CANADIAN HIV•AIDS LEGAL NETWORK | RÉSEAU JURIDIQUE CANADIEN VIH•SIDA

Human Rights, Global Responsibility and Access to Treatments in the Developing World

Presentations Made on the Occasion of the Canadian HIV/AIDS Legal Network Annual General Meeting and Skills Building Workshops

Montréal (Québec)
21-23 September 2001

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Ce document est également disponible en français.

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EXECUTIVE SUMMARY

The 2001 Annual General Meeting of the Canadian HIV/AIDS Legal Network was held in Montréal from Friday, September 21st to Sunday, September 23rd. The AGM opened on the evening of September 21st with a welcome session and a panel discussion on Access to Treatments in Developing Countries. The formal business of the AGM was conducted on September 22nd. On September 23rd, several skills building workshops were presented. The workshops were followed by a closing plenary, which featured two presentations on the topic AIDS, Human Rights and Global Responsibility. This document contains the texts of the presentations made at the panel discussion and the closing plenary.

The panel discussion on September 21st on Access to Treatments in Developing Countries featured four speakers: (a) Mark Heywood, Head, AIDS Law Project (South Africa), Secretary, Treatment Action Campaign; (b) Richard Elliott, Director, Policy & Research, Canadian HIV/AIDS Legal Network; (c) Marie-Hélène Bonin, Coordinator, Access to Essential Medicines Campaign, Médecin Sans Frontières / Doctors Without Borders (Canada); and (d) David J. Roy, Director, Centre for Bioethics, Clinical Research Institute of Montréal.

Mark Heywood provided a South African perspective, focusing on why the issue of access to medicines has become so critical to the response to the epidemic in that country. Marie-Hélène Bonin discussed the reasons why medicines are not available for many of the diseases that afflict the Third World. Richard Elliott explored the connection between the international struggle for access to treatments and the implications of the Trade Related Aspects of Intellectual Property Agreement (TRIPS) on equitable access to health care in Canada. David Roy looked at the moral and ethical imperatives for providing people in the Third World with affordable medicines.

Richard Elliott and Mark Heywood spoke again during the closing plenary discussion on September 23rd on AIDS, Human Rights and Global Responsibility. Richard's presentation focussed on what Canada needs to do to live up to its obligations under the UN Declaration of Commitment on HIV/AIDS. Mark explored the links between globalization, development and human rights, and then situated the issue of access to treatment in the context of these broader issues.

The presenters spoke about the urgency of addressing the issue of access to treatments in developing countries, and about the importance of not leaving 95% of the world's population in the lurch. They made a number of key observations:

- Society needs to move from perceiving global inequities as tragic facts about which little can be done, to perceiving them as morally intolerable, as totally incompatible with the relationship developed countries should have with developing countries, and as wrongs it must right. Society must turn away from the ethos that values production and profit over human dignity and move towards an ethos of humanity.

- Globalization is inescapable, but we must work to ensure that the globalization of morality and ethics keeps pace with the globalization of commerce and trade. We must work to bring about globalization in access to essential medicines.

- We must work on access to treatment issues at the same time as we work on broader issues such as improving health infrastructures and tackling the underlying causes of the epidemic.

- Access to treatments and health services has become the pivotal human rights issue in the response to the HIV/AIDS epidemic. The law has an important role to play in the campaign for access to treatments, but the law must go hand-in-hand with social mobilization and advocacy.

- The corporate agenda that has driven international trade agreements in recent years poses serious threats to the health and well-being of the world's poor.

The same corporate agenda also poses threats to the health and well-being of Canadians. The presenters made the following observations about the implications of this agenda for Canada:

- The Trade Related Aspects of Intellectual Property Agreement (TRIPS) has already been used in Canada to restrict access to lower cost generic medicines.

- Free trade agreements threaten to undermine the ability of countries like Canada to continue to provide equitable public health care services. It may only be a matter of time before pharmaceutical companies use the free trade agreements to challenge provincial government policies on generic substitution of patent medicines covered by provincial health care plans, or federal price control mechanisms.

The presenters identified several actions that civil society in Canada can take to address the issues of access to treatments:

- We need to become more trade literate. We need to understand how international trade agreements work to the detriment of people and communities.

- We must forcefully make the point to our government that in negotiating these agreements, our commitment to universal human rights, including the rights to health and to life, must take precedence over rules on patents and health care services that represent a wild imbalance between private profit and the public good. We must call on our government to become an advocate for the public good – for public health and human rights – in international trade forums.

- We must call on our government to firmly support developing country efforts to ensure that TRIPS and other international trade agreements are not used to block access to affordable medicines.

Opening Panel Discussion

ACCESS TO HIV/AIDS TREATMENTS IN DEVELOPING COUNTRIES

Friday, September 21, 2001

A South African Perspective

Mark Heywood
Head, AIDS Law Project
Secretary, Treatment Action Campaign

I would like to thank you for the opportunity to be here and to speak at this important meeting. I think that international partnerships of the sort that exist between the Canadian HIV/AIDS Legal Network (and its members) and the AIDS Law Project are extremely important, and will become more and more important as time goes on.

Talking about the issue of access to medicines in South Africa in fifteen minutes is difficult. It is particularly difficult because it is a very complex, tiring and, for me, emotional issue which actually could take many, many hours to describe. And yet, it is an issue which in certain respects is remarkable in its simplicity: There are a lot of people with AIDS and they need medicine. But it is also remarkable in its tragedy, and the growing depth of the tragedy, because I come from an odd country, one that has the best health infrastructure of any country in Africa, but almost no access to medicines for people with HIV – not just anti-retroviral medicines, medicines for fungal infections, and so forth. A country that has the most people living with HIV or AIDS of any country in Africa, but that also has the worst stigma, where people still get stoned and beaten up, kicked out of homes because the have HIV. And perhaps most perplexing of all – and this is something I really struggle to talk about, because in my life before AIDS I was an African National Congress (ANC) activist and member – a country that has the worst epidemic in Africa, but a President who does not believe that HIV causes AIDS, and whose major mission in life at the moment is to prevent the advent of access to medicines that are commonly available to people living with HIV in countries like Canada.

Those are difficult issues, and we can talk at length about each of them. But I am going to try to confine my comments to one or two questions. I would like to talk about the state and the stage of the HIV epidemics in South Africa. And I would like to talk about why the issue of access to medicines has become so critical and so central, and how I think a partnership such as this one can make a contribution to saving lives and to preventing infection.

State of HIV/AIDS in South Africa

When I was last in Canada in late 1998, and when I spoke at meetings of the Legal Network, it struck me that there was not a great deal of awareness of the extent of the HIV epidemic in South Africa, or in Africa as a whole. I think that that has changed now. As a result of the Durban Conference and the fight against the pharmaceutical companies, you all know what we face in Africa. But that change has perhaps brought something equally worrying, which is that whilst there is a wide awareness of the epidemic in South Africa, the statistics are so mind numbing that they breed paralysis about what the hell we do to respond. They are so mind numbing that we almost lose sight of the individual lives that are behind those statistics. We almost forget that there are strategies that can save those lives.

This is something that we confront everyday. The way I try to approach it is to think back to the days when we were fighting apartheid in South Africa, when our whole country of about 40 million people was trapped under apartheid. But even whilst we fought that government, we were able to fight for individuals. We knew the names of people in prison. We knew the names of communities that were being faced with forced removal. We published the names of people who were murdered in prisons. Fighting for each person's individual dignity and civil rights gave us strength and sustained us in our ability to mount an attack on the big edifice itself. I think that this approach has to inform our approach to HIV. So, before I talk about statistics, I would say to you: remember that each of those numbers is a mother, or a father, or a lover, or an employee or whatever. In South Africa, it is particularly important to remember this because it often strikes me that in South Africa there is almost a racism, even in our own government, about the way we respond to this epidemic – a racism that seems to say that black people are more able to endure pain and indignity, and the lack of things that we treat as absolutely fundamental to our lives. And these are critical things. So, it is important to mention some of these individuals.

In South Africa, the statistics are so mind numbing that they breed paralysis about what the hell we do to respond. We need to remember that each of those numbers is a mother, or a father, or a lover, or an employee. We need to give them names. We have to recognize that the fight is about people with names, histories and aspirations.

The Statistics and the People Behind the Statistics

Tomorrow, in Cape Town, we are burying a little girl called Sibonguilay. Her foster mother, three weeks ago, gave us an affidavit for our court case on mother-to-child transmission. That affidavit described how Sibonguilay's mother died two years ago. And now, two weeks ago, Sibonguilay herself, a five-year old child, died of HIV.

A few weeks ago, before I came out here, again as part of our mother-to-child transmission court case, I went on an expedition to collect affidavits from people in some of the townships around Johannesburg. I went to meet a young woman called Sara, who lives in Sharpville, which is a very famous township. It's where 68 people were shot dead in 1961. I walked into this home of this 30-year-old woman and it just struck me how horrible this epidemic is. Here was a woman who, seven years ago, when we had our election, was full of the zest and aspirations all South

Africans had for their new democracy. But in 2001, she has a CD-4 cell count of 64, and she gave birth to a 1.4 kg baby boy about a month ago without access to any antiretroviral medicines.

As if that was not enough, she told me the story about how two days before my visit, her brother had driven her out of her parent's home, telling people in the neighbourhood that she had AIDS. There was this shrivelled, pathetic, sad woman who lives with AIDS. There are thousands of people like that, all over South Africa. We need to give them names. We have to recognize that the fight is about people with names, people with histories and aspirations.

Sara is a woman who, seven years ago, when we had our election, was full of the zest and aspirations all South Africans had for their new democracy. But in 2001, she has a CD-4 cell count of 64, and she gave birth to a 1.4 kg baby boy about a month ago without access to any antiretroviral medicines.

Having made those points, I can talk a little about the state of this epidemic. I heard the last speaker say that we have to fight to stay ahead of the epidemic in Canada, and I thought, God, I wish we could say we were fighting to stay ahead of the South African AIDS epidemic. When I was last here in 1998, we had an HIV epidemic. Now, we have an HIV and an AIDS epidemic. According to government statistics, we have an HIV epidemic of 1,500 new infections a day, of 4.7 million people who live with HIV, which is about 8% or 9% of our population. Over the course of the last two or three years, we have developed a serious AIDS epidemic. In Gauteng, the province that I come from, where Johannesburg and Pretoria are located, an estimated 30,000 people will die of AIDS-related illnesses this year. Nationally, we are looking at 150,000 AIDS-related deaths a year. This is a big change. I have been working in HIV since about 1994. For the first four or five years of my life at the AIDS Law Project, we did not see many people ill, nor did we hear about many people dying. That has changed. And that is why the issue of access to medicines becomes so critical.

A new report which has just been completed by our Medical Research Council, and which our President is busy trying to suppress, shows that women are as likely to die in their mid-20s as they are in their mid-70s. This finding is based upon statistics, upon an analysis of death certificates between 1999 and 2001. We have crossed the threshold. People used to say that they did not know anybody who has got HIV or who has got AIDS. No longer. Everybody now knows people who are dying of HIV. Three or four days ago, we met with the Archbishop of Cape Town, and with the President of the Congress of South African Trade Unions, to try to form an alliance to counter the nonsense that goes on in our government. And the Archbishop of Cape Town, a very noble man said, "You know, we fought for life and not for death in the liberation struggle, and now our clergy are burying people every weekend." And it is true. In my law clinic, at the university in Johannesburg, a clinic of 28 people, three have died this year, two of them candidate attorneys. In the trade union that I work with, which has a staff of 100, five people have died this year. A few weeks ago, a very famous football player, Seesway Motamotung, died. Last year, the president's spokesperson, Parks Maklekana, died. Of course, he did not die of AIDS, because you can't die of AIDS if you work for our President, but it is hard to understand how a 36-year old man dies otherwise. This is what we are dealing with. It is this crossing over from the HIV epidemic to the AIDS epidemic that now poses the question of access to medicines so centrally.

