Hemophilia and Me On #RareDiseaseDay2021

February 28, 2021 By Shawn Decker

My earliest memory of hemophilia is when I was 4. Mom was out running errands, which meant it was time for some horseplay with my dad and brother, two years my elder. We'd laugh as we tried to wrestle dad from his knees to the ground... then the door would open.

Dad froze as mom commanded us all to stop, worried that I might get hurt. She was the one who'd take me to the hospital if something went wrong.

I didn't know what hemophilia was, but I knew I was the reason why the fun stopped. I probably assumed the worry about me getting injured was because I was the smallest grappler in the room...

As I got older, nosebleeds became the thing that defined my life with hemophilia. It was the reason why I'd see my trusty ENT doctor, Dr. Ron Fischer, and his wife Cynthia who worked the front desk in their two-room office space, a stand-alone house that had enough toys in the waiting to keep a kid like me happy. Ron would hum to the music in his office as he packed my nose with blue numbing solution, before sealing the bleed shut with a silver nitrate stick.

When something more serious occurred, I'd go to the big hospital, where my favorite nurse, Gail Johnson, worked. I'd only trust her with sticking me with the needle, which would send the clotting agent into my body and help stop whatever bleeding was happening that day.

But, by and large, I enjoyed a pretty typical, white, suburban childhood, filled with pick-up football games in the Summer and epic snowball fights in the Winter. Once we even had the good fortune of seeing our principal driving through the neighborhood... we reigned snowballs upon his car, then denied our involvement in his office the next day, our identities protected by our winter wardrobe and nimble escape routes.

My friends knew I had a bleeding disorder and, if anything went wrong while playing, they'd make sure I got home as quickly as possible. But those were rare occurrences, and your reflexes and physical disaster intuition gets pretty dialed in when you have hemophilia.

Through the use of blood product treatments, I was infected with hepatitis B at age 6. And then, a few years later, HIV. By the time I was diagnosed with HIV at age 11, I had hemophilia pretty well

figured out. A year or so before, Dr. Ron had performed an experimental surgery on my problematic nostril, which made nosebleeds far less common. I was also becoming less interested in sports, and more interested in art, making any bleeds few and far between.

So, with the attention-grabbing HIV in the mix, hemophilia fell by the wayside in my mind. When I think about junior high and high school, I can't even recall hemophilia causing me any significant problems.

It wasn't until my mid-20s that I felt the effects of a problematic ankle. My partner, Gwenn, and I were travelling like crazy, educating at colleges and conferences about HIV and safer sex. Sometimes we'd have to run through an airport to catch a connecting flight- by the time we got on the plane I was practically hobbled. Being crammed into my seat for a few hours certainly didn't help.

When I got an x-ray on my ankle, we discovered that the issue was that I had practically no cartilage in the joint. You could see dozens of tiny little fractures in the bone. I got an ankle brace to wear whenever the ankle would act up. Suddenly, hemophilia was calling out to me, "Hey, old pal, remember me?"

After a couple of bleeding incidents unrelated to the ankle, I realized that it was time to up my hemophilia game. I learned how to self-infuse so I wouldn't have to go to the hemophilia clinic when I had a problem. I started travelling with my hemophilia medication for the first time- I shudder at the thought of all the trips and travel I went on with no clotting factor on hand...

As far as the bleeding disorder goes, I've been lucky. Just that one joint in my ankle is the only real sign of my lifelong battle. Sure, I have patches on my jacket that represent hepatitis B and hepatitis C, but I've avoided any life-changing wounds on those fields. With my effective HIV treatment, it's no far stretch to think that one day I'll be cured of hemophilia. Of course, I'll be too old by then to train for the Olympics, but maybe I'll be able to join a bowling league again, with some regrown cartilage in my ankle joint. One of my goals is to join my dad and brother in rolling a perfect 300 game.

Whatever the future holds, I know that being a part of a "medical minority" has certainly made me a more empathetic person. And the discrimination I faced as a kid in a smalltown with a big, scary new virus in HIV definitely shaped the liberal adult I've become.

And I'm thankful for all of those hard lessons, as painful as they were.

Positively Yours,
Shawn

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