

**Intersectional “Inclusion”: Safety and Reproductive Justice in Clinical Studies of
Maternal-Fetal HIV Transmission**

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TABLE OF CONTENTS

Acknowledgements	3
Introduction	4
Part I: Historical Contexts	
Reproductive Health.....	8
Clinical Research.....	9
Part II: The Pre-Trial Years	
The Story of Carlotta.....	11
Women and HIV.....	14
Women of Color and HIV.....	16
Pregnancy and HIV.....	18
Activism for Inclusion.....	24
Part III: Trial 076	
The Stories of Sonia and Rosa.....	29
A Contested Meeting.....	30
The Trials.....	38
Part IV: The Aftermath	
The Stories of Anonymous Women.....	44
Testing Mandates and Reproductive Freedom.....	45
The Safety of AZT and Placebo Controls.....	48
What Pregnant Women with HIV Thought.....	50
Conclusion	50
Bibliography	53
Bibliographical Essay	60

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INTRODUCTION

Shouts. Blowhorns. A bloody fistfight.¹

The scene was not unusual for the AIDS Coalition to Unleash Power, or ACT UP, an activist group known for its dramatic direct actions pushing for urgent solutions to the AIDS crisis. It did, however, shock the group ACT UP disrupted: a panel of leading medical investigators and community activists.

They had just seated themselves for a panel discussion during the March 1991 conference of the NIH's AIDS Clinical Trial Group. The community activists represented multiple HIV advocacy organizations, many led by people of color. They hoped to discuss a developing clinical trial with researchers—some of whom, such as Dr. Janet Mitchell of New York's Harlem Hospital, also worked closely with and identified as people of color. The study, Trial 076, sought to administer the antiretroviral drug azidothymine (AZT) to pregnant women with HIV to reduce maternal-fetal transmission of the virus. The study would primarily impact women of color, who faced disproportionately high rates of HIV infection. Trial 076 brought hope to activist of colors' communities, which had been devastated by the epidemic. But right before their discussion began, the predominantly white feminists of ACT UP's Women Caucus interrupted, protesting to stop the trial.² The trial, they complained, prioritized fetal health over maternal health. And its employment of a placebo arm unethically withheld AZT treatment from participants.³

The activists of color would denounce ACT UP's actions as racist, a rude subversion of their attempts to learn more about Trial 076 on behalf of their communities.⁴ ACT UP's protests rejected, ACTG Trial 076 would proceed. It ran from 1991 to 1993, involving 477 pregnant

¹ Rollins, "A Seat at the Table," 63.

² Rollins, 63.

³ Schulman, *Let the Record Show*, 564.

⁴ Rollins, "A Seat at the Table," 64.

women, 79 percent of whom were non-white. Researchers found that administration of AZT led to a 67.5 percent reduction in maternal-fetal HIV transmission.⁵ In subsequent years, widespread administration of AZT to pregnant women with HIV would drastically improve outcomes for children.

Trial 076 began amidst new calls for clinical research equity in the 1980s. AIDS activist groups such as ACT UP adopted a “drugs into bodies” mentality, demanding a reformed drug development process that was faster, did not employ placebo controls, and included groups underrepresented in clinical research, such as women and people of color.⁶ This last demand stood in stark contrast to the history of clinical research involving vulnerable populations. For centuries, marginalized groups had had their safety threatened and bodies exploited in scientists’ quests for medical knowledge or innovation. Civil rights activists denounced these histories for their racist origins, while feminists protested them in the context of reproductive health. Attempts to prevent these abuses, however, led to restrictive research guidelines that excluded women and people of color, posing barriers for representative knowledge discovery. Driven in part by AIDS activism, throughout the 1990s, the medical field began to use deliberate inclusion of women and people of color as a key benchmark for equity.⁷

Though AIDS activists pushed for inclusion, gay, middle-class white men have dominated narratives of the epidemic. Historical accounts of HIV/AIDS medical research, from Randy Shilts’s *And the Band Played On* to Steven Epstein’s *Impure Science*, continue this trend. These texts center members of the gay community who participated in clinical research and research activism, alongside the scientists—also predominantly white men—with whom they

⁵ Connor et al., “Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment,” 1.

⁶ ACT UP, *Storm the N.I.H.*, 11-12.

⁷ Epstein, *Inclusion*, 30-52.

interacted.⁸ Existing literature on HIV/AIDS research tends to overlook the epidemic's ramifications for inclusive clinical research. It does not interrogate how the lived experiences of women and people of color influenced research participation in the epidemic.

ACTG Trial 076 serves as my lens to study this historical gap. The dramatic 1991 ACTG meeting epitomized the larger controversies of Trial 076. In turn, it reflected the messy struggles faced by pregnant women with HIV—the majority of whom were poor and non-white. ACT UP activists echoed common concerns surrounding the trial's ethics, including the safety of its protocols and its implications about women's reproductive rights. When activists of color denounced ACT UP as racist, they revealed the nuances and contradictions that accompany attempts at inclusionary clinical research. White ACT UP feminists spoke over women of color of activists, just as the historical record and colloquial narratives of the HIV epidemic erase the nuanced perspectives of women of color.

My essay attempts to reconstruct the lived experiences of pregnant women with HIV before, during, and after ACTG Trial 076. I lean on a variety of primary sources. I re-analyze records from medical professionals and activists—journal articles, advertisements, pamphlets, and oral histories—using the perspectives of pregnant women with HIV. I also refer to news articles, research papers, and obituaries that directly featured their words and stories. To uncover previously untold stories, I personally conducted oral histories with three medical professionals who treated pregnant women with HIV at Yale-New Haven Hospital.

Two controversies, as raised at the 1991 ACTG meeting, emerge in the discourse of Trial 076: the reproductive stigmatization of mothers with HIV and the safety of drug trials, shaped by racialized, gendered, and class-based contexts. Through these case studies, I argue that the

⁸ Shilts, *And the Band Played On: People, Politics, and the AIDS Epidemic*; Epstein, *Inclusion*.

interlocking and often contradictory fears and motivations of the women who participated in Trial 076 evaded the simplistic narratives of inclusion understood by medical researchers, government policymakers, and even activist organizations such as ACT UP. In this way, ACTG Trial 076 reveals the limits of clinical research “inclusion,” highlighting the necessity of intersectional frameworks for meaningful attempts at inclusion in future studies.

My analysis hinges on several definitions and frameworks. I define “reproductive stigma” as a social limitation to a woman’s healthcare decision-making that has roots in her potential to become pregnant. A woman might suffer from a societal perception that she is primarily a vessel for children, rather than an autonomous individual—thus, she may be expected to prioritize her fetus’s health over her own. A woman might also feel pressure to avoid or abort pregnancy due to her infection. I define “safety” in relation to risks that a clinical trial might pose to a research subject’s health. Patients could receive placebo controls when they desire experimental therapies, or an experimental drug may itself be toxic. The concept of intersectionality derives from the work of legal scholar Kimberlé Crenshaw. Based on the distinct violences faced by Black women, intersectionality maintains that oppressive systems based on categories of identity synergize into novel forms of injustice for those belonging to multiple categories.⁹ For the participants of Trial 076, gender, race, class, and disability status did not exist as separate spheres of marginalization; rather, they overlapped, shaping unique perspectives and struggles.

This story unfolds in four parts. Part I recounts historical inequalities that predated and informed the HIV/AIDS epidemic. I dissect decades-old tensions between inclusion and exploitation within clinical research, as well as interrogate lasting legacies of reproductive oppression. Part II recreates the social environments of the HIV/AIDS epidemic in the years

⁹ Crenshaw, “Mapping the Margins.”

prior to Trial 076. Layer by layer, I reconstruct the everyday difficulties faced by poor, pregnant women of color with HIV. Part III discusses Trial 076 itself. First, I cover the debates between white activists, activists of color, and medical practitioners of color surrounding Trial 076. I analyze how they did—or did not—reflect the experiences and decision-making of the women who would ultimately serve as the trial’s subjects. Then, I piece together women’s experiences during the trial. Part IV reveals how echoes of the same controversies persisted in the aftermath of Trial 076. The forces that shaped the research participation of pregnant women with HIV transcended Trial 076. Rather, they represented ongoing everyday realities with which pregnant women with HIV contended in their healthcare decision-making. Where possible, sections begin with narratives from pregnant women with AIDS. In this way, I seek to reinsert their voice in the historical record, as undiluted as possible.

PART I: HISTORICAL CONTEXTS

Reproductive Health: “The doubled discourse.”¹⁰

Long before the HIV/AIDS epidemic, women faced constraints in their reproductive decision-making. In the 19th century, white women and women of color faced diverging forms of oppression. Amidst the massive societal shifts brought by industrialization, the medical establishment characterized white women as “overcivilized” and “weak.”¹¹ White women bore responsibility for the future of the race through their childbirth, and their decreasing rates of childbirth triggered mass fears over a “race suicide.” In contrast, women of color were seen as “hardy” and “savage.”¹² Purporting to better society, medical practitioners subjected women

¹⁰ Briggs, “The Race of Hysteria,” 247.

¹¹ Briggs, “The Race of Hysteria,” 249-250.

¹² Briggs, 249-250.

deemed as “unfit”—women of color, poor women, and women with disabilities—to eugenic sterilizations throughout the early-20th century.¹³ Childbearing became a limiting responsibility for white women and an unattainable privilege for women possessing multiple categories of marginalization.

These alternative characterizations led white women and women of color to practice different forms of healthcare activism in the mid-20th century. White women denounced the notion that they were “vessels” or “vectors,” bodies for reproduction or agents of disease transmission to their children and sexual partners.¹⁴ To assert their autonomy, feminist activists pushed to expand access to birth control and abortion.¹⁵ Meanwhile, women of color defined reproductive freedom holistically, emphasizing their right to raise children. They sought an end to forced sterilization and advocated for greater access to childcare and medical care.¹⁶ Ideological tensions between white and non-white reproductive rights advocacy arose. For example, grassroots movements by women of color pushed for mandatory 30-day waiting periods for sterilization in the 1970s. But organizations run by middle-class white feminists, such as the National Organization for Women, opposed the proposals, viewing them as reproductively restrictive.¹⁷ In the debates over Trial 076, white feminist AIDS activists and AIDS activists of color would express similar viewpoints to their respective predecessors.

*Clinical Research: “When justice is reduced to distribution.”*¹⁸

¹³ Reilly, “Eugenics and Involuntary Sterilization.”

¹⁴ Faden, Kass, and McGraw, “Women as Vessels and Vectors: Lessons from the HIV Epidemic”; Eckenwiler, “Women and the Ethics of Clinical Research.”

¹⁵ ACT UP/New York Women and AIDS Book Group, *Women, AIDS, and Activism*, 203.

¹⁶ ACT UP/New York Women and AIDS Book Group, 201.

¹⁷ ACT UP/New York Women and AIDS Book Group, 201.

¹⁸ Eckenwiler, “Women and the Ethics of Clinical Research,” vi.

Throughout the mid-20th century, health care activists sought to ensure drug safety and prevent the exploitation of marginalized groups. They protested American scientists' centuries-long history of experimenting on Black, Indigenous, institutionalized, and poor people to develop medical innovations or build new understandings of disease. Scientists frequently employed coercive or misleading recruitment techniques, capitalizing off their subjects' need for food, housing, and medical care.¹⁹ In the 1960s and 1970s, feminists drew attention to ethical oversights in women's health. After the public learned in 1962 that thalidomide, a morning sickness drug for pregnant women, caused severe birth defects, women's health activists demanded more caution regarding the potential dangers of experimental drugs.²⁰ They also criticized the safety of the birth control pill—which was developed from experimentation on Puerto Rican women in the 1950s.^{21,22} Concerns over the exploitative potential of human subjects' research reached a climax in 1972, when the public learned of the Tuskegee Syphilis Study. For decades, U.S. Public Health Service researchers had withheld syphilis treatment from hundreds of poor, Black men in rural Alabama, misleading them about the nature of their illness. The public reacted with outrage. The federal government initiated Congressional committees and dispensed legislation and guidelines to protect human subjects in medical research. In 1974, the National Research Act formalized rigorous institutional review procedures that required informed consent and minimization of risk before investigators received federal funding.²³

¹⁹ Epstein, *Inclusion*, 42.

²⁰ Junod and Marks, "Women's Trials," 120.

²¹ Junod and Marks, 131.

²² For pregnant women of color, racialized conceptions of reproductive health created intersectional dangers in clinical research. In the 19th century, J. Marion Sims, the "father of modern gynecology," infamously developed his surgical cure for the vesicovaginal fistula through experimentation, without anesthesia, on enslaved women. As historian Laura Briggs writes, "the frailty and nervousness of [white women] provided the *raison d'être* of obstetrics and gynecology, while the insensate hardness of [women of color] offered the grounds on which they became the experimental "material" that defined its progress." The development of the birth control pill echoed this history. See Briggs, 247, 262-263.

²³ Epstein, *Inclusion*, 42-44.

But in their rush to avoid the exploitation of research subjects, legislators and research investigators overcompensated. In 1977, the FDA published its *General Conditions for the Clinical Evaluation of Drugs*. Ostensibly meant to protect women, the FDA advised that “women of childbearing potential should be excluded from the earliest dose ranging studies,” a policy that investigators tended to extend to all drug trial phases.²⁴ This practice barred researchers from gaining crucial information about dosing and efficacy. Protectionist policies also led the medical community to exclude Black Americans and other racial minorities from subsequent clinical trials.²⁵ Reflecting on these 1970s reforms to clinical research, historian Susan Reverby wrote, “The story [of the Tuskegee Syphilis Study] would become one of the failures of researchers to consider informed consent and of callous disregard of the vulnerable, often devoid of any analysis of race with barely a nod toward justice.”²⁶ True justice necessitated an understanding of ubiquitous medical hierarchies, which in some scenarios exploited bodies for experimentation and in others deemed groups as excludable. In the following decades, AIDS activists would push for this understanding.

PART II: THE PRE-TRIAL YEARS

*The Story of Carlotta: “A modern-day Typhoid Mary.”*²⁷

In 1983, fearful whispers about AIDS rippled through New Haven, Connecticut. The AIDS clinic of Yale-New Haven Hospital was tracking roughly 250 potential cases in the area—an number intimidating but small enough for individual cases to rise to notoriety.²⁸ Hospital staff

²⁴ Eckenwiler, “Women and the Ethics of Clinical Research,” 5.

