

EPILEPSY FOUNDATION LONG ISLAND

Raising Epilepsy Awareness

FALL 2020 NEWSLETTER

WALK TO END EPILEPSY

SEIZURE RECOGNITION & FIRST AID CERTIFICATION

KIDS CREW

MINORITY OUTREACH INITIATIVE

IN THEIR OWN WORDS

GET CONNECTED

1500 Hempstead Tpke.
East Meadow, NY 11554
(516) 739 - 7733

A MESSAGE FROM OUR PRESIDENT & CEO



Dear Friends,

Given that our Walk to END EPILEPSY is held every October, and November is Epilepsy Awareness Month, tradition dictates that our Fall Newsletter focuses on the Community Education and Outreach programs of the Epilepsy Foundation Long Island. As we all know, 2020 has been anything but traditional, routine, or the expected; and that is why we felt it was of the utmost importance to continue with this tradition: to provide the familiar, and hopefully, some comfort in this uncertain time.

We hope that you enjoy the pictures from the 2020 Virtual Walk to END EPILEPSY that was held October 17th. Even though we could not gather with hundreds of people in Eisenhower Park as we have in years past, there was still a shared sense of community and purpose. You will see from the pictures that we received from the families and teams that they were just as enthusiastic and passionate in their efforts to raise epilepsy awareness in their individual communities. Thank you to everyone who walked, supported, and donated to the cause - over \$60,000 was raised for our epilepsy education and outreach programs!

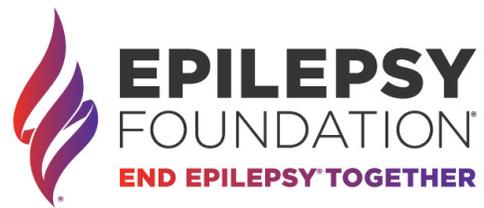
Our newsletter is filled with information on our epilepsy programs and services. You will learn of our recent grant award from the national Epilepsy Foundation to engage in a minority outreach initiative, and that we are part of the Epilepsy Foundation's nationwide effort to provide the *Seizure Recognition and First Aid Certification Program*. We are also proud to be involved with the *Kids Crew*, a collaboration with the Epilepsy Foundation network to connect children living with epilepsy and their peers.

Finally, I would like to bring special attention to the "In Their Own Words" section which showcases the personal stories of four people living with epilepsy. Although each story is unique, there are also universal themes - feelings of frustration and fear; difficulty coping; and at times, feelings of isolation but each person also expresses the importance of reaching out to others and feeling connected. They each emphasize that there are others living with epilepsy and that no one is alone in this journey - there is support and there is hope.

Wishing everyone happiness, health, and hope during the holiday season and in the New Year.



Thomas M. Hopkins
President & CEO



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... goes **VIRTUAL!**





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Seizure Recognition and First Aid Certification Program

The national Epilepsy Foundation has launched the first and only Seizure Recognition and First-Aid Certification Program to support the 3.4 million people living with epilepsy in the United States. The purpose of the training is to increase the knowledge, skills, and confidence in recognizing seizures and safely administering seizure first aid. Participants learn about the different ways in which seizures present, the appropriate first aid steps, and when to call for help. Knowing how to help someone during a seizure can make a difference and even save a life.

Closer to Home

This program benefits the approximately 35,000 individuals living with epilepsy on Long Island who never know when a seizure will happen, where they will be, and if there will be anyone there who knows what to do to help them. Two local Long Island students, Caroline and Giovanna, who live with epilepsy, have harnessed their passion for raising awareness and educating the community by urging people to get Seizure Recognition and First Aid certified. Caroline and Giovanna shared their stories of living with epilepsy during virtual August Recess visits with representatives from the offices of Senator Charles Schumer and Congressman Thomas Suozzi. During these meetings, they urged our representatives to advocate for increased funding for the Centers for Disease Control and Prevention epilepsy public health programs. This CDC funding is crucial to supporting the Seizure Recognition and First Aid Certification program as well as many other epilepsy programs and initiatives. Giovanna and Caroline also advocated for this funding in support of the various educational programs that the Epilepsy Foundation provides specifically designed for school staff. Giovanna sent emails and informational flyers to nurses in several local school districts, imploring them to schedule staff trainings. The importance of these trainings cannot be underestimated. As Caroline said, "Teachers and school faculty MUST be trained in seizure safety. The worst feeling in the world is feeling helpless and unsafe."

