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Strategic Plan 2007-2009

Approved
December 20, 2006



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Executive Summary

This strategic plan outlines NF Canada's commitment to building a national organization with a mission to improve the lives of Canadians living with Neurofibromatosis, an umbrella name for 3 distinct complex genetic disorders that share a common manifestation - tumour growth in the tissues that surround the nerves.

The four strategic directions that were identified in the strategic planning process as necessary to achieve the mission are:

1. To develop a solid foundation for NF Canada, which will allow for effective administration, while increasing growth and productivity of, and support for, the provincial organizations.
2. Increase the general public's awareness of NF as well as the visibility of NF Canada through the development and implementation of a public awareness campaign plan, which will include advertising, web presence and the development of media relationships.
3. To develop and implement programming that addresses the needs of individuals with NF, appropriately distribute operational funding to developing provincial organizations and to contribute to the maintenance of provincial organizations.
4. To increase the medical community's awareness and understanding of NF.

Although the organization has been driven to date by the strong voluntary leadership of NF Canada's President, Daniel Fournier, an astute businessman and a father of a child with NF, the Board agrees that it is time to hire staff to continue with the momentum that the strategic planning process and campaign plan have generated and to move NF Canada to the next level of its development.

To ensure that the goals are achieved, NF Canada has initiated a Capital Campaign under the leadership of professional fundraising counsel, Éleine Lalonde.



Organizational Description

BACKGROUND

The dream of founding a national Neurofibromatosis organization took seed in the minds of a few visionaries from the British Columbia Neurofibromatosis Foundation (BCNF), in 1997.

It was evident to those goal-driven individuals that something needed to be done about the lack of public awareness of the disorder, and the isolation of those living with Neurofibromatosis (NF). The work of developing a national organization came to rest upon the willing shoulders of the BCNF, partly because it was the only Canadian organization with paid staff to do the work, and partly because of its' strong Board leadership.

In 1998 BCNF received an extraordinary donation to launch the process of developing a national organization. With that initial seed funding, a consultant was contracted to determine which organizational model best suited the national.

BCNF then learned that a Canadian NF foundation had already been incorporated by Patricia Ordynec, a mother who had a son with NF. The organization, however, was not active. Consultations with legal counsel proved that revitalizing this organization would be costly and it was therefore decided to initiate a new organization from the ground up.

The national dream began to take shape as other provincial groups, L' Association de la Neurofibromatose du Québec (ANFQ) and NF Society of Ontario (NFSO), were invited into the initial consultations. After considerable exploration it was decided that a loose federal model¹ best suited the available resources of a new national organization.

With the staff leadership from BCNF and strong voluntary leadership from ANFQ and NFSO, NF Canada was incorporated and received charitable status in December 2004.

In 2004 Daniel Fournier, an astute businessman and a father of a child with NF, took on the role NF Canada President. His vision and passion for the NF cause has moved NF Canada to the next step in its development.

¹ A federal model is one in which there is one national umbrella organization with affiliate members (the provincial organizations) and individual members from each province.



With additional funding contributions from ANFQ and NFSO, NF Canada's Board of Directors held three meetings; in Montreal, Toronto and Vancouver. These meetings allowed for the development and review of strategic directions.

Since then, the Alberta Neurofibromatosis Association (ABNF) and other support groups from the Atlantic Provinces and from Manitoba, have joined NFC.

In September 2006, the Board took its next step by hiring two professional contractors to work on updating the organization's strategic plan, and to initiate a Capital Campaign. An administrative assistant was also hired on a part-time basis to assist with the Capital Campaign.



THE NEUROFIBROMATOSES

Neurofibromatosis is pronounced *neuro·fibroma·tosis* and is commonly referred to as NF.

Neurofibromatosis is an umbrella name for 3 distinct complex genetic disorders that share a common manifestation - tumour growth in the tissues that surround nerves.

