

CANADIAN TREATMENT ACTION COUNCIL



Canadian Treatment Action Council

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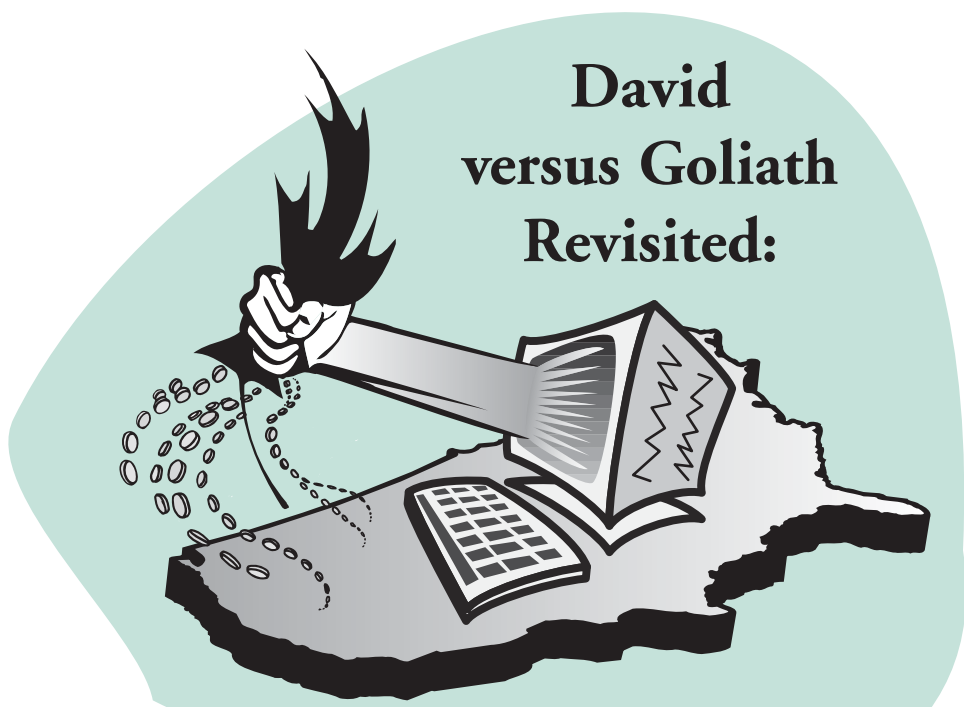
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David
versus Goliath
Revisited:

The Great Cross Border Internet Pharmacy Debacle

by Louise Binder, Chair, CTAC

WELL, IT'S DÉJÀ VU ALL OVER AGAIN.

The American government has returned to its favourite neo-colonial strategy to solve its high domestic drug pricing problems: purchasing Canadian drug supplies for a steal, so to speak.

You may recall that this was a serious problem just before the last U.S. election. Internet pharmacies had set up shop in Canada and were filling and shipping brand name prescription drugs designated for Canadian patients to U.S. patients. They were doing this using prescriptions faxed by U.S. doctors to Canadian doctors for co-signing.

No one involved in these ongoing transactions has clean hands. The U.S. doctors know that the pharmacists filling the prescriptions are not seeing the patients. The Canadian doctors know nothing about the patients nor their conditions other than what is on the prescriptions. The internet pharmacies know that they are not filling a prescription properly signed by the patient's doctor, and that the doctor and the pharmacist should see the patient to provide advice and counselling before handing the drug over.



David versus Goliath revisited: The Great Cross Border Internet Pharmacy Debacle

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They also know that manufacturers of pharmaceutical drugs do not provide unlimited quantities of drugs to the Canadian market, but rather, allocate an amount based on an analysis of reasonable domestic demand. Drugs sent across the border through internet pharmacies means that the supply available to fill prescriptions for Canadian patients is reduced.

Why do American patients want to take potential risks and import Canadian drugs? Because their drug prices are too high. Why are they so high? Because the U.S. government does not regulate brand name drug pricing and lets the free market system prevail.

In Canada, we created the Patented Medicine Prices Review Board (PMPRB) to monitor and regulate drug prices. This is a trade off for the patent protection (presently 20 years) allowing brand name drug companies to recoup the cost of research and development of new drugs. Removing this system of regulation would drive Canadian prices up, putting even more drugs out of the reach of Canadians who badly need them.

