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COMMUNITY • DONATE • ADVOCACY
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SCHOLARSHIPS • SCHWANNOMATOSIS
GIVE • CLINICS • MENTORS • WALKS
RESOURCES • VOLUNTEER • SUPPORT
MAKING A DIFFERENCE • PARTICIPATE
DEDICATION • GUIDANCE • AWARENESS
FOCUS • CONNECT • HOPE • CHA
NEUROFIBROMATOSIS
OUTREACH • DONA
RESEARCH
SPIRIT

NF MIDWEST 2024 PROGRAM BOOK



Basic NF/SWN Facts

NF has become a general abbreviation of several separate but similar conditions. It refers to a group of genetic conditions that cause tumors to grow on nerves throughout the body.

NF includes neurofibromatosis type 1 (NF1) and all types of schwannomatosis (SWN), including NF2-related schwannomatosis (NF2-SWN), formerly known as neurofibromatosis type 2.

How people are affected by NF1, NF2-SWN, and SWN can vary greatly. It is important to stay informed and to have a support community like NF Midwest.

Here are a few general facts about these conditions.

- They are genetically SEPARATE conditions.
- While they are mainly known for causing tumors, these conditions can cause other complications.
- NF Type 1 (NF1) is more common and occurs approximately 1 in every 2,500 births.
- NF2-SWN is rarer and is believed to affect 1 in 25,000.
- The other schwannomatosis (SWN) conditions are even rarer affecting approximately 1 in 70,000.
- ANY person may be born with NF1 or NF2-SWN due to a random change in a gene. This means anyone can get NF1 or NF2-SWN.
- A parent with NF1 or NF2-SWN has a 50% chance with each pregnancy of passing the condition on to their child. They must have it to pass it on. It does NOT skip generations, though symptoms may be mild.
- Other forms of schwannomatosis are less understood and may often occur due to an error in a gene and not be inherited.
- The severity of NF1, NF2-SWN, or SWN can present different physical signs and complications for each person, even within the same family.
- These are chronic conditions, and how someone is affected can change as the age or change very little.

In summary, ANYONE can be born with NF. Together more than one in every 2,000 people have NF. How a person is affected varies and can change.

We have included only basic information on these complex conditions and invite you to learn more.

Neurofibromatosis type 1 (NF1) affects the nervous system and causes the growth of tumors on nerve tissue. It is a relatively common condition affecting approximately 1 in 2,000 individuals.

Characteristic features of NF1 may include café-au-lait spots (pigmented birthmarks), freckling in the armpits or groin area, bone abnormalities, learning disabilities, and neurofibromas. Cutaneous neurofibromas are benign tumors that often occur on or in the skin. A plexiform neurofibroma is a more extensive and complex growth involving multiple nerves that can occur deeper in the body. Approximately 10% of plexiform neurofibromas may become malignant. Neurofibromas may cause disfigurement, pain, and other symptoms. People with NF1 may also develop different types of tumors, including optic nerve gliomas, which can lead to vision problems.

The severity of the condition can vary widely between individuals, even within families.

NF2-related schwannomatosis affects the nervous system and causes the growth of tumors on the nerves responsible for hearing and balance.

The hallmark feature of *NF2-SWN* is the development of bilateral vestibular schwannomas (acoustic neuromas), noncancerous tumors that grow on the nerves that connect the inner ear to the brain. These tumors can cause hearing loss, ear ringing (tinnitus), balance problems, and other neurological symptoms. In addition to vestibular schwannomas, people with *NF2-SWN* may also develop different types of tumors, such as meningiomas and schwannomas on other nerves.

Other features of *NF2-SWN* may include schwannomas (tumors) on the skin, cataracts, and abnormalities in the spinal cord or the brain.

Schwannomatosis (those other than *NF2-SWN*) causes the development of noncancerous tumors, called schwannomas, on nerves throughout the body. Schwannomas can occur on any nerve but are most commonly found on the peripheral nerves, which are the nerves outside of the brain and spinal cord.

The symptoms of schwannomatosis can vary widely depending on the location of the tumors. Common symptoms include pain, numbness, tingling, or weakness in the affected area. In some cases, tumors may cause no symptoms at all.

