Mothers Against AIDS in Kokomo, Indiana

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ABSTRACT: During the 1985–1986 school year, Kokomo, Indiana, area residents debated whether or not Ryan White—a thirteen-year-old with hemophilia and AIDS—should be allowed to attend school. Some feared their children would be exposed to the AIDS virus while others held confidence in expert assurances that the virus was not transmitted through casual contact. Community members used various avenues to learn more about AIDS, with mothers taking leadership roles as spokeswomen and lay medical experts. This paper considers how mothers on both sides of the conflict educated themselves. It provides a community study of the state of AIDS knowledge during the mid-1980s outside of the coastal epicenters and seeks to contextualize the Kokomo conflict based on available national and local information.

KEYWORDS: Indiana, Kokomo, HIV/AIDS, Ryan White, media

In July 1985, the Western School Corporation outside of Kokomo, Indiana, barred Ryan White—a thirteen-year-old with hemophilia and AIDS—from attending classes. As Ryan’s mother, Jeanne White, considered contesting the school’s decision, she stated, “I don’t think (most people) are educated enough to understand that other children are more of a threat to
Parents quickly organized to keep Ryan out of the classroom. Parent leader Mitzie Johnson asserted, “They don’t know how contagious it is and unless they can give us a 100 percent guarantee, he shouldn’t be in school.” Mothers Jeanne White and Mitzie Johnson became the spokeswomen in the conflict that divided the community. White fought against the stigma and fear associated with AIDS that threatened to exclude her child from getting an education. She strove to educate the public about AIDS. Johnson also struggled to secure public education about AIDS, but she fought to keep students with AIDS out of the classroom until other children’s safety could be guaranteed. As the story made national news, White and Johnson’s identities as mothers directed their actions and increased the media appeal of the conflict. The media pitted a mother’s love for one child against the fears of many others for their children.

This article considers the conflict through the role of women, particularly mothers, as one side addressed uncertainty with insistence of a guarantee of safety and the other asserted Ryan’s rights from a position of confidence. Traditional ideals of motherhood placed the responsibility for family health under the mothers’ purview. In the late-nineteenth century, germ theory turned the home into a battlefield in the war against unseen microbes. Educated women transformed their proscribed gender responsibility for home cleanliness into a more active public role in the Domestic Science movement. During the twentieth century, women’s role in protecting family and public health continued to expand while the male dominated field of physicians claimed authoritative knowledge. In the 1960s and 1970s, women challenged medical experts over issues including the safety of birth control and the need for radical breast cancer treatments. Natural childbirth and breastfeeding support groups affirmed that women rather than experts knew what was best for themselves and their children. Many individuals continued to trust and respect their family physicians

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3 Robert Hunt Ferguson discusses the “maternalistic campaign” of mothers whose children died from AIDS in the 1990s and demonstrates how their position as mothers increased their political clout. Robert Hunt Ferguson, “Mothers against Jesse in Congress: Grassroots Maternalism and the Cultural Politics of the AIDS Crisis in North Carolina,” Journal of Southern History 83, no. 1 (February 2017), 107–140.
Jeanne and Andrea White (Ryan’s mother and sister). Their F.O.R. (Friends of Ryan) badges promote a group that tried to raise funds for the White family.

Courtesy, Howard County Historical Society, Kokomo, Indiana

Mitzie Johnson, a leader of the Concerned Citizens group, at a meeting at Western High School, Russiaville, Indiana, August 13, 1985. Johnson was one of the public faces of worried parents, who quickly organized in summer 1985 to keep Ryan out of the classroom following his AIDS diagnosis.

Courtesy, Kokomo Tribune
but their faith in the medical system waned. Neither White nor Johnson had formal medical training or experience as public activists yet they spoke as authorities in the community.

In the mid-1980s, much of what was known about AIDS had been recently discovered. Many Americans were just beginning to consider AIDS as a medical issue that could reach their families, and they found the rapidly changing and conflicting research information difficult to interpret. In Kokomo, the conflict hinged on the credibility of available medical information. Disagreement over the communicability of AIDS dominated the conversation. Local newspaper accounts of White, Johnson, and other members of the community reveal citizens’ efforts to identify and analyze current AIDS research. Subsequent interviews—conducted by the Howard County Historical Society from 2011 to 2014 for the Ryan White Oral History Project—add additional insight into the state of AIDS knowledge and the research work community members had undertaken thirty years earlier. I originally read transcripts from the Ryan White Oral History Project in conjunction with research on the letters written to the White family that are held at the Children’s Museum of Indianapolis. I discovered that the transcripts offered a more nuanced view of the community than the media portrayed; the interviews led me to a deeper investigation of the medical information that was available in the mid-1980s to the Kokomo area community.

Public memories of Ryan White’s struggle to attend school with his peers often still center on the emotional responses of Kokomo area residents—especially those who reacted with ignorance and hostility. During the dispute, and in the years that followed, residents felt the national media unfairly portrayed them as ignorant. Ken Ferries, the Kokomo city attorney at the time, mentioned some of the stereotypes in his oral history interview. He noted how a television movie about the Whites depicted the community as

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5 The Western School Corporation is located in Russiaville, Indiana, approximately seven miles west of Kokomo. Some students with Kokomo addresses lived in the Western School Corporation, including the Whites. The parents involved identified as being from both Kokomo and Russiaville. I use Kokomo to refer to the parents generally, because both Jeanne White and Mitzie Johnson identified as being from Kokomo rather than Russiaville.
“a bunch of rubes,” “heartless,” and “close-minded.” Ferries also believed that Kokomo’s national image still remained that of a “very backwards community of self-satisfied, sanctimonious burghers.” Other interviewees mentioned distress over the bias of the general news coverage and television movie. In two recent articles, Allen Safianow, professor emeritus of history at Indiana University-Kokomo and chair of the Howard County Historical Society Oral History Committee, discussed the challenge and importance of documenting a community experience that “remained a sensitive issue in Howard County, with many still bitter or at least disturbed by what they felt to be an unfair portrayal of their community.”

The White family was ostracized and their home was vandalized. At one point, some parents considered having Jeanne White declared an unfit mother so that Ryan could be removed from her care. An unknown individual shot a gun at their home, damaging the front window. Ryan would later testify before the President’s Commission on the HIV Epidemic about the “discrimination, fear, panic, and lies” that surrounded him. He calmly stated, “I became the target of Ryan White jokes, lies about me biting people, spitting on vegetables and cookies, urinating on bathrooms walls, some restaurants threw away my dishes, my school locker was vandalized inside and folders were marked ‘fag’ and other obscenities…. I was not welcome anywhere.” This paper is not intended to cast aspersion on any of the oral history participants nor to excuse or justify the behaviors of some community members during the original crisis. Rather, this article provides a local study of the state of AIDS knowledge outside of the coastal epicenters and seeks to contextualize the Kokomo conflict based on available information. I investigate the local and national dissemination of AIDS information prior to and during the school conflict and interrogate stereotypes of Kokomo and its residents. I examine information that was available at the time in the local newspaper, the Kokomo Tribune, as well

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8 “Ryan White Relates the Prejudices and Hatred He Has Endured since Being Diagnosed with AIDS,” in In Our Own Words: Extraordinary Speeches of the American Century, eds., Robert Torricelli and Andrew Carroll (New York, 1999), 377–79.
Ryan in his bedroom at his Kokomo home.

as in national sources such as *Time* and *Newsweek*, the *New York Times*, and television.

