



ANNUAL REPORT 2022

Improving the lives of those affected by NF.



**Tumour
Foundation**
of BC



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WHAT IS NEUROFIBROMATOSIS?

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

To improve the lives of individuals affected by NF.

VISION

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

BOARD OF DIRECTORS

President	Jill Taylor
Vice-President	John Stylianou
Treasurer	Rajdeep Nijjar
Directors	Fatima Waqar
	Nitin Gaba
	Lauren Yip
	Suneeta Bangar
	(January 2022)

OUR STAFF TEAM

Executive Director	Desirée Sher
Clinic Nurse	Silvana Rangel
Administrative Assistant	Delina Squire
Web/Tech Support	David Snook
Graphic Design	Oculus Design

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Charitable Business No. 13104 1352 RR0001





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REPORT FROM THE DIRECTORS

Despite facing numerous challenges in the second year of the pandemic, the Tumour Foundation of BC has still carried out its mission to improve the health and well-being of patients and families living with neurofibromatosis. This has been achieved through our virtual care clinic as well as our many support and educational programs.

While continuing to navigate challenges that most other Canadian non-profits also face as a result of the pandemic—decreased revenue, increased program delivery costs, staff shortages and a decrease in volunteerism—we have risen to the challenge of meeting the 30% increase in demand for our programs this year.

The NF clinic, which began as a pilot project, is significantly and positively impacting the lives of many. Because of the consultative reports sent to family physicians after a visit at our clinic, patients are accessing treatment they were either previously denied or unaware of. These treatments include, but are not limited to MRIs, genetic testing, breast cancer screening, and electrodesiccation. Additionally, the clinic staff has been instrumental in helping patients access home support services for our most vulnerable community members.

We continue to feel the impact of the pandemic on our initiatives, particularly on our fundraising efforts. While we are brainstorming new fundraising ideas, our team is also focused on writing grants and seeking sponsorships to make future events possible. If you have a unique fundraising idea or would like to sponsor an event, please get in touch with our staff—we'd love your support!

As demand for our clinic and support programs steadily rises, we continue to rely on our generous volunteers and donors to ensure we have the necessary resources to carry out our mission. We are deeply grateful that you are here and walk the NF journey with us. We ask that you continue to open your hearts and get involved by volunteering or making a donation this holiday season.

Respectfully submitted,



Jill Taylor
President



Desiree Sher
Executive Director



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OUR PROGRAMS

NF VIRTUAL CLINIC

In October 2021, despite the challenges presented by the COVID-19 pandemic and the shortage of medical services around the world, the Tumour Foundation of BC launched a pilot project to address the medical needs of adult patients living with neurofibromatosis (NF) in BC. Working with physicians based in the Elisabeth Raab Neurofibromatosis Clinic and housed at the Toronto General Hospital, the Foundation organized online consultations with Canada's most highly regarded experts in NF. As a result of the pilot project, NF patients in BC are accessing specialized care for the first time.

In its first year of operation the clinic provided care to thirty-one adults with NF1 and NF2 across the province's five health regions. Most of the patients who were seen in the clinic had self-referred through our website. However, in recent months more patients are arriving with referrals from family physicians and community agencies such as TELUS Health.

The virtual NF clinic has quickly become a valued service to the patient community. In a recent follow-up survey 100% of the respondents believe that their medical care will improve as a result of the clinic consult. In addition, 100% of the respondents would recommend the clinic to another NF patient.

"Having a specialist to review and synthesize information is valuable. There's no one to tie all the pieces together otherwise. Trying to jigsaw all the various specialists care needs is a challenge. A combined approach to all medical avenues is very helpful."

"I find that it's great to have the recommendations of a specialist to help me better advocate for my care and for me to be taken more seriously to do that."

CLINIC DATA:

92% of patients needed MRIs

58% of the patients received an MRI within 7 months of referral

77% of patients received recommendations for follow up care in the clinic

If you would like to be seen in the clinic you can submit an online referral through our website or call → **800-385-2263** to speak to the clinic nurse.

→ tumourfoundation.ca/clinic



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SUPPORT & EMPOWERMENT

VIRTUAL SUPPORT GROUPS

Our online support groups keep the NF community connected. Patients and parents from across the province join the monthly meetings. Facilitated by our staff, and a nursing student, the virtual group is an uplifting and safe space to share and connect with others facing a diagnosis of NF.

