THE COMMUNITY MAGAZINE OF THE EPILEPSY FOUNDATION

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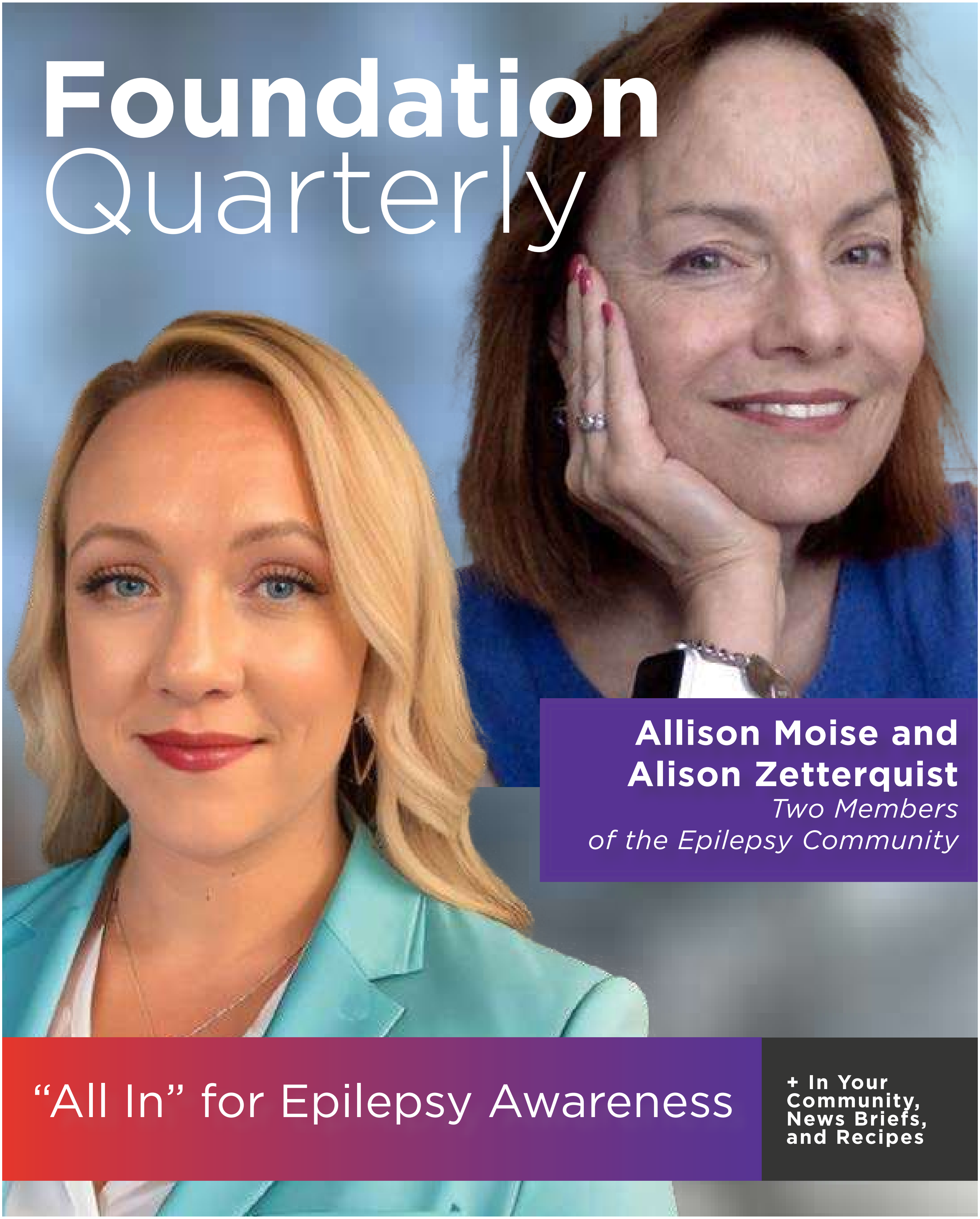

Allison Moise and Alison Zetterquist

Two Members of the Epilepsy Community

"All In" for Epilepsy Awareness

+ In Your Community, News Briefs, and Recipes

Issue 14, Fall/Winter 2025

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LETTER FROM THE CEO

Dear Friends,

Each November, we come together for **National Epilepsy Awareness Month (NEAM)**, a time to raise awareness, reduce stigma, and strengthen the community we share. This year's theme, "All In for Epilepsy Awareness," is about the power of collective action.

Being All In doesn't mean doing everything; it means doing something. Each action, whether learning more about epilepsy, sharing a story, wearing purple, or supporting someone you know with epilepsy matters. Every effort adds up, and we can ALL make a difference. Most importantly, we ensure that no one faces epilepsy alone.

This November, I invite you to go All In with us. Start a conversation, join an event, support advocacy, or help spread knowledge that can save lives. Let's build a stronger, more informed, more inclusive future for everyone affected by epilepsy.

We are also proud to highlight the launch of **EmpowER&D™ (Empowering Epilepsy Research & Development)**, which is our new initiative reimagining how epilepsy research moves forward. Through this secure platform, people living with epilepsy can share their health data, connect electronic medical records, and become active partners in driving discovery. Every data point contributes to a living dataset that can fuel innovation, advance new treatments, and ensure research reflects the realities of those living with epilepsy. This groundbreaking program is powered by the Epilepsy Foundation's partnership with the Iaso Ventures NeuroImpact Fund (NIF), a collaboration that blends philanthropy with strategic investment to accelerate solutions for our community. EmpowER&D is one more way we are going All In for epilepsy by transforming research and development for lasting impact.

As we continue our mission to improve the lives of people affected by epilepsy through education, advocacy, research, and connection, I'm inspired by the resilience and dedication of this community. Thank you for standing with us, for raising your voice, and for committing to action. Together, we are building a brighter future.

With gratitude,
Bernice "Bee" Martin Lee,
President & CEO,
Epilepsy Foundation

We are stronger, gentler, more resilient, an

d more beautiful than any of us imagine.

