



Dear Members,

March 27, 2021

We celebrated our 22nd. Anniversary in 2020 and despite the COVID-19 Pandemic, which turned pretty much everything upside down for everyone, we managed a successful, but different year. We continue our goals of improving patient *care*, disease *control*, vasculitis awareness and education, and funding research towards the *cause* and *cure* of all forms of vasculitis. It's a long road, but together we do make a difference, even during a pandemic!

VFC is an affiliate member of CORD (Canadian Organization for Rare Disorders), for many years and Ann Turuta and myself attended Rare Disease Day on March 3rd at Queens Park. Despite the lack of a rare disease strategy at both federal and provincial levels, improved access, and coverage to modern treatments remains unresolved.

In March, just days prior to the COVID-19 lockdown, I attended the 2020 CORD Conference in Ottawa, complete with a CORD protest on Parliament Hill! I met two MP's, and one MP's staff, and advocated for changes to Canada's Patented Medicine Price Review Board (PMPRB), and faster access, and coverage, to new treatments. Canada has one of the most complicated drug approval processes in the world and the proposed changes will make matters worse. Despite sympathetic ears minimal progress was made. This is a huge and complex issue which impacts vasculitis patients, and all Canadians in some way. Few Canadians could explain Canada's drug approval process, but the pandemic has more of us asking questions! While in Ottawa I met with Dr. Nataliya Milman from Ottawa's Vasculitis Clinic and made plans for the VFC Fall Lectures at Ottawa's Civic Hospital, of course, that plan changed!

Our 2020 AGM in April was held online and was attended by about 40+ folks via ZOOM with guest speaker Dr. Kim McKenzie. He made a timely presentation on dealing with stress, anxiety, isolation and coping with vasculitis, or COVID-19 even! He taught us techniques and coping strategies, like mindfulness, and meditation, to help us reconnect with ourselves so we can take control and choose how we navigate through each day.

On May 9th. Toronto Mayor John Tory proclaimed Vasculitis Awareness Day in Toronto and welcomed about 90 VFC'er's to the first Vasculitis and COVID-19 ZOOM meeting with Dr.'s: Pagnoux, Khalidi, Garner, Junec and Siminovitch answering patient questions on COVID-19 and Vasculitis. The panel provided more updates in October.

Our 22nd annual BBQ and walk was cancelled and contributed to a 2020 drop in income of ~40% over 2019! Despite this, VFC raised ~28,838. with expenses of ~37,896. for a loss of ~9K! However, our operating expenses were ~17,896. and our assets are ~153,995. which means VFC remains healthy. Our donations come from many sources and more frequently from Canada Helps. Lucy Dematos and myself tried virtual fundraisers using Canada Helps and raised over \$2000.00 - we encourage others to do likewise. Walk, Run, Ride, or just about anything, from anywhere is possible and we can help set up your own VFC fund raiser! Email us at contact@vasculitis.ca for ideas and help!

With Dr. Milman's help, VFC organized the first virtual VFC Fall Lectures via ZOOM. "Eight Lectures on Vasculitis", changed our meet-in-person format and had ~250 registrations from coast to coast. Speakers included Dr's.: Milman, and Fairhead in Ottawa, Siminovitch, Pagnoux, and Ridout in Toronto, Khalidi, Garner and Junec in Hamilton and our guest speaker Dr. John Stone was in Boston. We couldn't do that pre COVID-19 so 2020 had some silver linings!

Early in 2020 we funded 20K to Dr. Siminovitch to process about 100 Behcet's DNA samples, and she reported on this important work during her Fall Lecture. Without the dedication and fundraising efforts of Cindy Foster and Tracey Moorley this work never would have happened. Congratulations go out to both for sticking-it-out, through thick and thin, over many years! Our 2020 commitment to co-fund a vasculitis fellow to prepare unique patient tools, and more, was delayed, but Dr. Joanne Jiang's 6-month fellowship at Toronto's Vasculitis Clinic has started on January 1, 2021.

We continue to need a volunteer bookkeeper, and help with fundraising, video editing, our website, events, etc. If you, or someone you know, can fill a volunteer role, please reach out to me at jonstewart@rogers.com.

The vasculitis community remains at risk to COVID-19, please keep safe and take extra precautions in these challenging times. On behalf of the Board, stay safe, and stay well!

Jon Stewart

President, Vasculitis Foundation Canada

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