

## A MESSAGE FROM OUR PRESIDENT & CEO

Dear Friends,

November is a wonderful month for so many reasons: the leaves start to change color and create dramatic scenery all-around; we celebrate Thanksgiving with family and friends; and we feel the excited anticipation of the holidays ahead. For those of us who care about epilepsy, this month has added importance as Epilepsy Awareness Month. This is the month that we redouble our efforts to raise awareness about epilepsy among all Long Islanders and really, across the country.



As a friend of the Epilepsy Foundation of Long Island, you share our commitment to ensuring that our loved ones with epilepsy have access to services, support and information about epilepsy. With that in mind, I am so pleased to share with you this newsletter dedicated to November is Epilepsy Awareness Month and full of information about our work on behalf of all Long Islanders with epilepsy and the people who love them.

Sincerely,  
Tom Hopkins

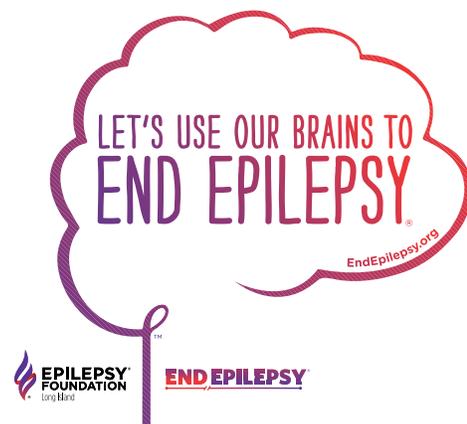
## LET'S USE OUR BRAINS TO END EPILEPSY

Let's use our brains to end epilepsy: an imperative message and ambitious goal. Yet, that is the call to action sounded by the Epilepsy Foundation to affiliates, communities and anyone impacted by epilepsy across the nation.

*Let's Use Our Brains to End Epilepsy* is a nationwide campaign to educate, activate and

motivate us all to work to end epilepsy. Not just the condition in all its forms, but also to end the stigma, the challenges, the myths and misconceptions, the bullying, the prejudice and all aspects of epilepsy that place limits on the men, women and children living with this condition. The campaign places a focus on the brain as the source of seizures and as the source of solutions to end epilepsy.

Until now, epilepsy has been misunderstood, underfunded and under-recognized, endangering the 3.4 million people in the United States living with epilepsy. This vibrant and far-reaching campaign challenges everyone to think about epilepsy and seizures differently. It shifts the conversation from ignorance to understanding and puts an end to the confusion, silence and lack of funding for epilepsy care, research and advocacy.



Look for the ads, articles and content on social media. If you would like to become an ambassador for our local campaign and share your epilepsy story, please contact Janet Romeo at [jromeo@epicli.org](mailto:jromeo@epicli.org).

Visit [EndEpilepsy.org](http://EndEpilepsy.org) for more about our nationwide campaign.

# WALK FOR EPILEPSY

On Saturday, October 13th, EPIC Long Island held its 8th Annual Walk for Epilepsy at Eisenhower Park. Hundreds of supporters turnout out, despite the rain and wind, to raise awareness and funds for programs and services that support Long Island's 35,000 children and adults who are living with epilepsy.

"Funding to support this condition lags behind others," explains Tom Hopkins, President & CEO, EPIC Long Island, "and for one-third of people living with epilepsy, no current medications or treatments are effective in controlling seizures. The Walk for Epilepsy brings our community together to support those we love, remember those we've lost and work for a cure to end epilepsy."

The program for the day included comments from Grand Marshal Madison Schmidt, who served as EPIC Long Island's "Teens Speak Up!" representative in Washington, D.C. this year, visiting legislators and advocating on behalf of all those with epilepsy. Ms. Schmidt relayed how thankful she was for so many supporters coming together to help children and adults with epilepsy, as well as those who care for people with epilepsy. Her call to action was simple – let's work together to end epilepsy once and for all and have an amazing Walk this year.





## AFFILIATION WITH THE NATIONAL EPILEPSY FOUNDATION

For more than 40 years, EPIC Long Island has been affiliated with the National Epilepsy Foundation (EF). According to Tom Hopkins, President and CEO of EPIC Long Island, it's going to stay that way. The Epilepsy Foundation of Long Island is a division of EPIC Long Island.

"During the past few years, some affiliates have questioned the focus of the national office and whether it's perhaps geared more toward research, rather than direct service to individuals with epilepsy," Mr. Hopkins explained. "After careful consideration by our agency's Board members and senior staff, the Epilepsy Foundation of Long Island has chosen to remain part of the national network in a dynamic agreement with EF."

The decision comes as seven EF affiliates recently split from the national organization, launching Epilepsy Alliance America on July 23rd.

