

# TREATMENT AIDS!



**AIDS ACTION NOW!** protests the federal government's failure to make experimental treatments available to people who are HIV-positive. From left to right, Bill Greenway, using aerosolized pentamidine; Michael Lynch taking naltrexone; James Thomas taking dextran sulfate; and Chuck Grochmal (not shown here) taking AL-721. Photo by Philip Hannan

## Your guide to AIDS treatments

- Anti-HIV DRUGS
- Infection Fighters
- AIDSpeak Glossary
- Immune Boosters
- AIDS as Syphilis
- The Pentamidine Project

# WHY YOU SHOULD READ THIS

The most important news to come out of the recent international AIDS conference in Stockholm is that while neither a vaccine nor a cure for AIDS has been discovered, advances in treatments are making it possible to extend and improve the quality of life, of people living with AIDS (PLWAs).

Increasingly, AIDS is coming to be seen, not as a fatal disease, but as a chronic illness that can be managed in much the same way as epilepsy or diabetes. This change in the prognosis for PLWAs and for all those who are HIV-positive, living longer, is creating a serious political problem: People living with Aids cannot expect *accelerated care* from hospitals without having to fight for it.

First and foremost, Canadian medical authorities have been caught with their pants down on this one. To date, only one experimental drug has been approved for use with HIV infected people, and that is AZT. At best some experimental drugs are being released on compassionate grounds, and in a few hospitals across the country it is possible to get aerosolized pentamidine. But that's all!

This situation has arisen because of gross negligence on the part of the federal government and the Federal Centre for AIDS. It must also be said that tertiary-care physicians (doctors consulting and carrying out research in hospital settings) have also failed to take an aggressive stance in this matter. The result is that Canadians with AIDS are not getting state-of-the-art medical care!

This is false economy. In fact, it is far more expensive to hospitalize individuals dying of AIDS than it is to dispense life-saving drugs to them on an out-patient basis. In addition, they may continue to work and lead productive lives.

One way to change this situation is for PLWAs, their friends and families, as well as those who are HIV positive, to demand of their physicians access to state-of-the-art medical care.

Secondly, the British Columbia Civil Liberties Association has recently published a brief on what it calls "catastrophic rights." In short, this is the right of individuals who have a terminal illness to have access to therapies and treatments they believe will be beneficial to themselves, so



Under medical supervision by Dr. Wayne Boone, Chuck Grochmal and Bill Greenway inhale Aerosol Pentamidine from different types of mist-producing "nebulizers." Photo by Chuck Grochmal

## Who Needs Aerosolized Pentamidine?

Most hospitals in Toronto do not offer Aerosolized Pentamidine (AP). According to

who have a terminal illness to have access to therapies and treatments they believe will be beneficial to themselves, so long as access to these treatments does not harm others. **AIDS ACTION NOW!** believes that these are two good reasons for people with AIDS-related conditions to know what treatments are available.

Consequently, **AIDS ACTION NOW!** is publishing this bulletin. Our goal is to assist people living with AIDS/HIV seek out, in consultation with their physicians, the treatments they believe will improve the quality of their medical care and their lives.

## AIDS ACTION NOW!

**TREATMENT AIDS** was prepared by the Media Committee of **AIDS ACTION NOW!** from: information published in medical journals; *Rites*, Canada's national lesbian and gay magazine; research reported at the Fourth International Conference on AIDS (Stockholm, June '88); and interviews with physicians and people living with AIDS and ARC.

Research by Sean Hosein

Written by Mark Gerson, Sean Hosein  
and George Smith

DeskTop Publishing and layout by Chuck Grochmal  
Photography by Chuck Grochmal and Philip Hannan

**AIDS ACTION NOW!** is a political advocacy group. We focus on government policies—and lack of policies with respect to the availability of drugs, treatments and health care delivery for people living with AIDS. **AIDS ACTION NOW!** seeks no funding from government and relies on donations from Toronto's gay community to support our programs.

Most hospitals in Toronto do not offer Aerosolized Pentamidine (AP). According to current medical thinking, AP is best used as a preventive measure against getting Pneumocystis Carinii Pneumonia (PCP). This is called "prophylaxis." It can also be used along with intravenous pentamidine (IVP) in a two-stage treatment for PCP. This is done by administering the high concentration of the drug in IV form only as long as necessary and then switching to aerosol to avoid the dangerous toxic buildup of the drug in body organs. The people most in need of AP are immune compromised individuals who have not yet developed PCP and people living with AIDS (PLWAs) who have had one or more bouts of PCP and are trying to prevent another outbreak of the disease. See back cover for information about getting Aerosolized Pentamidine.