Americans like the result of our drug regulation: lower prices for brand name drugs. In fact, it is the only part of the Canadian system many Americans seem to like — as long as it stays in Canada. They want to cherry pick the benefits of this part of our system without recognizing that it is only one part of the fabric of our healthcare system. To start pulling out this thread causes the entire fabric to unravel. Or maybe this analysis is too charitable; maybe they understand perfectly well, and in true neo-colonial fashion, they just do not care. Many American politicians go along with this band-aid solution to avoid facing the real issue: their unregulated, expensive drug market.

The controversy over cross border internet pharmacies appeared to have taken a back seat for awhile as the Americans had bigger issues to resolve and many Canadian internet pharmacy companies moved offshore.

Now it is back, with a vengeance. It started in September with a deal struck in Congress and signed by the

President to reopen the so-called “foot traffic” personal importation of prescription drugs by American patients. This is practical, however, only for people living in border states.

Recently, a series of events effectively reopened all channels of prescription drug importation to all U.S. patients. First, in October, the Department of Homeland Security announced it would cease confiscation by customs agents of prescription drugs mailed from Canada. The Food and Drug Administration (FDA) was given back this enforcement task, but the FDA admits it lacks the capacity to effectively monitor the movement of prescription drugs across the border. As a result, drugs from Canada via the internet and

mail order sales are available to all Americans.

On January 10, 2007, these changes were consolidated through a new legislative proposal in the new Democrat-controlled Congress. A bipartisan Bill, the *Pharmaceutical Market Access and Drug Safety Act of 2007*, has been introduced in both the Senate and the House of



CONGRATULATIONS

At each Annual General Meeting, the Canadian AIDS Society announces the winner of its Leadership Award. This award celebrates the national contributions made by an individual in the fight against HIV/AIDS.

Ron Rosenes, CTAC'S Vice-Chair, received the 1007 Leadership Award (Individual Category). As a member of the XVI International AIDS Conference Local Host, Ron's leadership was an invaluable contribution towards the conference's success.

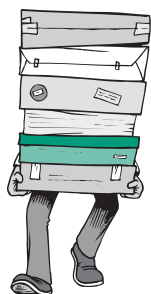
Congratulations, Ron — CTAC is proud!

TO RON ROSENEs

Representatives. This Bill legalizes the importation of prescription drugs from Canada by American patients, pharmacists and drug wholesalers. That means the legalization of not only personal importation by individual patients, but also the bulk importation by health maintenance organizations, state drug plans and other entities such as high volume retail chains. The Bill is predicted to pass because congressional leaders claim to have enough support in Congress to override a presidential veto.

If passed, this bill would have serious and dangerous ramifications for both U.S. and Canadian patients. We have not warned American patients of the problems of counterfeit drugs, of improper prescribing by doctors and pharmacists who have never seen the patients, of no counselling on the use of the drugs nor of contraindications. They tell us to mind our own business. To be charitable, I understand that when you either take these risks or forego lifesaving and life-enhancing drugs, you take the risks. Even when we explain that we are allocated a supply of drugs for Canada from drug manufacturers that cannot meet more than one month's supply for the U.S. market, they are unmoved because of their dire need.

What are the dangers for Canadian patients? They are grave. Manufacturers will not supply unlimited amounts of drugs to Canada. If it is clear that drugs allocated for the Canadian market are being diverted to the higher-priced U.S. market, the tap will be shut off. We could very quickly find drug shortages for Canadians across the country. For some, it is quite simply a question of life and death. For others, it will mean a profoundly reduced quality of life. This is simply intolerable.



Moved? Moving? Let us know!

Help us keep our records up to date by giving us your current mailing address. Email us at ctac@ctac.ca, phone or fax (416) 410-6538.

On a personal note...



What barriers stand in the way of accessing the HIV treatment that you need? Do you have a story to share about how you advocated for access to a treatment or therapy for yourself or on behalf of someone else? We want to hear your stories! Contact the CTAC office (see page 12) for more information. *Confidentiality will be respected. We may not print all stories submitted.*

In the longer run, there could be a strong pressure on Canada to deregulate drug prices and to create a North American drug price: namely, the high U.S. price. The American government and the pharmaceutical industry have long hoped for this result. It is simply unacceptable.

