

Did You See One of Our Printed Newsletters in 2022?

The answer is “NO”, though maybe you dreamed about us! We hope so.

Anyway, we’re very sorry that we’ve been absent. It’s hard work and a larger expense to put together and print a newsletter. We’re fairly sure you’d like our time and resources spent in the best way possible for the NF cause. However, we do like bringing NF news and updates (and of course pitches to donate or raise money) right to your door once in awhile and we hope you enjoy it.

If you’d like to receive news in a more timely manner, make sure we have your CURRENT email and that we’re not blocked by those pesky spam blockers. You know, the ones that block what you care about (like the NF/SWN cause), yet don’t manage to catch the store that sends you an ad every single day or the notices that you’ve inherited money (in case you don’t get those—don’t worry you’re not missing out on any money).

Also, frequently check out our [website](#) and [Facebook page](#). If you are in our service area join our private [Facebook group](#) or follow-us on [Instagram](#). Another great option is to get involved! Join a committee, come to online meetings, work on an event, and you’ll know a lot more about what’s going on in the NF world!

What the Heck is NF/SWN?

You may be sorry you asked or read this part! We’re going to keep the explanation simple.

Great minds (and we mean this seriously) appropriately decided that neurofibromatosis type 2 (NF2) is not an accurate name as NF2 does not typically have neurofibromas, the protein at play is not neurofibromin, and it is on a different gene. Rather, NF2 more frequently involves schwannomas and meningiomas, and is really a schwannomatosis related disorder. As you may know, there is already a disorder under our umbrella called schwannomatosis.

So for now (until we can come up with appropriate language amongst all entities—ie. docs and NF orgs), NF Midwest is calling NF2 “NF2/SWN” or “NF2 related schwannomatosis” (which is quite the mouthful) and often when referring to all we may use NF/SWN. Everything, however still falls under the more known NF umbrella.



Meet Sarah, Our Care and Outreach Coordinator

In November 2023

Neurofibromatosis Midwest was very excited to welcome Sarah Selogic, our Care and Outreach Coordinator. Sarah is from the Buckeye state of Ohio where she earned a degree in social work and her Ohio LSW. She has several

years of social work experience and has worked in diverse areas such as mental health, family support in schools, senior services, and foster care. Sarah’s job is to help our NF families and individuals in whatever ways possible to make sure that No One Fights Alone.

If you need help finding resources or direction Sarah will do her best to help. Sarah can help connect NF patients and parents with physicians and other community members and assist with insurance issues. However, her assistance does not have to be related to NF directly. She can help with finding resources in your area such as food, utility assistance, and other social service agencies to meet your needs. Sarah can also be helpful with navigating applications such as [SNAP](#), Medicaid, Medicare, and Medical Savings Programs.

If you are unsure if Sarah can help with your concern, reach out to her. If she doesn’t know the answer, she’ll do her best to find someone who does!

Email Sarah at
Outreach@nfmidwest.org

Examples of How Sarah May Help!

- Locating a healthcare provider
- Navigating insurance issues
- Public benefits
- Finding assistance and resources
- Navigating social services and their applications
- Connecting with others
- Enrolling in clinical trials or studies
- Applying for camp, scholarship, or other programs
- Moral support
- ...And more.



YOU MATTER! STAND UP AND BE COUNTED! Take the Survey.

To ensure that everyone with neurofibromatosis or schwannomatosis is served and that No One Fights Alone it’s vital that we know who you are, your needs, and how you or your family are affected. Please, stand up and be counted by participating in a survey at www.nfmidwest.org/stand_up. Please, share only what you are comfortable sharing.

Go to www.nfmidwest.org/stand_up



2022 Scholarship Recipients

In 2022 NF Midwest awarded four \$1,000 scholarships to adults affected by neurofibromatosis or schwannomatosis.

Our 2022 scholarship recipients were:

Christopher H. (Naperville, IL) is a Freshman at the University of Dayton. He is pursuing a degree in Supply Chain Management.

