

Dear Friends of the Epilepsy Foundation of Florida,

Happy August!

Have you ever wondered how you can make a significant difference for your favorite cause? This month, ERC Advisory Board Member, Kyle Skipper, shares some creative ways that anyone can leave a legacy in a tax efficient manner while still making a significant impact. As you consider ways to give, we hope you'll plan your next gift to help us continue providing services and resources for the more than 400,000 individuals who suffer from epilepsy across Florida.

Included in this issue is Stephanie Ramey's story about her experience at this year's National PAME (Partners Against Mortality in Epilepsy) conference. While there, she was able to learn and connect with others about epilepsy, particularly Sudden Unexpected Death in Epilepsy (SUDEP). We thank Stephanie for her courage in attending the conference and sharing her story as SUDEP has personally affected her life through the passing of her 10-year-old son, JT. If you'd like to learn more about SUDEP, please contact us at info@efof.org or (877) 553-7453.



*Sincerely,
Karen Basha Egozi*

*Chief Executive Officer
Epilepsy Foundation of Florida*

It's (Almost) Time to Celebrate!

On October 15, EFOF will officially reach its biggest milestone to date: its 45-year anniversary! The anniversary will kick off during EFOF's annual Let's Talk About It events being held in October across the state and will be celebrated throughout Epilepsy Awareness Month in November. This will be a significant moment in time for our organization, so stay tuned to learn more about the many ways you can get involved in celebrating with us as we continue our legacy of leading the fight against epilepsy in the state of Florida.



Justin Millares is Beating the Odds

Miami Clayton Feig Youth Awardee and Teens Speak Up! representative Justin Millares was selected to attend the Beating the Odds Summit in Washington, D.C. hosted by Michelle Obama! The Summit, which was held on July 19th at the White House, honored 140 college-bound students who have overcome great odds to go to college, and many are even first in their family to pursue further education after high school.

We are so proud of Justin's accomplishments and wish him the best as he begins this next chapter.



My Experience at the PAME Conference



By: *Stephanie Ramey*

Before going to the 2016 Partners Against Mortality in Epilepsy (PAME) conference, I had never heard about the partnership against mortality in epilepsy. I was asked if I was interested in representing the Epilepsy Foundation of Florida at the conference and I knew it was something I needed to do. I needed to try and get some answers, and to learn and connect with others that are working together in the fight against epilepsy.

I was uncertain if I was "ready" to attend the conference, though. My son, JT, passed away from Sudden Unexpected Death in Epilepsy (SUDEP) on September 17, 2015, after recently turning 10. SUDEP

was always my worst fear, but the strange thing is that it was never talked about. Only in doing my own research and hearing about other cases did I learn of SUDEP. Not once did a doctor talk to me about the possibility of death from epilepsy, more specifically a sudden and unexpected death.

I went to the conference searching for answers and learned that unfortunately there aren't any concrete answers about why SUDEP happens. We need more research, and more funding. There were many researchers at the conference that are working hard to try and get evidence-based answers but the funding is lacking. The PAME conference is an amazing organization that brings together researchers, scientists, and physicians with people that are facing the devastations of epilepsy. I spoke with one of the researchers who told me that hearing the stories of families and seeing pictures of those lost to epilepsy-related deaths literally puts a face on the work she is doing back home.

It's so important that we bring more awareness and more funding to epilepsy. In talking with other parents at the conference that have lost children to SUDEP, there was a common theme: anger and confusion that they were never told about this possibility. It's a tough conversation, but one that needs to happen. The feeling of guilt and regret that comes with SUDEP is very real, and the thing I heard a lot from other parents was "if only I had known." All the parents I met agreed, the tough conversation would have been worth having. After hearing the research, I firmly believe that all children with epilepsy should be given monitoring equipment, should have cardiac testing and caregivers should be informed.

I had an amazing, healing experience at this conference and want to continue to learn and spread awareness. I am looking forward to going back to the PAME conference in two years and I highly recommend it for anyone in the epilepsy community.

Faces of Epilepsy - Alaina Young

By: Aimee Young

Alaina Young is my teenage daughter who just happens to have epilepsy. Like many others, my husband and I began to notice unusual symptoms in elementary school. Alaina was eight, and would have times during school that she would just “space out” and lose a few minutes of a lesson. Fast forward to middle school. More symptoms more often. Weeks before her first appointment, I was awoken by Gary screaming across the house to call 911. Alaina was having her first grand mal. Thanks to the Epilepsy Foundation’s website, I knew what was going on and to record the seizure with my cell phone. Now we had some concrete proof. This first seizure was only two days after her 13th birthday.

In meeting with our neurologist, Dr. Abrams, we explained her history and discussed our concerns regarding her skating. Alaina has been playing junior roller derby since she was 10. I remember him just lifting his eyebrows in disbelief. He basically told us to let her live her life as she’s been doing and wait to see if she has another seizure. Four months later, another grand mal right before an out-of-state derby tournament. This time she needed to start medicine. We were all so scared about the side effects and how it would affect her. Amazingly, she did fine and Dr. Abrams just gave us a nod in regards to her skating and in a few months he upped her dosage a bit too.





