#WorldAIDSDay My Life With HIV

November 30, 2021 By Shawn Decker

World AIDS Day is here again!

I thought it would be a good time to reintroduce myself, and take a moment to share how HIV has affected my life and how my attitude about living with the medical condition has evolved. I'm Shawn, by the way. Thanks for taking the time to read this likely meandering tale. If this reads like a riddle that only partly makes sense, then I'll have done my job properly.

I grew up in Waynesboro, a small town in Virginia. Despite being born with a bleeding disorder, hemophilia, I enjoyed a active childhood. I played farm league baseball, I roughhoused with my friends who lived mere steps away from my home. The first decade of my life could be described as a pretty standard middle class existence, complete with two working parents and a big brother two years my elder. Most Gen X'ers know what it was like to be a "latchkey kid", and I for one really enjoyed getting home from school with no parents hanging around. Uninterrupted cartoon watchin'.

Advances in how hemophilia was treated really helped me enjoy the childhood I had. If a bleed occurred, I could treat quickly at home. At age 6, however, the first sign that something was wrong with the new treatments arrived in the form of a hepatitis B diagnosis. From then on, as the spector of AIDS began to loom, my parents and doctors decided that I'd be treated only if necessary. Treatments became fewer and farer in between the older I got, as my interests in sports became eclipsed by my interest in music and art.

The first sign that my immune system was compromised occured in 1984. I was a 4th grader, looking forward to a class field trip. Shingles had other plans, and a good portion of the left half on my upper body was affected. Still, I managed to make the trip, which my mom chapperoned in order to keep an eye on me. Now, I didn't grow up with hovercrafts as parents. The way my mom tells it, the toddler years were terrifying but after the hepatitis B diagnosis my big brother told my parents that they weren't letting me be a kid. They took his observation to heart, and I'm thankful they did so.

When I was in the 6th grade my parents decided that it was time for me to be tested for HIV: the test came back positive. My parents were devastated, but not entirely surprised. With two weeks of my school year remaining, I was kicked out of school as word got around town. I was shielded from a lot of that drama and, thankfully, I was allowed to attend junior high school (7th and 8th grade for me) after that first Summer navigating life with HIV. The first day of school a flyer was

passed out to every student, which explained the link between hemophilia and HIV. It also said that a student was in everyone's midst, living with this terrifying virus.

I hated being reminded of my HIV status. My plan was to get my life back on track and, aside from that pesky HIV pop quiz, I'd enjoyed a wonderful year socially. But I guess the school system did not believe my doctors in regard to the threat level I posed to other students. The flyer meant that every parent knew that their kids were walking the halls with someone who had HIV. And, just in case I internally combusted in Science class, caking my classmates in my plasma, the school could claim, "Well, hey, we told you about the risk!"

I missed over a hundred days of school that year. No matter how hard I tried, I couldn't get my feet back under me. The mountains of classwork that was piling up at home, though a distraction from HIV, stressed me out to no end. My mom, working the sympathy angle, convinced my teachers to only send us the most important assignments. Many of which she completed, because I'd get so overwhelmed by the work, which seemed rather inconsequential in the grand scheme of things.

Still, as bad as things were, I didn't want to get held back a year. The second half of the school year was way better. I had some solid friends, but I was starting to make some new ones as well; mostly girls, too! My parents, who had separated for several months, got back together. Sick of my hogging the landline to talk to all of my peeps, they sprung for the extra cost and gave me my own line. They were trying to pick a phone number that they could remember, and landed on 942-HEMO. There would have been bloodshed if I had known that at the time! But looking back, I'm glad they were able to do something and share a laugh over it.

Of course, puberty introduced a whole new bag of worms. I'd had a few girlfriends, with nothing going beyond kissing. But in high school, all of that changed. The problem was that my gameplan of not dealing with HIV made it impossible to disclose my status. I'd never spoken openly to my closest friends about it, friends who surely knew everything. After it came out that me and my girlfriend were engaging in oral sex, my mom and her parents had a summit. It was decided, rightfully so, that I wasn't allowed to see her anymore. We snuck around to talk, but I couldn't talk about HIV, so there was nowhere emotionally to go from there, and there was certainly no way of going back to how things were.

