2019

Director's Report

RARE DISEASE FOUNDATION

FONDATION DES MALADIES RARES

History

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

Vision

To revolutionize rare disease care through innovative solutions.

Mission

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

Our Board, Staff & Volunteer Leaders

Board Members

Chris Gilmor
Isabel Jordan
Tyler Jordan
Alana Newton
Dr. Bill McKellin
Dr. Millan Patel
James Radke
Owen Underhill
Sohail Vaghari

Staff

Executive Director
David Cox

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

Fund Development & P2P group Coordinator
Alyson Doughty (October 2018)

Key Initiative Leaders

David Cox – Rare Finds YVR chair (Vancouver)
Isabel Jordan – National Coordinator, P2P Network
Louise Berezowsky – Rare Finds YEG chair (Edmonton)
Chloe Lim – Research Program Coordinator
Sylvia Eng – Social Media Coordinator
Sohail Vaghari – Information Technology Director
Manroop Toor – Vaisakhi Coordinator, Surrey

Volunteer Leaders

Rosemarie Rupps, Vancouver
Jennifer Thompson, Vancouver – Special Events Volunteer Coordinator

This report covers the period: June 1, 2018 to May 31, 2019

Parent 2 Parent Resource Network Leads and Key Volunteers	
Northwest Canada	**The Prairies**
Whitehorse Natasha Phillips Shannon Ryan Melanie Boughen	**Regina** Ross McCreery **Winnipeg** Debbie Dutka Heather Foster
British Columbia	**Ontario**
Vancouver Rosemarie Rupps Susan Creighton Isabel Jordan Dr. Bill McKellin Alana Newton Jennifer Thompson Samantha Lauson **Victoria** Jocelyn Carter-Sim Sarah Edwards Jeannie Denton	**Toronto** Chris Gilmor Stacy Hewson Eriskay Liston Nada Quercia **Cobourg** Jennifer Cormier
Alberta	**Quebec & The Maritimes**
Calgary Rachel Marten Brenda McInnes **Edmonton** Louise Berezowsky Diane Plante	**Montreal** Juliana Arnone **Quebec City** Stephanie Leclerc **St. John's** Patti Bryant

Note from the Chair

The closing of this year has me reflecting on how fortunate I am to work with the rare disease community and with the community of volunteers that make up the Rare Disease Foundation. One of the greatest pleasures has been to work with an engaged and passionate board team in furthering the mission of the Rare Disease Foundation.

In the past two years, we have grown the board with the addition of Alana Newton, Jim Radke, and Chris Gilmor. Alana brings not only her breadth of experience in clinical counseling but a deep and relevant personal experience as a patient and caregiver in the rare disease world. Jim Radke also brings personal and professional experience in the rare disease world. For the first time, with the addition of Chris Gilmor, we have rare disease community representation on our board from outside of British Columbia. We recognize that we need to search for greater diversity and geographic representation throughout or organization.

Although it may sound counterintuitive, I believe our efforts on the board aren't to speak for the rare disease community. We're here not to be a voice, but rather a platform and a microphone for the people that need it most.

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. We have supported and grown our Resource Networks in Whitehorse, Yukon, Regina, Saskatchewan, and Cobourg, Ontario. We continue to build awareness through both new and existing events, primarily P2P Resource Networks, online communities, celebrations around International Rare Disease Day (last day of February every year) and other community building opportunities like family picnics.

Parent2Parent Resource Network Meetings

We previously produced and released a publication that standardizes the model for P2P Resource Networks in order to assist new and existing Network Coordinators get started and manage the group.

Challenges still exist in creating networks where there is a lack of genetic counselling support but we are trying to find other community resources that will provide similar professional 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.

To date, our groups enjoy engaging through four types of activities:

1. Group sharing
2. Educational activities
3. Social activities
4. Reaching out to the community for specific questions

Research

The Rare Disease Foundation Microgrant Program continued to be popular and received extremely generous support by a private Foundation and our Rare Finds Microgrant auction donors.

