# Our Story

# Why I Give

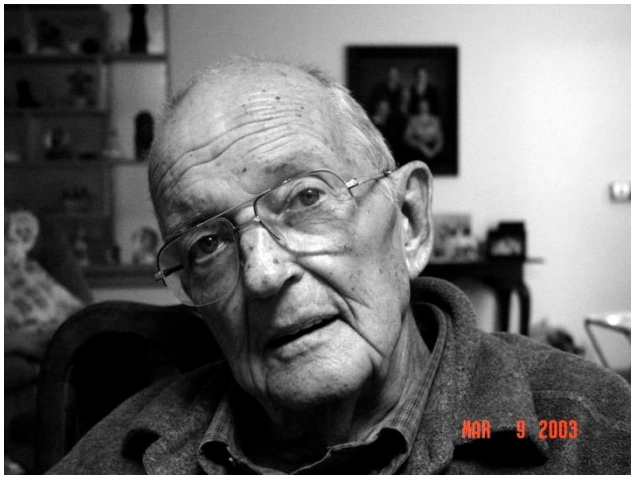
## By Eric Scheele

"We all benefited from the incredible amount of information from Cure HHT about HHT research and first-hand stories of other HHT patients."

HHT - Hereditary Hemorrhagic Telangiectasia - A disorder with a definition and diagnosis almost as difficult and elusive as it is to pronounce.

Allow me to begin by saying my father, Donald Scheele, passed away in July of 2003 at the age of 77. Like so many others who suffer from HHT, he struggled for many years with nosebleeds, transfusions, ablations and a host of other related issues. Also, like so many others, his HHT was not properly diagnosed for many, many years.

When I was a child, I didn't understand why my father was too tired to participate in family activities, why he looked pale and sullen, why his mood would drop because he had to rest. In fact, during most of that time, he and my mother had no idea what was wrong. They didn't know there was an underlying, undiagnosed condition slowly creating these problems. And the doctors he eventually went to offered no clear reason or solution.




Insidious became my choice of adjective to describe the condition I would later learn to be HHT.

My father rarely complained, even while HHT was slowly wearing him down. The most difficult part was watching it impact my late mother who was his primary caregiver. Given the hereditary nature of HHT, my mother made it a point to educate herself and the family about HHT. With an inheritance factor of 50 percent, and with three children, my mother wanted us to know about and understand exactly what it was affecting our father. She made it clear there was a good chance one or more of us would inherit it.

She would ask doctors about it as well as do her own research. Most importantly, she contacted the HHT Foundation and subscribed to their newsletter. We all benefited from the incredible amount of information from Cure HHT about HHT research and first-hand stories of other HHT patients.

As it turns out, I inherited HHT from my father. My brother and sister, thankfully, seem to have been spared. Growing up, I was plagued with random nosebleeds, some often difficult to stop. At 7-years-old, I tested positive for numerous environmental and animal allergies, to which the doctors attributed the nosebleeds.

Now, as an adult, the telangiectasias are clearly evident in my sinuses. I have sprouted the same little red "spots" on my skin that my father had. And my first colonoscopy revealed more telangiectasia in the mucous membranes. I also get a bit anemic sometimes and have to take iron therapy to raise my iron and ferritin levels.

All of this can be annoying, but what I really worry about are my two children. I have a 20-year-old daughter for whom nosebleeds and migraines have been constant companions. My 13-year-old son has had some nosebleeds, but does not exhibit any other symptoms. They have not been tested for the genetic markers.

I question whether I am wrong in not having this test done. My daughter's symptoms could be coincidental and it may be my son who has HHT. Then again, they both could have it or neither could have it.

I think, in the end, the truly important point is they are aware HHT is a possibility for them and they know what it is and how it can affect them. They can also alert their doctors to the possibility of having HHT. This is a supreme advantage, something my father and others in the past did not have.

Information and education about HHT is *CRITICAL* to patients who are suffering the ill effects of HHT. Education can be the difference in the quality of life for a HHT patient, maybe even between life and death.

My mother and father would be happy to know there have been so many advances in the study of HHT, and that many more people can be properly diagnosed and treated. It is my family's hope that eventually a cure will be found so others will not have to suffer the ill effects of HHT, that they will have the best quality of life and not have to refrain from family activities as my father did.

There are numerous other diseases considered more important, and research into their cures gains more public recognition (e.g. cancer, heart disease, diabetes). Of course, these are truly important and need to be researched, but HHT is also very important and affects a large percentage of the population.

On behalf of my family, I'd like to extend a heartfelt thank you to Cure HHT and all the doctors, researchers, staff and other individuals involved in making the goal of a cure a reality.

Donations to Cure HHT can be sent to:
Cure HHT
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