

Foundation Quarterly

**Meet Dulce,
a college
student living
with epilepsy -
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Back to School Issue

**+ In your
Community,
News Briefs,
Wellness Tips**

LETTER FROM THE CEO

Getting Ready for Back-to-School Season!

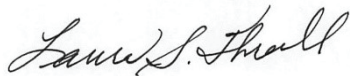
We are halfway through the summer and after a year of instruction impacted by the pandemic, families are getting ready to send their children back to the classroom. Traditionally, the end of the summer means children shopping for new school supplies, college students getting their dorms ready for move-in, and teachers preparing their classrooms. But for some families and educators, back to school may be a bit different this year amid COVID-19.

One of our stories in this issue, for example, highlights what some families with special needs children may need to consider as they decide whether to send their child back to school for in-person instruction. A mother's personal essay details the journey of her 10-year-old daughter with epilepsy who, instead of attending school this year, will be flying back and forth between Sweden and Salt Lake City to get the treatment she needs for her seizures.

We feature in our cover story a college student and early childhood educator who is using her journey with epilepsy, mental health, and anxiety to inspire others to pursue their dreams. You'll also meet a school nurse who helped pass legislation in her state for all school personnel to be trained in Seizure First Aid. Our centerfold highlights a few Kids Crew and Teens Speak Up! members sharing their thoughts on experiencing a more traditional academic year this coming school season.

From lemonade stands for epilepsy, to tips for preparing your child for school, to Seizure First Aid training for school personnel, you'll enjoy this latest issue of the Foundation Quarterly.

Let's make the most out of these last few weeks of summer and read on!



Laura Thrall
President & CEO



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Epilepsy Does Not Have Her

For this soon-to-be 23-year-old college student, these past few years have been the most challenging of her life. Having been diagnosed with epilepsy when she was a sophomore in high school, she has battled depression, fear of not knowing when the next seizure might strike, and even suicidal thoughts. But Dulce Garcia-Ceniceros has come a long way since. As an early childhood educator, Dulce has also seen children struggle with epilepsy, just like she did.

Dulce's epilepsy journey began at the age of 16 after she experienced two seizures in her sleep. She remembers waking up with everyone around her and not knowing what had happened. She spent two weeks in the hospital getting tests done to determine the source of her seizures. She missed a lot of school days, constantly having to go to appointments and struggling to keep her grades up.

But that wasn't the only thing affecting Dulce. Coming from a Hispanic family where epilepsy is a topic that was stigmatized and often criticized, Dulce also had obstacles at home to overcome. Some family members thought she could control her seizures, while others complained about having to take her to and from places because she could not drive. Insufficient knowledge about epilepsy, myths surrounding seizures, and lack of awareness all contributed to her family's misunderstanding of the condition. At one point, her family told her they didn't think she could go to college and be somebody

because of her epilepsy. This impacted Dulce's mental health.

"I love my family, but the way they complained about me when they thought I wasn't listening made me feel awful inside," she said. "I felt alone and misunderstood. I felt like a burden to them. The only thing I could do was cry and not say a word. I was scared and depressed. I felt worthless."



Photo courtesy Dulce Ceniceros



Pictured: The Cenicerros Family, Photo courtesy Dulce Cenicerros

Dulce took the initiative and began therapy, which turned out to be the best decision she made. Thanks to her therapist, she was able to feel happy again, live day by day, and set goals. One of those goals was not to let her epilepsy define her. She also sought to mend the relationship with her family by educating them about seizures and sharing her struggles with epilepsy. Watching Dulce experience the seizures, helped them understand what she was going through and that it was something she could not control.

Since, Dulce has learned to live her life as best as she could while managing her seizures. She says she's gotten to know herself and has taken opportunities that she wouldn't have taken before for fear that her epilepsy would get in the way. Dulce was able to finish high school and complete a cosmetology program at a vocational school.

“Having faith in God and getting closer to my family really helped me. After experiencing multiple setbacks, I can honestly say that my epilepsy has made me a stronger and more positive person.”

She says she has always loved kids but thought because of her epilepsy she was not going to be able to teach. But, according to Dulce, God proved her wrong. She earned a training certificate and became an early childhood educator. Not only did she get the opportunity to work with little ones, she also mustered the courage to start college to be what she's always wanted to be — an elementary school teacher.

Today, she is pursuing a teaching degree. Dulce also recently became an Epilepsy Advocacy Champion for the Epilepsy Foundation to educate and engage with her lawmakers about policies impacting people with epilepsy, as well as raise awareness about the epilepsies in her local community.

After experiencing multiple setbacks, I can honestly say that my epilepsy has made me a stronger and more positive person.

“I can finally say that I am in a good place; I love the person I am now. I have learned to live with my epilepsy, it is something I will have for as long as I live. I will always take medicine for it. I will always live not knowing when the next seizure will strike. But one thing is for sure, it will never stop me from being me or living my best life possible. I have epilepsy. Epilepsy does not have me.”



Learn how to become an
Epilepsy Awareness
Ambassador at
epilepsy.com/volunteer

My Daughter's Battle of Life and Death

By Mathina Molstad

On the night of October 21, 2017 everything changed for Edith and our family. Edith, an ordinary 10-year-old girl curious about life and school, was recovering from the flu. Fortunately, she slept in my bed that night. I woke up with Edith seizing, then everything happened very fast. Edith was rushed to the hospital where she was anesthetized because she was in a dangerous state — convulsive status epilepticus (severe seizures that do not stop).

Initially, doctors suspected it may be sepsis or meningitis. However, further tests showed a slight irritation around the hippocampus of the brain, and she was diagnosed with encephalitis. Several attempts were made to get Edith out of anesthesia, but aggressive seizures made it impossible.



Photo courtesy of Mathina Molstad

We later learned that Edith was struck by febrile infection-related epilepsy syndrome (FIRES), a rare catastrophic condition that inexplicably affects healthy school-aged children after brief exposure to a cold or a flu-like illness. Many children who develop FIRES do not even survive the initial acute phase. Among those who do, a great majority suffer serious permanent disabilities in addition to severe epileptic seizures, which have a devastating impact on every aspect of their lives.

