

REAL CHANGE, ENDURING CHANGE,
HAPPENS ONE STEP AT A TIME.

-- RUTH BADER GINSBERG



EPILEPSY
FOUNDATION
END EPILEPSY TOGETHER

ANNUAL REPORT
FY20



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LETTER FROM THE CEO

Dear Friends,

On behalf of the epilepsy community, I extend our deepest thanks to former Board Chair Bob Smith, who served as interim CEO for several months until I joined the Epilepsy Foundation in the final quarter of our 2020 fiscal year. With the COVID 19 pandemic on the rise, Foundation headquarters in Landover, MD were closed and our staff across the nation began working virtually. It's been a crazy year; tumultuous change driven by a global public health crisis, powerful social movements to eliminate systemic racial and gender-based injustices, and widespread - but disparate - economic upheaval among Americans.

But even before these seismic events, it was already apparent that change was afoot.

As one of the largest and longest-standing non-profit organizations dedicated to improving the lives of people living with epilepsy, the Foundation and its nation-wide network of local offices has long held a leadership role in advocacy, education, direct services, and research related to epilepsy. But...we know that the organizational model that has supported our work over the last 52 years is not sufficient to meet today's challenges, nor will it thrive over the next 50 years if we remain tied to our current model.

The fundraising environment during the pandemic is challenging and our general revenue was down significantly from FY 2019. However, as you review Epilepsy Foundation's Annual Report, you'll see that our financials actually reflect significantly higher revenue than FY '19. We were extremely fortunate to receive a large bequest from the estate of a woman who had epilepsy. This generous gift will allow us to build the digital capacity necessary to serve a far greater percentage of the 3.4 million people living in the US than we do today. By harnessing the power of our digital ecosystem, we will improve communication and engagement with our constituency, scale our education and training programs, and operate a leaner, more efficient organization. This digital transformation will also enable us to drive more people with epilepsy to opt into our data platforms so that patient data can drive improved treatment protocols and research outcomes.

I am honored to be a part of Epilepsy Foundation's future, and I am grateful to be on the journey with so many dedicated staff, volunteers, donors, people with epilepsy and those who care for them.



A handwritten signature in black ink that reads "Laura S. Thall".

Laura Thall
President & CEO

“Fight for the things that you care about, but do it in a way that will lead others to join you.”

~ Ruth Bader Ginsburg,
late Supreme Court Justice
and Change Maker

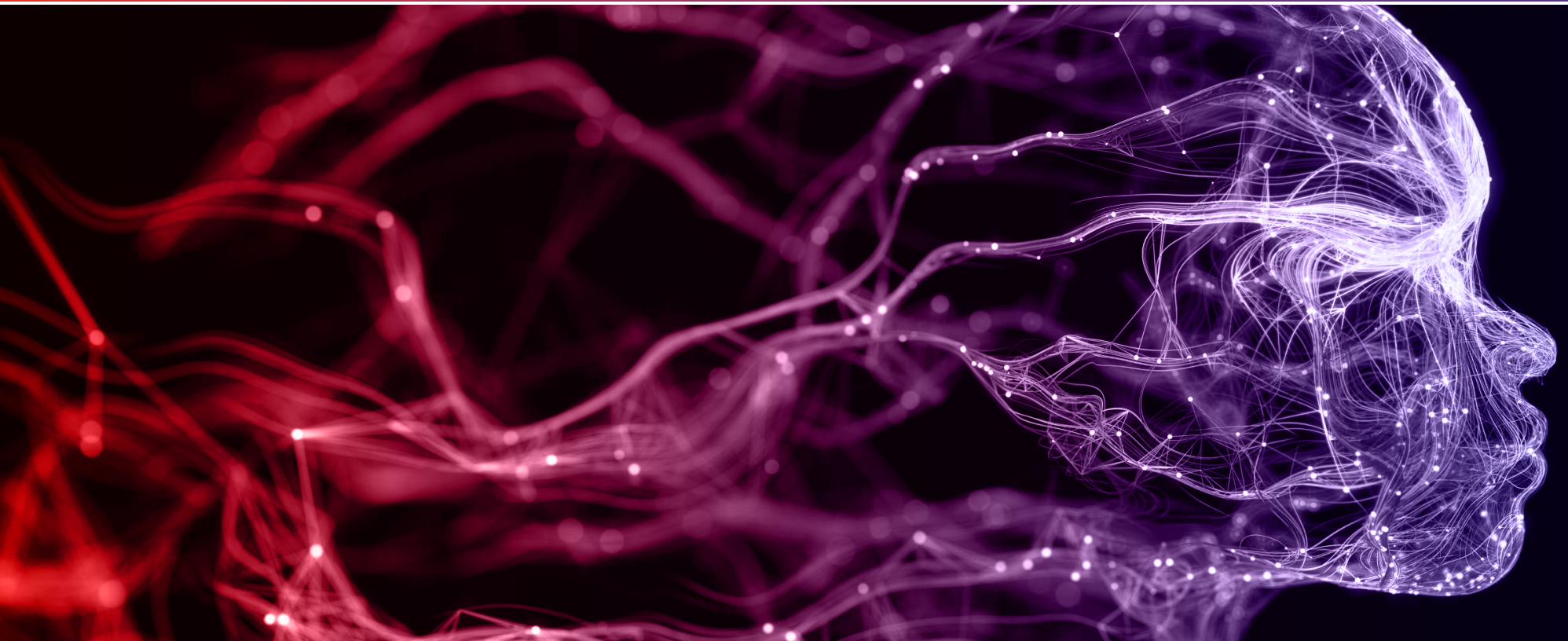
ABOUT THE EPILEPSIES

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

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

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

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



THE EPILEPSIES BY THE NUMBERS IN THE U.S.A.

3,400,000+

people live with
epilepsy

1 in 10

people will have a
seizure over a lifetime

200,000

people are diagnosed
with **epilepsy** each year

1 in 26

people will develop
epilepsy over a lifetime



EVERY NUMBER IS A REAL PERSON AND A REAL STORY —

REPRESENTING WOMEN AND MEN AND GIRLS AND BOYS OF EVERY AGE,
RACE, ETHNICITY, AND SOCIOECONOMIC GROUP.

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



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

OUR MISSION

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

OUR ORGANIZATION

The Epilepsy Foundation is a national nonprofit with over 40 local organizations nationwide. The Foundation has led the fight against seizures since 1968. We are an unwavering ally for individuals and families impacted by epilepsy and seizures.

OUR STRATEGIC PLAN 2025 — THE FIVE PILLARS

1

Lead the conversation about epilepsy.

Inform, inspire and engage everyone to join the movement.

2

Shape the future of epilepsy healthcare and research.

Accelerate innovation and partnerships in healthcare and research and improve access and care for all people with the epilepsies.

3

Harness the power of our united network to improve lives.

Improve the lives of people with the epilepsies by activating the field, volunteers and the broader community with the tools, programs and information they need.

4

Expand revenue sources beyond traditional fundraising.

Enable more people affected by the epilepsies to engage with us and benefit from our mission by generating new resources, activating new technology and innovations.

5

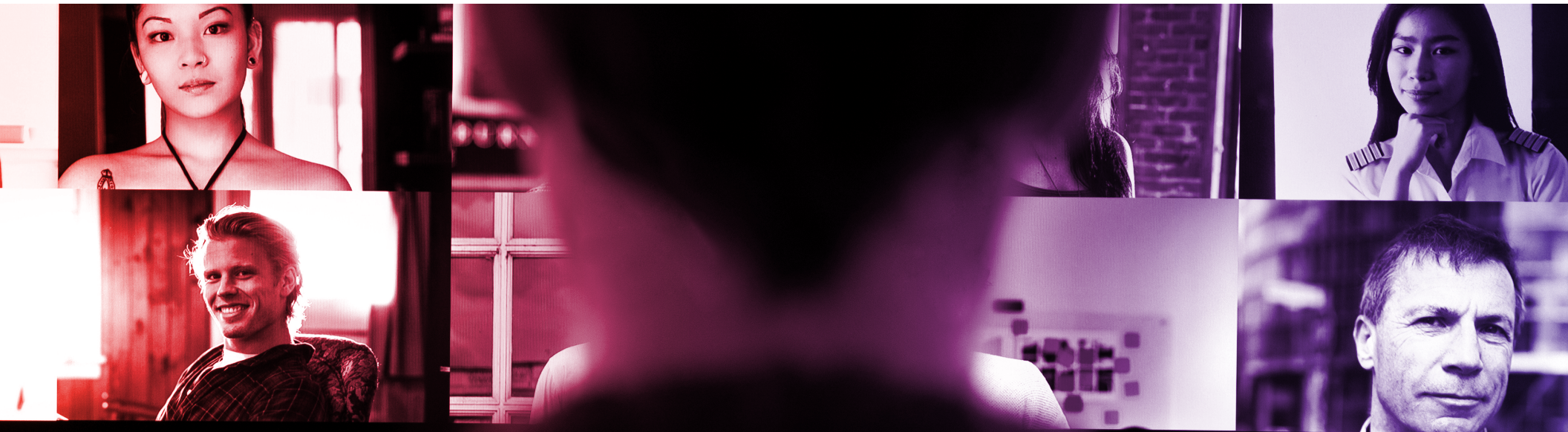
Become a best-in-class organization leveraging technology and digital assets for greater efficiency and mission delivery.

