

Vasculitis Foundation Canada Actively Supports Vasculitis Research
Now with Updated Info on Current Vasculitis Genetic Studies
October 2016

Get involved and help make a difference!

(We especially need more GPA (Wegener's)/MPA, Behcet's (BD) and Giant Cell Arteritis (GCA) patients!)

Vasculitis Foundation Canada (VFC), has a longstanding tradition of supporting research. To that end, **in the spring of 2001 VFC joined forces with Dr. Katherine Siminovitch, M.D., FRCP(C), from Toronto's Mount Sinai Hospital to help co-ordinate, with limited VFC funding, what is believed to be the first genetic research on Granulomatosis with Polyangiitis (GPA) (Wegener's), in the world.** Dr. Siminovitch is a Rheumatologist, Geneticist and Senior Investigator at the Samuel Lunenfeld Research Institute of Mount Sinai Hospital. We are pleased to advise that this ground breaking work continues at a more feverish pace than ever before, and is switching gears to Phase 2!

Today, there are multiple genetic studies underway on a growing number of vasculitic diseases. About 500 Canadian, and larger numbers of American patients have already participated in this GPA, and now MPA research. Study lab collections have been collected for close to 15 years, often at VFC meetings and lectures, and at local vasculitis clinics. **Study lab collections in person at VFC events are the most cost effective method of gathering patient samples.** For those patients who cannot participate in person, remote collections are possible throughout Canada at Life Labs, other collection options are being considered. American patients can participate in most studies listed below, from most States, via mail-in kits, or better yet, by attending VFC spring/fall meetings/lectures typically held in the Toronto, or short distances from Toronto. Note: Americans travelling to Toronto require passports to enter Canada.

Below is a summation of the various genetic studies currently underway, all of which are open for patient collection. For more information on how to participate, doctors and patients are encouraged to contact Dr. Siminovitch's research assistant Ilana Sutherland at (416) 586-4800 x-5493 or by email at: vasculitisgeneticstudy@mtsinai.on.ca

Ongoing Genetic Studies as of October 2016

1. Originally focused on just Granulomatosis with Polyangiitis (Wegener's)(GPA), **DNA samples are now being collected from any patient, consent required, with a vasculitis diagnosis and doctor confirmation.** Although samples are being collected, a minimum sample size for each vasculitic disease needs to be collected before genetic studies can begin. Collections are ongoing.
2. **Behcet's (BD), advanced genetics study.** Similar in scope to the original GPA (Wegener's) study (as above in 1.), a minimum of 100 patient samples are required

before the study can start. Collections for this study started in the Fall of 2014 and about 80 Behcet's samples are still required to reach the start point. Collections are ongoing.

3. **Giant Cell Arteritis (GCA), advanced genetics study.** Similar in scope to the original GPA (Wegener's) study (**as above in 1.**), a minimum of 100 patient samples are required before the study can start. Collections for this study started in the Fall of 2014 and about 90 GCA samples are still required to reach the start point. Collections are ongoing.
4. **Monitoring for genetic changes in GPA/MPA patients.** This study follows GPA & MPA patients, (ideally MpO(p) or Pr3(c) ANCA positive), **looking for genetic changes over time** and during the different phases of their disease. Collections for this study are ongoing on roughly a 6-month basis. However, **patients in this study must be able to attend either the VFC spring and fall meetings/lectures, or the Toronto Vasculitis Clinic** on roughly a 6-month basis, and perhaps on predetermined dates for batch processing, and **there are special time-to-lab requirements on the collection of these samples.** For this research to have minimal study power a target of 40 GPA/MPA patients are required. **Attending the VFC spring and fall meetings are an easy way to accomplish this objective.**
5. **Fresh Blood Cells from GPA/MPA patients.** In the spring on 2015 Dr. Siminovitch had an urgent need for fresh blood cells from GPA & MPA patients to hopefully identify the potential stimulus, in the already known exact single gene change, in the HLA gene region, that is implicated in GPA, & maybe MPA! Working with VFC, we were able to quickly collect a minimum number of samples for this new and exciting research. Collections for this study are ongoing but **there are special time-to-lab requirements on the collection of these samples which may limit participation,** contact Ilana, as noted above, to see if you are eligible.
6. **Vasculitis Study Controls.** An important part of any research study are study controls and these are needed in vasculitis research too! Spouses of patients are ideal candidates as they are not blood related, and can participate in the research with patients. Some restrictions apply, for example study controls should be healthy, and with no auto-immune diseases themselves. Collections of study controls is ongoing and can often be arranged to be done at the same time as patients.