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Epilepsy

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The Epilepsy Foundation

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“With epilepsy, it’s beneficial to establish a support system including doctors, caregivers, and trusted friends or family members.”
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KARAN BRAR AND SOPHIE REYNOLDS

The podcast co-hosts discuss the biggest challenges facing people with epilepsy

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Community and Connection Help Combat Stigma for People with Epilepsy

For the 1 in 26 people living with epilepsy in the United States, fostering community and connection plays a vital role in improving their care and quality of life.

Photo courtesy of The Epilepsy Foundation

Epilepsy, a neurological disorder characterized by recurring, unprovoked seizures, is often burdened by stigma and misconceptions. Although epilepsy is common, affecting an estimated 3.4 million people in the United States according to the CDC, individuals with epilepsy frequently experience societal stigma. This stigma shows up in many ways that may keep people from feeling safe to talk about seizures or to seek help. However, education, support groups and resources, and personal storytelling are powerful tools in combating stigma, shifting perceptions, and reinforcing the message that no one has to face epilepsy alone.

For over 50 years, the Epilepsy Foundation of America has been at the forefront of promoting epilepsy awareness and understanding. The Epilepsy Foundation has recently updated its mission and vision statements to better align with its focus on community support. The new vision serves as a call to action, emphasizing the importance of community: “So no one faces epilepsy alone.”

“These statements acknowledge the challenges people with epilepsy may face while empowering them to navigate their individual journeys with knowledge and hope,” said Bernice Martin Lee, chief executive officer of the Epilepsy Foundation.

A valued community

The Epilepsy Foundation is where empowered journeys begin, helping people navigate the complexities of epilepsy while serving as a trusted resource for education, advocacy, and support. The epilepsy community encompasses people from all walks of life, including adults and children, from the newly diagnosed to those who have lived with the disorder for decades, their caregivers, family members, and healthcare providers. Epilepsy knows no boundaries, affecting people of all genders, races, ethnic backgrounds, and socioeconomic backgrounds. In more than half of all cases, the cause is unknown.

One key initiative is its Seizure First Aid certification program, which equips people with the knowledge to recognize and respond to seizures. This training can make a life-saving difference and is recommended for anyone who knows, cares for, or works with individuals living with epilepsy.

The Epilepsy Foundation’s signature in-person event, the National Epilepsy Walk, was held in March in Washington, D.C. This event offers an opportunity to celebrate and unite the epilepsy community, raise awareness, and show solidarity with individuals living with epilepsy. Participants can connect with others, share their stories, and contribute to a collective effort to combat stigma and inspire change.

For continued community and connection, the Epilepsy Foundation encourages everyone to talk about epilepsy, share their story, participate in walks and awareness months, find their local Epilepsy Foundations, and more. For more information about epilepsy, please visit epilepsy.com. Together, we can create a world where no one faces epilepsy alone.

Written by **The Epilepsy Foundation**

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Former Bodybuilding Champion Doesn't Let Drug-Resistant Epilepsy Stop Her

Jenee Leger has always worked to be the best at everything she did — from track and field to bodybuilding.

Jenee Leger | Photo courtesy of LivaNova

She was a four-year college athlete, went on to be a Fitness Olympia competitor and participated in the International Federation of Bodybuilding & Fitness Professional League. Being a champion has always been in her DNA, but it hasn't always been easy, as she's dealt with seizures most of her life.

Leger began having seizures in elementary school, but at the time, they were written off as daydreaming. It wasn't until she was 25 that the seizures became more frequent, and she received an official epilepsy diagnosis from a neurologist. But this didn't stop Leger from staying on her path as a champion bodybuilder and living her life.

Searching for an answer

Over the coming years, Leger and her care team tried different medications and dosages while searching for what would work best. Experiencing 10-15 seizures a day for years, Leger found it harder to do the things she loved the most, like running, working out, and simply being a mom to her newborn. These seizures continued despite her taking upwards of three medications at the same time.

