Dear Friends,

“Action Together” is the theme of our Report for the 2018 fiscal year. One thing is certain – Action Together would not be possible without your support for the Epilepsy Foundation. You are key participants in our Action Together, and your contributions are critical to our mission.

The photo of the baby next to my letter is an unusual choice but powerful illustration of Action Together. Despite his age, this baby is a Hero, a Warrior – the words we hear and say most often when we talk about individuals living with epilepsy. Their lives exemplify and inspire Action Together. The lipstick kiss on this baby’s forehead symbolizes the actions of loving families that surround and support individuals with epilepsy. The surgical scar represents the actions of the epilepsy specialty teams – nurses, social workers, neurosurgeons, neurologists, and technicians – as well as researchers in the neurosciences who help advance knowledge and improve techniques and therapies. This photo was taken at our WALK TO END EPILEPSY where this baby was surrounded by family and friends showing their desire to take action on behalf of the broader community. They benefited from the Epilepsy Foundation and they wanted to give back to help other families.

This baby’s story – and the stories of thousands of other families – will continue to fuel more awareness and advocacy, more Helpline calls, more visits to epilepsy.com, more people getting trained in Seizure First Aid, more training of specialists, and more funding for research and new therapies.

You will see from our 2018 Report, that we are committed to a broad mission because our community is vast and diverse, is affected by the full spectrum of epilepsies, and faces a wide range of challenges. To fulfill our mission, we depend on many partners as we take Action Together. At our core, we are proud to be a nationwide organization that works closely with a network of affiliates and chapters delivering frontline services across the country. We partner with other advocacy organizations to effect change. We collaborate with specialists and researchers focused on specific rare epilepsies and on more common epilepsies. We partner with those fighting to end SUDEP. We partner with the Centers for Disease Control & Prevention to deliver broad public health awareness and training in epilepsy recognition and Seizure First Aid in communities across our country. Our advisors and board members, nationally and locally, are affiliated with hundreds of research and medical epilepsy centers across our country. We are closely connected to the global mission of epilepsy through our affiliation with the International Bureau for Epilepsy.

Truly, our mission depends upon Action Together. Our community depends upon us taking Action Together. And Action Together includes you and depends upon you.

Thank you for your generous and faithful support,

Philip M Gattone, M.Ed.
President & CEO

“Individually, we are one drop. Together, we are an ocean.”

- Ryunosuke Satoro
EPILEPSY BY THE NUMBERS

65 Million people around the world have epilepsy

3.4 Million people in the United States have epilepsy

1 in 10 people will have a seizure over a lifetime

1 in 26 people will develop epilepsy over a lifetime

EVERY NUMBER IS A REAL PERSON AND A REAL STORY.
3-4 out of 10 people with epilepsy continue to experience uncontrolled seizures.

More children die each year from SUDEP than from SIDS.

This is unacceptable, so please take action with us.
ABOUT EPILEPSY

When a person has two unprovoked seizures or one unprovoked seizure with the likelihood of more, they are considered to have epilepsy.

Epilepsy affects men and women of all ages and all races and ethnic groups. Epilepsy affects 3.4 million people in the U.S. and 65 million worldwide. This year, another 150,000 people will be diagnosed with epilepsy.

Despite all available treatments, 3-4 out of 10 people with epilepsy continue to experience uncontrolled seizures.

A range of different types of epilepsy and seizures affect people differently and impact many aspects of life – friendships, employment, mobility, overall health and wellbeing, and greater risk of injury and early death.
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.

OUR ORGANIZATION
The Epilepsy Foundation is a national nonprofit with about 50 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.
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**Stories are the thread of Action Together.**

Epilepsy is a complex spectrum of brain disorders that is best understood through simple, personal stories. We hear moving stories about the varying degrees of physical, economic, and psychosocial impact on families. We hear stories about children who are bullied and lose friends. Adults with epilepsy share about unfair treatment, lost jobs and relationships. We wish the stories of injury and early death just weren’t true, but they are. We are also privileged to hear stories of bravery and resilience through the medical gauntlet and to withstand loss while still dreaming big dreams. Each story of trial and triumph exemplifies and inspires ACTION TOGETHER.
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"Our research has no boundaries. Over the past ten years, we have funded research on 6 continents."

Sylvia’s story is an example of the power of individuals to influence and benefit from research.

Sylvia Olvera had her first seizure and was diagnosed with epilepsy in her last year of medical school. After two years of uncontrolled seizures, she had surgery for her epilepsy. That experience influenced her to switch her specialty to Neurology. Dr. Olvera’s personal experience of epilepsy, surgery, marriage, motherhood, and now her work as a neurologist caring for people with epilepsy reflects and inspires our research. In 2018, Dr. Olvera agreed to be an ambassador for the END EPILEPSY campaign.
RESEARCH OVERVIEW
Our purpose is to develop an epilepsy research ecosystem that covers the entire spectrum of discover – 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 2018
- 2 Thought Leadership Publications in high-profile journals (My Seizure Gauge / RRE)
- 9 workshops/conferences on topics such as seizure prediction, the future of cannabidiol research and rare epilepsies
- 18 research awards in amount of $892,000+ supporting entrepreneurship, conferences, early careers, and SUDEP prevention
- 30+ rare epilepsy organizations added to our Rare Epilepsy Network
- First clinical observation study launched with the Human Epilepsy Project
- 2,000+ people participated online in our Pipeline Conference online

ACTION TOGETHER
The Rare Epilepsy Network is a partnership with over 30 organizations for rare epilepsies.

DO YOU KNOW?
Between 2003 and 2018, we provided funding to half of the therapies in the epilepsy clinical pipeline.
Pipeline Conference 2018
Showcasing the Clinical Pipeline

The Epilepsy Foundation’s Pipeline Conference is a biannual gathering of clinicians, researchers, industry representatives, nonprofit organizations and people impacted by epilepsy. The conference provides a platform for companies to give brief updates on progress relating to devices and pharmaceuticals in various stages of clinical pipeline. Interspersed throughout the presentations are panel discussions relating to broad initiatives taking place within the community.

Following the two-day conference, we host a Community Day, where people living with epilepsy and their family, friends, and advocates gather for a day of learning, support, and networking and learn about new developments in the clinical pipeline.

The 2018 Pipeline Conference and Community Day, hosted in partnership with our affiliate in Northern California, took place on February 22–24 in San Francisco. The 2018 event was our largest event to date!

To learn more about what’s happening in the clinical pipeline, watch the videos online: www.epilepsy.com/pipeline2018

50+ Speakers
300+ In-Person Attendees
2000 + Views Online

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 26 submissions from 10 different countries around the world. Six of those were chosen as finalists and four were awarded a $5,000 prize. The finalists presented at the Epilepsy Foundation Pipeline Conference on February 22 in San Francisco.

This year’s Shark Tank winners were:

- 3D Machine Vision System for Surgical Navigation of the Human Brain, Aaron Bernstein, PhD, Advanced Scanners, Austin, Texas
- Virtual Reality Simulations for the Management of Status Epilepticus, Joshua Sherman, MD, and Todd Chang, MD, MAcM, Children’s Hospital Los Angeles, USC-Keck School of Medicine, Los Angeles, California.

See APPENDIX for more about these two projects.

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

ENGAGEMENT

More than half the drug/device developers presenting at the Pipeline Conference received seed funding from the Epilepsy Foundation!

- Kathleen Farrell, MB BCh BAO
Senior Director of Clinical Research
Transforming the Clinical Pipeline in A Timeframe That Matters
Three products that received Foundation early seed funding were approved by the U.S. Food & Drug Administration (FDA) this year.

