



BEHAVIORAL AND SOCIAL
SCIENCE VOLUNTEER
PROGRAM

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RING 2001

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NEWSLETTER OF THE BEHAVIORAL AND SOCIAL SCIENCE VOLUNTEER PROGRAM

Focusing on Infected Persons: Spending Scarce HIV Prevention Resources

By Robert W. Wood, MD

This article is solely the personal opinion of the individual author. It is not intended to be an endorsement or opinion from the Centers for Disease Control and Prevention (CDC).

This article presents one disease control officer's 20-year perspective on the prevention of HIV and AIDS. The intent is to encourage readers' interests in HIV/AIDS prevention research in real-life operational settings, particularly with respect to helping public health and community agencies find the most productive prevention interventions for the highest risk populations.

According to a recent Kaiser Family Foundation analysis, of the \$10 billion the federal government specifically allocated to the problem of HIV/AIDS in 1999, only about 8% went toward prevention. Further, about a quarter of the 8% was spent on prevention research, leaving only \$600 million dollars targeting actual risk reduction. Many of these resources target the low-risk, general population, leaving even fewer dollars to prevent HIV among men who have sex with men (MSM) and injection drug users (IDU), each group probably numbering about 4 million in the United States.

Early Prevention Paradigm

Those of us clinicians who watched the coming of AIDS, who saw HIV identified as the cause, and who began studying populations for their HIV seroprevalence were reasonably certain from early on that this was being spread in ways similar to that of hepatitis B virus infection: through sexual contact, from exposures to infected blood and other tissues, and vertically from mother to child. The initial solution seemed to be that we should educate especially the higher-risk populations about the existence of this new and frequently lethal condition by using media, posters, brochures, and one-on-one counsel-



Robert W. Wood, MD, Director, HIV/AIDS Control Program, Public Health-Seattle & King County; Associate Professor of Medicine & Health Services (Adjunct), University of Washington

ing of as many people as possible. The goal was to educate them about HIV transmission risks and to get them tested for HIV infection. We would help people identify ways to reduce their risks, and, thus, reduce transmission. In addition, people testing positive for HIV would be referred to care providers and would be encouraged to notify their sex and needle-sharing partners of their exposure to HIV.

But once the initial posttest counseling for HIV-infected persons was completed and the care referral was made, prevention efforts targeting HIV-positive persons pretty much ceased. Efforts ceased in part because in the early days, many people with AIDS and a fair number with progressing HIV infection were too ill or felt too unattractive to be very sexual. At the same time, studies showed that when people learned that they were HIV-positive, they often reduced their risk behaviors. Another reason targeting HIV-positive people for prevention ceased was

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because of the perception that they had enough to deal with as it was (frequent medical care, social stigmatization, potential job and housing discrimination) without the additional pressures of a sexual safety lecture. And then there was the statistical evidence of risk reduction: Sexually transmitted disease (STD) rates fell to all-time lows by the late 1980s and mid-90s.

For these reasons, until recently, persons with HIV were left to care providers and case managers (The care for these persons, over time, not only became more effective, but also considerably more complicated.),

while uninfected but at-risk people were the ones largely targeted for prevention efforts. For example, providers at Seattle's main HIV counseling and testing clinic recommended to MSM and IDU who test negative that they return for individualized counseling and testing at least every 6 months. In San Francisco for the past few years, people who have had risky (even unprotected oral) sex with someone who might possibly be HIV-infected have been given prescriptions for a month's worth of highly active antiretroviral cocktails. (This was because such postexposure prophylaxis has been shown to work in health care workers with job-related, substantial exposures to HIV infected people.)

