



THINK **BIG**

RESEARCH QUARTERLY

ISSUE 11: SEPTEMBER 2019

MY SEIZURE GAUGE

EPILEPSY LEARNING HEALTHCARE SYSTEM

SUDEP INSTITUTE

INNOVATOR SPOTLIGHT

FOUNDATION AWARDEES

IN THE NEWS



ENDEPILEPSY

WELCOME



Every year, the Epilepsy Foundation hosts a leadership conference that brings together local Epilepsy Foundations to share best practices from the network. This year's theme is **"THINK BIG."** I love this theme as it perfectly captures our strategic planning approach. We think big, so that we can act big, to make meaningful change today that will bring hope for tomorrow.

TO CELEBRATE THE THINK BIG THEME, we will be devoting this fall issue to the ways that we are thinking big - from driving therapeutic innovations, to changing outcomes, and saving lives. On page 4, you can learn about the exciting progress of the My Seizure Gauge team, an international consortium working together to create a seizure forecasting device that could assess the chance of seizures like a weather forecast. On page 6, you can learn about our leadership of the Epilepsy Learning Healthcare System, a new model to transform the healthcare system. On page 7, you can learn more about the important work of the SUDEP Institute, an Epilepsy Foundation program that provides education to families and healthcare providers, grief support, and funds research towards prevention strategies. A common theme in all of our programs is partnership. We recognize that to think big and act big, we cannot do it alone. We are incredibly grateful for all our partners who work with us to ensure that these big ideas can become reality.

In 1997, Apple launched their Think Different campaign, which brought new life into a company that would go on to help reshape how we interact with technology. The full text of the ad is below:

“

Here's to the crazy ones. The misfits. The rebels. The troublemakers. The round pegs in the square holes. The ones who see things differently. They're not fond of rules and they have no respect for the status quo. You can quote them, disagree with them, glorify or vilify them. About the only thing you can't do is ignore them. Because they change things. They push the human race forward. And while some may see them as the crazy ones, we see genius. Because the people who are crazy enough to think they can change the world are the ones who do.

”

To be honest - I am feeling a little crazy right now. I checked with the rest of the Foundation staff and the feeling is mutual! We have a lot of talent and passion, and we are tired of the status quo. I am incredibly humbled to be part of this amazing community of big thinkers and doers. Let's take a moment to celebrate the many ways in which we are thinking differently and thinking big.

Kind regards,

BRANDY FUREMAN, PH.D.

Vice President, Epilepsy Foundation

HISTORY CORNER



EEG 1969
(credit: bidmchealth)



EEG 2019
(credit: UNEEG)

Electricity in the Brain: **RECORDING PROGRESS**

Brain waves, a symphony of the natural rhythm of the brain, arise from the electric properties of brain cells, neurons, mediated by a complex neurochemical environment. Brain waves were first discovered in animals in the late 1800's and first recorded in humans almost 100 years ago. The discovery of the electrical properties of brain cells and the evolution of our ability to record, measure and analyze brain waves over the past century has led to a better understanding of both normal brain function and neurologic disease in humans.

The discovery of the electroencephalogram (EEG) by German psychiatrist Hans Berger in 1924, provided medicine with a powerful scientific and diagnostic tool to measure electrical activity in the brain. Scientists observed that some of these raw recordable electric brain signals were tied to basic physiologic states such as wakefulness and sleep. During seizures, neuroscientists observed a spike waveform pattern that was linked to excessive electrical activity.

The use of EEG intraoperatively to guide surgical treatment in epilepsy quickly followed. In 1939, the neurosurgeon Wilder Penfield placed EEG electrodes on the covering of the brain with the goal of lateralizing the origin of seizures in a patient with bitemporal epilepsy. Penfield harnessed the electrical properties of the brain to build critical brain maps in the operating room using electrocorticography (EEG recorded directly from the brain's surface) to guide the removal of pathologic brain tissue, while preserving critical regions of brain tissue.

The ability to detect and localize seizure activity to guide treatment for epilepsy continues to expand as new EEG technologies translate the brain's electricity in portable, noninvasive, high resolution, rapidly analyzable data sets which can be recorded for months at a time. Neuroscientists are pushing the limits of EEG even further and are working to use extended recordings of a person's brain waves to forecast when a seizure may occur. Please see page 4 of the Research Quarterly to learn more about our My Seizure Gauge Challenge.

