AIDS ACTION NOW!

Mandate

a) to improve the availability of drugs and treatments for people who are living with AIDS or HIV infection;

b) to improve the standard of care for people living with AIDS or HIV infection to meet their health-care needs;

c) to support progressive AIDS and AIDS related initiatives launched by other organizations and individuals;

d) to undertake any other activities that AAN! thinks will improve the quality of life for persons living with AIDS or HIV infection.

AIDS ACTION NOW!

Policy Options '90

Prepared for AAN!'s Annual General Meeting,

Church Street Elementary School
October 11th, 1989

Last year, the Annual General Meeting of AIDS ACTION NOW! approved a seven-point policy, supporting people with HIV infection with the aim of making AIDS a chronic but manageable illness. Progress has been made on a number of fronts, but our goal of transforming the approach of both doctors and patients alike to HIV infection has not yet been reached. Below we have set out a number of goals to work for in 1990.

While real progress has been made--for example, the release of DDI--problems have turned out to be a good deal more complex, and consequently, not easily resolved. Sometimes we have solved one problem only to create two more, as is the case of the federal Emergency Drug Release Program (EDRP). Now that the EDRP can be used to get new experimental AIDS drugs, problems have arisen with pharmaceutical companies who are not prepared to supply them, or doctors who are not prepared to prescribe them. Sometimes, what we thought was a solution to a problem has turned out to be a rather naive remedy. This turned out be the case with our demand that PLWAs be on all boards and committees concerned with the treatment of people with AIDS. What turned out to be needed was not just a PLWA, but a PLWA who is accountable to the community of people with AIDS or HIV infection.

The following overview of policy issues is put forward by the Steering Committee of AAN! as a basis for discussion and adoption.:

I. Political Organization

A. Restructure AAN! to improve access by PLWAs/HIVs

A restructuring of AAN! has been proposed that is designed to make the organization more accountable to PLWAs/HIVs. It has been suggested, for example, that meetings of PLWAs/HIVs and their supporters be held on a monthly basis to establish policies and strategies for AAN! to improve the delivery of treatments to PLWAs/HIVs.

B. Make Sure PLWAs/HIVs Sitting on Boards and Committees Are Accountable to Those They Represent.

It is proposed that procedures be established so that PLWAs/HIVs sitting on external boards and committees can be held accountable for the decisions they make on behalf of all PLWAs/HIVs. In the past, AAN! has demanded that PLWAs sit on boards and committees that are dealing with the health and lives of people living with AIDS. This should include any body that is dealing with any aspect of AIDS treatment, including hospital care, home care, human rights or education about AIDS.

There is a slow but gradual recognition of the rights of PLWAs/HIVs to sit on committees. However, we now face the problem of making sure that these individuals operate as representatives of PLWAs/HIVs and do not simply advance their own opinions. What is being proposed is that we work with other PWA organizations to

develop a system of accountability to make sure that these individuals function in the best interests of the people they represent.

C. Help in Creating a National PLWA/HIV Network

In conjunction with the last proposal, the Vancouver PWA Society, formerly the PWA Coalition, has instigated the creation of a new national network of PWA organizations to develop the political influence of PLWAs/HIVs on AIDS policy both nationally and provincially. This organization would be responsible, among other things, for establishing how PLWA representatives will be appointed and held accountable. It would also be responsible, for example, for making sure that clinical trials of pharmaceutical products are conducted in an ethically proper manner. It is proposed that AAN! help establish this coalition.

D. Act as Advocates of PLWAs/HIVs Incarcerated in Correctional Institutions on Issues of Treatment, and to Work to Make Sure Their Medical Care is as Good as that Received by People Outside Prison Facilities.

Last year AAN! protested the treatment of PLWAs in the Ontario correctional institutions. This resulted in a promise by provincial authorities to provide AIDS education to correctional staff, and to ensure that prisoners received the same standard of HIV-care received by PLWAs outside the prison system. In this process, AAN! also developed a working relation with the Ontario Public Service Employees Union, and the leadership of the union local representing the guards at the Don Jail. Important follow-up work must now be undertaken to insure that the government and the union are fulfilling the commitments they made last year.