Access to Treatments as a Legal and Human Rights Issue

No one in South Africa thinks that it is just a question of getting pills to people. Of course not. It is a question of social development, it is a question of tackling the real causes of this epidemic, it is a question of health service transformation, and so forth. But it is also a question of keeping people alive. It is access to medicines that has bettered the lives of many people in North America. Therefore, for anybody to suggest to us that we must first build our health services, and tackle these other issues, and that only later can we come to these questions of treatment access – as far as we are concerned, this is tantamount to saying: let your several hundred thousand people with AIDS die of AIDS, while we deal with the other questions first. It is nonsense. Although I was invited here with my AIDS Law Project hat, I speak increasingly in my capacity as the Secretary of the Treatment Action Campaign. But I do not think there's any discordance in that, because without question access to treatment and access to health care services has become the pivotal human rights and legal issue. That is the most challenging area of law, and it is the most challenging area of human rights for us in the midst of our type of epidemic.

Without question, access to treatment and access to health care services has become the pivotal human rights and legal issue. It is the issue on which other areas of human rights will ultimately stand or fall in our AIDS epidemic.

I would go so far as to say that it is the issue on which other areas of human rights will ultimately stand or fall in our AIDS epidemic. I say that despite having worked on civil and political rights. Two weeks ago, we finished the second edition of our resource manual, HIV/AIDS and the Law. Its 500 pages are mostly about civil and political rights. We have won cases in our Constitutional Court that stress people's right to equality and employment, to dignity and so forth. But while it is fine having equality and employment, it is not much good being employed if you can't stay well after a certain period of time. Our victories on civil and political rights have not changed the environment, or the course of the epidemic in South Africa, beyond the few thousand people that we have reached through those victories. Openness about HIV infection remains elusive. As we start to question ourselves about why that is the case, we think that the mood, the culture and the way people respond would change quite fundamentally if we could change perceptions of what it is like to live with HIV, if we could take away this belief that HIV is automatically a death sentence. Our government uses a slogan that says that prevention is the cure. That is fine if you don't have HIV, but it doesn't say much if you are already living with HIV. And that is why we think it is so critical to begin to address these kinds of questions.

The law has a role to play in this. The case earlier this year against the Pharmaceutical Manufacturers Association (PMA), in which the AIDS Law Project was involved, was both a legal and an extra-legal struggle. There is no doubt that the contribution of the Canadian HIV/AIDS Legal Network helped to get the PMA out of that court case and that it helped to bring down the price of medicines. Triple combination antiretroviral therapy in South Africa today costs about 1,000 rand a month; last January it cost 4,000 rand a month. One thousand rand a month is still beyond the reach of the vast majority of our population. Most people earn about 600 rand a month. So, the problem is far from being resolved. But that price drop means that we have gone from having 10,000 people, 10,000 out of 5 million, on antiretrovirals to a situation

where the antiretrovirals have become affordable to about 150,000 people. So, that struggle has saved lives.

The law also has a role to play in a case that we just launched a few weeks ago to compel our government to make the drug nevirapine available to reduce the risk of mother-to-child transmission of HIV, and to produce a national HIV treatment plan. We have cited people's rights of access to health care services in our arguments. To give you a sense of the urgency of this issue: 70,000 children are born annually in South Africa with HIV infection as a result of mother-to-child transmission. Yes, the law has a role, but increasingly we would say that the law must go side by side with social mobilization, with research and with advocacy. Law, in and of itself, can give you good research papers and good court judgements. But if we have not built social mobilization around those judgements, we will never enforce them. To be frank, we also sometimes have to ask ourselves whether laws have to be broken. We have to talk about morality. We have to talk about our consciences. We believe that certain patent laws, in the way they are used by pharmaceutical companies, are contrary to our constitution and to the rights that our constitution gives us. We are quite prepared to break those laws. We have launched a defiance campaign. We unlawfully import into South Africa a generic version of Pfizer's drug diflucan (also known as fluconazole) and we make that medicine available to a range of institutions for proper prescription by doctors and nurses. We think that this campaign is both moral and justifiable in the face of laws that are unjust. So, what we are saying is yes, respect the law but also, where necessary, transform the law, because we have to make the law work for us in responding to this epidemic. We have to make the law work in the interest of the broader society that law is meant to serve.

We should respect the law but also, where necessary, we should transform the law because we have to make the law work for us in responding to this epidemic. We have to make the law work in the interest of the broader society that law is meant to serve.

In conclusion, I think that these kinds of partnerships are incredibly important. I hope over the next two-and-a-half days, and over the months and years ahead, that we will be able to strengthen this partnership. And I would urge you to see South Africa, and your relationship with South Africa through the Legal Network, as a stage on which we can begin to resolve some of the global issues and challenges around access to treatment. In South Africa, we have one-tenth of the world's population of people who live with HIV, but we also have a society which is increasingly mobilized through the trade unions, through the churches, through the Treatment Action Campaign. We have a society where there is a will, perhaps stemming from our struggle against apartheid, to take these issues on and to win these issues. But I have to add that we do not have much time. We have 150,000 people who die of AIDS every year, and that number is going to grow, so it is urgent that we resolve these questions. What we do week by week counts.

What's TRIPS Got to Do With It?
And Why Should Canadians Care?

Richard Elliott
Director, Policy & Research
Canadian HIV/AIDS Legal Network

The Pharmaceutical Manufacturer's case in South Africa presents a very concrete example of how international agreements and private patent rights are invoked in an attempt to restrict countries' freedom to act in the public interest, to protect and promote the health and well-being of their citizens.

But I trust that it has also given you cause for hope, because it was one of those all-too-rare success stories. In the face of a terrible crisis, determined domestic activists, backed up by global solidarity, can successfully take on the world's most profitable industry. Sometimes justice does prevail – even if this is but one, very important, struggle in a much longer campaign.

In a moment, Marie-Hélène Bonin will outline MSF's global campaigning for access to essential medicines and research into neglected diseases, and will give you some idea of the key advocacy points that treatment activists must press in the coming months and years. And Dr. David Roy will comment on the question of our ethical obligation to care about the life and death issues of global access to treatment.

But by way of background to their remarks about why and how we, as Canadians, must take action, I want to explore with you the connection between the struggle by the Treatment Action Campaign, the AIDS Law Project and international allies in the South African context, and the implications of the corporate agenda behind the TRIPS Agreement for equitable access to health care in Canada.

I know that those of you in this room are moved by the profound injustice that Judge Edwin Cameron condemned so eloquently when he addressed the following remarks to the world at last year's International AIDS Conference in Durban:

> Amid the poverty of Africa, I stand before you because I am able to purchase health and vigour. *I am here because I can afford to pay for life itself.* To me this seems an iniquity of very considerable proportions that, simply because of relative affluence, I should be living when others have died; that I should remain fit and healthy when illness and death beset millions of others.[1]

[1] Justice Edwin Cameron. "The Deafening Silence of AIDS." Jonathan Mann Memorial Lecture, XIII International AIDS Conference, Durban, South Africa, 10 July 2000, reproduced at *Canadian HIV/AIDS Policy & Law Review* 2000; 5(4): 79-86 at 81.

We must and we should be moved to action by conscience. This, in itself, should be sufficient. But beyond an appeal to morality, we can also – and will likely need to – appeal to Canadians' enlightened self-interest. And of course, the first challenge will be to enlighten.

Therefore, I want to talk about three specific developments that illustrate why Canadians should be concerned about the agenda that led to TRIPS in the first place, and that is behind the current push for an even more unbalanced policy in the area of intellectual property rights.[2]

The critique could go much further and into much more detail. But these three developments should suffice to make the point that the corporate agenda behind so-called "free trade" agreements poses a very serious threat to the health and well-being not only of the world's poor, but also of those of us with the good fortune to live in a wealthy country.

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The *Generic Medicines* Case – A Dangerous Precedent

First, let us consider Canada's own experience to date with the TRIPS Agreement.

In May 2000, a panel of the World Trade Organization (WTO), the body which adjudicates disputes under WTO trade treaties, issued a ruling in one of the first cases to consider the interpretation of TRIPS as it applies to patents for medicines, a ruling that sets a dangerous precedent. In what is commonly referred to as the *Generic Medicines* case, the European Communities (EC), subsequently supported by the United States, filed a complaint with the WTO, alleging that two aspects of Canada's *Patent Act* violated the requirements of TRIPS.

Canada successfully defended the more important of the two provisions, which is not surprising, given that the U.S. and many European countries have similar provisions in their own legislation. But we lost on the other one – and we lost in a way that could be damaging in subsequent cases that challenge countries' patent laws as being in breach of the TRIPS Agreement. The decision is worrisome in two respects:

- first, because of the bias it may establish for subsequent interpretations of TRIPS, particularly as it applies to pharmaceutical policy; and
- second, because of what it does <u>not</u> say about the importance of balancing the protection of private patent rights with the public interest in promoting health and human rights.

Let us look at both of these.

First, the WTO Panel took a very narrow, biased approach to interpreting the TRIPS Agreement. Canada's law allowed generic drug manufacturers to "stockpile" their generic version of

[2] These remarks were delivered before the Canadian and U.S. governments threatened to over-ride Bayer's patent on the anti-anthrax drug ciprofloxacin in the light of concerns about bioterrorism.

patented drug in the six months before the patent expires, so as to be ready to enter the market immediately once it does. But, as you would expect, it did not allow the sale of generic products until the end of the patent term. In other words, the law in no way interfered with the patent-holder's market monopoly during the term of the patent – the single most important feature of a patent. Nonetheless, through some rather twisted reasoning, the Panel concluded that allowing generic companies to stockpile their product so as to prepare to enter the market was a "substantial curtailment" of patent-holders' exclusive rights. As such, it could not be a "limited exception" to exclusive patent rights that is permitted under TRIPS.

This goes well beyond what countries actually agreed to in signing TRIPS – namely, to give inventors 20 years of patent protection. It reads into the agreement a whole new entitlement for patent-holders – a "right" to additional market monopolies beyond the term of their patent. The Panel reasoned that countries must have intended this when they signed TRIPS, even though it is such a significant point that you would think countries would have made it clear if they had intended this outcome. In fact, Canada and a majority of the countries intervening in the dispute stated this had not been their intention. Furthermore, the TRIPS Agreement itself says that countries are not obliged to implement in their law more extensive patent protection than is required by TRIPS.

Second, the decision is significant for what it does not say, further reflecting the Panel's narrow, biased approach to interpreting TRIPS. In defending the provisions of its *Patent Act*, Canada argued that it had a legitimate "national interest in measures conducive to social welfare," and that it sought to protect public health by "promoting access to cost-effective generic medicines following patent expiry, taking into account the legitimate interests of individuals, private insurers and public sector entities that finance health care in maintaining access to affordable medicines."

