

Foundation Quarterly

**Matt Tifft,
Former NASCAR
Driver - page 4**

Take Action Issue

**+ In your
Community,
News Briefs,
and Ways to
Get Involved**

LETTER FROM THE CEO

It's time to take action.

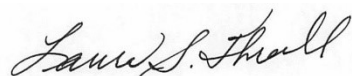
Happy start to 2022 to you and your family!

As we are gearing up for the Epilepsy Foundation's upcoming nationwide events and new initiatives, the enthusiasm and energy driving this work reminds me of how far we have come as an organization... despite the pandemic. We would not have been able to make the impact we have made, without the generous contributions and actions of our community and supporters.

This month's Foundation Quarterly focuses on giving and making a difference. Each story highlights individuals who are using their talents, time, money, and voice to support people living with the epilepsies. As you read these stories, I hope you feel inspired by their words.

It's no secret that giving not only helps others, but it also empowers individuals to take action. There are many ways to support people living with epilepsy. I challenge you to find your way of giving this February as we recognize Black History Month and Rare Disease Month.

No matter how you choose to give - whether it is through workplace giving, donating your personal stocks, vehicle, or money, sharing your story or your time - you can make a difference for the 3.4 million people in the U.S. who are living with epilepsy.



Laura Thrall
President & CEO

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Taking a Detour for Epilepsy

For 25-year-old former NASCAR driver Matt Tifft, taking a detour from his racing career due to an epilepsy diagnosis was not in the plan. Nevertheless, Tifft went from driving in the NASCAR Cup series with Front Row Motorsports, to being NASCAR's youngest co-owner of a Cup series team with Live Fast Motorsports. Today, Tifft is looking to leverage his platform to create awareness about epilepsy and help others struggling with seizures.

Tifft was diagnosed with epilepsy in 2019, the same year he started his Cup series career. Due to recurrent seizures, he had to put his racing career on hold. This led to anxiety, which he says at times, is still a constant day-to-day struggle.

"Epilepsy is the hardest thing I have ever experienced," he said. "When I first found out, it felt like a burden I had to deal with alone. I didn't want to tell anyone because of the stigma attached to it. I didn't want to leave the house for fear of a seizure coming on in public and not knowing what to do."

Eventually, the secret of his epilepsy weighed heavily on him. Tifft said he was depressed and angry because he thought he'd lost his whole career. He felt like he was a patient and not Matt. He had to rediscover who Matt is. Tifft sought out information about epilepsy and met with doctors to find available treatments that may help control his seizures.

Photos courtesy: Matt Tifft

COVER STORY

He also read numerous stories about others' epilepsy journeys. He began to see that there was a sense of togetherness among people with epilepsy, and he longed to feel that same sense of community.

"I wanted to connect with a community of people like me," he said. "I first told close friends and family before going public with my diagnosis, and it was such a relief to share my story with them. I received an overwhelming positive response. I realized that there are all these people I know that either have epilepsy or know someone who does. If they can go on and live their lives, I can too."

Tifft's seizures are now controlled, and he is back to driving street cars. Although, he is not back in the driver seat of a race car, as co-owner of a Cup series team, he is back in the racing scene and using his platform to give back and bring awareness to epilepsy.

"There's a lot of good I can do," he said. "I thought I was done with NASCAR and racing, but I found another thing within the racing world in which I can still be involved. It's an opportunity for me to share my story and bring awareness about epilepsy any way I can. It's a dream come true. It's really been a blessing."

Tifft was also recently named to Forbes Magazine's prestigious "30 Under 30" class of 2022.

"This is an incredible honor, especially as someone who has overcome an epilepsy diagnosis," he said. "This recognition opens more doors for me to keep the conversation going. The more I can talk about my epilepsy journey, the better. I want to help destigmatize epilepsy, help others find acceptance, and make sure they know they can still be themselves and fight."



Giving to Help Others

Research has shown that giving can boost our physical and mental health. Giving can take different forms — whether its volunteering for an organization, offering support to others around us, fundraising for an organization, or donating money to a charity — giving can make us feel good.

As you plan your year of giving, consider the many ways you can give back to the epilepsy community.

Give Stock

Maximize your impact by donating appreciated stock. Making a gift of stock is tax deductible, and you can avoid capital gains tax.

Workplace Giving

Do you work for a Matchmaker? Instantly find out if your employer will double or even triple your donations. Workplace giving is also an easy and efficient way to make tax-deductible donations directly from your paycheck to the causes you care about.

Cryptocurrency

Donating cryptocurrency is not taxable and allows you to avoid capital gains tax on the appreciated amount. This tax-deductible contribution makes Bitcoin and other cryptocurrency donations one of the most tax-efficient ways to support the Epilepsy Foundation.

Vehicle Donation

Turn your car into cash for the cause you care about. Vehicle donations have the potential to bring hundreds, and sometimes even thousands, of dollars in support of epilepsy programs. Donating is easy, the pick-up is free, and your gift is tax-deductible.

IRA Charitable Rollovers and Qualified Charitable Donations

If you are 70.5 or older and have a traditional IRA, you are uniquely eligible to save significantly on taxes by donating directly from your retirement account. Your required withdrawal can immediately support people living with epilepsy and their families.

