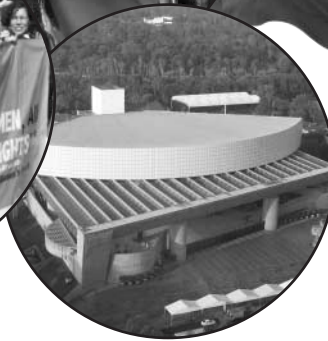


CANADIAN TREATMENT ACTION COUNCIL



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AT THE XVII INTERNATIONAL AIDS CONFERENCE

held in Mexico this past August the community focused on reclaiming ownership of the agenda, addressing human rights and social justice, bringing together community and evidence-based science, ensuring a long-term legacy for the region, and demanding accountability and action. Many CTAC members were in attendance. Here are various highlights of the conference in general and of CTAC's involvement.

Re-emphasized at the conference:

- 1 Access to treatments that are safe, effective and low / no cost are still on everyone's minds. Vaccine research is very disheartening. Microbicides are a distant oasis. No one even talks about a cure anymore. What we can hope for are treatments to reduce the virus that are not so toxic that they cause death. So far, none is that effective or benign.
- 2 Another buzz at the conference was "treatment as prevention." It is perhaps a possible public health approach but it ignores individual human rights to choose treatments when and if they want them.
- 3 There was a recognition of determinants of health e.g., education, food, housing, sex, race, and employment. However, there is not as much attention to policy in these areas as there should be. Although great





grassroots work is being done on these issues, we need to match practice with policy so that these determinants can be addressed on a larger scale.

We have a long way to go. Our federal government still has its feet planted in the last century with cutbacks to HIV funding and various programmes, including housing and women's issues, and the refusal to accept harm reduction as part of a prevention strategy.

CTAC Activities

The conference successfully highlighted many of the issues brought forth by our community in both the international and national media.

► **Monday, August 4:** The Blueprint for Action on Women and Girls and HIV/AIDS, of which CTAC is a founding and active member, hosted a press conference and a Global Village session. The focus was the launch of the 2008 Canadian Report Card analyzing governmental responses to HIV and AIDS issues related to women and girls. Other report cards, including those from Puntos de Encuentro (Nicaragua) and SAfAIDS (Zimbabwe), were presented. Issues from each country were highlighted and Canadian and international press picked up the story.

► **Tuesday, August 5:** Many CTAC members participated in the Women's and Girls' Rally and March. The theme was "All Women! All Rights!" The march route was through the historical centre of Mexico City and received a lot of public attention and media coverage, both local and international.

► Louise Binder also stood next to CTAC's poster on Community Mobilization and Leadership with Rwandan HIV/AIDS Leaders, further building international connections and interest in CTAC's advocacy, mentoring, and capacity building work.

An advocate's finest moment

Thanks to one of CTAC's advocates, doctors and researchers were reminded in the middle of a presentation about the detrimental side effects of an HIV/AIDS treatment, which he felt were being ignored. The advocate stood up and said: "I don't want HIV/AIDS to be convenient, I want drugs to be evaluated on how safe and effective they are and not get drugs that make me crazy."



Another Experience

At the conference, I attempted to experience a bit of everything. The Global Village was a great venue, the atmosphere was so dynamic and energetic! I also wanted to witness and experience local front line "action." The conference provided the opportunity to go on an engagement tour to a local agency, Colectivo Sol. This group has two Condomobiles, one for women and one for men. The workers provide the services in drag and are very busy! The volunteers/ interpreters were absolutely incredible! My experience was very positive and the people I met and the things I learned will stay with me.

► CTAC hosted two press conferences dealing with the lack of access to solid organ transplantation in Canada and with the "7 Deadly Sins" (an overview of the many areas where the federal government has failed to live up to its commitments towards critical issues that are presented by HIV/AIDS in Canada). Both were very successful and received national media coverage. ■

Treatment Information – Mexico 2008

by Brian Finch, CTAC Board

Presentations of treatment information at the XVII International AIDS conference in Mexico City focused on evaluations of both existing and newer classes of pharmaceutical therapies. Here are some the highlights from this year's clinical trials.

