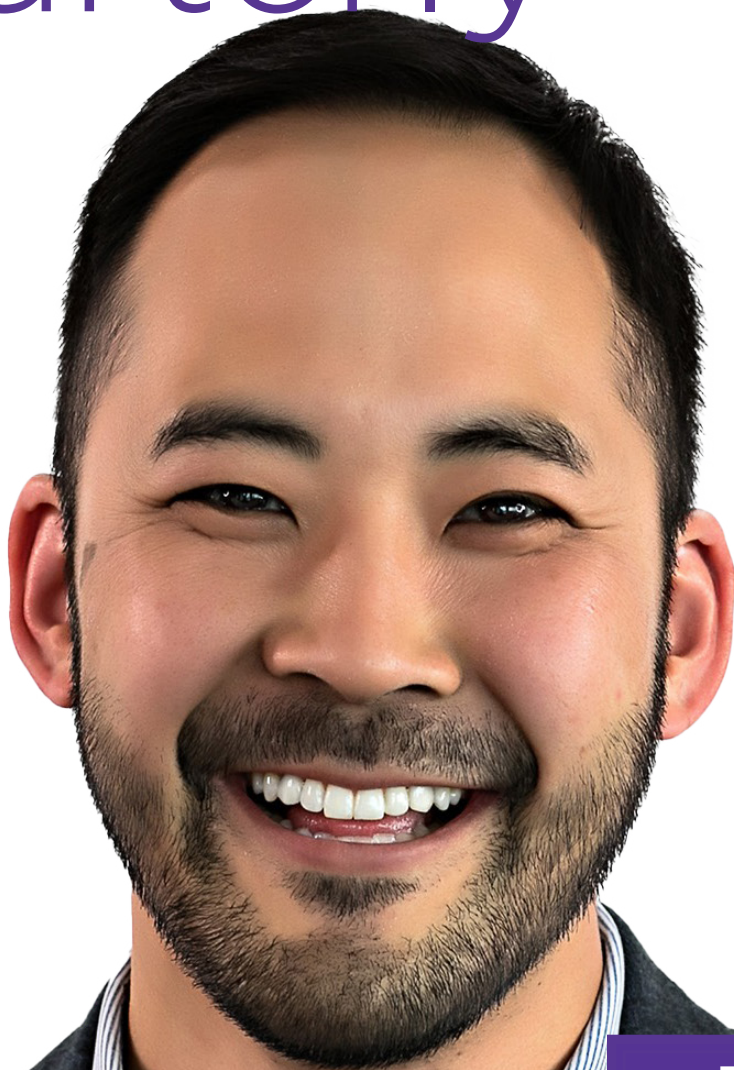


Foundation Quarterly



Blake Hamamoto
Local EF Board Chair
and Epilepsy Warrior

Our Purpose

+ In Your
Community,
News Briefs,
and Recipes

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Words from the Epilepsy Community

LETTER FROM THE CEO

The Epilepsy Foundation is here for you in your epilepsy journey.

Happy almost summer! Hard to believe we're almost half way through the calendar year, and what a great first half we've had. From launching our new Law Enforcement Seizure First Aid training and NeuroImpact Fund, to hosting Walks around the country and promoting epilepsy awareness, to working with legislators to create the Epilepsy Caucus – we have been making waves this quarter.

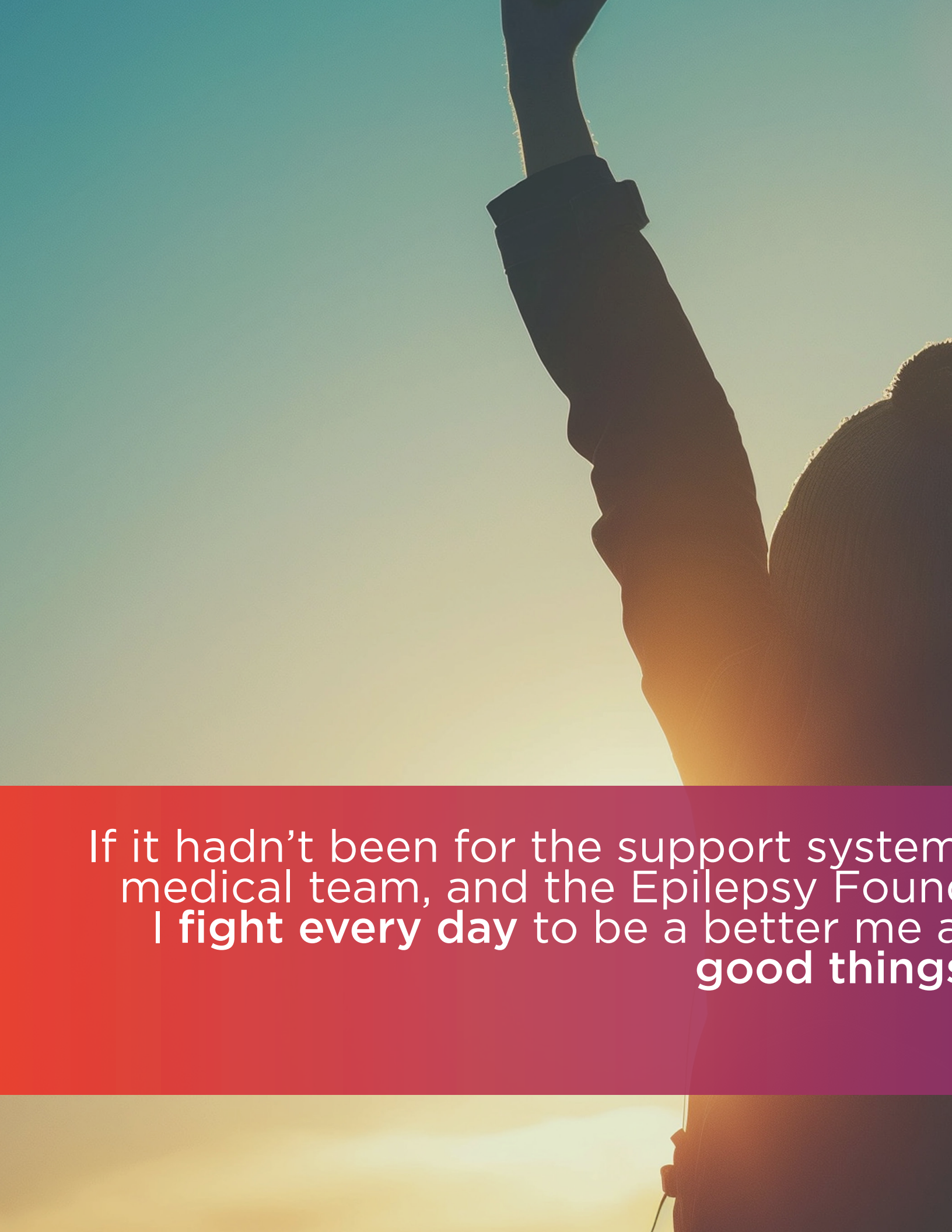
And so this issue highlights a few of the programs and initiatives offered by the Epilepsy Foundation which have had a huge impact on people in our community.

