Family Stories

HHT has devastating effects on not only the persons afflicted, but the entire family. Learn more about several local families whose lives have been affected by HHT.
Provided by ourhopesholdsthecure.org

The Nissans

No one should have to lose a family member to HHT, but that is exactly what happened to our family in 1999. Clay's mom passed away from this disease at the age of 57. A few short years later my husband and daughter were diagnosed with HHT. Now, Clay, his brother and our oldest daughter, Sydney, struggle daily with various symptoms. Clay has AVMs from the disease in his intestines, esophagus, mouth, nose and liver. He has had multiple surgeries to try and control the progression of this disease. He receives regular infusions to help counteract the blood loss. Our oldest daughter, Sydney, has manifestations in her lungs and suffers from daily nose bleeds. Our son is showing symptoms so only time will tell if he and our youngest daughter will be fighting the same battle. I hope that one day we will have a cure for this horrible disease so that people young and old will not have to fight the daily struggles this disease presents and not another person will lose their life to HHT.

The Veras

Adriana Vera has had an insurmountable amount of tragedy in her family. She and all of her siblings have HHT, along with her nieces and nephews. "My son, Robert, died in 2005 and my 11 year old, Sabrina, has AVMs in her brain, lungs, and liver. I have it in my lungs, liver, and GI but not in my brain." Many of Adriana's family members have died, suffered strokes, or experienced severe disability from this disorder. Adrianna and her brother-in-law, Yasuo, attended this conference with her daughter to learn as much as they could about this disorder in an attempt to alter the devastating medical history of their family. "My daughter and I met a lot of good people in Chicago. I would like to help in any way I can. The loss of my son haunts me every day. Now I am in the same battle with Sabrina."

The Carlisle-Browns

Greg has run the San Francisco ING Bay to Breakers Race many times in his life, but this year means the most to him. Greg is running, not to achieve a personal best time or prove that he can finish, but because he has HHT, his children have HHT, and his extended family have HHT. He is running to prove that with tenacity anything is possible, including finding a cure to this disease so that he can live to see a generation in his family without HHT. Greg has had two brain surgeries, one abdominal surgery, liver failure, daily nose bleeds and IV iron (every other week for four years) because of HHT. Greg's grandmother and his 12 year old cousin died from the disease. His sister had a stroke at 20 years old. Greg's children have lung and brain issues as well. Greg routinely visualizes himself crossing the finish line in an effort to motivate himself to keep training. His wife and he visualize a world without HHT, a world where their children are healthy and happy.

The Purdys

I myself do not have Hereditary Hemorrhagic Telangiectasia (HHT), however, it is a part of my everyday life. In 2007, my husband Don, and our two children, Emma and Elliot, were all diagnosed with HHT. Emma is 9 and Elliot is 5. I can honestly say that I count my blessings everyday that we are aware of this disease and can take precautionary measures to make certain they are all safe. It is hard as a parent, and I must say especially as a mother, because it is our job to keep our children healthy and safe. With HHT, I can't make it go away, nor can I make it better. But what I can do is continue to help raise funds and awareness for this uncommon disease that affects my family every day. My husband has nosebleeds, and has also had a pulmonary AVM, which had to be repaired at the Mayo Clinic. Our daughter, Emma, is doing well and just has an occasional nosebleed. Our son, Elliot, has daily nose bleeds and currently has a pulmonary AVM. Unfortunately for Elliot, the nosebleeds have hindered some of his classroom time, but we are very grateful for his teachers, who are always helpful when he is at school.

The Anzells

Our family's introduction to HHT began December 2006. Our son Anthony was a sophomore in high school when he developed what was diagnosed by our doctor and the local hospital as a migraine. After two weeks of misdiagnosis, Anthony began to lose weight, his coordination, his vision, and the ability to hold food down. The hospital, with much parental prodding, finally ordered a head CT. The scan showed a mass in his head taking up a quarter of his brain area. He was rushed to another hospital where the mass was diagnosed as a brain abscess – 120 ml worth. Anthony endured three separate surgeries to remove the abscess. During this time a liver abscess and two pulmonary AVM's were also discovered. The pulmonary AVM's were the causes of the brain and liver abscesses. Anthony suffered a stroke during his two week stay in ICU and has lost the peripheral vision on the right side of both eyes due to the entry location to remove the brain abscess. We are very fortunate and thankful to have him with us today. We are unaware if anyone else in the family has HHT or where it originated in our family. My husband Roy, our son Doug (Anthony's twin brother), and our daughters Rachael and Sarah will undergo screening at Washington University in St. Louis to understand if they are affected. Proper diagnosis and early screening may have prevented some of the trauma Anthony endured. Our hope is that HHT awareness spreads amongst the medical community to prevent misdiagnosis to other patients and early treatment.

The Urbaneks

In July 1999, Barry's father was diagnosed with HHT and Barry was screened, due to a lifetime of migraines. Three weeks after his screening, we were told he had a large cerebral AVM (CAVM). On September 23, 1999, Barry underwent surgery to remove his CAVM. There were complications when his CAVM ruptured during the surgery, causing stroke/major head trauma symptoms. He was paralyzed on his right side, unable to speak or move his head. After 31 days in two hospitals, he was discharged and continued outpatient therapy for the next 5 months to regain his motor skills. Six months after his brain surgery, Barry returned to work. In July 2011, we returned to Yale for Barry to have 2 PAVMs coiled and to get our daughter, Skyler, screened for HHT. It took 35 years for Barry's father to be properly diagnosed and treated for HHT. Thankfully, through family screening, we now know about Barry's brain and lung AVMs and his brother's brain, gastrointestinal and spinal AVMs. It is frustrating that HHT patients have to travel out of state to find doctors who have any knowledge of this disease, and can offer treatments that will not cause them more harm. Our goal now is to improve the medical community's awareness of HHT and to help advance HHT research through fundraising.