



# ANNUAL REPORT 2021

Improving the lives of those affected by NF.



**Tumour  
Foundation**  
of BC



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of BC**

## NEUROFIBROMATOSIS DEFINED

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

President	<b>Jill Taylor</b>
Vice-President	<b>John Stylianou</b>
Treasurer	<b>Rajdeep Nijjar</b>
Directors	<b>Fatima Waqar</b>
	<b>Nitin Gaba</b>
	<b>Suneeta Bangar</b>
	<b>Lauren Yip</b>
	<b>Shelby Michaels</b> (May 2020)

## OUR STAFF TEAM

Executive Director	<b>Desirée Sher</b>
Clinic Nurse	<b>Isabella Bradner</b>
Administrative Assistant	<b>Delina Squire</b>
Web/Tech Support	<b>David Snook</b>
Graphic Design	<b>Oculus Design</b>

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Charitable Business No. 13104 1352 RR0001





## REPORT FROM THE DIRECTORS

As the effects of the pandemic continue to ripple throughout the world, the Tumour Foundation of BC has persisted nonetheless, having faced both growth and challenges over the past year.

Our organization's leadership saw an opportunity as virtual healthcare became increasingly popular and accessible in 2020. As such, we made the decision to launch a pilot project to address the medical needs of adults with neurofibromatosis type 1 (NF1). The launch marked a milestone in the Foundation's twelve-year long journey for a clinic dedicated to the care of the more than 1700 people in BC living with neurofibromatosis (NF).

Yet, individuals of the NF community still experience ongoing hardship as a result of their medical afflictions. In our 2021 community survey of the effects of cutaneous neurofibromas on daily living, pain, anxiety, and depression were the issues identified, as living with NF greatly affects the emotional, physical, and mental well-being of individuals.

While the Tumour Foundation of BC continues to reduce the gap between what resources are needed and what resources are available to manage symptoms, lacking access to specialized care is still an unfortunate reality for British Columbians affected by neurofibromatosis.

With our pilot project beginning this fall, alongside our ongoing support and education programs, we continue to endeavour to optimize the health of people across the province with NF. We couldn't do this work without our dedicated volunteers and you: our generous donors who have supported us during these unprecedented times. We are deeply grateful that you walk the NF journey with us.



**Jill Taylor**  
President



**Desiree Sher**  
Executive Director





## OUR PROGRAMS

### MEDICAL CARE

In 2020, working with a neurosurgeon based at the Toronto General Hospital, we designed a pilot project clinic that would allow a small group of BC-based adult participants with NF1 to have an online consultation with some of Canada's most highly regarded experts in the field of NF.

Within five days of our initial announcement of the project, we received more than 40 requests from individuals wanting to participate. The majority of the requests came from patients who have never seen a physician with expertise in NF and patients who are living with complex symptoms, daily pain, and a great deal of uncertainty. The demand since that announcement has been overwhelming.

We welcomed Isabella Bradner to the team as the clinic nurse. Bella holds a Bachelor of Science in Nursing, with a specialty certificate in Emergency Nursing. She has spent the majority of her career working in rural settings. She has a passion for increasing the accessibility of healthcare to minority groups. You can reach Bella through our website or by calling **1-800-385-2263**.

### FAMILY GRANTS

In June 2021 we established a fund to provide individuals and families affected with neurofibromatosis with financial resources to access specialized care that otherwise would not be possible. The maximum possible contribution for an eligible purchase is up to 50% of the total cost with priority

given to funding specialized therapies and adaptive equipment for families with limited income.

→ [tumourfoundation.ca/family-fund-grants](https://tumourfoundation.ca/family-fund-grants)

### HEALTH MENTOR PROGRAM AT UBC

We encourage our community to engage with the UBC Health Mentors Program. This is a unique educational experience in which groups of students from different disciplines learn from and with mentors who have chronic conditions/disabilities (such as NF) and caregivers who provide long-term care to their loved ones. Our community strives to engage and educate upcoming physicians and healthcare providers on the unique needs of neurofibromatosis.

### SUPPORT & EMPOWERMENT

Monthly virtual support groups keep our community connected. Patients and parents from across the province and extending into the Rockies join our regular meetings. Facilitated by our staff and a nursing practicum student, the online group is an uplifting space to share and connect with others on the NF journey.

→ [tumourfoundation.ca/support-meetings-connections](https://tumourfoundation.ca/support-meetings-connections)



## OUR PROGRAMS

The Foundation's staff receives hundreds of inquiries each year from families and health care professionals throughout the province seeking information about managing and treating neurofibromatosis. We experienced a 38% rise in requests for support and information in 2020-2021.

