AIDS across agendas

Grief and strife on the rise in 1986

By Marea Murray

t's 1986, the bitter month of January, and I'm at home in the afternoon for some inexplicable reason when Tim calls. He tells me his buddy Rita has heard she doesn't have much time. Could I call her parents? I hear myself say, "Yes, what's the number?" Gulping, I dial before I get too upset. As a volunteer at Boston's AIDS Action Committee (AAC), I too have been a buddy to Rita. She's a Cuban transsexual who has had AIDS for three years now.

A woman answers the phone. It is Rita's

mother who speaks little BATTLES English. Thankfully, her husband is home and she puts him on. Rita may not last the night, can they get a plane? He says something in rapid Spanish to his wife and she starts to shout. Though unable to offer official aid, I tell them the Committee may be able to help them out if they can get a flight. They ring off and I run to PART 4 OF 5 the hospital, shaking slightly after being an

automaton long-distance. Tim is there with Bob Andrews, who also works with AAC. Peter, the Support Services Team (SST) or buddies coordinator at AAC, comes by later as do several of Rita's

friends and former roommates. Rita's friend Jana brings her boyfriend. The grapevine has worked like a charm.

Rita is lapsing into unconsciousness with the pain and meds. Her friends have slipped Southern Comfort into their cokes but she declines a taste. We talk in muted tones, taking turns holding her hand, keeping the washcloth on her forehead damp, sitting

Having just discovered an account of Rita's life in the recently published book by Cindy Patton Sex and Germs: The Politics of AIDS, I've brought it along. Frail and heavily sedated, Rita's eyes flutter as I read her the passage.

It's getting towards 11 p.m. and Tim and I worry her parents won't make it in time. Wearily, knowing I must go back to my internship at the hospital tomorrow, I decide to say good-bye and lift the cloth from her forehead to kiss her. She looks at me as I whisper I love her.

Rita's parents are delayed but make it to the hospital in time to bid farewell. Sad all day, I go about my duties at the hospital, the last place I want to be that day. Tim arranges her cremation and memorial at Emmanuel Church.

It is an eclectic crowd. I stand to read a speech I have written, my first eulogy. With emotion, I talk about my admiration for Rita, some of our times together, and how honored I am to have known her. Tim speaks and then comes the show. It's unclear if Rita's friends will be performing. They are in the front row, dressed to the teeth. My pod, or group of buddies affiliated with AAC, sits further back. AAC's executive director Larry Kessler and Bob Andrews are other familiar faces. I've been unable to find Maya, another buddy to Rita.

We get the tape recorder set up for Le Jazz Hot, one of Rita's favorites, and pause. A beautiful person - I can't tell if she's a woman, nor do I care — rises from her seat and decides to go for it. I move one of the bouquets the Committee has provid-

Shouting "This is for you, Rita," she dances gracefully to the tinny music. The audience claps appreciatively. Tim and I trade grins. This is the wildest memorial I've ever seen and very Rita.

Next, the group is invited to reminisce about her. Peter speaks, Jana rambles, the assembled listen. Amazing Grace is followed by her favorite Mahalia Jackson rendition on Memorex since Tim couldn't recruit any gospel singers. I brush away tears and the celebration is over. Jana kisses us, telling us to keep in touch and Larry asks for a copy of my speech. Peter gives us his patented hugs. My pod and I walk to Montillio's for dessert and coffee. I am glad of the men's company and support. The waiter checks us out. Looking androgynous in my suit, I am what I am. Working with Rita shored that up in a way that's hard to explain.

Over a year later, I see Jana's boyfriend near the bus station. He looks beaten up and leans on crutches. It's a cold night to be hustling. Slowing down, I consider giving him some money but decide against it because I don't want to insult him. He peers at me in the darkness but doesn't place me. I nod to him and walk on.

The "AIDS Scene," circa February 1986, has accelerated. The grief and exhaustion I feel - and aloneness as a lesbian AIDS activist - are harder to fend off. Very busy, I'm more depleted in spirit than in recent memory. Even dancing doesn't seem to help much anymore.

