Tumour
Foundation
of BC

2025

IMPACT REPORT

RESILIENCE AND RENEWAL

A YEAR OF COMMUNITY STRENGTH

For over forty-one years, the Tumour Foundation of BC has been a lifeline for individuals and families affected by neurofibromatosis (NF). This past year tested us like no other. The cancellation of our gala, a national postal strike, and ongoing political and economic uncertainties left the Foundation facing severe financial strain. In our April appeal, we shared openly that without immediate help, our doors could close.

The response was extraordinary. Our community stepped forward through donations, workplace campaigns, and by sharing their stories to raise awareness and revenue. Your collective action ensured our programs not only survived but continued to grow. This year became one of renewal and resilience, proving that together we are stronger than any challenge.

PRESIDENT'S MESSAGE

COLETTE MADSEN

2025 was a year of both challenge and triumph for the Tumour Foundation of BC. Despite early financial uncertainty and the cancellation of our annual gala, the Foundation finished the year strong thanks to the generosity of our community and the tireless efforts of our volunteers and leadership team.

We continued to provide vital support and education to individuals and families living with NF, including the Leadership Summit and Symposium, our educational bursary award, publication of new resources, and awareness-building through a meaningful Skytrain campaigns and community events across the province.

This year also brought transitions in our Board leadership. We bid farewell to long-serving members whose dedication helped shape our Foundation, and we welcomed new voices bringing diverse perspectives and renewed energy. One of our brightest highlights was the return of the Charity Challenge, where our spirited TFBC team of board members and volunteers raised over $18,000 to sustain essential programs and services.

Our renewed focus on community connection led to intimate gatherings and community dinners across BC. These moments reminded us that shared understanding and compassion can ease the isolation often felt by those living with NF.

We are profoundly grateful to our donors, volunteers, and partners who stepped forward when we needed them most. Your generosity and belief in our mission made possible a year of continued service and hope. As we look ahead, we remain steadfast in raising awareness, advocating for specialized NF care, and securing sustainable funding to ensure TFBC, BC’s only organization dedicated to supporting those affected by NF, continues to thrive.

Thank you for being part of our journey of resilience, connection, and care. We are grateful for your ongoing support.

HIGHLIGHTS

BIG YEAR. BIG IMPACTS.

41

Years supporting individuals and families living with NF

500+

People reached through the NF Health Line and direct support

500

Volunteer hours contributed by our incredible community

126,000

Daily commuters saw our SkyTrain campaign through May and June

$18,000

Raised by Charity Challenge participants across BC and Saskatchewan

17

BC landmarks lit up blue and green for Shine a Light on NF

80%

Facebook engagement

36%

Instagram reach

168%

Content interaction

REIGNITING EVENTS AND FUNDRAISING

CHARITY CHALLENGE RETURNS WITH $18,000 RAISED

After a multi-year hiatus, we proudly brought back the Charity Challenge. Fourteen community members ran and walked both locally and across BC and Saskatchewan, raising vital resources for the Foundation's programs. Beyond the dollars, the event brought energy and joy, showing the power of movement and togetherness. Families, patients, and supporters proudly wore the NF shirts, raising awareness in their communities. We look forward to welcoming even more participants at our 2026 Charity Challenge in June.

A NEW NIGHT OF GRATITUDE AND IMPROV

This year also saw the birth of a new donor event: A Night of Gratitude and Improv. The evening was simple yet powerful, blending community connection with laughter. Donors, physicians, and families celebrated together, and two physicians were honoured with the NF Star Awards for their dedication to caring for patients with NF. Feedback was resoundingly positive, with attendees remarking on how refreshing it was to have an event rooted in appreciation and ease.

"What a fun evening TFBC put on. It was good to laugh."

"The event was light and breezy. I loved it."

I was really touched by the whole evening. My wife and I also really enjoyed the improv…"

EDUCATION AND ADVOCACY

CREATING SAFE SPACES FOR CONNECTION AND LEARNING

Thanks to the financial support from Alexion and the Province of BC, we continued to provide safe and supportive spaces where the NF community could come together. From our annual symposium to local community gatherings in Vancouver, Kelowna, and New Westminster, families had the chance to connect, learn, and share stories. These moments of belonging are at the heart of our mission.

“This was a very meaningful day. Thank you for your incredible work.”

The day went on seamlessly – all of your planning and hard work showed. Your passion for those living with NF and their families is very apparent and appreciated.”

