



What is Neurofibromatosis?

Neurofibromatosis, type 1 (NF1) is a genetic condition that occurs in males and females of all racial and ethnic backgrounds. It mainly changes the development and growth of nerve cells affecting the skin, eyes, nerves and bones of the body. NF1 is found in about 1 in 3,000 people.

Michigan Resources & Support

Children's Tumor Foundation, Michigan Chapter

www.ctf.org/michigan/

NF Support Group of West Michigan

Phone: 616-451-3699

www.nfsupport.org/

Children's Special Health Care Services

Family Phone Line

Toll-free: 1-800-359-3722

E-mail: ppp@michigan.gov

www.michigan.gov/cshcs

Early On[®] Michigan

Toll-free: 1-800-EARLY ON

www.1800earlyon.org

Michigan Birth Defects Program

Nurse Follow-up Coordinator

Toll-free: 1-866-852-1247

E-mail: BDRfollowup@michigan.gov

Michigan Genetics Connection

www.migeneticsconnection.org

National Resources & Support

Neurofibromatosis, Inc.

Toll-free: 1-800-942-6825

www.nfinc.org

Family Village

www.familyvillage.wisc.edu

Genetics Home Reference

www.ghr.nlm.nih.gov/ghr/disease/neurofibromatosis/type1

March of Dimes

www.marchofdimes.com, click on Birth Defects & Genetics

National Institute of Neurological Disorders and Stroke

www.ninds.nih.gov/disorders/neurofibromatosis/neurofibromatosis.htm

How may neurofibromatosis affect my child?

Learning: Most people with NF1 have normal intelligence. Learning disabilities are seen in about half the children who have NF1.

Behavior: Attention deficit hyperactivity disorder (ADHD) is common in children with NF1.

Physical: Spots on the skin called "café au lait spots" (meaning the color of coffee with milk) develop during the first few years of life. The spots are present but may not be as obvious in people with NF1 who have darker skin color. Freckles usually develop under the arms or in the groin area. Head size may be larger

than average while a child's height may be shorter than other children the same age. Small nerve tumors called neurofibromas may grow on or under the skin. They are typically benign (non-cancerous). Lisch nodules are tiny bumps that may be seen in the iris of the eyes, but do not affect vision.

Medical: Tumors of the eye nerve (optic gliomas) or other tumors in the brain or spinal cord may develop in childhood. Sometimes cancerous tumors grow along the nerves. There is also an increased risk of other cancers and leukemia. Additional symptoms include bone abnormalities such as curvature of the spine (scoliosis), high blood pressure and seizures.

How does neurofibromatosis occur?

NF1 is caused by a change in a gene (mutation). A child with NF1 may be the first and only family member affected, or the NF1 gene may be passed down from an affected parent. Parents of a newly diagnosed child should be checked carefully to look for signs of NF1. There is a 1 in 2 chance that each child will have NF1 when a parent carries the gene. Genetic counseling is recommended for parents to learn about possible health risks for other family members.

How is neurofibromatosis treated?

NF1 cannot be cured, but some symptoms can be treated. Bone deformities or painful tumors may be treated by surgery. Any tumors that become cancerous may require chemotherapy, radiation or surgery. Yearly eye examinations are recommended to look for signs of optic glioma. Blood pressure should be monitored at regular check-ups. Other treatments may be needed for health problems as they arise. Infants and toddlers (birth to 3 years) should be connected with *Early On*[®] Michigan if there are concerns about learning, speech, or behavior; while children over 3 years of age should be referred for special education services if concerns arise. Children with NF1 and their families benefit from having a primary care physician who helps to coordinate their care with medical specialists and other community-based services.

For more information, call Michigan's Genetics & Birth Defects Program toll-free at 1-866-852-1247 or e-mail Genetics@michigan.gov

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