Learn more at [EPILEPSY.COM/MYSEIZUREGAUGE](https://www.epilepsy.com/myseizuregauge)

The innovative thinking of scientists and entrepreneurs are elevating the EEG technology from the 1920's, extending diagnostic purpose and changing outcomes and quality of life. At the Foundation, we believe in promoting a culture of entrepreneurship and innovation, to accelerate products that matter to our community onto the marketplace in a timeframe that matters. Recently, seed funds through the Epilepsy Foundation Shark Tank have helped the development of innovative EEG technologies to enter the marketplace. For example, we supported Zeto (SharkTank 2016), the first dry electrode EEG system cleared for clinical use by the FDA in 2018. We also provided seed-funds to UNEEG 24/7 (Shark Tank 2017), the first long-term EEG implant monitoring system entering the European market in 2019.

Our next SharkTank Competition will be in
March 2020 at the Pipeline Conference.
Learn more at [EPILEPSY.COM/SHARKTANK](https://www.epilepsy.com/sharktank)
or [EPILEPSY.COM/PIPELINE2020](https://www.epilepsy.com/pipeline2020)

Driving Therapeutic Innovations: My Seizure Gauge Challenge

In a 2016 Epilepsy Foundation 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.

THIS LED US TO ASK THE FOLLOWING QUESTION:

We are getting better
and better at forecasting the
weather, what if we could
do the same with seizures?

In October 2017, the Foundation convened a workshop to discuss and assess the state of the science behind seizure forecasting. During the collaborative workshop, clinicians, engineers, data scientists, and pharma/device companies reviewed feedback from people living with epilepsy and their families and decided to take on seizure forecasting as an innovation project of the Epilepsy Innovation Institute. The discussions of the workshop were published in *eNeuro* in December 2017.

The following year, in October 2018, the Epilepsy Innovation Institute awarded a \$3 million multi-year 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 forecasting. The international team leads for this effort are Dr. Benjamin Brinkmann (Mayo Clinic), Dr. Mark Richardson (Kings College London), and Dr. Dean Freestone (Seer Medical/Melbourne University). The team was selected following a seven-month long, peer-reviewed process. The team's plan is to recruit, and collect data from people with epilepsy who have received an implanted device that can measure brain activity — such as electroencephalogram (EEG) devices — and pair this with wearable devices to better understand changes in the body that induce or allow for seizure activity. Their charge is to definitively assess the types of measurements that are needed for a reliable seizure forecasting prototype device.

In the initial phase of the award, the Solution team leads are evaluating biosensors that can track an individual's physiology, behavior and environment from a range of commercially available devices. In the past year, the team has already recruited over 85 individuals for this effort and captured a couple hundred seizures from wearable devices in the process.

Following data quality assurance testing, the team will then select up to three peripheral sensors that move forward for seizure forecast testing in year two. Individuals will be pairing the peripheral sensors selected with their already implanted EEG recordings. The ambulatory EEG system used will depend on the recruitment site: Mayo Clinic (Medtronic RC+S intracranial device), King's College London (UNEEG 24/7 ambulatory subscalp EEG), and the University of Melbourne (Seer Medical ambulatory video EEG, SeerGP app, and subscalp EEG). In July of this year, the first patient at King's College London was already implanted with the long-term subscalp monitoring UNEEG device, where she will live with the implant for one year in order to investigate the feasibility of minimally invasive seizure forecasting.

In the third year of the initiative, data will also be shared with the research community through crowd-sourcing platforms to facilitate algorithm development. The platform for data-sharing has already been launched and is known as www.epilepsyecosystem.org

The My Seizure Gauge initiative lays the groundwork to know when a seizure is likely or unlikely – empowering people to take control of their actions, stop a seizure before it starts and explain why certain environments or states may trigger a seizure. It could also aid in developing personalized dosing of medication and device stimulation to reduce medication side effects.

“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.”

