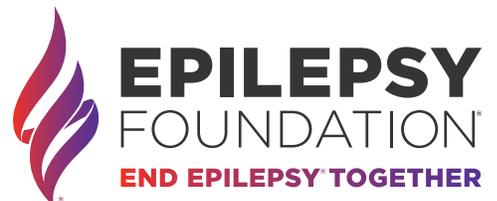


“Change is the law of life.  
And those who only look  
to the past or present are  
certain to miss the future,”  
-John F. Kennedy

# Foundation Quarterly

Issue 1, February 2021



# Welcome

to the inaugural issue of **Foundation Quarterly**, the Epilepsy Foundation's quarterly e-magazine.

While the 2020 global public health crisis brought many economic challenges for the Foundation, it also shed light on the way we currently deliver services to people living with epilepsy and how these efforts measure up against the impact of our mission. Last year, the Epilepsy Foundation underwent a significant transformation, and though our structure and strategies changed, our dedication to serving our community through advocacy, education, direct services, and research endures.

We discovered new ways to meet the challenges we faced with increased focus, stronger partnerships, greater scale and efficiency, as well as new ways to connect with our community in a virtual world. We leveraged our digital engine to get the right resources to those living with epilepsy despite the barriers brought on by the pandemic. We also continued to keep our community informed about our research pipeline and innovations through our print and digital magazine, *Research Quarterly*.

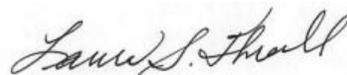
The new year brought exciting opportunities for us to harness the role we have as one of the largest and long-standing nonprofit organizations in the epilepsy community. One of those opportunities was transforming the *Research Quarterly* into a new, completely digital format designed to inspire and inform you on all the amazing work we do at the Epilepsy Foundation.

The revamped *Foundation Quarterly* features key initiatives that have had an impact on the epilepsy community and directly align with the five pillars of our 2025 Strategic Plan:

- Lead the conversation about epilepsy.
- Shape the future of epilepsy healthcare and research.
- Harness the power of our united network to improve lives.
- Expand revenue sources beyond traditional fundraising.
- Become a best-in-class organization leveraging technology and digital assets for greater efficiency and mission delivery.

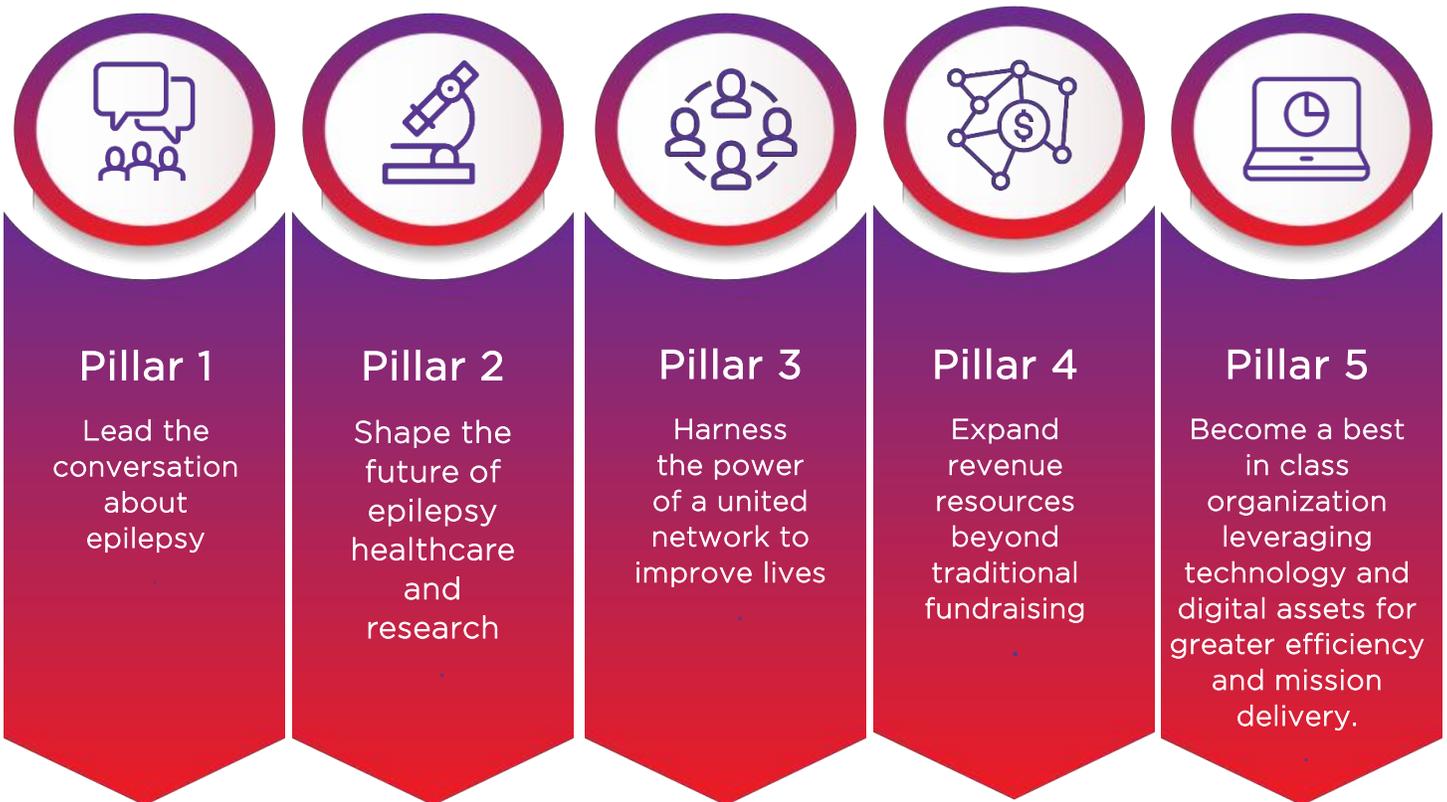
In this inaugural issue, you will read about the successful launch of our first-ever Seizure Recognition & First Aid Certification Training program designed to increase the knowledge, skills and confidence in recognizing seizures and safely respond to them with seizure first aid. In addition, you will learn more about our new Epilepsy Ventures Fund, which will help us accelerate commercialization of innovative epilepsy treatments through capital investment, market awareness and a shared commitment to improve the lives of people living with the epilepsies.

We hope you enjoy this new version and let us know what you think.



Laura Thrall  
President & CEO

# 2025 Strategic Plan - Five Objectives ('Five Pillars')



The Foundation's strategic vision for 2020 - 2025 has five objectives (the 'Five Pillars'). These Pillars were identified through surveys and collaborative discussions with our stakeholders during 2018 - 2019 and were endorsed by our Board of Directors. They create a bedrock for the structure of our organizational priorities over the next five years.

For each Pillar, the Foundation's executive staff leadership defined Key Results that will - if achieved over the five years of this plan - demonstrate dramatic progress toward the goal of Ending Epilepsy Together.

In order to achieve the Key Results, staff leadership will identify specific, measurable, organizational priorities for each year of this plan, and will implement those priorities through the work of its cross-functional teams and partnerships. We will measure and report our progress quarterly, seeking to be transparent with our internal teams and external partners, and to adapt strategies as needed to achieve our goals.



# Pillar 1:

## Lead the Conversation about Epilepsy

The Epilepsy Foundation is informing, inspiring, and engaging everyone to End Epilepsy® Together. In the last quarter, the Epilepsy Foundation has, with the power of the epilepsy community and our partners, accomplished:

- Certifying over 3,000 people during November Epilepsy Awareness Month in Seizure Recognition and First Aid (p. 5)
- Ensuring Access to Care, the COVID-19 Vaccine, and Critical Funding for Epilepsy Programs (p.6)
- Highlighting Community Stories through Our eJourney Blog (p. 7)

# November Seizure First Aid Certification Challenge

by Vicki Kopplin, Mission Outcomes Team Field Director

The Epilepsy Foundation is dedicated to creating and supporting a Seizure Safe Nation. In June 2020, the Epilepsy Foundation launched the first and only Seizure Recognition and First Aid Certification Training to support the 3.4 million people in the United States living with epilepsy. The Seizure Recognition and First Aid Certification Training provides information to increase knowledge, skills, and confidence in recognizing seizures and safely administering seizure first aid.