The Epilepsy Foundation of Long Island will continue to meet the needs of Long Islanders living with epilepsy while partnering with the national foundation to enhance resources, programs and advocacy. Teens Speak Up! is one such program that the agency participates in with EF each year. The initiative provides an opportunity for teenagers with epilepsy to participate in advocacy training and meet with legislators on Capitol Hill to share their journeys.

"Teens Speak Up! is a wonderful example of partnership at its best," said Irene Rodgers, LCSW-R, Director of Community Services, EPIC Long Island. "Without our affiliation with EF, teens would not have the opportunity to build important leadership and advocacy skills, or to come together with other adolescents living with epilepsy."

Partnership with the national Epilepsy Foundation will also enable the Epilepsy Foundation of Long Island to access current research, educate our community and share information about important legislative issues. Moving forward, affiliates including the Epilepsy Foundation of Long Island, will have opportunities to identify and fund research projects that are important to the local community.



"Together with the Epilepsy Foundation, we're striving to enhance the quality of services for people on Long Island while supporting research efforts to develop a cure for epilepsy," Mr. Hopkins said.

## TRANSITIONS

Adapting to change is never easy – for children or their parents! When they are 5 years old, we send our children off into the care of their school teachers hoping that they will treat them as their own. Moving up to middle and high school are the next transitions that students and families face. At 18+ years old, our children transition to adulthood, college, and/or employment and, once again, we hold our breath and hope that they will be able to take care of themselves. Imagine what this is like for the parents of a child with epilepsy -- when each moment is fraught with the ever-present concern about having a seizure.

The Community Education Department of the Epilepsy Foundation of Long Island is available to assist parents during these stressful moments – and every moment in between. Our epilepsy education specialists can listen and make recommendations, provide resources, support and actively participate in meetings with schools to access services. Our epilepsy education specialists can listen and make

recommendations, provide resources, support and actively participate in meetings with schools to access services. Our services have made a difference for hundreds of children with epilepsy. We have learned that families dealing with epilepsy are resilient and resourceful. The following stories, including 5 year old Amelia just entering Kindergarten and a group of teens who have navigated the school years and entered adulthood on their own terms, demonstrate that strength in the face of adversity.

Amelia was diagnosed with epilepsy at age 5, while in Kindergarten and after experiencing generalized seizures. Her mother, distraught over the diagnosis and overwhelmed by the impact of the condition on Amelia and their family, struggled to process the impact of epilepsy and put together a plan for Amelia. Amelia's grandmother called the staff of the Epilepsy Foundation of Long Island Community Education Department and asked what we could offer to the family. When Amelia was entering First Grade, our Community Educator visited the family at home and offered support and information about seizures and epilepsy. Our staff shared facts about epilepsy and anecdotes of families that share the same challenges.

In response to the family's request, our staff provided a list of Pediatric Epileptologists, neurologists who specializes in epilepsy and shared information about how to request a school district committee meeting to ensure that accommodations be put in place for Amelia.



As part of the supports and services that we offer to parents, our Community Educator accompanied Amelia's mother to the school committee meeting and outlined what accommodations Amelia would need to be safe in school while ensuring she had equal access to learning. Our staff advocated for a Section 504 Plan for Amelia which specified all the accommodations Amelia would receive in school. A school in-service was provided to train and educate the faculty about epilepsy and first aid for seizures. Amelia's needs had created the opportunity for a learning experience for the all the teachers in the school.

Another challenging transitional period is moving on from high school to work or college. On July 31, a group of young adults with epilepsy shared their experiences, ideas and advice during a conference on transitioning successfully beyond school years to life as an adult with epilepsy. The Epilepsy Foundation of Long Island hosted the half-day conference at SUNY – Farmingdale College for an audience packed with professionals in the fields of education, employment and neurology, as well as teens and families hoping to learn from the experiences of others. All listened with rapt attention to the panel of five young adults who bravely shared their experiences, successes, roadblocks, and advice about living successfully with epilepsy. The panel included college students, a photo journalist, and a poet. Most importantly, the teens and young adults in the audience were given the opportunity to meet peers who have walked in their shoes and helped each one to realize that they are not alone.



## A LAUNCH TO REMEMBER

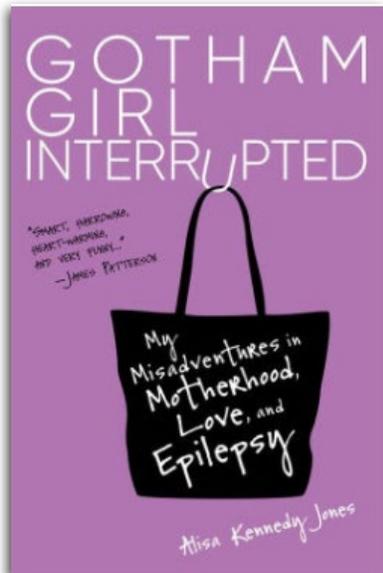


# LIVING WELL WITH EPILEPSY™

Using interviews, input from followers and advice from experts to share the challenges and realities of living with epilepsy, author Alisa Kennedy Jones and writer Jessica Kennan Smith will educate and raise awareness about epilepsy through their new podcast Fits 'n Starts. This online resource will air monthly and provide a forum for individuals to share their unique epilepsy stories, hear from experts and learn more about living with epilepsy. This podcast was postponed due to weather. Details about the live Podcast launch are coming soon and all are invited to attend.

