



650 Suffolk Street #405
Lowell, MA 01854
epilepsynewengland.org (617) 506-6041

WE'VE MOVED!

OPEN HOUSE NEW HOUSE

STARTING JANUARY 1, 2019
FIND US AT 650 SUFFOLK ST #405
LOWELL MA 01854

OPEN HOUSE FEBRUARY 28, 2019
4:00-7:00 PM
RSVP DAVID AT
DSEARLES@EPILEPSYNEWENGLAND.ORG

ANNUAL REPORT



2018

ANNUAL REPORT 2018



EPILEPSY FOUNDATION

New England

WWW.EPILEPSYNEWENGLAND.ORG



Above: Boston Young Leaders Network meeting.
Left to right: A Maine Camper; Mighty Mike Simmel visits RI; Tracey volunteers in honor of her late daughter Amber, with Team Leader Wendy, at our Springfield Walk for Epilepsy

LEADERSHIP



Epilepsy Foundation New England is a 501 c 3 nonprofit organization whose mission is to help people and families affected by epilepsy in New England.

Epilepsy Foundation NE is an independent affiliate of Epilepsy Foundation of America whose mission 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. We serve the approximately 100,000 people in Maine, Massachusetts, New Hampshire, and Rhode Island affected by epilepsy and the people who love them. Our vision statement is Help for Today, Hope for Tomorrow.

Founded in 1983,
2018 marks our 35th year.
Thank you for your support.

Above: Our record breaking 2018 Boston Walk for Epilepsy Raised \$210,000.
Below, from left: Dr. Dworetzky and Dr. Lee of Brigham and Women's Hospital, boys at sleepaway camp, and lighting up Boston's Prudential Center purple, with singer Gracelyn Rennick.



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Above, Nicole is a Young Leader who volunteers as an extraordinary face painter at our Walks; the Climbing Wall brings kids to new heights of accomplishment; inset, Dr. Phillip Pearl of Boston Children's Hospital volunteers as our pianist at our Boston Gala and is our 2018 Gala Honoree.

69%
 of our staff and Board members have a direct personal connection to epilepsy

**CELEBRATING
 35 YEARS**

TAKING FLIGHT



Above: A team of volunteer nurses from UMASS Memorial Medical Center provided 24-7 care for our Sleepaway Camp.

Below, from left: Amanda volunteers at camps and more; Sheri walks in honor of her late son, Tyler; New York Ranger Chris Kreider volunteers at our Slap Out Epilepsy fundraiser.

Volunteers contribute over \$150,000 in manpower to the Foundation each year. More than 400 volunteers across four states do everything from shredding paper, to event support, to delivering our My Friend Matty curriculum, to Board service, and so much more.

In 2018, we received a \$73,000 AmeriCorps Planning grant from VolunteerNH. Using Corps Members to activate volunteer networks, we are working toward enhanced services - especially Young Leaders Network, Kids Network, and Parent Support Groups - across the state of NH.

Whether you can give an hour a year or an hour a day, there's a place for everybody who wants to help Make Epilepsy History in New England.

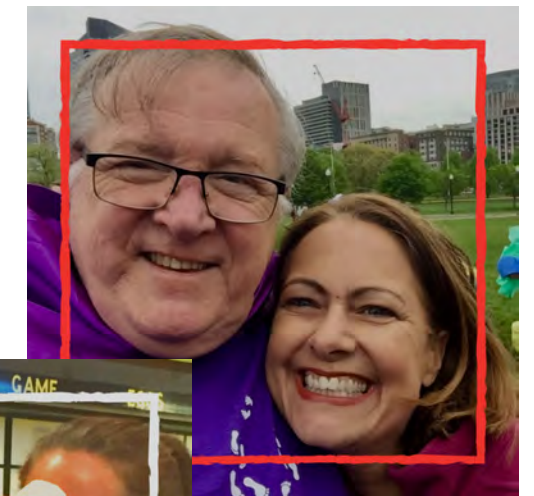


From our President & CEO, Susan Linn:

What a year it's been: from expanding our camp programs to 10 offerings, increasing our scholarship funds, fighting for insurance regulations to support our community, launching leadership Councils in all states, reaching our 125th Career Navigator client, establishing our endowment, expanding our Young Leaders Network to 250+ in six cities - not to mention 6 record-breaking walks/runs, 2 golf tournaments, 2 galas, educational conferences in every state, and more.

