

Network news

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CANADIAN HIV/AIDS LEGAL NETWORK

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Join the Listserv!

In March, the Network launched the AIDSPOLICYLAW-list, the first Canadian listserv dedicated to discussion of legal, ethical, and policy issues related to HIV/AIDS. The purpose of the list is to exchange information of interest among people and organizations who provide legal and advocacy services to people with HIV/AIDS or who are interested in public policy issues relevant to HIV/AIDS. The list is a forum for connecting lawyers, paralegals and community legal workers; community activists and other advocates; people working in AIDS service organizations and other organizations who are interested in legal and policy issues; and public policymakers.

If you are not among the 135 people who have already subscribed to the list, complete a short questionnaire on the Network's website at www.aidslaw.ca/mailling_list/subscription.htm and subscribe now (or contact Thomas Haig at thaig@aidslaw.ca for more information.

Partial Victory on Immigration and HIV/AIDS

On 12 June 2001, at a press conference in the House of Commons, the Network released *HIV/AIDS and Immigration: Final Report*. On the same day, Minister of Citizenship and Immigration Elinor Caplan announced that she would proceed with plans to mandatorily test all refugees and immigrants for HIV. However, contrary to what had been announced in September 2000, HIV-positive immigrants and refugees will not be considered a threat to public health and will therefore not be excluded from coming to Canada on that ground. Both the Network's press conference and the Minister's announcement received a significant amount of media attention.

Although the Network remains opposed to mandatory testing, the Minister's reversal of the plan to exclude all HIV-positive immigrants on public health grounds constitutes a huge victory for the Network and all those engaged in the fight for just immigration policies for people with HIV/AIDS. It means that nobody with HIV will be automatically excluded from coming to Canada; that HIV-positive refugees and HIV-positive spouses, common-law partners, and children of a Canadian citizen or permanent resident will be allowed to come to Canada; and that for everybody else, a case-by-case assessment will be made about whether the particular person "might reasonably be expected to cause excessive demand on health or social services."

The fight is not over. On 13 June, the Network wrote to Minister Caplan requesting a meeting with her to discuss two major concerns. First, if mandatory testing is implemented, Citizenship and Immigration Canada must ensure that examining physicians in Canada and outside Canada observe appropriate standards for HIV testing. Second, the demand an HIV-positive immigrant is expected to cause on health or social services



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Network news

Network News aims to keep readers up to date on activities undertaken by the Canadian HIV/AIDS Legal Network, and serves as a means of information sharing among Network members. It is published every four months by the Canadian HIV/AIDS Legal Network.

Contributions by Network members about their own HIV/AIDS-related activities in the area of law, ethics, and human rights are welcome and encouraged. Please submit such contributions in electronic format to Anne Renaud at:

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Canadian HIV/AIDS Legal Network

The Network is a charitable organization engaged in education, legal and ethical analysis, and policy development. We promote responses to HIV/AIDS that

- implement the International Guidelines on HIV/AIDS and Human Rights;
- respect the rights of people with HIV/AIDS and of those affected by the disease;
- facilitate HIV prevention efforts;
- facilitate care, treatment, and support to people with HIV/AIDS;
- minimize the adverse impact of HIV/AIDS on individuals and communities; and
- address the social and economic factors that increase vulnerability to HIV/AIDS and to human rights abuses.

We produce, and facilitate access to, accurate and up-to-date information and analysis on legal, ethical, and policy issues related to HIV/AIDS, in Canada and internationally. We consult, and give voice to, Network members and a wide range of participants, in particular communities of people with HIV/AIDS and those affected by HIV/AIDS, in identifying, analyzing, and addressing legal, ethical, and policy issues related to HIV/AIDS. We link people working on or concerned by these issues. We recognize the global implications of the epidemic and incorporate that perspective in our work.

The Network is a partner organization of the AIDS Law Project, South Africa. It is based in Montréal. We welcome new members. For membership information, contact Anne Renaud at arenaud@aidslaw.ca.

should be considered excessive only when the expected cost of government services estimated over a short period exceeds the estimated financial contribution that the immigrant will make over the same period, and also outweighs the potential social contributions that they are expected to make.

