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Through our research program, we strive to create a rich ecosystem that continually drives innovation forward to solve the challenges and remove the roadblocks that stand in the way of ending epilepsy.

GOALS



Innovation

Pushing new areas and ideas for epilepsy

- ▶ Epilepsy Innovation Institute
- ▶ Epilepsy Therapy Project
- ▶ Targeted Research Programs



Engagement

Building collaborative networks between people with epilepsy, their families, healthcare providers, researchers and investors

- ▶ Learning Healthcare System
- ▶ Human Epilepsy Project
- ▶ Rare Epilepsy Network
- ▶ Research Roundtable



Next Generation Scientists

Supporting our developing workforce

- ▶ Clinical Research Fellowships
- ▶ Junior Investigator Research Awards
- ▶ Clinical Apprenticeships



Digital Tools

Developing tools to support research infrastructure

- ▶ Clinical Trials Portal
- ▶ Pipeline Tracker
- ▶ My Seizure Diary

“Knowledge isn’t power, until it is applied”

– Dale Carnegie

Knowledge alone is not enough. We need to accelerate the ideas generated in the lab into tangible actions our community can use.

Research does not exist in a vacuum. In this issue, we share stories from the community about what it is like to live with epilepsy and how research is providing hope to the millions who live with uncontrolled seizures or worry about breakthrough seizures. The Epilepsy Foundation actively nurtures an ecosystem for innovation in the epilepsy community. In support of this work, please welcome Priscilla Kobi, our newest staff member, who will be involved in our clinical research coordinating efforts!

In this issue, we highlight the new therapies that we are supporting this year through the Epilepsy Therapy Project (page 2), the personalized medicine approaches that the Susan Spencer Clinical Research Fellow will be tackling (page 6), and announce our request for proposals for a new brain mapping initiative from our Epilepsy Innovation Institute (page 3).

We also want to promote the work of our partner organizations because we cannot do this alone.

On page 3, we highlight other grant opportunities from these sister organizations. On page 10, we list the epilepsy conferences happening in 2019. In May, at the Anti-Epileptic Drug and Device Trials Conference, we will be hosting our annual Epilepsy Foundation Shark Tank (page 9). We are also excited to share information about free genetic testing (page 7) for kids up to the age of 5 sponsored by Invitae, Stroke Therapeutics, and Xenon through their Behind the Seizures Program.

Our goal is to be pragmatic and focus on #EpilepsySolutions in a time frame that matters. We are shaking up the system with new approaches to address the roadblocks standing in the way of ending epilepsy. Already, in the first quarter of 2019, we have hit the ground running.

Sincerely,

Brandy Fureman, PhD

VP of Research & New Therapies

www.epilepsy.com/research

**EPILEPSY IS...
MORE COMMON
THAN YOU THINK**



65 MILLION
people around the world
who have epilepsy



1 IN 26
people in the United States
will develop epilepsy at
some point in their lifetime

Have Feedback or Questions about the Research Quarterly?

Please send your feedback to Sonya Dumanis,
sdumanis@efa.org.



Supporting the commercialization of 2 novel approaches to treating epilepsy #EpilepsySolutions

This past January, the Epilepsy Foundation awarded two [New Therapy Commercialization Grants](#) totaling \$300,000 to leading scientists with the goal of accelerating the development of therapies for those living with poorly controlled seizures.

One grant was awarded to Matthew Gentry PhD, professor at the University of Kentucky and the other to Greg Worrell MD, PhD, professor of neurology and chair of clinical neurophysiology at Mayo Clinic. Each of the awardees applied in partnership with a commercial entity which will match the grant funding. Both applications underwent a rigorous scientific advisory and a business review process and were selected among nine applicants. The grants were based on potential for impact and value to patients, likelihood of successful development — including regulatory approval — and the development timeframe.

