

Neurofibromatosis, Inc., Northeast  
9 Bedford Street, Burlington, MA 01803  
(781) 272-9936 ~ Fax: (781) 272-9937  
info@nfincne.org ~ www.nfincne.org



## Upcoming Events

**Saturday, August 29**  
**1st Annual Witter's Golf Tournament**  
Deerwood Golf Course  
North Tonawanda, NY



**Saturday, September 12**  
**Friends Bike Ride for NF**  
Cape Cod, MA



**Sunday, September 20**  
**Steps 2 Cure NF**  
Horn Pond, Woburn, MA  
*Walk or Run - Individuals and Teams!*



**Sunday, September 20**  
**NASCAR Race - Loudon, NH**  
*A fun day volunteering at the race track!*



**Monday, October 5**  
**11th Annual Golf Tournament**  
Hickory Hill Golf Club, Methuen, MA



**NF Symposium**  
**Saturday, September 26**

*Sponsored by the Harvard Medical  
School Center for NF and  
Allied Disorders  
at  
Children's Hospital Boston*

*Information about all of these events is  
available on our web site - [www.nfincne.org](http://www.nfincne.org)*

## How You Can Help

NF, Inc., Northeast is now accepting vehicle donations! Please call or email the NF office for details.

You can also help by sending in your used inkjet cartridges and toner cartridges for recycling.

If you'd like to organize a fundraiser for us, we can help. Just give us a call!

Thank you!

## Follow Us Online



**Facebook:**  
[causes.com/nf](http://causes.com/nf)



**MySpace:**  
[myspace.com/nfincne](http://myspace.com/nfincne)



**Twitter:**  
[twitter.com/nfincne](http://twitter.com/nfincne)

Neurofibromatosis, Inc., Northeast is a 501(c)3 non-profit organization dedicated to finding a treatment and cure for neurofibromatosis by promoting scientific research, creating awareness and supporting those who are affected by NF.

# NF NEWS

## NEUROFIBROMATOSIS, INC., Northeast

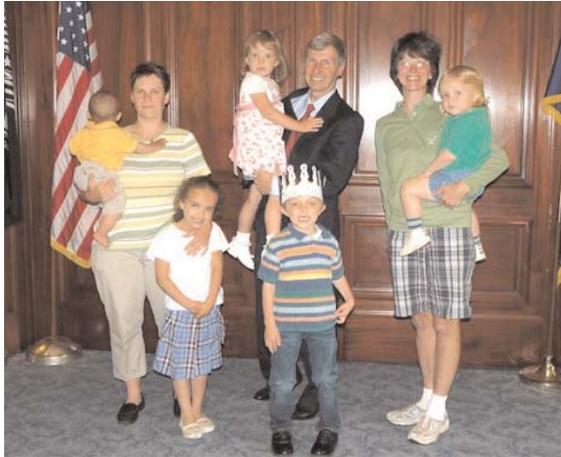
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Summer 2009

### Creating Awareness of Neurofibromatosis



New Hampshire families met with Governor John Lynch for the signing of the NF Awareness Proclamation. From left to right: Oliver, Sandra and Riley Early, Lydia and Wyatt Cramer, Governor Lynch, Dana Zulager and Clayton Cramer

Sheila and Mike Eisenstadt, who are known for their creative "fun-raisers", recently put together another spectacular event. Their Amazing Race was held at the Elm Bank Reservation in Wellesley and included a six-mile obstacle course relay. Following the outdoor activities, the teams and guests celebrated inside the big barn with a late night party complete with great food and music.

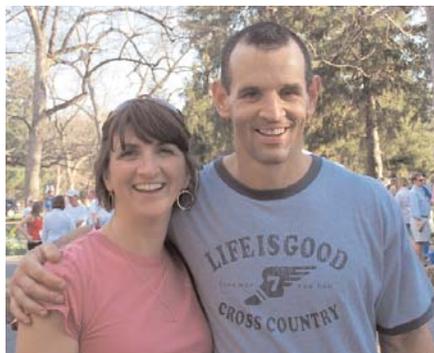
For the second year, the Manth family had a huge crowd of participants and volunteers at the Buffalo Marathon. With over 130 of their friends and family participating, it was a sea of green shirts with big NFs on the front. The Manths are dedicated to raising funds to support NF2 research and have had overwhelming support from their community.



The Manth Family: John, Linda, Leah, Christopher and Erin with Senator Maziarz of New York

Neurofibromatosis is the most common genetic disorder caused by a single gene. NF affects three times as many people as muscular dystrophy and cystic fibrosis combined, *yet many people have never even heard of NF.* We need to change that!

Across the northeast, governors have signed proclamations declaring May as NF Awareness Month and several governors met with local families. In the State of New York, the Senate adopted a Legislative Resolution supporting NF awareness. And in the spirit of the month, families throughout the region planned events.



Sheila and Mike Eisenstadt at The Amazing Race

### NF, Inc., NE - A Good Investment

Our most recent audited financials are available on our website - nfincne.org or at Guidestar.org. They demonstrate that your donation goes a long way to support our programs of research, awareness and providing resources and hope for NF patients.

