

ANNUAL REPORT 2020

Improving the lives of those affected by NF.



**Tumour
Foundation**
of BC



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 tumours grow on nerves throughout the body and can lead to deafness, bone deformities, learning disabilities, disabling pain, and cancer. There is no cure – *yet!*

HISTORY

Paul Ralfs founded the Tumour Foundation of BC in 1984. Paul had a vision that no one living with NF should walk the journey alone. We serve the NF community today because of his dream.

MISSION

Improving the lives of those affected by NF.

VISION

Optimize the health and well-being for British Columbians affected by NF.

BOARD OF DIRECTORS 2019-2020

President	Steve Billington
Directors	Candace McGuire
	Jill Taylor
	John Stylianou
	Alison Watts-Grant
	Shelby Michaels
	Nitin Gaba
	Suneeta Bangar
Executive Director	Desirée Sher
Administrative Assistant	Delina Squire
Social Media Coordinator	Kalika Smith
Community Engagement Coordinator	Brandy Meisner
Web/Tech Support	David Snook

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REPORT FROM THE DIRECTORS

This past year was the Tumour Foundation's time to shine and we couldn't have done it without you!

Our fiscal year kicked off in July 2019 with the publication of a freshly designed *Inspire* magazine, a symposium live-streamed across the province in October, and newly launched support groups in March – we were on a roll!

And then the pandemic struck.

We are proud to share that our programs were not derailed by COVID-19. Our board, staff, and volunteers have worked from remote offices for over a decade and were well positioned to continue supporting the community. Our small staff rose to the challenges of a pandemic, processing a 30% increase in support calls and emails from the NF community during a time of heightened fear and anxiety.

It has not been an easy time for families in BC and around the world. The virus changed the way we live, work, and play. The NF community is, however, no stranger to adversity. We have had families tell us that living with NF is like living with a ticking time bomb: you never know what symptoms of the disorder will arise or when. While the unknowns of the coronavirus and its effect on the NF patient continues, the Tumour Foundation strives to be the light in the darkness for all of those in BC affected by NF.

We continued to focus on the four priorities the Board identified in their strategic plan in the winter of 2019:

1. Increase education that is readily available, current, and diverse;
2. Increase 1:1 connections for people affected with NF and the community to the Foundation;
3. Increase support of medical care services; and,
4. Ensure financial stability.

You once again graciously showed your support for our work in May 2020 when we joined the global Give Now fundraising campaign to raise vital revenue lost because of fundraising events cancelled due to social distancing laws. We were in awe of the generous financial support the community provided at a time when we needed it most.

We are deeply grateful for every volunteer hour that is contributed to the Foundation. Highly skilled individuals from across the community shared their talents and expertise with us to develop new educational materials, implement an online health survey, and provide administrative support.

It is with the support of volunteers and our supporters' generous donations that we can continue our work to improve the lives of individuals and families affected by neurofibromatosis.

With gratitude,

Jill Taylor, President
Desiree Sher, Executive Director



SUPPORT & EMPOWERMENT

The Foundation launched support groups in March 2020. The groups provide an opportunity for patients and families living with NF to meet regularly to build a support community. The groups initially launched as in-person and virtually but went completely online as social distancing was implemented.

