

We believe...

Who are we?



Mission Statement

The British Columbia Neurofibromatosis Foundation is committed to empowering and improving the lives of individuals and families affected by Neurofibromatosis.

The BCNF provides information and support services, promotes awareness, and funds research to improve treatment and to one day find a cure.

Vision Statement

Together...Improving the lives of those with NF

Together...Reaching for a cure



The British Columbia Neurofibromatosis Foundation (BCNF) is a registered, non-profit charitable organization. It was established in 1984 by Paul Ralfs to respond to the needs of individuals with Neurofibromatosis (NF), their families, related health care professionals and other interested community members. The BCNF continues its work today through the efforts of its Board of Directors, staff, volunteers and membership.

To find out more, please call or visit our website

Contact us:

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Look for us on Facebook & Twitter

Together we can make a difference!



www.bcnf.bc.ca

The British Columbia Neurofibromatosis Foundation (BCNF)

Neurofibromatosis, or NF, is a term for three distinct genetic disorders which cause tumour growth on nerves anywhere in or on the body and may produce other abnormalities such as learning disabilities, disfigurement, internal complications, bone defects, deafness, blindness, pain and occasionally tumour malignancy. NF manifestations vary greatly in type and severity, and can cause serious health issues.

NF is not a rare condition. It is the most common single disorder of the human genome. There are over 13,000 Canadians currently diagnosed and living with neurofibromatosis type 1.

There are more Canadians living with neurofibromatosis than the combined number of Canadians living with cystic fibrosis, hereditary muscular dystrophy, Huntington's Disease and Tay-Sachs Disease.

The BCNF is here to help.



"Although the effects of neurofibromatosis vary greatly from person to person, most people with NF live fulfilling and productive lives. We know more now than in the past about how to diagnose, prevent and treat many serious complications of NF."

JM Friedman, MD, PhD
Professor of Medical Genetics,
University of British Columbia

What is Neurofibromatosis?

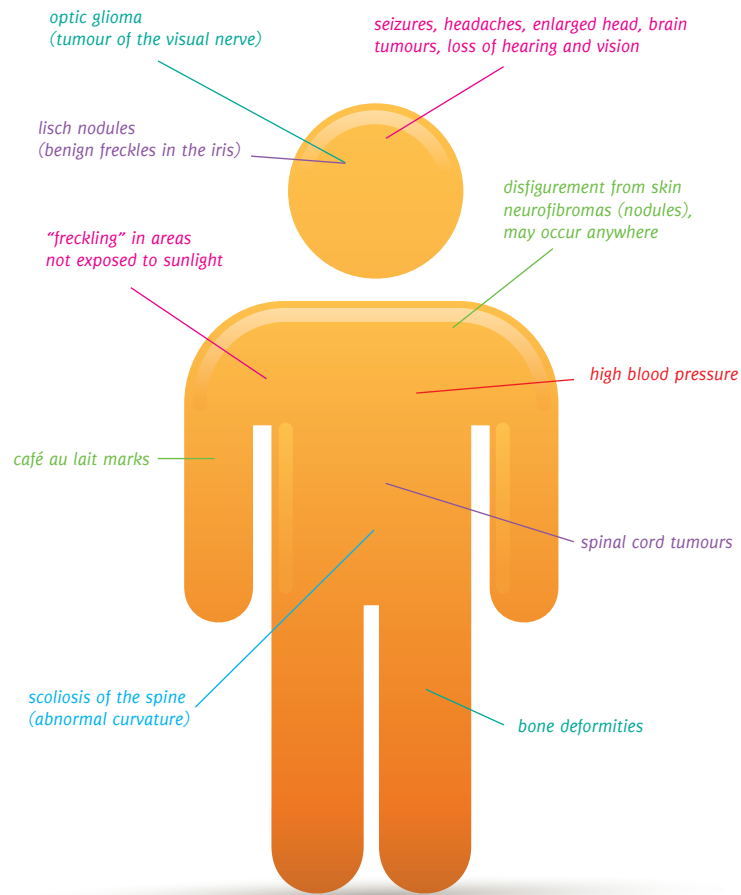
Neurofibromatosis, often referred to as NF, is the term for three distinct genetic disorders: NF1, NF2, and Schwannomatosis. All forms of NF can occur spontaneously from a genetic mutation, or be inherited from a parent with the disorder.

Neurofibromatosis Type 1 (NF1) is the most common form affecting 1 in 3,000 births. It can affect the nervous system, skin, bones and other tissues. To learn some of the characteristics of NF1, please see diagram. NF1 is a progressive disorder which affects all races, all ethnic groups and both sexes equally.

Neurofibromatosis Type 2 (NF2) is far less common than NF1, affecting about 1 in 35,000-40,000 births. NF2 is distinguished by multiple tumours in the brain and spine which may cause deafness, severe balance problems, facial nerve paralysis, and spinal cord compression. Signs and symptoms usually appear during adolescence or in one's early 20s. The most common early symptoms are: hearing loss, ringing in the ears (tinnitus), and loss of balance caused by tumours growing on the nerve from the ear to the brain.

Schwannomatosis is the third form of NF and has recently been recognized as a distinct disorder. It is estimated to occur in 1 of 40,000 births. Schwannomatosis symptoms usually appear first in adulthood. Individuals with Schwannomatosis develop multiple schwannomas (tumours that come from the cells that form a protective sheath around the body's nerve fibres) on cranial, spinal and peripheral nerves – but they do not develop vestibular tumours and do not normally cause deafness. Affected individuals usually have much greater difficulty with pain than with neurological disability, although as with all forms of NF, Schwannomatosis may vary greatly between patients.

Possible signs of NF1



Educational Challenges

- Learning difficulties
- Speech difficulties
- Development delay

Psychological Challenges

- Emotional adjustment
- Impact on family
- Uncertainty

While it is unlikely that any one person diagnosed with NF will experience all of these symptoms, it is difficult to predict the severity or progression of the disorder in any individual case. For detailed diagnostic criteria, please visit our website.

How we can help



Facing a life with neurofibromatosis may have you feeling anxious, scared and filled with questions. The most important thing to keep in mind is that you are not alone. There are approximately 13,000 Canadians who, just like you, are bravely dealing with the challenges of NF. The BCNF can help you by providing the following:

- Confidential support and information about NF.
- Information packages and numerous resources about the neurofibromatoses.
- Newsletter filled with information about research, living with NF and activities of the BCNF.
- An annual symposium bringing in NF experts from around the world.
- Regional NF information days throughout the province.
- Youth programs which include an NF camp and educational scholarship program.
- Informative website.

Get Involved!

You can make a difference to those battling NF.

- [Become A Member](#)
- [Donate Online](#)
- [Volunteer](#)

Visit us on the web:

bcnf.bc.ca