**zEEG by ZETO**
This year, the Epilepsy Foundation provided early funding for three products that received approval by the U.S. Food & Drug Administration (FDA). In May 2018, zEEG by Zeto became the first wireless, dry-electrode EEG headset and cloud software platform approved by the FDA for clinical use. Zeto was awarded $150,000 at the 2016 Epilepsy Foundation Shark Tank competition to improve the original design and software for clinical needs such as signal quality, comfort and convenience. In 2017, the Foundation provided further investment through its New Therapy Commercialization Grants program to assist in the manufacturing of device prototypes. zEEG Zeto will launch zEEG commercially in early 2019.

**EMBRACE by Empatica**
In February 2018, Embrace by Empatica was the first seizure-alerting smartwatch to receive approval from the FDA for use in identifying tonic-clonic seizures and sending alerts to caregivers. The team received early funding from the Foundation when it won the People’s Choice Award at the 2013 Epilepsy Foundation Shark Tank competition; the team later received $75,000 at the 2015 competition to upgrade Embrace’s hardware and software platforms and conduct further research. Through a crowd-funding partnership between Empatica and the Foundation in 2015-2016, more than 1,500 beta-version smartwatches were given to families in need. The data collected from this process led to further smartwatch improvements.

**EPIDIOLEX by Greenwich Biosciences**
In June 2018, Epidiolex by Greenwich Biosciences became the first CBD-derived product approved by the FDA for the treatment of Dravet and Lennox-Gastaut. In 2013, the Foundation awarded a $50,000 New Therapy Commercialization grant to Dr. Orrin Devinsky’s open-label clinical study to understand the safety profile of CBD.

“EF funding set the ball rolling for us. The validation helped position Zeto as a disruptive startup, gain credibility, raise investor funding and expedite our overall progress.”
- Aswin Gunasekar, Founder, Zeto

“The votes of confidence from the sharks and from the super-educated conference attendees helped get us important extra visibility and greater credibility when fundraising. This moved us significantly closer to where we are today: Improving Lives.”
- Roz Picard, SC.D, Chief Scientist and Co-Founder, Empatica

“The Epidiolex trial was awarded the Epilepsy Foundation’s Innovation Seal of Excellence research award, that provided critical seed funding for the open label study.”
- Orrin Devinsky, MD, Director of the NYU Comprehensive Epilepsy Center and the Saint Barnabas Institute of Neurology and Neurosurgery.
Infrastructure Grant Awarded to the Epilepsy Foundation

Imagine building a learning health system in which all people – family and community members, clinicians, researchers and health system leaders – work together. They design, implement, and share the results of collaborative research and quality improvement efforts. And this work leads to better health outcomes and increased quality, experience, and value in care. A learning health system approach can dramatically accelerate the ability to generate new knowledge and put it into practice.

In 2018, the Epilepsy Foundation was awarded a PCORNet Learning Health System Network Pilot Collaborative grant to establish an Epilepsy Learning Healthcare System.

Epilepsy Innovation Institute

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

My Seizure Gauge Initiative:

This past year, the institute hosted a workshop with thought leaders to assess the state of the science in seizure forecasting. Those proceedings were published in eNeuro, a journal supported by the Society for Neuroscience. Following the publication, the institute released a request for proposals for the My Seizure Gauge Initiative, to develop a seizure forecasting device. This attracted 100 different individuals from around the world applying separately or in teams to participate. To capitalize on the enthusiasm, Ei2 hosted a partnering workshop to foster collaboration between groups. Stay tuned for updates in 2019 of the Solution Team and their progress.

My Brain Map Initiative:

In 2018, the Institute also began exploring its second initiative known as My Brain Map. We want to create a Google Map for your brain that highlights your unique brain traffic pattern. With this map, we can better identify the routes your seizure could take, where the potential traffic jams might be, and how activity can get re-routed in the brain during those situations. Our purpose is to better define an individual’s brain network to enhance diagnosis and care.

- Sonya Dumanis, PhD
Senior Director of Innovation
**Pushing for Solutions to End SUDEP**

Sudden unexpected death in epilepsy (SUDEP) is the leading cause of death in young adults with uncontrolled seizures. Each year, more than 1 out of 1,000 people with epilepsy die from SUDEP. If seizures are uncontrolled, the risk of SUDEP increases to more than 1 out of 150.

One theory for SUDEP is the presence of compromised cardiac or respiratory function occurring before, during, or after the seizure. However, it is difficult to predict what a specific person’s risk level might be for SUDEP. The Epilepsy Foundation launched the SUDEP Biomarker Challenge which challenges researchers to find predictive biomarkers to identify people at risk for SUDEP or life-threatening seizures that compromise cardiac or respiratory function. A biomarker is a measurable biological substance in the body. For example, blood sugar can be a biomarker for diabetes risk or cholesterol for heart disease.

The Epilepsy Foundation received submissions from 11 teams from around the world for the Production of Proof of Concept Data challenge where applicants had to demonstrate that their proposed biomarker that indicates risk of SUDEP has the potential for real-world application. These could be pilot studies that are done in preclinical models or in human populations. Four teams were chosen and received an award to continue to develop their predictive tool for SUDEP.

For more information: epilepsy.com/SUDEP

**PROJECT:** Early Detection of Myocardial Injury as a Biomarker for SUDEP in Living Epilepsy Patients, TEAM: Barbara L. Kroner, PhD, John M. Schreiber, MD, Lowell H. Frank, MD

**PROJECT:** Cardio-Respiratory Biomarkers of SUDEP from an Unobtrusive Wearable Monitor, TEAM: Kristen H. Gilchrist, PhD, Meghan Hegarty-Craver, PhD, William Gaillard, MD

**PROJECT:** Multivariate computer-based classification of biomarkers for SUDEP, TEAM: Peter Carlen, MD, Berj Bardakjian, PhD, Stiliyan Kalitzin, PhD, Martin del Campo, MD

**PROJECT:** PRESUDEP - Brainstem MRI biomarker to Predict the risk of Sudden Unexpected Death in Epilepsy, TEAM: Carolina Ciumas, PhD, Philippe Ryvlin, MD, PhD, Samden Lhatoo, MD

These projects are described in APPENDIX.

The SUDEP Institute is looking for applicants to solve the remaining milestone!

Those interested, must now demonstrate that their selected biomarker(s) actually 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
  Director of SUDEP Institute

If we can identify who is at high risk, then we can try different interventions to prevent SUDEP from happening.
Thought Leadership — Facilitating Conversations

Research Roundtable for Epilepsy (RRE)
This 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.

This past year, the proceedings of the 2017 RRE, which centered on reducing placebo control in clinical trials, were published in the high-profile journal Neurology.

Evolving Concepts in Endpoints and Populations in Epilepsy Trials.
May 17-18, 2018, Washington, D.C.

Discussions centered around:
1. Current landscape of pediatric epilepsy clinical trials
2. Rationale for grouping vs. splitting populations by seizure type or by syndrome
3. How to assess epileptic conditions that comprise more than just seizures
4. Which co-occurring conditions with seizures are a priority to study from the perspective of those living with epilepsy and their caregivers
5. Learn from the experiences of drug and device companies who have incorporated multiple outcomes into their epilepsy trials
6. Identify potential methodologies and statistical considerations for incorporating non-seizure domains into epilepsy studies going forward.

As a follow-up from this session, the Epilepsy Foundation’s Research Roundtable in Epilepsy focused their subsequent two-day meeting on re-assessing populations and end-points in pediatric clinical trials, which included non-seizure outcomes.

Three members of the REN Steering Committee participated as speakers at the meeting: Dr. Steven Roberds (Tuberous Sclerosis Alliance), Dr. Tracy-Dixon Salazar (Lennox Gastaut Syndrome Foundation), and Ms. Mary Anne Meskis (Dravet Syndrome Foundation).

The 2019 Research Roundtable Topic will focus on “Efficient Trials in Epilepsy.”

