



# ANNUAL REPORT 2023

Improving the lives of those affected by NF



**Tumour  
Foundation**  
of BC



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Foundation  
of BC**

## WHAT IS NEUROFIBROMATOSIS?

Although not well known, neurofibromatosis (NF) results in one out of 2,500 births. There are over two million individuals affected worldwide. NF causes uncontrolled growth of tumours along the nerves of the brain and body, and can lead to blindness, deafness, severe disfigurement, cancer and death.

## 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	<b>Jill Taylor</b>
Vice-President	<b>John Stylianou</b>
Secretary	<b>Colette Madsen</b>
Directors	<b>Lauren Yip</b> <b>Qi Zhang</b>

## OUR STAFF TEAM

Executive Director	<b>Desirée Sher</b>
Clinic Nurse	<b>Silvana Rangel</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*





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## PRESIDENT'S REPORT

2023 has been another year of record growth for the Tumour Foundation of BC. The demand for our support is higher than ever as new families receive diagnoses and members of our community continue their journeys with NF. In addition to offering our long-term support programs, we tested some new initiatives this year, tailored to the needs of our youth: a mental health support program for teens and a fundraising initiative that resulted in two teens from our community attending an amazing NF Camp hosted by the Children's Tumour Foundation in Utah, USA.

Our Executive Director, members of the Board of Directors, and some very enthusiastic volunteers worked incredibly hard this year to stabilize the finances of the Foundation after the uncertainty and instability of the pandemic years. Thank you to all who donated through our annual appeal, our Cocktails for the Cure gala and auction, our corporate sponsorship program, and other initiatives this year. Your generosity ensures that the Tumour Foundation of BC can continue to support and advocate for families impacted by NF.

The Tumour Foundation of BC is continuing to advocate for a dedicated NF clinic in British Columbia and have met with multiple senior executives in the provincial government this year to share the outcomes of our self-funded clinic pilot project. What does self-funded mean? It means that our community came together to raise enough funds to hire a nurse, to purchase a license for medical

records management, and to navigate countless obstacles in order to prove to the province that a dedicated clinic is not only possible, but desperately needed. In a world where money talks, these actions scream. We only need one person to listen and I hope that we find that person very, very soon. Our community deserves it.

How can you help us find our clinic champion? Contact your Member of the Legislative Assembly (MLA) and tell them that the NF community has waited long enough for adequate medical care in BC. Tell them that our community deserves to have access to medical expertise in our own genetic disorder. Tell them that the standards of care available in other provinces are not offered here. Tell them that the results of these shortfalls can be deadly.

Respectfully submitted,



**Jill Taylor**  
President



## OUR PROGRAMS

### NF VIRTUAL CLINIC

Last November our hearts sank as the pilot project of the NF Virtual Clinic came to a close without securing funding for its continued operation. The disappointment was shared by many in the community, who expressed their frustrations to us. As a result, we currently have sixty-four patients anxiously waiting for follow-up care or their initial consultation, underscoring the urgent need for specialized NF care.

Our dedicated leadership team has continued to engage with both the Provincial Health Services Authority and the Ministry of Health, bringing to their attention the critical care requirements of the NF community. We remain steadfast in our pursuit of funding, but we are mindful that governmental processes often move at a deliberate pace.

Despite these challenges, we are committed to ensuring that individuals in our community receive the care they deserve. Our determination to support the NF community remains unwavering, and together, we can strive for better outcomes.







