



Neurofibromatosis

The neurofibromatoses are a group of three genetically distinct but related disorders of the nervous system that cause tumors to grow around the nerves. Tumors begin in the cells that make up the myelin sheath, a thin membrane that envelops and protects nerve fibers, and often spread into adjacent areas. The type of tumor that develops depends on its location in the body and the kind of cells involved. The most common tumors are neurofibromas, which develop in the tissue surrounding peripheral nerves. Most tumors are non-cancerous, although occasionally they become cancerous over time.

An estimated 100,000 Americans have a neurofibromatosis (the singular form of neurofibromatoses) disorder, which occurs in both sexes and in all races and ethnic groups. Scientists have classified the disorders as **neurofibromatosis type 1 (NF1)**, **neurofibromatosis type 2 (NF2)**, and a type that was once considered to be a variation of NF2 but is now called **schwannomatosis**.

Neurofibromas frequently grow on spinal nerve roots. If they compress the spinal cord, they can cause paralysis or disturbances in sensation in different parts of the body, depending on what part of the spinal cord is compressed.

Source: NINDS: Neurofibromatosis Info Page, Merck Manual

Websites

<http://www.ninds.nih.gov/disorders/neurofibromatosis/neurofibromatosis.htm>
NINDS: Neurofibromatosis Information Page

http://www.ninds.nih.gov/disorders/neurofibromatosis/detail_neurofibromatosis.htm
NINDS: Neurofibromatosis Fact Sheet

<http://www.nlm.nih.gov/medlineplus/neurofibromatosis.html>
MedlinePlus: Neurofibromatosis

http://www.merckmanuals.com/home/brain_spinal_cord_and_nerve_disorders/tumors_of_the_nervous_system/introduction.html

Merck Manual: Tumors of the Nervous System

<http://www.ctf.org/>

Children's Tumor Foundation: Ending Neurofibromatosis Through Research

95 Pine Street, 16th Floor

New York, NY 10005-1703

Phone: 212-344-6633, 800-323-7938 (Toll-free)

E-mail: info@ctf.org

<http://www.nfinc.org/>

Neurofibromatosis Inc.

P.O. Box 66884

Chicago, IL 60666

Phone: 800-942-6825

<http://kidshealth.org/parent/system/ill/nf.html>

KidsHealth: Neurofibromatosis

<http://www.neurologychannel.com/neurofibromatosis/index.shtml>

HealthCommunities: Neurofibromatosis

<http://emedicine.medscape.com/article/1177266-overview>

eMedicine: Neurofibromatosis, Type 1

<http://emedicine.medscape.com/article/1178283-overview>

eMedicine: Neurofibromatosis, Type 2

<http://en.wikipedia.org/wiki/Neurofibromatosis>

Wikipedia: Neurofibromatosis

<http://www.inspire.com/groups/neurofibromatosis-inc/>

Neurofibromatosis, Inc. Support Community

The following books are available for free loan from the PRC library. For more information, please see www.paralysis.org and click *Borrow from Our Lending Library* under PRC Quick Links.

Books

- Ashton, Kirsty. **Kirsty's Story: Living With Neurofibromatosis and Scoliosis.** Authorhouse, 2011.

- Farmer, Gladys Clark. **Karen's Test: The Courageous Life of Karen Backman.** Salt Lake City, Utah: Deseret Book Co., 1989.
- **Neurofibromatosis: A Handbook for Patients, Families, and Health Care Professionals.** New York: Thieme Medical Publishers, 2005. 2nd ed.
- **NF Buddies.** NF Inc. California <http://www.nfcalifornia.org/>
Children's book on NF.

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