



A Publication by NF Midwest for Neurofibromatosis Families

# Neurofibromatosis Newsletter

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## Who We Are

The NF community is fortunate to have many great organizations dedicated to neurofibromatosis. We know this can be confusing, but while there are some overlaps, there are more differences as most NF organizations focus more on a certain need or area.

NF Midwest for instance, is the only local/regional organization dedicated to serving and improving the lives of people in the neurofibromatosis community by focusing on improving care. We do this by improving **C**linics and access to clinics, raising **A**wareness, supporting **R**esearch, providing **E**ducation and **S**upport (C.A.R.E.S.).

Our funds and resources are mainly focused here in our region to support you or your **loved ones**. Since NF progresses differently in each person living with it, NF Midwest's efforts are varied to meet the needs of our community.

Examples of our efforts can be found in our years of dedication in pushing for better options for neurofibroma removal or treatment; our 32 years of providing free information packets to the newly diagnosed; the hours we spend on the phone or internet counseling and consoling the people in our community; our advocacy work to increase federal funding on NF research; our push for and support of new clinics including recently in Louisville, KY and in Chicago at Loyola; our behind the scenes work towards understanding the options of medical cannabis; our years of sending Midwest kids to camp; our work in local communities to build support networks; and our 25 years of symposiums and other educational opportunities. And there is so much more.

As one of NF Midwest's supporters recently said... NF Midwest is...

**Small Enough to Care...Big Enough to Make a Difference!**



Friends catch up at the 2014 NF Symposium held on October 25th

## Symposium—See 2014 Photos

NF Midwest has one of the longest running symposium programs for the education of NF families and individuals. On October 25, 2014 we held our 24th annual event which included speakers from the NIH and several NF clinics; a great breakfast and lunch; and a lot of socializing.

We look forward to an extra special 25th symposium on October 24th of 2015!

In 2015 we plan for the symposium to offer practical information for everyone dealing with NF and to provide lots of time for meeting and learning from others.

**Mark your calendars now  
for October 24th!**



## Board Of Directors

Gail Mavrogenes, President  
Charles Todd, Vice President  
Ellen Gallagher, Secretary  
Gordon Cooper, Treasurer  
Jean Nolan



## Mission Statement

NF Midwest is committed to improving the lives of children, adults, and families impacted by neurofibromatosis. Our continued focus and foundation is on **C**linics, **A**wareness, **R**esearch, **E**ducation and **S**upport in the states of Illinois, Indiana, Iowa, Kentucky, Wisconsin, and the eastern half of Missouri.

NF Midwest C.A.R.E.S.!

## 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."  
[www.nfmidwest.org](http://www.nfmidwest.org)

## High Quantity Removal of Neurofibromas

NF Midwest is focused on improving the lives of people with NF by improving care. For this reason we have been pushing for many years to learn more and to clarify the large quantity removal of neurofibromas through a technique that has **become commonly known as “electrodesiccation” or “ED” in the NF community.** This NF specific technique is thought to be performed by only a few plastic surgeons in the U.S.

We are not promoting, advocating or endorsing this procedure, rather we feel it is our duty to better understand it, explore the possibilities, and to study it for the good of our NF community. As such, we have been trying to generate interest in this technique by area plastic surgeons for many years. **This has been difficult and we’re not exactly sure why.**

Part of the problem may be that this popular term, **“electrodesiccation”, is inaccurate as ED is a common procedure performed by plastic surgeons and dermatologists. More accurately it is “electrosurgical removal of neurofibromas in high quantities under general anesthesia”.** There may also be a lack of understanding by plastic surgeons as to what this newer procedure is and sometimes there are issues with insurance coverage.

**Again, we aren’t sure why there is a reluctance by plastic surgeons to provide this procedure or something similar to remove high quantities of fibromas, but we are trying to find out. We do know that the NF community is clamoring for it and that it needs to be examined. NF Midwest is working closely with several doctors from around the country to better understand and clarify “the electrosurgical removal of neurofibromas in high quantities under general anesthesia” and the issues that surround it. We believe that any move forward will only benefit the NF community.**

NF Midwest is working closely with these doctors. In addition to pushing it along, providing support and representing the needs of the NF community, NF Midwest put together a detailed survey to determine the needs and experiences of the NF1 community regarding the removal of neurofibromas.

**If you have a lot of neurofibromas, we need to hear from you! Please, request a mailed survey by calling NF Midwest at 630.945.3562; emailing [info@nfmidwest.org](mailto:info@nfmidwest.org) or complete it online at [www.nfmidwest.org/neurofibroma\\_survey](http://www.nfmidwest.org/neurofibroma_survey).**

## UW Biotechnology Update

NF Midwest remains excited about pending new research at the University of Wisconsin through their Biotechnology Center. This project has now received initial seed funding. We will let you know when this moves forward and we are able to provide more details.

