



**EPILEPSY  
FOUNDATION**

New England

THANK YOU NOTES

2019  
ANNUAL  
REPORT

*"I was asked not to attend my prom because the school was afraid I'd have a seizure and impact the other students. Thanks to Epilepsy Foundation New England, I finally got to wear my prom dress."*

Quote by M, age 19.

Pictured, two of our young adults  
at our 1st prom, June 2019.

# SERVING YOUTH

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Our Young Leaders Network (YLN) engages 300+ 13-25 year olds in more than a dozen locations. Program evaluation data shows that YLN participants have significant growth in social support, communication, advocacy, knowledge of epilepsy, self-care, leadership skills, confidence, and happiness.

*"I have met some special people at EFNE that have shown me the importance of being myself and not being ashamed that I have epilepsy, and they mean everything to me."*

Sam, age 24, Mass



Brooke, age 18, Maine

In 2019, two Young Adult Retreat Weekends gave dozens of 18-30 year olds the chance to build friendships and gain skills in March 2019 in Groton, MA and October 2019 in Waterville, NH.

*"Before this weekend, I was feeling very down and depressed. I felt alone and hopeless. Now I've met all of you and I can honestly say it has been the best weekend of my life."*

Steve, age 24, Mass



The success of YLN inspired Kids Connect, an engagement program for Middle School students, growing in communities around New England.

Night at the Museum of Science  
Kids Connect, Oct 2018



"So many campers, including my daughter, made so many relationships and had many memorable experiences that will not be forgotten. Epilepsy Foundation New England is absolutely superb."

Michelle, mom, RI

In 2019, 300+ people participated in more than a dozen camps including sleepaway and family camps, young adult and adult retreats, surfing, sailing, outdoor adventure, and therapeutic horseback riding. Amid fun and recreation, participants make friends and build community.



Outdoor adventure camp, Charlemont Mass

When our eighteen November 2019 Adult Retreat participants (ages 30+) were surveyed about what they wanted to do in North Conway, NH, the #1 answer was "socialize." The Foundation enables an essential circle of support for many living in isolation.



Austin, surfing camp, Maine, July 2019



# EDUCATION

This year, we will provide seizure safety training to nearly 5,000 people.

*"Susan's presentation was engaging and very informative. She spoke on a personal level as well as an emotional one that allowed us to connect with her. She gently pushed away our misconceptions and inserted new concepts to help our church congregation be better equipped to help our member affected by epilepsy - and be a comfort in a time of need. This member is now coming to church regularly because she feels safe."*

In April, 4 Teens, 2 Young Adults, and 4 Staff traveled to DC to learn advocacy skills, which they bring back to their home states. We are working to pass the Seizure Safe Schools Act in MA, ME, NH, and RI to ensure schools are aware of epilepsy and our kids are safe in school. Almost 5,000 volunteers help us protect the rights of people affected by epilepsy in New England.



*"My daughter's confidence and happiness have grown so much thanks to EFNE."*

## ADVOCACY

# INVESTING IN RESEARCH

Research breakthroughs provide Hope for Tomorrow. In 2019, donors contributed \$120,000 to Epilepsy Foundation NE for the Epilepsy Innovation Institute. The Institute's 2019 priorities are research programs in Cannabinoids and Sudden Unexpected Death in Epilepsy (SUDEP). Recently, the Institute and Epilepsy Foundation NE worked together to support EpiHunter, a start-up company focused on detecting and alerting people to absence seizures. With the New Therapy Commercialization Grant they received, they partnered with Boston Children's Hospital to advance their solution.



# HELP FOR TODAY

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In FY19, thousands of people received helpdesk counseling, 63 families received emergency financial aid, 17 students received scholarships, and hundreds of people participated in more than 50 support groups.

Everyone needs a hand - or a paw - sometimes. Our team fields questions on service dogs every week.

"The relief it has caused is more than welcome and needed. It helps so much more than I think you realize! And our conversation gave me a feeling of solidarity- it was unlike any conversation I've had with another parent since H. was born."

A Mom, on receiving financial aid to prevent eviction; she stopped working after the birth of her child with severe epilepsy last year.



"I'm honestly so appreciative of everything that you do! Of course I appreciate the financial assistance so much but even if that were not possible I still feel like I have found an amazing support in you guys. When I filled out the application for assistance I did not expect to have such a personal conversation with someone. I didn't realize that the people who work for the foundation are so personally involved. I am so grateful for everything but especially because you helped me to realize that I am not alone."

