

**“A GREAT SURGE OF PURPOSE:”  
GAY PERSONS WITH AIDS AND ALTERNATIVE THERAPIES**

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In 1988 author Paul Monette said that merely seeking information about treatments for his partner's AIDS-related conditions "gave us a great surge of purpose that colored everything else. Any news about any drug could cut through my blackest despair."<sup>1</sup> People with AIDS and their caregivers advised that "all people with AIDS should be their own doctors."<sup>2</sup> Many described an accompanying attitude, saying that "we've found that the guys who don't accept their disease, who fight it, who perhaps get even a little rude and tough or bitchy about it, they seem to be doing better."<sup>3</sup> For gay PWAs, learning about their illness became an act of resistance and sharing that information with each other became an act of solidarity. These PWAs advised that "no matter what you get involved in, the involvement itself will help."<sup>4</sup>

Gay persons with AIDS (PWAs) utilized a variety of communities and services to assert control over their health in the early years of the AIDS epidemic.<sup>5</sup> Although reactions to their illness were varied, one method PWAs employed was the use of alternative therapies. However, that quest for alternative therapies was more than an act of desperation but one of many ways

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1. Paul Monette, *Borrowed Time: An AIDS Memoir* (New York: Harcourt Brace Javanovich, 1988), 109.
2. Jon Greenberg quoted by Elinor Burkett, *The Gravest Show on Earth: America in the Age of AIDS* (New York: Houghton Mifflin Company, 1995), 320.
3. Jeff Mandel quoted by Nathan Fain, "Changing Gay Lifestyles: AIDS and the Mind: Psychological Aspects of a Mysterious Disease," *The Advocate*, October 27, 1983.
4. Philip Lanzaratta quoted by Michael Helquist, "Alternative Therapies...Do They Offer Any Real Hope to People with AIDS," *The Advocate*, December 10, 1985.
5. For the purpose of this paper, "effective biomedical treatment" is defined the "triple drug cocktail" which effectively turned HIV disease into a largely manageable, chronic illness. The focus of the paper will be from approximately 1983 to 1990. I will be using the term "biomedicine" in this paper to describe traditional, orthodox medical treatment, including a range of activities from procuring advice from medical doctors to using chemotherapy. The choice of words reflects a common usage in alternative medicine texts and is useful for the implied emphasis on biology, a stark contrast to many alternative therapies. I have defined "alternative" as any system employed by PWAs that existed outside of the realm of biomedical authority.

that they acted on a need for purpose in the wake of their diagnosis. These alternative treatments penetrated the PWA experience to such a degree that, as of 2007, the use of alternative treatments for HIV diseases still far outpaced that of other illnesses.<sup>6</sup> Their quest for alternative therapies was a complicated one which did not involve the alternative practitioners exclusively. PWAs used AIDS service organizations (ASOs) and other means to find information regarding their illness and possible treatments while asserting that their biomedical doctors could not dominate medical discourse and decisions and, as a demonstration of this newfound power, sought alternative therapies for treatment. Community acted as the conduit by which information was acquired and used in an often solitary fight. It was not so much the treatment itself as the active involvement in seeking it that was helpful to PWAs.

The way that gay PWAs dealt with their illness, including the use of community and alternative practitioners, reflected the way that they coped with the reality of their illness. Sociologist Rose Weitz studied the coping mechanisms of PWAs and identified two broad strategies: avoidance and vigilance. Avoidance happened at all stages of the illness. Before diagnosis, a PWA might have avoided seeking a test which would confirm diagnosis or might have attributed the symptoms and signs of AIDS to other, less stigmatized and less serious, conditions. After diagnosis, a PWA might have constructed his disease identity as having HIV or ARC, rather than AIDS, to avoid the reality that his condition was terminal.<sup>7</sup> He might use his

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6. Karen Kaufman and William Gregory, "Discriminators of Complementary and Alternative Medicine Provider Use Among Men with HIV/AIDS," *American Journal of Health Behavior* 31 (2007): 592.

7. Rose Weitz, "Uncertainty and the Lives of Persons with AIDS," *Journal of Health and Social Behavior* 30, no. 3 (Sep. 1989): 270, 277; Susan Sontag, *AIDS and Its Metaphors* (New York: Farrar, Straus and Giroux, 1989), 35-36; ARC stands for AIDS-related Complex. It was a term that described swollen lymph nodes and a kind of pre-AIDS. It is a term that has been largely abandoned. Weitz is quick to point out that people with other chronic and terminal illnesses used the same strategies to cope as PWAs.

savings to travel in the hopes of enjoying the life he had left instead of using those funds to actively combat his illness.<sup>8</sup> Avoidance could be either denial or resignation.

Vigilance, in contrast, was learning and participating in methods which PWAs believed would prolong their life. The search for alternative therapies was one example of this vigilance but PWAs employed others, such as working to gain entrance to experimental drug trials. For example, PWA Ray Engerbretson sought entry into a clinical trial at the National Institutes of Health and was rejected after going through eight weeks of tests to determine his eligibility.<sup>9</sup> Engerbretson reacted to this rejection by seeing a holistic healer who employed “Zero Balancing,” a type of crystal therapy.<sup>10</sup> Engerbretson was open to alternative therapies before his diagnosis with AIDS, yet it was only after his rejection from the NIH trial that his desire to actively resist his illness led him to an alternative treatment practitioner.

Generally, those vigilant PWAs seeking information and treatment began with the advice of biomedical doctors, who were able to best track the progress of their illness and explore whatever biomedical options might be available to them.<sup>11</sup> Biomedical doctors, despite the prevalence of AIDS service organizations, newspapers, and other information dissemination systems, naturally remained an important source of information for PWAs. Journalist Chuck Frutchet wrote that “the first step to take is to see a doctor. Even if you decide to pursue an alternative therapy, there is no substitute for being followed by a doctor who can monitor your

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8. Ronald Bayer and Gerald M. Oppenheimer, *AIDS Doctors: Voices from the Epidemic* (New York: Oxford University Press, 2000), 69.

9. Lisa M. Keen, “When Pretending Stops...” *Washington Blade*, March 15, 1985; Lisa M. Keen, “Rejected by NIH, Frustrated by Bureaucracy,” *Washington Blade*, March 29, 1985.

