



A STORY FULL OF HOPE

Emma was diagnosed with NF when she was 18 months old. She has café au lait spots over a large portion of her body and a benign brain tumor. In October of 2017, when she was just 17 years old, Emma underwent surgery to have about 50% of her brain tumor removed. Then, in October of 2021, Emma was diagnosed with a seizure disorder that her doctors believe is related to her NF diagnosis. The good news is that Emma has been seizure free for 10 months!

Despite having NF and all that comes with the diagnosis, Emma participates in the Falmouth Road Race each year, as she has for the past several years. "I am so fortunate that my symptoms of NF do not affect my daily life. I race to be a voice for those with NF who cannot. I race to show how strong individuals with NF are and to

be a representative of those living with NF. NF Northeast means the world to me, and I am so fortunate to be able to race for a charity that holds a special place in my heart." — Emma M.

THANKS FROM THE EXECUTIVE DIRECTOR

We just wrapped up a busy spring event season with a very successful golf tournament grand finale. After 37 years, the golf committee has decided to focus on other ways to support NF Northeast.

This particular group convened even before our organization was created. The dedication, commitment, and leadership shown by these savvy individuals have helped NF Northeast raise critical funds to move the needle forward in NF research, patient education, and programs for kids and young adults, such as camp. They have been steadfast in their commitment to send as many kids with NF to camp as possible. Over the years, each tournament dinner program included a Fund a Kid for NF Camp ask, raising thousands of dollars and allowing hundreds of kids to greatly benefit from camp experiences. This last tournament was no exception. Nearly \$25,000 was raised for NF camps this year.

I would like to take this opportunity to thank Grand Circle Travel and the Lewis Family for supporting our tournaments with Presenting Sponsorships and also for donating trips auctioned off during our programs. In addition, I would like to acknowledge the many other sponsors who have stayed with us over the years, as well as the golfers who play each year and the volunteers who help make everything happen. And last, but not least, thank you to the golf committee who have worked relentlessly on achieving nothing short of great success. You have all truly made a difference in the lives of people living with NF.

Best wishes,
Sharon Klein, Executive Director
NF Northeast



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.

LET'S GET INVOLVED



A MESSAGE FROM THE BOARD CHAIR

May and June were incredibly busy months for the volunteers and staff of NF Northeast, who brought together NF patients, families, and friends through eight events in three states—six walks (3 in NY, 1 in NJ, 1 in CT, and 1 in MA), a golf tournament, and the Hats, Horses, and Hope Kentucky Derby Party.

The Ridgefield, New Jersey, and Hartford, Connecticut, walks were new this year, while the four other walks in New York and Massachusetts have been well established for many years. The golf tournament to benefit NF Northeast celebrated its 37th and final year. Not only did these terrific events allow people to get to know other NF families, but they raised much-needed funds for our mission to support NF families, doctors, clinics, and researchers. We truly want to thank our volunteers and staff for your endless dedication to our cause.

Our spring events, as well as fundraisers at other times during the year, contribute greatly to NF Northeast's success. However, if we want to grow as an organization, we need to expand our efforts. I encourage people to think of different events that not only capture the diversity of those affected by NF, but the diversity of potential donors as well. NF Northeast is a regional organization covering nine states. I would like to challenge all of you to, please, "Get Involved."

My goal is to have an event in all nine of our states next year. If you live in Pennsylvania, Vermont, Rhode Island, New Hampshire, or Maine, now is the time to think about how you can contribute. Of course, if you live in Massachusetts, New York, New Jersey, and Connecticut—the states where our fundraisers are currently held—you can still start a new event or join the committee of one of the current events. No idea is too small, and we will support you every step along the way!! The first step is to call me to discuss your ideas and get you started. Many events take a long time to plan, so it's never too early to start. I look forward to hearing from you. Feel free to call me at 716-930-4585, or email me at jmanth7028@aol.com. Together we can continue to fund our mission and grow as an organization!

