OUR STORIES

EPILEPSY FOUNDATION ANNUAL REPORT FY17
MISSION
To lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

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 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, 4 out of 10 people with epilepsy continue to experience uncontrolled seizures while many more experience less than optimal seizure control.

ABOUT THE EPILEPSY FOUNDATION
The Epilepsy Foundation, a national non-profit with over 50 local organizations throughout the U.S., has led the fight against seizures since 1968. The Foundation is an unwavering ally for individuals and families impacted by epilepsy and seizures. The mission of the Epilepsy Foundation is: to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential.

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Dear Friends,

With your support, the Epilepsy Foundation is proud to be an unwavering partner and amplify the voices of all people impacted by epilepsy in the United States. According to data released by the Centers for Disease Control and Prevention (CDC) in 2017, more people are living with epilepsy in the United States than ever before. The Epilepsy Foundation stands with more than 3.4 million people living with epilepsy and their families.

This report highlights how you help us fulfill our mission by sharing the remarkable stories from our community. Every story highlights how your support helps us lead the fight to overcome the challenges of living with epilepsy. You help us accelerate therapies to stop seizures, find cures, and save lives.

For many the burden of living with epilepsy goes beyond the seizures themselves. There is still a lack of understanding about what seizures are and what they are not. This misunderstanding creates fear. And, fear can lead to discrimination. While more people are learning about epilepsy and what to do if they see someone having a seizure, we see the impact of fear and discrimination too often in many aspects of our society. Lack of knowledge and fear creates disparities in employment, education, and personal fulfillment.

But, thanks to your support, the Epilepsy Foundation has a network of local organizations around the country providing a wide range of education, awareness, and direct services that help end disparities and bring hope. These services help support people like Taryn Sweeney, who used a program to help her depression and reduce the frequency of her seizures.

We have partnered with the CDC to educate community service personnel, such as school nurses, police officers, emergency medical technicians, and senior care providers, about how to properly identify and respond to seizures. During fiscal year 2017, over 9,000 school personnel received trainings both online and in person.

Our work with the CDC also builds public awareness to help combat misunderstanding. We work closely with CBS Community Partnerships to air public service announcements in major television markets and across the digital landscape.

Our digital presence includes epilepsy.com, the top global website focused on epilepsy and seizures. Epilepsy.com is visited by over 9 million people annually and hosts a robust community of individuals and families finding help, hope, and support from the Foundation and each other. Our information and referral specialists are available 24 hours a day, every day of the year through the website and our hotline (1-800-332-1000).

Our advocacy efforts focus on one of the biggest challenges for people living with epilepsy: access to care. While there is a growing range of new seizure treatments available, barriers persist creating an unacceptable treatment gap for individuals suffering with seizures and/or poor quality of life. Timely access to appropriate care and effective coverage for epilepsy medications is a critical concern for people living with epilepsy, because epilepsy medications are the most common and most cost-effective treatment for reducing or eliminating seizures. Individuals living with epilepsy who experience a delay in accessing their medication due to prior authorization and step therapy requirements, high cost-sharing, medication substitutions without physician and patient consent, and onerous drug monitoring requirements are at a high risk for developing breakthrough seizures and related complications. To learn more about the need for affordable care, and how it impacts people with epilepsy and their family, read Kyleigh’s story in the Advocacy section of the report.

In addition to access to care, our advocacy work includes pursuing ongoing funding for epilepsy research in the federal government. The Epilepsy Foundation supports funding increases for epilepsy research at the National Institutes of Health (NIH); epilepsy programs at the CDC focused on building safer communities for people living with epilepsy; and promoting safety, efficacy, and research at the Food and Drug Administration (FDA).

With your support, the Epilepsy Foundation funds innovative research and the development of new therapies. We are creating an epilepsy research ecosystem covering the entire spectrum of discovery - from idea to available therapy. We foster the development of new scientists and support research leading to better treatments and care. We strive for excellence, innovation, and radical thinking. We push new ideas for epilepsy care with our Epilepsy Innovation Institute. We get ideas connected to inventors and investors and develop new therapies faster with our Epilepsy Therapy Project. And, our targeted research program focuses on key topics like sudden unexpected death in epilepsy (SUDEP) and cannabinoids.

I mentioned earlier that epilepsy is misunderstood. One aspect of epilepsy especially needs more discussion. SUDEP is rare but important to understand. Seizures, even when believed to be controlled, can occur if treatments are missed or circumstances change. A breakthrough seizure can have severe consequences, which is why the Epilepsy Foundation’s SUDEP Institute focuses on important self-management skills to help mitigate risk. The SUDEP Institute also spearheads research to discover causes of sudden death, educates medical professionals, and provides support services to families who have lost loved ones to the most severe consequence of epilepsy.

Every day, we work to honor the memories of those we have lost to seizures. With your help, we also rededicate ourselves to our mission. Only together can we overcome challenges, accelerate therapies, find cures, stop seizures, and ultimately end epilepsy.

Thank you for standing with us.

Phil Gattone
President & CEO
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Our research program is guided by the Epilepsy Foundation vision, “to create a world without epilepsy and lives free from seizures and side effects.” We work to accomplish this by developing an epilepsy research ecosystem that supports bringing new and innovative ideas to market. From the bold approach of our Epilepsy Innovation Institute to our continued support of new researchers, we dare to push boundaries in the epilepsy research space. We hope you will join us.

In 2017, the Epilepsy Foundation launched the first initiative of the new Epilepsy Innovation Institute, or Ei². Our purpose is to continuously drive transformational innovation in the way we diagnose and treat epilepsy. We do this by encouraging and supporting radical new ideas and incorporating novel expertise and technologies from other fields of science.

Ei² will seek to solve the challenges and remove the roadblocks that stand in the way of meeting the needs of people living with epilepsy.

**ENGAGE**
Challenges will be selected by gathering and assessing input from all stakeholders, people living with epilepsy, caregivers, researchers, healthcare providers, and industry colleagues.

**IMAGINE**
We take an interdisciplinary approach to spark innovative ideas leading to transformative solutions.

**IMPLEMENT**
From Lab to Life: We fund solutions and build effective partnerships to address the challenges people living with epilepsy face every day.
EMPOWERING PEOPLE TO BETTER MANAGE THEIR SEIZURES

In our 2016 Community Survey, an overwhelming majority of respondents, regardless of seizure frequency and type, selected unpredictability of seizures as a top issue. Many wrote about the fear of not knowing when a seizure will start and not knowing what triggers the seizure onset.

In response, the Epilepsy Innovation Institute (Ei2) will be leading the effort to create an individualized seizure gauge that will allow a person with epilepsy to monitor the likelihood of a seizure daily. Our purpose is to identify and better understand the changes in the body that may precede the onset of a seizure, at a time course that may be hours or days before the clinical (observable) seizure.

Our goal for this initiative is multi-fold:
- Enhance seizure warning and prevention capabilities
- Improve quality of life and safety
- Better understand what triggers a seizure
- Identify new therapeutic targets to prevent or stop seizures

“MY SEIZURE GAUGE” – BRINGING BIG DATA TO PERSONALIZED HEALTH

For this challenge, a host of factors using both EEG (and other electrical measures) coupled with non-EEG based methods (from emerging biosensors to wearable device technology) will be considered. Although non-EEG devices are being created for seizure detection, they are developing in silos and are using only one or a few features to recognize an existing seizure.

Here, we want to integrate already ongoing initiatives, and pair them with EEG recordings to capitalize on innovative technologies developed in other communities. We do not want to measure a few components, but a myriad of factors, and then mine the data for new clues about what happens in the body in the hours and minutes before a seizure.

We believe this project will lay the groundwork to:
- Know when a seizure is likely or unlikely – empowering people to achieve better control
- Prevent or stop the progress of a seizure before it starts (tailoring the therapy to the start of seizure onset)
- Personalize dosing of medication and device stimulation (fine-tune it to when it is needed) to reduce treatment side-effects
- Incorporate new non-EEG based drug screening test in existing and new animal research models to improve a drug’s effectiveness for preventing seizures
- Identify and explain why certain situations, such as stress, may trigger a seizure
- Better understand the biological profiles of epilepsy syndromes, which in turn could improve diagnosis and address why seizures occur in an individual
- Suggest novel therapeutic targets that could be developed into new therapies for epilepsy

2017 SHARK TANK COMPETITION

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.

In total, 24 individuals or teams entered the 2017 Shark Tank competition from across the U.S. and 7 countries across the world. From this pool, six entries were chosen as finalists and three were awarded a $5,000 prize. The finalists presented at the Antiepileptic Drug Trials XIV Conference on May 18, 2017, at the Turnberry Isle Miami Hotel in Aventura, Florida.

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.

The winners use their prize to accelerate their innovations to the next phase of development, bringing it closer to being accessible to people living with epilepsy.

$75,000 AWARD
THE SOUND OF SEIZURES: AUTO-TRIGGERED SEIZURE DETECTION

Maysaa Basha MD
Associate Professor in the department of neurology at Wayne State University School of Medicine

- Developing a smartphone app that identifies seizures by detecting seizure-specific sounds
- The first step of the project will be the identification of seizure-specific sounds and generating 2 to 3 minute audio segments

$50,000 AWARD
DEVICE FOR EPILEPTIC SEIZURE PREDICTION

Paula Gomez PhD
CEO of Epistemic

- Wearable device sends an SOS message in advance of a seizure to an application in the smartphone of the caretaker.
- The algorithm to create this seizure-predicting device was created using approximately 1,000 EEGs from people with epilepsy.