Edith was one of the lucky ones who survived the acute phase, but she had to be placed under an induced coma and put on a respirator. It was a battle of life and death that lasted for almost four weeks. Her chances of survival were not good, and the doctors tried to prepare us for the worst. Finally, they managed to wake Edith and we were told that she survived the critical phase. Beyond this the doctors gave us little hope. They simply did not know her prognosis. We had no idea if she would be able to recognize us, talk or walk again.

Gradually, they began to wean her off the large amounts of medications that were given to her to save her life. This was a difficult time which forced Edith to endure tremendous drug withdrawals and severe seizures. Slowly, she began to make progress: a few whispering words, a hand moving. This was the beginning of the long journey back that is still ongoing for Edith and our family. Edith had to stay in the hospital for months and re-learn a lot of things, such as how to sit, stand and walk.

Edith is truly a fighter who does not give up. She has made tremendous progress. Unfortunately, she is still struggling with seizures which have impacted her quality of life. Without warning, severe seizures will cause her to lose consciousness, forcefully fall to the floor and stop breathing. She also has ongoing seizure activity throughout the day that disrupts her ability to function. All of this means that we must be by her side 24 hours a day, to make sure she does not fall and injure herself.

She must take heavy doses of medicines that bring on severe side effects, such as fatigue, stomach aches, headaches, dizziness, mood swings and periods of visual impairment, among other things.



Photos courtesy of Mathina Molstad

Edith's epilepsy forces her and our family to live a completely isolated life. Edith loves school and sports, but she has very limited mental energy, and physical exercise often generates seizures. Like other children, she loves playing with her friends, but moments when she is well enough to play and socialize are infrequent.

Now, we are in Salt Lake City awaiting the possibility of Edith undergoing a lifesaving brain procedure. For the last two years, we have been working with one of the top surgeons in the field to make it possible for her to come to the U.S. and get the care she so desperately needs. Edith can finally get a second chance at life thanks to a brain-responsive neurostimulation technique that uses a device implanted in the brain (similar to a pacemaker) to monitor and respond to brain activity.

This has been a huge step for us as a family — both emotionally to go abroad for a brain surgery, and financially since the Swedish healthcare system does not provide any financial support. Our hope is that this step will not only help Edith get her life back, but also help facilitate access in Sweden, and other European countries, to much-needed life-saving techniques and procedures for children with severe epilepsy.

Despite all the challenges our family has encountered through Edith's epilepsy journey, she still shows us in brief — but bright — moments that she is still there behind all the drugs and seizures. She is our beautiful and lovely ray of sunshine! She has not given up! We (her father, little brother and I) will never give up!

Mathina Molstad is Edith's mother; Edith and her family are based in Sweden.



To follow Edith's story,
visit her family's blog at
FiresFighterEdith.com.



Seizure Training for School Personnel

Seizure Training for School Nurses: Caring for Students

Help get the word out
about the Epilepsy Foundation's
Seizure Safe Schools courses
so more school personnel
are prepared to help!

**These courses
are On Demand on new
Epilepsy Learning Portal:
learn.epilepsy.com**

Alabama School Nurse Helps Pass Seizure Safe Schools Legislation in Her State

There are 470,000 children living with epilepsy in the U.S., and 7,500 are in Alabama. However, despite its prevalence, epilepsy is still highly misunderstood by the public. For students living with epilepsy, it is important that schools are well-equipped with the tools necessary to provide a safe and enriching environment.

According to the Centers for Disease Control and Prevention, the opportunity for academic success is increased when communities, schools, families, and students work together to meet the needs of students with chronic health conditions and provide safe and supportive learning environments. Direct access to school nursing and other health services, as well as disease-specific education, has been shown to improve health and academic outcomes among students with chronic health conditions.

That is why the Epilepsy Foundation launched the Seizure Safe Schools nationwide initiative in 2019 to help educate school personnel and bridge care gaps by calling on states to pass legislation. To date, 12 states have successfully passed Seizure Safe Schools: Alabama, Colorado, Illinois, Indiana, Kentucky, Minnesota, Nebraska, New Jersey, Oklahoma, Texas, Virginia and Washington.

Alabama is one of seven states that passed legislation this year. Nancy Tindell, a lead nurse in the Geneva County School System (Hartford, Ala.), was instrumental in getting the Seizure Safe Schools Act passed by facilitating conversations between the State Department of Education, school nurses around the state, and the Epilepsy Foundation. She first reached out to the State Department of Education inquiring about Seizure First Aid and learned that training and delegation was not available for unlicensed personnel. Ms. Tindell, along with numerous other people, reached out to their state senators to change that.