“Depending on the type of epilepsy, seizures can often change lives and result in the loss of friends, jobs, mobility, and even the ability to function. Seizures can also increase the risk of death. That’s why our New Therapy Commercialization Grants Program funds research that has the potential to discover new treatment options, and ultimately cures. Our focus is to encourage innovation and foster entrepreneurship in order to get new therapies to market faster for people living with epilepsy.”

- Sonya Dumanis, Ph.D., Senior Director of Innovation, Epilepsy Foundation

The grants are a part of the Foundation’s Epilepsy Therapy Project, a research program that seeks to advance innovative ideas in epilepsy, seizure treatment, and supportive care in a timeframe that matters.



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



Dr. Worrell was awarded \$150,000 to advance his work with Cadence Neuroscience which has developed a protocol that tests a variety of electrical stimulation parameters while an individual with intractable epilepsy is undergoing phase II evaluation for surgery. Preliminary evidence suggests that this procedure can be used to tailor brain stimulation therapy to each individual and enhance seizure control

compared to currently used protocols. Funds from this award will be used to develop a user-friendly workstation to allow other clinicians to personalize and optimize brain stimulation therapies for epilepsy.

Since 2006, the Foundation’s Epilepsy Therapy Project has invested more than \$8.3 million in 90 different initiatives and supported more than 40 percent of the products being developed for epilepsy in the clinical pipeline over the past decade. In 2007, the Epilepsy Foundation awarded a grant to UCLA School of Medicine to support a clinical trial for trigeminal nerve stimulation in those with poorly controlled epilepsy. The trial led to the development of the Monarch eTNS (Trigeminal Nerve Stimulation) System, which received approval in Europe in 2015 to treat depression and epilepsy. In 2013, Dr. Orrin Devinsky at New York University received a Foundation grant to support the early proof of concept open-label trial to test the safety of Epidiolex® in two severe epilepsies known as Lennox-Gastaut and Dravet syndromes. These trials helped pave the way for the development and commercialization of Epidiolex, which was approved by the U.S. Food & Drug Administration in 2018 to treat seizures associated with Lennox-Gastaut and Dravet syndromes in patients two years of age or older

SAVE THE DATE

Next cycle for New Therapy Commercialization Grants opens in June 2019!

How could these grants impact you?
Do you have an idea that could be a gamechanger for epilepsy?
Share your thoughts on social media.

**Tag us @EpilepsyFdn
#EpilepsySolutions**



Creating a Google Map for the Brain to Visualize Our Unique Brain Activity #EpilepsySolutions

Imagine having a Google Map for your brain that highlights your unique brain traffic pattern. With this map, you could better identify the routes your seizure could take, where the potential traffic jams might be, and how activity can get re-routed in the brain during those situations.



The Epilepsy Innovation Institute (Ei²) is pleased to announce a Request for Proposals for the My Brain Map initiative to fund pilot studies (up to \$200,000) that would propose novel exploratory ways to model seizure propagation in a personalized brain network model.



We are looking for proposals that seek to test novel, unconventional hypotheses or pursue major methodological or technical challenges in network modeling for epilepsy. We are interested in funding innovative multi-scale approaches to brain mapping.

Therefore, we encourage proposal submissions that can begin to correlate standard measures of macro-network activity (i.e. EEG and/or fMRI) with microphysiological mechanisms (such as oxygen, microdialysis of extracellular fluids, local field potentials, etc).

Our ultimate end goal is to create a user-friendly data visualization tool for seizure propagation personalized to the individual's brain network.

Learn More @

www.epilepsy.com/mybrainmap

How would you want to visualize your unique brain activity? Share your thoughts on social media.

