



Dear Members,

March 25, 2020

We celebrated our 21<sup>st</sup>. Anniversary in 2019 and enjoyed a pretty successful year that allows the continued pursuit of our goals of improving patient *care*, disease *control*, vasculitis awareness and education, and playing our role in research towards the *cause* and *cure* of all forms of vasculitis. It's a long road, but together we do make a difference!

Our 2019 AGM was attended by about 40+ members and featured our first ever cooking demo and lunch at The Kitchen, in the Kitchener Market. Prepared by June Martin, Registered Dietitian, and Chef's Ryan O'Donnell and Jenny Peters, it was an educational and gastronomic success! June Martin gave a very informative presentation on Canada's new Food Guide, and how to maintain a healthy diet especially for those with kidney involvement.

Our 21<sup>st</sup>. annual picnic and walk in Cambridge had picture perfect weather, once again, with one of our best turnouts of +/-100 participants who enjoyed a wonderful BBQ lunch, loaded prize tables, and great family entertainment by ZooToYou with their fun selection of interesting and unusual animals! The event raised over 15K for VFC programs.

In July I had the pleasure of attending the 2019 International Vasculitis Symposium in Minneapolis, MN, hosted by the Vasculitis Foundation, while Cindy Foster and Tracey Moorley attended the Behcet's Conference in Atlanta, GA. These symposium's provide valuable insight into the broader international vasculitis community, current trends, new therapies etc. **One issue that is becoming more apparent is the lagging access to new FDA approved therapies for Canadian's!** The Canadian Organization of Rare Disorders (CORD), has developed a strategy for rare diseases in Canada including improved drug access, and coverage. VFC is an affiliate member of CORD, and I regularly attend Rare Disease Day (typically February 28 or 29), at Queens Park. Despite acknowledgement of the problem by all parties, at both federal and provincial levels, a realistic solution to provide timely access, and coverage, to modern drug treatments, remains unresolved. **FYI please view this site: <https://www.fightforourlives.ca>**

The 2019 fall lectures, "Staying Current on Vasculitis", was attended by ~65 patients, friends and family at Toronto Western Hospital. Speakers included Dr's.: Pagnoux, Siminovitch, Leung, Mak, Kotra, along with guest speaker Dr. Peter Merkel from U of P in Philadelphia. Dr. Pagnoux provided insight into the scale of vasculitis activities by CanVasc, and at the Toronto vasculitis clinic, including increasing numbers of patients, studies, therapies, and the need to continue working on all vasculitis fronts. Dr. Siminovitch provided a deep look into the causes of GPA/MPA, with new data that **"even in remission, GPA patients manifest aberrant immune cell activation"**. This groundbreaking research, and immune profiling using CyTOF, continues, and **even more GPA/MPA patients are urgently needed**. This research looks for specific genetic changes and requires 4-6 blood samples from GPA, and fewer MPA, patients who are on, or off, medication over 2-3 years. **Interested patients must attend Toronto's Mount Sinai Hospital and should contact** Dr. Siminovitch's research assistant **Anna Park** at (416) 586-4800 x-5493 or: [vasculitisgeneticstudy@mtsina.on.ca](mailto:vasculitisgeneticstudy@mtsina.on.ca) Dr. Merkel gave an engaging presentation on the spectrum of vasculitis, discussed his involvement with the VCRC (see: [www.rarediseasesnetwork.org](http://www.rarediseasesnetwork.org)), and hosted a 1+ hour Q&A. Dr. Leung reviewed everything you need to know about ANCA, and Dr. Mak shed light on combating fatigue and key steps to improve your sleep, while Dr. Kotra gave us the introductory course on medical marijuana.

At our last board meeting of 2019 we approved a 20K grant to Dr. Siminovitch to process about 100 Behcet's DNA samples, related vasculitis research, and compare these results to other recent studies. We also agreed to co-fund a vasculitis fellow at ~20K to prepare educational content etc. for our website, for print, and perhaps for CanVasc ([www.canvasc.com](http://www.canvasc.com)). We also deferred a research request on medical cannabis for further input.

Finally, in 2019 VFC received 12K as a partial estate settlement from a thoughtful, but now deceased GPA patient. I encourage others to think likewise, **but** also to think of playing a **real-life** role in your VFC! Please reach out to me at [jonstewart@rogers.com](mailto:jonstewart@rogers.com) if you can volunteer with fundraising, bookkeeping, our website & events, or your specialty!

The vasculitis community is at increased risk to COVID-19, please keep safe and take extra precautions in these challenging times. On behalf of the Board, we look forward to seeing all of you in 2020, stay safe, and stay well!

Jon Stewart

President, Vasculitis Foundation Canada

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