



A Publication by NF, Inc. Midwest for Neurofibromatosis families.

# NF NEWS

Midwest

Volume 27, Issue 1  
Spring 2008

Published 3 times a year

Look inside for details on these important events!

## Moving Forward...Reaching Out...

*Finding hope in research and comfort in friends.*



**2008 Neurofibromatosis  
Symposium  
Saturday  
October 18, 2008  
Oak Brook, Illinois**

**NF, Inc. Midwest  
PO Box 1923  
Lombard, IL 60148**

### Office Hours

9:00 AM to 3:00 PM  
Monday - Friday

630-932-8111

1-800-322-NFNF (IL Only)

Fax: 630-932-8119

E-Mail: [info@nfmidwest.org](mailto:info@nfmidwest.org)



### **Mission Statement**

NF, Inc. Midwest is an organization dedicated to the support and education of people affected by the Neurofibromatoses, to the education of health care providers, and to the investment in research.

### **Disclaimer:**

*Neurofibromatosis, Inc. Midwest does not endorse any of the medications, treatments, or products reported in this newsletter. This information is intended only to keep our members informed. We strongly advise that you check any drugs or treatments mentioned with your physician.*

**FREE**

**Ask the Doctors  
April 27<sup>th</sup>, 2008  
2:00 – 4:00 pm**

**RSVP  
ASAP**

**Shriners Hospital, Chicago, IL**

# Great Steps for NF!

**Saturday  
June 7, 2008  
Naperville, IL**

## Don't Miss Our Premier **FUN**d-Raising Event!



Our 7th annual *Great Steps for NF* walk is scheduled for Saturday, June 7th. If you haven't joined us before, now is the time! This awesome event runs from approximately 9:00 am to 1:00 pm and includes **FREE food**, face painting, music and **TONS of fun!**

*Great Steps for NF* is a 3K walk along the scenic Naperville Riverwalk and is a major fundraising event for NF, Inc. Midwest. Funds raised support research studies, which have led to discoveries about not only NF, but also cancer and learning disabilities. They also provide support, education and hope for NF families.

**The walking is easy (less than 2 miles) and the fund raising is even easier!** Register and we'll send you all the tools you need. If it makes you uncomfortable, there is no need to ask for a sponsorship face to face. Simply send out letters to your friends, family, neighbors and co-workers with a donation slip and envelope. If they choose to donate, they can send it directly to us. We'll keep track of the funds you raise! You can also set-up on-line donations at [www.Firstgiving.com/nf](http://www.Firstgiving.com/nf) where you can create your own personalized webpage. You'll be amazed at the response you'll get! People are always happy to support a good cause.

**Consider forming a team** by recruiting your friends and family. A team is an excellent source of inspiration and support, results in more effective fundraising and is lots of fun.

Another great idea is to **form a corporate or company team!** Organize a corporate team! Working together to raise funds is a great team building exercise. It's also a great way to demonstrate involvement in the community!

Our goal for 2008 is to raise more than \$100,000 and with your help we can do it!

For more information contact 630.932.8111 or email us at [ilnfinc@sbcglobal.net](mailto:ilnfinc@sbcglobal.net).

### Saturday, June 7th

### 9:00 am to 1:00 pm Naperville River Walk Naperville, IL

#### Cost

**\$20.00**

(pre-registered by May 30)

**\$25.00**

(After May 30)

**FREE**

(for each individual raising over \$100)

Complimentary T-Shirts will be available on a first-come first-serve basis on the day of the walk.



*Coles Crew, the 2007 team fundraising winners, raised over \$7,000!*

## Volunteers are Needed!

A volunteer brings to the walk, smiles, energy and success! If you are interested in helping the day of the walk, please give us a call at 630.932.8111!



## Participate in Research

### One Patients Experience in an NIH Study

Last April I took my first of six trips to the National Institutes of Health in Bethesda, Maryland where I am enrolled in two research studies. I recommend that more people participate.

The first study takes two days to complete and is titled: Variation in Gene Expression in Neurofibromatosis Type 1. Its purpose is to isolate one or more genes and may determine the severity people with NF 1 will have during their lifetime. Blood work, genetic counseling, a dental exam and an MRI of the spine are part of this study.

The second study involves a commitment of two years and is titled, Natural History and Biology of Dermal Neurofibromas in Neurofibromatosis Type 1. Its purpose is to determine the gene responsible for neurofibroma growth and how often they occur. A small neurofibroma and regular piece of skin are surgically removed. Permission may be asked to remove a Cherry Hemangioma as well. While the areas removed are very small, it is a surgical procedure. Therefore, a blood test is performed to make sure bleeding is controlled during and after the procedure.

