

Foundation Quarterly

**Meet Father and
Daughter, Epilepsy
Warriors - page 4**

**National Epilepsy
Awareness Month Issue**

**+ In your
Community,
News Briefs,
Thanksgiving
Recipes**

LETTER FROM THE CEO

Welcome to November!

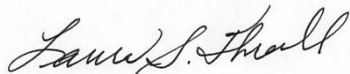
This month our community celebrates National Epilepsy Awareness Month. While every day is “epilepsy awareness” day at the Epilepsy Foundation, November is a moment in time when our community comes together to bring attention to epilepsy and rallies others to take action.

For too long, epilepsy has been an invisible disease. People don’t understand what it is or why it happens. That’s why this month we are leveraging our community’s strength to shed a light on epilepsy. Through a social media campaign called #RemoveTheFilter, we want to break the silence surrounding epilepsy and bring hope to those facing challenges.

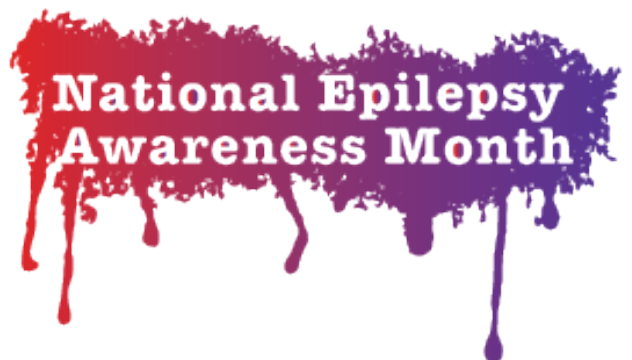
This issue of the magazine features stories of epilepsy warriors who have faced challenges and have overcome them. Stories of people who are using their journey to encourage others to come out of the shadows. As you read through their journey, learn how they removed the filter to make a change for everyone affected by epilepsy.

Most everyone knows someone with epilepsy. This National Epilepsy Awareness Month let’s take time to educate ourselves and advocate for others: the people we know — and those we don’t yet know — who have epilepsy and live with seizures.

Join me to #RemoveTheFilter this November. Check out the centerfold (pg. XX) to see how you can remove your filter.



Laura Thrall
President & CEO



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Same Fight, Yet Different

She was diagnosed at the age of 2, he was diagnosed as an adult. While their seizures are different, father and daughter share the same journey. Most children of people with epilepsy do not develop seizures or epilepsy. However, since genes are passed down through families, it is possible. If both parents have epilepsy, the risk of a child developing epilepsy is a bit higher. Most children will not inherit epilepsy from a parent, but the chance of inheriting some types of epilepsy is higher.

When his daughter Emma began spacing out, Manny Almazan and his wife knew it was not the typical daydreaming, they felt something wasn't right. They took Emma to a neurologist who diagnosed her with absence seizures. Seven to nine times an hour, every hour, every day, Emma would experience brief lapses of awareness unexpectedly. At that time, the family didn't know anything about epilepsy and had no idea what absence seizures were.

"I was confused at first," said Manny. "All we knew about epilepsy at the time was that it had something to do with seizures and that a seizure meant someone fell to the ground shaking. Emma's seizures were nothing like that."

Little did the Almazan family know that a year later Manny too, will be diagnosed with epilepsy. He and his wife were driving home from Las Vegas, Nev., when Manny began yelling and shaking in the passenger seat. Scared, his wife stopped on the side of the road to call 911.



Pictured Above: Emma Almazan, Photo courtesy: Almazan Family



Pictured: Emma Almazan, Photo courtesy: Almazan Family

While she waited for the ambulance to arrive, other cars stopped to help, one was a nurse, another an off-duty firefighter. Both told her that Manny was experiencing a seizure. When the paramedics finally arrived, they loaded him into the ambulance, and he had another seizure on the way to the hospital. After a series of tests and another seizure in the ER, the doctors diagnosed Manny with epilepsy.

“Emma’s seizures often go unnoticed, a lot of people don’t know she has them,” said Manny. “My seizures, however, are the convulsive type. When I was diagnosed, we had some knowledge of epilepsy because of Emma’s experience, so the fear wasn’t as prominent. I felt I was ready for the fight.”

And fight they did. Epilepsy has impacted their lives in different ways. For Emma, a seizure during learning time can throw her off track, affecting her academics. Having her thoughts interrupted then being too shy or scared to speak up to ask a question has been tough for her. And the side effects from her medications simply add to the complications.

“Emma’s new neurologist has finally found a combination of medications that have helped to better manage her seizures,” Manny said. “Now we’re dealing with the weight loss side effects from them. But she is finally improving in school.”

Manny, however, continues to experience challenges. Constant memory loss is frustrating to him, especially when he must constantly tell his co-workers “I don’t remember” and “sorry I forgot.”

Emma always calls us the Epilepsy Warrior Team!