- Mark Nepo

Connecting Research and Reality

How Two Members of the Epilepsy Community Are Shaping the Future of Care

By: Kaitlyn Gallagher

For many families and individuals affected by epilepsy, the journey often begins in an overwhelming manner. For Allison Moise, it started in the neonatal intensive care unit (NICU), watching her newborn son endure seizures. For Alison Zetterquist, it began decades earlier in a high school classroom, when a first seizure in the 1970s left her feeling "othered" and uncertain about her future. Despite their very different beginnings, both women have turned their personal experiences with epilepsy into powerful advocacy, helping to bridge the divide between lived experience and epilepsy research.

Both Allison M. and Alison Z. have taken on roles as Research Ambassadors for the Epilepsy Foundation of America. Their goal? To shape the direction of scientific research and discovery from the point of view of the community itself.

Alison with her family, Photo Credit: The Moise Family

Research Ambassador Program

The Research Ambassador Program is designed for people living with epilepsy, their caregivers, and others uniquely positioned to support the epilepsy community. The program empowers participants to actively engage in treatment development, address disparities in clinical trial representation, and ensure that research reflects the real needs of patients and caregivers.

Each year, 30 ambassadors are selected and given access to our online Clinical Research 101 series, a seven-part video curriculum covering the foundations of research, clinical trials, and patient engagement. The program then culminates in a full-day, immersive, in-person Ambassador Bootcamp. This experience provides insight into how new therapies are developed and ensures that people with epilepsy have a meaningful voice in shaping clinical research.

Learn more:
epilepsy.com/ResearchAmbassador

When Allison Moise's son, Rob, was born in 2017, he experienced seizures caused by hypoxic-ischemic encephalopathy (HIE). This is a type of brain injury resulting from lack of oxygen and blood flow. The seizures were resolved during his stay in the NICU, but at five months old, new movements during sleep raised fresh concerns.

Rob then received an early diagnosis of Infantile Spasms (IS), a form of epilepsy that typically begins in infancy. Rob's IS eventually resolved with treatment, but by the time he was one, new focal seizures appeared.

"The diagnostic process was very long and anxiety-provoking," she remembered. "Rob endured multiple EEGs and follow-up appointments." The family also faced obstacles outside the hospital. "Once he was diagnosed, the anxiety continued as we had to fight with insurance to get this medication approved. Then, while he was on the medication, he had to be closely monitored."

Through her involvement with the community at Hope for HIE, she learned the importance of observation and documentation in managing epilepsy. "As his epilepsy journey has continued, we still videotape any movements or behaviors that are atypical for him and send them over to his team," she explained. "This helps his team provide feedback and document any progression of his seizures."

When she first started to learn more about epilepsy, she began with the basics: pamphlets from her son's neurologist and trusted medical sources such as the Child Neurology Foundation and the Epilepsy Foundation of America.

"I heavily relied on other parents' experiences to help me get through this time in our journey," she said. "It was important to me to find science-backed articles to get my information from."

Rob was also diagnosed with cerebral palsy, cortical vision impairment, dystonia, and other complex conditions. Through all of this, Allison and her family found strength in connection. "Find your community," she said. "You are going to go through difficult things, but those things feel less difficult when you're surrounded by people who understand and empathize with what you are going through."

She also emphasizes partnership with healthcare teams. "Trust yourself with the help of your medical team," she advised. "Yes, they are the professionals, but you are the expert of you and your child. When something does not feel right, speak up until someone listens."

> Being able to talk to people who understood what we were going through was an invaluable resource, especially in those early days.

Her advocacy work continued through her involvement with Hope for HIE, a nonprofit founded in 2010 by three mothers who connected in an online chat room. The organization became a registered nonprofit in 2014 under Executive Director Betsy Pilon. "After my son was born, I had told my cousin what was going on at the hospital," she recalled. "She began to Google and found the Hope for HIE Facebook group and sent it to me. I joined while we were still in the NICU and began searching for answers and support."

She quickly became part of that network. “Being able to talk to people who understood what we were going through was an invaluable resource, especially in those early days.” Over time, her involvement evolved from seeking support to providing it.

In 2020, the organization expanded its structure, moving from a volunteer-run model to one with full-time staff, a board of directors, and a medical advisory board. “Hope for HIE went from being a 100% volunteer-run organization to now having seven paid, credentialed employees,” she explained. Today, the nonprofit offers direct support, education, and resources to families, as well as its “Halo of Support” model for families participating in research trials.

Her own work focuses on connecting the patient experience with research teams. “I provide 1:1 support for those families enrolled in clinical trials,” she said. “We are also able to report back to the studies if we are hearing anything about the trial from the participants while keeping the confidentiality of the trial.”

That connection to research motivated her to apply for the Epilepsy Foundation’s Research Ambassador Program, a national initiative designed to ensure that lived experience helps shape scientific priorities. “My work with Hope for HIE really pushed me to apply,” she said. “I feel that it is so important to have a seat at the table to make sure that the research reflects the needs and wants of the community.”

Her collaborations have since expanded to include Give an Hour, The Courageous Parents Network, the Rare Epilepsy Network, and advisory roles within pediatric palliative care and cortical vision impairment research. She currently participates in a long-term study at Boston Children’s Hospital with Dr. Christina Briscoe examining disparities in diagnosing Infantile Spasms.

“We have always viewed research trials as the opportunity to help those that come after us,” she explained. “After going through clinical trials myself and with my child, when the opportunity came around to help provide guidance and mentorship in the clinical trial setting with Hope for HIE, I was thrilled to participate.”

Her advice to families interested in contributing to research reflects her collaborative philosophy: “Talk with your child’s medical team and see if there are any current studies that your child would be eligible for,” she says. “Check with the community you have found and see if anyone else has been engaging in research in your rare epilepsy.”

> Talk with your child’s medical team and see if there are any current studies that your child would be eligible for. Check with the community you have found and see if anyone else has been engaging in research in your rare epilepsy.

Top Left: Rob; Bottom Right: Allison speaking at Epilepsy Foundation New England’s Epilepsy Convention
Photos Credit: The Moise Family

Alison Zetterquist, another advocate from New England, found her way to research via her own epilepsy diagnosis. Her story began decades earlier, when she had her first tonic-clonic seizure at age 18. “Waking up in the hospital, I was told I had epilepsy,” she said. “Seemingly, there was no guideline of having two or more seizures before diagnosis.”