After the surgical procedure, patients return to NIH for ½ day visits at 3, 6, 12, 18, and 24 months for an exam.

The only criteria to participate is that both parents of the patient must be willing to provide a blood sample which can be done locally. The NIH will pay for this.

These studies are for adults and with success will benefit all people. This truly pleases me, especially since adults with NF often feel left out as the focus has been on children.

Dr. Douglas Stewart, Dr. Jennifer Sloan, and the rest of the staff involved in these studies, have a vested interest in Neurofibromatosis. The treatment I have received has been remarkable. I received lots of information about my particular symptoms. I was able to take this information back to my own doctor. After years of insurance denials, little success in treatment options, etc, I have taken care of two major issues related to NF and my health status has improved.

Patients are not paid for their participation. However, the NIH does pay travel, hotel and most meals while at the NIH. Any additional time such as adding a vacation to clinic time has to be paid by the patient.

If you would like more information about either study, you may contact Dr. Jennifer Sloan at [jsloan@mail.nih.gov](mailto:jsloan@mail.nih.gov) or Dr. Douglas Stewart at [drstewart@mail.nih.gov](mailto:drstewart@mail.nih.gov). You can also phone the NIH at 301-451-9145.

I can also answer many questions about my own experience. If you would like to talk about this you can phone me at 630-291-9584 or e-mail me at [rmichaelforbes@yahoo.com](mailto:rmichaelforbes@yahoo.com).

Thank you,

Mike Forbes

---

## Federal Funding for NF Research Cut Drastically!

Since our inception IL NF, Inc. has awarded more than \$800,000 to scientists who are dedicated to studying NF. Using a Peer Review Grant Process we provide seed grants (\$25,000 to \$40,000) to researchers who may subsequently apply for larger grants from the US Army NF Research Program or the National Institutes of Health. In partnership with the National NF Coalition, we work with congressional representatives on both a local and national level to encourage continued and increased federal funding of NF research. We have submitted testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, and Education. However, due to budget cuts and the war in Iraq we are in danger of losing the Department of Defense's NF research program and appropriations are being cut yearly. In fiscal year 2005 the Department of Defense funding for NF was \$25 million. In 2006 it was \$17 million. In 2007 it was drastically cut to 10 million and now for FY 2008 it is only 8 million. There is a discouraging pattern here, but we won't give up!

Our work is cut out for us over the next year. We will ramp up our letter writing campaigns and continue to add names to our list of friends in Congress. We have established a strong base of supporters who most recently signed onto letters of support. We encourage NF families and friends to write to ask for support for federal funding of NF Research for fiscal 2009 in the amount of \$20 million. You can find your congressmen's contact information and a sample letter requesting support by going to [www.nfinc.org](http://www.nfinc.org).



**Arm Yourself  
With Knowledge**

**SAVE THE DATE  
FOR OUR OCTOBER SYMPOSIUM!**



Be sure to save the date for our well known, highly attended fall symposium. It is the event of the year!

Speakers are still being scheduled, but as usual this event will be very educational, supportive and well attended. If you'd like to make an early reservation please email us at [ILNFInc@sbcglobal.net](mailto:ILNFInc@sbcglobal.net) or call the office at (630)932-8111.

**Fall Symposium  
October 18, 2007  
McDonald's Corporate Center  
Hamburger University  
Oakbrook, IL**

**Save paper! Send us your email addresses!**

**We love to save some trees and bring you more timely updates via email. If we don't already have your email, please send it to us a [ilnfinc@sbcglobal.net](mailto:ilnfinc@sbcglobal.net)**



## Help & Support Each Other

### Adult NF Group

Michael Forbes has started an adult group for individuals with Neurofibromatosis. The first meeting took place on February 16. Michael discussed how his participation in research at the National Institutes of Health has been a major benefit to his life.

This group is looking to grow and expand. The focus areas for now are meetings on topics such as:

- Relationships
- Employment Issues
- Health Insurance
- Life Transitions

And group outings such as:

- Bowling
- Movies
- Dinners
- Concerts

Currently this group is meeting once a month, typically on a Saturday. As the group grows, more opportunities to meet will occur. This group is looking for more people to join. They also want people to speak to different topics related to NF.

Anyone is welcome to attend. However, keep in mind the focus is on adults.

For more information, contact Michael at 630-291-9584 or at [rmichaelforbes@yahoo.com](mailto:rmichaelforbes@yahoo.com).