“While I have been fortunate enough to work for managers who know about my condition and understand my situation, the industry I work in typically requires some driving for management positions. After 10 years with the company, I feel I have hit a wall with advancement because of my seizures.”

In the past 3 years, Manny has had fewer seizures, but he feels there is something to learn from each one. He almost went two years seizure-free. The father and daughter duo find humor and light in the negatives, and they have an even stronger bond.

“Emma always calls us the Epilepsy Warrior Team! Even though she does not completely grasp the concept of what epilepsy is, she’s always on top of my medication and her medication. We like saying cheers and tapping our bottles of water to take our meds. We make the best of it.”

Offering Hope



Jon Sadler was diagnosed with epilepsy in 1963, at the age of 4. He remembers the doctor telling his mother that he had epilepsy. She was terrified of the outcome and his sister thought he was going to die. This was based on what little they knew back then and the lack of support for families struggling with the unknowns of epilepsy. The only direction received was to never tell anyone about it.

Despite his diagnosis, Jon worked hard to live a full life. Although, he wanted to join the Navy, he was not able to do so because of his epilepsy. So, he got an engineering degree and went to work for the Navy as a civilian. He later became a project manager in the Army for the construction of one of the memorials on the Mall in Washington, DC.

In 2005, however, Jon's seizures became intractable, and he decided to have a lobectomy.

"My toughest experience was watching my teenage son talking to the paramedics as I lay on the floor, motionless from the seizure," he said. "That helped making the decision of having a lobectomy much easier."

The section of his brain that was removed during the lobectomy impacted his work as an engineer. But he never quit and believed there was a purpose to what he was experiencing. Jon's purpose came when he met a man who was traumatized by his young child's seizures and Jon's experience gave him and his family hope.

"I found hope early in my journey, and it pulled me through the many times seizures seemed to destroy me," he said. "What inspired me the most was learning that the acronym of HOPE stands for helping other people with epilepsy."

Jon went back to college and earned a master's degree in pastoral counseling, something that seemed impossible to him given the impact seizures and surgery had on his memory. The academic demands required his brain to rewire. At the end of the fourth year, his memory had greatly improved, and disability services were no longer required.



Photo courtesy of Jon Sadler

EPILEPSY FOUNDATION

EPICON

ENGAGE • CONNECT • LEARN • CREATE

May 13-15, 2022
Nashville, TN

Epic
Retreat

Epic
Connections

Epic
Experiences

At EpiCon, the power of you becomes the power of us. Join us this Spring, where the epilepsy community comes together to empower each other to live their best life.

Connect with influencers, learn from world-renowned experts, join in candid discussions and engage in a variety of on-hands exhibits.

Come meet new friends and create community with the people you care about.

epilepsy.com/EpiCon

Offering Hope (Cont).



Photo courtesy of Jon Sadler

It was a few years after the surgery that he met many people living with the unknowns of epilepsy. Jon became a mentor to others through a chapter of the Epilepsy Foundation and wrote two books to provide a first-hand perspective to other people and families affected by epilepsy.

“I have worked with many people and families living with epilepsy, many of whom asked me when I would write my story and reach more people,” he said. “One of my books is written from the perspectives of a mentor and counselor with the goal of educating and providing hope for those struggling with the trauma and stigma of seizures. I share my own experience living with, and recovering from, significant brain injury.”

Today, Jon still has simple focal seizures. He is a licensed counselor and works part time with groups of people dealing with seizure disorders.



For more information
about his books,
[visit jonsadlerbooks.com.](https://jonsadlerbooks.com)



Did You Know:

You can learn
Seizure First Aid basics
in 30 minutes?

Get Seizure First Aid Ready



Sign up at learn.epilepsy.com

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PERSONAL ESSAY

A Caregiver's Journey

By Joycelyn Huggins-Martin

Epilepsy has its challenges, not only for the person with epilepsy, but also those who care for them. The pressure of caring for someone with epilepsy can seem overwhelming at times but knowing what to do can help alleviate the stress and worry that come with helping a loved one navigate the journey.

For the past three years, I have been the caretaker for both of my 80 and 90-year-old parents. In 2017 and 2019, my mother Wulini Huggins suffered two strokes. Up until November 2020, she could still communicate clearly and walk with the help of a walker. Then suddenly, one night she took a sharp decline. I had just put her in bed and, as always before going to bed, I started doing my daily chores. I called out to her but to my dismay, I heard no response. This wasn't particularly unusual, but when I walked over to repeat the question, I noticed a funny look on her face - an absent, distant look. She was non-responsive to conversation or touch. Immediately, I realized that my mom was having an absence seizure.

Because of her age and the fact that she had previously had a stroke, I called 911. It was a good thing I did too because my mother had a second seizure in between the time of the call and the paramedics' arrival. While in the hospital, she continued to have frequent mini seizures. It took the hospital a week to get the seizures under control. Since, my mother has been unable to walk or clearly talk.

