Please Join Us!

Saturday, May 13, 2017
8th Annual Hudson Valley Stroll for Epilepsy
Dutchess County Wilcox Memorial Park
Route 199, Standfordville, NY 12581 (Town of Milan)

• Check-in begins at 11am - Stroll starts at noon
• Pre-registration preferred
• Registration fee is $25 per person ($30 day of event)
• Children 12 and under are FREE
• Students age 13 and up may participate for $10

Register online at http://bitly.com/HVStroll2017 or contact Robert Bain at (845) 883-6320 ext: 122 or via email at rbain@epilepsyneny.org.

Let’s Bowl!

Monday, June 5, 2017 - 5:30pm-8:00pm
26th Annual Bowl for Epilepsy
Spare Time Latham
375 Troy-Schenectady Road, Latham, NY 12110

• Check-In opens at 5:30pm - Bowling begins at 6pm
• Your registration includes 2 slices of pizza & unlimited soda
• Individual bowlers will be teamed up with others
• Registration required (no fee to bowl)
• Trophies awarded to top fundraisers
  (Friends & Family Team, Company Team, Individual)

Visit our website or Facebook page to register and fundraise online, or contact Susan at (518) 456-7501 Ext: 114 or via email at skaczynski@epilepsyneny.org.
Our Mission:
The mission of the Epilepsy Foundation is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

Staff:
Deborah Bain
Director of Educational Programs & Special Projects

Robert Bain
Special Events & Advocacy Coordinator

Darcy Below
Office Manager

Gwennan Booth
Marketing & Communications Coordinator

Mary Beth Champagne
Accounting & Human Resource Administrator

Erica DeNicola-Scher, MS
Health Educator / HRSA Grant Coordinator

Jeannine Garab
Executive Director

Jenny Guerette, MSEd
Director of Medicaid Programs & Waiver Services

Susan Kaczynski
Director of Development

Aaron Kent, MSEd
Independent Living Skills Coordinator

Lori Kidd, BSW
Assistant Director of Medicaid Service Coordination

Josh Leben
Medicaid Service Coordinator

Kathryn Raymond, MA
Counselor / TBI Service Coordinator

Jeff Riccio, MSEd
TBI Service Coordinator

Nicole Sanders
Medicaid Service Coordinator

Mike Schmidt
Assistant Director of Medicaid Service Coordination

Diana Voss
Administrative Assistant

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World Purple Day Workplace Challenge Results
Many friends of EFNENY all wore purple on March 26th to promote epilepsy awareness, however, you will have to go to our Facebook or Instagram page to see it in color! Thank you to all who participated!

News from Our Staff and Board of Directors

Welcome Nicole

We are excited to welcome a new Medicaid Service Coordinator to our team. Nicole Sanders joined us in April. Nicole has a Master’s Degree in Therapeutic Recreation/Child Life from Springfield College, and a Bachelor’s Degree in Psychology from Castleton State College.

Welcome Nicole!

Congratulations Jenny, Lori and Mike

We are pleased to announce a new title for Jenny Guerette, who will now serve as our Director of Medicaid Programs and Waiver Services. In her new role, Jenny will have more time to focus on growing the programs and services we provide to individuals who have epilepsy as the result of a traumatic brain injury, while continuing to oversee the Medicaid Service Coordination program. Jenny has been with the Epilepsy Foundation for 21 years serving most recently as Director of Service Coordination.

We are also excited to announce the promotion of two long-time staff members, Lori Kidd and Michael Schmidt who have been promoted to Assistant Directors of Medicaid Service Coordination. Lori has been with the Epilepsy Foundation for 19 years, serving as our Intake Coordinator. Mike has been with the Epilepsy Foundation for 13 years, serving as a Medicaid Service Coordinator.

Welcome Michelle

The Board of Directors is pleased to welcome Michelle Hebert. Michelle is Director of Communications at School Administrators Association of NYS. She is also the parent of a child with epilepsy. Michelle looks forward to serving on the Advocacy Committee and assisting with this year’s Saratoga Stroll for Epilepsy.
Epilepsy Awareness Events

Sunday, September 10, 2017
9th Annual Saratoga Stroll for Epilepsy
Saratoga Spa State Park - Columbia Pavilion

Join us for a 1 or 3-mile stroll through the beautiful Saratoga Spa State Park!

