

“When I Die, Please Don’t Bury Me in Kokomo”:

Ryan White’s Contribution to the History of AIDS in the United States

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In 1985, news from a small town in central Indiana brought a young boy into the international spotlight. A young boy, Ryan White, had contracted AIDS, an unfamiliar disease in the United States at the time which carried negative and fearful connotations. Unbeknownst to the people of Kokomo, Ryan's hometown, the ways in which they reacted to the news and perceived the boy would play a role in how AIDS was viewed by the public, and how it was treated in social settings. The timeframe and geographical location, in combination with the demographics of the people involved, proved to form the ideal context for this controversy to evolve into a story that would impact lives for generations in ever-changing ways.

This research further develops the existing body of work regarding HIV and AIDS in the United States in four primary ways. First, I argue that Ryan White's primary contribution to the HIV/AIDS epidemic helped the reluctant United States government publicly acknowledge the crisis for the first time by providing what they perceived to be an acceptable face of the disease. In doing so, he aided people locally and nationally in overcoming stigmas and ignorance surrounding the disease. Secondly, I demonstrate that Ryan White's presence in the Western School Corporation led state and local nurses and medical officials to pioneer medical best practices for HIV and AIDS that were universally implemented nationally and worldwide and remain so presently. My third addition to existing research is that Ryan White's influence as a spokesperson for the disease led to the passage of national legislation for victims of the HIV/AIDS crisis that provides relief for countless patients to this day. Fourth and finally, my contribution to these existing histories addresses how the ideologies during the time of Ryan's diagnosis have evolved over time. My work uses Ryan White as a case study of one of the first and most notable AIDS cases that changed how the public viewed the disease as well as the struggles that he encountered as a pioneer of the shifting ideology. Additionally, my work

exemplifies that more research, resources, and money are dedicated to curing diseases that afflict children.

In order to understand Ryan White's story and his rise to prominence in the eyes of the national and international communities, one must first examine the history of the HIV/AIDS epidemic in the United States, and the perceptions of children with diseases. While there are many factors that add complexity to the history of this particular case many histories to consider when determining why the public viewed Ryan White in the manner they did, HIV/AIDS and childhood disease are by far the most important.

The AIDS virus was initially identified in 1980 by a team of French and American scientists. There are conflicting arguments about when and where the virus first originated and how it was transferred to humans; however, the first confirmed case of HIV was eventually traced back to a male patient in 1959 in the Democratic Republic of the Congo.¹ Upon its initial discovery, it was viewed by the public, historians, and scientists as a homosexual disease. In fact, before being referred to as AIDS, or auto-immune deficiency syndrome, it was commonly known as GRID or gay-related immune deficiency.² This label and the perception it implied remained in place for years, and was not officially called AIDS until 1982.³ Many government officials and leading scientists pushed this narrative of the disease in order to avoid researching, curing, or addressing the issue whatsoever. Additionally, President Ronald Reagan's win in the 1980 election cemented a widespread shift in political ideology in the United States. This shift changed the public mindset to one that reflected prominent conservative beliefs, with strongly

¹ "A Timeline of HIV and AIDS." HIV.gov. March 12, 2019. <https://www.hiv.gov/hiv-basics/overview/history/hiv-and-aids-timeline>.

² Altman, Lawrence K. "New Homosexual Disorder Worries Health Officials." The New York Times. May 11, 1982.

³

rooted religious ideals.⁴ Therefore, the lifestyles of homosexuals and drug users, two of the main groups who were most severely affected by the disease were heavily criticized by the religious conservative Reagan Administration and its vast array of supporters as amoral. The general public viewed these people as sinful and in violation of the strong moral and/or religious ideologies of the new political majority resulting in inaction.⁵

In one of the earliest books published about the epidemic, *And the Band Played On* by Randy Shilts, he argues that the way in which the government failed to confront the disease, particularly because of the negative connotations surrounding its victims, led to the massive spread of the disease and the enormous loss of life that accompanied it. He also argued that for any action to be taken on the matter, it required a more innocently perceived victim, such as Ryan White or other young, white, and religiously and legally upright men to be diagnosed with the disease.⁶ However, it was this dangerous mentality that led to those victims contracting the disease. By the time the Reagan administration as well as the Center for Disease Control and Prevention, or the CDC, took action on informing the public of what recent research had discovered about the disease, 25,000 Americans, both within and outside of the gay community had already died of AIDS-related causes.^{7, 8}

⁴ Fisher, Marc. "GOP Platform through the Years Shows Party's Shift from Moderate to Conservative." The Washington Post. August 28, 2012.

