



A Publication by NF Midwest for Neurofibromatosis Families

# Neurofibromatosis Newsletter

Volume 30, Issue 2

Fall 2011

Published 2 times a year



## be informed

### 2011 NF Midwest Symposium

**Saturday, October 15**

**8:00 AM to 4:00 PM**

**NEW LOCATION!**

**Renaissance St. Louis Airport Hotel**

This is our 26th year holding this popular educational event, only this year; in an effort to spread the knowledge, it is being held in St. Louis.

Be sure to take advantage of this AWESOME opportunity. THE COST IS ONLY \$20 for adults and not only includes impressive information, but a continental breakfast and lunch. Children ages 12-17 are \$10 and those 5-11 are FREE. Unfortunately, we do not have childcare for kids under 5 and they are not permitted in the sessions.

We have a fantastic agenda including a general session on advocating for your child and/or yourself; NF1 sessions on integrating research and clinical care, cognitive issues, plexiform treatment, and vascular issues; and NF2 sessions on chemotherapy in the treatment of brain tumors, natural history of cranial tumors, treatment options and patient care at [Washington University NF2 Clinic](#); overview of hearing loss, evaluation procedures, treatment options, rehabilitation and resources for hearing-impaired individuals.

Be sure to check out the brochure and agenda online at [nfmidwest.org/symposium2011](http://nfmidwest.org/symposium2011). If you have any questions, please give us a call a 630-945-3562 or email us at [info@nfmidwest.org](mailto:info@nfmidwest.org).



### Send Us Your Personal Letters To Deliver to DC

Early next year we will once again head to Washington DC to bring the NF cause to the attention of Congress and to ask for continued funding of NF research. Bringing your stories to our senators and representatives has a great impact. Please write a letter to your two senators and your representative that we can hand deliver. Include your personal story and the need for NF research. Also, be sure to ask your family and friends to do the same for their members of Congress. The more letters, the greater impact. Write one today!

### Newsletters Will No Longer Be Mailed

Beginning with our next newsletter, **we will no longer be sending out a printed newsletter if we have your email address.** Let us know if you'd still like to receive a printed one. This will save money for the NF cause. Also, the online version has links for more information. If you are not receiving occasional emails from us, please confirm that we have your correct email address by sending us an email at [info@nfmidwest.org](mailto:info@nfmidwest.org) or calling 630-945-3562.

### Board Of Directors

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### Mission Statement

NF 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 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.*

**NF Midwest**  
473 Dunham Rd., Ste. 3  
St. Charles, IL 60174  
1.630.945.3562  
[info@nfmidwest.org](mailto:info@nfmidwest.org)

## Participate in Research

Want to further the NF cause? Participate in a research study. Below are a few of the opportunities that are available. Go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov) for more. Investigate any study carefully to be sure they are right for you or your loved one. **It is a good idea to consult with your “NF doctor” before participating.** These opportunities have been made available by grants from us or organizations like us and through federal funding. This federal funding is made possible only by continued pressure from the NF community. NF Midwest does not endorse any one study. These are studies that have been brought to our attention for various reasons.

### NF1 Registry

The [Washington University Neurofibromatosis \(NF\) Center](#) has launched a unique internet-based [NF1 Registry](#), which is a 30-minute questionnaire. This questionnaire will collect medical information to help physicians and researchers better understand the spectrum of medical problems found in children and adults. They have also established a one-of-a-kind [NF1 Genome Project](#) which is a DNA Bank that will collect blood samples from individuals with NF1. Learn more about how to participate in these promising projects at [nfcenter.wustl.edu](http://nfcenter.wustl.edu).

### Online Quality of Life Study

[Indiana University](#) is conducting a NF1 quality of life study. This study will help to better understand how **NF1 affects the patient’s health and well being.** It will also help measure how well new treatments for NF1 are working. If you are an adult with NF1, a parent of a child with NF1, or a teen 14 years old or older, use the following links to participate.

