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# AFRICAN-AMERICANS AND HIV/AIDS IN THE UNITED STATES

African-Americans' share of the U.S. AIDS burden has never been more disproportionate to their representation in the total population.

#### SURVEILLANCE

- In 2004, Blacks\* accounted for just 12.2 percent of the U.S. population but 49.3 percent of estimated new AIDS cases.<sup>1, 2</sup>
- At the end of 2004, it was estimated that 42.9 percent of people living with AIDS in the United States were Black, reflecting a continued increase over previous years.<sup>3</sup> The AIDS rate among adults (the number of people living with AIDS per 100,000 population) was 72.1 for Blacks, compared with 17.1 for the total U.S. population.<sup>4</sup>
- Black men and women account for an ever-growing number of U.S. deaths attributed to AIDS. Since the onset of the epidemic, an estimated 38 percent of deaths from AIDS have been among Blacks, and the proportion is increasing. In 2004, 50.5 percent of total AIDS mortality were among Blacks.<sup>5</sup>

#### Men

Blacks accounted for one-third of all men estimated to be living with AIDS in the United States at the end of 2004. An estimated 29.2 percent of Black men with AIDS had acquired the disease through injection drug use (IDU), and 18.1 percent had become infected through heterosexual contact—a much higher proportion than that for all men (21.1 percent IDU and 11.2 percent heterosexual contact). Men who have sex with men (MSM) was less likely to have been the reported HIV exposure category for Black men (43.7 percent) than for all men (58.3 percent) and, especially, for White men (75.2 percent).<sup>6</sup>

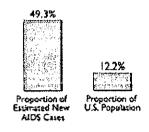
#### Women

At the end of 2004, 60.3 percent of all women estimated to be living with AIDS were Black. Heterosexual contact was the HIV exposure category for 65.2 percent of those cases. 6 The AIDS rate among adult Black women was 48.2, approximately 23 times that of White women (2.1).4

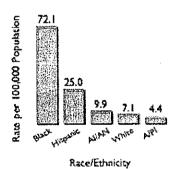
#### Children

One-half of all children under age 13 who were estimated to be living with

#### HIV/AIDS and African-Americans, 20041-3



#### Estimated AIDS Rate, by Race/Ethnicity, 2004\* (N=1,41 million)



AlliAN – American Indian/Alaska Native API – Assan/Packs Islander

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   Data Profile Highlights. 2004.
   Accessed January 4, 2006, at:http://factfinder.census.gov.
- Centers for Disease Control and Prevention (CDC). HIV/AIDS Surveillance Report. 2004;16 (1):12. Table 3.
- 3. CDC. HIV/AIDS Surveillance

AIDS at the end of 2004 were Black.<sup>4</sup> Since the onset of the epidemic, perinatal (mother-to-child) transmission has been the exposure category in 91.4 percent of cases in children.<sup>7</sup>

#### CRITICAL ISSUES

Blacks are more likely to be uninsured than their White counterparts (19.7 percent versus 11.3 percent).<sup>8</sup> Blacks have the highest poverty rate of all ethnic and racial groups.<sup>8</sup>

A study on infection patterns and risk behavior among young urban MSM found that HIV infection rates were high among Blacks (14 percent, compared with 3 percent for Whites).<sup>9</sup>

A correlation has been found between perceived discrimination in HIV treatment and the status of mental and physical health, medication adherence, and health care satisfaction. In a study of AIDS patient care, 71 percent of participants reported having experienced race-based discrimination in a health care setting, and 66 percent reported experiencing discrimination on the basis of socioeconomic status, social class, or position.<sup>10</sup>

African-Americans constitute 40 percent of the incarcerated population. Men who are incarcerated are at greater risk for HIV infection, thereby increasing the risk of transmission into other populations upon their release. Behavioral health risks associated with incarceration (and, thus, a greater incidence of HIV infection) include unprotected sexual contact, tattooing, and drug use. 12

African-American men over age 50 are another group at increasingly high risk for HIV infection; they are a subpopulation often overlooked in preventive measures. 11

Although it is more important than ever to ensure access to treatment for African-Americans, they are less likely than Whites to participate in clinical drug trials as a result of continued distrust of the health care system. <sup>13</sup>

#### AFRICAN-AMERICANS AND THE RYAN WHITE CARE ACT

In 2004, more than one-half (52 percent) of all Ryan White Comprehensive AIDS Resources Emergency (CARE) Act clients were African-American. The proportion was much higher in some care settings.

To increase access to quality care for minorities and respond to the need for additional minority providers of state-of-the-art HIV/AIDS care in underserved communities, the CARE Act funds the National Minority AIDS Education and Training Center program to expand clinical expertise in minority communities. More information is available at <a href="https://www.nmaetc.org">www.nmaetc.org</a>.

The Health Resources and Services Administration has supported a range of activities that address the epidemic among African-Americans.

Report. 2004;16(1): 20. Table 10.

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Highlights include the African-American Children's Initiative, funded through the CARE Act Title IV program for Women, Infants, Children, Youth, and Families; community consultations and collaborations with community organizations such as the National Minority AIDS Council; and publication of study findings related to the search for increasingly effective means for reaching underserved populations.

Capacity-building and planning grants have been targeted to underserved communities to expand the number of service settings available to vulnerable minority populations.

U.S. Department of Health and Human Services - Health Resources and Services Administration - HIV/AIDS Bureau 5600 Fishers Lune - Room 7-05 - Rockville, MD 20857 - 301-443-1993 - www.hab.hrsa.gov



# AMERICAN INDIANS, ALASKA NATIVES, AND HIV/AIDS IN THE UNITED STATES

American Indians and Alaska Natives (Al/ANs) make up 0.8 percent of the U.S. population and constitute hundreds of diverse tribes and cultures. <sup>1,2</sup> Approximately one-half of all Al/ANs in the United States live in just 10 States; California, Oklahoma, and Arizona have the largest Al/AN populations. Historically, Al/AN populations have suffered high rates of many health problems, reflecting widespread lack of access to health care and related information.

#### SURVEILLANCE

Among Al/ANs, there were an estimated 148 new AIDS diagnoses in 2004.<sup>3</sup> A total of 1,506 Al/ANs were estimated to be living with AIDS at the end of 2004.<sup>4</sup>

#### Men

- For Al/AN men living with AIDS at the end of 2004, men who have sex with men (MSM) was estimated to be the most common exposure category (56 percent)—lower than for White men (75 percent) and Asian/Pacific Islander (A/PI) men (72 percent), but higher than for other minority populations. Injection drug use (IDU) was the exposure category in 17 percent of cases, and MSM/IDU accounted for another 17 percent. Heterosexual contact was the exposure category in 8 percent of cases.<sup>4</sup>
- The estimated AIDS rate for AI/ANs was 9.9 per 100,000 population in 2004, higher than the rate among Whites (7.1) and A/PIs (4.4) but much lower than the rate among Blacks (72.1) and Hispanics (25.0).<sup>5</sup>

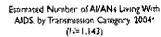
#### Women

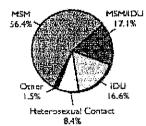
At 39 percent, AI/AN women estimated to be living with AIDS at the end of 2004 were more likely than women in any other minority population to have IDU as the exposure category. Heterosexual contact was the exposure category in 58 percent of cases; in comparison, heterosexual contact was the exposure category for 65 percent of His-panic and 76 percent of A/PI women living with AIDS.<sup>4</sup>

#### Children

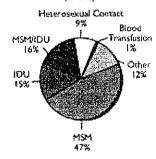
The estimated AIDS case rate in 2004 was twice as high for AI/AN children (0.2 per 100,000 population) than for Hispanic and A/PI children (0.1 per 100,000 population).<sup>5</sup>

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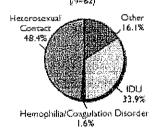




#### Reported AIDS Cases for Al/AN Men. by Transmission Category, 2004\* (I/= I 48)



#### Reported AIDS Cases for AVAN Womenby Transmission Caregory, 2004<sup>16</sup> (Ne62)



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#### CRITICAL ISSUES

Al/AN life spans are shorter than those of the average U.S. population by approximately 10 years. This difference is related to significantly higher rates of alcoholism, tuberculosis, diabetes, pneumonia, and influenza. One-third of all Al/ANs who die before age 45 do so because of drug and alcohol abuse. Drug and alcohol abuse, in combination with high poverty rates, creates barriers to sufficient HIV care among Al/ANs.<sup>6</sup>

Al/ANs may have higher incidence of late AIDS diagnosis caused by delayed reporting; underreporting due to misclassification of Al/ANs into other racial/ethnic groups is not uncommon.<sup>6</sup> Additionally, Al/ANs may refrain from accessing available services because they lack transportation and relevant information. Al/ANs have identified inconvenient office hours and inability to pay for services as barriers to care.

