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

NF Midwest NEWS

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Moving Forward...Reaching Out...

Finding hope in research and comfort in friends.

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

Our annual symposium is scheduled for Saturday, October 18. This is a wonderful social and educational event that runs from approximately 9:00 to 4:00 and includes a continental breakfast and a sit down lunch. The cost is $25 per person, but financial assistance is available. A brochure will be sent soon. In the meantime, if you plan on attending, please give us a call at 630.932.8111 or drop us an email at info@nfmidwest.org to help us get an advance head count.

Continue inside for more details!

A Big Move for Kim Bischoff

Kim Bischoff has left NF, Inc. Midwest, but have no fear, she is still with us and still carrying the torch for neurofibromatosis. Kim has become the Executive Director of NF, Inc's National office. While we will miss her passion and experience here at NF Inc. Midwest, we know that she can serve a far better purpose at a national level.

What's Up With The Name Change?

There have been some big, exciting changes around our offices. First of all, many of you may have noticed the gradual transition from the name Illinois NF, Inc. to NF, Inc. Midwest. This name change is part of a larger vision to broaden our national advocacy programs and to expand education and support through-out the United States. This is an evolving process which we will explain in more detail as changes progress.

NF Inc. Midwest will continue to support members in Illinois while also providing extra support to existing member organizations in our territories as needed. We will also work along with our national offices to support and educate in the Midwest areas where there are no member organizations or help to develop them there.

Our area includes Iowa, Indiana, Wisconsin, Kentucky, Tennessee and eastern Missouri which have no formal member organizations and Michigan and Minnesota where we will support the existing member organizations.

As part of these exciting changes, NF Inc National has moved it's offices to Illinois and Kim Bischoff as taken the position of Executive Director for the national office. Replacing Kim as Executive Director of NF Inc Midwest is Diana Haberkamp.

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NF

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.

New NF Midwest Executive Director

I am very pleased to accept the position of executive director of NF, Inc. Midwest and wish Kim Bischoff well in her new position at NF, Inc. National. I look forward to doing all I can for the NF cause.

Like Kim, I have family affected by NF. My husband and my two children ages 16 and 14 have NF-1. My passion is personal and my experience is real, but it still took great consideration on my part before accepting the position. I thought, did I really want to immerse myself and my family into NF on such a large scale and do I really have the qualifications for this position? But after great thought I believe this is the path I was meant to take. As far as immersing our lives into NF? Well, it's already a part of our lives, but it can never be our whole lives because there is so much more to all of us. But NF is the part of my husband and children that needs the most help. What better way to find hope and to know as much as possible about the disorder then to immerse myself in it?

As for my qualifications, while I have never directed a non-profit, I have been on the NF, Inc. Midwest board for over ten years and president for two years. I also have various job and personal experiences that I believe will serve me well. For the past 14 years, I have helped to run a successful real estate team. This included everything from marketing, to database management, sales and more. Before that, for 10 years, I ran the computer and purchasing department of a large tile distributor. I have also done side work for various businesses. Whatever abilities I lack ,I will make up for in my dedication to the cause and my personal experiences with NF. More importantly, Kim Bischoff has left a great foundation and also left me with the solid rock of our administrative assistant, Debbie Clegg.

My promise to you is to follow the mission of NF Inc Midwest and to dedicate myself "to the support and education of people affected by the Neurofibromatoses, to the education of health care providers, and to the investment in research". Two important things to know about me is that I love to "talk" (which is evident by my long rant here and my nickname "Babbles") and I've been around computers forever and love them! This means I really want to talk to people, I really want email addresses and I plan to improve our internet and computer presence. So, if you want to strike me before I strike you, send me your email address at Diana@nfmidwest.org!

New NF1 Study: "Living with NF1"

Announcing a new opportunity to participate in NF1 research! Researchers at the National Institutes of Health (NIH) and Johns Hopkins University are doing a study for adults with neurofibromatosis type 1 (NF1). The goal of the study is to learn what people think and feel about living with NF1. The researchers hope that the knowledge gained from this study will improve healthcare and counseling for individuals with NF1.