Improve overall outcomes for people with the epilepsies by developing a data infrastructure and cutting-edge technology that utilizes the data for self-monitoring and management, advancing research, identifying patient cohorts for clinical trials.

CONNECTING PERSONALLY



The world has changed. But epilepsy has not.



CONNECTING VIRTUALLY

Some **heroes** fight fires and storms.
Some **heroes** are fighting a virus.
Our **HEROES** are also fighting the epilepsies and seizures.



This #GirlDad and his “Epilepsy SHero” are among the thousands who inspire innovation to achieve mission outcomes, expand our reach, and take action together.

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RESEARCH AND NEW THERAPIES



“We aim to close any treatment gaps in our community by ensuring that products get to market in a timeframe that matters...”

– Sonya Dumanis, PhD, Senior Director of Innovation, Epilepsy Foundation



IMPROVING CARE

RESEARCH OVERVIEW

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

Research By the Numbers for 2020

- 11 research awards supporting entrepreneurship, conferences, and early careers
- 3 workshops on topics addressing regulatory roadblocks in therapeutic development, Sudden Unexpected Death in Epilepsy, and seizure forecasting.
- 3 thought leadership publications on the state of the pipeline, factors associated with caregivers sleep quality related to children with rare epilepsy syndromes and seizure forecasting using seizure diaries.
- 4 Next Gen Awards
- 1 ETP Award
- 6 Conferences (supported through travel grants)



USING TECHNOLOGY



For more information,
visit epilepsy.com/research

Epilepsy Learning Healthcare System

Designed in 2018 and launched in January 2019, the Epilepsy Learning Healthcare System (ELHS), an initiative of the Epilepsy Foundation, includes 12 epilepsy centers in both pediatric and adult practices. Data is captured in an organized way at every clinical encounter and real-time improvements are adopted by providers to improve the standard of care for all people living with epilepsy.

Since the outbreak of COVID-19, these centers have created a Telemedicine Workgroup with the goal of increasing the percentage of telemedicine visits completed by ELHS sites for patients with epilepsy from the pre-COVID-19 rate to 80% by August 1, 2020. In

parallel, the ELHS Community Core, comprised of patient family partners (PFPs), rare and local epilepsy organizations, have created a checklist tool for use by people with epilepsy preparing for a telemedicine visit. Gathering follow-up data via community survey will allow testing of modifications to improve outcomes and ensure that epilepsy community members have the best resources at hand.

Learn more at epilepsy.com/elhs and become a partner in the mission: all people living with epilepsy will live at their highest quality of life, striving for freedom from seizures and side effects, and we won't stop until we get there.



Shark Tank Awards - #EpilepsySolutions

The Epilepsy Foundation's Shark Tank competition seeks to advance innovative ideas in epilepsy and seizure treatment and care. The winners use their prize to accelerate their innovation to the next phase of development, bringing it closer to being accessible to people living with epilepsy. We received over 30 submissions from around the world.

(Due to COVID-19, the originally scheduled in person event was shifted to be a virtual event for August 2020.)

Five of those were chosen as finalists.

- **Aditya Kadambi** from Mocxa for their automated privacy enhancement for seizure videos
- **Atilla Borbath** from Synergia Medical for their NAO-VNS product
- **Boris Goldstein, PhD**, from Brain Scientific for his graphene electrodes in under the skin EEG implants
- **Jong Woo Lee, MD**, along with Product Architectures for their night-time SUDEP prevention device
- **Keely McCarthy**, parent of a child living with epilepsy, for her emergency epilepsy band

Epilepsy Innovation Institute

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

My Seizure Gauge Initiative

Unpredictability, not knowing when or why a seizure starts, is a major challenge for those living with epilepsy . . . we have a unique opportunity to create an individualized seizure gauge that will allow a person with epilepsy to monitor the likelihood of a seizure on a daily basis.”

In October 2018, the Epilepsy Innovation Institute awarded a \$3 million grant to an international team of scientists, researchers and interoperability experts to evaluate biosensors that can track an individual’s physiology, behavior, and environment to improve seizure prediction. Team members from Mayo Clinic, King’s College London and Seer Medical/The University of Melbourne will evaluate biosensors in a range of commercially available devices. The team will recruit, and collect data from, people with epilepsy who have received an implanted device that can measure brain activity — such as electroencephalogram (EEG) devices — to better understand changes in the body that induce or allow for seizure activity. The team receiving the grant was selected following a seven month long, peer-reviewed process. In year 1 of the award, the Solution team evaluated over 6 different biosensors in over 170 individuals and captured hundreds of seizures from wearable devices in the process.

The team is committed to sharing its findings with the community and has created a data sharing platform on the epilepsy ecosystem, which is currently sharing some of the data collected from year one.

The new frontier for epilepsy monitoring and seizure prediction is non-invasive wearable devices. This dataset affords a unique opportunity to develop new algorithms for epilepsy monitoring seizure detection and seizure prediction. What makes this data set unique is that we are sharing long-term recordings of epilepsy patients, which means there are more seizures per patient, and this offers more data to develop reliable patient-specific algorithms.

My 22 month old son, Ozzie, had his first seizure ... while recovering from brain surgery due to complications from hydrocephalus. He hasn’t gone one single day in the past 500 days without having multiple seizures, sometimes hundreds. He’s failed 10 medications and counting ... I fight and advocate every day in honor of my little warrior to raise awareness and find a cure so no one has to suffer like him. He’s my purpose, and my reason to never give up.

Rare Epilepsy Network

Over 1,450 individuals with a rare epilepsy were included in the REN survey. The data collected in the REN survey is available to be shared with other qualified researchers for additional analyses.

The Foundation is committed to sharing the data with the community and this past year created a public dashboard to highlight key community results. Please go to www.epilepsy.com/REN to learn more. Additionally, the Foundation participated in a co-authored publication that examined factors associated with caregivers sleep quality related to children with rare epilepsy syndromes.



Thought Leadership — Facilitating Conversations

The Research Roundtable for Epilepsy (RRE)

The Research Roundtable for Epilepsy (RRE) is an initiative of the Epilepsy Foundation to facilitate the development and implementation of new treatments and diagnostic tools for people with epilepsy, by collectively addressing roadblocks to research and development. Each RRE focuses on a single critical issue and allows an in-depth discussion in a pre-competitive space. Our consortium is composed of senior scientists from pharmaceutical, biotechnology, and diagnostic companies as well as regulatory agencies such as the FDA, the European Medicines Agency and patient organizations. All proceeding outcomes are written and published in a well-regarded academic journal to be shared with the broader community.

The fifth RRE went virtual on May 14-15, 2020 convening researchers, people living with epilepsy, 22 drug and device companies and regulators from the FDA and others for discussions. There were two topics this year.

The first was “Approval for focal epilepsy drugs for infants” and the other was “Innovative data capture, including electronic seizure diaries.”

At present, anti-seizure medications (ASMs) approved for focal epilepsy in adults can have efficacy from those trials extrapolated to the age 2 years, and can receive FDA approval with addition of only safety and pharmacokinetic data. Regarding infantile seizures, a major question is whether they are a separate entity analogous to the way neonatal seizures are a separate entity, or do infants have focal seizures that are similar to older age groups. And if they exist in a similar fashion, can data from older age groups also be extrapolated down to the 1 month to 2-year population to inform treatment choices. Pediatric epileptologists and researchers shared data demonstrating that the clinical picture of the way focal seizures begin and evolve, their characteristics and symptoms, EEG features and treatment response are similar to that of older children. These data support the possibility that no separate efficacy trials (which would be very difficult to accomplish) would be needed for these young children. In these circumstances, evidence of safety would need to be independently established in the infant age group and could not be extrapolated. If efficacy extrapolation is not possible, there are potential clinical trial designs to reduce or eliminate the need for a placebo group (where a person participating in the trial receives only the standard of care treatment, rather than the experimental treatment plus standard of care, and may experience a worsening of their seizures), for example a PK/PD design.