From 2002 to 2004, an average of 24.3 percent of Al/ANs lived in poverty, a rate comparable to that of Blacks (24.4 percent) but much higher than that of Whites (10.5 percent).<sup>7</sup> An average of 29 percent of Al/ANs lacked health insurance.<sup>7</sup> Poverty and lack of health insurance are associated with poor access to disease prevention and health care services.

Most Indian Health Service (IHS) providers live near tribal lands in rural areas; however, 62 percent of Al/ANs do not live in those areas. Frequent travel to visit family and friends and to participate in ceremonies and religious events can further complicate consistent adherence and access to health care.<sup>6</sup>

A 5-year study on HIV diagnosis in 25 States showed that AI/ANs living in the areas studied had an average rate of HIV diagnosis 1.5 times higher than that of Whites and nearly 2.5 times higher than that of A/PIs.<sup>8</sup>

#### AI/ANS AND THE RYAN WHITE CARE ACT

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Special Projects of National Significance American Indian/Alaska Native Initiative is funding six grantees (and an evaluation center) to develop integrated mental health, substance abuse treatment, rehabilitation, and HIV ambulatory medical care models. Grantees have incorporated cultural, spiritual, and traditional medicine practices of Native Americans into their approaches. This initiative began in 2003 and will end in 2007.

The Health Resources and Services Administration (HRSA) report Native Americans and HIV Disease: Summary of Ongoing Special Projects of National Significance describes successful models for serving the AI/AN population and is available through the HRSA Information Center (888-ASK-HRSA).

Al/ANs can receive CARE Act services even if they are eligible for care from other sources (e.g., through IHS, tribal, or urban Indian health programs and services). Information about IHS facilities' eligibility for CARE Act grants is

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available at http://hab.hrsa.gov/l/notice0001.htm.

The results of the publication Improving Care for HIV-Positive Men of Color Who Have Sex With Men: Barriers and Recommendations are shaping the process through which HRSA and the Centers for Disease Control and Prevention (CDC) are collaboratively responding to the epidemic among young MSM of color.

To increase access to quality care for minorities and respond to the need for additional minority providers of state-of-the-art HIV/AIDS care in underserved communities, the CARE Act funds the National Minority AIDS Education and Training Center program to expand clinical expertise in minority communities. More information is available at <a href="https://www.nmaetc.org">www.nmaetc.org</a>.

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# Becoming Adherent: Experiences of Persons Living With HIV/AIDS

Jennifer Gray, PhD, RN

Interviews were conducted with HIV-infected persons who had been taking antiretroviral medications for 6 months, reported high levels of adherence, and had low or stable viral loads consistent with adherence. Analysis of the qualitative data revealed five themes related to adherence. "Choosing life" was reflected in decisions about initiating treatment, changing one's lifestyle, and pursuing goals. "Riding it out" emerged from descriptions of adjusting to side effects and overcoming barriers to adherence. "Figuring it out" encompassed individual strategies for incorporating pill-taking into one's life, such as use of pillboxes and making a schedule. "Sticking to it" was overcoming internal resistance to maintaining adherence. "Realizing the benefits," the final theme, revealed successful adherers who had improved clinical outcomes and for whom pill-taking had become routine.

Key words: HIV/AIDS, medication adherence

Persons living with HIV/AIDS (PLWHA) are expected to adhere to complex regimens over an indefinite period of time (Chesney, Morin, & Sherr, 2000; Piliero & Colagreco, 2003) with strict adherence necessary for complete suppression of the virus (Garcia & Cote, 2003; World Health Organization, 2003). Factors related to compliance have been reported in numerous studies with persons with HIV infection and with AIDS (Halkitis, Parsons, Wolitski, & Remien, 2003). Negative influences on adherence have been described as depression (Sledjeski, Douglas, Delahanty, & Bogarty, 2005); perceived stress (Bottonari, Roberts, Ciesla, & Hewitt, 2005); residential patterns (Wagner, 2002); stigma (Siegel, Schrim-

shaw, & Ravies, 2000); addictions (Jimenez, Johnson, Hershow, & Wiebel, 1996); believing the drugs were ineffective (Murphy, Johnston Roberts, Hoffman, Molina, & Lu, 2003); denial of HIV status, side effects and symptoms (Balestra et al., 1996; Wagner, 2002); and increased alcohol intake and employment (Chesney & Ickovics, 1997; Murphy et al., 2003). Positive influences on adherence were the primary care provider's belief that the treatment was effective (Schrimshaw, Siegel, & Lekas, 2005; Seals, Hennessey, & Sowell, 1996), quality of the patient-provider relationship (van Servellan & Lombardi, 2005), the patient's view of life (Cederfjall, Languis-Eklof, Lidman, & Wredling, 2002), self-efficacy to adhere (Simoni, Frick, & Huang, 2006), and support from family and friends (Murphy et al., 2003; Simoni et al., 2006; van Servellan & Lombardi, 2005). The research clearly establishes that medication adherence is difficult. None of the medication adherence studies have produced a gold standard or consensus on the best interventions to promote adherence for PLWHA.

The study was motivated by two questions. Because studies of medication adherence have documented that 40% to 60% of PLWHA achieve a high level of adherence (Balestra et al., 1996; Halkitis et al., 2003), what can we learn from persons who are taking their medications correctly? How did adherent patients become adherent? To learn the answers to these questions, a qualitative study was conducted to

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Table 1. Demographic Characteristics of Sample:
Becoming Adherent Among PLWHA (N = 11)

Descriptor	Response Set	Frequency (%)
Income	Under \$10,000	7 (63.6%)
	\$10,000-19,999	2 (18.2%)
	\$20,000 or more	2 (18.2%)
Education	11th grade or less	3 (27.3%)
	HS graduate or GED	5 (45.5%)
	At least 2 years of	
	college	3 (27.2%)
Employment	Unable to work because	
	of illness	4 (36.4%)
	Unemployed	5 (45.5%)
	Employed	2 (18.2%)
Relationship status	Widowed/divorced	7 (63.6%)
•	Partnered	3 (27.3%)
	Single	2 (18.2%)
Medication regimen	2 protease inhibitors	3 (27.3%)
· ·	1 protease inhibitor	5 (45.5%)
	No protease inhibitor	3 (27.3%)
Self-reported adherence	Never miss	6 (54.5%)
-	Missed 1 to 6 months	
	ago	3 (27.3%)
	Missed in past month	2 (18.2%)

NOTE: GED = general educational development, HS = high school.

medications, whereas 2 admitted missing doses in the past 2 weeks. Transcripts for all of these interviews were analyzed and coded first by descriptions of experiences. Then, the descriptions were synthesized into themes (Table 2).

# **Exploration of Themes Related to Maintenance of Medication Adherence**

The themes that emerged from the transcripts were: (a) choosing life, (b) riding it out, (c) figuring it out, (d) sticking to it, and (e) realizing the benefits. Table 3 provides participant quotations for each theme.