If you have NF1 and are at least 18 years old, you are invited to participate. The study involves taking a survey. You can do the survey online, and it will take about 30 minutes to finish.

To take the survey online, or to find out more, go to: *www.NNF StudyF1study.com*

For more information or to request a survey by mail, please contact Julie Cohen, the lead associate investigator, at: cohenju@mail.nih.gov or (301) 443-1533.

Contact Information

Please note, our website and email addresses have changed, though the old ones will still work.

Office:	**1.630.932.8111**
1-800 (Illinois Only)	**1.800.322.NFNF**
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Website:	**NFMidwest.org**
Office Email:	**info@NFMidwest.org**
Diana Haberkamp, Executive Director:	**Diana@NFMidwest.org**
Debbie Clegg, Assistant Director:	**Debbie@NFMidwest.org**

Board Of Directors

Annual Board Meeting

NF Inc. Midwest will be holding it's annual board meeting at 7:00 pm on Tuesday, September 23 at 145 S Main Street, Lombard, IL. For more information please call the office at 630.932.8111.

Symposium *(Continued from page 1)*

This year we are very excited to have with us former fashion photographer Rick Guidotti, who will give a presentation about his organization, POSITIVE EXPOSURE, as well as take photographs and conduct video interviews with our group. POSITIVE EXPOSURE "provides the opportunity for participants and audiences alike to challenge stigma associated with difference by celebrating the beauty and richness of human diversity. This innovative arts organization is dedicated to empowering people living with genetic difference by portraying their strengths and individuality to a wide audience." The POSITIVE EXPOSURE program will inspire us to celebrate our differences and help us learn how to create positive exposure for the NF cause and people with NF.

We will also have an NF overview of the types of neurofibromatosis and once again we will have break out sessions for NF-1 and NF-2.

For the NF-1 break-out we are honored to have Dr. Nancy Ratner from Cincinnati who is a pioneer in understanding how neurofibromas form. Dr. Ratner has done careful laboratory studies over the last 15 years showing the contributions of different types of cells that make neurofibromas and she has recently created a mouse model for neurofibromas. This work is going help clinicians understand how to treat plexiform neurofibromas. Following this, Dr. Tonsgard will talk about the different kinds of neurofibromas and Dr. Listernick and Tonsgard will speak about the treatment of neurofibromas.

In the NF2 break out session, Dr. Tonsgard will summarize the presentations on NF2 at the most recent NF meeting, including a discussion of potential chemotherapy trials for NF2 patients. Dr. Redleaf, from the University of Chicago will talk about the team involved with NF2 patients and their approach to hearing loss and vestibular Schwannomas. There will also be an open and inspirational discussion by NF-2 affected people about the quality of life.

This schedule is subject to change as we are still adding and confirming speakers. Please, keep an eye out for our symposium brochure or you may sign-up now by calling the office at 630.932.8111.

NF2 News
From *NF2 Crew*

NF-2 Crew will be holding gathering in Pickerington, Ohio October 10th through the 12th at the Best Western Executive Suites. A social and fun time, this is an excellent opportunity to introduce yourself to the NF-2 support community. If you look for Pickerington on the map, it is a suburb of Columbus. When contacting the Best Western please, use the group code of 1120 to get the special room rate of $75 per night (plus tax). A block of rooms are being held until September 15th.

For more information contact Phyllis Lee via email at phyh64@yahoo.com

NF2 NIH Study

The National Institute of Neurological Disorders and Stroke (NINDS) is conducting *A Prospective Natural History Study of Patients with Neurofibromatosis Type 2* (Study 08-N-0044). This study will examine the long-term progress of patients with Neurofibromatosis Type 2. It will study patients' tumors to learn how fast they can grow and if certain factors might affect their growth. It will also examine the effects of the tumors on patients' abilities to carry out activities of daily living.

