

## *Celebrating 35 Years of Care!*

We're celebrating our 35th year. Please help us honor all those who have dedicated their time over the years in any and all the ways you can through 2017!

## Symposium and iNfo Fair

November 11, 2017



Neurofibromatosis Type 1, Type 2, and schwannomatosis are extremely complex disorders with many and varied physical complications as well as other issues. That's why an educated NF population is a cornerstone of NF Midwest's mission to improve care.

For over 25 years to help provide that education, NF Midwest has held an all day symposium. On November 5th, 2016, we held one of our best symposiums ever. We brought amazing experts from around the country to cover topics including medical cannabis and chronic pain; adult complications in NF1; NF2 research and

Avastin; the high quantity removal of neurofibromas (electrodessication); NF1, NF2, Schwannomatosis — "what's the difference"; hearing loss in NF2, brain tumors in NF1; and student advocacy (504s, IEPs, Etc). We also had our iNfo tables and a special "table session" in which attendees could circulate and learn more about topics such as medical cannabis dispensaries, participating in research, learning disabilities and school issues, social security, disability and insurance, NF clinics, making a difference—raising funds and awareness, parents of children with NF, and adults with NF.

There were approximately 150 attendees and the day included more than iNformation. We had a continental breakfast, buffet lunch, afternoon snack (I know...expand the waist band!), plus the kids enjoyed their own group.

Our 2017 symposium is scheduled for November 11th at the same place in Hoffman Estates, IL at the NIU extension building. Be sure to mark your calendars now and to check our website for updates on presenters and hotel information.

## Grants Awarded to University of Wisconsin and University of Chicago *UW/Milwaukee to identify reliable measurements for ADD in young children with NF1.*

NF Midwest recently awarded funds to [University of Wisconsin-Milwaukee](#) for a study to help identify reliable measurements for ADD in young children with NF1. Attention problems are one of the most common difficulties observed for school-age children with neurofibromatosis type 1 (NF1). While recent research indicates that attention problems and other cognitive and behavioral difficulties can be identified in the preschool years for children with NF1, and an increasing number of clinical trials include younger children, there is very little research about the appropriateness of the ways we measure attention for children with NF1 ages 6 and younger. Because attention problems in the preschool years can be subtle, it is important to know which measures are most likely to show those difficulties ("sensitive") and which measures provide results that are consistent ("reliable") and meaningful ("valid"). This study is to begin to identify sensitive, reliable and valid measures of attention problems for use with young children with NF1. This will allow researchers and clinicians to identify early indications of attention problems and track the effects of treatments on attention problems, (including within clinical trials research).

## *U of Chicago to fund clinical trial coordination.*

NF Midwest has awarded the Martin Ginsberg grant for research to the [University of Chicago](#) to support coordination of their clinical trials and other research. The University of Chicago NF clinic is an original member of the [NF consortium](#). They are considered one of the most productive clinics in the NF Consortium and have entered many patients into trials such as the lovastatin trial and MEK inhibitor trials. They have also provided many of the patients for the PRO study for pain.



NF Midwest CARES and we're here to make sure that no one fights NF alone, but this takes a community working together. Please, think of the ways that you can be apart of this support system whether it is a donation, a fundraiser or as a volunteer. Contact us and we'd love to bring you into the fight.

## Board Of Directors

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### 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.



2016 Scholarship Recipients

a full or part-time basis at an accredited, US-based institution, and live in NF Midwest's service region of Illinois, Indiana, Iowa, Kentucky, Wisconsin, and eastern Missouri.

In 2016, NF Midwest awarded scholarships to 17 amazing scholars!

If you'd like to be a recipient of one of our 2017 scholarships [apply now](#). The application deadline is April 30th. Please contact us or go to our website for more information.

## Lunch With The Docs



Every spring, NF Midwest sponsors **Lunch With The Docs** at various locations. These sessions include a informal lunch and a casual Q&A sessions with doctors from area NF clinics.

Do you have a question you would like answered by a health care professional with NF1 expertise? Do you wonder what other people's questions about NF1 are? Do you have a need to know how others find ways around the obstacles that NF1 can cause? If so, these are the events to attend.

### Indianapolis Lunch with the Docs

**Saturday, April 8, 2017  
11:00 am-2:00 pm EST**

Neuroscience Center at Goodman Hall  
Indiana University School of Medicine  
355 W. 16th St., Indianapolis, IN 46202

Includes a kids group for  
children ages 4 to 13.