Cross border trade in Canadian prescription drugs to the U.S. has the potential to have a devastating effect on access to badly needed medications for Canadians. This would most hurt those of us most in need, including people with HIV and co-infections.

What can you do about this? Well, we cannot stop the Americans from doing whatever it is they will do to avoid taking responsibility for this domestic problem. We can, however, demand that our politicians at both the federal and provincial levels use their legislative powers to ban internet pharmacies. Write to them to demand immediate action, so they are not scrambling to react once the horses are out of the barn.

We can also demand that provincial medical associations severely punish doctors who sign prescriptions for patients that are not their own.

And we can demand that pharmaceutical companies commit to ensure that no Canadian patient is forced to go without needed medication because of this practice. After all, it is not our fault that the U.S. is treating Canada as its personal medicine cabinet.

Act now. Your health is at stake. ■

Formularies Series:

Newfoundland and Labrador

by Richard Neron, Provincial Representative, CTAC

NEWFOUNDLAND AND LABRADOR PRESCRIPTION DRUG PROGRAM

On January 31, 2007, the Newfoundland and Labrador Prescription Drug Program (NLPDP) was expanded to include a new program called “NLPDP Low Income Drug Program” (www.health.gov.nl.ca/health/nlpdp/lidp). Prior to the development of this program, working individuals did not benefit from any government assistance for medication costs, and this plan should be an improvement on the status quo. Unfortunately, it is apparent from the criteria of the program that the government failed to conduct an adequate consultation with affected groups. Such a consultation would certainly have corrected the inadequacies of the program.

If the Newfoundland and Labrador government believes that it has come up with a new drug program that is going to help the working poor cover the costs of their medication, it is wrong. If we take a closer look, the program offers 30% coverage for single people making up to \$19,000 annually. What this means is that, if a single person has no coverage through his/her employer, he/she has to pay 70% of their drug cost. For a monthly medication cost of \$2,000, the total amount to pay is \$1,400 each month, or \$15,800.00 per year, leaving \$3,200 a year to pay all other expenses: rent, groceries and others. That just doesn’t seem fair. How is someone supposed to live on so little? The cost of rent alone for a year is more than the entire amount left over!

Let’s study another scenario. If you are a family with children and your yearly gross family income is \$30,000 a year, then through this new plan, government will pay 30% of your medication cost. If family members are ill and drug costs come to \$3,000 dollars per month, the family would have to pay \$2,100 a month or \$25,200 for the year, leaving \$4,800 for the family’s other expenses. How can such a family survive?

We need support from all levels of government to help pay our drug coverage. A National Catastrophic Drug Program with a payment of a small fee based on yearly salary is required. It only seems fair. ▶

**LOW INCOME DRUG PROGRAM
ELIGIBILITY EXAMPLES TABLE**

SINGLES		FAMILIES – WITH NO CHILDREN		FAMILIES – WITH CHILDREN	
Net Family Income Amount (\$)	Co-Pay Amount	Net Family Income Amount (\$)	Co-Pay Amount	Net Family Income Amount (\$)	Co-Pay Amount
Under 13,000	20.0%	Under 15,000	20.0%	Under 21,000	20.0%
14,000	28.3%	16,000	28.3%	22,000	25.6%
15,000	36.7%	17,000	36.7%	23,000	31.1%
16,000	45.0%	18,000	45.0%	24,000	36.7%
17,000	53.3%	19,000	53.3%	25,000	42.2%
18,000	61.7%	20,000	61.7%	26,000	47.8%
19,000	70.0%	21,000	70.0%	27,000	53.3%
				28,000	58.9%
				29,000	64.4%
				30,000	70.0%

If something doesn't get done about the NL Drug Program's obvious gaps, then it will force residents of the province who have major illnesses requiring treatment with several medications each month to stop working and go on Social Services. The government pays 100% of prescription medication costs for individuals on Social Services and the spending money allocated to these individuals is more than the money left over in either of the two examples studied above. Adjustments should be made to the NLPDP Low Income Drug Program so that the government is not paying 100% of drug costs without removing an individual's incentive to continue to work and pay taxes.

The citizens of Newfoundland and Labrador need to tell their government that this program will not benefit the working poor with high medication costs. We need to start letting the politicians know that if they do not put into place a prescription drug program that makes a real difference for the working poor then the cost of this group's medication will be borne entirely by the government through social assistance. Individuals will not be able to continue paying 70% of medication costs on an annual salary of \$19,000. With a federal election looming, we need to tell the federal government that our vote will depend on a promise of a catastrophic drug plan and a national formulary.