## University of Chicago Funding

The [University of Chicago NF clinic](#) opened its doors in 1989 after the founders of NF Midwest figuratively (and literally) walked the halls of this prestigious hospital to find doctors who would take on NF care.

NF Midwest has continuously supported this clinic with clinical and research support funds. These funds have helped to maintain a database that began in 1989 with the clinic. This database now has 1600+ participants – making it one of the most long-term and comprehensive collections of clinical information on NF. It is instrumental for tracking the natural history of NF and an invaluable tool for expanding our knowledge of NF.

The UoC NF clinic is also an original member of the NF Consortium of clinics established to conduct NF clinical trials. It **is also the leading contributor for NF Consortium’s investigation of [Lovastatin](#) as a potential treatment of learning disabilities, which stands as the largest clinical trial sponsored by the [NF Consortium](#)’s to date.**

A research study targeting quality of life and pain, as reported by people with NF, is forthcoming.

NF Midwest funds are also used to support the salary for an NF research coordinator at the UoC. Financially, institutions do not usually underwrite the costs of research and for all the progress being made with NF research, it is still underfunded. Therefore, the funding NF Midwest provides is critical because it fills the gap between what is needed to do research and what is available to support the projects. Research coordinators sit at the hub of the process and are critical to the success of our research. Without NF Midwest’s funding there would very possibly be no research coordinator or full ability to conduct research.

Funding is provided through the Martin Ginsberg Memorial Fund. If you would like to support NF research and care at the UoC please donate to this fund online at [www.nfmidwest.org/donate](http://www.nfmidwest.org/donate).

## NF Midwest Scholarship Fund

The NF Midwest Board has voted to start a Scholarship Program with funds left to NF Midwest through a charitable trust by Francis and Irma Napolilli.

One-time scholarships of \$1,000 will be awarded to people with Neurofibromatosis (NF) to further their education in undergraduate, vocational or graduate studies. Scholarship applicants must have neurofibromatosis and be in our region of Illinois, Indiana, Iowa, Wisconsin and the east half of Missouri. For more information contact our office or go to [www.nfmidwest.org/scholarship](http://www.nfmidwest.org/scholarship).

## NF Midwest Funded Studies Provide Valuable Information

Led by Bonnie Klein-Tasman Ph.D., collaborators from the University of Wisconsin – Milwaukee Dept. of Psychology have now published four papers based on cognitive studies of children with NF1 that have been funded by NF Midwest for several years. Also, one of the collaborators, Christy Casnar, had her research poster chosen as one of the top 3 in the clinical category at the annual national NF Conference.

These [articles](#) and the poster summarized the UWM team's research relating to cognitive and psychosocial functioning of children with NF1 ages 3 through 6; adaptive functioning of children ages 3 through 8 with NF1; language difficulties in children with NF1; and fine motor skills of young children with NF1.

You can find links to all three articles and the poster on our website blog [here](#). The three articles were in *International Journal of Pediatrics*, the *Journal of International Neuropsychological Society*, the *Journal of Clinical and Experimental Neuropsychology*, and *Research in Developmental Disabilities*.

We are excited and proud to have funded studies that have provided a great deal of information on cognitive issues in young children with NF. As an added benefit, these studies funded by NF Midwest also provided free neuropsychological testing to 65 children with neurofibromatosis type 1.

## NF Midwest Extends Funding on Cognitive Studies

In January, the NF Midwest board approved a \$10,000 grant to the University of Wisconsin – Milwaukee team mentioned above to extend their studies. This funding will allow them to follow-up on the psychosocial and cognitive functioning of the children with NF1 that they examined when they were younger. The children are now age 9-13 years. This will provide a broader base of information on how children with NF1 progress cognitively. It will help to determine if early cognitive signs are accurate predictors of later abilities. This study will also examine the occurrence of Autism Spectrum Disorder in NF1 and if there are early predictors.

We are very fortunate to have the chance to fund such a study at such a lower dollar amount only because at least one student is doing their dissertation on the subject and **has fellowship funding through the University**. It's wonderful to see our up and coming "great thinkers" take up such a passion for NF and to have the opportunity to nurture it.

