



**EPILEPSY**  
FOUNDATION

NORTHEASTERN  
NEW YORK

# NATIONAL EPILEPSY AWARENESS MONTH

**NOVEMBER 2023**



**EPILEPSY DOESN'T  
PREVENT ME FROM  
BEING A KID**



*PENELOPE MILKIEWICZ ~ 2023 WINNING KID*



*Check out our 2023  
Winning Kids,  
Madison & Penelope,  
this November on  
billboards throughout  
Northeastern  
New York!*



**EPILEPSY DOESN'T  
PREVENT ME FROM  
DOING GYMNASTICS**

*MADISON POSPISIL ~ 2023 WINNING KID*

## From the Executive Director's Desk

Message from **Jeannine Garab**  
[jgarab@epilepsyneny.org](mailto:jgarab@epilepsyneny.org) | 518-456-7501



### Dear Friends,

November is National Gratitude Month. On behalf of all of us at the Epilepsy Foundation of Northeastern New York, I want to thank the individuals who are living with epilepsy for your courage, patience, and strength. The social, emotional, and physical ramifications of this disorder can certainly take their toll, and I thank each of you for sharing your epilepsy journey with us. You teach by example, and you are an inspiration to all of us! I also want to thank our incredible staff team for the hard work and dedication they exhibit every day to make life better for people with epilepsy. I also want to recognize the volunteer hours that are donated by the members of our Board of Directors and Professional Advisory Board who support our mission through their time, talents, and treasures.

Finally, I want to thank our donors who make meaningful gifts towards the work we do so we can continue to provide all our programs and services at no charge to the individuals and families who need them most. To all of you, please accept my sincere gratitude for your support.

November is also National Epilepsy Awareness Month (NEAM). While we focus on awareness twelve months of the year, November is a special time to expand our message to reach new families who have not yet found our organization. The Epilepsy Foundation is here to help all families affected by epilepsy regardless of where you are in your journey. This November, in recognition of NEAM, our National Office is launching an anti-stigma awareness campaign nationwide. We invite you to share your journey living with epilepsy, any stigma you may have experienced, and the challenges you have overcome. Share your journey by emailing [schampagne@epilepsyneny.org](mailto:schampagne@epilepsyneny.org).

Thank you for believing in our organization. Your continued support is greatly appreciated so we can ensure the continuation and expansion of our programs for you, your family members, neighbors, colleagues, and friends in the future.

To make a year-end donation, please visit [www.efnny.org](http://www.efnny.org).

Sincerely,



Jeannine S. Garab  
Executive Director



## GET INVOLVED WITH EFNENY, BECOME A VOLUNTEER!



We are so thankful for the hardworking individuals who devote their time to our events. We could not do it without our dedicated event volunteers and committee members. Help our team further the success of our annual events, become a volunteer!

Please email our Special Events Manager at, [jdunn@epilepsyneny.org](mailto:jdunn@epilepsyneny.org), to learn more or to express your interest.

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## Year-End Giving:

In honor of Epilepsy Awareness Month and as we get closer to the end of the year, we thank our donors for their support in 2023. Because of their generosity, we can provide information and referrals to the newly diagnosed, provide counseling and support as we help individuals navigate through their epilepsy journey, offer on-going seizure education and first aid trainings to family members, school personnel and in the business community. We can offer seizure certification training so more people will know what to do in case someone has a seizure.

Not only are we able to help those living with epilepsy, but we are here for those with a traumatic brain injury (TBI) along with an epilepsy diagnosis. We can offer guidance, assistance at doctor appointments, transportation needs and more to help with the challenges they face on a daily basis.

In Northeastern New York, we have over 45,000 people fighting this battle every single day, enduring constant interferences in their daily life. For some, it's a fight they ultimately win. For others, epilepsy steals independence, health, and ability. It can even steal life. That is why we must all work together to END EPILEPSY®.

As you begin to think about how you want to make an impact before the year ends, we want you to know that when you donate to EFNENY, your dollar goes directly to supporting our 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. Your gift allows us to continue to provide more opportunities, greater hope, and a better life for people with epilepsy and their families. We hope you will consider supporting EFNENY when you make your year-end gift.

