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NF NEWS

NEUROFIBROMATOSIS, INC., Northeast

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Volume 22, No. 1

Summer 2010

Upcoming Events

Saturday, September 11
Friends Bike Ride for NF
 Cape Cod, MA

Sunday, September 19
NASCAR Race - Loudon, NH
A fun day volunteering at the race track!

Sunday, September 26
Steps 2 Cure NF
 Horn Pond, Woburn, MA
Walk or Run - Individuals and Teams!

Monday, October 4
12th Annual Golf Tournament
 Hickory Hill Golf Club, Methuen, MA

Friday, November 12
Committed to Curing NF
 Malden, MA
An evening of fun, dancing, great food and prizes

Look inside.....

*You might think that we are just having fun,
 but we are really working hard to cure NF!*

NF Symposium

Sunday, October 24th

**Simches Research Building
 185 Cambridge Street, Boston
 (in the MGH Campus)**

There will be:

- * Updates on research and clinical trials
- * Ask the neurofibromatosis experts
- * Meet other families living with NF
- * Share your thoughts, ideas and experiences...

Information about all of these events is on our web site - www.nfincne.org

How You Can Help

NF, Inc., Northeast is 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 NF, we can help. Just give us a call!

Thank you!

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

"NF Champions" Research Grant



Dr. James Gusella and Dr. Paul Epstein

NF, Inc., Northeast President, Dr. Paul Epstein, announced the NF Champions Grant at the 25th Annual NF Golf Tournament banquet. The grant for \$100,000 was presented to Dr. James Gusella, Director of the Harvard Medical School Center for NF and Allied Disorders (CNfAD) and is in honor of KC Jones, Tommy Heinsohn, Dwight and Susan Evans and Alan and Harriet Lewis (see photos on page 3).

Alan and Harriet Lewis, of Grand Circle Corporation, have been the Presenting Sponsor of the International Tournament for the past 25 years. KC Jones was the first Honorary Chairman and served for seven years. He was followed by Tommy Heinsohn for thirteen years, and Dwight and Susan Evans have been Honorary Chairpersons for the past five years.

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Camper's Testimony Helps Raise Funds

Who better to know the benefits of attending NF camp than a camper? Brittany Roche delivered a passionate plea for camp sponsorships to Camp New Friends at this year's 25th Annual NF Golf Tournament. Brittany once again will attend camp this summer. She took to the microphone and worked the crowd like a veteran performer with Bob Lobel, longtime NF supporter and Boston sports personality, at her side. Camp New Friends is held in Massanetta Springs, Virginia during July. All the campers from the northeast attended at no cost due to the generosity of donors. Camp is a safe haven where kids with NF are accepted in spite of their differences, and it provides an opportunity to make friends with other campers and staff who live with NF.



Brittany Roche and Bob Lobel

The following is Brittany's speech:

My name is Brittany Roche. When I was two years old I was diagnosed with NF also known as Neurofibromatosis type 1. I had radiation on my optic nerve for a tumor that caused me to lose the vision in my right eye. When I was six years old I had brain surgery to correct a blood flow problem to my brain. I had quite a few surgeries in my teen years to take out tumors that could have developed into something worse. Throughout my life we've had to make so many trips to Boston Children's Hospital. Sometimes it felt like my second home. I have been through so much because of NF.

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One Family's Fight to Cure NF



Michael and Melissa Malerba with Jonathan and Emma.

Melissa and Mike Malerba's life intersected with NF when their firstborn, Jonathan, was diagnosed in January 2010 at the age of two. Their world was obviously rocked. After their initial shock, Melissa decided "to not dwell or be sad, but be proactive".

After years of teaching other people's children she felt it time to teach her own. So she took a leave of absence from teaching to help Jonathan receive therapy and to teach him. The Malerba's first fundraising endeavor with NF, Inc. was the Northshore 30K. With the help of family, friends and matching company donations, they raised close to \$12,000.

Melissa decided "to not dwell or be sad, but be proactive"

Melissa then contacted the NF, Inc. office and "offered her assistance in any way, shape, or form" and to inform Karen Peluso, Executive Director, that she and Mike were planning their own event. The event, aptly named, **Committed to Curing NF, takes place on Friday, November 12 from 6-11pm at Anthony's of Malden.** The night will be filled with dancing, great food, exciting raffles and FUN! In addition to the Northshore 30K, the couple attended Table for Ten, helped at the 25th Annual Golf Tournament at the International and are assisting with the planning for Steps2Cure NF run/walk, Hickory Hill golf tournament and "whenever needed". Melissa and Mike are tireless volunteers and ambassadors in the race to cure NF. We thank you for your can-do spirit!

NF Patients and Families

Save the Date

**Sunday, October 24
 NF Symposium in Boston**

visit the CNfAD website - www.cnfad.org or contact the NF office

Here is what we have been up to.....

The Manth Family and Friends are a Powerful Force at the Buffalo Marathon
They are dedicated to raising funds to cure NF2!



At the heart of it all is Leah Manth

NF Volunteer, Michaela Bero receives MVP Award from the Kraft Family and The New England Patriots

Michaela Bero (in center) was recently honored at The Patriots Charitable Foundation annual Community MVP awards luncheon at Gillette Stadium. Michaela was honored for organizing "Pennies from Heaven" for Neurofibromatosis, Inc., NE Michaela created the townwide coin collection project three years ago, along with her friend David Santos. Pennies from Heaven has gone well beyond just pennies and to date has earned almost \$13,000. In Michaela's honor, NF, Inc., NE received a \$2,500 donation from the Charitable Foundation.