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## SUPPORT & EMPOWERMENT

### 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](https://facebook.com/tumourbc)

### 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](https://tumourfoundation.ca/supportgroup)

### 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](mailto:info@tumourfoundation.ca)





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## EDUCATION

### **RESOURCES: LEARNING DISABILITIES AND NF - A VALUABLE RESOURCE FOR PARENTS**

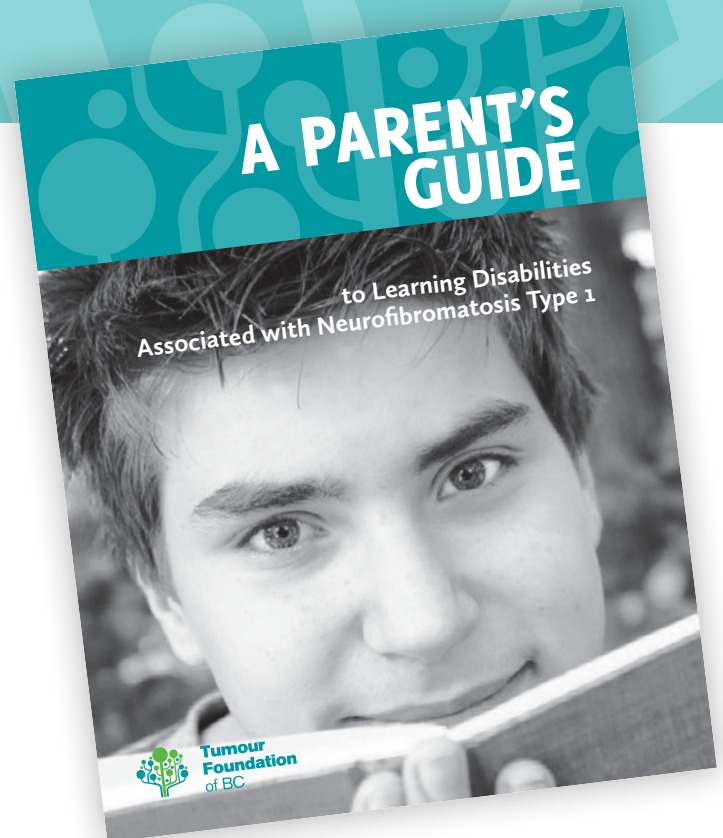
We are proud to have available as a free download **A Parent's Guide to Learning Disabilities in NF**, a comprehensive resource published by the Foundation specifically addressing the learning disabilities that accompany 60-80% of NF1 diagnoses. This invaluable guide has reached an impressive milestone, with over 15,000 copies distributed and downloaded to schools and families not only across BC, Canada, and the United States but also beyond our borders.

**The guide is now available to download in Chinese, Punjabi and Portugese.**

We encourage parents to share this vital resource with their child's teachers, counselors, and school libraries. By equipping educators with a deeper understanding of learning disabilities in NF, we can create more supportive and inclusive learning environments for NF-affected students. You can easily download a free digital copy online, or if you prefer a hard copy, don't hesitate to reach out to the Foundation.

Please note that at present, hard copies are only available in English. Nevertheless, we remain committed to enhancing access and support for families and individuals living with NF, and we will continue working to expand the availability of this resource in multiple languages.

➔ [tumourfoundation.ca/parent-guidebook](https://tumourfoundation.ca/parent-guidebook)



The Tumour Foundation of BC provides a range of supplementary resources designed to support patients and their families. These resources encompass Patient and Physician versions of the **Management Guidelines for NF1**, informational sheets on **Cutaneous Neurofibromas in NF1**, Guidelines for Self Monitoring for Malignancies, and an **Informed Consent Sheet** to help prepare you for your NF Surgery. All of these resources are available for free download from our website.

➔ [tumourfoundation.ca/resources](https://tumourfoundation.ca/resources)



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## EDUCATION

### **SYMPOSIUM: A TRANSFORMATIVE EDUCATIONAL EVENT FOR THE NF COMMUNITY**

Our annual symposium stands as a highly anticipated and cherished educational gathering, providing an invaluable platform for families, patients, and leaders in the field of NF to converge. At this event, we foster opportunities for learning, meaningful connections, and the shared exchange of experiences.

In 2022, we adapted to the changing times by offering a dynamic hybrid event that combined both in-person and virtual elements. This innovative approach allowed us to accommodate a broader audience, ensuring that the symposium reached participants from diverse locations, near and far.

Throughout the symposium, speakers addressed an array of compelling topics, empowering patients and families with essential knowledge and guidance to lead their best lives despite NF's challenges. The diverse range of subjects covered offered valuable insights, fostering a deeper understanding of NF and equipping attendees with practical strategies for navigating their unique journeys.

By bringing together experts, families, and patients in this supportive and informative environment, we believe that each symposium contributes to a stronger, more connected NF community. The shared wisdom, camaraderie, and collaboration during this event resonate far beyond its duration, leaving a lasting impact on the lives of all who participate.

→ [tumourfoundation.ca/events-current](https://tumourfoundation.ca/events-current)

***“THANK YOU SO MUCH FOR EVERYTHING. WITHOUT DAYS LIKE THIS AND THE TUMOUR FOUNDATION I WOULD BE LOST. THANK YOU. THANK YOU. THANK YOU.”***

***“INTERESTING PRESENTATIONS AND HEARTFELT STORIES THAT RESONATE AND RENEW MY COMMITMENT TO STAYING ON TOP OF MY HEALTH CARE.”***

***“THANK YOU FOR DOING THIS. IT'S GREAT TO BE ABLE TO LEARN MORE ABOUT MY NF.”***





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# AWARENESS

## **CELEBRATING GLOBAL AWARENESS: SHINE A LIGHT ON NF CAMPAIGN 2023**

The power of unity and support was on full display during this year's Shine a Light on NF campaign, as over 500 world-famous buildings, bridges, and architectural icons illuminated the skies in vibrant shades of blue and green. Together, they symbolized a global alliance in the fight against NF, showcasing the strength of our collective efforts.

