MEMBERSHIP/DONATION

VASCULITIS FOUNDATION CANADA

Suite 446, 425 Hespeler Rd, Cambridge, On N1R 8J6 • Toll Free: 1-877-572-9474
A not-for-profit Canadian Corporation – Registration No. 88827 6227 RR0001

Mr. / Mrs. / Miss / Ms. / Dr. Name: ____________________

Address: ____________________

____

Preferred Phone: ____________ Email: ____________

I am a: ☐ Patient ☐ Family Member/Friend of a patient ☐ New Member Use my donation towards: ☐ Research ☐ Vasculitis Foundation ☐ Both

Type of membership: ☐ Canadian Membership $20 ☐ Dual Membership $60

Additional Support: ☐ $5 ☐ $10 ☐ $25 ☐ $50 ☐ $100 ☐ $200 ☐ Other, $______

I have enclosed a total of $______ as follows: ☐ Credit Card ☐ Cheque ☐ Money Order – *payable to Vasculitis Foundation Canada*

☐ Visa ☐ Master Card Name on card: ____________ Card #: ____________

Expiry Date: Month: ______ Year: ______ Signature: ____________ Date: ______

Vasculitis Foundation Canada has a dual membership arrangement with the International Vasculitis Foundation Group to provide its members with exposure to a broad variety of information resources, cost savings and convenience. Vasculitis Foundation Canada and Vasculitis Foundation International hope to reach out to as many vasculitis patients, caregivers and supporters as possible, by coordinating our membership efforts we will be much more effective. Note that tax receipts are issued for donations of $25 or more only.

REMISSION

There is no cure for most types of vasculitis, but early diagnosis and proper treatment will be effective and the disease can be brought into sustained remission, with little or no damage. In most patients, long-term remissions can be maintained for years with medications, and close management. Regular laboratory tests help to monitor the disease and detect a relapse at its earliest and most treatable stage.

WE ARE HERE TO SUPPORT YOU

We established our support group in 1998 to demonstrate our concern, and care, for all those affected by vasculitis. We provide emotional and informational support, and assist patients, their families and caregivers to better understand the process of disease and recovery. Our vision and commitment is to raise awareness, to educate patients, and the public, and to support research into the **care, control, cause and cure** of all vasculitides. Our affiliation with the international organization, Vasculitis Foundation, strengthens us and we value its continued efforts on behalf of all vasculitis patients.

We want to help each individual to fight and not give up hope. We want them to know and believe that they can survive. Many support groups in other parts of the world can be reached by links on the websites: Vasculitis.ca or VasculitisFoundation.org

We are a not-for-profit Canadian corporation with charitable status. Our funds are provided by dues and donations as well as estate bequests. We could not continue without the generosity of patients, their family and friends, and your tax-deductible donations.

INFORMATION AVAILABLE

Information packets are available to patients and their families upon request from Vasculitis Foundation Canada and Vasculitis Foundation. Physician's packages of medical information on Vasculitis are also available upon request by a medical professional through Vasculitis Foundation.