Meghan S. (Waunakee, WI) is a Freshman at St. Norbert College. She is pursuing a degree in Elementary Education.

Luke M. (Wauwatosa, WI) is a Freshman at Milwaukee Area Technical College. He is pursuing a degree in Music Occupations.

Edgar A. (Aurora, IL) is a Freshman at Southern Illinois University. He is pursuing a degree in Zoology.

If you'd like to apply, the application process usually opens in early January and the deadline is March 31st.

2023 Young Adult Leadership Program



Diana joined Tracy Wirtanen of the [Littletest Tumor Foundation](#) and Cindy Hahn of [Texas NF](#) in Washington, DC, the first week in January to hold the third official **NF Young Adult Leadership Program (NFYA)**. This program offers young adults (18 or older) the opportunity to learn to advocate, develop

leadership skills and personal strengths, and help the NF community find effective treatments for NF1, NF2, and Schwannomatosis. This year young leaders from NF Midwest included Lily Whitehurst and Kelly Hammond from Indiana, Adelaide Ralston from Illinois, and Jalyn Jefferson from Ohio. Ohio is currently not technically NF Midwest's service area, but we're happy to spread our wings there a little with the help of leaders like Jalyn.

Young leaders and mentors meeting Rep. Gwen Moore of Wisconsin.



Woop! Woop! Camp New Friends is Back in Full Swing

This year Camp New Friends is scheduled July 16-22. Smack in the middle of your summer, camp may save the day (or week) as the summer heats up! For children with neurofibromatosis, this summer camp offers a week of fun, friendship, and a break for their parents!



Worried about sending your child so far away? Operated by Brainy Camps through Children's National Hospital and held on the beautiful grounds of the Blue Ridge School in Virginia, NF Midwest has trusted this group with the care of kids from our community since 2004. Camp New Friends volunteers and staff are on the grounds 24 hours a day, including NF medical personnel such as physicians, nurses, social workers, counselors, physical therapists, and psychologists. Also, if your child is flying, you can take them to the gate, and someone will meet them on the other end. If flying out of Chicago, there may be a group going together.

Worried about missing your child? Campers' days are filled with summer fun while learning valuable skills and a better understanding of their capabilities and strengths. There are so many activities, that while you might miss them, you may be disappointed that your child probably won't miss you!

Worried about the cost? Camp cost is \$1200 per camper, plus travel...whew that's a lot of cheddar! However, NF Midwest usually provides scholarship assistance for most travel and camp fees to campers from our service areas of Illinois, Indiana, Iowa, Kentucky, Wisconsin, and the Eastern half of Missouri. Applications for financial assistance must be made through Camp New Friends/Brainy Camps, and NF Midwest reimburses them.

Ready to get rid of your child for a week? Sign-up ASAP before it's too late! For more information or to apply, go to www.brainycamps.com.

Please, give Sarah, our Care and Outreach Coordinator, the heads up if you apply or need assistance by emailing her at outreach@nfmidwest.org.

**Make a Commitment to NF Midwest.
Become a Recurring
Donor and Keep Hope in Motion!**

NFMIDWEST.ORG/DONATE

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**MONTHLY
GIVING
CIRCLE**



Support, Care, and Education



Ask Sarah For Help

Email
outreach@nfmidwest.org

Facebook
Sarah NFMidwest



Parent Groups

NF Midwest has been holding monthly online meetings to bring together parents of children with NF to explore a myriad of topics. Our discussions were enriched by the expertise of many distinguished guests.

However, we're no strangers to change, and we have noticed a recent dip in attendance. So, we've put our heads together and come up with a new game plan. We will be switching to a new schedule and holding our Parent Group meetings approximately every three months. But don't you worry, we have some ace programs up our sleeves, and we will be hosting additional online events at other times. You can keep up with all the juicy details by visiting our events page or our [registration page](#).



Research Needs Your Help!

