



Life with NF

NF Canada/BCNF 2010 Spring Conference

April 9 & 10 Sheraton Vancouver Airport Hotel, 7551 Westminster Highway, Richmond, BC

The BCNF, in partnership with NF Canada, is excited to announce its upcoming medical symposium. This 2-day event will bring together prominent NF researchers and clinicians from Canada, the US and Europe. This is an excellent opportunity to learn about NF1, hear about new advances in research and meet with individuals and families living with the disorder from across Canada. Register today to learn more about NF, network with the experts and share experiences. It is going to be the NF event of the year and you won't want to miss it!

Top ten reasons to join us at the NF1 Symposium in Vancouver in April...

1. Thirteen speaker sessions to inspire and learn from.
2. Opportunity to meet and ask questions of some of the top researchers in the NF medical community.
3. Meet new friends and learn how other people have discovered blessings in their journey with NF1.
4. An excuse to visit beautiful British Columbia and see what the world saw in February 2010! An official Olympic torch will be on display in the hotel lobby!
5. Discount on hotel rooms.
6. Four free meals and coffee breaks.
7. The comedic talent of the hilarious David Roche.
8. Complimentary child care for children 0-6 years.
9. Local attractions: Stanley Park, Capilano Suspension Bridge, Grouse Mountain, English Bay Beach and more!
10. Chance to be part of the **Lucky to be Me** exhibit. Symposium participants are invited to sit for a portrait session with photographer Quinton Gordon. Gordon's project will culminate in an exhibition, creating awareness of NF1 through the portrayal of people living with the condition.



The dedicated Dr. Vincent M. Riccardi, MD

began his work with NF in 1972 and has used his skills as a clinical geneticist and cell biologist to explore the clinical issues and affects of the disorder ever since. He has been on the faculty of several medical schools, most recently that of UCLA. He has seen more than twelve hundred persons with NF in one form or another, and has published many articles, primarily about NF1.

The inspirational Reggie Bibbs spent most of his life "missing out on what life had to offer" due to NF – but not anymore! In his presentation, Reggie will talk about living with NF and enjoying life. You can do the same!



The talented David Roche

is an internationally known performer, speaker and author who has turned the experience of a congenital facial disfigurement from a source of personal shame to one of pride and inspiration. Come celebrate life with NF as we wine and dine and laugh the night away!

Visit www.bcnf.bc.ca or www.nfcanada.ca to download the conference brochure and to register. We are pleased to offer limited travel funds to assist individuals and families with defraying the costs of attending the Life with NF symposium. Please complete the Request for Travel Stipend form, available on both websites to apply for funds.

ED Report



Desirée Sher
Executive Director,
BCNF

“Unless someone like you cares a whole awful lot, nothing is going to get better. It’s not.”

~DR. SEUSS

When I look over the list of upcoming activities and events the BCNF has planned for 2010 it’s hard to believe that it’s just two part time staff and a handful of volunteers who make it all happen.

Almost a year of preparations are coming to a close as we finalize the last details for the upcoming NF1 symposium on April 9-10 in Richmond. There is still time to register! Please join us as we host some of the world’s premier NF researchers who will present their newest findings. It will be a day to learn and also hear inspiring stories from the other experts – the ones living daily with the disorder. You can [register on the BCNF website](#).

You don’t need to wait until the symposium to hear how others are coping and counting their blessings of life with NF. Please take the time to [visit the website](#) and view the new personal stories that are posted.

BCNF staff are also buzzing around as they prepare for the annual Jeans for Genes Dinner on April 24th in Victoria at the

Uplands Golf Club. If you would like to support the event by purchasing a ticket or you have a service or item to donate please call the office. We need everyone’s contributions to make this event our most successful in history!

The Education Award program and the Summer Camp program applications are now available to download from the website. If you know a youth affected with NF, direct them to the website to learn more.

With so much underway I give thanks to the talented staff and the volunteers who work so hard so you can enjoy these events. If you’d like to support the BCNF there are many ways you can help us. By registering for the symposium, purchasing an auction ticket, making a donation, or volunteering a few hours a month on the Board, you are making a difference. Join us today!

Here it Comes Again...