Another issue in Newfoundland and Labrador relates to obtaining drug cards. Human Resources, Labour and Employment will give a drug card to some individuals working at minimum wage to help cover their medication costs, but it is difficult to apply for and to obtain. This program is generally not well known to people in the province. The program allows a working person with a salary of \$19,000 per year and living costs not exceeding 80% of their income to be eligible for a drug card. What about single people who are making over \$20,000 a year? They get no break at all! It seems the government thinks that you can cover high drug cost yourself if you are making so much money!

This is just not acceptable. If the Newfoundland and Labrador government is not able to offer a better drug plan, it needs to start speaking up to our federal government and let them know that we need a National Catastrophic Drug Program in effect immediately. We cannot accept this

On a personal note...



HOW does a person living with HIV/AIDS in Newfoundland survive in light of the new Newfoundland and Labrador Prescription Drug Program's failure to address catastrophic drug costs? As a person living with HIV for almost 19 years, I am appalled by our government and how they treat me when it comes to my illness.

I work for a living and make a nice salary for this province, but can't afford to pay for my medication costs. Since I make over \$30,000 a year, I am not entitled to get my medication costs covered.

My medication costs about \$2,000 per month. I have drug coverage at work but this only covers 80% of my medication costs, leaving me with an out of pocket expense of \$400 a month. I have a partner who is also living with HIV with medication costs of about \$2,500 a month. He makes the same salary as me, and his out of pocket expenses are about \$500.

This means that with our combined income of around \$60,000 annually we will have to pay about \$10,800 per year for our medication costs. We are grateful to have a Health Fund at our local AIDS Service Organization (ASO) that covers the 20% right now, but this pot of money is getting low. As a result our ASO's Health Fund is going to cover only 10% starting March 2007.

When you figure out all the other expenses that we have — rent, utilities, food, car insurance and other daily costs — this does not leave us with much income to live on.

We wonder sometimes why we are working because we are not getting ahead in life. If we didn't work, we could get social services and let the government pay 100% of the coverage. I don't think the government wants this, or at least I wouldn't want that to happen.

Why doesn't our government pay part of our medication costs? Do they think it would be an added expense? That is just simply untrue. In fact, they would save money because we would not have the stress of having to worry about how we are going to pay this necessary medical bill every month, which in turn would help our immune system and in turn would help the

On a personal note...

continued from page 5



government because they wouldn't have to pay for any extra cost to the doctors for us to get medication to help relieve our stress. The government would also be providing an incentive for individuals with high medication costs to go back to work instead of being on social services, where government pays them to not work and pays 100% coverage of the medication. What is government thinking?

Government needs to open its eyes and think about the big picture. Or maybe they have thought about the big picture and they just don't care about individuals with catastrophic drug costs in Newfoundland. I guess I will have to wait and see.

Now, my partner and I are among the lucky ones in a way: we do have coverage at work. What if we left our place of employment and went to another organization that didn't have insurance coverage or what if our ASO's Health Fund ceased to exist? We would have to pay out over \$50,000 dollars in medication costs every year! It would be impossible for us to continue to work and live.

I guess we would have to go on social services and get them to pay for us to live day to day and sit back and do nothing.

Thanks for listening.

Anonymous

Formularies Series: Newfoundland and Labrador

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program. It is just not fair for someone with illnesses such as HIV, MS, and cancer to have to deal with the stress of figuring out how they are going to pay for their medications or be forced to stop taking the medication that makes them better because they simply cannot afford it. Does our government want people to go downhill healthwise or does it want to do something about it?

CTAC will be a part of a working group that is going to be campaigning to get our government to revisit this program. We are grateful for CTAC's assistance. ■

Clinical Trials:

Six essential conditions for achieving free and informed consent

*by Jean-Pierre Bélisle,
CTAC Clinical Trials Working Group*

ACCORDING to Sonya Audy (2005), six conditions must be met before obtaining the free and informed consent of clinical trial participants.

1

The potential participant must possess all information that is relevant to his or her decision-making process.

