

AIDS ACTION NOW!

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Dear Friend:

We have all been invited to the Ontario Drug Program Reform Secretariat's consultation this Friday as part of its 'Disease Groups' forum. We wanted to introduce ourselves to you before the meeting.

AIDS Action Now! is a Toronto-based activist group that fights for equal access to high-quality treatment and care for all people living with AIDS and HIV (PLWA/HIVs). We want to share with you a number of things here:

- what the current situation is for PLWA/HIVs; especially the tremendous financial barriers we face in getting access to the treatment and drugs we need;
- our initial reaction to the questions posed by the Secretariat; and
- our thoughts on how policy can be developed that will ensure equitable access to vital treatments for all people facing catastrophic illnesses.

We hope this meeting will be the beginning of working closely together towards our common goals of a health care system that meets all people's needs, whatever their illness or situation.

People Living with AIDS and HIV and Access to Treatment

The medical prognosis for HIV disease has dramatically changed in recent years. The rapid development of drugs and other treatments to prevent or alleviate the many opportunistic infections that strike PLWA/HIVs has significantly altered the nature of HIV disease. Many of the most life-threatening conditions can be prevented or significantly delayed, and their worst effects substantially alleviated. These treatments allow people to live longer with better health -- the potential to transform AIDS into a chronic manageable condition in the very near future is very much to hand. But the benefits of these

emerging treatments are inaccessible to many because of financial barriers.

The key treatments for HIV-related conditions are incredibly expensive. We will bring a background paper on these costs to the meeting, but many of the individual drugs can cost hundreds of dollars per month and many people pay a thousand or more each month for their drugs. For example, a common but treatable problem affecting many PLWA/HIVs is the fungal disease Candida (thrush). It is treated with Ketoconazole, or for those resistant, Fluconazole, which cost about \$135 and \$295 respectively a month.

Some PLWA/HIVs are lucky enough to have private or workplace insurance plans. However, many plans have high deductibles, lifetime limits on what they will pay out, or do not cover the full range of HIV treatments. Others are on the Ontario Drug Benefits Program which entitles them to some HIV drugs free of charge. To be eligible, a person must be over 65, on social assistance or receiving home health care --that is, PLWA/HIVs must be old enough, poor enough to get welfare or sick enough to require home care. In fact, many PLWA/HIVs are forced to quit their jobs and go on welfare even when they want to go on working in order to get the ODB card. But even then there are significant problems with ODB coverage of HIV treatment: including a new drug on the formulary takes up to six months after it has received its notice of compliance from the federal government; special exemptions designed to 'fast track' new HIV drugs are in fact slow and cumbersome; and the formulary does not include the full range of HIV treatments and has never covered the alternative and complementary therapies many use.

Other PLWA/HIVs fall between the cracks: for example, individuals on long-term disability can quickly reach the limit on their drug plan, but cannot qualify for ODB because their income is above the welfare rate. Similarly, those working, but with an inadequate or no drug plan, cannot get the ODB card because of their employment income. And in the worst situation of all, many PLWA/HIVs have no coverage at all.

In these ways, the high cost of drugs is a crucial barrier to equitable access to health care. Many PLWA/HIVs are forced to make their health care decisions for all the wrong reasons. They must decide on treatment options not in terms of what can contribute to a healthier and better quality life, but in terms of what they can afford. And many PLWA/HIVs are being denied life-saving treatments and get sick and die because they can't pay for the treatment they need.

Catastrophic Illnesses

The key issue missing from the questions posed by the Secretariat, and the issue that brings all of us together, is that of catastrophic illnesses. There are a range of special programs designed to ameliorate the devastating impact of some conditions. The problem is that all of these programs have evolved in an ad hoc and uncoordinated fashion and that they tend to be ineffective, inequitable and inadequate. It will be important for the Secretariat and the Ministry to hear exactly why these programs don't work from all of us.

HIV/AIDS clearly meets the two criteria set out by the Secretariat for a catastrophic condition. On the first factor of cost, PLWA/HIVs face incredibly high drug costs. The second criteria is that the treatments involve life-saving drugs not required by the general population: the treatments we need are almost entirely HIV-specific, designed to prevent or treat the opportunistic infections that affect people with HIV disease.

However, the province only funds four drugs from the wide range of HIV treatments:

- When anti-retroviral drugs received approval from the federal regulatory authorities Ontario covered their full cost. AZT, and then ddi and ddc, were distributed through the HIV Project Centre at Sunnybrook Hospital.
- The problem was that Ontario did not approve funding for each of the anti-retroviral drugs until the very last minute. PLWA/HIVs who had been receiving the drugs free of charge under clinical trials were facing the prospect of paying huge amounts to continue their treatment once the drugs were approved for marketing by the federal government. This scenario is currently being played out once again for PLWA/HIVs on Rifabutin; it will be receiving its notice of compliance shortly, but no decision has been made whether it will be funded. It is expected to cost about \$250 a month. The needless anxiety created for often very sick people by this provincial indecisiveness again speaks to the need for a comprehensive policy; one that would allow proper planning when treatments come onto the market.
- After considerable activist pressure, aerosolized pentamidine was also covered. It is a prophylaxis against PCP, a form of pneumonia which was the major cause of death for PLWA/HIVs in the early days. The contradiction here is that it is now generally seen to be the least effective of available prophylactic treatments, but the others are not funded.

