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The People Behind the Policy

U.S. Representative Steny Hoyer of Maryland reflects on the ADA, public service, and his personal connection to epilepsy

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Letter from the CEO

Dear Friends,

Every November, National Epilepsy Awareness Month brings our community together to raise awareness, challenge stigma, and celebrate the strength of people living with epilepsy.

This year, our call to action is Where Community Sparks Hope.

For me, hope begins when someone realizes, "I am seen. I am supported. I am not alone."

As someone living with epilepsy, I understand the power of that connection. A conversation can replace fear with understanding. A shared story can help someone feel less isolated. One informed person can make a school, workplace, or community safer and more welcoming.

But hope also requires action. It grows when we educate others, challenge misconceptions, advocate for change, advance research, and support people and families affected by epilepsy. It becomes even stronger when we come together around the belief that every person deserves access to care, opportunity, and a full life.

Throughout National Epilepsy Awareness Month, I invite you to spark hope wherever you are. Share your story. Start a conversation. Educate someone about epilepsy. Advocate for change. Support our mission.

Every voice matters. Every action matters. And every connection has the power to make a difference.

However you choose to participate, know that you are part of a community committed to ensuring that no one faces epilepsy alone. Together, we can deepen understanding, reduce stigma, strengthen meaningful connections, and build a future where every person affected by epilepsy can thrive.

With gratitude,



Bee Martin Lee

Bernice "Bee" Martin Lee

P.S. The spirit of connection does not end with November. In April 2027, we will gather in Washington, D.C., for the National Walk for Epilepsy to celebrate our shared strength, raise awareness, and take meaningful steps toward a brighter future. I hope you will join us.

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EPILEPSY FOUNDATION

The People Behind the Policy

U.S. Representative Steny Hoyer of Maryland reflects on the ADA, public service, and his personal connection to epilepsy.

"People should be recognized for what they can do, not defined by what they cannot do," said Steny Hoyer, a Maryland politician who has represented the state's 5th Congressional District in the U.S. House of Representatives since 1981.

This belief has been at the center of Hoyer's decades in politics. It influenced his leadership on the Americans with Disabilities Act (ADA) and his support for federal epilepsy research and, most recently, the National Plan for Epilepsy Act.

Hoyer is the longest-serving House member in Maryland history and the only Marylander to serve as House majority leader. Before entering Congress, he served as the president of the Maryland Senate. During more than four decades on Capitol Hill, Hoyer built a reputation as a consensus builder and legislative strategist. In January 2027, Hoyer will retire after a long and accomplished political career.

Hoyer's commitment to epilepsy is a personal one. It was shaped by his late wife, Judith "Judy" Hoyer, and his close friendship with former Rep. Tony Coelho, a leading voice for people with disabilities and a longtime champion for the epilepsy community. Judy Hoyer learned she had epilepsy when she was in her late 40s. The Hoyers were overseas when she had a seizure and involuntarily dropped a cup. The moment led to her diagnosis and opened a new chapter for their family. It also brought Judy closer to a community that understood the uncertainty and the resolve required to manage epilepsy.



Rep. Hoyer celebrates ADA passage with Sen. Orrin Hatch and advocates, July 13, 1990. Photo Courtesy of Rep Hoyer's Office

At the time, Hoyer was already close to Coelho, his colleague in Congress. Coelho had devoted much of his life to epilepsy and disability advocacy. He urged Judy to serve on the Epilepsy Foundation's Board of Directors. She welcomed the chance to support programs for people with epilepsy and to advance prevention and treatment.

Hoyer channeled the passion he saw in his then-wife into action where he had influence. In Congress, Hoyer pressed for federal investment in epilepsy programs and research at the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

Hoyer's most far-reaching work on disability policy came after Coelho left Congress. House Speaker Tom Foley and Coelho



Reps. Hoyer, Nadler, and Langevin before a House vote on the Americans with Disabilities Act Amendments Act in Washington on June 25, 2008. Photo Courtesy of Rep Hoyer's Office

entrusted him with helping to pass the ADA. Hoyer worked in a bipartisan, bicameral manner with Rep. Steve Bartlett of Texas and Sens. Tom Harkin of Iowa and Edward Kennedy of Massachusetts, among many others. Together, they moved the bill across committees, chambers, and party lines. President George H.W. Bush signed the ADA into law in 1990.

The law would affect workplaces, schools, transportation, public spaces, and everyday services. Hoyer listened as people described the discrimination they faced. He also watched people with profound disabilities speak up and change the debate. He said he marveled at their courage.

Looking back on 45 years in Congress, Hoyer called passing the ADA as "one of the most significant legislative activities" of his career.

Beyond the halls of Congress, passing the ADA was not easy as business owners, transit systems, and other stakeholders asked what compliance would require. They worried about costs and lawsuits. Transportation raised difficult questions because accessibility improvements could be expensive. Hoyer and Bartlett met with lawmakers across several committees. They sought input and addressed concerns without weakening the bill's purpose. Reasonable accommodation became a central standard. Expectations would reflect an organization's circumstances, while larger corporations would be expected to do more.

The result was sweeping. The ADA established broad civil rights protections for people with disabilities. It also reshaped expectations for access and inclusion in American life for generations to come. Other countries later used it as a model.