Adults with NF1:

[www.surveymonkey.com/s/NF1-Adultsurvey](http://www.surveymonkey.com/s/NF1-Adultsurvey)

Parents of children with NF1:

[www.surveymonkey.com/s/NF1-Parent](http://www.surveymonkey.com/s/NF1-Parent)

Youth 14 years or older with NF1:

[www.surveymonkey.com/s/NF1-teen](http://www.surveymonkey.com/s/NF1-teen)

### Learning Disabilities Trial

The University of Chicago [Neurofibromatosis Program](#) (Dr. Tongsgard), and the [NF Center](#) at Washington University, St. Louis (Dr. Gutmann) along with 7 other [NF Consortium](#) centers around the U.S. are conducting a study of learning to see if [Lovastatin](#), a conventional cholesterol lowering medicine, might improve learning in children with NF Type 1. This study furthers the work of [Dr. Silva](#) whose work on learning in NF mice was partially funded by NF Midwest. Dr. Silva observed that using cholesterol medicine on NF animals normalized learning. Participants must be between the age of 8 and 16. For more information please contact the University of Chicago at 773-702-6488 or the St. Louis NF Center at 314-632-7379.

### The Early Development of Children with NF1

The University of Wisconsin Milwaukee Dept. of Psychology ([Bonnie Klein-Tasman, Ph.D.](#)) is collaborating with the University of Chicago NF Program and **Children’s Hospital of Wisconsin NF Clinic** to learn about the cognitive, learning, and behavioral functioning of young children with NF1. They are looking at the functioning of 3 to 6-year-olds with NF1 as well as their siblings without NF1. First language must be English. Participation takes up to 4 hours. The researcher will play games with the child to look at reasoning, expressive and receptive language abilities, patience, and reactions to mild frustration. The research takes place at the Child Neurodevelopment Research Lab at the University of Wisconsin – Milwaukee or at Glenbrook Hospital in Glenview, IL. For more information please contact the Child Neurodevelopment Research Lab at the University of Wisconsin – Milwaukee at (414) 229-2586. Ask for Lorri or Kelly.

### Schwannomatosis International Database

A consortium of medical institutions is collecting limited information on schwannomatosis patients. This includes their symptoms, their management and medication, and whether receiving ongoing treatment, no treatment, or deceased. They hope that the information collected will help improve how patients are cared for, with the goal of understanding more about the symptoms of schwannomatosis and making treatments as effective as possible.

To read more about this project go to [schwannomatosis.com](http://schwannomatosis.com) or follow the link below to an interview with the SID coordinator, Amanda Bergner: [www.youtube.com/watch?v=kCHdKiJYnO4](http://www.youtube.com/watch?v=kCHdKiJYnO4)

### Breast Cancer in NF Study

Dr. Xia Wang at Henry Ford Hospital is working on a grant from the Department of Defense to study breast cancer in NF1. If you or a family member with NF1 has had breast cancer, regardless of how long ago, please consider contacting Dr. Wang to help her gather data. Simply email her at [xwang1@hfhs.org](mailto:xwang1@hfhs.org) or at 313.916-3188. **She’ll send you all the information you need to decide whether you wish to participate.**

## How do you say thank you?

Show us how you say "thank you." Help us thank all of our generous donors and volunteers, by making and sending us thank you cards that we can then send out during the year. These can be store bought or hand made. In the note you may put your personal thanks to our donors or volunteers. You might write how NF Midwest helped you, affected you, or informed you, however, try to leave a large area for us to write our own thank you. Please be specific. For instance, did your child go to camp or are they planning to go to camp? Did the NF Midwest office help you figure out a problem or lend an ear? Did you meet other families because of a particular event? Did you attend a symposium or Ask the Doc? Be creative and draw a card or insert a picture. Make several different cards with different thoughts by hand or have copies made (check out a printing website such as vistaprint.com or shutterfly.com) and send them to us at NF Midwest, 473 Dunham Rd, Suite 3, St. Charles, IL 60174.



## National Schwannomatosis Group

We are looking to form a schwannomatosis support group or action committee on a local or national level. If you are interested in the opportunity to be a part of such a group or know of an existing group, call us at 630.945.3562 or drop us an email at [schwanno@nfmidwest.org](mailto:schwanno@nfmidwest.org).

