

AIDS ACTION NOW!
ANNUAL RETREAT OCTOBER 31, 1993

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PRESENT: Tim McCaskell, Maggie Atkinson, John Drury, Brian Farlinger, Alan Cornwall, David Chu, Susan Kasurak, Lori, Charles Roy, Peter Amenta, Julia Barnett, Bill Leeming, Mark Freamo, Glen Brown, Linda Gardner, Bob Gardner, Darien Taylor, Wayne Hellard

A. Reports from Committees

These reports summarise the accomplishments and challenges of AAN! committees over the past year.

Treatment Access and Research Committee

The TAAR Committee produced the first edition of the AIDS Treatment Management Guide, and a revised second edition is due out in the next couple of weeks. It was one of the organizers of the August Treatment Activists Forum which brought together community treatment activists from across Canada and produced a document on the Canadian AIDS research priorities. Members have continued to consult with Glaxo, the manufacturers of the antiviral 3TC, so that a combination arm was introduced to their trials of 3TC and compassionate access was available shortly after 3TC went to trials. Members also lobbied for increased AIDS funding before the Parliamentary Ad Hoc Committee. It has been a challenge to recruit and integrate new members to this committee because of the level of expertise in the area of treatments required. This committee would like to get a newsletter on treatment information going but haven't been able to do this so far.

Provincial Committee

This committee has concentrated on their drug funding campaign for free drugs to people with catastrophic illnesses. They have been successful in mobilizing around this issue and in connecting with the Activist Brigade around its issues. They have produced policy papers, held demos and lobbies but a combination of bad luck and bad timing mean that we haven't won this issue. Reacting to cuts to the OHIP fee schedule, the Provincial Committee supported physicians working in HIV as an "underserviced area". Members assisted in the Standards of Care document being prepared by the Ontario Advisory Committee on HIV/AIDS and in consultations held by Wellesley Hospital on their HIV Ambulatory Care Unit. They continued their work against public health interventions that compromise the anonymity of people with HIV and produced a brief on Long Term Care. They work in coalition with the Advocacy Resource centre for the Handicapped (ARCH) and the Income Maintenance Group.

Activist Brigade

This committee was formed last summer. They did great work at Pride Day. David Chu keeps the mailing list updated. They do postering for actions. Upcoming are actions related to World AIDS Day, December 1st. The challenges are going from activity to activity without always feeling connected to the group of people

that are making the decisions about what actions we're going to do and when. They have about 8 active members.

Media Committee

The media committee no longer exists per se. David Chu, and recently Brent Patterson and Darien Taylor have brought out the newsletter. Glen Brown does a lot of media work or directs it to others. Maggie Atkinson discussed the need for media skills building in the organization (and beyond). DARIEN Taylor said that the media committee used to provide a point of connection for people coming into the organization where they could get a sense of the issues without the commitment to steering committee meetings. Peter Amenta talked about the importance of streamlining the organization to prevent burnout. Brian Farlinger said that he had noticed how effective good media work can be.

Fundraising

This is not a committee anymore but that hasn't caused any problems. Periodically, allies direct money our way and many members who have died have asked that people donate money in their memory to AAN! We've got lots of money.

Prisoners with AIDS Support Action Network (PASAN)

Condoms are now distributed in Ontario prisons but PASAN is still fighting for a comprehensive strategy re: prisoners and AIDS based on their brief. They now have two staff persons. Problems with OPSEU, the union representing the prison guards, are a challenge, as are recent statistics which show that many women are entering the prison system with HIV. They feel that PASAN could make better connections with the provincial Committee and do joint projects with the Community AIDS Treatment Information Exchange (CATIE) and Voices of Positive Women, etc.

Public Health

Members of AAN! have continued the committee room battle re: reportability. The Ontario Medical Association wants action on this issue but we've been playing a waiting game. In the meantime, we've gone from "crisis" to "crisis": Toronto, Oakville park sex, Newfoundland, London... The Canadian Bar Association is also about to finalize their report on public health issues. The Victoria Island PWA group is also pursuing reportability and we can link up with them. Health units in Ontario are starting to request anonymous testing themselves, so this may create a window of opportunity.

Insurance issues

This is an issue that was thrown at us due to the legalizing of viatical companies in Ontario. Living benefits and issues related to disability and life insurance are also on this agenda.

Women's Issues

We don't meet formally but we maintain a presence through the activist brigade's work at International Women's day. We led a policy discussion on women with AIDS and AAN! and brought AIDS

to do

Action Now!'s views on disclosure into an article for Canadian AIDS News. AAN! was involved as a co-sponsor of the recent forum which brought together HIV+ women and their physicians from across Ontario. We also assisted in the development of a proposal for an HIV Clinic for women and children through Women's college Hospital and the Hospital for Sick Children.

B. CHALLENGES PAST, PRESENT AND FUTURE

We broke into three groups to discuss the challenges of the past and upcoming year and strategies to deal with them. Each group reported back and we came up with the following list:

- a) Comprehensive Drug Funding Strategy
- b) Anonymity/ Disclosure Issues
- c) HIV Doctor and Specialist Shortage
- d) Income Maintenance
- e) Recruitment to AAN!
- f) Visibility and Relevance of AAN!
- g) Human Rights
- h) Organizational Structure

After discussion, we narrowed our focus to three areas:

- a) Human Rights (Anonymity, Disclosure, etc.)
- b) Shortage of HIV Doctors and Specialists
- c) Recruitment and Organizational Visibility

C. GENERAL DISCUSSION

This was done in a large group to generate a focus for action planning in small groups.

