

A MESSAGE FROM OUR PRESIDENT & CEO



Dear Friends,

I hope you are all enjoying these long summer days and relaxing time with family and friends. With the following newsletter, I offer you some light summer reading while

sharing highlights from EPIC Long Island's programs and services, as well as recent events. To learn more about our events and receive ongoing updates on programs and services, as well as valuable information, I encourage you

to join our email list and follow us on social media. If you are like me and enjoy reading something you can hold in your hand, look for our next newsletter in November as we mark November is Epilepsy Awareness Month.

Warm Regards,
Tom



YAPHANK RESIDENTS OVERJOYED BY VISIT FROM THE BOHL FAMILY

In early December 2018, Board member James Bohl, and his wife, Meryl, visited the Yaphank Residence to learn more about EPIC Long Island's residential program. The residents gave Mr. and Mrs. Bohl a tour, proudly showing them their specially decorated bedrooms, and chatted about their goals, their likes and dislikes, routines and places they enjoy visiting in the community.

A real connection was made, and the Yaphank residents invited the Bohl family to its annual Christmas Party. Before coming to the party, the Bohl's asked for a copy of the individuals' Christmas wish lists.

To the delight of the men and women living in our Yaphank residence, Mr. and Mrs. Bohl and their two sons arrived at the party with personalized gifts for each individual. The

smiles on the faces of our residents reflected the joy they felt when opening such thoughtful presents. There were television sets and DVD players, light-up pictures, custom Elvis wall stickers, bed comforters and the list goes on.

The Bohl's caring and thoughtful generosity will never be forgotten. EPIC Long Island is immensely grateful to the Bohls for being such an important part of our Yaphank family.



ANNUAL EPIC LONG ISLAND DINNER GALA CELEBRATES LOCAL HEROES

There's something wonderful about a Winter Wonderland, especially when friends gather to support a good cause and celebrate the heroes who make a difference in the lives of people with epilepsy, developmental disabilities and mental health challenges. On February 15th, EPIC Long Island's Annual Dinner Gala was an evening to remember and an opportunity for the nonprofit to thank its many supporters.

Held at the Garden City Hotel in Garden City, NY, guests enjoyed an elegant cocktail reception, an exquisite sit-down dinner and an awards ceremony that recognized leaders who share EPIC Long Island's mission and work tirelessly on behalf of the men, women and children in our community.

"The 2019 honorees are an outstanding example of leadership and commitment to enriching the lives of individuals with epilepsy and other challenges," said Tom Hopkins, President & CEO, EPIC Long Island. "We are very grateful to the many friends, supporters and partners who make it possible for EPIC Long Island to offer much-needed programs and services."

A Professional Leadership Award was given to Fred A. Lado, M.D., Ph.D., who is Director of Epilepsy, Northwell Health Central and Eastern Regions.

The South Shore Child Guidance Center Community Service Award was presented to Dr. Kishore Kuncham, Superintendent of Schools, Freeport Public Schools.

The Corporate Leadership Award was given to Greenwich Biosciences. Ryan Bovia, Vice President of Marketing, accepted the award on behalf of the corporation.

The Jones family—David, Meghan and Murphy—was honored with the Naomi and Barney Silverman Family of the Year Award.

In recognition of his years of dedicated service to EPIC Long Island, Joel Ackerman, who is a CPA and tax manager with Richards, Witt & Charles, LLP, received a special honor: The Lifetime of Service Award. Joel and his wife, Terri Ackerman, served as co-chairs of the gala committee.



Co-Chairs Joel Ackerman of Richards, Witt and Charles LLP and his wife Terri Ackerman.



Thank you...

...to the students at W. T. Clarke Middle School in East Meadow School District for including the Epilepsy Foundation Long Island in their 14th annual Change for Change Giving Ceremony on May 31st. Through the school's Service Learning Club, students researched and selected 11 non-profit organizations that hold significance for the club members. Throughout the year, the students collected approximately \$2,500 through various fundraising events to be split between the selected organizations. Janet Romeo, Community Education Coordinator, and Irene Rodgers, Director of Community Services, were there to accept the award on behalf of the Community Education Department at EFLI.



