

A MESSAGE FROM OUR PRESIDENT & CEO

As we come to the end of September and the onset of autumn, among the memories of summer here at EPIC Long Island are fresh produce from our community garden, family BBQs, the annual golf and tennis outing and many exciting developments in our programs and services. It has been a full and very busy summer at EPIC Long Island and I am so pleased to share with you a little bit on all of these activities in this issue of our newsletter.



I would also like to take a moment to highlight the end of a special week for EPIC Long Island and all agencies that provide services for people with developmental disabilities. It is the week of September 10 – DSP Recognition Week -- when we pause to recognize the great work of our Direct Support Professionals. EPIC Long Island celebrates each and every one of the 250 DSPs that work in our programs and I thank them for their hard work and dedication to the men and women in our care.

Of course, I will miss the long days of summer, but fall is actually my favorite time of year. I love watching the foliage change and feeling the crispness in the air. It also brings us closer to our annual Walk for Epilepsy – an enjoyable family day at Eisenhower Park that brings together all Long Islanders who care about someone with epilepsy. It is an incredible show of strength and solidarity for children and adults living with epilepsy and I hope you will all Walk for Epilepsy with me on Saturday, October 14 starting at 9:00am. I look forward to seeing you there!

TOM HOPKINS
PRESIDENT & CEO | EPIC LONG ISLAND

EPIC LI'S COMMUNITY GARDEN



How does our garden grow? It turns out, very well! EPIC LI's plot in an East Meadow community farm has blossomed with an abundance of fresh vegetables. Planted only in May of this year, the garden has produced beets, basil, cucumbers, zucchini, and tomatoes -- all organic. There are even gigantic sunflowers to brighten everyone's day. Avid gardeners at EPIC LI (with the help of an expert volunteer from the community farm named Ed) have been tending to the garden and collecting its bounty to serve at mealtime. *Bon appetit!*



UNIONDALE HIGH SCHOOL GETS ON-CAMPUS CLINIC

Starting this Fall, South Shore Child Guidance Center will be making a big difference in the lives of Uniondale High School students. A contract with Nassau County will fund an on-campus satellite clinic, staffed by a half-time social worker on call to provide clinical services.

Two other Nassau County middle schools have been benefitting in recent years from the same program. Now Uniondale's 2,220 students will have the same access to high-quality mental health assistance during the school year. Support will be just down the hall, so that students can easily get the help they need when they need it.

ONE PERSON CAN MAKE A DIFFERENCE: L.A. FITNESS UPDATES DISABILITY POLICY

When Christopher Ciatto of Copiague went to work out at his new gym in spring of 2015, little did he know he'd be making historic changes in the way L.A. Fitness does business in the state of New York.

Christopher has epilepsy and must be accompanied by an LPN during physical exercise. But when he showed up that fateful day, the manager told him his aide was a "guest," and insisted Christopher hand over an extra fee in order to use the gym he already officially belonged to.

No amount of reasoning would change the manager's mind, including the fact that L.A. Fitness had earlier confirmed with Claudia, Christopher's mother, a Community Educator at the Epilepsy Foundation of Long Island, that an LPN would be allowed to accompany her son at no cost.

Deeply unsettled by the manager's behavior, Christopher turned to his mother and asked, "Why did he speak to me like that?" She called L.A. Fitness for the answer, but ran up against the same uncooperative response.

The encounter smacked of discrimination and Claudia was having none of it. She took her complaint to the Attorney General's office, which filed a lawsuit accusing L.A. Fitness International LLC of violating the Americans with Disabilities Act and related state laws. On November 2, 2016, Attorney General Eric Schneiderman announced that L.A. Fitness had agreed to allow aides free admission when accompanying a disabled patron in all 29 gyms across the state, and promised it would better train its employees.



Christopher was awarded \$5,000 and an 18-month free gym membership, but it took him a while to take L.A. Fitness up on the offer. Returning dredged up bad memories. Claudia knew it was important, though, and for the next two months kept encouraging him to work out. Finally, one day, he bravely made the decision to return.

And when he did, thankfully the LPN was with him. Because in one of those early workouts back at L.A. Fitness, Christopher had a seizure.

Now 23 years old, Christopher can be proud of the fact that he's played an important role making sure anyone with a disability receives fair treatment. Claudia recalls an early conversation with her son, when she told him, "You could be instrumental in changing the law."

