

LE GROUPE D'ACTION-SIDA

# **AIDS ACTION NOW!**

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**National Treatment Registry**

**for HIV and AIDS**

**An Urgent Call to Action**

**March 13, 1990**

## **AAN Brief on a National Treatment Registry**

**March, 1990**

### **Introduction:**

AIDS ACTION NOW! is a community-based organization of AIDS activists in Toronto. It has approximately 350 members and enjoys wide political support both in Toronto and across Canada.

While other community-based groups carry out important public education and support work in the fight against this disease, AIDS ACTION NOW! is concerned specifically with the provision of treatment for people living with AIDS (PLWAs) and for those living with HIV infection (PLWHIVs).

AIDS ACTION NOW! believes that the lack of access to treatment experienced by many PLWAs/HIVs in Canada is primarily the result of political problems created by governments (federal and provincial), the medical profession (especially medical researchers), and international pharmaceutical corporations.

For nearly two years now, AIDS ACTION NOW! has been calling for the establishment of a National AIDS Treatment Registry. This call has been made both in writing to and in meetings with various Members of Parliament, officials of the Department of National Health and Welfare, and in a personal meeting with the Minister of Health, Mr. Perrin Beatty.

In Montreal in June 1989, Mr. Beatty promised a "National Strategy" to fight AIDS before year end. It is now March, and the only sign of any movement from the federal government on this promised strategy has been the circulation of a preliminary working outline.

People living with HIV and AIDS have no time to waste waiting for a "National Strategy" that will likely contain few concrete specifics. Action on treatment is long overdue and is urgently needed now.

A National Treatment Registry is a concrete, specific proposal which the federal health department could implement relatively quickly and relatively inexpensively. It would be enormously beneficial to those who are suffering and dying from the disease every day, across this country.

### **The Need for a National Treatment Registry**

In attempting to meet the AIDS crisis, both federal and provincial governments in Canada have developed various kinds of public health policies. Such policies have not, however, been concerned with the delivery of treatment. Some of these policies, in fact, have held back promising treatments for testing and licensing.

The medical profession has, in the past, managed the delivery of treatment. In the case of AIDS, however, where there are few specialists, and where the infection gives rise to a

wide variety of opportunistic infections, it has become very clear that the medical profession does not have the capacity to manage the delivery of treatment.

It is for this reason that AIDS ACTION NOW! is calling upon the federal government to take significant initiatives.

Canada's Emergency Drug Release Program has proven to be helpful, but it was never intended to manage something as extensive as the required flow of drugs to PLWAs/HIVs. It doesn't provide recommendations to doctors on how to use treatments it authorizes, and it has no provisions for the systematic collection of data on patients' responses to the treatments.

The Federal Centre for AIDS, meanwhile, has done nothing to improve treatment management in Canada.

What is needed, then, is a National Treatment Registry. The proposed registry could serve as an international model and make Canada a world leader in at least one front of the AIDS battle.

## **Registry Mandate:**

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The National Treatment Registry would do the following, as a minimum:

- (a) Collect treatment information from all possible sources (including pharmaceutical and complementary treatments, as well as all diagnostic developments);
- (b) Make available all of this treatment information to health care providers;
- (c) Make access to treatments possible (working in concert with the Emergency Drug Release Program to provide information about where and how the treatments are obtainable);
- (d) Provide suggested treatment (& diagnostic) regimens based on confidential patient profiles provided by physicians; and
- (e) Monitor, Evaluate and Revise these regimens, constantly.

NOTE: The Registry must be national in scope because:

- (a) data needs standardization, both within Canada and within international information resources, to be maximally effective;
- (b) treatment information is needed across Canada, and especially in less advantaged geographical and/or ethnocultural communities;
- (c) evaluation of treatment regimens is more effective with large patient input; and
- (d) the Registry would have epidemiological benefits through its ability to monitor HIV infection trends across the country, although this is at most a side benefit - not the Registry's central mandate.

## **Other Registries:**

AIDS ACTION NOW! has investigated several existing registries whose mandates and structures could provide useful bases of comparison (See Appendix #1). Some of the existing registries have epidemiological mandates or serve primarily as catalogues of existing data.

