



ANNUAL REPORT 2019

To empower those affected by NF through support, education and awareness.



**Tumour
Foundation**
of BC

EMPOWERING INDIVIDUALS WITH NF



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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

To empower those affected by NF.

VISION

A world without NF.

BOARD OF DIRECTORS 2017-2018

President **Steve Billington**

Directors **Candace McGuire**

Jill Taylor

John Stylianou

Mike Gauthier (Nov 2018)

Danielle Leonardi (Dec 2018)

Kelly Fogarty (Nov 2018)

Executive Director **Desirée Sher**

Administrative Assistant **Delina Squire**

Social Media Coordinator **Tara Sellers**

Social Media Coordinator **Kalika Smith**

Web/Tech Support **David Snook**

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Charitable Business No. 13104 1352 RR0001

REPORT FROM THE DIRECTORS

Looking back over the year, one word comes to mind – GRATITUDE. The Tumour Foundation of BC is so grateful for our growing community of donors and volunteers. We could not do the important work we do without your generous contributions of both time and financial support. It is with your donations we are able to continue to empower the neurofibromatosis community through support, education and research opportunities.

RESEARCH

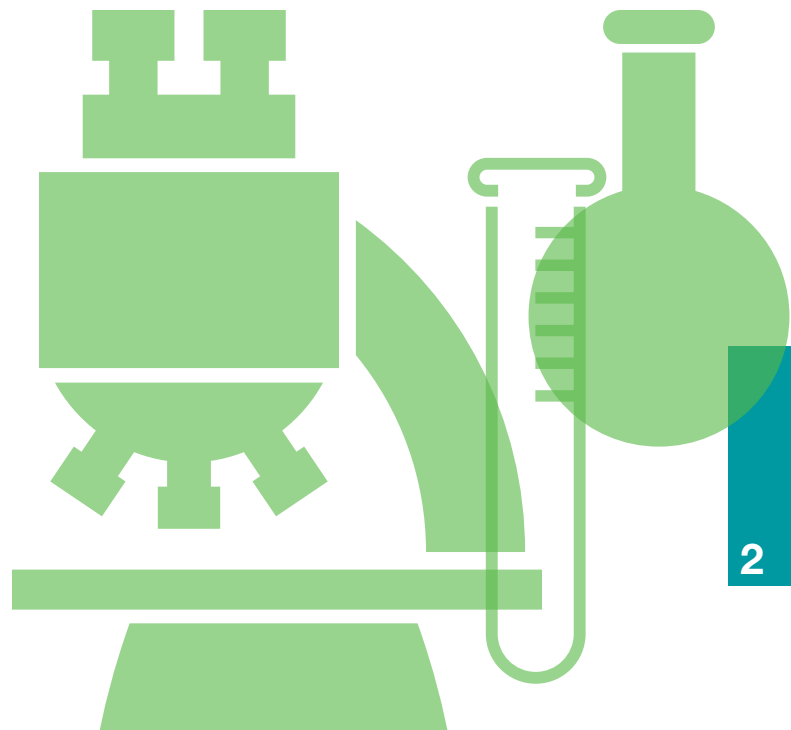
In 2018, The Tumour Foundation launched our research program with a focus on providing micro-financing for NF research. We worked with the Children's Tumour Foundation Clinic Network to share this funding opportunity that provides grants up to \$5,000 to expedite the exploration of new ideas for understanding neurofibromatosis with clinicians and researchers across North America. The next funding cycle is this fall and we eagerly await the applications.

THE NF CLINIC

We continue to be committed to having a coordinated NF care clinic. It has not been an easy journey, and the vision has changed shape throughout the years. However, the Board has generated new partnerships along with some new ideas that we are exploring. These ideas include a free-standing young adult clinic and a virtual clinic you can access using an app on your phone. We are working to turn over every stone to make the clinic a reality.

SUPPORT SERVICES

The Tumour Foundation of BC processes hundred of inquiries each year, from across the province, from families and physicians 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. In 2019, we experienced a rise in calls from general practitioners and pediatricians in remote areas. These medical professionals are also seeking a clinic, where they can refer their complex patients.