Leger battles drug-resistant epilepsy (DRE) — a diagnosis given to patients after two appropriately prescribed, tolerated, and properly used anti-seizure medications fail to achieve sustained seizure freedom. DRE is common, in fact, for 1 out of every 3 patients with epilepsy, medication alone fails to control seizure activity.

That's when her neurologist recommended VNS Therapy™, a device that helps prevent seizures before they start and stop them if they do.

VNS Therapy™

VNS Therapy™ is an add-on treatment for people 4 and older living with drug-resistant focal seizures. It has been Food and Drug Administration-approved since 1997. The VNS Therapy™ device sends mild pulses through the left vagus nerve to areas of the brain that are associated with seizures. The device is placed under the skin of the chest and connected to the left vagus nerve in the neck in an outpatient procedure.

VNS Therapy™ can safely lead to fewer, shorter seizures and better recovery after seizures. Studies also show many quality-of-life benefits including improved alertness, mood, and memory.

Commonly reported side effects of VNS Therapy™ include: voice alteration or hoarseness, increased coughing, sore throat, prickling or tingling of the skin, and shortness of breath. These side effects generally only occur during stimulation. They become less noticeable over time for most patients. Infection is the most common complication of the surgical procedure. Important Safety Information can be found at www.vnstherapy.com/safety.

Life in control

Individual results may vary, however, VNS Therapy™ has improved Leger's quality of life and allowed her to get back on track to becoming a champion.

With more control of her seizures, Leger is getting back to the things she loves most in life. "VNS Therapy™ is a life changer for me," she said. "I get to be present with my loved ones, exercise and run, pursue my passion for healthcare marketing, advocate for epilepsy awareness, and make a meaningful impact on my community every day."

Gaining back more control over her life, Leger has also developed a strong passion for advocating for others with epilepsy.

Even though she doesn't aim for gold medals now, Leger's days of being a champion aren't over. Now, she's a positive force for those with epilepsy in her community, working with local nonprofits to drive awareness of epilepsy and connect those affected.

"Having a support team and feeling connected really makes a difference," Leger said. In 2024, she hosted a first for her community: a 5k walk for epilepsy. Hundreds of people attended the event, but Leger isn't ready to stop there. "No one is alone in my community as long as I'm here," she said.

Written by **LivaNova**

To learn more about VNS Therapy™, visit **VNSTherapy.com**

VNS Therapy™

LivaNova Epilepsy

Living With Epilepsy or **Someone Who Has It**

Epilepsy presents many challenges. However, there are several best practices that may help you or someone you care for live a healthy and fulfilling life after an epilepsy diagnosis.

According to the U.S. Centers for Disease Control and Prevention (CDC), there are currently about 3.4 million people in the United States living with epilepsy. Nearly 4% of Americans develop epilepsy, while about 9% will experience a seizure at some point in their lives. Epilepsy affects people of all ages, but more frequently children and older adults.

Epilepsy causes seizures, or disruptions of the electrical communication in the brain. Seizures can present as changes in sensation, emotions, or behavior, or as convulsions, muscle spasms, or loss of consciousness. Only a doctor can diagnose epilepsy and recommend a specific course of treatment.

Approaches for treating epilepsy vary. For about 70% of epilepsy patients, seizures can be controlled with medication. When medication is ineffective or causes significant side effects, physicians might recommend surgery, or prescribe a special diet or neuromodulation device, which stimulates nerves or specific brain regions to disrupt abnormal brain activity leading up to a seizure.

While the frequency and severity of seizures can usually be managed, there's currently no cure for epilepsy. Additional research is needed to determine the origin points of seizures and to predict and prevent them from occurring.

Day-to-day challenges

Receiving an epilepsy diagnosis — for yourself, a child, or someone close to you — might feel overwhelming. You might worry about seizures occurring unexpectedly and interfering with daily life. Seizures might make it difficult to go to work or school, drive, or socialize, and some lifestyle adjustments might be necessary. Sometimes, epilepsy medications have side effects that make people feel tired, weak, or forgetful.

