

# Thank You to Our Loyal Supporters

## Did you know that NF Northeast raises 75% of its revenues at events?

Events serve many purposes: they help fuel our mission, they increase awareness of NF, and they bring our community together in a caring and supportive environment, and that was a good thing...until COVID-19!

Since March, most of our events have been **cancelled** or **postponed**, some will still happen **virtually**, and the others - well, we just don't know yet!

These are incredibly challenging times for everyone, and we are so very grateful to many friends in our community who generously supported NF Northeast during this crisis. When our events were cancelled, corporate sponsors still sent their sponsorship pledge, and many individuals said "NF can keep it as my donation" instead of taking refunds for their ticket purchases. It wasn't expected, and it meant so much. THANK YOU!!

### Friends of NFNE Continue to Help in Many Ways



Brendan Ahern is a great musician and a great friend to NF patient Ryan Feeney. Brendan did his final garage concert of the "Quarantine Season" to raise funds for NF Northeast. The concert was live on social media and he raised well over \$3,000 through online donations, and he auctioned off a personal concert to the highest bidder!



Ryan and Brendan

### For her birthday on May 17th, Jillian Gould posted this on Facebook and raised over \$1,000

For my birthday this year, I'm asking for donations to Neurofibromatosis Northeast. Given that May is NF awareness month as well as my birthday on May 17th, it lines up perfectly.



Addison

Addison is one of the many fighters with NF. I hope to help raise money for this cause so there can be more treatments and one day a cure, so by the time she has her own children, they will not have to fight this disease in the same ways we have to fight it now!

### Constantly Running



Scot DeDeo is constantly running and constantly raising funds and creating awareness of NF! Scot runs ultra-marathons and across mountain ranges, and he is always wearing an NF shirt. When Amy DeDeo is on her bike at the Coast to the Cure NF Bike Ride, Scot runs the route! Scot is the coach for the Falmouth Road Race team and Amy will join him as a runner this year. Scot and his friend Becca Pizzi established Ninja Feet running camp for NF. All this because the DeDeo's son Nat has NF, and they are constantly doing everything they can to end NF!



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# NF NEWS

## NEUROFIBROMATOSIS NORTHEAST

Promoting Research, Awareness and Advocacy since 1988

Volume 32, No. 1

Summer 2020

### Instead of focusing on the "what ifs" we decided to focus on the "what now." What can we do "now" to help our son?

Written by Melissa Malerba

Jonathan, now 13 years old, was officially diagnosed with neurofibromatosis at the age of 3. Like many other parents receiving the diagnosis, that word that was so difficult to pronounce, and seemed so foreign at the time, became a part of our daily lives. That scary, unknown reality had instantaneously become our new norm. Instead of focusing on the "what ifs" we decided to focus on the "what now." What can we do "now" to help our son?



Jonathan and Melissa Malerba

That "what now" has definitely shifted over these past three months due to Covid-19. Jonathan thrived off of his routine, and absolutely LOVED going to school. He was either at the bus stop too early or would ask me to drop him off at school when the doors would open so he could have some "extra" time there to see his peers and/or teachers.

Along with the rest of the world we were suddenly faced with a very different "what now" situation? What can we do "now" to help navigate this transition from a school he loved attending to virtual learning? What can we do "now" to help him not only academically, but emotionally. What can we do "now" to celebrate him becoming a teenager during this time of quarantine?

Well, to start we held his family birthday party on Zoom and he loved it! Now we have a new routine and new norms. Now we have a daily learning schedule that works for our family and is one that Jonathan enjoys following. Now he is even more tech savvy than he was a few weeks ago. Now Jonathan looks forward to his daily Zoom science and even Tae Kwon Do lessons! Finally, now we just try our best to stay happy and healthy and spread awareness for NF in a new way!

**Putting Words into Action** When Melissa and Mike Malerba learned that their son has neurofibromatosis, they contacted the NF Northeast office and said "what can we do?" Since that day, they have raised over \$700,000 at their annual Committed to Curing NF event, advocated in Washington (photo on left) for federally funded NF research, participated in walks, runs and bike rides, and opened their hearts and home to the NF community. Melissa is a member of the NF Northeast Board of Directors, and this fall will once again run the Boston Marathon (virtually) to raise funds and awareness for NF.



Thank you Melissa and Mike for all you have done for your son and for everyone who lives with NF!



# 2020 Scholarship Recipients

## Our Vision

**A world where the burden of neurofibromatosis does not exist.**

## Our Mission

**To bring hope to those affected by neurofibromatosis and allied disorders.**

*Patients and families are at the heart of NF Northeast's mission. We provide advocacy, support, and awareness while promoting research and enhanced clinical care.*

### A Message from the Executive Director



Karen Peluso

Dear friends,

I hope the photos of our scholarship recipients on the opposite page bring a smile to your face. Over the past 3 months our world has been shaken and it seems like the bad news just doesn't stop. These young students are a bright light, and they remind us that no matter what comes at us, we can't stop our fight to end NF.

The social and economic impact of COVID-19 will be long lasting, but NF Northeast has a 32 year history built on a strong foundation, and we will be stronger when we come out on the other side. Many things will change, and we will need to adjust, but our vision and mission won't change.

Social distancing goes against the core of NF Northeast. Our caring and supportive community grew through events, symposiums, play groups and "fun" fundraisers. It grew from one patient or parent reaching out to another to assure them that others have been down this road before them, and they are not alone in facing the frightening uncertainties of NF.

We have quickly learned how to use online meeting platforms to virtually keep our community informed and in touch, but we all look forward to the day when we can be together in person again. Until then, please stay safe.