By the Numbers

Our Community Education Coordinator, Janet Romeo, has been trained and certified to administer this training program for the general public. Since July of 2020, over 275 people on Long Island have received their certification. For more information, or to be certified, please contact jromeo@epicli.org.



The Epilepsy Foundation Long Island has partnered with the national Epilepsy Foundation to bring their Kids Crew program to Long Island. Kids Crew is a program that provides a forum for children with epilepsy to learn more about their condition and share experiences with their peers. This program will empower children to spread awareness and make a difference for all children living with epilepsy. The Kid's Crew program is free to join and open to children of all abilities diagnosed with epilepsy ages 7 to 14. Siblings, friends, and relatives of those with epilepsy are often the best advocates and are also eligible to join.

Members of Kids Crew are given the opportunity to:

- Experience a safe and welcoming environment.
- Learn about epilepsy and seizures.
- Connect with other members.
- Be able to participate no matter where they are or how much help they need.
- See that they have the power to give back and improve their communities.
- Become leaders and to develop skills they can use in the future.

Kids Crew members have the chance to be a part of something bigger, something that has an impact all over the country and the world, all while having fun! Throughout the year, members will be invited to join **virtual** events. Some of the past national events have included a virtual luau, talent show, and treasure hunt. On a local level, the Epilepsy Foundation Long Island recently offered families free “porch portraits” taken by Daniel Hopper, a professional photographer whose story is featured in this newsletter.



Join in on the fun of our next local Kids Crew virtual event:

Sketch-n-Stretch Art and Yoga for Children

Winter 2021!



To become a Kids Crew member, please visit <https://www.epilepsy.com/make-difference/get-involved/kids-crew>

For more information, please contact Janet Romeo

(516) 739-7733, option 4

jromeo@epicli.org



Epilepsy Can Affect Anyone

3.4 million Americans live with active epilepsy. Racial and ethnic minorities are just over 40% of people living with active epilepsy in America.

530,000 African Americans,

710,000 Hispanics,

51,000 American Indians and Alaskan Natives, and 225,000 Asian American

ALL LIVE WITH ACTIVE EPILEPSY.

You Don't Have to Manage Your Epilepsy Alone!

The Epilepsy Foundation Long Island provides the following FREE services:

- Information & Referral • Support Groups
- Educational Programs • Advocacy

For more information, please contact Janet Romeo, Community Education Coordinator
jromeo@epicli.org (516) 739-7733, option 4

#EPILEPSYEQUITY



Epilepsy Foundation Long Island
 1500 Hempstead Tpke.
 East Meadow, NY 11554
 516.739.7733
www.epicli.org

2020 Minority Outreach Mini-Grantee Program of the Enhancing Outreach to Minority Communities Initiative

The Epilepsy Foundation Long Island (EFLI) is one of eleven agencies from around the country to be awarded a limited, competitive grant from the national Epilepsy Foundation. The purpose of the *2020 Minority Outreach Mini-Grantee Program of the Enhancing Outreach to Minority Communities Initiative* is to “promote effective and impactful engagement with minority, racial, and ethnic populations to increase awareness of epilepsy education and resources and to link more diverse individuals living with epilepsy to care.” Such outreach is needed to dispel myths and stigma associated with epilepsy, and to bridge the gap in the disparities in care that burden our ethnic, racial, and minority communities.

According to the Centers for Disease Control and Prevention and 2018 census data, 42 % of people living with an epilepsy diagnosis in the United States are of racial and ethnic minorities. To engage and serve these communities, EFLI is reaching out to colleges, human service agencies, community health centers, places of worship, and other groups and organizations that serve minority populations on Long Island. We are providing our signature *Seizure Awareness and First Aid* education programs for individuals with epilepsy, family members affected by epilepsy, caregivers, and direct care staff so that they will be able to recognize and respond to seizures with the appropriate first aid protocol. By providing educational programs, the Epilepsy Foundation Long Island upholds its commitment to helping people with epilepsy lead productive and satisfying lives.

