

NF NEWS

NEUROFIBROMATOSIS, NORTHEAST

Promoting Research, Awareness and Advocacy since 1988

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Fall 2011

Raising Funds *and* Fueling Our Mission



Michelle and Mike Donovan celebrate at the finish line with their children Shea and Riley

“Coast to the Cure” Bike Ride

Five years ago Miguel and Andres Lessing and twelve friends, all of whom were united in their passion for cycling and their commitment to NF, set out from Woods Hole. Eighty miles later they arrived at their destination, Provincetown. Fast forward to this year, Miguel and Andres' vision still in tact, the bike ride relocated to the North Shore. Nearly 100 riders strong set out under sunny skies from Crane Beach in Ipswich, travelling one of three routes (36, 68 or 100 miles) while raising funds for NF Northeast. Michelle Donovan was the highest

fundraiser. New to cycling, Donovan also had the distinction of riding the longest distance - 102 miles! A post ride barbeque was held at the picturesque Steep Hill Beach on the grounds of the Crane Estate. Coast to the Cure 2012 will take place on Saturday, September 8th.

Promoting Federally Funded Research

Shown at right are members of the National NF Coalition during their visit to Capitol Hill. We need your help to continue federally funded NF research! Please write to your Member of Congress today. Everything you need, including a sample letter, are in our Advocacy Toolbox at www.nfincne.org



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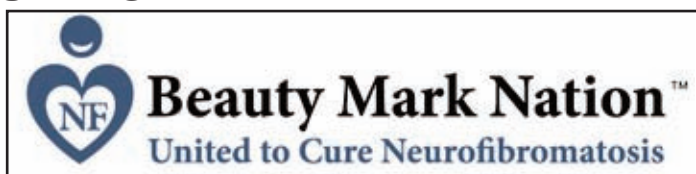
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The mission of Neurofibromatosis, Northeast is to find treatments and the cure for neurofibromatosis by promoting scientific research, creating awareness, and providing hope and support to those who are affected by NF.

INTRODUCING....



details inside

Neurofibromatosis, Northeast

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Advocates for NF Research... *Promoting, Funding and Participating*

Lovastatin Clinical Trial for Learning Disabilities Moves into Phase 2

Results from the Phase I study (Safety Evaluation) with the drug Lovastatin has shown that this medication can safely move onto the next phase of testing. The study was led by Maria T. Acosta, MD, a pediatric neurologist and researcher at Children's National Medical Center in Washington, D.C. Lovastatin was given to 23 children at various doses and it was found that the drug was tolerated very well, even at the highest dose. This drug has been used for years by adults and children as treatment for hypercholesterolemia. Animal models of NF1 demonstrated that Lovastatin improved learning deficits in mice with NF1 genetic defects. This study's results lead researchers to test the drug in humans with NF1

"While we originally set out to determine the safety of Lovastatin in NF1 patients, we also saw statistical improvements in memory and visual attention"

with the hope that it could also help with their learning disabilities. The results have been published in the journal *Pediatric Neurology*. "While we originally set out to determine Lovastatin continued on page 7

[Learn more about clinical trials at www.clinicaltrials.gov](http://www.clinicaltrials.gov)

US Conference on Rare Diseases and Orphan Products

Written by Lori Ryan, NFNE Board Member and Chair of the Medical and Science Committee

Promoting research, awareness and advocacy is at the heart of what Neurofibromatosis Inc., Northeast does. With that in mind, I recently attended the 1st Annual US Conference on Rare Diseases and Orphan Products with Kim Bischoff, Executive Director of the NF Network. The conference was organized by the National Organization for Rare Diseases (NORD) and had participants and speakers from the Food & Drug Administration (FDA), National Institute of Health (NIH), pharmaceutical/biotech industry, researchers, patient organizations, and other relevant organizations. This forum focused on orphan products (drug) research, development and access for rare diseases, as NORD Conference continued on page 7



Congressionally Directed Medical Research Program (CDMRP)

The Neurofibromatosis Research Program (NFRP) was established within the CDMRP in 1996. Since that time, more than \$230 million has been managed by the NFRP in an effort to decrease the clinical impact of NF. Over its 15 year history, the NFRP has invested in key initiatives to support the development of critical resources, sponsor multidisciplinary collaborations, bring talented investigators into the field, and promote the translation of promising ideas into the clinic. The innovative vision of research at the CDMRP integrates the experiences of Consumers and the Scientific community in the funding review process.



