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## Positive Women: Emotion, Memory, and the Power of Narrative in Women Organized to Respond to Life-Threatening Diseases, 1991-2020

Eleanor Naiman  
enaiman1@swarthmore.edu

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### Erratum

Please note that a section of this article has been redacted on request of a referenced source.

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**Positive Women:**  
**Emotion, Memory, and the Power of Narrative in Women Organized to Respond to**  
**Life-Threatening Diseases, 1991-2020**  
Eleanor Naiman  
Swarthmore College, Thesis

By 1992, the AIDS epidemic in the United States had reached seemingly catastrophic proportions. Over ten years after the first published report of AIDS-related lung infection, the number of AIDS cases in the United States far exceeded 100,000. It would be four years until the FDA approval of the first protease inhibitor.<sup>1</sup> Over ten thousand women had been diagnosed with the disease, and experts expected over ninety thousand more were already infected.<sup>2</sup> The disease, lacking effective treatment, increasingly struck women and people of color in the early 1990s; cases rose 151 percent among women and by 105 percent among men in 1993.<sup>3</sup> Without a cure in sight, women with HIV did not have much tangible reason for optimism. Nonetheless, in January 1992 Debra McCarthy cast her HIV diagnosis as the turning point in her journey towards personal fulfillment. “Even though I may be HIV positive,” she wrote, “I am more healed in my life than I ever have been.”<sup>4</sup>

Published in the newsletter *WORLD (Women Organized to Respond to Life-Threatening Diseases)*, McCarthy’s story of healing represented one of many such testimonials printed by the publication throughout the 1990s. Established in 1991, *WORLD* circulated among women living with HIV at a point in the AIDS epidemic marked by uncertainty and despair. The newsletter’s testimonials, however, maintained a consistent bent towards optimism; authors emphasized how HIV had provoked their own discoveries of life’s purpose and journeys of personal growth. By writing their stories within a standard narrative form, women with HIV cast themselves as

<sup>1</sup> “A Timeline of HIV/AIDS,” *AIDS.gov*, <https://www.hiv.gov/hiv-basics/overview/history/hiv-and-aids-timeline> (accessed October 11, 2019).

<sup>2</sup> Peggy Orenstein, “Women at Risk.” *Vogue*. November, 1990. Jessea Greenman P.E.R.S.O.N. Project Records, 1978-1997. San Francisco History Center, San Francisco Public Library. San Francisco, CA.

<sup>3</sup> Lawrence K. Altman, “Cases of AIDS Increase Among Heterosexuals,” *New York Times* (11 March, 1994):p.A8. in Schneider, Beth; Stoller, Nancy E. *Women Resisting AIDS*. Philadelphia: Temple University Press, 1995, 7.

<sup>4</sup> Debra McCarthy, “Positive Gifts” *WORLD* 9, January 1992

triumphant, empowered, and victorious over not disease but self-doubt, anger, and despair. These “negative” emotions, seemingly unprintable and nearly inexpressible within the context of the *WORLD* testimonial, nonetheless became key to *WORLD*’s protest efforts as the organization expanded from a newsletter to an activist network with a variety of projects and endeavors.

Nearly thirty years after the publication of the newsletter’s first issue, Rebecca Denison recounted her memories of *WORLD*’s early years in an oral history interview. As the founder and executive director of *WORLD* and the sole editor of its newsletter, Rebecca Denison played an integral role in the construction of her publication’s emotional register and content. My interview with Denison allows interpretation of yet another narrative: Denison’s performed and constructed memories of her time at *WORLD*. This narrative, much like the testimonials published in the earliest issues of *WORLD*, adheres to a specific emotional register and suggests the thematic and political motivations of its narrator. Denison’s memories of her time at *WORLD* incorporate a bent towards optimism and positivity evocative of that of *WORLD*’s testimonials. Conducted in the midst of the 2020 pandemic of coronavirus/COVID-19, Denison’s interview also reflects the social and political climate of the United States as it grapples with yet another public health crisis. Over the course of our interview, Denison’s narrative of positivity, love, and mutual support among members of the *WORLD* community confronted the more painful memories of grief and loss triggered and exposed by the political rhetoric and climbing death rate of the current pandemic.

Over the course of this paper, I will examine *WORLD*’s emotional codes and the discursive strategies of its members in two distinct moments: in the 1990s, in the midst of the AIDS crisis, and in 2020, at the height (or perhaps simply the beginning) of the global pandemic of COVID-19. My analysis will hinge on two different narrative genres: the testimonials printed

in the newsletter in the 1990s and the recounted memories of Rebecca Denison in our oral history interview in April of 2020. I will first trace the evolution of WORLD's register of permissible emotions over the course of the 1990s as the organization delineated which feelings were desirable and thus printable within the context of its newsletter. By preserving their organization's emotional codes despite the changing meaning of the epidemic and while increasingly engaging with activist communities with very different emotional norms, the women of WORLD maintained their ability to both advocate for their right to access and information while continuing to narrate their diagnoses and lives with HIV as stories of hope, optimism, and triumph. I will then examine the lingering influence of WORLD's emotional codes on Rebecca Denison's narrative of her time at WORLD. Denison's memories reflect the editorial influence of memory on the emotional context of the past. Her performance of these memories suggests the power and continued influence of the norms established among the organization's members in the 1990s. Her narrative also, however, points to the capacity of the present to disrupt elements of constructed memory narratives and to unearth emotional experiences of the past that fell outside of WORLD's register of expressible emotions. By analyzing these two moments and narratives at once and in conversation with one another, I hope to examine how stories shape the past both as it is experienced, remembered, and reimagined as an emotional and rhetorical framework through which we understand the present.

Scholars who have studied the AIDS epidemic have often done so from a perspective that consistently overlooks the role of women living with HIV and AIDS in the organized community response to the disease. Furthermore, scholarship on AIDS has often privileged the perspectives of health care workers over those of patients and activists. The earliest AIDS narratives, written

by journalists in the 1980s and early 1990s in the midst of the developing epidemic, contributed to general knowledge of the disease's spread and import, yet often lacked nuance and omitted analysis of its impact on women. Despite its overwhelming focus on white men with AIDS and lack of historical perspective, work by journalists Randy Shilts<sup>5</sup> and Elinor Burkett<sup>6</sup> offer valuable opportunities to examine the formation of scholarly discourse and to analyze the polemical nature and perhaps even political projects of both journalists.

More recent AIDS literature has highlighted the contributions of individual doctors and nurses during the later years of the epidemic. Work by doctors Susan C. Ball,<sup>7</sup> Ronald Bayer, and Gerald M. Oppenheimer<sup>8</sup> acknowledged the spread of AIDS to women, yet privileged the experiences of these doctors over those of their patients, and even over those of the nurses and caregivers with whom patients interacted with perhaps even greater frequency. More recently, scholars have also sought to portray the AIDS epidemic as rooted in historical continuity, rather than as a pathological or exceptionalist break from the past. Nan Boyd examined how San Francisco became known for its large LGBT communities and how those communities formed and came into conflict over time.<sup>9</sup> Jennifer Brier's history of AIDS policy identified continuity in the way in which existing discourses of radical gay liberation helped the gay community make sense of the epidemic, although debate emerged over how to interpret those principles in a new

<sup>5</sup> Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin's Griffin, 1988).

<sup>6</sup> Eleanor Burkett, *The Gravest Show on Earth*, (Boston: Houghton Mifflin Harcourt, 1995).

<sup>7</sup> Susan C. Ball, *Voices in the Band: A Doctor, Her Patients, and How the Outlook on AIDS Care Changed from Doomed to Hopeful*, (Ithaca: ILR Press, 2015).

<sup>8</sup> Ronald Bayer and Gerald M. Oppenheimer, *AIDS Doctors: Voices from the Epidemic*, (New York: Oxford University Press, 2000).

<sup>9</sup> Nan Boyd, *Wide Open Town: A History of Queer San Francisco to 1965*, (Berkeley: University of California Press, 2003).



context.<sup>10</sup> Tamar Carroll argued that HIV/AIDS activism in New York built on the 1970s contributions of the feminist health movement and that ACT UP benefitted from its collaboration with pro-choice and reproductive rights groups.<sup>11</sup>

A final and growing trend in AIDS historiography centers the narrative of the epidemic on the experiences of people with HIV/AIDS who do not fit the normative image of the young, white, gay, cisgender AIDS patient. Cindy Patton's book *Last Served? Gendering the HIV Pandemic* (1994) examines written representations of women with HIV/AIDS as well as public health strategies to prevent the spread of the epidemic among women.<sup>12</sup> Beth E. Schneider and Nancy E. Stoller's anthology of essays, *Women Resisting AIDS: Feminist Strategies of Empowerment* (1995) examines the experiences of women living with HIV from a wide range of perspectives.<sup>13</sup> Contributing authors address the experiences of African-American women, activism by sex workers, mandatory testing for pregnant women, lesbian involvement in the epidemic, and outreach to women drug users in San Francisco, among other topics. Other more contemporary examples of this historiographical trend are Alexis Shotwell's article "'Women Don't Get AIDS, They Just Die From It': Memory, Classification, and the Campaign to Change the Definition of AIDS"<sup>14</sup> and Kevin J. Mumford's *Not Straight, Not White: Black Gay Men from the March on Washington to the AIDS Crisis* (2016).<sup>15</sup> Both Shotwell and Mumford take

<sup>10</sup> Jennifer Brier, *Infectious Idea: U.S. Political Responses to the AIDS Crisis*, (Chapel Hill: University of North Carolina Press, 2009).