EFLI created an extensive digital and print advertising campaign during November, which is *Epilepsy Awareness Month*, to share information on our programs and services, promote this initiative, and to convey that we are a resource to all Long Island communities.

For more information, please contact Janet Romeo, Community Education Coordinator
jromeo@epicli.org or (516) 739 -7733, option 4

In Their Own Words

ALYSSA D'AMICO

I was diagnosed with epilepsy in 1994 and have been living with it ever since. It is now twenty-six years. Of course, being so young I didn't understand all that much and alternated between anger and sadness. As time passed, I realized that acceptance and knowledge are the best way to deal with it. I had many treatments done, yet it is still active and I consider it to be life-saving with my circumstance as well as a part of myself. After all, "There is no such thing as a normal human being."

"Short Circuit: An Epileptic Journey," is a poetic memoir I wrote about when I was diagnosed to now, in chronological order. It begins in elementary school, then high school, and all the way to college and the present. It covers medication side effects, surgeries, friendship, love, and of course seizures. My goal in writing this book was to let others, not only with epilepsy, but other problems as well, know that they are not alone. That others are experiencing similar things to you and that you can keep going and succeed. That it is important to stay strong and never give up. As my karate teacher used to say, "Winners never quit, and quitters never win."

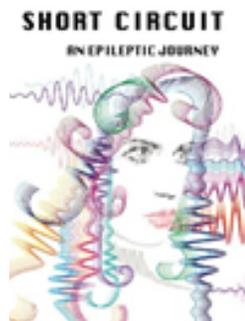
Rules That Can Help

Rule 1. Jealousy is of no use. Instead of comparing yourself and wishing to be in the same condition, try getting to know people possibly becoming friends and help each other.

Rule 2. Stay calm and more positive about yourself. Try to find a hobby or interest that you can enjoy doing. (art, music, writing, reading, crocheting etc.)

Rule 3. Find out what triggers a seizure to happen to you. Avoid what may cause a seizure, such as lack of sleep, caffeine, stress, alcohol, drugs etc.

Rule 4. Love others as you love yourself.





MICHELLE BRANCH grew up in Rocky Mountain, N. Carolina before moving to Maryland, New Jersey, and eventually Long Island. She is the baby of six children with two brothers and three sisters. Beginning in her high school years, Michelle began having episodes that she can't remember very well but that her sister can attest to and which were ultimately diagnosed as "Grand Mals." She does remember the long and frequent hospital stays and not being able to finish out high school. Michelle was given many trials of medications until an effective, yet tolerable, dosage level was achieved. Michelle always had a sense that her epilepsy should be kept a secret – that it was something that you did not talk about. As Michelle put it, "it was an eye-opening experience for her."

Michelle became involved with the Epilepsy Foundation Long Island (EFLI) in 2006 when she met with our staff to talk about her epilepsy and get help in finding employment. With our help, Michelle applied for a volunteer position at a local hospital. Over the years, she became a paid staff member at the hospital and eventually worked her way up to several different full-time positions, eventually securing a position in the Hospitality Services Department.

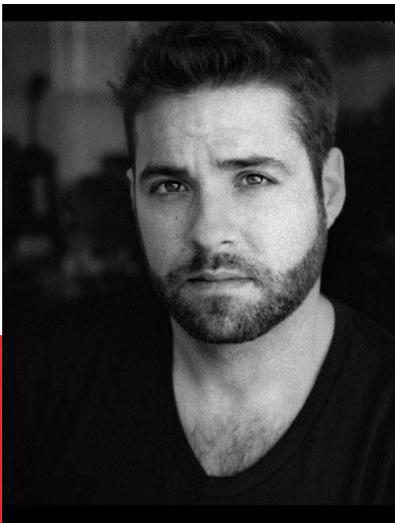
In 2014, Michelle contacted us to discuss issues that she was having with her supervisor. Michelle was experiencing memory gaps related to her seizures and her medications which affected the successful completion of her daily job assignments. Although Michelle tried to explain her condition and its side effects, her supervisor was not very understanding. This is when Michelle turned to EFLI once again. To assist Michelle, we wrote a letter to her supervisor requesting that they consider Michelle's disability and that they work with her to find a reasonable accommodation that could help her to be successful in her job. We explained seizures and epilepsy and its effect on memory. We suggested that they provide Michelle with a checklist of her expected tasks and duties for the day so that she could complete her work more effectively. This suggestion was eventually adopted and proved to be a good solution to the problem for the time being.

