



Dear Members,

April 22, 2022

We celebrated our 23rd. Anniversary in 2021 and despite the continuing COVID-19 Pandemic we managed another successful, but different year. Together we took another big step forward in 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!

As you know, VFC is an affiliate member of CORD (Canadian Organization for Rare Disorders at: <https://www.raredisorders.ca>), and pre-pandemic Ann Turuta and myself attended Rare Disease Days at Queens Park. In 2021, I attended multiple CORD Rare Disease Day virtual events, and others throughout the year. CORD remains deeply invested in developing a rare disease strategy at both federal and provincial levels, including timely access, and coverage to modern treatments. This is another long road, but there is light at the end of the tunnel!

Canada has one of the most complicated drug approval processes in the world and recently stepped back damaging changes to the Patented Medicine Price Review Board (PMPRB), but problems remain. This is a huge and complex issue which impacts vasculitis patients, and all Canadians in some way. Few Canadians could explain Canada's slow moving drug approval process that was plagued with delayed COVID vaccines and other COVID therapies.

In late February, VFC attended for the first time the Canadian Rheumatology Association annual meeting. This virtual event helped increase VFC awareness and our virtual booth included our brochure and other materials.

Our 2021 AGM in April was held online and was attended by about 40+ folks via ZOOM with guest speaker Dr. Joanne Jiang. **Dr. Jiang was VFC's first vasculitis fellow** and in February she conducted a patient survey on support needs for vasculitis patients. The results helped guide new resources, with patient input, including patient education material and tools on 10 of the more common forms of vasculitis. **This new material** was added to the VFC website, is downloadable, and **is some of the best vasculitis patient resource material anywhere.**

Our 23rd annual BBQ and walk was cancelled once again due to the pandemic. Despite this, VFC raised ~\$34,500.00 with expenses of ~\$31,500.00, for a small surplus on the year! Our total assets increased to ~\$198,000.00 meaning VFC remains in good fiscal health. Our donations come from many sources and more frequently from Canada Helps. **Lucy Dematos and myself did another virtual fundraiser using Canada Helps** and raised ~\$1500.00. **You too can organize a Walk-Run-Ride**, or just about any VFC fundraising idea you can imagine, **and we can help you set it up!** All donations further our cause, please email us at contact@vasculitis.ca for help setting up your fundraiser!

With Dr. Natasha Dehghan's help in Vancouver, VFC organized our second virtual VFC Fall Lectures via ZOOM. "Nine Lectures on Vasculitis" changed our meet-in-person format and had ~250 registrations from coast to coast. Speakers included Dr's.: Jiang in London, Yacyshyn, Tervaert and Clifford in Edmonton; Pagnoux in Toronto; Dehghan and Ennis in Vancouver; Fifi-Mah in Calgary and Baldwin in Victoria. We couldn't do any of this pre COVID-19, so 2021 had some silver linings in moving us to a more inclusive format.

Early in 2021 VFC granted ~\$18.5K to partially fund Dr. Jiang's six-month fellowship. Unable to meet in person during 2021 we rolled out "ZOOM meeting groups" for GPA, MPA, GCA, EGPA, and TAK, dates and times are posted on the VFC website. In late December VFC entered a Corporate Sponsorship Agreement with Otsuka Canada Pharmaceutical Inc. for the production of multiple projects that will enhance our patient information in both English and French.

Finally, **we continue to need volunteers** especially a bookkeeper, 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 contact@vasculitis.ca.

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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