

AIDS: Improving the Odds

TREATMENT INFORMATION HANDOUT

Columbia Gay Health Advocacy Project
400 John Jay Hall
Columbia University
New York, NY 10027
(212) 280-2878

This handout contains some information that may help orient you to the issues discussed by the panel tonight. We will be concerned mostly with treatments that are thought to be potentially beneficial for HIV-infected people who do not have a diagnosis of AIDS: that is, who are either asymptomatic, or who have only relatively mild symptoms such as swollen glands. Drugs that will be definitely be discussed tonight are:

Azidothymidine (AZT): the first FDA-approved anti-viral for HIV-related conditions, AZT's toxicity may be reduced for HIV-infected people if used in lower doses or in alternation with other treatments. AZT is thought to operate at the stage after the virus has entered the host cell, when the virus's genetic material is being transcribed.

Aerosol pentamidine: pentamidine is commonly given intravenously as treatment for *pneumocystis carinii* pneumonia (PCP), the disease which causes the majority of deaths from AIDS. Eventually, half of all people taking intravenous pentamidine become too sensitive to tolerate the drug. If people inhale low doses of pentamidine in the form of a fine mist, however, the drug is much easier to tolerate, and has been shown to be very effective as a preventive for PCP. HIV-infected people may choose to inhale regular (e.g. weekly) doses of aerosol pentamidine to prevent or postpone even a first occurrence of PCP.

AL 721: technically a food product rather than a drug, AL 721 is an anti-viral agent that is thought to reduce HIV's activity by making it more difficult for the virus to attach to the host cell. AL 721 is probably harmless, although there is some question of a "rebound effect" if the substance is suddenly halted. There are many different "versions" of AL 721 around, and there may be functional differences between different versions.

Imuthiol/antabuse: thought to be an immune booster or modulator, probably harmless, imuthiol has received a lot of attention recently. Antabuse is a metabolic precursor of imuthiol that has been used for years as a treatment for alcoholism.

Naltrexone: since this substance is familiar from its use in controlling opiate addiction, low doses of naltrexone are probably harmless. The drug may affect the opiate receptors of the neuro-endocrine system, and thereby have an immune-modulating effect.

More Information About Treatments Can be Found in the AmFAR Directory of Experimental Treatments for AIDS

There are many, many drugs for HIV disease out there, and it can get very confusing. The American Foundation for AIDS Research has just published a very useful directory of treatments. This directory includes: a listing of new drugs which are being studied for use in AIDS, ARC, and HIV infection; information about about the drugs'

mechanism of action; results of studies; toxicity and side-effects; and a listing of where drug trials are occurring. Call AmFAR at (212) 333-3118 for information about their directory. It costs \$50.00. Copies of the directory are available to read in the Gay Health Advocates treatment binder (see below). We went through the AmFAR directory to compile the following categories of drugs that may be relevant for infected people who do not have a diagnosis of AIDS.

Drugs obtainable through a physicians's prescription:

Azidothymidine (AZT)
Aerosol pentamidine
Antabuse
Naltrexone

Drugs that can be obtained through "guerilla clinics," AIDS treatment activist groups such as PWA Health Group, or health food stores:

AL 721 (active lipids, egg lipids)
Imuthiol (diethyldithiocarbamate or DTC)
Dinitrochlorobenzene (DNCB)
Monolaurin
Co-enzyme Q

Drugs that can be obtained in other countries:

Lentinan and dextran sulfate — Japan
Ribavirin and isoprinosine — Mexico
Imuthiol — France

Drugs that can be obtained through NYC-area protocols for HIV-infected people without AIDS: Some of these trials may not actually be occurring, or may not be enrolling new subjects.

Azidothymidine (AZT)
AL 721 (active lipids, egg lipids)
Naltrexone
Ribavirin
Isoprinosine
Imreg-1
Foscarnet

Other drugs being tested in clinical trials

The following drugs are either being tested in NYC-area protocols that require a diagnosis of AIDS, or are being tested in protocols outside the NYC area.

Ampligen
Alpha and beta interferon
Granulocyte-macrophage colony stimulating factor (GM-CSF)
D-Penicillamine
Dideoxycytidine (DDC)
Dextran sulfate (UA001)
Fusidic acid
Peptide T

To keep up with the alternative treatment movement, you should read *AIDS Treatment News* and the Project Inform newsletter:

How to Subscribe to *AIDS Treatment News*

Send \$25 per quarter (\$8 for people with AIDS or ARC) to John S. James, P.O. Box 411256, San Francisco, CA 94141. Or call him at (415) 282-0110, any time 24 hours a day, to start your subscription immediately. Subscriptions include several back issues at no extra charge. If you want the complete set of over 40 back issues, include \$30 (\$12 for persons with AIDS or ARC) in addition to the subscription price. You may order the back issues separately if you want. Back issues — and future issues — include information on AL 721, DTC (Imuthiol), dextran sulfate, lentinan, propolis, coenzyme Q, monolaurin, fu zheng herbal therapy, DNCB, aerosol pentamidine, fluconazole, and other experimental or alternative treatments. To pro-

tect your privacy, *AIDS Treatment News* is mailed first class without mentioning AIDS on the envelope, and the subscriber list is kept confidential. Outside North America, add \$5.00 for airmail postage.