Read through Blake's story, whose role at one of the biggest global technology companies provided him with a platform to fundraise and get involved in our efforts while sharing his journey. Then there is Paula, whose epilepsy diagnosis as an adult turned her life upside, yet she rose above it all and is making an impact in her local community. And Greg, who is an early adopter of our new Law Enforcement training and has set out to train hundreds of other law enforcement officers in his region. Last but not least is Jillian, whose family partnered with the Epilepsy Foundation and other advocacy organizations to advance the legislative agenda and increase federal funding for the epilepsies.

These stories only scratch the surface of the many programs and resources we offer to our community. I hope you will join me in sharing these amazing journeys and continuing to advance the work that we do with our partners at the national and local level.



Bernice "Bee" Martin Lee
President & CEO,
Epilepsy Foundation

A silhouette of a person's arm raised against a sunset sky. The person is wearing a dark, long-sleeved shirt. The background is a gradient of colors from teal at the top to yellow and orange at the bottom, suggesting a sunset or sunrise. The person's arm is raised high, and the hand is near the top of the frame. The overall mood is one of hope and resilience.

If it hadn't been for the support system,
medical team, and the Epilepsy Found
I fight every day to be a better me a
good things

A silhouette of a person's arm and hand holding a rope, set against a background that transitions from a teal color at the top to a yellowish-gold at the bottom. The person's arm is on the left side of the frame, and the rope extends upwards from their hand.

n of my family and significant other, my
dation, I'm not sure where I would be.
and remember that on the bad days,
s will come.

- Emily Marzini



Championing **Epilepsy** **Awareness** at the **Corporate Level**

By: Jacqueline Aker

He had his first seizure in second grade and didn't tell anyone, keeping it hidden for years for fear of the unknown. It wasn't until he had a seizure in 9th grade during PE that his seizures came to light.

For Blake Hamamoto, growing up with seizures was scary, especially when he began having more than 30 a day. He has focal onset aware seizures; the right side of his body is somewhat paralyzed, his arm is pulled in and his speech is slurred. His PE teacher noticed he was experiencing a seizure during a routine fitness test and sent him to the school nurse. Soon after, his parents took him to the local hospital where he underwent testing. At first, doctors thought it was a heart condition and he was evaluated for such, but they eventually realized it was not heart-related and he was referred to a neurologist.

"The first neurologist I visited was dismissive and attributed what I was experiencing to stress," he said. "My parents were not satisfied and advocated for a second opinion. "I visited a second neurologist who immediately knew I was experiencing seizures. They performed more tests, brain scans and did a stay at a sleep monitoring unit, but they did not find anything conclusive. It wasn't until I experienced a seizure in front of the doctor that I was officially diagnosed."

Fortunately for Hamamoto, the first anti-seizure medication he was put on to control his seizures has kept his seizures at bay, to this day. But his journey hasn't been without its share of challenges. At first, it took him a while to get adjusted to the right dosage of the medication, which had side effects. When it came time to get his driver's permit, he had to wait to be free of seizures for at least one year to get his license. Then in college, his doctor tried to wean him off the medication with no success.

By then, he had been accepted to Loyola Fast forward 20 years, and not only is he able to drive now that he is seizure-free with medication, but he's no longer "hiding" his epilepsy. He has embarked on efforts to educate his colleagues at one of the largest technology corporations in the world about epilepsy and seizures.

"When I started at Microsoft, not many people were aware I had epilepsy," said Hamamoto. "It wasn't something that I talked about much, in part because my seizures didn't really impact my life. But Microsoft's annual Giving Campaign was coming up and I wanted to do something different and personal. I had just attended Microsoft's Ability Summit, and hearing others' stories living with varying disabilities, I decided to share my own experience and tell my teammates all about my epilepsy."

In addition to sharing his story with colleagues, Hamamoto also advocated for an epilepsy-focused community within Microsoft. While there were many neurodiversity groups for various disorders, at that time there wasn't one for people with epilepsy.

"I went on a mission to build this community, and though it was no easy task to find people within the organization living with seizures, an epilepsy-specific group eventually got established," he said. "I began by telling my story which led to people within the company reaching out to me from around the globe wanting to learn more or sharing their own experiences. I also wanted my teammates to know what to do in the event I had a seizure, so I shared seizure first aid information with them."



Several Microsoft employees taking Seizure First Aid training
Photo courtesy: Epilepsy Foundation Washington

Beyond the neurodiverse community for epilepsy he helped create, Hamamoto has also hosted informational events and seizure first aid training workshops for his colleagues. In 2020, Hamamoto partnered with the Epilepsy Foundation Washington to train more than 200 employees in Seizure Recognition and First Aid and raised funds, which Microsoft matched, from every hour each employee spent in the training.

Today, Blake is chair of the Epilepsy Foundation Washington Advisory Board and continuing to promote awareness efforts beyond Microsoft.

