



Dear Vasculitis Foundation Canada Members and Friends,

April 4, 2024

In 2023, we celebrated our 25<sup>th</sup> Anniversary and had our most ambitious year to date. We attended multiple events to enhance vasculitis awareness and patient education, while remaining true to **our long-held motto** of advocating for patient *care*, and disease *control* while supporting research towards the *cause* and *cure* of all forms of vasculitis. It was a busy and productive year, **and together we are making a difference!**

In January 2023, Dr. Pagnoux, and myself, presented the vasculitis specialist, and GPA/MPA patient, perspectives to a group of private and public insurance payers in the hope of building support for insurance coverage for the new Tavneos (Avacopan) steroid-sparing therapy. In February, **for the first time, VFC attended in-person** the Canadian Rheumatology Association's (CRA), annual meeting in Quebec City. This event increased VFC awareness, showcased our patient tools, and resources. VFC funded two CRA presenters, Dr. Gözde Yardimci on our prednisone survey results, and med student Kareen Nanda on the Canadian Access to Vasculitis Care survey.

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 timely access to new therapies for rare diseases, like vasculitis, and has a rare disease strategy for federal and provincial governments. I also attended CORD's Ottawa conference in March and conveyed our CORD and VFC messaging to our federal MP's.

May was insanely busy with Vasculitis Awareness month and **"illuminating red"** the Toronto Sign, the CN and Calgary Towers, and **Niagara Falls**. It was **spectacular** when both the Canadian and American Falls turned **vasculitis red!** Lucy De Matos and I attended two conferences, Pri-Med (for primary care physicians, RPN's RN's and frontline healthcare workers), and the Canadian Association of Emergency Physicians (CAEP). **It is essential to get our message, and resources, to the frontlines where vasculitis patients are being diagnosed. We believe, this community can improve both the diagnosis of vasculitis patients and patient outcomes!**

Our April 2023 AGM, on ZOOM, with guest speaker Kareena Nanda had about 45 attendees. Kareena, a med student with Dr. Yacyshyn in Edmonton, gave us **real insight** on the Access to Vasculitis Care in Canada survey.

Our 25<sup>th</sup> Annual Picnic & Walk in June was back in the great outdoors at Riverside Park in Cambridge. It was complete with prize bidding tables, cake, entertainment from Zoo-To-You and a full pita lunch with salads. Lucy and I attended the July VF conference in Chicago. Lucy spoke on diet & Vasculitis to ~800 in a fall VF webinar!

In 2023, VFC had income of ~\$131,431.32 with expenses of ~\$77,608.40 for a yearly surplus of ~\$53,822.92! Our total assets remain healthy at ~\$321,515.91 up considerably over 2022. Our donations of ~\$56,000.00 come from many sources and more frequently from Canada Helps. In the fall, we helped organize the first **Matt Zupanc memorial golf tournament** that raised ~15K to assist young vasculitis patients attend a vasculitis event, or lectures, to be with peers their age. **You can also donate financially, or organize a fund-raising event, and we can help!**

Once again, **we organized our 4<sup>th</sup> annual VFC Fall Lectures on ZOOM**. "Nine Lectures on Vasculitis" had ~250 registrations from coast to coast. Speakers included our own Lucy De Matos and, Drs': LaFleur-Careau, Yardimci & Pagnoux in Toronto, Junek in Hamilton, Mendel in Montreal; Fifi-Mah, Garner and Velma Mockett all in Calgary.

We continued our ZOOM meetings for GPA/MPA/EGPA, GCA,&TAK - the VFC website has the new dates and times. We received more support grants from Otsuka Canada, and AstraZeneca. **Finally**, we are thrilled our prednisone survey, by Dr's: Yardimci, Pagnoux & me, was published in Clinical and Experimental Rheumatology!

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

**We all want to be done with Covid, but Covid is not done with many of us, especially those on B cell depletion therapy** and other immune suppressing drugs! **Discuss with your doctors, plan, and be prepared!**

**2023 was an exciting and productive 25<sup>th</sup> Anniversary year, and there is more to come!**

**On behalf of the Board keep well,**

Jon Stewart  
President, Vasculitis Foundation Canada

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