NF Northeast

NEUROFIBROMATOSIS NORTHEAST NEWSLETTER

FALL 2025
Volume 39, No. 3

GOING THE DISTANCE !

We were incredibly fortunate to have two dedicated individuals secure running bibs in two separate marathons to represent NF Northeast. Each runner has her own personal reason for taking on this challenge—and both trained hard and raised funds in support of our mission.

Meet Chantelle!

Chantelle, a music teacher in New York state and mother of three, runs for her husband, Pete, and daughter Amelia, both living with NF2-related schwannomatosis (SWN).

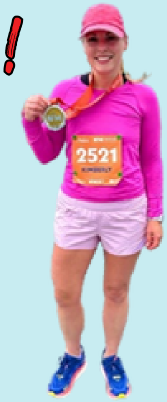
Pete was diagnosed in 2008 with a mild, atypical case caused by a spontaneous mutation—no family history, few symptoms, and no urgency for genetic testing. At the recommendation of the only neurologists at a Syracuse, NY, hospital, he underwent a non-invasive procedure using highly focused beams of radiation (Gamma Knife radiosurgery) to treat benign tumors on the vestibulocochlear nerve that affect balance and hearing (vestibular schwanommas). Only one was found when Pete had his first MRI, and then another was spotted right before the surgery, so both were removed. There were no other NF specialist there at the time, and this was what was recommended to them.

Chantelle and Pete were still hesitant to think Pete had NF2-SWN because he wasn't showing any other symptoms. That changed when their 4-year-old daughter, Amelia, developed what appeared to be a lazy eye. Trusting their instincts, Chantelle and Pete pushed for testing despite initial doubts from hospital staff. A CT scan revealed a golf-ball-sized brain tumor, leading to emergency surgery. Amelia was later diagnosed with NF2-SWN in 2015, with multiple spinal tumors and other complications. Now 14, Amelia continues to face challenges far beyond her years, traveling regularly to Boston for specialized care. Her NF2 journey has been far more severe than her father's.

Chantelle began running after her mother's passing in 2016, finding that it "filled the silence." This past spring, she ran the Buffalo Marathon, supporting the mission of NF Northeast, channeling her love for her family into raising awareness and funds.

For Chantelle, every mile is a promise—a promise of hope, progress, and a future where families like hers don't have to face NF alone.

Meet Kim!



Kim ran the Boston Marathon for the first time, fulfilling a dream since she began running at 42. She ran in honor of her sister-in-law, niece, and nephew—all diagnosed with NF1 at a young age.

"Neurofibromatosis Northeast is an incredible organization dedicated to supporting individuals and families affected by NF," says Kim. "I was fortunate to secure my Boston Marathon bib through my company, which allowed me to choose a charity—and I couldn't think of a better one. With a strong community at its heart, NF Northeast provides vital research funding and resources to improve the quality of life for those living with this condition."

Kim is no stranger to our cause—she first ran with our team at the 2013 Falmouth Road Race. Her brother also joined the fight, running Falmouth last year and again this year with our NF Northeast team.

"I was so proud to be able to support a cause that is so meaningful to our family. My sister-in-law, niece, and nephew all mean the world to me. They go through so much living with NF, but make it look easy. Their strength is what kept my training going, on days when I wanted to give up."

WORKING TOGETHER

COMPREHENSIVE, COORDINATED NF CARE AT COLUMBIA


NF Program lab team members

The Columbia Neurofibromatosis (NF) Program at New York-Presbyterian/Columbia University Irving Medical Center (NYP/CUIMC) offers comprehensive, multidisciplinary care for individuals with NF across their lifespans. Patients are seen by a team that includes neurologists, neurosurgeons, geneticists, oncologists, dermatologists, psychologists, and orthopedic specialists—all of whom meet regularly to develop and coordinate personalized care plans. This collaborative approach helps streamline referrals, ensures timely access to subspecialty care, and supports better outcomes over time.

The center, led by Dr. Gurcharanjeet (Bonnie) Kaur, is structured around four core pillars:

· **Integrated clinical care**, with particular emphasis on children and young adults navigating lifelong NF management.

· **Research**, including both basic and translational studies, aimed at improving quality of life and expanding treatment options.

· **Education**, to train future providers in NF care and advance the field through academic exchange.

