



LIGHTS, CAMERA, ACTION!

When Executive Director Sharon Klein reached out to Gavin Morello about creating a video for NF Northeast while at the Coast to the Cure cycle event, she had no idea that he and his friend Brady would arrive at the event like consummate professionals. Gavin Morello (left), along with classmate and friend Brady Antaya (right), debuted their video and interview skills at the Coast to the Cure event this past September 9th at Stage Fort Park in Gloucester, MA. They had prepared lists of interview questions for cyclists and supporters, and they knew exactly how the day would roll out for videoing the group. They began by checking the lighting at the park and arranged their video equipment in high-traffic areas also quiet enough for audio. Gavin and Brady were not shy about introducing themselves and were up and running in no time! The classmates immediately put their interviewees' minds at ease.

Gavin and Brady attend Methuen High School and are in the 11th grade. Both have a keen interest in broadcast media, as well as film and video production. Working with their teacher Mr. Wilkins, the pair created a marvelous video about NF Northeast with a focus on Coast to the Cure. "Seeing what goes on behind the scenes is what sparked my interest in creating a video for NF Northeast," says Gavin. "In the past, we have created infographics about the school and silent movies."

As a young person with NF1 himself, Gavin was curious to talk to cyclists and family members about why they support Coast to the Cure and NF Northeast. Gavin has a passion for meeting new people and learning about why they ride. Many cyclists explained that they participate in honor of someone or a family who has been touched by NF. Being a part of Coast to the Cure gives them a way to support a loved one or friend.

When asked what the most challenging part of this project was, Gavin said the editing process, as there was so much great footage. Check out their video by visiting *Who We Are - Neurofibromatosis Northeast* at www.nfnortheast.org.

IN LOVING MEMORY



IN LOVING MEMORY OF BERT PELUSO, CO-FOUNDER, NF NORTHEAST

Nearly four decades ago, Bert and Karen Peluso started what is now NF Northeast with a mission to find therapies and cures for neurofibromatosis (NF) and allied disorders, as well as to provide patient education, resources, and advocacy.

Bert Peluso was dedicated to helping patients with NF, and passionate about research. He was relentless in his commitment to transform the diagnosis and treatment of the disorder. This sense of urgency motivated both Bert and Karen to raise seed funding to establish the Harvard Medical School Center for NF and Allied Disorders in 2002. From that time on, Bert's unwavering commitment to help patients and families in their quest to find therapies and eventual cures for NF was steadfast.

Bert passed away this past October, and, in loving memory, NF Northeast has established the Bert Peluso Research Award Fund to support investigation in his name. We are on the cusp of so many NF therapy possibilities, with more dollars directed to studying NF and allied disorders than ever before.

For more information on how you can make a gift in Bert's memory, visit :

<http://weblink.donorperfect.com/BertPelusoNFResearchAward>

LET'S GET INVOLVED



A MESSAGE FROM THE BOARD CHAIR

As one of the founding organizations of the NF Network, NF Northeast, along with other NF organizations, created the NF Advocacy Program. Since 1996, we have worked closely with members of the United States House and Senate to secure more than \$425 million for NF research through the Department of Defense's Congressionally Directed Medical Research Program (CDMRP). We have also effectively requested that report language on NF research at the National Institutes of Health (NIH) be included in the Labor, Health and Human Services and Education Appropriations Bill.

I became involved in advocacy 15 years ago when I participated in my first meeting in Washington, D.C. The experience truly changed my life, and I have committed myself to advocate for federal funding for as long as I possibly can. I have been accompanied by my wife Linda, daughters Erin and Leah, and my son Chris. Several extended family members have joined us along the way as well.