We recognize our responsibility to the volunteers and donors who give so generously. We continually strive to be worthy of your trust and support by being financially accountable.

The greatest return on your investment will be realized when we have reached our ultimate goal - a cure for NF.

Thank You!

### Promoting Research

Neurofibromatosis, Inc., Northeast has been an advocate for government-funded NF research since 1996. Congress has given the Army's Research Program strong bipartisan support, and from FY1996 through FY2009, the funding amounted to \$200.3 million.

During that time approximately 223 awards have been granted to researchers across the country. NF, Inc., NE Executive Director, Karen Peluso recently submitted testimony to both the House Appropriations Subcommittee on Labor, Health, Human Services and Education as well as the House Appropriations Subcommittee on Defense.



Karen Peluso

**The following is an edited version of the House Defense testimony. Both are available in their entirety on our web site - www.nfincne.org**

**Mr. Chairman:** I speak on behalf of the 100 million Americans who live with NF as well as the approximately 175 million Americans who suffer from diseases linked to NF such as cancer, brain tumors, heart disease, memory loss and learning disabilities.

I am requesting increased support, in the amount of \$20 million, to continue the Army's highly successful Neurofibromatosis Research Program (NFRP), which is now conducting clinical trials at nation-wide centers created by NF funding. These clinical trials involve drugs that have already succeeded in eliminating tumor growth in humans and rescuing learning deficits in mice. Because of the enormous advances that have been made as a result of the Army's NF Research Program, research in NF has truly become one of the great success stories in the current revolution in molecular genetics. Accordingly, many researchers believe that NF should serve as a model to study all diseases.

Research on NF stands to benefit the military because this disorder is closely linked to conditions such as brain tumors, learning disabilities, brain tissue degeneration, nervous system degeneration, deafness, memory loss, and balance. Because NF manifests itself in the nervous system, findings generated by the Army-supported research on NF address peripheral nerve

continued on page

**On these pages, you'll meet volunteers and supporters who help us fulfill our mission, and provide hope to those who are affected by NF. In short, these are people like you, doing what they can to make a difference. We hope you'll enjoy their stories.**

## DEX and the City

The Endicott College chapter of Delta Epsilon Chi (DEX), the national business club for students, raised funds for NF at their 7th annual fashion show on March 4. The theme for the evening was *Dex and the City* and guests also enjoyed a VIP cocktail reception before the show. Catherine Morrissette and Kerry Taylor (shown in photo) organized the event. Julie Gentile, Adjunct Professor at Endicott, made a special appearance to talk about her family's experiences with NF.



## Derek Brown Keeps Running



Derek Brown is still on his mission to run a marathon in every state for NF. In January he traveled to Phoenix with his dad Jeff, his cousin Sarah and Mel Barrett to run in the Rock 'N' Roll Marathon. In April he ran the Boston Marathon with his dad and cousin Hilary Ritter, and in May he joined the Manth family at the Buffalo Marathon.

Watch for Derek as he runs the Baltimore Marathon this fall, and who knows where else he will be crossing the finish line this year!

## Table for TEN

Our 10th Annual Table for TEN event on March 31 was a great success! Michael Dearing of Fleming's was this year's Honorary Chairman. Together with Fleming's and our Gold Sponsors Harold Leach and Mela Lew, we sent 170 diners to dinner at 16 fine restaurants throughout Boston. After dinner, guests convened at the Parris Club in Faneuil Hall Marketplace for an elegant dessert reception courtesy of Montilio's. Our Master of Ceremonies for the evening was Ron DellaChiesa and in addition to the live music, raffle and silent auction, we took a few minutes to introduce our Boston Marathon team, and to honor David Eisenstadt and Mel Barrett (see below).

Two weeks later, our team ran the Boston Marathon, and we're proud to say that every runner finished with spectacular results. Great job, Marathoners!



David Eisenstadt and Melissa Barrett were honored at this year's Table for TEN event. David was named Honorary Marathon Team Captain and Mel was crowned with a symbolic laurel wreath and dubbed Marathon Fundraising Champion. Our congratulations and thanks to these two outstanding volunteers!



Christine Terramane presents Michael Dearing of Fleming's with a commemorative plate for his work as Honorary Chairman.

## NF's Marathon Team

Melissa Barrett  
Ann Bitetti  
Derek Brown  
Jeff Brown  
Tyler Crumley  
Paul Danehy  
Scott Day  
Molly Flanagan  
Cynthia Gerlin  
Shayne Going

Jason Hamilt  
Liz Milner  
Dave Paterso  
Maryellen Re  
Chris Reilly  
Hilary Ritte  
Kelly Robbin  
Ben Rogers  
John Tallari  
Barbara Wip



Scott Day with his sons Max, Anthony and Noah at the finish line.

