



NF NEWS

NEUROFIBROMATOSIS NORTHEAST

Promoting Research, Awareness and Advocacy since 1988

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An Aspiring Dentist Struggled with Debilitating Pain Finally, the Diagnosis of Schwannomatosis

Tina's journey with schwannomatosis started during her endodontic residency at the age of 35 when she sought medical attention for a large growth under her mandible. After seeking a diagnosis from many physicians and undergoing unsuccessful painful needle aspirations and a multitude of tests, it was then decided that surgery was the only option, as they were suspecting a malignancy. A few days after the surgery she learned that it was a schwannoma - about the size of a golf ball.

With much relief that it was "nothing serious" she went on to graduate with her Masters in Endodontics and moved back to Maine to work in a private practice with aspirations of opening her own practice one day.

Slowly she started developing pain in her right arm. She had another tumor deep in the muscle in the upper portion of her humerus. After it was surgically removed, the biopsy result was another schwannoma. But this time the pain didn't completely subside. It

slowly grew in intensiveness - seeming to speed up and grow more painful throughout the months she was pregnant with her son. Soon the pain was traveling to her hand and back. She sought the help of multiple physicians and neurologists, again looking for answers. She was told all along that she had carpal tunnel syndrome - a common problem among practicing dentists. Knowing deep down this was not accurate, and with her pain increasing, she found Massachusetts General Hospital's website and that there was a clinic for NF and schwannomatosis patients and their families. She immediately made an appointment.

She was told all along that she had carpal tunnel syndrome - a common problem among practicing dentists.



Dr. Tina Kell

Her pain had gotten to the point where she couldn't rest her back on anything - a bed, soft chair or even a car seat. She would rock herself uncontrollably to help take her mind off the pain. Unbeknownst to her she had a tumor at the nerve root of C7 in her neck. She was told by one surgeon that the tumor could be removed but it would likely paralyze her arm leaving her unable to practice. Knowing paralysis would be the end of her new

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Resiliency for NF Study a research project to enhance stress and symptom management *Are you feeling stressed? Are your NF symptoms bothersome?*

The Family Center for Neurofibromatosis and the Integrated Brain Health Clinical and Research Program (IBHCRP) at the Massachusetts General Hospital are conducting a research study to compare 2 programs that teach stress and symptom management skills for adult patients (18 and older) with NF1, NF2, or schwannomatosis. They are testing 2 resiliency programs, both delivered via video in groups, to see which one works best in improving quality of life, well-being, anxiety, depression and pain. Group times are flexible and folks can participate from the comfort of their home using Vidyo, a secure software program. No travel is involved, and no medication is involved.

Please see their video - <https://www.youtube.com/watch?v=waJitGPAkgM>. You can also feel free to reach out to the Principle Investigator of the study, Ana-Maria Vranceanu, PhD at avranceanu@mgh.harvard.edu.

The Department of Defense is paying for this study, and NF Northeast is providing additional funding over the next two years. A study involving adolescents will be announced shortly.

A change in leadership will be coming to NF Northeast in 2020. See Karen Peluso's message on page 2.

The mission of

Neurofibromatosis Northeast is to find treatments and the cure for neurofibromatosis by promoting scientific research, creating awareness, and providing hope and support to those who are affected by NF.

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 **Beauty Mark Nation**
 United to Cure Neurofibromatosis
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#The word is
NEURO-FIBROMA-TOSIS

2020 Will Bring New Leadership to NF Northeast

A Letter From Executive Director, Karen Peluso

Dear Friends,

I am writing to tell you that after much thought and consideration, I will be stepping down as executive director of Neurofibromatosis Northeast in 2020.

It has been my honor and privilege to serve as the executive director of this highly regarded and very effective organization within the neurofibromatosis community. I am proud to have played a part in building the organization's reputation earned over 30 years by a succession of dedicated board leaders, volunteers, and talented and hard-working staff.

I am confident that the board and staff will find a dynamic, new leader who can build on the strong foundation that we have built together. I will continue to work alongside the board and staff until mid-2020 and assist in finding a successor to take on the executive director role. Our organization is well-positioned for growth and the time is right for new leadership.

This is definitely not goodbye! I am not retiring from the fight to find effective treatments for neurofibromatosis. I will be an advocate for research for as long as I am able. I hope you will continue your support for this incredible organization and continue to fight with me.

I have loved this job and I am grateful for what we have achieved. It wouldn't have been possible without wonderful partners like you. Thank you for your guidance, friendship and support.

Sincerely,

Karen Peluso



With Your Support Neurofibromatosis Northeast Has Impact!

