



LE GROUPE D'ACTION-SIDA

# AIDS ACTION NOW!

Suite 321 - 517 College Street, Toronto, Ontario M6G 1A8  
Phone (416) 928-2206 Fax (416) 593-5607

**AIDS ACTION NOW!  
Annual General Meeting  
November 19, 1991  
519 Church Street Community Centre  
Agenda**

- 1. Welcome: AAN! Co-chairs Glen Brown & Darien Taylor.**
- 2. Adoption of Agenda.**
- 3. The Year in Review: Darien Taylor.  
Discussion**
- 4. Financial Statement**
- 5. Introduction of Committees.**
- 6. "The Cupboard's Not Bare" demonstration: John Clarke, Ontario Coalition  
Against Poverty.**
- 7. Nominations for 1991-92 Steering Committee**
- 8. Introduction of Steering Committee nominees.**
- 9. Election of 1991-92 Steering Committee.**
- 10. The Year Ahead; Policy Options 1992: Glen Brown.  
Discussion**
- 11. Coffee.**





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## Policy Options 1992

At the AIDS ACTION NOW! retreat in September, the consensus among active members was that our policy direction was generally sound, but needed updating. The following policy notes outline current and planned commitments. We welcome your input at the Annual Meeting.

### 1.0 Research

#### 1.1 Research Agenda

The amount and direction of HIV/AIDS research is a continuing problem. Little basic research is conducted in Canada; clinical research is directed by pharmaceutical agendas; the needs and interests of PLWA/HIVs are neglected. AAN! believes more research is needed in areas such as immune boosters, opportunistic infection fighters, treatment problems of neglected populations (women, IV drug users, people of colour), and non-allopathic treatment options. AAN! will:

- support the CAS' development of research priorities policy through our contacts on the CAS Therapies Committee.
- push for federal government & Clinical Trials Network development of a National HIV/AIDS Research Agenda.
- participate in advisory bodies to the Clinical Trials Network and the Community Research Initiative of Toronto and push for research initiatives that meet the needs of PLWA/HIVs.
- push for direct federal government investment in basic and clinical research.
- further our understanding of the provincial role in research.
- support the development of Observational Data Bases (Sunnybrook Project Centre, CATIE Medlog project, CRIT data base etc.) to evaluate the effectiveness of treatments apart from clinical trials, while protecting patients right to confidentiality and unfettered access to treatment.
- support community-based research such as CRIT and the Chinese Medicine Project initiated by the Vancouver PWA Society.
- participate in consultations with researchers, pharmaceutical companies and networks to improve research priorities, protocols and designs.

#### 1.2 Research Ethics

AAN! believes that clinical trial ethics must be enforced, and the distinction between treatment and research made clear. This means that compassionate access to experimental treatments must

be guaranteed so that people are not forced to enter trials attempting to save their lives. Clinical trials should be designed to be safe and attractive to PLWA/HIVs, and must be based on informed voluntary participation. AAN! will:

- publish and distribute a booklet on participation in clinical trials.
- push the federal government to formally recognize compassionate access as a necessity for ethical trials.
- push for government funding of compassionate access costs.
- push for expanded compassionate access through our contacts on review boards and advisory bodies, and through our consultations with researchers, pharmaceutical companies and allies.
- push for truly informed consent through culturally and literacy appropriate consent mechanisms.
- mount campaigns for compassionate access to specific treatments, targeting governments or pharmaceutical companies.
- further develop our analysis of trial designs and protocols.

## **2.0 Treatment Access**

### **2.1 Emergency Drug Release Program**

AAN! believes that people with a life-threatening illness such as HIV infection have a catastrophic right to treatment that overrides governmental regulatory restrictions or pharmaceutical patent concerns. We believe that PLWA/HIVs, in concert with their physician, should have compassionate access to treatments which have cleared initial safety tests. AAN! will:

- push the federal government to formally recognize catastrophic rights, thereby putting more pressure on pharmaceutical companies to comply.
- publicize potential emerging treatments and the process for EDRP applications.
- develop appropriate paperwork support for EDRP applications.
- establish an EDRP advocate to help steer people through EDRP mechanisms and identify barriers.
- mount campaigns against the barriers identified, which could include ineffective EDRP mechanisms, pharmaceutical companies refusing to release experimental treatments, etc.

