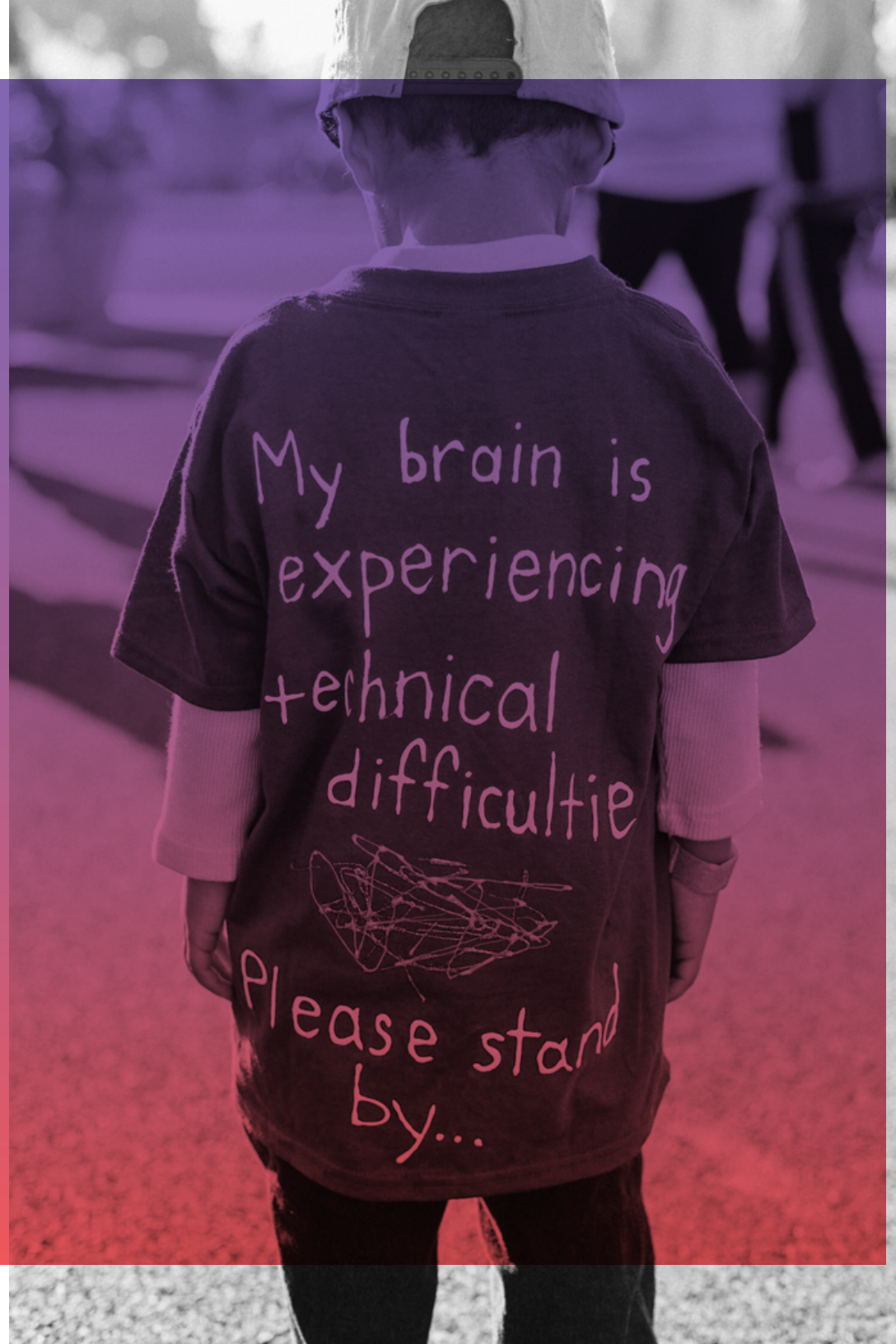




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Dear Friends,

My child was diagnosed with epilepsy. Today, I am glad to say that my child is seizure free.

For our family, the gap between those two statements was loaded with endless pursuit of information, a myriad of doctors' visits, sleepless nights, life changes, and the ever-present fear of the next seizure.

You or someone you know probably empathizes with my first statement, and I hope more and more of us can claim the second statement.

So, when someone asks me, "Why is END EPILEPSY important to the Epilepsy Foundation?" I think they are asking me, "Do I want to lead an organization that is in pursuit of ending epilepsy or lead an organization that accepts the status quo?" The answer is easy. Let's END EPILEPSY.

END EPILEPSY is full of rich meaning and cannot be casually spoken. END EPILEPSY is the reason WHY we exist as an organization. END EPILEPSY is our North Star, our vision, and our call to action.

President Theodore Roosevelt had epilepsy and was prone to seizures. In light of that, two of his well-known quotes — "Believe you can, and you're halfway there." And "Do what you can, with what you have, where you are." — have special meaning in the fight to END EPILEPSY.

END EPILEPSY is about our nationwide network and movement. END EPILEPSY is about overcoming the challenges of living with seizures while simultaneously fighting for cures for the epilepsies. END EPILEPSY is about pursuing care and freedom from seizures relentlessly, advocating tirelessly, sharing stories boldly, and taking action courageously. Our epilepsy warriors embody the spirit of END EPILEPSY. Together, let's not let epilepsy win.

As a nationwide network organization, our priority continues to be: ensure people with epilepsy feel safer, can get good care, are connected to information and each other, know they are not alone, can share their stories effectively for greater awareness, and can take action when and how they wish — while we are accelerating research and new therapies.

As we enter our second half-century as an organization, we boldly say that we are mobilizing action to END EPILEPSY because we want to shut our doors. We do not want to maintain the status quo. We want people with epilepsy and everyone else to see this cause for what it is: a fiercely underfunded and overlooked brain disorder. So be inspired and take action.

Thank you for your generous and faithful support,



Robert Smith,
President & CEO

“Believe you
can, and you’re
halfway there.”

“Do what you
can, with what
you have,
where you are.”

~ Theodore Roosevelt,
26th U.S. President
and person with epilepsy

EPILEPSY BY THE NUMBERS

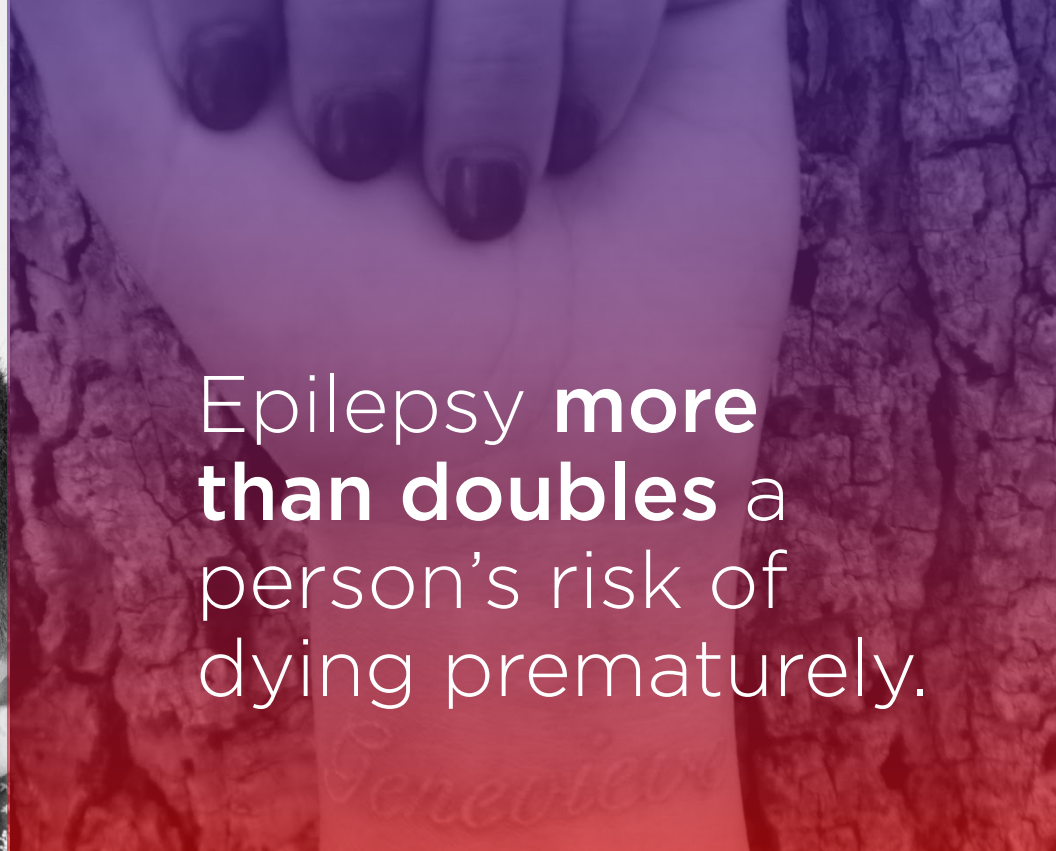
65 Million
people around
the **world**
have epilepsy

1 in 10
people will
have a seizure
over a lifetime

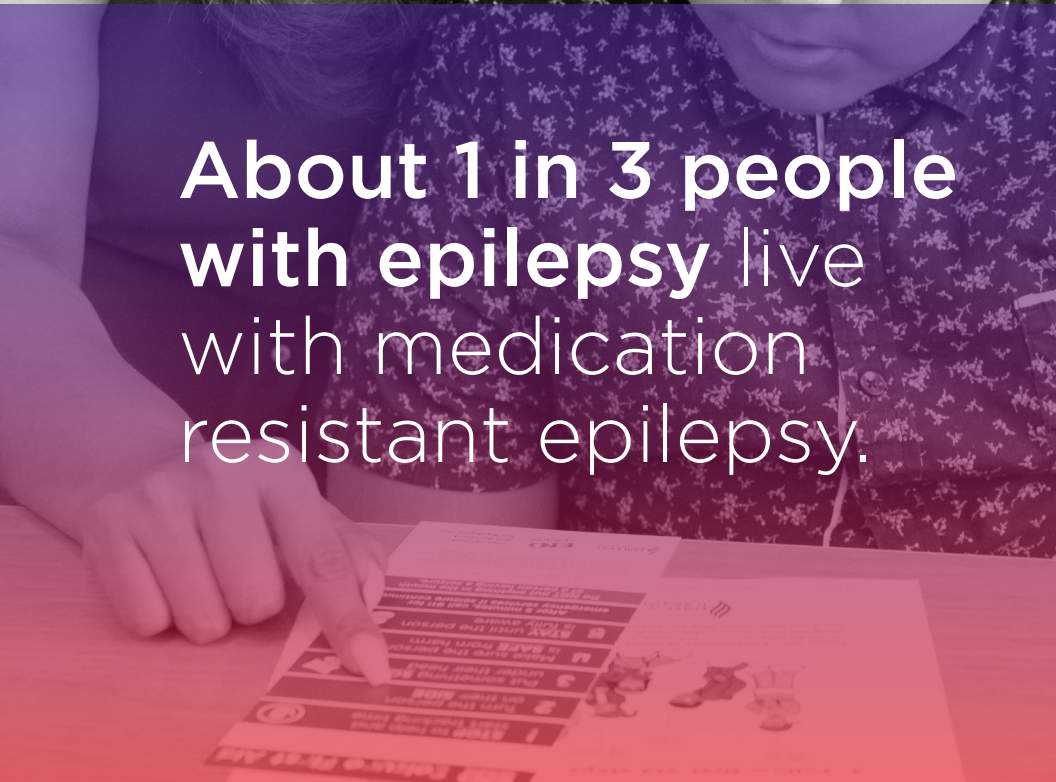
3.4 Million
people in the
United States
have epilepsy