Schwannomatosis is a form of neurofibromatosis that is not well understood. Patients with schwannomatosis have benign (non-cancerous) tumors called schwannomas that form on many nerves in the body. Many people with schwannomatosis also have very severe pain. Only 10% of patients with schwannomatosis inherited the disease from a family member. Scientists do not completely understand the genetics of schwannomatosis.

## Heard Around the NF "Circuit"

Below are nuggets of wisdom or information we've come across that we wanted to share.

- Research on mice with NF not only helps us to test therapies to treat the complications of NF, but added benefit is that scientists find deficiencies in the mice that can then be looked for in **humans with NF**. For instance, **Alcino Silva's lab** found deficits in working memory in mice with NF1. Now clinicians know that this may be a problem in some people with NF1.
- "Nothing that is boring is going to click in the mind of a child." - Alcino Silva, Ph.D.
- "Approach a teacher with a plan instead of saying Johnny has ADD what are you going to do?" Maria Acosta, MD

## Removal of Fibromas MAY BE COVERED BY INSURANCE

When coded correctly and properly documented by a doctor, the removal of neurofibromas for people with NF is covered by most insurance plans. Be sure that your physician uses the correct diagnostic codes and includes proper documentation. Also, it is HIGHLY recommended that you do not see a dermatologist for removal, but a plastic surgeon. Preferably one referred to you by a reputable "NF doctor". For more information on this, please call the office.

Diagnostic codes: 237.70 NF unspecified  
237.71 NF1  
237.72 NF2



## Ask the Doctor

We held "Ask the Doctor" events last April in Chicago and Indianapolis. These are excellent opportunities to have an informal question and answer session about NF with NF experts. It is also a great way to meet other families with NF and to learn from each other. Look for more of these sessions this spring.

## Do You Want to Build the NF Community?

Help build the NF community by holding a Meet4NF meeting in your neck of the woods. Call the office to see if we have identified enough people near you to hold a small informal meet and greet. If so, you'll help put it together and we'll help get the word out and supply you with materials or awareness merchandise. Isn't this a simple way to start building an NF community in your area?







## Listen Online and Learn More about NF.

Be sure to arm yourself with knowledge by watching the 1 hour recorded webinar [\*\*10 Things Everyone Should Know About Their NF.\*\*](#) This webinar was given by Dr.

Doug Stewart of the National Institutes of Health and hosted by NF Inc. You can find an easy link the webinar at [nfmidwest.org/education](http://nfmidwest.org/education).

## How Are You?

Have you ever been seen at the University of Chicago NF Clinic? Have you lost touch with them? If so, Dr. Tongsgard is looking at long term outcomes of NF patients and would like to know how you are doing. This information could be VERY valuable in helping clinicians and researchers better understand NF. Call Debbie today at 773-834-1927 .

**URGENT**

## Filmmaker documents individuals with genetic disorders

[Rick Guidotti](#) of [Positive Exposure](#) is working on a documentary and web engagement campaign with [Joanna Rudnick](#) of [Kartemquin Films](#), the company known for the documentary “Hoop Dreams”. This new project seeks to “boldly challenge the way we see and treat all individuals with genetic diseases—asking every viewer to participate in a global conversation surrounding the dangers of intolerance, judgment, and fear.” They are looking for support by social media as well as financial support.

Check out the I Am Beauty campaign at [iambeauty.me](http://iambeauty.me). See Rick Guidotti talk about meeting Valerie a young girl with NF at <http://iambeauty.me/character-webisodes/>

## Gordon Cummings

Imagine keeping passionate dedication to one cause for over 30 years. We have a few people who have done so. They started with no NF community to turn to; no NF clinics and no awareness of neurofibromatosis. Funds and any interest in the cause was very difficult to find, but they persevered.



Gordon Cummings is one of those small handful of people that was there at the beginning and hung on for the long haul. Just this year as he turns 80, he resigned from the NF Midwest board. Several years ago he lost his wife, Shirley, and very recently his **daughter, Lisa, to the disorder, but for him NF isn't** just personal. He cares about the people with NF and he fought not only for research, but also for awareness, support and better care. For 30 years not only was he serving at various times as board president and treasurer, he was in the trenches with his sleeves rolled up at plant sales, symposiums, and various fundraising events. More recently, you would find **him as a witness on the “hole-in-one” contest at golf** benefits. Gordon, and others like him, are a rare breed and we owe them a debt of gratitude. Thank you, Gordon for your time, your passion and your grace. Can we clone him?



