A Publication by NF, Inc. Midwest for Neurofibromatosis

Neurofibromatosis Newsletter

Volume 28, Issue 2 **Summer 2009** **Published 3 times a year**

Save the Date! Be informed!

2009 Neurofibromatosis Symposium
Saturday, October 17, 2009
NIU Hoffman Estates, IL

Join NF, Inc. Midwest and a panel of specialists who will share updates on research, current treatment options, cognitive issues, executive functioning, learning disabilities and more. There will be break out sessions in the afternoon for NF1 and NF2 groups. In the morning, and once again in the afternoon, there will be time for snacks and socializing.

Children 5-17 years are welcome and are split into 2 kids' groups. For the kids it's a fun day full of games and activities, as well as a great opportunity meet others with NF.

Speakers and subjects include:

Living with NF: Personal Perspectives
Featuring Marie Drew and Mike Forbes

Attention, Executive Function, and Learning Disabilities in NF Type 1
Presented By Scott Hunter, PhD, University of Chicago

Cognitive Issues in Neurofibromatosis Type 1
Presented by Bonnie Klein-Tasman, PhD, University of Wisconsin-Milwaukee

Survey of NF-1 Clinical and Basic Research Panel
Panel includes James Tonsgard, MD, PhD, University of Chicago; Robert Listernick, MD, Children's Memorial Hospital; Cynthia Hingtgen, MD, PhD, University of Indiana; Fawn Leigh, MD, Massachusetts General Hospital; Yuan Zhu, PhD, University of Michigan

Preclinical Mouse Models of NF Type 2: The Potential for Prediction
Presented by Marco Giovannini, MD, PhD House Ear Institute, University of Southern California Los Angeles

The Use of Cyberknife on NF-2 Tumors
Presented by Robert Leiberson, MD, Stanford University Medical Center, CA

NF-2 Research at Massachussets General Hospital
Presented by Fawn Leigh, MD, Massachusetts General Hospital

***Living with NF Teen Session* (for children ages 12 to 18)**
Facilitated by Kelly Lowry, PhD, Child Psychologist, Children's Memorial, Chicago

GIOVAN'S
RESTAURANT & PIZZERIA

Don't miss the Ravioli Eating Contest at Giovan's Restaurant & Pizzeria! See inside for details!

Don't miss another event. Sign up for email updates at nfmidwest.org!

Inside This Issue

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.

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Thank You eDOC Communications

Phil Rokosz and eDOC Communications have been donating printing services to NF, Inc. Midwest for many years. This has been, and continues to be, a tremendous savings to us and is a phenomenal help to the NF cause. To honor them we stopped by the eDOC offices with an Outstanding Service Award and some delicious treats.

If you are in need of any printing services consider eDOC for your needs, this would be a great way to show your appreciation for their dedication to the neurofibromatosis cause. They are located at 662 Wheeling Road, Wheeling, Illinois and can be reached at (847) 459-5610.

Phil Rokosz (center) and his team at eDOC Communications accepts an Outstanding Service award from NF, Inc. Midwest.

Meet Joan

Some of you may have noticed a new face and/or voice at the NF Midwest office. Joan Pilkinton is now working as Assistant Director. Joan has been working with us for years on our Great Steps walk and we welcome her energy and enthusiasm!

May 2009 Illinois NF Awareness Month

The House of Representative of the 96th General Assembly of the State of Illinois passed a resolution proclaiming May of 2009 as Neurofibromatosis Month in the State of Illinois. Thanks go to Michael Forbes and Representative Michael G. Connelly for their help in instituting this resolution.

Annual Board Meeting
6:30 pm, October 13

NF, Inc. Midwest will be holding their annual board meeting at 6:30 pm on Tuesday, October 13 at the NF Midwest office, 145 S Main Street, Lombard, IL.

Washington, DC

In February our executive director, Diana Haberkamp, joined other NF crusaders from around the country in Washington DC to advocate for funding of NF research. Diana visited the offices of Senators and Representatives from the Midwest. It involved a great deal of walking and talking, but we were all motivated for the job.