In celebration of National Epilepsy Awareness Month 2020, the Epilepsy Foundation launched a challenge. Can 2,020 people become certified in seizure first aid in November? The community, partners, and other supporters heard the call and exceeded expectations!

**During November, 3,901 people were certified in seizure first aid. The challenge reached people from 18 to 79 years old from across the country and the world.**

Since seizures can happen anywhere, at any time, and to anyone, the Foundation aimed to reach a broad range of audiences. People with epilepsy need to feel safe everywhere they go. There are now seizure first aid certified people at multiple places of employment, including:

- Airlines
- Schools
- Grocery stores
- Universities
- Fast food restaurants
- Hospitals
- City, county, and state employers

“Thank you so much for the information. It was very informative, and I feel confident now to assist others should they have a seizure.”



[Registration for upcoming classes can be found at learn.epilepsy.com.](https://www.learn.epilepsy.com)

The Epilepsy Foundation would like to thank our partners that invited their employees to take the training and made it possible for more people to become seizure first aid certified by promoting the challenge:

- Cook Children’s Medical Center (Fort Worth, Texas)
- Morehouse School of Medicine (Atlanta, GA)
- American Association of Neuroscience Nurses
- Zeta Phi Beta Sorority
- Neurelis
- LivaNova
- Walgreens
- Illumination Foundation
- Byteflies
- Dow Chemical
- Aquestive
- Monteris Medical
- NextGen Neuro
- UCB

The reach of the seizure first aid certification is global. In addition to certifying at least one person from all 50 states, the Epilepsy Foundation reached 110 people from outside the United States including Israel, Colombia, India, the Bahamas, Germany, Australia, and Belgium.

Since the launch in June, more than 9,000 people have become seizure first aid certified. And the Epilepsy Foundation is not done yet in our pursuit for a Seizure Safe Nation.

# Epilepsy Foundation Tenacious Advocacy Efforts During 2020

by the Epilepsy Foundation Advocacy Team

The Epilepsy Foundation continued to fight for people with the epilepsies and their families despite the challenges during 2020 by:

- Ensuring access to health care, including access to medications and telehealth services
- Advocating for nondiscrimination in care in hospital settings across the country
- Making sure people living with the epilepsies are not left behind in the COVID-19 vaccine rollout
- Fighting, successfully, for funding for important epilepsy-related research and programs

## **Ensuring Access to Care During the COVID-19 Pandemic**

Through advocacy, the Epilepsy Foundation and our grassroots advocates are helping ensure that people living with the epilepsies and their families have access to needed healthcare and other support throughout the COVID-19 public health emergency. Early on in the pandemic, the Foundation was successful in requiring Medicare plans to allow up to a 90-day supply of anti-seizure medications and, with partners, relax flexibilities so people could access healthcare via telehealth.

## **Vaccine Access in Long-Term Care Facilities**

As the possibility of a COVID-19 vaccine came to light, the Foundation advocated for people with epilepsy to receive the vaccine at the appropriate phase of allocation. As a result, changes were made to the Centers for Disease Control and Prevention (CDC)'s recommendations so that people of all ages in congregate settings were included in Phase 1(a) of the vaccine rollout. Also, the term "health care personnel" was broadly defined in Phase 1(a) to include important providers like home health workers. This ensures people with epilepsy who live in congregate settings, like long-term care facilities, and their professional care providers are not left behind in receiving the vaccine.

## **Funding for Critical Epilepsy Programs**

Congress's end-of year package included appropriations for federal agencies and programs in Fiscal Year 2021, COVID-19 relief, and other miscellaneous policies. As part of that package, many priorities the Foundation advocated for that will help the epilepsy community were included such as:

- A \$1 million increase for the CDC's Epilepsy program (\$10.5 million total)
- A \$1.250 billion increase for the National Institutes of Health (NIH) (\$42.934 billion total)
- \$1.250 billion in emergency funding for NIH for COVID-19-related efforts
- A \$42.45 million increase for the Food and Drug Administration (FDA)
- \$55 million for the FDA specifically for COVID-19-related efforts
- A suggested increased investment in the VA Epilepsy Centers of Excellence
- Legislation to end surprise medical billing

# Your Stories: Launch of the eJourney Community Blog

By Liz Dueweke MPH, CHES, Manager of Communications and Digital Strategy

For National Epilepsy Awareness Month, the Epilepsy Foundation launched the eJourney Community Blog. As with many great ideas, the eJourney initiative came from a conversation with leaders in the epilepsy community. Board members Camila Coelho and Cynthia Hudson suggested a new approach to telling the stories behind the fight against epilepsy. Camila had recently shared her story with the Foundation via a blog, and the idea behind eJourney was born.

The Epilepsy Foundation will be using our Foundation Quarterly to highlight blogs from the community. In this issue, read an excerpt from Janine F's blog, "What Seizure Freedom Means to Me."

Read more stories at [epilepsy.com/EJourney](http://epilepsy.com/EJourney).



## Janine's Story

Being seizure free has given a whole new meaning to life. I feel reborn, taking chances I never believed I could. I've been given the opportunity for a new beginning.

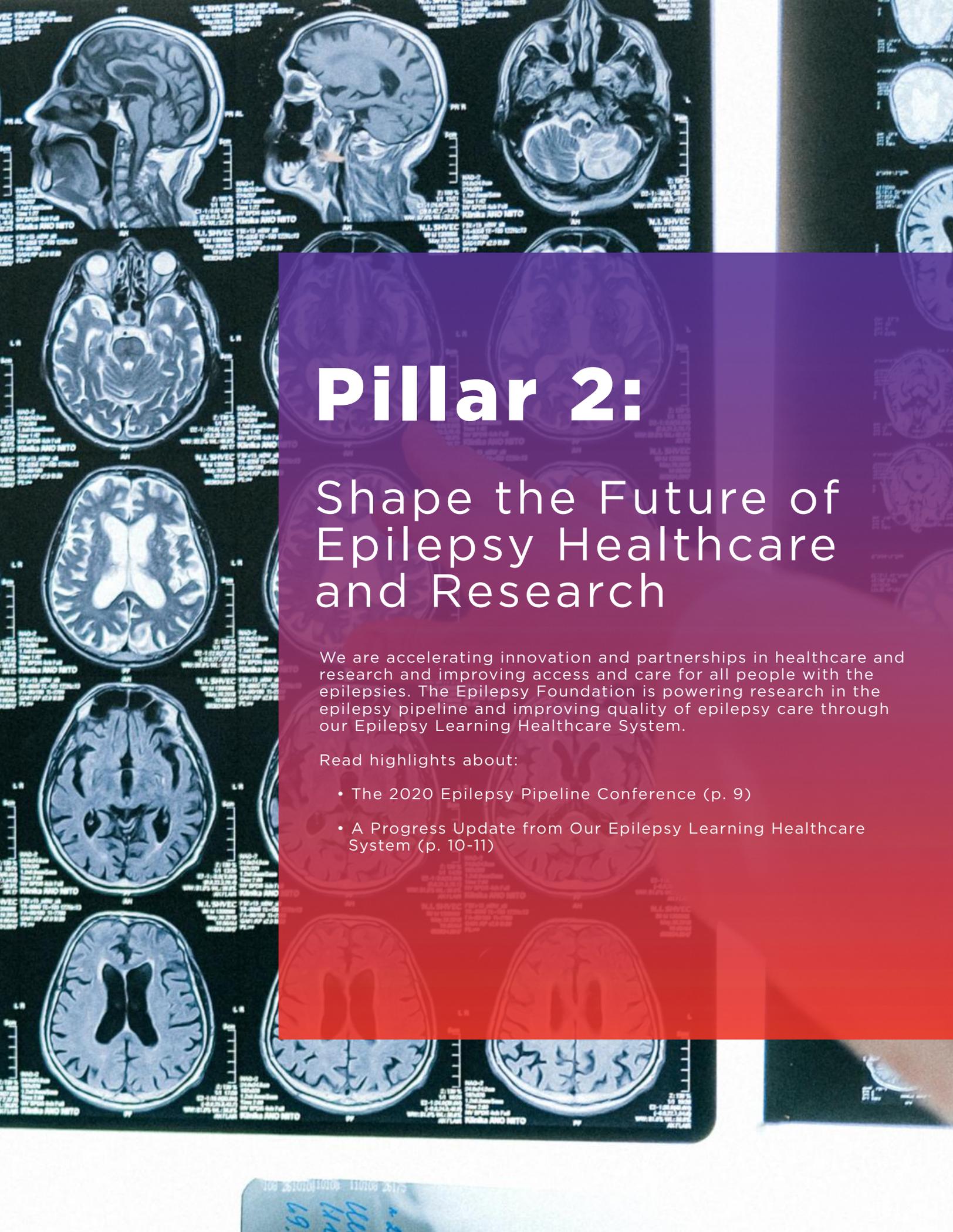
Before my seizures started, I once knew what it was like to be independent. I lost that in a split second. It changed my life because it made me feel helpless in ways I never used to feel before. I was diagnosed with epilepsy at the age of 13 and my life took a huge turn from there. I was living with the constant fear of having a seizure at anytime and anywhere because my epilepsy wasn't controlled by medication

