

# Patients Will Soon Be Able to Predict Seizures With the Help of Forecasting Devices

By Sonya B. Dumanis

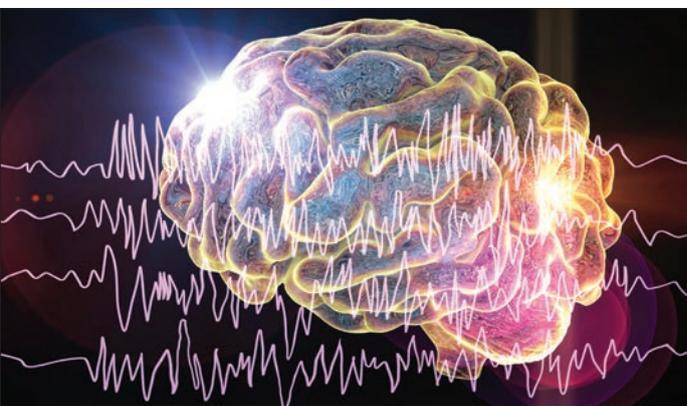
According to the World Health Organization, around 50 million people live with epilepsy around the globe. Thirty percent of whom do not have seizure control. This reality for the 30 percent has not changed in decades, despite 15 plus therapies entering the market since the 1990s. It is this reality that needs, and is going, to change.

The Epilepsy Foundation is shaking up the system by accelerating and de-risking discovery and development for epilepsy therapeutics. The Foundation champions an open-innovation philosophy with a focus on developing a rich ecosystem for research and discovery. To this end, the Foundation creates and disseminates tools to help people with epilepsy, families, researchers and healthcare providers improve outcomes, care and move toward a reality where personalized healthcare can unlock the mysteries behind the how and why treatments work.

Harnessing the power of digital engagement, the Epilepsy Foundation has implemented strategic initiatives that brings innovative science to the person living with epilepsy.

## Big Data Keeps Track

The Epilepsy Foundation My Seizure Diary is a self-management tool to help record, track, and manage one's seizures and epilepsy. Using a diary tool can help someone understand their specific seizures, identify triggers to avoid and create



action plans for when those triggers happen. This past year, the Epilepsy Foundation upgraded diary features to make it a compatible resource for clinical trials and research use. For example, the diary is integrated in the Human Epilepsy Project 2 clinical observational study, which tracks

seizures in those with drug-resistant focal epilepsy.

## Incubator for Innovation

The Epilepsy Innovation Institute, an innovation incubator supported by the Epilepsy Foundation is developing a personalized seizure advisory system tool through the My Seizure Gauge initiative. We are getting better and better at forecasting the weather, what if we could do the same with seizures? Unpredictability, in the when or the why of a seizure starts, is a top issue for the epilepsy community. Leveraging the exciting research coming out of the seizure forecasting field, emerging wearable technologies and machine learning, the Foundation is spearheading the development of a seizure forecasting device.

The plan is unique. There are over a thousand individuals who have been implanted with ambulatory intracranial EEG recording devices. Coupling these recordings to peripheral measurements from emerging biosensors and wearable device technology and syncing it up to a data collection platform may provide new relationships and insights. The vision is to not just measure a few components, but a myriad of factors, and then mine the data for new clues about what happens in the

the hours and minutes before a seizure. Currently in the first phase of the challenge, work is being done to access the total scope of measurements that are needed for a reliable seizure forecasting prototype device.

My Seizure Gauge will lay 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 will also aid in developing personalized dosing of medication & device stimulation to reduce medication side effect, assess whether there are potential new targets for drug discovery platforms (such as new non-EEG based assays to be used in existing or new animal models) and

bring a better understand the molecular profiles of epilepsy subtypes, which in turn could improve diagnosis and address WHY seizures arise in an individual.

## People In Clinical Trials

Eighty percent of people living with epilepsy are interested in participating in clinical trials, although 20 percent of them ever do participate. The number one reason for not participating is the lack of information regarding open clinical trials. The Epilepsy Foundation has launched a Clinical Trials Portal to connect people to active trials. The Foundation is ideally positioned to do so, as nearly 1 million unique IP users per month visit [epilepsy.com](http://epilepsy.com).



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## Databank for Rare Diseases

The manifestation of epilepsy, in terms of seizure type, severity and age of onset has been shown to vary

widely among people living with epilepsy. Just like there are many different cancer subtypes and severities which require tailored individualized treatment, epilepsy is starting to be viewed as the epilepsies with many different subtypes. Unfortunately, the biological and clinical profiles of all epilepsy subtypes are not well known. In response, the Epilepsy Foundation is spearheading the Rare Epilepsy Network, a collection of more than 30 organizations, to create a comprehensive registry, identify common and unique targets among the epilepsy subtypes, and facilitate a precision medicine pipeline.

A key component to the platform is also creating a return of results dashboard, to ensure that the community grows from the information collected. If you are involved with registries, patient engagement platforms, or precision medicine, please let us know about your initiatives!

The Epilepsy Foundation knows that together, with industry partners, the needle can be moved to improve the lives of people living with epilepsy. We welcome and celebrate our partners and look forward to a future where each person living with epilepsy can have a good quality of life and find the correct treatment in a timeframe that matters. 