⁵ American Psychological Association.

⁶ *And the Band Played On*. Directed by Roger Spottiswoode. Performed by Matthew Modine, Richard Gere, Phil Collins. United States: HBO; NBC, 1993. TV.

⁷ Ibid.

⁸ According to the CDC definition, the key difference between HIV and AIDS is that HIV is a virus while AIDS is a condition. Therefore, those infected with HIV, or human immunodeficiency virus, may or may not develop into AIDS, depending on the progression of the disease and the treatments that are administered to contain the virus. ["HIV vs. AIDS: What's the Difference?" Healthline.]

The failure by government officials and national organizations to address the disease factored into the initial infections of people during the early spread of AIDS.⁹ Blood banks were not required to test blood for HIV and AIDS until 1985, the year that Ryan White was diagnosed. At that time, estimates suggested that around 28,000 patients had already received AIDS-tainted blood.¹⁰ Since hemophiliacs are one of the largest populations to receive regular blood transfusions, they were severely impacted by this. At one point in time, it was said that around eighty-five percent of hemophiliacs were positive for HIV or AIDS.^{11, 12}

My research provides support for Shilts' argument as it highlights how Ryan White was the "poster child" of the AIDS epidemic because he was the opposite of the stereotypes and he generated a large increase in support from the general public. Additionally, my work argues that action was taken by the federal government shortly after Ryan White's diagnosis because of his personal demographics. He was a straight, white child who fit the conservative standards of purity, innocence, and moral/religious ideals, warranting further action to be taken by these political actors.

The history of children with diseases is arguably more complex than initially understood. As the public generally views childhood diseases with more compassion, raising funds and awareness through programs such as the March of Dimes, Riley Dance Marathon, or St. Jude's pop tab collection for the Ronald McDonald House. AIDS serves as one of the most severe examples of this phenomenon. Throughout history, people have been more sympathetic to

⁹ Randy Shilts, *And the Band Played on: Politics, People, and the AIDS Epidemic*, (New York City, St. Martin's Press, 1984).

¹⁰ Ibid, Spottiswoode.

¹¹ Ibid.

¹² As of May 1988, the CDC reported that 652 hemophiliacs in the U.S. had developed AIDS and 386 had died of AIDS-related causes. Additionally, an unknown amount of others carried HIV that could develop into AIDS or be passed to someone else. [Kolata, Gina. "Hemophilia and AIDS: Silent Suffering." *The New York Times*. May 16, 1988. Accessed April 18, 2019. <https://www.nytimes.com/1988/05/16/us/hemophilia-and-aids-silent-suffering.html>.]

children with diseases than any other population. When children were diagnosed with diseases like cancer, people tended to raise awareness, funds, and conduct research. However, these efforts pale in comparison to the reactions to the AIDS epidemic. In 2020, many people share a concern for and have become more aware of pediatric cancer, however, they are also aware and concerned about adult cancer. Despite their dedication to fighting the disease, only four percent of federal cancer research goes toward pediatric cancer.¹³ Alternatively, when children began to acquire AIDS, it sparked the first instance of the United States government publicly acknowledging the disease.

Ryan White was born on December 6, 1971, in Kokomo, Indiana. Shortly after his birth, he was given a routine circumcision, however, the doctors were unable to stop the bleeding during the procedure. After a substantial amount of time Dr. Donald Fields, one of the doctors that helped deliver Ryan recommended that he be sent to a nearby hospital as he suspected that the excessive bleeding could have been the result of severe hemophilia.¹⁴ Hemophilia is a hereditary disease in which patients' blood lacks certain proteins that allow blood to clot so that bleeding stops.¹⁵ People with severe hemophilia are unable to stop bleeding and, for example, if a severe hemophiliac were to bump their arm, blood would pool in the area, potentially causing joint damage and limiting their range of motion, leading to severe pain and discomfort in patients. This phenomenon is referred to simply as a "bleed".¹⁶

The protein that is responsible for blood clotting is called Factor VIII. In 1965, Dr. Judith Graham Pool discovered that a powdered version of this protein could be made from extracting it

¹³ "Facts About Childhood Cancer." National Pediatric Cancer Foundation.