10. Lisa M. Keen, “A Lot of Medicine and Advice, A Little Relief,” *Washington Blade*, April 26, 1985.

11. Betty Clare Moffatt, Judith Spiegel, Steve Parrish, and Michael Helquist, *AIDS: A Self-Care Manual*, (Los Angeles: AIDS Project Los Angeles, 1987), 119.

vital signs, blood work, etc.”<sup>12</sup> Frutchey then clarified this advice, careful to warn those vigilant PWAs that:

While it is a good idea to *consult* your doctor, it is not a good idea to *surrender* your decision-making entirely. The decisions are yours, and you should prepare yourself to make them intelligently. Use your doctor, your friends, and other people with AIDS/ARC as resources, but retain and exercise your right to make choices about your own health - choices that are in your best interest.<sup>13</sup>

Historian Allan Brandt discussed this democratization of medicine, wherein doctors, loved ones, and other PWAs had equal voices, as an outgrowth of a growing lack of faith in the therapeutic abilities of biomedical medicine.<sup>14</sup> Historian Charles Rosenberg also discussed the devaluation of medical authority as a consequence of the peak of optimism in scientific and medical advances, prevalent before the 1940s. As the knowledge gained by scientific observation grew, a gap developed between what medical consumers expected of science and what the scientists were able to deliver. In response, the public began to hold “resentment at medicine’s inability to comply with these imperial expectations.”<sup>15</sup>

Another element contributing to gay PWAs’ resistance to medical authority was that biomedical doctors, not unlike the rest of society, were not exempt from homophobia, which led to a less welcoming care environment for PWAs.<sup>16</sup> According to one PWA, his doctor told him that “I don’t approve of your lifestyle and what it represents. It is ungodly in my view. But that

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12. Chuck Frutchey, “Choosing Alternative Therapies,” *Bay Area Reporter*, May 1, 1986.

13. Chuck Frutchey, “Use Your Rights in Choosing Treatments,” *Bay Area Reporter*, May 8, 1986.

14. Allan Brandt, “AIDS and Metaphor,” in *In Time of Plague*, ed. Arien Mack (New York: New York UP, 1991), 103.

15. Charles E. Rosenberg, “Disease and Social Order in America: Perceptions and Expectation,” in *AIDS : The Burdens of History*, ed. Elizabeth Fee and Daniel M. Fox (Berkeley, CA: University of California Press, 1988), 14, 16.

16. Michael J. Yedidia, Judith K. Barr, and Carolyn A. Berry, “Physicians’ Attitudes Toward AIDS at Different Career Stages: A Comparison of Internists and Surgeons,” *Journal of Health and Social Behavior* 34, no. 3 (Sep. 1993): 281.

doesn't mean that I won't continue to take good care of you." The PWA, in response, declared, "oh yes it does!"<sup>17</sup> Some in the biomedical community tried to counter these feelings. Dr. David Wright described a doctor who felt that treating gay patients was contradictory to his religious faith and was unwilling to see any AIDS patients. Wright said to him, "well, you got to put that aside. You took the Hippocratic Oath, just like I did."<sup>18</sup>

Further, despite the Hippocratic Oath, many doctors and healthcare workers held stigmatizing views of AIDS. These doctors and health care workers may not have been homophobic but still had nightmares about AIDS infection and avoided working with PWAs.<sup>19</sup> Those who were forced to work with PWAs sometimes took outlandish steps to ensure their own safety. Janitors used makeshift "space suits" to clean the AIDS ward at San Francisco General Hospital. Other workers in the hospital, such as food service employees, also felt scared of infection and left trays of food in the corner of patients' rooms.<sup>20</sup> PWAs reacted to this perceived insensitivity, based on either homophobia or fear, by seeking more personalized care, which they found through alternative practitioners or sympathetic biomedical doctors.<sup>21</sup> Some biomedical doctors, more familiar with the disease, adapted their strategies for dealing with their patients

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17. Abraham Verghese, *My Own Country: A Doctor's Story of a Town and Its People in the Age of AIDS* (New York: Simon and Schuster, 1994), 97.

18. Bayer and Oppenheimer, 104.

19. Carol Pogash, *As Real As It Gets: The Life of a Hospital at the Center of the AIDS Epidemic* (New York: Birch Lane Press, 1992), 19-20; Verghese, 88.

20. Pogash, 20, 22.

21. Max Navarre, "Fighting the Victim Label," in *AIDS: Cultural Analysis, Cultural Activism*, ed. Douglas Crimp (Cambridge, MA: MIT Press, 1988), 146; Martha L. Hare, "The Emergence of an Urban U.S. Chinese Medicine," *Medical Anthropology Quarterly* 7, no. 1 (Mar. 1993): 34; Jill Wolhandler, Kenneth Hale-Wehmann, and Read Weaver, "Alternative Health Approaches to AIDS – A Conference Report," *Gay Community News*, March 15, 1986; Bonnie Blair O'Connor, *Healing Traditions: Alternative Medicine and the Health Professions* (Philadelphia: University of Pennsylvania, 1995), 149; O'Connor discusses PWAs' use of "doctor report cards" in the evaluation of physicians' compassion and skills.

and made a concerted effort to listen to and learn from them. These doctors found that their patients were as much seeking caring and compassion from them as they were seeking a cure. At least one doctor said that he learned to “return to an older tradition of caring,” which included listening to his patients’ wishes and honoring them as well as he could. These wishes included the right to seek treatment through alternative practitioners in conjunction with biomedical treatment.<sup>22</sup>

These vigilant, gay PWAs insisted that their biomedical doctors take their concerns seriously, including their desire for alternative treatments as a supplement to their biomedical treatment, and left their biomedical doctors with little choice, despite any misgivings they might have about those alternative therapies, but to incorporate alternatives into their therapeutic plan. These doctors realized that if they ignored their patients’ desire for alternative therapies their patients would either withhold information about what they were doing outside of the biomedical realm or would seek treatment elsewhere. The more candid doctors were with their patients regarding these treatments, the more likely the patients would be compliant with their biomedical treatments and come to them for advice in the future.<sup>23</sup>

However, not all PWAs could access these alternative therapies equally and they were mostly utilized by those who could afford them. Alternative therapies were generally not covered by insurance providers, meaning that PWAs needed enough disposable income to pay for these treatments.<sup>24</sup> Although generally expensive, the cost of these treatments varied. For instance, the

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22. Katrien De Moor, “The Doctor’s Role of Witness and Companion: Medical and Literary Ethics of Care in AIDS Physicians’ Memoirs,” *Literature and Medicine* 22, no. 2 (2003): 212-213.

