In this issue, we highlight some of the partnerships our research team has developed to make a bigger impact for people with epilepsy. Our research covers the entire spectrum of discovery – from idea to market. We cannot do it alone.

On page 2, we provide updates on the Rare Epilepsy Network (REN), a coalition of nearly 30 different organizations working together to facilitate research that improves the outcomes of those living with rare epilepsies.

On page 3, clinicians from Thomas Jefferson University Hospital in Philadelphia, PA reflect on how the Epilepsy Foundation’s support early on in their career encouraged them to pursue research within the field. Supporting the development of early career investigators is done in proud partnership with the American Epilepsy Society (AES). This collaborative effort ensures that we can pool our resources, reduce administrative cost and maximize impact. Supporting our professional workforce is one of the ways in which we can ensure that the best and the brightest are tackling the challenges that our community face. We could not do this without our partners at AES.

On page 5, we provide staff reports on the conferences attended this past quarter from the Nonprofits Forum at the National Institutes of Health, to meeting new companies at Bio Conference, to facilitating discussions on how medical devices can impact SUDEP and epilepsy care with the Food and Drug Administration.

We are creating a research environment in which partnerships spur innovation and exciting discoveries to end epilepsy. To paraphrase Yoko Ono, this dream when dreamt alone is just a dream. But this dream, working with our community, can become reality. Join us. There is room for you.

Please visit our website to learn of the exciting initiatives that we have underway.

www.epilepsy.com/research

Sincerely,

Brandy Fureman, PhD
VP of Research & New Therapies
What is the Rare Epilepsy Network (REN)?

The Rare Epilepsy Network (REN) is spearheaded by the Epilepsy Foundation. It is a partnership between the Foundation, rare epilepsy organizations, Columbia University, and Research Triangle International (RTI). The network conducts and facilitates research to improve outcomes for people with rare conditions associated with epilepsy and seizures.

Goals of the REN

The goals of REN are to unlock the causes of rare epilepsies, improve diagnosis (avoiding delay and misdiagnosis), treatment and quality of life, and find cures.

Who can participate?

You or your loved one may be eligible for the REN registry if a diagnosis of a rare epilepsy syndrome has been made by a physician.

Research Studies Currently Underway:

✓ Understanding the risk factors for pneumonia in rare epilepsies
✓ Developing a new sleep scale
✓ Developing a caregiver stress and benefits scale

Stay tuned for the next quarterly to learn the results!

Requests for data and new studies are being accepted now!

Learn more at https://ren.rti.org

Who is currently enrolled?

✓ 1,314 Participants enrolled across 6 continents
✓ 39 Rare Epilepsy Subtypes Represented

REN Dashboard

RTI has created a dashboard, which provides an at-a-glance overview of the epilepsy subtypes represented, prescribed medications, and associated conditions with the different disorders.

The dashboard and comparisons allows one to take a deep dive into a specific epilepsy subtype.

For example, the graph below shows the breakdown of associated conditions in rare epilepsy subtypes impacting our REN community in addition to seizures.

Perhaps not surprisingly, cognitive issues ranked highest among our enrolled participants. In the dashboard, one can then click on a specific epilepsy subtype to see how the breakdown changes within each group.

Go to https://ren.rti.org/dashboard to learn more.

Commitments of REN

To address the urgent health challenges of our rare epilepsy community by:

✓ Engaging people living with epilepsy and their care partners
✓ Making data available to researchers
✓ Investigating causes and consequences
As Benjamin Franklin famously said, “Time is money,” and this is even more true for busy physician-scientists who must balance their many clinical responsibilities with hours in the research lab. For Thomas Jefferson University Hospital doctors, Michael R. Sperling, MD, and Shennan A. Weiss, MD, PhD, generous funding from the Epilepsy Foundation not only bought them more than time for research—it launched their careers. It also led to novel lines of investigation and discoveries that are still yielding dividends, providing a better understanding of epilepsy and better ways to treat it.

“Carrying the project out really helped launch my research career.”

Michael R. Sperling, MD, is director of the internationally renowned Jefferson Comprehensive Epilepsy Center and co-editor-in-chief of Epilepsia, the major international epilepsy journal. He established the Center when he came to Jefferson in 1997, which has grown into one of the premier epilepsy surgery programs in the world, with robust academic and clinical programs, and researchers—like Sperling himself—who are transforming the way epilepsy is diagnosed and treated. For Dr. Sperling, it all began with his epilepsy fellowship at UCLA and a life-defining 1984 grant from the Epilepsy Foundation.