CANVASC PARTNERS

Province	City	Principal Core Members	Associated Members
ON	Toronto	Dr. Christian Pagnoux (Rheu) *416-586-4800 Ext. 8549* Dr. Rae Yeung (Paediatric)	Dr. Simon Carette (Rheu) Dr. Heather Reich (Neph) Dr. Laurence Rubin (Rheu) Dr. Ian Witterick (ENT) Dr. Joanne Bargman (Neph) Dr. Mary Bell
	Hamilton	Dr. Nader Khalidi (Rheu) *905-521-9034*	Dr. Michael Walsh (Neph) Dr. Gerard P. Cox (Resp) Dr. Parameswaran Nair (Resp) Dr. Sankalp Bhavsar (Burlington)
	Ottawa	Dr. Nataliya Milman *613-738-8400, ext. 81871*	Dr. Douglas C. Smith Dr. Shaun Kilty (ENT) Dr. Brendon McCormick (Neph) Dr. Peter Magner (Neph) Dr. Nav Voduc (Resp) Dr. Shawn Aaron (Resp) Dr. Kanigsberg (Derm) Dr. Marco Gomez (Lung Path)
	Kingston	Dr. Tanveer Towheed *613-533-6896*	Dr. Marie Clements-Baker Dr. Michel Melanson (Neur) Dr. Andre Tan (ENT); Dr. David Holland (Neph) Dr. Christine D'Arsigny (Resp)
	London	Dr. Lillian Barra (Rheu) *519-646-5986*	Dr. Shih-Han Susan Huang (Neph) Dr. William Clark (Neph) Dr. Robert McFadden (Resp)
	Cambridge	Dr. Leilani Famorca *519-743-4351*	Dr. Brian Hanna Dr. Louise Y. Vitou (non CanVasc)
	Newmarket	Dr. Carter Thorne *905-895-1666*	Dr. Nooshin Samadi
QC	Sherbrooke	Dr. Patrick Liang *519-346-1110 x13549*	Dr. Ariel Masetto Dr. Guylaine Arsenault Dr. Dominique Dorion (ENT) Dr. Martin Plaisance (Neph) Dr. Pierre Larrivée (Resp) Dr. François Lamontagne (ICU)
	Montréal	Dr. Michelle Goulet Dr. Christian Pineau *514-934-8037*	Dr. Yves Troyanov Dr. Eric Rich; Dr. Sonia Brachemi Dr. Evelyne Vinet Dr. Emil Nashi Dr. Ann E. Clarke
	Québec	Dr. Judith Trudeau	Dr. Paul Fortin Dr. David Philibert (Neph) Dr. Renée Leclerc (GInt) Dr. Nathalie Roy (Rheu-Levis) Dr. Claude Blier (Rheu-Levis)
NS	Halifax	Dr. Christine Dipchand *902-473-3818* Dr. Volodko Bakowsky	Dr Colm McParland (Resp) Dr. John Hanly
NL	St John's	Dr. Majed Khraishi	
BC	Vancouver	Dr. Natasha Dehghan (Rheu) *604-806-9400* Dr. David Cabral (Paediatric) *604-875-2437*	Dr. John Esdaile Dr. Kim Morishita (Paed) Dr. Kam Shojania Dr. Barry Kassen Dr. Pearce Wilcox (Resp) Dr. Phil Teal (Neur) Dr. Adeera Levin (Neph) Dr. Amin Javek (ENT) Dr. Jan Dutz (Derm-rheu) Dr. Avina-Zubieta Dr. Navjot Dhindsa
AB	Edmonton	Dr. Elaine Yacyshyn *780-407-2121*	Dr. Alison Clifford Dr. Joanne Homik Dr. Allan Murray (Neph) Dr. Neesh Pannu (Neph) Dr. M Allegretto (ENT) Dr. M. Bibeau (Resp) Dr. R. Damant (Resp)
	Calgary	Dr Aurore Fifi-Mah (Rheu) *403-943-3895* Dr. Susan Benseler (Paediatric) *403-955-7771*	Dr Diane Mosher Dr Charlene Fell (Resp)
SK	Saskatoon	Dr. Regina Taylor-Gjevre *306-966-8271*	Dr. Bindu Nair Dr. Jim Barton (Neph) Dr. Julian Midgley (NephPaed) Dr. Peter D Spafford (ENT) Dr. Judith Klassen (Neph) Dr. Mark E Fenton (Resp) Dr. Peter Hull (Derm)
MB	Winnipeg	Dr. David Robinson	

Canadian vasculitis patients are encouraged to see CanVasc core members and their team on a regular basis for up-to-date vasculitis treatment options, study information and disease monitoring.

To learn more about CanVasc and it's partners, visit
www.canvasc.ca

Version française disponible sur demande.
Veuillez contacter la fondation.

1-877-572-9474 www.vasculitis.ca contact@vasculitis.ca

LIVING WITH VASCULITIS

CARE 🍁 CONTROL 🍁 CAUSE 🍁 CURE

WHAT IS VASCULITIS?

Vasculitis is an inflammation of the wall of blood vessels, arteries, veins, or capillaries. When such inflammation occurs, it causes changes in the blood vessel lumen, such as weakening and narrowing that can progress to the point of blood vessel blockage or hemorrhage. **There is no known cause, or cure, for the primary types of vasculitis.** There are some probable causes, and "cures" in rare drug and bacterial (meningitis), triggered vasculitis.