- **SONYA DUMANIS, PH.D.**,
Senior Director of Innovation,
Epilepsy Foundation

TO LEARN MORE, GO TO [EPILEPSY.COM/ELHS](https://www.epilepsy.com/elhs)

Epilepsy Learning Healthcare System: Changing Outcomes - Transforming Healthcare

“ Our current healthcare and community services system is fragmented; we intend to change that with a system where we learn from every person with epilepsy and, in turn, improve outcomes for everyone living with epilepsy. ”

- **BRANDY FUREMAN, PH.D.**, VP of Research and New Therapies, Epilepsy Foundation

In 2018, the Foundation was awarded a PCORNet Learning Health System Network Pilot Collaborative grant to establish an Epilepsy Learning Healthcare System. Our purpose is to create a quality improvement and research network dedicated to improving outcomes for children and adults with epilepsy. Our vision is for all people with epilepsy to live their highest quality of life, striving for freedom from seizures and side effects, and we won't stop until we get there.

The ELHS network is designed to gather data about people with epilepsy from clinics around the country and analyze it centrally to identify practices that lead to better outcomes. Six pioneer hospitals, accredited by the National Association of Epilepsy Centers (NAEC), have committed to the ELHS: Children's Healthcare of Atlanta, Partners Healthcare (including the Massachusetts General Hospital and Brigham and Women's Hospital), Beth Israel Deaconess Medical Center, Barrow Neurological Institute, and Children's Hospital of Philadelphia.

The hospitals cannot do it alone. The Foundation is spearheading the Community Engagement Core (CEC), a group of volunteers comprised of patients, families, and advocates from across the country working with the ELHS healthcare provider teams to improve the design, implementation, and sharing of the results from the collaborative research and quality improvement efforts. Together, we are stronger.

For community-based providers who are in the areas where a local hospital is participating, we have also activated a Community Services Core (CSC). The CSC brings local Epilepsy Foundation offices and rare epilepsy organizations, such as Ring14USA, Dup15q Alliance, etc., together to ensure that the hospitals are aware of the wide-ranging services offered in their local area.

It's time to transform healthcare. Join us.



If you're interested in joining a community engagement core or a local community services core, please email us at: ELHS@EFA.ORG

Saving Lives: SUDEP Institute

Sadly, sudden unexpected death in epilepsy (SUDEP) has been making a lot of headlines. And while the public is just learning more about it, the Epilepsy Foundation's SUDEP Institute has been aggressively seeking awareness of this loss from epilepsy since its establishment in 2013.

Mortality in epilepsy such as SUDEP is difficult to speak about, especially without a resolve on how to prevent it. But, 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.

Our four top priorities are:

1 AWARENESS AND EDUCATION

Each person living with epilepsy is different, and we want to make sure everyone is living their life to the fullest. We empower those living with epilepsy by providing information and resources to discuss SUDEP with their medical team to understand their seizure management. We also encourage medical professionals to openly discuss SUDEP to help their patients reduce their risk. Knowledge is Power.

Go to EPILEPSY.COM/SUDEP to learn more.

“ We have moved the needle in SUDEP awareness over the last 10 years but more needs to be done to make sure its discussed and eradicated. ”

– **SALLY SCHAEFFER,**
Senior Director of SUDEP Institute

2 SUPPORT

Very often, many are never told about SUDEP and this sudden and unexpected passing can be a shock leaving loved ones with more questions than answers. They feel alone and isolated with this loss. To help those who have lost from epilepsy, we offer several bereavement modalities.

Request free assistance from our grief support specialist by calling our **24/7 HELPLINE: 1-800-332-1000**

Our support specialist can talk to individuals via phone, email or text – however you feel comfortable. We also have a secure, online support group with other bereaved individuals. This group offers a chance for others to meet and talk about their losses from SUDEP.

3 DEVELOP SUDEP PREVENTION STRATEGIES

One theory for why SUDEP happens relates to compromised cardiac or respiratory function occurring before, during, or after the seizure. However, it is difficult to predict what a specific person's risk level might be for SUDEP. We are currently funding two next generation scientists through the American Epilepsy Society / Epilepsy Foundation (AES/EF) partnership to encourage the best and brightest to be focusing on understanding SUDEP causes.

The SUDEP Institute is also sponsoring the SUDEP Biomarker Challenge which challenges researchers to find predictive biomarkers to identify people at risk for SUDEP or life-threatening seizures that compromise those cardiac or respiratory functions. If we can identify who and why a person is at high risk, we can try different interventions to prevent SUDEP from happening.

