

# Foundation Quarterly

DJ Hapa,  
"DJ Coach"  
and Epilepsy  
Warrior - page 6

Inspiration Issue

+ In Your  
Community,  
News Briefs,  
and Recipes for  
Healthy Summer  
Eating



# How are we halfway through the summer?

It feels like school was just out, especially because beach weather is still in full swing. And although we would like to make summer last a little longer, we find ourselves counting the last days of warm weather. We are getting ready to put away our swimsuits, bikes, and running shoes.

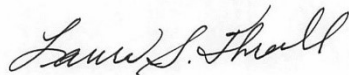
But, for triathlete Rowan Haffner, he is keeping his swimsuit and bike ready for the next chapter of his life post high-school graduation. You will read about Haffner's story in this month's Foundation Quarterly and how he did not let an epilepsy diagnosis interfere with his desire to cross the finish line. He has completed 25 triathlons and Ironman races and plans to continue to compete as he heads off to Duke this fall.

We did not want summer to end without highlighting inspirational stories from our community. A great example is our cover story featuring renowned DJ HAPA whom you may have spotted at EpiCon. DJ HAPA has been a long-time advocate and supporter of the Epilepsy Foundation and recently sat down with us to share his journey filled with challenges and perseverance.

We also feature one of our epilepsy awareness ambassadors who has struggled with seizures since she was 8 years old. In her personal essay, she recounts the time when she had to take a certification test nine times to become an occupational therapist. She succeeded.

If you could not join us in Nashville this year for our first-ever annual convention, check out our centerfold which features pictures from EpiCon. It was certainly one to remember! And if you enjoy grilling during the summer, make sure to check out our Recipe Corner, courtesy of our friends at Charlie Foundation for Ketogenic Therapies.

Let us enjoy the sunshine and warm temperatures a while longer.



Laura Thrall  
President & CEO

**Read Rowan's story  
and be inspired!**



# Inside of the **Foundation** Quarterly

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## **THOUGHT OF THE DAY:**

**Our community is comprised of strong individuals ready to conquer any challenges that may come their way.**

**Be proud and share your accomplishments with others.**





# The Gift of Epilepsy

Renowned DJ HAPA is considered one of the best DJs in the music industry. He is known for blending a variety of genres together to create unique soundtracks. He has shared the stage with artists such as Michael Jackson, Earth Wind & Fire, Drake, and Bruno Mars. But for years, behind the scenes, he struggled with seizures.

DJ HAPA was diagnosed with epilepsy during his senior year in high school. Up until then, he had the picture-perfect senior year and was graduating at the top of his class. He also had just been accepted to the University of California Los Angeles (UCLA) on a full academic scholarship. Originally from San Francisco, Calif., he was just getting into DJing and was excited to be going off to college in the heart of the entertainment industry — Los Angeles.

After waking up one night in the middle of the floor in a pool of blood, he was rushed to the emergency room. He was treated by a neurologist in the ER and later put on anti-seizure medications which gave him side effects.

Photo Courtesy: DJ Hapa



## COVER STORY

“It was a complete 180 for me,” he said. “I thought I was at the peak of my life and felt untouchable. I thought I was running the world. Yet, I was sitting there feeling like a vegetable due to the medications. My neurologist at that time schooled me on the kind of ‘box’ I needed to live in from now on, including doing away with college. But being 17 and borderline cocky played in my favor, it was the fuel I needed to prove to people I can do this. So off to college I went.”

It was a pivotal time in DJ HAPA’s life. He was moving away from home for the first time ever, had just been diagnosed with epilepsy and his seizures were not yet controlled. His parents weren’t thrilled about the idea of him going away to college, but they trusted him to make the right decision and manage his epilepsy while at school.

While at UCLA, he had a big seizure the night before a major midterm and went into a depressive state. He even contemplated suicide and checked in to the health clinic at school. One of his roommates suggested DJ HAPA find an epilepsy specialist to discuss other potential treatment options that may help him better control his seizures.

“I finally felt I had someone in my corner who understood my lifestyles and was there to advocate for me,” he said. “The key was finding a neurologist who would partner with me to thrive and not just survive.”

DJ HAPA was at UCLA for 5 years. As graduation day got closer, his counselor asked him to consider being a keynote speaker for the graduation. She knew his story and the obstacles he had to overcome while in college. It was the first public platform DJ HAPA would use to share his story. However, it took a while after that graduation speech before he began to share his story again. DJ HAPA’s career started to grow, and his public platform became bigger and bigger. Yet, sharing his struggles with seizures was not something he felt comfortable doing.