tumourfoundation.ca/support-meetings-connections

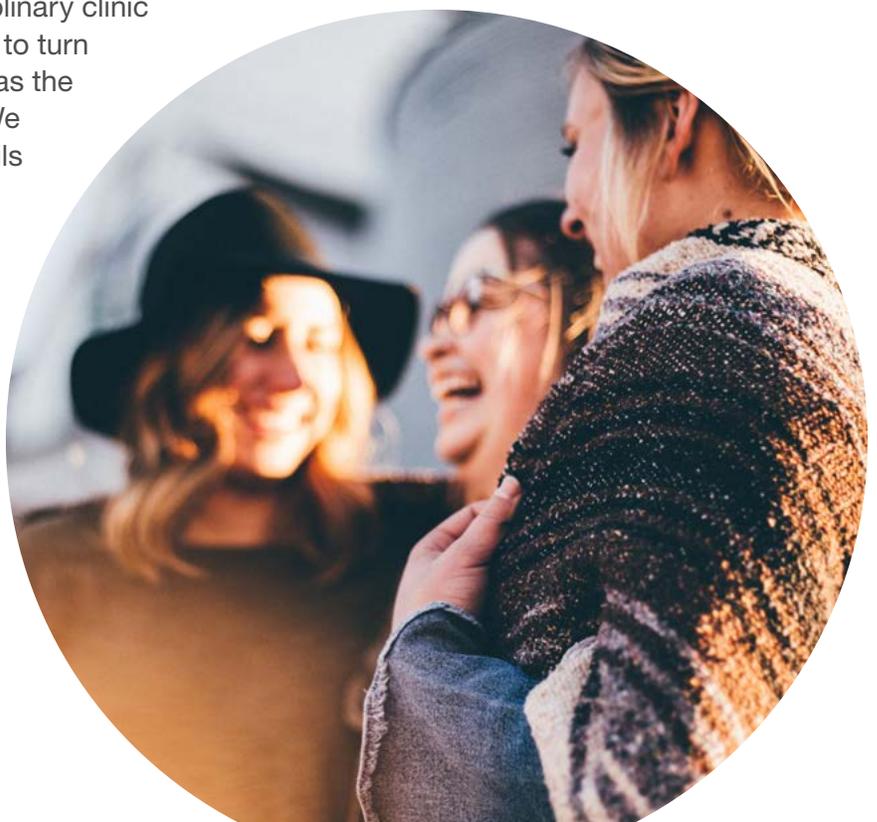
A PHONE CALL AWAY

The Tumour Foundation of BC processes hundred of inquiries each year from families and physicians throughout the province seeking information about neurofibromatosis. Without a multi-disciplinary clinic or any medical expert for the community to turn to, the Foundation has established itself as the source for information on all things NF. We experienced a 30% rise in calls and emails when the pandemic hit this past spring.

You can call 1-800-385-2263 or send an email to speak to our staff about your concerns or requests for resources.

“I LOVE OUR WEEKLY MEETINGS. IT’S SO NICE TO TALK TO SOMEBODY WHO UNDERSTANDS.”

Support Group Participant





EDUCATION

NEW RESOURCE: GUIDELINES FOR CARE OF ADULTS WITH NF1

This year, we produced two new brochures that synthesize the latest research for managing the care and treatment of adults with NF1. We produced one brochure for patients and a second version for physicians. Both of these documents are available to download from our website.

SYMPOSIUM

Providing resources and up-to-date information is an important part of our mission. Last year's symposium was attended by fifty families in person and twenty-five across the province. Historically, meeting face-to-face was one of the highlights of this event where connections and friendships were made.

"Thank you for another great event. Amazing speakers and I learned so much!"

Symposium Participant

EDUCATIONAL AWARDS

For the past eleven years, the Foundation has provided scholarships for youth with NF pursuing post-secondary education. The goal of this program is to provide financial support to students with NF who wish to increase their employability. This year's recipient was a young man with NF1 who is pursuing a degree in Electrical Engineering at the University of Waterloo.

tumourfoundation.ca/scholarship-program

INSPIRE

"Thank you for the beautiful magazine. It arrived just when I hit a difficult time. The stories reminded me there are better days ahead."

Parent of a child with NF

Our Inspire magazine is published yearly and shared with families across the province. This year's magazine was an extended edition with new writers contributing fifty pages of powerful stories and tips for living your best life. You can download your copy from our website.

tumourfoundation.ca/magazine

LEARNING DISABILITIES AND NF

This year, we distributed 738 copies of *A Parent's Guide to Learning Disabilities in NF* to schools and families across Canada and the US. This is a unique resource specific to the learning disabilities that accompany 70-80% of NF diagnoses. If you would like a copy for your child's teacher, counselor, and/or school library, you can download a free copy online or contact the Foundation for a free hard copy.

tumourfoundation.ca/parent-handbook





MEDICAL CARE

In 2018, we launched our research program with a focus on providing micro-financing for NF research. However, there has been little interest in this funding. This caused the Board to rethink our ability to impact NF research. They made the tough decision to begin shifting from funding research to improving the care options available to NF patients once our financial commitments are carried out.

HEALTH CARE SURVEY

This query about how we can improve the care of individuals with NF launched our health care survey in the spring of 2020. The greatest challenges that survey participants identified were:

- **the lack of knowledge and awareness of NF and its subtypes by the public or by physicians;**
- **mental health challenges (like depression or anxiety); and,**
- **lack of support for coordinating care or lack of access to specific forms of care, including educational resources to support learning differences.**

Some also noted social stigma (including difficulties in finding employment) and NF symptoms such as pain or loss of vision. The results of the survey will help to guide the Foundation's activities over the coming years.