$75,000 PEOPLE’S CHOICE AWARD
24/7 PORTABLE, ULTRA-LONG TERM EEG RECORDING DEVICE

Jonas Duun-Henriksen PhD
Senior Scientific Researcher at UNEEG medical A/S

- Discreet monitoring system, called the 24/7 EEG™ SubQ, includes implanted electrodes in a person’s head and a receiver.
- The device is intended to record EEG activity for up to 30 days outside of a hospital.
**Epilepsy Therapy Project**

The Epilepsy Therapy Project of the Epilepsy Foundation accelerates ideas into therapies for people living with epilepsy and seizures. We fund new, innovative research from leading scientists and startup companies. Focus is 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.

The Epilog patch has two electrodes and is a discrete, square device worn at the person's hairline. The device can be worn anywhere on the head and is waterproof. It records seizures 24 hours a day for a full week. The person wearing it or their caretaker can spot check whether the patch is working by holding up a handheld smart device to the patch.

After seven days, the patch is removed and returned to an epileptologist (a neurologist who specializes in epilepsy) who reads the results and records them in the person’s electronic medical record. The results are also shared with the person’s medical team so together they can discuss potential changes to their seizure treatment plan.

**Ataluren for non-sense mutation in CDKL5 and Dravet Syndrome**

Awarded January 1, 2017-December 31, 2018

$348,551 award

Orrin Devinsky MD, New York University School of Medicine

Drug-resistant epilepsy negatively impacts patients’ quality of life and significantly increases risk for sudden unexpected death in epilepsy (SUDEP). CDKL5 and Dravet syndrome are rare genetic disorders associated with epilepsy resistant to available U.S. Food and Drug Administration approved treatments. This study explores the use of ataluren, developed by PTC Therapeutics, Inc., for individuals living with CDKL5 and Dravet syndrome who also have a certain genetic mutation in their DNA known as a nonsense mutation.

**Epilog (EEG Patch)**

Non-Invasive Seizure Counting

Awarded October 1, 2016-September 30, 2018

$264,330 award

Mark Lehmkuhle PhD, Epitel, Inc.

The Epilog patch has two electrodes and is a discrete, square device worn at the person's hairline. The device can be worn anywhere on the head and is waterproof. It records seizures 24 hours a day for a full week. The person wearing it or their caretaker can spot check whether the patch is working by holding up a handheld smart device to the patch.

After seven days, the patch is removed and returned to an epileptologist (a neurologist who specializes in epilepsy) who reads the results and records them in the person’s electronic medical record. The results are also shared with the person’s medical team so together they can discuss potential changes to their seizure treatment plan.

**2017 Research Roundtable for Epilepsy**

Pediatric Drug Development: Moving Toward a Framework for Antiepileptic Drug Use in Children


Topics included:

- Why is placebo control important?
- Why limit placebo exposure in epilepsy trials?
- What Phase III design proposals can we consider?

The 2018 RRE topic is, “Evolving Concepts in Endpoints and Populations in Epilepsy Trials.”

**2018 Research Roundtable for Epilepsy**

Evolving Concepts in Endpoints and Populations in Epilepsy Trials

March 1-2, 2018, Washington, D.C.

Topics included:

- What endpoints are appropriate for different populations?
- Which populations are most suitable for inclusion in clinical trials?
- How can we improve the accuracy of efficacy assessments in epilepsy trials?
CLINICAL TRIALS PORTAL LAUNCHED

When we asked people with epilepsy why they did not participate in clinical trials, the number one response was that their doctor had never talked with them about clinical trials. Clinical trials are research studies that are designed to test a new approach, treatment, or diagnostic test in people. This type of research is critical to developing new therapies for all types of epilepsy. In April 2017, epilepsy.com launched a new and improved Clinical Trials Portal, where you can find information about ongoing clinical trials in epilepsy. This tool will help connect you to trials that match you to the type of epilepsy you or your loved one has. You will also find tools to help you learn about trials and other clinical research studies, and to help you consider this type of research is critical to developing new therapies for all types of epilepsy.

Why are Clinical Trials Important?

- Clinical trials are the only way new treatments can be approved and made available to people with epilepsy
- Clinical trials can help determine if a treatment is safe and effective

NEXT GENERATION SCIENTISTS

Over the past 10 years, over $12 million went to support researchers in the early stages of their career throughout the U.S.

1. Junior Investigators – The Epilepsy Foundation and AES support researchers who have recently started their own independent labs to study epilepsy.
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.
3. Clinical Research Apprenticeship – We support mentorship awards for clinical fellows to attend meetings, take additional classes, and do independent scholarship that result in publications.
4. 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.

Did you know?

- Several large epilepsy trials funded by the National Institutes of Health had to be terminated due to insufficient enrollment.
- 80% of people living with epilepsy say they would participate in a clinical trial.
- But fewer than 20% ever do.
- 84% of volunteers for epilepsy clinical trials would be willing to participate again.

NEXT GENERATION SCIENTISTS

Clinical Research Apprenticeship
Lu Lin, MD, PhD
Beth Israel Deaconess Medical Center

Title: Assessing Efficacy and Adverse Events of New AEDs in Hospitalized Patients
Summary: Dr. Lin is developing a standardized assessment tool to collect prospective information on patients to better report antiepileptic drug (AED) dosing and indications, adverse effects, and efficacy.

Research Training Fellowship for Clinicians
Adam Numis, MD
University of California, San Francisco

Title: An inflammatory molecular profile in treatment response of infantile spasms
Summary: Dr. Numis will study whether inflammatory markers in the blood change during treatment with prednisolone, adrenocorticotropin hormone, or vigabatrin, and whether these markers could predict who responds better to treatment of infantile spasms.

Susan Spencer Clinical Research Fellowship
Alice Lam MD, PhD
Massachusetts General Hospital

Research Topic: Developing a Neurophysiologic Toolbox for Diagnosing Epilepsy in Alzheimer’s Disease
Dr. Lam will study the following questions:
1) What is the actual prevalence of epilepsy in the AD population?
2) Can the abnormal electrical activity be detected through non-invasive EEG wearables?
3) Is the brain electrical activity associated with changes in electrodermal activity?

Research Training Fellowship for Clinicians
Luca Bartolini, MD
National Institute of Neurological Disorders and Stroke

Title: Research study on viral and inflammatory causes of epilepsy
Summary: Dr. Luca Bartolini will examine the frequency of herpes virus and Epstein Barr virus (EBV) infection in children with acute seizures. Specifically, he will test whether children with come to the clinic with high fevers and acute seizures are more likely to be infected with the herpes virus or EBV compared to those who appear in the clinic with high fevers but no seizures, or compared to healthy children. These studies will contribute to our knowledge about the relationship between inflammation, acute seizures, and epilepsy.

Junior Investigator Research Award
Gemma Carville, PhD
Northwestern University – Chicago

Title: Expanding epilepsy genetics beyond the exome
Summary: The overall mission of Dr. Gemma Carville’s lab is to define the genetic basis of epilepsy; understand disease mechanisms, and develop new therapeutics. Current medications only treat the symptoms of a seizure but not the underlying cause. Genetics provide a clue to potential mechanisms about why the epilepsy begins.
TARGETED RESEARCH INITIATIVE FOR RESEARCH REGARDING CANNABINOMIDS AND EPILEPSY

The Epilepsy Foundation is pleased to continue its Targeted Research Initiative program. This program recognizes the increasing need for research regarding cannabinoids. The Epilepsy Foundation supports translational clinical, and behavioral research leading to advances into the diagnosis and care of persons with seizures and epilepsy.

AWARDEE

Research Training Fellowship for Clinicians

Rama Maganti, MD
University of Wisconsin, Madison

Title: Cannabidiol, mTOR and the excitation/inhibition balance in epilepsy

Summary: Cannabidiol (CBD) is a major component in marijuana believed to offer anticonvulsant effects in certain patient groups with epilepsy. Dr. Maganti will investigate major metabolic signaling pathways critical to neuronal health and survival and will undertake a thorough investigation of CBD action on the excitatory/inhibitory balance in the brain.

RARE EPILEPSY NETWORK

Rare Epilepsy Network (REN) Strategic Planning Workshop was held December 1, 2016, in Houston at the annual meeting of the American Epilepsy Society. The goal of this workshop was to develop a REN research strategic plan, and implementation strategies for the next 1 and 5 years.

There were 170 enrollments during FY17.

MY SEIZURE DIARY

The Epilepsy Foundation’s My Seizure Diary continues to expand as a way to track seizures, medicine adherence, health events, and more. It has evolved as a self-management resource for epilepsy care – thousands of people have created diaries and track events so far.

LEMONADE FOR LIVY - SALUTE TO SHOPKO

Lemonade for Livy raises epilepsy awareness and supports the Epilepsy Foundation’s work to stop seizures, find cures, and save lives through lemonade stands and parties. During FY17 we partnered with Shopko to collect donations at the register and hold in-store lemonade stands.

Through this effort, the Shopko Lemonade for Livy campaign raised $77,000. In total, Lemonade for Livy raised $128,000.

Peter McMahon, Shopko CEO, had the following to say about Shopko’s support of the campaign: The Epilepsy Foundation provides critical support to families across the country, so Shopko is proud to partner with the organization on its ‘Lemonade for Livy’ campaign,” said Peter McMahon, Shopko CEO. “Simple acts of kindness, such as donating to this campaign while visiting Shopko, are important to the success of the communities we are privileged to serve.”
In Fiscal Year 2017, 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 Centers for Disease Control and 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.