A New Situation

In Seattle, new AIDS case diagnoses peaked and began declining in 1994. It is probable this was a result of the "10-years-later effect" of the 1983-1984 peaking of incident HIV infections, with AIDS typically following HIV infection by about a decade. Then, this decline became more precipitous with the advent of highly active antiretroviral therapy (HAART). No longer are AIDS wards and hospices filled by AIDS cases; no more in the streets of gay neighborhoods are emaciated, KS-ridden people to be seen. For much of the general American population, AIDS has gone away. But, in reality, AIDS is just being forestalled. The truth is that even with the estimated 40,000 new cases of HIV infection each year holding steady for at least a decade in the United States, and HIV progressing to AIDS and death in much smaller numbers, the number of persons with HIV infection and AIDS is gradually rising, in Seattle by about 5 percent per year. Never have there been more HIV-infected persons in my jurisdiction.

Not only are numbers of HIV-positive people on the rise, but, thanks to HAART, many with HIV are looking better, feeling healthier, and again interested in having a sexual life. By

1995-1996 Seattle had practically eliminated syphilis, and gonorrhea and chlamydia were at all-time lows. But beginning in 1997 syphilis appeared again, and, for the period 1998-2000, about 80 cases of syphilis per year—an ongoing epidemic—were reported. Nearly all cases were in MSM, and 75% of these men told us they also had HIV disease; most were seeing care practitioners and taking HAART. Estimating 40,000 MSM in Seattle, rates of syphilis are now hovering at 150 cases per 100,000—about 100 times the rate in heterosexuals—and the syphilis rate in gay men is now equal to what was seen at the time AIDS began. Gonorrhea (GC) and chlamydia trachomatis (CT) have also risen to several times their earlier levels—mostly in MSM, although with lower levels of co-existing HIV infection. The theory that these are young MSM, new to the gay scene and unaware of HIV/AIDS and other STDs, would seem to be ruled out by the fact that the mean age is 35 years. That's the same mean age of another epidemic of syphilis in MSM, many also with HIV, in Los Angeles (for the year 2000). This return of STD is not limited to Seattle or the United States. It has been discovered in a large number of cities, including Chicago, Philadelphia, New York, San Francisco, Toronto, London, Bristol, Amsterdam, and Sydney.

People are speculating that many reasons may explain this resurgence of STD and HIV. It seems likely that many MSM have changed their "risk calculus" now that HIV and AIDS are more treatable, and life for HIV-infected persons is much prolonged and improved. People no longer see KS-marked faces, the emaciated bodies of people with AIDS; and the media pays much less attention to the epidemic than in the early days. That half of patients are at least age 35 suggests that some people with HIV

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From the Program Director's Desk...

E. Duane Wilkerson, MPH

The focus of this issue The Linkage is on the expanded emphasis by the Centers for Disease Control and Prevention (CDC) on HIV prevention with people who are HIV-positive. This emphasis, called SAFE, is described in the article by Walt Senterfitt, PhD. Dr. Senterfitt is the CDC coordinator for this new emphasis and a long-time spokesperson for effective HIV prevention efforts in the face of political and structural challenges to effective HIV programs.

The cover article, by Dr. Bob Wood, is a measured reflection on the

meaning and potential impact of this new CDC emphasis for HIV prevention, from the perspective of a long-time clinician, public health professional, and advocate in the arena of HIV prevention and care. Dr. Wood is a highly respected voice nationally, and in Washington State, raising the concerns of HIV infection from both a public health and a medical perspective since 1981.

We are pleased to be able to bring you these articles. I hope you will plan to join us in the follow-up conference call with Drs. Wood and Senterfitt, during which you may ask



questions and respond to their articles (see page 7 with information on how to participate in this national conference call). ▼

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may have burned out on risk-reduction messages or the consistent and correct use of condoms. And, since HAART often reduces HIV virus to undetectable levels in the blood, many people with HIV may feel less dangerous to their partners, despite evidence to the contrary.