My family and I are honored and humbled to work with you to lead the way to a better tomorrow. That's me with former Board member and parent to a person with epilepsy, David Price, at our Boston Walk for Epilepsy, the first on the Boston Common. Next, Chanda lets Young Leader Olivia celebrate one month seizure-free with a cupcake to the face (ketogenic, of course!). Finally, Gertie is a Purple camper-leader. No I didn't forget Lawton! He's just 4 in the picture on the front cover (he's 9 now), but it perfectly sums up how far we've come and where we are going: Up, forward - with joy.

This year, we spent 35 days at Camp, including 17 days away from home. Yes, it is "a lot," and it is so very much when we see the connections made, hear the laughter, and photograph the memories - just see one mom's comments to the right. Joey* and his family's story and all of the amazing energy you see in the following pages would not be possible without supporters like you helping us take flight. Thank you.



"Thank you so much for offering our family this opportunity! Every time I try to describe how amazing and truly special this whole experience was for all of us, but especially Joey, I find myself at a loss for words. Just the fact that he was able to get through several days away from us, let alone ENJOY pretty much every moment, is extraordinary... And then there's the fact that I was able to say goodbye and be away from HIM for several days, only because I knew he was in such good hands. Of course all parents worry, but there's a very unique set of worries that come along with parenting a child with epilepsy; you worry about safety differently, you think about your child's limits differently. This experience has taught us all so much about Joey and about our family, and given us a whole new appreciation for just how AWESOME he truly is. To call him my hero is completely inadequate, and to say this was a milestone summer for all of us is an understatement. We all gained such renewed confidence in him. Amazing. Thank you again."

VOLUNTEER IMPACT

ADVOCACY



Above: Northeastern University Student Andie's 6-month placement with us included preparing special meals for our 8 sleepaway campers on dietary therapies.

Below, from left: Camp Matty Therapeutic Horseback Riding at Ironstone Farm, MA; High Ropes Courses at our Portland ME Camp; building connection at our Rock Climbing Camp in Worcester MA.

Our 20th year of Camp included 10 unique programs serving 220 campers: all abilities, all ages. Family camps, day camps, young adult retreats, a new Sailing Camp, and much more. Program evaluation data shows that our camps exceed their goals in helping kids try new things, improving self-confidence, building friendships, and having fun. Here's what our campers say:

"I didn't know what to expect, I'd never been away from my parents for that long. It's been great to spend time with all these people because you never feel alone and that's something important for everyone with some kind of issue so this was a really important experience for me."

"My school is tough. You're told that you're the only one. And you come here and see that's not true. And there are so many people like me."

"At school you can't talk about it, having seizures. Then you come here and see that you're not alone. Other people have seizures."