The 14th Annual Jeans for Genes Dinner and Auction

April 24, 2010 at the Uplands Golf Club, Victoria BC

This year’s annual fundraiser will have something for every taste, something for every budget. Looking for a sailing getaway? Having a bad hair day? In search of a one-of-a-kind gift? We’ve got the solution. Join us for a night of fun and frivolity as we dine, laugh and outbid each other during the silent, live and cake auction. Tickets are \$75 and are available by calling the BCNF office. This is an event not to be missed!

If you or your company would like to support the event with a cash donation or prize contribution contact the Executive Director desiree@bcnf.bc.ca

Thank you to our sponsors:



25 Years of Service to the NF Community!

Congratulations BCNF!



Our daughter was diagnosed with NF1 back in February of 1991 at the age of 8. We were sent for a barrage of tests at Kelowna General Hospital. We were told that our daughter had NF1 and her bone growth was 1 year older than her chronological age. Further evaluation was needed at BC's Children's Hospital in Vancouver.

There was very little information on NF1 at that time and our paediatrician could not tell us much. My husband and I said we can't sit and wait in Kelowna for 5 to 6 months not knowing-what medical condition our little girl had or what was in store in her future. We managed to speed up the wait and were at Children's Hospital by the end of February 1991.

There, they found her bone growth was actually 2 years older than her chronological age. She was diagnosed with precocious puberty as a symptom of her NF. We had to make a decision – she was too young to go through puberty at 8^{1/2} years old (emotionally and physically). She then became part of a Canada-wide study, the 9th or 10th child to be injected with a drug to stop precocious puberty. They did not have long-term data regarding the outcome of the effects of this drug, but we knew we had to do something! My husband, myself and

our daughter also took part in the September 2000 final report of this study entitled *To Provide and Protect: The Never Ending Journey – Parents' Perceptions of the Experience of Caring for a Child with Precocious Puberty*.

We found Children's Hospital to be a loving and caring place – the best place to be when going through a medical challenge with your child. My daughter and myself met with Paul Ralfs when he was just getting BCNF started. We had **NO** idea how diverse this condition can be. We have been members ever since. It has been **GREAT** getting factual information from the BCNF over the years and learning of the struggles and triumphs of others living with this disorder. Thank you from the bottom of my heart!

Keep up the **GOOD** work BCNF! Our daughter is married and lives in Kelowna and we live in Grande Prairie, Alberta where we run our own business. I'm hoping to attend the April, 2010 Symposium. We hope to see you there!

Sincerely,
Sandra and Barry Straza

Bloggers Wanted

The BCNF is seeking bloggers with a sense of fun who are interested in telling the world about life with NF1 or NF2 through weekly blog contributions.

The BCNF blog will offer you a platform to show off your writing talent to the world while at the same time showing the world what NF is really all about.

We are not looking for thousands of words. A good blog post need be little more than a paragraph or two if it has something interesting to say and says it well. And it doesn't just have to be words. We can publish just about anything if it's in digital format. It could be a picture, sound clip or video. The ultimate test of a good blog post is to ask yourself: would you want to read it if someone else had written it and would it make you want to come back for more?

If you want to rant against doctors or teachers, then this is probably not your platform. We don't deny for a moment people with NF face many challenges, but we are much more interested in how they are being dealt with and overcome.

What's in it for you?

Well, it's a great way for you to educate the world about NF and showcase your writing talent. Our editor will make you look your best. Other incentives are under consideration including a small honorarium.

Want to apply?

Please email info@bcnf.bc.ca using the subject line "Blogger". Include a few details about yourself and a brief summary of why you want to blog.

BCNF Supporting Research...



For the last ten years, we have been concerned that vascular (blood vessel) disease affects people with NF1 more often than average, and at a younger age. Two years ago we began a pilot project, with eight BC volunteers, aimed at learning more about vascular issues in NF1.

The results from our preliminary study were exciting and warranted further research so we applied for US Army funding. We are partnering with Dr. David Ingram and his team from the University of Indiana. Dr. Ingram has done related laboratory studies in mice and has performed the cellular studies that were crucial to our pilot project. We are thrilled to announce that we have been awarded a grant to study the vascular health of a further 40 individuals in depth. We will enrol 20 people here and 20 in Indiana in a study that we hope to begin in early April. We will be looking for individuals with NF1 who are between the ages of 18 and 40 and who can spare half a day for this study. If you are interested, stay tuned for more information and for how to participate. Travel subsidies will be available.