**REGISTRATION:** $25 per person / $30 day of event; students 13 and older - $10; children 12 and under free. Contact Susan at skaczynski@epilepsyneny.org or (518) 456-7501 Ext: 114 for more information. Visit our website or Facebook page for up-to-date information.

Trophies will be awarded to the top fundraisers in the following categories: Individual, Friends & Family Team and Company Team.

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Monday, September 25, 2017
Jake Straughter Memorial Golf Tournament for Epilepsy
Wolferts Roost Country Club

Registration is required (register early, this event sells out fast!), **sponsorship opportunities** available at many levels! To register, sponsor, or for more information, contact Susan at skaczynski@epilepsyneny.org or (518) 456-7501 Ext: 114. Visit our website or Facebook page for up to date information.

Presenting Sponsor: **Turf Hotels**

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**We Need YOUR Feedback: Take Our Survey!**

Our top priority is providing the best possible programs and services for our consumers. As you know, we host a conference each year that features several different speakers and addresses topics that are most important to those living with epilepsy and their loved ones/caregivers.

We ask you to please complete this brief survey to help us plan our 2017 Annual Conference. Your important feedback will ensure we choose topics and speakers that are of interest to you and meet the preferences of as many potential attendees as possible. We appreciate your time!

To take the survey, please visit: [https://www.surveymonkey.com/r/EFNENYconferences](https://www.surveymonkey.com/r/EFNENYconferences)

*Don’t Delay! Deadline to complete the survey is May 26, 2017.*
29th Annual Confections in Chocolate Gala

A Gallery of Hope

Saturday, March, 11, 2017 at Glen Sanders Mansion

We are pleased to announce over 250 people attended this year’s Confections in Chocolate Gala, and over $75,750 has been raised to date! Thank you if you were a supporter of this event!

The evening began with a cocktail hour followed by the program, dinner and an assortment of exquisite chocolate desserts donated by local pastry chefs and restaurants, the highlight of the evening! Phil Bayly of NewsChannel 13 served as Master of Ceremony and live music was performed by TS Ensemble!

Over 100 silent auction packages were available for bidding as well as several live auction items, which was led by Auctioneer Randy Passonno of Collar City Auctions. Such items included overnight packages, jewelry, gift cards to local restaurants, sports memorabilia, and much more! The always popular Wine & Dine Pull included coupons to Sonic, Outback Steakhouse and Texas Roadhouse. Also back this year was the Lottery Tree – congratulations to Kevin V. for winning over 18 chances to become a millionaire!

The 2017 Flame of Hope Award was presented to Lundbeck, a global pharmaceutical company specializing in neurological disorders, including epilepsy. This award recognized the hope that Lundbeck has brought to people with epilepsy in our community through their generous funding of the Studio E Art Therapy program as well as programs and services we provide.

The 2017 Winning Kids were also introduced: Jaina Davis and Jacob Miner, both 7 years old. Volunteer and advocate, Stephen Piorkowskis, was our Care and Cure speaker, sharing his amazing journey with epilepsy and how it has affected his life. Mazzone Hospitality was the winner once again (second year in a row!) of the Best Themed Chocolate Dessert. Visit our web site or Facebook page to view photos from the event. The website will also list silent auction items still available.

Special Thanks to our Event Partner!

And other Top Sponsors...

Additional Support Provided By: Hannoush Jewelers, NewsChannel 13, Times Union, B95.5, Arbonne/ North Country Contracting, Pioneer Bank, Rensselaer Polytechnic Institute, Capital Care, GE, Sonic, CDPHP, Mazzone Hospitality, UAlbany Foundation, Cohoes Savings Foundation and Nigro Companies

As with all our fundraising events, funds raised help provide programs and services needed by individuals affected by epilepsy within the twenty-two counties we serve.

SAVE THE DATE for next year’s gala - March 10, 2018! Interested in joining the planning committee? Contact Susan at (518) 456-7501 or skaczynski@epilepsyneny.org.
Support Group for Adults with Epilepsy

Please join us for our Support Group meetings for adults, 18 and over, diagnosed with epilepsy. The support group is an open forum for individuals struggling with epilepsy and related issues to find encouragement from others in our community. We cover topics such as employment, relationships, medications, driving, advocacy and resources.