**Cost is \$5 for adults  
Kids are free**

**Register online at  
[nfmidwest.org/indylunch2017](http://nfmidwest.org/indylunch2017)**

## NF Midwest Scholarships

Applications are now being accepted for NF Midwest's Napolilli scholarship program.

Established in 2015 with funds donated by the Napolilli family, the program offers \$1,000 scholarships to students pursuing undergraduate or vocational programs of study.

To qualify, students must have an NF diagnosis, be entering or continuing undergraduate (Associate's, Bachelor's or Vocational) school on

### Chicago Lunch with the Docs

**Sunday, April 30, 2017  
1:30 pm-4:00 pm CST**

Shriners Hospital for Children  
2211 N Oak Park, Chicago, IL

Includes a kids group for  
children ages 4 to 13.

**Cost is \$5 for adults  
Kids are free**

**Register online at  
[nfmidwest.org/chicagolunch2017](http://nfmidwest.org/chicagolunch2017)**

## New Clinic in the Chicago Suburbs

Big news! We have now established an neurofibromatosis (NF) clinic in the Chicago suburbs for adults and children with NF. Amita Health/St. Alexius is looking to build a comprehensive NF Clinic directed by Nikolas Mata-Machado, MD. Dr. Mata-Machado is an adult and pediatric neurologist who speaks fluent English, Spanish and Portuguese. Having served a neurological fellowship under Dr. James Tonsgard at the University of Chicago, he has a deep interest in neurofibromatosis. In fact, you can find Dr. Mata-Machado on the cover of our third edition of [Understanding Neurofibromatosis](#) booklet. He will be seeing children and adults with NF1 and NF2 in Hoffman Estates and Wheaton.

Appointments can be made by calling 847-490-4222.

Note: Dr. Mata-Machado is no longer with Loyola. Learn out more about finding an NF doctor at [www.nfmidwest.org/findadoctor](http://www.nfmidwest.org/findadoctor).

**SORRY**  
You May Have Missed This Event  
Please make sure you are receiving emails and checking our website regularly updates so you don't miss future events!



## Don't Just Walk, Come Out To Party!

Join NF Midwest at a Great Steps 4NF and you are guaranteed a good time. Sign-up now to raise funds and awareness to improve the lives of everyone with neurofibromatosis and schwannomatosis.

**You have seven walks/parties to choose from!**

### Madison, WI – Saturday, May 13th

Another fantastic, fun walk is set to take off at the Capital Brewery in Middleton. We always have an awesome morning in the beer garden with a light breakfast, a walk, followed by lunch, raffles, silent auction, and usually some crazy dancing. This year look for there to be brats on the grill! We have an incredible committee! If you'd like to help or get involved in some way with NF in Madison, email Tim at [Madison@nfmidwest.org](mailto:Madison@nfmidwest.org). [Sign-up Now!](#)

### Chippewa Falls, WI – Saturday, May 20th



This year's walk in Chippewa Falls is in memory of Myshell Reith, the originator of the Chippewa walk and all time champion of NF awareness. This is an amazing event from start to finish. It includes a walk around beautiful Irvine Park and Zoo (which you should save time to visit!)

Hosted by Alex & Cora from WAXX 104.5, there is always fun music, a huge raffle and delicious home cooked food in a great family picnic atmosphere....and always cake! If you have a prize or raffle donation for the Chippewa walk, or want more information about the West Central Wisconsin group, contact Crystal at [wcvwisconsin@nfmidwest.org](mailto:wcvwisconsin@nfmidwest.org). [Sign-up Now!](#)

### Naperville – Saturday, June 3

This event is the largest walk for NF in the country! Usually we have around 1,000 people attend representing approximately 70 families with NF. It's really more of a party in the park, with a little walk in the middle where you actually get to collect "goodies" as you walk! There's music, food, ice cream, superheroes, bounce houses, dancing, great raffle prizes, and more! [Sign-up Now!](#)

### Recognition Prizes

This year recognition prizes will be given to individual fundraisers rather than the team captain (unless fundraisers under a team choose to "pool" their efforts and want us to give the prizes to the team captain. Receive the following recognition prizes:

\$1,500 Doin' It 4NF Bag Chair  
\$3,000 NF Midwest Coozie Picnic Cooler  
\$5,000 2017 Top Fundraising Flag