Choosing life. "Choosing life" was related to the fact that most of the participants were severely ill

Table 2. Initial Descriptions and Themes in Becoming Adherent to Medications Among PLWHA (N = 11)

Description	Theme
Life and death	Choosing life
Lifestyle choices	
Coping	
Adjusting	Riding it out
Advice	
Challenges-barriers	•
Side effects	
Medication taking strategy	Figuring it out
Reminders	
Paying attention	
What doesn't work	
What to take with meds	
Time issues	
Do not give up	Sticking to it
Doing what you need to do	
Providers	
People who help	
Results	Realizing the benefits
Automatic	ĺ
No problem	`

when they were diagnosed and started on medications. One participant recalled being told that the doctors did not think he would survive the night when he was admitted to the hospital. When another described his motivation for taking medications, he said, "Ah, just the simple fact that if I didn't do it, I would not live. That was enough to get me to do it." Another participant, a woman, said, "You're going to remember to take them because your life is going to depend on it." Although primarily an initial factor in adherence, this theme also emerged when participants described HIV-infected persons who died after stopping their prescribed regimens and cited this awareness as one of the reasons they chose to continue their medications.

Participants described removing from their lives conditions that they perceived as interfering with the medications or a positive lifestyle. For example, two men discussed how they had given up a homosexual lifestyle and drinking. One of these men repla

think that is a majorly important thing. . . if we can deal with the fear aspect, the fear of being alone, the fear of dying, or the fear of whatever it may be."

Riding it out. "Riding it out" describes the period of adjustment, especially that of enduring the initial side effects. For example, a mother described her extreme nausea that prevented her from taking her child to school without stopping on the way to vomit. Whether to attribute symptoms to the disease process or to the medications resulted in uncertainty. As one person noted, "The medicines compounded the way I felt, how badly I felt." One participant said, "It seemed the end of the road to me at the time. . .but you have to work your way through that, and it is not always easy." Another said, "You just get sick. Let it take its toll and then you'll get over it." Another participant identified the difficulty of the initial adjustment as a deterrent against stopping the medications, commenting, "You start them up all over again, you're going to get sick all over again." The advice of the participants for persons starting on antiretrovirals was to recognize that there would be side effects and to ride it out. These participants were role models of this ride-out approach as exemplified by this participant's statement, "I kept taking them because I knew it [feeling bad] was just temporary."

Figuring it out. "Figuring it out" involved finding a strategy or strategies to ensure adherence to the regimen. Participants described using pill organizers, developing a routine or schedule, setting an alarm, and taking pills along when socializing or traveling. Although some participants used commercially available pill organizers, one participant described small plastic bags into which he divided his medication once a month; one bag for each dose. In the mornings he removed two bags full of medications, and in the evenings he returned the empty bags, which served as validation that he had taken his medications that day. Linking doses to routine events such as meals was discussed by several of the participants. One participant described experimenting with different foods until she found those she could eat with her medications, whereas another adjusted the timing of doses to allow her stomach "a chance to rest" before the next dose. The advice of one participant was to

"find something, some way of taking your medicines that is not as hard on you as taking it by itself."

Figuring it out was not a one-time challenge but had to be repeated each time the regimen changed or the person's schedule changed. For example, "... my hours have changed, so I'll take it around 4:30 to 5:00 and then take it around midnight." When traveling, participants took their medications with them. Social events were challenging, especially for the participant whose medications could not be taken with food.

Sticking to it. All participants described "sticking to it" as doing what you need to do. This theme involved internal and external components. The internal aspects were overcoming one's own psychological resistance to medications. The participant who repeatedly said during the interview, "I complain within myself, but I take them anyway," provided an exemplar of this resistance and sticking it out. Other participants demonstrated this same approach by saying, "You know, it's this idea, if you want the medications to work you have to do what you have to do," and "Take it whether you want to take it or not." The label assigned to this theme came from participants' statements such as "find something and stick with it," "There are a few of us who stuck in there," and "Stick to it. Have the determination to stick to it because this disease can be managed."

The interviewer asked each participant who helped him or her with adherence. Some participants stated that no one helped them take their medications, saying, "It is not that someone has to tell me," "I don't have anyone to help me take it,' and "Nobody tells me. Just me." Others acknowledged the importance of having a "few of my friends that had really cared before and they are still there." Seeing providers as partners was also a frequent comment. One man gave as a reason for taking medications that the doctor had prescribed them, and "he's prescribing it to help your situation." When side effects occur, this participant encouraged others to "take it down to him [the doctor]. Let him know about this so he could get you another formula or better medicine for you." Others explained how they had changed providers when they did not feel the providers were meeting their needs because these unmet needs were positive outcomes may be feedback that increases motivation to take medications.

#### Limitations

Although the sample was intended to have demographic characteristics similar to those of the HIV population at large, the sample consisted of a larger percentage of women (45%) than the HIV/AIDS population in the United States (20%) (CDC, 2004). Hispanic women were not represented. Concerns about confidentiality may have limited the willingness of HIV-infected persons to participate. Most of the participants were very open about their diagnosis, as was anticipated because they were receiving care in an HIV specialty clinic. Two participants, however, described the impact of stigma on disclosure and noted that some family members did not know of their HIV status. These limitations and the small sample size do not support generalizing these findings to other groups but provide a beginning place for further research.

# **Implications**

Implications for practice include the need for recognizing the unique nature of the responses of PL-WHA to taking medications. For example, the process of "figuring it out" was found in the transcripts of all participants, but the specific strategies and reminders used were unique to each individual (Williams, 2001). HIV care providers will need to inquire about what strategies the infected person may be using to adhere to medications. Suggestions from the experiences of other PLWHA may be more helpful to patients than professional advice. All of the participants identified events that challenged their adherence, and 2 had missed doses recently. Consistent with the theory of relapse prevention (Marlatt & George, 1984), clinicians might suggest situations that could interfere with adherence and encourage patients to develop plans to deal with these challenges.

#### Conclusions

This qualitative study with 11 participants who were successfully adhering to complex HIV/AIDS medication regimens revealed five process themes, beginning with choosing life. This choice provided motivation for the riding it out and figuring it out aspects of learning to adhere to medications. As medication-taking became routine, the participants described dealing with ongoing challenges using the phrase "sticking to it." When adherence resulted in improved laboratory values and improved physical health, the benefits of adherence were obvious and further validated the actions taken to achieve adherence.

# Acknowledgment

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#### **Boundaries Without Walls**

Setting boundaries is about learning to take care of ourselves, no matter what happens, where we go, or who we're with. Boundaries emerge from deep decisions about what we believe we deserve and don't deserve; they spring from a belief that what we want and need, like and dislike, is important.

The goal of having and setting boundaries isn't to build thick walls around ourselves. The purpose is to gain enough security and sense of self to be able to develop relationships with others without feeling like we are losing ourselves or being invaded, and without infringing on another person's sense of self or creating confusion in a relationship. When we have a sense of self, we are able to better develop closeness and intimacy with others. However, the most important consideration in setting boundaries at work, is that the client with whom we work is always a priority.

As Community follow-Up Workers, setting healthy boundaries between ourselves and our clients is important to the work we do, and also require us to understand the power that we hold. Given the nature of the work, maintaining these boundaries can sometimes be a challenge. Often, CFWs come from the same or similar communities as the client; sometimes they may have relatives who are receiving services from other COBRA teams, and sometimes CFWs have transitioned from being a client to being a CFW.

While any similarity between you and your client is a strength because of your ability to relate to their situation, it can also be a challenge when feelings get attached to the client. This might nappen because that person reminds you of someone else, of yourself, or of a situation you have been through (transference). Sometimes, it is the client that attaches their feelings for someone else onto you (counter transference). While certain boundaries may be quite clear, such as the restriction on engaging in intimate relationships with clients, in other situations, maintaining healthy boundaries may be more challenging and confusing. Sometimes, you may not be able to sort it out yourself and you may need to use your supervision as support for you to figure out a strategy in dealing with the issue at hand. Recognizing boundaries and sticking to them is an ongoing process that will require patience on your part, and an understanding that it is your responsibility – not the client's – to set healthy boundaries.