20 YEARS OF CAMP

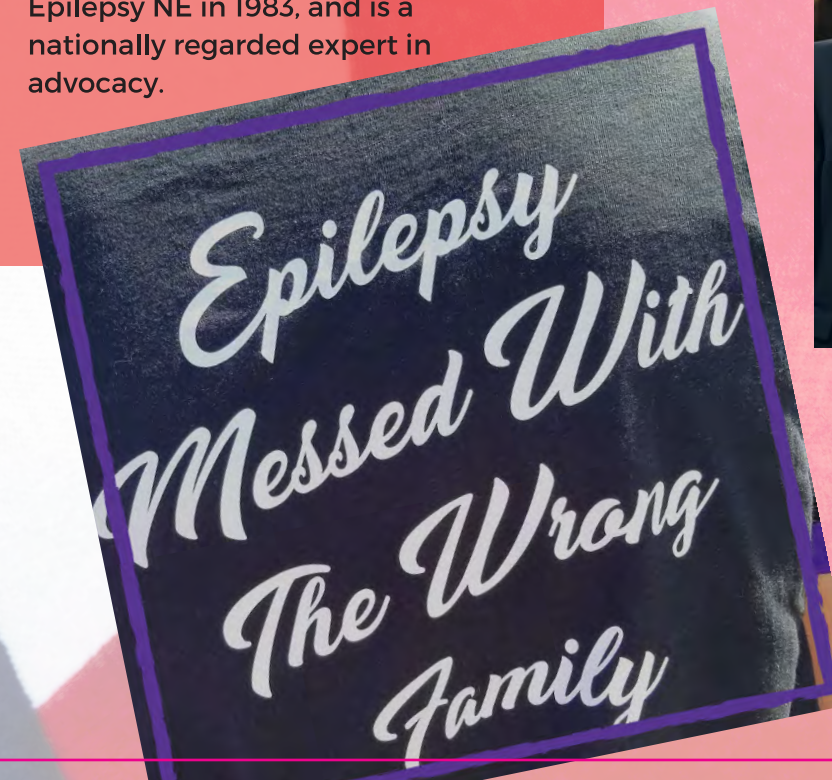
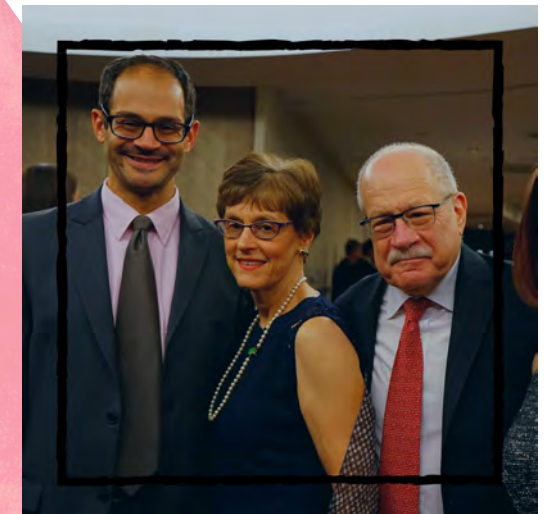
Epilepsy Foundation New England is committed to protecting the rights of people with epilepsy and ensuring that they have access to needed treatments and services. We do this by helping individuals by supporting policies, regulations, and laws. For example, on June 25, 2018, the FDA approved Epidiolex (cannabidiol) [CBD] oral solution for the treatment of seizures associated with two rare and severe forms of epilepsy, Lennox-Gastaut syndrome and Dravet syndrome. Epilepsy Foundation NE, in partnership, with the national office, works with appropriate state agencies to promote needed state drug scheduling changes to allow access to FDA-approved CBD based products.

Did You Know? Our Director of Advocacy and Public Policy, William Murphy, above far left, was the founding Executive Director of Epilepsy NE in 1983, and is a nationally regarded expert in advocacy.



Above: This year, 3 New England teens spent 2 days learning advocacy skills in DC, and then proceeded to meet with their Senators and Representatives.

Below: Volunteer, Advocacy leader, and Board Vice Chair Audrey Kadis was honored at our 34th Candlelight Dinner, pictured with her son and husband.



4,156

Advocates who lend their voices and emails to our efforts - up 20% from last year. Will you be # 4,157? It only takes a minute.



Above: Our Maine Council's summer celebration. Right: Western/Central MA Field Service Manager and Camp Administrator Sarah Specht, with her son, Hunter, who lives with epilepsy, at our first Sailing Camp, 2018. Below, left: a fun and games meet-up in Portland, ME; right, the 16th Annual Matthew Siravo Memorial Golf Tournament raised \$27,000 in RI September 2018.