Continued on next page



Hoyer's work did not end with the passage of the ADA. He remained involved in protecting the law's implementation, including after a Supreme Court decision limited its reach. Of all the legislative battles he joined, he said, "the ADA was the best and the most important."

In being a champion for research funding and public health over the years, the need is measured in millions of lives. Epilepsy can be deeply debilitating, but its effects vary widely. No single story captures the full experience. Federal research can uncover why seizures begin, improve early diagnosis, and identify better treatments. Public health programs like the CDC Epilepsy Program raise awareness and strengthen care. Hoyer said the investment is critical because epilepsy carries both a human and an economic cost.

The National Plan for Epilepsy Act offers a next step. It calls for a coordinated federal effort to prevent, diagnose, treat, and ultimately cure epilepsy. As a co-sponsor, Hoyer sees coordination as a practical way to speed discovery. "The more you coordinate, the more you talk with one another, the more you have interdisciplinary focus, the more likely you are to find something to prevent."

His charge to future lawmakers is just as direct: "Keep your eye on the ball until we resolve this issue and have a cure, prevention, and an early diagnosis ability."



Rep. Hoyer at Epilepsy Foundation of America Congressional Caucus briefing, November 2023 Photo Courtesy of Rep Hoyer's Office

About the National Plan for Epilepsy Act

The National Plan for Epilepsy Act has been introduced in Congress. If passed, it would require the federal government to establish and maintain a national plan that would improve coordination among epilepsy programs and seek to increase investment over time. Its goals are to improve prevention, diagnosis and treatment; advance the search for cures; and support the well-being of people with epilepsy and their families.

More than 125 bipartisan members of Congress have co-sponsored the bill. On Aug. 4, 2026, the U.S. Senate unanimously passed a modified version that preserves the bill's intent and approach. On Sept. 15, the House Energy and Commerce Subcommittee on Health discussed the National Plan at a hearing.

A parent advocate, Gabi Conecker, testified in support of the legislation. The Epilepsy Foundation alongside 190 other organizations is urging Congress to pass the bill by the end of December 2026. The House and Senate must approve the same version before it can go to the president for a signature.



What You Should Know About Visually Provoked Seizures

Two leading epilepsy experts clarify how flashing lights and visual patterns may affect some people with seizures.

Flashing lights, rapidly changing images, and certain visual patterns can trigger seizures in some people with epilepsy. Misconceptions persist about who is at risk, what may trigger a seizure, and how people can protect themselves.

Epilepsy specialists Dorothée Kasteleijn-Nolst Trenité, M.D., Ph.D., MPH and Robert Fisher, M.D., Ph.D. answered our questions. Their insights can help the community better understand these complex symptoms.

Understanding the connection between light and seizures

Fisher's interest in visually provoked seizures began through his advocacy work with the Epilepsy Foundation of America. He joined a committee studying flashing lights used in fire alarms designed for people who are hard of hearing after a seizure was reported during alarm testing. Later, Fisher consulted on a case in which a visual waterfall display at a science center triggered a seizure.

Kasteleijn-Nolst Trenité's path began at a children's epilepsy department in the Netherlands. There, she worked with colleagues who studied electroencephalograms, or EEGs and became interested in how brain activity during light stimulation related to patients' experiences.

Both physicians stress that terminology matters. The widely used term "photosensitive epilepsy" does not always accurately describe what happens during a seizure.

Photosensitivity may refer to an abnormal electrical response in the brain detected during an EEG, even when the person does not have a seizure. A visually provoked seizure is different: It is a seizure triggered by a visual stimulus. Triggers may include flashing lights, high-contrast patterns, color changes or other changing images.

Not every symptom triggered by visual stimulation is a seizure, either. Some people may experience headaches, migraines, or dizziness.

That distinction matters. An abnormal EEG response to flashing lights does not necessarily mean a person will experience visually provoked seizure, but it is a risk factor. A clinician must also consider the individual's medical history and symptoms.

Separating risk from misconception

How common are visually provoked seizures? There is no single answer, according to the physicians. Estimates vary by the population studied and the type of epilepsy involved. They also depend on how seizures are identified.

Some people may never realize they are susceptible. Their symptoms may be mild, or they may never have a seizure that leads to medical evaluation.

The physicians also pointed to the potential influence of visual patterns, not just flashing lights. Certain combinations of brightness, contrast, size, color changes and flashing frequency may increase risk for susceptible individuals.

Fisher emphasized the need for awareness without unnecessary restrictions. A child with epilepsy should not automatically be prevented from playing video games. Such a restriction may be unwarranted when there is no evidence of photosensitivity.

Research that everyone can understand

The Epilepsy Foundation's work on visually provoked epilepsy education grew from a practical need: The epilepsy community frequently asks questions about visually provoked seizures.

Research reviews and consensus recommendations published in 2004 and 2005 needed to be updated. Technology had advanced, and the body of scientific evidence had grown.

The resulting collaboration produced three publications with distinct audiences: a scientific review for researchers and medical professionals, consensus recommendations for groups such as video game developers and media producers, and a frequently asked questions resource written for the public.