**Beauty Mark Nation™**  
United to Cure Neurofibromatosis

**Join the Beauty Mark Nation  
at [www.beautymarknation.com](http://www.beautymarknation.com)!**

If the site isn't up, please check back.



*NF Midwest kids return triumphantly from camp.*



Your generous support enabled NF Midwest to send 14 kids with NF to [Camp New Friends](#) in Harrisonburg, VA. This incredible camp is run by the [Brainy Camps Association](#), which is a subsidiary of the [Children's National Medical Center](#). Kids attend for a week and make con-

nections that will last them a lifetime.

Check out photos at [brainycamps.smugmug.com](http://brainycamps.smugmug.com).



It's been quite the busy [Great Steps for NF](#) season with four "official" Midwest walks. We say "official" because [some energetic teams](#) such as [Alex's Angels](#) in Malden, MO have held their own walks for the cause. Walks such as theirs have the same spirit and raise awareness and community, but require minimal support from the NF office.

All of the Great Steps walks are not only phenomenal in the funds and awareness that they raise on the day of the event, **but they continue the cause for most of the year as team's hold events or reach out for donations. In both ways teams raise hope by raising their voices.**

This year we hit a huge milestone as our combined total in the Midwest for our walks over 10 years has now raised over \$1,000,000 (look at all those zeros). Most of this was raised by one walk in Naperville. Now that we have more walks will get to our next million it at least half the time!

### **Naperville, June 4th (see [photos](#))**

Saturday, June 4th was our 10th walk in Naperville, the grand-daddy of all our walks nationwide and it was a beautiful day! We had over 1,000 participants, had 53 teams and raised over \$120,000. Plus, we had a new chairperson, Dave Tipton, who did a fantastic job! Thank you, Dave for your hard work. We also had a great corporate sponsor, [Enterprise Rent-a-Car](#), a great committee that included Joan Pilkinton, Marge Griest, Kelli Dompke and Lesli Wegner and a whole ton a very, special volunteers!

### **Madison, May 21st**

Wisconsin held its 2nd annual Great Steps Walk for NF in the Madison area on May 21st. Thank you to our wonderful Madison committee of Kristin Pilgrim, Katy Freye and Tim Eberle this years walk grew a bit from last year. The Wisconsin NF community is making a difference!

### **Effingham, June 18th (see [photos](#))**

Effingham's 4th annual Great Steps Walk for NF was WET, but the spirit of the walkers wasn't dampened and they proved that the NF community and it's supporters can weather any storm. Thanks once again to Effingham chair, Laura Didier and her team for all their hard work.

### **Fort Wayne, September 10 (see [photos](#))**

Fort Wayne's Inaugural Great Steps Walk (and the 1st one in Indiana) was amazing with 12 teams. This is fantastic for an inaugural walk and the credit goes to a bunch of energetic families in the area. Special thanks to Liz Taylor for chairing the walk.

### **By The Numbers**

All total NF Midwest Great Steps Walks raised over \$148,000 so far in 2011! While over half of our teams raised \$1,000 or more, every effort is appreciated and needed. **It's not just about the funds raised for the cause, but also about the awareness the efforts raise. Good job everyone!**

#### **Naperville**

Amount Raised: \$120,500  
 Participants: 1000+  
 1st Place: [Team Doodle](#) \$15,711  
 2nd Place: [Tim's Gang](#) \$7,754  
 3rd Place: Kate \$5,472  
 Most Creative: Motely Cure (Happykampers)

#### **Madison**

Amount Raised: \$5,300  
 Participants: 50

#### **Effingham**

Amount Raised: \$17,500  
 Participants: 150  
 1st Place: [Alex's Angels](#) \$6,876  
 2nd Place: Little Buddies \$3,158  
 Most Creative: Little Buddies

#### **Fort Wayne**

Amount Raised: \$4,850  
 Participants: 75

### **Honorable Mentions**

**2Addi's is a great example of what a NF team can do. This team is two families and their friends who work together all year long to raise awareness and funds. The team of friends and family then travel 250 miles to the Naperville walk to celebrate their accomplishments and the lives of their children. Some of 2Addi's funds came in after our Thursday deadline, so they actually raised \$6,696 which would have put them in 3rd place!**

Team Jenni, a rookie team in Wisconsin raised \$1,146 in the span of about two weeks for NF Type 2.