Thanks,
John Manth, Board Chair

NF NORTHEAST BOARD OF DIRECTORS

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NF NORTHEAST IS FEELING **GRATEFUL**

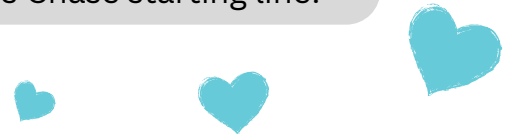


Cupid's Chase raised over \$4,000 in support of NF Northeast this past winter. Special thanks to event coordinator Beth Hanlon, who runs Cupid's Chase each year.

Pictured here from left to right: Kevin Ryan, Lori Ryan, Beth Hanlon, Mike Malerba, and Melissa Malerba



Cupid's Chase starting line!



A KENTUCKY DERBY PARTY
TO BENEFIT NEUROFIBROMATOSIS NORTHEAST

Hats, Horses, & Hope



Congratulations and Thanks to Melissa White for another successful Hats, Horses, and Hope event this past May!



Pictured above: Melissa White and Jessica Bruno



Friends enjoying the food, drink, and raffles at Hats, Horses, and Hope

BRIGHT FUTURES

2023 SCHOLARSHIP RECIPIENTS



Cairo Gordon-Somers-Archer from NY will attend Dean College as a freshman



Grace Burke from PA will attend Vet Tech Institute as a freshman



Joshua Jones from PA will attend Kutztown University as a freshman



Emmett Joyce from CT will attend School of Visual Arts as a sophomore



Curtis Merrill from MA will attend Montana State University as a freshman



Olivia Rogers from NY will attend Niagara County Community College as a freshman



Samantha Saraceno from NY will attend Seton Hall University as a freshman



Kaitlyn Woolard from MA will attend Mount Aloysius College as a freshman

MISSION: FAMILY

OLIVIA'S ORGANICS HONORED AT THE 37TH ANNUAL GOLF TOURNAMENT GRAND FINALE

NF Northeast presented Ken Reagan, Vice President of Sales and Marketing at State Garden, Inc., and Olivia's Organics Brand, with a special Appreciation Award at our Grand Finale Golf Tournament last month. We have been so fortunate that Olivia Organics chose NF Northeast as one of the charities included on four of their salad packages--Spinach, Spring Mix 11 oz. and 16 oz., and Baby Kale. This means approximately 35,000,000 awareness views of information about NF and NF Northeast annually through Olivia Organics salad sales! Much like NF Northeast's close-knit community, Olivia's Organics mission is FAMILY. "Family is about loving, caring, protecting, and nurturing." They are committed to health and the planet too!

Spring Mix 11 oz.

Nutrition Facts	
servings per container: about 3.5	
Serving Size 2 cups (85g)	
Amount per serving	
Calories	15
<small>% Daily Value*</small>	
Total Fat 0g	0%
Saturated Fat 0g	0%
Trans Fat 0g	
Cholesterol 0mg	0%
Sodium 50mg	2%
Total Carbohydrate 3g	1%
Dietary Fiber 2g	6%
Total Sugars 1g	
Incl. 0g Added Sugars	0%
Protein 2g	
Vitamin D 0mcg	0%
Calcium 60mg	4%
Iron 1.2mg	6%
Potassium 280mg	6%
Vitamin A 50%	Vitamin C 20%
Magnesium 6%	Vitamin K190%
Folate 15%	
<small>*The % 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.</small>	
Organic Ingredients: Red & Green Leaf Lettuce, Red & Green Oak, Red & Green Chard, Tango, Lolla Rossa, Spinach, Arugula, Beet Greens, Butter Lettuce, Mizuna, Frisée, Radicchio, Kale, Collard, Red Mustard, Tat-Soi	
<small>Ingredients in each package vary.</small>	

Olivia's Organics
Children's
Foundation
Investing in the lives of children

Olivia's family proudly supports:

Neurofibromatosis
NORTHEAST

Neurofibromatosis Northeast is dedicated to finding 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.org

Product of USA
Olivia's Organics
Division of State Garden, Inc.
P.O. Box 6277, Chelsea, MA 02150
www.oliviasorganics.org

Certified Organic by QAI

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7-89707-72021-2

BPA FREE

THANK YOU

**NF Northeast
Advocates!**



In late June, we learned that the House Appropriations Committee included \$25 million for the Neurofibromatosis Research Program (NFRP) in their Fiscal year 2024 Defense spending bill.