### **2.2 Drug Regulation**

Any unnecessary delay in processing drug patents and licenses slows access and discourages pharmaceutical investment; faster processing may be possible without any reductions in standards. However, there are both advantages and dangers in loosening of drug regulation standards for PLWA/HIVS: while looser standards might ease access for some, and provide incentives for pharmaceutical investment, the potential for exploitation of a vulnerable population

is immense. AAN! will:

- analyze the drug regulation system and compare it with other nations to identify unnecessary delays.
- further our understanding of the pros and cons of reduced standards for licensing, including the potential of post-licensing clinical trials.

### **2.3 Treatment Funding**

Access to treatments which is conditional on one's ability to pay is unacceptable. Catastrophic rights must include the right to treatments regardless of income. AAN! will:

- push the Ontario government for a comprehensive drug funding policy to fully cover treatments for life-threatening illnesses, including non-allopathic treatments.
- develop alliances with other disability groups on drug funding policy.
- push the federal government to endorse national standards on catastrophic drug funding, and to exert influence on pharmaceutical companies and provincial governments.

## **3.0 Treatment Management**

### **3.1 Treatment Information**

PLWA/HIVs and their care-givers need and deserve up-to-date, culturally appropriate information on treatment options and strategies. Health care professionals need efficient, credible systems to update their knowledge and practices. AAN! will:

- push for the speedy completion of the AIDS Treatment Information System (formerly TISAH), with equal access for doctors and patients and inclusion of non-allopathic treatment information.
- push at a federal level for medical upgrading initiatives such as a national study of accelerated care and medical college education.
- push for co-ordination of treatment information/medical upgrading initiatives at a provincial level through the Ontario Advisory Committee on HIV/AIDS
- support treatment information services such as CATIE, and participate in co-ordination forums such as that initiated through the ACT Treatment and Wellness group.
- highlight the particular problem of lack of treatment information for neglected populations: women, IV drug users, youth, people of colour.
- support or initiate public information forums on treatment.
- push the CAS to co-ordinate treatment information initiatives among community groups.

### **3.2 Treatment Standards**

There are few systems in place in Canada for developing, upgrading or evaluating standards of medical care (sometimes referred to as "quality assurance"). This is especially dangerous in a

new, complex and rapidly evolving field such as HIV treatment. The result is sub-optimal care, especially for people outside the downtown "networks"; geographically, ethnically or sexually marginalized PLWA/HIVs. AAN! believes that new systems of treatment standards must be developed with PLWA/HIV input. These systems could provide models for quality assurance in other medical areas. AAN! will:

- work through the Ontario Advisory Committee on HIV/AIDS (OACHA) to examine current initiatives and develop mechanisms for improving standards of care.
- develop a position paper on how HIV/AIDS can provide leadership models for quality assurance in other fields.
- support and publicize the development of models of optimal/accelerated care.

### 3.3 Treatment Delivery

Health care professionals and institutions must be challenged to efficiently deliver optimal care, and to respect the rights of PLWA/HIVs. AAN! will:

- work through OACHA to monitor and participate in an evaluation of HIV clinics, with the goals to co-ordinate and expand clinic services, examine new models for delivery, and ensure culturally appropriate services.
- continue to support and attend meetings of the Toronto Primary Care Physicians Groups.
- participate in advisory bodies such as the Wellesley Hospital Advisory Committee to push for improved care.
- support improved access to and evaluation of complementary therapies.
- participate in the Metro co-ordination body initiated by Sunnybrook Hospital.
- continue to participate in the Ontario Advocacy Coalition to defend the rights of patients to make their own health care decisions or appoint their own advocates to do so.

