

AUTHOR CHRONICLES STRUGGLES, VICTORIES OF LIFE WITH HEMOPHILIA, HIV IN NEW BOOK

Shelby Smoak was just 18 in 1990 when he found out that he was infected with the HIV virus several years earlier by tainted blood products used to treat his hemophilia. He chronicles his struggle to adapt to life with the disease, while finding his way in the world during college and his early 20s in his book, "Bleeder," which just hit bookstores on February 1.

Shelby is a new member of HACA, having recently relocated to Northern Virginia with his wife, Vicky Hawk. He is a writing instructor at Northern Virginia Community College.

"Bleeder" is available at Amazon.com and BarnesandNoble.com, as well as independent bookstores around the country. Shelby will be doing a book signing at Politics and Prose in DC on Saturday, February 16, at 6 p.m. He will also be a presenter at the Gaithersburg Book Festival on May 18. More book signings are in the works; for more information, go to www.shelbysmoak.com.

Shelby took some time from his busy schedule to answer a few questions via email:

◆ The raw emotion and pain that you experienced are palpable throughout the book. How did those experiences shape your life? Is there a "silver lining" to the struggles that you went through?

I think any person becomes a collection of their experiences, so for me, hemophilia and HIV became and remain identifying markers. I am an HIV-positive hemophiliac. That identity looms (in my mind) larger than others such as that I am a teacher, a writer, a husband, a brother, a son, etc. That is, it's really hard for me to know who I might be, what kind of person I might have become, without hemophilia or HIV. Of course I imagine it (and sometimes let my happy fantasy go too far!) but ultimately these illnesses and experiences made me more thoughtful and pushed me towards books and writing in a way I may not have come to without them; the silver lining here is that I have something I love and daily look forward to: reading, writing, discovering. On another level, I think these experiences gave me a deep appreciation for family and friends. In general, I just love being able to do the things I can with myself, my wife, my friends, my colleagues.

◆ A lot of the details are very personal. How did your family react to that?

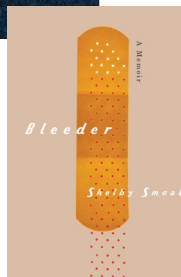
To be honest, my family hasn't yet read "Bleeder." When I was writing short stories and fiction, I shared all these with them and was ever-encouraged by their support. However, when I came round to writing "Bleeder," I knew I just had to write it and not share it for how external suggestions or feelings might change the narrative. At this point, they know its basic content and their role in it (to a degree), but I think it will be emotionally difficult for them to read it, and I think there are some passages in there that would be better unread by close family members – these are just too raw and sad. I know it was extremely taxing for me to write, and even now I wonder how I might read some passages aloud without getting a bit tight in the throat. With that, I guess I'm waiting to see if they choose to read it or not. (I keep telling Mom I'm sending her a framed copy for her wall, not to be read!) After they decide (to read or not to read), I suppose I'll see the reaction. As I've remarked in other places, for "Bleeder," I just had to write it without imagining an audience (including my family). Now, I suppose I await to see what results that brings.

◆ As a person living with HIV, do you think that peoples' attitudes toward the disease have gotten more positive over the years?

Indeed it has. I think the media's portrayal of HIV in the 1980s was simply devastating in its effect upon the American population. Then, there was virtually nothing positive about being positive. Today, thankfully, media has made large strides to redirect misguided perceptions of the illness. Along with that, people in general have shed the gloom, doom, and fear and replaced it with care, concern, and compassion. This has been a happy turnaround to witness. In many ways, if you look around at people and organizations supporting and aiding HIV, it highlights that real sense of pride one can have with humanity, in the way they can become so giving and thoughtful to something that was once anathema to that kind of thinking.

◆ How is your health today?

Today, I'm doing quite well. I have the occasional hemophilia bleed that knocks me down for a few days, but I'm still able to juggle work and activity with that. The HIV has been managed through drugs so that I don't suffer too many complications from that. I swim, hike, bike, and am generally pretty active, which in



Continued on page 5

THANKS TO OUR DONORS

The Hemophilia Association of the Capital Area gratefully acknowledges our donors who have given so generously. Below are donations received from November 1-December 31, 2012.

INDIVIDUAL CONTRIBUTORS

- ◆ Michael Burke
- ◆ Jean Callahan
- ◆ Larry Didato
- ◆ David Elliott
- ◆ Carol Fannan
- ◆ Francis & Linda Falgiano
- ◆ Miriam Goldstein & David Hubbert
- ◆ Carole Hennessey
- ◆ Jim Holmberg
- ◆ Greg Key
- ◆ Jaesun Lee
- ◆ Dr. and Mrs. Randall Lewis
- ◆ Albert & Hilda McPherson
- ◆ George and Linda Price
- ◆ Margaret Scanlon
- ◆ Elizabeth Tawil
- ◆ Charlotte Williams
- ◆ Srujana Yadlapalli

ORGANIZATIONAL CONTRIBUTORS

- ◆ Baxter
- ◆ Biogen Idec
- ◆ CSL Behring
- ◆ Factor Support Network
- ◆ Global Prairie
- ◆ Good Search
- ◆ National Hemophilia Foundation
- ◆ Novo Nordisk
- ◆ Pfizer

CFC DONORS

- ◆ John Dring
- ◆ Jay Epstein
- ◆ Theresa Henderson
- ◆ David Hubbert and Miriam Goldstein
- ◆ RK Hurrington
- ◆ Paul Krumpke
- ◆ Amy Pfisterer

Continued from page 4

turn keeps me healthy. The biggest battle I now face is likely HCV (Hepatitis C). I left this out of “Bleeder” for storyline reasons, but unfortunately HIV wasn’t the only taint in the 1980s blood supply; Hep C also came to those of us using blood products. Treatment in this field is promising but, sadly, it will be something I will have to endure to try and eliminate that virus from my blood. At present, it’s just another lurking danger among the others, and, like those, my doctors and I keep close guard of these illnesses’ progress and have plans to react when we must.

-
- ◆ Gregory Sinclitico
 - ◆ Paulette Van Norman
 - ◆ William Walsh
 - ◆ Patricia Wolz

Please consider donating to HACA. We rely on your support to run the organization. To donate, send a check to our offices at 10560 Main Street, Suite 419, Fairfax VA 22030. You can also pay by credit card by phone (703-352-7641), fax (540-427-6589) or using PayPal at the “contact us” link on our website, www.HACAcare.org.

Every effort has been made to ensure the accuracy of this list. Please contact us if you notice any errors.



Biotherapies for Life™

We know that people with bleeding disorders face unique challenges in getting diagnoses, raising awareness, securing access to care, and finding the information and support they need. That’s why CSL Behring is dedicated to partnering with patients, research scientists, advocacy groups, healthcare professionals and government to improve the quality of life for individuals who need our therapies.

CSL Behring