1 in 26
people will
develop epilepsy
over a lifetime

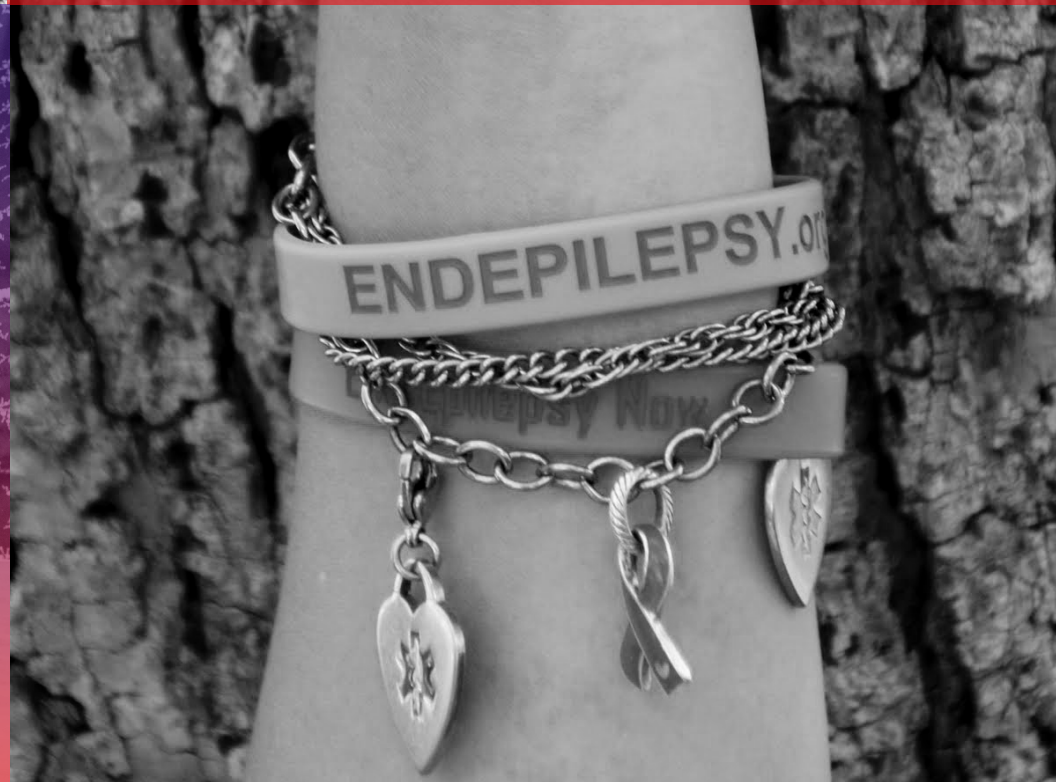
EVERY NUMBER IS A REAL PERSON AND A REAL STORY.



Epilepsy **more than doubles** a person's risk of dying prematurely.



About **1 in 3** people with **epilepsy** live with medication resistant epilepsy.





ABOUT EPILEPSIES

Every person's brain has a potential to have a seizure. When a person has two unprovoked seizures or one unprovoked seizure with the likelihood of more or the diagnosis of an epilepsy syndrome, they are considered to have epilepsy.

Epilepsy affects men and women of all ages and all races and ethnic groups.

This year, in the U.S., another 200,000 people will be diagnosed with epilepsy.

Epilepsy is unpredictable, chronic, and disabling. The impact of epilepsy has ripple effects for families and communities.

Different types of epilepsies and seizures affect people differently and can impact friendships, employment, mobility, overall health and wellbeing, and lead to a greater risk of injury and early death.

A range of treatment options from anti-seizure medications, to dietary therapies, to epilepsy surgery and neurostimulation help some people gain control of their seizures.

OUR MISSION

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

We are mobilizing action to END EPILEPSY.

OUR ORGANIZATION

The Epilepsy Foundation is a national nonprofit with over 40 local organizations nationwide.

The Foundation has led the fight against seizures since 1968. We are an unwavering ally for individuals and families impacted by epilepsy and seizures.

The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential.





[Katrina and her son, Nico](#)
[END EPILEPSY Ambassadors](#)

For me, at this moment, END EPILEPSY means being very involved in my son's journey with doctors. When I knew my son had epilepsy, I knew I had to take charge and find a community. I found that with the Epilepsy Foundation.

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Landover, Maryland

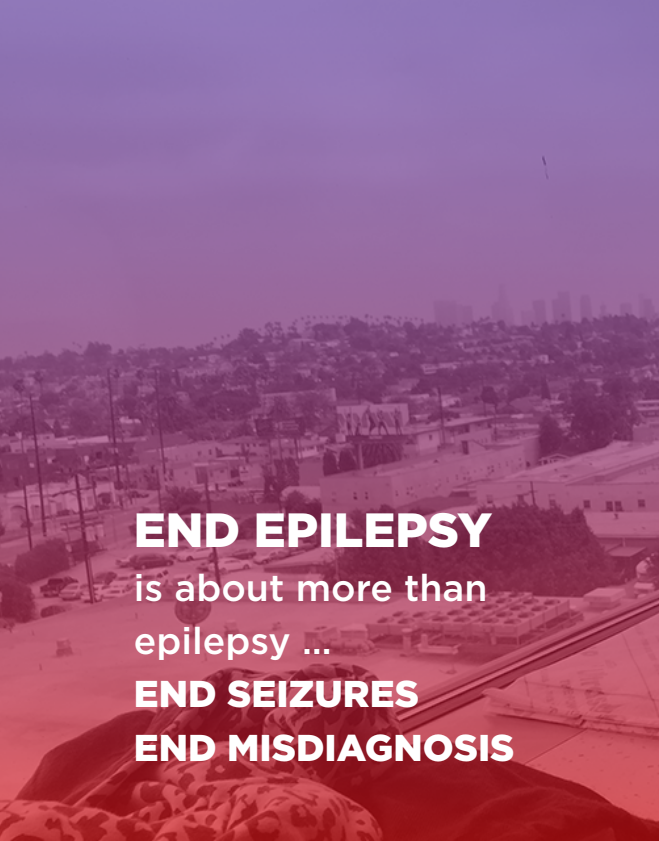
Liz Schreiber
Program Manager
Landover, Maryland

RESEARCH & NEW THERAPIES



“

Our research has no boundaries. Over the past ten years, we have funded research on 6 continents.



END EPILEPSY
 is about more than
 epilepsy ...
END SEIZURES
END MISDIAGNOSIS



OUR ACTION

Partnerships and research and training grants aim for and accelerate seizure control.

RESEARCH OVERVIEW

Our purpose is to develop an epilepsy research ecosystem that covers the entire spectrum of discovery - from the idea to market. We foster the development of new scientists and support research that leads to better treatments and care. We strive for excellence, innovation, and radical thinking to find cures.

Research By the Numbers for 2019

- 9 research awards in amount of \$3.8 million supporting entrepreneurship, conferences, and early careers
- 4 workshops on topics spanning rare epilepsies, addressing regulatory roadblocks in therapeutic development, improving epilepsy data infrastructure and mapping the spread of seizures in the brain.
- 3 thought leadership publications on the state of cannabidiol, comorbidities in rare epilepsies, and engaging the community for post-traumatic epilepsy research.



For more information,
 visit [epilepsy.com/research](https://www.epilepsy.com/research)

Epilepsy Learning Healthcare System

Designed in 2018 and launched in January 2019, the Epilepsy Learning Healthcare System is a quality improvement and research network... for all children and adults with epilepsy. In FY19, six clinics joined ELHS.


Site teams (made up of clinicians and patient & family partners from the Community Engagement Core) are currently working on improving seizure documentation both on the clinician and patient sides. The next phase of work will focus on medication adherence (a key driver of seizure control)



EPILEPSY LEARNING HEALTHCARE SYSTEM
PARTNERING TO IMPROVE OUTCOMES

Be part of the change. Let's improve outcomes for people living with epilepsy. Together.

Learn more at Epilepsy.com/ELHS



Learning from every patient with epilepsy

ELHS centers learn from every patient at every visit. Data is gathered from ELHS clinics across the country into a registry. The data is analyzed centrally to find best practices that will lead to better outcomes for patients and their families. Patients and families are integrated at every step to drive priorities, design new initiatives, and provide insight.

THE AREAS OF FOCUS
The ELHS has identified high impact outcomes to focus on and improve:

- Seizure Control
- Quality of Life
- Treatment Adherence
- Screening and Treatment of Depression and Anxiety
- Status Epilepticus
- Patient Transition from Pediatric to Adult Care
- Counseling on Contraception and Pregnancy

Make a difference in someone's life.

Join the ELHS and help us transform healthcare all over the country as we seek out ways to improve health and outcomes for patients with epilepsy.

ELHS works together with healthcare teams at epilepsy centers, community-based service providers, researchers, patients and their families.

ELHS empowers all people with epilepsy to live their highest quality of life, striving for freedom from seizures and side effects. **We won't stop until we get there.**

EPILEPSY LEARNING HEALTHCARE SYSTEM

The ELHS is building a quality improvement and research network to improve outcomes for children and adults with epilepsy.

Meet our ELHS Coordinating Committee:

- Brandy Furman, PhD
Principal Investigator
- Jeffrey Buchhalter, MD, PhD
Co-Principal Investigator
- Susan Herman, MD
Co-Principal Investigator
- Kathleen Farrell, MB BCH BAO
Program Director
- Pam Jacques, MS, CPW, CHES
Community Services Core Co-lead
- Priscilla Kobi, MS, MSHS
IRB & Legal Contact
- Alison Kukla, MPH
Community Engagement Core lead
- Steven Owens, MD, MPH
Community Services Core Co-lead

Learn more Epilepsy.com/ELHS



Shark Tank Awards – #EpilepsySolutions

The Epilepsy Foundation's Shark Tank competition seeks to advance innovative ideas in epilepsy and seizure treatment and care. The winners use their prize to accelerate their innovation to the next phase of development, bringing it closer to being accessible to people living with epilepsy.

