



Ryan White's Legacy

A new book puts the late AIDS activist's life into context.

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When it comes to media coverage of HIV, few Americans have garnered as many headlines as Ryan White. But there is a difference between the person and the cultural figure. In his new book, *The Life and Death of Ryan White* (The University of North Carolina Press), Paul Renfro, PhD, associate professor of history at Florida State University, plumbs the depths of those contrasts.

White, who had hemophilia, contracted HIV in 1984 at age 13 from a blood transfusion. He faced intense AIDS-related discrimination from his Indiana community when he attempted to return to school after his diagnosis. He gained worldwide attention as he fought tirelessly for his right to attend school. White died in 1990 at age 18.

At the core of Renfro's book is the notion of innocence. The book, out this month, also examines how White's story tugged at America's heartstrings while sometimes reinforcing hierarchies of people with AIDS.

"Innocence is such a powerful idea," Renfro says. "A lot of AIDS activists sought to counteract the power of that perceived innocence." Renfro spoke to POZ about why he wrote this book, what it has to say about illness in 2024 and what White's story means in relation to other figures with HIV, such as the infamous Patient Zero. This interview has been edited and condensed for clarity.

When did you become interested in Ryan White's story and dedicate a book to it?

It's a story that I grew up with. As soon as I was kind of conscious of what HIV and AIDS were, he was deeply embedded in my mind. I realized that it hadn't received a book-length treatment that matched the enormity and importance of the story. The story has a pedagogical element to it, and that's how I first encountered it: as a child in school, where the story is harnessed to teach lessons about tolerance. I thought there was an opportunity to complicate that story in a way that could be accessible for a variety of audiences.

You open the book with a discussion of the artist collective Gran Fury's piece All People With AIDS Are Innocent. Why did you want that to be the first thing readers encounter?

Innocence is such a powerful idea and one that governs how people approach a variety of issues, not just HIV and AIDS. I wrote my first book about mass incarceration, and innocence is paramount to how people approach that issue, how they understand who is good or bad, who is or isn't incarcerated. It still governs how people approach disease, how they approach the criminal legal system, how we tend to rank and judge each other. So I wanted to foreground that, to demonstrate: OK, this is how a lot of people conceive of Ryan's story but also how a lot of AIDS activists sought to counteract the power of that perceived innocence.

It reminded me of Richard McKay's book, Patient Zero: The Making of the AIDS Epidemic, which looks at a figure on the other end of the cultural spectrum regarding innocence.

I love that book. People still use "patient zero" as a descriptor, and it has this tremendous power. Richard is—and, hopefully, I am—trying to dislodge some of that and complicate how people conceive of these things that are firmly entrenched.

Your book is coming out at a time when a lot of books about AIDS are getting published. People are really reexamining the AIDS crisis and adding more and more stories to it. Why did you want to revisit Ryan White's story, and what do you think it has to say in 2024?

There's this notion of the "pastness" of AIDS. There's a desire to localize it within the '80s and '90s, which is not the case. The ongoing COVID-19 crisis looms over the book. It's complicated, because people want to make really easy analogies, but it's not that simple. There are lessons or patterns that we can look to and say, "This same sort of thing is happening." And this isn't just unique to HIV and comparing it to COVID. In the book, I talk about mpox and these sorts of patterns of blame and this desire to "move past" each one.

This book is also about disability, not only in terms of HIV but in terms of Ryan's status as a person living with hemophilia. Were you looking to make this about disability as well?

That first chapter is very much animated by disability studies. Ryan's family approached disability as overcoming adversity. It's something I view within the context of the book as aligning with this discourse of perseverance and resilience. It translates into how he approaches AIDS.

People with hemophilia have an interesting position within HIV and AIDS. They face HIV at

enormous rates, and they're understood to be uniquely susceptible, but they have this position as a group with a disability that has a sense of innocence that is not afforded to other populations that are disproportionately affected by AIDS, especially in the early years of the epidemic.

That understanding of disability shapes how Ryan's story gets presented, and it enables him to become a really major figure within the early history of AIDS in the United States and beyond, because of the attitude that he is an exceptional person with AIDS.

Later in that chapter, too, you talk about how in his autobiography, Ryan discusses people in Kokomo, Indiana, where he grew up, and how he says some stigmatizing things about people who use drugs. Did it worry you at all to take Ryan's family to task or say something critical of someone who is so universally cherished?

In this passage in his book, he is saying something to the effect of, "People who use drugs are doing that because it's a choice, it's something they don't fully understand the implications of because I'm someone who has to be stuck with needles." It's a troubling claim, but it's also unclear whether he is the one who's expressing these ideas or if it's Ann Marie Cunningham, who was the coauthor of his autobiography, which was posthumously published.

To answer your question directly: Yes, I was concerned. I don't try to just take the White family to task during the book, because I think there's a lot to admire about his story. It's a complicated story, one that doesn't have heroes and villains. The ways in which Ryan's story has been deployed by him and by others can be understood to be problematic. But at the same time, there's also a criticism to be leveled or a critique to be developed, and I wanted to wrestle with that while at the same time—hopefully—honoring the really admirable parts of his story.

I think your book asks us to look at Ryan's story as well as the media construction of his story—the person and the figure.

You have people from the late Senator Jesse Helms to AIDS activists who were deploying it for these different purposes, and that speaks to the kind of malleability of his story. It would be difficult for a Ryan White-caliber figure to emerge in a time before cable news and the developing 24-hour news cycle. It says a lot about celebrity. Ryan White is very clearly the product of that cultural construction.

He was a person, but at the same time, he was larger than life. The fact that he was unassailable is important because no one, even people who were saying, "I don't want this kid in our middle school," was going to say, "I hate this child." They're all saying, "Our enemy is not Ryan White."