Several studies were gender specific. Boosted Atazanavir (Reyataz) and Lopinavir treatment regimens were found to be just as effective in achieving an undetectable viral load (less than 50 copies) in treatment naïve subjects of either gender. A study of Darunavir also indicated that treatment was equally effective in both genders and that there was no need for dosage adjustments during the course of administration.

Although Efavirenz proved more effective than Lopinavir in difficult-to-treat populations in poor resource settings, it demonstrated more complications, including altered lipid profile, central nervous system side effects, and rash.

One study opposed Raltegravir to Efavirenz in a head to head trial. Results indicated that 80 percent of the study participants receiving Raltegravir achieved undetectable status at the 96-week mark. No new side effects showed up, and the lipid profile remained more stable than was the case for those receiving Efavirenz.

Rilpivirine (TMC278) has been clinically demonstrated to be able to sustain viral suppression at 96 weeks, with fewer side effects than previously developed drugs. Rilpivirine treatment was correlated with a much reduced incidence of rash. However, a minority of the study's subjects experienced some central nervous system side effects. Rilpivirine is a second generation once a day NNRTI, which has broad activity against NNRTI-resistant virus. Rilpivirine has also been studied in a depot formulation for injection providing prolonged exposure to the drug, and was found to be well tolerated.

A combination of Raltegravir, Etravirine, and Darunavir/Ritonavir was administered to treatment-

experienced patients with multidrug resistance and few treatment options (Trio Study). With low adverse events, 90% of the trial subjects were undetectable by week 24.

It has been found that switching from Enfuvirtide (Fusion) to Raltegravir (Cheer trial) among heavily treatment-experienced patients maintains immunological control over a period of 24 weeks. These conclusions lead the way to expanding future treatment options for those with multi-drug resistant virus.

A study of Maraviroc (Motivate 1&2) demonstrated that viral loads were significantly suppressed in triple class experienced subjects receiving this treatment in comparison with those who received placebos.

The conference's presentations also brought news of late-breaking treatment innovations. Several studies of second generation NNRTI's presented phase one data. Both IDX899 and RDEA806 were dosed once a day, saw favorable tolerability, and demonstrated broad activity against NNRTI-resistant virus with efficacy similar to that of Etravirine (TMC125) and Rilpivirine (TMC278).

Heated discussion took place in the wake of GSK's presentation of 52 Abacavir studies which claimed to have found no increase of cardiovascular risk. New data from the Smart trial suggests that this is not the case. The findings from the Smart trial were consistent with recent conclusions from the D:A:D study showing increased risk of cardiovascular disease. Patients using Abacavir were 4.3 times more likely to have a heart attack than those not using the drug.

On the lipodystrophy front, Tesamorelin, a daily injection, was found to stimulate the natural production of human growth hormone, improve triglyceride levels, decrease abdominal adipose tissue, improve body image and is well tolerated.

Finally, a quick mention that Abbot has come out with a non-heat sensitive formulation of Ritonavir; an added welcome, especially for those who live in warm climates. ■

Craving

Liver and Onions



or

Steak and Kidney Pie:



Can't find your favourite organ on the menu?

*by Ruth Pritchard,
CTAC Senior Policy Analyst*

In the pre-Highly Active Anti-Retroviral Therapy (HAART) era, transplants were virtually a non-issue for our community. Simply put, people living with HIV/AIDS and/or co-infections weren't living long enough for organ damage to necessitate transplants.

Since 1996 anti-retroviral therapy has drastically improved the life expectancy of people living with HIV/AIDS and/or Hepatitis. But this benefit is a double edged sword: both the virus and the drugs used to fight it can negatively impact liver and kidney function as well as other organs. As a result, single organ transplants (SOT) is now very much a critical issue.

Public awareness and understanding of HIV/AIDS issues has progressively grown. But have the same gains been made within the medical community?

