

Ryan White, Testimony before President's Commission on AIDS (1988)

"Thank You, Commissioners:

My name is Ryan White. I am sixteen years old. I have hemophilia, and I have AIDS.

When I was three days old, the doctors told my parents I was a severe hemophiliac, meaning my blood does not clot. Lucky for me, there was a product just approved by the Food and Drug Administration. It was called Factor VIII, which contains the clotting agent found in blood.

While I was growing up, I had many bleeds or hemorrhages in my joints which make it very painful. Twice a week I would receive injections or IV's of Factor VIII which clotted the blood and then broke it down. A bleed occurs from a broken blood vessel or vein. The blood then had nowhere to go so it would swell up in a joint. You could compare it to trying to pour a quart of milk into a pint-sized container of milk.

The first five to six years of my life were spent in and out of the hospital. All in all I led a pretty normal life. Most recently my battle has been against AIDS and the discrimination surrounding it. On December 17, 1984, I had surgery to remove two inches of my left lung due to pneumonia. After two hours of surgery the doctors told my mother I had AIDS. I contracted AIDS through my Factor VIII which is made from blood. When I came out of surgery, I was on a respirator and had a tube in my left lung. I spent Christmas and the next thirty days in the hospital. A lot of my time was spent searching, thinking and planning my life.

I came face to face with death at thirteen years old. I was diagnosed with AIDS: a killer. Doctors told me I'm not contagious. Given six months to live and being the fighter that I am, I set high goals for myself. It was my decision to live a normal life, go to school, be with my friends, and enjoying day to day activities. It was not going to be easy.

The school I was going to said they had no guidelines for a person with AIDS. The school board, my teachers, and my principal voted to keep me out of the classroom even after the guidelines were set by the I.S.B.H., for fear of someone getting AIDS from me by casual contact. Rumors of sneezing, kissing, tears, sweat, and saliva spreading AIDS caused people to panic.

We began a series of court battles for nine months, while I was attending classes by telephone. Eventually, I won the right to attend school, but the prejudice was still there. Listening to medical facts was not enough. People wanted one hundred percent guarantees. There are no one hundred percent guarantees in life, but concessions were made by Mom and me to help ease the fear. We decided to meet them halfway:

- Separate restrooms
- No gym
- Separate drinking fountains
- Disposable eating utensils and trays

Even though we knew AIDS was not spread through casual contact. Nevertheless, parents of twenty students started their own school. They were still not convinced. Because of the lack of education on AIDS, discrimination, fear, panic, and lies surrounded me:

- I became the target of Ryan White jokes

- Lies about me biting people
- Spitting on vegetables and cookies
- Urinating on bathroom walls
- Some restaurants threw away my dishes
- My school locker was vandalized inside and folders were marked FAG and other obscenities

I was labeled a troublemaker, my mom an unfit mother, and I was not welcome anywhere. People would get up and leave so they would not have to sit anywhere near me. Even at church, people would not shake my hand.

This brought on the news media, TV crews, interviews, and numerous public appearances. I became known as the AIDS boy. I received thousands of letters of support from all around the world, all because I wanted to go to school. Mayor Koch, of New York, was the first public figure to give me support. Entertainers, athletes, and stars started giving me support. I met some of the greatest like Elton John, Greg Louganis, Max Headroom, Alyssa Milano (my teen idol), Lyndon King (Los Angeles Raiders), and Charlie Sheen. All of these plus many more became my friends, but I had very few friends at school. How could these people in the public eye not be afraid of me, but my whole town was?

It was difficult, at times, to handle; but I tried to ignore the injustice, because I knew the people were wrong. My family and I held no hatred for those people because we realized they were victims of their own ignorance. We had great faith that with patience, understanding, and education, that my family and I could be helpful in changing their minds and attitudes around. Financial hardships were rough on us, even though Mom had a good job at G.M. The more I was sick, the more work she had to miss. Bills became impossible to pay. My sister, Andrea, was a championship roller skater who had to sacrifice too. There was no money for her lessons and travel. AIDS can destroy a family if you let it, but luckily for my sister and me, Mom taught us to keep going. Don't give up, be proud of who you are, and never feel sorry for yourself.

After two and a half years of declining health, two attacks of pneumocystis, shingles, a rare form of whooping cough, and liver problems, I faced fighting chills, fevers, coughing, tiredness, and vomiting. I was very ill and being tutored at home. The desire to move into a bigger house, to avoid living AIDS daily, and a dream to be accepted by a community and school, became possible and a reality with a movie about my life, *The Ryan White Story*.

My life is better now. At the end of the school year (1986-87), my family and I decided to move to Cicero, Indiana. We did a lot of hoping and praying that the community would welcome us, and they did. For the first time in three years, we feel we have a home, a supportive school, and lots of friends. The communities of Cicero, Atlanta, Arcadia, and Noblesville, Indiana, are now what we call "home." I'm feeling great. I am a normal happy teenager again. I have a learner's permit. I attend sports functions and dances. My studies are important to me. I made the honor roll just recently, with 2 A's and 2 B's. I'm just one of the kids, and all because the students at Hamilton Heights High School listened to the facts, educated their parents and themselves, and believed in me.

I believe in myself as I look forward to graduating from Hamilton Heights High School in 1991.

Hamilton Heights High School is proof that AIDS EDUCATION in schools works.