The group discussed special safety issues in children. The risks of evolution from focal seizures to infantile spasms and other seizure types or syndromes cannot be discounted, although to date there is no indication that specific drugs increase this risk. Cognition is a safety issue of particular importance in infants.

The second part of the meeting focused on electronic seizure diaries: their current use in clinical trials, barriers to completion, and possible alternatives or options to broaden their use. Regulators recommend that sponsors engage with the agencies early in development to discuss options for electronic seizure diaries. People living with epilepsy and caregivers shared their experiences, including their preference for a longer window for completion of seizure documentation (up to a week after the event, rather than the typical 1-2 days), and their reasoning for using various tracking tools such as spreadsheets rather than a particular digital diary tool. Industry members expressed willingness to collaborate to explore the potential of a standardized, more user-friendly seizure diary option.

Pushing in Bold New Directions — Human Epilepsy Project

The Epilepsy Foundation, in collaboration with the Epilepsy Study Consortia, supports the Human Epilepsy Project 2: Resistant Focal Seizures (HEP2) to better understand the challenges of living with focal seizures that do not respond to medication and determine biomarkers of epilepsy severity and treatment response. This research study is another step in our efforts to better understand focal epilepsy and uncover data that will help accelerate therapies to help people with epilepsy have seizure-free lives. The HEP2 study has recruited 157 people with treatment-resistant focal epilepsy (with seizures that occur at least 4 times per month) over a two-year period to measure changes in seizure frequency, treatments used, adverse events, presence of comorbidities such as depression and anxiety, healthcare costs, and quality of life. Due to COVID19, the study is now transitioning from clinical sites to continue in a virtual setting, with individuals participating online for their follow up.

New Therapy Commercialization Grants - #EpilepsySolutions

The Epilepsy Therapy Project, an entrepreneurship incubator of the Epilepsy Foundation, is dedicated to advancing innovative ideas in epilepsy, seizure treatment, and care in a timeframe that matters. These are primarily done through either commercialization grants or housekeeping Seals of approval that are reviewed by both a business and scientific advisory board at the Foundation. Through this program we fund new, innovative research from leading scientists and startup companies with a focus on accelerating the progress of breakthrough research and new therapies “from the bench to the bedside.” Grants are up to \$200,000 per year, over a two- year period, and are awarded twice a year. Our funding approach has been restructured from a traditional grant to an investment that would allow us to achieve a return when a product reaches the marketplace.

This fiscal year, epihunter was awarded a \$200,000 grant, which will go towards funding a partnership with Boston’s Children to validate the EEG wearable and the information tracked as a potential solution to inform clinical decision making for neurologists. We also awarded an Innovation Seal of Excellence to Bloom Sciences, a company that wants to hack the ketogenic diet to identify microbes (probiotics) that could have therapeutic potential for the treatment of epilepsy. Although this company is still in early days, their approach could open up a new therapeutic avenue for those living with epilepsy.

“ We aim to close any treatment gaps in our community by ensuring that products get to market in a timeframe that matters. That is why we support startups and fund innovative ideas to accelerate therapies onto the marketplace. We are committed to encouraging and fostering entrepreneurship to discover new treatment options and ultimately, cures, for the 3.4 million people in the U.S. — and 65 million in the world — living with epilepsy. ”

— Sonya Dumanis PhD
Senior Director of Innovation
Epilepsy Foundation

Supporting the Next Generation of Scientists

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

AES/EF Junior Investigator Research Awards

Leah Blank, MD, MPH

Icahn School of Medicine at Mount Sinai

Determinants of Guideline Adherent Therapy in Newly Diagnosed Epilepsy

David Klorig, PhD

Wake Forest University Health Sciences

Evaluating Gene Therapy Strategies to Treat Epilepsy Using a Novel Method

AES/EF Clinical Research & Training Fellowship

Susanna O’Kula, MD

New York University

Healthcare Utilization & Workplace Productivity in Hispanic PWE

Susan S. Spencer Clinical Research Training Fellowship in Epilepsy Award

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

Colin Ellis, MD

The Florey Institute of Neuroscience
University of Pennsylvania

Polygenic Risk Transmission in Familial Epilepsy

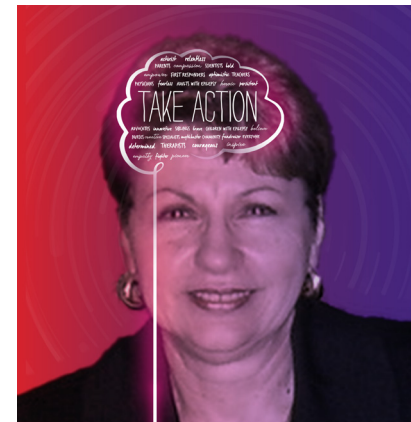
The Kevin’s Fellows program

For AWARD partners, see APPENDIX.

Lifetime Accelerator Award

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

The winner of the 2020 Lifetime Accelerator Award this was **MaryAnn Brodie** who has devoted more than 30 years of her life towards advancing clinical trials in epilepsy.



SUDEP Institute — Moving the needle to #ENDSUDEP

- Each year 1 out of 1,000 adults and children with epilepsy die from SUDEP.
- For people with poorly controlled seizures, the risk of SUDEP is much higher — 1 out of 150 each year.
- Since 2013, the SUDEP Institute has been raising awareness, providing bereavement support and funding research to end SUDEP.

Biomarker Challenge

We have been hosting a series of challenges, and are now in the last stage of the competition known as the Biomarker Challenge. Those interested, must now demonstrate that their selected biomarker(s) have predictive efficacy and value in the broader human population. A researcher did not need to apply to the other parts of the challenge to participate. The challenge is a race to the finish, with solutions accepted on a rolling basis up to October 10, 2020. Submissions will be reviewed as they are received and at the discretion of the SUDEP Institute. The first submission that meets all the challenge criteria will be awarded the \$800,000 prize for successful completion.

SUDEP COALITION SUMMIT

The goal of the SUDEP Coalition Summit is to develop an implementation plan for what the SUDEP community needs to do in the areas of basic science, clinical action, behavior and awareness, and public health/epidemiology in the next 5 years to END SUDEP. For this effort, the Foundation convened over 50 stakeholders from around the world on monthly calls to flush out the recommendations of what is needed to push the needle forward. The group met in June and is now working on drafting an implementation plan to make these recommendations a reality.

The Epilepsy Foundation Partners with Cameron Boyce Foundation

The Epilepsy Foundation and The Cameron Boyce Foundation launched a new initiative called “K(NO)W SUDEP NOW” to raise awareness about epilepsy and the risk of sudden unexpected death in epilepsy (SUDEP), particularly among youth and young adults. The initiative features a public service announcement with Cameron Boyce’s parents and friends, as well as a new website KnowSUDEPNow.org to provide information about SUDEP and encourage donations.

Mr. & Mrs. Boyce and Sally Schaeffer, Senior Director of the SUDEP Institute, have appeared twice on Good Morning America, the daytime show, The Doctors, as well as many other media outlets sharing information and educating about SUDEP.

Sally Schaeffer said, “K(NO)W SUDEP NOW is about accelerating research and education to end SUDEP. We felt this partnership was mutually beneficial given the work we are doing at the Epilepsy Foundation’s SUDEP Institute and the efforts The Cameron Boyce Foundation has embarked on to shine a light on SUDEP. The goal of this initiative is to educate people unaware of epilepsy, and empower those living with epilepsy to discuss SUDEP with their medical professional so they can reduce or mitigate their risk.”

For more information, visit [KnowSUDEPNow.org](https://www.knowsudepnow.org)

Improving public awareness of epilepsy and SUDEP will drive more research dollars to help end SUDEP and END EPILEPSY®. K(NO)W SUDEP NOW provides a national platform to bring awareness to epilepsy and SUDEP and offers tools and resources for individuals and families to engage with their healthcare team about reducing their risk of SUDEP.