The Network also raised these issues in a presentation made to the Standing Committee on Citizenship and Immigration on 4 May 2001. Together with other organizations, we will continue to work on these issues.

Copies of all the Network documents on HIV/AIDS and immigration are available online at www.aidslaw.ca/Maincontent/issues/immigration.htm. For more information about our work in this area, contact Ralf Jürgens at ralfj@aidslaw.ca.

Injection Drug Use and HIV/AIDS: 565 Days and Counting

565 days ago the Legal Network released its report on legal and ethical issues related to injection drug use and HIV/AIDS. At the time, Allan Rock, Minister of Health, responding to a question in the House of Commons, promised to "provide a detailed response to the [report's] recommendations in the months to come." The Minister's response is now ready, and will be released soon.

In the meantime, the Legal Network is continuing to follow up on the report's recommendations in a variety of ways.

The Network Has Moved

After three years at 484 McGill Street, the Network's office moved to a new location in Old Montréal. We are now at 417 Saint-Pierre Street, just a couple of blocks from our old offices, but in bigger and brighter offices that provide a better work environment for staff and the increasing number of volunteers and interns that spend time at the Network, more room for the Network's rapidly expanding Resource Centre, and a meeting room. We moved on 15 June, the hottest day of the year, and very quickly started appreciating the fact that our new offices are air conditioned. On 7 July, during the Canadian Skills Building Symposium, we will be having an open house, and hope that many of our members and other people attending the Symposium will be visiting us at 417 Saint Pierre, Suite 408, Montréal H2Y 2M4 (phone and fax numbers remain unchanged).



In April we provided comments on "Reducing the Harm Associated with Injection Drug Use in Canada," a working document released for consultation by the Advisory Committee on Population Health and four federal/provincial/territorial committees on drugs, AIDS, corrections, and justice. The paper is the federal/provincial/territorial response to a "significant number of recent, well-researched reports and consultations recommending action to reduce the harm associated with injection drug use in Canada," including the Network's report. We had many positive things to say about the paper, but disagreed with the assessment in the paper that "[w]hile new dollars may be required in the medium term, the focus in the short term should be on intensive, high level, cross-governmental and multi-stakeholder consultation to further communicate and build consensus around the priorities presented in the paper." This is what we had to say: "The public health tragedy of HIV/AIDS and hepatitis C among injection drug users has been underway for many years, and at least some of it could have been prevented had governments moved from meetings and further consultations to actually doing something about the problems at hand. In some ways, the situation resembles that of the blood tragedy in the 1980s, when decision-makers did exactly what is now being done with regard to injection drug use: meet, consult, and act too late.... The high level, cross-governmental consultations referred to in the paper need to happen, but they should not serve as a convenient excuse to further delay long-overdue action; and securing the additional funds necessary in federal and provincial/territorial budgets that would make implementation of the short- and long-term activities proposed possible."

The full text of the Legal Network's comments on the paper can be found online at www.aidslaw.ca/Maincontent/issues/druglaws.htm.

Also in April, Ralf Jürgens gave a presentation on the legal and ethical issues related to the establishment of supervised injection sites to the Task Group on Supervised Injection Site Research, which was formed in response to one of the recommendations in "Reducing the Harm Associated with Injection Drug Use in Canada." Ralf's presentation was based on the work on supervised injection sites that Ian Malkin, a law lecturer from the University of Melbourne, Australia, undertook while on sabbatical at the Network last summer (see *Network News* 5, pages 6-7).

Finally, Jennifer Gold, a law student who is currently an intern at the Network, is working on a project concerning ethical issues facing health-care and service providers with respect to injection drug users living with or at risk for HIV/AIDS. Among the issues Jennifer will be working on over the summer are ethical issues facing service providers who work in facilities in which needle exchange is prohibited (ie, prisons), ethical issues arising from the provision of sterile injection equipment to minors, and ethical issues arising from the creation of supervised injection sites.

For more information about the Legal Network's activities in this area, contact Ralf Jürgens at ralfj@aidslaw.ca.