NF Northeast works hand-in-hand with the NF Network and several other organizations to make this important program happen. Our Founder, Karen Peluso, was part of the first group of five attendees who travelled to D.C. to advocate for federal funding, and she hasn't missed a year since! Fast forward to this past February, when we had 96 people from across the country advocating on behalf of all NF patients. The group included three NFNE staff members and nine volunteers from the Northeast region. They attended meetings with Senators' and Representatives' staffers in all nine Northeast states. Attendees included Sharon Klein, Executive Director; Anne Patterson, Director of Patient and Clinic Outreach; Jenny McDonald, Gift and Data Coordinator; Karen Peluso (MA); Mike and Melissa Malerba (MA); Kevin Ryan (MA); Chantelle and Amelia Nobis (NY); Marybeth Shaw (NY); John Manth (NY); Jeffrey Malone (NY); Theresa Owhady (NJ); Jesse and Suzanne Hunsberger (PA); and Sean and Natalie Keeley (PA). Thank you to everyone who made the trip and worked so hard.

I truly believe that federal advocacy is the most important thing that NFNE can do to find a cure for all forms of NF. There is no greater return on our investment of funds and resources to this cause!

Many thanks,
John Manth, Board Chair



Theresa Owhady,
Advocate for New Jersey



From left to right: Jesse and Suzanne Hunsberger, PA, with Staffer in Representative Susan Wild's office

ADVOCATES IN ACTION

NF NORTHEAST VISITS OUR NATION'S CAPITAL FOR THE ANNUAL ADVOCACY MEETING



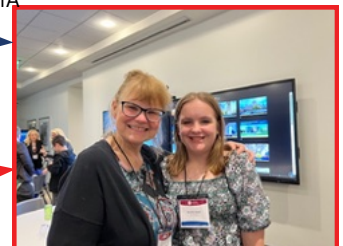
NF Advocates set out for meetings with members of Congress



Advocates from NF Northeast



From left to right: Jeff Malone, Advocate from NY; TayLore Reliford, Staffer in Representative Daniel Goldman's office; Anne Patterson, NY; and Sharon Klein, MA

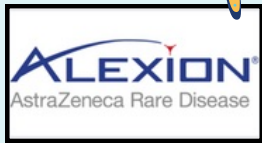


Sharon Klein, Executive Director, NF Northeast, and Amelia Nobis, Advocate from Taberg, NY, at the advocacy training hosted by Van Scoyoc Associates and the NF Network

NF NORTHEAST IS FEELING GRATEFUL



SPECIAL THANKS TO
ALEXION
PHARMACEUTICALS, OUR
COAST TO THE CURE
MISSION AREA SPONSOR!



Riders from all over the Northeast region came together to raise funds and ride in our 12th Annual Coast to the Cure event. They raised nearly \$120,000 in support of NF Northeast's patient and healthcare professional education, research, and advocacy programs. Beginning and ending at Stage Fort Park, riders of all ability levels enjoyed 24-, 40-, and 66-mile scenic bike routes through 13 towns in and around Cape Ann on a beautiful September day. Michelle Hirsch Donovan (third from right) was, once again, the top fundraiser for the event. Special thanks to WCVB Channel 5 Media Sponsor and reporter Emily Maher, who emceed the Coast program.



Emily Maher, Reporter
WCVB Channel 5

CONGRATULATIONS, ONCE AGAIN, NF NORTHEAST FALMOUTH TEAM!



Thirty runners participated in the 51st ASICS Falmouth Road Race to raise funds for NF Northeast this past August.

From left to right: Liam Powers, Kristen Powers, and Alex Cellucci



Alex Cellucci with daughter, Maible



FALMOUTH 2024!
REGISTRATION OPENS
MARCH 1st!!
To register go to:
<https://bit.ly/frr2024>



MANY THANKS AND CONGRATULATIONS TO OUR RUNNERS WHO PARTICIPATED IN THE MAINE MARATHON LAST OCTOBER

Runners on behalf of NF Northeast chose the full, half, or relay marathon distances. Some families made a weekend of it and stayed in the Portland area filled with great restaurants, shops, and entertainment.

Special thanks to Beth Hanlon, NF Northeast Team Mentor and participant, and Scot DeDeo, NF Northeast Marathon Coach and participant.