My first research grant was from the Epilepsy Foundation, known as “the Merritt-Putnam Fellowship at the time,” Dr. Sperling says. The grant allowed him to work on a project studying hormone release associated with seizures, which he completed successfully with collaborators across the country. “Carrying the project out really helped launch my research career.”

The grant gave Dr. Sperling the support he needed to spend most of his fellowship time on research, and learn how to do research from mentors who could train him well. He also credits it with helping him get his first academic faculty position, creating the foundation that led to NIH funding and ultimately his directorship of the Comprehensive Epilepsy Center at Jefferson and his current research focus, investigational therapeutics and outcomes research. Sperling’s colleague Shennan A. Weiss, MD, PhD assistant professor in Neurology – Epilepsy, tells a similar story.

“If it wasn’t for the Epilepsy Foundation, I would never have been able to pursue this work”

As a resident and fellow, it’s almost impossible to conduct the type of research that I do, which is very quantitative,” Dr. Weiss explains. “We use custom computer software to analyze very complex terabytes of data. It’s not something that a clinician in training can easily do in their spare time.”

During a two-year fellowship in epilepsy, also at UCLA, a grant from the Epilepsy Foundation allowed Dr. Weiss to investigate a biomarker known as high frequency oscillation, which promises less time in the hospital having their epilepsy diagnosed and better, more targeted surgical interventions.

“I’m very, very grateful to the Epilepsy Foundation”

“That grant lasted two years and really allowed me to develop my project, that turned into my independent NIH funding … [it] tested the hypothesis that the brain oscillations in sleep and dreaming could be used as a way of mathematically defining the high frequency oscillations that are associated with epilepsy,” Dr. Weiss says.

Because of the Foundation’s grant, and the connections it fostered for Dr. Weiss—including his mentorship with Dr. Sperling—he was able to continue his work at the Computational Epilepsy Research Lab at Jefferson, which leads the field in studying this biomarker and improving its accuracy.

“If it wasn’t for the Epilepsy Foundation, I would never have been able to pursue this work and have the strong mentorship that I did and make the leaps and bounds into pioneering work,” Dr. Weiss says. “I would never have had the time to do the work, I would never have had the support from other physicians and researchers who know the essential details and pitfalls of doing this type of research. So I’m very, very grateful to the Epilepsy Foundation.”

Join the Epilepsy Foundation and the American Epilepsy Society in supporting the Next Generation of Scientists.

Donate Today

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For many people living with epilepsy, a seizure occurs during a certain time of day or after every couple of weeks. Understanding these brain rhythms, why they happen and how they can influence seizure occurrences may be key to understanding seizure susceptibility for the individual.

**The My Seizure Gauge Challenge**

**Bringing Big Data to Personalized Health**

This October 11th, we will start accepting proposals on how to best implement data collection on a research cohort of individuals with intracranial EEG implants for over a year. The objective is to pair these longitudinal intracranial EEG recordings with a host of peripheral measurements (such as biosensors, digital markers, passive measurements, etc.).

We do not want to measure a few components, but a myriad of factors, and then mine the data for new clues about what happens in the body in the days, hours and minutes before a seizure. These insights can then be expanded to developing a seizure gauge.

**We will want your input**

As we look to the future and begin to think about seizure forecasting devices on the market, we also want your opinion on what device would work for you. Therefore, we will also be launching a survey in late November to ask you your thoughts on seizure forecasting, and whether such a device would be meaningful to you. Stay tuned to learn more about participating in this initiative.

**Are you a Researcher? Clinician? Data Scientists? Device Developer?**

Our request for proposals for those interested in the My Seizure Gauge Challenge will be out on October 11th, 2017. Please go to [www.epilepsy.com/myseizuregauge](http://www.epilepsy.com/myseizuregauge) to learn more.