Jerry Patterson

Two representatives from Neurofibromatosis, Northeast, Andres Lessing and Jerry Patterson, recently served as Consumer Reviewers. They were full voting members along with prominent scientists at meetings to help determine how the \$16 million appropriated by Congress for FY2011 will be spent on neurofibromatosis research. There were 83 neurofibromatosis research applications reviewed for FY2011 funds.

As someone living with NF1, Andres Lessing knows the importance of moving science forward. "I am on the panel representing all individuals with NF, my goal is to ensure that the funds available are used for the

best possible research studies" says Andres.

NF Consumers are involved in all aspects of the review process. They add perspective, passion, and a sense of urgency that ensures the human dimension is incorporated in the program policy, investment strategy, and research focus. They read and evaluate research study applications for relevance to the consumer community's needs and concerns and actively participate in peer review panel discussions.

Jerry Patterson's eleven year old granddaughter was diagnosed with NF2 three years ago and this is his second year of participation on the panel. Jerry reflects "Serving on the panel as a Consumer Advocate was truly rewarding and enriching. The NFRP is such a unique program, bringing together NF families, scientific reviewers, and the front-line researchers, all united in the quest to find a cure for neurofibromatosis."



Andres Lessing

Raising Awareness

Beauty Mark Nation is Born!

To generate global awareness and a “buzz” around NF, the Beauty Mark Nation is rising up and joining forces to make a difference because – NF patients do matter and have stayed in the shadows for too long.



Just as those who know and love cancer patients will shave their own heads in solidarity and support of their loved ones in treatment, those who know and love NF patients will be encouraged to show their solidarity and support by donning beauty marks—temporary tattoos, face paint, body paint, “war paint”.

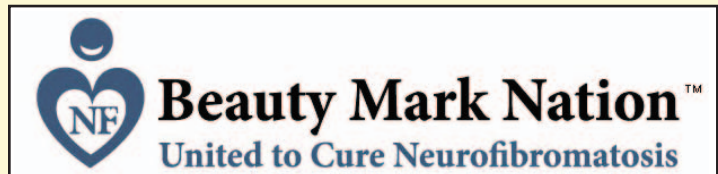


Beauty Mark Nation will be omnipresent at NF walks, golf tournaments, bike rides and even at fine dining events! It will command public attention, challenge public perception and create a high degree of visibility for the NF cause. This bold commitment will ultimately bring us closer to the cure for NF!



We invite you to become a card carrying member of Beauty Mark Nation at www.beautymarknation.org

And, please “like” the Beauty Mark Nation Facebook page!



May is NF Awareness Month



Governor Lincoln Chafee of Rhode Island



Governor John Lynch of New Hampshire

Governors throughout the Northeast signed proclamations declaring May as Neurofibromatosis Awareness Month and met with members of the NF Community to show their support.



Wheelabrator Golf Tournament

NF, Northeast thanks Wheelabrator Technologies for once again choosing NF to be a beneficiary of their annual golf tournament. Always well attended and lots of fun, Wheelabrator employees Manny Da-Costa and Steve Cacciola, shown with NF Northeast Founder, Bert Peluso, are the organizers of the event held at Hillview Golf Course.



13th Annual Fall Golf Classic

A brief downpour just as golfers took to the course didn't dampen the spirits of the 143 individuals who played in the 13th Annual NF Fall Classic. The popular and enduring event relocated this year to the Black Swan Country Club in Georgetown, MA. Following their round of golf, participants were treated to a delicious Italian themed dinner. The banquet included awards, raffles and a live and silent auction. Next year's date is Monday, October 1, 2012.

