

Foundation Quarterly

Lisa Lindahl,
Inventor of the
Jogbra and
Epilepsy Warrior

The Women Issue

+ In Your
Community,
News Briefs,
and Recipes
for Spring

LETTER FROM THE CHIEF OUTCOMES OFFICER

Happy Spring!

Welcome to spring and our Women's Issue! We recently celebrated women as part of Women's History Month and International Women's Day in March. And, as we head into May, we will be celebrating Mother's Day, which is why our spring issue is focused on women.

We feature four women from different walks of life: young Christina Conti who recently competed in Miss New Jersey USA 2023 pageant and lives with epilepsy. We also learn from pediatric neurogenetics specialist Dr. Xilma Ortiz-Gonzales about how genetics can influence treatment decisions. The personal essay featured in this issue is written by journalist Faith Brar, who first chronicled her journey with epilepsy in 2020 with a story she published in Shape magazine.

Last, but not least, our cover story features entrepreneur, book author, and person with epilepsy Lisa Lindahl. Lindahl invented the "Jogbra," the first sports bra which helped enable girls and women to participate in sports. And if you're anything like the millions of women and young girls today, you probably prefer a sports bra over a traditional bra. You won't want to miss her journey!

Grab your iced tea, sit in your favorite chair outside, and relax as you read through this quarter's issue of Foundation Quarterly.

Enjoy!

Brandy Furman, Ph.D.
Chief Outcomes Officer
Epilepsy Foundation

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- Mary Lou Retton



Innovator, Entrepreneur, Advocate

By Jackie Aker

She's an inventor and entrepreneur, and an epilepsy advocate. She travels the world, runs two businesses, and has overcome obstacles despite her seizure disorder.

Lisa Lindahl learned she had epilepsy at the age of 4 when she began having absence seizures. As she hit puberty her seizures evolved. During class in sixth grade, she experienced a tonic-clonic seizure and remembers a boy laughing as she was having a seizure. While she was embarrassed, she was not ashamed.

"I remember making the decision right there and then, that when I went back to class if someone made fun of me, it was going to be their problem, not mine," she said. "That's been my attitude all along, and it's worked for me. Having epilepsy is only one part of what makes me who I am."

According to Lindahl, her epilepsy has both created limitations and opportunities. She credits having an innovative mindset and creative problem-solving abilities to her experience managing the condition.

"In our lives, we have many teachers, some warm, some uplifting, and some who are 'shadow teachers'," she said. "These shadow teachers are often in the form of difficult events and attitudes that having epilepsy can create. They can challenge us and be obstacles. But surprisingly, they are also an opportunity to 'see it differently' and solve or overcome the obstacle in a new and creative way. I always say persevere! For me it's a form of competition: who's going to win here, me or epilepsy? My shadow teacher called epilepsy has taught me that."

COVER STORY

For me it's a form of competition: who's going to win here, me or epilepsy?

In her 20s during the fitness boom, Lindahl took up running. She didn't have a driver's license because of her epilepsy, so she had to either walk or take the bus. Her minimum wage employment wasn't fulfilling. Running became important in her daily routine, strengthening her relationship with her body and her self-confidence. While Lindahl loved her runs, there was a problem — she was uncomfortable running in a regular bra. The straps would fall off, the underwire would dig in, and hardware chafed. There was no athletic alternative for women back then, so she invented one, the sports bra.

Lindahl's sister had also taken up running and they commiserated about how uncomfortable it was to run in a regular bra. "She said to me, 'why isn't there a jockstrap for women?' and I thought, why indeed? I remember after our conversation I started making a list of all the ideal features of a jockstrap for women. Straps wouldn't fall, it was lightweight, breathable, supportive but comfortable and it'd be modest enough for me to wear without a shirt, if I chose to."



Photo Courtesy: Lisa Lindahl

What started as a joke between Lindahl and her sister became the greatest athletic invention for women.

Although, Lindahl had a vision for how this garment would perform and look, she did not possess any sewing skills. She enlisted the help of her friend Polly Smith, who was renting a room from her that summer. Smith was a costume designer back then, working at the local theatre. After several prototypes created by Smith and tested by Lindahl, Smith took two jockstraps, deconstructed them, and recreated them as the "jockbra". She then refined it using appropriate elastics and fabrics. Lindahl named the invention the Jogbra® and patented it.

The Jogbra became a sensation. Lindahl found a partner to help with the funding and production, setting up her business. Lindahl's business was successful from the beginning, with an average 25% increase in revenues each year. The company was eventually sold to a big corporation. Now it is sold under the Champion brand.

Lindahl went on to innovate, but this time for the epilepsy community. After selling the company, she decided to volunteer for the Epilepsy Foundation, serving on the board of directors. She was the first person with epilepsy at that time to serve on the board.



Lisa with Polly Smith (Left)

“Until then, I really wasn’t vocal about my epilepsy,” she said. “I didn’t hide it, but neither did I talk about it. Yet, I found that there is an entire community of people who are active advocates, creating awareness and educating others about this condition. And I had so much to learn! I realized that I very much wanted to be a part of, and contribute to, this community.”

As a board member, Lindahl started the women and epilepsy initiative at the Foundation which paved the way for research into the gender differences in epilepsy. With the help of Foundation staff, she raised enough money to identify and bring together a small group of medical experts to discuss the issue. That led to a white paper identifying and supporting the need for this research. It served as the catalyst for the initiative.

“When I was trying to live my life in my 20s, 30s, and 40s, nothing had yet been documented about epilepsy and hormonal changes,” she said. “There was no viable research. After the women and epilepsy initiative started in the 90s at the Epilepsy Foundation, we were able to get funding for research, and more neurologists started paying attention to this area of epilepsy. Today the gender

differences in epilepsy are universally recognized.”

Lindahl’s work continues as a thought leader, author, and epilepsy advocate. Last year, she was inducted in the National Inventors Hall of Fame for her invention of the sports bra. She is the author of two books, *Beauty as Action*, and *Unleash the Girls, The Untold Story of the Invention of the Sports Bra and How It Changed the World (And Me)*.

“Today, I can look back and understand some of the dynamics and advantages of aging — perspective! When I was a young woman, there were no expectations for me to achieve anything. Yet, I learned to be independent and manage my seizures. When I embarked on the Jogbra business, I had no idea of the cultural impact that the sports bra would have. Now, not only can I be an inspiration for all young entrepreneurs, I’ve learned I can also be an example for women with epilepsy. That is fulfilling.”



PERSONAL ESSAY

I Was Diagnosed with Epilepsy Without Even Knowing I Was Having Seizures

By Faith Brar

On October 29, 2019, I was diagnosed with epilepsy. I sat across from my neurologist at Brigham and Women's Hospital in Boston, my eyes welling and heart aching, as he told me I had an incurable illness that I'd have to live with for the rest of my life. I left his office with a prescription script, a couple of brochures for support groups, and a million questions: "How much is my life going to change?" "What are people going to think?" "Am I ever going to feel normal again?" — the list goes on.

I know most people who get diagnosed with a chronic illness aren't prepared for it, but perhaps what made it more shocking to me was that I wasn't even aware that I was having seizures until two months prior.

Struggling with My Health

Most 26-year-olds feel pretty invincible. I know I did. In my mind, I was the epitome of healthy: I worked out four to six times a week, I ate a fairly balanced diet, I practiced self-care and kept my mental health in check by routinely going to therapy.

Then, in March 2019, everything changed.

For two months, I was sick — first with an ear infection then with two (yes, two) rounds of the flu. Yet, even after the fevers and chills were finally gone, my health didn't seem to rebound.

