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

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

MedlinePlus: Neurofibromatosis

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

Neurofibromatosis Network
www.nfnetwork.org
213 S. Wheaton Ave.
P.O. Box 1530
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.

eMedicine: Neurofibromatosis, Type 1

eMedicine: Neurofibromatosis, Type 2

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

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

Thriving with Neurofibromatosis
www.thrivingwithnf.com

Wikipedia: Neurofibromatosis
http://en.wikipedia.org/wiki/Neurofibromatosis
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This publication is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $8,700,000 with 100 percent funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.