→ tumourfoundation.ca/supportgroup

“I look forward to the meetings as no one in my family has NF and understands tumour pain.”

“I love how the group allows us to share our NF journey but also helps us focus on other things like what we enjoy in life.”



INDIVIDUAL SUPPORT

Requests for 1:1 support continue to be in high demand. Our program staff—including a trained health coach and a community nurse—offer tools and strategies to each caller to navigate their concerns of living with a chronic tumour disorder. Requests for support have increased an additional 30% over last year’s 38% increase.

Additionally, our staff matches newly diagnosed parents and patients with members of our community further along in their NF journey. This year four families asked to be connected. Daily connections are also made on the NF Families’ Facebook page where both parents and patients encourage, support and guide each other.

→ facebook.com/tumourbc

SUPPORT THROUGH TECHNOLOGY

The Foundation is pleased to provide closed-captioning for our hard of hearing community both at events and in the clinic setting. If you require this support to participate in the Foundation’s activities please get in touch as the staff will be happy to arrange the service.

→ info@tumourfoundation.ca



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EDUCATION

NEW RESOURCES AVAILABLE

This year, with input from the patient community, the Foundation published two new NF information sheets: *Self-Monitoring for Malignancies in NF1* and *Cutaneous Neurofibromas in NF1*. This was in response to the questions patients were asking in the clinic setting. You can find these new resources and other information on managing life NF on the website.

→ tumourfoundation.ca/info-sheets/

INSPIRE MAGAZINE

The final edition of *Inspire* magazine will be distributed this fall. We are thankful for the contributions from patients and families over the last nine years that have made the magazine a cherished resource of the Foundation. Increased printing costs, a shortage of writers and a decline in families willing to share their story, have made publishing the magazine increasingly challenging. We will explore alternate ways to share stories, which newly diagnosed families highly value, in the year ahead. You can find all nine editions on the website.

→ tumourfoundation.ca/magazine

SYMPOSIUM

Our symposium is a highlight for many of our families as patients and world-renowned NF clinicians and researchers come together in an informal and educational setting. This year's event will be a hybrid symposium. Families will attend in New Westminster on October 29th while speakers from across North America will join virtually. This year we have speakers addressing the following topics: NF education, patient advocacy, transitioning youth to adult care settings, drug development, clinical trials, mental wellness and patient support. You can find the full agenda for this year's event by visiting the link below:

→ tumourfoundation.ca/events

EDUCATIONAL AWARDS

For the past twelve years the Foundation has provided awards to youth with NF pursuing post-secondary education. In the past year one award was distributed to a youth pursuing a post secondary education at the University of British Columbia in the fields of science and math. If you have a child heading off to university they can apply here.