“Excellent symposium for allowing NF community to get together and hear about relevant developments and allow for discussion. This was very much needed.”

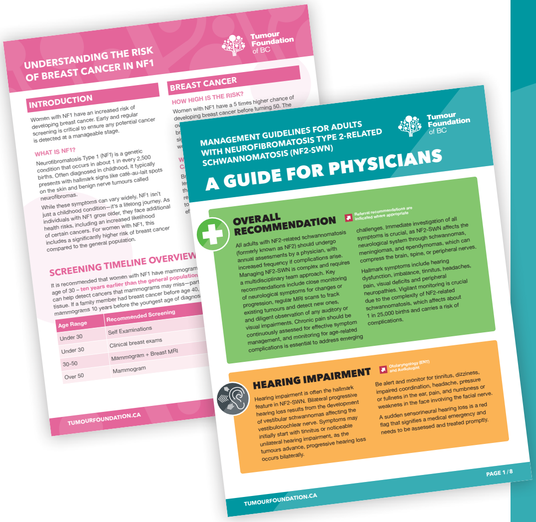
“The community gatherings are really special. I love attending. Please have them again.”

TWO NEW EDUCATIONAL RESOURCES PUBLISHED

We released two new educational tools to help individuals and families navigate the challenges of living with NF.

- **Breast Cancer Risk for Women with NF1**, a first-of-its-kind resource in BC to raise awareness of critical health risks.
- **Management Guidelines for Adults with Neurofibromatosis Type 2 (NF2-SWN)** designed to empower patients and improve physician knowledge of this rare and complex condition.

Both resources are already in circulation, filling gaps in care and supporting individuals in advocating for themselves. They can be → **downloaded from our website**.



UNDERSTANDING THE RISK OF BREAST CANCER IN NF1

Tumour Foundation of BC

INTRODUCTION

Women with NF1 have an increased risk of developing breast cancer. Early and regular screening is critical to ensure any potential cancer is detected at a manageable stage.

WHAT IS NF1?

Neurofibromatosis Type 1 (NF1) is a genetic condition that occurs in about 1 in every 2,500 births. Often diagnosed in childhood, it typically presents with hallmark signs like café-au-lait spots on the skin and benign nerve tumours called neurofibromas.

While these symptoms can vary widely, NF1 isn't just a childhood condition—it's a lifelong journey. As individuals with NF1 grow older, they face additional health risks, including an increased likelihood of certain cancers. For women with NF1, this includes a significantly higher risk of breast cancer compared to the general population.

SCREENING TIMELINE OVERVIEW

It is recommended that women with NF1 have mammogram
age of 30 – ten years earlier than the general population
can help detect cancers that mammograms may miss—part
tissue. If a family member had breast cancer before age 40,
mammograms 10 years before the youngest age of diagnos

Age Range	Recommended Screening
Under 30	Self Examinations
Under 30	Clinical breast exams
30-50	Mammogram + Breast MRI
Over 50	Mammogram

BREAST CANCER

HOW HIGH IS THE RISK?

Women with NF1 have a 5 times higher chance of developing breast cancer before turning 50. The

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MANAGEMENT GUIDELINES FOR ADULTS WITH NEUROFIBROMATOSIS TYPE 2-RELATED SCHWANNOMATOSIS (NF2-SWN)

A GUIDE FOR PHYSICIANS

Tumour Foundation of BC

OVERALL RECOMMENDATION

Referral recommendations are indicated where appropriate

All adults with NF2-related schwannomatosis (formerly known as NF2) should undergo annual assessments by a physician, with increased frequency if complications arise. Managing NF2-SWN is complex and requires a multidisciplinary team approach. Key recommendations include close monitoring of neurological symptoms for changes or progression, regular MRI scans to track existing tumours and detect new ones, and diligent observation of any auditory or visual impairments. Chronic pain should be continuously assessed for effective symptom management, and monitoring for age-related complications is essential to address emerging challenges. Immediate investigation of all symptoms is crucial, as NF2-SWN affects the neurological system through schwannomas, meningiomas, and ependymomas, which can compress the brain, spine, or peripheral nerves.

Hallmark symptoms include hearing dysfunction, imbalance, tinnitus, headaches, pain, visual deficits and peripheral neuropathies. Vigilant monitoring is crucial due to the complexity of NF2-related schwannomatosis, which affects about 1 in 25,000 births and carries a risk of complications.