L. to R.: Kim Bischoff, Diana Haberkamp, Representative Debbie Halvorson (Illinois 11th Dist.), Justin Nesmith, and Beverly Oberlander

Good News!

All your efforts in writing your senators and representatives is starting to pay off in the form of hope for NF!

We asked for $20 million and the House 2010 Defense appropriations bill passed the full House with **$25 million** marked for the Army's NF Research program!

The Senate has yet to take up the Defense bill. The Senate Defense Subcommittee is not expected to consider their bill until September so we may need more help from you in the future, but this is a BIG step! We'll keep you informed.

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Board Of Directors

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Ken Schoening, Director

Life's Challenges Bring Perspective

By Gaby Arnhardt

(Gaby is a writer for the Aurora Herald. We have reprinted her first column with her permission.)

Hello. As this is my first column, I thought it best to introduce myself. My name is Gaby. I am 52 and have been married 29 years. Sadly, we were not blessed with children. My husband and I met at the Old Chicago amusement park in Bolingbrook. He was a security officer, and I worked in the laundry department. The manner in which we met is worthy of a column of its own.

I am a bit of a shutterbug who enjoys the outdoors, long walks, fishing and studying nature in all of God's wonder. I would like to learn to ride and rehabilitate horses some day. I am an avid reader and admit without shame that most of what I read is strictly romantic.

[If you were to see my picture it would be] very clear that I don't look like most people.

I have neurofibromatosis. Or NF. The long and the short of this disorder is that it can affect many areas of the body, including the brain.

Blindness and hearing impairments are not uncommon. Tumors in the brain can cause seizures. And there are often varying degrees of learning developmental difficulties, which can range anywhere from severe, to relatively mild—I certainly have had my challenges. Challenges that I now believe have enabled me to view life in a greater perspective.

It wasn't until a few years ago that I decided that I wanted to write. I had always been a deep thinker. My head was always in the clouds. But write, me?

Fearing ridicule, I revealed this dream to a scant few.

After all, my spelling and grammar were so poor that an anthropology instructor once said to me, "You speak so well. How is it that your spelling and grammar are so poor?"

I could only shrug my shoulders. What could I say?

However, there is something to be said about determination. I bought a good dictionary and began to write.

Then, not long ago, I began writing to certain columnists because I wanted to let them know how much I enjoyed their columns and to encourage them to keep up the good work. They, in turn, encouraged me.

Little did I dream, however, that I would be asked to join the ranks of writers I have so admired.

I am a believer in Jesus Christ. I have no doubt that some of what I write will ruffle a few feathers. However, I hope that for the most part, I will be able to touch a chord with some of you.

Ask The Doctors

Approximately 40 people joined us for our annual *Ask the Doctors* forum. *Ask the Doctors* is a free informal question and answer session in which attendees can ask questions of NF experts. It is held every April at the Shriner's Hospital in Chicago.

Dr. James Tonsgard of the University of Chicago and Dr. Robert Listernick of Children's Memorial answered questions for 1.5 hours after which we broke off into groups to share experiences and information with each other.

Don't want to miss this event next year? Be sure to sign up for email updates at www.nfmidwest.org or call us at 630.932.8111 with your email address!

NF Gathering

August 28-30 saw an *NF gathering* at Cedar Point Amusement Park in Sandusky, Ohio. NF children, adults and families met up to make new friends, have fun and to build awareness for NF because "you need to be seen in order to be heard!" If you are interested in future NF gatherings and opportunities, give us a call (630.932.8111) or sign up for mailings on our website at www.nfmidwest.org.

NF needs your participation in the Combined Federal Campaign (CFC)

Neurofibromatosis, Inc. CFC code #10227

Get Involved! If you are a federal government employee or military employee, the CFC program will allow you to make pledges to Neurofibromatosis, Inc. Pledges made during the campaign season (September 1st to December 15th) support eligible non-profit organizations like Neurofibromatosis, Inc.