Meetings are held from 6:00 - 7:30pm on the last Thursday of every month at the Crossgates Mall Community Room (3rd floor above Best Buy).
For more information or to RSVP please contact Kathryn Raymond at (518) 456-7501 ext. 109 or via email at kraymond@epilepsyneny.org.

Next Meeting Dates: April 27 - May 25 - June 29 - July 27 - August 31 - September 28. October, November and December dates to be determined. Refreshments will be served.

Teen to Teen
A SOCIAL SUPPORT GROUP FOR TEENS WITH EPILEPSY (AGES 13-19)

Is it hard to be around others who don’t understand or who aren’t willing to understand? We know, we understand, and we care. We will inspire you to be yourself, and empower you to accomplish your goals.

Please join us for our upcoming TEEN TO TEEN Support Group meetings. Meetings are held from 6:00 - 7:30pm on the third Thursday of every month at the Albany office. Please contact Kathryn Raymond at (518) 456-7501 ext. 109 or via email at kraymond@epilepsyneny.org to RSVP or for more information.

Next Meeting Dates: April 20 - May 18. This group does not meet during the summer months however persons 18 years and older are welcome to attend the Adult Support Group meetings in June, July and August. September, October, November and December dates to be determined. Refreshments will be served.

It’s Not Too Late to Participate

If you would like to sign up for Studio E, please contact Deborah Bain at (518) 456-7501 ext. 103 or via email at dbain@epilepsyneny.org. Admission is Free. Please note that this program is offered exclusively to adults with epilepsy. For more information about the program, visit www.epilepsy.com/northeastern-new-york.

Place: Honest Weight Food Co-op - 100 Watervliet Avenue, Albany
Dates: Saturday, May 13, June 10, July 8, August 12, September 9, October 14, November 4
Time: 10:00am - 12:00 noon

Additional Weeknight sessions at a different location!
Place: Center for Disability Services, 1164 Western Avenue, Albany
Dates: Thursday, May 25, June 29, July 20, August 24, September 21, October 26, November 16
Time: 6:30pm - 8:30pm

Sponsored By: 

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We want you to get to know us!

Each issue, you’ll find new EFNENY Staff Spotlights that describe a bit about our role at the Foundation and life outside it. By introducing you to the members of the staff, we hope it will help you better understand who to reach out to when you have a question or comment.

Darcy Below
Since 2005, Darcy is one of the very first people you’ll see when you come into the office and one of the first you’ll speak to when you call! Darcy started at the Epilepsy Foundation of Northeastern New York as an Administrative Assistant and was promoted to Office Manager. In addition to ensuring our operations here are running smoothly, she keeps us all on task and fully stocked! Darcy makes sure our mailings, post cards and invitations arrive safely at your door, and is responsible for this very newsletter you’re reading. She also assists with our many special events throughout the year and proudly serves on the Confections in Chocolate planning committee. Many of the themes and decorations have started as Darcy’s ideas! When she’s not keeping track of our staff, Darcy loves country music, reading and travelling; especially to warm, tropical places. She’s known throughout the office for her amazing baking talents and is a huge Elvis fan! Darcy enjoys spending time with her husband and family and looks forward to volunteering at a Christian camp for children each summer.

Diana Voss
Diana will celebrate 20 years at the Foundation in November! Often the voice on the phone when you call, Diana is the Administrative Assistant for all of our Medicaid Service Coordinators, Traumatic Brain Injury Service Coordinators and our Counselor. She ensures their days are running smoothly and efficiently! Diana is in charge of accepting applications for our Tara Fund and Jake Fund, and disseminating the proper information to the committees that decide the recipients. Diana says that when she first started at the Foundation in 1997, there were only nine people on staff. She says it has been a joy for her to watch our programs and services flourish and grow. She’s thankful for all the on the job training she’s had over the past two decades, and loves that her skillset has grown as the agency grows. In her personal time, Diana loves being outside and enjoying the outdoors. She’s an avid Crossfitter and is known to the local Crossfit community as Lady Di! Diana and her husband are the owners of a sailboat that they love to race!

