

# What can you do?

There is a lot you can do to provide hope and improve the future of someone with NF. Most importantly, you can be proactive and involved in the NF cause and community.



## Join an event

Check our website to find an event near you. Have a good idea for an event? Contact the NF Network office and we will help you put your ideas in motion.



## Spread the word

Share NF awareness information. LIKE us on Facebook (Neurofibromatosis Network), Instagram (@NFNetwork) and on X (@NFNetwork).



## Participate in NF Research

Enroll in NF registries, respond to surveys, and seek out clinical trials. Consult your physician for help in finding appropriate clinical trials. Alternatively go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov).



## Become an NF Advocate

Educate Congress on the importance of NF research funding through the highly successful NF Network Advocacy Program. For details, go to [www.nfnetwork.org](http://www.nfnetwork.org) where it's featured on the Home page.



## Donate

Make a financial contribution to help us accomplish our mission and move toward the ultimate goal of effective treatments and a cure. You can donate on our website at [www.nfnetwork.org](http://www.nfnetwork.org).



## Support Cutting-Edge Research

Invest in PROJECT DREAM. The NF Network Scientific Advisory Board selects the most promising proposals for funding. Call the Network for specifics on supporting PROJECT DREAM - 630-510-1115.

More information on these options is available at [nfnetwork.org](http://nfnetwork.org).



## NF Network Member Organizations

### NF Arizona

[www.nfnetwork.org](http://www.nfnetwork.org)  
[admin@nfnetwork.org](mailto:admin@nfnetwork.org)  
602-910-7632

### NF California

[www.nfcalifornia.org](http://www.nfcalifornia.org)  
[info@nfcalifornia.org](mailto:info@nfcalifornia.org)  
707-469-0467

### NF Central Plains

[www.nfcentralplains.org](http://www.nfcentralplains.org)  
[nfcentralplains@gmail.com](mailto:nfcentralplains@gmail.com)

### NF Michigan

[www.nfmich.org](http://www.nfmich.org)  
[nfwestmich@aol.com](mailto:nfwestmich@aol.com)  
616-451-3699

### NF Northeast

[www.nfnortheast.org](http://www.nfnortheast.org)  
[info@nfnortheast.org](mailto:info@nfnortheast.org)  
781-272-9936

### NF North Central

[www.nfnorthcentral.org](http://www.nfnorthcentral.org)  
[ericksog@hotmail.com](mailto:ericksog@hotmail.com)  
507-990-6363

### NF Tennessee

[www.nftennessee.org](http://www.nftennessee.org)  
[contact@nftennessee.org](mailto:contact@nftennessee.org)

### NF2-SWN Support

630-510-1115

## Neurofibromatosis Network

P.O. Box 1530 Wheaton, IL 60187  
[admin@nfnetwork.org](mailto:admin@nfnetwork.org)  
630-510-1115

Leading Advocacy,  
Building NF Community!



[nfnetwork.org](http://nfnetwork.org)

# Someone you know has **NEUROFIBROMATOSIS or SCHWANNOMATOSIS**

## What is NF?

NF refers to a group of genetic conditions that causes tumors to grow on nerves throughout the body. There are three types of NF — neurofibromatosis type 1 (NF1), neurofibromatosis type 2-related schwannomatosis (NF2-SWN), and non-NF2-related schwannomatosis (SWN).

A child born to a parent with any form of NF has a 50% chance of inheriting the gene. Importantly, about half of affected patients have no prior family history. Children born with either the NF1 or NF2-SWN gene will show signs of the condition. However, not everyone who inherits an SWN gene will show signs of it.

Often these disorders are confused or thought to be varying degrees of each other. One type of NF does not change into another type. They are separate disorders caused by different genes on different chromosomes. They are progressive disorders which affect all races and both sexes equally and can occur in any family.

More information, including diagnostic criteria, can be found at [www.nfnetwork.org](http://www.nfnetwork.org).



### **NF Type 1 (NF1)**

NF1 is the most common type of neurofibromatosis, affecting approximately 1 in 2500 births. Symptoms are usually apparent in childhood. **Findings may include:**



Coffee-colored (café-au-lait) skin spots and freckling in the underarm and groin

Tiny nodules on the iris (Lisch nodules), not affecting vision

Nerve tumors - neurofibromas and plexiform neurofibromas

Optic pathway gliomas (tumors)

Increased risk for cancer, especially breast, brain and nerve sheath cancer, and for a few rare tumors (adrenal, GI, etc.)

Learning disabilities and developmental delays including ADHD, autism, and social skills issues

Bone development issues (scoliosis, long bone curvature)

Hypertension and blood vessel abnormalities

### **NF2-Related Schwannomatosis (NF2-SWN)**

NF2-SWN affects about 1 person in 60,000. Symptoms usually appear in teen years or early adulthood. **Findings may include:**



Tumors (vestibular schwannomas) along hearing/balance nerves, typically leading to hearing loss, deafness and balance problems

Schwannomas on nerves throughout the body and other tumors of the brain and spine

Vision issues (cataracts or other eye anomalies)

### **Non-NF2 Schwannomatosis (SWN)**

Schwannomatosis is the least common form of NF and affects approximately 1 in 100,000 adults. Symptoms rarely appear before adulthood. **Findings may include:**



Benign tumors (schwannomas) occurring most often on spinal or peripheral nerves

Chronic nerve pain, not always related to a specific tumor

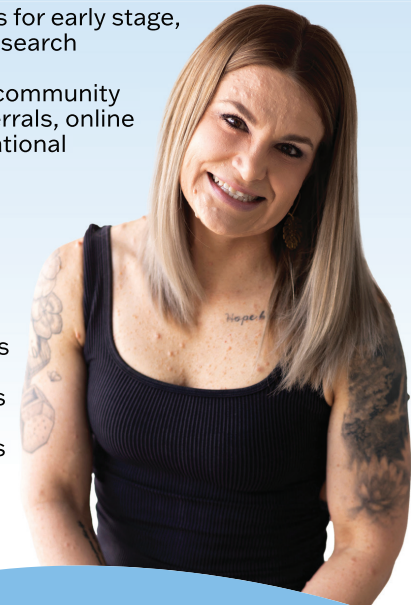
**Because symptoms of NF are extremely variable, the NF Network strongly recommends that patients seek care from providers with NF expertise, preferably at an NF Clinic.**

## The NF Network

The NF Network was founded in 1988. We are the leading national organization advocating for federal funding for NF research and the development of local NF organizations. We seek treatments and a cure by promoting research and improved clinical care. We offer hope and support to those affected by NF through education, awareness and community building. The NF Network's goal is to eradicate the health issues, pain, isolation and uncertainty that often come with the diagnosis.

### **NF Network services include:**

- Pursuing NF treatments and a cure
- Advocating for Congressional funding of NF research
- Raising awareness of NF among healthcare professionals, legislators and the general public
- Promoting opportunities for participation in NF research studies and clinical trials
- Representing the NF patient community as advocates who help direct research priorities
- Funding seed grants for early stage, high potential NF research
- Supporting the NF community through clinical referrals, online webinars and educational meetings
- Providing the NF Heartline, a hotline for patient support
- Distributing NF educational materials for those affected and their loved ones
- Hosting social events and fundraisers to build relationships within the NF community



[nfnetwork.org](http://nfnetwork.org)

[admin@nfnetwork.org](mailto:admin@nfnetwork.org)  
NF Heartline: 800.942.6825