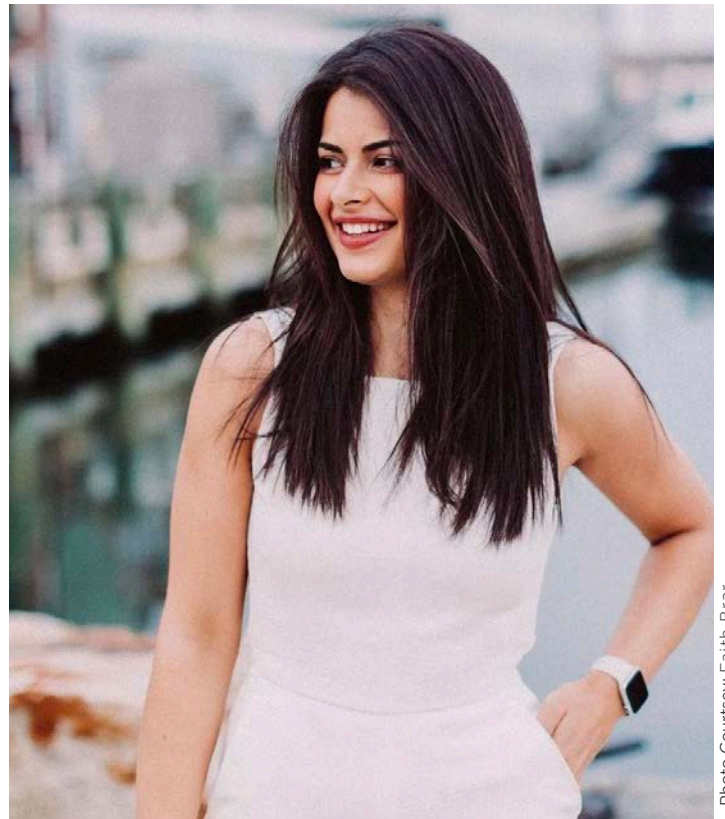


Photo Courtesy: Faith Brar

Blood tests revealed that I had a severe B-12 deficiency — one that had gone undiagnosed for so long that it seriously affected my energy levels and went as far as damaging the nerves in my legs. However, after a few doses of B-12 shots, and a couple of months later, the treatment proved to be successful.

By the end of May, I was thinking clearly again, feeling more energized, and experiencing far less tingling in my legs. Things were starting to look up and, for a few weeks, life went back to normal — that is, until one day while typing up a story, the world went dark.

It happened so fast. One moment I was watching words fill the computer screen in front of me as I've done so many times before, and the next, I felt an overwhelming surge of emotion rise from the pit of my stomach. It was as if someone had given me the world's most terrible news — and so I subconsciously stopped pounding the keyboard. My eyes welled up, and I was almost sure I was going to start bawling hysterically. But then, I started getting tunnel vision and eventually couldn't see at all, even though my eyes were open.

One moment I was watching words fill the computer screen in front of me as I've done so many times before, and the next, I felt an overwhelming surge of emotion rise from the pit of my stomach.

When I finally came to — whether it was seconds or minutes later, I still don't know — I was sitting at my desk and immediately started to cry. Why? Not a clue. I had no idea what just happened, but I told myself that it was probably just a result of everything my body had been through over the past few months. So, I took a moment to gather myself, chalked it up to dehydration, and continued typing away.

But then it happened again the next day — and the day after that and the day after that and, soon, these “episodes” as I called them, intensified. When I blacked out, I'd hear music that wasn't actually playing and hallucinate shadowy figures talking to one another, but I couldn't make out what they were saying.

It sounds like a nightmare, I know. But it didn't feel like one. If anything, I actually felt euphoric whenever I went into this dream-like state. Seriously — I felt so happy that, even in a delusion, I thought I was smiling. The instant I snapped out of it, however, I felt deep sadness and fear, which was usually followed by extreme bouts of nausea. Every time it happened, I was alone. The entire experience was so weird and bizarre that I hesitated to tell anyone about it. Frankly, I felt like I was going crazy.

Realizing There Was a Problem

Come July, I started forgetting things. If my husband and I had a conversation in the morning, I couldn't remember our discussion by night. Friends and family members pointed out that I kept repeating myself, bringing up topics and instances that we'd already spoken about at length just minutes or hours before. The only possible explanation for all of

my newfound memory struggles? The recurring “episodes”— which, despite happening on the regular, were still a mystery to me. I couldn't figure out what brought them on or even establish some type of pattern. At this point, they were happening at all hours of the day, every day, regardless of where I was or what I was doing.

So, about a month after my first blackout, I finally told my husband. But it wasn't until he actually saw one for himself that he — and I — truly grasped the seriousness of the situation. Here's my husband's description of the incident, as I still have no memory of the event: It happened while I was standing by our bathroom sink. After calling out to me a few times sans-response, my husband headed to the bathroom to check in, only to find me, shoulders slumped, staring blankly at the ground, smacking my lips together as I drooled. He came up behind me and grabbed my shoulders trying to shake me. But I just fell back into his arms, completely unresponsive, my eyes now blinking uncontrollably as well. Minutes passed before I woke up. But to me, the time passed felt like a blur.



Learning That I Was Having Seizures

About two weeks later, I went to see my primary care physician. After telling her about my symptoms, she suspected these “episodes” were likely seizures. “Seizures? No way,” I instantly responded. Seizures happen when you fall to the ground and convulse while foaming at the mouth. I had never experienced such a thing in my life! These dream-like blackouts had to be something else.

My doctor was quick to correct my understanding; while the falling-then-convulsing scenario is what comes to mind for most people when they think of seizures, it's actually only one type of seizure. She said I was likely having some type of focal seizure, but that we'd have to do some tests and immediately referred me to a neurologist to be sure.

I was scheduled for an electroencephalogram (EEG) and a magnetic resonance imaging (MRI). The 30-minute EEG came back normal, which was to be expected since I didn't have a seizure during the exam. The MRI, on the other hand, showed that my hippocampus, a part of the temporal lobe that regulates learning and memory, was damaged. This malformation, otherwise known as hippocampal sclerosis, can lead to focal seizures, even though this isn't the case for everyone.

Getting Diagnosed with Epilepsy

For the next two months, I sat on the information that there was something inherently wrong with my brain. At this point, all I knew was that my EEG was normal, my MRI showed an irregularity, and I wouldn't understand what any of this meant until I saw a specialist. In the meantime, my seizures got worse. I went from having one a day to having several, sometimes back-to-back and each lasting anywhere between 30 seconds to 2 minutes.

My mind felt foggy, my memory continued to fail me, and by the time August of 2019 rolled around, my speech took a hit. Forming basic sentences required all of my energy and even still, they wouldn't come out as intended. I became introverted—nervous to speak so I didn't come off as dumb.

Besides being emotionally and mentally draining, my seizures affected me physically. They've caused me to fall, hit my head, bump into things, and burn myself after losing consciousness at the wrong moment. I stopped driving out of the fear that I might hurt someone or myself.

The neurologist walked me through my MRI, showing me how the hippocampus on the right side of my brain was shriveled and much smaller than the one on the left. He said that this type of malformation can cause seizures. The overall diagnosis? Temporal Lobe Epilepsy (TLE). Since the hippocampus is located in the middle (inner) of the temporal lobe, I was experiencing focal seizures that affected the formation of memories, spatial awareness, and emotional responses.

I was likely born with the malformation on my hippocampus, but the seizures were triggered by the high fevers and health issues I had earlier on in the year, according to my doctor. The fevers triggered the seizures as they inflamed that part of my brain, but the onset of seizures could have otherwise happened at any time, without cause or warning. The best course of action, he said, was to go on medication to control the seizures. There were several to choose from, but each came with a long list of side effects, including birth defects if I were to get pregnant. Since my husband and I had plans to start a family, we made my treatment decision based on that fact.

That day, my neurologist also revoked my license, saying I couldn't drive until I was seizure-free for at least six months. He also told me to avoid doing anything that could trigger my seizures, which entails drinking little to no alcohol, keeping stress to a minimum, getting plenty of sleep, and not skipping medication. Other than that, the best thing I could do was to live a healthy lifestyle and hope for the best. As for exercising? There didn't appear to be any reason I should avoid it, especially since it could help with the emotional burden of dealing with my diagnosis, he explained.

How I Coped with the Diagnosis

Once I started the treatment, it took three months to become acclimated to my seizure meds. They made me extremely lethargic, nauseated, and foggy, as well as gave me mood swings—all of which are common side effects but challenging, nonetheless. Still, within just weeks of starting the meds, they began to work. I stopped having as many seizures, maybe a few a week, and when I did, they weren't as intense.

a few a week, and when I did, they weren't as intense.