Pictured at EpiCon (right), DJ Hapa with Epilepsy Foundation CEO Laura Thrall, Board Member Josh Golden, Author Mary Philpott, and former NASCAR driver Matt Tifft

“I spoke about it during my graduation ceremony and that was it. I checked it off the box and moved on. It wasn’t something I wanted to talk about openly, especially in the industry I worked in. Telling people about it was on a need-to-know-basis. I didn’t hear people talking about epilepsy, so I didn’t want to do so either.”

I didn’t hear people talking about epilepsy, so I didn’t want to do so either.

Today, DJ HAPA believes that epilepsy is the best thing that happened to him. He is 14 years seizure-free. He coaches and mentors youth who are pursuing a career in music and those who aspire to be DJs. While he leads with who he is as a person and not his epilepsy, he continues to share his story every chance he gets. He hopes that by sharing his journey, he can inspire others, especially young people with epilepsy, to pursue their passion and push the boundaries.

“Epilepsy has been the biggest challenge I ever faced in my life, and the biggest proof of my faith. I perform regularly and spread joy through the speakers, television, and phone screens. Each day, I celebrate the wins. No matter how big or small. This is the gift of epilepsy. This is walking into it.”

“Each day, I celebrate the wins. No matter how big or small. This is the gift of epilepsy. This is walking into it.”



Photo Courtesy: DJ Hapa

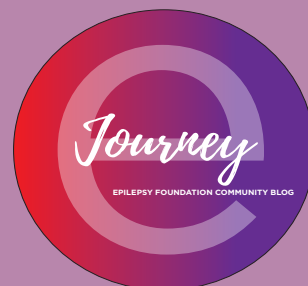




# November is National Epilepsy Awareness Month.

The Epilepsy Foundation has begun planning for NEAM this November, and we're looking for stories. Share your story to increase awareness and continue the conversation about the challenges living with epilepsy.

Be inspired at  
[epilepsy.com/eJourney](https://epilepsy.com/eJourney)







Pictured: Kylie (above) Photos Courtesy: Kylie

## One Day at a Time

by Kylie

On November 12, 1989, I turned 8 years old and was going to celebrate with my family and friends at an indoor swimming club. Later that day at the party, I don't remember what happened next because I ended up having a grand mal seizure and collapsing in my parents' arms.

Doctors said I had meningitis and a possible tumor in my head. The hospital where I was taken to was not equipped to address my seizures, so I was moved to a children's hospital where I stayed for months with my parents by my side. I continued to have seizures and doctors did what they could to control them.

I eventually returned to school, medicated and stable. Unfortunately, my seizures continued up to the age of 17. I was severely bullied, had anxiety, and depression. I would cry every day because I was scared. I never told my mom about the anxiety and the severity of the bullying because I didn't understand why I felt so different from others. Many times, I did not want to go on. I wanted the pain to go away. I felt alone. I felt like a girl looking through the window while everyone was enjoying life and wondering why I couldn't be like that.

I was considered seizure free by age 18 because my EEG showed no seizure activity. But I continued to suffer from severe anxiety which I hid well because I did not want to be judged. I went to a community college for two years to take a few courses and then transferred to a four-year university. No one in school knew I had epilepsy. During my time in college I experienced auras. While working at a small restaurant during my junior year, I collapsed behind the counter. The doctors, however, did not classify it as a seizure.



Photos Courtesy: Kylie

## PERSONAL ESSAY



I suffered from severe panic attacks and struggled in school. I would have to prepare for a test months in advance to be able to retain any information. I had to retake multiple classes I did not pass. Eventually, I graduated college and worked, but I felt that I wanted something different. I decided I wanted to be an occupational therapist, but I did not take any courses to go into that profession. I knew it was going to be an uphill battle, but what kept me going were all the people who told me I would never be anything because I have epilepsy.

I ended up going back to community college to get the prerequisites to apply to school for occupational therapy. At this point in my life, I wasn't having any seizures, but I was extremely anxious and had to seek help. I was seen by many doctors, some of whom told me I had "been dealt bad cards" and that it was "all in my head".

I knew it was going to be an uphill battle, but what kept me going were all the people who told me I would never be anything because I have epilepsy.

When I finally finished my prerequisites, I applied to one of the top schools for occupational therapy in my area. Although, I did well in my classes, it was not enough. I needed high GRE scores in order to get into the program. After a lot of persistence, the dean of admissions finally agreed for me to come in for an interview despite my low GRE scores. I found out two weeks later I had been accepted into the program!

During the summer of 2007, after I got home from the university orientation with my mom, I had a severe grand mal seizure and went back on anti-seizure medications. I was in graduate school, and I really struggled with processing and remembering the material I was studying. It was hard for me to finish the work in the time the teacher allowed. During my clinicals one day, I sat down to discuss my mid-term review with my supervisor; she had written FAILED with a big X on my review. She told me I have a delay in processing and said, “you will never be an occupational therapist”. The staff at the school did not feel I would be able to handle the academic caseload and did not support me.