"One of the things I often hear from people is that they don't want to disclose their epilepsy for fear they would be treated differently if they told their manager they have seizures. That's why my goal is to bridge relationships between the Epilepsy Foundation and other corporations in the area so that we can continue to advance epilepsy awareness and find solutions for families impacted by epilepsy."



Learn more about your local Epilepsy Foundation at epilepsy.com/local



Hamamoto (center) with Epilepsy Foundation CEO, Bee Martin Lee (right)
Photo courtesy: Epilepsy Foundation Washington

Maximize your impact with Smart Giving!

The Epilepsy Foundation provides essential programs and services to the 3.4 million people in the U.S. who are living with epilepsy. You can support our mission without any direct impact on your bank account through our Smartgiving suite of resources, provided at no cost to you in partnership with FreeWill. Certain gifts may even qualify for tax savings, enhancing the impact of your contribution. By donating non-cash assets, you can help us improve the lives of people affected by epilepsy through education, advocacy, research, and connection.



Smart giving includes:

- Stock and Securities
- Donor-Advised Fund (DAF)
- Qualified Charitable Distribution (IRA DONATION)
- Cryptocurrency

SCAN ME



freewill.com/smartgiving/epilepsy

Finding My Strength

By: Colby Aguayo



Epilepsy caused a significant turning point in my life. It all started when I was 13 years old. I had my very first seizure around midnight on my little brother's 7th birthday. It was a tonic-clonic seizure. While I didn't think I was going to make it, it was my brother who saved me. He alerted my parents when he woke up and heard that I was choking. It was the scariest thing I have ever experienced. I remember waking up crying in the emergency room. It was then that I was diagnosed with juvenile myoclonic epilepsy (JME), and everything changed.

I have always felt different from everybody else, being misunderstood and judged since my diagnosis. A lot of kids were embarrassed to be seen with me and didn't want to have anything to do with me simply because I had epilepsy. I was alone. It didn't help when I was partially paralyzed due to my seizures. I couldn't walk properly, and it kept me from playing the sports I loved: football, cross-country, as well as track and field.

My inability to walk made it even more challenging for me to live an everyday life, and I was already struggling to make friends. I was bullied a lot when I was younger. My grades suffered because I couldn't focus on my classes, and I would get easily frustrated when I couldn't do as well as the other kids. I was afraid of failure. Yet, I had a sunny disposition about my situation, even though people would look at me as if I was crazy or weird.

I knew I wouldn't go down without a fight. I stayed true to myself and stuck close to the

people I trusted with my feelings and lifestyle. In school, I always made sure my teachers were aware of my situation and communicated with them whenever I needed help. I knew I could count on them for assistance if I needed more time to work on an assignment, tutoring, or to open up about my feelings.

I did physical therapy for two months, and after those two months passed, I could use my legs again. I felt stronger than ever. Although I couldn't continue playing football, that didn't stop me from doing cross country, and track and field. I ran like the wind! I won two district championships during my sophomore and senior years in high school — one in cross country and the other in track and field.

At 14, I hit a year of being seizure-free. My mom found a summer event called "Camp Candlelight" offered by the Epilepsy Foundation in Arizona. I was nervous about going, but in the end, I was glad I did. I met some of my best friends at camp that year. I've been going to Camp Candlelight every year, first as a camper and now, a counselor.

Today, I am a sophomore at Grand Canyon University studying digital filmography, hoping to pursue a career in acting, filmmaking, writing, and creating content for YouTube. Although I did not have a normal childhood and teenage life, I do not regret my life now.

Epilepsy is not going to stop me as I am striving for greatness. I thank God for the strength to keep moving forward to live fully.

I knew
I wouldn't go
down without
a fight.

I stayed true
to myself and
stuck close to
the people I
trusted with
my feelings
and lifestyle.



A Guiding Light for Change

By: Jacqueline Aker



Nicolas during an EMU visit, Photo courtesy of the Copeland family

Imagine having to establish a school for your child because you could not find one that catered to people with epilepsy and other disabilities. Or building an apartment complex to ensure your son could live independently as an adult in a place that addressed his special needs. Jillian Copeland and her husband did just that.

The Copeland's son, Nicolas, began having seizures when he was 8 months old. His seizures lasted for hours and required hospitalization. For years, the family tried a variety of treatments, including brain surgery, but the frequency and severity of his seizures continued. Nicolas also began experiencing other hurdles, such as developmental delays, sensory issues, and anxiety. When it came time for him to start school, Copeland began searching for a school that addressed Nicolas' unique needs with language, learning and social development. They also tried different learning interventions, as well as behavioral and occupational approaches, but there was nothing out there for children like Nicolas.

"Schooling was certainly a challenge; teachers and school administrators did not understand the life impact of epilepsy or neurodiversity," said his mom, Jillian. "We felt Nicolas needed a specialized school where people were accountable and could be trained on sensory behavior protocols and seizures. There was nothing like that anywhere. The metropolitan area lacked programs that would offer an academic experience while providing kids like Nicolas, practical social and developmental growth."

Not having any options for what Nicolas needed, worked with educational and developmental experts around the country to create a program for children with learning differences and establish the Diener School in 2007. It was a game changer. The school started with five students and trained educators who were trained to understand social thinking, multi-sensory learning, and celebrate all the attributes of students with special needs. The Diener School still thrives today serving 75 students and moving to a home of their own in September in Bethesda, MD.

Schooling was certainly a challenge; teachers and school administrators did not understand the life impact of epilepsy or neurodiversity.

Nicolas attended the school for 6 years, and then moved on to middle and high school. Although he was still struggling with seizures and a few other developmental challenges, Nicolas accomplished many things that his doctors initially said he would never be able to do.

But as Nicolas moved into adulthood, Copeland turned her attention to housing and community engagement options for him. Again, she found that there weren't many inclusive, independent living options, if any, for young adults with cognitive issues and developmental challenges. The Copelands once again set out to fill the gap for Nicolas and in 2017, Mainstreet was born. Mainstreet is an inclusive, affordable, accessible housing complex and membership community center in Rockville, Maryland for adults of all ages and stages in life. The universal design of the building and programming is inclusive for adults with epilepsy and other disabilities who reside at Mainstreet and/or join the center's weekly activities.