The EC responded by stating that such considerations were "of little, if any relevance" in interpreting the TRIPS Agreement. The EC claimed that TRIPS is "neutral vis-à-vis societal values", that "none of [these] public policy considerations could be invoked to justify measures ... inconsistent with...TRIPS," and that "public health, nutrition and other public interests were to be considered subordinate to the protection of the intellectual property rights...guaranteed by TRIPS." The EC expressly rejected the idea that "consumers or society at large" could have any "legitimate interests" to be considered in interpreting TRIPS. It even went so far as to nonsensically assert that the purchase or consumption of a medicine by a patient was of no relevance in patent terms, and that there "could be no adverse interests between the consumer and the patent holder." In the EC's view, the TRIPS Agreement "was not...aimed at solving the public health problems of the entire world."

But the notion that public health or other public interest considerations are irrelevant to the interpretation of TRIPS is simply wrong. And what is particularly worrisome is that, in basing its interpretation so heavily on the interests of private patent holders, the WTO Panel seems to have ignored some absolutely fundamental parts of the Agreement, parts which speak directly to this issue of striking a balance between private corporate interests and the public good.

Article 8 of the TRIPS Agreement, which Canada invoked in its defence, expressly says that in making their own laws, countries may adopt measures necessary to protect public health and to promote the public interest in sectors of vital importance to their development. It also says that measures may be needed to prevent the abuse of intellectual property or the resort to practices that unreasonably restrain trade or affect the international transfer of technology. Furthermore, Article 7 of TRIPS says that the purpose of protecting intellectual property rights should be to promote innovation and the dissemination of technology "to the mutual advantage of producers and users.. and in a manner conducive to social and economic welfare." It also refers expressly to "a balance of rights and obligations."

Canada has now amended its *Patent Act* to remove this provision allowing generic drug companies to stockpile their product and be ready for marketing as soon as a patent expires. Such delays represent additional costs to individual patients and to public and private insurers.

But in the *Generic Medicines* case, the Panel completely ignored these over-arching elements of the TRIPS Agreement. Rather than considering the public interest, as urged upon it by Canada, it looked exclusively at patent-holders' expectations of "economic returns anticipated from a patent's grant of market exclusivity." Rather than considering the need to strike a balance between different social and economic interests, the Panel decided that, because patent-holders expected that they would enjoy market monopolies even beyond their patent terms – by preventing generic drugs from being manufactured in the lead-up time to patent expiry and consequently delaying them from getting to market – then this must be part of the "normal" exploitation of a patent, and Canada's interference with patent-holders' normal expectations could not be justified.

Note that in adopting this very narrow interpretation of what exceptions to patent right countries are entitled to include in their own laws, the Panel ignored not only these two foundational articles of the Agreement, but also basic principles of treaty interpretation that are well-established by a previous convention (the 1969 *Vienna Convention on the Law of Treaties*). It even ignored the principle stated by the WTO's Appellate Body in an earlier case that, where there is more than one plausible approach to interpreting a treaty, the one that is less restrictive of countries' sovereignty should be adopted.[3]

For whatever reason, the Canadian government chose not to appeal this decision to the WTO's Appellate Body. Maybe they feared – and perhaps with good reason – that the would lose again, thereby establishing a damaging precedent at an even higher level. Canada has now amended its *Patent Act* to remove this provision allowing generic drug companies to stockpile their product and be ready for marketing as soon as a patent expires. Such delays represent additional costs to individual patients and to public and private insurers.

[3] See: R Howse. The Canadian Generic Medicines Panel: A Dangerous Precedent in Dangerous Times. *Journal of World Intellectual Property* 2000; 3(4): 493-507.

International Solidarity?

As shown by the *Generic Medicines* case, Canada – and not just developing countries – has suffered a setback in the area of sound pharmaceutical policy as a result of TRIPS. You might think this would lead the Canadian government to feel a sense of understanding, sympathy – perhaps even solidarity – with other, developing countries that have faced similar pressure and that seek to use the flexibility that ostensibly exists under the TRIPS Agreement to promote access to affordable medicines. But sadly, you would be wrong, as is demonstrated by Canada's utter silence in the recent WTO dispute between the U.S. and Brazil, and by its unfortunate conduct at the most recent meetings of the WTO's Council for TRIPS. Let us look at each of these in turn.

Brazil is frequently referred to as one of those developing countries that, as part of a successful AIDS policy, has provided free drugs – including antiretrovirals – to over 90,000 people living with HIV/AIDS who could not otherwise afford them, thereby drastically reducing rates of death and opportunistic disease. The treatment program has been so successful that Médecins Sans Frontières just announced a few days ago that it will be working with Brazil to replicate this success elsewhere in the developing world.

You will recall that the U.S. and Brazil recently settled – at least for now – their dispute over a provision in Brazil's patent law. That provision said that if patent-holders wanted to enjoy full patent rights in Brazil for their inventions, then within three years of obtaining a patent they would have to "work" the patent locally – in other words, make patented medicines in Brazil – if it was economically viable to do so. If they did not, then a compulsory licence could be issued allowing someone else to manufacture that product in Brazil, with the payment of adequate compensation to the patent-holder as required by TRIPS.

While the pharmaceutical industry and the U.S. criticized this "local working" requirement as a protectionist measure aimed at fostering Brazilian jobs (as if this were a bad objective), treatment activists have also pointed out that local production of medicines, as opposed to just importing drugs:

- helps insulate the Brazilian price of medicines against the effects of currency devaluations;
- stimulates a domestic knowledge base in that field of technology that can be used in the production of generic drugs, either once patents expire, or if a compulsory license needs to be issued before then to control the abuse of patent rights, or if a patent-holding company should decide to stop manufacturing a drug that is still medically necessary in a country but for which there is no longer a large enough worldwide market to make it profitable; and
- fulfils one of the stated objectives of TRIPS, namely the transfer and dissemination of technology.

Activists repeatedly called upon the Canadian government to support Brazil in this dispute. As we pointed out, if our government feels that legal measures designed to promote access to affordable medicines are defensible as the acts of a sovereign country acting to protect public health, as it argued in its own defence before the WTO in the *Generic Medicines* case, then surely the same reasoning applies in the case of a developing country facing U.S. pressure that

will undermine a highly successful HIV/AIDS treatment program? Surely Brazilians deserve the same consideration as Canadians? Our government, however, did the quintessentially Canadian thing – it sat on the fence and told us it would "monitor" the situation. This is not bold leadership.

And, sadly, over the past few days, Canada has gone from fence-sitting to actual obstructionism. The WTO's Council on TRIPS has been meeting this past week in Geneva, and the primary item of discussion is the need to ensure that TRIPS does not impair countries' freedom to balance intellectual property rights against the public interest in health. A group of 52 developing countries from Africa, Asia and South America have put forward proposals that would ensure the TRIPS Agreement is not used to block governments from implementing public health measures aimed at making medicines more affordable. The U.S. has presented counter-proposals that, as a representative of one NGO put it, "could have been a cut and paste job" from the website of Pharmaceutical Research and Manufacturers of America (PhRMA), the brand-name industry lobby group in the U.S. Somewhat surprisingly, Canada has endorsed the U.S. position.

The Canadian government must firmly support developing country efforts to improve access to affordable medicines. On this issue, as on so many others, Canada must show moral leadership, and not unquestioningly endorse action by the U.S. government that will result in death and suffering for millions.

This is not only shameful and deserving of very public criticism here in Canada. It is also breathtakingly short-sighted – and Canada, having already witnessed firsthand the inflexibility with which TRIPS can be interpreted, and the short shrift that has been given to public health concerns in the interpretation of TRIPS to date, should know better. The Canadian government must change its position on this issue at the WTO and firmly support developing country efforts at the upcoming WTO Ministerial Conference in November. On this issue, as on so many others, Canada must show moral leadership, and not unquestioningly endorse action by the U.S. government that will result in death and suffering for millions.

Predictive Genetic Testing for Breast Cancer

To illustrate why such a position is short-sighted, let me turn to the second example that should convince Canadians that we need to be active in the struggle to ensure that international trade and patent regimes do not impede access to affordable health care.

This week, the media reported that the Ontario government is "defying" a U.S. company, Myriad Genetic Laboratories, which is asserting patent rights that would prohibit anyone else from using a genetic screening test that can be used to detect genes that are correlated, in some women, with a heightened risk of breast cancer.[4] Myriad claims patent rights on the BRCA1 and BRCA2

[4] R Mackie. Harris battles firm over gene patenting. *The Globe & Mail*, 20 September 2001; R Benzie. Ontario to defy US patents on cancer genes. *National Post*, 20 September 2001; C Mallan. Gene tests for cancer won't stop. *Toronto Star*, 20 September 2001; Ontario defies US gene company over cancer test, arguing health care at risk. *Canadian Press Wire*, 19 September 2001; H Kent. Patenting move ends BC's gene testing program. *Canadian Medical Association Journal* 2001; 165(6): 812.

genes, and has demanded that all cancer-screening tests based on these two genes be done by its own labs or labs to whom it has issued a licence to use the genes.

Until recently, several provinces' health plans had been covering the $800 cost of doing the testing at Canadian hospitals. But Myriad will charge $3850 per test, 4 ½times as much. The B.C. Cancer Authority and the Alberta government have both given in to Myriad's demand and announced they will no longer fund the test (although it was just reported that they are perhaps reconsidering this position). The Ontario government, however, has stated that it will continue funding these tests and that it plans to put this issue on the agenda at next week's meeting of health ministers. We have heard some astonishing statements from the Ontario government in the past few days. Premier Mike Harris declared that the benefits of the human genome project "should not be the property of a handful of people or companies." He was further quoted as saying that

> "The federal government should examine Canadian patent laws to make sure all citizens can share the benefits of this new research frontier. If we have the ability to save a life, we have a responsibility to do so";

and, in reference to curbing pharmaceutical patents, he said that:

> "When it comes to the practical help and benefits to humanity... there have been other instances of significant changes in limitations to what the patent laws allow."

Similarly, the provincial minister of health asked whether the benefits of human genome research "are going to come down to a series of monopolies setting exclusive prices for tests which most of Canada – indeed most of the world, especially poor countries – cannot afford?"

Strong rhetoric from men whose allegiance to private corporations is, judging from their record to date, often immune to any appeal to human rights or even basic decency. Yet we still have – for the moment – a publicly-funded and ostensibly universal health care system in this country, and they recognize the tremendous financial implications of gene patenting to the public purse.

For now, they are talking tough about re-examining the balance between private profit and the affordability of health care. But it could also be very easy for them to change their tune, to begin using this as yet another excuse for chipping away at Canada's public health care system. We must be sceptical of their sudden concern for the health and well-being of the poor, here in Canada and abroad, but we must seize this opportunity. It will be our challenge to make sure that the focus is, and remains, squarely on the issue of achieving a fair balance between patent protection and the public good.

Current Threats: NAFTA, FTAA and GATS

Finally, I want to mention some other developments that are currently underway that should drive home to you why Canadians, and not just South Africans or people living in other developing countries, should be concerned about access to health care. I call them the "unholier trio" – three other trade agreements that threaten to undermine the ability of countries like Canada to maintain public health care systems providing relatively equitable access to health

care services. These are: the North American Free Trade Agreement (NAFTA), the Free Trade Agreement of the Americas (FTAA) & the WTO's General Agreement on Trade in Services (GATS).

NAFTA

One of the most nefarious features of NAFTA, and one that is unprecedented in trade agreements, is "Chapter 11," a set of provisions that give corporations the independent right to sue governments in special tribunals (which operate largely in secret with little public transparency) for cash compensation if they believe government policies or actions affect the value of their private property.

