



ANNUAL REPORT 2017

To empower those affected by NF through support, education and awareness.



**Tumour
Foundation**
of BC

EMPOWERING INDIVIDUALS WITH NF

WHAT IS NF?

Neurofibromatosis (NF) is an umbrella term for three distinct genetic disorders: NF1, NF2 and Schwannomatosis. These three disorders share the common manifestation of tumour growth. NF can cause tumours to grow on nerves throughout the body and can lead to blindness, deafness, bone deformities, learning disabilities, disabling pain and cancer. There is no cure.

HISTORY

The organization was founded in 1984 by Paul Ralfs and became a charitable organization in 1986. We previously operated under the name of The British Columbia Neurofibromatosis Foundation. The name change to the Tumour Foundation of BC was approved in January 2017.

MISSION

To empower those affected by NF through support, education and awareness.

VISION

A world without NF.

BOARD OF DIRECTORS 2016-2017

| | |
|--------------------------|-------------------------|
| President | Steve Billington |
| Vice- President | Gerry Stolz |
| Treasurer | Luis Alonso |
| Directors | Candace McGuire |
| | Maria Coutu |
| | Kelly Fogarty |
| | John Styliano |
| Executive Director | Desirée Sher |
| Administrative Assistant | Delina Squire |
| Phone Line Counselor | Dallas Genereaux |
| Web Support | David Snook |

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REPORT FROM THE PRESIDENT



Well, doesn't this feel like a watershed year?

Thank you so much for your continued support through this past year with new initiatives, progress in so many areas, and a lot of activity that I and your new board hope you have supported or will consider supporting in the year ahead.

For those keeping track, your new board is: Steve Billington, President; Luis Alonso, Treasurer; and directors Candace McGuire, Kelly Fogarty, John Stylianou, Danielle Leonardi, Maria Couto, Jill Taylor, and Mike Gauthier. Our long-time board member, Gerry Stolz, who brought experience and continuity from the board from 2012-2017 has stepped down. We acknowledge his assistance and advice and thank him for all his years of serving the NF community in BC.

We've come a long way in the past year and while it feels like there is far to go, I'd like to review our progress through 2017.

Your new board has been fueled with excitement coming into the new year. We made several goals for ourselves at the planning session in July: continue to promote and fundraise for an NF clinic, continue to fundraise for general revenues to keep our foundation financially afloat, raise awareness of NF generally and of the Tumour Foundation of BC. We also want to connect to you, our NF community.

Our goal for an NF clinic continues. It is both taking shape and may change shape as we move around obstacles in the path, and move with our evolving awareness of what will best help our NF community. And of course any goal, and a clinic goal – whether bricks-and-mortar, or (more likely) some kind of virtual clinic directing NF patients and families to appropriate expert care, needs cash. So our main fundraising goal this past year was toward providing for such a clinic.

And our eyes were certainly opened this year about the complexities of getting a dedicated NF clinic in BC! As so many of us know, when you deal with the medical system in BC (or almost anywhere), you run up against an establishment with attitudes and bureaucracy that are challenging. But we are not giving up. We can rise to the challenge and continue to press for a much-needed clinic that your board thinks can really enhance the lives of those living with NF.

REPORT FROM THE PRESIDENT

We plan to move toward a clinic on two fronts. First, we are working with prominent health professionals in the NF field to seek out a ‘champion’ to assist in pushing our clinic agenda with the relevant provincial ministry. Second, we are considering the simpler (and perhaps more wide-reaching) idea of a ‘virtual clinic’. For that to take shape we will need an IT champion, so we’ll continue to update you, the NF community, on our progress as this clinic goal may stretch into several years.

Fundraising is such a big part of what we need to do as a community, and your new board has been hard at work on that front too.

Our Cocktails for a Cure fundraiser netted approximately \$20,000 and we felt it enough of a success we are going to put it on again in 2018. There are other irons in the fire for fundraising goals, such as the Scotiabank Charity Challenge half-marathon and 5k run which we feel has a lot of potential, even though it didn’t meet that potential in 2017. We’ll be adding to the fundraising mix this year, the Funny Fun Fundraiser comedy night at the Rio Theatre in Vancouver.