EDUCATION

SYMPOSIUM

Providing resources and up-to-date information is an important part of our mission. This year's symposium was moved from the spring to the fall to allow time for staff to locate a more affordable venue. With increasing hotel and catering costs, we moved the 2019 event to a smaller venue in Richmond. The symposium will continue to have the live stream viewing option for families unable to attend.

Despite all the online opportunities to connect with one another, there is a magical synergy that occurs when families come together to connect and share stories in person. This year's symposium agenda was created in direct response to the community who responded to our survey topics. The presentations include inspiring personal stories of overcoming hardships, genotype and phenotype correlation in NF, reproductive options in NF, employment solutions, advocating for your own health care, and more! Visit the website to learn more about this year's event.

EDUCATIONAL AWARDS

For the past ten years, the Foundation has offered scholarships for individuals pursuing post-secondary education. The goal of this program is to provide a little financial support to students with NF who are working to increase their employability. This year's recipient was a young woman with NF1 who is pursuing a nursing degree at the University of BC. She hopes to improve healthcare for the NF community.



RESOURCES & EVENTS

RESOURCES

INSPIRE

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 50 pages of raw and powerful stories and tips for living your best life. You can download your copy from our website.

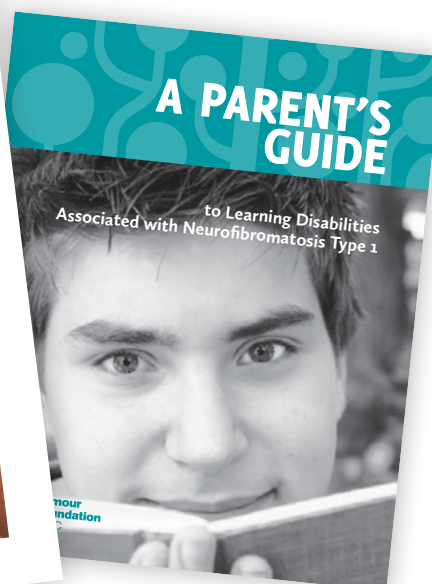
LEARNING DISABILITIES AND NF

This year we received a generous donation to distribute *A Parent's Guide to Learning Disabilities in NF* to schools throughout British Columbia. If you would like a copy for your school teacher, counselor and/or school library please contact the Foundation.

COMMUNITY EVENTS

We offered more community events this year both in Victoria and in the lower mainland. The theme this year was "getting mad about science". Families and children came together to learn in two streams. Parents met with a medical geneticist to deepen their knowledge of NF, while the children learned basic science from the Mad Scientist organization.

On the island, we partnered with Jeneece Place to host our event, bringing families together to learn more from the experts and each other. Witnessing a child who thought they were the only one with NF discovering there are others that like them is a powerful moment. The connections that arise from these events cannot be replicated online. Face-to-face community events build connections and reduce isolation that many people with NF experience. The Foundation is planning more community events for 2020.



FUNDRAISING

FUNDRAISING EVENTS

This year we tried something new for our annual holiday campaign and put together a gift giving guide. The guide offers symbolic gifts that could be purchased for a loved one for the holiday gift giving season. The response was incredible with a 53 percent increase in holiday giving in 2018!

Thanks to the mighty effort of our volunteers, we also continued with our core events of Cocktails for a Cure, Comedy for a Cure, and the Scotiabank Charity Challenge.

Cocktails for a Cure was another lively success! Despite the windstorm that kept our island staff from attending the event, the gala was executed smoothly thanks to the outstanding efforts of a team of volunteers. With both a silent and live auction, our hard working volunteers and generous guests raised \$30,000.

We held our second annual Comedy for a Cure fundraiser in January. This was a stand up comedy event held at the Rio Theatre with three of Canada's top comedians – Charlie Demers, Katie-ellen Humphries and Jacob Samuels. It was a wonderful evening made possible by the Board leadership of Candace McGuire.

We once again participated in the Scotiabank Charity Challenge in June. This year our team of 20 runners and seven fundraisers generated \$6,420. The Board is exploring ways to increase engagement and revenue in 2020 as this event has almost no overhead costs and low impact on our staff, which makes it an event we think has great potential.

COMMUNITY BUILDING

Our Board and staff believe that we are stronger when we work together. The Tumour Foundation of BC continues to have strong partnerships with the Rare Disease Foundation, Friedman Lab, B.C.'s Children's Hospital, and the Children's Tumour Foundation. We continue to explore partnership possibilities with the other NF groups across the country.