HEARING IMPAIRMENT

Otolaryngology (ENT) and Audiologist

Hearing impairment is often the hallmark feature in NF2-SWN. Bilateral progressive hearing loss results from the development of vestibular schwannomas affecting the vestibulocochlear nerve. Symptoms may initially start with tinnitus or noticeable unilateral hearing impairment, as the tumours advance, progressive hearing loss occurs bilaterally.

Be alert and monitor for tinnitus, dizziness, impaired coordination, headache, pressure or fullness in the ear, pain, and numbness or weakness in the face involving the facial nerve.

A sudden sensorineural hearing loss is a red flag that signifies a medical emergency and needs to be assessed and treated promptly.

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SCHOLARSHIP RECIPIENT: KATY LEVESQUE

The Foundation has provided ten youth with educational awards in support of their post-secondary goals. This year's Tumour Foundation scholarship was awarded to Katy Levesque, a student pursuing her Bachelor of Arts in Psychology at the University of British Columbia, Okanagan.

Diagnosed with NF1 and congenital pseudoarthrosis of the tibia as an infant, Katy has faced both visible and invisible challenges throughout her life. In classrooms, her pain and learning differences were sometimes dismissed, leaving her feeling unseen and misunderstood. Yet, instead of giving up, Katy transformed adversity into motivation. She has learned to view her challenges as a source of strength, fueling her determination to succeed academically and personally.

Thanks to the generosity of our donors, Katy can now focus on her studies with less financial strain. This award not only provides tuition support but also sends a powerful message: she is seen, valued, and supported by her community.

As Katy shared:

> *"I want to continue to see the adversity that I faced as a strength, as it has made me who I am, and I would not take that back. I am so grateful to the Tumour Foundation of BC for giving myself and others with NF this opportunity."*

Katy's story reflects the heart of donor impact-turning challenges into opportunities and building a future filled with possibility.

EXPANDING AWARENESS

Our **SkyTrain Awareness Campaign** continued to be one of our most effective outreach efforts. With our new “Tumours Suck” campaign posters distributed in thethe Expo Line cars which is one of the busiest routes in the city with over 126,000 boardings every weekday we amplified NF awareness. Every day, thousands of commuters saw our message, leading not only to increased visibility but also to new donors and new volunteers joining the cause.

The **Shine a Light on NF** campaign also returned, with seventeen iconic BC landmarks glowing blue and green on May 17th and throughout the month. Each illuminated building was a symbol of hope, reminding families that they are not alone.

CONNECTION AND SUPPORT

A LIFELINE OF COMPASSION

Our small staff of one supported over 500 individuals and families through the NF Health Line and direct connections. Every call, email, and message was answered with compassion and expertise.

> ***“I am not sure what we would have done if we hadn’t found the Tumour Foundation of BC – years ago when it was the BCNF. The staff’s commitment to the NF community and to our family over the years has made a significant difference to how we handled our son’s NF plexiform tumour. The staff at the Foundation are always there listening, researching, and reminding us that we are not alone – a true gift.”***

Even physicians turn to the Tumour Foundation when NF touches their families. In 2025, we provided direct support to a parent-physician navigating their infant’s NF diagnosis. Through ongoing conversations, Foundation staff offered perspective and reassurance, shifting the focus away from overwhelming research toward celebrating the joy of early parenthood.

COMMUNITY DINNERS: FINDING BELONGING AND FRIENDSHIP

This year, we hosted smaller community dinners in Kelowna, New Westminster, and Vancouver. These informal gatherings created space for meaningful conversations and genuine connection among parents of children with NF as well as adults living with the condition. The intimate setting allowed participants to share their stories, find common ground, and form new friendships. In total, 29 families joined us around the table, strengthening bonds and building community.

CONNECTING IN NEW WAYS: BUILDING OUR ONLINE COMMUNITY

Our digital platforms continued to be a vital space for connection, advocacy, and awareness this year. Facebook engagement grew by 80%, Instagram reach by 36%, and overall content interaction by 168%. This growth means more families are finding resources, more stories are being shared, and more people are learning about NF than ever before.

We're grateful to Tiffany Coolican for her creative leadership of our social media over the past two years, helping us expand our reach and deepen community connections. As she moves on to new pursuits, we thank her for helping to strengthen and grow our online community.

CELEBRATING EXCELLENCE IN CARE

While the need for a multidisciplinary NF clinic in BC remains urgent, we also celebrate the extraordinary physicians already making a profound difference in the lives of people with NF. To honour their dedication, the Tumour Foundation created the NF Star Award for Healthcare Excellence, an annual recognition of healthcare professionals nominated by patients and families for their exceptional care and compassion.