She later realized her first seizure had occurred six years earlier, at summer camp — a focal aware seizure that went unrecognized. “I was sent to a psychiatrist, but with no follow-up,” she recalled. “Most likely, my parents were told I was severely homesick and should tough it out for the remaining four weeks of camp.”

Unfortunately, stigma around epilepsy was just as widespread back then as it is today. “With controlled epilepsy, the disease’s most profound impact on me was its stigma and, in turn, how it made me feel that I was ‘the other,’ moving through life,” she explained.

She pursued a successful career in educational publishing, rising to the level of vice president. But it wasn’t until retirement that she turned her focus toward the epilepsy community. “After retiring from my career in educational publishing, I decided to contact Epilepsy Foundation New England, volunteering to lecture on seizure recognition and basic safety in schools and other institutions.”

Alison quickly became more involved. “After meeting then CEO Susan Linn, she proposed that I be on the Board,” she recalled. “Over time, I became the Vice Chair and, after my term as Interim CEO of Epilepsy Foundation of America, I stepped in as Chair.”

As interim CEO of the Epilepsy Foundation of America from October 2022 to July 2023, she gained a broad perspective on the intersection of patient advocacy, policy, and research. “It was an honor and a welcome challenge, bringing me out of retirement,” she said. “Beyond its support for people living with epilepsy and driving awareness, it’s a far-reaching organization with mission-driven staff and well-known experts serving as conduits to the research community and government agencies.”

> With controlled epilepsy, the disease’s most profound impact on me was its stigma and, in turn, how it made me feel that I was ‘the other,’ moving through life.

Alison’s first exposure to research evaluation came through the Department of Defense’s epilepsy research grant program, where she served as a consumer reviewer. “Having to review lengthy research proposals and engage in discussions with scientists on the relative merits of the options, I fast learned the difference lived experience perspectives can make in helping the funding agencies award research grants,” she explained.

She went on to review proposals for the Epilepsy Foundation’s Shark Tank and Blue Skies Challenge and spoke at Research Roundtables and the Pipeline Conference on patient perspectives. She also worked closely with neurologist Dr. Jacqueline French and researcher Dr. Caitlin Grzeskowiak, as well as colleagues in advocacy including Bill Murphy, Director of Advocacy and Public Policy for Epilepsy Foundation New England, and Laura Weidner, Chief Advocacy and Government Relations Officer for the national office. “I have fond memories of visiting the White House with Laura during the 2023 celebration of the Americans with Disabilities Act. Meeting individuals from other health-related nonprofits while finding joy in the accomplishments of those who came before us confirmed, in my mind, that my time was more than well spent with Epilepsy Foundation of America.”

Her ongoing research collaborations extend to work with ZOR LLC, an innovative epilepsy research venture founded by Mukki Gill, who is developing therapies that mimic the mechanisms service dogs use to detect seizures. "I've given my thoughts on her therapeutic concept," she explained. "However, during focus groups and one-on-one conversations, I've given the most feedback as she develops a new epilepsy journal app."

Alison Z. collaborates closely with Allison M. to provide feedback from the patient and caregiver perspective.

Asked which area of epilepsy research she believes is most urgent, her answer is pragmatic: "If there is only one, I would focus on developing a widely accessible therapy with little to no side effects, especially cognitive and emotional. It would have to be covered by insurance, Medicaid, and Medicare and be as inexpensive as possible."

Her commitment extends beyond research to advocacy for access. She continues to work with legislators to improve coverage for therapies, reduce barriers such as step therapy, and strengthen pathways for care.

Though their journeys began in different places — one as a young woman navigating stigma in the 1970s, the other as a mother fighting for her child's care — both have found purpose in the intersection of science, policy, and lived experience. Their shared belief is clear: research must reflect the realities of life with epilepsy.

As Allison M. puts it simply, "Epilepsy is more than just seizures and can affect all parts of someone's life. Compassion goes a long way. If you see someone having a seizure, ask how you can help, take a basic seizure training course offered by the Epilepsy Foundation. You never know when that knowledge will be helpful."

Any member of the epilepsy community can make a difference, learn more about epilepsy, and help create community, just like Allison M. and Alison Z. Here's how:

•The Epilepsy Foundation of America's EmpowER&D program invites people living with epilepsy to share their health data and experiences to advance research. By securely connecting real-world patient information with researchers and clinicians, the platform can fuel new discoveries, support better treatments, and accelerate innovation in epilepsy care. Learn more and sign up.

•The Foundation is proud to introduce Sage — a 24/7 AI assistant built in partnership with Amazon Web Services (AWS) that helps users navigate epilepsy-related information easily. On epilepsy.com, click "Chat With Us", ask your question (about seizures, treatments, caregiving, etc.), and Sage searches thousands of expert pages to generate helpful responses. The AI remembers your chat history for personalized follow-ups, is available in multiple languages, and works securely under Epilepsy Foundation governance. No data is shared with Amazon.

•Join our community this November 2025 for National Epilepsy Awareness Month (NEAM). The Foundation encourages everyone to "Go All In" to raise awareness, show support, and create positive change for the epilepsy community, just like Allison M. and Alison Z. Through small actions like posting on social media, joining awareness events, or completing free seizure first-aid training, everyone can make a difference.

Photos Credit: Alison Zetterquist

PERSONAL ESSAY


Luke, pictured here with Rep. Steny Hoyer (MD-05), at Public Policy Institute 2022

Speaking Up for People Like Me

By: Luke Birkes

Close your eyes and imagine that you are playing baseball with your brother on a hot summer day, enjoying the warmth of childhood innocence that accompanies being 7. After an hour, you take a water break but next thing you know, you are in a confused and dazed state, covered in water and told you had temporarily lost all motor function and cognitive awareness. You are frightened, confused, and even when you later learn that you had a seizure precipitated by your epilepsy, you still have difficulty understanding the gravity of the diagnosis.

