



# ANNUAL REPORT 2018

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



**Tumour  
Foundation**  
of BC

EMPOWERING INDIVIDUALS WITH NF

## 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 through support, education and awareness.

## VISION

A world without NF.

## BOARD OF DIRECTORS 2017-2018

President **Steve Billington**

Treasurer **Luis Alonso**

Directors **Maria Coutu**

**Jill Taylor**

**Mike Gauthier**

**Danielle Leonardi**

**Candace McGuire**

**Kelly Fogarty**

**John Styliano**

Executive Director **Desirée Sher**

Administrative Assistant **Delina Squire**

Social Media Coordinator **Tara Sellers**

Web Support **David Snook**

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# REPORT FROM THE DIRECTORS

2017/2018 was an incredible year of growth for the Tumour Foundation of BC!

This past year, we experienced ongoing successes in fundraising, increased our volunteer engagement, developed new community partnerships, and provided support to families across the province newly diagnosed with NF.

## RESEARCH

In 2018, we launched our research program with a new focus on providing micro-financing for NF research.

In partnership with the Rare Disease Foundation, we now provide grants up to \$5,000 that expedite the exploration of new ideas for understanding neurofibromatosis and improve patient care. For patients with neurofibromatosis and other rare diseases, **research is care**. This program was made possible thanks to a legacy gift from our founder, Paul Ralfs.

Additionally, we will continue our support of NF research at Friedman Lab through the funding of a summer student research project in 2019.

## THE NF CLINIC

Our goal to have a coordinated care clinic for children with neurofibromatosis, continues to be a priority. Physicians at BC's Children's Hospital recently shared that they continue to push to make this happen. We remain optimistic that a clinic will be available for families in 2019.

## SUPPORT SERVICES

In June, the board made the hard decision to close the NF Support Line. After 18 months of service, we recognized that having just two nights of phone support weren't enough to provide adequate support to our entire community.

We have applied for government funding to hire an additional staff member to expand our 1:1 support services. Our goal for 2019 is to bring back the Family Support Coordinator (a position we had previously cut due to funding shortfalls). In the meantime, our Executive Director continues to respond to queries and provide phone support to patients and families.



# EDUCATION

## SYMPOSIUM

Providing resources and up-to-date information is an important part of our mission. At this year's annual symposium, we brought in speakers from across North America to share their knowledge on living with NF, advances in research, pain management, and mindfulness. The speakers who shared their personal stories of conquering NF also inspired us.

With generous support from the Sick Kids Foundation we were able to livestream the symposium, breaking down the geographical barriers that keep families away from events in the lower mainland. We also provided travel assistance for out-of-town families who wanted to attend the live event.

Sponsorships from Thermal Fisher Scientific and Xenon allowed for an expanded program, including a hot breakfast before the speaker series began.

The backdrop of a snowstorm created some truly magical connections as many of our guests were stranded in the hotel for three days!

## SCHOLARSHIPS

For the past ten years, the Foundation has offered scholarships for individuals pursuing post-secondary education. The goal of this program is to provide students with NF, who wish to increase their employability, with a little financial support. Past recipients have included a student who became a teacher despite having learning disabilities, a music producer who pursued his passion even as tumours robbed him of his hearing, and many other successes. Last year, we did not receive any applications so please share this program with the student in your life. More information can be found on our website.



# RESOURCES AND EVENTS

## RESOURCES

### !NSP!RE

Our !NSP!RE magazine is published yearly and shared with families across the province and globally. Sharing stories, insights, and research, each issue offers hope, information, and up to date resources on living the best life possible with NF.

### LEARNING DISABILITIES AND NF

In 2018 we updated our popular resource: *A Parent's Guide to Learning Disabilities in NF*. This book is free to download from our website and a printed version is available to purchase. We have sold the guide to NF groups throughout Canada and the United States. This year alone we distributed almost 500 copies!



## COMMUNITY EVENTS

### ITALIAN DAYS

In June we participated in the popular Italian Days on Commercial Drive in Vancouver. An event this size, with over 300,000 visitors was a huge undertaking for our staff and volunteers. The day allowed us to share the NF message with a new community, engage in powerful conversations, and promote the services of the Foundation.

### FAMILY TO FAMILY CONNECTIONS

Our summer picnic in Burnaby was filled with good food, games, crafts and new friends! We expanded our family events to Victoria with a Harvest Luncheon last November.

# FUNDRAISING

## FUNDRAISING

### EVENTS

This year, we continued with our core events of Cocktails for a Cure and the Scotiabank Charity Challenge.

**Cocktails for a Cure** (our annual dinner and auction) sold out in 2018! It was a new venue: The Inn at the Quay. With both a silent and live auction, our hard-working volunteers and generous guests raised \$30,000 to fund research.

**The 2018 Scotiabank Charity Challenge** had its best year yet, with nine fundraisers raising over \$17,000 by securing pledges and committing to walk or run the 5km and half marathon events. Our little team was awarded a \$1,500 gift from Scotiabank for having the third highest amount of funds raised per runner!

In the fall of 2017 we added a new event, under the leadership of our board member Candace McGuire – **The Funny Fun Fundraiser**. This was a stand-up comedy event held at the Rio Theatre with three of Canada’s topic comics: Mike McGuire, Kyle Bottom and Mayce Galoni. This event raised almost \$2,000 and, even more importantly, brought our community together to laugh ferociously despite the challenges of living with NF.

The next event is set for January 2019. Stay tuned to the website for more details.