My teenage years were the peak. Sometimes I'd have 4-5 seizures a day. With time they became less frequent, but still never went away. I was given the permission to drive for a couple of years, but then I had to give that up too. The day I gave up my license was the day I felt completely disabled and it changed my whole lifestyle. First my independence was lost, and then my license.

In the late 90s, I was told that I was a candidate for surgery, and as great as that was at the time, I decided to take my chances with medication. I never lost hope until I had taken all the epilepsy medications available. I turned to alternative medicine and made logs of what may have triggered my seizures, but that treatment plan didn't work for me either. I had no other choice but to be dependent on others. As difficult as that was, my husband, family, and friends made it possible for me to not feel like a burden with their unconditional love, care, and support. My 2 boys, very young at the time, used to help me if I had a seizure in their presence. It was heartbreaking to see them do that and for them to see me in that state.

My only remaining hope was to finally have that surgery: amygdalohippocampectomy. It feels amazing now to see my children so relieved and to hear the excitement in their voices when they tell their friends about how their mom no longer has seizures.

I will do everything in my power to support people who live with epilepsy in any possible way that I can.

The background of the entire page is a collage of various brain MRI scans. At the top, there are three sagittal views of the brain. Below them are several axial views showing different cross-sections of the brain. The scans are in grayscale and show detailed anatomical structures. A semi-transparent purple and red gradient overlay covers the right side of the page, where the text is placed.

# Pillar 2:

## Shape the Future of Epilepsy Healthcare and Research

We are accelerating innovation and partnerships in healthcare and research and improving access and care for all people with the epilepsies. The Epilepsy Foundation is powering research in the epilepsy pipeline and improving quality of epilepsy care through our Epilepsy Learning Healthcare System.

Read highlights about:

- The 2020 Epilepsy Pipeline Conference (p. 9)
- A Progress Update from Our Epilepsy Learning Healthcare System (p. 10-11)

# 2020 Pipeline Conference and Shark Tank Competition

by Dr. Jacqueline French, Chief Medical and Innovation Officer

On a bi-annual basis, the Epilepsy Foundation organizes the Pipeline Conference which allows the epilepsy community to learn about new innovations in the pipeline, including new therapeutic and diagnostic medications, devices, and other interventions. This convening is designed to foster collaboration within our community by bringing together researchers, industry partners, as well as patients' and caregivers' perspectives to reflect on our progress, assess the state of the field, and determine where we need to continue to invest our resources.

This year, the COVID-19 pandemic provided the opportunity to virtually host our Pipeline Conference. As a result, over 500 people from all over the world attended the event, which represents the largest audience to date. The virtual nature of the conference also allowed us to provide access to many of the talks on our website. Visit [Epilepsy.com/Pipeline2020](https://www.epilepsy.com/Pipeline2020) to learn about the latest epilepsy product development and watch some of the sessions.

Attendees learned about many exciting and novel therapies currently in development, including genetic therapies, cell therapies, treatments for rare and ultra-rare epilepsy syndromes, and rescue therapies for epilepsy emergencies.

Despite the pandemic, epilepsy therapeutic development has not stopped. For example, the pipeline highlighted some of the first potential disease-modifying therapies targeting the genetic underpinnings of Dravet syndrome, a rare epilepsy. Early trials for these therapies are already underway.

The audience also heard from researchers working on diagnosis and detection devices including a discussion about SUDEP prevention, and devices for improving seizure control. The conference also included important sessions to discuss the unmet needs within the epilepsy community, including patient and caregiver perspectives about possible improvements in designing evaluation metrics for more personalized interventions.

Our pipeline conference also includes the Epilepsy Foundation "Shark Tank," the epilepsy community's opportunity to showcase and fund entrepreneurs creating products to improve the lives of people with epilepsy. This year, two entrepreneurs received funding in the Shark Tank.



Jong Woo Lee MD and Andres Rodriguez (Soterya) won for a night-time smart-mattress intended to reposition individuals and stimulate them post-seizure to prevent sudden unexpected death in epilepsy (SUDEP).

The other winner was Keely McArthur (Talia Newman Wearables, LLC), parent of a child living with epilepsy, for an emergency epilepsy band accessory to ensure that rescue medications are always where a person needs them to be.



## Stay Tuned for the 2021 Shark Tank Competition

Momentum is growing for innovation in epilepsy. The Epilepsy Foundation is thrilled to be able to foster this innovation, and to bring information to our community. Look for the next Shark Tank competition at the Anti-Epileptic Drug and Device meeting, held on June 16-18, 2021. The 2021 Shark Tank competition will have both an investment prize up to \$250,000 for a promising new epilepsy product, technology, or therapy and a new "community impact award" of \$ 25,000 for an innovation voted on by the community, for the community.

More information is available at [epilepsy.com/SharkTank](https://www.epilepsy.com/SharkTank).

# Epilepsy Learning Healthcare System: Improving Care and Quality of Life

Kathleen Farrell MB BCH BAO, Senior Director, ELHS

The Epilepsy Learning Healthcare System (ELHS) mission is to design and implement a system of co-production that will improve outcomes for people with epilepsy and their families/caregivers, specifically by improving quality of life, seizure control, and rates of seizure freedom. The network vision is for all people with epilepsy to live their highest quality of life, striving for freedom from seizures and side effects, and we won't stop until we get there.

Two years after launch, ELHS includes 13 National Association of Epilepsy Centers-accredited pediatric and adult epilepsy centers, multiple local Epilepsy Foundation offices, other national or community-based non-profit organizations (including those that represent rare epilepsies), and patients and family partners.

The network has demonstrated proof of concept by:

- Completing milestones on epilepsy center recruitment and retention
- Case report form and measures development
- Registry build and data collection. (Read more about the ELHS registry in our next issue of the Foundation Quarterly)
- Quality improvement (QI) testing

Quality improvement testing is a systematic approach using specific methods to improve quality with the goal of achieving successful and sustained improvement. ELHS QI testing resulted in more patients at our partner NAEC centers documenting their seizures, the rapid creation of telehealth resources in response to the COVID-19 pandemic, and generation of QI reports on key measures.

## Current ELHS priority areas include:

- Improving seizure documentation
- Addressing barriers to medication adherence
- Quality of life for all people with epilepsy
- Focusing on telemedicine
- Check out patient tools developed by ELHS.

