

THE COMMUNITY MAGAZINE
OF THE EPILEPSY FOUNDATION

epilepsy.com



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Empowered Journeys

Reimagining Epilepsy Care

The Epilepsy Foundation's newest initiatives, SAGE and empowER&D, represent an exciting evolution in how technology can serve the epilepsy community.



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Dear Friends and Supporters,

Over the past year, our focus has been on you, the epilepsy community we are honored to serve. We are excited to introduce Empowered Journeys, our newly reimagined magazine. Published twice a year, it celebrates the people, stories, and passion that define the epilepsy community. While the name and timing have evolved, our mission remains the same: to improve the lives of people affected by epilepsy through education, advocacy, research, and connection. We are here for every step of your journey, through challenges and triumphs, working to ensure that no one faces epilepsy alone.

We are also continuing to build momentum. In recent months, we have made significant progress

in strengthening our leadership within the epilepsy community, and we are working every day to make an even greater impact. A key part of this work is empowER&D™ (Empowering Epilepsy Research and Development), our latest research initiative designed to advance epilepsy care, deepen connection, and elevate the importance of research shaped by lived experience.

Your voice, and your data, are powerful. By securely sharing your experiences, you can become an active partner in driving discoveries and increasing understanding of epilepsy. Every contribution helps build a more robust dataset that can fuel innovation, support the development of new treatments, and ensure research reflects the realities of those living with epilepsy.

We are also leveraging new technology to expand access to trusted information and support. SAGE, our AI Epilepsy Assistant, makes it easier than ever to find answers and resources. By visiting epilepsy.com, you can explore reliable information and connect with SAGE to quickly

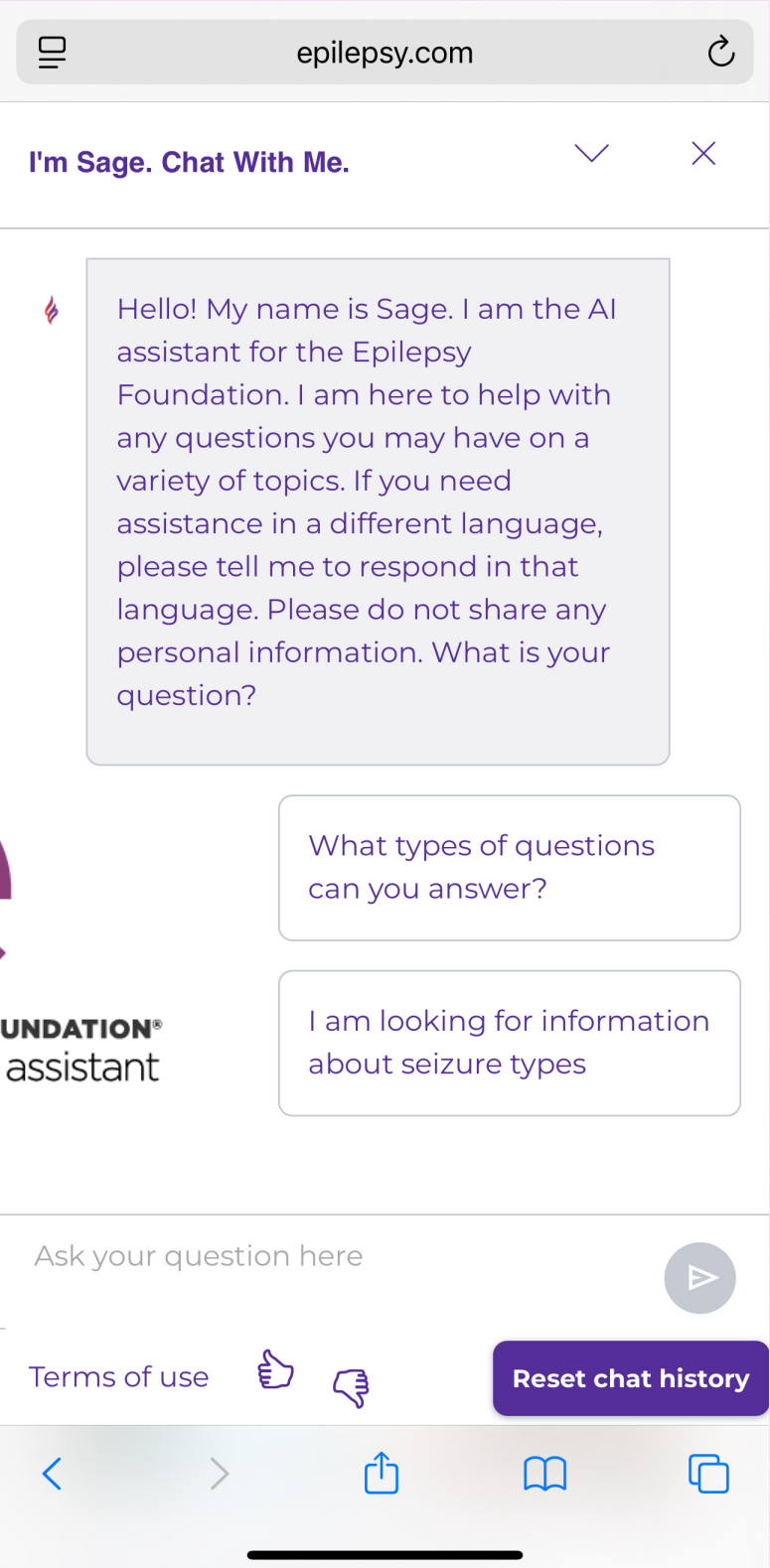
find personalized guidance and support that can help you navigate your epilepsy journey with greater confidence.