23. Bayer and Oppenheimer, 167-168.

24. Bonnie Blair O’Connor, *Healing Traditions: Alternative Medicine and the Health Professions* (Philadelphia: University of Pennsylvania Press, 1995), 155; Miranda Kolbe, “A PWA Movement of Guerrilla Clinics,” *Gay Community News*, August 7-13, 1988.

cost of many alternative therapies was lower in San Francisco, likely due to market pressure in a city that offered such diversity, especially in regard to its Asian population. One student with AIDS made monthly plane flights to San Francisco because the cost of the acupuncture and massage was less expensive and the quality much higher.<sup>25</sup> Given the high cost, Martin Delaney of Project Inform admonished PWAs to give up luxuries to afford alternative treatments. Delaney suggested that PWAs might have to get a roommate or delay purchasing a new car to stay healthy. At least one PWA found Delaney's expectations unreasonable; responding in *Gay Community News*, reporter Christopher Wittke wrote that he had "\$46 in my checking account and \$6 in savings. And he's saying I may have to hold off a year on that Mercedes so that I can save my health?"<sup>26</sup> Even with a will, there was not always a way.

Therefore, the high level of income necessary to utilize alternative therapies precluded the possibility of PWAs from lower socio-economic brackets from seeking them in great numbers. Ethnographer Bonnie Blair O'Connor makes the contrast between these different groups clear by stating that it is not those in the inner-city who:

subscribe to alternative treatment newsletters, fax their drug and supplement orders, which they pay by credit card, to buyers clubs, peruse the medical and scientific journals, negotiate with physicians, reach on-line treatment information services by modem from their home computers, and draw upon their discretionary income to pay for foreign pharmaceuticals and other complementary therapies.<sup>27</sup>

However, ASOs made concerted efforts to include all other groups, recognizing that the epidemic affected more than just those middle-class, white gay men. Ruth Schwartz of the San Francisco AIDS Foundation wrote a letter to *Gay Community News*, encouraging them to write

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25. Pogash, 162.

26. Christopher Wittke, "Buyer Beware," *Gay Community News*, August 7-13, 1988.

27. O'Connor, 155.



in a simpler style as the “majority of the United States population is best able to comprehend material written at a 7th or 8th grade level,” pointing out that, in evaluating an article in the newspaper, she found that the staff wrote at a “13th” grade level.<sup>28</sup> Yet this inclusiveness did not often translate to successful outreach to other PWA populations.

There were other reasons, beyond simple economics, which predicted how likely other PWA populations were to seek alternative therapies. According to *Gay Community News*, reporting from an alternative therapy conference, “[a]lmost everyone at the conference was white.”<sup>29</sup> Dr. Donna Futterman reinforced the observation, stating that African American and Latino PWAs “don’t really clamor” for alternative therapies.<sup>30</sup> Many African American and Latino PWAs did not participate in these gay-centered networks because they did not want to be identified as gay.<sup>31</sup> In one case, members of the African American community of Washington, D.C. came to resent the gay-oriented Whitman-Walker Clinic, which received a majority of the AIDS funding in Washington D.C. The clinic, feeling that they were being accused of racism, countered to African American leaders that it was homophobia that prevented them from taking advantage of Whitman-Walker’s services. One African American PWA responded, “[t]his is not about homophobia... it’s about dollars and cents and my life. I have the right to live my last days in an environment I choose. We have a right to want the services in our community.”<sup>32</sup>

Geography and PWAs’ distance from an urban center also foretold the level to which they would be interested in alternative therapies. The gay PWA population of Johnson City,

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28. Ruth Schwartz to *Gay Community News*, May 22-28, 1988.

29. Wolhandler, Hale-Wehmann, and Weaver.

30. Bayer and Oppenheimer, 162.

31. O’Connor, 154.

32. Burkett, 148-149.

Tennessee, according to infectious disease specialist Abraham Verghese, did not respond in the same way as those in larger cities. He stated that “everywhere but in our town, people infected with the virus were chasing down alternative therapies.”<sup>33</sup> Verghese traced the infections in his small town and observed that almost all of the AIDS cases in Johnson City had come from larger cities.<sup>34</sup> Many of Verghese’s patients were men who had returned to their families for care, despite the prevalence of AIDS service organizations. They would have stayed in larger cities where these services were more readily available if they had had the means or the motivation to seek alternative therapies. Even after the organization of the Tri-City AIDS Project in Johnson City, the search for alternative therapies never became prevalent there.

Those vigilant, gay PWAs in urban areas with the means to seek information about alternative therapies utilized both formal networks and informal networks, such as friends, acquaintances, and support groups. The anecdotal evidence from informal social networks commanded similar authority to that of the AIDS service organizations.<sup>35</sup> Paul Monette described using this type of informal network as his primary source of information in his memoir, *Borrowed Time: An AIDS Memoir*. Monette described his friend Craig as his “research associate,” because Monette was able to ask him questions about treatments for AIDS and he was able to answer them effectively.<sup>36</sup> Later in the memoir, after his lover began to go blind from an AIDS-related complication, Monette used this informal network to seek information about the correlation between AIDS and blindness.<sup>37</sup> In another example, two men, both enrolled in a

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33. Verghese, 222.

34. *Ibid.*, 319-320.