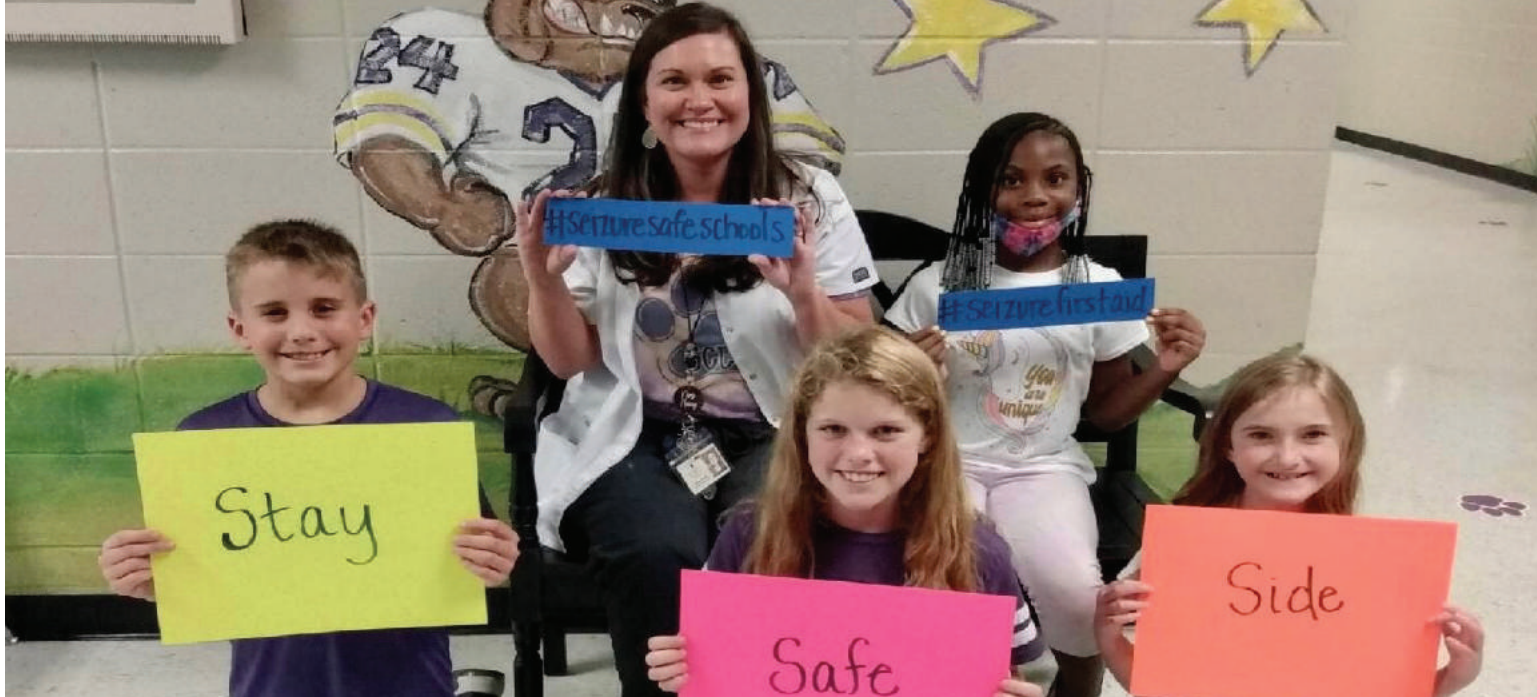


Pictured: Nancy (right), Photos Courtesy: Nancy Tindell

Calls were made from nurses inside and outside of her district, the superintendent, principals, teachers, and parents of students with epilepsy who wanted their children's teachers to be prepared and know what to do in the event of a seizure. Ms. Tindell also spoke at the Senate Healthcare Committee in support of the bill.

"If you had told me a year ago that I would be speaking before the Senate Healthcare Committee, I would've laughed," said Ms. Tindell. "But, as a rural school nurse, it was an amazing honor to present my perspective to our senators. They were very encouraging and seemed to understand the daily challenges school nurses face while caring for our students."

According to Ms. Tindell, unlicensed school personnel are trained to assist students with diabetes management and anaphylaxis emergency treatment, but not anti-seizure medications. Before the legislation passed in her state, Ms. Tindell would conduct one-on-one trainings individualized to each student based on their healthcare plan.



What is Seizure Safe Schools?

While Seizure Safe Schools legislation varies by state, the Epilepsy Foundation's model bill has five key components requiring all public schools to:

- Train school personnel on seizure detection and first aid response
- Mandate Seizure Action Plans be on file for every student diagnosed with epilepsy or a seizure disorder, and require those plans be available to all personnel responsible for the student
- Ensure the administration of medications approved by the U.S. Food & Drug Administration
- Educate and train students about epilepsy and seizure first aid response
- Protect individuals who act in good faith in accordance with the bill's provisions through a Good Samaritan Clause

However, she felt more training was needed to ensure that everyone at school — not just the nurses — could administer aid and support a student having a seizure.

“Seeing it from a parent’s perspective really opened my eyes. It’s so important for all school staff members to know how to recognize a seizure and know what to do,” said Ms. Tindell. “The bill stipulated that any school with delegated seizure rescue medicines must have a nurse on staff — that is a win for both sides. School nurses will be available in schools, staff members will have proper training, life-saving seizure rescue medicines will be readily available, and students with epilepsy will attend school in a much safer environment than before.”

The legislation makes certain that school personnel, including nurses, teachers, and volunteers, are not only prepared but can recognize and respond appropriately and efficiently to the student experiencing a seizure. Even more importantly, the legislation safeguards physician-directed care in the school setting allowing students to access necessary and oftentimes life-saving medication. Lastly, by bringing awareness to the entire educational community, students living with epilepsy — or a seizure disorder — can feel safe in school, reach their full academic potential, and build meaningful friendships without fear of being stigmatized.

While most state legislative sessions have adjourned, a few bills remain active, including in Michigan and Rhode Island. Most recently, Ohio’s state legislature also introduced a Seizure Safe Schools bill, HB 370. The Foundation, grassroots advocates, staff, and state elected officials will continue to ramp up efforts in the fall to prepare to pass bills across the country in the 2022 state legislative session.