Accessibility was central to the researchers' work. Scientific papers can be hard for the public to navigate, especially when technical language hides practical advice. The consumer resource translates the research into information people can use every day.



What patients and families can do

Anyone who suspects that flashing lights or visual patterns may be triggering symptoms should talk with a healthcare professional. A clinician can help identify the symptoms and explain how an individual's sensitivity may affect daily activities.

Most importantly, an epilepsy diagnosis does not automatically mean a person is sensitive to flashing lights.

Kasteleijn-Nolst Trenité offered reassurance. Epilepsy care should be tailored to each person's age, circumstances, and symptoms.

Continued research and collaboration can help make visual environments safer. The goal is to reduce risk without creating unnecessary fear or limiting everyday participation.

Bringing Epilepsy Out of the Shadows

For Eric Ladd and his wife, Kaley Burns, epilepsy awareness isn't just a cause. It's personal.

When their young son, Haydon, began experiencing seizures, Eric and Kaley encountered a reality no parent wants to experience: the helplessness of watching their child struggle while searching for answers.

After Haydon was diagnosed with epilepsy, their family entered a frightening new reality marked by doctor visits and uncertainty about what came next. Now 3 years old, Haydon has spent countless hours in hospitals as his parents worked to find the care he needed.

"Our son Haydon was diagnosed with epilepsy about a year ago, and since then, through our journey, we've come to recognize how great the need is for people with epilepsy and their families, and how underserved that community is," Ladd said. "There's so much more work to be done in research and healthcare to turn up the volume for epilepsy."

Despite doctors doing their best to help and Kaley's own connections to the medical community as a naturopathic doctor, finding answers about Haydon's seizures wasn't easy. After multiple misdiagnoses in emergency rooms, they began to see firsthand the gaps families can encounter in epilepsy care. His family needed more than answers. They needed people who understood epilepsy and the fear, uncertainty and emotional weight that came with it.

They found that understanding in the Epilepsy Foundation. As the Ladd family found support and connection, they began thinking about how he could help other families find it, too.

"We've sat in enough hospitals to see kids lined up with this disease, and it is very powerful to find connection and be able to help," Ladd said.

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Eric Ladd, his wife Kaley Burns, and their son, Haydon
Photo Courtesy of the Ladd Family



“There’s so much more work to be done in research and healthcare to turn up the volume for epilepsy.”

Ladd is CEO of Outlaw Partners, the company behind Big Sky PBR, which has brought large-scale events to the Montana community for years. This summer, Outlaw Partners turned that platform into an opportunity to shine a light on epilepsy, naming the Epilepsy Foundation the first-night beneficiary of Big Sky PBR. They raised over $200,000 and donated it to the organization to support its important work.

For Ladd, one of the most meaningful moments came when the arena filled with purple, bringing thousands of people together in support of epilepsy awareness.

“Seeing people I’ve known for years rally behind a cause that means so much to our family was something else,” he said. “Watching thousands of fans and cowboys from around the world wear purple and come together for epilepsy awareness was incredible.”

The image carried special meaning for him.

“People with epilepsy need a lot of strength,” Ladd said. “The irony of having cowboys there as a symbol of strength and to lend their hand that night was very powerful.”

Now, he hopes sharing his family’s story encourages others to share theirs.

“Epilepsy has been hiding in the shadows and bringing it into the light is long overdue,” Ladd said. “We have to start the conversations to build awareness and once we can do that, we can start to change it.”

For families beginning a journey like their own, the Ladd family’s message is just as important: keep advocating, seek out others who understand, and know that even on the hardest days, there is reason to hope.



Eric (R) presenting check to Epilepsy Foundation of Montana
Photo Courtesy of the Ladd Family

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Rising Leaders for Epilepsy

Teen advocate Jordan Moreira-Davidson transformed his family's epilepsy journey and his love of padel into a tournament that raised more than $91,200 for the epilepsy community.

Jordan Moreira-Davidson wants to make a difference for people affected by epilepsy. His motivation is personal. For years, he watched his mother search for an explanation for her symptoms, visiting doctor after doctor before finally receiving an epilepsy diagnosis.

As Jordan learned more about epilepsy, he wanted to better understand the condition and advocate for others facing challenges like those his mother experienced.

That opportunity came through the Epilepsy Foundation's teen program called "Rising Leaders for Epilepsy." The eight-week course educates participants on how to spread awareness for epilepsy in their local communities. They also complete seizure first aid training and plan their own fundraising events.

Moreira-Davidson built his project around padel, a fast-paced racquet sport that combines elements of tennis and squash. He organized a tournament in Miami that encouraged friendly competition amongst supporters. There was also an educational component so players could learn more about seizures. The event was more successful than he ever imagined, raising more than $91,000 and earning him the "Rising Impact" Award.

The amount of money the tournament generated was very unexpected, but Moreira-Davidson said the conversations at the tournament surprised him most. When attendees asked why he had organized the tournament, he shared his mother's story. Because 1 in 26 people are affected by epilepsy, many described their own experiences or connections to someone with a seizure disorder.

Some Rising Leaders participants live with epilepsy; others, like Moreira-Davidson, have seen its impact on a loved one. Their stories showed him that the program's impact reaches far beyond any single experience. Fundraising is important but changing even one person's understanding of epilepsy is just as meaningful.