Give Your Time

We value your time. By giving the gift of time, you can reduce stigmas surrounding epilepsy and seizure disorders. Epilepsy Awareness Ambassadors are passionate and dedicated volunteers tasked with virtually growing epilepsy awareness across communities to instill hope for people impacted by epilepsy.

Monthly Donations

As a monthly partner in the Epilepsy Foundation's efforts to overcome the challenges of living with epilepsy, you are one of our most dedicated supporters. By providing steadfast income throughout the year, your generosity helps fund high-impact research, education, and advocacy.

Bequests And Wills

Legacy planning does not require great wealth. What it does require is generosity of spirit – the desire to share what you have for the benefit of others. By making a bequest to the Epilepsy Foundation, you can ensure future funding for critical epilepsy programs and resources.



Grateful Giving

In 1989 when he was working as an attorney, volunteering in his community, and preparing for his upcoming wedding, James Bohrer had a partial complex seizure.

Over the next seven years he had several more seizures, occurring with increasing frequency and severity. He tried as many prescription medications as were approved at the time but none of them provided effective control. Finally, in 1996, he sought treatment at an epilepsy center and the doctors and surgeons there performed temporal lobe surgery. He has been seizure-free ever since.

Bohrer is aware of the life-altering effects a seizure disorder diagnosis has on a person and their family. At the time of his first seizure, he desperately wanted to know more about what was going on and relied heavily on educational information and online resources.

After he was diagnosed and prescription drug treatment proved ineffective, he relied on the Epilepsy Foundation to provide connections to other patients and their families. He heard their stories about the emotional aspects of dealing with a chronic disorder.

“When I became seizure-free, I wanted to do all that I could to help people with epilepsy who were still dealing with the effects of a seizure disorder,” he said. “I decided to support the Epilepsy Foundation with annual gifts. I also chose to make a planned gift to leave a legacy and help fund the next generation while instilling the value of giving back. Showing loved ones that we are part of a larger world — and that what we put into it is what we get out — ensures the next generation understands the importance of philanthropy.”

By talking with family members now about your charitable goals, and engaging in acts of service, you become a role model and inspire others to follow your lead

It's going to be Epic.
It's going to be Epic.



EPILEPSY FOUNDATION

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REGISTER TO ATTEND AT
[EPILEPSY.COM/EPICON](https://www.epilepsy.com/epicon)



Pictured: Jack (above) Photos Courtesy: Jack Navarro

More than A Personal Challenge

When Jack Navarro decided to bike ride for 3,000 miles, from coast to coast, over the span of 49-days, he never imagined the challenge would be so rewarding. Inspired by the lives of close friends whose families have been impacted by epilepsy, he mapped out his cycling odyssey, starting off in San Diego, California, and ending in St. Augustine, Florida with the goal of raising \$75,000 to fund research and increase awareness about epilepsy.

In 2021, Navarro decided to embark on a bicycle ride across the country. He knew it was going to be a full-time commitment which he whole-heartedly embraced to support three young people with epilepsy: siblings 22-year-old Abbie and 20-year-old Sevi Werner, as well as 10-year-old Liv Mosness.

“I had been thinking of making a long-distance bike trip, but I wanted it to be purpose-driven,” he said. “I have seen first-hand the effects seizures have had on the lives of my friends’ kids. Yet, I was surprised that epilepsy is a topic that does not get much attention. That inspired me to turn my bike ride into more than just a personal challenge— I wanted it to be for a great cause.”

Having run marathons for other fundraisers in the past, pushing himself physically on this ride was nothing new to Navarro. But he also had to push himself mentally given the emotional aspect that comes with such an experience. According to Navarro, amazing things happened during the trip, which had a dramatic effect on his life. Every town he rode into, he found opportunities to share educational information about epilepsy and encourage people to donate to his fundraiser.

One place where he particularly wanted to make a stop in New Orleans was Preservation Hall. Since the 70s, going to Preservation Hall for live jazz has been a tradition in the Navarro family, and this time would not be any different. When he arrived in town, Navarro immediately went to the box office to get a ticket for that evening’s show and found that tickets were sold out. A gentleman standing in line overheard Navarro talking to the attendant about his cycling journey and the cause behind it. The gentleman shared how he had previously lost his uncle to epilepsy and offered Navarro his extra ticket.

FEATURE STORY



“Every day during the trip, I met so many generous people willing to share their own epilepsy stories or wanting to donate because they were somehow connected to the cause,” he said. “If someone didn’t know someone affected by epilepsy, then they wanted to give money. Although raising money was important and the reason why I was there, bringing the topic of epilepsy to the forefront and encouraging conversations about it was just as important.”

Not only did Navarro exceed his initial goal by raising \$106,051 in total, but he also increased awareness about epilepsy along the way. He met numerous people whose lives had been changed due to epilepsy and, to him, that was priceless.

“This was by far the longest adventure I’ve ever had,” he said. “I got to see our beautiful country at 60-70 miles a day, and I got the opportunity to test myself. I got to do something that’s important for others, and to me, that’s what a good life represents.”



Create your own
Fundraise Your Way event
at [epilepsy.com/
fundraise-your-way](https://epilepsy.com/fundraise-your-way)



Using My Passion to Help Others

By Lorraine Newborn-Palmer, DNP, RN, ACNS-BC, CNRN, CBIS

Sometimes it seems like yesterday, but I know it was more than 40 years ago that I began my journey as a nurse. Over the years, my career has taken me through many different paths that cover life and death for countless people.