We were deeply honored to have the participation of numerous landmarks from cities across British Columbia, including Vancouver, Burnaby, Coquitlam, New Westminster, Surrey, and White Rock, all of whom joined hands to raise awareness for NF in 2023.

As we continue to build momentum, we were thrilled to welcome Burnaby City Hall as a new partner in the campaign. Their addition to the list of iconic sites brought even more visibility and impact to our cause, shining a beacon of hope alongside esteemed landmarks such as the Burrard Street Bridge, New Westminster City Hall, White Rock Pier, BC Place, Bloedel Conservatory, Vancouver City Hall, Canada Place, Science World, Lafarge Lake Fountain, Skytrain Guide Pillars & Lights Coquitlam, Telus Garden, Leckie Building, Vancouver Convention Centre, and the Olympic Cauldron.

Each illuminated structure served as a reminder that together, we can make a difference in the lives of

those affected by NF. The outpouring of support from these landmarks and communities demonstrates the growing awareness and commitment to finding a cure for NF and providing vital support to those living with this condition.

We extend our deepest gratitude to all the participating landmarks, sponsors, and individuals who contributed to the success of this year's Shine a Light on NF campaign. Their solidarity and dedication bring us one step closer to a world free from NF, and we look forward to continuing this inspiring journey with you all.

→ [tumourfoundation.ca/shine](https://tumourfoundation.ca/shine)







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# AWARENESS

## EMPOWERING AWARENESS THROUGH THE NF TRUTH CAMPAIGN

In May 2023, we embarked on an inspiring journey with the NF truth campaign, aiming to make 'NF' a familiar term in every person's vocabulary. Our primary objective was to shine a light on the challenges faced by individuals with disfiguring plexiform neurofibromas and cutaneous dermal fibromas, especially concerning issues of bullying and victimization. We were determined to raise awareness about NF and foster understanding and compassion within our communities.

To maximize our impact, we strategically placed hundreds of posters throughout the busy Expo line, a transportation hub experiencing an impressive 126,000 boardings per weekday. This widespread exposure enabled us to capture the attention of commuters and passersby, all contributing to our mission of increasing NF awareness.

The results of our initiative were truly heartening. We witnessed a remarkable increase in website visitors and donations, indicating a growing desire within the community to learn more about NF and its impact on individuals' lives. Our efforts on social media were particularly impactful, as we saw a staggering 400% rise in engagement on Facebook, with over 3,200 people reached during the month of May. The consistent daily truths about NF struck a chord with audiences, igniting conversations and expanding awareness about this condition.



The success of the NFtruth campaign demonstrates the power of public education and awareness in effecting positive change. By shedding light on the challenges faced by those with NF and fostering empathy and understanding, we take significant steps towards building a more inclusive and compassionate society for everyone.

We extend our heartfelt gratitude to all those who supported the campaign, whether by sharing the message, donating, or simply taking the time to learn more about NF. Your involvement has been instrumental in our efforts to make 'NF' a part of every person's lexicon, increasing awareness and creating a more supportive environment for individuals living with this condition.



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## YOUTH PROGRAMS

### STEPPING INTO YOUR LIFE - ACT-BASED WORKSHOP

In April, we took a significant step in supporting the mental wellness of our youth community by launching our first-ever Acceptance and Commitment Therapy (ACT) program. This unique four-week workshop was tailored specifically for youth aged 14-18, providing them with invaluable tools and strategies to transition from merely surviving with NF to thriving in their lives.

ACT is a powerful therapeutic approach that encourages individuals to accept the aspects of life that are beyond their control and, instead, commit to actions that enrich and empower them. The core goal of ACT is to help participants create a rich and meaningful life, even amidst the challenges and pain that may arise. By embracing acceptance and committing to positive actions, our young participants were empowered to navigate their NF journey with greater resilience and purpose.