A result of vasculitis is that the tissues and organs supplied by the affected blood vessels do not get enough blood. This can result in organ and tissue damage, which can be irreversible, thus causing morbidities, and sometimes lead to death. Vasculitis is a family of about 26 separate, but related, diseases within the larger family of more than 110 arthritic diseases.

The different types of vasculitis are classified according to the size and location of the blood vessels that are affected. **All are considered rare diseases, and affect people of all ages, gender and ethnicity.** Though some specific forms of vasculitis can improve on their own, most require treatment. The duration of treatment varies, with some people using medications for an extended period of time, often years. **Vasculitis is more common than you think, and can be more serious than you expect!**

THE VASCULITIS FAMILY

Large Vessel Vasculitis (LVV)

- Takayasu Arteritis (TAK)
- Giant Cell Arteritis (GCA)

Medium Vessel Vasculitis (MVV)

- Polyarteritis Nodosa (PAN)
- Kawasaki Disease (KD)

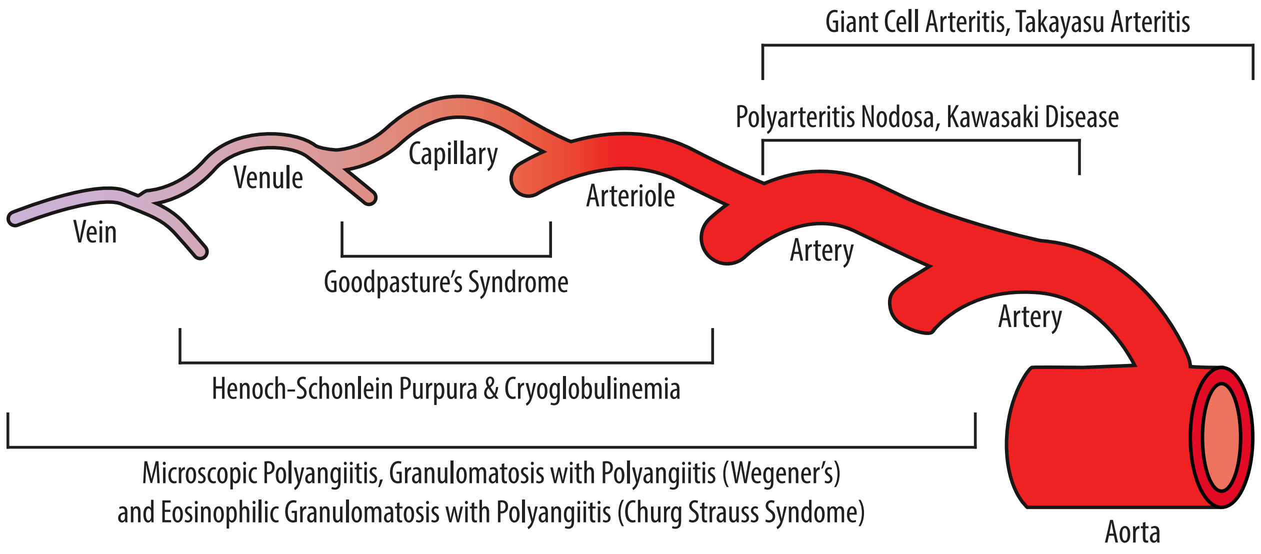
Small Vessel Vasculitis (SVV)

Antineutrophil cytoplasmic antibody (ANCA)–associated vasculitis (AAV)

- Microscopic Polyangiitis (MPA)
- Granulomatosis with Polyangiitis (Wegener's) (GPA)
- Eosinophilic Granulomatosis with Polyangiitis (Churg-Strauss) (EGPA)

Immune Complex SVV

- Anti–glomerular basement membrane (anti-GBM) disease
- Cryoglobulinemic Vasculitis (CV)
- IgA vasculitis (Henoch-Schonlein) (IgAV)
- Hypocomplementemic urticarial vasculitis (HUV) (anti-C1q vasculitis)



Variable Vessel Vasculitis (VVV)

- Behçet's Disease (BD)
- Cogan's Syndrome (CS)

Single-Organ Vasculitis (SOV)