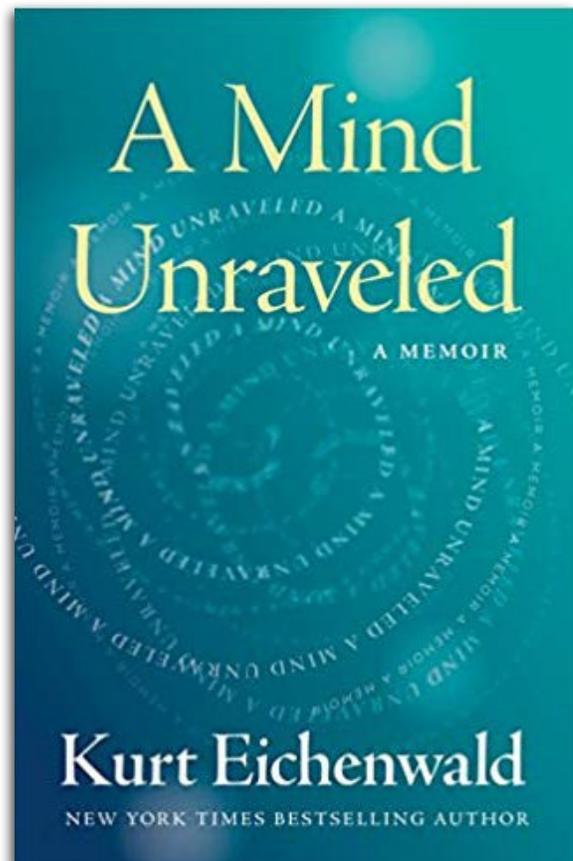
Alisa Kennedy Jones is the author of *Gotham Girl Interrupted: My Misadventures in Motherhood, Love and Epilepsy*.

This memoir chronicles her experiences and offers poignant insights that may be familiar to those with epilepsy but will resonate among those without epilepsy as well. Blogger Jessica Keenan Smith communicates daily with an audience of thousands through the online platform [livingwellwithepilepsy.com](http://livingwellwithepilepsy.com).



## FORMER NEW YORK TIMES REPORTER CHRONICLES PERSONAL EPILEPSY JOURNEY

In his newest book, *A Mind Unraveled*, New York Times bestselling author and investigative journalist, Kurt Eichenwald, shares his sometimes stark and harrowing experiences after developing intractable epilepsy as a young adult. He also shares the many important ways it helped to shape his life and impact his career as a writer. The author has said that he wrote this book in hopes of showing young people with epilepsy that they don't have to abandon their dreams and to provide public education about the truth and fiction of seizures. His goal is to broaden the conversation about epilepsy beyond those that are directly impacted.



## BLOG RELAY FOR NOVEMBER

NOV 1-30 2018

# EPILEPSY BLOG RELAY™

LIVINGWELLWITHEPILEPSY.COM

#EPILEPSYBLOGRELAY

Thursday is the 1st day of Epilepsy Awareness Month! EPIC Long Island is proud to once again be a media partner for the November 2018 Epilepsy Blog relay with our friends at [www.livingwellwithepilepsy.com](http://www.livingwellwithepilepsy.com). Thirty bloggers in thirty days will be raising awareness by sharing their personal stories about living with epilepsy and how it has affected their lives. We are happy to offer our support to those who want to raise their voices in the fight for epilepsy awareness and against the stigma surrounding it. Each week will have a focus meant to encourage greater collaboration:

- WEEK 1 – Epilepsy in Everyday Life (Nov. 1 – 7)
- WEEK 2 – Epilepsy and Families: Awareness Matters (Nov. 8 – 14)
- WEEK 3 – Tech and Innovation in Epilepsy (Nov. 15 – 21)
- WEEK 4 – Creativity and Epilepsy (Nov. 22 – 30)