Network Starts Community-Based Research Project

Developing good public policy that promotes and protects the health of individuals, communities, and populations is best done (and is more likely) if sound research that supports certain policy choices over others is available. Yet data on laws and policies as structural determinants of health are underdeveloped. What data are needed in order to inform law/policy-making so that sound public policy from the perspective of human rights and public health can be made, and how can that data be gathered? To answer this question, the Network submitted a proposal to the National Health Research and Development Program (NHRDP) in September 2000, under the community-based research funding stream of the Canadian Strategy on HIV/AIDS. In June 2001, after providing further information to the reviewers and obtaining an ethics review certificate, we obtained "project formulation funding." At the time of writing, we were starting work on the

project. Entitled "Healthy Public Policy: Assessing the Impact of Law and Policy on Human Rights and HIV Prevention and Care," the project has two goals.

- (1) We want to identify what research has already been done, and what research still needs to be done, on the impact of laws and policies on the human rights of people and communities living with and affected by HIV/AIDS, and how this affects their health.
- (2) Based on this, we want to identify an issue or area that still needs this kind of research, and design a project to do that research on the impact of human rights and health law.



The purpose of this research project is to ensure that we have data that can be used to guide elected legislators, government policymakers, judges, and individuals and organizations that run programs or provide services to people living with HIV/AIDS, in making choices between various laws and policies. With data about the effects on health and human rights of various kinds of laws and policies, decision-makers can avoid enacting laws, or making judgments, or creating policies that violate human rights and damage the health of people by undermining HIV prevention efforts or by impeding access to care, treatment, and support related to HIV/AIDS.

As part of the research, we will do the following:

- (1) Review reports and research studies in medical, legal, public health, or other journals or publications that examine any connection between people's health (specifically in relation to HIV/AIDS) and the adoption or implementation of laws or policies that respect or violate human rights standards. For example, does a law requiring people to disclose their HIV-positive status to some people on pain of criminal prosecution affect willingness to test for HIV (and/or a preference for anonymous versus nominal testing)? Does it affect to whom they disclose, how, and in what circumstances?
- (2) Carry out an environmental scan of important issues where the possible link between a law or policy and an effect on human rights and health should be investigated. This will be done by conducting interviews with several key respondents about what they see as the major issues that are important to better understand the role the law plays in affecting HIV prevention or people's access to medical care or support services.
- (3) Prepare a synthesis report from the results of the literature review and the environmental scan interviews. On those issues where the research already done has produced sufficient data, the report will draw some conclusions about how different laws and policies affect human rights and health. It will also identify those areas where there is little research, and make recommendations about which research should be pursued.
- (4) With the participation of one or more other community-based organizations, and one or more people with experience in designing and conducting different kinds of research studies, we will design a community-based research project to gather data on a key, under-researched area where we need to better understand the relationship between the law, human rights, and health. These partners in the research will be identified through the course of conducting the literature review and the environmental scan. Once we have designed the research project, we will seek additional funding to carry out that research.

For more information on the project, contact Richard Elliott at relliott@aidslaw.ca.

Evaluation Demonstrates Impact of Network's Work

As reported in *Network News* 6, the Network engaged a team of consultants to undertake an evaluation of selected components of the Network's work in order to assess its impact. The evaluation focused on three areas of the Network's expertise and programs: rapid HIV testing, prisons and HIV/AIDS, and injection drug use and HIV/AIDS.

In March 2001, the consultants reviewed the activities carried out by the Network in these areas, conducted a total of 54 in-depth interviews with individuals from 30 organizations, and prepared an evaluation report that provides conclusions and suggestions for future action in each of the three program areas. Some of the highlights of the report include (all quotes are taken from the report):

- Participants felt that the Legal Network publications are "extremely thorough, comprehensive and well researched." They were called "valuable resources and excellent reference materials for policy makers and advocacy groups."
- A large portion of participants identified the open, inclusive, and broad representative nature of the Legal Network's collaboration and consultation mechanisms as one of its successes. "They felt there was a genuine effort to seek their opinions and were satisfied with the amount of time given to provide input."
- A vast majority of participants felt that the Network is successful "at putting issues on the agenda of policy makers, changing the practices of those working with people with HIV/AIDS, and increasing the skills and capacity of other organizations."
- "When asked to describe what the Legal Network did to achieve its success, a large portion of stakeholders agreed that



the depth and high quality of its research, combined with the comprehensive and thorough analysis of the issues, were important factors. Participants also considered the Legal Network's broad and inclusive consultation process, its collaborative nature and commitment to the issues, as well as its credibility and integrity, to be key reasons for its success."

