



Our Story

An Infection Changed My Life Forever

By Anita Runck

As a child growing up I would often watch my grandmother and father deal with severe nosebleeds. I would watch my father bleed into the bathroom sink and wonder how he could always get that big mess cleaned up. I remember my mother driving my grandmother to the hospital for regular blood transfusions. My grandmother died when I was eight years old. I was told by my mother that dad and grandma has Osler's, short for Osler-Weber-Rendu Syndrome, and she hoped my siblings and I did not have it too.

Like most young children, I did not worry about this. I had more important things to think about than inheriting a disease that I didn't show any symptoms for. I was also told our family (my grandmother, my aunt, and my father) only had it in the nose and I was not having nosebleeds. My father died at the age 59. I would never know what older years might have brought him or what I would have learned from his experience with this disease.

When I was 23, I married immediately out of college. I was always energetic, adventurous, and my husband would say, "Bubbly". I was very active physically, also. I occasionally would have a nosebleed but nothing regular. At 28 we decided to start a family. I wasn't sure about this "children thing," but thought we should at least give it a try and have one child. I ended up with an ectopic pregnancy and lost the

baby and had to be given five units of blood from the internal bleeding.

The next year we conceived and gave birth to a healthy baby boy. Needless to say my wanting one child soon disappeared as I learned how great it was to be a parent. I started having more bloody noses, and thought "I wonder if I did get Osler's from dad. Oh well, it's only in our nose." We then had two more children in the next few years. When I was 42, surprise, I had our bonus baby. The pregnancy was harder but that was to be expected because of my age, and bloody noses were worse so I was anemic. It wasn't long after our fourth child was born I started to get severe nosebleeds and was always anemic. Bleeding into a trash can was common but I still was able to work as a dancer and run my dance studio.

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In the summer of 2008, my life changed. We went to the Black Hills in South Dakota for a family vacation. I got an insect bite while hiking. I also noticed that I was getting out of breath quite easily. Like any woman, I vowed to lose some weight. We got home and I headed straight to Minneapolis for a convention for my job. After four days, I returned home and began to have trouble walking. Convinced a chiropractor could help, I scheduled an appointment. After a few days in bed, I was hardly able to move, and could hardly get to the bathroom. I thought I'd better see my doctor since I was having trouble walking and the pain had spread to both knees.

They admitted me to the hospital that day with pneumonia and I was to get an MRI of my hip. I was given IV antibiotic. My knee, where I had been bit, started to swell and turn red. In the course of about 7-10 days, I went from being vibrant and healthy to an invalid. They diagnosed me with a rare form of arthritis and sent me home. Fortunately, the doctor thought I should go to Mayo for a second opinion because he wasn't 100% sure of his diagnosis. He also knew my family history with Osler's, but didn't know a lot about the disease and its' effect on my health.

I headed to the Mayo Clinic in Rochester, Minnesota and saw a doctor who would try to diagnose what was wrong with me through examinations and tests. He was baffled. He said if it was infection it was another whole ballgame. He sent me on to the Orthopedic and Pulmonary departments.

It wasn't until I met with Dr. Karen Swanson, Director of the HHT Center of Excellence at the Mayo Clinic that the situation started to make sense. She diagnosed me immediately. An infection had gotten into my bloodstream and through two large PAVMs had caused an infection that had disintegrated my right hip cartilage and manubrial joint in my sternum in just three weeks. She explained that the PAVM's were most likely a result of HHT. I explained the mysterious bug bite and my symptoms, but we also discovered that the infection could have entered my bloodstream as result of dental work that I had done previously. We will never know the exact cause of the infection. Although I was relieved to finally find out what had happened, I was devastated too. I asked, with my family present and in tears, "Am I going to die?" She said, "No." She contacted the other departments (thoracic, orthopedic, infectious disease) and they would need to decide if they should repair the hip first or fix the lungs first. Dr. Swanson was pushing on getting the lungs repaired first so a stroke or worse wouldn't happen. Also there

would be a risk of more bacteria going through the bloodstream and not getting filtered in the lungs if they did it in reverse order.

I was informed that I was going into surgery the next day (I was planning to move my second child to college that day). They would do an embolization in my lungs on two AVMs. I was scared. That was the easy part of what was to come. They wanted to grow a culture of what bacteria was growing in me so they would better know what antibiotic to put me on. Unfortunately, due to the fact that I had already been on antibiotics nothing could be detected.

I went back to Rochester (a four hour drive) to go back into surgery for the purpose of removing my right hip and manubrial joint in my sternum. Fearing the worst, I left a note with my husband for my kids in case I didn't make it through surgery.

Needless to say, I survived that surgery, but the infection

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returned. I have had to undergo several more surgeries and countless sessions of physical therapy. I will never be able to dance as I once did, but I continue to teach my dance students with help from my wonderful employees. My doctors have put me on antibiotics for the rest of my life. I wish I had known more about my family's medical history. I now realize that people with HHT can suffer from a myriad of health problems and medical professionals need to be educated about this disease. Everyone with a history of HHT needs to be screened for AVMs in the brain and lung.

Three of my four children have been diagnosed with HHT. My oldest has been screened at the Mayo clinic. I am planning to schedule screenings for my other children.

I wish I had known about the urgency to be screened. My life has changed forever. I just want to help as many people as possible get diagnosed that don't know they have it. I don't want to see people go through what I've gone through. I feel fortunate that it was only my sternum and hip, it could have been a lot worse.

I am now a member of the HHT Foundation. Their website has been an invaluable source of information for my family. Trish Linke, the Patient Education Liaison on the HHT Foundation forum, has been amazing. She has said things that brought tears to my eyes. I told my husband it is the first time I had ever talked with someone who has this disease and knows what I am going through. It has meant the world to me. I feel blessed to be alive and to be with my family for hopefully many years to come.