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Ryan Wayne White (December 6, 1971 – April 8, 1990)^[1] was an American teenager from Kokomo, Indiana, who became a national poster child for HIV/AIDS in the United States after being expelled from middle school because of his infection. As a hemophiliac, he became infected with HIV from a contaminated blood treatment and, when diagnosed in December 1984, was given six months to live. Doctors said he posed no risk to other students, but AIDS was poorly understood at the time. When White tried to return to school, many parents and teachers in Kokomo rallied against his attendance due to concerns of the disease spreading through bodily fluid transfer. Western School was actually located in Russiaville outside of Kokomo and was not part of the local Kokomo school system. [2] A lengthy legal battle with the school system ensued, and media coverage of the case made White into a national celebrity and spokesman for AIDS research and public education. Surprising his doctors, White lived five years longer than predicted but died in April 1990, one month before his high school graduation.

Before White, AIDS was a disease widely associated with the male gay community, because it was first diagnosed among gay men. That perception shifted as White and other prominent HIV-infected people such as Magic Johnson, Arthur Ashe, the Ray brothers, and Kimberly Bergalis appeared in the media to advocate for more AIDS research and public education to address the epidemic. The U.S. Congress passed a major piece of AIDS legislation, the Ryan White Care Act, shortly after

Ryan White



White in 1989

Born December 6, 1971

Kokomo, Indiana, United States

Died April 8, 1990 (aged 18)

Indianapolis, Indiana, United States

Cause of Complications from AIDS

death

Occupation Student

Parent(s)

Jeanne Elaine Hale (mother)

Hubert Wayne White (father)

Website ryanwhite.com

(http://ryanwhite.com)

White's death. The Act has been reauthorized twice; Ryan White Programs are the largest provider of services for people living with HIV/AIDS in the United States.

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Early life and illness

Ryan White was born at St. Joseph Memorial Hospital in Kokomo, Indiana, to Jeanne Elaine Hale and Hubert Wayne White. When he was circumcised, the bleeding would not stop.^[3] When he was three days old,^[4] doctors diagnosed him with severe hemophilia A, a hereditary blood coagulation disorder associated with the X chromosome, which causes even minor injuries to result in severe bleeding. For treatment, he received weekly transfusions of Factor VIII, a blood product created from pooled plasma of non-hemophiliacs, an increasingly common treatment for hemophiliacs at the time.^[5]

Healthy for most of his childhood, he became extremely ill with pneumonia in December 1984. On December 17, 1984, during a partial-lung removal procedure, White was diagnosed with AIDS. The scientific community knew little about AIDS at the time: scientists had only realized earlier that year that HTLV-III, now called HIV, was the cause of AIDS. White had apparently received a contaminated treatment of Factor VIII that was infected with HTLV-III, although exactly when he was infected remains unknown to this day. At that time, because the retrovirus that causes AIDS had been recently identified, much of the pooled factor VIII concentrate supply in hospitals was tainted because doctors did not know how to test for the disease, and donors often did not know they were infected or that blood was a factor in the transmission of the virus. Among hemophiliacs treated with blood-clotting factors between 1979 and 1984, nearly 90% became infected with HIV.^[5] At the time of his diagnosis, his T-cell count had dropped to 25 (a healthy individual without HIV will have around 500–1200). Doctors predicted White had only six months to live.^[4]

After the diagnosis, White was too ill to return to school, but by early 1985 he began to feel better. His mother asked if he could return to school, but was told by school officials that he could not. On June 30, 1985, a formal request to permit re-admittance to school was denied by Western School Corporation superintendent James O. Smith, sparking a legal battle that lasted for eight months. ^[6]

Battle with schools

Timeline of legal battle

Western Middle School in Russiaville faced enormous pressure from many parents and faculty to ban White from the campus after his diagnosis became widely known. 117 parents (from a school of 360 total students) and 50 teachers signed a petition encouraging school leaders to ban White from school. Due to the widespread fear and ignorance of AIDS, the principal and later the school board succumbed to this pressure and banned White. The White family filed a lawsuit seeking to overturn the ban. The Whites initially filed suit in the U.S. District Court in Indianapolis. The court, however, declined to hear the case until administrative appeals had been resolved.^[20] On November 25, an Indiana Department of Education officer ruled that the school must follow the Indiana Board of Health guidelines and that White must be allowed to attend school. [21]

