

# Our Story

## Never Give Up!

## One Woman's Motto on Life.

By Misa Leonessa Garavaglia



One of my daughter's earliest memories is sitting in the ENT's office waiting for me to have my nose cauterized. It was a trip oft repeated during her childhood. Dealing with my bloody noses has just been part of daily life for my family. Stained clothes and sheets, blood on my desk, computer, wall, floor, and even in my food has been a "normal" part of our lives. My youngest daughter is like a trained seal when it comes to sprinting for the tissue box - I only need to put my hand to my nose for her to jump to the nearest Kleenex dispensary. Tissue boxes adorn every room in our house. We should have invested in Kleenex stock decades ago.

I remember going to the ENT as young as 6 or 7 for my first cautery. No one else in my family bled, and I was teased mercilessly about it. "If you didn't pick your nose, it wouldn't bleed," they told me. I didn't pick my nose any more than any other kid. As with all of my health issues, which included bad allergies, asthma, and digestive problems, my father and siblings accused me of "just trying to get attention" or it being "all in my head." Needless to say, I didn't grow up in a real healthy environment, but that is another story.

By my twenties I was bleeding several times a day. I began seeing an ENT in Los Gatos, California who was fresh out of his residency. He spotted the purple dot on my lip and asked if anyone else in the family had a similar one. Yes, I told him, my mother did, and it bled sometimes. Bingo! He had read about a disease called Osler-Weber Rendu and diagnosed me with it, though he had never seen it before. All he knew about it was that it caused nosebleeds. Neither of us had any idea that "Epistaxis" was just the tip of the iceberg.

This ENT did 4 surgeries on me in addition to cauterizing me every four to six months for 13 years. Feeling the surgeries were not really necessary, I started to refuse any more and, in 1998 he told me he would not continue to treat me. The insurance companies just didn't pay enough for the in-office laser procedures to make it worth his while, he said. He warned me that other ENTs would feel the same way and to expect to be refused treatment by all of them.

Meanwhile, I had done some research about my disease on the internet in the mid 1990's and discovered the HHT Foundation.

I learned that HHT could affect any part of the body and that my daughters and I all needed to be tested. We flew out to the nearest HHT clinic in Utah and underwent brain MRIs, lung x-rays, and echo-bubble tests. A three cm vascular malformation (PAVM) was detected in my lung, so I underwent surgery soon thereafter. I was told that my PAVM could easily have killed me during both of my childbirths. Evidently, Someone decided I wasn't finished here yet! Both girls were diagnosed with HHT as well, and my youngest daughter was found to have two small PAVMs in her lung, not large enough to be embolized. Our experience with Dr. Frank Miller and the HHT clinic at the University of Utah was wonderful.

I encouraged the rest of my family of origin to get tested for HHT, knowing that they had a 50% chance of carrying it on to their children. Despite the fact that a couple of my nephews get nosebleeds, they have chosen not to be tested or treated.

By 2001, I was bleeding 10-12 times in 24 hours, losing about 1/8-1/4 cup of blood each time. Fortunately, I never lost sufficient blood to need a transfusion, or even become anemic, though I did become weak after such constant bleeding. I looked for another local ENT, but the

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first doctor was right- no one was interested in treating me. Eventually I went to a doctor who was an "HHT expert" who put me under a general anesthetic and carpeted both sides of my nose with the laser. It was my 24th surgery.

We lived on the edge financially from the heavy burden of medical bills. My children's college funds lined the pockets of several doctors, hospitals, and anesthesiologists. My body was getting weaker and

weaker and my other health issues were spiraling out of control because I was unable to treat them. All of the medicines I was supposed to use to help me made me bleed.

After the last nose surgery, I came home with two large “perforations” in my septum and my bleeding was twice as severe as it was before the surgery. I hung over the sink and gushed a half cup of blood or more at a time, several times a day. I have concluded after all of my cauterizations, in retrospect, that cauterizing the nose doesn't work for HHT. The standard treatment for nosebleeds is ineffectual for someone with abnormal capillaries. In the long-run, the treatments made it worse.

