



The BC Neurofibromatosis Foundation

ANNUAL REPORT 2010

Review from the Executive Director



Desirée Sher, Executive Director
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For so many organizations this past year continued to be a tough period financially, but at the BCNF I am pleased to report we more than survived - we thrived. During the past year we continued to improve our effectiveness as an organization and improve our overall fiscal health, no small feat in what were clearly challenging economic times.

On the mission front, perhaps our greatest achievement was in education. Hosting the NF1 symposium in April 2010, in partnership with NF Canada, allowed us to reach more families, over 100 people from across Canada and the US, bring in numerous renowned NF experts, and all the while keeping our costs down.

Partnerships continued to be explored including with the Canadian Organization for Rare Disorder. This year we attended the Rare Disorder Action Day on Parliament Hill and the rare disorders conference. While we continue to advocate for awareness for NF, when partnered with CORD our voice is more powerful. Over 2.7 million Canadians live with a rare disorder. The message we took to the MPs was that Canada needs a framework for rare disorders including an orphan drug policy. With Canada being the only developed country without a definition of rare disorders (rare disorders is defined in most countries as affecting fewer than 1 in 2,000) there are no incentives for the development of new drugs, guidance in conducting clinical trials and pathways to approval. The end result is that without a rare disorder plan Canadian patients lack access to clinical trials, drugs and treatments that are available in other countries.

We continued our commitment to providing support services to families by implementing the *Support Through Technology* project. Through the use of online video clips parents of children newly diagnosed with NF are now able to learn from the experiences of more seasoned parents. This project has had such an overwhelming response more online clips will be added in 2011.

Research continues to be an important area of investment. Last year we were once again able to contribute to an innovative NF research project underway at Friedman Lab at the University of BC which explores various drug therapies for NF1 Vasculopathy.

At the heart of our mission's work are our volunteers and families who are the backbone of the organization. In 2009 their efforts through our fundraising events, including the Campbell River Recycling Program and the Victoria based Jeans for Genes dinner & auction, raised much needed funds for research and all our programs.

The organization's reliance on gaming revenue continues. Now that our three year \$180,000 gaming grant has come to a close we must once again state our case for funding. As the only organization in the province serving the NF community we make a good appeal. Our application has been submitted and we wait to hear a favourable response.

Right now our momentum is great and our mission has never been stronger. I look forward to our upcoming year with both pride and optimism. I hope you will join me in celebrating what we have accomplished and share in the confidence that our upcoming year will be even better. Thank you for your continued support in helping the families and individuals across BC who are affected by NF.

Programs and Services: The Year in Review



Susan Wood, Program Coordinator
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COMMUNITY SERVICES

Individual Support/Inquiries and Information

BCNF deals with hundred of telephone calls and thousands of emails each year from individuals with the condition and interested community members. These calls typically deal in three areas; individuals recently diagnosed and trying to learn about the disorder or learn how to cope with the knowledge of their condition; individuals who are having difficulty with the medical system and need guidance and information; and, ongoing support and information regarding symptoms that have developed with the progress of the disorder. Last year over 300 phone calls were handled by two part time staff members as well as over 5,000 email queries from across the province, Canada and the global NF community.

Website

BCNF maintains extensive web site providing information related to NF, latest research information, personal stories by those with the condition, Foundation news and many other features. The site averages 1,500 unique visitors from around the province, across Canada and from international communities. This year the BCNF expanded its online community to include Facebook and Twitter

iNFo Newsletter

The BCNF newsletter is produced three times per year and is distributed to seventy communities throughout the province, the country and to many international destinations. The newsletter is the only regular publication dealing with NF and provides a powerful vehicle for raising awareness and keeping families informed of upcoming activities.

EDUCATION & AWARENESS

NF1 Symposium

This year's NF1 symposium was held April 8-10 in partnership with NF Canada in Richmond, BC. With over 100 people in attendance from across Canada and the US, and speakers from all across North America and Europe, the symposium was a great success!

The 2010 symposium was rated excellent by 72% of the participants and 28% rated it very good. Overall those in attendance were very satisfied with the facilities (75%), the speakers (80%), session length (97%) and thought the event was well organized (100%).



“Just a quick note to say thanks again for the conference. It was a great conference and as usual, I took away a whole lot. There is always much to learn but there is also the connection felt in the room amongst everyone there. And I believe the researchers understand and respect the people affected by NF. I always come away with a sense of hope for the future for my son. Emotionally, it is always tough but always worth the time.” Terri

Information Days

Each year educational and support meetings are held in Kelowna and Vancouver to provide opportunities for direct contact with those with NF. These meetings also include an educational component usually facilitated by a local expert, and cover a variety of topics including coping strategies and disorder progression and management. Meetings vary in size from 12-35 people who are keen to meet others on a similar journey. In September Dr. Jan Friedman and Patricia Birch, Canada’s NF experts, traveled to Kelowna to present at the community’s information day.

Resources

The BCNF continues to distribute its vital resources to parents, teachers and other NF groups across the globe. “A Parent’s Guide to the Learning Disabilities Associated with NF1” continues to be in demand.

Support Through Technology

In 2009 with funding from an external grant source the BCNF moved to adding online information and support to allow for easier access to resources and information. Regardless of where an individual may live in the province, the country or the world, through the use of online video clips we are able to provide parents of children newly diagnosed with NF, with the necessary tools and emotional support to cope more effectively with the diagnosis of NF and navigate the NF medical and educational systems. Armed with information, parents will be able to make informed choices about their child’s health care and ultimately become more effective advocates for their child. More online clips will be added in the spring of 2011.