Rare Epilepsy Network
The Rare Epilepsy Network (REN) Strategic Planning Workshop was held December 2017 in Washington, D.C. during the annual meeting of the American Epilepsy Society.

We are in this to find cures ...
There must be a determination and a willingness to not remain silent about epilepsy ... because at the core this is a very real and serious fight.

~ Jilly’s mom, Jeannett
Pushing in Bold New Directions — Human Epilepsy Project

In 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 can join the HEP2 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.

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.

We believe HEP2 could have a major impact on prevention strategies, treatments and cures for those who have not responded to current treatments.

- Dr. Brandy Fureman, VP for Research and New Therapies
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. Recently, we restructured our funding approach 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. Wolfgang Löscher, DVM who partnered with PIQUR Therapeutics to test their lead compounds on a battery of animal models to assess the compounds effectiveness at reducing seizures. If the data are promising, these studies will be the preliminary evidence needed to start a small clinical trial in Tuberous Sclerosis patients within 24 months.

We also awarded a grant to Aswin Gunasekar, MS. of Zeto, Inc., in Santa Clara, CA. The project was on developing wireless headset EEGs. Since 1924, the EEG reading procedure in the hospital has not really changed. A trained technician measures the head, sorts through hair, marks electrode locations, and applies paste and electrodes to the scalp, eventually tethering the patient to a box with wires. The procedure requires about an hour, and one leaves with goo stuck in the hair.

In 2016, Zeto won a shark tank award from the Epilepsy Foundation to improve EEG technology using dry electrodes and wireless technology. This past year, Zeto applied for a New Therapies Commercialization Grant as they prepare to come to the market with their product zEEG. Following a business and science peer-review, the Foundation is investing $200,000 in their company. Shortly after we invested, zEEG received FDA approval as the first dry electrode wireless headset for the epilepsy community.

Supporting the Next Generation of Scientists

This year, the Epilepsy Foundation supported three different projects in partnership with our sister organizations.

Junior Investigators
David Scott Auerbach, PhD University of Rochester.
Mechanisms for Seizures in Long QT Syndrome Type 2

Clinical Research & Training Fellowships
Garnett Smith, MD, University of Michigan.
Using Biomarkers to Construct Spatial Models of the Epileptic Network

Susan S. Spencer Clinical Research Training Fellowship in Epilepsy Award
Hiroki Nariai, MD, UCLA Medical Center.
High Frequency Oscillations (HFOs): A Specific Biomarker of Pharmaco-resistant Epilepsy

The Kevin’s Fellows program

Supporting the Next Generation of Scientists

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 2018 Lifetime Accelerator Award this was Wolfgang Lösch PhD. Dr. Lösch has made many contributions to the field of epilepsy research, including the development of new medications. Among his many accomplishments, Dr. Lösch’s research team helped identify the first available animal model of refractory seizures. These models were used to characterize mechanisms involved in drug resistance and to find new drugs with better efficacy.

For past awardees, see APPENDIX.
Dr. Gemma Carvill, Assistant Professor of Neurology at Northwestern University, was just awarded the prestigious NIH New Innovators Directors Award. This award goes to support exceptionally creative investigators who propose innovative, high-impact projects. We are proud to have supported Dr. Carvill early in her career and congratulate her on this new accomplishment!

In 2013, the Foundation had awarded Dr. Carvill a postdoctoral fellowship to study epilepsy. In 2017, through our partnership with the American Epilepsy Society (AES), the Foundation also funded her work in genetics through an AES/EF Junior Research Investigator award.

Over the past few years, there has been tremendous progress in identifying novel genetic causes for pediatric epilepsy subtypes. The overall mission of Dr. Gemma Carvill’s lab is to define the genetic basis of epilepsy, understand disease mechanisms, and develop new therapeutics. Current medications only treat the outward symptoms of a seizure but not the underlying cause. Genetics provide a clue to the potential mechanisms for why the epilepsy begins. Dr. Carville studies how genetics can impact brain function in epilepsy as well as how prevalent these mutations are in the population.

“This New Innovator Award focuses on identify genetic and epigenetic variation in epilepsy, much of the preliminary work and ideas in this award stem from research supported by the Epilepsy Foundation, both as a postdoctoral fellow, and last year as a … Junior Investigator Awardee. Early career support from the Epilepsy Foundation gives young scientists, including myself, the opportunity to explore new and innovative ideas that can serve as a spring board to getting their independent labs off the ground. More importantly they sponsor research that will impact the lives of patients, by facilitating better diagnoses and cures.”  - Dr. Gemma Carville

Many of today’s educators, senior investigators, and thought leaders for epilepsy were supported in their early careers with financial assistance from the Epilepsy Foundation. Since the 1960s, we have been planting the seeds for our future, supporting the careers of over 3,000 epilepsy researchers.  
- Phil Gattone  
President & CEO

Planting the Seeds of Our Future
ADVOCACY

“If your dreams don’t scare you, they aren’t big enough.”

- Quote by E. J. Sirleaf that inspires Aryn

ARYN is one of many teens who has participated in the Epilepsy Foundation’s Teens Speak Up! program.

Aryn was having active seizures when she and her Dad first came to the Epilepsy Foundation in Los Angeles. Aryn was determined to participate and was invited to Teens Speak Up! in Washington, D.C. There, she learned how to be an effective advocate and shared her story on Capitol Hill. In connecting with other teens living with epilepsy, Aryn realized that their collective power is limitless. Aryn was empowered and active during her Year of Service — volunteering at local programs and events. In 2018, Aryn agreed to be an ambassador of our END EPILEPSY campaign.
ACTION TOGETHER
Epilepsy Foundation signed onto 38 letters with various coalition partners to advocate for issues that matter to our community.

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 2018, the Epilepsy Foundation:

- Sent 1,453 letters at the state level and 2,136 letters at the federal level;
- Signed on to 38 letters with various coalition partners; and
- Nearly 6,000 of the Foundation’s Speak Up! Speak Out advocacy network sent 16,599 letters to elected and agency officials related to these issues.

Through the Teens Speak Up! (TSU) and Public Policy Institute (PPI), the 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 2018 TSU & PPI, 150 participants met with nearly 200 members of Congress. 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.

DO YOU KNOW?
Nearly 6,000 epilepsy advocates sent 16,599 letters to elected and agency officials on issues that matter to our community.
ADVOCACY IMPACT

During FY 2018, the Epilepsy Foundation’s advocacy team, chapters and affiliates, state advocacy leaders, 99,732-strong online Speak Up, Speak Out! advocacy network, and coalition partners achieved many accomplishments.

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

- Reauthorization of the Children’s Health Insurance Program—ensuring funding for the program for 10 years which currently provides health coverage for nine million children;
- Passage of the Lyndsey Crunk Act which improves the care of students with epilepsy and seizure disorders in Kentucky schools. The legislation ensures the administration of prescribed medications approved by the U.S. Food & Drug Administration to treat seizure disorders. It also requires school personnel to complete a seizure recognition first-aid response training using Epilepsy Foundation training materials, life-saving seizure first aid training for students, and maintenance of a seizure action plan for students living with epilepsy;
- Testified before an FDA Advisory Committee in support of approval of Epidiolex®, the first ever drug derived from cannabidiol (CBD), for the treatment of seizures associated with Dravet and Lennox-Gastaut syndromes. The FDA Peripheral and Central Nervous System Drug Advisory Committee unanimously voted on April 19, 2018 to recommend approval, followed by the FDA approval on June 25, 2018. The Drug Enforcement Administration later placed Epidiolex at Schedule V. The Foundation subsequently advocated for pathways in all states and the District of Columbia to be created so that physicians can legally prescribe and consumers can legally access the medication.
- Submitted comments to Administration’s Blueprint to Lower Drug Prices and Out-of-Pocket costs including urging the Administration to protect Medicare’s Six Protected Classes which ensures access to the full range of anti-seizure medications; and
- Submitted comments opposing the expansion of association health and short-term limited-duration health plans which do not have to comply with critical patient protections and can exclude or charge people with pre-existing conditions more.