A New Paradigm

Enter the Centers for Disease Control and Prevention (CDC) Serostatus Approach to Fighting the Epidemic (SAFE) initiative (see Senterfitt article). It's not surprising that HIV can only be acquired from a partnership in which one partner is infected; all infections must involve an infected partner. With this fact and the recent and widespread occurrence of STD among MSM (many of whom are also infected with HIV) in multiple cities on three continents, the notion of providing special prevention assistance to HIV-infected people has come to make great sense. Even HIV-infected persons in community prevention planning groups agree. SAFE suggests not only that increased prevention resources be

brought to bear on the HIV-infected population, but that interventions designed for HIV-seropositive persons are very likely to be different from those already tested and proven effective for high-risk seronegative persons. Such interventions must avoid being judgmental, must be delivered by trusted providers (in Seattle, a 2000 needs assessment suggested that HIV-positive persons would accept help from care providers and case managers), must not increase stigma and discrimination, and must often work with chemically dependent and psychologically impaired persons.

The Need for Behavioral and Social Science Partners

While interventions targeting at-risk negatives have been studied and reported on repeatedly in professional journals, the science of designing, testing, and proving HIV-prevention interventions for HIV-infected persons is a new endeavor in great need of applied expertise. Clearly not all HIV-seropositive persons risk infecting their partners; evidence is quite clear that most persons with HIV do not want to spread this disease. But in the heat of the

moment, perhaps with partners who want raw sex (without condoms), while under the influence of drugs such as poppers and crystal methamphetamine (which heightens sexual desire and can greatly prolong encounters), some MSM may take extraordinary risks.

One important area calling for better research is understanding the sexual networks of MSM with HIV and STD: Who comprise these core groups at greatest risk, and how can they best be identified and reached? Another important area for investigation is designing interventions that will be attractive to HIV-infected persons and effective at reducing risk. An increasing number of cities are implementing something the CDC calls Prevention Case Management (PCM), but, at a recent meeting for community planning groups responsible for prioritizing prevention resources, few people seemed to know how to define PCM, let alone demonstrate its effectiveness. ▼

Robert W. Wood is also the director of the HIV/AIDS Control Program, Public Health, and has been a member of the Washington State HIV Prevention Community Planning Group since 1994.

What's SAFE?...Cutting the Annual Number of New HIV Infections in the United States in Half

By Walt Senterfitt, RN, MPH, PhD

Coordinator of the Prevention for HIV-Infected Persons Project

This article is printed with permission from the March 2001 issue of the Being Alive Newsletter.

At the Eighth Conference on Retroviruses and Opportunistic Infections, the Centers for Disease Control (CDC) rolled out its newly expanded initiative to cut in half the estimated 40,000 new HIV infections a year in the United States. The director of the CDC's DHAP-SE/IRS, Dr. Rob Janssen, explained that although previous CDC, state, and local prevention efforts and the self-organization of gay men (in large part) have succeeded in reducing the annual rate of new infections from its epidemic high in the mid-1980s, we have not driven it down in the past 8 years. By the CDC's estimate, it has been stuck at around 40,000 per year since 1992.

What's the CDC's strategy for jump-starting the curve downward again? It is called SAFE: Serostatus Approach to Fighting the Epidemic. It is essentially an approach that centers on enlisting and supporting HIV-positive people in caring for our partners, our communities, and ourselves.

What is SAFE?

Experience has shown that effective prevention interventions must target the needs of the individuals for whom they are intended. SAFE is based on the knowledge that services and interventions for high-risk negative individuals may not address the needs of individuals living with HIV. SAFE targets directly the prevention needs of individuals living with HIV and their partners.