This year, we were proud to present the 2025 NF Star Awards to **Dr. Brian Westerberg** and **Dr. Juliette Hutkin**.

Dr. Westerberg is known for his skill, honesty, and kindness. Families describe him as not only one of the best in his field, but also a deeply compassionate physician who brings reassurance and even laughter to difficult moments.

Dr. Hutkin has been a steady source of guidance for families navigating NF. Her coordination of care, calm presence, and heartfelt support have brought comfort and clarity through every stage of a child's journey.

We are deeply grateful to both physicians for their exceptional leadership and compassion. They are shining examples of what's possible when expertise and humanity come together in NF care.

STRENGTHENING LEADERSHIP AND BOARD DIVERSITY

This year, the Tumour Foundation continued to strengthen its governance with new directors who bring diverse perspectives, lived NF experience, and professional expertise to guide our future. Their voices ensure our leadership reflects the community we serve and helps shape programs that truly meet families' needs.

We also extend heartfelt thanks to John Styliano and Lauren Yip, who each concluded their terms after many years of service. John's sound financial stewardship and steadfast support helped the Foundation navigate seasons of change, while Lauren's energy and creativity as President inspired successful fundraising and community engagement.

As we express our gratitude for their contributions, we also look ahead to the next chapter of leadership and collaboration in advancing care, awareness, and hope for everyone affected by NF.

VOLUNTEERS

From board leadership to event support, fundraising, and ongoing volunteer roles, community contributed over 500 volunteers hours this year. Their time, skills, and dedication are at the heart of our mission.

CHALLENGES AND COMMUNITY RESPONSE

This past year was not without obstacles. The cancellation of our gala, the disruption of a postal strike during the holiday appeal, and broader economic uncertainty created significant financial strain. Most difficult of all was the loss of our Nurse Navigator role, which had been a vital lifeline for families navigating NF's complexity.

Yet, even in the face of these hardships, the resilience of our community shone through. Families rallied with workplace fundraisers, donors stepped forward with unexpected gifts, and volunteers amplified our voice by sharing their NF stories more widely than ever before. Two individuals, Lia Sherman and Shawn Baturin, mobilized extraordinary networks of support, reminding us of the power of personal leadership in difficult times.

These efforts carried us through one of the toughest financial years in our history. While challenges remain, such as the urgent need for a multidisciplinary NF clinic in BC, we are moving forward with renewed strength. Our community's creativity, courage, and generosity continue to prove that together we can overcome setbacks and create lasting impact.

LOOKING AHEAD

The year ahead is one of renewal and collective action. With the support of Alexion, we will launch a new website—our first major update in nine years—that will improve accessibility and better connect families with resources. We are planning for the 2026 Charity Challenge, expanding our educational resources, and continuing to grow our community gatherings that bring families together in support and solidarity.

But more than programs and events, this year has taught us a vital lesson: when our community shares its stories, change happens. Time and again, we have seen how families opening up about the impact of NF has inspired donors to give, volunteers to get involved, and decision-makers to pay attention. These voices are the most powerful force we have.

For too long, NF has remained in the shadows. It is time to bring our experiences into the light—through conversations with politicians, posts on social media, and the everyday courage of telling our stories to those who may not yet understand. While no one should ever feel pressured to share, each voice adds to a growing chorus that cannot be ignored.

This is especially critical as we look toward our long-term vision: the creation of a multidisciplinary NF clinic in BC. Such a clinic would transform healthcare for our community, providing coordinated, specialized care for a condition that is complex, multisystemic, and too often misunderstood. Other provinces have already begun to take steps forward and, here in BC, we must ensure our voices are strong enough to be heard.

We know from experience that major change requires both advocacy and resources. Large-scale donations, like the one that made a clinic in Toronto possible, begin with awareness—and awareness begins with us. Each story told, each connection made, and each conversation sparked has the potential to move us closer to this reality.

The power of our community has carried us through hardship before, and it will be the key to building the future we envision. Together, we are not only surviving—we are thriving, amplifying, and shaping a brighter future for everyone living with NF.