My mother's seizures were a result of her stroke. Our doctors never warned us that she could have a seizure. We didn't know that Black people are at an even higher risk of



post-stroke seizures or that a diagnosis of epilepsy may follow multiple stroke-related seizures. Just knowing these facts may have better prepared us for what my mother experienced.

My family's epilepsy journey did not start with my mother, however. It started years ago with my sister, Glenda, who has been living with epilepsy since high school and throughout her adult life. My sister had her own share of challenges that came with her diagnosis. Glenda was dismissed from her job as a kindergarten teacher for having seizures in front of the students. One morning, while ironing her clothes for work, she had a seizure. She fell to the ground with the iron in her hand causing burns to her leg. The continuous seizures also caused her to go deaf in one ear and lose 50% of her hearing in the other. She continued to experience uncontrolled seizures for 10 years before the doctors were able to find the right medication combination. But just when we thought things could get better, the medications caused her to have severe depression.

Despite all the setbacks, my family always believed that Glenda would be healed. She eventually decided to have laser surgery treatment to help her better manage her seizures. Following the procedure, she had to adjust to a new norm. Her brain had to relearn to do everything on its right side.

Since the surgery 8 years ago, Glenda has only experienced three seizures. Her doctors have been able to reduce her seizure medication and she is now more outgoing and able to do things on her own without supervision. Most importantly, she can now help me take care of our parents instead of us taking care of her.



Joycelyn's mom, Wulini (right)

Photos Courtesy: Joycelyn Huggins-Martin

Being Part of the Change

Diagnosed at the age of 5 with focal aware seizures, Kailey Rayala, knows firsthand how an epilepsy diagnosis can impact someone's life. From needing rooms with special lights, to not being able to drive a car, and battling depression, Kailey's journey has been filled with one challenge after another.

"I felt so different growing up," she said. "My parents didn't know much about epilepsy. They knew I had seizures, but I felt that they didn't fully understand how much I was going through. I was ashamed. I felt I had to hide my epilepsy. It took years before I could feel comfortable enough to be vocal about it."

Kailey's social outings were limited growing up, not only because of the frequency of her seizures, but also because her family didn't want to talk about it, so it was hidden. This made it difficult to form friendships. Her family lived in a small town, and they didn't know anyone with epilepsy. Kailey felt so alone that it impacted her self-esteem and created anxiety.

High school was even harder for Kailey because she couldn't share what was going on. When it came time for college, Kailey couldn't attend classes because her seizures got so bad, she couldn't function.

Kailey's seizures often occur when she's anxious or stressed. She feels pain in one side of her head, and the right side of her body shakes uncontrollably. She also experiences nocturnal seizures when she's sleeping or resting. She's tried more than 20 medications in the 15 years since she was diagnosed. Seven months ago, Kailey had a responsive neurostimulation (RNS) device implanted to treat her drug-resistant epilepsy. But she had some setbacks with the procedure, including issues with her vision.

Yet, despite it all, she's come a long way and is now using the power of her voice to create awareness in her own community. For the past 7 years, Kailey has been actively sharing her story and raising money as part of the Walk to END EPILEPSY®. Most recently, she became an Epilepsy Awareness Ambassador and spends time handing out information about seizure first aid to local businesses. She hopes to one day start a local support group for people with epilepsy and their family.

"I've been through a lot of trials and have learned a lot. My life changed when I started meeting other people with epilepsy. When I #RemovedTheFilter, I learned more about myself. My epilepsy shaped me into the person I am today. I feel my purpose in life is to help others not feel so alone with this condition. I want to make a difference. We need change and to break the stigma that surrounds epilepsy. I am part of that change."



Photos Courtesy:Kailey Rayala

IN YOUR COMMUNITY

County of San Diego Awards Grant to Epilepsy Foundation of San Diego

The Epilepsy Foundation of San Diego County has been granted a Community Development Block Grant from the County of San Diego to expand programs and services to San Diegans that are affected by epilepsy and the COVID 19 pandemic. The one-time grant will allow the Foundation to create a new program designed to provide supplementary support to families and help them in the recovery process of the pandemic and outreach to new demographics. The project will consist of three components: mini-grants to provide financial assistance to clients and their families; transportation assistance to help clients get to doctor's appointments, the grocery store, support groups, and other vital locations; and expanded outreach efforts specifically in the Spanish-speaking community. Epilepsy Foundation of San Diego is planning to hire a part-time Spanish-speaking outreach worker to develop resources for Spanish-speaking audiences and those who have been severely impacted by the COVID pandemic.