Microgrant Summary

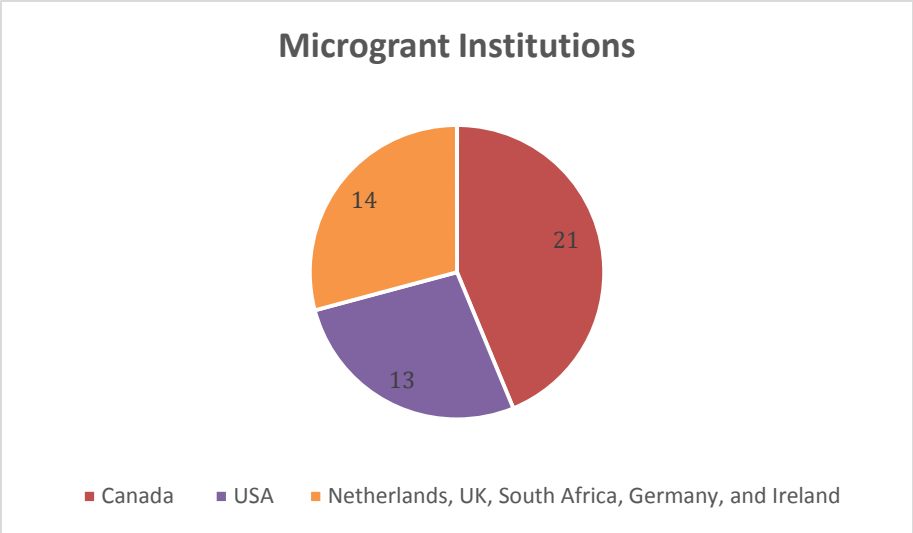
Microgrants 2017-18	Total Value	Microgrants 2018-19	Total Value
84	$326K	63	$365K

The 63 microgrants awarded during 2018-2019 is a 24% decrease in number of microgrants (from 83 in the previous year) but a 9% increase in total value (from $326K in the previous year). This is due to raising the value of a microgrant by 43% to $5,000.

As always, research funding was distributed within 3-4 weeks of each competition's closing date to immediately start the process of improving the health of children and families with rare or undescribed diseases.

Microgrant Distribution

To date we have awarded funding to 534 microgrants totaling over $1.98 million, which have been distributed to 48 institutions on 4 continents.



Results

Since inception of this program, the following results have advanced treatment for rare disease:

- 12 significant therapies for different diseases have been developed
- A number of new clinical algorithms developed
- Dozens of new disease genes found

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.

Microgrant Spotlight

One surprising but unheralded microgrant type is for the translation of a validated instrument. In this scenario, there is a validated tool to guide physiotherapists in how to care for Charcot-Marie-Tooth (CMT), a rare nerve disease, in English.

However, many of the patients are French speaking, so several rounds of translation are required until the original precisely matches the re-translated version. Only then can the tool be considered valid in French.

Solution: By spending a $3,500 microgrant to do this properly, one group has now enabled thousands of CMT patients in 29 French speaking countries to have their physiotherapists care for them using a validated guide that is proven to lead to better outcomes.

Now that's value for money!

Innovative Therapies Program

Thanks to funding provided by our generous donors, Angela and Ted Longstaffe, along with a Foundation who wishes to remain anonymous, we rebranded and relaunched the Minigrant program as the Innovative Therapies Program (ITP).

This program is comprised of $25,000 grants and specifically funds early stage human clinical trials. These early trials are simply the only economical way for good ideas to transition away from the lab bench and into the clinic. By funding small scale human trials, we will allow investigators to generate pilot data that can be used to obtain the much larger grant funding required to do a definitive trial. We want to support today's patients!

We continue to develop and enhance our rare disease research program identity by identifying the gaps in our system and filling them, to help rare disease patients everywhere.

Treasurer's Report

At our financial year-end on May 31st, 2019, the Foundation recognized $886,000 in revenue during the year, compared to $754,000 in the prior year.

We continue to raise funds from general donations, grants, and our Rare Finds events. Revenue this year was significantly boosted by the Outrun Rare cross-Canada attempt which raised just over $300,000.

Our non-program expenses for the year increased due to investment in personnel and spending on the Outrun Rare campaign.

Total non-program expenses were $438,000 vs $244,000 in the prior year. Our main program expense was research funding for our Microgrant and Minigrant/ITP grant programs. We awarded $365,000 in grants during the year, compared to $242,000 in the year prior.

The Foundation finished the year with $825,000 in cash on hand. Our net unrestricted assets were $441,000, compared to $350,000 twelve months earlier. (Unrestricted assets are assets that can be used for any expense or program – they are not limited to a specific purpose.)

Community Events

Each community can find the best ways to connect as volunteers, families and individuals, supported by the Rare Disease Foundation. This year, our community enjoyed a picnic in Vancouver and our Victoria members participated in the local Pride Parade. Edmonton had a campout that was very well attended.

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, 2019 and the global theme was 'Bridging health and social care'. This year's campaign focused on the need to better coordinate all aspects of care to improve the lives of people living with a rare disease. The event brought together our diverse communities of families, researchers, and clinicians to talk about research, support programs and services. Alyson Doughty (Montreal) was National Rare Disease Day Coordinator and we thank her for her leadership in this area.

With funding from our national sponsor, Takeda Canada, 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 our volunteers across Canada who put in considerable time and effort to make Rare Disease Day a huge success. Most importantly, none of the celebrations would have happened without the ongoing support of Takeda Canada. (https://www.takeda.com/en-ca/).