“While there have been so many breakthroughs in therapeutics and devices for people with epilepsy in the last 20 years, one area where we have not been able to move the needle is the impact of epilepsy on young adults,” she said. “Similarly, the demand of living and community engagement for adults with disabilities, many of whom have epilepsy, is also limited. There is a huge need to provide a space for all adults to belong, to connect with each other and the broader community, to live independently and thrive together.”

Mainstreet’s housing complex has one-, two-, and three-bedroom apartments with 110 residents. It also has a café that employs people of all abilities, a large family room and kitchen, an art gallery and classroom, and a wellness center. Nicolas was Mainstreet’s first resident, and it has resulted in significant improvement in overall quality of life and psychological wellbeing for him and other people with epilepsy and for others with and without disabilities. But the Copelands didn’t stop there.

They are also focusing on advocacy. Their group, the Epilepsies Action Network, seeks to advance national policies and programs to improve the lives and outcomes of those living and struggling with the epilepsies. They have joined the Epilepsy Foundation and other partner organizations in raising awareness about and urging increased investment for epilepsy-related government programs.



Left: Nicolas (third from left) with his brothers, Above: Nicolas with his mom, Photos courtesy: The Copeland Family

“It’s time to better understand this challenging condition, support those with epilepsy and to provide successful patient outcomes,” said Copeland. “Nicolas is our greatest gift. He lives his life with positivity and is a light for us. We use his light to guide us. Epilepsy doesn’t have to take us down. Together with partner epilepsy organizations and advocates, we hope to be change makers. Together, we can change lives and celebrate people with epilepsy around the world.”

Nicolas is our greatest gift. He lives his life with positivity and is a light for us. We use his light to guide us.

GIVE US A CALL



WE'RE HERE TO HELP

The **Epilepsy & Seizures 24/7 Helpline** has **trained information specialists** standing by to answer your questions about epilepsy and seizures and provide you with **help, hope, support, guidance,** and **access** to national and local resources.



Phone (English): 1-800-332-1000
(en español) 1-866-748-8008
[epilepsy.com/Helpline](https://www.epilepsy.com/Helpline)



Interpreters available for more than 200 languages



A Force in the Community

By: Jacqueline Aker

Her life was turned upside down when she began experiencing seizures at 30. But instead of feeling sorry for herself, she re-directed her energy to help others battling seizures.

A single mom, Paula Moreland, experienced two seizures while driving, but she has no memory of it. Her family suggested she see a specialist to find out what was causing the seizures. She underwent diagnostic procedures, including brain surgery, and was in the hospital for a month in an induced coma. The cause of her seizures is still unknown, but doctors believe it may have been the result of a previous car accident.

“I had an almost 3-year-old baby, and I worked in the corporate world,” she said. “But after the procedure, I lost my independence. I couldn’t drive to work and had to rely on public transportation to get to and from places. I became depressed. Fortunately, my

family jumped in to help, especially my mom and sister.”

Dealing with her diagnosis, the changes to her lifestyle and not having control of her own life, was a lot for her. She was prescribed anti-seizure medications, but they did not control her seizures. Her doctor referred her to an epilepsy self-management program offered at Morehouse School of Medicine (Atlanta) to help improve her mood and quality of life. Her sister, and the rest of her family, also educated themselves on seizure first aid so that they could assist Moreland during a seizure and help alleviate some of her anxiety. A year later, her doctor told her about a clinical study for a device that would deliver deep brain stimulation to the part of the brain where the seizures originated.



Advocate Public Policy Institute visit with Congressman Hank Johnson Feb. 2024; Photo courtesy of Paula Moreland

She's very active in her local community, volunteering at local schools and the Rockland County Sheriff's Department, participating in community events, and presenting at nursing school career fairs. She has even written and directed gospel plays at her church, and has appeared as an extra in the film, "Selma".

"My mom always told me: 'don't pity yourself, you need to forge on and do more in life,'" said Moreland. "It has been a journey, but I've been supported by a ton of people in my community, my daughter, sister, and local leaders. Instead of pitying me, they're using my energy and my story to promote awareness and advocate for people with epilepsy. My mom would be proud."

"This experimental treatment sounded scary and risky to me, but I decided to enroll in the trial," she said. "I had the device implanted and it affected my short-term memory. I couldn't remember things that had just happened, but I could remember things from years ago. But in the end, the device has helped decrease the frequency of my seizures. Now I only have one from time to time."

With her seizures somewhat controlled, and her depression behind, Moreland set out to help others in similar situations. She joined the Epilepsy Community Advisory Board at Morehouse and co-facilitated programs to offer resources, information, and support to people with epilepsy. She has participated in the Epilepsy Foundation's Public Policy Institute to receive advocacy training. She's met with elected officials to discuss issues to discuss issues affecting people with epilepsy in Georgia, including veterans, cost of medications and access to epilepsy care. She also collaborated with the family who helped pass Seizure Safe Schools legislation, AJ's Law, in the state.



Dr. Paula Moreland received her Honorary Doctorate in May 2023, Photo courtesy of Paula Moreland



We take action together.

Join us this spring:

Santa Barbara, California • Iowa City, IA •
Lawrence Township, NJ • Louisville, KY • Dayton, OH •
Greenville, SC • Lexington, KY • Madison, WI •
Denver, CO • Paducah, KY • Portland, OR • Salt Lake City, UT •
Owensboro, KY • Seattle, WA • Appleton, WI

Walk to
END EPILEPSY
EPILEPSY FOUNDATION

Register. Create a team. Donate.
WalktoEndEpilepsy.org/Locations

In Your Community



Epilepsy Advocates Advance Key Policies During Day on Capitol Hill

The Epilepsy Foundation recently hosted its annual signature advocacy event, the Public Policy Institute (PPI), culminating with Capitol Hill Day. This year's event focused on bringing to Washington, D.C., the Foundation's Epilepsy Advocacy Champions, a grass-tops volunteer program that the Foundation launched in 2020. These advocacy volunteers include people living with epilepsy, caregivers, healthcare providers, and researchers. Participants received legislative training and met with more than 105 congressional offices to share their experiences and advocate on behalf of the epilepsy community.

