



March 2017 Newsletter

Dear Friends of the Epilepsy Foundation of Florida,

We're kicking off our busy spring season this month with the first Walk the Talk for Epilepsy event in Gainesville on March 25. Walks in Naples, Daytona (New Smyrna Beach), Pensacola, West Palm Beach (Lake Worth), Miami, Broward (Hollywood), and Jacksonville will follow during April and May. If you haven't already done so, now is the time to put your teams together and make plans to help raise funding and awareness for epilepsy. Information about each walk follows in this newsletter.

The Epilepsy Foundation of Florida honored lawmakers who have been special supporters of EFOF and the cause for epilepsy at the Purple = Red + Blue Reception on February 22. Many thanks to all of you who attended this important event in Tallahassee and showed your appreciation for these amazing individuals. Champion of the Heart awardees were Senator Anitere Flores, Senator Audrey Gibson, Senator Dana Young, and Representative Jason Brodeur.

It's with a somber heart that I share the news of the passing of one of our beloved team members, Lillian Ledegang. She served the membership of EFOF for almost two years, and her commitment and service to this organization was unmatched. Her legacy of selflessness and giving continues as her family would ask that in lieu of flowers, donations be made to EFOF to support children attending Camp Boggy Creek. To learn more, visit www.efof.org/leeslegacy/.

Let your voice be heard this month as, together, we fight the battle against epilepsy!

Sincerely,



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

Four Legislators Honored with the Champion of the Heart Award



Last month, the Epilepsy Foundation of Florida hosted a reception in Tallahassee to honor four Florida lawmakers for their extraordinary support of the epilepsy community.

CEO Karen Basha Egozi said, "These legislators have worked tirelessly to ensure that the 400,000 Floridians living with epilepsy have the support they need to deal with this serious disease. On behalf of those with epilepsy and related seizure diseases and disorders, it is our distinct pleasure to celebrate the accomplishments of these stellar individuals."

Those honored with the EFOF Champion of the Heart award at the Purple = Red + Blue Reception were:

- Senator Anitere Flores
- Senator Audrey Gibson
- Senator Dana Young
- Representative Jason Brodeur

[Check out photos from our Purple = Red + Blue reception here!](#)

In addition to the award ceremony, staff and members of the EFOF board, including Vice President Steve Schale, Michael Bowen and his wife Stephani Bowen, Daniel Perez and Molly McCann, daughter of board Secretary Stephanie McCann, met with more than 20 legislators throughout the day. The organization also had a table with educational materials set up at the entrance of the Capitol.



EFOF staff & board members with Senator Aaron Bean



Representative Jeanette Núñez kindly hosted a big group from the EFOF team!



Representative Nick Duran meets with staff and board member Steve Schale!



Staff & BOD with Senators Keith Perry & Frank Artiles

Lee's Legacy



On February 27th, the Foundation mourned the passing of a beloved employee and friend to all. Lillian Ledegang (1957-2017), known to all as Lee, served as our Database Management Coordinator, but more than that, she served as a beacon of kindness and understanding to all of us. She never had a negative word and always approached her work and life with a constant smile. We are all devastated by the loss of our dear Lee. Our hearts and prayers are with her family and loved ones at this time. Lee is survived by her daughter, two sisters and brother, and countless friends. Lee's family has requested that in lieu of flowers, donations be made to the Epilepsy Foundation of Florida. All donations will go to support children to attend Camp Boggy Creek. To learn more about Lee's Legacy, [click here](#).

Don't Miss the Chance to Walk the Talk for Epilepsy!



Our official Walk the Talk 2017 PSA is now available on YouTube. Please use this video as a way to spread the word about the walks to others in your network!

The popular and exciting Walk the Talk for Epilepsy series kicks off in Gainesville at University of Florida's Flavet Field (Woodlawn Drive) on Saturday, March 25, raising awareness and funds for Floridians impacted by epilepsy. Registration will open at 8 a.m., with the walk following at 9 a.m.

The Walk the Talk events follow throughout the state in eight total locations and ends May 20th in Jacksonville. In addition to the walk, each venue will feature information booths, music, vendors, food, and family-friendly entertainment for children and adults.

Statewide sponsors for the events include: [Nicklaus Children's Hospital](#), [Sunovion](#), [Liva Nova](#) and [Lundbeck](#).

For more information and to register visit www.efof.org/walkthetalk

Saturday, March 25

Gainesville

University of Florida
Flavet Field

Saturday, April 1

Naples

North Collier Regional Park
15000 Livingston Road

Saturday, April 1

Daytona

Mary Bethune Park
6656 S. Atlantic Avenue

Saturday, April 8

Pensacola

Blue Wahoos Stadium
351 W Cedar St.