"I can, Mom?"
"Yes, you can!"

Yes, Christopher, not only you can, but you did.

MENTAL HEALTH CLINIC MILESTONES

EPIC LI's Mental Health Clinic has been offering confidential, comprehensive therapeutic assistance to adults since 2009. About a year and a half ago, the clinic extended its services to children under the age of 18.

In that short span of time, over 170 children and their families have received support. To date, the Mental Health Clinic serves 400 patients overall. In the month of June alone, the Clinic received 1,000 visits.

The number of Long Islanders seeking help suggests that the Mental Health Clinic is providing a life-changing service to individuals who otherwise might not have reached out. The Clinic is open six days a week, with Saturday and evening appointments available. This private and accessible therapy helps remove the stigma associated with mental health challenges and reassures people who are struggling, young and old, that they are not alone.

GETTING SCHOOL NURSES UP TO SPEED

It's often the nurses who are the first responders during a school medical emergency. Training them and other staff about seizure disorders is essential if every student is to receive appropriate seizure management and response when needed.

Our Community Education staff has provided seizure awareness and first aid training for school faculty, staff and school nurses throughout Long Island for several decades. Thanks to a \$5,000 competitive grant from the National Epilepsy Foundation, this Fall, a new supplemental training program will be implemented to educate school nurses on three specific topics including Psychogenic Non-Epileptic Seizures, Rescue Medications, and Advocating for Section 504 and IEP Plans to assist students with epilepsy.

STUDIO E

EPIC LI's East Meadow location was transformed into an art gallery on July 11 when original works by participants in the Studio E Art Therapy Program proudly went on display.



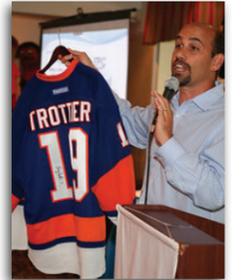
The initiative, now in its sixth year with support from Lundbeck and the Epilepsy Foundation, invites adolescents and young adults living with epilepsy to connect with each other and express themselves through art. Beginning in May, participants spent eight weeks choosing from a wide range of media, including collage, charcoal, plaster, and paint. Art therapist Lilly Polishuk provided guidance and weekly themes, which this year were Conflicting Emotions, Supporting Hands, Freedom through Grayscale, Zentangle, The Bigger Picture, Awareness Ribbon, Dream Boards/Stones, and Letters to Self.

The results were truly spectacular. But don't take our word for it! See some of the artwork for yourself at EPIC LI's Facebook page.

SWINGING FOR A GOOD CAUSE: THE ANNUAL GOLF & TENNIS CLASSIC

On August 7, the Mill River Club served as the stunning site for this year's Annual Don Luneburg Golf and Tennis Classic, featuring a wide range of activities that garnered financial support for EPIC LI's services and programs.

Despite a rainy day, there was a strong, enthusiastic turnout. Guests enjoyed contests, raffles, and therapeutic massages. Brunch and a gourmet dinner were served, followed by two auctions, one silent and one live.



Former NFL offensive lineman and Long Island native Gary Big Brown made a special appearance, joining in on the day's many activities. The 1996 Super Bowl champion is a passionate advocate for mental health, and EPIC LI was truly honored that he took the time to participate in this year's Classic.

The Golf and Tennis Classic was renamed in 2015 in honor of EPIC LI Board Member Don Luneburg, CEO of FDR Services Corp. He and his wife, Grace, have given generously to EPIC LI of their time and resources, and tirelessly championed our mission. In 2015, they were honored with EPIC LI's Lifetime of Service Award.



In addition to the Luneburgs, EPIC LI also wishes to thank the following sponsors for their generous support: FDR Services Corp. • Encompass Group, LLC • CJM Wealth Management • DeVerna Family • Direct Machinery Sales • Mendon Leasing Corp. • The Northeast Group at Morgan Stanley • Skaggs-Walsh • Phoenix Textile Corporation • Sentinel Risk Advisors • Venus Group, Inc. • Borrelli & Associates, PLLC • NYU Winthrop Hospital • Dunkin Donuts • Fusion Architecture, PLLC • Bob & Melanie Cassandro.

For more photos from our this year's event, please visit our facebook page!

