

November 2017 Newsletter

Dear Friends of the Epilepsy Foundation of Florida,

Happy National Epilepsy Awareness Month!

Did you know that epilepsy is a condition more people live with than autism, Parkinson's disease, multiple sclerosis and cerebral palsy – combined? The family of epilepsy diseases is the fourth-most prevalent neurological condition in the United States, striking approximately three million people nationally and more than 400,000 in Florida. Here at EFOF, we're proud to promote education and awareness about epilepsy, and provide access to resources and accelerated therapies designed to stop seizures and save lives. To learn more about the many services we provide and how we impact our Florida communities, I hope you'll take some time to read the below "EFOF 101" section.

I also hope you can join us in celebration and support for one of our signature Let's Talk About It! events that are taking place across the state this month. These events not only raise critical funds for EFOF, but increase awareness about epilepsy to help support the thousands of Floridians and their families affected by the disorder. I also encourage you to [host your own Do-It-Yourself \(DIY\) event](#) to help spread further epilepsy awareness in your community.

Not only during the month of November, but every day, it's our mission to raise awareness, end fear, fight discrimination, and show support for people impacted by epilepsy and seizures. With your support, we are increasing education and understanding within our communities, eliminating stigma, and empowering those affected by the disorder. Now, and always, thank you for helping us move one step closer to finding a cure.

Sincerely,



*Karen Basha Egozi
Chief Executive Officer
Epilepsy Foundation of Florida*



The Epilepsy Foundation of Florida leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

The Foundation provides numerous services to individuals and families, regardless of financial situation, such as advocacy and individualized case management, prevention and education, direct medical and psychological services, as well as research and other programs.

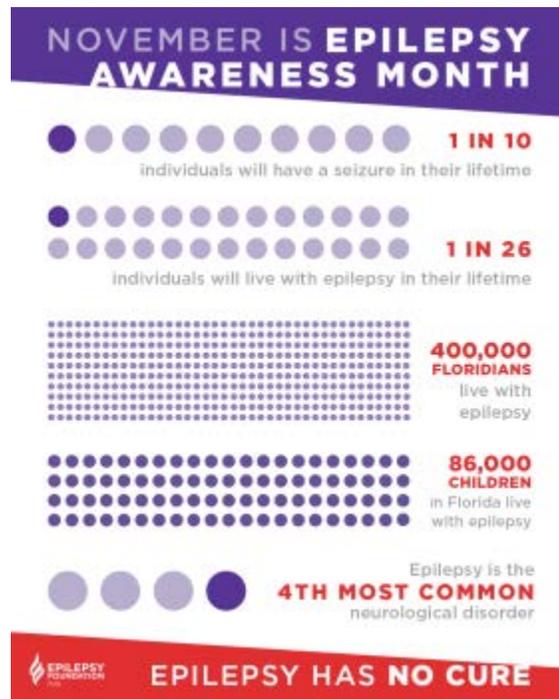
[Learn more.](#)

By the Numbers: EFOF Services in 2016-2017



2016-2017 Annual Report

Review our successes and progress made in the 2016-2017 year by [viewing our Annual Report](#).



Help Spread Awareness

Share this infographic on social media and with your family and friends to help spread epilepsy awareness in November.

[Click here to download the infographic.](#)

Let's Talk About It!

Unmasking Epilepsy | Miami

We officially kicked off National Epilepsy Awareness Month on October 19th in Miami at our 4th Annual 'Unmasking Epilepsy' event! Thank you so much to everyone who was able to join us and provide support; we had an amazing turn out, and believe it set the tone for the rest of this month.



Cheers for Charity | Pensacola

A huge thank you is also in order for everyone who helped make our 'Cheers for Charity' event on November 2nd in Pensacola a success!



Join Us!

There are still five more signature 'Let's Talk About It!' events taking place across the state – and you're invited! Will you join us as we celebrate epilepsy awareness, honor those who have made an impact in their community, and raise funds to provide services and support to those who need it most?



Cocktail Reception | November 9



Gala | November 9



Cocktail Reception | November 14



Ribbon Cutting Cocktail | November 15



Brewery Event | November 18

DIY (Do-It-Yourself)

**NOVEMBER IS
EPILEPSY AWARENESS
MONTH**

*Let's Talk
About It!*

**Thinking of hosting a DIY event?
Here are some ideas to get you started!**

Video Game Tournament	Cooking Party
Lemonade Stand	Talent/Fashion Show
Bake Sale	Bingo Night
Game Night with a Purpose	Percentage of Sales at Restaurant or Local Business
Movie/TV Night with a Purpose	Percentage of Product Sales
Sports Tournament	Chili Cook-Off
Chess/Domino Tournament	Walk/Run
Pub Crawl <i>(21+ years old)</i>	Bowling Night
Pint Night at local establishment <i>(21+ years old)</i>	Car Wash
Wine & Cheese Night <i>(21+ years old)</i>	50/50 Raffle
Painting with a Purpose	Jeans Day at the Office
Party with a Purpose	Garage Sale
Karaoke Night	Workout Class for Charity
Poetry Night	Boxing Match
Comedy Night	Spa Day

**REGISTER YOUR EVENT AT
WWW.EFOF.ORG/HOST-A-DIY**

 **EPILEPSY
FOUNDATION**
Since 1927

1-877-553-7453 | WWW.EFOF.ORG

Next-Generation of VNS Therapy



The FDA has just approved the next generation of VNS Therapy® System for the treatment of patients with drug-resistant epilepsy. Designed to prevent seizures before they start and automatically deliver extra therapy to stop them if they do, the new [VNS Therapy](#) System consists of:

- SenTiva™, the smallest and lightest responsive therapy for epilepsy
- The next-generation VNS Therapy Programming System, which features a wireless wand and new user interface on a small tablet

Together, the components offer patients with drug-resistant epilepsy a physician-directed customizable therapy with smart technology and proven results to reduce the number of seizures, lessen the duration of seizures and enable a faster recovery.