<sup>11</sup> Tamar Carroll, *Mobilizing New York: AIDS, Antipoverty, and Feminist Activism*, (Chapel Hill: University of North Carolina Press, 2015).

<sup>12</sup> Cindy Patton, *Last Served? Gendering the HIV Pandemic*, (Bristol: Taylor & Francis, 1994).

<sup>13</sup> Beth E. Schneider and Nancy E. Stoller, *Women Resisting AIDS: Feminist Strategies of Empowerment*, (Philadelphia: Temple University Press, 1995).

<sup>14</sup> Alexis Shotwell, "'Women Don't Get AIDS, They Just Die From It': Memory, Classification, and the Campaign to Change the Definition of AIDS," *Hypatia* 29, no. 2 (Spring 2014): 509-525.

<sup>15</sup> Kevin J. Mumford, *Not Straight, Not White: Black Gay Men from the March on Washington to the AIDS Crisis*, (Chapel Hill: University of North Carolina Press, 2016).

important steps in addressing a dearth in historical scholarship focused on the experiences of people with HIV/AIDS who do not fit the established image of an AIDS patient. I hope to place my research within this growing literature, centering my narrative of the AIDS epidemic on the varied experiences of HIV+ women in the San Francisco Bay Area in the 1990s whose stories have largely been neglected.

Founded by Rebecca Denison in 1991, *WORLD* emerged as one woman's response to the lack of community organizations built by and for women like herself. Denison, a white college graduate then in her late twenties, initially assumed her HIV diagnosis in 1990 meant "an automatic death sentence."<sup>16</sup> Isolated and confused, Denison struggled to find support groups for women with HIV despite the strength of AIDS organizing in the Bay Area.<sup>17</sup> The first issue of *WORLD*, published on May 1, 1991, reflected Denison's personal yearning for a supportive and informed community of HIV+ women. She hoped to help women "make the friends that sustain them."<sup>18</sup> Despite this dream of friendship, Denison did most of the organization's work herself in its first year. Without funding, she worked out of her own home and without pay.<sup>19</sup> When asked to narrate *WORLD*'s origin story to the press, however, Denison highlighted not the long hours she'd worked or the newsletter's economic trials, but rather the uplifting emotional journey she had experienced throughout the organization's first year. In a profile published in

<sup>16</sup> Schneider and Stoller, *Women Resisting AIDS*, 1995, 195.

<sup>17</sup> Ibid, 196.

<sup>18</sup> Susan Gerhard, "Brave New W.O.R.L.D. : Women with HIV Speak Up Through Berkeley Newsletter," *The Bay Guardian*. December 2, 1992. Jessea Greenman P.E.R.S.O.N. Project Records, 1978-1997. San Francisco History Center, San Francisco Public Library. San Francisco, CA.

<sup>19</sup> Women's AIDS Network Executive Board, "Minutes of WAN Meeting December 1, 1992" and "Minutes of WAN Meeting September 1, 1992," Meeting Minutes, 1991-1993. The Nancy Stoller Papers, 1981-1995. UCSF Special Collections. San Francisco, CA.

*The Bay Guardian* in 1992, Denison recounted her own story of renewed purpose and personal triumph. Despite the trials of life with HIV and of running an underfunded and fledgling organization, Denison felt fulfilled. “Emotionally,” she explained in 1992, “this work has given me my life back.”<sup>20</sup> Editing *WORLD* had renewed her sense of purpose in a life she once thought lost forever. By choosing to structure her own personal narrative around positive emotions, Denison set the tone for the newsletter’s subsequent editorial choices. The theme of renewed purpose and hope emphasized in her *The Bay Guardian* feature would emerge countless times in the newsletter’s articles in the early 1990s.

Denison played an active role in the construction of each testimonial, from the selection of its narrator to the themes and information highlighted throughout. The newsletter’s first issue, Denison explained in our interview, presented an opportunity to incorporate the voices and experiences of women of color from the start. Denison’s experience in the anti-nuclear movement, which she described as “such a white movement,” provided a cautionary example of what not to do: “It’s not cool to create a movement and lay down a culture and then say to other people, you should come join this.”<sup>21</sup> She actively sought out women of color to join her fledgling organization, calling every organization she could think of that might have HIV positive women of color as clients and asking whether they might know of someone eager to share her story. A case manager at the Mission Neighborhood Health Center in San Francisco connected Denison with a woman named Alba who would become the narrator of the newsletter’s first testimonial. Denison and Alba met in the back of a café. As Alba recounted her

<sup>20</sup> Gerhard, “Brave New W.O.R.L.D.”

<sup>21</sup> Rebecca Denison, interview by author, Berkeley, April 19, 2020.

story, Denison copied it down. “I type really fast,” Denison remembered, “so I just typed verbatim what she said and then helped her edit it down.”<sup>22</sup>

This process of recording and transcribing other peoples’ stories was not new to Denison: working as an immigration paralegal before her diagnosis, Denison interviewed asylum-seekers and helped them transform their stories into the written affidavit for their asylum case. Often the process involved editing and translating an oral account from Spanish into written English while preserving the integrity of the story itself. Although Denison was heavily involved in the construction of the written affidavit, the interviewee needed to feel, at the end of the process, as though they had written the story themselves and as though the words on the page reflected the essence of the experience they would be questioned about when they took the stand before a judge. Denison took a similar approach when meeting with women with HIV whose stories she published in *WORLD*. The stories, she explained, resulted from a “collaborative process” in which Denison interviewed the narrator and took notes. After editing the woman’s words into about a page and a half, Denison met with the author once again to make sure the language, voice, and vocabulary used in the written account matched that used by the testimonial’s author. The process of meeting with and composing a testimonial with Denison often allowed women who had only recently “come out” as HIV positive to incorporate themselves more fully into the *WORLD* community. Although some women had been involved with *WORLD*’s support groups or programming efforts for years before contributing a testimonial, others shared their stories after their first retreat with the organization. Sharing their story represented the first step in a journey to being on *WORLD*’s staff or to becoming a peer advocate for other women with HIV.

<sup>22</sup> Rebecca Denison, interview by author, Berkeley, April 19, 2020.

As *WORLD* grew over the course of the 1990s, the newsletter's testimonials became increasingly thematic and topical. Denison began to match the topics mentioned in each issue's testimonial to the medical information and resources provided throughout the pages of the issue. Often, these themes or topics emerged as Denison worked with a woman to construct her testimonial. For other issues, the topic of the month emerged as Denison spoke with nurses and case managers who identified specific needs and interests of their clients with HIV. Denison then sought out a specific woman whom she knew could provide a first-person narrative related to the topic in question, whether it be pregnancy and HIV or addiction and recovery. By including a testimonial, related medical information, and resources within the same monthly issue, Denison translated complicated topics into legible and emotionally resonant stories that *WORLD*'s readers could digest and understand regardless of their proficiency with the English language or degree of literacy. Guided by the belief that "people really learn through stories," Denison aimed to present information at about an eighth grade reading level.<sup>23</sup> The language and themes that appeared in *WORLD*'s testimonials thus represented an attempt not only to connect women with HIV to one another but also to educate the newsletter's readers through a narrative medium far more accessible than the studies published in medical journals or even the fact sheets and informational brochures published by other AIDS advocacy organizations.

Beyond their topical relevance, each *WORLD* testimonial reflected a similar bent towards optimism and a desire to inspire the newsletter's readers. Each testimonial, whether intentionally or, as Denison put it, "intuitively," reflected authors' hope to "lift up someone else" just as they themselves had been lifted up and inspired by the testimonials printed in previous issues. The testimonials provided models for women hungry to understand what it looked like to not simply

<sup>23</sup> Rebecca Denison, interview by author, Berkeley, April 19, 2020.

live with HIV/AIDS but to “thrive” with the disease. “If I feel like I can’t survive something, and then I see that someone else did it, that lifts me up,” Denison explained. Of the collaborative process through which she helped women narrate their stories, Denison says, “I did want it to be a positive experience.”<sup>24</sup> Denison’s desire to make both the construction and the consumption of her newsletter’s testimonials a “positive experience” for women with HIV informed not only the content and structure of each testimonial, but the emotional register to which each narrative adhered.

### **I. Testimonial as Narrative**

Printed on page one of *WORLD*’s first issue, “Testimonial” by a woman named Alba represented the newsletter’s longest article.<sup>25</sup> Alba’s testimonial wove indirect references to *WORLD*’s mission between more specific details from the anonymous author’s personal experience coming to terms with life as an HIV+ woman. As an artistic expression of personal experience, Alba’s “Testimonial” permits analysis as a literary work and features many characteristics of normative narrative form. Much like a conventional written story, “Testimonial” features the basic elements of traditional dramatic structure: exposition, rising action, climax or turning point, falling action, and dénouement or resolution. In her exposition, Alba defined her identity: “I am a woman, a Latina, a mother and a grandmother.” The rising action begins with Alba’s HIV test and grows as her emotional response transitions from disbelief (“I couldn’t believe it! I was sure that it had to be a mistake”) to grief (“I felt so terribly sad. It was like I became another person”). She detailed the unraveling of the life she had built pre-diagnosis, precipitated by her abandonment by an angry boyfriend. The rising action of her

<sup>24</sup> Rebecca Denison, interview by author, Berkeley, April 19, 2020.