Following the passing of their son Cameron Boyce due to SUDEP, Victor and Libby expanded the focus of the foundation Cameron had established earlier this year to include epilepsy and SUDEP.

“We would like to shine more of a light on epilepsy by getting more funding, more research and more people involved. And we hope that Cameron’s reach can do that,” said Victor and Libby Boyce.

ADVOCACY



“... I feel like my voice has meaning now. I want to change the world and show others with epilepsy that they aren’t alone. I want to raise awareness all over the place. I feel like I can do anything ... thanks to the people at the Epilepsy Foundation.”

— 2020 Teens Speak Up! Participant

ON CAPITOL HILL



ADVOCACY OVERVIEW

Through public policy, legal advocacy and grassroots engagement, the Epilepsy Foundation works to improve access to affordable, comprehensive, physician-directed and person-centered health care; end epilepsy-related discrimination and protect the rights of people with disabilities; raise awareness and promote education about the epilepsies; and fuel research and innovation

- 2 Seizure Safe Schools bills were signed into law—in Illinois and New Jersey. To date, five Seizure Safe School bills have been signed into law.
- The Foundation’s Speak Up, Speak Out! grassroots advocacy network sent 16,172 letters to their members of Congress and 25,166 letters to their state-level officials about key policies impacting the epilepsy community.
- The Foundation sent 362 letters on state-level policies and 25 letters on federal-level policies, as well as signed on to 184 letters with coalition partners.
- Achieved a \$1 million increase for the CDC’s Epilepsy program.
- At least 750 individuals living with or affected by epilepsy were advised on their rights through the Jeanne A. Carpenter Legal Defense Fund.

IN OUR COMMUNITIES



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

ADVOCACY IMPACT

During FY 2020, the Epilepsy Foundation's advocacy team, chapters and affiliates, state advocacy leaders, 60,00-strong online Speak Up, Speak Out! Advocacy network, and coalition partners achieved many accomplishments. Much of this year's advocacy focused on ensuring that people with the epilepsies had access to care and other critical supports through the COVID-19 public health emergency.

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

- Required Medicare Part D plans to allow up to a 90-day supply of medications through the COVID-19 public health emergency. This was achieved through multi-faceted advocacy including the Foundation leading a letter which was signed by 212 organizations and sent to Congress.
- Helped secure a 6.2 percent increase to state Medicaid programs through the COVID-19 public health emergency.
- Most states deemed medical cannabis dispensaries essential so that with physician direction, people can continue this treatment through the pandemic.
- Joined 20 national patient and health advocacy organizations in filing an amicus curiae brief with the U.S. Supreme Court in California v. Texas, highlighting the devastating impact people with pre-existing conditions like epilepsy would face should the court invalidate the entire Affordable Care Act.
- Released updated principles and positions on Access to Prescription Medications and urged Congress to pass bipartisan solutions including capping out-of-pocket costs in Medicare Part D, passing step therapy reform and increasing transparency across the drug supply chain.
- Helped get proposed cuts to technical in-home EEG codes withdrawn and cuts to professional EEG codes lessened. This was accomplished by the Foundation's Speak Up, Speak Out network sending 3,850 emails to Congress about the issue, helping secure 68 members of Congress on a letter and submitting comments to the Centers for Medicare and Medicaid Services on behalf of the Foundation and the Epilepsy Leadership Council.

Ending Epilepsy-related Discrimination & Protecting Rights

- Advised at least 750 individuals living with or affected by epilepsy about their rights in areas including employment, education, community living and access to health care through the Jeanne A. Carpenter Legal Defense Fund.
- Worked to ensure that federal disability rights were enforced as treatment rationing plans were developed and care delivered during the COVID-19 pandemic.

Awareness & Education

- Achieved a \$1 million increase for the Centers for Disease Control (CDC)'s Epilepsy program.
- Launched a nationwide initiative to pass Seizure Safe Schools legislation in all states. During FY 2020, the Foundation, our local offices and grassroots advocates led such bills being signed into law in two more states, Illinois and New Jersey. Before the COVID-19 pandemic shifted state legislatures' attention, 18 states had introduced Seizure Safe Schools legislation for the 2020 session.
- Through the Foundation's chapter and affiliate network, had epilepsy awareness proclamations signed or resolutions passed in at least 11 states.
- Hosted a briefing on Capitol Hill, educating and training 25 people including 15 congressional offices about epilepsy and seizure first aid.

Fueling Research & Innovation

Helped secure:

- A \$2.6 billion increase for the National Institutes of Health.
- \$5 million for the National Neurological Conditions Surveillance System.
- Reauthorization of the Patient-Centered Outcomes Research Institute for ten years.
- A \$91 million increase for the Food & Drug Administration.



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





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

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

At the 2020 TSU & PPI, more than 175 participants met with more than 180 members of Congress and congressional staff.

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

Jeanne A. Carpenter Epilepsy Legal Defense Fund

The Jeanne A. Carpenter Epilepsy Legal Defense Fund fights epilepsy-related discrimination across all aspects of life including work, school, health care and community life. During FY 2020, the Legal Defense Fund educated more than 750 individuals about rights and connected them to resources—leading to a more inclusive society. For example, the Fund educated an attorney for a summer camp about his client's rights and responsibilities related to accessibility and with that information, the camp for the first time was able to welcome children with severe epilepsy and other disabilities. The Fund also advised many employees with epilepsy and employers through the reasonable accommodation process in order for people to retain meaningful employment.





Sela
TSU Ambassador

“The most important thing I learned at TSU is that my voice can help make a difference. Thanks to the training I received, I was able to go back home and stay connected with my members of Congress as well as start relationships with my state-level legislators about another Epilepsy Foundation priority — Seizure Safe Schools legislation. I feel proud of sharing my story and of what we accomplished together at Teens Speak Up!”

Sela, TSU participant 2020

Sela’s Story

Sela was diagnosed with epilepsy in May 2017, shortly after turning 13 years old. After being diagnosed, she felt like no one understood what she was going through and people were treating her differently. This all changed when Sela was selected to participate in the 2019 Teens Speak Up! program on behalf of Epilepsy Foundation of Hawaii. Sela came to Washington, D.C. to receive advocacy training and share her story with her lawmakers to advocate for policies impacting the epilepsy community. After attending the program and meeting other teens living with epilepsy from across the country — she was empowered and no longer felt alone in her journey. Sela was inspired after hearing about the Foundation’s Seizure Safe Schools initiative during the program and when she went back home after TSU, she began working with her local office and advocating for a Seizure Safe Schools bill in Hawaii. Sela was selected to participate in the 2020 Teens Speak Up! program as an Ambassador, where she served as a mentor to the new teens and helped to facilitate the teen training sessions. Sela now knows that epilepsy does not hold her back and is excited to continue raising awareness to help fight the stigma.

MISSION OUTCOMES



“Outstanding [organizations] have one thing in common: an absolute sense of mission”.

—Zig Ziglar

LOCAL CARE & CONNECTION

IN THIS FAMILY NO ONE FIGHTS ALONE

BOUNDLESS DIGITAL REACH

MISSION OUTCOMES OVERVIEW

In January 2020, to maximize efficiencies and to enhance communication with the EF Network and our partners, the Epilepsy Foundation streamlined activities under Mission Outcomes and created a new Chief of Mission Outcomes position to lead the efforts.

Mission Outcome activities include:

- Research
- Advocacy
- Public Health & Education
- SUDEP Institute
- Wellness Institute
- Epilepsy Learning Healthcare System

With the support of our partnership with the US Centers for Disease Control & Prevention (CDC), the Epilepsy Foundation focused on Mental and Behavioral Health initiatives with the Managing Epilepsy Well programs, Project ECHO for School Nurses and Advance Practice Providers and the Epilepsy Learning Healthcare System.

The Public Health and Education initiatives span from Multicultural Outreach to the 24/7 Epilepsy & Seizures Helpline to trainings and resources that educate thousands of people across the country about seizures and epilepsy. In March 2020, the Epilepsy Foundation launched the first ever certification program for Seizure Recognition & First Aid.



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

PUBLIC HEALTH & EDUCATION

Seizure Recognition & First Aid Certification

The Epilepsy Foundation's Professional Advisory Board approved the curriculum for the new Seizure Recognition and First Aid Certification Course in late 2019. This one-of-a-kind two-year certification course teaches the public how to recognize seizures and how to respond safely when someone has a seizure – including identifying when seizures are a medical emergency.

