



A Publication by NF Midwest for Neurofibromatosis Families

Neurofibromatosis Newsletter

Volume 31, Issue 2

Fall 2012

Published 2 times a year

Letter from a Parent

My family's lives have been tremendously impacted by the NF Midwest family. That's truly what they have become to us-family. Earlier this spring, we had the opportunity to go to the NF Midwest office in St. Charles, IL. I'm not quite sure what I expected, but there were only three people running this organization that serves NF families in six states! Little did I realize that this visit would lead to the biggest adventure in all of my son Silas' 9 years, as Si got to go to Camp New Friends in Virginia. Not a day goes by since he came home that Camp New Friends isn't mentioned. Even more remarkable than that is that those campers' experiences were made possible by people who just want to make a difference. Making positive differences in the lives of people with NF is ultimately what NF Midwest represents to me. Of course, their contributions to research are extraordinary, and our family has seen first-hand how wonderful camp can be, but I am just as moved when I see a simple message from the staff at NF Midwest offering thoughts and support for someone who is scared and anxious about a test result.

The uncertainties of NF can be too much for people to bear and can leave them feeling powerless (yes, I am speaking from personal experience). Our participation in NF Midwest has helped us take some of that power back, and has given us hope. I am asking for your financial support to help keep that momentum going that NF Midwest has created, to keep those smiles on those campers' faces, and to keep making those differences. It's all done from the little office in St. Charles, but not everyone realizes that it takes money just to keep that office running day to day. It takes money to make copies, buy stamps and keep the lights on.

Don't forget about NF Midwest this year. They don't forget about you. Please include NF Midwest on your giving list and donate \$10, \$20 or even \$50 so that they can continue the NF Midwest mission. It's easy and quick to donate online at nfmidwest.org or simply mail a check today!

Thanks!

Andrea



NF Midwest Funds Four Projects in 2012

This year Neurofibromatosis Midwest funded four varied and important projects that further research into finding treatments and a cure for neurofibromatosis. Below are very brief summaries of these projects. For more details, visit www.nfmidwest.org.

Dermal Fibroma Study at Harvard Medical School—Neurofibromatosis Northeast and Neurofibromatosis Midwest united in funding [Dr. Fawn Leigh](#) of Harvard Medical School and Massachusetts General Hospital to support her research on dermal neurofibromas and specifically why some adults with NF1 have many fibromas on the skin and others don't.

NF2 Research at Ohio State University—Neurofibromatosis Midwest is excited to provide funding to [D. Bradley Welling](#), M.D., Ph.D. and [Long-Sheng Chang, Ph.D.](#) of

(Continued on page 2)

Board Of Directors

Dennis Pilkinton, President
Steve Griest, Vice President
Jean Nolan, Secretary
Gail Cooper
Patrick Cullen
John O'Donnell

Executive Director

Diana Haberkamp

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 Road, Suite 3
St. Charles, IL 60174
1.630.945.3562
info@nfmidwest.org

Be sure to mark us a "safe sender."

(Continued from page 1- NF Midwest Funds Four Projects)

Ohio State University and Nationwide Children's Hospital for a project on the "Potential Chemotherapeutic Agents for the Treatment of NF2-associated Schwannoma and Meningioma".

University of Wisconsin NF1 Early Childhood Study- Neurofibromatosis Midwest has continued to fund the University of Wisconsin Milwaukee Dept. of Psychology ([Bonnie Klein-Tasman Ph.D](#)) for the study of cognitive, learning and behavioral functioning of young children with NF1.

University of Chicago Clinic and Database—The 2012 Martin Ginsberg grant has again been awarded to the [University of Chicago NF clinic](#) for the maintenance of a longitudinal database and for additional clinic hours. Martin Ginsberg was a founding member and long time board member of Neurofibromatosis Midwest. He was much loved and is much missed. We are honored to continue work in his name.