While some people might be sympathetic to the notion that property should not be expropriated by government without compensation, the experience to date with NAFTA shows that corporations are using the treaty not to protect against state seizure of their property, but rather to challenge policies and laws aimed at protecting the environment, health or other public interests.

It may only be a matter of time before patent-holding pharmaceutical companies challenge either provincial government policies implementing generic substitution of medicines covered by provincial health plans, or price control mechanisms as the Patented Medicines Price Review Board.

Efforts to characterize public interest regulations by government as expropriations requiring compensation have generally been rejected in the laws of at least the U.S. and Canada. So companies have pursued this agenda before NAFTA tribunals, which have been much more accommodating. In fact, Canada has faced the biggest attack to date in the first seven years of NAFTA challenges to public interest laws, with corporations claiming US$ 11 billion from Canadian taxpayers as compensation for government regulations.[5]

For example, the Canadian government has already paid out US$ 13 million to Ethyl Corporation to settle the company's claim that Canada's ban on the import of gasoline additive MMT (which is known to be toxic) constituted an "expropriation" of its property. Canada has removed its ban on MMT. (I should point out that this amount is equal to just under one-half of Canada's entire annual spending on the Canadian Strategy on HIV/AIDS.) Other examples include: successful challenges to Canada's implementation of two international environmental agreements; successful challenges to a Mexican municipality for denying a construction permit for a toxic waste facility; and, currently, an active challenge by the courier company UPS to the operation of parcel and courier services by the government through Canada Post.

You can see what the implications are for government measures aimed at increasing access to affordable generic medicines. It may only be a matter of time before patent-holding pharmaceutical companies challenge provincial government policies implementing generic substitution of medicines covered by provincial health plans, or price control mechanisms such as the Patented Medicines Price Review Board (PMPRB), implemented as the consolation prize

[5] Public Citizen. NAFTA Chapter 11 Investor-to-State Cases: Bankrupting Democracy – Lessons for Fast Track and the Free Trade Area of the Americas. Public Citizen & Friends of the Earth, September 2001 (www.citizen.org).

for consumers when the Mulroney government abolished most compulsory licensing under Canada's *Patent Act* in 1987 and 1993. (In fact, the pharmaceutical companies are already challenging the *jurisdiction* of the PMPRB.)

Indeed, NAFTA could present a major barrier to Canada ever re-introducing broader compulsory licensing provisions in our law, because it would almost certainly be challenged as a form of government expropriation. In this sense, Canada has already gone considerably beyond the requirements of the WTO TRIPS agreement which came into force in 1995. That agreement does permit countries to incorporate compulsory licensing provisions in their domestic legislation, although there are some restrictions that pose potential problems, particularly for countries without the industrial capacity to produce their own generic medicines domestically.

FTAA

The Free Trade Agreement of the Americas (FTAA) is basically the worst of NAFTA and TRIPS expanded to the entire hemisphere. While the text is still being negotiated, all signs so far spell trouble for equitable access to affordable health care.[6] Developing countries in Latin America and the Caribbean are likely to be the hardest hit, but no country will be immune.

On the intellectual property front, there is a strong push to incorporate "TRIPS-plus" provisions on intellectual property – in other words, going even further than TRIPS already requires – by expanding monopoly rights and further limiting the options that currently remain in TRIPS (such as the provisions on compulsory licensing) that provide some flexibility for countries to address their domestic public health concerns. It also threatens to further restrict the possibility of issuing compulsory licenses that would allow the export of generic drugs – for example, to developing countries that lack the ability to establish their own generic drug manufacturing.

And the U.S. has indicated it is pushing for FTAA provisions that will allow for further extension of patent terms, delaying even further the entry of generic drugs onto the market. And finally, harkening back to the issue of gene patenting that I mentioned a moment ago, proposed text in the FTAA would expand the monopoly power of companies who hold patents on genes – rather than exempting genetic discoveries (which are arguably not "inventions") from patentability.

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In addition to ratcheting up protection for private intellectual property rights, the draft text also proposes to include a NAFTA-style section giving corporations the ability to sue governments directly for interfering with their profits – including through any laws or policies that might limit exclusive patent rights in the public interest.

[6] For an analysis, see: R Weissman. Comments on the draft FTAA text. Washington DC: Essential Action, 22 August 2001.

In other words, the FTAA is a double-barrelled attack that will impose even more stringent patent rules on countries, and let industry enforce them directly.

GATS

Finally, the General Agreement on Trade in Services (GATS), one of the WTO trade agreements, restricts government actions affecting services – such as health care services. As with other trade agreements, GATS is aimed at allowing challenges to public interest regulations that affect private corporate interests.

Furthermore, GATS is subject to a built-in agenda of negotiations aimed at continuously expanding its scope. At the moment, there is a very real threat that health care services (among others) will fall under the rubric of GATS. Although the agreement says that services "provided in the exercise of governmental authority" are excluded from the agreement, the definition of these services is so narrow that this clause is of little practical value.[7] All government services provided on a commercial basis, or supplied in competition with any other suppliers (e.g., private health care providers), are subject to GATS. So any area of services provided through a mix of public and private delivery and funding is vulnerable – such as health care in Canada today, and increasingly so with the drive toward privatization of various components of health care delivery.

The people of Canada should be just as concerned as the people of South Africa about the so-called "free trade" agenda that gave us the TRIPS Agreement. The same forces that invoked private patent rights and international agreements to delay the South African government's measures to make medicines more affordable are also gunning for Canada.

A good example is the threat posed by Alberta's Bill 11 that would authorize private clinics that receive partial reimbursement for medical procedures from the provincial health plan. Under GATS, any right to reimbursement granted to one foreign private company providing these services must be "immediately and unconditionally" extended to every other similar foreign provider. As Scott Sinclair from the Canadian Centre for Policy Alternatives points out, this could "turn a crack in the public system into a fissure."[8] Furthermore, once this step has been taken, government action to reverse course could expose all Canadians to a WTO complaint and possible retaliatory trade measures from other countries, because companies interested in the significant profits to be made in the Canadian health care market will almost certainly challenge such steps as "expropriating" their "property."

[7] For a detailed analysis of GATS, see: S Sinclair. GATS: How the World Trade Organization's new "services" negotiations threaten democracy. Ottawa: Canadian Centre for Policy Alternatives, 2000 (available via www.policyalternatives.ca).

[8] Ibid, at 36.

Conclusion

I hope these examples have brought home to you why the people of Canada should be just as concerned as the people of South Africa about the so-called "free trade" agenda that gave us the TRIPS Agreement. The same forces that invoked private patent rights and international agreements to delay the South African government's measures to make medicines more affordable are also gunning for Canada.

Consider that in February of this year, PhRMA, the U.S. industry lobby group, included Canada among the 13 countries on its annual "priority watch list" and is urging the U.S. government to place Canada on the government's official priority watch list, an advance warning to countries that they face trade pressure and possible retaliation from the U.S. if they maintain policies the U.S. government (and its industry) find objectionable.[9] We cannot pretend that what happens "over there" is not related to what is happening, and will happen, "right here."

So what is to be done? The AIDS movement has an inspiring history, born of necessity, of activists and ordinary people educating ourselves and our communities about complex medical matters – from the basics of virology to the design of clinical trials to the process for approving new drug treatments. Informed and empowered, "treatment literate" AIDS activists rejected the passive position of merely relying upon government authorities or medical experts, and demanded a voice in shaping law and policy that affected the lives of people living with HIV/AIDS.

We must insist – loudly, forcefully, and repeatedly, it would seem – to our governments negotiating these treaties that our commitment to universal human rights, including the rights to health and to life, must take precedence over rules on patents and health care services that represent a wild imbalance between private profit and the public good.

Now, to face the next challenge, that of corporate globalization, we need to become "trade literate." We need to understand how international trade agreements already in place, or currently being negotiated, work to the detriment of individual people, entire communities, and the public health at large. We must insist – loudly, forcefully, and repeatedly, it would seem – to our governments negotiating these treaties that our commitment to universal human rights, including the rights to health and to life, must take precedence over rules on patents and health care services that represent a wild imbalance between private profit and the public good. Again, let me return to Justice Cameron's remarks in Durban, at a satellite conference on critical legal issues and HIV/AIDS. He reminded participants that not only do we need the right concepts and actions in responding to this epidemic, we also need the right feelings – our outrage, our compassion, and our grief must move us to action.

[9] Letter dated 16 February 2001 from Shannon SS Herzfeld, Senior Vice President (International Affairs), Pharmaceutical Research and Manufacturers Association of America, to J Papovich, Assistant U.S. Trade Representative for Services, Investment & Intellectual Property, and *PhRMA Special 301 Submission*, 20 February 2001 (available on-line at: www.pharma.org/intnatl/news/2001-02-20.40.pdf).

His words then reminded me of something Paul Monette wrote several years ago. He described a scene in which he sat on a hilltop in a cemetery, reflecting on the loss of a loved one to AIDS and the indifference, hate and greed that has fuelled the epidemic and so many deaths. He concluded with a call to action: “Grief is a sword, or else it is nothing.”

The many threats posed by corporate globalization are one of the defining features of this era. We must respond to those threats – we cannot afford not to. And we must do it now – the millions who are already living (and dying) with HIV, and the millions more who will contract it, cannot afford any further delay.

Accessing Essential Medicines: Why We Need a Global Campaign

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Médecin Sans Frontières / Doctors Without Borders (Canada)

It is a real pleasure and honour to be invited to speak alongside people whom I much admire and who help me greatly every day in my work. I am honestly surprised to see my name associated with this publication on patents.[10] Six months ago I knew nothing about patents or legal and trade issues, and it is only with the help of those I have just mentioned that I have been able not only to understand the importance of access to essential medicines, both in Canada and worldwide, but also to try and make other people understand.

As you know, Médecins Sans Frontières (MSF, also known as Doctors Without Borders in English-speaking Canada) is a humanitarian medical assistance organization and is thus not particularly familiar with trade or legal issues. I hope, therefore, that you will excuse me for not concentrating on this aspect of the discussion this evening.

MSF has been in existence for 30 years and over this time has become the world's largest NGO dealing with humanitarian medical assistance. It now operates in more than 85 countries, including those under rather alarming threat. MSF is primarily concerned with the most vulnerable populations – those in danger, or those who have to deal with war, conflicts, or natural disasters. Refugees or displaced populations, who are often very poor. I emphasize the words "very poor": MSF acts and operates first and foremost in developing countries, and within those countries we work with the most deprived and marginalized, the victims of conflicts and disasters.

In 2001, the funds devoted to health research will amount to between 60 and 70 billion dollars. Of this money, less than 10 percent will go to health problems that affect 90 percent of the world's population. Imagine the result.

We therefore work every day with people who have the least access to medicines – and we are not talking here about a minority of the people on the planet. As you know, the great majority of the world's population lives in developing countries and these people only have a limited access to the medicines they need.

Without getting into too many depressing statistics, I would like to remind ourselves that 14 million people die every year from communicable diseases such as AIDS, tuberculosis, malaria and many others – and that most of them (97%) live in developing countries.[11] Meanwhile, in many cases, treatments exist but very few people have

[10] Elliott R, Bonin M-H. *Patents, International Trade Law and Access to Essential Medicines*. Montréal and Ottawa: Canadian HIV/AIDS Legal Network and Médecins Sans Frontières, 2001. Available at http://www.aidslaw.ca/Maincontent/issues/cts/Patents-international-trade-law-and-access.doc

[11] MSF / Doctors Without Borders Canada, *Medicine Shouldn't Be a Luxury; How Politics is Failing the Dying*, 2001.

access to them. This does not help our work. It has thus been through our concrete, everyday experience in the field that MSF has over the years been increasingly confronted with the growing problem of lack of access to drugs.