ONE DAY, TWO MILES AND 100 PEOPLE CREATE A WONDERFUL “SPRING FLING” FOR SOUTH SHORE CHILD GUIDANCE CENTER

The first beautiful day of spring was May 18th, and it coincided with South Shore Child Guidance Center’s (SSCGC) Spring Fling in Freeport’s Cow Meadow Park.

Every year, the two-mile walk attracts greater numbers, and this year was no exception, with about 100 people participating. The walk is held to benefit SSCGC’s behavioral health services for children from 5 to 18 years of age, as well as services for siblings and parents.

The Walk was led by “The Sparkles”—a group of teenagers who volunteer regularly at SSCGC—followed by the Freeport High School Color Guard. Among the walkers were EPIC Long Island and SSCGC board members and staff members.

There were plenty of activities for people of all ages at the Spring Fling. Live music, raffles and games of tug-of-war made for a fun day! First responders also took an active role in entertaining the children. Local fire fighters let them try on Fire Department gear, and police officers let youngsters take a look inside a patrol car.

Delicious treats were provided by McDonald’s, Jersey Mike’s Subs and Gala Foods Supermarket. Duryea’s Flower Shop decorated the area with balloons. Raffle prizes included a springtime plant from Atlantic Nursery and treatments from The Little Spa On the Mile. Among many generous sponsors were Gold Coast Home Comfort, Inc. and New York Life Insurance Company.

It wasn’t just the great weather that made Spring Fling such a success. It is thanks to the enthusiastic support of staff members, friends, families and volunteers who made this year’s Spring Fling such a success!

LONG ISLANDERS PARTICIPATE IN NATIONAL WALK TO END EPILEPSY

The Teens Speak Up!/Public Policy Institute Program is a national initiative by the Epilepsy Foundation bringing teens together from all over the United States to receive advocacy training, meet with their legislators and share their personal stories of living with epilepsy. Nicholas (Nico) Rivera, a 16-year-old from East Rockaway, NY, was selected as this year’s representative of the Teens Speak Up! Program for EPIC Long Island. He received training on advocacy and legislative issues with more than 40 teenagers from around the country.

Nico will continue to raise awareness about epilepsy throughout the year. He has already held an education program with his school and plans to speak with everyone at the school so they know what to do if someone has a seizure. He will volunteer at a children’s event with EPIC Long Island this summer. Plans are in the works for Nico to meet with New York legislators as well.

Sonia Rivera, Nico’s mother, spoke enthusiastically about the experience in Washington, D.C.: “Being together with the other moms and kids was overwhelming and emotional. You get everyone’s story and hear about the obstacles they went through. If you’ve never spoken to anyone about this, you are suddenly with people who understand what you go through.” Sonia said that Nico has had many trials and tribulations, but he doesn’t want to be treated any differently than other kids. “He does great, and I see the benefit already of the trip to Washington. It was a huge transformation for him to share his story and talk about epilepsy.”



EPIC LONG ISLAND DAY HAB PRESENTS A MEMORABLE “CINDERELLA”

There wasn't a dry eye in the house as EPIC Long Island's Day Hab presented “Once Upon a Time . . . Cinderella” on the afternoon of May 9th.

The enchanting play was brought to life by 20 individuals who attend EPIC Day Hab. To give everyone a chance to shine, the roles of Cinderella, the Stepmother, the Knights and the Prince were performed by multiple actors. EPIC Dreamer's, an ensemble of 13 men and women in Day program, sang several numbers and provided a stirring close to the show. Songs included “This Is Me” and “My Girl.” Treatment Team Leader Yvette Blackwood, who formed the group in December 2017, works with them weekly.

More than 100 parents and friends were thrilled to see their loved ones on stage. “It was the first time many families were seeing their child on stage singing or acting. There were tears in their eyes,” said Jasmine Beach, Program Manager, Day Habilitation who was involved in everything from auditions and casting in January to three months of rehearsals to up-to-the-minute preparations.