### 3.4 Care and Support

AAN! believes that optimal health care includes much more than medical care: adequate housing, nutrition, freedom from poverty, and appropriate care and support are all key to the health of PLWA/HIVs. We will continue to push for "consumer-driven" community-based models of delivering a continuum of care and support. AAN! will:

- push for, and participate in, co-ordination initiatives among service providers to reduce overlap, identify gaps, and evaluate services from a consumer standpoint.
- push for adequate government support for community-based support groups, and recognize the needs of diverse communities.
- renew our push for increased social assistance levels, and update our brief on social assistance reform for PLWA/HIVs.
- continue to participate in the Ontario Coalition Against Poverty and the Ontario Coalition for Social Justice to fight for adequate social services for PLWA/HIVs.

- expand our understanding of the barriers to optimal homecare for PLWA/HIVs and campaign for reform.
- continue to participate in the Homecare Advocacy Coalition.
- expand our understanding of barriers to housing, in consultation with housing allies.

## **4.0 Prisons**

AAN! believes that adequate HIV prevention, education and treatment must be provided within prisons and psychiatric institutions. AAN! will:

- continue to build and support coalitions such as the Prisoners AIDS Support and Action Network to confront government AIDS/HIV policy in institutions.

## **5.0 Public Health**

AAN! must continue to defend PLWA/HIVs against surveillance and inappropriate coercive actions from public health officials. These attitudes and actions from public health officials will only serve to scare people away from the health care system, which jeopardizes their health and reduces opportunities for prevention counselling. AAN! will:

- monitor the implementation of anonymous testing in Ontario.
- push for a full end to any reporting of HIV for public health surveillance purposes, while supporting anonymous epidemiological data collection.
- continue to participate in the Ontario Law Reform Commission review of public health law and HIV.
- complete the AAN! brief on public health intervention and HIV for the Ontario Advisory Committee on AIDS/HIV.
- participate in Toronto Public Health community consultations on this issue.
- oppose mandatory testing of health care workers or patients.

## **6.0 Discrimination**

Stigma associated with HIV infection and AIDS, accompanied by homophobia, racism and sexism, poses a continuing threat to the rights of PLWA/HIVs. AAN is committed to ending discrimination and to maintain an anti-sexist, anti-racist and anti-heterosexist standpoint. AAN! will:

- continue to work in coalition with groups defending the rights of oppressed communities.
- continue to press the Human Rights Commission to act quickly and effectively in response to HIV discrimination.
- continue to support the Advocacy Resource Centre for the Handicapped, and to work with the ARCH HIV Mentor to explore legal options for responding to discrimination.

## **7.0 Alliances & Representation**

AAN! will continue to work in coalition with other PLWA/HIV groups, AIDS community groups, health care advocates and progressive organizations. We will continue to fight for accountable representation of PLWA/HIVs on all bodies which advocate, provide services, or set policy on AIDS/HIV. AAN! will continue to actively participate in:

- Canadian Network of Organizations of PLWA/HIVs.
- Ontario AIDS Network.
- Canadian AIDS Society.
- Ontario Coalition Against Poverty.
- Ontario Advocacy Coalition.
- Advocacy Resource Centre for the Handicapped.
- Ontario Coalition for Social Justice.

## **8.0 Organization**

AAN! is an open and democratic organization. It is vital to our success that we be as accessible and responsive to all PLWA/HIVs as possible. AAN! will:

- continue to host general meetings on treatment issues.
- improve our membership orientation process to give people easier access to becoming involved.
- maintain a membership phone-tree to keep members informed of actions and meetings.

# AIDS ACTION NOW!

## BASIS OF UNITY

• AIDS ACTION NOW! is a community-based group engaged in the struggle against AIDS. Our work is fundamentally driven by the needs of people living with AIDS and HIV infection (PLWA/HIV). While our work comes primarily from the gay/lesbian community, we are committed to the empowerment of all PLWA/HIVs and all communities affected by the AIDS crisis. AIDS ACTION NOW! welcomes all PLWA/HIVs as well as other individuals who are in basic agreement with this list of principles.