While such functions are useful, the most important function we are proposing for a National AIDS Treatment Registry is the fully interactive process of treatment regimen development, evaluation and revision.

Furthermore, there is a growing number of international AIDS treatment data bases and catalogue-style registries. The National Registry, we propose, should be designed to interact with them.

## **Gathering Available Treatment Data:**

Canada's National AIDS Treatment Registry should interact with the Health Sciences Resource Centre of the Canada Institute for Scientific and Technical Information for published and computerized databases (See Appendix #2).

The Registry could also seek out new databases such as the CDC/FDA "AIDSTRIALS" databases from the United States.

The Registry could access treatment resources of community groups in Canada (such as AIDS ACTION NOW!'s Treatment Information Exchange project, and the Canadian AIDS Society) and in the United States (such as Project Inform, Community Research Initiatives, and the AIDS Coalition to Unleash Power).

The Registry should actively consult with frontline physicians and specialists, and facilitate access to their advice.

The Registry should deal with treatments broadly defined so as to include nutrition, naturopathy, Chinese medicine, and other complementary therapies.

The Registry must be pro-active, gathering treatment and diagnostic information specifically referenced to women, to IV drug users, and to take in various social and environmental factors.

## **Making the Data Available:**

There would have to be an aggressive national advertising campaign to bring the Registry to the attention of all Canadian health care providers, particularly those who may be isolated for geographical and/or ethnocultural reasons.

The Registry's data should be available to a variety of physicians, specialists, researchers, naturopaths, homeopaths, clinics and community groups (although direct participation in the treatment regimen process would have to be more restrictive to ensure that the information would be reliable and standardized).

Registry access should also accommodate different resources available to its potential users - so that information would be accessible through, for instance telephone consultations, computer networks, and mail/fax services.

## **Monitoring, Evaluating and Revision:**

Suggested treatment regimens should be generated by computer/consultant analysis of complete patient profiles. Diagnostic and monitoring procedures should also be suggested. Key to the success of the Registry would be an interactive "feedback loop".

A health care provider who accesses these regimens would be obliged (through written contract perhaps) to monitor her/his patient's progress and report back to the Registry. The Registry would add this information to its data banks and, if appropriate, issue revised regimens.

The Registry would have to be firmly pro-active in collecting and evaluating information about effects of regimens on patients and, if appropriate, in contacting health care providers with new treatment developments.

All aspects of patient identification and registration would have to be completely confidential.

## **Structure:**

There is currently no structure within the federal Health Department with a clear mandate to improve treatment resources or management. It would be important that the National AIDS Treatment Registry and its mandate be clearly established within a new structure, rather than being attached to an existing bureaucracy with a public health mandate.

The Federal Centre for AIDS could be an appropriate body to manage the Registry, but only if its own mandate were redrawn so as to give priority to treatment management.

The Registry would require a staff which must include statisticians, physicians, epidemiologists and workers from nongovernmental organizations.

Finally, but by no means last in importance, PLWAs/HIVs who are accountable to PLWA/HIV organizations would have to be closely involved in managing the Registry to ensure its credibility and success among those it is designed to serve.

## **Appendix I**

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### **Existing Treatment Registries**

AAN! has been in contact with the following agencies which will provide complementary information on databasing, accessing treatment information and registry protocols:

- Ontario Cancer Treatment and Research Foundation
- U.S. Bone Marrow Transplant Registry
- International Bone Marrow Transplant Registry of Wisconsin
- U.S. National Cancer Institute
- National Institute of Allergies and Infectious Diseases (U.S.)
- Toronto Lupus Foundation
- Multiple Sclerosis Society of Ontario
- Canadian Institute for Science and Technology, Ottawa

Other possible resources are being investigated at the Provincial Ministry of Health Library and the Princess Margaret Hospital Library, Toronto.

