

A Time of Reflection and Change. We Can Do It Together.

The events of the past several months have created a need for great reflection at NF Midwest. As COVID shut-down our communities and our events, we have wondered if we can financially afford to continue our work. Instead, we have decided to focus our energy on the greater questions such as what does our community need and how can we help.

Most nonprofits are currently struggling to keep programs afloat and many are scaling way back as they wait to see what tomorrow brings. While NF Midwest has cancelled all "in person" events, we are not scaling back our programs and our work. We will continue in every and all ways we can until we simply can no longer do so.

We will also continue to raise funds and awareness in the hopes of sustaining our work, however, it will be done through one big community effort. Since much of our summer and fall fundraising comes from our walks, we have created one event called "The Walk That Wasn't". Like our walks, this will invite individuals and teams to raise funds and awareness through fundraising pages, letters, events, and whatever crazy, imaginative, and fun ways they can think of. Then on October 17th at 10 AM CST we will hold an online CELEBRATHON and will celebrate our NF community. This will require our NF Midwest community to

come together like never before, starting now and all the way up to October 17th (and beyond!). Learn more about "The Walk That Wasn't" later in this newsletter.

Something else that has caused us great reflection is the Black Lives Matters movement. We are aware that there are inequities in

medical treatment, and we recognize the need for more diversity and inclusiveness in those we serve as well as within our staff and/or board. We also acknowledge the implicit and unconscious biases in all of us.

We promise to do better and to continue to reflect, listen, and work towards concrete actions to improve the lives of everyone with neurofibromatosis and schwannomatosis without prejudice or bias. We ask that everyone, and especially anyone who feels disenfranchised because of their race, gender, sexual orientation, financial status, etc. to work with us and bring awareness to these discriminations. We can all learn from each other

and grow into a more accepting, inclusive community.

In these difficult days we have often heard the phrase "we're in this together". NF Midwest is truly here for our community and together we will make sure that No One Fights Alone.



Four NF Midwest Grants to Support Care and Research

NF Midwest Collaborates to Fund NF2 Gene Therapy Research



NF Midwest, NF Northeast, and [NF2 BioSolutions](#) have joined forces to fund an NF2 Gene Therapy Research Study at the [Mueller Lab](#) at the Gene Therapy Center, UMass Medical School. This \$65,000 grant will be used to design, manufacture and test potential gene therapy vectors for neurofibromatosis type 2. Dr.

Katharina Meijboom, a postdoctoral researcher, is heading up the project. Her research will focus on several different approaches and will be tested in both cell lines and mouse models. The Mueller Laboratory at the [UMass Gene Therapy Center](#) has a long history of using recombinant AAV as a platform for gene therapy in a plethora of different diseases, ranging from liver diseases to central nervous system diseases, such as ALS.

Other NF Midwest Grants

In addition to the grant to UMass, since the publishing of our last newsletter, NF Midwest has awarded grants to the following:

- Dr. Vranceanu and Ethan Lester from Massachusetts General Hospital received a grant from NF Midwest in collaboration with NF Northeast to support their work on adapting an evidence-based neurofibromatosis resiliency training program for web-based delivery.
- [Bonnie Klein-Tasman](#) and The University of Wisconsin received a grant to study Adolescent Outcomes in NF1: Attention, Social, and Academic Functioning.
- An NF Midwest **Care Impact Grant** was awarded to the NF Clinic at the University of Illinois/Chicago to provide some assistance to families in need to come to the clinic.
- [Brainy Camps](#) in support of Camp New Friends.

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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.

Elections for New Board Members are in September

We are always excited to have new board members. Our new term starts in October with elections in September. If you are interested in joining the board please email us at info@nfmidwest.org for an application and more information.

2019 Scholarship Recipients

In 2019, NF Midwest awarded ten academic [scholarships](#) to adults with neurofibromatosis or schwannomatosis. The program provides \$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. Academic record, community service, and teacher/employer recommendations are also considered.

In it's 5th year our scholarship program was launched with funds from a charitable trust left to NF Midwest by Frances and Irma Napolilli, however it relies on the generosity of donors to continue. 2020 scholars will be announced soon and 2021 applications, will begin to be accepted in January.