²⁵ Epstein, *Inclusion*, 60.

²⁶ Reverby, *Examining Tuskegee*, 188.

²⁷ Sides, “Lana: A Story of Scarlet Letters and Public Risks,” 17. New Haven residents gossiping about Carlotta’s HIV/AIDS status would allude to the infamous Mary Malone, the Irish immigrant cook scapegoated for spreading typhoid fever to dozens in the early-20th century.

²⁸ Sides, 16.

suspected that an unnamed local sex worker had AIDS after she gave birth to a child with alarming symptoms. Journalists pestered medical professionals with “invasive questions” seeking her identity.²⁹ Scholars, government officials, community activists, and law enforcement debated the sex worker’s rights to privacy in matters of public health.³⁰ In early 1984, local news outlets reported the arrest of Carlotta Locklear, a Black sex worker, on drug-related charges. Locklear, the stories emphasized, had AIDS.³¹ A flood of national coverage—including a dedicated *60 Minutes* segment—ensued.³²

Carlotta Locklear was born in Detroit, Michigan in 1955.³³ Her mother, a single parent who struggled with alcoholism, died when Carlotta was a child. Later, a relative sexually abused her. As a teen, she aspired to be a nurse. But after a pregnancy at age fifteen, she turned to sex work, navigating emotional turmoil after she put her child up for adoption.³⁴ She developed a heroin dependency that cost her \$200 a day, though she sought rehabilitation at multiple drug treatment programs.³⁵ In 1983, she became pregnant with a boy. She “thought it was a miracle” and named the child Rayshaun.³⁶

Described as “sweet” and “soft-spoken” by her friends and family, Carlotta loved and provided. She cared for neighbors ignored by others, loaned money to those with less than her. Above all, she loved Rayshaun. She grew “distracted” after he fell ill. When the state attempted to remove him from her care, she distanced herself from drugs and sex work to search for a new

²⁹ Stern, “Rethinking Complicity in the Surveillance of Sex Workers: Policing and Prostitution in America’s Model City,” 466.

³⁰ Sides, 16-20.

³¹ Megan, “Program Gets AIDS Suspect.”

³² Gerber, “‘A Modern-Day Typhoid Mary’: The Response to a New Haven Prostitute with AIDS in the Early 1980s,” 26.

³³ Gerber, 11.

³⁴ Chinlund, “AIDS Claims a Woman--and Her Hopes.”

³⁵ Chinlund; Sides, “Lana: A Story of Scarlet Letters and Public Risks,” 16.

³⁶ Sides, “Lana: A Story of Scarlet Letters and Public Risks”; Chinlund, “AIDS Claims a Woman--and Her Hopes.”

apartment. She ultimately lost her case, giving up Rayshaun in an “extraordinarily painful” decision.³⁷ His condition kept at him at the hospital until he died at age two-and-a-half.³⁸

Trauma, financial instability, drug dependency, separation from loved ones—these comprised Carlotta’s main concerns when she received her AIDS diagnosis. At the end of 1983, she checked herself into a hospital with pneumonia, a likely result of AIDS. Fear did not shake her—“she had been hustling for nine years” already. She longed for Rayshaun, “pull[ing] down three polaroid snapshots of her baby from the wall” of her room. After her stay in the hospital, she returned to sex work to support herself.³⁹

When media outlets nationwide revealed Carlotta’s identity, she faced the added burden of stigma. Friends turned their backs on her and medical professionals refused to treat her.⁴⁰ People threw rocks at her and left rooms when she entered. Harassment by clients angry at her AIDS status compromised her sex work: “I can’t even walk to a car because I’m afraid they’ll blow my head off,” she recounted to local newspapers.⁴¹

Carlotta died in January of 1985. She did not trust her doctors, who had taken her baby from her, shunned her, and diagnosed her with an illness that brought her national stigma. She delayed a hospital visit until illness made it unavoidable. Her death certificate named the primary cause of death as pneumonia, with a secondary cause of AIDS.⁴²

From Carlotta Locklear, we might envision the experiences of other pregnant women of color with HIV. Among women, HIV disproportionately threatened those Black and Latine.⁴³ Like Carlotta, many bore the weight of intergenerational trauma and financial insecurity—

³⁷ Chinlund, “AIDS Claims a Woman--and Her Hopes.”

³⁸ “Son of AIDS Victim Dies.”

³⁹ Sides, 16.

⁴⁰ Kearns, “Treatment Refused to AIDS Victim”; Chinlund, “AIDS Claims a Woman--and Her Hopes.”

⁴¹ Chinlund, “AIDS Claims a Woman--and Her Hopes”; Kearns, “Treatment Refused to AIDS Victim.”

⁴² Chinlund, “AIDS Claims a Woman--and Her Hopes.”

⁴³ Centers for Disease Control and Prevention, “Update: AIDS Among Women -- United States, 1994.”

shaped by centuries of oppressive racial, socioeconomic, and gender structures—that limited their career or familial choices and made them more vulnerable to drug use. Many, upon their diagnosis with HIV, faced isolation and fear after being stigmatized as a vector of disease for their children or sexual partners. Their medical practitioners may have treated them with callousness, instilling distrust.

With this in mind, we might reframe the narrative of Carlotta’s decision to continue sex work knowing her AIDS status. She had no other options: she had to work to support herself. She did not trust her doctors. She was afraid. Her choice, when contextualized by her life both before and after her diagnosis, reflects an attempt at agency within a system that had severely limited that for her. And through it all, she loved her child, his health always at the forefront of her mind.

Women and HIV: “The difference between life and death.”⁴⁴

Early in the HIV/AIDS epidemic, the public focused on the virus’s spread among gay men. In sharp contrast to “innocent victims”—those who unluckily received transfusions of infected blood, or children born to mothers with HIV—gay men faced heavy stigmatization, their diagnosis painted as a moral failing.⁴⁵ Though other marginalized groups, like sex workers and people who inject drugs, also faced similar AIDS-related stigma, gay men predominated conceptions of the epidemic.⁴⁶ Members of the gay community helmed activism efforts that demanded recognition of the crisis and sought protections for the rights of people with AIDS. By 1987, researchers showed that the drug azidothymidine (AZT), also known as zidovudine,

⁴⁴ Banzhaf, ACT UP Oral History Project. Banzhaf referred to women’s exclusion from definitions of AIDS.

⁴⁵ Kazanjian, “The AIDS Pandemic in Historic Perspective,” 353-356.

⁴⁶ Kazanjian, 353-356.

improved AIDS outcomes by preventing viral replication.⁴⁷ AZT, however, was far from a “magic bullet” therapy: the virus often developed resistance within a year of treatment.⁴⁸ AIDS activists, dissatisfied with the state of drug development, protested for better options. The AIDS Coalition to Unleash Power (ACT UP) formed that year.⁴⁹

Among other demands, ACT UP sought reforms to the clinical trial process helmed by government agencies such the Food and Drug Administration (FDA) and the National Institute of Allergy and Infectious Diseases (NIAID), a division of the National Institutes of Health (NIH). In ACT UP’s first demonstration, held in March of 1987, hundreds of activists shut down traffic for over three hours on New York’s Wall Street. Flyers urged “Immediate release by the Federal Food & Drug Administration of drugs that might help save our lives” and “Immediate abolishment of cruel double-blind studies wherein some get new drugs and some don’t.”⁵⁰ Amidst this activism, in December of 1987, the NIAID held its first AIDS Clinical Trials Group (ACTG) meeting.⁵¹ The demographics of subsequent ACTG-helmed studies mirrored those in common media depictions of AIDS: in 1988, 95% of participants were men, and 83% were white.⁵²

Women with AIDS, in turn, saw their symptoms dismissed by medical providers, forcing them to face illness without appropriate assistance. In 1989, women represented 9 percent of U.S. AIDS cases; roughly half were exposed to the virus through intravenous drug use, while around one-third received it through heterosexual contact.⁵³ Physicians underdiagnosed women,

⁴⁷ Fischl et al., “The Efficacy of Azidothymidine (AZT) in the Treatment of Patients with AIDS and AIDS-Related Complex.”

⁴⁸ Kazanjian, “The AIDS Pandemic in Historic Perspective,” 357.

⁴⁹ Schulman, *Let the Record Show*, 9.

⁵⁰ “Flyer of the First ACT UP Action March 24, 1987, Wall Street, New York City”; “MASSIVE DEMONSTRATION BY ACT-UP.”

⁵¹ Rollins, “A Seat at the Table,” 47.

⁵² Mueller, “‘Women and Minorities’ in Federal Research for AIDS.”

⁵³ ACT UP/New York Women and AIDS Book Group, *Women, AIDS, and Activism*, 2-3.

dismissing their claims as “hysterical.”⁵⁴ The CDC’s case definitions for AIDS, built primarily on studies of gay men, excluded women-specific experiences such as cervical cancer and pelvic inflammatory disease.⁵⁵ In 1988, Elizabeth Ramos, a native of Boston, died after her healthcare providers at the Harvard Community Health Plan refused to recognize her pneumonia as a sign of AIDS.⁵⁶ Without a clear diagnosis, women also could not access disability benefits to afford treatment.⁵⁷

*Women of Color and HIV: “They treat you so bad, it’s terrible.”*⁵⁸

Living in majority-Black and Latine Harlem, Rosanne Perez received her AIDS diagnosis a few years after she had successfully overcome a heroin dependency. She bore her AIDS symptoms—quivering hands and weak legs, “sheet-soaking fevers,” and pain so severe she “just [lay] in [her] bed and cr[ied]”—while surviving on welfare and food stamps worth less than \$400 a month.⁵⁹ The epidemic did not harm all women equally. The first reports of women with HIV emerged in early 1983, when the CDC’s *MMWR* described two case studies, a 37-year-old Black woman and a 23-year-old Latine woman who developed immune failure after sexual relations with men with AIDS.⁶⁰ By the end of the decade, Black and Latine women comprised 70 to 80 percent of women with AIDS in the United States.⁶¹

⁵⁴ Murray, “‘It Is Time to Come’; An Activist Perspective on the First National Women and HIV Conference.”

⁵⁵ Johnson, “Women with HIV Infection,” 2-4.

⁵⁶ Murray, “‘It Is Time to Come’; An Activist Perspective on the First National Women and HIV Conference.”

⁵⁷ Johnson, “Women with HIV Infection,” 4.

⁵⁸ Cooper, “The AIDS Epidemic in Harlem.” Rosanne Perez, a woman of color with AIDS, used this language in reference to her physicians, reflecting the inadequacy of the medical care she encountered and the ensuing distrust she felt.

⁵⁹ Cooper.

⁶⁰ Centers for Disease Control and Prevention, “Immunodeficiency among Female Sexual Partners of Males with Acquired Immune Deficiency Syndrome (AIDS) -- New York.”

⁶¹ Navarro, “In Hispanic Community, Many Ignore AIDS”; Murray, “‘It Is Time to Come’; An Activist Perspective on the First National Women and HIV Conference”; Nealon, “‘We’re Not Counting Everyone’; Activists from around the Country Return to the Centers for Disease Control to Demand Expanded Definitions of AIDS That Include Conditions Affecting Women.”

Black and Latine women faced, in short, medical and economic manifestations of structural racism. Increased rates of poverty decreased access to treatment and prevention.⁶² Medical professionals noted that Black and Latine people with AIDS often received treatment from public hospitals “ready to collapse... scarcely able to provide even basic services.”⁶³ In the immediate years following AZT’s approval, treatment cost \$8000 a year and could reach upwards of \$15,000.⁶⁴ Though Medicaid and social security disability programs theoretically provided financial assistance for AIDS treatment since 1983, discriminatory or stringent policies left gaps in insurance until the federal government passed the Ryan White Comprehensive AIDS Resources Emergency Act in 1990.⁶⁵ Some poor women, moreover, struggled to afford basic preventative measures: “Asking a woman on a fixed income to purchase condoms ‘in case’ when food is always needed [exemplifies that] education is not the same as knowledge,” said Vickie Mays, a UCLA psychologist, at the 1990 National Women and HIV Conference.⁶⁶ Racially disparate economic conditions decreased women of color’s access to preventative and therapeutic medical care, heightening risk and worsening outcomes for HIV/AIDS.

Beyond medical care, poor people with AIDS also struggled to access their basic needs. An ACT UP pamphlet from the early-1990s advertised that “50% of women with AIDS virus in San Francisco have been HOMELESS at some point during their HIV+ status.”⁶⁷ At Yale-New Haven Hospital, where Black or Latine people represented 75% of patients with AIDS, women with AIDS frequently received assistance through a social worker for food, housing,

⁶² Navarro, “In Hispanic Community, Many Ignore AIDS”; Cooper, “The AIDS Epidemic in Harlem.”

⁶³ Children and HIV Infection, 26.

⁶⁴ Johnson, “Women with HIV Infection,” 4; “AZT’s Inhuman Cost.”

⁶⁵ Padamsee, “Fighting an Epidemic in Political Context,” 1009.

⁶⁶ Murray, “‘It Is Time to Come’: An Activist Perspective on the First National Women and HIV Conference.”

⁶⁷ ACT UP Golden Gate, “WORLD AIDS DAY: THE CENTER FOR DISEASE CONTROL’S POLICIES ON WOMEN WITH HIV INFECTION.”

transportation, and access to medical insurance.⁶⁸ For women of color, HIV—and medical care more broadly—represented just one threat among a slew of limitations to their everyday survival.

Some women of color also dreaded medical care, aware of historical and ongoing oversight or abuse by medical professionals. Sunny Rumsey, an Afro-Caribbean and Indigenous AIDS activist, wrote, “When people of color with AIDS entered the overburdened medical system, they saw they weren’t given the same level of care as their white counterparts.”⁶⁹

Rosanne Perez did not trust her medical providers, telling *New York Amsterdam Times*, “The doctors ignore you, it’s like you don’t exist.”⁷⁰ Women of color sometimes delayed AIDS treatment until death seemed imminent.⁷¹ Others may have resisted clinical trials. Cuban American physician Hortensia Amaro said that she was “suspicious of the wish for ‘research subjects,’” alluding to past exploitations of women and people of color at the hands of clinical research.⁷² Histories and personal experiences of medical neglect influenced women of color’s hesitancy to accept care and participate in clinical trials.