Neuroscience nursing seemed to grab my attention early on in my nursing career and it has stayed a part of my professional journey up until now. For the past 11 years I have been working as a clinical program coordinator, and now as a clinical program manager at a hospital in Baltimore. One of the two primary specialties that I work in is epilepsy, which includes the medical and surgical aspects of it in both inpatient and outpatient settings.

Over the years, I have made a strong effort to support the Epilepsy Foundation by participating in educational events, presenting at local and regional conferences, promoting educational trainings, and conducting seizure first aid trainings for small and large groups. I've also had the opportunity to collaborate with others on the Public Health Institute hosted by the Foundation and the CDC every year. I've served as a presenter for ECHO programs and participated in several epilepsy walks in Washington, D.C. Each opportunity provides a platform to share my knowledge and my support for those in the epilepsy community, making my journey an ongoing story.

In today's current climate and the growing need for education, there is a need for multicultural outreach programs, specifically in the epilepsy field. As an African American

and neuroscience nurse, I have been able to use my skills to give back to my community by engaging in epilepsy awareness outreach initiatives targeting people of color. I value the opportunity to spread the word and teach others not only about epilepsy but also about the human spirit, diversity, inclusion, and perseverance.

My experiences over the years have given me a new perspective with each person that I meet. Having been involved with epilepsy support groups and engaging with people with epilepsy and their family members, has certainly elevated my passion about neuroscience nursing. Sometimes it is more challenging than others, but the journey carries on for now. It is not all about me.



Pictured: Lorraine (right), teaching Seizure First Aid
Photos Courtesy: Lorraine Newborn-Palmer



Become a volunteer
at [epilepsy.com/volunteer](https://www.epilepsy.com/volunteer)

Rare Epilepsy in a Black American Family

Getting an accurate and timely diagnosis for a rare disease is challenging on its own. People of color often face even greater challenges. According to the National Institutes for Health, there are between 25-30 million Americans who have a rare disease. Getting an accurate diagnosis often takes years, and only after having visited many doctors. Deavin Arnold-Hadley and her family experienced the gravity of this when they were seeking diagnosis, treatment, and support for their son who had a rare form of epilepsy.

Arnold-Hadley and her husband had their second child, Mason, in 2010. Early on, Mason was on track with his developmental milestones. But, around the age of 2, he began to show symptoms of epilepsy. It took consultations with multiple doctors to finally diagnose Mason with Doose syndrome or myoclonic atonic epilepsy. Doose syndrome is a rare form of epilepsy which presents itself in early childhood. It accounts for 1-2% of all childhood-onset epilepsies. Children with Doose syndrome usually have many seizure types, including drop attacks.

“It was excruciating to watch Mason endure hundreds of seizures a day. There were times when we had no idea how to manage so many seizures outside of our home. We feared Mason would experience a severe injury if we took him out.”

**There are between
25-30 million
Americans who
have a rare disease.**

Source: National Institutes of Health



Pictured: Mason (above), Arnold-Hadley Family (right)
Photos Courtesy: Arnold-Hadley Family



FEATURE STORY

Mason's family began to fear for his future when he stopped talking and walking. His cognitive abilities were deteriorating, and they were at a loss for what to do next. No matter what they tried, the medications did not work for him. In fact, they were making him worse.

"My husband and I decided to travel to a hospital in another state to see a new neurologist," Arnold-Hadley said. "It was at this facility that we finally received the diagnosis of Doose syndrome. What I had previously read about Doose syndrome scared me. The prognosis was not good. I experienced a level of fear that I had never felt before."

The Arnold-Hadley family was introduced to a new medication which, they were told, may worsen certain seizure types. They decided to try the medication. Months later, however, Mason started showing negative signs. He had to stop treatment immediately. Although Mason slowly recovered, he was still having side effects from the medication. It was then that his family decided to put Mason on a medical ketogenic diet. Research has shown keto to be effective in mitigating symptoms of epilepsy, especially in people with Doose syndrome.

"We believed that the ketogenic diet was the next best step for us," Arnold-Palmer said. "We were discouraged by several doctors to start this diet. They said it was 'too difficult' and 'not worth the effort'. Fortunately, the diet was a smashing success. At 10, Mason is still using a keto diet to manage his seizures.


Today, the family uses their experience to empower other Black Americans and advocate for others with epilepsy. Arnold-Hadley has spoken to medical professionals on behalf of the Black Women's Health Imperative, shedding light on the negative impacts of a delayed diagnosis and treatment. She's also been a keynote speaker at epilepsy-related conferences and retreats helping guide parents facing similar situations.

"When we began our journey, we had no idea how to advocate for our son. But finding the right treatment and the right neurologist made the difference for our family. Some physicians were not a good fit for us. However, we were able to find one that worked together with us and didn't just tell us what to do. We made all medical decisions together."

...But finding the right treatment and the right neurologist made the difference for our family.



For more information about Doose Syndrome, [click here.](#)



**Of the 300 million
people worldwide
living with
a rare disease,
a growing number
of them have
a rare epilepsy.**



EPILEPSY
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#RareEpilepsies
epilepsy.com/learn



The Gift of Participation

Seven-year-old Susannah was 2 when she was diagnosed with a rare, neurodegenerative condition called KIF1A Associated Neurological Disorder (KAND). At the time of her diagnosis, Susannah was the only child in the world known to have a specific mutation in the KIF1A gene, and one of only a handful of people identified with the disorder. KAND is caused by mutations in the KIF1A gene, a gene which makes a protein that is important for brain function.

