



The Importance of Remembering Ryan White

Why the heroic boy from Indiana is more than just the namesake for the Ryan White CARE Act

August 10, 2010 By [Shawn Decker](#)

Twenty years ago, the HIV community lost one of its fiercest allies when Ryan White passed to spirit at the tender age of 18—just a month shy of graduating from high school. In junior high he had been banned from public school when it was discovered he was living with HIV.

But though he never had a chance to don his cap and gown, White more than earned his diploma in the field of HIV/AIDS awareness. By sharing his own experiences with discrimination, he helped bridge the vast gap between fearful ignorance and compassionate understanding about HIV/AIDS. And he did so in an era that was far from conducive to his message.

Today's president, Barack Obama, has signed legislation that lifts the U.S. travel ban on people living with HIV and that reauthorizes funding for the Ryan White CARE Act. But when White was diagnosed with AIDS in 1984, President Ronald Reagan said very little about a sexually transmitted infection that was affecting the gay community, and when he did, it was cryptic. In 1987, when referencing the need for more government-led prevention efforts, he said: "...when it comes to preventing AIDS, don't medicine and morality teach the same lessons?"

Fortunately, that same year, 15-year-old Ryan White decided to address the issue with compassion, explaining that HIV/AIDS is a disease that affects not only gay people but also kids, too, and that all people living with HIV—be they gay or not—deserve the same human and health care rights as everyone else.

Like many others (including yours truly) living with hemophilia in the days before the national blood supply was carefully screened, White contracted HIV through tainted blood products. He did not know he was positive until a bout with pneumonia necessitated a partial lung removal. While in the hospital he was diagnosed with AIDS and given six months to live. As if that news wasn't enough, his family also discovered that their community in Kokomo, Indiana, did not want White to attend the public school where he was a seventh grader.

While White fought to regain his health, attending classes by telephone from home, his mother, Jeanne White, began a battle with school officials in the hopes that when her son was healthy and

ready he could once again sit in class with his friends. White's expulsion from his Indiana school and the ensuing eight-month battle to get him readmitted made the local news and soon after, the national media.

Headlines about discrimination introduced the country to White, who, in response, spoke out publicly about his situation in an attempt to raise awareness about how HIV is and isn't transmitted. But despite his valiant efforts, White remained the victim of insensitivity and discrimination in his hometown. After he was readmitted to his school, students vandalized his locker with the word "fag," and he became the target of jokes named after him—Ryan White jokes. Can you imagine being a teenager and having your name be a punch line? Through it all, he held his head high, appearing on talk shows and being beamed into America's living rooms, his sweet, gentle demeanor reminding many parents of their own kids. He opened hearts as he advocated love and compassion for all people living with HIV—not just for himself. While most of his 15-year-old peers were struggling with the weight of their backpacks, White carried on his shoulder the responsibility of how a nation viewed a life-threatening illness, and how fear and misinformation around HIV led to stigmatization, discrimination and defamation of those living with the virus.

Many A-list celebrities rallied to White's side, including Elizabeth Taylor, Sir Elton John and Michael Jackson. But when asked about his own stardom, White said that he would trade it in a heartbeat to have HIV permanently removed from his life. Earlier this year, Elton John wrote a public letter to his fallen pal in honor of their friendship and said that he would give away his fame and fortune for one more conversation with White.

As for the conversations the young boy from Indiana had with our country over the course of his half decade in the spotlight, White admitted that one of the toughest aspects of his role was the fact that he had to say the same things over and over again. It was very taxing having to repeatedly explain that he wasn't a public health risk. It's ironic that White's attempts to educate the public ended up negatively influencing his own health, already compromised by HIV in a time when there were no effective treatments.

His influence continued postmortem. Shortly after White's passing in 1990, President Ronald Reagan—then out of office for two years—wrote a tribute to White that was published in *The Washington Post*. And Reagan's successor, President George H.W. Bush, signed the Ryan White CARE Act into law, providing the first and largest federal aid program for people living with HIV in the United States.

