



A Publication by NF Midwest for Neurofibromatosis Families

Neurofibromatosis Newsletter

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2013 NF Midwest Symposium—A Day of Learning Saturday, October 12th, 8:30 to 4:00

Register NOW

Register now for our annual educational neurofibromatosis symposium and take advantage of this AWESOME opportunity. The cost is \$25 for adults and includes not only 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.

Our agenda isn't complete but what we have is already fantastic. It includes an introduction to NF; a presentation from an MPNST survivor; presentations on [reproductive options](#), [optic gliomas](#), NF2 drug discovery updates, NF2 research, communication apps for those with hearing loss, quality of life study of those on Avastin; and *Lessons Learned* a collection of helpful info from parents and patients with NF1. Plus, we are still adding topics.

Check out the brochure and agenda online at nfmidwest.org/event/symposium2013.

If you have any questions, please give us a call a 630-945-3562 or email us at info@nfmidwest.org.

Highlighted Clinical Trials

Be sure to check out the clinical trials on our website that we are promoting at the request of various researchers or go to clinicaltrials.gov to research all NF trials and studies. We have listed a few new ones here:

NF2 Communication Study—Amanda Bergner, MS CGC from Johns Hopkins is looking for people with NF2 and hearing loss to complete a 10 minute confidential online survey. You can find the survey on our website or email abergne1@jhmi.edu.

NF1 and Breast Cancer Study—Researchers at Henry Ford Hospital in Detroit, MI are conducting a study to evaluate the genetic and molecular characteristics of breast cancer in NF1 patients. They are looking for men or women with NF1 who also have a history of breast cancer. Travel is not necessary for participation. For more information please contact Renée Tousignant, MS, GC at 313-916-6970 or rtousig1@hfhs.org.

NF1 and Scoliosis Genetic Study—Participants are needed by researchers at the University of Minnesota for a study entitled: Genetic Evaluation for the Scoliosis Gene(s) in Patients with Neurofibromatosis 1 and Scoliosis. Participants must have a confirmed diagnosis of NF1 and Scoliosis. For further information please contact: Ivana Ninkovic, MPH MS, at 612-273-8082 or nink0002@umn.edu.



Board Of Directors

Dennis Pilkinton, President
Steve Griest, Vice President
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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.

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Be sure to mark us a "safe sender."

iNformation OVERLOAD.

So many ways to stay in touch...this newsletter isn't one of them!

Those of you who have been around awhile remember the days when information on neurofibromatosis was scarce and knowing someone with it was rare. Now we have an abundance of opportunities to learn through webinars, local educational meetings, symposiums, articles online and from each other through online forums such as the [Inspire site](#). We also have tons of opportunities to meet each other online and through events such as [Great Steps Walks](#), NF Family Days, and local DoIt4NF meetings and fundraisers put on by families and individuals who are inspired to help the cause.

The downfall of our times is that it is difficult to track all these opportunities and to get them out to the NF community in a timely manner. Mail such as this newsletter is slow, cumbersome and expensive. Providing information via the internet through social media and email is inexpensive and timely, but most of us are now so inundated by email, Facebook, Twitter, etc that we still often miss the NF news and alerts that are being given to us. EVERYTHING in this newsletter has already been posted online once or several times, and if you haven't seen it already you are out of the loop.

If you want in the loop and are interested in what is happening with neurofibromatosis, you now need to make a conscious and determined effort to get it. Here's how:

1. **Make sure we have your [CURRENT email](#)** and that we aren't being blocked. If you have an email and haven't been receiving updates from us then we don't have an accurate email or we are being blocked somewhere.
2. **Join our NF Midwest [Facebook Group](#).** This is one of the best and easiest ways to stay in the loop. The group is private and limited to people in our region with a high interest in NF. If you don't have or want Facebook, it's worth it to simply have a Facebook account for this. To find us search "NF Midwest" and click on the "closed group" then click "join group" on upper right.
3. **"Like" our NF Midwest [Facebook page](#).** This does NOT work so well for updates as our statuses may or may not show up on your Facebook feed depending on the whims of Facebook.
4. **[Follow us on Twitter](#).** You may follow us the traditional way online and/or text "follow nfmidwest" to 40404 to get twitter texts. You may send an "unfollow nfmidwest" text if it gets to be too much.
5. **Check our website www.nfmidwest.org regularly.**

EVERYTHING in this newsletter has already been posted online once or several times...