I felt completely worthless and defeated, but I refused to give up or drop out of school. With the support of my parents, I went to another clinic, and they thought I was amazing. I wasn't used to someone believing in me. I graduated from the occupational therapy program in December 2009, and after taking the exam NINE times I finally passed. It took me two and a half years from graduation to get a job offer because I had to retake the exam so many times. Though, within a few months I was offered the lead therapist position. A few years later, I was able to find an epileptologist who diagnosed me with temporal lobe epilepsy and adjusted my medication.

Today, I share my story to help others. So that they don't have to suffer. So that they don't feel lost and confused. I take it one day at a time.

I battle epilepsy daily. I continue to have depression and anxiety. There are still people who stigmatize me, put me down and judge me. But now, I don't let it bother me. I love who I am and what I offer to the world. Although, there is pain and sorrow behind my smile, there is also strength. I used to be scared to live and to enjoy life. Today, I share my story to help others. So that they don't have to suffer. So that they don't feel lost and confused. I take it one day at a time. One day at a time; that's all we can do.



Inspire others and  
share your story at  
[epilepsy.com/ejourney](https://epilepsy.com/ejourney)





## On Your Mark, Get Set, Go!

Recent high-school graduate Rowan Haffner just crossed the finish line at the Ironman Lake Placid in New York, which draws triathletes from all over the world to test themselves. And test he did. For an 18-year-old with epilepsy, he has raced more than 1,000 miles, including 25 triathlons and Ironmans. Last November, he was selected and competed for Team USA in Spain.

Haffner's first seizure came as a surprise to him. After all, he was young, healthy, and athletic. But, one minute he was having a conversation with his dad, and the next he woke up in the back of an ambulance heading to the emergency room. Two weeks later he was diagnosed with juvenile myoclonic epilepsy.

"I would sometimes have jerking movements while working out," he said. "Never did it cross my mind that I was having seizures. I was shocked because I always thought most people with epilepsy had a family history of the condition. I was wrong!"

Competing in triathlons certainly isn't for the faint of heart — swimming for hours, running and biking for miles. Add in seizures to the mix, and you're in a new level of challenge. Yet, Haffner has taken the challenge head on. He's using his diagnosis to fuel him and has found a way to train and compete despite it all.

"For years, everything in my life revolved around sports and later, my races," he said. "So when my diagnosis came, I asked myself, 'what's the craziest thing I can do now with my epilepsy?' I was not going to let it stop me."

With that in mind, Haffner went to his neurologist to see how he can adjust his training to keep pursuing his passion. His doctor gave him the green light to compete as long as he could manage seizure triggers and have a seizure action plan in place during competitions. So on race days, he works with the onsite directors to find reasonable accommodations. Whether it is having someone on a motorcycle come check on him along the bike route, or an extra kayak nearby when he swims, everyone he has proactively reached out to has been very supportive and accommodating.

Now, Haffner is off to his first year in college majoring in neuroscience. He wants to be a neurologist specializing in epilepsy. He also plans to compete in more triathlons and Ironmans. He has begun using his races for good by creating awareness about epilepsy and fundraising for the cause.

"It feels amazing to share my story and show others that you can still do what you want to do even if you have epilepsy," he said. "Yes, the diagnosis makes your life a lot harder, but it shouldn't stop you from doing what you love. You just need to champion it and feel motivated to do more things with it."



Photos Courtesy: Rowan Haffner

# Epilepsy & Seizures 24/7 Helpline

[epilepsy.com/Helpline](http://epilepsy.com/Helpline)

Providing HELP, HOPE, and  
SUPPORT to families and  
people living with epilepsy and  
seizures nationwide



Call **1-800-332-1000**  
en español **1-866-748-8008**

Interpreters available for more than 200 languages



# An Advocate for Rare Epilepsies

In June, we recognized CDKL5 Deficiency Disorder (CDD) Awareness Month, a rare X-linked genetic disorder. Most people affected by CDD have seizures that begin within the first few months of life. Children with CDD also have other non-seizure related symptoms that impact cognitive, motor, speech, and visual function.

In 2009, Karen Utley, BSN, RN, cofounded the International Foundation for CDKL5 Research (IFCR) with a group of parents following her daughter Samantha's CDD diagnosis at 20 months. Samantha had her first seizure at 10 weeks of age.

"When Samantha was diagnosed, I was told nothing was known about this disorder," said Karen. "A geneticist at a world-renowned facility handed me a paper about a study that discussed how mutations on the CDKL5 gene seem to cause severe epilepsy; I was told that was all the information available at that time."

