


Foundation Quarterly

A portrait of Carla Jeffery, a young Black woman with long, dark, curly hair styled in a high bun. She is wearing a pink headband with a blue and pink pattern, glasses, and a bright pink jacket over a black top. She is smiling warmly at the camera. The background is a solid blue color with several white starburst graphics scattered around her.

Carla Jeffery,
Disney Star
and Epilepsy
Warrior

The All About Me Issue

+ In Your
Community,
News Briefs, and
Purple Recipes
for Epilepsy
Awareness

LETTER FROM THE CEO

This month, it's all about YOU!

You heard that right. We wouldn't be able to do the work we do at the Epilepsy Foundation without the collaboration and support of our community — YOU.

When I was named chair of the national board this past summer, I knew it was going to be an exciting and memorable journey. As a person with epilepsy, and the father of a child with epilepsy, I have seen how our community always rallies together to bring hope and effect change for everyone impacted by the epilepsies.

It takes dedicated epilepsy warriors, caregivers, advocates, partners, and the healthcare community to bring our mission to life — funding research for innovative treatments as well as key initiatives that bring a spotlight to epilepsy and seizures.

You are our greatest asset, and we are rallying around you and for you. That's why this issue of the magazine highlights people in our community who are using their stories to help those with epilepsy overcome the challenges that come with it.

You will read about Disney Channel star Carla Jeffery who, for the first time, is sharing her epilepsy journey. Also get to know a mom whose child had brain surgery at 3-months-old which led her to form an organization to support other parents of children undergoing epilepsy surgery.

The magazine also coincides with National Epilepsy Awareness Month (NEAM), so the centerfold spotlights individuals throughout our network and their NEAM action. I invite you to join me in taking action for every one of us who has been affected by epilepsy.

Thank you for your meaningful efforts, not just in November, but all year-round. Without you, there is no NEAM. Without you, there is no Epilepsy Foundation.

Jeff Parent
Chair, Board of Directors, Epilepsy Foundation
President and General Manager, Gulf States
Toyota, Texas

FOUNDATION QUARTERLY STAFF

Jackie Aker
Lead Writer and Editor

Kaitlyn Gallagher
Contributor writer

Michelle Bareng
Design and Layout

Sara Wyen
Contributor writer

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Be proud of you.

- Oprah Winfrey

Disney

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ZOYME



#MyNEAMAction: Sharing my Journey

She plays Bree in Disney+'s "ZOMBIES" movies. Just like the third movie which is focused on embracing your differences, Carla Jeffery is embracing her epilepsy and sharing it with the world.

This past summer, Jeffery opened up about living with epilepsy in a public service announcement (PSA) that celebrated all abilities which aired during Disability Pride Month on the Disney Channel. When Disney asked her to participate in the PSA and talk about her experience with epilepsy, she was hesitant. She had never publicly discussed it, and up until that point, only people who needed to know were aware of her condition.

"When I first got into acting, I was not comfortable talking about my epilepsy," Jeffery said. "I was worried that I would have a seizure while reading lines or on set. I was even scared to tell my manager for fear that she wouldn't send me on any auditions. But, on the contrary, once I told her, she encouraged me to not let it hold me back. It helped me realize there was more to me than just my epilepsy."

COVER STORY

Jeffery found out she had seizures at 18, an age when teens want to go out with friends, date, have fun, and begin experiencing life as an adult. But for her it was different. She didn't want to go out as much or put it on her friends to watch over her in case she experienced a seizure in public. Her mom, twin brother, and close friends were always around her trying to help in any way possible. Dating was also a challenge. She once had a seizure while on a date and it pushed her date away, so sharing her condition with others was not something she wanted to do at that time.

Then one day, while filming "ZOMBIES 1" Jeffery had a seizure and woke up in an ambulance. It was at that point she told Disney and others on set about her epilepsy. Her manager advised her to do so in case she had another seizure on set. This way, someone could assist Jeffery if needed. Disney was more than accepting about her condition; they supported her every step of the way.

I was worried that I would have a seizure while reading lines or on set.



Photo Courtesy: Carla Jeffery

"I eventually agreed to do the PSA, and I'm so glad I did! I felt that if my story can help others, then let it be known. I had the opportunity to come together with other Disney stars to bring awareness and encourage acceptance of all disabilities. When the PSA aired, I received so much support from everywhere, and people were sharing their own stories with pride."

Jeffery is working with a healthcare team to identify her seizure triggers and find the right treatment to help her achieve seizure control. In the meantime, she wants others, who may be struggling with shame or embarrassment, to know that while it may take time to accept their epilepsy diagnosis, it shouldn't stop them from getting the help they need.

“I want everyone to know, not to be scared of who you are,” she said. “I’ve had this for years, and it’s not going anywhere. I just have to work around it. I’m going to keep doing what I love, and at the same time, use my story to help others. I want to be an inspiration. I want you to know that you can do what you want to do despite it all.”

I want everyone to know, not to be scared of who you are.



Photo Courtesy: Carla Jeffery



#MyNEAMAction:

Turning a Hobby into A Cause

It was 2017 when Zach Beckemeyer picked up a black sharpie and a sketch pad and began what would be a career as an artist, and a therapeutic journey to help him cope with his epilepsy.

For him, drawing started as a hobby making birthday cards for family members. It was also an “out” from the emotional turmoil he was experiencing at home. Beckemeyer would walk to a local café every morning and sketch — single lines, bottles, a silly monster, anything that would come to mind and around which he can build a story.