Get Social with EFNENY

Find us on Facebook@efneny
Follow us on Twitter@efneny
Follow us on Instagram@epilepsyfoundationneny
Look for us on LinkedIn
www.epilepsy.com/northeastern-new-york
Raise Awareness and Show Your Support

BREAK THE SILENCE: A Silent Disco for Epilepsy
As an agency, we are committed to always finding creative ways to raise awareness. We had the exciting opportunity to pilot a brand new awareness event for college campuses called BREAK THE SILENCE: A Silent Disco for Epilepsy. We partnered with SUNY Plattsburgh and Alpha Delta Phi, a community service oriented student Greek organization. At the event, each participant wore headphones that streamed music to dance to. For observers, the room was completely silent, representing the silence that still surrounds epilepsy. At the end of the night, participants sang aloud to the music in their headphones in a ceremonial “breaking the silence” surrounding epilepsy. We were hugely encouraged by the feedback we received from the students and are looking to take the event to other campuses in the future. We’d like to say a special thank you to Rylie Mainville for telling her story of being a college student living with epilepsy.

C.R.E.A.T.E Studios Hosts Paint Purple for Epilepsy Event
In honor of World Purple Day®, owner of CREATE Studios Heather Hutchison organized an awareness and fundraising event that featured all things purple! The participants showcased their artistic talents and spent the afternoon engaging in an open, encouraging and welcoming dialogue about epilepsy. We’re so pleased to report the event was standing room only! We’re grateful to CREATE Studios for their generous donation that helps us to provide valuable programs and services for people living with epilepsy, and we’re thankful to everyone who “painted purple” and raised awareness!
To Our Contributors . . .
Thank You!

The Epilepsy Foundation of Northeastern New York could not accomplish its mission were it not for the generosity of our donors. We recognize these donors with a sincere sense of pride and thanks for their support in helping us touch the lives of people living with epilepsy and seizure disorders and their families and loved ones. Please visit our website to view the complete list of individuals and businesses that made gifts to the Epilepsy Foundation between January 2017 and April 2017.

To make a donation visit: http://www.epilepsy.com/northeastern-new-york or forward your donation to: EFNENY, 3 Washington Square, Albany, NY 12205

Don’t forget to check with your employer to see if they have a matching gift program. Please notify us if your donation will be matched by your employer. If you participate in workplace giving campaigns, including CFC, Community Health Charities, SEFA, and United Way, please designate the Epilepsy Foundation of NENY.

The Epilepsy Foundation wishes to express our gratitude to those contributors who wish to remain anonymous.

Stewart’s Holiday Match

We’d like to take a moment to express our gratitude to Stewart’s Shops and their Holiday Match program. Each year between Thanksgiving and Christmas, Stewart’s collects donations from customers, and then matches the contributions. We were chosen again this past holiday season as a recipient! Stewart’s Shops donated a generous $2,000, which will be used for our “Tara Kaminski Family Services Fund” that provides medical equipment for children with epilepsy whose families would not be able to afford it without assistance. We’re deeply honored that Stewart’s chose the Foundation as a recipient of the Holiday Match program. The program set a record for the third consecutive year, raising over $1.85 million!

In Memory of Lucile Brewer . . .

It is with sadness that we announce the passing of a long time member of our organization, Lucile Brewer. Lucile was one of the founding members of the first Albany Adult Epilepsy Support Group. For many years, she served as the facilitator of this group, lining up speakers and topics of interest to the members, and always making everyone who attended feel welcome. She was passionate about our cause, and a tireless advocate for people with epilepsy. Lucile was also very dedicated to improving public transportation for individuals with all disabilities. She founded Citizens for Transportation, and never allowed her own disability to stop her from attending meetings or organizing rallies. Lucile was also a regular attendee at our Bowl for Epilepsy, and many of our family conferences. She was a true champion for people with epilepsy!
DIY Community Events and Fundraisers

Do you have a Community Fundraiser Idea?
Together we have power and Do-It-Yourself (DIY) fundraising is a fun and easy way to support and raise awareness for the Epilepsy Foundation! By organizing and mobilizing people, resources and talents, we leverage the power of local people and knowledge, working together towards a common goal. You will also make a difference in the lives of people with epilepsy! Hosting a DIY Fundraiser means you create, plan, organize and run a fundraising event with proceeds donated to the Epilepsy Foundation of Northeastern New York. Use your imagination and be creative when planning an event. This is your chance to shine and have fun! Remember, Do It Yourself Events are events you organize to raise funds on behalf of the Epilepsy Foundation of Northeastern New York. If you are interested in organizing an event to support EFNENY, please contact Robert Bain at (518) 456-7501 ext. 122 or rbain@epilepsyneny.org to discuss.