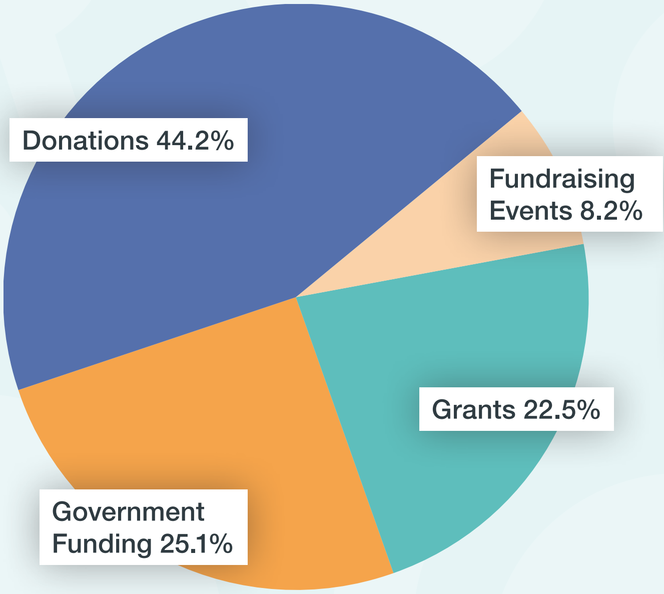
FINANCIAL OVERVIEW

This year presented significant financial challenges for the Foundation, with early declines in revenue due to the cancellation of our gala, a postal strike, and shifting donor trends. Yet, thanks to the generosity of our community and the careful stewardship of resources, the Foundation ended the fiscal year on solid footing.

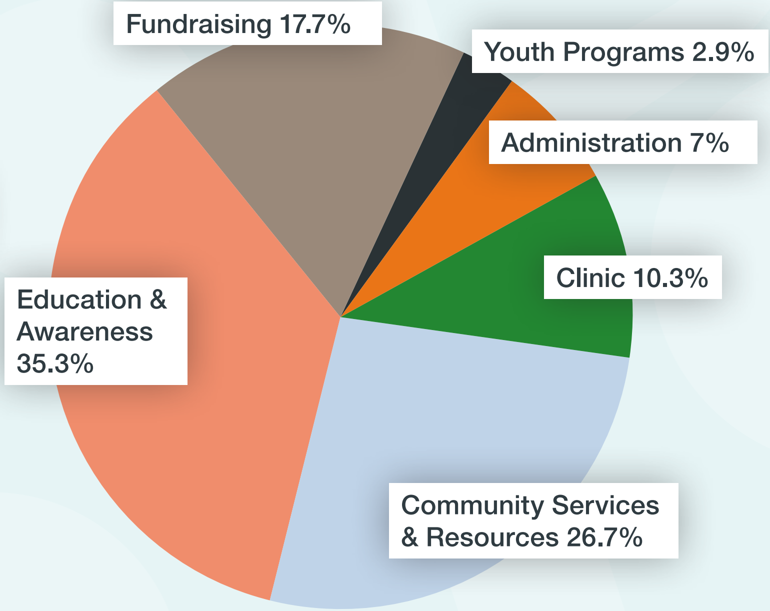
Critical funds were raised through the return of the Charity Challenge, workplace campaigns, and individual donations. These efforts combined with extraordinary leadership from community members who rallied their networks enabled us to sustain and grow our core programs, expand educational resources, and continue offering direct support to families.

We are also grateful for the support of the Province of British Columbia, Alexion, and our new corporate sponsor, Terra Nova Medical Clinic.

Every dollar entrusted to us has been directed with intention, ensuring the greatest possible impact for individuals and families living with NF. While we continue to seek sustainable, multi-year funding for key initiatives such as the Nurse Navigator role, the progress made this year demonstrates both the resilience of our community and our ongoing commitment to transparency and accountability.



REVENUE $207,234



EXPENSES $248,219

FROM THE HEARTS OF OUR DONORS

It takes a community to create lasting change. We are grateful to every donor whose contributions make it possible for us to support families affected by NF across BC.

Every year, we hear from donors who remind us why our work matters.

One donor wrote with her gift:

> ***"Thank you for the work you do… Please don't forget to take care of yourselves, too."***

She even tucked in a Tim Hortons gift card so our staff could enjoy a coffee on her.

A funder who attended the symposium shared:

> ***"I wanted to congratulate you on the successful annual NF symposium this past weekend. Your passion and dedication were truly inspiring, and your hard work brought people together in a meaningful way."***

Another donor wrote:

> ***"I know how tough things are now. I really appreciate all the work you and the Board are doing to keep the Foundation going."***

FUNDING PARTNERS

We gratefully acknowledge our donors and partners whose generosity makes our programs and services possible. Their support strengthens our ability to serve the NF community across BC.