2012 NF Midwest Symposium [PHOTOS](#)

Individuals and families, young and old who are affected by NF1, NF2 & Schwannomatosis gathered together on Oct. 13 at the beautiful [NIU conference center](#) in Hoffman Estates to learn the latest on a variety of pertinent NF topics, presented by leading NF Doctors who shared their knowledge from clinical and research perspectives. Attendees learned from the experts, but also from each other while having the chance to see old friends and make new ones. Lunch and snacks were enjoyed by all. Plan to attend next year!

Friday night and Saturday were very much worth the 301 miles we drove, and the best meeting we have attended anywhere considering our NF2 interests. Of course doctors Marco Giovannani and Bradley Welling were responsible for the in-depth knowledge and understandings we acquired. And Matt Hay's account of his Ironman achievement was an inspiration for all.

Symposium Attendees Give Blood for Research

Those who attended our Symposium on Oct. 13th had a rare opportunity to participate in an on-site dermal fibroma study. People with neurofibromatosis type 1 with a very low or a very high neurofibroma tumor volume were able to give blood for a study which is looking for genetic modifiers that might provide insight as to why some people have many or few cutaneous neurofibromas. Our participants were eager and enthusiastic to have this chance to be part of research and to make a difference. Neurofibromatosis Midwest is pleased to help fund part of this study and is very grateful to Dr. Fawn Leigh of Harvard Medical School and Massachusetts General Hospital for her work and dedication to our cause.

High Volume Electrodesiccation For Dermal Fibromas

NF Midwest has been working for some time now to find plastic surgeons in the Midwest who use the [electrodesiccation](#) technique pioneered by Dr. Weinberg on people with a lot of dermal fibromas. We are now pleased and excited to announce that the University of Chicago has plastic surgeons that are now considering the technique on some neurofibromatosis type 1 patients. If you are interested please contact us at 630.945.3562.

Matching and Monthly Giving

Our kind donors have really been rocking it with matching gifts. When you donate don't forget to see if your company **will match your kindness. If they don't have a Matching Gift Program** or your company is small, be sure to ask. Companies find that supporting the causes that their employees believe in is the best and easiest way to give.

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](#).

NF Midwest Board Has Limited Openings!

The Neurofibromatosis Midwest [Board](#) currently has openings for three new board members.

Expectations include:

- Attending regular meetings held 4 times per year in January, April, July and October in St. Charles, IL. We can accommodate people from remote areas via video or phone if necessary.
- 2 Year Term
- A "Give or Get" fundraising minimum
- A dedication to and interest in NF Midwest and its mission and a passion for the neurofibromatosis cause.

For more information or to express an interest contact Diana@nfmidwest.org or call 630.945.3562.

New NF Midwest Board Member

We are very excited to welcome our newest member to the NF Midwest Board, Patrick Cullen, who was voted in at **the November meeting. Patrick's son was recently diagnosed with NF1.** He and his wife, Jaime live west of Milwaukee and are eager to help raise awareness and funds in the area.

Be iNFormed Educational Series

Neurofibromatosis Midwest is excited to start a new education initiative called **be iNFormed**. As part of this initiative we will be working with neurofibromatosis experts and our sister NF organizations throughout the world to create simple articles about specific complications or areas of interest with regards to neurofibromatosis.

You may call and request articles, but the best way to get quick, easy access is through our website www.nfmidwest.org. There you will also find links to various webinars and other educational information on NF.

You should also be sure to contact us with your email so that you can get periodic updates regarding new articles and events. **"Liking" us on Facebook**, however, is the best way to get immediate updates. Even if you aren't a Facebook user you may want to consider creating a page and using it only for that purpose. If you want to chat with others from our region and discuss regional NF happenings and share stories you should also ask to join our [NF Midwest Facebook Group](#).

Be iNFormed articles currently include the following topics:

- [NF1 Information for Teachers](#)
- [Optic Gliomas in NF 1](#)
- [Reproductive Options for People with NF1, NF2 and Schwannomatosis](#)
- [Learning in NF1](#)
- [Comprehensive Neuropsychological Evaluations for Children with NF1](#)
- [Vascular Issues in NF1](#)

There are many, many more topics to cover. If you have one that you'd like to request, please email us at info@nfmidwest.org.