With so little known about CDD, Karen decided she needed to be proactive to help make a difference, not just for Samantha, but also for other families. She made this a priority and immediately set out to connect with others impacted by this disorder.

"I found a Yahoo email support group with a small number of families, and very quickly, we started communicating about creating an organization," said Karen. "Eventually, we incorporated our nonprofit to provide support and help fund research for treatments and a cure."

Karen's belief that a cure is possible led her to pursue and earn a bachelor's degree in nursing. She uses her knowledge in science and clinical care to improve the lives of those diagnosed with CDD, including her now 15-year-old daughter.

Samantha struggles with limited hand mobility, gastrointestinal complications, walking and communication issues which require around-the-clock care. While Samantha does have some seizure-free days, most days are filled with multiple seizures which require additional care. Samantha recently made strides: after eight years of not eating by mouth, she began eating soft foods again.

For Karen, interacting with her daughter and hearing her giggle and laugh makes her day. Samantha loves all music genres, so music therapy is the highlight of her week.

"Her music taste is quite eclectic! She'll listen to pop music, some country, oldies, praise and worship music, Disney sing-a-longs, and she loves Billy Joel! If she doesn't like a song, you'll know immediately by her facial expression."

CDD poses many challenges, not just for the person living with the disorder but also their families. For the past 13 years, the IFCR has served the CDD community by providing family support, education, and leading advocacy efforts. The organization has also funded ground-breaking research and established CDKL5 Centers of Excellence throughout the United States to bring specialized care to families.

"It's important for people who are not familiar with CDD to ask questions. My hope is that no other family ever feels alone because of a CDD diagnosis. I want to improve the quality of life for our kids."



[Learn more about CDD.](#)









# Flight or Fight

Eleven-year-old Chloe had her first seizure in 2021. As she went to hug her mom, she began to have jerking movements in her mom's arms. Her mom rushed her to the emergency room, but they wouldn't admit her, instead they referred her to a neurologist for an electroencephalogram (EEG). The EEG showed that Chloe was having absence seizures and tonic clonic seizures every six days. Two weeks later, she was diagnosed with epilepsy.

"We were in flight or fight mode for a while," said her mom. "The process has been traumatic. I couldn't see the light at the end of the tunnel. I'm still on edge, if I hear her drop something in the other room, I run to see her. Thank God Chloe doesn't remember her seizures. I do, though, all of them, but I've found coping strategies and therapy to help us process."



Photos Courtesy: Chloe Marantez

When Chloe was first diagnosed, her seizures were not controlled. Thanks to her uncle who is an ER nurse, Chloe was connected to an epileptologist. They detected 19 seizures in three days following her diagnosis. She was prescribed anti-seizure medications and together with her doctor found one that helped control her seizures

“I do competitive dancing and dance four times week, and I’m always wondering what if – what if I hurt myself, what if I have a seizure in the middle of a dance,” said Chloe. “One day, I had a seizure at school and my friends got scared. The school nurse and my teacher immediately cleared the room and moved things around so that I was safe.”

Chloe and her mom decided to fight epilepsy and started by educating her classmates. Last May, with the help of her school nurse, Chloe planned and hosted an epilepsy awareness day. She put up a huge banner in front of the school and passed out purple bracelets and ribbons. She also did a speech and shared information about seizures.

“The awareness day made it less scary for kids,” said Chloe. “They understood more about it, so I didn’t feel as nervous having a seizure at school. Some kids even came up to me after my speech to tell me they got seizures too. School has been a big family to me.”

The awareness day made it less scary for kids. They understood more about it, so I didn’t feel as nervous having a seizure at school.

Chloe recently graduated from the 5th grade and will be entering middle school. She wants to be a voice and advocate for epilepsy by producing a documentary. Her documentary will focus on how epilepsy is viewed in other countries. She hopes to help remove the stigma for other kids.

“I want other kids to know that they’re not alone in this. They have other people who love them and will help them get through it. We just need to be strong and fight it.”



Become an Awareness  
Ambassador at  
[epilepsy.com/volunteer](https://epilepsy.com/volunteer)



## RECAP STORY

More than

# 450

attended the first ever epilepsy convention in Nashville, Tenn.



One of our Epilepsy Awareness Ambassadors sharing what makes her Epic.



Our EPIC wall photo opportunity



A participant interacting with our panelist



Epilepsy Foundation chief outcomes director, Health Haynes-Smith, and Health & Education program manager

# First Ever Conve

# EPIC

Life-changing  
for some,  
and a welcoming  
experience  
for others

ation staff L-R: Brandy Furman, officer; Tom Buckley, senior Information Services; LaQueisa senior director, Training, Public ion; and Cheryl Houston, er, Public Health & Education.