The ways in which HIV spread were not fully understood in the 1980s. Scientists knew it spread via blood and was not transmittable by any sort of casual contact, but as recently as 1983, the American Medical Association had thought that "Evidence Suggests Household Contact May Transmit AIDS", and the belief that the disease could easily spread persisted.^[22] Children with AIDS were still rare: at the time of White's rejection from school, the Centers for Disease Control knew of only 148 cases of pediatric AIDS in the United States.^[7] Many families in Kokomo believed his presence posed an unacceptable risk. [23] When White was permitted to return to school for one day in February 1986, 151 of 360 students stayed home. He also worked as a paperboy, and many of the people on his route canceled their subscriptions, believing that HIV could be transmitted through newsprint. [6]

The Indiana state health commissioner, Dr. Woodrow Myers, who had extensive experience treating AIDS patients in San Francisco, and the Centers for Disease Control both notified the board that White posed no risk to other students, but the school board and many parents ignored their statements. [6] In February 1986, the *New England Journal of Medicine* published a study of 101

1985–86 school year

- June 30 Superintendent James O. Smith denies White admittance to school.^[7]
- Aug. 26 First day of school. White is allowed to listen to his classes via telephone.^[8]
- Oct. 2 School principal upholds decision to prohibit White.^[9]
- Nov. 25 Indiana Department of Education rules that White must be admitted.^[10]
- Dec. 17 The school board votes 7–0 to appeal the ruling.^[11]
- Feb. 6 Indiana DOE again rules White can attend school, after inspection by Howard County health officers.^[12]
- Feb. 13 Howard County health officer determines
 White is fit for school. [13]
- Feb. 19 Howard County judge refuses to issue an injunction against White.^[14]
- Feb. 21 White returns to school. A different judge grants a restraining order that afternoon to again bar him. [15]
- Mar. 2 White's opponents hold an auction in the school gymnasium to raise money to keep White out.^[16]
- April 9 White's case is presented in Circuit Court.^[17]
- April 10 Circuit Court Judge Jack R. O'Neill dissolves restraining order. Ryan returns to school. [18]
- July 18 Indiana Court of Appeals declines to hear any further appeals.^[19]

people who had spent three months living in close but non-sexual contact with people with AIDS. The study concluded that the risk of infection was "minimal to nonexistent," even when contact included sharing toothbrushes, razors, clothing, combs and drinking glasses; sleeping in the same bed; and hugging and kissing.^[24]

When White was finally readmitted in April, a group of families withdrew their children and started an alternative school. [25] Threats of violence and lawsuits persisted. According to White's mother, people on the street would often yell, "we know you're queer" at Ryan. [23] The editors and publishers of the *Kokomo Tribune*, which supported White both editorially and financially, were also ridiculed by members of the community and threatened with death for their actions. [23] Others felt such actions were both hypocritical and contradictory: those hostile implied that Ryan was likely a homosexual to have contracted HIV, but also maintained that HIV could be transmitted by casual contact.

White attended Western Middle School for eighth grade for the entire 1986–87 school year, but was deeply unhappy and had few friends. The school required him to eat with disposable utensils, use separate bathrooms, and waived his requirement to enroll in a gym class.^[26] Threats continued. When a bullet was fired through the Whites' living room window (no one was home at the time), the family decided to leave Kokomo.^[4] After finishing the school year, his family moved to Cicero, Indiana, where White enrolled at Hamilton Heights High School. On August 31, 1987, a "very nervous" White was greeted by school principal Tony Cook, school system superintendent Bob G. Carnal, and a handful of students who had been educated about AIDS and were unafraid to shake White's hand.^[27]

National spokesman

The publicity of White's trial catapulted him into the national spotlight, amidst a growing wave of AIDS coverage in the news media. Between 1985 and 1987, the number of news stories about AIDS in the American media doubled. [28] While isolated in middle school, White appeared frequently on national television and in newspapers to discuss his tribulations with the disease. Eventually he became known as a poster child for the AIDS crisis, appearing in fundraising and educational campaigns for the syndrome. White participated in numerous public benefits for children with AIDS. Many celebrities appeared with White, starting during his trial and continuing for the rest of his life, to help publicly destignatize socializing with people with AIDS. Singers John Cougar Mellencamp, Elton John and Michael Jackson, actor Matt Frewer, diver Greg Louganis, President Ronald Reagan and Nancy Reagan, Surgeon General Dr. C. Everett Koop, Indiana University basketball coach Bobby Knight and basketball player Kareem Abdul-Jabbar all befriended White. He also was a friend to many children with AIDS or other potentially debilitating conditions. [4]