We have problems because a great many epidemics are growing rather than being eradicated, for a number of reasons. Among these, access to treatment is a neglected factor. There are many obstacles to access. To name the main ones: the price of medicines; the concentration of the global pharmaceutical industry; the monopolistic control the pharmaceutical industry has over markets through the patent system; the barriers these private firms place on the production and marketing of medicines if the market is not lucrative "enough" for them; the very fact that research and the development of medicines is primarily determined by market profitability – i.e., no market, no research; and the fact that governments are increasingly adopting the same kind of reasoning as the pharmaceutical industry (which leads to the investment of public money only into what corresponds to this "logic" of profit).

The research and development of medicines is primarily determined by market profitability – i.e., no market, no research.

Thus, for example, even public funds invested in university research are increasingly subject to the criteria that govern the private pharmaceutical industry's investments. Whether researchers are funded by a government ministry or are supported by a major pharmaceutical company, they have to do the same work and meet the same requirements. There is less and less investment into developing treatments of diseases that do not promise lucrative markets, even though such diseases often affect the very great majority of the world's population. Transmissible diseases such as HIV/AIDS, as well as malaria, tuberculosis, sleeping sickness, Chagas disease, leishmaniasis, dengue fever, leprosy and Ebola hemorrhagic fever, are the daily lot of most people on the planet. It is estimated that in 2001, the funds devoted to health research will reach an unprecedented amount, between 60 and 70 billion dollars. Nevertheless, experts estimate that only 10 percent of all funds devoted to research are directed to health problems that affect 90 percent of the world's population.[12] Imagine the result.

This is the upstream problem, at the research stage. If we look downstream, towards the production stage, the reality I have just described determines what will or will not be manufactured – it even happens that the production of medicines that are already developed and marketable is stopped.

For example, you have surely followed the story of eflornithine, a medicine used to treat sleeping sickness.[13] This was a new, efficient treatment for the disease, but it was not being used all that

[12] MSF Campaign for Access to Essential Medicines and Drugs for Neglected Diseases Working Group, *Fatal Imbalance*, 2001; Pharmaceutical Research and Manufacturers of America, *2001 Industry Profile*; Global Forum for Health Research, *The 10/90 Report on Health Research*, 2000. Available on-line: http://www.globalforumhealth.org

[13] Sleeping sickness is transmitted by the tsetse fly. Until recently this has been little spoken of in Canada. The Guardian reported that in central Africa, where it was nearly eradicated in the sixties, sleeping sickness is now spreading three times faster than the HIV epidemic. In Angola, for example, at the time of independence (1974), there were three reported cases, whereas recent estimates are that there are more than 100,000 cases. (Dr. Josenando Theophile, Director of the Institute for Combat and Control of Sleeping Sickness, The Guardian, August 18, 2001).

much because it was expensive. Drug companies suddenly decided to stop producing it – because there were too few buyers. This meant that once stocks would run out, MSF doctors would find themselves in a position where they would have to start reusing an old medicine that was not only ineffective, but dangerous and toxic (this medicine is said to have killed up to five percent of patients). For two years, the World Health Organization and MSF put frantic pressure on the industry to restart the production of eflornithine before stocks were depleted. They were unsuccessful until the industry discovered that the active ingredient of eflornithine was effective in the production of a facial-hair removal cream, which had great marketing potential in the United States. Many, many women would likely be interested is such a cream, so the production of the ingredient in question was suddenly started up again in order to manufacture and market this promising product. The scandalous incongruity of the situation was made public by MSF and others, and it was only then that an agreement could (eventually) be reached to restart the production of eflornithine for medical purposes.

From Research to Production and Marketing

Let us keep looking downstream – the product has made the difficult transition from the research stage to the development and production stages, and we arrive at the marketing stage. Assuming that the market criteria have determined that a particular medicine will be produced, what price will be set for it? It is at this point that we get into the tragic reality of pharmaceutical industry concentration which, in turn, is related to another reality that my friends explain better than I can: the new legal and regulatory challenges posed by the globalization of the patent system.

In the past, if I understand correctly, patents were a national matter, with each country carrying on its own affairs: if a country could afford to have patents, it had them; but if it could not, it did not (or it had patents only on some pharmaceutical products, but not on essential medicines). Now it is different. Today, everything is globalized (from the point of view of trade, that is, not to be confused with what is not being globalized – the right to health, to a certain quality of life, to care and to treatment[14]). The right to affirm and control one's market share is being globalized at all costs – a process that is becoming increasingly firmly established and will become more firmly established if we do not take care.

The World Trade Organization's intellectual property agreement (the TRIPS Agreement) could, within a few years, make it impossible for countries currently able to afford lower-cost medicines to continue producing or purchasing them. As a result, one would no longer necessarily be able to obtain the best product at the best price. This would affect the few developing country governments that can access affordable medicines. The major consequences of this would be felt primarily by the average citizens of these countries, because in most cases they pay for medicines out of their own pocket. Such people would be directly affected, along

[14] "MSF believes that the definition of essential medicines adopted in 1999 does not require any changes. In this definition, we attach particular value to the term ' therefore.' It is because these drugs are essential that they should be rendered financially accessible (by the governments of the North and the South, the pharmaceutical industry, international institutions, etc.) and not the other way round. Drugs should not be judged essential only when they are affordable. (…) [In the current revision of the WHO model for a list], MSF considers that essential drugs remain essential drugs even if they are expensive or difficult to use. They must therefore remain on the list, with specifications of their distinctive features (difficult to use, expensive, etc.)." – Dr. Bernard Pecoul, Director, MSF Campaign for Access to Essential Medicines, 2001.

with organizations such as ours: we would no longer always be able to transport medicines throughout the world as we have done so far.

Faced with this, MSF has become aware of the importance of alerting public opinion. We have a double mission: humanitarian medical assistance, of course, but also a mission to defend humanitarian rights and to denounce the abuses we witness in the course of our work. In a conference of international NGOs in Amsterdam in 1999, an initial Declaration was adopted by Médecins Sans Frontières, Health Action International and the Consumer Project on Technology. We realized that the problem exceeded our capacities; that alliances and partnerships would have to be established with various organizations, and that commitments from governments were needed. The declaration led to a first presentation of these issues, by Dr. Bernard Pécoul of MSF, at the WTO meeting in Seattle.

Campaign for Access to Essential Medicines

In the same year, MSF was awarded the Nobel Peace Prize and decided to use the money to launch an international campaign for access to essential medicines. The campaign has three main pillars: legislation, provision of medicines, and research. The first pillar involves legislative issues, such as the international trade framework and its effects on our work and on access to medicines – i.e., how the trade agreements affect the possibility of creating the conditions that will result in quality, low-priced generic medicines being made available. MSF action in this regard is one of information, alliance building and advocacy. The second pillar concerns the provision of existing medicines, and, in particular, how to ensure that the manufacture of needed medicines is not stopped, that what can be produced is produced, and that these medicines are delivered to the countries that need them. We are helping various governments and our other partners in the world identify the best options. This work involves logistics, pharmaceutics, shopping, research and analysis of the best means of procuring medicines, and their delivery to the populations who need them. The third pillar concerns research and development of new drugs and diagnostic tools: we are trying to facilitate exchanges among researchers who are working on the most neglected diseases and to stimulate public and private investments in research and development in this field.

This campaign and the three pillars on which it is based go far beyond the framework of our daily activities in the field missions – be they in Afghanistan, Congo, or elsewhere. This is why we are creating partnerships with those who have the abilities and experience we lack. It has therefore been a pleasure to learn about the work of the Canadian HIV/AIDS Legal Network. We also have an in-the-field relationship with the Treatment Action Campaign in South Africa, and with local NGOs and associations of people with HIV in other countries.

I do not think this will be an easy fight, but I do believe these alliances will enable us to make gains and to progress (as they have already done for the past year or two). I also think that Mark Heywood is entirely right to say that we cannot let ourselves get bogged down in procedural issues, and that we cannot forget that every day people are dying because of lack of access to medicines that would enable them to live.

Work on legal issues is very important, particularly on the eve of a new World Trade Organization ministerial conference in November, in Qatar, at which issues concerning the TRIPS Agreement are on the table. The coming weeks will be crucial. But we should not put all our eggs in a single basket – a basket of approaches and procedures that sometimes tend to prolong unduly the "search for solutions" to serious and urgent problems. We have to consider a wider range of approaches, use various leveraging tactics at the same time, develop multiple strategies and partnerships – sometimes without knowing what will really work, perhaps with a little hit and miss, perhaps with more of a gut feeling about what is right than with certainty about what the most appropriate approach to take is.

Guided by our principles, our moral values, our expertise, our personal experiences and those of our friends, spouses, families, neighbours – here and abroad – we will be able to perform miracles. Of that I am certain.

Ethical Imperative for Action
OR
Why Should We Care?

David J. Roy
Director, Centre for Bioethics, Clinical Research Institute of Montréal
Research Professor, Faculty of Medicine, Université de Montréal
Director, FRSQ Network for Research in Clinical Ethics
Editor-in-Chief, *Journal of Palliative Care*

The title for this brief presentation comes from two sources. Richard Elliott is the first. When I asked him the other day what he wanted me to talk about, he said, among other things, that he would like to hear me respond to the question of why we in the rich countries of the North should be concerned about the plight of those living thousands of kilometres away from us. So my lead question for this presentation is: "Why should we care?"

The second source is the journalist, C. Mihill. Ten years ago, on the occasion of the 7th International Conference on AIDS, Mr. Mihill expressed his sense of unreality at the indifference he recognized among the participants of the rich countries of the North towards the absolutely catastrophic impact of HIV infection and disease on countries in the underdeveloped or developing regions of this planet. His statement in the *Manchester Guardian Weekly* (July 7, 1991, p. 10) was: "Even if a workable vaccine is found by the year 2000, millions of people may have died, and untold millions more will carry the virus. But they will be black or brown or yellow, and they won't live in the West, so cynics will shrug and ask: "Why should we care?"[15] Indeed, why?

The disparities regarding the basic necessities of life; regarding access to medicines and health care; regarding education and abilities to earn a living; regarding the resources needed to develop as a country and a people – these disparities between the rich and poorer peoples on the earth function as a gradient for the rise of violence in the world.

First, because we should be contributing to the creation of a wider culture of peace in the world.

The existing and recently exacerbated disparities regarding the basic necessities of life; regarding access to medicines and health care; regarding education and abilities to earn a living; regarding the resources needed to develop as a country and a people – these disparities between the rich and poorer peoples on the earth function as a gradient for the rise of violence in the world.

Shortly after the recent attacks on the World Trade Centre and the Pentagon, Mario Cuomo, the former Governor of New York State, in a radio interview with a Canadian journalist, said a great truth. He said that terrorism will never be vanquished with guns, bombs, and violence. We will only contribute to the reduction of terrorism, he said, when the rich and strong peoples of the

[15] Mihill C. A deadly division. *The Manchester Guardian Weekly* July 7, 1991:10.

earth turn their attention consistently and effectively to help the poorer and weaker people of the earth. We will contribute effectively to the decline of terrorism and the rise of peace only if we can mobilize efforts to spread civilization throughout the world – civilization, let it be emphasized, not being equal to the spread of any one existing culture or way of life. Civilization means at least: respect for diversity among peoples; respect for the moral equality of all peoples regarding human dignity and the basic conditions that have to be justified if that dignity is to be achieved and sustained.

