

What You Can Do

There is a lot you can do to keep hope alive and improve the future of someone with neurofibromatosis (NF). Most importantly is to be proactive and involved in the NF cause and community. NF Midwest provides opportunities to make a difference in the NF cause and also invites you to create more.

Join in a *Great Steps Walk*

Check the website www.greatsteps.org for dates and locations of a *Great Steps for NF Walk* near you.

Support NF Community Events

Support NF events or create one of your own. Contact us for ideas or look for more information on our website.

Become an Advocate

Every year we advocate for federal funds for research. Commit to writing and/or visiting your representatives.

Raise Awareness

Distribute awareness information. Contact us for materials. Also, look for NF merchandise on the website or at various events.

Attend an NF Educational Event

Come to our annual symposium held every October and/or to an *Ask The Doctors* meeting in the spring. These events are always a great way to connect with other NF families and network with NF experts.

Volunteer

Step forward with your time and talent to fight NF. Visit our website for ideas on how you can help.

What We Do

NF Midwest is dedicated to providing comfort to those with neurofibromatosis through support and education and to offering hope through clinical support and the promise of research.

You may have just been diagnosed or know someone who has neurofibromatosis. It may seem like a big, scary and unknown word, but there are A LOT of people with NF. You are not alone. We are here to help each other. Whether you need more information about the disorder; would like someone to talk to who has personal experience with it; want to help raise awareness; wish to find out about research; or would like to find a good NF physician, NF Midwest will help you.

Founded in 1982 by families with neurofibromatosis, NF Midwest exists solely to improve the lives and future of people with NF. Administered by people with a passion for and a direct interest in the NF cause, we provide education and support to individuals and families affected by NF; work to improve NF clinical care; fund and advocate for research; and raise public awareness.

For more information about neurofibromatosis, NF Midwest and NF events happening in your area sign-up NOW at our website www.nfmidwest.org or send us an email at info@nfmidwest.org.

Neurofibromatosis Midwest

For More Information Contact Us

NF Midwest

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Follow us:

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Be sure to sign-up for email updates by contacting us or signing up through our website.

Providing support, education and hope to NF families in Illinois, Wisconsin, Indiana, Kentucky, Iowa and Eastern Missouri



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www.nfmidwest.org
630.945.3562

Basic NF Facts

- Neurofibromatosis (NF) is a genetic disorder that causes tumors to grow on nerve tissue, producing skin and bone abnormalities and other complications.
- There are three main types of NF.
- NF Type 1 (NF1) is more common occurring in approximately 1 of every 3,000 births
- NF Type 2 (NF2) is rarer and is believed to affect 1 in 25,000.
- Schwannomatosis is the rarest of the three, affecting approximately 1 in 40,000.
- NF1, NF2 and Schwannomatosis are three different disorders with each occurring on a different chromosome.
- There are several other rare and less understood types of NF.
- NF1 and NF2 are NOT degrees of severity.
- It is HIGHLY unlikely to have both NF1 and NF2.
- Neurofibromatosis affects all races and both sexes equally. It can occur in **ANY** family.
- Approximately half of NF1 and NF2 cases are inherited from an affected parent. The other half are spontaneous occurrences.
- A parent affected by NF1 or NF2 has a 50% chance of passing it on to each child. Unaffected children who have not inherited a parent's NF **CANNOT** pass it on to the next generation.
- The severity of NF varies greatly. In families where more than one person has NF, it can present with different physical signs and complications for each person.

To ensure you have the proper information about neurofibromatosis go to www.nfmidwest.org, email us at info@nfmidwest.org or contact our office at 630.945.3562.

Improving the lives and future of people with neurofibromatosis through...



Education

Knowledge is power and NF Midwest strives to empower families with NF by providing many opportunities to learn about neurofibromatosis, including:

- An annual family symposium with research updates
- *Ask the Doctors* question and answer sessions with NF experts
- Access to materials about neurofibromatosis
- A bi-annual newsletter, email updates and an up-to-date website

Support

Understanding friends give us the strength that helps us endure. There is a strong, determined community of people with NF that are eager to work together and help each other. NF Midwest is an active, supporting part of this community. If you need to talk we offer many opportunities, including:

- Inspire board at www.nfmidwest.org
- Informal support groups or the ability to connect you with someone who may have been where you are
- Staff at our office that are affected or have affected family and are available for information and support
- Information on NF family and children camps
- NF social events

Improving NF Care

Connecting and staying connected to the best possible medical care is key in any chronic condition. Neurofibromatosis is an extremely variable disorder. While many people go through their lives without any serious problems, it is important to be followed by a physician with a lot of NF knowledge and a clinical team of specialists that share that knowledge and interest. NF Midwest works to improve the clinical care of NF patients by:

- Identifying knowledgeable NF physicians and clinics
- Working with NF centers to improve care
- Providing information packets for NF patients to share with their primary care doctors

Research

Research is where we find hope. NF Midwest furthers research by:

- Providing grants for care to NF Clinics that support clinical trials
- Providing grants for supplementary research and basic science
- Advocating for federal funds for research through the National Institutes of Health (NIH) and the Congressionally Directed Medical Research Program (CDMRP)

Public Awareness

We envision a day when someone mentions they have neurofibromatosis and rarely hears the response "huh" or "what's that", but are instead greeted with an understanding nod and no need to explain what it is. This includes knowing that NF is highly variable with a host of complications and that it is not a "cosmetic disorder". Without a high profile spokesperson and a big budget, we have to chip away at awareness through word of mouth and public events.

