#WorldHemophiliaDay How Hemophilia Prepared Me For HIV and Life

April 17, 2019 By Shawn Decker

Today is World Hemophilia Day. Being born with this rare bleeding disorder has certainly shaped who I am. I know people like to say their “illness” doesn’t define them: I get it. I know where the sentiment comes from because I’ve shared that feeling as well. But I do think we sell ourselves short when we don’t acknowledge some of the ways that these challenges have made us stronger.

I think back to the days of my childhood. I felt so angry and embarrassed whenever hemophilia would cut short a playdate. Or when icing a hemorrhage kept me from being able to see my friends.

It sucked.

I’m glad my mom did her best to make doctor’s visits fun. She’d draw mazes for me while I waited for my factor to take and calm down a bleed, because she knew that calming me down was just as important as giving my body the clotting factor that it is deficient of. In those situations there was short-term problem, the bleed, and a long-term issue to be dealt with as well. Mom never let me feel TOO sorry for myself. Sure, she consoled me and made me feel safe, but she also reminded me that other people had it much worse. She was teaching me coping mechanisms and acceptance of who I was. That we all have challenges in life.

She was younger than I am now when she was doing that. Maybe that’s why I can relate more to what her struggles were than being able to connect to my own experiences at that time.

How hemophilia was dealt with laid the groundwork for how I dealt with HIV. Sure, I was in denial for many years... I didn’t want to talk about it. I didn’t want to go to the doctor because, unlike hemophilia, there was no short-term fixes to be had at the time. But I did have acceptance that, at some point, my health may decline and do so dramatically.

So it was very important for me to do my best to enjoy my life. To live in spite of HIV for however long I had... to, well, not let it define me.

Now that I am in my 40s, I’m focusing more on my overall health than I ever have before. I’m trying to do the things I need to address not only my physical health, but my emotional health as well. The medical conditions are a juggling act and it can be frustrating: my HIV meds that work so well in keeping that in check are causing my cholesterol to go off the charts. Last year I tried cholesterol medication and that made my liver enzymes skyrocket (hepatitis B).

But I’m up for those challenges. I have a wonderful and loving partner in Gwenn, who helps me take

steps forward when I start to feel frozen in my tracks by all of this.

Ultimately, though, I am proud of who I am. And I can’t imagine a life without hemophilia, which I guess you could say was my gateway condition. And I know many in the bleeding disorders community have dealt with the loss of loved ones. I think of how many people didn’t have a chance to make it as far as I have, and that is a heavy thing to deal with.

It’s another reason why I fight for myself: it’s to honor my brothers and sisters who have moved on to whatever the next big spiritual adventure is. One we’ll all be embarking on at some point, whenever that time comes.

In the meantime, thanks for caring. And much love to all of my peeps in the bleeding disorders community.

Happy World Hemophilia Day.

Positively Yours,
Shawn

© 2026 Smart + Strong All Rights Reserved.

http://beta.docker.poz.com/blog/worldhemophiliaday-hemophilia-prepared-hiv-life