Second, because, on the basis of an ethic of humanity, existing inequities in our world are intolerable.

Clearly, there are terrible international inequities marking the shares of food, hospital care, and medicines that people receive within the global community. But how do we perceive these inequities? How do we judge them? Simply as facts, tragic indeed, but still as facts deriving from presumably unchangeable behavioural laws, based on national interests, that govern the relationships between nations? Are we really capable of perceiving and judging these inequities as morally intolerable? As wrongs we must right? Are we capable of seeing these inequities as totally incompatible with the relationships we in the developed world should have to people in developing countries?

There are terrible international inequities marking the shares of food, hospital care, and medicines that people receive within the global community. Are we really capable of perceiving and judging these inequities as morally intolerable? As wrongs we must right? As totally incompatible with the relationships we in the developed world should have to people in developing countries?

The 1980 report of the North-South Commission, chaired by W. Brandt, former Chancellor of West Germany, repeatedly stresses its cardinal premise that the survival of mankind is a global challenge, an imperative powerful enough to create a bond of global solidarity.[16] But we have not yet grown up to a mature consciousness of global community, and we remain wishy-washy, indeed even doubtful. about the extent of our moral imperative to work mightily for the survival of others and for assuring them standards of sustenance that are essential for human dignity.

Indeed, our current concepts of justice are rudimentary, underdeveloped, fragmented, contradictory, and so often shaped within notions of community reaching no further than local or national interest. Our governing concepts and theories of justice have not yet been fashioned to hear and respond effectively to the millions of cries across the world of those who live and die in pain and misery. Our vision of justice is foggy and uncertain, for it is far from clear to us, as was said twenty-five years ago, that "everyone in the world has a claim on everyone else, simply because we are all human beings, or that rich nations have an obligation to share their wealth and technology. One has an obligation to provide for the well-being of one's own children, for example, but not necessarily for the children of others."[17]

[16] Nord-Sud Kommission. *Das Überleben Sichern.* Köln: Kiepenheuer, 1980.

[17] Levine C. Ethics, justice and international health. *Hastings Center Report* April 1977;7:5-7.

So justice, as currently understood, is inadequate to support the breadth of solidarity needed for the relief of pain and suffering. We need a higher viewpoint to work effectively within the horizon of global solidarity. For that viewpoint we turn to the principle of humanity, the principle that there are no strangers to us among those who suffer, be it from poverty, marginalization, hunger, illness, pain, or impending death. This is the principle that everyone in the world does have a claim on everyone else for the essentials needed for human survival and dignity. The basis for this claim in the principle of humanity is simply that we are all human beings.

The principle of humanity says that there are no strangers to us among those who suffer, be it from poverty, marginalization, hunger, illness, pain, or impending death. That everyone in the world does have a claim on everyone else for the essentials needed for human survival and dignity. The basis for this claim in the principle of humanity is simply that we are all human beings.

However, are we prepared to live and act within an ethic of humanity?

If humanity is the imperative measure of an ethics for AIDS then, our Northern ethic, to paraphrase Hans Jonas, is sadly unprepared for its planetary challenge. An ethic is dependent upon an ethos, an image or vision of what "being human" means and, as well, of the society and community towards which human beings should aspire. But what sense of community do we have now? I am not asking about the idealistic, philanthropic or even utopian ideas about world community that some people may hold personally dear, and even proclaim publicly on solemn occasions. I direct attention rather to the operative image of a human being, and the operative idea of human society, that currently determine the way power is shared, the way money and capital are amassed, and the way goods and services are distributed within the affluent nations of the North, and between these nations and countries struggling development.

Our liberal, democratic societies of the developed world, if the late C.B. Macpherson's analysis is correct, harbour an inherent contradiction between two freedoms. Liberal "can mean freedom of the stronger to do down the weaker by following market rules; or it can mean equal effective freedom of all to use and develop their capacities. The latter freedom is inconsistent with the former."[18] Capitalistic market freedom supersedes, when it does not outrightly contradict, the effective freedom of all for self-development.

Democracy, within the equilibrium or pluralist elitist model of liberal democracy prevailing in affluent Western societies since the middle of the 20th century, has been judged in the Macpherson analysis, of being little more than a market mechanism for registering the desires of people as they are, or as they are seen to be by power elites within the dominant, oligopolistic economic market. Democracy has failed to be a transforming principle advancing people towards what they might be or might wish to be. The ethos of equilibrium democracy perpetuates the image of human beings as consumers, as maximizers of their own satisfactions and of the benefits and utilities that flow to them from society.

[18] Macpherson CB. *The Life and Times of Liberal Democracy*. Toronto: Oxford University Press, 1977:1.

It is unlikely that international inequities, even terribly tragic inequities, will be seen as morally intolerable when perceptions, judgments, and policies are shaped by an ethos that presents human beings as maximizers of their own consumer interests in a society that requires an equilibrium of inequality. A global ethic for AIDS, hunger and poverty will require an epochal change in consciousness, a change that will lead to a preference for community over affluence.

As a closing reflection, a question: Can we come to care and to live the ethic of humanity without ourselves undergoing profound and sustained change?

We do not lack in images powerful enough to galvanize and mobilize the forces for humanity latent in the hearts and minds of women and men across the world, nor do we lack the technology to transmit those images into our Northern havens of comfort. To attend for a moment only to Rwanda's summer of hell. How many of us seven years ago did not see or read about the thousands who, cholera stricken, died in their own feces and vomit, only then to be scraped up and bulldozed into a common hole? And then again, there is Kevin Carter's Pulitzer prize-winning photograph of the little girl in Sudan, struggling alone on foot to make it to the food station in the village of Ayod. She stumbles, too weak to take more than a step or two at a time. She falls again, bent over, her face in the dust, and a few meters behind her, in the same position, a vulture sits and waits, waits for the little girl to die. This photograph, Edgar Roskis, believes, would never have circled the globe, would never have won the prize, had it not been for the juxtaposition of the vulture and the little starving girl. The little girl alone would have attracted no prize-winning notice.[19]

We do not lack in images powerful enough to galvanize and mobilize the forces for humanity latent in the hearts and minds of women and men across the world, nor do we lack the technology to transmit those images into our Northern havens of comfort.

So, while that picture made it around the world, our humanity stumbles along, far behind, and in some parts of the world, hours only away from us by flight, vultures rather than humans accompany the dying or wait for those without food and medicines to die.

As a closing reflection, a position statement: Within the current global economic order, there will be no active ethic of humanity without transcendence, and there will be no transcendence without conversion.

We lack not voices, few they may be, now speaking out, as did prophets of old, about the need for transcendence. For Maurice King, writing in the medical journal, *The Lancet*, in 1990, transcendence is a condition necessary for sustaining the capacity of this planet to support the health and existence of future generations.[20] Of all the criteria of human achievement, King reminds us, none more universally commands respect than the transcendence of self to care for what is not oneself; and that transcendence will exact of us a reduction in luxurious consumption, indeed, will require renewed respect for a "deliberate quest of poverty," once considered a virtue and worthy of a vow in the West. Vaclav Havel has spoken of transcendence as the ability to go

[19] Roskis E. Images et vautours. *Le Monde diplomatique* Août 1994:32.

[20] King M. Health is a sustainable state. *The Lancet* 1990;336:666.

beyond the surface globalization of our lives and to anchor a new world order in the awareness that we are not alone on this planet nor here for ourselves alone. Transcendence, the process that will activate a global ethic of humanity, begins with a conversion: with a turning away from the ethos that values production and profit over the human dignity of the living and the dying, and towards the ethos of humanity that enables us to see our own personal fate and the fate of us all in the starving and stumbling little girl under the vulture's eye in Ayod.

The process that will activate a global ethic of humanity, begins with a conversion: with a turning away from the ethos that values production and profit over the human dignity of the living and the dying, and towards the ethos of humanity that enables us to see our own personal fate and the fate of us all in the poorer and weaker people of the earth.

As a closing reflection, listen to the poet Robbie Burns speaking about man's dominion breaking nature's social union.

In November, 1785, Robbie Burns, the Scottish poet, wrote a poem *To a Mouse*, the mouse he had turned up in her nest while he was ploughing the land.

> I'm truly sorry man's dominion
> Has broken nature's social union,
> An' justifies that ill opinion
> which makes thee startle
> At me, thy poor, earth-born companion
> An' fellow mortal![21]

The discussion about access of people around the world to medications that can help them to live and to reduce their suffering is, quite surely, a discussion about whether man's economic and political dominions have broken nature's social unions between equal human beings, all fellow mortals, throughout the world.

The drama of global poverty and of the exclusion of so many people from the HIV medications and care they need to live is simultaneously the drama of an ethic of humanity. Will both dramas continue to unfold as forms of tragedy? Tragic drama, as George Steiner has explained, centres on catastrophe. Tragic dramas end badly, and tragic personages are broken by forces which can be neither fully understood nor mastered by powers of rational planning. Tragic drama expresses a view of the world in which the spheres of reason, order, and justice are terribly limited and cannot be expanded by any progress in science or technology.

Can we possibly imagine the reviving of an ethic of humanity, expressed not only in the poetry of words but intensively in the poetry of action, that would free our fellow earth-born companions from what seems to be the tragic determinism of global poverty and the determinisms of exclusion, an exclusion that Ignacio Ramonet has called the great social crime of our times? If we are entering a new age, what will dominate: an ethic of humanity that binds together our broken social union or an ethic of indifference that bows its head to the immutable forces of tragic determinism?

[21] Burns R. To a mouse. In: *Burns - Poems and Songs*. Edited by James Kinsley. London: Oxford University Press, 1969:101.

Closing Plenary

AIDS, HUMAN RIGHTS AND GLOBAL RESPONSIBILITY

Sunday, September 23, 2001

Canada After the UNGASS on HIV/AIDS

Richard Elliott
Director, Policy & Research
Canadian HIV/AIDS Legal Network

At the recent UN General Assembly Special Session (UNGASS) on HIV/AIDS, held at the end of June 2001, the governments of the world discussed and debated a global response to the epidemic. It was recognized, at least in theory, that a global crisis representing "one of the most formidable challenges to human life and dignity" is, of necessity, a global responsibility. So what must Canada do to live up to its obligations under the Declaration?

What is the Value of the UN's Declaration of Commitment on HIV/AIDS?

The Declaration is not a binding convention, but rather a declaration of commitment adopted unanimously by all the member countries of the UN General Assembly on 27 June 2001. But despite not being binding, and even though the process of reaching the Declaration was sometimes painful and ugly, revealing the many prejudices and divisions that continue to shape the global epidemic, it is an important statement of commitment which all countries have agreed to implement. As such, it represents an important advocacy tool for civil society vis-a-vis government.

What are the Key Elements of the Declaration?

The Declaration contains commitments, agreed to by governments, in 11 areas which overlap considerably: They are:

- leadership
- prevention
- care, support & treatment
- human rights
- reducing vulnerability
- children orphaned and made vulnerable by HIV/AIDS
- alleviating social & economic impact
- research & development
- HIV/AIDS in conflict- and disaster-affected regions

- resources
- follow-up

What Does Civil Society Need to Do in Canada Following UNGASS?