All federal employees have the opportunity to participate, so please check with your company's Human Resources Department for information on how to enroll in this worthwhile program where you can make a difference. Our CFC code is #10227. Many thanks to you for supporting our cause.

Spread the word to anyone you know who may qualify for this successful charity campaign!

Clinical Trials

One of the best ways to improve the future of people with NF and related disorders is to participate in Clinical Trials. There are many ongoing trials looking for participants. We've included brief information on a few below, but there are far too many to highlight here. A clinical trial is sometimes a great way to get extra care and input. For up-to-date information clinical trials go to www.clinicaltrials.gov and search *neurofibromatosis*.

Spinal Abnormalities in NF Type1 (Indentifier NCT00667836); Shriners Hospitals for Children, Age 3-18 with NF1, Contact: Susan J Geyer, CCRP, 801-536-3561 Email: sgeyer@shrinenet.org

Natural History and Biology of Skin Neurofibromas in NF1 (Indentifier: NCT00314119) National Institutes of Health & University of Alabama; Ages 20-50 with NF1 and biological parents available Contact: Patient Recruitment and Public Liaison Office at (800) 411-1222, Email: prpl@mail.cc.nih.gov

Phase I Clinical Study of the Safety of Photodynamic Therapy (PDT) Using LS11 in Children With Plexiform Neurofibromas (Indentifier:NCT00716469) Children's Hospital of Philadelphia; Ages 3-21; Patients must have a debilitating, severely disfiguring, life-threatening, or progressive plexiform neurofibroma (PN), which is not surgically resectable and for which there is no other standard medical management.
Contact: Michael Fisher, MD at 215-590-2800, Email: fisherm@email.chop.edu

Pass the VERY Big Word

Merchandise is available to help raise NF awareness.

We currently have NF Midwest license plate frames available for $6.00 each or 2 for $10. This price includes postage. The frames are blue. The top says **www.*NFMidwest.org*** and the bottom says ***End Neuro •fibroma • tosis***. Please, contact the office at 630.932.8111 or by email at info@nfmidwest.org to order.

eNuF NF shirts (see design below) and other *eNuF NF* merchandise are also available at www.zazzle.com/nfmidwest.

Camp New Focus 2009

Depending on the speed in which you receive this newsletter, there may still be time to sign up for *Camp New Focus* for NF families. Running Friday, September 18 through Sunday, September 20, this new camp is bound to bring loads of laughter and friendship. The camp is being held at Eagle Village Adventure Learning Center in Hersey, Michigan (near Reed City) where families can participate in activities including arts & crafts, canoeing, ropes course, and team building exercises. Support groups and role playing for children and parents are also planned. The cost of the weekend family camp is $140 for children and $100 each for adults, but MANY camperships are available to offset most of these fees.

Kane County Cougars NF Family Day

An evening of Fun, Food and Fireworks!

Due to heavy rains Friday, May 15th the Kane County Cougars NF Family Day was postponed to the following Friday, May 22nd. This proved to be the right choice for not only was it dry, but the Cougars won the game. Thank you to the Kane County Cougars for accommodating us with the change.

Tyler and Shaun Neppl enjoy the sun and fun!

About 100 family and friends joined together to share some food, stories, baseball and fireworks. It was a great informal way to meet other families coping with NF. It's nice to know we are not alone.

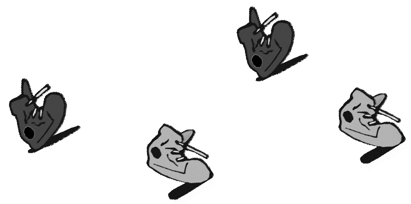
Lindsey was the winner of a Derrick Lee jersey donated by Julie Rutter. This was raffled off to the all in attendance at the game. How awesome one of our NF families was the recipient of this prize! Congratulations Lindsey!

Thank you to the Parent's Action Committee (PAC) for coordinating this event.

Sunshine wasn't the only thing lighting up the field. Joey Accordino's smile beams a light of its own.