AWARENESS & ENGAGEMENT

MAY 17TH PROCLAIMED WORLD NF AWARENESS DAY

This year we celebrated the BC government passing our proclamation to declare May 17th as World NF Awareness Day in our province. This enhanced our ability to persuade more buildings and sites to get on board with the Shine a Light campaign.

SHINE A LIGHT ON NF

We had another great year for the Shine A Light on NF campaign! With the support of the City of Vancouver, we brought NF out of the shadows on World Awareness Day on May 17th. The following buildings and structures lit up in blue and green in support of the campaign:

- BC Place
- Telus World of Science
- Vancouver Trade and Convention Center
- Vancouver City Hall
- Rogers Arena
- Surrey Civic Centre
- Anvil Centre, New Westminster
- Telus Spark in Calgary
- Calgary Tower
- Edmonton High Level Bridge



BOARD DEVELOPMENT

At the end of this year we said good-bye to three dedicated board members: Danielle Leonardi, Kelly Fogarty and Mike Gauthier. We are grateful for the many contributions they gave the Foundation while on the board.

We continue to invite dedicated individuals to join the Board who have a love for fundraising, community building, and governance. If this sounds interesting to you please contact us to learn more.

VOLUNTEERS

Once again, we are so grateful for the dozens of volunteers that contributed hundreds of hours at fundraising and educational events, as well as behind the scenes with administrative tasks. We are working to move our volunteer program to the Purposely.ca online platform. This will allow us to bring volunteers into the organization with greater efficiency and track volunteer contributions with increased ease.