Another challenge is that the public generally doesn't understand epilepsy well. Others may not have witnessed a seizure before and may be unsure how to respond. Or, they might assume epilepsy is universally debilitating and perpetuate stigmas about it. Therefore, it's important to share accurate information. The Epilepsy Foundation provides excellent resources for patients, families, and communities.

How to manage epilepsy

With epilepsy, it's beneficial to establish a support system that includes doctors, caregivers, and trusted friends or family members. The CDC recommends some additional strategies to manage epilepsy, feel better, and enjoy an improved quality of life.

- First, you'll want to understand epilepsy and your treatment. Talk to your doctor about health concerns and other medications, and take prescribed seizure medicines as directed.
- If you're experiencing seizures, try to track when they happen. See if there might be a pattern to their occurrence or if something triggers them.
- Try to maintain a healthy lifestyle, get about eight hours of sleep per night, exercise regularly and safely, eat a balanced diet, avoid tobacco and unprescribed drugs, and limit alcohol consumption.
- Practice stress reduction techniques, talk to someone about how you're feeling emotionally, try exercises or games to boost memory, and keep in touch with friends and family.
- Explore epilepsy self-management programs. Typically, after a few training sessions, these can then be practiced on your own to better manage symptoms independently. The Managing Epilepsy Well Network outlines several effective programs.
- For questions about epilepsy, call the Epilepsy Foundation's 24/7 Helpline. Available in English (1-800-332-1000) and Spanish (1-866-748-8008), the helpline's specialists can answer questions and connect you to nearby resources.

Written by **American Brain Foundation**

The Podcast Teaching Young Adults What They Need to Know About Epilepsy

Actors Karan Brar and Sophie Reynolds, co-hosts of "The Now What Podcast: Young Adults and Epilepsy," discuss the biggest challenges facing people with epilepsy and what the public should know to provide better support.

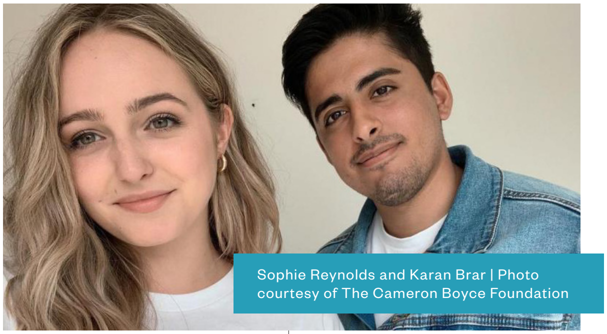
What inspired you to start "The Now What Podcast"?

Karan Brar: With the rise of podcasts, we wanted to create a meaningful platform for discussing epilepsy. Our goal was to engage listeners with The Cameron Boyce Foundation by offering clear, relatable information, like speaking to a peer.

Sophie Reynolds: Many epilepsy podcasts focus on older adults or parents, so we wanted to create a space for younger voices. Our podcast blends serious discussions with medical professionals and lighter episodes on lifestyle, showing how epilepsy fits into everyday life. It's about balancing the challenges with the realities of living with epilepsy, making the experience relatable and engaging.

What do you think are the biggest knowledge gaps about epilepsy, and what can we do to close those gaps?

SR: A major gap in understanding epilepsy is the many misconceptions, like the different types of seizures and what causes epilepsy. It's an individual condition, and the stigma often prevents people from asking questions. To close these gaps, we need open conversations and for people to educate themselves. This allows us to support each other and makes it easier for those with epilepsy to share their experiences.


Sophie Reynolds and Karan Brar | Photo courtesy of The Cameron Boyce Foundation

What do you think are the most important things someone living with epilepsy — or someone who knows and supports someone with epilepsy — should understand about the condition?

KB: Epilepsy is unique to each individual, and it's important to discuss it openly. A moment that stood out to me was when I told my mom about Cameron's epilepsy, and she assumed medication was the end of it. However, epilepsy is ongoing — it requires evolving treatment and understanding as the person's needs change. It's crucial to keep this in mind to ensure ongoing support.