Perhaps the most difficult part about being diagnosed and adapting to my new normal, so-to-speak, was telling people about it. My doctor explained that talking about my diagnosis could be liberating, not to mention essential for those around me in case I had a seizure and needed help. I quickly realized that no one knew anything about epilepsy—and trying to explain was frustrating, to say the least.

“But you don't look sick,” some friends told me. Others asked if I'd tried “thinking away” the seizures. Better yet, I was told to find comfort in the fact that “at least I didn't have the bad kind of epilepsy,” as if there's any good kind.

I found that every time my epilepsy was desensitized by ignorant comments and suggestions, I felt weak—and I struggled to separate myself from my diagnosis.

It took working with a therapist and an insane amount of love and support for me to realize that my illness did not and does not have to define me. But this didn't happen overnight. So, whenever I lacked emotional strength, I tried making up for it physically.

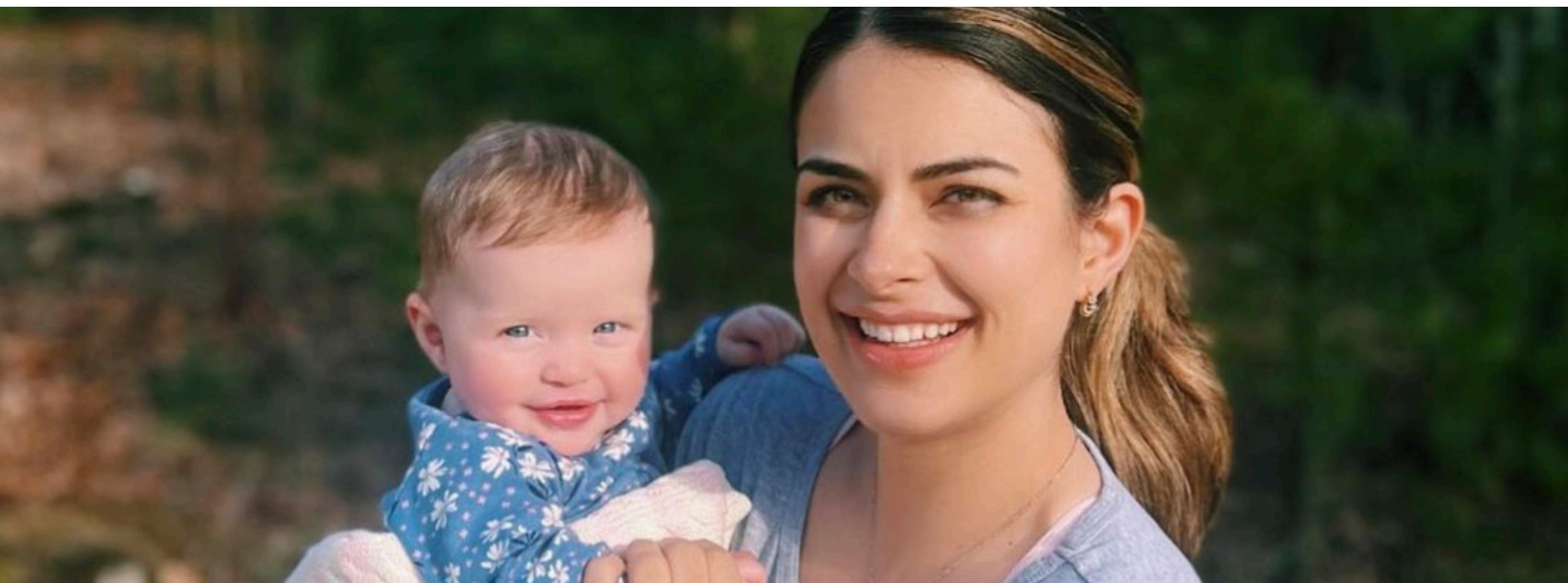
With all of my health struggles that year, going to the gym had taken a backseat. In January 2020, as the fog caused by my seizures started to clear, I decided to start running again. It's something that had offered me a lot of comfort when I was diagnosed with depression as a teenager, and I hoped it would do the same now.

And guess what? It did—after all, running is bursting with mind and body benefits. If there was a day when I struggled with my words and felt embarrassed, I laced up my sneakers and ran it out. When I had night terrors because of my meds, I'd log some miles the next day. Running just made me feel better: less of a person with epilepsy and more myself, someone who's in control, capable, and strong.

What I've Learned Today

I've been three years seizure-free. I've also had a baby girl since my epilepsy journey began. The pregnancy was a bit challenging, getting my blood drawn every month and adjusting medication levels each time. I also had to have anatomy scans every month to watch for congenital abnormalities, which was always nerve wracking. After I had the baby, the lack of sleep made me very nervous about seizures — especially because I wanted to keep my daughter safe. But I was diligent with my medications and have still remained seizure free. Given that I had a rough pregnancy, less than ideal labor, and still struggle with sleep deprivation, my seizures remain at bay and I couldn't be more grateful. I really do thank my medication for that.

Faith Brar is a health and wellness freelance writer and content creator. She originally published her epilepsy journey in August 2020 in Shape magazine.





Pageant for Awareness

She was her high school class valedictorian, is an Epilepsy Awareness Ambassador, and was recently chosen to represent Hillsdale in the Miss New Jersey USA 2023 pageant. But for 21-year-old Christina Conti living with epilepsy has brought its share of challenges.

Diagnosed with epilepsy at the age of 6, Conti had to endure curious stares, pointed fingers and children teasing her. She also experienced side effects from different anti-seizure medications, such as rashes on her skin and falling asleep in class. She felt isolated and found it difficult to talk to anyone about her epilepsy, including her teachers.

“When I was young, my seizures made me forget things, so I got bullied a lot,” she said. “I felt that I didn’t want epilepsy to be a part of me, I wanted it buried. I didn’t want to talk about it because I would get teased and that made me uncomfortable. I didn’t want epilepsy to be part of my identity.”

I didn’t want epilepsy to be part of my identity.

As she got older, she struggled with auras and migraines. Sometimes her seizures would make her seem as if she was “daydreaming”, or they would cause her to laugh hysterically, or sob uncontrollably. In 2022, she lost her driver’s license temporarily due to her uncontrollable seizures.

However, her struggles with epilepsy did not stop her from pursuing her academic goals and other extra-curricular activities. She competed in 2021 for a spot in the Miss New Jersey USA where she advanced to the semi-finals but did not place that year. She competed again this year and advanced to the 2023 competition which took place in March.

Before she began competing, her impression of pageants was a lot different than what it is now. Back then, she thought it was all about looks. But she soon realized that pageants are a platform to talk about your challenges, goals and what you can bring to the table.



Photo Courtesy: Christina Conti

“As you get older, you become more comfortable about who you are and how you can use your experiences to affect change,” she said. “If I had seen someone with epilepsy on a pageant stage, it would have made me feel a thousand times more powerful as a young girl. Now, I think about this thing in my life that I’d buried for so long. I feel that if I share my epilepsy story with people and have them see someone like me in the media, then it’d help them too.”

Conti feels it’s important to show another side of epilepsy, and not just the portrayal that is common in TV shows and on viral videos on YouTube. Her reason for competing goes beyond just winning the title. It’s about educating people about epilepsy and seizures.

Today, I can help others by creating awareness and helping to destigmatize seizures by sharing my own story.

“When I was a kid, I didn’t know anyone with epilepsy. All I knew was what I saw on TV – people making fun of others experiencing seizures. This only adds to the stigma. Today, I can help others by creating awareness and helping to destigmatize seizures by sharing my own story. And if I have a platform, why not take that opportunity to do so?”