“People like to look at art, and a lot of it is about guessing,” he said. “I like to express what artwork is about by adding a story to get people’s interest. Not only do I learn stuff myself, but it also adds more fun to the artwork.”

He was 22 years old in the passenger seat of his mom’s car when he experienced his first seizure. Soon after, he was diagnosed with epilepsy. He was unable

to work, play music, and do other things that he usually enjoyed doing. Over time, his seizures evolved, and they began to affect his ability to speak and remember words.

After multiple tests and different types of treatments, his healthcare team was able to pinpoint where in the brain his seizures were happening. Beckemeyer opted for surgery to try and control his seizures. His first procedure was to remove a part of his skull; days later, he had a second surgery to remove brain tissue.

“After my procedure, I had to learn to walk, speak, read, and write again,” he said. “My memories were obliterated. Two weeks after discharge, I developed inflammation and an abnormality over my incision. Luckily it was caught in time, but that put a pause on my art for the next four years.”



Prince Purple Rain Tour by Beckemeyer

While the surgeries helped decrease seizure activity, he experienced hand and body tremors which impacted his ability to draw, and it affected him emotionally. He inadvertently pushed people away.

In 2021, Beckemeyer was comfortable enough to pick up a pencil and a sharpie again. He explored ways to evolve his drawings by adding color using Adobe Illustrator. He also inserted cultural and historical facts to the stories around each design.

Today, he has 154 pieces, three of which debuted and sold at the Hidden Truths Project: Art of Epilepsy art exhibit. He has also participated in other local events, and recently two of his designs were chosen for the Costa Mesa (Calif.) Utility Box Art Program, an initiative in his hometown that spotlights the work of local artists in public places throughout the city.

Beckemeyer says his next art project will be a series of drawings depicting epilepsy, including the brain, nerves, and connections which he hopes to continue to shine a light on epilepsy.

“It’s been one heck of a journey, but the more I can accomplish, the more I stay peaceful. Art and music have been the most powerful medications for me, it’s what keeps me going, mentally and physically. All this acceptance and love has made me feel less like a grain of sand on the beach and more like a stone rolling on top. Now I want to use my art for a cause while I continue my epilepsy journey.”



For more information about Beckemeyer, visit zjbarts1.wordpress.com



#MyNEAMAction: Passing Legislation

In collaboration with the Epilepsy Foundation of Kentuckiana, 17-year-old Lyndsey Crunk advocated for two years for the passage of a bill to address seizure recognition and first aid training in schools. In April 2018, Kentucky passed the Lyndsey Crunk Act into law. This legislation helped to create the model bill for the Epilepsy Foundation's Seizure Safe Schools initiative. As a result of the Lyndsey Crunk Act, the Epilepsy Foundation began working with its network of partners to pilot the initiative in other states. A year later, three additional states became leaders in this national movement by passing versions of Seizure Safe Schools legislation: Indiana, Texas, and Illinois.

Today, **there are 19 states that have passed legislation**, including Alabama, Arizona, Colorado, Florida, Louisiana, Maryland, Minnesota, Missouri, Nebraska, New Jersey, Oklahoma, Utah, Virginia, Washington, and the latest — California, which was signed into law this past September.

In the United States, there are approximately 500,000 children — or about 6 in 1,000 — who live with epilepsy and seizures. In California alone, there are nearly 60,000 children and teenagers living with epilepsy, including California State Assemblymember Marc Levine's son. His own family's epilepsy journey is what led him to author the Seizure Safe Schools Act, a bill championed by the Epilepsy Foundation Los Angeles that allows public and charter schools in California to designate volunteers to receive training and education on caring for students with seizure disorders.

As a parent of a school-aged child with epilepsy, he understands first-hand the challenges that come with the disorder. Assemblymember Levine's son was diagnosed with epilepsy at 10 years of age, and has experienced seizures at school, camp, and other places throughout his epilepsy journey. Most importantly, the assemblymember knows how it feels to send off your child with epilepsy to school not knowing if there will be someone there to assist them in the event of a seizure. So, he set out to change that.

"Children with seizures can be as safe at school as they are at home," said Assemblymember Levine. "Families are not powerless — we are empowered with tools to help our children live full, enriched and dynamic lives. The Seizure Safe Schools Act makes sure that the same tools used to keep children with seizures safe at home are available to children on a school campus. I authored this important legislation for my child and for children throughout California who deserve to thrive in a safe and supportive learning environment."

To date, additional states, including Pennsylvania and South Dakota, have taken important steps to raise awareness and lay the groundwork for passing comprehensive Seizure Safe Schools legislation in the future. In the meantime, the Epilepsy Foundation is working with local Epilepsy Foundation offices, grassroots advocates, stakeholders, and organizational partners to push this legislation in all 50 states and Washington, D.C.



Learn more at epilepsy.com/seizure-safe-schools

#MyNEAMAction: Spreading Awareness

by Sapna Modi



I was diagnosed with epilepsy when I was 8 years old. I remember sitting in third grade when my very first absence seizure happened. My seizures were not controlled, so I had three or four a day. It got to the point where I had to be pulled out of school early at least three times a week.

For me, the side effects of the seizures were worse than the seizures themselves. I was left with an unbearable migraine and an overall lack of awareness of my surroundings. I remember spending much of my childhood years in the school nurse's office. Sometimes, it seemed like I was in there more than I was in the classroom.