Highlights You'll Find on Our Website

We are constantly adding to www.nfmidwest.org and making it a premier site for NF information and community. We still have a lot to do and will never stop trying to make it better. Here are a few of the things you will currently find on it.

- Resources for [NF1](#), [NF2](#) and Schwannomatosis including:
 - [Webinar Recordings](#)
 - Articles on [NF Complications](#)
 - Helpful material for [teachers](#) and [doctors](#)
- [Research updates](#) including the *NF Network Edge* which is published quarterly and gives summaries on clinical and research advances.
- [Highlighted trials](#) and [ways to participate](#)
- [Past newsletters](#) in full color, with links and additional information
- A [great video](#) of the largest NF walk
- Video speech on "[Happiness](#)" from a man with NF
- [Inspirational video](#) from two mom's at a Great Steps 4NF Walk
- A [special letter](#) from our board president
- Different [ways to give](#) to and/or support the neurofibromatosis cause.
- [Photos](#) from past events
- Listings of past and upcoming [events](#)
- A "store" with NF awareness [merchandise](#)
- Ideas on [fundraising](#) for NF

And much, much more.

NF Awareness Store

Check out the merchandise at NF Midwest's [Awareness Store](#).

We have "I Love Someone with Neurofibromatosis" shirts, wristbands, license plate frames, shopping bags and more—including a special shirt that we can't show here.



There are Many Ways to Give to NF!

An Attorney Called Us

Recently we received a call from attorney looking for information because they had not one, but two people who want to bequest assets to NF Midwest to support the neurofibromatosis cause in their will. Whoever you are we appreciate your kindness, but wish you a long, happy life. Thank you for your consideration. Anyone can create a [legacy](#) and leave any amount in their will for the neurofibromatosis cause. Simply let your attorney know or give us a call if you need more guidance.

Give to NF Midwest Through United Way



United Way

If your workplace encourages you to participate in a United Way fundraising campaign, you can designate Neurofibromatosis Midwest as the organization to receive your donation. Partnering with a local organization such as your United Way who

can mobilize your resources to benefit the NF community will really make your contribution count. Thank you for thinking of NF Midwest.

Monthly Giving Program

Don't forget about monthly giving. An automatic \$10 monthly donation is a painless, effortless way to support NF and NF Midwest. Your monthly generosity gives NF Midwest a reliable income stream so that we can focus more of our resources on the battle of neurofibromatosis. To set up monthly giving give us a call or go to our website, www.nfmidwest.org and click on [Donate Today](#).

Volunteer

We are always looking for volunteers, especially to chair and help at events. Also, we are also always looking for skilled volunteers in law, accounting, marketing, writing, graphic design, social media, public relations, etc. Please contact us if you'd like to give your time.

Don't Miss The
Chicago Area
[NF Family Day](#)
Saturday, Aug 10



Camp New Friends

[Camp New Friends](#) is a week-long summer camp held in West Virginia for kids with neurofibromatosis. Run by [Brainy Camps Association](#) and developed by the Center of Neuroscience and Behavioral Medicine at Children's National Medical Center, Camp NF helps to reduce the stigma and isolation that kids with NF

often experience. The camp also helps them make friends, find support, learn more about their condition and develop adaptive behaviors.

We are excited to send 14 kids from the Midwest region July 21- 27. Some of these kids received camp and/or travel assistance from NF Midwest which would not be possible without the support of our donors.

The Call Will Be Coming Soon!



In a few months we will be revving up the [advocacy](#) machine and reaching out to our legislators asking for continued and increase funding for neurofibromatosis research. Keep an eye out for how you can help with this important campaign. We will specifically be asking you to write letters and to contact your members of congress. If you have a special interest in the legislative process and are interested in playing a larger role in advocacy please [contact us](#).



Laura Didier, Ali Didier, Diana Haberkamp and Susan Buono get ready to visit congressional offices in Washington DC this past February.

Annual Board Meeting is Coming Up In October!

We don't have the date set but our annual meeting is coming up in October. If you would like to learn more about serving on our board contact Diana@nfmidwest.org or call 630.945.3562.

What Will You Do 4NF?

We all know that there is not enough neurofibromatosis and schwannomatosis awareness. We know that our cause is underfunded and deserves much more, but it takes a community of "do-ers" to get it done.