Information for Medical Professionals

NF Midwest has created a [special sheet](#) for medical professionals regarding NF1. It provides "anticipatory guidance" for non NF specialists by giving them a quick overview of NF1 and information on the types of complications a patient with NF1 might have. The idea is to help the patient and doctor coordinate care. You may print off a sheet to bring to your doctor by going to www.nfmidwest.org or you may call the office and request one.



July 21-27, 2013

This summer NF Midwest helped send 14 kids to [Camp New Friends](#), a camp in Virginia for children with neurofibromatosis.

In 2013 the camp is moving to a new more exciting location at [Camp Timber Ridge](#) in High View, WV. This magnificent campsite is just over the Maryland line and 90 miles from DC, and it has something to offer for everyone. This includes swimming in an Olympic-size pool, shooting hoops on a regulation-size basketball court, go-carting around a race track, learning to ride a horse, the list just goes on and on.

Registration opens soon. Go to www.brainycamps.com for more information. Funding is available to help campers in need, but due to rising camp fees and camper interest, your help is needed to fundraise for NF Midwest toward the cost of camp sponsorships.



NF Adult Retreat

The people who bring us [Camp New Friends](#) have announced an adult retreat for people 23-35 years old with NF. This retreat is being held July 19-21 in High View, WV at [Camp Timber Ridge](#). It will run the weekend before Camp New Friends and share one day with the younger campers. The cost is \$250 plus travel. Look for more information at www.brainycamps.com or call our office at 630.945.3562.

NF Awareness Store

Check out the merchandise at NF Midwest's new Awareness Store at www.nfmidwest.org/store.

We have new "I Love Someone with Neurofibromatosis" shirts, wristbands, license plate frames, shopping bags and more!



NF
MIDWEST

Information for
Medical Professionals



I've been diagnosed...

Neurofibromatosis Type 1 (NF 1) is an autosomal dominant condition with a high degree of variability between individuals. NF 1 occurs in 1/3400 individuals and 50% of individuals have an affected parent. It affects all ethnicities and occurs equally in males and females. NF 1 can be associated with most systems in the body including the nervous system, eyes, skin and bones.

Diagnosis

Two or more of the following signs:

- Six or more café-au-lait macules >5 mm in prepubertal individuals or >15 mm after puberty
- Two or more neurofibromas of any type or one or more plexiform neurofibroma
- Freckling in the axillae or inguinal region
- Tumor of the optic nerve pathway

You Can Do It 4NF!

When you look through this newsletter and see all the great things that go on at NF Midwest, remember that it is because of you that these things are possible. The bulk of funds used for research and educational opportunities comes from individuals like you.

Yes, every person makes a difference! Each time you ask a neighbor to donate, it helps fund a clinic. When you step outside your comfort zone and ask your local grocery store to be an event sponsor, it benefits NF research. Each of the Great Steps walks has come about because one person stepped up and said "I can [do it 4NF!](http://www.nfmidwest.org)" What will you do to help?



ILLINOIS

Chicago Area Family Day [PHOTOS](#)

Our Chicago area chapter held a Family Day at Gameworks in Chicago on May 20th. This was a chance for NF families and NF adults to get together as an NF community.

Golf 4NF

We had two golf benefits in Illinois. August 10th was the 13th annual [Take a Swing for NF](#) outing in West Chicago. Thanks to [Professional Business Consultants](#) for bringing in many golfers and sponsors. [Circle Metal](#) was the premier sponsor for the 3rd annual [Chip in Fore NF](#) on August 9th at Cog Hill in Lemont. Thanks to them and to [Crown Corr](#), [Harmon Inc.](#), and many others for their generous sponsorships.

