Directors' Report

May 31 2018

History
Founded as a non-profit in 2008 with charitable status (81932 6224 RR0001) granted in 2009, we operate from Vancouver, BC.

Vision
Revolutionizing rare disease care

Mission
To create communities of patients, caregivers, healthcare providers, researchers & supporters, that work together to transform the lives of those living with rare disease.

Board Members

Dr. Tammie Dewan
Isabel Jordan
Tyler Jordan
Alana Newton
Allison Jones
Dr. Bill McKellin
Dr. Millan Patel
Owen Underhill
Sohail Vaghari

Executive Director
David Cox

Fund Development & Community Engagement Coordinator
Sylvia Eng (June 2018)

Key Initiative Leaders
David Cox / Alana Newton – Rare Finds YVR co-chairs (Vancouver)
Isabel Jordan – National Coordinator, P2P Network
Louise Berezowsky – Rare Finds YEG chair (Edmonton)
Kerstin Mueller –Research Program Coordinator
Kirsten Bartels – Social Media Coordinator
Sohail Vaghari – Information Technology Director
Allison Jones – National Coordinator, Rare Disease Day
Manroop Toor – Vaisakhi Coordinator, Surrey

Volunteer Leaders
Rosemarie Rupps, Vancouver
Jennifer Thompson, Vancouver – Volunteer Coordinator

Peer2Peer and Parent2Parent Resource Network Facilitators

Victoria
Jocelyn Carter-Sim
Sarah Edwards
Lindsay Burnell

Vancouver
Susan Creighton
Allison Jones
Isabel Jordan
Rosemarie Rupps
Jennifer Thompson

Whitehorse
Natasha Phillips
Shannon Ryan
Melanie Boughen
Kyla Flynn

Calgary
Rachel Marten
Brenda McInnes

Edmonton
Louise and Paul Berezowsky
Alison and David Keppler
Meghan and Luke Johannsson
Shaun and Christina Fehr

Regina (Peer2Peer)
Ross McCreery

Winnipeg
Debbie Dutka
Niri Carroll

Toronto
Chris Gilmor
Stacy Hewson

Cobourg
Jennifer Cormier

St. John's
Patty Bryant

Research

The Rare Disease Foundation Microgrant Program continued its growth awarding 83 Microgrants (17% increase over 71 the previous year) for $326K (35% increase over $242K the previous year). As always, research funding was distributed within 3-4 weeks of each competition closing date to immediately start the process of improving the health of children with rare or undescribed diseases.

- To date we have awarded funding to 460 Microgrants for over $1.623 million, which have been distributed to 21 institutions in Canada, 10 in the U.S., and 13 institutions across the Netherlands, UK, South Africa, Germany and Ireland. Past recipients report that they approach ultra-rare or undiagnosed patients differently now that they know that there are funds and institutional support for better care through patient-focused research.

- To date, 11 significant therapies for different diseases have been developed from this program and 15 new genes causing rare diseases have been discovered. In addition, an exercise booklet has been developed for children with mitochondrial disorders for whom exercise can be a two-edged sword, and a better treatment was developed for MELAS - Mitochondrial encephalomyopathy, lactic acidosis, and stroke-like episodes. An educational booklet developed for patients with congenital hypogonadotropic hypogonadism using a microgrant was translated into 20 languages to help patients worldwide with this rare disease.

- We will continue to expand our Microgrant research program abroad through active promotion and communication.

- Thanks to funding provided by two of our premier donors, Angela and Ted Longstaffe, we were able to launch a Minigrant program ($20K - $25K) by funding two projects in February 2017. In 2018 they reloaded the funding bucket for this program allowing it to continue its trajectory of funding innovative advances alongside our existing popular Microgrant program.

- Following a pilot program in call #23 (February 2018) a decision was made to permanently raise the limit on Microgrants from $3,500 to $5,000 effective with call #25 in August 2018.

We continue to develop and enhance our rare disease research program identity by offering a larger grant program and offering our programs more widely to help rare disease patients everywhere.

Our goal is to continue to increase the reach of our programs while maintaining a funding success rate around 50%. We were successful on both counts in the past year, increasing the number of awards given by 17%, expanding to the African continent and maintaining an application success rate of 46%. In conjunction with that goal we are committed to working with our funded researchers to have reports submitted for all completed research projects so we can properly track and report on the outcomes of our research funding program.

Community Building

Our greatest resource as an organization is the community we serve. Our community is made up of rare disease patients, families, and their supporters. This community expands into a greater community of volunteers, researchers, clinicians, and health care providers that support and celebrate our mission.