The future of epilepsy care is bright, and so is the future of the Epilepsy Foundation. As we continue to invest in tools, research, and programs that strengthen our community, we remain grounded in why we do this work: to empower, to inspire, and to bring people together.

Thank you for being part of this journey and for helping shape the future of epilepsy care.

A handwritten signature in black ink that reads "Bee Martin Lee". The signature is written in a cursive, flowing style.

BERNICE "BEE" MARTIN LEE



sage

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Reimagining Epilepsy Care

How AI and Living Data Are Powering a New Era

By: Kaitlyn Gallagher

The Epilepsy Foundation's newest initiatives, SAGE and empower&D, represent an evolution in how technology can serve the epilepsy community. One is deeply personal and immediate. The other is expansive and forward-thinking. Epilepsy care is entering a new era defined by technology that meets people where they are. At the intersection of compassion and technology, a more connected and responsive future is beginning to take shape.

SAGE - YOUR NEW AI COMPANION

Health questions don't wait for office hours, so the Epilepsy Foundation of America is reimagining support to meet the community's needs. Part of this shift is SAGE, an AI-powered assistant designed to provide trusted information, guidance, and reassurance whenever it's needed most.

"SAGE is your always-available epilepsy companion," explained David-Alexandre Jost, Chief Technology & Innovations Officer, Epilepsy Foundation of America. "An AI-powered assistant that

can answer your questions in almost any language, help you understand your diagnosis, and make you feel a little less alone at 2 a.m. when something worrying happens and the doctor's office is closed."

SAGE is built on more than two decades of trusted epilepsy knowledge. It is based on thousands of pages of medically reviewed content developed by experts and shaped by the community.



David-Alexandre Jost, Epilepsy Foundation of America's Chief Technology & Innovations Officer, presenting at AWS Imagine.

"I always describe it simply," said David-Alexandre. "It's like having a knowledgeable, compassionate friend who knows everything about epilepsy and is always there when you need them."

A traditional search engine offers links which are often overwhelming, sometimes misleading, and occasionally frightening. SAGE offers something different.

"When you type a question into Google, you get ten blue links; some good, some not," said David-Alexandre. "SAGE meets you where you are, understands the context of what you're asking, and responds the way a knowledgeable person would: with clarity, warmth, and accuracy. It doesn't send you somewhere else. It stays with you."

Epilepsy does not exist in isolation. It weaves itself into daily routines, relationships, decisions, and identity. It is as much about lived experience as it is about clinical management. SAGE was designed with that reality in mind.

A parent may notice subtle behavioral changes in their child after a medication adjustment. A newly diagnosed adult may struggle to understand unfamiliar terminology. A caregiver could witness a breakthrough seizure that continues to upset them long after the seizure is over.

“SAGE is built for those moments,” David-Alexandre explained. “It provides clear, compassionate information whenever people need it.”

This emphasis on meeting people where they’re at is one of SAGE’s most powerful features. It recognizes that the need for support is not scheduled.

DESIGNING AI FOR EMPATHY AND ACCURACY

In healthcare technology, accuracy is essential. But David-Alexandre and his team took it one step further. Empathy was treated as a core requirement for this AI chatbot, not just an enhancement.

“We made a deliberate decision that SAGE would recognize emotional needs and respond to the human being first, before the information,” shared David-Alexandre.

This philosophy influenced every aspect of development, including the choice of AI model.

“The AI we chose to power SAGE... was selected in large part because of its exceptional capacity for empathy and safety. Those qualities aren’t nice-to-haves in a healthcare AI. They’re non-negotiable.”

One story, shared by David-Alexandre, powerfully captures this impact.

A mother reached out late at night, concerned about her toddler’s behavior. The child had been acting aggressively and holding her unusually tight. She was frightened, exhausted, and searching for answers. SAGE walked her through the medical context, explaining how certain seizure types and medication side effects can manifest as behavioral changes in young children. But SAGE also acknowledged her feelings. It let her know that what she was experiencing emotionally, the exhaustion and the worry and the guilt, is something many caregivers carry, and that it’s okay to feel that way.

Her response was simple:

“You have no idea what you have, your words are exactly what I need — it feels like a hug.... Thank you so much and good night.”



You have no idea what you have, your words are exactly what I need – it feels like a hug.... Thank you so much and good night.

TRUST AS A CONTINUOUS PRACTICE

In healthcare, trust is not assumed. It is earned and re-earned. To ensure reliability, SAGE operates within a tightly controlled knowledge environment. It does not browse the open internet. It does not speculate. It draws exclusively from a curated, expert-reviewed knowledge base.

“If the information isn’t in our verified knowledge base, SAGE says so and directs the user to our Helpline or their healthcare provider,” explained David-Alexandre.

Additional safeguards reinforce this foundation. SAGE adheres to strict domain boundaries, declining questions outside of epilepsy. It includes emergency protocols, directing users to call 911 in crisis situations. And it is continuously evaluated by clinical experts and patient advocates.

Privacy is equally central. Built on secure infrastructure with HIPAA-aligned capabilities, SAGE ensures that user interactions remain anonymous and protected. All sessions are anonymous, and SAGE’s guardrails strip out personally identifiable

information.

FROM VISION TO REALITY

The creation of SAGE was not a single moment of innovation. It was the culmination of a multi-year digital strategy. In 2022, the Epilepsy Foundation of America convened a group of leaders to reimagine how digital tools could better serve the community. What emerged was a product concept and a broader vision at the same time. The concept and vision recognized the importance of data infrastructure as the foundation for meaningful AI.