Luke Rosen and Sally Jackson began noticing their daughter's symptoms early on — a few missed milestones, low muscle tone and mobility, severe twitching in her sleep, and seizures. After an emergency room visit, a neurologist ordered an MRI, an EEG and extensive genetic testing. The following months were filled with uncertainty as her health began to deteriorate while Rosen and his family waited to get the test results. Susannah was having more seizures, balance and coordination problems and started to lose her vision.

Finally, the Rosens got the results. Susannah had a genetic anomaly that impacted her ability to walk, talk, and see — all of which were made worse by her seizures. And the prognosis was not promising.

"Susannah's condition becomes more and more severe as it progresses," Rosen said. "We monitor her closely because she has different seizures during the day. And, at night, one of us always sleeps with her. She twitches throughout the night and her breathing slows. Sometimes I wake her just to make sure she hasn't stopped breathing."



Pictures Provided for Article by the Rosen Family



Epilepsy is just one part of Susannah's genetic disorder. There are no treatments or cure for KAND. Although, the Rosens have worked with many doctors to try and find the right medications to treat her seizures, it's only a temporary fix filled with side effects.

"We need new treatments today. Not tomorrow, not in one year or 10 years," Rosen said. "If we wait any longer nothing will come in time to help Susannah and kids like her. We need to drive rare disease research. We need help to develop treatment before the damage is beyond repair. We need treatment that slows degeneration and makes life less severe for kids with KAND."

It was this drive for a cure for his daughter — and the lack of information and resources available — that led Rosen to give up his film career to start a nonprofit. In 2016, Rosen and Jackson founded the KIF1A.ORG to help Susannah and other families affected by KAND. The mission of the organization is to fund research to find treatments and a cure, and to identify more families with this genetic disorder. Since it's founding, the organization has increased understanding of KAND and the genetic mutations that cause it.

According to Rosen, KAND affects far more people than are identified today. Since Susannah's diagnosis, there are now close to 400 families impacted, and the community keeps growing. While KAND is a neurodegenerative disease, it does not affect any two people the same way. There are

currently more than 80 mutations that carry different rates of progression, and Susannah is one of only two people in the US known to have her specific mutation.

Rosen and members of KIF1A.ORG have also established a network of researchers, clinicians, industry leaders and innovators from around the world willing to give of their time and expertise to discover and accelerate a treatment for KAND.

"There is so much more to give that goes beyond a check," Rosen said. "Every family, person, researcher in the scientific community, caregiver and medical expert can give something. Their skillset is beyond measure. There are scientists that have reached out to us asking how they can help. We have families wanting to be a part of the KAND community to help raise awareness, or to participate in our research efforts. Giving the gift of participation is just as critical as giving money."

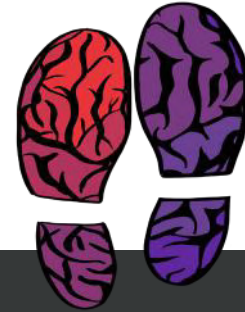


Learn more about our
Rare Epilepsy Network.

This is Why We Walk: Our Walkers Share Their

We have 3.4 million+ reasons why we must raise awareness and funds for epilepsy. 1 in 26 people will be diagnosed with epilepsy in their lifetime and it is critical that we continue to combat the challenges epilepsy brings to our community.

Be inspired by our walkers' words and participate this spring. **Let's take action together.**



"I want to ensure that people with epilepsy can live their own life, in whatever way they choose, regardless of seizures or stigmas."

- Cody, New Orleans

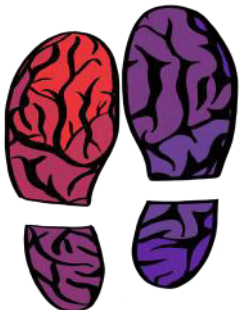
"We never imagined we would be 1 in 26, but now we are a part of a community where we can educate and support others."

- Gene, South Dakota



"There is this unwarranted stigma associated with epilepsy that impedes the mental and physical well-being of those affected. That's why I am involved in this fight."

- Shanon, Tampa



"I would like people to be prepared to recognize epilepsy as a congenital, developmental or acquired condition that affects families indiscriminately."

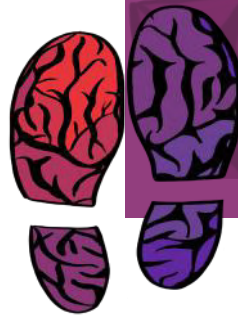
- Nicole, New Orleans

Reasons



“Epilepsy impacts us all in one way or another. Walking is my way of giving back, paying forward, and coming together with others for a great cause!”

- Tom, South Dakota



“My family and I walk for my son Mahonry who started having seizures just before he turned 2 years old. He is now 8 years old. I hope that Mahonry will be able to live without being affected by seizures at some point in his life.”

- Mahonry, Oklahoma

“We walk to fight for a cure for epilepsy!”

- Prue, North Carolina



ed with epilepsy that
g of those with epilepsy.



“I want people with epilepsy to know that their disease never has to define them or hold them back from reaching their goals.”