Our 2019 scholarship recipients were: Gaoyeeng Vang, Ben Miller, Lauren Marker, Lily Whitehurst, Cole Besteman, Garrett Dohlke, Emily Jurgenson, Lee von Nositz, Ainsley Owen, Ashlee Moore



2020 Young Adult Leaders

In late 2019, NF Midwest sponsored five young adults from the NF Midwest service region to participate in the [NF Young Adult Leadership](#) program (NFYA). In its second year, this program is a collaboration between the Littleton Tumor Foundation and Texas NF. The NF Young Adult Leadership Program is an opportunity for NF-affected young adults to learn effective advocacy skills and speak directly to policymakers about NF. At the center piece is a 5-day program in Washington DC during which our future leaders learn leadership skills from a professional facilitator; meet Senators and Representatives; drop-in on Congressional offices; use social media to

follow-up; and it all culminates with a Senate briefing and a House briefing. Young leaders are invited to continue participation virtually with various programs and social gatherings.

This year NF Midwest's sponsored young leaders were Tori Doubek, Garrett Dohlke, Paris Patrick, Adrian Solis, and Gaoyeeng Vang.

NF Midwest will once again sponsor four to five young adults this year who will attend the Washington DC training June 7th through 11th in 2021. Applications are now being accepted at www.nfmidwest.org/blog/nfya-2021-applications.

Camp New Friends



Last July, NF Midwest sent twelve kids with NF to [Camp New Friends](#) in Virginia. This year camp was held virtually from July 20th to 24, yet NF Midwest sent a grant to Brainy Camps to help sustain their work. We also offered to automatically cover half of the fees for children from the Midwest to attend the virtual camp and the entire fee if needed. In addition, to encourage attendance and to bring a little "sunshine" to these crazy days we are sending a gift card to all children from the NF Midwest region who participated in camp. If you'd like to find out more about camp and how your child can participate next year, please email us at info@nfmidwest.org or call 630-989-2621.

Guidelines for Children and Adults with NF1

Within the past two years guidelines have been created to provide guidance in the care of children and adults with neurofibromatosis type 1.

These guidelines were created by dedicated, interdisciplinary groups of experts in the care of individuals with NF1 and are meant as tools for physicians treating children and adults with NF1 such as pediatricians, family practitioners, geneticists, neurologists, dermatologists, etc. We encourage patients and parents to share these guidelines with any one who might play a role in their care.

Guidelines can be found at:

[NF1 Child Guidelines](#)

[NF1 Adult Guidelines](#)



Drug Approved for NF1 Plexiforms in Children with NF1

In April, the drug Koselugo™ (selumetinib) from AstraZeneca and Merck & Co., Inc. was approved by the FDA for the treatment of plexiform tumors in

children with neurofibromatosis type 1.

NF Midwest, NF Northeast, and Texas NF worked together with experts to put together answers to the many questions about this drug in a **Frequently Asked Questions (FAQ)** that can be found at

[Koselugo FAQ](#)

Securing Millions for NF Research

Due the dedication of volunteer advocates, people who wrote personal letters, people who contacted members of Congress, and the efforts of NF Midwest, and other NF organizations, \$15 million was provided for NF and schwannomatosis research through the Congressionally Directed Medical Research Program for FY2020.

This year we insisted on trying for \$20 million. Advocating for this is a multi-organization collaboration. NF Midwest's work begins as we select young leaders to learn to advocate, tell their stories, and be general leaders for the NF cause. We work collaboratively on this with the Littlest Tumor Foundation and Texas NF. In January, we go with these young leaders to Washington DC where they learn and hone these skills as they visit the office of every Senator and Representative to invite them to a briefing and share their stories when possible. They also follow-up the invitations through social media. Their stories, in their voices are very powerful. The briefing then provides Congressional offices information on how funding for NF research benefits science.

In February, we go back with another team of advocates and teams from other organizations to offices and ask for support. After that we encourage the NF community to contact their offices at appropriate milestones in the process.

As of the printing of this newsletter, the \$20 million has been approved in committee but the appropriations bill is still winding it's way through the process. We are very hopeful! We will keep you posted!

New Be iNFormed Articles

NF Midwest develops "Be iNFormed" articles on various complications and subjects with regard to neurofibromatosis. These articles are written specifically for the NF community without a lot of scientific jargon and with the information that we believe the patient and affected families want and need. We are also careful to have them written and endorsed by experts so that they can be shared with other doctors and seen as a respectable source of information.