*Pregnancy and HIV: “Am I heartless to bring a child into the world to die?”*⁷³

Like Carlotta Locklear, Frankie Mason grew up with a single mother who struggled with alcoholism. Though for a period Frankie faced drug dependency and relied on sex work for income, she spent time at a detoxification center in Washington, D.C. and “began to want to live differently.”⁷⁴ She fell in love, became pregnant, and “was happy and very hopeful”—until she

⁶⁸ Andiman, interview.

⁶⁹ ACT UP/New York Women and AIDS Book Group, *Women, AIDS, and Activism*, 104.

⁷⁰ Cooper, “The AIDS Epidemic in Harlem.”

⁷¹ Navarro, “In Hispanic Community, Many Ignore AIDS.”

⁷² Murray, “‘It Is Time to Come’; An Activist Perspective on the First National Women and HIV Conference.”

⁷³ Kurth, *Until the Cure: Caring for Women with HIV*, 212. Spoken by Cheryl Smith, a pregnant woman with HIV, this quote epitomizes the profound turmoil those in her situation faced regarding their reproductive healthcare decisions.

⁷⁴ Kurth, *Until the Cure: Caring for Women with HIV*, 19.

received a positive test for AIDS.⁷⁵ Her doctors counseled her to receive an abortion, because her baby “would stand a fifty-fifty chance of living with full-blown AIDS and dying in three to five years, or dying within weeks after birth.”⁷⁶ In reality, with no treatment yet available, women with HIV had roughly a one-quarter chance of having a child with HIV.⁷⁷ Whether Frankie misremembered this or whether her physician misled remains unclear. Pregnant women with HIV like Frankie faced a unique set of frustrations and pressures. Illness added to the pressures of pregnancy, already a battleground for issues of bodily autonomy.

Some pregnant women with HIV were pushed to receive abortions or heard widely propagated rumors about the practice.⁷⁸ When their physicians introduced the possibility of abortion without appropriate thoroughness or sensitivity, their distress heightened. Frankie, for example, felt her years of personal growth disintegrate: “I went on a mission of suicide for my baby and myself,” she said, turning back to sex work “in the hopes that someone would help me kill myself because the alcohol and drugs were not doing it.”⁷⁹ Frankie did not elect to receive an abortion,⁸⁰ but the counseling she received contributed to her sense of helplessness.

Frankie, a Black woman, contended with more than her individual turmoil: when women of color made reproductive decisions, they maintained awareness of historical eugenic sterilization abuse. Rumsey reflected on these legacies, writing, “There’s a lot of subtle and not so subtle pressure on HIV-positive women, most of whom are women of color, to have abortions or get sterilized.” This, in combination with histories of neglect, led “some segments of these

⁷⁵ Kurth, 20.

⁷⁶ Kurth, 20.

⁷⁷ Centers for Disease Control and Prevention, “Recommendations of the U.S. Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus,” 3.

⁷⁸ ACT UP/New York Women and AIDS Book Group, *Women, AIDS, and Activism*, 159.

⁷⁹ Kurth, *Until the Cure: Caring for Women with HIV*.

⁸⁰ Kurth, 20.

communities to suspect the government of wanting to eliminate part of the population.”⁸¹ Rumsey’s words are contextualized by fears within the African American community that the government had developed AIDS—particularly AIDS in women—as a targeted means of population control. In 1990, *Essence* magazine published an article entitled “Is it Genocide?” Citing the abuses of slavery and the Tuskegee Syphilis Study, some researchers in the article believed that “the virus was produced to limit the number of African people and people of color in the world.”⁸² These discussions centered on Black women. Reverend Cecil Williams proposed that “the introduction of... the AIDS that crack-addicted prostitutes often contract was conceived expressly to prevent the Black community’s functioning.”⁸³ The article emphasized that medical and social supports could “decrease the numbers of women who are contracting AIDS... and subsequently passing it on to their children.”⁸⁴ Black women with AIDS who became pregnant may have felt the weight of this discourse in their childbearing decisions, heightening both their emotional burden and their distrust in medical providers.

Analyzing women’s decisions to continue with pregnancy after learning of their HIV status—or choosing to become pregnant while knowing it—reveals the emotional strength they derived from their childbearing decisions. Women with AIDS maintained a multidimensional protectiveness over their reproductive freedoms—not just the right to abortion, a hallmark demand of white feminists, but also to have and provide for healthy, loved children. Janet Mitchell, an obstetrician at Harlem Hospital, observed that for some women, pregnancy gave purpose. “Numerous studies have shown that pregnancy is a strong motive for women [who used

⁸¹ ACT UP/New York Women and AIDS Book Group, *Women, AIDS, and Activism*, 104.

⁸² Bates, “Is It Genocide?,” 78.

⁸³ Bates, 78.

⁸⁴ Bates, 118.

drugs] to go ‘straight,’” she said.⁸⁵ A child represented companionship, ownership, and love: “I really wanted something of mine, you know, mine, mine. I don’t have nothing in this world... nothing that I really care about,” a woman with HIV told an anthropological researcher.⁸⁶ For some women, this love transcended to the afterlife. In less than two years, AIDS took Alicia Gonzales’s husband, brother, and three brothers-in-law. When Gonzales, who had HIV, learned of her pregnancy, she “decided to bear the child... in honor of the memory of her husband.”⁸⁷ Gonzales, like many women with HIV, had dealt with profound loss throughout the epidemic. A new child provided solace.

Pregnant women were well-aware of the risks of their pregnancy but persevered out of a sense of hope and duty. Diane, a woman Brooklyn, received her positive HIV test while two months pregnant. She “spent weeks calling prenatal clinics, university research centers and AIDS hot lines seeking the latest information on the risks to herself and the fetus.”⁸⁸ Ultimately, she chose to have the baby for religious reasons. In an interview with *The New York Times*, she emphasized, “I didn’t say, ‘I’m going to have the baby and that’s it.’ I got the facts.”⁸⁹ When Cheryl Smith learned of her HIV positive status, several family members encouraged abortion. After significant turmoil, Smith gave birth to her child, a girl, saying “Hopefully, I’ll have the strength to deal with it if she does get sick. I’m hoping that if I take care of myself it’ll be okay for my baby.”⁹⁰ Pregnant women with HIV understood the risks in their decision to have

⁸⁵ Levine and Dubler, “Uncertain Risks and Bitter Realities,” 334.

⁸⁶ Levine and Dubler, 334-335.

⁸⁷ Pivnick, “HIV Infection and the Meaning of Condoms,” 435.

⁸⁸ Navarro, “Women With AIDS Virus.”

⁸⁹ Navarro.

⁹⁰ Kurth, *Until the Cure: Caring for Women with HIV*, 212-213.

children. But when viewed alongside the loss and fear that the virus had brought upon them and their families, the purpose, love, and hope a child represented outweighed the risk.⁹¹

Though many pregnant women with HIV strived to raise and protect children, some may have felt their own health deprioritized for their fetus's. This echoed feminist oppositions to the portrayal of women as “vectors” and “vessels.”⁹² Government responses embodied this practice: *MMWR*'s first documentation of a woman with AIDS occurred as an afterthought in a report on infants with “unexplained immunodeficiency and opportunistic infections.”⁹³ Congress's held its first in-depth discussion of women with HIV at its *Children and HIV Infection* hearing in 1989.⁹⁴ And the earliest women-focused HIV research efforts—including the first three ACTG studies involving women—focused specifically on maternal-fetal transmission.⁹⁵ Dr. Janet Mitchell, Chief of Perinatology at Harlem Hospital, reflected, “The whole issue of women and AIDS didn't come to fruition because women were getting sick and dying. It came because of pediatric AIDS and those poor innocent children.”⁹⁶ Black and Latine women experienced the frustration of medical neglect on two fronts: as people of color devalued relative to their white counterparts and as women devalued relative to their fetuses.

The “vessels” and “vectors” perception also made pregnant women particularly vulnerable to stigma. HIV activist Judith Walker wrote that if a pregnant women gave birth to a child with HIV, “it [could] mean being treated as if she [was] solely responsible for her child's

⁹¹ Some women, after delivery, would not get to take their babies home. By law, hospitals could not discharge babies to women struggling with addiction—and about half of women with HIV used intravenous drugs. In these instances, women faced the raw trauma of separation. See Andiman, interview.

⁹² Faden, Kass, and McGraw, “Women as Vessels and Vectors: Lessons from the HIV Epidemic”; Eckenwiler, “Women and the Ethics of Clinical Research.”

⁹³ Centers for Disease Control and Prevention, “Unexplained Immunodeficiency and Opportunistic Infections in Infants -- New York, New Jersey, California.”

⁹⁴ *Children and HIV Infection*.

⁹⁵ Faden, Kass, and McGraw, “Women as Vessels and Vectors: Lessons from the HIV Epidemic,” 262.

⁹⁶ Lovvorn, Quinn, and Jolly, “HIV Testing of Pregnant Women,” 408.

illness (as if men did not play a role in HIV transmission).⁹⁷ A 1988 flyer pushing women to seek HIV testing before pregnancy embodied this stigma. “She has her father’s eyes and her mother’s AIDS,” it proclaimed, next to a photograph of a Black baby sitting against a pastel pink background (Figure 1).⁹⁸ Placing blame for the child’s AIDS status on a woman implied to be Black, the ad reinforced gendered and racialized dimensions of blame. From stigma to dismissal, pregnant women felt amplified versions of the frustrations others with HIV experienced.



Figure 1. A 1988 ad urging HIV testing before pregnancy.⁹⁹

Ultimately, pregnant women with HIV were people with HIV, contending with the profound fear and frustration that accompanied diagnosis. Heather Reynolds, directory of nurse-

⁹⁷ ACT UP/New York Women and AIDS Book Group, *Women, AIDS, and Activism*, 171.

⁹⁸ Clement Communications, *She Has Her Father's Eyes and Her Mother's AIDS*.

⁹⁹ Clement Communications.

midwifery practice at Yale-New Haven Hospital at the height of the epidemic, recalled one “beautiful” and “wonderful” young woman who tested positive for HIV while pregnant.¹⁰⁰ Reynolds informed the woman in a social worker’s office. “The panic and fear that she exhibited—there was no treatment [at the time]. So this was like a death sentence,” Reynolds recounted. “She was like, ‘So that’s it? That’s all?’ It was almost like her life was over.”¹⁰¹

Some pregnant women sought to weaponize their experiences for change. Dr. Nancy Angoff, who treated AIDS patients at Yale-New Haven Hospital in the early-1990s, recalled a woman who learned of her HIV-positive status after eight years of trying to become pregnant. Initially, Angoff said, the woman was “legitimately angry” and expressed suicidal thoughts.¹⁰² She gave birth to a child with HIV. Over time, she became a proud AIDS activist: she pushed for lessons on HIV at her child’s school, and, when others questioned her right to park her red convertible in handicap spaces at Stop and Shop, “She would stand up and go, ‘I have AIDS.’”¹⁰³

“She really went from feeling her life wasn’t worth anything to feeling, ‘This is my cause. I’m going to make a difference,’” Angoff said. The woman died when her child was six.¹⁰⁴

*Activism for Inclusion: “We’re not counting everyone.”*¹⁰⁵

When CDC officials arrived at their agency’s Atlanta headquarters on December 3, 1990, they met a group of 500 angry activists.¹⁰⁶ “Blood-red handprints” decorated the walls of the

¹⁰⁰ Reynolds, interview.

¹⁰¹ Reynolds.

¹⁰² Angoff, interview.

¹⁰³ Angoff.

¹⁰⁴ Angoff.

¹⁰⁵ Nealon, “‘We’re Not Counting Everyone’; Activists from around the Country Return to the Centers for Disease Control to Demand Expanded Definitions of AIDS That Include Conditions Affecting Women.”

¹⁰⁶ Nealon.

buildings.¹⁰⁷ The ACT UP Women’s Caucus had organized the demonstration, demanding that the agency change its definition of AIDS to include symptoms specific to women.¹⁰⁸

ACT UP’s Women’s Caucus—comprised of predominantly white women, some who lived with HIV¹⁰⁹—organized a slew of demonstrations highlighting women’s AIDS issues. In 1990, they published the landmark book *Women, AIDS, and Activism*. A collection of essays authored by ACT UP women’s activists and their non-white peers, the book sought to “advance research by and about women in the AIDS crisis, provide information about women’s particular needs, analyze the impact of AIDS on women’s lives from a feminist perspective, and promote grassroots evidence.”¹¹⁰ The book’s message paralleled the group’s larger goals. Their activism worked, leading government officials and scientists to make tangible steps by 1990: the ACTG formed a Women’s Committee in November, and in December, the FDA and NIH sponsored the first National Women and HIV Conference.¹¹¹

ACT UP activists also advocated for reform to clinical research protocols that excluded women and people of color. At another protest in 1990, 1,500 activists “storm[ed] the NIH,” calling for an “end [to] medical apartheid.”¹¹² They demanded that new clinical trials include underrepresented groups, such as women and people of color. To do this, a pamphlet for the protest specified, the ACTG should “provid[e] health care, transportation subsidies, child care, and addiction treatment,” a recognition of the structural barriers to underrepresented groups’ research participation.¹¹³

¹⁰⁷ Nealon.

¹⁰⁸ Nealon.

¹⁰⁹ ACT UP/New York Women and AIDS Book Group, *Women, AIDS, and Activism*, vii.

¹¹⁰ ACT UP/New York Women and AIDS Book Group.

¹¹¹ Murray, “‘It Is Time to Come’; An Activist Perspective on the First National Women and HIV Conference.”

¹¹² Schulman, *Let the Record Show*, 663; ACT UP, *Storm the N.I.H.*, 11.

¹¹³ ACT UP, *Storm the N.I.H.*, 11.

ACT UP activists joined health reformers in the mid-1980s who advocated for the clinical research inclusion of marginalized groups, such as women and people of color. Restrictive research guidelines, issued in the 1970s to prevent exploitative practices, had contradictorily led to the underrepresentation of these groups in clinical trials.¹¹⁴ Sociologist Steven Epstein has termed this “the inclusion-and-difference paradigm”: a shifting attention towards the inclusion—rather than the protection—of marginalized and underrepresented groups in clinical research, based on logic that observing inter-group differences will improve treatment outcomes.¹¹⁵ By 1993, the NIH established quotas for the inclusion of women and racial minorities in studies seeking federal funding.¹¹⁶ AIDS activists worked parallel to—and contributed significantly towards understandings of—new frameworks for equity clinical research.