In Canada, informed consent forms must at the very least contain the information listed in article 4.8.10 of the document Good Clinical Practice (GCP). When the research is conducted in a public institution, the concepts outlined in chapter two of the Tri-Council Policy Statement (TCPS) apply. The resulting list is very long, hence the growing complexity of today's consent forms, but does not offer much information about the potential participant's perspective or real needs. In the field of HIV/AIDS research, these needs vary according to whether the trial is designed for newly infected individuals, treatment-naïve or treatment-experienced patients.

2

The potential participant must fully understand the information provided.

With regard to informed consent, the Research Ethics Board's (REB) involvement is too often limited to overseeing the content of the consent form. Despite adherence to highly commendable rules regarding its wording, the form invariably ends up being too long and complex for the average person to understand. Alternative methods of communication should be encouraged and properly structured to convey the information. These other methods often have a real impact on the potential

participant's decision-making process. The REB must ensure that the information provided is not biased by any conflict of interest or slanted perspective that the research team may generate despite its best intentions to the contrary. The potential participant must have access to resources other than those provided by the research team in order to support his or her decision-making process.

3

Consent must be voluntary.

As stated in the TCPS, consent must be voluntary and granted without manipulation, coercion or excessive influence. Examples of excessive influence include exaggerated monetary incentives or the exertion of power or authority over a potential participant. The physician's opinion weighs heavily in the balance, so attention must be paid to the level of confidence and dependence that characterize the doctor-patient relationship.

4

The potential participant must be capable of understanding and making decisions.

The road traveled by any person living with HIV is inevitably punctuated with a series of shocks that jeopardize his stability, cause him distress and increase his vulnerability: the diagnosis; the realization that it's time to begin treatment or that treatment is failing; the detection of complex multiresistant virus; the death of a loved one

from the same disease, etc. Each of these shocks can induce what Audy refers to as a "temporary inaptitude". This must be taken into account when identifying additional measures to support the decision-making process in this situation.

5

The potential participant must be given sufficient time to consider his decision.

It takes a long time to digest all the information that a potential participant must understand. The potential participant must receive a copy of the consent form so he can review it as thoroughly as he wishes before making the decision to sign. He must be given enough time to consult friends and family and to study the form with whomever he chooses. We must challenge the climate of urgency and the pressure to make a quick decision that too often prevail in the AIDS world.

6

The potential participant's ongoing freedom must be guaranteed.

The TCPS defines informed consent as an ongoing process that begins at the initial contact with the potential participant and does not end until the project's conclusion. It must be made clear to the participant that he or she can withdraw his or her consent and leave the project at any time. The participant must also be guaranteed access to any new information that comes to light during the trial that might influence his or her decision. ■

References:

1. Sonya AUDY, 2005. Rédiger un formulaire de consentement respectueux de l'autonomie des sujets pressentis ; une mission impossible? Document du Comité de liaison en éthique de la recherche de l'Université de Montréal. www.recherche.umontreal.ca/PDF/FdCFINAL2005.pdf
2. Health Canada, 1997. Good Clinical Practice: Consolidated guideline- ICH topic E6. www.hc-sc.gc.ca/dhp-mps/prodpharma/applic-demande/guide-ld/ich/efficac/e6_e.html
3. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, 1998 (with 2000, 2002 and 2005 amendments). Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. www.pre.ethics.gc.ca/english/policystatement/policystatement.cfm

INTERNATIONAL

Time to Deliver (or not)

*by Richard Elliott, CTAC Council member.
Richard Elliott is Deputy Director of the
Canadian HIV/AIDS Legal Network
(www.aidslaw.ca), Canada's leading advocacy
organization working on the legal and human
rights issues raised by HIV/AIDS.*

Despite Prime Minister Harper's unfortunate statement that the recent XVI International AIDS Conference in Toronto (AIDS 2006) was no time for the government to make announcements about AIDS, one issue could not be avoided.

Two years ago, Parliament unanimously passed a law to ease access to lower-cost, generic medicines for developing countries confronting an ongoing tide of suffering and death. But so far not a single pill has left Canada. During AIDS 2006, federal Health Minister Tony Clement promised that the government would review the law and fix it to make it work.

So why hasn't it been used? And what can be done?

In 2001, the member countries of the World Trade Organization (WTO) unanimously recognized that countries have the right to grant "compulsory licences" that allow generic manufacturers to produce lower-cost versions of patented, brand-name drugs in exchange for royalties. Breaking the monopoly of patent-holders allows market competition, which brings down medicine prices.