Read more:

<https://www.epilepsy.com/stories/epilepsy-advocates-advance-key-policies-on-capitol-hill>



professionals taught the new Law Enforcement Informed Training to equip law enforcement with the tools needed to respond effectively when they encounter someone having a seizure. In addition, the team also attended the American Association of Neuroscience Nurses Annual Conference in Salt Lake City, Utah to provide resources and train more than 80 attendees to become Seizure First Aid certified.

Educating Students about Seizures in New Jersey

Alyssa Lovill, executive director of the Epilepsy Foundation in New Jersey, and Adelyn, Teens Speak Up! Representative, shared information about epilepsy and seizures at a community school in Perth Amboy, New Jersey. More than 100 students from Middlesex STEM Charter school participated in the sessions and learned

how to be a helpful peer when someone is having a seizure. Adelyn shared her journey with epilepsy and demonstrated STAY, SAFE, SIDE Seizure First Aid.



Making Communities Safer with Seizure First Aid Trainings

The Epilepsy Foundation recently participated in the Commission on Accreditation for Law Enforcement Agencies, Inc. (CALEA®), conference in Montgomery, Al. At this conference, our trained Seizure First Aid

Epilepsy Foundation Washington's Gala Sets a New Fundraising Record

The Epilepsy Foundation Washington's annual "Light the Flame" Gala raised a record \$365,000 to support programs and services offered throughout the state.





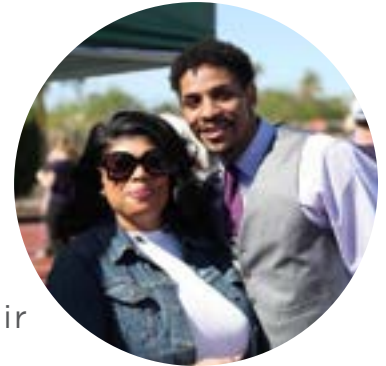
Championing Seizure Safe Schools Legislation

Local chapter board members and advocates in Mississippi recently attended a Seizure Safe Schools Bill Advocacy Day at the Capitol alongside Epilepsy Foundation Mississippi and the bill champions, Rep. Jill Ford and Sen. Nicole Boyd. Legislators were informed about the importance of the legislation and heard from various advocates, including Miss Mississippi Vivian O’Neal, Vicksburg Mayor George Flagg, and Mississippi State Women’s Basketball Coach Corry Irvin, who shared why Mississippi needs to be a seizure safe state. Excitedly, Governor Tate Reeves signed Mississippi’s Seizure Safe Schools bill, H.B. 346, into law in early May! The Foundation congratulates all advocates, partners, stakeholders, and legislators who worked diligently to get this bill across the finish line.

Additionally, several advocates attended the Iowa Seizure Safe Schools Advocacy Day at the Iowa State Capitol to educate legislators on HF 608. Adults, teenagers, and children with epilepsy shared how epilepsy has impacted their lives and why Seizure Safe Schools legislation is important to them.

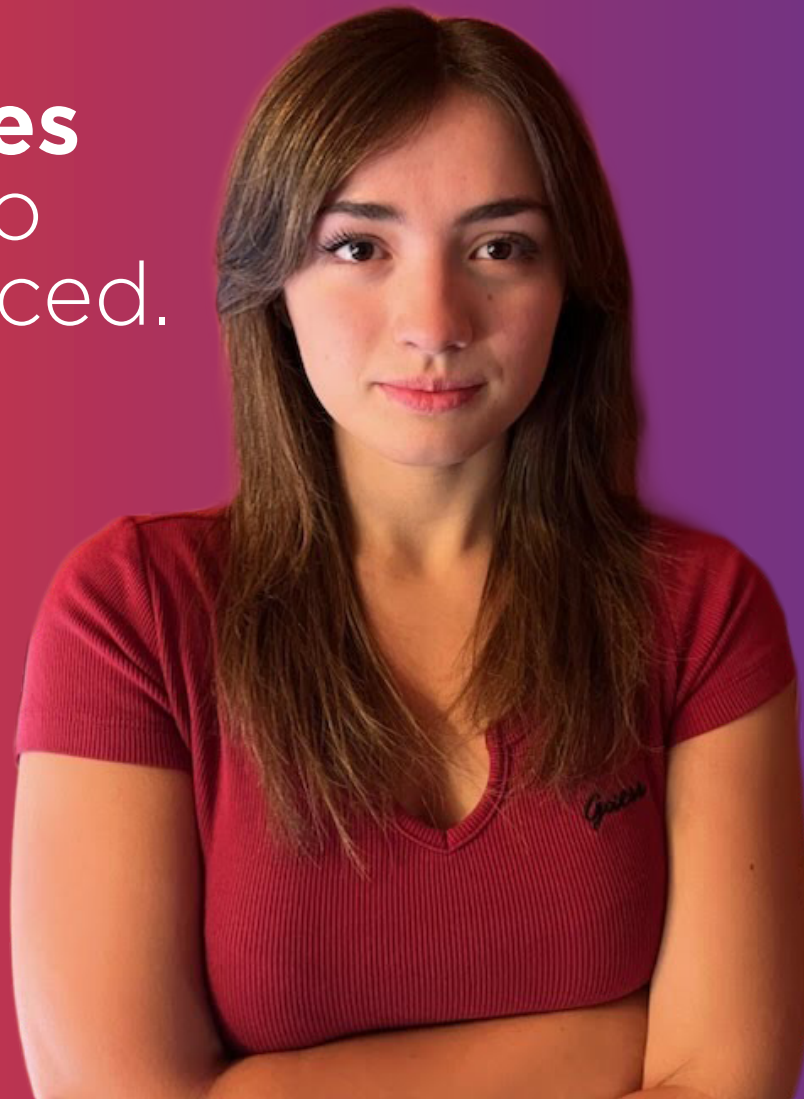
Hundreds Gather for the Walk to END EPILEPSY® in Arizona and Oklahoma

Arizona’s Walk to END EPILEPSY featured approximately 700 participants who walked in honor of their loved ones with epilepsy. With their support, the Epilepsy Foundation in Arizona raised more than \$120,000. Bernice Martin Lee, chief executive officer, the Epilepsy Foundation, kicked off the walk, and epilepsy advocate Marcus Ball, Arizona State University alumni and PAC 12 athlete, shared his journey with epilepsy.