ALEXION

BRITISH COLUMBIA

TERRA NOVA
MEDICAL CLINICS

VICTORIA FOUNDATION

CALL TO ACTION

Are you ready to make a difference? You have the power to change lives for those living with NF. Here are meaningful ways to get involved:

Donate: Every gift matters. Your support helps deliver vital programs and moves us closer to our long-term goal of establishing a multidisciplinary NF clinic in BC. Consider becoming a monthly donor to create lasting impact.

Visit → **tumourfoundation.ca** to donate
or call → **1-800-385-2263** to give today.

Volunteer: Our volunteers are the heart of the Foundation. Whether helping at events, fundraising, or lending professional skills, your time makes a difference. We're also seeking new volunteer directors to help guide our mission. Email → **info@tumourfoundation.ca** to learn more.

Spread Awareness: Share our mission with your friends, family, and online community. Telling your personal NF story is one of the most powerful ways to inspire understanding and action.

Join Our Events: Take part in the Charity Challenge, awareness campaigns, or local gatherings. Every event strengthens our community and expands our reach.

Be an Advocate: Use your voice to promote understanding and call for better access to specialized NF care. Together, we can ensure every person with NF receives the treatment and support they deserve.

Together, we're building a future where no one faces NF alone. Your donation, time, and voice fuel that vision. Thank you for being part of it.

SUCCESS STORY

FROM SMALL STEPS TO BIG IMPACT: BRENDON'S STORY

BRENDON POMMIER

At last year's symposium, Brendon took a brave step outside his comfort zone. Though fearful of public speaking, he chose to share his NF journey with honesty and heart. His words moved many in the audience, reminding us all of the power of authenticity and courage.

That single act of courage has since blossomed into a remarkable journey of impact. Brendon was invited to co-author a manuscript with European NF organizations, contributing his lived experience to a publication on transitioning from pediatric to adult NF care. Soon after, he was asked to bring his perspective and expertise to a collaboration between BC Cancer and the Tumour Foundation, spearheaded by Dr. Rebecca Harrison. This project aims to establish a care pathway for patients with NF1 in British Columbia, an initiative that could transform the future of NF care in our province.

Brendon's story is a powerful reminder that small, personal steps –like finding the courage to share your story – can inspire change far beyond what you imagine. His journey reflects the very heart of our mission: when voices in the NF community are lifted, they create ripples of awareness, advocacy, and progress that benefit us all.

YOUR VOICE MATTERS

Brendon's experience shows us that when stories are shared, they can open doors, spark partnerships, and even shift the healthcare landscape. As we look ahead to continuing with our vision to create a NF clinic in BC, we know that change begins when we come together and speak up. If you feel ready, we invite you to share your own story – with your community, with us, or even with your elected officials. Every story helps bring NF out of the shadows and closer to the care and recognition it deserves.

UNDERSTANDING NF

Neurofibromatosis (NF) is a group of genetic conditions that cause tumours to grow on nerves. Affecting about 1 in every 2,000 births, NF can lead to challenges with hearing, vision, learning, pain, or cancer. Behind every diagnosis is a child, adult, or family. We are here to ensure they never face the journey alone by offering support, connection, education and hope.

OUR MISSION & VISION

History: Our story began in 1984, when Paul Ralfs imagined a world where people living with NF could find strength in community. That vision became the Tumour Foundation of BC, and to this day, his dream fuels our commitment to walk beside every family living with NF.

Mission: To improve the lives of individuals affected by NF.

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

OUR TEAM

The work we do to ensure families don’t face the NF journey alone takes a team both in governance and in daily operations. We are deeply grateful to the people whose leadership, passion, and commitment make our mission possible.

BOARD OF DIRECTORS:

Colette Madsen, *President*
Kirsten Niedner, *Vice-President*
Edie Dullaghan, *Treasurer*
Shawn Baturin
Bernice Chan
Samyuktha Suresh
Lauren Jones

STAFF TEAM:

Desirée Sher, *Executive Director*
Delina Squire, *Administrative Assistant*
David Snook, *Web/Tech Support*
Matt Politano, *Oculus Design*

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tumourfoundation.ca | info@tumourfoundation.ca

Charitable Business No. 13104 1352 RR0001

We gratefully acknowledge that we work and play on unceded xʷməθkʷəy̓əm (Musqueam), səl̓ílwətaʔɬ (Tsleil-Waututh) and Skwxwú7mesh (Squamish) territories.