Last February, nearly 30 advocates from NF Northeast joined the NF Network for our annual Advocacy Days on the Hill in Washington DC. Each year, NF Northeast co-sponsors the event with the NF Network. Advocates met with members of Congress to tell their NF stories and why research is critical to finding therapies and eventually cures for this debilitating disorder. The program has been a constant for over 20 years and our advocates have helped to generate more than \$427 million for NF research.

What's next? The legislation will make its way through Congress. We will keep you updated as the process continues. Thank you for sharing your NF stories with Congressional offices as we stress the importance of NF research dollars.

For more information on how you can become an advocate, email us at info@nfnortheast.org.



Olive saying "Hello" to one of the horses

HEALTH AND HAPPINESS

A MESSAGE FROM AN NF MOM

I'm writing this full of hope, optimism, and inspiration, having just picked up my NF hero Olive (age 7) from her first ever sleepaway camp adventure at the beyond-incredible Double H Ranch in the Adirondacks. A nonprofit co-founded by Charles R. Wood and Paul Newman, Double H Ranch has a mission to provide specialized programs and year-round support for children and their families dealing with life-threatening illnesses. What does Double H stand for? Health and Happiness!



Gabe, camp counselor and Theresa Owhady

Upon arrival at camp, we were greeted by one of Olive's counselors--Gabe, an NF hero himself--who warmly introduced himself and showed Olive that he, too, has café au lait spots. Their bond was immediate. Nothing, though, could have prepared me for the profoundly impactful experience of my site visit, where I was greeted at every turn by the most compassionate, loving, and caring volunteers and staff members. This place is magical. Hearing Olive talk about her adventures--riding horses, "flying through the sky" (zip-lining), making ice cream and banana boats, and making new friends warmed my heart in ways indescribable. In 4 short days, her confidence and independence soared. We are so incredibly grateful to have been given this opportunity and cannot wait to return, not only for camp next summer but for family weekends and adventures throughout the year. Thank you from the bottom of my heart to NF Northeast and Double H Ranch. You've impacted our lives more than you'll ever know.



Theresa Owhady, NFNE Board member and Olive's mom; Jacqui Royael, Director of Operations, Double H; Maureen O'Brien, Double H volunteer and Gabe's mom; Sharon Klein, NFNE Executive Director; Marybeth Shaw, NFNE Board member; Anne Patterson NFNE Director of Patient and Clinic Outreach

IT WAS GRAND

37th

Grand Finale

Golf Tournament

NF Northeast Golf Committee Wraps up 37 Years with Golf Tournament and Grand Finale Celebration!

In June, the NF Northeast golf committee hosted its last tournament in great style, once again, with Grand Circle Travel as Presenting Sponsor. The event sold out months in advance. Golfers, including former Red Sox player Dwight Evans (1972-1990), had the opportunity to play at the Ferncroft Country Club in Middletown to support NF Northeast's mission. The event was

dedicated to Grand Circle Travel's and Kensington Investments' Alan Lewis, who passed away suddenly last November. The golf committee felt it most fitting to dedicate this last tournament in Alan's memory to recognize his generous support and commitment to helping find therapies and a cure for NF over the last 38 years.