The severity of all these conditions can vary widely between individuals, even within families. There is currently no cure for any of these conditions, and limited treatments to manage symptoms and prevent complications.

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. NF Midwest C.A.R.E.S.!

VISION

Our vision is that No One Fights Alone. We here to help and support our community while working towards treatments and a cure.



AREAS OF SERVICE

NF Midwest serves the states of Illinois, Indiana, Iowa, Kentucky, Missouri, and Wisconsin. This is a lot of area to cover. Let us know if you'd like to help develop support in your region.

NF Midwest works to improve the lives and future of children and adults with neurofibromatosis and schwannomatosis through C.A.R.E.S.

Clinics are the cornerstone of care. NF Midwest's priority is ensuring those with NF/SWN get the best care. We support the efforts of clinics in our area, and act as a "middleman" between the clinics and the community.

Awareness leads to understanding and compassion. NF Midwest works to raise awareness in many ways, including an informative website, social media, materials, and awareness merchandise.

Research is where we find hope. NF Midwest furthers research by providing funds to NF Clinics in our region to support clinical trials, providing research grants, and advocating for federal research funds.

Education is the first defense if you or a loved one has NF or SWN. NF Midwest empowers patients through educational events, materials, and by opportunities to learn from the experiences of each other.

Support is a vital life ring for the children, adults, and families affected by NF/SWN. This is why NF Midwest has a dedicated Care and Outreach Coordinator with a social work background.

Dedicated Care & Outreach Support



Ask Sarah For Help

Email: Outreach@nfmidwest.org

Facebook: Sarah NFMidwest

Phone: 630-945-3562 Ext. 4

Web Form: nfmidwest.org/contact



A Few 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.

NEWLY DIAGNOSED? Request a **FREE** packet of iNfo, send a question, or get provide your contact information for updates at nfmidwest.org/contact.

Stay in Touch and Meet Others

NF Midwest Facebook Group

This private group is exclusively for individuals affected by NF or those with an affected child. Extended family members may join with the family's permission. It's regularly updated and a great place to connect within the community.

facebook.com/groups/nfmidwest

NF Midwest Website

We frequently update the NF Midwest website with blog posts on various subjects. Additionally, we regularly refresh the LEARN section with educational material. We aim to provide information that is helpful to the community and presented in "plain" language whenever possible.

nfmidwest.org/learn

NF Midwest Facebook Page

"Follow" our Facebook page for regular public updates at facebook.com/nfmidwest

YouTube Channel

Youtube.com/@nfmidwest

Instagram

Instagram.com/nfmidwest

For online parent and adult group meetings and virtual "office hours" please check events on our website.

Programs for CHILDREN AND ADULTS to ensure they are well prepared and DON'T FIGHT ALONE.



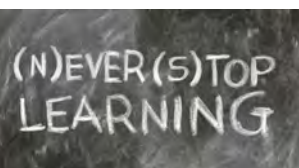
NF Midwest sponsors kids with NF from our community to attend camp in Virginia. The group running this camp has been doing so for over 20 years! The camp helps our children with NF learn to live well and develop adaptive behaviors to cope with their disorders and meet friends for life.

2024 Camp is From July 21-27



**Young Adult
Leadership
Program**

Every year three to five young adults from the NF Midwest region are selected to participate in our Young Adult Leadership Program which is a collaboration between NF Midwest, The Littlest Tumor Foundation, and Texas NF. As part of the program, they will join approximately 10 to 15 other young adults in Washington, DC to learn skills in advocacy and leadership.



Scholarship Program for Continued Education

Adults with NF in our service area may apply for a scholarship to aid post-high school education costs. This community college, trade schools, certifications, and other career advancing education programs. Funds are limited and may vary from year to year. Applications are evaluated based on perseverance despite NF challenges, academic performance, community service, participation in NF Midwest, and recommendations. The 2025 application cycle opens in January 2025.



Neurofibromatosis iNFO Fair

OCTOBER 26, 2024

Northern Illinois University Center in Naperville, IL.

