

The HHT Foundation receives numerous calls, emails, and discussion forum posts everyday from individuals who are searching for answers, need medical advice, need referrals to HHT experts, or just need a listening ear and moral support. This, in addition to funding research and discovering advancements in medical treatments, is why the HHT Foundation exists. We count on your support to help us uphold our mission - to find a cure for HHT while saving the lives and improving the well-being of individuals and families affected by HHT.

We know times are tough, but they will get tougher for some if they don't get the answers, advice, and referrals they need. Please **DONATE GENEROUSLY** to the HHT Annual Appeal and **DOUBLE** your gift through this year's unprecedented matching program.

Our Stories

Listen to one woman's story of a Family Secret Revealed...

One HHT Discussion Forum Post

... I was hoping by posting on the HHT discussion forum it would make me feel better. I've gotta go now, my son has more tests tomorrow and we have to get up early to take him to Rochester, MN.

If you have any more info that I can read about my son's condition I would really appreciate it. And how do I tell my child this. He's already scared of everything.

Thanks for all your help.

— From one scared mom

Another HHT Discussion Forum Post

I am so tired of people telling me that it's not so bad or that it could be worse. And, you know, they are right - it could be worse. But I feel like no one understands my point of view and that I am alone in this. -- Thanks for listening to me ramble.

An email conversation based on previous HHT Discussion Forum Posts – The Story

This story is about my family. In early to mid spring my husband told me that his dad had been hospitalized and was in critical condition. At that

time, my father-in-law was very secretive about what was wrong. We later found out that he had a ruptured PAVM that was bleeding into his lungs. It turns out that my father-in-law was about 4 minutes away from death. He survived and is now home. However, we were NOT TOLD that this was HHT or that my husband and kids should get tested because it is a genetic disorder. So, we thought nothing of it.

In June, I took our son to the doctor because he had purple finger nails. The doctor ordered an x-ray and discovered a 3cm AVM on his left lung. I remember getting the phone call from the nurse and she said, "Well, I have good news. It's not cancer. He has an AVM that is 3cm on his left lung". I didn't know what to say. I do remember thinking, "And that is good news because why?" So I did some research on the internet to try to learn more about lung AVMs while we waited for the referral to go and see a doctor at the Children's hospital in St. Paul, MN. I discovered HHT and the Foundation and we transferred our care to the Mayo clinic in Rochester, MN where we got everyone tested.

I found out in June 2009 that my husband (34), our daughter (8) and our son (6) have HHT. Our youngest son is clear and doesn't carry the gene. Within two days, after we went through ALL of the tests, we found out that my husband was a walking AVM. He has several in his brain and lungs, one on his pancreas, and he has chronic nosebleeds that vary in severity. My husband is also extremely anemic, to the point that he may need a transfusion. So far he has undergone one procedure on his lung and one procedure on his brain. He will need to have more procedures done on his lungs and brain some time in the near future. Our son (6) has had two procedures done on his lung. He is done for now. He also suffers with nosebleeds but they are not too bad. Before our son had this procedure done his O2 stats were 84%. Now they are at 94%. My daughter has a very small AVM on her lung so it is a waiting game with her. She doesn't currently suffer from nosebleeds.

At this time everyone is living happily ever after. ■