

NF NEWS

NEUROFIBROMATOSIS NORTHEAST

Promoting Research, Awareness and Advocacy since 1988

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Summer 2022

Welcoming Summer with Enthusiasm and Hope!

As we enjoy the summer season of warm weather and being outside, I am so excited to reflect back on the many programs and events that NF Northeast has successfully delivered over this past year. From our focus on programs for young adults and resources to help guide them through their NF journey, to the special events that were back in person, we have had a year chock full of activities and much to be proud of. Our calendar keeps growing! We have begun offering a new category of events called NF Northeast Endurance events. This category of outdoor fun will encompass running, walking, cycling, hiking, and triathlons. We hope to take you to new destinations both in the Northeast and beyond.

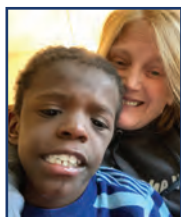


Sharon Klein

So much of our mission success lies in the ease of finding resources and care for our patients. In this day with so much information online and on social media, it can be overwhelming to someone who is newly diagnosed with NF. Technology can be a tool, but it can also be a deterrent if it's not easy to use. I remain steadfast in my focus on NF patients and families as you will see reflected in our new and refreshed website launching this summer...Stay tuned!

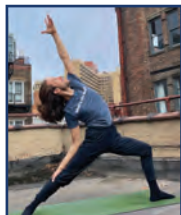
Sharon Klein
Executive Director
NF Northeast

May - NF Awareness Month!



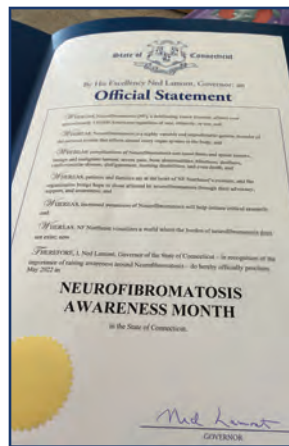
Governors across the country signed Proclamations in the month of May to recognize NF and create awareness and education about the disease.

Pictured here are Jessica and Cameron Lord. Jessica was thrilled to receive the Proclamation signed by Governor Ned Lamont, proclaiming May NF Awareness month in the state of Connecticut.



Avery Rausch, certified Yoga Instructor and Theater Artist

This past May was full of great programs and social media, promoting NF awareness and education. Special thanks to Avery Rausch who shared his yoga talent with NF patients and families hosting two yoga sessions, one on May 17th, National NF Awareness Day, and on May 22nd.



Looking to talk with someone who has NF or NF in their family?
Matched for Hope pairs trained volunteers with newly diagnosed patients and families to share their experience and provide them with resources and support.
For more information, email us at info@nfnortheast.org or call us at 781-272-9936.

Dear NF Community,

It is hard to believe we are midway through 2022 and are finally having in-person events! I hope you were able to participate in an activity or event to raise awareness for Neurofibromatosis (NF) during NF Awareness Month in May, although every month deserves to be NF Awareness Month! Raising awareness and funds for NF Northeast programs is so important, particularly our research grant program to advance treatment options and ultimately find a cure. Since 1990, NF Northeast has granted more than \$3,000,000 to researchers/institutions and continues to fund selected research proposals that are vetted by the NF Northeast Medical & Science Committee. I am grateful that we have such an esteemed and dedicated Committee to review the research proposals. The Committee is comprised of Nicole Ullrich, MD, PhD, Justin Jordan, MD, MPH, John Thomson, PhD, Marissa Powers, PhD and me. We focus on seed and pilot projects that will allow the researchers to gather more data to apply for other grants through larger funding sources, such as the National Institutes of Health (NIH) or the Department of Defense Congressionally Directed Medical Research Programs. In 2022, we have already funded several researchers, including:



Lori Ryan, RN, MS, Chair

- Brad Welling, MD, PhD, from Mass Eye and Ear Institution for research titled, “Doxycycline Injection of Cutaneous Schwannoma in NF Type 2”
- Bonnie Klein-Tasman, PhD, from University of Wisconsin, requested additional funding for her previously funded project title, “Effectiveness of a Telehealth Group for Improving Peer Relationships from Adolescents with NF Type 1.” This project is co-funded with other NF organizations.
- Vanessa Merker, PhD, from MGH for research title, “Expanding Patient-Centered Outcome Assessment in a NF Consortium Trial of Selumetinib plus Cabozantinib for Growing or Symptomatic Plexiform Neurofibromas: A Qualitative Interview Study”

Without the support of our donors, sponsors, and event participants, we would not be able to fund research programs and other important educational, advocacy and support programs that focus on the multifaceted challenges of NF. Let’s work together to make every month NF Awareness Month and continue to promote and fund NF research! As stated by Carl Sagan, “Somewhere, something incredible is waiting to be known.”

Sincerely,

Lori Ryan

NF Northeast Board of Directors

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.*

Lori Ryan, RN, MS, Chair
Robert Ryan, Treasurer
Melissa Malerba, Secretary
Frank Buono, PhD
Patrick Callahan, Esq.
Tamara Indianer

Alexandra Powers Cellucci
Justin Jordan, MD, MPH
Andres Lessing
John Shea
John Thomson, PhD
Nicole Ullrich, MD, PhD

NF Northeast Founders, Bert and Karen Peluso

Congratulations to Our Scholarship Recipients for 2022!



