# AIDS TREATMENT NEWS

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### **AIDS Treatment News**

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#### **Statement of Purpose:**

AIDS Treatment News reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations which work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

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# Global Epidemic, U.S. Response: A Winning Strategy, What You Can Do

by John S. James

How to change the lack of political will now blocking worldwide AIDS control.

World consciousness on the HIV epidemic in developing countries -- about 90% of the global epidemic -- has changed greatly in the last three years. In 1998 the World AIDS Conference in Geneva took the theme "Bridging the Gap" -- meaning the gap between access to treatment in rich and poor countries. But outside the conference there was no institutional support for saving lives in poor countries; once the speeches were done, that was it. And we all knew it.

Now it is no longer OK to let tens of millions of people die without treatment when treatment is available. And especially since the XIII International AIDS Conference last summer in Durban, South Africa, real changes have begun. Prices of antiretrovirals have been reduced up to 90% in some poor countries -- either by generic manufacturers, or by major pharmaceutical companies trying to head them off. Treatment is now widely recognized as an important part of HIV prevention and control, especially since it gives people incentive to get tested and work with the public-health system. (With no chance of treatment, they have the opposite incentives.)

The big problem now is funding. Even with the price reductions many countries cannot pay for the necessary prevention and treatment programs without help. United Nations Secretary General Kofi Annan proposed a global fund of \$7 to \$10 billion per year to control HIV, tuberculosis, and malaria; economists agree that the money is available, and health experts agree that if well spent, it could do the job. Yet the Global AIDS and Health Fund is going to start with only a fraction of the amount required -- and even that includes one-time contributions, multiyear contributions all counted in a single year, and money already being spent on AIDS that has been redirected or renamed to make the Fund look bigger. (For current pledge totals to the Global AIDS and Health Fund, see http://www.un.org/News/ossg/aids.htm.)

The problem is not lack of money -- many institutions and some individuals could write a check for the entire amount required from all countries in the world -- but lack of political will. In the U.S., we are hearing from political experts that the biggest problem is not policy disagreements about what to do about global AIDS, but rather that global AIDS is not a priority for either political party -- simply because Congress is not hearing from constituents that this is a problem for them. These experts tell us that if Congress received 10,000 calls or letters per month expressing concern about the global AIDS epidemic and other infections diseases, the entire situation would be transformed.

That's about one call or letter per month for every 25,000 people in the United States -- to entirely change our country's response to the greatest epidemic of modern times. And it would change much of the world's response as well. If the world's only superpower takes global AIDS seriously, many other countries will also.

So why hasn't it happened already?

A big part of the problem has been the lack of good legislative vehicles (such as bills or amendments) for expressing concern -- or rather, the lack of knowledge about how to use the vehicles that do exist. With the way Congress works, letters and phone calls should target actual legislation or other decisions in front of Congress at the time; otherwise they may never be counted, because the office staff will probably not categorize, total, and report them, among the many thousands of communications that come in to each Congressional office.

To overcome this problem, advocates and the public alike must understand that what is most important is that Congress knows the public it represents does care about AIDS and other epidemics in developing countries. So even if specific legislation fails, or is flawed, or was not introduced in a politically astute way, your call or letter is still important because it adds up to the 10,000 communications per month that Congress needs to get from throughout the U.S. -- to know that people in their district care about the global epidemic (and therefore they need to care about it as well, and act accordingly).

When you write or call it helps to know that you are not trying to change anyone's position (the Senator or Representative and their advisers and office staff probably agree with you already), but to let them know you care about the issue, and want them to give it the priority it deserves. You don't need to debate or make technical arguments.

Political organizers can miss this reality because they are used to controversial issues where the most important part of a call or letter is where it makes clear which side the writer takes. Here it's not an question of sides, but of priority. Political organizations can also miss the point because usually their main goal is to pass or block specific legislation or other policies -- while the main goal here is cumulative impact on prioritizing the issue.

Also, lobbyists may find it hard to work on both domestic and international AIDS; but for the public, calls or letters to Congress or the White House on each of these add to the total momentum on AIDS, infectious diseases, and health, increasing the priority (the political will) on both U.S. and international AIDS.