To donate, please visit [www.efneny.org](http://www.efneny.org) to make an online donation or mail your check (payable to EFNENY) to Epilepsy Foundation NENY, 3 Washington Square, Albany, NY 12205.

Learn more about the impact your donation makes by visiting our website at [www.efneny.org](http://www.efneny.org).



# SAVE THE DATE

## Annual Awards Luncheon

**November 7, 2023**  
**Italian American Community Center, Albany**

Please join us for lunch to celebrate the individuals, donors, and sponsors that enable us to help those affected by epilepsy.

Please contact Susan for more information or with any questions by emailing [skaczynski@epilepsyneny.org](mailto:skaczynski@epilepsyneny.org) or calling (518) 456-7501.

**Scan QR code to learn more about this years honorees and luncheon!**



## Mark Your Calendars

**Confections in Chocolate  
Gala for Hope 2024**

April 20, 2024  
Old Daley on Crooked Lake, Averill Park

Proceeds from all of our events support the programs and services we provide in the 22 counties served. More information is available on our Facebook page and website, or contact Susan at [skaczynski@epilepsyneny.org](mailto:skaczynski@epilepsyneny.org) or (518) 456-7501

# JOIN US!

## Pediatric Treatment Updates Webinar



**REGISTER HERE**

Join us virtually on Wednesday, November 8th at 12:30 PM to learn about pediatric treatment updates with guest speakers Steven Wolf MD & Patricia McGoldrick, NP.

For questions or concerns please email our Health Educator at [ryattaw@epilepsyneny.org](mailto:ryattaw@epilepsyneny.org)

## Meet Our New Staff Members:

### Kathy Gavitt



Kathy started in January 2023 as a TBI Service Coordinator. Her goals are to provide services to TBI waiver individuals in the most inclusive, creative, and resourceful way possible.

Kathy joins our team with years of experience from careers in a variety of fields including, therapeutic, medical, and educational. Kathy has been a perfect fit for the service coordination program as she brings in experience from her time as an Independent Life Skills Trainer here in the Capital Region.

### Gabrielle Kernozeck



Gabrielle started in February 2023 as the Marketing, Communications & Special Events Coordinator.

Her goals focus on but are not limited to increasing awareness of the Foundation's mission, promoting fundraising efforts, and fostering a tight-knit community both in person and digitally.

Gabrielle graduated with a bachelor's degree in Business Administration with a concentration in Marketing from Massachusetts College of Liberal Arts.

## The EFNENY Team!



## North Country Medical Travel Reimbursement Fund

Thanks to a partnership with the Adirondack Foundation and the generosity of an anonymous donor, we are pleased to offer a fund to reimburse families from the North Country who must travel a distance from home to seek medical care and/or treatment for their family member who has epilepsy, and lacks adequate financial resources for the cost of this travel. Individuals must live in one of the counties of the North Country (Jefferson, St. Lawrence, Franklin, Clinton, Essex, Hamilton or Lewis) and be traveling for epilepsy medical services for a family member. Reimbursement may include mileage, meals and accommodations. Receipts are required. To request an application, and discuss your particular need, please contact Sam at 518-456-7501 or [schampagne@epilepsyneny.org](mailto:schampagne@epilepsyneny.org).



## EFNENY Staff

### Jeannine Garab

*Executive Director*

### Darcy Below

*Office Manager*

### Mary Beth Champagne

*Accounting & Human Resource Administrator*

### Samantha Champagne, LMHC

*Counselor & Program Coordinator*

### Jordan Dunn

*Special Events Manager*

### Kathy Gavitt, MS

*TBI Service Coordinator*

### Susan Kaczynski

*Director of Donor Engagement*

### Gabrielle Kernozeck

*Marketing, Communications & Special Events Coordinator*

### Jeff Riccio, MEd

*Director of TBI Services*

### Suzanna Ritchey

*TBI Service Coordinator*

### Diana Voss

*Administrative Assistant*

### Rachel Yattaw

*Health Educator & Advocacy Coordinator*

**Serving all people with epilepsy in the Capital Region, North Country and Upper Hudson Valley:**

*Albany, Clinton, Columbia, Dutchess, Essex, Franklin, Fulton, Greene, Hamilton, Herkimer, Jefferson, Lewis, Montgomery, Rensselaer, St. Lawrence, Saratoga, Schenectady, Schoharie, Sullivan, Ulster, Warren, and Washington counties.*