Studies and surveys are a vital part of learning about NF and SWN and the development of potential treatments. Here is a list of current studies looking for participants. This is NOT a complete list!

- Adults over 40 and with NF1 are needed for a study to understand how other genes may affect the development of cutaneous neurofibromas and other features of NF1. **Find more info [here](#).**
- People with NF1 are eligible to participate in the Natural History study for Patients with NF1. This study will help to look at how cutaneous fibromas develop and change over time. **Find more info [here](#).**
- Participants ages 12-17 with NF1 are welcome to join the PEERS study to explore the effectiveness of a telehealth group on improving peer relationships for teens with NF1. **Go [here](#).**
- Adults with NF1 and cNF are invited to join a study for testing the effectiveness of 2 concentrations of NFX-179 gels compared with a placebo gel in reducing the appearance of cNFs. **Find more info [here](#).**
- Those with NF1 can join a study that is looking to identify and understand tumor biomarkers in children and adults with NF1. **Find more info [here](#).**

To find more opportunities to participate in research, go to www.nfmidwest.org/blog/category/research-posts, or www.clinicaltrials.gov, and sign up on the [NF Patient Registry](#).



Adult Advisory Committee

We're thrilled to announce that we've launched an Adult Advisory Committee, and we want YOU to join the ranks of our awesome members. We've already hosted several meetings with some exceptional young adults, and now we're looking to expand our group to people of all ages.

The aim of this group is to help us at NF Midwest produce top-notch programs and events that cater specifically to adults with NF or SWN. We're planning to meet every month or so, and we'd love to have your input as we strive to provide the best programming and support for the adult members of our community.

This is a big deal, and we need all hands on deck! If you're interested in participating, please don't hesitate to reach out to the one and only Sarah. We can't wait to have you on board and to work together to create meaningful and impactful experiences for our community.



Check Out Our Website Frequently!

We strive to provide a wide variety of iNformation on our website to help in all aspects of dealing with NF and SWN. We especially like

to post frequently. You can find our most recent posts on our home page and click more articles to see them all.

Our posts often include research studies looking for participants; updates on programs and events; stories from patients with NF; or ways to fundraise and participate.

We also post other helpful information. For instance, in the last several months we've had posts titled:

- Public Health Emergency is Ending. Check Your Mail for Important Medicaid Information!
- What to Do if You Have an Insurance Issue
- Optic Pathway Glioma and Vision Testing
- 211 Call Line to Find Resources
- Resources for Common Needs
- NF Type 1 and Cancer Risk Screening

We also have a [LEARN](#) section, where we are always adding more resources and articles. Let us know if there is a post you'd like us to make or an article or resource you'd like added.



Neurofibromatosis iNFO Fair

KNOW NF

OCTOBER 21, 2023

Get ready to join us for an intellectual extravaganza! Our annual Symposium and iNFO Fair is finally back in person! Mark your calendars for Saturday, October 21st, at the Northern Illinois University Center in Naperville, IL, for an event packed with knowledge and inspiration. From 9 to 4, we will be delving into the latest insights and perspectives on neurofibromas and plexiform fibromas, NF2 sessions, and more.

We are still working on the content and are excited to announce that we will have panels of patients and parents sharing their experiences and valuable "hind sight." Furthermore, we will have tables of iNFO available for everyone to dive deeper into the subject matter.

We understand that science-heavy jargon can be intimidating, and our mission is to provide education that positively impacts people's lives. Our aim is to gain a comprehensive understanding of what is known, what is suspected, what needs to be known, and how we can get there. The iNFO Fair is also an opportunity to learn from the experiences of others, creating a supportive community that empowers individuals to thrive.

Do you have questions, input, or want to contribute? Please don't hesitate to reach out to us via email at info@nfmidwest.org or call us at 630-945-3562. We can't wait to see you there!



