



Neurofibromatosis Manitoba  
**Strategic Plan**

## Executive Summary

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The Manitoba Neurofibromatosis Support Group was formed in 2005. The group provides an opportunity for families and individuals affected by NF to share their stories and resources. MBNF received its charitable status in August 2007.

### **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 aids in funding research to improve treatment and ultimately find a cure.*

### **Vision Statement**

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

### **What We Do**

MBNF provides confidential support and distributes information about NF to members, families, health care professionals, and various customessaywriter.co.uk organizations. We publish an annual newsletter and hold two Support Group Meetings each year. We host an up-to-date website and a discussion forum on Facebook. We host a variety of fundraising events and get-togethers in support of those living with neurofibromatosis and we continually look for ways to advance the awareness of NF.

### **Strategic Planning**

On June 11, 2017 the Neurofibromatosis Manitoba Board and staff met to undertake a strategic planning session. Working collectively in a democratic environment the team determined the goals and objectives for the organization over the next 2 – 5 years.

The Neurofibromatosis Manitoba undertook this exercise for the following reasons:

- To clarify its future direction
- To think strategically and develop effective strategies
- To establish priorities
- To improve performance
- To build teamwork and expertise



Team building with Brenda Miller, Lyndon Demers, Becky Penner, Christa DeGagne, Kathleen Demers, Nancy Anderson, Suzanne Lendvoy

## Strengths, Weaknesses, Opportunities, and Threats Analysis

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Strengths	Weaknesses
<ul style="list-style-type: none"><li>○ Commitment of the families</li><li>○ Friendships</li><li>○ Passion</li><li>○ Ability to share knowledge about NF</li><li>○ Lived experience</li><li>○ Some funding; enough to support part time staff</li><li>○ Charitable status</li><li>○ Connections with other organizations – BC Tumour Foundation, CTF</li><li>○ 700 people on the Sumac database</li></ul>	<ul style="list-style-type: none"><li>○ Sometimes over-exceed expectations</li><li>○ Lack of new volunteers; volunteer fatigue</li><li>○ Volunteers have other commitments that pull them away, including medical needs</li><li>○ Volunteers are mostly parents, not adults with NF</li><li>○ Distance/geographic area that our members live in</li><li>○ Name of the organization is limiting</li><li>○ Lack of national organization</li><li>○ Lack of awareness of the disease, lack of awareness of MBNF</li><li>○ Lack of communication with members</li><li>○ Database not being used to its potential</li><li>○ Not all members have an email address</li><li>○ Need more money!</li><li>○ Variability of NF; not as 'sexy' and not easy to 'market' to solicit funding</li><li>○ Lack of physician awareness</li><li>○ Lack of parent awareness of rights in education system</li></ul>

## Opportunities

- Formal membership program
- Permission for email communication
- Training on using the database
- Connection with more members who might be able to provide volunteering
- Funding e.g. grants
- National affiliation with other NF groups
- Connection with CTF
- Connection with NF Clinic in Toronto
- Having another symposium
- Connection with other provinces' NF organization
- Lobby for newborn screening (5 year goal?)

## Threats

- Volunteer burn-out
- Lack of sufficient funds
- Provincial government – lack of funding
- Competition for fundraising

## Blue Sky Goal Development

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- Have newborn screening for NF
- Have a database of medical practitioners who are knowledgeable about NF
- Have a database of people who are willing to talk to new members, based on need, age of person, geographical area, etc.
- Have an office location to store library materials, information for members, promotional materials; possibly donated
- Connect with another organization to assist with office support
- Have stable funding for a full time administrator/Managing Director
- Grow our endowment fund to \$1,000,000
- To have active and involved membership
- Have a devoted NF clinic
- Have another symposium
- To find out the needs of the membership and provide appropriate support by providing education
- To provide education in schools and medical community about NF; be the go – to place for NF
- To provide a kit to new families to give to the school and medical practitioners (welcome membership package)
- Provide educational presentation to schools, employers, etc.
- To explore options for name change e.g. Prairie NF Group
- To make more formal connections with other groups e.g. other provinces, CTF, a national NF group
- To clean up our database and firm up our membership
- To have a strong presence and up to date website and other social media
- Upgrade our donor program
- To provide support to members with health needs
- To provide scholarships for post-secondary education
- To do an annual information campaign
- Continue to send kids to camp
- Send family to camp in Ontario in Halliburton, ON (Sept 8-10, 2017)
- Have our own family camp
- Provide board education e.g. send to a symposium
- Continue to use PSA
- Creating other fundraising initiatives
- Do a volunteer drive
- Defining and starting sub-committees to build more volunteer capacity
- Improve governance model e.g. Create an annual calendar/plan for each sub-committee, duties of each position
- Provide education about NF to nurses, physicians, teachers, etc., as well as students who are studying in these professions
- Promote interest and provide funding for research about NF at the university level.

We voted...

#### TOP PRIORITIES

1. Database
2. NF clinic
3. Symposium
4. Education and awareness
5. Membership – e.g. camp, scholarship, formal membership package, up to date website and facebook
6. Office space
7. Increase funding

#### TOP 3

1. Membership/Database – donors, members, partnerships
2. Increase funding
3. Education & awareness

## Goals and Objectives

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### **Goal #1 Have an updated and current Membership List and Database**

#### **Objectives:**

- Creation of a form e.g. preferred method of contact; email consent; what kind of info does the person want; decide on membership fee
  - Maintain confidential access to SUMAC - - Create policies for database use.
  - Clean up database
  - Share information as appropriate to members and to executive
  - Create lists of who wants what e.g. education, funding, clinical trials, physician interest, etc.
  - Member only/member log in section
  - Establish solid membership committee with terms of reference
  - Hold a membership planning session – plan priorities, etc.
  - Provide need to know information – to members, to physicians, to donors, etc.
  - Provide SUMAC training
  - Recruitment of volunteers
  - What does membership include?? E.g. support group, get to know you events, children's activities; have events that are member driven
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### **Goal #2 Develop a Fundraising Strategy**

#### **Objectives:**

- Find funding for projects
  - Increase fundraising (needs to include volunteer management) – events, grants, mail-outs (may need funding to do development)
  - Fundraising committee – solidify this committee, including terms of reference; stream-line fundraising;
  - Partnering with high profile individuals e.g. sports team – find NF champions
  - Fundraising with Gold-Eyes, Jets, etc.
  - Provision of post-secondary scholarship
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### **Goal #3 Increase illness awareness and raise the profile of Neurofibromatosis Manitoba.**

#### **Objectives:**

- Create a welcome kit and a membership package
  - Planning for May 2018 NF Awareness month
  - Creation/Review of a generic powerpoint and education package about NF – for schools, potential donors (for us to provide, for child to share with his/her class, for a volunteer to give to an organization)
  - Have a Gold-eyes night and use PSA
  - Support attendance at workshop, conferences and camps
  - St. Vital table – awareness day
  - Collaborate with health care education programs
  - Review and revise pamphlet
  - Review MBNF name
  - Come up with third party event guidelines
  - Thank you process for donors – donor recognition
  - Provide support groups - 'NF Coffee Talk'
  - Quick presentation and handouts at the picnic; draft a membership form to use at picnic
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