## Connect With Us!

Epilepsy Foundation  
of Northeastern New York  
3 Washington Square Albany, NY 12205  
Phone: 518.456.7501  
Fax: 518.452.1282



# 2023 Epilepsy Education



## Educational Programs:

Educational programs are provided free of charge to:

- **K-12 Students**
- **College classes and groups**
- **School Personnel**
- **School Nurses**
- **Transportation Personnel**
- **Professional Organizations**
- **Childcare Agencies**
- **First Responders**
- **Affected Families**
- **The public!**

Each program covers the basics of seizures, seizure recognition, seizure first aid, and seizure emergencies. Each program is tailored to fit the general needs and ideas of each group. Most educational programs are an hour long and school-aged programs are tailored to an age-appropriate level of information.



Please contact: [ryattaw@epilepsyneny.org](mailto:ryattaw@epilepsyneny.org) to schedule a program.

\*Many thanks to Jazz Pharmaceuticals for signing on as our 2023-2024 Educational Programs Sponsor!  
Thanks to their generosity, we are able to offer FREE training.



## Seizure First Aid

How to help someone having a seizure

1	<b>STAY</b> with the person until they are awake and alert after the seizure.		<ul style="list-style-type: none"> <li>✓ Time the seizure</li> <li>✓ Check for <b>Medical ID</b></li> <li>✓ Remain <b>calm</b></li> </ul>
2	Keep the person <b>SAFE</b>		<ul style="list-style-type: none"> <li>✓ Move or guide away from <b>harm</b>.</li> </ul>
3	Turn the person onto their <b>SIDE</b> if they are not awake and aware.		<ul style="list-style-type: none"> <li>✓ Keep <b>airway clear</b></li> <li>✓ <b>Loosen tight clothes</b> around the neck</li> <li>✓ Put <b>something small and soft</b> under the head</li> </ul>
Call 911 if...	<ul style="list-style-type: none"> <li style="width: 33%;">▶ The seizure lasts longer than 5 minutes</li> <li style="width: 33%;">▶ Repeated seizures</li> <li style="width: 33%;">▶ Difficulty breathing</li> <li style="width: 33%;">▶ The person does not return to their usual state</li> <li style="width: 33%;">▶ First-time seizure</li> <li style="width: 33%;">▶ Seizure occurs in water</li> <li style="width: 33%;">▶ The person is injured, pregnant, or sick</li> </ul>		
Do NOT	<ul style="list-style-type: none"> <li>✗ Do <b>not</b> restrain.</li> <li>✗ Do <b>not</b> put any objects in their mouth.</li> </ul>		

# CDSMP

## Chronic Disease Self-Management Program

### You matter.

#### About **CDSMP**:

The Chronic Disease Self Management Program (CDSMP) is a FREE workshop for adults with at least one chronic health condition, which may include epilepsy. It focuses on disease management skills including decision making, problem solving and action planning



#### What is the benefit?

This interactive program aims to increase:

- Confidence
- Physical and psychological well-being
- Knowledge of ways to manage chronic conditions; and
- Motivation to manage challenges associated with chronic diseases.

#### When does the program meet?

This 7-week program meets on Zoom every Tuesday from November 7th to December 19th from 9 AM – 11:30 AM

If you would like to sign up or have any questions please contact Sam Champagne, via email at [schampagne@epilepsyneny.org](mailto:schampagne@epilepsyneny.org).

Funding for this program was made possible by the Centers for Disease Control and Prevention under cooperative agreement number 5 NU58DP006965-03-00.