· **Community outreach**, especially to underserved populations, while also serving patients from across the U.S. and abroad seeking expert evaluation or second opinions.

L-R Dr. Taemin Oh, Dr. Bonnie Kaur, and Dr. Christopher Winfree

As part of an academic medical center in New York City, the NF Program at Columbia combines access to clinical trials and emerging treatments with a longstanding commitment to individualized, expert care. Patients benefit from a tightly integrated system of subspecialists who understand the complexity of NF and work together to manage its diverse manifestations across age groups.

FOR MORE INFORMATION:
Contact Kaleah Miller | �� 212-342-3587 | ✉ NYPNFcenter@cumc.columbia.edu

MAKE AN APPOINTMENT:
To make an appointment, you can request an appointment online or call 212-342-3587.

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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NF Northeast

SUMMER AND BEYOND NF RESEARCH STUDIES

NF1 TUMOR EARLY DETECTION (NF1-TED) STUDY

Dana-Farber Cancer Institute and Boston Children's Hospital. This study aims to discover whether a blood test can detect malignant peripheral nerve sheath tumors (MPNSTs) in participants with NF1 earlier than the current standard of care. Participants must be 18 years or older, have NF1 and a plexiform neurofibroma (PN). Participants are eligible to earn up to $450 over the five-year follow-up period.

Learn more HERE or 617-355-4518 or 617-355-4517 or Email us: NF1-TED@childrens.harvard.edu

HELP TO IMPROVE THE FUTURE CARE OF NF1 PATIENTS!

Massachusetts General Hospital is enrolling participants for two studies testing healthcare ideas that patients and caregivers can use at their annual physical with their primary care doctor. Learn more HERE or https://nfsleep.massgeneral.org/nf1sleepstudy/ for any of the studies listed below.

MY NF GUIDE PEER STUDY

The goal is to help adults with NF1 prepare for and improve the quality of care at your next visit with your primary care doctor. Participants are eligible to receive up to $80 for their participation.

MY NF GUIDE RESEARCH STUDY

This study aims to improve the quality of NF1 care you/your child receives at your next primary care visit by providing NF1 information to you and your doctor. Participants are eligible to receive up to $150 for participating.

Learn more HERE or https://redcap.link/nfpeer
You can also contact study coordinator Sophia Carias at sccarias@mgh.harvard.edu or 617-643-8267.

NF1 SLEEP STUDIES AT MASSACHUSETTS GENERAL HOSPITAL (MGH)

Sleep disturbances are a commonly reported symptom in patients with NF1.

NF1 ADULT SLEEP STUDIES

- MGH has two active sleep studies focused on identifying relationships between NF1 and sleep.
You can learn more HERE or https://nfsleep.massgeneral.org/nf1sleepstudy/

NF1 CHILDREN'S SLEEP STUDIES

– MGH is interested in expanding its objective sleep study to adolescents with NF1. Previous studies have reported that children with NF1 are significantly more likely to have sleep disturbances. Learn more HERE or https://nfsleep.massgeneral.org/nf1sleepstudy/

A PATIENT'S PERSPECTIVE

A PATIENT'S PERSPECTIVE

BY REBEKAH CUTHBERTSON

NF presents differently in every individual. My grandmother had NF1, and both my mother and I also have this disease.

In 2022, I was diagnosed with an NF-related tumor on my right hypoglossal nerve, one of the cranial nerves in the brainstem. Doctors believe this slow-growing tumor has been present since birth. This type of tumor is extremely rare, even among NF1 patients. Initially, I sought the expertise of top neurosurgeons in Philadelphia, only to be told that surgery was too risky due to the tumor's location. Each specialist recommended alternative treatments such as radiation, Gamma Knife, or chemotherapy—options that are not viable for NF patients due to the increased risk of the tumor becoming malignant.

Determined to find the best care, I traveled to Vanderbilt University to consult one of the leading neurosurgeons in the country with experience in this tumor type. Unfortunately, this also did not lead to the right treatment plan.

But in 2023, I found a neurosurgeon who specializes in NF and has experience with tumors like mine. Since then, my tumor has been monitored annually, with the goal of removing it surgically when necessary.