**PROJECT UPLIFT**

Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) is a home-based depression treatment program designed for adults with epilepsy. The program was developed and tested at Emory University by Dr. Nancy Thompson, with Epilepsy Foundation CDC Program support. UPLIFT is delivered over the phone by a trained mental health facilitator and by a person with epilepsy. Project UPLIFT is part of our Managing Epilepsy Well Network. The Epilepsy Foundation, with funding from the CDC, awards two UPLIFT grants per year.

**Outcomes:**

- 100% of participants agreed that, as a result of Project UPLIFT, they have new skills they plan to use to reduce symptoms of depression and/or anxiety and to cope with epilepsy in daily life.
- 100% of participants agreed that, as a result of Project UPLIFT, they are more optimistic about their future.

**MANAGING STUDENTS WITH SEIZURES: A TRAINING FOR SCHOOL NURSES**

Managing Students with Seizures: A Training for School Nurses is a free training program 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, the Epilepsy Foundation nationwide network trained 1,394 school nurses both online and in-person. In addition, the Epilepsy Foundation is piloting three new school nurse modules focusing on the following topics: rescue therapies, 504 and Individualized Education Plans (IEP), and psychogenic nonepileptic seizures. Each module is 1 hour in length and the topics were selected based on feedback from local Epilepsy Foundation staff and the school nurses they have trained over the years.
Wellness Institute activities over FY17 have included:

- Continued partnership with the Charlie Foundation to provide content on diet and nutrition
- Worked with Athletes vs Epilepsy to produce weekly exercise videos for the Summer Fitness Challenge
- Launched our new staff workplace wellness program, Staying Happy, Healthy, Informed and Productive (SHHIP)

We are especially grateful for the epilepsy and wellness experts who have joined our newly-formed Wellness Institute Advisory Board.
The Epilepsy Foundation SUDEP Institute provides SUDEP education and awareness programs for people touched by epilepsy and for 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.

In response to the urgent need to raise awareness of SUDEP among people with epilepsy and their caregivers, the Epilepsy Foundation’s SUDEP Institute issued a special expert consensus report, #AimForZero: Striving Toward a Future Free from Sudden Unexpected Death in Epilepsy.

The report was based on published research, a survey of more than 1,000 people with epilepsy and caregivers, and interviews with the following leading epilepsy specialists:

- Orrin Devinsky MD, Professor of Neurology at the NYU School of Medicine and Director of the NYU Langone Comprehensive Epilepsy Center and North American SUDEP Registry
- Jacqueline French MD, Chief Scientific Officer for the Epilepsy Foundation and Professor of Neurology at New York University
- Dale C. Hesdorffer PhD, Professor of Epidemiology at Columbia University
- Samden Lhatoo MD, Professor of Neurology, Case Western Reserve University School of Medicine
- Philippe Ryvlin MD, PhD, Professor of Neurology, Lyon University, France
- Joseph Sirven MD, epilepsy.com Editor-in-Chief and Professor of Neurology and Chairman of the Department of Neurology, Mayo Clinic, Arizona

In 2017, the Studio E: The Epilepsy Art Therapy Program included a total of 48 local Epilepsy Foundations and over 60 markets. 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.

Epilepsy.com recently featured a story from Kaitlyn B., a former Studio E participant, who shared her experience with the program: “The people who participated in Studio E helped me more than they could know. I met so many wonderful people, learned a lot... and became a better person. I can say that I am honestly looking forward to the rest of my life.”

REMEMBERING CASEY

Casey Cordova passed away from SUDEP on August 1, 2017. She was only 32 years old. Casey was born in Minnesota and grew up in Naperville, Illinois. She obtained her MBA from DePaul University and had relocated to Austin, Texas, for work. She spent her young life advocating on a national level for other people with epilepsy, and she volunteered for the Epilepsy Foundation of Greater Chicago to help others who live with seizures. Casey’s family raised money in her memory to benefit the SUDEP Institute at the national #EpilepsyWalk. The Epilepsy Foundation is incredibly saddened by the loss of such an incredible, young advocate. She will be missed by all that knew her.
Epilepsy.com is the premiere epilepsy and seizure information and engagement website in the world. Over 9 million users from more than 230 countries accessed the site between July 1, 2016 and June 30, 2017. Epilepsy.com is overseen by some of the top epilepsy specialists in the world, guaranteeing our content is accurate and current. The site provides a wide range of information for people living with epilepsy and their caregivers including information about diagnosis, treatment, management and wellness. In addition, epilepsy.com hosts a large interactive community where people find help, hope, and support from epilepsy experts and each other.

The report also served as the centerpiece of a multi-channel campaign to motivate people with epilepsy to strive for their best possible seizure control to reduce their risk of SUDEP, speak with their health care team about SUDEP, and use the dedicated #AimForZero hashtag to drive discussions of SUDEP. The #AimForZero campaign urges people with epilepsy to adopt key self-management actions to help avoid SUDEP.

1. Taking epilepsy medications as prescribed is critical because these medicines are only effective when taken regularly.
2. Getting enough sleep helps avoid sleep deprivation, which can trigger seizures.
3. Limiting alcohol and illicit substances consumption is important because seizure medicines can lower the tolerance for alcohol and people with epilepsy are at a higher risk of seizures after drinking alcoholic beverages.
4. Finally, striving to stop seizures motivates people with epilepsy and their caregivers to strive for zero seizures and talk to their healthcare providers about the risk of continued seizures and SUDEP.

Our community continues to engage with epilepsy.com for reliable, up-to-date news and information. The following newsletter articles resonated with our community during FY17:

1. 2017 Revised Classification of Seizures
2. Study Finds Infantile Spasms Misdiagnosis and Treatment Delay Can Lead to Intellectual Disability, Autism, Death
3. FDA Issues Safety Alert on Improperly Labeled Lamotrigine
4. What Kind of Seizure Do I (You) Have?
5. Study Demonstrates 72 Percent Seizure Reduction at 7 Years with the RNS® System
6. Research Update on Epilog Patch from Epitel, Inc.
7. Food for Thought: Does the Ketogenic Diet Improve Thinking and Behavior?
8. Teens and Young Adults Needed for Epilepsy Self-Management Study
9. Does a Seizure Always Occur in SUDEP?
10. Ketogenic Diet Guidelines for Infants
OUR ONLINE COMMUNITY

One way the Epilepsy Foundation engages with our online community is through our epilepsy.com Community Corner. Written by Patricia Osborne Shafer RN, MN, epilepsy.com’s associate editor, the Community Corner provides updates on epilepsy news and highlights various topics relevant to those living with seizures.

Here are FY17’s top five Community Corner pages:
1. Get Informed – More about Medical Cannabis
2. Seizures and Summer Fun
3. MRI-guided Laser Surgery for Epilepsy
4. Seizures in Older People
5. Know More about Marijuana and Epilepsy and Share Your Opinion!

Epilepsy.com also leads frequent online chats, called Chat Abouts, on various topics that are pertinent to the epilepsy community. Guest experts from our Professional Advisory Board, other leading experts, people with epilepsy, and parents may help answer questions and guide discussions.

The following Chat About topics were covered in the reporting period:
• Epilepsy, Thinking, Memory, and More
• Seizure Medicines
• Seizures, Hormones, and Menses
• Getting Involved with Your Epilepsy Foundation
• Epilepsy and the Family
• Seizures in Adults and Children – Is there a difference?
• #EpilepsyLifeHacks
• Fitness and Seizures: Getting Started
• Epilepsy Monitoring Units
• Nonepileptic Events: What are They and How Can They Be Treated?
• Seizures Come in All Different Shapes in Sizes
• EEG
• Treating Epilepsy
• Epilepsy and Families

Finally, the epilepsy.com Community Forums and chat room provide people an opportunity to converse with each other about living with epilepsy and seizures. The Epilepsy Foundation’s volunteer community mentors help facilitate these forums and navigation of the website for new users.

The following were the most frequently used forum topics in the reporting period:
• Living with epilepsy for adults
• New to epilepsy.com
• Medications
• Women’s issues

Common forum question topics include:
• First seizure or new diagnosis: Looking for answers and experiences from others
• Asking questions about whether or not symptoms are due to seizures
• Medicines or side effects
• Cannabis
• Finding an epilepsy specialist
• Surgery, devices and EEG monitoring

\"The Epilepsy Foundation is grateful to our online community for making epilepsy.com their home.\"
GEAR UP FOR EPILEPSY

Gear Up for Epilepsy is an Athletes vs Epilepsy initiative that was inspired by a young cyclist, Charlie, who dreamed of riding with his father across the United States. Unfortunately, he would not be able to accomplish that dream as his ride was cut short by SUDEP in August of 2016.

To celebrate Charlie’s memory, Charlie’s parent Clif and Arleen departed on a 2-month cross-country bicycle trek that their son dreamed of accomplishing on June 18, 2017. Clif and Arleen were joined by family and friends throughout the trip.

The Coast to Coast Charlie Team cycled 3,712 miles across the United States for Charlie to help raise awareness for SUDEP and epilepsy and funds for the Epilepsy Foundation. The Athletes vs Epilepsy Gear Up for Epilepsy teams joined the family in spirit and rode over 20,000 miles, raising over $54,000. Over 50 people participated in the event.

Gear up for Epilepsy was launched on May 15, 2017 and closed August 31, 2017. The fundraiser was covered by CBS Boston, Greenfield Recorder, and WDAY, Fargo.