It was the biggest play production in EPIC Day Hab's history. From musical direction to costumes and makeup to set design, stage wizardry and ushering, many people worked together to put on the show. Day Hab staff helped actors

learn their lines, created the set, and assisted behind the scenes. Angels of Long Island, a wonderful nonprofit and thrift store, generously donated costumes, sets and props.

Congratulations to EPIC Day Hab and everyone who helped bring a truly memorable production of Cinderella to the stage!





AMY WALSLIBEN CELEBRATES 30 YEARS OF SERVICE

Congratulations to Amy Walsleben, Senior Director of Residential Services, who is celebrating 30 years of employment at EPIC Long Island!

“When I first started employment with EPIC, I had a sense that I could work here for a long time,” said Walsleben, who has worked in the field for more than 40 years. “Here I am over 30 years later!”

After volunteering for the Special Olympics while in high school, Walsleben decided to pursue a career helping individuals with developmental disabilities. “I was a buddy for a little girl with Down syndrome,” she said. “When the event ended earlier than expected, I wanted to contact her father to come pick her up. She gave me a phone number, and I subsequently called him. Her dad said that it was the first time she knew her phone number. That story always stuck with me.”

Before coming to EPIC Long Island, Walsleben worked at various day programs as a Therapeutic Recreation Specialist and Day Program Supervisor. At EPIC Long Island, Walsleben has had an impressive career trajectory, having held the following positions: Treatment Team Leader; Training Coordinator; Director of Quality Improvement; and, currently, Senior Director of Residential Services.

“I love the individuals we serve,” she said. “I always want to ensure that they have the best quality of life that they can.” She reflected on how fortunate she feels to have a strong staff, calling the Residential team the “glue” of the program.

Among many career highlights, Walsleben served as a volunteer Chairperson on the “New York State Surrogate Decision Making Committee” for the Commission on Quality of Care and Advocacy for People with Disabilities from the time of the program’s inception in 1999 until 2005. With staff members, she developed and implemented an Agency Orientation program for new employees at EPIC Long Island. She is a contributor to “The Art of Advocacy: Eight Steps to Successfully Advocating for Your Loved One in a Group Home,” by Craig R. Marcott.

Walsleben offered this advice for other professionals: “I have worked in day programs, residential services, quality improvement and staff development and training. These experiences have provided me with a global perspective of the field. These are challenging times with having to do more with less. The key to success is being flexible, staying positive and developing solutions with your team.”

EPIC Long Island salutes Amy Walsleben for her dedication to the profession and for making a difference in the lives of the individuals we serve.



NY SENATORS URGED TO PROPOSE LEGISLATION FOR SEIZURE SAFE SCHOOLS

On June 3rd, staff from the Epilepsy Foundations of Northeastern New York and Long Island joined parents and children living with epilepsy to meet with their New York Senators, Assembly Members and their aides to discuss proposed legislation for “Seizure Safe Schools.” We are so proud of our staff for playing an active role in advocacy.

Armed with leave-behind packets of epilepsy data and letters of support from the members of the Epilepsy Coalition of New York State, the advocates provided information, shared personal stories of living with epilepsy and conveyed the importance of requiring that all schools have awareness programs.

The Lobby Day also provided an opportunity to better understand what the legislators needed with regard to information about the impact of epilepsy. Likewise, advocates gleaned a sense of the level of support for such legislation.

Currently, in New York, educators from agencies including the Epilepsy Foundation of Long Island and other members of the Epilepsy Coalition provide programs on seizure recognition and first aid to students, teachers, administrative personnel and nurses. These programs are provided upon request from the schools; however, there is no mandate that makes it a requirement.

There is much work ahead. The numbers help tell the story. On Long Island alone, there are 660 public schools. In any given year, between 40 and 50 schools receive some form of epilepsy education. Long Island is not the exception: These numbers mirror the rest of the New York State.

During the visits, the children and their families shared their experiences with epilepsy in the school setting. They described some situations that resulted in negative outcomes, as the symptoms were not recognized as seizures. Thankfully, the children and their families were able to take these negative experiences and turn them into fuel for advocacy—advocating for all students living with epilepsy.