# You Are Never Alone

## Join a support group today!

### Studio E: The Epilepsy Art Therapy Support Group

Artistic expression can be powerful for people with epilepsy. Art can say things that words can't. Saturday meetings are being held in person at 71 Fuller Road #6 - Albany, NY 12205 or virtually on Thursday through ZOOM.

**Next Thursday meeting:**  
December 21st  
6:30 - 8:00 PM

**Next Saturday meeting:**  
November 11th  
1-3 PM

### Adult Support Group

We are very excited to continue our virtual support group for individuals, 18 and over, with epilepsy. Adult Support Group is an open forum for individuals struggling with epilepsy related issues to freely share and find encouragement from their peers.

**Next meeting:**  
November 14th  
7-8 PM

If you have any questions, would like more information, or would like to confirm your attendance, please contact our Program Coordinator, Sam Champagne, via email at [schampagne@epilepsyneny.org](mailto:schampagne@epilepsyneny.org).

## News from Our Board of Directors

We would like to congratulate our new officers who are beginning a two-year term on our Board of Directors. Our new officers include Betty DiMaria, President; Nick Zarrelli, Vice-President; Michael Brunell, Treasurer; Ryan Senecal, Secretary. Betty DiMaria chairs the Human Resources Committee and is Co-Chair for Confections in Chocolate. Nick Zarrelli chairs the Finance Committee and serves as Co-Chair for the Epilepsy Golf Tournament. Michael Brunell is a member of both the Finance Committee and the Epilepsy Golf Tournament Committee. Ryan Senecal serves on the Communications Committee and the Confections in Chocolate Committee.

## Are You Interested in Joining the Board of Directors?

The Epilepsy Foundation is governed by a Board of Directors. Our Board is composed of individuals with a variety of professional backgrounds, and we are always looking for new individuals to share their time and talents. If you are interested in being considered for membership on the Board of Directors as openings arise, or would like additional information, please contact Jeannine Garab, Executive Director at **518-456-7501** or by emailing [jgarab@epilepsyneny.org](mailto:jgarab@epilepsyneny.org).



## Board of Directors

### Betty DiMaria President

*The College of Saint Rose*

### Nicholas Zarrelli Vice President

*Saratoga National Bank & Trust Company*

### Michael Brunell Treasurer

*Marvin and Company, PC*

### Ryan Senecal Secretary

*Broadview Federal Credit Union*

### Kevin Volk Past President

*Retired*

### Cathryn Sheehy MVP Health Care

### Daniel Lehane Retired

### Deborah Stevens Greenberg Traurig LLP

### Gerald Silverman Retired

### H. Michael Okby Morgan Stanley

### Harriet Kang, MD Mount Sinai School of Medicine

### John Harwick, Esq. E Stewart Jones Hacker Murphy

### Karen Wachs Jazz Pharmaceuticals

### Lynne Longtin SUNY Polytechnic Institute

### Matthew Dahl Pioneer Bank

### Shelley Friel Harold Grinspoon Foundation

### Tim Ronk Sunmark Credit Union

### Yvonne "Bonnie" Lutz Town of Inlet

### Zachary Miller Meerkat Pest Control



## SEIZURE FIRST AID CERTIFICATION TRAINING

This program is now a monthly Seizure Recognition and First Aid Certification course.

To become seizure first aid certified, participants are required to complete a pre-test, attend a 1.5-hour training, and pass a post-test. Participants who successfully complete the course will receive a certification that is valid for two years.



### REGISTER HERE

For questions or concerns please email our Health Educator at [ryattaw@epilepsyneny.org](mailto:ryattaw@epilepsyneny.org)



#### WHEN

1ST WEDNESDAY OF EVERY MONTH  
3:00 - 4:30



#### WHERE

VIRTUAL VIA ZOOM



#### SPEAKER:

RACHEL YATTAW  
Health Educator

### FREE TO ATTEND!

# WAYS TO SUPPORT EFNENY

## Donate Your Car



Vehicle donations have the potential to drive thousands of dollars for EFNENY. One way you can support EFNENY is by donating your unwanted car, truck, motorcycle, RV, or boat to help fund our programs and services. The process is easy and free, and we'll use the proceeds for our foundation.