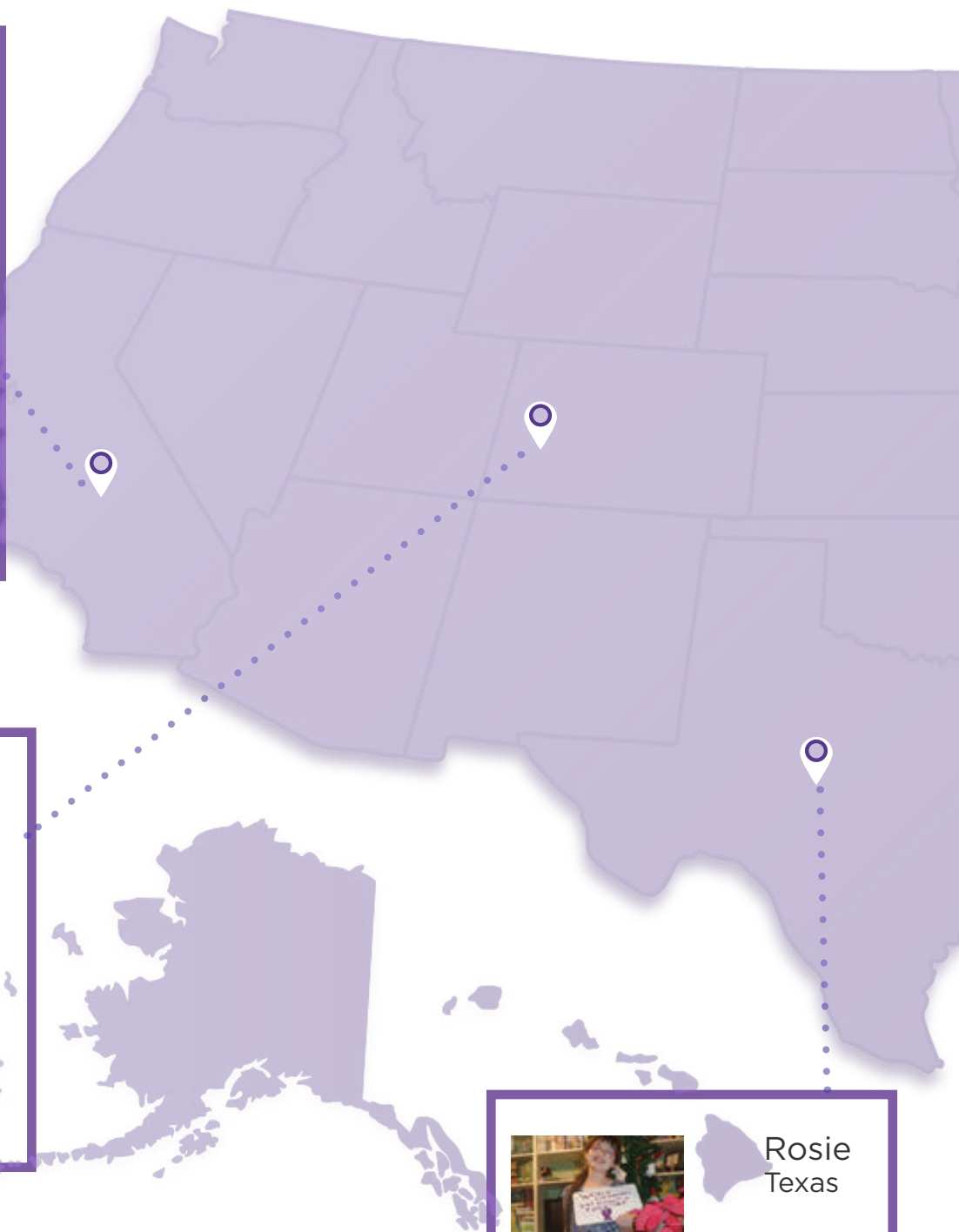


Be part of your local advocacy efforts. Find your local office: epilepsy.com/local.

Foundation Quarterly, Issue 3, Summer 2021

Post COVID: What Kids Say

Parents and students get ready to return to in-person classes and some normalcy following a year and a half of online and hybrid learning due to the pandemic. We asked students around the country to share with us what they are looking forward to this coming school year.



Celesta, 17
California

What I am looking forward to this fall when I go back to school has a lot to do with running my Epilepsy Awareness Club, senior year events and more. But I have to say, one of the things I am most excited for is continuing to be an advocate for the Foundation and being involved in the fight to END EPILEPSY®!



Alex, 18
Colorado

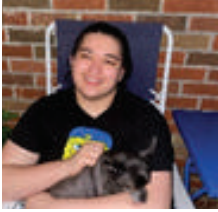
I am most excited to get out again and to make new friends. I also want to be more independent as I am going off to college this year.



Rosie
Texas

Telling my friends about my summer when I go back to school this fall.

About Going Back to School



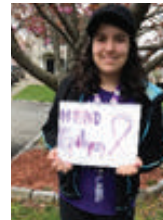
Julius, 17
Illinois

I can't wait to finally meet up with old friends again. It's been so long since I've seen them, and it would be very nice talk to all of them again.



Sailor
New Jersey

I'm excited to go back to school, meeting my new teacher and doing band!



Kristina
New Jersey

Seeing my friends and teachers again!



Eva
Alabama

Playing my clarinet in the band.

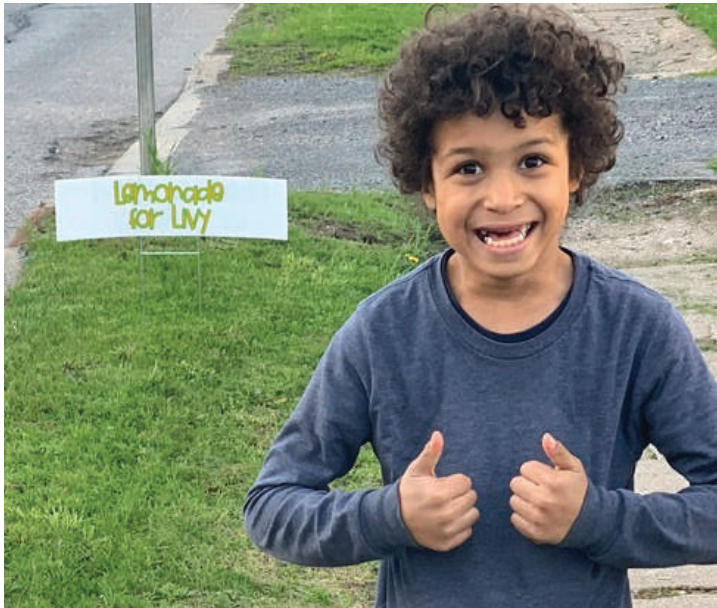


Kaylee, 15
Tennessee

What I am looking forward to is attending my first year of high school.

IN YOUR COMMUNITY

Make a Stand Against Epilepsy



Photos Courtesy: Cairo's family (left and top right), Lucas' family (bottom right)

In May 2021, the Epilepsy Foundation kicked off its annual Lemonade for Livy fundraiser which brings people from around the world together to give hope to those living with the epilepsies, and their families. What started as a neighborhood lemonade stand has grown into a global movement to raise funds for, and awareness about, epilepsy. Each year, individuals, families, and businesses host lemonade stands, parties, and events in their local communities to help the more than 65 million people around the world affected by epilepsy.

Lemonade for Livy began in 2011 with one lemonade stand in Clearwater, Fla. to honor Olivia (Livy) Scheinman, who since birth has been plagued by the damaging effects of epilepsy. Lemonade for Livy stands are taking place around the U.S. with fundraising to continue throughout the year. However, you can continue to raise money throughout the year. The goal is to raise \$40,000, and to date, individuals and teams have raised half of that goal.