Sponsored by

Fox Valley WOMEN & CHILDREN'S HEALTH PARTNERS



Go Great Steppers!

Great Steppers have shown they have had eNuF Neurofibromatosis by coming out in record numbers to build awareness and raise funds for research. Naperville's 8th annual Great Steps for NF walk had over 1,000 participants in attendance on June 6th bringing in over $130,000! Effingham's 2nd annual Great Steps for NF walk had over 100 participants in attendance on June 20th and brought in over $8,000! Congratulations one and all for your amazing effort and enthusiasm. Your hard work and determination is the key to giving us and our loved ones hope.

Great Steps for NF is a **fun**tastic event for everyone to participate in. Mark your calendars for the 9th annual Great Steps walk in Naperville to be held June 5, 2010 and the 3rd annual Great Steps walk in Effingham to be held on June 19, 2010.

1st Annual Great Steps for NF Walk Kansas City

Naperville Top Winners

1st Place: Cole's Crew $12,182
2nd Place: Team Doodle $8,912
3rd Place: Team Addalyn $8,034
Most Creative Accessory:
Team Haberkamp Kiss off NF)
Cartridges/Cells: Friends of Abby

Katie's Kruisers tell us it is time to cure NF!

Let NF, Inc. Midwest know if you are interested in starting a walk in your area, we have all the tools you need to get going. Two women in Kansas City started their 1st annual Great Steps for NF Walk June 13th in Kansas City- this could be you!

Effingham Top Winners

1st Place: Rear in Gear for the Cure
Creative Accessory: Shannonigans

Check out the many great photos online at www.photobucket.com/greatsteps2009_album for Naperville and www.flickr.com/photos/madphotosink/sets/7215762055 for Effingham.

Thank you!

Thank you Great Steps Sponsors for making the walk a success!

Presenting Sponsor:	Harmon, Inc
Supporting Sponsor:	eDOC Communications, Gardner Metal Systems, Circle Metal Specialties, Giovan's Restaurant and Pizzeria
Participating Sponsor:	American Chartered Bank, Crown Corr, Inc., Therese Meike with Raymond James & Associates, Viracon, Inc., Stevenson Crane Service, Inc.
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Others we would like to thank:

Classic Party Rental
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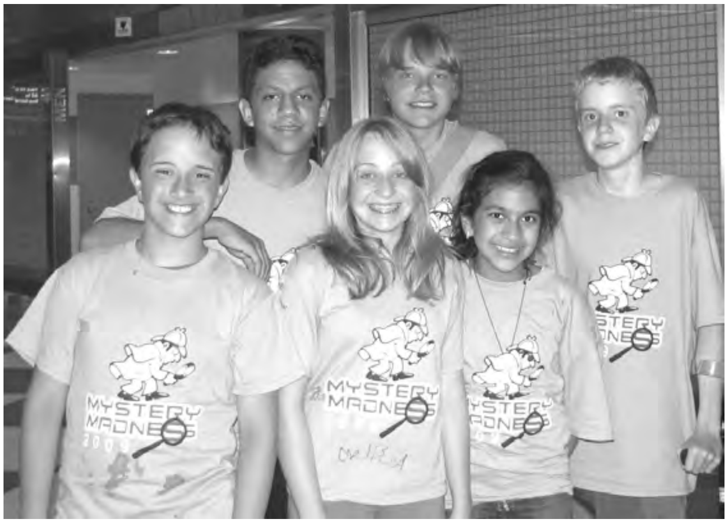
Chris/Music2Go
WasteBox Inc.
Casey's Foods
Sign-a-Rama
Logomax
Trader Joe's
Michael's Fresh Market
Brown's Chicken Naperville
Connie's Pizza

This year NF, Inc. Midwest and a very special donor, sent 7 kids to Camp New Friends at their new location in Virginia. All but one were new to the experience and they all had a great time!

Run by the National Children's Medical Center with help from NF, Inc. Mid-Atlantic, Camp New Friends gives kids with NF an opportunity to meet others kids and adults with NF. From this they learn more about NF in a supportive, fun environment. They also build self-esteem and make lasting friendships.



