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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

Children's Tumor Foundation: Ending Neurofibromatosis Through Research
http://www.ctf.org/
697 Third Avenue, Ste. 418
New York, NY 10017
Phone: 1-800-323-7938
E-mail: info@ctf.org

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

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

KidsHealth: **Neurofibromatosis**
https://kidshealth.org/en/parents/nf.html?ref=search

Mayo Clinic: Neurofibromatosis
https://www.mayoclinic.org/diseases-conditions/neurofibromatosis-type-1/symptoms-causes/syc-20350490

MedlinePlus: Neurofibromatosis Type 1
http://www.nlm.nih.gov/medlineplus/neurofibromatosis.html

Merck Manual Consumer Manual: Neurofibromatosis Quick Facts
https://www.merckmanuals.com/home/quick-facts-children-s-health-issues/neurocutaneous-syndromes-in-children/neurofibromatosis?query=neurofibromatosis

Neurofibromatosis Network
www.nfnetwork.org
610 W. Roosevelt Rd. D2
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.

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

NINDS: Neurofibromatosis Information Page
https://www.ninds.nih.gov/Disorders/All-Disorders/Neurofibromatosis-Information-Page

NINDS: Neurofibromatosis Fact Sheet
https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Neurofibromatosis-Fact-Sheet

NINDS: Neurofibromatosis booklet
https://www.ninds.nih.gov/publications/neurofibromatosis

Thriving with Neurofibromatosis
www.thrivingwithnf.com

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

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