Epilepsy Foundation of Colorado & Wyoming Raise \$420K



The Epilepsy Foundation of Colorado & Wyoming held their annual Summits & Stars Gala on October 2 which raised a record-smashing \$420,000. Revelers enjoyed a silent auction including artwork crafted by campers, inspirational speakers and a silent disco. The featured speaker was Colorado State Representative Iman Jodeh who shared her epilepsy journey, and how she and the Foundation recently passed ground-breaking legislation to ensure all Colorado public schools receive seizure first aid training.

Epilepsy Foundation of Greater Chicago Returns to In-Person Events

The Epilepsy Foundation of Greater Chicago returned both annual walks to in-person events following a year of virtual participation. This year the Fall Fest 5k, presented by Northwestern Medicine, hosted events at Cantigny Park in Wheaton and Montrose Harbor in Chicago. These events welcomed more than 1,300 attendees and has raised nearly \$190,000, to date.



Honoring a Fraternity Brother Lost to SUDEP



Phi Gamma Delta at the University of Central Arkansas held a DIY fundraiser in honor of a fraternity brother they lost to SUDEP. Remarks were given by the sister of the honoree and Shealyn Chestnut of Havana who is the Epilepsy Advocacy Champion in Arkansas. The event raised more than \$1,700.

Epilepsy Foundation in Orange County Meets with Leading Providers

The Epilepsy Foundation in Greater Orange County recently held a meet and greet bringing together leading epilepsy providers in the region. The event provided an opportunity for providers to share what has been successful in their practices, as well as discuss any issues they face while treating and supporting those living with the epilepsies. The Epilepsy Foundation also discussed ways to work with local providers and their hospitals/clinics in the future.



Iowa Race Raises More than \$30,000

The Trashmore 5K Dash to Bash Epilepsy was held on Mt. Trashmore in Cedar Rapids, Iowa. There were 250 participants and Dr. Ciliberto, pediatric epileptologist with the University of Iowa Comprehensive Epilepsy Center, sounded the horn to start the race for the event which raised over \$30,000.

IN YOUR COMMUNITY

Texans Rappel a Side of a 22-Story High-Rise to Raise Money for Epilepsy



The Epilepsy Foundation Texas hosted a new fundraising event called “Over the Edge” on October 9 which allowed participants to rappel over the side of a 22-story high-rise building in downtown Dallas. Those that signed up were required to raise \$1,000 in order to go “over the edge”. The Epilepsy Foundation Texas was thrilled with the amount of money raised and the number of those in the epilepsy community that wanted to take part in the event.

Carnival for a Cure

With the help of her family, Sophia Angiuli turned her 6th birthday party into a carnival for a cure to raise funds for epilepsy research. Despite the heat in Columbus Ohio, Sophia’s parents,



Stephanie and Rodney Kale brought many people together through a fun carnival-themed party filled with games, food, and music all while educating the community on the importance of pediatric epilepsy research. Sophia was diagnosed with epilepsy two years ago, and then a year later, with leukodystrophy, a rare neurological disorder. The Kale family raised more than \$20,000 to support the Epilepsy Foundation.

Teen with Epilepsy Wins Miss Tulsa State Fair Outstanding Teen Competition



Chloe Cavinder from Idabel, Oklahoma won the Miss Tulsa State Fair Outstanding Teen competition. Her social impact, “Seize Your Dreams: Empowering and Educating Today’s Youth”. Chloe was diagnosed with epilepsy when she was 6 years old and is a passionate advocate for the cause. She has been doing seizure education and awareness in school classrooms and in her community. She competes at the Miss Oklahoma Outstanding Teen competition in June 2022.

Take a Swing at Epilepsy

The Epilepsy Foundation in Alabama recently held a “Take a Swing at Epilepsy” event at Topgolf in Birmingham. This outdoor event raised more than \$25,000 for the and had more than 125 attendees. People were thrilled to safely gather for the event, which brought together healthcare professionals, board members, people with epilepsy and other supporters.



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

Photo Contest Raises \$50,000 to Support Dravet Syndrome Community

Members of the epilepsy and Dravet syndrome community raised a total of \$50,000 through a photo contest sponsored by Zogenix. Designed as a charitable campaign, the FINTEPLA Photo Diary encouraged the community to share photos of their everyday moments with fewer seizures for a chance to win one of three prizes. In addition, Zogenix pledged \$25 for every photo liked or shared on the Photo Diary to support the Dravet Syndrome Foundation and the Epilepsy Foundation equally. The contest generated more than 200 submissions, one of which was Ryker's, who was diagnosed with Dravet syndrome at 8 months old.

Ryker's seizures started when he was 5 months old. His mom, Erika Anderson, was giving him a bath when she noticed Ryker was acting funny. Erika knew something wasn't right. He had another seizure about a month later and his doctor recommended genetic testing. Three months later, genetic testing pointed to Dravet Syndrome, a rare, genetic form of epilepsy that causes frequent and prolonged seizures that don't respond well to medications.