**We would like to thank the following organizations and individuals for supporting Ei2:**

- Anonymous Donors
- Bob & Terri Smith
- Dennis & Sally Runey
- Eisai, Ltd
- Epilepsy Foundation of Greater Chicago
- Frank and Jeanne Fischer
- Greater Cincinnati Foundation
- Loeffel Epilepsy Foundation
- Julie & Roger Heldman
- Dr. Matthew and Brooklyn Thom
- Marc & Margo Pinto
- Neu Family
- Tony Coelho
- Warren Lammert

**Interested in also supporting Ei2?**

Contact: Geoff Hoyt  
Senior Director of Major and Planned Giving,  
National Office Epilepsy Foundation  
ghoyt@efa.org
Epilepsy Foundation Staff and Advocates Testify at the Food and Drug Administration

On August 17, 2017, Epilepsy Foundation staff and advocates testified at a Food and Drug Administration (FDA) patient engagement meeting about the need for additional research into the use of medical devices to treat epilepsy and SUDEP. During the meeting, Dr. Sonya Dumanis, Senior Director of Innovation presented the Epilepsy Foundation’s current device initiatives. Dr. Dumanis was joined as a presenter by Kennedy Witcher, 16, a 2017 Teens Speak Up! participant from Alabama, in addition to three other advocates from the epilepsy community. Kennedy (shown at the meeting on the left) testified at the FDA as part of her Teens Speak Up! Year of Service. Dr. Greg Bergey, Director of the Epilepsy Center at Johns Hopkins University and a member of the Epilepsy Foundation’s Professional Advisory Board also presented on the current practices in the clinic regarding devices.

Epilepsy Foundation Goes to BIO International Conference – Staff Report

On July 19-21, a group of 4 representatives from the Epilepsy Foundation attended the 2017 Bio International Convention at the San Diego Convention Center. The Bio International Conference is the largest of its type providing exposure to biotech and pharma industry thought-leaders with over 1,500 education sessions, and networking opportunities with over 16,000 participants from around the world.

Our objective at the Bio Convention was to meet with leaders from biotech/pharma companies to explore ways in which the Epilepsy Foundation could support them in bringing new therapies and devices to market, engage with other foundations to advance EF’s advocacy mission, create awareness for EF and epilepsy, and stay abreast of current trends. Some key activities included:

- Meetings with over 20 companies and institutions to explore potential alliances and explain ways in which the foundation could support their research through its multiple programs and grants,
- Presentation about the newly launched Epilepsy Innovation Institute (E²),
- Attendance at multiple talks to learn about current trends in: innovation in the rare disease space, multiparty pharma-institute deals, business models for breakthrough therapies, factors driving patient adherence to drug therapy, and increasing patient engagement through digital strategies.

Epilepsy Foundation Goes to the NonProfit Forum – Staff Report

The Vice President of Research and New Therapies, Dr. Brandy Fureman, represented the Epilepsy Foundation at the National Institute of Neurological Disorders and Stroke's 2017 Nonprofit Forum on September 5-6, 2017. The theme of the meeting was "Progress through Partnerships" and it featured talks on access to new drugs for rare diseases, new tools for patient-focused drug development, lessons learned about overcoming challenges along the spectrum from discovery to clinical research, and FDA viewpoints on neurologic scales and outcomes. One of the Foundation's partners in the Rare Epilepsy Network (REN), Dr. Steve Roberds of the TS Alliance, presented during the session on "Maximizing Impact in a Tough Budget Era" and shared the Alliance's strategy to provide key infrastructure supporting therapy development and clinical trials in tuberous sclerosis, which includes a trial aimed at preventing epilepsy and developmental delay in infants with TSC. The PREVENT trial is currently recruiting participants and can be viewed on the Foundation’s Clinical Trials Portal. Several other REN partners, including JayEtta Hecker (Wishes for Elliot), Ilene Miller (Hope for Hypothalamic Hamartomas), Geraldine Bliss and Megan O’Boyle (Phelan-McDermid Syndrome Foundation), and representatives of epilepsies professional organizations Penny Dacks and Joanna Crooks (American Epilepsy Society and Epilepsy Leadership Council) and Ellen Riker and Jen McCrindle (National Association of Epilepsy Centers) also participated in the meeting.

Interested in getting involved in advocacy & research efforts at the Epilepsy Foundation?

Email: ContactUs@efa.org
This Hot Topic was requested by one of our readers. To address her request, we turned to one of the foremost experts on Psychogenic Non-Epileptic Seizures (PNES), Dr. W. Curt LaFrance, Jr. and asked him to answer the questions below.

Dr. W. Curt LaFrance, Jr. is the Director of Neuropsychiatry and Behavioral Neurology at Rhode Island Hospital and Associate Professor of Psychiatry and Neurology at Brown University. Dr. La France also serves on the Epilepsy Foundation Professional Advisory Board. His main area of focus is non-epileptic seizures and has published 5 articles on this topic in the past two years alone.