Human Rights (Anonymity, Disclosure, etc.):

- legal issues regarding transmission, criminal law, mental/ civil law, public health
- public health agenda
- duty to disclose
- unwilling and unable
- marginalization of people with HIV
- what are the needs of people with HIV
- non-nominal and anonymous testing
- potential for widespread discrimination
- physicians- how can they become allies?
- upcoming surveillance studies
- communication strategy

HIV Doctors Shortage:

- need a comprehensive strategy
- existing general practitioners and new
- standards of care
- medical students training
- billing issues: OMA Tariff Committee
- need to focus on Ontario Medical Association and College of Physicians and Surgeons
- sharing information with community groups
- specialists services: gynaecologists, dentists

- mentor program: is it working? evaluation
- improve our work with doctors
- HOOD observational data base

Recruitment/ Visibility/ Organizational Structure/ Relevance of AAN!:

- how to pull in new members, especially people with HIV
- roles of HIV+s and HIV-s
- role of skilled and less skilled members
- how to better represent entire HIV community
- communication with infected/ affected community
- "AIDS fatigue", information saturation
- do people really know who we are and what we do?
- = expectations
- training and integration of new members
- steering committee members outreach: everyone try to bring in one new potential member
- prioritize consultations we get involved in: briefing, support. reporting back, accountability
- impact of structure on recruiting

D. STRATEGIC PLANNING

After a general discussion we again broke into groups based on our interest, to discuss strategies to address the above three issues.

Human Rights (Anonymity, Disclosure, etc):

This group felt that it was important to popularise our arguments based on work we've already done in existing policy documents and other sources. WE need to draw out the implications of the legal context of this debate, noting that the worst case scenarios do not define this issue. The role of public health and criminal law needs to be clarified. We can circulate our work to the office of the Attorney General, the Ministry of Justice, the AIDS community, HIV doctors, etc. We also need to respond to the notion of "reckless endangerment" being put forth by the federal government, the Canadian Bankers Association report through active monitoring and lobbying. We need to continue to participate in committees and policies involved in issues of disclosure, reportability, anonymous testing, etc. Active lobbying on legislation related to these issues such as Bill 89 ("The Firefighters Bill") and "reckless endangerment" is necessary. A media strategy should be developed. Perhaps a working committee needs to be struck to deal with these issues, as well as coalition building to get other groups to take on some of this work. As far as seroprevalence and other surveillance studies go, we need to clarify the motivation and the use of the results of these studies. The Canadian AIDS Society is starting a process to look at surveillance and seroprevalence studies. Alan Cornwall and Maggie Atkinson volunteered to lead a strategy discussion on these issues at our November policy discussion meeting.

Shortage of HIV Doctors:

There is a need for more HIV doctors providing quality care to people with HIV/AIDS. One of the ways to ensure this is to demand

changes in administrative areas, and part of circulatory

changes in the ways that doctors are paid and to demand administrative support for doctors. WE also need to better communicate to doctors the support we have given them in these areas, and will continue to give. We need to ensure that HIV is a part of the curriculum at medical schools. One strategy is to circulate a letter to doctors asking whether they are willing to take on HIV patients, also outlining the supports that are available to them. There are practice guidelines developed or in the process of being developed through the Federal government, the Ontario Advisory Committee on HIV/AIDS and Wellesley Hospital and these should be disseminated widely. HIV standards of care quality assurance could become a pilot project. The mentor program sponsored by La Roche as well as other training projects need to be evaluated. The small group from this retreat and others interested will meet before the next primary care physicians group to pull together a strategy paper that we'll ask to present at this meeting. After this presentation to the primary care doctors we'll meet to discuss our strategy and hopefully these issues can be absorbed into the Provincial Committee.

Visibility/ Relevance/ Recruitment/ Organization:

This group noted that AAN! is often viewed as an "impenetrable" organization. One way of coping with this is to assign a greeter at Steering Committee for new members. Perter Amenta agreed to do this. An orientation kit for new members will be put together. In the near future, we'll hold an orientation/ recruitment meeting where everyone is asked to bring one potential new member. It was decided that the Annual General Meeting would be a good place to do this. Some ideas for upcoming general meetings include: insurance issues, the disclosure debate, a seroprevalence debate. David Chu agreed to take on the task of putting out periodic one-page reports on what's going on at AAN! We will look into the cost of a poster squad to poster popularized AAN! messages across the city. We will also look into the possibility of a column in Xtra! Glen Brown will organize a January workshop on media skills for AAN! members and others. The TAAR committee will look into the possibility of AIDS Treatment 101 workshops for newcomers. We also decided to call steering committee meetings "general meetings" to give a better sense that they are open to everyone.

E. THE ANNUAL GENERAL MEETING

Tim McCaskell reported that 15 people, 7 of whom are HIV+ have agreed to stand for election for steering committee. David Chu and the activist brigade are busy posterizing. Alan Cornwall will revise our Policy Paper and Darien will record the proceedings of the retreat for consideration.