#### **BREACHES IN BOUNDARIES include:**

(any circumstances that are defined by our personal needs rather than the needs of our clients)

- Engaging in sexual activities with clients
- Any behavior that is seen as exploitative, coercive or manipulative with our clients
- Accepting gifts
- Giving gifts
- Selling things to clients
- Buying things from clients

## Recognizing boundaries keeps us aware of:

- Not crossing them
- The fact that the client's needs come first
- The purpose of working with the client is to meet the needs of the client, not to have your needs met
- Keeps you on target on what is acceptable and what is not



# **CD4 CELL TESTS**

HAT ARE CD4 CELLS?

34 cells are a type of lymphocyte (white blood cell). They are an important part of the immune system. CD4 cells are sometimes called T-cells. There are two main types of T-cells, T-4 cells, also called CD4, are "helper" cells. They lead the attack against infections. T-8 cells (CD8) "suppressor" cells that end the immune response. CD8 cells can also be "killer" cells that kill cancer cells and cells infected with a virus.

Researchers can tell these cells apart by specific proteins on the cell surface. A T-4 cell is a T-cell with CD4 molecules on its surface. This type of Tcell is also called "CD4 positive," or CD4.

#### WHY ARF **CELLS** CD4 IMPORTANT IN HIV?

When HIV infects humans, the cells it infects most often are CD4 cells. The virus becomes part of the cells, and "then they multiply to fight an infection. y also make more copies of HIV.

When someone is infected with HIV for a long time, the number of CD4 cells they have (their CD4 cell count) goes down. This is a sign that the immune system is being weakened. The lower the CD4 cell count, the more likely the person will get sick.

There are millions of different families of CD4 cells. Each family is designed to fight a specific type of germ. When HIV reduces the number of CD4 cells, some of these families can be totally wiped out. You can lose the ability to fight off the particular germs those families were designed for. If this happens, you might develop an opportunistic infection (See Fact Sheet 500).

## WHAT FACTORS INFLUENCE A CD4 CELL COUNT?

The CD4 cell value bounces around a lot. Time of day, fatigue, and stress can affect the test results. It's best to have od drawn at the same time of day for ach CD4 cell test, and to use the same laboratory.

Infections can have a large impact on CD4 cell counts. When your body fights an infection, the number of white blood cells (lymphocytes) goes up. CD4 and CD8 counts go up, too. Vaccinations can cause the same effects. Don't check your CD4 cells until a couple of weeks after you recover from an infection or get a vaccination.

#### HOW ARE THE **TEST** RESULTS REPORTED?

CD4 cell tests are normally reported as the number of cells in a cubic millimeter of blood, or mm<sup>3</sup>. There is some disagreement about the normal range for CD4 cell counts, but normal counts are between 500 and 1600, and CD8<sup>t</sup> counts are between 375 and 1100. CD4 counts drop dramatically in people with HIV, in some cases down to zero.

The ratio of CD4 cells to CD8 cells is often reported. This is calculated by dividing the CD4 value by the CD8 value. In healthy people, this ratio is between 0.9 and 1.9, meaning that there are about 1 to 2 CD4 cells for every CD8 cell. In people with HIV infection, this ratio drops dramatically, meaning that there are many times more CD8 cells than CD4 cells.

Because the CD4 cell counts are so variable, some health care providers prefer to look at the CD4 cell percentages. These percentages refer to total lymphocytes. If your test reports CD4% = 34%, that means that 34% of your lymphocytes were CD4 cells. This percentage is more stable than the number of CD4 cells. The normal range is between 20% and 40%. A CD4 percentage below 14% indicates serious immune damage. It is a sign of AIDS in people with HIV infection. A recent study showed that the CD4% is a predictor of HIV disease progression.

# WHAT DO THE NUMBERS **MEAN?**

The meaning of CD8 cell counts is not clear, but it is being studied.

The CD4 cell count is a key measure of the health of the immune system. The

lower the count, the greater damage HIV has done. Anyone who has less than 200 CD4 cells, or a CD4 percentage less than 14%. considered to have AIDS according to the US Centers for Disease Control.

CD4 counts are used together with the viral load to estimate how long someone will stay healthy. See Fact Sheet 125 for more information on the viral load test.

CD4 counts are also used to indicate when to start certain types of drug therapy:

When to start antiretroviral therapy (ART): When the CD4 count goes below 350, most health care providers begin ART (see Fact Sheet 403). Some health care providers use the CD4% going below 15% as a sign to start aggressive ART, even if the CD4 count is high. More conservative health care providers might wait until the CD4 count drops to near 200 before starting treatment. A recent study found that starting treatment with a CD4% below 5% was strongly linked to a poor outcome.

#### When to start drugs to prevent opportunistic infections:

Most health care providers prescribe drugs to prevent opportunistic infections at the following CD4 levels:

- Less than 200: pneumocystis pneumonia (PCP, see Fact Sheet 515)
- Less than 100: toxoplasmosis (see Fact Sheet 517) and cryptococcosis (see Fact Sheet 503)
- Less than 75: mycobacterium avium complex (MAC, see Fact Sheet 514)

Because they are such an important indicator of the strength of the immune system, official treatment quidelines in the US suggest that CD4 counts be monitored every 3 to 4 months. See Fact Sheet 404 for more information on the treatment quidelines.

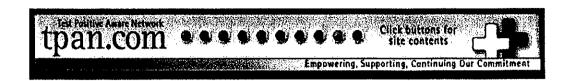
Revised February 20, 2007

# **Common Side Effects and Possible Treatments**

Side Effect	Possible Treatments
Fat Redistribution-Lipodystrophy, Lipatrophy and	Currently there are no treatments that have been
Lipadiposity	proven effective for body-shape changes.
	Switching regimens might be an option.
	Serostim-reduces fat buildup not FDA approved for
	Lipodystrophy.
	Liposuction
	Sculptra-Injection of fat or fat substitutes
Fatigue, tiredness, weakness, lack of energy	Discuss with doctor, change in diet, rest and sleep.
Nausea, vomiting	Antiemetics-Compazine, Zofran
	Eat small meals, Eat bland foods (low in fat and high
	in starch/carbohydrages)
i	Relax before meals, eat slowly
Loss of appetite due to nausea and vomiting	Antiemetics-Compazine, Zofran
•	Megace to treat anorexia. Marinol to stimulate
	appetite
	Some people opt for marijuana
Diaarhea /watery stools	OTC-Imodium AD, Kaopectate, Metamucil, Lomotil
	These meds work best if taken 30-45 minutes before
	taking medications that cause diarrhea.
	Dietary change using the BRATT diet-Bananas, Rice
	(white), Apple juice or sauce and Toast and Tea
	(herbal)
	Drink water to combat dehydration.
Gas and bloating	Dietary changes by eliminating gas producing foods
	such as broccoli, beans, vegetable skins.
	OTC-Gas-X
Heartburn/acid reflux	Dietary changes-avoid foods that are spicy or fatty,
	vinegar, peppermint, pickles, alcohol, caffeine (soda,
,	tea, coffee, chocolate), citrus fruits and juices
	(orange, grapefruit, lemon, tomato)
	Avoid aspiring, ibuprofen that irritate the stomach
<del></del>	OTC-Mylanta, Maalox, Tagamet, Zantac, Pepcid
Liver damage	Discuss with doctor-possibly change in ARVs
rr. 1	Decrease alcohol consumption  Possible change in medications, Increase in water
Kidney stones	
Towned To Continue	intake, Anti-fungal such as Monistat, prescription-Diflucan
Fungal Infections	Consult with doctor, antihistamines-Benadryl
Skin rashes/Stevens-Johnson Syndrome	Good skin moisturizer if dry skin
Peripheral Neuropathy	Consult with doctor-change in ARVs
Lempheral memopanty	Anti-inflammatory meds-Ibuprofen
	Applying topical creams-Ben Gay
	Prescribed Medications-Neurontin
Musela degranga or washness musela pair er icint	
Muscle decrease or weakness, muscle pain or joint	Anni-mitanamatory drugo-1 yronor
pain	Procrit and Epogen. Doctor may want to change
Anemia	medications
	THIEGICAGORS

Adherence: Barriers and Strategies

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# **Drug - Nutrient Interactions and HIV**

by Joanne Maurice

The science of drug-drug interactions and drug-nutrient interactions has advanced and improved in the past few years. There are several interactions and mechanisms that take place that can affect how well a drug is or is not absorbed, and many of these factors we have no control over. Drugs can be absorbed differently depending on race, age, gender, weight, and metabolic rates. Pharmaceutical companies have spent billions of dollars running drug trials to discover the most effective methods of taking a medication that will result in the best absorption and with the fewest adverse side effects.