But for some groups, such as ACT UP’s Women’s Caucus, the historical legacies of mid-20th century research abuses still lingered. In *Women, AIDS, and Activism*, for example, members cited examples of thalidomide and the birth control pill in urging caution in HIV drug clinical research.¹¹⁷ They concluded that “the AIDS activist agenda has always pushed for accelerated drug approval, but this may represent a conflict between the interests of men and women in the AIDS epidemic.”¹¹⁸ Divisions within ACT UP echoed philosophical tensions within the field of clinical research.

*Centering Love: “Is your love healthy?”*¹¹⁹

¹¹⁴ Epstein, *Inclusion*, 54-73.

¹¹⁵ Epstein, 6.

¹¹⁶ Epstein, 184.

¹¹⁷ ACT UP/New York Women and AIDS Book Group, *Women, AIDS, and Activism*, 207.

¹¹⁸ ACT UP/New York Women and AIDS Book Group, 206-207.

¹¹⁹ Royles, *To Make the Wounded Whole*, 200. A question Dazon Dixon Diallo asked participants at her “Healthy Love” workshops.

Women of color developed their own approaches to AIDS activism, tailored to the multifaceted challenges faced by their communities. When Dazon Dixon Diallo talked to Black women about AIDS, she approached the topic not from ACT UP's esoteric angles of clinical research or disease definition, but instead, with a series of questions: "If you love someone who beats on you and yells constantly, is your love healthy? If your partner is using drugs, and you may have tried them because you love him/her, is your love healthy?"¹²⁰

Diallo's "Healthy Love" curriculum originated through her work with the Women AIDS Prevention Project in Atlanta, Georgia. In 1989, she started a new organization, SisterLove. SisterLove approached AIDS with a distinct awareness for the "gigantic Pandora's box of the social ills and oppression that women of color are existing or surviving through."¹²¹ It sometimes partnered with ACT UP, both organizations recognizing AIDS's disparate impact on poor women of color. Diallo, for example, wrote a chapter in ACT UP's *Women, AIDS, and Activism* book.¹²² But SisterLove's members did not feel safe adopting ACT UP's more confrontational tactics: "As southern women and black southern women, we learned for generations that... the more angry you get, the worse your punishment will be, not the better," Diallo said.¹²³ Instead, SisterLove's programs focused on education and prevention. The organization championed "self-help"—a concept originating within the women's health movement that, within Black feminism, "came to mean therapeutic collective conversation about Black women's experiences" with racism and sexism, particularly within sexuality and reproductive health.¹²⁴

¹²⁰ Royles, 200.

¹²¹ Royles, 203.

¹²² ACT UP/New York Women and AIDS Book Group, *Women, AIDS, and Activism*, 227-229.

¹²³ Royles, *To Make the Wounded Whole*, 204.

¹²⁴ Royles, 198.

SisterLove's approach reminds us of the multilayered challenges pregnant women—particularly poor and non-white—faced while living with HIV. It reminds us of Carlotta Locklear's story, of Frankie Mason's story, of Cheryl Smith's story. Even before they contracted the virus and became pregnant, many of the women at the center of the HIV/AIDS epidemic struggled with trauma, abuse, violence, drug dependency, or poverty—a product of the intergenerational legacies of structural racism. Aware of continuous patterns of neglect, they may have distrusted their medical providers. These factors, everyday burdens as well as barriers to quality medical care, made their communities more vulnerable to the virus's worst impacts. When women lived with HIV, they faced the same fear that every other person with HIV encountered: physical pain, a confrontation with mortality, the loss of loved ones who had also contracted the disease. But though HIV loomed large, it was never the only threat.

Pregnant women with HIV also contended with burdens specific to their gender and childbearing status. Frustrated by the medical community's disregard of women's experiences with HIV/AIDS, some struggled to gain treatment or financial assistance. Their pregnancies also forced them into the contentious arena of reproductive freedom. Many pregnant women of color reported pressures to obtain abortions, building on long histories of sterilization abuse. Others felt social stigma from their decision to continue pregnancy—on top of the stigma of their HIV status—leaving them isolated from their communities. This increased their emotional burdens. But time and time again, pregnant women demonstrated a profound care for their children. Children represented hope, love, and sense of purpose.

All of these struggles added to existing tensions within clinical research. Some pregnant women, apprehensive towards a medical establishment that continuously neglected their communities, might have doubted the safety of experimental drugs. Others might have

desperately sought access to cutting edge therapies to help themselves and their children. Still others might have felt apathy towards the process, preoccupied with innumerable other life challenges. Researchers' attempts to include pregnant women with HIV—or activists' attempts to defend their rights—could not assume one unilateral approach.

PART III: TRIAL 076

*The Stories of Sonia and Rosa: "None of us know when our time is going to be up."*¹²⁵

Sonia Alvarez, age 23, felt nervous. She had learned of her HIV-positive status in the late-1980s. Her two children had tested negative for the virus, but now, she was pregnant with a third and feared her luck had run out. When she heard about a new clinical trial for the HIV drug AZT, she saw a glimmer of hope. The trial, launched in 1991, specifically investigated whether AZT could prevent mothers from passing the virus to their children. Sonia eagerly enrolled, sticking by the treatment regimen throughout and after her pregnancy. She gave birth to a boy who, according to postpartum tests, did not have HIV. Overjoyed, she advocated for the drug to other pregnant women with HIV. "Women need this drug. This drug saved my baby," she said.¹²⁶

Six months later, her baby boy's skin broke out in rashes. Lethargy and unresponsiveness replaced his once-abundant energy. At the clinic, physicians re-tested him for HIV. When the results came back, she burst into tears. He was positive. *SPIN* reporter Celia Farber, a staunch opponent to mainstream HIV medical research, capitalized on Sonia's pain in a 1995 feature questioning the results of the trial, which had been published the previous year.¹²⁷

¹²⁵ Farber, "AIDS: Words From the Front," 192. Spoken by Rosa Harris, when questioned on her decision to have a child.

¹²⁶ Farber, 192.

¹²⁷ Farber, 192.

Rosa Harris had also enrolled in the trial. Like Alvarez, she already had two children and hoped to shield her third—a daughter, Distiani—from the virus. The drug worked: Distiani’s HIV tests came back negative. In 1994, Rosa appeared on the popular *Montel Williams Show* to share her experience. She faced an onslaught of criticism: the public villainized her for having children while aware of her HIV status. “I felt persecuted on that show,” Rosa told Farber for the same *SPIN* article.¹²⁸

Sonia and Rosa, two women who participated in ACTG Study 076, felt the lived impacts of ongoing controversies over clinical trial drug safety and the reproductive freedoms of mothers with HIV. Their stories reveal the emotional impact of these discourses: Sonia’s hope for her child and devastation at the drug’s shortcomings; Rosa’s shame for her childbearing decisions. They also faced a slew of concerns outside of the trials, as both women grappled with their personal HIV statuses while caring for their families. They bore these pains, enrolling in Trial 076 out of a sense of responsibility to their unborn children.

*A Contested Meeting: “Blood on the floor.”*¹²⁹

In March of 1991, activists, scientists, and medical professionals convened in Washington, D.C. for a quarterly ACTG meeting.¹³⁰ A few days of intensity loomed: on the docket was Trial 076, which sought to probe AZT’s ability to prevent pregnant women with HIV from transmitting the virus to their fetuses. The Pediatric Committee—not the Women’s Committee—spearheaded design of the protocol.¹³¹ AIDS activists organizations had fought hard

¹²⁸ Farber, 214.

¹²⁹ Rollins, “A Seat at the Table,” 63. Used by an activist of color to describe the chaos of the March 1991 ACTG meeting.

¹³⁰ Rollins, 62.

¹³¹ Rollins, 63.

for their access to these ACTG meetings. In 1990, the ACTG listened, establishing the Community Constituency Group (CCG) comprised of twenty-three representatives from a wide range of activist groups. Those from majority-white groups such as ACT UP New York and San Francisco worked alongside those advocating for Black, Latine, Indigenous, and Asian communities.¹³² Many, but not all, CCG members lived with HIV.¹³³

Since the CCG's inception, activists of color felt marginalized by ACT UP members. Rochelle Rollins, from the Boston ACTG Community Advisory Board, recounted one ACTG conference in which ACT UP founder Larry Kramer "interrupted a CCG session and ordered the people of color to 'get your own CCG.'"¹³⁴ At another conference, ACT UP members used designated CCG presentation time to make their own demands, against the wishes of activists of color.¹³⁵ One activist of color noted that "although we were at the table, we had to fight for something to eat because... [ACT UP members] didn't feel the need to include us."¹³⁶ They feared that concerns "particularly important to people of color," such as equitable trial access, would be overlooked.¹³⁷ People of color within ACT UP expressed similar concerns about the group's lack of racial diversity, particularly as it coordinated a response to Trial 076. In a national ACT UP conference call to develop a strategic approach to protesting the trial, only three of over thirty participants were women of color. "Where the hell are the women of color in ACT UP?" wrote Nima Eshghi, an activist of color from ACT UP Seattle. She warned that "HIV+ women of color, the group which will be most affected by this trial, were ironically, also,

¹³² Rollins, 54-55; 64.

¹³³ Rollins, 68.

¹³⁴ Rollins, 61.

¹³⁵ Rollins, 61-62.

¹³⁶ Rollins, 62.

¹³⁷ Rollins, 58.

the most underrepresented group.”¹³⁸ Even prior to the March 1991 ACTG meeting, activists of color felt that ACT UP disrespected their work and overlooked their concerns.

Though activists helped shape clinical research directions, medical professionals like Dr. Janet Mitchell comprised the backbone of the ACTG and drove Trial 076’s development. Mitchell, a Black obstetrician, helmed the Department of Perinatology at Harlem Hospital. Her department, “the largest prenatal program for pregnant, drug-addicted women in New York City,” delivered babies for hundreds of women with HIV per year.¹³⁹ Mitchell had testified before Congress at its 1989 Children and HIV Infection hearing, seeking more funding for her patients, who “c[a]me with poverty, homelessness, and illiteracy” to “a public hospital system ready to collapse.”¹⁴⁰ She respected mothers as individuals deserving of their own healthcare, emphasizing, “for every infected child you hear about, there is one and possible two infected parents, also in need of care and support.”¹⁴¹ Her actions reflected this, as she “refuse[d] to turn away uninsured, HIV-infected women” and “sen[t] Harlem Hospital Center staff out into the neighborhood” to find patients who missed appointments.¹⁴² In this way, Mitchell embedded herself within her community. She also advocated for the representation of women of color—not just white women—in clinical trials: “Those parties concerned with the exclusion of women from clinical studies... are less willing to consider the possibility that defining society and norms on the basis of white Anglo- or Euro-centric beliefs may also be flawed,” she wrote.¹⁴³ Mitchell critiqued those who viewed clinical research with a one-dimensional feminist perspective that

¹³⁸ Eshghi, “National People of Color AIDS Activist Conference.”

¹³⁹ Frere and Wallace, “Working in the Trenches with HIV Infected ‘Boarder Babies,’” 70; Children and HIV Infection, 29.

¹⁴⁰ Children and HIV Infection, 28-29.

¹⁴¹ Children and HIV Infection, 28.

¹⁴² Frere and Wallace, 70.

¹⁴³ Frere and Wallace, 70.

overlooked the influence of race. Both gender and racial awareness, instilled by her clinical practice, informed Mitchell's research goals and her push for Trial 076's implementation.

Ironically, white feminists of the ACT UP Women's Caucus envisioned themselves to have the same awareness—even as they worked to stop Trial 076, directly impeding Mitchell. They raised concerns about the ethics of Trial 076, concerned over its safety and implications for reproductive freedom.¹⁴⁴ In stark contrast to most clinical trial demographics, poor women of color would be overrepresented in Trial 076, as they comprised the largest group of women impacted by HIV. Because of this, Rollins recounted, “white lesbians in ACT UP... had staged an impressive media campaign against the trial calling it a genocide against people of color” for months before March of 1991.¹⁴⁵ ACT UP activists of color, like Nima Eshghi, did not agree with this tactic. Eshghi critiqued white ACT UP activists' tendency to claim to “‘work’ on behalf of people of color” as self-serving “‘charity’ work” and “a symptom of well-meaning liberal racism.”^{146,147} White ACT UP activists sought to advocate for women of color, but they lacked personal exposure to women of color's lived experiences.

ACT UP activists doubted the safety of the trial's placebo arm. Trial 076, following the standard for similar clinical trials, evaluated the efficacy of AZT by comparing outcomes of women who received it with those of women who received a placebo. ACT UP had long denounced this practice as “cruel,” withholding potential life-saving treatments.¹⁴⁸ Some white ACT UP activists framed their safety concerns through the perspective of the Black community. Activist Marion Banzhaf had worked with Black-led groups such as African American Women

¹⁴⁴ Schulman, *Let the Record Show*, 562-575.

¹⁴⁵ Rollins, “A Seat at the Table,” 63.

¹⁴⁶ Eshghi, “National People of Color AIDS Activist Conference.”

¹⁴⁷ Despite her opposition to white ACT UP activists' tactics, Eshghi also opposed Trial 076 out of safety concerns. She critiqued “the UNINFORMED CONSENT for the FATAL trial” of “a highly toxic drug, AZT.” See Eshghi, “National People of Color AIDS Activist Conference.”

¹⁴⁸ “Flyer of the First ACT UP Action March 24, 1987, Wall Street, New York City.”

United Against AIDS. Banzhaf recalled that, “Because... of the history of experimentation on black people in this country—re the syphilis, Tuskegee experiments—African American women signing up for this clinical trial was going to be a big deal.”¹⁴⁹ This, Banzhaf argued, made the employment of a placebo arm for a trial that heavily involved Black women particularly unethical, “because to have a placebo arm would be to deny those women access to the drug, and that’s the only reason they’d be joining the trial in the first place.”¹⁵⁰ Drawing on historical concerns over clinical research exploitation, ACT UP activists criticized the trial’s safety.