The program also reshaped his view of leadership. Before joining the program, he believed it meant being in charge. Now he sees leadership as taking responsibility for an event or program and seeing it through to the end, no matter the outcome.

Moreira-Davidson hopes other young people learn that epilepsy affects each person differently and should never be a reason for stigma or discrimination. Inspired by his mother's journey, he's turned that belief into action. What began as an effort to honor her has evolved into an ongoing commitment to supporting the epilepsy community. Plans are already underway to hold the padel tournament twice a year and raise even more funds for the cause.

In addition to Jordan's work, his family has also embraced the Epilepsy Foundation's mission in a meaningful way by organizing their own fundraising events to support and uplift the epilepsy community at large.

Pictured: Jordan Moreira-Davidson



2025-2026 Teen Impact Award Participants



Sophie Bohner, Grade 11



Kennedy Hagan, Grade 10



Piper Kaplan, Grade 9



Olivia Kertesz, Grade 11



Samuel Stevenson, Grade 11



Hemakshi Vashist, Grade 8



The Voice on the Other End of the Helpline

A personal reflection from the Epilepsy & Seizures Helpline team.



Tom Buckley
Senior Director

"Can you help me?" That question is often the first thing we hear when the Epilepsy & Seizures Helpline is answered.

Though it is only four words long, this question often carries deep uncertainty. Sometimes it comes from a parent worried about a child's nighttime seizure. Other times, it comes from someone who lost a job after a seizure at work or having to choose between medication and rent. A newly diagnosed caller may simply be frightened about what comes next. No matter how someone contacts us, we enter their story at a moment when they need information and support.

The Epilepsy Foundation of America's Helpline is staffed by trained information specialists whose varied experience strengthens the support we provide. We listen closely to understand what each caller needs. We also assess urgency and make sure the caller is safe. The Helpline is accredited by Inform USA, which helps ensure that every person receives accurate, consistent assistance.

Behind every conversation is work people rarely see. Helpline staff seek out programs and resources suited to each person's circumstances. One caller may need immediate help paying for medication and another help with transportation for an appointment. To make every referral accurate, the organization maintains a database of 513 agencies offering 891 programs to help.

Other moments stay with us because they reveal the resilience of the epilepsy community. Even amid the challenges of epilepsy, people continue their education and build careers. They also learn to advocate for themselves and others.

This work can be emotionally heavy, and no one carries it alone. The Helpline team supports one another through difficult situations. We share useful resources and seek a second opinion when a call is especially hard.

Across thousands of calls, one pattern is clear: people affected by epilepsy are constantly asked to advocate for themselves. They explain their needs at work and at school. They navigate complex systems to obtain insurance coverage and medication, then work with doctors and communities that may not understand seizures. They often do all this while under tremendous emotional or financial strain. The Helpline exists so they do not have to do it alone.

We hope readers understand that the Helpline is a service which promises to treat each person's question as worthy of time and care. We may not always have an answer, but we can help identify next steps.

At the end of the day, our work returns to that first question: "Can you help me?" Our answer begins before we find a resource or send a referral. It begins by staying on the line and listening closely enough that someone feels less alone. If someone hangs up the phone feeling heard and reassured, they may be better able to take the next step. That is when the Helpline has fulfilled its purpose.

For questions regarding epilepsy and seizures, call the Epilepsy & Seizures Helpline at 1-800-332-1000 (or 1-866-748-8008 en español), available Monday–Friday from 8:00 a.m. to 8:00 p.m. EST. You can also connect with a specialist via the online help form.

Written by Tom Buckley, Senior Director of Health Information Services at the Epilepsy Foundation. Tom oversees the Epilepsy Resource Center, which includes the Epilepsy & Seizures Helpline and the National Epilepsy Library. A Board-Certified Human Services Practitioner, Tom holds a Master of Human Services degree from Lincoln University and has certifications in community resource specialization, crisis support, aging and disability, and database curation. He brings four decades of experience in crisis services, information and referral, emergency communications, public safety, public health outreach, and nonprofit program leadership to his work.

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10 in 10

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At the Epilepsy Foundation's Public Health Institute, August 2026

Celebrating Five Years of CDC Partnership

By Liz Dueweke

Dr. Desmond Delk, MPH, Associate Professor and Chair of the Department of Health, Physical Education, and Recreation at Langston University, first heard of the Epilepsy Foundation at the 2024 Society for Public Health Education Conference. The Foundation was holding a Seizure First Aid and Recognition Training to reach public health professionals as part of our education outreach. Connecting public health professionals across disciplines is a key goal of the cooperative agreement between the Epilepsy Foundation and the Centers for Disease Control and Prevention.

"The Epilepsy Foundation training gave me more understanding of seizures," said Delk. "I learned the information to respond properly and connect people with resources."

Dr. Delk became a seizure first aid instructor, establishing himself as a key resource on seizures and epilepsy at Langston University. As the Foundation reflects on the last 5 years of the CDC cooperative agreement, relationships with instructors like Dr. Delk are examples of the impact that one outreach can bring. Reaching Dr. Delk in 2024 had a positive cascading effect. After speaking at the 2025 Public Health Institute at Howard University, he helped shepherd Langston University as host for the 2026 event.