Eventually, Michelle's seizures became more frequent causing her to miss many days from work. Once again, her supervisor began writing her up for poor job performance and frequent absenteeism. After speaking with her doctor, the suggestion was made that her seizures were not resolving and that perhaps the stress of her job was adding to the problem. It is at this time that Michelle made the decision to apply for disability benefits.

Currently, Michelle is enjoying every day walking, exercising, and spending time with friends. She still avails herself of EFLI's services by being an active member of the Professional Adult Support Group and joins us every year at Eisenhower Park for our Walk to End Epilepsy. Michelle's advice to people with epilepsy is to not compare yourself to others. She says "Everybody's condition is different...don't give up on yourself...just accept it...and don't carry the burden alone!"

DANIEL HOPPER

My name is Daniel Hopper, I'm thirty-three years old and have lived in North Babylon most of my life, I moved back to the island last year. I am one of six children and was first diagnosed with epilepsy at 15 years old, two years after being hit by a car. I didn't remember the accident due to the head trauma, but I'll never forget my first seizure. It was the scariest moment of my life. At first, my seizures were bad having 3 to 4 seizures a day. Eventually, with a lot of tests and help from my doctors, we found the right medication to reduce the seizures enough for me to work but I still felt a void in my life. It wasn't until I started doing photography at 18 years old that I found meaning again, a way to express myself and be appreciated for doing so. Flashing light didn't affect my seizures, so I started working with a production company shooting weddings and events. There were many times I had to miss an event due to a seizure or couldn't take a job because I had no transportation. At 22 years old my seizures started to increase and after countless tests, we decided to try brain surgery. I was referred to a new doctor and introduced to EPIC LI. It was perfect timing for me, I was depressed about having epilepsy and scared I would never achieve my goals. The surgery didn't work in my case and I was still having seizures. The Epilepsy Foundation Long Island helped me overcome fears by giving me resources and help to manage life with epilepsy as well as providing a place to talk about my concerns with others who have had the same fears. They even helped me find a state program so I could go to school. With their encouragement and a newfound belief in myself in 2014, I graduated with honors from a commercial photography school in Massachusetts. Photography has opened many doors I never thought possible and gave me a meaning when I felt hopeless. After graduation I started my own photography company and moved to Boston, it was a great experience to be on my own but my family, my support system and my doctors were in New York, so it was short-lived. After two years I was homesick and ready for a change of scenery, so I moved to Brooklyn with a friend from school. Since moving back to New York and with the support of friends and family I have been able to accelerate my career and make the connections I need to give back to the epilepsy community. We are starting a charity called Carpe Diem for children with epilepsy based around art and focused on improving the mental state of a child. In my line of work and with the help from EPIC LI I've had the opportunity to travel, meet celebrities, and work with people I've looked up to my whole career. I've had the opportunity to live a life I never thought possible when I was first diagnosed. I started photography as a job and found a passion. My main focus in photography is to show the world around me from a different perspective. I went to school to learn how to share my vision with others through portraiture, specializing in flash-free photography for people with light-sensitive medical conditions. Photography gave me something that epilepsy can never take away, it gave me hope when hopeless, courage when afraid, and joy from what I've been able to accomplish. Epilepsy can be scary, challenging, even frustrating, but it's not the end. With the right mindset, determination, and some help along the way anything is achievable. For anyone living with epilepsy that feels like you can't achieve your goals or life is too hard I'd like to quote Henry Ford "When everything seems to be going against you, remember that the airplane takes off against the wind, not with it."