By the time I got to fifth grade, my doctor was able to get my seizures under control. From the beginning of middle school to the end of high school, I lived a completely normal life. Unfortunately, that changed when my seizures came back my first year in college. It took over my life. My grades started to suffer. I felt just like I did when I was a child, except so much more was at stake. My dream was to pursue business and work on Wall Street, but I didn't know if that would happen. I began to wonder if I would be able to drive, or if I would even graduate from college at all.

After numerous tests, and trying out different types of medications, my doctor was able to get my seizures under control again. I went back to living my life and pursuing my dreams, only my dreams had changed. The seizures and what my doctor did for me really helped put things into perspective. I decided that even after experiencing seizures again, I had no right to complain. Ultimately, I realized how lucky I was to be able to live a normal life now.

My experience led me down a new path. I decided to use every opportunity to my advantage, and do whatever I could to spread awareness about epilepsy. Shortly after, I took on multiple volunteer and advocacy roles on behalf of the Epilepsy Foundation. I became an Epilepsy Awareness Ambassador, a team captain liaison for the Walk to END EPILEPSY®, and a Kids Crew mentor, which has been my favorite role so far.

Now, I am 21 years old and currently in my last year of college. After my own experiences, volunteering, and working with kids with epilepsy, I became very inspired and developed an interest in neurology. Today, my dream is to go to medical school and become a pediatric neurologist. I realize I have a true passion for helping people.



Photos provided by Sapna Modi



Become an Awareness
Ambassador at
epilepsy.com/volunteer



The fight begins with us

Register at your local **Walk to END EPILEPSY** events*

Birmingham, AL
Phoenix, AZ
Orange County, CA
Farmington, CT
Killingworth, CT
New Milford, CT
New London, CT
Orange, CT
Tolland, CT
Stamford, CT
Iowa City, IA
West Des Moines, IA
Indianapolis, IN

New Orleans, LA
Omaha, NE
Fargo, ND
Dayton, OH
Oklahoma City, OK
Portland, OR
Charlotte, NC
Raleigh, NC
Sioux Falls, SD
Dallas, TX
El Paso, TX
Fort Worth, TX
Galveston, TX
Houston, TX

Lubbock, TX
San Antonio, TX
The Woodlands, TX
Tyler, TX
Salt Lake City, UT
Seattle, WA
Washington, D.C.

***Please check our website as more Walk to END EPILEPSY locations will be announced**

Walk to
END EPILEPSY
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Take action for our epilepsy community

WalktoEndEpilepsy.org

**Join us
in person in DC**

Walk to
END EPILEPSY
EPILEPSY FOUNDATION



#MyNEAMAction:

Inspiring Research

Getting part of your brain removed is scary, but for someone with drug-resistant epilepsy, it can mean a chance to improve seizure control. And when it comes to brain surgery in a child, it is even more frightening as more than just seizure control is at stake. Will my child learn to walk? Will my child learn to talk? How do I get my child to reach their full potential? These questions were going through the minds of Monika Jones and her husband after their oldest son, Henry, had a hemispherotomy (a type of epilepsy surgery) at 3 months old to stop his seizures.

“We had an infant and had to start thinking about taking half of his brain out,” said Jones. “We searched and searched for answers, and even went to see a renowned neurologist and all he said was ‘I don’t know, get a lot of therapy’. There was no plan. No one can look at us and say, ‘this is what you can do afterward to help with his developmental milestones’. It was so frustrating.”

His seizures returned a year later, and he had a second hemispherotomy, followed by an anatomic hemispherectomy, another type of epilepsy surgery. He also underwent multiple procedures that caused abnormal fluid to build up deep within his brain.



FEATURE STORY

Jones and her husband found that there was limited information in the medical and physical therapy community on the developmental challenges that may arise from Henry's epilepsy surgeries. In 2011, Jones and her husband co-founded the Pediatric Epilepsy Surgery Alliance (formerly known as the Brain Recovery Project) to initiate and fund research to better understand neurorehabilitation after epilepsy surgery.

"From the start, somebody has to address life after brain surgery in a child with epilepsy," said Jones. "That's why we started the organization; we wanted to give parents a roadmap. It's important for them to understand the pros and the cons of every epilepsy surgery and have a plan for the aftermath. It is as important as preparing for, and getting the child to, the surgery itself."

Soon after founding the organization, Jones joined several social media groups with families of children with drug-resistant epilepsy, and quickly learned about the challenges that exist for children in underserved communities after having brain surgery to stop their seizures.

"I found that people who live in rural communities and those who are experiencing financial challenges can't easily get to an epilepsy center or get on a plane to get their child to a hospital to be evaluated for epilepsy surgery," said Jones. "So we implemented a surgical evaluation scholarship where we award families up to \$1K to travel to an epilepsy center. This helps families get their child evaluated to determine if surgery is an option for them."

That's why we started the organization; we wanted to give parents a roadmap.

Jones and her team also looked at other ways they can help address these challenges. At first, the organization was only focused on neurorehabilitation following a hemispherectomy. However, Jones said they expanded to serve a community of families with children who need any type of brain surgery to treat drug-resistant epilepsy. They also broadened their focus to fund research to better understand outcomes for all types of epilepsy surgeries.





One of those research projects is the Global Pediatric Epilepsy Surgery Registry launched in 2019 which allows families to share their experiences with surgery.

Data from the registry is analyzed for changes in a child's function over time and looked at to determine whether some surgical procedures are more effective than others at stopping seizures.