Additionally, we offer parents and patients the opportunity to connect with others facing similar health challenges. We match newly diagnosed parents/patients with seasoned parents/patients to empower one another. This year, we formally matched eight patients and families in addition to the daily connections that are made on our BC NF Families' Facebook page.

### **SUPPORT THROUGH TECHNOLOGY**

In 2021, we added a video series to our library called NF Stories Live where patients and families are interviewed to share their unique journey with NF. This video series has been very impactful in reaching new families across the province. The series will continue this fall as additional members of the community step forward to bring NF out of the shadows.

→ [tumourfoundation.ca/nf-stories](https://tumourfoundation.ca/nf-stories)

***“THROUGH THE SUPPORT GROUP I LEARNED BECAUSE OF MY NF I NEED TO GET REGULAR MAMMOGRAMS LONG BEFORE MY DOCTOR THOUGHT I SHOULD.”***

*Support Group Participant*

### **YOUTH**

**Power over Pain Portal: A stepped-care virtual solution to empower Canadian youth with chronic pain**

This summer, we partnered with a medical research team at Sick Kids Hospital in Toronto to trial a new app for youth 12-25 dealing with chronic pain. In addition to having youth with NF provide their voice in development workshops, one of our scholarship recipients, Winne Kwan, joined the research team as a patient partner.



# EDUCATION

## NEW RESOURCE: INFORMED SURGICAL CONSENT

This year, we produced a new brochure in response to the many patients asking for support when faced with the decision of having their NF tumours surgically removed. With patient input, we produced a list of questions to ask your surgeon to help make an informed decision about treatment. In the first week of publishing the document, the resource was downloaded and shared almost 1,000 times. You can find the resource at:

→ [tumourfoundation.ca/questions-to-ask-before-your-nf-surgery](https://tumourfoundation.ca/questions-to-ask-before-your-nf-surgery)

Our other new resources, *Guidelines for Care for Adults with NF1* and *The Patient Checklist*, continue to be valuable resources for our community. Patients are regularly downloading this resource and requesting paper copies to share with their health care practitioners. Additionally, in 2021 we sent the updated guidelines to the College of Physicians and Surgeons of British Columbia, urging them to distribute the resource with general practitioners across the province in hopes of improving care.

## SYMPOSIUM

Our symposium is a highlight for many of our families as we bring together patients and world-renowned NF clinicians and researchers in an informal setting. While prior symposiums were offered both in-person and with a live streaming component to bridge the geographical barriers of our province, social gathering restrictions in 2020 limited us to a Zoom event. We are hoping an in-person event will be possible in 2022.

## LEARNING DISABILITIES AND NF

Over 15,000 copies of *A Parent's Guide to Learning Disabilities in NF* have been distributed and downloaded to schools and families throughout BC, Canada, the United States and beyond. This unique resource published by the Foundation is specific to the learning disabilities that accompany 70-80% of NF1 diagnoses. If you would like one to share with 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](https://tumourfoundation.ca/parent-handbook)





## EDUCATIONAL AWARDS

For the past eleven years, the Foundation has provided scholarships to youth with NF pursuing post-secondary education. The goal of this program is to provide students with NF who wish to increase their employability with financial support. This year we awarded three scholarships.

→ [tumourfoundation.ca/scholarship-program](https://tumourfoundation.ca/scholarship-program)

Meet two of the recipients:

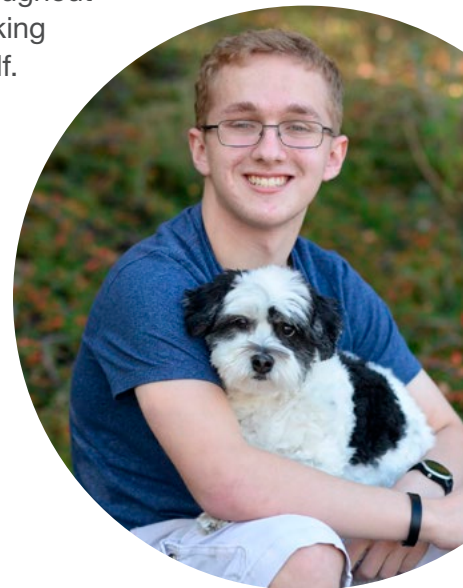
### MEET GABRIEL

Gabriel is an incoming first-year student at UBC. He is an active member of his community, having worked as a mentor for younger students in Kung Fu while balancing a part-time job. Gabriel has always been interested in science and math. “I felt that university is what all my hard work has been leading to, and I can’t wait to begin my studies”, Gabriel shared. He is grateful for the support of the Tumour Foundation, as he says the scholarship will help him turn his passion for STEM into a fulfilling career.



