#RareDiseaseDay (Life) and Common Sick Days

February 29, 2020 By Shawn Decker

Another Rare Disease Day is here. And I'm chiming in because I have hemophilia. I also have HIV and hepatitis B. But they are the popular kids in school. Hemophilia is the one that does pretty good in class, keeps a smaller select group of friends and tends to thrive later in life.

Hemophilia is so rare that, as I'm writing this, I'm being constantly reminded with a squiggly red line underneath the word, alerting me that I may have spelled it wrong. But since hemophilia is a bleeding disorder, I kind of like the red line. It's like the word itself is having a bleeding problem and is in need of some clotting factor. It's the clotting factor (tainted with HIV in the early 1980s) that ushered in hepatitis B at age 6- hepatitis B was the friend that my mom thought I knew better than I did. I always forgot it's name. We'd be in the hospital for some hemophilia-related drama and my mom would say, "Tell the doctor what else you have... it starts with 'h'..."

"Hemophilia?"

"No!" Mom would yell before throwing a shoe at me. You get pretty damn good at dodging shoes when you have a bleeding disorder. And no one could touch me on the dodgeball field.

I'm kidding. Mom never threw a shoe at me. If you're related to me and your stalking me on here please do not tell her I wrote that she threw a shoe at me in the hospital. It didn't happen. As a writer the thought crossed my mind and I found a doctor's reaction to the mother of a hemophiliac throwing a shoe at her son to be darkly humorous. I'm a little off the rails because I've been sick with a cough among other little pesky things that aren't so rare. As I sit, here taxed with the pressure that comes with being someone living with a rare bleeding disorder on Rare Disease Day, my patience in my current recovery is running thin. Thus, instead of inspirational anecdotes on how hemophilia and medical adversity have shaped who I am in very meaningful ways, all I can offer you is misdirected violent imagery.

I'm all hopped up on cough drops. I know enough about my body and sore throats and coughs to know the difference between a viral infection and a bacterial one, the latter of which you can take antibiotics for. Still, after two weeks I scheduled an appointment with my doctor, in part because I know a lot of friends thinking I'm probably on death's door but mainly because I started hearing my pulse in my ear. Best way to describe the sound is that it sounds like the muffled, consistent bark of a jack russell terrier three townhomes down. See, I've never had the experience of hearing

my pulse loudly in my ear, so it was a little disconcerting.

But no, it’s typical in relation to the kind of viral infection that I have. Which means I just have to wait it all out.

And I will. I’ll survive. Overall, my health is good. I’ve made leaps and bounds over the last several years in dealing with hemophilia, which became a little estranged after it introduced me to HIV at age 11. I wasn’t getting banged up because I wasn’t rough-housing as much, and my interest in sports had turned to music and art. I never felt like my life was in danger with hemophilia, but HIV had a whole different aura. Yet, here I am, all these years later. On effective HIV treatment, with a healthy prognosis and unable to transmit the virus.

My hope is that, eventually, there is a cure for hemophilia. It will certainly aide in how well I get around in my golden years, if I’m fortunate enough to get there. But, in a lot of ways, I feel greedy even thinking about that. Even though I overcame the odds and did get hemophilia, I feel lucky to be here after all of the medical bumps in the road that I’ve had.

Positively Yours,
Shawn

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