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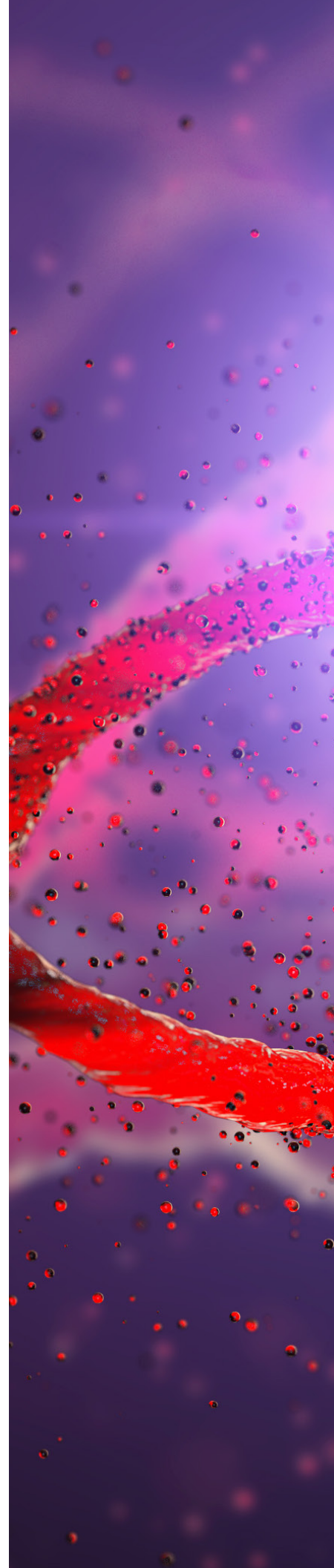
Understanding Rare Epilepsies from the Inside Out

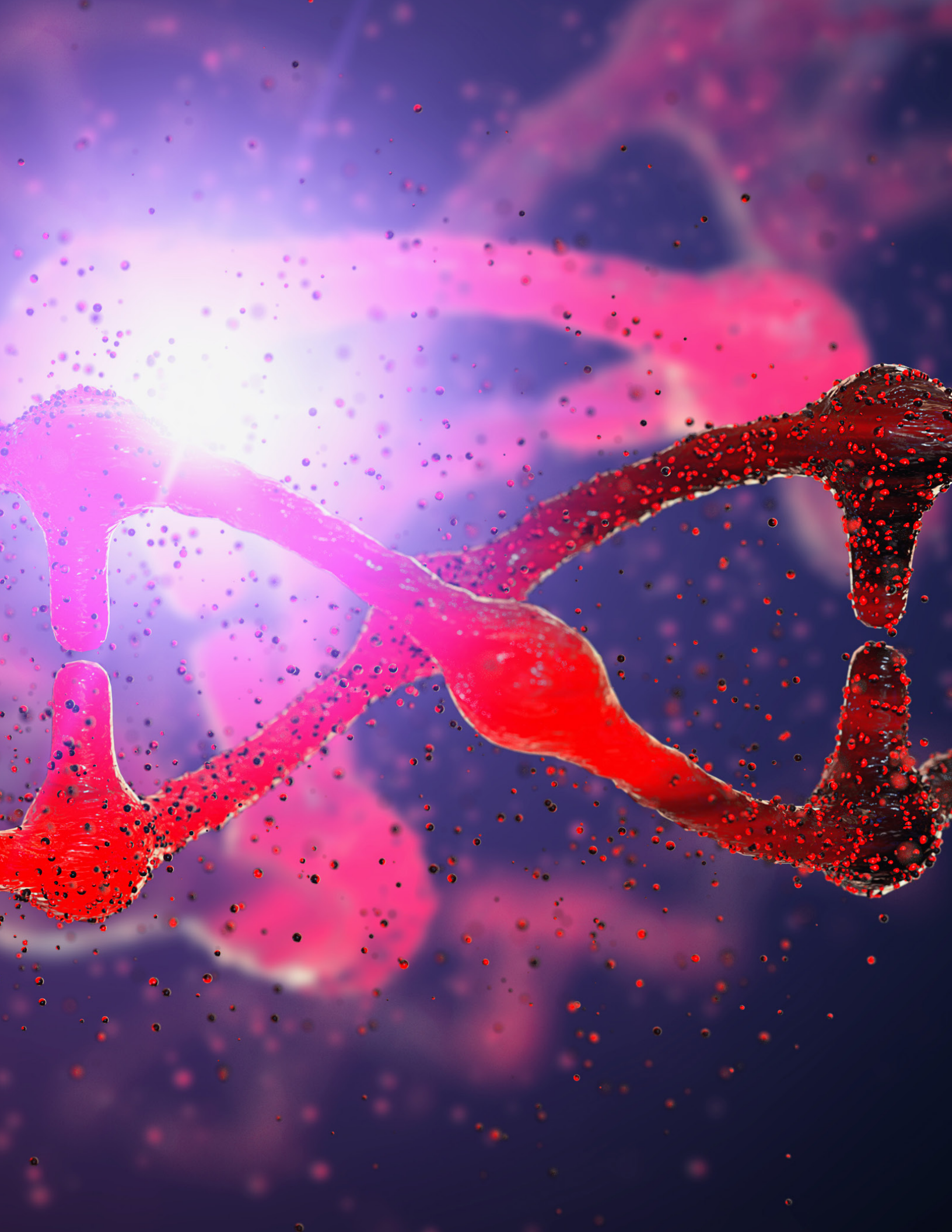
Genetic testing has evolved in the last decade, giving neurologists new ways to diagnose and treat rare epilepsies. Understanding how varying genes mutate to cause rare conditions, can influence treatment decisions and in some cases, potentially change a person's prognosis.



Xilma Ortiz-Gonzalez, M.D.

Until now, research for diagnosing and treating rare epilepsies has been limited. And for people with co-morbidities, it's like finding a piece of a puzzle, according to Xilma Ortiz-Gonzalez, M.D., Ph.D, assistant professor of Neurology & Pediatrics at Children's Hospital of Philadelphia (CHOP). This is what inspired Dr. Ortiz-Gonzalez to specialize in pediatric neurogenetics. She has dedicated her career to helping families find answers for their child's rare neurodevelopmental disorders.





FEATURE STORY

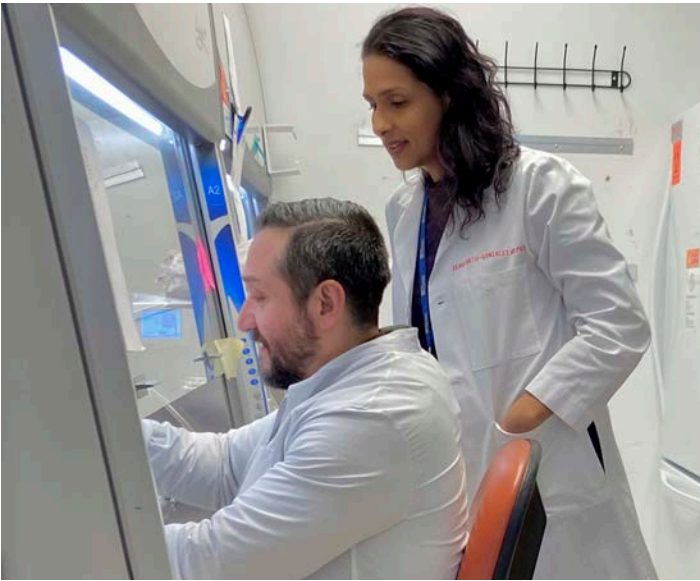


Photo Courtesy: Dr. Ortiz-Gonzalez

“During my rotations at CHOP, parents would come in wanting to know why their child had a particular form of epilepsy,” she said. “Their child had seizures, along with other medical conditions and developmental delays. At that time, there wasn’t much genetic testing being done, so the journey to find answers was a long one for them.”

Genetic testing can provide some answers, but not everyone’s symptoms manifest in the same way so the genetic results aren’t as clear cut. Such is the case for the Boricua mutation in the TBCK gene, which causes developmental and epileptic encephalopathy. Dr. Ortiz-Gonzalez’s team discovered that TBCK encephalopathy predominantly affects children of Puerto Rican (Boricua) descent. At first, they noticed that the children had similar symptoms, but they didn’t know it was linked to the TBCK gene.