We received 35 submissions from 9 different countries around the world. Six of those were chosen as finalists and three were awarded a \$5,000 prize. The finalists presented at the Antiepileptic Drug & Device (AEDD) Trials XV Conference on May 24 in Florida

This year's Shark Tank winners were:

- Detecting Seizures with an Eye-Opening Solution
[Rachel Kuperman, MD](#)
Eysz, Inc., San Francisco, California
- Falling Down the Rabbit Hole of Medication Adherence
[Jody McNannay](#)
Curadite, Inc., Beaverton, Oregon

See APPENDIX for more about these two projects.

To learn more about our Shark Tank winners, see APPENDIX and visit epilepsy.com.

Epilepsy Innovation Institute

The Epilepsy Foundation's Epilepsy Innovation Institute (Ei2) is an innovation incubator at tackling high-risk projects


My Seizure Gauge Initiative

In October 2018, the Epilepsy Innovation Institute awarded a \$3 million grant to an international team of scientists, researchers and interoperability experts to evaluate biosensors that can track an individual's physiology, behavior, and environment to improve seizure prediction. Team members from Mayo Clinic, King's College London and Seer Medical/The University of Melbourne will evaluate biosensors in a range of commercially available devices. The team will recruit, and collect data from, people with epilepsy who have received an implanted device that can measure brain activity — such as electroencephalogram (EEG) devices — to better understand changes in the body that induce or allow for seizure activity. The team receiving the grant was selected following a seven-month long, peer-reviewed process. The ultimate goal of this award is to definitively assess the types of measurements that are needed for a reliable seizure forecasting prototype device.

My Brain Map Initiative

We know people living with epilepsy are not having seizures one hundred percent of the time, so why are the seizures happening when they do? What is it about the pathways in the brain in the moments before a seizure starts? What is it about the brain activity that activates those pathways in that specific area of that brain in that specific moment? And what causes the seizure to then spread or not spread when the initiation occurs? Although researchers have been studying seizures for over a century, we still cannot answer the questions of why seizures start, how seizures spread and why they stop when they do for those impacted by epilepsy.

On September 6 and 7, 2018, the Epilepsy Innovation Institute (Ei2) hosted an innovation workshop to assess the state of the science on personalized brain network mapping in epilepsy. The workshop convened multiple stakeholders including people impacted by epilepsy, neuroscientists, basic scientists, clinicians, mathematicians, engineers, and industry representatives. Conversations centered on what is currently possible, what are potential future directions, and what critical infrastructure is needed to move the field forward. The results of that meeting launched the My Brain Map project to better map seizure propagation in the brain.



Research Quarterly

The reformatted and rebranded Research Quarterly launched in June 2019.

[🔗 Summer 2019 issue](#)

[🔗 Read this and other RQ issues](#)



[Dr. Sylvia Olvera](#)
2018 END EPILEPSY Ambassador

Having epilepsy has helped me to become a better neurologist. I understand some of what [my patients] are going through. ... It's not easy lose independence ... and have to depend on others. I empathize.

Rare Epilepsy Network

Over 1,450 individuals with a rare epilepsy were included in the REN survey. The first REN publication describing comorbidities across rare epilepsies was published in 2018. The data collected in the REN survey is available to be shared with other qualified researchers for additional analyses.

Thought Leadership — Facilitating Conversations

The Research Roundtable for Epilepsy (RRE) is an initiative of the Epilepsy Foundation to facilitate the development and implementation of new treatments and diagnostic tools for people with epilepsy, by collectively addressing roadblocks to research and development.

Each RRE focuses on a single critical issue and allows an in-depth discussion in a pre-competitive space. Our consortium is composed of senior scientists from pharmaceutical, biotechnology, and diagnostic companies as well as regulatory agencies such as the FDA, the European Medicines Agency and patient organizations. All proceeding outcomes are written and published in a well-regarded academic journal to be shared with the broader community.

The fourth meeting of the Research Roundtable in Washington, DC in March 2019 focused on the topic “Efficient Trials in Epilepsy.”

Pushing in Bold New Directions — Human Epilepsy Project

In April 2018, in collaboration with the Epilepsy Study Consortium, the Epilepsy Foundation launched a new partnership called the Human Epilepsy Project. This study, the Human Epilepsy Project 2: Resistant Focal Seizures (HEP2) is designed to better understand the challenges of living with focal seizures that do not respond to medication and determine biomarkers of epilepsy severity and treatment response.

This new research study is another step in our efforts to better understand focal epilepsy and uncover data that will help accelerate therapies to help people with epilepsy have seizure-free lives.

The HEP2 study will monitor 200 people with treatment-resistant focal epilepsy (with seizures that occur at least 4 times per month) over a two-year period to measure changes in seizure frequency, treatments used, adverse events, presence of comorbidities such as depression and anxiety, healthcare costs, and quality of life.

HEP2 Study Participants – Who Can Join and Where?

Participants are enrolled for the HEP@ study at any of ten recruiting study epilepsy centers selected because of their track record of conducting high-quality research in epilepsy and efficiently recruiting participants into studies. The designated nine US sites for the HEP2 study are located in New York, California, Pennsylvania, Connecticut, Minnesota, and Tennessee in the United States. There are two international sites in Canada and in Finland. Enrollment is expected to end by June 2020.

HEP2 Study Participants – What Do You Need to Do?

Study participants are asked to track their seizures, symptoms and medications using My Seizure Diary, a self-management web tool developed by the Epilepsy Foundation specifically for seizures and epilepsy. In addition, participants will need to share their medical records with the research investigators and travel to the clinical site two or three times over the course of the study for health visits and blood samples. A participant may enroll in the HEP2 study but continue to receive their standard epilepsy care with their current physician.

New Therapy Commercialization Grants – #EpilepsySolutions

The Epilepsy Foundation’s Epilepsy Therapy Project accelerates ideas into therapies for people living with epilepsy and seizures. The Project funds new, innovative research from leading scientists and startup companies with a focus on accelerating the progress of breakthrough research and new therapies “from the bench to the bedside.” Grants are up to \$350,000 per year, over a two- year period, and are awarded twice a year. Our funding approach has been restructured from a traditional grant to an investment that would allow us to achieve a return when a product reaches the marketplace.

We awarded a grant to Dr. Matthew Gentry, PhD, professor at the University of Kentucky. Dr. Gentry was awarded \$150,000 to support pre-clinical testing of a compound (VAL-1221) that has the potential to treat Lafora disease, a progressive epilepsy. Lafora disease is a rare and fatal epilepsy that starts in childhood and is caused by genetic abnormalities altering the brain’s ability to process glycogen. Dr. Gentry partnered with Valerion Therapeutics to develop VAL-1221, which is currently in clinical trials for another glycogen storage disease called Pompe disease. Preliminary evidence suggests that VAL-1221 can degrade the aberrant glycogen accumulations found in the cells of those diagnosed with Lafora epilepsy

We also awarded a grant to Gregory Worrell, MD, PhD from Mayo Clinic (Minnesota) and Cadence Neuroscience. Dr. Worrell was awarded \$150,000 to advance his work with Cadence Neuroscience which has developed a protocol that tests a variety of electrical stimulation parameters while an individual with intractable epilepsy is undergoing phase II evaluation for surgery. Preliminary evidence suggests that this procedure can be used to tailor brain stimulation therapy to each individual and enhance seizure control compared to currently used protocols. Funds from this award will be used to develop a user-friendly workstation to allow other clinicians to personalize and optimize brain stimulation therapies for epilepsy.

Supporting the Next Generation of Scientists

This year, the Epilepsy Foundation supported three different projects in partnership with our sister organizations. We partner with the American Academy of Neurology, the American Brain Foundation, and the American Epilepsy Society to pool our resources and reduce administrative overhead.

AES/EF Junior Investigator Research Awards

William Nobis, MD, PhD

Vanderbilt University Medical Center
The Role of the Extended Amygdala in Respiratory Control and SUDEP

Alicia Guemez Gamboa, PhD

Northwestern University
Uncovering Altered Connectivity in Epilepsy due to Somatic Mutations

AES/EF Clinical Research & Training Fellowship

Behnaz Esmaeili, MD

Brigham and Women's Hospital
Intracranial EEG Suppression and Heart Rate Variability in Epilepsy

Susan S. Spencer Clinical Research Training Fellowship in Epilepsy Award

Cosponsored by the American Academy of Neurology, the American Brain Foundation, the American Epilepsy Society, and the Epilepsy Foundation

Liseth Burbano, MD

The Florey Institute of Neuroscience, Melbourne, VIC, Australia. Development of a Precision Therapy in KCNT1 Epileptic Encephalopathy.

The Kevin's Fellows program

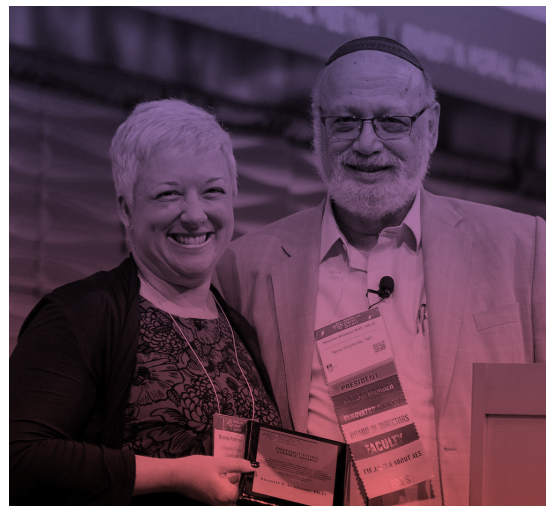
For AWARD partners, see APPENDIX.

Lifetime Accelerator Award

The Lifetime Accelerator Award was established in 2012 to honor physicians, scientists, industry leaders, and others who have demonstrated a lifelong commitment to bringing new therapies to people living with epilepsy.

The winner of the 2019 Lifetime Accelerator Award this was Professor Martin J. Brodie, MD, president of the International Bureau for Epilepsy.

Dr. Brodie has been involved in epilepsy drug development for more than 30 years and was principal investigator on numerous trials that brought new therapies to market. He was an innovator of novel trial designs and is arguably the most recognized speaker on new anti-epileptic drugs in the world. For past awardees, see APPENDIX.



Distinguished Service Award Presented to Brandy Fureman, PhD

Dr. Brandy Fureman, vice president of Research and New Therapies at the Epilepsy Foundation, was awarded the American Epilepsy Society Distinguished Service Award at the Annual Meeting of the American Epilepsy Society in 2018 in New Orleans. The award was presented by Dr. Shlomo Shinnar, AES president.

