“Impossible is not a fact. It’s an opinion. Impossible is not a declaration. It’s a dare. Impossible is potential. Impossible is temporary. Impossible is nothing.”

– Mohammed Ali

About a third of people living with epilepsy do not have seizure control because no available treatment works for them. Those whose seizures are controlled are still at risk of breakthrough seizures. This staggering number has not changed in decades, despite over 15 new therapies for epilepsy entering the market since the 1990s.

This may seem like an insurmountable challenge, but we at the research department have taken Ali’s quote to heart. Our vision is a world without epilepsy and lives free from seizures and side effects.

This past quarter, we have assessed the landscape to identify research areas and programs that would have the most impact for epilepsy. We’ve sustained successful research programs, and added new ones to strengthen the research ecosystem.

We are excited to share with you what we have done and what we want to do. Every quarter, we will provide updates on our activities, highlight our impact on previously funded grants, as well as update you on the newest grant awardees and ways you can get involved.

Let’s make the impossible, possible.

Sincerely,

Brandy Fureman, PhD
VP of Research & New Therapies

Upcoming Conferences for 2nd Quarter of 2017

End Epilepsy Summit for the Community
April 29th, 2017
Epilepsy Foundation Greater LA, Los Angeles, CA
https://endepilepsy.org/event/summit-family/

Antiepileptic Epilepsy Drug & Device Trials XIV Conference
May 17-19, 2017
Aventura, FL
https://aedtrials.com/

Have a conference that you want to share?
Email ahansell@efa.org
Seize Control of Epilepsy: Empowering People to Better Manage Life

In the fall of 2016, the Epilepsy Foundation launched the Epilepsy Innovation Institute (Ei²) as a platform for continuous innovation in epilepsy sponsoring high-risk/high-reward projects.

Our platform can be broken down into 4 components:

- Select Topic
- Define Challenge
- Fund Solution
- Provide Mentorship

Our First Topic

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

**You spoke. We listened.**

Ei² will be leading the effort to create an individualized seizure gauge that will allow a person with epilepsy to monitor the daily likelihood of a seizure. Our purpose is to identify and better understand changes in the body that may precede the onset of a seizure in the hours or days before the clinical seizure.

**My Seizure Gauge – An Early Warning Detection System**

For this challenge, a host of factors using both EEG (and other electrical measures) coupled with non-EEG based methods from emerging biosensors and wearable technologies will be considered.

An August Innovation Workshop is being planned to assess how best to structure the challenge for maximal impact.

**Supporting Innovation in Clinical Trials**

**2017 New Therapies Commercialization Grant, Epilepsy Therapy Project**

The Epilepsy Foundation awarded Dr. Orrin Devinsky of New York University a New Therapies Commercialization Grant to test whether Ataluren (PTC Therapeutics) can reduce the impact of changes in genes associated with Dravet Syndrome or CDKL5 in human clinical trials.

“The promise of a genetic therapy for epileptic encephalopathies due to single gene mutations has been the hope of parents and researchers for decades. Support from the Epilepsy Foundation has allowed the first trial of a genetic therapy in epilepsy.”

- Dr. Orrin Devinsky, MD, Director of NYU Comprehensive Epilepsy Center & Saint Barnabas Institute of Neurology and Neurosurgery
Clinical Trials Portal Launching April 2017

Clinical trials are research studies that are designed to test a new approach, treatment or diagnostic test in people. This type of research is critical to developing new therapies for all types of epilepsy.

When we asked people with epilepsy why they did not participate in clinical trials, the number one response was that their doctor had never talked with them about clinical trials.

This April, epilepsy.com will launch a new Clinical Trials Portal, where you’ll find information about ongoing clinical trials in epilepsy. This tool will help connect you to trials that match you to the type of epilepsy you or your loved one has.

You will also find tools to help you learn about trials and other clinical research studies, and to help you consider whether joining a study is right for your situation.

Engagement with Stakeholders

This March, the Epilepsy Foundation brought representatives from the U.S. Food and Drug Administration and the European Medicines Agency together with senior scientists from pharmaceutical companies, pediatric neurologists, and patient representatives from epilepsy nonprofits to discuss ways to improve pediatric drug development. A summary of these discussions will be published in the coming months.

The Rare Epilepsy Network (REN) is a partnership between rare epilepsy organizations, the Epilepsy Foundation, Columbia University, and Research Triangle International. The network will conduct and facilitate research to improve outcomes of people with rare conditions associated with epilepsy and seizures. Requests for studies and data are being accepted now. Interested in participating and learning more? Visit https://ren.rti.org/
Next Generation Scientist Update

The Susan B. Spencer Clinical Research Fellow will be announced at the American Neurological Association Meeting in Boston, MA this April. The Epilepsy Foundation supports this fellowship in partnership with the American Academy of Neurology and the American Epilepsy Society.

Hot Topic – Genetics & Epilepsy

In conversations with our local Epilepsy organizations, genetics continually comes up in discussions they have with their constituents.

**Update on gene discovery in epilepsy** – There are now over 90 known epilepsy genes, and genetics is becoming a more frequently recognized cause of epilepsy than ever before. Twenty new epilepsy genes were discovered in 2016 alone! In rare epilepsies, as many as 30-40% of patients now receive a definitive genetic diagnosis, and there is growing evidence that some of the more common epilepsies may be caused by genetic factors as well.

In the coming months, we will be posting information about the latest in genetics news here. For our first post, we wanted to include a list of other resources on where one can go to get the latest information for genetics and epilepsy.

**Resources Include:**

- Beyond the Ion Channel blog
- Epilepsy Phenome/Genome Project (EPGP) website
- EPGP Facebook Page
- Epi4K: Gene Discovery in Epilepsy website
- Epilepsy Genetics Initiative (EGI)
- Global Genes Epilepsy Registry

Post-Award Update

**Pregnancy & Epilepsy**

In 2011, the Epilepsy Foundation awarded a Targeted Research Grant on Women to Dr. Angela Birnbaum of the University of Minnesota to better understand how early pregnancy can impact Lamotrigine levels in the body.

**Grant Finding**

Approximately 75% of women studied have changes in how their body processes Lamotrigine that necessitate dose changes throughout pregnancy. These findings were published in the Annals of Clinical and Translational Neurology.

**What next?**

Dr. Birnbaum has teamed up with other researchers to better identify which women may need changes in dosing within the first trimester of pregnancy.

**Get Involved?**

If you’re already taking anticonvulsants and are pregnant, please consider sharing your experience. [http://www.aedpregnancyregistry.org/](http://www.aedpregnancyregistry.org/)

If there is a specific topic you would like to learn more about, do not hesitate to let us know (email sdumanis@efa.org and put Hot Topic in the subject line).