

# Our Story



## My NOT-SO-SCARY Lung AVM Embolization Experience

By Sara Palmer, PhD

My name is Sara and I've worn many "HHT hats" in my day. I am one of four generations in my family affected by HHT. As a caregiver, I helped my son cope with nosebleeds and my mom cope with transfusion-dependence due to GI bleeding. As a volunteer, I've led a regional patient group, raised funds for Cure HHT and participated in HHT walks and Capitol Hill Days. As a psychologist specializing in chronic illness and disability, I've given lectures and workshops about the emotional and social side of HHT. My new "hats" include serving as a Cure HHT board member and authoring a new book about HHT. But there's one hat I wear every day: HHT patient - and that requires regular maintenance!

Recently, my HHT checkup showed a lung AVM in need of treatment. Though it wasn't causing any symptoms, if left untreated, it would put me at risk of stroke or brain abscess. Treatment could prevent these terrible events. If you have a lung AVM, your doctor may have recommended the same procedure I had, called an embolization. But maybe you've put it off, because you're scared of doctors, hospitals, surgery and pain. So I'd like to tell you what it was like for me - *and why it's not so scary!*

You may not realize this, but an embolization is not actually surgery - it's a procedure that uses x-ray pictures of blood vessels to guide the placement of a catheter and insertion of a small plug or coil into the vessel supplying the AVM with blood. There is no general anesthesia, cutting, stitches or pain during an embolization. My procedure was performed at Johns Hopkins Hospital by Dr. Sally Mitchell, Interventional Radiologist and Co-Director of the Hopkins HHT Center.

### Here's how it went:

I arrived early in the morning, a little nervous and cranky from not having any coffee or breakfast. After changing into a hospital gown, I climbed into a bed and was covered with warm blankets. My nurse asked about my medical history, allergies and so on, and made some jokes to calm my nerves. Dr. Mitchell and her resident explained to me (and my husband) what would happen during the procedure, answered our questions and got my consent.

A technician started an IV, to give me medicine that would make me relaxed and drowsy. There was no general anesthesia. Starting the IV was a little uncomfortable, but only took a few seconds.

When the doctors were ready, I was wheeled into the procedure suite and moved onto the procedure table. An aide shaved the spot where the catheter would be inserted, to reduce the chance of infection. The spot was numbed with local anesthetic and a tiny puncture was made to insert the catheter. This was totally painless. Once the procedure began, x-ray pictures were taken to guide the placement of the catheter through my blood vessels, into my lungs and then into the vessel that was supplying blood to my AVM. *I felt no pain!*

I could see the doctors and nurses, and followed their directions to take a deep breath or move my arms a certain way. I could hear them talking about trying a bunch of different catheter sizes in order to get into the vessel that needed plugging, but I had no worries - I was in my own "happy place," awake but extremely relaxed with not a care in the world.

After the procedure, I went to a recovery room. I had a bit of a headache, because I hadn't eaten since the night before, but after gobbling up a sandwich, I felt fine. The doctors came to tell us that everything had gone well.

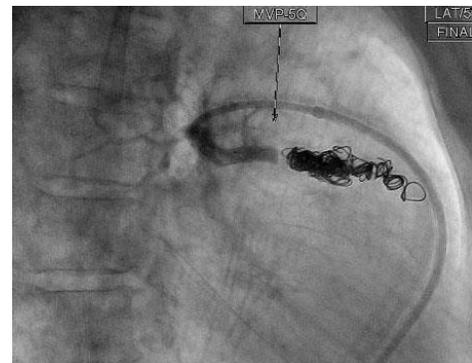
Although my AVM was complicated, they were able to close off the vessel with a micro-vascular plug. I had to rest for a couple of hours, to make sure the tiny wound in my groin was closed. Then I went home and had a nice nap before dinner.

AND THAT WAS IT - Basically, a piece of cake for me (not so much for Dr. Mitchell and her team!). The next day, I could drive and do my regular activities, and within a few days I was able to resume my exercise routine.

I hope my story shows you that embolization treatment for a lung AVM is nothing to be afraid of. And it sure beats having a stroke or brain abscess!



Before: An x-ray showing blood flow to the AVM through coils from a previous procedure.



After: An x-ray showing blood flow to the AVM is completely blocked by embolization with the microvascular plug.