



THE EPILEPSY FOUNDATION OF FLORIDA'S MONTHLY NEWSLETTER IS DEDICATED TO BRINGING YOU THE LATEST NEWS, EVENTS AND HOT TOPICS IMPACTING FLORIDA'S EPILEPSY COMMUNITY.

## Educate for Hope

### Message from the CEO:



Spring is finally upon us and the year shows no signs of slowing down. Legislative session just ended without the passage of medical marijuana measures. We'll continue to keep you updated on this important issue.

Earlier this month, EFOF headed to the state capital to honor legislative members who have dedicated themselves to elevating and advancing our organization's advocacy efforts to the over 400,000 individuals impacted by epilepsy statewide.

Two weeks ago, our last of the eight Walk the Talk events took place in Daytona. The last two months of walk events have been outstanding, and the foundation has not only brought attention to those impacted by epilepsy but raised over \$410,000 and counting! Thank you to all who participated and promoted these events.

We look forward to hearing from you and I hope you have a great month!

Sincerely,  
**Karen Basha Egozi,**

Chief Executive Officer  
Epilepsy Foundation of Florida

## Champion of the Heart Award

### Epilepsy Foundation of Florida Honors Six Lawmakers with Champion of the Heart Award



The Epilepsy Foundation of Florida (EFOF) honored six Florida lawmakers at a reception in Tallahassee with the Champions of the Heart award for their individual efforts to help residents and families impacted by epilepsy.

Lawmakers honored with the Champions of the Heart designation by EFOF included:

- Senator Jeff Brandes
- Representative Katie A. Edwards
- Representative Matt Gaetz
- Senator Rene Garcia
- Senator Denise Grimsley
- Representative Matt Hudson

"These legislative leaders ensure the 400,000 individuals living with the disease have access to information and medical care that will allow them to better live their everyday lives," said Karen Basha Egozi, chief executive officer of EFOF. "These Champions help to uphold funding so our organization can be a conduit of information for our members, improve the general public's perception of epilepsy and pursue options that could result in a cure."

These elected leaders were chosen for their support and efforts as they ensure resources are preserved and promote new treatment options for epilepsy patients, like medical marijuana, are explored and advocated for during the Legislative Session. Previous Champion of the Heart awardees have included Senator Aaron Bean, former Representative Adam Hasner and former Senator Nan Rich.

## 2015 Epilepsy Pipeline Community Conference Coming in May, hosted by Epilepsy Foundation of Florida & Epilepsy Foundation of America

Curious about the latest news on rare epilepsies, new seizure medications including medical marijuana, and research on thinking, behavior and mood? Leading epilepsy experts will discuss updates on these topics and more at the 2015 Epilepsy Pipeline Community Conference on Saturday, May 16, 2015, dedicated to people living with epilepsy and seizures, their loved ones, and epilepsy advocates. Registration for the Pipeline Conference is open and free to the community. [Click here](#) to learn more.

## Technological Innovations Impacting the Treatment of Epilepsy

### Zebrafish Can Be Key to the Study of Human Epilepsy Genes

Adult rodents have been useful to study genetic genes when it is absolutely necessary, however, a new breakthrough has rose to the surface. Dr. Vincent Cunliffe and his colleagues at the University of Sheffield were presented with a pilot grant to investigate [zebrafish as a model of genetic epilepsy](#).

Zebrafish and the human brain are similar anatomically and susceptible to experimentally-induced epileptic seizures. A positive attribute to having zebrafish in the laboratory is that it is economically easier to breed them. The larvae in a zebrafish is transparent, meaning that the activity of individual brain cells can be easily observed.

During the study, multiple mutations of young zebrafish were created that equaled to three different human epilepsy genes. One gene called *stxbp1b* had reduced motility, suggesting that this gene is important for regulating movement. This gene is active in the pineal gland, a light-sensitive region of the brain, and therefore also regulate the brain's response to light. It is possible that defects in *stxbp1b* make the brain sensitive to seizure-inducing stimuli. None of the mutations examined rendered the zebrafish more susceptible to seizures when exposed to a powerful chemical convulsant.

The significance of this has shown that zebrafish are a powerful tool to characterized epilepsy-related mutations.

### Focusing on Brain Metabolism Might Be a Way to Treat Epilepsy

There has been evidence that epilepsy may be a disorder of energy metabolism. [According to Japanese researchers](#), this discovery could offer a fresh approach to developing more effective anti-epileptic drugs. This discovery occurred when researchers shut down a metabolic pathway that fuels misfiring neurons that suppress seizures in mice.

It has been known that people with epilepsy get relief by following the ketogenic diet. This diet consists of high in fat and low in carbohydrates. The metabolic balance of the brain shifts, so that the neurons' primary energy source switches from glucose to a class of compound called ketones. Tsuyoshi Inoue and his colleagues from Okayama University, located in Japan, report that one of the existing epilepsy drugs called stiripentol can control seizures by mimicking the metabolic effects of a ketogenic diet.

### NeuroPace RNC System Reduces Seizures

NeuroPace Inc, announced recently that their results from an ongoing long-term treatment (LTT) study demonstrate the RNS System significantly reduces ongoing seizure frequency among adults who have a common form of epilepsy that is difficult to treat with medication.

