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T HE WEIGHT OF A CRISIS

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On May 16, 1969, a sixteen-year-old boy named Robert Rayford died in Deaconess Hospital in St. Louis. Baffled by the multitude of symptoms he had exhibited, doctors attributed his death to the generic “loss of vitality,” trying to describe how the young boy had gone pale and skinny. According to one of his doctors, Dr. Memory Elvin-Lewis, eventually “his entire body constituted almost one wave of hard lumps and watery swellings” (People) but no one knew why. I can’t imagine how frightened and alone he must have felt among the rows and rows of hospital beds, like stark-white rows of gravestones in progress. Robert had appeared to be stabilizing in late 1968 after nearly a year in the hospital, but with the new year came a vicious return of his symptoms. His body was swollen and aching, and he exhibited genital warts, a septic chlamydia infection, and shortness of breath in addition to his increasingly pale complexion and loss of weight. When he died, his doctors had no idea what killed him.

In 1984, a thirty-one-year-old man named Gaëtan Dugas died of a new virus that was cutting a swath through the gay community of the United States. Canadian-born himself, Dugas had begun working for Air Canada as a flight attendant in 1974, at age 20 or 21. Working for the Canadian airline meant that he spent much of his time in his native country, but by his own admission he did travel to San Francisco and New York City: hotspots for what was colloquially referred to as “gay cancer” in the late 1970s. Mysterious purplish lesions would appear on gay men, a hallmark that they too would soon fall deathly ill. Gaëtan was first diagnosed with Kaposi sarcoma, the official medical designation for “gay cancer,” in 1981. When he died, blood samples he had donated were preserved in a Centers for Disease Control study of this new epidemic: AIDS.

I first came across Robert Rayford in October 2017, completely by accident. My sister, Juliana, is studying to be a nurse. She loves medicine and medical facts, and loves to report the weird or gross or just plain interesting ones to me whenever she can. In October, in the midst of a conversation about schoolwork, I asked her in passing if she had any good “fun facts” for me. It was only her first semester in nursing school and I knew she loved to talk about it, so I was expecting some disturbingly detailed account of a dissection in her anatomy lab. What I got instead was this:

“Did you know AIDS was first called GRID? Gay related immunodeficiency.”

My stomach physically rolled and my mouth dropped open a little. I didn’t know much about the history of AIDS, so this was shocking to me. Even beyond that, I knew I was having such a visceral reaction to the not-so-fun fact because I identify as part of what we now call the LGBTQ+ community. My sister knows this; it’s why she thought I might be interested in this particular fact, and she wasn’t entirely wrong. The AIDS epidemic is an important part of LGBTQ+ history, and one I had never studied too far in depth. While we continued to text about classes and schoolwork, I pulled up Google on my computer and headed to my favorite, reliable information source: Wikipedia. As I was skimming past the scientific medical information I didn’t understand, I stumbled upon an interesting tidbit under the “History of Spread” section. One of the subheadings was “1969: Robert Rayford” and contained exactly three sentences. I learned three things from those

three sentences: first, Robert Rayford was black and sixteen years old when he died; second, doctors did not know that it was AIDS that killed him until 1987, almost twenty years after his death; and third, the doctors who treated him “suspected he was a prostitute or victim of sexual abuse.” He was, according to this timeline, the first patient in the United States confirmed to have an AIDS diagnosis. But these three sentences about Robert, the meager few paragraphs on his page, and the select few articles that cover his case are very nearly irrelevant compared to the library of information about Dugas.

The first study on AIDS was conducted in Los Angeles by the CDC, and its goal was to find out what exactly the mysterious illness killing gay men was. As part of that study, Dugas had willingly reported the names of more than seventy of his sexual partners and admitted that he generally had around 250 partners per year. He offered blood samples for the CDC researchers to run tests on. Scientists and doctors definitively diagnosed him with Kaposi sarcoma, but had no explanation for why he had developed this cancer. In the write-up of the study, men were grouped by their location of origin. Gaëtan, the only non-American, was labeled “Patient O” (pronounced oh, not the numeric value zero) for “Outside of California.” For the next three years, he was essentially unknown to anyone outside of the CDC--until Randy Shilts stepped into the picture of the AIDS crisis.