My name is CAROLINE GROSS. I am 16 and a junior in high school. My whole life changed two years ago when I was in science class at school, and out of the blue I lost consciousness and began to exhibit signs of an epileptic seizure. I was unable to speak and I became catatonic. As my head was uncontrollably shaking, my right hand was flapping over my face, and I was terrified. I remember seeing everyone around me, staring.

This was the first time that this happened to me at school, and no one knew what to do. My teachers and nurses at my Long Island high school were not trained in seizure safety. The adults that I trusted the most were not prepared for this emergency. My teacher called 911 and waited for the school nurse to come across the building to help me. It took 30 minutes to get proper help. As I was lying on the floor for waiting for help, I remember feeling terribly frightened and I thought I was going to die. Afterwards my friends told me that they all huddled, crying in the cafeteria, praying that I would be ok. My teachers were hoping the same, and they were just as scared.

Months later I had a second seizure on an airplane. It was 35,000 feet in the sky when the same unconsciousness and epileptic spasm occurred. I felt my head uncontrollably shake and my world completely blacked out. My family was frantic, screaming for help as everyone around me, including flight attendants, were helpless. NO ONE was trained in epileptic seizure safety protocol. NO one knew how to help keep me safe. The people that I relied on to keep me calm, couldn't calm down themselves. All I could see was the blur of my family and flight attendants squeezing into the tight aisle, and standing there thinking "what do we do?" The adults that were supposed to be prepared to help me, were unprepared, untrained, and helpless.

Between the ages of two and four, I suffered from seven febrile seizures. Each time I was sick with a virus that caused a spike in temperature, my brain seized. My parents took me to multiple doctors, all saying that I would grow out of these seizures, and it was just the way my immature neurological system controlled my body temperature. They were told that these seizures were not epilepsy. The doctors were mistaken. Twelve years after my last febrile seizure, my brain started seizing that awful day at school. I knew that something was wrong. The seizure lasted for so long, and I was not able to speak postictal (after the seizure). It seems as the more seizures I have, the longer the postictal stage lasts. Multiple EEG's, CT Scans, and MRI tests were performed. It took several months until I was able to have a formal diagnosis. I suffer from a Partial Seizure Complex Disorder. Epilepsy. It was official. And it was here to stay. I am not growing out of this disease. It is part of my life forever.

Luckily, I am on medication that seems to control most of my seizures. But like all other sufferers, you never know when a seizure will occur. When a seizure strikes, I am unable to take care of myself. This thought is so frightening. For now, I cannot drive, swim, shower, or babysit. I am limited in so many ways. However, the only thing that gives me comfort is knowing that I am surrounded by people trained in seizure safety. Epileptic seizures are a part of my life but the seizures will not limit my life. No kid like me should ever be in the position that I was - lying on the floor and convulsing while teachers and guardians stood around helpless and lacking the very simple education of how to help children like me.

Teachers and school faculty MUST be trained in seizure safety. The worst feeling in the world is feeling helpless and unsafe.

For People With Epilepsy
and Those Who Love Them
CURRENTLY, ALL GROUPS
ARE OFFERED ON A SECURE
VIRTUAL PLATFORM

Nassau County
Support Groups

Meetings held at:
1500 Hempstead Turnpike
East Meadow, NY 11554
(516) 739-7733
(please dial "1" before the
extension)

For Young Adult Group—
call **Cheryl at x 401**

For Professional Support Group—
call **Steve at x 729**

For Parent Support Group—
call **Debra at X 324**

Young Adult
Support Group

(for ages 18-30)
*1st Wednesday of each month
at 7:00 p.m*

Professional
Support Group

(for adults with epilepsy)
*2nd Wednesday of each month
at 7:30 p.m*

Parent Support Group

*4th Tuesday of each month
at 7:30 p.m.*

Suffolk County
Support Group

(for adults with epilepsy and their
loved ones as well as parents/
caregivers of children with epilepsy)

*1st Thursday of each month
at 6:30 p.m.*



Suffolk County
Support Group

Meetings held at:
Stony Brook
Neurology Associates
181 N. Belle Mead Road, Suite 5
East Setauket, NY 11733

To join this group,
please call:

**Karen Craig
(631) 444-8119**

Get Social With Us!



www.epicli.org

