

Our Story



By Jim LeDrew

It Takes a Simple Test

“My goal in life right now is to make sure those I love are getting tested and looked after in a clinic if they have HHT.”

It started when I was 11 or 12 years old - I found myself coughing up blood from time and time and suffering from dizzy spells.

Finally, my parents took me to the emergency room where they packed my nose with about a yard of gauze. It was really gross after a day or two.

For many years it seemed like I got nosebleeds all the time. I thought I had a glass nose. When I was playing sports I wouldn't have the energy or lung capacity to excel as others did. I would just run out of steam. It really bothered me and affected my involvement in sports and other physical activities.

At the age of 23, I joined the Canadian Armed forces. A few weeks into boot camp, they were doing some standard health tests and found something that looked to be either TB or Cancer. So, they released me on medical discharge to get it checked out.

After many tests, and even a biopsy, a doctor opened me up with a 12-inch incision in my left side. He broke a rib or two to get at my lung and found what they called an arteriovenous malformation, or AVM.

I took a little while to heal from that, but that's when I was told about HHT or Osler-Weber-Rendu Syndrome, another name for HHT.

Then my journey truly began, and I found that I had many more symptoms that I did not initially understand the cause of.

In 1990, I found myself with major headaches, a lack of energy and limited ability to care for myself.

A couple weeks before Christmas that year, my wife came home from work and found me laying on the floor in the living room - not something I would normally do. With much difficulty, she got me up and in the car to take me to the emergency room.

I laid on a gurney for 24 hours, constantly being asked if I took any illegal drugs or if there is something I could have done to trigger the condition. I told them I had been taking a lot of pain killers, even more than prescribed, which I found through a friend of a friend.

Finally, I just crashed. As my condition was worsening, I was having seizures and blacking out. They did a CT scan and found an abscess the size of a lime in the front lobe on the right side of my brain.

Though it was removed, no one knew what caused it. Some said it was caused by a tooth infection, while others thought it could be a sinus infection.

I now go for regular visits to the HHT clinic at St. Michaels Hospital in Toronto, headed up by Dr. Marie Faughnan, who seems to spend all her time helping us in Ontario, and

even outside the province.

I now have 20 platinum coils in my left lung to plug off the leakage caused by AVMs. I am on oxygen to survive, as I was I also diagnosed with pulmonary hypertension and COPD, and trying to hold a job while suffering from this dreaded disease. I take more medications and supplements a day than I can afford.

My mother, my brother and my sister all suffer from this disease. My mother had a stroke many years ago, but no one knew why or what caused it until several years later.

My brother suffered a brain aneurism, which caused a stroke and he is still not 100 percent these days. He loses so much blood that he gets regular blood and iron transfusions.

In July last year, we lost our aunt, my mother's last sibling out of seven children. Most died early not knowing if they had HHT or not as the information was not available at the time.

My goal in life right now is to make sure those I love are getting tested and looked after in a clinic if they have HHT. Once I know my family is taken care of, I'll move on to all my friends and make sure everyone is tested. It's only a minor blood test and the results come within a few weeks.

Please listen to our story and please get tested if you have any of the symptoms.

Signs and Symptoms

Bleeding- The earliest symptoms of HHT is usually nosebleeds, often developing in adolescence. These can last for a few minutes or for hours. Triggers vary from person to person.

Telangiectasia - This occurs in the area where an artery directly connects to a vein as it is a fragile site that can rupture and bleed easily. Telangiectasias appear as red spots and can most commonly be found on the skin, face, hands and lining of the nose or mouth.

Artery Malformations (AVMs) – An AVM refers to a larger abnormality, comprised of tangled arteries and veins, that occurs in a larger blood vessel. These can form in most major organs, including the lungs, liver and brain. The best precautionary measure is to get regular screenings as not all AVMs give warning signs.

For more information, visit www.curehht.org