

Our Story



My Great-Grandfather's Death Certificate Led to My HHT Diagnosis

By Katie Jones

Bleeding was a normal thing in the Grimmert family. My great-grandfather, Benjiman Grimmert, struggled with bleeding problems all his life and his mother suffered from horrible nosebleeds. By the time my great-grandfather reached his 70s, he needed regular blood transfusions. His bleeding became worse and worse, and in 1974, at the age of 79, he passed away from the consequences of internal bleeding. My grandfather and father also inherited the bleeding condition and continued to live with the annoying daily nosebleeds.

I was born in 1990 and the doctors soon discovered that something was terribly wrong. I was blind. After an examination, an ophthalmologist determined I had been born without optic nerves and declared I would never see. My parents did all they could for me and implored their family and friends to pray.

After weeks of praying and waiting, one day my father came into our living room and noticed that, for the first time, I looked up at him and followed him across the room with my eyes. My parents took me to the doctor, where the pediatric ophthalmologist fell to his knees, thanking God for doing what neither he nor any other physician was able to do.

From that point on, I continued to grow into a healthy young girl, except for one thing - I began to get the family nosebleeds. I required cauterization of my nose from time to time and dealt with the bleeds as they came along. However, in December of 1999, I had an experience my family and I will never forget.

During the night of December 8, my parents heard me coughing and my mother came to check on me. She found me lying in a pool of blood and I was rushed to the emergency room. The ENT performed surgery and stopped the bleeding from my throat. Two weeks later I had another attack, which was worse than the first. I lost so much blood I went into shock. I was given a blood transfusion, and the doctor performed surgery on my throat once again.

My family started to realize the inherited bleeding condition was more than just an annoying nosebleed problem. Soon afterwards, my grandmother found my great-grandfather's death certificate and discovered the name of this strange condition, Osler Weber Rendu Syndrome.

Osler Weber Rendu Syndrome, or Hereditary Hemorrhagic Telangiectasia as it is now commonly referred to, is an inherited bleeding disorder which affects approximately one in 5,000 people. HHT affects the nose, skin, lungs, brain, liver, spine and other organs. Though it is known for causing debilitating nosebleeds, HHT can also cause telangiectasias on the skin or arteriovenous malformations in the organs, which can cause serious damage, such as stroke or brain abscess, if left untreated. HHT affects men and women equally, and affected individuals have a 50% chance of passing the disorder to their children. With this knowledge, my family now had the power to fight this rare condition.

After my throat surgery, I had a CT scan to check for AVMs on my lungs. The test showed I had two malformations, and I



Katie, at age 9, pictured with the doctors of the HHT University of Utah Medical Center.

was sent to the nearest HHT treatment center at the time, which was in Salt Lake City, Utah. While in Utah, I had coils put in my lungs to fix the AVMs, and in 2011, I had the same procedure at the newly opened HHT Treatment Center in Dallas, Texas. I now have 10 coils and a plug in both of my lungs. I require follow-ups every few years to check for new AVMs.

In addition to the lung scans, I had a MRI of my brain in August of 2012. The MRI revealed a small brain AVM and that part of my brain had never developed. The doctor at the HHT Center in Little Rock concluded that the brain AVM triggered me to have a stroke while in the womb, causing a portion of my brain to not develop.

We now know why I was born without eyesight. This discovery has been the most recent part of my journey with HHT, though the disorder continues to have an impact on my family.

The greatest inspiration in my life has always been my grandfather, Harold Grimmert. He battled nosebleeds from a young age, and as he aged, his bleeding became continually worse, requiring blood transfusions at times. However, in spite of the hardship, he had a zeal for life and a great love for his family. He always wanted to know how I was doing and how my bleeding was. My grandfather never focused on himself. Instead, he desired to help and be a friend to everyone around him.

Unfortunately, we lost my grandfather in October of 2011 because of a stroke. The exact cause of the stroke will never be known, but one thing is for sure - no one will ever take his place. HHT has caused too many tragedies in my own family and in countless other lives. For this reason, I am on a mission to spread the word about HHT and encourage people to give blood for those who suffer. Education is power, and it is my desire, that through my efforts, others will be saved from tragedies and will get diagnosed and treated before it is too late.

Donations to Cure HHT can be sent to:

Cure HHT

PO Box 329

Monkton, MD 21111

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