**Overview of AIDS in the News**

In recent interviews, several people involved in the Kokomo dispute commented on their lack of prior knowledge about AIDS. Bev Ashcraft, the school nurse, recalled, “At that particular time, all I knew about AIDS was that if you got AIDS, it was a death sentence.” Dr. Alan Adler, the health officer at the Howard County Health Department, remembered that Ryan was his first contact with AIDS. He stated, “I knew nothing about AIDS, to be very honest.” Similarly, Mitzie Johnson remembered, “At that time nobody really had even heard of the disease.” Although Jeanne White knew that “homosexuals” and older men with hemophilia who had needed blood transfusions had contracted AIDS, she did not associate the Factor VIII blood products Ryan used to control bleeding with AIDS. At a recent presentation, she recounted the experience of telling Ryan he had the disease: “I knew nothing about AIDS…. I didn’t know how much he knew. I thought he might know more than me.” In 1985, health care providers and lay individuals lacked knowledge of the communicability and treatment of AIDS.

Before evaluating the content of media accounts, one should consider factors that limited coverage. Early in the crisis, AIDS activists decried the lack of media coverage. Larry Kramer, founding member of Gay Men's Health Crisis (GMHC), appeared on the first CBS news segment about an unknown disease. Dan Rather opened the segment by questioning why “federal health officials consider it an epidemic yet you rarely hear a thing about it.” Kramer noted that the disease had more victims than Toxic Shock Syndrome and Legionnaires combined and asserted, “Most of the country doesn’t know about this cancer.” An unidentified female voice asked why.

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13 Jeanne White-Ginder, lecture, April 3, 2015, author's personal transcript, notes, and recording, Children's Museum of Indianapolis, Indiana.
His matter-of-fact reply: “Well, I think it’s because it’s gay cancer.” At the time of the CBS broadcast, a year had passed since the Centers for Disease Control and Prevention (CDC) had identified the unusual cases of skin cancer and pneumonia. While television news was just beginning to cover the epidemic, activists had already organized and reached out to educate gay men. The GMHC had published their first newsletter, “AID-Acquired Immune Deficiency” the month before. The thirty-four-page publication included an analysis of current medical information and discussion of emotional and social issues. Rather suggested that many in the news audience had not heard about the skin cancers; however, gay men certainly had.

Comments from other journalists support Kramer’s assumption of intentional neglect. Randy Shilts argued, “Prejudices regarding sexual preference were preventing everybody, from the budget people to the newspaper reporters, from taking this scourge seriously.” He continued, “Editors were killing pieces … because they didn’t want stories about gays and all those distasteful sexual habits littering their newspapers.” Robert Bazell, science and medical correspondent for NBC, concurred. In a 1987 panel discussion on journalism and AIDS, he noted how difficult it had been to convince producers and editors to include AIDS stories in 1982 and 1983. He described their standard response: “Why would we want to put on a story about a disease that is affecting gays and drug addicts … there’s not that many of them, it’s not that big of a deal, there [are] not many cases.”

James Kinsella looked more broadly at the medical information distribution process in *Covering the Plague: AIDS and the American Media*. The CDC distributed copies of the *Morbidity and Mortality Weekly Report (MMWR)* to media outlets but, as Kinsella noted, “The MMWR’s lack of influence had something to do with reporters’ lack of interest in AIDS.” Reporters

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15 “AID: Acquired Immune Deficiency,” GMHC Newsletter, July 1982, folder 7, box 43, Gay Men’s Health Crisis records, Manuscripts and Archives Division, The New York Public Library. After the publication of the GMHC article, the CDC labeled the symptoms AIDS-Acquired Immune Deficiency Syndrome at a July meeting. Prior to July the media used numerous acronyms.


looked to the prestigious *Journal of the American Medical Association* (JAMA) and the *New England Journal of Medicine* (NEJM) to identify newsworthy stories. The journals’ peer review process resulted in a time lag between research discovery and publication that hindered the public’s access to the most current research findings. Kinsella also placed some of the blame on the CDC’s failure to proactively alert the public. Prior to the school conflict in Kokomo, the federal government had not directly distributed educational material to the public. The *Kokomo Tribune* did not report information from several of the early MMWR releases.19

1981: A Medical Mystery on the Horizon

On June 15 and July 3, 1981, the weekly CDC reports alerted the medical community that gay men had contracted pneumocystis pneumonia, an unusual disease in people with healthy immune systems, and Kaposi sarcoma, a rare form of skin cancer.20 A *New York Times* article covered the July 3 report, including explicit information about the men’s sexual activity. Journalist Lawrence Altman, M.D. reported, “Most of the cases involved homosexual men who have had multiple and frequent sexual encounters with different partners, as many as 10 sexual encounters each night up to four times a week.” Altman’s portrayal matched stereotypes that marked gay men as lacking self-control. His descriptive language likely disturbed some readers; however, the article reassured the public that women and heterosexual men need not worry. Interviewee Dr. James Curran from the CDC claimed, “The best evidence against contagion is that no cases have been reported to date outside the homosexual community or in women.”21

On August 29, the *New York Times* and the *Kokomo Tribune* alerted readers that unusual diseases had struck one-hundred homosexual men “killing almost half of them.” Embedded in the statistics, readers learned of the startling sixty percent pneumonia mortality rate. The *Times* article

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19 Kokomo is the county seat of Howard County, which in 1980 had a population of 86,896. During the 1980s, the average daily circulation of the *Kokomo Tribune* ranged between 20,000 to 22,000 papers with Sunday circulation ranging from 24,000 to 26,000. Robin Harper, Regional Director of Circulation, *Kokomo Tribune*, email to author, April 8, 2015.


