

WE PROVIDE

- Parent and peer support groups facilitated by trained volunteers and professionals.
- Educational resources and public awareness initiatives about Neurofibromatosis.
- Community events and family networking opportunities across Ontario.
- Support for research to improve diagnosis, treatment, and quality of life for individuals affected by Neurofibromatosis.
- Information sharing to help newly diagnosed families find guidance and connection.
- Advocacy for better care, access to services, and awareness of Neurofibromatosis in schools, workplaces, and healthcare settings.



NEUROFIBROMATOSIS SOCIETY OF ONTARIO

REGISTRATION NUMBER: 119053775RR0001

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NEUROFIBROMATOSIS SOCIETY OF ONTARIO

AWARENESS • EDUCATION • ADVOCACY • RESEARCH • SUPPORT

WWW.NFON.CA



ANNUAL EVENTS

Each year, the Neurofibromatosis Society of Ontario hosts two major events that bring together families, medical experts, and advocates from across the province:

The Neurofibromatosis Family Camp Weekend - a fun, inclusive retreat where families affected by Neurofibromatosis can relax, connect, and build lifelong friendships in a supportive environment.

The Neurofibromatosis Forum - an educational event featuring medical professionals, researchers, and community speakers who share the latest in Neurofibromatosis research, treatments, and lived experiences.

MEMBERSHIP

Becoming a member of the Neurofibromatosis Society of Ontario means joining a compassionate community that understands the challenges of living with Neurofibromatosis. Members receive updates on educational events, research news, and opportunities to connect with others across the province.

VOLUNTEER-DRIVEN COMMITMENT

Our organization is powered by volunteers — people who give their time, expertise, and energy to make a difference. Every donation and membership directly supports our mission to promote awareness, provide support, and fund research for Neurofibromatosis.

Together, we bring hope, knowledge, and strength to the Neurofibromatosis community.



WHAT IS NEUROFIBROMATOSIS?

Neurofibromatosis can occur in any family — including yours. It is a group of three distinct genetic conditions that cause tumors to grow along nerves in the body. These conditions can affect the skin, brain, bones, and other organs. Neurofibromatosis is a complex multisystem disorder that can vary greatly in how it appears from person to person.

Neurofibromatosis can be inherited from a parent, as it does not skip generations - it can be passed from grandparent to parent to child. A parent with Neurofibromatosis has a 50% (one in two) chance of passing the condition on to each child. In approximately 30 to 50 percent of cases, Neurofibromatosis occurs spontaneously, meaning the genetic change happens for the first time in that person. This spontaneous mutation usually occurs in the egg, sperm, or very early embryo. Even without a previous family history, the individual with a new (spontaneous) mutation can then pass Neurofibromatosis on to their own children.



NEUROFIBROMATOSIS TYPE 1 (NF1)

Neurofibromatosis Type 1 is the most common form, occurring in about 1 in 2,500 people. It is caused by a change in the NF1 gene on chromosome 17, which produces a protein called neurofibromin. Common signs include café-au-lait spots (light brown skin patches), freckling in the armpit or groin, tumors on or under the skin, and Lisch nodules (tiny growths on the iris of the eye). Some individuals may develop optic gliomas, which are tumors on the optic nerve that can lead to vision loss. In some cases, it can cause bone deformities, learning differences, or other medical complications. Although most people with Neurofibromatosis Type 1 can lead healthy and productive lives, complications can occur and require medical management. Neurofibromatosis Type 1 is a complex, multisystem condition that can vary widely between individuals - even within the same family.

NEUROFIBROMATOSIS TYPE 2 (NF2-RELATED SCHWANNOMATOSIS)

Previously known as Neurofibromatosis Type 2, this condition is caused by a change in the NF2 gene on chromosome 22, which produces a protein called merlin. Individuals typically develop tumors on the nerves responsible for hearing and balance (vestibular schwannomas), which may cause hearing loss, ringing in the ears, or problems with balance. Tumors may also occur on other nerves in the brain or spinal cord. Neurofibromatosis Type 2 is a complex disorder that can lead to significant medical complications and requires ongoing care.

SCHWANNOMATOSIS

Schwannomatosis is genetically distinct from Neurofibromatosis Type 1 and Type 2. It involves changes in genes such as SMARCB1 or LZTR1. This condition is characterized by multiple schwannomas (tumors of the nerve sheath) throughout the body, but usually without involvement of the vestibular nerve. Chronic pain is a common symptom, and diagnosis often requires genetic testing to distinguish it from other forms of Neurofibromatosis.

Monitoring is vital for individuals with Neurofibromatosis. There is an increased risk for certain complications and malignancies, although many people with Neurofibromatosis do not experience these issues. Regular medical follow-up allows early detection and management of any changes that may occur.

While there is currently no cure for Neurofibromatosis, ongoing research continues to improve understanding, management, and treatment options. Early diagnosis and consistent care can help individuals maintain the best possible quality of life.