Six-year-old Lucas from Omaha, Nebraska has epilepsy and recently hosted a virtual lemonade stand. Lucas delivered and shipped lemonade and epilepsy-themed lemonade baskets to his donors following the virtual event.

“I liked doing my lemonade stand because I got to meet some new people and helped to raise awareness at the same time,” said Lucas.

Cairo, who is also 6 years old, and his mom partnered with a local coffee shop to host a stand in Boonville, New York.

“The first day of our stand I noticed just how big of a mark this was making not just on him, but on me as well,” said Maureen, Cairo’s mom. “He actually told people that stopped by that he has epilepsy, something that he wouldn’t do prior. With each day that we set up our stand I noticed him becoming more and more empowered.”

Cairo also set up an auction for Lemonade for Livy featuring a work of art called “Pink Lemonade,” which was generously donated by a French artist and his daughters.

Join Lucas, Cairo and others. Make a stand for yourself, your loved one, a friend or just to help others living with the challenges of epilepsy.



Make a Lemonade Stand
for epilepsy awareness, visit
epilepsy.com/lemonadeforlivy

Back-to-School May Not Look the Same for Children with Special Needs

By Allison Scheinman

My 16-year-old daughter Olivia (Livy) was born with a brain malformation and was diagnosed with multi-focal partial epilepsy and cerebral palsy. Livy has significant developmental delays and relies on others for her care. She has been attending a public school for students with special needs since the age of 3. At school, she receives general instruction along with numerous therapies. As a mom to a child with challenging medical needs, I always like to have a plan. My plan changed in March of 2020.

When I picked Livy up from school on her final day before spring break last March, I had a feeling that she would not be returning any time soon. With COVID-19 spreading around the country, we could see that life was about to change dramatically. Her school began offering virtual lessons, but it was all so new and challenging for the teachers and therapists to create an online environment for their students with special needs.

When the new school year started in the fall of 2020, Livy attended virtual classes. It was not an ideal situation, but families made the best of it. I felt it was important that Livy still saw and heard her teachers, therapists, and fellow students. She did surprisingly well. She was also able to sleep on her own schedule, which we think significantly reduced her seizure activity. Over this past year and a half, Livy has been healthier than she has ever been.

Now that we are at the beginning of another school year, we are faced with some hard decisions. Livy is not able to wear a mask for an extended period of time. We do not feel comfortable with the rising infection numbers in our state. Without knowing if school staff or other students are vaccinated, we do not feel confident that sending her to school would be safe for her. Online schooling will no longer be offered this year, so we are struggling with what path to take with Livy. There is a hospital/homebound



Photos Courtesy: Allison Scheinman (left), with daughter, Livy.

program available, but we have been told the qualifications have changed and are not sure if she will be accepted. Another option for us is homeschooling. However, if we withdraw Livy from her school, she would no longer be covered under her Individualized Education Plan (IEP) which means she would not qualify for any services in our state.

Many families around the country are facing similar issues. In the end, it's a personal determination that families need to make depending on their child's medical condition and specific needs. My advice to others would be to talk with your child's doctor, teacher, and other school professionals. Also, connecting with families going through the same decision-making process is helpful. As with many other areas of the epilepsy journey, no one should have to experience this alone.

When we make our final choice, our goal will be to have Livy in the best learning environment possible and to keep her safe and healthy. As we sort out what will come next for her, we are thankful that we have several alternatives from which to choose although none of them are ideal at this point. Determining what to do for kids with challenging medical conditions is hard enough. COVID has only magnified the stress parents face. But as we do with the numerous facets of our journey, we remind ourselves that we are part of a community and we are all going through this together.



[Click here for more information about federal laws and guidance.](#)



November is National Epilepsy Awareness Month

Help tell the story
about epilepsy by
sharing your epilepsy
journey.

Be inspired at
epilepsy.com/eJourney

CDC Selects Epilepsy Foundation to Receive \$17.5M Under New Cooperative Agreement

The Epilepsy Foundation was selected as a funding recipient by the CDC's National Center for Chronic Disease Prevention and Health Promotion to fund activities under of the "Improving Epilepsy Education, Systems of Care, and Health Outcomes through National and Community Partnerships" project. The funding is part of a new 5-year cooperative agreement focused on improving the social environment for people with epilepsy; strengthening the health system to improve epilepsy care; fostering connections between clinical services and community programs; and addressing social determinants of health to improve quality of life for people with epilepsy. For the past two decades, the Epilepsy Foundation has partnered with the CDC to improve access to care for people with epilepsy, expand its digital reach and online resources in homes across the country, and

trained more than 600,000 people in seizure recognition and first aid. This new grant will provide \$17.5 million in funding over the next five years for the Epilepsy Foundation and its partners to create and sustain a strong American public health infrastructure for epilepsy, advance health equity, improve quality of life and achieve the best outcomes for all people living with the epilepsies. Dr. Brandy Fureman, chief outcomes officer, will serve as the grant's principal investigator. Cate Bocker, MSN, APRN, FNP-C will serve as project director, supported by other staff from the Foundation's Mission Outcomes team. The Epilepsy Foundation looks forward to collaborating with partners to lead the fight to overcome the challenges of living with epilepsy, and to accelerate therapies to stop seizures, find cures, and save lives.

School Nurses and School Personnel Training Now Available On-Demand

Earlier this year, the Epilepsy Foundation launched the Epilepsy Learning Portal, a one-stop shop where the public can access all the Foundation's virtual, live, and on-demand trainings about epilepsy and seizures to help create a Seizure Safe Nation for everyone. School nurses and school personnel can now access the Foundation's Seizure First Aid trainings through the Epilepsy Learning Portal, on-demand and instructor-led virtual sessions. According to the CDC, on average 49% of lead health education teachers in secondary schools want professional development on epilepsy and seizures, yet only 18.2% received professional development. The Epilepsy Foundation wants to train all school personnel, from bus drivers to hallway monitors, to teachers. The courses available for school personnel and school nurses include:

- Seizure Training for School Personnel (on demand)
- Seizure Training for School Nurses: Caring for Students (on demand)
- Seizure Training for School Nurses: Using Rescue Therapies in Epilepsy Care
- Seizure Training for School Nurses: Caring for Students for Psychogenic Seizures
- Seizure Recognition and First Aid Certification (instructor-led)

Since July 2020, the Epilepsy Foundation has trained more than 172,000 school nurses and school personnel.