If you, or someone you love has NF, you don't want to miss this important day. We'll spend a whole day learning and sharing with each other and experts. Your support helps us keep this program affordable.



nfmidwest.org/info-fair

Topics and speakers are still being determined. This year we plan to have a focus on research.

Cost is \$25 per person, \$10 for kids 5-17. Contact us for financial assistance, if needed.

Children ages 5 to 17 will be entertained in a separate area. Sorry, we can't provide childcare for children under 5.

Continental Breakfast starts at 8:00 am CST. Sessions start at 9:00 am CST. Day will end at approximately 4:00 pm CST.

A small block of rooms has been reserved at the Naperville Holiday Inn Express for \$119 per night. Rooms must be reserved before the number of blocked rooms runs out and by September 25th to get that rate (whichever comes first!) This hotel is within easy walking distance of the iNFO Fair Venue.

Please us www.nfmidwest.org/2024hotel to make your reservation at the Holiday Inn Express, 1837 Centre Point Circle, Naperville, IL 60563.

Plans are in the works for a Friday Night Social before the iNFO Fair. Check for updates.

Do It Your Way

DIY Personal Fundraising

A Powerful Way to Make a Difference

Consider starting your own fundraiser to support the NF/SWN community. It's a fantastic way to raise awareness for the cause while doing something you're passionate about!

- ◆ **Double the Impact:** Your fundraiser raises critical funds *and* spreads awareness about NF/SWN.
- ◆ **Do What You Love:** Choose an activity that aligns with your interests and skills, making the fundraising process enjoyable.
- ◆ **Target Your Audience:** Design your fundraiser to resonate with your specific network of friends and family.
- ◆ **The Power of Personal Connection:** DIY fundraisers, like the Ice Bucket Challenge, can spark movements and inspire others.

DIY Fundraising Ideas:

- ◆ **Birthday or Anniversary Fundraiser:** Set up a fundraising page in honor of a special occasion and encourage donations instead of gifts.
- ◆ **Challenge Fundraiser:** Make a fun pledge, like dyeing your hair an outrageous color, if you reach a specific fundraising goal.
- ◆ **Host an Event:** Organize a trivia night, concert, or another activity that appeals to your interests and attracts your audience.
- ◆ **Use an Existing Event:** Cycling events, marathons, or something similar is a great opportunities for family, friends, and coworkers to support you!

These are a few ideas to get you started. With a little creativity, you can design a personal fundraiser that's both meaningful and enjoyable, making a real difference for the NF community.



We have lots of ideas and ways to help! Email events@nfmidwest.org if you're interested in doing something on your own for the cause!

FIND WAYS TO GIVE OR FUNDRAISE AT

[NFMIDWEST.ORG/GIVE](https://www.nfmidwest.org/give)

Create your own fundraising pages and/or hold your own events to raise funds and awareness to support NF Midwest. Below are options to create your own hosted event, recognize a loved one, or sign up for a Walk4NF.



Celebrate a special day such as birthday, end of chemo, or an anniversary by giving friends the opportunity to donate to the NF cause in lieu of a gift. Simply set up your page by going to...

give.nfmidwest.org/celebrations



Find or create a Do It Your Way (D.I.Y.) fundraiser or event. This might be a trivia night, garage sale, raffle, home party, bake sale, bike-a-thon, etc. You can create your own page on NF Midwest's fundraising platform by checking out...

give.nfmidwest.org/diy



Create a tribute to your loved one with a page in honor or memory of them. Create or find one easily and receive donation alerts to express gratitude to supporters. You can begin the process by visiting...

give.nfmidwest.org/tributes

If you participate in a walk or any other fundraising type of competition with NF Midwest, we can credit your donations to your efforts if you let us know.

RESEARCH, CARE and EDUCATION

NF Midwest supports research in many different ways. Our grants mainly support smaller projects and/or research that can quickly affect care or help people in our community. We also work with other organizations to advocate for research funds and other support from the federal government. Another way we support research is by connecting researchers to people in our community and giving input to researchers. If you'd like to learn more about what we do for research, participating in research, or any of the websites or organizations involved, don't hesitate to contact Diana Haberkamp.