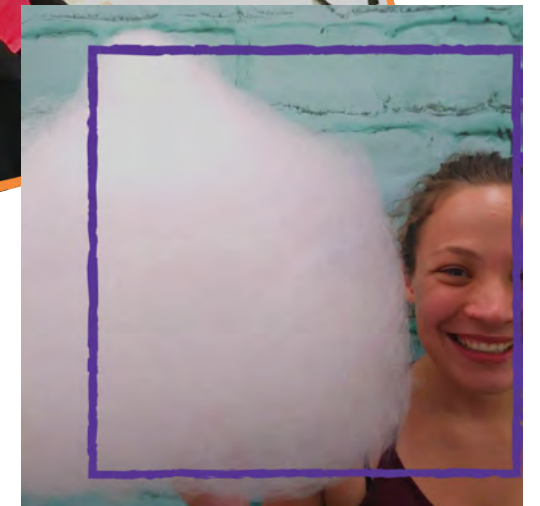
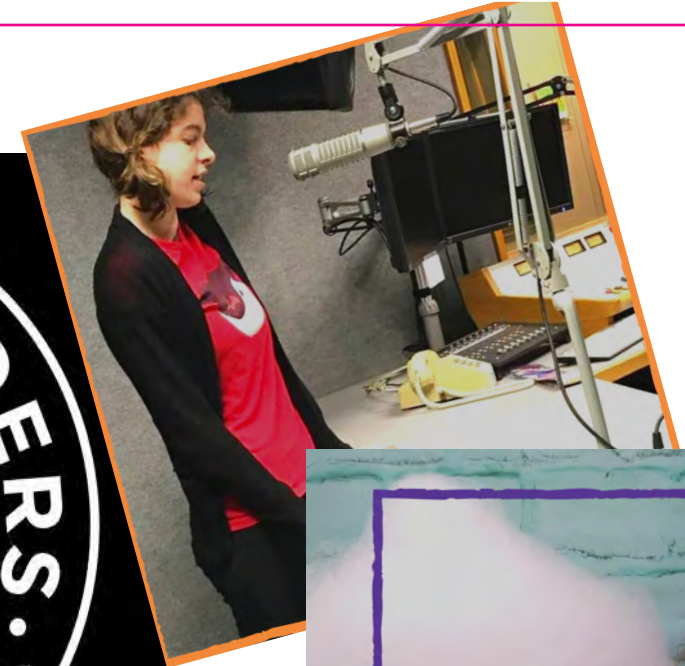
Regional Councils are leading the way for more programs and services in RI, Central & Western MA, NH, and Southern ME. Committed Field Service Managers are creating opportunities and connection, ensuring that we are our serving our local community needs across New England.



Each area adapts to meet local priorities, such as a youth mental health support group in Worcester MA, all ages and abilities sailing camp in Newport RI, a teen-focused Studio e program in Manchester NH, and an adult support group in Bangor ME.



SERVING NEW ENGLAND



Above left: Maine Young Leader Liv recording a PSA for Maine radio. Right: Allison, our Youth Programming Assistant, with cotton candy, at our Sailing Camp in Newport, which included a Young Adult Retreat. Allison, a doctoral psychology student, had surgery that ended her seizures.

Below left: Our first "Studio e" focused on teens, with the Brush Gallery in Lowell MA. Right: Young Leaders Network founder Chanda Gunn, at our Boston Walk for Epilepsy, where "YLN" was the largest team. Chanda's Olympic Hockey Career gave her a platform to advocate for epilepsy for the past 15 years. Chanda is a person living with epilepsy and the leader of our youth services.

Juggling school, work, friends, and growing into one's own is no easy feat for any young adult, and epilepsy often aggravates the transition to adulthood. Piloted in 2017 with 5 young people in Boston, today the Young Leaders Network includes 225+ members and more than 25 volunteers meeting monthly in 7 cities across our 4 states.

A 2018 Program Evaluation found that the Young Leaders Network makes a significant impact on participants' communication, leadership, and advocacy skills. But the data is dwarfed by seeing the friendships and smiles. Participants were asked, What is one thing you've learned from being in Young Leaders Network? Here's what they said:

"I'm not alone."

"I have learned how different types of epilepsy affect people in varying ways; how they have and continue to deal with their epilepsy."

"You need to advocate for yourself and let others know how you feel about certain things and that's the only way you will find the change you desire."

"I learned to work with groups and know when to ask for help when needed."