### NF2 Crew News

Living with Neurofibromatosis II (NF2) can be very frightening and complicated. Meandering through the maze of doctors appointments, surgery complications and outcome can cause uncertainty and high anxiety. Fortunately, there is a support network of online individuals spanning the globe. The support group with over 600 members consist of patients and family members with NF2. If you are interested in the NF2 Crew please see <http://www.nf2crew.org> for more information and a variety of ways to participate. Here are some of the ways to join in:

**Group Lists:** This group can be likened to an extended family that shares heartfelt friendship, information and support.

**Message Board:** Topics are organized in sections, so it is easy to find exactly what one is looking for.

**Real-time Chats** After registering just submit your screenname to the crew and someone will contact you.

#### Social gatherings:

"NF2Con" in Las Vegas to be held May 22-25, 2008, which is the most well attended and the "official" Con.

Columbus Day weekend get together in Columbus, Ohio on the 10th-12th.

Boston get together, on May 17th and 18th.

The RoadCrew, which has been to Australia in the summertime.

If you interested in the NF2 Crew please see <http://www.nf2crew.org> for more information.

### Camp New Friends 2008

Camp New Friends has been scheduled for July 13-19 in Buckeystown, Maryland. This is an excellent opportunity for children with NF to meet other children NF and to realize that they are not so different after all. The camp is lead by an excellent staff with The Children's National Medical Center's Department of Neurology. Don't let a lack of finances stop your child from attending as scholarships are available.

*"Campers participate and choose from activities including hiking, arts and crafts, canoeing, team sports, a low and high ropes confidence course, camp Olympics, swimming, yoga and drama. Support groups and educational programs promote knowledge, skill development and social connections. At Camp New Friends children and teens gain a better understanding of their condition, strengths, and self-worth."*

Excerpt from *Camp New Friends Brochure*

**Don't let  
finances  
stop you!  
Scholarships  
are  
available!**



**Raise FUNds or Help  
In Raising FUNds!**

# Great Steps for NF!

**Over \$100,000 Raised at  
Great Steps 2007!**

*Great Steps 2007* was a huge success! It was a gorgeous June day filled with joy, camaraderie, laughter and oh... a little competition too. The day began early with the volunteers busily working like ants in anticipation of our 6th annual walk. This year's walk brought in over \$100,000!

The dedication and spirit of all our walkers shows that we are making a difference in the fight against NF. While every little bit helps, we want to acknowledge the top teams and put a challenge out there to knock them off their post next year! The top teams were as follows:

1st Place: *Coles Crew* raising an amazing \$7,074!

2nd Place: *Pedersen's Pink Pigs* with \$5,204

3rd Place: *Harmon Team* with \$4,066



These are the numbers needed to work towards a cure. Let's continue our fight to "feed NF to the sharks" as stated by our winning creative accessories team, Katie's Cruisers, who were dressed as pirates!

Many thanks to Centimark for their donation of \$10,000 and to eDOC Communications for their generous contribution of printing services! This is just a sampling of the wonderful support NF, Inc. Midwest receives towards helping improve the lives of those affected by NF. It doesn't stop here; the fight must continue and you have a chance to do just that on Saturday, June 7th, 2008. Join us to battle NF with our great steps towards a cure. Registration will begin at 9:00 a.m. at the Grand Pavilion. Contact the office or visit [www.greatsteps.org](http://www.greatsteps.org) for more information.



TAKE A  
SWING AT NF

**Friday,  
August 15**

Plans are under way for our 9th golf outing and we need your help! We need energetic volunteers to help put this event together. We also need sponsors and golfers! Please consider joining our golf committee and "talk-up" the golf outing to everyone you know. This year's outing will be held Friday, August 15. Look for

further information in future publications or call 630-932-8111.

**We need help!  
Call 630.932.8111  
to join the golf committee!**



*Happy faces from 2007's golf outing!*

## Surf the web and raise money for NF!

Use **GoodSearch.com** as your search engine and every search can earn funds for the NF cause.

GoodSearch.com is a Yahoo-powered search engine that donates half its advertising revenue, about a penny per search, to the charities its users designate. Use it just as you would any search engine, get quality search results from Yahoo, and watch the donations add up!

GoodShop.com is a new online shopping mall which donates up to 37 percent of each purchase to your favorite cause! Hundreds of great stores including Amazon, Target, Gap, Best Buy, ebay, Macy's and Barnes & Noble have teamed up with GoodShop and every time you place an order, you'll be supporting your favorite cause.