Go to EPILEPSY.COM/RESEARCH (click upcoming grants)

4 WORKING WITH OTHERS

We cannot do this important work in a vacuum. To accomplish our goals, the SUDEP Institute works with other leading epilepsy organizations to promote information sharing and facilitate coordination and collaboration. We believe that by working together, we can more quickly raise awareness, drive research and promote prevention.

Innovator Spotlight: **DR. FRANCESCA SOFIA**

Dr. Francesca Sofia is the Chief Scientific Officer of the Italian Epilepsy Foundation.

Dr. Sofia has a daughter with treatment resistant epilepsy. We sat down with her to learn more about what motivates her and the challenges that she wants to tackle in the community.



Q: What is your personal connection to epilepsy?

A: When my youngest daughter Beatrice was 20 months old, she had her first seizure. She started spinning around in the doorway. I looked at her, and although her body was there, I could see that her mind was not. After several hospital stays, and after multiple tests and exams, she was diagnosed with focal epilepsy.

Beatrice is now 10 years old and over the years her condition has changed becoming more and more complex. She is resistant to all possible medications and has developed multiple seizure types including convulsive tonic-clonic seizures. Her cognitive development has been impacted and her speech has not developed normally. She has also developed a skin disorder that might be related to the drugs she has to take, although we cannot say this for certain.

Learn about potential side effects of antiseizure medications at [EPILEPSY.COM/learn/treating-seizures-and-epilepsy/seizure-and-epilepsy-medicines/side-effects](https://www.epilepsy.com/learn/treating-seizures-and-epilepsy/seizure-and-epilepsy-medicines/side-effects)

Q: What do you want to change?

A: When I think about people with epilepsy, there are so many things that need to change: just thinking that in 2019 we still have to deal with the stigma of epilepsy is unacceptable. If I had to choose just one thing, that would be our ability to manage the disease in everyday life. We need innovative, reliable and effective tools and support systems to bring the families out of a constant state of fear. Because this is what we experience every day.

Learn about some of the resources that the Foundation provides to those starting out on the epilepsy journey at [EPILEPSY.COM/TOOLBOX](https://www.epilepsy.com/toolbox)

I have a lively and joyful daughter who wants to run, climb trees, go to the swimming pool — participate in normal activities for young girls like her. But some of those things are either impossible or feasible only with one or two experienced people always by her side. I know most epilepsy families live like that, literally devoting even much of their sleeping time to caring for their kids. We must find better ways to ensure a normal life for persons with epilepsy.

Q: How do you use your talents to tackle the issues your daughter faces?

A: My story has been linked to epilepsy since before I was even aware of it. As a PhD student in molecular biology, I was involved in a study which led to the identification of the connection between the *Emx1* gene and epilepsy. After my dissertation, I got a master's degree in International Healthcare Economics, Policy and Management, which led me to work as a research program manager with a major Italian charity, the Telethon Foundation focusing on rare genetic diseases. Those were very exciting years for the foundation because important breakthroughs were being achieved in the field of gene therapy for rare diseases.

With my daughter's diagnosis, my immediate reaction was to push for a cure. I had the background and the professional tools to make that happen. This is how I became an epilepsy advocate. Soon after that, I was appointed by the Italian Epilepsy Federation to help them develop a program aimed at gaining knowledge

on the genetic basis of the disease through genotyping of children with epilepsy.

As we were working to get this project up and running, my deeper knowledge of the field and of the rapidly evolving health system scenario, together with my experience as a caregiver, led me to envision the next step for these studies. The ultimate goal is the integration of data - from genetic to clinical to real world and patient reported outcomes- and it must start now. Better knowledge of what is going on in our children's brain will help to achieve better therapy and better disease management as well.

Q: Is there anything you would like to add?

A: I believe that what really drives progress today is not only the quality of the science but, most of all, the power of a whole community who believes that changes can be made. At the basis of the most rapidly advancing research fields, there is a shared vision among all stakeholders. We need, now more than ever, to reinforce this idea in our community through education and engagement efforts.

“
Knowledge is
power and right
now we are
powerless.
”

Q: How did your son's experience inspire you to start epihunter?