Register for the next
Seizure Training at
learn.epilepsy.com

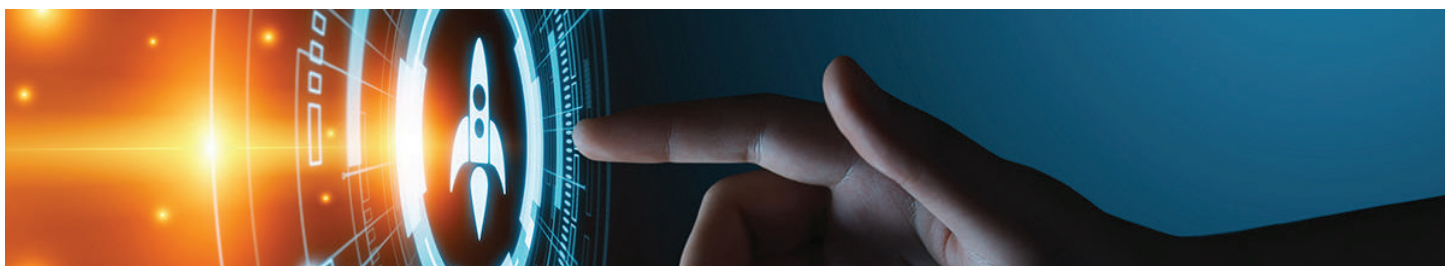
NEWS BRIEFS

Epilepsy Learning Healthcare System Expands to 14 Centers



The Epilepsy Learning Healthcare System (ELHS) recently welcomed its 14th clinical site, the University of Colorado Anschutz adult epilepsy team. To date, the ELHS Data Registry has captured data from 3,971 unique patients, 8,691 encounters, as well as six pediatric and adult clinical centers. Data includes clinical and patient-reported sources in areas such as seizure type and frequency, medications, barriers to medication adherence and side effects, as well as quality of life, mental and women's health. Coproduction is at the heart of ELHS' quality improvement and community site teams (e.g. local Epilepsy Foundation offices, rare epilepsy groups and other community

service organizations, etc.) which have been carrying out Plan-Do-Study-Act (PDSA) cycles focused on increasing the rate of screening for medication adherence challenges. The goal is to appropriately identify when a person is encountering a barrier to taking their medication as prescribed, and address and remove that barrier. Teams survey their clients who take medication and educate them on how to overcome barriers using the ELHS Medicine Toolkit, which includes guidance on addressing issues like covering medication costs, taking medications and managing side effects. To join ELHS or learn more, please contact elhs@efa.org.



Accelerator Course for Start Ups

The Epilepsy Foundation is currently accepting applications for a 6-week virtual startup course to be held October–November 2021. The Foundation launched a series of courses last year for new startups in the epilepsy community to provide the tools needed to bring new products to market. This year, topics will focus on elements critical to creating an investor pitch, such as framing the value proposition, creating the target product profile, understanding the market, and building a strong team to make the most impact for the epilepsy community. The program will feature case studies from successful entrepreneurs in epilepsy, market research from world leaders in epilepsy treatment, personalized feedback for each company's team and the final pitch. At the end of the course, startups will have the opportunity to pitch their venture and may receive funding from epilepsy-focused investors and epilepsy community.



Click here for more information about the Accelerator Course.



Nearly 5,000 Individuals and Families Walked 2.6 million miles to Raise \$1M+

The Epilepsy Foundation culminated the 2021 Walk to END EPILEPSY series and 2.6 million challenge with a closing ceremony on June 5. Nearly 5,000 individuals and families walked a total of 2.6 million miles and raised \$1,039,494.51 to create awareness about epilepsy. The top three teams included: Team Tootie (Seattle) which raised \$21,840; Team T-Money (Phoenix) which raised \$21,336; and Spike and Wave (Seattle) which raised \$12,889. The Foundation would like to thank its nationwide presenting sponsors: Greenwich Biosciences and SK Life Science, Inc.; as well as its nationwide signature sponsors: Eisai, LivaNova, UCB and Danny Did Foundation.

Now Accepting Crypto Currency Donations

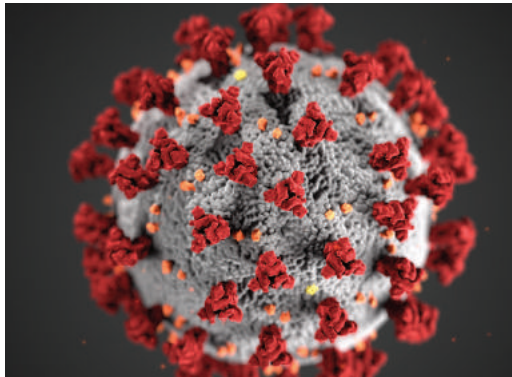


The Epilepsy Foundation recently launched its cryptocurrency program with the first \$65,000 gift received from crypto charity Hope Token. While there is a small learning curve to get into cryptocurrency, transactions are a breeze once you are in. Donating cryptocurrency to a nonprofit, such as the Epilepsy Foundation, is non-taxable. This means you do not owe capital gains tax on the appreciated amount. You can deduct it on your taxes. This makes Bitcoin and other cryptocurrency donations one of the most tax-efficient ways to support the Foundation. When you provide an email, you will automatically receive a tax receipt after donating. You can donate to the Epilepsy Foundation through a widget facilitated by The Giving Block, the Epilepsy Foundation's cryptocurrency charity partner. Transaction fees are minimal compared to most credit/debit cards and traditional platforms.



Got some crypto and want to make an impact? Visit epilepsy.com/crypto

Back-to-School COVID-19 Guidelines



The Centers for Disease Control and Prevention (CDC) and the American Academy of Pediatrics (AAP) have issued separate sets of guidance related to safely returning to school amidst the COVID-19 pandemic. Both entities recommend that all students over age 2 and all school staff wear masks inside school buildings except those with medical or developmental conditions prohibiting use. States, counties and school districts may have different public health policies in place so it is important for you to check with your school district regarding local policies.