35. Chuck Frutchley, “Choosing Alternative Therapies.”

36. Monette, 94-95.

37. *Ibid.*, 250.

clinical trial for Compound Q, exemplified the contrast between those that relied on formal networks and those that relied on informal networks for their information. One man read all of the gay papers and stayed involved in the procurement of information while the other relied on a friend “who [read] everything” to explain things to him.<sup>38</sup>

Vigilant PWAs who used formal networks to seek information often relied on AIDS service organizations. These ASOs were mostly run by and tailored to gay men, which helps to explain the appeal to gay men in particular. The number of AIDS service organizations grew rapidly; by 1994, there were over 18,000 in the United States offering a variety of services.<sup>39</sup> Some of the ASOs started as health organizations for gays and lesbians well before the AIDS epidemic.<sup>40</sup> For example, the Whitman-Walker Clinic in Washington D.C., originally founded in 1973 as “the gay men’s VD division of the Washington Free Clinic,” was already treating 10,000 people per year for various sexually transmitted diseases by 1981.<sup>41</sup> When AIDS began to dramatically affect the gay population of the city, it was logical to channel funding to the Whitman-Walker clinic, since it was already dealing with the affected population, and over time the clinic focused increasingly on AIDS and on providing services to PWAs. Many founders of ASOs were gay men that had experience dealing with political advocacy.<sup>42</sup> For example, Fred

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38. Pogash, 193.

39. Burkett, 145.

40. Hippler, “Looking Out for Ourselves: AIDS Support Groups Part I” *Bay Area Reporter*, December 26, 1985; specifically listed in this article are the Bay Area Physicians for Human Rights (BAPHR), which was founded in the mid-1970s to focus on gay and lesbian health concerns and Operation Concern, focused on mental health for gays and lesbians and founded in 1979.

41. Sandra R. Gregg, “Clinic for Gays Provides Specialized Treatment; D.C.’s Clinic for Gays,” *Washington Post*, March 5, 1981.

42. Mark Hippler, “Looking Out for Ourselves: AIDS Support Groups Part I;” Mark Hippler, “Looking Out for Ourselves: AIDS Support Groups Part II,” *Bay Area Reporter*, January 2, 1986; mentioned in these articles are the AIDS Health Project, founded in 1984 by gay mental health professionals, The Stop AIDS Project which was

Goodson, the founder of the Tri-City AIDS Project had previous experience with gay-oriented political groups. He formed a “Gay Liberation Front” in college, worked for East Tennessee’s first gay periodical, and organized a “Gay Cover Group” which organized the efforts of the multiple, small gay groups in the area. It was this experience organizing gay political movements that aided Goodson as he developed the Tri-City AIDS Project, which by 1988 was successfully holding regular support meetings.<sup>43</sup>

Government funding at the state level reinforced AIDS service organizations at the expense of the health departments, meaning that the ASOs were often the only services available for PWAs. Part of the motivation for the community response to the epidemic was the lackluster response of government agencies. The gay groups felt they had to organize as a result of government indifference and fundraising was, in the earliest years of the epidemic, primarily a gay endeavor.<sup>44</sup> As their political clout and the range and quality of their services increased, ASOs easily overtook the under-funded local health departments as the preferred providers of AIDS services. The health departments began to send PWAs to these gay run ASOs for the services that they were unable to offer.<sup>45</sup> However, in 1985, when the government was poised to channel significant funds into combating the epidemic, the health departments felt they should get a budget increase so that they would be able to deal more effectively with the crisis. ASOs vehemently argued against this, stating that the health departments had sent PWAs to area ASOs

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founded in January 1985 specifically to discuss gay and bisexual male response to the epidemic, People With AIDS which was founded in 1983, Pacific Center AIDS Project which was founded in 1983, and the San Francisco AIDS Foundation, “founded in June 1982 by a group of community activists and health professionals.”

43. Verghese, 102, 149-150, 156, 253.

44. Burkett, 146; Michael Specter, “Gay Groups Mobilize Against AIDS; Communities Fight for U.S. Funds, Battle Erosion of Civil Rights,” *Washington Post*, August 2, 1985; Alma Guillermoprieto, “Epidemic of Fear: D.C. Homosexuals Face AIDS,” *Washington Post*, June 5, 1983; Bob Ross, “Let’s Stick Together,” *Bay Area Reporter*, January 14, 1985.

45. Specter.

for years and that they should not be the recipient of federal funding now that the government was finally getting involved.<sup>46</sup> The gay-oriented ASOs argued that they had become the de facto experts for AIDS support services and that it made more sense to continue funding them instead of channeling funds to an inexperienced agency.

The federal government distributed the funds to ASOs disproportionately, favoring more urban organizations in the biggest cities, which were affected earliest by the epidemic. It was this disproportionate funding that fostered the viability of alternative medicine for AIDS in these areas. In 1990, Doug Nelson of the AIDS Resource Center in Milwaukee noticed that San Francisco was due for an increase in funding, per PWA, six times higher than Milwaukee. In reviewing the services available in other cities compared with his, Nelson noted that Miami was able to pay for vitamins for its PWAs while he was unable to assist with the purchase of AZT; also, he observed that ASOs in San Francisco paid for acupuncture and psychotherapy while he was unable to pay for a counselor.<sup>47</sup> Therefore, again, geography made a significant impact on the degree to which PWAs were able to seek alternative treatments by reducing the socio-economic threshold that the PWA in some regions needed to meet to receive the services.

Another formal network, the gay-targeted newspapers, acted as a preexisting information dissemination mechanism for the community. One way that these newspapers were able to aid the spread of AIDS-related information was to print AIDS Resource Lists, which began appearing early in the epidemic.<sup>48</sup> Beyond channeling their readers to appropriate service organizations, these newspapers also acted as an outlet for community suggestions and

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46. Ibid.

47. Burkett, 141-142.

48. "AIDS Resource List," *Gay Community News*, July 14, 1984.

frustrations. One reader, Ronald Poe, wrote two letters to the *Bay Area Reporter*, spaced approximately four months apart from each other, with two different theories of the cause and the possible solution to the AIDS epidemic. It would appear that Poe read two books, both of which touched on “new age” concepts, which Poe then connected to AIDS and felt compelled to share with the *Bay Area Reporter* readership.<sup>49</sup> These newspapers printed articles that highlighted various alternative therapies, reported from alternative therapy conferences, and mentioned alternatives tangentially in profiles of PWAs. Advertisements used to support the newspaper financially acted as a community awareness vehicle for potentially beneficial products and services, especially vitamins and conferences. As a cornerstone of the gay community, these newspapers were uniquely situated to spread information to gay PWAs.