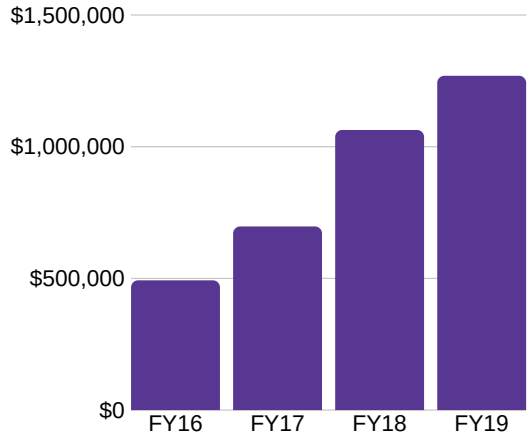
The June 23 Joseph's Hope Scholarship Benefit Concert included award presentations to our recipients. To the left are Francesco and Vicky Salituro, who started the scholarship fund in honor of their son Joseph, who died of SUDEP in 2011 at age 27.



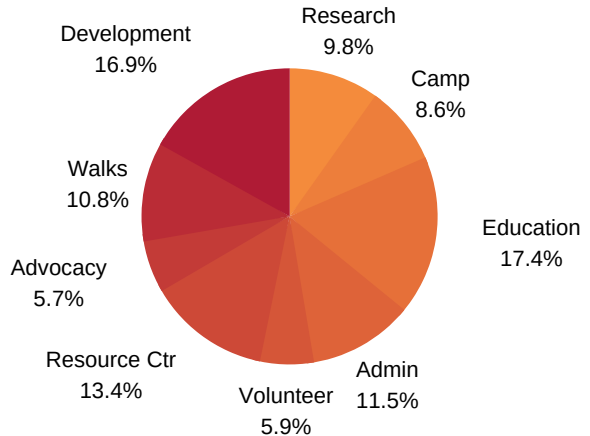
# NUMBERS

What's behind these numbers? New services to support more people. Over the past 3 years, our camp program grew from 2 to 15, we've held 3 young adult retreats and 2 adult retreats, and we increased scholarships from 1 to 20 per year. We started our Young Leaders Network (now serving 300+ high school and college aged youth), launched Kids Connect for middle school students, expanded our volunteer base to hundreds, brought the PreK-Gr 3 My Friend Matty curriculum from RI to all the states we serve, and formed leadership councils in RI, ME, NH, Western MA, and Eastern MA. Thanks to three 2018-2020 federal grants totalling \$375,000, we will be dramatically expanding our service to rural areas.

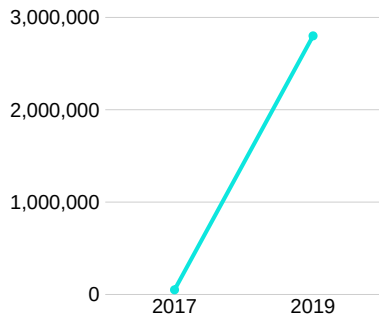
### Donations to the Foundation



### FY19 Expenses by Category



### Value of Our Endowment





# AMERICORPS SERVES HERE

AmeriCorps is a national service program in which people provide a year of service; they receive a stipend and educational award. Thanks to \$375,000 in federal grants, we now have 14 AmeriCorps Members providing services to youth and families across the state of NH and expanded youth programs in MA through 2 Corps Members and a new Youth Programming Specialist.



Our NH Community Health Corps kicked off with a 3-day orientation in Waterville NH October 16-18, 2019

*"I wish these programs had been here when I was a kid 20 years ago. Today, my seizures are in control. I choose to serve because I want kids living with epilepsy to have what I wish I had: friends who understand."*



Hundreds of volunteers help with every aspect of Epilepsy Foundation New England. Pictured here, our Sept 28 2019 Maine Walk to Make Epilepsy History volunteers.



Volunteers will contribute an estimated \$125,000 in service to the Foundation this year.





650 Suffolk St #405  
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*"The most caring, generous staff. They go above and beyond to take care of everyone involved. My son has epilepsy and the staff here are not just staff but my family now."*

## 2019 ANNUAL REPORT THANK YOU NOTES

Pictured, July 2019 Purple Sleepaway Camp