Websites You Should Visit About Research

Clinical Trials—clinicaltrials.gov

NF Consortium—www.uab.edu/nfconsortium

REiNS Collaboration—ccrod.cancer.gov/confluence/display/REiNS/

Websites You Should Visit About Care

nfmidwest.org/findadoctor—only lists trusted physicians and clinics in our region

ctf.org/find-a-doctor—only lists NF Clinic Network Clinics (NFCN)

nfcollective.org—lists NF Clinic Network and other physicians and clinics. Also, NF Collective organizations have access to other physicians through this site. You must contact and NF Collective org such as NF Midwest.

Websites You Should Visit To Learn

nfmidwest.org/learn—lists NF Clinic Network and other physicians

www.ninds.nih.gov/health-information/disorders/neurofibromatosis

<https://www.ctf.org/resources/>

We encourage you to use the internet and social media, but carefully! There is old information out there and misinformation. We recommend using reputable websites to help you know what questions to ask your physician.

Social media and community boards can be helpful, but they can also be harmful and scary. Internet websites and social media attract the proactive (which is great); however, there are also more people on these sites with more NF challenges than in reality. In other words, people who have complications and concerns will naturally share more on the internet than those who don't.

We're happy to share our NF experiences with you and guide you or connect you with others.

Join NF Midwest's private Facebook group at facebook.com/groups/nfmidwest and follow our page at facebook.com/nfmidwest.

Walk4NF

Stroll, Celebrate, Connect!

Honoring loved ones, celebrating progress, uniting for a cause
and raising awareness and funds together.

Join a walk today!



www.walk4nf.org

Join us at one of four walks or hold your own virtual walk in 2024!

2024 Walk Dates

Columbia, MO—April 20th

Madison, WI—May 11th

Indianapolis, IN—May 18th

Naperville, IL—June 8th

Virtual— Anywhere, Anytime

Congratulations to our top 2023 Walk4NF Fundraisers!

E's Hulksters from the Columbia, MO Walk4NF was our top fundraiser out of all the walks. Eilis had the honor of choosing the t-shirt colors for 2024!

Top Teams from Each Walk

E's Hulksters—Columbia

The Dozer's—Madison

Nanette Julian—Indianapolis

The Jay-Walkers—Naperville



Jay of The Jay-Walkers shows off the 2024 Naperville top fundraising trophy they won in Naperville in 2023 while wearing his t-shirt colors for being the top Walk4NF fundraiser overall in 2022.



E's Hulksters hosted a trivia night to raise donations which helped them to become the top fundraising team at the Columbia Walk4NF in 2023.

We cannot continue our programs without help from the community. If you'd like to participate in planning and providing input please let us know. We have a place for you!

Thank You!

We appreciate everyone who helped with our programming throughout last year and so far in 2024 and look forward to working with more of you in the future.

It takes a lot of volunteers to produce programs and events in six states. We know we lack programming in some areas. We need support to serve this wonderful community better. Please, let us know if you'd like to help in any way.

Listed here are the **LEAD** volunteers for various events and committees. **MANY other awesome people have helped in many big and small ways, and it all matters! Please, do not take offense if we haven't listed you!**

Columbia Walk4NF

*Christina Thomas
Kristi Saylor*

Madison Walk4NF

Mary Chapman

Indianapolis Walk4NF

Alicia Turner

Naperville Walk4NF

*Keelin Murphy
Dawn Pederson
Lesli Wegner
Medlik Family
Many Others*

Program Committee

*Denise Dulceak
Gail Mavrogenes*

NF2 Action Committee

*Susan Buono
Laura Didier
Steve Reason*

Adult Advisory Group

*Adelaide Ralston
Garret Dohlke
Kelly Hammond
Lily Whitehurst*

Our 2024 Regional Advocates

*Laura Haslam
Christina Thomas
Adam Rosenberg
Whitney Scheibel
Kassie Thomas
Don Haberkamp*



What Will Your Legacy Be?

