World Hemophilia Day

April 17, 2015 By Shawn Decker

Today is World Hemophilia Day.

This rare, bleeding disorder has shaped my life in so many ways. As a kid, I was able to enjoy a normal childhood that included baseball, rasslin around with my big brother and the kinds of daredevil stunts that give parent's heart palpitations. It wasn't easy having playtime interrupted by a bleed that required treating, but at the same time the medical condition gave me access to an entirely different social circle- my grown-up friends at the hospital.

Of course, when HIV entered the mix, things got difficult. Unlike hemophilia, which did cause some concerns at school from time to time, HIV brought an entirely new concern. Not just medical, but social ramifications. I was kicked out of school in the 6th grade and had a lot of fallout with friends whose parents wouldn't let me hang out with them anymore. After HIV, hemophilia kind of took a backseat. I was also a lot less physically reckless after the age of 11 (when I was diagnosed with HIV), so bleeds were way less common.

A couple of years ago, I had to play a little bit of catch-up with hemophilia. A new HIV combo caused increased bleeding episodes, which necessitated my need to learn the art of self-infusion. Which basically means sticking myself with a needle. I was a bit of human pin cushion the first few times, but thanks to friends (one a piercer, the other a nurse) I learned the skills to handle the situation on my own.

And now, I feel like I have a good handle on all of my medical conditions. Hemophilia has been rough at times, but I feel like I'm an empathetic human being because of it. Either it's just the precarious nature of having a bleeding disorder, or growing up and spending a lot of time in the hospital, or great parenting... or a combination of all those things.

I wouldn't trade who I am for more clotting factor, but I do believe I will outlive hemophilia. And HIV. They will be cured or functionally cured (I'll be the first to put the "FUN" in "FUNctionally cured", that's for sure) in my lifetime. And the odds of my lifetime being long enough to fulfill that goal have increased dramatically as I've learned more of the ins and outs of living with hemophilia as an adult.

Hope this finds you all well. Big hemo hugs.

Positively Yours,
Shawn

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