## ELHS Accomplishments in 2020

- ELHS featured twice in 2020 in the neurology insert of USA Today. Read the most recent article.
- A QI Science Leadership Consortium was established in Summer 2020 to discuss the landscape of Quality Improvement (QI) Science efforts in epilepsy and in leveraging data to establish and evaluate healthcare utilization, health economics, and quality outcomes measures. The Consortium will inform areas of value in ELHS work and catalyze ELHS work based on priority areas, and includes in its membership 7 industry partners, in addition to representatives from the Centers for Disease Control and Prevention (CDC) and National Association of Epilepsy Centers (NAEC).
- In December 2020, ELHS was awarded a 2020 PhRMA Challenge Award in Value Assessment application entitled "Co-Production in Learning Healthcare Systems is the Key to Unlocking True Healthcare Value."

2021 will bring new opportunities for growth and demonstration of value for ELHS as the vehicle for epilepsy care improvement, and the network looks forward to sharing more soon!

Learn more at [epilepsy.com/ELHS](https://epilepsy.com/ELHS) or contact [elhs@efa.org](mailto:elhs@efa.org)

# EPILEPSY LEARNING HEALTH SYSTEM (ELHS) 2020 IN REVIEW

## ELHS Representation



**12** U.S. states



**13** clinical teams  
comprised of 68 clinical  
personnel and 13 Patient  
Family Partners (PFPs)



**18** community teams  
(local Epilepsy Foundations,  
Rare Epilepsy Network  
organizations and advocacy  
non-profits)



**Data Registry  
with:**

**14** QI Metrics  
**5** Case Reports Forms  
**3** Data Quality Measures



**6**  
new clinical and  
community leaders  
of QI workgroups

**3**

Quality Improvement-phase  
Workgroups - Telemedicine,  
Seizure Documentation, Barriers  
to Medication Adherence



Seeking to improve upon  
**86.84%**  
Seizure Documentation rate  
to include all network sites

**3**

publications  
(+ more accepted!)

**2**

virtual  
Learning Sessions  
involving  
170+ attendees

**11**

Action Period  
(AP) webinars  
reaching 570+  
participants

**2**



academic posters at the  
American Epilepsy  
Society meeting

**1**

Telemedicine Visit  
Checklist developed  
(available in both  
English & Spanish)



**1**

PhRMA  
Foundation  
grant awarded

**1**



Barriers to Medication  
Adherence Toolkit containing  
Barriers to Adherence  
assessment surveys and 10  
Adherence Educational Tools.

**3**

module IHI Open  
School introductory  
course on Quality  
Improvement made  
available at no cost to  
our network members

**1**



virtual QISLC  
Roundtable meeting  
with a total of 84  
business hours with  
industry focused on  
Quality Improvement



**Social Engagement**

**46**

social media posts

**208K**

social media impression

**8.4k**

social media engagements  
(**308% increase**  
in engagements  
compared to 2019)

**57.5k**

engagements with ELHS  
through the Epilepsy  
Foundation weekly  
e-newsletter compared  
to 2019

**2**

features  
in the national  
newspaper  
USA Today,  
reaching a daily  
readership of  
**2+ million**  
people  
Educational  
Tools.

**10**

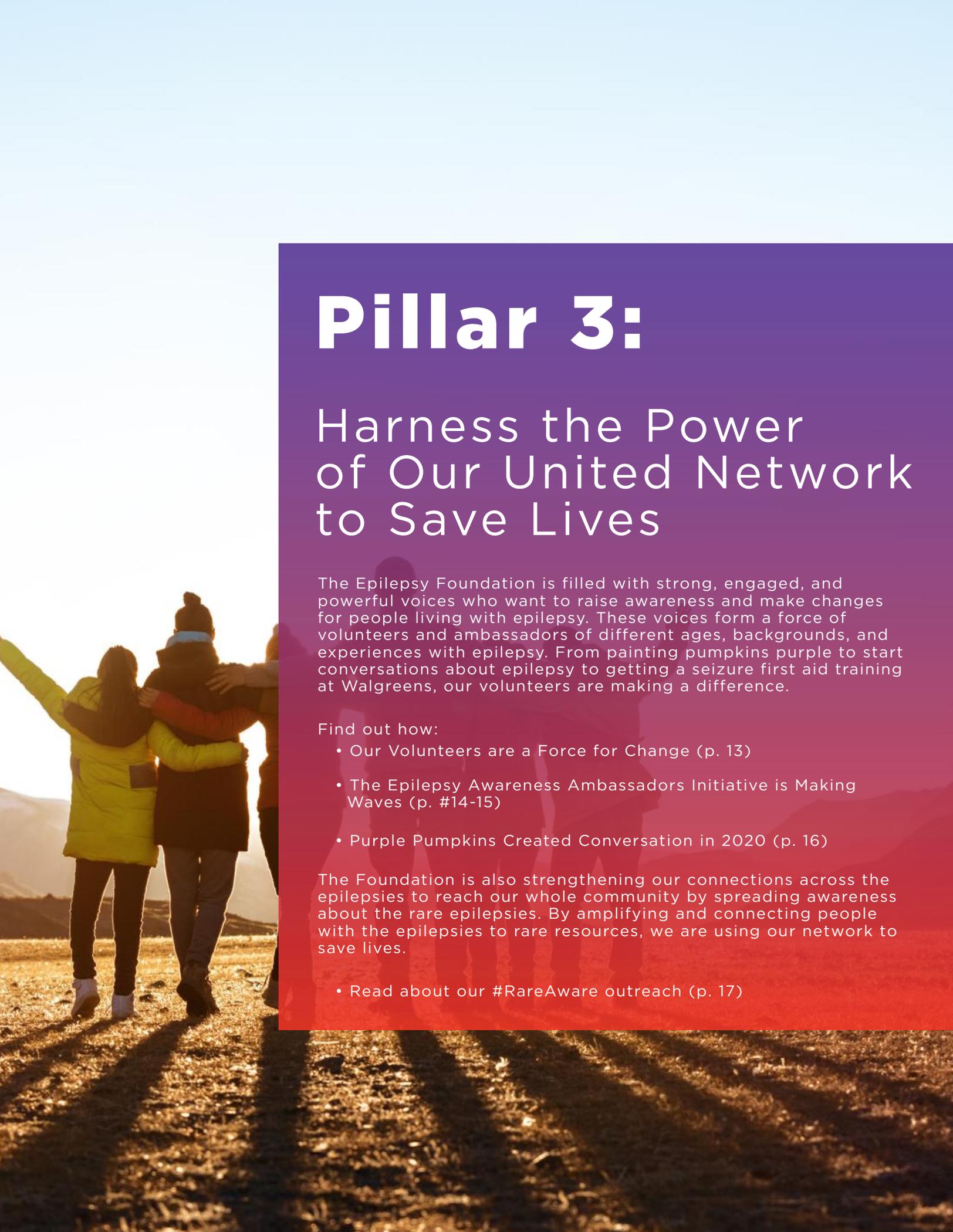
e-newsletters hitting  
1,480+ inboxes



**1,372**

visits to ELHS website

**Learn More:  
Epilepsy.com/  
ELHS**

A group of people, including a child, are hugging on a grassy hill at sunset. The scene is backlit by the sun, creating a warm, golden glow. The people are wearing winter coats, and their shadows are cast long on the ground. The background shows a clear sky and distant hills.

# Pillar 3:

## Harness the Power of Our United Network to Save Lives

The Epilepsy Foundation is filled with strong, engaged, and powerful voices who want to raise awareness and make changes for people living with epilepsy. These voices form a force of volunteers and ambassadors of different ages, backgrounds, and experiences with epilepsy. From painting pumpkins purple to start conversations about epilepsy to getting a seizure first aid training at Walgreens, our volunteers are making a difference.

Find out how:

- Our Volunteers are a Force for Change (p. 13)
- The Epilepsy Awareness Ambassadors Initiative is Making Waves (p. #14-15)
- Purple Pumpkins Created Conversation in 2020 (p. 16)

The Foundation is also strengthening our connections across the epilepsies to reach our whole community by spreading awareness about the rare epilepsies. By amplifying and connecting people with the epilepsies to rare resources, we are using our network to save lives.