### GRANTS & SPONSORSHIPS

Sick Kids Foundation supported our symposium with a \$5,000 grant. We were deeply grateful for their

support as it is challenging to secure grants with our small community. (Most funders want to see larger numbers impacted.)

This year, thanks to the perseverance of our board member John Stylianou, sponsorships from Xenon and Thermal Fisher Scientific were received to support our symposium. We continue to identify corporations who want to make a difference. If the company you work for has a sponsorship program, please let us know!

### LEGACY GIFTS

We were deeply saddened by the passing of our founder Paul Ralfs in February. Paul’s commitment to the charity rarely wavered for more than three decades. His dedication to the NF community continued with a legacy gift from his estate.



### COMMUNITY BUILDING

***“We are stronger together.”***

Our Board and staff believe that we are stronger when we work together. We have had strong partnerships with Friedman’s Lab, B.C.’s Children’s Hospital, the Children’s Tumour Foundation, and provincial NF groups across the country for decades. This year we were thrilled to build a new partnership with the Rare Disease Foundation. Their board and staff helped us to launch our new microgrant program for which we are deeply grateful!

# AWARENESS

## 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 17<sup>th</sup>. 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



## OUTDOOR CAMPAIGN

With ongoing support from Pattison Outdoor, we once again launched an outdoor awareness campaign in Vancouver, during May, the NF Awareness month. This year we had three large display boards promoting the NF message and charity. One board was located on Broadway and Alberta, the other on Clark Street at Terminal. We additionally had one poster at the ferry terminal in Tsawwassen, which was displayed through to the end of August.

## SOCIAL MEDIA

Our goal to engage more families and increase the awareness of NF led to the hiring of Tara Sellers as our new Social Media Coordinator. Tara is a familiar face to the Foundation, as she has volunteered for over 20 years! By using Facebook and Twitter, we will continue to expand our reach online.

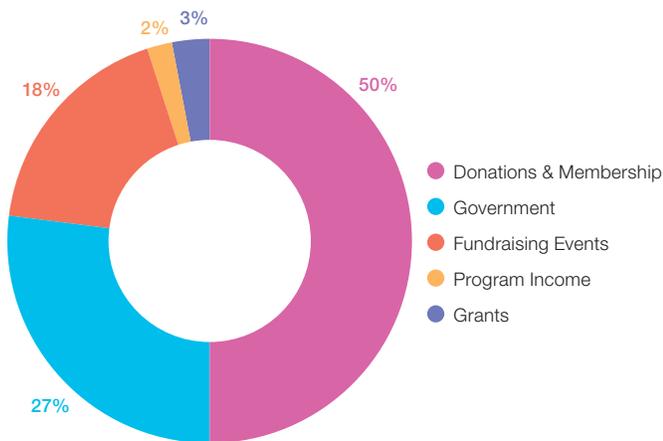


## MAKE YOUR MARK

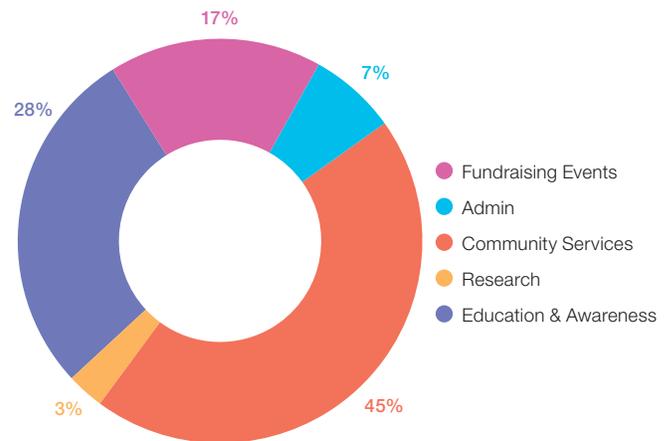
Make Your Mark was a new initiative spearheaded by our member Lisa Lewis. Lisa had the idea to have children with NF draw an image of what NF means to them. From the submissions, the Board selected two of the artistic contributions to be transformed into promotional postcards and bookmarks.



## SOURCES OF FUNDING



## USE OF FUNDS



More detailed financial information is available online.

## BOARD DEVELOPMENT

At the end of this year we said good-bye to two dedicated board members: Luis Alonso and Maria Coutu. We are grateful for the many contributions they gave the Foundation while on the board.

We continue to invite dedicated individuals to the Board who have a love for fundraising and governance.

## VOLUNTEERS

This year we added an online application form to our website to simplify the process for individuals interested in volunteering with the Foundation. In 2017/2018, the organization benefited from forty volunteers who shared their time, skills and talents with us. Volunteers participated at fundraising and educational events, as well as behind the scenes with administrative tasks. If you would like to share your skills and a few hours, impacting the NF community, please visit our volunteer page at [tumourfoundation.ca/volunteer](http://tumourfoundation.ca/volunteer).

## FINANCIAL REPORT

In the 2017/18 fiscal year, the Tumour Foundation continued to build various revenue streams. We raised revenue from individual donations, grants, corporate sponsorships, and multiple fundraising events.

However, it is through the generous support of our committed donors that we have strengthened our Foundation with vital resources. Thanks to your support, we have breathed new life into a charity that has a dream to create a world without NF.

## CONCLUSION

Overall, the Tumour Foundation had another successful year! The rebranding of our charity in 2016-2017 was a leap of faith, but with growing resources, an expanded volunteer base, and increased family engagement, the evidence is clear we made the right decision. In the year ahead, we will continue to work for the coordinated care clinic, widen our research program, and carry on with our founder's dream that no one with NF walks the journey alone.