SUDEP Institute

Moving the needle to #ENDSUDEP

**EACH YEAR 1 OUT OF 1,000
ADULTS AND CHILDREN WITH
EPILEPSY DIE FROM SUDEP.**

FOR PEOPLE WITH POORLY
CONTROLLED SEIZURES,
THE RISK OF SUDEP IS MUCH
HIGHER — 1 OUT OF 150 EACH
YEAR. SINCE 2013, THE SUDEP
INSTITUTE HAS BEEN RAISING
AWARENESS, PROVIDING
BEREAVEMENT SUPPORT
AND FUNDING RESEARCH TO
END SUDEP.

Biomarker Challenge

We have been hosting a series of challenges, and are now in the last stage of the competition known as the Biomarker Challenge.

Those interested, must now demonstrate that their selected biomarker(s) have predictive efficacy and value in the broader human population. A researcher did not need to apply to the other parts of the challenge to participate. The challenge is a race to the finish, with solutions accepted on a rolling basis up to October 20, 2020. Submissions will be reviewed as they are received and at the discretion of the SUDEP Institute. The first submission that meets all the challenge criteria will be awarded the \$800,000 prize for successful completion.



Sally Schaeffer
[Senior Director, SUDEP Institute and END EPILEPSY Ambassador](#)

[My daughter] is the reason I'm working with the SUDEP Institute. My passion for advocating and educating is me turning my passion into purpose. I'm using my brain every day to let people know that SUDEP is real and it is happening and we need to make it stop.

ADVOCACY



“I joined the Teens Speak Up Program. I went back home and helped create a new law in Kentucky to educate teachers about what to do if a student is having a seizure. ...

[Through advocacy] I have a chance to change other peoples' lives.”



END EPILEPSY

is about more than
epilepsy ...

END SILENCE

END DISCRIMINATION



OUR ACTION

Grow our Speak Up!
Speak Out! Advocacy
network

ADVOCACY OVERVIEW

The Epilepsy Foundation advocates at the national and state levels to advance public policy that improves access to affordable, comprehensive, physician-directed and person-centered health care, secures funding for epilepsy, ensures disability rights and fuels research and innovation. In FY 2019, the Epilepsy Foundation

- Sent 845 letters at the state level and 467 letters at the federal level;
- Helped 17 bills get signed into law;
- The Foundation's Speak Up! Speak Out advocacy network sent 5,476 letters to their members of Congress, 875 comments on proposed federal rules and 2,821 letters to their state-level officials; and
- Signed on to 38 letters with coalition partners.



For more information,
visit advocacy.epilepsy.com.

ADVOCACY IMPACT

During FY 2019, the Epilepsy Foundation's advocacy team, chapters and affiliates, state advocacy leaders, nearly 100,00-strong online Speak Up, Speak Out! Advocacy network, and coalition partners achieved many accomplishments.

Access to Affordable, Comprehensive, Physician-directed and Person-centered Care

- Preserved Medicare's Six Protected Classes policy which ensures that Medicare beneficiaries have access to the full range of approved anti-seizure medications;
- Passage of Seizure Safe Schools legislation in Indiana, Texas and Illinois. The model legislation requires school personnel to complete a seizure recognition and first-aid response training; mandates that a Seizure Action Plan is made part of the student's file and made available for school personnel and volunteers responsible for the student; ensures the administration of prescribed medications approved by the U.S. Food & Drug Administration to treat seizure disorders; and educates and trains students about epilepsy and first-aid response;
- Helped ensure pathways to Epidiolex®, the first FDA-approved treatment derived from cannabidiol (CBD) for seizures associated with two rare forms of epilepsy to ensure it could be prescribed and accessed;
- Testified at the FDA's Public Hearing on Scientific Data and Information about Products Containing Cannabis or Cannabis-Derived Compounds in support of regulations to ensure safe and continued access to therapeutic CBD products;
- Fought to maintain protections and comprehensive coverage for people with pre-existing conditions by urging the courts to uphold the Affordable Care Act and opposing expansion of short-term limited-duration health plans;
- Supported federal legislation that was signed into law banning pharmacy gag clauses in commercial insurance plans and Medicare prescription drug plans, in turn, allowing pharmacists to inform consumers when they can pay less for their prescriptions;
- Helped pass step therapy reform in Delaware, Georgia, Maine, Oklahoma, Virginia and Washington that will help people with epilepsy access the most effective medications in a timely manner;
- Supported Medicaid expansion that was adopted in Idaho, Nebraska and Utah; and
- Helped pass bills in Arizona and West Virginia that ensure copay amounts in any form—including copay assistance programs—count towards an individual's deductible, relieving financial burden on individuals and helping them access needed medications.

Funding for Epilepsy Research, Programs and a Cure

- Secured \$8.5 million for epilepsy programs through the U.S. Centers for Disease Control & Prevention's Chronic Disease and Health Promotion program to increase public awareness and knowledge around epilepsy, as well as improve epilepsy care and self-management;
- Secured a \$2 billion increase for the National Institutes of Health; and
- Secured \$5 million for the National Neurological Conditions Surveillance System.

Disability Discrimination

- Called on the Institute for Clinical Economic Review (ICER) to abandon its use of the quality-adjusted-life-years (QALY) metric which takes a one-size-fits-all approach, ignores individual needs and preferences and in a discriminatory manner, values individuals in "perfect health" more highly than those with chronic conditions or disabilities.

Personal stories and advocacy are at the core of action together to END EPILEPSY.





Teens Speak Up! (TSU) and Public Policy Institute (PPI)

Through the Teens Speak Up! (TSU) and Public Policy Institute (PPI), the Epilepsy Foundation brings teens living with epilepsy and their families to Washington, D.C. to receive advocacy training and share their stories with their members of Congress to advance important policy priorities.

At the 2019 TSU & PPI, more than 175 participants met with more than 180 members of Congress and congressional staff.

This life-changing program empowers teens and families because it helps them realize that they are not alone and they experience first-hand that their story matters and can make a difference.

Jeanne A. Carpenter Epilepsy Legal Defense Fund

The Jeanne A. Carpenter Epilepsy Legal Defense Fund fights epilepsy discrimination across all aspects of life including work, school, health care and community life.

In FY 2019, the Fund provided education, legal information and/or referrals to attorneys or other community services to at least 550 individuals.



PROGRAMS & SERVICES



The Foundation helped us get quickly to the best treatments, the best opportunities. We always felt like we were home.



END EPILEPSY

is about more than
epilepsy ...

END DEPRESSION

END HEALTH INEQUITY

END STIGMA



PROGRAM AND SERVICES OVERVIEW

In Fiscal Year 2018, the Epilepsy Foundation continued to expand its reach of Programs and Services for people with epilepsy and their families.

With the support of our partnership with the U.S. Centers for Disease Control & Prevention (CDC), the Epilepsy Foundation helped people with epilepsy improve their overall wellness, including coping with depression and/or anxiety and memory function.

Additionally, the Epilepsy Foundation continued to benefit the lives of children living with epilepsy in schools by providing training to school nurses, school personnel, and students' peers.

It is an honor for the Epilepsy Foundation to work daily to help improve and save lives through community service and public education across the United States.



OUR ACTION

Our Helpline, Institutes for Wellness and for SUDEP, and our trainings impact individuals and families.



For more information,
visit epilepsy.com.

INFORMATION AND REFERRAL

The Epilepsy & Seizures 24/7 Helpline: Ways We Restore Hope & Provide Resources

The Epilepsy & Seizures 24/7 Helpline (1-800- 332-1000) is a continual service offered by the Epilepsy Foundation to provide around-the-clock support for people living with epilepsy, their family and caregivers, and anyone who needs information about epilepsy and seizures. During the past year, the Helpline launched an online public resource directory to better serve people seeking services and resources 24-hours a day.

During the past year, the Epilepsy & Seizures Helpline worked with the Alliance of Information & Referral services to make recommendations for adding 9 additional rare epilepsy search terms to the taxonomy of human services bringing the total rare epilepsy terms to 14. These terms are used by the Epilepsy Foundation as well as hundreds of other information and referral programs throughout the United States and Canada to help individuals find relevant helpful programs and resources.

In mid-2019, the helpline performed the initial screening for the Human Epilepsy Project 2 clinical trial study and conducted surveys to offer resources to connect people with epilepsy to epilepsy centers, and information on tracking and recording their seizure activity. During this period, the Helpline received 15,203 inquires, continuing to screen for depression and suicide. Of those screened, 26.5% of those assessed indicated possible depression, with 17.1% scoring high enough to ask about suicide, with 4.5% indicating they had thoughts of suicide.

EDUCATION

OVERVIEW OF PROGRAMS AND ACCOMPLISHMENTS

Managing Students with Seizures: A Training for School Nurses

This free training program is designed to provide the school nurse with information, strategies, and resources to better manage students with seizures by supporting positive treatment outcomes, maximizing educational and developmental opportunities, and ensuring a safe and supportive environment.

During the most recent fiscal year:

- **1,674 school nurses trained both online and in-person** by Epilepsy Foundation and network
- **3 new school nurse modules being piloted** by Epilepsy Foundation
 - Rescue therapies,
 - 504 and Individualized Education Plans (IEP)
 - Psychogenic nonepileptic seizures

Managing Epilepsy Well (MEW) Network

The Foundation worked with its MEW partner, Dartmouth University, to expand HOBSCOTCH (Home-Based Self-Management and Cognitive Training Changing Lives) in more communities to teach skills for improving memory function to improve quality of life.

- **Supported training of 4 memory coaches** to offer the HOBSCOTCH program throughout the country

Seizure Training for School Personnel

This free CDC accredited training program helps promote a positive social and educational environment for students living with seizures and epilepsy.

- **14,905 school personnel** trained both online and in person by Epilepsy Foundation network.

Special Training Programs: Children, Adolescents and Young Adults

Seizure Training for Child Care Personnel is an accredited curriculum for child care providers developed by the Epilepsy Foundation. It provides instructions about proper seizure first aid to support young children who may not be able to provide information about their conditions or participate in their treatment.

Seizures and You: Take Charge of the Facts is an epilepsy awareness program geared toward teens in high school. The program educates teens and promotes inclusion of epilepsy education in school health and science classes. As we expand the reach of the program from childcare age to adolescents, the knowledge of epilepsy awareness in this population will continue to rise. Take Charge program growing and becoming more interactive and innovative, those numbers continue to rise.

- Take Charge of the Facts – **over 284,212 students** since its inception in 2008.
- Take Charge Jr. – **nearly 9,000 children, adolescents and young adults** in 2018 alone.

Seniors & Seizures Educational Program for Organizations Serving Older Adults

The Seniors and Seizures Training is a continuing education program designed to provide caregivers and staff of adult day care centers, senior centers, long-term facilities, nursing homes, and other senior-serving organizations with strategies to better recognize and respond to seizures among older adults.