Action Steps

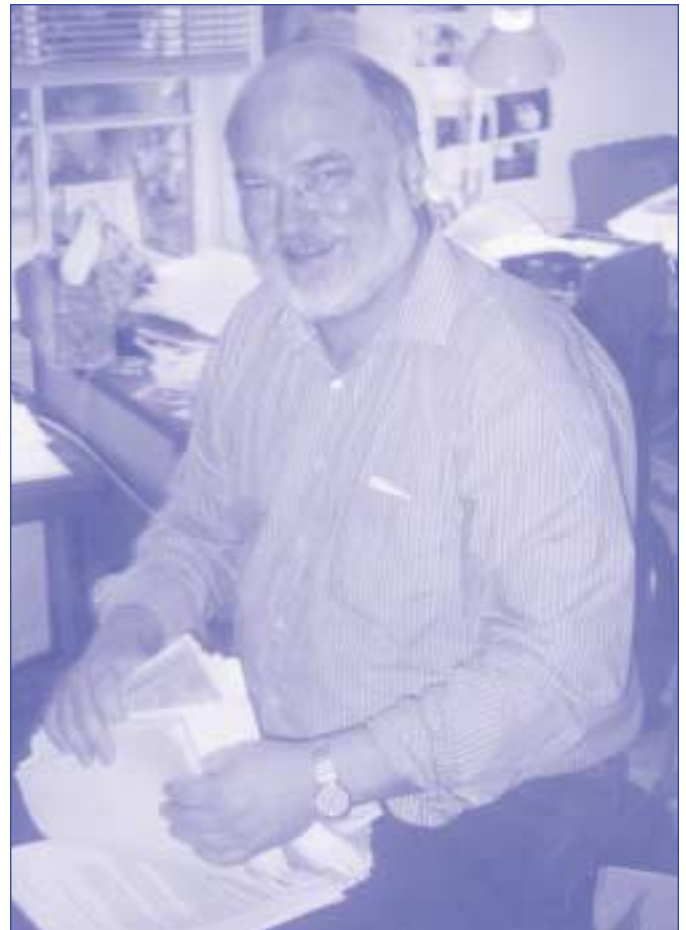
There are five action steps to the SAFE initiative. For each action step, CDC, in collaboration with its partners

in the public and private sectors, is undertaking specific activities. Janssen's plenary talk and press conference at the Retrovirus Conference was intended to promote support and involvement by health care providers for individuals living with HIV.

Action Step 1

The first step is to increase the number of infected individuals who know their HIV status and who know it as early after infection as possible. The CDC estimates that between 800,000 and 900,000 persons in the United States are infected with HIV. Of these, it estimates that 625,000 people know they are infected, while 175,000 to 275,000 do not. The CDC suspects that an important proportion of transmission is occurring from those who do not know they are infected. We have little data as yet to evaluate this suspicion, but one recent study at the Options Project at San Francisco General found that individuals who did not know they were infected, infected 11 of 17 persons with recent HIV infection diagnosed during 2000.

Sometimes public health can benefit from detection of diseases where there is little to offer the infected individual. Fortunately, this is not the case with HIV any longer—the benefits of



knowing one's status clearly accrue to the individual as well as to the community. Just since 1996, HAART has increased the time it takes from acquiring an HIV infection to an AIDS diagnosis from a mean of 9 years to more than 11 years. Similarly, the time of survival after an AIDS diagnosis has increased from about 1.5 years to more than 6 years—and both the symptom-free period and total life span are continuing to lengthen on average. Yet, we have a long way to go in sharing these benefits with all who are infected: A persistent 25% (some studies show as many as 40%) of people who are diagnosed with AIDS each year find out their HIV sta-

tus only at the point they are sick and go to an emergency room or clinic for treatment of what turns out to be their AIDS-defining illness.

From the public health standpoint, several studies have now shown that persons who know they are infected make efforts to reduce their high-risk behavior, decreasing the possibility of HIV transmission. (This is certainly the anecdotal and personal experience of most of us, and it is heartening to see confirmatory details emerging from research studies.)

A CDC study conducted in three states interviewed 148 gay and bisexual men and heterosexual men and women within 12 months after they found out they were HIV positive. The study found that 90% have changed their sexual risk behavior after learning of their infection. Sixty percent used condoms more often, 49% had sex less often (not that this change is necessarily desirable or sustainable over time!), 39% reported not having any sex, and 10% had sex only with other positive persons.