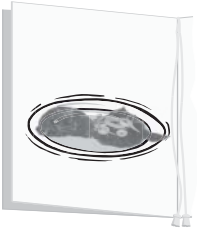
The pre-HAART days were some of the darkest in terms of stigma, discrimination and public hysteria surrounding

people living with HIV/AIDS. This was just as true within the medical community. Many surgeons did not want to "risk being infected" while performing surgeries on HIV-positive and/or co-infected people, or "waste" scarce organs on someone with a fatal disease. This discriminatory attitude remains despite the markedly different response of HIV and Hepatitis viruses in patients receiving HAART. As a result, solid organ transplants are still not available to Canadians living with HIV/AIDS or co-infection.

Recently, Dr. Curtis Cooper, an HIV/AIDS and Hepatitis specialist in Ottawa, conducted a survey asking what barriers exist to explain the lack of transplants. He found that after the failure by most Canadians to sign their donor cards, the biggest obstacle is surgical team reluctance.¹

In 2005, Dr. Scott D. Halpern reported that physicians believed Hepatitis C patients were good candidates to transplant. Yet only one-third of these same physicians felt the same about HIV-infected patients even though post





transplant clinical outcomes in both groups were similar.²

The need for transplants for HIV/AIDS or co-infected patients is clear. In 2007, 20%, or 12,700, Canadian HIV patients had concurrent disease: 20% had Hepatitis C, 5% had Hepatitis B, and 5% had alcohol related damage. On average, 2 patients per CTN site were thought to be appropriate for consideration for a liver transplant.³ Yet very few Canadians with HIV/AIDS or co-infections are receiving solid organ transplants. Since physicians know the outcomes for both populations (Hepatitis and HIV patients) are similar, something else must be at play to explain their unwillingness.

One explanation for this is the belief that anti-rejection drugs, which suppress the immune system, will negatively impact HIV. New research demonstrates that this misgiving is unfounded. A recent study conducted in the United States (where liver transplants have been performed on HIV+ subjects) has demonstrated that HAART effectively keeps HIV in check after a transplant.⁴ Furthermore, HIV-positive transplant recipients on HAART maintain viral suppression after transplant—in fact, many of the anti-rejection drugs used after a transplant have similar anti-viral effects as components of HAART. Transplant physicians routinely give prophylaxis to their patients to prevent opportunistic infections post-transplant: the same drugs used against opportunistic infections in the HIV population.

So what does this mean in terms of clinical outcomes of solid organ transplants for HIV-positive and/or co-infected people?

A great deal!

In 2008, the American Journal of Transplantation published one- and three-year outcome data from a transplant study done in California. This data demonstrates that “improvements in...HIV-associated mortality make it difficult to deny transplantation based on futility.”⁵ The study, following the results from 11 liver and 18 kidney transplants for a median of 3.4 years, found that:

- 1- and 3-year liver survival was 91% and 64%

- 1- and 3-year kidney survival was 94%
- CD4+ counts and HIV RNA levels were stable
- 2 Opportunistic Infections (OIs) occurred
- 1- and 3-year cumulative incidence of kidney rejection was 52% and 70%
- Two-thirds of Hepatitis C infection but no Hepatitis B infections recurred

It seems fair to agree with Dr. Haplern’s assertion: “HIV-infected patients should have equal access to organs unless or until evidence emerges that they fare substantially worse than other potential recipients.”⁶ The treatment is effective, and it saves lives.

So how do other countries stack up in accessing transplants?

Better than Canada.

For example, in the United States, third-party payers are increasingly paying for transplants in HIV-infected people when HIV is well controlled. Other examples of guideline change include the United Network of Organs Sharing and the United States Veteran Affairs Administration. Spain and Great Britain have also revised their guidelines, as have other European countries.⁷

So what does this mean for Canadians who are co-infected and/or living with HIV/AIDS?

This community has a great deal of advocacy to do to ensure that there is more equitable access to transplants in this country.