We think the criteria outlined by the Secretariat to distinguish catastrophic illnesses requiring special funding programs make sense, but they cover only a very few of the essential HIV-related treatments. Is this also the case for your area? We think the criteria should be applied comprehensively. **All drugs deemed to be clinically significant to the treatment of catastrophic conditions should be fully funded.**

Eligibility and Equity

The first question posed by the Secretariat is who should be eligible? We think the answer to this fundamental question is quite simple: **all people with the designated catastrophic conditions must be eligible for special funding programs.** The criteria should be clinical and medical; economic or social factors should not determine access to care and treatment.

This leads to the question of whether ability to pay should be a consideration. It is now -- in the worst possible way. The great majority of treatments are not publicly funded, most PLWA/HIVs are not on ODB, private insurance plans leave serious gaps, and huge numbers of PLWA/HIVs are not covered at all. For most treatments, for most people, PLWA/HIVs will have to pay the often horrendous costs themselves -- or they will go without treatment.

The Secretariat's Dilemma: Which Is More Fair?

The Secretariat poses a dilemma between limiting the number of people who can receive benefits (but presumably giving full benefits to those deemed eligible) and limiting the benefits available (presumably to all people with the particular illness).

This either/or does not capture the way in which the existing system fails PLWA/HIVs: there are no drug funding programs for which any HIV+ person automatically qualifies; programs for which large numbers of PLWA/HIVs are eligible are very limited (the four drugs funded by the province); and the numbers who can receive ODB benefits certainly are limited, but then the treatments covered are also highly restricted. This is demonstrably unfair and can have a dramatic effect on people's health. You may have seen our press conference last month with James Thatcher, former co-chair of AIDS Action Now!. James was advised to begin treatment with high dose acyclovir, an experimental prophylaxis for CMV (cytomegalovirus), a virus that causes a number of severe neurological conditions, including blindness. CMV is the most common viral cause of life-threatening opportunistic infections for PLWA/HIVs. James was unable to afford the cost of over \$800 a month. James did lose his sight from CMV and died of neurological complications last month.

The answer to their question -- put most simply -- is that all who need them should have access to the full range of available treatments. In fact, we reject the terms of the Secretariat's question. It is posed narrowly as who should be eligible for benefits under government assistance plans. It invites answers in terms of who is most vulnerable or most deserving.

We would restructure the Secretariat's assumptions. We see drugs and other treatments as essential components of health care, no different than visits to clinics or services from physicians. For example, why should a particular drug be free when provided in hospital, but have to be paid for, or foregone if too expensive, when at home. The contradictions of this anomaly are clear and brutal: a member of AIDS Action Now's steering committee has recently been hospitalized for treatment of PCP. He responded well to a new treatment, Mepron, and was well enough to be released. However, the ODB formulary does not yet cover Mepron and he could not afford the \$415 the remaining two week course of treatment cost. This example shows the cost of not having an overall policy on funding catastrophic drugs. Rather than simply covering the \$415 for the drug, which it is paying in any case, the province is paying over \$11,000 (two weeks of unnecessary hospitalization at over \$800 a day) to keep a person in hospital unnecessarily. This kind of waste and misallocation of scarce resources is by no means uncommon for PLWA/HIVs. Are there parallel cases in your area?

Public and Private Sectors

The system is currently mixed and private and workplace insurance plays an important role in covering many individuals. It is up to the private sector to demonstrate that their participation contributes to the efficiency and equity of the system as a whole. We are certainly aware of many problems in relation to HIV/AIDS: insurers refusing to cover HIV+ people, attempting to limit the range of drugs they cover, etc. We would expect that the system will remain mixed for the immediate future. But this underlines the government's responsibility to regulate the private sector in such away that equitable access is ensured.

Government as Payer of Last Resort

We think private insurers should be required to cover the full costs of drugs and treatments for those on plans. This will lower public expenditure.

Patient Participation

As with many other consumer and health movements we would emphasize empowerment as opposed to simply participation. A vital factor to being able to manage one's own health care is information. The AIDS movement, drawing on the legacy of the

women's and other health movements, has established community-controlled information resources, such as the Community AIDS Treatment Information Exchange (CATIE) in Toronto. We have also demanded a national treatment registry (although the scandalously delayed federal government sponsored ATIS is not yet operational).

We think the province must be prepared to fund community-based efforts in other areas as well where activists identify the need.