#### **Next Steps**

In August, September, and October of this year international AIDS will come before Congress many times, as the new Global AIDS and Health Fund begins. Many AIDS organizations will put out action alerts when calls or letters are needed. Remember that what often counts most is letting Congress know you care about international AIDS, rather than the particulars of the legislation or amendment at issue.

We believe that a winning strategy is to use each appropriate piece of legislation to build cumulative momentum on this issue. Can we organize friendly contests on who can get the most communications from constituents to Congress (and/or to the White House)?

Every U.S. citizen can contribute substantially to better worldwide control of AIDS and other infectious diseases -- saving millions of lives, contributing to the safety of our country, and improving the quality of life for everyone. A few hundred committed, determined activists -- with the widespread community support they already have -- would be more than enough to do it.

Better political mobilization would help. We see action alerts with no date, with misspellings, or with no indication of whether they are still current. Or the action alerts are hard to find on a Web site. Some of them direct users only to an automated email response, without justifying whether emails to Congress are effective (despite widespread doubt that Congress listens to email).

Some give little guidance -- for example, urging readers to write the Treasury Department with no further details. None seems to have benefited from simple focus groups that ask supporters not familiar with writing Congress, etc. to relate what questions and obstacles come up as they try to respond to the alert. And many apparently lack a winning legislative strategy -- or if they do have one, they conceal it well from readers.

Years ago we noted the bad state of AIDS action alerts and grassroots organizing. Much of the problem stemmed from the ambivalence of inside-the-Beltway organizations toward grassroots action: they needed it to be effective, but were threatened by it as well. The community still urgently need organizers who define grassroots as their mission, and learn do it well.

The epidemic will not wait for perfect organization, and neither can we. Determined individuals throughout the country can use the information available (and insist on better information when necessary) to make sure the U.S. and other governments respond seriously to the worldwide epidemic -- not only in rhetoric, but in resources as well.

### Treatment Interruption: Serious Error in Press Report

### by John S. James

On July 20 an erroneous Reuters report on structured treatment interruption (STI -- also called structured intermittent therapy, or SIT), titled "Experts Caution Against an AIDS Therapy," appeared in several newspapers, including the Web site of *The New York Times*. The report said that STI does not work, and quoted Dr. Bruce D. Walker of Harvard as saying it had shown poor results. We were at the meeting reported -- a two-day clinical discussion organized by the International Association of Physicians in AIDS Care -- and

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in fact the information on STI was mostly positive, although the physicians agreed that it should be done in careful research studies and is not ready for widespread use until more is known.

Dr. Walker issued the following correction, which was widely distributed on email lists:

"I am quite upset to have been grossly misquoted in a recent report from Reuters regarding my views on STI. Augmentation of immune responses from STI has been clearly shown in treated acute HIV infection, and our own studies continue to show success in the majority of persons who have participated in a complicated STI trial. Although the durability of control and the exact clinical benefit in terms of overall outcome of infection has not been shown, the results show that at least transient immune control can be achieved. In contrast to the promising results in acute infection, similar immune boosting and control of viremia in chronically-infected individuals appear to be difficult to achieve. However, there may be benefit from reduced drug exposure in persons with chronic infection, and there are also other adjunctive measures that may confer benefit, such as vaccines. At **Massachusetts** therapeutic General Hospital we have a trial that is ongoing looking at therapeutic vaccination and STI in chronic infection, and others are soon to open. For now I recommend that persons not try STI on their own but that these approaches be supervised in a research setting to enhance safety and to ensure that we learn the most we can in the most expeditious fashion. We and others have clearly shown that the immune response to HIV can be boosted after a person becomes infected, and we have to believe that we can be smart enough to induce even better responses that will lead to persistent clinical benefit."

Another physician's name was misspelled in

the article (making the erroneous report easy to find through computer searches -- look for "Steerer").

#### Comment

The reason for concern is that patients may change treatment decisions or drop out of clinical trials, based on wrong information.

What happened here is that this story was not written by Reuters Health, the unit which usually writes medical stories for the wire service, but by a reporter from another Reuters unit who had never covered an AIDS meeting before. And this event was hard to report because it was not intended for media (although not closed to the press either). IAPAC brought together some of the leading HIV physicians and clinical researchers in the country to discuss difficult issues in antiretroviral treatment, so that guidelines for physicians can be prepared. The two-day meeting itself was excellent, and we look forward to the guidelines, which should be published in a few weeks.

