CHRISTOPHER & DANA REEVE FOUNDATION
PARALYSIS RESOURCE CENTER

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 neurofibromatos***is*** (the singular form of neurofibromatos***es***) 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

https://catalog.ninds.nih.gov/pubstatic//11-2126/11-2126.pdf
NINDS: Neurofibromatosis booklet

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
120 Wall Street, 16th Floor
New York, NY 10005-3904
Phone: 212-344-6633
E-mail: info@ctf.org

www.nfnetwork.org
Neurofibromatosis Network
213 S. Wheaton Ave.
Wheaton, IL 60187
Phone: 630.510.1115
Toll-free: 800-942-6825
Email: admin@nfnetwork.org
Neurofibromatosis Network is a national organization advocating for federal funding for NF research and the development of local NF organizations.

http://emedicine.medscape.com/article/1177266-overview
eMedicine: Neurofibromatosis, Type 1

http://emedicine.medscape.com/article/1178283-overview
eMedicine: Neurofibromatosis, Type 2

http://www.neurologychannel.com/neurofibromatosis/index.shtml
HealthCommunities: Neurofibromatosis

http://kidshealth.org/parent/system/ill/nf.html
KidsHealth: **Neurofibromatosis**

http://www.inspire.com/groups/neurofibromatosis-inc/
Neurofibromatosis, Inc. Support Community

www.thrivingwithnf.com
Thriving with Neurofibromataosis

http://en.wikipedia.org/wiki/Neurofibromatosis
Wikipedia: Neurofibromatosis

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LENDING LIBRARY

The following books and videos are available for free loan from the PRC library. For more information, please visit the online catalog at: http://www1.youseemore.com/ReevePRC/default.asp

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.

- Hopkins, Kristi. **Thriving with Neurofibromatosis**. Broomfield, Colo.: Perflexativity Press, 2010.
  Hopkins has NF and three of her six children have it. She spent much of her life trying to hide it and then accepted it and decided to thrive with it.

- Michaels, Anthony. **Neurofibromatosis: Causes, Tests and Treatment Options**. 2012.

- **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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