To find other articles go to:

[Be Informed](#) or [Learn](#)

Malignant Nerve Sheath Tumors in NF Type 1

NF Midwest has had a very important article written about **Malignant Peripheral Nerve Sheath Tumors** (or MPNSTs) in neurofibromatosis Type 1. MPNSTs are cancerous and often aggressive. They develop in plexiform tumors and are believed to occur in approximately one out of ten people with NF type 1.

It is very important that people with NF type 1 be aware of them and the signs to look for – "especially new pain, worsening of existing pain, and especially pain that wakes one up from sleep".

Thank you to Dr. Andrea Gross from the National Cancer Institute at the National Institutes of Health for writing this article for the NF community.

A link to the article on MPNST can be found at:

[MPNSTs in NF1](#)

Gastrointestinal Tumors in NF Type 1

Dr. James Tonsgard, MD, of the University of Chicago, graciously contributed an overview of Gastrointestinal Stromal Tumors (GISTs) for our *Be iNFormed* series. GISTs are one of the most common tumors in the GI tract. They can occur in the stomach, small intestine and large intestine. These tumors can produce bleeding which the patient can discover in frank bleeding or result in more subtle findings such as anemia or low blood count. These tumors can produce abdominal pain, vomiting and in some instances, bowel obstruction, which would result in requiring surgery.

A link to the article on GISTs can be found at:

[GISTs in NF1](#)



NF Midwest volunteer advocates this year included (from L to R) Rachel Campana, Heather Reyes, Susan Buono, Denise Dulceak, Diana Haberkamp, Max Obermann, Laura Obermann, Karissa Haberkamp (not pictured)



The Walk That Wasn't

COMING TOGETHER WHILE STAYING APART

Join the NF Midwest community in raising FUNds and Awareness in the time leading up to October 17th when we will have an online community *CELEBRATHON!*

Due to COVID our physical walks are cancelled but we're still following our walk motto that **"No One Fights Alone When We All Party Together!"** and we need the NF Midwest community to come together more now than ever before!

Join us in this special journey by signing up now at [The Walk That Wasn't](#).

How To Participate in TWTW

Phase One—Individuals Raise FUNds and Awareness!

- Sign up NOW as an individual or as a TEAM of individuals and start raising funds and awareness through whatever fun ways you can think of or by simply sharing your personal fundraising page.
- Compete for prizes and earn recognition gifts.
- Have fun, be crazy, get people to join in and raise awareness.
- Be sure to invite individuals to fundraise under your team so that you have the honor of raising the most and choosing next year's t-shirt colors.
- Registered fundraisers will get a *Walk that Wasn't* t-shirt if they raise \$100 or pay the \$25 fee. (Note: Registration fees will NOT be added to fundraising totals.) T-shirts will be given to team Captains (when applicable).
- Create a recording (this is optional) of your team, about NF, about a loved one with NF, maybe an interesting talent, or anything you can think of and send it to NF Midwest.

Phase Two—Come to the TWTW CELEBRATHON!

- Join us (and invite everyone you know) to our October 17th *Walk that Wasn't Celebrathon*. This will replace our actual walks.
- We'll celebrate our community and our fundraisers.
- There will be raffles and more.
- Show the best submitted videos (don't worry if your video isn't show we will share it in other ways.)

BE A HERO

Be a Hero! Find a Sponsor!

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.

Individual Fundraiser Recognition Gifts

Recognition prizes will be given to INDIVIDUAL fundraisers based on what they raise through their online fundraising page. This puts the FUN in FUNdraising, plus you'll be raising awareness with these items!

- \$500 NF Midwest Contigo Stainless Steel Bottle
- \$1,000 NFM Baseball Hat + Contigo Stainless Steel Bottle
- \$2,500 Awesome NFM Jacket + Hat + Bottle



Top Fundraiser or Team Picks Next Years Colors!

The team or fundraiser (which ever is the highest) wins the right to choose the t-shirt and ink color for next years walks (all of them). In 2019 Hartigan's Heroes was our top fundraiser and chose the colors of heather blue with green ink for our 2020 shirts. This will be the color of our special edition *The Walk That Wasn't* t-shirts. The team or individual fundraiser that raises the most in 2020 will choose the colors for next year!

