



Dear Friends of the Epilepsy Foundation of Florida,

With back-to-school bells ringing, I'm so proud this month to recognize our Jacksonville and West Palm Beach offices for working hard to support their local communities through a backpack give-a-way and a school supply drive! It's inspiring to see them going above and beyond our everyday commitment to our mission to further support those they serve. Thank you, and kudos to you!

Every now and then, we need a reminder of why the work we do is so important. This month, I think you'll find that in our Faces of Epilepsy story by Alanna Sedlitz-Ippolito. Her son, Steven, has lived with epilepsy since birth and she shares how her family has navigated the winding road its laid before them. The Sedlitz family annually hosts a Chili Cook-Off in St. Johns to raise funds in support of EFOF and those we serve. More details on this event can be found below.

We hope you can join us on September 13 for part two of our "Medical Cannabis: All Access" webinar series. It will feature an inside look at the Knox Medical cannabis lab, and a tour from Lead Chemical Engineer Alexander Karol. No registration is necessary – just plan to join us through Facebook Live by visiting our [Facebook page](#) at 6:30 p.m. on that day! If you didn't get the opportunity to watch or join us for part one of the webinar series, you can find a link below with the entire video of the dispensary tour, Florida law overview, product display and live Q & A segment.

As the path of Hurricane Irma is still unclear, preparation is key. We have included some important information and tips for epilepsy safety below that we hope everyone will take time to read.

I am hoping you and your families remain safe as Hurricane Irma approaches our Florida coast.

*Sincerely,*



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

### **HURRICANE PREPAREDNESS CHECKLIST**

- Check your medication supply and make sure you have at least a 2 week supply of prescribed medication. If more medication is needed, please contact your pharmacy or doctor immediately to request a refill.
- If you leave your home, take your medication with you and keep it in a safe waterproof location.
- Have on you at all times a medical id bracelet or some form of ID indicating that you have epilepsy.
- Keep a list of important phone numbers handy (pharmacy, doctor, EFOF)

In addition to the above preparations, please be sure consult this [list of helpful tips](#) and [www.ready.gov/hurricanes](http://www.ready.gov/hurricanes).

## *Back-to-School, Back to Giving*

A big shout out to our Jacksonville and West Palm Beach offices who have been busy helping their local communities get ready to go back-to-school!



### **Jacksonville**

In Jacksonville, a generous client along with the Jacksonville area Walmart, donated to our backpack give-a-way! Special thanks to Board Member Marques Hunter for reaching out to Walmart managers in the area!



### **West Palm Beach**

The WPB Support Group collected school supplies for children who are registered with the Foundation in Palm Beach county. The group had been collecting supplies since June - and no outside resources or large corporations had been solicited. This initiative was solely from our clients to our clients and embodied the true spirit of giving!

## Clayton Feig Legacy Fund - Faces of Epilepsy

**By: Alanna Sedlitz-Ippolito**



Have you ever heard a story that gave you chills down your spine? A story that you couldn't help but feel as if it was you in that story? Well I have one for you. Imagine, you're 18 years old, and having your first baby. A little boy to be exact. His room is all set up, the car seat is in place, all you need now, is the baby to fill that beautiful wooden bed, with the car bed sheets. Labor day arrives, and it is exactly everything you hoped it could be, plus that much more. You can't believe that you just created one of the biggest miracles known to man. At 3:40pm, weighing in at 7 pounds 5 ounces, and all of 19 inches long, an image of perfection, a little piece of you. You start immediately craving all of those bonding moments. Until the morning after, before visiting hours, something strange happens. As you're feeding your precious new baby, and you stop to burp him, he starts making an odd clicking noise. You pull him from your chest to see what's going on, and see that the noise is coming from his mouth. His bottom lip is sucked in. The noise stops, and you take a deep breath in. You stare down at this little miracle in your arms, when he starts to turn blue. His eyes are fixated on you, they glaze over, his head drops in your hands, while your heart drops to the floor. You call for the nurses, but while waiting for them to arrive, he starts breathing again. The nurses show up and tell you that this is normal, blamed the coarseness of his skin on the lighting in the room, and the abnormal movements of his body on an immature nervous system. This happened four times the day he was born, and no one would listen. I was a young mom, but I knew something was wrong. I refused to leave the hospital without an answer. This is how my story with parenthood, and epilepsy, begins.

Steven's life started just as I had stated, beautiful and oh so scary. I was determined to find out what was happening with my baby, and told every doctor or nurse that came to visit us, what was happening with my newborn, every single time I saw them, and no one was concerned, until I spoke with the pediatrician on call. She witnessed what I had been witnessing, but this time, it lasted much longer, with more convulsing than before. She immediately brought him to the NICU. Now I knew that it wasn't just in my mind, that something was actually wrong with my baby. I was terrified...