ONLINE LEARNING

Launched in 2016 at learn.epilepsy.com, our new 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.

Updates:

• In 2016-17 we hosted over 2,600 users on learn.epilepsy.com.
• We increased the number of new educational classes available on the LMS by 50%.
• All six educational classes are available with health literacy materials designed for dissemination on demand by authenticated users.

BUILDING PARTNERSHIPS

Through epilepsy.com the Epilepsy Foundation works to build relationships with organizations complementing our mission. During FY17, we continued our collaboration with the Epilepsy Center at George Washington University to webcast their monthly Epilepsy Grand Rounds. Topics included:

• The Importance of Cardiovascular Fitness and Epilepsy
• Decodification of the Brain Using Electrocoorticography
• Naming in Epilepsy and Epilepsy Surgery
• PET Scanning Epilepsy: Clinical and Research Applications
• Appropriate Aggressive Treatment of Seizures in Critically Ill Patients
• New Treatment for Intractable Epilepsy
• Epileptic Foci Identified by Combining EEG and fMRI
• Pediatric Epilepsy Surgery; Treating the Epileptic Encephalopathy
• Psychogenic Nonepileptic Seizures
• Glycolysis as a Metabolic Target for Treatment of Seizures and Consequences of TBI

The Epilepsy Foundation also cohosted a webinar with Hope for Hypothalamic Hamartomas. The webinar entitled “Focused Ultrasound and Potential New Technologies for Difficult to Control Seizures” was moderated by Patty Osborne Shafer RN, MN, associate editor of epilepsy.com and featured the following panelists:

• Nathan Fountain MD, Professor Neurology and Director of the F.E. Dreifuss Comprehensive Epilepsy
• Travis Tierney MD, Pediatric Neurosurgeon with Nicklaus Children’s Hospital 56 people attended the webinar.

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• New Treatment for Intractable Epilepsy
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With our network of local organizations, the Epilepsy Foundation continues to spread epilepsy awareness and build support for people living with seizures and their families across the country. From training police officers to hosting summer camps, the Epilepsy Foundation is fostering community for the 3.4 million people living with seizures in America.

**COMMUNITY ACTION NETWORK**

The purpose of the Epilepsy Foundation's Community Action Network is to expand the reach of the Epilepsy Foundation by providing assistance to groups of volunteers who want to develop an activity related to epilepsy that raises funds for the Epilepsy Foundation, increases advocacy, brings services, or raises awareness about epilepsy within communities around the country. The goal is to mobilize a nationwide movement that delivers meaningful and lasting impact for people living with epilepsy.

The Community Action Network functions under four specific goals established by the Epilepsy Foundation known as ASAP (Acceptance, Support, Advancement, and Participation). ASAP was selected to illustrate that people living with epilepsy can no longer wait to receive the services and treatments they need. Each Community Action Network group works under the same framework so a unified message can be spread across the country. For far too long, a cohesive, consistent story has not been heard. Speaking with one voice will transform our ability to make an impact, change the perception of epilepsy, provide valuable information to the community, and fund research that will lead to new treatments and cures.
Zoey joined the Kids Crew in June of 2016. She is a very happy 7-year-old little girl who loves to explore outside, attend Sunday School, play with her little sister, and draw pictures to cover the entire fridge. She also loves play dates with her best friends.

Zoey has three kinds of seizures and none of them are stopped with medicine. She now takes two medicines - and has tried several other ones - but still has seizures almost every day. She and her parents are talking with doctors about trying other ways to stop her seizures, including trying a VNS device.

Zoey has kept her fun and silly nature despite facing seizures daily. Even after all Zoey has been through, she hasn’t let the seizures take that sparkle from her eyes and she doesn’t let her epilepsy get her down. Zoey is setting a wonderful example for kids in her community as well as the rest of the Kids Crew. She is educating others about epilepsy, participating at walks, and has held several lemonade stands for Lemonade for Livy. She is not letting epilepsy stop her despite the challenges she faces and is committed to helping others.

The Epilepsy Foundation created the Kids Crew to help kids share their stories about epilepsy, generate awareness of epilepsy, educate others, and to encourage them to participate in events. The Kids Crew empowers kids to take action! At the same time, kids are recognized and celebrated for helping expand the reach of our mission. When kids are registered, they receive a new member kit in the mail and then have the opportunity to earn themed pins for completing activities. The Kids Crew is a free program for all kids 14 and under.

The Epilepsy and TBI training that Margo provided for the Salt Lake Police Department was very well received by our officers. The training has increased officers’ awareness of and ability to recognize seizure disorders and how presentation differs. Officers also learned the best way to render aid to a person who is having a seizure, to keep them safe and not compound the problem.

From April 2017 to June 2017, there were a total of 402 Salt Lake City Police Department officers that received trainings on epilepsy and traumatic brain injury (TBI) from Margo Thurman, executive director of the Epilepsy Foundation of Utah. Lieutenant J. Eddie Cameron of the training division at the police department provided the following quote on the experience:

“The Epilepsy and TBI training that Margo provided for the Salt Lake Police Department was very well received by our officers. The training has increased officers’ awareness of and ability to recognize seizure disorders and how presentation differs. Officers also learned the best way to render aid to a person who is having a seizure, to keep them safe and not compound the problem.”

The Salt Lake City Police Department plans to have this block of training, along with the other ADA training, conducted during the next police academy in 2018.
In FY17, the Epilepsy Foundation’s Connectors Project helped improve public health education in underserved areas for both individuals with epilepsy and professionals. The project was tested in 4 states – Michigan, Nevada, Oklahoma, and West Virginia, but people visiting epilepsy.com can still view the training videos in the Epilepsy Foundation Learning Management System (LMS).

To help meet the need in West Virginia, the Epilepsy Foundation of Greater Cincinnati and Columbus stepped up to raise the bar for epilepsy care in the state. A mountainous state located in the Appalachian Mountains, West Virginia has three major centers where the Connectors Project focused their work: Morgantown, Charleston, and Huntington.

“People in this state were really hungry for information,” said Mark Findley, Assistant Director, Epilepsy Foundation of Greater Cincinnati and Columbus.

To cover the professional side, Director of Community Education at the Epilepsy Foundation of Greater Cincinnati and Columbus Tom Koprowski fostered a relationship with family physicians and attended several conferences to provide expanded education about epilepsy. Additionally, Tom helped expand education for school nurses. Training school nurses proved extremely critical, since many children receive primary care from their school nurse in West Virginia. The team also helped arrange the West Virginia Epilepsy Conference.

The Connectors Project represented the Epilepsy Foundation at the following events:

• Family Medicine Foundation of West Virginia
• KidsStrong Conference
• West Virginia Academy of Family Physicians
• And small, local meetings with clinicians and consumers

Because West Virginia has such diverse geography, getting people with epilepsy to come to events proved challenging. As a solution, the project hosted three webinars featuring West Virginia doctors from different parts of the state and Epilepsy Foundation experts. This provided valuable education to people with epilepsy across the state, as well as helped them identify local physicians if they need future support. Webinar topics included:

• Epilepsy 101: What You Need to Know to Get Started, by Dr. Samip Borad, CAMC, Charleston, WV
• #LifeHacks for Managing Seizures & Epilepsy: Partnering with Your Health Care Team When Medicines Don’t Work, by Dr. Viji Rajasekaran, West Virginia University, Morgantown, WV
• Women and Epilepsy – from Puberty to Pregnancy and Menopause, by Dr. Sona Shah, Marshall University, Huntington, WV

The Epilepsy Foundation gratefully acknowledges UCB’s support of the Connectors Project.
Claire Caldwell was diagnosed with absence seizures several years ago. Her parents, Lynne and Dr. Gregory Caldwell DMD, MD, and two brothers are engaged advocates for the Epilepsy Foundation. The Caldwells recently made a major gift to support the work of the Epilepsy Foundation. In addition to this generous commitment, the Caldwells have participated in the Epilepsy Foundation New England walk each year, attended the Epilepsy Foundation New England gala in Boston, and has held 3 lemonade stands with Lemonade for Livy. Claire even donates out of her allowance each year!

Lynne Caldwell said the following about the Epilepsy Foundation:

“We have been involved with the Epilepsy Foundation for over 2 years now. Once we got involved we immediately felt we were not alone in this journey and it opened our daughter’s eyes to the fact she is one of many people affected by this disease. The sense of support and inspiration we have received from the Epilepsy Foundation has been truly such a blessing in our lives. It has motivated us all as a family to get involved and do what we can to help support the Foundation in its efforts to cure this disease. From lemonade sales to the annual gala and Boston walk, we feel fortunate to be able to be involved, help out, and connect with others who are affected by epilepsy.”
The more everyone talks about epilepsy, the less people living with the condition have to fear discrimination, worry about receiving improper first aid, or keep their epilepsy hidden in the shadows. One-third of people living with epilepsy have seizures that cannot be controlled with current treatments, and all people living with epilepsy have the risk of a potential “breakthrough” seizure. The uncertainty of when and where the next seizure may occur has a dramatic impact on the lives of all people living with epilepsy and on their loved ones. For these reasons and more, the Epilepsy Foundation is dedicated to improving public understanding of epilepsy and seizures through our public awareness campaigns and social media channels.