Ryker has tried several therapies, including a combination of six different daily medications, vitamins, and supplements. Each medication has side-effects, and most aren't good for his overall health and development. At 15 months old, Ryker also tried the classic Ketogenic diet to help with seizure control. Today, Ryker's seizures are shorter, somewhat intense, and less frequent.

Erika heard about the Photo Contest from a friend and decided to submit a photo of Ryker and encouraged her friends and family to like the photo. She received tremendous support from the community.

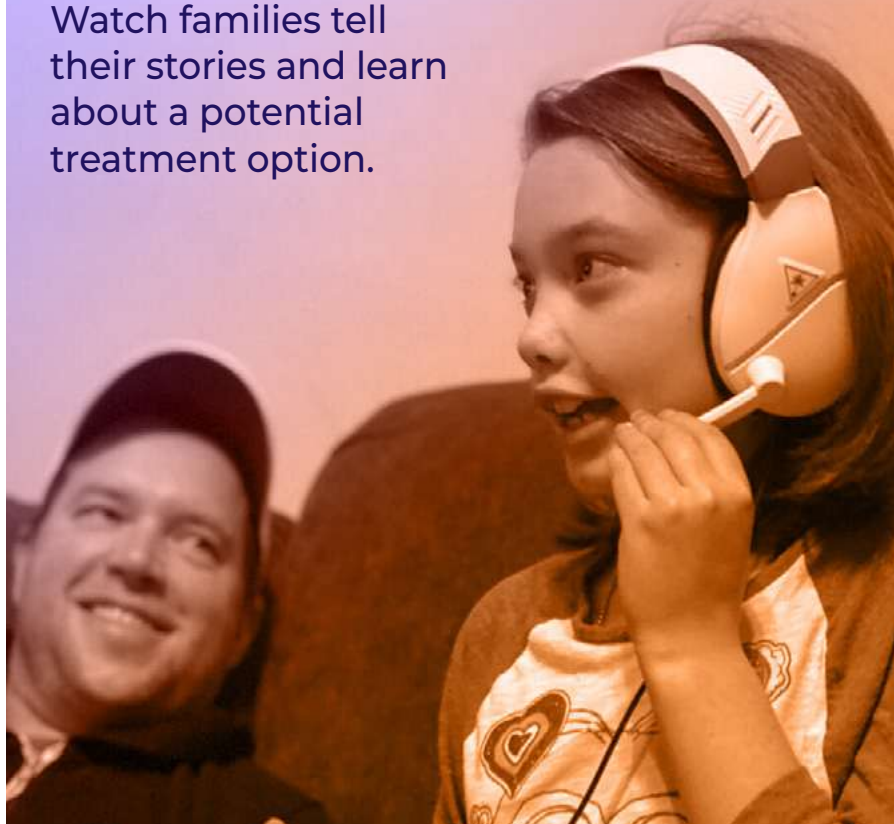
Ryker's photo, which featured him and his siblings cheering on the Chicago Cubs, received the most likes and earned first prize — a professional family photo shoot. Two other families, who had the second and third most likes, received the runners-up prizes — brand new iPads.



[Click here for more information about Dravet syndrome.](#)

HEAR INSPIRING DRAVET SYNDROME STORIES

Watch families tell their stories and learn about a potential treatment option.



[Click here to watch now at **UnfoldTheirSmiles.com**](#)

November is National Epilepsy Awareness Month



I am trying to raise awareness of epilepsy so that someday everyone will understand that the scary thing about epilepsy... is having epilepsy... and dealing with the stigma that comes from it.

- Helen, Oregon



Click here to see other awareness ideas for November, epilepsy.com/NEAM

Use the power of your journey

Part of telling the epilepsy story is to highlight the challenges associated with epilepsy and how they can affect the epilepsy community physically, mentally, and emotionally. This November for National Epilepsy Awareness Month, join the Epilepsy Foundation by using the power of your journey to reduce the fear surrounding epilepsy and bring hope to those facing challenges. Through a social media campaign called #RemoveTheFilter, the Foundation is asking everyone to “remove the filter” and make a difference for the more than 3.4 million people with epilepsy nationwide.

You too, can #RemoveTheFilter by:

Inspiring Hope

Share your epilepsy story with the world – wherever you find yourselves in the fight. This includes family, friends, caregivers and anyone with an epilepsy journey. Videos, words, and photos all make this story real and can create understanding, support and outcomes that can shift the tide in the battle our community faces every day. Read community stories and submit yours today for our eJourney Community Blog.

Helping to Save a Life

The Seizure First Aid Ready On Demand training is now available! This is a great resource that educates the public on the Epilepsy Foundation’s basic procedures for responding to someone having a seizure. The Seizure First Aid Ready course, available online anywhere and at any time, is presented in an interactive eLearning format that includes animations, videos, and activities. After completing the course, participants will be able to recognize common seizures, identify correct and incorrect steps for helping a person having a seizure, and identify when it would be necessary to call 911 in the event of a seizure.