- 753 people became Seizure First Aid Certified from March to June 2020.
- 82 people were trained as Seizure First Aid Certification Instructors – expanding the reach across the country.

“I thought it was a great course and am going to encourage all our medical students and residents to get certified.”

~Dr. Gena Ghearing

University of Iowa Comprehensive Epilepsy Center

Managing Students with Seizures: A Training for School Nurses

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

- 3,566 school nurses trained through live webinars and on demand online trainings

WELLNESS INSTITUTE

Improving the quality of life and well-being of people living with epilepsy and those who care for them, the Epilepsy Foundation continues to put a priority on wellness. The Wellness Institute focuses on eight dimensions of wellness that contribute to the overall health and well-being of someone living with epilepsy and their family, friends, and caregivers. The Epilepsy Foundation has developed strategic partnerships with the National Association of County Behavioral Health & Developmental Disability Directors and the National Association for Rural Mental Health organizations, along with others to implement the Managing Epilepsy Well programs across the country.

- 71 EF Network Staff received Mental Health Training

Seizure Training for School Personnel

This free training program helps promote a positive social and educational environment for students living with epilepsy. With several states passing “Seizure Safe School” legislation, the Epilepsy Foundation became a major partner in providing seizure education to school personnel.

- 84,018 school personnel trained through live webinars and on demand online trainings

INFORMATION AND REFERRAL

The Epilepsy & Seizures 24/7 Helpline: Connecting people with epilepsy, their families and caregivers to information resources and services nationwide

The Epilepsy & Seizures 24/7 Helpline (1-800-332-1000) is a 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. The Helpline offers help in Spanish through our 24/7 Spanish helpline and assistance in over 200 other languages via a telephone interpreter service. Helpline Information Specialists are all Certified Resources Specialist through the Alliance of Information and Referral Services and are trained in Suicide Intervention.

- 14,503 calls, emails, contacts people helped in FY20

“I coach at a local high school and have first aid training every year. Seizures are never discussed. I hope to use this info to help educate others.”

~Scott

#EpilepsyEquity – Multicultural Outreach

Racial and ethnic minorities represent more than 40% of the 3.4 million people living with epilepsy in America. The Multicultural Outreach Program strives to address epilepsy-related disparities among racial and ethnic groups, neglected and underserved populations, rural and hard-to-reach communities. Through culturally and linguistically appropriate health education campaigns, national partnerships, and tailored communication and media efforts, the program enhances outreach and epilepsy awareness efforts to multicultural populations while promoting diversity, equity, and inclusion.

Media Efforts

The hashtag #EpilepsyEquity was created to promote health equity and epilepsy awareness. Culturally relevant communication efforts have increased the awareness of epilepsy-related disparities among racial and ethnic populations on a national scale.

- #EpilepsyEquity has garnered more than 12 million impressions
- Essence magazine feature highlighting two African American women living with epilepsy
- Hispanic Communications Network sharing #ShareMySeizure campaign
- Created Seizure First Aid poster in Chinese for Chinese New Year in America and China through the World Journal

Publishing a “COVID-19 and Epilepsy” article in Korean for The Korea Times

Minority Outreach Mini-Grants

The Epilepsy Foundation collaborated with national and local minority health agencies to increase epilepsy outreach in minority communities to pilot an Epilepsy Minority Outreach Mini-Grantee Project.

Through a competitive grant process in partnership with the National Association of State Offices of Minority Health, the Foundation identified community-based organizations to implement epilepsy awareness projects in African American communities.

- Nearly 3,000 people reached through outreach activities,
- 307 minority health providers being trained about seizures and epilepsy
- More than 1 million social media impressions were created with hashtag #EpilepsyEquity



National Partnerships

Epilepsy disparities among racial and ethnic populations exist due to many reasons, such as lack of access to epilepsy specialists, lower efficacy of epilepsy self-management, and lack of education and awareness about epilepsy. By partnering with national organizations with expertise in minority health, health disparities and health equity, the Foundation is driving systemic change to address epilepsy-related disparities and to achieve health equity through collaboration.

- National Association of State Offices of Minority Health
- National Association for Rural Mental Health
- National Association of Black Nurses
- Veteran Affairs Epilepsy Centers of Excellence
- National Association of County Behavioral Health & Developmental Disability Directors
- Chi Eta Phi Nursing Sorority
- American Academy of Pediatrics
- National Medical Association
- American Public Health Association
- Association of Asian and Pacific Community Health Organizations

Thometta Cozart, MS, MPH, CHES, CPH, the Epilepsy Foundation's Multicultural Outreach and Health Equity Director, received the K. Everett M. Rogers Award from the American Public Health Association's Public Health Education and Health Promotion section for the Foundation's #EpilepsyEquity efforts and minority media campaigns.

COMMUNICATIONS



“The Epilepsy Foundation has been a great resource for us the past six years and really helped us to understand that either epilepsy was going to define our daughter or she was going to define epilepsy.”

—Marcella S.

April 23, 2020

8:00 P.M. ET



SOURCE OF INFORMATION

COMMUNICATIONS OVERVIEW

The Epilepsy Foundation's reach is nationwide and even global through the work of our Communications and Digital team. Epilepsy.com is the top global resource for epilepsy. Our social media platform continues to be a vital tool to connect and engage with and among the epilepsy community. Our page about the COVID-19 pandemic provides our community relevant updates and information related to epilepsy. Our partnership with the Centers for Disease Control & Prevention and with CBS TV Community Partnership Division drive our Share My Seizure public awareness campaign to promote seizure recognition and first aid.



VIRTUAL COMMUNITY



For more information,
visit epilepsy.com.

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

Social Media

The Epilepsy Foundation uses social media as a vital tool for connection and engagement with and among the epilepsy community. Foundation content can be found on Twitter, Facebook, Instagram, LinkedIn and YouTube. Our global impression reached 39 million. Popular posts include community members celebrating seizure freedom milestones and photos from local Epilepsy Foundation events around the country.

COVID-19 Educational Content

During the COVID-19 pandemic, the Epilepsy Foundation Communications & Digital Strategies team produced Facebook Lives to educate the epilepsy community. The team produced 8 education Facebook Lives with over 50,000 views. On YouTube, the Epilepsy Foundation shared 32 education videos (including an interview in Spanish) with over 22,000 views total.

From March-June 2020, over 320,000 individuals viewed our COVID-19 content on Epilepsy.com.

Based on a poll regarding our COVID-19 content, over **86% of users** were satisfied with the content.

Share My Seizure

The Epilepsy Foundation, the U.S. Centers for Disease Control and Prevention and CBS television Community Partnership Division collaborated in a public awareness campaign for seizure recognition and proper Seizure First Aid. This was the fourth year of a five-year effort. Public service announcements ran on CBS television stations in Chicago, Philadelphia, and Los Angeles and the CW station in Atlanta and Tampa. Seizure First Aid messages featured a youth basketball team learning how to help a teammate who lives with epilepsy. The announcements were seen by over 29 million 18 and older over air and nearly 11 million on digital channels. For more, visit www.epilepsy.com/sharemyseizure.



The Epilepsy Foundation uses our social media channels to celebrate seizure freedom milestones for our epilepsy warriors. Here is Sam, who recently celebrated his seizure freedom anniversary. As a first-time parent to a 6-month-old, Sam is motivated to find the right neurology team to help him find long-lasting seizure control. Cher Marie, Sam's wife, says "Having #epilepsy will not stop this man ever!"

Epilepsy.com

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

Epilepsy.com numbers in millions

9.2 Million visits in CY2020

Top pages on Epilepsy.com

1. What is Epilepsy?
2. Types of Seizures
3. Seizure Medications List
4. Absence Seizures
5. COVID-19 and Epilepsy
6. Tonic Clonic Seizures
7. Our Training and Education
8. Medical Marijuana and Epilepsy
9. Psychogenic Nonepileptic Seizures
10. What Happens During a Seizure?

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COMMUNITY ENGAGEMENT



This image is a reminder of a 'thousand points of light' popularized by President George H.W. Bush. We seek thousands taking action together.

“Community is much more than belonging to something; it’s about doing something together that makes belonging matter.”

—Brian Solis

CONNECT



COMMUNITY ENGAGEMENT OVERVIEW

Our outreach continues to grow across the nation, and indeed, throughout the world. Kids Crew, Teens Speak Up, the Advocacy Network, SUDEP Institute, the Wellness Institute, Ambassador Programs — all engage thousands of dedicated and talented volunteers that represent the Foundation and promote awareness. As the Foundation grows so does community involvement and better understanding of the unique issues that challenge people with epilepsy. Our ever-growing network of volunteers keeps our message alive and our mission vibrant.