**SOCIAL MEDIA**

The Epilepsy Foundation uses its social media channels to raise awareness and spread information about epilepsy and seizures. During the reporting period, the Epilepsy Foundation Facebook and Twitter account activities resulted in:

- 39,323,577 impressions
- 738,711 engagements
- 253,097 link clicks
- Over 200,000 views on Facebook videos

Our presence on social media only continues to grow, which is a testament for our community’s desire for more information about living with epilepsy. Social media growth in the last fiscal year included 17,296 followers on Facebook and Twitter and 3,928 followers on Instagram. Follower account on Facebook and Twitter represents a growth of 11.6% from FY16 and Instagram growth was 57.2%.

Our top content on social media continues to be focused on the community with posts like milestones, picture requests, and epilepsy in local and national news.
During FY17, the Epilepsy Foundation Facebook account held 9 Facebook Live chats. In total, these events had over 33,000 views. Facebook Live topics and events included:

- #AimForZero
- American Epilepsy Society Annual Meeting
- "Talk About It for Epilepsy!" Netathon presented by Sunovion
- Hypothalamic Hamartomas
- Lemonade for Livy
- New seizure classifications

**PUBLIC AWARENESS CAMPAIGNS**

### #BACKTOSCHOOL

The 2016 Back To School campaign ran from August 29 to September 2. The campaign focused on helping parents and students prepare for school and the challenges they might face.

The campaign resulted in the following during the reporting period:

- 28,234 impressions
- 1,796 engagements
- 676 clicks
#MYEPILEPSYHERO

During National Epilepsy Awareness Month, the Epilepsy Foundation partnered with Sunovion and celebrity advocate Greg Grunberg to recognize the people who have made a positive difference in the lives of those living with epilepsy. The social media campaign #MyEpilepsyHero gave people impacted by epilepsy the chance to recognize someone who has provided them support or inspiration in their epilepsy journey.

The campaign continued beyond November at the 2017 National Walk for Epilepsy where we asked people to share their epilepsy hero at the Talk About It! booth.

The social media campaign created the following during the reporting period:

- 215,880 impressions
- 2,506 engagements
- 5,265 link clicks

#SHAREMYSEIZURE

The main campaign for National Epilepsy Awareness Month was #ShareMySeizure, part of the Epilepsy Foundation’s cooperative agreement with the Centers for Disease Control and Prevention. The initiative focused on highlighting the full spectrum of seizures, beyond what people usually see in the media.

Two public service announcements were produced for the #ShareMySeizure campaign with the help of the CBS Community Partnership. The videos featured Wendy Miller PhD, RN, and Sarah Carlson. In addition to raising awareness of what different seizure types looked like, the PSAs invited viewers to learn more about epilepsy and how to help someone who is having a seizure on epilepsy.com.

These public service announcements ran as a pilot on CBS Television in Chicago, on the Health Media Network (specialized programming on television monitors in doctors’ offices) in Illinois, Ohio, and Texas, and across all the CBS digital platforms nationwide. Our combined efforts resulted in over 34 million impressions nationwide.

During National Epilepsy Awareness Month, social media activity for #ShareMySeizure resulted in:

- 236,335 impressions
- 4,859 engagements
- 14,780 link clicks

The Epilepsy.com page on #ShareMySeizure received over 58,000 unique page views during the reporting period. The #ShareMySeizure videos had a reach of nearly 200,000 and received nearly 60,000 views.

#AIMFORZERO

#AimForZero is an ongoing campaign launched during the 2016 National Epilepsy Awareness Month. The campaign followed the recommendations of the Epilepsy Foundation’s SUDEP Institute’s report, “#AimForZero: Striving Toward a Future Free from Sudden Unexpected Death in Epilepsy.” Messaging followed four key behaviors people with epilepsy can take to improve seizure control and reduce their risk of SUDEP:

- Take medication as prescribed
- Get enough sleep
- Limit alcohol and other illicit substances
- Strive to stop seizures

In addition to social messaging on these topics in November, the Epilepsy Foundation held a Facebook Live and Twitter Chat.

The campaign resulted in the following during the reporting period:

- 1,252,347 impressions
- 26,861 engagements
- 38,636 clicks

Other tactics to promote #AimForZero included:

- Feature article in a USA Today supplement
- Inviting our audience to #AimForZero for their New Year’s Resolution
- Weekly e-Newsletter ads (starting January 18, 2017)
- Increased crosslinking throughout epilepsy.com
Talk About It! uses its social media channels to raise awareness and fight misconceptions and fear about epilepsy and seizures. The Epilepsy Foundation post once a week on the Talk About It! Facebook and Twitter channels. The posts revolve around the videos on the Talk About It! website that have celebrities in them or are from the community.

Posts are short, easy to digest, and have a light and playful tone in an attempt to not raise fear about epilepsy and seizures.

“Talk About It for Epilepsy!” Netathon Presented by Sunovion

On May 6, 2017, the Epilepsy Foundation hosted its second “Talk About It for Epilepsy!” Netathon Presented by Sunovion. The event broadcasted live on epilepsy.com, YouTube, talkabout.org, Twitch.tv, and CBSlocal.com/epilepsy. Spokesperson and celebrity Greg Grunberg hosted the event alongside Phil Gattone and DJ HAPA.

The event was promoted through mass email, e-newsletter articles, a press release, epilepsy.com house ads and a promotional banner, social media, and Save the Date cards that were distributed at the Epilepsy Foundation’s National Walk for Epilepsy, Teens Speak Up! / Public Policy Institute, Skill Building Institute Conference, and Leadership Conference. A communications guide including talking points, graphics, reminders, and a promotion video by Greg Grunberg was shared broadly among the partners for the event.

Social media promotion for the netathon began on March 31, 2017. In the lead up to the event, the Epilepsy Foundation held two Facebook Lives, including one with Greg Grunberg. During the netathon, two Facebook Lives were posted. From March 23-May 6, social media created:

- 287,543 impressions
- 5,521 engagements
- 4,568 clicks

As of May 23, 2017, the broadcast had been viewed a total of 2,311 times on YouTube and the landing page for the event received 6,068 pageviews. Twitch had over 121,000 views.

The livestream event was viewed across the nation in seven locations and each party spoke in an on-air segment featuring their chapter. From enjoying food to sharing personal stories, each watch party brought communities together in a meaningful way.

In addition to broadcasting the event, CBS Local’s digital promotional campaign led to over 1 million impressions and nearly 6 thousand clicks. Additionally, over 5.5 million adults heard about epilepsy and the netathon on CBS 2 TV Chicago.

“The Epilepsy Foundation Central & South Texas (EFCST), our staff, volunteers, participating families, and business neighbors were honored to have hosted a fantastic Fiesta-themed watch party for the 2017 Talk About It for Epilepsy! Netathon. Participants enjoyed the sunny day, festive décor, live mariachi music, face painting, bouncy houses, and grilled foods. We valued the opportunity to talk about how EFCST’s medical clinics, support groups, and counseling services help our families, meet needs, and improve the lives of people living with epilepsy. We enjoyed being part of the larger epilepsy community and watched fellow affiliates across the nation tell their stories as we celebrated Fiesta-style!”
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.

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

- The Helpline received an email from a person in a rural part of the United States who had lost hope.
- The Helpline staff connected them with their local 2-1-1 in an area not presently covered by a local Epilepsy Foundation. The 2-1-1 followed up with immediate and intensive support and stated that our team probably saved the person’s life.

A parent in an area of the United States not currently covered by a local Epilepsy Foundation called about their 20-year-old child who was having trouble accepting their diagnosis and self-managing their epilepsy. The young person’s resistance was harming their health, as well as academic and employment options. Helpline staff connected the parent with a parent support chat group on epilepsy.com, provided links for support for the young person to use when ready, and counseled the parent on ways to help their child begin to cope effectively with their diagnosis. The Helpline also supported the parent who called by helping them recruit support from local and family helpers.
EPILEPSY FOUNDATION PUBLIC POLICY ENGAGEMENT

FEDERAL ENGAGEMENT

During FY17, the 114th Congress came to an end, and the 115th Congress went into session. A new Administration also began in January 2017. During this time, the Epilepsy Foundation has been continuously engaged in advocacy with Congress and the Administration on behalf of people with epilepsy.

Our federal advocacy focuses on four main policy priorities:

• Securing federal funding for epilepsy research & programs
• Ensuring access to affordable, quality health care
• Promoting research & innovation
• Protecting disability rights & ending discrimination

Federal Public Policy & Grassroots Engagement by the Numbers:

• The Epilepsy Foundation sent more than 190 advocacy letters to the Administration and Congress and 17 policy alerts to our national network of 53,000 grassroots advocates.

• Driven to action by our policy alerts, grassroots advocates have sent more than 13,500 emails and made more than one hundred calls to members of Congress.

2017 FEDERAL PRIORITY ISSUES

Federal Funding for Epilepsy Research & Programs

The Epilepsy Foundation supports increases in federal funding for epilepsy research at the National Institutes of Health (NIH), epilepsy programs at the Centers for Disease Control and Prevention (CDC), and research into ensuring safe and effective treatments at the Food and Drug Administration (FDA).