Learn more about this program by emailing [skaczynski@epilepsyneny.org](mailto:skaczynski@epilepsyneny.org)

## Hannaford Community Bag Program

EFNENY has been selected by the Store Leadership Team at Hannaford. This means our foundation will receive \$1 from every \$2.50 reusable Community Bag sold during the month of November 2023 at:

78 Oak Street, Walden NY



## CLYNK

How CLYNK helps EFNENY: Organizations like EFNENY can distribute tagged bags to our supporters and ask them to fill those bags with returnable bottles and drop them at participating Hannaford locations on our behalf.

You can leverage CLYNK's online fundraising options whereby CLYNK customers can donate some or all of their deposit balance directly into EFNENY's CLYNK to Give account.

Email [gkernozeck@epilepsyneny.org](mailto:gkernozeck@epilepsyneny.org) to receive more information on how to partner with EFNENY through CLYNK!

## Celebrate your Birthday with EFNENY!

Celebrate your birthday (or anniversary, wedding, etc) by taking steps toward a brighter future. Consider creating a Facebook Birthday Fundraiser to benefit EFNENY!

Proceeds from Facebook Birthday Fundraisers will help support the programs and services the Epilepsy Foundation provides to people affected by epilepsy within the twenty-two counties we serve. Learn more about Facebook Fundraisers by emailing [gkernozeck@epilepsyneny.org](mailto:gkernozeck@epilepsyneny.org).



## Parent Support Group

Parent Support Group is a community for parents of children with epilepsy who are looking to connect with other parents.



Interested in learning more?

Complete the short form by scanning the QR code!



# BOWLING



Games, shoes and pizza included for the kids!

Stay tuned for more details!

# Walk to **END** EPILEPSY

## WALK TO END EPILEPSY 2023 2 WALKS. OVER 450 WALKERS. 1 MARATHON. **OVER \$60,000 RAISED**

Thank you to everyone who participated in our **WALK TO END EPILEPSY** on Sunday, Sept. 10th. Whether you walked with us in person or in your own community, we were walking together! We are excited to announce that this year's walk has raised over \$60,000! Thank you to our fundraisers, sponsors, and donors. With your help, we are able to educate, raise awareness, and lead the fight to overcome the challenges of living with epilepsy.

Special thanks to our Champion Sponsor, Jazz Pharmaceuticals. Additional top sponsors for this event include UCB, Neurelis, and Sumitomo Pharma.



### 26.2 miles for Epilepsy Awareness!

Past board member, advocate, and volunteer, Derrick Rumenapp, ran a full marathon once again to honor the 1 in 26 that will be diagnosed with epilepsy. On October 8th, Derrick ran 26.2 miles in the Mohawk Hudson River Marathon to raise awareness and collect donations for EFNENY, raising over \$6,300 to date! Derrick has been an advocate for epilepsy awareness since 2009 when his son Matthew was diagnosed and has seen firsthand the fear and pain this seizure disorder can cause. EFNENY provided them with the programs and services desperately needed throughout their epilepsy journey.

If you would like to learn more about Derrick's journey or support Derrick in his fundraising efforts for EFNENY, scan the QR code!



## GOLF TOURNAMENT FOR EPILEPSY 2023 **Over \$77,000 Raised!**

It was another beautiful fall day for our annual Golf Tournament for Epilepsy. We extend our appreciation to the 120 golfers who came to participate and to those who sponsored this great event. A 19th Hole Cocktail Hour Celebration was held immediately following golf and was emceed by Rodger Wyland, Sports Director, WNYT NewsChannel 13. Rodger showcased the tournament live during his #RodgOnTheRoad segments.

Special thanks to the leading sponsor, the Melissa D. Bisaccia Scholarship Fund. Additional top sponsors for this event include UCB, BBL, Norvest Financial Services, and Jazz Pharmaceuticals.