Of course, a large portion of our funding comes from the BC Gaming grant – but we need, and are thankful for, the financial support of our dedicated members and donors. As our membership numbers grow, that will be reflected in increased funding. And, as is always the case, we owe a debt of gratitude to our Executive Director, Desirée Sher, and to our great volunteers. We’d be lost without them.

We continue to need membership, volunteers, directors, donations, ideas, energy, and participation. Can you provide any of those? Your board wants to help the NF community in BC. We hope that our new director from Vancouver Island, Jill Taylor, will help us find ways to assist the NF community there. Reaching into the interior is also a goal and we’ll miss the connection through Gerry Stolz. Please get in touch if you know anyone touched by NF who is excited to join our efforts in the Okanagan.

We want to grow our membership by simply formalizing the relationship between the individuals and families touched by this common genetic disorder and the foundation representing them. Please pass along the Tumour Foundation of BC contact information and don’t hesitate to give us feedback and ideas of how we can improve.

Help us help you shine a light on neurofibromatosis for our province-wide community.

REPORT FROM THE EXECUTIVE DIRECTOR



What a long way we have come, and in a very short time!

Our fiscal year started on July 1, 2016. At that time it was a whole different world. In less than six months the organization experienced a huge transformational shift which included: a new leadership team, a new name, a new logo, new programming and a new priority to establish a NF clinic in British Columbia.

Changing the name after 32 years came with some trepidation. However, we needed to do something bold to survive. This new identity as the Tumour Foundation of BC has already served the organization and our community well, in the six short months we have had. We have attracted dozens of new donors and skilled volunteers who have strengthened our organization and helped carry us through the identity change.

This project continues to move forward but slowly. This year, we worked with two doctors at BC Children’s Hospital to identify a potential model of care for the NF clinic. The next step is to present the project to the Executive Board later this fall. The Hospital Executive will need to agree that the clinic has merit to invest in stage two, which is the creation of a business plan for the clinic.

Additionally, this past June, I met with staff from the Deputy Minister of Health. It was a chance to introduce them to neurofibromatosis, the work of our Foundation, and the need for a clinic for people in British Columbia affected with NF. While there was no money offered to support the clinic, I did share with them another idea we had using “virtual care in primary care” which they were excited about. We will be exploring a new virtual clinic pathway in conjunction with a bricks and mortar clinic in the months and years ahead.

PROGRAMS

Under the leadership of a new and expanded board, we continued with our old programming as well as piloted a new program: the NF Support Line.

INSPIRE MAGAZINE

This publication is also eagerly anticipated and shared with families across the province and Canada. Sharing stories, insights and research, each issue offers hope, information and up-to-date resources on living the best life possible with NF. Producing this magazine is costly which at this time prevents us from publishing more than once a year.



SYMPOSIUM

The May symposium was another great success. This year, close to 100 families participated in person and via live stream from cities across North America. The symposium is an event families wait all year for, as it is an opportunity to learn and connect with others living with the same disorder. We were thankful to our incredibly courageous speakers who shared their personal stories, and to the physicians and community of health care professionals who came from across Canada and the US to educate and entertain us. We learned about new advances in NF care and research, mindfulness, whole hearted living, and left with skills to keep our relationships strong when living with a chronic health condition.

*“Best
symposium
ever!”*

*“I’ve honestly
never felt so
connected with people.
This is the first event I
have ever attended where
I felt like I really got to
know other people
and their stories.”*

PROGRAMS

Under the leadership of a new and expanded board, we continued with our old programming as well as piloted a new program: the NF Support Line.

NF SUPPORT LINE

In January, the NF Support Line was launched. The toll-free phone line started out being manned one night a week by a clinician knowledgeable in NF. The calls were consistent enough that, after six months, we expanded the service to a second night.