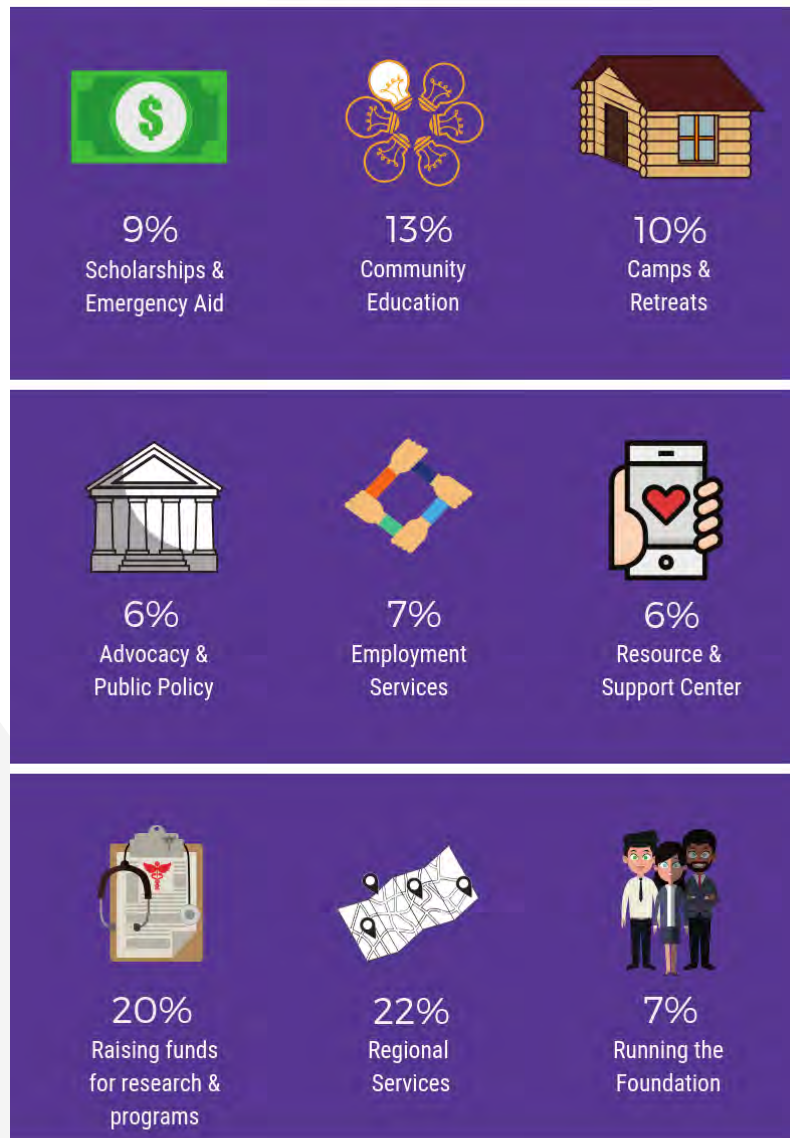


The Foundation's \$1.7 M budget supports services in 4 states with a team of 15 people. Headquartered in MA, virtual offices expand our reach to the four states we serve. Our annual independent audit, published on our website, demonstrates our commitment to financial transparency.



Thanks to a partnership with Savers, gently used clothing and household items donated to Epilepsy Foundation NE and at 15 Savers stores in New England generate \$500,000 per year in revenue for programs and services.

Because of your support, we are growing. We are doing more for people with epilepsy when they need us.

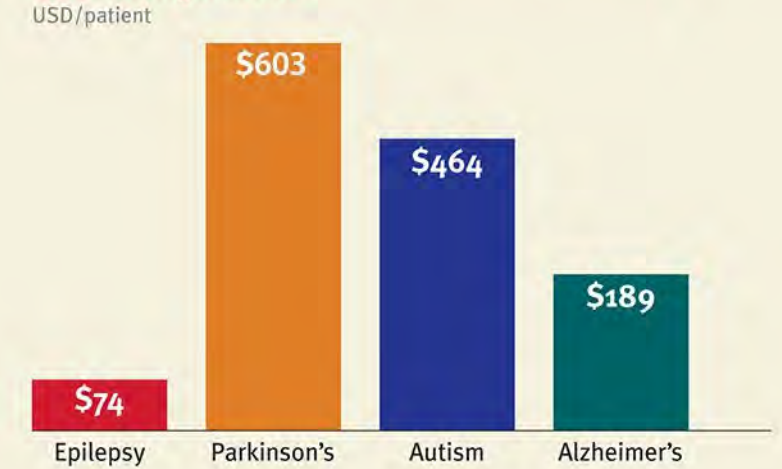


INVESTING IN RESEARCH

According to the American Epilepsy Society, Epilepsy is the second leading cause of death from a neurological condition and affects more people in the U.S. than multiple sclerosis, cerebral palsy, muscular dystrophy, and Parkinson's combined, yet receives fewer federal dollars per patient than each of these.