"Parents want to know what is going to happen after half their child's brain is removed," said Jones. "The registry tracks a child's development after surgery. For example, we recently published a study based on our registry which shows that a percentage of children go into early puberty after surgery. This is key to helping parents navigate that journey and being prepared for what's to come."

While Jones spent years diving into the literature to fully understand how to best support Henry in his rehabilitation after surgery, she and her husband have helped to make the journey easier for other parents. Today, after 11 brain surgeries — three of which were epilepsy procedures — Henry is a joyous fifteen-year-old who can walk and communicate well with his family through a device.

"When I get asked how he is doing now, I like to say that Henry is doing a thousand times better than he would have been without the surgery. He is happy and loves to fight with his little brother."

When I get asked how he is doing now, I like to say that Henry is doing a thousand times better than he would have been without the surgery.



Learn more about the
Pediatric Epilepsy
Surgery Alliance at
brainrecoveryproject.org

There is no **NEAM** without **ME!**

That's our theme for this year's National Epilepsy

Awareness Month (NEAM). We chose this because November is all about our community, and without your collaboration and support, we wouldn't be able to build a seizure safe nation. Together, we are raising awareness and funds, educating the general public about the epilepsies and seizures, and pushing for more research to improve outcomes for people with epilepsy.



What's Your NEAM Action?

From Epilepsy Foundation staff to corporate partners, to buildings and landmarks lighting purple, everyone is taking action this month to make November the loudest and purple-est National Epilepsy Awareness Month ever for our community — YOU!

We asked colleagues within the Foundation and around our Network ...



... to champion the passage of the Seizure Safe Schools Act (HB4790) in Michigan.

- Brianna Romines

... to make sure people affected by epilepsy know they are not alone and there is a community of thousands who are here to offer support and guidance.

- Rebekkah Halliwell



... to educate as many people as possible on how to recognize and respond to a seizure.

- Roxanne Cogil

... to raise awareness about epilepsy throughout northeastern New York where more than 45,000 people are living with this condition.

- Jeannine Garab



... to motivate and inspire people living with epilepsy to focus on their goals.

- Veronica Crowe

... to raise awareness about epilepsy and seizures among Latinos.

- Jackie Aker



... to support those who have lost someone due to epilepsy in our community.

- Alison Kukla



... to attend a #WalktoEndEpilepsy in November and encourage those around me that they aren't alone in the epilepsy journey.

- Sara Franklin



#MyNEAMAction Light the Night with Purple

Check out these buildings lighting up for epilepsy awareness

We asked partners ...

Rebecca Moran, Director, Corporate Advocacy, Eisai Inc.

... we are training our field force in seizure first aid to truly put ourselves in the shoes of the patients and care partners whom we serve. At Eisai Inc, we stand by our belief that patients and their families come first, and we have a responsibility to listen to, and learn from, them.

Elizabeth Clark, Registered Nurse, National Association of School Nurses

... we trained more than 1,000 of our members at our annual conference to help drive education about epilepsy and seizures in underrepresented communities. NASN recognizes the essential role of school nurses to promote a safe and inclusive school environment and to implement evidence-based clinical care for students with seizures and epilepsy.

Jessica Chappell, Business Analyst, Walgreens

... we are hosting epilepsy awareness events for all Walgreens team members across the organization and completing seizure first aid certification trainings. Walgreens has been, and continues to be, a leading healthcare provider that understands and supports epilepsy warriors everywhere.



Share your NEAM Action on the Epilepsy Foundation's Facebook and Instagram channels using the hashtag #MyNEAMAction. For NEAM action ideas, visit epilepsy.com/NEAM.

Seattle, WA

T-Mobile Park (Home of the Seattle Mariners) - Nov. 1

Grand Rapids, MI

Blue Bridge - Nov. 1-6

Oklahoma City, OK

Skydance Bridge - Nov. 2

Cedar Rapids, IA

- St. Luke's Hospital - Nov. 2
- Alliant Energy Tower - Nov. 4-10

Davenport, IA

Downtown SkyBridge - Nov. 21-27

Des Moines, IA

- Financial Building
- Capital Square
- Krause Gateway Center

Annapolis, MD

Maryland Government House - Nov. 22



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.



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

Former National Board Member Honored with Award



Brooke Gordon (right) and her husband, Tom
Photo Courtesy: Epilepsy Foundation Colorado & Wyoming

Brooke Gordon and her husband, Tom, were honored with the Wellington E. Webb Award for Excellence in Healthcare Philanthropy at the Denver Health Foundation's 2022 NightShine Gala. In addition, her family surprised her by arranging a \$1 million donation in her honor to help fund and expand the Brooke Gordon Epilepsy Center at Denver Health Hospital. Gordon, who lives with epilepsy, established the Brooke Gordon Leadership Fund for mental health programs at the Epilepsy Foundation of Colorado & Wyoming, where she currently serves on the board. She previously served on the Epilepsy Foundation's national board of directors.



Honoree Speaker Kate Gallego
Photo Courtesy: Epilepsy Foundation in Arizona

Enterprising Women Luncheon

In September, attendees, speakers, sponsors, and volunteers gathered at Phoenix Country Club for an annual women luncheon hosted by the Epilepsy Foundation in Arizona. The event, "Enterprising Women Luncheon: Working with Epilepsy, Seizures and Related Conditions" was created to increase awareness about policies and issues affecting women's health in the workplace, with a specific focus on epilepsy, seizures, and related diagnoses. Attendance included Representatives Dr. Amish Shah and Jennifer Pawlik, and Phoenix Mayor Kate Gallego who spoke at the event.