Once a pill is ingested, it goes into the gut, dissolves and is absorbed through the intestinal tract. From this point on, what happens to the drug and how it is measured forms the basis for the various recommendations providers, pharmacists and dietitians give to their clients. Foods can have an effect on a drug by increasing, decreasing or accelerating its absorption or metabolism. The composition of a food, or meal, can affect the bioavailability of a medication by affecting acid level in the stomach, increasing or decreasing transit time through the gastrointestinal (GI) tract, or inducing or inhibiting the different metabolic enzymes in the intestine and liver. Adhering to diet recommendations and timing of meals can make the difference between a drug having the most effect, or helping to decrease the side effects that can come with the medications.

To understand what is happening after a drug is ingested, a little background and some definitions are needed. Pharmacists and drug companies often cite the Cmax of a drug. This is the maximun concentration reached by a drug, where the rate for a drug being absorbed into the plasma is the same rate that it is being eliminated from the plasma. Cmin, or minimum concentration, is when a drug is at its lowest concentration, often just before the next recommended dose. Area under the curve or AUC, is a way of measuring the exposure to a drug during a full dosing interval. AUC is often viewed as the best way to see if a drug is working. Cmin is often used to predict the efficacy of the drug, where Cmax is associated with the severity and frequency of side effects.

Many studies and drug trials will list the effect that a single dose of another drug or nutrient has on the medication in question. A steady-state response, where there are no more changes after repeated doses, may be a more fair indication of an interaction. The effect of grapefruit juice on the absorption of Crixivan (indinavir) is one example where the effect seen during a single dose was different during steady-state conditions.

Once a drug is absorbed, it must be metabolized (broken down by the body's system). There are several systems in the body, one of the best known is the cytochrome P450 (CYP450) system. Within this system there are several isoforms that can be induced or inhibited by a multitude of drugs and some nutrients. The level that a drug reaches in the plasma can be determined by the extent to which these isoforms are induced or inhibited. St. John's wort is an example of such a drug-nutrient interaction. It can compete with Crixivan for the isoform CYP3A4 system, reducing significantly the amount

of Crixivan available to fight the virus. The AUC for Crixivan is reduced by about 60% with St. John's wort, prompting the warning of increased risk of drug failure and viral resistance due to suboptimal levels of Crixivan in persons who were also taking St. John's wort.

Grapefruit juice deserves its own mention as a having a significant effect on the isoform CYP3A4 of the CYP450 system. The components of the flavonoids found in grapefruit juice have various degrees of activity on CYP3A4. There are other components besides the flavonoids in grapefruit juice that can have an effect on the CYP3A4 activity. The same does not seem to hold true for other citrus fruits such as lemon, limes and oranges. The effect that grapefruit juice has can be very different depending on the PI or other medication involved. For Fortovase (saquinavir soft-gel), the grapefruit juice significantly increases its bioavailability. Grapefruit juice, in the first studies of Crixivan, indicated a significant decrease in the bioavailability of Crixivan with a single dose of grapefruit juice. However, when studied during steady-state conditions, the adverse effect on Crixivan was not seen.

Using the AUC, it was found that a high fat meal increased the bioavailability of saquinavir by 670%, Viracept (nelfinavir) by 200 to 300%, and Norvir (ritonavir) by 15%. There are thoughts that not taking these medications with a meal providing adequate fat could be the reason for some treatment failures. Every study seemed to define high fat differently, but for the most part a high fat meal was along the order of 50 grams of fat per meal. For those of you without your fat gram counting books, that works out to be a burger and fries kind of meal, a large muffin, or a significant amount of chips. On the other side of the coin, Crixivan, without the Norvir booster, needs to be taken with a meal containing essentially no fat. Agenerase (amprenavir) can be taken with food, but should not be taken with the same kind of high fat meal that boosts the efficacy of saquinavir. Sustiva (efavirenz), like Agenerase, should not be taken with a high fat meal, because the fat increases the absorption and increases the magnitude of the side effects. Due to the presence of Norvir, Kaletra (lopinavir/ritonavir) should also be taken with food to increase its bioavailability and decrease intra- and intervariability.

Garlic is also being studied for the effects it may have on HIV medications. Touted for its immune enhancing properties, and its safety as a supplement, garlic is beginning to be studied for potential adverse effects on medication metabolism. It appears to decrease the AUC significantly for saquinavir. There was a small decrease when looking at Norvir, but it was not significant.

The lesson here is that don't assume that it is okay to take medications without regard to the instructions given by qualified HIV health care providers. There are reasons when doctors and service providers inform you that a medication needs to be taken with more than just a cup of coffee or a banana. It's also not safe to assume that just because a product is "natural" or an herb, that there are no potential side effects or interactions with other medications. The process of metabolism is extremely complicated and the same substrate can be both an inhibitor or inducer of the process. So stay tuned, the science is young, and more answers are yet to come.

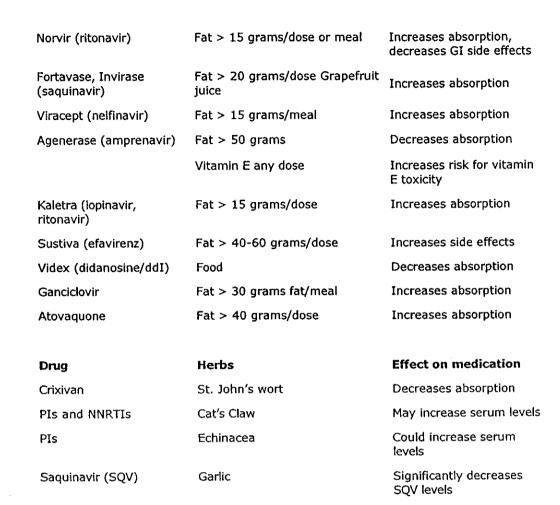
Joanne Maurice can be contacted via email at <u>jmaurice@u.washington.edu</u>. References are available from author upon request.

Drug

Nutrient

Effect on medication

Crixivan (indinavir) (If taken without Norvir) Grapefruit juice Protein > 6 grams/meal; Fat > 2 grams/meal Decreases absorption



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# **EXERCISE AND HIV**

#### WHY IS EXERCISE IMPORTANT?

Exercise helps many people with HIV disease feel better and might strengthen your immune system.

Exercise cannot control or fight HIV disease, but it may help you feel better and fight many of the side effects of HIV disease and HIV medications.

# WHAT ARE THE ADVANTAGES OF EXERCISE?

Regular, moderate exercise has many of the same advantages for people with HIV disease as it does for most people. Exercise can:

- Improve muscle mass, strength and endurance
- Improve heart and lung endurance
- Improve your energy level so you feel less tired
- Reduce stress
- · Enhance your sense of well-being.
- Help stabilize or prevent declines in CD4 cell counts. See Fact Sheet 124 for more information on CD4 cells.
- · Increase bone strength
- Decrease cholesterol and triglycerides (see fact sheet 123)
- Decrease fat in the abdomen
- Improve appetite
- Improve sleep
- Improve the way the body uses and controls blood sugar (glucose)

# WHAT ARE THE RISKS OF EXERCISE?

- You can get dehydrated (lose too much water) if you do not drink enough liquids to keep up your fluid levels.
- Injuries may take more time to heal.
- You can lose lean body mass if you exercise too much. Serious cases can lead to AIDS wasting (see fact sheet 519).
- You can injure yourself if you use the wrong "form" in exercises.
- Exercise can help those with heart disease, but talk to your doctor to make sure that you are able to exercise safely!