What are some of the challenges people living with epilepsy face in their daily lives, and how can friends, family, and communities provide better support?

KB: A major challenge is finding the right medication. It can be time-consuming and difficult, especially when medications lose effectiveness over time. Additionally, managing symptoms often involves diet and routine changes that require constant attention. Friends and family can help by being patient, understanding, and offering consistent encouragement. Small acts of support can ease this burden.

What's one actionable step you'd encourage our readers to take to support individuals living with epilepsy?

SR: I recommend visiting the Cameron Boyce Foundation website to learn about epilepsy and how to help during a seizure. Understanding epilepsy and knowing what to do in an emergency makes you more prepared.

Bridging the Treatment Gap: Uniting for Global Epilepsy Care and Awareness

Despite affecting over 50 million people globally, epilepsy often remains misunderstood and inadequately treated, particularly in low-income countries where stigma and resource shortages prevail.

Epilepsy seizures are caused by abnormal electrical signaling in the brain. Most people probably think of a seizure as jerking or thrashing, but there are other types. Some seizures look as if the person is "zoned out," while during others, people may see or hear things that aren't there, scream or make other noises, or collapse on the ground. When someone has a seizure, they usually don't know what's going on around them.

Unfortunately, of the 50 million people with epilepsy worldwide, more than 30 million are not being treated. This treatment gap is estimated at 75% in low- and middle-income countries, meaning that three-fourths of people with epilepsy are not receiving treatment. In some areas of Africa and Asia, the treatment gap exceeds 90%.

Within the field, we often talk about "coming out of the shadows." We want to erase the stigma so that people who have seizures don't feel ashamed or afraid, and so that everyone can understand how epilepsy affects people's lives. Many people with epilepsy and their families have come out of the shadows, but they need support.

The public, healthcare providers, the media, schools — each part of a community has a role in improving epilepsy awareness and understanding and breaking down barriers to treatment. Together, we can work toward a world where no person's life is limited by their seizures.

Written by **League Against Epilepsy**

Safety Precautions to **Enhance Quality of Life for People With Epilepsy**

An epilepsy diagnosis, which can come at any age, can provoke questions, anxieties, and doubts about the future.

Many people with epilepsy and their caregivers grapple with fears about the imminent threat of a seizure and how it could limit their ability to stay safe or live a full life. As understandable as these concerns are, for many people living with epilepsy, a full and rewarding life is still possible, especially when simple safety precautions are followed.

Plan ahead

One of the most important tips for ensuring your safety is preparation. Having a seizure action plan in place and sharing it with people in your life empowers friends, family, and co-workers to respond appropriately in case of a seizure. A seizure action plan provides information in one place about your seizures and how others can and should respond, including if and when to call 911 and when to just stay calm and keep you safe. It may provide information about where to find your emergency rescue medication if you have one and when to administer it if needed.

> **One of the most important tips for ensuring your safety is preparation.**

Safety at home

Home is where we spend the majority of our time and where we should feel the safest and most comfortable. Putting the following safeguards in place can help ensure your home is set up with your safety in mind.

People with epilepsy should take showers instead of baths and never lock the bathroom door. Beds should be low to the floor. Precautions should be taken in the kitchen when working with open flames and sharp objects.

Safety in water

People with epilepsy can swim and participate in water sports, as long as appropriate safety measures are followed diligently. Always talk to your healthcare provider to determine if swimming or other water activities are right for you. People with epilepsy are at an increased risk of drowning, so taking extra precautions around water is of critical importance.

Some safety tips include:

- Never swim alone, and whenever possible, swim with a lifeguard on duty.
- Always swim with someone who knows you have seizures and can assist you if needed.
  • Wear brightly colored swim gear.
- Avoid colors that blend in with water and your surroundings.
- If you are in a pool, swim in an outside lane so it is easier for someone to help you if necessary.
- Wearing a life jacket is recommended for most water sports.
- It is also important to have someone with you who knows how to help if you have a seizure, like a coach or instructor.