While in Oklahoma, the Walk to END EPILEPSY was the biggest yet since the pandemic with more than 270 participants and 29 fundraising teams who raised approximately \$33,000. Participants included several neurologists, nurses, staff, and their families from Oklahoma University Health Epilepsy Center, INTEGRIS Health, and Bethany Children’s Health Center; as well as 2024 Miss Oklahoma City who shared her epilepsy journey.

**My
seizures
may go
unnoticed.**



**My
epilepsy
story
will not.**

#ChangeOurEpilepsyStory

Change Our Epilepsy Story is an awareness campaign. The campaign encourages our community to start talking about their epilepsy and seizures so that others will be empowered to seek help. If we keep sharing our stories about epilepsy, we can educate those around us, and in turn, address the misconceptions and lack of awareness that exists about epilepsy and seizures.



ChangeOurStory.org
1.800.332.1000

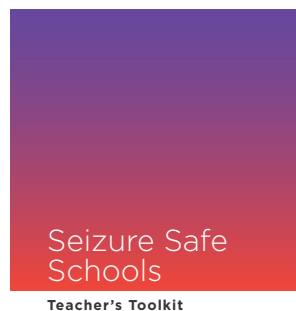


NEWS BRIEFS

News that matters to our community

Venture Philanthropy Fund Supports Development of New Therapies & Devices

The Epilepsy Foundation and Iaso Ventures recently established the NeuroImpact Fund to advance therapies, diagnostics, and digital health tools that address unmet needs in epilepsy care. This partnership brings together expertise in healthcare innovation and venture capital to accelerate the development of promising technologies and redefine epilepsy treatment paradigms. The NeuroImpact Fund will serve as the primary source of funding to help accelerate therapies and improve the lives of people living with epilepsy.



Seizure Safe Schools Teacher's Toolkit Now Available



The Epilepsy Foundation recently introduced a new Seizure Safe Schools toolkit to empower teachers in delivering successful seizure recognition and first aid training in the classroom. This toolkit includes an epilepsy overview, classroom resources, and PowerPoint presentations. Additionally, school teachers also have access to the Epilepsy Foundation's online training portal, a platform to help them learn more about epilepsy and seizures.



Learn more: www.epilepsy.com/stories/epilepsy-foundation-partners-iaso-ventures-launch-neuroimpact-fund



Access the Toolkit: https://www.epilepsy.com/sites/default/files/2024-03/EF_SFA_Teacher_Toolkit.pdf

News Briefs compiled by Kaitlyn Gallagher

Free Mobile App Can Be Early Warning System for Seizures

Developed by a group of Microsoft employees as part of the Microsoft Global Hackathon, MirrorHR® – Epilepsy Research Kit for Kids, is a mobile app for Apple iPhone that can be connected to an Apple Watch wearable device to send alerts to parents when a child is experiencing irregular heart rate which may indicate seizure activity. MirrorHR uses biometric data artificial intelligence to capture, process, and monitor data for signs of an imminent seizure. These alerts help parents tend to their child before a potential seizure occurs. Roberto D’Angelo’s 13-year-old son, Mario, has experienced seizures since the age of 3. He was born a preemie and was diagnosed with a massive brain stroke at 10 days of age. Since Mario began having seizures, his quality of life, and that of D’Angelo’s and his wife, began taking a toll. D’Angelo felt there was a need for an app that could help them monitor their son’s sleep in case a seizure occurred. In 2019, D’Angelo leveraged the Hackathon to engage a few of his global colleagues to create MirrorHR; the project won the Global Prize. Today, with the support of community of parents, MirrorHR is now operated and maintained by the FightTheStroke, Foundation a nonprofit organization that D’Angelo and his wife founded in 2014.



MirrorHR is available at MirrorHR – FightTheStroke: <https://www.fightthestroke.org/mirrorhr-eng>

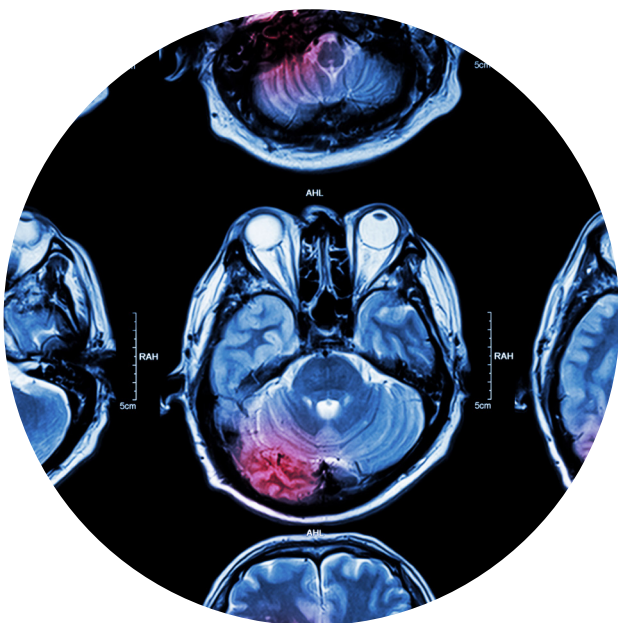
Note the app is not a Microsoft product and there is no affiliation between MirrorHR and Microsoft.