<sup>25</sup> Alba, “Testimonial,” *WORLD* 1, May 1, 1991.

testimonial depicts a period of deterioration eloquently summed up in the sentence, “I think the first year is so different, because your mind and soul are sick as well as your body.”

The climax, or turning point, of Alba’s story arrives suddenly. She wrote, “Then one day I decided it was time to begin to put the pieces of my life back together. I realized that there are things I want to do on this earth.” This sudden commitment to finding purpose after diagnosis stimulates the story’s falling action, in which Alba reconnects with her faith and “internal God,” asserts that all women should “become experts about our own bodies,” and declares a determination to live and to “grow” despite the lack of “instructions” for how to do so. Finally, Alba’s story’s dénouement, or resolution, arrives with a statement of purpose: “I feel like I want to do something, to educate people and to reach out to other women who are living with this disease.” Her story resolves, ultimately and comfortably, with her assertion of reclaimed identity: “Now, finally, I am me again.”

Alba’s use of dramatic structure, a normative literary form, as the means through which to convey the experience of living with HIV transformed this experience into something easily understood and consumed. Dramatic structure minimized the uncertainty often associated with the epidemic. Though many HIV+ women, faced with a disease lacking adequate or effective treatment, lived in doubt and with ambiguous outcomes, the familiar nature of dramatic structure transformed this experience into one marked by comforting predictability.

Over the past twenty years, scholars of HIV/AIDS have similarly analyzed the artistic and literary production that emerged from the epidemic as a window into the experiences, emotions, and memories of people living with HIV. Ross Chambers provided an early contribution to this line of scholarship with *Facing It: AIDS Diaries and the Death of the Author*

(1998).<sup>26</sup> Through the theoretical framework of literary criticism, Chambers analyzed the genre of AIDS biography in the epidemic's first decade. Chambers saw AIDS writing as a form of revolt in which the author refuses, through the process of witnessing and describing their experience, to become a victim of their disease. Chambers further analyzed AIDS writing as a process of construction, in which autobiographers construct and make meaning of their experiences. This process of construction through artistic production represented a main focus of Roger Hallas's *Reframing Bodies: AIDS, Bearing Witness and the Queer Moving Image* (2009).<sup>27</sup> Hallas, a professor of media studies, examined queer AIDS media and activist videography in the early years of the epidemic. To Hallas, these cinematic testimonials represented attempts to bear witness to traumatic experiences that, by "reframing the intersubjective space between the speaking subject and the listening viewer," defamiliarized and disrupt the normative and objectifying media representations of the epidemic and the AIDS patient.<sup>28</sup> Both Chambers and Hallas understood artistic works produced by people with AIDS as active attempts to revolt against both stereotype and the disease itself. Their work examines artistic production as a purposeful and intentional process through which people with HIV constructed their own experiences and memories and rebelled against normative portrayals of AIDS disseminated in the mass media. Alba's testimonial, through its emphasis of positive emotions and personal triumph, represented a similar form of revolt against normative AIDS narratives that cast those living with HIV as victims of a terrifyingly uncontrollable disease.

<sup>26</sup> Ross Chambers, *Facing It: AIDS Diaries and the Death of the Author*. (Ann Arbor: University of Michigan Press, 1998).

<sup>27</sup> Roger Hallas, *Reframing Bodies: AIDS, Bearing Witness and the Queer Moving Image*, (Durham, NC: Duke University Press, 2009).

<sup>28</sup> Ibid, 9-10.



The adaptation of Alba's story into a literary work further transformed, or reinterpreted, the HIV experience by casting its antagonist not as the disease itself, but as grief and self-doubt. Typically, "falling action" denotes the portion of a dramatic or literary work in which the conflict between the protagonist and the antagonist unravels. In her testimonial's falling action, Alba, the protagonist, regains her "lost confidence" and realizes she "still had [her] faith, and that kept [her] going." Alba's antagonist, then, is not HIV/AIDS, but her own initial emotional response to her diagnosis. Once she has defeated self-doubt, her story reaches a satisfying resolution marked by catharsis, purpose, and hope for the future. Alba's written testimonial transformed an experience characterized by uncertainty, fear, and doubt into one easily consumed and understood that leaves its readers with a comforting sense that, despite the absence of a medical cure, women could defeat the epidemic by prevailing over their own personal and emotional weakness. *WORLD*'s selection of Alba's narrative as its first printed article foregrounded the emotional valence of the organization's work and reflected the organization's desire to bring comfort to its readers as they navigated an often isolating and confusing life with HIV.

Over the next five years of the newsletter's circulation, the testimonials published in *WORLD* adopted the narrative structure first presented in Alba's story. Authors highlighted their personal triumph over emotional distress and urged other women to similarly overcome unhappiness and self-doubt. In the third issue of *WORLD* published in July 1991, Bonnie W. wrote of the deep unhappiness she experienced upon both the receipt of her HIV diagnosis and the death of her mother: "I was already deeply depressed when my mother died (I had found out about the HIV 6 months earlier) and I really thought this additional pain and anguish would send me over the edge."<sup>29</sup> Bonnie detailed how reaching out to those around her and divulging her

<sup>29</sup> Bonnie W., "To Say Good-bye," *WORLD* 3, July 1, 1991.

HIV status ultimately allowed her to achieve happiness in life. She wrote, “It is the love that we share with others that allows us to transcend unhappiness, loneliness, and tragedy in our lives.”<sup>30</sup> Bonnie’s story echoed Alba’s, centering her narrative of living with HIV on her personal victory over depression. Likewise, a contributor called “Anonymous M.” wrote in May 1995 of her personal victory over sadness. Throughout the testimonial, Anonymous M. highlighted her agency in effecting meaningful personal change and growth. She wrote, “It took a lot of hard work and a lot of pain before I was able to change my negative thinking. I set my goals high and regardless of what may happen, I never give up on my dreams. I’ve come to learn that destiny is not a matter of chance, but a matter of choice.”<sup>31</sup> The framing of these testimonials as victorious battles against emotional turmoil allowed *WORLD*’s contributors to cast themselves as protagonists with agency despite the ultimate impossibility of controlling or fully comprehending the HIV/AIDS in the early 1990s.

Many of *WORLD*’s early contributors presented their narrative as not merely a story of emotional resilience, but a tale of personal growth prompted by their diagnosis. The authors of these testimonials portrayed their HIV diagnosis as the catalyst of positive change and the antidote to life struggles ranging from drug use to depression. In her January 1992 testimonial titled “Positive Gifts,” Debra McCarthy portrayed her HIV diagnosis as not “the end of my life,” but “only the beginning.” She explained how only after contracting HIV did she find herself capable of defeating the “disease of denial” and the “disease of alcoholism.” In McCarthy’s narrative, HIV became a sort of ironic cure. Suzin Gartland, writing in September 1993, credited HIV for her own positive personal growth. “My HIV disease,” she wrote, brought her and her

<sup>30</sup> Ibid.

<sup>31</sup> Anonymous M., “Believing in miracles,” *WORLD* 49, May 1995.

children “closer together” and taught her to “look inside and listen... to ‘see’ with my heart.”<sup>32</sup>

Gartland did not go quite as far as McCarthy. To her, HIV represented more of a catalyst for reflection and self-improvement rather than the cure itself. Gartland wrote, “I am responsible for the goodness that has come into my life, but HIV has been a tremendous incentive.” She thus cast herself as an actor with agency while nonetheless representing her diagnosis as a positive force in her life.

Other contributing writers found it important to admit their anger and resentment towards the disease before acknowledging the positive changes it effected in their lives. In her October 1993 testimonial “There’ll Be Time to Worry Later,” Teresa acknowledged the newfound purpose and motivation characteristic of her post-diagnosis life despite her continued anger at having been diagnosed in the first place. She wrote, “I hate this disease, but it has helped me to find myself at a time when I thought I knew who I was and where I was going. My life has become much more valuable to me and I am filling it up with meaningful experiences and relationships.”<sup>33</sup> In presenting HIV as a sort of catalyst for positive personal change, the authors of these testimonials cast themselves not as victims or as helpless patients, but rather as women granted a second chance at achieving personal fulfillment.

These early WORLD testimonials reflected the limits of the organization’s *emotional habitus*, or the limits placed upon the emotional possibilities expressed by the newsletter’s contributing authors. In *Moving Politics: Emotion and ACT UP’s Fight against AIDS* (2009), sociologist Deborah Gould details the role of affect and emotion in the rise and fall of ACT

<sup>32</sup> Suzin Gartland, “Look inside... ‘see’ with my heart,” *WORLD* 29, September 1993.

<sup>33</sup> Teresa, “There’ll Be Time to Worry Later,” *WORLD* 30, October 1993

UP.<sup>34</sup> A former member of ACT UP/Chicago, Gould bases her research on interviews and written archival texts. Key to her work is the concept of “emotional habitus,” or “a social grouping’s collective and only partly conscious emotional dispositions, that is, members’ embodied, axiomatic inclinations toward certain feelings and ways of emoting.”<sup>35</sup> Gould explains that within this emotional habitus of ACT UP, certain emotions, such as anger and optimism, became normalized and celebrated, while others, such as despair, became inexpressible. Such a theory helps explain how and why certain emotions, such as hope and joy, became characteristic of *WORLD*’s testimonials, while others, such as grief, became nearly inexpressible.