CTAC continues this work by meeting with government, hospital administrators and surgeons, and by working with the HIV physicians within our communities. To date, CTAC has held two press conferences (one in Ottawa and one in Mexico City) calling for a Centre of Excellence for SOT in HIV/AIDS and Co-infection to be established. We need a centre where surgeons and surgical teams, HIV-specialists and pharmacists can learn from each other to better understand the drugs we take and the impact they have on transplantation.

continued on page 7

Formularies Series:

Prince Edward Island

By Troy Perrot, CTAC Prince Edward Island Representative

Like other Atlantic Provinces, the list of drugs considered for reimbursement in Prince Edward Island is the result of the decisions of several regulatory bodies. The national Common Drug Review (CDR)'s recommendations are considered by the Minister of Social Services and Seniors, who is advised by the PEI Pharmacy Advisory Committee. If the CDR does not recommend a specific drug for coverage, the Atlantic Drug Review meets to decide whether to recommend it. Only medications that have been recommended for coverage by one of these review processes will make it on to PEI's drug formulary, although a recommendation does not guarantee that the provincial ministry will approve the coverage.

In the case of people living with HIV/AIDS, access to drugs approved for reimbursement results when the patient's physician contacts the Chief Health Officer, who then approves the request. Most retroviral medications are automatically covered, although some medications require that the patient's physician complete an Exceptional Drug Request form, as is the case with Enfuvirtide or Tenofovir. Tenofovir is used in combination retroviral therapies when other combinations have proved less effective. Enfuvirtide is used to treat individuals with virus resistant to multiple antiretroviral drug classes.

The drug formulary in PEI effectively facilitates access to primary medical treatment of HIV/AIDS. However, there are still many difficulties which people living with HIV/AIDS experience as a result of government policies which must be revised in order to be more compassionate. An immediate issue is the general lack of information regarding the treatment of HIV/AIDS. While the cost of retroviral drugs is, in fact, reimbursed, there is very little information made available about how this happens. The provincial website (www.gov.pe.ca) details coverage programs specifically

geared towards people living with diabetes, multiple sclerosis, chronic renal failure, cancer, rheumatoid arthritis, Crohn's disease, kidney failure, and even patients requiring antibiotics to treat sexually transmitted infections (STIs). However, there is no information about HIV/AIDS testing or treatment that I could find. AIDS PEI provides this information to the people who need it and refers clients to support services. Still, the general lack of openness and information about the treatment of HIV/AIDS is doubly troubling. For one thing, it can cause frustration, pessimism and alienation for people living with HIV/AIDS, or those who suspect they may have been exposed to the virus, as they try to find out more information about their medical care options. For another, the lack of an informed public further contributes to the stigmatization and isolation experienced by people living with HIV/AIDS.

Both of these factors act as a deterrent to testing, a serious issue made worse by the lack of on-island anonymous testing facilities. On PEI, testing is non-nominal, meaning the patient's sample is not identified by the use of his or her name. However, there are many risks in this procedure which make the unwanted disclosure of HIV status a real possibility. Rather than take the chance, many people choose to go off-island to get tested, but this is inconvenient and costly, which means yet another deterrent. The general lack of local medical facilities is a constant difficulty which must be overcome by people living with HIV/AIDS. At present, there is no physician in PEI who is a specialist in HIV/Hep C treatment, even though there is over one thousand people in the province living with Hep C alone, which ought to amply justify the cost to the province of hiring a doctor who would be able to provide comprehensive care for people living with HIV/AIDS/Hep C. However, at this point, people seeking testing or treatment must travel at least as far as Moncton to receive proper medical care. This has implications for patient confidentiality, preservation of health, and reasonable quality of life.

Another quality of life issue is the province's failure to



reimburse the cost of secondary medications for problems associated with HIV/AIDS infection or side effects of retroviral therapy. The one exception is Diflucan, an antifungal for the treatment of thrush. However, this cost is only reimbursed if the patient fills the prescription at the provincial pharmacy, which many people living with HIV/AIDS are unaware of. Many end up filling the prescription locally and swallowing the thirteen or fourteen dollar cost along with every pill. Most other secondary medications are, although costly, not even partially covered by the provincial government.