**GOLF** has introduced many New Friends to our organization! We started the season in June with the **24th Annual International Golf Tournament**, and the **15th Annual Beverly Depot Restaurant Tournament**. The **Wheelabrator Golf Tournament** took place on August 10, and new this year was the **Golf-a-thon** held at Ferncroft Country Club, where golfers (shown below) played 54 holes in one day and secured pledges to raise funds for NF. It was the equivalent of a "golf marathon"!



Save the Date - June 21, 2010  
**25th Annual NF Golf Tournament at The International**  
Join the celebration!



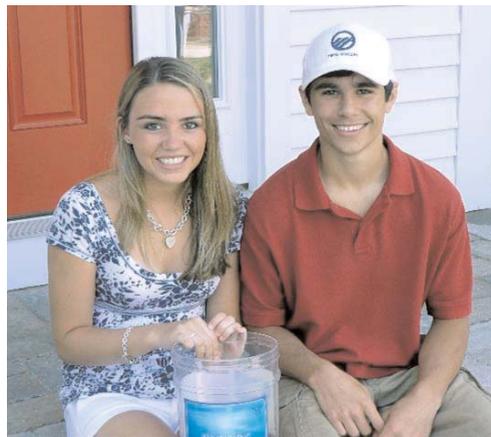
Dwight Evans (center) and Tournament Chairperson Steve Picardi (end right) present (l to r) Mike Dowd, Bob Dine and Joe Cali from Grand Circle Travel with a sponsorship plaque at The International.

# May - Neurofibromatosis Awareness Month

Making neurofibromatosis a household word is an important part of our mission, and we want to give a big round of applause to our friends who helped, especially during the month of May! Governors signed proclamations, Michaela Bero and David Santos organized the 2nd Pennies from Heaven spare change collection day, and the LeColst family, along with Brian Simpson, hosted the 2nd Hair Cut-a-thon at Brian Simpson's Salon and Day Spa. Thank you all for helping to spread the word!



Gov. Baldacci of Maine signs a golf ball (and proclamation!) for Nathanael Batson



Michaela Bero and David Santos prepare for their Pennies From Heaven spare change collection day.



The LeColst family at Brian Simpson's Salon during the Hair Cut-a-thon.

## Promoting Research continued from page 1

regeneration after injury from such things as missile wounds and chemical toxins, and is important to gaining a better understanding of wound healing and war-related illnesses. In addition, NF research now includes important investigations into genetic mechanisms which involve not just the nervous system but also other cancers.

Thanks in large measure to this Subcommittee's support, major advances in just the past few

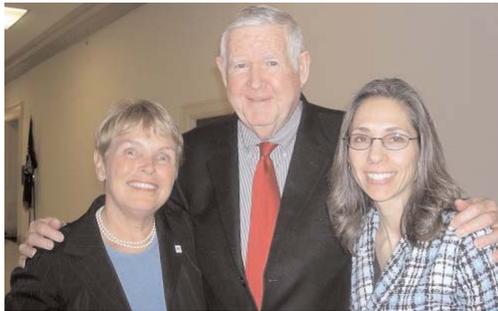
*The program has now advanced to the translational and clinical research stages, which are the most promising, yet the most expensive direction that NF research has taken.*

years have ushered in an exciting era of clinical and translational research in NF with broad implications for

the general population. The program has now advanced to the translational and clinical research stages, which are the most promising, yet the most expensive direction that NF research has taken. The program has succeeded in its mission to bring new researchers and new approaches to research into the field. Therefore, increased funding is now needed to take advantage of promising avenues of investigation, to continue to build on the successes of this program, and to fund this promising research thereby continuing the enormous return on the taxpayers' investment. **Specifically, future investment in the following areas would continue to advance research on NF:**

- Clinical trials; Funding of a clinical trials network to connect patients with experimental therapies;*
- DNA Analysis of NF tissues;*
- Development of NF Centers, tissue banks, and patient registries;*
- Development of new drug and genetic*

## John Murtha - A Friend in Congress



Congressman John Murtha, Chair of the House Appropriations Subcommittee on Defense, with Karen Peluso and Lori Ryan



Members of the National NF Coalition came from around the country to gather in Washington, DC in February to enlist support for NF research

therapies;

*Further development of advanced animal models;*

*Expansion of biochemical research on the functions of the NF gene and discovery of new targets for drug therapy; and*

*Natural history studies and identification of modifier genes.*

Mr. Chairman, leading researchers now believe that we are on the threshold of a treatment and a cure for this terrible disease and with this Subcommittee's continued support, we will prevail.

Thank you for your support of this program and I appreciate the opportunity to submit this testimony to the Subcommittee.

## Camp New Friends



Samantha Cooper and Bryan Pullaro from Connecticut shown with their Angel Flight Pilot, Tom Olson

Camp New Friends took place in Massanutten Springs, VA from July 12-28. All the campers from the northeast were sponsored by generous donors to our Camp Fund, thanks to Angel Flight, they were transported to and from camp at no cost!

Camp provides opportunities for children to build self-esteem, gain independence, establish social connections with other campers and staff who live with NF.



After we got the luggage in the plane, there was still room for David Gould and Dylan Flynn on their Angel Flight to Massachusetts to camp.