Wellness Institute

The Wellness Institute reached significant milestones this year, beginning with the redesign of its program model to include the 8 quality of life epilepsy dimensions identified in the 2012 Institute of Medicine's Epilepsy Across the Spectrum report: emotional health, stress management, sleep, social relationships, independent living, education and employment, diet and nutrition, and physical activity. We are excited at the momentum that is building for our new content on epilepsy.com as well as weekly social media wellness tips and motivational messaging, and monthly newsletter.

Studio E: The Epilepsy Art Program continues as one of the hallmarks of the Wellness Institute's emotional health initiative, which seeks to empower those who face the challenges of epilepsy and comorbidities, such as depression.

In 2019, the Studio E: The Epilepsy Art Therapy Program included a total of 27 local Epilepsy Foundations. Since its inception in 2011, Studio E has helped over 2,900 individuals living with epilepsy by offering a safe and supportive space to express themselves through various forms of therapeutic art led by credentialed art therapists. Participants gain healthy strategies to address difficult feelings that often accompany living with epilepsy, while connecting with others also impacted by seizures.

SUDEP Institute

The Epilepsy Foundation SUDEP Institute provides SUDEP (Sudden Unexpected Death in Epilepsy) education and awareness programs for people touched by epilepsy and medical professionals. The Institute drives and supports research into the causes and prevention of SUDEP. The Institute offers a bereavement support network providing support services and resources for individuals and families affected by SUDEP.

Online Learning

Since 2016, our learning management system (LMS) houses all of the Epilepsy Foundation's trainings and webinars for health professionals, our network, and consumers. Previously many of these resources were spread out and hosted with partner organizations.

Having all of the materials now available at learn.epilepsy.com allows users to learn about aspects of epilepsy in multiple mediums.

Free continuing education units (CEUs) are also available for many of the trainings for health professionals through our partnership with the CDC. In 2019, over 8,400 users received training through LMS.

 [Learning Management System \(LMS\)](#)

COMMUNICATIONS



Each of us chose to reflect on our experiences and use the ups and downs to fuel our fight for change.



Elizabeth Dueweke,
Epilepsy Foundation
Communications
Department manager,
reflects on her connection
and shared experiences with
her Golden Light Awardees
at the 2019 International
Epilepsy Congress.

END EPILEPSY

is about more than
epilepsy ...

END STIGMA

END ISOLATION

END INACTION

I HAVE A DREAM

MARTIN LUTHER KING, JR.

ON WASHINGTON
AND FREEDOM



OUR ACTION

Main and grow our online
presence and most used
epilepsy website.

COMMUNICATIONS OVERVIEW

The Epilepsy Foundation's reach is nationwide and even global through the work of our Communications and Digital team. Epilepsy.com is the top global resource for epilepsy, social media is a vital tool for connection and engagement with and among the epilepsy community, and our partnership with the Centers for Disease Control & Prevention and with CBS TV Community Partnership Division drive our Share My Seizure public awareness campaign to promote seizure recognition and first aid. Our TalkAboutIt! initiatives are a partnership with Greg Grunberg.



For more information,
visit epilepsy.com.

Here are highlights of our Communications initiatives and our digital reach.

Social Media

The Epilepsy Foundation uses social media as a vital tool for connection and engagement with and among the epilepsy community. Foundation content can be found on Twitter, Facebook, Instagram, LinkedIn and YouTube. We reached 29 million people on social media. Popular posts include community members celebrating seizure freedom milestones and photos from local Epilepsy Foundation events around the country.

TalkAboutIt.org

For many years, the Epilepsy Foundation has partnered with actor Greg Grunberg, who has a son living with epilepsy, to create a celebrity-based epilepsy information and awareness website called TalkAboutIt.org.

Celebrities 'host' information platforms about all aspects of epilepsy and seizures. The most popular platforms include Chris Pine and Zachary Quinto (stars of "Star Trek") on proper Seizure First Aid; Milo Ventimiglia ("This is Us") on bullying and Kristen Bell ("The Good Place") on talking about epilepsy with friends.

Share My Seizure

The Epilepsy Foundation, the U.S. Centers for Disease Control and Prevention and CBS television Community Partnership Division collaborated in a public awareness campaign for seizure recognition and proper Seizure First Aid. This was the third year of a five-year effort. Public service announcements ran on CBS television stations in Chicago and Philadelphia and the CW station in Atlanta. Seizure First Aid messages featured a youth basketball team learning how to help a teammate who lives with epilepsy. These messages ran during the NCAA March Madness tournament. Messages also ran on the CBS, CDC and Epilepsy Foundation digital platforms showing more rare forms of seizures to help raise awareness that seizures are more than the typically understood tonic-clonic convulsive seizures. The announcements were seen by 27.6 million 18 and older over air and 11 million on digital channels.

For more, visit www.epilepsy.com/sharemyseizure.

Epilepsy.com

The Epilepsy Foundation website is the top global online resource center for epilepsy and seizure information, engagement and awareness. Approximately nine million people visited the site this year, with more than 20 million pages viewed around the world. About 40 percent of the site traffic is international, from countries including the United Kingdom, India, Canada, Australia and South Africa.

Epilepsy.com *numbers in millions*

9.2 Million visits in CY2019

Top pages on Epilepsy.com

1. What is Epilepsy?
2. Absence Seizures
3. Seizure Types
4. Seizure Medications List
5. What is a Seizure?
6. Medical Marijuana and Epilepsy
7. Tonic Clonic Seizures
8. Seizure Warning Signs
9. Focal Onset Aware Seizures
10. Ketogenic Diet
11. Psychogenic Nonepileptic Seizures
12. What Happens During a Seizure?
13. Temporal Lobe Epilepsy
14. Myoclonic Seizures
15. Seizure Triggers
16. What Causes Epilepsy and Seizures?
17. Status Epilepticus
18. Driving Laws
19. Focal Onset Impaired Awareness Seizures
20. Vagus Nerve Stimulation

Top Countries visiting Epilepsy.com after the U.S.A

1. United Kingdom
2. Canada
3. India
4. Australia
5. South Africa
6. Philippines
7. Ireland
8. Malaysia
9. New Zealand

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AWARENESS



“

What makes me angry is the way people perceive epilepsy.

And I think that's something that we can change.

END EPILEPSY
is about more than
epilepsy ...
END STIGMA
END ISOLATION

OUR ACTION
Main and grow our online
presence and most used
epilepsy website.

AWARENESS AND OUR END EPILEPSY® MOVEMENT

Our work in FY18 had established these challenges and objectives for the launch of the END EPILEPSY campaign in FY19.

Campaign Objectives

1. Unite the Epilepsy Foundation with a single, consistent brand campaign that can make a difference in the lives of people living with epilepsy.
2. Put epilepsy on the map in terms of public awareness, engagement, and advocacy.
3. Mobilize action inside, and outside the epilepsy community to help fund vital services, care and research.

Challenges

Lack of awareness, engagement and action.

The answer to this challenge lies in using the brain as our common ground to open new doors to a new conversation about epilepsy and to rewire the 'fight or flight' response from avoidance to empathy.

Lack of urgency.

The answer to this challenge lies in highlighting the urgency which drives a unifying call to action — END EPILEPSY. END EPILEPSY is about finding cures and about overcoming the challenges that surround epilepsy.



For more information,
visit EndEpilepsy.org

END EPILEPSY NATIONWIDE CAMPAIGN

Building upon our earlier work, in FY19, we launched our campaign, Let's Use Our Brains to END EPILEPSY.

Campaign Launch:

The internal launch was during the Leadership Conference in October 2018. The public launch on the East Coast included an interview with John O'Hurley on Megyn Kelly TODAY, ADWEEK, Satellite Media Tour, Newsweek ad, and ads in Times Square.

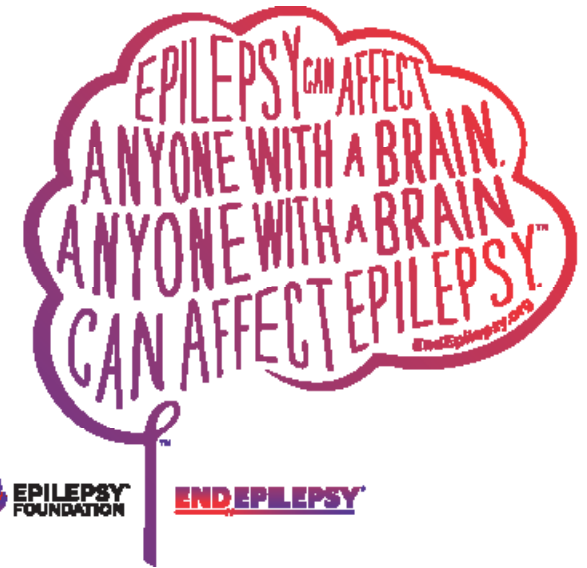
The West Coast launch included a Live Art Exhibit with artist SABER. Event video.

Public Service Announcement:

We created a :30 and :60 second Public Service Announcement which was aired nationwide.

[View PSA](#)

20,765	Airings
156,015,500	Audience/Impressions
\$3,758,425	Ad Publicity Value



[View Campaign Launch in Los Angeles Video](#)

A major feature of our "Let's Use Our Brains to END EPILEPSY" campaign included the ambassadors' stories and Brain Art with print and video interviews. These can be viewed at EndEpilepsy.org/stories.

The Brain Art of most of the ambassadors is featured in this Annual Report.

SEIZURE FIRST AID STARTS WITH USING YOUR BRAIN

STAY • STAY with the person until the seizure ends.

SAFE • Keep the person **SAFE** and start timing the seizure.

SIDE • Turn the person on their **SIDE** if they start convulsing or are not awake.

CALL 911

- If the seizure lasts longer than 5 minutes
- If another seizure starts or the person is injured or in distress

⊗ Do **NOT** hold someone down or restrain them

⊗ Do **NOT** put anything in their mouth

Simple Seizure First Aid. **STAY. SAFE. SIDE.**
Learn more at: ENDEPILEPSY.ORG

 **END EPILEPSY**

DETAILED SEIZURE FIRST AID

STAY with the person until the seizure ends • Remain calm • Check for medical ID • Keep the person **SAFE** • Move nearby hazards and people from away from danger • If the person starts convulsing, is not awake, or can't respond, ease them to the ground • Turn the person on their **SIDE** and continue to make sure they are **SAFE** • Loosen anything tight around their neck • Put something soft under their head • Time the seizure • Most seizures end in a few minutes and don't need emergency medical help • **STAY** with them until they are awake and alert • After the seizure, reassure the person and explain what happened • Offer to call someone for them • **CALL 911** if the seizure lasts longer than 5 minutes • **CALL 911** if the seizure repeats or breathing is difficult • **CALL 911** if seizure happens in water • **CALL 911** if person is injured, pregnant, sick or does not return to full awareness • **Do NOT** hold someone down or restrain them • **Do NOT** put anything in their mouth.

The marketing team also created the shortened Seizure First Aid: Stay. Safe. Side.