Other ACT UP activists criticized the trial’s treatment of reproductive issues, particularly in its privileging of fetal health over maternal health. The premise of the trial, some argued, embodied this. Margaret McCarthy’s biggest objection to the trial was that “women were seen as vectors of transmission to men or fetuses... nobody cared about these pregnant women getting treatment. Like, it’s all about giving this treatment that maybe the baby will be born without HIV.”¹⁵¹ The trial’s implementation and effects reflected these priorities, activists argued. They raised alarms that, under the 076 protocol, women were not guaranteed free AZT treatment and medical care after six weeks postpartum, even though their infant’s health would be followed for 78 weeks.¹⁵² They also worried that AZT could directly harm women. Maxine Wolfe, in 2004, reflected that she would always regard Trial 076 as a “big mistake”: “In order to save the next one percent of children, we’ve probably killed many, many women.”¹⁵³ Informed consent forms, ACT UP activists noted, failed to mention that in rat and mice models, AZT increased risk for

¹⁴⁹ Banzhaf, ACT UP Oral History Project.

¹⁵⁰ Banzhaf, ACT UP Oral History Project.

¹⁵¹ McCarthy, ACT UP Oral History Project.

¹⁵² Harrington, “ACTG Protocol 076: Summary, Problems, Alternatives + Recommended Changes: A Report to the CCG 076 Working Group.”

¹⁵³ Wolfe, ACT UP Oral History Project.

vaginal cancer.¹⁵⁴ Moreover, a woman who took AZT while pregnant could develop resistance to other, more effective HIV drugs developed later.¹⁵⁵ The activists' objection to the prioritization of fetal health did reflect concerns expressed by some women with HIV. In a focus group on Trial 076, one told the Institute for Family-Centered Care, "Don't just take notice of me because I can have a child."¹⁵⁶ ACT UP women, in this way, leaned on the classical feminist critique of the "women as vessels" understanding of reproductive health.

Despite ACT UP's opposition, support for the trial among pregnant women remained high. ACT UP activists seemed aware of this. Banzhaf recalled, "In talking to women, women really didn't want to infect their kids. And so women were really also hoping it would work... So they were clamoring for the trial, also."¹⁵⁷ ACT UP activists protested Trial 076 despite knowing pregnant women's positive opinions of it.

Controversy over Trial 076 reached its climax at the March meeting. Immediately prior, two members of the Pediatric Committee had received death threats so frightening that "one investigator decided not to go to the March meeting, the other went with bodyguards."¹⁵⁸ On the second day of the event, CCG activists eagerly anticipated a session with NIAID researchers, their first opportunity to ask detailed questions about the trial. But as soon as both parties sat down, members of the ACT UP Women's Caucus entered, reading a prepared statement through blowhorns. The researchers left, leaving chaos behind. Some activists engaged in a fist fight. One activist of color recalled, "There were tears, people running out of the room, there was violence, I remember somebody throwing a folding chair!"¹⁵⁹ ACT UP activists ideologically, verbally,

¹⁵⁴ Harrington, "ACTG Protocol 076: Summary, Problems, Alternatives + Recommended Changes: A Report to the CCG 076 Working Group."

¹⁵⁵ Schulman, *Let the Record Show*, 564.

¹⁵⁶ Lovvorn, Quinn, and Jolly, "HIV Testing of Pregnant Women," 408.

¹⁵⁷ Banzhaf, ACT UP Oral History Project.

¹⁵⁸ Rollins, "A Seat at the Table," 63.

¹⁵⁹ Rollins, 63.

and physically disrupted an event for activists of color to hear about Trial 076 from medical professionals—some of whom, like Mitchell, worked closely with pregnant women of color with HIV.

In response, women of color, both activists and medical professionals, denounced the majority-white ACT UP activists for speaking on their behalf. Immediately after the event, CCG activists of color issued a statement, quoted in part below:

We will not allow ACT-UP, primarily representative of white gay men and women, to dictate the agenda for the research that will affect men, women, and children of color — whether gay or not. The lines have been drawn, and we clearly see these actions as racist and genocidal. . . . The paternalistic audacity of taking an action that prohibits us from making an informed decision by hearing all sides of the story is racist and resembles tactics utilized by plantation overseers during the years of overt slavery. We are still enslaved. We are not confused. We will not continue to be oppressed and have people make decisions for our community which should properly be made by us. ACT-UP ignored the women and the people of color on the CCG, paternalistically depriving us of our right to know and to decide what is appropriate for our communities. We do not see ourselves as vessels for fetuses. We instead see ourselves as women, mothers, fathers, and the trustees of the future of our communities.¹⁶⁰

The CCG’s statement reflects profound frustration and rage. That they repeatedly called ACT UP “paternalistic” reveals their frustration at the continuous erasure of their perspectives in HIV/AIDS activism. Their references to slavery contextualize this erasure amidst centuries of oppression. When speaking for themselves, CCG activists employed the same language as did ACT UP activists—“genocide,” “vessels for fetuses”—but did so in vastly different contexts. “Genocidal” referred not to their exploitation in the clinical trial process, but to a silencing that prevented them from learning about life-saving treatments. “Vessel for fetuses” was not an inescapable identity, but one they actively rejected.

Mitchell reflected on the event with equally scathing language. In a feature for *Mother Jones*, Mitchell characterized ACT UP’s disruption as “A bunch of gay white women deciding

¹⁶⁰ Rollins, 64-65.

what's right for people of color." She elaborated, "I felt the activists were paternalistic and didn't understand the trial was an opportunity for women to have all the options available to them. Poor doesn't mean dumb."¹⁶¹ Reiterating insinuations of ACT UP's "paternalism," Mitchell bluntly asserted women of color's ability to defend themselves.

The chaos at the March 1991 ACTG meeting epitomized the difficulties of designing inclusive studies. ACT UP activists presumed to advocate for the poor women of color who would comprise Trial 076's main subjects—in fact, some, like Banzhaf, even had a history of working with them. But despite aspirations toward justice and allyship, ACT UP's protests of Trial 076 spoke over poor women of color's own activism, naively attempting to distill their concerns into white feminist understandings of reproductive autonomy and safety. The communities most affected by Trial 076 had infinitely more nuanced perspectives. Poor women of color, represented at the ACTG meeting by the CCG and their medical providers such as Janet Mitchell, directly bore the painful impacts of HIV. Safety, for some, meant access to life-saving treatments with legitimate scientific backing; the minutiae of placebo controls felt less urgent. Contrary to ACT UP's portrayals, they conceived of themselves as far more than powerless victims to racism and misogyny: they viewed their childbearing capabilities not as chains but with pride, understanding their capacity to strengthen their communities. Poverty did not preclude their ability to critically consider new therapies for themselves and their children.

Reactions to Trial 076 were not all black and white. Some women of color distrusted the ACTG's clinical trial process. Malina Ricardo, a member of the CCG who had HIV, spoke out against Trial 076 in an interview for Farber's 1995 *SPIN* article. Ricardo noted the novelty of her opinion: "I was the first woman of color that these people ever heard be against 076. They

¹⁶¹ "Mojo's October Hellraiser!"

thought it was only white women, that it was a racist thing to be against 076.” She did not trust the safety of drugs. Her five-year-old daughter, who had HIV, was enrolled in a trial for a drug similar to AZT, but Ricardo “flush[ed] the medications down the toilet” because her daughter “was only sick when she was on [them].”¹⁶² The perspectives of women of color with HIV evade monolithic categorization. Always, however, they centered their children’s well-being.

*The Trials: “All self-care actions... for the health of the unborn baby.”*¹⁶³

Ultimately, ACT UP’s protests failed. Large research hospitals around the country started to recruit participants for the study. ACTG Trial 076 ran from April 1991 to December 1993. It was a massive undertaking, spanning forty-two research institutions in the United States, France, and Puerto Rico, the majority of which were large, urban, and university-affiliated.¹⁶⁴ The 477 participants of Trial 076 represented groups typically underrepresented in clinical trials. All were identified as women. Seventy-nine percent—or 375 total—were non-white. Many experienced other forms of vulnerability, evident even in the scant statistics provided in the official *New England Journal of Medicine* paper on the study: 76 women had used intravenous drugs, 54 also faced syphilis, and 49 experienced another STI.¹⁶⁵

The researchers recruited women with HIV who were between 14 and 34 weeks pregnant who had not yet developed AIDS.¹⁶⁶ Women would receive free medication, clinical visits, and laboratory tests while on the trial, but would have to pay for their own delivery and their

¹⁶² Farber, “AIDS: Words From the Front,” 192.

¹⁶³ Bunting and Seaton, “Health Care Participation of Perinatal Women with HIV,” 568. Bunting and Seaton interviewed women who participated in Trial 076 about their motivation for doing so. They drew this conclusion based on their research.

¹⁶⁴ Connor et al., “Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment.”

¹⁶⁵ Connor et al.

¹⁶⁶ Connor et al.

newborns' nursery care.¹⁶⁷ In the beginning, researchers encountered recruitment. By late-1991, scientists had only managed to recruit 66 women, a mere 20% of those eligible.¹⁶⁸ Healthcare workers provided patients with small incentives to help ensure their compliance, with a survey finding that "'gifts of love'... ie: new gown for hospital, maternity bra or other clothing, lunch vouchers, bus tokens, etc... [were] especially useful for low-income patients." One site also found that patients eagerly accepted housing and phone access.¹⁶⁹

Some activists took issue with the investigators' informed consent process. To "enhance" the traditional consent form, investigators created a video that included "cartoon figures of AZT vs. placebo (in which AZT was a super-hero type persona)." While clinic staff "found [the videos] very useful," ACT-UP activist Virg. E. Parks "had a problem with the 'informed' part because... potential toxicity was glossed-over."¹⁷⁰ Pre-trial concerns over safety had not dissolved. Investigators also did not develop a Spanish alternate to the English video due to "financial" reasons. Many activists objected to this, and one Black member of the CCG demanded "totally new community specific versions featuring Hispanic or black actors."¹⁷¹ Of note, women did not have complete agency over their enrollment: when available, the researchers sought paternal consent as well.¹⁷²

Trial 076, like many modern clinical trials, employed a double-blind, placebo-controlled methodology. Half of participants received zidovudine treatment (the drug name for AZT), while

¹⁶⁷ National Institute of Allergy and Infectious Diseases, "Backgrounder: ACTG Protocol 076--Questions and Answers."

¹⁶⁸ Sbrizzi, "My ACTG Excellent, Most Excellent (and Sometimes Bogus) Adventure."

¹⁶⁹ Parks, "ACTG Reportbacks."

¹⁷⁰ Parks.

¹⁷¹ Here, we see residual racial tensions between ACT UP activists and activists of color. Parks, a member of ACT UP, suggested that researchers "simply over-dub the existing video or seek out a (perhaps hispanic-owned?) video production company to donate services." In turn, Parks expressed anger at the Black CCG activists' demands, questioning, "WHY do folks always have to complicate simple answers?" See Parks, "ACTG Reportbacks."

¹⁷² Connor et al., "Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment."

half received a placebo. Prior to birth, participants took 100 mg of oral zidovudine, five times a day—the standard dosage for adults. They traveled to a medical center every four weeks for monitoring, then weekly at 32 weeks of pregnancy. During delivery, mothers received intravenous infusions of the drug. After birth, women provided their newborns with oral zidovudine every six hours for six weeks.¹⁷³ Some measures existed to protect women—if a woman’s HIV/AIDS progressed severely, for example, she could receive open-label zidovudine treatment.¹⁷⁴

The protocol did not prioritize mothers’ postpartum medical care. In their *New England Journal of Medicine* report, researchers did not provide details on mothers’ treatment after delivery. A NIAID protocol released prior to the trial specified that women could access open-label AZT for six weeks after birth, after which they would be referred to another facility.¹⁷⁵ Dr. Nancy Angoff, a physician who implemented Trial 076’s protocol at Yale-New Haven Hospital after the study’s conclusion, recalled that physicians used individual women’s medical presentations to determine their postpartum treatment regimens. “If I felt as the provider that AZT was working for the mother... then I might’ve kept her on it,” she said. “That wasn’t, I don’t think, part of the [076] protocol. The protocol was to prevent transmission to the baby.”¹⁷⁶ Medical professionals intended Trial 076 to focus on fetal health, not maternal health.

The results for those who remained were damning: without any difference in adverse effects, mothers treated with zidovudine were over two-thirds less likely to give birth to babies

¹⁷³ Connor et al. note that most mothers completed the intensive regimen. Four women, however, “refused all medications and follow-up after receiving some treatment.” The report provides no additional detail. Perhaps the mothers developed a suspicion towards their medical providers after one-too-many negative encounters at the hospital. Perhaps life got in the way, detracting from their ability to commit to the trial’s intense treatment regimen or frequent check-in appointments.

¹⁷⁴ Connor et al.

¹⁷⁵ National Institute of Allergy and Infectious Diseases, “Backgrounder: ACTG Protocol 076--Questions and Answers.”

¹⁷⁶ Angoff, interview.

with HIV, the report announced in its prominent abstract section. Tucked away in a secondary “Maternal Safety” section were descriptions of AZT’s effects on women themselves: Six months postpartum, women who received AZT had equivalent disease progression to those in the placebo control.¹⁷⁷ The first result—the drastic reduction in maternal-fetal HIV transmission—excited the medical community. Satisfied with their data, the researchers stopped the protocol in February of 1994. They offered zidovudine to pregnant women in the placebo group. News outlets reported on the “major finding,” and the National Library of Medicine distributed a global alert.¹⁷⁸

The August edition of the CDC’s *MMWR* formally announced the U.S. Public Health Service’s recommendations for ZDV administration to pregnant women. Finding the drug to provide “substantial benefit” with “short-term safety,” the guidelines urged medical providers to encourage pregnant women with HIV to receive AZT treatment in accordance with protocols established by Trial 076.¹⁷⁹ Public health officials also acknowledged residual safety questions, writing that women “must also be informed that the long-term risks of ZDV therapy to themselves and their children are unknown.”¹⁸⁰ They highlighted the importance of consent, noting, “Discussions of treatment should be noncoercive, and the final decision to accept or reject ZDV treatment recommended for herself and her child is the right and responsibility of the women.”¹⁸¹ The U.S. Public Health Service’s reflected awareness of activists’ safety- and consent-based objections to Trial 076. Nevertheless, the agency reiterated confidence in the trial’s results.

¹⁷⁷ Connor et al.

