Neurofibromatosis Type 1 (NF1)

Neurofibromatosis type 1 (NF1) is a family cancer syndrome associated with a malignant peripheral nerve sheath tumor (MPNST) and an increased risk of other cancers.

What is neurofibromatosis type 1 (NF1)?

Neurofibromatosis type 1 (NF1) is a genetic condition where tumors (mostly benign) grow on skin, nerves, and bones. It is also known as **von Recklinghausen disease**.

Signs and symptoms of neurofibromatosis type 1

NF1 symptoms can vary from person to person. Some people have mild symptoms, which might keep them from getting diagnosed right away. Symptoms of NF1 include:

- **Café-au-lait spots** are light brown areas on the skin. Having six or more of these spots, especially if they are larger than 5 mm (about ¼ inch) in children or 15 mm (almost 5/8 inch) after puberty, may mean NF1.
- **Neurofibromas** are tumors, usually non-cancerous, that grow from nerve cells and are soft bumps in or under the skin. Larger growths that involve many nerves and

- Two or more Lisch nodules
- Bone changes

If a child **has a parent** with NF1, a diagnosis can be made if that child has **one or more** of the above criteria. Genetic testing can also be done to confirm the diagnosis.

Does neurofibromatosis type 1 (NF1) increase a person's cancer risk?

Most NF1 tumors are benign (non-cancerous). However, about 10% of people with NF1 may develop a cancerous tumor called a **malignant peripheral nerve sheath tumor (MPNST)**. This type of tumor grows quickly and can spread to other areas. Early detection and treatment are important.

NF1 is also associated with increased risk of other cancers, such as _____ _____ _____

However, large plexiform neurofibromas can be harder to remove without affecting nearby nerves.

- **Medicines**: **Selumetinib (Koselugo)** and **mirdametinib (Gomekli)** are approved to treat NF1 in children ages 2 years and older with symptomatic plexiform neurofibromas that cannot be surgically removed. They are used to slow the tumor's growth or shrink it,

Questions to ask your doctor

If you or a family member has NF1, consider asking your doctor:

- What symptoms should I watch for?
- What is my risk of developing malignant tumors or other cancers?
- Are there new treatments or clinical trials I should know about?

Know Your Cancer Risk [5]
Take the ACS CancerRisk360™ assessment to learn more about what you can change to improve your health. By taking 5 minutes to answer a few questions, we will give you a personalized roadmap of actions with helpful resources you can use to lower your risk of cancer.

Hyperlinks

1. www.cancer.org/cancer/understanding-cancer/genes-and-cancer/oncogenes-tumor-suppressor-genes.html
2. www.cancer.org/cancer/types/breast-cancer.html
3. www.cancer.org/cancer/types/gastrointestinal-stromal-tumor.html
4. www.cancer.org/cancer/types/soft-tissue-sarcoma.html
5. acscancerrisk360.cancer.org/

References

Children's Tumor Foundation. What is NF1?. 2023. Accessed at https://www.ctf.org/nf1/ on February 13, 2025.

National Institute of Neurological Disorders and Stroke/National Institutes of Health.

Neurofibromatosis fact sheet. 2023. Accessed at https://www.ninds.nih.gov/health-information/disorders/neurofibromatosis on February 13, 2025.

National Cancer Institute. Research and clinical trials for NF1. 2023. Available at https://www.cancer.gov

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