### What is a Non-Epileptic Seizure?

These are seizures but they are not caused by electrical activity in the brain. They can be psychogenic or physiologic.

### What does a psychogenic non-epileptic seizure (PNES) mean?

Psychogenic (si-ko-JEN-ik) means beginning in the mind or functional. Psychogenic non-epileptic seizures (PNES) are associated with emotions or stressors. PNES are psychological in nature, and are not purposely produced. When seizures begin, the person with PNES sometimes is not aware that the events are not epileptic. The type of seizure can be demonstrated by capturing it on EEG.

### How common is PNES?

Up to 1% (3.4 million) of people in the United States are diagnosed with seizures. Many of these are presumed to be epilepsy; however, from 5 to 20% of these individuals have PNES (~100,000 to 400,000 individuals), making PNES as common as multiple sclerosis or Parkinson's disease.

### How common is PNES in the epilepsy population?

10% of people with PNES also have epilepsy.

### Can PNES be treated?

Yes, but not with anti-epileptic drugs. Treatment with psychotherapy directed at seizures, common co-occurring symptoms (such as, depression, anxiety, and PTSD) and underlying stressors could help reduce seizures and symptoms.

The VA has released a video of a veteran with PNES who describes receiving the treatment. One can view it here: [http://www.epilepsy.com/learn/types-seizures/nonepileptic-seizures-or-events](http://www.epilepsy.com/learn/types-seizures/nonepileptic-seizures-or-events)

In 2014, Dr. LaFrance and collaborators published a multicenter pilot treatment trial for PNES. Here, they showed that a 12-session seizure treatment consisting of weekly therapy with a trained therapist could decrease seizures, depression and anxiety and improve quality of life for individuals diagnosed with PNES.

### What is currently being researched?

A recently funded multi-site project will study brain imaging using fMRI to examine brain changes in patients with epilepsy or with PNES before and after receiving the therapy. This research may identify mechanisms in PNES and epilepsy and abnormal brain networks in patients with seizures.

Please go to [www.epilepsy.com](http://www.epilepsy.com) to learn more.
Clinical Trials Portal

This past April, the Epilepsy Foundation launched the Clinical Trials Portal, where you’ll find information about ongoing clinical trials and observational studies in epilepsy. This tool will help connect you to studies that match the type of epilepsy you or your loved one has.

Studies currently recruiting:

Fenfluramine Assessment in Rare Epilepsy (FAiRE): ZX008-1501/1504

FAiRE is exploring whether the investigational drug (ZX008) improve seizure control in children and young adults with Dravet syndrome. The goal of the ZX008-1501/1504 trials is to show that ZX008 is a safe and effective treatment for children and adolescents with Dravet syndrome when added on to their other seizure medications.

Preventing Epilepsy Using Vigabatrin In Infants with Tuberous Sclerosis Complex

This trial tests 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 uncontrolled seizures.

Focused Ultrasound for Treatment of Epilepsy

The study will evaluate the effectiveness and safety of an investigational device that uses sound waves (ultrasound) 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.

Go to our portal to learn more!
www.epilepsy.com/clinical_trials
Upcoming Conferences for 2017

American Epilepsy Society Annual Meeting 2017
December 1-5th, Washington, D.C.
https://www.aesnet.org/annual_meeting/about

Hope for Hypothalamic Hamartomas Family Forum
December 2-3rd, Washington, D.C.
http://www.hopeforhh.org/?s=family+forum

Epilepsy Foundation Pipeline Conference
February 22-24th 2018, San Francisco, CA
https://www.epilepsy.com/pipeline2018

Have a conference that you want to share?
Email ahansell@efa.org

GRANT SUBMISSION DEADLINES:


❖ SUDEP Biomarker Challenge Submissions due October 10, 2017. Learn more at https://www.innocentive.com/ar/challenge/9933784

❖ Shark Tank Letters of Intent due October 16, 2017. Learn more at www.epilepsy.com/sharktank

❖ Epilepsy Innovation Institute My Seizure Gauge Letters of Intent due December 22nd, 2017. Learn more at www.epilepsy.com/myseizuregauge

Interested in other grant opportunities?
The Epilepsy Research Connection is a collaborative effort to assist epilepsy researchers in looking for funding opportunities across different organizations:

http://epilepsyresearchconnection.org/

Saturday April 14th, 2018
National Mall, Washington DC
Register * Donate * Volunteer
www.walkforepilepsy.org