People between 8 and 75 years of age with NF2 may be eligible for this study. Participants undergo initial evaluation, including hearing, eye and balance testing; gait (walk) testing; MRI scans of the brain and spine; blood tests; and physical and neurological examinations. The study also includes MRI scans of the brain and spine every 6 months; physical and neurological examinations and blood tests every 6 months; auditory tests every 12 months; eye examination every 1 to 2 years; gait testing every 12 months if a spinal cord tumor causes problems with sensation or muscle control in the arms and legs; and vestibular testing if the patient experiences changes in balance or undergoes treatment for vestibular schwannoma .

For more information call 1-800-366-5165 (TTY 1-866-411-1010) and a recruitment specialist will assist you. If you leave a voice message, please include a telephone number where you can be reached between the hours of 8:00AM -6:00PM EST Monday through Friday. You may also check it out on the internet at *clinicaltrials.gov.*

Be In The Know!

Keep up to date on NF Midwest happenings via email. Send us you email addresses and you will receive regular updates on research, support and education opportunities and much more. Just drop us an email at info@nfmidwest.org.

Crazy Fun! Great Steps for NF! Razing Fund$!

Everyone had tons of crazy fun while raising tons of funds for neurofibromatosis research and support at our 8th annual ***Great Steps for NF*** held Saturday, June 7th.

This year over $120,000 was raised due to the hard work of our walkers, volunteers and sponsors. This is an amazing feat of feets!

We had over 800 walkers and 55 teams pre-registered. Clearly there was a lot of dedication and determination, (and maybe a little bit of competiveness) in our teams as many of the team totals were awe inspiring. Our top fundraising team, Cole's Crew, blew the top off of their own goal of $10,000 raising $14,634 by the day of the walk. Second place went to Harmon R Us with $7,126, while third place went to Pedersen's Pigs with a grand total of $6,251.

Other winners included the Crazy Daisies for best accessories, Lori Solwish for the most print cartridges, and Ty Dyes for the most cell phones.

But the real winner is the NF cause and all of us who enjoyed a beautiful day filled with food, friends, music, more food, fun, new friends and a little bit of exercise.

Thank you to Joan Pilkinton and all her wonderful volunteers for pulling of another wonderful Great Steps Walk. Also, thank you to Bethany Brass Quintet for providing beautiful music, Mayor Pradel for once again kicking us off, and to ALL our generous sponsors who not only donated money, but food, ice cream, candy and much more. This event has so many people giving to the NF cause in so many different ways, that it is impossible to thank them all except to say "thank you all, whoever and wherever you are"!

Be sure to check out photos at photobucket.com (type *stevenjaneshannon* in the search box). There are some wonderful pictures! It's just our opinion, but everyone looks good in red!

Next years walk is set for Saturday, June 6th. Mark your calendars now and start planning for some fun and fundraising!

***Coles Crew**, the 2008 team fundraising winners, raised $14,634!*

Hiking Across the U.S.

(From R toL) Diana Haberkamp, Josh Howell, Jodi Harrington, Kim Bischoff and Joan Pilkinton visit at the NF office.

In May, we had the unbelievable experience of meeting two extremely fascinating and remarkable people, Jodi Harrington and Josh Howell. Josh and Jodi are walking across the U.S. via the American Discovery Trail for their respective charities. Josh is walking for Alzhiemers, in honor of his mother, while Jodi is walking for neurofibromatosis in honor of a friend with NF Type2. They have started in Delaware and are going all the way to California! Together they hope to raise one million dollars for their charities and one million hugs for humanity. While here we set-up a simple meet and greet at Bannerman's Sports Grill in Bartlett where they collected hugs and donations while truly inspiring us all. It is impossible to describe the affect of meeting and spending time with them. They are very inspirational, fascinating, insightful and full of love and concern for people and the earth. If you get a chance to meet them, do it! If not, at least visit their journal, follow their journey and show your support. For more information go to Hike4NF.org and look for the ***Meet Hike4NF*** button or go to hugsforhumanity.com.