RAIN DIDN'T STOP THE 24TH ANNUAL FALL GOLF CLASSIC TO BENEFIT NF NORTHEAST!



More than 100 golfers came out to participate in the annual Fall Golf Classic, and it poured all day. Golfers braved the weather to support our cause, which is so important to many who have played in this tournament for the past 24 years. Special thanks to Jean Morello, pictured here, who was our mission speaker and a volunteer at the event. Jean talked about her husband Gary and son Gavin, who both have NF1, and how grateful she and her family are to the many golfers and donors who support the Fall Golf Classic year after year.



HIKE FOR NF

Never Stop Climbing



HIKE FOR NF IN MINNEWASKA STATE PARK, NEW YORK



Hikers set out for a half-day hike in the beautiful wilderness of Rainbow Falls, a 5.1-mile trek at Minnewaska State Park. Special thanks to REI Co-op and our hike leader, Chris, for a wonderful event.



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.



Neurofibromatosis Northeast ~ 9 Bedford Street ~ Burlington, MA 01803
781-272-9936 ~ info@nfnortheast.org ~ www.nfnortheast.org



Melissa Malerba (fourth from the left) with friends, who came out to support her and the event.



COMMITTED TO CURING NF

ANOTHER GREAT EVENT!

MANY ATTENDED THE ANNUAL COMMITTED TO CURING NF CASINO NIGHT HOSTED BY MELISSA AND MIKE MALERBA LAST NOVEMBER.



Family and friends of the Malerbas enjoy dinner while bidding on auction items.



WELCOME TO OUR NEWEST BOARD MEMBER



KAREN PELUSO, FOUNDER, NF NORTHEAST

NF Northeast is so pleased to welcome Karen Peluso to the Board. Karen has been an NF advocate for over 40 years, and, along with her late husband Bert, founded Neurofibromatosis Northeast. After their critically-ill young daughter was diagnosed with NF, Karen and Bert became frustrated by the limited information available and the lack of research being conducted to better understand or treat the disease. They made a commitment to change that and began organizing fundraising events and holding information sessions. Despite numerous challenges, including pre-dating the internet, Karen and Bert remained determined—and the organization now known as

Neurofibromatosis Northeast began at their kitchen table.

Karen served as Executive Director from 1994 until her retirement in 2021. Under her leadership, NF Northeast presented \$3 million in research grants to scientists using funds raised primarily at events. Seeing an opportunity for federally-funded research through the Department of Defense, Karen joined a handful of NF advocates to lobby Congress, and, in 1996, they made their first trip to Washington, D.C., where they secured \$8 million for NF research. Returning to our nation's capital each year since then, with more and more advocates, Karen and NF advocates have secured \$425 million to date. Karen has presented testimony before the House and Senate Appropriations Committees and continues to go to the Hill as a mentor for new NF advocates.



NF NORTHEAST BOARD OF DIRECTORS

- | | |
|------------------------------|-------------------------|
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NF NORTHEAST FOUNDERS

Bert and Karen Peluso

NF NORTHEAST STAFF

- Sharon Klein, Executive Director
- Anne Patterson, Director of Patient and Clinic Outreach
- Kim Trainor, Operations Manager
- Lauren Gilbert, Director of Fundraising
- Sara-Jane Griffin, Fundraising Manager
- Jenny McDonald, Gift Processor and Data Coordinator
- Catherine Mooney, Digital Marketing Manager



TUESDAY TAKEAWAYS!

TUESDAY TAKEAWAYS! A FOUR-PART LUNCH AND LEARN SERIES

The NF Northeast Tuesday Takeaways speaker series continues to be well attended! These one-hour educational lunchtime sessions are geared towards sharing updates and relevant information with our NF community. We would like to thank all of our speakers who presented in our fall series.

In our current series, Leah Manth, MSW, presented “The Use of Service Dogs in Neurofibromatosis.” This topic captured the attention of many in our NF community! Leah talked about the benefits and process of obtaining a service dog, as well as the cost, responsibility, and training involved.