¹⁴ Dr. Donald Fields Interviewed by Judy Lausch. Ryan White Oral History Project, Howard County Historical Society. June 6, 2011. 7.

¹⁵ "What Is Hemophilia | CDC." Centers for Disease Control and Prevention.

¹⁶ White, Ryan, and Ann Marie. Cunningham. *Ryan White, My Own Story*. New York: Penguin Books, 1992.

from the blood of donors and that it could be transfused into hemophiliac blood to diminish bleeding and reverse symptoms of bleeds. As aforementioned, the creation of this Factor required the blood from a large number of donors. Therefore, if even one of those donors tested positive for HIV, the entire Factor would be contaminated and the recipients of the tainted transfusion would be infected with the virus. Since severe hemophiliacs receive countless transfusions throughout their life and each of the transfusions required several donors, the chance they acquire HIV is extraordinarily high compared to non-hemophiliacs. This also makes it impossible to determine when Ryan was infected and by whom. However, estimates place his infection around 1980 as untreated HIV typically transforms into full-blown AIDS within approximately five years.

As further advancements in HIV/AIDS research have brought new technological and medical practices to light, social perceptions of the virus and disease have evolved. From 2009 to 2014 the Howard County Historical Society in Kokomo attempted to highlight the changes that occurred in the twenty-five to thirty-year period since Ryan White's experience with AIDS. Through a series of interviews with members of the Kokomo and Russiaville communities that interacted with Ryan in a variety of ways, this project chronicles the evolution of public opinion of the HIV/AIDS epidemic in one of the most controversial areas of the disease's history.

Ryan White was diagnosed with AIDS on December 17, 1984, shortly after his thirteenth birthday.¹⁷ After exhibiting flu-like symptoms the day after his birthday, December 7, he visited his pediatrician, Dr. Donald Fields. Dr. Fields said in his interview that, "[he] was suspicious of the disease that occurred in people that had AIDS, called pneumocystis carinii." He had heard that hemophiliacs were contracting HIV from blood transfusion of contaminated Factor VIII

¹⁷ "Who Was Ryan White?" HRSA. October 01, 2016.

which Dr. Field knew Ryan had been receiving since birth. This quote shows that when he recognized symptoms of pneumonia he was immediately concerned about the still nameless disease at the time that would eventually be called AIDS.^{18, 19} Dr. Fields ordered Ryan to be admitted to James Whitcomb Riley Children's Hospital²⁰ in Indianapolis where they performed a biopsy on his lung to test for AIDS, the only test available at the time. However, this was an extraordinarily high-risk procedure as performing invasive surgeries on severe hemophiliacs for any reason requires extreme caution to prevent bleed outs and significant amounts of blood and Factor to replenish what is lost and cease its flow.²¹

When the results of this test came back positive, most doctors were in a state of disbelief. Interviewer Judy Lausch stated in her interview with Dr. Fields that, “. . . it took a while to come up with the diagnosis itself . . . they didn't have much experience with [AIDS] in Indianapolis . . .” to which Dr. Fields responded, “Zero. In children, zero. In the United States it was zero, just about.”²² While it is likely that Ryan was not the first child in the United States to contract HIV or be diagnosed with AIDS, this interaction proves how rare it was even in one of the largest cities in the country. This made Dr. Fields and the doctors at Riley very reluctant to relay the news on to Ryan's mother, Jeanne. Dr. Fields recounts his hesitation by saying, “When I sent him down, I was really reluctant to talk to Jeanne about [his suspicions] because I knew that there'd be a big ado from here if I suggested he had AIDS at that time. So I didn't mention AIDS at that

¹⁸ Ibid. Lausch, Fields. 10.

¹⁹ At the time HIV was more commonly known as human T-cell lymphotropic virus-type III/lymphadenopathy-associated virus or HTLV-III/LAV by the scientific community or gay related immune deficiency or GRID by the public. The disease did not receive the official name of autoimmune deficiency syndrome or AIDS until late 1982, only two years before Ryan's diagnosis and the term was not picked up by the public until around 1985 when the Reagan Administration gave its first public statement on the disease. ["Where Did HIV Come From?" Where Did HIV Come From? | The AIDS Institute.]

²⁰ Hereafter referred to as “Riley”

²¹ Ibid. White, Cunningham.