There are number of areas in which both government and civil society in Canada must act to ensure the Declaration from the UNGASS has any concrete effect. As civil society, we must review the Declaration and identify areas in which Canada needs to take action to satisfy its commitments. In some areas covered by the Declaration, Canada is already meeting the stated commitments; in other areas, there is much work yet to be done. We must then communicate with government, through all available channels, what actions we see as necessary to meet Canada's commitments under the Declaration. And we must be vigilant, monitoring the government's action – or inaction – and ensure that, when it comes time to take "official" stock of countries' progress in implementing the Declaration, an accurate portrayal of Canada's efforts is presented.

Civil Society must be vigilant. It must monitor the government's action – or inaction – and ensure that, when it comes time to take "official" stock of countries' progress in implementing the Declaration of Commitment on HIV/AIDS, an accurate portrayal of Canada's efforts is presented.

What Should the Canadian Government Do to Live Up to its Obligations Under the UNGASS Declaration?

There are several key areas where Canada needs to act, and act swiftly.

1. Global AIDS and Health Fund[22]

Canada must make an adequate contribution to the UN's Global AIDS and Health Fund. Based on approximate GNP figures for the year 2000, Oxfam has estimated that Canada's proportional contribution, among OECD countries, should be in the realm of US$ 291 million (almost $450 million Canadian) per year. To date we have contributed CAN$ 150 million – over 3 years. This works out to less than $2 a year per person - the price of a cup of coffee. As a recent editorial in the Globe & Mail pointed out, the governments of the world together spent about $800 billion a year on armaments, so "what's $9 billion to fight a plague?"[23]

2. Official Development Assistance ("Foreign Aid")

We should welcome the increased and increasing contribution of the Canadian International Development Agency to funding for HIV/AIDS work in developing countries. But let us also remember that Canada, one of the rich countries of the world, and one that has repeatedly been

[22] Since the AGM of the Canadian HIV/AIDS Legal Network was held, this fund has been re-named the Global Fund to Fight AIDS, Tuberculosis and Malaria.

[23] Editorial. "What's $9-billion to fight a plague?" *The Globe & Mail*, 23 June 2001: A12.

ranked by the UN as having one of the highest "human development indices," is woefully inadequate in its spending on official development assistance (ODA).

The UN General Assembly first affirmed in 1970 that rich donor countries should dedicate 0.7% of their gross national product for official development assistance,[24] and has repeatedly reaffirmed that target over the past 3 decades. Yet, as of 1999, Canada's spending on ODA actually *dropped* to 0.28% of GNP. (Only four wealthy countries are meeting or exceeding the 0.7% target: Denmark, Norway, Netherlands & Sweden.)[25] History teaches us that getting wealthy countries to live up to their agreed-upon commitments is a long-term effort; we should no doubt be prepared for a similar challenge with the implementation of the Declaration of Commitment on HIV/AIDS.

Canada, one of the rich countries of the world, and one that has repeatedly been ranked by the UN as having one of the highest "human development indices," is woefully inadequate in its spending on official development assistance.

3. International Trade and the Right to Health

As mentioned in my earlier remarks at the opening panel discussion, Canada must become an advocate for the public good – for public health and for human rights – in international trade forums. It should support developing countries in their efforts to ensure that the WTO's TRIPS Agreement is not used to block access to affordable medicines where they are desperately needed. And it must defend equitable access to health care (including, but not limited to, medicines) in other trade negotiations currently underway, such as those relating to the Free Trade Agreement of the Americas (FTAA) and the General Agreement on Trade in Services (GATS).

4. Investing in the Domestic Response

Finally, while the focus of these remarks is principally upon Canada's obligation to respond on a global level, of course a fundamental part of the global response is the action that each country takes at home. On the domestic level, Canada must significantly strengthen its response – a including, fundamentally, increasing spending.

In a report prepared earlier this year, *Taking Stock*, an independent evaluator assessed the adequacy of the federal government's investment in the Canadian Strategy on HIV/AIDS and found it sadly lacking. In 1994, the federal government increased its financial commitment to the Strategy to $42.2 million a year. But for seven years, that figure has not changed, even though the number of people living with HIV/AIDS in Canada has increased by 43% since the mid-1990s and the demographics of the epidemic continue to change – meaning that our efforts at prevention and care must reach multiple populations through multiple approaches. Furthermore, over time, the real value of that investment has eroded because of inflation. All of this has

[24] UN General Assembly, Resolution 2626 (XXV), 24 October 1970.

[25] "Foreign Aid." *The Economist*, 1 March 2001, citing figures provided by the OECD.

happened while the federal government has increasingly accumulated repeated, record budget surpluses, now standing at an accumulated total of roughly $40 billion (roughly 1,000 times the current level of funding for the Strategy).[26]

As the independent report I mentioned points out, doubling the funding to $85 million a year could not only compensate for inflation, ensure that spending was consistent with the pattern in the health care sector more broadly, and roughly keep pace with the growth of the epidemic that has already occurred, but could also:

For seven years, the federal government's commitment to the Canadian Strategy on HIV/AIDS has remained at $42.2 million a year, even though the number of people living with HIV/AIDS in Canada has increased by 43% over that period. Meanwhile, the federal government has amassed record budget surpluses, now standing at an accumulated total of about $40 billion (roughly 1,000 times the current level of funding for the Strategy).

- support efforts to "get out in front" of the epidemic;
- expand harm reduction initiatives proven to be effective;
- increase outreach to communities most at risk of infection;
- improve access to affordable housing, and improve other social and economic conditions that affect the health of people living with HIV/AIDS;
- support Aboriginal organizations in implementing programs appropriate to their communities, in both the south and north of the country;
- increase the ability of NGOs to respond more effectively and adequately to the many community needs;
- improve our epidemiological surveillance system; and
- expand Canadian research capacity in the field of HIV/AIDS.[27]

All of these are areas which urgently need attention within Canada, and which will complement the contributions Canada must make to the global response to the global epidemic.

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[26] Martin Spigelman Research Associates. *Taking Stock: Assessing the Adequacy of the Government of Canada Investment in the Canadian Strategy on HIV/AIDS*. Prepared for the Championing Committee, Ministerial Council on HIV/AIDS, January 2001.

[27] Spigelman, *supra* note 4 at 33-34.

Some Reflections on Globalization, Development, Human Rights, and Access to Medicines

Mark Heywood
Head, AIDS Law Project
Secretary, Treatment Action Campaign

Before the Durban International AIDS Conference last year, quite a few people from Canada and the United States called me to ask how safe it was to come to a country with such a terrible crime rate, with lions all over the place, and so forth. And I assured them that it was perfectly safe. So, I found myself in a strange position last week when I told people that I was going to Canada and the United States, and I was constantly greeted with raised eyebrows, to put it mildly.

I feel privileged to attend a meeting like this. I look at this kind of meeting and I look forward to the day when, in South Africa, we can build a network as diverse as this kind of network. This is a network the existence of which should make people with HIV and AIDS, and people who are vulnerable to HIV and AIDS, feel very secure. So, congratulations and keep it up. I think that your domestic response in Canada is critical. In light of the comments that I will now make about the international response, I do not want you to think for a minute that I underestimate your epidemic, or the need to control the epidemic in countries such as Canada, the United States and Europe.

I am trying to wear the shoes I was asked to wear, which are those of Michael Kirby,[28] but they do not really fit. I have taken the title of the speech he was going to give, *AIDS, human rights and global responsibilit*y, and I have added to it some reflections, not a hardened position, just some reflections, many of which have come to me in the last couple of days. These reflections build upon points made by Dr. David Roy on Friday evening. I think that establishing or re-establishing a global ethic around dignity, a global morality around dignity, is critical to the success of human rights projects, particularly in developing countries, and is critical to the success of the struggle for access to medicines. Actually, it is also critical to the success of the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS. I am less optimistic about UNGASS than Richard Elliott is, because I feel that we do not have time for another failed United Nations declaration. If the Declaration of Commitment is to be of any benefit to people in the part of the world that I come from, we do not have one, two, three, four or five years to monitor its implementation, or lack of implementation. The questions of ethics and morality that underlie that are absolutely critical. So here are some reflections, reflections of a person who feels quite disoriented by global disparities and globalization.

A few days ago I jumped onto a plane in Johannesburg, in a country where the rate of HIV infection amongst pregnant women is 25%, and where the per capita monthly income is CAN$ 100. I left the plane 15 hours later in a country with a very low HIV prevalence, although it is nothing to be sniffed at, and a very high standard of living. I got on the plane in a place where many aspects of society are out of control. Even though it has a semblance of control, if one

[28] Mark replaced the scheduled speaker, Justice Michael Kirby of Australia, who was unable to attend the AGM.

scratches underneath the surface of our poor countries, one finds that many things are out of control. And then I come to a place like this, where there is a great deal of control. The differences are shocking. I listened to one speaker talk about a heroin trial involving an investment of $20,000-$25,000 per person, per year. While I fully support everything I heard about the trial, the amounts cited rung strangely in my ears because I have heard governments, including the Canadian government, say that an expenditure of $750 per person, per year, for people with HIV in South Africa, or in Africa, is far too much – i.e., that that kind of life is not worth that kind of investment.

In the context of HIV, the globalization of commerce, trade and communications has outstripped the globalization of morality, identity and ethics.

So, to be quite honest, it makes one feel almost like we are living on different planets. One could say the same about globalization. What should concern us, as human rights activists, is that these disparities exist and that they are accepted. They are not accepted by us in this room, obviously. But, more significantly, they are accepted by most of the people outside of this room. What should concern us, as AIDS activists, is that the HIV/AIDS epidemic is going to make the disparities worse.

Globalization

UNGASS forces us to consider global responsibility, which means that we have to get a grip on this thing called globalization. There is no doubt that globalization is inescapable, so I would not place myself in any camp that says that to return to decency and morality, we must de-globalize the world. That will not ever happen. In the context of HIV, we have to recognize that certain aspects of globalization have far outstripped others. The globalization of commerce, trade and communications has outstripped the globalization of morality, identity and ethics. In fact, in terms of the globalization of identity, we have probably gone backwards in the last few decades. We have to recognize that globalization has as much potential to divide the world as it does to unite it. In this respect, I think it is important to correct the impression that countries like South Africa are developing countries. Many so-called developing countries of the third world are actually undeveloping countries. They are going backwards. If we use terminology like "developing countries," we give the impression that the whole world is moving in the same direction, albeit at varying rates. The whole world is not moving in the same direction.

HIV takes advantage of the fault lines in our society, of the inequities and inequalities, in order to spread. And HIV makes these fault lines far, far wider.

To confirm this, just look at the United Nations human development reports of the last few years. On the whole range of vital indicators, development is now being reversed by HIV. In South Africa, in 1992, two decades of progress in reducing infant mortality were put into reverse thrust. Infant mortality is on the rise again. Adult life expectancy is going down. Poverty is increasing. AIDS is a major factor in all of this, because HIV does two things. First, HIV takes advantage of the fault lines in our society, of the inequities and inequalities, in order to spread. Second, HIV makes these fault lines far, far wider. This is very apparent in South Africa. My country is supposed to be de-racionalized, but the people who have access to antiretrovirals are white, and the people who have access to paracetamol (also known as

acetaminophen, a headache remedy) are black. HIV widens the divisions that already existed. This poses very serious threats. A few years ago, I attended a meeting in Geneva where Kevin DeCock, a CDC epidemiologist, and a rather conservative person, said that AIDS is going to do more to under-develop Africa in the 21st century, than slavery did in the 19th century. His statement was prophetic.