- Read about our #RareAware outreach (p. 17)

# A Force for Change: The Epilepsy Foundation's Volunteer Network

By Gail Pundsack, Vice President, Field Operations

Volunteers have been driving the mission of the Epilepsy Foundation for over 50 years. Our army of volunteers span from coast to coast with people from every walk of life involved at both the local and national level.

Every day, there are volunteers working towards a collective goal to improve health outcomes for individuals and families living with seizures. These treasured volunteers help us:

- Advocate for federal and state initiatives that impact everyone living with the epilepsies
- Spread awareness through social media and bring vibrance to in-person corporate and classroom presentations
- Organize fundraising events that expand our reach to thousands who need help

And much, much more!

These large and small acts, given freely, bind our epilepsy community together and lead to enormous change. The Foundation grows stronger every day because of these selfless acts of kindness.

## Volunteers help us to:

### Bring Awareness to Communities



Alyssa brought epilepsy awareness to her town in New Jersey through:

- The painting of a town rock
- A Proclamation from her mayor declaring November Epilepsy Awareness Month

### Lead Our Initiatives

- Steve in Orange County has been a board leader and hands-on presenter at conferences and Zoom meetings to lend a hand of caring and support to others who have had brain surgery.



### Educate & Inspire Others

- In Illinois, Jessica Chappell hosted a National Epilepsy Awareness Month event for over 90 of her Walgreens colleagues. Her event focused on sharing her story, educating others about epilepsy, and encouraging her colleagues to get certified. Through Jessica's effort, 39 Walgreens employees became seizure first aid certified.

### Build Our Capacity & Help Us Expand Our Reach

- 10 Epilepsy Awareness Ambassadors served as beta testers for the Epilepsy Foundation's new Epilepsy Learning Portal (learn more about the Epilepsy Learning Portal on page #). This system allows the Epilepsy Foundation to further expand its reach in educating people about epilepsy and seizure safety.

### Get Involved with Volunteer Outreach

The Foundation has opportunities for volunteers to play an important part in our organization and we welcome the contributions of your time and talents to better serve those living with epilepsy and their families.

To learn more, please visit our volunteer page: [epilepsy.com/Volunteer](https://epilepsy.com/Volunteer) or email us at [volunteer@efa.org](mailto:volunteer@efa.org).

# Quarterly Update on Epilepsy Awareness Ambassador Activities

by Valerie DiCristoforo, Senior Manager Volunteer Engagement

Epilepsy Awareness Ambassadors are passionate and dedicated volunteers tasked with virtually growing epilepsy awareness across their community. Ambassadors engage in monthly activities that promote all areas of the Epilepsy Foundation's mission to both people living epilepsy and the general public.

Originally launched in May 2020 as an opportunity for volunteers to continue to spread awareness about epilepsy despite the COVID-19 pandemic has grown into a national community of 147 ambassadors.

Activities focus on:

- Educating their local community through social media
- Participation in and promotion of Epilepsy Foundation programs and resources
- Organization and execution of awareness-based activities & events

The Ambassador initiative is a “choose your own adventure” volunteer opportunity designed to provide options for Ambassadors with different interests and availability, allowing them to incorporate epilepsy awareness into their daily life by participating in a minimum of 3 activities a month. Each month, Ambassadors are provided with a list of 12-15 activities from the Epilepsy Foundation. Over the last quarter, the Epilepsy Awareness Ambassador community surpassed 100 Ambassadors.

**Ambassadors participated in 1,615 awareness-building activities and contributing more than 1,424 volunteer hours since May.**

Interested in becoming an Ambassador? Sign-up for an Information Session on March 3rd (2-3:00 p.m. ET) or email [volunteer@efa.org](mailto:volunteer@efa.org) for more information.



Thank You  
Volunteers

## Popular activities in the last quarter include:



- Promoting National Epilepsy Awareness Month (NEAM) through participating in epilepsy Instagram bingo, posting NEAM social media banners, sharing facts about epilepsy, and creating social media polls to educate others
- Carving and painting pumpkins as part of the Purple Pumpkin Project
- Encouraging community members to become seizure first aid certified. To date, 452 of the Ambassador's community members have become seizure first aid certified.
- Creating holiday decorations and epilepsy-themed wreaths to integrate awareness with the cheer of the winter holidays
- Using art, essays, songs, and poetry to highlight and share the stories of epilepsy
- Starting a monthly epilepsy-focused book club to read stories about epilepsy and lift up the work of authors discussing epilepsy
- Posting unique content on social media as well as raising SUDEP awareness on SUDEP Action Day, and promoting epilepsy wellness through the Foundation's Wellness Institute
- Joining a Discord server exclusively designed to further strengthen and connect the Epilepsy Awareness Ambassador community.
- Participating in a quarterly meeting to connect with each other and learn about how to get further involved from Epilepsy Foundation staff

The Epilepsy Foundation is constantly in awe and inspired by all the Ambassadors accomplish and are tremendously grateful to them for sharing their passion, talents, creativity, and enthusiasm.

# Starting Conversations About Epilepsy with Purple Pumpkins

by Jon Scheinman, Director, Youth Programs

The Purple Pumpkin Project™ is a yearly Epilepsy Foundation initiative that takes place in the fall. The goal is to raise epilepsy awareness by painting pumpkins purple and setting them out for all to see. When people are asked, “Why are your pumpkins purple?” they get to discuss epilepsy facts and share their story.



The initiative was started by Ron Lamontagne from Connecticut. Ron’s youngest son has epilepsy. While on a drive one Sunday morning with his family, Ron was brainstorming ideas on how to spread epilepsy awareness. The local pumpkin patch provided the solution. Since kids would soon be carving and decorating pumpkins. He thought, why not make one purple and tell people about epilepsy when asked, “Why is your pumpkin purple?” The idea caught on and soon families across the country were painting their pumpkins purple to spread epilepsy awareness.

In 2020, there was some confusion about what a purple pumpkin meant because of a new social media movement that used purple pumpkins to alert people that their house was open for trick or treating during COVID-19. There was an increase in media coverage due to the two initiatives, which placed a spotlight on our Purple Pumpkin Project and more epilepsy awareness. Now, more people are aware of seizures and how they impact individuals and families across the United States.

To celebrate the end of the campaign this year, the Epilepsy Foundation Kids Crew hosted a virtual Purple Pumpkin Project Fall Festival. During the hour-long event, members participated in a scavenger hunt, completed arts and crafts, and played games. There were also prizes awarded for the best creative decorations for two members who decorated their rooms for the festival. Participants got to engage with other kids who have epilepsy, answer fun questions to learn about one another, and talk about why they are thankful despite their health challenges.

At the end of the event, the National Kids Crew Purple Pumpkin project contest winners were announced. Brooklyn from Louisiana won “Most Creative” with her epilepsy princess-themed pumpkin. Aarlin from Texas won “Best Awareness” with her pumpkin patch filled with epilepsy facts. Members did an amazing job spreading awareness during the season and continued to learn how big an impact they can make when they work together.



The Kids Crew is open to ALL kids 14 and under. For more information and to register your kids, visit [epilepsy.com/Kids-Crew](https://epilepsy.com/Kids-Crew).

# Epilepsy Foundation: A Partner in Raising Awareness on Rares

By Ilene Penn Miller, Epilepsy Foundation Advisor on Rare Epilepsies

Advances in basic science, neuroimaging, and genetic sequencing have caused an explosion in rare epilepsy diagnoses in the past decade. In Fall 2020, the Epilepsy Foundation launched several initiatives to increase awareness and information of the rare epilepsies (otherwise known as the rares).

A Rare Aware column has been added to our weekly eNewsletter and social media. The column describes the rare epilepsies, promotes the importance of genetic and other testing, explains comorbidities (symptoms and side effects) common across rare diagnoses, and shines the spotlight on individual rare diagnoses. The Rare Aware outreach efforts have resulted in more people with epilepsy and their families connecting with rare organizations and communities that reflect their experiences for support, information, and community.