STEPS Toward Zero panel: Landis Weidner (left), Kenzie O'Connell, and MNatalie Beavers



May 13-15, 2022  
Nashville, TN

Annual  
Convention:

CON

20  
interactive sessions

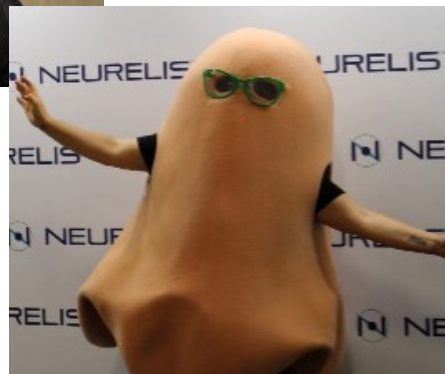


Our Parent & Caregiver panel (L-R): Jonathan Scheinman, Dr. Katy Lalor, Tonya Nash, and Courtney Watson



Thank you to our partners, Music City Pets who brought their therapy dogs to interact with our community.

Great time at Neurelis' booth



A group of epilepsy warriors

33 exhibitors



**Celebrating your  
accomplishment  
can make  
a difference for the  
3.4 million people  
living with epilepsy.**



Raise Awareness And  
Fundraise Your Way for  
the Epilepsy Foundation

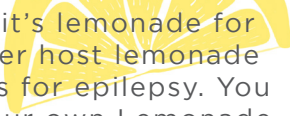


**Fundraise Your Way at  
[epilepsy.com/fundraise-  
your-way](https://www.epilepsy.com/fundraise-your-way)**





# When Life Gives You Lemons, Fundraise!



Nothing says summertime like a glass of refreshing lemonade. And when it's lemonade for a good cause, it's even more refreshing! Hundreds of families each summer host lemonade stands and participate in Lemonade for Livy to raise funds and awareness for epilepsy. You can also make a difference in your community and beyond by creating your own Lemonade for Livy fundraiser. Host an in-person lemonade stand or virtual fundraiser, ask your friends or family members to “adopt a lemon,” and share on social media to help make your fundraiser a success. This year, the Epilepsy Foundation hopes to raise \$50,000, one glass of lemonade at a time!



by the numbers  
in 2021

**231**  
participated nationwide

**\$53,598**  
raised



Visit [epilepsy.com/lemonadeforlivy](https://epilepsy.com/lemonadeforlivy)  
to sign up

## IN YOUR COMMUNITY

# Epilepsy Foundation of Northeastern NY Awards Scholarships

The Epilepsy Foundation of Northeastern New York awarded five college scholarships to graduating high school seniors and students who are enrolling at any post high school institution of higher education.

The recipients of the scholarships are students with epilepsy that also reside in one of the 22 counties served by the Epilepsy Foundation of Northeastern New York: Brianna Stevens, Tess Harrington, Lindsay Pierce, Benjamin Parker, and Kennedy Foley.



## Rare Epilepsies Conference Sessions Now Available

If you missed the recent Upper Midwest Rare Epilepsies Conference presented by the Epilepsy Foundations of Greater Chicago, Michigan, Minnesota and Wisconsin, the sessions are now available for viewing on YouTube. The conference featured national thought leaders on topics including accessing care, managing neuropsychiatric and cognitive comorbidities, optimizing telemedicine visits, understanding seizure detection devices, genetics and rare epilepsies, and more. Although focused on the rare epilepsies, these topics have application to all persons touched by epilepsies.



To listen to the conference sessions, visit [Upper Midwest Rare Epilepsies Conference - YouTube](#).

# 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*

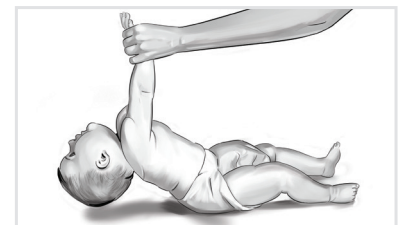
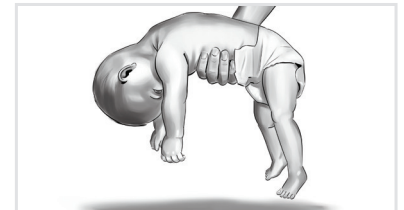
## Similar signs and symptoms between certain subtypes of epilepsy and AADC deficiency include:

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

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

## Signs and symptoms of AADC deficiency not seen in epilepsy:

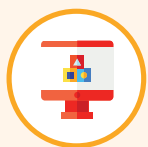
- › Involuntary eye movements called oculogyric crises
  - Episodes when eyes suddenly roll upward that can last anywhere from a few seconds to hours, and can happen several times a day or several times a week. When this happens, it can look like the child is having a seizure
- › Normal brain scans
-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



*Illustration of hypotonia*



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



Learn more at [AboutAADC.com](https://www.AboutAADC.com)



## NEWS BRIEFS



Amir Helmy, co-founder of Epipal, received the Shark Tank Community Impact Award at the 2022 Pipeline Conference.