## Question to Dr. Klein-Tasman

**Now that you have been learning about the cognitive and behavioral functioning of young children with NF1 for seven years, what would you say are the most important things that parents of a child with NF1 can do for their child?**

We are finding that when young children with NF1 show difficulties, they are often quite mild. We hope to learn whether even these mild difficulties help us understand needs for additional support as children get older. Here are some things parents of young children can do to support development:

- **Practice fine motor tasks** (e.g., drawing, cutting with scissors, stringing beads, gluing). These may be frustrating for your child, and it is tempting to just not ask them to do these tasks, but then they don't get practice and may fall further behind.
- **Work on developing attention span.** Spend some time each day doing a task that requires concentration. Get in the habit of doing "work" at a child-sized table. Gradually build up the amount of "table time." You can even set a timer and set some challenges for your child (e.g., *Let's see if you can work on this puzzle all the way until the timer goes off, and then we can play with bubbles*). Make sure to set the beginning expectations at a reasonable level to ensure that your child has success, and then gradually increase expectations.
- **Alternate between tasks your child likes and tasks your child is less fond of** to develop the ability to stick with tough tasks. Let your child know that you see the effort, and don't concentrate too much on success. Over time, the tasks will get easier, and learning this persistence and the value of practice will set the stage for learning.



Bonnie Klein-Tasman and her graduate student team from the University of Wisconsin. (L to R) Nathanael Schwarz, Natalie Brei, Bonnie Klein-Tasman, Brianna Yund, and Christy Casnar.





## A Moment in History

In the photo above, members of NF Midwest, NF Northeast and Texas NF visited Cold Spring Harbor laboratory in New York in the 90s. Included in the visit was [Dr. Alcino Silva](#) whose research was funded by NF Midwest in 1997, 2000, 2002 and 2006. NF Midwest was an early funder of **Dr. Silva's work on learning disabilities in NF mice. It was through this research that Dr. Silva's team discovered that Lovastatin (a common cholesterol lowering drug) reversed learning disabilities in these mice. That research has now gone on to clinical trials in children and adults with NF with results expected soon.**

NF Midwest, NF Northeast and Texas NF have a long history of "seeding and feeding" neurofibromatosis research and were the first U.S. NF organizations able to support "up and coming" researchers and research projects.

We thank those who worked so hard so many years ago - many of them are still in the trenches today. We also thank our donors and everyone that supports the cause yesterday, today and tomorrow!

## Advocacy Update

In February NF Midwest joined the NF Network Advocacy Partnership in DC to walk the hill looking for support for federal funding of neurofibromatosis research. Organized advocacy efforts started in 1996 and NF Midwest was involved from the beginning. Since then over 287 million has been granted for NF research through the [Congressional Directed Medical Research Program](#) (CDRMP) which is administered by the Department of Defense (DOD). In addition, the NF advocacy group petitions for additional research through the National Institutes of Health. The actual amount for specific disease research through the NIH is not established by Congress, but it is estimated that close to the same amount (another 287 million) has been spent on NF research through the NIH since 1996.

Three advocates from NF Midwest covered the states of Illinois, Indiana, Iowa, Kentucky and part of Missouri and contacted 47 offices! One of our advocates, Susan Buono, has lobbied with us for six years! Thank you Susan!

Also, thank you to everyone who sent personal letters. We delivered them all! They provide impact and perspective that really helps the process.



*2015 NF advocates get ready to storm the Hill!*

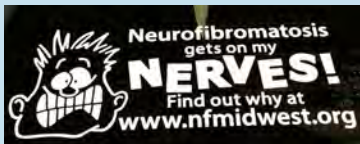


## NF A-Wear-Ness Store NEW PRODUCTS

"Neurofibromatosis Gets On My Nerves" is one of our themes and is available in a t-shirt and vehicle sticker. The t-shirt is bright yellow and encourages people to "Ask Me Why". You can't be shy in this shirt and have to be ready to explain! The vehicle sticker is the white ink and transparent. It is meant to go on the back window of a car, but we've seen people put it on their laptops, folders, home windows, doors and even a food truck!

Our tie-dye wristbands are also back in stock!

Find these and other merchandise and materials to raise awareness at our store at [www.nfmidwest.org/store](http://www.nfmidwest.org/store).



## Like What You Read? Support the Cost of this Newsletter and the NF Midwest Mission!

Please use the enclosed remittance envelope to [make a donation](#) to cover the cost of this newsletter and to support the NF Midwest mission. \$500, \$100, \$50, \$20....any amount makes a difference!

## NF Midwest Service Survey

Thank you to everyone who completed our NF Midwest “Service Survey” online and through the mail. This was a quick, helpful survey of 110 individuals and families affected by neurofibromatosis. The main idea was to determine the needs and interests of the NF Midwest community and to determine their preferred way to communicate.

Our goal was to gauge the importance of each of our five areas of focus to the NF community. These areas are Clinics, Awareness, Research, Education and Support.

