

# Mission Statement

The Manitoba Neurofibromatosis Support Group is committed to improving the lives of individuals and families affected by NF. MBNF provides support, promotes awareness by educating the public and helps fund research to improve treatment and find a cure.

# Vision Statement

MBNF envisions lives freed of physical and emotional pain caused by Neurofibromatosis.

# What We Offer

MBNF provides confidential support and distributes information about NF to members, families, health care professionals and various organizations. MBNF hosts an up-to-date website with a members forum, publishes an annual newsletter and holds two support group meetings each year. In addition, we host a variety of fundraising events and group get-togethers to support those living with NF. We continually look for ways to advance the awareness of NF.

# What is MBNF?

The Manitoba Neurofibromatosis Support Group was formed in 2005. It is a registered non-profit voluntary organization. The group provides an opportunity for families and individuals affected by NF to connect and develop friendships while sharing resources on this largely unheard of, yet common disorder.

**Contact: Manitoba Neurofibromatosis Support Group**

C/O Tracy Gregorash  
Box 2025  
Minnedosa, MB  
R0J 1E0

**Telephone:** (204) 867-3219

**Website:** [www.mbnf.ca](http://www.mbnf.ca)

**Email:** [tracy@mbnf.ca](mailto:tracy@mbnf.ca)

**OR:**

Christa DeGagne  
Winnipeg, MB  
(204) 256-9655



# MBNF

New Friends Make the Difference!

MANITOBA NEUROFIBROMATOSIS  
SUPPORT GROUP

# MBNF

New Friends Make the Difference!

Taking the steps  
to improve the lives of  
our friends living with NF!

# What We Do

- ☺ MBNF provides confidential support and information about NF.
- ☺ Distribute information for adults with NF, parents of children with NF and teaching professionals.
- ☺ Publish an annual newsletter.
- ☺ Develop and distribute resources about living with NF to families, health care professionals and other community organizations.
- ☺ Make members aware of NF Symposiums and Educational opportunities to learn about NF.
- ☺ Continually find ways to advertise to help increase the understanding of the disorder.
- ☺ Work with volunteers in communities throughout the province to develop and maintain NF support groups.
- ☺ Provide opportunities for individuals with NF to attend specific NF camps throughout North America.
- ☺ Host an up-to-date website with a Forum, providing contact opportunity and support.
- ☺ Host a variety of annual fundraising events that support NF research initiatives, programs and support those living with NF.

# What is Neurofibromatosis?

Neurofibromatosis, often referred to as NF, is the term for three distinct genetic disorders: NF1, NF2, and Schwannomatosis. Half of all cases are inherited from a parent who has NF; half of all cases are not inherited but the result of a new or spontaneous mutation.

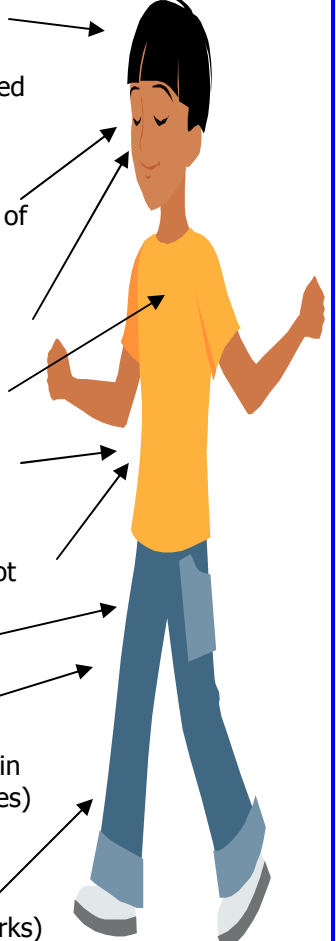
**Neurofibromatosis Type 1 (NF1)** is the most common form affecting 1 in 3,000 births. It can affect the nervous system, skin, bones and other tissues. To learn some of the characteristics of NF1, please see diagram. NF1 is a progressive disorder which affects all races, all ethnic groups and both sexes equally. About 50% of all people with NF also have learning difficulties.

**Neurofibromatosis Type 2 (NF2)** is far less common than NF1, affecting 1 in 25,000 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 fibers) 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.

# Signs of Neurofibromatosis

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 case.

- 
- \* Physical Challenges headaches, seizures, brain tumours, enlarged head, loss of hearing and/or vision
  - \* Optic Glioma (tumour of the visual nerve)
  - \* Lisch Nodules (benign freckles in the iris)
  - \* High blood pressure
  - \* Scoliosis of the spine (abnormal curvature)
  - \* "Freckling" in areas not exposed to sunlight
  - \* Bone deformities
  - \* Cosmetic disfigurement from skin neurofibromas (nodules) may occur anywhere
  - \* Café-au-lait marks (more than 5 birthmarks)

## Educational Challenges      Psychological Challenges

- \* Learning Difficulties
- \* Speech Difficulties
- \* Development delay
- \* Emotional adjustment
- \* Impact on family
- \* Uncertainty