**AIDS ACTION NOW!** does not recommend particular drugs or therapies. Our aim is to make you aware of the various options available.

This special **AIDS ACTION NOW!** publication is sponsored by: *Xtra!*, Toronto's gay news and entertainment magazine, for contributing the use of their production facilities and the **Trillium Monarchist Society**

## AIDS ACTION NOW!

Box 325  
253 College Street  
Toronto  
Ontario  
M5T 1R5

591-8489



TRILLIUM  
MONARCHIST  
SOCIETY

The TMS is a non-profit organization serving the Lesbian and Gay community. We promote fun, unity and friendship through entertainment. Proceeds of the group are donated to support community projects.



Published by Pink Triangle Press

**FOR YOUR SUBSCRIPTION  
TO XTRA CALL  
(416)925-6665**

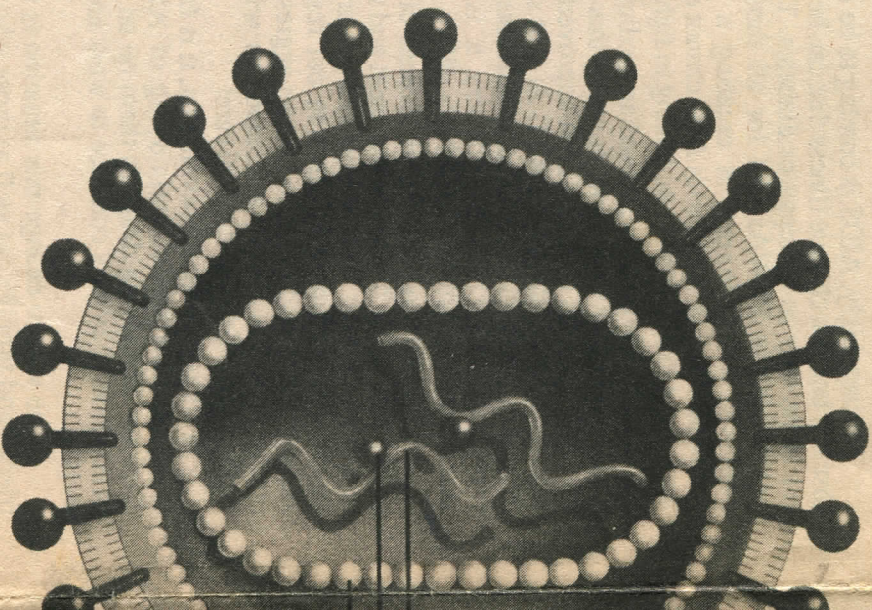
or write to us at Box 7289,  
Stn A, Toronto ON M5W 1X9

**Your key to Toronto's  
lesbian and gay community**

# AIDS ACT

# HIV

HUMAN IMMUNODEFICIENCY VIRUS



## ANTI-HIV DRUGS

These drugs lower the level of the AIDS virus in people already infected. Some also act as immune boosters.

**AL-721**—This non-toxic combination of natural lipids (fats) seems to block the AIDS virus from infecting healthy cells. Unavailable until recently, it is now sold in U.S. health food stores as a food supplement. It will be available in Canadian health food stores [Supplements Plus, 451 Church Street, Toronto] in July.

[IV Internal Conf. On AIDS, Stockholm, 1988 abstract 3529,3530,3531]

**ALPHA INTERFERON**—Taken with AZT, alpha interferon has stopped the AIDS virus from reproducing itself in some people with AIDS and Kaposi's sarcoma. It also reduced the size of their tumours and stabilized their condition. [Clinical Research, 1988;36:438A]

**AMPLIGEN**—When doctors in Philadelphia gave high doses of this anti-cancer drug to people with AIDS and ARC, it lowered their level of HIV infection with no serious side effects. Ampligen has also been shown to boost the immune system and has decreased such ARC symptoms as fatigue, swollen glands, weight gain and chronic yeast infection. [IV Internal Conf. On AIDS, Stockholm, 1988 ab. 3046]

**"ANTISENSE" DNA/RNA**—These small strips of modified DNA or RNA have been found to slow or stop the production of the AIDS virus in infected cells. [Clinical Research, 1988;36:463A]

**AZT**—Fools HIV by letting dividing virus incorporate a fake building block inhibiting viral reproduction. May cause serious side effects including anaemia and low T-cell counts. AZT penetrates the brain but not all infected cells in the blood but it is not a cure for AIDS. Preliminary research indicates that AZT may achieve better results in patients who begin the drug early in their diagnosis.