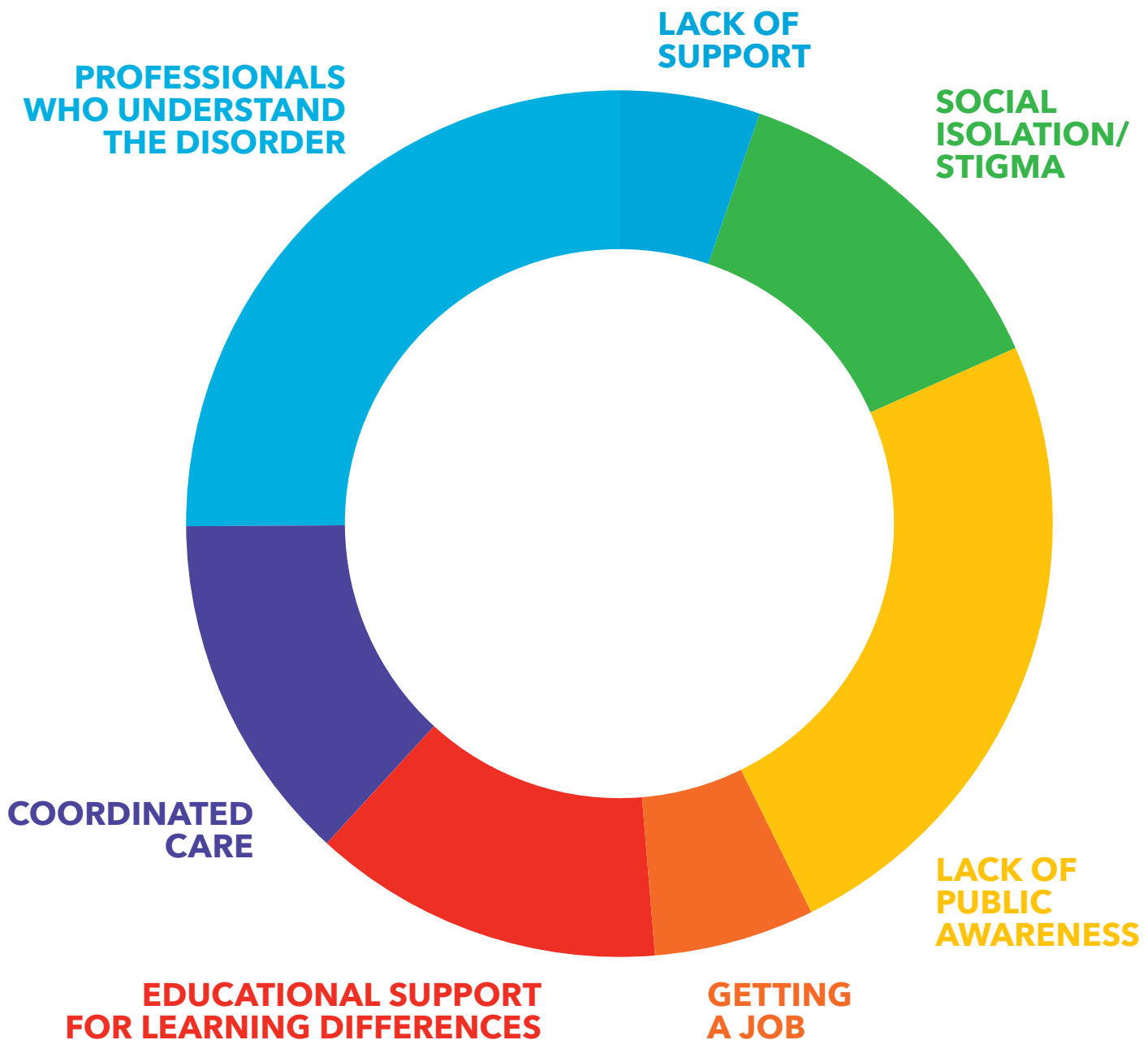


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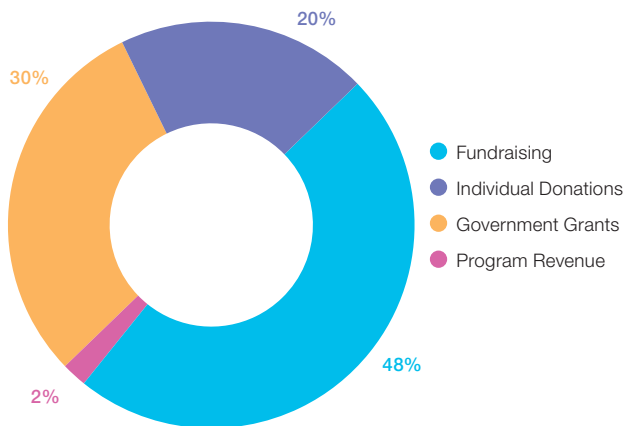
WHAT ARE THE BIGGEST CHALLENGES PEOPLE AFFECTED BY NF FACE?

Self-reported data from our community.

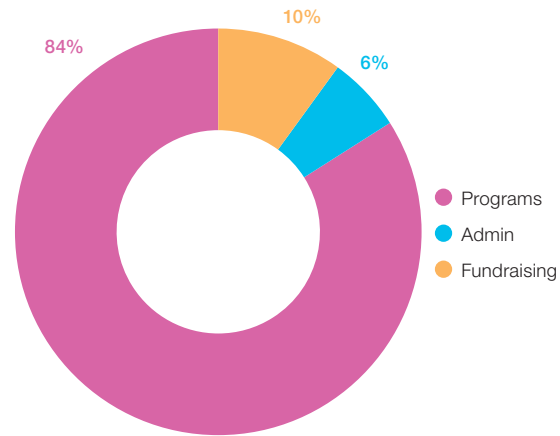


Self-reported data from our community.

SOURCES OF FUNDING



USE OF FUNDS



For full financial statements please visit tumourfoundation.ca

FINANCE REPORT

The Tumour Foundation of BC is grateful for the continued support of our generous donors that keep the lights on and our programs funded. Thanks to your support, we continue our founder, Paul Ralfs', dream that no one with NF walks the journey alone. Above is a look of our financial performance from July 1, 2018 to June 30, 2019.

CONCLUSION

As the Board focuses on the years ahead, they have identified four strategic priorities that the Foundation's team will address:

1. To increase community connections for people affected by NF.
2. Update and diversify NF information .
3. Increase support of medical care services.
4. Ensure financial stability.

HOW YOU CAN HELP

The Foundation, and the NF community, rely on the support of our volunteers and the financial contributions of our community to deliver the programs we offer families living with neurofibromatosis.

To donate or volunteer you can visit our website at tumourfoundation.ca or call 1-800-385-2263.

WE ARE STRONGER TOGETHER.