Sean Strub and the Legacy of AIDS

January 28, 2015 By Mark S. King

Before my interview with activist **Sean Strub**, author of **Body Counts: A Memoir of Politics, Sex, AIDS, and Survival**, let me share a revealing story.

It was late 2011 and my life was in shambles. The breakup of a long term relationship had sent me into a spiral, followed closely by a devastating drug addiction relapse. I had weathered the fallout and taken refuge at my mother's home in Louisiana.

And then came a phone call from Sean Strub, founder of **POZ Magazine** and lifelong advocate for those of us living with HIV. We were acquainted but not yet close friends and the request he made during the call surprised me. Would I be willing, he wondered, to come visit him for a few weeks and help get his new HIV anti-criminalization effort, **The Sero Project**, off the ground?

Sean had read a blog posting I had written **about my breakup and relapse**, and must have known I wasn't exactly firing on all cylinders. I was a recovering addict with a trail of wreckage in my recent past, and yet he wanted me to come work with him. Like, in his home.

Within days I drove 1,400 miles to **his Pennsylvania town**. I managed to get some work done but mostly I piddled around his home office, getting my bearings again while we traded war stories and gossip from across our desks. Sean was passionate about every topic and a great teacher on contemporary HIV advocacy issues.

Before long, the real purpose of Sean's long distance invitation became clear to me. He didn't really need much help, but he knew that I did. He saw someone with potential who would benefit from a little mentorship, encouragement, and a friend. And God, he was right. Our time together strengthened and refocused me. Since then, I have heard many stories about Sean Strub taking people under his wing and helping to lift them up to a better place.

My admiration makes it nearly impossible to objectively review his remarkable memoir, Body Counts. I am an unapologetic fan and grateful friend. That being said, you must finish reading this article and go directly to Amazon and **buy his book**.

Body Counts is one of the most wide-ranging and well written remembrances to come out of the AIDS crisis. It seamlessly combines the social, political, and sexual landscape of Sean's journey. It moved me to tears more than once, and taught me a lot about what happened behind the scenes during the dawn of the century's greatest public health crisis.

All that, and there's a ton of great celebrity stories about people like John and Yoko (**Sean was there** the night Lennon was shot), Andy Warhol, and a host of colorful others.

Sean agreed to a conversation to discuss everything from his memoir to body image, sexual abuse, the legacy of AIDS, and the state of the HIV community today.

Here is that conversation:

Body Counts is such a marvelous achievement, Sean. So much history here, personal and otherwise, and witnessed from such close proximity. Thanks for not holding back the juicy stuff about politicians and celebrities!

For better or worse, politicians and celebrities are intertwined with the history of the epidemic, in ways both bad and good. My perspective at times is unusual-like when I was running the “Senators Only” elevator in the U.S. Capitol-and I tried to present the humanity, good and bad, of those I write about.

Also, in terms of the epidemic, it was a conscious decision and key strategy to exploit celebrities to gain attention and action in response to the epidemic. Elizabeth Taylor knew this better than anyone and she was amazing at getting others to join her in spending their celebrity capital on behalf of something important.

And you’re our tour guide through those years. I think your criticism of President Bill Clinton’s AIDS response might be surprising to people. Aren’t we supposed to love him?

Others have suggested that Clinton’s post-presidency focus on the global epidemic is an effort to atone for his failing in this regard during his presidency. When **salon.com published an excerpt** from Body Counts that was about the Clinton Administration, it generated a lot of nasty comments. It was the epidemic driving a generation of gay men out of the closet and into activism that ultimately was critical to electing Bill Clinton, yet as soon as he was elected it seems like the air was let out of our activist balloon.

In some ways I think we-as a queer community-are more effective as outsiders, where we had to learn to survive, than we are as insiders, where we haven’t been as welcome or skilled. When Clinton was elected, many of our leaders became insiders and didn’t take everyone with them.

I’m glad you’re not letting people off the hook. Was it important for you to save our AIDS history from those who might revision it?

Initially the impetus for writing Body Counts came from the realization that, as time passed, there were fewer and fewer of us around from the early days who could tell what happened first-hand. It was also a way of validating my own life. I didn’t grow up wanting to be an AIDS activist; I had other plans, but in the early 80’s my life was hijacked by the epidemic. WritingBody Counts gave me some understanding of why I made the choices I made.

But the more I dug into the history I also saw how those years have been misrepresented or misunderstood, particularly the role of people with AIDS and HIV. Grassroots community efforts are often dismissed, minimized or ignored.

Historical truth is always more complex than the simplified-and sometimes manipulated-version of popular history we are led to believe. The epidemic’s history has been, to an extent, commodified,

rewritten to serve some agenda.

I think it is important to have as many first-person accounts, especially from people with HIV who were on the frontlines, so our experiences get documented and preserved. And as time passes, there will be more archives available, with documents from those years that will tell an even fuller picture.