# EXERCISE GUIDELINES FOR PEOPLE WITH HIV

#### Don't Overdo It!

A moderate exercise program will help your body turn your food into muscle. Take it easy, and work exercise into your daily activities.

Work up to a schedule of at least 20 minutes, at least three times per week as long as you are feeling better. This can lead to significant improvements in your fitness level and you may feel better.

People with HIV can improve their fitness levels through training like those who do not have HIV. However, people with HIV may find it harder to continue with a training program because of fatigue (see Fact Sheet 551).

Start exercising while you are still healthy. This can help you hold off symptoms of HIV that make you feel bad. Keep your exercise fresh. Find new ways to keep yourself motivated to maintain your exercise program.

Your fitness level may be different than it used to be. It is very important that you work your way into an exercise program to avoid injury.

#### Eat and Drink Correctly

Drinking enough liquids is very important when you exercise. Extra water can help you replace the fluids you lose. Remember that drinking tea, coffee, colas, chocolate, or alcohol can actually make you lose body liquid.

Don't eat when you exercise. In fact, it's best to wait up to 2 hours after a full meal before an exercise session. Also, wait about an hour after a workout before you eat your next meal.

Proper nutrition is also important. With increased activity, you may need to eat more catories to avoid losing weight.

#### Choose Something You Enjoy

Choose activities that you like. Whether it is yoga, running, bicycling, or another sport, doing something you like will encourage you to maintain your program. Don't get into a rut! Change your activities if you need to so that you stay motivated.

If your fitness level is good, you can compete in competitive sports. Taking part

in competitive or team sports does not pose a risk of spreading HIV to other athletes coaches.

If you get hurt and you're bleeding, the risk of HIV being spread to other people is very small. However, if you bleed during a sport, you should get out of the game and cover your injuries before returning to the game.

#### **Exercise with Weights**

Weight training (resistance exercise) is one of the best ways to increase lean body mass that may be lost through HIV disease and aging. Working out three times a week for an hour should be enough if done well. Combining weight training with 30 minutes of cardiovascular exercise may be the best way to improve body composition and keep your blood lipids and sugar down. Cardiovascular exercise means working large muscle groups continuously for at least 30 minutes. Activities such as brisk walking, jogging, bicycling or swimming can be cardiovascular exercise.

#### THE BOTTOM LINE

Exercise can improve strength, fight fatigue and depression, improve endurance, increase cardiovascular fitness, help to reduce stress and promote muscle strett may also help the immune system better.

## FOR MORE INFORMATION

You can get more information on exercise and HIV from the following:

AIDS and Exercise, from the American Council on Fitness, at http://www.acefitness.org/fitfacts/pdfs/fitfacts/itemid\_63.pdf

HIV: Nutrition and Exercise When You Have HIV, at http://familydoctor.org/x2066.xml

HIV and Exercise: http://www.thebody.com/tpan/julaug\_02/exercise.html

Medibolics web site (written by HIV-positive people): http://www.medibolics.com/exercise.html

Ten Things You Can Do to Improve Your Physical Fitness: http://www.thebody.com/bp/10things/fitness.html

Revised February 1 206

# **Four Types of Communication**

## **Passive**

People who are passive do not say what you think, feel, want, or believe in order to avoid conflicts. It communicates a message of inferiority. By being passive you are allowing the wants, needs, and rights of others to be more important than our own. Passive behavior helps to create "win-lose" situations. A person behaving passively will lose while allowing others to win. Following this communication style will lead to being a victim, not a winner.

# **Aggressive**

Behavior that "acts out" to resolve conflicts or achieve goals, but in the process violates others rights. (Either by:1. Direct attack. 2. Indirect manipulation.) The person who engages in this style of communication may behave in an honest or dishonest manner, but this person will always give an impression of superiority and disrespect. By being aggressive you put your wants, needs and rights above those of others. People who are aggressive always "win" by making sure others "lose," but in doing so they set themselves up for retaliation. No one likes a bully.

# Passive-Aggressive

People who are passive-aggressive appear to be upfront with their feelings however; they voice their true feelings secretively. This can be done by either talking to a third person about the problem you have with another (not talking directly to the source of the conflict) or by acting out in such a way to demonstrate you have a problem with what was said or done to you. (i.e. doing something that you know will negatively impact the person you are upset with.) The passive-aggressive person's goal is to block the goals of the other person which creates a "lose-lose" situation.

### **Assertive**

An assertive person engages in behavior that allows them to express honest feelings comfortable, to be direct and straightforward, and to exercise personal rights without denying the rights of others or experiencing guilt or anxiety. By being assertive you view your wants, needs, and rights as equal with others around you. You work toward "win-win" outcomes. An assertive person wins by influencing, listening, and negotiating so that others choose to cooperate willingly. This allows for honest, open relationships.

Which type fits your style of communication?



# HISPANICS AND HIV/AIDS IN THE UNITED STATES

People who are Hispanic shoulder a highly disproportionate burden of AIDS in the United States. Many Hispanics face significant barriers to health information, HIV counseling and testing, and care. Poverty, language differences, lack of health insurance, and cultural issues are critical factors.

#### SURVEILLANCE

- Although Hispanics composed just 14 percent of the U.S. population in 2004, they accounted for an estimated 20.4 percent of new AIDS cases reported that year.<sup>1,2</sup> Hispanics represented an estimated 20.2 percent of people living with AIDS at the end of 2004.<sup>3</sup>
- In 2004, an estimated 20.4 percent of all deaths attributed to AIDS were among Hispanics, compared with 17.8 percent in 2002 and 17.6 percent in 2000.<sup>4</sup> In 2002, HIV/AIDS was the fourth leading cause of death in the United States for Hispanics ages 35 to 44. For Hispanics ages 25 to 34 and 45 to 54, it was the sixth leading cause of death.<sup>5</sup>

#### Men

Among Hispanic men living with AIDS at the end of 2004, men who have sex with men (MSM) was the HIV exposure category in an estimated 51.6 percent of cases. <sup>6</sup> Injection drug use (IDU) was the HIV exposure category in an estimated 28.3 percent of male cases. <sup>6</sup>

#### Women

An estimated 17,780 Hispanic women were living with AIDS in the United States at the end of 2004.<sup>6</sup> Among Hispanic women living with AIDS at the end of 2004, heterosexual contact was the HIV transmission category in an estimated 65 percent of cases.<sup>6</sup> IDU was the transmission category for an estimated 32.6 percent of cases among Hispanic women living with AIDS.<sup>6</sup>

#### CRITICAL ISSUES

Hispanics often face considerable socioeconomic barriers to health information and care. Only 58.4 percent of Hispanics age 25 and older have a high school diploma, compared with 80.6 percent of African-Americans, 86.8 percent of Asians, and 90 percent of Whites. In 2004, 21.9 percent of Hispanics in the United States were living below the Federal Poverty Level, compared with 8.6 percent of non-Hispanic Whites.

For some subpopulations of Hispanics—such as migrant farmworkers —

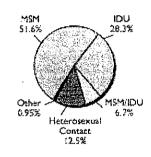
#### This document is available in pdf format: Download PDF (80K)

Hispanics Account for a Disproportionate Number of AIDS Cases in the United States\*\*





Hispanic Men Living With AIDS, by Exposure Category, 2004 (N=65.373)



iDu – injenien drug ese MSM – man wire nave sex with men

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economic circumstances are especially dire. <sup>9</sup> More than 85 percent of all migrant farmworkers are minorities, 95 percent of whom are Hispanic. It is estimated that only 12 percent of this group speaks English and that the median education level is sixth grade. <sup>10</sup> Gaining access to health care is difficult for this population.