AIDS service organizations printed newsletters focused on AIDS which were similar, if more targeted, to gay-oriented newspapers. These newsletters contained articles discussing alternative therapies, as well as experimental treatments and clinical trials, including follow-up articles which tracked the efficacy of the treatments. They contained calendars, resource guides, and sometimes offered sections devoted to letters from readers. ASOs also established toll-free hotlines for information which were staffed by volunteers. Given the nature of the discussion and the stigmatization surrounding the illness, organizations trained the volunteers to deal with both the information aspect of the job and the psychological aspect of speaking with potential PWAs<sup>50</sup>

Although less common than hotlines and newsletters, PWAs also accessed electronic “bulletin boards” from their home computers. These bulletin boards were often not moderated

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49. Ronald Poe to *Bay Area Reporter*, May 9, 1985; Ronald Poe to *Bay Area Reporter*, September 19, 1985.

50. “AIDS Resource List,” Kolbe; William Burks, “AIDS Organizations: Donations/Resources for the Holidays,” *Windy City Times*, December 26, 1985; Burkett, 26.

and unproven theories shared equal weight with biomedical drug trials and other topics only marginally related to AIDS, such as politics and religion.<sup>51</sup> AIDS networks were able to utilize computer systems very early because those men that were organizing and participating in these networks were drawn from the very group that was revolutionizing the information industry: men in their early thirties.<sup>52</sup> In June 1984, IDK Enterprises established a free bulletin board system for PWAs at the behest of a former Whitman-Walker Clinic hotline employee who had noticed that callers had worried about being identified by their voice. By 1986, the bulletin board had ninety users per month. In November 1984, the Los Angeles Gay and Lesbian Community Center established the Computerized AIDS Information Network (CAIN). Unlike other bulletin boards, CAIN remained a purely technical resource for PWAs, and included statistics, articles, transcripts, and meeting notices exclusively. CAIN's administrators did not encourage the use of the bulletin board as an emotional support mechanism. By 1986, CAIN had three hundred users per month.<sup>53</sup> In 1985, the Dubose Triangle Bulletin Board System offered pre-recorded telephone messages twenty-three hours a day for voice callers and also maintained a system for modem users. They accepted information from any source, asking only that uncorroborated information be disclaimed, but reserved the right to refuse information which they interpreted as false or misleading.<sup>54</sup>

In contrast to the ubiquitous free hotlines and bulletin boards, at least two companies tried to capitalize on the desire for information on AIDS with a for-profit toll line. In late 1985, advertisements began appearing for "976-AIDS" in the *Bay Area Reporter* and *The Advocate*.

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51. Burkett, 301.

52. Bayer and Oppenheimer, 158.

53. Margaret Engel, "AIDS Sufferers Find Solace in Computer Network," *Washington Post*, January 26, 1986.

54. "AIDS Information by Computer," *Bay Area Reporter*, July 25, 1985.

The advertisements enticed callers with the promise of the most up-to-date information. These ads ran in the *Bay Area Reporter* from October 24th to November 7th, then in *The Advocate* from November 12th to November 26<sup>th</sup>, but disappeared thereafter demonstrating that information was so readily and freely available through the many newsletters, support groups, toll-free hotlines, and databases that potential callers had no need to use this pay service. Even the promise that the hotline would donate fifteen percent of proceeds to an “AIDS research program” was not enough to entice people to call.<sup>55</sup> American International Communications established another “976” toll number in San Diego in 1987. The company established this toll number as part of a for-profit network of “976” numbers designed for the dissemination of medical information about a variety of illnesses. The “976” number dedicated to AIDS came under criticism from AIDS service organizations; for instance, Michael Hughes of the California Office of AIDS stated that his concerns were two-fold: that a variety of toll-free information lines provided the same information for free and that the toll-number offered a one minute, pre-recorded message when, in his opinion, trained volunteers should have been giving that information.<sup>56</sup>

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55. AIDS Information Projects Network, “976-AIDS,” advertisement, *The Advocate*, November 26, 1985.

56. Cheryl Clark, “Officials Wary of Hot-Line’s \$2-a-call Fee for AIDS Tips,” *San Diego Union-Tribune*, July 23, 1989.



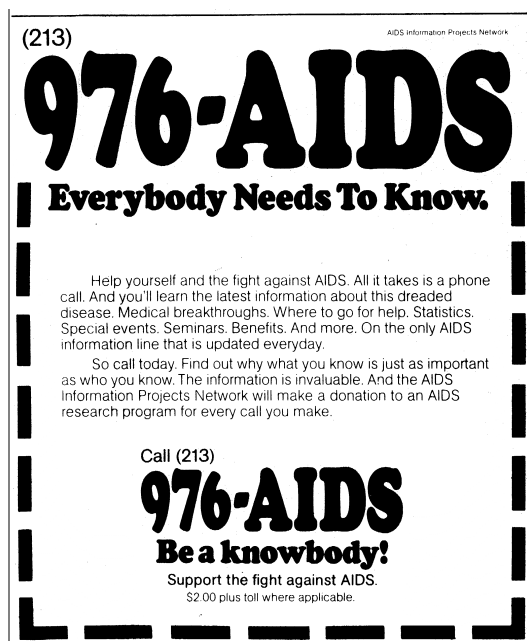


Figure 1. AIDS Information Projects Network, “976-AIDS,” advertisement, *Bay Area Reporter*, October 24, 1985.

Through these informal and formal networks, a consensus developed among PWAS that alternatives were the best available option to promote overall health and wellness, to address the side-effects of biomedical therapies, and to manage the symptoms of AIDS, but that biomedical treatment was more likely to succeed in killing the virus.<sup>57</sup> Alternative practitioners too felt that the work they were doing was wholly different than their biomedical counterparts, that there was no conflict of interest for PWAs, and that PWAs needed a combination of both disciplines to effectively manage their illness.<sup>58</sup> A few alternative practitioners, however, did prefer that their clients seek treatment from them exclusively.<sup>59</sup> PWAs could choose from a great variety of

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57. Michael Helquist; “Recovering from the Effects of AIDS: Video Features Asymptomatic Person with AIDS,” *Gay Community News*, July 20-26, 1986.