I began to learn about things that thinned my blood and started experimenting with avoiding different things I found that “triggered” my nosebleeds. Due to other health issues, I stopped eating dairy products and, later, sugar. I went for several months at a time with greatly reduced bleeding. But something would always trigger it again and sometimes I couldn't detect what had caused it. After another negative experience with an ENT, I decided to stick with my own experimentation and suggestions from other HHT families. In the past six months I have discovered that a combination of things has nearly stopped my nosebleeds. That combination will be different for everyone, but I encourage you to experiment too. Here is my regime:

- Vitamin C twice a day
- Vitamin K-1 once a day
- Quercetin (a type of bioflavonoid) twice a day
- Bach's Black Current Pastilles twice a day (the orange flavor don't work, for some reason)
- Shark Oil (found in hemorrhoid cream- I recommend you have a SEPARATE tube from anyone else who uses it for its intended purpose ☺) up each nostril twice a day

I am thrilled to be hardly bleeding at all right now. I still have to be careful of trigger foods if I am taking any kind of medicine that thins my blood, but my lifestyle has greatly improved and I cringe to think of living with the chronic bleeding that I did for so many years.

I have developed more PAVMs that are currently too small to be treated and are beginning to affect my oxygen levels which my local pulmonary specialist is keeping an eye on for me. I now know what havoc HHT can wreak on me and my children and we try to be as proactive as possible in our lifestyle choices. HHT is a condition that can require medical intervention, and there are fabulous doctors available at the HHT clinics around the world. HHT also requires that we educate ourselves, take superb care of ourselves, and take ultimate responsibility for our own health. I recently wrote a blog on Hubpages.com entitled, “More than a Nosebleed: HHT” and posted a link on the HHT Foundation's Facebook page.

My family's HHT has not been as severe as many we have heard stories from, and I feel very fortunate about that. Even so, the mix of my three health issues and the challenge of healing from intense childhood abuse have sometimes tempted me to despair. I can imagine a little bit of the despair that some families with more serious HHT symptoms must struggle with. Chronic health problems can drain the life out of a family, emotionally, relationally, and financially.

Having this genetic vascular disease can be challenging, but I have found a bright side to it, as well. I take much better care of myself than I would otherwise. It has taken a lot of rewiring of my brain to understand that I AM worth taking care of as a result of the abuse I grew up under. I eat well, exercise, get lots of fresh air, and slow down and rest when I need to. Though I have faced many hardships in life, I have developed a no-quit attitude and a very strong commitment to pursuing physical, emotional,



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relational and spiritual health. I have also learned to have a voice about what is done to my body- another feat that didn't come easily from an abusive childhood. I now know that I am the expert on me. While I am open to learning, I make the final decisions. As a result, I am passing on a new inheritance to my children. Along with the dreaded HHT, they are receiving the lessons that perseverance, courage, and good self-care are precious commodities. They have watched me struggle and watched me heal. They have seen me learn to let myself be weak and reach out for support. They have heard my prayers for strength and seen me live my motto “never give up!” through good times and bad. They have watched me go back to school after 15 years of homeschooling to become a life coach, spiritual director, writer, and speaker. I hike, kayak, and garden in my free time, and have learned how to thrive, even in the midst of struggles and pain. And now, I help others learn to do the same.

As Monte Python says “I'm not dead yet!” Far from it- I am very much alive. I can tell from that little bit of blood that leaked out of my nose this morning.

*Misa Leonessa Garavaglia is a life coach and spiritual director, specializing in relationships, communication and spiritual coaching. She has a B.A. in Sociology and Non-Profit Administration from University of the Pacific, is a graduate from Life Skills International and Mercy Center's Spiritual Director Institute in Burlingame, Ca. She is a TEDx speaker trainer and also works one on one and with groups of people who are committed to pursuing greater relational, emotional and spiritual wholeness. Misa has 2 beautiful daughters whom she homeschooled from kindergarten through high school and has been married for 27 years. She lives in Felton, California, with her husband Lou and her dog Gizmo. Misa loves to read, write, and walk in the Redwoods. She also enjoys growing flowers, singing, and artistic expression.*