

EPIC Family



END OF YEAR 2021 Newsletter

EPIC Long Island & Epilepsy Foundation Long Island

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A MESSAGE FROM OUR PRESIDENT & CEO TOM HOPKINS



"Life is what happens to you when you're busy making other plans."

— John Lennon

Welcome to our end-of-the-year newsletter. It's been a far too eventful year for me to attempt to tie up the loose ends of 2021. Suffice it to say that it was not the year when, despite our best hopes, we returned to "normal". Whatever grand plans we had for the year just did not work out! We were, however, able to deal with the days of the year as they came, playing it safe when we could, taking risks when we must.

The dance that we all did with COVID is all too familiar to those with epilepsy and their families. The challenge of living with epilepsy occurs daily and involves repeated decisions about safety and risk. Questions abound. How confident am I in my seizure control? How cautious do I need to be? Can I drive, swim, drink? How can I make myself safe at night?

None of these questions has an easy or permanent answer. And it's hard to formulate answers without help – help from your family, your friends, your doctor, and from the Epilepsy Foundation Long Island.

The Walk to END Epilepsy in October saw hundreds of people gather in a dramatic show of support, the Regional Epilepsy Conference in November highlighted recent research and treatment options, and our ongoing Community Education series continued to provide information vital to coping with the challenges of the disease. You will find out more about these events in this newsletter.

So, as we begin another year optimistically hoping for better times, yet realistically expecting all sorts of surprises and challenges, let's take inspiration from people with epilepsy. They can show us how to have the confidence to make big plans and the courage to confront each day's risks and challenges. Not a bad strategy for 2022!