E. Support Efforts to Improve the Diagnoses and Treatment of Women With HIV Infection.

Up to this time, work on the diagnosis and treatment of HIV infection has focused almost entirely on this disease in men. For a variety of reasons, the symptoms of HIV infection and its treatment are different for women. One result of this situation is that women are often diagnosed far later in their disease than men, making it more difficult to arrest the progression of the disease.

F. Work, in Cooperation With Other Community AIDS-support Groups, to Provide Treatment Information and Support to Other Communities Affected by AIDS, Including: People Who Use IV-drugs, the Women's Community, youth groups, the Black and Asian Communities etc.

In the beginning AIDS was described as a disease of gay men--a view reinforced by the fact that in Canada 85% of all AIDS cases are to be found among gay men. AIDS ACTION NOW! was created by gay men with AIDS or HIV infection and their supporters with the aim of improving access to better medical treatment. For political reasons it was seen to be important that AAN!, as an organization, be out of the closet as a gay community group. We know, of course, that AIDS is not a gay disease. Without forsaking its gay roots, AAN! recognizes the need to work cooperatively with other AIDS organizations from other communities in the struggle to make AIDS a chronic but manageable illness.

G. Help meet the AIDS crisis in the Third World

At the V International Conference on AIDS in Montréal in June AIDS ACTION NOW! along with ACT UP New York issued Le Manifeste de Montréal in which we called upon the federal government to do more to meet the crisis of the AIDS epidemic in the Third World. It is proposed that, for its part, AAN! investigate the possibility of establishing links with one Caribbean or Latin American AIDS action group with a view to determining if we could make a contribution, in terms of our areas of interest, to the fight against AIDS in these countries. The possibility of such a linkage would depend upon whether or not the kind of contribution we could make is needed.

H. Begin Planning for the VI International AIDS Conference in San Francisco

It became clear from AAN!'s participation in the V International AIDS conference in Montréal that people with AIDS or HIV infection have to participate in these conferences to counter homophobia and other forms of discrimination against prostitutes, prisoners, and IV drug users that shape the reporting of AIDS research. Scientists conducting this research are often completely out of touch, carrying out their research as part of a plan for their career advancement rather than as helping those who are infected, sick, or critically ill.

It is proposed that AAN! establish working relationships with US PLWA/HIV groups as part of planning political initiatives for or around the San Francisco conference next June.

II. The Politics of Treatment

A. Access to Treatment

1. Defend the Catastrophic Rights of PLWAs/HIVs

PLWAs and others in catastrophic life-threatening situations have an unrestricted right to treatments which they and their physicians believe to be beneficial. This includes access to and availability of all drugs and treatments that can be used to treat HIV-positive people and people living with AIDS.

This argument for catastrophic rights has been launched in Canada by the British Columbia Civil Liberties Association. The argument is a strong one, and one that AAN! supports. This argument has come under increasing attack, however, by researchers involved in the testing of pharmaceutical products (i.e., new drugs) because it denies them the ability to force PLWAs/HIVs into clinical trials to get new, experimental AIDS drugs.

2. Work to Maintain and Expand the Emergency Drug Release Program (EDRP)

The EDRP was established, historically, to provide treatments, not approved by Canadian authorities, to people who were ill with unusual diseases not common in Canada. The release of drugs under the EDRP are normally approved on compassionate grounds. At the beginning of this year, the federal government agreed to release new, experimental AIDS drugs, such as aerosolized pentamidine, and alpha interferon, through the EDRP.