Not surprisingly, when it came to ranking these areas many people found it difficult and thought them to be equally important. One respondent put it perfectly:

***This is a tough one. What sets NF Midwest apart from NF [sic] organizations is the level of support it offers. Ideally, research would be the #1 priority, so that a cure would be found sooner. But a cure is likely several years off; until then, we need to figure out a way to live with NF without falling apart. Support is critical to living with NF in a way that is meaningful--especially if people with NF are not being seen regularly at NF clinics. We need support until we have a cure. That brings us to clinics. That should be the #2 priority. But many with NF don't even use them; does that mean that clinics should be put down as less of a priority or even more of a priority? Of course, awareness is important, so it should be the #3 priority. But awareness without education is almost meaningless (or at least panic-inducing), so education should be higher than awareness. We're sharing our thoughts on this, so you can understand why we ranked these areas the way we did. It's not an easy task.***

We also asked people to give points to each area allowing them to score things all the same or differently. In the end it was very close. The pie chart to the right tallies the “points” given to each area. Research is slightly higher and support lower. The ranking chart (where respondents were forced to rank) gives a slightly better, though forced view—research barely edges out clinics. Support is again the least important, however support was seen by most as a feature of Clinics, Awareness, Research and Education.

## Communication Preferences

We also learned how our NF community prefers to communicate and how people like to learn about NF.

There was a strong preference for reading materials (either printer or online) over watching videos/webinars, symposi-

ums, and sharing with others. After reading materials there was fairly equal interest in the other ways to learn. There was a slightly higher preference (61% vs. 51%) for reading printed materials vs. reading materials online.

For communications from us email was the clear favorite, followed by snail mail (through the mail) and then by Facebook.

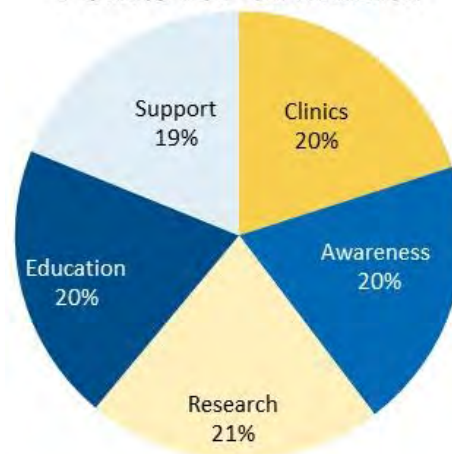
For sharing and teaching others about neurofibromatosis, 89% said they were comfortable doing so, but many found that it was a difficult topic to explain.

Regarding our clinic questions it is clear that many people are looking for better access to NF doctors who treat adults. Also, a somewhat disappointing result was that 23% of our respondents do not see an NF specialist.

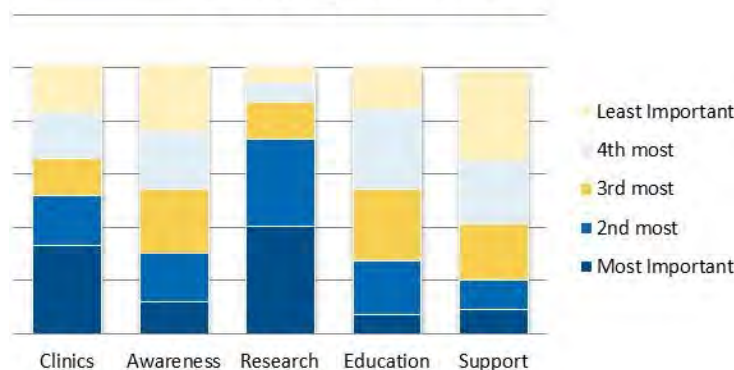
We have more results and will attempt to publish them on our website soon.

The important thing is that NF Midwest is very interested in the needs of the NF community and is focused on improving lives of those with NF in the Midwest. This survey helps us to clarify those needs. Thank you to all who participated.

**Points for C.A.R.E.S.**



**Ranking of C.A.R.E.S.**





## NF Midwest Looking to Expand Board

NF Midwest is looking to build a diverse Board of Directors that consists of men and women representing varied constituencies and regions in our community. Potential members of the board should be passionate about our mission and willing to contribute their time, talents and/or treasures in order to meet our goals.

The following is a general wish list for board members, but is not limited to this list.

- Marketing/Advertising/PR
- Experienced Fund Raisers
- Entertainment/Media Industry
- Business Executives (Officers, Key Corporate Positions)
- Physicians
- Accountant/Financial
- Attorney

If you would like more information, please contact Diana at 630-945-3562 or email [Diana@nfmidwest.org](mailto:Diana@nfmidwest.org).

## Welcome to Two New Board Members

We are very excited to have two new warm and passionate bodies join the NF Midwest board last fall.

