

AIDS ACTION NOW!

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AIDS ACTION NOW! POLICY OPTIONS '91

AIDS ACTION NOW!'s Policy Options '90 focused on three major areas: the political organization of AIDS ACTION NOW!; the politics of treatment; and the politics of clinical trials. At the recent AIDS ACTION NOW! retreat attended by about 25 members, the general feeling was that our organization is strong. Still, many old challenges, especially in the areas of treatment and trials remain to be met, while new challenges, particularly those dealing with the various HIV affected/infected communities, are presenting themselves to our attention.

1.0 POLITICAL ORGANIZATION

1.1 Internal

AIDS ACTION NOW!'s constitution guarantees that a majority of HIV+ individuals are members of the Steering Committee, in keeping with our policy of accountability to PLWA/HIVs.

Effective communications within AIDS ACTION NOW! continue to be a priority. Communication between standing committees and the Steering Committee need to be strengthened, as well as communication with our membership. Monthly open meetings will continue to be an important forum for dialogue and information sharing. Other ways of making our interorganizational communication more effective involve strengthening the phone tree and revising our mailing lists. A "buddy system" which would pair new members of AIDS ACTION NOW! with more experienced members would enhance information sharing and improve the accessibility of AIDS ACTION NOW!.

1.2 External

As PLWA/HIVs are increasingly represented on the external boards and committees of organizations making decisions which affect our lives, the issue of their accountability to the organizations they represent becomes important. We must continue to work with other AIDS organizations in order to determine the means of ensuring accountability. At the same time, AIDS ACTION NOW! should continue to support the National HIV Network which is responsible for National boards.

2.0 POLITICS OF TREATMENT

2.1 Confront restrictions limiting EDRP release to ensure recognition of catastrophic rights for all PLWA/HIVs

As we have seen with the release of ddI and ddc, the EDRP has not thus far proven to be an effective treatment alternative to participation in clinical trials. Pharmaceutical companies have established criteria for the release of treatments under the EDRP that makes them available only to people excluded from the trials. The distinction between clinical trials and treatment must be enforced. PLWA/HIVs should not be forced into trials in order to get treatment. AIDS ACTION NOW! will have to consider in the forthcoming year whether a body other than the EDRP is best suited for pursuing the catastrophic rights of PLWA/HIVs.

2.2 Improve flexibility of the Provincial Funding Programs to include new, experimental, complementary and nutritional therapies

The province's programs must be expanded to acknowledge the variety of treatments which PLWA/HIVs are using in their efforts to make HIV a chronic illness. The process by which treatments are added to the drug formulary must be streamlined. AIDS ACTION NOW! needs to continue to work with anti-poverty groups such as Bread not Circuses to ensure that AIDS is represented as a poverty issue. The province's Drug Assistance Program must reflect state-of-the-art HIV treatments being used in the HIV community. The costs of treatments must be subsidized or otherwise regulated so that people are not forced by prohibitive costs to go on assistance in order to get treatments.

2.3 Continue our work on Anonymous Testing

Although the battle for anonymous testing appears to be won, it is important that we participate in the implementation of strategies that will ensure province-wide accessibility to anonymous testing and counselling services. And although anonymous testing may soon be more widely available, it is important to continue to fight for the principle of anonymity, and against surveillance, in various aspects of HIV testing and treatment. We believe that the assurance of anonymity leads to early testing and that early testing is crucially important in the management of HIV illness.

2.4 Continue to participate in the National Treatment Registry

One of AIDS ACTION NOW!'s most important successes in 1990 was the federal government's decision to implement a National Treatment Registry, a proposal which we initiated. We must continue to fight for those aspects of the National Treatment Registry which are most important to the HIV/AIDS community: accountable representation by PLWA/HIVs on boards and committees relating to the National Treatment Registry; access to the treatment information it provides by both doctors and patients; provision of information support to HIV physicians.

2.5 Physician Support

HIV physicians need to be compensated accordingly for the extra paper work, counselling, education, etc. that they undertake with their HIV patients. According to the current OHIP billing system they are unable to bill for this. Revision to the OHIP schedule that reflects the extra time spent by HIV physicians should be examined. HIV physicians should be supported by data collectors, and should be able to better access training and upgrading that would add to the current model of palliative care a model of active, aggressive treatment.

2.6 Expand and support AIDS ACTION NOW!'s Treatment Information Exchange (TIE) project

In 1990, the Treatment Information Exchange (TIE) Project hired a full-time staff person, Eric Mitchell. In 1991, we would like to make funding available for a second staff person, who would perhaps focus on volunteer coordination.

Treatment Update/Traitement Sida should continue to be published bilingually. A similar publication which deals exclusively with complementary therapies in the treatment of HIV might be initiated this year.