Click here for more information about epilepsy and COVID-19, including vaccinations.

Unstoppable Me: Living with Epilepsy

Jordynn Farley began experiencing seizures at the age of 6. Now at 10, she has written a book about her epilepsy journey to show others that epilepsy does not have to get in the way of pursuing the things you want to do. At a young age, Jordyn has accomplished many things, including modeling and performing in theatre plays and films. She secured a part in the upcoming movie, “Love, Loyalty and Death”. In addition, Jordynn is part of the Epilepsy Foundation’s Kids Crew and is using tools provided by the Foundation to create awareness about epilepsy in her community. Her book is the most recent project on which she has embarked. To get a copy of her book, “Unstoppable Me: Living with Epilepsy,” visit BeautyfromAshes44.com.

Epilepsy Foundation of Colorado Expands to Serve Wyoming

The Epilepsy Foundation of Colorado has expanded its territory to include the state of Wyoming and it is now known as the Epilepsy Foundation of Colorado & Wyoming. Together with its partners at the Wyoming Institute for Disabilities, the Foundation is looking forward to bringing programs, services, and support to the nearly 6,000 people in Wyoming who are living with epilepsy. The Foundation also recently hosted its Walk to END EPILEPSY® in two new locations: Northern Colorado (Fort Collins) and the Western Slope (Grand Junction). More than 100 attendees participated in each event thanks to the recruitment efforts of the newly formed Walk committees. The Foundation is looking forward to hosting its 2022 Walks in new locations in Wyoming.

Epilepsy & Seizures 24/7 Helpline

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with epilepsy & seizures
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CALENDAR OF EVENTS

See what's happening this fall!

Illinois

2021 Epilepsy Fall Fest 5K

September 25 & October 9;
8 am - 12 pm

Cantigny Park Wheaton, IL
(Sept. 25)

Montrose Harbor Chicago, IL
(Oct. 9)

Join the Epilepsy Foundation Chicago as we walk as one to celebrate and honor those affected by epilepsy. Registration is free and includes food, drinks, games and fun for the whole family.

More information:
312-939-8622 ext. 208
or <https://getinvolved.epilepsychicago.org/20215k>.

11th Annual Consumer Conference

November 20, 2021; 8 am
Radisson Blu Aqua Hotel -
Chicago IL

The Consumer Conference covers a wide variety of topics and aims to provide education and advance the quality of patient care within the epilepsy community. Registration is free and includes food and drinks.

More information:
312-939-8622 or
www.epilepsychicago.org.

Colorado

Epilepsy Connect Symposium

November

This annual conference brings together the brightest minds in epilepsy research and treatment. Experts will offer the latest and most relevant information to educate and empower the community in Colorado and Wyoming. Held in November, Epilepsy Connect is our centerpiece educational event of the year.

More information:
<https://www.epilepsycolorado.org/symposium/>.

Young Adult Retreat

October 2021

This pilot program will target young adults between the ages of 18-30 in Colorado and Wyoming. Attendees will connect virtually and develop life skills related to mindfulness and coping, taking charge of their medical care, employment, financial literacy, and more.

More information:
303-377-9774.

Th1nk26 (Virtual)

Fourth Wednesday
of the month

This free educational program is offered virtually so that it is accessible to anyone living throughout Colorado and Wyoming. Led by healthcare specialists, these webinars cover thought-provoking topics centered around epilepsy, diagnosis, treatment options, mental health, and more.

For upcoming webinars or to register: <https://www.givesignup.org/TicketEvent/>

Charlas Sobre la Epilepsia (Virtual)

Monday of each month;
5:30-6:30 p.m.

These Spanish-language webinars focus on different topics related to epilepsy. These webinars often attract participants from multiple cities and countries.

More information: Leigh@
epilepsycolorado.org or
<https://www.givesignup.org/TicketEvent/Epilepsia>.

Best Practices for Counseling Clients with Epilepsy and Non-epileptic Seizures

November

This is a training program that will teach mental health professionals how to better work with people impacted by epilepsy, applying for NBCC accreditation. The training helps those living with seizures receive quality mental healthcare.

More information:
larissa@epilepsycolorado.org
or 303-502-5979.

Project UPLIFT (Virtual)

August 4 - September 22;
Wednesdays, 12-1 pm

This is an 8-week program, held via Zoom, to empower people with epilepsy to improve their own mental health through mindfulness and cognitive-behavioral skills.

More information:
larissa@epilepsycolorado.org
or call 303-502-5979.

See what's happening this fall! (cont.)

PACES (Virtual)

August 5 - September 30;
Thursdays, 6:30-7:30 pm

This is an 8-week program, held via Zoom, that improves self-management, confidence, depression, and quality of life in people with epilepsy.

More information:
303-502-5979.

Maryland

Sail 4 Epilepsy

September 18, 2021; 12-2 pm
Portland ME, Boston MA,
Philadelphia PA, and
Annapolis MD

An east coast expedition where children living with epilepsy team up to sail up and down the east coast. The event will take place at the new South Annapolis Yacht Centre on the beautiful grounds and marina of Spa Creek Annapolis. Children will learn about the constellations stars, making flags, sailing, how to tie sail-boat knots, and other fun outdoor activities.

More information:
SailforEpilepsy.org.



New York

Walk to END EPILEPSY

September 12
Saratoga Spa State Park,
Saratoga Springs, NY

This will be a hybrid event at the park, or virtually wherever you choose.

More information: <https://bit.ly/EFNENYW2EE2021>,
skaczynski@epilepsyneny.org
or 518-456-7501.

Golf Tournament for Epilepsy

October 4
Wolferts Roost Country Club,
Albany, NY

Your day will include lunch at the turn, food and beer tastings on the course, a \$5,000 Putting Challenge, Poker Challenge, raffle, auction items, and more. A 19th Hole Celebration Cocktail Hour will be held immediately following golf to present prizes to the top foursomes and hole contest winners.

More information:
www.epilepsynenygolf.com,
skaczynski@epilepsyneny.org
or 518-456-7501.

Washington

Innovations in Epilepsy Conference

November 6, 2021
Seattle Children's Hospital

This event is offered at no charge to individuals and families impacted by epilepsy, as well as medical professionals.