Birdies for Charity

Steve Reason and his wife Diane of Buffalo Prairie, IL successfully added NF Midwest to John Deere's [Birdies for Charity](#) event. This event asked people to guess the number of birdies that would be made during the John Deere Classic pro golf tournament and pledge an amount per birdie or make a flat donation. The correct guess won a Chevy Malibu. Steve raised over \$2000 and is gearing up for next year. John Deere pays all administrative costs for this event and every penny that Steve collects is donated to NF Midwest!

Ask the Doctors Chicago

On April 15th the Chicago area had their annual Ask the Doc meeting at Shriner's Hospital in Oak Park. Drs. Tonggard (University of Chicago) and Listernick (Lurie Children's Hospital) answered a mix of questions during this casual 2 hour event. It is scheduled for Sunday, April 28th in 2013.

Great Steps Teams and Others Do It 4NF!

The Illinois [Great Steps 4NF](#) walks in Naperville and Effingham have quite a few teams that do events ahead of time to raise awareness and funds for their teams. We also have people who simply do events 4NF. We are sure to have missed some, but we definitely appreciate them all.

Zombie Pub Crawl-The Mount Prospect Jaycees organized a frightfully good evening to benefit NF Midwest.

Michael Blaha-Michael Blaha has been running half marathons all over the country to raise funds and awareness for NF. His goal is 12 in 12 months. He and his wife, Annamarie, also had an awareness booth at a [health fair](#) in Palos Heights and set up a booth at The House of Harley in Kenosha to raise awareness as well as funds for the cause.

Smiles for Sarah-This was the 12th annual benefit walk organized and hosted by the Panozzo family. About 200

people attended on the beautiful October morning. [Photos](#)

Texas Hold'em Poker Tournament-Simon Camaj had a full house when he rounded up all his friends for this evening of cards, food and fun.

Corner Collecting-The teams of Git-R-Done, Team Monkey (Naperville GS) and others worked together to collect at street corners in Tinley Park, IL. They tell us they met many people eager to learn about NF and to donate to the cause.

Bowling-GS Naperville Team 66, Peanut's Gang, held a bowling fundraiser in Elgin. [PHOTOS](#)

Garage Sale-A member of the Austinators held a garage sale over the summer.

Trivia Nite-A member of the Austinators also held an extremely fun and easy [trivia night](#) for their friends.

Buffalo Wild Wings Fundraiser and raffled off Blackhawks tickets-15% of the bill went to the NF cause in Jacob's Warriors BWW fundraisers, plus they held a raffle for Blackhawks tickets.

Pockets-Lindsey's Lifesavers had very yummy event at Pockets where the owners agreed to donate 50% of the bill from people who Ate4NF!

Celebrating Silas-[Colour Line Studio](#), Geneva held a wonderful party and raffle at McNally's Irish Pub in St. Charles.

Tastefully Simple-Logan's Heroes held a Tastefully Simple vendor night 4NF!

Charming Charlies-4Kate held a vendor night with part of the proceeds being donated.

We know that there is no way we listed everyone that recently held an event in Illinois. As home to the largest walk for NF, we definitely have a very active and supportive community. We know you all do it 4NF and thank you!



Lindsey's Lifesavers collect a big check from their Pockets fundraiser.

INDIANA

New Chapters

Indiana now has two NF Midwest chapters.

Fort Wayne Chapter

Our Fort Wayne chapter anchors the north and is currently chaired by Liz and Ryan Taylor of Fort Wayne and has a terrific group of NF Fighters. In September they held two events to raise funds and awareness for the cause.



The 2nd annual **Great Steps for NF Walk** was held at the Eel River Elementary School on September 8 with a turn out of over 150 people and a doubling of funds raised from the first year. Special mention goes to Team Kourtney who had a DoIt4NF event, a lasagna dinner to increase their team totals.

Marnée Concert—After the walk, walkers and the public were able to attend a special concert at the Sweetwater Auditorium by young, local talent Marnée with an opening set by Atticus. A free will

donation was collected. Check out [video](#) from the event there are more on YouTube.