My name is Luke Birkes, and epilepsy has defined my life for more than two decades. My childhood was fraught with memory loss, difficulty studying, burdensome medical tests and procedures, and a depression rooted in the fundamental concept that I was different, so my epilepsy journey was initially rooted in sadness and anger. However, those feelings quickly turned into hope. I hoped that I would overcome this disease, hoped that I would find success despite it, and most importantly, hoped that my epilepsy journey may show others that they are not alone and not forgotten.

Fueled by this hope, I have dedicated my life to helping those with epilepsy. This has taken many forms, including fundraising for local walks, serving as a Teen Speak Up! Representative for the Commonwealth of Kentucky and making Morehead State University the first Seizure Smart College in the nation, having trained the faculty, staff, police, and residential advisors in seizure first aid. Additionally, since 2022, I have served as the Epilepsy Foundation of America's Epilepsy Advocacy Champion for Kentucky, representing people with epilepsy both within the Commonwealth of Kentucky and throughout the nation, by meeting with legislators and lobbying for key legislation and funding.

Poker players say you should go "all in" when you're strong or when your opponent is weak. Today, the epilepsy community grows stronger every day, powered by advocates, families, and organizations across the nation. Meanwhile, our opponents - stigma, misinformation, and silence - are losing ground. So, what would a poker player do? Go all in for epilepsy. It's time to bet everything on awareness, support, and change.

My journey has not been easy, but I will never stop fighting for myself and others, for the importance of epilepsy education and stigma eradication.

> My journey has not been easy, but I will never stop fighting for myself and others, for the importance of epilepsy education and stigma eradication.

Together, We’re Redefining Epilepsy Research.

Your contributions fuel breakthroughs and make research more representative. Share your health data through **EmpowER&D**, a new initiative of the Epilepsy Foundation of America.

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Building a Legacy of Hope

Why One Leader Believes in Investing in the Future of Epilepsy Care

By: Kaitlyn Gallagher

When Jeff Parent was around seven years old, he began having absence seizures. "I'd blank out for a few seconds and come right back," he recalls. Diagnosed with epilepsy, he was prescribed an anti-seizure medication and his seizures stopped by age twelve. For years, Jeff didn't experience another seizure until a fire alarm during his sophomore year of college changed everything. "The last thing I remember was the sound of the trucks," he says. "I woke up in the emergency room."

The fire alarm triggered a tonic clonic seizure. This marked the beginning of a lifelong connection with epilepsy, one that would eventually lead him to become Board Chair Emeritus of the Epilepsy Foundation of America (EFA) and a passionate advocate for the Foundation's newly established Endowment Fund.

"Epilepsy has been generational in my family," he explains. His father experienced a seizure while serving in the Air Force, and both his daughter and son were diagnosed with absence seizures in high school. When his daughter later experienced a tonic clonic seizure, it was the turning point that brought him closer to the Foundation. "She was a warrior from the start," he says. "Her courage made me want to do more. For her, for my family, and for everyone living with epilepsy."

For Jeff, supporting the Foundation's mission has always been deeply personal. A veteran of the automobile industry, he built a successful career leading major companies like Nissan Canada and AutoNation. But his work with the Foundation, he says, has been "the most rewarding experience of my life."

"I've had a wonderful career, but being able to bring my whole self without hiding my story and use my experience to help others, that's what matters most."

Why Endowment Giving Matters

When an anonymous donor seeded EFA's new Endowment Fund, Jeff didn't hesitate to contribute. "As officers of the organization, we need to lean into this," he says. "Nonprofits need stable, long-term funding. Annual gifts are essential for immediate needs, but an endowment ensures the Foundation will be here for generations to come."

The past few years have underscored the challenge nonprofits face: unpredictable giving cycles, economic uncertainty, and rising demand for services. "Short-term support keeps the lights on," he says, "but the endowment gives us a foundation to focus on the future."

That future, he believes, is bright. "Having an endowment legitimizes the organization. It tells the world that the Epilepsy Foundation of America is here to stay. It builds confidence among donors, attracts larger gifts, and gives us momentum to grow."

Strengthening the Community, Together

For Jeff and his family, epilepsy has been manageable. But he knows many others struggle to find the right treatment or access care. “Some people spend years trying to find the right medication or surgical solution,” he says. “We need to bring together researchers, clinicians, and technology partners to move faster so people can live full, independent lives.”

He’s energized by the Foundation’s growing partnerships and data-driven initiatives. “For the first time, we have real momentum,” he says. “Organizations that used to work separately are coming together. We weren’t there five years ago. But we’re there now.”

A Call to Invest in the Future

Asked what he would say to others considering a gift to the Endowment Fund, his answer is simple: “If you’re looking to make a long-term commitment to the epilepsy community, this is it. The bigger we can grow the endowment, the stronger and more sustainable this organization becomes. That’s why I gave. And why I’ll give again.”

He’s quick to note the generosity of the anonymous donor who launched the fund, which includes a matching gift to encourage others. “Their gift is making a huge difference,” he says. “Now it’s on all of us to build on that foundation.”

For Jeff, supporting also helps break down the major stigma associated with epilepsy. “Most people with epilepsy don’t talk about it because they’re scared of how others will react, or they feel ashamed,” he says. “But when we share our stories, something powerful happens. We inspire others to step forward too.”

This is how real change begins: one story, one family, and one enduring investment in the future.

For more information about the Epilepsy Foundation’s Endowment Fund and to donate, please visit epilepsy.com/donate.

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

With the 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.