Once again, a huge thank you to all those who volunteered for the pilot study! You know who you are and we aren't allowed to say! This is exciting news for NF1 vascular research.

To put yourself on a list to be informed about upcoming studies, please contact Patricia Birch, Research Nurse: birch@interchange.ubc.ca or phone 604-875-2000 ext 5622.

NF Resources Across Canada:

Visit www.bcnf.bc.ca/resources/links for a list of NF resources across the country.

NF Dream Team

Join the NF Dream Team and help NF Canada reach its goal to end NF! Run, cycle, or swim in support of the thousands of Canadians suffering with neurofibromatosis.



The NF Dream Team is a national fundraising program of NF Canada that provides individuals with the opportunity to participate in physically challenging events and to raise money for research that will improve treatment options and find a cure for NF.

You can make a difference for the thousands of Canadians living with NF and experience an adventure you'll never forget by joining the team. You don't have to be an athlete to join! The NF Dream Team prepares you for the physical challenge with our online coach and specific training programs, while providing you with the support you need to achieve your fundraising goals. Upcoming events include: Seattle to Portland bike ride, San Francisco Marathon, the Disneyland half marathon plus many more exciting events.

Visit www.nfcanada.ca to learn more.

NFfax

- NF is more common than Lou Gehrig's Disease, Duchenne Muscular Dystrophy and Huntington Disease combined
- NF causes tumour growth in the tissues that surround nerves (inside and on the surface of the body) and can cause disfigurement, bone deformities, blindness, deafness, and most commonly – learning disabilities
- NF affects about 1 in 3,000 Canadians
- NF is the most common single gene disorder
- 50% of the cases diagnosed today are new gene alterations
- NF is equally prevalent across the world and is not limited by any racial, gender, social or economic boundaries

Support Through Technology



Through BCNF website's **Support Through Technology** video vignettes, you will learn of individual and family journeys with NF. With the help of a grant from NF Canada, the BCNF has produced an assortment of video vignettes featuring individuals and families sharing

their personal journeys, reflections and hopes while living their lives with NF.

Through the sharing of these experiences and insights, the BCNF hopes to provide other individuals and parents of children with NF, regardless of where they may live in the province, the country or the world, with the necessary tools and emotional support to cope effectively with the diagnosis of NF1 and 2.

"Seek out others affected by NF, especially those living full lives in spite of it. They will have much wisdom to share and will inspire you. But, give yourself time to get used to the diagnosis. It can be frightening to see those who are severely affected. Know that each person will manifest symptoms of the disorder quite differently. Educate yourself on NF. Find good medical care. If you are a parent of a diagnosed child, allow yourself time to grieve. And if you are having a hard time emotionally, get help for yourself too. Find a good counsellor/therapist to deal with your anxiety and sadness. Be kind to yourself. While it may not feel like it at the time of diagnosis or anytime shortly thereafter, life will go on and you will feel less overwhelmed, less sad, at some point. If you are open to this experience you didn't ask



or bargain for, there will be gifts in the experience. Your child's life is still a miracle and you as a parent can be such a support for them, if you are able to take care of yourself and figure out what you need in terms of support too."

~ A PARENT OF A CHILD WITH NF1

"NF is just something I have and will always carry with me. It has shaped who I am – and I like who I am. It hasn't always been fun, and it hasn't always been easy. As cheesy and cliché as I know it may sound, we all have our battles to fight, we all have our low moments, we all have our high moments. So I just try and take it as it comes, ask for help when I need help, cry when I need to cry and talk when I need to talk. And most importantly, listen to others when they need someone to listen to them.

Don't be afraid to reach out to your support systems – family, friends and organizations such as BCNF. I have found that more often than not it is the parents that need support and reassurance during a new diagnosis. From what I've been told, it really helps to see someone my age who seems 'normal' so to speak and who seems to have survived 'all' of it intact. I think it is important to offer support, but also try not to sugar coat it. Say what worked for you, and what didn't. And again, listen, listen, listen. Often they just need someone who will listen to all their insecurities about their new – and what might seem to be scary – future. "

~ A YOUNG ADULT WITH NF1



Counter clockwise from top: Desormeaux family, Hugh, the McNaughtons, Tara and Cynthia

14th Annual NF Summer Camp | Saturday July 17 – Friday July 23, 2010

Calling All Campers!