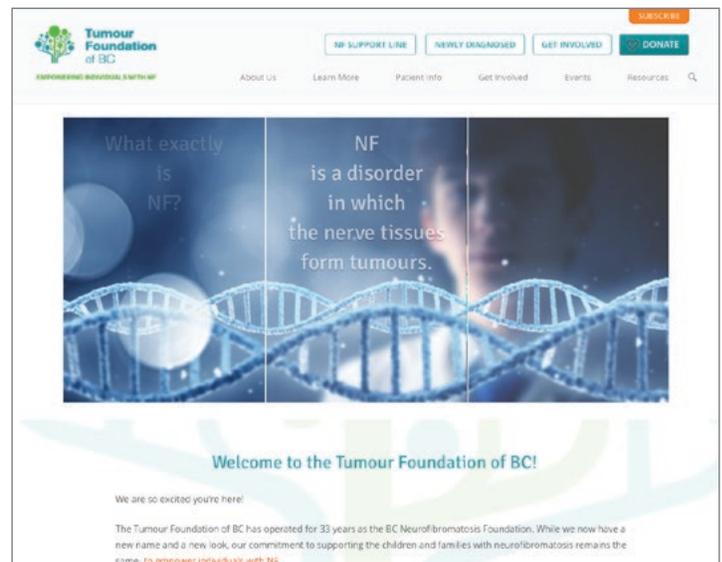
EDUCATIONAL SCHOLARSHIPS

For the past nine years the Foundation has offered two \$500 scholarships for individuals pursuing post-secondary education. The goal of this program is to provide students with NF, who wish to increase their employability, with a little financial support. Past recipients have included a student who became a

teacher despite having learning disabilities, a music producer who pursued his passion even as tumours robbed him of his hearing, and many other successes. Last year, we did not receive any applications so please share this program with the student in your life. More information can be found on our website.

WEBSITE

Have you checked out our updated and expanded website? The website continues to evolve as the organization grows. On the website you can learn about NF, get involved in upcoming events, watch videos, share your story and more. We will be adding two new resources in the weeks ahead, including a handout for health care professionals.



AWARENESS



SHINE A LIGHT ON NF

We had a terrific inaugural year for this campaign! With the support of the City of Vancouver and Port Coquitlam, we brought NF out of the shadows. The following buildings and structures lit up in blue and green for NF:

- BC Place
- Telus Science World
- Vancouver Trade and Convention Center
- Vancouver City Hall
- Port Coquitlam Sky Train Pillars
- Lafarge Lake
- Coquitlam Boundary Sign

The staff was pleased to spend time with families at these sites. It was exciting to see the kids' faces light up with pride as the city lit up for them.

OUTDOOR CAMPAIGN

Thanks to Pattison Outdoor and our energetic volunteer, Mike Gauthier, we launched an outdoor awareness campaign in Vancouver on Expo Blvd near BC Place. Over 23,000 viewers see the ad in this location daily. This means a whole lot of people saw the NF message during the month of June.

SOCIAL MEDIA

Thanks to the volunteers on our Social Media team, we launched a new Facebook page and a Twitter account to spread the NF message, increase awareness of the disorder, and share the support services we offer. We continue to work with an incredible team who have plans of increasing our presence in the year ahead. The team also created our first infographic, which was shared on social media.



FUNDRAISING

COCKTAILS FOR A CURE

This new fundraiser was a huge success. We had over 100 businesses and individuals contribute wonderful prizes for our guests to bid on in one of the most spectacular settings in the city. With a full room at the Vancouver Yacht Club, Scott Melville, from the Melville Auction Group, led our guests through the live auction, raising vital revenue for our clinic project. Thanks to the Blue Jazz Trio, some of our guests even tried out their dancing skills.



MONSTER RUN

This year volunteers on Vancouver Island launched a virtual race for NF. Masterminded by Jill Taylor, this event had a successful start in 2017. There are plans to expand the Monster Run in 2018, so if you missed it this year you can lace up your sneakers in 2018.