58. Magnolia Goh and Tang Zhaoliang, *Alternative Treatments for HIV Infection* (New York: Science Press New York Ltd., 1994), 21; Warren King, “AIDS-Treatment Alternatives Tested – Healthful Diet, Exercise Focus of John Bastyr Study,” *The Seattle Times*, November 7, 1990; “Chinese Medicine and AIDS: What Has Been Learned? Interview with Misha Cohen,” *AIDS Treatment News* 68 (1988), <http://www.aids.org/atn/a-068-03.html> (accessed April 12, 2008); O’Connor, 133.

59. O’Connor, 133.

therapy options, and they often used alternatives in conjunction with one another. Among the most popular alternative treatments PWAs utilized were Traditional Chinese Medicine (both acupuncture and herbal remedies), nutrition and vitamin therapy, new age techniques, and “body work,” such as chiropractic and massage therapy<sup>60</sup>

Perhaps the most popular alternative therapy, Traditional Chinese Medicine (TCM) appealed strongly to many PWAs. One flyer at a discussion group for alternative therapies declared, “100 percent of Long Term Survivors are using some form of Chinese Medicine weekly.”<sup>61</sup> Due to the popularity of TCM with PWAs, many TCM clinics catered primarily to their needs. For instance, one TCM clinic run by Dr. Jing Wu in Washington, D.C. depended on funds from gay-oriented AIDS organizations for continued operation.<sup>62</sup> Some claimed to be able to offer relief for specific symptoms. Acupuncture, for example, became a popular treatment for peripheral neuropathy, a painful AIDS-related condition.<sup>63</sup> Dr. Jing Wu’s assistant said of new clients entering into treatment that “they come straggling in here like it was the last saloon in town. [...] They just figure, why not try this? Then, when they start feeling better, they wonder why they didn’t come here in the first place.”<sup>64</sup>

Other alternative therapies and treatments involved taking vitamins and minerals as well as using other nutritional techniques on a daily basis. Even when PWAs felt uncomfortable with other alternative therapies, vitamins and nutrition were well within the limits of normalcy that

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60. O’Connor, 134-136; Goh and Zhaoliang, 120.

61. O’Connor, 132-133.

62. Courtland Milloy, “A Unique Use for Acupuncture,” *Washington Post*, October 11, 1987.

63. Moffatt, Spiegel, Parrish, and Helquist, 118.

64. Milloy.

they could be approached without a radical rethinking of scientific principles.<sup>65</sup> In 1989, the Consumer Health Education Council called forty-one health food stores to ask for advice about AIDS. All of them suggested at least one of their products for use against AIDS-related symptoms and thirty said they carried vitamins or minerals that actually cured the illness. At least one vitamin distributor claimed that the HIV virus could be inhibited by twelve grams of vitamin C taken daily.<sup>66</sup> Vitamin “mega-dosing,” in which PWAs took many times the normal recommended dose of vitamins, was very popular.<sup>67</sup> Some believed that vitamins were the cure but others continued to look elsewhere. The Anti-Yeast Diet, operating under the premise that foods containing yeast and other “yeast-promoting” foods created an environment which encouraged the development of yeast-related opportunistic infections, called for the PWA to avoid these foods.<sup>68</sup> The Immune Power Diet, although not specifically formulated for the use against AIDS, recommended eliminating “immuno-toxic” foods and became popular with PWAs.<sup>69</sup> More traditional nutritional systems like macrobiotics, which focused on dietary imbalances and the imbalances they created in the body, were also very popular with PWAs.<sup>70</sup>

Many theories about positive thinking and visualization as the keys to wellness developed and often claimed that AIDS was the direct result of negative thinking. Some even claimed that the current political climate, in which gay men were subjected to the attacks of the rising Moral

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65. Monette, 116.

66. Burkett, 112-113.

67. Lenny Giteck, “Face to Face: How a Couple Copes with AIDS,” *The Advocate*, April 3, 1984.

68. O’Connor, 122-123.

69. O’Connor, 123; Helquist; within twenty minutes of diet creator Dr. Stuart Berger’s appearance on a San Francisco talk show, the Crown Books on Castro Street completely sold out of all of its copies of *Immune Power Diet*.

70. O’Connor, 122-123.

Majority, was to blame for the sudden surge in AIDS cases.<sup>71</sup> Practitioners of these methods to decrease stress and improve mental health described them as meditation, visualization, stress reduction, and positive thinking.<sup>72</sup> These metaphysical systems tended to attribute responsibility for the illness to the PWA directly, although they acknowledged almost uniformly that the illness was a result of the subconscious.<sup>73</sup> PWAs used positive thinking methods as an attempt to overcome specific symptoms and opportunistic infections, but used them more often for general wellness and healing.<sup>74</sup> The visualization process was unique to each individual, suiting their own purposes and beliefs. PWA Bobby Reynolds explained that he, in seeking to use visualization as a way of combating his Kaposi's sarcoma, imagined "thousands of little Pac-Men gobbling up my cancer cells."<sup>75</sup> PWA Bill Misenheimer claimed to have gone into "remission" of AIDS for one year due to metaphysical therapy, stating that it "has given me such a sense of well-being that I am convinced that is what has saved me. I certainly would recommend therapy to anybody, although no one can promise that it will work for a specific person. All I know is that it has worked for me."<sup>76</sup>

The sentiment that "all I know is that it has worked for me" illustrates well the inexact nature of the claims made by alternative therapies and, given that, fraud was difficult to prove; nonetheless, litigation exposed several fraudulent therapies. Federal and state regulators

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71. Nathan Fain, "Long Live Bizarre Speculation," *The Advocate*, April 17, 1984.

72. Helquist; O'Connor, 134; "Study Seeks Subjects for AIDS-Stress Link," *Bay Area Reporter*, April 24, 1986.

73. Nathan Fain, "Changing Gay Lifestyles: AIDS and the Mind: Psychological Aspects of a Mysterious Disease," *The Advocate*, October 27, 1983.