Our 2nd Annual Evening to Support Breakthroughs in Epilepsy raised \$50,000 for the Epilepsy Innovation Institute, and this year's goal is \$100,000. The Institute's purpose is to continuously drive transformational innovation in the way we diagnose and treat epilepsy, by encouraging and supporting radical new ideas and incorporating novel expertise and technologies from other fields of science.

Estimated NIH and Private per Patient Funding for Research by Disease



Per patient estimates based on prevalence numbers in the IOM report of 2012. Research dollars include 2011 NIH and private funding only.

Graphic by Citizens United for Research in Epilepsy, 2016

"I didn't have anyone to turn to until I found Epilepsy Foundation New England. The research innovations the Foundation supports give me hope where once I had none."
 - Oliver, 19 year old hockey player, college freshmen, MA resident, Young Leaders Network member, and person living with epilepsy

YOUR GIFTS AT WORK





Caring for people who have lost loved ones to epilepsy and raising awareness of Sudden Unexpected Death in Epilepsy (SUDEP) are core to our work. Our Memorial Wall honors those we have lost. On display in our central office as a constant reminder to us of the urgency of our work, the Wall travels to our walks around New England.

Our 1st Annual #LightTheWayToday campaign (www.lighthewaytoday.org) invited our community to light real and virtual candles in honor of our epilepsy heroes. This March 26, we plan to go from hundreds of participants to thousands.

When someone in our community dies, we deploy a series of supports that include phone calls and visits and touch points in the months and years after the death. Our Remembrance Network is comprised of people who have lost someone to epilepsy. Network members are trained in Mental Health First Aid and stand at the ready to provide a listening ear, comfort, and support to newly bereaved families.

In 2017, Epilepsy Foundation New England accepted our first Endowed Fund. The "Celebrating Sharon Gath Campership" was established by a \$25,000 gift from Sharon's mom, Donna Cridwell. Sharon died in 2013 at age 35 in an epilepsy related death. Every year, 5% of the value of the Fund or \$1,000 supports a high need camper and his/her family.