[Click here to continue reading Alanna's story.](#)

## 4th Annual St. Johns Professional Alliance Chili Cook-Off

Each year, the Sedlitz family hosts a Chili Cook-Off to raise funds for individuals living with epilepsy, like Steven. This year's event will be held on Saturday, Nov. 18 from 11 a.m. to 3 p.m. at Faith Community Church in St. Johns. To register, donate, sponsor, become a vendor, or purchase Chili Cook-Off taste and judge passes, please [click here](#).

*Join Us for Our September Webinar!*

**SEPTEMBER 13, 2017**  
6:30 - 8:00 P.M. EST

**EPILEPSY EXCHANGE**  
Webinar

WHERE CAN I GET IT?  
WHAT DOES IT DO?  
IS IT SAFE?  
HOW WILL IT HELP?  
HOW DOES IT WORK?  
CBD

**EPILEPSY EXCHANGE**  
Medical Cannabis: All Access  
A Two-Part Series

### Join us for EFOF's upcoming "Epilepsy Exchange" webinar on Facebook Live!

The webinar will feature an inside look at the Knox Medical cannabis lab, and a live Q & A session.

This event will be through Facebook Live. No registration is required for this event. Submit your questions for the live Q & A session to [ibitton@efof.org](mailto:ibitton@efof.org).



[WWW.EPILEPSYFLA.ORG](http://WWW.EPILEPSYFLA.ORG)

[WWW.FACEBOOK.COM/EPILEPSYFLA](http://WWW.FACEBOOK.COM/EPILEPSYFLA)

[WWW.TWITTER.COM/EFOF](http://WWW.TWITTER.COM/EFOF)



### Get to Know Our Guest Speaker: Alexander Karol

Knox's Lead Chemical Engineer Alexander Karol will serve as a guest speaker during this webinar. Learn a bit more about him below!

- While a student at Tufts University, he co-founded the Sharewood Project which provides free health care services to underprivileged people.
- He performed novel research in immunology and utilized the proprietary MIMIC® (Modular Immune Invitro Construct) system as the foundation for his research; this led to a patent and numerous publications.
- He hopes to advance the research of cannabinoids in treating those, including his own mother who is struggling with early-onset Alzheimer's, about this safer, more efficient, and cheaper way of treating disorders and diseases.

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### [Video: Medical Cannabis: All Access - Part One \(Dispensary Tour\)](#)



## Let's Talk About It!

### NOVEMBER IS EPILEPSY AWARENESS MONTH

## Let's Talk About It!

In celebration of Epilepsy Awareness Month, the Epilepsy Foundation of Florida is hosting six signature *Let's Talk About It!* events. Will you join us?

### Unmasking Epilepsy

MASQUERADE COCKTAIL PARTY  
THURSDAY | OCTOBER 19  
CORAL GABLES MUSEUM | MIAMI

### Purple Hat NIGHT OUT

COCKTAIL PARTY  
THURSDAY | NOVEMBER 9  
THE GRATEFUL PALATE | FT LAUDERDALE

### ALL Shades of Purple GALA

GALA  
THURSDAY | NOVEMBER 9  
WJCT TV STUDIOS | JACKSONVILLE

### PURPLE PINT NIGHT

BREWERY EVENT  
SATURDAY | NOVEMBER 18  
TWISTED TRUNK BREWING | PALM BEACH GARDENS

### Snacks & Swizzles

COCKTAIL PARTY  
TUESDAY | NOVEMBER 14  
BRANNON CIVIC CENTER | DAYTONA

### NAPLES EPILEPSY RESOURCE CENTER GRAND OPENING

RIBBON CUTTING COCKTAIL  
WEDNESDAY | NOVEMBER 15  
YMCA | NAPLES

### CHEERS FOR CHARITY

PINT NIGHT | THURSDAY | OCTOBER 12 | WORLD OF BEER | PENSACOLA

GET YOUR TICKETS TO THE EVENT NEAREST YOU!  
VISIT [WWW.EFOF.ORG/UPCOMING-EVENTS](http://WWW.EFOF.ORG/UPCOMING-EVENTS)

## DIY (Do-It-Yourself)

### Help spread epilepsy awareness by hosting your own DIY event in five easy steps!

- **Step 1** - Identify the type of event you would like to host (ideas below)
- **Step 2** - Register your event by visiting [www.efof.org/host-a-diy](http://www.efof.org/host-a-diy)
- **Step 3** - Include all event details (date, time, location, etc.) on your fundraising page
- **Step 4** - Promote the event to your friends and family
- **Step 5** - Take pictures for social media and share with EFOF

**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 <small>(21+ years old)</small>	Bowling Night
Pint Night at local establishment <small>(21+ years old)</small>	Car Wash
Wine & Cheese Night <small>(21+ years old)</small>	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** 1-877-553-7453 | WWW.EFOF.ORG

**Register  
Your DIY!**

## Upcoming Events



**Painting with a Purpose**  
Naples | Oct. 15



**Sisters Walk for Epilepsy**  
Jacksonville | Nov. 4



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



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

## 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](#).

*\*sponsored\**

# 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](http://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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