

A MESSAGE FROM OUR PRESIDENT & CEO



and we are already talking about the next one!

For those of you who joined our Walk to End Epilepsy in October, I thank you for sharing your support of our community and I hope you enjoyed the day as much as I did. We had a record turnout of Walkers and dozens of teams that worked hard to help us raise funds to End Epilepsy and all the challenges presented by epilepsy. Thank you!

This special edition of our newsletter for November is Epilepsy Awareness Month is dedicated to you—our community—because with your support, we can make a difference.

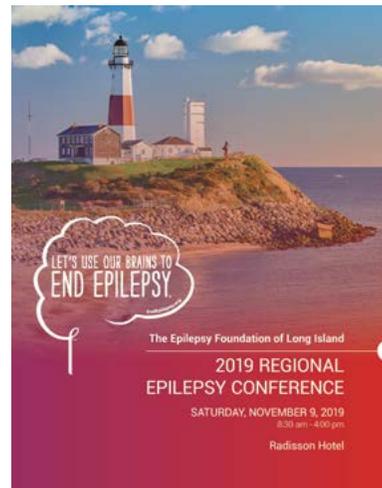
Thank you for being a part of our community and working with us to End Epilepsy.

Happy Thanksgiving!

Tom Hopkins

Dear Friends,

Here at the Epilepsy Foundation of Long Island—and EPIC Long Island—we celebrate November in a big way. Most of you can guess why! This year, during Epilepsy Awareness Month we hosted the 2019 Regional Epilepsy Conference. Our speakers included an amazing group of accomplished epilepsy specialists that presented a wealth of information to attendees. Everyone present left the conference with a better understanding of epilepsy, helpful information about living with epilepsy, current treatments and hope for new therapies on the horizon. This is an event worth repeating



MISSION STATEMENT

The Epilepsy Foundation of Long Island leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures and save lives.

REGIONAL EPILEPSY CONFERENCE

The Epilepsy Foundation of Long Island hosted a special celebration for Epilepsy Awareness month this October with the 2019 Regional Epilepsy Conference on Saturday, November 9 at the Radisson Hotel in Hauppauge. Dozens of attendees listened with rapt attention to a stellar list of speakers that shared a wealth of information on all aspects of epilepsy. The important takeaway: current research offers reasons to be hopeful about new therapies and tools for coping with everyday challenges.

Keynote speaker, Jacqueline French, MD, of NYU Langone Comprehensive Epilepsy Center and Chief Medical/Innovation Officer of the national Epilepsy Foundation outlined new therapies on the horizon and explained that recent research provides a better understanding of the genetics of epilepsy. She encouraged participants to be hopeful, "There is much new in the pipeline for advances that will lead to a better quality of life for people with epilepsy."

Presentations throughout the day also included information about current trends in diagnosing and classifying seizures, safety and epilepsy, new surgical treatments and devices and the impact of epilepsy on mental health. The presentations were followed by a question and answer panel where participants could pose their questions to the experts.

Other specialists participating in the event included: Dr. Josiane LaJoie of NYU Langone; Dr. Sanjeev Kothare of Cohen Children's Medical Center at Northwell Health; Dr. W. Curt LaFrance, Director of Neuropsychiatry and Behavioral Neurology at Rhode Island Hospital; Dr. Sean T. Hwang, Northwell Health; Dr. Shefali Karkare, Cohen Children's Medical Center at Northwell Health; Dr. Louis Manganas of Stony Brook Medicine; Dr. Rebecca Spiegel of Stony Brook Medicine and Dr. David Ansel of St. Charles Hospital. Dr. Alan Ettinger, Medical Director of United Diagnostics served as the moderator for the event.



DR. JOSIANE LAJOIE JOINS BOARD OF DIRECTORS

In September, EPIC Long Island and the Epilepsy Foundation of Long Island welcomed Dr. Josiane LaJoie as our newest Board member. Dr. LaJoie, a native Long Islander, has practiced pediatric neurology for more than 20 years. She is affiliated with NYU Langone with offices in Manhattan and Huntington. She has served on our Professional Advisory Board for many years, as well as the advisory Board of the Epilepsy Foundation of Metro New York. Dr. LaJoie is a passionate advocate for children with epilepsy and we are happy to have her leadership and expertise on our Board of Directors.



WALK TO END EPILEPSY

On Saturday, October 5, hundreds of Long Islanders joined our Walk to End Epilepsy. Walkers from across Long Island and beyond enjoyed the brisk October morning in Eisenhower Park to support our epilepsy community and raise awareness about epilepsy. This exhilarating event marked the Epilepsy Foundation of Long Island's 9th Annual walk for epilepsy and has grown to include over 700 participants. This year, the event raised over \$80,000 for our Community Education and Outreach Program.