- Maggie, Tampa





**THE WALK TO END EPILEPSY IS HERE.
WALK YOUR WAY THIS SPRING!**

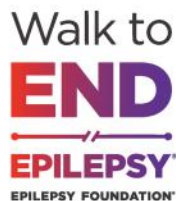
In-Person Events (various dates)

Phoenix, AZ
 Fountain Valley, CA
 Colorado Springs, CO
 Denver, CO
 Northern Colorado, CO
 Western Slope, CO
 Farmington, CT
 Killingworth, CT
 New Milford, CT
 New London, CT
 Orange, CT
 Tolland, CT
 Stamford, CT
 Tampa, FL

Iowa City, IA
 West Des Moines, IA
 Indianapolis, IN
 Lexington, KY
 Louisville, KY
 Owensboro, KY
 Paducah, KY
 New Orleans, LA
 Annapolis, MD
 Omaha, NE
 Fargo, ND
 Dayton, OH
 Oklahoma City, OK
 Portland, OR

Lehigh Valley, PA
 Philadelphia, PA
 Sioux Falls, SD
 Amarillo, TX
 Bryan/College Station, TX
 Dallas, TX
 Fort Worth, TX
 Houston, TX
 Lubbock, TX
 Salt Lake City, UT
 Seattle, WA
 Eau Claire, WI
 Madison, WI
 Wyoming

Nationwide Virtual Celebration- June 4, 2022



**Register today for a walk
in your community at
WalktoEndEpilepsy.org**

Epilepsy Foundation Wisconsin Accepting Scholarship Applications



The Epilepsy Foundation Wisconsin's "Seize Your Education College Scholarship" is celebrating its 8th year and is now accepting applications through May 2, 2022. Thanks to generous donations and fundraising, three individuals will be awarded a \$1,000 scholarship in each of the following categories: traditional student, non-traditional student, and caregiver of someone with epilepsy.



Visit epilepsywisconsin.org/scholarships to get more information

Summer Research Scholarships in Child Neurology



To honor the legacy of Dr. Swaiman and his contribution to child neurology, the Child Neurology Foundation's (CNF) board of directors recently announced the establishment of the Dr. Kenneth F. Swaiman Medical Student Scholarship, thanks to the support of his wife and pediatric neurologist Dr. Phyllis Sher. Administered annually beginning in May 2022, the \$5,000 summer research scholarship will be given to each of three (3) U.S. or Canadian medical students who have an interest in exploring a career in child neurology. In addition, travel expenses up to \$1,000 will be provided to attend the annual Child Neurology Society meeting. The award will be open to second- or third-year medical students for a basic or clinical research project in child neurology conducted under the direction of a child neurologist. Deadline for applications is April 11, 2022.



Click here to learn more about this opportunity.

IN YOUR COMMUNITY

SUDEP Day Proclamation Signed by Nebraska Governor



Last December, the Mantzios family from Lincoln, Nebraska championed a SUDEP Day Proclamation signed by Governor Pete Ricketts to recognize every December 1 as SUDEP Day in Nebraska. The Mantzios lost their son Chris to SUDEP on December 1, 2019 and chose this day to honor his life and memory. The Governor's kind remarks of gratitude for this recognition included sharing his family's own experience in losing a loved one due to seizures.

Be a Voice for the Epilepsy Community

Are you from Connecticut, Hawaii, Louisiana, Maine, Minnesota, Mississippi, Montana, New Hampshire, New Mexico, Nevada, Rhode Island, Tennessee, Vermont, or West Virginia? If so, apply to become an Epilepsy Advocacy Champion! Champions will learn how to educate federal lawmakers about epilepsy and the policies that can impact the epilepsy community. No legislative or prior advocacy experience is required, just a willingness to share your experiences. The volunteer program is open to those over the age of 18 who are living with, or are affected by, the epilepsies. Champions will receive specialized training, resources, and support from the Epilepsy Foundation's national advocacy team, be connected with their local Epilepsy Foundation, if they aren't already, and be eligible to attend a biennial advocacy conference in Washington, D.C. to advocate on Capitol Hill. Advocates are expected to serve two-year terms with the possibility of renewal. Learn more and apply [here](#).



Apply here to become an Epilepsy Advocacy Champion

EPILEPSY FOUNDATION

PIPELINE Conference



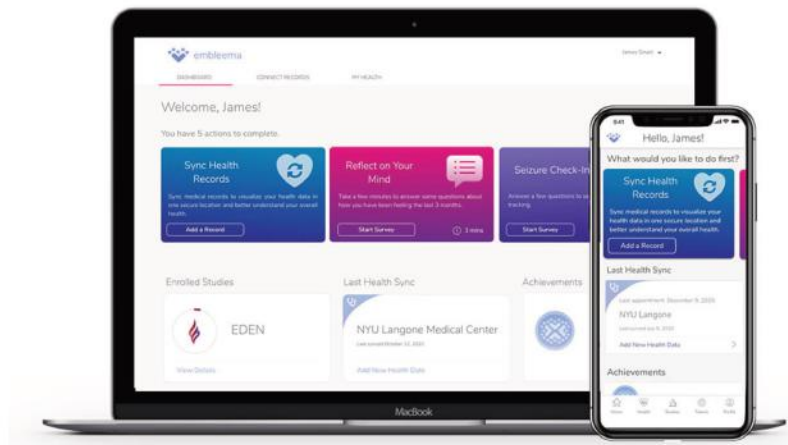
June 5-6, 2022 Santa Clara, CA

This premiere event is to bring together decision-makers in the field of epilepsy treatment, therapeutic innovation, and product development.

