A Rare Existence #RareDiseaseDay

February 28, 2022 By Shawn Decker

I've been transferring old VHS tapes to digital. If I'm brave, a few clips may end up on here at some point. But these days I feel far from brave most of the time. So don't expect to see adorable content of me as a toddler bopping around anytime soon. Nope, this is not a place for adorable content.

Not on my watch.

My writing can be pretty nuanced, so I'm not sure if you've gathered from the above but I've been a little hard on myself recently. Watching the old footage has been a joy, and as I am viewing my humble beginnings I can't help but think how very short my journey could have been. Like the scene where I'm almost a year old, sitting in the yard in my diaper. Kip, my big brother who is two years and two months my elder, wanders over to show me the work he's put into his golf drive. He places a large, orange plastic ball near me...

Oh sweet! Something to slobber on. Let me shift my weight slightly to the side, the weight of the humongous diaper will do the rest of the gravitational work to reposition myself. Then I'll be crawling to that ball, a couple of feet away. Damn this grass is sharp! OK.... almost there- damn! That's a mighty breeze we got going here today... now, where was I? Oh, the ball... where the hell is that ball?

It was an impressive hit! Using a man's golf club, Kip managed to make solid contact with his target whilst avoiding his little brother's fragile skull, which would have surely shaved yards off of his drive. I laughed, because I understand that parenting and safety and the luck of the draw is something that guides all of our journeys. And sure, the distraction of being able to record one's offspring on video for the first time in the history of humanity had to be mighty. Plus, at that time, we didn't even know I had a bleeding disorder... just some unusual bruising.

Being born with hemophilia certainly altered the family dynamic. Mom would take care of any medical mishaps, and dad would teach us how to throw a ball and swing a club. I got to do pretty much everything my brother did, thanks to advances in how blood product treatments were made. Of course, major gaps in safety protocols (watch the documentary, Bad Blood) led to hepatitis B (age 6), HIV (age 11) and hepatitis C (age 18), respectively. I'm thankful for the experiences that my gory fate allowed. Mom taught me that others had it worse in those early hemophilia days, when I was at the hospital with a particularly bad nosebleed or bonk of some sort. That helped me see a world of suffering outside of my own hopsital room, and shifted my focus from the games I

was missing back in my neighborhood.

I didn't realize it at the time, but Mom was trying to do some psychological patching up as the clotting factor worked it's magic on my bleed.

There's a wonderful recording of my brother and me, around the time of that glorious golf swing. We are in a circus roundabout car ride, just zipping by as my dad films. The first time I have my little hands on my wheel. Kip was probably showing me what's up. After the first lap, however, I was snuggled up beside him- partly for comfort but mostly just a result of the g-force. I don't think there were "You Must Be This Tall To Ride" signs in 1975. Up until a couple of years later, both me and my brother's lives were expected to be pretty similar. And just when we had the hang of hemophilia and the prospect of the same kind of life my brother would have, that's when the hemophilia community were being recognized as a high risk group for HIV infection.

After age 11, there'd never be another moment where what was expected of my brother (college, job, marriage, kids) would also be expected of me. HIV in 1987 made that impossible. My mom's goal was to see me graduate from high school seven years after my diagnosis. It was the kind of outlandishly hopeful imagery that only a mother could manifest. When I was kicked out of 6th Grade after my diagnosis, mom realized she may have to step over a few bodies to get a good picture of me receiving a diploma. But her goal came true. I made it in part because of luck but also because I had the luxary of living in a stable home environment. Being diagnosed right before puberty was tough, but never having known a dedicated boner without HIV was a blessing of sorts.

I guess? Shit, I don't know. What I do know is that I am deeply thankful for my life. We all get dealt challenges of some sort, and a rare bleeding disorder was the first big one for me. Like many challenges, one can lead to the next and so on. It's easy to be overwhelmed, and I've certainly dealt with those feelings of uncertainty at various points in my life. Right now, I fully recognize that I am going through a mid-life crisis, another silver lining in the average life expectancy modern HIV treatment has afforded me. Tomorrow isn't guaranteed for any of us, of course, and I must admit that I'm kind of embarrassed about this mid-life crisis thing...

It's so fucking... normal. Which is funny because at the very least a sense of normalcy is what we all thrive for at one time or another. Even if it's a predictable sprinkling of chaotic elements, we all want to feel like we are on solid ground with stable, human support systems in place. In reality, we are all as vulnerable as a nation sharing a border with a powerful madman. There are huge elements that are far beyond our control and medical conditions often fall into that category, and it's pretty scary shit to think about.

I'm proud of the path I've limped with hemophilia. Is it a pain once in awhile? Yes, literally and figuratively. But it's been a learning experience. Through the challenges presented by not only my medical conditions but the attitudes surrounding them, I've discovered who I am. A lot of the best and worst things in my life have been a result of my medical resume, and my greatest triumphs were when I decided I'd own my own storyline.

Positively Yours,

Shawn

© 2026 Smart + Strong All Rights Reserved.