During the 115th Congress, the Epilepsy Foundation sent 14 letters to Congressional leaders urging increases in federal spending on epilepsy research and programs for FY17. We engaged our grassroots network, urging advocates to write to their members of Congress about increasing federal funding for epilepsy. We also sent an alert through a targeted social media campaign. In response, advocates sent more than 4,000 e-mails to the House and Senate. As a result of this work, our grassroots advocates, and other stakeholders, Congress passed and the President signed a $1.07 trillion FY17 spending bill that includes a $2 billion funding increase for the NIH and a $22 million funding increase for the CDC.
ACCESS TO AFFORDABLE, QUALITY HEALTH CARE IN THE ACA MARKETPLACE AND MEDICAID

Prior to the start of the new Administration in January, the Epilepsy Foundation had continuously communicated with the Department of Health and Humans Services (HHS) regarding ways to improve and effectively implement the Affordable Care Act (ACA). These efforts were primarily completed on behalf of the I Am Essential coalition – a coalition of patient advocacy organization focused on encouraging access to health care for individuals on the ACA Marketplace. The Epilepsy Foundation leads the I Am Essential coalition with The AIDS Institute and the National Alliance on Mental Illness.

As the new Administration began and the 115th Congress began considering the repeal and replacement of the ACA, the Epilepsy Foundation continued to raise awareness about the important role that the ACA’s patient protections play in ensuring that people with epilepsy have access to affordable, quality care. Since January, we sent 46 letters to Congress and the Administration detailing how the House and Senate proposals to repeal and replace the ACA would impact our community.

The Epilepsy Foundation Public Policy team also launched a public education campaign to publicize the importance of ACA patient protections and the current structure of the Medicaid program. In June, we published a blog detailing the current health care debate and proposals. We also communicated updates regularly with affiliate and chapter leadership and provided them with opportunities and tools to engage.

Since January, we sent four nationwide alerts to our 53,000 grassroots advocates, urging them to write to their members of Congress about protecting access to health care. After receiving our alerts, advocates have sent more than 5,000 e-mails to members of the House and Senate.

KYLEIGH’S STORY

Kyleigh, 9, has lived with uncontrollable seizures since she was three years old. In the early days of her diagnosis, Kyleigh was in the hospital frequently because of her seizures. Every time she returned, she was prescribed a new, expensive medication — and eventually would try eleven antiepileptic drugs in five years.

The frequent hospital stays made it difficult for Kyleigh’s mother, Tiffany, to be at work regularly, and she lost her job as a result. Even though Kyleigh received health insurance through her father’s employer, it was still hard to keep up with the cost of co-pays and coinsurance. When the cost of Kyleigh’s first hospital stay reached $10,000, the hospital social worker encouraged Tiffany to apply for Medicaid. Medicaid covered the full cost of the hospital stay, and Tiffany could worry about paying for rent and Kyleigh’s special ketogenic diet — not her hospital bills.

“Medicaid was about survival.” Tiffany said. “I have a college education, but I had no way to work because Kyleigh was so sick. She couldn’t even do half-day preschool because of her seizures.

Today, Kyleigh has seizures nearly every day. Medicaid helps to supplement the cost of her medications and therapy and allows her to see epilepsy specialists. Without Medicaid, her family would pay thousands of dollars per month, even with their private insurance. Tiffany says that supplemental Medicaid “allows my family to find doctors that actually understand Kyleigh’s needs, without wondering how we’re going to pay for them.”

THE CHILDREN’S HEALTH INSURANCE PROGRAM

The Epilepsy Foundation strongly supports the Children’s Health Insurance Program (CHIP), an essential source of health care coverage for nearly 9 million children, including many with epilepsy. In June, we sent a letter to eight key Congressional leaders urging a prompt long-term funding extension for CHIP.

PROTECTING AND STRENGTHENING MEDICARE

The Centers for Medicare and Medicaid Services (CMS) has been exploring ways to enhance Medicare Part D, the program’s prescription drug benefit. As CMS considered changes to Medicare Part D, the Epilepsy Foundation urged the agency to make continued access to physician-directed care a policymaking priority. We support the existing Medicare Part D Six Protected Classes policy, which ensures greater protections for six classes of medications, including anticonvulsants for epilepsy.

Medicare Part D plans currently provide lower levels of coverage for anticonvulsants than many commercial health care plans, and we have urged CMS to address this deficit. During FY17, the Epilepsy Foundation submitted three comments and sent one letter to CMS and conducted many meetings with key legislators and their staffs to educate them about the Medicare Six Protected Classes policy.

IMPROVING ACCESS TO MEDICAL CANNABIS

The Epilepsy Foundation supported several bills that would advance access to medical cannabis and/or CBD and protect existing state medical cannabis and/or CBD programs.

We support:
1. The Compassionate Access, Research Expansion, and Respect States (CARERS) Act of 2017
2. The Compassionate Access Act

Further, we also support and appreciate the research opportunities promised by the Cannabidiol Research Expansion Act, which would require the Attorney General to determine whether CBD should be a controlled substance and expand research on the possible medical benefits of CBD and other marijuana components. We will continue to support these bills and others with similar objectives as they are debated by Congress.

REDUCING STEP THERAPY AND BARRIERS TO CARE

Step therapy, or “fall first,” is a process used by insurance companies that requires individuals to try and fail one or more medications preferred by the insurer before receiving coverage for the treatment their physician originally prescribed. Step therapy requirements delay access to the medication physician-directed care, prolongs ineffective treatment, and can lead to interruptions in regimes that work.

In FY17, the Epilepsy Foundation supported the Restoring the Patient’s Voice Act, which would require employer-based group health plans to provide a clear exemption process for any step therapy protocol.

IMPROVING ACCESS TO MEDICAL CANNABIS
ACCESS TO EMERGENCY MEDICATION

On January 9, 2017, the House unanimously passed the Emergency Medications Act, which would make changes to the Drug Enforcement Agency’s registration process for emergency medical services (EMS) agencies, and clarify that EMS personnel can administer certain approved medications to their patients. The Epilepsy Foundation advocated for the passage of the Emergency Medications Act, sending a letter to the chair and ranking member of the House Energy & Commerce Committee in 2016. We will continue to advocate for this bill to pass the Senate and be signed by the President.

PASSAGE OF 21ST CENTURY CURES ACT

On December 12, 2016, the 21st Century Cures Act was signed into law. This groundbreaking legislation was the result of many years of discussion and negotiation, and the final bill, which incorporated many policy proposals, had strong bipartisan support. Further, important provisions were included in the legislation to support the Precision Medicine Initiative and the BRAIN Initiative, which set the goal of helping researchers find new ways to treat, cure, and prevent brain disorders, including epilepsy.

It also requires the Centers for Disease Control and Prevention (CDC) to set up a surveillance system for neurological diseases. The Epilepsy Foundation specially advocated for the neurodata surveillance system and will continue to advocate for epilepsy to be one of the conditions included in the new system. The Epilepsy Foundation advocated for the passage of the 21st Century Cures Act, and our grassroots advocates sent 2,265 letters to legislators in support of the legislation.

ACCELERATING DRUG AND DEVICE DEVELOPMENT AND APPROVAL AT THE FOOD AND DRUG ADMINISTRATION

The FDA is currently partially funded by industry user fees, which support a personnel level that allows the agency to approve new treatments in a timely and more efficient manner. The Epilepsy Foundation strongly supports the FDA user fee agreements, which must be reauthorized every five years. The Epilepsy Foundation is committed to accelerating the development and approval of new therapies. In FY17, we sent 71 letters to members of Congress on key committees in support of prompt reauthorization of the FDA user fee agreements, which include several new FDA initiatives that would support increased patient involvement at the agency. Our grassroots advocates amplified our message by sending an additional 1,355 emails to members of Congress in response to several of our action alerts.

INCLUDING THE PATIENT PRESCRIPTIVE IN CONVERSATIONS ABOUT VALUE-BASED APPROACH TO HEALTH CARE DELIVERY REFORM

As policymakers consider reforms intended to improve the delivery of quality and bend the ever-growing cost curve, the Epilepsy Foundation advocates for the patient voice to be included in these conversations. In late 2016, the Epilepsy Foundation joined more than forty other groups in public comments submitted by the Partnership to Improve Patient Care (PIPC) to the Institute for Clinical and Economic Review (ICER) in response to their Value Assessment Framework. As members of the PIPC Steering Committee, we will continue to participate in the dialog around value and advocate for including the patient perspective as a critical stakeholder for successful reforms.

SUPPORTING THE AMERICANS WITH DISABILITIES ACT

In FY17, the Epilepsy Foundation opposed the ADA Education and Reform Act, which would shift the burden of ADA compliance from business owners to people with disabilities. Together with other patient advocacy groups in the disability community, we wrote two letters to Congressional leaders in opposition to the bill. In response to our call for grassroots advocacy, our epilepsy advocates sent 863 emails to members of the House of Representatives expressing opposition to the bill.

INCLUDING THE EPILEPSY COMMUNITY IN AUTONOMOUS CAR DEVELOPMENT AND POLICY

As automobile manufacturers and technology companies move closer to the development of fully autonomous vehicles or “self-driving cars,” the Epilepsy Foundation is focused on the possible benefits of these vehicles for people with epilepsy, especially for those who cannot legally drive due to seizures. Autonomous vehicles could expand mobility for members of the epilepsy community who cannot safely operate a traditional motor vehicle. We urge federal, state, and local policymakers to encourage innovation related to autonomous vehicles, and oppose unnecessarily restricting manufacture and use of such vehicles. Policies requiring riders of fully autonomous vehicles to hold drivers’ licenses would needlessly restrict some people with epilepsy from realizing the full benefits of this new technology.