Full medical coverage is provided by the provincial government via the Financial Assistance program. This program is, like the formulary, administered through the Ministry of Social Services and Seniors. However, eligibility for the program is based mainly on considerations of employability. As the provincial policy manual states, social assistance benefits are applied to individuals only after they have proven that they do not have "sufficient income to meet basic need requirements," and have exhausted all other resources, including family resources, short-term credit, any assets, and any opportunity for employment or employment training. The manual further states that "the cause of need can only be determined by the worker and the applicant, following a mutual decision to do so, examining the various circumstances that lead up to his/her decision to seek assistance." People can become eligible for the full medical coverage offered through the Financial Assistance program if it is ruled that their medical disability makes it difficult to meet their needs on their own. However, this is still determined by the criteria of employability.

In fact, tacitly, the program is intended to assist people with permanent intellectual disabilities, and the decision about whose medical issues affect their ability to provide themselves with a decent quality of life rests entirely with the caseworker, who, because of the lack of clearly defined guidelines, is invested with the power to decide without being easily held accountable for their decisions. If caseworkers can qualify an individual for a minimum of one dollar of social assistance, that person receives secondary medical coverage, even if this is the only actual social assistance they receive. However, at least two people living

with HIV/AIDS in PEI have failed to qualify for the Financial Assistance program, even though they were not well enough to work, and could not afford the secondary medical costs not covered by the PEI formulary.

A medical disability support program should be open to anyone who needs support because of medical disabilities. It is apparent that the provincial policy regarding this issue is failing. The Prince Edward Island Council for the Disabled has spearheaded attempts to reform this policy in order to render it more transparent, more accountable, and more compassionate. Advocates for people living with HIV/AIDS have been liaising with the Council for the Disabled in the hopes that this injustice can be overcome. ■

Can't find your favourite organ on the menu?

continued from page 5

We encourage you to contact CTAC to learn more about what you can do in your community and province to move this issue along. We must have equitably determined access for appropriate HIV and co-infected candidates to the transplants on which their lives depend. ■

¹ Curtis L. Cooper, Barriers preventing liver transplantation in Canadians with HIV infection-Perceptions of HIV specialists, *Canadian Journal of Gastroenterology*, March 2007, Vol. 21 No.3: 179-182

² Scott D. Halpern, Determinants of Transplant Surgeons' Willingness to Provide Organs to Patients Infected with HBV, HCV or HIV. *American Journal of Transplantation*, 2005, 5: 1319-1325

³ Cooper, 179-82.

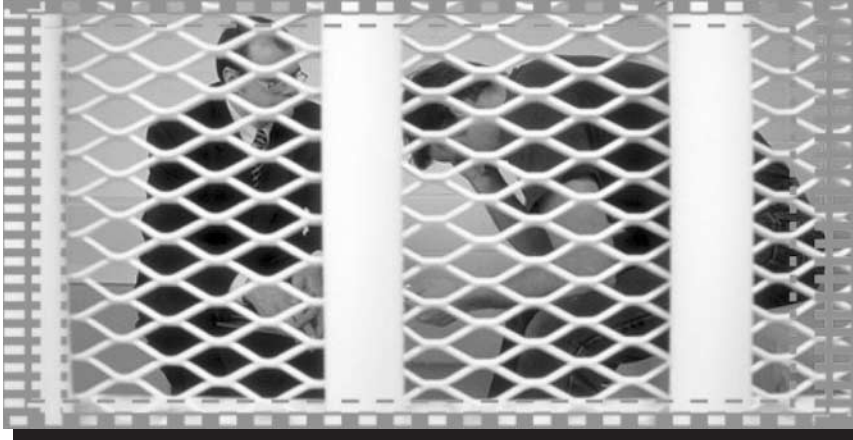
⁴ Peter G. Stock and Michelle E. Roland, Evolving Clinical Strategies for Transplantation in the HIV-Positive Recipient. *Transplantation*, September 15, 2007, Vol.8, No.5: 563-571.