Although it is useful to collect data on people who take AIDS treatments under the EDRP, it is important that the EDRP not be turned into an open-arm clinical trial. This has already happened in the release of DDI. Clinical trials and the EDRP must remain separate and distinct. There is reason to believe that researchers interested in testing new drugs want to push back the gains made earlier this year by preventing PLWAs/HIVs who need treatments from getting them from the EDRP. They want this change so that they will be able to force people who need treatment to join clinical trials. Because the EDRP operates on compassionate grounds, it is extremely important to the protection of the catastrophic rights of PLWAs/HIVs.

3. Work to Ensure that Provincial Drug Assistance Programs Provide Adequate Coverage for PLWA/HIV Needs.

At the moment, the government of Ontario has refused to pay for AZT that is used for early intervention in HIV infection. And while areosolized pentamidine is available free in Toronto, this is not the case across the rest of the province. Lastly, the provincial government is presently studying what drugs will be included on the province's drug formulary (the list of drugs for which the province pays in the case of individuals on social assistance, among others). Results of this study have 1) posed new limits to the number of drugs on the formulary, 2) instituted new bureaucratic procedures for approving the inclusion on new treatments on the formulary; and 3) guaranteed only a one year extension for nutritional supplements (e.g., vitamins, Ensure, etc.)

It is important that all promising AIDS treatments be paid for by government, that mechanisms be devised for fast-tracking the process of putting new treatments on the provincial formulary, and that the inclusion of nutritional supplements be extended.

4. Support the fight for Anonymous Testing

The first step in the treatment of HIV infection is for people to be aware of their HIV status. That is, they have to know if they are infected or not so that they can begin early intervention if it necessary. The lack of facilities for anonymous testing is a major impediment to people knowing their HIV status. At present Hassle Free Clinic is the only site of anonymous testing in Ontario, and there is pressure both from within the Toronto Department of Health and the Provincial Government to close down this facility. Without an anonymous testing site, the lives of people with HIV infection will be cut short because intervention in their illness will be delayed usually until the occurrence of their first opportunistic infection.

B. The Management of Treatment

1. Work to Ensure the Development of a Federal/Provincial Support System for the Delivery of Treatments to PLWAs/HIVs

At the present time, there is no support system for the delivery of AIDS treatments to PLWAs/HIVs in Ontario. There are, for example, no standards of care. There is no group of specialists dealing with the various AIDS opportunistic

infections providing a high level of medical support to primary-care HIV physicians, as is usually the case with other illnesses. More and more primary-care physicians in Toronto will have to become involved in AIDS medicine, yet there is nowhere they can turn to upgrade their medical knowledge of AIDS. To make matters worse, doctors with AIDS patients tend to lose money because these patients take a lot of time that cannot be billed to OHIP.

It is proposed that AAN! require both the federal and provincial governments, faculties of medicine etc. to provide support to doctors treating people with HIV infection. This would include: up to date information, development of standards of care for HIV illness, development of a national treatment registry, a system of computer conferencing and access to on-line AIDS treatment data bases etc

2. Demand the Establishment of a National Treatment Registry

A national treatment registry should be established. Such a registry would be composed of a variety of treatment protocols thought to be of use in treating people living with AIDS or HIV infection. Primary-care physicians would access this registry with inquiries for treatment protocols to suit the individual needs of their patients. Reports to the registry of individuals' treatments and health status would be made on a continual basis. These reports would be used to modify protocols and to identify those that were effective.

3. Work to Develop a computer conferencing facility, and a computer data base on the latest information in AIDS treatments for HIV physicians'*

Computer conferencing requires each doctor to have a computer and a modem. Doctors are able to access a central computer where they can ask questions of their colleagues, answer questions, or just talk about proposals for treatment etc. Doctors can do this at times which fit their own schedules. It could be done once a week, or at the end of each day, etc. This dialogue would be recorded on computer disk and could be searched using key terms etc.