In 1987, Shilts published *And the Band Played On*, a book claiming to detail the movement of AIDS through the United States during the ongoing crisis. In the book, Shilts mislabels Gaëtan with the numeric “zero” instead of the alphabetic designation “O” and refers to him throughout as “Patient Zero.” Shilts admitted that he was confused by the labeling, and when he heard some people at the CDC refer to Dugas as “Patient Zero” he thought that it was catchy and decided to use it. While the book never outright claims that Gaëtan was the man who brought AIDS to the United States, it doesn’t do much to refute the idea. Shilts mentions Gaëtan’s profession as a flight attendant and the fact that he had sexual partners in nearly every city he visited. On top of that, “patient zero” is used by the medical community as a colloquial way to refer to index patients: the patient who is the first recorded case in an outbreak. This language and implied connection caught on in the public like wildfire. Gaëtan Dugas became one of the most hated dead men in the world; the *New York Post* wrote a front-page story about him with the headline, “The Man Who Gave Us AIDS.” The public’s anger only rose when they learned of Gaëtan’s sexual promiscuity and heard tales of his flamboyant personality. The gay community at the time condemned the single-patient zero angle that Shilts’ book seemed to promote, arguing that it would lay blame, and subsequently hatred, on the gay community as a whole. Inevitably, that’s exactly what happened. The gay community was bashed in the media and in everyday conversation, incorrectly identified as the sole carrier of AIDS. “AIDS patient” became synonymous with “homosexual,” to the point where the disease was thought of largely as a “gay disease” even when it began spreading into heterosexual individuals. But what if history hadn’t gone like that?

“He was the typical 15-year-old who is not going to talk to adults, especially when I’m white and he’s black,” Dr. Elvin-Lewis remembered in a 1987 *Chicago Tribune* article. She was one of the doctors assigned to Robert’s case in St. Louis, Missouri, way back in 1968. Closed into the hospital for over a year, dying of a disease that had no name, tumult seemed to surround Robert at every turn. According to census records, he and his family lived close to or on St. Louis’ infamous Delmar Boulevard, just blocks from City Hospital where he initially checked himself in. The east-west line Delmar creates as it runs across St. Louis is sometimes referred to as the “Delmar Divide:” black people live mostly to the south, white people live mostly to the north. This housing divide runs sharply along the line of Delmar Boulevard and tensions would have been at an all-time high with the rising power of the Civil Rights Movement.

Sometime during 1968, Robert was moved out of City Hospital, first to Barnes Hospital and then to Deaconess Hospital, all of which were in St. Louis. I can’t help but wonder if his movements were timed with the upheavals of 1968. Martin Luther King, Jr. was assassinated in April 1968; was that when Robert was moved to Barnes Hospital, tucked a little further south of Delmar, deeper into familiar territory? Was it the rising threat of race riots that sent Robert to Deaconess, deeper still into St. Louis’ black neighborhoods? Did his doctors move him to improve his care, or was his mother Constance afraid that staying too close to Delmar might mean an attack on the hospital protecting her young son?

Based on census records, Constance Rayford was around twenty-one years old when Robert was born in 1953. Rayford is her family name; she appears in census records as the daughter of Percy and Sadie Rayford of St. Louis. They might have all lived together, crowding into one too-small apartment to save money and have more hands to raise the young Robert. The neighborhood they lived in, now called Skinker DeBaliviere was comprised of mostly low-income black families. Robert came from modest means, to say the least. There is a chance Robert grew up in one of the city’s new public housing units, which went up in the 1950s and were known nationally for their low-quality construction and high crime rates. He may also have grown up in a small, run-down apartment with his mother and his grandparents, all struggling to make ends meet. Doctors from the time of Robert’s hospitalization suspected that he might have been slightly mentally disabled, based on how little and how simply he spoke; I wonder if the time he spent in the hospital was something of a relief to his mother. With Robert under lock and key in City or Barnes or Deaconess, Constance wouldn’t have had to keep an eye on him while she worked to support him.

After Robert’s death in 1969, two of his doctors, Dr. Elvin-Lewis and Dr. Marlys Witte, took blood and tissue samples from his body. They had been utterly perplexed by the sheer number and strength of diseases Robert had been carrying in his body; they hypothesized that something was suppressing his immune system, but had no way of knowing what. Dr. Witte took her samples with her when she accepted a job in Tucson, Arizona; Dr. Elvin-Lewis took a job at Washington University in St. Louis and kept her samples there with her.

When AIDS rose to the front of medical research in the early 1980s, Dr. Witte thawed her samples and tested them in 1984. She remembered Robert’s symptoms and wondered if this new virus might have been what killed him. She found evidence of “Herpes simplex, Cytomegalovirus and Epstein-Barr disease” (*Tribune*), three opportunistic infections that were common in AIDS patients. But at the time of Witte’s test, there was not yet a test for AIDS. As Gaëtan Dugas died and was immortalized in the CDC study, Witte had to sit back and wait for medicine to progress far enough that she could get the final answer to the question of whether or not Robert had died of AIDS.

By 1987, the Western Blot test had been developed and could finally give a definitive diagnosis of AIDS. Dr. Witte called her old colleague, Dr. Elvin-Lewis, to ask if she had any samples remaining in St. Louis. Dr. Elvin-Lewis dug “a half-teaspoon of Robert’s blood and a few specks of tissue” (*Tribune*) out of her freezer and let Dr. Witte send them to a microbiologist friend at Tulane University in New Orleans. Lo and behold, Robert’s samples tested positive for AIDS. He was officially the earliest confirmed case in the United States.