⁵ M.E. Roland et al, HIV-Infected Liver and Kidney Transplant Recipients: 1- and 3-Year Outcomes, *American Journal of Transplantation*, 2008; 8: 355-365.

⁶ Halpern. p. 1319.

⁷ Roland and Stock. p. 570.

ARV treatment compliance for prisoners:



A day in the life of a prison outreach worker

By Terry Howard, MSc PPH- Prison Outreach worker at BC Persons with AIDS Society, Vancouver

COMPLIANCE to antiretroviral medications (ARV) is a difficult, multi-faceted problem for prisoners living with HIV and the community outreach workers that support them. Many people discontinue their HIV medications when incarcerated for fear of being stigmatized when other prisoners find out. Even when they are willing to continue ARVs, prisoners have a difficult time obtaining them consistently. To counteract these barriers, when prisoners initiate HIV medications, outreach workers thoroughly counsel them on the importance of compliancy, both while incarcerated and upon release.

Compliance problems are compounded by high rates of recidivism (in B.C. the average length of stay in a provincial jail is 14 days). Getting incarcerated without ARVs can mean a delay of several days before treatment can be resumed.

Given the hurdles many prisoners face in maintaining ARV compliance, it is important that they receive support during their period of incarceration. Unfortunately, those who advocate for health care of prisoners encounter daily difficul-

ties due to the exterior location of a community agency attempting to deal with issues occurring inside a correctional facility. The dichotomous task of building relationships with health care staff while providing advocacy for prisoner patients can often require extraordinary diplomacy on the part of the advocate in order to obtain successful resolution of issues while maintaining a harmonious working relationship with internal staff and retaining prison entry privileges.

Encouraging the ARV compliance of incarcerated clients is an area of high-needs advocacy work as prisoners routinely report running out of medications, or being told by health care staff to take what medications they have remaining and resume taking the remainder when the refill arrives from a central pharmacy.

The lack of resources available to community service organizations that would provide support to prisoners living with HIV/AIDS in Canadian prisons is also prohibitive to ARV compliance as prisoners become discouraged by the lengthy internal grievance process and feel that to advocate on their own behalf is to speak to deaf ears. When no one hears their cry for help, prisoners give up trying to remain compliant.

The following journal entry illustrates the time and resources required to resolve a single issue of one prisoner's attempt at ARV compliance.

WEDNESDAY JANUARY 9, 2008

—08:15am— Received a voicemail message from a prisoner who had run out of HIV medications three days prior asking for assistance in obtaining them. Prison health care staff told him daily for the past three days that he would receive them as soon as they arrived. The prisoner then called the outreach worker for assistance and reported that he had submitted a request for refill six days before, but had not yet received the medication refill.



—09:10am— Placed a call to the prison health care pharmacy where I stated the reason for my call, and inquired when the prisoner might receive his medications. The nurse told me that the refill order had been faxed to the central pharmacy and the prisoner should receive them that afternoon. She told me that this prisoner had been warned previously about not re-ordering his medications in a timely manner. I asked if it was appropriate to leave the onus for re-ordering medications on the prisoner, and if there was not a way to “flag” medications that require ongoing refills. She replied that with 600 prisoners in the facility they would need to triple the staff to keep up with the demand. I asked when he had requested his refill, and she told me he ordered them six days before.

—09:20am— Notified the prison’s private health care operations manager via e-mail of the situation, the importance of compliance to ARVs, and requested that we work together to institute an automatic refill system.

—10:40am— I contacted the local hospital pharmacy that dispenses HIV medications to inquire about instituting an automatic notification system. The pharmacist informed me that it already exists. The pharmacist was familiar with the prison central pharmacy system, and stated that the prison pharmacy system was more technologically sophisticated than the hospital pharmacy. She suggested that I call and speak to them about automation for the onsite prison medication dispensary.