Evansville Chapter

We also have a chapter just starting up in Evansville in the far south of Indiana. This chapter is being chaired by Andrea Miller, who has a son with NF1. Other active members of the Evansville chapter include Michelle Elpers, Jane Gerth, and Judy Euler. For more information email Evansville@nfmidwest.org.

Ask the Doctors Indianapolis

On April 21 we held our 2nd Annual Ask The Doctor session at the University of Indiana in Indianapolis with Dr. Cynthia Hingtgen.

Clinic Update

Dr. Hingtgen is no longer at Indiana University. NF patients are being seen by Drs. Laurence Walsh and Lisa Smith.

The Indiana University [Neurofibromatosis Clinic](#) is based at Riley Hospital for Children in Indianapolis, Indiana. They see both children and adults with NF1, NF2 and Schwannomatosis and is currently the only clinic for comprehensive care of those with neurofibromatosis in the state of Indiana. Appointments may be made by calling 317.948.7450.

IOWA

Dr. Pamela Trapane at Symposium

We were very pleased to have [Dr. Trapane](#) from the University of Iowa Hospitals Neurofibromatosis Clinic give an overview of NF at our symposium in October. Dr. Trapane sees adults and children with NF. Appointments may be made by calling 319.356.2229.

WISCONSIN

The third annual Great Steps for NF walk was held at Token Creek just outside of Madison in May. The Great Steps committee there did a fantastic job and managed to order up a gorgeous day! All the credit goes to Katy Freye, Kristen Pilgrim and Tim Eberle. [PHOTOS](#)

A family day picnic was also planned for August but amazingly despite the drought, it was rained out.

MISSOURI

Great Steps Malden

Crystal Presson did a fantastic job in chairing this year's inaugural Malden Great Steps for NF walk and immediately set a date of June 8th for next year. She has also already registered her team and is planning events to raise funds and awareness. [PHOTOS](#)

Columbia Chapter

Christina Thomas is leading a new chapter in Columbia, MO. Currently an Adult NF Support Group is planned for the 3rd Friday of every month from 6:30 pm to 7:30 pm at the Central Missouri Community Action Building in Columbia. For more info contact us or email the chapter at Columbia@nfmidwest.org.

Family Day at the Zoo—Christina Thomas helped organize the 2nd Annual St. Louis Fun Day held on May 5th at the St. Louis Zoo. Way to do it 4NF, Christina!

You Can Join or Form an Chapter!

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.

Ask The Doctor Chicago



Sunday, April 28th from 2 to 4 has been set for an Ask the Doctor session at **Shriner's Hospital in Oak Park, IL**. Look for more information, but mark your calendars now. Additional "Ask the Doc's" may still be scheduled in other areas. Be on the look out!

We'll Deliver Your Letters To Congress

On February 4th and 5th, NF Midwest executive director Diana Haberkamp and others will be visiting congressional offices in Washington, DC to ask for support for NF research through the National Institutes of Health (NIH) and the **Department of Defense's (DOD) Congressionally Directed Medical Research Program (CDMRP)**. For more information on these programs and our advocacy efforts go to www.nfadvocacy.org.

What we need from you are personal letters (see [example](#)) to take to your representative and senators. These letters should tell the story of how NF affects you and/or your loved ones and encourage your congressman/woman to care. Include your address and a picture (if possible) and mail or [email](#) it to us. We will personally deliver the letters for you.

Run4NF

NF Midwest's [Run4NF](#) program is in full swing after a great start at the Chicago Marathon. Four enthusiastic runners dedicated their marathon experience to the special NF person in their life. Michael Blaha, Simon Camaj, Nikki Jendras and Katie Sullivan all spent months working hard, both training and fundraising. FirstGiving fundraising pages, emailed letters to friends and hosting 3rd party events all helped in raising almost \$10,000!

A pasta dinner the night before helped fuel each runner. We were fortunate to have 3 runners from NF Northeast join us. Derek Brown, Jeff Brown and Hilary Ritter made the trek westward to also run for NF.

