

July 2017 Newsletter

Dear Friends of the Epilepsy Foundation of Florida,

This month, as we commemorate the birth of our nation, we also celebrate the many ways the Epilepsy Foundation of Florida is able to help our clients achieve independence in their own lives. Through the myriad of services we provide, including support groups, individualized case management, medical services, advocacy, and much more, we restore independence to the lives of thousands of Floridians and their families.

Congratulations are due to our second "Caught in the Act of Excellence" employee – Gainesville Social Services Case Manager, Janna Edwards! Janna, despite having only been an EFOF staff member for a short while, the impact you've made on our organization is everlasting. The level of service you provide to your clients is unparalleled, and we are so thankful for your dedication to our cause. We applaud you!

I'm also thrilled to recognize the appointment of two new EFOF board members: Patricia Dean and Jeff Klauk. We welcome you to the EFOF family- Jeff, and Pat- welcome back!

While perusing this month's newsletter, please don't forget to check out our wonderful advertisers: Pfizer, Sunovion and Memorial Neuroscience Institute. Their ads are located at the bottom of this newsletter, and provide some great information on how they're respectively helping in the fight against epilepsy. Our partnership with our sponsors and advertisers allow the foundation to continue providing much needed services and support to individuals living with epilepsy across the state, so we thank them for their continued dedication to our mission.

Wishing you a safe and happy July!



Sincerely,

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

Clayton Feig Legacy Fund - Faces of Epilepsy

By: Mary Lawrence

During my childhood and throughout adulthood, I've had trouble with my parents, mentors, and acquaintances understanding my epilepsy. Some called my seizures fits/tantrums or even disrespect. This program (EFOF) has given clarity and realization of details on this issue. I first became involved with EFOF after it was recommended by associates, family, and medical professionals after having a stroke and brain surgery in 2007. I attend the support group meetings regularly and attend as many of the extra events that are hosted and sponsored by EFOF as possible. The support groups have made a difference in

my life because I now have a place to go to learn more about my seizures, a place where I can learn more every month about epilepsy, speak to others who have been through what I've been through, and support others, as well. EFOF has provided resources in the area available to me, and it's also helped me learn how to talk to others about epilepsy. The support group has especially been a great tool and resource for me and others.

These programs have changed my life by helping create new relationships and understanding while on my epilepsy journey.

In 2017, it will be the 10-year anniversary of my brain issues. In 1973, at three-years-old and after an intense seizure experience, it was discovered that I have a birth defect: a gap in my skull, indicating the bone tissue did not develop properly. At seven years of age, surgery was performed attempting to repair it. Every 10 years since then, I've had a problem from the



Mary Lawrence (right), client since 2011, with her EFOF Case Manager Christal Davie (left).

surgery: at seven-years-old, uncontrollable temperatures; at 17, a seizure; at 27, a stroke; and at 37, a discovery of bleeding on the brain.

I will be 47-years-old this year. Who knows what will come next in my epilepsy journey – a mystery solved, hopefully. Although the year is still young, I may have discovered where the next chapter to this story will lead me. On March 4, I woke up with what felt like a sinus headache. By the following day I began having issues with double vision, but not the kind that can be treated with glasses. It is where I see things one on top of the other. I went to the ER at the insistence of my family and was admitted overnight for a CAT scan and MRI. No evidence of a stroke was found. Eye exams show that I have a clear vision in each eye, they just aren't working together. But this will not stop me from living my life to the fullest and participating in as many EFOF events as I can.

[Read more stories on our Faces of Epilepsy blog and submit yours!](#)

Ron Sarraf, a Valley Fever Survivor, has Hope because of the Affordable Care Act

The Epilepsy Foundation of Florida has been assisting thousands through our Healthcare Navigation Program. This federally certified healthcare enrollment program, through the Affordable Care Act, provides in-person education, counseling and enrollment assistance to Floridians wanting to shop and enroll for health coverage, or have questions concerning their health insurance. Call 877-553-7453 for assistance or visit www.efof.org/acanavigation.