This exciting meeting provides a forum for evaluating new therapies in development, exploring future advancements, and encouraging collaborations and partnerships.

Learn more:

epilepsy.com/2022Pipeline



Looking for App Beta Testers

The Epilepsy Foundation is looking for people with epilepsy interested in testing its soon-to-be launched app — the Epilepsy Digital Experience Navigator (EDEN). Last year, the Epilepsy Foundation partnered with Eisai Inc. and Embleema, a technology company, to build EDEN to enable people with epilepsy to get connected to care, resources, and information tailored to their experience. The goal is to use data to better understand and improve the epilepsy journey. EDEN centralizes health records, allows users to log seizures, share outcome surveys all in one place using secure blockchain technology in a regulatory-grade data storage system.



To sign up as a beta tester,
email eden@efa.org.

Dr. Regan Lemley Receives Fellowship Award

Regan Lemley, MD, of Brigham and Women's Hospital/Harvard Medical School, was recently awarded the "2022 Susan S. Spencer, MD, Clinical Research Training Scholarship in Epilepsy" by the American Epilepsy Society, American Brain Foundation, and the Epilepsy Foundation in collaboration with the American Academy of Neurology. The two-year award supports clinical research training in the field of epilepsy and is given in honor of the late Dr. Susan Spencer, an internationally renowned epileptologist who exemplified the qualities of a clinician-investigator. The award recognizes the importance of good clinical research and encourages young investigators in clinical studies in epilepsy. Dr. Lemley will be studying the role of the gut microbiome in drug-resistant epilepsy.

Epilepsy & Seizures 24/7 Helpline Receives Re-Accreditation

The Epilepsy Foundation's Epilepsy & Seizures 24/7 Helpline, the nation's leader in epilepsy and seizure information, was recently re-accredited by the Alliance of Information and Referral Systems (AIRS), in recognition of the quality of information and referral service it provides to the epilepsy community. The 24/7 Helpline remains the first and only national specialized information & referral (I&R) helpline to achieve AIRS accreditation. The AIRS Accreditation Program is a multi-phase process that assesses more than 200 distinct components of an I&R service's operation and includes an expert review of the agency's resource database, a "secret shopper" monitoring of service delivery, and culminates in a detailed onsite review. The Epilepsy Foundation's re-accreditation is based on the excellent performance of its I&R services in five key areas: anonymous and nonjudgmental service delivery; up-to-date database of community resources; cooperative relationships with other I&R services at the local, regional, state/provincial and national level; preparedness and activation of I&R services and information related to an emergency and/or disaster; and organizational effectiveness to ensure quality assurance. The Epilepsy & Seizures 24/7 Helpline can be accessed by calling 1-800-332-1000 (English) or 866-748-8008 (Spanish).



Seizure Safe Schools Legislation Forges Ahead Across the Country

With the start of the 2022 state legislative session this month, many Seizure Safe Schools bills have also been introduced or re-introduced. The Epilepsy Foundation is excited to continue working with grassroots advocates, local Epilepsy Foundation staff, state legislators, and partner organizations to pass this legislation in all 50 states and Washington, D.C. Currently, there is active legislation in Florida, Hawaii, Iowa, Maryland, Michigan, Missouri, Rhode Island, South Carolina, and Vermont - with many more bills in the works. Most recently, Maryland, Missouri, and South Carolina's bills were heard by the committees of jurisdiction. South Carolina's bill successfully passed through the committee and will now move to the House floor. Missouri's bill is pending votes by the committee. Michigan's bill passed through the House before the holiday season and has gone to the Senate. If you are interested in learning more about your state's legislative efforts on this issue or would like to become involved, contact publicpolicy@efa.org or your local Epilepsy Foundation office.



To get involved,
contact publicpolicy@efa.org or your
local Epilepsy Foundation office.

CALENDAR OF EVENTS

See what's happening this spring!

Arizona

Camp Candlelight

June 19-24, 2022
Whispering Hope Ranch
Payson, AZ

Registration is now open! Camp Candlelight is a resident overnight camp for children entering 2nd Grade - Senior Year of High School, with epilepsy or a related seizure diagnosis.

Register:
<https://app.campdoc.com/register/efa>

California

Enterprising Women Luncheon: Working with Epilepsy, Seizures, and Related Conditions

May 25, 2022
Ritz Carlton
Dana Point, CA

The Epilepsy Foundation Greater Orange County will be hosting their inaugural Enterprising Women Luncheon: Working with Epilepsy, Seizures, and Related Conditions. The intention of this program is to increase awareness about the policies and issues affecting women's health in the workplace, with a specific focus on epilepsy, seizures, and related diagnoses. We appreciate our partners helping to raise awareness alongside us at this luncheon.

100% of event proceeds support programs, client services, advocacy

More information:
EpilepsyOrangeCounty.org

Epilepsy Pipeline Conference

June 5-6, 2022
Marriott Santa Clara -
San Clara, CA

This premiere event is held every two years to bring together decision-makers in the field of epilepsy treatment, therapeutic innovation, and product development.