Another CDC study, the Young Men's Study, looked at unprotected insertive anal sex among young gay and bisexual men ages 15-22 in

From the public health standpoint, several studies have now shown that persons who know they are infected make efforts to reduce their high-risk behavior . . .

seven cities (including Hollywood and West Hollywood) from 1994 through 1998. Thirty percent of HIV-negative men reported having had intercourse without a condom in the previous 6 months, compared with 37% of HIV-positive young men who did not know their status, and just 15% of the HIV-positive young men who did know they were infected. Other studies show similar positive benefits from knowing one's status, although risk behavior likely increases over time.

Besides leading us to change our behaviors to protect our partners and ourselves, another public health benefit is the fact that effective antiviral therapy reduces infectiousness if and when we do have unprotected sex with a person who is negative. We do not know exactly how much infectiousness is reduced, but we do know that for many or perhaps most people, it is not reduced all the way to zero. Nevertheless, on a community basis, it is almost certain that for an increasing proportion of people living with HIV and being effectively treated so as to minimize their HIV viral loads, transmission is substantially reduced.

The two main strategies the CDC is employing for Action Step 1 are targeted efforts to encourage people at highest risk who do not know their status to get tested and, secondly, to make testing more available in a variety of ways. A new media campaign, "Know Now," will target testing messages to very specific neighborhoods and demographic groups, based on the same sophisticated marketing analyses and techniques that corporations use to get us to buy things. A part of this campaign will be efforts to decrease stigma against persons living with HIV, which is a main deterrent to testing in many communities. The specific messages will be developed in each local community and will primarily run on radio and be used in neighborhood marketing techniques.

The effort to make testing more available will be pushing to get rapid



A 7-year old boy living with AIDS.

HIV tests (such as those that have been available for pregnancy for a long time) available and approved, initially for use by prevention organizations, HIV test centers, and health care providers. This opens up the possibility of taking testing to many more places and venues, from community health fairs, to bars and sex clubs and bath houses and cruising parks, gay pride festivals, street corners, and emergency rooms and clinics.

Action Step 2

The second step is to facilitate and promote the entry into health care and prevention services, once people discover they are infected, or when they are ready and able to deal with their infection. Studies have shown that between 17% and 50% of persons who find out they are positive delay entering health care for more than 3 months. Some individuals, for a variety of personal, social, economic, and other reasons, delay for 5 years or more.

Entering health care, and getting supportive social services and prevention services, does not necessarily mean starting on HAART right away. The decision as to when to start antiviral therapy remains for an individual and his/her health care provider to make, and the official

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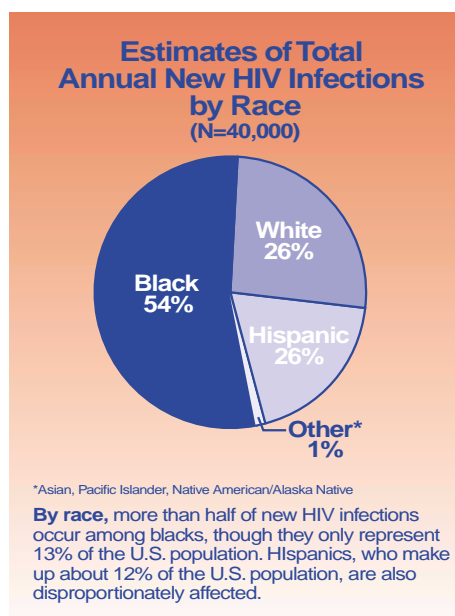
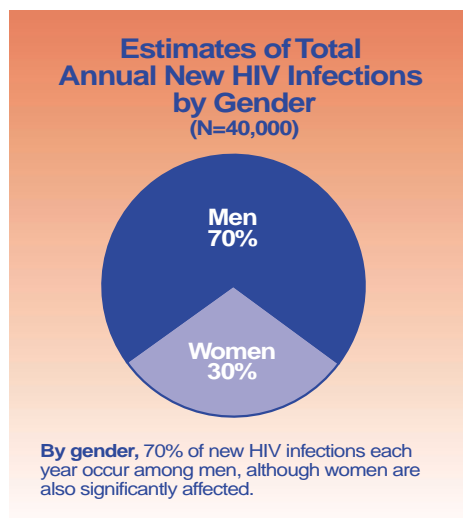
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guidelines are being revised to indicate the uncertainty among researchers and physicians as to just when is the best time to start. However, it is clear that getting regular health care, getting one's immune system status monitored, and getting other conditions treated that if untreated may hasten HIV's progression are associated with living better and longer and with giving a person more control over his or her status.