²² Ibid. Lausch, Fields. 11.

time. They took a week or two before they mentioned AIDS after he got there.”²³ After the two weeks ended and doctors felt more confident in the diagnosis they informed his mother. She recalled her own disbelief by describing a comment she made to one of Ryan’s teachers, ““Well they said he has AIDS [but] I think they’re going to find out it’s something else.”” She also recalled praying for the diagnosis to be wrong saying, ““Lord, please, please, please, please, please, have this not be AIDS. Have this be something else.’ So, we kind of felt like maybe it could be something else and they’re going to find out later.”²⁴ Her reaction was very similar to that of the doctors. She waited a few weeks before finally coming to terms that the diagnosis was very likely correct. She realized that she now had an even more difficult task, breaking the news to Ryan.

She remembered the night around Christmas Day of 1984 when she approached Ryan and said, ““Ryan, you know you have been really sick.’ And he said, ‘Yes.’ And I said, ‘Well, they say you have AIDS.” He said, ‘Am I gonna die?’ And I said, ‘We’re all gonna die someday, Ryan, we just don’t know when.’ He goes, ‘Let’s just pretend I don’t have it.’”²⁵ This heartbreaking interaction shows how difficult it was for everyone to come to terms with the reality of this horrifying disease. At this time Ryan was given only six months to live and was in poor condition. The thought of going back to school was not at the forefront of anyone’s mind and, therefore, no one was making preparations or considering the logistics of what Ryan going back to school would look like. However, by February of 1985, about two months after his initial diagnosis, his condition had rehabilitated tremendously and when his health improved, he was

²³ Ibid. Lausch, Fields. 11.

²⁴ Jeanne White Ginder Interviewed by Allen Safianow. Ryan White Oral History Project, Howard County Historical Society, October 28, 2014.

²⁵ Ibid. Safianow, White Ginder. 14.

eager to return to his normal life as a teenager. One of the first questions he asked his mother was if he could return to school.

While Ryan hoped for a seamless transition back to Western Middle School, he faced several obstacles to overcome before he was able to do so. As aforementioned, Ryan was one of the first children in the United States to be diagnosed with AIDS and, therefore, hardly any children were attempting to attend school with the disease. Due to the rarity of this occurrence at the time, the Western School Corporation in Russiaville, Indiana, where Ryan attended middle school acted as the pioneer of how to handle children with AIDS in an educational setting. The school nurse for Western Middle School, Beverly Ashcraft, a Public Health Nurse for the Howard County Health Department, Jeri Malone, and the County Health Officer for the Howard County Health Department, Dr. Alan Adler, worked together to create guidelines on behalf of the Western School Corporation in order for Ryan to attend school while safeguarding the health, safety, and well-being of himself and his classmates. In the words of Beverly Ashcraft, “we were just thinking about what we needed at school to protect Ryan, because his immune system was depressed, compromised. And, of course, there was also the issue of if you got AIDS, you died, so we felt like we were not only needing to plan to protect Ryan but the other students as well.”²⁶

The first obstacles that these three health officials faced were the Indiana state-mandated guidelines preventing children from attending school with infectious diseases, which AIDS was classified as at the time. During this time, information about the disease and its spread was scarce. This proved to further complicate matters for the rural Indiana towns of Kokomo and Russiaville. In the early 1980s, when the HIV/AIDS epidemic began in the United States, it disproportionately affected cities and communities with large populations of gay and bisexual

²⁶ Beverly Ashcraft Interviewed by Judy Lausch. Ryan White Oral History Project, Howard County Historical Society, January 27, 2011.

men. Cities like New York and San Francisco were most severely impacted by the epidemic.²⁷ While this is extraordinarily unfortunate, these communities were able to understand the disease much better and stayed up-to-date on recent findings new information. When almost everyone in the community was personally impacted or knew of someone who was suffering from HIV or AIDS, they tended to be much more understanding and accepting and less fearful of people who suffered from it. Therefore, the opposite was true for communities like Kokomo and Russiaville who rarely had any interaction with gay or bisexual men and thus little to no interaction with the disease. The fear of the unknown overcame many members of this school district and community and caused many to react in extreme ways and made it even more difficult for school health officials to create guidelines in order to smoothly transition Ryan into the Western school system. They relied heavily on information and advice from Dr. Martin Kleiman at Riley to inform their decisions when creating guidelines for Ryan to attend school.