For the rest of his life he appeared frequently on Phil Donahue's talk show. His celebrity crush, Alyssa Milano of the then-popular TV show *Who's the Boss?*, met White and gave him a friendship bracelet and a kiss.^[4] Elton John loaned Jeanne White \$16,500 to put toward a down payment on the Cicero home, and rather than accept repayment, placed the repaid money into a college fund for Ryan's sister.^[29] In high school White drove a red Mustang convertible, a gift from Michael Jackson.^[2] Despite the fame and donations, White stated that he disliked the public spotlight, loathed remarks that seemingly blamed his mother or his upbringing for his illness, and emphasized that he would be willing at any moment to trade his fame for freedom from the disease.^[2]

In 1988, White spoke before the President's Commission on the HIV Epidemic. White told the commission of the discrimination he had faced when he first tried to return to school, but how education



Wikisource has the speech Ryan gave before the commission:

White's speech

about the disease had made him welcome in the town of Cicero. White emphasized his differing experiences in Kokomo and Cicero as an example of the power and importance of AIDS education. [26]

In 1989, ABC aired the television movie *The Ryan White Story*, starring Lukas Haas as Ryan, Judith Light as Jeanne and Nikki Cox as his sister Andrea. White had a small cameo appearance in the film, playing a boy also suffering from HIV who befriends Haas. Others in the film included Sarah Jessica Parker as a sympathetic nurse, George Dzundza as his doctor, and George C. Scott as White's attorney, who legally argued against school board authorities.^[30] Nielsen estimated that the movie was seen by 15 million viewers.^[31] Some residents of Kokomo felt that the movie portrayed their entire town in an unfairly negative light. After the film aired, the office of Kokomo mayor Robert F. Sargent was flooded with complaints from across the country, although Sargent had not been elected to the office during the time of the controversy.^{[30][31]}

By early 1990, White's health was deteriorating rapidly. In his final public appearance, he hosted an after-Oscars party with former president Ronald Reagan and first lady Nancy Reagan in California. [32] Although his health was deteriorating, White spoke to the Reagans about his date to the prom and his hopes of attending college. [33]

Death

On March 29, 1990, White entered Riley Hospital for Children in Indianapolis with a respiratory infection. As his condition deteriorated, he was placed on a ventilator and sedated. He was visited by Elton John and the hospital was deluged with calls from well-wishers. White died on April 8, 1990.^[2]

Over 1,500 people attended White's funeral on April 11, a standing-room only event held at the Second Presbyterian Church on Meridian Street in Indianapolis.^[32] White's pallbearers included Elton John, football star Howie Long and Phil Donahue.

"We owe it to Ryan to make sure that the fear and ignorance that chased him from his home and his school will be eliminated. We owe it to Ryan to open our hearts and our minds to those with AIDS. We owe it to Ryan to be compassionate, caring and tolerant toward those with AIDS, their families and friends. It's the disease that's frightening, not the people who have it."

—Former U.S. President Ronald Reagan, April 11, 1990^[33]

Elton John performed "Skyline Pigeon" at the funeral. The funeral was also attended by Michael Jackson and First Lady Barbara Bush. On the day of the funeral, former President Ronald Reagan wrote a tribute to White that appeared in *The Washington Post*.^{[32][33]} Reagan's statement about AIDS and White's funeral were seen as indicators of how greatly White had helped change perceptions of AIDS.^[32]

White is buried in Cicero, close to the home of his mother. In the year following his death, his grave was vandalized on four occasions.^[34] As time passed, White's grave became a shrine for his admirers.^[35]

Legacy

White was one of a handful of highly visible people with AIDS in the 1980s and early 1990s who helped change the public perception of the disease. White, along with actor Rock Hudson, was one of the earliest public faces of AIDS. Along with later public figures who became associated with HIV/AIDS, such as the

Ray brothers, Magic Johnson, Arthur Ashe, The Brady Bunch's Robert Reed, Tim Richmond, Kimberly Bergalis, Elizabeth Glaser, Liberace and Freddie Mercury, White helped to increase public awareness that HIV/AIDS was a significant epidemic.^[28]

Numerous charities formed around White's death. The Indiana University Dance Marathon, started in 1991, raises money for the Riley Hospital for Children. Between 1991 and 2013, this event helped raise over \$16 million for children at Riley. The money raised has also helped found the Ryan White Infectious Disease Clinic at the hospital to take care of the nation's sickest children. White's personal physician, with whom he was close friends, Dr. Martin Kleiman, became the Ryan White Professor of Pediatrics at Indiana University School of Medicine in Indianapolis. In a 1993 interview, prominent gay rights and AIDS activist Larry Kramer said, "I think little Ryan White probably did more to change the face of this illness and to move people than anyone. And he continues to be a presence through his mom, Jeanne White. She has an incredibly moving presence as she speaks around the world." [37]

