25 Years Ago My Life Changed

December 29, 2021 By Shawn Decker

We have moments- both grand and grim- that are gamechangers in our bumblefuck journeys through this physical plain. For me, a couple of those moments are wrapped snuggly around “my pet virus”, or HIV, as most know it.

My HIV diagnosis at age 11 ranks pretty high on the list of gamechangers. I’d have to study to become a monk, or train to be the guy that returns mimery to its former glory as a means of entertainment to knock that diagnosis out of my Top 5. Receiving that news in 1987 at such a tender age not only changed expectations for me, it changed the way I looked at the world. I didn’t fit as snugly into society’s expectations as, say, my brother who is two years older than me. I’m not sure if it was a self-defense mechanism, but I found some solace in that. My perspective was skewed, because instead of a book filled with blank pages I had a an Etch-a-Sketch. I could draw up a loose plan, then shake it up as needed when I wanted to see something different for my future.

But in all of the shaking that comes from teenage angst and wonder, I never envisioned a future that involved HIV beyond dying from it. And up until that moment, I vowed that I wouldn’t waste any of my time on it. In Waynesboro, Virginia, my particulate brand of teenage rebelion involved listening to synthpop and imagining a future that was shaped by me and not HIV. My fantasy? To be a rockstar, of course!

In my adulthood, I’ve settled for being a musician. I’m proud of the songs I’ve written and the modest shows I’ve been able to be a part of. The biggest crowds I’ve played to have been in the hundreds, and usually with my 80s coverband Film on Girls, where I get to act like a rockstar and sing some of my favorite new wave classics like “You Spin Me Round” and “Tainted Love”. I think the teenager who was first starting to fiddle around with a synthesizer, plucking out Depeche Mode hooks, would have been happy to see where all of that time and energy would lead to.

While music hasn’t been the defining characteristic of my life, I credit it with being a line that connects the kid who refused to talk about HIV to the dude in his mid-40s who is trying to figure out what’s next. Depeche Mode is still my favorite band, and meeting them through the Make-A-Wish Foundation when I was 14 fueled my desire to spend time on my music and dream of a future following in their Doc-steps. In being able to have that dream, I was able to ignore some of the nightmare that was living with HIV in the pre-medication days... as my friend in the hemophilia community once said, “Until there’s a cure... there’s The Cure.”

During this new, strange pandemic that we are all living through, I've been doing some soul searching that actually began before COVID hit. It's been the longest stretch of not having a real plan for myself since those months before I decided to open up about HIV at age 20 by putting up a website on the internet 1.0 and disclosing my HIV status through it. There weren't too many HIV sites around, I could only find a few when I went online thinking I'd see a version of what was to come with social media. There was a void to be filled, and of the three or four pages authored by someone living with HIV that I did find encouraged me to put up what I was looking for: a light-hearted look at living with HIV.

The life gamechanger was running with that first thought that, hey, what if HIV wasn't a secret anymore? That thought and the action that followed freed me of the albatross the silent treatment plan had become. After fleshing out my site a little and discovering my love of writing through it, I wrote the fan letter to Sean Strub at POZ Magazine that lead to the invitation to New York City that resulted in being a POZ cover boy. I'm somebody that needs big signs from time to time, and that showed me that- undoubtedly- I was doing exactly what I was supposed to be doing. Many more signs followed- the biggest one of course was meeting the love of my life, Gwenn, at a talk given by Ryan White's mom, Jeanne White-Ginder, two years after opening up about HIV. Had I never run with that energy and let the chips fall where they may, my life would have turned out much differently.

So yeah, maybe I didn't get to be a rockstar in the classic sense of the word, but alongside Gwenn I did get to tour the US, educating college students about HIV, safer sex, testing and disclosure. Instead of being on MTV in music videos, I was on educational programming on the network, just being me with HIV in the hopes that somewhere, someone saw a little of themselves in me and their own situation living with HIV seemed a little less bleak. I'm not bragging- far from it. Ultimately, the life I saved by opening up was my own. I just hope that anyone who stumbled upon my messaging left with more information and hope than they had before. The best we can do in life is to pull each other up just a little- I know I've been spoiled on the receiving end of that type of love and inspiration.

At 46, I guess part of me is waiting around for another big sign, while the other part of me says, "Relax, you are where you are meant to be. Enjoy it." For the most part, I do. One pill a day? Undetectable? No need for condoms anymore? These are things that I both take for granted and things that also blow me away, like it all just happened yesterday. That's why, when I saw my face on the sidebar of POZ with the words, "25 Years Ago", I felt a sense of pride. Because that was the moment when I got to be a rockstar, and nothing would ever quite be the same again.

It was a crowning moment that came after months of self-reflection and confusion about where I should place my energy. These days, I'm actually more in tune with who I was in that timeframe before I opened up about HIV, because I have an uneasiness in not having a definitive idea of what I should be doing with my time. And how much I want to make HIV a focus of my life, educationally speaking.

We shall see. As Depeche Mode said, “Life is full of surprises, it advertises nothing.” Here’s to hoping you embrace your inner rockstar, and that if a moment suddenly arrives unanounced, you feel ready to tackle it. Even if it’s something that you never thought you needed or wanted to confront, I hope you are able to go with it if your heart and mind are in sync… as a result, you just might surprise yourself and begin an exciting new chapter in your own journey.

Positively Yours,
Shawn

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