Just go to [www.goodsearch.com](http://www.goodsearch.com) and enter *Neurofibromatosis, Inc - Midwest* as the charity you want to support. And, be sure to spread the word!

**GoodSearch**

You Search or Shop...  
We Give!

SMILES FOR SARAH



RUN FOR NF RESEARCH  
5K RUN/WALK  
1 MILE YOUTH RUN

**Smiles for Sarah**  
5K Run/Walk  
Scheduled for Sunday,  
October 5, 2008

Once again, a 5K run/walk will be held in honor of Sarah Panazzo. Once again this year's event will be held in Tinley Park. For more information, please call the NF Inc. Midwest office at 630-932-8111.

## Use Your Federal Tax Rebate To Help NF!

In 2005 NF directed funding from the US government was 25 million. It has been cut drastically over the last 3 years and is now at 8 million! This has unfortunately happened when research was really taking off.

If you receive a rebate please consider donating a portion to NF. An envelope has been enclosed.

**We're asking again in case you missed it on page 4 !  
Send us your email addresses!**

**We love to save some trees and bring you more timely updates via email. If we don't already have your email, please send it to [ilnfinc@sbcglobal.net](mailto:ilnfinc@sbcglobal.net).**

## Hiking Across the U.S. for NF!

Three admirable and obviously very energetic adults have started a hike across the U.S. to raise funds for NF in honor of a friend with NF Type-2. They have started in Delaware and are going all the way to California! Obviously, they deserve a lot of support and encouragement. The best way to do this by donating to their cause and showing them you appreciate their efforts by mail, email or by simply showing up at places to walk with them. To donate or for more information go to [Hike4NF.org](http://Hike4NF.org) and look for the *Meet Hike4NF* button.

**Check out their trail journals and sign into their guestbook at [Hike4NF.org](http://Hike4NF.org)!**

Please, consider meeting them, encouraging them, feeding them and finding them a place to sleep, if they come to your area. They should be coming through Indiana in late April and Illinois in early May. Please, call the office at 630.932.8111 if you have some ideas on how to help them out!

# REQUEST FOR INFORMATION AND WAYS I CAN HELP Form

For information on the following, please check off the appropriate items and mail to:

**Illinois/Midwest NF, Inc  
PO Box 1923  
Lombard, IL 60148**

**Be sure to consider other ways in which you may help the NF cause.**

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

E-Mail \_\_\_\_\_



**To include your name, address and phone number!**

- "Ask the Doctor" Program
- Working on New Fundraising Opportunities
- Golf Event (Planning for 2008)
- Volunteer Opportunities
- Office Help
- NF Meetings, Symposiums
- Funding Factory Recycling
- Support Groups
- Interested in Telling My NF Story
- Employer Matching Grants
- Public Relations
- Newsletter creation
- Advocate for NF Federal Funding
- Other (Please Specify)

**Illinois/Midwest  
Neurofibromatosis, Inc.**  
PO Box 1923  
Lombard, IL 60148

Designate NF, Inc. CFC #1132

Non-Profit Org  
U.S. Postage  
**PAID**  
Mt. Prospect, IL  
Permit #65



630-932-8111  
1-800-322-NFNF (IL Only)  
Fax: 630-932-8119  
E-Mail: ILNFInc@sbcglobal.net

**ADDRESS SERVICE REQUESTED**

## **Illinois/Midwest NF Clinic Information**

### *Treating Children Only*

#### **Children's Memorial Hospital**

2300 Children's Plaza  
P.O. Box 59  
Chicago, IL 60614

**773-880-4462**

Joel Charrow, M.D.  
Robert Listernick, M.D.

### *Treating Children and Adults*

#### **The University of Chicago**

**Children's Hospital**  
5839 S. Maryland Avenue  
MC3055  
Chicago, IL 60637

**773-203-2344 Cynthia MacKenzie, RN**  
General Inquiries & Research

**773-834-8064 Sharon Morton**  
Appointments

**773-702-6487 James Tonsgard, M.D.**

### *Treating Children and Adults*

#### **St. Louis Memorial Hospital**

Neurofibromatosis Clinic  
Division of Medical Genetics  
One Children's Place  
Campus Box 8116  
St. Louis, MO 63110

**314-454-6093**

Linda Piersall, M.S.  
David H. Gutmann, M.D.

**Illinois NF, Inc., is registered as a 501(c)3, not for profit organization in the State of Illinois. At this time the NF affected families in the unrepresented states of Iowa, Indiana, Kentucky, Tennessee and eastern Missouri will be served by the Illinois/Midwest Chapter.**