Also, the Epilepsy Foundation supported the Rare Epilepsy Landscape Analysis (RELA). The RELA was a project started in collaboration with rare organization leaders and other epilepsy stakeholders to better understand the rare epilepsy ecosystem. This novel analysis identified many shared challenges as well as opportunities for collaboration around research, information, support, professional education, and advocacy across 44 rare epilepsy organizations. It also included information about their founding, mission, staffing, infrastructure, and funding.

The Analysis and Appendix are publicly available. The RELA has been featured in:

- The Epilepsy & Behavior journal
- RARE Revolution Magazine
- The International Bureau for Epilepsy's International Epilepsy News
- A presentation at the Foundation's Pipeline meeting
- A poster at the annual American Epilepsy Society conference.

The critical findings have been shared throughout the Epilepsy Foundation's network internally and externally. These findings are informing strategic and other program planning across the epilepsy landscape.

Harnessing the power of the Epilepsy Foundation's network is helping the rare epilepsy community:

- Raise awareness
- Identify shared priorities and challenges
- Seed collaborations
- Support research to improve lives, care, and cures

The Epilepsy Foundation's 24/7 Helpline is also supporting the rare community. The Helpline helps connect families with rare diagnosis to resources and partner organizations that can help them. From October-December 2020, the Helpline connected over 20 families to a rare epilepsy organization.

Learn more about how the Foundation supports the rare community through the Rare Epilepsy Network registry on p. # of this issue.

The Epilepsy Foundation thanks our collaborators in the rare epilepsy community for helping us represent, and advance care for, everyone living with the epilepsies.



Share your rare epilepsy story with the hashtag #RareAware on social media.



# Pillar 4:

## Expand Revenue Sources Beyond Traditional

Expand Revenue Sources Beyond Traditional Fundraising

We are inspiring and enabling more people affected by the epilepsies to engage with us and benefit from our mission.

Learn about how we are changing the fundraising landscape:

- Epilepsy Ventures Fund (p. 19)
- Give 26 in the Fight Against Epilepsy (p. 20)
- Stream for Epilepsy: A New Digital Fundraising Initiative (p. 21)

# Introducing the Epilepsy Ventures Fund

By Laura Thrall, CEO & President

The Epilepsy Foundation strives to improve the lives of people with epilepsy. In addition to supporting better public awareness, education, and quality of life, the Foundation also pushes for better treatments and potential cures for the epilepsies. While surgery may eliminate seizures in some people, managing seizures through medication has long been the primary treatment protocol. Until now we have only had access to “anti-seizure medicines” (ASMs) that need to be taken daily and do not alter the course of the disease (they are only symptomatic therapies). Disease-modifying therapies include multiple drugs, gene therapies, and genetic modifiers, among others.

There was a time in the early 2010s when large pharmaceutical companies left the epilepsy space, citing a too-crowded field for anti-seizure medications. But now, a decade later, the explosion of technology and innovation in healthcare is creating new options for controlling, mitigating, and even predicting seizures. We have the opportunity to dramatically change the epilepsy treatment landscape.

As the largest nonprofit organization in the epilepsy space, the Epilepsy Foundation is in a unique position to recognize, evaluate, and support high-potential projects. Our internal knowledge, expert volunteer advisory councils, and credibility within the epilepsy community brings added validation to the projects we choose to invest in. Our broad reach in the epilepsy community keeps us abreast of critical needs in this population, while access to critical patient data can further inform our work with selected partners.



## Leveraging the Power of Our Support

The Epilepsy Foundation has supported a number of promising innovations through its ‘Shark Tank’ awards, New Therapy Commercialization Awards, and Epilepsy Innovation Seal of Excellence awards. While some of these products and therapeutics have been commercialized and made available to people with epilepsy, the Epilepsy Foundation has rarely participated in any financial return generated. Through the Epilepsy Ventures Fund (‘EVF’), we plan to harness the power of our extensive expertise, pipeline perspective, unique brain trust, and broad reach among people with epilepsy, to expand our commitment to driving innovation, while participating in revenue generated by these projects. In turn, generated returns can be invested in additional promising therapeutics and technologies.

The Epilepsy Ventures Fund will be supported by donors seeking to leverage the power of their gifts through a portfolio of high-impact projects, potentially generating additional revenue for the Foundation which can be invested back into the portfolio. Through EVF we will accelerate commercialization of innovative epilepsy treatments through capital investment, market awareness, and a shared commitment to improve the lives of people with epilepsy (“PWE”).

For more information on the Epilepsy Ventures Fund, contact Geoff DeLizzio, [gdelizzio@efa.org](mailto:gdelizzio@efa.org).

# Give 26 in the Fight Against Epilepsy

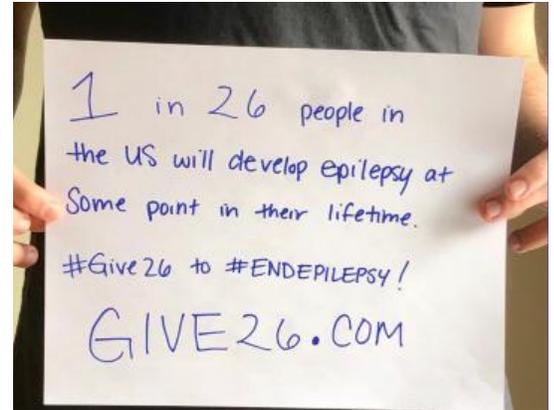
By Liz Dueweke MPH, CHES, Manager of Communications and Digital Strategies

On February 26, 2020, the Epilepsy Foundation launched a new initiative called Give 26. Give 26 is centered on the fact that 1 in 26 people in the U.S. will develop epilepsy in their lifetime. 1 in 26 people is a lot.

But you know what's not a lot? \$26. By inspiring many to give just \$26, the Epilepsy Foundation can make a huge difference.

Did you know that:

- 10 people giving \$26 funds the 24/7 Epilepsy Helpline for a day
- 100 people giving \$26 funds bereavement services after SUDEP (sudden unexpected death in epilepsy)
- 1,000 people giving \$26 funds a Seizure Safe Summer Camp for kids living with epilepsy
- 100,000 people giving \$26 funds making 26,000 classrooms Seizure Safe
- 1,000,000 people giving \$26 funds bringing cures for epilepsy to mark



