

Drugs, hospital care, activism define AIDS Action Now!

TORONTO—AIDS ACTION NOW! held its first annual general meeting on October 6 with about 75 people attending at the 519 Church Street Community Centre. Items on the agenda included a report on progress, a seven point program for policy direction (see below) and the election of a new steering committee.

Activism = life

The meeting opened with greetings from other AIDS organizations. Art Wood, the chair of the AIDS Committee of Toronto, brought congratulations for the political work that AANI does and said that he sees the work that the two groups do as "complementary." Jeff Braff, the newly elected president of the Canadian AIDS Society, gave a short history of the CAS stressing that its role is to provide "strength of unity without taking away from the autonomy of the individual community groups" that make up the CAS. Pointing out that AANI demonstrations show that "activism = life," Braff said that

AANI had had a real effect on the federal government. Jake Epp's recent announcement that he was setting up a working group to look at AIDS issues is, according to insiders, a direct result of heat resulting from AANI's earlier actions, including the burning of the minister in effigy in May. This working group, with Braff as one of its members, will be reporting directly to the minister and will not, in Braff's words, "be a whitewash."

Early treatment

George Smith then gave a talk stressing that AANI's most important task is to focus on treatment and that this means early intervention. Said Smith: "You get AIDS when you become infected with HIV. Early intervention improves results."

In the immediate future, AANI will be organizing around the consensus conference that the province has organized for December which will look to standardizing the quality of care people with AIDS receive in different hospitals; dealing with the federal election in

which all three parties have agreed that AIDS should not become an issue; and waging a public campaign against the use of placebos in the recently announced trials of five AIDS drugs.

Intolerable conditions

Members of the meeting also heard stories of the terrible care and treatment that people living with AIDS are continuing to receive. Ned Lytleton, a counsellor with AIDS Support, said that "PLWAs are treated in hospitals as if they were already dead." Although he hears some good stories about care people receive, Lytleton says that there is no hospital with a universally good reputation and PLWAs face constant "subtle and not-so-subtle homophobia". Chuck Grochmal then described a new group, Citizens' AIDS Review Committee, that has just begun and will be looking into some of the intolerable conditions existing in hospitals.

After adopting the seven point policy programme the meeting

Patients' rights advocated in AANI policy program

AANI POLICY PAPER
The following AIDS ACTION NOW! Policy Paper was adopted by the general membership of AIDS ACTION NOW! at its Annual General Meeting on October 6, 1988.

Advances in the fight against AIDS have brought us to the point where we can begin to look at AIDS as a chronic illness rather than a universally fatal illness. Unfortunately, we are still faced with a variety of problems that prevent us from adequately dealing with it as such. AIDS ACTION NOW! has come up with seven main policies that would make treating AIDS as a chronic illness a reality. We list them here and plan to fight for their adoption in the year to come.

Catastrophic Rights

People living with AIDS 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. These drugs should be available free of charge—even when they have not been given government approval for regular distribution. People in life-threatening situations do not need to have their treatments hampered by government bureaucracies or medical researchers who work within the government's restrictive regulations. The policies that they have in place are clearly designed for situations that are not life-threatening.

When people discover that they are HIV-positive they are faced with many decisions regarding their health care. These decisions, which can be life and death

decisions, are now made in a situation that does not allow for the full range of treatment possibilities. Our government continues to deny us treatments that have proven successful elsewhere and, in collusion with the pharmaceutical industry, is inflicting unethical placebo testing on Canadians in life-threatening situations.

Drug Trials and Placebos

Placebos have no place in the treatment of people living with AIDS. People in life threatening situations should not have to put their lives in jeopardy by receiving no treatment at all. As it stands now, multinational pharmaceutical companies, in conjunction with governments and medical professionals, are engaging in and promoting "double blind" placebo tests. These tests stipulate that a portion of the test group (usually one-half) will receive the drug being tested and the other portion will receive a placebo—a practice that means one-half will receive something that is designed to look like medication but is in fact a substance with no medicinal qualities at all.

AIDS ACTION NOW! supports full testing of drugs—with the stipulation that they should still be available in "catastrophic" situations even while undergoing tests and that the tests should be done only using either historical controls or comparative studies where other drugs are given.