Tag us @EpilepsyFdn
#EpilepsySolutions

2019 Epilepsy Grant Opportunities



SUDEP Biomarker Challenge

Submission open now
Prize for \$800,000

Child Neurology Society & Foundation Awards

Applications due April 1
Awards up to \$100,000 over 2 years

TS Alliance Postdoctoral and Research Grants

Letters of Intent due April 8
Award up to \$150,000 over 2 years

Lennox-Gastaut-Syndrome Foundation Research Award

Applications due June 1
Award up to \$50,000 over two-years

Epilepsy Foundation My Brain Map Research Grants

Letters of Intent due June 21
Award up to \$200,000

Epilepsy Foundation New Therapy Commercialization Grants

Submission opens in June
Letters of Intent due July 22
Award up to \$350,000

Do you have a research funding opportunity to share?

Email grants@efa.org



Meet Priscilla Kobi, MS, Clinical Research Coordinator

Please welcome our newest staff member!

Prior to joining the Epilepsy Foundation, Priscilla worked as a research assistant at the Howard Hughes Medical Institute working on engaging undergraduate students through authentic scientific research experiences while generating data on bacterial phage diversity through phage isolation, sequencing, annotation and bioinformatics. She is currently pursuing her second master's in clinical research administration at the George Washington University with an aim of contributing to drug/new therapies development. Priscilla is a cancer survivor and lives with epilepsy. She is thrilled to be at the Foundation supporting research to improve treatment options and quality of life.



Pipeline Update! Q&A with a former Epilepsy Therapy Project Grantee Dr. Steve Schachter

This past fall, Biscayne NeuroTherapeutics merged with Supernus Pharmaceuticals. Biscayne had been developing a therapy for epilepsy based on a novel synthetic form of the herbal supplement huperzine A, which has its roots in traditional Chinese medicine. Supernus has renamed this compound as SPN-817 and will be further developing and clinically testing it.

In 2006, the Epilepsy Foundation supported the first clinical trial for testing the safety and tolerability of Huperzine A as an add-on therapy for persons with uncontrolled seizures. The grant was awarded to Dr. Steve Schachter, co-founder of Insero Health, which soon after became Biscayne NeuroTherapeutics.

The Foundation sat down with Steve to talk about his efforts and the journey of getting this therapy closer to being available for patients whose seizures are not adequately controlled.

What is huperzine A?



Huperzine A is a compound found in the Chinese clubmoss *Huperzia serrata* and to a lesser extent in other related clubmosses around the world. It is available as a dietary supplement in the United States for memory enhancement. But the amounts of huperzine A in the supplement vary widely from pill to pill, even in the same bottle, and are far less than the dose we think will be needed for seizure control.

Why did you think that huperzine A might be helpful to people with epilepsy?

I had set up a program at Harvard Medical School to test botanicals in animal models of epilepsy. I chose huperzine A to test first because it was known to block glutamate (an excitatory chemical in the brain), which could be important as a way to stop seizures. I was able to send a sample of huperzine A to the Anticonvulsant Screening Program, which is supported by the National Institute of Neurological Disorders and Stroke. [The program is now known as the Epilepsy Therapy Screening Program.] There, it was tested in a variety of epilepsy animal models to see how effective it was in stopping seizures. The results that came back showed that huperzine A was indeed really good at stopping seizures and didn't seem to cause serious side effects in these animal models.

If I can get huperzine A as a dietary supplement, why should I wait until it is FDA approved?

Most importantly, at this time, we do not have enough proof that huperzine A is safe or effective in people with epilepsy to recommend that someone try it. We also don't know how it might interact with other seizure medications. Just as important, the manufacturing quality of dietary supplements is not as carefully monitored as it is for prescription drugs.

How is huperzine A working to stop seizures?

We now believe that huperzine A actually does not work by affecting glutamate after all. Rather, it interacts with a different pathway in the brain called the cholinergic pathway. This would be a completely new mechanism for an epilepsy therapy which is one of the things that makes it so exciting.

Once you learned that Huperzine A was effective at stopping seizures in animal models, what did you do?