This incident illustrates that news reports on medical subjects too often include serious errors. Media stories -- in treatment newsletters as well as the general press -- can be used as leads for further investigation, but should never be the main reason for changing treatment decisions.

### Vaccines: Major Conference Sept. 5-8 in Philadelphia

AIDS Vaccine 2001, a major scientific conference on AIDS vaccine development, will take place September 5-8 at the Philadelphia Marriott. Sponsors include the U.S. National Institutes of Health, U.S. Centers for Disease Control and Prevention, UNAIDS, the World Health Organization, and the Agence Nationale de Recherches sur le SIDA, in France. The organizing committee is David L. Baltimore, Ph.D., Beatrice H. Hahn, M.D., Norman L. Letvin, M.D., Douglas D. Richman, M.D., and Melissa Sordyl. The program committee includes scientists from China, France, India, Kenya, South Africa, Uganda, and UK, as well as the U.S.

The advance registration deadline has recently been extended to August 17. After that, persons should register onsite at the Philadelphia Marriott.

International press note: "Representatives from non-U.S. media are required to preregister by Friday, August 24, 2001 in order to receive press credentials to attend the AIDS Vaccine 2001 conference. On-site media registration is not available for non-U.S. media due to the need to verify media credentials in advance" (quoted from the conference Web site, August 5). This has been a problem in at least one previous AIDS conference, as reporters are not used to registering in advance to cover news, and will often not learn of the requirement in time. We are concerned that international journalists may be turned away.

#### Program

The conference has more than 60 sessions. Talks include:

\* The Global Need for an AIDS Vaccine (keynote talk in opening session)

\* Lessons from Acute Infection and Relevance to Vaccine Development

\* Innate Immunity

\* Candidate Vaccines

\* Access and Implementation

\* Novel Envelope Immunogens

\* Experience with AIDS Clinical Trials in Humans: What We've Learned \* Design, Oversight, and Review of Phase III Efficacy Trials

\* Therapeutic Vaccines and Immune Response

\* The Genesis of HIV Diversity

\* Late Breaker and Innovative Strategies Session

In addition there are many poster sessions, mostly on technical topics.

For more information, see the conference Web site, http://www.aidsvaccine2001.org.

## IAS Buenos Aires Conference: Medscape CME Summaries

On July 31 the Medscape Web site, named the official provider of online coverage for the new International AIDS Society conference which took place July 8-11, 2001 in Buenos Aires, Argentina, released three Continuing Medical Education programs for medical professionals. Anyone can use them for a review of current knowledge in some of the major areas of HIV treatment. These programs will remain online for one year.

The Medscape site requires a one-time registration, but it is cost-free.

Here we list the titles of the programs and the articles required for CME credit in each one. Each program also has several other articles available which are not listed here.

### I. Current Patient Management:

\* New Light Through Old Windows: Finetuning the Use of Approved Antiretrovirals, by Graeme Moyle, M.D., M.B.B.S.

\* Pharmacokinetics, Pharmacodynamics, and Pharmacogenomics: The Continuing Evolution of Pharmacologic Issues in HIV Disease, by Stephen Becker, M.D.

\* Update on Antiretroviral Drug Resistance, by Daniel R. Kuritzkes, M.D.

\* Management of HIV-Infected Women and Mother-to-Child HIV Transmission, by Alexandra M. Levine, M.D.

#### **II. Novel Therapeutic Strategies**

\* HIV Entry -- From Molecular Insights to Specific Inhibitors, by William A. O'Brien, M.D., M.S.

\* Investigational Antiretrovirals in Existing Classes, Mike Youle, M.B.B.S.

\* Strategies for Immune Reconstitution in HIV Disease, by Ronald T. Mitsuyasu, M.D.

\* Insights From Basic Science: Implications for HIV Treatment and Prevention, Mark A. Wainberg, Ph.D.

#### **III.** Complications of HIV Disease

\* Opportunistic Infections: Still a World-Wide Problem, Even in the HAART Era, by Henry Masur, M.D.