IN YOUR COMMUNITY



Camp Participants at Camp Discovery
Photo Courtesy: Epilepsy Foundation in Washington

Camp Discovery Celebrates its 33rd Anniversary

This year marked Camp Discovery's 33rd anniversary and the Epilepsy Foundation in Washington celebrated with 45 young campers and 25 volunteers. Attendees spent four days and three nights in Auburn, Wash. swimming, doing archery, art therapy, ropes course, and zip lining. There was also a special guest appearance from The Reptile Man. In addition, the Seattle Mariners, Major League Baseball team, graciously graciously donated hats for all campers and volunteers.

Medical Students Get Seizure First Aid Certified

Howard University (Washington, D.C.) recently trained and certified 46 medical students in seizure first aid. The program was in partnership with the Howard University College of Medicine's neurology club.



Students participating at the Seizure First Aid training
Photo Courtesy: Epilepsy Foundation in Maryland

Older Adults Making a Difference

In partnership with the Michigan Public Health Endowment, the Epilepsy Foundation of Michigan received a two-year grant to host a support group for older adults living with epilepsy. This community of older adults, and their caregivers, gather weekly over Zoom to provide support and encouragement to one another and use their wisdom and passion to spread epilepsy awareness. They demonstrate the vital truth that people of all ages can serve as advocates for the epilepsy community.



Photo Courtesy: Epilepsy Foundation Michigan

Say "Cheese!"

This past summer, the Epilepsy Foundation of Southeast Tennessee hosted a free photography workshop, SnapChatt, created by board member Tony Cepak, which provided children with instant Polaroid cameras to encourage them to learn a new skill and help them overcome the challenges they face each day. Cepak lives with epilepsy and hopes that SnapChatt will encourage kids to be creative with photography beyond the program.



Epilepsy Foundation Southeast Tennessee Board Member and creator of SnapChatt, Tony Cepak

Supporting Health Equity

Recently, more than 30,000 participants joined the African American Male Wellness Agency (AAMWA) at its 5K Health Walk & Run in Columbus, Ohio. The event is meant to create awareness about preventable diseases among Black men so that they live longer, healthier lives. This year, the Epilepsy Foundation in Ohio had a booth at the event as part of its collaboration with the AAMWA. Foundation staff members, Crystal Hagans and Thometta Cozart, distributed educational materials at the event.



Photo Courtesy: Epilepsy Foundation in Ohio



Photo Courtesy: Epilepsy Foundation in Ohio

Mud Volleyball Tournament Draws Thousands

The Epilepsy Foundation in Ohio held its 31st Mud Volleyball Tournament in Dayton with more than 3,000 attendees. People traveled from New York and Texas to be a part of this fundraiser, which raised an estimated \$100K.

AADC DEFICIENCY AND EPILEPSY



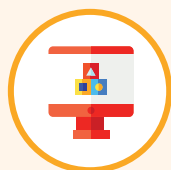
Aromatic L-amino Acid Decarboxylase (AADC) deficiency is a rare genetic disorder that affects the brain, causes weak muscle tone, and affects how a child develops

Because AADC deficiency is rare, it is not easy to diagnose and many healthcare professionals may never encounter a patient with this disorder.

Some signs and symptoms of AADC deficiency may be mistaken for certain types of epilepsy or seizures

Epilepsy is a group of disorders that cause seizures. Seizures are caused by a sudden rush of abnormal electrical activity in the brain that results in different symptoms.

Sign or symptom of AADC deficiency	May be mistaken for	Type of seizure or epilepsy
Involuntary eye movements called oculogyric crises	>	Versive seizures , or a type of seizure involving forced turning of the head, neck, and eyes
Symptoms affecting involuntary body functions (motor and autonomic symptoms)	>	Simple partial (focal) seizures , or a type of seizures that does not affect awareness, but may involve muscle tightening, unusual movements, sweating, or a rapid pulse
Low muscle tone (hypotonia), developmental delay, and oculogyric crises	>	Hypoxic ischemic encephalopathy (HIE) seizure , or a type of seizure that typically occurs shortly after birth and is caused by a lack of oxygen or blood flow to the brain for a period of time



When AADC is misdiagnosed or goes undiagnosed, treatment and proper management is delayed.

For more information, visit AboutAADC.com

Epilepsy Foundation Elects New Board Members & Chair

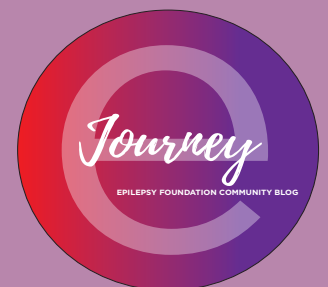
The Epilepsy Foundation recently selected Jeff Parent as chair of its governing Board of Directors. Parent succeeds Bradley P. Boyer, Esq., who served as chair for two years. In addition, the Foundation elected nine new board members, who together with the staff leadership, will help bridge the Foundation's traditional and digital efforts for greater scale and impact. "I am thrilled and humbled to have this opportunity to serve on the Epilepsy Foundation's Board of Directors," said Parent, president, and general manager, Gulf States Toyota in Texas. "As both a person with epilepsy and the father of a child with epilepsy, I am excited to work with the existing and new board members to continue to effect positive change for our community. As chair, I am honored to help the Foundation leverage cutting-edge technology and traditional marketing strategies to reach and engage everyone impacted by the epilepsies."