David Aronstein is named Director of Client Services at AAC and Marcia Tanur is Director of Social Services. Peter goes on a long-overdue vacation. David takes over his office the next day. Some of the veteran volunteers have left, others are taking on leadership roles as AAC grows by leaps and

I have received minutes for a planning group on care for PWAs. Marcia, Patrick (the SST chair) and Victor, who weeks later will be the first on staff to die with AIDS, are among the familiar names. Peter has volunteered me for the group and the chair, Stan, is the lover of a man in my pod.

We hear that buddies are being overloaded with practical tasks like laundry, cleaning and cooking and that there is a burgeoning volunteer pool of people with some time available but not enough to be buddies. It is suggested that the work be split so that there are exclusively "emotional" and exclusively "practical" buddies. There is resistance and discourse in the ranks about the specialization of AIDS servicing, the move toward terming PWAs and PWARCs "clients," and perceived differentiation between the "new" and the "veteran" buddies.

I am nominated to chair the new practical support subcommittee-in-the-works. Since I don't have the emotional energy to take another buddy assignment for some time, if ever again, I agree.

In our first official meeting, Patrick leans forward and tells me Bob, who was in buddy training with me, has been diagnosed. Tears well up involuntarily. It is so fucking unfair. After a moment's pause, we begin the meeting. Michael, a PWARC, and Alan, a PWA, have lots to say and we're glad for the input of those who know intimately what is needed.

Meanwhile, several of us SSTers meet to hammer out a statement to Larry Kessler, via Patrick, to the Steering Committee of AIDS Action about the need to address AIDS in political context across agendas. As much as AAC tries to battle AIDS as a single issue organization, the reality is AIDS is not a single-issue phenomenon. At the intersection of sex, drugs, "isms" and death, the AIDS epidemic is a paradigm for much in this society. There are also continuing debates about how to represent the growing community of persons at risk and about AAC events that feature Governor Michael Dukakis (proponent of a homophobic foster care policy) and reflect pricetags out of range for some volunteers and other members of the community.

At the same time, I am still reading Cindy Patton's book on AIDS, which came out in December of '85. Sex and Germs articulates many of the feelings of AIDS activists and it's penned by none other than a former Boston AIDS Action Committee (AAC) Steering Committee member, then co-editor of the lesbian sex magazine Bad Attitude, and a sometime-emergency medical technician. Patton puts AIDS organizing in a context apart from many grassroots issueoriented groups. She notes the reactive, crisis-oriented birthing of AIDS groups in this country and their predominantly white, middle-upper class, gay male composition. Thus, she points out, sexism, classism, and racism fester within the very organizations aimed at serving people with AIDS and those at risk. This means people of color, women, lesbians, and IV-drug users are often neither reached by nor willing to get involved with AIDS groups.

Some of the men I've met assumed the Reagan Administration would pour money Continued on page 7



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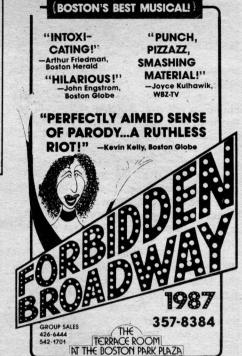
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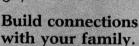
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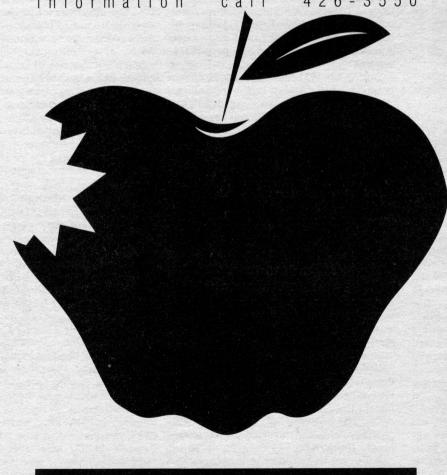
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Demonstration against Mass. Governor Michael Dukakis's homophobic foster care policy, Boston.

Agendas

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into AIDS (after all, it is the number one public health priority). They've been shocked by the lack of concern and by the often vitriolic homophobia offered instead. To use a strong word, their very entitlement fuels their rage, a sharp contrast to activists working in other liberation movements.