## 2022 Pipeline Conference

This past June, the Epilepsy Foundation hosted its biannual Pipeline Conference in Santa Clara, Calif. The event was a hybrid in-person and virtual conference with more than 200 attendees onsite and approximately 100 virtually. The conference showcased the latest developments in the epilepsy pipeline from pre-clinical to right before approval. The event featured industry leaders from around the world who came together to share ideas and insights in the epilepsy field. The conference is also the platform for the Foundation's Shark Tank Competition.

This year, Amir Helmy, co-founder of Epipal, received the Shark Tank Community Impact Award to develop a software system for seizure detection and management. In addition, Lynn Kramer, M.D., vice president and chief clinical officer of the Neurology Business Group at Eisai, was honored during the conference with the 2022 Epilepsy Foundation Lifetime Accelerator Award. Dr. Kramer was recognized for his contributions to the epilepsy community, including the advancement of novel therapies development of numerous anti-seizure medications.



Learn more about this year's Pipeline at [epilepsy.com/2022pipeline](https://epilepsy.com/2022pipeline)



Dr. Lynn Kramer, received the 2022 Epilepsy Foundation Lifetime Accelerator Award at the 2022 Pipeline Conference.

# More than \$696K Raised for Epilepsy Programs

In April, the Epilepsy Foundation kicked off its Walk to END EPILEPSY® series across the country with in-person events and the 2.6-Million-Mile Challenge Walk Your Way to fundraise for the 3.4 million Americans living with epilepsy and their families. No matter how people chose to participate, everyone’s support was recognized and celebrated during a virtual livestream celebration in June. This year’s Walk to END EPILEPSY series and 2.6 Million Mile Challenge raised \$696K with 6,000 participants virtually and in person supporting the epilepsy community.



6000  
participants  
virtually and  
in person



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

- Gene, South Dakota



Take action at your local Walk at [WalktoEndEpilepsy.org](http://WalktoEndEpilepsy.org)



# Advocating for Epilepsy on Capitol Hill

The Epilepsy Foundation recently hosted its annual Public Policy Institute, which brought together 44 advocates virtually and in person on Capitol Hill in Washington D.C. Majority Leader Steny Hoyer (MD-05) stopped by the conference to share words of wisdom with attendees before they went on the Hill. The Foundation also awarded the annual Tony Coelho Impact Award to Senator Chuck Grassley (IA) and Representative Earl Blumenauer (OR-03) for their work advancing medical cannabis research legislation and other important policies. Advocates are continuing to schedule virtual meetings with their legislators to discuss ongoing policy issues, including urging the passage of legislation that caps out-of-pocket expenses in Medicare's prescription drug benefit, as well as legislation to facilitate research into the potential benefits and harms of medical cannabis.



Learn more about  
our advocacy efforts at  
[advocacy.epilepsy.com](https://advocacy.epilepsy.com)





## Seizure Safe Schools in 18 States

Six new states recently enacted Seizure Safe Schools legislation: Utah, Florida, Maryland, Arizona, Missouri, and Louisiana thanks to grassroots advocates who were instrumental in getting these bills across the finish line. The Epilepsy Foundation played a leadership role in many of these states and provided support to coalition partners in some of the states.



[Learn more about our Seizure Safe Schools.](#)

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## Memory Loss & Epilepsy

More than half of people with seizures experience memory problems and feel that seizures interfere with memory. While some forgetting is considered normal, people with epilepsy generally report more significant problems. Memory and thinking challenges are common among people with epilepsy and can have a greater impact on quality of life than epilepsy itself. Cognitive challenges can impact a person's work, school, and social activities.

Such was the case for Joanne who has struggled with seizures for about 14 years. She began to have memory issues, such as forgetting words when she was speaking with someone. Following her psychologist's recommendation, she enrolled in Dartmouth's HOME-Based Self-Management and COgnitive Training CHanges Lives (HOBSCOTCH) program.

"At first, I wasn't so sure about it, I was a little nervous. But given the short-term memory problems I was having and other issues, I decided to give HOBSCOTCH a try. Signing up is probably one of the best things I've ever done."

HOBSCOTCH is an evidence-based program designed to help people with epilepsy find ways to manage and cope with their memory and thinking challenges in order to lead happier, more productive lives. Each participant receives eight one-on-one sessions with a trained cognitive coach who will guide them through the program. HOBSCOTCH is a free telehealth program so anyone can participate from anywhere in the comfort of their home.



To learn more, visit [HOBSCOTCH.org](https://www.HOBSCOTCH.org)

## CALENDAR OF EVENTS

See what's happening in the coming months!