### Effingham – Saturday, June 17

The Didiers have been hosting this walk for 10 years and in honor of their incredible hard work and dedication we want to make this one AMAZING! People come from all over central and southern Illinois, western Indiana, and even the St. Louis area to enjoy a breakfast, snacks, pizza, more snacks, drinks, a bake sale, raffle...and a fun little walk! **Be sure to join us for this special walk #10!!!** [Sign Up Now!](#)

### Indianapolis, IN – Saturday, Aug. 19th

Our Indianapolis group will be holding their 2nd Great Steps 4NF Walk at Hummel Park in Plainfield, IN on Saturday, August 19th. Last year several families came out and made a great morning of it. It was extra exciting and memorable since a thunderstorm joined in the fun! Sign up now to join us in this walk. Also, we are in need of people who want to help in planning! If you'd like to get involved in NF in Indianapolis to help build awareness and community please send an email to [indy@nfmidwest.org](mailto:indy@nfmidwest.org). [Sign Up Now!](#)

### Fort Wayne, IN – Saturday, Sept. 16

Come out to Parkview Field, home of the MLB TinCaps baseball team, for the 7th annual Great Steps 4NF Walk in Fort Wayne. This is a fun walk inside the stadium. You'll enjoy food, music, raffle, and more! The Fort Wayne committee is energized and ready to go. If you'd like to join them in organizing this event or others, please send an email to [fortwayne@nfmidwest.org](mailto:fortwayne@nfmidwest.org). [Sign Up Now!](#)

### Taylorville – Saturday, September 23

The 3rd Annual Great Steps 4NF Walk and 5K Run in Taylorville, IL will be held once again at the gorgeous Manners Park. The Layton family and friends always put together a walk that is full of fun! Last years even included live music, a bounce house, cotton candy machine, bake sale, a 50/50 & a silent auction. The energy and community is incredible. [Sign Up Now!](#)

### We Need Business Support

The NF Community needs corporate and small business support. Please think of who you know in the business community that might like to sponsor a walk or provide a material donation for raffle or giveaway! Email us at [info@nfmidwest.org](mailto:info@nfmidwest.org).





## New Board Member - Lesli Wegner



In October the NF Midwest board elected a new board member, Lesli Wegner.

Lesli has amazed us for eight years as she has dedicated her time to supervising the food, drinks, and treats at our Naperville Walk! This is something we all especially love at the walk and it couldn't be done without her.

Lesli has a child with NF-1 and has been involved in the organization since 2001. She is also a Registered Nurse with 20 years experience in Hematology/Oncology nursing.

If you would like to be contacted by the board for ways that you too can be involved, please contact NF Midwest.

## NF Midwest Awarded Grant for Care



*Driven to Care Illinois/Wisconsin Regional Team at NF Midwest in St. Charles*

We're lucky to have supporters that care about NF Midwest's mission and community. It's because of one such wonderful person, Erin, and her amazing colleagues on the Illinois/Wisconsin Driven to Care regional team that NF Midwest was invited to apply for a [Driven to](#)

[Care](#) grant which is funded by the Diane and Bruce Halle Foundation, the philanthropic arm of Discount Tire.

NF Midwest was awarded a \$20,000 grant to pilot our Patient Navigator/Care Assistance program. The Patient Navigator program includes a staff member whose primary focus is to ensure that No One Fights Alone. They're dedicated to improving clinics, identifying physicians, finding resources, and being there to listen to and help everyone in our Midwest community who reaches out to us.

We're awed at the generosity of [Discount Tire](#) and the Diane and Bruce Halle Foundation. Working with Erin, Chandra, and the other members of the Driven to Care team we discovered inspirational people who truly care and a company that truly gives back!

## New Development Director

We're thrilled to welcome Danise Habun as our new development director. Danise is a resident of Elgin, IL and has an extensive history working in the nonprofit arena. She brings her experience in fundraising, grant writing, fund development, strategic planning, organizational development, and program development to NF Midwest. Danise has served as the Director of Development Services with the Children's Advocacy Center of North and Northwest Cook County and as the Executive Director with both the Hanover Township Mental Health Board and the Coordinated Care Alliance. She serves on the Elgin Human Relations Commission as well as the Elgin Police Citizens Advisory Council. You can email Danise at [danise@nfmidwest.org](mailto:danise@nfmidwest.org).

## Camp New Friends July 16— 22



**This could be some you love with NF! Jammin' out and havin' fun!**

If a child with NF wants to go to camp, we want to make sure to get them there!

The opportunity to go to this special camp for kids with NF is available for every child with neurofibromatosis. It's an amazing place to make friends, to develop self esteem, and to learn to care for themselves as well as others.