Gould’s work builds on scholarship within the growing field of “emotions history,” or the study of feelings as socially, politically, and historically constructed entities. Emotions history emerged in the 1980s, as scholars trained in social or “bottom up” history expanded such methodology to incorporate analysis of individual and collective emotional expression.<sup>36</sup> Peter N. Stearns and Carol Z. Stearns delineated what they termed “emotionology,” or the social conventions that ruled emotional expression in a given time and space.<sup>37</sup> Stearns and Stearns acknowledged that the study of emotionological codes offered a valuable window into the study of feelings, but should be paired with further analysis of “emotional expressions across time” so as to examine “people’s efforts to mediate between emotional standards and emotional

<sup>34</sup> Deborah Gould, *Moving Politics: Emotion and ACT UP’s Fight against AIDS*, (Chicago: University of Chicago Press, 2009).

<sup>35</sup> Gould, *Moving Politics*, 32.

<sup>36</sup> Susan J. Matt and Peter N. Stearns, “Introduction,” in *Doing Emotions History* edited by Susan J. Matt and Peter N. Stearns (Champaign: University of Illinois Press, 2014), 4.

<sup>37</sup> Susan J. Matt, “Recovering the Invisible: Methods for the Historical Study of the Emotions,” in *Doing Emotions History* edited by Susan J. Matt and Peter N. Stearns (Champaign: University of Illinois Press, 2014), 45.

experience.”<sup>38</sup> Scholars Barbara Rosenwein and William Reddy have analyzed the spatial dimensions of such emotional conventions. In her work on the Middle Ages, Rosenwein argued “emotional communities,” or spaces and groups that require specific modes of emotional expression, often exist in tandem and require individuals to calibrate their feelings as they move from one such community to another.<sup>39</sup> Reddy called such communities that prescribe and inhibit forms of affective expression “emotional regimes.” The most rigid regimes, he explained, forbid a range of specific “emotives,” or the words and phrases individuals use to describe their feelings. Emotives, Reddy wrote, have power — they “do something to the world.”<sup>40</sup> Verbal expressions of emotion, he explains, are tools that reinforce, cast doubt upon, or provoke feelings themselves; they thus have the power to transform the emotional experiences of both the speaker or writer and the listener or reader. Regimes that restrict specific emotives thus limit the power of the individual to shape and transform emotional experience.

The *WORLD* testimonial, then, with its adherence to a strict and editorially enforced emotional habitus, represents one such “regime” or “community” in which participants narrated their stories of diagnosis and resilience through the “emotives,” metaphors, and expressions prescribed and permitted by the newsletter’s emotionological codes. That is not to say that contributing authors did not feel anger or experience a wide range of seemingly unaccepted emotions. Rather, authors learned to adapt their descriptions and expressions of such feelings within the accepted parameters of the *WORLD* testimonial’s narrative structure.

<sup>38</sup> Peter N. Stearns and Carol Z. Stearns, “Emotionology: Clarifying the History of Emotions and Emotional Standards,” *American Historical Review* 90 (October 1985), 825.

<sup>39</sup> Barbara Rosenwein, *Emotional Communities in the Early Middle Ages* (Ithaca, N.Y.: Cornell University Press, 2006).<sup>[11]</sup><sup>[SEP]</sup>

<sup>40</sup> William M. Reddy, *The Navigation of Feeling: A Framework for the History of Emotions* (2001), 104.

Although many of the newsletter's testimonials do acknowledge the author's anger, they do so in passing or within the story's "rising action." In November 1993, Beneva Williams Nyamu compiled a list of "some of the angers associated with the possession of this virus" as part of her testimonial.<sup>41</sup> Many of these "angers" featured a positive spin: Nyamu explained feeling frustrated that "people put me in the sick category and discount everything I was, am now, and have been prior to becoming infected," when, in reality, "having this virus has had some very positive effects on my emotional and psychological development." The following month, Becky Trotter described the "rage" she "dealt with daily" since her diagnosis. This rage, "compounded with grief, sadness and pain," had not simply disappeared. Nor had Trotter totally vanquished these negative emotions. Rather, Trotter suggested her journey of self-improvement and acceptance included attempting to move past these feelings: "Through the help of a counselor, I process these feelings, but it is an ongoing process."<sup>42</sup> *WORLD*'s emotional habitus thus featured slightly more flexibility than that described by Gould in her analysis of ACT UP. Women with HIV clearly felt anger and despair and acknowledged the conditions, both social and medical, that contributed to these emotions. Nonetheless, the testimonials published in the organization's newsletter suggest that certain emotions, such as anger and grief, certainly proved more difficult to incorporate into the newsletter's typical narrative structure even if these feelings hadn't become entirely "inexpressible." The emotional habitus or emotionological codes of the *WORLD* testimonial genre might therefore represent more of an editorial screen privileging optimism rather than a communal censorship of pain and negativity. Anger and grief were perhaps unprintable, rather than inexpressible.

<sup>41</sup>Beneva Williams Nyamu, "Working for hope, healing, prevention, and recovery" *WORLD* 31, November 1993

<sup>42</sup> Becky Trotter, "So let's talk!," *WORLD* 32, December 1993.

The newsletter's editorial influence made itself known in other ways, too. The *WORLD* testimonials' genre and narrative structure, carefully reconstructed and imitated month after month, reflected both the newsletter's limited emotional habitus and the influence of the organization's strategic messaging. The first two pages of *WORLD*'s first issue featured a welcome message and a personal testimonial. The welcome message described Denison's aspirations for the organization. The message acknowledged the diversity of women affected by the epidemic: "Women living with HIV and AIDS represent every race, class, age, and sexual orientation." It asserts women's right to "services" and "the information we need to make decisions in our lives." It then acknowledged how few opportunities women with HIV have to connect with each other, and how isolation often contributes to feelings of loneliness and fear among women grappling with a recent HIV diagnosis. These themes reappeared throughout *WORLD*'s first issue, both woven throughout the printed personal testimonial on pages 2 and 3 and addressed through the publication of articles such as "Gynecological Manifestations of HIV Disease" (page 4), a calendar of support group meetings and protest actions, calls for medical study participants, and a survey asking readers to "Express Yourself!" The organization's slogan, "You are not alone!", appeared for the first time on the first issue's seventh page.

The welcome message's themes and even the organization's slogan itself resurfaced in testimonial after testimonial over the course of the organization's early years. In a testimonial titled "Welcome to America!," 'Angelica' described her fears of deportation as an undocumented immigrant living with HIV in the United States. Of her decision to share her story, she wrote, "I believe that the only way we can end bigotry and abuse is by exposing it. I know there are other HIV+ women out there putting up with abuse, shame and isolation. Wherever you are, 'legal' or

‘illegal,’ nobody deserves to be abused. Reach out. You are not alone!’<sup>43</sup> Her inclusion of WORLD’s slogan and echo of the organization’s message seemingly reflect the presence of a strategic editor.

The titles of *WORLD*’s printed testimonials offer the most easily discernible evidence of editorial influence over and enforcement of the newsletter’s positive emotional habitus. Printed in large font on the front page of each issue, the monthly testimonial’s title allowed the editor, presumably Denison herself, an opportunity to craft her publication’s opening message with strict adherence to the accepted register of expressible emotions each subsequent article sought to convey. Although many testimonials did acknowledge emotions such as anger and grief, their titles uniformly carried messages of hope and positivity. Titles including “Look inside... ‘see’ with my heart,”<sup>44</sup> “Believing in miracles,”<sup>45</sup> “Positive Gifts,”<sup>46</sup> “Working for hope, healing, prevention, and recovery,”<sup>47</sup> and “There’ll be time to worry later”<sup>48</sup> set the reader’s expectations of the article’s emotional register and set the tone for the newsletter’s overarching messaging. These titles embraced the newsletter’s discourse of positive thinking to an almost spiritual extent and implicitly compared contributing authors’ personal growth narratives to biblical or mythical stories of salvation and epiphany. Through these titles, then, WORLD’s editorial staff further enforced a narrative of the HIV/AIDS experience contingent on the positive emotional trajectory of its author. The strong editorial influence throughout *WORLD*’s issues suggest the newsletter

<sup>43</sup> Angelica, “Welcome to America!,” *WORLD* 45, January 1995, 2.

<sup>44</sup> Gartland, “Look inside... ‘see’ with my heart.”

<sup>45</sup> Anonymous M., “Believing in miracles.”

<sup>46</sup> McCarthy, “Positive Gifts.”

<sup>47</sup> Nyamu, “Working for hope, healing, prevention, and recovery.”

<sup>48</sup> Teresa, “There’ll Be Time to Worry Later.”



represented not merely a venue for women with HIV to voice their stories, but an active participant in the production of their narratives.

Despite the hopeful and triumphant narratives featured in *WORLD*, the realities of living with HIV as a woman in the early 1990s were far from positive. Women faced not only the medical uncertainty of living with an incurable disease, but also the burden of doing so while excluded from medical research. Reporting on the Sixth International Conference on AIDS in San Francisco for *Out Week* in 1990, nurse and health advocate Risa Denenberg expressed frustration at the conference's scarcity of presentations on the experiences of women. The conference had highlighted women with HIV only when involved in cases of "vertical transmission" or as vectors spreading the disease to men. Of the abstracts nominally related to women included in the conference's collection, "over 75 percent" were "really about HIV in children."<sup>49</sup> Denenberg criticized the CDC for seeming "willing to study us" only "if we are pregnant."<sup>50</sup> Similarly, despite an "intense debate over how efficiently women transmit the disease to men," few studies examined "what factors predict acquiring HIV from men."<sup>51</sup>

Women thus suffered from a particular politics of blame in which their bodies became sources of fear and disease that put both men and children at risk of contracting HIV. Seen as suffering the just consequences of promiscuity or irresponsible drug use,<sup>52</sup> women struggled to attract medical interest as victims of the disease themselves.<sup>53</sup> Further complicating the experiences of women

<sup>49</sup> Risa Denenberg, "What About Women?" *Out Week*. July 11, 1990. Survive AIDS—ACT UP/Golden Gate Records. James C. Hormel LGBTQIA Center, San Francisco Public Library. San Francisco, CA.