Ashcraft, Malone, and Adler were working with very limited information and virtually no assistance from state health officials. Nonetheless, they attempted to educate the public as effectively as possible with the resources they had. In his interview, Dr. Adler described actions the Howard County Health Department took to inform themselves and the public on all of the information they were able to acquire about the disease. “Our Health Department spent a lot of time researching [AIDS] trying to figure out if we did return him to school, under what conditions. We felt that it was probably safe, but we had some meetings with the patrons at Western [Middle] School.”²⁸ These meetings were made possible by the cooperation and collaboration of the Western Middle School Principal at the time, Ronald Colby. Former

²⁷ *Gay Men and the History of the Ryan White HIV/AIDS Program*, Health Resources and Services Administration, 2010.

²⁸ Dr. Alan Adler Interviewed by Judy Lausch. Ryan White Oral History Project, Howard County Historical Society, March 23, 2009.

Principal Colby was a huge proponent of public forums to educate students, parents, members of the media, and other public citizens in order to curb fear and misconception.

. . . we had gone through all of this education. We've done everything we, and the public, we've had this great big meeting in the middle school gymnasium attended by four or five hundred people and kids. Every time something would come up during the fall of '85 and winter of '86, if there was something come up and the students would question whatever, we'd have a meeting right there, I'd just bring them right down to the gymnasium and we'd just confront them right there. Boom! Answer their questions, dispel their fears if we could.²⁹

Nonetheless, the school and health officials managed to overcome these obstacles and develop guidelines and safety measures that are still widely used in schools throughout the United States over thirty years later, in 2020.

Describing the invention of the universal precautions, Howard County Health Department Nurse, Jeri Malone said, “we did this ourselves; you know, we didn't copy it from anyplace . . . we formulated this. And, my understanding is, as soon as it was done . . . it was sent to hundreds of schools . . . we were on the cutting edge here, it was pretty exciting.”³⁰ In addition to the precautions, Ashcraft, Malone, and Adler created spill kits that were placed in every classroom and hallway throughout Western Middle School. “The spill kit was a plastic bag that sealed at the top, you can get at the grocery store . . . we ordered little bottles and put bleach water in [them], we had rubber gloves in [them].”³¹ They trained vast numbers of people on how to handle blood spills from AIDS patients from schools across the country to the Kokomo police department, jails, and people around the world who requested help or information. After Ryan returned to school, the Health Department continued its efforts to educate and assist people in

²⁹ Ronald Colby Interviewed by Diane Knight and Allen Safianow. Ryan White Oral History Project, Howard County Historical Society, May 24, 2011. 15.

³⁰ Jeri Malone Interviewed by Judy Lausch. Ryan White Oral History Project, Howard County Historical Society, February 9, 2011. 8.

³¹ Ibid. Lausch, Malone. 11.

Howard County and throughout the world. They started an AIDS support group in Howard County, and helped “[develop] curricula for all six school in the county that mandated and approved around HIV and AIDS and prevention and control.”³²

Despite all of these efforts and cautionary procedures, there was still tremendous push-back and controversy from the public. When Jeanne told the media of Ryan’s plans to return to school, it sparked immediate outrage. One organization, the Concerned Parents of Western School Corporation, arose shortly after the announcement of Ryan’s intentions became public knowledge. When hosts of Male Call on WWKI, a local Kokomo radio station made negative comments toward the Western School Corporation’s³³ expression of hesitation to allow Ryan to attend school. One listener and parent of two young children in the WSC, Mitzie Johnson:

Called [WKKI] and told them that, you know, as a parent, and I kind of knew J.O. Smith [WSC Superintendent], I knew the [state] board of health had advised the school board not to take on that responsibility. And so I called the radio station and I, you know, told them [Concerned Parents of WSC were] not against Ryan, it had nothing to do with the child, it’s the virus. The [state] board of health had advised the school board not to take on that legal responsibility because there was very little known about the disease at that time, and they just didn’t think that there was quite enough known about it. That it was not a good idea, wasn’t the proper choice . . . so I told them at the radio station, I said, “We want answers. We’re not trying to be mean to the child, we’re backing the school board. We just want to make sure this is the right thing to do because we can’t even get simple answers. We’re not asking complicated questions, and we just want somebody to be able to answer them.”³⁴

This was an extremely interesting look into the ideals of one side of the argument that is often ignored because of the overwhelmingly negative perceptions of members of Concerned Parents of WSC. It is also important to note that the reason Johnson emerged

³² Ibid. Lausch, Malone. 15

³³ Hereafter referred to as WSC.