Golf-a-thon for NF

Eight golfers representing NF teed off at dawn and played til dusk to complete 54 holes of golf (three rounds) in one day. They participated in the Golf-a-Thon at Ferncroft Country Club and secured pledges on behalf of NF from their family and friends. Playing in the marathon day of golf were: l to r, Dave D'Amico, Toby Ahern, Steve Picardi, Michael Picardi, Manny Carco, John Driscoll, Larry Perreault and Karl Russo.



26th Annual International Golf Tournament

As usual, both courses at The International GC were full of golfers who came out to support NF.

Along with a great day of golf and a fabulous banquet, guests were treated to performances by talented comedians Lenny Clarke, Tony V, Graig Murphy (at left with agent Mike Clarke) as well as the hilarious Paul D'Angelo. Sports personality Bob Lobel introduced Fabiola LeColst who made an impassioned plea for Camp New Friends sponsorships. Shown in the photo with Honorary Chairpersons Dwight and Susan Evans are Fabiola, her son Stephan and husband Doug. NF thanks Presenting Sponsor, Grand Circle Travel for their commitment to the success of the event.



Donato Frattaroli, owner of Lucia Ristorante, and Jenny Johnson, Producer of NECN's TV Diner, were the Honorary Chairs of Table for TEN on April 6, 2011. Twenty five of Boston's most exclusive restaurants participated in the fine dining event and provided a three course meal for a table of ten diners while the Martignetti Companies supplied the wine. Following their dinner guests reconvened at Parris in Faneuil Hall Marketplace for entertainment, a silent auction and a divine dessert reception catered by Montilio's Bakery. Shown to the right of Donato and Jenny is Ron Della Chiesa the emcee of this truly enjoyable evening. Please plan on joining us at Table for TEN on Wednesday, April 4, 2012.



Boston Marathon



NF, Northeast has had a team running in the venerable Boston Marathon since 1988. In April nine individuals representing NF completed the marathon and raised pledges for NF research. Don White, on left, led the pack in fundraising in

his first year as a member of Team NF. Way to go, Don! Pictured at the finish line are Jeff Brown and Matt McGonagle. If you are interested in running for NF in the Boston Marathon on April 16, 2012 contact the NF office.



Committed to Curing NF



The Second Annual Committed to Curing NF Dinner Dance was held in November and exceeded all expectations once again! Nearly 600 people packed into Anthony's of Malden, enjoying a buffet dinner, music, a live and silent auction and raffles. It was a fun night to reconnect with old friends and family. Mike and Melissa Malerba organized and hosted the event in honor of their son, Jonathan, who has NF. We are grateful to Mike and Melissa for their exhaustive efforts raising both money and awareness for NF. There is no doubt that Mike and Melissa are committed to curing NF.

Steps2Cure NF

The sun shone on the Fifth Annual Steps2Cure NF held at its new location on Lake Quannapowitt in Wakefield. Over 250 individuals participated making this the biggest field of walkers and runners yet. Team Deniro was the high fundraiser and also looked pretty snappy in their matching red shirts.



Pictured at left is the team's namesake who took time out for face painting. A big shout out to Dean Bruno who provided the event's sound system and music and radio personality Hank Morse, emcee extraordinaire. Congratulations to Lori Ryan the Chairperson and Founder of Steps2Cure NF.



NF Northeast raises 70% of its revenues at events. Events serve many purposes. They raise funds, increase awareness and build community by bringing patients, families and friends together - all while having fun!

NF Steps Out In The Malls

Satellite versions of the original Steps2Cure NF sprung up in two Simon Malls this year. Organized by Naomi Higgins Dias, the two mall events were held at Cape Cod Mall in April and The Mall of New Hampshire in Manchester in October. Providing optimum conditions by hosting the event indoors, this concept extends the life of the walking event into the colder months of the year. Along with many friends and families who turned out to show their support, the Beauty Mark Nation was ever present!