Funding for Epilepsy Research, Programs and a Cure

- Secured $8.5 million for epilepsy programs through the U.S. Centers for Disease Control & Prevention Chronic Disease and Health Promotion program to increase public awareness and knowledge around epilepsy, as well as improve epilepsy care and self-management; and
- Secured a $3 billion increase for the National Institutes of Health.

Disability Discrimination

- Helped stop a federal bill — the ADA Education and Reform Act — that would weaken ADA protections and put the onerous on individuals with disabilities to provide notification to businesses that have failed to comply with the ADA.

For more information: advocacy.epilepsy.com.

JEANNE A. CARPENTER EPILEPSY LEGAL DEFENSE FUND

The Jeanne A. Carpenter Epilepsy Legal Defense Fund receives hundreds of consumer inquiries annually about the legal rights for people with epilepsy related to employment, education, criminal justice and seizure behaviors, public accommodations and other areas where quality of life is impacted by discriminatory practices. In FY 2018, the Fund responded to 489 inquiries providing education, legal information and/or referrals to attorneys and other community services to help fight discriminatory practices.
Personal stories and advocacy are at the core of Action Together
Nehe is an example of thousands of children and families who benefit from our services.

Out of the blue, Nehe started having seizures. In desperation, his parents called the Epilepsy Foundation. They participated in our epilepsy conferences, sought specialty care and benefited from dietary therapy. His mom invited us to train Nehe’s school on how to recognize seizures and offer first aid. Nehe’s family was active in the Walk to END EPILEPSY and participated in camp. In 2018, Nehe and his dad agreed to participate as ambassadors of our END EPILEPSY campaign.

“The Foundation helped us “get quickly to the best treatments, the best opportunities. We always felt like we were home.” - Juno, Nehe’s Dad
DO YOU KNOW?
The Epilepsy Foundation offers a 24/7/365 Helpline for individuals and families facing a new diagnosis of epilepsy or a new challenge of living with epilepsy.

ACTION TOGETHER
The Epilepsy Foundation has a partnership with the U.S. Centers for Disease Control & Prevention to provide programs nationwide.

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.
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.

In mid-2018, we piloted depression screening and referral program through the Helpline. During this period, the Helpline receive 12,074 inquiries. One in three of the callers identified as adults with epilepsy. The depression referral protocol identified 283 of adults with epilepsy having psychosocial emotional issues. 162 of these individuals were screened for depression: 40 identified as depressed, 27 asked about suicide and six identified with suicide ideation. Our helpline staff was able to make appropriate referral for these individuals to receive support and services in their communities.

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:

- **1,214 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 41 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.

- **8,133 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 educate 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 276,765 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 2018, 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 2,500 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, affiliates, 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 2018, over 1000 users received training through LMS.
“Doctor, if you want me to be seizure free, I can’t be salt [water] free.” — Jared

Jared is an example of the power of our digital communication to reach people everywhere.

Jared wouldn’t accept his doctor’s orders to stay out of the ocean. One of the thousands living with uncontrolled seizures, Jared contacted our Epilepsy Foundation and was referred to specialty care. He was evaluated and diagnosed with cortical dysplasia as the cause of his epilepsy. He had surgery and got back to surfing. He has done live fundraisers from his surfboard and been contacted by countless others with epilepsy who were inspired by his story. In 2018, Jared agreed to participate as an ambassador of our END EPILEPSY campaign.
ACTION TOGETHER

Epilepsy.com is possible because of the large number of experts and advisors who help with the content.

DO YOU KNOW?

Epilepsy.com is the top global online resource center for epilepsy and seizure information.

COMMUNICATIONS OVERVIEW

The Epilepsy Foundation’s reach is nationwide and even global through the work of our Communications and digital team. The Epilepsy.com website is the top global resource for epilepsy, social media is an important communications and engagement platform, and our partnership with the Centers for Disease Control & Prevention and with CBS TV network drive our ShareMySeizure public awareness campaign to promote seizure recognition. Our TalkAboutIt! initiatives are a partnership with Greg Grunberg.
Here are highlights of our Communications initiatives and our digital reach.

Social Media
The Epilepsy Foundation uses social media as an important communications and engagement platform. Foundation content can be found on Twitter, Facebook, Instagram and YouTube. We reached 27.2 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 network collaborated in a public awareness campaign for seizure recognition. This was the second year of a five-year effort. Public service announcements ran on CBS television stations in Chicago and Philadelphia, and 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 more than 39 million adults 18 and older.

For more, visit 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

- Sessions: 12.7M
- Users: 8.9M
- Page views: 20.3M

Top pages searched on Epilepsy.com
1. What is Epilepsy?
2. Seizure Types
3. Absence Seizure
4. Seizure Medications List
5. Medical Marijuana and Epilepsy
6. What is a Seizure?
7. Tonic Clonic Seizures
8. Focal Onset Aware Seizures
9. Seizure Triggers
10. What Happens During a Seizure?
11. Myoclonic Seizures
12. Psychogenic Nonepileptic Seizures
13. Ketogenic Diet
14. Seizure Warning Signs
15. Focal Onset Impaired Awareness Seizures
16. What Causes Epilepsy and Seizures?
17. Driving Laws
18. Vagus Nerve Stimulation
19. Temporal Lobe Epilepsy
20. Epilepsy 101

Top Countries visiting Epilepsy.com after the U.S.A
1. United Kingdom
2. India
3. Canada
4. Australia
5. South Africa
6. Philippines
7. Ireland
8. Malaysia
9. New Zealand
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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.

- Epilepsy Foundation’s Manifesto

END EPILEPSY CAMPAIGN

Your generosity and the merger of the Epilepsy Foundation of Greater Los Angeles with the Epilepsy Foundation, allowed us to dream big about the potential for a trajectory change for our organization. A trajectory change — that would help unite our organization with a single message and mobilize action inside and outside our community.

The Epilepsy Foundation of Greater Los Angeles had been using END EPILEPSY as their single call to action. We saw the potential for this call to action to resonate across our country — whether someone has a seizure once a year or every hour, or whether someone lives a full life or is debilitated by seizures.

We spent a lot of time this year, interviewing hundreds of people as we prepared to launch this new campaign.

We identified two significant challenges:

1. 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.

2. 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.
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.

ACTIVATION
1. UNDERSTAND
Make the connection between epilepsy and the brain to help people UNDERSTAND epilepsy.
2. FEEL
Share powerful stories of epilepsy so that people can FEEL the urgency and the human struggle.
3. ACT
Give everyone a platform and clear directive to ACT to END isolation, misdiagnosis, ignorance, silence and END EPILEPSY.

GUIDING PURPOSE
These challenges and opportunities led our preparations for the launch of our nationwide, multi-year campaign, “Let’s Use Our Brains to END EPILEPSY” in October 2018.
We want our community to know that they are part of a nationwide movement.
We believe the time is now to make a powerful change for and with people with epilepsy. Together, we can make a radical shift.
COMMUNITY ENGAGEMENT

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

We have always been a network organization for families living with epilepsy, shining a light to promote epilepsy awareness and understanding, and advocating for laws that matter to people with epilepsy.
ACTION TOGETHER

We partnered with Shopko Stores for Lemonade for Livy to raise $134,000 and spread awareness in more than 370 stores.

DO YOU KNOW?

Over 160 Lemonade for Livy events were hosted by some of our 500 Kids Crew members nationwide.

