

EPIC Long Island aims to replace the stigma of epilepsy

Epilepsy affects one percent of the U.S. population. On Long Island, 35,000 people live with the diagnosis. Of those, 30 to 40 percent do not have good control of their seizures, even with medication.

Living with epilepsy can have a profound impact on families, friends, classmates and colleagues. Statistics have shown that many people with epilepsy also experience anxiety and depression. Side effects from anti-epileptic medication can also cause problems. EPIC Long Island is working to educate students, teachers, health care professionals, and employers, along with individuals, families and friends to create a greater understanding of epilepsy and seizures.

Advocacy and community education are not new to the agency. Since 1953, EPIC Long Island has been working with individuals and families living with epilepsy and has expanded to include services for people with intellectual and developmental disabilities, and behavioral health challenges.

“Our unwavering commitment is to help individuals and families,” said Tom Hopkins, President and CEO, EPIC Long Island. “It’s vitally important that everyone become aware of epilepsy and how to respond to seizures. That’s why we bring our educational programs to wherever there is a need – in the community, in the school, in the home.”

Throughout Long Island, there are free programs for all ages. The “Kids on the Block” puppet show for grades 3 and 4 and the “Take Charge of the Facts” program for middle and high school students help to dispel myths about epilepsy. Programs are offered to students at a young age in the hopes

that they will share this knowledge; promoting acceptance and understanding of all differences. EPIC Long Island conducts a Community Education Workshop Series for the public and “Seizure Awareness and First Aid Training” for staff in various settings on Long Island, including schools, human service agencies, senior-serving agencies, and others. Through its advocacy program, the Community Education Department also assists parents in negotiating services for their children in school, and assists adults with workplace issues arising from their epilepsy.

People often need support in navigating life with epilepsy. EPIC LI offers support groups for adults, young adults, and parents, a Youth Council, an advocacy training program for teens and young adults, as well as the Studio E Art Therapy Program. Every year, EPIC L.I. participates in the “Teens Speak Up” program whereby a teen is selected to participate in public policy advocacy training in Washington D.C. On the final day of the conference teens from all over the country meet with their representatives on Capitol Hill to advocate for increased awareness and funding for research. Just last month, Jericho High School student, Tara Silberg, represented Long Island at the event.

The vast majority of EPIC Long Island’s community education and outreach programs, bringing knowledge and understanding to every corner of Long Island, are free of charge. For more information, please contact Janet Romeo, Community Education Coordinator, at 516-739-7733, ext. 145 or email jromeo@epicli.org.