

## Our Mission

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

## Our 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.

## Our Vision

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



## Contact

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Charitable Registration No.  
867306904 RR0001

You can also find us on  
Twitter and Facebook



## How You Can Help

- Donate online at [www.nfcanada.ca](http://www.nfcanada.ca) or by phone or mail
- Join the Dream Team
- Volunteer

# NF CANADA ANNUAL REPORT 2009

Ron Turley, President  
Desirée Sher, Executive Director

2009 was a challenging year for many non profits across Canada, including NF Canada, but our activities highlighted the efforts we took to ensure that the organization remained strong and viable during tough economic times.

Continuing to be a 'virtual office' with contracted staff working from home offices across the country, NF Canada endeavoured to keep its overhead expenses at a minimum, maximizing its limited resources to fund initiatives which included education and public awareness projects, outreach and support of the provincial NF organizations, and funding research.

Without a store front we recognized the need to strengthen our online presence. This included redesigning the website and engaging in social networking tools.

At a media focus group with parents of children with NF, adults affected with NF, staff, volunteers and medical professionals gathered from across Canada to present their concerns about living with NF to our media consultant. Creating awareness and moving NF out of the shadows was one of the top concerns. The Faces of NF concept was born and the bilingual website's innovative design in black and white was positioned to focus on the individuals battling NF. A bilingual newsletter titled Faces was also launched.

To expand our online presence we utilized social networking tools. These tools have become essential in the way that non-profits do business. The results were quickly measurable as our Facebook and Twitter sites grew in fans and followers. delegates which were comprised of researchers and clinicians, individuals affected with NF and their families and

## Report from the President and Executive Director



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other health care and educational professionals from across Canada, Europe and the US. Seeking out ways to diversify our revenue streams to support our goals, the Board with the help of a consultant, developed a three year fundraising plan.

Strategies identified to increase our revenue included expanding and relaunching the marathon team, developing Friends of NF and NF Champions programs.

Board development and training was another area in which NF Canada sought external expertise. The yearly face to face meeting of volunteers directors was held in Calgary with a facilitator from Centrepoint Non-Profit Management. The Board members returned home with an increased commitment to the organization's priorities and goals.

Recognizing the need to partner with and support the provincial NF organizations, NF Canada developed special project grant and a core operational services grant. Groups from across the country received funding for new projects and existing program delivery in 2009.

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Last year NF Canada had the good fortune to partner with the Canadian Institute of Health Research (Canada's agency responsible for funding health research in Canada) through their Small Health Organization Partnership Program. This partnership strengthened our research support capacity by CIHR matching our research dollars 1:1.

In the spring of 2010 NF Canada also partnered with the BC Neurofibromatosis Foundation to deliver a three day symposium Day in the Life with NF1. The conference was a phenomenal success offering families and professionals a variety of presenters including world renowned researchers, local NF experts, health care professionals, advocates, youth with NF and their families, as well as affected adults. Attendance included 125 delegates which were comprised of researchers and clinicians, individuals affected with NF and their families, and other health care and educational professionals from across Canada, Europe and the US.

The theme of partnering continued with our participation in national coalitions including the Coalition for Genetic Fairness and the Health Charities Canada Coalition. Participation at both these tables has provided opportunities to spread the word about NF to government, the media, and the community. As we look at our goals in 2010 and beyond board development is a high priority. We need to recruit skilled and passionate individuals who are willing to use their connections, resources and expertise to move the NF cause forward. If you are keen to get involved we want to hear from you!

To survive NF Canada will need to be bold and creative in the way it creates awareness, raises revenue and supports its communities. We continue to explore ways to maximize our limited resources as we fulfill our mission to improve the lives of people affected with NF.

We give thanks to the dedicated staff and volunteers who bring their expertise, energy and commitment to the organization as it continues to grow and respond to the needs of the NF community. Thank you to our generous donors who choose to support NF Canada. We couldn't do it without you but together we can face NF and make a real difference.



## 2009 Board of Directors

**Ron Turley**  
(President)  
Ontario

**Inara Kundzins**  
(Vice-President)  
British Columbia

**Susan Wood**  
(Secretary)  
British Columbia

**Ellien Seto**  
(Treasurer)  
Ontario

**Penni Dawn Kernot**  
Ontario

**Christa DeGagne**  
Manitoba

**Lise Gagner-Frenette**  
Quebec

**Cathy Gordon**  
Alberta

**Christine Manu**  
Ontario

**Kim McGinn**  
Nova Scotia

**Patricia Ordyne**  
Alberta

## Contract Staff

**Desirée Sher**  
Executive Director

**Delina Squire**  
Administrative Assistant

## Volunteers

**Eva Grozina**  
**Erica Denomme**  
**Martha Flores**  
**Ed Dagohey**  
**Karla Flores**  
**Dan Wood**

## Affiliate Member Organizations

**Alberta NF Organization**

**Atlantic Provinces Support Group**

**BC Neurofibromatosis Foundation**

**L'Association de la Neurofibromatose du Québec**

**Manitoba Neurofibromatosis Support Group**

**NF Society of Ontario**



*"I enjoyed the opportunity to hear what the researchers/clinicians are working on and the chance to directly ask questions of the Drs. Their availability and approachability was wonderful."*

Symposium Participant

*"Many, many thanks for organizing this event. I am at the very beginning of my journey with NF1 and I can't imagine a better way to learn a great deal so quickly."*

Symposium Participant

*"Best part of the event was the chance to be around people 'like me.' Too often we feel isolated and this gives me a chance to be around people who share the same condition as well as parents of children/youths."*

Symposium Participant

*"I thought the conference was fabulous. You all did a great job. Everything was perfect."*

Symposium Participant

*Thank you helping us finding us a medical geneticist. I had a duty do anything I can that will aid us in preparing for our family.*

Received by email

## Did You Know Facts and Stats

- > NF is the most common neurological disorder caused by a single gene.
- > NF has been classified into three distinct types, NF1 and NF2 and Schwannomatosis. They are caused by different genes, located on different chromosomes.
- > NF1 is the more common form of NF, affecting approximately 1 in 3,000 births throughout the world.
- > NF2 affects about 1 in 30,000 - 40,000 people; Schwannomatosis 1 in 40,000.
- > Both NF1 and NF2 are genetically-determined disorders which affect more than 10,000 Canadians making NF more prevalent than Cystic Fibrosis, hereditary Muscular Dystrophy, Huntington's Disease and Tay Sachs combined.
- > Both forms of NF are autosomal dominant genetic disorders which can be inherited from a parent who has NF or may be the result of a new or "spontaneous mutation" (change) in the sperm or egg cell.
- > Each child of an affected parent has a 50% chance of inheriting the gene and developing NF.
- > NF can appear in any family.
- > Although most cases of NF1 are mild to moderate, NF can lead to disfigurement; blindness; deafness; skeletal abnormalities; dermal, brain and spinal tumors; loss of limbs; malignancies; and learning disabilities.
- > NF also has a connection to developmental problems, especially learning disabilities, which are five times more common in the NF population than in the general population. Accordingly, NF research may benefit the thousands of Canadians with cancer and learning disabilities.