This evidence-based program was inspired by the insights shared by Dr. Staci Martin Peron, one of our esteemed symposium speakers in 2018. Dr. Peron's research showcased the efficacy of ACT in assisting youth with NF to reduce pain, conquer negative thinking patterns, and alleviate anxiety.

While we did not have enough participants to run the program in the spring we are excited to announce that we will be offering this valuable program again in the winter of 2023. We invite all eligible youth with NF to participate in this empowering journey of self-discovery and growth.

At the Tumour Foundation of BC, we are dedicated to continuously expanding our services and initiatives to meet the evolving needs of our community. Our commitment to evidence-based approaches ensures that we provide the most effective and impactful programs, fostering positive change and lasting empowerment.

We extend our gratitude to Dr. Staci Martin Peron for her invaluable research. Stay tuned for more details on our upcoming winter 2023 ACT-based workshop for youth, and join us in stepping into a life of greater resilience, acceptance, and empowerment.

### EMPOWERING YOUTH WITH NF: RELAUNCH OF THE NF CAMP SCHOLARSHIP PROGRAM

At the Tumour Foundation of BC, we deeply understand the feelings of isolation and loneliness that often accompany youth living with NF. In recognition of this, we are thrilled to announce the re-launch of our long-standing NF Camp Scholarship program, made possible with the generous support of individual donors.

For nearly two decades, our Foundation operated the camp scholarship fund, enabling teens with NF to attend the US camp hosted by the Children's Tumor Foundation. This NF camp serves as a transformative experience, offering a safe space where these teens can come together, connect with others facing similar



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## YOUTH PROGRAMS

challenges, and engage in a wide array of activities amidst the beauty of nature.

From rope climbing to horseback riding, the camp provides unique opportunities for personal growth, fostering camaraderie, and forging lasting friendships. Beyond the recreational aspect, the camp places great emphasis on education. To this end, NF specialists are invited to deliver informative talks, enabling camp attendees to gain valuable insights and knowledge about their condition from experts in the field.

The impact of the COVID-19 pandemic on our fundraising efforts forced us to put the NF Camp Scholarship program on hold. The costs associated with sending Canadian youth to the US camp, including tuition and flights, became prohibitive for most families. Nevertheless, this year, our Foundation managed to sponsor two deserving youth to attend the camp in Salt Lake City, which brought immense joy and inspiration to all involved.

Our vision stretches far beyond this, and we are determined to expand the program further. In the coming year, we aim to send 8-10 youth from Canada to the NF camp, providing them with an unforgettable experience that will empower them to face their challenges with resilience and hope.

We extend our heartfelt gratitude to all the donors who have made this revitalized NF Camp Scholarship program possible. Your support changes lives, creating a positive impact on the mental and emotional well-being of young individuals with

NF. Together, we can continue to empower these courageous youth and ensure they have access to transformative experiences that foster personal growth and lasting connections.





## CAMPER'S LETTERS

### FROM KYLEE:

*NF Camp was an amazing experience.*

*Going to camp was my first time being out of Canada and being on the plane. That was such an amazing thing to check off my bucket list. I'm so happy I got to make new friendships and memories. I can't imagine not being able to go to camp. This camp made me feel less alone with my NF journey and the struggles I've been dealing with over the past few years.*

*At camp I got to try many new and fun things, I got to try horseback riding. We also went to an adventure park, water park, museum, and arcade. At the adventure park we went on so many fun rides. My favorite was called the spider. It went so fast and was just so much fun.*

*When we went to the water slides my friends and I went onto a very scary ride. I am really proud of myself for conquering my fear and going down the slide. That was one of my favourite memories! The museum was also really fun and interesting. And when we went to the arcade we also went bowling and that was so fun I didn't care that I came in last.*

*I am so incredibly thankful for the opportunity to attend camp. I would never take this camp for granted. I may be living with a really stressful condition but this camp made me helped me feel less alone and helped lessen my pain.*

### FROM CHEYANNE:

*I had an amazing time at NF camp and met a lot of people from all over the world. It was fun and I loved meeting new people. I have a hard time making friends but when I got to camp it wasn't hard. It was so easy there and I'm so thankful for that. Camp helped make me new friends and show me I am not alone with NF.*

*I love that the leaders had cool names. Milk and Pepper were the best leaders ever. Everyone made me feel welcome and I had so much fun. I wish the food was better and I wish it wasn't so hard to climb the hill to the horses but other than that I had a great time and I really hope I can go back again next year. I'm so grateful for the scholarship so I could experience it.*





## RESEARCH & COMMUNITY COLLABORATIONS

### BEING A VOICE FOR NF1 AND PLEXIFORM NEUROFIBROMAS PATIENTS

At the Tumour Foundation of BC, we are committed to advocating for the needs of individuals with NF1 and plexiform neurofibromas. When the opportunity arose to provide input into the Canadian Agency Drug Technology and Health (CADTH) Review Process for the public funding of selumetinib, our staff went above and beyond, dedicating their time outside of their regular hours to organize a focus group and conduct an online survey to gather valuable data on how NF1 and plexiform neurofibromas impact patients and their families.