[DoIt4NF in 2013!](#) The neurofibromatosis cause needs you. No matter your talents or time, there is definitely something you can do for NF.



ILLINOIS

UPCOMING EVENTS

Chicago Area **Family Day**—Saturday, August 10th

Kane County Cougars Game—Saturday, August 10th. People with NF are FREE. Everyone else is \$25 each. Includes the game, picnic and fireworks. Everyone is welcome! Invite your friends.

Golf Benefits—Two golf benefits are scheduled for the Chicago area in August. Please ask your friends who golf (or try to golf) to join us and consider any associates that might like to be a sponsor. More information may be found on our website under [Do It 4NF EVENTS](#).

Chip in Fore NF—Thursday, August 8th at Cog Hill Golf Club, Lemont, IL

Take a Swing at NF—Friday, August 9th at Prairie Landing Golf Club, West Chicago, IL

Hillbilly Throwdown & Tailgate Hoedown—See page 6

Annual Symposium—See front page

PAST EVENTS

Ask the Doctors Chicago—On April 28th the Chicago area held their annual Ask the Doc meeting at Shriner's Hospital in Oak Park. Drs. Tonsgard (University of Chicago) and Listerick (Lurie Children's Hospital) answered a mix of questions during this casual 2 hour event.

Great Steps—Illinois had 2 Great Steps 4NF events this year. The largest NF walk in the country in [Naperville](#) on June 1st and the 5th annual walk in [Effingham](#) on June 15th.



Face Paintin' in Naperville at Great Steps 4NF!

THEY DID IT 4NF!

Here is a listing of some of the things people Did4NF in the Chicago area. We know we've missed some people, but this is a good thing. It means that the NF community is very active.

Birdies for Charity—Steve and Diane Reason once again added NF Midwest to the John Deere's Birdies for Charity event and oversaw everything with it. In this event people make a pledge and guess at the number of birdies that will be made during the event. The correct guess wins a Chevy Equinox. John Deere underwrites the entire expense so the entire donation is given to NF Midwest, plus a yet to be determined bonus of 5% to 8%.



Tinley Park Corner Collecting—In May, the GS Naperville Teams of Git-R-Done and 4Kate worked together to collect donations at street corners and raised over \$1,800 dollars!

St. Damian Fun Fair—The 8th grade class of St. Damian in Oak Forest generously donated a portion of their profits to NF Midwest.

Pockets—The GS Naperville team of *Lindsey's Lifesavers* once again arranged a day in which 50% of a persons bill could be designated to NF.

Village Tavern—Team *NF Hirts* (GS Naperville) organized a day in May in which people could designate 15% of their tab to the NF cause when eating at the [Village Tavern](#).

Smiles for Sarah White Sox Outing—The Panozzo family organized a baseball outing for NF and in honor of their daughter Sarah on July 19th.

Edelen Family Garage Sale—The Edelen family graciously donated proceeds from their garage sale.

Minooka High School—Joey Niuman, student at Minooka High School and Camp New Friends camper, organized a blow-pop candy sale at his school and raised \$400. Joey wrote, "I'm going to the camp in July and I want \$ which will go to NF Midwest for the kids that can't afford to go to [Camp New Friends](#)." Thanks for paying it forward Joey.

Popcorn and Parade—Derango Family Dental, sold popcorn and pop for NF Midwest and walked in the Bartlett 4th of July parade handing out NF information.

INDIANA

UPCOMING EVENTS

Evansville Meeting—Monday, August 5th the [Evansville Chapter](#) will be meeting at the Hornet's Nest, 11845 Old Petersburg Rd at 6:00 pm. For more info or to express your interest please email Evansville@nfmidwest.org.

Great Steps Fort Wayne—Saturday, September 14th The 3rd annual **Great Steps for NF Walk** will be held Saturday, September 14th at the Eel River Elementary School. Please sign-up early and show your support at www.greatsteps.org.

PAST EVENTS

NF Family Day in Evansville—The [Evansville chapter](#) of NF Midwest planned a Family Day/Awareness Month celebration picnic for May 11th at Sunset Park. Unfortunately Mother Nature didn't get the memo and it was rained out.

Ask the Doctor Indianapolis—On April 14th The Indianapolis chapter hosted a Ask the Doctor session at Indiana University. Drs. Lisa Smith and Laurence Walsh of the NF Clinic there answered questions for 2 hours.