Creating Awareness of NF
Governors in the northeast sign proclamations



Governor Baldacci of Maine met with NF families when he signed the proclamation declaring May as Neurofibromatosis Awareness Month

North Shore 30K and Boston Marathon



Terrible weather conditions didn't dampen the spirits of runners and volunteers at the 30K road race for NF! NF thanks Hap Pratt (far left) for organizing the race.



Jenn Soule, Nan Hill and Mike Duff (on right) are three of the fourteen runners who helped Spread the Word and crossed the Boston Marathon finish line to raise funds for NF



25th Annual Golf Tournament at the International CC
Celebrating a great milestone as well as millions of dollars raised for NF research



Steve Picardi, Tournament Chairman (2nd from right) with his family and Dwight Evans



Paul D'Angelo and Tony V brought the house down with their comedy



Table for TEN

Thanks to nineteen of Boston's finest restaurants and our Gold Sponsors, Harold Leach and Mela Lew, Table for TEN was another great success. The elegant dessert reception that followed dinner was at the Millennium Bostonian Hotel and was hosted by Montilio's Bakery. During the evening Master of Ceremonies, Ron DellaChiesa, introduced NF's Boston Marathon team and we honored our Champion Fundraiser, Michael Eisenstadt. Two weeks later, the team ran the Boston Marathon, and finished strong!



A Table for TEN at Union Oyster House



Lucca was one of many North End restaurants that participated in Table for TEN

Nickels for NF



Kallie McGonagle's school had a "Nickels for NF" collection. Kallie is shown (in center) with her classmates.



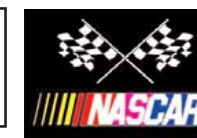
25th Annual Tournament Committee

Wheelabrator Supports NF



Bert Peluso (2nd from right) thanked Manny DaCosta and Steve Cacciola from Wheelabrator and RJ Tindle (right) for their participation in the annual Wheelabrator Golf Tournament. The event has raised a total of \$53,000 over the past few years

And, here is what's coming up!!!



September 19th
The Roche family and many volunteers will represent NF at NASCAR Races in Loudon, NH



Friends Ride for NF
September 11th
across Cape Cod



September 26th
NF families and friends come from near and far to Woburn, MA for Steps2Cure NF



Friday, November 12
Committed to Curing NF
Malden, MA ~ 6PM-11PM
An evening of fun, dancing, great food and prizes

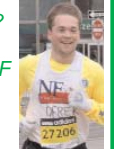


Melissa and Michael Malerba invite you to attend the first annual **Committed to Curing NF** fundraising event that they are hosting in honor of their three year old son Jonathan (shown in photo). It will be a festive and informative evening filled with fun, dancing, great food and exciting raffle prizes.

Get more information or register for upcoming events at www.nfincne.org

Hickory Hill Golf Tournament
Methuen, MA
October 4th

Where's Derek?
He's running a marathon for NF in every state! Have you seen him??



NF Champions Grant *continued from page 1*

The \$100,000 grant is for one year and will support CNfAD research activities that include collection of blood samples, tumor samples and descriptive information from NF subjects. The grant includes funding for a half-time research coordinator at the Children's Hospital Boston to attend the NF clinic and

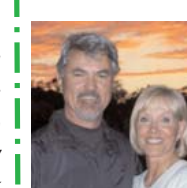
Brittany talks about NF and camp *continued from page 1*

The obstacles I've faced were hard but I knew that I needed to be brave and things would turn out okay. My mom, dad, sister, her fiancé, aunts, uncles, cousins and friends have all helped me through my ups and downs of NF. Every bit of support has gotten me to where I am today and I am very thankful I have a loving and supportive family who is there when I need them.

When I was fifteen I was given a scholarship by NF Inc, NE to attend a camp called Camp New Friends. Camp New Friends is a camp just for kids, teens, and adults who have NF. It's a camp where all worries and negative thoughts about NF disappear for the week. Camp New Friends has a lot of activities to do and allows the campers to talk to others their age about their struggles with NF. At home no one really knows how it feels to have NF. How it feels to be afraid every time you have an MRI because you never know what the news will be. At NF camp everyone knows and feels the same thing. I was fortunate to be able to go to Camp New Friends the next two summers, and I'm happy to say that I'm going again this summer, and I'm very excited. Thank you NF Inc. NE for giving me this opportunity once again.

facilitate the recruitment of patients to multiple NF research studies. This individual coordinates directly with a full-time clinical and research coordinator located at the Massachusetts General Hospital who performs the same functions, as well as overseeing the CNfAD database and CNfAD-wide activities. By funding this important infrastructure NF, Inc. Northeast is filling a gap that exists in most federal grants. This collaboration, and collection of biological samples and clinical data, makes the members of the CNfAD more competitive for grants and therefore has a proportionally greater impact on NF research than specific project support.

The NF Champions



Dwight and Susan Evans



K.C. Jones



Harriet and Alan Lewis



Tommy Heinsoh

Welcome new NF staff member



Sonja Nathan has assumed the position of Director of Special Events for NF, Inc., Northeast. She brings over 20 years of special event experience with non-profit organizations including the American Cancer Society, the Easter Seal Society, Harvard Pilgrim Health Care and Northeast Senior Health Systems. Sonja is looking forward to working with volunteers on existing events, cultivating new and current donors and helping to bring NF to the next level. Please feel free to contact her at 781-272-9936 ext. 204 or snathan@nfincne.org.