Leave a legacy through planned giving. This may include bequests in your will, donated appreciated assets like stocks, establish trusts that provide you with income while ultimately benefiting the organization. These thoughtful giving methods allow you to make a significant contribution to finding a cure for NF while potentially receiving tax advantages. Please contact us to learn more.

Neurofibromatosis Midwest
473 Dunham Road, Suite 3
St. Charles, IL 60174



www.nfmidwest.org
info@nfmidwest.org
630.942.3562

2024 Dates of Note

as of May 1, 2024

Columbia, MO Walk4NF—April 20

Awareness Month Kick-Off with CTF
@Harp and Fiddle in Park Ridge, IL — May 1
Madison, WI Walk4NF — May 11

World Awareness Day (Wear Blue and Green) — May 17th

Indianapolis Walk4NF — May 18

NF2-SWN Awareness Day (Wear Green and Blue) — May 22

Naperville, IL Walk4NF—June 8

Birdies for Charity Pledges Due to Win a Car—June 16

Camp NF — July 21-27

North Shore Century Ride with CTF — Sept 15

End of 2024 Fundraising — Sept 30 at 6 pm

iNFo Fair in Naperville, IL — Oct 26

Online *Celebrathon*—Sunday, Feb. 2nd, 2025

2025 Scholarship Applications Open — Mid January

2025 Scholarship Application Due — March 31, 2025

Set your giving on auto pilot!



**MONTHLY
GIVING
CIRCLE**

Support Research and NF Programs!

Become a Recurring Donor
and Keep Hope in Motion!

NFMIDWEST.ORG/DONATE.

What is the NF1-TED clinical research study?

The NF1-TED study will determine whether a blood test can detect malignant peripheral nerve sheath tumors (MPNSTs) in participants with NF1 earlier than the current standard of care.

Am I eligible to participate?

We are looking for:

- Adults (18 years or older)
- Diagnosis of Neurofibromatosis Type 1 (NF1)
- History of plexiform neurofibroma (PN)

Why should I participate?

There will be the opportunity to earn up to \$425.00 over the five-year follow-up period. You will also be participating in a study that could help improve the lives of people with NF1 in the future.

What will I be expected to do?

- At the beginning of the study, and every six months during the five-year follow-up period, you will be asked to provide a blood sample and complete a brief online questionnaire.
- If you develop an MPNST, the study team will request additional clinical data and a sample from the MPNST collected during regular clinical care from your doctor.

What is the time commitment?

Over the course of a year, you would spend approximately 5 hours or less of your time on the NF1-TED study.

Interested in joining the study? Follow these steps:

Step 1: Use the QR code to access our website to learn more and see if you are eligible.

Step 2: If eligible, make an appointment to meet with the study team to complete the enrollment process.



Dana-Farber/Boston Children's Cancer and Blood Disorders Center



PEOPLE LIVING WITH
NEUROFIBROMATOSIS NEED
MORE OPTIONS

LET'S DIG DEEPER FOR THEM.

At SpringWorks Therapeutics, we know that people living with rare tumors need more treatments and are relentless in our search for answers. We are proud to sponsor NF Midwest's Walk4NF events to benefit individuals and families affected by neurofibromatosis.



 Recursion.



POPLAR

Efficacy and Safety of REC-2282
in Patients With Progressive
Neurofibromatosis Type 2 (NF2)
Mutated Meningiomas (POPLAR-NF2)

Visit PoplarNF2.com
for more information.

WE NEED YOU!

Community members have always driven NF Midwest and requires active community involvement. Together, we can improve the lives of those we love with NF.

Please let us know if you want to help in any way.

**Your input and donations
are invaluable!**

Email info@nfmidwest.org or
diana@nfmidwest.org or go to
www.nfmidwest.org/contact.



Complimentary and Individualized for Patient and Caregiver Support

Helping the NFI PN (Neurofibromatosis Type 1 Plexiform Neurofibromas) Community

Living with NFI PN?

OneSource is always here to help



To Learn More, Call **1.888.765.4747**



Health Insurance Navigation



Disease Information



Continuity of Care



Community Connections

Enroll Today at:

www.AlexionOneSource.com



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