Lauren Bentz from New York, will attend SUNY Cortland as a sophomore



Kaitlyn Franks from Pennsylvania, will attend Mount Aloysius College as a freshman



Alison Guarente from Massachusetts, will attend Johnson & Wales University as a freshman



Kristen Guarente from Massachusetts, will attend Merrimack College as a freshman



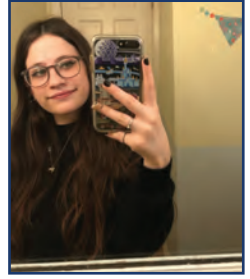
Fiona Marshall from New Hampshire, will attend Maine College of Art & Design as a freshman



Samantha Mosca from New York, will attend Western Connecticut State as a freshman



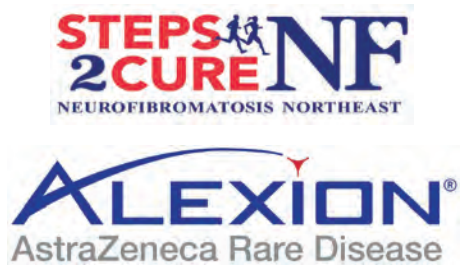
Bailey Royhab from Pennsylvania, will attend Penn West (Clarion) University as a sophomore



Camille Willard, from New York, will attend SUNY Brockport as a senior

Special thanks to Alexion Pharmaceuticals - Mission Area Sponsor

Steps2Cure events were held in Wakefield, MA, Albany, NY, Camden, NY & South Wales, NY



Pictured are cadets from several cities and towns across the Commonwealth who supported NF Northeast's Steps2Cure NF event in Wakefield. Cadets attend Northern Essex Community College & Methuen Police Academy.

Photos courtesy of John Roy

Welcome to Our Newest Members of the NF Northeast Board



Tamara Indianer, AIF® CFP®

Tamara Indianer serves as the Regional Vice President at Northeast Lincoln Investment. In her current position, she helps Lincoln Investment manage the transition and integration of new offices and advisors into their region. Tamara oversees the administration, operations, and finances of the New England branch. She is a dedicated member of the NF Community, attending many NF events, such as Steps2Cure NF in Wakefield.



Frank Buono, PhD

Dr. Frank D. Buono is an Associate Research Scientist in the Department of Psychiatry at Yale School of Medicine. He completed his postdoctoral appointment at Yale School of Medicine after obtaining Masters and Doctorate degrees at Southern Illinois University in Applied Behavior Analysis. Additionally, Dr. Buono was diagnosed with Neurofibromatosis Type 2 (NF2) at the age of nine. This, along with his professional training, provides him with a deeper understanding of the physical and clinical manifestations of the disease, as well as co-occurring diseases and disorders. He is funded through Congressionally Directed Medical Research Programs (CDMRP), Children's Tumor Foundation and other private organizations.

Business Friends Corner



Eryn (aka Erin Dawson) passed away from NF in 2016 due to a brain tumor as a result of having 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 part of Eryn's Angels, contact Trish at the phone number or email listed below.



Trish Mahoney-Diefenbach,

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

NF Northeast Staff

Sharon Klein, *Executive Director*
Anne Patterson, *Director of Patient and Clinic Outreach*
Lisa Leger, *Director of Fundraising and Innovation*
Kim Trainor, *Bookkeeper and Operations*
Catherine Mooney, *Digital Marketing Manager*
Jenny McDonald, *Gift and Data Coordinator*
Christi Shannon, *Administrative Assistant*



Leadership in Action!

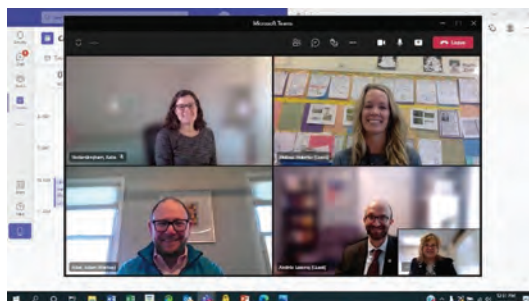
This past winter, we kicked off our Young Adult Series with a program entitled *Success in Different Ways*. Five young adult NF patients were featured in the webinar in which they discussed life after high school. The goal of the talk was to present the varied directions NF patients have chosen to take and to let others know that success can be defined differently for everyone – and whatever path you choose is the right one for you. Our speakers shared their experiences with attending college, opening a dog-grooming business, photography, and self-care.



We were also honored to have Meredith A. Chambers, M. Ed., Education Specialist Multidisciplinary Neurofibromatosis Program, Boston Children's Hospital, participate in our webinar. Ms. Chambers assists patients and their families with navigating educational challenges. In this webinar she spoke about ways for patients to prepare for life after high school when educational resources may end.

Advocacy Continues in the Virtual World!

This past February, advocates from around the country took part in virtual Capitol Hill visits to urge their senators and representatives to support NF research funding through the Congressionally Directed Medical Research Programs (CDMRP) and the National Institutes of Health (NIH). Continued congressional funding is critical to the clinical trials that may ultimately lead to treatments and a cure for NF and related disorders. We were thrilled to announce that \$25 million was awarded this year for NF research. That's a \$5 million increase from last year.



Pictured are advocates from Massachusetts talking with Senator Markey's office.

Looking Forward!

Sunday, August 21st - Falmouth Road Race - **Falmouth, MA**

Saturday, September 10th - Coast to the Cure, Stage Fort Park - **Gloucester, MA**

Monday, September 19th - Fall Golf Classic, Four Oaks Country Club - **Dracut, MA**

Saturday, September 24th - Hike for NF - Never Stop Climbing - **Mt. Monadnock Region of New Hampshire**

Sunday, October 2nd - Steps2Cure NF, Dunkin Donuts Park - **Hartford, CT**

Monday, October 3rd - Worcester Golf Tournament, Worcester Country Club - **Worcester, MA**

Saturday, November 12th - Committed to Curing NF, Anthony's of Malden - **Malden, MA**

Saturday and Sunday, November 19th-20th - Philadelphia Marathon - **Philadelphia, PA**