I felt horrible about the drama I'd caused. My big plan to protect her and not have to disclose was basically tantric sex. One time I didn't have the powers of Sting, so my girlfriend had to be tested for HIV, which came back negative. My doctor explained to me that HIV was present in pre-cum, something I'd never heard about. Once I'd tried to call the National AIDS Hotline to get specifics on oral sex and HIV, but I hung up pretty quickly because I was so uncomfortable talking about HIV, and the person on the other was quick to tell me that any sex act was capable of transmitting the virus.

The one thing that came out of that debacle was: I'd never engage in sexual activity again without first disclosing my status. Every relationship in high school after that basically had the invisible

bitty at the school dance, constantly reminding me to keep a safe distance between my body and my girlfriend's. But I was okay with a platonic dating life over the atomic one that had blown up in face.

After high school I had no plan to go to college. And my synth work needed work if I was ever going to make it big with music, the only way out of Waynesboro by my calculations. At age 20, I had the craziest thought of my life to that point: why not talk about HIV? This epiphany occured after a few months of depression and shortly after watching a Real World Reunion on MTV. Judd Winick was talking about Pedro Zamora, who had passed the year before. By living openly with HIV in front of the cameras, Pedro became my first real-time hero. And even though I was straight, I thought it was pretty cool that his boyfriend (also HIV positive) was named "Sean" (Sean Sasser), too.

On the Reunion, Judd got emotional and just asked anyone watching to "do something". I realized that I could do something... something I never thought I would. In 1996 I put up a website and met others online who were living with HIV. One of the first bloggers online, Steve Schachlin, not only encouraged me to change my site's format and add a blog in place of essays, he also visited me in Waynesboro and helped me record an audition tape for The Real World. The best part of it was when a bee started buzzing near my head, and Steve said, "Watch out! If that thing stings you you'll probably explode!" He laughed, but I was way too tense and serious about it to come across as anything but a massive bore.

Writing was my strong suit, anyway, and after going public with my site I was featured in POZ and, soon thereafter I was writing a column for the magazine called Positoid, a word I'd created to describe myself as someone living with HIV. When I went to nab the name on AOL Messenger, it was already taken! Sean Strub said that he heard it being bantied about socially in New York City... I was 21, a columnist for a national magazine and telling everyone I met about my status.

What a difference a year can make. I consider those college-aged years to be the best education of my life, and folks like Steve and Sean and other members of the AIDS community were not only my professors, but my friends as well. To make things even better, life-saving HIV medications would literally save our lives over the course of the following three years. It was a magical time, and I felt like I was doing more than "something". I learned how small the HIV/AIDS community was when I met Sean Sasser, totally starstruck of course. "Oh, I know you from your Positoid column."

Amazing.

One of the most difficult aspects of the earlier days of my diagnosis was the anxiety that the prospect of dating and sex caused. By going public at 20, I never had to worry about when to disclose again. And that was a relief. I had a relationship with someone I met online who lived in Brazil, so I added international romancer to my resume. And though the relationship didn't work out, it was a wonderful experience made all the better by the fact that HIV had nothing to do with

the break up.

At age 23 I was able to move out of my parents home. Not because I was making big bucks, it was due to a class action lawsuit on behalf of people who'd been infected via bad blood. There were a lot of warning signs that were not heeded, the more I found out about it from members of the hemophilia community the more I tried to keep the happy-go-lucky approach to living with HIV that was working out so well for me. The timing of it all was perfect, because I met a graduate student through my HIV work; Gwenn.

And we fell in love pretty fast! After her graduate program (an hour away from where I lived) was over, she moved in with me. She worked at a AIDS Service Organization part time, and one of her co-workers said that we'd make a great team if we educated together. After our first talk in front of about twenty college students, his hunch was right. When we applied to a speaker's bureau, we were accepted. We sat in our hottub, discussing which angles of our relationship and lives would pack the most educational impact. Gwenn was by far the better speaker, but I did manage to lose my "ummmmmms" pretty quickly.

Thankfully, I started on HIV medications for the first time just after Gwenn moved in with me but before our speaking gigs were sending us all over the country. While my life as an HIV educator, writer and lover were thriving, my health was in an increasingly dire state of being. I drug my feet, because my t-cells had always gone back up "on their own" after a dip... Steve finally had enough. After a visit, where he surely noticed the thirty pounds I'd lost since he'd last seen me, he said: "SHAWN. You are going to DIE if you don't start taking meds!"