—11:10am— Spoke to the prison central pharmacy manager who was able to locate the pharmacy file for the prisoner and told me that there was no refill order on file. He explained that the process requires the prison to fax over a refill order for medication and that they process ARV refills immediately. When I explained that this prisoner had been without his medications for three days, he advised me to call back to the prison pharmacy and have them fax over the refill order immediately. He would deliver the refill to the prison within one hour. He said that there was no reason for any prisoner to go without medication, as they were located within a ten minute drive to the prison and always deliver ARV refills the same day they are ordered. He urged me to

The need for Prison Officials and ASO/NGO to work together

Worldwide, levels of HIV prevalence within inmate populations tend to be much higher than in the general population. Several countries have reported HIV prevalence rates ranging from 10 to 25 percent.

The primary mission of most prisons is custody and control; rehabilitation is often times an afterthought. NGOs, with their health positive and non punitive messages, are not always welcome into the prison. However, prison officials who have worked with NGOs have shown that the collaboration can be beneficial for the prison, the NGO, the prisoner and the community. In recent years, many European countries have developed collaboration models that are showing excellent results. It is my belief that these models of effective collaborations between NGOs and prisons should to be implemented in North America.

*—Greg Simmons,
CTAC Representative for Prisoners/Ex-Prisoners*

report this incident, as maintaining HIV medication compliance is very important to the patient’s health. I asked about the automatic refill and he told me that the average length of stay is seven days and it was unusual for someone to require more than the 28-day supply they are given upon entry. The reason for requiring a refill fax from the prison pharmacy is to confirm that the prisoner is still onsite after the 28-day supply has run out.

—3:00pm— Called back to the prison pharmacy nurse and asked if she had received the medications for the prisoner. She told me that they were definitely on order and not to worry, that the prisoner would get them as soon as they arrived. I asked if she had them on hand and she said no, they had been ordered and they were waiting for the



CALENDAR OF EVENTS

FALL/WINTER 2008

► OCTOBER

4th Gay Men's Health Summit**30-31**
Vancouver, BC
www.gaysummit.ca

► NOVEMBER

Ontario HIV Treatment Network – Research Conference 2008 –**13 & 14**
Toronto, Ontario
www.ohtn.on.ca/OHTNConf2008_program.htm

Canadian Centre on Substance Abuse National Conference**15-18**
Halifax, Nova Scotia
www.ccsa.ca

► DECEMBER

World AIDS Day**1**
Aboriginal AIDS Awareness Week**1-5**
www.caan.ca

International Conference on AIDS and STIs in Africa**3-7**
Dakar, Senegal
www.icasadakar2008.org/en

On page 3 of CTAC's Summer 2008 issue, information about harm reduction programs across Canada was taken from *Learning From Each Other: Enhancing Community-Based Harm Reduction Programs and Practices in Canada*, a report written by the Canadian Harm Reduction Network and the Canadian AIDS Society.

We encourage you to read this report for more information on innovative and useful ways that harm reduction programs and practices are offered in Canada's small to mid-size cities.

The report is available at
www.cdn aids.ca/learning_from_each_other

medications to be delivered. I told her that I had spoken to the central prison pharmacy manager who stated that no order had been received and there was no reorder in process for this prisoner. She said she would check on it and resend the order if necessary.

—**3:45pm**— I called back to the central prison pharmacy and asked if they had received the refill order. The manager confirmed that he had received the fax, filled the order, and delivered it to the prison 20 minutes before my call.

Discussion:

This account is disturbing for several reasons. Aside from the excessive staff resources required to deal with one issue for a single prisoner, the demonstrated lack of awareness or concern of the prison health care staff about the necessity of HIV medication compliance is alarming. In May 2007, barely seven months prior to this incident, I delivered a lecture at a conference for BC Corrections health care staff on the topic of supporting prisoners living with HIV. I lectured about the importance of medication compliance and the difficulties faced by incarcerated people coping with dangerous health conditions exacerbated by the added factor of multiple morbidities. The message I delivered was that everyone involved in the health care of prisoners needs to work together to help them remain compliant when they are on ARVs. This message needs to be emphasized until incidents such as the one I described are unthinkable.