- More than three-quarters of the respondents cited the efforts of the Legal Network as a factor leading to changes in the way prisons deal with HIV/AIDS. Further, almost all respondents felt that the Network had either "a great deal" or "some" influence in affecting changes.
- Respondents felt that the Legal Network's work in the area of rapid HIV testing had been successful in alerting people to potential concerns and sparking a more detailed analysis of the use of the test kits. "The Network is credited with initiating discussions on this issue in some provinces and identifying the need for further investigation. Those who have implemented the tests on a limited basis feel the Network helped to ensure the tests are being used effectively."
- All respondents felt that the Network had either "some" or a "great deal" of influence in the area of injection drug use and HIV/AIDS. Respondents said that the Network had provided good information and analysis of the legal, ethical, and policy issues involved; had raised awareness of these issues; had stimulated discussion and debate; and had succeeded in putting the issue on the agenda of policymakers.

The evaluation report also contains a number of excellent suggestions for future action, and recommendations on how we can more easily evaluate our programs on an ongoing basis. Legal Network staff and Board are currently studying the report, and look forward to implementing its recommendations. Obviously, we are pleased with the evaluators' conclusion, which says that the "Legal Network has clearly established itself as an important voice in the issue of HIV/AIDS. Its work has been shown, through this evaluation, to be extremely well respected and effective."

For more information about the Network's evaluation activities or a copy of the evaluation report, contact Glen Bugg at gbugg@aidslaw.ca. The report will soon also be available on the Network's website (www.aidslaw.ca).

Comments and Feedback

The following comments were made to the evaluation team by people interviewed during the evaluation of the Legal Network's programs.

Their credibility, at the national level, is incredibly high. Without their ongoing efforts, many advancements would not have happened.... Their role is key.

Their integrity (is the one thing that stands out). Since day one, they have produced excellence and as a result have earned the credibility and respect of everyone in the movement, our government and at the international scene.

The Network has been extremely effective in the area of prisons. They have taken on a sector that has a history of being a very closed environment that is very resistant to change. The Network has succeeded in keeping the pressure on and this has forced Corrections to look at the issues. The results have been invaluable.

[The Legal Network's work on rapid HIV testing] allowed the government to be proactive, rather than reactive, which was critical, in that it made for an intelligent debate at policy level before it became an emotional issue. We used the Legal Network's documents to guide our discussion.

The (Network's) IDU report woke people up. It was definitely a catalyst to the way in which we look at addictions and substance abuse issues.

We have a new community methadone program, secured in part by the solid rationale provided in Legal Network documents.



Project on Global Access to Treatment

In May 2001, the Legal Network and our partner organization, the AIDS Law Project of South Africa (ALP), wrapped up a joint project on legal issues related to treatment access for people with HIV/AIDS in South Africa and other developing countries. This project was undertaken with funding from the HIV/AIDS Small Grants Program established by the Canadian International Development Agency (CIDA) to strengthen partnerships between HIV/AIDS or development organizations in Canada and organizations in developing countries. The project consisted of three major components.

First, Richard Elliott, the Network's Director of Policy & Research, spent five weeks in April and May 2001 in Johannesburg, working with ALP on a variety of activities including:

- assisting ALP in its representation of the Treatment Action Campaign (TAC) in its intervention in the case of *Pharmaceutical Manufacturers Association of South Africa v Republic of South Africa* on the validity of legislative measures aimed at improving access to essential medicines;
- preparing a discussion paper, *Action for Health and Human Rights*, on strategies for Canadian organizations to undertake work in support of treatment advocacy in South Africa and other developing countries;
- research for a joint legal analysis on access to treatment and international law; and
- research for litigation regarding compulsory licensing under South African law.