As we get more perspective, the epidemic and our response to it, is understood in new ways and that's a good thing.

The ongoing theme to your AIDS work, in fact, has been a respect and focus on people living with the virus themselves. You carry that banner fiercely.

I don't think the LGBT community, or people with HIV, have gotten the credit we deserve for what we did in those early years. How we came together to love and care for each other was something remarkable. We should the world our very best face and what we did then should be celebrated and recognized as a model, worthy of emulation in many kinds of situations. I also know that it was other people with HIV who comforted me, educated me and enabled me to survive.

The book is a reclamation on your body -- from shame about it, from infection, from the sexual abuse you suffered. Do you think it's a common challenge for gay men to love their physical selves?

The title, Body Counts, is an intentional double entendre, referring to the loss of life from the epidemic, of course, but also my personal lifelong struggle for control of my body. It has had many enemies: the Catholic church which taught me that they owned my body, sexual abusers who exploited me, a government that sought to control my sexual expression, HIV itself and even the drugs to treat HIV. It has gotten better over time, but shame-shedding doesn't happen in an instant, it is incremental and I suspect, for me, will be a lifelong process.

I can't imagine revisiting some of the trauma you describe in the book, such as childhood sexual abuse and a rape by a roommate. Was it brutal to write?

I wouldn't call revisiting those memories brutal, but it was at times emotionally draining. Ultimately, it was healthy for me to process pain, hurt, guilt and shame that I had carried for years.

You write that it took 20 years to recognize the rape for what it was. Do we have a problem as gay men seeing ourselves as victims of abuse?

When it happened I didn't even think of the word rape as having any applicability to men. I was still so ashamed of my sexual desire and also conflicted about the degree of responsibility I bore for what happened. For many years I blocked out the sexual abuse and sexual violence I had experienced; it made me uncomfortable to think about because I didn't think there was anything constructive I could do with those memories except feel bad about them.

Now I can look back and see that while I may have been precocious in some ways, I was incredibly naive and vulnerable in other ways. In the process, I not only forgave those who hurt me but I ended up, quite unexpectedly, forgiving myself as well.

You were absolutely on death's door for a few years, and squeaked through in time for new medications to save you. And you were outright defiant about showing the Karposi's Sarcoma (KS) lesions that covered your body during that time.

I think if more of my identity and self-worth had been found in my body I might have been more likely to pursue cosmetic treatments for the KS. And the objectification of bodies is practically in the DNA of gay culture. Even as I began to accept my own body, it was within a context that clearly told me the body I had wasn't a gay ideal. I'm skinny, have no chest and am not especially athletic.

On the other hand, not conforming to that ideal, not being as invested in it, made it perhaps a bit easier when my body become so obviously ravaged by AIDS and, especially, Kaposi's Sarcoma. Less of my self-identity was in my body, so its decline didn't degrade my self-worth as much as it might have for others.

I didn't treat the visible KS lesions because I knew there were no treatments that would slow their growth and I already spent too much time in doctors offices. That was almost unimaginable to many people who were horrified that I had visible lesions and took no steps to even disguise them with makeup.

I make the mistake of assuming people know that AIDS advocacy changed the entire patient/physician dynamic, or that our response to what we endured will forever be remembered. Obviously that isn't necessarily so, and why books like yours are important.

There is an understanding that AIDS has been different, in many ways, and has had a profound impact on the culture, society, the healthcare system, drug development and approval processes, even geopolitics. I don't think it is widely understood how different the epidemic might have been had it not been for the self-empowerment movement, or how truly radical those early PWA pioneers were.

While ACT UP has been an important part of my life and advocacy, so too has the advocacy that precedes ACT UP, that set the stage for our movement. That earliest history hasn't been as well studied or understood and I tried to give some attention to those years in Body Counts. Randy Shilts' And the Band Played On provide an important and detailed view of the early years from his vantage point in San Francisco; the story from those years in New York hasn't been nearly as thoroughly explored. Also, And the Band Played On was written before ACT UP came on the scene.

When you first arrived at the offices of a coalition of people with AIDS, you write about having found a place you belonged, at last, even after having begun a business career and worked in politics. What about it struck you so deeply?

Total solidarity. I felt so welcome and safe that it enabled me to overcome the fear of stigma. That's what I've tried to do for others ever since.

What are the greatest threats to people living with HIV today, or at least to the kind of empowerment groups for us that have been so important to you?

Lack of respect for the principle of patient autonomy. This is happening across the board, as public health becomes militarized, disease securitized and treatments more complex and costly. The concept of the physician as a healer, providing individualized treatment, has too often given way to the physician as an extension of and agent of the state and the pharmaceutical industry, treating populations instead of individuals.

You are known to be skeptical of pharma and caution that medication side effects are too often ignored. Some people might find that ironic, given that new medications saved your life. Is that fair?