After this meeting, there was a period of intensive groundwork, which included building the architecture, structuring the data, and laying the foundation for what SAGE would become.

By 2024, a working prototype was ready for presentation. From there, development accelerated. Within months, SAGE moved from concept to live deployment, already supporting thousands of interactions.

“Four years from whiteboard to 50,000 conversations,” said David-Alexandre. “And we’re just getting started.”

EMPOWERING THE EPILEPSY COMMUNITY

While SAGE focuses on the individual experience, delivering information and support in real time, empowerER&D expands the lens.

EmpowerER&D (Empowering Epilepsy Research and Development) was designed to address a persistent gap between the questions that matter most to people with epilepsy and the data that researchers, clinicians, and industry have traditionally accessed.

Historically, research was limited by disconnected sources of data. Clinical records may be in one place, while recorded patient experiences live in another. This limits mechanisms for capturing change over time from both experiences. EmpowerER&D seeks to unify these sources into a single, evolving ecosystem. The idea behind empowerER&D is to create a “living dataset.”

“A living dataset simply means it evolves over time,” explained Caitlin Grzeskowiak, Ph.D., Chief Research and Innovation Officer, Epilepsy Foundation of America. “Instead of collecting information once and letting it sit, empowerER&D is designed to grow and build upon each participant’s journey with epilepsy.”

This approach creates a longitudinal, de-identified data resource capable of capturing changes in health, treatment, outcomes, and lived experience in a way that reflects real life for research use. One of empowerER&D’s most exciting features is its ability to integrate electronic health records with patient-reported data.

“Clinical records can tell us what has happened in the healthcare system,” said Caitlin. “And data reported by the participant helps us understand impact, symptoms, quality of life, treatment burden, and what isn’t documented in clinical visits.”

This combination offers a more complete picture of epilepsy. This goes beyond clinical metrics to include the realities of real life with epilepsy.

By bringing these data streams together, empowerER&D has the potential to generate insights that are more relevant for treatment development, clinical care, and quality-of-life improvements.



“The more representative the data, the more representative the science,” shares Caitlin.

A NEW MODEL FOR RESEARCH PARTICIPATION

Empower&D also redefines the role of participants in research. Rather than serving as passive data contributors, individuals become active partners in discovery. Participants can engage with the platform, explore de-identified data, and even begin to act like researchers themselves.

As with SAGE, trust is foundational to empower&D. The platform is designed with rigorous safeguards, including independent ethical review and approval with an independent Institutional Review Board (IRB), secure data infrastructure only the Epilepsy Foundation can access, and de-identification protocols.

“Participant data is maintained in a secure data lake environment designed to align with the best current industry standards for protecting sensitive health information,” said Caitlin

Equally important is transparency.

“We think very carefully how to steward this data responsibly,” Caitlin added. “That includes clear consent processes, controlled access, defined data governance, and a commitment to transparency

about how information is collected, protected, and used.”

These measures are essential for building confidence, particularly in communities that have historical reasons to be cautious about data sharing.

I hope empower&D helps unlock a deeper understanding of the complexity of epilepsy



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EMPOWER EPILEPSY RESEARCH



“Representation has to be intentional,” Caitlin noted. “It requires thoughtful outreach, trusted community partnerships, constant iteration, and sustained engagement strategies.”

The goal of empowerER&D is not simply to collect data, but to answer meaningful questions, especially those that have remained elusive.

“Why do people with similar epilepsy diagnoses have very different real-world outcomes?” Caitlin wondered. “That is the kind of simple, basic questions we need to address, and we still don’t fully understand.”

By capturing longitudinal data that reflects both clinical and lived experience, the platform has the potential to uncover patterns related to treatment response, quality of life, mental health, and access to care. It can illuminate the complexities of epilepsy in ways that traditional studies cannot.

“I hope empowerER&D helps unlock a deeper understanding of the complexity of epilepsy,” said Caitlin, pointing to challenges ranging from driving restrictions to long and difficult treatment journeys.

A FUTURE DEFINED BY CONNECTION

The creation of both SAGE and empowerER&D is the result of technological innovations that help keep the epilepsy community safer.

EmpowerER&D is creating pathways for individuals to contribute to research in meaningful ways. SAGE is building systems that listen as much as they inform.

“That you are not alone,” David said, reflecting on what they hope people take away. “Whatever you’re facing... there is a place you can go that will meet you with accurate information and genuine compassion, any time you need it.”

And for those considering participation in empowerER&D, the message is equally clear:

“Their experience matters, and research is stronger when it reflects real life,” said Caitlin.

As SAGE continues to evolve and empowerER&D grows, the Epilepsy Foundation is redefining what support, research, and community can look like in the digital age.

EpiWatch's Continuous Seizure Monitor (CSM)TM



Utilizes AI/Machine Learning based algorithm detects and alerts for seizure activity

Runs on the ubiquitous Apple Watch

Accurately, discreetly, and passively monitoring and alerting caregivers for life-threatening tonic-clonic seizures while collecting real-world biosensor data

Evolved from a long-term research relationship with Apple, Johns Hopkins University, EpiWatch

Strong IP/Patent position

FDA 510(k) Clearance pending



Always On

How Wearable Technology Is Transforming Seizure Monitoring with EpiWatch

By: Kaitlyn Gallagher

In an era where digital health tools are reshaping how we understand and manage chronic conditions, wearable technology opens new doors for people with epilepsy. Among these innovations, EpiWatch stands out as a clinically validated, FDA-cleared solution designed to bring greater safety and peace of mind to individuals and their families.