Projects and studies currently being funded:

Vijaya Ramesh, Ph.D., MGH Center for Genomic Medicine - NF2

Ana-Maria Vranceanu, Ph.D., MGH - Resiliency Study

Emilie Doucet, Ph.D., Inserm Occitanie Mediterranee, Montpellier, France - NF1

Partnered with NF Network to produce the NetworkEdge, a summary of NF research and trials

Clinic Care Grant to Albany Medical/Melodies Center NF Clinic

Grant for NF Education Liaison at Boston Children's Hospital

15 College Scholarships awarded to students with NF

Grant to Brainy Camps for Camp New Friends sponsorships

CLINIC & PATIENT SUPPORT

Meetings and symposia:

Global Genes - RARE Drug Development Symposium in Philadelphia

NF2 BioSolutions Gene Therapy consortium in Boston

Boston Children's Hospital NF Symposium

NF Northeast Board Chair, Lori Ryan, R.N., M.S. was

moderator of MassBio's "Power of the Patient" Program

Rare Disease and Orphan Products Breakthrough Summit in Washington, DC

Memorial Sloane Kettering, NY - Lecture on peripheral nerve sheath tumors

Plastic Surgery Conference, NYC - dermal and plexiform tumors

RESEARCH

AWARENESS

Advocacy is one of the most important ongoing programs of NF Northeast, and our efforts have paid off! Working closely with the House and Senate we've helped secure over \$600 million for NF research between the NIH and DOD.

NF Network Advocacy Program



Leadership Council

Members of
REINS
 International
 Collaboration



Response Evaluation in
 Neurofibromatosis and
 Schwannomatosis

2019 Scholarship Recipients

NF Northeast offers college scholarships for individuals who have neurofibromatosis and are continuing their education after high school. The annual deadline for applications is April 15th. Applicants must live in or attend a college in the northeast (Massachusetts, Connecticut, Rhode Island, New Hampshire, Maine, Vermont, New York, New Jersey and Pennsylvania). This program was established with funds raised at the Steps2Cure NF road races and walks.



Benjamin Aliber
from Massachusetts, will attend Westfield State as a freshman



Nathanael Batson
from Maine, will attend University of Maine as a freshman



Tallulah Becza-Levitt
from New Jersey, will attend Drexel University as a freshman



Zoe Comiskey
from New Jersey, will attend Millersville University as a freshman



Victoria Dalton
from Massachusetts, will attend Southern New Hampshire University as a freshman



Miguel DeGrazia
from Massachusetts, will attend Quincy College as a junior



Charles Eisenstadt
from Massachusetts, will attend Mitchell College as a freshman



Angelo Gabbia
from New Jersey, will attend Kean University as a junior



Celia Livolsi
from Massachusetts, will attend Johnson and Wales University as a sophomore



Timothy McKelvey
from Massachusetts, will attend University of Denver as a freshman



Karynna Munoz
from Massachusetts, will attend Emmanuel College as a freshman



Cassidy Nicholson
from Pennsylvania, will attend DeSales University as a sophomore



Christine Panza
from New Jersey, will attend Northeastern University as a sophomore



Joshua Patterson
from New York, will attend CUNY School of Professional Studies as a junior



Caitlin Stokes
from New York, will attend Manhattanville College as a freshman

NF Symposium at Boston Children's Hospital



Diana Flahive, Jenny McDonald, Karen Peluso and Anne Patterson

NF Northeast was proud to sponsor the symposium on March 30th. Diana Flahive and Anne Patterson represented NFNE during the program and gave an informative presentation, and Jenny McDonald hosted the NF information table. We also provided a display of portraits by Rachel Mindrup from her collection "Many Faces of Neurofibromatosis". Learn more at rmindrup.com.



B the Difference is a non-profit foundation formed to support individuals with NF and their families through the B Happy program. B Happy sends selected recipients (age 13 to 30) and their families on a five day all-expense paid vacation to locations around the United States. Self-referrals or referrals from immediate family members are not eligible. Visit their website at bthedifference.org, or contact the NFNE office.

Increasing Awareness of Neurofibromatosis

May is **NF Awareness Month**, and Governors and legislative leaders throughout the Northeast met with patients and families and signed official Proclamations.