I am surprised, given her wide experience, that Patton doesn't specifically address the divisiveness the epidemic has brought to the "lesbian/gay community" and the "women's community" (paradoxic and loaded terms in themselves). As far as I can see, lesbians' relationship to the AIDS epidemic has been almost totally negated. We are called the "lowest risk group" for AIDS as if we are somehow immune, or unaffected or homogeneous. The Centers for Disease Control keep no statistics on us; therefore, we're safe and we don't exist. Lesbians and IV-drug-using women who are PWAs are placed in desexualizing statistical groupings - they are junkies, not heterosexuals, bisexuals or lesbians.

In addition, many of the women who have AIDS have little access to informed health providers, so they may go underreported. The little research that has been done on women and AIDS focuses on women as vehicles for transmission: prostitutes were called "vectors of transmission" at the international AIDS conference and mothers have been called "vessels of transmission" to innocent children.

Yet, even the statistics we do have show that women comprise the fastest growing group of people with AIDS. Women are also among the primary caretakers of people with AIDS and lesbians are deeply affected by the homophobia surrounding the disease.

Ironically, some within the women's community also argue that AIDS is not a women's issue. There is even the accusation that women working on AIDS do so at the expense of women's causes or in service to patriarchy. At the same time, many lesbians including AIDS activists - wonder whether gay men would rally financial and other support for their "gay sisters" if AIDS were indeed affecting us to the extent it has gay and bisexual men.

In Boston, the SSTers at AAC decide to take on a number of issues. In early February of '86, I type up our st have already spoken privately with Larry and now four of us go on record: John, Katie, Paul-David and I. (See letter, p. 10.) Others, including some on staff, voice support. Larry agrees to meet with us. Paul-David is not present and David Aronstein sits in at Larry's behest. We present our case. On the subject of the Governor's homophobic foster care policy, we are told Steering believes it is not in the interest of AAC or the people we serve to take a stand. I argue not making any statement amounts to "taking a stand." Katie cautions me on my "confrontational" tactics later. Angry, I tell her confrontation is sometimes necessary. Besides, I have proven by work and energy how committed I am to people with AIDS and at risk and the work of AAC.

In March, William Buckley pens his infamous column calling for tattooing "AIDS carriers" and there is more than talk about mandatory testing in the military, of immigrants and for prisoners. Frontline on PBS finally decides to take on AIDS. The

report is exploitive, featuring a Black gay man who is homeless, has AIDS, and hustles for survival. The film crew doesn't make any attempts to direct him to services, though. Officials are trying to quarantine him and he seems to be suffering from CNS (Central Nervous System damage). Activists protest the television showing around the country. Public Image Limited's refrain 'Anger is an energy" from their anthem "Rise" plays repeatedly in my mind.

John and I decide to organize about AIDS politics outside AAC in an attempt to appeal to a larger constituency. Letters and notices are sent out for our first forum on the politics of AIDS; Kevin Cathcart of Gay and Lesbian Advocates and Defenders (GLAD) agrees to speak. Some twenty men and I meet. I'm disappointed no women and no press come, pleased to see Michael and Alan present and vocal. There is one man of color, who has been in prison and is the only non-AAC-affiliated person. My friend Mary, a Northeastern Law student (who is straight) comes into the room and promptly leaves, "overwhelmed" by the men.

Cathcart discusses the groundwork being laid for military testing, insurance discrimination and redlining gay neighborhoods. It is not an optimistic report. Several men speak articulately about the politics of treatment protocols. Others, including Andrew, a former buddy and now an advocate on staff, and Dmitri from SST, talk about the sense of futility and depression. Five people attend the next meeting. Eventually, John and I and Dan, his friend who's joined us, give up on a formal "AIDS Political Front." Thus far, everything Kevin has discussed, short of quarantine, has occ-

It's another all-day Saturday meeting of Client Services and I am representing Basic Services Team (BST). We are brainstorming task forces for groups needing specific attention. IV-drug users, people with ARC, the homeless.... Someone says children, another, women. David says women and children and begins to write as if it is one task force. Marcia objects, as do I. We make a case for two separate task forces. For one thing, all women don't have kids.