21 In 1981, many publications used “homosexual” rather than gay. When I summarize articles, I will use the language of the article to maintain historic context. Lawrence K. Altman, “Rare Cancer Seen in 41 Homosexuals,” *New York Times*, July 3, 1981.
indicated that the earlier report of no cases “outside of the homosexual community” was inaccurate: “One additional case was that of a woman who contracted pneumocystis.”22 The Tribune article did not include this fact. In both newspapers, Dr. Harold Jaffe, a CDC epidemiologist, speculated on the diseases’ link to “sexual lifestyle, drug use or some other environmental cause.” The Kokomo paper added Jaffe’s more doubtful statement: “To be fair, there is no evidence at this point these diseases are sexually transmitted.”23

During the school conflict, people in the Kokomo area struggled with how to interpret safety claims that relied on phrases such as “no evidence.” Even after the virus that caused AIDS had been identified in 1983 and 1984, researchers still relied on epidemiological studies to establish disease transmission vectors. Human testing was not an option. No matter how certain scientists were, the rigor of scientific language did not permit absolute statements. Later in 1985, Western School Corporation would argue that the medical evidence offered by health officials and the CDC was inadequate, pointing to reliance on phrases such as “current evidence,” “should not result,” “no current evidence,” “currently seems,” and “no evidence to date.”24

In December 1981, an article in the NEJM was discussed by Time magazine, which reported on cases of homosexual men coming down with “bacteria, fungi and offbeat viruses, all in quick succession.” Physicians speculated on possible contributing factors, including drugs used “to enhance orgasm,” or “immunologic overload” caused by multiple infections contracted through having numerous sex partners. A New York Times summary of the article contained additional worrisome information. Readers learned some heterosexual men and two women had contracted the syndrome. Immunologist Dr. Frederick Siegal cautioned, “It’s an extraordinary business and really quite frightening because nobody knows the cause.” He warned, “I think it may be premature to say it is a homosexual disease.”25

23 “Two Rare Diseases Killing Homosexuals,” Kokomo Tribune, August 29, 1981.
The Tribune did not carry the early summer *Morbidity and Mortality Weekly Reports* or the *New England Journal of Medicine* articles.

Four years later, when Kokomo parents were searching for information about AIDS, they may have reviewed the early CDC reports and medical journal articles. Much of the medical information would have been difficult for those without medical training to analyze; however, the descriptions of patients’ medical conditions clearly indicated the suffering people with AIDS endured. For people whose partners, family, and friends were dying of AIDS-related infections, these four years were excruciatingly long. For Kokomo parents, four years might have seemed like a short time to establish conclusive evidence about the disease’s transmission.

**1982: A YEAR OF APPREHENSION AND UNCERTAINTY**

In June 1982, the CDC met with blood industry representatives and leaders from affected groups to discuss the potential of blood-borne transmission of the immune system syndrome. At the meeting, the CDC adopted the term AIDS (acquired immune deficiency syndrome) to categorize the constellation of infections. Ryan remembered learning about AIDS from television news in 1982 and from *Time* magazine. He might have watched the NBC *Nightly News* in June, a CBS report in August, an ABC segment in October, or read *Time* stories in September and December of that year.

NBC revealed that heterosexual men and women had contracted the “mysterious newly discovered disease.” Robert Bazell indicated that scientists had found the disease in sex partners and continued, “The scientists say this probably means they are dealing with some new, deadly sexually transmitted disease.” In August, CBS reported on unusual skin cancers. With a series of still images, correspondent Barry Peterson dramatically

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intoned “no one knows why” the disease had spread to Haitians, heavy drug users in New York City, and hemophiliacs. The CBS segment speculated the causal agent was a form of herpes, a known sexually transmitted disease. In December, Ted Koppel introduced an episode of ABC News Nightline with an ominous statement, “AIDS is now spreading in epidemic proportions to other segments of the population.” In the first report, pediatrician James Oleske expressed alarm at the “epidemic event we’ve seen—many children with very unusual immunological defects.” In the next segment, researcher Dr. Spartaco Bellomo explained that contact with any excretion or secretion such as blood, saliva, urine, feces, or sperm could transmit AIDS. Another segment highlighted concern about blood banks and their inability to determine the unknown disease agents. The disease’s expanding reach and the uncertainty woven through television reports about AIDS had the potential to resonate in the heterosexual population.

The August CBS broadcast might have been the first time the White family learned that hemophiliacs had been diagnosed with AIDS. A September Time article also mentioned hemophiliacs with AIDS. Journalist Claudia Wallis presciently wrote, “The [three] hemophiliac cases raise the frightening possibility that it [AIDS] can also be transferred through blood transfusions.” In December, Time covered MMWR issues that revealed the possibility of transfusion-associated AIDS cases and unexplained infections in infants. The article also mentioned, “The illness may pose a significant risk for patients with hemophilia.” With the raising number of cases among hemophiliacs and people outside of the gay community, and the death toll at 312, people had reason for concern, but scientists still had few answers.

Despite media stories labeling AIDS an epidemic, the growing crisis still received limited attention. Shilts claimed, “In the entire last quarter of 1982, only thirty articles appeared in the nation’s leading news magazines and newspapers, and most of those were in the year’s final days, reporting on the babies and transfusion threat.” The Kokomo Tribune printed one article in 1982, warning: “The United States may be on the verge of a ‘huge outbreak’… This disease may be highly contagious.”

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31 “Young Victims,” Time, December 27, 1982, p. 79.
32 Shilts, And the Band Played On, 213.
cover the reports about hemophiliacs, blood transfusions, or the disease in children. By the end of the year news stories about AIDS confirmed that the disease was spreading outside the gay community and beyond big cities. Due to sparse media coverage, many Kokomo residents probably still had minimal knowledge about AIDS. For those who were aware, the key themes of the year’s news stories were apprehension and uncertainty.

1983: The AIDS Crisis in the Headlines

In 1983, news coverage of the AIDS epidemic grew dramatically. The Kokomo Tribune had run one article in 1982; in 1983, it published thirty-eight stories. Time ran a cover story about AIDS in July; Newsweek published AIDS covers in April and August. A variety of magazines including Black Enterprise, Cosmopolitan, Ladies Home Journal, Ms., People, Reader’s Digest, Rolling Stone, and Saturday Evening Post carried articles about AIDS. Media coverage now centered on AIDS transmission beyond the gay community. Stories linking AIDS to blood transfusions resulted in a drop in summer blood donations and blood supply shortages across the country, including the central Indiana region. Reports noted that AIDS had spread through heterosexual contact and household contact. As public hysteria grew, the federal government opened a toll-free AIDS hotline and provided some educational material for organizations supporting populations “at risk.” In congressional hearings, the Department of Health & Human Services revealed the Public Health Service’s use of the news media to disseminate AIDS information. Their report stated: “Basic information about the syndrome has already been made available to the public through . . . effective articles in the press and by appearances of knowledgeable health officials on television and radio interviews.” Activists such as Virginia Apuzzo of

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34 Since the acronym “AIDS” was not in common use until the end of 1982, I found segments and stories using multiple search terms including cancer, Kaposi, pneumonia, homosexual, and names of known spokespersons such as James Curran. The virus causing AIDS was identified by French researchers in 1983 as LAV and by U.S. researchers in 1984 as HTLV-III. The scientific community agreed on the acronym “HIV”—Human Immunodeficiency Virus—in 1986.


the National Gay Task Force and Steve Endean of the Gay Rights National Lobby, who also testified at the hearings, blamed some of the hysteria on the lack of public education.\(^\text{38}\)