Recently I read a book called King Leopold's Ghost, about how the government of the Belgian Congo killed 9 million people, between 1890 and 1910, in the Congo. Look what is happening in the Congo in 2001.There is a direct relationship between Kabila and the other dictators, and the original disruption and dislocation of that society that began with slavery. What kind of African renaissance can we have with two million people dying of AIDS-related illnesses on the African continent, every year, and with the likelihood that this will continue for the foreseeable future? As Marie-Hélène Bonin said on Friday, HIV is not the only virus or bacteria that is causing this. There are concurrent epidemics in Africa of tuberculosis, malaria, sleeping sickness, and other diseases.

It is shocking to me that all this is happening in a period where there has been an historic and unprecedented focus on the disease called AIDS. Think about it. Since 1988, or thereabouts, we have had a global program on AIDS, UNAIDS, and so on. There has probably never been a disease that has been more talked up, more studied, more thought about, and more conferenced about. But it has not stopped this epidemic. That brings me to the subject of human rights, because I think we have to ask ourselves why we are not containing the HIV epidemic in most parts of the world. (I think that you are containing it here, not amongst all vulnerable peoples, but amongst most people.) Why are human rights violations mounting, in relation to HIV?

The most serious human rights violation is the violation that denies a person the right to dignity. When sick people are refused the medicine that, by watching CNN or BBC, they know is easily available on the other side of the world, that is the most profound of human rights violations.

Edwin Cameron makes the point that the most serious human rights violation is the violation that denies a person the right to dignity. You can take away a person's job, or you can deny a child the right to go to school, both of which are unpleasant. But when sick people are refused the medicine that, by watching CNN or BBC, they know is easily available on the other side of the world, that is the most profound of human rights violations. I think that what is being done here is marvellous, but I think that what we are doing in the Third World is not working. We have to ask why.

Development

Thinking about the answer to that question brings me to the subject of development, about which David Roy spoke on Friday. As I was thinking about this presentation, I thought that David Roy and Karl Marx make good bedfellows. A long, long time ago, Karl Marx made the point that, people's conditions determine how they look at the world, how they think about the world, and how they respond to threats. He said conditions determine consciousness. I have no doubt that conditions determine behaviour. For people who live in squalor and filth, and daily indignities,

HIV, a funny little virus that will begin to make them sick in seven or eight years, is not the primary threat to their lives. In the last 90 years, 90,000 people have died in the mines in South Africa. Recently, one mine worker was asked by a researcher about his attitudes to HIV. He said: "You know every time I go underground, I put a helmet on my head and I don't know if I'm coming out alive this evening. Then these people come to me and say that in my leisure time, when I like to get drunk, have sex, and so on, I must put a helmet on my penis. No way, forget about it." HIV is not seen as a primary threat.

We need to reassess human rights, to focus on the values on which human rights are founded, and to campaign, organize and mobilize for these rights.

The situation is similar with sex workers. There is a high awareness about HIV among sex workers. But some guy comes along and says that he will give the sex worker two bottles of beer more for what is called skin-to-skin, and the sex worker will have skin-to-skin. So, poverty is undoubtedly a major factor. There is also a flip side to poverty. The flip side is that people who live in conditions of affluence have very little sympathy with the suffering and the epidemics of people on the other side of the world.

That is why, as David Roy said, values and the human ethic, or the lack of same, determine how countries respond and how they allocate resources. Just look at the events of the last few days. I was as shocked as everybody else about what happened in the United States on September 11th. It was criminal and horrible. But, whilst I have been at this meeting, I have heard talk about allocating US$ 55 billion to bail out the airline industry. But no one seems prepared to allocate that kind of money for 40 million people infected with HIV, despite what we know about what those 40 million deaths ultimately are going to do to skew the world.

Human Rights

I think, therefore, that we need to reassess human rights, to rediscover the values that underlie these rights, and to campaign, organize and mobilize for these rights. My sense is that people are blasé about human rights. Most people do not pay much attention to human rights or to human rights instruments, preferring to leave the work to a few activists. But if we focus on the values on which human rights are founded, then we can work on campaigns that build solidarity and legal strategies around those values.

In many poor countries, the links between human rights and HIV prevention are broken because of the broken society in which they operate.

I want to make two other points about rights, and I do so as a spokesperson of the so-called developing world. There is definitely a dissonance in the global discourse about rights. The rights discourse has to begin to privilege the rights needs of the most vulnerable of the world. I refer particularly to social and economic rights – i.e., basic social standards. In the last six years, the AIDS Law Project has put in place in South Africa a fabulous legal framework for people with HIV, one that is probably almost as progressive as Canada's. But it is not of much use because people do not have access to the law. As a result, they do not use the law. Therefore, basic principles such as "human rights are essential to HIV prevention," whilst fine theoretically, cannot be

implemented in practice. The links between human rights and HIV prevention are broken because of the broken society in which they operate.

We also need to look at the fact that the people who are most in need of rights are often the ones least able to articulate them. I am not a person living with HIV from Alexandra township, in Johannesburg, who earns 500 rand a month (if he or she is lucky). I cannot give expression to that anger. In fact, like many people of my ilk, I am quite capable of getting too caught up in international travel and conferences and the like. That is not much good to the people who are most affected; we have to remain alert to that. I have a friend, Zackie Achmat. He is somebody who has HIV and who almost has AIDS, and he is always very rude. But I often think: good for you, Zackie, keep people uncomfortable. Don't let people slip into complacency. You have a right to keep people in that kind of discomfort. Zackie has a right to keep me in discomfort as his comrade and colleague, because I do not have HIV. I am just a missionary.

Access to Medicines

I believe that development premised on socio-economic rights, and not on charity, is the most important human right to fight for. I also believe that access to medicines is now a key part of the struggle for development, because lack of access to medicines causes under-development and poverty. This brings us back to where we started on Friday night: the discussion about access to medicine and why this issue is so pertinent now. It is pertinent because at least two million people die of AIDS-related illnesses every year in Third World countries. Of course, medicines are not a cure. But medicines prolong life, improve life, stem the orphan problem, allow people to work, and allow people to maintain dignity.

The greatest tragedy is that whilst there has been a globalization of medical science, there has not been a globalization in access to medicines.

There are also other issues related to globalization. Disease has been globalized. The economic and political processes that have made our world global have made many people in the world more vulnerable to diseases than they were before these processes started. The greatest tragedy is that whilst there has been a globalization of medical science, there has not been a globalization in access to medicines. A poor person sitting in a township in Botswana or Malawi can read about effective medicines on the internet, but has not got a hope in hell of obtaining those medicines personally or getting to a health centre that can obtain them. This is a disparity and a tragedy of enormous proportions. Therefore, one of the most pivotal questions is: whose right is it to have access to the fruits of medical science? Whose right is it? Let me try to illustrate this point with a concrete example. GlaxoSmithKline now has a new pill called trizivir, a triple combination medicine that takes away many of the problems associated with taking drug combinations of the past. That would be an ideal medicine for people in developing countries where there are problems with literacy, and with drug literacy, problems that are much more serious than here. But I do not imagine that people in the developing world are going to see much trizivir for quite some time to come, even though it is an indicated medicine for people with AIDS.

On the other hand, Cipla has a medicine called triomune, which is a copy of trizivir, and for which I believe they have now obtained bio-equivalence certificates. But we cannot use triomune

in South Africa. If we bring triomune into South Africa, we are breaking the law. If we import it, if we put it in people's mouths, if we prescribe it, we are breaking the law. If Cipla even tries to register triomune with our Medicines Control Council, it is breaking patent law.

The question is, is it moral to respect that kind of law? I personally think that it is not. I personally am committed to breaking those kinds of laws, and I would do it with triomune, just as I would do it with diflucan, if I thought that it was possible to do so in a sensible and responsible way. As we all know, one does not start people on antiretroviral therapy if there is not a possibility of sustaining access to that medicine. That is the reason we do not do it at the moment.

The problem of accessing essential medicines in poor countries has to do with the de-valuing of human life; and with the taking of something that for many people is as essential as water for human life, and turning it into something that makes profits for shareholders in countries primarily of the First World.

Why do we have this problem? The problem is not because Jean-Paul Garnier, the CEO of GlaxoSmithKline, is a wicked man. Actually, he is probably quite a nice man. And if you have ever met Richard Sikes, the former boss of GlazoSmithKline, you would have seen that he was a very lovely man. No, the problem is about the gradual skewing of values, which gets us back to what David Roy was talking about on Friday night. It has to do with the commodification and privatization of medicine; with the de-valuing of human life; and with the taking of something that for many people is as essential as water for human life, and turning it into something that makes profits for shareholders in countries primarily of the First World. That is what it is about. And this is made possible by the silent, but very deliberate, shifting of certain rights away from the values that inspired them.

The whole notion, historically, of patents is that a patent is a reward for a public return. But patents do not give any public return to three quarters of the world's population. Why was TRIPS put in place? TRIPS, the Trade-Related Aspects of Intellectual Property Agreement, which extends patent law to all countries of the world, was implemented in the middle of the 1990s, driven by companies like Pfizer and IBM. One of the reasons is that Pfizer, in its far-sighted way, understood that disease is being globalized and there was going to be a global demand for its medicines, and that the harmless, or fairly harmless, copying that went on in the 1960s, 1970s and 1980s by companies like Cipla might begin to eat into its bottom line. So, it is no accident that suddenly patent law begins to extend to medicines worldwide in the middle of the 1990s.

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But the consequences are disastrous. Intellectual property is not an inalienable right, like life or dignity. It was a right that was created for a purpose, and that purpose is now being abused. These are the values that we have to change.

Conclusion

That bring me back to what I was asked to speak about: human rights, AIDS and global responsibility. If the United Nations General Assembly declaration is going to save lives, then it has to be driven by a sense of global responsibility and urgency. For me, this means four things. First, it means that

people in rich countries must somehow be assisted to be as infuriated by the suffering of their far neighbours as by the suffering of their near neighbours. Second, it means that we have to learn to give as much attention to international law as to national law. That is clearly happening in this network. Third, it means that we have to consciously seek to change norms, to change morality, and to devise strategies to do this. Finally, in the same way that, in the 1950s and 1960s, racism was removed from statute books by civil disobedience of laws that were considered to be unjust, it means that laws that discriminate against people on the grounds of poverty etc. must be defied, and must be changed, and there must be advocacy to that effect.

For me, it is about global morality. But in making that argument, one can also make an argument about global self-interest. South Africa is a country of two nations still, one white and one black. White people used to be, and still very much are, contemptuous of black people. Their standard of living is not in the same league at all. But the poverty that white people created drove black people into vicious crime and dehumanized black people, and this led to a situation where the freedom of white people ended up being taken away. I am not talking about apartheid. I am talking about the freedom in Johannesburg to drive out of your front door without thinking that you might be shot, or to walk to the shops, or to go out in the evening to the theatre. So, there is a direct link between the world that rich people constructed for themselves and the way that poor people, not deliberately, but driven by the way they were barbarized, began to impinge upon that world. When we look at AIDS, globalization and human rights, we see exactly the same thing. The world cannot tolerate for much longer this kind of division. The First World will not be able to isolate itself from the disruption, the decay and the disease of the Third World, for anything beyond the short term.