This April, however, she thought she didn't "need" her medicine anymore and guess what – BOOM!!! Lesson learned. You have epilepsy. That seizure was really humbling for her. It made her realize that she does need to take her medicine and listen to her body. Back when she was first diagnosed, we kept it quiet from everyone, except family. We felt scared that if we told people she wouldn't be invited to any more parties or sleepovers. We didn't want her life to change any more than it had already. Funny thing, the more people we tell and more questions we get to answer. Most people don't know much about epilepsy and are surprisingly open when we explain how Alaina deals with it. The responses have been nothing but

positive. No more hiding her condition for this family.

We are very proud of her and her accomplishments. I know how very lucky she is to be able to compete in sports because epilepsy affects people in so many ways. I hope that she will inspire others to live their life and try to follow their dreams just like she has. Alaina currently plays for Jacksonville Junior Roller Derby and was selected to be part of a team that represents the South/South-East region of the United States in the AAU Junior Olympics in Nebraska. JJRD is currently ranked 8th in the nation and her Olympic team won bronze. We are so proud of her!

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

Creating a Legacy to Continue a Legacy

By: Kyle Skipper, ERC Advisory Board Member

I have started my own personal legacy for the Epilepsy Foundation of Florida with a permanent life insurance policy as myself as the insured. I believe that most people are charitable by nature, but maybe don't believe that what they can afford to give will make any significant difference to their favorite cause. However, there are creative ways that almost anyone can give to their favorite charity in a tax efficient manner and still leave a significant gift.

By giving an affordable monthly or annual gift, it is possible to leave the qualified charitable foundation a very substantial gift at a later date. Let's take a look at an example if we were to use life insurance to create your gift to a charity. If you wanted to leave the qualified foundation \$100,000 you could purchase a permanent life insurance policy to guarantee that you could one day leave them a minimum of \$100,000. By making the qualified foundation the owner and beneficiary of the policy, they would maintain control of the cash value of the policy that they could potentially use at a later date and would receive the death benefit upon your passing. You, the donor, would be the insured and the payer and your annual premiums paid for life insurance owned by the qualifying charity would be income tax deductible to the extent allowed by current tax law.

So what are the benefits for the donor and the qualified foundation? The donor gets to leave a substantial legacy to the qualified foundation in an efficient and tax favorable way that requires minimal cost. The qualified foundation gains control of the policy to access the cash value during the insured's living years and will receive the death benefit at the passing of the insured. Throughout the years the policy will continue to grow through dividends, which means the donor will leave a much larger legacy than expected.

If you have any questions on how to properly plan your next gift/legacy for a qualified foundation, please don't hesitate to call me.

Kyle Skipper

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Upcoming Community DIY Events



Pixelated

Jacksonville | Aug. 13

Calling all video gamers: Prove you're the true champion of Super Smash Bros. Melee – all for a good cause!

[Learn more →](#)



Quarter Auction

Royal Palm Beach | Sept. 21

Join us for a night of fun, prizes, and good friends!

[Learn more →](#)



Seizure Smart Talk 5k Run/Walk

Clay County | Nov. 5

Whether you run or walk, your participation will help EFOF get one step closer to a cure.

[Learn more →](#)



Miami Dolphins Game to Benefit EFOF

Miami | Nov. 27

Let the good times roll as you watch the Miami Dolphins take on the San Francisco 49ers. \$10 of each ticket sold will benefit EFOF.

[Learn more →](#)

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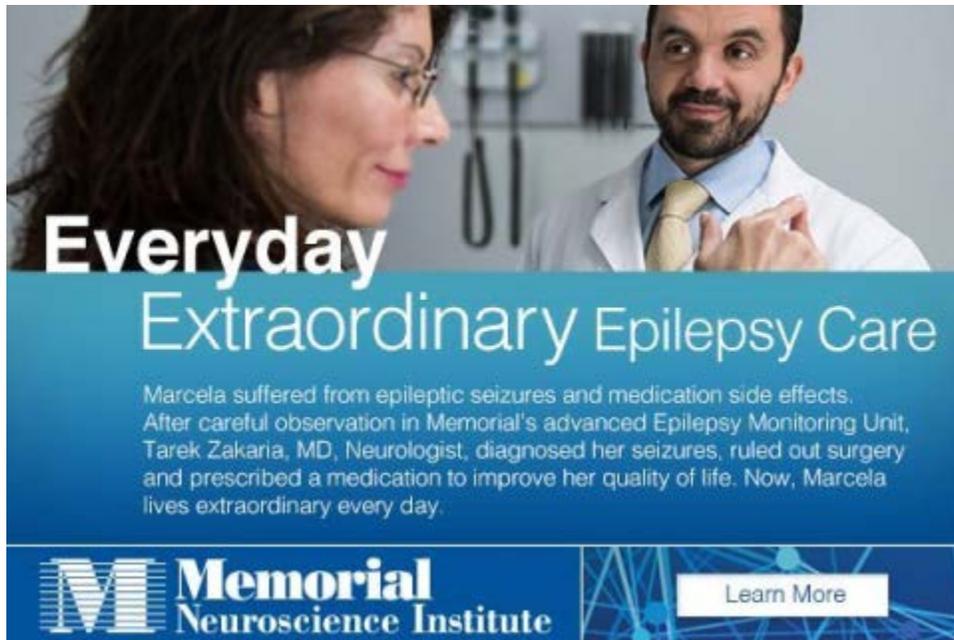
No one can prepare for a seizure as it can happen at the most unexpected time. There are currently more than 400,000 individuals who suffer from epilepsy across Florida with more than 89,000 of those sufferers being children. Prevention and education can better prepare those impacted by the disease. 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
- 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

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