Doctor, Patient and Society Program (DPAS)

BCNF and its members participated in the University of British Columbia, Faculty of Medicine, Undergraduate Education Program project known as Doctor, Patient and Society Program, or DPAS. This program is part of the medical and dental students’ training. One of the goals of the DPAS program is to place medical and dental students in greater contact with people in the community and provide a fuller understanding of health issues outside of the clinic setting. In 2009 and 2010 the BCNF benefitted by having a first medical student volunteer with the organization. This is part of the UBC Medical Program known as DPAS 420 CSLO Student Placement. Her duties involved interviewing families for the filming of the Support through Technology Project and updating the medical literature through research.

Community Awareness

Educating the public about NF is critical for increasing tolerance for the children and adults who struggle with disfigurement caused by the disorder. BCNF reaches out to educate the community and recruit volunteers through fairs, mall displays and speaker presentations. Last year the BCNF participated in the Volunteer Victoria Fair, Community Health Fair at the University of BC, and hosted an informational booth at various malls throughout the province.

YOUTH PROGRAM

Kids' Summer Camp

The BCNF continues to be proud of its youth summer camp program. This year, the BCNF once again partnered with the Children's Tumor Foundation, to provide six kids with camp scholarships and travel to attend the NF Camp in Utah. We extend our deepest appreciation to LBL Holdings Ltd. and the Province of British Columbia for their financial support, which makes this program possible.



Thank you very much for sending me to the NF camp. I saw many of my friends from last year and made many new ones. The whole camp was extremely fun, words are not enough to thank you for sending me.

It is so good to see people with the same illnesses as I have and to see how they cope with it and see how it differs from my way. We have a special bond that you can only have with people with the same illnesses as I have.

The whole camp from the second I came to the second I left were some of the best days of my life. It is even better that I have their face book so I can talk with them all year round and only build on our friendship. Again I thank you for sending me and words can't describe how much fun it is.

Adam

RESEARCH

In 2010, in partnership with NF Canada the BCNF funded a research project at the University of BC which explores various drug therapies for NF1 Vasculopathy, a disease of the blood vessels.

Vascular disease is a serious manifestation of NF1. In conjunction with Dr. David Ingram at the University of Indiana they are currently exploring vascular disease in individuals with NF1 and this project will allow for the exploration of possible treatment options. A small pilot study performed suggested everyone with NF1 likely has some degree of vascular disease and signs of chronic inflammation even if it is not clinically apparent. Some evidence suggests current therapy is not always effective so developing new ways to treat NF1 vascular disease is very important. This study is one of the first steps in developing new therapies. It also extends current work being done in the lab and in collaboration with Dr. Ingram's lab because the study design allows for the examination of not only treatment options, but also to examine the role chronic inflammation and the overproduction of cytokines has NF1 vessel lesion formation.



Kimberley Jett, the lead investigator, has promised to provide us with progress reports in 6 months and in 1 year.

VOLUNTEERS

The BCNF's success depends on the commitment of volunteers who provide assistance in numerous to the Foundation's programs and fundraising events. This year we thank the following individuals who gave generously of both of their time and energy: Ivan Junek, Teresa Stokes, Dorian and Dave Wuttunee, Dan Wood, Courtney Moore, Rob McIntyre, Suzana Mitrovic, Loni Patterson, Andrea Meadows, Eva Grozina, Cara Grimshaw, Sam Chua, Tara Turley Dean, Cynthia Turley, Hugh Tollet, David and Lalaine McNaughton, Suzanne Sorensen, Haven and Cove Desormeaux, Betty Hersey, Terri Lang, Leslie and Murray Tollington, Ted Gordon, Bryce Little, Alan Meadows, Holly Meadows and Paul Ralfs.

The **Paul Ralfs Volunteer Award** is given annually to an individual who demonstrates excellence in volunteerism on behalf of the Foundation and Neurofibromatosis. This year's award was presented to Patricia and Don Anderson in recognition of their incredible efforts in supporting the BCNF's recycling program. This fundraising initiative has raised over \$65,000 for the organization and could not happen without their dedication to sorting the bottles. Thanks Patricia and Don!



Thank you to all our volunteers!

Treasurer's Report

I am pleased to present the year end financial statements prepared by Collins & Co for the organization's 2010 fiscal year. The statements show the Foundation to be on solid footing as revenue increased in 2010 thanks to the generous contributions of our donors and members.



Bryce Little, CFP
Little & Davies Insurance | Financial Planning

Last year BCNF also received a \$20,000 anonymous donation which was directed towards research and increasing awareness through the development of a communications plan. 2009 marked the end of our three year gaming grant and this year staff will have to submit a new application for funding. Although the Board continues to seek other revenue streams our dependency on gaming revenue continues.

BCNF runs a very tight skeletal program budget. One of our greatest savings is that we don't have an office or the overhead that comes from renting space. This allows us to put more of our funds directly into program costs which continue to rise each year with inflation and tax increases.

Overall the BCNF board and staff are working hard at being good stewards of the funds that the organization receives, ensuring that the mission of empowering and improving the lives of individuals and families affected by NF continues.

Reviewed financial statements are available on request.

Thank You for Your Support!

While we have made every attempt to ensure the accuracy of our records please accept our deepest apologies if we have omitted your name. Please let us know our error by calling the office at 1-800-385-2263.

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Mission Statement

The BCNF is committed to empowering and improving the lives of individuals and families affected by NF. The BCNF provides information and support services, promotes awareness and funds research to improve treatment and find a cure.

2009 - 2010 Board of Directors

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Ted Gordon

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