



April 14, 2019

Dear Members,

In 2018 we celebrated the milestone of our 20th Anniversary since our formal incorporation in 1998 as the Wegener's Granulomatosis Support Group of Canada, the predecessor of today's VFC. Our first meeting, with Gary Timmons and Peter Gerry, was held in Bob and Donna Wall's Condo meeting room! There have been tremendous changes over 20 years, but as we embark on our third decade we truly are stronger together and your continued support over many years, and in many ways, sustains us. Your participation allows us to continue to pursue our goals of improving patient *care* and disease *control* with vasculitis awareness, at all levels, and patient education, while we continue to push research towards the *cause* and *cure* of all forms of vasculitis. It has been a long road, but we have seen tremendous improvements and we know our presence has helped, in many ways, those living with vasculitis.

Our 2018 AGM marked another milestone in that we held our first AGM electronically, due to a last minute and somewhat appropriate mid-April Canadian ice storm, via ZOOM conferencing and organized by fellow board member Sheri Leigh-Liddard. Included via Zoom, was an excellent PowerPoint presentation by our guest speaker June Martin, Registered Dietician from the Renal Unit at the Grand River Hospital in Kitchener, a place all vasculitis patients want to stay away from!

We hosted our 20th annual picnic and walk in Cambridge with a good turnout of about 60 participants who enjoyed a wonderful BBQ lunch and great entertainment with the return of the crowd-pleasing Vladimir the magician, a fun time was had by all! The event raised about 10K in important funds for awareness, education and research.

The 2018 fall lectures, "The many faces of Vasculitis", was very well organized by Dr. Lillian Barra at St. Joseph's Heath Care in London, Ontario. The lectures were well attended, with very positive feedback, and included seven informative presentations by Dr's.: Barra, Mandzia, Siminovitch, Bursztyn, Demirkaya and Sowerby. The lectures truly covered the many faces of vasculitis, including small, medium, variable and large vessel vasculitis, as well as a cross section of some of the types of organ involvement in vasculitis.

We funded no additional research projects in 2018 although we continue to encourage patient participation in the ongoing, and the ever evolving, genetic research by Dr. Siminovitch. Her fresh blood cell (FBC), research utilizes a newer technology called CyTOF and uses the FBC's from GPA patients. This time sensitive study can only be done at the Toronto Vasculitis Clinic and also collects routine labs, ANCA, ESR, CRP etc. to form a complete GPA lab "picture" along with the FBC results. For information on all vasculitis genetic studies you can reach out to longtime VFC member, and volunteer, Ann Turuta at research@vasculitis.ca or Dr. Siminovitch's new study assistant Klaudia Rymaszewski at: klaudia.rymaszewski@clinicalgenomics.ca. or at 416-586-4800 ext. 5492.

Together with CanVasc (<http://www.canvasc.com/index.html>), we continued to lobby to extend Rituximab funding/coverage for maintenance treatment in GPA/MPA, which is now FDA approved for maintenance therapy. We hope that by late 2019 funding/coverage will be in place for both Rituximab induction, and maintenance, therapy.

I encourage all of you to play a role and get involved in some way in the activities of your organization. In particular, we can always use more volunteers to help with fundraising, bookkeeping, our website, assistance with our events and programs like QuickBooks, Blackbaud, WordPress, Canada Helps, GoToMeeting, ZOOM etc.

I look forward to seeing all of you throughout 2019 and wish you, and yours, the best of health.

Warm regards,

Jon Stewart
President, Vasculitis Foundation Canada

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