### Congratulations to our Top Foursomes:

- 1st Place (Net):** Scot VanSickle, Joe Reilly, Charles Day & Robert Leary
- 2nd Place (Net):** Todd McClurg, Sam Greco, Martin Miller & Ryan Hanley
- 3rd Place (Net):** Kevin Smith, Katie Randall, Jason Horowitz & Justin Smith
- 1st Place (Gross):** Bill Wasserbach, Paul Wasserbach, Eric Wasserbach & Stan Milos



## Purple Legacy Society



Purple is more than just a color at the Epilepsy Foundation of Northeastern New York. It is a promise to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

When planning your estate, please consider the Epilepsy Foundation of Northeastern New York in your plans and show your passion to end epilepsy and help those suffering after your lifetime. By naming the Epilepsy Foundation of Northeastern New York in your estate plans, you will become a member of our **Purple Legacy Society** and will help us continue to lead the fight to overcome the challenges of living with epilepsy for years to come. Your gift may be through a bequest, charitable trust, life insurance, or other form of charitable giving through estate planning.

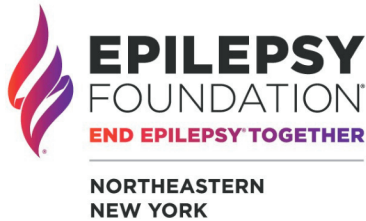
Please let us know if you decide to leave a gift to the Epilepsy Foundation of Northeastern New York in your will or estate plans. We want to celebrate your decision TODAY to help EFNENY in the future! Please contact Susan Kaczynski, Director of Donor Engagement, to inform her of your plans or to learn more. She may be reached at [skaczynski@epilepsyneny.org](mailto:skaczynski@epilepsyneny.org) or **518-456-7501**.



## Unable to Afford Your Epilepsy Medications?

Maria's Medication Fund is available for people with epilepsy who are unable to afford their epilepsy medications. Individuals must have a confirmed diagnosis of epilepsy, and provide documentation from their doctor. Individuals must reside in one of the twenty-two counties covered by the Epilepsy Foundation of Northeastern New York. Typically, the fund will cover up to a 30 day supply, not to exceed \$250. This fund is intended to be a bridge until insurance is approved or the individual can access a patient assistance program. This fund is named in honor of Maria Lutz, 18, of Inlet, NY who used her Wish from Make- A-Wish Northeast New York to establish this fund. Maria knows the importance of taking epilepsy medications, and would never want anyone to skip their meds simply because they cannot afford them. Please call our office to receive an application for **"Maria's Epilepsy Medication Emergency Fund."**





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3 Washington Square, Albany, NY 12205  
Phone: 518.456.7501  
Fax: 518.452.1282  
Toll Free: 800.894.3223  
www.efneny.org

If your name or address has changed or is misspelled, or if you receive multiple copies of our newsletter, or simply wish to be removed from our mailing list, please contact Darcy at [dbelow@epilepsyneny.org](mailto:dbelow@epilepsyneny.org).

## Raise Awareness and Show Your Support!

You can help us make a direct impact on the lives of those affected by epilepsy. November is the perfect time to show support!



This **November 28th** you have the power to make an incredible impact for our agency by joining a global movement called Giving Tuesday.

On this day, charitable organizations around the world utilize social media to encourage people to give any amount they can. We will be joining this campaign, and you can help get the word out!

## Holiday Gift Card Drive

Many of our families just need a little extra help at the holidays. If you are interested in donating gift cards to our families in need, we would greatly appreciate gift cards for Target, Walmart, Price Chopper, or Hannaford.

For more information or to donate, please contact Samantha at [schampagne@epilepsyneny.org](mailto:schampagne@epilepsyneny.org) or 518-456-7501 - Ext: 105.

## 2024 Signature Raffle for Epilepsy

**ONLY** 100 tickets are available for our 2024 special raffle at only \$100 per ticket!

**First Place Prize is \$4,000**

Additionally, there will be TWO second-prize winners who will each receive **\$500!**

The remaining funds will be used to support EFNENY's programs and services that we offer at no cost to an estimated 45,000 people affected by epilepsy in Northeastern New York.

The drawing will be held on **April 20th, 2024**

Purchase your tickets now by emailing Darcy at [dbelow@epilepsyneny.org](mailto:dbelow@epilepsyneny.org)