Since becoming an instructor, Dr. Delk has brought seizure first aid and recognition to students on campus, reaching approximately 150 people.

Since 2021, the training and education team at the Foundation has continued towards the mission of a seizure safe society. Over the past 5 years, 1.7 million people have been trained across all the Foundation's training programs. This number only tells part of the story, with evaluations of participants showing gains in confidence and self-efficacy.

"Not only are we improving the knowledge gained in each training, but we are also helping to create safe spaces for people with epilepsy to continue to thrive in their everyday life," said Lily Komraus, MS, senior firector, training & education. "Because of the reach, we are able to build confident communities where people with epilepsy can feel safe."

These accomplishments are only part of the story of the work of the CDC cooperative agreement over the last five years. Key programs like the Chronic Disease Self-Management Program were launched, helping over 100 people with epilepsy self-management. Millions saw the anti-stigma awareness campaign "Change Our Epilepsy Story" across the country, leading to over a thousand new eJourney blog entries.

Continued on next page

“The Epilepsy Foundation training gave me more understanding of seizures.I learned the information to respond properly and connect people with resources.”

Over 300 providers increased their knowledge about rare epilepsies with the “Advancing Knowledge of Not So Rare Epilepsies” Extension for Community Healthcare Outcomes (ECHO). Grants sent to multicultural areas provided epilepsy education in diverse communities. People with epilepsy and caregivers visited Epilepsy.com to reach the Epilepsy Foundation Helpline and SAGE, an AI assistant, for information and support.

“The goal of the CDC cooperative agreement is to achieve the best outcomes, health equity, and quality of life for all people living with epilepsy,” said Dr. Brandy Fureman, Chief Outcomes Officer. “Accomplishing these goals requires a systematic approach, including access to high-quality care, connection to community services, support in safe environments, and empowered individuals and families. Both in person and digitally, the Foundation made incredible strides in improving the lives of people with epilepsy during the past 5 years.”

Together, the epilepsy community remains committed to advancing toward a seizure-safe nation.

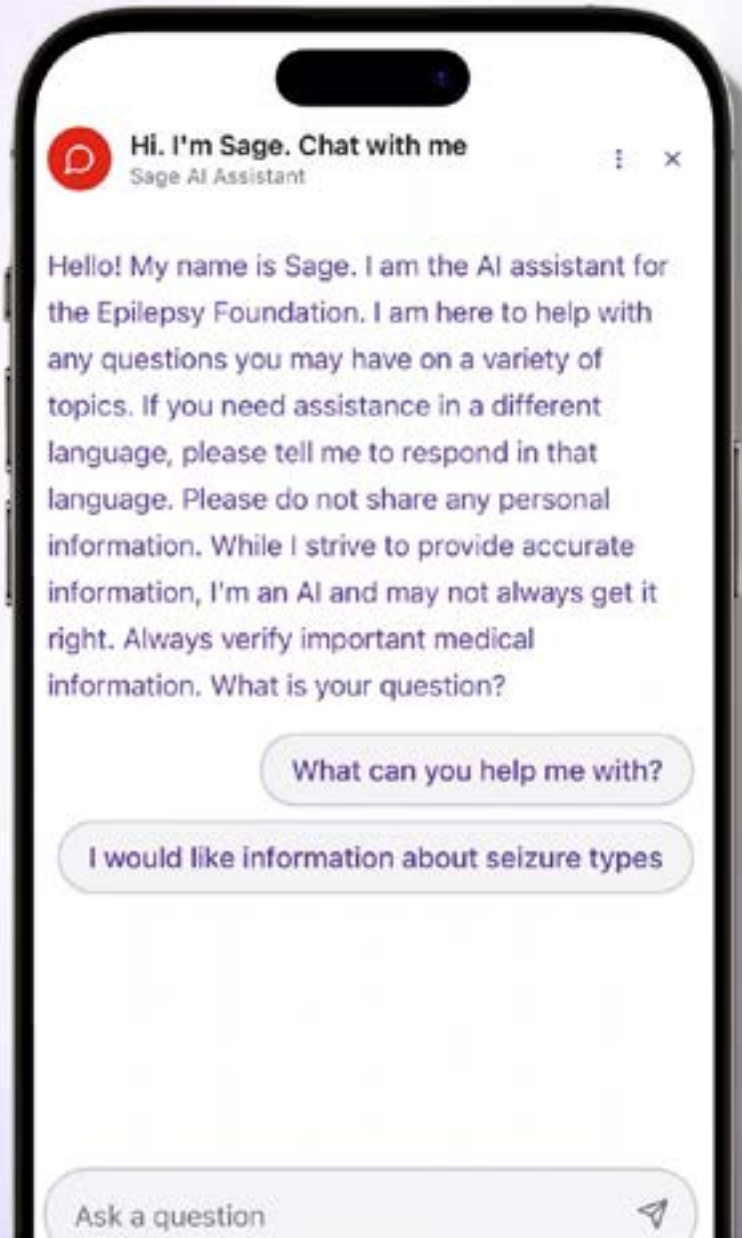


At the Epilepsy Foundation’s Public Health Institute, March 2025

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A Foundation for the Future

Two donors explain why a permanent fund can support the epilepsy community for generations to come.