Many developing countries can't afford patented, brand-name medicines and lack the industrial capacity to manufacture their own generic ones, meaning they rely on imported medicines. So, in 2003, WTO countries adopted a mechanism that would ostensibly allow for issuing compulsory licences in one country to produce lower-cost generic drugs for

export to developing countries in need. The following year, Canada enacted legislation to implement this decision.

In theory, Canadian generic drug manufacturers can export lower-cost medicines to eligible developing countries. But when the previous government drafted the existing law, it sought to "balance the interests of all stakeholders." In other words, it bowed to pressure from the multinational pharmaceutical industry by building extra hurdles into an already cumbersome WTO framework. Canada should abolish the unnecessary barriers built into its law.

The more fundamental problem is the 2003 WTO decision on which Canada's law is based. The result: in the three years since the decision was adopted, not a single country has successfully used the WTO-approved mechanism.

The WTO decision embodied in Canada's law ignores the realities of both generic drug manufacturers and developing countries. Developing countries need simple contract processes that will ensure sustainable supplies of essential medicines or other pharmaceutical products; these contracts must be flexible enough to adjust to changing needs. The WTO decision enacted by Canada, however, forces generic companies through unnecessary red tape to get a licence to manufacture and export each patented drug, and only in a pre-negotiated quantity and to a single country.

What can Minister Clement do to fix this situation? He can streamline the legal process so that developing countries and generic drug companies can and will use it.

Generic manufacturers should be able to apply at the outset for a compulsory licence to manufacture and export any patented medicine, not just those on the limited list attached to the original legislation. With such a licence in hand, they should be able to negotiate multiple purchasing contracts with multiple developing countries, not just one-off agreements on a country-by-country, order-by-order basis for which a separate licence must then be obtained each time, as is currently the case.

There should be no arbitrary time limits on the length of

the compulsory licence. Currently, there is a two-year cap, limiting the economies of scale needed to make compulsory licensing viable for generic manufacturers, and throwing the long-term sustainability of supplies into question for potential developing-country purchasers.

There should be no mandatory 30-day negotiation period between generic manufacturers and brand-name patent-holders; rather, getting the licence to produce for export to eligible developing countries should be automatic.

And, as is currently the case, generic manufacturers should be required to pay royalties to the patent-holders for each contract they negotiate with a purchasing country. The current law already contains a sensible formula for determining the applicable royalty, based on the level of development of the importing developing country.

Such a mechanism would give generic manufacturers and developing countries much more incentive to make use of the law and realize the goal of getting medicines to people who need them in developing countries. Canada has implemented the mechanism negotiated at the WTO in 2003; so far, it hasn't worked. But WTO countries also agreed their decision did not preclude using other "flexibilities" in the WTO treaty on intellectual property, which they said should be interpreted and implemented so as to promote access to medicines. Under the treaty, countries can create "limited exceptions" to patent rights in their own laws. Canada can legislate the simpler, streamlined mechanism described above as one such exception. The question now is whether Minister Clement and his government will do so to deliver on the promise made. ■

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Canada's Time to Deliver

by Marco Gomes

While CTAC is well known for its work in access to treatments in Canada, the organization is now seeking ways to work with communities internationally on issues of mutual interest. We have been early supporters of the work of our colleagues at the Canadian HIV Legal Network to ensure the implementation of Canada's new legislation to facilitate the export of low cost generic medications to low and middle income countries. This includes eliminating the systemic barriers that have so far prevented a single pill from being exported.

CTAC is in the process of preparing a paper on generic drug pricing in Canada. This paper

intends to show the need for greater regulation of the generic drug industry in Canada, including price regulation similar to that of the patented drug industry.

To learn more about generic pricing and how you can help, visit the Global Treatment Access Group at www.aidslaw.ca/gtac.