Our donors make it possible for NF Midwest to fund kids from our region who need help with travel and tuition to attend Camp New Friends in West Virginia. Applications for camp and for assistance are taken by Camp New Friends Brainy Camps and reimbursed by NF Midwest. Please contact us if you'd like more information or go to [brainycamps.com](http://brainycamps.com). [Register or Learn More!](#)

## Family Provides \$10,000 Challenge Match



Last May, in honor of NF Awareness Month, the grandparents of Sera Leavy, Cesar and Shirley Regalado, generously pledged up to \$10,000 in a dollar for dollar match challenge for donations of \$100 and over to NF Midwest, PLUS they gave \$100 for each donor who signed up to give a monthly recurring gift by joining our Monthly Giving Circle. Our supporters met the challenge and Sera and Regalado's presented a check for \$10,000 at the Naperville walk.

## Libby Huffer on the Doctors



Our very own NF Midwest family member, Libby Huffer, appeared on an episode of the television show *The Doctors* in November! *The Doctors* is a talk show in which team of medical professionals discuss a wide range of health related topics. Libby shared her emotional NF story and let the world see her body covered in neurofibromas. She also raised awareness for the cause and the struggles for better medical care for people with NF. Libby is the

administrator of the public Facebook group [Faces of Neurofibromatosis](#) which expands on NF Midwest's *Faces of NF* brochure by allowing people from everywhere to share their "faces" and stories with the world. We congratulate Libby on her amazing work!

[WATCH THE VIDEOS!](#)

## New NF Midwest Website

NF1, NF2 and schwannomatosis are very complicated and variable disorders and the best weapon for our NF community is knowledge. We built our new website with this in mind. Our goal is to create a meaningful site focused on providing lots of information to improve the lives of children and adults with NF. Please check it out at [www.nfmidwest.org](http://www.nfmidwest.org).

## New Material on Our Website

We've added several new articles and links to our website. A few highlights include...

### New Articles

- [Neurofibromas \(What They Are and Types Of\)](#)
- [Procedure Codes for Removing a High Quantity of Neurofibromas](#)
- [Communication Skills of Individuals with NF1](#)
- [Parent's Guide to Learning Disabilities Associated with NF1 \(summary\)](#)
- [What to do if your personal physician doesn't know a lot about NF?](#)
- [Selumetinib Research Question Answered](#)

Many other articles are on the website and more are always being added.

### 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 an interest in NF and NF Midwest. Go to [nfmidwest.org/facebookgroup](http://nfmidwest.org/facebookgroup).
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. Send an "unfollow nfmidwest" to unsubscribe.**
7. **Check our website [www.nfmidwest.org](http://www.nfmidwest.org) regularly.**

## Like What You Read?

### Support the Cost of this Newsletter and the NF Midwest Mission!

Please make a donation at [www.nfmidwest.org/donate](http://www.nfmidwest.org/donate) to cover the cost of this newsletter and to support the NF Midwest mission. \$500, \$100, \$50, \$20....any amount makes a difference!

## SamJam, Unplugged in the Prairie

September 16th in Carlinville, IL



The Oswald family and friends are holding their 4th [SamJam4NF, Unplugged in the Prairie](#) all day music fest in Carlinville, IL.

What a great time! Last year we had a few NF families and a whole lot of music lovers at

this fantastic event. Make the trip from wherever you are and enjoy progressive bluegrass, Americana and Roots music, plus food, beer, and bags!

Make plans now to join us! Find out more and order tickets at [www.samjam4nf.com](http://www.samjam4nf.com).

**WARNING: You might feel a little bad having so much fun!**



## NF Midwest Work Helps Raise Over 300 Million for Research

Since 1998 NF Midwest has advocated for NF research through the National Institutes of Health (NIH) and the Congressionally Directed Medical Research Program (CDMRP) managed by the Department of Defense. During that time more than 300 million has been spent on NF research through these programs.

In February, volunteers once again went to the nation's capital going office to office raising awareness and asking for continued support of neurofibromatosis.



2017 Advocates on Capitol Hill



## Birdies for Charity



Steve and Diane Reason, avid NF supporters, have once again enrolled NF Midwest in the John Deere Classic *Birdies for Charity*. This is an awesome opportunity to support NF without attending anything AND possibly win a lot of great prizes!