For a full list of board members, visit epilepsy.com/about/leadership

Your story
is power for
our community.

Be inspired and add to the strength of our community at epilepsy.com/eJourney



FDA Approves First Autoinjector Therapy for Status Epilepticus



The Food & Drug Administration (FDA) recently approved the first auto-injectable product for the treatment of status epilepticus or prolonged seizures in adults. Status epilepticus is said to occur when a seizure lasts too long or when seizures occur close together and the person doesn't recover between seizures. While there are other rescue treatments with different routes of administration, according to Rafa Laboratories, its 10 mg midazolam autoinjector can be administered without requiring an intravenous line. Rafa collaborated with the U.S. Department of Defense's Joint Program Executive Office for Chemical, Biological, Radiological and Nuclear Defense to develop the product. The midazolam autoinjector is administered into the thigh and can be done through clothing providing a significant advantage for urgent treatment, helping to reduce injury and lessening the chance of serious complications.



For more about status epilepticus and other seizure emergencies, visit epilepsy.com/complications-risks/emergencies

Do You Have What It Takes to Face the Sharks?

The 2023 Shark Tank Competition, hosted by the Epilepsy Study Consortium in collaboration with the Epilepsy Foundation, is now open! The deadline to submit your proposal for the most innovative new ideas in epilepsy treatment and care is Dec. 23. The finalists will compete for awards totaling up to \$75,000 to support the development and commercialization of their new product, technology, or therapeutic concept to help people with epilepsy. The Shark Tank review committee will select as many as five finalists to present their concepts at the 2023 Epilepsy Therapy and Device Development Conference in mid-2023.



To submit your proposal, visit epilepsy.com/Sharktank



Take Part in Clinical Research Studies

Clinical trials are used to evaluate the effectiveness and safety of new medications, therapies, and devices for treating medical conditions. The studies collect information about a particular disease or disorder. Many of the medicines and devices available today are the result of clinical studies. There are several studies currently being done to evaluate treatments for different types of seizures. A few are listed below.

STARS (Stand Together Against Prolonged Seizures) is searching for people with epilepsy to take part in a clinical research study. Viable clinical trial candidates are people who experience seizures that last more than several minutes. The STARS Study is testing an inhaler containing an investigational drug that is designed to potentially stop a prolonged seizure once it has begun. Learn more and find your study site at StarEpilepsyStudy.com.

EXPAND Study is researching a potential new medication for people with childhood absence epilepsy (CAE) or juvenile absence epilepsy (JAE). People with CAE or JAE have brief episodes of staring and unresponsiveness called absence seizures. Treatment options are limited and many of the anti-seizure

medications currently available may not work for everyone. The investigational medication in this study is believed to work differently from other therapies already approved for absence seizures. Learn more at ExpandStudy.com.

Skyline Study is researching an investigational medication for children, teens, and young adults diagnosed with Dravet syndrome who are currently using 0-4 anti-seizure medications to manage symptoms and are still experiencing seizures. The investigational drug works differently than currently approved medications and is being tested as an add-on therapy in the clinical research study. To learn more about the study, visit skyline.researchstudytrial.com.



CALENDAR OF EVENTS

See what's happening for NEAM!

Arizona

Epilep-Tea Party

November 6, 2022, 1:00 p.m.
The Clayton House
Scottsdale, AZ

The Epilepsy Foundation Arizona will be hosting our Signature Fundraising Event in Arizona, the Epilep-TEA Party, to bring more local awareness to epilepsy. We hope you can join us for this special event.

100% of event proceeds support programs and services including, but not limited to Camp Candlelight, Seizure Training & Education, Advocacy, Information & Referral Service, SUDEP & Bereavement Support and Research & Innovation.

Register:
epilepsyaz.org/event/8477/



California

Care & Cure Institute Gala 2022

November 9, 2022, 6 p.m.
Paramount Pictures Studios
Hollywood, CA

Join us for a benefit to END EPILEPSY® in children honoring academy award winning producer Graham King.

Details at CareandCure.org.

Delaware

6th Annual Delaware Epilepsy Conference: Family Centered Approaches to Epilepsy Care

November 19, 2022, 8:30 a.m.
Christiana Hospital
Newark, DE

Get your questions about epilepsy answered by local experts, find support among others affected by epilepsy, and discover local epilepsy resources!

Register at
www.efde.org/events/6th-annual-delaware-epilepsy-conference-family-centered-approaches-to-epilepsy-care

Kentucky

END EPILEPSY Statewide Conference

November 5, 2022, 10 a.m.
Founders Union Building
at University of Louisville
ShelbyHurst Campus
Louisville, KY

The 2022 END EPILEPSY conference is for individuals school age and up. The program will feature a day of educational sessions presented by experts in the field of epilepsy. These sessions are designed to help you understand more about living with seizures and how to better cope with this neurological condition.

Register:
www.efky.org/conference-560268.html

Michigan

Seizure Smart Psychotherapy: Training For Mental Health Professionals

November 15, 2022, 8 a.m. CT
Virtual

The Epilepsy Foundation of Michigan is pleased to invite

mental health professionals to an insightful training opportunity to learn about psychogenic nonepileptic seizures, epilepsy, and their unique connections to mental health comorbidities, such as depression, anxiety, and PTSD.