Most of these tumours are benign, although occasionally they can become malignant. NF may also cause additional complications such as disfigurement, bone deformities and learning disabilities. Neurofibromatosis equally affects males and females of all ethnic groups.

The 3 types of Neurofibromatosis are:

- **Neurofibromatosis Type 1 (NF1):** the most common form affecting approximately 1 in 3,000 to 4,000 births.
- **Neurofibromatosis Type 2 (NF2):** the less common form, affecting approximately 1 in 40,000 births.
- **Schwannomatosis** appears to occur as often as NF2.

NF1 is the most common form of neurofibromatosis, causing developmental changes in the nervous system, skin, bones, and other tissues. NF1 is commonly characterized by the presence of café-au-lait spots, auxiliary freckling, cutaneous neurofibromas (tumours) and Lische nodules (freckles on the iris of the eye). Half of the cases of NF1 result from spontaneous genetic alteration, while the remainder of the cases are inherited from one or both of the parents.

NF1 affects each person differently. Some people are quite mildly affected and may never know they have the disorder while others are more severely affected and require increased medical treatment. Each individual with NF1 - even those in the same family - can be affected to a completely different manner.

Overall, it is estimated that about half of the people with NF1 are moderately to severely affected by the disorder. While it is very unlikely that any one person diagnosed with NF will experience all of the associated complications, it is difficult to predict the severity or progression of the disorder in any individual case.



Although more common than Cystic Fibrosis, Duchenne Muscular Dystrophy, Huntington's disease and Tay-Sachs disease combined, Neurofibromatosis is largely unknown and misunderstood in the general population. This lack of awareness results in isolation for those living with NF.

Even the Canadian medical community is largely unaware of this disorder and has difficulty to this day making an accurate and timely diagnosis. Even when general practitioners are able to detect the first symptoms of NF in a child, they are hesitant to make a diagnosis of NF because they feel very little can be done - there is no cure, and treatment strategies are still in the trial stages.



Mission, Vision and Value Statements

VISION

NF Canada envisions a world without the emotional and physical pain caused by Neurofibromatosis.

MISSION

The mission of NF Canada is to improve the lives of Canadians living with Neurofibromatosis.

VALUES

NF Canada believes in and approaches all of our activities with the following values:

- **Open Communication** Open and honest dialogue and belief in making decisions and resolving differences using consensus-building processes.
- **Accountability** Board members, staff, volunteers and affiliates are accountable for their actions to each other, NF Canada, its members and supporters.
- **Teamwork** Conduct business as a unified voice for NF, in partnership with the provincial organizations.
- **Integrity** Strive to meet the highest standards of professionalism, integrity and trustworthiness in all aspects of our organization, including stewardship of donor funds.
- **Diversity** Value differences among individuals and families and volunteers in respect to language, geography, and ethnicity.
- **Excellence** Commitment to excellence in every aspect as we work to complete our mission.



Toward that end, NF Canada is dedicated to:

- Promoting awareness of Neurofibromatosis and its affects to healthcare and education professionals, government authorities and the public in general.
- Educating the medical establishment about the care, management, and treatment of patients with NF.
- Providing current and accurate information and resources to individuals with NF, their families and others.
- Supporting research to improve the understanding, treatment and management of NF symptoms, and work toward a cure.
- Promoting and supporting the development of provincial NF organizations and support groups across Canada and to contribute to the maintenance of existing organizations.



Critical Issues

A strategic analysis was undertaken to examine the factors likely to have the greatest impact on the future of the organization. From this analysis, several critical issues were identified. These issues are:

1. NF has a low public profile in the general community.

Causes: NF has a low incidence rate compared to some of the more “popular” disorders, i.e. cancer, multiple sclerosis, HIV/AIDS, and heart or kidney disease.

Conclusion: Public awareness campaign is required to increase the visibility of the disorder and the profile of the organization. Canada needs a champion for the cause.

2. No sustainable revenue stream.

Causes: NF Canada is still in its development stage and has not yet undertaken a fundraising campaign. Competition for funding from other more well-known charities is fierce.