EpiWatch was created to address one of the most urgent challenges in epilepsy care: knowing when a seizure is happening. This is especially

important when no one is there to witness it.

“People with epilepsy, their families, and caregivers can benefit from continuously monitoring for life-threatening seizures, with an easy-to-use, discreet, passive, and wearable monitor to alert caregivers if their loved one has a seizure while unattended,” shared Teresa Prego, CEO, EpiWatch.

For people with uncontrolled tonic-clonic seizures, particularly those that occur at night, risks can be profound. Sudden Unexpected Death

in Epilepsy (SUDEP) is the sudden, unexpected death of someone with epilepsy, who was otherwise healthy. In SUDEP cases, no other cause of death is found when an autopsy is done. Each year, more than 1 in 1,000 people with epilepsy die from SUDEP. This is the leading cause of death in people with uncontrolled seizures.

“SUDEP risk can be reduced by prompt intervention from a caregiver, loved one, or parent – but first, they must know a seizure is occurring,” said Teresa.

EpiWatch addresses this gap by turning a familiar, consumer-friendly device into a medical tool. Built to run on a widely used smartwatch platform, it blends seamlessly into daily life while delivering continuous monitoring.

The user experience is straightforward. After downloading the app and activating a subscription, users simply start monitoring from their watch. From there, the technology works quietly in the background. If a tonic-clonic seizure is detected, the watch immediately engages the user.

“An alert will show on the watch that indicates a seizure has been detected and asks if they are OK,” said Teresa.

If the alert is dismissed, no further action is taken. But if there is no response, the system escalates, automatically notifying pre-selected emergency contacts.

Notifications can be customized to reach caregivers through phone calls, text messages, or email, ensuring flexibility in urgent situations.

In clinical trials, EpiWatch demonstrated a 98% detection rate for tonic-clonic seizures. This is a level of reliability that is critical



for both safety and trust in the use of a wearable device.

“What we have heard from patients and families is a sense of relief, that loved ones will know when a seizure is happening,” explained Teresa.

For families who have long relied on constant vigilance, like sleeping nearby, checking frequently, or living with uncertainty, this technology offers a new layer of protection and support.

EpiWatch is both a monitoring tool and a data engine. By capturing objective physiological signals, it helps bridge a longstanding gap in epilepsy care. It can otherwise be difficult for people with epilepsy and their families to provide accurate seizure reporting to their physician.

“Because we are able to capture objective data, and auto-populate the seizure journal with detected seizures, we can help make the ‘how have your seizures been’ part of the clinical discussion more well-informed,” said Teresa.

This capability has meaningful implications for treatment decisions. In some cases, users have even combined EpiWatch data with neurostimulation device data to better understand seizure patterns and optimize therapy.

For Teresa, her work with EpiWatch is both part of her professional and personal life. One of her children has epilepsy and was diagnosed at the age of five. She recognizes how difficult it is to worry about missing a seizure or not knowing one is happening.



“I had developed a personal algorithm for my daughter to help our family understand her seizure cycle... so when the opportunity to play a role at EpiWatch came up, I was very excited to join the team,” shared Teresa.

Like many digital health innovations, EpiWatch has navigated complex challenges on its path to market, including regulatory approval, clinical validation, and reimbursement. Even after achieving FDA clearance, questions remain about how such tools fit into clinical workflows and how they are covered by insurance.

“We are working with several advocacy groups like the Epilepsy Foundation of America on continuing to advocate and lobby for mandated reimbursement for seizure detection devices,” said Teresa.

In a world where technology is often measured in features and functionality, EpiWatch offers something more enduring. Confidence and the possibility of greater independence with support are within reach.

A Season to Grow Something Meaningful

By: Tiffany Tulowitzki-Johnston

As we continue to welcome spring, let's bring growth, renewal, and hope to more than just your garden. Explore ways to support the epilepsy community that are both impactful today and sustainable for the future. Whether you choose to **give monthly**, take advantage of **employee matching**, or consider **planned giving**, each option offers a thoughtful way to plant the seeds of generosity.

Monthly giving is one of the simplest ways to make a lasting difference. By setting up a recurring gift, you provide steady, reliable funding that allows the Epilepsy Foundation to plan ahead, expand programs, and respond to urgent needs year-round. It's a flexible and convenient way to watch your impact blossom over time.

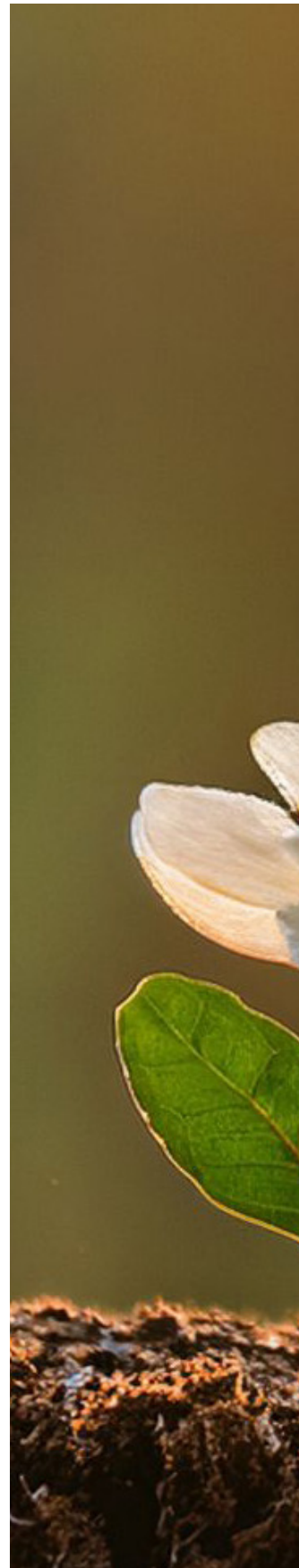
You can also grow your contribution through **employee matching**. Many companies will match donations made by their employees, sometimes doubling or even tripling your gift at no additional cost to you. While

making a donation through our website, you can easily search to see if your employer offers a matching gift program.