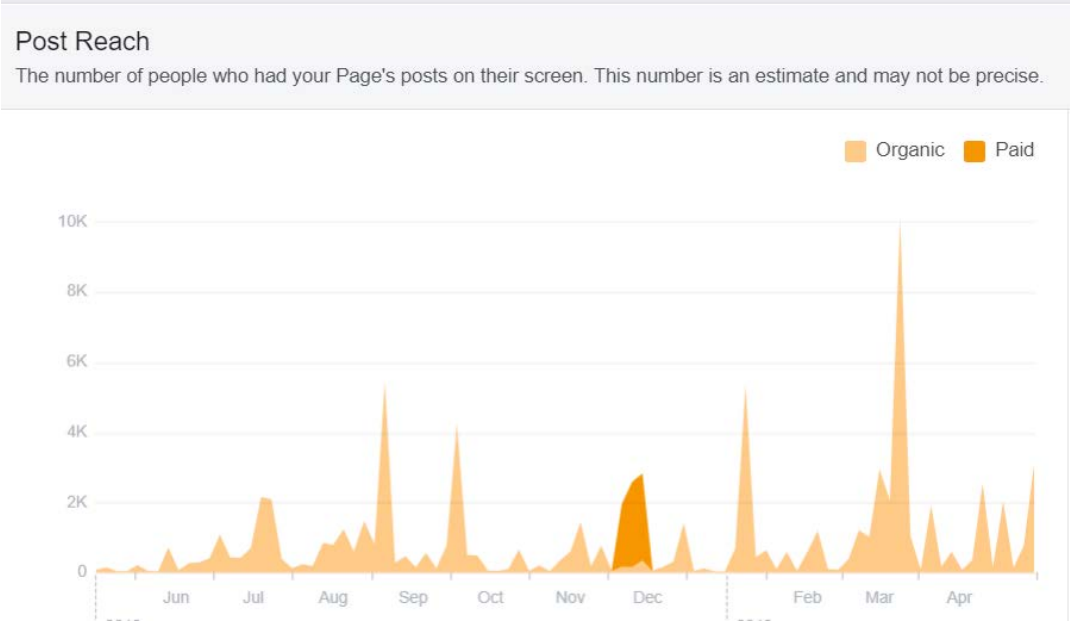
Rare Disease Day promises to be even bigger and better in 2020 so join us in your nearest city on February 28, 2020.

Website & Social Media Outreach

Our three social media platforms (Facebook, Twitter and Instagram) had a combined increase of 2,222 new followers and a reach of 432,133. Facebook had the most significant growth of an increase of 19% in followers over the fiscal year. The social media community continued to become more engaged and respond to the curated content.

An experiment in paid exposure was found to be only equally as effective as organic reach generated through the page content.

Growth During Fiscal Year 2018-2019



RDF Facebook Global Reach

Country	Facebook Fans
United States of America	3,026
Canada	1,887
United Kingdom	290
Australia	176
India	101
Brazil	62
Mexico	61
Italy	57
Portugal	45
South Africa	45

Fundraising

We expanded our primary fundraising events further this year to fuel the research and peer resource programs that we provide.

Our 2018-2019 events consisted of:

- Lace Up for Kids (UBC Student Recreation)
- Rare Finds YVR (Vancouver)
- Rare Finds YEG (Edmonton)

We also laid the groundwork for a 2019 Rare Finds YUL (Montreal) event.

Other noteworthy events included:

Vaisakhi Parade in Surrey, B.C. where we hosted a hospitality tent on the parade route amidst 40,000 revelers (Manroop Toor)

Scotiabank Charity Challenge Run in Vancouver where ultra-athlete Dave Proctor from Outrun Rare had many supporters wearing RDF orange.

This year we integrated the Intellectual Property and team from Outrun Rare, a cross-Canada record breaking run planned for 2020 by Dave Proctor of Okotoks, Alberta. Dave is a supremely passionate voice for rare disease in Canada and we are very grateful to have the privilege of working with him and the superb team he has assembled at Outrun.

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. On November 15, 2018 they raised over $18,000 for Microgrant research awards. By partnering with UBC Recreation & BC Children's Hospital Foundation, we continue to increase our exposure and advocacy through the University and BC Children's Hospital communities.