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

PARTICIPATE



For more information,
visit epilepsy.com/local

Our Impact – Our Volunteers

The Epilepsy Foundation works hand in hand with volunteers to achieve our mission. We know that volunteers play a vital role in reaching our goals with and for the epilepsy community. Volunteers from coast to coast are involved at both the local and national levels where they help us advocate, spread awareness, organize and run events, support programming and research, and fundraise to increase our impact.

In FY20, the Epilepsy Foundation's Volunteer Program:

- **Created a Volunteer Spotlight Committee** to help us better appreciate our volunteers at a national level. On a quarterly basis, we recognize outstanding volunteers from across the network.
- **Developed new volunteer roles** as a result of strategic initiatives and further standardization of the volunteer journey at the Epilepsy Foundation.

Highlights include:

- **Epilepsy Awareness Ambassadors** – Role launched in May, participate in awareness-based activities on a monthly basis.

Between May and June 2020, 16 Ambassadors completed 93 awareness activities.

- **Lemonade for Livy Ambassadors** – Role launched in March, support growth of fundraising and awareness initiatives in their communities.

Through June 2020, 8 Ambassadors spread awareness about Lemonade for Livy.

- **Developed new volunteer positions** to build capacity across departments. These will launch in FY21:
 - Support Group Volunteers
 - Advocacy Volunteers
 - Seizure First Aid Instructors

Our volunteers have used their creative ideas and passion to support our mission. They have inspired our organization as we innovate and rethink our operations as we continue to shift into a more virtual space.

Volunteers have a profound influence within local and nationwide communities, providing a vital extension to the resources and expertise of Epilepsy Foundation staff members across the country.

The Epilepsy Foundation is proud to support over 40 governing and advisory boards across the country, bringing local insight and expertise to the Foundation's national Board of Directors through involvement in strategic planning, fund raising, strengthening direct programs and services.

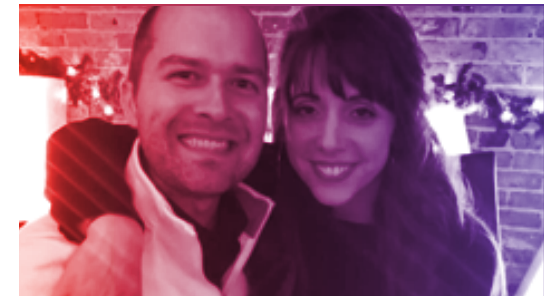
Volunteer Spotlight Recipients



Matthew Summerfield



Ann and Jim Render



Tom Cota



Jerry Silverman

Lemonade for Livy
Ambassadors made a
“stand against epilepsy”
across the country.



“I was diagnosed with epilepsy when I was about three years old and have had medication-resistant ... seizures almost my entire life. Even though I didn’t keep my disorder a secret, I didn’t exactly share it openly or embrace it as a part of my identity either. ... I didn’t realize that accepting epilepsy is a part of me took much more strength and courage than keeping it to myself. I signed up to volunteer with the Epilepsy Foundation this year as a first step toward self-acceptance, and I signed up for the walk and to raise money in part to share my condition more publicly. I was amazed by the support from my family and friends, and I’ve learned that I’m not in this alone. ... This pandemic has shown me that we are all stronger when we help each other out. I became an Epilepsy Awareness Ambassador for that reason: because we are all in this together.”

— Epilepsy Awareness Ambassador Erika

Kids Crew

Kids Crew, the Foundation's signature program for children and teens 14 and under, has grown to over 2,900 members.

This program provides a forum for any child to learn more about epilepsy, teach others, spread awareness, raise funds, and participate in events. They are encouraged to complete specific activities to earn themed pins which can make an impact personally as well as in the community. As an example, Kids Crew members exceeded the goal of educating 1,000 of their classmates for International Epilepsy Day.

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

Members are now participating in national virtual Kids Crew events to engage with kids, see they are not alone, learn, and have fun. Some events included bingo parties, a talent show, and an end of school year luau.

A number of local Epilepsy Foundations are also bringing members together for smaller, more personal virtual gatherings such as story time, making cards for kids in hospitals, and bowling. Kids get to know others like them, and parents can interact and share their stories.

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

Hailey Scheinman, Chair of the Kids Crew Leadership Council, was featured in Marvel's Hero Project airing on Disney+. The episode covered her and her family's journey with epilepsy and the work Hailey has done for her twin sister Livy, who has epilepsy, Lemonade for Livy, and the Kids Crew.



“Thank you for allowing my son to not only learn more about his seizures, but also feel comfortable and confident with himself again. The supportive community found in Kids Crew has helped my son in more ways than I could have ever imagined.”



OUR NETWORK IN FISCAL YEAR 2020

ALABAMA

- Epilepsy Foundation Alabama

ALASKA

- Epilepsy Foundation Alaska

ARIZONA

- Epilepsy Foundation Arizona

CALIFORNIA

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

COLORADO

- Epilepsy Foundation Colorado

CONNECTICUT

- Epilepsy Foundation Connecticut

DELAWARE

- Epilepsy Foundation Delaware

DISTRICT OF COLUMBIA

- Epilepsy Foundation Metro DC

FLORIDA

- Epilepsy Foundation Florida

GEORGIA

- Epilepsy Foundation Georgia

HAWAII

- Epilepsy Foundation Hawaii

IDAHO

- Epilepsy Foundation Idaho

ILLINOIS

- Epilepsy Foundation Greater Chicago
- Epilepsy Foundation Greater Southern Illinois

INDIANA

- Epilepsy Foundation Indiana

IOWA

- Epilepsy Foundation Iowa

KENTUCKY

- Epilepsy Foundation Kentuckiana

MAINE

- Epilepsy Foundation New England

MARYLAND

- Epilepsy Foundation Maryland

MASSACHUSETTS

- Epilepsy Foundation New England

MICHIGAN

- Epilepsy Foundation Michigan

MINNESOTA

- Epilepsy Foundation Minnesota

MISSISSIPPI

- Epilepsy Foundation Mississippi

MISSOURI

- Epilepsy Foundation Missouri & Kansas

NEBRASKA

- Epilepsy Foundation Nebraska

NEVADA

- Epilepsy Foundation Nevada

NEW HAMPSHIRE

- Epilepsy Foundation New England

NEW YORK

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

NORTH DAKOTA

- Epilepsy Foundation Minnesota

OHIO

- Epilepsy Foundation Ohio

OKLAHOMA

- Epilepsy Foundation Oklahoma

OREGON

- Epilepsy Foundation Oregon

PENNSYLVANIA

- Epilepsy Foundation Eastern Pennsylvania

RHODE ISLAND

- Epilepsy Foundation New England

SOUTH DAKOTA

- Epilepsy Foundation South Dakota

TENNESSEE

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

TEXAS

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

UTAH

- Epilepsy Foundation Utah

VERMONT

- Epilepsy Foundation Vermont

VIRGINIA

- Epilepsy Foundation Virginia

WASHINGTON

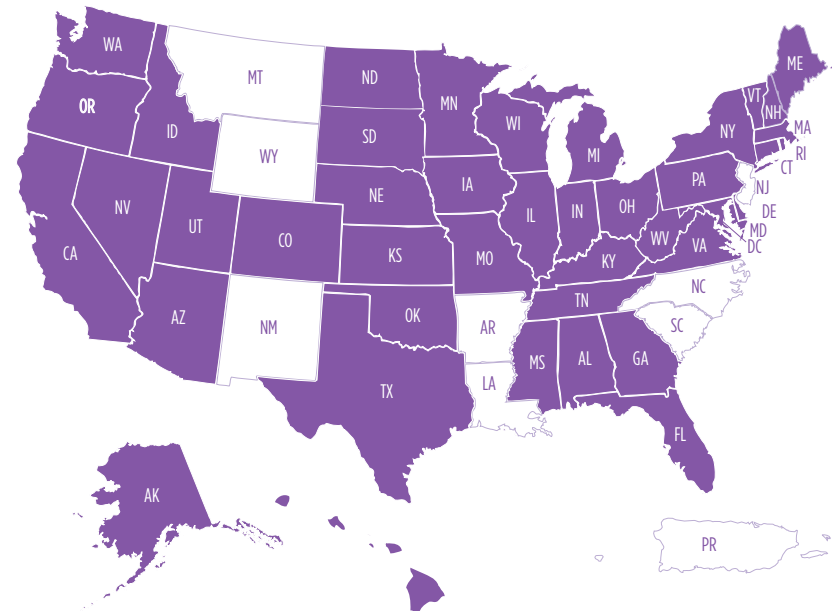
- Epilepsy Foundation Washington

WEST VIRGINIA

- Epilepsy Foundation West Virginia

WISCONSIN

- Epilepsy Foundation Heart of Wisconsin
- Epilepsy Foundation Western Wisconsin



Our Reach – Our Network and our Network Leadership

Leadership Conference

Our 2019 Leadership Conference titled “Think Big” truly lived up to its name.