As the public began to grasp the magnitude of the crisis, reports on the communicability of AIDS caused confusion. In March, the CDC announced, “Blood products or blood appeared responsible for AIDS among hemophilia patients.”\(^\text{39}\) In June, the Tribune cautioned, “Physicians should give transfusions only when medically necessary, and wherever possible individuals should be their own blood donors.”\(^\text{40}\) Yet, in August, the president of the American Blood Commission assured the public, “The risk of getting AIDS from blood transfusions is exceedingly small, about one in a million” and the director of the American Association of Blood Banks claimed, “AIDS is not a blood disease. It is probably a virus.”\(^\text{41}\) The inability of public health officials and blood industry officials to reach a consensus on blood safety policies contributed to the mixed signals about risk. By the end of the year, thirty-one cases of transfusion-associated AIDS had been identified.\(^\text{42}\)

Similarly, the contradictory information about children with AIDS created anxiety. On May 6, 1983, JAMA published three articles about AIDS transmission in children. An article by James Oleske suggested: “Children living in high-risk households are susceptible to AIDS... sexual contact, drug abuse, or exposure to blood products is not necessary for disease transmission.”\(^\text{43}\) Kinsella described the coverage of Oleske’s article as “the first time a media firestorm erupted around AIDS news” and argued that


most media outlets, in the rush to get the story out, ignored the work of
the other experts published in the same issue.44

The Tribune pulled the story from the Associated Press. The first
paragraph warned “[It] could mean the general population is at greater
risk.” Dr. Anthony Fauci of the National Institutes of Health worried, “If
‘routine’ personal contact among family members in a household is enough
to spread the illness, then AIDS takes on an entirely new dimension.”45
A few months later, the CDC reported, “There has been no evidence of
transmission by casual contact or airborne spread.”46 Although the “casual
contact” theory was abandoned, Kinsella asserted that the press and JAMA
never issued a correction. When parents studied medical reports in 1985,
researchers had still not found evidence that casual contact spread AIDS;
however, new reports about the virus in saliva and tears contributed to
parents’ doubt.

In 1983, Tribune readers had access to relatively basic AIDS news in
comparison to New York Times readers, and they also had fewer oppor-
tunities to empathize with people living with AIDS. The New York Times
discussed specific emotional, social, medical, and economic distress caused
by AIDS—the Tribune did not. Tribune readers also missed the debates about
research funding, the vigils held for AIDS victims, and research updates.
While Kokomo residents could have gained knowledge about AIDS from the
local paper, they lacked a framework to relate the crisis to their hometown.

1984: The “Disappearing Epidemic”

In 1984, learning about AIDS took more effort. James Kinsella, referred
to 1984 as the year of the “Disappearing Epidemic” where “there was no
major medical news, and the AIDS story vanished from the pages.”47 In

44 In the same issue of JAMA, an article suggests perinatal or in utero transmission. Arye Rubinstein,
M.D., Marc Sicklick, M.D., Asha Gupta, M.D., et al. “Acquired Immunodeficiency With Reversed
T4/T8 Ratios in Infants Born to Promiscuous and Drug-Addicted Mothers,” Journal of the American
Medical Association vol. 249, no. 17 (May 6, 1983), 2350–2356. See also, Anthony S. Fauci, M.D.,
“The Acquired Immune Deficiency Syndrome: The Ever-Broadening Clinical Spectrum,” Journal
of the American Medical Association vol. 249, no. 17 (May 6, 1983), 2375–2376; Kinsella, Covering
the Plague, 57–58, 106–107.


46 “Acquired Immunodeficiency Syndrome (AIDS): Precautions for Health-Care Workers and Allied

47 Kinsella, Covering the Plague, 101. A 2004 Kaiser Family Foundation analysis of national
and regional newspapers and network news verified Kinsella’s observations of a dip in media
Kokomo, the year began with a story suggesting that new AIDS cases were slowing down. Yet, by the end of November, almost 7,000 people met the criteria for AIDS nationwide with cases reported in 45 states. News stories in 1984 included identification of a viral agent by a U.S. researcher, speculation of a possible vaccine, and increased coverage of the social ostracism experienced by people with AIDS.

During the year, AIDS activists continued to push the federal government for more funding for research, services, treatment, and education. The newly formed AIDS Action Council hoped to shift the focus away from AIDS as a “gay disease” and bring attention to AIDS as a general public health issue. Their strategy emphasized that the study of AIDS could result in a better understanding of autoimmune disorders and cancer. Additionally, they sought to “[expose] the human tragedy of AIDS and the authentic human identity of those who suffer the disease disproportionately.” Activists saw familiarity as the key to public compassion.

As the epidemic’s impact travelled closer to Kokomo, the local paper reported on a few AIDS cases in Indiana. Amy Sloan’s story might have prompted public sympathy: in 1982, Sloan had received three units of contaminated blood. Now newly married and pregnant, she had contracted AIDS. However, an exchange on the Kokomo Tribune’s editorial page revealed that some readers struggled to recognize the humanity of those who lived with AIDS. On July 22, the paper printed a letter from former Kokomo resident William Stosine criticizing Moral Majority leader Jerry Falwell’s exploitation...
of “AIDS hysteria.”54 In mid-August, Stosine wrote a second letter describing the responses he had received. Some people thanked him for writing what they were afraid to express; other anonymous respondents wrote negative replies. One writer hoped that AIDS “will get rid of a bunch of trash.”55

In fall 1984, Ryan White entered Western Middle School as a seventh-grader. In December, he was admitted to Riley Hospital for Children with pneumonia. The diagnostic lung biopsy came back positive for pneumocystis pneumonia—Ryan had AIDS.56

1985: Ryan’s Battle Begins

In January, the Tribune reported that an unnamed 13-year-old Howard County boy with hemophilia was currently being treated at Riley Hospital had been diagnosed with AIDS. After a month-long hospital stay, Ryan returned home to spend the rest of the school year recuperating. In March, a sympathetic Tribune article shared Ryan’s identity and his diagnosis with the community. The Whites took the opportunity to educate others about AIDS. Jeanne explained: “The only way that they know of that AIDS can be spread is through the blood or through contact with semen.” Ryan shared why the doctors and nurses treating him wore gloves. “If they had a cut on their hand and my blood touched the cut and got into their blood then they could get AIDS too.”57 This first story is exemplary of many of the conversations Jeanne had with the press. She shared the information she had received as a parent from Ryan’s health care providers.