Ellen Gallagher is a property manager and an active member of the St. Charles community. Ellen brings a great perspective and passion to the NF cause as she doesn't have a loved one affected by NF but is moved by NF Midwest's programs and the needs of the NF community.

Charles Todd's passion for the NF cause comes from the loss of a friend to the disorder. Charles is a director at [Apttus](http://Apttus.com), a former account executive at Sprint and co-founder of Luxe Living. He looks forward to using his business skills and contacts to further the mission of NF Midwest.



### Hello Kelli!

In November, Kelli Westphal came on board as our new Event and Marketing (think awareness!) coordinator. Kelli worked for us briefly back in 2009 and has an MBA in marketing. Affected with NF1, Kelli carries a passion and understanding for the NF cause and

is excited to be back with NF Midwest!

Kelli replaces Jenny Perkins who was with us for several years, but decided to work a lot closer to home. We miss Jenni, but she promises to be there for Great Steps in Naperville!



## Camp New Friends

*Building a foundation of strength and knowledge; and developing a circle of friends that understand and will always be there...can make a lifelong difference.*

**July 19— July 25, 2015  
West Virginia.**

To register for camp and to apply for financial aid for camp tuition and/or travel, contact Brainy Camps directly at [www.brainycamps.com](http://www.brainycamps.com).

**Camp is NOT too costly.** For 10 years, NF Midwest has financially supported kids from the Midwest to attend Camp New Friends by helping with travel and camp fees.

**Camp is NOT too far.** The staff at Camp NF help kids travel safely and if they fly out of Chicago, NF Midwest has a group that travels together with young adults as chaperones.

**Your child couldn't be in better hands!** At least two child neurologists and experts in NF head the medical team for the week of camp. Plus nurses, social workers, physical therapist and psychologists, are on-site 24 hours a day. Counselors are trained in dealing with the issues associated with NF. Many counselors and volunteers have NF themselves and share their experiences with the campers.

If you have any general questions about camp or travel, call the NF Midwest office at 630-945-3562. NF Midwest staff has sent their own kids to Camp New Friends, so feel free to contact us!



## Camper Videos

At the end of December a few of our past campers stopped by the office (see photo above) to say thank you to donors for supporting camp and to share how camp has affected them. You can view these videos on our website at [www.nfmidwest.org/camp-new-friends-thank-you-videos/](http://www.nfmidwest.org/camp-new-friends-thank-you-videos/).

## Remember NF in Workplace Giving



#75126

NF Midwest is now a part of the Combined Federal Campaign (CFC). This means that Federal employees can select NF Midwest as their charity of choice to receive donations through their paycheck.

Our CFC number is 75126.

We are also listed in some Community Health Charities or United Way workplace campaigns or you may be able to designate NF Midwest.

CFC and other workplace campaigns generally won't open until late in the year. Please, remember NF Midwest when your workplace campaign season rolls around.

## MISSOURI

### Upcoming Missouri Events

#### Color Me a Cure 4NF — Saturday, May 2nd



Alex's Angels are doin' it 4NF again with another fun [Color Me a Cure 4NF](#) 5K/1 Mile Family Fun Run/Walk to benefit NF Midwest. The event includes raffle and silent auction and will be held at Malden City Park. Registration is from 8:00-9:00 am. Mail entry and payment to: Crystal Presson; 3404 State Hwy 25, Malden, MO 63863

## New Walk Near St. Louis!

**Great Steps 4NF in Valley Park**—The first St. Louis area Great Steps 4NF walk will be held on September 26th! Go to [www.greatsteps.org](http://www.greatsteps.org) for more information. [REGISTER](#)

**Central Missouri Support Meetings**—The Central Missouri (formerly Columbus) chapter holds monthly meetings on the 3rd Thursday of every month at the Columbia Public Library. For more info contact us or email the chapter at [CentralMissouri@nfmidwest.org](mailto:CentralMissouri@nfmidwest.org).

**Family Day**—The Central Missouri Chapter is working on a St. Louis area family day. For more info or to help please contact us or email the chapter at [CentralMissouri@nfmidwest.org](mailto:CentralMissouri@nfmidwest.org).

## Keep Hope in Motion

Set your giving on auto pilot!



You can be someone who keeps hope in motion. Join our Monthly Giving Circle by signing up for automatic monthly giving at [nfmidwest.org/monthly-donation](http://nfmidwest.org/monthly-donation). In the last year we have nearly doubled the number of people who are giving monthly. You can help us double down again!