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Find your local office at
epilepsy.com/local

Transferring Knowledge from Experts to Frontline Doctors: The (Not So Rare) Epilepsies ECHO

By Ilene Penn Miller, JD, LLM, Rare Epilepsy Network, Director

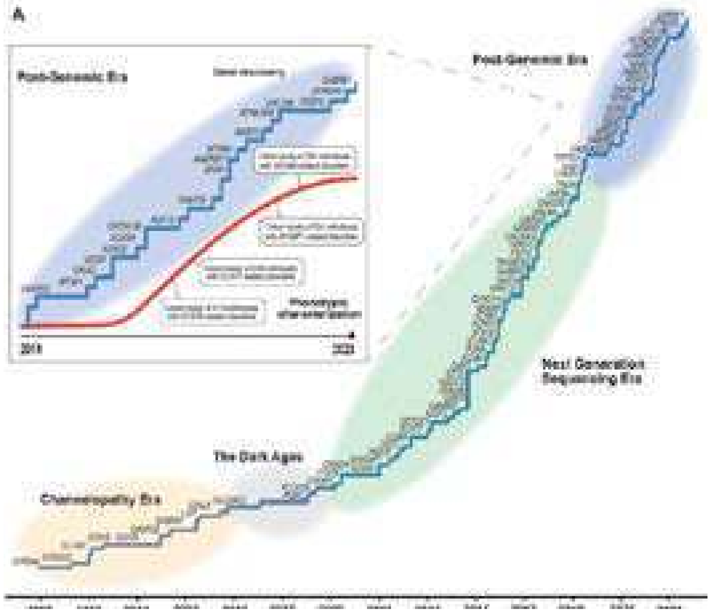
As the fourth most common neurological disease worldwide, epilepsy is not rare. With thousands of distinct causes, many affecting fewer than 200,000 individuals, epilepsy, or more accurately the epilepsies, is a disease comprised of many rare disorders.

With so many rare epilepsy disorders and more discoveries ongoing, finding expert care is a challenge. Rare epilepsy patients need specialists who can manage these complex and often catastrophic diagnoses. They may experience multiple seizure types that are often not responsive to anti-seizure medications or other interventions like surgery, diet, or devices. In addition to seizures, patients frequently live with comorbid symptoms across each body system including many of the basics – like the ability to talk, walk, feed, use the toilet, learn, breathe, and more. They also have a higher risk of Sudden Unexpected Death in Epilepsy (SUDEP) and mortality.

Of the 10,000 known rare disorders, 1000 or 1/10th feature seizures

Too Few Doctors to Care for Rare

At the same time, new diagnoses and treatments are increasing demand for care. There is a growing national shortage of neurologists and epileptologists (specialty trained providers). There is a shortfall of 16-20% for adult and child neurologists. And 50% of postal codes have no epileptologist within a 30-mile radius. Moreover, 40% of areas with specialty expertise have doctors who are already over capacity.



Credit: Ruggiero et al., Curr Opin Neurol, 2023

ECHO to the Rescue

This challenge led the Epilepsy Foundation and Rare Epilepsy Network (REN) to organize "The (Not So Rare) Epilepsies ECHO Series" to transfer knowledge and learnings from experts to doctors caring for patients. The program was first launched in 2023 and was followed by a second program in January 2025. Each program brought together leading doctors in the rare epilepsy field from national epilepsy centers with expertise in neurology, epileptology, genetic counseling, developmental pediatrics, and adult transitions. They also included caregivers with firsthand experience of rare epilepsies, such as parents of children diagnosed with Ring14 and Malan Syndrome, who were also founders and leaders of advocacy organizations for these conditions. They shared insights into the challenges of obtaining an accurate diagnosis, managing comorbidities, communicating effectively with healthcare providers, and navigating the transition from pediatric to adult care.

Each program engaged over 100 participants, including neurologists, epileptologists, nurses, genetic counselors, and other specialists, representing half of all U.S. states. Notably, both programs drew strong interest from two groups: early-career practitioners (fewer than five years in practice) and those with more than 15 years of experience. For newer clinicians, the appeal stemmed from the fact that rare epilepsies receive minimal attention in medical school, residency, and even epilepsy fellowships. For more experienced practitioners, participation reflected a recognition that their training may be outdated and that reliable opportunities to access current knowledge about rare epilepsies remain limited.

> I have been practicing for over 20 years, and the field is ever changing and now changing ever more quickly. I want to make sure I'm not missing diagnoses I should be making.

Each session featured concise didactic presentations led by experts, followed by in-depth case discussions. Physicians presented their most challenging cases to leading specialists from across the country, while experts collaborated to address regional barriers such as limited access to genetic testing, counseling, and other critical resources. Over the course of six sessions, both participants and experts expanded their knowledge and strengthened their professional networks.

In 2023, 70% reported they changed their "application of current best practices, procedures or guidelines in their work." And in 2025, 83% identified actions "they will apply to work." Those changes included ordering genetic testing earlier, connecting families to patient advocacy groups, offering care plans, and better managing comorbidities and transitions.

Given the positive evaluations and feedback from participants and faculty alike, the Epilepsy Foundation and Rare Epilepsy Network are planning a third program that will launch on January 20, 2026, co-chaired by Heather Mefford, MD, PhD (St. Jude) and Pavel Klein, MD (Mid-Atlantic Epilepsy & Sleep Center). This program titled, "The (Not So Rare) Epilepsies Series: Integrating Genetic Insights Into Clinical Care" will take an even deeper dive into genetic testing and counseling, and precision therapies. Neurologists, epileptologists, genetic counselors, nurses, advanced practice providers, and trainees across all specialties are strongly encouraged to apply. Providers based in rural and underserved areas will be prioritized.

For more information,
visit the Epilepsies ECHO Hub:
www.epilepsy.com/programs/echo

To register for the ECHO:
Registration Link:
Bit.ly/3XeTZCx

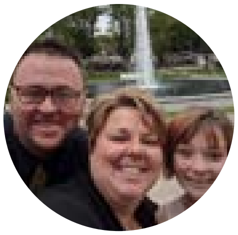
"Being All In for epilepsy awareness means recognizing that epilepsy is something I have, not something I am. When I was diagnosed, I worried that it would shape how others saw me, and for a while, I let it shape how I saw myself. But over time, I learned that while epilepsy is a part of my life, it doesn't have to control it. It's influenced my path, but it hasn't set my limits. Now, as a student at a top law school, I'm proud of how far I've come, not in spite of epilepsy, but alongside it. Being All In means advocating, educating, and showing others that you are always more than a diagnosis."

- Lizzie, person with epilepsy

What does it mean to be

"Telling as many people as possible"

- Jessica, person with epilepsy



"It means living a life with epilepsy but not letting epilepsy define me"

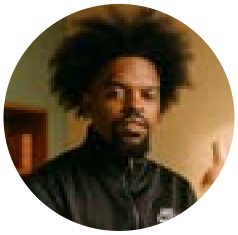
- Chris, person with epilepsy
  and a parent of a child with epilepsy

“Being all in for epilepsy awareness means we’re all about spreading knowledge and support for those affected by epilepsy. It’s about breaking the stigma, sharing stories, and showing that we stand together to raise awareness and advocate for better treatment and understanding.”