More than 150 Epilepsy Foundation staff and volunteers throughout our nationwide network attended the conference in Kansas City, MO.

In addition to General Sessions, the conference offered tracks for Volunteer Leadership and Capacity Building. Kicking off with a keynote presentation by Jeff Barnes, bestselling author of “The Wisdom of Walt” attendees were invited to consider how one person’s vision journey created the greatest entertainment mecca in the world. Bob Smith, EFA Board Chair, Phil Gattone, CEO, and May Liang, Strategic Planning Chair, launched the framework for the 2025 Strategic Plan. A Research Panel embraced the Think Big theme with discussions about big ideas in research and community engagement. Other sessions included State of the Foundation; Direction of Epilepsy through the Lens of Public Health; the Power, Promise and Potential of our Brand and; SUDEP.

With the hotel being just steps away from Kansas City’s Power & Light District attendees had plenty of opportunities for evening entertainment and networking at Kansas City’s Power and Light District, just steps from the hotel.







PUBLIC SUPPORT



“Don’t give to get. Give to inspire others to give.”

-Anonymous



RAISING FUNDS



PUBLIC SUPPORT OVERVIEW

The Epilepsy Foundation depends on public and private support and the generosity of individual and corporate donors. Our donors' generosity enables the Epilepsy Foundation to be the consistent and strong voice for change on behalf of those impacted by epilepsy. We celebrate the diversity of individuals, families, charitable giving foundations, businesses and corporations raising their hands to support our work and mission. Each and every donation is connected to a unique story of generosity and compassion. In recognition of the powerful stories our donors carry, we wanted to highlight a few.

- Walk to END EPILEPSY
 - 51 Walks
 - 19,000 participants
 - 38,000 miles walked OR the same as walking the width of Massachusetts EVERY DAY FOR A YEAR
 - 1,600 Teams
 - Total Raised: \$2.46M
- Social stats
 - 330 posts
 - 2.1M+ impressions
 - 73,000 engagements
 - 35,000 donors
 - 100+ corporate partners



RAISING AWARENESS

EPILEPSY FOUNDATION TRAINING IS PUT TO USE IN REAL WORLD

Marla Wright spends her professional life thinking about epilepsy. As director of payer marketing at Greenwich Biosciences Inc., a leader in researching cannabinoid medicines for rare epilepsies, she's on the front lines of addressing the disease that affects roughly one out of every 26 people.

But Wright never thought she would be on the front lines of helping someone in the midst of a full-blown tonic-clonic seizure. Especially so soon after receiving epilepsy first aid training. The month before, the Carlsbad, Calif.-based biopharmaceutical company had arranged for the Epilepsy Foundation to train its staff on assisting someone having a seizure.

"I went to the training and was thinking, 'Gosh, I've never seen anyone have a seizure, I wouldn't know what to do. Yet I realized it was simple and easy to learn, it's simpler than CPR,'" Wright says. "But honestly, I thought to myself, this is nice to know, but I'll never have to use it."

Fast forward a month and Wright is in Las Vegas attending a conference of the American Society of Health System Pharmacists, a bustling meeting of more than 80,000 attendees who take over an entire convention center.

On this day, Wright had met up with a business acquaintance and the two had set off to find a quiet spot to talk.

"My colleague had just opened up her computer and was showing me something, when all of a sudden, directly to my right, I hear this thump," Wright remembers. "I looked over and there was a relatively young gentleman, in his 20s, and he was having a full tonic-clonic seizure. Right there beside me, he was on the ground."

Wright immediately jumped into action.

I was like, 'Oh my god, I know what to do. I was just trained by the Epilepsy Foundation'" she remembers telling those around her. "I go, we need to get him on his side, we need to get something under his head. He had his badge around his neck, and I asked if anyone knew him, and there were some of his pharmacy student colleagues with

him. I told his colleagues to please get down on the floor with me. I want him to see them when he became aware, I want him to see some familiar faces," she said.

Wright recognizes the serendipity of the event. She had taken first aid training just the month before. She was in the right place in a mammoth convention center. And she works for a biopharmaceutical company that develops epilepsy drugs.

"It was pretty exciting, and I was just so glad I knew what to do," she says. She also realized that she was perhaps unique among the crowd. The other 50 people had their eyes glued on her, because nobody knew what to do, except calling 911. The training is so simple, everyone should take it, she advises. Wright now passes out first aid cards from the Foundation to her friends.

Wright also credits the training for helping keep everyone calm in what is a scary, unfamiliar situation.

"The way you create calmness is through competence," she says. "You know what to do. I just felt empowered. I'm proud of my company and proud of the Epilepsy Foundation. It was a really good feeling. I was flying high that day. I helped somebody."



MARLA WRIGHT
Director of Payer Marketing
Greenwich Biosciences Inc.

THE DELMAN FAMILY'S JOURNEY TO SEIZURE FREEDOM

Our family first became involved with the Epilepsy Foundation by participating in the annual Walk in Washington, D.C, in 2012. We wanted to contribute in any small way we could to support their research. We gathered our family and friends and totally enjoyed the day!

Our son, Zachary, started having petit mal seizures when he was a freshman in high school. He tried every new drug that was available on the market, but with no success. As with so many families, the constant roller coaster of trying to find the “miracle drug” was exhausting. He had to withdraw from college due to the severity of his seizures. Then, in 2004, Zachary had brain surgery as a hope in stopping the seizures, yet that was unsuccessful.

In early 2011, Zach's neurologist suggested he try an old “tried and true” drug, as it was about the only one he had not tried. Remarkably, Zach has been seizure-free since December of 2011 and went on to finish college and live in his own apartment!

We consider ourselves extremely blessed to have the Epilepsy Foundation as our partner and “go to” resource for Zach's continuing journey. It was only natural that our Family Foundation started giving an annual donation to this wonderful organization that is a superb advocate for our family and so many others.

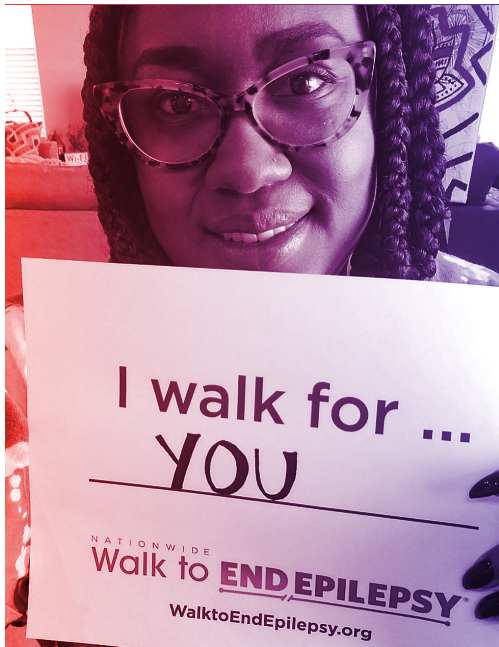


Support the Epilepsy Foundation

Here are just a few ways our community supports us.

- Volunteering
- Donating, both in-kind and cash
- Sponsoring special events
- Encouraging others to get involved
- Charitable grant funding
- Designating the Epilepsy Foundation in a workplace giving deduction
- Shopping at retailers giving back
- Donating home goods and vehicles
- Getting Seizure First Aid Trained

Please refer to page ** for more financial information regarding charitable support of the Epilepsy Foundation from July 1, 2019 – June 30, 2020.