### New Additions on Our Website

- Transcripts and material from our symposium
  - [Transitioning to Adult Care](#)
  - [Mutations and Biological Behavior of NF2-Associated Schwannomas and Meningiomas and Potential Therapies](#)
  - [Volumetric Measurement of NF Tumors](#)
- New Articles
  - [Gene Deletion in NF1](#)
- New Webinars and Videos
  - [Social Emotional Development in NF—Webinar Recording](#)
  - [Understanding Seizures in NF1 Webinar Recording](#)

**And more (because we're sure we missed something!)**

To really be in the NF Loop:

1. **Make sure we have your CURRENT email**
2. **Join our NF Midwest Facebook Group** - The group is private and limited to people in our region with a high interest in NF and NF Midwest. Go to [nfmidwest.org/facebookgroup](http://nfmidwest.org/facebookgroup) to request to join.
3. **Join our NF Midwest News Facebook Group**—This is open to anyone and is another great way to receive updates. Simply search [NF Midwest News](#).
4. **“Like” our NF Midwest Facebook page at [facebook.com/nfmidwest](https://facebook.com/nfmidwest)**
5. **Follow us on Twitter at [twitter.com/nfmidwest](https://twitter.com/nfmidwest)**
6. **Get our Twitter updates as text** by texting “follow nfmidwest” to 40404. You may send an “unfollow nfmidwest” text if it gets to be too much.
7. **Check our website [www.nfmidwest.org](http://www.nfmidwest.org) regularly and subscribe to updates.**



## ILLINOIS

## Upcoming Illinois Events

**Take a Swing at NF—Friday, August 7th** at Prairie Landing Golf Club, West Chicago, IL. This will be the 17th running of this event which raises funds to send kids to Camp New Friends and for other kids related programs.

**Great Steps 4NF Naperville—Saturday, June 6th** Sign-up now for the largest walk for NF in the country at [www.greatsteps.org](http://www.greatsteps.org). This includes our popular “goodie” collection along the way.

**Great Steps 4NF Effingham—Saturday, June 20th** Sign-up now for the Effingham Walk and Bake Sale at [www.greatsteps.org](http://www.greatsteps.org).

**Chicago Area Family Day—Saturday, September 5th**



Mark your calendars now for the Chicago Area NF Family day which will be held at the Kane County Cougars in Geneva, IL. Join us for a baseball game, a picnic on the deck and fireworks. Midwest is absorbing a large portion of the cost for this event.

Tickets will be greatly discounted. If you know a business that would like to sponsor this upcoming event or any others, please let us know.

**SamJam, Unplugged in the Prairie—October 10th**

The Oswald family and friends are holding [SamJam4NF](http://SamJam4NF) 2015 in Carlinville, IL. See more below.



*NF Midwest Director, Diana Haberkamp receives a check from Sam and Pete Oswald II, at the October symposium*

## They Did It 4NF!

**Great Steps 4NF Walks**—Illinois had two walks in 2014 both on June 21st. Thank you to Laura Didier, her family and friends who make the Effingham walk happen and to all of our Naperville volunteers and our committee members!

**Golf Benefits**—In August, two golf outings were held in Illinois for the benefit of NF Midwest and the NF cause. They included the 16th **Take a Swing at NF** golf benefit in West Chicago and **Chip in Fore NF** at Cog Hill in Lemont. [Swing 2014 Photos](#)

**Birdies for Charity**—Steve Reason guided us through the [Birdies for Charity](#) fundraiser and raised over \$2000!

**Martin Chevy**—Thank you to [Martin Chevy](#) in Crystal Lake, IL and to all who voted and helped NF Midwest win \$500 in two different months for \$1000 total.

**Vendor/Craft Fair**—Team Sunshine of Great Steps Naperville held a vendor fair on Dec. 6th to raise funds for NF Midwest and their GS team. Vendors included Jamberry Nails, thirty-one, Tupperware, Wildtree, [Half Acre Beer Company](#), Premier Designs, The Kitchen Table, Bootsie Marie Boutique, Sew Divertimento, and much, much more!!



*NF moms come together 4NF at the Vendor/Craft Fair!*

## SAM JAM, UNPLUGGED ON THE PRAIRIE

The Oswald family and friends put together a music event for NF in honor of Sam Oswald to benefit NF Midwest in September.

Held at the [Macoupin County Fairgrounds](#) in Carlinville, IL.

“SamJam” featured 12 hours of progressive bluegrass, Americana, and Roots music, plus bag tournaments and other fun stuff. Look for it in 2015 on October 10th!





## WISCONSIN

### Upcoming Wisconsin Events

**Madison Steps 4NF Walk —May 9th** at Capital Brewery in Middleton. [Sign-up NOW](#).

**Chippewa Falls Great Steps 4NF Walk**—May 16th at Irvine Park. [Sign-up NOW](#).



Team Dozer at the finish line at the Madison GS4NF Walk!

### They Did It 4NF

**Madison Great Steps 4NF Walk**—The 5th annual Madison area Great Steps 4NF walk was held at the [Capital Brewery and Bier Garten](#) in Middleton on May 10th.