The Medical Publishing Group in the US, connected to the *New England Journal of Medicine*, puts out a CD-ROM computer disk that contains the AIDS Knowledge Base electronic textbook from the San Francisco General Hospital, the MEDLINE AIDS, and AIDS data-base of the Bureau of Hygiene and Tropical Diseases among other sources of information on AIDS. This is just one of a number of computerized sources of medical information on AIDS. HIV physicians would be able to access this information on AIDS using computers in their offices

4. Develop a Treatment Information Exchange for PLWAs/HIVs*

AAN! is proposing to develop a computer-based system for voluntary, anonymous monitoring of PLWAs/HIVs who are engaged in using various treatment regimens, both traditional and complementary, to treat their HIV infection. The aim of this program would be to collect anecdotal information on what

*items are part of the Trillium Project Mandate

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regimens appear to be efficacious, and to make this information available to other PLWAs/HIVs.

5. **Continue the publication of *TreatmentUpdate/TraitementSida****

Since the spring of 1989, AAN! has published TreatmentUpdate, reprints of which appear in *Xtra* and *Rites* magazines. *TreatmentUpdate/TraitementSida* is published in both English and French. It reviews developments in AIDS treatments in 90 medical journals most concerned with HIV medicine.

6. **Work to encourage HIV physicians, in treating individuals with HIV infection, to move from a palliative care strategy to a treatment regimen for managing a chronic illness.**

So long as doctors believe that AIDS is a fatal disease they will continue to treat PLWAs/HIVs simply as people waiting to die. This kind of thinking means that they will intervene to curb opportunistic infections, but do little more. In other words, they will only intervene to give a kind of palliative care. AAN! believes that this form of treatment is not adequate. Physicians should intervene in the progress of HIV infection with a view to extending the life of the patient. This framework requires taking on AIDS as a chronic but manageable illness. Restoring a PLWA/HIV to health is not simply a matter of patching him or her up to survive another opportunistic infection. Rather the treatment of AIDS, as those who are surviving have found out, requires total health care.

7. **Demand Improvement in Hospital Care of PLWAs**

While the hospital care of PLWAs has improved over the past year, it is still the case that hospitals in Toronto have still not developed state-of-the-art diagnostic and treatment protocols in handling patients with HIV infection. It also appears that it is still the case that hospital staffs are undertrained in handling patients with HIV infection.

III. The Politics of Clinical Trials

A. Work to Develop the Procedures to Ensure Voluntary, Informed Consent for Clinical Trials of AIDS Pharmaceuticals

AAN!'s position on clinical trials for new experimental AIDS treatments is that individuals who participate in these trials should not do so to get treatment, but to help in the fight against AIDS. In other words, people should not be forced into clinical trials to get treatment. The purpose of a clinical trial is not to treat individuals, but to test a pharmaceutical product. What this means is that the health of the patient is not paramount in a clinical trial. In treating a patient, the physician in charge should be able to regulate dosage (a good example here is AZT), and try out combinations of drugs. Both these options are impossible when what a physician is able to do is limited by the clinical trial protocol.

The AIDS research community in Canada has not, as yet, understood the ethical issues surrounding clinical trials. A hopeful sign is that there is a move now to clear clinical trial protocols with representative PLWAs/HIVs. AAN! should take part in these discus-

sions to assure that clinical trials in Canada meet the highest ethical standards which includes not forcing patients to take part in clinical trials in order to get treatment.

B. Work to Ensure That PLWAs/HIVs Have Access to New, Experimental Treatments Independently of Clinical Trials

The establishment of the use of the federal EDRP for the release of new, experimental AIDS treatments has made it theoretically possible for Canadian PLWAs/HIVs to get new, experimental AIDS treatments without joining clinical trials. At the moment, this mechanism is being compromised by the release of DDI where limitations have been placed on patient access to this drug by Bristol Myers. These limitations have turned the EDRP into an open trial arm (i.e., a clinical trial where there is not a control arm, i.e., placebo, comparative, or historical). AANI believes that it is important to restore PLWA access to treatments through the EDRP. This is an important program because it prevents people from being forced into clinical trials to get treatment.