This has been a year of strong community building behind the scenes – building resources to expand our Resource Network in Whitehorse, Yukon, Regina, Saskatchewan, and Cobourg, Ontario. We continue to build awareness through both new and existing events, primarily P2P Resource Networks, celebrations around International Rare Disease Day (last day of February every year) and other community building opportunities like family picnics.

Going forward our Strategic Plan 2016-2019 formalizes a process to complement our existing Parent2Parent Resource Networks with Peer2Peer Resource Networks for adults with rare disorders, recognizing our long-held belief to provide support wherever possible to all people living with rare disease, not just children. Our specific objective is to grow and nurture our P2P Resource Networks to become the go to representative for rare disease patients and families by;

- Define and formalize relationships (legal and role expectations) with those Resource Networks and Network leaders,
- Establish P2P Resource Networks in smaller communities,
- Provide administrative support necessary to support local Network coordinators
- Improve access to P2P Resource Networks through virtual and webcast technology.

Parent2Parent Resource Network Meetings

We previously produced and released a publication that standardizes the model for P2P Resource Networks to assist new and existing Network coordinators get started and manage the group. Challenges still exist in creating Networks where there is a lack genetic counselling support but we are trying to find other community resources that will provide similar volunteer support as we grow into new areas. We expect that it will be our patient/family facilitators that will take the lead in showing us what will work in their local communities.

Community Events

This past year saw our first-ever donor appreciation event – a cruise around Vancouver's Burrard Inlet and Indian Arm aboard the Oriana, a 96' superyacht kindly loaned to us by Mark Sager, former Mayor of West Vancouver.

There was a community picnic in Vancouver and our Victoria members participated in the local Pride Parade. Each community can find the best ways to connect as volunteers, families and individuals, supported by the Rare Disease Foundation. Coming together outside of our regular Resource Network meetings allows us to know each other better and to work together for shared goals. As our Resource Networks grow, we hope that many more community events are created, each with the flavour and needs of the local rare disease community. Together, each local community can come up with their own ideas, and learn from the ideas of other Resource Networks. This is the beauty of connection.

Rare Disease Day

International Rare Disease Day was on February 28, 2018 and the global theme was 'Research', which fits very well with the mission of this Foundation. The event brought together our multi-centred communities of families, researchers, and clinicians to talk about research, support programs and services. Allison Jones (Vancouver) once again volunteered as National Rare Disease Day Coordinator and we thank her for her ongoing leadership in this area.

With funding from our national sponsor, Shire Canada Inc., we hosted events in cities across

Canada. With the help of local parents across the country we were able to obtain civic and provincial proclamations recognizing Rare Disease Day in many of these cities and in several cases civic flag raisings and special lighting on civic structures.

Many cities hosted similar events that included parent and research speakers, appetizers and a cocktail reception.

We could not have done this without all of the volunteers across Canada who put in their time and effort to make Rare Disease Day a huge success. And none of the celebrations would have happened without the ongoing

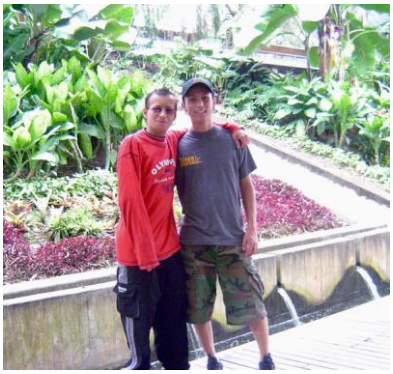
support of Shire Canada Inc. (www.**shirecanada**.com). Rare Disease Day promises to be even bigger and better in 2019 so join us in your nearest city on February 28, 2019.

Website & Social Media Outreach
Our reach on online platforms continued to grow, albeit more slowly compared to the previous year. Website growth has increased by 11%. This slowdown in growth may represent a more sustainable growth, as the previous year was the first that we had two volunteers working on social media outreach. It will be interesting to see what will happen in the coming year or two as we develop a more organized and cohesive social media strategy using analytics to better guide our use.

As with the website, social media channels showed growth but at a slower rate than last year. This is true for at least for Twitter and Facebook where we saw growth of 19% and 11%, respectively, Interestingly, we saw Instagram followers go up by over 30% as we learned how to better use this platform. Again, as we move forward, we hope to use social media analytics and a well-developed strategy to help drive the conversations that will spark engagement. Social media gives us the opportunity to educate and empower, as well as to help us meet our fundraising goals. We're excited about the opportunities moving forward.