This exciting meeting provides a forum for evaluating new therapies in development, exploring future advancements, and encouraging collaborations and partnership

More information:
<https://www.epilepsy.com/about-us/research-and-new-therapies/engagement/2022-epilepsy-pipeline-conference>



Maryland

AvE | Take a Swing at Epilepsy

March 31, 2022, 6-9pm
Top Golf National Harbor,
Oxon Hill, MD

Want to 'Take a Swing at Epilepsy?' Show your support of the Epilepsy Foundation Maryland and register today to participate in 'Take a Swing at Epilepsy' at Topgolf National Harbor! There's no pressure to have a good golf swing or score a lot of points. It's all about fun, food, and showing support for those living with the challenges of epilepsy.

More information:
EpilepsyMaryland.org

Nebraska

Epilepsy Night with the Stars

April 8, 2022, 7pm
Ice Box Arena
Lincoln, NE

More information:
epilepsy.com/Nebraska



Oregon

AvE | Take a Swing at Epilepsy

May 22, 2022, 1-4pm
Top Golf Hillsboro,
Hillsboro, OR

Show your support of the Epilepsy Foundation Oregon and register today to participate in 'Take a Swing at Epilepsy' at Topgolf National Harbor! There's no pressure to have a good golf swing or score a lot of points. It's all about fun, food, and showing support for those living with the challenges of epilepsy.

More information:
EpilepsyOregon.org

Camp Discovery

July 31 - August 3, 2022,
Camp Magruder
Rockaway Beach, OR

More information:
EpilepsyOregon.org

South Dakota

Epilepsy Advocacy Day at the Capitol

March 8, 2022, 8am -12pm
State Capitol
Pierre, SD

More information:
epilepsy.com/SouthDakota

Washington

Light The Flame Gala

March 12, 2022 at 6pm
W Bellevue Hotel,
Bellevue, Wash.

Join us for the 21st Annual Dinner and Auction supporting programs and services offered by the Epilepsy Foundation Washington.

More information at
EpilepsyWashington.org

Camp Discovery

August 14-17, 2022
Black Diamond Camp
Black Diamond, WA

More information at
EpilepsyWashington.org

UTAH

Warriors of Epilepsy: An Evening with Warriors with Epilepsy

April 16, 2022, 6pm
Little America Hotel
Salt Lake City, UT

More information:
epilepsy.com/Utah

NATIONWIDE

EpiCon

May 13-15, 2022
Gaylord Opryland Resort
Nashville, TN

A 3-day convention where the epilepsy community comes together to empower each other to live their best life. Exhibits. Workshops. Opportunities to connect.