For those looking to make a legacy impact, **planned giving** offers a powerful opportunity to support the future of the epilepsy community. Options such as including the Epilepsy Foundation in your will, designating the Foundation as a beneficiary, or contributing through other long-term financial plans can help to strengthen our roots for generations to come.

However you choose to give, know that your support leads to a future where no one faces epilepsy alone.

Learn more at
epilepsy.com





Where Empowered Journeys Meet the Rare Epilepsies

In the world of epilepsy, a diagnosis is just the beginning of a journey. For those with rare conditions, that journey often requires a specialized map and a collective voice.

As Empowered Journeys comes to life at the Epilepsy Foundation of America (EFA), the Rare Epilepsies Network (REN) is right there helping ensure the rare epilepsy community is seen, heard, and connected every step of the way.

Born from an EFA registry project funded by a \$3 million PCORI grant with just ten founding partners in 2013, REN has grown - thirteen years later - into a standalone 501c3 nonprofit organization and network of hundreds of rare epilepsy organizations representing the spectrum including Developmental and Epileptic Encephalopathies, “ultrarare” or “nano rare” epilepsies, and more. Thanks to advances in genetic testing and advanced imaging, rare and genetic epilepsies are being diagnosed more than ever before,

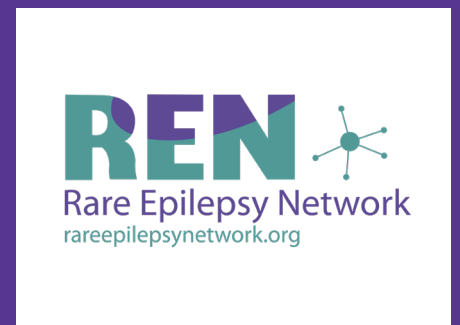
reshaping how we understand all of epilepsy.

REN creates collaborative research, advocacy, education, and care opportunities for all rare epilepsies. Each of these organizations supports families with disorder-specific information, education, and community, while also advancing research and creating opportunities to participate in clinical trials. At the same time, they are helping train neurologists and other healthcare providers to better understand the natural history of these conditions and how to care for patients. They are also on the frontlines of developing precision therapies - treatments designed to address the underlying cause of disease and change the future for patients and families.

If you have been diagnosed with epilepsy, but don't know the cause, learn how to find your “why”.

If you have a rare diagnosis, find your community among our hundreds of members and partners

If you care for patients, connect



to research and grants; patient resources, and a broader network of support.

If you want to stay up to date on all rare epilepsy trends, news, innovations, leaders, and trials, subscribe to our newsletter.

In the Rare Epilepsy Network, we believe that while our diagnoses are unique, our strength is found in our shared mission. Together, we are The Rare Epilepsy Voice.

For more information, please visit: rareepilepsynetwork.org



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From the Big Screen to Real Life

A Nationwide Effort to Raise Seizure Safety Awareness with SeizeSense

By: Kaitlyn Gallagher



Cristian Veloso

For many, a trip to the movies is a chance to relax, escape, and enjoy a story on the big screen. This past spring, moviegoers across the country were also invited into a different kind of story rooted in awareness and empathy.

Through a collaboration between the Epilepsy Foundation and a nonprofit called SeizeSense, a new public service announcement (PSA) brought seizure safety education to audiences nationwide. The animated spot, created to teach viewers how to recognize and respond to a seizure, was shown in AMC Theatres locations across the country. The PSA appeared on approximately 7,000 screens in more than 530 theaters from March through the beginning of April 2026.

Behind SeizeSense is a deeply personal story. Its founder, Cristian Veloso, was diagnosed with epilepsy at just four years old after experiencing a tonic-clonic seizure while on a family trip to Spain. What followed were years of careful monitoring, daily medication, and limitations that set him apart from his peers. Simple childhood activities required extra planning. Currently, Cristian receives ongoing care, which includes regular EEGs at Boston Children's Hospital.

Despite the challenges he faces with epilepsy and seizures, Cristian created his own nonprofit, SeizeSense. The mission of SeizeSense is simple but powerful. Cristian hopes to educate everyone with the knowledge they need to respond effectively when someone has a seizure, while

also reducing stigma and building more inclusive communities. This mission also helped to inspire the creation of the PSA.

"Movie theaters are such popular public spaces," Cristian shared. "They're also places where seizures can happen. It felt like the perfect opportunity to reach a broad audience and make a real impact."

Bringing the PSA to life was a collaborative effort, developed alongside a creative team at Blancolorenz.com. Over several weeks, they worked together to shape the message, visuals, and tone, ensuring the final piece was both engaging and informative, while meeting the technical requirements for national distribution.

The result is a brief but meaningful moment before the previews roll that provided the audience with a chance to learn something that could one day help a member of the epilepsy community.

By meeting people in everyday spaces like movie theaters, the Foundation continues to expand awareness and ensure more people feel confident stepping in to help.

We thank Cristian for his ingenuity and help in reaching an even larger audience on the big screen.

To watch the PSA, visit the Foundation's Youtube channel.