A: We would regularly talk about his epilepsy during our father-son bedtime conversations. A common theme was that people at school were always angry at him. They didn't understand why he wouldn't just pay attention, do the test, answer the question that was asked, participate in class... he wanted there to be a way to let people know that he wasn't ignoring them on purpose. And on March 15, 2015, he asked:

“Dad, you work in digital, can you create a light that turns on when my brain switches off?”

That simple question is the inspiration for our company. I realized that the biggest change to his life wouldn't be a magic pill but digital technology. By turning on a light, his difficult-to-notice seizures become visible. His teacher would know when to interact and when to pause. It could create understanding, and when needed, additional time for taking a school test. After exploring the technology needed and learning that more than 9 million families worldwide struggle with the same needs, I quit my job as the global digital lead for Bose and founded epihunter.

Q: What is epihunter about?

A: I regularly compare what we do with glasses. Eyeglasses were invented in 1290 in Pisa, Italy. And this technology never cured our eyes, but more than 50% of the world's population wears them. Why? Because they do what they need to do, remove the impact of bad eyesight on daily life.

I strongly believe that the digital technologies around us can have the same impact as glasses to the lives of people with neurological conditions and specifically for those with epilepsy. For the first time ever, we have minimally invasive wearables that can look inside the brain, throughout the day. At epihunter we externalize brain state. The algorithms in our smartphone app analyze the data from a slim EEG headband in real-time to detect silent, difficult-to-notice absence-like seizures. When such seizures occur, we have the smartphone perform an action that changes the moment. For children in a classroom,

we turn on the smartphone light. With the smartphone being upright on the child's desk, the teacher notices the light turning on and can react accordingly. We remove the misunderstandings and frustration by providing information and clarity. At home, the smartphone can make a sound to alert the parent, or the smartphone can start automatically recording the seizure from start to end for the doctor to see.

Q: What advice do you have for other parents going through their own seizure journey with their children?

A: Don't lose hope. And yes, your normal will be redefined but force yourself to still enjoy the small moments – especially those split moments, where you forget about epilepsy. They are so important to keep moving. Find information and find each other. We are more than 65 million families worldwide.

Q: Anything else that you want to add?

A: The Epilepsy Foundation has been incredibly helpful. The Foundation's website epilepsy.com is a great source of crucial information. It helped my wife and me to understand the terminology doctors were using.

The Foundation was also incredibly helpful to us as a startup. They helped with navigating the epilepsy community through both their professional and family network. When we were in Boston, Epilepsy Foundation of New England was instrumental in helping us run an absence focus group. And now, with the New Therapy Commercialization Grant that we received, we are able to partner with Boston's Children to validate the information we track as a potential solution to inform clinical decision making for neurologists. Epihunter is still a small startup but we have a CE certified product currently available in Belgium, the Netherlands and the UK. We won't stop tackling the challenges our community faces. I do this for my son and for families like ours.

FURTHER READING:

EPILEPSY.COM/research

EPILEPSY.COM/seizuretypes

EPILEPSY.COM/treatment

EPIHUNTER.COM

EPILEPSY.COM/schoolpersonneltraining

RING20researchsupport.co.uk/



Think Big with Dr. French – New Therapies in the Pipeline

Dr. Jacqueline French is the Chief Medical and Innovation Officer at the Epilepsy Foundation

For 20 years, I have been involved in evaluating new therapies for epilepsy that are in the pipeline. Even though there are many new medications available, some studies suggest that we have not really made any big advances towards better epilepsy treatments, only small incremental ones. Nonetheless, I can truly say that there is reason to be very excited in 2019.


“All of the listed advances are a real reason to be hopeful for the future. We need to continue to **“think big”** to forge new paths and improve the lives of people with epilepsy.”