Directions for Reform

One response we might get from the Secretariat and the Ministry to our demands for speedy action is that drug reform is a long and complex process. This is certainly true. But it does not mean that people facing life-threatening illnesses can afford to wait, especially when treatments are available but effectively inaccessible because of their high cost. There is no reason why well-planned emergency action on catastrophic illnesses cannot be smoothly integrated into the longer-term comprehensive restructuring of drug policy and programs. We, and no doubt all of you, would be happy to work with the Secretariat and Ministry in planning how this can be done.

Similarly, because a policy issue is complex does not mean it is insurmountable. In early 1992 the AIDS Bureau of the Ministry of Health called together a representative working group to develop a policy for HIV/AIDS. Composed of a primary care physician, clinic director, community activist, and members of the Drug Programs Branch and the AIDS Bureau, the group produced a draft *Comprehensive Drug Distribution and Payment Policy For Drugs Used in Treatment of HIV and HIV-Related Illnesses*. The goal of this program was to remove the financial barriers that prevent equitable access to the vital drugs used in the treatment of HIV/AIDS.

- The basic principle is that eligibility for the program would be based on diagnosis and clinical need, not an individual's financial resources.
- The cost of all drugs used in the treatment of HIV-related illnesses would be covered by the province.
 - Third party insurers would be expected to pay for HIV drugs to the limit of individuals' coverage (as is the case with the special funding program for cancer). Public funding would then kick in to cover the remainder of treatment costs. Individuals would subrogate their benefits to the Ministry.
- Clear mechanisms and processes were outlined. For example, an expert panel would develop the list of treatments to be

covered, determine the most effective distribution channels and ensure quality assurance.

- The program would build on existing infrastructure and programs. For example, it would be administered through the Project Centre at Sunnybrook Hospital and through existing networks of hospital and community pharmacies.
- Other means of making the program cost-effective are outlined. The Ontario Government Pharmaceutical and Medical Supply Services would purchase drugs from the pharmaceutical manufacturers, in effect acting as bulk buyer. In addition, as with the recent agreement with Burroughs-Wellcome, such a role for the provincial government would ensure economies of scale and other benefits to HIV programs.
- This program would be well coordinated with other related initiatives. For example, it would use a 'buddy' system in which experienced physicians support those new to the field. This will help to ensure the most up-to-date prescribing and treatment practice and to facilitate consistent standards of care.

One would think that a well-developed policy proposal from the most experienced people in the area would be welcomed by the Secretariat -- that it would be seen at the very least as a useful starting point; at best as the foundations for policy that could be implemented very quickly. However, when this plan was submitted to the Minister of Health and to the Drug Programs Reform Secretariat last spring it disappeared without trace. The Manager of the AIDS Bureau attempted to contact the Head of the Secretariat on different occasions but his calls were not returned. On December 18, 1992, the AIDS Bureau again called together the working group to meet with a senior official from the Drug Programs Reform Secretariat. While expressing polite interest in the issues and proposals raised, she admitted that she had not read the policy proposal submitted by the working group.

Immediate Actions Needed

We have been calling for two immediate measures to address the crisis PLWA/HIVs face in getting the treatment we need. First of all,

The Minister of Health should instruct her officials to immediately begin to implement the program proposed by the AIDS Bureau working group. Ministry staff should work closely with the Bureau working group in developing the program. The program should be up and working by July 1, 1993.

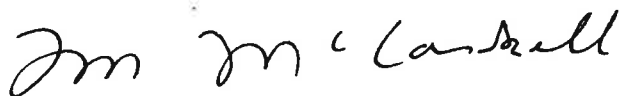
But we see no reason why PLWA/HIVs should have to continue to wait for access to treatment as this policy is being implemented. The Minister has a means of immediate action at hand. The Ontario Drug Benefits program can be used as an emergency interim measure. We demanded that:

The Minister of Health should immediately expand the ODB to 1) automatically include all people with HIV and 2) cover all treatments for HIV-related illnesses prescribed by a physician.

We have not wanted to speak for other groups, so we have not made similar specific demands for other conditions (although we do think that the ODB card for everyone with particular catastrophic conditions may be a useful starting point in other areas as well). However, we have always stressed that the same financial barriers are preventing others facing catastrophic illnesses from getting equitable health care and treatment, and that the government should move equally quickly to fully fund all necessary treatments for other catastrophic conditions. We are certainly happy to support demands being made by yourselves and other groups for action in your particular areas.

I am sure all of us see the danger of being portrayed as competing with each other for funding, the attention of the government and media, the sympathy of the public, etc. We think the best way of avoiding this danger is making common demands on the government for the necessary funding to ensure all those facing catastrophic conditions have equitable access to the treatments they need. The first step to such common policy and action is to know each other's situations better. We hope this information will help you understand the problems for PLWA/HIVs and we are sure we will develop a better understanding of the problems you are facing when we meet on Friday.

Thanks very much.



Tim McCaskell