Our Story

Advocacy, Education, Fundraising: The Power of the Written Word

By Arline Williams, HHT Foundation Member

The Mission of the HHT Foundation is to educate, advocate, and support families affected by HHT while funding research and engaging the medical and scientific community. This is a large task and we cannot do it alone! In fact, the message is far more powerful, especially when presented to Congress, when it comes from those who live with this disorder on a daily basis.

Arline Williams, an HHT Foundation member, saw the Long Beach Marathon fundraiser as an opportunity to educate her family, friends, and community while raising money for the Foundation. Ms. Williams spoke to her local newspaper and had an article published about HHT. She also reached out to those who know her by writing an honest and powerful letter about how this disorder has affected her life.

I have HHT. It is extreme, and sooner rather than later, it will claim my life. If I can write an open letter telling of my experience and perhaps urging you to tenaciously seek early treatment of possible symptoms, then my time here will have been worthwhile. Perhaps, during your lifetime, prevention/cure for HHT will be developed.

But, to participate in making that cure happen, I believe you first must listen to my story:

I am 64 years old. I suffered from nosebleeds and arrhythmia in my 20s. I thought it was stress brought on by college and then by working and raising a family. Then, about 8 years ago, I developed a noticeable heart murmur. Cardiology begins! Coronary symptoms escalated over the next 5 years. Irregular heart rhythm caused shortness of breath (catheter ablation was done unsuccessfully). Then cardiac catheterization followed. The specialist said there was a hole in my heart and could be easily fixed. A solution! Then, he called and said "no hole", but an anomalous pulmonary vein…a birth defect! But no; the next diagnosis was leaking mitral and tricuspid valves. But I was denied surgery to fix them. My cardiologist said my symptoms didn't "line up." All this time my heart function was deteriorating, and the right side was being overworked and enlarging. Three years ago, I was sent to a heart transplant clinic as a candidate. I was scared. This was BIG surgery. The punch line was, "You are not a transplant candidate, because you have HHT!" In that moment, all of the symptoms I'd experienced over the years came into focus!

During the next three years, I had a serious intestinal surgery, and bled abnormally, producing a life threatening situation. I returned to the hospital to receive a very large transfusion. (I have had 3 more since then.) I was also admitted to the hospital when I turned blue from excessive fluid in my lungs. I began to suffer from malnutrition because my liver was enlarged and not giving my stomach enough room to hold much food. Enlarged heart, small stomach, enlarged liver, profuse nosebleeds, fatigue…who is this person? It couldn't be the robust woman who walked 3-4 miles a day and was just learning horseback riding. I came to the realization I was, at the very least, hobbled by HHT. And it would be lifelong. This was mind-numbing.

What I have written is not a litany of woes. It is to let you know the long path the HHT afflicted might travel.

Currently, I receive iron infusions every week, significant injections of Procrit® weekly, heart medications, a high dose of diuretics and treatment for nosebleeds every 2-3 months. My liver is damaged and does not retain iron so the infusions will be ongoing. The liver AVMs cannot be treated, and transplant is not an option. My heart has been severely damaged because not enough was known to treat my HHT. Yet, I am called a phenomenon by my doctors, because my spirits are always high, and with treatment, I am able to maintain an unexpected level of energy. But there are discouraging days too. What will happen when the symptoms overcome the known treatment?

Please remember HHT is genetic, and never skips a generation.

Please remember HHT is genetic, and never skips a generation. Many, still unaware, will be touched by it. Many unborn children will have it. Research is the only way we can break through to the other side, so no one must ever again live under the cloud of a condition of unknown progression, forced to play the roulette of symptom management.

I am honored to write a letter that may promote the further research and development of a viable cure for HHT.

I am supported by the love and strength of my family. They are the best. One of my sons will be running for HHT in the Long Beach Marathon, to show his support of me and others with HHT. I know you are not all runners, but you CAN help by contributing even $10 to help us reach our goal of 3K.

Sincerely, and with great hopes for the future,

Arline Williams

Bless you Arline, for sharing your story, encouraging others, and realizing that the only way to battle the progression of this disorder is to better understand HHT through continued research.

We encourage more members to write letters like this to their family members to encourage screening and prevent death or disability. We encourage members to write letters like this to their Congressmen so that HHT can receive the federal funding it rightly deserves. And, we encourage members to write letters like this to their friends and community leaders in an effort to raise awareness of HHT, increase identification of the disease, and hopefully, raise money to continue the work of the HHT Foundation.

If you have a story to share that can benefit others who are struggling to convince family members about the impact of this disorder, please contact the HHT Foundation at nicole.schaefer@hht.org. We can possibly share your story in the newsletter or on the website.