Safety at school

If you have a student with epilepsy in your care, there are steps you can take to ensure a safe school year. In addition to helping create a safer school environment, working with your school to inform and educate classmates and teachers will help spread awareness and reduce the stigma often associated with epilepsy.

Ensure that all staff at the school are trained in seizure recognition and first aid. Schedule a meeting with school staff to discuss any accommodation needs and the student's seizure action plan. Share specific details of your student's seizures — this will help the school personalize care for your child more confidently.

It can be scary to navigate an epilepsy diagnosis, but with preparation and some minor modifications to home life and certain activities, individuals with epilepsy can live a full and safe life.

Written by **Epilepsy Alliance America**

When to Seek Care at an Epilepsy Center

More than 300 specialized epilepsy centers in the United States provide access to the full range of diagnostic and treatment options with the goal of controlling seizures and improving quality of life for people living with epilepsy.

Epilepsy is one of the most common chronic neurologic conditions worldwide, affecting 3.4 million people in the United States. Epilepsy affects a person's quality of life and is associated with an increased risk for related physical and mental health problems, and a higher mortality rate than the general population. A new diagnosis of epilepsy has a profound impact on an individual and their family. Among the difficult choices faced is the decision about where and how to pursue medical treatment.

Most often, people begin their epilepsy care with a neurologist in their community. General neurologists have training in seizure diagnosis and treatment, but may not have the expertise of epilepsy center staff. They also do not have access to the full range of diagnostic and treatment options found at specialized epilepsy centers in the United States.

In contrast, epilepsy centers that are accredited by the National Association of Epilepsy Centers (NAEC) have multidisciplinary teams with advanced training in epilepsy care and provide a broad range of diagnostic services and medical, surgical, and dietary therapies. Although the NAEC offers tools to help patients find an epilepsy center, the nearest one may require travel or may have a wait for new appointments. So, how should someone decide when to seek care from an epilepsy center?

The Epilepsy Foundation, American Epilepsy Society, and NAEC recommend that patients seek evaluation at an epilepsy center if they are:

- Continuing to have seizures despite treatment for more than one year
- Continuing to have seizures despite treatment with two different medications
- Experiencing unacceptable side effects from epilepsy therapy
- Concerned about how epilepsy affects their health and daily life
- Pregnant or want to become pregnant
- Seeking a higher level of epilepsy care
- Interested in learning more about what caused their seizures, or about all potential options to treat or cure their epilepsy

Greater expertise, greater outcomes

In the past, the most common reason for referral to an epilepsy center was the search for better seizure control. Approximately 30% of patients with epilepsy have refractory seizures despite treatment with anti-seizure medications. These individuals may benefit from non-medication therapies offered by epilepsy centers, including epilepsy surgery, the ketogenic diet, and neurostimulators.

Even patients who are not candidates for surgery can benefit from the expertise that epilepsy centers offer in the use of newer antiseizure medications and in selecting the most appropriate therapy. Epilepsy centers use advanced diagnostic tools, such as genetic testing, specialized brain imaging, or evaluation in an Epilepsy Monitoring Unit, to better understand each patient's seizures and to select the best treatment option. In some cases, centers may even discover that the diagnosis of epilepsy is incorrect, leading to a more appropriate diagnosis and treatment.

Holistic care

Care in a modern epilepsy center is about more than just seizure control. A multidisciplinary approach means that centers also have resources to improve quality of life and address other ways in which epilepsy impacts a person's life. This may include addressing cognitive, behavioral, or mental health concerns; pregnancy planning and reproductive health; genetic counselling for individuals with complex epilepsy syndromes; or assisting with overcoming barriers to medication access. Centers also offer educational resources designed to help people with epilepsy and their families throughout their epilepsy care journey.

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visit **futureofpersonalhealth.com**