³⁴ Mitzie Johnson Interviewed by Diane Knight. Ryan White Oral History Project, Howard County Historical Society, June 28, 2011. 3.

as the leader of the group and the eventual face of the opposition movement was because of the call she made to the Male Call program.

Once Johnson called into the program, the hosts began to call their own views on the issue into question. Johnson says, “So a couple of the guys at the radio station started doing the same, they started looking into it and asking questions and they got the same response [Concerned Parents of WSC] got. Basically, nobody wanted to talk about [AIDS], nobody wanted to answer any questions about it, nobody really had any answers for sure.”³⁵ While it is understandable to react with some alarm or concern to the lack of answers to questions that directly affect their children’s health, this view was somewhat narrow. Additionally, as Principal Colby alluded to in his interview, Ryan most likely contracted HIV as early as 1980 due to his diagnosis of AIDS in December of 1984. Therefore, he certainly had it in when he first enrolled in Western Middle School in the fall of that same year. This means that the same parents who were extraordinarily concerned with the health of their children had unknowingly been sending them to school with Ryan for at least four months in which no one contracted HIV or AIDS.³⁶ As Johnson acknowledges in her previous comment, not much was known about the disease or its spread at this time and therefore it was difficult for top scientists and leading medical professions to understand and present clear answers to these questions. Additionally, the people these groups were reaching out to for answers were the very health officials that refused to assist Ashcraft, Malone, Alder, and Colby who were actively seeking answers to these pressing questions. This narrative also downplays the efforts of these four members of the WSC and fails to acknowledge their hard work and

³⁵ Ibid. Knight, Johnson. 4.

³⁶ Ibid. Knight, Safianow, Colby. 19.

efforts to educate the public as best they could. Both community members in the Concerned Parents of WSC and health and school officials working for the WSC had the common interest in the well-being of all children in the school system, however, each failed to acknowledge the intentions of the opposition and why they were reacting the way they did.

In her interview, Diane Knight asked Johnson three questions that were vital to the understanding of the shift in public opinion when she said, “Some 25 years have passed since the White controversy erupted. Have your views changed over the years? Do you feel anything good had come out of this controversy? Do you feel any lessons have been learned?” to which Johnson replied:

Well, number one, I hope that we’ve all learned to protect ourselves. We know that this virus is out there. At this time, I think there are well over 8,000 people known that carried or had the virus, and now I’m sure there are well over a million. So we know it definitely can be caught, can be passed on in some ways, and that we’re responsible for protecting ourselves and our children from it. But nobody is going to protect you but you.³⁷

This comment shows how she is still skeptical of the way the situation was handled, most likely due to her feeling of dissatisfaction with the lack of answers that were available to her at the time. It shows that part of the reason that she took on the leadership role that she did was that she believed that she, her children, and the members of her community needed to be protected and that if she wanted to ensure that what she wanted to be accomplished was, she should do it herself. Her frustration with the situation most likely stemmed from the fact that despite her greatest efforts, she could not control the reality that the answers she sought were not there.

While some people, like Mitzie Johnson, are often portrayed as bullies who mistreated an innocent child, that label is far more complex than it may initially seem. However, not all of the

³⁷ Ibid. Knight, Johnson. 12-13.

opposition was as misunderstood as the Concerned Parents of WSC. While media such as the popular film, *The Ryan White Story*, exaggerated many several instances of bullying that Ryan dealt with, he did have a few negative encounters.³⁸ As Ryan's childhood neighbor and best friend's sister, Wanda Bowen Bilodeau recalled, "Ryan talked about garbage being thrown in his yard and insults tossed at him . . . there was the word 'faggot' that was spray painted [on] the side of the house or their barn, I can't recall. And then, the BB gun through their glass windows."³⁹ There were additional accounts of graffiti with homophobic slurs painted or written on Ryan's locker and school supplies. This speaks to the view of HIV/AIDS at the time and how heavily it was associated with the gay community. Children and parents accused a thirteen-year-old boy of contracting the disease sexually because they could not fathom the reality of how he became infected. Additionally, it shows the extreme homophobia that was rampant in the United States at the time that was worsened by the government's ignoring of the disease and refusing to discuss the reality due to the same ideology.