¹⁷⁸ Altman, “In Major Finding, Drug Curbs H.I.V. Infection in Newborns.”

¹⁷⁹ Centers for Disease Control and Prevention, “Recommendations of the U.S. Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus,” 6-7.

¹⁸⁰ Centers for Disease Control and Prevention, 6-7.

¹⁸¹ Centers for Disease Control and Prevention, 7.

Narratives of women who participated in Trial 076 evade the historical record, obscured by both privacy laws and historiographical biases. But the documents of medical professionals and activists are telling on their own. Women of color from urban areas comprised the core of the trial. A substantial number of them struggled with drug use. Some of them lived with other STIs, including syphilis—which both added to their physical discomfort and reflected their larger struggles within the medical system. That researchers found it helpful to offer everyday essentials—bus tokens, lunch vouchers, housing and phone access—as incentives for compliance hints at many women’s low-income status.

Participants in Trial 076, such as Sonia Alvarez and Rosa Harris, grappled with the same struggles as did other pregnant women with HIV, particularly those poor and non-white. The clinical trial’s protocols reflected these struggles. The requirement of paternal consent, for example, conjured up long-held debates over women’s bodily autonomy, while the trial’s focus on fetal, not maternal, health echoed the “women as vessels” discourse. Women who consented to the trial bore the weight of these discourses. Some, like Rosa, experienced barrages of stigmatization for their reproductive decisions. Other women may have feared the experimental drug’s safety; even the CDC’s formal endorsement of AZT cited lingering unknowns over the drug’s long-term effects. When Sonia’s child developed HIV after the trial’s conclusion, Sonia bore the weight of these unknowns. Moreover, the treatment regimen of a five-times-a-day dosage with frequent appointments might have been logistically complicated for women navigating numerous other everyday instabilities.

Sonia Alvarez, Rosa Harris, and 475 other women who completed the trial committed to these regimens and uncertainties out of protectiveness over their children’s health. In the years following the conclusion of Trial 076, two nurses—Sheila Bunting and Regina Seaton—

interviewed participants to confirm as much. “Women who participated in the 076 drug trials... said that their primary reason for doing so was the hope of saving their baby from infection,” Bunting and Seaton wrote.¹⁸² The participants in Trial 076 put their children above all else, adopting their children’s health as their own.

ACT UP’s protests of Trial 076, particularly regarding its safety and implications for women’s reproductive rights, had both valid contentions and serious deficiencies. Some of Trial 076’s methodologies did reflect a prioritization of fetal health over maternal health. The placebo arm, by design, withheld treatment from some women, and unknowns about the drug’s long-term safety lingered long after the trial. Medical investigators’ attempts to include women sometimes lacked sensitivity towards these concerns. Their failure to develop a Spanish-language informational video, for example, calls into question whether all women provided true informed consent. But ACT UP activists themselves also impeded on the agency of women of color within the CCG, an embodiment of the very racial and patriarchal structures they thought they were dismantling.

Sonia and Rosa’s stories, and a deeper understanding of Trial 076’s methodologies, reveal a more intersectional perspective. Parallel to the “women as vessels” discourse ran women’s legitimate and fierce protectiveness over their children. Parallel to the safety concerns over AZT or the placebo arm ran the proven lethality of HIV/AIDS, an epidemic that historical racial and socioeconomic discrimination disproportionately wrought upon poor communities of color. For some women, ACT UP’s concerns held more weight: many eligible women refused to enroll in the trial. But for themselves and their families, the women who participated in Trial 076 demanded treatment.

¹⁸² Bunting and Seaton, “Health Care Participation of Perinatal Women with HIV,” 568.

PART IV: THE AFTERMATH

*The Stories of Anonymous Women: “Nobody can take care of your child like you can.”*¹⁸³

In the years after Trial 076, nurses Sheila Bunting and Regina Seaton interviewed eighteen pregnant or postpartum women with HIV. Almost all were Black. None had college degrees. All were low income—the highest monthly salary was \$1,100. With their words, the anonymous women revealed a complex web of emotion and experience underlying their participation in medical care.

Many hated the doctor’s office. One woman, who frequently missed appointments, emphasized the sense of “panic” she felt when forced to confront her HIV status: “They goin’ tell me something bad every time I go so I don’t be wanting to go... I see patients come in and they be looking so bad. Look like they be in so much pain... Feel like it’s just cutting me on the inside of my heart.” Another, juggling childcare with public transport, noted the logistical challenges a visit posed: “I don’t have nobody to keep [my child]... I know that if I leave him there he’s goin’ cry, holler. And then sometimes I miss my bus and I be waiting on the bus so long, I be tired, I be sleepy, I be aching and just wanting to lay down.” Women also expressed frustration at their medical providers’ apparent neglect. “If you don’t follow up and take care of yourself, then you won’t get your health care,” one said. Some questioned the racial dimensions of this neglect. “I wonder, would it be different for me if I was White. They treat them better when they go to the doctor than they do Blacks,” one woman said. The struggles of pregnant women with HIV did not change after Trial 076: apprehension over their HIV status, exhaustion with a lack of structural support, mistrust in the racially disparate medical system.

¹⁸³ Bunting and Seaton. Spoken by one woman with HIV.

Despite this, women persevered with their medical care, drawing strength for and from their children. “I love her so much... I have felt down and depressed, I’ve even thought I don’t want to live this life, you know, and I should commit suicide. And then I look at my baby and I think, ‘No.’ How could I guarantee she would be taken care of... She is an inspiration for me,” one woman said. The weight of an HIV/AIDS diagnosis drove many women to feelings of hopelessness. But, just as before and during Trial 076, their fierce love for their children instilled in them a new hope, a drive to persist.

In the year after investigators reported the results of Trial 076, administration of AZT to pregnant women rapidly increased, drastically reducing maternal-fetal transmission rates.¹⁸⁴ But just as pregnant women’s experiences remained unchanged, so too did public discourse on Trial 076 and its legacy. New debates rehashed concerns about reproductive stigmatization and safety: the ethics of mandatory testing, the trustworthiness of Trial 076’s data regarding the safety and efficacy of AZT, and the ethics of placebo-controlled trials in lower income countries.

*Testing Mandates and Reproductive Freedom: “I have a chance to save my baby.”*¹⁸⁵

At the end of 1994, at a county-funded HIV clinic, Susanna learned she was pregnant with her first child. Her providers offered her a free HIV test, which she accepted. “It’s my first baby. My only one, I guess... I [didn’t] want to take any risks,” she told *Los Angeles Times* reporter Pamela Warrick. “Why wouldn’t I [take the AIDS test]?”¹⁸⁶ Her results came back positive. In Susanna’s 13th week of pregnancy, she began an AZT treatment regimen, paid for by a federal health program.¹⁸⁷

¹⁸⁴ Cooper et al., “After AIDS Clinical Trial 076.”

¹⁸⁵ Warrick, “Whose Life Is It?” Expressed by Susanna, a pregnant women with HIV.

¹⁸⁶ Warrick.

¹⁸⁷ Warrick.

With AZT's proven efficacy, medical practitioners pushed pregnant women to seek HIV tests to identify those whose unborn babies would benefit from treatment. Many women, such as Susanna, voluntarily accepted the testing and subsequent AZT treatment to protect their children. But when lawmakers across the country proposed legislation mandating testing, the debate once again touched upon issues of women's reproductive rights. Those who opposed the mandates noted that they infringed upon women's privacy, making them vulnerable to the immense stigma wrought by an HIV-positive status.¹⁸⁸ Ginny Foat, director of Caring for Babies with AIDS, a Los Angeles organization, more explicitly recalled the "women as vessels" discourse: "Out front, this all sounds very good for the good of the children, but you have to understand that women are not little ovens that babies come in. Women are separate individuals with rights and choices."^{189,190} In contrast, many prominent proponents of testing mandates were also noted abortion opponents, such as columnist Nat Hentoff. Hentoff said that if women kept their privacy, "their children [would] have the privacy of the grave," echoing similar arguments of the anti-abortion movement.¹⁹¹ In this way, testing mandates drew from common discourses in women's reproductive autonomy.

Low-income women bore the direct impacts of these debates. Mark Senak of AIDS Project Los Angeles, who also opposed testing mandates, observed, "an HIV test does not occur in a medical vacuum. It is a test of your insurability, your access to health care, your relationship with your partner, your family, your church."¹⁹² Ethicists noted that beyond HIV, low-income women often lacked access to health care within the American system, meaning that "too many

¹⁸⁸ Lovvorn, Quinn, and Jolly, "HIV Testing of Pregnant Women"

¹⁸⁹ Warrick, "Whose Life Is It?"

¹⁹⁰ Foat also drew attention to the gendered hypocrisy of these arguments, saying, "If you want to stop the spread of AIDS, why not castrate men—remove their penises!" See Warrick.

¹⁹¹ Warrick, "Whose Life Is It?"

¹⁹² Warrick.

women at risk for HIV receive[d] either no perinatal care or inadequate care.”¹⁹³ As such, some testing mandate opponents feared that many low-income women would not be able to access Trial 076’s AZT regimen, even once they received their positive test. “It would be a cruel hoax to test someone, find out they’re positive and not be able to offer... [AZT] and other clinical follow-up,” noted Mervyn Silverman, president of the American Foundation for AIDS research.¹⁹⁴ Low-income women, already more at-risk for pregnancy complications and HIV infection due to inequalities in the American health care system, also faced limited treatment options in the case of a positive test.

Both sides of the debate manifested in the implementation of testing policies in Connecticut. In 1999, despite opposition from groups like the Connecticut Hospital Association, the state legislature passed a law that mandated HIV testing. Providers were to counsel pregnant women to receive an HIV test and, if the woman refused to consent during delivery, could administer a test to their infants.¹⁹⁵ Women did, as activists feared, face significant stigma upon learning of their positive results. In a partner notification process, medical providers informed sexual and needle-sharing partners about their close contact with a person with HIV, revealing women’s statuses. Dr. Warren Andiman, who directed the Pediatric HIV/AIDS Program at Yale-New Haven Hospital, recalled the subsequent response: “It was horrendous... The woman was certainly threatened... as if it were her fault, which of course it wasn’t,” he said.¹⁹⁶ Nevertheless, most women consented to HIV testing. In his years of practice, Andiman could recall “less than

¹⁹³ Lowe, “HIV Study Raises Ethical Concerns for the Treatment of Pregnant Women,” 181.

¹⁹⁴ Lowe, 181.

¹⁹⁵ Andiman, “Where Have All the ‘AIDS Babies’ Gone?”

¹⁹⁶ Andiman, interview.

three or four times” in which practitioners tested infants because their mother had refused a test during delivery.¹⁹⁷ “Mothers want their babies to be healthy,” he said.¹⁹⁸

*The Safety of AZT and Placebo Controls: “An evil hoax.”*¹⁹⁹

Debates also rose over the safety of Trial 076. Some questioned the safety of AZT, while others questioned the ethics of employing placebo controls in future trials. After the conclusion of the trial, radical feminists continued to critique conclusions about AZT’s safety. Celia Farber, a contributor to *SPIN* magazine who often expressed doubt at the medical establishment’s HIV research, penned a 1995 article summarizing these fears. Referencing feminists’ classical example of thalidomide, Farber noted that “from that point on, no potentially mutagenic chemical was to be taken by pregnant women, for any reason. AZT in pregnant women represents a radical break in tradition.”²⁰⁰ Farber questioned the safety of AZT from multiple angles: anecdotal reports of its linkage to birth defects, its unclear long-term effects on children. Farber also critiqued the process of obtaining informed consent for AZT treatment from “poor, afraid, ill-informed, and disempowered” women.²⁰¹ She quoted a member of ACT-UP who distrusted Trial 076: “Of course [pregnant women] are being coerced. The consent form is eight pages long and basically says that if you don’t take this, your baby is probably going to die. These women are going to read that first paragraph and say, ‘Where do I sign?’”²⁰² Like ACT-UP activists before Trial 076, Farber legitimized her objections by citing historical examples of

¹⁹⁷ Andiman.

¹⁹⁸ Andiman.

¹⁹⁹ Farber, “AIDS: Words From the Front,” 193. Expressed by Mary Lucy, a woman with HIV who doubted Trial 076.

²⁰⁰ Farber, 190.

²⁰¹ Farber, 193.

²⁰² Farber, 193.

safety oversight in women's health and centering the vulnerability of women in marginalized positions.

Farber did provide an alternative perspective: that of Dr. Janet Mitchell, the Harlem Hospital obstetrician who had driven Trial 076's development. Mitchell, as before, defended the intelligence of pregnant women with HIV, noting their intense drive to protect their children. "These women are not foolish," Mitchell said, "Many of them always refused to take AZT for themselves, but when it comes down to the maternal instinct, it's a whole different question."²⁰³ The implementation of Trial 076's protocols at Yale-New Haven Hospital reflected Mitchell's perspective: Andiman could not recall a single woman refusing AZT treatment.²⁰⁴

Ethical debates over Trial 076's safety protocols took a global angle when, after the trial's conclusion in the United States and France, researchers sought to continue investigation in Africa, Asia, and Latin America. The researchers hoped to reduce cost of treatment in lower-income countries by investigating alternative AZT treatment regimens.²⁰⁵ The key point of contention: the trials employed a no-treatment placebo control, despite Trial 076's establishment of AZT as an effect standard. Physicians Peter Lurie and Sidney Wolfe brought the public's attention to the issue in a 1997 *New England Journal of Medicine* article.²⁰⁶ They argued that researchers should have opted for an equivalency study, comparing new, less expensive regimens to the established regimen of Trial 076. In the same issue, Marcia Angell, editor-in-chief of the *Journal*, wrote a letter concurring with Lurie and Wolfe's opinion. Angell cited the Tuskegee Syphilis Study as a "textbook example of unethical research" for which "the justifications [of

²⁰³ Farber, 214.

²⁰⁴ Andiman, interview.

²⁰⁵ Lurie and Wolfe, "Unethical Trials of Interventions to Reduce Perinatal Transmission of the Human Immunodeficiency Virus in Developing Countries."

²⁰⁶ Lurie and Wolfe.

Trial 076 were] reminiscent.”²⁰⁷ Prior to Trial 076’s implementation in the U.S., ACT UP activists had drawn on Tuskegee and other instances of research abuse to criticize its placebo control methodology. Protests of the trial’s implementation in other countries drew on the same examples and rhetoric to reject placebos as well.