Saturday at AAC and we are interviewing the last few candidates for the next SST training. Tim, Patrick and I have just finished interviewing Ken, who is part of the nascent Rhode Island Project AIDS (RIPAIDS).

Gail, another staffer at AAC, calls me into a nearby office. Thom, the lover of a man I had been buddies with (Charlie), is in intensive care at Mass. General. I had no idea Thom was sick. He is allowed no visitors. I contact Jason and Bob, who are lovers and used to be Charlie's roomates, asking them to let me know when the memorial will be. I've been thinking of them lately because it was last year around this time that Thom's beloved Charlie died.

The memorial invitation this spring is lavender.

I receive the winter issue of On Our Backs. Given how often we lesbians deny our sexuality in service of progressive causes, a subscription is one small measure of resisitance. There is an article on lesbians and AIDS. Reading through the safe sex guidelines, I'm jolted by a reference to menstrual blood. Of course. It hadn't even occurred to me and I've been doing this work for years. Hurriedly, I make copies for Patrick, Anne (AAC's Health Education Director) and Marcia, then write the magazine to thank them and request reprint permission.

In May, off our backs finally runs something on women and AIDS, declining to publish the On Our Backs guidelines because they deem them "too vague and broad to be useful." I'm angry because there is so little information out there. At AAC's Mental Health and AIDS conference I attend local physician and activist P. Clay Stephens' workshop on Women and AIDS. I'm pleased to meet another sex-positive feminist doing AIDS work. She hands out the On Our Backs guidelines.

I go to the Steering Committee in April with a formal request for Basic Services representation on the board. I've been told there may be objections because there are now so many AAC subcommittees represented; staff is approaching 20 people and the volunteer pool is over 500. As chair of the BST planning group I've already been Continued on page 10



Oprah

Continued from back page

ly as a therapist. Joanne was very endearing and funny and looked lovely in her string of pearls. She made good points about lesbians being women who love women (not who hate men) and about how we're people trying to survive just like anyone else.

I have to admit, there were some very nice moments on the show. At one point the camera pulled back and you could see that all the panelists were holding hands. When Pat described coming out to her teenage daughter who hugged her and said, "Mom, I'm so glad you're finally happy," I nearly cried (although I have to admit here that I am a first class sap). But for the most part, this program was a circus. Oprah Winfrey was the perennial devil's advocate, no matter whom she was talking to. "Why do you look so butchy?" she asked from the audience. But later, when a Black woman in the audience said "The first three [Sara, Pat, and Maria] I appreciated, but you three over here got it all wrong," Oprah said "Why, because they don't behave like you?" There were the usual statements from call-in and audience members of the god squad, and a whole bunch of run-of-the-mill questions from callers and people in the studio who were as curious as they were

I was glad to hear women on national TV proclaim how much we want each other (although they hardly talked about sex). But to be honest with you, the medium is still the message, dykes or no dykes. Oprah Winfrey sells a lot of soap. And I still have the flu.

Agendas

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sitting in on Steering Committee meetings every two weeks. Aside from Rhonda, who chairs Mental Health and is the grande dame of AAC, the only other subcommittee chaired by a woman is Wholistic Therapies with Hara Klein as their part-time staffer. Brianne Comella, R.N., is the new IV-drug health educator; the "Minority Concerns" subcommittee comes together and is officially sanctioned; and Liz Page presents plans for the upcoming Walk for Life fundraiser. Basic Services is voted on board.

There is talk more staff advocates for PWAs are needed and discussion of the role of staff in a largely volunteer organization. I'm going to as many as four meetings a week with SST, BST and Steering. Friends kid me I may as well be on staff and get paid for all the time I'm putting in on top of school and work for pay. The thought has crossed my mind. When more staff advocate openings are foreseen in the next few months, I consider applying though it would be a job and my second internship for my Master's. Marcia, who has been on BST with me, is encouraging. I anticipate some of the concerns — my politics, my mouth. But I apply, tell my closest friends, and wait for an interview. School ends. Joe, formerly of my pod and an editor of the SST Express newsletter, calls and says they'd like to feature me as the "Do-er's Profile" in a special "women's issue."