DAY HAB

EPIC'S OSCAR AWARDS

Every year, EPIC LI celebrates the individuals in our program by presenting them with certificates of appreciation for a variety of tasks they do every day. This year, there were 12 categories: perfect attendance, most helpful, best female dancer, best male dancer, best dresser, most likable (peer-2-peer) most unique, most social, most creative, funniest, biggest sports fan and most outgoing. Once the "envelopes were sealed" after classroom staff make their final decisions, a "red carpet" was rolled out in EPIC Commons, leading to stage where recipients picked up their Oscars (actually, a specially produced certificate).

FOURTH OF JULY CELEBRATION

Red, white, and blue took over EPIC LI on the nation's birthday this year! Each classroom made banners of the flag's colors and the same color scheme dressed up the hallways. Individuals, dressed in one of the three colors, made cookies and drinks in red, white (or clear), or blue. Everyone learned about Independence Day and discussed its origins and meaning.

It was indeed a happy fourth!



PIZZA DAY AT DAY HAB

The owner of Borrelli's Restaurant in East Meadow visited EPIC LI's Day Habilitation program for a demonstration on how to make pizza. Day Hab participants then jumped right in, making their own individual pies, which everyone agreed were delicious!



DAY HAB

CINCO DE MAYO

In keeping with a tradition established several years ago by a family member of our Day Hab and residential programs, volunteers from Neuberger Berman transformed our Day program into a Cinco De Mayo party that was enjoyed by program participants and staff alike. Volunteers decorated, served pizza and beverages and distributed party favors. Following lunch, volunteers made sure everyone had a maraca and the dance party lasted all afternoon! Thank you to Neuberger Berman for a wonderful party!

SIP-N-PAINT

On May 11th and 12th, EPIC Commons was the site of apple cider sipping and paint-brush dipping as individuals gathered to create works of art for their families. Over the two-day period, all were encouraged to turn a blank canvas into anything of their choosing with a "wine glass" of sparkling apple cider by their side, and the results were very creative. Staff was always on hand to assist based on individual needs.



SUPER BOWL CHAMPION GARY BIG BROWN DAZZLES DAY HAB

Gary Big Brown, former NFL offensive lineman for the Green Bay Packers and Super Bowl champion, visited EPIC LI's Day Hab on Tuesday, August 22, where he was welcomed with signs and posters in his team colors. Gary, a Long Island native and long-time advocate for mental health, brought his team helmet, wore his Super Bowl championship ring, signed autographs, posed for photos, and took the time to answer tons of questions



about football and his NFL career from the enthralled

EPIC LI group. Huge thanks to Gary for giving our Day Hab participants the thrill of a lifetime!



AUTISM AWARENESS MONTH

On April 27th, EPIC LI celebrated and acknowledged the uniqueness of all the individuals in our program with Autism. On this special day, everyone -- including staff -- wore a blue piece of clothing, which bathed the entire group in a sea of supportive color. Red, yellow, and green T-shirts were worn by staff and individuals in Activity Room 2 to reflect the many colors in the autism spectrum ribbon. Program manager Edith Chamberlain focused on awareness with a brief presentation and discussion. Puzzle pieces, a symbol for autism, were handed out, along with pencils, key rings and ribbons. It was a great day to remind those in our autism program just how special they truly are!

TWO BOARDS OF DIRECTORS SELECT TOM HOPKINS AS NEW MEMBER

The Interagency Council and The Epilepsy Coalition have invited EPIC LI's President and CEO to join their Boards.

Both non-profits work in the area of human services. The Interagency Council plans, coordinates, and integrates voluntary operated services in the greater New York metropolitan area. The Epilepsy Coalition promotes awareness of epilepsy and its consequences to public and private New York state sectors and improves the service system throughout the state.

"I'm deeply honored to be selected to join these Boards," Hopkins says. "These are two non-profits that share EPIC LI's commitment to ensure the well-being and success of the very special community we serve."

C.A.R.E. CENTER RESPONDS TO SURGE IN OPIOID ADDICTIONS AND HEROIN OVERDOSES

The national rise in opioid abuse and heroin overdoses has tragically hit home, affecting an unprecedented number of Long Islanders. The medical examiner's offices in Suffolk and Nassau Counties reported that, just last year, nearly 500 of our neighbors suffered fatal overdoses.

Many of those struggling are turning to the South Shore Child Guidance Center's C.A.R.E. Center (Children's Addiction Resource & Education Center) in Freeport for treatment, dramatically swelling the clientele number. There's been a significant change in the age of clients, as well. The recovery center treats adults, along with their children, and, in most years, that registers as 70 percent adults, 30 percent children. But this year, the percentages are closer to 50-50.