### Arizona

#### Enterprising Women's Luncheon

September 20, 2022  
Phoenix Country Club  
Phoenix, AZ

The Epilepsy Foundation Arizona is hosting their Enterprising Women Luncheon. The intention of this program is to increase awareness about the policies and issues affecting women's health in the workplace, with a specific focus on epilepsy, seizures, and related diagnoses.

Register:  
[efazwomen22.givesmart.com](http://efazwomen22.givesmart.com)



#### Epilep-Tea Party

November 6, 2022  
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/](http://epilepsyaz.org/event/8477/)

### Massachusetts

#### Creative Golf Tournament

September 30, 2022  
Southers Marsh Golf Club  
Plymouth, MA

The Epilepsy Foundation New England is hosting the second Annual Creative Wealth Golf Tournament. Registration includes cart and green fees, as well as dinner. Enjoy the putting contest and other on-course contests throughout the day.

Register at: <https://www.classy.org/event/the-2022-creative-wealth-solutions-golf-tournament/e407517>

### Michigan

#### Back-to-School Webinar

August 13, 2022, 10a.m. ET  
Virtual

The Epilepsy Foundation of Michigan is hosting a free, online conference to discuss various ways that healthcare professionals and parents can help students with epilepsy succeed in school. The event is designed for adults, however, high school students with a strong interest in learning more about their epilepsy, self-advocacy, and self-management may benefit from participating.

Register at <https://epilepsymichigan.org/back-to-school-conference/>.

### New York

#### Walk to END EPILEPSY - Saratoga

September 11, 2022  
Saratoga Spa State Park  
Saratoga, NY

Register at <https://app.mobilecause.com/vf/22EFNENYWALK>

### Walk to END EPILEPSY - Inlet

September 11, 2022  
Arrowhead Park  
Inlet, NY

Register at <https://app.mobilecause.com/vf/22EFWALKINLET>

### Golf Tournament for Epilepsy

October 3, 2022  
Wolferts Roost Country Club  
Albany, NY

Shotgun start, lunch at the turn, 19th Hole Cocktail Hour Celebration immediately following golf to present awards.

For information, contact Susan Kaczynski at [skaczynski@epilepsyneny.org](mailto:skaczynski@epilepsyneny.org) or (518) 456-7501.

### Nebraska

#### Blackstone Stroll

October 15, 2022  
Lincoln, NE

More information:  
[epilepsy.com/Nebraska](http://epilepsy.com/Nebraska)

### PENNSYLVANIA

#### Attention & Executive Functioning Skills in Individuals with Epilepsy

August 24, 2022, 6p.m. ET  
Virtual

Epilepsy Foundation Eastern PA's webinar will cover common issues with attention and executive functioning experienced by individuals with epilepsy. In addition, the social, psychological, and academic effects of these cognitive difficulties will be reviewed. A brief description of the benefits of a neuropsychological evaluation will be included as well as a discussion of frequently used interventions.



## Walk to END EPILEPSY - NEPA

October 15, 2022  
Moosic, PA

The EFEPa is thrilled to announce your efforts for the Walk to END EPILEPSY - NEPA will once again be put towards opening an epilepsy space right here in Northeast PA! But, we cannot do it without the full support of our NEPA community members! Join us in our dream of bringing an EFEPa community center to NEPA where we can gather, meet, connect and volunteer in Wilkes-Barre, PA.

Register at: [www.efepa.org/walk-to-end-epilepsy/](http://www.efepa.org/walk-to-end-epilepsy/)

## Walk to END EPILEPSY - Lancaster

October 21, 2022  
Lancaster, PA

The world may look a little different, but one thing hasn't changed: our commitment to supporting our local epilepsy community. Celebrate, honor, and remember the strength of our Epilepsy Warriors at the Walk to END EPILEPSY - Lancaster on Saturday, October 22, 2022!

Register at: [www.efepa.org/walk-to-end-epilepsy/](http://www.efepa.org/walk-to-end-epilepsy/)

## Washington

### Camp Discovery

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

More information at  
[EpilepsyWashington.org](http://EpilepsyWashington.org)

## SEIZURE FIRST AID CERTIFICATION TRAINING - LIVE

Register at

[learn.epilepsy.com](http://learn.epilepsy.com)

### In English

- August 2 at 4 p.m. ET
- September 6 at 4 p.m. ET
- October 4 at 4 p.m. ET

### In Spanish

- August 18 at 8 p.m. ET
- September 15 at 8 p.m. ET - In Collaboration with National Hispanic Medical Association, and in recognition of National Hispanic Heritage Month
- October 20 at 8 p.m. ET



The Skyline study for children, teens,  
and young adults with Dravet syndrome  
is now enrolling.