I think skepticism about pharma, when it was pharmaceutical treatments that saved my life, isn't ironic but common sense. Anti-retrovirals, like many medicines, are powerful treatments. Anything very powerful can be used in a negative or positive way; the more powerful the more important it is to be careful, cautious and skeptical.

Skepticism saved my life. Had I not been so skeptical, I would have taken more treatments that, in hindsight, we now know would have hurt me more than helped me. I am alive because I was lucky or smart or skeptical enough to refuse pharmaceutical treatments at one point, when they were strongly recommended to me by the medical establishment, as well as because they were available to me and I took them at another point, when I needed them.

The irony isn't found in me. The irony is that a healthcare system that purports to heal and a scientific establishment that purports to be interested in discovery has so often refused to listen to or learn from those living with the disease. Had our voices been valued more highly, the epidemic would never have gotten as big as it has.

I'm a little surprised that your book is the first memoir by a major imprint about those early years in New York City and the early ACT UP era. What do you make of the recent interest on film about AIDS in the 1980's, such as How to Survive a Plague and Dallas Buyers Club?

Enough time has past since the worst years that those who survived can reflect with greater objectivity. Many survivors feel compelled to remember the dead and bear witness to what we experienced. That has become a sense of obligation, even a compulsion, for many of us, particularly as we age and realize there are fewer and fewer of us around to speak first-hand about those years.

For many it is a delayed grieving; when friends were dying so fast and in such great numbers it wasn't possible to fully grieve them. But we filed away that pain, to process later. Now it is later.

The explosion in cultural production in the last few years, the films you mention as well as books and exhibitions, is somewhat analogous to the cultural production following the Holocaust. Not so much in the 40's and 50's, but by the early 60's it had started to grow dramatically. Yet 15 or 20 years past the worst of those days, the memories and words and testimonials start to come forth.

But even Dallas Buyers Club and other works of art haven't done well with their bottom line. We might be taking a look back, but it isn't exactly a highly commercial enterprise, is it?

No, it isn't, to many people anything about AIDS is such a downer they aren't interested. Many gay men have created lives that have protected them, emotionally, from the pain of the epidemic and they don't want to be reminded of it.

But I'm not sure we would be in any better position in terms of addressing the epidemic if the books and films about its earlier years were enormously profitable. There is an historical record that, in time, will be vastly more important than how many copies or tickets are sold today.

Body Counts seemingly has everything, from Washington politics to brushes with celebrity to your own sex life, and the book had major endorsements. I will admit I thought it would be a bestseller, and rightfully so. Or at least it should have been.

I suspect every author wishes their book sold better and I'm no exception. But while I didn't make the NY Times bestseller list, Body Counts has gotten excellent reviews -- almost across the board -- and hundreds of people who read it have contacted me with appreciative comments, which is cool.

The publisher early on told me she expected the book to have a long sale and she has been proven correct. It is getting assigned in college coursework and continues to sell, even though it has been a year since the original publication date.

College kids are studying your book? That has to be gratifying, and it sounds like the perfect use for your account of this history.

Yeah, that's cool, isn't it? I spoke at a dozen colleges and universities last year and found student audiences to be engaged, stimulating and helpful for keeping my own thinking fresh.

The cover artwork and even the subtitle of the book were changed for the paperback. Why?

The hardcover has a picture of me kissing Michael Misove, my partner who died in 1988 and the subtitle was “A Memoir of Politics, Sex, AIDS and Survival.” For the paperback, the photograph was changed to one of a young and cute me looking directly at the camera. The thought was that the picture of Michael and me, while very sweet, may imply the book is about that one relationship between these two men and if someone wasn’t interested in that they may pass on the book. The picture of just me alone wouldn’t be so narrow.

The subtitle for the paperback was changed to “A Memoir of Politics, Activism and Survival” in the belief that the word “AIDS” may turn off some buyers. That was weird, but I think probably true. My point was and remains to get as many people to read the book as possible, so I was supportive of any change that would help achieve that goal.

So what next for you? I know you’ve been doing a book tour and events.

I want to continue working to help people with HIV find greater agency and empowerment, particularly through support of and strengthening of networks of people with HIV. In time, I think the self-empowerment advocacy will start to blur the lines of specific distinctions between diseases and conditions; it will be about a broader movement to take back healthcare and choices about our health and bodies from the corporate grip that has been so damaging to the lives and health of many.

I’m increasingly aware of the march of time. Is it too soon to ask how you want to be remembered?

There’s no question but that time becomes more precious as one ages and for those of us, like you and me, who have been lucky to survive when so many of our peers did not, it only makes that sense more intense.

It is peculiar to think about how one would like to be remembered because, first of all, no one wants to be remembered for spending much time thinking about how they would like to be remembered. What is important is what I am doing today and if I’m doing that well, it won’t matter how I’m remembered.

I think I’m going to start this piece by telling people about your kindness to me after my breakup. Would that embarrass you?

I’m beyond embarrassment, I think. And I could not be more proud of our friendship.

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