**Chippewa Falls Great Steps 4NF Walk**—The West Central Wisconsin chapter held their first Great Steps 4NF walk on May 17th. Join them this year on May 16th.

**Picnic in the Park 4NF Chippewa Falls**—The Chippewa Falls chapter held a picnic at Irvine Park in July.

**Links for Lauren**—Aerotek held the 2nd Annual *Links for Lauren* Golf Benefit at the prestigious Nakoma Golf Club in Madison, WI on August 25th.



Tim Eberle collects a check from the Regency Beauty Institute in Madison, WI.

### West Central Wisconsin's Strategy!

Crystal Reith has a great strategy for raising NF awareness through the West Central Wisconsin NF Midwest group that she manages. They don't just **Do It 4NF**, they do it for others! Crystal explains it best...

*When I started the West Central Wisconsin Chapter I made it clear to our community that not only did we want help from them, but we want to help them. We are active in the parades (spreads awareness about us). We also participate in Earth Day Clean Up and anything else they throw at us that we can come up with. After the walk last year we sent out picture thank you cards (with some of our walk pictures on a card). Today I was out delivering some Christmas Goodie baskets to some of the people that were very helpful to us last year and to say they appreciated it and were shocked would be an understatement...Their faces lit up with the biggest smiles and one even gave me a big hug and said we were the best local organization in this area and loved the fact that we are so involved and looks forward to telling people how great we are! Yeah West Central Wisconsin on a great job!*

Email [wcwisconsin@nfmidwest.org](mailto:wcwisconsin@nfmidwest.org) for more information or to get involved in the NF cause in West Central Wisconsin.



West Central Wisconsin members ring the bell in Chippewa Falls!

**YOU CAN Do It 4NF!**  
www.nfmidwest.org

[Do It 4NF](#) in 2015! The neurofibromatosis cause needs you. No matter your talents or time, there is definitely something you can DO 4NF! What will it be?

## INDIANA

### Upcoming Indiana Events

**Lunch with the Docs** — Our annual *Ask the Doc* session in Indianapolis has changed its name to **Lunch with the Docs**, but it's still an excellent opportunity to get your questions answered.

Experts in attendance will include doctors from the Indianapolis NF clinic as well as an oncologist, ophthalmologist and possibly a social worker.

There will be a kids group for children ages 4 to 13 with crafts and games.

For more information or to sign-up call 630.945.3562 or go to [www.nfmidwest.org/indylunch2015](http://www.nfmidwest.org/indylunch2015).

SIGN UP  
NOW

**Lunch with the Docs**  
**In Indianapolis @ Indiana University**

**Saturday, April 18, 2015**  
**11:00 am-2:00 pm EST**

**Cost is \$5.00 for adults/children are FREE**  
**(cost includes lunch)**

### Fort Wayne GS 4NF Walk —September 12th

Fort Wayne will be holding its 5th annual walk. [Sign-up NOW!](#)

### They Did It 4NF

**Fort Wayne Great Steps 4NF Walk** —Fort Wayne had another awesome walk with a fantastic spread of raffle prizes on September 13th. Join them in 2015 for their 5th walk on September 12th at Eel Creek Elementary.

**Evansville Meetings**—The Evansville NF Midwest chapter regularly holds meetings. For more info email Jane at [evansville@nfmidwest.org](mailto:evansville@nfmidwest.org).

**Groovin' 4NF**—Using the connections and concerns of her musical friends, Libby Huffer held a concert called Groovin' 4NF at the Sweetwater Auditorium on Saturday, August 2nd, 2014. The concert headliner was [Pink Floyd](#), a popular Pink Floyd tribute band with an opening by [Marnée](#), another well-known musician in the area.



## IOWA



When we learned from Jamie Dornbush about how many, including her, in her extended family from Clinton, IA were recently found to have neurofibromatosis type 2 and saw the surgeries that several of them were facing together...we encouraged them to reach out and share their story.

It has been a very difficult year for Jamie and the Barrette family and that sharing was a hard process to add during this time. But they **did it 4NF** because they wanted to bring awareness to a disorder that unknown to them, had been quietly devastating their world.

Their story was written up and printed in the Quad City Times. If you'd like to read their story, you can find the link on our blog at [www.nfmidwest.org](http://www.nfmidwest.org).

## KENTUCKY

At least one family in Western Kentucky is looking for people to connect with and to build an NF community. If you are interested in being a part of this or want to work on building a community elsewhere in Kentucky, please email [info@nfmidwest.org](mailto:info@nfmidwest.org).



Remembering Kambi at GS4NF Fort Wayne.