Why this change? Explains Carolyn Walsh, MSW, C.A.R.E. Center Director, "As adults and parents experiment with substances, it leads to more adolescents experimenting as well. And because adult use of substances is high, we are seeing more and more children come through our doors."

The C.A.R.E. Center provides talk therapy and play therapy to children ages five through 18. Adults receive individual and group therapy, with the goal of being drug-free. This year, the Center introduced a 16-week program called SPARCS (Structured Psychotherapy for Adolescents Responding to Chronic Stress), initiated by the Adelphi University Trauma Institute, to help young people with a history of trauma recognize and cope with their feelings. Sixteen adolescents have completed the program successfully.

Also available is an eight-week Multi-Family Substance Abuse Awareness Group for all members of families affected by addiction.

The social workers at The C.A.R.E. Center are working hard to meet the mounting numbers of new clients desperate for a way out.

SPLASHES OF HOPE MURAL

Thanks to a generous gift from Astoria Bank, a stunning mural now graces EPIC LI's Mental Health Clinic.

Volunteer artists and designers from the non-profit Splashes of Hope spent the day hand-painting the custom-designed mural, specially created to provide comfort and an uplifting visual focus for the clinic's patients and their families.



KEEPING UP WITH MURPHY JONES

When her daughter Murphy was diagnosed with epilepsy four years ago, Meghan Jones didn't know where to turn. "I knew nothing," she recalls. "I had no clue what we were up against."

Thankfully, her doctor recommended contacting EPIC. Janet Romeo, EPIC LI Community Education Coordinator, immediately armed Meghan with information ("I still have the binder Janet gave me") and gave Murphy books she could use with her kindergarten classmates to help them understand her condition. In the ensuing four years, EPIC has continued to provide the Joneses with answers and resources.

Now 8 years old, Murphy has thrived and she and her family have become valuable members of the EPIC community, devoting time and energy to all kinds of fund- and awareness-raising activities. This summer marked Murphy's second Lemonade for Livy stand, and the Joneses have participated in the Walk, sold t-shirts, and even came up with their own fundraising event: the Annual Pub Crawl. "It was my husband's idea," Meghan says, noting that this year it'll take place on September 30. In the spring, the Jones clan will head to Washington, DC to take part for the first time in the 2018 National Walk for Epilepsy.

In the meantime, Murphy will be starting 3rd grade this Fall at Clayton Huey Elementary in Center Moriches. She's an avid reader who loves history. A descendent of President Ulysses S. Grant, she's currently reading a biography of him, with another on President Barack Obama on deck. Her true love is acting, and she's active in the CM Performing Arts Center in Oakdale. According to her mother, Murphy likes "big plans," which include attending Harvard (like President Obama) and a presidential bid (like another actor turned President, Ronald Reagan).

Meghan adds, "She is truly an extraordinary child, with big plans to change the world. First, she will fight to cure epilepsy, then help the rest of the world. One problem at a time!"

GRANT FROM TD CHARITABLE FOUNDATION



Living with a diagnosis of epilepsy or seizure disorder entails challenges that go beyond accessing necessary medical treatment. A \$5,000 grant through the TD Charitable Foundation, toward our Community Education and Outreach Program will help EPIC Long Island to provide Long Islanders with the support, information, advocacy and education they need to overcome these challenges. Further, this grant will assist EPIC Long Island in our efforts to train our community in seizure safety: recognizing seizures and providing first aid in the event of a seizure. For more information about services available through the Community Education and Outreach Program, visit our website at <http://www.epicli.org/epilepsy-services/> or call Janet Romeo at 516-739-7733 ext. 145.

TEAM CAPTAINS BOWL BEFORE THEY WALK!

2017 Walk for Epilepsy Captains got together on July 20 for bowling and pizza in preparation for the October 14 fundraising event. Bowlers and non-bowlers met at Farmingdale Lanes for a lively evening of games and Team Captain orientation. This year's Grand Marshal is 17-year-old Lily Freed from Bayside, Queens, a whiz at rallying family and friends for support. Want to join Lily and others? There's still time to be a Team Captain! Contact Eileen Colletti at 516-739-7733 ext. 626 for more information.



SAVE THE DATE!

For our 2017
Walk for Epilepsy
OCTOBER 14, 2017