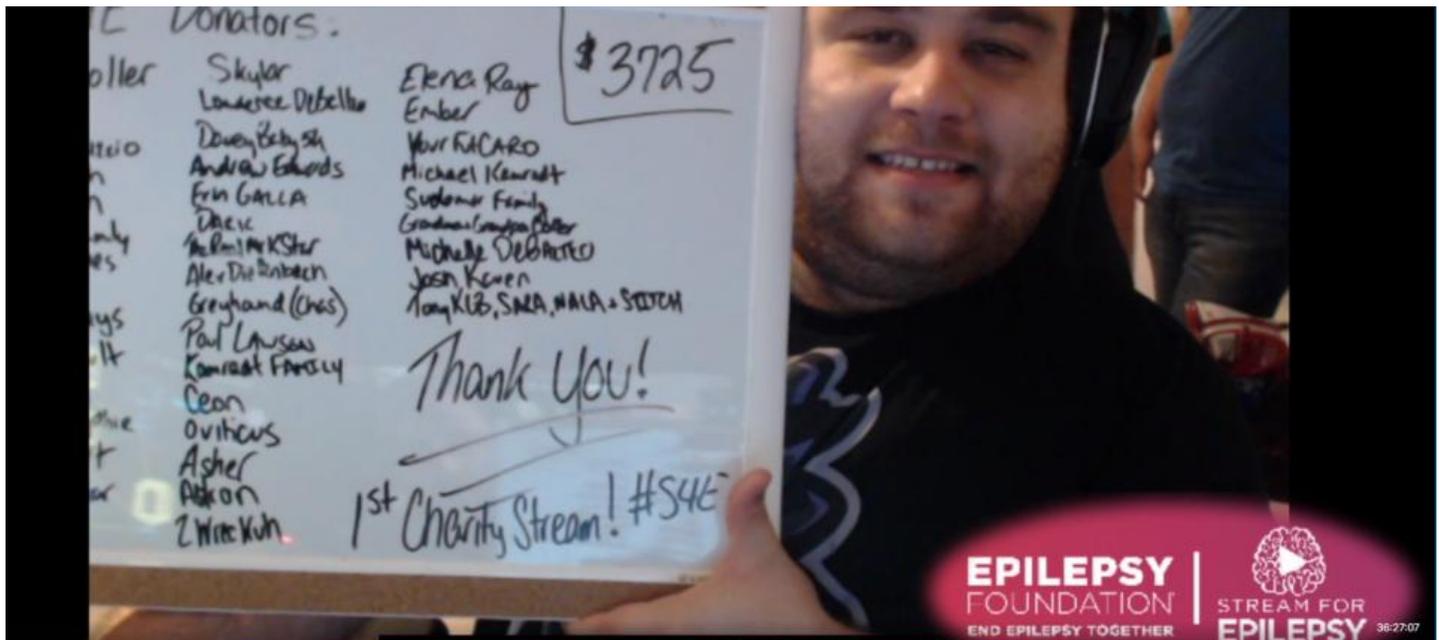
The Epilepsy Foundation community showed up in a big way to support this initiative. You generously donated and shared on social media your reasons for donating to the Foundation. During a challenging year for everyone, you helped keep the fight against epilepsy alive. The Epilepsy Foundation is still here due to your support.



In 2021, the Foundation launched “Give \$26 in the Fight Against Epilepsy.” You can help continue the fight for epilepsy warriors by donating \$26 and receive either a 2021 version of last year’s magnet or a “Resting Warrior Face” Give \$26 facemask.

After you donate, share your selfie sign (find the template on Give26.com) on social media and make sure to tag the Epilepsy Foundation to spread the word. The Epilepsy Foundation wants to know why this cause means so much to you.

With your help, the Epilepsy Foundation continues its mission in the fight against epilepsy and the many challenges of living with seizures.



One of our Stream Ambassadors, @TheTonyKGB, raised over \$3,800 for epilepsy awareness

## Stream for Epilepsy: A New Digital Fundraising Initiative

By Sarah Kaider, Social Media Coordinator

With the challenges of the COVID-19 pandemic upon us, the Epilepsy Foundation had to innovate to stay connected with our community. And so, Stream for Epilepsy came to be. The Epilepsy Foundation's Stream for Epilepsy initiative is a way for artists, gamers, dancers, musicians, and more to livestream themselves doing their favorite activity while raising awareness and funds for people living with epilepsy. The initiative launched on Video Game Day, September 12, 2020, to better connect with our community digitally.

Stream for Epilepsy currently has over 60 participants and 10 ambassadors. The Stream for Epilepsy team is actively recruiting more streamers and ambassadors to join the cause.

Starting with a major stream by @TheTonyKGB on Twitch in October 2020, who raised more than \$3,800 in memory of his cousin who passed from sudden unexpected death in epilepsy (SUDEP), Stream for Epilepsy raised over \$11,000 in four months.

Another streamer, @thedaleplays, raised over \$1,000 and spread epilepsy awareness in an online game called DayZ by announcing epilepsy facts over an in-game PA system.

Stream for Epilepsy also hosts our own streaming efforts, including streams with Epilepsy Foundation staff and Stream for Epilepsy ambassadors who talk about epilepsy while playing a videogame or doing an activity. One stream involved Epilepsy Foundation's Chief Development Officer Geoff DeLizzio playing a bowling game with professional bowler EJ Tackett.

Thank you to this community for showing up and supporting this initiative in a big way. We are looking forward to seeing Stream for Epilepsy grow and engaging more with the gaming community.

Help us raise \$100,000 for people living with the epilepsies and their families by 2021. We hope you'll join us. Anyone interested in streaming can sign up at [streamforepilepsy.com](https://streamforepilepsy.com).

Any questions? Please email [stream@efa.org](mailto:stream@efa.org)

# Pillar 5:

## Become a Best In Class Organization Leveraging Technology

The Epilepsy Foundation has a wealth of digital and technology resources at our fingertips and its time we used them efficiently. To begin, the former Research Quarterly is now the Foundational Quarterly, one outlet where you can read everything you could want to know about the Foundation's work.

We've continued to prioritize efficiency, invest in our digital resources, and leverage data to create change for people with epilepsy by:

- Creating the Epilepsy Learning Portal (p. 23)
- Continuing to Support and Accept Requests for Rare Epilepsy Data with the Rare Epilepsy Network Dashboard (p. 24)
- Launching the New Advocacy Website on Epilepsy.com (p. 25)

# The Epilepsy Foundation Launches the Epilepsy Learning Portal to Create a Seizure Safe Nation

By Liz Dueweke MPH, CHES, Manager of Communications and Digital Strategy

The Epilepsy Learning Portal is your one-stop shop to access the Epilepsy Foundation's online and on-demand trainings about epilepsy and seizures. By launching this portal, the Foundation is helping create a Seizure Safe Nation for the 3.4 million Americans living with epilepsy.

With this resource, professionals, people with epilepsy, their caregivers, and the general public can learn more about epilepsy, seizures, and seizure first aid. The more people learn and gain skills about epilepsy and seizures, the more confident we can be that people living with epilepsy will be surrounded by caregivers and professionals who understand how to respond to their seizures.

The Epilepsy Learning Portal creates the opportunity to combine multiple forms of learning including eLearning, on-demand, live online, and blended learning. These programs are accessible from around the world and on a variety of devices: computers, laptops, notebooks and mobile devices.

## Currently Available Trainings

The Epilepsy Foundation will be expanding the variety of online educational offerings on the Epilepsy Learning Portal. Current trainings include:

- **Seizure Training for School Personnel:**
- **Seizure Training for School Nurses: Caring for Students**
- **Seizure First Aid Certification**

Create Your Account at [learn.epilepsy.com](https://www.epilepsy.com/learn)

## What People Are Saying About the Trainings

"Now I know what to do [if someone has a seizure]. And I won't be helpless and afraid. And anybody who potentially has a seizure around me doesn't have to be alone," Seizure First Aid Certification Training  
- Participant

"This was a great webinar and it really needs to get out to all school personnel, especially bus drivers and monitors,"  
- Seizure Training for School Personnel Participant

"This was an excellent course! I emailed all of our other school nurses in our school system and encouraged them to take this class. Thank you so much for providing this for us,"  
- Seizure Training for School Nurses: Caring for Students Participant

## Acknowledgement/Disclaimers

The development and maintenance of the Epilepsy Learning Portal and the development of some of its content is partially supported with funding from the Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award under cooperative agreement number 1U58DP0026256-02-00, CFDA 93.850, funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

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# Accelerating Research through the Rare Epilepsy Network

Kathleen Farrell MB BCH BAO, Senior Director, ELHS

On February 26, 2020, the Epilepsy Foundation (Epilepsy can be caused by many different problems, including:

- Brain injury or infection in the brain,
- Structural malformations that happen during brain development, or
- By autoimmune, metabolic, or genetic causes.

However, many people living with epilepsy (approximately 60%) do not know what caused their epilepsy. For children and adults living with the most severe epilepsy syndromes, though, the picture is changing. In many rare epilepsies, genetic causes are being identified at a rapid pace. This change is helpful because knowing the genetic basis for a disease is a starting point for developing more effective treatments, and eventually, methods to prevent or cure the disease.

A rare epilepsy is often a syndrome, meaning that a group of other features is present in addition to seizures. Rare epilepsy syndromes often include difficult comorbidities, such as autism and/or developmental delays, behavioral issues, sleep issues, digestive issues, or problems with other body systems. The incidence of treatment-resistant seizures and early mortality can be much higher in rare epilepsy syndrome populations than in the population of people with more common forms of epilepsy. Finding effective and safe treatments for rare epilepsies and delivering them as early as possible after diagnosis is a high priority for the epilepsy community and for the Foundation.