Roger with picture of his sister, Jeanette
Photo Courtesy of Roger Paschke

For the Epilepsy Foundation of America, establishing an endowment is both a financial milestone and a promise to serve people with epilepsy and their families for generations.

A permanent endowment generates income year after year, providing predictable revenue and giving leaders room to plan beyond immediate needs.

It also signals long-term stewardship. Donors can honor or remember someone through gifts to a fund. For Roger Pashcke and Jim Swanson, this fund is inseparable from the people they love and the change they hope to see for the epilepsy community.

Featured Donor: Roger Pashcke

Roger Pashcke's connection to epilepsy is through his family. Four of his siblings have epilepsy, including his late sister Jeanette, and his brother, Ray. Jeanette began having seizures as a teenager in the 1960s. Ray developed epilepsy later in life, as did two of Roger's other siblings.

At the time, genetic testing was not available to help understand why epilepsy was so prevalent in the family. However, Roger did see the toll epilepsy takes on a person and the importance of meeting the condition head on with determination.

For people and families facing epilepsy, he encourages a mindset rooted in management, not fear. “Epilepsy is shrouded in misunderstanding,” Roger said. “You wouldn’t wish this condition on anyone, but you can manage it with a sense of empowerment by not being afraid of it.”

Roger brings this outlook to the Epilepsy Foundation’s Development Committee. As vice president and chief investment officer at the Hearst Foundation, he understands how disciplined philanthropy can direct resources where they will have the greatest effect. “The endowment provides a form of stability,” he said. “As the fund grows, so can the annual amount available for the Foundation’s priorities. The endowment provides a source of permanence… a stake in the ground for generations to come.”

When thinking of the future, Roger is reminded of a Foundation program, “Teens Speak Up!” that encourages younger members of the epilepsy community to speak out and share their stories.

Roger’s heart remains close to Teens Speak Up!, the Foundation’s advocacy program for young people. He attended the program in Washington D.C. in 2020, just before the COVID-19 pandemic halted in-person gatherings. He remembers the teenagers’ energy and commitment. That spirit, he said, is what donors can help sustain. Featured

Featured Donor: Jim Swanson

When Jim Swanson’s 9-year-old daughter, Danielle, suddenly fell while decorating the family Christmas tree, he knew so little about epilepsy that he began CPR. Her younger sister ran next door for help, and Danielle spent the next month in a hospital neurology unit.

Her mother, Janet, later spoke at Danielle’s school to help classmates and educators understand epilepsy.

Jim still remembers parents saying they did not want their children to play with Danielle. Such reactions, he said, stem from ignorance and persistent stereotypes. Epilepsy is “not a mysterious disease that just takes over,” he said. “Education is essential to replacing fear with knowledge.”

Those experiences drew Jim to organizations combining patient support and science. Through years of involvement with the Foundation and Boston Children’s Hospital, he has followed emerging work in gene editing and research on genetic forms of epilepsy.

He cites zebrafish research as a faster way to investigate genetic questions and artificial intelligence as a tool to accelerate data gathering and analysis. The technology still depends on rigorous human research, he said, but could shorten parts of the discovery process.

Before retiring, Jim was chief investment strategist at MFS Investment Management and, earlier, a mutual fund portfolio manager. Years of speaking nationwide about markets and investing shape how he views the endowment.

“You can’t get things done without money,” Jim said. He sees an endowment as an intelligent way to sustain promising projects and direct dollars toward work with the greatest potential.

For information on how you may invest in the Endowment, please contact Jane Armitage at jarmitage@efa.org.

Beyond the Spasms:
Why the Underlying Diagnosis Matters

December marks Infantile Spasms Awareness Week (ISAW), observed each year from December 1–7 through the Infantile Spasms Action Network (ISAN). For more than a decade, the campaign has carried an urgent message: know the signs and seek treatment quickly. Yet many parents and primary care providers are still unfamiliar with infantile spasms, which can lead to delays in diagnosis.

For families, recognizing these seizures is only the first step. Understanding their underlying cause can help guide treatment and provide important insight into what a child's epilepsy journey may look like moving forward.

Infantile Spasms May Be Only the Beginning

Infantile spasms are a type of seizure that occurs in babies, sometimes also called epileptic spasms. When epileptic spasms begin between 1 and 24 months of age and occur with characteristic EEG abnormalities, a child may be diagnosed with infantile epileptic spasms syndrome (IESS). A syndrome describes the broader pattern of a child's epilepsy, including seizure types, age at onset, and other clinical features. Recognizing this syndrome helps doctors choose the right treatment.

STOP INFANTILE SPASMS

You may also hear the older term West syndrome, which doctors have largely moved away from using. What's most important is that treatment for infantile spasms should never be delayed while waiting to see if a child meets every criterion associated with that older term.

Infantile spasms describe what is happening, but not necessarily why. They can have many underlying causes, including differences in brain development, earlier brain injury, metabolic or chromosomal conditions, and changes in many different genes.