“As sequencing became more accessible, we found that all children shared a mutation in the TBCK gene,” she said. “But we noticed that there is a particular change that occurs in this gene among patients of Puerto Rican descent. We now want to better understand how this genetic change leads to neurologic symptoms, so sequencing can be helpful and meaningful to families. Our end goal is to have better treatment options for TBCK encephalopathy.”

According to Dr. Ortiz-Gonzalez, finding the genetic diagnosis helps give families some answers, but there can still be genetic results that are difficult to interpret. While there have been advances in how seizures can be treated in certain rare epilepsies, she says there is still a lot of work to be done to develop more personalized approaches to treat and manage rare epilepsy syndromes

We now want to better understand how this genetic change leads to neurologic symptoms, so sequencing can be helpful and meaningful to families.

“We can answer the why, we can determine the recurrence risk, but we have yet to learn more about how to manage the varying rare epilepsies that we can now identify,” she said. “We need to understand how genetic changes lead to rare disorders so that we’re not just managing the symptoms, but also altering the course of the disease. We need better treatment options for children with rare epilepsies. This is a great opportunity for growth in our field.”

Dr. Ortiz-Gonzalez is contributing toward that growth by training and inspiring 129 providers to effectively diagnose and treat rare or genetic epilepsies as part of the Project ECHO® for rare epilepsies.



Learn more about the
Rare Epilepsy Network:
bit.ly/3UOiX9Z



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Getting Closer to Forecasting Seizures

Not knowing when or why a seizure may happen is a top concern for those living with epilepsy. There is both the fear of not knowing when a seizure will start and what may trigger them. So why can't we forecast a seizure the way we can forecast the weather?

In the last few years, many researchers have aimed to do just that. And today, the idea of being able to predict a seizure before it happens is closer to becoming a reality with a seizure risk forecasting app that uses seizure history to gauge seizure likelihood.

Seizure forecasting can show you when you are at higher risk or lower risk for having a seizure at any given time. Understanding that risk could allow people to adjust their plans if they knew a seizure was more likely and manage their life with epilepsy.

For 71-year-old Kent Watson, the constant fear of when a seizure may strike impacted his day-to-day and quality of life. After struggling with uncontrollable seizures for more than 30 years, trying multiple medications and therapies, Watson set out on a quest to find something that could help him better understand his seizures.

"The difficult part is not knowing when they might happen," said Watson. "I don't get auras, and the factors that I have been told trigger my seizures are not always true for me. I figured that if I'm going to continue to experience seizures, then I need to be able to know when they're coming so that I could manage my life around them."

Born in the small town of Borger, Texas, Watson had never heard of the term epilepsy until he experienced his first seizure. The first responders and law enforcement who arrived at his home to offer emergency care during his first seizure also didn't know anything about epilepsy. Watson ended up handcuffed because they thought he was under the influence of drugs; they didn't know he was experiencing a seizure.

For the next 20 years, he had occasional night seizures, and at times, had seizures that required him to be admitted to the hospital. But for the most part, he said he made it through the workday okay. But soon after his wife was diagnosed with Non-Hodgkin's Lymphoma. She eventually overcame her cancer, and it went into remission, but then Watson's seizures became more frequent and severe. His doctor put him on newer medications and had him try Vagus Nerve Stimulation therapy, to no avail.

Doctors later suggested responsive neurostimulation (RNS) as another option, however, it would require a longer stay in the hospital which posed challenges for Watson and his wife, who was in remission. He decided to pass on the RNS and began his search for something that could possibly predict his seizures before they happened.

I figured that if I'm going to continue to experience seizures, then I need to be able to know when they're coming so that I could manage my life around them.

“I learned about Seer Medical® and studies being done based on seizures happening in a cyclic pattern, even up to three to four weeks apart,” he said. “When I looked back at my own past seizure history, I found that my seizures also occurred on a regular cycle. I reached out to Seer to get more information and find out how I could be part of their research efforts.”

Seer’s research found that cyclic rhythms outside the brain could strengthen seizure risk forecasting and be tracked with a non-invasive wearable device. Watson, along with other research participants, wear a Fitbit smartwatch to record data on heart rate, stress, sleep, and physical activity, and use the Seer app to record events believed to be a seizure. The wearable device records heart rate which shows slow changes connected to a person’s seizure risk cycles. The device is then paired with the Seer app to provide more insight into when people might be more or less likely to have a seizure.

“The best way to track someone’s cycle is to continuously measure their brain activity since seizures begin in the brain,” said Pip Karoly, Ph.D., data scientist at Seer Medical. “Long-term recordings of brain waves show very clear, multiday cycles that are strongly predictive of seizure risk. However, these cycles have only been found using implanted brain recording devices which are not a fit for everyone. Instead, the Seer research team studied the heart which is connected to the brain and might also show long-term cycles related to seizure risk.”

According to Seer’s research, for some people with epilepsy, their heart rate has multiday cycles, and their seizures tend to occur at specific parts of that cycle. Among other things, stress and hormonal changes are also reported to be seizure triggers and have been known to affect heart rate. Additional research is needed to determine whether the same changes in the brain that lead to seizures could also drive heart rate cycles.



Photo Courtesy: Dr. Ortiz-Gonzalez

But for Watson, being able to have some idea of when his seizure might happen has been a blessing. Working with the Epilepsy Foundation of Colorado & Wyoming, he and his wife now lead a virtual support group for people with epilepsy. What started as a small virtual group via Zoom in Denver during COVID, has now expanded to the entire state of Colorado and Wyoming.

“While more research is needed, the Seer app seems to do a pretty good job of helping me understand when I am at higher risk of experiencing a seizure,” said Watson. “Dealing with my wife’s cancer early on and not knowing when I might have a seizure was difficult. Now, I can host a support group and can better prepare for a seizure. But we could not have done it without a deep belief in God, prayer, and close support from friends wherever we lived.”

Seer Medical is part of an international team of scientists that received a \$3 million grant from the Epilepsy Foundation to evaluate biosensors that can track an individual’s physiology, behavior, and environment to improve seizure detection.



Learn more about
Seer Medical at
seermedical.com

Change Our Epilepsy Story/ Cambiemos la historia de nuestra epilepsia

A New Awareness Campaign

People with epilepsy — and their caregivers — often bear the negative attitudes and beliefs surrounding epilepsy, and they don't often talk about it as a result. This has generally steered people with epilepsy toward silence, ignorance, and away from the motivation to seek better care.

Because no one is talking about epilepsy, misconceptions and lack of understanding about seizures remain.

But what if everyone shares their epilepsy story, and how they managed to overcome the challenges so that we shift the conversation to education, safety, and cures?

What if we
#ChangeOurEpilepsyStory

Change Our Epilepsy Story is an awareness campaign initially being rolled out in Philadelphia and Phoenix, focusing on the Black/African American and Hispanic communities. 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.



Seizures and the Black/African American Community

Many Black/African Americans experience seizures and epilepsy, so receiving care is critical. Access to quality care helps with seizure control and improves daily life.

Reducing misconceptions about seizures encourages people to seek the care they need. While anyone can have a seizure, below are facts about seizures in the Black/African Americans community.

More than 25,000 Black/African Americans are diagnosed with seizures or epilepsy each year. In fact, African Americans are more likely to be diagnosed with epilepsy than White Americans.

While Black/African Americans with seizures and epilepsy are more likely to experience the critical issues mentioned above, they are less likely to experience active epilepsy than White Americans.* This means, African Americans are more likely to have seizures that are controlled by medication.

Seizures and the Hispanic Community

Hispanics are made up of diverse cultures and values. They are also one of many other ethnic and racial groups disproportionately impacted by health disparities.

In some Hispanic cultures, epilepsy may be perceived as contagious, or a mental or psychiatric condition adds to misunderstandings and delays in getting the proper treatment.

Hispanics in the U.S. are less likely to have access to health insurance or an epilepsy specialist limiting their ability to get the proper seizure control.

Help us stop the stigma and participate in our social media campaign, #ChangeOurEpilepsyStory, to spread awareness in your community.