Rare Finds Events

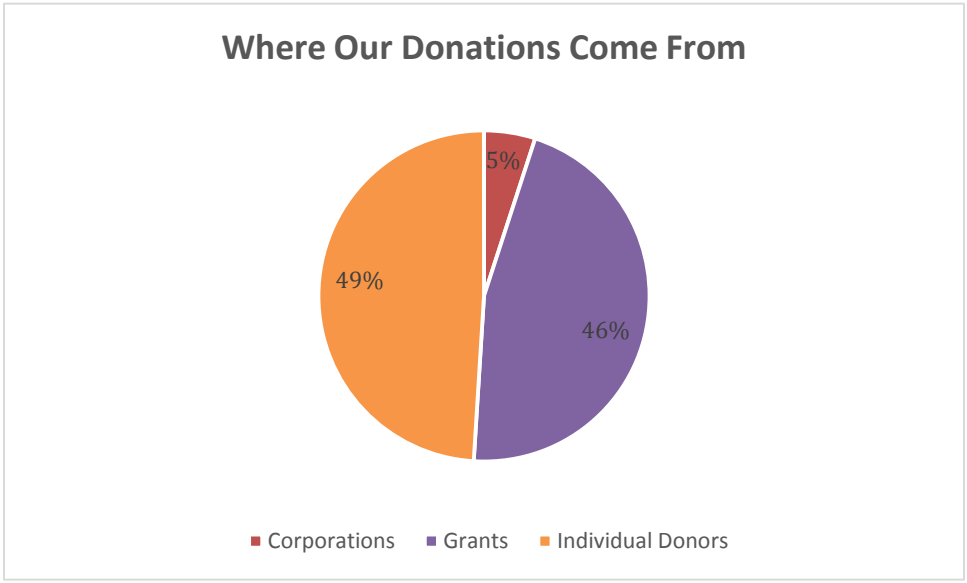
Rare Finds Vancouver was held on April 27, 2019, in its 10th year as our premier fundraising event. We raised over $82,000 while experiencing delicacies crafted from over a dozen of Vancouver's amazing (and generous) chefs. Three mixologists concocted unique cocktails and three craft brewers allowed guests to sample their interesting wares. Under the amazing stewardship of Louise and Paul Berezowsky, Rare Finds YEG (Edmonton) in September 2018 increased the value raised by nearly 50% in its second year to $90,000! 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 several years, our work and organization would not exist in its current form if not for the ongoing support of one major supportive family, the Longstaffes. 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.

Partnerships and sponsorships are key to our ability to offer programs and services of value. We are entering the fourth year of a partnership with a private Foundation for a four-year program of support for Microgrant awards to 2020. Takeda Canada was our national partner for Rare Disease Day activities across Canada and another private Foundation joined us as 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 continue to receive 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 or annual commitment to help us in our mission.



Outrun Rare

On March 8, 2019 our organization contracted Dave Proctor, an ultra-marathon runner and father of three based in Okotoks, Alberta to be a Brand Ambassador. Dave's 10-year old son Sam is afflicted with RECA, a rare brain and muscle disorder.

In 2018, Dave and a core team of equally passionate individuals launched the Outrun Rare national campaign. The premise of this campaign was for Dave to run across Canada in 66 days in order to raise awareness and funds for rare disease. The Outrun Rare team cultivated a strong following through online channels (www.outrunrare.com , Facebook, Twitter and Instagram), fundraisers, and numerous interviews with the press.

Dave's charisma, passion for running, commitment, and love for Sam shone through, drawing national attention and support. Over 20 local sponsors supported Dave's run, through in-kind and financial donations.

In the summer of 2018, Dave set out to run across Canada and after running 2,400 km in 28 days, was forced to stop after suffering an injury. In total, over $311,000 was raised for RDF.

Now fully healed, Dave is preparing to run across Canada again in May 2020. This time, he is not only seeking to raise funds for rare disease but also break the "Fastest Crossing of Canada on Foot" Guinness World Record. We are so excited!

Acquisition of Outrun Rare Brand

Rare Disease Foundation has integrated the Outrun Rare brand which includes intellectual property in the form of the Outrun rare website (www.outrunrare.com), blogs, photographs, videos, materials, information, data, and sound recordings, all thanks to the generosity of its owner, Dave Proctor.

Core Team

Dave Proctor, Endurance Athlete and "Rare Parent"
Stephanie Gillis-Paulgaard, Take Roots Communications Consulting
Bret Paulgaard, Boss Digital Media

The Outrun Rare core team is also supported with a team of 68 passionate and dedicated volunteers, many from local running communities across Canada.

As a Brand Ambassador for our organization, Dave is fully supported by not just his core team but by Rare Disease Foundation's executive leadership and staff to ensure this run is a success.

Conclusion

We look forward to a transformative 2019-2020. We will add a Rare Finds event in Montreal, reimagine our organizational structure and P2P groups, expand our staff, and drive hard toward a watershed moment for rare diseases in Canada with Outrun Rare 2020 as a springboard.

We very much appreciate all our partners and well-wishers' support as we strive to transform the world of rare disease care.