More information:
washington@efa.org

Seizure First Aid Trainings

learn.epilepsy.com

September 9, 2021
at 4 p.M.ET

November 2, 2021
at 4 p.m. ET

November 9, 2021
at 12 p.m. ET

November 23, 2021 at
4 p.m. ET

November 30, 2021 at
12 p.m. ET

Trainings in Spanish

October 7, 2021
at 7 p.m. ET - Live

November 16, 2021
at 8 p.m. ET - Live

December 9, 2021
at 8 p.m. ET - Live

Sign up at
learn.epilepsy.com



Start Taking STEPS Toward Zero! Zero seizures should be the goal — here are 3 steps to help you get there.

Reaching zero seizures is the optimal treatment goal for people with epilepsy, yet it can be hard to know how and where to begin the journey. To help guide adults who continue to experience partial-onset (focal) seizures despite taking medication, SK life science, an Epilepsy Foundation sponsor, created the STEPS Toward Zero movement to educate, inspire and activate the epilepsy community to reimagine their goals and have candid conversations with their doctors about them.

Professional golfer and STEPS Toward Zero Champion Kenzie O’Connell knows the challenges of living with epilepsy and — more importantly — the significance of potentially living with zero seizures. “When you have an episode, it can sometimes affect your whole day,” O’Connell says. “Zero means a lot to me. It means not having my family go through so much and not feeling like I’m putting as much stress on them as I feel like I do.”

Below are steps that can help you move closer to zero seizures.

- **Talk to your doctor.** Being candid with your healthcare provider can make a big difference in finding a treatment plan that’s right for you. “I think having honest

conversations with your healthcare team is so important,” O’Connell says. “Tell them exactly how you feel. Ask questions even if you think they have nothing to do with your epilepsy.” [Using the STEPS discussion guide](#) can prepare you for conversations with your doctor and reviewing [this telehealth tip sheet](#) can help you get the most out of virtual visits.

- **Learn more about your epilepsy.** Epilepsy can look different for every person so it can be helpful to track your seizures, specifically patterns and triggers, using [a journal](#) or these apps. When you know more about how your epilepsy affects you, you can work better with your doctor to get closer to zero seizures.

- **Seek an effective epilepsy treatment plan:** Your epilepsy is unique to you, and seizure treatments work differently from person to person. Don’t settle for a treatment regimen that isn’t helping you reach your goals. Work closely with your healthcare provider to find options that are right for you and your lifestyle.

To learn more about the STEPS Toward Zero movement and to get involved, visit STEPSTowardZero.com.

What would zero seizures mean to you? Tell us on social media using [#STEPSTowardZero](#). For every social media post featuring [#STEPSTowardZero](#), SK life science will donate \$1 to the Epilepsy Foundation for a maximum of \$15,000.



“Your epilepsy is personal to you, but it feels good to know there’s a whole community rallying behind you wanting the same thing.”

-Kenzie O’Connell,
Professional Golfer and
Person Living with Epilepsy



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is around
the corner

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awareness gear.

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WELLNESS CORNER

Preparing Your Child for the Start of the School Year



As the new school year begins, epilepsy can bring additional considerations and challenges for students and their families. Use the tips below as a guide to work toward a healthy and positive start to the new school year.

1. Allow time to adjust.

The last few weeks of summer are a good time to slowly adjust schedules to fit the new school year. This might mean adjusting bedtimes, mealtimes, and, in some cases, medication times with the advice of your epilepsy medical team.

2. Set routines.

Children tend to do best when they help create routines and stick to them. Routines will help you and your child's epilepsy care team assess how well a medication is working and whether or not side effects from the medication could be affecting their learning.

3. Address your child's concerns.

Talk with your child about concerns they have managing their seizures at school. Children of different ages will have different concerns. You might be surprised by the questions they ask you or feelings they share. Your child may benefit from extra reassurance about the possibility of having a seizure at school.

4. Plan meetings for your child.

Schedule time for your child to meet with their teacher and the school nurse. Encourage your child to share concerns about having a seizure at school. Plan a special visit with your child's epilepsy nurse, doctor, or social worker. Talk about how together you will coordinate and communicate with school personnel to keep your child safe at school.

5. Visit the school with your child.

For many children (and parents!) a sense of familiarity with the school brings comfort. Take your child to visit the school before school starts. Visit their classroom and the school nurse's office. Even if you cannot tour the hallways and classroom early, a visit to the school can be a good time to explore the outdoor space, including the playground. Parents can assess the area for seizure related safety concerns and make sure the appropriate precautions are in place for recess and outdoor play times.

6. Create a special place for homework.

Set up a dedicated space at home for schoolwork. Let your child decorate their space and prepare it for the year ahead. Having some control of their learning space and preparing it in advance can build positive energy around the return to school.

7. Celebrate the return to school.

Start a tradition of celebrating the first day of school. This will give your child something positive to focus on, besides the first day of school jitters. Whether it is a candle in their breakfast pancake, a silly family photo with back-to-school hats, after school popsicles on the playground with a friend, an after-school bike ride with mom or dad, or just reserved quiet time for listening to all the details of their first day, lending the spirit of celebration will help make the first day of school something your child looks forward to.



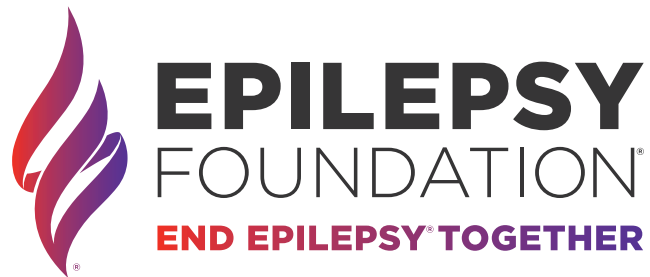
Click here for additional tips to prepare the schools, having the right paperwork and maximizing your child's learning



Words from the epilepsy community

... I am passionate about spreading epilepsy awareness and as someone who has epilepsy, I believe there is still a lot of work to do to spread awareness. I want to share my stories with others, connect with people who also have epilepsy and use the resources provided by the Epilepsy Foundation to continue to educate people in my community.

-Allison, Epilepsy Awareness Ambassador



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