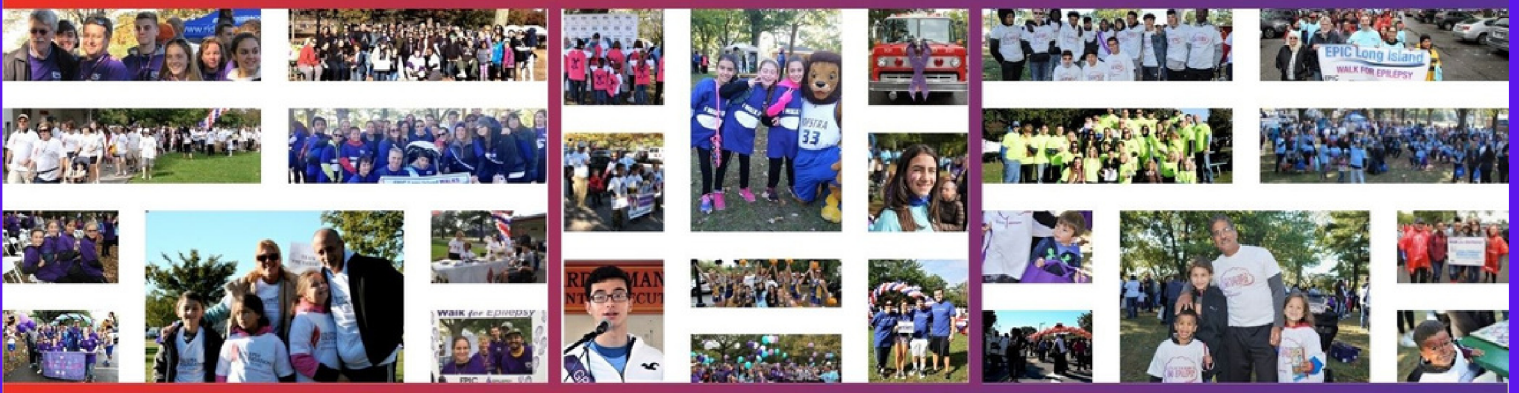
-Tom

President & CEO



Walk to END EPILEPSY





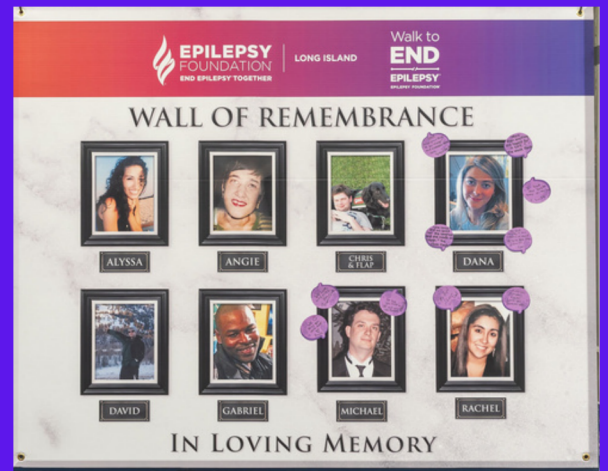
2021 Walk to END EPILEPSY

Every year, we host the Epilepsy Foundation Long Island Walk to END EPILEPSY in mid-October to bring our community together, raise awareness, and raise funds for our epilepsy education and outreach programs and services. The Walk also serves as a kick-off to November is Epilepsy Awareness Month.

This year, we celebrated our 10th Anniversary of walking in Eisenhower Park. Our Walk was lead by Grand Marshal Giovanna Veteri with her team of family and friends including her seizure response dog, Cade. Following close behind were previous Grand Marshals: The Bohl Family, Lily Freed & her family, and The Rivera Family.

While we were able to host the Walk in person, we faced challenges related to COVID as we had to limit the number of participants. For those who could not join us at Eisenhower Park, we encouraged individuals and families to walk in small groups in their communities. Despite these limitations, the participants, our supporters, and the walkers were never more on 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.

The pictures illustrate the enthusiasm, sense of community and the importance of continuing to raise awareness - all of these efforts lead to better treatment options, decreased stigma, and better health outcomes for those living with epilepsy across all communities.



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**The Dr. Adele V. Deckinger
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AGENDA

- 9:00AM Welcome**
Thomas M. Hopkins, President & CEO
- Introduction of Keynote Speaker**
Alan B. Ettinger, MD, MBA
- 9:15AM Keynote Presentation: CBD and Epilepsy**
Orrin Devinsky, MD
- 9:45AM Inflammation & Seizures: Targets for Epilepsy Prevention**
Louis N. Manganas, MD, PhD
- 10:15AM Mindfulness Exercise**
MaryAnn Schwartz
- 10:20AM Genetics/Syndromes of Epilepsy**
Jill Miller-Horn, MD, MS, FAES
- 10:50AM Special Consideration for Pediatric Patients**
Josiane LaJoie, MD
- 11:20AM Morning Panel - Q&A**
- 12:00PM Break**
- 12:15PM Music and the Brain**
Alan B. Ettinger, MD, MBA
- 12:45PM Current Trends in Epilepsy Treatment**
Sean T. Hwang, MD
- 1:15PM Yoga Exercise**
MaryAnn Schwartz
- 1:20PM SUDEP/Safety Devices**
Sanjeev V. Kothare, MD, FAES, FAAN, FAASM
- 1:50PM Women & Epilepsy: What Women AND Men Need to Know**
Rebecca Spiegel, MD, MA, FAES
- 2:20PM Afternoon Panel - Q&A**
- 2:55PM Closing Remarks**
Thomas M. Hopkins, President & CEO



2021 REGIONAL EPILEPSY CONFERENCE

SATURDAY, NOVEMBER 13, 2021
9:00 am - 3:00 pm

Virtual Event

Epilepsy Foundation Long Island

The Epilepsy Foundation Long Island 2021 Regional Epilepsy Conference

Furthering our mission, for November is Epilepsy Awareness Month, the Epilepsy Foundation Long Island hosted a Regional Epilepsy Conference with speakers from Level 4 Comprehensive Epilepsy Centers in the Long Island/Metro New York area. Despite many advancements in research and treatments, seizures remain a challenge for those living with active epilepsy.