At my 2025 annual appointment, my care team determined that my tumor had grown significantly, and it was time for surgery. This summer, I will undergo a procedure to remove as much of the tumor as possible. Potential complications include damage to my lower cranial nerves, which could affect swallowing, speech, facial sensation, articulation, hearing, and shoulder strength. While these risks are daunting, I am grateful to have found a medical team with the expertise to provide the best possible care for my unique needs as an NF patient.

NF has impacted my life in many ways, including hypermobility syndrome, chronic pain, neurodivergence, scoliosis, and other bone-related issues, all of which affect my daily experience. However, my tumor diagnosis has been the most challenging aspect of my journey. Despite its difficulties, it has also been a catalyst for positive change—driving me to advocate for more research, better resources, and increased awareness for those living with disorders like NF.

DOUBLE YOUR IMPACT

HAVE YOU EVER THOUGHT OF MAKING YOUR DONATION GO FURTHER?

Double Your Donation—At No Extra Cost to You!

Did you know your gift to NF Northeast might be eligible for a match from your employer? Many companies offer matching gift programs, and it's one of the easiest ways to make your donation go further.
Just visit nfnortheast.org/matching-gifts, type in your company name, and follow the steps to submit a match—even if you've already donated! (Deadlines for past donations vary by employer.)

If you're fundraising through Qgiv, you'll also see a prompt to check your eligibility—don't miss it!
Make your impact go twice as far with just a few clicks.

RECORD BREAKING SUCCESS!!

NF Northeast

Steps2CureNF

AND THAT'S A WRAP!
This spring, walkers from across the region came together in an incredible show of support—helping us hit an all-time high in participants, dollars raised, and volunteer involvement!

At a time when research funding is facing setbacks and our patients are feeling even greater uncertainty, these walks ignited a powerful sense of community, teamwork, and hope. Together, we proved that even in challenging times, we can move forward—stronger and more united than ever.

More than 1,050 walkers, including 103 patients and 83 teams, as well as 50 volunteers were all part of the effort that raised nearly $270,000 in support of NF Northeast's programs.

GREATER BOSTON

HARTFORD

ALEXION
AstraZeneca Rare Disease

SPECIAL THANKS TO ALEXION PHARMACEUTICALS WHO SPONSORED THE MISSION AREAS AT ALL 9 WALK LOCATIONS

SpringWorks
THERAPEUTICS

SPECIAL THANKS TO SPRINGWORKS AS A GOLD LEVEL SPONSOR OF ALL 9 WALK LOCATIONS

HONDA
ROUTE 128 Honda

SPECIAL THANKS TO RTE 128 HONDA WHO SPONSORED THE GREATER BOSTON WALK IN WAKEFIELD, MA

NF
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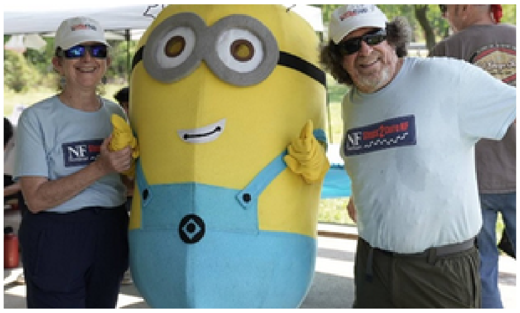
Steps2CureNF