After a day of good weather and great golfing, the group gathered for a dinner and program celebration. The fun included raffle tables, silent and live auctions, and two giant 75-inch flat-screen TV door prizes. Special thanks go out to local comedians Tony Viveiros ("Tony V") and Paul D'Angelo, who have given of their time and talent for many years and teamed up to emcee this event. NF Northeast Board member and NF specialist at Boston Children's Hospital, Dr. Nicole Ullrich, gave a brief talk about neurofibromatosis in which she described the disorder and how it affects patients differently. Francisco Fernandez, PhD candidate in Harvard University's Biological and Biomedical Sciences Program and member of the Walker Lab at Massachusetts General Hospital, shared his personal NF story, as well as the NF Northeast-funded NF1-focused project on which he is working. The Lewis Family and Grand Circle Travel, along with Francisco, received special recognition awards.



IT WAS GRAND

37th GOLF TOURNAMENT
TO BENEFIT NF NORTHEAST
Ferncroft Country Club – Middleton, MA



HOPE FOR A WORLD WITHOUT NF



NF NORTHEAST CELEBRATED ANOTHER SUCCESSFUL STEPS2CURE NF SEASON

Six Steps2Cure NF events took place this past May during NF Awareness month. NF Northeast is grateful to all walkers, runners, and volunteers who worked tirelessly to make each event a success. Collectively, the walk/run events raised more than \$100,000 in support of NF Northeast’s mission.

SPECIAL THANKS TO OUR MISSION SPONSOR OF THE SIX STEPS2CURE EVENTS, ALEXION PHARMACEUTICALS



Riverworks ~ Buffalo, NY, Walk



Forest Park
Camden, NY, Walk



Overpeck Park ~ Ridgefield, NJ, Walk



Dunkin Park ~ Hartford, CT, Walk



Central Park, Schenectady
Capital District NY, Walk/Run

Special thanks to media sponsor Times Union for supporting our Schenectady Walk.



Special thanks to SpringWorks Therapeutics for supporting the NY and NJ Walk events.



Lake Quannapowitt
Wakefield, MA, Walk/Run



TUESDAY TAKEAWAYS!

TUESDAY TAKEAWAYS! A FOUR-PART LUNCH AND LEARN SERIES

This past spring, NF Northeast hosted virtual talks by NF experts. Topics included:

- How to Navigate Clinicaltrials.gov and the Network Edge
- Basic science of NF1 tumors
- Identifying new targets for NF1
- Pain management in NF1, NF2-related schwannomatosis, and schwannomatosis

Special thanks to Vanessa Merker, PhD; Rebecca Dodd, PhD; James Walker, PhD; Frank Buono, PhD; Dale Berg, patient advocate, and caregiver Maureen Hussey, who hosted the calls.

STAY TUNED FOR THE FALL TUESDAY TAKEAWAY SERIES!



VOLUNTEER

APPRECIATION

NF NORTHEAST VOLUNTEER APPRECIATION NIGHT!

This past spring, NF Northeast hosted a night to say, “Thank you”, to the many volunteers who make our work possible. The event was held at Salvatore’s in Lawrence, Massachusetts. Top fundraisers and committee volunteers who participated in 2022 were acknowledged for all 5 of the Steps2Cure NF walks, Coast to the Cure, the Falmouth Road Race, the Philadelphia Marathon, Fall Golf Classic, Committed to Curing NF, Cupid’s Chase, Hike for NF, and, our longest running event, the NF Golf Tournament.

Awards were given out to:

Melissa Malerba, Advocacy Award

Michelle Ventola, Patient Services Award

Vanessa Merker, PhD, NF Northeast Research Award

Beth Hanlon, Special Recognition—Mentor Award, NF Northeast Endurance

Scot DeDeo, Special Recognition—Coach Award, NF Northeast Endurance

Lori Ryan, Volunteer of the Year Award



Deniro Bruno, top fundraiser for Steps2Cure NF Wakefield, MA, along with Executive Director Sharon Klein.



Lori Ryan receiving the Volunteer of the Year Award presented by NF Northeast Board Chair John Manth.



Michelle Ventola, Program Specialist for Pediatric NF at John R. Oishei Children's Hospital in Buffalo, NY, (left) receives NF Northeast Patient Services Award from Anne Patterson, Director of Patient and Clinic Outreach (right)



NF Northeast Founder Karen Peluso recognizing Melissa Malerba (right) for her exceptional work in Advocacy.

