25 Years Ago Yesterday: The Ray Brothers' Home Burned Down

August 29, 2012 By Shawn Decker

In the history of how some people in America dealt with the emerging AIDS epidemic in the 1980s, it is hard to find a more egregious example of fear and ignorance than what happened to the Ray Family in Florida 25 years ago...

Three boys- Ricky, Robert and Randy- all born with hemophilia and diagnosed with HIV as children in 1986, were not allowed to attend school following their positive test results. After a court ruled the following year that they had every legal right to attend, their family's home was burned to the ground a week after the decision. Needless to say, the family chose not to stay in Arcadia, FL, and moved to Sarasota. Sadly, Ricky Ray passed to spirit in 1992 at the age of 15. He was hoping to marry his girlfriend, but a judge blocked the attempt due to his age.

In 2000, Robert, the middle brother of the trio, passed shortly before the Ricky Ray Relief Fund Act was inacted.

In short, here's a description of the Ricky Ray Relief Fund Act:

"*The Ricky Ray Hemophilia Relief Fund Act of 1998 (Public Law 105-369) established the Ricky Ray Hemophilia Relief Fund Program to provide compassionate payments to certain individuals with blood-clotting disorders, such as hemophilia, who were treated with antihemophilic factor between July 1, 1982, and December 31, 1987 and contracted HIV. The Act also provides for payments to certain persons who contracted HIV from the foregoing individuals. The spouse or former spouse of such an individual, who acquired HIV from that individual is eligible for payment, as are children who acquired HIV through perinatal transmission from an eligible parent. In addition to these individuals, certain survivors also are eligible.Congress appropriated $75 million to support the Ricky Ray Hemophilia Relief Fund Program during Fiscal Year (FY) 2000.*" - source, The Federal Register

A part of my own history with HIV involves being kicked out of school due to my HIV status. This happened in 1987. There was no trial, I was asked to leave one day near the end of my sixth grade school year because school officials was scared and, as word got around my small hometown, some parents were frightened as well. It wasn't until a lawyer got involved and a lawsuit was threatened that I was allowed back in, just in time for junior high school after a summer of headaches for my parents and doctors.

I thank Ryan White and the Rays for blazing the painful path that showed those in my own community 25 years ago that they would lose if they chose to take their case to court.

In relation to this topic, just last year a teenager applied to the private boarding school for disadvantaged youth, The Milton Hershey School, and was denied solely because of his HIV status. After close to a year- and after a court gave the green light to the boy to pursue a legal case- the school's principal said the student would be welcomed at school. The teenager has opted to pursue his lawsuit instead of an education at Milton Hershey.

Which I support. See, I have no legal proof of what happened to me back in 1987. When I educate, I share my history of what my family and I dealt with. I wrote extensively about it in my book, *My Pet Virus*. When the local paper here in Charlottesville interviewed me in regard to the book, they contacted the man who was the superintendent for the Waynesboro School system. (My current hometown of C'ville is only about 25 miles from my birthplace of Waynesboro.) The superintendent said that I had never been kicked out of school, that me and my family were liars.

At first I was pissed. At that point, it had been twenty years since I had been kicked out of school. I'd gotten over it a very long time ago. My editor on the book, Ken Siman, calmed me down on the phone. He encouraged me to do what I do- be funny. So when the paper asked for my reaction to the superintendent, I offered to go have a beer and chat it out with him- and if they didn't work we could always mud wrestle.

The Hershey incident sheds light on the need for more HIV education in schools, both private and public, in the year of 2012 and beyond. To many, HIV is the rest of the world's problem, so when it lands in their backyard they hit the panic button. They make irrational, quick fix decisions intent on making the "problem" go away instead of working on a solution in which the problem isn't really much of problem after all.

In 1987 my doctor knew I wasn't a physical risk to other students. Last year, several people contacted the Milton Hershey School offering to provide education about HIV transmission. It fell on deaf ears. The legal footnote needs to be made that, in 2012, a student who made the grades where it counts was discriminated against for failing one test that shouldn't matter: an HIV test.

The youngest of the Rays, Randy, is still alive today. Let's make sure the legacy of his family's ordeal lives on as well.

Positively Yours,
Shawn

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