\* New Developments in AIDS-Related Hematology and Oncology, by Alexandra M. Levine, M.D.

\* Adverse Effects of Antiretroviral Therapy: More Noise, Less Clarity?, by William G. Powderly, M.D.

### FDA: New Email List on HIV/AIDS

The U.S. Food and Drug Administration has started an email list anyone can join, to provide AIDS-related information from the Agency. The official announcement, below, gives details.

Note: The sign-up process shows users

confusing options -- but they can be ignored. Just stay with the defaults provided, unless you know you want something else.

"An e-mail list has been established by the Division of Antiviral Drug Products (Center for Drug Evaluation and Research) and the Office of Special Health Issues (Office of the Commissioner) of the Food and Drug Administration (FDA) to provide updates on safety and regulatory issues related to HIV/AIDS products.

"The purpose of this e-mail list is to give patients, industry, academia, other government agencies and other interested parties one source for FDA HIV/AIDS related information. Information such as product approvals, significant labeling changes, safety warnings, notices of upcoming public meetings and alerts to proposed regulatory guidances for comment will be distributed through this e-mail list.

"To join the e-mail list, please go to <a href="http://list.nih.gov/archives/fda-hiv-aids.html">http://list.nih.gov/archives/fda-hiv-aids.html</a>. Your name and e-mail address is considered confidential and will not be released.

"If you are interested in regulatory guidance and requirements for blood safety, you should also register for the FDA's Center for Biologics Evaluation and Research e-mail list at http://www.fda.gov/cber/pubinfo/elists.htm.

"The HIV/AIDS e-mail list is not intended or designed to accept comments or input, but merely to disseminate important HIV/AIDSrelated information and alert interested parties about HIV/AIDS related issues for public comment.

"Information will be distributed through this e-mail list as it becomes available, rather than on a regularly scheduled basis.

"For additional information about the FDA HIV/AIDS e-mail list please contact the Office of Special Health Issues at oshi@oc.fda.gov."

### Science Project Director Wanted -- Treatment Action Group (TAG)

On August 5 the Treatment Action Group circulated a 3-page job announcement and description for Basic Science Project Director. The full announcement may be available through http://treatmentactiongroup.org.

From the announcement:

Job Description. The Basic Science Project Director will be responsible for developing and implementing TAG policy, programs and advocacy projects focusing on basic and applied research on HIV infection, including:

\* Etiology and pathogenesis of HIV infection;

\* Epidemiology and natural history of HIV infection;

\* Fundamental primate and human immunology;

\* HIV virology, viral dynamics, and virus-host interactions;

\* Discovery and pre-clinical development of potential drugs against new anti-HIV targets;

\* Discovery and development of anti-HIV vaccines;

\* Discovery and development of anti-HIV (and anti-STD) microbicides;

\* Discovery and development of immune-based therapies (IBTs) useful for treating HIV infection; and

\* Other relevant basic, pre-clinical and early clinical research relevant to TAG's mission of expediting research leading to more effective treatments, a vaccine, and a cure for HIV infection.

The Basic Science Project Director will report directly to TAG's Senior Policy Director and will work closely with other TAG policy and program staff and consultants, developing and implementing advocacy strategies to ensure the most expeditious, ethical and efficacious development of useful new drugs, biologics, treatment regimens and strategies to treat HIV in the USA and internationally.

The Basic Science Project Director will develop, implement, and advocate for TAG's basic science and immunology research advocacy efforts with other HIV community advocates and organizations as well as with the pharmaceutical, biotechnology and diagnostics industries, academic and community based researchers, clinicians, U.S. government agencies such as the Food and Drug Administration (FDA) and National Institutes of Health (NIH), and other local, state, and national AIDS research, treatment and policymaking bodies as well as organizations such as UNAIDS, the World Health Organization (WHO), and other multilateral agencies and foundations.

... [background on TAG]

To Apply. Interested candidates should send a letter expressing their qualifications and interest in the position with a resume/C.V. and three references with contact information to:

Basic Science Project Director Search c/o Regina Gillis Treatment Action Group (TAG)

350 Seventh Ave. Ste. 1603

New York, NY 10001