Promising Research on a New Treatment for Epilepsy

Researchers at Stanford University have developed a new treatment for epilepsy using a method called low-intensity focused ultrasound pulsation (LIFUP). This technique targets specific areas of the brain involved in seizures without the need for surgery. In experiments with mice, LIFUP successfully reduced seizure activity without causing harm to brain tissue. The ultrasound waves change how brain cells behave, disrupting the abnormal activity that leads to seizures. This discovery could lead to safer and more effective treatments for epilepsy in humans, offering an alternative to surgery or medication for managing this condition.



Read more: <https://med.stanford.edu/news/all-news/2024/04/epilepsy-treatment.html>



CALENDAR OF EVENTS

Check Out What's Happening Around Town

Arizona

Epilepsy Foundation
Arizona



Camp Candlelight 2024

Jun 16 - Jun 21, 2024
Payson, Arizona

Camp Candlelight is an overnight, safe, and secure camp experience for youth and teens with epilepsy. Campers gain a greater understanding of their own epilepsy diagnosis and treatment. Our Camp programs intentionally develop peer-to-peer support, increase independence and self-confidence, and foster a sense of belonging. Campers will discover new skills and interests and develop the skills they need to advocate for themselves.

Learn more here:
www.epilepsy.com/events/2024/camp-candlelight-2024

California

Epilepsy Foundation
Los Angeles

Epilepsy Summer Camp

Jul 24, 2024 - Jul 28, 2024

Epilepsy Foundation Los Angeles invites children ages 7-16 years old to the Epilepsy Summer Camp at The Painted Turtle during the Special Diagnoses Summer Session, June 24-28. Campers

with the primary diagnosis of epilepsy are invited to make new friends in a supportive environment. Join other campers with epilepsy, and return home with new friends and a life-changing experience.

Learn more here: <https://epilepsylosangeles.org/elfa-event/summer-camp/>

Michigan

Epilepsy Foundation
Michigan



Paul Neu Memorial Golf Classic

Mon, Jun 24, 2024, 1 - 7 p.m.,
Byron Center, MI

Each year, Paul's family and friends honor his memory by working together for a cause he loved while participating in a sport he loved. Paul believed in the mission of the Epilepsy Foundation of Michigan and its educational programs, outreach efforts, summer camp experiences for children with epilepsy, and above all, the hope for a cure. We hope you will join us in support of this worthy cause while celebrating Paul's life. Participating and/or sponsoring this event will provide you with a variety of value-added and offer excitement and comradery to all that attend.

Learn more here: <https://www.epilepsy.com/events/2024/paul-neu-memorial-golf-classic-byron-center-michigan>

Family Camp

Fri, Jul 19 - Sun, Jul 21, 2024,
Pinckney, MI

Carefully crafted for families in Michigan with children aged 17 years or younger who are living with epilepsy, as well as their family members residing in the same household. Family Camp is designed to create a nurturing environment where unity thrives. Our paramount goal is to offer a unique opportunity for families to step outside of their typical daily routines, recharge, nurture family relationships, and create lasting memories together. Moreover, camp provides a platform for special connections with other families who share similar experiences.

Learn more here:
www.epilepsy.com/events/2024/family-camp-michigan

Massachusetts

Epilepsy Foundation
New England

Golf Tournament To Benefit EFNE

August 9, 2024
Plymouth, MA

Join us to benefit Epilepsy Foundation New England in the fourth Annual Creative Wealth Golf Tournament held at the Southers Marsh Golf Club in Plymouth, MA. Registration includes cart & green fees and dinner. Enjoy the putting contest and other on-course contests throughout the day.

Learn more here:
epilepsynewengland.org/events/2024-08-09/golf-tournament-to-benefit-efne

Oregon

Epilepsy Foundation
Oregon

Camp Discovery - Oregon

Wed., July 31 - Sat., August 3,
2024, Rockaway Beach, OR

Camp Discovery is an annual summer camp where children experience archery, rock climbing, canoeing, hiking, swimming, arts/crafts, campfire games and much more. Thanks to our sponsors and generous donors, Camp Discovery is free of charge to all campers living with epilepsy and one sibling. Additional siblings may attend for a minimal charge of \$150 per sibling. Volunteer opportunities are also available.

Visit epilepsy.com/Oregon for registration information.

Washington

Epilepsy Foundation
Washington

Camp Discovery - Washington

Wed., July 31 - Sat., August 3,
2024, Rockaway Beach, OR

Camp Discovery is an annual summer camp where children experience archery, rock climbing, canoeing, hiking, swimming, arts/crafts, campfire games and much more. Thanks to our sponsors and generous donors, Camp Discovery is free of charge to all campers living with epilepsy and one sibling. Additional siblings may attend for a minimal charge of \$150 per sibling. Volunteer opportunities are also available.

Visit epilepsy.com/Washington for registration information.

Nationwide

Seizure Recognition and First Aid Certification Trainings

- in English

June 4, 2024, 4 p.m. ET

Register at
<https://learn.epilepsy.com/courses/SFA-Cert-ILT-v2>

- en español

June 20, 2024, 1 p.m. ET

Register at
<https://aprende.epilepsy.com/courses/cert-crisis-epil-envivo-v1>

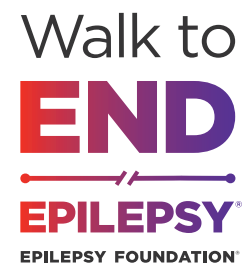
Support Groups

Ongoing



Whether you're facing tough times managing epilepsy or seeking connection with others who understand, know that you are not alone! The Epilepsy Foundation provides a range of in-person and virtual support groups for young adults, parents, caregivers, and siblings affected by Sudden Unexpected Death in Epilepsy (SUDEP). Explore our support groups to find the right fit for your journey.

Find a support group here:
https://www.epilepsy.com/events?f%5B0%5D=event_type%3A33196



Spring into action
for epilepsy awareness!

Get ready with
your team and join
a Walk to END Epilepsy®
event in your area.