The BCNF is pleased to once again have full scholarships available to send five campers (age 13–18 years) to the Children’s Tumor Foundation’s 14th Annual NF Summer Camp 2010.

The BCNF will cover flight costs and camp fees... all you have to do is get ready for a fun and memorable experience! If you have NF1 or NF2, are 13–18 years old and would like to attend NF Summer Camp, we would like to sponsor you.

Camp will be held Saturday, July 17 to Friday July 23, 2010. Camp Kostopoulos, located 35 min from Salt Lake City Airport in Emigration Canyon Utah, will host the NF Camp for the 14th year. Activities include swimming, horseback riding, camp fires, ropes course, climbing wall, canoeing, fishing and more. Offsite activities will include a day at the water park, movie night and more. NF Summer Camp has always provided an exciting and valued experience and we are pleased to offer the opportunity for sponsorship again this year.

Please write a brief paragraph telling us a bit about yourself and why you would like to attend camp. Send it with your guardian’s signature before April 30th, 2010, by fax or regular post to the BCNF. (Don’t forget to include your address and phone number.) Check out our website www.bcnf.bc.ca to download and print the Camp Sponsorship Application Form, or email susan@bcnf.bc.ca



Campers will be selected on a lottery basis. Returning campers are welcome to apply. Please keep in mind priority will be given to first-time campers. Parents/guardians are responsible for required travel documentation and are advised that campers may be required to fly unescorted to and from camp. The BCNF makes every effort to provide direct flights and unaccompanied minor status if possible, when current airline policy allows.

Have questions? Please contact Susan at the BCNF office for more information. You can also learn more about camp at www.ctf.org. Don’t delay – send in your application today!

Due to liability insurance requirements, campers must be BCNF members. New membership is welcome at a cost of \$35. Contact the BCNF or you can print a membership form at www.bcnf.bc.ca

4th Annual BCNF Education Award

We Can Help You Pursue Your Dreams...

The BCNF is please to be accepting applications for the 4th Annual BCNF Education Award. If you have Neurofibromatosis and you’re thinking about furthering your education or training, educational funds may be available for you. Whether you’re going into the trades or have an academic pursuit in mind, we may be able to help!

chef... teacher... nurse... writer... veterinarian... teaching assistant... auto mechanic... community support worker... administrative assistant... journalist... graphic artist... carpenter... computer programmer... photographer... accountant... high school completion...

Application Deadline: May 1, annually. Details and application forms are available online at www.bcnf.bc.ca or by contacting the BCNF office.



Life with NF

Thanks to all who have contributed photos and please, keep them coming!

We are looking for photos of children and adults with NF experiencing the pleasant moments of daily living with family, friends or on their own. Our emphasis is on portraying people with NF in their communities enjoying life. These will be added to the newsletter and website as *Life with NF*.

Please send us your photos, either digitally or in hard copy and we will send you a mug with your photo on it. Its our way of saying 'thanks!' Please do not send in your originals as we cannot return them to you. So only send us a duplicate!

Please submit your digital photos by email to info@bcnf.bc.ca or mail a duplicate to: The BCNF, Box 5339, Victoria, BC V8X 6S4

**You will receive a BCNF mug with your photo on it!
Just send us photos of your life!**

One mug per family.



Jan Friedman, MD, PhD
Professor of Medical Genetics, University of British Columbia

There is no cure... yet

The reality of it all...

Although the effects of neurofibromatosis vary greatly from person to person, most people with NF live fulfilling and productive lives. We know more now than in the past about how to diagnose, prevent and treat many serious complications of NF. Certainly, there is still a great need to learn more, but if NF research labs and organizations such as BCNF continue to work together, our understanding of this complex disorder and our ability to treat it effectively will be much better tomorrow than it is today.

Donor Recognition: A Heartfelt Thank You!

Thank you to all of our donors who have contributed to the BCNF since our last newsletter:

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

Together we are making a difference!

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The articles in this newsletter are for general interest only. The BCNF does not support, endorse or recommend any of the content found therein.

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We welcome your comments and contributions.

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