Please also visit www.freethedrugs.org to sign a petition calling on the Government of Canada to change Canada's law on exporting lower-cost medicines to developing countries so that its professed goal stands a greater chance of being realized. ■

Towards a Consumer-Centred Approach to Post Approval Surveillance

by Patrick Cupdio, Treasurer, CTAC

From its inception, CTAC has recognized the need for an improved post-approval surveillance system (PASS) to monitor the safety and efficacy of drugs and other treatments after they have come to market. Accurate, up-to-date information is essential for making informed treatment decisions; and yet, since the advent of highly active antiretroviral therapy (HAART), people living with HIV/AIDS have been experiencing adverse events (side effects) which were not detected in pre-approval clinical trials. Not only do adverse events have a detrimental impact on quality of life, research has also shown that people living with HIV/AIDS who experience unexpected adverse events are more likely to have difficulties with adherence, which can impair the effectiveness of treatment and cause resistance.

CTAC conducted the National PASS Study to build the case for a more proactive, consumer-centred post-approval surveillance system. The study demonstrated both the willingness of people living with HIV/AIDS to report adverse events and the value that community-based organizations could play in an improved PASS. The subsequent dissemination and consultation phase of the study generated widespread support for continued work on PASS, including the need to collaborate with a broad range of other stakeholders and the engagement of community-based organizations as "sentinels" who could assist in detecting emerging trends in adverse events reported by people living with HIV/AIDS.

Since that time, the PASS working group has taken action on a number of fronts to engage both the HIV/AIDS community and other stakeholders in furthering our work. Poster and oral presentations on CTAC's PASS work were delivered at the XVI International AIDS Conference (Toronto, August 2006), the 4^e Conférence francophone sur le VIH/sida

(Paris, March 2007) and the Canadian Agency for Drugs and Technologies in Health Invitational Symposium (Ottawa, April 2007).

A skills building workshop on PASS was added to the Tools for Action series and presented for the first time in conjunction with the Canadian AIDS Society's PHA Forum in June, 2006.

In an attempt to create more intentional collaborations with other stakeholders, CTAC hosted a symposium in Ottawa on March 8-9, 2007, entitled "Ensuring Greater Involvement of Consumers in Post Approval Surveillance System", inviting representatives from the Marketed Health Products Directorate, the Office of Consumer and Public Involvement of Health Canada, Best Medicines Coalition, Canadian Arthritis Patients Alliance, Canadian AIDS Treatment Information Exchange, Canadian Cancer Society, Cancer Advocacy Coalition of Canada, DES Action Canada, PharmaWatch, and Shire Biochem. Presentations by Health Canada, CTAC and DES Action Canada on their PASS activities were followed by a discussion on the continued barriers to consumer adverse event reporting and how all concerned organizations could work together to overcome them. The NGO representatives were receptive to the creation of a network of organizations interested in PASS issues, for which CTAC will be providing logistical support. A final report will also be available in the coming months from this meeting.

The PASS working group has incorporated into its mandate the development of a proposal for a pilot project of sentinel sites to collect adverse event data. The PASS working group also welcomes new members with a passion for this area of CTAC's work. If interested, please contact Sonika Lal, Project Coordinator at sonika@ctac.ca.

For further information about CTAC's work on PASS please see past newsletter issues Vol 6 #1, March 2004, Vol 8 #2, Spring 2006 and CTAC reports on www.ctac.ca. ■

CALENDAR OF EVENTS

SPRING/SUMMER 2007

► JUNE

**Comité des Personnes Atteintes du VIH..... 9
du Québec (CPAVIH) AGM**
Montreal, Quebec
Centre St. Pierre, Room 100
Contact: (514) 521-8720 or 1 800 927-2844
www.cpavih.org/actions/2_1_sante-conferences

**Canadian Association for Health 12-14
Services and Policy Research**
Toronto, Ontario
www.cahspr.ca/conference/index.html

**Canadian AIDS Society (CAS) 13-17
People Living With HIV/AIDS Forum
and AGM**
Ottawa, Ontario
Contact: Darren Fisher at Tel: (613) 230-3580 ext. 135,
Toll free: 1 877 998-9991, Fax: (613) 563-4998,
E-mail: darren@cdnaids.ca
www.cdnaids.ca/web/casmisc.nsf/pages/cas-gen-0073

► JULY

**International Women's Summit 4-7
Women's Leadership Making a
Difference on HIV and AIDS**
Nairobi, Kenya
[www.worldywca.info/index.php/ywca/
world_council_07/iws_women_s_summit](http://www.worldywca.info/index.php/ywca/world_council_07/iws_women_s_summit)