In addition, SenTiva's compact size allows for a more comfortable experience for pediatric patients, which is beneficial now that VNS Therapy is the first and only system that is FDA approved for drug-resistant epilepsy in [children as young as four years of age](#).

More information can be found by clicking [here](#).

Clayton Feig Legacy Fund - Faces of Epilepsy

By: Jennifer Field

The Epilepsy Foundation of Florida has been by my side since 2011 after I lost my job due to my seizures and side effects. I was diagnosed in 2008 and I voluntarily gave up my driver's license after a car accident. I had been having the sensation of déjà vu and having a weird taste in my mouth. It turned out, I was having seizures that whole time. I was diagnosed at the age of 24.



When I became a client of EFOF, I wasn't able to pay for my neurological care or medication. The medications I was on at the time were over \$1,000 a month. EFOF assisted me with access to PAPs, so I was able to get my medications for FREE! I was also able to see a neurologist regularly without having to pay out-of-pocket.

Since becoming a client, I have participated in many events and activities with the Foundation. I participate in the Walks every year and have raised over \$2,000 total for them. I have attended the support group meetings, the Let's Talk About It Dinner, and I volunteered at the Athlete's vs. Epilepsy Golf Tournament. My goal is to raise more money for the walk next year and continue to help with events like the Golf Tournament.

The support group meetings were essential to me and my family to understand and manage my epilepsy. At the support group meetings, I was able to learn more about the different types of seizures and what resources are available in our area. Also, it was a way for me to meet other people who have also been diagnosed with epilepsy, hear their stories, and learn about their journey.

On August 12, 2016, I had the Vagal Nerve Stimulator (VNS) implanted to help reduce, if not beat my epilepsy. I have been seizure free for four months now, and driving is a real goal that I see in my near future! With every setback and frustration on my journey, every time I have to start back at square-one, I know is not really a setback but a way for me to grow stronger, with more resolve.

Check out more Faces of Epilepsy stories [here!](#)



WEAR-TV (ABC) produced a special story for the station's morning show which aired on Wednesday, November 1st and featured an interview with EFOF client Carrie Grimm of Pensacola. She spoke of her personal story and struggles with epilepsy, but highlighted the impact and importance that the Epilepsy Foundation of Florida has had on providing assistance and support to her. Click the image above to watch the interview and hear her story!

Upcoming Events



Painting for Epilepsy
Jupiter | Nov. 12



Poker Tournament for Epilepsy
Pensacola | Nov. 17



**4th Annual St. Johns Professional
Alliance Chili Cook-Off**
St. Johns | Nov. 18



Pallets for a Purpose
Fernandina Beach | Nov. 20

Has Your Family Been Affected by Childhood Epilepsy?



If so, you may be interested in the Daisy Study, which is investigating an 'add-on' therapy for infants who are between 1 month old and less than 4 years old, who have been diagnosed with epilepsy.

If you would like more information about this clinical research study, please contact:

- Denise Hubert, Study Administrator, Pediatric Neurology, PA (7485 Sand Lake Commons Blvd., Orlando, FL 32819) at **(407) 293-1122, ext. 226**
- Mayra Ferreira, Study Administrator, Pediatric Epilepsy & Neurology Associates (508 S Habana Ave., Tampa, FL 33609) at **(813) 873- 7367**

Asking for further information does not obligate you to enroll your child in this study; participation is entirely voluntary. Study-related medication, procedures, and visits will be provided at no charge.

To read the Daisy Study brochure, click [HERE](#).

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SUPPORT YOUR EPILEPSY FOUNDATION OF FLORIDA

No one can prepare for a seizure as it can happen at the most unexpected time. There are currently more than 400,000 individuals who suffer from epilepsy across Florida with more than 89,000 of those sufferers being children. Prevention and education can better prepare those impacted by the disease. The Epilepsy Foundation of Florida (EFOF) is here to help provide services and resources to those needing it most, and to those seeking more information.

EFOF offers extensive and supportive services and programs to individuals, families, friends and the community at large including:

- Educational presentations
- Current epilepsy resources and information
- Medical services
- Support groups
- Sponsorship & Volunteer Opportunities
- Summer Camp
- Patient Navigation
- So much more!

To become a client and for more information about the organization, the individuals it serves and the resources provided to those in need, visit www.epilepsyfla.org or call 1-877-553-7453.

[Make a Donation](#)



Everyday Extraordinary Epilepsy Care

Marcela suffered from epileptic seizures and medication side effects. After careful observation in Memorial's advanced Epilepsy Monitoring Unit, Tarek Zakaria, MD, Neurologist, diagnosed her seizures, ruled out surgery and prescribed a medication to improve her quality of life. Now, Marcela lives extraordinary every day.

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