

2018 Symposium Set for October 20th!



On November 11th NF Midwest held their 27th educational Symposium and iNFo Fair. We had over 150 people in attendance!

The next NF Symposium and iNFo Fair will be held October 20th in Hoffman Estates, IL. We are still setting up speakers, but look for it to be full of learning and friendship.

This year we hope to have a social gathering Friday the night before so plan accordingly if you are interested.

“Who” NF Midwest Is

As we put this newsletter together we found ourselves reflecting on “who” NF Midwest is. What is our role? What have we done? How can we do more? And other questions we ask ourselves every day.

All of the staff and board at NF Midwest have a personal connection to NF. So it is not lost on us that the disorders of neurofibromatosis and schwannomatosis are very complex, confusing, and frustrating. It can be difficult to navigate and understand them. We understand these difficulties and we’re right there with you.

We are also fully aware that there a number of NF organizations and that it can be confusing to understand who they all are and what they all do. All we can say is who NF Midwest is.

NF Midwest was founded 36 years ago and has always been directed by people who are passionate about NF and devoted to the adults, children, and families who have it. We’ve had our own ups and downs in the battle of NF with ourselves or our loved ones. We’ve had our ups and downs in the battle that is the NF cause.

Today, NF Midwest is an independent, regional organization committed to improving the lives of children and adults in our region with neurofibromatosis and schwannomatosis. This includes supporting research, but also focusing a strong effort on care, support, and education, and ensuring that no one fights alone.

We are not just an organization, but a community. Everyone who is an active part of our community **IS** NF Midwest. We are not just staff and a board, we consist of our area leaders, our volunteers, our moms and dads; grandpas and grandmas, friends and neighbors, and anyone who works on the NF Midwest mission to improve lives.

We are not an affiliate or chapter of ANY other organization and receive no funds from any of them to assist in our mission. We are, however, determined to collaborate and work collectively with other NF organizations and the NF community in whatever way we can to move the NF cause forward.

NF Midwest’s Research Work

NF2 Grant Awarded to MGH!

NF Midwest, in collaboration with NF Northeast, has awarded [Dr. Vijaya Ramesh](#) from Massachusetts General Hospital, a grant for research in neurofibromatosis type 2 to test the combination of a novel drug with an mTORC1/mTORC2 inhibitor in meningioma and schwannoma cell systems.

NF Midwest Collaborates to Fund University of Minnesota Research

NF Midwest and NF Upper Midwest are excited to be collaborating to support the University of Minnesota’s Minnesota Investigators in Neurodevelopmental Disabilities ([MIND](#)) Group. Led by Dr. Rene Pierpont this team is looking to develop intervention and parent coaching programs to enhance the development and mental health of children with NF1 particularly in the area of socialization.

Funding for this project at was made possible by the special fundraising efforts of the Bjork Family!

NF Midwest Work Aids Development of Orphan Drug for NF

In February, AstraZeneca and Merck announced that the U.S. Food and Drug Administration (FDA) granted Orphan Drug Designation (ODD) for selumetinib, a MEK 1/2 inhibitor, for the treatment of neurofibromatosis type 1 (NF1). Research and clinical trials on selumetinib and other MEK inhibitors have been possible in great part due to the lobbying work of NF Midwest, the NF Midwest community, and other NF organizations in support of federal funding for research. NF Midwest donors have also supported MEK inhibitor trials at the University of Chicago. So far, over 70% of participants in selumetinib MEK clinical trials are showing reductions in tumor size of 20-50% of plexiform tumors. Read more details about the designation of selumetinib as an orphan drug on NF Midwest’s website or [here](#).

Keep Hope in Motion



Be a hero and keep hope in motion. Join our Monthly Giving Circle by signing up for automatic monthly giving at nfmidwest.org/donation.

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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.



