Long-Term Survivors Day and the #StrangerThings HIV Connection #HLTSAD

June 5, 2019 By Shawn Decker

HIV Long-Term Survivors Awareness Day is upon us once again. This year marks the 6th year of its existence, thanks to Tez Anderson.

It kind of snuck up on me this year. When I woke up today it was just another Hump Day. Even though just yesterday I had a nice long talk with a couple of folks who have walked a similar path as mine- being diagnosed early and pretty much going through your entire dating existence under the spectre of HIV. Still, as I was getting dressed today and thumbing through my shirts, I dug down a little bit, gravitating toward my Keith Haring tee. Something in my soul told me that was the right fit.

Days go by when I don't even talk about HIV. Or really think about it. Sure, I take my meds as part of my daily routine, but I don't have any side effects that remind me about them, outside of my skyrocketing cholesterol which I hear about at every meeting with my primary care physician. Thanks to U=U, sexy time no longer requires a condom. So no reminders in the bedroom. I'm living a life free of HIV's grasp that I could have only dreamt about in the earliest days of my diagnosis. (1987, age 11, for newbies to this blog.)

But last night, while playing video games with my nerd squad, the topic of chicken pox came up. "Did you ever get that, Shawn?" I couldn't remember if I did. Something like chicken pox has a way of disappearing from your memory when there are layers and layers of incidents with hemophilia and decades of HIV appointments. I did get shingles in the 4th grade, two years before my HIV diagnosis. "So, that pretty much means I was probably already living with HIV for at least a year," I explained.

That would put my actual contraction of HIV at around 1983. That's the year that the kids of Hawkins and Stranger Things start to have their lives turned upside down.

By the way, Stranger Things is totally about HIV. Especially Season 2. Spoiler alert. I mentioned above how I can go days without thinking about HIV but, man, watching the character of Will sends some chills down my spine. In Season One he disappears. He's isolated from his friends who continue to go to school- they have no other option. It turns out he's in another realm, being

tormented by a looming monster of some sort. He eventually gets rescued, but in Season 2 there are doctors appointments. They don't know how to really treat Will. They just observe. There's talks of trying to cure the virus. There's talk of the virus replicating in his system.

Plus, this is all happening in INDIANA. A fictional town called Hawkins. Ryan White and all of his bullshit with getting kicked out of school took place in Indiana. (I was kicked out of school in 1987 after I tested positive, for you newbie blog readers.) Oh and here's the Will (on the right) character side-by-side with Ryan White, the most famous kid ever with HIV.

The Ryan White/Will Byers Theory is compelling...

OK, putting my HIV Stranger Things theories aside (for now), I find that a lot of my thoughts about HIV tend to be from the past. Since I started speaking out about HIV nearly two decades ago, I've heard people tell me how brave I must have been to deal with the diagnosis that young. I usually shut it down, or redirect the compliment towards my mom's bravery in dealing with it. Part of my reasoning for doing that is that, as an educator, there is no value in presenting myself as some kind of hero. Or that "being brave" is how I survived. There were plenty of brave people who didn't make it, that's for sure.

But watching Will in Season 2, getting needles poked in his arm, having tests run in secrecy, being pulled from real life to an alternate reality against his will... well, it conjures up some very deep-seeded feelings and pain that I buried decades ago. It wasn't easy back then. I was scared. I felt powerless. I was just a kid, doing his best to be a normal kid.

And, well, here I am. It's fucking 2019. Sometimes when my mind takes me back to that pain, it's

almost as if a time portal has opened up and dropped me where I now stand. That thirty-two years just kind of happened. I don't run away from feeling those emotions anymore, either. I'm connecting with part of my story in a genuine way. And not as a means to educate others, but more as a way of completely understanding who I am and where I came from.

I'm doing well these days, and I'm very thankful for the dumb luck that allowed me to survive my own childhood monster. In a month, I'll be performing in town with my band for a Stranger Things themed night. I'd like to think that the kid who got that terrible news thirty-two years ago would think what he would be doing in the future was cool. That he could relate to the adult version of himself and be proud of the man he became. Who knows, maybe he'd think I was a dork and poke fun at my hair. It's likely, because that kid had yet to be exposed to The Cure.

What I do know is that I look back at the kid's struggles with a great sense of pride. He was brave. He dealt with his monster to the best of his abilities, and got braver and less scared with every victory. And, yes, every set back, too. And like Will Byers, he wasn't alone. He had his own monster squad to help shoulder the load.

Positively Yours,

Shawn

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