

## WHAT YOU CAN DO

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

### Make a Donation

Your donation helps us accomplish our mission and move toward the ultimate goal of effective treatments and a cure for neurofibromatosis. You can donate on our website at [www.nfnetwork.org](http://www.nfnetwork.org).

### Join an event

Check our website [www.nfnetwork.org](http://www.nfnetwork.org) and participate in an event near you. Have a good idea for an event? Contact the NF Network office at 630-510-1115, and we will help you put your ideas in motion.

### Spread the word

Distribute awareness information. LIKE us on Facebook (search Neurofibromatosis Network) and follow us on Twitter at #NFNetwork.

### Become an NF Activist

Help promote government funding of NF research by educating your Congressional representatives in the importance of NF research. Go to [www.nfnetworkadvocacy.org](http://www.nfnetworkadvocacy.org).

To learn more about neurofibromatosis and the NF Network visit our website at [www.nfnetwork.org](http://www.nfnetwork.org).

## Why Invest in Neurofibromatosis Research?

- Rare but not so rare – NF affects 100,000 people just in the US
- NF designated under Orphan Drug Act – FDA committed to orphan product development
- Research may positively affect millions of people without NF with similar conditions (tumor disorders, cancer, seizures, learning/attention disabilities, hearing loss, vision loss, scoliosis/bony abnormalities, cardiovascular, disease, etc.)
- Gene detected for NF1 and NF2 – has facilitated pre-clinical research
- Viable disorder for translational medicine approach
- Clinical centers for NF set up across US to facilitate clinical research and subject enrollment
- Strong national and local patient advocacy organization
- Strong collaboration with NIH, DoD NF Medical Research Program, and NORD
- Most importantly, lack of effective treatments for those suffering or dying from Neurofibromatosis every day

## NF NETWORK MEMBER ORGANIZATIONS

### NF Arizona

[www.nfarizona.org](http://www.nfarizona.org)  
480-945-9650

### NF California

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

### NF Central Plains

[www.nfcentralplains.org](http://www.nfcentralplains.org)  
316-295-3332

### NF Michigan

[www.nfsupport.org](http://www.nfsupport.org)  
616-451-3699

### NF Midwest

[www.nfmidwest.org](http://www.nfmidwest.org)  
630-945-3562

### NF, Inc. Minnesota

[www.nfinc-mn.org](http://www.nfinc-mn.org)  
(651) 204-0067

### NF, Inc. Northeast

[www.nfincne.org](http://www.nfincne.org)  
781-272-9936

## AFFILIATES

### Washington State NF Families

[www.wsnfsupport.org](http://www.wsnfsupport.org)  
425-672-9610

### NF2 Support

[admin@nfnetwork.org](mailto:admin@nfnetwork.org)

Leading NF Advocacy  
Building NF Community



## NEUROFIBROMATOSIS NETWORK

213 S. Wheaton Ave.  
Wheaton, IL 60187  
630-510-1115 800-942-6825  
[admin@nfnetwork.org](mailto:admin@nfnetwork.org)

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



## Someone you know has **NEUROFIBROMATOSIS**

While you may not have heard of Neurofibromatosis (NF), it affects more people than Muscular Dystrophy, Tay-Sachs and Huntington's Disease combined.

### **ABOUT NEUROFIBROMATOSIS**

The Neurofibromatoses (NF) are genetic disorders of the nervous system which cause tumors to form on the covering of the nerves anywhere in the body at any time. They are progressive disorders which affect all races and both sexes equally, and may be associated with deafness, vision impairment, seizures, and cancer. Three genetically distinct forms of neurofibromatosis have been identified: NF1, NF2, and schwannomatosis.

Neurofibromatosis can occur in any family. Approximately half of NF1 and NF2 cases inherit it 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. Children who do not inherit a parent's NF cannot pass it on to the next generation. Additional information, including diagnostic criteria for NF1, NF2, and schwannomatosis can be found at [www.nfnetwork.org](http://www.nfnetwork.org).

### **Neurofibromatosis Type 1**

NF1 is estimated to occur in 1 in 3,000 births.

**Symptoms may be present at birth and may include:**

- Multiple café-au-lait spots on the skin
- Tumors of varying sizes on or under the skin
- Lisch nodules on the iris of the eyes
- Freckling in the underarm or groin area
- Learning disabilities
- Bone deformities
- Optic glioma

### **Neurofibromatosis Type 2**

NF2 is estimated to occur in 1 in 25,000 births. NF2 symptoms usually appear during or after puberty, but may appear in very young children.

**NF2 is characterized by:**

- Tumors (vestibular schwannomas) on both hearing nerves
- Multiple brain and spinal tumors
- Skin tumors
- Cataracts at an early age
- Other eye findings including retinal abnormalities and orbital meningiomas

### **Schwannomatosis**

Schwannomatosis is estimated to occur in 1 in 40,000 births. The inheritance pattern of schwannomatosis is not well understood. The risk of transmitting the disorder to offspring is about 15%. Symptoms usually first appear in adulthood.

**Schwannomatosis is characterized by:**

- Multiple schwannomas (nerve sheath tumors) without evidence of vestibular schwannoma
- Pain associated with the schwannomas
- Symptoms possibly limited to one area of the body

### **THE NF NETWORK**

The NF Network (formerly NF, Inc.) 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 for neurofibromatosis by promoting scientific research and improved clinical care, and by providing outreach through education and awareness, offering hope and support to those affected by NF. The NF Network's goal is to eradicate the health issues, pain, isolation and uncertainty that the diagnosis of NF inflicts.

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

- The active pursuit of NF treatments and a cure
- A highly successful advocacy program for Congressional funding of NF research
- Increased awareness of NF and its effects among healthcare professionals, government officials and the general public
- Opportunities for participation with NF researchers and clinicians at scientific meetings and medical conferences
- Seed grants for NF research
- Patient outreach through clinical referrals, peer support, online webinars and educational meetings
- Coordination of state and regional efforts to maximize impact at the national level
- The publication of NF educational materials for those affected and their supporters