Learn more at
epilepsymichigan.org/events/seizure-smart-psychotherapy-training-for-mental-health-professionals-2/

Wellness & Epilepsy Conference

November 19, 2022, 8 a.m.
VisTaTech Center
Livonia, MI

The conference is designed primarily for people with epilepsy and their families, but we also encourage professionals to share in this time together. This year's conference will feature a diverse array of session topics and opportunities to gather socially.

Register at
epilepsymichigan.org/wellness-epilepsy-conference/

Mississippi

Glow the Night to End the Fight

November 15, 2022, 6 p.m.
District at Eastover
Jackson, MS

Come glow the night with the Epilepsy Foundation Mississippi at its 2nd annual event for glow stick and neon fun to spread epilepsy awareness.

Click here for details:
<https://donate.epilepsy.com/index.cfm?fuseaction=donorDrive.event&eventID=1059>

Ohio

Women in Epilepsy Brunch

November 4, 2022, 11 a.m.
The Dayton Women's Club
Dayton, OH

Epilepsy Foundation Ohio is hosting their first Women in Epilepsy Brunch! This event will provide a space where both women and men can come together and discuss epilepsy. Dr. Stephanie Callow from the Cincinnati Epilepsy Center will be the main speaker. There will also be a panel discussion and an ignite talk.

Register for the 2022 Women in Epilepsy Brunch at <https://wiebrunchdayton.givesmart.com/>.

New York

Statewide Epilepsy (Virtual) Conference, Nov. 19 at 9 a.m. ET

November 19, 2022, 9 a.m. ET
Virtual

Join the Epilepsy Foundation Northeastern New York, Epilepsy Foundation Metropolitan New York, and Epilepsy Foundation Long Island, as well as three other epilepsy organizations for the first-ever statewide epilepsy conference. This no-cost virtual event will include conversations and presentations including seizures and safety, legal matters that impact adults and children, new treatments, and wellness.

Click here for details:
epiny.ejoinme.org/



Tennessee

Walk for Epilepsy

November 12, 2022, 10 a.m.
Renaissance Park
Chattanooga, TN

The Epilepsy Foundation of Southeast Tennessee is excited to be hosting the 2022 Chattanooga Walk for Epilepsy on November 12, 2022. The Chattanooga Walk for Epilepsy is a chance to come together as a city to actively support those we care about who are impacted by epilepsy.

Register at <https://epilepsy-setn.kindful.com/e/2022-chattanooga-walk-for-epilepsy>

Washington

Innovations in Epilepsy Conference

November 12, 2022, 9 a.m.
Seattle Children's Hospital
Wright Auditorium
Seattle, WA

Join the Epilepsy Foundation in Washington for its annual in-person event.

Email washington@efa.org for more information.

Seizure Recognition and First Aid Certification Trainings

- in English

November 1, 2022, 4 p.m. ET
November 8, 2022, 4 p.m. ET
November 15, 2022, 4 p.m. ET
November 22, 2022, 4 p.m. ET
November 29, 2022, 8 p.m. ET

- in Spanish

November 17, 2022, 1 p.m. ET

Register: learn.epilepsy.com

Walk to END EPILEPSY

EPILEPSY FOUNDATION

Birmingham, AL

Nov. 5 at 10 a.m. CT
Railroad Park
walktoendepilepsy.org/birmingham

Rio Grande Valley, TX

Nov. 5 at 8:30 a.m. CT
Edinburg Municipal Park,
<https://fundraise.givesmart.com/vf/RGVWALK>

Raleigh, NC

Nov. 5 at 9:30 a.m. CT
Brier Creek Park,
walktoendepilepsy.org/raleigh

Charlotte, NC

Nov. 12 at 10 a.m. CT
Whitewater Center,
walktoendepilepsy.org/charlotte

El Paso, TX

Nov. 12 at 9 a.m. CT
Ascarate Park
<https://give.eftx.org/event/el-paso-walk-to-end-epilepsy-2022/e415675>

Galveston, TX

Nov. 12 at 8 a.m. CT
Moody Gardens
<https://give.eftx.org/event/2022-galveston-walk/e417010>

Tyler, TX

Nov. 12 at 8 a.m. CT
Legacy Trail
<https://give.eftx.org/event/tyler-walk-to-end-epilepsy-2022/e412302>

The Woodlands, TX

Nov. 12 at 8 a.m. CT
Rob Fleming Park
<https://give.eftx.org/event/2022-woodlands-walk/e417004>

San Antonio, TX

Nov. 12 at 8:30 a.m. CT
Morgan's Wonderland
<https://fundraise.givesmart.com/vf/SAWALK>

Shopping for a cause

Need some gift ideas for the loved ones on your holiday list? Consider shopping from one of our retail partners while supporting the Epilepsy Foundation. These retailers have agreed to donate proceeds of their sales back to the Foundation.



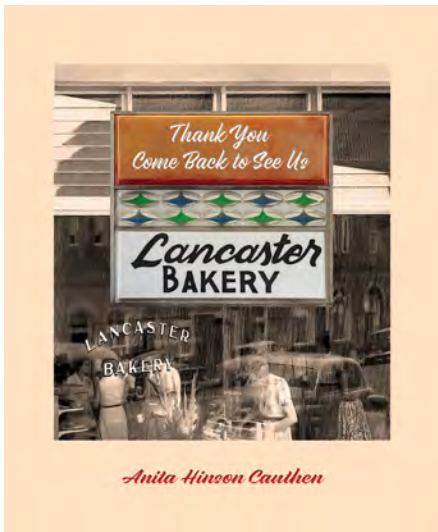
A&V Treasures

This family owned, online store offers a variety of options for kids, including toys, Funko Pops, dolls, action figures, games, and collectibles. Their daughter, Alexandria, has epilepsy and because of that the family believes in delivering smiles and giving back 10% of their sales. Each order is pulled and packaged by Alexandria, who puts a special touch to each package. Shop at toyznow.com.