The response from the NF community was overwhelming, and we are immensely grateful to everyone who participated in the focus group and shared their experiences with incredible openness and vulnerability. The insights gathered highlighted the significant challenges faced by individuals living with NF1, including the impact on daily living, social activities, and the financial stress that often accompanies a diagnosis. Additionally, the limited treatment options were shown to have a negative effect on the emotional well-being of patients and their families.

As a result of our advocacy efforts and the collaborative input from the NF community, we are pleased to share that selumetinib (Koselugo) has been approved by CADTH for its efficacy, receiving positive recommendations for the

pediatric population affected by NF1 and inoperable symptomatic plexiform neurofibromas. However, we are aware that the journey to access this life-changing drug is still ongoing, as we wait for the pan-Canadian Pharmaceutical Alliance to engage in discussions with the manufacturer to negotiate pricing.

While there may be challenges ahead, we remain steadfast in our commitment to being a strong voice for patients with NF. Through our advocacy efforts and the unwavering support of the NF community, we will continue to work towards ensuring that access to vital treatments and therapies becomes a reality for all those in need.

We are deeply grateful to everyone who has contributed to this important cause. Your courage, determination, and willingness to share your experiences have been instrumental in advocating for improved treatments and better outcomes for those living with NF1 and plexiform neurofibromas. Together, we can create a brighter and more hopeful future for the NF community. Thank you for standing with us on this journey.



## LEADERSHIP

### CHALLENGES AND SEEKING NEW BOARD MEMBERS

The Tumour Foundation of BC, like many nonprofit organizations, has faced significant challenges in the post-pandemic period, resulting in a higher turnover rate and a shortage of volunteers and board members. In 2023, the departure of three valued board members – Mariam Aqeel, Tara Kruyt, and Randy Bassi – marked a transition for our organization. Their dedication and contributions have been invaluable, and we are deeply grateful for the impact they made during their tenure.

Several factors have contributed to the current situation, including the heightened workload and emotional toll experienced by volunteers, leading to burnout and fatigue. The pandemic's economic repercussions have also impacted individuals' ability to volunteer. The lack of in-person interactions has affected motivation and commitment, and virtual fatigue has led some board members to reduce their participation in online activities and meetings.

Despite these challenges, we remain committed to our mission of supporting individuals affected by NF and their families. We recognize the importance of fresh perspectives, energy, and passion in driving positive change. That's why we extend an invitation to our community to contribute their skills and expertise to a cause that truly matters.

By joining our Board, you can play a significant role in shaping our strategies and guiding us through these

complexities. Your involvement will be instrumental in supporting our community and helping us address the current demands and opportunities we face.

As we navigate these unprecedented times, we are dedicated to building a stronger and more resilient Foundation. Together, with your dedication and creativity, we can continue to make a meaningful impact in the lives of those we serve.

If you are passionate about making a difference and contributing to our cause, we encourage you to get in touch with us. Your commitment will help us create a brighter future for individuals living with NF, and together, we can achieve great things for our community.





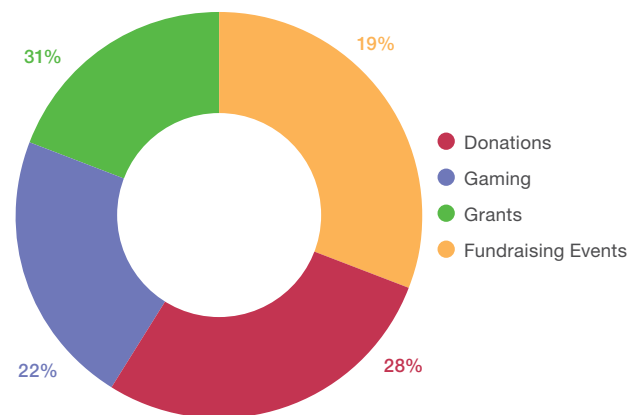
## TREASURER'S REPORT

As we reflect on the accomplishments of the past fiscal year, we are thrilled to share with you the incredible impact your support has had on families with NF1. It is with immense gratitude that we acknowledge the vital contribution from Alexion, which provided essential program funding that fueled our endeavors right from the start of our fiscal year. Their generous backing bolstered our leadership team as we embarked on the annual appeal campaign, brimming with confidence and determination.