"The Walk is a special moment for our epilepsy community as hundreds gather together to support those we love, remember those we have lost and walk to End Epilepsy," explains Eileen Colletti, Director of Development, "Each year, the walk grows as awareness grows."

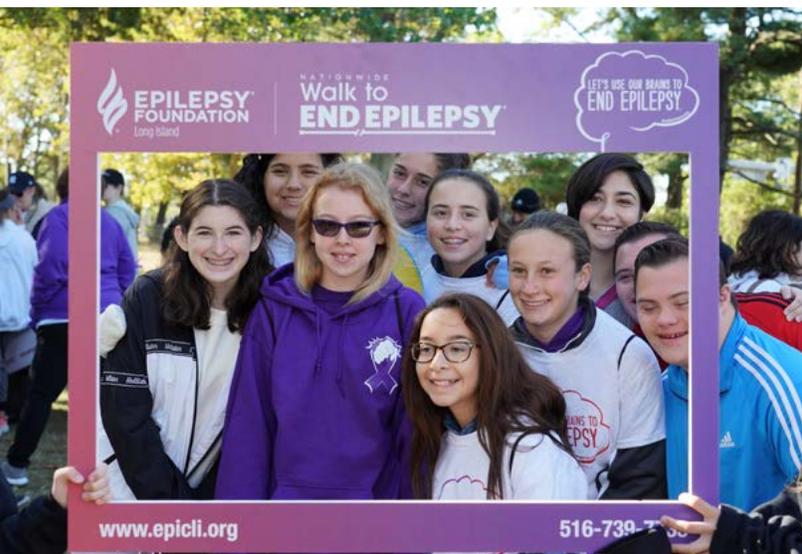
This year, the Epilepsy Foundation of Long Island teamed up with Epilepsy Foundation affiliates and chapters across

the country to brand the event as the Walk to End Epilepsy. Irene Rodgers, Director of Community Services, describes the change, "Our walk is a part of a movement across the nation to act with a cohesive mission to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures and save lives."

Nico Rivera served as Grand Marshal of the event, gathering dozens of team members to lead the walk with him. Setting a new standard for school participation, East Rockaway High School, where Nico is a senior, provided a bus to bring classmates and support Nico!

Thanks to all of our Sponsors, Teams and Walkers for helping to make the event a success!





SUPERHEROES OF THE EPILEPSY FOUNDATION OF LONG ISLAND

Here are just a few of the stats for 2018: 1,831 students reached during 67 school presentations; 18 in-service trainings for school and healthcare staff for a total of 715 people trained to identify seizures and administer first aid; 8 meetings with schools and/or employers to provide advocacy support; 9 home visits to provide guidance and information for families who have a loved one recently diagnosed with epilepsy.

Surprisingly, these results are not credited to an army of activists. This is the work of the Epilepsy Foundation of Long Island's staff in the Community Education and Outreach Program. Together, this small but mighty staff of 3, supports children and adults with epilepsy, provides education, training, information and referrals throughout Long Island.

Much of the hands-on training and education is provided by Janet Romeo, Community Education Coordinator. Janet has worked tirelessly for Long Islanders living with epilepsy for the past 22 years in her roles at the agency and has touched the lives of thousands of children and adults. With a BS and an MBA in Marketing, Janet combines her business skills, compassion and commitment to helping those with epilepsy to drive her efforts.

Janet explains that her goal is to, "make a difference in the lives of people with epilepsy by ensuring that children and adults have every opportunity to participate in life without stigma or prejudice through education, training, advocacy and seizure awareness."

Irene Rodgers, LCSW, Director of Community Services, has been with the Epilepsy Foundation of Long Island for nearly 20 years and has overseen the Community Education department since 2010. Having started in the Clinic as a therapist and resource for patients with epilepsy, she has found that her role leading the program brought her full circle, "It is gratifying to have been part of the evolution of our

services for people with epilepsy and work so closely with many dedicated staff. The synergy of our team has a positive impact on our services."

For those who follow the agency's Twitter and Facebook accounts, you have met Jean Dunn, administrative assistant, online many times. Jean supports the work of the Community Education and Outreach Program, while keeping online followers informed of events, aware of valuable information and ensuring that our community knows that we are listening. "I respond to questions and feedback from our online community and share the stories of people making a difference," explains Jean, "that includes our staff of epilepsy superheroes."



Com Ed – Superheroes of epilepsy from left to right: Janet Romeo, Jean Dunn and Irene Rodgers.



Epilepsy Warrior: Gianna, an intern with the Community Education & Outreach Program, works with staff to spread awareness about epilepsy and is among the 35,000 Long Islanders living with epilepsy.