2017 Scholarship Recipients

In 2017, NF Midwest awarded twelve academic scholarships to adults with neurofibromatosis or schwannomatosis. Now in its third year, our scholarship program was launched with funds from a charitable trust left to NF Midwest by Frances and Irma Napolilli. The program awards \$1,000 scholarships to students from our service area who are diagnosed with NF and are pursuing a post high school education. Applications are scored based on participation in NF Midwest and a demonstrated drive to succeed despite the challenges associated with living with NF. Aspects such as academic record, community service, and teacher/employer recommendations are also considered. We were able to award many scholarships in 2017 but our ability to do so in the future is limited by the support of our wonderful donors.

Our 2017 scholarship recipients were:

Victoria Doubek, Adelaide Ralston, Zachary Scheffer, Rachel Campana, Sarah Panozzo, Allison Kukman, and Brandon Mendel from Illinois; Melissa Farr from Indiana; Megan Wroblewski from Kentucky; Emily Newell, Jesse Tofte, and Madeline Brazas from Wisconsin.

Learn more about our 2017 scholars at www.nfmidwest.org. 2018 awards will be announced in June.

Dr. Mata-Machado

Dr. Mata-Machado is no longer with Amita Health and St. Alexius. He now has an NF clinic at the University of Illinois in Chicago (not to be confused with the University of Chicago). He is seeing people with NF ages 0 to 39. Appointments may be made by calling 312-996-8450. More information can be found on our website at nfmidwest.org/findadoctor.

Please, Help Support the Cost of this Newsletter and the NF Midwest Mission! Make a Donation...

at www.nfmidwest.org/donation or send a check using the envelope included in this newsletter.... any amount makes a difference!

Bring your tent, your RV, or grab a hotel room! Join us for a day of fun and music!

If you're coming from Chicago or St. Louis you can even take the train!

SamJam4NF, Unplugged in the Prairie September 22nd in Carlinville, IL

Come out for the 5th annual *SamJam4NF*, all day music fest in Carlinville, IL.

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.

This event is present by the Oswald Family and Friends for the benefit of NF. #DoIt4NF





It's **Not Just a Walk**, It's a **Family Fun Day!**

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

Wisconsin NF Walk — Saturday, May 19th

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 delicious brats and pizza! 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.

Illinois NF Walk — Saturday, June 2nd

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, costumed characters, bounce houses, dancing, great raffle prizes, and more!

Indiana NF Walk — Saturday, September 15th

Come out to Parkview Field, home of the MLB TinCaps baseball team, for the 8th annual Great Steps Walk 4NF in Fort Wayne. This is a fun walk inside the stadium. You'll enjoy food, music, raffles, 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.

Individual Fundraiser Recognition Gifts

Recognition prizes will be given to INDIVIDUAL fundraisers based on what they raise through their online fundraising page. The gifts are not "cumulative", meaning fundraisers only receive the one gift that is in their fundraising category. This puts the FUN in FUNDraising.

- \$500 NF Midwest Bluetooth Speakers
- \$1,000 NF Midwest Virtual Reality Goggles
- \$1,500 NF Midwest Collapsible Table
- \$2,500 Inflatable Air Lounger

Team Recognition Gifts

New this year! The TOP FUNDRAISING team of all the walks will choose the color combination for next years t-shirts!

Also, if a TEAM raises over \$5,000 the team captain will receive an NF Midwest jacket and a "Top Fundraising" Flag.



Be a Hero! Find a Sponsor!

The NF Community needs corporate and small business support. Please think of who your 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.

New Event Coordinator—Christine Christensen



We are excited to welcome Christine Christensen as our new Event Coordinator! Christine started in January and immediately implemented some fun fundraising and awareness ideas into Great Steps Walks 4NF and other event and fundraising efforts.

Many of you already know Christine as a passionate NF community member. Though her daughter, Caitlin, passed away from an NF1 MPNST in 2013, Christine keeps her memory alive by helping others with NF. She has been a top fundraiser for Great Steps, on the scholarship committee, and brings a vast background and lots ideas to serve NF Midwest.