The results from their ongoing study, which was published in *Neurology*, contained data on 230 people with medically intractable partial onset epilepsy enrolled at 33 Comprehensive Centers in the United States.

The LTT that was conducted was an ongoing seven-year study. The study demonstrated significant improvements in overall quality of life. It also indicated a more positive perception of cognitive function, relationships and social function, overall health and vulnerability to seizures.

The RNS System is the first closed-loop responsive brain stimulation system. The system is designed to treat partial onset seizures by detecting specific types of electrical activity in the brain through leads containing electrodes that are placed near the patient's seizure focus or foci. When detection thresholds are met, the device delivers small bursts of electrical stimulation intended to reduce the frequency of seizures. Physicians can program the detection and stimulation parameters of the implanted RNS Neurostimulator non-invasively to customize therapy for each individual.

### Seeking Educational Accommodations for Students of All Ages

by *Judy Siskind, Ph.D., EFOF Staff Psychologist*

Most students with epilepsy, whether in kindergarten or college, have more challenges to academic achievement than do their peers without epilepsy. This is not because they are less intelligent as a group—in fact, many are gifted in some of their academic skills. However, epilepsy itself interferes with memory functioning. Most seizures start in the temporal lobes, where recent memories are stored in a structure called the hippocampus. The bursts of excessive electrical activity interfere with normal memory storage, causing students with epilepsy to have more trouble retaining information they have learned.

Related difficulties with attention and concentration, due both to the seizure activity and to the required anti-seizure medications, also make it harder for students with epilepsy to achieve at the level they otherwise could. Furthermore, processing speed (speed of performing the tasks related to completing an academic assignment or test question) is typically slower for students with seizure disorders.

Because of all these additional challenges, it is important for teachers to be aware of the extra time and other sorts of extra help (such as smaller classes or individual tutoring) that these students often need. The measures taken to provide more support and flexibility for students with epilepsy, among others with learning differences, are called educational accommodations. They are provided to students shown to need them by federal laws enacted through the Americans with Disabilities Act (ADA).

One of the services I provide to our clients as a clinical psychologist licensed in Florida is to do what is called psycho-educational testing so that I can document both the strengths and difficulties the individual student is experiencing and show that he or she is eligible for the additional help and support of the accommodations. I provide a detailed report that is used by the school staff as information directly relevant to educational planning. Most of our clients cannot afford this evaluation privately, as it costs close to \$1000 when done by a private psychologist.

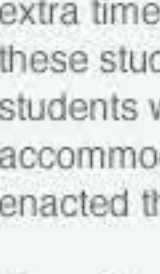
Usually my evaluation is part of a set of procedures (including parent interview, vision and hearing screening, and questionnaires completed by the teachers) leading to creation of an Individual Educational Plan (IEP) for the student. The plan will follow that student throughout his or her years in school, with modification made annually as each year's progress is reviewed.

Although the public schools do have school psychologists, each shared by several schools, students can wait many months to be tested. Furthermore, school psychologists are typically not aware of the negative side effects of even subtle seizure activity and of most anti-epileptic drugs, which can lower concentration and therefore also performance speed. School psychologists express gratitude to have my consultation on these aspects of our clients' learning, and both older students and parents are glad to be able to meet institutional requirements in documenting the extent and areas of learning difficulty that make them or their children eligible for the accommodations needed for them to earn their degrees and work successfully towards personal career goals.

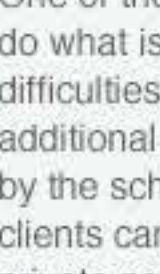
### Cleveland Clinic Florida Expands Braathen Neurological Center and the Maroone Cancer Center

On Feb. 19, 2015, Cleveland Clinic Florida hosted an official ribbon-cutting ceremony and VIP opening celebration for the new Egil and Pauline Braathen Center, a five-story, 143,000-square-foot building on the Weston Campus that houses the expanded Pauline Braathen Neurological Center and the Maroone Cancer Center. Cleveland Clinic's leadership, supporters and local government officials gathered to commemorate the occasion and recognize the generosity of donors such as visionary and longtime patient Pauline Braathen as well as Al and Mike Maroone, co-chairs of The Campaign for Cleveland Clinic Florida.

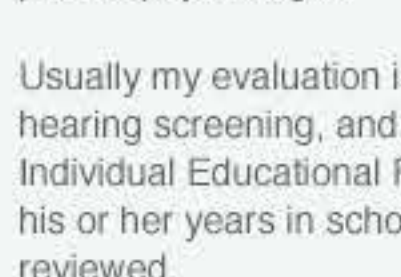
Cleveland Clinic Florida broke ground on the Egil and Pauline Braathen Center in November 2013 and opened to patients on March 2, 2015. Located on the Weston campus, the expanded Pauline Braathen Neurological Center and the Maroone Cancer Center combine advanced diagnostic and treatment capabilities, major technology investments, holistic patient services and a multidisciplinary health care team in an outpatient setting.



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The Epilepsy Foundation of Florida (EFOF)  
1200 N. W. 78 Avenue, Suite 400  
Miami, FL 33126  
<http://www.efof.org/>  
1-877-55-EPILEPSY (1-877-553-7453)