TED EARLY DETECTION STUDY

Neurofibromatosis Type 1 (NF1) Tumor Early Detection (TED) Study

The NF1 TED study aims to determine the clinical utility of liquid biopsy for early detection of MPNST in participants with NF1. People with NF1 are at an increased risk of developing a form of cancer called malignant peripheral nerve sheath tumor (MPNST). The treatment is challenging. This liquid biopsy is a blood test that can detect the presence of a tumor, possibly before it has symptoms.

Dr. David Miller, Principal Investigator, and Katherine Piculell, Research Coordinator, are enrolling young adults ages 18-40 with NF1. **For more information on how you can participate**, email Katherine.piculell@childrens.harvard.edu or David.miller2@childrens.harvard.edu.



ARE YOU INTERESTED IN APPLYING FOR NF RESEARCH FUNDING?

NF Northeast is accepting proposals:

<https://www.nfnortheast.org/for-researchers/#grant-application>



WELCOME TO OUR NEWEST BOARD MEMBERS



TERESA OWHADY

Theresa Owhady's introduction to neurofibromatosis began when her daughter Olive (now age 7) was diagnosed with NF1 at 3 months old. Given that Olive's mutation was spontaneous, Theresa had not been familiar with NF until that time, but she quickly worked to build a strong and supportive community of physicians and parents. Theresa is involved with NF Northeast advocacy, working to secure medical research funding in Washington, D.C., and has spearheaded NF Northeast's inaugural Steps2Cure NF walk in New Jersey. Theresa's professional background spans 20 years in account

management and sales operations focused on private equity and financial services clients at professional services and consulting firms. She has been with Ernst & Young for over 10 years, and has a Bachelor's degree from Fordham University. In her free time, Theresa loves gardening, cooking, meditation, being outdoors, community involvement, and spending time with Olive where they live in Paramus, NJ.



KRISTINA RATH, MD

Dr. Kristina Rath graduated from Yale University with a Bachelor of Science in Mechanical Engineering. She earned her medical degree from the University of Pittsburgh Medical School. She completed her internship and residency in Obstetrics and Gynecology at Yale-New Haven Hospital. Dr. Rath is a Clinical Instructor in the Department of Obstetrics and Gynecology at Yale University School of Medicine and works in private practice gynecology in the New Haven area. Dr. Rath is the mother of three children. Her youngest daughter, Jane, was diagnosed with NF1 as an infant. Jane

was one of the first children in the world to take the MEK-inhibitor selumetinib in a clinical trial in 2014; in 2020 the drug became the first medication ever approved by the FDA for neurofibromatosis. Dr. Rath is an avid runner—since 2009, she has run dozens of marathons and raised over a quarter of a million dollars for NF charities. She has been a member of the Children's Tumor Foundation Volunteer Leadership Council since its inception in 2015, and has served on the Medical Board of the Childhood Tumour Trust in the United Kingdom since 2019.

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/johnnysdiecastcornerstore



ERYN'S ANGELS

Eryn (aka Erin Dawson) passed away from NF 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 proud 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.



Neurofibromatosis Northeast ~ 9 Bedford Street ~ Burlington, MA 01803
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- **NOVEMBER 4** Committed to Curing NF, Anthony's of Malden, Malden MA
- **OCTOBER 1** Maine Marathon, Portland, ME
- **SEPTEMBER 30** Hike for NF, Minnewaska State Park, Kerhonkson, NY
- **SEPTEMBER 18** Fall Golf Classic, Four Oaks Country Club, Dracut, MA
- **SEPTEMBER 9** Coast to the Cure cycle event, Gloucester, MA
- **AUGUST 20** Falmouth Road Race, Falmouth, MA

UPCOMING EVENTS



Follow us on social media!



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



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



the organization with heart

NEUROFIBROMATOSIS N O R T H E A S T



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