

= Ryan White =

Ryan Wayne White (December 6 , 1971 ? April 8 , 1990) 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 . A lengthy legal battle with the school system ensued , and news of the court case turned White into a popular celebrity and advocate 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 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 .

= = 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 . When he was three days old , 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 .

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 . 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 .

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 .

= = Battle with schools = =

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 . 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 .

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 . 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 . Many families in Kokomo believed his presence posed an unacceptable risk . 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 .

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 . In February 1986 , the New England Journal of Medicine published a study of 101 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 .

When White was finally readmitted in April , a group of families withdrew their children and started an alternative school . 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 . 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 .

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 . 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 . After finishing the school year , his family moved to Cicero , Indiana , where White enrolled at Hamilton Heights High School , located in Arcadia , Indiana . 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 .

= = 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 . 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 destigmatize 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 , businessman Donald Trump (

who also paid for White 's medical expenses) , 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 .

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 . 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 . In high school White drove a red Mustang convertible , a gift from Michael Jackson . 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 .

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 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 .

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 . Nielsen estimated that the movie was seen by 15 million viewers . 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 .

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 . Although his health was deteriorating , White spoke to the Reagans about his date to the prom and his hopes of attending college .

= = 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 .

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 . White 's pallbearers included Elton John , football star Howie Long and Phil Donahue . 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 . Reagan 's statement about AIDS and White 's funeral were seen as indicators of how greatly White had helped change perceptions of AIDS .

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 . As time passed , White 's grave became a shrine for his admirers .

= = 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 .

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 . "

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. 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 . 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 . 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 .

= = = 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 .

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 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 .

The Ryan White CARE Act was set to expire on September 30 , 2009 , although efforts began to obtain an extension to the act . 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 .