“Diagnosed with epilepsy in early childhood, Jody Mayer persevered against many obstacles, including being terminated unfairly from her job. After losing her job, she and her husband Larry began to support the Epilepsy Foundation both financially and through hard work. The Mayer’s assisted the Foundation in lobbying Capitol Hill in a multi-organizational effort, which culminated in the signing of the Americans with Disabilities Act in July of 1990. “I will personally never forget what the Epilepsy Foundation did for us emotionally and otherwise,” said Larry. “and I continue to provide financial support to the organization even a decade after Jody’s untimely death, and I planned for my ultimate gift, a bequest. “

“"
STATE ENGAGEMENT

During FY17, state legislators considered hundreds of bills of importance to the epilepsy community and passed 16 into law. Our primary policy priority in the states is ensuring access to care – mainly epilepsy medications across a variety of payers – as this is the policy priority that states have some control over.

Opologies are also needed. The Epilepsy Foundation supported “model bills” that used similar language to accomplish comparable policy outcomes in different states.

State Public Policy & Grassroots Engagement by the Numbers:

- In FY17, the Epilepsy Foundation has sent 746 advocacy letters to state legislators and policymakers and 34 policy alerts to grassroots advocates across the country.

- Driven to action by our policy action alerts, 1,000 grassroots advocates from 15 states have sent 1,384 letters and made 62 calls to state officials.

2017 STATE PRIORITY ISSUES

STEP THERAPY

Five states passed step therapy protections into law: Arkansas, Colorado, Iowa, Texas, and West Virginia.

STATE RESCHEDULING FOR FDA-APPROVED THERAPIES DERIVED FROM CANNABIDIOL

This year, we have sent letters to 81 legislators and policymakers in eight states, urging changes to state scheduling laws to allow patient access to CBD-derived, FDA-approved therapies. Grassroots epilepsy advocates have amplified our message with 143 additional emails to legislators. Five states have created legislative pathways for FDA-approved, CBD-derived medications: Arkansas, Arizona, Kentucky, Utah, and Wisconsin.

STATE MEDICAL CANNABIS AND CANNABIDIOL PROGRAMS

46 states and the District of Columbia have created programs allowing medical access to cannabis or cannabidiol (CBD). This year, the Epilepsy Foundation sent letters of support for access to medical cannabis and CBD to 29 legislators and policymakers in three states. Grassroots epilepsy advocates have amplified our message with 316 additional emails to legislators.

- On April 26, 2017, Indiana Governor Eric Holcomb signed House Bill 1148 into law, legalizing the use of CBD as a treatment option for epilepsy and seizures.

- On May 12, 2017, Iowa Governor Terry Branstad signed House File 524 into law, which expanded the existing state law related to the use of CBD. The new law allows the state to authorize up to two facilities to grow and produce CBD and five dispensaries to sell CBD.

MEDICATION SYNCHRONIZATION

In FY17, the Epilepsy Foundation supported model medication synchronization legislation that would allow patients to pick up all their prescriptions on the same day each month and ensure that costs are appropriately prorated. Three states passed medication synchronization bills into law this fiscal year: Florida, Georgia, and Oklahoma.

OPPOSING THE ADA EDUCATION AND REFORM ACT

In FY17, the Epilepsy Foundation opposed the ADA Education and Reform Act, which would shift the burden of ADA compliance from business owners to people with disabilities. Together with other patient advocacy groups in the disability community, we wrote two letters to Congressional leaders in opposition to the bill. In response to our call for grassroots advocacy, our epilepsy advocates sent 863 emails to members of the House of Representatives expressing opposition to the bill.
The Jeanne A. Carpenter Epilepsy Legal Defense Fund receives hundreds of consumer inquiries annually related to legal rights in the areas of employment, education, criminal justice where arrests are related to seizure behaviors, public accommodations and other areas where quality of life is impacted by discriminatory practices. In FY17, the Fund responded to over 250 consumers providing legal information and resources to help fight discriminatory practices.

Highlights include:

- Three significant ADA employment cases that were litigated and resolved in favor of the plaintiffs.
  - An aspiring police officer who was disqualified for employment because of his history of epilepsy and his employer’s discriminatory employment policy.
  - An employee who was terminated as a result of employment discrimination based on her epilepsy.
  - A schoolteacher who was subject to harassment and unjust termination because of his epilepsy.
- Advocating for restoration of access to epilepsy medications for an Ohio inmate and the reversal of disciplinary penalties inappropriately imposed on the inmate as a result of seizures.
- Supporting 19 criminal defense attorneys with LDF resources to defend clients against criminal charges related to seizure behavior.
- Developing a factsheet to educate the public about the medical and disability-related rights of prisoners with epilepsy in correctional facilities.
- Revising the Foundation’s factsheet to reflect newly adopted provisions of Section 501 of the Rehabilitation Act.
- Revising two of the Fund’s signature brochures used to educate the public.

MEDICAID

In FY17, the Epilepsy Foundation supported a variety of state legislative and regulatory initiatives to protect the health of people with epilepsy who rely on Medicaid, and sent more than 60 letters to state legislators and policymakers in support of preserving, creating, or strengthening protections for epilepsy medication in state Medicaid programs.

- In Texas, the Epilepsy Foundation sent letters to Senate leaders and Governor Greg Abbott in support of House Bill 1917, a bill that would maintain open access to epilepsy medications by preserving the single formulary policy in the Texas Medicaid program. Governor Abbott signed this bill into law on June 14, 2017.
- In New York, the Epilepsy Foundation sent letters to 7 Senate and Assembly leaders and Governor Andrew Cuomo in support of the “Prescriber Prevails” policy that protects access to physician-directed care in the state Medicaid program. This policy was preserved in the annual budget.
- In Michigan, Governor Rick Snyder signed a 2018 budget into law that renewed the protection for epilepsy medications in the state Medicaid program. The Epilepsy Foundation affiliate in Michigan has participated in several coalition efforts to emphasize the importance of this protection.
- In Indiana, the Epilepsy Foundation sent letters to state legislators and administrators in support of the reinstating step therapy protections in the state Medicaid program. Eventually these discussions led to the creation of a Gold Card program that allows neurologist to have open access to epilepsy medications and only one step for all other physicians.
- Massachusetts and New Jersey are still in session and efforts continue in these states related to protections in the Medicaid programs.

STATE PRESCRIPTION DRUG MONITORING PROGRAMS

The Epilepsy Foundation supports exempting all Schedule V non-opioid, non-narcotic medications, which are primarily epilepsy medications, from state monitoring programs. This year, the Epilepsy Foundation sent letters to 81 state legislators and policymakers in four states urging the exclusion of Schedule V epilepsy medications from state drug monitoring programs. Grassroots advocates have amplified our message with an additional 207 emails to their state legislators.

On June 29, 2017, North Carolina Governor Roy Cooper signed HB 243, a bill that will require state physicians to participate in North Carolina’s prescription drug monitoring program. The final bill draft exempted Schedule V medications from the highest level of monitoring – ensuring that people with epilepsy who rely on Schedule V medications will not encounter additional barriers to accessing care. On March 10, 2017, the Epilepsy Foundation wrote to the sponsors of HB 243, requesting the exemption that was included in the final law.

In Pennsylvania, advocacy continues and it is likely a bill to exempt Schedule V epilepsy medications from the state prescription drug monitoring program that we have supported will pass this session. The Epilepsy Foundation has continuously communicated with legislators and published an op-ed in local media outlets urging support for the bill.
The Epilepsy Foundation’s mission is funded through the generous support of both the public and our partner organizations. This support comes through many forms. From hosting lemonade stands to biking across the country, our community and 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.

Eisai
Sunovion
UCB

NATIONAL STRATEGIC PARTNERS

Corporate partners who have committed $100,000- $499,999 toward joining the quest to end epilepsy.

Greenwich Biosciences
LivaNova
Lundbeck Inc.
Pfizer Inc.

NATIONAL SPONSOR

Corporate partners who have committed $25,000- $99,999 toward joining the quest to end epilepsy.

Adamas Pharmaceuticals, Inc.
Anavex Life Sciences
Axcella Health Inc.
Mayo Clinic
MonoSol Rx, LLC
Neurelis, Inc.
Ovid Therapeutics
PhRMA
SAGE Therapeutics
Supernus Pharmaceuticals, Inc.
Takeda Pharmaceuticals, Inc.
The Shopko Foundation
Upsher-Smith Laboratories
Zogenix
Zynerba Pharmaceuticals, Inc.
Friends

Bio Technology Industry Organization
Modus Outcomes LLP
NeuroPace, Inc.
Nutricia North America, Inc.
Ultragenyx
The Keepers of the Promise Society is a prestigious association of individuals and families who show extraordinary generosity by leaving legacy gifts to the Foundation in their wills and estate plans. Their 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 passions. Because of their indelible love of life and concern for others, their thoughtfulness will never be extinguished, and their gifts will remind us how each of us can make a difference in lives impacted by epilepsy and seizures.

Elizabeth Adams Fund
Tana F. Alexander, Estate
Darlene Andrus Trust
Howard Andrus Trust
Vaneeda Bennett
Suzanne Bruley
James Crawford Estate
Dominick De Nardo
Alexander & Hazel Dillon
Estate of Dorothy Duncan
Margaret Ehmke, Estate
Joseph C. Ferree, Trust
Alan Fraser Estate
Thomas Garrity, Trust
Irene Gebauer
Jerome Goldstein, Estate
Ruth Grogan
Anna Haneke Estate
Mary Hileman Estate
Leonard & Eustelle Hudson Estate
Virginia Jordan Estate
Richard Kelly Estate
Peter D. & Andrea B. Klein
Dorothy Morgan, TTEE
Charles Petrimoulx Estate
Tommie Reynolds Estate
Gloria Roberts
Grace Rourk Trust
Dennis & Sally Runey
Doris Schmidt
Ethel Solnick
Lonnie Stephens Trust
Pauline Tepper
Anne Travalia
Marjorie Tweed
Isabelle Weber Estate
Earl Wickerham
Larry & Judy Wilcox

The Keepers of the Flame Society can qualify for membership in the Keepers of the Flame Society — our highest level of recognition — 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.