25 Million for NF FY2023

\$25 million has been allocated specifically for the [Neurofibromatosis Research Program \(NFRP\)](#) in the Fiscal Year 2023 Omnibus bill. **That's \$5 million more than last year!!**

Every year NF Midwest and other NF organizations and volunteer advocates work very

hard to secure this vital funding for neurofibromatosis and schwannomatosis research and to encourage research through the [National Institutes of Health](#).

This is a process that starts over again every year. In January, NF Midwest helped young leaders learn how to raise their voices in DC and in February NF Midwest and other volunteers went to DC to start the work on funding for in 2024.

The work of securing this funding is only made possible by the donations we have received from donors and the work of our fundraisers. Thank you to all! You made this happen!

2022 Top 5 Walk Fundraisers

Congratulations to our Top Fundraising Teams of 2022. Thank you to you and all of our fundraisers and participants. We can do nothing without your hard work and dedication.

Team Dozer (Madison)	\$11,709
Audrey's Army (Naperville)	\$11,680
E's Hulksters (Columbia)	\$10,804
Team Levi (Naperville)	\$6,630
Cole's Crew (Naperville)	\$6,540



Audrey, inspiration of Audrey's Army (top Naperville 2022 team) and friend enjoyed the amazing face painting by Michelle, owner of GAWI Entertainment, Inc.

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

at www.nfmidwest.org/donation or mail a check to NF Midwest, 473 Dunham Rd, Suite 3, St. Charles, IL 60174!

Any amount makes a difference!

Also, Consider These Other Ways to Give

- Become an automatic monthly recurring donor
- Donate stock directly or from your IRA or 401C
- Add NF Midwest to your will or as a benefactor of your life insurance
- Think of businesses you work with or buy from and ask them about sponsorships or in-kind donations

If you can make a larger donation, considering funding a match challenge.



Casual Walks, Serious Fun

LEARN MORE AT WWW.WALK4NF.ORG

2023 Individual Fundraiser Appreciation Gifts

Though most of our fundraisers raise for a team, appreciation gifts are given for their INDIVIDUAL effort. These gifts are awarded based on what they raise through THEIR online fundraising page. This means many people from one team could earn a gift. Gifts are cumulative, meaning each level also get the gift from the level below. Earn gifts to raise awareness.

Gifts are Cumulative

Platinum
Fundraiser
\$5,000
LLBean Jacket



Gold
Fundraiser
\$2,500
Chair



Silver
Fundraiser
\$1,000
Canvas Bag



Bronze
Fundraiser
\$500
Beach Blanket



Raise
\$100
T-Shirt &
Registration

Raise \$100 and receive a t-shirt and registration fee is waived. Choose this option at registration.

Register Now & Gather Your Friends

Last year was our first year back with in-person walks since COVID, and while many came out, the attendance was still down. It's VITAL to the cause, our community, and simply for our sanity that we gather together. Please sign-up now and encourage friends and family to join you.

All walks include a t-shirt to any one who raises \$100 or pays the registration fee. The registration fee is \$25 for anyone over age 12 and \$15 for children age 2-12.

2023 Walk Dates

Learn more at www.walk4nf.org

Madison, WI—May 13th at Capital Brewery
Indianapolis, IN—May 20th in White River State Park
Naperville, IL—June 3rd at the Naperville Riverwalk
Columbia, MO—June 24th at Stephens Lake Park
Can't make a walk? Then walk virtually, let us know.

Top Fundraising Team Chooses the Colors!

For the last few years we've had the top fundraising team out of ALL the walks choose the t-shirt colors for the following year. In 2021, after raising over \$13,000 by fundraising throughout the WHOLE year (from Oct. 2020 to Sept. 2021), the Jay-Walkers from the Naperville, IL walk earned the honor of choosing the 2022 colors. Jay, their NF fighter, chose red shirts with blue writing.

The team choosing the t-shirt colors for 2024 will be the team with the highest fundraising total on their fundraising page on September 30th at 6:00 PM CST. Because teams from all walks are currently not viewable on one page, to track this you will need to look at every walk to find the top team.