CENTRAL NEW YORK

NEW HAMPSHIRE

WESTCHESTER COUNTY, NY

NORTHERN NEW JERSEY



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Steps2CureNF

GREATER PHILADELPHIA

CAPITAL DISTRICT NEW YORK

WCVB MEDIA SPONSOR FOR

GREATER BOSTON
SPECIAL THANK YOU TO EMILY MAHER, EVENT HOST AND WCVB REPORTER

WCVB 5 abc
BOSTON'S COMMUNITY LEADER

CAPITAL DISTRICT SPONSORS

THANK YOU ALBANY MEDICAL CENTER AND TIMES UNION

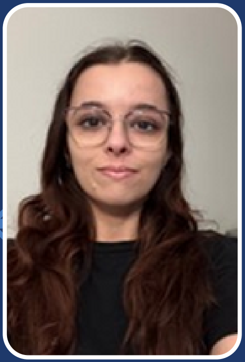
ALBANY MED
Health System

TIMES UNION

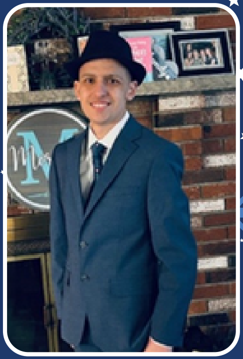
WESTERN NEW YORK

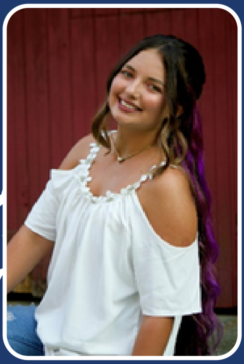
BRIGHT FUTURES

★ ★ ★ CONGRATULATIONS ★ ★ ★
TO OUR 2025 SCHOLARSHIP RECIPIENTS


MADISON DENNEHEY
Community College of Allegheny, PA


JONATHAN MALERBA
University of MA, Boston


GAVIN MORELLO
University of ME


ALEXIS SWANTER
Lebanon Valley College, PA

JANE CONSTABLE (not shown)
Dickinson College, PA


MCKENNA WANGEN
Clarkson University, NY

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Bert and Karen Peluso

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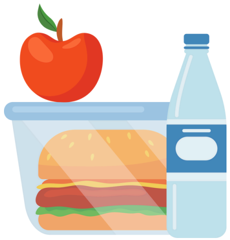
PATIENT SERVICES

TUESDAY TAKEAWAYS!
A FOUR-PART LUNCH AND LEARN SERIES



TUESDAY TAKEAWAY LUNCH 'N LEARN SESSION
MARK YOUR CALENDARS FOR OUR VIRTUAL UPCOMING EVENT!

Tuesday, September 30th, at noon—"*Music Therapy and Neurofibromatosis"* with Carey Pink, Board certified Music Therapist specializing in neurologic music therapy.

REGISTER HERE

SAVE THE DATE!

BEYOND SOUND, AN IN-PERSON WORKSHOP FOR NF2-RELATED SWN PATIENTS WHO ARE DEAF OR HAVE HEARING LOSS

SATURDAY, NOVEMBER 8, 2025 10:30 AM - 3:30 PM | SARATOGA SPRINGS, NY

Our panelists will share personal experiences and practical tools they rely on in daily life. Topics will encompass: the role of service animals in communication; use of smart phones and mobile apps; other innovative solutions and assistive technologies.

Featured speakers in the field of NF will include Brad Welling, MD, PhD, FACS, Massachusetts Eye and Ear, and Lauren Weintraub, MD, Albany Medical Center.

A limited number of stipends will be available to help offset the cost of travel and lodging for patients who need them. For more information on how to register, contact Anne Patterson, Director of Patient and Clinic Outreach, at apatterson@nfnortheast.org.

THANKS TO OUR GENEROUS SPONSORS

The Shaw Family
NF2 Wellness + Enrichment Fund

Xander

ALBANY MED
Health System

TREATMENT LANDSCAPE AND UPDATES IN NF1 PN, VIRTUAL PROGRAM
THURSDAY, OCTOBER 16TH, 6:30-8PM

Michelle with daughter, Samantha, program presenter

Join us for a virtual event featuring speakers Vanessa Merker, PhD, Family Center for NF and SWN, Mass General Hospital; and Gurcharanjeet (Bonnie) Kaur, MD, Division of Child Neurology, Columbia University Department of Neurology. Samantha will share a patient perspective.

Registration information will be coming soon via email and our website. www.nfnortheast.org

This program is generously sponsored by SpringWorks Therapeutics.

SpringWorks THERAPEUTICS

Congratulations to Watson!

This past June, Watson did a bike-a-thon, riding as many miles as he could with his owner, Laura Gray, who is riding in Coast to the Cure this September! Watson raised over $1,000 in honor of Laura's nephew Nat, who has NF1.

SPECIAL THANKS TO OLIVIA'S ORGANICS FOR YOUR ONGOING SUPPORT AWARENESS ABOUT NF AND NF NORTHEAST!

Spring Mix 11 oz.