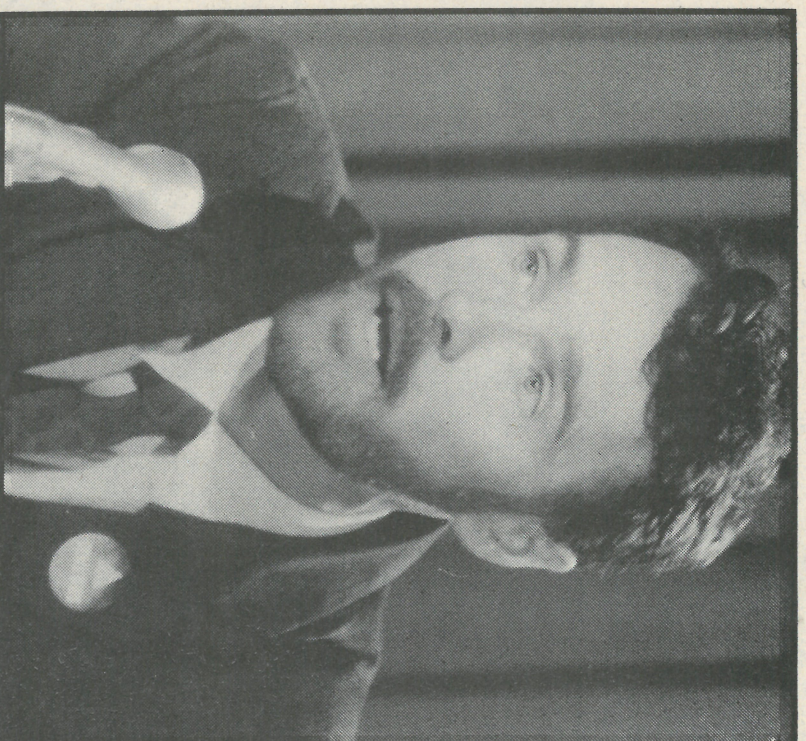
Anonymous Testing

All levels of government should be working together to provide sites for anonymous testing in Canada. At present seven Canadian provinces require the reporting of HIV positive people to authorities. These requirements should be al-



Epp feels the heat of AIDS activism.

tered so that people can have the tests anonymously—that is to say by being able to receive their results without the people giving them the results being required to report their status to provincial medical authorities. Anonymity should be guaranteed when wanted and at all times people should be able to expect complete confidentiality of their medical records. People should have the right to know their health status without fear that their



CHUCK GROCHMAL

Tim McCaskell, recently elected chairperson at AIDS Action Now's first ever annual general meeting.

went on to elect a new steering committee. The new executive is composed of Tim McCaskell as chair; Russell Armstrong as secretary and James McPhee as treasurer. At-large members of the steering committee

are: Bernard Courte, George Smith, Sean Hosen, Gary Kinsman, Renee du Plessis, Chuck Grochmal, Max Allen, Roger Spalding, Dennis Conway and Michael Hulton.
Patrick Barnholden

condition will be reported to the authorities or perhaps leaked to their employer or elsewhere.

PLWAs on all Boards and Committees

Boards and committees that are dealing with the health and lives of people living with AIDS should always have PLWAs as members. This should include any body that is dealing with any aspect of AIDS—issues such as hospital care, home care, human rights or education about AIDS can only be adequately dealt with through the full involvement of PLWAs. Prerequisites for the full participation of PLWAs are anti-discrimination legislation and the guarantee of no quarantine legislation.

National Treatment Registry

A national treatment registry should be established. Such a registry will be composed of a variety of treatment protocols thought to be of use to 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. Treatments of all types, including those that are not part of the medical mainstream, would be recorded. Both physicians and PLWAs should have access to the information in the registry so that PLWAs can be active participants in their own treatment. This registry should be established and run by a body that includes the full participation of PLWAs.

The national treatment registry will be a very important tool in bringing together the existing

knowledge about AIDS and the ever-widening scope of treatment options. It is important that the registry be connected with other such registries in other countries. This will also allow the treatment of PLWAs and HIV-positive people to move away from a strictly hospital setting and more into the home and primary physician's office.

Hospital Care

Hospital administrations must work much harder at establishing state-of-the-art diagnostic and treatment protocols to deal with the health of PLWAs. At present there is no uniformity in care available for PLWAs in different hospital settings. PLWAs are continuing to have horrific experiences as they deal with hospitals where a "hit and miss" approach governs present attempts at AIDS care.

It is the responsibility of the provincial Ministry of Health to establish standard protocols for all hospitals so that care can be brought up to an acceptable level.

Home Care

In conjunction with the national treatment registry and better hospital care we need to establish a comprehensive approach to home care. The needs of PLWAs can often better be met at home than in the hospital with the help of their primary care physicians. In addition, it must be clear that people being released from hospitals are being released to situations where their needs are being fully met. It is nurses who will be able to do the most to make home care a viable alternative for most people. This will require more education for nurses about dealing with PLWAs and a recognition of the importance of this work by health care workers.