If you would like more information about participating in a Great Steps Walk 4NF, #DoIt4NF fundraising, or any general fundraising information, please contact Christine@nfmidwest.org. If you have a connection to a business, sponsor, or a great fundraising idea, please let her know.



Last year we were all pretty in pink? Who will choose 2019's colors?

TIPPITY TOP TEAM PRIZE! CHOOSE 2019 T-SHIRT COLORS!

The team that raises the absolute MOST out of ALL the Great Steps teams will have the honor and fun of choosing the t-shirt colors (shirt and print color) for next year!

Care and Outreach—Liz Campana



We are now over a year into our new Outreach and Care Program. The ultimate goal of this program is to make sure **No One Fights Alone** in the NF Midwest Community. The cornerstone of this program is our outreach/care coordinator whose main job is to keep in touch with individuals in our community and to be a resource for information and guidance whenever possible.

Last May, Liz Campana stepped into this position, and since then many of you, especially those of you are new to us have probably heard from her. Liz has been involved with NF Midwest and the NF cause for over twenty years. While her priority is to follow-up with, and for, the NF Midwest community, she is also working together with leaders in our local groups to build community locally, and often as a liaison to our NF clinics to help improve care.

If you'd like to contact Liz, please email her at liz@nfmidwest.org.

NF Midwest Awarded Grant for Care



Discount Tire "Driven to Care" Regional Team and Midwest Staff.

NF Midwest has once again been awarded \$20,000 from the [Driven to Care](#) program which is funded by the Diane and Bruce Halle Foundation, the philanthropic arm of Discount Tire. This funding helps to support our Care and Outreach Program and to help

ensure that **No One Fights Alone**! Thank you to Jonathan and Erin, parents of a child with NF, for recommending us for this program. Also, thank you to Chandra and all the wonderful members of the regional Driven to Care team. These are amazing, caring people, and Discount Tire is a company that truly gives back!

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.

Leland Busch
Jeff Counts
Rosalie Howe
Chris Lambrecht
Don Lands
Carl Lowry

Robert McGaffney
Brenda Stewart
Joe Von Tuyle
Dave Thomas
Urban Peter Wagner
Alex Williamson



Memorial

Donations

Camp New Friends August 4-10



Raise some awareness! The NF Midwest Hoo-Rags, shown here, can be found at the Store on NF Midwest's website.

Thanks to the support of our donors, NF Midwest once again sent children to Camp New Friends in West Virginia, along with some Hoo-Rags for all the kids to enjoy! We're looking to send a big crop of kids this year, so if you have a child who has NF between the ages of 7 and 17 you might want to think about signing them up! If a child with NF wants to go to camp, we want to make sure to get them there!

Camp New Friends is an amazing, safe place to make friends, to develop self esteem, and for kids with NF to learn to care for themselves as well as others.

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.

Below are Research Studies or Surveys Looking for Participants



Kids Age 4 to 6 to Participate in a Study in Wisconsin

In a project funded by NF Midwest, the University of Wisconsin-Milwaukee Child Neurodevelopment Research Lab is looking for families with children ages 4 to 6 to

participate in a study of how best to measure attention in young children with NF1. For more info go to www.nfmidwest.org/addstudy or www.people.uwm.edu/bklein/current.

Caregivers of Children With NF1

In a study funded by NF Midwest, the MIND group at the University of Minnesota is looking for caregivers of children between the ages of 3 and 18 to participate in an online survey. Please take a few moments to help by going to www.nfmidwest.org/3-18survey and clicking the "survey" link.

Adults for Online Study on Resiliency

Researchers at Massachusetts General are looking for people with NF1, NF2, or schwannomatosis who are 18 and over to participate in a study on resiliency. This will involve participating in 8 group sessions from home via video. Learn more at www.nfmidwest.org/resiliencystudy.