- Kristence, person with epilepsy

ALL IN

for National Epilepsy Awareness Month



“Being All In for epilepsy awareness means I don’t just talk about it when it’s convenient, it’s part of how I live, create, and show up every single day. To me, it’s about refusing to let epilepsy be hidden in the shadows. It’s standing tall, unapologetically, and making sure people see us, hear us, and recognize us for more than just the condition. It means using my voice, my art, and my platform to break myths, to educate, to fight stigma, and to uplift others who feel unseen. It’s about showing the world that epilepsy doesn’t define who we are, but it does unite us in strength, resilience, and courage. Being All In means not halfway, not sometimes, but fully committed to building a world where awareness is automatic, compassion is instinctive, and recognition is power.”

- Damani, person with epilepsy

In Your Community

Laser Tag Tournament Players Raise Funds for Epilepsy Foundation

Laser tag players from across six states participated in Tag 4 A Cause, helping to raise over $1,100 to benefit the Epilepsy Foundation. This was included as a side event during the September Laser Storm regional draft tournament held at Skyway Laser Storm in Warren, Ohio with the fundraiser portion of the event organized by laser tag blogger Laurie Jean Britton (TiviachickLovesLaserTag.com).

Tournament players were invited to donate directly to the Epilepsy Foundation and in thanks they received a medal and the chance to compete in special games for the "Top Gun" golden phaser trophy, which was won by Corbin Raptis.

Britton observed that "When laser tag players participate in tournaments there is a strong sense of community. Supporting a great cause like the Epilepsy Foundation is something we can all get behind while at the same time enjoying the laser tag that brings us all together."

Laser tag tournament players gather to show support for the Epilepsy Foundation during the Tag 4 A Cause event held at Skyway Laser Storm in Ohio.

In Your Community compiled by Ashley Grese


TIVIACHICK LOVES
LASER TAG .COM
TIVIACHICK'S
TAG 4 A CAUSE
LASER TAG
CHALLENGE
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$1000
JUST A GIRL WHO LOVES LASER TAG
TO PARTICIPATE IN
TAG 4 A CAUSE
TO BENEFIT THE
EPILEPSY FOUNDATION
PLEASE
DONATE
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TIVIACHICK'S
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CAUSE
LASER TAG
5K CHALLENGE
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Iowa Seizure Safe Schools Legislation

On May 27, Governor Kim Reynolds signed HF 835 into law, making Iowa the latest state to pass Seizure Safe Schools legislation. This law ensures school personnel are trained to recognize and respond to seizures, creating a safer environment for students with epilepsy. We're incredibly grateful to our legislative consultants, advocacy team, families, and dedicated advocates who made this victory possible.

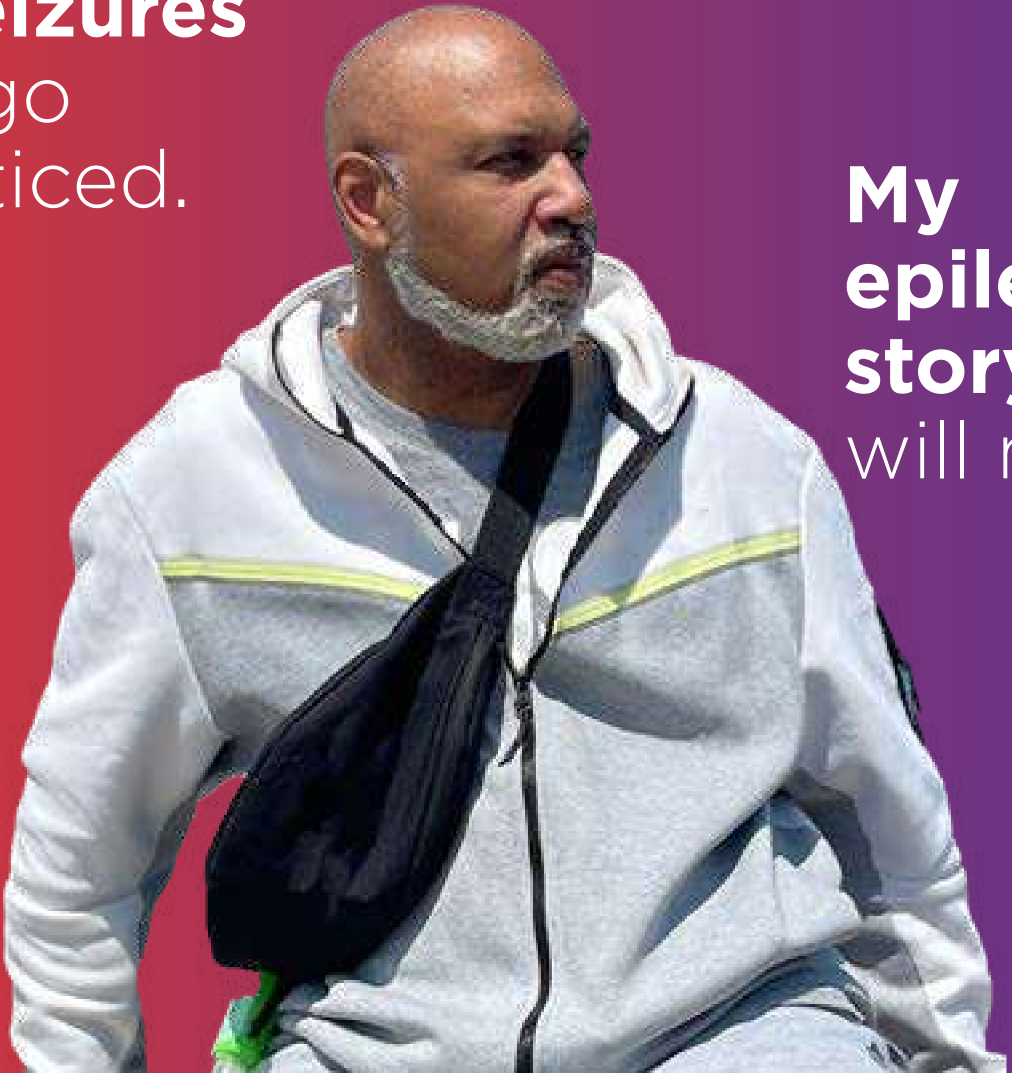
$10,000 Grant Expands Seizure Safety for Kids in Florida

Florida Epilepsy Services announced a new partnership with Suncoast Credit Union, the largest credit union in Florida. Suncoast awarded $10,000 to fund the Seizure Safety for Kids initiative, which provides child-focused epilepsy education and Seizure Safety Kits to families across the region. This partnership will help ensure children living with epilepsy receive the tools and resources they need to stay safe and thrive.