If you would like to organize Steps2Cure NF at your local mall contact Naomi at nfmom.dad@gmail.com



On Memorial Day weekend in Buffalo, NY you will find **the Manth family** amidst a sea of green Run4NF t-shirts. Since 2008, the Manths have had a commanding presence

at the Buffalo Marathon. Eleven year old Leah Manth, who has NF2, is the catalyst for this amazing outpouring of support, and the reason that hundreds of runners and volunteers take to the streets to raise funds and awareness for NF.

The Roche family of New Hampshire are another driving force for NF. When NASCAR is in town they gather family and friends to volunteer at the event in Loudon, NH. In return for the manpower, New Hampshire Motor Speedway makes a donation to NF. Shown at right with her dad is Brittany Roche the inspiration behind this one family's efforts.



There are many ways to increase awareness and raise funds for NF. On these pages are just a few examples.

The Dockside Restaurant in Wakefield, MA offered a Dine for Dollars event with the proceeds benefitting NF. Rosemary Sullivan organized the evening that featured a raffle table chockfull of great prizes, great food and fun. NF received 25 percent of the Dockside's food sales along with the proceeds from the raffle ticket sales. Thanks so much to Rosemary and her daughter, Kerry, for a job well done!

On The Border, Mexican Grill & Cantina, in Woburn, MA designated an NF Night. The restaurant generously donated a portion of the patrons' checks to NF. In addition, the employees had a bake sale that featured lots of delicious, homemade goodies. A tip of the sombrero to NF parent Jill Tozza Feeney for all that she did to pull the event together!

NF, Inc., Northeast accepts vehicle donations. Next day pick-up is possible.



www.nfincne.org

Recycle cartridges and cell phones for NF

We recycle through the FundingFactory. Our ID# is 43816. You or your business can register at FundingFactory.com and provide our ID# as the charity to benefit from your recycling. They will provide the shipping boxes and everything you need to start recycling. There is no cost for you to participate.



NORD Conference *continued*

well as the challenges, opportunities and future strategies. Because Neurofibromatosis is a rare disorder it meets the criteria for an orphan disease and under the Orphan Drug Act, there are incentives for pharmaceutical/biotechs to develop products for rare diseases. It is important that the NF community be represented at these types of conferences to gain knowledge and network to help facilitate NF research. The importance of patient involvement and advocacy was stressed at this conference. Also, highlighted was the need for rare diseases to be “clinical trial ready”, meaning having the infrastructure in place to execute clinical trials, such as having a consortium of clinical trial sites that have the expertise to run the clinical trials, identifying biomarkers and patient outcomes to help in the design of clinical trials, gathering information to better understand the natural progression of the disease, and also developing registries of potential clinical trial participants to facilitate clinical trial recruitment. These are some of the efforts that will make it more feasible for pharmaceutical/biotech companies and researchers to research new and already approved drugs in a rare disease. Recently, there has been significant progress in these areas for NF research and these are areas that NF, Northeast will continue to support and be involved in. Although there are many challenges involved in rare disease research, there is great hope that the current research efforts will change tomorrow’s treatment options for people with NF. The NF community’s voice must be strong and united to advocate and support NF research and to generate change now.

Lovastatin *continued*

the safety of Lovastatin in NF1 patients, we also saw statistical improvements in memory and visual attention, which is a big step towards helping improve our patients’ quality of life and in evaluating biologic agents which may be effective therapies for NF1,” stated Dr. Acosta. “While this is a relatively small study, we now have strong baseline information, and we are working with other institutions in the country and throughout the world to perform a definitive study to replicate these findings on a larger scale.” The Phase II study to evaluate Lovastatin’s effect on attention and working memory in children with NF1 is already underway. The study will be conducted in nine other research centers across the country (as well as one in Australia).

Children’s Hospital Boston is one of the centers conducting the Phase 2 clinical trial and they are currently enrolling participants. Please contact Dr. Nicole Ullrich or Elissa Maunus, study coordinator, for more information at NFClinic@childrens.harvard.edu or 617-632-4595.