The news lull of 1984 turned into a deluge in the second half of 1985. In July, Life magazine published a dramatic cover proclaiming, “Now No One is Safe from AIDS.” Inside, an article ominously warned, “The AIDS minorities are beginning to infect the heterosexual, drug-free majority.” James Oleske, the pediatrician who had announced an epidemic of children with immune problems on Nightline in 1982 and had co-authored

54 The front page of the July 1983 Moral Majority Report pictures a family with medical masks covering their faces and the caption “AIDS: Homosexual Diseases Threaten American Families.”
55 William Stosine, “Reader Blasts Jerry Falwell,” Kokomo Tribune, July 22, 1984, p. 7; “Reader Responds to His Critics,” Kokomo Tribune, August 15, 1984, p. 5. Stosine was a former Kokomo resident. He sent letters to several papers. It is not clear if the particular anonymous letters he quotes are from Kokomo.
56 Ryan received frequent injections of blood clotting factors to treat his hemophilia. The products pooled from many sources increasing the possibility of transferring HIV.
On July 30, 1985, the superintendent of Western School Corporation barred Ryan from attending school, and the White family filed an action against the school system. On August 2, Von Roebuck, an official with the Indiana State Board of Health, escorted Ryan and his mother to Indianapolis for a hearing. Courtesy, Kokomo Tribune

the 1983 reports about household contact transmitting AIDS, mournfully stated: “I don’t know how much longer I can continue to watch children die.” On July 25th, actor Rock Hudson’s AIDS diagnosis flooded television and print news.

During the same month, Western School Superintendent James Smith determined whether or not Ryan could attend school with his peers. Stories

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about AIDS would have been difficult for Smith to overlook while making a decision about Ryan’s attendance.

On July 30, Western School Corporation barred Ryan from attending school. The White family filed an action under the Education for All Handicapped Children Act to force the school to admit Ryan to classes. On November 25, the Indiana Department of Education ordered the school corporation to allow Ryan to attend school. On December 17, the school board voted to appeal. When Ryan won the appeal on February 6, 1986, the Concerned Citizens parent group secured a restraining order that resulted in his removal from school on February 21st—his first day back. A higher court lifted the restraining order April 10th. In July, the Indiana Court of Appeals rejected further appeals. Ryan returned to school in the fall.59

Kokomo in the National News

The national media, eager for news stories about AIDS, followed the legal exchange between the Whites, Western School Corporation, and parent groups—while also covering school protests in other places such as Queens, New York. Kinsella counted close to forty stories of the protracted legal conflict reported on national television.60 The international press also followed Ryan’s story. In 1985, a Japanese television station sent a team to interview the White family and others; in 1986, the Whites traveled to Rome to appear on an Italian television news magazine program.61 Ryan received mail from Poland, France, Italy, Switzerland, the Netherlands, East Germany, and West Germany.62 While many of the media accounts played up what were labeled as hysterical or emotional responses, the articles and programs educated the readers and audiences. Readers could study statistical charts and inspect graphic representation of how the virus damaged T-cells. They learned of the latest research reaffirming that casual

59 This summary is a broad overview and does not include all legal events. The February 6, 1986, ruling required a physician to clear Ryan before attending school. On February 13, Dr. Adler cleared Ryan but due to an outbreak of the flu, his first day back was delayed.

60 Kinsella, Covering the Plague, 191.


contact did not spread AIDS. Newsweek confronted irresponsible press coverage, specifically a dramatic July Life cover story that promoted fear of AIDS, and also recognized that conflicting views caused public confusion. The fall media blitz provided an opportunity for the public to learn about the current research on AIDS.

In the Kokomo area, disagreement over interpretation of the available medical information undergirded the dispute about Ryan’s school attendance. Those opposed stressed the communicability of AIDS and asked for a guarantee of safety. Those in support of Ryan’s attendance emphasized that AIDS could not be transmitted through casual contact. Ryan’s supporters appealed to their neighbors for compassion. Others asserted Ryan’s civil right to attend school.

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Historian Philip Jenkins describes the late 1970s and early 1980s as a time of heightened fears about child safety. Exposés on day care sex abuse, child abductions, and youth under the influence of PCP contributed to a sense of panic. Parents, Jenkins concluded, reacted as if “it was a matter of war.” Women took leadership roles in responding to perceived moral risks and physical threats. In Florida, Anita Bryant organized the “Save Our Children” campaign to protect children from the alleged recruitment of gay men. Mothers whose children had died as a result of impaired drivers founded Mothers Against Drunk Drivers. Tipper Gore and Susan Baker pushed the music industry and Congress to require warning labels on music with sexually explicit lyrics. As the war on drugs continued, First Lady Nancy Reagan urged children to “Just Say No.” Anxiety about the threats to childhood surrounded parents in the Kokomo area. Mothers were not willing to let medical experts make safety decisions for their children. They had confidence in their own ability to evaluate medical claims and insisted that their voices be heard.

Mitzie Johnson, a spokesperson for the Concerned Citizens of the Western School Corporation, had a daughter in kindergarten and a three-year-old son. She graduated from a Howard County high school in 1979. Johnson remembers getting involved in the conflict after hearing a radio program that criticized the school board’s decision to keep Ryan out of school. She called the station to defend the board’s decision and argue that parents needed more information. As a result, the media turned to her as a representative of concerned parents. Early in the conflict, Johnson helped organize a meeting for parents with local pathologist Jeffrey Squires as speaker. Johnson asserted, “People don’t know how AIDS is communicated. Since they’re not homosexual or hemophiliac, they think, ‘Hey,
we’re safe.’ That’s not true and I want it out.” Parents at the meeting asked questions about saliva, nosebleeds, and mosquitoes. When a father asked for a guarantee that his child could not get AIDS by helping Ryan, Squires responded, “You’re asking for a guarantee and that’s just not available.” Squires also mentioned that it was possible for a mosquito to transfer the disease.68 One mother wrote to the Tribune following the meeting. Rhonda Abresch noted: “A pathologist was asked if mucous from a cough or sneeze could spread the AIDS virus. He said it had not been determined.”69 The Tribune editor attempted to clarify the point, adding with information from famed immunologist Michael Gottlieb: “There is absolutely no evidence that AIDS is spread by casual contact with infected individuals. It cannot be spread by sharing towels, food or eating utensils . . . touching, hugging


or body contact other than sexual intimacy.” Gottlieb’s assertion of “no evidence” was not the guarantee parents sought.

In recent interviews conducted by the Howard County Historical Society for the Ryan White Oral History Project, parents who had opposed Ryan’s school attendance described their efforts to educate themselves about the AIDS epidemic. Paula Adair, the president of the teachers’ union and a parent, developed a list of questions to ask local and national experts. She remembered: “All of those places gave me the same answer . . . that it was a communicable disease, that they didn’t know how it could be spread, and they couldn’t guarantee that students would be safe in that environment.” At the parents’ meeting with Jeffrey Squires, Adair challenged the authority of the CDC, telling the crowd: “Their information is inconclusive, just like everyone else’s. It’s ambiguous.” Adair’s role as both a parent and president of the teachers’ union validated many parents’ fears of the unknown.

Mitzie Johnson’s diligent research efforts established her authoritative voice in the Kokomo conflict. She reflected, “We were probably one of the best educated communities about the disease because we did . . . research. We didn’t just grab at straws. We looked, we researched . . . we read medical journals, we read different areas of research projects.” At a September 1985 meeting, Johnson referred to CDC reports and medical journals while she shared some of the information she had found. She argued that conflicting reports from medical professionals and the unidentified cause of AIDS in six percent of the cases was “enough for schools to not allow students to be exposed to the lethal virus carried by another student.” She also presented information about “the communicability of the virus through saliva, tear drops and other non-sexual modes of transmission.” Johnson argued that the language the CDC employed, such as “very difficult to catch” and “extremely low” chance of communicability in the classroom, offered an insufficient guarantee. Johnson supported her argument with reference to specific medical claims but also appealed

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emotionally to her peers about the risk their children might face if a child with AIDS entered the classroom.