→ tumourfoundation.ca/scholarship



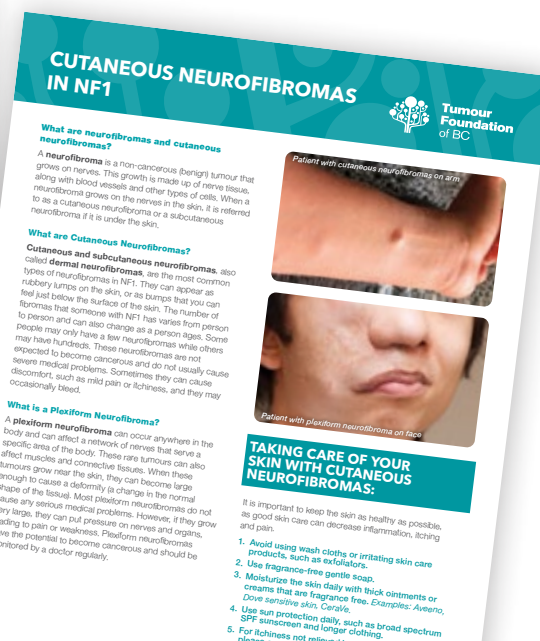
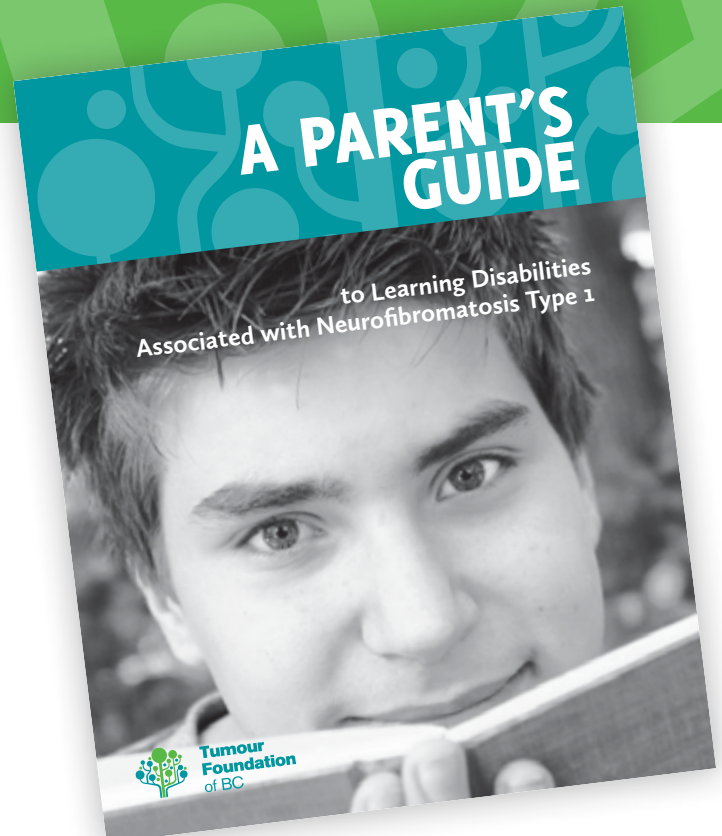


EDUCATION

LEARNING DISABILITIES AND NF

A Parent's Guide to Learning Disabilities in NF is a resource published by the Foundation specific to the learning disabilities that accompany 60-80% of NF1 diagnoses. Over 15,000 copies have been distributed and downloaded to schools and families throughout BC, Canada, the United States and beyond. The guide is now available in Portuguese. Editions in Chinese and Punjabi are coming soon! If you would to share this resource with your child's teacher, counselor, and/or school library, you can download a free copy online or contact the Foundation for a hard copy. Hard copies are only available in English at this time.

➔ tumourfoundation.ca/parent-handbook





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AWARENESS

This year, more than 575 locations, around the world in 14 countries, raised awareness of neurofibromatosis in the Shine a Light on NF campaign. This global campaign has iconic buildings lighting up in blue or green (the colours of NF) to help bring NF out of the shadows on May 17th, World NF Awareness Day.

This year we were excited to welcome new partners which included: The Burrard Street Bridge, New Westminster City Hall, White Rock Pier and The Lookout on Hastings.

We are grateful for the continued support of the following landmarks: BC Place, Bloedel Conservatory, Vancouver City Hall, Science World, Anvil Centre, Canada Place, Lafarge Lake Fountain, Skytrain Guide Pillars & Lights Coquitlam, Telus Garden, Surrey Civic Plaza, Leckie Building and the Olympic Cauldron. You can download tools to invite the landmarks in your community to light up in 2023.

→ tumourfoundation.ca/shine

Additionally, with the support of Pattison Outdoors, we were able to share our message on two billboards in the lower mainland. We are slowly increasing awareness of the services available to the NF community.





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RESEARCH & COMMUNITY COLLABORATIONS

POWER OVER PAIN PORTAL: A STEPPED-CARE VIRTUAL SOLUTION TO EMPOWER CANADIAN YOUTH WITH CHRONIC PAIN

The Foundation has continued its partnership with the research team at Sick Kids Hospital in Toronto for a pain study. The study is for an online platform, co-designed by Canadian youth which chronic pain during the COVID-19 pandemic. It encompasses a participant registration, self-assessment tools, and evidence based virtual educational (pain, neuroscience education) and cognitive behavioural therapy pain interventions that are delivered in a stepped manner based on participant needs/preference. The study is currently undergoing ethic approval. We will begin recruiting youth with NF to participate later this fall.