Well, I wanted to test whether it could work to prevent seizures in people with epilepsy. At the time, it was being studied in people with Alzheimer's disease, and it appeared to be well tolerated at the doses used in that study. I applied to the Epilepsy Therapy Project at the Epilepsy Foundation for support of an early-stage clinical trial. It took a while to get up and running, but the results were promising and so a company called Insero Health which was later renamed to Biscayne NeuroTherapeutics was started to help with further testing. Eventually, Dr. Stephen Collins joined the company as the CEO and his efforts eventually resulted in the merger with Supernus Pharmaceuticals. It's been a long but extremely exciting journey so far.

How helpful was the Epilepsy Foundation award in moving this compound through the clinical pipeline?

The backing from the Foundation was extremely important because of the seed funds provided and the advice and support of fellow epilepsy doctors and scientists. It takes a village to go from an idea to a promising new treatment and the Foundation was a huge part of that.



Rare Epilepsy Network Spotlight – Hope for Hypothalamic Hamartomas #ShareMySeizure



Of the 50 million plus people living with epilepsy worldwide, a significant number have a rare form of epilepsy. A rare epilepsy, by definition, impacts less than 200,000 people. Though each syndrome / disease / condition is different, people living with rare epilepsies share many common seizure types, symptoms and side effects. However, because each rare syndrome population is small in size, research to unlock answers is not moving fast enough. Together, we can be stronger.

The Epilepsy Foundation spearheads the Rare Epilepsy Network (REN), a coalition of 30 plus rare epilepsy organizations, to better understand these conditions



For this issue, we sat down with Ilene Miller, President of Hope for Hypothalamic Hamartomas (HH), a rare epilepsy nonprofit to talk about her experiences.

When did your son get diagnosed with HH?

My son Mark started having seizures at birth. However, because they were staring (absence) and laughing (gelastic seizures), we didn't even realize they were seizures until they progressed to four distinct seizure types (absence, gelastic, complex partial (focal without awareness) and grand mal (tonic-clonic)) around age 4. He was having 10-20 plus seizures a day. It took us five anxiety-filled years to correctly diagnose him including many misdiagnoses along the way. An MRI originally reviewed as normal was reviewed a second time following an interaction with a radiologist who asked about Mark's symptoms. The peculiar laughing was the tip that led to the discovery of the tiny lesion on Mark's hypothalamus. A serendipitous interaction was what gave us the answer we were searching for.

Why did you start Hope for Hypothalamic Hamartomas (hopeforhh.org)?

Five years of knowing something is wrong with your child takes a great toll on parents, especially new ones. I found similarly situated parents on an HH list-serve and joined forces with several other extraordinary moms to found Hope for Hypothalamic Hamartomas (hopeforhh.org). Our priorities are to provide coordinated multi-disciplinary care and support for the patient and caregiver to manage the disease over the lifetime as it waxes and wanes and educate the medical professionals about the spectrum of side effects beyond the seizures.

What words of advice would you give to other parents who are dealing with a rare epilepsy?

For parents dealing with a rare epilepsy, you have to trust your gut that no one knows your child better than you do. And when your gut is screaming that the information you are receiving is just not right, ask questions and seek second, third and even fourth opinions. Many top epilepsy centers will evaluate your records, films, and reports without you requiring a trip to the institute itself. The journey to diagnosis and treatment (if one even exists) will be long and this is going to be a marathon not a sprint. Find ways to take care of yourself emotionally and physically if you are the caregiver (or patient) and ask others for help.

How has the REN supported you in this journey?

The Rare Epilepsy Network (REN) encourages research both on individual conditions as well as into common symptoms and side effects across the rare epilepsies. We had no idea how many co-morbidities we shared with other diseases, but this initiative has really brought that to light. For example, recently we learned that not only do HH patients suffer from behavioral rages which we thought (incorrectly) was unique to our community but patients diagnosed with Lennox Gastaut, Dravet, Tuberous Sclerosis and other rare epilepsy syndromes do as well. Knowing this enables our small communities to work together toward finding solutions and support for our families. The Epilepsy Foundation has been a valued partner in raising the profile on hypothalamic hamartomas and many other rare epilepsies.