**International AIDS Society (IAS) 22-25
4th Annual Conference on HIV Pathogenesis,
Treatment and Prevention**
Sydney, Australia
www.ias2007.org/start.aspx

► AUGUST

Annual PHA Skills Building Symposium..... 2-5
Newfoundland
Contact: John Baker or Fran Keough at
(709) 579-8656

BCPWA AGM 18
Vancouver, British Columbia
Contact: Tel: (604) 893-2200, Toll Free 1 800 994-2437,
Fax: (604) 893-2251, E-mail: info@bcpwa.org
www.bcpwa.org/evagm.php

CHAIR'S REPORT

Spring 2007

by Louise Binder



LIKE THE BUDS OF SPRING FLOWERS,

Mr. Harper has awoken. He has pronounced that HIV is indeed a problem and his "new" government is going to join Bill Gates to help solve it. How? Well, unless you have been in winter hibernation, you know that he is putting \$111 million into vaccine research and manufacture and Mr. Gates is putting in \$28 million as well.

Who can argue with that? Not I. I think it is wonderful. Vaccines are desperately needed and seem very hard to discover. Canada has excellent researchers who should be put on the case. We are told that it will take at least ten years to develop such a vaccine. If our contribution speeds up that work, we should be very proud as Canadians.

Since I am paid to worry (well, actually, I just volunteer to worry for free), I do feel obliged to raise some issues about this announcement. Let's follow the money. This is not "new" money being provided. It is actually money redeployed from the Canadian International Development Agency (CIDA) and from the Canadian Institutes for Health Research (CIHR), which gets its AIDS money from the Federal Initiative on HIV/AIDS. The Federal Initiative dollars are the monies allocated to deal with HIV/AIDS issues in Canada and to do some limited international work.

Having been around the table when the money was allocated, I can tell you unequivocally that the stakeholders were all clear that this money did not include funding for vaccines. This is not because we did not consider vaccines a very important piece of research but because it is monumentally expensive to mount such research and it is an issue that must be tackled in an international effort.

With 58,000+ people with HIV around the country needing care, treatment and support as well as human rights help; with prevention for all populations and geographic areas badly needed; and with other research priorities, Canada's Federal Initiative dollars were already not enough to go around. They still are not. The new government agreed to that in the joint Standing Committee on Health report in 2003 that proposed \$100 million per year (we are at \$84.4 million promised by 2008-2009).

So, I am worried that other badly needed services are being sacrificed to this pledge. This would mean that we are abandoning, to some degree at least, the people we can save with presently available prevention and harm reduction measures and/or the people we can treat and care for during this time, both in Canada and internationally. Surely that cannot be Mr. Harper's intent.

Let's each write to him to get a clarification that in fact no Federal Initiative money will be moved to this research from present Federal Initiative programmes nor from the work being done by CIDA internationally. We need "new" funding from the "new" government. ■

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Ward Health Strategies

CTAC POSITION PAPERS

Papers

- 2006 – “Timeliness and Transparency: Assessing the Review Process for HIV Drugs.” Revised April 2006. Author: David Garmaise.
- 2004 – “Roadmap for Addressing the Epidemic of HIV and Hepatitis C Co-Infection in Canada.” Author: Paula Braitstein.
- 2001 – “Improving our Health: The Need to Enhance the Post-Approval Surveillance System for HIV/AIDS Drugs in Canada.” Author: David Garmaise.
- 2001 – “Making Treatments Accessible: A Policy Paper on Determining Appropriate Pricing for Brand-name Pharmaceutical Treatments for HIV/AIDS in Canada.” Author: Glen Brown.
- 2000 – “Position Paper on Direct to Consumer Advertising (DTCA) of Prescription Medications.” Author: Philip Lundrigan.

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- Persons living with HIV/AIDS
- Groups, organizations and/or projects with a substantial HIV/AIDS mandate

Associate Membership is open to

- Any individual, group, organization or project that supports CTAC’s mandate and objectives

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CTAC’s Mandate

To secure and ensure access to therapies and treatments for people living with HIV/AIDS by working with the public, private and not-for-profit sectors.

CTAC...

- Informs research and public policy, and promotes public awareness;
- Provides mentoring and skills building in these areas to people living with HIV/AIDS;
- Encourages and facilitates the exchange of related information to stakeholders;
- Builds and works with coalitions to address broader health care issues impacting access to therapies and treatments.

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