*What Pregnant Women with HIV Thought: “Mothers will be mothers.”*²⁰⁸

The same thematic debates that surrounded Trial 076’s development plagued attempts to realize its treatment implications. This reveals larger truths about clinical research that includes women and people of color: concerns over reproductive freedom and safety are—due to long histories of injustice, exploitation, and oversight—unavoidable.

In the historical record, journalists, physicians, and government policymakers drove these debates. Some pregnant women with HIV advocated for themselves, but their words remain hard to find. Instead, when history remembers the voices of pregnant women with HIV, it recalls the everyday. Their exhaustion. Their fear. Their frustration. Their love. These emotions originated from the same social contexts as did debates over reproductive rights or safety—medical manifestations of racism, socioeconomic inequality, heteropatriarchal oppression. But they also originated from a much more basic human instinct. “If you want [mothers] to do right by their children, maybe all you got to do is ask,” said Deandra, a woman pregnant with her second child and on an AZT treatment child.²⁰⁹

CONCLUSION

²⁰⁷ Angell, “The Ethics of Clinical Research in the Third World.”

²⁰⁸ Warrick, “Whose Life Is It?” Said by Deandra, a pregnant woman with HIV.

²⁰⁹ Warrick.

Today, clinical trials—like the rest of the medical field—aspire towards “diversity and inclusion.” These efforts are not unjustified. As the HIV epidemic made clear, and as the COVID-19 pandemic has reminded us, marginalized segments of society, including women and poor communities of color, are often most at-risk in matters of medicine and public health. But the term “diversity and inclusion” and the medical concepts associated with it—“health disparities,” “mistrust”—can become meaningless, even dangerous, in their vagueness and generalization.

HIV activism popularized “inclusion” as a marker of ethical clinical research. The most well-known narratives of the epidemic, as memorialized in existing literature, center gay men in this activism. Trial 076 brought poor, pregnant women of color into the conversation. In turn, medical providers, government officials, the media, and white activists tried to enforce their own values upon the trials. Some prioritized the protection of women’s “innocent victim” fetuses, stigmatizing women for their reproductive decisions. Others thought they protected women’s safety by seeking to stop the trials entirely. Reconstructing the stories of Trial 076’s participants, however, reveals a much more complicated story, one that requires analysis on the individual scale. Intertwined, contradictory structural and personal histories determined each woman’s decision to enroll in clinical trials, her experience within that trial, and her experience within the medical system as a whole. A truly intersectional approach to inclusionary research should capture those multidimensional understandings.

That intersectionality, admittedly, can be hard to implement—particularly as the groups so desired by clinical research “inclusion” are also underrepresented in the institutions implementing that research. I draw attention to the work of SisterLove, the organization founded by Dazon Dixon Diallo to support Black women in the HIV epidemic in 1989. Since its start

with Diallo’s “Healthy Love” curriculum, SisterLove has never viewed HIV/AIDS as an isolated medical crisis. Today, while some of SisterLove’s programs are specific to HIV/AIDS—its testing and counseling services, for example—many others tackle the broad range of structural forces that impact women’s experiences with HIV/AIDS: workshops on sexuality, reproductive justice advocacy, and broader awareness-raising on racial disparities in healthcare.²¹⁰

“Our very existence is a reflection of the women who have shared their struggles, wisdom and strength with other women in the name of love and survival,” their website proclaims.²¹¹ In this way, SisterLove centers the women it serves. That, ultimately, is true inclusion.

Word Count: 12,664

²¹⁰ “What We Do.”

²¹¹ “Our Herstory.”

BIBLIOGRAPHY

Primary Sources

ACT UP. *Storm the N.I.H.: Your Guide to Action*, 1990.
<http://name.umdl.umich.edu/5571095.0422.001>.

ACT UP Golden Gate. “WORLD AIDS DAY: THE CENTER FOR DISEASE CONTROL’S POLICIES ON WOMEN WITH HIV INFECTION,” 1993 1990. MSS 98-47, Box 1 Folder 2. General Meetings, etc., ACT-UP Golden Gate Records, 1988-1993, UC San Francisco Library. <https://calisphere.org/item/ark:/81983/s9kp7r/>.

The ACT UP Historical Archive. “Flyer of the First ACT UP Action March 24, 1987, Wall Street, New York City.” Accessed February 8, 2022.
<https://actupny.org/documents/1stFlyer.html>.

The ACT UP Historical Archive. “MASSIVE DEMONSTRATION BY ACT-UP.” Accessed February 8, 2022. <https://actupny.org/10thanniversary/10th%20repor.html>.

ACT UP/New York Women and AIDS Book Group. *Women, AIDS, and Activism*. Boston, MA: South End Press, 1990. <https://catalog.hathitrust.org/Record/002426147>.

Altman, Lawrence K. “In Major Finding, Drug Curbs H.I.V. Infection in Newborns.” *New York Times*. February 21, 1994, sec. A.

Andiman, Warren. Interview by Isabella Li, April 1, 2022.

Andiman, Warren A. “Where Have All the ‘AIDS Babies’ Gone? A Historical Memoir of the Pediatric AIDS Epidemic in New Haven and Its Eventual Eradication.” *The Yale Journal of Biology and Medicine* 93, no. 4 (September 30, 2020): 625–35.

Angell, Marcia. “The Ethics of Clinical Research in the Third World.” *New England Journal of Medicine* 337, no. 12 (September 18, 1997): 847–49.
<https://doi.org/10.1056/NEJM199709183371209>.

Angoff, Nancy. Interview by Isabella Li, March 16, 2022.

The New York Times. “AZT’s Inhuman Cost,” August 28, 1989, sec. Opinion.

Banzhaf, Marion. ACT UP Oral History Project. Interview by Sarah Schulman, 2007.

Bates, Karen Grigsby. “Is It Genocide?” *Essence*. New York, United States: Essence Communications, Inc., September 1990.

Bunting, Sheila McGuire, and Regina Seaton. “Health Care Participation of Perinatal Women with HIV: What Helps and What Gets in the Way?” *Health Care for Women*

- International* 20, no. 6 (May 1, 1999): 563–78.
<https://doi.org/10.1080/073993399245467>.
- Centers for Disease Control and Prevention. “Immunodeficiency among Female Sexual Partners of Males with Acquired Immune Deficiency Syndrome (AIDS) -- New York.” *Morbidity and Mortality Weekly Report* 31, no. 52 (January 7, 1983): 697–98.
- . “Recommendations of the U.S. Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus.” *Morbidity and Mortality Weekly Report* 43, no. RR-11 (August 5, 1994).
- . “Unexplained Immunodeficiency and Opportunistic Infections in Infants -- New York, New Jersey, California.” *Morbidity and Mortality Weekly Report* 31, no. 52 (December 17, 1982): 665–67.
- . “Update: AIDS Among Women -- United States, 1994.” *Morbidity and Mortality Weekly Report* 44, no. 5 (February 10, 1995): 81–84.
- Children and HIV Infection, Pub. L. No. HRG-1989-OPH-0018, § House Committee on Government Operations (1989).
<https://congressional.proquest.com/congressional/result/congressional/congdocumentview?accountid=15172&groupid=94346&parmId=17BB957899F&rsId=17BB957660B>.
- Chinlund, Chis. “AIDS Claims a Woman--and Her Hopes.” *Boston Globe*. January 20, 1985.
- Clement Communications. *She Has Her Father’s Eyes and Her Mother’s AIDS*. 1988. Poster. U.S. National Library of Medicine. <https://collections.nlm.nih.gov/catalog/nlm:nlmuid-101584655X91-img>.
- Connor, Edward M., Rhoda S. Sperling, Richard Gelber, Pavel Kiselev, Gwendolyn Scott, Mary Jo O’Sullivan, Russell VanDyke, et al. “Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment.” *New England Journal of Medicine* 331, no. 18 (November 3, 1994): 1173–80.
<https://doi.org/10.1056/NEJM199411033311801>.
- Cooper, Ellen R., Robert P. Nugent, Clemente Diaz, Jane Pitt, Celine Hanson, Leslie A. Kalish, Hermann Mendez, et al. “After AIDS Clinical Trial 076: The Changing Pattern of Zidovudine Use during Pregnancy, and the Subsequent Reduction in the Vertical Transmission of Human Immunodeficiency Virus in a Cohort of Infected Women and Their Infants.” *The Journal of Infectious Diseases* 174, no. 6 (December 1, 1996): 1207–11. <https://doi.org/10.1093/infdis/174.6.1207>.
- Cooper, Peter A. “Community under Siege: The AIDS Epidemic in Harlem.” *New York Amsterdam News*. July 23, 1988.
- Farber, Celia. “AIDS: Words From the Front.” *SPIN*, April 1995.

- Fischl, Margaret A., Douglas D. Richman, Michael H. Grieco, Michael S. Gottlieb, Paul A. Volberding, Oscar L. Laskin, John M. Leedom, et al. "The Efficacy of Azidothymidine (AZT) in the Treatment of Patients with AIDS and AIDS-Related Complex." *New England Journal of Medicine* 317, no. 4 (July 23, 1987): 185–91. <https://doi.org/10.1056/NEJM198707233170401>.
- Eshghi, Nima. "National People of Color AIDS Activist Conference," 1991. Box 141, Folder 2. New York Public Library, ACT UP: The AIDS Coalition to Unleash Power, Series X. Published and near Print Material. https://go.gale.com/ps/retrieve.do?tabID=Manuscripts&resultListType=RESULT_LIST&searchResultsType=SingleTab&hitCount=196&searchType=AdvancedSearchForm¤tPosition=8&docId=GALE%7CHBMYDN403692229&docType=Report&sort=Relevance&contentSegment=ZHSI&prodId=AHSI&pageNum=1&contentSet=GALE%7CHBMYDN403692229&searchId=R1&userGroupName=29002&inPS=true.
- Harrington, Mark. "ACTG Protocol 076: Summary, Problems, Alternatives + Recommended Changes: A Report to the CCG 076 Working Group," 1991. Box 63, Folder 4. New York Public Library, ACT UP: The AIDS Coalition to Unleash Power, Series VII: Committees. https://go.gale.com/ps/retrieve.do?tabID=Manuscripts&resultListType=RESULT_LIST&searchResultsType=SingleTab&hitCount=196&searchType=AdvancedSearchForm¤tPosition=2&docId=GALE%7CHUBBIL028966368&docType=Report&sort=Relevance&contentSegment=ZHSI&prodId=AHSI&pageNum=1&contentSet=GALE%7CHUBBIL028966368&searchId=R1&userGroupName=29002&inPS=true.
- Johnson, Judith. "Women with HIV Infection." Science Policy Research Division (Congressional Research Service), March 16, 1992. <https://congressional.proquest.com/congressional/result/congressional/congdocumentview?accountid=15172&groupid=94346&parmId=17BB957A55C&rsId=17BB957660B#548>.
- Kearns, Martin. "Treatment Refused to AIDS Victim." *The Hartford Courant*. February 25, 1984, sec. Connecticut.
- Kurth, Ann, ed. *Until the Cure: Caring for Women with HIV*. Yale University Press, 1993. <https://www.jstor.org/stable/j.ctt1dxg7r1.6>.
- Levine, Carol, and Nancy Neveloff Dubler. "Uncertain Risks and Bitter Realities: The Reproductive Choices of HIV-Infected Women." *The Milbank Quarterly* 68, no. 3 (1990): 321–51. <https://doi.org/10.2307/3350109>.
- Lovvorn, Amy E., Sandra Crouse Quinn, and David H. Jolly. "HIV Testing of Pregnant Women: A Policy Analysis." *Journal of Public Health Policy* 18, no. 4 (1997): 401–32. <https://doi.org/10.2307/3343522>.

- Lowe, David. "HIV Study Raises Ethical Concerns for the Treatment of Pregnant Women." *Berkeley Women's Law Journal* 10 (January 31, 1995): 176.
- Lurie, Peter, and Sidney M. Wolfe. "Unethical Trials of Interventions to Reduce Perinatal Transmission of the Human Immunodeficiency Virus in Developing Countries." *New England Journal of Medicine* 337, no. 12 (September 18, 1997): 853–56. <https://doi.org/10.1056/NEJM199709183371212>.
- McCarthy, Margaret. ACT UP Oral History Project. Interview by Sarah Schulman, February 19, 2015.
- Megan, Kathleen. "Program Gets AIDS Suspect." *The Hartford Courant*. February 18, 1984.
- Mother Jones Magazine. "Mojo's October Hellraiser!," October 1994.
- Murray, Marea. "'It Is Time to Come'; An Activist Perspective on the First National Women and HIV Conference." *Gay Community News*. Boston, United States: Northeastern University, January 13, 1991.
- National Institute of Allergy and Infectious Diseases. "Backgrounder: ACTG Protocol 076-- Questions and Answers," March 8, 1991. Box 140, Folder 16. New York Public Library, ACT UP: The AIDS Coalition to Unleash Power, Series X. Published and near Print Material. https://go.gale.com/ps/retrieve.do?tabID=Manuscripts&resultListType=RESULT_LIST&searchResultsType=SingleTab&hitCount=196&searchType=AdvancedSearchForm¤tPosition=14&docId=GALE%7CGZMXZD231857127&docType=Report&sort=Relevance&contentSegment=ZHSI&prodId=AHSI&pageNum=1&contentSet=GALE%7CGZMXZD231857127&searchId=R1&userGroupName=29002&inPS=true.
- Navarro, Mireya. "In Hispanic Community, Many Ignore AIDS." *New York Times*. December 29, 1989.
- . "Women With AIDS Virus: Hard Choices on Motherhood: AIDS Toughens Pregnancy Choices." *New York Times*. July 23, 1991.
- Nealon, Chris. "'We're Not Counting Everyone'; Activists from around the Country Return to the Centers for Disease Control to Demand Expanded Definitions of AIDS That Include Conditions Affecting Women." *Gay Community News*. Boston, United States: Northeastern University, December 15, 1990.
- Parks, Virg. E. "ACTG Reportbacks," 1991. MSS 98-47, Box 1 Folder 12. 14th AIDS Clinical Trials Group Meeting/ACT-UP Golden Gate Report-backs (ACTG), ACT-UP Golden Gate Records, 1988-1993, UC San Francisco Library. <http://s3-us-west-2.amazonaws.com/uclidc-nuxeo-ref-media/b486ef63-f71a-4292-8068-4dc42c252b80>.