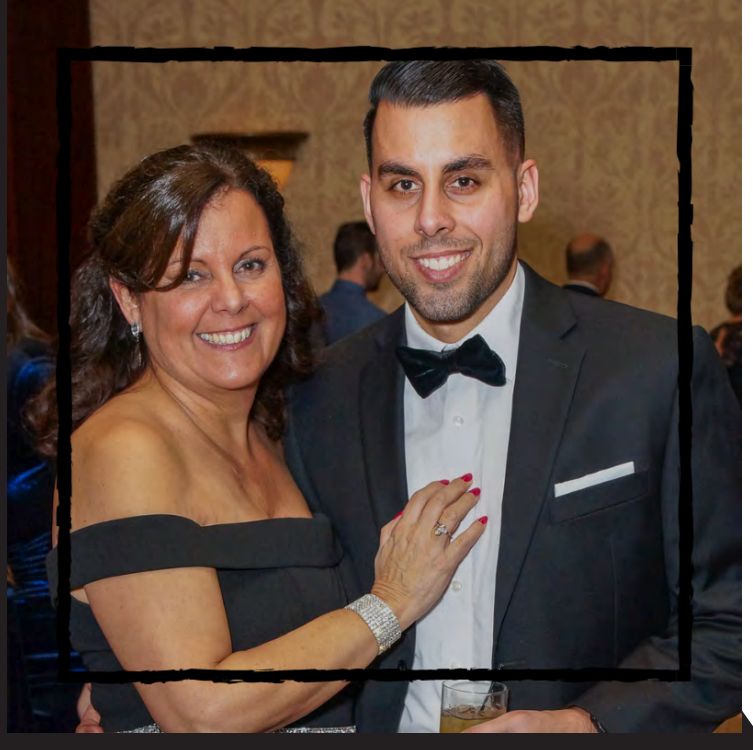


Above: NH Council Member Chris Donovan with our Boston Gala Speaker, John O'Hurley, actor (e.g., Seinfeld). Below, left: "Almost the Cure's" performance in the 2018 Battle of the Biotech Bands resulted in \$15,000 for scholarships. Center in the collage is Francesco Salituro, PhD, Board Member, VP of Chemistry at Sage Therapeutics, who lost his son Joseph to SUDEP at age 27 in 2011. Right: Debra Siravo founded the Matty Fund with her husband Richard after the 2003 death of their five year old son, Matty, from epilepsy-related complications. Deb is pictured with her son, Joseph Siravo, who serves on our Board of Directors, at our annual Matty Project Gala.

Our Development Department is guided by their mission to ensure that people with epilepsy have access to the resources they need and that Epilepsy Foundation New England is able to meet the evolving needs of the epilepsy community in New England. Grounded in core values of Integrity, Donor-Centrism, Transparency, Quality, Respect, Service, and Stewardship, our Development team spearheads 4 special events that yield \$390,000 and 6 walks/runs that generate \$310,000 per year. More than \$250,000 is given to the Foundation by individuals, and we receive \$130,000 in grants. "Do It Yourself" fundraisers - from Zumbathons to Car shows - and third party events (see below left) bring us another \$50,000 a year for services. We are incredibly grateful!

Investing in the Future

Thanks to our supporters, a Board of Directors filled with business leaders and finance experts, and the success of our clothing and household items Donation Center, we are proud to announce the establishment of our \$500,000 Endowment. managed by Vanguard.





A listening ear and advice by phone, online Knowledge Center, 40+ online and in-person SHARE groups a year, connecting families to resources, scholarships - Epilepsy Foundation NE helps thousands of people. Over the past 12 months, we assisted 38 families with \$50-\$1,000 one-time emergency aid gifts when epilepsy caused dire financial stress. For example, we helped Annie, age 29, who became significantly physically disabled following status epilepticus requiring a 2-month medically induced coma. Annie's Occupational Therapist contacted us to request help with medical supplies after she was discharged from short-term rehab because her insurance ran out. Annie was sent home to live with her bedridden mother who suffers from MS, without much needed supplies, which are not covered by her insurance. We were able to provide the medical equipment (e.g., bed rail) she needed and have it shipped to her house.

Above: A 2018 Scholarship winner and her mom at our Springfield MA Walk. Last year, the Foundation made 14 awards valued at \$24,000. The annual application deadline is March 1. Below, from left: Hunter at our NH Walk for Epilepsy, Living for Kimberly Foundation supporters, and RI Council Member Adriana Pineda and RI Field Service Manager Christina Vilardi at our annual Matty Project Fundraiser.



"The oil delivery is a great help. More than you would realize. It is very difficult to live off my income from disability, and the financial stress never stops. That's Life, but knowing we do not have to worry about being cold right now means a lot." - Cal, age 67



RESOURCES & SUPPORT



Above, Director of Community Education, Susan Welby, and volunteer Richard Mills, at a community fair in Springfield MA. Below, Girl Scouts in Hampton NH raise awareness and funds for epilepsy in honor of Annabelle's (center) brother. Bottom: 2018 Maine Walk for Epilepsy



Over the past year, we provided 31 trainings attended by 600 people. In addition, educational conferences in each state are tailored to meet the needs of the community. Working with our 30-member Professional Advisory Board and world class epilepsy centers, we provide an array of educational programs that include My Friend Matty, a curriculum for preschoolers and elementary school aged children, to credit-bearing classes for nurses, and training for police, fire, and paramedics. Our new middle school curriculum is rolling out this fall alongside our Kids Connect programming for grades 5-8, launching in each state.

Did you know?

We customize trainings on request and we provide workshops online. Free! This summer, we were pleased to support Massachusetts General Hospital to convene a conference on Sunflower Syndrome, a rare epilepsy, bringing together 50 families, most of whom had never met anyone else affected by the syndrome.

Thanks to a grant from Epilepsy Foundation of America, we are working to reach underserved communities in urban centers in Western MA, Boston, and Providence, including outreach to Faith Based Organizations with predominantly Spanish-speaking and African American congregations.



EDUCATING THE NORTHEAST