What's Next?

We are co-organizing the [4th International Symposium on Hypothalamic Hamartomas](#) with Children's National Health System in Washington D.C. in September 12-14, 2019. The Symposium will bring together senior, mid-level and young international clinicians and researchers – thought leaders in HH to identify gaps in our understanding of this complex syndrome and its co-morbidities. Scholarships for Young Investigators (YI) interested in HH are available and interested YI's should visit our site or contact ilenepennmiller@gmail.com.

#ShareMySeizure

In the coming year, we are sharing more stories from our community about living with seizures and tying those stories to our research efforts. Tag us [@EpilepsyFdn](#)



Susan Spencer Clinical Research Fellowship Awarded

The Susan Spencer Clinical Research Training Fellowship

The Susan Spencer Clinical Research Training Fellowship supports investigators who are pursuing careers in patient-oriented epilepsy research. The award is made possible by the American Academy of Neurology with funding from the Epilepsy Foundation, the American Epilepsy Society, and the American Brain Foundation.



This year's awardee is **Dr. Lisseth Burbano**, who is developing a therapy for severe epilepsy syndromes caused by KCNT1 gene mutations.

She is conducting this research in the Ion Channels and Human Disease Lab overseen by Professor Steven Petrou at the Florey Institute of Neuroscience and Mental Health in Australia.

What are KCNT1 Epileptic Encephalopathies?

KCNT1 gene mutations (also called variants) are associated with several severe early-onset pediatric epilepsy syndromes, including epilepsy of infancy with migrating focal seizures (EIMFS). KCNT1 associated epilepsies are resistant to currently available treatment options.

How could KCNT1 be causing epilepsy?

The KCNT1 variants associated with these epilepsies cause too much activity in the KCNT1 protein, which is a potassium channel. Too much potassium entering brain cells at the wrong time can disrupt normal functions and lead to seizures.

Tailoring treatment to KCNT1 epilepsy

The treatment strategy that Dr. Burbano's team is working on focuses on reducing the amount of overactive KCNT1 proteins in brain cells to target the root cause of the disease.

The strategy goes like this:

- The KCNT1 gene contains the architectural blueprint for building the KCNT1 protein.
- If we can disrupt the next step in building the protein (by silencing the variant KCNT1 RNA), we can stop the abnormal KCNT1 protein from ever being made.

Treating KCNT1 with Antisense Oligonucleotides ASOs

Antisense Oligonucleotides (ASOs) are short-stranded oligonucleotides that can be tailored to silence specific pieces of RNA by attaching to them and targeting them for degradation.

Dr. Burbano's team has partnered with Ionis Pharmaceuticals, which has developed ASOs that target the KCNT1 RNA. For her fellowship, Dr. Burbano will test whether these ASOs are clinging correctly to the KCNT1 RNA and thereby reduce the levels of abnormal KCTN1 protein. The next step is to check whether the reduced KCNT1 protein levels bring cell function back to normal. She will test this strategy in an animal model of epilepsy caused by a KCNT1 mutation to see if it will stop seizures and whether there are potential side effects to this approach.

Recently, ASOs have seen success in the clinic for other disease areas such as spinal muscular atrophy. This means that a commercialization pathway already exists for getting this type of approach tested and into the clinic. Dr. Burbano's studies, using the ASO approach, are an exciting first step towards developing a precision therapy tailored for KCNT1 epilepsies.

Treatment Strategy

Overview

The KCNT1 gene contains the architectural blueprint for building the KCNT1 protein. KCNT1 RNA is the intermediary step. This consists of reading the KCNT1 gene schematics and specifying how the KCNT1 protein should be assembled. By getting to the abnormal KCNT1 RNA before construction begins, the abnormal KCNT1 protein can be stopped from being made.