It is important to get the MEDLOG database up and running as soon as possible, to collect information profiles about therapies being used in the community.

A final goal for the TIE project concerns the accessibility of its information resources. Work will be done to increase its profile through workshops, videos, outreach, and effective management of volunteer staff.

2.7 Establish minimum standards of care for PLWA/HIVs in hospitals and medical practices

While hospital care of PLWA/HIVs continues in general to improve, standards of care vary widely from hospital to hospital, even within Toronto. Abuses are all too common. Diagnosis of opportunistic infections and treatment of patients with HIV is inconsistent; hospital staff, physicians and researchers overburdened in their work load and often undertrained. AIDS ACTION NOW! would like to see the mandatory training of medical students in HIV illnesses.

3.0 THE POLITICS OF CLINICAL TRIALS

3.1 Work with the Clinical Trial Network and the Community Research Initiative of Toronto (CRIT) to ensure ethical drug trials

Voluntary informed consent is the foundation for ethical drug trials. AIDS ACTION NOW! needs to continue to work with the Clinical Trials Network and CRIT to design a consent form for use in trials. This consent form would outline the distinctions between trials and treatment. Treatment would be available outside of the trial and the patient would be aware of how to

access it. The person entering the trial would be aware that s/he was doing so not primarily to get treatment but to test a pharmaceutical product. The issue of readability is also important here. Comprehensible consent forms assist voluntary informed consent. They should also be available in at least the two official languages of Canada.

3.2 Confront pharmaceutical companies on issues of access to treatments

If the distinction between treatment and drug trials is to be enforced, and people not forced to enter trials in order to get treatment, then AIDS ACTION NOW! must actively confront those pharmaceutical companies which place limitations on patient access. Pharmaceutical companies like Bristol-Myers in its release of ddI have compromised the use of the EDRP as a mechanism for accessing experimental treatments outside of clinical trials.

4.0 THE POLITICS OF SOCIAL SERVICES

4.1 Guarantee adequate levels of support for PLWA/HIVs unable to support themselves

Few PLWA/HIVs understand how to fully access the social services system. AIDS ACTION NOW! needs to improve its understanding of the system of social services in order to play an effective advocacy role. We also need to build coalitions with anti-poverty groups, other AIDS organizations, and other social justice movements which have experience in acting as brokers between PLWA/HIVs and social service organizations.

5.0 THE POLITICS OF AFFECTED/INFECTED COMMUNITIES

5.1 Reiterate "The Montréal Manifesto/le Manifeste de Montréal"

AIDS ACTION NOW! stands by the demands of "The Montréal Manifesto/ le Manifeste de Montréal", which is a declaration of the universal rights and needs of PLWA/HIVs. This document was prepared by AIDS ACTION NOW! and ACTUP New York for distribution at the Fifth International Conference on AIDS, held in Montreal in June 1989.

5.2 Push for the inclusion of sexual orientation in the Canadian Human Rights Code

This guarantees basic human rights to lesbians and gays.

5.3 Oppose discriminatory immigration requirements

HIV testing should not be part of the battery of medical tests to which potential immigrants to Canada are subjected. AIDS ACTION NOW! is aware that HIV testing is used to threaten and coerce immigrants and visitors to Canada.

5.4 Join with prison reform groups to exert pressure for proper care, treatment, access to education and prevention in the prison system and other institutions

PLWA/HIVs in the prison system and in other institutions should have equal access to education and prevention in terms of safer sex and safe drug use, and to standards of care and treatment of HIV illness. AIDS ACTION NOW! should continue to work alongside prison reform groups and with PLWA/HIVs who are or have been inmates in order to renew our pressure on this front.

5.5 Strengthen our understanding of AIDS in developing nations

AIDS ACTION NOW! has informally exchanged information with individuals involved in AIDS organizations in developing countries such as Trinidad and South Africa. These contacts have enabled us to understand the global and specific impact of AIDS and HIV, and the differences in concepts of treatment in different cultures. We would like to continue to build on this dialogue in the coming year.

5.6 Identify and explore issues of women living with HIV and AIDS

AIDS ACTION NOW!'s Women's Caucus has recently formed and has begun to examine resources for women living with HIV and AIDS, and to compile treatment information. December 1st 1990, World AIDS Day, focuses this year on women and AIDS. This presents us with the opportunity to foreground women's issues and to examine the particular role which the Women's Caucus may play in relation to other AIDS organizations providing services to women.

5.7 Cooperate with AIDS projects in marginalized HIV communities

AIDS ACTION NOW! seeks to work closely with HIV groups in Toronto's Asian, Black, First Nations, Francophone, and gay and lesbian communities and with organizations working with homeless and street people, youth, injection drug users, prostitutes groups, etc. to ensure that we understand the issues of these communities and are able to effectively involve their issues in our work when appropriate.