Nutrition Facts

ervings per container: about 3.5

erving Size 2 cups (85g)

mount per serving

Calories	**15**
	% Daily Value*
otal Fat 0g	**0%**
Saturated Fat 0g	**0%**
Trans Fat 0g	
holesterol 0mg	**0%**
odium 50mg	**2%**
otal Carbohydrate 3g	**1%**
Dietary Fiber 2g	**6%**
Total Sugars 1g	
Incl. 0g Added Sugars	**0%**
rotein 2g	
itamin D 0mcg	0%
alcium 60mg	4%
on 1.2mg	6%
otassium 280mg	6%
itamin A 50% • Vitamin C 20%	
agnesium 6% • Vitamin K190%	
olate 15%	

he % Daily Value tells you how much a nutrient in a serving of food contributes to a daily diet. 2,000 calories a day is used for general nutrition advice.

rganic Ingredients: Red & Green Leaf Lettuce, Red & Green Oak, Red & Green Chard, Tango, olla Rosa, Spinach, Arugula, Beet Greens, utter Lettuce, Mizuna, Frisee, Radicchio, Kale, ollard, Red Mustard, Tat-Soi ngredients in each package vary.

Olivia's Organics Children's Foundation

Investing in the lives of childre

Olivia's family proudly supports:

NF NEUROFIBROMATOSIS NORTHEAST NFNORTHEAST.ORG

Neurofibromatosis Northeast is dedicated to findi treatments and cures for Neurofibromatosis (NF). NF is a genetic condition causing tumors to grow on nerves throughout the body at any age. NF affects three times as many people as muscular dystrophy and cystic fibrosis combined. There are three distinct types of disorders- NF1, NF2, and schwannomatosis. NF can cause deafness, vision impairment, epilepsy, learning disabilities, and cancer. Learn more about the NFNE mission and how you can help visit: **www.nfnortheast.o**

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www.oliviasorganics.org

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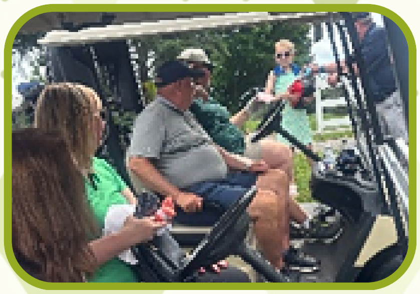
7-89707-72021-2

THE 6TH ANNUAL TIM KRURNOWSKI MEMORIAL GOLF TOURNAMENT IN MEMORY OF TIM KRURNOWSKI WAS HELD ON JUNE 21ST TO BENEFIT NEUROFIBROMATOSIS NORTHEAST'S PROGRAMS.



Tim was a dedicated husband, father, brother, grandfather, uncle, friend and role model. He fought cancer for over a decade and passed on September 27th, 2018. NF Northeast is honored to be the recipient of the funds raised from this year's tournament.

NF Northeast UPCOMING EVENTS

SATURDAY SEP 6

COAST TO THE CURE
STAGE FORT PARK
GLOUCESTER, MA

MONDAY SEP 15

FALL GOLF CLASSIC
FOUR OAKS COUNTRY CLUB
DRACUT, MA

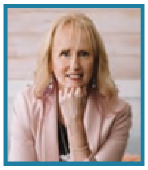
BUSINESS FRIENDS CORNER

JOHNNY’S DIECAST CORNER STORE

JT Bradley lost his cousin and friend Jennifer to NF. He donates 10% of his ebay sales of diecast cars!
ebay.com/str/johhnysdiecastcornerstore

ERYN'S ANGELS

Eryn (aka Erin Dawson) passed away in 2016 due to a brain tumor as a result of NF. As a way to celebrate Eryn’s life, Trish Mahoney-Diefenbach honors her daughter’s legacy through her work as a real estate agent. She donates 10% of her commissions to NF Northeast. If you would like information on how to become a part of Eryn’s Angels, contact Trish directly.



Trish Mahoney-Diefenbach, Keller Williams Evolution,
500 Cummings Center, Suite 1550, Beverly, MA 01915
Cell: (978) 304-9026   Email: trish@dalbon.com

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.

NEUROFIBROMATOSIS NORTHEAST

the organization with heart

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

NF Northeast

Location
9 Bedford Street
Burlington, MA 01803

Email
info@nfnortheast.org

Phone
781-272-9936

For more information, scan the QR code or visit www.nfnortheast.org

Follow us on social media!