• We recognize the potential for HIV infection to be a chronic manageable illness.

• We stand by the demands of *Le Manifeste de Montréal, A Declaration of the Universal Rights and Needs of People Living with HIV Disease*. This is a document prepared by AIDS ACTION NOW! in Toronto and ACTUP in New York for distribution at the V<sup>e</sup> International Conference on AIDS held in Montréal in June 1989.

• In confronting institutional inaction and mismanagement around AIDS, we are committed to an activism which includes, among others, such activities as lobbying, direct action, demonstrations, civil disobedience, and education aimed at solving the AIDS crisis.

• We recognize that the politics of AIDS raises profound questions about the way our society is organized. For our work to be relevant to PLWA/HIVs, it is necessary for us to deal with issues of social inequality around race, sex, class, sexuality, ability, etc., both inside and outside our organization. Therefore our work incorporates an anti-racist, anti-sexist and anti-heterosexual perspective.

• We are committed to working in a coalition with other groups to fulfil the needs of PLWA/HIVs.

• We are committed to democratic process within our organization.

## MANDATE

- To improve the availability of drugs and treatments for people who are living with AIDS or HIV infections;
- To improve the standard of care for people living with AIDS or HIV infection to meet their health-care needs;
- To support progressive AIDS related initiatives launched by other organizations and individuals;
- To undertake any other activities that AAN! thinks will improve the quality of life for persons living with AIDS or HIV infection.

## PRINCIPES DE CONSENSUS

• Le groupe d'action-sida AIDS ACTION NOW! est un groupe communautaire engagé dans la lutte contre le sida. Notre travail est essentiellement de répondre aux besoins des personnes atteintes du sida et du virus du VIH (PAS/PAVIH). Quoique ce travail provienne principalement de la communauté gaie et lesbienne, notre engagement est vis-à-vis toutes personnes atteintes du sida ou du VIH, et toutes communautés affectées par la crise du sida. Le groupe d'action-sida AAN! invite toutes PAS/PAVIH et quiconque est en accord avec les principes suivants à se joindre à lui.

• Nous reconnaissons que l'infection au VIH peut être considérée potentiellement comme une maladie chronique traitable.

• Nous soutenons les revendications du *Manifeste de Montréal, Déclaration des droits et des besoins de la personne atteinte du VIH*. Il s'agit d'un document préparé par le groupe d'action-sida AAN! de Toronto et par ACTUP de New York pour la V<sup>e</sup> Conférence internationale sur le sida, tenue à Montréal en juin 1989.

• En mettant en évidence l'inaction institutionnelle et la mauvaise gestion entourant le sida, nous prônons un activisme faisant appel, entre autres, au lobbying, à l'action directe, aux manifestations, à la désobéissance civile et à l'éducation pour contrer la crise du sida.

• Nous reconnaissons que le sida soulève de profondes questions quant à l'organisation de notre société. Pour que nos efforts touchent toutes les PAS/PAVIH, il nous faut confronter la question des inégalités sociales basées sur la race, le sexe, la classe, la sexualité, les capacités, etc. aussi bien à l'intérieur qu'à l'extérieur de notre organisation. Par conséquent, notre travail s'oriente dans une perspective anti-raciste, anti-sexiste et anti-hétérosexiste.

• Nous sommes engagés à travailler en collaboration avec d'autres groupes afin de répondre aux besoins des PAS/PAVIH.

• Nous sommes engagés à procéder démocratiquement à l'intérieur de notre organisation.

## MANDAT

- Améliorer la disponibilité des médicaments et traitements offerts aux personnes atteintes du sida ou d'une infection au VIH.
- Améliorer le standard des soins apportés aux personnes atteintes du sida ou d'une infection au VIH afin de répondre adéquatement à leurs besoins médicaux.
- Appuyer les initiatives progressistes concernant le sida venant d'autres organisations ou individus.
- Entreprendre toute autre activité qui, selon le groupe d'action-sida AAN!, améliorera la qualité de vie des personnes atteintes du sida ou du VIH.