A VOICE FOR PEDIATRIC LOW GRADE GLIOMAS

The Foundation staff participated in the Canadian Agency Drug Technology and Health (CADTH) multi-stakeholder meetings for the purpose of optimizing the use of real-world evidence for decision making for pediatric low grade gliomas in Canada. It was a powerful opportunity to lend our voice to the meetings of physicians, researchers, government agencies and families. This topic is of particular interest to our community, as approximately 10-15% of children with NF1 will develop a low-grade optic glioma.

LEADERSHIP

Suneeta Bangar stepped down from the Board in January 2022. Her contributions over the time she served the Foundation helped guide the organization through the pandemic.

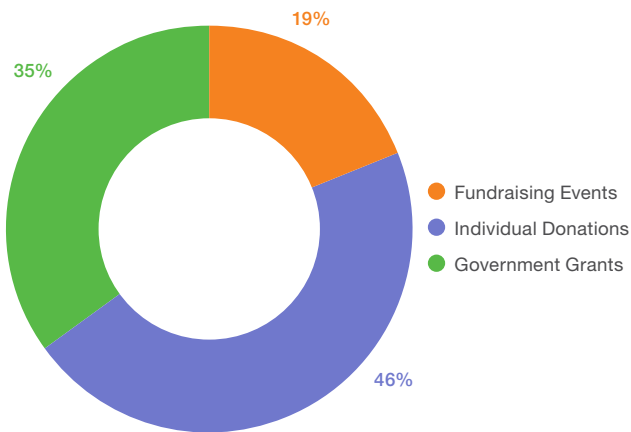
We are currently in the process of recruiting new members for the leadership team.

The Foundation invites energetic, passionate and creative thinkers to join our board. We seek individuals who have experience in the areas of fundraising, marketing and provincial advocacy. Please get in touch with our → **Executive Director** to learn more about the application process.

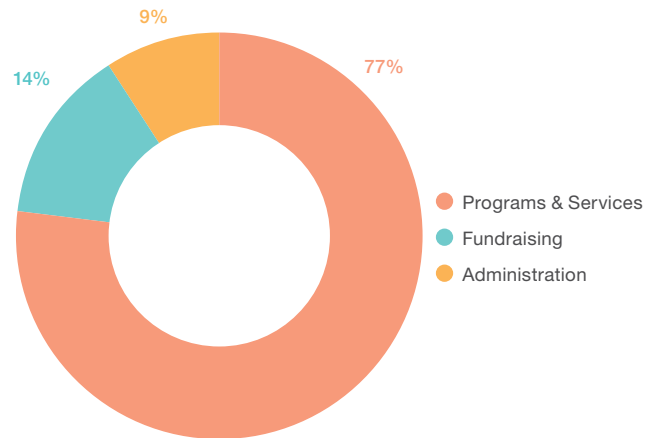




TOTAL REVENUE \$156,293



TOTAL EXPENSES \$178,924



For full financial statements please visit tumourfoundation.ca

FINANCIAL PERFORMANCE FROM JULY 1, 2021 TO JUNE 30, 2022

The 2022 Cocktails for a Cure dinner and auction was a sell-out. We were overwhelmed with support from the business community who generously donated items, gift cards and services to the event. We ask that you please support these local companies with your patronage. You can view the full donor list here:

➔ tumourfoundation.ca/events/auction

After eleven years of running, walking and strolling in the Scotiabank Vancouver Half-Marathon and Charity Challenge our participation in this event has come to an end. We are grateful to have had this opportunity. Over the years \$120,000 was raised to support the clinic development, various research initiatives and other programs. We are excited to bring a new run/walk event to the community in 2024. Stay tuned for updates next spring.

We continue to be grateful for the support received from the Province of BC. Funds awarded to us through the community grant allow the Foundation to provide essential programs and services. We are also thankful for the continued financial support from our individual donors. When we work together we are stronger and ensure that no one with NF ever has to walk the journey alone.

ORGANIZATIONAL GROWTH IN 2021-2022

29% increase in email subscribers

30% increase requests for support, information and advocacy assistance

70% increase in Facebook engagement



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HOW YOU CAN HELP

We rely on the support of our volunteers and the financial contributions of our community to deliver our programs and services. 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.