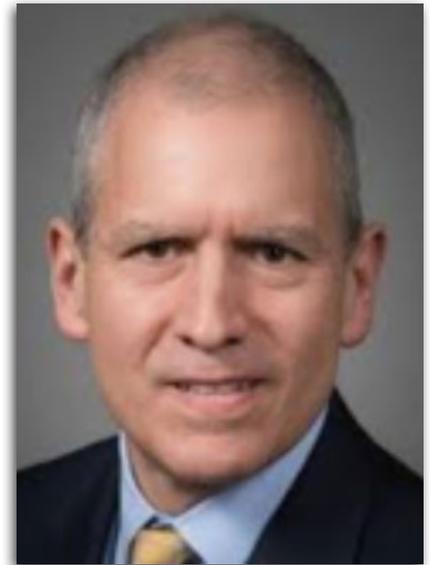
We encourage you to take a few moments throughout the month to read these blogs. Please comment/share/follow the bloggers who inspire you! For the 35,000 people on Long Island living with epilepsy, as well as the more than 65 million worldwide, let's shine a light on their stories as we work together to end epilepsy!

[livingwellwithepilepsy.com/epilepsy-blog-relay](http://livingwellwithepilepsy.com/epilepsy-blog-relay)

## WORKSHOP ON MEDICAL MARIJUANA

On Wednesday, November 7th, the Epilepsy Foundation's Sheila and Fred Abrams Community Education Series hosted a workshop on "Medical Marijuana in the Treatment of Epilepsy" which had wide appeal to people looking for another weapon in their arsenal against seizures. The workshop attracted an audience of 75 individuals with epilepsy, parents and caregivers, school nurses, EPIC staff, and other professionals in the field.

The workshop was presented by Dr. Fred A. Lado, Director of the Epilepsy Division for the Central and Eastern Regions of Northwell Health. Dr. Lado presented to a captivated audience on the history of medical marijuana, CBD and when it might be helpful in the treatment of epilepsy, clinical studies, and the release of Epidiolex, a pharmaceutical grade CBD product.



For more information about upcoming workshops, please contact [jromeo@epicli.org](mailto:jromeo@epicli.org).

**SAVE THE DATE**



## Improving Outcomes and Decreasing Invasiveness of Epilepsy Surgery

**WEDNESDAY,  
DECEMBER 5, 2018**

*Presented by*

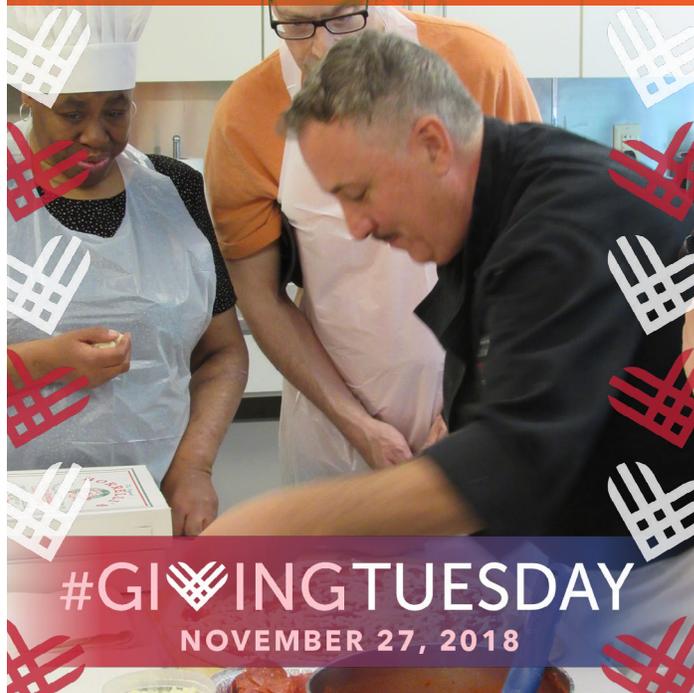
**Ashesh D. Mehta, M.D., Ph.D.**

**6:30PM TO 8:00PM**

**Epilepsy Foundation of Long Island**  
1500 Hempstead Turnpike,  
East Meadow

*To register, please call Janet Romeo at*  
**516-739-7733 Option 1 ext. 145**

**#GIVINGTUESDAY**



**#GIVINGTUESDAY**  
NOVEMBER 27, 2018

On **#GivingTuesday**, EPIC Long Island give thanks to all those in our community who selflessly give to others, like our neighbor, Frank Borrelli of Borrelli's Restaurant, who volunteers to teach our program participants how to make pizza!" Thanks, Frank!

Share your unselfie with us on social media and show us how you choose to celebrate **#unselfie!**

### Is the Epilepsy Foundation of Long Island in your will?

Please let us know if you have included the Epilepsy Foundation of Long Island in your will even if you wish your gift to remain anonymous.

It's important your bequest is worded correctly. Please call **516-739-7733 ext. 626** or email [ecolletti@epicli.org](mailto:ecolletti@epicli.org).

For more information, visit our website at [www.epicli.org](http://www.epicli.org).



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