A UCLA study and a Los Angeles *Times* poll finds that the public perceives lesbians to be in the same "high risk" category for AIDS as gay men. The non-profit lesbian educational organization, Southern California Women for Understanding reports a national insurance company is moving to screen clients whose lifestyles it decides may be at risk for AIDS. The profile of a highrisk individual is a single adult, between the ages of 20 and 50, who lives in a large metropolitan city. Specifically, it targets anyone who lives "an illicit lifestyle"

and/or names someone other than spouse or child as beneficiary.

Stan, chair of the Search Committee, Marcia, Andrew, Dmitri, and Alan interview me. It is friendly and we chuckle when I'm asked to describe why I want to work for the AAC. Alan asks me some questions about how I'd fare given my politics. I strive to make it clear my priority is PWAs, PWARCs, those deemed infected and at risk. I feel good about the meeting.

Dmitri asks me to list my references and I name Fred, my old boss. Then there's my supervisor at the hospital, though I'm a bit wary given her hesitation about the prospect of my second placement combined with a job and her objections to my seeking an alternative internship at Gay and Lesbian Counseling Services (GLCS) because "it will limit career opportunities." Finally, Peter or Leo from the Committee know my work. Allowing myself some optimism, I wait to

icai.

Letter to AAC

February 3, 1986

Larry Kessler, Executive Director AIDS ACTION COMMITTEE and Patrick Riggs Support Services Team Chair/ Representative to the Steering Committee 661 Boylston Street Boston, MA 02116

Dear Larry and Patrick:

We, members of the SST/AIDS Action Committee, feel the time has come for those of us with political feelings around AIDS to get together and address certain issues which face all of us now, have in the past, and will further down the road.

The AIDS Action Committee has a stated goal to be accessible to all people in the community regardless of racial, ethnic/cultural background, sexual preference (etc.). At the same time, we need to remain accessible and sensitive to the community and to those volunteers who make up the backbone of the Committee. These are predominantly gay men, lesbians and straight women. One element which all three groups share is that of oppression in American society. Out of this experience a certain sensitivity enables us to acknowledge each other's differences and recognize each others' needs for support and mutual respect.

The need for active fundraising and participation in the mainstream is crucial to the Committee's continuation. Equally important is active recruitment of volunteers who reflect the socioeconomic, racial and sexual make-up of the community we seek to serve. To that end, we must be very careful that in our fundraising efforts and in our statements (or non-statements) to the press we do not alienate the community of persons who make up the Committee "workforce". As members of that voluntary contingent, we feel that to serve more effectively we need:

- 1. Always strive to be representative of the com-
- 2. To remain sensitive in all our dealings with issues of classism, racism, sexism and other forms of oppression so implicit in meeting the needs of persons with AIDS, the gay/lesbian and larger communities and our diverse workforce.
- 3. To avoid the use of the Committee in name or function as a forum to legitimize those persons who oppress members of our community. This item specifically refers to the Committee's invitation to Governor Dukakis to "keynote" past fundraising efforts (ARTSCetera). His presence at these events furthers a political strategy that says he is not anti-gay while he endorses a foster care policy which is anti-gay, anti-lesbian, and anti-single parent.

While we recognize the Governor has been accessible to the AAC in terms of funding, his foster care policy implicitly and explicitly allows discrimination against the above groups and furthers stereotypes played upon by those members of the legislature; press, and public who believe we are unfit to be parents; who play upon the AIDS crisis to crush human rights legislation efforts in the Commonwealth; and who have the power to quarantine persons with AIDS.

If we turn our backs on issues which affect our community to the extent that the foster care policy and human rights legislation do, we undermine the interests of gay men, lesbians and single women. In short, we sell ourselves out for a price.

There is always a need to compromise, especially when we serve a community as large and diverse as that served by the AIDS Action Committee, but there is a point at which we must take a principled stance. We feel a non-discriminatory foster care policy and human rights protection are central to *all* our interests and it's time for us to make our feelings known to you and the Committee at large.

Respectfully submitted,

John Paul-David Marea

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