COMMUNITY ENGAGEMENT OVERVIEW

The Epilepsy Foundation is proud to be a nationwide network organization comprised of affiliates and chapters in 40 states across the nation. As a network organization, we can provide front-line programs and services to families and individuals affected by epilepsy.

Since 2016, our network has expanded to include four new and previous unserved states – Nevada, Utah, Oklahoma and West Virginia.
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. In late 2018 investment was made in a new software platform to reframe and strengthen how the Foundation recruits, sustains and values this legion of unsung heroes.

This past year the Epilepsy Foundation embarked on a nationwide initiative to connect volunteer board leaders from across the country through the formation of nationwide advisory boards. These boards bring local insight and expertise to the Epilepsy Foundation’s national board of directors through involvement in strategic planning, strengthening direct programs and services, and lending visionary thinking toward our collective goal: to End Epilepsy. More than 40 vested volunteer board leaders will represent the voice of their local office(s) as we move into 2020 and beyond.

Special Initiatives
Kids’ Crew, the Foundation’s signature youth program for children and teens 14 and under has grown by more than 145 percent since its inception in 2017. With approximately 500 members across the country and beyond, this program provides a forum for children living with epilepsy, siblings and friends to engage in education, awareness and fundraising activities to support their local community or program of their choice. In addition to local projects such as Lemonade for Livy lemonade stands, this past year Kids’ Crew embarked on a creative video project to educate youth through an animated character named Professor SaraBell. Watch for Professor SaraBell in her video debut, to be released in early 2019.

To register for Kids’ Crew go to epilepsy.com/kids-crew.

Leadership Conference
We are planning for our Leadership Conference in Phoenix, Arizona, in September 2018. We anticipate about 150 staff and board volunteer participants from our Epilepsy Foundation network. The theme will be focused on Information, Empowerment and Engagement of our network in the delivery of the Foundation’s collective mission. This annual forum provides a platform to discuss and embrace overarching themes of building capacity for volunteer development, fundraising to support mission delivery, research impact and a guiding light into the future.
OUR NETWORK IN FISCAL YEAR 2018

ALABAMA
Epilepsy Foundation Alabama

ALASKA
Epilepsy Foundation Northwest

ARIZONA
Epilepsy Foundation Arizona

CALIFORNIA
Epilepsy Foundation Greater Los Angeles
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 Metropolitan Washington

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

KENTUCKY
Epilepsy Foundation Kentuckiana

LOUISIANA
Epilepsy Foundation Louisiana

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 Missouri & Kansas

NEVADA
Epilepsy Foundation Nevada

NEW JERSEY
Epilepsy Foundation New Jersey

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 Northwest

Pennsylvania
Epilepsy Foundation Eastern Pennsylvania
Epilepsy Foundation West Central Pennsylvania

PUERTO RICO
Sociedad Puertorriquena De Epilepsia

RHODE ISLAND
Epilepsy Foundation New England

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 Northwest

WISCONSIN
Epilepsy Foundation Heart of Wisconsin
Epilepsy Foundation Western Wisconsin
PUBLIC SUPPORT

“We go to the walks ... and have an immediate connection. We share our stories...” - Vicky from Team #AlmazanDuo

Two members of Vicky’s family have epilepsy - both her husband and her daughter. Her husband has convulsive seizures and her daughter has absence seizures with staring spells. Vicky and her family face double challenges each day with both a parent and a child living with epilepsy. After attending an epilepsy conference, Vicky’s family got active in the local walk.
ACTION TOGETHER

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

PUBLIC SUPPORT OVERVIEW

The Epilepsy Foundation depends on public support and the generosity of individual and corporate donors. Your donations enable us to TAKE ACTION with all – our partners, our community, and the general public.

Your donations help us provide the HUG and HOPE along the way. The HUG is felt through our Helpline, supportive care programs, education, and referrals to specialty care. The HOPE is found in our innovative research, relentless advocacy, and the inspirational stories of ACTION TOGETHER.

Truly, our mission depends upon Action Together. Our community depends upon us taking Action Together. And Action Together includes you and depends upon continued support for our mission.

DO YOU KNOW?

Stories are like gold in our fight to END EPILEPSY – including the stories of our Veterans who face epilepsy as a result of traumatic brain injury.
PUBLIC SUPPORT
The Epilepsy Foundation’s mission is funded through the generous support of both public and our partner organizations. This support comes through many forms; from hosting lemonade stands to biking across the country, our community partners continue to find creative ways to show what the Epilepsy Foundation means to them.

Our Donors’ Generosity
The Epilepsy Foundation is fortunate to be supported by committed donors whose stories represent the challenges our community face. Through their generosity, the Epilepsy Foundation continues to grow closer to preventing another life lost to seizures.

The Lyte Guild
In 1578, a British botanist, Henry Lyte translated Flemish physician Rembert Dodoens’ famous herbal text, Cruydeboek. In his translation, Lyte showed a clear preference for the term epilepsy rather than the common-terminology of “falling sickness”. Lyte was the first to trigger a perception change from being one of mysterious “sacred disease” toward a medically explained disease/condition.

The Lyte Guild is special membership that recognizes corporate partners who committed $500,000 or more joining the quest to end epilepsy. The following corporate partners are members of the Lyte Guild.

- UCB
- Sunovion Pharmaceuticals, Inc.

National Corporate Partners
Our National Corporate Partners demonstrate a high level of commitment to our mission through financial support and efforts to lead the fight to overcome the challenges of living with epilepsy. The following National Corporate Partners have committed $100,000–$499,999 to partner in our quest to END EPILEPSY.

- Greenwich Biosciences
- Eisai Co. Ltd.
- Pfizer
- Lundbeck
- LivaNova
- Supernus Pharmaceuticals

... I am so grateful to those who have reached out to help us on our journey and will forever pay it forward in the fight to END EPILEPSY.  ~ Finny’s Mom, Annie
Community Partners
Our Community Partners show the true call to action for the epilepsy community by devoting funds and expertise toward helping the diverse spectrum of epilepsies. The following Community Partners have committed $25,000–$99,999 to partner in our quest to END EPILEPSY.

- Zogenix
- NeuroPace, Inc.
- Axcella
- Takeda
- Zynbera Pharmaceuticals
- Engage Therapeutics
- SAGE Therapeutics
- Adamas Pharmaceuticals
- Anavex Life Sciences
- Cavion
- Cerecor, Inc.
- Idorsia Pharmaceuticals, Ltd.
- Aquestive Therapeutics
- Neurelis
- Otsuka
- Ovid Therapeutics
- PhRMA
- SK Life Sciences
- Upsher-Smith Laboratories

Keepers of the Promise Society
The Keepers of the Promise Society is a prestigious association of individuals and families who demonstrate extraordinary generosity by including the Foundation in their wills and estate plans. Their ultimate gifts ensure the long-term sustainability of the Epilepsy Foundation’s mission. Members of the “Keepers of the Promise Society” come from all walks of life — with different income levels, professions, and interests, and yet they all share a passion for ending this terrible disorder. Because of their boundless love of life and concern for others, their spirit of generosity will endure and their gifts will remind each of us how we all can make a difference in the lives of those impacted by epilepsy.