Other:

Some of our other activities included

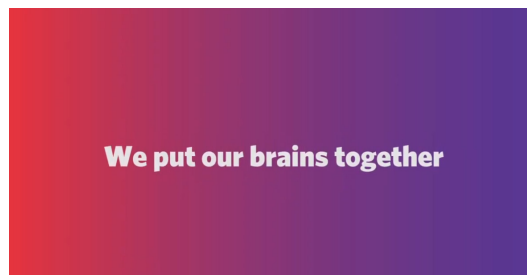
- Establishing the campaign website EndEpilepsy.org
- Creating a Brand Style Guide
- Media Relations Toolkit

The END EPILEPSY call to action was infused into our

- corporate partner appeals
- direct mail appeals,
- launch of our new online store: shop.epilepsy.com

A video of the first year of the campaign was created.

 [View video](#)



Saber
[Brain Art Artist and END EPILEPSY Ambassador](#)

END EPILEPSY means to me that we find the tools together. That we come together collaboratively and use our tools to battle this condition. ... I seek ideas and try to explore them in a creative way. ... For me art making is a path to healing.



LET'S USE OUR BRAINS TO END EPILEPSY®

Epilepsy can affect anyone with a brain. It does not discriminate.

It does not care about your race, your gender, your age, your religion.

If you have a brain, you can get epilepsy. Period.

But here's something that's just as important to know,
anyone with a brain can affect epilepsy.

So let's start using our brains to do just that.

Let's change the way people think about epilepsy.

The way they think about seizures.

Let's use our brains to do more innovative brain research.

Let's use our brains to educate where there is ignorance.

Let's use our brains to create an environment
where those who live with epilepsy can share their stories freely.

Because if all of us can get epilepsy, all of us can
END EPILEPSY.



END EPILEPSY

COMMUNITY ENGAGEMENT



Our active and engaged nationwide network, is an unwavering ally on the journey ... and dedicated to improving lives affected by epilepsy.



END EPILEPSY

is about more than epilepsy ...

END TREATMENT DELAYS

END HIDING

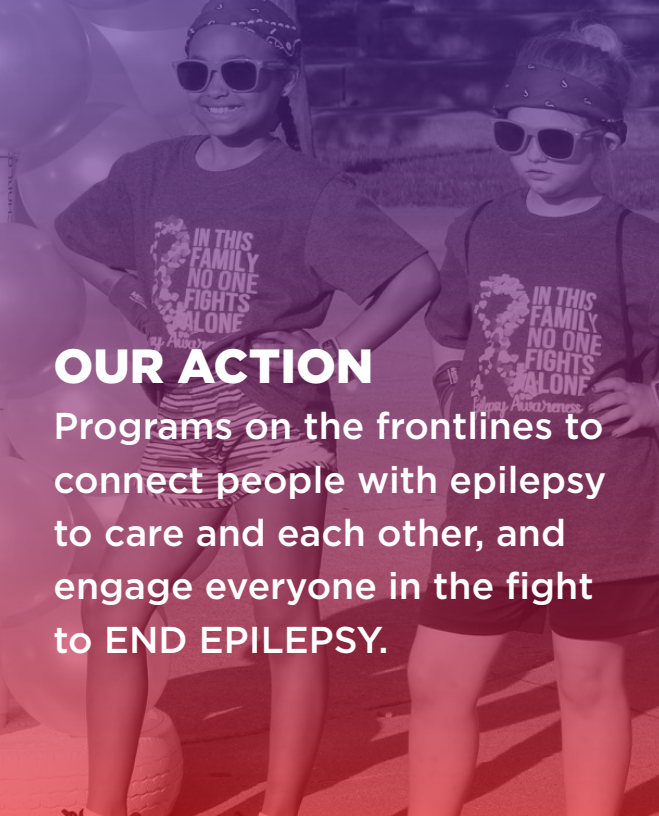


COMMUNITY ENGAGEMENT OVERVIEW

The Foundation is proud to support governing and advisory boards from our network of 49 local Epilepsy Foundations across the country, bringing local insight and expertise to the Foundation's national board of directors through involvement in strategic planning, fund raising, strengthening direct programs and services, and lending visionary thinking toward our collective goal: to END EPILEPSY.

We acknowledge and thank our network partners for sharing photos of their programs and services for this Annual Report.

- Epilepsy Foundation Alabama
- Epilepsy Foundation Greater Los Angeles
- Epilepsy Foundation Michigan
- Epilepsy Foundation Mississippi
- Epilepsy Foundation Nevada
- Epilepsy Foundation Ohio
- Epilepsy Foundation East Tennessee
- Epilepsy Foundation Utah
- Epilepsy Foundation Washington



OUR ACTION

Programs on the frontlines to connect people with epilepsy to care and each other, and engage everyone in the fight to END EPILEPSY.



For more information, visit [epilepsy.com/local](https://www.epilepsy.com/local)



Whitney
END EPILEPSY Ambassador

When the Epilepsy Foundation came to my school – that’s when I opened up about having epilepsy. It’s important for me to tell people about epilepsy because it will encourage kids who are very shy ... to speak up and tell other kids they know.

Our Reach – Our Volunteers

Volunteers have always been critical to reaching far beyond brick and mortar. They have a profound influence within local and nationwide communities, providing a vital extension to the resources and expertise of almost 300 Epilepsy Foundation staff members across the country. The investment we made in our volunteer management platform, along with developing a formalized process to orient, train, and recognize our volunteer team, has positioned us to better support this legion of unsung heroes and to help them deliver our mission.

The Foundation is proud to support 43 governing and advisory boards across the county, bringing local insight and expertise to the Epilepsy Foundation’s national board of directors through involvement in strategic planning, fund raising, strengthening direct programs and services, and lending visionary thinking toward our collective goal: to END EPILEPSY.

Our Reach – Our Network Leadership

Leadership Conference

Our 2018 Leadership Conference included Epilepsy Foundation staff and volunteers from throughout our nationwide network. The conference was held at the Paradise Valley Resort by Hilton in Scottsdale, Arizona, from September 26-28, 2018

Besides General Sessions, the conference offered a special track for Volunteer Leadership and a track on “Building Capacity” for staff involved in development, marketing, and programs.

Keynote speaker Benita Fitzgerald Mosley spoke about Building Leaders and Championship Teams. The new “Let’s Use Our Brains to END EPILEPSY” campaign was launched with a presentation about the research and strategy that went into crafting the campaign. Other sessions included: Wellness & Epilepsy, Building and Sustaining Successful Chapter Boards, Media Landscape, From Good to Great Fund Raising, How Data Tells The Story, Government Relations and Advocacy, Changing the Outcome: How People and families can have an Impact on Epilepsy Research and the Quality of Healthcare, and more.

We are planning for our Leadership Conference 2019 in Kansas City, in September 2019. The theme will be “Think Big”.

OUR NETWORK IN FISCAL YEAR 2019

ALABAMA

- Epilepsy Foundation Alabama

ALASKA

- Epilepsy Foundation Alaska

ARIZONA

- Epilepsy Foundation Arizona

CALIFORNIA

- Epilepsy Foundation Greater Los Angeles
- Epilepsy Foundation Orange County
- Epilepsy Foundation San Diego County
- Epilepsy Foundation Northern California

COLORADO

- Epilepsy Foundation Colorado

CONNECTICUT

- Epilepsy Foundation Connecticut

DELAWARE

- Epilepsy Foundation Delaware

DISTRICT OF COLUMBIA

- Epilepsy Foundation Metro DC

FLORIDA

- Epilepsy Foundation Florida

GEORGIA

- Epilepsy Foundation Georgia

HAWAII

- Epilepsy Foundation Hawaii

IDAHO

- Epilepsy Foundation Idaho

ILLINOIS

- Epilepsy Foundation Greater Chicago
- Epilepsy Foundation North/Central Illinois
- Epilepsy Foundation Greater Southern Illinois

INDIANA

- Epilepsy Foundation Indiana

IOWA

- Epilepsy Foundation Iowa

KANSAS

- Epilepsy Foundation Kansas & Missouri

KENTUCKY

- Epilepsy Foundation Kentuckiana

MAINE

- Epilepsy Foundation New England

MARYLAND

- Epilepsy Foundation Maryland

MASSACHUSETTS

- Epilepsy Foundation New England

MICHIGAN

- Epilepsy Foundation Michigan

MINNESOTA

- Epilepsy Foundation Minnesota

MISSISSIPPI

- Epilepsy Foundation Mississippi

MISSOURI

- Epilepsy Foundation Kansas & Missouri

NEBRASKA

- Epilepsy Foundation Nebraska

NEVADA

- Epilepsy Foundation Nevada

NEW HAMPSHIRE

- Epilepsy Foundation New England

NEW YORK

- Epilepsy Foundation Northeastern New York
- Epilepsy Foundation Metropolitan New York
- Epilepsy Foundation Long Island

NORTH DAKOTA

- Epilepsy Foundation Minnesota

OHIO

- Epilepsy Foundation Ohio

OKLAHOMA

- Epilepsy Foundation Oklahoma

OREGON

- Epilepsy Foundation Oregon

PENNSYLVANIA

- Epilepsy Foundation Eastern Pennsylvania

RHODE ISLAND

- Epilepsy Foundation New England

SOUTH DAKOTA

- Epilepsy Foundation South Dakota

TENNESSEE

- Epilepsy Foundation Middle & West Tennessee
- Epilepsy Foundation Southeast Tennessee
- Epilepsy Foundation East Tennessee

TEXAS

- Epilepsy Foundation Central & South Texas
- Epilepsy Foundation Texas - Houston/Dallas-Fort Worth/West Texas

UTAH

- Epilepsy Foundation Utah

VERMONT

- Epilepsy Foundation Vermont

VIRGINIA

- Epilepsy Foundation Virginia

WASHINGTON

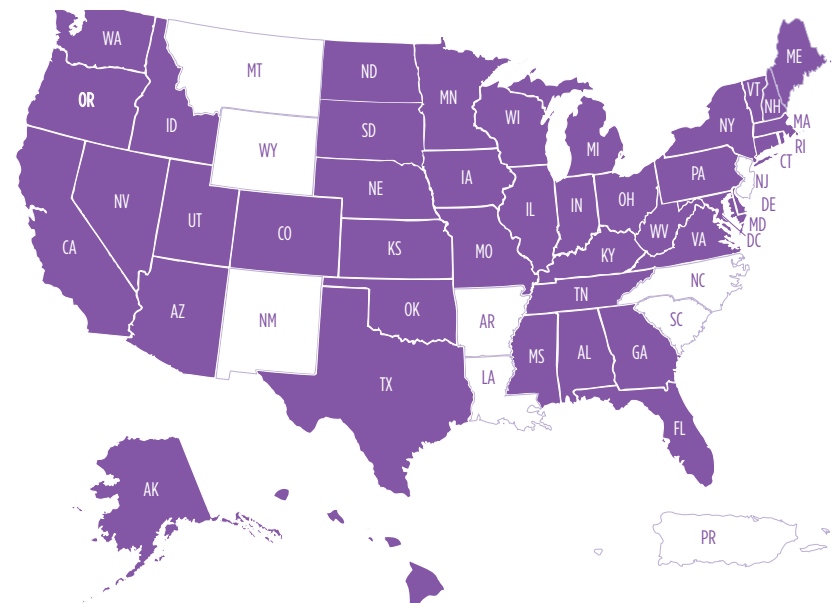
- Epilepsy Foundation Washington

WEST VIRGINIA

- Epilepsy Foundation West Virginia

WISCONSIN

- Epilepsy Foundation Heart of Wisconsin
- Epilepsy Foundation Western Wisconsin



Special Initiatives

Kids Crew, the Foundation's signature program for children and teens 14 and under, has grown to over 1,640 members.

