



Neurofibromatosis Midwest

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NF Midwest is a not for profit 501(c)3



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WWW.NFMIDWEST.ORG/GIVE

Dear Foe of NF,

This is a letter with news in place of a fancy newsletter! **We believe this approach will save us time and money**, two things we'd all rather dedicate directly to the cause. Most of this update will be brief. Check out our website, social media, email, or call for more information.

FYI, A New Way of Talking About NF

When discussing NF, NF clinicians, researchers, and patient advocacy organizations use new language and figures. **NF type 2 is now known as NF2-related schwannomatosis (NF2-SWN)**. NF type 1 (NF1) is still the same. All other schwannomatosis is SWN. **NF refers to all these conditions at once**. NF1 affects one in 2,500 people (instead of 1 in 3,000), NF2-SWN still affects 1 in 25,000, and all other SWN affects 1 in 40,000. Collectively, all NF conditions affect 1 in 2,000 individuals.

Good Research News!

We have secured \$25 million for NF research through the Congressionally Directed Medical Research Program (CDMRP) for Fiscal Year 24 and worked to get language supporting NF research through the National Institutes of Health. We began working on funding for fiscal year 2025 in February, asking for another 25 million and NIH support. Be on the lookout for requests to contact Congress.

Springworks Pharmaceutical is seeking FDA approval for mirdametinib, a MEK inhibitor, **to treat plexiform tumors in children AND adults**. You may recall that in 2020, the first drug specifically for an NF complication (Koselugo for plexiform tumors) was approved only for children with NF1. However, it is sometimes used "off-label" for adults. This is very exciting news!

Participate in Research

We frequently receive requests from researchers for research participants. These requests may involve anything from a complex clinical study to an interview or a simple survey. Pay attention to our website, social media, and email for these requests and participate whenever possible. **Your participation speeds up research.**

Clinic News

Check out our YouTube channel at youtube.com/@nfmidwest. We've been working on videos with NF clinics in our region. These videos feature interviews with clinicians and clinic personnel about NF care at their institution, with questions about NF sprinkled in. We think they are worth watching, and we continue to add videos.

CONTACT US

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NF Midwest Social/Educational Opportunities

Learn more about research and build connections at our family iNFo Fair in Naperville, IL, on October 26th. Check [nfmidwest.org/infofair](https://www.nfmidwest.org/infofair) for updates. We plan to build a lot of research information into this event.

**iNFo Fair is October 26 in
Naperville, IL**

We're also working collaboratively with the Children's Tumor Foundation to create smaller social and educational opportunities in other areas. **On April 27th, we'll be at Riley's/Indiana University for an educational meeting in Indianapolis. Before 2024 ends, we hope to have events in Lexington, KY, and Madison, WI.**

May NF Awareness Month

NF Midwest and CTF will kick off NF Awareness Month together on May 1st with a **gathering at the Harp and Fiddle in Park Ridge, IL**. Clinicians and researchers from the area will join us from 6:00 to 8:00 PM CST. To learn more or RSVP, contact Sarah.

May is a month to raise public awareness. **We have ribbons for purchase, and we encourage you to turn your lights blue and green.** If you are comfortable with it, we encourage everyone to share their NF connection in any way possible. **Please contact us if you'd like to create a short video** for us to share, starting with the phrase "I Care About NF Because....".

Watch our website, emails, and social media for other opportunities, and let us know if you would like to host an event during May for awareness.

Finding Support at NF Midwest

NF Midwest supports anyone impacted by NF through Sarah Selogic, a social worker. She can help find resources, navigate challenges, and much more. She will do her best to help or connect you to someone who can. **No One Fights Alone** – contact Sarah at sselogic@nfmidwest.org or visit our website for more information.

Ongoing Online Support and Chats

Looking for support and connection with others who understand Neurofibromatosis? **NF Midwest offers virtual chat groups specifically for parents and adults with NF! We also have virtual office hours once a week.** These virtual chats are a great way to find support, share resources, and build connections with others in the NF Midwest community. For more information, visit the NF Midwest event page at <https://www.nfmidwest.org/events>

Camp NF

NF Midwest is supporting "Camp NF" for kids with NF. This is a "new" camp in name only by Brainy Ridges, Inc. The location and staff are the same. They have been running a camp for kids with NF for over 20 years. **Camp NF will run from July 21-27.** There is also a teen leadership camp that is not NF-specific from July 14-20. If you'd like more information, please get in touch with Sarah.

Young Leadership and Scholarships

The scholarship application deadline was March 31st. Awardees will be announced soon. We'll be accepting new applications in January '25. **Applications for the Young Adult Leadership program will be opened soon.** For more on these programs, check online or contact [Sarah](#).

Walk4NF

Your support and the dedication of our fundraisers are why we can fund research and support our community. Please consider participating in one of our Walk4NF events. Learn more at walk4nf.org. Big crowds and an active community help raise funds and awareness. Also, researchers, clinicians, and pharmaceutical companies need to see that a community needs their help and will support their efforts.

The fundraiser (this is usually a team but can be an individual) who has raised the **most funds by September 30th will choose the color for 2025 walk t-shirts**. We have some great appreciation gifts this year. They include a special *Spark of Hope* cooling towel for people who raise \$250; an NF Midwest imitation Stanley large tumbler for \$750; a very cool hand-sprayed carry-all box for \$1500; a light NF Midwest fleece for \$3,000; and **a Solo Bonfire stove drop shipped to people (or teams) who raise \$7500**. All gifts are accumulative and meant to raise awareness. All gifts will be awarded to the individual who raised the funds, not the team or team captain, except the Solo stove.

WALK4NF DATES

Columbia, MO - April 20th
Madison, WI - May 11th
Indianapolis, IN - May 18th
Naperville, IL - June 8th
Virtual - Anywhere, anytime,
anyway you want!

These People Are Extra Awesome

All our supporters are incredible, but we have special shoutouts! Thank you again to **Pete Oswald and his family for holding SamJam4NF** (a DIY event) last September and donating \$10,000!

Congratulations to E's Hulksters for raising the most funds of all the walks at over \$8,800. Their young fighter, Eilis, chose the colors for this year's walks, which will be revealed soon. Also, **a big thanks to the Frano family**. They put a team in a wiffle ball tournament, got second place, and directed the prize of \$5,000 to NF Midwest! We have an amazing community with many amazing people we haven't mentioned. We'll do our best to get them in the next update!

We Need You to Help Launch New Events

We are also planning some new fundraisers. **We need people to help with planning**. Please let us know if you want to make a difference and join us. We can't do it without help!

How Creative Can You Be?

Another way to help is to hold your own event. Do It Yourway (DIY) fundraising is a fantastic way to raise funds and awareness. Do something you know and love. Consider what your friends might be interested in and who might help you.

Many Ways to Give

Did you know that **we can also accept ACH, stocks, qualified retirement distributions**, in-kind donations, that crazy thing called cryptocurrency, and more?

Contact Ted Woodlock at tedwoodlock@nfmidwest.org if you have any questions about donating, sponsoring, or fundraising.

We'd Like to Contact You Better or Not Contact You at All

To *Know You More in '24*, we've developed a survey to tell us about your contact preferences and how NF affects you or your family. It would be extremely helpful if you could participate in this survey. You can limit what you share and even opt out of communications like this through the survey. **Go to http://www.nfmidwest.org/survey_m**.