Neurofibromatosis Society of Ontario

PO Box 91119 Bayview Village,
Willowdale, Ontario
M2K 2Y6
Phone: (905) 683-0811
1-866-843-6376
Charitable Registration
11905 3775 RR0001
Email: info@nfon.ca
Website: www.nfon.ca

@nfontario

Neurofibromatosis.Ontario

facebook.com/NFOntario

To donate visit: www.canadahelps.org

The Common Disorder

You've Never Heard Of...

NFON

Neurofibromatosis Society of Ontario

GENERAL INFORMATION

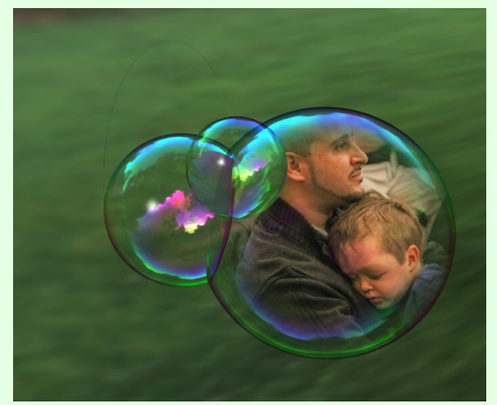
The Neurofibromatosis Society of Ontario (NFON) is a non-profit, registered charity dedicated to supporting people with Neurofibromatosis (NF) and their families.

EDUCATION and AWARENESS is important to us. We strive to educate and promote NF awareness among the public as well as medical professionals. Through fundraising, we have a strong commitment to furthering Neurofibromatosis research. This, in essence, is our mission: SUPPORT, EDUCATE, RAISE AWARENESS, and FUND RESEARCH.

We hold bi-annual membership meetings in the spring and fall, and members, as well as the general public, come from across the province to hear our guest speakers. This is an opportunity for our members to meet and share concerns, support one another, and learn about the most current treatments and trends in Neurofibromatosis research.

Our NFON social events hosted throughout the year provide opportunities where people can meet in a friendly, casual atmosphere, knowing they are accepted and supported.

Through DEDICATION and DETERMINATION, we have established a good working relationship with doctors, clinics and professionals in their field. We also keep in regular contact with other Neurofibromatosis organizations worldwide. These connections ensure we are up to date with current research and are supporting our members and the NF community adequately.



MEMBERSHIP & SUPPORT

All of our work is done by volunteers. There is an optional membership fee of $10 and no one wishing to join will be refused. ALL ARE WELCOME!!!

There are several avenues of support provided by NFON, which include:

- We network with physicians knowledgeable about NF and Neurofibromatosis clinics throughout the province and internationally.

- We work with volunteers throughout Ontario to develop support groups.

- We maintain a member registry where we connect people wanting support in their area.

- We provide information to the medical community, teachers, the media, the public and newly diagnosed patients and their families.

- We utilize Social Media such as Facebook, Twitter and Instagram to increase awareness for Neurofibromatosis by providing information, answering questions and promoting NFON socials and events.

NEUROFIBROMATOSIS

Neurofibromatosis (NF) is a multi-system genetic disorder that causes tumours to develop on the nerves, brain, spine, skin and other body systems. NF can be inherited from a parent however, 50% of cases occur via spontaneous mutation without family history.

There are three genetically distinct forms of Neurofibromatosis: **NF1, NF2,** and **Schwannomatosis.** The effects of Neurofibromatosis are unpredictable and have varying manifestations and degrees of severity. Despite the identification of both the NF1 and NF2 gene, there is **NO KNOWN CURE** for Neurofibromatosis.

Treatment options may include surgical removal, chemotherapy and, in some instances, radiation. However, the tumours will often recur.

CLASSIFICATIONS

NF1 is the more common type of Neurofibromatosis, occurring in about 1 in 3,000 individuals. Although symptoms can be mild and patients are able to live normal and productive lives, in some cases NF1 can be severely debilitating. Complications that can arise in individuals with NF1 include disfiguring tumours on the skin, invasive internal tumours on nerves and organs, increased risk of cancer, bone deformities that may lead to amputation, optic gliomas, severe scoliosis, blindness and chronic disabling pain.

NF2 is estimated to affect 1 in 25,000 to 1 in 40,000 individuals and is characterized by bilateral tumours on the eighth cranial nerve which affect the head and neck but can involve the brain stem. Complications usually result in partial to total hearing loss and may cause headaches, dizziness, weakness, facial paralysis, cataracts, malignancy and severe pain.

Schwannomatosis is a rare form of NF. The rate of occurrence is unknown. Affected individuals develop multiple benign tumours composed of Schwann cells on the insulating myelin coating (sheath) which cover nerves. These tumours can develop on cranial, spinal and peripheral nerves (a network of nerves that connect the brain and spine). In terms of complications, Schwannomatosis includes severe pain, weakness, numbness and tingling in the extremities.