Check out their trail journals and sign into their guestbook at Hike4NF.org!

Thank you to Murray Friedman and Bobbi Kraklio of Bannerman's Sports Grill in Bartlett who donated food, the proceeds from the food and tips to the NF cause.

A Beautiful Day!

The 10th annual NF Inc, Midwest Golf Benefit held on Friday, August 15th couldn't have been a more beautiful day! Sixty golfers soaked in the fun with blue skies, perfect temperatures in the mid 70's and a nice breeze. Afterwards everyone enjoyed a nice dinner, raffle and silent auction. $10,000 was raised for the NF cause!

Consider joining us next year when this event will be feature a morning start and a luncheon rather than a dinner. The date has already been set for August 14th so mark your calendar now!

Mark your calendar for next golf outing on August 14, 2009!

The *NFers*

If you are an adult with NF Type 1 you're invited to join the *NFers*. This is a social group that meets online in the nf.org chat room or on MySpace at http://www.myspace.com/mustangjenny1966. While members of this group may have children with NF, the purpose of their gatherings are generally for NF adults and their significant others only. This years gathering was held in June in Grafton, IL along the Great River Road and featured a Mexican Feista. The *NFers* are looking forward to a luau at their 6th annual meeting in 2009. For more information email Jenny at foppes@gtec.com or show up at any of the sites above. Include NFers in all subject lines to ensure a response.

The NFers gather at the Piassa Bird along the Great River Road in Grafton, Illinois.

Insurance Coverage For Neurofibroma Removal

All neurofibroma removals, properly documented, for people with neurofibromatosis, should be covered by most insurance plans. This is medically justified for two reasons:

1) The possibility (though small, but statistically significant) that the individual tumors can become malignant; and
2) The fact that they can cause nerve damage when they grow.

Another sure coverage is if the patient alleges itching.

If a patient is turned down by the insurance company, check with the doctor's office to assure that the claim was fully documented. This is frequently the problem and the reason the claims are denied is the lack of full information from the physician. The patient or doctor should request a reconsideration stressing that the patient has this disease and the circumstances explained above. If they again are denied and they are under a private insurer, they should write a letter to the State Health Insurance Commissioner (whose number can be found in the blue pages of the phone book). If the insurance is through the employer, the claimant should also let his company benefits coordinator know the problems which are occurring with the insurance plan.

If they are covered by Medicaid, there should not be a problem, because all rendered medical care is covered. The only possible problem might be a physician who is ignorant of the neurofibromatosis and refuses to remove a tumor because he/she considers it cosmetic surgery. A call to most state Medicaid offices should be sufficient to clarify coverage.

Medicare will cover it. Again, when a denial occurs it is usually because of a lack of documentation. The beneficiary should follow the steps listed above for private insurers.

Diagnostic codes are: 237.70 NF unspecified
237.71 NF1
237.72 NF2

The billing code for removal of neurofibromas from the face is CPT64788. Both diagnosis code and billing code must be on the insurance claim form.

Above information provided by:
Paul Mendelsohn
Formerly Consumer Liason for Disability Issues
Center for Beneficiary Services
Health Care Financing Administration

Marty Ginsberg Grant Update

Once again NF, Inc. Midwest has provided the Marty Ginsberg Grant to the University of Chicago to aid in the development of their NF patient database. Having probably the largest continuous experience with NF1, Dr. Tonsgard's database has proven to be very valuable for research projects including malignant peripheral nerve sheath tumors, seizures in NF1, and the natural history of NF1.

Marty Ginsberg, was a founding member of our organization. We are honored to be able to continue his legacy.

Are You Interested in NF1 Research?

Since bone health problems are common in people with NF1, a four year study of children's spines is taking place (in Cincinnati, Utah, Vancouver, and England) in order to examine the frequency and clinical history of spinal problems in children and the effectiveness of various methods of screening for scoliosis.

