50... Ryan White Would Have Turned 50 Years Old Today.

Born with hemophilia, Ryan was diagnosed with HIV as a kid. Before- and after- passing at the age of 18, his spirit changed the world.

December 6, 2021 By Shawn Decker

Today would have been Ryan White's 50th birthday. As some of you may know, there are some similarities between his story and my own. However, as time goes by that changes. The biggest difference is no longer in how each of us responded to the earliest days of our diagnosis: him by embracing the chance to go public and educate people about HIV and me, ignoring HIV to the best of my ability.

The biggest difference now between me and Ryan White is the very thing that has made the HIV/AIDS epidemic so painful: the randomness of it all. How it takes some of us early... some of us later... and then leaves others to live with wounds both small and monumental. Of course, with early detection and treatment today, the newly diagnosed have a completely different landscape ahead of them. But for those of us who were diagnosed before effective treatment, the effect of having our lives saved by treatment when others didn't get the chance stirs up a lot of emotions.

Gratitude. Guilt. Elation. Confusion.

I'm in my mid-40s, where I am both relishing and resenting this opportunity to really get into the weeds of this whole adult thing. If Ryan had not passed, he'd been setting foot into his 50s today. When I was a kid, the fours years of age he had on me seemed like a lot. Because it was then. But now, we'd be basically the same age. Maybe experiencing some of the same physical mannerisms that come with decades of life with a bleeding disorder*. Our differences would probably be made more profound if he'd, say, decided to have children. Or look down on people his age who genuinely enjoy Hallmark Christmas movies.

It doesn't seem fair.

Ryan may have passed far too soon, but while he was here he certainly discovered his purpose and maximized it's impact. Through his kind spirit, Ryan White made the world a safer place for everyone living with HIV. His belief that you could share the truth with people changed a lot of hearts and minds. And I know I'm not alone as an HIV educator in how I've relied on Ryan's lessons on how to handle the insensitivity that can come with this job.

I wish I'd been able to meet him. But I am deeply thankful to have met his mother, Jeanne. Especially since I met my life partner, Gwenn, at talk that Jeanne gave in 1998. I always say that Ryan was the one that put us in a line beside each other, just two educators excited to have a moment to say thanks to Jeanne for sharing her- and Ryan's- story. From that meeting, Gwenn and I fell in love and started educating as a sero-diverse couple.

I didn't realize it then, but the AIDS community is so small: you have a really good chance of meeting your heroes... but the downside is that there's also a good chance that they are no longer with us. So many of our greatest fighters, advocates and educators have passed, graciously leaving their legacies to guide us.

And Ryan White's legacy and light continues to shine bright.

So, what the hell, Happy 50th Birthday, Ryan. You may have passed before I had the courage to open up about HIV, but you've never been missing from my life. And never will be for as many days, months or years I have left. Ultimately, my belief system allows me the hope that, when I once again follow a brave path that you have taken before me, I will indeed have the opportunity to say, simply, THANK YOU.

Positively Yours,
Shawn

*Like HIV treatment, treatment for hemophilia has advanced over the years and, these days, helps people live longer and more comfortable lives.

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