<sup>50</sup> Ibid.

<sup>51</sup> Ibid.

<sup>52</sup> Orenstein, "Women at Risk."

<sup>53</sup> K Kaufmann, "Nancy Stoller: Speaking Out about the Inequities Faced by Women with AIDS." *S.F. Frontiers*. April 27, 1995. Jessea Greenman P.E.R.S.O.N. Project Records, 1978-1997. San Francisco History Center, San Francisco Public Library. San Francisco, CA.

with HIV, doctors tended to not to recognize pelvic inflammatory disease or other gynecological problems as symptoms of HIV infection.<sup>54</sup> The compounded impact of medical bias and ignorance meant many women went undiagnosed and untreated much longer than their male counterparts. Despite the positive bent of *WORLD*'s testimonials, the organization's members were not immune to the frustration caused by these injustices and sought out alternate outlets for these "unprintable" emotions.

As *WORLD* expanded from a newsletter to an organization of activists engaged in protest and dissent, the emotional habitus of its newsletter testimonials increasingly contrasted with the anger and frustration expressed by members in activist spheres. *WORLD*'s members increasingly engaged with such emotions, calibrating their affective styles as they moved from one emotional "community" to another. Even Rebecca Denison, the newsletter's editor and thus the ultimate arbitrator of its emotional limits, leaned into "unprintable" emotions when confronted by activists who refused to adequately address the concerns of women with HIV. In a letter to the director of the San Francisco AIDS Office in July 1991, Rebecca Denison voiced her frustration with the exclusion of HIV+ women from an office meeting about the CDC definition of AIDS. In a phone call to the AIDS Office, Denison had requested "the opportunity" to attend the meeting and had been informed she needed an "invitation" to do so. When she asked how to obtain such an invitation, the office spokesperson told her, "You can't."<sup>55</sup> Denison wrote, "the experience upset me a lot." San Francisco "has had great difficulties meeting the needs of HIV-positive women," she wrote. "If you want to meet our needs, you need to hear our voices" rather

<sup>54</sup> Orenstein, "Women at Risk."

<sup>55</sup> Rebecca Denison, Rebecca Denison to Sandra Hernandez, Oakland, CA, July 30, 1991. San Francisco Department of Public Health AIDS Office Records. San Francisco History Center, San Francisco Public Library. San Francisco, CA.

than treat women as an “unwelcome intrusion.”<sup>56</sup> Denison further embraced conflict in meetings of the Women’s AIDS Network, an advocacy organization established in 1984 to support women affected by HIV. Members included health care practitioners, social service providers, community activists, and political advocates. The organization notably did not include many women infected with HIV. In a 1988 draft of WAN’s “Purpose, Mission, Goals and Objectives,” a section listed “no PWAs,” or People with AIDS, as both a strength and a weakness of the organization. Perhaps sensing this ambivalence to her presence at meetings, as well as the added responsibility of regularly being the sole woman with HIV in attendance, Denison did not shy away from voicing her concerns and demands. These concerns included the “real problem of accessibility for HIV+ women” at the First Western Regional Conference on Women and HIV in 1991,<sup>57</sup> the deaths of original WORLD members, and the “serious financial crunch” in which WORLD found itself when planning a retreat in May of 1992. “We would like to know resources and skills that women at WAN can offer to WORLD,” Denison stated at WAN’s meeting that month. “We don’t have the postage to send out newsletters right now,” she admitted. “We need emergency money.”<sup>58</sup> A WAN board member made the organization’s limited interest in assisting WORLD known when she admitted that supporting Denison’s organization represented a “secondary commitment.”<sup>59</sup> Denison had reason to be angry. Within spaces not dominated by women with HIV, Denison allowed herself to express the frustration and anger seemingly unprintable within the context of the *WORLD* testimonial.

<sup>56</sup> Ibid.

<sup>57</sup> Women’s AIDS Network Executive Board. Meeting Minutes, November 5, 1991. The Nancy Stoller Papers, 1981-1995. UCSF Special Collections. San Francisco, CA.

<sup>58</sup> Women’s AIDS Network Executive Board. Meeting Minutes, May 5, 1992. The Nancy Stoller Papers, 1981-1995. UCSF Special Collections. San Francisco, CA.

<sup>59</sup> Ibid.

In protests and op-eds, WORLD members similarly expressed their anger at the injustices and invisibility faced by women living with HIV. In an article published in the political journal *Breakthrough* in 1993, members of WORLD listed what they perceived as the most pressing issues they faced as women with HIV.<sup>60</sup> Their demands included access to information and to services, reproductive choice, outreach to prostitutes, an end to restrictive immigration policies, and, above all else, a cure. The combative tone of the article contrasted sharply with that of the newsletter's testimonials. WORLD members wrote, "a cure for HIV/AIDS is our highest priority, and we are fighting for our lives." They urged others to join their struggle, arguing, "we can be victims and hang out waiting to die or we can become actively involved in fighting for our lives and for the people we care about." Echoing the "AIDS activists who went before us," the contributing writers ended their piece with the slogan not of their own organization, but one chanted by members of ACT UP: "Silence=Death" but "Action=Life!"<sup>61</sup> Writing for a journal with readers presumably beyond the scope of WORLD's membership, the article's authors made the deliberate choice to fuel their call to action with the "unprintable" emotions beyond the emotional habitus of the newsletter's testimonials.

The discrepancy between the emotions WORLD members expressed to each other and to the outside world emerged clearly in an article published in the *San Francisco Bay Times* in 1994 about a protest in support of activists in the Central California Women's Facility (CCWF) in Cowchilla that WORLD members attended in 1994. A crowd of approximately 150 activists from six organizations including WORLD and ACT UP loudly voiced their anger at the

<sup>60</sup> *WORLD*, "Unmasking the Epidemic: Women with HIV Speak Out." *Breakthrough* 17, no. 1. (Spring 1993): 22-24. Jessea Greenman P.E.R.S.O.N. Project Records, 1978-1997. San Francisco History Center, San Francisco Public Library. San Francisco, CA.

<sup>61</sup> *WORLD*, "Unmasking the Epidemic."

inhumane conditions incarcerated women with HIV faced within the Cowchilla women's prison. Protesters "marched down the road as far as the guards would allow, and sent a balloon-borne banner sailing over the prison" that read, 'Medical neglect is murder!'" The combative nature of the banner contrasted in tone with the messages of support and camaraderie these same protesters called to their allies within the prison: "As loud as they could—trying to send their message through the prison walls—the crowd chanted 'Sisters inside, we love you!'"<sup>62</sup> The crowd, like Rebecca Denison and her fellow members of WORLD, seemingly navigated two contrasting emotional registers steeped in strategy and self-protection. Despite their seemingly steady commitment to positivity when expressing their feelings to other women with HIV, WORLD's members demonstrated deft ability to express themselves within the emotionological rules of ACT-UP and the broader HIV/AIDS activist community that not only permitted but also encouraged the vocal and tactical expression of anger and pain.

The members of WORLD thus maintained and protected their own emotional community while allowing themselves the freedom to engage with members of alternate communities with distinctive emotionological codes. Within their own communal spaces, women with HIV shared uplifting messages of optimism and hope. When in communication with those not included in this self-regulated community of HIV+ women, WORLD members allowed themselves the frustration, anger, and despair they did not voice to one another. Doing so allowed women to make demands of those who ignored them and build solidarity with other people living with HIV with experiences and concerns similar to, if not identical to, their own. Nonetheless, maintaining the integrity and rigidity of their own emotional habitus allowed the women of WORLD to

<sup>62</sup> Marcy Rein, "Poor Medical Care Alleged at Prison Protest." *San Francisco Bay Times*. February 10, 1994. Jessea Greenman P.E.R.S.O.N. Project Records, 1978-1997. San Francisco History Center, San Francisco Public Library. San Francisco, CA.

By the late 1990s, medical advances had changed the meaning of an HIV diagnosis. Although many women continued to die from HIV/AIDS, the disease no longer guaranteed a death sentence. The development of protease inhibitors and combination antiretroviral drug therapies had once again changed the experience and meaning of living with HIV/AIDS. As treatment options expanded for women living with HIV over the course of the 1990s, the narrative structure of *WORLD*'s testimonials began to shift. The authors of the newsletter's testimonials maintained the positive and triumphant tone adopted by their predecessors. However, increasingly their stories ended with triumph over the disease itself rather than over fear and self-doubt.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED] [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

\_\_\_\_\_

The next month, *WORLD* featured a similar story of triumph over illness. Angie, or “Ms. Kansas City,” wrote of her positive outlook on life ever since learning that her HIV diagnosis didn’t represent an immediate death sentence: “Oh yes, HIV is truly something to live with, but I am happy to know I can live.” She, too, provided proof of the positive changes in her life in the results of her lab tests. “I am excited about the changes in my life,” she wrote. “I have had bad ones too, but right now it’s working. On June 30, 1995 my T-cell count was 234. On triple combination therapy it went up over 1,000.”<sup>64</sup> In 1998, an artist called JAKO explained that her “undetectable” viral load and higher T-cell count had given her “more life.”<sup>65</sup> Medications allowed her a sort of rebirth not unlike the new beginnings so prominently featured in *WORLD*’s earlier testimonials. Unlike those earlier writers, however, JAKO’s new lease on life did not come from a renewed commitment to pursuing her passions or reconnecting with those she loved, but from a literal increase of her life expectancy: “It is an amazing feeling to know that the medications are extending and improving my life.” Although the emotional habitus of *WORLD*’s testimonials remained the same, the way in which women achieved their happiness and success had shifted.