SCOTIABANK CHARITY CHALLENGE

Thanks to our team of volunteers, who ran and walked at the Scotiabank Half Marathon and Charity Challenge in June, \$12,444 was raised for NF. We also had the opportunity to share the NF message with over 7,000 participants at the booth we hosted at the Charity Village in Stanley Park.



CONCLUSION

Overall, we had a powerful start to 2017. With a board of eight dedicated members, a team of skilled program volunteers, clear priorities, and new fundraising events planned for 2017/2018, the organization is sitting on a stronger Foundation than we have in years.

Transformation isn't always easy.

To rise from the ashes you first have to burn. Our community deserved more than having the organization just disappear so we have risen; to a new world with renewed strength and continued hope for a stronger tomorrow for families living with NF.

HIGHLIGHTS FROM THE TREASURER

Luis Alonso

This year with a new Board of Directors at the helm of the Foundation, we started building a solid base and future of opportunity for the association. We focused on fundraising events that gave us a better return on our efforts, which contributed in part to an increase in revenues compared to prior year. We also reviewed our expenses and eliminated or reduced those that did not add value to our mission. The funds raised together with your donations helped us support various successful initiatives such as the NF



Support Line, awareness campaigns, and research on the NF clinic, among others.

Even though it was a good year in terms of revenues, we need to continue our laser focus on fundraising activities and utilizing our limited resources as efficiently as possible so that our charity can continue to provide its programs and further expand its services to our members, including our efforts to establish the NF clinic.

It takes team effort and resources to organize these activities and it was great to see all Board members participating and getting involved. We would like to encourage all our members to participate: if you have an idea for a fundraising event or other type of community activity please contact our office to explore these ideas and receive guidance and support to make it happen.

Let's all get involved!

We cannot thank all of our donors enough for their continuing contributions and gifts to keep our charity operating and helping achieve the mission of the Foundation. We would like to invite everyone to support us with a donation so that we can continue to assist those affected by NF. You can donate online at tumourfoundation.ca. Everything counts, no matter how large or small, what is important is to be part of this journey.

In closing I want to thank you for helping us empower and enhance the lives of individuals with NF, and our efforts to increase awareness in our community. Together we can help eliminate NF.

Compiled financial statements available on request.

IT TAKES A VILLAGE!

Thank you to all our amazing volunteers who helped out with our programs and fundraisers. We could not have made it through the year without you.

THANK YOU FOR YOUR SUPPORT!

We rely on the generous financial support of our community to sustain our services. Thank you to all of our donors and funders whose gifts made a difference to the lives of many.

Luis Alonso
Shawn Baturin
Noah Billington
Steve Billington
Priyanka Borkar
Jana Brusco
Carmen Chan
Maria Couto
Kelly Fogarty
Laura Galloway
Shannon Gauthier
Mike Gauthier
Laura Hole
Andrea Jones
Maya Kennedy
Lucy Lee

Jenny Lee
Henry Lee
Kathy Leung
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Michael Martin
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Brandy Meisner
Chantelle Ng
Martin Russell
Landon Sellers
Geryy Stolz
Orla Sturgess
Jill Taylor
John Styliano

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Malahat Lions Club
Provincial Employees Community Serv Fund
Sierra Electric Inc.
T.J. Kier Ltd.
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Victoria Foundation
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William Arnold
Nicola Bakker

Gerry Barnes
Jugoslav Bajkin
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Steve Billington & Ms. Candace McGuire
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Don Delcourt
Corrie Delislie
Carole Desormeaux
Dan Dussault
Fatima Feltham
Mark & Melanie Francis

THANK YOU FOR YOUR SUPPORT!

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Denis & Dorothy Goodale
Janet Goodale
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Neil Turley
Ivan & Penny Velan
John Wells
Tracie Wells
Hans & Helga Worster
Peter Yap
Elizabeth Young
Community Gaming Grant, Province of BC

A heartfelt **thank you** to all the donors who supported the Cocktails for a Cure auction and our marathon runners!

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.

Thank you to all of our anonymous donors who generously support our efforts.