Sylvia Payne, a well-known Kokomo seamstress and mother of a freshman at Western, is not mentioned as a speaker or organizer in the conflict; however, over the course of the school year, the Tribune published at least seven of her letters. An August 25, 1985, letter indicates Payne had some association with other parents who were researching AIDS. The letter began in an emotional tone, stating that parents had “found the real dangers to children in a classroom and school setting existed,” and concluded with a comparison to prison and jail procedures which isolated people with AIDS. Her final statement expressed outrage: “Are our children due any less protection in our schools than convicted felons? I think not.” Despite the intensity of its introduction and closing, the core content of Payne’s letter demonstrated that parents were involved in a sophisticated search for information: “Our research was from the Medical Information Center via Dow Jones Information Center via computer with medical doctors, not news released via biased media. It also consisted of a doctor from the Pasteur Institute of Research, Paris, where the virus was first isolated.” The letter included a summary of the specific research findings that parents used to conclude that there were “real dangers.”

Like most parents, Payne strongly felt that schools should be a safe place. When her son was in third grade, she had written a letter to the Tribune expressing concern about a recent court decision that would allow students who had committed drug offenses to attend school. She urged parents to back the school policy of expulsion over the court decision.

The school’s legal brief filed in 1985 sheds further light on the dynamics of the disagreement. In some cases, the information and arguments parents shared with the press matched the information and arguments presented by Western School Corporation. In their post-hearing brief,

On August 19, 1985, the Tribune published an article about Howard County jail guidelines to isolate anyone suspected of AIDS. Payne’s death in 2000 precluded her participation in the Ryan White Oral History Project.


76 I examined and compared all the 1985 Morbidity and Mortality Weekly Reports that discussed AIDS, LAV, and HTLV-III; the available documents from Western School’s exhibit list (attached to the “Notice of Hearing” In Re: The Educational Needs of Ryan White); and the factual claims parents made. Almost all of the factual claims were drawn from material in the Department of Education hearings exhibit list. A few of the exhibit list citations were incomplete.
the corporation argued that “Ryan’s exclusion is justified to prevent any risk of AIDS transmission.” This point matched the parents’ argument for a one hundred percent guarantee of safety. Much of what was viewed as emotional or hysterical language from parents involved pleas to protect their children from even the slightest danger. For example, an editorial in the *Kokomo Tribune* belittled parents’ desire for a guarantee. The editor noted, “No one, except a fool, is going to put his John Henry [signature] on any sure-thing document” and compared the risk of getting AIDS to getting hit by a car. “If you don’t walk in the street, you won’t run any real risk of getting hit by a car—unless the car runs up on the sidewalk.” His analogy meant to imply that people who avoided unsafe sex, intravenous drugs, and blood transfusions did not need to worry about AIDS.\(^{77}\)

The corporation’s brief did not demand a guarantee, but their rationale of avoiding risk was the same: “Western has chosen to eliminate the possibility of infection by removing Ryan from the classroom and providing him homebound instruction. Surely this decision . . . is a reasonable response to this problem.” In the closing paragraphs, Western reframed the locus of emotionality. Recognizing the poignant nature of Ryan’s desire to have a normal childhood, the brief continued, “But those desires cannot blind us to reality.”\(^{78}\) Both the school and parents assessed the risk of possible danger and determined it to be unacceptable.

The school substantiated their lack of confidence in medical assurances with information from CDC reports, medical journals, and news articles. Parents had access to the same sources. Larry Gabbard, who had a child in Ryan White’s class, recalled parents contacting the CDC and asking them to send information. Johnson brought reports from medical journals to a parent meeting.\(^ {79}\) She and Payne spoke and wrote about the most recent medical updates on the presence of the virus in tears and saliva, the number of AIDS cases of unknown origin, the lengthy period of “incubation,” and a report that the AIDS virus could live outside the body for ten days. The school and parent knowledge base incorporated information published after the July decision to deny Ryan’s school admission. This included

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preliminary August newspaper articles about the virus found in tears, followed by the associated research published in September, and a short report published in *The Lancet* on September 28 about the ten day virus survival rate.80 The authors’ supposition that the virus’s ability to survive at room temperature “may explain the appearance of some AIDS cases in non-risks groups,” confirmed parent fears about AIDS cases of unknown origin.81 Payne included the information from *The Lancet* in a December 4 letter to the *Tribune*.82 Western mentioned these issues and others in their legal brief. The school contended, “It is prudent to err on the side of protecting the health of all students and staff until more information about AIDS is developed.” It is not clear if the parents and the school shared research information.

The school and the parents made valid arguments about the fluctuating nature of AIDS knowledge. Both used the example of health care worker transmission to demonstrate that lack of evidence did not provide assurance. On February 22, 1985, a CDC *Morbidity and Mortality Weekly Report* noted, “To date, there are no reported cases of AIDS among HCW [health care workers] in the United States that can be linked to a specific occupational exposure.”83 The *Indiana Guidelines for Children with AIDS/ARC Attending School* also applied the lack of “documented instance” of patient to HCW transmission as evidence against the possibility of casual transmission. The *Kokomo Tribune* editor relied on that same information to claim AIDS was not a danger in the classroom: “If it is, then why

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83 “Current Trends Update: Prospective Evaluation of Health-Care Workers Exposed via the Parenteral or Mucous-Membrane Route to Blood or Body Fluids from Patients with Acquired Immunodeficiency Syndrome—United States,” *Morbidity and Mortality Weekly Report* vol. 34, no. 7 (February 22, 1985), 101–103.
haven’t doctors and nurses caught it from patients?” Two weeks later, a radio commercial in opposition to the school’s decision mentioned the same information as an example of the difficulty of understanding AIDS transmission: “There is no evidence of AIDS transmission between patients and health care workers.” Nevertheless, in September the CDC reported that two health-care workers who tested positive for AIDS were infected by needlestick injuries. A needlestick injury was an occupational hazard quite different than casual contact, yet the assurance of “no evidence of transmission” lost its credibility.

The school and concerned parents also questioned why the CDC and the Indiana Board of Health put forward safety guidelines if AIDS was so hard to catch. They viewed the potential of contact with accidental blood spills as probable due to Ryan’s history of nosebleeds. The guidelines requiring rubber gloves and bleach intensified the perception of danger. The recommendation of handwashing after contact with blood and saliva reinforced the apprehension about saliva. Additionally, during August and September, the Tribune reported on Ryan White’s hospital stays with fevers and coughing. Ryan’s perceived medical frailty likely contributed to parent concerns that guidelines would not protect their children.