You too can Run4NF! Pick any run you like and **do it for NF!** If you are a casual runner, choose a 5k in your town. If you want a bit more of a challenge, try a half marathon. Fun Runs are really popular, with obstacles, mud or costumes. Let us know your plans, and we will get you started. **Please note:** If you would like to run the 2013 Chicago Marathon for NF Midwest, register yourself as soon as registration opens (near the end of January). Registration for the 2012 marathon closed in 6 days, compared to 31 days in **2011. Don't wait to register. Contact jenny@nfmidwest.org** for any questions about Run4NF.



Michael Blaha, Simon Camaj, Derek Brown, Hilary Ritter, Nikki Jendras and Jeff Brown at dinner before the Chicago Marathon.

Welcome Liz Campana

New Administrative Assistant

Welcome New Office Staff "Hi everyone, my name is Liz Campana and I am excited to be working at the Neurofibromatosis Midwest office. It's been a dream of mine to be able to dedicate more of my time to the NF cause and especially to NF Midwest.



My daughter has NF1 and sixteen years ago when we were first diagnosed, scared and totally uncertain of her future, NF Midwest was there for my family. I already knew of the organization because of the awesome plant sales they organized throughout the Chicagoland area to raise money for research. I remember when I called the office for help, I got accurate, comprehensive information, words of encouragement and the support my family needed to know that we were not alone. NF Midwest has always been my lifeline to Neurofibromatosis.

I am proud to join this team of local, driven and dedicated folks who all have close loved ones affected by NF. I am proud and excited to be part of a team with personal and strong motivation to work hard and fight for a cure. I bring to you years of administrative and bookkeeping experience as well as past Board member, fundraising and volunteer NF involvement. But more importantly, I am here with a **friendly voice and listening ear when you call the office.** "

Don't Miss All the Action!

NF news and events are evolving quickly all the time. The only way to stay on top of them is the use the tools of the internet.

- Check out our NEW website at www.nfmidwest.org
- Provide us with your current email address through our website or by emailing us at info@nfmidwest.org
- Like our Facebook Fan Page at [facebook.com/nfmidwest](https://www.facebook.com/nfmidwest)...even if you don't use Facebook for anything else.
- Ask to join our private [NF Midwest Group](#) on Facebook—you must be in our region to join.
- [Follow NFMidwest](#) on Twitter or text "Follow NFMidwest" at 40404.

Great Steps 4NF 2012

The summer fundraising season blew through like a whirlwind with 5 Great Steps for NF walks! It was a fun and busy time for everyone involved. Great Steps chairs put a ton of hard work into organizing each event, volunteers were instrumental in getting things done, and our Great Steps teams were outstanding!



Malden, MO—Inaugural Year! [PHOTOS](#)

Congratulations to Crystal for a job well done! \$7,000 was raised in the inaugural Great Steps for NF Walk in Malden on April 28th. The community came out in support of NF, and the day couldn't have been better. This walk was such a huge hit that as soon as it was over Crystal started planning next year's walk.

Madison, WI—Tripled Last Year! [PHOTOS](#)

3 cheers for Madison! We have **3** chairpeople that organized the **third** year for the walk on May 28th and **tripled** what they raised from last year. Thanks to Katy Freye, Kristin Pilgrim and Tim Eberle, Wisconsin rocked it and raised almost \$17,000! Thanks also to Team Lauren who registered a few short weeks before the walk and really pounded the pavement for NF.

Naperville, IL –The Biggest Walk for NF in the Country! [PHOTOS](#)

It was another great turnout for the 11th year at the beautiful Naperville River-walk. Held on June 2nd, Naperville raised almost \$120,000 as 65 teams participated with many of them returning and a bunch of new ones. The weather was perfect for the 3k walk. Thanks to Dave Tipton for again taking the reins and making this walk great! Also, this walk could not happen without help from our MANY volunteers including Marge Griest and Lesli Wegner.