Antisense Oligonucleotides (ASOs) are short-stranded oligonucleotides that can be tailored to stick to specific pieces of RNA and target them to be broken down. ASOs then stop the RNA from being able to build the protein. ASOs for KCNT1 have been created.

Dr. Lisseth Burbano's research will examine whether we can use these tailored ASOs to stop abnormal KCNT1 protein from being made and improve brain function.



Personal Stories that Our Research Can Impact

What drives our community are the stories of the unmet need. Starting this year, we will be taking a deeper dive into stories from our community and tie these stories to the research that we are supporting. In this issue, Azita Fatheree shares the story of her son who has a KCNT1 genetic mutation. The Epilepsy Foundation through the Susan Spencer Clinical Research Fellowship is supporting the development of a personalized therapy for KCNT1 epilepsies (see page 6 to learn more about the research).



Epilepsy can affect anyone with a brain. In 2002, at 6 months old, our chubby, happy infant son began to have a few facial twitches. This quickly morphed into status epilepticus, a dangerous situation when the seizures last over five minutes or when the seizures occur so close together that he wasn't regaining consciousness in between. Our son was having over 200 seizure occurrences daily. The doctors placed him in the idiopathic category, a fancy way of saying cause unknown.

It took 15 years to get the genetic diagnosis.

After exhausting 14 anticonvulsant medications, consulting with a dozen pediatric neurologists, undergoing 3 surgeries, witnessing tens of thousands of seizures, spending countless weeks in the hospital, and providing the necessary 24-hour care to our son, we discovered a golden piece to the puzzle which we had desperately been trying to solve on borrowed time.

The test, which had been unavailable to us in 2002, showed that he has a de novo KCNT1 mutation. While this new information hasn't given him seizure control and puts us in a very rare epilepsy category, it also gives us the promise for more accurate treatment. We are witnesses to the dedication of researchers who are undeterred by the rarity of our son's epilepsy and a new fervor to tailor therapy that may increase his life span and improve the quality of his life.

While we spent the first half of our son's life mourning the loss of his physical and cognitive abilities and reimagining his future life, we have spent the later part of his life celebrating the small milestones and daily smiles and hugs often under appreciated by others who receive them without thought. The fragility of our now seventeen-year-old's mortality has caused us pain and worry on a molecular level that cannot be repaired, but the joy this precious human has brought to our lives is beyond measure and has gifted us with super powers we did not know we possessed. We are grateful to be in this fight to end epilepsy with so many others who are tireless in this effort.

#EndEpilepsy #EpilepsySolutions

Join the conversation – Share your story and tag us online @EpilepsyFdn

Do you have a child with epilepsy who hasn't been genetically tested?
FREE EPILEPSY GENETIC PANEL TESTING OPPORTUNITY

Invitae, BioMarin, Stoke Therapeutics, and Xenon Pharmaceuticals have a [Behind the Seizure](#) Program that provides free epilepsy genetic panel testing for kids living with seizures from 0 to 60 months of age.

www.behindtheseizure.com

Dr. Brandy Fureman honored with the American Epilepsy Society (AES) 2018 Distinguished Service Award



“AES is pleased to have this opportunity to publicly recognize Dr. Fureman with one of our highest honors of service, acknowledging her outstanding leadership and contributions to the entire epilepsy community,”

- **Eileen Murray, executive director, American Epilepsy Society.**



Congratulations

to the 6 Epilepsy Foundation Shark Tank competition finalists who will be making their pitch at the Anti-Epileptic Drug and Devices Trial. These finalists will be convincing "Sharks" to support their innovative project.

Avani Modi, PhD, Professor, Department of Pediatrics, Cincinnati Children's Hospital Center: The goal is to further develop Epilepsy Journey, a gamified, web-based intervention, in which adolescents navigate through various "lands" (learning modules) in order to develop problem-solving skills to address executive function deficits associated with epilepsy.