This program provides a forum for any child to learn more about epilepsy, teach others, spread awareness, raise funds, and participate in events. They are encouraged to complete specific activities to earn themed pins which can make an impact personally as well as in the community.

The Kids Crew quarterly printed newsletter, that is delivered right to mailboxes, continues to be a highlight of the program with its Kids Crew updates, wonderful member stories, informative epilepsy facts, and fun games. We are so proud of our amazing members for all that they are doing to change the world!

This year, Kids Crew President and Founder, Hailey Scheinman was chosen to be featured in the new Marvel Hero Project.

Hailey's twin sister Livy was born with cerebral palsy and has epilepsy, which brings a sibling's special perspective to the challenges of living with disabilities.

To register for Kids' Crew, visit epilepsy.com/kids-crew









PUBLIC SUPPORT



The nationwide Walk is a place of connection and action together to END EPILEPSY.

EPIDEMIOLOGY
HOPE AWARENESS
FAITH
COURAGE
LOVE
RESEARCH
OVERCOME
STRENGTH
WIN
EDUCATE
FIGHT
CONQUER
CURE

MADDIE MOVIE

EPIL

END EPILEPSY Stories
our like gold in our fight to
END EPILEPSY. Your story
inspires you and others to
give and get involved.



PUBLIC SUPPORT OVERVIEW

The Epilepsy Foundation depends on public and private support and the generosity of individual and corporate donors. Our donors' generosity enables the Epilepsy Foundation to continue its mission to lead the movement to END EPILEPSY. We celebrate the diversity of individuals, families, charitable giving foundations, businesses and corporations raising their hands to support our work and mission.

And as each and every donation brings us closer in our mission to END EPILEPSY; each and every donation is connected to a unique story of generosity and compassion. In recognition of the powerful stories our donors carry, we wanted to highlight a few.



OUR ACTION
Walkers and Walk Teams
in communities across the
country started joining the
first ever nationwide Walk
to END EPILEPSY.



A STORY OF GRATEFUL GIVING

Donor Story: James F. Bohrer

IN 1989, WHEN I WAS WORKING AS AN ATTORNEY, volunteering in my community, and preparing for my upcoming wedding, I had a complex partial seizure. Over the next seven years, I had several more seizures, and they occurred with increasing frequency and severity. I tried as many prescription medications as were approved at the time, but none of them provided effective control. Finally, in 1996, I sought treatment at the Mayo Clinic, and the doctors and surgeons there performed temporal lobe surgery, and I have been seizure-free ever since.

I am aware of the life-altering effects a seizure disorder diagnosis has on a patient and their family. At the time of my first seizure, I desperately wanted to know more about what was going on and relied heavily upon the Epilepsy Foundation's educational information and website. After I was diagnosed and prescription drug treatment proved ineffective, I relied on the Epilepsy Foundation providing connections with other patients and their families who shared stories about the emotional aspects of dealing with a chronic disorder.

When I became seizure-free, I wanted to do all that I could to help patients and their families who were still dealing with the effects of a seizure disorder. I starting giving to the Epilepsy Foundation.

After years of being a dedicated financial support, in 2018, I chose to make a planned gift to the Epilepsy Foundation. Designating a portion of my retirement savings account to the Epilepsy Foundation was an easy way for me to give back.

I feel personally fulfilled that my gift to the Epilepsy Foundation assures after my passing, funds will be available to support further research and advocacy, and to connect patients and their families to support one another in their search for effective treatments and cures.



Support the Epilepsy Foundation

Here are just a few ways our community supports us.

- Volunteering
- Giving donations, both in-kind and cash
- Corporate and business sponsorship and support
- Hosting in-your-community events
- Athletes vs. Epilepsy
- Walk to END EPILEPSY
- Charitable grant funding
- Employee workplace giving
- Amazon Smile
- Donation of home goods and vehicles

WITH HONOR AND LOVE

Donor Story: Ronald J. Currie, through the words of Deborah Van Horn

RONALD J. CURRIE, OTHERWISE KNOWN AS “CURRIE” and my stepdad, knows the grief and loss epilepsy leaves in its wake. As a newly married couple, Currie lost his first wife, Mary (“Tiny”) at 26, to a seizure when their beloved daughter, Traci, was only a few months old. It was life-altering as Currie faced the reality of raising Traci without her mother.

Fast forward to a few healing years later, Currie began dating and ultimately married my mom, Pat, to begin life again as a new family that eventually grew to include four children. My new sister, Traci, was two when we became family and by that time I already knew that Traci lived with seizures.

By the age of 20, Traci began the process of “weaning” off of her current prescribed treatment when she suffered her final seizure just a few weeks after turning 21 years old. The paramedics were called, but

by the time they arrived and got her heart beating again, she was brain dead. It was such a tragic loss for our family and especially hard for Currie, who now just lost his daughter, Traci, the same way he lost Tiny.

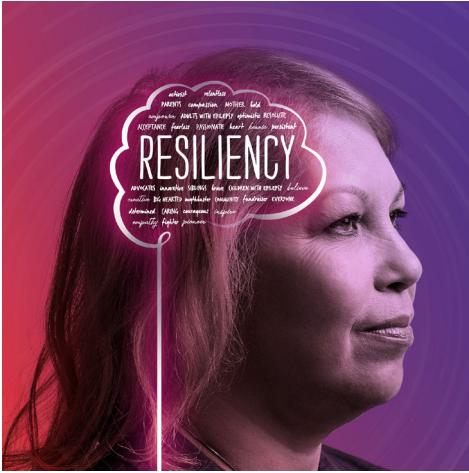
Currie was forever changed.

Upon the passing of my mom, Pat, in 2016 and Currie in 2018, my siblings and I were charged with handling the estate which included a very significant portion of the estate in donation to the Epilepsy Foundation on behalf of Traci and really on behalf of Tiny as well.

Currie’s life was totally shattered by the loss of his wife and daughter at such young ages. It is our hope this donation will further research and inspire others to support the critical efforts to stop this life ending condition.



Please refer to page 40 for more financial information regarding charitable support of the Epilepsy Foundation from July 1, 2018 – June 30, 2019.



Veronica
 END EPILEPSY Ambassador

I found the Epilepsy Foundation after my son, Gabriel, passed away. My cousin and I went on the Walk to End Epilepsy ... I was amazed at how many people have epilepsy and it goes unnoticed. And I really wish that a lot of people would learn more about it.

NATIONWIDE Walk to **END EPILEPSY**

We created the central WalktoEndEpilepsy.org website to host and promote the first-ever nationwide walk which was growing many walks nationwide. Supported the network with Walk promotion: media relations activities, social media posts, sponsored ads, and the Walk 2019 Public Service Announcement [View PSA](#).

46 Walks to
 END EPILEPSY
 nationwide events

77 News stories /
 Calendar listings
 (11 mo)

29 Network
 organizations
 participate

89M+ Audience/
 Impressions



Epilepsy Foundation and Epilepsy Research Foundation Summary Consolidated Financial Statements \$ In Thousands

CONSOLIDATED STATEMENT OF FINANCIAL POSITION

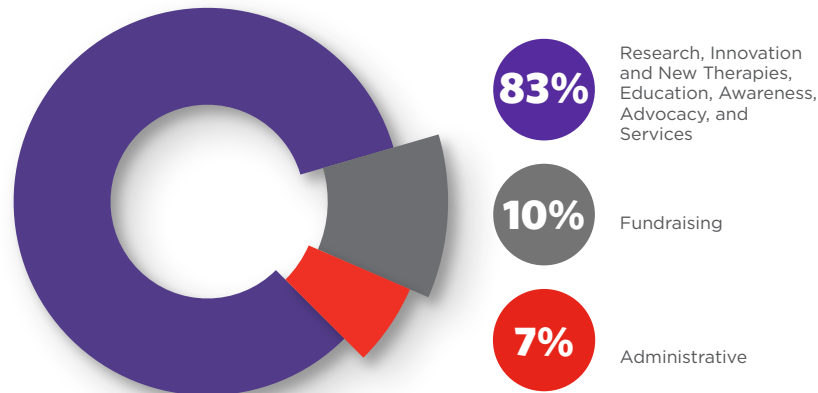
As of June 30

ASSETS	2019	2018
Cash and cash equivalents	2,702	4,983
Investments	8,326	7,938
Receivables	2,522	2,148
Prepaid expenses and Inventory	257	337
Fixed assets, net	795	683
Deferred rent asset	136	230
Beneficial interest in perpetual trusts and other assets	5,454	5,183
	<u>20,192</u>	<u>21,502</u>

LIABILITIES AND NET ASSETS

Accounts payable and accrued expenses	1,936	1,228
Grants payable	1,093	590
Deferred revenue	79	101
	<u>3,108</u>	<u>1,919</u>
Net Assets	17,084	19,583
TOTAL LIABILITIES & NET ASSETS	<u>20,192</u>	<u>21,502</u>

Epilepsy Foundation Spending Percentages - Fiscal Year Ending 2019



CONSOLIDATED STATEMENT OF OF ACTIVITIES

For the year ended June 30

REVENUE	2019	2018
Contributions	11,305	17,877
Government and other grants	4,719	3,770
Affiliate fees	461	390
Special events, net of direct cost	3,229	1,470
Investment Income	630	374
Change in value of beneficial interests in trusts	260	17
Other	419	155
	<u>21,023</u>	<u>24,053</u>

EXPENSES

Program Services		
Research, Innovations and New Therapies	3,475	3,080
Education and Awareness	4,286	3,634
Advocacy and Services for Individuals, Families and communities	11,774	8,036
Supporting Services		
Administrative	1,583	1,021
Fundraising	2,404	1,956
TOTAL EXPENSES	<u>23,522</u>	<u>17,727</u>

Change in net assets	(2,499)	6,326
Net assets beginning of year	19,583	13,247
Net assets ending of year	<u>17,084</u>	<u>19,583</u>

APPENDIX

SHARK TANK WINNERS 2019

The Shark Tank winners were selected through live voting by conference attendees and a panel of judges (“Sharks”) representing physicians and scientists, corporate executives, leading industry investors, people with epilepsy, and advocates.