Encouraging Action

Follow us on social media and change your Facebook profile picture or upload it on Instagram to help us #RemovetheFilter and share life-saving information about epilepsy during NEAM. Challenge your friends to do the same and use the following hashtags in

your social media posts: #NEAM2021, #RemovetheFilter, #SeizureFirstAid.

Raising Awareness

Epilepsy Awareness Ambassadors are passionate and dedicated volunteers tasked with virtually growing epilepsy awareness across their community. Ambassadors engage in monthly activities that promote all areas of the Epilepsy Foundation’s mission to both people living with epilepsy and the general public. Choose your own volunteer opportunity based on your interests and availability. Apply to be an Epilepsy Awareness Ambassador.

Walking for the Cause

The Epilepsy Foundation’s Walk to END EPILEPSY series and 2.6-million-mile challenge is back! Starting in November, use your creativity and challenge yourself alongside others across the country to help those impacted by epilepsy and seizures. No matter when, how or where you participate, it’s your Walk, your way! Let’s start moving. Walk with us.

Engaging Other Kids

Get your community and school involved! From getting your class to wear purple during a day/week in November, to planting purple flowers in your community, to “painting the town purple” using purple chalk, kids can make a difference too.

#RemoveTheFilter this November.

See the whole picture



Get the whole story...

Remove the filter.



See the journey...



Use your story
to help **increase
awareness and action**
for our community.

Be inspired by our community.
epilepsy.com/eJourney

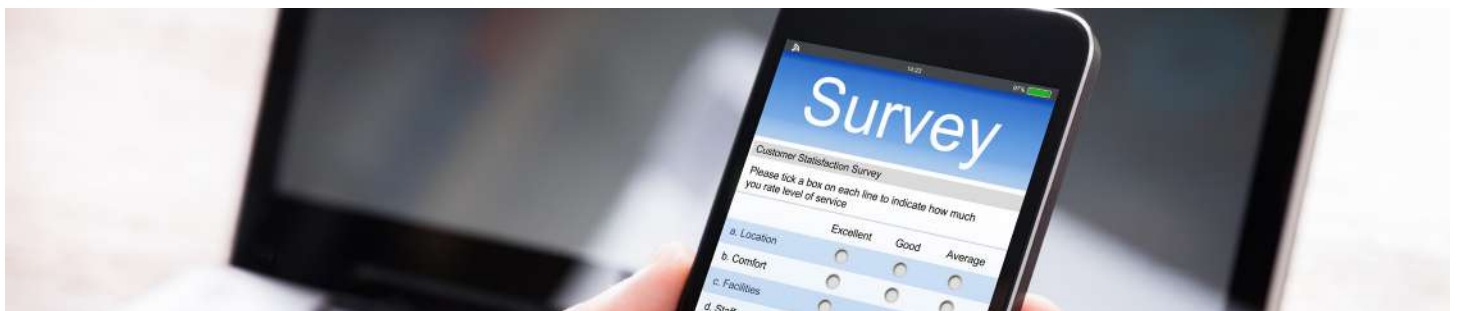


Nominations Open for Lifetime Accelerator Award

The Epilepsy Foundation welcomes nominations for the 2022 Lifetime Accelerator Award to be presented at the Epilepsy Foundation Pipeline Conference in Santa Clara, Calif., March 3-5, 2022. Nomination deadline is December 31, 2021. The Epilepsy Foundation Pipeline is our national conference that brings together decision makers with a stake in the field of epilepsy treatment, therapeutic innovation, and product development.



Click here for more information about the Accelerator Course.



EXPAND Study Now Enrolling Participants

The EXPAND Study is researching medication for people with childhood absence epilepsy (CAE) or juvenile absence epilepsy (JAE). Anti-epileptic medicines that are currently available may not work for everyone, may stop working over time, or may have to be stopped due to side effects, but this investigational medication is believed to work differently and has been approved in several countries to treat partial-onset seizures. It is hoped that the investigational medication might be a valuable treatment option for people with CAE and JAE.



Find your nearest study center:
www.expandstudy.com.

NEWS BRIEFS

Dog Treats for a Cause

Meet Hayley. In March of 2020, Hayley was diagnosed with epilepsy at the age of eight. Since then, she has become involved with the Epilepsy Foundation as a Kids Crew member and has been an inspiration to those in her community by raising awareness for epilepsy. This past Spring, Hayley held a fundraiser to bring attention to epilepsy while doing something she loves - making homemade treats for dogs. During her fundraiser, she sold more than 50 orders of treats and raised approximately \$650 to benefit the Foundation. Everyday people in their communities are doing incredible work to raise awareness around the challenges those living with epilepsy face and to raise critical funds to help the Epilepsy Foundation reach its goal of a world free from epilepsy and from fear of the next seizure. You can fundraise doing what you love too.



FUNDRAISE YOUR WAY!