June 1, 2024

Santa Barbara (California)
Iowa City (Iowa)
Lawrence Township
(New Jersey)
Louisville (Kentucky)

June 2, 2024

Dayton (Ohio)
Greenville (South Carolina)

June 8, 2024

Lexington (Kentucky)
Madison (Wisconsin)

June 9, 2024

Denver (Colorado)

June 15, 2024

Paducah (Kentucky)
Portland (Oregon)
Salt Lake City (Utah)

June 22, 2024

Owensboro (Kentucky)
Seattle (Washington)

August 18, 2024

Appleton (Wisconsin)

**Find your walk:
[walktoendepilepsy.org/
locations](https://walktoendepilepsy.org/locations)**



Fresh Flavors of Spring Featuring Berries

compiled by Sara Wyen

Embrace the season with vibrant and flavorful recipes that are certain to delight your tastebuds.

Recipes courtesy of Nutricia/KetoCal®



Click here for more recipes
by Nutricia/KetoCal®

KetoCal Strawberry Smoothie (3:1)

Ingredients

- 200 g Ketocal 4:1 LQ (Vanilla or Unflavored)
- 34 g frozen strawberries

- Optional: Carbohydrate-free sweetener to taste
- Ice cubes

Directions

1. Place the Ketocal LQ, strawberries, and optional sweetener and ice cubes into a blender.
2. Blend for approximately 1 minute (or until the mixture is smooth)

Nutrition Information (for entire recipe):

Calories: 307
Fat: 29.7 g
Protein: 6.3 g
Carbohydrate: 3.6 g
Ratio: 3:1

KetoCal Cinnamon and Blueberry Toast (3:1)

Ingredients

- 30 g Ketocal 3:1 powder
- Optional: carbohydrate-free sweetener, to taste
- 20 g blueberries, frozen, unsweetened

- 16 g butter
- 15 g eggs, raw, well mixed
- 15 g (mL) water
- 2 g baking powder

Directions

1. Preheat the oven to 350°F
2. Mix the Ketocal 3:1 powder with water, baking powder, egg, and optional carbohydrate-free liquid sweetener in a bowl
3. Melt the butter and add to the mixture
4. Chop the blueberry into small pieces and add to the mixture
5. Place to mixture on to a sheet of

baking/parchment paper

6. Spread out thinly in to a 6" square

7. Cook at 350°F for 8 minutes or until golden brown

Nutrition Information (for entire recipe):

Calories: 307
Fat: 29.7 g
Protein: 6.3 g
Carbohydrate: 3.6 g
Ratio: 3:1

Please remember, the ketogenic diet should only be used under close medical supervision. Always check with your healthcare provider before making any keto recipes.

Is it a Seizure or Disorderly Misconduct?

By: Jacqueline Aker



When a law enforcement officer encounters someone having a seizure, knowing the difference between a seizure and disorderly misconduct could mean the difference between life or trouble with the law.

Seizures often go unrecognized by law enforcement officers. It is not unusual for the police to fail to recognize that a seizure is occurring, has occurred, and/or that someone might be in a state of post-seizure confusion. And among those who do recognize a seizure, they may not know how to respond appropriately.

It is very common for a person experiencing a seizure to have a period of confusion, dazedness, and lack of awareness following the seizure. This impacts the person's ability to respond to directions or commands and behave in unusual ways. Unfortunately, this sometimes results in police mishandling of the seizure, and the person with epilepsy facing arrest, and at times, criminal charges.

"As a 30-year law enforcement officer, I have seen many people experience seizures and come out of a seizure while I was in the field," said Officer Greg Byers, who leads Learning & Development for the Southeastern Louisiana Area Health Education Center (AHEC). "It was confusing at best, unless there was a family member present to inform us that the person was having a seizure."

The Epilepsy Foundation receives hundreds of calls each year about negative encounters with law enforcement officers during or post seizures. In response, the Foundation recently launched a Law Enforcement Informed Training for Recognizing and Responding to Seizures. The goal is to protect the health and safety of those living with epilepsy when they may not be able to respond to a law enforcement officer's request. The training aims to help public safety professionals better understand epilepsy and increase their knowledge about seizures.

"Sometimes a person's behavior during or after a seizure may be misinterpreted if the officer on the scene is not aware of the signs of a seizure, especially if the person is resisting arrest," said Byers. "That is why this law enforcement training is so important. The training will enhance an officer's knowledge of seizures and help tell

the difference between a person experiencing a medical episode and person under the influence."

For Byers, seizure first aid is not just another training course, it is also personal. One of his cousins, also a law enforcement officer, experienced uncontrolled seizures for years. So when the Epilepsy Foundation approached AHEC to collaborate on the design and implementation of the law enforcement training, he jumped at the opportunity to become an instructor and train other officers on the course.

The training educates officers on how to **enhance the outcomes** for a person experiencing a seizure and **engage** the person post seizure.

"I am a licensed emergency response medic, certified in Seizure First Aid, and teach emergency response programs in rural parts of Louisiana, so this law enforcement training fits perfectly with the work I do," said Byers. "The training educates officers on how to enhance the outcomes for a person experiencing a seizure and engage the person post seizure. So far, officers I've connected with on the training tend to be early adopters as some have family members with epilepsy."

The Epilepsy Foundation recognizes the value of police-community relations, and is partnering with law enforcement professionals, departments, and agencies to equip law enforcement with the knowledge and tools needed when responding to critical incidents involving seizure recognition and response.



To become an instructor or to host a law enforcement training with your department, visit epilepsy.com/lawenforcement.



Words from the epilepsy community

When I was researching epilepsy and how I could help my sister and others enduring the pain and suffering of epilepsy, I came across the Epilepsy Foundation, which changed my life forever. Not only was I able to get accurate information about epilepsy and its effects on people and their families, but I was able to become Seizure First Aid Certified. In doing so, I become more aware of how to help my sister and others around me.

-- Lauren, Epilepsy Warrior



The mission of the Epilepsy Foundation is to improve the lives of people affected by epilepsy through education, advocacy, research, and connection.

Learn more at epilepsy.com