**CYCLOSPORIN A**—Cyclosporin A is commonly used to stop the body from rejecting transplanted organs. In tests at the University of Paris, it raised the level of vital T4 cells and eliminated swollen lymph glands in some people with ARC and mild HIV infection. It also inhibited HIV production and prevented the virus from attaching itself to healthy cells. However, a few years ago a Toronto-based study was abandoned by researchers at Mt. Sinai Hospital who got "disastrous" results. [Clinical Immunology and Immunopathology 1988;46:181-89]

**D4T**—In test tube studies D4T blocks viral replication and is 100 times less toxic than AZT. [Antiviral Research, 1988;9:119]

**DEXTRAN SULFATE**—Dextran sulfate stops the AIDS virus from attacking healthy cells. Although it is manufactured in Toronto, Health and Welfare Canada has refused its sale or trial in this country, even on compassionate grounds. Canadians using dextran sulfate must smuggle it in from Japan, where it is sold over the counter to Japanese citizens. [IV Internal Conf. On AIDS, Stockholm, 1988 ab. 3580]

**GAMMA INTERFERON**—see: TNF

**LITHIUM**—Taken with AZT, this prescription drug, which is used in Canada to treat manic-depressive illnesses, appears to increase the number of white blood cells and may have HIV-fighting properties. [Clinical Research, 1988;36:620A]

**PEPTIDE T**—Clinical tests in Sweden show that Peptide T prevents the AIDS virus from infecting healthy cells and may prevent it from growing in already-infected cells. It also diminishes such symptoms of AIDS-dementia as memory loss. [IV Internal Conf. On AIDS, Stockholm, 1988 ab. 3102,3103,3104,3105]

**RIBAVARIN**—Used illicitly in Canada and the U.S., this Mexican-made drug has prevented people with ARC from developing AIDS. In fact, some people using Ribavarin have tested negative for the virus during treatment. Although its side effects are not as serious as those associated with AZT, it has only been approved for highly selective experiments in Canada. The cost of smuggling ribavarin into Canada from Mexico has forced a number of Vancouver PLWAs into bankruptcy. [IV Internal Conf. On AIDS, Stockholm, 1988 ab. 3570]

THIS DIAGRAM DEPICTS THE PHYSICAL FEATURES

# CTION NOW!

## THE SYPHILIS CONNECTION

One treatment that appears to be lengthening people's lives is a therapy developed by a New York doctor, Stephen Catazza, who believes there is a link between AIDS and improperly treated syphilis. He has treated more than 200 PLWAs using high doses of penicillin, doxycycline and the anti-herpes drug acyclovir. After a year on this regimen, none of his patients has died. Many researchers attribute Dr. Catazza's success rate to the "accelerated care" he gives his patients and acknowledge that syphilis may be a co-factor in AIDS. Dr. Catazza's patients also use aerosolized pentamidine as a prevention from PCP.

## INFECTION FIGHTERS

These drugs treat and in some cases prevent infections that attack the body when its immune system is weak. These infections are often referred to as "opportunistic" and include:

- PCP (pneumocystis carinii pneumonia), affects some 60 per cent of people with AIDS.
- TOXO (toxoplasmosis gondii), a parasite that causes a serious brain infection.
- CRYPTO (cryptosporidium), a fungus that causes debilitating diarrhea and severe weight loss.
- CMV (cytomegalovirus), a virus that can lead to blindness.