“MOVIE THEATERS ARE SUCH POPULAR PUBLIC SPACES. THEY’RE ALSO PLACES WHERE SEIZURES CAN HAPPEN. IT FELT LIKE THE PERFECT OPPORTUNITY TO REACH A BROAD AUDIENCE AND MAKE A REAL IMPACT.”

-Cristian



Creating Community through an Online Self-Management Program



Taryn F.,
CDSMP participant

By: Liz Dueweke

From balancing medications, sleep schedules, and communication with healthcare providers, self-management with epilepsy is an ongoing challenge. For those in more rural areas of the United States, these hurdles can be increased with isolation and lack of a close-knit epilepsy community. The need for additional resources, as well as connection, brought Taryn F. from Michigan's Upper Peninsula (UP) to the Chronic Disease Self-Management Program (CDSMP) hosted by the Epilepsy Foundation of Michigan.

"I joined because I wanted to be proactive, since life can be so unpredictable with epilepsy. I wanted to be able to find out about things I could use in daily life," Taryn said. "I also wanted the connection. In the UP we are pretty isolated. Sometimes you feel kind of alone but it's nice to connect with others who understand what it's like to navigate this condition. Even though I was up in the Upper Peninsula, there were participants from all over Michigan."

Funded by the Epilepsy Foundation's Centers for Disease Control and Prevention's cooperative agreement, the CDSMP program is a free, virtual, six-week program that teaches life skills and mindfulness to help manage epilepsy.

Delivered by eight affiliate Epilepsy Foundation organizations across the national network, the program goes beyond self-management best practices by equipping participants with practical strategies for communicating effectively with healthcare providers and support systems, navigating epilepsy care, and developing a personalized action plan.

"While I am at my neurologist appointments, I always come prepared with notes and questions that are captured in my phone and written on large index cards," said an anonymous participant who took the program with the Epilepsy Foundation of Eastern Pennsylvania.

The program is free to people with epilepsy and caregivers over the age of 18 who help manage the condition. The family member's contribution is key, since epilepsy impacts the entire family.

Since EF's CDSMP program was launched in 2023, the Epilepsy Foundation network has served over 100 people with epilepsy. A recent poster presented at the American Epilepsy Society Meeting noted that participants in the program showed improvements in epilepsy self-management, depression, and self-efficacy.

"The classes have enabled me to learn more about my epilepsy and the tools to navigate it, which include eating habits, resting, breathing, more active participation with healthcare providers, creating an action plan and problem-solving techniques," the anonymous participant said.

After participants complete the program, they are welcomed to join continuing support groups to stay in touch with other participants and talk about self-management.

"We are thankful we can create a bridge to those that have done CDSMP to continue on their journey of self-management by offering the support group now," said Maureen Slotnick, Director of Programs & Partnerships.

The program will continue to be delivered across the Epilepsy Foundation's national network. To find out more about the program, email CDSMP@efa.org.

"I went in not knowing what to expect, and it was such a welcoming environment, and I felt so comfortable sharing," said Taryn. "I would tell anyone to give it a try. Everything feels so supportive."

Raising Awareness for Athletes with Epilepsy and Reaching the Finish Line

By: Ashley Grese

This February, 21-year-old Rowan Haffner raced in the USA Track & Field 100-Mile Road National Championships to raise funds for GIVE26, honoring the 1 in 26 people who will develop epilepsy in their lifetime. After his own epilepsy diagnosis at age 17, Rowan uses endurance sport to reclaim agency, challenge stigma, and show what's possible for athletes living with epilepsy.

The USA Track & Field 100-Mile Road National Championships is a 1.1-mile loop completed 85 times. "This race was without question the hardest challenge I've ever taken on," Rowan said. He trained relentlessly and set a goal to complete the race in under 26 hours.

"The race went super well! I finished in 22 hours and 35 minutes, placing 10th overall among males and first in the under-30 age group."

Rowan also raced in support of the Epilepsy Foundation's Athletes vs. Epilepsy initiative, which highlights athletes living with epilepsy and aims to raise awareness through sporting events. Rowan wore a custom shirt featuring the Athletes vs. Epilepsy logo, "to help spark conversation and awareness with every mile."

In just a few years since being diagnosed with juvenile myoclonic epilepsy, Rowan has gone on to complete an Ironman, set a Guinness World Record, and place third overall at the USATF 50-Mile National Championships. He also gave a TEDx talk, "Overcoming the Incurable: My Story with Epilepsy," reflecting on how endurance sport became a central part of his journey with epilepsy.

Rowan is currently pursuing a master's degree in positive psychology at UPenn, where his capstone research examines post-traumatic growth in people with epilepsy. "I'm driven to understand what enables individuals with epilepsy to flourish and how we can better support youth on this journey," Rowan said.

For Rowan, the finish line is just the beginning. He plans to pursue a career in medicine, where he can continue serving those with epilepsy and neurological disorders — and help them find their own start line.



Rowan Haffner

Raceclock™
ELECTRO NUMERICS

03:14.42





If You've Got It, You Get It

By: Jessica Veach

Support within the epilepsy community is strong and reliable. Thanks to the Walk for Epilepsy, hundreds of people with epilepsy can gather each year to connect with one another for the first time, or revisit with old friends.



When I was first diagnosed with epilepsy, it felt like I was managing a private battle that most people don't see or understand. It was isolating and confusing. However, once I got to know others in the epilepsy community, it was a huge relief to meet others who were going through the same things as I was. No need to explain. They just understood.

Being a part of the epilepsy community is a shift from just "having a condition" to being part of a movement. It means taking the challenges we face—the side effects, the uncertainty, the recovery time—and using them to build a support system that ensures nobody has to figure this out alone.