- Anonymous
- Elaine Lundby Trust
- Elizabeth Adams Fund
- Elizabeth Reymann
- Estate of Alice Smith Franks
- Estate of Elizabeth M. McKee
- Estate of Harold Morganstern
- Estate of Marilyn S. Davis
- Estate of Mary Lou Cronin
- Estate of Rodolfo A. Parisi
- Eugene P. Smith Trust
- Hazel Briller Gluck Estate
- Herbert Gardner
- Hudson Charitable Trust
- Irene Gebauer
- Irene R. Radlo 2003 Trust
- James Crawford Estate
- Joseph C. Ferrer, Trust
- Kenneth & Mildred Black Charitable Remainder Trust
- Lillian Pozefsky Charitable Remainder Unitrust
- Lonnie Stephens Trust
- Margaret Robbins Estate
- Ronald Currie Estate
- Rosenbaum Family Trust
- Ruth G. Arnold Revocable Living Trust
- The Dillon Foundation
- The Madigan Revocable Trust Of 1995
- Thomas Garrity, Trust
- William Blank

Chairman’s Roundtable
Members of the Chairman’s Roundtable are those who’ve supported the Foundation at the $1M+ level, outright and cumulatively. These donors and families are truly visionary in their giving and share a unique determination to drive our mission forward in significant ways and bring us closer to world without seizure and to end epilepsy.

- Anonymous
- Ruth G. Arnold Revocable Living Trust
President’s Circle

Members of the President’s Circle are those who’ve made gifts of $100,000 or more to the Epilepsy Foundation. Families and individuals who’ve chosen to support our work at this level demonstrate a singular generosity focused on driving research, new therapy and device development and programs supporting the epilepsy warriors we serve each and every day.

- Anonymous
- Eric & Danae Delman & Delman Mortenson Charitable Foundation
- Epilepsy Foundation Minnesota
- Margaret Anne French
- Herbert Gardner
- Shopko Stores Operating Co. LLC
- Robert & Terri Smith
- Steven Tisch
- Steven and Karen Wolfson

 Keepers of the Flame Society

Friends of the Epilepsy Foundation can qualify for membership in the Keepers of the Flame Society with a gift of $10,000 or more. “Keepers of the Flame Society” members are an elite group of supporters who take a leadership role in the future of the Epilepsy Foundation and the epilepsy community. Through their remarkable giving, these philanthropic investors enable the Foundation to strive to become the world’s most respected epilepsy organization. These special gifts allow the Foundation to reinvest these resources to uphold its mission and to ensure that people with seizures have the opportunity to live their lives to their fullest potential.

To join the Keepers of the Flame Society, please contact Donor Services at (800) 213-5821 or rdev@efa.org

- A+E Networks/History
- Anonymous
- Aristocrat Technologies
- Thomas & Johanna Baruch
- Betbar Properties LLC
- William Blank
- Ben & Sue Boley
- David & Traute Bushley
- CHOC Children’s
- Shirley Cobb
- Danis Building Construction Company
- The Dillon Foundation
- Epilepsy Foundation Greater Los Angeles
- Epilepsy Foundation New England
- Epilepsy Foundation Texas - Houston/Dallas-Fort Worth/West Texas

- Frank & Jeanne Fischer
- Phil & Jill Gattone
- Golf Planner Pro LLC
- Edward Whitfield Grayson
- David & Megan Hawk
- Roger & Julie Heldman
- Intermountain Healthcare
- Evan Jones Memorial Fund
- Stewart & Lori Karger
- Robert Kirschnik
- Andrea B. & Peter D. Klein
- KOH Charitable Foundation
- Bill & Sheila Lambert
- Warren Lammert & Xiaohong Sang
- Loeffel Epilepsy Foundation
- May Liang & Jim Lintott
- Jean Maddux & France-Merrick Foundation Inc.
- Brian McNally
- Randy & Patsy Norton
- PGA Tour Inc.
- Michael Provo
- Rust Foundation & The Montgomery Family
- Eric & Penny Schmitz
- Seven ‘S’ Foundation Inc.
- William Smith
- Station Casinos LLC
- Elbridge & Evelyn Stuart Foundation
- James Swanson
- The Allergan Foundation
- The Anschutz Foundation
- The Earnest Herman Foundation
- The Gilbert J. Martin Foundation
- The Salice Family Foundation
- Dylan Seff & Cortney Seff Memorial Fund
- Anne Travalia
Pioneer Society

The Honor Roll includes those generous individuals who made outright gifts of $1K to $9,999. These vital investments allow the Epilepsy Foundation to continue its critical mission work in leading the fight to overcome the challenges of living with epilepsy, and accelerating therapies to stop seizures, find cures and save lives.

- Gerard Abdelnour
- Sarah Ackerman
- Andrew Adams
- Agarwal Family Foundation
- Lisa Aiesi
- Neil Akeson
- Thomas Albright
- Alpine Pools Inc.
- James Alsdurf
- Altapointe Health Inc.
- Laurel Alyea
- Dan Amato
- Steve Anderson
- Anderson Dairy Inc.
- John De Angelo
- Anonymous
- Anthem Blue Cross Blue Shield
- Robbi Anthony
- Arkansas Community Foundation
- Bruce Armitage
- Doug & Jane Armitage
- Arthur Carter & Knights of Columbus
- Ascension
- Marty Atoui
- Veronica Babin
- Bahaar Family & Carol Nowacki Family Trust
- Barbara Baker
- Ted & Janie Bakke
- Zela Balouzian
- Banner Health
- Sue Ellen & Nicholas Barbaro
- Annamarie Bardonski
- Philip Bareck
- Robert Barfield
- Paul Barnes
- Stephen Barnett
- Dennis Barsema
- Randolph & Maud Barton
- Basin Marine Inc.
- Battle Born Batteries
- Sara Beckett
- Beckett Collectibles
- Jean Corbin Bedford
- James Bennett
- Leonard Berenfield
- Robert Bergman
- Edward Bernard
- Powell Bernhardt
- Elizabeth Berry
- Betbar Properties LLC
- Kim Biddle
- Big Ten Alumni of Southwest Florida
- Adele Binder
- Amy Biviano
- David Black
- Gerald Black
- Beata Blank
- Blue Cross Blue Shield of Mississippi
- Cheryl Boccia
- Michael Bocianowski
- James Bohrer
- Janelle Boltz
- Joan Bozigian
- Brainard Strategy
- John & Nancy Brandon
- William Braunlich
- Michelle Brazelton
- Holly & Leigh Brent
- Brews & Cues on The Boulevard
- Bright Funds Foundation
- Broadlawns Medical Center
- Kathy Brown
- Charles Brown
- Mark Bruemmer
- Jim Bruton
- Peter & Elizabeth Bueckert
- Ashley Burdette
- Wesley Bush
- Greg & Lynne Caldwell
- Caldwell Family Foundation
- Martin Campbell
- Yanka Cantor
- Peggy Cantrell
- Jerry Carle
- Karson & Alma Carpenter
- Marc & Linda Carrasco
- Mark Carson
- Orlando Carvalho
- Cedar Falls Scheels
- Charitocracy
- Jason Chew
- Darrell & Abigail Chiavetta
- Chicago Fine Motors LLC
- Chisick Family Foundation
- Chris Ash Football Camp LLC
- Chris Mueller & Skanska USA Building Inc.
- Donald & Amy Chupp
Premier Health
Patrick Prendiville
Chris Price
Prism Medical Productions LLC
Julianna Pyott
Kenny Qualls
Jim Query
Jasmine Quiles
William Quinby
John Quinn
Keith Rainwater
Cynthia Ramirez
Randy Taylor Consulting Inc.
David & Lyn Rasmussen
Anne & Jim Render
William Renna
Rob Renner
Beth Rentschler
Elizabeth Reymann
Joanne & Mark Reynolds
Larry Richmond
Barton Richwine
Rick Harrison & Gold & Silver Pawn Shop Inc.
Roger Rinker
Kathleen Rittinger
Riversource Life Insurance
Stephen & Annette Roberts
Kristen Rodgers
Chris Rogers
Michael & Kristen Rogers
Erica & John Rolston
Rosalie Rosenzweg
Vicki Taylor-Roskopf
Rotary Children’s Foundation
Denni Runey
Larry Ruvo
Matthew Ryan
S C Benjamin Foundation
Safeline Autoglass Foundation
Safelite Fulfillment Inc.
Kevin & Lorena Saltzman
Manuel Sanchez
Michelle Sanguiliano
Brendan Savage
Michael Sawyers
Jonathan Scheinman
Robert Schommer
Michael Schulz
Eugene Schweitzer
Gustav Sengenberger
Jeff Serafin
Patty Osborne Shafer
Jiten Shah
Will Sheehan
Patricia Shell
Eric & Olga Shewfelt
Melvin & Sherry Shope
Richard & Gail Silvera
Joseph Sirven
SK Life Sciences
Lauretta Skigen
Bernard Small
Robert Smith
Michele Smith
Richard & Betty Snow
Glenn Snyder
Sonora Quest Laboratories LLC
Veronica Sosa
Amy Souders
South Carolina Federal Credit Union
Joaquina Soza
St. Dominic Health Services
Jeanne Stadtlander
State of Alabama, Department of Finance
Cynthia Steckel
Marissa Steinmetz
Steptoe & Johnson LLP
Virginia Stewart
Alan Stivers
David Stout
William Stromberg
Stuart & Eileen Kaufman Foundation Inc.
T. M. & Ellen Stutsman
Anne Stuzin
Peter Swenson
Ravi & Eleanor Talwar
TASC
Tatum Family Foundation
TD Ameritrade Clearing
Temkin
Anthony Teta
The Allstate Foundation
The Apatow-Mann Family Foundation Inc.
The Bernd Group Inc.
The Caring Foundation
The David E. Gallo Foundation
The Don Allen Foundation Inc.
The Leroy Thom, Jean Thom & T-L Foundation Inc.
The Marksmen Company
The Neel Foundation
The Paul & Ellen Gaske Foundation
The Reynolds & Reynolds Company
The Sevan Charitable Foundation Inc.
The Stone Foundation
The Thalia & George Liberatos Foundation Inc.
The University of Iowa
The William D. Rhodes Foundation
The Winokur Family Foundation Inc.
Matthew & Brooklyn Thom
Thomas J. & Nancy B. Campbell Charitable Foundation
Edward Thompson
Julie Thurber
National Walk for Epilepsy