Sunday, April 30

Lake Worth

John Prince Memorial Park
2700 6th Avenue South

Saturday, May 6

Miami

Tropical Park
7900 SW 40th Street

Sunday, May 7

Hollywood

North Park Beach
3601 N Ocean Drive

Saturday, May 20

Jacksonville

Metropolitan Park
1410 Gator Bowl Blvd.

Golfer Jeff Klauk Wins \$15,000 for EFOF



Professional golfer Jeff Klauk won first place at The Charity Challenge of THE PLAYERS Championship held March 7th, winning \$15,000 for the Epilepsy Foundation of Florida!

Celebrity golfer Jason Day, last year's PLAYERS Championship winner, announced that he was donating an additional \$5,000 to each of the 10 charities - which gave the Epilepsy Foundation of Florida an immediate \$15,000 donation.

For Jeff, this charity event was very personal. He was stricken with a series of seizures in 2006 that continue to impact him to this day and actively works with his neurologist to find the correct medications to help control his seizures. Despite the challenges of living with epilepsy, he accomplished his dream of earning his PGA Tour Card in 2008. Jeff's wife, Shanna, became a member of the Board of Directors of the Epilepsy Foundation of Florida after his diagnosis and knows first-hand the challenges of a family member battling epilepsy on a daily basis.

Next comes Klauk's debut event, the national Athletes vs. Epilepsy \$1 Million Shootout on Monday, April 10 in St. Augustine, Florida. According to Jeff, "This event is personal to me as I know first-hand what living with epilepsy is like, including the triumphs and setbacks that occur each and every day while managing the disease. I encourage anyone interested in raising funds and awareness to assist the more than 3 million people in the United States, including the more than 400,000 in Florida, living with epilepsy and other seizure diseases and disorders to play in North Florida's most exciting event."

[Click here for more information and to register for the \\$1 Million Dollar Shootout!](#)

Clayton Feig Legacy Fund - Faces of Epilepsy

By: Heather Kidd

Hi, my name is Heather, and I would like to take you on a journey through my life with epilepsy. Yes, I have epilepsy, but it doesn't have me.

I was diagnosed with epilepsy when I was 12 years old. My parents didn't know much about epilepsy back then. We are so blessed to have the Epilepsy Foundation to give out information that was not available at that time. My teenage years were full of trying different medications, but not much helped or changed. I'm so grateful I have a father that showed me how to be independent, and not let epilepsy limit me, and a mother who helped me become compassionate and want to help others, but my life changed when I went to the Epilepsy Foundation. I attended the support groups, and participated in the employment program. I then realized I was not alone.

One of the things that helped my seizure control was the VNS device or Vagal Nerve Stimulator. It's a small implant that goes in your chest wall area, and has wire leads that coil around your vagus nerve. It works like a pacemaker, and sends electrical impulses to the brain to help stop seizures. I decided to have the surgery, and in a short period of time I no longer had seizures that had me exhausted afterwards. I was also able to lower my medication as well. I then felt like I had more control over my life. A friend told me it looked like I "woke up."

I enjoy being an advocate for epilepsy awareness. I was able to share my story about having epilepsy at a walk the Epilepsy Foundation of Missouri and Kansas had. I never thought I would be able to speak in front of a group of roughly three hundred people. That showed me I could do anything I put my mind to. Never underestimate what you are capable of.

The one thing I really enjoy is writing. I write articles about epilepsy and other health issues with hopes that someone will be able to relate somehow. My credit union lets me write in their newsletter each November. I title it "November is Epilepsy Awareness Month." I always include educational information about epilepsy, along with my personal story. Now if I'm not doing that, you might find me at a walk the Epilepsy Foundation of America has or trying to find a way to get items for a gala to raise money for the Epilepsy Foundation.

I would never be able to do the things I enjoy so much without the support of others. That would be from my mom who always gives me suggestions for articles to write. My father who bought my computer I write articles on, or my sister who always listens to me when I share what I want to do next. You might even find the support you need when you open up your computer. You will find social media will be there for you. Facebook can connect you to someone who might live down the street or on the other side of the globe. You will find that you are never alone.



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.

**M Memorial
Neuroscience Institute**

[Learn More](#)



A Global Leader in Pediatric Epilepsy Care

[LEARN MORE](#)

 Nicklaus
Children's
Hospital
MIAMI CHILDREN'S HEALTH SYSTEM

Brain Institute



[Home](#) [Contact](#) [About Us](#) [Giving](#)

[Privacy Policy](#) | [Unsubscribe](#)

[Epilepsy Foundation of Florida](#)
1200 NW 78th Ave Ste 400, Miami, FL 33126