HERE ARE A FEW TRENDS THAT WE SEE FOR THE NEAR FUTURE:

- **Treatments for “focal” (partial) epilepsy that has not responded to other medications.**
There are medications that are being evaluated for approval by the FDA that could be of benefit, even when other anti-seizure medicines have failed. These could reach the clinic within the next year!
- **Treatments for rare epilepsies**
Drug makers have really been focusing on treatments for rare epilepsies, some of which have no current available treatments. Several examples include the recent approval of Epidiolex as the first drug proven to work in a rare epilepsy called “Dravet Syndrome”, and the approval of Everolimus as the first drug to specifically treat seizures associated with Tuberous Sclerosis. Another new drug for Dravet is close behind. There are also drugs being developed for other rare syndromes such as CDKL5, Lafora Disease, and KCNQ2 encephalopathy (a severe epilepsy of infancy), to name a few.
- **From anti-seizure to anti-epilepsy**
Up until now, all of the drugs available to treat epilepsy are actually anti-seizure drugs. They do not act to stop the cause of seizures, they just prevent the seizures from occurring. In other words, they treat seizures as a symptom. (It’s the same as giving an anti-itch treatment for a rash, but not treating the cause of the rash) As we gain a better understanding of what causes seizures (in many people we still don’t know!!), we will be able to treat the root cause. This could lead to so-called disease modifying treatments, that eventually lead to either a cure, or a reduction not only in seizures, but also some of the problems that go along with epilepsy such as mood and memory problems. Some drugs are already in development that could do exactly that.

Epilepsy Therapy Grant Awardees for this Cycle

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. In this last cycle, 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. Please see page 10 for an interview with the founder of epihunter. 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.



The Foundation is current accepting letters of intent for commercialization grants (letters are due **SEPTEMBER 28, 2019**. Go to EPILEPSY.COM/research and click on upcoming grants to learn more).

Foundation Grant Awardees in the News

New Therapy Commercialization Grant awardee Matthew Gentry PhD is developing a new therapy for Lafora disease, a rare fatal form of epilepsy. The new treatment has shown promise by eliminating Lafora bodies, found in the cells of mice living with the disease. Lafora bodies are abnormal clusters of glycogen (the way the body stores sugar) in the cells. In July, Dr. Gentry published his findings in *Cell Metabolism*.¹

Targeted Research grant awardee Angela Birnbaum, PhD is interested in how food can impact the absorption of cannabidiol (CBD) in the body. Her Foundation supported study examined how the levels of CBD after different diets could impact how CBD is absorbed. The study found that levels of CBD are increased four-fold when taken with high fatty food compared to when someone is fasting.² In August, Dr. Birnbaum published her findings in *Epilepsia*.

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1. Read the press release: EUREKALERT.ORG/pub_releases/2019-07/uok-pso072419.php
 2. Read the press release: EUREKALERT.ORG/pub_releases/2019-08/uom-rbh081319.php

Clinical Trial Portal List

Clinical trials are the way new treatments are tested for safety and effectiveness before being approved and made available to people with epilepsy.

Go to [EPILEPSY.COM/clinical_trials](https://www.epilepsy.com/clinical_trials) to learn more.

Rare Epilepsy Syndrome Trials

CANNABIDIOL AS AN ADD-ON THERAPY IN TUBEROUS SCLEROSIS COMPLEX

This study is looking at how effective and safe cannabidiol (CBD) is in people 1 year to 65 years old living with Tuberous Sclerosis Complex (TSC). CBD is given in addition to their current anti-seizure medications.

PREVENTING EPILEPSY USING VIGABATRIN IN INFANTS WITH TUBEROUS SCLEROSIS COMPLEX

This Phase IIb trial will test whether earlier treatment versus standard treatment with vigabatrin in infants with tuberous sclerosis complex (TSC) will have a positive impact on developmental outcomes at 24 months of age. It also tests whether early treatment prevents or lowers the risk of developing infantile spasms and refractory seizures. It is a randomized, double-blind, placebo-controlled clinical trial design. Infants under the age of 6 months diagnosed with TSC but without history of seizures or infantile spasms may be eligible.

FOCUSED ULTRASOUND FOR TREATMENT OF EPILEPSY

The University of Virginia Comprehensive Epilepsy Program is conducting a research study on the use of focused ultrasound to treat deep lesions in the brain causing intractable epilepsy in adults 18 to 80 years old. The study will evaluate the effectiveness and safety of an investigational device that uses ultrasound or sound waves from outside the head to treat seizures that are not well controlled by medication and are due to a small growth of abnormal cells in the middle of the brain, most commonly hypothalamic hamartomas.

PERAMPANEL STUDY FOR INFANTS WITH EPILEPSY

This clinical research study is being done to learn more about the safety of Perampanel (E2007), the study drug, and how well it's tolerated in infants, from 1 month to less than 24 months old (<2 years), who have epilepsy.