- Cutaneous leukocytoclastic angiitis
- Cutaneous arteritis
- Primary central nervous system vasculitis
- Isolated aortitis

Vasculitis Associated with Systemic Disease

- Lupus vasculitis
- Rheumatoid vasculitis
- Sarcoid vasculitis

Vasculitis Associated with Probable Etiology

- Hepatitis C virus–associated cryoglobulinemic vasculitis
- Hepatitis B virus–associated vasculitis
- Syphilis-associated aortitis
- Drug-associated immune complex vasculitis
- Drug-associated ANCA-associated vasculitis
- Cancer-associated vasculitis

HOW IS VASCULITIS DIAGNOSED?

Blood and urine laboratory tests, biopsies of tissue, together with x-rays and angiograms, are crucial in detecting abnormalities related to each disease. Early diagnosis and treatment is critical for the best treatment outcome and to prevent organ failure.

WHAT ARE THE SIGNS & SYMPTOMS OF VASCULITIS?

Depending on which vasculitis is being observed, symptoms can vary, and may include:

- Fever/fatigue/weakness/weight loss
- Joint pain/arthritis
- Chronic sinusitis/nasal allergies/runny nose that fails to respond to the usual therapeutic measures/facial soreness/saddle nose deformity
- Cough (with or without blood)/shortness of breath/subglottic stenosis/lung inflammation or asthma
- Abdominal pain/gastrointestinal bleeding
- Kidney problems (trace blood in urine, dark urine)
- Peripheral nerve problems (numbness, weakness, pain in limbs, hands, feet)
- Eye inflammation or vision problems/changes
- Ear inflammation with hearing problems/changes
- Headaches/stroke/seizure
- Skin lesions/rashes

All patients do not experience all of these symptoms. Be aware that the symptoms of any vasculitis and their severity can vary among patients. If any symptoms persist, consider referral to a vasculitis specialist.

WHAT IS THE TREATMENT & PROGNOSIS

Early diagnosis and proper treatment can bring vasculitis into remission. Many patients lead full, productive lives with the right management of their chronic disease, others do not.

Treatment usually consists of a combination of powerful drugs such as Rituximab, Cyclophosphamide, Methotrexate, Azathioprine, or others, with glucocorticoids (prednisone). Although basic treatment is similar, it will vary depending on the specific vasculitis, severity of symptoms, the patient's general health status and associated conditions/comorbidities.

Treatment is often divided into two stages: firstly, the induction of disease remission, and secondly, the maintenance of disease remission. Patients must follow treatment instructions carefully, for example, oral cyclophosphamide should be followed with plenty of water to flush away harmful by-products, and requires frequent lab monitoring. Ideally, its use will be limited to a 3 to 6 month duration, and a +/-25g lifetime exposure limit, with follow-up and long-term cancer screening via urine dipstick etc.

Effective treatment may require a "team" approach with specialists like a: nephrologist (kidney), otolaryngologist (ear, nose/sinus, throat), ophtalmologist (eye), pulmonologist/respirologist (lung), others as needed, and always consult with a vasculitis specialist, usually a rheumatologist/immunologist.

It is imperative to have a close, continuous and long-term follow-up, even when in remission and off drug therapy since the disease, in some patients, can relapse. For example, in ANCA associated vasculitis relapses and "flares" occur in over 50% of patients as time goes on.

To help manage their disease, patients must maintain a good relationship with their doctors, understand and follow instructions carefully. Many patients find it useful to maintain a diary listing medications, test results, and notes on any symptoms they are experiencing. These notes can be reviewed during a patient/doctor appointment.

VASCULITIS FOUNDATION CANADA
Suite 446, 425 Hespeler Road
Cambridge, Ontario N1R 8J6
1-877-572-9474 www.vasculitis.ca
contact@vasculitis.ca

A not-for-profit Canadian Corporation
Registration No. 88827 6227 RR0001.
Dues and Donations provide our funding.

Affiliate Member of
Canadian Order of Rare Disorders (CORD),
Arthritis and Autoimmune Research Centre (AARC)

/Vasc.Canada
/vasculitis-foundation-canada
@Vasculitis_CND

This brochure was printed with the help of an education grant from Roche Canada.