The CDC will work largely with the federal agencies that administer the Ryan White HIV CARE Act programs as well as Medicaid/Medicare and Medicare to promote smoother and faster and more universal access.

Action Step 3

The third step is to increase the number of persons who are receiving state-of-the-art care. Once again, the CDC is working with other public health service agencies, organizations of doctors and nurses, and managed care and insurance companies to establish and promote guidelines of excellent care. In addition, the CDC is developing a population-based indicator survey to assess access to and utilization of care on an ongoing basis. This is to call attention to communities and populations who do not have access to good care or do not have support to overcome barriers to utilizing that care, so



additional strategies and programs can be developed (or at least advocated!).

Action Step 4

For an HIV-infected person, getting into care is a challenge. Staying on medications for the rest of one's life is even more of a challenge, as most of us know all too well. Adherence is a problem for maintaining maximum benefit for ourselves as individuals and for reducing the chance that others coming later may have it even worse than we do.

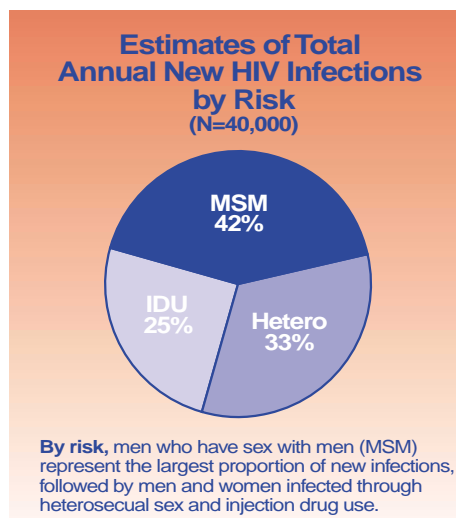
Three recent studies show that up to 16% of persons newly infected with HIV were infected with a drug-resistant strain. This may mean that those being newly infected in 2001 start out with an infection that is more difficult to treat with the available therapies. The CDC will maintain its ongoing surveillance system to track the proportion of persons newly infected who start with resistant viruses.

The CDC and other federal health agencies are funding studies to assess the extent of the adherence problems and how strongly these are associated with the leveling of AIDS deaths after several years of steep decline. These studies are also seeking to determine the best strategies to motivate and help with adherence.

Action Step 5

The last action step seeks to promote and maintain risk-reduction behavior among persons living with HIV. This is the part that is central for many of us, especially those of us already long aware of our infection and already accessing the health care that is available to us. Many people with HIV feel healthier on HAART than we did before such treatments became available. In addition, the impression that HIV is a treatable disease, and the fact that HAART reduces infectiousness to some, albeit to an unknown degree, may be leading to increases in risky behavior over time. While most people who learn they are positive reduce behaviors that may put others at risk, a considerable fraction continue to have unprotected sex with persons who are negative or whose status is unknown.

One clear indicator of a worrisome trend is STD data from Seattle and King County in Washington. The estimated incidence of early syphilis among gay men in Seattle has increased more than 3 times from 1997 through 2000 (from about 60 new cases per 100,000 population to nearly 200 per 100,000). Most disturbing, however, is that the incidence rate among HIV-positive gay men went from 60 per 100,000 in 1997 (same as for gay men overall) to over 1,000 per 100,000 in 1999 and 2000, a rate more than 16 times higher than just 2 to 3 years before.





Three HIV-positive volunteers with the AIDS Project of Los Angeles (APLA).