This shift in the testimonial template proved applicable only to the stories of women who had, in fact, successfully increased their T-cell count and warded off harmful symptoms; those who could not or did not experience the benefits of these newer treatment options found themselves incapable of adopting this newer narrative trend that was grounded in medical, rather than emotional, triumph. In a December 1997 testimonial called “Please don’t forget about us,” Cheryl Erichsen urged readers of *WORLD* not to overlook the women with HIV to whom new

<sup>64</sup> Angie (“Ms. Kansas City”), “Living a *WORLD* of difference,” *WORLD* 81, January 1998

<sup>65</sup> JAKO, “Young & Positive,” *WORLD* 85, May 1998

treatment options did not represent a new lease on life. Erichsen, a nurse with an immunodeficiency disorder unrelated to her HIV status, had decided to “go off my antivirals” and to “stop measuring my T-cells and viral load.”<sup>66</sup> To Erichsen, medication brought not miracles but debilitating side effects. She wrote, “I’d rather live a short time but really be living than to live a longer time but merely exist, due to side effects from the drugs.” Erichsen reminded her readers that, despite the media’s fixation on the life-saving capabilities of medication, “one-third or more of people with AIDS” were “trying to fight but not having any success from the new drugs.” “People who are still dying from HIV need our caring and support,” she wrote. “We can’t just forget them.” Erichsen ended her testimonial with a passage reminiscent of early testimonials published in *WORLD*. She urged readers to find success and personal fulfillment by trying to “overcome the negative things—hate, despair, anger and envy—that weigh us down” and to “strive to fill each day with all the good, positive things life has to offer—joy, caring, humor, and above all, love.” With this message of optimism, Erichsen reinforced the parameters of *WORLD*’s emotional habitus and urged a return to a more inclusive narrative structure that allowed women like her to triumph over not illness, but a similarly fearsome, albeit abstract, antagonist: despair.

By the late 1990s, the meaning of HIV and AIDS had shifted. An HIV diagnosis, while still rife with uncertainty, no longer meant certain and rapid physical decline. The women of *WORLD* adapted to this changing meaning of HIV, molding their medical success stories into the existing template of the newsletter’s testimonials and the organization’s largely preserved emotional habitus. Anger and despair, once seemingly inexpressible within the context of the

<sup>66</sup> Cheryl Erichsen, LPN. “Please Don’t Forget About Us,” *WORLD* 80, December 1997.



newsletter's testimonial, had proved strategic and necessary as the organization increasingly engaged in activism. Beyond the confines of the *WORLD* emotional community, "unprintable" emotions became both permissible and essential as women with HIV struggled to dismantle barriers to medical studies, services, and treatment. Nonetheless, within the pages of *WORLD*, women continued to narrate their diagnoses and lives with HIV as stories of hope, optimism, and triumph. As the decade progressed, longer life expectancy became an increasingly common form of tangible evidence of such triumph where none had existed before. Nonetheless, the standard narrative structure of the *WORLD* testimonial remained largely unchanged, even as the meaning and outcome of the disease itself had undergone a dramatic transition. The women of *WORLD* had revolted against the uncertainty of the epidemic, creating a space dictated by continuity and positivity within a larger context wracked by anger, fear, and unpredictability.

## II. Memory as Narrative

On April 19, 2020, I conducted an oral history interview with Rebecca Denison, the founder and former executive director of *WORLD* and the sole editor of its newsletter. Our interview took place under unanticipated and peculiar circumstances: a month into California's shelter in place order, both Denison and I found ourselves quarantined in our own respective homes in the same Bay Area city. Our conversation took place over the videoconferencing platform Zoom; far from the methodological ideal, the medium through which we communicated served as a constant reminder of the public health crisis raging across the country that had already claimed the lives of nearly 170,000 people worldwide by the time of our interview.<sup>67</sup> Over the course of our two-hour conversation, Denison recounted her initial reaction to being

<sup>67</sup> "COVID-19 Coronavirus Pandemic," *Worldometer*, May 16, 2020, [https://www.worldometers.info/coronavirus/?utm\\_campaign=GenericUAblogposts?](https://www.worldometers.info/coronavirus/?utm_campaign=GenericUAblogposts?)

diagnosed as HIV positive, her search for support groups for asymptomatic women with HIV, her interactions with and collaboration with other activist groups, and her decision to establish a newsletter that would inform, inspire, and mobilize other women with HIV. Denison spoke of the collaborative nature of WORLD's horizontal structure and democratic approach to programming and decision making as the newsletter became a larger organization that facilitated a wide range of projects and priorities. Even as Denison remained the sole editor of WORLD's newsletter, the organization began to take on a variety of projects that reflected the diversity of perspective and background of its members. Denison spoke of the changing meaning and experience of HIV/AIDS upon the emergence of more effective treatments and explained that the arrival of such medications proved an ultimately demobilizing factor with the HIV/AIDS community. Throughout this narrated account of her time at WORLD, Denison's focus remained the loving, positive, and supportive nature of the organization's community of women.

As the founder and executive director of WORLD and the sole editor of its newsletter, Rebecca Denison played an integral role in the construction of her publication's emotional register and content. Denison's memories of her time at WORLD reflect a bent towards optimism and positivity not unlike that of *WORLD's* testimonials. Denison's oral history, a narrative in its own right, reflects the editorial influence of memory on the emotional context of the past. Constructed over decades, Denison's life story suggests the ways in which WORLD's emotional habitus has embedded itself into Denison's memories of the HIV/AIDS epidemic. Only when filtered and reinterpreted through the framework of the contemporary coronavirus pandemic do Denison's memories depart from the positivity of WORLD's emotional habitus. The present context thus disrupts Denison's constructed memories of the AIDS epidemic, both

allowing and compelling Denison to address the pain and trauma she has seemingly edited out of her narrative of the past.

My oral history interview with Rebecca Denison thus offers an opportunity to examine the emotional habitus and legacy of *WORLD* through yet another narrative source: memory. The written testimonials printed in *WORLD*'s earliest issues were crafted through a conversation between Denison and the author; Denison's narrative formed over the course of a two-hour conversation between the two of us. The testimonials' common adherence to a cohesive emotional register reflect the broader mission of the organization; Denison's memories reflect both the joint editorial influence of time and repeated performance as well as her priorities and identity at the time of the interview. My analysis of Denison's narrative thus relies on just one specific instance of remembering or performance of memory; nonetheless, it reflects an attempt to make sense of not only the past and of the role of *WORLD* in it, but of the complicated and exceedingly confusing moment in which Denison and I constructed this narrative together.

The production of long-term memory, like that of newsletter testimonials, requires a complex process of meaning making, editing, and forgetting. Memories do not necessarily reproduce the past in its factual entirety; rather, they reflect the subject's active, if subconscious, attempt to make sense of the past from within the context of the present. Alessandro Portelli characterizes memory as not a "passive depository of facts," but rather "an active process of creation of meanings." Analyzing oral sources, Portelli argues, allows us to examine the discrepancies between memory and accepted fact and to uncover the "narrators' effort to make sense of the past and to give a form to their lives."<sup>68</sup> Alistair Thomson understands

<sup>68</sup> Alessandro Portelli, "What Makes Oral History Different," in *The Oral History Reader*, eds. Robert Perks and Alistair Thomson (New York: Routledge, 1998), 38.

“remembering” as an active process through which the subject creates “meanings in the social and cultural context of the present.”<sup>69</sup> Remembering is an action that occurs in the present and thus necessarily builds a version of the past shaped by contemporary hopes, fears, and priorities.

Both Thomson and Portelli analyze draw comparisons between memory and narrative. Portelli writes that oral histories such as those he conducts and analyzes are narrative sources in their own right; analysis of such sources thus requires a foundation in theoretical framework developed in relation to literature and folklore.<sup>70</sup> The field of narrative theory offers one such framework, providing an interdisciplinary approach that defines narrative as an attempt to “create meanings for our lives and coherence in our self.”<sup>71</sup> Such narratives are themselves constructed through storytelling and performance. “The creation and repetition of the story about an event,” Thomson writes, “converts that event into a meaningful experience and consolidates it in memory.”<sup>72</sup> Each repetition of the story both further ingrains the experience into long-term memory and subtly changes the meaning of the experience as the context of the storytelling shifts from performance to performance. As the narrator remembers, and especially as they do so in the context of an oral interview, they adapt their performance to a specific and intended audience. The identity of the interviewer, and the expectations both the narrator and the interviewer have of each other, shape the narrator’s performance and thus alter their narrative of the past.