Similar legislation has already passed in Kentucky, Illinois, Indiana, and Texas, thanks to the efforts of people living with epilepsy. For New York, the Lobby Day in Albany in June was just the beginning! The effort continues, as the Epilepsy Foundation of Long Island, as well as other Epilepsy Coalition members and families living with epilepsy, will be scheduling visits with State Legislators in their district offices to continue to fight for “Seizure Safe Schools!”

OUR NEWEST RESIDENCE IS OPEN AND THRIVING

On February 22nd, EPIC Long Island opened 11th Avenue, a new residence in Farmingdale, NY, which is now home to six individuals. This marks our organization’s 18th residential opening.

“Although developing a new residence is challenging and complicated, we successfully completed the process,” said Amy Walsleben, Director of Residential Services. “The individuals and their families were very excited when their loved ones moved into their new home.”

The neighbors on the block have also been very welcoming! During weekdays, 11th Avenue residents contribute to the community by volunteering through our “Program Without Walls.” Activities range from helping neighbors with chores to making deliveries for “Rebuilding Together Long Island” to distributing food for “Angels of Long Island,” and much more.

A special shout out to the 11th Avenue team for making the new residence such a success. Thanks to Cristina Ruiz, Manager; Tiara Clemons, Assistant Manager; Kathy Mandeli, RN; and Alesia Krause, Assistant Program Director. Kudos to Gladys Brown, Director of Intake Services, and the entire team for all of their hard work and commitment to opening this house!

THE MOBILE CRISIS TEAM ASSESSES AND STABILIZES CRISES SEVEN DAYS A WEEK

When you're dealing with crises among children, families and individuals in the community, no two days are alike.

Seven days a week, from 10 a.m. to 11 p.m., a team of social workers is ready to respond to emotional, interpersonal, or psychiatric crises in Nassau County. Led by Director Patricia Devery, RN, they make up the Mobile Crisis Team, which goes into action to help people who are at risk. Their days are made up of assessing and stabilizing crises; diffusing situations; often working with law enforcement personnel, hospital staff, therapists, clergy members and school administrators.

Operated by the South Shore Guidance Center, which is a partner agency of EPIC Long Island, the Mobile Crisis Team is a viable and often preferable alternative to going immediately to the ER. "We see people wherever they are and determine the needs," said Devery, who credited the staff of seven social workers for doing great work for the community.

A recent example illustrates how the team works within Nassau County. When the police received a call from a high school about a student who had a history of violence and was threatening to buy a gun and shoot kids who were bullying him, the police immediately contacted the Mobile Crisis Team.

Christine Bogle-Austein, Team Coordinator, was handling intake that day. She learned that the student was at home. She met police at an alternative location. The Terrorism Task Force had also been called in. They created a plan in which Bogle-Austein and a plainclothes police officer would go to the family's residence, knock on the door and ask to speak with the parents and the child.

While anything can happen on any given day, the team was successful in talking with the family.

"The boy was a risk, with a solid plan, and we were able to avert action in a way that was non-traumatic for the child," Bogle-Austein said. "There could have been a whole lot of other scenarios, but we made a difference in what happened going forward."

The boy was taken by ambulance to the hospital, and Bogle-Austein called the hospital to inform them about the situation. The child was given needed treatment and was eventually stabilized. Also, she kept the parents informed and offered to be of further help at any point.

"The police and the Terrorism Task Force were incredible," Bogle-Austein recalled. Not every situation includes closure, but in this case, the mother later called the Mobile Crisis Team to let them know that her son was home after two weeks in the hospital.

"She reached out to us and that's huge," Bogle-Austein said. "As a team, that means we did a good job. "

Kudos to the Mobile Crisis Team for the tremendous work they do, day in and day out, helping people through crises, introducing them to programs and services that have the potential to change lives.

SAVE THE DATE!

Walk to End Epilepsy
Saturday, October 5

Regional Epilepsy Conference
Saturday, November 9



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Extraordinary People In Care

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