74. Wolhandler, Hale-Wehmann, and Weaver.

75. Helquist.\=

76. San Diego Gazette, "Talk About a Real Superman! AIDS Case Goes in Remission," *Bay Area Reporter*, September 5, 1985.

generally responded to fraudulent cures, treatments, and devices through the court system. Two clinics in Houston and Dallas were charged with violations of fair trade practices for claiming that urine injections would cure AIDS.<sup>77</sup> Mail going to “R.E.V. Treatment,” a company that claimed a cure was available through a series of \$1900 “vaccines” administered in Germany or Mexico, was halted by judicial process in 1983.<sup>78</sup> Virus Guard Incorporated was found guilty of false advertising for claiming that their product could cure both AIDS and Herpes in 1986.<sup>79</sup> Three PWAs sued Biosystems Incorporated for emotional distress for claiming that their treatment would cure them. This treatment, according to the company, “channel[ed] the body into a desired regulatory response through biophysical catalysts” by having the PWA lie down on a bed, over copper coils, as light shone through a special glass.<sup>80</sup> PWAs often needed to travel out of the country to receive the most extreme of these strange “cures,” making litigation for many clearly fraudulent cures difficult.<sup>81</sup>

However, even when state regulation proved inadequate, the PWA community was adept at quickly spreading word of fraudulent therapies. A consortium of concerned law students wrote an open letter to the *The Advocate* accusing the magazine of a history of running fraudulent advertisements, citing Viral AID, an electronic device that claimed to destroy the virus that

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77. Elizabeth Pincus, “Urine as an AIDS Treatment,” *Gay Community News*, September 18-24, 1988; Marc Stein, “You’re in the Money,” *Gay Community News*, October 4-10, 1987.

78. “A Lost Angeles-area Mail Order Firm.”

79. New York Native, “Judge Tells Proxy to Quit Selling Phony AIDS Cure,” *Bay Area Reporter*, March 20, 1986.

80. Allen White, “No Cure as Claimed Leads to Lawsuit,” *Bay Area Reporter*, June 19, 1986.

81. Burkett, 111-112; Jonathan Engel, *The Epidemic: A Global History of AIDS* (New York: Smithsonian Books, 2006), 127. “A Los Angeles-area Mail Order Firm,” *The Advocate*, August 30, 1983.

caused AIDS, and Immune Pack, a tablet that claimed to restore normal immune function.<sup>82</sup> Activists clamored for the San Francisco AIDS Foundation to create an organization similar to the Better Business Bureau, which would be empowered to investigate and evaluate claims made by companies and to provide the community with fast information about potential frauds.<sup>83</sup> Overall, the PWA community desired to limit state intrusion into the marketplace of therapeutic ideas. Keeping the government response to fraudulent and misleading cures and treatments to a minimum ensured that the full spectrum of possibilities remained open for the PWAs and that the bureaucracy that they had come to fear would not arbitrarily limit their options.

Both fraudulent and more altruistic alternative practitioners and organizations cultivated their clients through a variety of methods. Advertising offered a successful means for alternative practitioners and services to reach new audiences. Alternative practitioners incorporated language into their advertisements that the PWA empowerment movement had already established. This language appealed to vigilant PWAs' belief in medical and personal autonomy, advising PWAs to use their services to "develop [their] own health improvement plan."<sup>84</sup> Advertisements were also polarizing to the PWA community. The aforementioned open letter to *The Advocate* was only one example of the *The Advocate*'s perceived unwillingness to remove the advertisements that the community considered false or misleading. One upset reader even called advertisements for vitamin supplements "nutrition quackery."<sup>85</sup> *The Advocate* published a

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82. Tomas Medina, Stephen Matchett, and Alissa Friedman to *Gay Community News*, November 23-29, 1986; see figures 2 and 3.

83. White.

84. "The AIDS Health Project," Advertisement, *Bay Area Reporter*, July 11, 1985; Burkett, 114-115.

85. Peter McKnight to *The Advocate*, September 29, 1983.

message in 1985 meant to reassure their readers of the quality of the products and services that advertised in their magazine.<sup>86</sup>

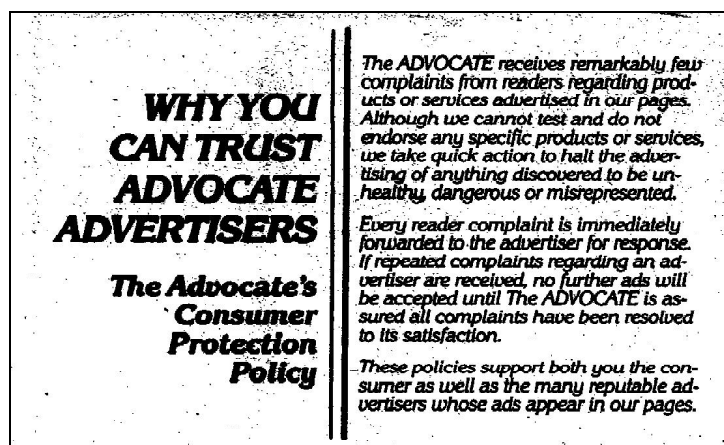


Figure 2. The Advocate, “Why You Can Trust Advocate Advertisers,” *The Advocate*, May 28, 1985.

However, a year and a half later, the publisher of the magazine, Niles Merton, clarified his position on advertising. He stated, “for the most part, you try not to become involved in the process of evaluating products – if for no other reason than the fact that you’re not qualified or equipped to do so. [...] It’s hardly the role of the publisher – or of the publication itself – to choose sides in [...] dispute[s].” Merton then, however, contradicted himself and reasserted that *The Advocate* had “turned down any number of ads that have been offered to us – ads that were false or misleading, or that advertised products that were clearly dangerous.”<sup>87</sup> The stakes were higher in regard to these advertisements and Merton was trying to do the right thing, but his position was difficult as a publisher of a magazine which depended on that advertising revenue for profitability. The community response to these advertisements demonstrated the collective sense of responsibility shared by PWAs and other gay community members.

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86. The Advocate, “Why You Can Trust Advocate Advertisers,” *The Advocate*, May 28, 1985.

87. “Free to Choose, But Not Free to Deceive,” *The Advocate*, November 11, 1986.