Ages 8 to 20 with NF1 for Reading Study

Vanderbilt University in Tennessee is looking for participants for a reading study. You must travel to Tennessee. Compensation is included. For more info go to www.nfmidwest.org/readingstudy.

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.

New Material on Our Website

We've added several new [articles and links](#) to our website. A few highlights include...

New Material

- Brainstem Tumors in NF1
- Autism Spectrum Disorder in NF1
- NF1—A Deeper Overview
- Scoliosis in NF1
- Recognizing Problems That Require Further Evaluation in Children with NF1
- Updated NF1 Information Sheet for Medical Professionals
- Medical Imaging for NF1: Radiation Exposure

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 and aren't blocked.
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.
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.
5. Follow us on Twitter at 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 regularly.

Check out WWW.NFMIDWEST/NEWS to read many old posts on NF news, education and more!

Step Up...We Need You!

We have many opportunities for you to help NF Midwest. If you're interested in stepping up with your time and/or talents please email info@nfmidwest.org. We also need business contacts for sponsorships or service donations such as printing, accounting, etc. Please think of who you know that may be able to help the NF Midwest community.

New Online NF Community That Does So Much More!

GeneFo NF Community



Supported By The Littlest Tumor Foundation, NF Midwest and Texas NF Foundation

NF Midwest, The Texas NF Foundation, and The Littlest Tumor Foundation have collaborated with [GeneFo](#) on a new NF Community/Patient Platform. We invite people with NF and their caregivers from all over the world to join!

While this site is for posting and sharing with others, it is also a "social listening" site. This means that data may be collected so that eventually NF researchers, clinicians, NF organizations, and people with NF can have a better understanding of how people are affected by NF, what the needs of the community are, and what might help.

Any personal information and user identification is removed in collection. We know that this can be a little nerve wracking, but what it means is that if people talk about (or track under symptoms) something such as having stomach pains it can be tracked to see if there is a trend of stomach pain among people with NF. Also, people can share treatments. So, for instance, if people share that acupuncture is working, then clinicians may start to consider it more.

People can post and share with each other just like many social sites, but you can also rate docs; track your (or your child's symptoms) in your personal health chart; use MedHub store resources and important information related to managing your condition such as interesting clinical trials, news and patient posts from GeneFo, medical files and doctor's appointments; receive NF news updates; ask questions to doctors; and more!

What is really cool is that it is ALL happening in one single page - no more juggling many different pages, forums, and groups, or scrolling through endless posts! Sign up now at www.tinyurl.com/NFHello.

Thank You to NF Midwest Advocates for Getting \$15 Million in Research Funding

Thanks to NF Midwest [lobbying work](#), along with other NF organizations, and to the letter writing and petition signing of our community, NF research will be getting \$15 million in federal funding for fiscal year 2018. Over \$300 million has been provided in federal funding since 1998. Thank you to Heather Reyes, and Laura and Kyle Obermann for joining us on Capitol Hill this year. If you are interested in going to DC to lobby in February 2019, please email diana@nfmidwest.org.



2018 Advocates on Capitol Hill

#Dolt4NF

Raise Funds and Awareness for the Cause!

NF Midwest is an independent, regional organization. We receive no financial support from other organizations or the government. We work together with the NF Midwest community to raise us all up, and to make sure **No one Fights alone**. As such, we are very dependent on the grass root, passionate fundraising of our NF Midwest community and friends.

Many members of the NF Midwest community participate in fundraising through our Great Steps Walks 4NF by sharing their stories and asking their network of friends, family, neighbors, co-workers, etc to donate. Some also hold events for credit towards their team and to help the cause.

Do It Yourway



Just #Dolt4NF

However, you DO NOT have to walk to raise funds and awareness. You can #Dolt4NF in many ways...on your own or with our help, by creating your own #Dolt4NF (DIY) event.

Please consider holding a #Dolt4NF event and/or creating a fundraising page for NF Midwest in 2018! Funds are used to improve the lives of people in the Midwest through **Clinics**,

Awareness, Research, Education, and Support or (C.A.R.E.S.).

