

Our Story



Warning Signs of Deeper Symptoms

By Mary Geake

I said, "What does having bloody noses have to do with my lungs?"

I was born in 1955, and in 1966 I, along with my dad and two brothers, was diagnosed with Osler Weber Rendu, what I considered a nosebleed disorder at the time. I spent all summer washing out my nose with salt water, which just caused my nose to bleed more. I never actually saw the doctor though my dad and brothers did.

In 1982 I was extremely busy with my three sons. The five-year-old was having trouble with his tonsils, so we saw an ENT. While seeing him, I told him about OWR and he got all excited because he knew of something to take care of my nosebleeds.

He took a skin graft from my upper arm and put it in my nose to cover up the telangiectasias. Done deal. And it did seem to work for a long time.

But one night eight years later, I had so much trouble with a nosebleed that I was taken by squad car (I worked for a police department at the time) to the hospital and they cauterized my nose to stop the bleeding.

The difficulties continued in 1991 when I suffered a major stroke. I was even seen by a doctor the day before. I lost the use of my right side, my arm, partial use of my leg and my brain had a lot of dead tissue because of bleeding in the brain.

A year later, I thought I was having another stroke, as I couldn't see or talk so my boyfriend took me to the hospital. They took an x-ray of my lungs and found AVMs, but the medical staff never told me.

They determined my issues were a result of a painless migraine headache (referred to as a colorful migraine, which I was diagnosed with in 2000). They never told me about the AVMs even though I had the stroke as a result of them.

In 2000 I was having trouble breathing. I saw my doctor who sent me to the hospital, where they took x-rays and had me admitted because they saw something on my lung and didn't know what it was.

I thought it was cancer, and all I could think was that I couldn't put my sons through that. I was scared to death. After three nights without sleep and feeling crazy, I was assigned a doctor who knew what was wrong with me - I had OWR!

I said, "What does having bloody noses have to do with my lungs?" That started my true education of OWR, or now HHT.



Since then, I have had three operations on my lungs, and my doctor is carefully watching an AVM located on my lung.

I have encouraged my family to get genetic testing to determine if they have HHT. Two of my sons have been tested and both are negative. However, I have two brothers in denial and six nieces and nephews who will not get tested, even though four of them have bloody noses.

I have been to Washington to get the HHT DATA Act passed; in fact my Congressman Jim Himes has co-sponsored it each year after the first bill failed. Guess you don't forget a woman like me!

Today, at the age of 60, I have started having trouble with my liver and might have AVMs in that area. But I have taken action and am now in a study being conducted out of the Boston area that was approved by Cure HHT.



Are you . . .

- over the age of 18
- ever been told by a doctor that you have HHT
- living within 100 miles of Boston, MA

If so, you are eligible to participate in research that will be essential to improving treatments and diagnostics. Participation is simple and is voluntary and all participants will be reimbursed \$50 for their time.

Sign up now and a Sanguine representative will be in touch shortly to confirm your health information, diagnosis, and the date and time of your appointment: https://donate.sanguinebio.com/specific.php?id=106&utm_source=npo

Good through the end of July 2015