Effingham, IL—Effingham Wild Women Come Through Again!

[PHOTOS](#)

Whew! The rain stayed away for year number 5. On June 16th Laura Didier and her long-time friends again did an awesome job of organizing this great day and raised almost \$9,000. The raffle and bake sale were both a big hit, and the walk through downtown Effingham was perfect for awareness. Thanks to the Effingham Wild Women (and Ron) and to the Kohls volunteers that came out for the day.

Fort Wayne, IN – Doubled Last Year! [PHOTOS](#)

Liz and Ryan Taylor "stepped up" again to chair the 2nd Fort Wayne Great Steps walk on September 8th and more than doubled last year's donations raising over \$10,500! The weather was beautiful, and the walk was enjoyed by all. The raffle was outstanding thanks to Ryan's mom who was very persistent in getting donations. Way to go! A special thanks to those that walked in memory of a loved one—Team Kourtney who walked for [Kambi](#) and Team Live Life to the Fullest who walked for [Matt](#).



Sign Up Now for 2013!

[Madison](#), WI now at the [Capitol Brewery!](#)—May 11

[Naperville](#), IL June 1

[Malden](#), MO June 8

[Effingham](#), IL June 15

[Fort Wayne](#), Sept. TBD

More May Be Announced!

Teamwork

All the Great Steps teams put huge effort into fundraising. Here is a run down of the top ten:

Team Lauren	\$12,673
Team Doodle	\$12,171
Austinators	\$7,289
Jacob's Warriors	\$5,807
Team Shepard	\$5,525
2 ADDIs	\$5,374
Team Caitlyn	\$4,735
Cole's Crew	\$4,624
Ali's Gators	\$4,237
Alex's Angels	\$3,860

Some of our teams go all out with costumes and accessories that make **them our most "spired" teams**. Some of the most enthusiastic this year were:

Miranda's Mission, Malden

Team Hunter, Madison

Marissa's Mighty Mob, Madison

Team Shepard, Naperville

Happy Kampers, Naperville

Rockstars for Wyatt, Effingham

Little Buddies, Effingham

Team Kourtney, Fort Wayne



HELP TELL THE STORY OF NF

The neurofibromatoses are complicated, varied disorders. They're difficult to explain and awareness is very low. We need your help to tell the world about NF with real, compelling profiles of children and adults with NF.

Send us your stories. If you need help, ask the creative writer in your life or send us the details and we'll give it a shot. Include a photo. If you're really feeling it, put together a video.

Email info@nfmidwest.org



Midwest Area NF & Schwannomatosis Clinic Information

For more doctors call 630.945.3562

[Ann & Robert H. Lurie Children's Hospital of Chicago](#)

Children Only
Chicago, IL

312-227-6120
Joel Charrow, MD
Robert Listernick, MD

[Riley Hospital for Children and Indiana University NF Clinic](#)

Children and Adults
Indianapolis, IN

317-948-7450
Laurence E. Walsh, MD
Lisa H. Smith, MD

[St. Louis Children's Hospital NF Center](#)

Children and Adults
St. Louis, MO

314-454-6120
David H. Gutmann, MD
Anne Albers, PNP

[University of Chicago NF Clinic](#)

Children and Adults
Chicago & Palos Heights, IL

773-702-6169 - Chicago
708-448-8000 - Palos Heights
James Tonsgard, MD

[University of Iowa Hospitals and Clinics Neurofibromatosis Clinic](#)

Children and Adults
Iowa City, IA

319-356-2229
Pamela Trapane, MD

[Cardinal Glennon Children's Medical Center](#)

Children and Adults
1465 S. Grand Boulevard
St. Louis, MO 63104-1095
314-577-5397
Thomas Geller MD

[Children's Hospital of Wisconsin NF and RASopathy Center](#)

Children and Adults for first evaluation
Milwaukee, WI

414-607-5280/877-607-5280
Donald Basel, MD/Dawn Siegel, MD

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.