**Send in your videos for our October 17th TWTW CELEBRATHON!
We'll be celebrating our NF Community!**



Thank You to our 2019 Great Step Volunteers, Fundraisers, and Walkers!

Great Steps 2019 Recap

In 2019 four Great Steps Walks4NF were held. They included Columbia, MO; Madison, WI; Naperville, IL; and Fort Wayne, IN. We thank all our chairs and volunteers for their work last year and for their work, unfortunately on “walks that weren’t”.

Our top teams were NF Fighters (Columbia); Team Dozers (Madison); Hartigan’s Heroes (Naperville); and Team Owen (Fort Wayne).

Walking in honor of Merrick, Hartigan’s Heroes raised the most with a final total of \$11,534.



Hartigan’s Heroes at GS Walk4NF in Naperville.

Superman Tim

Meet Tim and Sue! Tim is one of our amazing, out of this world, extraordinary volunteers who heads up the Madison Great Steps Walk 4NF! The walks started out very small with little food items and only a handful of raffle prizes. He took it upon himself to seek out donations for raffle prizes, silent auction items, and food/beverages.



He did all of this to make the event more enjoyable for all of those in attendance. He developed lasting relationships in the area simply by asking if local businesses would like to be involved in the Great Steps event. “I would call it my ‘proud parent’ moment as I would watch everyone having a fun time, and watching the number of participants and funds raised increase each year. Last year we had about 225 participants and raised about \$25,000. The event now also has several food and beverage items added to the point where a nice breakfast and lunch are available.”

Tim is looking to take a step back and hand the reigns over to another person or team. He hopes to help with the 2021 walk in a way to leave the walk with someone who will keep it going. He plans on sharing contacts and strategies for

success. Sound like something you’d like to do? Let us know!

Thank you so much Tim for your dedication and hard work! Your passion is truly second to none!



In these difficult times we invite people to fundraise by simply asking for \$5 in our #GiveMe5 campaign. There are many creative ways to do this. Have fun and send us your ideas or what you’ve done!



MavMan Sidekicks Raise Almost \$4K in 7 Days!

MavMan Sidekicks did something extraordinary in just 7 days! Using social media, Maverick’s mom, Kara, and his aunt, Dayna, used videos and social media posts to announce and promote their fundraiser (we loved their Facebook Live launch!). Dayna also made a short video about Maverick’s NF journey. Then for every \$5 donated, donors received an entry

for prizes which Maverick chose daily. They had 130 donors! They used smaller daily prizes like Dunkin’ gift cards and a Scentsy basket and several donated grand prizes and raised an incredible \$3,855.



The Jay-Walkers Raise Almost \$7,000!

Right around the same time that MavMan Sidekick’s were holding their big fundraising push, Laura Haslam contacted us with her idea of simply asking for \$5 in these hard times. We loved the idea and suggested she try it out. They offered entry into drawings for \$5 donations and they raised over \$6,000 in two weeks. As we type this

they are at \$6,965! And from Laura’s idea we have started #GiveMe5!



Willow Strong Has Raised \$2,241

Willow Strong, who was fundraising for the cancelled Madison walk, is also doing an amazing job at fundraising already! They’re doing it for 2 year old Willow and mom, Marie, raised most of their \$2,241 total so far.

Way to go MavMan Sidekicks, The Jay-Walkers, and Willow Strong! We look forward to seeing you at *The Walk that Wasn’t* Celebrathon on October 17th! !

NF Collective Launches New Website to Connect NF Patients with Doctors



Last year NF Midwest, in collaboration with several other NF organizations called the NF Collective, launched the nfcollective.org website. [The NF Collective](http://nfcollective.org) is a group of organizations dedicated to improving the lives of neurofibromatosis (NF) patients and their families. The new nfcollective.org website currently provides accurate information on NF experts and their contact information and will be expanded to include other resources in the future.

Easy Ways to Participate in Research: Studies Looking for Participants

There are several studies and surveys looking for participants from the NF community. Some include:

- An survey for adults with NF1, NF2, or schwannomatosis.
- Resiliency studies for adults and adolescence with NF1, NF2 or schwannomatosis.
- A study in Wisconsin looking for 4 to 6 year olds with NF1.