Leading epileptologists from three Comprehensive Epilepsy Centers: Northwell Health, Stony Brook University Hospital, and NYU Langone Health presented on several topics related to epilepsy. Patients, caregivers, and professionals attended the 6-hour online webinar conference which included live Question & Answer panel sessions during the morning and afternoon programs.

We are fortunate to have four comprehensive epilepsy centers on Long Island. In other areas of the country, people living with epilepsy seek treatment hours away from home or travel to other states to receive the specialized care and treatment that epilepsy often requires. We are truly grateful for the dedication and commitment of the epileptologists who shared their expertise.

The Epilepsy Foundation Long Island received support for this conference through the generosity of the Epilepsy Coalition of New York State, the Thomas and Jeanne Elmezzi Private Foundation, Biocodex, Zogenix, and our 2021 EPIC Family Sponsor, SK Life Science.



Epilepsy Advocate

Caroline Gross is currently a Senior at Jericho High School in Long Island, New York. She was diagnosed with epilepsy three years ago; instead of allowing the diagnosis to dictate the trajectory of her life, she has channeled her time and energy into advocacy, research, and fundraising. We met Caroline in late February of 2020, shortly before the Covid-19 pandemic began to have its devastating impact on communities across the United States. Caroline has not let seizures or COVID stop her from raising epilepsy awareness. Since March of 2020, she has continued to persevere and is actively involved in advocacy efforts coordinated by the national Epilepsy Foundation in collaboration with its network of affiliates and chapters, including the 2020 & 2021 August Recess virtual visits with members of Congress, the 2021 Teens Speak Up! Program; and working with the Epilepsy Foundation, the Northeastern New York and Long Island affiliates, as well as other epilepsy agencies throughout New York to move forward with proposed legislation for Seizure Safe Schools.

During her junior year, Caroline completed a research paper on the impact of epilepsy on the family system. To read a summary of her research, click link: <https://www.epicli.org/wp-content/uploads/2022/02/Research-Blurb.pdf>

Besides being an effective advocate and strong student, Caroline is also a creative and incredible fundraiser for our organization. She and her family have supported our main fundraising events: The Gala, the Spring Fling, the Don Luneburg Golf & Tennis Classic, and the Walk to END EPILEPSY. Additionally, she has developed her own ongoing fundraising campaign in the community by placing donation cans at local businesses including Ben's Kosher Deli in Greenvale, Bagel Boss in East Norwich, Roslyn Kosher Butcher, Albertson Seafood Market, Ambiance Hair Salon, Gold Coast Kids in Jericho, Dolce Vita Pizza, and Wheatley Beauty Nails. Once picking up the donations, Caroline forwards the proceeds to our organization. Since November of 2020, she has raised \$1,900 with this campaign! Many thanks to Caroline for her efforts and to the businesses that have supported her cause.

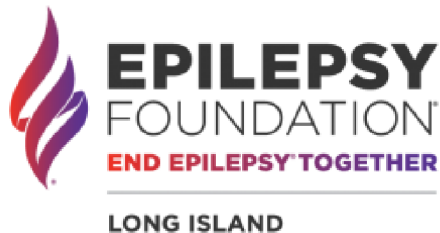
Caroline is a smart, dynamic, and eloquent young woman – we are lucky to have her on our team at the Epilepsy Foundation Long Island!

Seizure Recognition and First Aid Certification

Since last fall, our Community Education programs have expanded to offer the Seizure Recognition and First Aid Certification training, a national initiative developed by the Epilepsy Foundation, partnering affiliates and chapters with funding from the Centers for Disease Control and Prevention.

Over **500** people have been trained!

To find out more about these programs and services, please reach out to Janet Romeo, Community Education Coordinator (516) 739 - 7733, option 4. or jromeo@epicli.org



We are looking forward to 2022 and keeping our friends and supporters apprised of the work of our family of services at EPIC Long Island, South Shore Child Guidance Center & the Epilepsy Foundation Long Island!