$100,000 & ABOVE
Brooke Gordon
Robert & Terri Smith
Steve & Benita Wulchin

$50,000 - $99,999
Warren Lammert
Epilepsy Foundation Greater Los Angeles
Roger Heldman

$20,000 - $49,999
Allen & Suzanne Duemey
The May Liang and James Lintott Foundation
James McInerney

$10,000 - $19,999
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$5,000 - $9,999
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$10,000 - $19,999
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$5,000 - $9,999
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$1,000 - $4,999
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$500 - $999
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$100 - $299
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$50 - $99
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$25 - $49
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$10 - $24
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$5 - $9
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.

$1 - $4
American Epilepsy Society
Mr. & Mrs. Benjamin Boley
Genesis Maintenance Corporation
Phil & Jill Gattone
Brian Gladden
Rick Harrison
Stewart & Lori Karger
Stuart and Eileen Kaufman Foundation Inc.
EPILEPSY FOUNDATION HONOR ROLL

The Honor Roll includes those generous individuals who made outright gifts of $1K to $9,999. These donations 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.

$5,000 - $9,999
The Apple Lane Foundation
Kristan Bagley Jones
Bob Barton
Randolph & Maud Barton
George Bartusek, Sr.
Mary Berger
Karen Blake
Bloomberg L.P.
Travis Brown
Stacey & John Burns
Butler Family Fund of the Community Foundation
Shirley Cobb
William Flowers
The Paul & Ellen Gaske Foundation
Paul Gaske
Andrew Giangrave
Lisa Gordon
Lindsay Gould
Laura Herlovich
Hoag Memorial Hospital Presbyterian
Louise Hoffman
Sally Hoffman
Patrick & Elizabeth Knox
Susan & Warren Lammert
The Nihla & Bob Lapidus Foundation, Inc.
Leftfield Pictures of NY Holdings LLC
The Thalia & George Liberatos Foundation, Inc
Jaclyn McCoy
Brian McNerney
Jon McMurtrie
Medstar Health Inc
Mark & Kelly Miller
Robert & Debbie Myman
William Parrish
Denise Peppard
Michael Provo
Jim & Anne Render
The William D. Rhodes Foundation
Jeffrey Rieder
Dennis & Sally Runey
Michelle Sangiuliano
Margaret Sheehan Estate
James Swanson
James & Jean Thom
Anne Travalia
Tsymmetry
University of Utah
Christopher Wiegand
Ahern Rentals Inc.
Neil Akeson, Jr.
T. Albright
Tonya Alexander
Laurie Allard
Alpine Pools
American Residential Services LLC
Panayiotis Anastasiou
Anonymous
Argarwal Family Foundation
Steven Asaro
Anderson Allergy Asthma
Nicholas Barbaro
Anthony Barbera
Robert Barfield
Patricia Barnes
Mr. & Mrs. Stephen Barnett
Barr Charitable Foundation
Mark Barrows
Cynthia Battel
Mary Beatty
Rebecca Beck
Elinor Beidler Siklossy Foundation
Nancy Bean
Patrick Beith
Joyce Bender
Mr. & Mrs. James Bennett
Vanessa Bennett
Leonard Berenfield
Kay Berger
Edward Bernard
Sturbridge Eye Care
Janet & Brian Bird
R. Bischoff
Thomas & Cheryl Boccia
James Bohrer
June & William Braunlich
Romkaew Broehm
Arthur Browning
David & Traute Bushley
Cal Family Foundation
Greg & Lynne Caldwell
Lisa & Robert Caldwell
George & Pauline Calevas
Jason Caminiti
Thomas J. & Nancy B. Campbell
Charitable Foundation
Jaime Cannon
Robert Caplan
Karson Carpenter
Marc & Linda Carrasco
John Cassell
Scott Cawthon
Russell Chapman
Rakesh Chilakapati
Kristy & Peter Cirelli
Cilio
Sally Clemente
David Cochran
Kurt Cohen
Ascension Health Ministry
SVC CTR
Steve & Nancy Collins
Community Health Network, Inc.
Diane Conde
Kevin Cooney
Michael & Rhoda Danziger
Christopher Davis
Richard Davis
Tim Degraye
Marisol Dela Ossa
Eric & Danae Delman
DePaul Society
DGR The Source for Legal Support
The Don Allen Foundation, Inc.
Mark Dunaway
Mary Dunbrack
Eric Dusenbury
Lois Dyk
Eastland Development Group, Inc.
Liz Easton
Clara Edwards
Bradley Ehrman
David Ellis
Enterprise Holdings Foundation
William Ewing Foundation
Patrick Fahey
Louis & Helyn Fanaroff Charitable Foundation
Terry Fegan
Franciscan Alliance
Jeanne & Frank Fischer
Dr. Kurt Fox
Jacqueline French
Carolyn Frigmanski
Elisa Frischling
William & Ella Gagnon
Mr. & Mrs. Bob Gallagher
Lydia Garnett
Gibbs V Lehmann Enterprises, Inc.
Susan & William Glasser
Jeffrey & Janet Glidden
Sarah Goldman
Charles Goochey
GovSource, Inc.
Peter Graber-Lipperman
Joachim Grabo
Joyce Gregonis
James Grogan
Hilary Grounds
James Guiry
H. Beck, Inc.
James & Lois Hanko
Rick Harrison
George Hart
Lisa Heinz
Randal Heisey
Helen Heisler
Clifford Hemphill
Heather Hemphill
Lyle Henderson
Keith Hernandez
Mr. & Mrs. Tom Herrmann
John Hlay
Grady Hobbs
Ellen Hobby
Kris Hoffman
Epilepsy Foundation and Epilepsy Research Foundation Summary Consolidated Financial Statements $ In Thousands

### CONSOLIDATED STATEMENT OF FINANCIAL POSITION

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Cash and cash equivalents</td>
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<td>Investments</td>
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<td>Receivables</td>
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<td>Prepaid expenses and Inventory</td>
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<td>Fixed assets, net</td>
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<td>Deferred rent asset</td>
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<td>355</td>
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<tr>
<td>Beneficial interest in perpetual trusts and other assets</td>
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<td>3,165</td>
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<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td><strong>14,872</strong></td>
<td><strong>15,879</strong></td>
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<tr>
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<tbody>
<tr>
<td>Accounts Payable and accrued expenses</td>
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<td>Grants Payable</td>
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<td>Deferred revenue</td>
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<td><strong>TOTAL LIABILITIES &amp; NET ASSETS</strong></td>
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<td><strong>TOTAL LIABILITIES &amp; NET ASSETS</strong></td>
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<td><strong>13,634</strong></td>
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<tbody>
<tr>
<td><strong>TOTAL LIABILITIES &amp; NET ASSETS</strong></td>
<td><strong>14,872</strong></td>
<td><strong>15,879</strong></td>
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### CONSOLIDATED STATEMENT OF ACTIVITIES

#### REVENUE

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<td>JUNE 30, 2016</td>
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<td>Contributions</td>
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<td>Government and other grants</td>
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<td>Affiliate fees</td>
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<td>Special events, net of direct cost</td>
<td>932</td>
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<tr>
<td>Investment Income</td>
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<td>Change in value of beneficial interests in trusts</td>
<td>156</td>
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<tr>
<td>Other</td>
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<tr>
<td><strong>TOTAL REVENUE</strong></td>
<td><strong>15,225</strong></td>
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#### EXPENSES

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<th>FOR THE YEAR ENDED</th>
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<td>JUNE 30, 2017</td>
<td>JUNE 30, 2016</td>
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<tr>
<td>Research</td>
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<td>Public health education</td>
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<td>Professional education</td>
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<tr>
<td>Community services</td>
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<tr>
<td>Patient services</td>
<td>481</td>
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<tr>
<td><strong>TOTAL EXPENSES</strong></td>
<td><strong>15,602</strong></td>
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#### TOTAL EXPENSES

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<tr>
<th>FOR THE YEAR ENDED</th>
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</tr>
</thead>
<tbody>
<tr>
<td>JUNE 30, 2017</td>
<td>JUNE 30, 2016</td>
</tr>
<tr>
<td>Change in net assets</td>
<td>(377)</td>
</tr>
<tr>
<td>Net assets beginning of year</td>
<td>13,634</td>
</tr>
<tr>
<td>Net assets ending of year</td>
<td>13,257</td>
</tr>
</tbody>
</table>
HOW IS OUR MONEY INVESTED?

The Epilepsy Foundation's mission is funded through the generous gifts of individual donors and many partner organizations, including corporations and corporate foundations, member organizations, and both state and federal government agencies, including the Centers for Disease Control and Prevention.

Our generous donors have the right to know how their dollars are invested in the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

The Better Business Bureau (BBB) Wise Giving Alliance dictates that nonprofit organizations should spend at least 65% of their total expenses on programs, research, and services, and no more than 35% on fundraising.

As shown in the graph, we are proud to report that we are well within those limits. In fact, at 13.26%, we are well below the 35% fundraising limit, and $.78 of every dollar is used to fund research into new therapies, education and awareness, and advocacy efforts.