Jay sharing his 2022 color choice



What Will Be the Color This Year? AWAITING THE GREAT REVEAL

The right to choose the 2023 t-shirt colors was earned by Team Dozer from the Madison, WI walk. The Dozers raised \$11,709 by holding events during the year, during the walk season, and beyond. They wanted their team fighter, Eli, to have the honor of choosing the colors. Stay tuned for the "color reveal".

D.I.Y.— DO IT YOUR WAY

Personal Fundraising

For those of you with sharp eyes, we know DIY fundraising should be “Do-It-Yourself”. But doing it yourself means going it alone and not having some experienced help. DIY reminds us of the guy next door who decided to DIY their swimming pool by digging a large hole in the backyard and filling it with the garden hose. The result was a swamp full of mosquito larvae and some furious neighbors.

When you're fundraising YOUR WAY, you choose something meaningful to you, whatever fits your personality and skills, and the platform that works best for your goals. You get to be creative and innovative, and you can make a real impact on the neurofibromatosis cause, and raise funds and awareness in your unique way.

The possibilities are endless, whether you want to run a marathon, hold a carnival in your yard, create a unique event, or start a crowdfunding campaign. And the best part, it's YOUR WAY, but it's not by YOURSELF. NF Midwest is here to help.

We'll provide you with all the tools and resources you need to get started, but the rest is up to you. Email Maggie at events@nfmidwest.org or check out our website.

If you'd like to start with something simple, you can create fundraising pages on our platform. This includes a page to celebrate a milestone like a birthday, anniversary, or wedding or to collect donations for an event or challenge (like dyeing your hair blue and painting your face green if you raise \$1,000— we heard you wanted to do that!). We also have the option for you to create tribute pages in memory or honor of someone. If you'd like to do something simple, you might want to consider a Facebook fundraiser on our Facebook page at www.facebook.com/nfmidwest.

Note: Whatever you do, if you participate in a walk, we can add your year-long fundraising efforts to your walk page.

E's Hulksters DIY Trivia Night

Last year the Columbia Walk4NF team E's Hulksters, held a Trivia Night to raise funds for their team. Led by mom, Dawni Henry, they raised around \$5,000 holding this DIY (Do It Your Way) event for NF Midwest. Dawni and her team chose this event because Trivia Nights have always been a fun outing for her and her friends, and they thought they could do a good job holding one themselves....and they did.

The best part of the evening is seeing everyone having fun and knowing they are there to support our girl, that is what means the most to us.

- Dawni Henry

Dawni put together all the questions and used a Power Point presentation to share them at the event. Her husband, Seth, took care of silent auction items. The Henri's were “blown away” by the support. There were even tables of people they didn't know. Everyone is looking forward to another one, so in April of 2023, E's Hulksters are holding their 2nd Annual Trivia Night.

If you're interested in holding a DIY event let us know and we'd love to help out however we can. Dawni says if you want some advice on a trivia night, “I will help in any way I can, just holler.”

Win a 2-Year Lease on a 2023 Lexus NX



When it comes to Do-It-Your Way (DIY) fundraising Steve and Diane Reason are experts with their annual John Deere Classic Birdies for Charity event. All you have to do is complete a simple form and make a pledge by June 16th. 100% of the pledges will go to NF Midwest. Birdies for Charity guarantees a 5-10% match!

In addition to supporting NF Midwest pledgers have a shot at winning a 2- year lease on a 2023 Lexus NX by guessing the correct number of birdies by the PGA TOURS Pros during the John Deere Classic on July 5-9th.

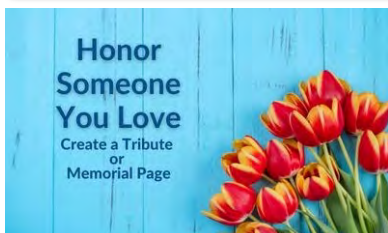
To make your pledge and win a Lexus visit www.nfmidwest.org/birdies or contact Steve at steveNF2@frontiernet.net. You may also visit www.birdiesforcharity.com. Our charity # is 1815.