Rhode Island Governor Gina Raimondo signed a proclamation and spent time to learn about NF and the unmet needs of patients and families



Governor Chris Sununu of New Hampshire even wore his Beauty Mark Nation socks to help increase awareness of NF



Mira, Rachel and Amit Sakofs received the proclamation from New Jersey Governor Phil Murphy



Suzanne, Jesse and Jesse Hunsberger display the proclamation signed by Pennsylvania Governor Tom Wolf



Isaak DePelteau (I) and Ilya Layton represented both the NF1 and NF2 communities at the Rare Disease Day Program at the New Hampshire Senate



Alan Abreu and his family met with Dr. Yvonne Spicer, Mayor of the City of Framingham, MA, who proclaimed May 17, 2019 as World Neurofibromatosis Awareness Day in Framingham

New York, Pennsylvania and New Jersey - Have you met Anne?

Anne Patterson is NFNE's Outreach Coordinator in NY, PA and NJ and has a large area to cover. Along with being our contact person for NF patients she meets with clinicians and specialists throughout the region. Anne is working with the NF team at the **Albany Medical/Melodies Center**

to plan a symposium on November 2nd. She is available once a month to meet with patients at the **NF Clinic at Oishei Children's Hospital in Buffalo** and helps organize fun outings including NF Night at the Buffalo Bandits. In New York City she met with Dr. Anna Piotrowski at **Memorial Sloan Kettering** (at left) while attending her lecture on NF and Dr. Robert Spinner's lecture on peripheral nerve sheath tumors. They discussed how NFNE can help grow

the NF Clinic at MSK. She participated in the **NF Surgery Conference** in NYC hosted by Dr. Andres Panossian, Plastic and Reconstructive Surgeon, where the focus was on removal of dermal and plexiform tumors. Anne helps plan and attends NF walks and gatherings around the region including the recent **NF Clinics Association of Pittsburgh** walk in Presque Isle (pictured at right). If you live in the Tri-State area and need information about NF or want to become more involved in the community contact **Anne Patterson** at apatterson@nfnortheast.org.



New York State Senator Jim Tedisco met with families and presented an NF Awareness Legislative Resolution

Fighting NF at Fenway

Congratulations to Michelle Hirsch Donovan and Melissa White who organized **NF Night at Fenway Park**. Over 250 members of the NF Northeast Community came out to the Boston Red Sox game on May 14th to cheer on our home team as well as NF Advocate and Colorado Rockies #20, Ian Desmond. "Desi" met with the neurofibromatosis group and took photos and signed autographs. We thank him for his ongoing support of NF research and awareness!



Michelle, Desi and Melissa



NF Northeast Welcomes New Board Member



Rob Klouda and his family are very familiar with neurofibromatosis. Rob's brother, Richard, was diagnosed with NF1 in 1987 while they both attended Northeastern University. Sadly, Richard passed away on August 10, 2017 at the age of 52 due to complications from his NF. Before he passed away, Rob helped his brother start a blog about living with NF and purchased the domain www.nfnortheast.org as a platform to share the blog. Unfortunately, the blog was never completed, but Rob and his family generously donated the domain name to NF Northeast, and the website is now the home to the online presence of NFNE.

Rob has become an active member of the NF Northeast community. An avid golfer, he has supported our ongoing tournaments, and is now on the steering committee for the "Driving Out NF" Golf Tournament to be held in Glastonbury, CT. He hosted a fundraiser to help launch a new NF clinic at Yale New Haven Hospital and is a staunch advocate for federally funded NF research.

Professionally, Rob is a Regional Sales Manager for Zscaler, a global cloud-based information security company that is listed on the NASDAQ.

Rob earned his BSEE from Northeastern University, and resides in Branford, CT with his wife Christin.

Tina Kell continued from page 1 practice and she would be unable to hold her newborn son, and unable to pay back her astounding student loan or to provide for her family, she sought out another opinion by a different neurosurgeon. Dr. Jean-Valery Coumans compassionately listened to her and took into consideration all that she had worked for and gone through. He put a plan in place that would have a good chance for a full recovery with a little luck, a lot of his skill and even more praying. He was able to decompress and devascularize the tumor since removing it completely would have rendered her right arm almost unusable. After several months of rest and with the help of family and friends, Dr. Tina Kell made close to a full recovery. She still has times where she experiences pain due to neuropathy, but certainly not to the same level or quality.



Shannon, Chance and Tina

To date she has had 3 tumors removed and knows that her C spine is speckled with schwannomas as well as a few other smaller ones in her extremities. Every day she struggles with the pain inflicted upon her by these tumors as well as the fear that she may have passed this on to her son. Still throughout all this she persevered and opened up her own endodontic practice in Maine. She owes so much to God and the constant support of her loving husband Shannon, her son Chance and the wonderful team of physicians that have aided her through this journey.