Get your network of friends and family to join you and be sure to do something fun! Also, take photos and send them to us.

We look forward to sharing your events in our fall newsletter and can't wait to see the clever and fun ways you come up with to #Dolt4NF!

Find tips and ideas for events and how to create your own fundraising page on our website, pick up the phone (630.945.3562), or shoot us an email at info@nfmidwest.org. We'd be thrilled to talk to you about your ideas!

Guess the Right Number and You Could Win a 2 Year Lease on a Lexus!



Steve and Diane Reason have once again enrolled NF Midwest in the John Deere Classic *Birdies for Charity*. This is basically a raffle to win a 2 year lease on a 2018 Lexus NX. All you have to do is pledge a donation and guess a number. NF Midwest will receive your entire donation PLUS 5 to 10% more! You may also win other prizes. You need to submit your pledge and guess

by July 6th.

Email Steve at steveNF2@frontiernet.net to submit your pledge or find a pledge for and more information [HERE](#). You may also make your donation and guess online on at the Birdies for Charity site at www.birdiesforcharity.com and search for Neurofibromatosis Midwest or #1815.

Local Meetings/Groups



Below is information on groups that meet regularly for support and/or socializing. If you want to be notified of future events from the groups below, or other groups, please email liz@nfmidwest.org. You may ALSO email the group leader when possible, but be sure to let Liz know of your interest. Also, join NF Midwest's private Facebook group for more timely updates.

Note: There are other groups that are occasionally meeting that aren't listed here, plus new groups popping up all the time. If you'd like to put a group or social event together, please email liz@nfmidwest.org.

Kentucky Support Group

A group in the Lexington, Kentucky area has been meeting regularly...usually on the third Saturday of the month. Check our website and your email frequently for updates on new meetings. You may also email Kentucky@nfmidwest.org for more information.

Evansville, IN Meetings

The Evansville NF Midwest chapter holds occasional meetings. They just held a meeting Monday, April 23rd at Cambridge Golf Course.

Central Missouri Support Meetings

The Central Missouri group usually holds a meeting 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 CentralMissouri@nfmidwest.org.

Chicago Adult Nights

In April, a group of adults with NF met at Bridget McNeill's Pub for pizza and trivia and had a ton of fun. Another adult night is scheduled for Thursday, May 10th at Diag Bar & Grill at 2856 N Southport Ave. There will be pizza and BINGO!

Fort Wayne Family Night

The NF Midwest Fort Wayne group is holding a family night at the Tin Caps baseball game against the South Bend Cubs on Friday, May 18, 2018. Come out meet others, raise awareness, and have some fun. There are two ticket prices. For \$13 you receive a game ticket, plus game favors. For \$25 you will receive a special NF Family Night T-shirt plus game favors. The game starts at 7:00 pm. It will be a fun night with postgame fireworks and a Grease 40th Anniversary tribute!

Madison Area Neighbor Day & Night

The Fillmore family of McFarland, WI (near Madison) is holding Neighbor Night on June 19th from 4 to 8 pm and a Neighbor Day at July 29 from 11 to 7 pm. Both will be at Lewis Park in McFarland and will feature music, family fun, food, kids crafts, and outdoor games. The proceeds will benefit NF Midwest and other charities.

The Fillmore family would like the NF community to come out and join them for these fun event! Look for more information on our website, on this Facebook page [here](#), or email Laura@lcjfillmore@gmail.com.

Celebrating 36 Years!

Of Improving the lives of children and adults with neurofibromatosis and schwannomatosis. NF Midwest C.A.R.E.S. by focusing on Clinics, Awareness, Research, Education, and Support.