Richard also participated in discussions and planning sessions with the ALP staff regarding the Network/ALP partnership and future joint activities. Here is what he had to say about the experience:

"It was both sobering and profoundly inspiring at the same time. Knowing on an intellectual level the scope of the epidemic in South Africa is one thing; spending an extended period of time working in South Africa at ALP brought home the reality of it on a much more personal, emotional level. The sense of urgency and crisis is that much more

palpable, as is the sheer frustration of coping with the terrible lack of political leadership on the part of the government. At the same time, despite the many reasons to feel disheartened, it was tremendously inspiring to work with ALP and TAC. These are incredibly effective activists who have succeeded in drawing the world's attention to the tragedy unfolding in a country still struggling with the legacy of apartheid, and who faced down the world's most profitable industry.

It was a wonderful example of how legal advocacy and community mobilization can, indeed must, mutually reinforce each other in successfully advancing human rights and social justice. The legal arguments and evidence that ALP and TAC marshalled were critical in changing the tenor of the court case and pointing out the weakness of the legal arguments put forward by the Pharmaceutical Manufacturers Association. They also provided a rallying point for community mobilization. And the protests, demonstrations, and campaigning gave the legal arguments moral weight and captured public attention, winning the case in the court of worldwide public opinion and ultimately causing the pharmaceutical companies to abandon their challenge to the legislation.

I also feel it was tremendously valuable to have these further opportunities for in-person contact over an extended period of time. Aside from the extra learning to be gained from working first-hand in other countries and settings, personal connections with colleagues working on the same issues are an important part of strengthening the partnership between the Legal Network and ALP."

Second, the Network invited an ALP staff lawyer and a legal researcher with expertise in international patent law to Canada, to raise awareness and knowledge of the South African litigation and situation regarding access to treatment for people with HIV/AIDS. In collaboration with the Interagency Coalition on AIDS and Development (ICAD), and with our South African partners from ALP, we organized a day-long meeting of organizations and experts to discuss how Canadians can best support efforts to improve access to treatment in developing countries. The Network and ALP also met with officials from CIDA and the federal Departments of Health, Foreign Affairs & International Trade, and Industry to discuss the South African case and the role the Canadian government could and should play in improving global treatment access.

Finally, the ALP organized a two-day national workshop in South Africa with experienced and new treatment activists. Over 30 participants developed their skills to do advocacy on the issue of access to treatment as a fundamental human rights issue.



A number of follow-up activities will be undertaken as part of the Network/ALP partnership. The discussion paper on Canadian initiatives for action on global treatment access is being finalized and will soon be distributed. The Network and ALP will continue joint research into legal and human rights aspects of treatment access, and will continue to undertake public education to support efforts by HIV/AIDS and human rights activists on these fronts. Finally, we will organize joint activities in the coming

year(s) on access to treatment issues, including a satellite conference at the 14th International AIDS Conference in Barcelona in 2002.

For more information about the project and the Legal Network's other activities in this area, contact Richard Elliott at relliott@aidslaw.ca.

Network Staff and Board

On 15 June 2001, *David Patterson* joined the Network staff as Director, International Programs and Capacity Building. David is originally from Sydney, Australia, and has a Master of Law degree (Human Rights) from McGill University and a Master of Science degree (Public Policy and Management) from the University of London, School of Oriental and African Studies.

David's association with the Network is as old as the Network itself. "As a law student in Australia, I had been active with the Legal Working Group of the AIDS Council of New South Wales, and after graduation spent a couple of years on staff with the Legal Project of the Australian Federation of AIDS Service Organisations," says David. "But when I came to Canada in 1992 I found that the kind of national networking we had in Australia around HIV-related legal issues did not exist. That's when I met Ralf Jürgens and the rest, as they say, is history."

After graduating from McGill, David worked for the United Nations Development Programme's HIV and Development Programme in New York, and later with the Joint United Nations Programme on HIV/AIDS (UNAIDS) in Geneva as a human rights adviser. The past two years he has worked freelance for the World Health Organization, UNAIDS, the Legal Network, the Interagency Coalition on AIDS and Development (ICAD), the International HIV/AIDS Alliance, and other organizations. While in Geneva he represented the International Council of AIDS Service Organizations (ICASO) at the United Nations, particularly the UN Commission on Human Rights.