All you have to do is pledge an amount per birdie made during the John Deere Classic pro golf tournament that is being held July 10 – 16. So if 1990 Birdies are made and you pledged one cent per birdie you would owe \$19.90. Instead of pledging per birdie you may also simply pledge a flat amount. To win a prize you can guess how many Birdies will be made and if you guess the right amount you could win a car, a lawn tractor, or whatever amazing prizes they come up with. They haven't announced them yet.

So in a nutshell, you basically guess a number; make a pledge or donation and wait to see if you won! For the last 8 years the amount of birdies have ranged from 1,1914 to 2,160. So you might want to find your lucky number somewhere around those numbers.

The awesome part is that John Deere covers ALL the expenses so 100% of your donation goes to the charity you choose (i.e. NF Midwest) PLUS another 5% or more is matched by Birdies for Charity. In 2016 the match was 10% so \$20 donations became \$22.00!

To participate in this AMAZING program contact Steve with your pledge at [steveNF2@frontiernet.net](mailto:steveNF2@frontiernet.net) or look for a pledge form online at [www.nfmidwest.org](http://www.nfmidwest.org). You may also make your tax deductible donation directly on the Birdies for Charity site and search for Neurofibromatosis Midwest or #1815.

## EndNF Open 4D Barrel Race and Fun Show By Team Aydin



On October 9th, Team Aydin, the Bjork family and supporters held their first #EndNF Open 4D Barrel Race and Fun Show in Chetek, Wisconsin at Red Cedar Riders. The team raised over \$8,600 for NF Midwest and the neurofibromatosis cause. Thank you to the many volunteers, sponsors and participants to making this such a great event 4NF!

## Keep Hope in Motion

Set your giving on auto pilot!



**MONTHLY  
GIVING  
CIRCLE**

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



## DIY Fundraising and Awareness

Raise awareness and funds by creating your own Third Party (DIY) event. This is a great way to give more than your individual donation and to raise funds to support Clinics, Awareness, Research, Education, and Support. Include your friends to help improve the lives of children and adults with neurofibromatosis in meaningful ways.

Whether you have organized an event before, or this is your first time, we want your fundraiser to be a great success and we're here to help you. Combined with NF Midwest's expertise in planning, tax receipting, policies, and recognition, you can easily hold your own fundraising event that is meaningful for everyone. We know organizing and planning a fundraising event can be a huge task, which is why our team of experienced event staff are happy to support you and provide the tools you need.

Find tips and ideas for events and how to create your own fundraising page at [www.nfmidwest.org/get-involved/fundraise/create-an-event](http://www.nfmidwest.org/get-involved/fundraise/create-an-event).

...or pick up the phone (630.945.3562) or shoot us an email at [info@nfmidwest.org](mailto:info@nfmidwest.org). We'd be happy to talk to you about your ideas.

## Local Support Groups



### Kentucky Support Group

Our new Eastern Kentucky group has already held three well attended meetings this year. All were held at the University of Kentucky with support from the NF clinic there. Check frequently on our website or in your email for updates on new meetings. You can also email

[Kentucky@nfmidwest.org](mailto:Kentucky@nfmidwest.org) for more information.

### Evansville, IN Meetings

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

### Central Missouri Support Meetings

The Central Missouri (formerly Columbus) chapter holds monthly meetings on the 3rd Wednesday of every month at the Columbia Public Library from 6:30 to 8:00 pm. For more info contact us or email the chapter at [CentralMissouri@nfmidwest.org](mailto:CentralMissouri@nfmidwest.org).

There are other groups that are occasionally meeting. Please, watch your emails, visit our website or join our NF Midwest Facebook group for more timely updates.



## GuideStar Silver

NF Midwest has received the Silver endorsement from [GuideStar](#) for our level of transparency. All of our financials are available on our website. We're going for gold!



## Great Nonprofits

In November, NF Midwest was awarded a 2016 Top-Rated badge from [GreatNonprofits](#).

"Savvy donors want to see the impact of their donations more than ever," said Perla Ni, CEO of GreatNonprofits, "People with direct

experience with NF Midwest have voted that the organization is making a real difference."



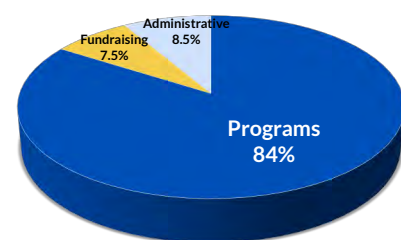
## Community Health Charities

NF Midwest is a member of the [Community Health Charities](#) organization, a federation of the nation's leading nonprofit voluntary health agencies. Many state, local and private employers allow employees to donate to worthy organizations through a payroll deduction program. Look for the national Community Health Charities federation when you fill in your pledge card. To support NF Midwest use code #75126.