A special mention goes to ALL the people who came out for the Effingham walk despite the torrential rain!

We had several new teams in Naperville that did a tremendous job for their first time out including Team Carter (\$4,500); Team Peltzer (\$1,760) and Thumbs up for Thaddeus which is a team that participated in both Madison and Naperville.

## Thank You to Our Sponsors

Over the summer we have had many successful events to raise awareness and funds for neurofibromatosis. We couldn't have done it without the support of our many business sponsors. Please, consider their contribution when you are looking to use their services and be sure to thank them when possible. Below are our larger sponsors. There were many other businesses that have supported us and we wish we had the space to thank them all.

### Great Steps Naperville



[Enterprise Rent-a-Car](#) Presenting Sponsor  
[Collision Centers of America](#) Participating Sponsor

### Take a Swing at NF Golf Benefit



[First Merit Bank](#) Corporate Sponsor  
[Michigan Avenue Real Estate Group](#) Corporate Sponsor  
[Oak Asset Management Professional Business Consultants](#) Raffle Grand Prize  
[Athletico](#) Party Sponsor  
[Rothschild Investment Corp](#) Lunch Sponsor  
[Baxter International Inc.](#) Beverage Cart

### Chip in Fore NF Golf Benefit



[Circle Metal](#) Title Sponsor  
[Crown Corr, Inc.](#) Title Sponsor  
[Circle Metal Specialties, Inc.](#) Lunch Sponsor  
[Harmon, Inc.](#) Beverage Sponsor  
[Mortenson Construction](#) Cart Sponsor  
[Doralco](#) Cart Sponsor  
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[Gardner Metal Systems, Inc.](#) Tee Sponsor  
[Mid-States Glass and Metal](#) Tee Sponsor

## Great Steps Teams Hold Community Events to Raise Funds and Awareness!

Some of our enthusiastic Great Steps teams fundraise for the cause and their team all year long by holding various fun and clever events. This is quite often how they end up being a leading team. Doing this also has the equally important benefit of raising awareness. We have seen various restaurant based fundraisers, bowling events, sock hops, trivia nights, poker nights, vendor nights and more. If you'd like to hold a [community event](#) and need ideas or help please contact us.



*Naperville Great Steps Team Lindsey's Lifesavers collected \$553 in their Pockets fundraiser.*

## Chicagoland NF Family Day

In May, in celebration of NF awareness month and to come together as a community, the Chicago NF Midwest chapter held a Family Day of bowling in Lake Zurich, IL. Look for another event in May. If you'd like to hold an event in your area, please call the office and we'll help you put it together.



*Paige W has fun with her mom at the Chicago area NF Family Day!*



## Did You See Something You Liked?

Do you see value in our newsletter and what we do? Can you support our efforts with a small [donation](#)?

Please take a moment to consider the time and costs that it takes to provide for research, educational programs, improved clinical care and support. What do **you like and what do you support? If you'd like to support our work**, here are some amounts to think about.

- **\$20** will cover 40 newsletters. This newsletter costs \$1800 or .55 each.
- **\$25** shows you care about support. Almost daily we receive calls from people looking for information, support or a listening ear.
- **\$40** helps build a stronger NF community. Donate to continue our work with groups to organize events like NF Family Days, Great Steps Walks, or NF chats to build a community.
- **\$50** can become \$10,000 in federal spending on NF research. Our advocacy efforts in DC provide research funds of more than 200 times what we spend. This is a great investment.
- **\$55** will cover the extra cost of one attendee. The symposium is made available at a cost of only \$20 per adult. It has an actual cost of approximately \$75 per person.
- **\$200** to fund research and clinical care. We provide direct grants for research and clinical care.
- **\$750** sends a child to Camp New Friends.