Be sure to participate! It's basically a raffle but you pick your number!

We don't know if this is the exact car you'll win, but we're pretty sure you'll be happy any way when you win!



FIND WAYS TO GIVE OR FUNDRAISE AT NFMIDWEST.ORG GIVE



A World NF Day **LIVE** Event

Join NF Midwest as we Celebrate with CTF

MAY 17
8:00 PM ET
5:00 PM PT

Make **NF** Visible

Look for details online or in your email soon!



NF MIDWEST & OTHERS FUND RESEARCH

In 2022, NF Midwest, NF Northeast, NF North Central, and NF Upper Midwest collaborated to fund a collaboration between the University of Wisconsin and the University of Minnesota to expand the

University of Wisconsin's [PEERS-NF Research Program](#). The goal of this collaboration is to expand participation and prove whether the program will work at multiple sites. The PEERS-NF program examines the effectiveness and acceptability of PEERS intervention (Program for the Enrichment and Educational of Relational Skills) in a virtual setting for teens with NF1. The PEERS program uses an online telehealth style to improve social skills and peer interactions for adolescents with NF1. Results from the University of Wisconsin's previous study of use of PEERS in adolescence with NF1 supports the promise of this resource for medical providers, school personnel, researchers, and clinicians who work with individuals with NF1.



Together we can make sure **No One Fights Alone!**

Please, think of the ways that you can be a part of this support system whether it is a donation, a fundraiser or as a volunteer.

Memorials Received

Since our last newsletter, 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 received in lieu of flowers. We thank the families who thought of NF Midwest in their time of grief.

Mike Kean
David Bjoralt
Faye Fuchs
Deborah Penderghast
Catharine Buktenika
Maureen Hoener

Edna Stippich
Irene Szwaglis
Sidney Thirwall
Cecelia Lund
Dorene Smith
Dave Haxby



Memorial Donations

GET READY FOR NF AWARENESS MONTH!

May is NF Awareness month, May 17th is World NF Awareness Day, and May 22nd is the day to recognize NF2/SWN. Here are ways you can participate and raise awareness.

SAVE THE DATE TO CELEBRATE WORLD NF DAY!

NF Midwest is joining the Children's Tumor Foundation to celebrate World NF Day on May 17th. If you are in the Chicagoland area on May 17, save the date to join us for a World NF Awareness Day event and 'Blue and Green' viewing party to watch CTF's new two-part short documentary following two families living with NF1 and NF2. If you can't make the event, join us virtually at ctf.org/live.

WEAR BLUE AND GREEN

There's probably no reason to explain it! Wear blue and green on the May 17th and Blue on May 22nd...or the whole month and see if anyone notices your fashion choice! Also, consider buying other NF "a-wear-ness" items at the [NF Midwest Store](#).



SHINE A LIGHT ON NF

If you're smart and have smart porch lights, turn them blue and green in May. Also, ask local buildings and landmarks to turn their lights blue and green for the month. If you need more information, go to ctf.org/get-involved/shine-a-light.

OBTAIN A PROCLAMATION

Getting a proclamation from your governor, mayor, or city council is a great way to raise awareness about NF.

If you work on getting one, especially from a state, please let us know so we can collaborate with other NF orgs who also may be working on it.

SHARE YOUR STORY AND NF FACTS

Share your story and facts about NF and SWN wherever and however you can. This could include social media, including Facebook, Instagram, and Tik Tok, or maybe leave some literature around work and drop something at the store (though we don't condone littering!)



Neurofibromatosis Midwest
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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**.

SAVE THE DATE



Neurofibromatosis iNFO Fair

OCTOBER 21, 2023
Naperville, IL



Thank You to Our 2023 Corporate Sponsors

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Recursion[®]



SpringWorks[®]
THERAPEUTICS



Sign-up to Walk Now



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.