

Our Story



Starting the HHT Conversation

By Lauren Linhard

It's safe to say that Savannah Schott's first date was not the experience she had been hoping for. Instead, at 16-years-old, she spent the whole day being nervous only to choke when he showed up – literally. Her nose started bleeding a little, and then all of a sudden she coughed up a blood clot.

The date that never started came to an unexpected end when she was transported to the ER, bleeding from both her nose and mouth. The episode lasted for 45 minutes before doctors had to manually cauterize the epistaxis with silver nitrate sticks.

"Have you ever bled for 45 minutes straight, bleeding so hard it comes out both nostrils and down your throat," Savannah asked, recounting the experience. "Nearly filled a sink up with your own blood? Contemplating the thought that you might die? It's awful."

Thankfully the bleeding stopped after the cauterization, but it was only 12 hours later before the bleeding started again and Savannah was back in the hospital.

Now 23-years-old and looking back at the experience, Savannah said she believes if the doctors had been educated on the proper treatment technique, perhaps the second visit could have been prevented.

"I'm just starting my journey, which is amazing because I have lived with this my whole life," Savannah said.

But she isn't the only one who has suffered in her family because of the medical community's general ignorance of HHT. A year after Savannah's brother was born, her mother started bleeding every time she had a bowel movement – she was bleeding from the colon.

The doctors couldn't determine what was wrong, and a colonoscopy procedure made the bleeding worse, Savannah said. Her mother almost died on the table and has a heart murmur because of the experience.

But it's Savannah's Uncle Andy who has had it the worse, going to the hospital with what doctors diagnosed as mini seizures when it was actually a stroke caused by bleeding in the brain. He has had seven strokes in his lifetime.

"We never really talked about the disease, it was just something we had," said Savannah, adding that her family sat down for the first time in September 2015 to really talk about HHT. "I had no idea the gravity of how my family had been affected. It really sparked something in me."

Savannah said her family was able to trace the line of HHT from her great grandmother, who had nosebleeds, to her grandfather, who has GI bleeding, to her mother and uncle, and finally to her and her brother.

She is now leading the advocacy charge in Iowa to introduce an act similar to the HHT Diagnosis and Treatment Act in the Senate. With help from Cure HHT legislative liaisons, Savannah contacted Senator Chuck Grassley and plans to assist with efforts on Capitol Hill when she is in town.

"If you don't educate others and advocate for your disease, it's just going to spiral," Savannah said. "It's our responsibility to increase awareness – all you can ask for at this point is to start a conversation."

Sign Savannah's Petition: <http://chn.ge/1j9Uglx>

Lay Down the Cure HHT Law

The HHT Diagnosis and Treatment Act HR 1849 was introduced in the House of Representatives on April 16, 2015 as part of the 114th Congress.

The bill would be the first to create a federally led and financed initiative for early diagnosis and appropriate treatment of hereditary hemorrhagic telangiectasia.

The HHT DATA Act would require the Centers for Disease Control and Prevention to conduct surveillance initiatives, start an internal HHT resource center and conduct public awareness programs.

The act would also authorize the appropriation of \$5 million per year for the next five years to be used to improve early detection, screening, diagnosis and treatment of HHT.

For more information, click [here](#)