Camp New Friends



Shown in her own private plane (thanks to Angel Flight) is Leah Manth from Buffalo, NY. Leah was on her way to Camp New Friends in Mas-

sanetta Springs, VA. Camp offers children and teens with neurofibromatosis (ages 7-15) seven days and six nights of summer fun and social connections. Camp New Friends and all of the camps developed by Children’s National Medical Center’s Brainy Camps serve to reduce the stigma and isolation that is often associated with neurological disorders and chronic health conditions. NF, Northeast is proud to provide scholarships to youngsters to attend Camp New Friends. For more information contact the NF office or www.brainycamps.com

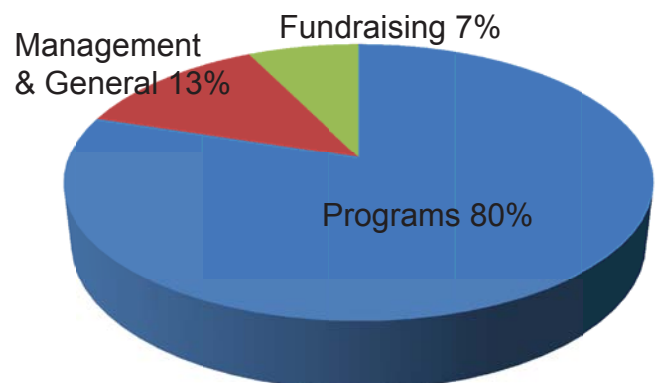
Your NF Funds at Work

The chart below displays our functional expenses for the year 2010.

Programs include; funding of scientific and clinical research, public awareness, advocacy, patient outreach and support, and scholarships for youngsters to attend Camp New Friends.

Please consider making a donation today.

Your support is important to us and goes a long way to help us fulfill our mission.



Creating Awareness and Fundraising Starts at an Early Age....

Innovative youngsters around the region have been raising awareness and funds for NF in their respective communities.

A Girl Scout troop in New York held a yard sale with the proceeds designated for NF.

Aly Reid, a middle school student satisfied her community service requirement by organizing a bake sale held at her school on election day.



The fifth grade at Ambrose School held a Read-a-thon and solicited pledges based on how many pages they read. Twenty different charitable organizations were considered. Following a compelling presentation about NF by David Joseph, John Abbott and Justin Yew, their classmates voted and chose NF, Northeast to receive the funds.



Mary Bertocchi opted to have her tenth birthday celebration at the Steps2Cure NF event. Her invited guests were asked to make donations to NF in lieu of gifts. Led by the event emcee, the crowd serenaded Mary with a rousing rendition of Happy Birthday!

Are you on our email list?

Join our email list to receive updates from NFNE. Sign up on our website. If you would like to stop receiving communications from us, or have any questions or comments, please let us know. We want to hear from you!
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CALENDAR OF EVENTS

a partial listing of what is coming up in 2012

Wednesday, April 4

TABLE for TEN

Monday, April 16

Boston Marathon

Monday, June 18

27th Annual Golf Tournament at The International

Saturday, September 8

Coast to the Cure Bike Ride

Monday, October 1

14th Annual NF Fall Classic Golf Tournament

Saturday, November 10

3rd Annual Committed to Curing NF

NF1 Quality of Life Survey

Are you (or your child) willing to take a survey about NF1 and how it affects your health and well being? The Indiana University School of Medicine needs volunteers because they want to better understand how NF affects your health and well being, and measure how well new treatments for NF are working. They need: Adults with NF1, Parents of children with NF1, and youth 14 years or older with NF1 to answer a confidential survey.

Adults with NF1 go to:

<https://www.surveymonkey.com/s/NF1-Adultsurvey>

Parents of children with NF1 go to:

<https://www.surveymonkey.com/s/NF1-Parent>

Youth 14 years or older with NF1 go to:

<https://www.surveymonkey.com/s/NF1-teen>

THANK YOU FOR YOUR HELP!!

If you'd like to make a contribution to NF in memory of someone, in honor of someone, or for any occasion, we will acknowledge your donation per your instructions.

Secure donations may be made through our website at www.nfincne.org.

Checks are payable to NF, Northeast. Mail to 9 Bedford Street, Burlington, MA 01803