

We are
dedicated
to supporting
patients with
HHT

Our Mission

- To become a Canadian hub for HHT awareness and education
- To support affected individuals and families
- To raise funds for HHT research and healthcare in Canada

Contact Us

For questions and concerns, email us
@ info@hhtcanada.com

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Education ~ Research ~ Healthcare
Hereditary Hemorrhagic
Telangiectasia (HHT)

How much
do you know
about
HHT?



hhtcanada.com



Symptoms

Symptoms of HHT vary drastically, even among affected family members. For example, a parent may have severe nose bleeds, but no AVMs. Yet, their child may have mild nose bleeds and a brain AVM. Nose bleed severity in no way can predict AVM presence/severity and vice-versa.

Characteristics of HHT

I. Telangiectasias – Commonly appearing on the face, lips, mouth and hands are red/purplish dots. These surface telangiectasias can bleed and typically increase in number as patients age.



II. Nosebleeds – The most common characteristic of HHT, usually beginning in early adolescence, affects approximately 90% of patients. Nose bleeds are caused by telangiectasias present in the nostrils. These telangiectasias are prone to bleeding and may cause mild (short, infrequent bleeds) or severe (long, frequent bleeds) nose bleeds. Chronic bleeding can cause anemia and iron deficiency.

III. Gastrointestinal (GI) Bleeding – Roughly 25% of HHT patients age 50 and over develop GI bleeding. GI bleeding is chronic and difficult to detect and may cause anemia.

The key to fighting HHT is detecting symptoms early and taking action!

IV. Lung AVMs – Lung AVMs affect roughly 50% of HHT patients and can bleed spontaneously leading to anemia. Lung AVMs allow blood clots and blood borne bacteria to travel to the brain making patients at risk of stroke or brain infections, respectively. Lung AVMs can also cause severe fatigue and breathlessness.

What is HHT?

HHT is a rare genetic disorder that causes the development of abnormal blood vessels and is passed down from parent to child.

Approximately 1 in 5000 to 10,000 people worldwide have HHT (~1.5 million people).

Abnormal Blood Vessels

HHT patients may develop small abnormal blood vessels called telangiectasias [tel-an"je-ek-ta'zhah] and large abnormal blood vessels called arteriovenous malformations (AVMs). The location of these abnormal blood vessels in the body determines what problems may arise. Both telangiectasias and AVMs are prone to bleeding, which can be recurrent and spontaneous.

- 90% of HHT patients develop nose bleeds, which may be mild or severe (blood transfusion may be required)
- 50% of patients develop lung AVMs, which can cause fatigue, loss of breath or stroke
- 10% of patients develop brain AVMs, which can be fatal

V. Liver Telangiectasias/AVMs – Occurring in at least 30% of patients, liver AVMs typically don't cause complications, but could lead to heart failure if untreated.

VI. Brain AVMs – Present in about 10% of patients, brain AVMs can develop early in life and bleed spontaneously. Bleeding in the brain can be life threatening or disabling, making early detection by MRI vital. Upon detection most brain AVMs are treatable.

Treatments

HHT has a wide variety of treatments available for nosebleeds, anemia, iron deficiency and AVMs. Ask your doctor/HHT specialist if you are interested in learning more about treatment options. Please consult your physician prior to taking new medications or undergoing a medical procedure if you suspect or have HHT.

Seeking Help?

Canadian HHT Centres

Toronto HHT Centre

Site: St. Michael's Hospital
Director: Dr. Marie E. Faughnan
Contact: 416-864-6060, Ext. 2407
Website: hhttoronto.com

Edmonton HHT Centre

Director: Dr. Dilini Vethanayagam
Referral only

Montreal HHT Centre

Site: CHUM, Hotel Dieu
Director: Dr. Andr anne Gauthier
Contact: 514-890-8000, Ext. 15672

Vancouver HHT Centre

Site: St. Paul's Hospital
Director: Dr. Pearce Wilcox
Contact: 604-682-2344

Winnipeg HHT Centre

Site: Grace Hospital AMC
Director: Dr. E.M. de Gussem
Contact: 204-837-0790