- Pivnick, Anitra. "HIV Infection and the Meaning of Condoms." *Culture, Medicine and Psychiatry* 17, no. 4 (December 1993): 431–53. <https://doi.org/10.1007/BF01379309>.
- Reilly, Philip R. "Eugenics and Involuntary Sterilization: 1907–2015." *Annual Review of Genomics and Human Genetics* 16, no. 1 (2015): 351–68. <https://doi.org/10.1146/annurev-genom-090314-024930>.
- Reynolds, Heather. Interview by Isabella Li, February 8, 2022.
- Rollins, Rochelle Lizette. "A Seat at the Table: A Case Study of Collaboration between AIDS Activists and AIDS Researchers in the Design of AIDS Clinical Trials." Ph.D., Brandeis University, The Heller School for Social Policy and Management, 1995. <https://www.proquest.com/docview/304234125/abstract/84CE54A4D31E4FE0PQ/37>.
- Sbrizzi, Paul. "My ACTG Excellent, Most Excellent (and Sometimes Bogus) Adventure," 1991. MSS 98-47, Box 1 Folder 2. General Meetings, etc., ACT-UP Golden Gate Records, 1988-1993, UC San Francisco Library. <http://s3-us-west-2.amazonaws.com/ucldc-nuxeo-ref-media/a09464f9-5f2d-4b0e-a0d2-d4d1acd3e03a>.
- The Hartford Courant. "Son of AIDS Victim Dies." May 7, 1985, sec. B.
- Warrick, Pamela. "Whose Life Is It?: Weighing the Ethics of Keeping Unborn Babies Safe From HIV." *Los Angeles Times*. February 7, 1995. <https://www.proquest.com/docview/2021894817/abstract/802D339489D744C0PQ/1>.
- SisterLove. "Our Herstory," 2018. <https://www.sisterlove.org/who-we-are>.
- SisterLove. "What We Do," 2018. <https://www.sisterlove.org/what-we-do>.
- Wolfe, Maxine. ACT UP Oral History Project. Interview by Jim Hubbard, 2004.

Secondary Sources

- Briggs, Laura. "The Race of Hysteria: 'Overcivilization' and the 'Savage' Woman in Late Nineteenth-Century Obstetrics and Gynecology." *American Quarterly* 52, no. 2 (2000): 246–73. <https://doi.org/10.1353/aq.2000.0013>.
- Crenshaw, Kimberle. "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color." *Stanford Law Review* 43, no. 6 (1991): 1241–99. <https://doi.org/10.2307/1229039>.
- Eckenwiler, Lisa Ann. "Women and the Ethics of Clinical Research: Broadening Conceptions of Justice." Ph.D., The University of Tennessee, 1997. <https://www.proquest.com/docview/304373176/abstract/7C077CC267B43BCPQ/4>.

- Epstein, Steven. *Inclusion: The Politics of Difference in Medical Research*. University of Chicago Press, 2007. <http://ebookcentral.proquest.com/lib/yale-ebooks/detail.action?docID=408322>.
- Faden, Ruth, Nancy Kass, and Deven McGraw. "Women as Vessels and Vectors: Lessons from the HIV Epidemic." In *Feminism and Bioethics: Beyond Reproduction*, edited by Susan M. Wolf, 252–81. New York, N.Y.: Oxford University Press, Incorporated, 1996. <http://ebookcentral.proquest.com/lib/yale-ebooks/detail.action?docID=3052057>.
- Frere, Maxine, and Barbara C Wallace. "Working in the Trenches with HIV Infected 'Boarder Babies.'" *The Journal of Equity in Health* 3, no. 1 (February 2014): 66–88.
- Gerber, Michael. "'A Modern-Day Typhoid Mary': The Response to a New Haven Prostitute with AIDS in the Early 1980s." Yale University, 2001.
- Junod, Suzanne, and Marks. "Women's Trials: The Approval of the First Oral Contraceptive Pill in the United States and Great Britain." *Journal of the History of Medicine and Allied Sciences* 57, no. 2 (April 1, 2002): 117–60. <https://doi.org/10.1093/jhmas/57.2.117>.
- Kazanjian, Powel. "The AIDS Pandemic in Historic Perspective." *Journal of the History of Medicine and Allied Sciences* 69, no. 3 (2014): 351–82.
- Mueller, Mary-Rose. "'Women and Minorities' in Federal Research for AIDS." *Race, Gender & Class* 5, no. 2 (April 30, 1998): 79.
- Padamsee, Tasleem J. "Fighting an Epidemic in Political Context: Thirty-Five Years of HIV/AIDS Policy Making in the United States." *Social History of Medicine* 33, no. 3 (August 1, 2020): 1001–28. <https://doi.org/10.1093/shm/hky108>.
- Reverby, Susan. *Examining Tuskegee: The Infamous Syphilis Study and Its Legacy*. University of North Carolina Press, 2009.
- Royles, Dan. *To Make the Wounded Whole: The African American Struggle against HIV/AIDS*. Chapel Hill: The University of North Carolina Press, 2020. <https://muse.jhu.edu/book/77107>.
- Schulman, Sarah. *Let the Record Show: A Political History of ACT UP New York, 1987-1993*. Farrar, Straus and Giroux, 2021.
- Shilts, Randy. *And the Band Played On: People, Politics, and the AIDS Epidemic*. New York, N.Y.: St. Martin's Press, 1987.
- Sides, W. Hampton. "Lana: A Story of Scarlet Letters and Public Risks." *The New Journal*, December 1983.

Stern, Scott. "Rethinking Complicity in the Surveillance of Sex Workers: Policing and Prostitution in America's Model City." *Yale Journal of Law and Feminism* 31, no. 2 (2020): 411–96.

BIBLIOGRAPHICAL ESSAY

Throughout my time as a History of Science, Medicine, and Public Health major, my professors have taught me to focus on everyday stories obscured by the historical record. That mentality has become foundational to my approach to the field and this project. In the story of an HIV clinical study, three points of view emerge: that of medical professionals, that of activist groups, and that of patients. The last—which I center in this project—has proven to be frustratingly elusive. My attempt to reconstruct it has taken me on a winding series of leads, dead ends, and occasional treasures.

Approaching my senior project, I had a broad interest in clinical research involving historically marginalized groups. In previous classes, I read several foundational texts. *Inclusion* by Steven Epstein introduced to me the modern clinical research aspiration towards inclusion and the societal paradoxes that accompany it. *Examining Tuskegee* by Susan Reverby explored our nation's most notorious case study of exploitative human subjects research. Grounding her work in the stories of study participants, Reverby provided a thoughtful analysis on the foundational role of race in the Tuskegee Syphilis Studies. As I sought to maintain an awareness of race alongside other forms of marginalization, Kimberlé Crenshaw's writings on intersectionality drove my philosophical approach throughout this project.

With a broad interest in mind, I began to search for a more specific case study of clinical research. HIV drew my interest. Throughout college, I had researched the scientific dimensions of the virus at a lab at the medical school. But I sought the human dimensions as well, and I knew, vaguely, of the extensive clinical research-focused activism that surrounded the epidemic. In the summer, I stumbled upon Michael Specter's *New Yorker* book review of Sarah Schulman's *Let the Record Show*, a history of ACT UP. The review, and Schulman's work,

discussed the controversy of Trial 076. Its primary participants immediately drew my attention: poor women of color, as opposed to the middle-class white men typically associated with the HIV/AIDS epidemic in the 1980s and 1990s. Multiple angles of analysis would be required to honor their stories—feminism and women’s health, race, class—angles not frequently associated with narratives of HIV/AIDS. Intrigued, my project was cemented.

I gained broad context on clinical research and the AIDS epidemic, particularly with regards to women, poor people, and people of color. Secondary sources, including Steven Epstein’s book, *Impure Science*, and Lisa Eckenweiler’s dissertation, “Women and the ethics of clinical research,” informed me on clinical research in the AIDS epidemic and involving women, respectively. Congressional hearings and reports introduced me to general discourses on women with HIV the epidemic. Other primary sources—the ACT UP Women’s Caucus’s *Women, AIDS, and Activism* book, alongside digitized newspaper articles on the epidemic in Black and Latine communities—captured the struggles of women, pregnant women, and people of color.

I next explored the history of AIDS activism on Trial 076. I sought ACT UP primary sources: the ACT UP Oral History Project, ACT UP archival material digitized by the University of California San Francisco and the New York Public Library, and *Women, AIDS, and Activism*, a book published by the ACT UP Women’s Caucus. These sources provided me a nuanced understanding of objections to the trial, including at the dramatic 1991 March ACTG meeting. But ACT UP, known to be predominantly white, could not wholly represent the perspective of the poor women of color who comprised the majority of Trial 076’s participants.

I scoured online databases for sources on AIDS activism led by women of color. I found primary and secondary sources on Dazon Dixon Diallo’s work with SisterLove, including a chapter from Dan Royles’s *To Make the Wounded Whole*. Here, I learned about women of

color's holistic approach towards the HIV/AIDS epidemic, centering not just the minutiae of the disease, but also its social, economic, and emotional dimensions. With this perspective in mind, I read a dissertation by Rochelle Rollins, a woman of color and AIDS activist who was present at the 1991 meeting. Through her account of the meeting, I understood the eagerness with which some women of color embraced Trial 076, driven by their broader hopes to protect their children and communities. Rollins's work also illuminated racial tensions within AIDS activist circles. I envisioned that these tensions reflected larger truths about the erasure of women of color's perspectives within clinical research. But while the perspectives of women of color activists presented closer approximations of the perspectives of the participants in Trial 076, they were far from perfect: many activists were not pregnant and did not live with HIV/AIDS.

I searched several online databases—ProQuest News and Newspapers and Women's Health Archive, Google Books, the Medical Heritage Library, the National Library of Medicine Digital Collections—with the “076” keyword. Through Google Books, I found a 1995 article by Celia Farber for *SPIN* magazine. Tucked into the piece were the stories of “Rosa Harris” and “Sonia Alvarez,” pseudonyms for two women who had participated in Trial 076. Their words reflected larger societal themes I had perceived throughout my research, while also revealing the women's profound personal love for their children. Nevertheless, their stories could not comprehensively represent those of all Trial 076 participants. Most glaringly, Farber's article aimed to cast doubt over the safety of AZT and critique Trial 076's methodologies. Rosa and Sonia's words had likely been manipulated to suit this purpose. I unsuccessfully attempted to seek more information. Rosa, for example, had been interviewed on the *Montel Williams Show*, but the episode remained inaccessible to both me and Dr. Melissa Grafe of the Yale Medical Historical Library, whose help I solicited.

Unable to locate additional stories of the other 475 participants in Trial 076, I settled on a new approach: reconstructing their perspectives through those of pregnant women with HIV, before and after the trials. Contexts I had gleaned from earlier research hinted at these experiences, but here, I adopted a more deliberate approach: I wanted words directly from pregnant women with HIV, or intimate stories of their experiences. In online databases, I tracked newspaper articles with interviews, including Pamela Warrick's "Whose Life is It?" and Mireya Navarro's "Women with AIDS Virus." Later, I uncovered a variety of journal articles and books that interviewed pregnant women with HIV. Authored by nurses and social science researchers, some used these interviews to educate health care providers on ideal care practices, while others used them to advise on health policy. These works included personal narratives and direct quotations from pregnant women with HIV. Like Rosa and Sonia, their perspectives reflected the race, class, and gender-based structures around them, while also revealing a profound fear for their personal well-being and love for their children.

Serendipitously, in October, I saw Scott Stern's article in *The New York Times*, "An AIDS Activist's Archive." Stern referenced the story of Carlotta Locklear, a sex worker in New Haven who faced national stigma in the early-'80s for her HIV status after she gave birth to a boy with AIDS at Yale-New Haven Hospital. Seeking more information, I identified primary sources, including newspaper clippings, an obituary, and an article from the Yale undergraduate publication *The New Journal*. With the help of my advisor Dr. Kelly O'Donnell, I also reached out to Stern personally. He kindly shared with me an article he had written for the *Yale Journal of Law and Feminism*, as well as a History of Science, Medicine, and Public Health thesis on Carlotta Locklear written by Yale undergraduate Michael Gerber in 2001. Through the mosaic of

these sources, I pieced together a more holistic and empathetic understanding of Carlotta's story, grounded in the multilayered social structures that limited her decisions.

Stern also advised that I reach out to Heather Reynolds, who directed nurse-midwifery at Yale-New Haven Hospital during the epidemic. This launched me on the final—and most rewarding—leg of my research for this project: conducting oral histories with medical professionals at Yale who had directly interacted with pregnant women with HIV. I reached out to Ms. Reynolds, who kindly agreed to speak with me over Zoom. The patient stories she shared shed light on the raw fear—and beautiful humanity—of pregnant women with HIV. Later, Dr. Randi Epstein—whose seminar, *Writing About Medicine*, I am taking this semester—put me in contact with Dr. Nancy Angoff and Dr. Warren Andiman, two physicians who worked with pregnant women and their children during the epidemic at Yale-New Haven Hospital. Dr. Angoff, who I spoke with over Zoom, recounted stories about the resilience of pregnant women with HIV. Dr. Andiman provided insight into the difficulties of implementing treatment protocols. Speaking with these medical professionals provided me a valuable opportunity to ask questions whose answers evaded the historical record. In doing so, I unearthed powerful stories of pregnant women with HIV as they negotiated their medical care.

When I evaluate my sources, I am keenly aware that I was not able to directly speak with a pregnant woman with HIV—especially one who participated in Trial 076. My quotations and stories have been filtered through other researchers, writers, and medical professionals with their own agendas and biases. In attempting to reconstruct the story of Trial 076, I, too, have exerted my own bias. This problem stands at the heart of my project and motivated its very conception: in the field of history, just as in attempts at “inclusive” clinical research, we too often obscure the voices of those marginalized—by race, class, gender, sexuality, disability status, and more. The

problem becomes more severe when the perspectives we seek identify with more than one category of marginalization. Before historians create narratives on key events, and before researchers and activists design or advocate for research protocols and methodologies, we ought to listen. We ought to seek the stories of those whose voice have been systemically hidden, and we ought to orient our work to honor those stories.