Hemophilia: The Neglected of the Neglected Pandemic

June 8, 2021 By Shawn Decker

Vice aired a special program called 'HIV: The Neglected Pandemic' to commemorate four decades of HIV/AIDS. Jonathan Van Ness narrated the program, and it was bopping along at a nice pace. But when it got to Ryan White, the boy with hemophilia who did his best to represent everyone with HIV honorably, I was taken aback by how it was framed. He was described as a boy who contracted HIV through "a blood transfusion", was kicked out of school and used his spotlight to educate a public that desperately needed educating in the mid-80s.

The use of "blood transfusion" is probably the one thing that people get wrong the most about hemophilia and HIV. Blood product treatments were the norm for people with hemophilia during the early days of the AIDS crisis, before advances and safety measures made the reliance on human-derived clotting protein less risky. The difference between a blood transfusion and a blood product treatment is the difference between getting hit by one car and a hundred cars. The tainted blood product treatments people with hemophilia relied on are what made the community one of the initial high risk groups for HIV. One blood product treatment contained plasma from thousands of donor sources.

Thus, the clotting protein that people with hemophilia required wasn't a simple one donor one recipient situation.

In a lot of cases with the media, you'll hear "infected via a blood transfusion used to treat hemophilia". And that's fine, I know time constraints and not wanting to confuse people in the weeds of a rare medical condition are just part of the deal. But Vice's team, for some reason, felt the need to completely omit Ryan White's hemophilia. Without hemophilia, he'd have never contracted HIV. He'd never have educated millions of people worldwide. He'd have never appeared so briefly and so clunkily in 'HIV: The Neglected Pandemic'.

It's a ghastly insensitive oversight and unforced error. The hemophilia community is still reeling from the atomic bomb that blew up during what was supposed to be "the golden days" of treatment. In the 1930s snake venom was used to treat the bleeding disorder, before frozen plasma in hospitals became the norm in the 1960s. At the beginning of that decade, the life expectancy of someone with hemophilia had risen to just under 20. The more convenient blood product treatments came in the 1970s, when the concentrated clotting protein that was culled from multiple sources was able to be administered at home by the patients themselves.

Gone were the days when people with hemophilia had to endure long stays in the hospital to get over a bleeding episode. Then, just as everyone was getting the hang of it, the long stays at the hospital for a mysterious- and fatal- illness began...

To add salt in the open wound, blood companies knew they were peddling a tainted product. Hepatitis B infection had run rampant in people with hemophilia after the advent of the more convenient concentrated blood plasma, and before the AIDS epidemic. Cries for a safer, hepatitis B-free, blood gathering process fell on capitalist ears: it would have been too expensive. The risk of liver damage due to hepatitis B was just a trade off for the new, normal lifespans that were promised to this blessed, new generation of people with bleeding disorders. Many of the decision-makers in the hemophilia community initially sided with the companies, because they wanted to believe them and couldn't imagine returning to the restrictive lifestyles of years past when treating hemophilia was a time-consuming psychological burden.

As time went on, the hemophilia community rallied to draw attention to the blood product crisis. Blood products because safer as a result of the tragedy- in much the same way the gay community had to take the message of safer sex into their own hands. The general society at large benefited because these two populations were desperately trying to save themselves at the same time they were experiencing unimaginable grief.

I don't expect any network television program to address the blood scandal. It's dark, but one thing we've learned in recent times is that it's better to acknowledge and explore the dark corners of actual reality than it is to continue to perpetuate a grand lie. But I do expect the bleeding disorders community's most visible and important figure of the last century to be acknowledged as someone who was living with hemophilia.

The Vice special took great pains to have people describe how they contracted HIV from a partner who was either unfaithful, or who had a history of using IV drugs. The special also dedicated a huge portion of time to fucking bugchasers...

Jonathan Van Ness narrated the special, and he's been such a beloved and effective spokesperson for HIV issues since going public with his HIV status, battling stigma and promoting U=U. I wish they'd just let him have a round table with a lot of the people they interviewed for the special, because Jonathan is certainly more knowledgeable about the epidemic than the team that was responsible for what did and didn't make it into 'HIV: The Neglected Pandemic'.

Positively Yours,
Shawn

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http://beta.docker.poz.com/blog/hemophilia-neglected-neglected-pandemic-jvn