EF Greater Chicago Hosted Inspiring Art Workshops

In partnership with the Hidden Truths Project, the Epilepsy Foundation of Greater Chicago hosted two Art Workshops, one for kids and teens, and another for adults. Participants tapped into their creativity while learning new artistic techniques in a fun, engaging, and supportive space. These sessions offered a meaningful outlet for self-expression and connection within the epilepsy community.

My seizures
may go
unnoticed.



**My
epilepsy
story**
will not.

#ChangeOurEpilepsyStory

Change Our Epilepsy Story is an awareness campaign that encourages our community to start talking about their epilepsy and seizures so that others will be empowered to seek help. If we keep sharing our stories about epilepsy, we can educate those around us, and in turn, address the misconceptions and lack of awareness that exists about epilepsy and seizures.

EPILEPSY
FOUNDATION®

ChangeOurStory.org
1.800.332.1000

This flyer is supported by the CDC/US Dept. of HHS as part of a financial assistance award totaling $55 with 100% funded by the CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, CDC/HHS, or the US Government.

NEWS BRIEFS

News that matters to our community

2025 Shark Tank Winners

The Epilepsy Foundation of America awarded $250,000 in funding to innovative projects aimed at improving epilepsy care during its 13th Annual Shark Tank Competition this May. Winning innovations include an AI seizure detection app, a wearable EEG for absence epilepsy, and a groundbreaking RNA therapy targeting the root cause of epilepsy.

Read the press release on epilepsy.com

News Briefs compiled by Ashley Grese

Epilepsy Foundation Launched New AI Assistant

In August, the Epilepsy Foundation launched its revolutionary AI epilepsy assistant, Sage, on epilepsy.com. Developed in partnership with Amazon Web Services, Sage marks the culmination of a five-year digital transformation. Built specifically for the epilepsy community, Sage combines emotional awareness with trusted medical knowledge to offer real-time support in multiple languages, 24/7.

Read the press release on epilepsy.com

Lifetime Accelerator Award

Internationally acclaimed neurologist and epilepsy researcher Dr. Orrin Devinsky was honored with the Lifetime Accelerator Award during the Epilepsy Therapies & Diagnostics Development Symposium in Leesburg, Va. on May 29, 2025. This award was given in recognition of Dr. Devinsky's groundbreaking work advancing epilepsy treatment, pioneering therapeutic development, and his unwavering dedication to improving the lives of people with epilepsy.

Read the press release on epilepsy.com

The Epilepsy Foundation Welcomes New National Board Members

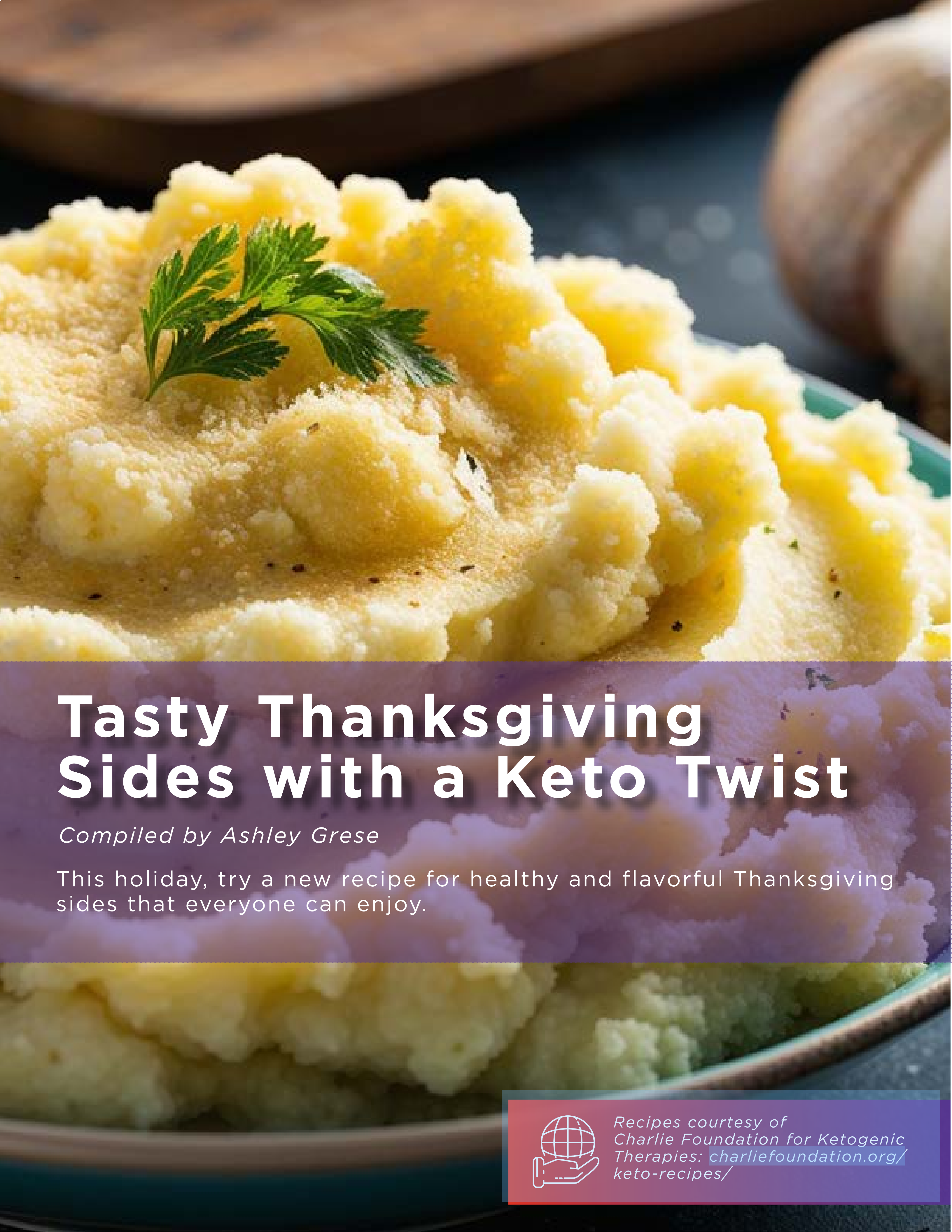
The Epilepsy Foundation is proud to welcome four new leaders to our Board of Directors, bringing diverse expertise and commitment to community to help shape the future of epilepsy care, research, and advocacy. Together, we're advancing our mission to support the nearly 3.4 million people in the U.S. living with epilepsy and working toward a world where no one faces epilepsy alone.