# Great Steps 4NF 2014

## What a Year! You Did it!

This year's Great Steps 4NF walks were outstanding! Many families and teams came together to make a difference by raising awareness and funds for NF programs. Each walk is chaired by an individual or a family that has stepped up to volunteer their time and effort to put together a great event for everyone to enjoy. If you would like to start a walk in your area or want to volunteer your time at an existing walk, don't hesitate to let us know. **We count on volunteers to make a difference!**

**Madison, WI** – The first Great Steps 4NF walk of the 2014 season was a hit at the Capital Brewery. We had the addition of a 5K run and a DJ, so everyone was pumped for a good day. Join in the fun this year on May 9th! [SEE 2014 PHOTOS](#)

**Chippewa Falls, WI** – The Inaugural Chippewa Falls Great Steps 4NF walk held on May 17th at Irvine Park was a huge success. Crystal Reith and family organized this event which was hosted by the local radio station, WAXX 104.5. Socializing, great food, and raffles were enjoyed by all after the scenic walk around the park. They're looking for an every bigger turn-out on May 16th this year! [SEE 2014 PHOTOS](#)

**Naperville, IL** – It was lucky number 13 (years that is) for Naperville's Great Steps 4NF walk. With approximately 900 walkers spread across 61 teams, this walk continues to be the largest walk for NF in the country! With outstanding weather, everyone enjoyed the walk along the Riverwalk, the cool DJ, delicious food, raffles and bounce houses (well that was mostly the kids). Our NF champion for this year's walk was Caitlin Ostrom, who passed away in November 2013. Her mom Christine gave a very inspirational speech which can be viewed [here](#). Note that next year's walk has moved back to the 1<sup>st</sup> Saturday in June....we hope to see you there on June 6th! [SEE 2014 PHOTOS](#)

**Effingham, IL** – The second oldest walk in the Midwest, our NF supporters in Effingham keep going strong. They are incredibly dedicated and fun group and it's a great walk through Effingham. Sign-up to represent central Illinois (or wherever you want to come from) and walk with us on June 20th! [SEE 2014 PHOTOS](#)

**Fort Wayne, IN** – The Fort Wayne walk was the last of the 2014 season and they finished us with a bang! Once again the Taylor family and friends put together a fantastic raffle! Where do they get all that stuff? Come check out the goods and the fun on September 12th this year! [SEE 2014 PHOTOS](#)

**Contact Kelli at 630-945-3562 or**  
[kelli@nfmidwest.org](mailto:kelli@nfmidwest.org) with any questions  
 about this years walks!



### PICK A DATE! PICK A PLACE!

Below are the dates for this year's walks. Get more information at [www.GreatSteps.org](http://www.GreatSteps.org).

[Madison, WI](#) • May 9  
[Chippewa Falls, WI](#) • May 16  
[Naperville, IL](#) • June 6  
[Effingham, IL](#) • June 20  
[Fort Wayne, IN](#) • Sept. 12  
[Valley Park, MO](#) • Sept. 26

### 2014 By The Numbers

#### Madison

Raised: \$27,000  
 1st Place: Team Konsitske \$6,000  
 2nd Place: Marissa's Mighty Mob \$3,202  
 3rd Place: The Dozers \$3,153

#### Chippewa Falls

Raised: \$8,600  
 1st Place: Myshell's Steps 4 A Cure \$2,246  
 2nd Place: Cal's Crew \$1,788  
 3rd Place: Team Aydin \$1,470

#### Naperville

Raised: \$125,000  
 1st Place: Team Caitlin \$21,125  
 2nd Place: Brody Bunch \$11,095  
 3rd Place: Team Doodle \$10,821

#### Effingham

Raised: \$8,900  
 1st Place: Rockstars for Wyatt \$1,829  
 2nd Place: Shannonigans \$850  
 3rd Place: Gabe's Gang \$755

#### Fort Wayne

Raised: \$14,000  
 1st Place: Team Owen \$3,705  
 2nd Place: Shelby's Superstars \$2,831  
 3rd Place: Team Kambi \$2,226



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Save paper and our expense. If you would no longer like to receive mailings such as these, please call us or send us an email.



## 25th Annual NF SYMPOSIUM

*A Day of Learning  
And Socializing*

October 24, 2015

8:30 to 4:00

Hoffman Estates, IL



**Great Steps 4NF  
6 Locations!  
Sign-up Now**

Chippewa Falls, WI  
Madison, WI  
Naperville, IL  
Effingham, IL  
Fort Wayne, IN  
Valley Park, MO



NF Midwest is registered 501(c)3, not for profit organization. Currently our service area includes the states of Illinois, Iowa, Indiana, Wisconsin, Kentucky and the eastern half of Missouri.