For example, Hypoxic-ischemic encephalopathy (HIE), a brain injury caused by insufficient oxygen and blood flow, is a leading cause of infantile spasms. CDKL5 deficiency disorder is one example of a genetic diagnosis that can cause infantile spasms. Metabolic diseases often can also be identified through genetic testing.

Menkes disease (a copper transport disorder) is an example of a metabolic disease that can cause infantile spasms. For about 1 in 3 children with infantile spasms, the cause remains unknown.

The Underlying Diagnosis Can Inform Treatment

Finding that cause can also directly affect care in some cases. For most infants, first-line treatment includes hormonal therapy such as prednisolone or adrenocorticotropic hormone (ACTH). However, Tuberous Sclerosis Complex (TSC) provides a clear example of why knowing the underlying diagnosis matters. For children with TSC-associated infantile spasms, Vigabatrin is recommended as a first-line treatment. For children with brain malformations, epilepsy surgery can sometimes be an option.

While this is an exception currently, with ongoing advances, the underlying diagnosis may help inform treatment increasingly going forward. This connection is particularly relevant to the Rare Epilepsy Network (REN), which brings together communities affected by rare epilepsies with hundreds of different underlying causes.



Fast Intervention Is Critical

Recognizing and treating infantile spasms quickly is critical because each week of delay can worsen long-term developmental outcomes. That makes awareness important at every step. Recognizing the signs can help a child receive treatment sooner, while understanding what is causing the spasms can help families know what to expect as their child grows, identify other health concerns to watch for, and determine whether condition-specific treatments or research opportunities may be available.

This Infantile Spasms Awareness Week, learn what infantile spasms look like and help others recognize the signs. Share this important information with parents and caregivers in your community so more children can get the care they need sooner. Visit ISAN to learn the signs and help spread awareness and explore the Rare Epilepsy Network (REN) to connect with resources and organizations supporting the rare epilepsy community.

By Emma Tucker, Clinical Research Assistant, Rare Epilepsy Network (REN)

Clinical review by Christina Briscoe, MD, EdM, Instructor of Neurology, Boston Children's Hospital/Harvard Medical School

News Briefs



14th Annual Shark Tank Awards $250K

The Epilepsy Foundation of America awarded $250,000 in funding at its 2026 Shark Tank Competition, held during the Pipeline Conference in Leesburg, Virginia. Five finalists presented innovative ideas in epilepsy treatment, care, and community outreach, competing for funding to advance new solutions for people with epilepsy.

Read more: epilepsy.com/stories/14th-annual-shark-tank-competition-awards-250k

Joyce A. Cramer Receives Lifetime Accelerator Award

We're proud to honor Joyce A. Cramer as this year's Lifetime Accelerator Award recipient for transformative contributions to clinical research and epilepsy innovation. This award recognizes individuals whose work has had a lasting impact on the development of epilepsy therapies. Joyce's contributions continue to drive innovation for our community.

Read more: epilepsy.com/stories/cramer-receives-lifetime-accelerator-award-contributions-epilepsy



Senate Unanimously Passes National Plan for Epilepsy Act

In a major milestone for the epilepsy community, the U.S. Senate unanimously passed the National Plan for Epilepsy Act (S. 494), advancing a coordinated national strategy to improve epilepsy care, accelerate research, and enhance quality of life for people living with epilepsy. This historic achievement reflects years of dedicated advocacy by individuals with epilepsy, families, caregivers, healthcare professionals, researchers, and partner organizations nationwide.

Read more: .epilepsy.com/stories/epilepsy-community-celebrates-passage-epilepsy-act





PHI 2026: Building More Inclusive Communities

The 2026 Public Health Institute (PHI) brought together public health professionals, community leaders, advocates, researchers, and people impacted by epilepsy in Tulsa, Oklahoma, Aug. 26–28. Hosted in partnership with Langston University, the event fostered meaningful connections and collaboration to advance health equity and improve outcomes for diverse epilepsy communities. Participants shared ideas and built partnerships that can help create stronger, healthier, and more inclusive communities for people impacted by epilepsy.

Learn more: epilepsy.com/programs/public-health-education/phi-conference

In your community



Marquette Mini-Stroll Highlights the Power of Community

On October 25, the Epilepsy Foundation of Michigan partnered with Northern Michigan University to host the second annual Mini-Stroll for Epilepsy in Marquette. Led by student advocate Alex Hopper, the event brought local students and families together for a day of education, connection, and support. This meaningful program highlights the Foundation's commitment to serving rural communities across the Upper Peninsula, reinforcing that no one facing epilepsy is alone.



A Spooktacular Halloween Celebration in Southern Illinois

Ghouls, ghosts, and costumed guests gathered for a spooktacular time at the Epilepsy Foundation of Greater Southern Illinois' Halloween party on October 23.

Complete with festive decorations, seasonal treats, and plenty of Halloween fun, the event provided a welcoming space for clients, families, and supporters to connect and celebrate together. It was a truly boo-tiful evening filled with laughter, community, and Halloween spirit.



Team Epilepsy Foundation Greater Chicago (EFGC) Raises More Than $140,000 at Chicago Marathon

On October 12, 58 runners representing Team EFGC took on the Bank of America Chicago Marathon, persevering through unusually warm weather in support of the epilepsy community. Together, the team raised over $140,000 to fund EFGC's vital programs and services for affected individuals and families. Their incredible dedication demonstrates the power of coming together to make a lasting impact.