The CDC's initiative involves developing more effective programs and interventions to help positive people adopt and maintain less risky behaviors, making those programs more widely available in communities and increasing prevention activities in HIV primary health care settings.

Nationally, Prevention for HIV-Infected Persons Project, or PHIPP, is conducting pilot programs of a variety of different approaches to support healthy, safer lives, from social marketing and media campaigns, to promoting ways for HIV-positive people to find others who are HIV positive for intimacy and friendship and social support (and, yes, sex), to community forums on thorny issues like disclosure, to weekend plus-type retreats and/or weekly prevention/sex/safety-related support groups, to short-term

individual counseling and assistance with other life problems, to long-term intensive individual support (sometimes known as prevention case management).

People With HIV Must Help Lead SAFE and SAFE-Like Efforts

These are a start, but the input of as many people as possible from HIV-infected communities is essential. We know that whereas most people who are positive want to protect themselves and their partners, other strong needs sometimes get in the way (such as needs for intimacy, for not having to think about HIV all the time, for being free of discomfort and rejection, for sex, for being high, for having sex while being high, for money and survival).

Starting and promoting risk-reduction programs is not like building the baseball stadium in the cornfields in the movie *Field of Dreams*: "If you build it, they will come."

Programs will only be accepted by the folks who need them if they are perceived as helpful to live a well-rounded life with HIV, including living with medication side effects, dealing with friends and family and work and money, and regaining a robust and lusty sex life, if that is among a person's needs. ▼

Walt Senterfitt, RN, MPH, PhD, an epidemiologist with the Centers for Disease Control and Prevention, was formerly the chief of the Planning Section, Office of AIDS Programs and Policy, Los Angeles County Department of Health Sciences.

CONFERENCE CALL WITH BOB WOOD, MD and WALT SENTERFITT, RN, MPH, PHD Scheduled for June 5

Take part in a conference call with **Bob Wood, MD, and Walt Senterfitt, RN, MPH, PhD**, to discuss *HIV Prevention for HIV-Positive Persons*.

Please see details below.

Host Name: BSSV Program

Date: June 5, 2001

Time: 1:00 p.m. (EST)

Conference Code: 145179

Federal participants, call:

404-639-3277

Nonfederal participants, call:

1-800-311-3437

JUNE 2001

African American HIV Training Institute, "AIDS: Health, Hope, and Vitality for All," 2-year fellowship program training conducted by the University of Southern California through funding from HRSA.

For more information, contact the registrar at (213)353-3610 or via e-mail: aahti@aainstitute.org. Visit the following Web site for additional information: <http://www.blackaids.org/university/index.htm>.

Web Site Resources

New HIV-Prevention Community Planning Web Site

The Academy of Educational Development (AED) and the National Association of State and Territorial AIDS Directors (NASTAD) announce their new jointly sponsored Web site for HIV-prevention community planning.

The Web site is
www.hivaidsta.org.

From this site, visitors can download materials and peer samples, information on getting technical assistance, and links to other community planning groups, as well as sign up for a listserv and many more options.

Upcoming Conferences

June 27, 2001

National HIV Testing Day. Sponsored by the National Association of People With AIDS. For more information, contact Catina Perkins, cperkins@napwa.org or Hector Rivera-Larroy, hrivera@napawa.org.

August 12-15, 2001

2001 National HIV Prevention Conference, Atlanta, GA. Sponsored by CDC. For more information, visit: www.2001HIVPrevConf.org or call the conference hotline at: 404-233-6446.

September 7-9th, 2001

"Helping Communities Build Leadership: 2001 Regional Training," Cincinnati, OH. Prevention and care planning skills building training sponsored by the National Association of People Living With AIDS (NAPWA). For more information, contact NAPWA at (202) 898-0414 or visit their Web site at www.napwa.org.

September 14-16, 2001

U.S. Conference on AIDS (USCA), Miami, FL. Sponsored by NMAC. For more information, contact NMAC at (202) 483-6622 or <http://www.nmac.org>.



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