But how will we get there? This is where the Rare Epilepsy Network registry comes in.

The Foundation has a long history of partnering with rare epilepsy organizations. From 2013-2018, the Epilepsy Foundation hosted a collaboration supported by a \$3 million Patient-Centered Outcomes Research Institute (PCORI) grant that built the first-of-its-kind **Rare Epilepsy Network (REN) registry**. The registry includes information for 1,459 rare patients, across 40 different epilepsy diagnoses.

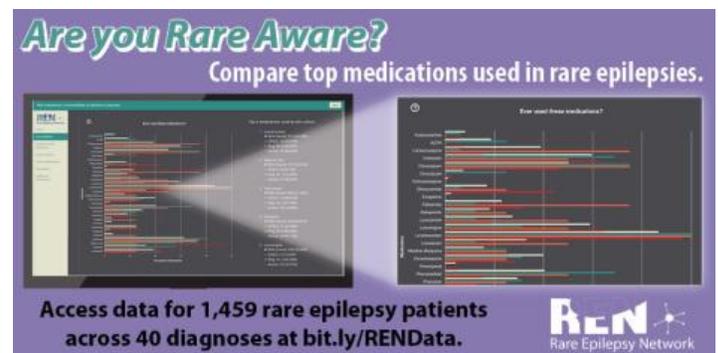
The Foundation built the registry in partnership with Research Triangle Institute (RTI), Columbia University, and with multiple rare epilepsy groups, which has grown over the years from 10 to 32 rare epilepsy organizations.

**Explore the interactive REN dashboard available** on the REN registry site to learn more about each rare disease individually, the rare community as a whole, and to make comparisons between rare diagnoses.

By helping support and host the REN registry, the Epilepsy Foundation is helping advance science in the rarer space. Publications that have resulted from the REN registry data include “Comorbidities of Rare Epilepsies: Results from the Rare Epilepsy Network” (Ho et al., J Pediatr. 2018) and “Factors Associated with Caregiver Sleep Quality Related to Children with Rare Epilepsy Syndromes” (Hesdorffer et al., J Pediatr X. 2020), with others in preparation.

The Epilepsy Foundation continues to field requests from academia and industry to analyze information in the registry about seizure medications, seizure frequency, comorbidities, side effects, developmental milestones and more.

[Requests access to the registry data.](#)



**Are you Rare Aware?**  
Compare top medications used in rare epilepsies.

Access data for 1,459 rare epilepsy patients across 40 diagnoses at [bit.ly/RENData](https://bit.ly/RENData).

**REN**  
Rare Epilepsy Network

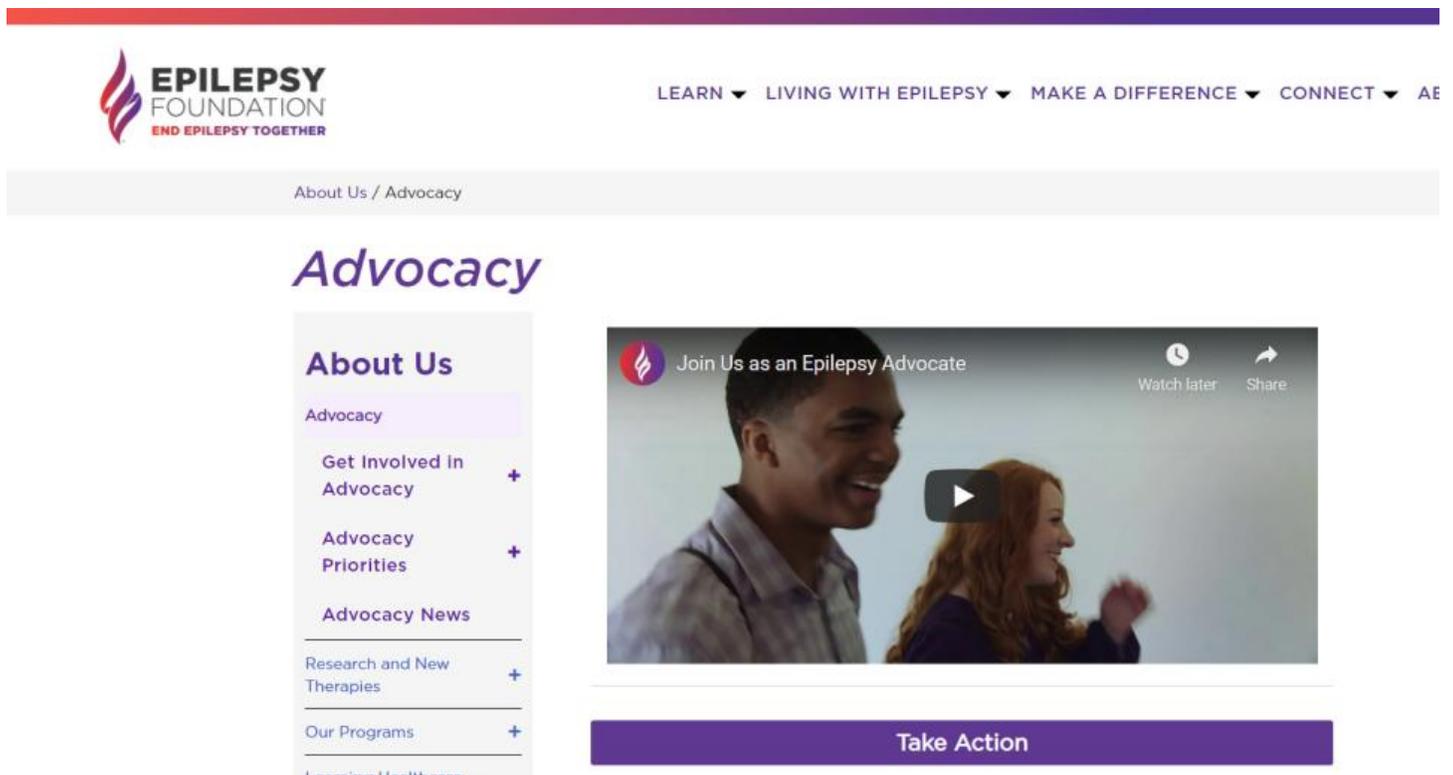
# Epilepsy Foundation Advocacy's New Home on Epilepsy.com

by the Epilepsy Foundation Advocacy Team

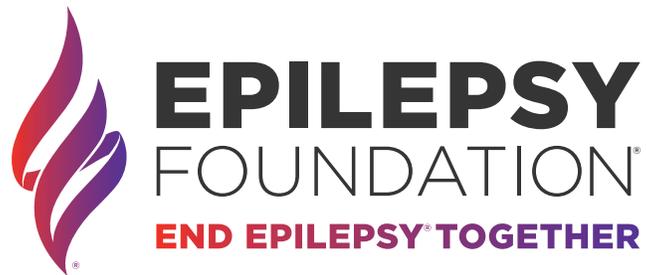
For too long, the integral efforts of the Epilepsy Foundation's advocacy team have lived digitally on a separate website, away from Epilepsy.com. To increase the reach of our advocacy efforts and truly reflect the importance of advocacy to our mission, the formerly separate advocacy microsite migrated its content to Epilepsy.com.

Leading up to this migration, the advocacy pages were entirely restructured, redone and consolidated to be more timely, relevant, and manageable for the community. By presenting advocacy issues and opportunities in an easier to navigate manner, the Foundation aims to inspire more people to get engaged in advocacy and in turn, have a more meaningful impact for our community.

By incorporating the Foundation's advocacy efforts into a home at Epilepsy.com, we better reflect how every part of our mission aligns with what the epilepsy community needs.



Visit [epilepsy.com/Advocacy](https://www.epilepsy.com/Advocacy) to learn more and get involved.



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](http://epilepsy.com)