

For the Love of the Thinbloods

September 19, 2007 By [Shawn Decker](#)

Last weekend I participated in an adult retreat for people with hemophilia and other bleeding disorders, such as Von Willebrand Disease.

I have somewhat of a complex in regard to my “mild” hemophilia status, and it is intimidating to speak to a roomful of people with bleeding disorders that they deal with on a daily basis. Some of the jokes that naturally flow off my tongue to the usual audience of thickbloods could be perceived as insensitive.

I wasn't sure what room in the hotel the festivities were taking place, but I saw a guy in his 20's limping around the lobby. “Hey, what room is the adult retreat taking place in?” He smiled at me stupidly, and started saying something but the words didn't register in my brain, so likely I just stared stupidly back at him. “You're not here for the bleeding disorders thing?” “No, I work for the Navy.” “Oh, sorry, I noticed your limp and assumed...” “Nah, this is just a result of my stupidity.”

I noticed all the crutches and the large group of folks in the hotel Max and Erma's, and knew those were my peeps. Gwenn and I got a bite to eat, and I found a few passages to read from my book that were related to hemophilia.

As I got ready to speak, I felt more nervous than usual, but from the get-go the 20 plus people in the room were just like any post-dinner audience: bloated and ready for a nap. I made a joke that likened myself, and my mild status, to Barack Obama's perceived “lack of blackness”. That got a healthy chuckle, and then I was off and running.

One of the biggest changes since the book came has been my immersion into the bleeding disorders community. I know that sounds odd, but the AIDS community kind of swept me under their wing when I reached out back in 1996, and I was all about the AIDS then; I was just so excited to be talking about *it*. The big skeleton in my closet. THE AIDS. I was conquering the big bastard in my own way.

Hemophilia, as a stand alone, is boring in comparison. Sure, as a kid I had my struggles with the

disease, but found bleeding episodes to be far less of an occurrence when I started chasing girls and stopped chasing footballs. (Though I did take a nasty kick to the nads once, in 5th grade. The perp and I went to prom together years later, this fact will be in a future edition of MPV.)

Back to the narrative: basically, in developing my voice as an HIV/AIDS educator, I had to downplay my hemophilia. Not that I was ashamed, I just didn't want to be painted as an "innocent victim". I didn't want to play a part in drawing a line between me and anyone else with an HIV diagnosis. In order to be credible, I needed to be viewed as an adult, as a sexual being.

So, when AHF (American Home Federation, a hemophilia services group) wanted to help me get my book in front of the community, it was a bit of a risk on their part. My generation of people with hemophilia? "thinbloods", as I christened the community? were and are somewhat of a taboo topic. Our existence and survival is a painful reminder of a community that was let down by lots of folks in the 1980's, as tainted blood continued to wreak havoc until the early 90's, where a hepatitis C outbreak did further damage.

Those of who survived, now as thinblooded positoids, often bumbled through puberty and into adulthood, trying to juggle hemophilia, HIV and dating. Now we're adults, but nobody really wanted to talk about sex. With me, talking about HIV and safer sex is just part of the package.

When Gwenn and I were done, I was asked if I was going on the fishing trip the following day. My last joke was, "Are you kidding me? I don't trust you guys with all those hooks flying around!"

It was a great trip down to Virginia Beach, and I saw an increasing amount of familiar faces from conferences I attended earlier this year and last fall. One of my new thinblood friends, an older fellow and a huge wrestling fan, greeted me with a firm handshake, "You like Ric Flair, eh? I read your book!" We talked some wrestling shop, and then after Gwenn and I spoke, he said, "Let's thank Shawn for being here..." Then he looked over at me with a smile, and added in a southern accent, "Now, I'm gonna give you a send off like you've never had: this guy here is kiss-stealin', wheelin' dealin', limousine ridin', jet-flyin' son of a gun!"

A few of the fellow wrestling fans recognized Ric Flair's self-aggrandizing catchphrase (one of many), everyone else looked puzzled. It was a magical moment, and I cherish my spot in this big, limping, loveable family.

Positively Yours,
Shawn

SUPPORT: I met the fine folks at The Positive Project while at the Staying Alive conference. If you are positive, and would like to share your story, click on Support and learn more about their goal

to raise awareness about HIV/AIDS by utilizing those living with the virus.

Check out Shawn's new CD- co-written with Kyle Wiggins- featuring the Tori Amos cover, "[Raspberry Swirl](#)", and [original 80's-inspired](#) New Wave/Electronic music... *get with the programs!* ALSO AVAILABLE on iTUNES!!!

© 2026 Smart + Strong All Rights Reserved.

<http://beta.docker.poz.com/blog/for-the-love-of>