

## GENEROSITY IN ACTION



Marybeth and Duncan Shaw  
with their niece Leah

One of our main focus areas at NF Northeast is finding resources and making them accessible to all NF patients. Quality of life is key to helping our community build confidence and encouraging them to explore activities that they enjoy. Several months ago, Marybeth Shaw, board member and volunteer, approached NF Northeast with an idea to incorporate adventure, education, and opportunity for NF patients to try something new, perhaps something that they never thought possible due to their NF diagnosis. This idea led to the creation of an award in memory of Marybeth's late husband Duncan, a lover of life and an avid supporter of finding cures and therapies for NF2-related schwannomatosis (NF2-SWN) in honor of their niece Leah.

In collaboration with NF Northeast, Marybeth and her adult children, Marissa and Mitchell, created an application and set award guidelines for candidates who have NF2. In fall 2023, the Shaw Family NF2 Enrichment and Adventure Award was established and the first grant awarded.

## BRAVE, DETERMINED, AND BACK IN THE SADDLE



### MEET AMELIA!

At age 4, Amelia began experiencing signs and symptoms that gave her parents, Chantelle and Pete, cause for concern. They brought her to the emergency room for what looked like a lazy eye. A CT scan revealed a golf ball-sized tumor in the left side of her brain. She was rushed to the OR for surgery. Doctors removed the tumor, along with surrounding healthy tissue (a full resection), and gave Amelia a small blood infusion during the procedure. After surgery, doctors told Chantelle and Pete that Amelia had a rare grade 3 cancer (meningioma). Further testing showed several spinal tumors, including a cervical spine tumor at the top of her spine, as well as a cataract in her right eye. Genetic testing verified that Amelia had neurofibromatosis type 2-related schwannomatosis (NF2-SWN).

Since that time, Amelia continually sees several specialists in Boston every few months as part of her NF treatment. She underwent three major surgeries between May and August 2020 for a rare leg tumor called a perineurioma and now needs twice weekly physical therapy to strengthen her nerves so she can follow a somewhat normal lifestyle.

The emotional toll that NF2-SWN has taken on Amelia is one that no one should have to endure, especially not a young person. But, even with all her ongoing challenges, Amelia, now 14, always pushes through. She lives her life celebrating the small stuff and strives to not let NF2-SWN define who she is or what she does. One of those activities is horseback riding. Amelia loves horses!! When Chantelle heard of the Shaw Family NF2-SWN Enrichment and Adventure Award, she quickly filled out the application and, soon after, Amelia received a grant for 22 weeks of adaptive horseback riding, equine science, and animal care lessons. She was ecstatic. "Timing was perfect," says Chantelle. "[Amelia] really needed this."

## BRAVE, DETERMINED, AND BACK IN THE SADDLE (CONT.)

As with many people dealing with NF2-SWN, anticipating what comes next is a terrible waiting game. A few months ago, Amelia learned she had another tumor in her brain. On April 19, she underwent surgery in which a piece of her skull was removed (a craniotomy) to access a grade 2 meningioma. Three weeks later, Amelia ran in a track meet. This is not to say that the surgery wasn't one of the scariest 8-hour periods of her life, and that Amelia doesn't have after effects, but Amelia chooses to not let NF2-SWN dictate how she lives her life.

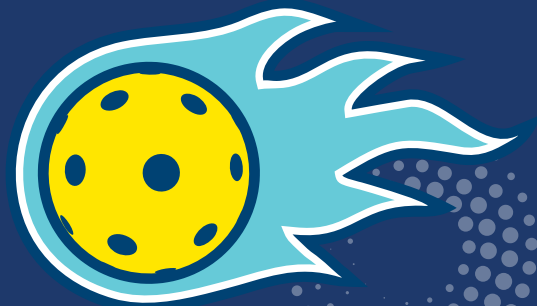
This summer, Amelia and her family will travel to Hawaii, where she will use the skills that she has learned so far in her horseback riding classes to ride in a tropical paradise. Thank you to the Shaw Family for giving Amelia the opportunity to discover this new passion, which she can share with her family.

The Shaw Family NF2 Award can be used for many different sports, music, or educational activities, as well as for adaptive equipment, gaming consoles, and more.

To learn how you can apply for a grant from the Shaw Family NF2 Enrichment and Adventure Fund, visit "Additional Resources" under the "For Patients & Families" section on our website or click on the following link: [CLICK HERE](#)

## SPRING/EARLY SUMMER HAPPENINGS AT NF NORTHEAST

# DID SOMEONE SAY... PICKLEBALL?



Special thanks to everyone who came out to play in our first NF Northeast pickleball event this past March at the Wimbledon Tennis & Pickleball Club in Walpole, Massachusetts.