Find studies and surveys at:
[Research Posts](#)



New Board Member

Dena Hasselberg was elected in October to the NF Midwest board and is serving as board secretary. Dena is currently a school psychologist in the Valley View School District located in Romeoville, Illinois. She has 18 years of experience as a school psychologist. Dena earned a Bachelor of Psychology degree and a Master of School Psychology degree from Governors State University. She earned a Master of Educational Leadership degree from St. Xavier University. She earned a certificate in Special Education Advocacy from the William and Mary Law School Institute of Special Education Advocacy. Dena has a personal and professional interest in the educational implications of children with health conditions.

Dena has been involved in the NF community and fundraising for the past 15 years. Dena is married with 5 children, including her daughter, Sera who has NF1.

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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.

Dave Anderson
 Brea Ann Zoll
 Jean Van Tuyle
 Nora Schroeder
 Derek Winker

Greyson Hartje
 Tim Camenisch
 Faye Fuchs
 Aaron Hoene
 Jillian Clark



Memorial

Donations



Event Coordinator—Maggie Wright

Last September Maggie Wright joined us as our new part-time fundraising and event coordinator. Maggie has been working very hard since then with do-it-yourself fundraisers and on our walks. It's unfortunate that her wonderful plans and

ideas were somewhat destroyed by the COVID crisis. However, Maggie is very excited to help us explore new opportunities in the "virtual" world and looks forward to working with our community in the next several months as we come together to raise awareness and funds and celebrate on October 17th.

She lives in St. Charles along with her husband, 3 children, 2 dogs, and 7 chickens. She holds a Bachelors in Communication from Alverno College and also owns a wedding photography business.

Care and Outreach Director — Paul J. LeBlanc, RN, BS, CCM

In January Paul LeBlanc, RN, BS, CCM joined us to work part-time as our Care and Outreach Director.



Paul, a second career nurse, obtained his RN in 1995 and is currently licensed in TX and IL. He earned a BS at Louisiana State University (LSU) and his AD-Nursing at Houston (TX) Community College. He is also a Certified Case Manager. His primary area of Nursing practice has been in Management and Administration in Seniors' case management and in the workers comp realm, helping folks navigate through the medical treatment world. He also served several years in high-tech home nursing. Paul does not have a direct connection with NF. Paul is married with five children, ten grandchildren and a cat.

NF Midwest Super Hero Pen—Give One! Gift One!



For a limited time become a Giving Circle Member by signing up for automatic monthly giving and we'll send you a NF Midwest Super Hero Mop Topper Pen to two people of your choice.

Think about your favorite care giver or doctor and your loved one with NF.

Sign up for automatic monthly giving [HERE](#)





TopGolf 2020

On February 23, 2020 NF Midwest hosted its annual [TopGolf](#) event in Naperville. We had an amazing turnout of 130 people on what turned out to be one of the warmest days of the winter! In addition to swinging the clubs there was a delicious lunch buffet, cookies, and non-alcoholic beverages served. With a table full of raffle prizes, there was a little something for everyone including an Amazon Kindle Fire, FitBit, and an assorted wine basket. There was also a 50/50 raffle and the big winner graciously donated 1/2 to NF Midwest.

Thank you so much for all who attended, helped with sponsors and raffle baskets, assisted at the event, and more. Hopefully luck will strike twice and we will have another stellar day next year!



Leave a Legacy

We've been very fortunate to have a few generous benefactors remember NF Midwest in their end of life plans. This has allowed us to expand or develop new programs. If you've set up a plan to benefit NF Midwest, neurofibromatosis and schwannomatosis please let us know if you want us to recognize you in our Legacy Society. This may include listing NF Midwest as a recipient in whole or in part of your estate, your life insurance, or in a remainder trust.

We Take Stock and IRA/401C Transfers

Sometimes it may be financially beneficial for tax reasons, or just for convenience, to transfer a gift in the form of stock or from an IRA or 401C. NF Midwest is able to take gifts in this way. If you, or someone you know, would like to give in this way please call the office at 630-945-3562 or email info@nfmidwest.org.

Join the NF2 Action Committee (NF2ACT!)