Indiana Clinic Update

The [NF clinic](#) at the Riley Hospital for Children/Indiana University is working on adding sub-specialists to improve the multi-disciplinary aspect of their clinic and to provide well rounded care for the various complications of NF and are excited by the recent addition of Dr. Michael Ferguson, who is a Hematologist-Oncologist and Dr. Karen Myung, Pediatric Orthopedist. Drs. Lisa Smith and Laurence Walsh see both adults and children at the Indianapolis based NF clinic. For more information or to make an appointment call 317-948-7450.

MISSOURI

Great Steps Malden—June 8th The 2nd annual Great Steps walk was held June 8th at the Malden Community Center. [SEE PHOTOS](#)

Central Missouri Support Meetings—The [Central Missouri](#) (formerly Columbus) chapter is planning monthly meetings for the 3rd Thursday of every month at the Columbia Public Library. For more info and to make sure a meeting is still scheduled, contact us or email the chapter at CentralMissouri@nfmidwest.org.

Family Day at the Zoo—The [Central Missouri Chapter](#) arranged for a NF Family Day at the St. Louis Zoo on Saturday, May 4th. This was a great way for families and individuals with NF to meet and to build community.

WISCONSIN

UPCOMING EVENTS

Links for Lauren—Monday, August 26th



The Geier Family and their loving supporters are holding their first Links for Lauren Golf Benefit at the prestigious [Nakoma Golf Club](#) in Madison, WI. Proceeds will benefit NF Midwest and the neurofibromatosis cause. Register now at www.golfinvite.com/linksforlauren.

New Great Steps 4NF Walk—West Central Wisconsin is getting a Great Steps 4NF walk! The Inaugural Chippewa Falls walk is scheduled on NF Awareness day, May 17th, 2014. Our energetic Chair is Crystal Reith. Email Crystal at wewisconsin@nfmidwest.org if you'd like to help "do it 4NF".

PAST EVENTS

Great Steps 4NF—May 11th saw the 4th Annual Madison Great Steps 4NF Walk. This year it was held at the [Capital Brewery](#) in Middleton. [SEE PHOTOS](#)

Educational Seminar—The clinic at Children's Hospital in Milwaukee held an educational seminar on Saturday, May 4th.

THEY DID IT 4NF!

USBC Bowling Tournament—Jaime Cullen arranged for \$10 from each entry into the *USBC Ladies Scratch Trios Bowling Tournament* in New Berlin to go to NF Midwest. She also had a banner posted for awareness.

Regency Beauty School Education Event—At the suggestion of a parent, NF Midwest board member and ambassador, Patrick Cullen, spoke about NF at the Regency Beauty Institute.

Pat Z. speaks up about NF—Patrick Zakrzewski, an RN who is affected by NF1, regularly speaks to clinical nursing students at Gateway Technical Nursing School in Kenosha WI to teach them about NF and share what it's like to live with NF from a patient's perspective. Thanks for speaking up Pat and raising awareness.

WHAT ABOUT IOWA & KENTUCKY?

If you'd like to represent Iowa or Kentucky and raise awareness and funds for the cause and help create a system of support, give us a call! Anyone can start a local chapter to help the NF cause. NF Midwest will do as much of the work as possible, but we need "boots on the ground" to build the NF community in your area. Give us a call at 630.945.3562 if you'd like more information.

Another GREAT year 4 GREAT STEPS!

Great Steps 4NF 2013

With the *Fort Wayne Great Steps 4NF Walk* still on the horizon, here's a look at the other walks that have already been enjoyed this year...

Madison, WI – The Capital Brewery was the fun new location for this year's walk. Katy Frye, Tim Eberle and Kristin Pilgrim did a great job organizing the event again this year. The walk route circled participants through the surrounding neighborhood, throwing one challenging hill in the mix. [SEE PHOTOS](#)

Malden, MO – Board President Dennis Pilkinton, his wife Joan and Development Director Jenny Perkins attended this year's Malden walk. A great outpouring of support from family and friends made this year's walk outstanding. Chairperson Crystal Presson made the day do double duty to help her team by hosting an Alex's Angels pageant right after the walk. [SEE PHOTOS](#)