EPILEPSY FOUNDATION®

No matter your idea, every effort and dollar raised makes an impact for the epilepsy community. Do you have a fun, innovative idea to fundraise your way for the Epilepsy Foundation? Whether you are hosting a backyard barbecue or climbing Mt. Everest, you can make a difference for those living with epilepsy.

Register today and receive resources, tips, and tools to help lead you to fundraising success!

Some ideas could include:



Create Your Own

Host a Fundraiser - a backyard barbecue, game night, bake sale, golf outing, etc.



Dedicate Your Day

Dedicate your special day - whether your birthday or anniversary - and start a fundraiser.



Celebrate a Loved one

Fundraising for a cause is a great way to honor or remember a loved one. Create a page in your loved one's name to support their cause.

... and more!!!



Get involved at
[epilepsy.com/fundraise-your-way](https://www.epilepsy.com/fundraise-your-way)

One Man's Journey from California to Florida



On September 20, Jack Navarro set out on a 55-day, coast-to-coast bicycle ride to raise funds that will make a difference in the lives of those living with epilepsy. He was inspired by three young people with epilepsy: 22-year-old Abbie Werner and 20-year-old Sevi Werner, siblings with epilepsy; and 10-year-old Liv Mosness. Although these young people remain positive and continue to fight for the best possible outcome, more research and better day-to-day solutions are still needed to make their lives easier. Jack is riding his bike across the country from California to Florida — not only as a personal challenge, but to help give hope and encouragement to those affected by epilepsy. The goal of the 55-day odyssey is to raise \$75,000 to fund research and increase awareness. At the time of this publication, Jack had raised nearly \$45,000.



To follow Jack's journey, visit www.lesslost.net/

Game Over Epilepsy

Stream for Epilepsy's Game Over Epilepsy event unites people from around the world as they stream epilepsy-friendly content and get creative while using their platforms to help the Epilepsy Foundation get one step closer to its goal: a world free from epilepsy and fear of the next seizure. Held during the month of November as a part of NEAM, creators are welcome to stream as often as they would like during the event. However long you stream, you will be helping to raise money for research and awareness, as well as rally support for the epilepsy community. Register to #StreamforEpilepsy, and aim to raise \$75 or more to earn Season One Level Up! incentives!



Learn more about how to participate: <https://bit.ly/3nIWodj>

CALENDAR OF EVENTS

See what's happening this fall!

Arizona

Epilep-TEA Party

November 7, 2021; 1pm - 4pm
The Clayton House -
Scottsdale, AZ

The Epilepsy Foundation Arizona will be hosting a first of its kind Signature Fundraising Event in Arizona, the Epilep-TEA Party, to bring more local awareness to epilepsy.

More information:
<https://epilepsyaz.org/event/8477/>

California

Gingerbread City: Sky's the Limit

December 9, 2021; 5:30pm
San Diego Air and Space Museum -
San Diego, CA

Come soar at the Epilepsy Foundation San Diego's premiere holiday philanthropic event and nationally recognized gingerbread competition.

More information:
<https://epilepsysandiego.org/events/gingerbread-city/>

Epilepsy Pipeline Conference

SAVE THE DATE

March 3-4, 2022
Marriott Santa Clara -
San Clara, CA

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

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

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

Illinois

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.epilepsyichicago.org.

Colorado

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)

Third 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>

Oklahoma

Oklahoma Seizure Smart Conference

November 13, 2021;
8:30 am - 12pm
Virtual

The Epilepsy Foundation Iowa and Isaiah Stone Foundation have partnered together to co-host the very first Oklahoma Seizure Smart Conference, which will be held on November 13, 2021 from 8:30 AM - 12:00 PM as a virtual conference on zoom!

More information:
OKSSC.givesmart.com

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 Live Certification Trainings

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

November 16, 2021
at 8 p.m. ET

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

Sign up at
learn.epilepsy.com

Donate this Season during Stock Monday and Giving Tuesday



Stock Monday - November 29

A gift of stock is a gift that matters. Thanks to generous supporters, the Epilepsy Foundation provides essential programs and services to the 3.4 million Americans who live with epilepsy,



[Click here for more information about stock donation](#)

BRAIN IT ON!
GIVINGTUESDAY



Giving Tuesday - November 30

Giving Tuesday is a global movement that unleashes the power of radical generosity around the world.

Donate on Giving Tuesday and let's BRAIN IT ON against epilepsy!



[Click to donate here for Giving Tuesday](#)



Words from the epilepsy community

I was afraid and hid the fact that I had epilepsy from everyone I knew when I was a little kid. Since I started coaching various sports, I want nothing more than to show the boys I coach that there's nothing to be afraid of, and that they never have to change who they are because of something like epilepsy.