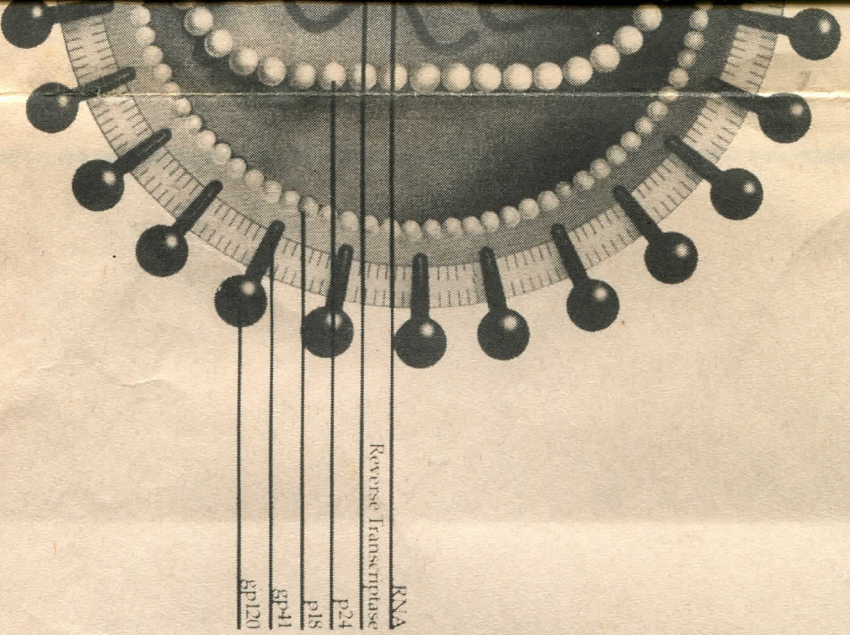
### PCP FIGHTERS

**AEROSOLIZED PENTAMIDINE**—Pentamidine is the most common treatment for PCP. Taken intravenously, pentamidine is highly toxic and has serious side effects. However, when inhaled as an aerosol mist, pentamidine has few side effects and, during the early stages of the disease, is considerably more effective because it goes directly to the lungs. It has also been shown to prevent PCP. Until recently, Health and Welfare Canada routinely refused doctors's requests for aerosolized pentamidine but this situation is changing. For help in getting aerosolized pentamidine for prevention, call The Pentamidine Project at 591-8489.

**DAPSONE**—Tesis using dapsone, a prescription drug available in Canada for the treatment of leprosy, show that it can prevent the occurrence of PCP in in some PLWAs, with minor side effects. It is sometimes administered in combination with another PCP fighter, trimethoprim. [Antimicrobial Agents and Chemotherapy 1988;32:626-51]

**PIRITREXIN**—Test tube and animal experiments suggest that piritrexin could be very effective as a PCP and Toxo fighter, and considerably less toxic than other treatments. [Antimicrobial Agents and Chemotherapy April 1988]

**SEPTRA**—Burroughs Wellcome's trade name for BACTRIM, a combination of trimethoprim plus a sulfa drug. In spite of the frequency of adverse reactions to this drug, SEPTRA is the treatment-of-choice for treating PCP in Canadian hospitals.



TURES OF THE HUMAN IMMUNODEFICIENCY VIRUS

PIRITREXIN—Test tube and animal experiments suggest that piritrexin could be very effective as a PCP and Toxo fighter, and considerably less toxic than other treatments. [Antimicrobial Agents and Chemotherapy, April 1988]

SEPTRA—Burroughs Wellcome's trade name for BACTRIM, a combination of trimethoprim plus a sulfa drug. In spite of the frequency of adverse reactions to this drug, SEPTRA is the treatment-of-choice for treating PCP in Canadian hospitals.

### TOXO FIGHTERS

**AZITHROMYCIN**—U.S. tests on rats suggest that this drug could be an effective toxo fighter. [Antimicrobial Agents and Chemotherapy (1988;32:755-7)]

**BACTRIM**—Bactrim, also known as septra, has demonstrated anti-toxo properties in test tube experiments, but many PLWAs suffer unpleasant side effects from it. [Antimicrobial Agents and Chemotherapy (1988;32:755-7)]

**CLINDAMYCIN**—Clindamycin has demonstrated anti-toxo properties in test tube experiments. [Antimicrobial Agents and Chemotherapy (1988;32:755-7)]

**GAMMA INTERFERON**—This natural chemical appears to inhibit the growth of the toxo parasite. It also enhances the anti-HIV properties of TNF. [Science 1988;240:516-518]