Parents and caregivers are invited to learn more.

**CLICK HERE.**





# Summer Favorites with a Twist

Recipes created by the Charlie Foundation for Ketogenic Therapies



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



## Hamburger on A Stick - 4:1 Ratio

Forget the buns! Serve food on a stick, it usually goes over well with kids and adults alike. This is a typical grilled hamburger, deconstructed and put on a stick. It has all the traditional ingredients, including the pickle on top. Instead of mustard as the flavor for the dipping sauce, you can use sugar-free ketchup, mayonnaise or even ranch dressing. The mustard dip makes a large portion, so if you're not a "heavy dipper", then serve some fat on the side in a way that you prefer.

### Ingredients

- 29g 80% lean ground beef, RAW
- 5g fresh tomato, cut into one chunk
- 3g iceberg lettuce cut the same size as the tomato
- 3g dill pickle, I used Bubbies brand
- 15g butter\* room temperature
- 7g olive oil
- 10g yellow mustard
- salt/pepper, garlic powder
- wooden skewer

### Directions

1. Soak wooden skewers in water for at least 30 minutes to prevent them from catching on fire!
2. Season the raw meat with salt, pepper, and a pinch of garlic powder. Press it onto the skewer into a ball making sure it is an even thickness around all sides. Carefully grill the meat until it is cooked thoroughly.
3. Skewer the lettuce, tomato, and pickle on the end of the skewer.
4. Mix the room temperature butter, oil and mustard together until it is well combined. You will need to use a fork or a small whisk to help the butter blend in. Serve the dip with the hamburger stick.

## Broccoli Slaw - 174 Calories 4:1 Ratio

A hamburger cannot be served without a side dish! This broccoli slaw is a different twist on regular coleslaw. The broccoli is raw, but you could lightly steam it to make the broccoli more mellow. Additionally, if pomegranate seeds are not available, use a little shredded apple.

### Ingredients

- 29g raw broccoli
- 15g Hellmann's Mayonnaise
- 7.6g pomegranate seeds
- 7g macadamia nuts, crushed into tiny pieces
- 2g cider vinegar
- 1g Truvia
- salt/pepper

### Directions

1. Wash the broccoli well. Cut the florets off the thick stem and break them into very small pieces.
2. Shred the stems using a shredder. Mix the stems and the florets together very well to evenly incorporate them. If you want to steam the broccoli, now is the time! Weigh the portion you need and then lightly steam.
3. Finish by mixing in the remaining ingredients and season to your liking.

It is best if you allow this recipe to sit overnight so all the flavors have time to blend together, and the broccoli has time to soften a little. The entire meal is a total of 427 calories and a 4:1 ratio. The broccoli slaw does not need to be served together.

Notation: casein-free if ghee is used in place of butter

# Keeping Safe During Summer



Warm weather brings exciting plans and activities! Visiting the beach, taking a hike on a new trail, or seeing your favorite band at an outdoor concert are all great options to enjoy your time. Summer also means a well-deserved break from the school year. This is a great opportunity for kids to unwind with friends, join a summer camp, or try a new hobby or sport.

Review these tips to avoid seizure triggers so that you or a loved one living with epilepsy stay safe when the temperature climbs and new activities begin.

1

**Take medications on time.** When traveling, make sure you continue to take your anti-seizure medication on time. Set a reminder on your phone or ask your loved one to keep track of the time if you frequently forget to take your medication. Travel with a pill organizer that is easy to access so you can take your medication along with you. If you are traveling somewhere that is in a different time zone, ask a healthcare provider about the best way to manage the time difference.

2

**Stay hydrated.** Bring a reusable water bottle along with you on any outdoor trips. Ideally, your water bottle should hold enough liquid to last the length of the trip.

3

## Talk to your neurologist about water safety.

Water activities and swimming hold an inherent risk for some people with seizures. Water precautions may vary depending on the type and frequency of seizures, and whether it is an adult or child. Some may be advised not to swim at all, whereas others may be allowed to swim with appropriate precautions and supervision.

4

## Wear a helmet.

For any activity that involves climbing or biking, be sure to wear a helmet in case of a fall. Stay away from trails that are too difficult and never climb or bike alone.

5

## Exercise safely.

Before starting any new exercise routine or sports this summer, check with your healthcare provider to make sure it is right for you or a loved one. If you can, exercise during the coolest parts of the day.



[Click here to find more information on how to manage seizure triggers](#)





## Words from an epilepsy warrior”

Epilepsy changed my life. I struggle every day worrying about having another seizure, but having epilepsy taught me one major lesson that I am sure other people with epilepsy understand: we can persevere through the darkest places to reach the light - and we won't stop fighting.

-- Tori Woods



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](https://www.epilepsy.com)