Update on Community Fundraisers

Sonic of Troy Grand Opening
Sonic Drive-In of the Capital District NY celebrated another grand opening in Troy, located at 120 Hoosick Street, in February. Once again, proceeds raised from their Friends and Family Night were donated to EFNENY, raising $1,000! Thank you to the Sonic staff and management for your generosity and continued support!

Bellini’s Counter
The Epilepsy Project, created and managed by students of the Albany College of Pharmacy and Health Sciences, held a fundraiser at Bellini’s Counter in Albany on March 9th. The group, spear-headed by Yahya Rasouly, Pharm D. Candidate Class of 2018, raised $83 and helped raise awareness of epilepsy to patrons that evening. Thank you to these students for taking time out of their busy schedules to help raise funds and awareness for EFNENY!

Special Raffle Update
Thank you to everyone who purchased a raffle ticket for the opportunity to win up to $4,000! All 100 raffle tickets were purchased which means $5,000 will be used towards the programs and services we provide! First Prize of $4,000 went to Charlotte S.; two Second Prize winners of $500 each were Jerry S. and Elaine P. Congratulations!
Here Comes Summer!

Summer Camp Scholarships Available
Camp can be beneficial for all children and especially for children with epilepsy. It can increase self-confidence, foster independence, raise self-esteem and promote self-awareness.

The Epilepsy Foundation of Northeastern New York will be offering “Camperships” to children ages 5-18 with epilepsy/seizure disorders to attend a summer camp program of their choice. “Camperships” will be awarded on a first come, first serve basis. Families whose children will be unable to attend camp without financial assistance will be given priority. For more information or to receive an application form, please contact Deborah Bain at (518) 456-7501 ext. 103 or via e-mail at dbain@epilepsyneny.org. Applications can also be found on our website at: www.epilepsy.com/northeastern-new-york.

Deadline for completed applications is June 2, 2017

You Can Send a Child to Summer Camp
EFNENY is accepting donations for “Camperships” for children with epilepsy to attend summer camp. You can make a difference. To help send a child to camp send your tax-deductable donation to: EFNENY, 3 Washington Square, Albany, NY 12205. Your donation is greatly appreciated.

Tips for Summer Camp Safety
• Talk to your child’s neurologist before sending them to camp about any specific concerns regarding their epilepsy, seizure control, or medications.
• Update your child’s medical alert bracelet information and make sure they know to wear it at all times.
• Talk to camp medical staff about your child’s epilepsy ahead of time, and obtain or prepare a seizure action plan that you can provide them.
• Sleep-away camp: Talk to camp staff and your child about the importance of getting plenty of sleep while away from home; make sure you provide camp medical staff with enough medication doses for the entire duration of your child’s stay.
• Talk to your child about being their own advocate! They should not be afraid to let camp staff know when they need a break; severe overheating and overexertion are common triggers for seizures; they should also make sure to stay hydrated.
• Swimming: Obtain approval from your child’s neurologist and camp personnel for your child to participate in swimming; make sure your child knows that they should not swim unless they have someone to supervise them one-on-one. Some may want to wear a life jacket or other flotation device as a precaution.
• Call the Epilepsy Foundation of Northeastern NY to request an in-service program from our Health Educator to teach camp staff about epilepsy and appropriate seizure first aid. To schedule a training please contact Erica DeNicola-Scher at (518) 456-7501 ext. 107 or via e-mail at edenicola@epilepsyneny.org.
World Purple Day® Workplace Challenge

World Purple Day® is held each year on March 26th. This is a day to raise awareness and encourage people to show their support for those living with epilepsy. This year, we issued a challenge to offices throughout our region to select a day in March to “go purple” for epilepsy. We’re so thrilled by the enthusiastic response! Thank you to our participating organizations. Your show of support actively makes a difference for people living with epilepsy in our community! Mark your calendars for next year – on Monday, March 26th we will issue the same challenge!

Workplace photos from top to bottom: Auto/Mate Dealership Systems, Price Chopper with our 2017 Winning Kid Jacob Miner and his mom, Teal Becker Chiaramonte CPA’s PC, Spectrum News, Spectrum Reach Sales and I Love Books