The winners receive international recognition and share awards totaling \$200,000 to support the development and commercialization of their ideas.

DETECTING SEIZURES WITH AN EYE-OPENING SOLUTION

Rachel Kuperman, MD CEO of Eysz, Inc. San Francisco, California, \$75,000 Audience Choice award + \$75,000 Judges Award

With this project, Dr. Kuperman plans to develop and deploy 100 eye-tracking wearables that will be used in a clinical study at the University of California San Francisco (UCSF). The clinical study will refine the wearables’ patented seizure-detection algorithm for absence seizures.

Dr. Kuperman’s mission with Eysz is to give clinicians and patients the tools they need to improve patient outcomes and quality of life. This device will help provide specific, sensitive means for detecting seizures, a relief from intensive EEG monitoring currently needed to detect seizures and seizure-related events. Dr. Kuperman’s project comes from her ten

years of clinical practice at the University of California San Francisco Benioff Children’s Hospital as a pediatric epileptologist.

FALLING DOWN THE RABBIT HOLE OF MEDICATION ADHERENCE

Jody McNannay, CoFounder Curadite, Inc. and parent of daughter with epilepsy. Beaverton, Oregon.

\$50,000 Judges Award

Curadite hopes to optimize its innovative medication management platform, which incorporates intelligent packaging, patient reminders, and a clinician dashboard for the epilepsy community. Jody brings her experience as a mother with a child with epilepsy to the project. She has learned firsthand the difficulty of managing medication adherence.

The platform provides timely support for individuals with epilepsy. It also alerts care teams when loved ones are struggling to take medication as prescribed. Shark Tank funds will be used to develop and customize the platform for strict seizure medication adherence. They will also work closely with their research partner to complete the pilot design and recruit the clinicians, patients, and care teams needed for the pilot. More information on the SUDEP Biomarker Challenge projects awarded:

Past Awardees of the Lifetime Accelerator Award

2012: [Harvey Kupferberg PhD](#), past Chief of the Preclinical Pharmacology Section, Epilepsy Branch, NINDS, NIH

2013: [Henrik Klitgaard PhD](#), Vice President, Head CNS Research, UCB

2014: [H. Steven White PhD](#), Professor of Pharmacology and Toxicology and Principal Investigator of the (NIH)-sponsored Anticonvulsant Drug Development Program at the University of Utah College of Pharmacy

2015: [Roger J. Porter MD](#), academic and pharmaceutical industry consultant and past Chief Scientific Officer of the Foundation

2016: [Jack Pellock MD](#), Professor of Neurology, Pediatrics, Pharmacy and Pharmacuetics at Virginia Commonwealth University

2017: [Elinor Ben-Menachem MD](#), Professor of Neurology at the University of Gothenburg, Sweden

2018: [Wolfgang Löscher DVM, PhD](#), Head, Department of Pharmacology, Toxicology and Pharmacy, University of Veterinary Medicine Hannover and Head, Center for Systems Neuroscience Hannover

Supporting the Next Generation of Scientists

The Epilepsy Foundation has supported over 3000 research careers since 1968. This year, the Epilepsy Foundation supported four different projects in partnership with our sister organizations, including the American Epilepsy Society (AES).

1. Junior Investigators – The Epilepsy Foundation partners with the American Epilepsy Society (AES) support researchers who have recently started their own independent labs to study epilepsy.

2019 Awardees:

William Nobis, MD, PhD Vanderbilt University Medical Center. The Role of the Extended Amygdala in Respiratory Control and SUDEP

Alicia Guemez Gamboa, PhD Northwestern University. Uncovering Altered Connectivity in Epilepsy due to Somatic Mutations

2. Clinical Research & Training Fellowships – We have partnered with AES to provide mentored support for clinical fellows or recently appointed clinical faculty who intend to pursue basic, translational, or clinical epilepsy research.

2019 Awardee: Behnaz Esmaeili, MD Brigham and Women's Hospital. Intracranial EEG Suppression and Heart Rate Variability in Epilepsy

3. Susan S. Spencer Clinical Research Training Fellowship in Epilepsy Award – We co-sponsor a clinical research fellowship with the American Epilepsy Society, the American Academy of Neurology, and the American Brain Foundation.

2019 Awardee: Lisseth Burbano, MD, The Florey Institute of Neuroscience, Melbourne, VIC, Australia. Development of a Precision Therapy in KCNT1 Epileptic Encephalopathy.

4. The Kevin's Fellows program – Helps support awardees in the Next Generation scientists program.

LET'S MEET THE GRANTEES.

AES/EF Junior Investigator Research Awards

William Nobis, MD, PhD

Vanderbilt University Medical Center

Research Topic: The Role of Extended Amygdala in Respiratory Control and SUDEP

Sudden unexpected death in epilepsy (SUDEP) is the leading cause of death in people with uncontrolled seizures. Seizure-related apneas (cessation of breathing during a seizure) are being observed in epilepsy units where respiratory status is consistently monitored. When SUDEP has occurred in a healthcare setting, apnea has been observed prior to the terminal cardiac arrhythmias. This suggests that SUDEP might be a lethal combination of a seizure-related apnea along with impaired consciousness in the individual post-seizure.

In previous work, Dr. Nobis established that an area of the brain known as the extended amygdala causes apnea when stimulated. Dr. Nobis hypothesizes that this region or the parabrachial nucleus, another area implicated in respiratory control, may be activated during a seizure and thus cause the observed seizure-induced apneas. Using animal models that study SUDEP, he will test whether and how these brain regions are impacted during a seizure, and how this can impact respiratory control. Understanding this pathway and its role could open up new prevention strategies for those at high risk of SUDEP.

Alicia Guemez Gamboa, PhD

Northwestern University

Research Topic: Uncovering Altered Connectivity in Epilepsy due to Somatic Mutations

A somatic mutation is a genetic mutation that occurs as a cell divides in the developing body. If there is a genetic mutation that occurs during the division, this would be contained to the cell that the mutation occurred in and the other cells that this cell helped to create afterwards. There is evidence of somatic diversity in the brain, which means that specific brain cell populations have a genetic mutation in their DNA not associated with other brain cells or organs in the body. Some of these somatic mutations in the developing brain have been linked to focal cortical malformations associated with pediatric drug-resistant epilepsy.

To better understand how somatic mutations could impact epilepsy and brain circuits, Dr. Gamboa has created a mouse model that causes brain cell-specific genetic mutations that activate the mTOR pathway during cortical development. There are many studies that observe a frequent hyperactivation of mTOR signaling in epilepsy. For example, seizures associated with Tuberous Sclerosis, a rare genetic epilepsy syndrome, is treated by mTOR inhibitors. In this research proposal, she will explore how somatic mutations in the mTOR pathway in a contained population of neurons result in network abnormalities that lead to epilepsy. The disease mechanisms that arise from this research could lay the groundwork for new therapeutic approaches.

AES/EF Clinical Research Training Fellowship

Behnaz Esmaeili, MD

Brigham and Women's Hospital

Research Topic: Intracranial EEG Suppression and Heart Rate Variability in Epilepsy

SUDEP is the sudden, unexpected death of someone with epilepsy who was otherwise healthy. In SUDEP cases, no other cause of death is found when an autopsy is done. Each year, more than 1 in 1,000 people with epilepsy die from SUDEP. The mechanism(s) of SUDEP are still under intense investigation by researchers in the U.S. and across the world.

The most consistent risk factor for SUDEP is frequent generalized tonic-clonic (GTC) seizures. Certain individuals experience a dramatic suppression of brain activity after a GTC seizure. This phenomenon is also linked to the altered state of consciousness post-seizure, which can last between 5 to 30 minutes. In addition to the change in brain activity, clinicians have also observed decreased heartrate variability in individuals post-seizure.

In a healthy heartbeat, you would experience healthy irregularities. For example, if you place a finger on your pulse, you would notice that your pulse can change based on how you breath (exhale versus inhale). These heart rate variabilities are dampened post-seizure. The question remains about whether the characteristics of the brain activity suppression and the decrease in heart rate variability post-seizure could be indicators of increased risk for SUDEP.

To answer this question, Dr. Esmaeili will be mining data from a data repository from the epilepsy monitoring unit of 5 major academic epilepsy centers to understand the range of characteristics of the brain activity and heart rate variability post-seizure. She will be observing whether there are any significant factors in either of these two measurements in confirmed SUDEP cases. This work could highlight physiological factors that indicate who is at higher risk of SUDEP.

Susan S. Spencer Clinical Research and Training Fellowship

Cosponsored by the American Academy of Neurology, the American Brain Foundation, the American Epilepsy Society, and the Epilepsy Foundation

Lisseth Burbano, MD

The Florey Institute of Neuroscience, Melbourne, VIC, Australia

Research Topic: Development of a Precision Therapy in KCNT1 Epileptic Encephalopathy.

The KCNT1 gene encodes a protein that forms a sodium-activated potassium channel. This channel is widely expressed in the nervous system and has a role in the regulation of neuronal communication. Mutations in the KCNT1 gene can produce a severe neurological condition with epilepsy and cognitive impairments. These mutations cause considerably higher levels of channel activity which is thought to be the primary mechanism leading to the disease.

Dr. Burbano's research aims to develop a gene modulation therapy that will block the KCNT1 gene's protein production. The hope is that by blocking KCNT1, it would abolish the channel hyperactivity and control the disease activity and progression.

The social and economic burdens of neurogenetic disorders are enormous as patients require constant care. The results of this research could lead to the development of a specific therapy, that would aim to address the core problem in a condition that is so far untreatable.

Kevin's Fellow

The Kevin's Fellow award is a way for donors to recognize and fund young researchers working in the field of epilepsy. Each year, a donor may select a fellow from our Next Generation Scientist Program, support their research grant, and track the progress of the investigator throughout their career. Kevin's Fellows are named after Kevin Andrew Mateczun, a young man who struggled with epilepsy, and lost his life in an epilepsy-related accident. Thank you to our donors who have made early-career funding possible! If you are interested in being a Kevin's Fellow, please contact donate@efa.org.

WE BELIEVE ...

Now is the time to make a powerful change for and with people with epilepsy.

Together we are on the front lines to empower a radical shift.

From acceptance to active fight, from ignorance to understanding, from stigmatized to belonging, from mystery to illumination, from hidden to hero, from the status quo to the stratosphere of what's possible, from individual action to action together — because we know it can't be done alone.

Acting together, from a place of common ground. We unite in a common cause — bringing together diverse experiences, people and expertise to create a lasting change for people living with epilepsy.

It's time to take **Action Together.**

It's time to **END EPILEPSY®**

We are the **Epilepsy Foundation.**~