The female adult and adolescent AIDS rate in the United States for Hispanics (11.1 per 100,000) is second only to that of Blacks (48.2 per 100,000). 11 Cultural factors that tend to reinforce traditional gender roles can make communication about sex difficult and ultimately contribute to increased risk for HIV transmission among women. 12

In a recent survey conducted by the Henry J. Kaiser Family Foundation, 73 percent of Hispanics reported that they receive most of their information about HIV/AIDS from the media. <sup>13</sup> As with other groups, Hispanic awareness about HIV transmission is a combination of accurate information mixed with widely accepted myths. For example, 31 percent of Hispanic survey respondents reported that a person could contract HIV by touching a toilet seat. <sup>13</sup> However, 57 percent of Hispanics (compared with 36 percent of Whites) were aware that the presence of a sexually transmitted infection raises a person's risk of contracting HIV. <sup>13</sup> Another obstacle to HIV prevention is that the Hispanic community does not have a cultural tradition of preventive care. <sup>12</sup>

Hispanics tend to be tested for HIV late in their illness. They are more likely than non-Hispanic Whites to have AIDS-defining conditions at the time of their first test or within the first year after diagnosis.<sup>14</sup>

Although 59.7 percent of Hispanics living in the United States were born here, <sup>15</sup> they face cultural and language barriers that complicate their ability to communicate effectively with health care providers. The medical system in the United States differs from the systems in other countries, increasing the level of frustration for many immigrants—not just Hispanics—who need care. Hispanics often need the help of translators and seek out bilingual caregivers.

#### HISPANICS AND THE RYAN WHITE CARE ACT

Hispanic/Latino(a) clients accounted for 23 percent of all Ryan White Comprehensive AIDS Resources Emergency (CARE) Act clients in 2004. Hispanic populations are served through all CARE Act programs. For example, the Title IV program for women, infants, children, youth, and families has funded programs in South Texas, southern California, Puerto Rico, and sections of New York City, where high concentrations of HIV-positive Hispanic women reside.

The Health Resources and Services Administration has implemented programs that target subpopulations of Hispanics. For example, the CARE Act Special Projects of National Significance Border Health Initiative targeted people living along the U.S.-Mexico Border. The Initiative funded five grantees (and an evaluation center) to develop improved models of community-based health networks for underserved people living with HIV disease. For more information, go to <a href="https://www.hab.hrsa.gov/special/">www.hab.hrsa.gov/special/</a>

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border\_overview.htm.



To increase access to quality care for minorities and respond to the need for additional minority providers of state-of-the-art HIV/AIDS care in underserved communities, the CARE Act funds the National Minority AIDS Education and Training Center program to expand clinical expertise in minority communities. More information is available at <a href="https://www.nmaetc.org">www.nmaetc.org</a>.

U.S. Department of Health and Fluman Services - Health Resources and Services Administration - HIV/AIDS Bureau 5600 Fishers Lane - Room 7-05 - Rockville, MD 20857 - 301-443-1993 - www.hab.hrsa.gov

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# HIV/AIDS Informational Web Sites, Addresses, and Phone Numbers

# Organizations and Web Sites

# AIDS Clinical Trials Information Service

(ACTIS) Info in Spanish and English on federal and other clinical drug trials. 800 –TRIALS-A; TTY/TDD 888-480-3739 www.actis.org

# AIDS Educational Global Information System

(AEGIS) Daily news updates, newsletters, trials, search engines; run by Sister Mary Elizabeth www.aegis.com

## aidsinfonyc.org

Cooperative site run by ATON, PWA Health Group, Treatment Action Group (TAG) and other organizations www.aidsinfonyc.org

# AIDS Project Los Angeles

(APLA) 1313 North Vine St. Los Angeles, CA 90028 323-993-1600 www.apla.org

#### AIDS Treatment Data Network

(ATDN) Clinical trials listing, many glossaries, ADAP, alternative treatments, also in Spanish 611 Broadway
Suite 613
New York, NY 10012
800-734-7104
www.aidsinfonyc.org/network

# The Body

A central spot for HIV Info www.thebody.com

#### Gay Men's Health Crisis

(GMHC) Legal issues, prevention, treatment, counseling and support groups. 119 W. 24<sup>th</sup> St New York, NY 10011 212-367-1000; Hotline 800-AIDS-NYC www.gmhc.org

# HIV/AIDS Treatment Information Service

(ATIS) Info in English and Spanish on FDA approved treatments. 800-HIV-0440 www.hivatis.org

#### HIV Insite

A top-notch website run by UCSF hivinsite.ucsf.edu

# HIVNET - Information Service

www.hivnet.org

# Medscape

A commercial website with conference reports and physicians' and activists' updates. www.hiv.medscape.com

# National AIDS Treatment Advocacy Project

580 Broadway Suite 403 New York, NY, 10012 212-219-0106 www.natap.org

Project Inform 205 13<sup>th</sup> St. Suite 2001 San Francisco, CA 94103 Treatment hot line 800-822-7422 415-558-8669 www.projectinform.org

PositiveWords.com HIV/AIDS Newsletter Resource www.positivewords.com

### **Publications**

# AIDS/HIV Treatment Directory

Comprehensive info on approved and experimental treatments, clinical trials, by amfAR 120 Wall St 13<sup>th</sup> Floor New York, NY 10005 800-38-amfAR www.amfar.org

#### AIDS Treatment News

The ultimate resource, by John James P.O. Box 411256 San Francisco, CA 94141 800-TREAT12 www.aidsnews.org

# BETA: Bulletin of Experimental Treatment for AIDS

E-Mail – beta@sfaf.org www.sfaf.org/beta.html

#### POZ

Glossy monthly for HIV-infected and HIV affected people; profiles, news, opinion, also in Spanish 349 W. 12<sup>th</sup> St.
New York, NY 10014-1721 212-242-2163 www.poz.com

#### SIDA Ahora

En español, by Body Positive 19 Fulton St Suite 308B New York, NY 10038 212566-7333

# Special Groups

## **CHILDREN**

# Pediatric AIDS Foundation

2950 31 St Suite 125 Santa Monica, CA 90405 310-395-9051 and 888-499-4673 www.pedaids.org

# PEOPLE WITH HEMOPHILIA

# Hemophilia and AIDS/HIV Network for the Dissemination of Information (HANDI) Care of the National Hemophilia Foundation 800-424-2634, in Spanish: ext-3754 www.hemophilia.org

## INJECTION DRUG USERS

# Harm Reduction Coalition

22 W. 27<sup>th</sup> St. 9<sup>th</sup> Floor New York, NY 10001 212-213-6376 www.harmreduction.org

#### TRANSGENDER

# International Foundation for Gender Education

Transgender hot/line, referrals P.O. Box 5400229 Waltham, MA 02454-0229 781-899-2212 www.ifge.org

## PROSTITUtES/SEX WORKERS

### Bayswan

Box 210256 San Francisco, CA 94121 415-751-1659 www.bayswan.org

#### PEOPLE OF COLOR

# National Asian/Pacific Islander Consortium on AIDS and STDs

Care of Asian/Pacific Islander American Health Forum 942 Market St.
Suite 200
San Francisco, CA 94102
415-954-9988
www.apiahf.org

# National Black Leadership Commission on AIDS

105 E. 22<sup>nd</sup> St Suite 711 New York, NY 10010 212-614-0023 www.blca.org

## Latino Commissions on AIDS

80 Fifth Ave Suite 1501 New York, NY 10011 212-675-3288

# National Minority AIDS Council

1931 13<sup>th</sup> St N.W., Washington, DC 20009 202-483-6622 www.nmac.org

# National Native American AIDS Prevention Center 436 14th St. Suite 1020

Oakland, CA 94612 510-444-2051

www.nnaapc.org

## **LESBIANS**

# Lesbian AIDS Project

A division of Gay Men's Health Crisis 212-367-1355 and 212-367-1363

## INCARCERATED INDIVIDUALS

# American Civil Liberties Union National Prison Project

1875 Connecticut Ave Suite 410 Washington, DC 20009 202-234-4830

# **TEENAGERS**

# Adolescent AIDS Program

Montefiore Medical Center 111 E. 210<sup>th</sup> St. Bronx, NY 10467 718-882-0023

#### **WOMEN**

# Sister Connect

Hot/line for women with HIV 800-747-1108

# FOR INFORMATION ON DRUG-DRUG INTERACTIONS SEE:

http://HIV.med scape.com/med scape/HIV/drug interactions/index.cfm

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#### **HIV and AIDS Resources**