The Midwest kids are all smiles upon returning from Camp New Friends. (L-R) Joey, Armondo, Rachel, Jake, Dalia and Brandon. Also attending was Hallie, not pictured.

NF Adult Group (NAG)

Our NF-1 Adult Group continues to meet regularly. Choosing to be proactive and taking NF head on, this group develops fundraisers, increases awareness and finds support in friendships and socializing. Meetings are generally planned a month in advance. If you'd like to be notified of NAG happenings please contact the office at 630.932.8111 or drop an email to nag@nfmidwest.org.

Parents Action Committee (NF-PAC)

This is an informal group that anyone with an NF child or young adult may participate in. The focus of the committee is to create opportunities for kids with NF to meet and socialize; to promote NF awareness; to support each other; and to share and learn from each others experiences. Our meetings are not set on a regular schedule. If you want to be informed of meetings and events you need to call us at 630.932.8111 or drop an email to parents@nfmidwest.org.

NF2 News

Anti-angiogenesis treatment improves hearing in some NF2 patients

Scott Plotkin, MD, PhD, and his team of researchers from Massachusetts General Hospital report success in their trial of bevacizumab (Avastin) on NF-2 patients with vestibular schwannomas. "This kind of treatment response is unprecedented," says Scott Plotkin. "Our study is the first to provide evidence that a drug can shrink vestibular schwannomas - benign tumors on the balance and hearing nerves - and the first to show that patients' hearing can be improved." Bevacizumab, which is an FDA-approved treatment of several forms of cancer, was offered to NF2 patients in danger of complete hearing loss or other significant neurological damage. Among the first ten NF2 patients to receive bevacizumab, treatment led to tumor shrinkage in nine, and six had 20 percent or greater reduction in tumor size. In those six patients, tumor shrinkage lasted from 11 to 16 months, longer than the four months typically seen in bevacizumab treatment of malignant brain tumors. Of seven patients who had started to lose their hearing before treatment, four experienced some hearing restoration - two returning to work or school as a result - improvement that has also lasted for up to 16 months. In one patient without significant tumor shrinkage or hearing improvement (he had lost all hearing prior to treatment), treatment alleviated headaches and nausea caused by brainstem compression, allowing him also to return to school.

Based on the results of this study, Plotkin's team just opened the first formal clinical trial of a drug treatment for NF2 and are now testing an exciting new, oral VEGF inhibitor (PTC299) that will be easier for patients to take - bevacizumab is administered intravenously - and may have fewer side effects."

Please do an online search for more information on this exciting research.

NF2 Clinical Trial

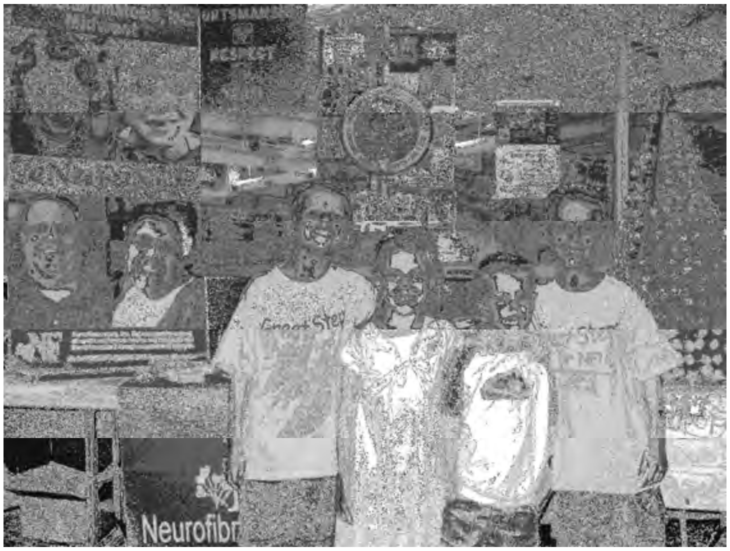
Massachusetts General is currently recruiting participants for a Phase 2 study of PTC299. Participants must be 18 years or older; have a diagnosis of NF2; the presence of vestibular schwannomas; evidence of progressive increase in vestibular schwannoma size or worsening hearing loss due to vestibular schwannoma; NO prior exposure to another anti-angiogenic therapy (eg, bevacizumab, sunitinib). There are other requirements and restrictions. For more information go to www.clinicaltrials.gov and use the identifier, NCT00911248, or contact Diane M Goetz at (908) 912-9256 or send her an email at dgoetz@ptcbio.com.