Ron Sarraf with his husband, Daniel Berrios, and step-son, Adam Berrios.

In 2006, Ron Sarraf was driving through Napa Valley in California when the spores of a fungi plant happened to be wafting through the dry, desert air. Sarraf had the misfortune to breathe in those spores, which unbeknownst to him, carried the fungal disease coccidioidomycosis, also known as "Valley Fever." The air-borne fungus attacks the lungs, causing flu-like symptoms and, in worst case scenarios, a chronic form of pneumonia.

Within a few weeks, Ron developed flu-like symptoms. His lungs filled with fluid; he suffered high fevers. He was initially treated for pneumonia but never got well. His fever shot up to 105, and he became delirious. A

hospital took him in as a charity case. That was the first step in a long battle to getting

diagnosed and then treated. The journey would include 17 days in a hospital. For ten years, he has been on a roller coaster ride of illness followed by treatment followed by remission followed by illness again.

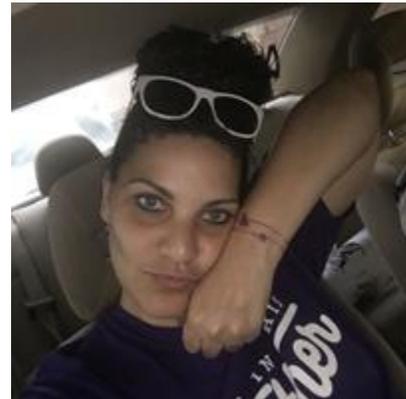
He is grateful the Affordable Care Act was passed, which finally allowed him to have health insurance, regardless of his employment.

"I wasn't even a supporter of the ACA when it passed," Ron said. "I didn't really understand it. Only after I became sick did I begin to understand how important it was, and how it saves lives. It saved my life..." [Read the rest of Ron's story here.](#)

Caught in the Act of Excellence!

EFOF recently launched a new employee recognition program called "Caught in the Act of Excellence." Employees are encouraged to make nominations of their fellow co-workers who are "caught" going above and beyond their daily work-related responsibilities. An award is then presented to the deserving individual on a quarterly basis.

Our second employee to receive this prestigious award is our Gainesville Social Services Case Manager, Janna Edwards, who began working with the Foundation in December 2016. Although Janna has only been with our Foundation for six months, she has been involved with EFOF for some time as the Foundation helped her through her own personal battle with epilepsy. Clients feel extremely supported by Janna because she is not only their case manager, but someone who fully understands their journey. Janna recognizes the needs of all her clients and works to the best of her abilities to fulfill them.



Janna was "caught in the act of excellence" on March 25, 2017 during the Gainesville Walk the Talk for Epilepsy when one of her clients had a prolonged seizure and was taken to the hospital by emergency rescue. This particular client is homeless and does not have family in the area, so Janna drove to the hospital and stayed with him until he was admitted. She made sure the client received the care and medical attention he needed and continued to check on him until he was released.

Janna not only has a sunny personality but is very caring, and we are honored to have her as part of our family and team. Thank you, Janna, for your passion and dedication to the Foundation and to those living with epilepsy!

Allstate Foundation supports EFOF



(From left to right) Mary Gomez, VP of Business Development, Lauren Torres, Social Services Case Manager, Lori McHale, Allstate Insurance, Marie Phillips, Medical Case Manager and Sheen Mayberry, WPB Development Associate.

6 Allstate agency owners and staff from the Palm Beach and Broward county areas recently came together to secure \$4,000 from The [Allstate Foundation](#) Helping Hands in the Community grant program that went to support the West Palm Beach Walk the Talk for Epilepsy event this past April.

Participating Allstate agency owners and staff included, Frazier Amanda, Diana Bradley, Sara Callahan, Alesia Gutierrez, Taylor Jackson and Cliff Petty. EFOF's West Palm Beach office hosted a Walk the Talk team captain appreciation event on June 27, 2017 at [Total Wine and Spirit](#) where a \$4,000 check was presented by Lori McHale of Allstate Insurance.