Another effective method alternative practitioners used was to stage conferences and seminars which focused on alternative therapies. Attendance at the workshops and seminars was generally free for PWAs and, consequently, acted as both outreach and advertising for the practitioners.<sup>88</sup> One popular traveling workshop, “The AIDS Mastery Workshop” paid to advertise in gay newspapers well in advance of its appearance, but promoters of the workshop also benefited from newspaper articles written about it, a type of advertising that other workshops and seminars relied on for spreading awareness of their existence to the PWA community.<sup>89</sup> These conferences, seminars, workshops, and retreats also brought together many types of alternatives under one roof, exposing the PWAs to demonstrations of massage, macrobiotics meals, positive thinking, chiropractic therapy, and acupuncture.<sup>90</sup> This was a particularly important technique that the alternative practitioners employed to ensure that they were reaching both an uneducated and interested audience as “most people at the conference[s] were already involved to some extent and not totally new to all these ideas.”<sup>91</sup> The conferences were a way of exposing PWAs, who were already skilled at gathering and disseminating information, to new alternative treatments which would then continue to be fed back into the PWA community through both formal and informal networks. These conferences, among them “The AIDS Mastery Workshop,” also served to energize these PWAs anew and gave them fortitude to continue fighting. Activist Terry Sutton attended “The AIDS Mastery Workshop”

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88. “Celebrating Life: Positive Approach to AIDS,” *Windy City Times*, May 15, 1986; Jennie McKnight, “Boston AIDS Mastery Workshop,” *Gay Community News*, July 10-16, 1988.

89. “AIDS Mastery Workshop,” *Windy City Times*, July 10, 1986.

90. Wolhandler, Hale-Wehmann, and Weaver; Jamie Morris to *Bay Area Reporter*, February 7, 1985; Walta Borawski, “Healing and Staying Healthy,” *Gay Community News*, June 5-11, 1988; “AIDS Spiritual Retreat,” *Bay Area Reporter*, December 19, 1985;

91. Wolhandler, Hale-Wehmann, and Weaver.




and, according to his friends, “he got in touch with his power. Before the mastery he was very shy, and quiet. The mastery lit his fire.”<sup>92</sup>

## AIDS MASTERY 3-DAY SEMINAR

**The AIDS MASTERY** unleashes your power, creativity and self love so that you can directly effect the quality of your life. It will put you in touch with choice, with the will to see and exercise options. Do you suffer by dwelling on illness and fear, or do you surround yourself with healing, nurturing support? The Mastery will use one on one, group interaction and visualization. If you see the possibilities in everything, then anything is possible.

**SALLY FISHER** co-director of the Actors Institute, teaches and coaches professional actors in New York and London. She is currently traveling across the United States and Europe teaching The AIDS Mastery, the Visualization Workshop and Special Healing Evenings.

Her Visualization Workshop arose from her personal encounter with healing. Her son, actor Fisher Stevens, was successfully guided through an episode with cancer by healer and friend, Louise Hey. As AIDS emerged in the theatrical community, Ms. Fisher recommended the Mastery to include healing, visualization and emotional work to specifically address this phenomenon.



**P.W.A. ENDORSEMENTS**

"I've seen great movement happen in the Mastery. We hoped it would work with people with AIDS. It does. The workshop is perfect. Sally Fisher is an expert at what she does."

"I couldn't be more positive about it. It was a great way to begin the New Year. I sincerely hope that my brothers and sisters in the community open themselves to it and find out more about it."

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### The Visualization Workshop

with our self-worth, love and power. It allows us to re-align habitual behavior patterns into dynamic expressions of choice. Visualization is the opportunity to step into our Vision and be Healed.

**VISUALIZATION I.** Breaking Patterns and Completing Relationships.

**VISUALIZATION II.** Love, Intimacy and Sex. Taboo vs. Freedom and Desire.

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### AIDS MASTERY & VISUALIZATION WORKSHOP CALENDAR

MONTH-PLACE	AIDS MASTERY	VISUAL	TELEPHONE #
Feb. N.Y.C.	28-2		924-8888
March-Vanc.	7-9	11/12	604-681-8877
March-L.A.	14-16	22/23	818-509-0444
March-S.P.	28-30	25/26	415-861-0266
April-London	4-6		011-44-1-251-6178
April-Atlanta		30 (1 Even.)	404-371-4031
May-N.Y.C.	2-4	7 (1 Even.)	212-924-8888
May-N.Y.C.		13/14	212-924-8888
May-Miami/Ft. L.	16-18	20/21	212-924-8888
May-Dallas	23-25	27/28	212-924-8888
May-Austin	4-6	29/30	512-452-5989
July-Boston	16-20	8/9	617-266-6562
July-N.Y.C.	16-20	22/23	212-924-8888
July-Chicago	25-27	29/30	312-973-5285

Figure 3. AIDS Mastery Workshop, “AIDS Mastery and Visualization Workshop,” Advertisement, *The Advocate*, March 18, 1986.

No matter the method, the act of resistance itself was the therapy for many PWAs and vigilant activity provided the tools to resist. The AIDS activists who protested outside of the National Institutes of Health did so to prod the government to change. This was an act of resistance. Ray Engerbretson used crystal therapy after being disappointed by his rejection from an NIH trial to continue his fight. This too was an act of resistance. After his death from AIDS, Carolyn Helmke shared Terry Sutton’s answering machine message with the readers of *Gay Community News*. Sutton said:

92. “Terry Sutton, 1955-1989,” *AIDS Treatment News* 77 (1989), <http://www.aids.org/atn/a-077-08.html> (accessed October 19, 2008).

When the history of this epidemic is told, let it be known that gay men, lesbians, and women were our warriors; that we took care of our sick and we fought a government that seemed not to care. And we did it with integrity, compassion, and love.

For gay men dealing with the AIDS epidemic in the early years, it was both a personal struggle and a community effort. Community was a means to procure information about strategies which would allow them to assert their dominance over the illness, otherwise invisible, ravaging their body. By using both formal networks, including AIDS service organizations and gay-oriented newspapers, and informal networks to procure information, these vigilant PWAs remained actively involved in their personal health. This information allowed them to question biomedical authority and to find the bravery to seek out alternative therapies.

When Monette described his “great surge of purpose,” it was information that gave it to him. When caregivers stated that PWAs should “be their own doctors,” they spoke of autonomy and self-reliance. It was those same people with AIDS that were “a little rude and tough and bitchy” that Weitz described as vigilant. The fire the AIDS Mastery Workshop lit for Terry Sutton was the same one lit, through many other means, for all of these PWAs. In the absence of effective biomedical treatment, PWAs expressed their vigilance in a variety of ways including active involvement in learning about their illness and seeking therapies which might or might not cure them. The cure was absent, so the cure itself became less important than the fight.

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