Membership Dues

NF, Inc. Midwest does have yearly membership dues of $25.00 per member. While we don't strictly enforce these dues because we believe in serving the Neurofibromatosis community regardless of their ability to pay, membership dues help us to provide the very basic services of a newsletter, website, etc. If you are able, please consider sending in your annual membership dues of $25 to let us know that you are still interested in our work and services on behalf of the NF community.

Community Fundraising

Consider a community or family fundraiser to raise funds and awareness for the NF cause. Community/Family Fundraisers are events that are put on by NF Midwest members or their friends and family to benefit NF research or support various programs. Often these are in honor of a loved one affected by NF or for a Great Steps team. They can be anything from a slightly time consuming event such as a golf outing to something simpler like a home party. No matter what the event, they are always fun and bring awareness to the NF cause!



Ryan, Keaton and Jacob Munter support their cousin, Katie, with a roller skating party for NF.

4th Annual Ravioli Eating Contest & Buffet Dinner To Benefit NF

Inspired by Angel Szoldatits who has NF2. Created by Joanne and Ken Kottke (Angel's parents) and of course Giovan's.

When: Thursday, September 10, 2009
Doors open at 6:30 p.m. Contest at 7:00 p.m.

Where: Giovan's Restaurant & Pizzeria
Crest Hill, IL

What a bargain for $15/person you get an all you can eat buffet of pizza, ravioli, chicken, salad, soda & beer! If you are the competitive type and love ravioli join the contestants and see if you have the appetite you always thought. It's $40 to enter the contest.

Tickets are available now. Reserve a table if you have ten or more people. Call Giovan's at 815-725-6000. Space is limited.

You won't want to miss out on the food, raffle prizes, music and laughter! It's guaranteed to be a good time!

Volunteers are needed along with prizes for the raffle. Get involved, now is the time. Call NF, Inc. Midwest at 630-932-8111 if you can help out. Thanks for your consideration.

11th Annual Golf Benefit

We had yet another beautiful day for our 11th Annual Golf Benefit for NF. Held at the Prairie Landing Golf Club in West Chicago, 66 golfers relaxed, laughed, and of course cursed a little, for the NF cause. Eighteen holes were followed by a reception with silent auction and raffle.

Not taking his eye off the ball this golfer takes a swing for neurofibromatosis!

Paul Blake shows of his stash from the silent auction.

Thank you to all of our sponsors, volunteers and golfers, especially (though we've sure to have forgotten someone special):

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Sharon Wadelin
Gordon Cummings
eDoc Communications
Jay Sanders

I.S.M.A. 2009 NF Poker Run

Another community fundraiser was held by the Iron Skulls Motorcycle Association of Pecatonica Illinois. The group held a poker run on Saturday, August 28 in honor of Ali, a 13 year old with NF Type 2.

Ali looks cool and cycle ready the Poker Run!

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Midwest NF Clinic Information

For more Doctors go to www.nfinc.org/directory.shmtl

Treating Children Only

Children's Memorial Hospital
2300 Children's Plaza
PO Box 59
Chicago, IL 60614

773-880-4462

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

Treating Children and Adults

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Sharon Morton
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Treating Children and Adults

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Neurofibromatosis Clinic
Division of Medical Genetics
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314-454-6120

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. Currently our coverage includes the states of Iowa, Indiana, Wisconsin, Kentucky, Tennessee and eastern Missouri.

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