



A Thinblood's Tale

March 13, 2007 By [Shawn Decker](#)

In an earlier blog, I mentioned a National Hemophilia Foundation (NHF) conference that I attended last fall. I wrote about how nervous I was, and that everything turned out well in the end... they liked me, they really liked me!

Well, two weeks ago, thanks to American Home Federation (AHF), I went to another conference in Albuquerque hosted by the Hemophilia Federation of America (HFA). I know this is all RFC (Really Fucking Confusing), but stay with me on this blog entry.

The talk that Gwenn and I gave was a rarity. Most of the 50 people in the room had hemophilia, and a good portion also had HIV. More than once, a young guy about my age came up to me and said, "I'm in the Triple H Club, too!" (Hemophilia, HIV, hepatitis C) Usually when we speak at universities and colleges, I'm the only diagnosed person in the room, which means inevitably I am representing the community to negatoid audiences.

Not so in Albuquerque. I was in a room with all generations of thinbloods, including my own? the guys who contracted HIV as children, had to go through puberty with HIV and have survived into adulthood. Often times, there haven't been too many answers, mainly because we didn't want to ask the questions that needed to be asked. Trial by fire.

The first response about the book that I got from someone in the community didn't come at a conference. It came on MySpace. I was being flooded with responses? overwhelmingly good? but one message resonated. It was from a guy named Tommy.

September 29, 2006 8:23 PM

I'm sure you get tons of these so I will try to keep this brief. I read your book in pretty much one sitting (there was a nap break about 3/4 of the way through). I just wanted to thank you for writing this book and showing me that there are others out there who have been through many of the same things as I.

As a Hemophiliac who was diagnosed with HIV as I child, many of the occurances and feelings you

recounted in your book seem to parrallel with my own. But whereas you have gone public with your illness, I have mostly kept mine private.

Never until now have I reached out to any other HIV positive people. I would like very much to stop hiding. If you have any information or advice as to how I can go about “coming out” so to speak, it would be much appreciated.

I’m 29 years old and have lived far longer than anyone anticipated. Myself included. It’s time for me to start moving forward and hopefully do something meaningful in the process.

Thank You,

Tommy

 corresponded with Tommy, but didn’t hear from him after the book tour, which lead into the holidays and then the new year. Last week, just after I got home from Albuquerque, I had a message from [his account on MySpace](#). It was from his mother, she was informing me that Tommy had passed to spirit. He was in the hospital for two months, and his mom read parts of it to him as he was drifting in and out of conciousness, because he had told her that my perspective mirrored his.

I can’t even type this without tearing up. Last fall, I thought guys like Tommy might be pissed at how I approached living with HIV and hemophilia in my book. I never, ever, imagined that it would reach someone on this deep of a level.

I asked his mother if I could share his story, and she said yes. Though I wish I’d gotten the opportunity to meet Tommy in person, I’m so glad he fired off a message that he thought I’d read a hundred times before. It was one that I needed to read and, presumably, he needed to write.

Thank You,
Shawn

PS... If you’re politically inclined, you can support the thinblooded community by telling your congressperson to [support HR 1282](#). It’s fast and easy.

PPS... Click on Tommy to hear his band, Raised Under Reagan.