White's legacy lives on in many ways today. Recently it was added to the Children's Museum of Indianapolis exhibit titled *The Power of Children: Making a Difference*, which highlights the struggles faced by children. In one room, an old radio plays the kind of music that the universally known Dutch-Jewish teenager Anne Frank listened to with her family while they were forced into hiding for fear of being killed by Nazis. Walk to the next room and you'll find a typical 1960 elementary school classroom, only you'll see it through the eyes of Ruby Bridges, who was escorted into her first-grade classroom by federal marshals as one of the first African-American students integrated into public schools.

Then you enter a zone designed to replicate White's experience. You can open a vandalized school locker door and hear a recording of the disparaging whispers that must have followed him down the hallways. A replica of his bedroom includes items from his actual room, which was preserved by his mother. His teenage refuge shows that what he said was true: He was just like every other straight kid in the 1980s—doing his homework while Alyssa Milano stared down at him from her poster with a subtle smile, her earrings resting upon her shoulder pads. A clear plastic wall prevents museum visitors from jumping on Ryan's bed as he must have done, and it seems strangely appropriate—an unintentional tip of the hat to the ridiculous precautionary measures people thought were necessary in the days before White helped them understand how HIV is transmitted. "Yeah, Tommy can spend the night with Ryan this weekend," one can imagine a concerned mom explaining to Mrs. White on a big, rotary phone. "So long as you put up that plastic wall!"

I was so thrilled to see White's story and the topic of discrimination based on a medical condition highlighted in the museum alongside cases of extreme ethnic and racial prejudice. My hope is that, as parents guide their children through the White display, they will follow up the museum visit by having frank discussions with their kids about how to protect their sexual health. Nearly 30 percent of all new HIV infections in the United States occur in people younger than 30. White would be heartbroken to know that, while the blood supply that infected him is now much safer than it once was, people his age today are still at risk for contracting HIV and other sexually transmitted infections because of a lack of comprehensive sex education in America's school.

The HIV/AIDS community has done a wonderful job of carrying White's torch for the past two decades, but eight years of abstinence-only sex education has resulted in a new wave of young people who risk becoming sick and dying, as White did.

I'm thankful Obama has cut funding for most abstinence-only sex education programs and has given the direction that school-based sex ed should focus on preventing teenage pregnancies. But I wish our president's leadership would extend further and ensure that The Ryan White CARE Act would include more than just funding for people already living with HIV. I wish the CARE Act could fund HIV-specific education that includes teaching children and young people the art of condom negotiations as well as the proper techniques of condom application and removal. This would ensure the greatest protection from that life-saving prophylactic. If parents have a problem with such topics being taught in school, then someone should teach kids these lessons using YouTube or videos embedded on Facebook.

If White were alive today, I wonder how he'd be advocating for HIV issues as someone nearing his 40s. Would he be fighting for AIDS Drug Assistance Program funding, thus preventing people in the United States from dying while waiting for HIV medications? Or would he have thrown his hands up in the air, choosing to move to France or some tropical island retreat?

No, he'd still be in the fight.

It has been 20 years since we lost White, and I am worried that even the HIV/AIDS community may

eventually forget about him. As we continue to lose our first generation of fighters and to focus on nurturing and guiding the newly diagnosed—many of whom were born after White passed—it's critical that the torch lit by Ryan White remains burning brightly. Many of us have benefited (by being recipients of services provided by the Ryan White CARE Act) from his celebrity and sacrifice. We must acknowledge his influence in our country's strange, sometimes depressing, sometimes inspiring and ever-evolving history with HIV/AIDS. Most important, it's critical that Ryan White's name live on as more than the title of a piece of legislation or as a museum exhibition. For if we forget all that Ryan White personally stood for, then we risk losing a hell of a lot more than we've ever communally received from the CARE Act named after him.

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