**Consider Donating  
\$30 for 30 years  
that we have been working  
for the NF cause.**

Please go to [www.nfmidwest.org/donation](http://www.nfmidwest.org/donation) to make a quick donation and note what it is you support or send a check to NF Midwest, 473 Dunham Rd, Suite 3, St. Charles, IL 60174. There are also other ways to give or support the organization, please call 630.945.3562 for more information.



## Do You Have a Celebrity Connection?



We're looking for celebrities to doodle for National [Doodle Day](#) which is held as part of Neurofibromatosis (NF) Awareness month in May. Celebrity doodles are available for auction on eBay during the month of May to raise money to benefit the NF Network.

Please, let us know of any connections you might have and we'll get a packet out to you in the spring. Also, be sure to check out the auctions on eBay in May and don't forget to spread the word!

## Charitable Dawgs



Here's something fun and edible for the NF cause! The neurofibromatosis cause will be the focus of **Franks 'N' Dawgs** (1863 N Clybourn Ave. in Chicago) Charitable Dawg from 12/9/2011 through 1/12/2011. Proceeds will benefit NF Midwest. We will be working with Franks 'N' Dawgs to come up with the accoutrements (stuff on top) for our special Charitable Dawg. So, if you have some ideas, let us know. **Frank 'N' Dawgs is not your everyday hot dog joint it's "five star dining on a bun". Their sausages are "hand crafted artisan sausages that are house made daily using only the finest cuts of meats that will redefine your sausage experience".**

Be sure to mark this on your calendar and visit **Franks 'n' Dogs** around the holidays. At that time of year you know you'll breaking your diet anyway! They aren't just a regular hotdog place. This would be a great outing with friends. Check them out at [franksndawgs.com](http://franksndawgs.com).

## eNuF NF Merchandise

|                       |         |
|-----------------------|---------|
| Heather gray t-shirts | \$12.00 |
| Women's blue t-shirts | \$14.00 |
| Great Steps Hoodies   | \$30.00 |
| Bracelets             | \$1.00  |
| License Plate Frames  | \$1.00  |



Call 630.945.3562 or email [info@nfmidwest.org](mailto:info@nfmidwest.org) to place an order. Shipping will be figured and added to all purchases.

Get more timely and detailed news by [signing up](#) for email updates at [nfmidwest.org](http://nfmidwest.org)!

## Neurofibromatosis Midwest

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630-945-3562

Fax: 630-689-1213

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

## Midwest Area NF Clinic Information

For more doctors go to [www.nfinc.org](http://www.nfinc.org)

### Children's Memorial Hospital

*(Children Only)*

2300 Children's Plaza

PO Box 59

Chicago, IL 60614

773-880-4462

Joel Charrow, MD

Robert Listernick, MD

### Indiana University NF Clinic

*(Children and Adults)*

Riley Hospital for Children

669 West Drive, RR208

Indianapolis, IN 46202-5119

Cynthia Hingtgen, MD, PhD (Director)

317-948-7450

*for scheduling & information*

Yvonne Hayden, RN (Clinic Coordinator)

[www.indiananf.com](http://www.indiananf.com)

### University of Chicago

*(Children and Adults)*

5839 S. Maryland Avenue MC3055

Chicago, IL 60637

James Tonggard, MD (Director)

773-702-6487

Cynthia MacKenzie, RN

773-203-2344

*General Inquiries & Research*

773-702-6169 (Chicago)

708-448-8000 (Palos Heights)

*Appointments*

[www.uchicagokidshospital.org/nf](http://www.uchicagokidshospital.org/nf)

### St. Louis Children's Hospital

*(Children and Adults)*

NF Center

Neurology Department

Washington University

Campus Box 8118

St. Louis, MO 63110

314-454-6120

[www.nfcenter.wustl.edu](http://www.nfcenter.wustl.edu)

David H. Gutmann, MD (Director)

Anne Albers, PNP

**NF Midwest is registered as a 501(c)3, not for profit organization in the State of Illinois. Currently our coverage includes the states of Illinois, Iowa, Indiana, Wisconsin, Kentucky, Tennessee and eastern Missouri.**