

AIDS ACTION NOW! Policy Paper

Adopted by the General Meeting Held October 5, 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 disease. 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 compa-

nies, in conjunction with governments and medical professionals, are engaging in and promoting placebo-controlled 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 testing and that the tests should be done only using either historical or comparative controls where different dosages or other drugs are administered.

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

PLWA'S ON ALL BOARDS AND COMMITTEES

Boards and committees that are dealing with the health and lives of people living with AIDS should always have PLWA's 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 PLWA's. Prerequisites for the full participation of

PLWA's 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 PLWA's should have access to the information in the registry so that PLWA's can be active participants in their own treatment. This registry should be established and run by a body that includes the full participation of PLWA's.

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 PLWA's 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 PLWA's. At present there is no uniformity in care available for PLWA's in different hospital settings. PLWA's 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.