-Cody, Epilepsy Awareness Ambassador

You Are What You Eat

It is true when people say, “you are what you eat.” What we eat and drink is central to our health in so many ways. Over the years, researchers have looked at the relationship nutrition habits have on our health and have found that poor dietary choices result in increased health risks for a range of health conditions, including epilepsy.

People with epilepsy have long reported that some foods may aggravate seizures or that going long periods of time without eating or “not eating well” can lead to poor seizure control. Dietary therapies can help control various types of seizures in both children and adults when medicines alone don’t work. There are four major dietary therapies used today for epilepsy. They are all low in carbohydrates (like sugar, pasta, and bread) and high in fat (like butter, oils, bacon, and avocados).



- The classic ketogenic diet, a special high-fat, low-carbohydrate diet, is prescribed and monitored by a physician and nutritionist. It can help both children and adults with refractory seizures.
- The modified Atkins diet limits the number of carbohydrates you eat to usually 20 grams each day. Eating fat in the diet is encouraged. It can be started at home and doesn’t need specific meal plans. This means you can eat a wider variety of foods. This is the most common epilepsy diet used for adults and teenagers with epilepsy.
- The MCT diet focuses on a specific type of fat called MCT, which refers to the type of oil used (medium chain triglycerides). MCT oil can be used as a supplement instead of normal fats in the diet.
- The Low Glycemic Index Treatment limits the type of carbohydrates you can eat. This diet allows carbohydrates that are less likely to raise your blood sugar quickly, like whole grains and berries. Foods that raise your blood sugar a lot (called high glycemic index foods) are avoided. Like the MAD diet, it is started at home and foods don’t have to be weighed.

Dietary therapy for seizures isn’t like a weight-loss diet, you can’t just do it on your own. It’s important to consult a neurologist or epileptologist before you start any special diet for seizures and epilepsy.



Check out some healthy recipes, provided by the Charlie Foundation, on page 26.

Foundation Quarterly, Issue 4: Fall 2021



A Thanksgiving Feast with All the Fixings

Recipes created by the Charlie Foundation for Ketogenic Therapies

Stuffing - Ratio 3:1

Bread Ingredients

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

Mixture Ingredients

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

Bread Directions

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

Mixture Directions

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

Cauli-Mash - Ratio 2:1

Ingredients

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



Directions

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

Butternut Squash - Ratio 2:1

Ingredients

200g butternut squash
300g coconut cream
dash of curry powder
30g onions - raw
67.5g olive oil



Directions

Bake a butternut squash; cut it down the middle then scoop out the strings and seeds. Turn both pieces face down on a foil covered baking sheet and bake for 30 minutes at 375 degrees. You can also cook cut the flesh into chunks and micro-wave until soft. Sautee raw onions in olive oil in a small sauce pan. Add cooked squash, coconut milk and curry powder and mix well with a silicone spatula, mashing squash into liquids. Simmer for 10 minutes on low heat to blend flavors. Water may be added for thinner consistency. Soup may be refrigerated for 2 days or frozen.

Pumpkin Pie - Ratio 2:1

Ingredients

50 gm almond flour
6 gm coconut flour
40 gm butter, room temperature pinch of xanthan gum
pinch of baking soda
30 gm raw egg yolk
75 gm pumpkin puree, unsweetened
30 gm 36% heavy cream 1 gm cinnamon
7 gm Truvia
tiny pinch of salt



Directions

Pre-heat oven to 350 degrees. Combine almond flour, coconut flour, butter, xanthan gum and baking soda in a small bowl. Mix well with silicone spatula until all flour and butter are incorporated, leaving a thick dough. Cover bowl with plastic wrap and refrigerate for 20-30 minutes, allowing butter to firm. Divide dough into 4 equal portions by weight. Place each portion into a mini pie pan. You may use parchment or foil liners. With wet fingers, press dough into the wells, covering the bottoms and sides, re-wet your fingers if dough sticks. Combine egg yolk, pumpkin puree, heavy cream, cinnamon, Truvia and salt in a small bowl. Whisk the ingredients together very well. Divide the batter into 4 portions, about 35 grams each, and pour the mixture into each pie crust. Bake for about 15-20 minutes or until the center of the pie is set.



[Click here for more holiday cookie recipe collection, courtesy of the Charlie Foundation.](#)

Are you living with epilepsy or caring for someone with epilepsy?

Cerevel Therapeutics invites you to share your experiences.

We are seeking to transform the lives of people suffering from neuroscience diseases by hearing directly from members of the epilepsy community.

Share your story to...



Inform researchers what it's like to live with epilepsy



Learn more about medical research focused on epilepsy treatments



Communicate your needs and those of the epilepsy community

To get started, take the brief, 9-minute survey:
bit.ly/epilepsy-survey



Disclaimer: By completing the survey, you give permission for the collection and processing of your contact information and personal information about your epilepsy journey that you choose to share, in accordance with data privacy laws. Cerevel may offer other opportunities for you to share your experiences. You can opt out of further contact at any time.



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