## ★★★★★★★★ KIDS EMPOWERMENT THROUGH IMPROV! ★★★★★★★★

This past winter, NF Northeast was honored to host our first ever Kids Empowerment through Improv event at Workbar in Quincy, Massachusetts. Robyn Fatseas, MA, NBCC, a complex child development specialist and founder of Robyn's N.E.S.T. Psychology, facilitated the session geared toward NF kids in grades three through six. Special thanks to Robyn for her creativity and skill in making this gathering a huge success.



★★★★★★★★

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Thank you, also, to Workbar for donating the space and promoting our Steps2Cure NF walk series as well as NF Awareness month during a Red Sox Home Opener celebration for their members.

**NF**  
Northeast

**Steps2CureNF**



**PARTICIPANTS,  
VOLUNTEERS, AND  
DONORS  
STEP OUT FOR  
NF NORTHEAST!**



*Pictured above Steps2Cure NF Buffalo, NY*

This past April and May, we hosted 7 successful Steps2Cure NF events throughout the Northeast that brought together over 760 attendees to raise awareness and support for those living with NF. The energy and enthusiasm from participants showed the impact that we can have on bringing hope to those affected by NF.

Thanks to the generous support of our community, we are very close to reaching our combined fundraising goal, for all seven walks, of \$177,500. Participant and team fundraising pages are still live (for one month following each event), so we encourage you to continue your personal or team fundraising to help us meet our goal. Please also consider a matching gift, if your employer offers this benefit. Thank you in advance for any additional donations that will help us cross our fundraising finish line.

The money we raise together will go a long way in funding research, advocacy efforts, and patient programs that are crucial in providing support and resources for those in our NF Northeast community and beyond. We are grateful for everyone who participated, donated, and volunteered to make it possible. Together, we truly stepped stronger, and we continue to make a difference in the lives of those affected by NF.

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KENDRA SCOTT

*Shine Bright, Do Good*

## GIVE BACK PROGRAM



Maible, Kendall, and Fiona designing NF Northeast signature pieces in blue and white.



Elaine Powers and Sarah D'Arcy

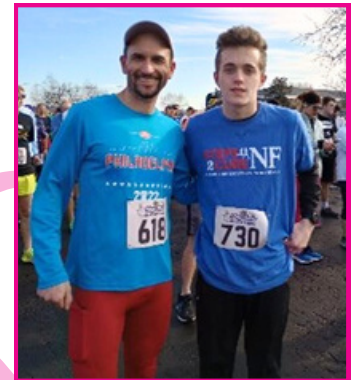
Kendra Scott in Paramus, NJ; Dedham, MA; and Lynnfield, MA, hosted NF Northeast for Give Back events that donated 20% of all in-store and online sales to NF Northeast. The three stores raised nearly \$1,500 combined!



## CUPID'S CHASE HITS RECORD-BREAKING NUMBERS!



More than 400 runners gathered for the 5K run around Lake Quannopowitt in Wakefield, Massachusetts, in February. Special thanks to Beth Hanlon for another incredibly successful event!



# NEUROFIBROMATOSIS N O R T H E A S T

the organization with heart



Improving the lives of patients living with  
Neurofibromatosis Type 1 (NF1),  
NF2-Related Schwannomatosis (NF2-SWN)  
& Schwannomatosis (SWN)

For more information, scan the  
QR code or visit  
[www.nfnortheast.org](http://www.nfnortheast.org)



## NF UPCOMING EVENTS Northeast

- **JULY 15** Holes for Hope, Ferncroft Country Club, Middleton, MA
- **AUGUST 18** ASICS Falmouth Road Race, Falmouth, MA
- **SEPTEMBER 7** Coast to the Cure NF, Gloucester, MA
- **SEPTEMBER 16** Fall Golf Classic, Dracut, MA
- **OCTOBER 13** Amica Newport Marathon (full and half), Newport, RI
- **OCTOBER 19** "A Reason for 'Ritas: A Celebration of NF Northeast at Margaritaville," Faneuil Hall, Boston, MA
- **NOVEMBER 9** Committed to Curing NF, Malden, MA
- **STAY TUNED!** Night-Time Hike Massachusetts North Shore Area

## Who is Neurofibromatosis Northeast?

We are a non-profit health organization that has advocated for those with neurofibromatosis since our founding in 1988. Our vision is a world where the burden of the genetic disorder known as neurofibromatosis (NF) does not exist. We seek to accomplish this vision through advocacy, raising awareness, and providing support for those affected by NF and allied disorders.

NF Northeast is involved in every aspect of the NF journey. Our primary focus is providing resources to those affected by NF in the form of mentorship programs, scholarships, educational opportunities, online support communities, and more. We are also committed to finding treatments—and a cure—for NF by supporting medical research through our grant programs. We are proud to advocate for federal NF research funding by lobbying Congress on a national level.

We are pleased to serve Pennsylvania, New Jersey, New York, Connecticut, Rhode Island, Massachusetts, Vermont, New Hampshire, and Maine. However, we are committed to helping any NF patient regardless of where they live.



**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.



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