SEIZURE SAFE SCHOOLS

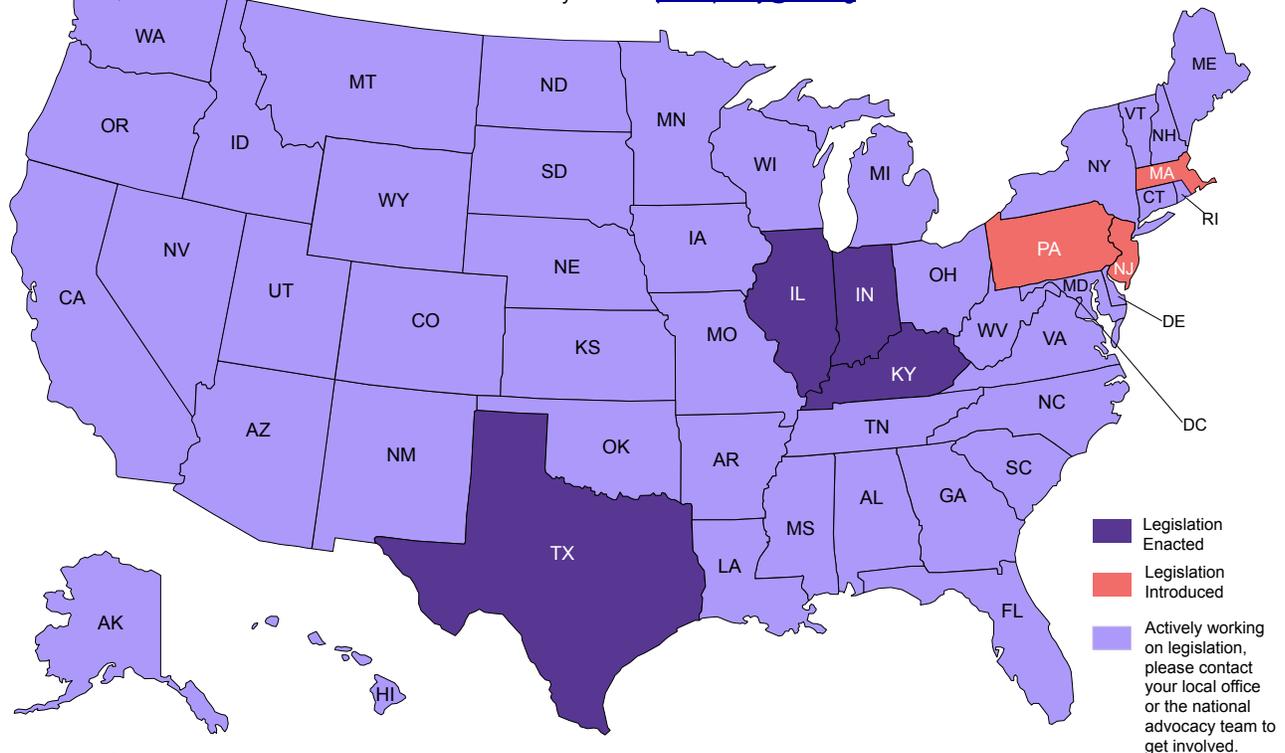
The Epilepsy Foundation's Seizure Safe Schools Act aims to ensure all school personnel, including nurses, teachers, coaches, administrators and volunteers, are not only prepared, but can recognize and respond appropriately and efficiently to students experiencing seizures. The legislation safeguards physician-directed care in the school setting, allowing students to access necessary and oftentimes life-saving medication. By bringing awareness to the entire educational community students living with epilepsy or a seizure disorder can feel safe in school, reach their potential and build meaningful relationships without fear of being stigmatized.

To date, four states—Kentucky, Indiana, Texas, and Illinois—have successfully passed Seizure Safe Schools legislation. The Epilepsy Foundation invites state-level elected officials and grassroots volunteers—parents, community organizers, health care providers, etc.—to learn more about our initiative and join the Foundation's Seizure Safe Schools Act efforts.

To join our email list and keep updated on legislation, contact Janet Romeo at jromeo@epicli.org.

Seizure Safe Schools Legislative Activity

Please contact your local Epilepsy Foundation office to learn more about the specifics of the legislation in your area and ways to get involved or contact the Epilepsy Foundation's national advocacy team at publicpolicy@efa.org.



#UNselfie



#GIVINGTUESDAY
DECEMBER 3, 2019

#GIVINGTUESDAY

Volunteers from Gold Coast Home Comfort, Tom Stackpole with his crew, Kevin, Emma and Thomas, along with EPIC Long Island volunteers Shari and Jake, helped to serve water to thirsty walkers at the Walk to End Epilepsy.

SAVE THE DATE!

Leaping into 2020: Our Perfect Vision for the Future *Dinner Gala*

Friday, February 28, 2020

Garden City Hotel

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