Dr. Rebecca Brown, MD, PhD, spoke about “The Role of Hormones in Neurofibromatosis.” Her presentation dissected the evidence (or lack thereof) of how hormones affect tumors in NF1 – from puberty to birth control, pregnancy, gender affirmation, and more. The talk was well attended and generated many questions during the Q & A session.

We continue to be grateful to our speakers who shed much needed light on relevant topics within our NF community. Tune in one Tuesday per month at 12:00pm EST via Zoom. Our Spring 2024 series is listed on our website at www.nfnortheast.org and on our NF Northeast Facebook events page. We hope you can join us for one or all!



Leah and her service dog, Dasher Manth, attending graduation and receiving a Master’s in Social Work from Roberts Wesleyan University



TRULY PRICELESS WORDS FROM A PROUD AND GRATEFUL MOM, THERESA OWHADY

A WEEKEND AT DOUBLE H RANCH!

I know I'll never be able to find the words to fully describe the impact of Double H Ranch's adaptive winter sports family weekend. I also recognize it will be difficult to properly thank the countless individuals who made this all possible. I want to try though,

because this experience was —without exaggeration— life-changing.

I'm writing through tears as I think about how Olive was taught to ski by the most considerate and caring teachers, who understood that she would learn differently, and adapted their approach for her very specific needs. A child's dream-come-true of hot chocolate, slime, glitter, and laughter awaited Olive, while the opportunity to really, truly relax and focus on myself on the slope was given to me. Such a gift to both of us.

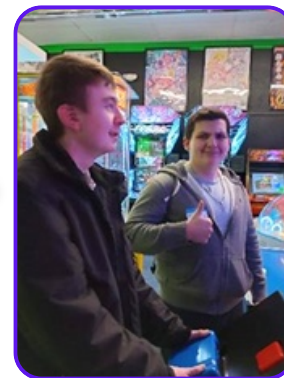


Olive with her mom, Theresa, heading out to the slopes!

We wrote about Double H Ranch (Health and Happiness co-founded by Charles R. Wood and Paul Newman) in our last newsletter. Located in the picturesque woods of the Adirondacks in Lake Lucerne, NY, Double H is a year-round camp focused on children and their families who are dealing with life-threatening illnesses. NF Northeast is pleased to offer a limited number of scholarships at Double H this summer as well as other camp offerings. We will host a camp information session on Tuesday, March 19 from noon-1:00pm. For more information, please contact Anne Patterson at apatterson@nfnortheast.org.



VIDEO GAMES ABOUND!



NF Northeast hosted a free Kids/Teens Video Game Social at Game Underground in Waltham, MA, in January. Special thanks to Deniro Bruno for creating the artwork for the poster.

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 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 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) & Schwannomatosis (SWN)

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



Follow us on social media!



UPCOMING EVENTS

- **MARCH 7** Kids Empowerment Workshop “Improv as a Confidence Builder,” Quincy, MA
- **MARCH 8** Pickleball, Walpole, MA
- **APRIL 27** Steps2Cure NF Hartford, CT
- **MAY 4** Steps2Cure NF Greater Boston, Wakefield, MA
- **MAY 5** Steps2Cure NF Capital District, Schenectady, NY
- **MAY 11** Steps2Cure NF Western New York, Buffalo, NY
- **MAY 11** Steps2Cure NF Camden, NY
- **MAY 18** Steps2Cure NF Greater NYC/NJ, Ridgefield Park, NJ
- **MAY 19** Steps2Cure NF Greater Philadelphia, Norristown, PA - **NEW THIS YEAR!**
- **AUGUST 18** ASICS Falmouth Road Race 2024, Falmouth, MA
- **SEPTEMBER 7** Coast to Cure cycle event, Gloucester, MA
- **SEPTEMBER 16** Fall Golf Classic, Dracut, MA
- **OCTOBER 19** Margaritaville, Boston, MA
- **NOVEMBER 9** Committed to Curing NF, Malden, MA



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