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, 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 vasculitis. 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.

CANSVCS PARTNERS

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

To learn more about CanVasc and its partners, visit www.vasculitis.ca

Version française disponible sur demande. Veuillez contacter la fondation.

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OCTOBER 2015

1-877-542-9474 • www.vasculitis.ca • contact@vasculitis.ca

CARE • CONTROL • CAUSE • CURE

LIVING WITH VASCULITIS
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 morbidity, and sometimes leads 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!

WHAT ARE THE SIGNS & SYMPTOMS OF VASCULITIS?

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

- Fever/Tachycardia/weight loss
- Rash/pain/articuits
- Chronic insulitis/nausal/allergies/moony nose that fails to respond to the usual therapeutic measures/local soreness/laddle nose deformity
- Cough (with or without blood)/shortness of breath/subglottic stress/bronchial fibrosis/asthma
- Abdominal pain/gastrointestinal bleeding
- Kidney problems (trace blood in urine, dark urine)
- Perinatal nerve problems (numbness, weakness, pain in limbs, hands, feet)
- Eye inflammation or vision problems/changes
- Ear inflammation or hearing problems/changes
- Headaches/instake/acute
- Skin lesions/leshes

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, Steroids, or others, with glucocorticoids (prednison). 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/symptoms.

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 course will be limited to 3 to 6 months 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/throat), ophthalmologist (eye), rheumatologist (connective joints), others as needed, and always consult with a vasculitis specialist, usually a rheumatologist/immmunologist.

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 symptoms, the patient’s general health status and associated conditions/symptoms. These notes can be reviewed during a patient/doctor relationship with their doctors, understand and follow instructions carefully. Many patients find it useful to maintain a diary listing symptoms, the patient’s general health status and associated conditions/symptoms. These notes can be reviewed during a patient/doctor.