4
Research
Projects



\$ 15 Million
Federal Research
Funding For Fiscal 2018

12
Scholarships



106
New Families
Added to our support network



150
Symposium
Attendees



18
Educational Pieces



13
Clinics
Supported in our region



**NO ONE
FIGHTS
ALONE**

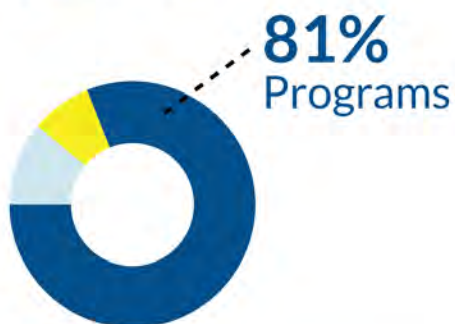
ONE
Awesome Care and
Outreach Program!

NF Midwest adheres to the upmost standards for non-profits. This includes providing the last three years of financial statements and 990s on our website. Numbers, of course, do not tell the whole story. We are happy to answer any questions or to provide more information. All you have to do is ask!

WWW.NFMIDWEST.ORG

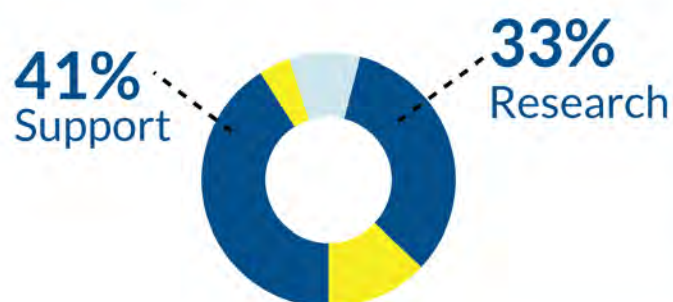
2017 Functional Expenses

Administrative (11%) Fundraising (8%)
Programs (81%)



2017 Program Expenses

Support (41%) Clinics (4%) Awareness (9%)
Research (33%) Education (13%)





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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.

Thank You To...

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Who make the mission possible!

Our Volunteers

Who move the mission!

The Oswald Family and SamJam4NF

To Pete, Sam, Pete 2, and their friends and family for creating and continuing SamJam4NF! What an amazing event!

NF2ACT To Susan, Laura, and Steve (members of our NF2 Action Committee) for being the voice for all things NF2 and for helping with the symposium!

Laura Didier and her family for holding a walk in Effingham for 10 YEARS and for all the other things you do.

Susan Caris For chairing the Fort Wayne Walk 4NF and for being a great sounding board...and also for her, and the FW team for creating a family night for the NF community.

Tim Eberle The energizer bunny...for chairing the Madison Walk 4NF for so many years and for just going above and beyond!

Libby Huffer For her Faces of NF Facebook group and for being a voice for the NF community and a champion for awareness.

Linda Bell For the photos and ideas for our project.

Erin Carter For that great TV interview in Rockford and for the shout out to NF Midwest and the walk in Naperville.

The Fillmore Family Laura, Duane, and the *Mighty* Marissa for helping with the Madison walk and making NF Midwest a beneficiary of their Neighbor Day & Night events...and for inviting the NF Community to come out.

Steve Reason For arranging the Birdies for Charity fundraiser AGAIN!

Heather Reyes For chairing our scholarship committee and for joining us to lobby in Washington, DC.

Ruth Taylor and Nicoya Miller For holding a Holiday party for the NF community in Indianapolis.

Ilene and Emily Bluestein For starting an Adult Group in Chicago! Trivia was fun...can't wait for BINGO!

Various Writers To our various doctors and experts for writing simple articles about the complications of NF for us!

Christina Thomas and Kristi Saylor For offering support group meetings and doing what they can in Columbia, MO.

Jane Gerth and Michelle Elpers For their efforts to provide support in Evansville, IN.

Holly Layton and her family and friends for the walks and work in Taylorville, IL.

The Board To the NF Midwest Board—Gail, Gordon, Charles, Pete, Denise, and Lesli.

To Those We Forgot We are blessed with so many who help. We appreciate you all!

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.