<sup>69</sup> Alistair Thomson, “Anzac Memories Revisited: Trauma, Memory and Oral History,” *The Oral History Review* 42 (Winter/Spring 2015): 26.

<sup>70</sup> Portelli, “What Makes Oral History Different,” 35.

<sup>71</sup> Alistair Thomson, “Memory and Remembering in Oral History,” in *The Oxford Handbook of Oral History*, ed. Donald A. Ritchie, (New York: Routledge, 2016), 84.

<sup>72</sup> Thomson, “Anzac Memories Revisited: Trauma, Memory and Oral History,” 26

Denison's narrative of her time at WORLD adheres to the emotional habitus of the newsletter's testimonials. Denison repeatedly highlighted the collaborative and loving nature of the WORLD community. She characterized the organizing work and programming conducted by WORLD as the result of a dynamic and collaborative process in which every woman had a chance to shape the nature of the organization's work. The organization's popular retreats grew out of conversations among members of a WORLD support group held at The Women's Building in San Francisco. Denison explained that the priorities of WORLD's members steered the organization away from direct action and towards other forms of advocacy. Rather than adopt a strict policy agenda, WORLD allowed its members to "follow their vocation" and to create programs in response to the needs and interests of its members.<sup>73</sup> She admitted that, although initially she "thought we would do more marching in the street kind of stuff," she soon realized that many WORLD members had negative responses with such forms of direct action due to cultural or personal experiences foreign to Denison: "a lot of the women were like, my people got beaten with dogs and batons when they marched in the street, I don't really want to do that kind of activism."<sup>74</sup> Rather, the organization's focus shifted to "building coalitions" and to getting women with HIV a "seat at the table" where decisions were being made.<sup>75</sup> Denison's narrative suggests that WORLD's flexibility with regard to programming and strategy expanded opportunities for activism to women for whom the more aggressive and direct tactics of other organizations might have proven inaccessible or unappealing. Even when she briefly expressed regret at the organization's lack of a cohesive policy agenda, Denison quickly adjusted her interpretation of the past and came to peace with WORLD's horizontal structure: "I don't

<sup>73</sup> Rebecca Denison, interview by author, Berkeley, April 19, 2020.

<sup>74</sup> Ibid.

<sup>75</sup> Ibid.

honestly feel like I was being very strategic and I beat myself up a lot about that. But actually, as I'm talking to you, what was nice about it was women really got to pursue what they were passionate about. I don't think anybody felt like they had to do a particular thing."<sup>76</sup> With this pivot from regret to acceptance and positivity, Denison edited her perception of the past to fit the emotional register of the narrative she was in the process of performing.

Although, when asked, Denison acknowledged that conflict must have existed among the women of WORLD, she noted that it does not feature prominently in her memories of her time with the organization. While responding to a question about differences among the treatment plans adopted by WORLD's various members, Denison countered the assumption of tension among women experiencing different health outcomes from treatment in the late '90s that had been implicit in my question. She explained, "It's not that we didn't have conflict, because we did, but it's just not what rises to the top for me in terms of what I remember."<sup>77</sup> Denison's narrative does not eliminate conflict, rather it generalizes and blurs moments of tension to such an extent that they fade to the background and only appear upon explicit questioning. When asked about how WORLD formed an inclusive community, Denison answered, "If somebody was explicitly racist or homophobic or unkind in some way, I tried to address it. I probably would be more likely to do it privately than publicly."<sup>78</sup> This response, both hypothetical and vague, at once acknowledges that such moments of intolerance must have occurred and indicates that they do not belong among the key events that structure Denison's memory narrative. Scholar Naomi Norquay writes, "What we deem as not worth remembering is as important to identify

<sup>76</sup> Ibid.

<sup>77</sup> Rebecca Denison, interview by author, Berkeley, April 19, 2020.

<sup>78</sup> Ibid.

construction as what we do remember, what we do include, and what is worth remembering.”<sup>79</sup> Denison’s inability to recall or to describe specific instances of conflict points to the positive and joyful nature of her narrative in general. Norquay writes, “Forgetting is the effect of an active process which can involve denial, refusal discrediting, silencing and omitting.”<sup>80</sup> Forgetting might be understood, then, as the result of a process just as active and meaningful as “remembering.” Forgetting occurs once the subject has edited certain elements out of their constructed narrative of memory. Alistair Thomson explains that we might edit such moments out of memory as a sort of coping mechanism that allows us to “manage our lives effectively by focusing on important tasks and memories.” Thomson writes, “Mental good health requires us to forget much more than we remember.”<sup>81</sup> Denison’s omission of specific instances of conflict or of pain and grief more generally from her narrative of the AIDS epidemic may allow her to manage the present more effectively.

Denison’s characterization of the HIV/AIDS activist community in the Bay Area as loving and supportive extended beyond WORLD; Denison had equally fond memories of interactions with members of ACT UP and the Women’s AIDS Network. Denison credited the people she met in ACT UP for coming up with WORLD’s name, supporting her financially (“My first hundred dollars came from ACT UP”), and enabling her to attend a conference on AIDS and women in Washington, DC. The members of the Women’s AIDS Network, an advocacy organization made up primarily of female health care practitioners and social service providers working with AIDS patients, appeared equally favorably in Denison’s narrative of the

<sup>79</sup> Naomi Norquay, “Identity and Forgetting,” *The Oral History Review* 26 no. 1 (Winter/Spring 1999): 2

<sup>80</sup> Ibid.

<sup>81</sup> Thomson, “Memory and Remembering in Oral History,” 83.

epidemic. Denison called the members of WAN “wonderful,” “amazing,” and “so excited” at the prospect of a newsletter they could pass along to their female patients.<sup>82</sup> In Denison’s memories, the network of activists in the Bay Area in the 1990s built supportive and collaborative relationships across organizations and strategic priorities. She explained, “I think the AIDS community is a very loving, very accepting, very nonjudgmental community. Beyond women, the AIDS community, it’s a community of people that are used to being really marginalized and treated like shit. And we were like, no, we are going to love on you, we are going to love on each other.”<sup>83</sup> Denison’s representation of the HIV/AIDS activist community contrasts with historiographical emphasis on AIDS activist anger and on discord and conflict among the activist community.

Recent scholarship of the HIV/AIDS epidemic has highlighted the divisions and conflict among various networks of activists, often in an attempt to disrupt the hegemonic historiographical representation of AIDS activists as a cohesive community of white, middle-class, gay men with uniform priorities and tactical approaches to activism. As the 1990s wore on, disparities between white, gay, male, middle class activists and women and activists of color became increasingly apparent within activist organizations. Jennifer Brier analyzes the splintering of New York’s chapter of ACT UP as demonstrative of broader debates about the priorities and meaning of AIDS activism. While some, namely members of the Treatment and Data Committee (T & D), thought getting “drugs into bodies” should be ACT UP’s ultimate goal, others pointed to the exclusionary nature of expensive drugs and called for intersectional activism that explicitly acknowledged the role of racism, sexism, and class inequality in

<sup>82</sup> Rebecca Denison, interview by author, Berkeley, April 19, 2020.

<sup>83</sup> Ibid.



perpetuating the epidemic. Brier argues that ultimately ACT UP's direct action failed to produce "the conditions under which all people with AIDS would receive treatment."<sup>84</sup> Peter Cohen analyzes how these schisms pointed to the varied class backgrounds of activists within organizations like ACT UP. Cohen examines how class shaped ACT UP's tactics. He argues that the AIDS epidemic provoked a "class dislocation" for white middle class gay men by limiting their ability to pass as straight and by forcing them to identify with a stigmatized group. ACT UP's members, primarily white middle class gay men, came to AIDS activism with certain expectations of the privileges and entitlements their class status implied. Their class privilege made them far more comfortable working with government officials than women and people of color. Cohen argues that their class status also encouraged a more cautious approach to direct action that preserved members' ability to maintain their "high-paying professional jobs" and that did not seek to overthrow existing institutions."<sup>85</sup> Within ACT UP, certain committees reflected the influence of class privilege more than others: Treatment and Data's collaboration with pharmaceutical companies and government agencies notably reflected a willingness to "work on the 'inside'" and presents, to Cohen, "the strongest evidence of the extent to which the class style of middle-class men came to dominate the group's tactics."<sup>86</sup> Scholarship by Cohen, Brier, and others that highlights the divisions among and disagreements between AIDS activists contrasts with Denison's memories of cohesion and harmony among her peers.

Only when she filtered her memories through the coronavirus pandemic did Denison's memories veer into negative territory and include references to death, trauma, and despair. She

<sup>84</sup> Brier, *Infectious Ideas: U.S. Political Responses to the AIDS Crisis*, 159.

<sup>85</sup> Peter F. Cohen, "'All They Need': AIDS, Consumption, and the Politics of Class," *Journal of the History of Sexuality* 8, no. 1 (1997), 95.

