



**Run4NF** is a national fundraising program that coordinates NF marathons, walks, and similar events in cities across the US throughout the year. Find out more and get involved at [www.run4nf.org](http://www.run4nf.org)!

## How to Help

**National Doodle Day** is NF, Inc.'s celebrity Doodle auction, held annually in May as part of NF Awareness Month. To learn more and view Doodles from previous auctions, visit [www.doodledayusa.org](http://www.doodledayusa.org).



Please help us win the fight against neurofibromatosis. All monies received by NF, Inc. are used to support education, research, and services for those affected by NF. NF, Inc. is a 501(c)3 organization; all donations are tax deductible to the extent of the law.

Donations may be made by credit card at [www.nfinc.org](http://www.nfinc.org) or by mailing a check to:

Neurofibromatosis, Inc.  
P.O. Box 66884  
Chicago, IL 60666

## The Organization with a Heart

### Disclaimer

Information contained in this publication is intended for informational purposes only and does not constitute medical advice. Please consult a physician for specific medical management and treatment recommendations. NF, Inc. does not recommend, endorse, or guarantee the adequacy or reliability of other sources of information and services.



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## Local Neurofibromatosis, Inc. Member Organizations

NF, Inc. Arizona 480-945-9650  
[www.nfaz.org](http://www.nfaz.org)  
[nfaz@nfinc.org](mailto:nfaz@nfinc.org)

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

NF, Inc. Indiana 765-620-8460  
[www.nfmidwest.org](http://www.nfmidwest.org)  
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NF, Inc. Kansas/Central Plains 620-669-8453  
[www.nfinc.org/kansas](http://www.nfinc.org/kansas)  
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NF, Inc. Mid-Atlantic 301-577-8984  
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NF, Inc. Michigan 616-451-3699  
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NF, Inc. Midwest 630-932-8111  
[www.nfmidwest.org](http://www.nfmidwest.org)  
[info@nfmidwest.org](mailto:info@nfmidwest.org)

NF, Inc. Minnesota 651-225-1720  
[www.nfincmn.org](http://www.nfincmn.org)  
[nfmn@nfinc.org](mailto:nfmn@nfinc.org)

NF, Inc. Northeast 781-272-9936  
[www.nfincne.org](http://www.nfincne.org)  
[info@nfincne.org](mailto:info@nfincne.org)

Texas NF Foundation 972-868-7943  
[www.texasnf.org](http://www.texasnf.org)  
[patientoutreach@texasnf.org](mailto:patientoutreach@texasnf.org)

Washington State NF Families 425-672-9610  
[www.wsnfsupport.org](http://www.wsnfsupport.org)  
[info@wsnfsupport.org](mailto:info@wsnfsupport.org)

NF2 Support  
[www.nfinc.org/nf2.shtml](http://www.nfinc.org/nf2.shtml)  
[nf2info@nfinc.org](mailto:nf2info@nfinc.org)



The National Network Serving  
Neurofibromatosis Families



*Creating a  
community of  
support for those  
affected by NF  
through  
education,  
advocacy,  
coalitions, raising  
public awareness,  
and supporting  
research  
for treatments and  
a cure*

## Neurofibromatosis, Inc.

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*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 and 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.nfinc.org](http://www.nfinc.org).

*Neurofibromatosis 1 (NF1)* is estimated to occur in 1 of 2,500 births. Symptoms may be present at birth.

#### NF1 symptoms may include:

- multiple café-au-lait colored 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 2 (NF2)* is estimated to occur in 1 of 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* 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%. Schwannomatosis 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

### *What We Do:*

- ♥ Operate at the grassroots level via a network of local/regional organizations (listed on reverse)
- ♥ Maintain a website, [www.nfinc.org](http://www.nfinc.org), on current NF activities



- ♥ Promote participation and provide funding for scientifically evaluated research
- ♥ Identify local NF medical resources and make referrals



- ♥ Conduct camps for children, teens, and young adults with NF1 or NF2
- ♥ Provide information about NF to individuals and families affected by NF and to healthcare professionals
- ♥ Instill respect for the dignity of those affected by NF

- ♥ Network with other health organizations
- ♥ Identify and develop community neurofibromatosis organizations



- ♥ Educate federal, state, and local governments regarding the needs of NF families and care providers
- ♥ Sponsor national and local conferences for NF families