Unexplainable cases of AIDS alarmed parents and were also included in the school brief. The CDC reported 829 of the 13,061 cases (6.34 percent) of AIDS occurred in people with no known risk factors. The count relied on self-reported drug use and sexual contact history. The article went on to discuss sex workers, bidirectional transmission, and the number of sex partners. Although it might seem obvious that some patients would not report truthfully or know of the sexual and drug use history of all their partners, parents drew the conclusion that some of the cases could be due to casual contact. The CDC could not prove otherwise.

Kokomo parents were not the only ones who questioned the state of medical knowledge. President Ronald Reagan supported parents’ concerns. In response to a question about children with AIDS attending school,

Reagan concluded, “And yet medicine has not come forth unequivocally and said, ‘This we know for a fact, that it is safe.’” In September, a poll assessed public knowledge and found many respondents felt they could catch AIDS from sharing a glass, kissing, or public toilet seats. Journalist Erik Eckholm concluded, “Federal medical officials have either failed to reach or failed to convince close to half the people with their conclusion that the disorder cannot be contracted through casual association.” After completing their own diligent research, the Kokomo parents were among those unconvinced.

The crush of the national media presence weighed heavily on both sides. White described the media attention in her memoir *Weeding Out the Tears*: “The media arrive on your doorstep. They ring your phone off the hook. They demand; they plead . . . sometimes they threaten you.” Although “intimidated” and bothered by “casual exaggerations,” White also felt the media could help educate the public. Johnson recalled, “My phone rang off the wall, it got to the point where you quit answering the phone and you quit answering the door. There was always media outside the door. It was like a circus.” She did note, “The local media wasn’t quite as bad as some of the others.” Other community members recalled inaccurate or paraphrased quotes and feelings of bias. After the first few days of national attention, Western superintendent James Smith felt “the media contact has been pretty good overall” but also mentioned a few “who conveyed a how-can-you-be-so-ignorant kind of attitude.” A few days later, he related, “It does seem there is an attempt to create what I call a David-and-Goliath story: here’s a poor little boy fighting against a big school system.” At the end of the month, Tribune reporter Christopher MacNeil evaluated the media coverage and, as one would expect, he found some who viewed the coverage as accurate and objective and others who complained that

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89 Erik Eckholm, “Poll Finds Many AIDS Fears That the Experts Say Are Groundless,” *New York Times*, September 12, 1985. The poll was conducted at the national level and included 762 participants. The results indicated that forty-seven percent of people feared “sharing [a] glass,” thirty-two percent feared “kissing,” and twenty-eight percent feared transmission from a “toilet seat.”
90 White and Dworkin, *Weeding Out the Tears*, 96–97.
the media “entered the case convinced of who was right and wrong and refused to be moved by the facts.”\textsuperscript{93} Johnson later complained that the media had not “really bothered to ask us what medical information we’ve researched to maintain our position.”\textsuperscript{94} The media was a constant presence at parent meetings and legal decisions.

\textbf{CONFIDENCE AND RIGHTS: THE WHITE FAMILY}

Jeanne White graduated from Kokomo High School in 1965, and shortly afterward started to work for Delco Electronics. She recalls that her goal in life “was to get married, [and] have kids.” As the parent of a child with hemophilia, White learned to negotiate the healthcare system. At times, she advocated for Ryan’s medical needs in opposition to medical doctors who were unfamiliar with the treatment of hemophilia. Like many parents of children with chronic health issues, White became an expert in her child’s care.\textsuperscript{95}

Jeanne White remembered knowing little about AIDS before Ryan’s diagnosis but being immediately assured by the CDC “that no family member [had] ever come down with AIDS and we had nothing to worry about.”\textsuperscript{96} The sister of one of Ryan’s friends remembered informational pamphlets the White family shared with her family when he came home from the hospital.\textsuperscript{97} White also trusted Dr. Martin Kleiman, Ryan’s infectious disease specialist at Riley Hospital. At times, she turned to Dr. Kleiman to answer her questions. After White was confident Ryan did not pose a risk to the family or community, she focused her research efforts on treatments and cures. Kleiman connected her to the American Foundation for AIDS Research (AmFAR) where she met Terry Beirn. Her friendship with Beirn put her in touch with the most current treatment information, and White continued to make calls “all over the country” investigating claims of cures.\textsuperscript{98}

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\item \textsuperscript{94} “Pro-Western Group to Meet,” \textit{Kokomo Tribune}, September 23, 1985, p. 3.
\item \textsuperscript{96} Ibid., p. 8.
\item \textsuperscript{97} Wanda Bowen Bilodeau, interview by Allen Safianow, June 7, 2011, transcript, p. 6, Ryan White Oral History Project.
\item \textsuperscript{98} White and Dworkin, \textit{Weeding Out the Tears}, 90, 99.
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Most of the comments from Jeanne White that were published in the *Tribune* either shared human interest updates on Ryan’s condition or discussed the need for AIDS education. At times, she expressed frustration with those whom she viewed as unwilling to learn. On one occasion, she disputed a parent claim about how long the AIDS virus could live outside the body but, in general, she rarely engaged in medical debates, focusing on the need for public education to remove the social stigma associated with AIDS. When asked about the press, White stated: “I can’t stress enough that I would like to have more doctors involved with the press to educate people about AIDS. It’s really going to take a lot of people (doctors and in the press) to wake the country up about the disease and the fear people have for AIDS patients.”99 After one contentious school meeting, White responded optimistically: “Just to educate people about AIDS is good. But I think with the kind of evidence we heard today, we’re getting more people to listen.” In January 1986, while waiting for the appeal decision, Jeanne spoke during AIDS Awareness Week and encouraged people to “send a card, make a call or just show you care.” She also addressed the harsh judgments and blame placed on homosexual and bisexual men: “I don’t think it’s our role as Christians to judge anybody with AIDS or at risk of it, or treat them badly or shun them. They need our compassion and support.”100 As Jeanne updated the press on Ryan’s health, his reactions to the delays in his return to school, and his resolve to return, those following the story in Kokomo and the nation had an opportunity to get to know someone with AIDS and empathize.

Ryan’s fight to return to school divided the community; however, not everyone took sides, convinced that AIDS education was the key to normalcy. Rita Bagby lived in Ryan’s neighborhood and had three children at Western schools. Ryan delivered her paper. Initially, Bagby felt concerned about the school situation due to a lack of information, so she educated herself by reading magazine articles and books. She also recalled following what the doctors and attorneys said. When Ryan was allowed back in school, she felt she could trust the people in charge to keep her children safe. Her children later reminded her of how strongly she had expressed their need to attend school despite the disruption caused by the media’s presence. Bagby had been hesitant to participate in the Ryan


White Oral History Project because she did not want to take sides. She hoped “that everybody would see it as I see it, and that is, in situations like this, there’s no good guy, bad guy.” Bagby did not know the Concerned Citizens group or Jeanne White and did not engage in any public disputes. Although a quiet member of the community, she still conducted her own research and assessed the risk.