Naperville, IL – Year number 12 brought the threat of rain, but the day ended up being spectacular! Two special NF heroes, Addalyn and Addison and their moms made a special appearance and talked about how NF and NF Midwest have been a part of their lives. Great raffles, great food and an awesome DJ rounded out the day. [SEE PHOTOS](#)

Effingham, IL – This most recent Great Steps walk was on a picture perfect day with the best turn-out to date. Seven new teams joined us as well as a State Trooper to help with traffic safety. Kids' games, a yummy bake sale and the raffle table kept everyone busy. [SEE PHOTOS](#)

A special **SHOUT OUT** to the *Kohls Cares* program. At the Madison, Naperville and Effingham Great Steps walks, Kohls employees have come out for the day to volunteer. (Unfortunately, Malden doesn't have a Kohls near them.)

Register NOW **Fort Wayne, IN** – Sept. 14th – Make sure to [register](#) for Northern Indiana's Great Steps 4NF walk. This is sure to be another great day planned by The Taylor Family! Register today at www.GreatSteps.org.



Start working now for 2014!

NEW

Chippewa Falls, WI
May 17

Madison, WI
May 10

Naperville, IL
June 7

Malden, MO
TBD

Effingham, IL
June 14

Fort Wayne, IN
Sept. TBD

More May Be Announced!



Just Chillin' in Madison at the Capital Brewery!



Chillin' and Snugglin' in Effingham!



We Have Much Sought After Spots Available for the Inaugural Naperville Marathon!

NF Midwest's [Run 4NF Team](#) is in full swing, training for the Inaugural [Naperville Marathon](#) and Half Marathon. This highly anticipated marathon filled up quickly

and registration closed in just days, but we have a few open spots for anyone that wants to run or knows someone that wants to run for NF Midwest. Since NF Midwest is a partici-

pating charity at the marathon, we will have a tent set up to cheer on the runners, and everyone is welcome to come out and join us. To grab one of the last remaining open spots, please call Jenny at the office for info and the code to get registered. More info about the Run 4NF program and the Naperville marathon can be found at www.nfmidwest.org/get-involved/run-4nf.

Hillbilly Throw Down & Tailgate Hoedown

Teams of 4

Crazy Games

Saturday, September 28th

1:00 pm

Newark, IL

Country Music

Tailgating

Must be 18 or Over

\$25 For Those with True Grit (includes t-shirt & awards)

\$5 Peeping Only (those too timid to compete)

www.nfmidwest.org/event/hillbilly_throwdown

Ya'll need to come out and git-er-dun at our Hillbilly Throwdown and Tailgate Hoedown. Invite your kinfolk, city folk and cousins to come out. Sign-up in packs of 4 to show your guts and gumption in our country styled challenges. Then prepare your vittles and show off your grub. Goodies will go the best team and the best tailgaters. It'll be a hoot and a holler!



Board Legends and Leaders Reunite and Reminisce

In March, a few past and founding board members (l to r) Gordon Cummings, Bev Oberlander, Gert Ginsberg and Gail (Cooper) Mavrogenes gathered for lunch and reminiscing.

Without these 4, we would not exist today. Starting and growing something from nothing takes a lot of dedication and strength. They not only have what it takes, but they keep giving it!

GIVING TO NF MADE EASY

NF Midwest and the neurofibromatosis cause really need your continued support, but we know that for some people times are hard and sometimes it can be difficult to find the extra cash to make a difference. Here are some more painless ways to give in addition to what you already do.



If your company has a United Way program, see if you can select NF Midwest to be your charity of choice and have an small amount deducted regularly from your pay check. **If you don't have this option you may also sign up directly with us to donate automatically and [monthly](#) through your credit card.**



Educate and raise money for the cause with your own fundraising website. Many people do this to raise funds for their team for a Great Steps Walk, but you can also do this any time.



Use [GoodSearch](#) as your search engine and select NF Midwest as your charity of choice and neurofibromatosis will earn every time you search. Also, check into [GoodShop](#) and [GoodDining](#).



Help the environment and NF Midwest by collecting empty cartridges, cell phones, small electronics, and laptops from the community or your company and sending them to FundingFactory. In return NF Midwest will get cash. Sign up at [FundingFactory.com](#) and use give them our **ID #45767** and they will sent you FREE prepaid shipping labels.

Midwest Area NF & Schwannomatosis Clinic Information

For more doctors call 630.945.3562

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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 and the eastern half of Missouri.