

Our Story



A Journey To Healing

By Neeta Pai

“Had there been awareness, we could have prevented all the heartbreak and trauma my family experienced.”

I lost my independence in September 2004 with a diagnosis of Idiopathic Pulmonary Arterial Hypertension (PAH) in its final stage. My health had so badly depleted by then, I was already grieving over the loss of what my life had been.

I could no longer continue my career in sales management, my many charity work interests or even take my dog on the long walks we both enjoyed. My short term memory was affected along with my vocabulary and the ability to speak in full sentences. My cardiologist told my husband not to let me write any checks or make any major decisions on my own.

It was six more years of ER visits, severe nosebleeds, fainting spells and undependable nosebleed treatments, before I received an additional diagnosis of HHT. In that timespan my husband, Nick, and I moved from New York

to Connecticut to downsize to a condominium apartment without stairs. I was forced to abandon my vegetarian lifestyle because of iron deficiency anemia and had to receive emergency treatments to stop bleeds that lasted for hours.

It didn't matter what I tried, the bleeding just got worse, once lasting a span of 16 hours. At that point, I would have done anything to stop the bleed, including turning into a non-vegetarian for health reasons.

Most of the famous specialists in hematology and otorhinolaryngology did not know what caused the severe nosebleeds that only continued to get worse.

During this time, we were referred to Mayo clinic, where we had been making annual visits to the PH specialists since summer of 2007. The cardiologist suspected HHT and sent a sample of my blood to Vanderbilt University for research in 2009. He also ordered a brain MRI, liver CT scan and some blood tests.

The results showed liver AVMs and I was referred to Mayo Clinic's HHT specialist, who ordered a genetic test, the results of which did not have any known markers to specify HHT. It was not made clear to us if I had HHT, but I was definitely stressed since there was no treatment at the time except for what I was already receiving. At this point

we were confused if the PH drugs were the cause of my nosebleeds or if it was HHT.

The blood tests also showed some curious results for which I was referred to a hematologist, who then introduced us to Mayo's hemophilia center, where I was given another diagnosis – Acquired Von Willebrands Factor VIII Insufficiency – a clotting disorder. I was really fortunate to have had the blood tests from both specialists to accurately diagnose this difficult condition.

As this was a rare combination of diseases, with only three known diagnosed patients in the US, as per the Mayo Clinic hematologist, who sat on the National Board of Hematology, they took much interest in my case. He requested four visits a year for follow-up care, stressing how serious HHT was, especially when combined with Acquired Von Willebrands and PH. So, we moved to Rochester, MN in November 2009 to be close to the Mayo clinic after my husband's retirement.

My dear husband, Nick is a rock of steady strength standing beside me, changing his work schedule to take me to many medical appointments. He encouraged me to be strong, both emotionally and spiritually, and to fight this disease with a positive attitude and be happy living in the present.

But the next five years were difficult to say the least. Most of my faints were blamed on PH. I had 40 emergency visits to stop the bleeds in the four years after my diagnosis. I have fainted four times at home and four times in the emergency department.

We eventually came to the following conclusion: Pulmonary hypertension may be an HHT-associated disease. The clotting disorder was not inherited, but acquired from an unknown cause. The bleeds from HHT did not stop due to the clotting disorder. It all made sense; however, there was still no proper treatment or a cure for

HHT, the main disease, which, though diagnosed later, caused all the complications.

It was my final faint in February 2014 that led my HHT physicians to administer Avastin Infusion treatments, a cancer drug, as a trial for a few weeks after a laser procedure.

The emergency department was under construction at the time, and waits that were previously non-existent had started to be hours long.

We had gone seeking help for a particularly severe nosebleed. The emergency nurse practitioner placed a clamp on my nostrils, which only re-directed the blood into the gut.

By the time the ENT arrived three hours later, I threw up three buckets of blood and fainted. I woke up and threw up another five buckets of blood. Then everything went dark as my heart stopped and the doctors worked to revive me. The episode was followed by a couple of days in the ICU, two more days at the

hospital and days of rest at home.

All of this could have been avoided if only the emergency staff was educated about HHT. Had they known a patient had to be treated quickly and in a certain way, had there been awareness, had there been knowledge of HHT in medical schools, we could have prevented all the heartbreak and trauma my family experienced.

If this occurred at our nation's number one hospital, what could be expected from a general local hospital with a staff that has not even heard of HHT? But thanks to the Avastin Infusion therapy treatments, I have been bleed free since April 2014.

I am now dedicated to spreading awareness about HHT, both to the general community and medical community. If we all join together to support the Cure HHT cause, there will be less people who have to go through ordeals like I did. Join me at the annual Rochester, MN Cure HHT Team Walk.

Join Neeta's Fight!

The first Cure HHT Team Rochester Walk is being held on May 30 at Soldier Memorial Field. This is an exciting time to join the fight to cure HHT and to take on the challenge of this awareness and fundraising endeavor. Our efforts, together, move the needle closer to finding the cure for HHT. For more information visit <http://curehhtrochesterwalk.causevox.com/>