## Appendix II

### Canadian Institute for Scientific and Technical Information Resources (Reprinted from "CISTI Medlars in Canada" - NRCC Pamphlet)

#### MEDLARS in Canada

MEDLARS\* is the computerized literature retrieval system of the U.S. National Library of Medicine (NLM) in Bethesda, Maryland. This comprehensive system of online databases, which provides access to the world's professional literature in the health sciences, contains over 10 million references to journal articles and books. MEDLARS may be searched by subject to produce a retrospective bibliography or to provide a current awareness service.

#### Access to MEDLARS

Through an agreement with NLM, the Canada Institute for Scientific and Technical Information (CISTI) offers these databases to Canadian users. CISTI's Health Sciences Resource Centre (HSRC) coordinates a growing network of Canadians who have direct access to the NLM system. The nationwide network of more than 1,000 MEDLARS subscribers includes all of the Canadian medical schools, other universities and colleges, government agencies, information centres in many hospitals, commercial and research organizations, as well as individual users.

Canadian organizations or individuals with a continuing need to access MEDLARS may obtain a user code by signing an agreement with CISTI. Information for prospective subscribers is available on request from HSRC.

#### CISTI's resources

CISTI houses Canada's largest collection of published material in science, technology and medicine. There are approximately 3,500 biomedical journals indexed for the MEDLINE file and CISTI holds over 2,300 titles in medicine. Many articles identified by a MEDLINE search can thus be obtained as a photocopy upon request. Extensive collections of conference proceedings and technical reports are also available at CISTI. If CISTI does not own the requested document, it will help find alternate locations in Canada.

#### Services to MEDLARS subscribers

HSRC provides administrative services to the network of subscribers and offers a comprehensive program of training and customer support. A free customer hotline service is maintained by HSRC staff from 08:30 to 16:30 (Eastern Time), Monday to Friday, to provide assistance with system or search-related problems. Subscribers may also make contact through Envoy 100, an electronic messaging facility of Telecom Canada, or through the GRATEFUL MED Bulletin Board Service. Each subscriber receives the *NLM Technical Bulletin* together with *MEDLARS Canada*, a newsletter prepared by HSRC staff which contains items of interest to Canadian users.

#### MEDLARS databases available in Canada

##### AIDSLINE

AIDSLINE contains citations about acquired immunodeficiency syndrome from MEDLINE and other MEDLARS files back through 1980. Eventually it will include records from sources of published literature not in MEDLARS.

##### BIOETHICSLINE

BIOETHICSLINE is a file of approximately 25,000 references to materials on bioethical topics such as human experimentation, reproductive technologies and professional ethics. They are selected from the literature of health sciences, philosophy, law, religion, psychology, and from the popular media. BIOETHICSLINE is developed at the Kennedy Institute of Ethics, Georgetown University.

##### CCRIS (TOXNET)

Chemical Carcinogenesis Research Information System is a scientifically evaluated and fully referenced data bank, developed and maintained by the National Cancer Institute (NCI), containing carcinogenicity, tumor promotion, and mutagenicity test results. Data are derived from the scanning of primary journals, current awareness tools, and a special core set of sources, including a wide range of NCI reports. Test results have been reviewed by experts in carcinogenesis. CCRIS is organized by chemical record and now contains some 1,200 such records.

##### MEDLINE

MEDLINE, the largest and most frequently used database, contains references to recent biomedical journal articles. In MEDLINE and its backfiles, which cover the literature from 1966, there are approximately 6 million records. The MEDLINE database contains citations from about 3,500 biomedical journals published in the U.S. and 70 other countries. It corresponds to the printed tools *Index Medicus*, *Index to Dental Literature* and *International Nursing Index*. Approximately 70% of the references are English language articles and over 60% of the citations since 1975 include abstracts.

##### TOXLINE

Toxicology Information Online contains references from 1940 to the present on published human and animal toxicity studies, effects of environmental chemicals and pollutants and adverse drug reactions. TOXLINE and its backfile TOXLINE65 have over 1.3 million references, most of which include abstracts. Several individual sources comprise its subfiles, including MEDLINE, BIOSIS, *International Pharmaceutical Abstracts*, the International Labour Office and NIOSH.

(Excerpted from the full list of 27 available databases)