World Hemophilia Day 2020

April 17, 2020 By Shawn Decker

It’s World Hemophilia Day and, I gotta say, I’m willing myself to write this blog. It seems like every day these days there is a Day. From French Toast to Thumb Wrestling, there’s a day set aside for everything. But these days, every day is Coronavirus Day. As it should be…

But I’d be remiss if I didn’t take this opportunity to reflect on how hemophilia has shaped my life.

Age four is the first time I remember hemophilia being a thing that affected me. My brother, who is two years older, and my dad would wrestle around in the living room sometimes. I remember Mom coming in, like from running an errand, and telling us to stop. “Shawn will get hurt!” There was something in the tone that got my dad’s attention. It had less to do with me being the smallest competitor, and more to do with the lack of blood-clotting factor my little body had.

It’s a distant memory- but it’s real. It isn’t backed up by photographs of the three of us battling it out. I just remember the feeling of joy being replaced by the feeling that I was the reason why the fun stopped. Ref Mom made the only call she could. And I understand. I’m not scarred by the memory. In fact, it enhances the feelings I always have about my family- that they love me and often have shown that love in the best ways that each individual can.

Growing up, I had so many trips to the hospital to treat a bleed. I was among the first batch of grandchildren on both sides, so I was smothered with love and empathy as a result of having a medical condition that made me just a little bit different from the rest of the grandkids. The hugs were softer, but a whole lot longer. I got more toys, especially after a hospital visit. It wasn’t easy going from playing with friends in the neighborhood to treating a severe nosebleed. Still, the affection and care I was shown by not just my friends and family, but my “family” of nurses and doctors at the hospital, certainly has had a lasting impression on me.

Of course, one of the darker sides of growing up in the 80s with hemophilia is how the blood industry responded to the growing crisis. At age 11, when I was diagnosed with HIV, it wasn’t a surprise at all. My experience with hemophilia made dealing with HIV a confusing ordeal- there were no physical signs that I was any different. But some of the social fabric around me was splintered by friend’s parents who were afraid of transmission and officials at school who decided to send me home (kick my little ass out) with two weeks left in the school year.

When I decided to speak out about being HIV positive at age 20, I minimized the influence that hemophilia had on my life. As a mild hemophiliac, I wasn’t dealing with the condition with any regularity, due to my interest in music and the fact that I'd long since retired from Living Room Wrestling with the fam. One of the reasons why I wanted to downplay hemophilia was because I didn't want anyone to focus on how I'd transmitted HIV. I didn't want any "special treatment". I went out of my to immediately talk about the new friends I'd made online when someone started to focus on "the tragedy" of my infection, pointing out that it's hard for anyone living with the virus regardless of how they contracted it.

My intentions were admirable. If I was going to be a "Ryan White" in peoples' eyes (at the time he'd only been gone for six years), I wanted to be the edgier version, not afraid to drop an f-bomb if called for. Or make a crude safe sex joke. I didn't really see any personal or educational advantage in talking about hemophilia...

As time went on, that changed. I made lots of friends with hemophilia after my humorous memoir, My Pet Virus, was published in 2006. I was always afraid that the community was consumed with anger, due to the loss and circumstances surrounding how people were infected and lied to about from sources they trusted. Of course, that anger and hurt is there, and will always be. In recent decades, waves of deaths as a result of hepatitis C have devastated the community all over again.

But I'm so glad I was open to being a part of a community that I was already a part of. The dark sense of humor in the bleeding disorders community, I discovered, rivalled that of the friends I'd made in the gay community after I opened up about HIV at age 20. Also, as a medical condition, hemophilia started to present itself again, and I had to actually learn how to self-infuse (for my blood-clotting treatments) as a result. Before COVID-19 broke out, me and a group of my fellow bleeders were starting to make time to meet up and have lunch, and discuss our varied adult lives with the disorder in between crude sex jokes.

And it was a lot of fun. The new tradition, of course, is on hold for the time being.

What isn't on hold anymore? My appreciation for life. For life with hemophilia. It was the awkward childhood friend that introduced me to HIV. These medical conditions introduced me to loving people I'd never have met otherwise. The lessons I've learned through the adversity presented by each condition has made me who I am today.

Hope you find strength in your own adversities out there.

Positively Yours,
Shawn