Learn more about the campaign:

epilepsy.com/ChangeOurStory
epilepsy.com/NuestraEpilepsia

Quotes from our Ambassadors

Epilepsy can be a silent and isolating disease for many people, and they might also have anxiety and depression. I want people to know they are not alone.

- Alejandra, campaign ambassador



There was no one around to discuss this condition and the people who thought they knew about it were incorrect. Being labeled gave me the feeling of being different, so I decided to prove people wrong.

- Lowell, campaign ambassador





Addressing Gaps in Epilepsy Care

People of color, particularly those in low and middle-income and rural communities, are disproportionately affected by epilepsy. Limited access to trained health professionals and shortages of epileptologists and epilepsy centers in rural areas are all factors that impact care and adherence to treatment among these populations.

Achieving the best possible outcome and highest possible quality of life for every person with epilepsy requires access to high-quality medical care; community services; supportive environments in which to live, learn, work, and play; and an activated individual and family.

Unfortunately, today, a healthcare system that supports people with epilepsy often does not have all these components, or if they do, they don't function as a cohesive

system. Healthcare, social support and self-management programs are isolated from each other, making it difficult for anyone to experience truly comprehensive care.

The Epilepsy Foundation recently partnered with UCB to engage community health workers (CHWs) and Promotores de Salud to address these challenges among people with epilepsy, and in particular Hispanics. With financial support from UCB, the Epilepsy Foundation worked with Umemba Health, LLC to create an On-Demand curriculum for CHWs. The curriculum is based on the Foundation's Epilepsy CHW Program which was created with the American Academy of Pediatrics in 2021 as part of the Project ECHO® (Extension for Community Healthcare Outcomes) series targeting CHWs.

The free, on-demand course, “Epilepsy Self-Management Training for Community Health Workers,” includes eight video modules offering tools and resources to help CHWs and Promotores provide self-management support for people with epilepsy. The English version is currently available in the Epilepsy Foundation’s Epilepsy Learning Portal. The Spanish version will be available later this month which includes a downloadable culturally relevant curriculum, implementation guides, learning activities and assessments in Spanish to complement the modules.

Since 2003, Hispanics have become the largest racial and ethnic group in the United States. According to 2020 Census data, more than 62 million people in the U.S. are Hispanic. And, among the nation’s 3.4 million people who live with epilepsy, 710,000 are Hispanic.

Last year, UCB developed a multi-phased research project called Hispanic CARE (Cultural Attitudes Regarding Epilepsy) where UCB engaged in dialogue with Hispanic American health professionals, patients, families, and colleagues to gather key insights centered on the role of the family in epilepsy care. The findings showed that language barriers and cultural beliefs among this population can contribute to people not seeking care, getting a delayed diagnosis, or being misdiagnosed or underdiagnosed.

“Personally, I am extremely passionate about the work we are doing to bridge gaps and facilitate healthy equity,” said Brad Chapman, head of U.S. Epilepsy & Rare Syndromes at UCB. “Our partnership with the Epilepsy Foundation on the Community Health Workers program further builds on our commitment to provide more equitable care, enhance patient-provider communication, establish trust, and improve outcomes for people living with epilepsy and those who are dedicated to their care.”

CHWs are trusted members of the community who meet individuals where they are, provide information in a way that is easy to understand, and they can relate to the community’s cultural values and norms. Equipping CHWs with the right tools and training will help people with epilepsy better control their seizures, prevent injuries, make healthier lifestyle choices, and improve their quality of life.

“Often overlooked, epilepsy can affect the physical and psychosocial aspects of a person’s life,” said Quisha Umemba, chief executive officer, Umemba Health. “With the right understanding and proper training, CHWs can provide interventions that can have a positive impact for people with epilepsy. We are excited to partner with the Epilepsy Foundation to make this free training accessible for CHWs everywhere.”

The course includes a certificate of completion, and continuing education credits for CHWs and Promotores. To take the course, visit learn.epilepsy.com

**EPILEPSY
SELF-MANAGEMENT
TRAINING FOR COMMUNITY
HEALTH WORKERS**

Help provide self-management support to people with epilepsy in your community.

learn.epilepsy.com

Inspired by patients.
Driven by science.

EPILEPSY
FOUNDATION

Learn more about UCB’s research project:
bit.ly/43qTkQv

Register for this course at
learn.epilepsy.com

Seizure Safe Schools Across the Nation



Advocates, families, legislators, and other community partners recently helped pass Seizure Safe Schools legislation in Arkansas. House Bill 1315 was signed into law on March 16, bringing Seizure Safe Schools legislation to 20 states in the nation. The legislation, which lead sponsor was Representative Denise Jones Ennett (District 80), will require training for all school personnel in seizure recognition and first-aid response every two years, as well as an age-appropriate seizure education program for students. The Epilepsy Foundation's Seizure Safe Schools nationwide initiative is making great progress with even more states than ever introducing bills to protect students with epilepsy in the classroom. In the Iowa legislature, the Senate Education Committee recently passed the Seizure Action Plan Bill (SF 177), and the House passed Seizure Action Bill (HF 379) on a unanimous vote, bringing Seizure Safe Schools legislation closer to the finish line in Iowa.



Photos Courtesy: Epilepsy Foundation in Arkansas

Epilepsy Advocates Bring Awareness and Advance Key Policies in the Nation's Capital

By Britt Dorfman



The Epilepsy Foundation held its signature advocacy event, the Teens Speak Up! & Public Policy Institute, on February 26 - 28, 2023 in Washington, D.C. The Teens Speak Up! program provides an opportunity for teens living with epilepsy and their parents to visit the nation's capital, receive advocacy training, meet with legislators, and tell their personal stories to make a difference. The event brought together over 150 advocates representing 35 states, including 45 teen representatives and ambassadors living with the epilepsies.



Participants held over 115 congressional meetings and advocated for issues important to the epilepsy community. For Fiscal Year 2024, advocates asked members of Congress to provide \$13 million for the Centers for Disease Control and Prevention's (CDC) Epilepsy Program; \$19 million for the VA Epilepsy Centers of Excellence; and \$164 million for the CDC's Safe Motherhood/Infant Health Program to support the Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry which gives states the ability to track SUDEP-related deaths in young people. Participants also asked their U.S. Representatives to join the new Congressional Epilepsy Caucus.





Photo Credit: Joe Shymanski

During the event, the Foundation awarded the Tony Coelho Impact Award to U.S. Representatives Greg Murphy, MD (R-NC-03) and Jim Costa (D-CA-21) for their leadership in launching the bipartisan Congressional Epilepsy Caucus and supporting other priorities for the epilepsy community. The Sara Stubblefield Advocacy Award was presented to the Van Cleave family for leading the passage of multiple state bills in Virginia, including Seizure Safe Schools and seizure aware businesses.

150 advocates representing 35 states

Upon their return home, Teens Speak Up! participants complete a year of service focused on raising awareness, educating others about epilepsy in their communities, and continuing to advocate with state and federal lawmakers.



Learn about our advocacy efforts: visit epilepsy.com/advocacy



Your local
EPILEPSY FOUNDATION
is here to help you in
your epilepsy journey.

With the **nationwide network of partners** throughout the United States, the **Epilepsy Foundation** connects people to treatment, support, and resources; leads advocacy efforts; funds innovative research and the training of specialists; and educates the public about epilepsy and seizure first aid.



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

New Congressional Epilepsy Caucus

U.S. Representatives Jim Costa (CA-21) and Gregory Murphy, M.D. (NC-03) recently launched a bipartisan Congressional Epilepsy Caucus. The goal is to bring together members of Congress and experts to raise awareness and understanding about epilepsy, implement meaningful legislation, and advocate for research funding in the U.S. Congress. The Caucus, which is a result of the Epilepsy Foundation's efforts, will be co-chaired by representatives and co-founders, Jim Costa, and Dr. Greg Murphy.