The Epilepsy Foundation National Walk for Epilepsy is a community fundraising and awareness event that has tremendous support from epilepsy advocates and warriors across the United States and internationally. The Foundation hosted its National Walk for Epilepsy in April on the National Mall in Washington, D.C. The 2018 walk was historic. It was the third highest national walk fundraiser in the twelve-year history. A total of $1,115,375 was raised, exceed our $1M goal set for the event. We are grateful to our sponsors who contributed nearly $500,000, our 337 teams, and approximately 2,800 walkers and volunteers who helped make this such a successful and FUN event. Special congratulations goes out to “Team Katie” who was the top fundraising team having raised $95,653.

To learn more, about our nationwide Walk to END EPILEPSY, visit WalkToEndEpilepsy.org
### Epilepsy Foundation and Epilepsy Research Foundation

#### Summary Consolidated Financial Statements $ In Thousands

**CONSORTIUM STATEMENT OF FINANCIAL POSITION**

<table>
<thead>
<tr>
<th>Description</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>4,983</td>
<td>619</td>
</tr>
<tr>
<td>Investments</td>
<td>7,938</td>
<td>7,323</td>
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<tr>
<td>Receivables</td>
<td>2,148</td>
<td>2,171</td>
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<tr>
<td>Prepaid expenses and Inventory</td>
<td>337</td>
<td>337</td>
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<tr>
<td>Fixed assets, net</td>
<td>683</td>
<td>693</td>
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<tr>
<td>Deferred rent asset</td>
<td>230</td>
<td>230</td>
</tr>
<tr>
<td>Beneficial interest in perpetual trusts and other assets</td>
<td>5,183</td>
<td>3,347</td>
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<tr>
<td><strong>ASSETS</strong></td>
<td><strong>21,502</strong></td>
<td><strong>14,872</strong></td>
</tr>
</tbody>
</table>

**LIABILITIES AND NET ASSETS**

<table>
<thead>
<tr>
<th>Description</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>1,228</td>
<td>864</td>
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<tr>
<td>Grants payable</td>
<td>590</td>
<td>732</td>
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<tr>
<td>Deferred revenue</td>
<td>101</td>
<td>19</td>
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<tr>
<td><strong>LIABILITIES</strong></td>
<td><strong>1,919</strong></td>
<td><strong>1,615</strong></td>
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<tr>
<td><strong>NET ASSETS</strong></td>
<td><strong>19,583</strong></td>
<td><strong>13,257</strong></td>
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</tbody>
</table>

**TOTAL LIABILITIES & NET ASSETS**

<table>
<thead>
<tr>
<th>Description</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>21,502</strong></td>
<td><strong>14,872</strong></td>
</tr>
</tbody>
</table>

**CONSORTIUM STATEMENT OF ACTIVITIES**

**REVENUE**

<table>
<thead>
<tr>
<th>Description</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>17,877</td>
<td>9,502</td>
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<tr>
<td>Government and other grants</td>
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<td>3,787</td>
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<tr>
<td>Affiliate fees</td>
<td>390</td>
<td>373</td>
</tr>
<tr>
<td>Special events, net of direct cost</td>
<td>1,470</td>
<td>932</td>
</tr>
<tr>
<td>Investment Income</td>
<td>374</td>
<td>431</td>
</tr>
<tr>
<td>Change in value of beneficial interests in trusts</td>
<td>17</td>
<td>156</td>
</tr>
<tr>
<td>Other</td>
<td>155</td>
<td>44</td>
</tr>
<tr>
<td><strong>REVENUE</strong></td>
<td><strong>24,053</strong></td>
<td><strong>15,225</strong></td>
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</table>

**EXPENSES**

<table>
<thead>
<tr>
<th>Description</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Services</td>
<td>17,727</td>
<td>15,602</td>
</tr>
<tr>
<td>Research, Innovations and New Therapies</td>
<td>3,080</td>
<td>2,298</td>
</tr>
<tr>
<td>Education and Awareness</td>
<td>3,634</td>
<td>2,969</td>
</tr>
<tr>
<td>Advocacy and Services for Individuals, Families and communities</td>
<td>8,036</td>
<td>7,231</td>
</tr>
<tr>
<td>Supporting Services</td>
<td>1,021</td>
<td>994</td>
</tr>
<tr>
<td>Administrative</td>
<td>1,956</td>
<td>2,110</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>19,583</strong></td>
<td><strong>13,257</strong></td>
</tr>
</tbody>
</table>

**Net assets beginning of year**

- 2018: 13,257
- 2017: 13,634

**Net assets ending of year**

- 2018: 19,583
- 2017: 13,257

**Epilepsy Foundation Spending Percentages – Fiscal Year Ending 2018**

- Research, Innovation and New Therapies, Education, Awareness, Advocacy, and Services: 83%
- Fundraising: 11%
- Administrative: 6%
SHARK TANK WINNERS 2018

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

3D Machine Vision System for Surgical Navigation of the Human Brain
Aaron Bernstein, PhD
President and CTO
Advanced Scanners
Austin, Texas
$75,000 Audience Choice award + $75,000 Judges Award

Open brain surgery begins with the surgeon creating an opening in the skull. The surgeons rely on image-guided navigation systems to track their movements within the brain. These navigation systems rely on previously scanned images of the patient’s brain. The problem is that when you open the skull, the brain changes its shape. Advanced Scanners wants to improve navigational systems and surgical outcomes with a rapid, noninvasive 3D scanning approach. Working with neurologists and neurosurgeons at the Dell Children’s Comprehensive Center in Austin, Texas, Advanced Scanners has been developing an intelligent 3D Machine vision system that inter-operatively watches and tracks the exposed brain with sub-millimeter accuracy to improve results in each of the 3 major steps of a typical 2-stage epilepsy surgery. These steps include providing accurate location of the grid electrodes, mapping at high resolution the surface of the brain during surgery to improve what the neurosurgeon sees, and updating the brain shape changes during real time. This all contributes to a more precise navigation system for the surgeon to rely on. Which in turn, should make the brain surgery procedure safer for the patient.