The study involves:

- A clinical exam with an NF expert
- An MRI (usually done only at the first visit)
- A spinal x-ray
- A DXA and pQCT (painless tests of bone density and architecture)
- A urine sample

The study takes about half a day per year, for four years, and U.S. residents may visit the Cincinnati or Utah locations (as long as space is available). There is a travel allowance and small honorarium, plus parents will be given the test results.

Participants may have scoliosis or a normal spine, but must be between 6 and 9 years old when first enrolled; have had no previous surgical treatment for scoliosis; and have no signs of puberty.

Surf the web and raise money for NF!

Don't forget to use ***GoodSearch.com*** as your search engine. Every search can earn funds for the NF cause.

Just go to 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!

Kids climb upwards, conquering hurdles at Camp New Friends!

Check out *Camp New Friends* at the brand new BrainyCamps.com website. Run by the Children's National Medical Center, *Camp New Fr*iends is for children age 7 to 16 with neurofibromatosis. This years camp ran July 13-19 and once again NF Inc. Midwest sponsored 5 children.

Want to know what's so great about Camp New Friends? A child says it all! Below is a post, pulled with permission, from the new NFInc.org bulletin board at nfinc.inspire.com.

A Child Says It All!

Hi My name is Maddy Gorham and i have nf 1. I've been going to Camp New Friends since it open, which is 5 years ago. I am the only one in my family that has nf. I decide to share my info. Camp New Friends is the place to be at for me. Before camp i never knew other people had nf. Also Camp taught tons things abput nf too. Also after the first year of camp i was able to [let] people i know about how my nf affects [me]. I look forward to going there every year. I Love Camp New Friends!

Group Holds *SimulWalk* in Effingham!

With gas prices so high, one group down in Effingham, Illinois decided that since it wasn't practical to drive up for our Great Steps event, they would hold a walk simultaneously in Effingham. Approximately one week before our Great Steps Walk in Naperville, Debbie Worman, took on the task in honor, Ali, her friends' daughter who has NF-2. The team Ali's Gaitors already had a large contingent raising money for the walk and planning to attend, but Debbie and other's from Ali's mother's hometown wanted to join in. Soon Debbie heard of others in the Effingham area affected by NF and this inspired her more. In fact, cutting the ribbon that morning were Frank and Betty Esker whose daughter, Mary, passed away from NF. With only **one week** of preparation, Debbie was able to get a newspaper article published, an advertisement and a radio ad. On the day of the walk, they had 21 walkers, 5 volunteers, two walk-up visitors and raised over $2,100...not to mention a lot of NF awareness!

Over $2,100 raised in one week!

Mighty Effingham walkers!

Run4NF Looking for Runners and Volunteers!

Run4NF.org is excited to announce that we will be spreading awareness as we walk/run/jog/cheer through the following cities this fall!

Baltimore—Oct.11
Kansas City—Oct.18
Detroit—Oct. 19
Philadelphia—Nov. 23
Seattle—Nov. 30
Phoenix—Jan. 18

All events have full marathons and shorter options. We are also looking for extra NF hands as Run4NF partners with the Seattle Marathon.

Consider especially joining us in Detroit on October 19th. Walk or run 5K (3.1 miles), half or full marathon, or create a 5 person team for a relay. In a wheelchair? We may have a runner to help! We also be working a water station. Join us for a great time and get free dinner and free gear!

Smiles for Sarah

5K Fun Walk Scheduled for Sunday, October 12, 2008 Oak Forest, Illinois

Once again, a 5K fun walk will be held in honor of Sarah - Panazzo. For more information, please call the NF Inc. Midwest office at 630-932-8111.

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Designate NF, Inc. CFC #1132

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Midwest NF Clinic Information

Treating Children Only

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2300 Children's Plaza
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Chicago, IL 60614

773-880-4462

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

Treating Children and Adults

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

Illinois NF, Inc. (dba NF, Inc. Midwest) 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 NF Inc Midwest.

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