Benjamin Vandendriessche, PhD, CMO, ByteFlies: The goal is to validate the Sensor Dot, a tiny multimodal wearable that can continuously monitor cardiovascular, respiratory, nervous and musculoskeletal systems, in people with epilepsy.

Jody McNannay, parent of a daughter with epilepsy, co-founder, Curadite: The goal is to upgrade their existing medication management platform which incorporates smart pillbox tracking with reminders to be specific for the epilepsy community.

Matthew Musser, CEO & Founder, Seize the Wheel: The goal is to develop a virtual reality driving simulator that incorporates a traditional EEG diagnostic exam to assist physicians on how patients with interictal discharges are impacted.

Rachel Kuperman, MD, CEO, Eysz, Inc.: The goal is to develop and deploy 100 eye-tracking wearables that will be used in a clinical study at UCSF on 300 patients to refine their patented seizure detection algorithm.

Sharon Chiang, MD, PhD, Neurology Resident, University of California San Francisco: The goal is to deploy an algorithm developed with Seizure Tracker that assesses an individual's risk of having a seizure based on patient diary support and validate it as a clinical decision support tool.

www.epilepsy.com/sharktank

Thank you to Epilepsy Foundation Minnesota for supporting this program!



Clinical Trials Portal – Studies Actively Recruiting

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

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.

Partial-Onset (Focal) 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).

www.epilepsy.com/clinical_trials

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

The Epilepsy Foundation is launching a new partnership, called the Human Epilepsy Project, in collaboration with the Epilepsy Study Consortium. 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

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 (**S**taccato **A**lprazolam **T**erminates **E**pilepsy **S**eizures).

Epilepsy Genetics Initiative (EGI)

The Epilepsy Genetics Initiative (EGI) was created by Citizens United for Research in Epilepsy (CURE) to house and analyze the genetic data of people with epilepsy in a centralized database.

Upcoming Conferences

71st Annual American Academic of Neurology Meeting

May 4-10, 2019, Philadelphia, PA

<https://www.aan.com/conferences-community/upcoming-conference-dates/>

Anti-Epileptic Drug and Device Trials XV Conference

May 22-24, 2019, Aventura, FL

<https://aedtrials.com/>

2019 International Tuberous Sclerosis Complex Research Conference: Changing the Course of TSC

June 20-22, 2019, Toronto, Ontario CA

<https://www.tsalliance.org/researchers/research-conferences/>

International Conference for Technology and Analysis of Seizures (ICTALS).

September 2-5, 2019, University of Exeter, UK

<http://www.exeter.ac.uk/livingsystems/newsandevents/events/ictals2019/>

4th International Symposium on Hypothalamic Hamartomas

September 12-14, 2019, Washington, D.C.

<http://www.hopeforhh.org/4th-international-symposium-on-hypothalamic-hamartomas/>

Park City Epilepsy Meeting

October 6-9, 2019, Park City, UT

<http://www.parkcityepilepsymeeting.com/>

Child Neurology Society 48th Annual Meeting

October 23-26, 2019 Charlotte, NC

<https://www.childneurologysociety.org/meetings/future-cns-annual-meetings>

American Epilepsy Society Annual Meeting 2019

December 6-10, 2019 Baltimore, MD

<https://meeting.aesnet.org/about/future-meetings>

Have a conference that you want to share?

Email Ischreiber@efa.org

Walk to END EPILEPSY

Ocean City, MD
Indianapolis, IN
Brandon, MS
McAllen, TX
Birmingham, AL
Biloxi, MS
Los Angeles, CA
Peoria, AZ
Washington, D.C.
Las Vegas, NV
Oklahoma City, OK
Dayton, OH
West Des Moines, IA
Iowa City, IA
Waterloo, IA
Seattle, WA
Spokane, WA
Portland, OR
Bend, OR
Eugene, OR
Anchorage, AK
Ketchikan, AK
Salt Lake City, UT

and many more to come...

WalktoEndEpilepsy.org