NATIONWIDE Walk to **ENDEPILEPSY**

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

51 Walks to
END EPILEPSY
nationwide events

2.46
MILLION WAS RAISED
FOR THE
FOUNDATION

38
THOUSAND TOTAL MILES
WALKED

16
HUNDRED TEAMS
PARTICIPATED



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

CONSOLIDATED STATEMENT OF FINANCIAL POSITION

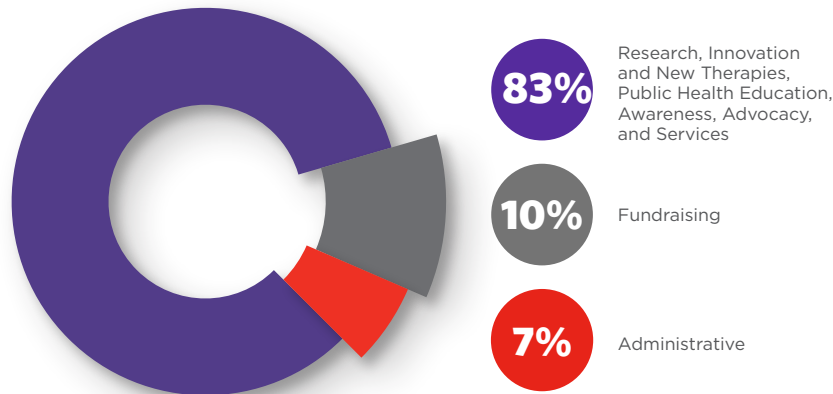
As of June 30

ASSETS	2020	2019
Cash and cash equivalents	10,757	2,702
Investments	7,548	8,326
Receivables	1,644	2,522
Prepaid expenses and Inventory	402	257
Fixed assets, net	752	795
Deferred rent asset	39	136
Beneficial interest in perpetual trusts and other assets	5,161	5,454
	<u>26,303</u>	<u>20,192</u>

LIABILITIES AND NET ASSETS

Accounts payable and accrued expenses	1,624	1,936
Grants payable	2,405	1,093
Deferred revenue and refundable advances	774	79
Paycheck Protection Program Loan payable	2,001	
	6,444	3,108
Net Assets	<u>19,859</u>	<u>17,084</u>
TOTAL LIABILITIES & NET ASSETS	<u>26,303</u>	<u>20,192</u>

Epilepsy Foundation Spending Percentages - FY20 July 2019 - June 2020



CONSOLIDATED STATEMENT OF OF ACTIVITIES

For the year ended June 30

REVENUE	2020	2019
Contributions	22,171	11,305
Government and other grants	4,057	4,719
Affiliate fees	351	461
Special events, net of direct cost	1,974	3,229
Investment Income	(13)	630
Change in value of beneficial interests in trusts	(279)	260
Other	174	419
	<u>28,435</u>	<u>21,023</u>

EXPENSES

Program Services		
Research, Innovations and New Therapies	3,763	3,475
Education and Awareness	5,200	4,286
Advocacy and Services for Individuals, Families and communities	12,237	11,744
Supporting Services		
Administrative	1,780	1,583
Fundraising	2,680	2,404
TOTAL EXPENSES	<u>25,660</u>	<u>23,522</u>

Change in net assets	2,775	(2,499)
Net assets beginning of year	<u>17,084</u>	<u>19,583</u>
Net assets ending of year	19,859	17,084

APPENDIX

Past Awardees of the Lifetime Accelerator Award

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

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

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

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

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

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

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

2019: [Martin J. Brodie MD](#), Head of the International Bureau of Epilepsy

Supporting the Next Generation of Scientists

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

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

2020 Awardees:

[Leah Blank, MD, MPH](#), Icahn School of Medicine at Mount Sinai, **Determinants of Guideline Adherent Therapy in Newly Diagnosed Epilepsy**

[David Klorig, PhD](#), Wake Forest University Health Sciences, **Evaluating Gene Therapy Strategies to Treat Epilepsy Using a Novel Method**

2. Clinical Research & Training Fellowships – We have partnered with AES to provide mentored support for clinical fellows who want to gain experience in a larger research endeavor.

2020 Awardee: [Susanna O’Kula, MD](#), New York University, **Healthcare Utilization & Workplace Productivity in Hispanic PWE**

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.

2020 Awardee: [Colin Ellis, MD](#), TUniversity of Pennsylvania, **Polygenic Risk Transmission in Familial Epilepsy**

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

LET'S MEET THE GRANTEES.

AES/EF Junior Investigator Research Awards

Leah Blank, MD, MPH

Icahn School of Medicine at Mount Sinai

Research Topic: Determinants of Guideline Adherent Therapy in Newly Diagnosed Epilepsy

Although national and international societies have made evidence-based recommendations supporting the use of newer anti-seizure drugs with demonstrated efficacy and decreased side effects, these same drugs are often not prescribed. Instead, for reasons that remain unexplained, older anti-seizure drugs with serious side effects are still often used as first line agents in adults with new onset epilepsy.

Dr. Leah Blank will use detailed medical record data from the Mount Sinai health system to understand the patient, practice, and provider characteristics that might influence first drug choice for adults with new onset epilepsy. For example, does the insurance type or care setting impact who gets on which medication first? Dr. Blank will then use national data to determine the effect that these choices have on patient outcomes overall, including drug discontinuation (how long they remain on that first-choice drug) and health care utilization (how likely are they to be seen in the emergency room).

This study will lay the groundwork for the development of an intervention targeted at ensuring that those with new onset adult epilepsy are getting to the right treatment faster.

AES/EF Junior Investigator Award

David Klorig, PhD

Wake Forest University Health Sciences

Research Topic: Evaluating Gene Therapy Strategies to Treat Epilepsy Using a Novel Method

When developing a gene therapy strategy, one wants to know quickly if the treatment worked. Dr. Klorig has developed a new experimental tool that allows him to measure seizure susceptibility in animal models based on brain activity measurements, to quickly assess whether previous impaired brain activity is repaired. He now wants to test whether this tool can be used as an outcome for optimizing gene therapy strategies in epilepsy.

For this effort, he is going to test two different gene therapy strategies involving the potassium channel Kv1.1. The two strategies focus on targeting the gene therapy to different types of brain cells (neurons versus astrocytes). Using his new tool, he can then see how brain activity changes with these two different approaches, and which one will be better for repairing brain activity. This work will reveal important information about how these different brain cells impact seizure susceptibility and could also develop a new way to inform strategy for epilepsy gene therapies in the clinic.

Susan S. Spencer Clinical Research and Training Fellowship

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

Colin Ellis, MD

University of Pennsylvania

Research Topic: Polygenic Risk Transmission in Familial Epilepsy

There has been substantial progress over the past decade in identifying monogenetic causes of epilepsy. Monogenetic means that the cause of the epilepsy is linked to one gene. However, there is a lot of evidence that many epilepsy cases could be polygenetic, meaning that there are multiple genes involved. For example, there are studies in large families where epilepsy is more common than the general population, but there does not seem to be one key gene that is explaining why that is the case.

Recently, polygenic risk scores were developed for epilepsy that looked at multiple common variants associated with epilepsy across the board. Dr. Ellis will be assessing the polygenic risk scores for two large families where epilepsy seems to be fairly common, to test whether those that have epilepsy have higher risk scores, and whether tweaks to the mathematical modelling for calculating the score improve the algorithm for determining who in the family is likely to develop epilepsy.

AES/EF Clinical Research Training Apprenticeship

Susanna O’Kula, MD

New York University

Research Topic: Healthcare Utilization & Workplace Productivity in Hispanic PWE

Depression affects up to 55% of people living with epilepsy. It is associated with diminished quality of life, worsened seizure control, and an increased risk of premature mortality due to suicide. Unfortunately, depression is often under-diagnosed and left untreated in people living with epilepsy. In under-served communities, there are increasing challenges due to disparities in access to care, language barriers, discrimination and low socioeconomic status.

Dr. O’Kula wants to better understand how depression impacts Hispanics living with epilepsy and to create culturally tailored interventions to address depressive symptoms in this community. A telephone-delivered, group mindfulness-based program (UPLIFT, Using Practice and Learning to Increase Favorable Thoughts) has shown promise in treating depression in people living with epilepsy. This study will evaluate how this program improves workplace productivity and use of healthcare services in Hispanics living with epilepsy enrolled in the program. Dr. O’Kula will also run focus groups to identify barriers and in a follow-on study will test whether addressing those barriers improved outcomes from this initial study.

The overarching goal is to improve quality of life and health of those living with epilepsy, ensuring that appropriate outreach care strategies are used.

Kevin’s Fellow

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

WE BELIEVE ...

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

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

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

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

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

We are the **Epilepsy Foundation.**