Schwannomatosis affects approximately one in 40,000 people and is genetically and clinically distinct from NF1 and NF2. Like NF2, Schwannomatosis is located on chromosome 22 but is distinguishable from NF2 in that people affected by this condition do not develop tumors on the hearing nerves (vestibular nerves). Schwannomatosis causes tumors (called schwannomas) to grow on the spine and on peripheral nerves throughout the body. It is recognized most often in people over the age of 30. Schwannomatosis can cause severe, debilitating pain and neurological dysfunction. For some people, it is not easy to identify the cause of the extremely intense pain they experience. Other symptoms that may be experienced include numbness, tingling, or weakness due to nerve or spinal cord compression.

NF Northeast Annual Sponsor Program

Companies make one annual donation and provide support and participate in many events!

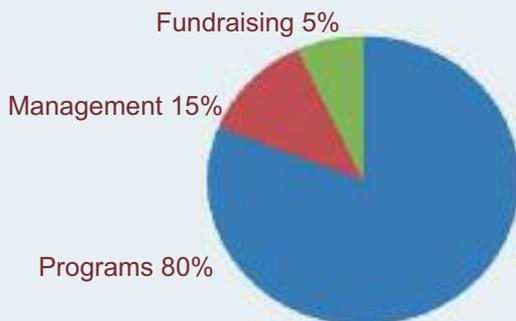
Why not give it a try?



When you give to NFNE this is where your support goes

The Programs of NF Northeast are:

- Promoting and funding NF research
- Creating awareness of NF
- Providing hope and support to patients and families



Source - NF Northeast Audited Financials

Become a **Sustaining Giver**
Join others who make a regular monthly donation to NFNE through their credit card. It is convenient, and a little each month adds up to a lot in a year!

Making a difference in the fight to cure NF...



Teddy Lee



Scot DeDeo

Our many thanks and congratulations to Teddy Lee of Hingham, MA and Scot DeDeo of Belmont, MA for running the **Boston Marathon** on Monday, April 15th while fundraising and spreading awareness of neurofibromatosis. Both men ran in honor of their children with neurofibromatosis.

On April 3rd, NF Northeast celebrated the 20th Annual **Table for TEN** dining event in Boston with Honorary Chair Dan Andelman, host of Phantom Gourmet. Diners enjoyed a three-course meal at twenty-three of Boston's best restaurants and then gathered at the University of Massachusetts Club to feast on desserts donated by Montilio's Bakery. Guests enjoyed live music by Ancient Mysteries plus silent and live auctions. During the evening, special recognition was given to John Foster and Michelle Sceppa from **Apex New England Construction** - the Presenting Sponsor of Table for TEN.



Karen Peluso with John Foster and Michelle Sceppa



4th Annual Hats, Horses & Hope

On May 4th Melissa White and 130 of her closest friends and NF Northeast supporters cheered on the Kentucky Derby – one for the history books! Well-dressed and stylish guests feasted on a BBQ dinner, enjoyed silent auction items and raffles and participated in contests such as best hat and best dressed couple!



May 11th was a perfect spring day for the **First Responders Fight NF2 Walk** in North Tonawanda, NY. Family and friends of Leah Manth came together to coordinate this unique walk where first responder vehicles were on display from 10 local fire departments! Over 100 walkers enjoyed the walk, basket raffle and delicious BBQ lunch.

2nd Annual NF Night at the Buffalo Bandits Game

On March 21st, NF Northeast, OCH and the Buffalo Bandits Lacrosse collaborated to host a special night. Over 40 people attended this fun event that included a pizza party, special visits from the Bandit players, cheerleaders and mascot, in addition to an exciting lacrosse game!



On June 19th, the **34th Annual NF Golf Tournament** took place at the International Golf Club with golfers on both the Oaks and the Pines courses. The success of this event would not be possible without the longstanding support and generosity of Presenting Sponsor **Grand Circle Corporation**, the many corporate sponsors, volunteers and the dedicated golf committee led by Chairperson Steve Picardi. New England Patriots great Rob Ninkovich joined us as Honorary Chairperson and is pictured at right with Corporate Sponsor, Maria DeFrancesco and her first place winning team (Oaks Course). Following golf, Tony V provided comedy during the fabulous banquet. It was a great day for golf and a great day for NF!



Awareness is Key - Once again Bill and Kim Palmer gathered friends and family for a night of laughs on June 8th at the 5th Annual Awareness Is Key Comedy Night. Local comedians such as Dave Rattigan and Mike McDonald (at left) took the stage at the American Legion in Raynham, MA and entertained the crowd. A last minute addition to the program was Arnie Bearak, a member of our NF community making his comedy debut! Guests also enjoyed a BBQ feast and great raffle items!