Jeannine Garab

Anna Milz, MD, MPH

Cynthia B. Plawker

Kathleen W. Tregoning



Tasty Thanksgiving Sides with a Keto Twist

Compiled by Ashley Grese

This holiday, try a new recipe for healthy and flavorful Thanksgiving sides that everyone can enjoy.

Recipes courtesy of Charlie Foundation for Ketogenic Therapies: charliefoundation.org/keto-recipes/

Stuffing

Ratio: 3:1

Ingredients

Bread Ingredients
- 8g raw egg, mixed well
- 6g olive oil
- 4g water
- 3g coconut flour
- 1g psyllium husks, whole or powdered
- 0.2g baking powder
- 0.2g baking soda
- pinch of salt

Mixture Ingredients
- 5g diced onions
- 7g diced celery
- 3.5g butter
- 10g chicken broth
- pinch of sage
- pinch of herbs de provence
- pinch of salt & pepper

Directions

Bread Directions

Mix all of the bread ingredients together very well. Place the dough in the shape of a roll on a piece of parchment paper and bake in a pre-heated 300 degree oven for 15 minutes. Once the roll is baked, cut it into small cubes.

Mixture Directions

In a small non stick pan, sauté the onions, celery in the butter. Add the herbs, salt and pepper. Stir to combine. Add the bread cubes and chicken broth to the celery and onion mixture and let the bread absorb all of the broth. Scrape all of the stuffing into a small ramekin that has been lightly oiled. Bake for 15 minutes at 350 degrees.

Cauli-Mash

Ratio: 2:1

Ingredients

- 1 large cauliflower (700g)
- 1 small white onion (70g)
- 2 cloves garlic
- ¼ cup ghee, butter or lard + 4 tbsp for topping (110g)
- ½ tsp salt or more to taste (pink himalayan)
- freshly ground black pepper
- optionally: ½ cup cream cheese or soured cream

optionally: ½ cup cream cheese or soured

Directions

Cut cauliflower into florets. Place on a steaming rack inside a pot filled with 2 inches of water. Bring to a boil and cook for about 10 minutes. Heat a pan greased with 2 tablespoons of the ghee and add chopped onion and garlic. Cook for about 5 minutes until slightly browned. Keep stirring to prevent burning and take off the heat. Place the cooked cauliflower into a blender and add the cooked onion and another 2 tablespoons of butter or ghee. Season with salt and pepper. Pulse until smooth and creamy. For an even creamier texture, add soured cream or cream cheese.

Please remember, the ketogenic diet should only be used under close medical supervision. Always check with your healthcare provider before making any keto recipes.

WELLNESS CORNER

Starting the New Year Strong

By Sara Wyen

The start of a new year is a natural time to pause, reflect, and set intentions for the months ahead. For people living with epilepsy, and their loved ones, this can mean taking steps to feel more prepared, supported, and connected.

One of the most important things you can do is review your Seizure Action Plan. Make sure it reflects any recent changes in medications, health status, or lifestyle. Share it with family, friends, teachers, or coworkers so they know how to help in an emergency.

It's also a good idea to update your insurance information with your healthcare providers and pharmacy. Doing so early in the year helps avoid surprises with coverage or delays in accessing prescriptions and care. Consider scheduling a check-in with your healthcare team to review treatment options, ask questions, and ensure you're on track with important screenings.

The new year is also a great time to strengthen your support network. Connect with your local Epilepsy Foundation, support groups, reach out online, or simply share your story with a trusted friend. Encourage loved ones to get Seizure First Aid certified, so they feel confident in knowing what to do if a seizure happens.

For both people with epilepsy and their caregivers, remember that self-care matters too. Setting boundaries, asking for help, and making time for rest are essential to sustaining the energy it takes to manage epilepsy treatment and care.

Above all, remember that no one faces epilepsy alone, and even small steps add up to make a big difference for your health.

Feel more prepared, supported, and connected as you head into the new year. For people with epilepsy and caregivers:

- ✓ Update your Seizure Action Plan to reflect any changes in medication, health, or lifestyle.
- ✓ Confirm insurance details with your providers and pharmacy to prevent coverage gaps or delays.
- ✓ Schedule a healthcare check-in to review treatment options and ask questions.
- ✓ Get Seizure First Aid Certified and encourage family, friends, or coworkers to do the same.
- ✓ Strengthen your support network by connecting with your local Epilepsy Foundation or online support groups.
- ✓ Prioritize self-care through rest, routines, and asking for help.

Connect to resources with Sage.
Visit epilepsy.com/Sage to talk to your AI epilepsy assistant.

Words from the epilepsy community

Whether you're newly diagnosed or have been living with epilepsy for years, your story matters. Your life has purpose. **To anyone living with epilepsy: you are stronger than you know.** Your journey may not be easy, and some days may feel overwhelming, but please remember, you are not alone. Don't be afraid to ask questions, speak up, and seek support. Surround yourself with people who uplift you and never let fear define your future.

- Brina, Epilepsy Warrior

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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.

Learn more at epilepsy.com