In 1992, White's mother founded the national nonprofit Ryan White Foundation. The foundation worked to increase awareness of HIV/AIDS-related issues, with a focus on hemophiliacs like Ryan White, and on families caring for relatives with the disease. The foundation was active throughout the 1990s, with donations reaching \$300,000 a year in 1997. Between 1997 and 2000, however, AIDS donations declined nationwide by 21%, and the Ryan White Foundation saw its donation level drop to \$100,000 a year. In 2000, White's mother closed the foundation, and merged its remaining assets with AIDS Action, a larger charity. She became a spokeswoman for AIDS activism and continues to arrange speaking events through the site devoted to her son, ryanwhite.com (http://ryanwhite.com/). White's high school, Hamilton Heights, has had a student-government sponsored annual Aids Walk, with proceeds going to a Ryan White Scholarship Fund.

White's death inspired Elton John to create the Elton John AIDS Foundation. White also became the inspiration for a handful of popular songs. Elton John donated proceeds from "The Last Song," which appears on his album *The One*, to a Ryan White fund at Riley Hospital. Michael Jackson dedicated the song "Gone Too Soon" from his *Dangerous* album to White, as did 1980s pop star Tiffany with the song "Here in My Heart" on her *New Inside* album. In November 2007, The Children's Museum of Indianapolis opened an exhibit called "The Power of Children: Making a Difference," which remains a sobering, featured exhibit and continues to develop, while it features White's bedroom and belongings alongside similar tributes to Anne Frank and Ruby Bridges.

Ryan White and public perception of AIDS

In the early 1980s, AIDS was known as gay-related immune deficiency, because the disease had first been identified among primarily homosexual communities in New York City and San Francisco. At the start of the HIV/AIDS epidemic in the United States, the disease was thought to be a "homosexual problem" and was largely ignored by policy makers.^[22] White's diagnosis demonstrated to many that AIDS was not exclusive to LGBT, minority, and poor people. In his advocacy for AIDS research, White always rejected any criticism of homosexuality, although not gay himself.

White was seen by some as an "innocent victim" of the AIDS epidemic.^[38] White and his family strongly rejected the language of "innocent victim" because the phrase was often used to imply that gays with AIDS were "guilty". White's mother told *The New York Times*,

Ryan always said, 'I'm just like everyone else with AIDS, no matter how I got it.' And he would never have lived as long as he did without the gay community. The people we knew in New York made sure we knew about the latest treatments way before we would have known in Indiana. I hear mothers today say they're not gonna work with no gay community on anything. Well, if it comes to your son's life, you better start changing your heart and your attitude around. [38]

Ryan White Care Act

In August 1990, four months after White's death, Congress enacted The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (often known simply as the Ryan White Care Act), in his honor. The act is the United States' largest federally funded program for people living with HIV/AIDS. The Ryan White Care Act funds programs to improve availability of care for low-income, uninsured and under-insured victims of AIDS and their families.^[45]

Ryan White programs are "payers of last resort," which subsidize treatment when no other resources are available. The act was reauthorized in 1996, 2000, 2006 and 2009 and remains an active piece of legislation today. The program provides some level of care



President Obama signs the Ryan White HIV/AIDS Treatment Extension Act of 2009.

for around 500,000 people a year and, in 2004, provided funds to 2,567 organizations. The Ryan White programs also provide funding and technical assistance to local and state primary medical care providers, support services, healthcare provider and training programs.^{[45][46]}

The Ryan White Act was set to expire on September 30, 2009, although efforts began to obtain an extension to the act.^[47] The Ryan White HIV/AIDS Treatment Extension Act of 2009 was signed on October 30, 2009 by President Barack Obama, who announced that implementation was progressing on repeal of the ban on travel and immigration to the U.S. by individuals with HIV that had been passed by Congress.

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External links

- Ryan White (http://www.ryanwhite.com/)
- Indiana Dance Marathon (http://www.iudm.org/about/history.php)
- Ryan White interview 1986 (http://www.history.com/videos/history-uncut-ryan-white-1986)
- Photos and essay by photographer Taro Yamasaki, who documented White's life (http://www.digitaljournalist.org/issue0106/visions_yamasaki1.htm)
- Ryan White (http://www.findagrave.com/cgi-bin/fg.cgi?page=gr&GRid=1612) at Find A Grave

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Categories: 1971 births | 1990 deaths | AIDS-related deaths in Indiana | American child activists | American health activists | Burials in Indiana | HIV/AIDS activists | People from Indianapolis, Indiana | People from Kokomo, Indiana | Recipients of contaminated haemophilia blood products | History of HIV/AIDS

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