Arletta Reith, Jeanne White’s co-worker at Delco, befriended the White family after reading about Ryan’s AIDS diagnosis in the Kokomo Tribune. She visited the Whites’ home on several occasions. To educate herself about AIDS, Reith conducted research at the library and read papers from New York and Los Angeles—two areas hit hard by the epidemic—as well as Chicago. She concluded: “From what I read, there was no danger in my contracting AIDS through casual contact with Ryan…. I had no fear, none.” In her oral history interview, Reith shared an example of misinformation that had circulated. While at work, she heard a radio caller who warned that “AIDS droplets’ when Ryan sneezed came out of his mouth.” This example suggests that the level of AIDS knowledge in the Kokomo area varied significantly. As the interview concluded, Reith shared some lessons that could be learned from the conflict: “Educate yourself from experts. Listen to what they say. Don’t just act on emotion.” Reith recognized that parents were frightened of AIDS, but she did not appear to be aware of other parents’ research efforts.

Parents who supported the school’s decision to exclude Ryan frequently expressed their compassion for the White family; however, their sympathy did not overcome their worries. In addition to disputing medical information, both sides framed their position as opposing rights. The crux of the difference rested on the classification of AIDS as either a communicable disease or a disability. Western maintained that it would be illegal for them to grant Ryan White permission to attend school because state law mandated students with “communicable disease” be excluded. In support, concerned parents argued their children had the right to attend a school free from communicable diseases. Sylvia Payne went a step farther and urged the school not to give up their right to set local policy. Payne disputed the Indiana Department of Education, the state Board of Health, and the governor’s right to direct Western schools. In her words, “He [Governor

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Robert Orr] has no right, nor do his appointed officials, to break the law that protects my child, to any degree whatsoever.”103 Parents and community members also expressed suspicion that the case was being used to set state and national precedent. Portia Plummer openly speculated, “Is the concern the failure of the school corporation to admit a 13-year-old suffering AIDS or is the concern that this is the first real AIDS case in Indiana and could set a precedent for other states?”104 Kokomo residents were not the only ones who viewed the conflict as a test case. United Press International journalist Andrea Neal suggested the U.S. District Court in Indianapolis might resolve the dispute over whether AIDS was a contagious disease or disability.105 Two years later, the U.S. Supreme Court addressed the issue in the 1997 School Board of Nassau County, Florida v. Arline decision that ruled individuals with contagious diseases could qualify as handicapped under the Rehabilitation Act of 1973.

The case in support of Ryan’s school attendance stood on the protection against discrimination offered by the Education for All Handicapped Children Act of 1975.106 The law required schools to provide a free and appropriate public education that placed eligible children in schools and classrooms with children without disability to “the maximum extent appropriate.” Within days of the school’s decision to exclude Ryan, the Indiana Civil Liberties Union (ICLU) offered their assistance to the Whites’ attorney. The National Gay Task Force also considered taking legal action “on the grounds that this is a violation of the boy’s civil rights.”107 Two days after the initial decision barring Ryan from attendance, the Kokomo Tribune published an opinion piece that supported the State Board of Health guidelines as sufficient and achievable. The editorial compared parents’ fear of AIDS to past fears of people who had handicaps, epilepsy, and cancer, and argued Ryan had “every right to attend.” 108 In the response to Western’s

106 In the first legal phase, White’s attorney Charles Vaughan attempted to bring the case directly to federal court under Section 504 of the Rehabilitation Act. The U.S. District judge returned the case to the educational appeals process. Ryan qualified as a “handicapped child” because of his hemophilia and AIDS.
December appeal, the State Appeals Board found that Ryan’s homebound placement did not fulfill the school’s obligation to provide the least restrictive environment. The board also ruled that the first hearing officer did not have authority to circumvent state law requiring a health certificate. The new order stipulated that the regular classroom was the appropriate placement. Additionally, the school needed to acquire a Certificate of Health prior to Ryan’s readmission. In terms of rights, the board concluded, “The school system was acting within its legal rights not to admit the student under Indiana law without such a certificate.”

After receiving a health certificate and resolving a parent injunction, Ryan returned to Western schools for the 1986–1987 school year.

In 1987, the Whites moved to Cicero, Indiana, where they received a welcome reception at Hamilton Heights High School. Ryan continued his advocacy for AIDS education. He appeared on TV shows including 3–2–1 Contact, West 57th Street, and the Phil Donahue Show. Publications such as People and The Saturday Evening Post placed his story on the cover. His struggle caught the attention of several celebrities who befriended the family. Through it all, he insisted he was just a normal kid. As he told an audience of children, “I just try to do everything like everyone else, I always have, always will.” In many ways, Ryan did experience life as a normal teenager before his death in 1990. He earned his driver’s license, worked at a local skate shop, and attended prom. Learning about AIDS from Ryan White’s experience expanded the nation’s perception of normal. People with AIDS were family members, neighbors, classmates, and fellow workers. They continued to live their lives in the community. After his death in 1990, the Indiana State Board of Health recognized his accomplishments: “Ryan put a face and a name on the AIDS epidemic. He made the disease real and gave it a human element at a time when most people feared the disease and those who carried it.”

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110 “I Have AIDS: a Teenager’s Story,” 3–2–1 Contact series, directed by Ozzie Alfonso (New York, N.Y.: Children’s Television Workshop, 1988), VHS.

In *Impure Science: AIDS, Activism, and the Politics of Knowledge*, Steven Epstein investigated “credibility struggles” over the authority of AIDS knowledge, particularly the role of lay people as activists who influenced “the production of biomedical knowledge.” Kokomo parents did not stand within the sphere of scientific knowledge, but their dispute did demonstrate a struggle over the authority of knowledge. Parents trusted their own ability and authority to evaluate AIDS research. Mothers such as Mitzie Johnson organized and demanded a guarantee of safety. Emotion certainly influenced the actions of those opposed to Ryan’s school attendance, however, my research suggests that many parents also rationally evaluated information on AIDS communicability. The boundaries between parents, the school board, and the school administration are unclear. Within the political system of the local school, parent research appeared credible and marshalled community responses, some of which were deplorable. Jeanne White’s expertise originated in her personal contact with specialists and grew through her efforts to find treatment for her son. Although she did not have a group of organized parents supporting her efforts to get Ryan back in school, the weight of public medical opinion, the media, and the sympathy of many were on her side.

What happened in the Kokomo area was more than the story of a child. It was also a story of parents, a school, and a community. This article considers part of the story that has been concealed by the emotional tenor of the debate between parents who were fearful for their own children’s safety and the heartbreaking desire of a dying child’s wish to attend school. The public remembers agitated parent meetings in the auditorium, accounts of vandalism and ostracism, and Ryan’s perseverance. There is more to the story. The underlying disagreement centered on who should be the community gatekeeper of AIDS expertise. On both sides, mothers took responsibility to educate themselves and advocate for their children as leaders and lay medical experts as they fought against AIDS. The debate engaged the nation and brought the need for public education to the fore.

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