Conclusion: Fundraising campaign needs to be established.

3. Lack of staff leadership has hindered the growth of NF Canada.

Causes: Inconsistent board communication, and the geographical spread of individual board members located across the country, inhibits the organization’s decision making processes. There is currently insufficient sustainable funding to hire professional staff.



Conclusion: Maintain and recruit a diverse Board to ensure strong organizational leadership. Recruit and hire a qualified bilingual Executive Director to support the Board in its role.

4. Lack of programs and services for those with NF.

Causes: Lack of funds and leadership has resulted in a deficiency of programs.

Conclusion: NF Canada needs to develop programs that meet the unique needs of individuals with NF. The youth summer camp offered by various international NF groups would be one program for NF Canada to build upon.

5. Medical professionals have limited knowledge about the management of the disorder.

Causes: Physicians receive very little medical and media exposure to the disorder. Unless the physician takes a particular interest in NF, the disorder is “forgotten.”

Conclusion: Need to increase medical professionals’ awareness and understanding of NF.



Strategic Directions

Four strategic areas have been identified and are ranked here in order of importance to the organization's success.

1. Establish a Strong National NF Organization

To develop a solid foundation for NF Canada, which will allow for effective administration, while increasing growth and productivity of, and support for, the provincial organizations.

2. National Awareness Campaign

Increase the general public's awareness of NF as well as the visibility of NF Canada through the development and implementation of a public awareness campaign plan, which will include advertising, web presence and the development of media relationships.

3. Program Development - Helping Individuals with NF

To develop and implement programming that addresses the needs of individuals with NF, appropriately distribute operational funding to developing provincial organizations, and to contribute to the maintenance of existing organizations.

4. Education of the Medical Establishment

To increase the medical community's awareness and understanding of NF.



Strategic Direction #1: Establish a Strong National NF Organization

Strategic Goal:

To develop a solid foundation for NF Canada, which will allow for effective administration, while increasing growth and productivity of, and support for, the provincial organizations.

Strategies:

1. Develop and implement a capital campaign strategy to secure the necessary financial resources needed to support the organization's strategies.
2. Hire an interim coordinator to oversee the daily operations.
3. Recruit and hire a qualified bilingual Executive Director.
4. Develop organizational, financial and human resource policies and procedures.
5. Develop strong support for the provinces through the hiring of a Provincial Liaison Coordinator, bilingual is possible.
6. Develop collaborative relationships with other similar organizations; for example, About Face, Canadian Organization of Rare Disorders (CORD), Cleft Palate Foundation.
7. Develop international relationships to ensure NF Canada's role in the global NF community.

Performance Indicators:

- *Interim coordinator hired to carry out the daily operations by January 2007.*
- *Policies and systems in place to oversee the effective management of the organization by April 2007.*



- *25% of the budgeted resources secured by the capital campaign to initiate the strategic plan by September 2007.*
- *Professional bilingual Executive Director retained by January 2008.*
- *Provincial Liaison Coordinator, bilingual if possible, on staff by June 2008.*
- *Increased awareness of the programs and services of NF Canada within the local, national and global NF community by 2009.*



Strategic Direction #2: National Awareness Campaign

Strategic Goal:

Increase the general public's awareness of NF as well as the visibility of NF Canada through the development and implementation of a public awareness campaign plan, which will include advertising, web presence and the development of media relationships.

Strategies:

1. Develop a request for proposals to retain a public awareness consultant, bilingual if possible.
2. Launch a two-year national awareness campaign that holistically recognizes the concerns, needs and qualities of individuals with NF.
3. Identify a spokesperson who can increase the awareness of NF, i.e. film or music celebrity, sports star, politician, media personality.