**PIRITREXIN**—see: PCP FIGHTERS

**ROXITHROMYCIN**—This French antibiotic has inhibited toxo in test tube experiments. [Antimicrobial Agents and Chemotherapy, April 1988]

**SEPTRA**—see: BACTRIM

**SPIRAMYCIN**—Used in Europe as an alternative to the standard North American treatment, which is highly toxic. [Antimicrobial Agents and Chemotherapy 1988;32:755-7]

**TNF-BETA**—Laboratory experiments suggest that TNF-beta inhibits the growth of toxo. [Clinical Research, April 1988]

### CRYPTO FIGHTERS

**BOVINE TRANSFER FACTOR (BTF)**—When this extract, prepared from cows that have been immunized against crypto, was given to 11 people with severe HIV infection, seven gained weight and reported a "significant decrease" in diarrhea. [Clinical Research, April 1988]

**SOMATOSTATIN**—Somatostatin is a hormone that appears to ease crypto symptoms and may have anti-HIV properties. Encouraging results have been reported in two cases, one at McMaster University [Annals of Internal Medicine 1988;108:708-9] and the other at the University of Arizona, where PLWAs have been treated with chemical equivalents of somatostatin. [Drug Intelligence and Clinical Pharmacy 1988;22:134-136]

### CMV FIGHTERS

**ACYCLOVIR**—High doses of this drug seem to inhibit CMV. [Annals of Internal Medicine, April 1988]

**ISOPRINOSINE**—Isoprinosine eliminated CMV from the blood of four people in a recent study of five infected men. [Annals of Internal Medicine, April 1988]

...tion that is believed to result from prolonged infection by a virus may be made without establishing the presence of the HIV virus.) ...s ability to fight off other life-threatening diseases like Kaposi's

...among its symptoms are loss of muscle control, loss of sense of ...e clinical symptoms of AIDS (swollen lymph glands, night sweats, ...e) of the major opportunistic infections (PCP, Kaposi's sarcoma,

...oring and testing of a patient's health in order to discover and treat ...reby ward off serious complications. There is no standard protocol ...ess pneumonias other than PCP. **CRYPTO** (cryptosporidium)—A ...ght loss.

...by most to be the main cause of AIDS. Some scientists believe it ...IDS, was rarely found. ...ll to conventional anti-cancer therapy.

...s-type bacteria which contributes to the development of respiratory ...fe-threatening, that strike people with AIDS. They include CMV,

...onia that is identified as the cause of death in over 40 percent of the ...es itself. ...fessional assassins, seeking out and killing invading germs. AIDS ...ning/opportunistic infections. ...erious brain infection.

# ed Pentamidine. CALL 591-8489

developing AIDS. In fact, some people using Ribavirin have tested negative for the virus during treatment. Although its side effects are not as serious as those associated with AZT, it has only been approved for highly selective experiments in Canada. The cost of smuggling ribavirin into Canada from Mexico has forced a number of Vancouver PLWAs into bankruptcy. [IV Internat. Conf. On AIDS, Stockholm, 1988 ab. 3570]

**RIFABUTIN**—Rifabutin is an antibiotic that appears to protect T4 cells from the AIDS virus. It is being tested in the U.S. to see if it will also help the body replenish its stock of T4 cells and to treat MAI infections. [IV Internat. Conf. On AIDS, Stockholm, 1988 ab. 3592, 3593, 3594]

**TNF (TUMOUR NECROSIS FACTOR)**—TNF is an anti-cancer drug produced in blood cells. Tests at the University of Texas found that it can stop the HIV virus from reproducing itself, particularly when combined with gamma interferon. [Clinical Research 1988;36:464A]

## IMMUNE BOOSTERS

These drugs improve the body's ability to fight off many of the infections linked with AIDS by replenishing its supply of T4 cells. Some immune boosters also act as anti-HIV agents.