How to Subscribe to *Project Inform*

Project Inform is a San Francisco-based group which publishes periodic reports on AIDS treatments. Call 1-800-822-7422 to subscribe.

Medical Journal Articles on Treatment Available in the Columbia Gay Health Advocates Treatment Binder

Our group here at Columbia maintains a looseleaf binder of journal articles and other written material describing treatments, including AmFAR's excellent experimental drug directory. Although medical journals are usually months behind the latest news, it can be very helpful to read these articles to gain perspective. Columbia affiliates can come to the Gay Health Advocates' headquarters in 400 John Jay Hall to read the treatment binder. People not affiliated with Columbia should contact the PWA Coalition at (212) 627-1810. The Coalition has generously agreed to provide the general public with access to their duplicate of the Gay Health Advocates treatment binder.

Can't Afford AZT?

The AIDS Drug Assistance Program (ADAP) is a federal assistance program administered by the New York State Dept. of Health AIDS Institute. ADAP provides Retrovir (AZT, azidothymidine) to financially and medically eligible people in New York State. For information regarding the program or to obtain an application, call toll-free:

ADAP (800) 542-2437.

or write:

ADAP
Empire Station
P.O. Box 2052
Albany NY 12220

AL 721 Available Through PWA Health Group

You can obtain kilogram jars of AL 721 from the PWA Health Group (an offshoot of the PWA Coalition). One kilo is about the size of a large mayonnaise jar, and typically represents a two-month supply. The price is currently \$175 per kilo, but since the price is changing you should call for exact information. You do not need to order in advance, simply bring your payment to the pick-up site at 155 W. 23rd St., 9th Fl., between 9:30 a.m. and 11:30 a.m., Monday through Friday. The only forms of payment accepted are certified check, money order, or bank teller's check (cashier's check). No cash, personal checks, or credit cards are accepted. Call (212) 955-5846 or (212) 242-9102 for information (the 955 number may be out of service for a few days — the phone company will have it fixed soon). You can speak to a staff person Monday through Friday, by calling (212) 242-9102. The staffer is always there during pick-up hours as above, but may sometimes also be reached at other times.

Services for Columbia Affiliates Available Through the Columbia Gay Health Advocacy Project (CGHAP)

Anonymous one-on-one peer counseling and anonymous HIV antibody testing are available to members of the Columbia University Community students, faculty, and staff. CGHAP provides information and discussion of all aspects of HIV infection including: AIDS anxiety, pros and cons of antibody testing, treatment

referrals, help with homophobic or AIDS-related discrimination or harassment. Call (212) 280-2878 for an appointment with a counselor; you will be asked to give only your first name, and you may give a false first name if you like.

HIV-⊕ SUPPORT GROUPS IN THE NYC AREA

(The following information is mostly but not completely up-to-date — sorry.)

Body Positive

263A W. 19th St., New York, NY 10011.

Contact Michael Hirsch, (212) 633-1782.

Body Positive is a drop-in peer-run support organization for people who are HIV-⊕. Activities include meetings twice per month, monthly newsletter, support group, public forums, social activities. December meetings are Tues., 12/8 and Tues., 12/22, 7:30 p.m., at the Gay and Lesbian Community Center, 208 W. 13th St.

Community Health Project HIV-⊕ Support Group

208 W. 13th St., New York, NY 10011

Contact Gail Spindell, (212) 459-8144.

St. Clare's Hospital HIV-⊕ Support Group

415 W. 51st St., New York, NY 10019

Contact George LaFountain, (212) 459-8144.

Stuyvesant Polyclinic HIV-⊕ Support Group

137 Second Ave., New York, NY 10003

Contact Dooley Worth, (212) 674-0220

AIDS Center of Queens Cty. HIV-⊕ Support Group

113-20 Jamaica Ave., Richmond Hill, NY 11418

Contact Claudette Irwin, (718) 575-8855.

Identity House HIV-⊕ Support Group

544 Sixth Ave. (at 15th St.), New York, NY 10011

Contact HIV-⊕ Support Group Leader, (212) 243-8181.

Bronx AIDS Community Service, HIV-⊕ Support Group

529 Courtlandt Ave., 4th Floor, Bronx, NY 10451

Contact Nyda Morales, (212) 402-1300

New York City Dept. of Health, HIV-⊕ Support Group

Contact Karen Solomon, (212) 239-1793.

FOLLOW-UP TO TONIGHT'S MEETING

WEDNESDAY, DECEMBER 2, 7:30 P.M.
ST. PAUL'S CHAPEL BASEMENT,
GUASTAVINO ROOM

CGHAP is sponsoring a follow-up meeting to "AIDS: Improving the Odds" for interested members of the audience who know that they are themselves HIV-infected. The follow-up meeting will give you the chance to talk with people in similar situations about how the issues raised by the panel discussion affect your lives and health care decisions. An on-going **Columbia-based HIV-⊕ support group** will develop out of this meeting. We hope to share strategies and information about health care for HIV-⊕ people, including referrals to physicians and clinics.

IF YOU WOULD LIKE MORE INFORMATION,
CALL LAURA PINSKY AT (212) 280-2878.