"I am very excited about my move back to Canada and to the Legal Network, at a time when there is a real growth in interest

in both the epidemic in developing countries, and in the rights-based approach to HIV/AIDS and development generally. Canada is a world leader in promoting and protecting human rights and it is a short step to applying this approach to HIV/AIDS," he says.

Part of David's work will be to develop the capacity of Canadian legal and related institutions to respond to the epidemic nationally. "Over ten years the Legal Network has developed a unique and valuable knowledge base on HIV/AIDS law and policy," says David. "I am looking forward to making these materials more accessible to the legal profession, students, and others working with people with HIV/AIDS and affected communities. There are several models in other countries as to how we can do this."

David can be contacted by phone at 514 397 6828 ext 228 and by email at dpatterson@aidslaw.ca.

Barney Hickey, Secretary of the Legal Network's Board, was given an award of excellence for exceptional contributions to HIV/AIDS care in Canada at the annual general meeting of the Canadian Association of Nurses in AIDS Care, held in Québec City in April 2001. Congratulations, Barney!

Bios of all staff and board members are at www.aidslaw.ca/about.htm.



Important Dates

Montréal, 21-23 September 2001: The Network 2001 AGM and Skillsbuilding Event

Highlights include:

- four presentations on global access to HIV/AIDS treatments by Dr David Roy (Centre for Bioethics, Clinical Research Institute of Montréal), Mark Heywood (AIDS Law Project, South Africa), Richard Elliott (Canadian HIV/AIDS Legal Network), and Marie-Hélène Bonin (Médecins Sans Frontières) on Friday evening, 21 September;
- a chance to provide input into the Legal Network's workplans on Saturday, 22 September;
- four skillsbuilding workshops on Sunday, 23 September on (1) safe injection sites: legal and ethical issues; (2) needle exchange in prisons: how and why; (3) mandatory HIV testing: issues and questions; and (4) HIV/AIDS vaccines: legal and ethical issues;

- a keynote presentation on Sunday afternoon, 23 September, by Justice Michael Kirby from the High Court of Australia, on HIV/AIDS and global responsibilities; and
- a keynote presentation on heroin trials, also on Sunday afternoon, 23 September.

To register, contact Anne Renaud at arenaud@aidslaw.ca or tel: 514 397-6828 ext 222.

Barcelona, July 2002: Critical Legal Issues and HIV/AIDS

Because of the success of "Putting Third First – Critical Legal Issues and HIV/AIDS" the Legal Network and our partner organization, the AIDS Law Project, have started planning another satellite conference on legal issues and HIV/AIDS at the International AIDS Conference in Barcelona in 2002. The conference will focus again on legal strategies to advance the human rights of those most vulnerable to HIV/AIDS and to discrimination: people in the developing world, and people who, although they live in the industrialized world, suffer from poverty and marginalization, and are at high risk of contracting HIV. For more information, contact Glen Bugg at gbugg@aidslaw.ca.

New Resources

The following new resources produced by the Network have become available on our website at www.aidslaw.ca or from the Canadian HIV/AIDS Clearinghouse. Tel: 1-877-999-7740; email: aid/sida@cpha.ca.

- *HIV/AIDS and Immigration: Final Report*; and
- a series of revised and updated info sheets on *HIV/AIDS in Prisons*.

Other new resources produced by the Network, but available only on our website or by contacting Éric Nolet at enolet@aidslaw.ca, include

- *HIV/AIDS and Immigration: Frequently Asked Questions* (2nd revised and updated edition, June 2001);
- the Network's submission on the proposed Marijuana Medical Access Regulations;
- the Network's brief to the Standing Committee on Citizenship and Immigration on Bill C-11;
- a background paper on the Network's international program; and
- a paper entitled, "Victory in South Africa, but the Struggle Continues," explaining recent developments in access to treatments internationally.

A series of papers, including one on complementary health care, the legal and ethical issues related to the development and eventual availability of a vaccine for HIV/AIDS, and one on mandatory HIV testing of people who may have exposed others to HIV, will be released in the coming months.

For a full list of publications, contact Éric via email or by phone at 514 397-6828 ext 227.