Fundraising

We again added to our primary fundraising events to fuel the research and programs that we provide – Lace Up for Kids (UBC Student Recreation) and Rare Finds YEG (Edmonton) and Rare Finds YVR (Vancouver).



Specifically this past year saw events such as Tough Mudder Whistler (Allison Jones), Vaisakhi (Manroop Toor), and the Scotiabank Charity Challenge Run in Vancouver (Bianca Blake) added to our fundraising event calendar. Next year will see our largest-ever fundraising event, Outrun Rare, a cross-Canada record breaking run by Dave Proctor of Okotoks, AB. At press time, Dave had just recently cancelled the run after reaching Winnipeg on schedule. He endured a pre-event injury that simply prohibited him from continuing but he vows to "finish what he started" so we can all stay tuned to learn more about what that means in due course. His goal is to raise $1 million for Rare Disease Foundation in honour of his rare son, Sam and it looks like he will raise approximately $250k in spite of having to stop the run only halfway to his target. We have a number of other smaller but equally amazing events planned throughout the summer and fall of 2018 which we will update in next years' annual report.

Lace Up for Kids

Lace Up for Kids is a wonderful event put on by the University of British Columbia student recreation
department in conjunction with BC Children's Hospital Foundation. In November 2017 they raised roughly $14,000 for Microgrant research awards. There is a commitment to host this annual event again on November 15, 2018 at Thunderbird Arena at UBC. By partnering with UBC Recreation & BC Children's Hospital Foundation, we continue to increase our exposure and advocacy through this Vancouver-based university and BC Children's Hospital communities.

Rare Finds Events

Rare Finds Vancouver proved to be very popular again on April 26, 2018, its 9th year as our premier fundraising event. We raised over $100,000 while experiencing over a dozen of Vancouver's amazing (and generous) chefs, three mixologists concocting unique cocktails and three craft brewers allowing guests to sample their interesting wares. We also had a special guest – Dave Proctor of Outrun Rare – as one of our keynote speakers. This is already our most successful fundraising event, but we see its potential for growth and reputation across the country as we had Rare Finds YEG (Edmonton) in September 2017 set a record for a first-year

Rare Finds event by raising $60,000! Thanks to Stephanie Patel and the super couple of Paul and Louise Berezowsky for making it such a successful and fun event for everyone.

Rare Finds YEG returns on September 15, 2018 with Louise and Paul chairing the event, and big plans are in place to try to outdo their inaugural 2017 results. We are always looking for motivated and creative individuals to lead new events in other cities anywhere in the world.

Grants and other donations
As has been the case for a number of years, our work and organization would not exist if not for the ongoing support of one major private donor family, the Longstaffe's. On behalf of our board, our staff and volunteers, and most especially our affected families, patients and children, we wish to express our sincere gratitude to them for their ongoing support. They have increased their annual contribution to us over each of the past four years and donated a substantial sum by way of a stock donation in 2018. Keep in mind that stock donations have many benefits to both the Foundation and to the donor. If you would like to know more about this giving option, please contact our Executive Director, David Cox. If not for the Longstaffe donations, we would not have been able to launch or maintain our Minigrant program or our future Sibling Appreciation Day events across Canada.

As already mentioned, partnerships and sponsorships are key to our ability to offer programs and services of value. We are entering the third year of a partnership with a private Foundation for a four-year program of support for Microgrant awards to 2020; Shire Canada has been our national partner for Rare Disease Day activities across Canada since 2016 and another private Foundation joined us a partner in 2016 and continues to support the Microgrant program. We use a combination of both local and national partner grants to support and sustain the work of our Resource Networks across the country.

Additionally, we have had the many continuing, smaller donations from individuals through our website as well as through memorials and in honour of family members. As our public profile and recognition grows, we are striving to increase the number of committed monthly donors, as monthly donations are the foundation of every successful long-standing charitable organization. If you haven't done so already, please consider a small monthly commitment to help us in our mission.

Conclusion
2017-18 has been another active year of growth. We are committed to building an efficient and robust infrastructure to support our many activities, but we are still very reliant on our broad cast of wonderful volunteers to activate our organization and engage our members and stakeholders. Communities still hold the ability to grow our capacity to fundraise, build advocacy and expand opportunities for community to direct the research agenda.

Our research program has had numerous successes in both outreach and scope and looking forward, a continued influx of funds will allow it to expand its reach and volume.

Professionalizing our systems, creating capacity, and increasing our profile will all contribute to realizing our community outreach and research goals moving forward to 2019. During 2019 we will be reviewing and updating our 3-year Strategic Plan so we invite you to provide input on our mission and work prior to the end of 2018.