The Walk for Epilepsy is the cornerstone of that effort. On the surface, it's a fundraiser for research and local programs, which is incredibly important. But on a personal level, the Walk is where the invisible becomes visible. There is a specific kind of strength that comes from standing in a crowd where you don't have to explain yourself. You're surrounded by people who understand the weight of a diagnosis but are choosing to move forward and support one another.

I stay active in the community because it gives me the chance to show the world that while epilepsy is part of my life, it doesn't limit my potential or my ability to support others. This connection provides a vital sense of belonging, proving we aren't just managing a diagnosis alone, but are part of a powerful, united front. It serves as a constant reminder that even when things feel unpredictable, we have a massive, dedicated team standing right alongside us.

News Briefs



CELEBRATING NEAM AT THE NEW YORK STOCK EXCHANGE

In November 2025, the Foundation had the exciting opportunity to ring the Closing Bell® at the New York Stock Exchange in honor of National Epilepsy Awareness Month (NEAM). Beyond celebrating NEAM, this was an opportunity to raise awareness and recognize the 1 in 26 people who will be diagnosed with epilepsy in their lifetime.

ACCREDITED BEHAVIORAL HEALTH SERIES

Our Epilepsy Learning Portal now includes a five-part Behavioral Health Series accredited for behavioral health providers. Behavioral health providers can learn about common comorbidities, challenges present for people living with epilepsy, self-management programs, and more.



WALK FOR EPILEPSY NOW NATIONWIDE

The nationwide Walk for Epilepsy has a new name with the same powerful mission: to inspire, empower, and spotlight the epilepsy community. Join us to walk together, raise awareness, and help create a future where everyone affected by epilepsy feels seen, supported, and celebrated.

Visit www.WalkforEpilepsy.org to find your local Walk.



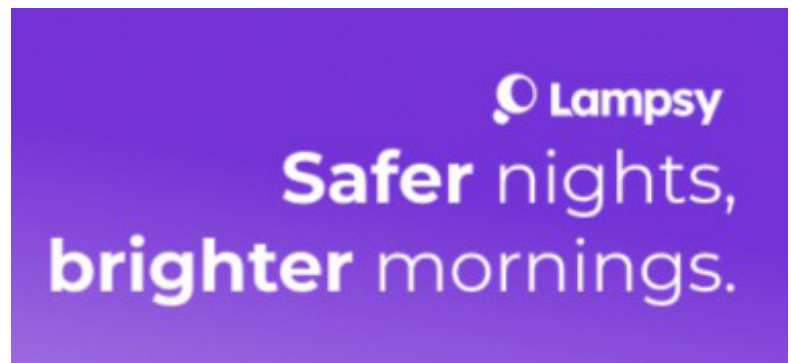
THE PURPLE DAY® EXPO

The Epilepsy Foundation is proud to sponsor the Purple Day® Expo on March 28, 2026 at Disney's Coronado Springs Resort alongside The Anita Kaufmann Foundation. We connected with families in the epilepsy community and shared how empowER&D™ brings lived experiences directly into the heart of research and care.



LAMPSY HEALTH NAMED WINNER OF 2025 STARTUP ACCELERATOR

Lampsy Health was the winner of the 2025 Epilepsy Foundation Startup Accelerator Course, a six-week virtual program that supports startup companies working to improve the lives of people with epilepsy. Lampsy Health developed an AI-powered smart lamp aimed to reduce the risk of Sudden Unexpected Death in Epilepsy (SUDEP), particularly during nighttime and other periods when supervision may be limited.



EMPOWERED JOURNEYS PODCAST SERIES

The Empowered Journeys podcast features the Foundation's people, programs, and ideas that are driving progress throughout the epilepsy community. These conversations are meant to inform, connect, and empower anyone impacted by epilepsy, through knowledge and ways to get involved.

Three episodes are out now: "EF's Blueprint for Modern Nonprofit Leadership" with Bee Martin Lee and "How the Epilepsy Foundation is Turning Data Into Hope," with Caitlin Grzeskowiak, Chief Research and Innovation Officer, and "Building Outcomes-Driven Support" with Brandy Fureman, Chief Mission Outcomes Officer.



In your community



NEW TRANSPORTATION ASSISTANCE PROGRAM FOR ALABAMA RESIDENTS

The Epilepsy Foundation Alabama launched a new Transportation Assistance Program for Alabama residents to apply for support to safely travel to and from their provider appointments through one of two options: an Uber ride coordinated through Uber Health, or a local transit authority voucher. This program directly supports individuals living with epilepsy in Alabama and helps us ensure no one faces epilepsy alone.

Learn more: epilepsyalabama.com/programs/direct-services



AMERICAN EPILEPSY SOCIETY (AES) ANNUAL MEETING

The Epilepsy Foundation network joined clinicians, researchers, and advocates from around the world at the American Epilepsy Society Annual Meeting in December 2025. The AES Annual Meeting brings together professionals from across industries who are dedicated to better outcomes for people with epilepsy. The Foundation helped attendees learn more about connecting with their local offices, using our AI assistant on epilepsy.com, empowER&D™, and behavioral health courses designed to support the mental health needs of people living with epilepsy.



LOS ANGELES EPILEPSY WALK TEEN COMMITTEE

On Super Bowl Sunday, nine teens affected by epilepsy met in Los Angeles for the first 2026 Epilepsy Walk Teen Committee meeting. After a pizza-making icebreaker, they began planning the Teen Zone at the Rose Bowl and organizing community outreach and in-kind donations. The third annual Teen Zone continues building connection and leadership.



