



Dear Vasculitis Foundation Canada Members,

April 2, 2023

We celebrated our 24<sup>th</sup> Anniversary in 2022, and we managed another successful, but different year. 2022 was a busy year as we move forward with our goals of improving patient education, disease *care and control*, and vasculitis awareness. During the pandemic, we still managed to raise funds for research towards the *cause* and *cure* of all forms of vasculitis. Together, we do make a difference!

In January, Dr. Siminovitch, and myself, presented to the Mount Sinai Hospital Foundation on precision medicine, my vasculitis journey, and the role of ANCA as an example of targeted and precise medicine. VFC attended the Canadian Rheumatology Association's virtual annual meeting for the second time in February. This event helps increase VFC awareness, and our virtual booth included our brochure and other materials for download.

Once again, I attended the annual Rare Disease Day at Queen's Park, organized by CORD (Canadian Organization for Rare Disorders at: <https://www.raredisorders.ca>). CORD advocates for those with rare diseases, like vasculitis, and is attended by some Ontario MPP's. CORD has developed a rare disease strategy for both the federal and provincial levels, including timely access, and coverage to modern treatments.

With input from VFC, Canada stepped back from damaging changes to the Patented Medicine Price Review Board (PMPRB), but problems remain. Improving Canada's slow-moving drug approval process is a complex issue which impacts vasculitis patients, and all Canadians. **For example**, Paxlovid, was found to reduce hospitalizations and death from COVID by ~88%, but it took ~28 days after FDA approval for Health Canada to approve this drug! During those 28 days ~1624 Canadians died from COVID. **Had Paxlovid been available, ~88% of those lives, or ~1429 people, could have been saved! To save Canadian lives, this must change!**

In April, together with Drs': Pagnoux & Mockett, Lucy DeMatos & myself, we launched a Prednisone/Avacopan survey for our CADTH Avacopan (now approved for GPA/MPA), patient submission. The results were eye-opening! We also collaborated with Dr. Yacyshyn in Edmonton on her survey on Access to Vasculitis Care in Canada.

Our 2022 AGM in May was held on ZOOM and was attended by ~40+ attendees with guest speaker Dr. Velma Mockett. Velma is a licenced and experienced mental health expert, vasculitis patient, and Calgary Vasculitis Association co-founder, see: <https://calgaryvasculitis.com> She spoke on coping with Vasculitis and Covid-19.

Our 24<sup>th</sup> annual BBQ & Walk was cancelled again due to the pandemic. Despite this, VFC raised ~\$32,500.00 with expenses of ~\$15,000.00, for a surplus on the year! Our total assets remain healthy at ~\$233,601.00 up over 2022. Our donations come from many sources and more frequently from Canada Helps. **You too can organize a Walk-Run-Ride**, or just about any fundraising idea, with Canada Helps, **and we can help you set it up!**

**With Dr. Pagnoux's help in Toronto, VFC organized our 3<sup>rd</sup> annual VFC Fall Lectures on ZOOM.** "Eight Lectures on Vasculitis" had ~250 registrations from coast to coast. Speakers included myself, Drs': Carette, Abbey, & Pagnoux in Toronto, Walsh in Hamilton, Tervaert in Edmonton; Garner in Calgary, and Geetha in Baltimore.

We continued our "ZOOM meetings" for GPA/MPA/EGPA GCA, & TAK - the VFC website has dates & times. Our patient information and tools were translated into French and have started to appear on our website. We applied for more support grants from Otsuka Canada, and AstraZeneca. I also had the privilege to attend a European patient conference in Madrid, Spain to share our Canadian experiences, and learn from European experience.

**We need volunteers** - if you, or someone you know, can help, contact us at: [contact@vasculitis.ca](mailto:contact@vasculitis.ca).

**Even though we are done with Covid, Covid is not done with us! On behalf of the Board, keep well,**

Jon Stewart

President, Vasculitis Foundation Canada

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