You can see the full results of the health care survey on our website:

tumourfoundation.ca/health-survey

NF CLINIC

We continue to be committed to establishing a coordinated NF care clinic. It has not been an easy journey and the vision for our clinic has changed shape throughout the years. However, the Board has committed to the clinic and is in the process of developing an advocacy strategy to move this initiative forward within the provincial government. Join our Facebook page to stay up-to-date on our work in this area, and other programs.

facebook.com/tumourbc

PHYSICIAN REFERRAL NETWORK

In the winter of 2019, the Foundation launched the Physician Health Network, turning to the community for recommendations for medical professionals for other families. After gathering forty referrals, our volunteers set out to contact each physician to ensure they'd take on more NF patients and approve their name to be listed on our website. While only four physicians have committed to being part of the network thus far, we will continue to add to this list as we move forward.





AWARENESS

SHINE A LIGHT ON NF

We once again participated in the Shine a Light for NF awareness campaign. This global campaign has iconic buildings light up in blue or green (the colours of NF) to help bring NF out of the shadows. Despite COVID-19, 167 landmarks in eleven countries helped shine a light on NF! This year was many things – none of it what we planned or expected – and it’s amazing that so many buildings in British Columbia were able to participate despite the challenging times.

- BC Place
- Telus World of Science
- Vancouver City Hall
- Vancouver Trade and Convention Center
- Anvil Centre, New Westminster

LEADERSHIP

At the end of this fiscal year, we said good-bye to two Directors on the Board: Candace McGuire and Alison Watts-Grant. Candace was the driving force behind two of our most successful fundraising events: Cocktails for a Cure and Comedy for a Cure. Her passion and vision to dream big also supported the transition of the Foundation to our new name and clinic plan.

Alison lent her experience of living with NF to become a strong voice for adults with NF in the organization. She helped the Foundation launch the support groups, as it was her belief that that an engaged community is an empowered community.

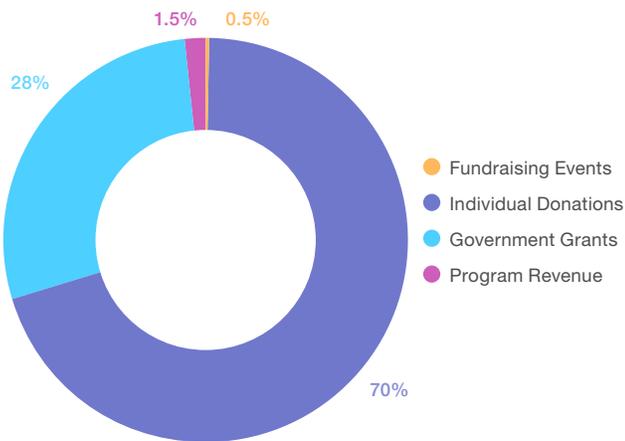
We thank these dedicated volunteers for their work supporting NF families and look forward to seeing them at future events.

“THE SUPPORT OF THE FOUNDATION IN THE LAST MONTHS HAS BEEN INVALUABLE. I APPRECIATE EVERYTHING YOU HAVE DONE FOR ME AND MY FAMILY.”

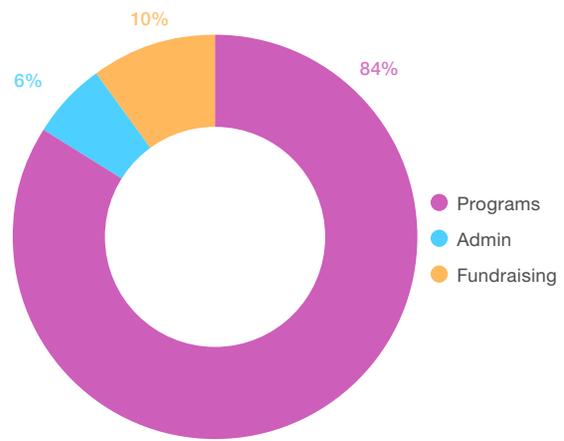




SOURCES OF FUNDS



USE OF FUNDS



For full financial statements please visit tumourfoundation.ca

We are grateful for the continued support of our generous donors that keeps our programs funded. Thanks to your support, we continue to uphold our founder's dream that no one with NF walks their journey alone. Here is a look of our financial performance from July 1, 2019 to June 30, 2020.

HOW YOU CAN HELP

We rely on the support of our volunteers and the financial contributions of our community to deliver our programs. To donate or volunteer, you can visit our website at tumourfoundation.ca or call **1-800-385-2263** for more information.

WE ARE STRONGER TOGETHER.