among Adults With Epilepsy — United States, 2021–2022. *Prev Chronic Dis.* 2024;21:240313. doi:10.5888/pcd21.240313.; Lu E, Pyatka N, Burant CJ, Sajatovic M. Systematic Literature Review of Psychiatric Comorbidities in Adults with Epilepsy. *J Clin Neurol.* 2021;17(2):176–186. doi:10.3988/jcn.2021.17.2.176.

[6] 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.

[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.

[8] Tian, N., Kobau, R., Zack, M M., & Greenlund, K.J. Barriers to and disparities in access to healthcare among adults ≥ 18 years with epilepsy – United States, 2015 and 2017. Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report. May 27, 2022; 71(21): 697-702.

[9] Begley, C.E. & Durgin, T.L. (2015). The direct cost of epilepsy to the United States: A systematic review of the estimates. *Epilepsia, 56*(9), 1376-87. Retrieved from https://onlinelibrary.wiley.com/doi/full/10.1111/epi 13084.

diagnosis, more informed treatment, and better outcomes for people with epilepsy. The legislation, which is modeled on the successful national plans for Alzheimer's and Parkinson's Disease, would direct the Secretary of Health and Human Services (HHS) to establish and maintain a National Plan for Epilepsy. The Secretary would review existing epilepsy programs and provide recommendations to Congress, strengthening federal coordination and advancing a unified approach to the prevention, diagnosis, treatment, and ultimately, cure of epilepsy. This coordinated approach would help improve affordability and quality of life for people with epilepsy while reducing burdens on health care providers. To inform this work, the Secretary would regularly convene and solicit input from relevant federal agencies and key stakeholders, including patient advocates and subject matter experts. The community has already convened to develop consensus priorities for what could be included in a National Plan for Epilepsy. If and when the legislation is passed, we look forward to working with Congress and the Secretary to advance this life-saving work.

Despite the vast number of Americans impacted by epilepsy, there is still so much that is unknown, and many people go undiagnosed and untreated. That is why I am part of the Epilepsies Action Network and why I started organizations to address these gaps in the system I have been fighting against for the last 13 years. There are hundreds of thousands of parents like me doing everything they can to find answers, treatments, and a better quality of life for our children with epilepsy[10]. But we cannot succeed alone. We need your leadership and support.

Thank you for considering my testimony. We have an opportunity to address the systemic challenges that for too long have delayed the translation of rapidly advancing scientific knowledge about the epilepsies into better care, treatments, and outcomes. Congress has the chance to change the trajectory for the millions of Americans living with epilepsy. Passage of the National Plan for Epilepsy Act (H.R. 1189) this year is necessary to make care more affordable, reduce the significant economic burden of epilepsy on our country, and ensure healthcare providers have the knowledge and resources to deliver safer, faster, more effective, and cost-efficient epilepsy care. It would be a historic step toward ending decades of fragmentation[11] to improve the lives of the roughly 3.4 million Americans living with epilepsy, giving them a future defined not by fear, but by progress. We appreciate the Committee's consideration of this important legislation and stand ready to work with Congress, the Department of Health and Human Services, other government agencies with epilepsy programs, and the broader epilepsy community to advance this effort and improve outcomes for people living with epilepsy and their families.

[10] The Rare Epilepsy Network

[11] Berg AT, Goldman S. Getting serious about the early-life epilepsies: Lessons from the world of pediatric oncology. Neurology. 2018 May 1;90(18):842-848. doi: 10.1212/WNL.0000000000005423. Epub 2018 Apr 4. PMID: 29618625.