Performance Indicators:

- *Website content updated and expanded by April 2007.*
- *Awareness consultant hired by September 2007.*
- *National awareness campaign plan is developed and implemented through various mediums by January 2008.*
- *Increase in requests for support and information.*
- *A high profile spokesperson is identified and is working with NF Canada by December 2009.*
- *Increased recognition of NF and NF Canada's messages within the general community.*



Strategic Direction #3: Program Development- Helping Individuals with NF

Strategic Goal:

To develop and implement programming that addresses the needs of individuals with NF, appropriately distribute operational funding to developing provincial organizations, and to contribute to the maintenance of existing organizations.

Strategies:

1. Send youth with NF from across Canada to specifically designated NF camps worldwide. Develop a similar retreat for adults with NF.
2. Develop and disseminate educational materials on NF, i.e. fact sheets, brochures, medical guides, etc.
3. Develop peer support services for teens and adults. For teens: Friendship groups; for adults online forum and chat lines.
4. Host an annual NF symposium which addresses both the medical and psycho-social aspects of living with NF.
5. Design a National Contact Registry of Professionals (physicians and geneticists) to allow individuals and families affected with NF to locate the nearest doctor or clinic specializing in the diagnosis and management of the disorder.
6. Develop a partnership with the Learning Disabilities Association and implement a bursary program for families to access this organization's social skills training and tutoring programs.

Performance Indicators:

- *10 youth participating in a designated NF camp by July 2008.*
- *Bilingual educational literature developed and available for dissemination to the provincial groups and the community at large by December 2008.*



- *National Contract registry operational by December 2008.*
- *Bilingual adult retreat developed by June 2009.*
- *First annual NF symposium held in the spring of 2009.*
- *Increase in website visitors.*
- *Increase in requests for information.*



Strategic Direction #4: Education of the Medical Establishment

Strategic Goal:

To increase the medical community's awareness and understanding of NF.

Strategies:

1. Develop and implement a physician's education campaign.
2. Develop a bilingual physician's package for the general practitioner detailing the management and treatment of NF.
3. Develop bilingual NF awareness materials for community health care professionals such as, occupational therapists, psychologists and speech therapists.
4. Facilitation of bilingual meetings and medical symposia which educate and facilitate the exchange of knowledge and research.
5. Identify and financially support a bilingual Canadian physician/researcher to champion the NF cause through the development of global partnerships.

Performance Indicators:

- *Increased awareness of the diagnosis and management of NF within the medical and health care community.*
- *Increase in requests for professional support.*
- *Medical symposium organized by December 2009.*
- *A Canadian physician/researcher/geneticist identified as a champion for the NF community by December 2009.*



Implementation Plan Overview 2007-2009

Year 1 - 2007

KEY TASKS	MONITORING	COMPLETION TARGET DATE
1. Interim coordinator hired	Board	January 2007
2. Policy and procedure manuals written	Board/Staff	April 2007
3. Website content updated and expanded	Staff	April 2007
4. 25% of the budgeted resources secured	Board/Campaign Committee	September 2007
5. Awareness Consultant hired	Board/Staff	September 2007



Year 2 - 2008

KEY TASKS	MONITORING	COMPLETION TARGET DATE
1. Hire Executive Director	Board	January 2008
2. National awareness campaign plan developed and initiated	Staff	January 2008
3. Provincial Liaison Coordinator hired	Staff	June 2008
4. Organize youth to NF camp	Staff	July 2008
5. 50% of the capital campaign goal secured	Board/Campaign Committee/Staff	December 2008
6. Educational literature developed and available for distribution	Staff	December 2008
7. National Contract Registry operational	Staff	December 2008



Year 3 - 2009

KEY TASKS	MONITORING	COMPLETED BY
1. Symposium for NF individuals organized	Staff	Spring 2009
2. Adult retreat developed and operational	Staff	June 2009
3. First medical symposium for healthcare professionals organized	Staff	Fall 2009
4. Capital Campaign goal achieved	Board/Campaign Committee	December 2009
5. A high profile spokesperson is identified	Board/Staff	December 2009
6. A Canadian physician or researcher identified as a champion for the NF community	Staff	December 2009