We invite anyone who is interested to join our NF2 Action Committee. This committee helps direct research support for NF2 and provide education, including creating material, for NF2. If you are interested, please call 630-945-3562 and ask for Diana or email info@nfmidwest.org.

The NF Midwest Dream Team

If you have an interest in supporting the mission of NF Midwest and have some time to dedicate to it, you could be a [Dream Maker](#) by joining our Dream Team. The Dream Team meets to discuss the needs of NF Midwest and to find solutions. This could mean helping with a

Raise Your HAND 4NF!



project, serving on a committee, providing expertise, etc. You also may know someone in your sphere of influence that might be able to help.

There are jobs big and small and a niche for everyone who would like to help.

Dream Makers receive frequent emails regarding the needs of NF Midwest and are invited to meetings (often online) to discuss the programs of NF Midwest and the needs of the NF Midwest community.

Local Meetings/Groups



Below is information on groups that meet regularly for support and/or socializing. During COVID these groups may not be meeting or may be offering an online option. If you want to be notified of future events from the groups below, or other groups, please email info@nfmidwest.org. 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.

Kentucky Support Group

For more info about the Kentucky NF Support Group, please email kentucky@nfmidwest.org.

Central Missouri Support Meetings

The Central Missouri group generally meets in Columbia, MO or online. Email CentralMissouri@nfmidwest.org for more info.

Due to the pandemic there will be no *NF Midwest Symposium and iNFo Fair* this year. Look for opportunities online to learn and socialize with NF Midwest or other NF orgs. For the most timely updates please make sure we have a current email address and join our [Facebook Group](#) at facebook.com/groups/nfmidwest.



Hoosier Crane Casino Night

We get asked all the time, "What is a DIY fundraising event?" Here is a perfect example of one! The wonderful folks at [Hoosier Crane](#) in Indiana contacted us about being the beneficiary non-profit for their annual Employee Holiday Party. This year's theme was Casino Night. It looks like it was a lot of fun!

Thank you so much Jason and Amanda for being the NF Midwest ambassadors at the party.

Thank you so much to Hoosier Crane and their employees, their party raised over \$4000!



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Non-Profit Org
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630-945-3562
www.nfmidwest.org
info@nfmidwest.org

If you have the means **PLEASE** make a donation **NOW** in honor of your loved one or friend with neurofibromatosis or schwannomatosis at NFMIDWEST.ORG/DONATE.

Thank You To...

Our Donors
 Who make the mission possible!

Our Volunteers
 Who move the mission!

Tim Eberle Who has chaired the Madison walk for many years and is now stepping down...but not out!

The Oswald Family and SamJam4NF
 To Pete, Sam, Pete 2, and their friends and family for their ongoing work on SamJam4NF! We look forward to next year!

Kara Cano For your ideas and support! We loved watching you and Dayna on Facebook!

Cara Calloway Our Canadian virtual volunteer for our virtual event.

Dena Hasselberg For joining the NF Midwest board and for your guidance of people in our community with school issues including the dreaded IEPs!

Sharon Arens and Susan Caris
 For your work and dedication on the Fort Wayne walk and family night...though neither came to be.

Steve Reason For arranging the Birdies for Charity fundraiser again in 2020 event through this crazy time!

Julie Rutter For walking us through our PPP loan!

Adrian, Gaoveeng, Garrett, Paris, Tori
 Our 2020 NF Midwest area Young Adult Leaders! We look forward to working with you more!

Jonathan H Our Salesforce volunteer!

Rachel, Heather, Denise, Susan, Laura, Max, and Karissa For lobbying

Christina Thomas and Kristi Saylor
 For your Columbia, MO support group and the walk (sorry there won't "physically" be one!)

Annie Hartigan For your work on GS Naperville and your ongoing support and your stint (wish it was longer) as event coordinator!

The Board The NF Midwest Board –Gail, Gordon, Pete, Denise, Lesli and Dena.

Laura Haslam
 For your great ideas and all your support!

Jessica Rheault For your proof reading skills and support!

Heather Reyes For chairing our scholarship committee again!!

Brad Duthie
 For renting the truck for GS Walk4NF Naperville and DRIVING IT!!!

Christine Christensen For your awesome work and dedication as our event coordinator! We miss you!

Morgan Prato For your continued help with graphics and marketing!

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.