**AS-101**—Israeli tests of AS-101 show that it can stimulate the immune system of people who are seriously ill with AIDS. It also helps the body produce cancer- and HIV-fighting agents like interferon. [IV Internat. Conf. On AIDS, Stockholm, 1988 ab. 3036, 3037, 3038, 3039]

**CARRISYN**—According to scientists in Texas, this drug made from the aloe vera plant is an effective immune booster and also helps lower HIV levels. [IV Internat. Conf. On AIDS, Stockholm, 1988 ab. 3032]

**DISULFURAM**—People with AIDS in New York who are fed up with government inaction have set up "guerrilla" clinics to test Disulfiram, a drug resembling DTC. Their results, presented at the recent AIDS conference in Stockholm, showed that it helped reduce AIDS-related symptoms and increased the number of T4 cells. [IV Internat. Conf. On AIDS, Stockholm, 1988 ab. 3042]

**DTC**—This French drug reduces AIDS-related symptoms in people with ARC and seems to prevent them from getting AIDS. [IV Internat. Conf. On AIDS, Stockholm, 1988 ab. 3041]

**IMREG 1**—Imreg 1 is an extract of healthy white blood cells that in preliminary French-U.S. tests halted the onset of new AIDS-related symptoms in people with AIDS and ARC. Additional tests are ongoing. [IV Internat. Conf. On AIDS, Stockholm, 1988 ab. 3048, 3049, 3050]

**NALTREXONE**—Used in Canada and the U.S. to help people recover from drug addiction, Naltrexone has recently been given in small doses to people with AIDS. It helped boost the immune system in two-thirds of the test group. [IV Internat. Conf. On AIDS, Stockholm, 1988 ab. 3056]

**ZINC**—The mineral zinc is believed to boost the immune system by activating the hormone thymulin, which is produced by your thymus gland. Unless it contains enough zinc, thymulin becomes inactive and prevents your immune system from functioning properly. [Journal of the American Medical Association, 1988;259:839-846]

## AIDSpeak GLOSSARY

**AIDS (acquired immune deficiency syndrome)**—A condition that is known as HIV. (Although a diagnosis of AIDS may be made without a blood test, the depletion of T4 blood cells weakens the body's ability to fight off infections.)

**AIDS DEMENTIA**—Brain damage caused by AIDS. Among its symptoms are touch and in extreme cases progressive memory loss.

**ARC (AIDS-related complex)**—People with ARC have the clinical symptoms of AIDS (fever, weight loss, diarrhea, fatigue, etc.) but have not had one (or more) of the major symptoms of AIDS.

**ACCELERATED CARE**—Ongoing comprehensive monitoring and testing for infections and diseases in their earliest stages and thereby ward off for accelerated care.

**CMV (cytomegalovirus)**—A virus that can lead to blindness pneumonia and other complications. It is a fungus that causes debilitating diarrhea and severe weight loss.

**HIV (human immunodeficiency virus)**—A virus believed by most to be the cause of AIDS.

**KAPOSI'S SARCOMA**—A skin cancer which, prior to AIDS, was rare.

**LYMPHOMA**—Lymph node cancer. Does not respond well to conventional treatments.

**MAI (mycobacterium avium intracellulare)**—A tuberculosis-type bacterial infection.

**OPPORTUNISTIC INFECTIONS**—Diseases, some life-threatening, that occur because of the immune system's weakness.

**PCP (pneumocystis carinii pneumonia)**—A severe pneumonia that is deadly to people with AIDS who have died.

**PLWA**—People (or person) Living With AIDS.

**REPLICATION**—A term used when any virus reproduces itself.

**T4 CELLS**—White blood cells that act as your body's professional assassins. They destroy T4 cells, leaving the body open to life-threatening opportunistic infections.

**TOXO (toxoplasmosis gondii)**—A parasite that causes a serious brain infection.

If you've had PCP you may need

# **THE PENTAMIDINE PROJECT**

To make aerosolized pentamidine (AP) immediately available under the supervision of their physician, *AIDS ACTION NOW!* has started **The Pentamidine Project**.

Here's how it works. **PHYSICIAN INFORMATION PACKAGES** about the indications and use of AP are prepared and distributed to doctors on request who care for people living with Aids. A phone line (591-8489) is established and publicized. By calling this number, people get:

- **INFORMATION ABOUT THE DRUG**
- **WHERE TO GET IT IN BUFFALO**
- **HOW MUCH IT COSTS**
- **WHICH DOCTORS WILL SUPERVISE ITS USE**
- **PATIENT INFORMATION PACKAGE**

*AIDS ACTION NOW!* helps co-ordinate funding when needed via the AIDS Committee of Toronto and the Toronto PWA Foundation and have organized a car pool for going to Buffalo

**591-8489**