### MEET ERIC:

Eric is an incoming first-year student at UBC Okanagan campus studying Computer Science and Data Science. Eric is a diligent and highly motivated student, having balanced a part-time job at McDonalds with maintaining stellar grades, allowing him to gain entry into his first choice university program. He also participated in a leadership program throughout high school, eventually taking on leadership roles himself. As well, Eric has taken part in an NF clinic trial, which lasted 18 months. Although he was diagnosed early on in his life with NF1, Eric shared that “it has been a difficult road but I do not let it deter me from doing anything”.





## AWARENESS

Educating the public about NF is critical for increasing tolerance for the children and adults who struggle with disfigurement caused by the disorder. We once again participated in the world-wide initiative to Shine a Light for NF. 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 17<sup>th</sup>, World NF Awareness Day. This year, the following local landmarks showed their support: Canada Place, the Trade and Convention Centre, the Olympic Torch, BC Place, Bloedel Conservatory at Queen Elizabeth Park, Vancouver City Hall, Surrey Civic Centre, Leckie Building, and the Anvil Centre. In total, over 300 sites in twelve countries raised awareness of neurofibromatosis.

Additionally, with the support of Pattison Outdoors, we were able to share our message on two billboards in the lower mainland. Coupled with our story in the Richmond News during volunteer week in April, we are increasing awareness of our services available to the community.

### QUICK FACTS FROM 2020-2021

- 37% increase in email subscribers
- 38% increase requests for support, information and advocacy assistance
- 170% increase in Facebook engagement

## LEADERSHIP

Last year Jill Taylor and John Stylianou stepped up to take the helm of the Foundation in the President and Vice-President roles. Their steadfast leadership guided the Foundation through the most challenging time in our history. We appreciate their ongoing commitment to the Foundation and look forward to brighter days ahead.

This spring we said good-bye to our Board member Shelby Michaels. Her contributions in the areas of governance, fundraising and policy development were deeply appreciated.

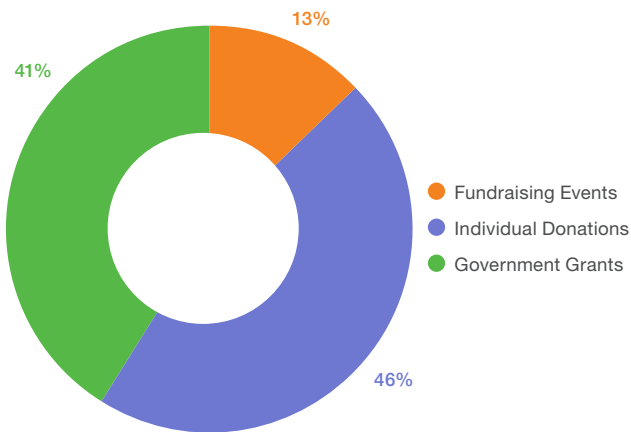
We are always seeking energetic, passionate and creative thinkers to join our board. We need support in the areas of fundraising, marketing and communication, and governance. Please get in touch to learn more if you have time and skills to share with the Foundation.



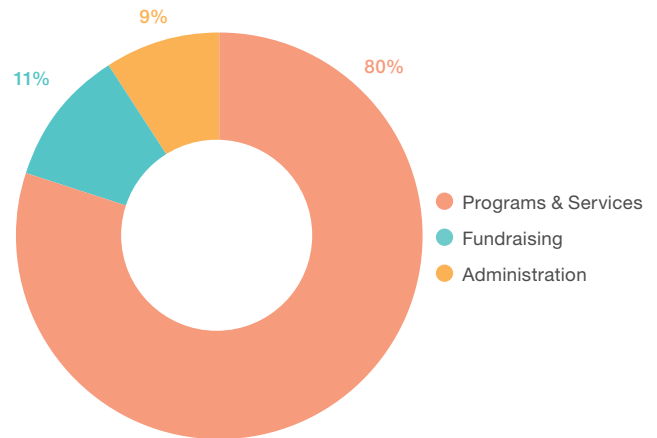




## TOTAL REVENUE \$131,578



## TOTAL EXPENSES \$179,072



For full financial statements please visit [tumourfoundation.ca](http://tumourfoundation.ca)

### FINANCIAL PERFORMANCE FROM JULY 1, 2020 TO JUNE 30, 2021

The ongoing effects of the pandemic drastically impacted our fundraising program this past year. Our annual Cocktails for a Cure dinner and auction gala became a small online auction. Our participation in the Scotiabank Charity Challenge was once again a virtual event, which didn't resonate with our community as "Zoom fatigue" became a new health challenge to cope with.

However, we are grateful for the continued support of our generous donors and the Province of BC for our community gaming grant, which helped keep our doors open in these turbulent times. Thanks to your support, we continue to support our founder's dream that no one with NF walks the journey alone.

### 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](http://tumourfoundation.ca) or call **1-800-385-2263** for more information.

### WE ARE STRONGER TOGETHER.