Virtual Reality Simulations for the Management of Status Epilepticus
Joshua Sherman, MD
Todd Chang, MD MACM
Faculty Attending – Division of Emergency Medicine
Children’s Hospital Los Angeles
Assistant Professor of Pediatrics
USC-Keck School of Medicine
$50,000 Judges Award

Drs. Sherman and Chang want to develop virtual reality simulations to allow the community to better train both medical and non-medical professionals for high emergency epilepsy situations. Usually trainings are done using mannequins and actors, which are expensive and time-constrained to when the actors are available. In contrast a virtual reality module is portable, standardized, and still allows for an immersive experience. Moreover, VR allows for training at any time of day. The doctors had partnered up with Oculus’ VR for Good program and companies AiSolve and Bioflight to design a module for status epilepticus in the pediatric population. This simulation won Best Virtual Reality Education Project at the 2018 VR Fest and was written up in USA Today and Buzzfeed. Using an Occulus Simulator, trainees can be assessed on their training readiness and taught what to do in high-stakes situations like status epilepticus. Drs. Sherman and Chang will use the Shark Tank funds to create other virtual reality simulations for other use-case epilepsy scenarios recreating the stressful emergency environment to better prepare providers and improve care. They were recently featured on a CBS special highlighting this innovative idea.
MORE INFORMATION ON THE SUDEP BIOMARKER CHALLENGE PROJECTS AWARDED:

Eleven teams from around the world submitted to our Production of Proof of Concept Data challenge. Applicants had to demonstrate that their proposed biomarker that indicates risk of SUDEP has the potential for real-world application. These could be pilot studies that are done in preclinical models or in human populations.

The four awarded teams are now continuing to develop their predictive tool for SUDEP. These projects were:

TEAM: Barbara L. Kroner, PhD, John M. Schreiber, MD, Lowell H. Frank, MD
PROJECT: Early Detection of Myocardial Injury as a Biomarker for SUDEP in Living Epilepsy Patients
This team tested a relatively easy to perform and non-invasive tool to image the heart and look for ventricular myocardial deformation as an indicator for SUDEP risk.

TEAM: Kristen H. Gilchrist, PhD, Meghan Hegarty-Craver, PhD, William Gaillard, MD
PROJECT: Cardio-Respiratory Biomarkers of SUDEP from an Unobtrusive Wearable Monitor
This team developed a seizure detection algorithm from a commercial Electrocardiogram (ECG) wearable sensor that can analyze both heart rate variability and respiratory changes to identify those at Risk of SUDEP.

TEAM: Peter Carlen, MD, Berj Bardakjian, PhD, Stiliyan Kalitzin, PhD, Martin del Campo, MD
PROJECT: Multivariate computer-based classification of biomarkers for SUDEP
This team will use a machine learning algorithm to identify a panel of markers linking EEG, heart rate and respiration data to identify those at high risk of SUDEP.

TEAM: Carolina Ciumas, PhD, Philippe Ryvlin, MD, PhD, Samden Lhatoo, MD
PROJECT: PRESUDEP - Brainstem MRI biomarker to Predict the risk of Sudden Unexpected Death in Epilepsy
This team is developing an imaging diagnostic tool that checks brainstem response to respiratory stress as a potential indicator for SUDEP risk.

Supporting the Next Generation of Scientists

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

These awards are defined below, together with this year’s funded projects

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.
2018 Awardee: David Scott Auerbach, PhD University of Rochester, Mechanisms for Seizures in Long QT Syndrome Type 2.

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.
2018 Awardee: Garnett Smith, MD, University of Michigan. Using Biomarkers to Construct Spatial Models of the Epileptic Network

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.
2018 Awardee: Hiroti Nariai, MD, UCLA Medical Center. High Frequency Oscillations (HFOs): A Specific Biomarker of Pharmaco-resistant Epilepsy

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

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
Let's meet the fellows!

AES/EF Junior Investigator Research Award
David Scott Auerbach, PhD
University of Rochester
Research Topic: Mechanisms for Seizures in Long QT Syndrome Type 2
The goal of this project is to understand how cardiac abnormalities may contribute to sudden unexpected death in epilepsy (SUDEP). Dr. Auerbach is interested in the cross-talk between the heart and the brain. Specifically, he studies genetic diseases that develop electrical disturbances in the brain (seizures) and in the heart (arrhythmias) which result in sudden death. Previously, Dr. Auerbach demonstrated that in Dravet (a severe genetic form of epilepsy), there is not only alterations in electrical function in the brain but also in the heart. These findings suggested that cardiac dysfunction could be a risk factor and underlying cause for SUDEP. Now, he is approaching the brain-heart link in the opposite direction.

Specifically, he is focusing on Long QT Syndrome-2 (LQTS2), a classically studied cardiac disease associated with sudden death. Recently, he showed that LQTS2 can also be associated with higher rates of seizures. Yet, the mechanisms for why LQTS2 can lead to seizures is unknown. Around 60% of LQTS2 patients have a mutation that alters their potassium channels, which are important in stabilizing neuronal electrical activity. Dr. Auerbach has developed a rabbit model of LQTS2 to better study how the potassium channels are changed in the brain. Understanding the brain-heart connection can help shed new light on sudden death and lead to future prevention strategies.

AES/EF Clinical Research Training Fellowship
Garnett Smith, MD
University of Michigan
Research Topic: Using Biomarkers to Construct Spatial Models of the Epileptic Network
The goal of this project is to combine information from electroencephalograms (EEGs) between seizures and during seizures to make a 3-D tool to help physicians localize the epileptic network. Epileptic networks are the brain regions that are involved in producing and propagating seizures. These brain regions often produce abnormal electrical activity. Computerized analysis of EEG signals has allowed researchers to detect this abnormal activity and use it to better understand where seizures might be coming from in a patient’s brain. The proposed study uses previously published methods to combine information about electric signals that occur between seizures (called high frequency oscillations or HFOs) with information about activity that occurs at the time that seizures start and spread (called an epileptogenicity index). Dr. Garnett Smith will map these HFOs and epileptogenicity index onto a 3-D map of the patient’s brain to show areas of the brain that are likely involved in producing seizures. Improved knowledge of where seizures arise has the potential to improve the success rate of epilepsy surgery.

Susan S. Spencer Clinical Research and Training Fellowship
Hiroki Nariai, MD
UCLA Medical Center
Research Topic: High Frequency Oscillations (HFOs): A Specific Biomarker of Pharmacoresistant Epilepsy
The goal of this project is to test whether high-frequency oscillations could be a predictor of who would respond well to surgery as a treatment option for drug-resistant epilepsy. Traditionally, EEG analysis for clinical interpretation is analyzed at frequencies under 30Hz. With advances in technical equipment and optimized analysis, researchers are starting to look at high frequency oscillations (HFOs) observed on the EEG. In contrast to traditional EEG analysis, these are frequencies detected above 80Hz. These HFOs have generated a lot of interest, as they are a relatively new frontier for assessing brain activity. The community is still trying to understand what this activity could mean.

Dr. Hiroki Nariai will be using his fellowship to prospectively sample and analyze HFOs in scalp EEG for individuals undergoing pre-surgical evaluation. Dr. Nariai can then use this technique to potentially better localize seizure onset zones and test whether the analysis can predict who would be a responder versus non-responder to surgery.
LET’S TAKE ACTION TOGETHER