**Transition Update:** A year ago I announced that I would be stepping down from my position as Executive Director in June 2020. In preparation for the leadership transition the Board of Directors has been working with the non-profit specialists at TSNE MissionWorks to develop and implement a succession plan. Everything was on schedule, and in March the transition committee was just beginning to schedule interviews with candidates. And then the COVID-19 pandemic put everything on pause. So, that's where we are. On pause!

I am grateful that I am able to stay on temporarily to assist this organization that I am so very proud to be part of. When we emerge into the new reality, we will know when the time is right to reopen the search for the next Executive Director. In the meantime, I thank you for being my partners in the fight to end NF.

Sincerely,

### NF Northeast Board of Directors

Lori Ryan, RN, MS, Chair  
Robert Ryan, Treasurer  
Melissa Malerba, Secretary  
Patrick Callahan, Esq  
Alexandra Powers Cellucci  
Justin Jordan, MD, MPH

Robert Klouda  
Andrés Lessing  
John Manth  
John Shea  
John Thomson, PhD  
Nicole Ullrich, MD, PhD

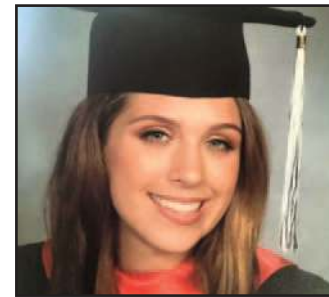
*Bert Peluso, Founder*



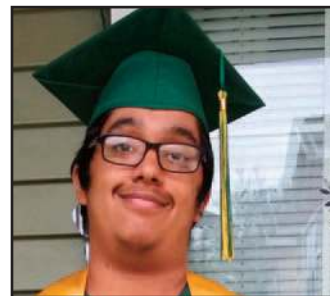
**Jureilis Belliard**  
from Massachusetts, will attend Salem State University as a freshman



**Mary Bertocchi**  
from Massachusetts, will attend Husson University as a freshman



**Juliana Cave**  
from Pennsylvania, will attend Bucks County Community Coll. as a freshman



**Keenan Good**  
from New York, will attend SUNY Schenectady Community Coll. as a freshman



**Taylor Hazlett**  
from New Jersey, will attend Boston University as a senior - graduating 2020



**Madeleine Mann**  
from Pennsylvania, will attend University of Rochester as a freshman



**Erika Mead**  
from Vermont will attend Saint Michael's College as a freshman



**Alexandria Rodemoyer**  
from Pennsylvania, will attend Indiana University of Pennsylvania as a freshman



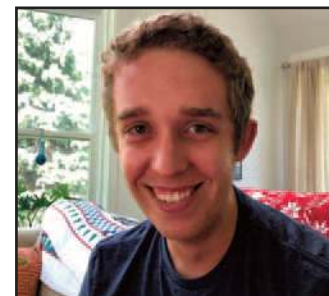
**Aidan Ryan**  
from Massachusetts, will attend Roger Williams University as a freshman



**Alexa Tossone**  
from New York will attend Saint John's University as a freshman



**Amy Travers**  
from New York will attend SUNY University of Buffalo as a freshman



**Tanner Williams**  
from Vermont will attend Champlain College as a freshman

### The Good News we needed!

The U.S. Food and Drug Administration has approved **KOSELUGO** (selumetinib) for the treatment of pediatric patients, 2 years and older, with plexiform neurofibromas – a type of tumor that occurs in patients with neurofibromatosis type 1 (NF1). Koselugo is a MEK inhibitor which was co-developed by AstraZeneca and Merck & Co. While this is a huge step for our NF community, we aren't finished yet! We are hopeful for the future of treatments for all types of NF.

### Coming soon:

**NFlection Therapeutics** has just announced that they will be opening clinical trials in August for a soft MEK inhibitor. The gel will be applied topically on cutaneous tumors that affect NF1 patients. We will keep you updated and announce the clinical trial sites once they are identified.

NF Northeast is proud to partner with AstraZeneca to advocate for NF patients



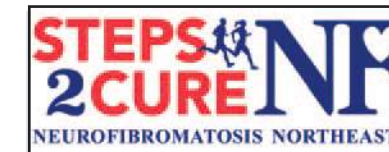
NF Camp is a fun and supportive environment for kids ages 7-17 with neurofibromatosis. Camp New Friends will be virtual this year and this is a great opportunity for you to learn more about this great program without leaving home!

### Join NF Northeast's Falmouth Road Race Team!

The New Balance Falmouth Road Race At-Home Edition will be run anytime between **August 15 – August 29**. You will have a personalized fundraising webpage on GoFundMe Charity, an NF Northeast team singlet, team e-newsletters, access to an endurance coach and training plans and so much more!

July 20-24, 2020  
learn more at  
[brainycamps.com](http://brainycamps.com)

Questions about any of our events??  
Contact Diana Flahive  
[dflahive@nfnortheast.org](mailto:dflahive@nfnortheast.org)



Steps2Cure NF walks and road races are held annually at many locations around the northeast.

This year we will have one Steps2Cure NF event that will bring all of our groups together virtually. Now everyone can participate - no matter where you are located!

Register now and you will receive a great giveaway, plus you have a whole week during which you can do your walk or run for NF.

**July 18 – July 25**

All the information you need is available on the NF Northeast website - [nfnortheast.org](http://nfnortheast.org)

### NF Northeast College Scholarship Program

NF Northeast offers college scholarships for individuals who have neurofibromatosis and are continuing their education after high school. Grants are awarded annually to go towards college-related expenses, such as tuition/fees and books. Applicants must live in or attend a college in the northeast (Massachusetts, Connecticut, Rhode Island, New Hampshire, Maine, Vermont, New York, New Jersey and Pennsylvania). Applications for 2021 will be available on our website in January. Deadline for applications is April 15th. This program was established with funds raised at the Steps2Cure NF walks.