## Every Dollar Matters

NF Midwest is a nonprofit organization under section 501(c)(3) of the Internal Revenue Code. Donations are tax deductible. Books and records are audited annually in accordance with generally accepted accounting standards. We keep three years of our most recent 990's and financial statements on our website for review.

We are dedicated to improving the lives of children and adults in our region through C.A.R.E.S. or Clinics, Awareness, Research, Education, and Support. We rely on charitable donations to fund



### 2016 Expense Breakdown

regarding the use of your donations.

our programs and are governed by people personally dedicated to the NF community. Your support is respected and funds are used to provide the greatest impact.

Please don't hesitate to contact us if you have any questions or concerns

## Fort Wayne NF Family Night- Thursday, May 18

Fort Wayne TinCaps will be raising NF awareness at their May 18<sup>th</sup> game against Great Lakes. NF Midwest's Fort Wayne group put this together and wants the whole NF community to come out!



Susan, our Fort Wayne leader tells us, "It's going to be a fun night! Game starts at 7:05. There will be the Indianapolis Colts Cheerleaders and select players there. Blue, the Colts mascot, will also be there and to end the night they will have fireworks!"

The more people we have, the more awareness we raise...so bring your family and friends! This will be a perfect chance to watch baseball and register for the Great Steps 4NF Fort Wayne Walk which takes place on Saturday, September 16, 2017.

Reserved tickets sold out quickly but you can still buy tickets through the [TinCap box office](#). The NF group will be in Section 114 and the cost of ticket for the area is \$9.25.

For more information email [fortwayne@nfmidwest.org](mailto:fortwayne@nfmidwest.org).

## Smiles for Sarah Sox Outing

### Sunday, May 28, 2017



Join the Panozzo Family at their [5th Annual Smiles for Sarah Sox Outing](#) to benefit NF Midwest and Lurie Children's Hospital Brain Tumor Research. The game is the White Sox vs. Tigers at 1:10 pm. Tickets are reserved/bleachers and cost \$20. For information on how to order tickets email us at [info@nfmidwest.org](mailto:info@nfmidwest.org).

## Memorials Received

In the past year NF Midwest has received memorials in memory of the people listed below. They are not necessarily people who have passed away from NF, but memorials requested in lieu of flowers. We thank the families who thought of NF Midwest in their time of grief.

Eric Ostrom  
Justine Goss  
Frank Cantrell

John Manser  
Nancy Oliver  
Myshell Reith

Memorial

Donations



## NF Midwest Executive Director Given *Everyday Hero* Award

The executive director of NF Midwest was given the 2016 [Everyday Hero](#) award by the Kane County Chronicle. This award is given to her and several others who live or work in Kane County for going above and beyond to help those most in need. "I'm honored to be recognized," said Diana, "but this award really belongs to our staff, board, volunteers and donors. It's a magnificent group effort." Diana was honored along with the others at 2016 *Everyday Heroes Awards Breakfast* this past November.

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## **WHERE WILL WE SEE YOU IN 2017?**

### **2017 Great Steps 4NF Walks**

Madison, WI • May 13  
Chippewa Falls, WI • May 20  
Naperville, IL • June 3  
Effingham, IL • June 17  
Indianapolis, IN • August 19th  
Fort Wayne, IN • September 16th  
Taylorville, IL • September 23

**Lunch with the Docs in Indy - April 8th**

**Lunch with the Docs in Chicago - April 30th**

**NF Family Night in Fort Wayne - May 18th**

**Camp New Friends - July 16-22**

**SamJam 4NF - September 16th**

**NF Symposium - November 11th**

**Columbia MO Support Meetings**  
Every 3rd Wednesday

**Lexington, KY Support Meetings**  
Various Saturdays

We are always adding events and NF supporters are often holding events. To see an updated listing of events go to [www.nfmidwest.org/events](http://www.nfmidwest.org/events). If you'd like to [hold an event](#) please email us at [info@nfmidwest.org](mailto:info@nfmidwest.org) or call 630.945.3562.

### **NF Midwest's Mission**

NF Midwest is committed to improving the lives of children, adults, and families impacted by neurofibromatosis. Our continued focus and foundation is on Clinics, Awareness, Research, Education and Support in the states of Illinois, Indiana, Iowa, Kentucky, Wisconsin, and the eastern half of Missouri.