It was a reality check. Before my longtime doctor retired, he prescribed me marinol (synthetic THC) to help me with my appetite. I'd never smoked pot, so I didn't know what I was in for. My appetite returned with a vengeance, and my anti-meds stance softened. With my treatment history with hemophilia, which resulted in hepatitis B, HIV and hepatitis C infections, it's no wonder that I was concerned with side effects. The HIV medications had an instant impact of bringing my t-cells up and cutting my viral load from close to a million copies down to triple digits in six weeks time.

The proudest work of my life is the educating that Gwenn and I have been able to do together as a "magnetic couple" (positive/negative). This year marks half a lifetime-to-date spent together. We've gone from publicly discussing how we approach safer sex in our relationship ("The condom is my friend!") to the breakthrough that is U=U. I remember the first time I incorporated that into our talk at Fredonia College, and how receptive the group that brought us was to the information, which they surely shared with peers on campus after we left.

One thing I'll never forget is when I was giving a little pep talk at my friend Jason Elliott's annual Little White Party, which lands around World AIDS Day every year. After I mentioned U=U and the fact that the efficacy of my HIV meds meant that Gwenn and I could have sex without condoms people cheered... loudly.

I'm sure I've missed some important details, but that is pretty much my life with HIV up to this point. I'm 46, and so thankful to have had the opportunity to live the life I've had. The older I've gotten, the more willing I've become to address my health needs outside of HIV and hemophilia, which are thankfully on auto-pilot these days. When I was first educating, people would say, "You're so brave!" I appreciated the compliment, but I didn't feel particularly brave. Because when I decided to speak up about being HIV positive, it felt like a natural and easy choice... hardly a choice at all, really. It would have been much harder to stay quiet when I came to the realization that my "silent treatment" strategy had run its course and was no longer useful, but detrimental in actuality.

But these days? I do feel brave. I've spent my forties addressing my mental health, and acknowledging the role that depression has played in my life. Having not traveled as much in the last several years, I was able to look at my life as an entire entity, and not a series of bullet points that pack the most educational impact. Plus, when I put up my website at age 20, I didn't want sympathy. HIV was a breath of fresh air that actually bailed me out of the longest bout of depression I had experienced since my diagnosis a decade before.

By looking at my life in a more complete way, I'm giving myself the best chance to live as healthily and happily with depression (which runs in my family) as I am with HIV. I have a normal life expectency, but I know another week for any of us isn't a guarantee. As long as I'm alive, I want to be the best version of myself. Not just for me, but for my loved ones as well. Part of that is not being too rough on myself and allowing myself to feel the lows and sort through them when the arrive. And that's been way better than pretending to be okay and just waiting for those clouds to pass.

We all have challenges in life, which we rise to meet sometimes and duck to survive at other times. I wrote a song once when I was traveling alone to talk about hemophilia, and was having a real rough time as I sat alone in a hotel room, eager to get back home the next afternoon. I wasn't quite there yet in terms of having a real strategy for depression, or even an understanding of the necesity for one. The song I wrote was simple, "Do Your Best". I remember crying as I sang the melody, both thankful for the artistic outlet in the immediate and also grateful for my entire life. That I had a safe home to return to. I was confused by the depressive state I was in that night, because there wasn't a clear trigger.

Of course, now I realize that brain chemistry and this strange journey we are on does not require triggers to end up in the emotional mud. All we can do is our best, even if it means missing the dartboard more times than we hit those bullseyes.

I'm thankful for a life that affords me the opportunity and time to get into the weeds. And a partner in Gwenn that encourages and supports me in my attempt to try and better myself and not be my own worst enemy. Ironically, in the darkest times it's my previous work in HIV education that helps bail me out of what would surely be a bigger crash. And the pride in my HIV work helps me acknowledge that I once considered anything associated with HIV to be the absolute worst aspect of life. Those days are so far back in my rear-view mirror that it almost seems like a

different life altogether… but that was me. And it’s proof that life can offer some pretty interesting twists and turns that we’d never be able to predict.

Here’s to doing our best. And thanks for taking the time out of your own unique journey to read this.

Positively Yours,
Shawn

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