Although the controversy was extremely unfortunate, there were still several positive outcomes that resulted from it. "What happened was infection control, effective disposal of needles, universal precautions"⁴⁰ were tremendous feats in modern disease control and prevention. Additionally, as the lawyer who represented the Concerned Parents of WSC, David Rosselot recalled:

When Ryan White passed away, his funeral was held in Indianapolis. Me and Marcia said, 'Should we go to this?' And there was, I think maybe we started to go and then turned around and not to go to his funeral. And we ended up going . . . I remember standing in line and being very uncomfortable. What if somebody recognizes us? What if we get thrown out of this? How embarrassing could it be to be thrown out of a funeral, you know? But, all the time I kept going through

³⁸ *The Ryan White Story*. Directed by John Herzfeld. 1989.

³⁹ Wanda Bowen Bilodeau Interviewed by Allen Safianow. Ryan White Oral History Project, Howard County Historical Society, June 7, 2011.

⁴⁰ *Ibid.* Lausch, Malone. 17.

my mind, I wondered if we're here, I wonder what people think of why we're here. And, I just wanted to say my goodbyes . . . I remember tapping Jeanne on the shoulder and she looked up at me, and I said 'Oh, Jeanne, I'm sorry.' And, she stood up, hugged us, and said to me, 'You made Ryan what he is.' And I know she meant in a complimentary fashion, I know she meant it in saying, 'I'm not [mad] at you, I don't hate you.'⁴¹

Jeanne shares this sentiment in her interview saying, "I think if people could really stop and just listen to Ryan and listen to his story, I think people would be amazed at the kid he became. And, yes, it was because of Kokomo but I think it's a thing where we have to adapt and move on and say 'Golly, you know, this kid was really not the kid we thought he was.'⁴²

Ryan passed away from AIDS-related pneumonia on April 8, 1990. He died at the age of eighteen after struggling through a number of illnesses he contracted due to his compromised immune system. His battle lasted six years despite being given three to six months upon his initial diagnosis. His death cemented his legacy as not only the boy who defined what it meant to be a child with AIDS but one who made a lasting change in the AIDS community and saved countless lives by putting up such a valiant fight.

2020 marks thirty-six years since Ryan White's AIDS diagnosis. His legacy lives on as he was one of the first children and hemophiliacs in the country to be diagnosed with the disease. However, perhaps more importantly, he redefined what being an AIDS patient meant. He drew sympathy for all AIDS patients, increasing research and funding for the disease and helping a considerable number of people. Additionally, in 1990 the Ryan White Comprehensive AIDS Resources Emergency Act, also known as the Ryan White CARE Act, co-sponsored by Senators

⁴¹ David Rosselot Interviewed by Diane Knight. Ryan White Oral History Project, Howard County Historical Society, October 11, 2011.

⁴² Ibid. Safianow, White Ginder. 23.

Edward Kennedy and Orrin Hatch, passed overwhelmingly in the Senate, honoring Ryan's legacy and saving the lives of countless children after him.⁴³

Despite the amount of support Ryan White received from members of the Kokomo community and his personal strength during his fight against AIDS, the experience took a toll on his emotional well-being. The title quote of this paper, "When I die, please don't bury me in Kokomo," is taken from the made-for-TV movie *The Ryan White Story* that was watched by millions across the country when it premiered in 1989. While it is a dramatization from a particularly intense scene, it seems to be somewhat consistent with the opinions he expressed about his experience with members of the Kokomo and Russiaville communities in various interviews and his book. As a young person who was unexpectedly thrust into the spotlight where he faced criticism from countless people, Ryan White handled his situation with grace and professionalism far exceeding his years. However, I believe it is important to acknowledge that despite the strength he demonstrated throughout his tragically short life; it is evident that he struggled with the hostility he faced until his death.

While Kokomo is typically portrayed as the city that treated the poster child for AIDS as public enemy number one, it is often overlooked that without the controversy, the world may have never heard of Ryan White. This may not seem significant to many, yet, without Ryan's role of giving an innocent face to what was thought to be a disease of sinners, it may have taken much longer for the government to acknowledge and take action of the HIV/AIDS crisis. Dichotomizing the controversy in Russiaville and Kokomo does an enormous disservice to everyone involved. Labeling those involved as good or evil or failing to contextualize the events in temporal and spatial contexts underplays how complex things really were. Although Ryan

⁴³ HRSA. February 01, 2019.

understandably expressed anger and frustration with the town of Kokomo and was buried in Cicero as he requested, they helped his legacy survive for these thirty years, and for many still to come. Ryan's legacy has carried on into 2020, with the second patient in history being cured of HIV, a milestone that would not have been possible without the ideological shift sparked by his story.

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