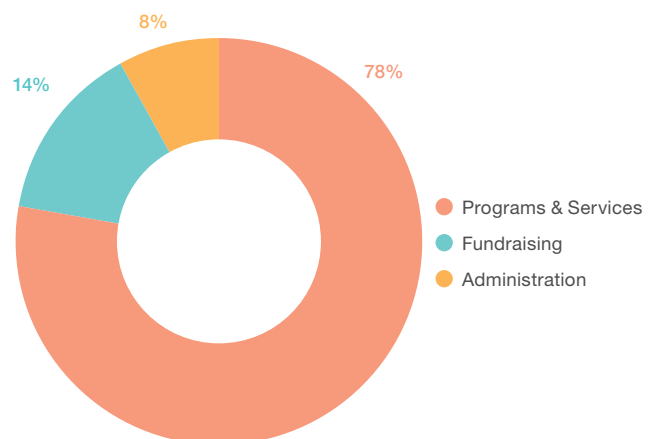
Our small yet dedicated team wasted no time in launching the 2023 Cocktails for a Cure dinner and auction. We were thrilled by the tremendous success of this year's fundraiser, which surpassed all expectations. Thanks to your unwavering support, we witnessed a remarkable doubling of donations compared to the previous year. We were truly awestruck by the contributions of 170 items, gift cards, and services generously provided by 125 small businesses. The event's live auction, expertly hosted by professional auctioneers Scott and Nancy Melville, created an atmosphere where our guests felt comfortable offering their financial support for the most significant items on offer.

We would also like to express our heartfelt gratitude to the Province of BC for their unwavering support. The funds awarded to us through the community grant have been instrumental in allowing the Foundation to provide essential programs and services, making a tangible difference in the lives of those we serve.

## REVENUE \$241,976



## EXPENDITURES \$197,292



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



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Last but certainly not least, we extend our sincere thanks to our individual donors, whose continuous financial support makes our work possible. Your compassion and dedication to our cause inspire us every day, and we are truly humbled by your commitment to making a positive impact on families facing the challenges of NF.

It is through your generosity and unwavering belief in our mission that we can continue to make a meaningful difference in the lives of those who need it most. We are immensely grateful for your partnership and look forward to the opportunities that lie ahead as we continue to work together in the pursuit of a brighter future.



**John (Ioannis) M Styliano** PH.D.  
Treasurer





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## YOU CAN HELP

You can play a crucial role in helping us carry out our mission and make a positive impact in the lives of those affected by NF. Here's how you can support us:

**Donate:** Your financial contributions make a significant difference in enabling us to deliver our programs and services. Whether it's a one-time donation or regular contributions, every amount counts and helps us continue our vital work. To donate, please visit our website at → [tumourfoundation.ca](https://tumourfoundation.ca) or contact us at → **1-800-385-2263** for more information.

**Volunteer:** Our dedicated volunteers are the backbone of our organization. By giving your time and skills, you can make a meaningful difference in the lives of individuals with NF and their families. Whether you can offer your expertise in event planning, fundraising, or providing support to our community, your contribution is invaluable. To learn more about volunteering opportunities please reach out to us at → [info@tumourfoundation.ca](mailto:info@tumourfoundation.ca)

**Spread Awareness:** Help us raise awareness about NF and the challenges faced by those living with this condition. Share our mission and initiatives with your friends, family, and on social media. Together, we can create a greater understanding of NF and build a more supportive community for those affected.

**Join Events:** Participate in our events and campaigns, as they play a significant role in supporting our cause. Whether it's attending fundraisers, awareness events, or educational programs, your presence and support make a positive impact.

**Advocate:** Be an advocate for individuals with NF, promoting inclusivity, compassion, and understanding in your community. By speaking up for those affected by NF, you contribute to a more compassionate and supportive society.

Remember, we are stronger together. Your support, whether through donations, volunteering, spreading awareness, or advocacy, plays a vital role in helping us continue our mission. Together, we can make a difference and create a brighter future for individuals living with NF and their families.

Visit our website at → [tumourfoundation.ca](https://tumourfoundation.ca) or call → **1-800-385-2263** for more information.

## WE ARE STRONGER TOGETHER