<sup>86</sup> *Ibid*, 102.

used coronavirus to explain the painful parts of the epidemic that she had seemingly filtered out of her master narrative of the epidemic. Towards the end of our conversation, Denison spoke of the impact of protease inhibitors and improved treatment options on the WORLD community. She explained that the arrival of more effective medications revealed more explicitly than ever before the vast differences in privilege and resources among WORLD's members. Whereas some women took the medications and went back to work and to otherwise stable middle class lives, others faced lingering issues that medications could not remedy, from food instability to discrimination, that HIV/AIDS had simply exacerbated. To explain this phenomenon, Denison turned to a social media post about the coronavirus pandemic that had been circulating among her friends and family online: "My cousin posted this thing on Facebook today and she's like, I'm so tired of people saying about coronavirus, we're in the same boat. She's like, we are not in the same boat. We are in the same storm. Everybody's in a different boat depending on their resources and the support they have. [...] I think when the medications came back, a lot of the class differences, the educational differences, made the boats more different than they were before."<sup>87</sup> Denison's comparison of AIDS to COVID-19 serves as a mechanism through which to explain how institutional racism and social inequality led to disparate infection rates among different population sectors in the 1990s and reflects a similar, if opposite, comparative tendency adopted by the U.S. news media in the spring of 2020.

The pandemic of coronavirus/COVID-19 has provoked a renewal of cultural interest in the legacy of the AIDS epidemic. Journalists have stoked this interest with articles drawing comparisons between the mysterious and alarming spread of AIDS in the 1980s to the rapid growth of coronavirus cases throughout the United States. An article published by *USNews* on

<sup>87</sup> Rebecca Denison, interview by author, Berkeley, April 19, 2020.

April 29 featured interview snippets with male public health officials and activists. Titled “For Those Who’ve Lived Both, COVID-19 Carries Echoes of the Early AIDS Crisis,” the article drew explicit parallels between the rapid social changes wrought by both diseases: “Seemingly overnight, the terms ‘safe sex’ and ‘AIDS hysteria’ became part of the national lexicon, just as the COVID-19 pandemic has added ‘social distancing’ ‘shelter in place’ and ‘quarantine dreams’ to our present-day vocabulary.” “Face masks,” the article declared, “are the new condoms.”<sup>88</sup>

Throughout the end of March and April of 2020, the *New York Times* alone published a slew of articles about the epidemic, nearly all of which centered the perspectives and experiences of the members of New York’s chapter of ACT UP. A profile of Larry Kramer, a famed early AIDS activist, published on March 28, 2020 recounted Kramer’s decision to write a play about survivors of AIDS in the age of COVID-19, the newest American plague.<sup>89</sup> A week later, the paper published the article “For H.I.V. Survivors, a Feeling of Weary Déjà Vu,” a piece similar in content and form to the earlier *USNews* article that compiled interviews with several well-known AIDS activists including Peter Staley and David France.<sup>90</sup> France, the director of the 2012 documentary “How to Survive a Plague,” penned his own article celebrating the legacy of ACT UP published in the *Times*’s magazine on April 13. The hosts of the *New York Times* podcast *Still Processing* discussed France’s documentary on April 16, aiming to “apply its

<sup>88</sup> Joseph P. Williams, “For Those Who’ve Lived Both, COVID-19 Carries Echoes of the Early AIDS Crisis,” *USNews*, April 29, 2020, <https://www.usnews.com/news/healthiest-communities/articles/2020-04-29/hiv-and-the-coronavirus-pandemic-carries-echoes-of-early-aids-crisis>

<sup>89</sup> John Leland, “Larry Kramer, AIDS Warrior, Takes on Another Plague,” *New York Times*, March 28, 2020.

<sup>90</sup> Jacob Bernstein “For H.I.V. Survivors, a Feeling of Weary Déjà Vu,” *New York Times*, April 8, 2020, <https://www.nytimes.com/2020/04/08/style/coronavirus-hiv.html?searchResultPosition=15>

lessons to the Covid-19 crisis.”<sup>91</sup> The characterization of France’s documentary as a model through which to understand the AIDS epidemic should not go unchallenged; scholar Jih-Fei Cheng has criticized France’s documentary as an example of mainstream media’s erasure of the contributions of women and people of color to AIDS activism and of its overall commodification of the epidemic.<sup>92</sup> Nonetheless, each of these comparisons points to an attempt to understand the current moment through narratives of activist struggle and success during the AIDS epidemic.

Many of these recent articles also reflect an attempt to call attention to COVID-19’s disproportionate impact on people of color and low-income communities by drawing attention to the similarly disproportionate rates of infection during the AIDS epidemic. David France commented in one *New York Times* article, “Pandemics never hit fairly.” COVID-19, he pointed out, while seemingly unlike AIDS in that it is not “confined mostly to a despised population,” nonetheless has been “most heavily concentrated [...] in neighborhoods that are filled with people who are not rich and are often black and brown.”<sup>93</sup> Wesley Morris, critic and host of the podcast *Still Processing*, remarked, “the people who are still suffering most greatly with AIDS and HIV are black people and Latinos, and those are also the same people dying disproportionately right now of COVID-19.”<sup>94</sup> These articles look to the past to illustrate and contextualize the inequality of the present; they thus represent a refraction of Denison’s use of

<sup>91</sup> Wesley Morris and Jenna Wortham, produced by Hans Buetow, “How to Learn from a Plague,” *New York Times*, podcast audio, April 16, 2020, <https://www.nytimes.com/2020/04/16/podcasts/still-processing-AIDS-survive-coronavirus.html?>

<sup>92</sup> Jih-Fei Cheng, “How to Survive: AIDS and Its Afterlives in Popular Media,” *WSQ: Women’s Studies Quarterly* 44 (2016), 73-92.<sup>[1]</sup><sup>[SEP]</sup>

<sup>93</sup> Jacob Bernstein “For H.I.V. Survivors, a Feeling of Weary Déjà Vu,” *New York Times*, April 8, 2020, <https://www.nytimes.com/2020/04/08/style/coronavirus-hiv.html?searchResultPosition=15>

<sup>94</sup> Wesley Morris and Jenna Wortham, produced by Hans Buetow, “How to Learn from a Plague,” *New York Times*, podcast audio, April 16, 2020, <https://www.nytimes.com/2020/04/16/podcasts/still-processing-AIDS-survive-coronavirus.html?>

the present to help explain and unearth memories of the discrepancies among women's experiences of HIV/AIDS in the 1990s.

In the final moments of our conversation, Denison spoke to the emotional and psychological toll the coronavirus pandemic had had on people with HIV who had lived through the AIDS epidemic of the 1990s. She explained that the government's relatively quick response to the spread of COVID-19 over the course of the past few weeks had caused many people with HIV to be "very, very triggered right now" as they understood that "we could have had the resources to mobilize more to save people's lives but because it was marginalized people, we didn't bother. But now that it's anybody who went on a cruise can have it, now we're mobilizing resources."<sup>95</sup> She used the term "triggered" again a few moments later as she explained that the present pandemic had provoked "trauma" among the HIV/AIDS activists forced to confront their memories of a time when "people we knew died every week" and when "every time the Bay Area Reporter came out once a week, you turned to the obituary page to see how many people on that page you knew."<sup>96</sup> Both the similar experience of constant loss and the faster response by the US government to the current health crisis provoked specific and powerful memories of pain and grief. Alistair Thomson writes of "moments when a smell, taste, or image will trigger a powerful though not always clear or coherent memory of an earlier time in our life. The physical, sensory elements of the original experience have lingered in memory—not necessarily in the same region of the brain that remembers the event—and the sensory cue now elicits that associated memory."<sup>97</sup> Although Thomson referred to sensory elements such as specific smells or flavors,

<sup>95</sup> Rebecca Denison, interview by author, Berkeley, April 19, 2020.

<sup>96</sup> Rebecca Denison, interview by author, Berkeley, April 19, 2020.

<sup>97</sup> Thomson, "Memory and Remembering in Oral History," 83

one could extend such an argument to include emotional sensations that, once experienced, remind the subject of similar emotional experiences of the past that have been filtered out of long-term memory. The death and grief of the coronavirus pandemic, then, had acted as a cue eliciting memories of the death and grief of the health crisis of the 1980s and 1990s. These emotions had been utterly absent from the narrative of the AIDS epidemic that Denison had just performed for me before we began to discuss the current outbreak of disease. By using the intense emotion of the present to frame her narrative of the past, Denison allowed herself to access and reinterpret elements of her past experience that she had, over time, edited out of her positive and joyful account of the early years of *WORLD*.

Although representative of distinct historical moments and narrative genres, the testimonials printed in *WORLD* in the 1990s and my recent interview with Rebecca Denison suggest the extent to which narratives construct the past, the present, and their relationship to one another. By composing their testimonials in a standard narrative form and by adhering to a positive emotional habitus, the women of *WORLD* transformed the uncertainty and despair of life with HIV in the early 1990s into possibility and hope. Their stories reinterpreted the present, allowing contributing authors and readers alike to reformulate their experiences of HIV/AIDS to mirror the narratives of personal triumph and positive change published within the pages of *WORLD*. Decades later, Denison's constructed memories of her time at *WORLD* suggest the lingering and persistent influence of these stories on her understanding of the past: Denison's narrative featured an emotional bent toward positivity evocative of that adopted by the authors of *WORLD*'s testimonials.

The past and the present are mutually constructive. As journalists and public health officials increasingly turn to the AIDS epidemic in an attempt to understand and make sense of the pandemic of coronavirus/COVID-19, the stories they unearth and the stories they construct will undoubtedly reshape not only our understanding of the past but our experience of the present. Diseases, like memories, are socially constructed; my analysis of the lingering presence of *WORLD*'s emotional habitus among Denison's memory narrative of the past points to the key role that such stories play in the construction of pandemics. As we seek to understand the ongoing public health crisis, we must think carefully about whose stories we choose to narrate the present and upon which histories we construct our experience of the now.

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