No one remembers Robert Rayford as the first AIDS patient because he is hardly spoken of at all. Other than a few newspaper articles from 1987, there is little mention of Robert Rayford in the history of AIDS. One reason could be the issues surrounding the scientific tests of his samples. Dr. Witte’s results from the 1987 Western Blot test were never published in a peer-reviewed journal before being leaked to the press, so some in the scientific community are skeptical of them. On top of that, Hurricane Katrina destroyed whatever remained of Robert’s tissue in 2005, when Tulane’s labs, and more importantly their freezers, lost power and many of their frozen samples were defrosted and contaminated.

But still, this story is undoubtedly sensational. Robert was just sixteen when he died, compared to Gaëtan’s thirty-

one. In fact, Robert and Gaëtan were born in the same year: 1953. If things had gone differently, if AIDS had never carved through the United States, perhaps they would have met. Perhaps one of Gaëtan's flights would have landed him in St. Louis and he would have taken a stroll down Delmar Boulevard to see the great race divide of the city and run into a black man named Robert, the same age as him. They could have talked about politics or the state of the city, or they could have walked right past each other without even noticing one another. Gaëtan might never have gone to Robert's neighborhood, or made it to St. Louis at all. But AIDS made it so we will never know.

Gaëtan Dugas has been highly publicized and politicized. A flamboyant, gay man infamous for sexual promiscuity made for the perfect scapegoat in the AIDS epidemic. He was easy to categorize and easy to warp into a villain, whether he was one or not. Robert's case is not so easy. He was only sixteen and insisted he had only ever participated in heterosexual sex. During the autopsy, however, the pathologist found anal scarring that indicated otherwise: was he gay but closeted? Or perhaps, as Dr. Witte theorized, he was a child prostitute? Is it possible that he was abused? And Robert's sexuality wasn't the only mystery about him; his reticence with his doctors meant that little personal information about him survives. It is difficult to scapegoat someone when no one seems to know anything about him. He was also black at a time when race was as much of a hot-button issue as AIDS. Would AIDS have been seen as a "black disease" instead of a gay one?

I know firsthand the way AIDS has changed not just the way outsiders look into the LGBTQ+ community, but the way the community looks at itself. While most people no longer assume that being non-straight automatically means you have AIDS, the fear of the virus is now embedded in the community's DNA. After years, decades of attacks and accusations from the outside, we have internalized others' fears of AIDS and turned them inward. I know there are a multitude of reasons for why the most comprehensive sex education I've ever received is from older LGBTQ+ friends, but I also know that AIDS is one of them because the phrase "safe sex" is tossed out at every available opportunity. I am intensely conscious of all STDs, not just AIDS, in a way that I know is different from many of my straight friends. My roommate often asks me questions about all kinds of topics, including health, sex, and sexuality, and when I ask why she's coming to me she tells me that I am the person she trusts to know the most about all of these topics. My community has been scarred by the AIDS epidemic; we are distrustful of each other in a way that would have been alien to Dugas during the sexual freedom of the 1970s. Our community was characterized by freedom and excess in the 70s, but it has changed to the caution and fear I see now, and AIDS and Gaëtan Dugas are the reasons.

Robert, on the other hand, was not openly queer; he never claimed any identity other than heterosexuality. But he was black. I can't help but wonder if, had his case been publicized and accepted the way Dugas' was, AIDS would have been known as a "black disease" more than a "gay disease." Or maybe it would have had neither of those identities. Maybe, had flamboyant, promiscuous Dugas and quiet, young Robert both been presented as the "first" victims of AIDS, Americans would have been forced to reconsider their prejudices and avoid attaching the disease to one group or another. Maybe if Robert had gained the same publicity that Dugas had, the LGBTQ+ community wouldn't have been hurt the way it was.

Robert Rayford and Gaëtan Dugas may not have been hurt by history in the same way, but that doesn't mean they weren't both hurt. Robert was forgotten, set aside in favor of a better, easier face for a disease: Dugas was attacked viciously and unwittingly became the symbol of the hate and stereotypes intertwined in the AIDS crisis. Putting them next to each other feels strange. Their legacies were disparate but they are unshakably connected by four little letters that changed, then ended, their lives. Perhaps it is not an accident that two such different people have both been placed at the beginning of AIDS in America. Together, Robert Rayford and Gaëtan Dugas have reminded me that nothing is as one-sided or simple as it seems. Knowing that the

history of AIDS has been rewritten and might go through more change in the future gives me hope that maybe one day my community can step outside the fear of AIDS and can heal from them is trust that has been cultivated by the weight of a crisis.

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