Steps2Cure NF

Is there a Steps2Cure NF walk in your area? If not, perhaps you would like to start one!



The 6th Annual Steps2Cure NF Walk in Camden, NY: The dedicated efforts of the Metott and Nobis families made for another successful day. This event continues to grow each year, and over 100 walkers enjoyed the scenic trails in Forest Park all while raising awareness and research funds for neurofibromatosis.



Wakefield, MA: Over 200 NF patients, supporters and friends came out to celebrate May NF Awareness Month and the **13th Annual Steps2Cure NF Walk and 5K Run** on May 11th. In addition to the popular Kid's Dash, a 5K officially timed race and the walk around Lake Quannapowitt everyone enjoyed hot dogs, meatball sliders and many refreshments. We thank Antoinette Antonio of WCVB TV5 who joined us as MC and who also filmed a Wake-Up Call about neurofibromatosis for the morning news.

Did you know NF Northeast raises 70% of its revenue at events?

Events serve many purposes:

- * they help fuel our mission to cure NF
- * they increase awareness of NF
- * they bring our community together in a caring and supportive environment, and that's a good thing!

Do you want to meet other patients and families who are living with NF?

The NF Families and Community Committee's mission is to create local communities of peer support among NF patients and their families throughout the northeast.

Recent gatherings have taken place at a cafe in Rochester, NY, Kidz Planet in Norwell, MA, a yogurt shop in Glastonbury, CT, and shown at right, a group in Hoboken, NJ where new friends were made!

Watch the NFNE website and Facebook for information about these informal get-togethers, or contact **Alex Cellucci, Committee Chair at Apowers54@gmail.com.**



IN MEMORIAM



Justin Dwight Evans
March 29, 1977 - April 21, 2019

Justin's smiling face was a familiar sight at many NF events where he would volunteer and help in any way he could. He never talked about the many challenges he had to face because of NF, instead he lived a life of giving and teaching others to be kind.



John James Sullivan
December 24, 1974 - April 5, 2018
John was known for his positive outlook on life and his incredible perseverance. Despite limitations and pain, he participated in marathons and NF walks. He pushed himself beyond perceived capabilities to raise funds and increase awareness of NF.

ARE YOU GEOCACHING ??

The NF Northeast Travel Bug Bracelet is on the move. It has travelled from Utica, Rochester, Hemlock Lake and most recently in the Thousand Islands, NY. If you would like to follow or locate this geocaching



Travel Bug, search:

<https://coord.info/TB8JNNC>



Save the Date - October 7th
Connecticut will be Driving Out NF!



9 Bedford Street
Burlington, MA 01803

NEUROFIBROMATOSIS
NORTHEAST

return service requested

Upcoming Events *Why so many events? See page 7.*

Steps2Cure NF Walk & NF Families and Community Picnic, Central New York, at Green Lakes State Park, Sunday, July 28th

Cruising with Motown for NF, Marina Bay, Quincy, MA, Saturday, August 17th

The NF Team runs the Falmouth Road Race, Sunday, August 18th

Western New York Steps2Cure NF Walk at the Stohrer's Lodge at Emery Park in South Wales, NY, Saturday, August 24th

Coast to the Cure NF Bike Ride starts and finishes at Stage Fort Park in Gloucester, MA, Saturday, September 14th

Clubbing for Caden, Brockton Country Club (MA), Saturday, September 14th

Fall Golf Classic, Four Oaks Country Club, Dracut, MA, Monday, September 23rd

Steps2Cure NF Walk - at the Crossings of Colonie, South Pavilion in Loudonville, NY, Saturday, October 5th

Steps2Cure NF Walk - at Rotary Park in Putnam, CT, Saturday, October 5th

Driving out NF Golf Tournament, Glastonbury Hills Country Club, Glastonbury, CT, Monday, October 7th

Committed to Curing NF at Anthony's of Malden, MA, Saturday, November 2nd

more information available at nfnortheast.org

**#The word is
NEURO-FIBROMA-TOSIS**

**Stock up on your
NF Northeast gear!**
visit the Merchandise Shop
at nfnortheast.org



*Tshirts,
Sweatshirts,
Hats, Socks
and more!*



Save the Date
Saturday, November 2nd
9:00 AM - 1:00 PM
Albany NF Symposium
Albany Medical School
Sponsored by NF Northeast