More information at
epilepsy.com/epicon

Walk to END EPILEPSY

Virtual Celebration

June 4, 2022

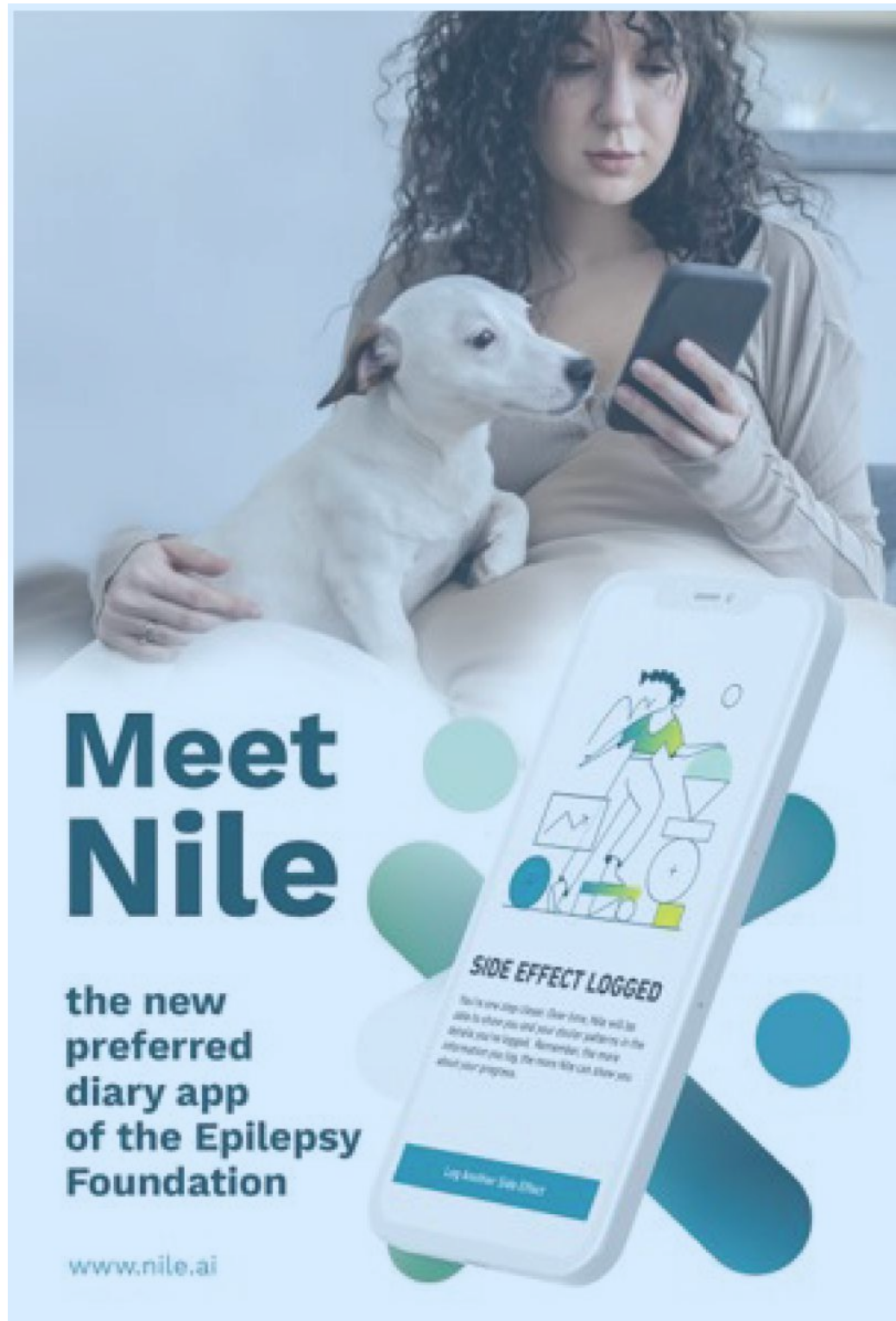
In Person - Spring

March - June 2022

More information:
WalktoEndEpilepsy.org

SEIZURE FIRST AID CERTIFICATION TRAINING - LIVE

3/29/2022 8:00 p.m. ET
Seizure First Aid certification



Meet Nile

the new preferred diary app of the Epilepsy Foundation

www.nile.ai

SIDE EFFECT LOGGED

You're one step closer there, Nile. We will be able to share you and your doctor's patterns in the details you've logged. Remember, the more information you log, the more Nile can show you about your progress.

Log Another Side Effect



Giving for Better Outcomes

How partnerships in care and research can increase our community's chances to live a seizure-free life.

Quick Snapshot: Impact of Epilepsy Learning Health System (ELHS)



18 community teams
(local Epilepsy
Foundations, Rare
Epilepsy Network
organizations and
advocacy non-profits)



Seeking to improve
upon **87%**
Seizure Frequency
Documentation rate
and to include all
network sites



5100+
visits to ELHS website



Seeking to improve
upon **56%**
Intervention rate
for identified Barriers
to Medication Adherence
and to include all
network **sites**



7
industry partners in the
QI Science Leadership



The Epilepsy Learning Healthcare System (ELHS) was established in 2018 with a PCORNet Learning Health System Network Pilot Collaborative grant, and today has participation from 18 community organizations and 14 clinical epilepsy centers in 13 states.

Accomplishments in 2021 would not be possible without the contributions of all members, and most importantly, people living with epilepsy, their families and caregivers. ELHS clinicians, researchers and health system leaders would not be able to help improve health outcomes without the Patient Family Partners (PFPs). PFPs played a critical part in identifying key areas of Seizure Documentation and Barriers to Medication Adherence as the most critical issues to address by the ELHS network. With data coming from the patient and also clinically reported, the efforts of all involved will lead to increased quality, experience and value in epilepsy care. In a Learning Health Network, it is the unique expertise and perspectives of all stakeholders that drive change.



Learn more:
epilepsy.com/elhs

AADC DEFICIENCY AND EPILEPSY

Similar signs and symptoms between certain subtypes of epilepsy and AADC deficiency include:

- Low muscle tone, or hypotonia
- Movement problems, such as turning movement of the head and neck or contractions of the limbs and trunk
- Delays in development, such as learning disabilities
- Autonomic symptoms, such as the body being unable to control its temperature (temperature instability), sweating, and changes in blood pressure

Every individual is different, so symptoms may vary from person to person.

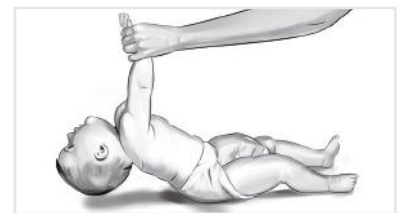


Illustration of hypotonia

Signs and symptoms of AADC deficiency not seen in epilepsy:

- Involuntary eye movements called oculogyric crises
 - Episodes when eyes suddenly roll upward that can last anywhere from a few seconds to hours, and can happen several times a day or several times a week. When this happens, it can look like the child is having a seizure
- Normal brain scans
- Symptoms become worse or more noticeable later in the day and improve with sleep
- Symptoms do not respond to antiepileptic medications



Illustrations depicting (A) an oculogyric crisis and (B) involuntary movements that may accompany an episode



If your child is showing one or a combination of these signs and symptoms, you may want to talk to your child's doctor about testing for AADC deficiency.



Words from the epilepsy community

Nothing prepares you for this journey. Helplessly watching your child have a seizure is the worst feeling ever. Epilepsy has an agenda, and it robs you and your family of so much.

One thing is certain: we have a princess with the strength of a warrior. She is the true definition of fortitude and bravery. Her fighting spirit shines through daily, and epilepsy will not define her.

-Thandi, mom of a child with epilepsy



The mission of the Epilepsy Foundation
is to lead the fight to overcome
the challenges of living with epilepsy
and to accelerate therapies
to stop seizures, find cures, and save lives.

Learn more at epilepsy.com