

Surviving Bleeding Disorders and HIV

Checking in with hemophiliacs who grew up in the 1980s AIDS epidemic.

October 1, 2013 By [Shawn Decker](#)

When combination therapy was introduced in the mid-1990s, it was a turning point in the HIV/AIDS epidemic. For those living with genetic blood-clotting disorders such as hemophilia, the early 1970s offered a similar hope; advances in science meant that someone with hemophilia no longer had to spend days in the hospital receiving treatment for a bleed. Sadly, when HIV emerged in the early '80s, the best of times quickly transformed into the worst for the bleeding disorders community. Very few hemophiliacs growing up during that time were unaffected.

Nick Cady, 29, was born with severe hemophilia a few years before crucial precautions were implemented to ensure the safety of the blood supply. At age 3, he tested HIV positive. "I started AZT at age 5 and two years later was diagnosed with AIDS. Every time a new drug came out, my doctors put me on it and took me off the old drug. When drug cocktails became available, my virus was already too resistant to build an effective regimen."

The closest curtain call for Nick came when he had his second bout with Pneumocystis pneumonia (PCP).

"I ended up in the hospital, spiked a 105-degree fever and began to lose touch with reality. I told my fiancée [now wife] that I had defecated on the floor of Elvis's piano room...right next to his baby grand." Nick shared his "faux pas" with a priest the next morning who'd come to administer last rites. Fortunately, Nick fully recovered, and in 2008 he finally found an HIV drug regimen that worked for him.

Justin Levesque, 27, is only two years younger than Nick. But that short time span made all the difference in terms of his not contracting HIV via blood product treatments. Still, his childhood wasn't devoid of the virus's presence. When he was 5, Justin met another boy with hemophilia who was just a couple of years older. Desperate to hang out, Justin became confused when his mother wouldn't set up a play date. Eventually, she had to sit Justin down and tell him that the boy had died from AIDS-related complications.

As fate would have it, living with hemophilia wasn't the only category that put him at high risk of HIV in the 1980s. When he was 13, Justin's mother stumbled upon his journal; she panicked when she discovered her son was gay. "[She] tried to scare me straight with the threat of HIV from gay

sex,” he recalls. “In hindsight, the closest to contracting HIV I’ve probably ever been was as a baby—and by her own hand while injecting me with plasma-derived factor.”

Does Justin feel like he dodged a bullet? “I try not to think of it that way,” he explains. “There’s an implicit level of skill and foresight needed to dodge a bullet.”

Instead, Justin sees the timing of his birth as something to draw from, as opposed to run away from. “From that experience came an acute awareness...for developing positive and responsible views on sexual health much earlier than my peers.” And what about his mother’s feelings about his sexual orientation today? “She’s all about her gay son and having grandchildren.”

Speaking of fatherhood, Mark Zatyorka, 33, is a brand-new father to twin baby girls. He was born with severe hemophilia A and diagnosed with HIV at age 11. During his youth, Mark grew angry that his friends were dying and that he too seemed to be living on borrowed time; he became deeply troubled by how his own passing would affect his family. Despite the odds, Mark survived and did his best to stay upbeat. “I knew it wouldn’t do me any good living life pissed off. I wanted to make the most out of life.”

Nick Cady agrees with that philosophy. “For kids diagnosed with an opportunistic infection in the late ’80s and very early ’90s, [the] median time of survival was just 10 to 17 months,” Nick says. “There aren’t many of us left. I feel immensely blessed to be alive.”

So, even though it’s a bit harder for Mark to carry his daughters around on his hip than most new dads, and even though Nick takes a dozen pills a day for HIV and has the arthritic ankle of a man 50 years his senior due to the cumulative effects of living with hemophilia, there is a sense of incredible gratitude. As Nick points out, facing the day-to-day challenges “beats pooping on Elvis’s floor.”