LolasLuv

Logan Conners founded Lolaluv to spread awareness and love to those around her. She has lived with epilepsy since she was 6 years old and is donating 10% of all profits. Logan's brand has meaning behind it. The phrase SelfLuv is stitched in the corner of each product to highlight the importance of loving yourself no matter what challenges come your way. From hoodies, to beanies, to T-shirts, you can find clothing for all ages at Lolaluv.com.





Memoir Cookbook: “Lancaster Bakery”

“Lancaster Bakery: Thank You, Come Back to See Us,” is a cookbook that celebrates the sweet and savory memories of the author’s childhood and the bond she formed with her twin sister, Rita Ann Hinson. Rita was diagnosed with epilepsy during her infancy. The author is donating 10% of book royalties in memory of her sister. The pages are filled with bakery recipes paired with stories of an extended family living in a small southern town during the 50s and 60s. To get your copy, visit AnitaHinsonCauthen.com.



Carma Cup

Carma Cup believes that businesses should become a tool to support others and donate to relevant causes. Each Carma Cup purchase supports nonprofit organizations that align with the company’s vision to drive real change and give back to those in need. For every cup sold, Carma Cup will donate 50%. Whether you’re going to the gym, the park with your kids, or traveling, pick up a collapsible Carma Cup at CarmaCup.com.

ConnecTogether & Fourth Quarter Faith

The family who founded the company created an epilepsy awareness line in support of their daughter who has epilepsy. The company is donating 26% of their profits which is based on the 1 in 26 people that will develop epilepsy in their lifetime. In addition, they are also educating their community about seizures and promoting seizure first aid training efforts. Visit merch.undergroundshirts.com/collections/fourth-quarter-faith.





Spice Up Your Table with “Purple-Inspired” Snacks

Recipes courtesy of Nutricia KetoCal®



[Click here for more recipes by Nutricia KetoCal®](#)

Blueberry Smoothie - 4:1 Ratio (418 calories)

Grab your blender and whip up this refreshing blueberry smoothie.

Ingredients

- 200 g KetoCal 4:1 LQ Unflavored or Vanilla
- 30 g blueberries, frozen, unsweetened
- 12 g canola oil
- Ice cubes

- Carbohydrate-free sweetener (optional, recommended if using the unflavored KetoCal LQ)

Directions

1. Place the KetoCal LQ, blueberries, oil, about 4 ice cubes, and optional carb-free sweetener into a blender
2. Blend until smooth

Blueberry Almond Muffins - 4:1 Ratio (444 calories)

Start your day with delicious blueberry muffins or mix up a batch for a snack.

Ingredients

- 10 g KetoCal 4:1 Powder
- 10 g frozen blueberries
- 10 g ground almond flour
- 25 g butter

Directions

1. Preheat the oven to 350°F
2. Beat the eggs
3. Mix all the ingredients together
4. If possible, use a silicone muffin tray or silicone baking cups, as this helps the muffins stay together and makes them easier to remove
5. Cook for 30-35 minutes on 350°F

Can the **medical ketogenic diet** help you manage your refractory epilepsy?



BLUEBERRY SMOOTHIE



Find out by visiting

[KetogenicDietForEpilepsy.com](https://www.KetogenicDietForEpilepsy.com)

4:1 BLUEBERRY MUFFIN





Coping with Grief During the Holidays

While we get ready for the holidays, some may still be grieving and struggling with the loneliness and hurt that grieving the loss of a loved one brings. Unlike those around you, being merry, socializing, and taking part in festivities may not be what you want right now. Remember there are no simple guidelines that will take the hurt away or the renewed sense of grief that may come with the holidays. And, while you can't go back to the way things were before the loss of your loved one, there are things you can do to help ease the pain. Below are a few suggestions to help you get through the holidays:

Continue a tradition that was special to your loved one. Cooking some of your loved one's favorite foods or sharing recollections of things they enjoyed during the holidays — and then doing them — may bring positive memories.

Consider creating a new tradition to honor your loved one during the holidays. Host a dinner or toast friends and family to celebrate your loved one's memory. Don't be afraid to cry or laugh.

Visit the cemetery or memorial site. Plant a tree or donate in your loved one's memory.

Attend a prayer service or donate flowers to your place of worship in their memory.

Do things because you want to, not because they are expected. Avoid things that cause you stress. Take time to care for your own needs.

Forgive yourself in advance for enjoying parts of the holiday. This is not a betrayal of your loved one.

Embrace your memories. They are one of the legacies that exist after the passing of a loved one. Instead of ignoring the memories, share them with family and friends.



Call the Helpline at
800.332.1000
or visit [Epilepsy.com/Helpline](https://www.epilepsy.com/Helpline)



5 years seizure free!

(give or take)

Words from the epilepsy community

I am glad there is a community of people out there sharing stories about their own experiences. Spreading awareness is the first step in combating epilepsy.

Anish K., adult 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