Focal (Partial-Onset) Seizures Trials

ESLICARBAZEPINE ACETATE (ESL) AS FIRST OR LATER ADD-ON THERAPY FOR THE TREATMENT OF PARTIAL- ONSET SEIZURES

This study is looking at how effective and safe eslicarbazepine acetate (also known as ESL) is in people 18 years of age or older with partial-onset (focal) seizures, when it is added to their current anti-seizure medication(s).

PFIZER A0081096: LOOKING FOR CHANGES IN EYESIGHT FROM USING PREGABALIN

This study will look at people between 18-65 years old, taking their own anti-seizure medications in addition to either the study drug (Pregabalin) or a placebo. The aim is to look for changes in eyesight.

EPILEPSY FOUNDATION'S HUMAN EPILEPSY PROJECT (HEP2): RESISTANT FOCAL SEIZURES STUDY

This study, the Human Epilepsy Project 2: Resistant Focal Seizures (HEP2) is designed to better understand the challenges of living with focal seizures that do not respond to medication and determine biomarkers of epilepsy severity and treatment response

[Focal or Generalized Seizures Trials](#)

STEREOTACTIC LASER ABLATION FOR TEMPORAL LOBE EPILEPSY (SLATE)

This study is looking at the safety and efficacy of MRI-guided laser ablation therapy with Visualase™ (laser ablation may also be called laser interstitial thermal therapy or LITT) for seizures coming from the temporal lobe in people who are taking seizure medicines.

EFFECTIVENESS OF INHALED STACCATO ALPRAZOLAM IN TREATING AN EPISODE OF FOCAL OR GENERALIZED SEIZURES

A new clinical trial is looking at how effective and safe orally-inhaled alprazolam (also known as STAP-001) is in people 18 years of age or older with focal or generalized epilepsy when given at the time of a seizure episode. This study is commonly referred to as StATEs (Staccato Alprazolam Terminates Epilepsy Seizures).

Upcoming Research Grants

SUDEP BIOMARKER CHALLENGE

> Submissions [open now](#)

Prize for \$800,000

EPILEPSY FOUNDATION SHARK TANK AWARDS

> Letters of Intent due [September 16, 2019](#)

Award up to \$200,000

EPILEPSY FOUNDATION NEW THERAPY COMMERCIALIZATION GRANTS

> Letters of Intent due [September 28, 2019](#)

Award up to \$200,000

EPILEPSY FOUNDATION CLINICAL RESEARCH TRAINING APPRENTICESHIP AWARDS

> Applications due [September 30, 2019](#)

Award up to \$35,000 for three months of research spread out throughout the year

SUSAN S. SPENCER CLINICAL RESEARCH FELLOWSHIP

> Applications due [October 1, 2019](#)

Award up to \$150,000 over 2 year

Do you have questions or a research funding opportunity to share? Email GRANTS@EFA.ORG

Want to donate funds to research? Go to: DONATE.EPILEPSY.COM/donate-research

Pipeline Conference
March 12-13, 2020

Shark Tank
March 12, 2020

Community Day
March 14, 2020

Santa Clara Marriott
Santa Clara, California

Dr. Sylvia Olvera

EPILEPSY FOUNDATION | **END EPILEPSY**

Upcoming Conferences

PARK CITY EPILEPSY MEETING

October 6-8, 2019, Park City, UT

> parkcityepilepsymeeting.com

CHILD NEUROLOGY SOCIETY 48TH ANNUAL MEETING

October 23-26, Charlotte, NC

> childneurologysociety.org/meetings/future-cns-annual-meetings

BRIDGE THE GAP FAMILY MEET UP

November 9-10, 2019, Johns Hopkins School of Medicine and Kennedy Krieger Institute, Baltimore MD

> bridgesyngap.org/syngapinternationalconference/attachment/baltimore-meetup/

AMERICAN EPILEPSY SOCIETY ANNUAL MEETING 2019

December 6-10, 2019, Baltimore, MD

> meeting.aesnet.org/about/future-meetings

PIPELINE CONFERENCE 2020

March 12 -14 2020, Santa Clara, CA

> epilepsy.com/pipeline2020

Have a conference that you want to share? Email LSCHREIBER@EFA.ORG