The Epilepsy Foundation of Florida is honored to be one of thousands of organizations this year to receive an Allstate Foundation Helping Hands in the Community grant secured by agency owners and financial specialists on behalf of the nonprofits where they volunteer. A big thank you to the participating Allstate agency owners for your support and dedication to EFOF's mission!

Welcome: New EFOF Board Members

The Foundation is excited to welcome – and welcome back – two members to EFOF's 2017-2018 Board of Directors! These amazing individuals bring new perspectives and expertise, and we're very excited to have them on our team.



Patricia Dean
"Welcome Back!"

Patricia Dean, ARNP, MSN is clinical coordinator of the Comprehensive Epilepsy Center at Nicklaus Children's Hospital in Miami, FL. She received her BS in nursing from Downstate Medical Center and her Masters of Nursing at the University of Miami. As a past president for EFOF's Board of Directors and board member for the Epilepsy Foundation of America (EFOA), Patricia has been extremely involved with and dedicated to the Foundation for a number of years. She is nationally recognized for her work with children with epilepsy and has been involved with the consumer side of epilepsy on local, state, and national levels. She is the recipient of the Volunteer of the Year Award from the EFOA, and has served on the Governor's Task Force on Epilepsy. Patricia is also a highly sought-after lecturer and has published numerous articles. Her research



Jeff Klauk
"Welcome!"

Jeff Klauk graduated from Florida Southern College in 2000. A professional golfer, he qualified for the Web.com Tour in 2001 and in 2003 and won his first professional tournament at the Web.com Wichita Open; one of two wins during his Web.com Tour career. In 2006, Jeff experienced his first tonic-clonic seizure and was diagnosed with epilepsy. After finishing third on the Web.com money list and earning his PGA Tour card in 2008, he went on to qualify for the PGA Tour. A short time later, Jeff had his first complex partial seizure and continued to have them several times a week. He started 2011 on the PGA Tour but after eight events, realized he needed to focus on what was causing his seizures. After undergoing several tests and trying many different medications, he underwent intracranial-monitoring surgery at Emory Hospital. The monitoring revealed that his seizures were

interests are on the antecedents of developmental pathology in intractable epilepsy and self-management skills in epilepsy. The Foundation's new annual award, the Beacon Award, was renamed the Patricia Dean Beacon Award in 2012 to honor her "diligent and tireless efforts to improve the lives of those living with epilepsy through exceptional and passionate care services."

originating in his left frontal lobe, the part of the brain that controls motor skills. He eventually tried a new medication called Vimpat, which he says changed his life and has controlled his seizures. After a successful career in golf, Jeff recently announced that he will retire from the sport and focus on his health, family, and charitable epilepsy initiatives.

[Learn more about EFOF's Board of Directors](#)

Upcoming Events



**Make a Stand Against
Epilepsy - Lemonade for
Livy**
July 28-30



Painting with a Purpose
Naples | Oct. 15



Seizure Smart Talk 5K
Green Cove Springs | Nov.
11

Help Fight Epilepsy with a Bequest to EFOF

You can help ensure a better world for people living with epilepsy by including a charitable bequest to the Epilepsy Foundation of Florida in your will. A bequest is a simple way to help protect the future of our Foundation, and can be any dollar amount, a specific asset, or a percentage of your estate.

By considering this long-term approach to your charitable giving, you can make a positive difference for people with epilepsy and bring us one step closer to a cure. For more

information on making a bequest, please contact:

Mary Gomez

Vice President of Business Development

(954) 779-1509 | mgomez@efof.org

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



Has your young child been affected with epilepsy?
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Learn about the study

[Learn More](#)

For age group: 1 month - <4 years

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HOLD HER BACK.**

[Watch the video](#)

6/17 APT106-17





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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