Minnesota Walkers Show Their Support - Rain or Shine

Rain or shine, Minnesota communities came together to support people affected by epilepsy through this year's Epilepsy Walks.

Thanks to the dedication and generosity of participants, volunteers, sponsors, and supporters, the walks raised $209,262 to help fund vital programs, services, education, advocacy, and support for individuals and families impacted by epilepsy.



Camp Starlight Creates Lasting Memories and Connections

Starlight 2026, Arizona's Family Camp, was a wonderful success hosted by the Epilepsy Foundation Arizona. Families spent a beautiful fall weekend making lasting memories and connecting with others who understand the epilepsy journey. It gave participants a chance to relax, have fun, and build strong support networks within the community.

Your local Epilepsy Foundation is here to help you in your epilepsy journey.

With our nationwide network of partners throughout the United States, the Epilepsy Foundation connects people to treatment, support, and resources. We lead advocacy efforts, fund innovative research, train specialists, and educate the public about epilepsy and seizure first aid.

Find your local office **epilepsy.com/local**



Recipe Corner - A Taste of Fall

Recipes courtesy of KetoCal Nutricia

PUMPKIN SPICE SHAKE

228 calories, 4:1 Ratio

Bring the flavors of fall home with this tasty treat, no drive-thru required!

Ingredients
120 g KetoCal 4:1 LQ Vanilla
15 g pumpkin, canned, unsweetened
5 g canola oil
1 g cinnamon

Instructions
1. Add all ingredients into a blender.
2. Blend until smooth.
3. Once prepared, serve immediately or store in a refrigerator for up to 24 hours.

Apple Crisp

303 calories, 4:1 Ratio

This warm and comforting apple crisp is the perfect seasonal dessert.

Ingredients
15 g apple, raw without skin, diced
20 g cream, 36%
1 g cinnamon, ground
2 g Truvia® sweetener
15 g KetoCal 4:1 powder
6 g almond flour, ground blanched almonds
12 g butter

Instructions
1. Preheat oven to 325°F.
2. Weigh ingredients separately.
3. In a small oven safe dish, place apple, cream, cinnamon, and Truvia.
4. In a separate bowl, mix KetoCal with flour and butter until crumbly.
5. Pour mixture over apples.
6. Bake in preheated oven for 15-20 minutes.
7. Cool before serving.

Please remember, the ketogenic diet should only be used under close medical supervision. Always check with your healthcare professional to ensure that a recipe is appropriate for your situation.



The Link Between Mental Health, Connection & Belonging

Wellness is a balance of mind, body, emotions, and social relationships. For people living with a chronic illness such as epilepsy, connecting with others who share similar experiences can strengthen mental health.

Belonging is a basic human need that can reduce stress and anxiety—because there is no health without mental health.

The Epilepsy Foundation of America helps people build supportive relationships through in-person and virtual support groups, educational webinars, and self-management programs. These resources can make it easier to navigate challenges, get enough sleep, maintain relationships, and live independently.

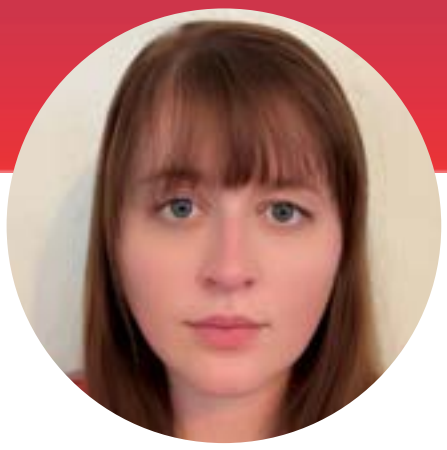
The Foundation also offers local, state, and national walks that raise epilepsy awareness. On its eJourney platform, individuals can share their stories and use writing as a therapeutic outlet. Such opportunities are valuable because socially connected adults tend to be healthier, live longer, and function better at school or work.

Together, these resources advance the Foundation's vision that no one faces epilepsy alone.

Maureen "Mo" Ernst Slotnick, MBA, MSW, currently serves as Director of Programs and Partnerships at the Epilepsy Foundation of America. She works with people with epilepsy, their caregivers, doctors, and researchers who treat individuals living with epilepsy.

Epilepsy Stories from the Community

"Before sharing my story, I had never heard of the Epilepsy Foundation. One day, I saw an Epilepsy Foundation advertisement on a Regional Transit Authority (RTA) bus in New Orleans and felt inspired to add my voice to the thousands of others fighting the same battle. No one fights alone. Don't let epilepsy define you or hold you back. No matter what you're thinking or feeling in the moment, every day you get back up and keep moving forward, you're winning. And that's something epilepsy can never take away from you."



ELIZABETH KRISTINE
Oklahoma

Where Empowered Journeys Begin



2025 National Epilepsy Walk

THE COMMUNITY MAGAZINE OF THE EPILEPSY FOUNDATION

The mission of the Epilepsy Foundation is to improve the lives of people affected by epilepsy through education, advocacy, research, and connection.

EPILEPSY FOUNDATION

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