Pictured: Rep. Gregory Murphy - NC-03 (Left), Epilepsy Foundation Intermin CEO Alison Zetterquist, and Rep Jim Costa - CA 21
Photo Credit: Joe Shymanski

New Implantable Device for Drug-Resistant Epilepsy



LivaNova launched Sentiva DUO™, an implantable pulse generator (IPG) that provides vagus nerve stimulation therapy for people with drug-resistant epilepsy. The device has a dual-pin header that provides stimulation in response to rapid heart rate increases, which may be associated with seizures. The device also logs low heart rate and prone position events and allows for day-night programming. Sentiva DUO received clearance from the U.S. Food and Drug Administration and is now available in the United States.



Learn more about
this new device:
bit.ly/402HkBN

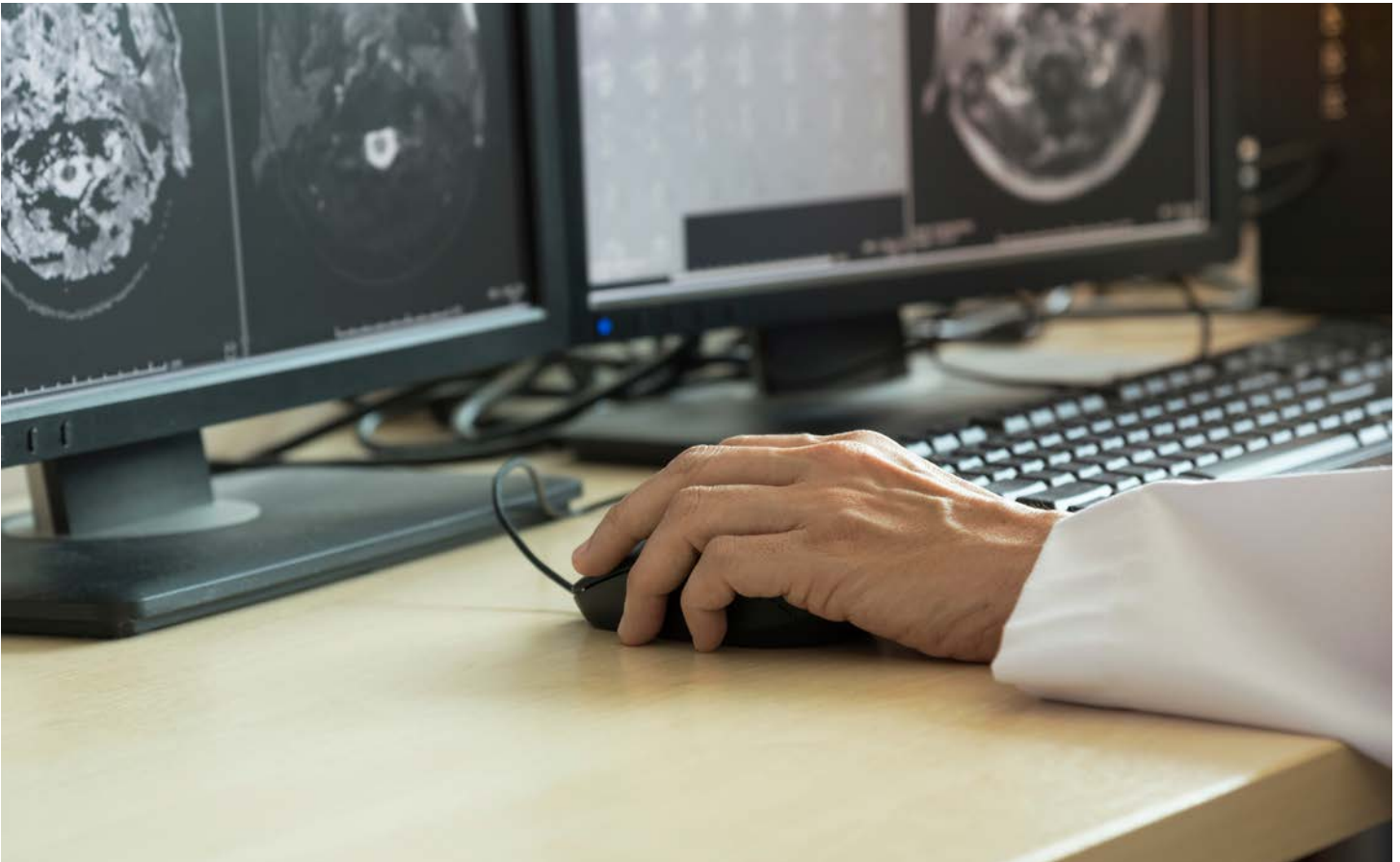
Epilepsy & Hunger Health Equity

The Epilepsy Foundation recently collaborated with Feeding America to create a health brief focused on food insecurity and epilepsy. Unfortunately, many people living with epilepsy struggle with being able to afford nutritious and healthy foods for themselves and their families. The brief, *Hunger Health Equity: Spotlight on Epilepsy*, provides an overview of how food insecurity can impact a person's health and wellbeing, and offers ways to assist those facing hunger so that they can get the help they need to manage their seizures.



Learn more about
the initiative's efforts:
bit.ly/43udE3u





Rare Epilepsies ECHO®

Recently, the Epilepsy Foundation, Rare Epilepsy Network (REN) and American Academy of Pediatrics launched a Project ECHO® (Extension for Community Healthcare Outcomes) for rare epilepsies. The four-month learning collaboration called “The (not so rare) Epilepsies: Hard to Diagnose & Hard to Treat ECHO” was created to increase the knowledge and skills of providers to diagnose and treat rare or genetic epilepsy, developmental and epileptic encephalopathies (DEEs), and epilepsy syndromes, as well as its comorbidities. This initiative brings together 14 thought leaders in rare epilepsies from institutions around the country, including Boston Children’s Hospital, Children’s Hospital of Philadelphia, and Stanford Children’s Hospital. The nine sessions include participation from 129 neurologists, trainees, pediatricians, and other health professionals. The Project ECHO model creates knowledge networks by connecting health care providers with an expert team through a tele-mentoring program using case-based presentations. This model has been shown to increase the capacity for healthcare providers to identify, treat, and manage patient care.

*News Briefs compiled
by Kaitlyn Gallagher*

CALENDAR OF EVENTS

See what's happening this season!

Arizona

Camp Candlelight

June 18-23, 2023
Whispering Hope Ranch
Payson, AZ

Join a safe overnight and secure camp experience for youth and teens with epilepsy. Campers will gain a greater understanding of their epilepsy diagnosis and treatment while developing peer-to-peer support, increasing independence and self-confidence, and fostering a sense of belonging.

Register:
<https://app.campdoc.com/!/dn/login?r=epilepsyaow>



Colorado

Purple Peaks Young Adult Retrea

April 28-30
Larkspur, CA

This retreat is for young adults (ages 18-30) who are diagnosed with epilepsy or non-epileptic seizures. Connect with other young adults with epilepsy, who live independently, to explore various aspects of self-care. Sessions include yoga, art expression, Ask the Doc, disclosing epilepsy, and social activities.

Register at <https://bit.ly/camp-retreat>

Michigan

Paul Neu Memorial Golf Classic

June 26, 2023
Byron Center MI

Each year, Paul's family and friends honor his memory by working together to raise awareness and funds for epilepsy by participating in a sport he loved. Support the cause and celebrate Paul's life.

Learn more at epilepsy.com/events/2023/paul-neu-memorial-golf-classic

New Jersey

EpiPalooza IV Concert,

April 29, 2023
Debonair Music Hall
Teaneck, NJ

Come together for a night of rock music and raising awareness. Featured performers include The Iron Roses, Elizabeth and the Catapult, the Real Matt Perrone Band, and Toy Canon. All proceeds from the concert will benefit the Epilepsy Foundation.

Register at www.EpiPalooza.net



Pennsylvania

Young Adult Retreat

May 4-7, 2023
Green Lane, PA

Are you a young adult (ages of 18-30) diagnosed with epilepsy? Connect with others facing similar experiences and build a supportive community. This event will help you prioritize time for socialization and relaxation. Learn about stress-management techniques and planning, and talk with medical professionals. This exciting weekend will leave you feeling refreshed and energized!

Register at <https://app.campdoc.com/!/dn/login?r=efepcom/>.