If this prisoner did not have an outside source of support advocating on his behalf, how long might he have continued to request his medications without receiving them? The frustration prisoners experience at the apathy and lack of results they encounter when attempting to obtain necessary medication through the proper channels often leads to acting out, resulting in punitive measures like segregation as well as the self-punitive measure of voluntary discontinuation of medications until after release. The reality for many prisoners trying to comply with ARV treatment is that the deck is stacked against them. ■



CHAIR'S REPORT

Fall 2008

by Louise Binder

THIS SUMMER BROUGHT the XVII Annual International AIDS Conference in Mexico. Along with the scientific and policy presentations were the usual discussions I hear at these and other events about apathy in the HIV activist community, the need for new blood (please excuse the pun), and the lack of fresh thinking.

I see it quite differently. In most of the world, which is lower income, the quality of young activists and their ideas and enthusiasm is very high. A plenary given by a 12-year-old girl from Honduras is indicative of this. At this year's conference, we heard lots about projects for microbusinesses, peer-led counseling, property rights protection coalitions, sex trade worker groups, and Indigenous Peoples' rights groups. I cannot do justice to the vibrancy in the halls. The two day HIV+ pre-summit was also buzzing with ideas. And it was not just the same faces there either, although luckily many were. I met a great young man from Paris just starting out in advocacy and another in Toronto. I also met many young women on the go.

Fortunately, we in the higher income countries are at a different place with this epidemic. We often have access to treatments and at least a reasonable level of care. In the areas where we do not—for Aboriginal people, prisoners, sex trade workers, gay men and other groups overrepresented in the epidemic—we are aware of this: there is active work going on to secure and protect their human rights, including the right to access to treatments for those who are not getting it. Also, many people are well enough to work and carry out other activities of daily living with episodic periods of illness. And why should they not? Is that not one standard for which we fought, even while the elusive cure and vaccine are still the ultimate success towards which we strive? Some moved on when we achieved this standard and others decided to stand on guard for the rest as their ongoing contribution.

I suggest that a few main rules continue to apply now, in this movement, as always. Those that want to continue to do this work, do so, with the knowledge that they have the support of the community. This continues to be done through political channels, by preparing evaluations of access to treatment from the point of view of the people who are receiving treatment, and through direct grassroots contact.

There is an amazing base for active, direct, grassroots involvement that is successfully mobilized to confront various issues surrounding the health and wellness of the HIV community. We have seen this loud and clear with our response to the federal government funding cuts and its lack of support for harm reduction as well as the City of Ottawa's crack pipe distribution policy. Another example is the mobilization of activists regarding the need for a centre of excellence for organ transplantation. In all of these cases, local, provincial and national groups sounded the call and people responded.

Everyone did their job and will continue to do it as long as these issues arise. And young people will continue to be mentored.

I think that sometimes we confuse apathy with a level of success. We cannot rest on our laurels as we well know. And let us never forget, any of us, the stigma and discrimination against people with HIV that lies, if not always on the surface, then very close to it and easily brought there when people feel threatened. Criminalization has surely taught us that message. Working to end this stigmatization continues to be an ongoing job for all of us. ■

For more information about CTAC,
please visit our website:

www.ctac.ca

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CTAC POSITION PAPERS

Papers

- 2007 – “Generic Drugs in Canada : A Policy Paper.” Authors: CTAC and Ward Health Strategies.
- 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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MEMBERSHIP

Membership applications are available by contacting the CTAC office or by visiting the CTAC web site at www.ctac.ca/en/membership.

Full Membership is reserved for

- 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

CONTACT US

Canadian Treatment Action Council (CTAC)

P.O. Box 203
 555 Richmond St. W., Suite 1109B
 Toronto, Ontario M5V 3B1

Phone and Fax: (416) 410-6538
Email: ctac@ctac.ca
Website: www.ctac.ca

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.

[position_papers](#) or on hard copy from the CTAC office (see contact information below).

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Editorial Committee: Béatrice Cardin / Laurette Lévy / Leah Stephenson / Theresa Wojtasiewicz / Eileen Wennekers

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