SYNERGY SUPPORT CIRCLES IN MICHIGAN

The Epilepsy Foundation of Michigan, with support from the Community Foundation for Southeast Michigan, launched Synergy Support Circles, training eight peer leaders to host in-person groups with transportation support. The program reached 45 unique participants across 21 gatherings statewide. This peer-led model aims to reduce isolation and will continue expanding in 2026 to reach even more individuals across Michigan.



EPILEPSY FOUNDATION WASHINGTON'S 25TH ANNUAL LIGHT THE FLAME GALA

The Washington Epilepsy Foundation hosted its 25th Annual Light the Flame Gala on March 7, welcoming more than 200 attendees and raising \$315,000 in support of its mission. Bee Martin Lee shared empowER&D with an audience that included practitioners, industry partners, individuals and families affected by epilepsy, a Washington Representative and Senator, and 20 dedicated volunteers.

**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, leads advocacy efforts, funds innovative research and the training of specialists, and educates the public about epilepsy and seizure first aid.

Find your local office [epilepsy.com/local](https://www.epilepsy.com/local)



RECIPE CORNER

Keto Ice Cream and Popsicles for Summer

Recipes courtesy of the Charlie Foundation for Ketogenic Therapies

Berries and cream combine for these simple, sweet alternatives to classic summer treats when the weather heats up.

BERRIES & CREAM MINI POPSICLES

Yield: 1 Serving

6g Fat | 1g Protein | 1g Net Carb

Macronutrient ratio: 3.7:1

Ingredients

- 5 grams fresh blueberries
- 5 grams fresh raspberries
- 15 grams 40% heavy cream
- *Optional:* liquid stevia drops (optional)
- water to fill the popsicle molds (if needed)

Directions

1. Place the berries in the popsicle molds.
2. Add the heavy cream and liquid stevia to the berries. Add water to the molds to fill to the top.
3. Note: The ring pop molds are slightly different sizes. Start with the smallest mold and adjust your snack calculation to fit your specific needs, making sure the ingredients fit into the mold. For the larger molds, dilute the cream with water to fill the remaining headspace.

KETO ICE CREAM

Ingredients

- Heavy whipping cream (36 or 40%)
- Fruit such as fresh or frozen unsweetened blueberries or strawberries
- *Optional ingredients:* unsweetened cocoa, macadamia nuts, extracts or sugar-free flavorings (DaVincii Gourmet, allowed sweeteners, Fage Total Yogurt, egg white powder)

Directions

1. Whip enough heavy cream to make several servings.
2. Weigh the whipped cream.
3. Stir desired ingredients into whipped cream. Divide into individual servings then freeze for 15 minutes. If frozen longer, thaw for 10-15 minutes before eating.

Living with Epilepsy: Why Mental Health Matters

By: Sara Wyen

Just as you care for your physical health, it is important to care for your mental health as well. May is Mental Health Awareness Month, observed each year since 1949. It focuses on raising awareness, reducing stigma, and connecting people with support for mental health conditions.

It is not uncommon for people living with epilepsy and seizures to experience mental health challenges. Depression and anxiety are among the most common concerns. Depression and anxiety affect about 1 in 3 people with seizures and up to 1 in 2 people with uncontrolled epilepsy. Seizures can make life feel unpredictable, which may lead people living with epilepsy to feel less secure. When these feelings go unaddressed, they can develop into depression or anxiety. Epilepsy can also affect many areas of life, including learning, employment, relationships, independence, and daily routines. These changes can add to the emotional impact someone may experience. In addition, epilepsy

is often unpredictable, and many people living with it fear having a seizure in public more than the seizure itself, which can increase feelings of anxiety and uncertainty.

If you are newly diagnosed with epilepsy, you may also feel fear, sadness, or shock. Adjusting to new information about your health can be difficult. Some anti-seizure medications may also affect mood and make a person feel more irritable, down, or depressed. This can occur more often in people who already have a mood disorder or who have experienced mood challenges in the past. A family history of mood disorders may also increase the likelihood of these side effects. If you notice changes in your mood, tell your healthcare provider. There is help available and you don't have to struggle alone.

If you or someone you love is living with epilepsy or seizures, it is important to care for mental health just as you would physical health. Mental health involves being aware of your

feelings, mood, and behavior, and recognizing and discussing changes with family, friends, and healthcare providers can be an important step toward improving overall well-being. It is also important to talk with your healthcare team if you are concerned about mood-related side effects from anti-seizure medications. The Epilepsy Foundation's Chronic Disease Self-Management Program (CDSMP) is a free, virtual workshop designed to empower individuals, including adults (18+) living with epilepsy and their caregivers, to take control of their health journey and build skills to support mental well-being.

For healthcare providers, the Epilepsy Foundation now offers an accredited behavioral health learning series. Psychiatric and cognitive conditions are common among people living with epilepsy, and self-management programs can play an important role in helping individuals navigate these challenges.

“I decided to tell my story because, for a long time, I felt like my journey with epilepsy was something I had to hide. I learned early on how easy it was for people to misunderstand my condition, and that fear of being judged or treated differently often kept me silent. But over time, I realized that silence was heavier than honesty. As I grew more confident in who I am and what I’ve overcome, I began to understand that my story has power. It represents resilience, perseverance, and strength in the face of uncertainty. Sharing my experience is a way of reclaiming my voice and acknowledging everything I’ve endured, rather than allowing epilepsy to define me in silence.”

ERIS
California



Epilepsy stories from the community

Where Empowered Journeys Begin

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



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