Utah

An Evening with Warriors of Epilepsy Gala

June 2, 2023
Salt Lake City, UT

Attend an exciting evening to help raise funds for services, programs and support for people living with epilepsy in Utah. The educational evening will include a sit-down dinner, a keynote speaker, entertainment, and silent and live auction. In addition, the Epilepsy Foundation will recognize the warriors who take on the challenges that come with having epilepsy and those fighting alongside to END EPILEPSY®.

Register: <https://e.givesmart.com/events/vQF/>

**Virtual
Virtual Pediatric
Epilepsy Conference**
May 23, 2023

Topics & Speakers:
Medication and More: the
Latest in Anti-Epileptic
Medications & When to
Consider Devices

Speaker: Dr. Todd
Barron, Wellspan Health
Neurosciences Director

Neuropsychological Testing:
What, Why, and When This
Key Testing Should Occur

Speaker: Dr. Tom Flynn,
Pediatric Neuropsychologist
and Director of
Neuropsychology at CHOP

Register: https://us02web.zoom.us/webinar/register/WN_IVH4-YXeQjepQil75Tzu1g#/registration

**Young Adult
Bereavement Support
Group**

The Epilepsy Foundation is expanding its bereavement support services to offer a Young Adult Bereavement Virtual Support Group. The group is for 18-26-year-olds who have lost a sibling to epilepsy and are looking to connect with others who have experienced the same loss. Meetings will be held monthly on the third Tuesday of each month.

Registration is required:
https://efaorg.az1.qualtrics.com/jfe/form/SV_09cRXmJcFHILvU2

**Seizure
Recognition and
First Aid
Certification
Trainings**

- in English

May 2, 2023, 4 p.m. ET
June 6, 2023, 4 p.m. ET
(Session in recognition of
Men's Health Month)

Register at
learn.epilepsy.com

- in Spanish

May 11, 2023, 1 p.m. ET
Register at bit.ly/3UMxKlq

June 8, 2023, 1 p.m. ET
Register at bit.ly/3UMxXol

**Walk to END
EPILEPSY events**

New Milford, CT • May 6

Plainfield, CT • May 7

Tolland, CT • May 7

Farmington, CT • May 13

Orange, CT • May 13

Denver, CO • June 11

West Des Moines, IA •
April 29

Iowa City, IA • June 3

Indianapolis, IN • April 29

Lexington, KY • June 10

Owensboro, KY • June 17

Paducah, KY • June 17

Louisville, KY • June 24

Billings, MT • May 20

Omaha, NE • April 22

Reno, NV • May 6

Lawrenceville, NJ • June 3

Fargo, ND • June 8

Mason, OH • June 3

Portland, OR • June 17

Lehigh Valley, PA •
June 10

Philadelphia, PA • June 17

Waco, TX • April 29

Sioux Falls, SD • June 10

Salt Lake City, UT •
June 17

Seattle, WA • June 24

Washington, D.C. • May 6

Eau Claire, WI • May 21

Madison, June 10

Find updated locations at
[WalktoEndEpilepsy.org/
Locations](http://WalktoEndEpilepsy.org/Locations)

**Visit for
[epilepsy.com/
events](http://epilepsy.com/events) to see
more events in
your area.**

*Calendar compiled
by Sara Wyen*



Spring into Savory Dishes

As we head into spring, add some zest to your routine with one of these savory dinner dishes.

Recipes courtesy of Nutricia KetoCal®



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

Mushroom and Spinach Curry - 4:1 Ratio (201 Calories)

Ingredients

- 20 g KetoCal 4:1 LQ Unflavored
- 16 g olive oil
- 12 g mushrooms, raw, white
- 12 g peppers, green, raw
- 20 g spinach, raw
- 1 g tomato puree
- 5 g spring onions or scallions, raw, bulbs and tops
- 2 g garlic paste
- 31 g tomatoes, canned, diced
- 1 g curry powder

Directions

1. Heat the oil in a pan.
2. Place the spring onions, peppers, mushroom, garlic, tomato puree into the pan and cook on a medium heat for 5 minutes.
3. Add the chopped tomatoes, curry powder, spinach and cook for 5 minutes further on low heat
4. Mix in the KetoCal (unflavored) into the curry and serve.

Cream-of-Taco Soup - 4:1 Ratio (358 Calories)

Ingredients

- 120 g (about half a tetra box) of KetoCal 4:1 LQ Unflavored
- 2 g chicken bouillon granules, dissolved in 1 tbsp (15 g) water
- 16 g olive oil
- 10 g tomato paste
- 10 g green pepper, diced
- 5 g red onion, diced
- 10 g avocado, diced
- 1 g cilantro, chopped
- 0.5 g chili powder
- 0.5 g cumin
- 0.5 g paprika
- 0.5 g oregano

Directions

1. Heat olive oil in a pan on low.
2. Add green peppers and onions to oil and saute until slightly tender (about 5-10 minutes).
3. Add bouillon (dissolved in the 1 tbsp water) and KetoCal LQ, blend together.
4. Add tomato paste, stir well.
5. Add spices 0.5 g each of chili powder, cumin, paprika, and oregano (Note- This may be spicy for little ones so consider adding less and adjusting to taste).
6. Stir well over low heat until ingredients are well blended (do not overheat on higher temperatures or cook too long, this alters the texture).
7. Pour soup into a bowl, top with diced avocado and chopped cilantro.

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

Stress & Seizures

By Kaitlyn Gallagher



April is recognized as National Stress Awareness Month. Stress commonly refers to mental or physical strain or tension and can be caused by many things from major life events to everyday activities. Stress can be a trigger for seizures. It causes changes in the brain and body that can affect the brain's electrical activity and make it more likely for a seizure to occur. Stress can also disrupt sleep patterns, and lack of sleep is also a trigger for seizures in some people with epilepsy.

Below are a few suggestions to help you manage stress:

Practice meditation and mindfulness. Meditation is a great practice for people who do not have a lot of time in their day but need help minimizing stress.

Meditation and mindfulness can help you reflect on positive thoughts and cope with day-to-day challenges.

Exercise on a regular basis. Yoga, light jogging, or taking a walk are just a few ways you can practice self-care and reduce stress through exercise. Physical activity can help improve your own health by lowering blood pressure, improving mental health and cognitive function, and lowering your risk of stroke. Before beginning any exercise routine, check in with your healthcare provider and make sure that it's safe to begin any new type of exercise.

Join a support group. Talking to other people who are experiencing similar challenges can help reduce the loneliness and stress that comes with living with a chronic illness. There are many support groups available online or in-person to help you connect with others when you are searching for community.

Keep a diary. Log the stressful thoughts you have during the day as they come up. Reflect on why you felt stressed at that time and see if you can make any connections between certain activities or situations that make you more anxious than usual. Once you've identified these triggers, do the best you can to eliminate them from your daily routine.

Have a daily routine, which includes a consistent bedtime schedule. Getting enough sleep is one of the most important priorities for people living with epilepsy. Reduce noise, light, and any distractions as best as you can before heading to bed. The more consistent your nighttime routine, the more likely your body will recognize when it's time to go to sleep. Avoid using electronic devices at least one hour before going to sleep to help your body wind down. The better your sleep quality, the less likely you are to feel stressed out the next day.

Remember, it's important to seek help if you're feeling overwhelmed or having trouble managing your seizures due to stress. The Epilepsy Foundation's 24/7 Helpline (800.332.1000) offers supportive listening, assistance, and referrals to services.





Words from the epilepsy community

As a playwright and actor, I finally decided to channel my frustration with the medication and our situation into the best way I could express myself. I decided to write a play called “Seize the Day After” about parents who support their children with seizures and the obstacles they overcome.

Through theater, I hoped other people would know what it felt like to care for a child with epilepsy, and I hoped to connect families going through similar struggles.

Nadine, parent of a child with epilepsy



The mission of the Epilepsy Foundation
is to lead the fight to overcome
the challenges of living with epilepsy
and to accelerate therapies
to stop seizures, find cures, and save lives.

Learn more at epilepsy.com