

# Our Story



## The Power of Awareness

By [Caz Rose Coxall](#)

I have had health problems my whole life. As a baby in 1973, my parents were told I had a tumour with an abnormal blood supply in my mouth. During surgery to remove the tumour, I lost a lot of blood and the doctors couldn't explain why.

A number of other health problems came up as I grew older, all of which seemed unrelated at the time.

At 20-years-old, I gave birth to my oldest daughter. She was born six weeks early at a good healthy weight of five-pounds, but she always had problems with her breathing. At first I was told it was because she was premature, then because of asthma.

But once she hit her teen years, her asthma and overall health just kept getting worse. There were more trips to doctors and hospitals than I can count and each time we were given a different reason for why she was so unwell. Who was I to question them? They are the professionals.

My daughter left for college when she was 18, at which point her health took another bad turn. My once healthy child was now very sick - her body wasn't getting the oxygen it needed and it was damaging her organs.

Luckily a doctor at a hospital near her school thought she might know what was wrong. It was an AVM - three letters I'd never heard of before. The scan showed that my daughter had a massive complex AVM in her lung, so large and so complex doctors scratched their heads as how to treat it.

No one thought this AVM could be linked to HHT as it was so different from AVMs normally associated with the disease. But when the doctor saw red marks on my skin, she asked for a test, and sure enough the result was positive for HHT.

Shortly after, my daughter's AVM was treated and I received a clinical diagnosis of HHT with pulmonary AVMS. We all had genetic testing, and my son was diagnosed with HHT because of his nosebleeds. He's now 16 and we hope to find out soon if he has any AVMS.

Thanks to the doctor who was aware of AVMS and HHT, this story doesn't have as sad an ending as others.