#### **Hotlines**

AIDS Statistical Information Line 888-332-4570

AIDSinfo: 800-HIV-0440 (1-800-448-0440) TTY: 1-888-480-3739

Committee of Ten Thousand (AIDS): 800-488-2688

GMHC AIDS Hotline: 1-800-AIDS-NYC (1-800-243-7692) TTY: 1-212-645-7470

International: 1-212-807-6655

Hemophilia AIDS Network/National Hemophilia Foundation: 1-800-424-2634

International: 1-212-328-3700

Hemophilia and AIDS/HIV Network for the Dissemination of Information (HANDI): 800-

42-HANDI

HIPS Hotline: 800-676-HIPS or 800-676-4477

HIV/AIDS National Resources Center: 800-362-0071 International: 1-973-972-0410

National AIDS Hotline: 800-CDC-INFO (1-800-232-4636) TTY: 888-232-6348

National Association of People With AIDS Hotline: 1-202-898-0414

National Gay & Lesbian Youth Hotline: 1-800-347-Teen

National Indian AIDS Hotline: 800-283-2437

National Native American AIDS Prevention Center: 510-444-2051 Automated fax

information: 1-800-283-6880

National Prevention Information Network: 800-458-5231 TTY/TDD: 1-800-243-7012

International: 1-301-562-1098

PEPline: 1-888-448-4911 Advice for Clinicians

Teens Teaching AIDS Prevention (800) 234-TEEN

Project Inform (HIV Treatment Hotline): 800-822-7422

Project Inform: National HIV treatment line: 800-822-7422

The Center for Disease Control Info: 1-800-CDC-INFO (800-232-4636) 1-888-232-6348

TTY 24 hours/day

e-mail: cdcinfo@cdc.gov

The Gay and Lesbian National Hotline: 1-888-THE-GLNH (1-888-843-4564)

The Teen AIDS Hotline: 1-800-4440-TEEN

US AIDS Hotlines State by State

Warmline (The National HIV Telephone Consultation Service) 1-800-933-3413 For physicians and other health care providers who have question regarding HIV care and treatment for their patients.

Women Alive: 800-554-4876 International: 1-323-965-1564



**Patient Information** 

## HIV GenoSURE™

1912 Alexander Drive Research Triangle Park NC, 27709 (800) 533-0567

**Account Information** 

**GENOTYPING REPORT** 

**Routing Information** 

	inca yens massa		Acc	LebCorp #D/: 195-413-6110-0 ount Number: 24813065 LS Client ID: Collected: 07/14/2005 Reported: 07/23/2005	KANSAS CITY FREE HEALTH OLISIC 3516 BROADWAY KANSAS CITY MO 64111 MOB12  Phone: (816):753-5144 Fax: ATTN: LEIN Delivery Route: 30 Mail Info: 1
	Trade Name	Generic Name	Interpretation	Associated Mutations	Comments
NNRTI	- Mutation Summ	ary (103N, 108I)			
R	Rescriptor®	Delavirdine	Resistant	103N	
R	Sustiva®	Efavirenz	Resistant	103N, 108I	
R	Viramune®	Nevirapine	Resistant	103N, 108I	
NRTI	-				
# <b>S</b> **	Hivid®	Zalcitabine	Sensitive		
<b>.\$</b> ?	Epivir®	Lamivudine	Sensitive		
ି\$ି.	Retrovir®	Zidovudine	Sensitive		
ે\$∜	Videx®	Didanosine	Sensitive		
95 %	Zerit®	Stavudine	Sensitive		
S	Ziagen®	Abacavir	Sensitive		
₹ <b>S</b> `ş	Viread®	Tenofovir	Sensitive :		
S	Emtriva®	Emtricitabine	Sensitive		

P1 - Mutation Summary (771)

	Lexiva®	Fosamprenavir	Sensitive	
″\$ી	Crixivan®	Indinavir	Sensitive	$\pi$
S.	Invirase®/Fortovase®	Saquinavir	Sensitive	
∂\$≪	Norvir®	Ritonavir	Sensitive	
\$	Viracept®	Nelfinavir	Sensitive	771
~S	Kaletra®	Lopinavir/r	Sensitive	
<b>ે\$</b> ે	Reyataz®	Atazanavir	Sensitive	

Legend:

S. Sensitive

RP Resistance Possible

"R Resistant

[] Denotes Major PI Mutation

A patient's response to therapy depends on multiple factors including the percentage of a patient's viral population that is resistant, drug pharmacokinetics, and medication compliance. Therefore, this test result should be interpreted in conjunction with the patient's antiretroviral treatment history, viral load count, and clinical status when making therapeutic decisions. This test may be unsuccessful if the plasma HIV RNA viral load is < 1000 copies of virus per ml of plasma, measured with Roche Amplicor Monitor assay (tm) (Roche Diagnostic Systems, Branchburg NJ).

For NY State only: This test result is confidential HIV information and may not be redisclosed except as outlined by NY State Law (art. 27F)

This document contains private and confidential health information protected by state and federal law. This HIV Genotyping assay (GenoSURE) was developed and validated by LabCorp. Results from different test methods may provide different resistance interpretations.

#### Center for Molecular Biology and Pathology

Technical Director
Joseph Sebastian, Ph. D.

V.P. CMBP Operations Hawazin Faruki, DrPH Medical Director Myla Lai-Goldman, M.D.

Page 1 of

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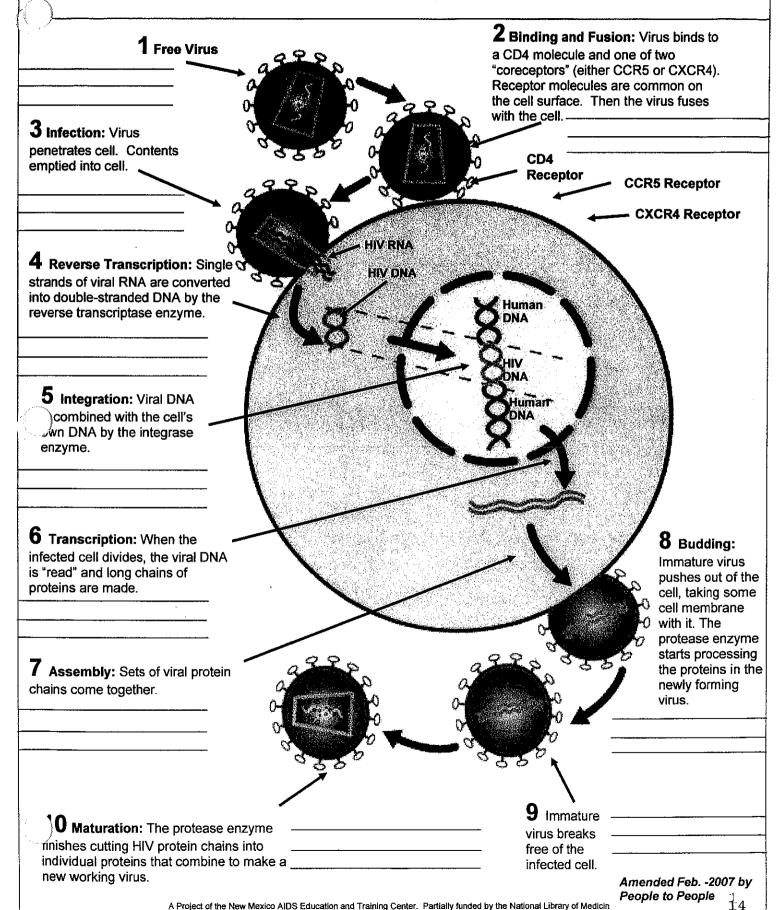


AIDS InfoNet

www.aidsinfonet.org

**Fact Sheet Number 106** 

# **HIV LIFE CYCLE**



Fact Sheets can be downloaded from the Internet at http://www.aidsinfonet.org

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## **HIV RESISTANCE TESTING**

#### IAT IS RESISTANCE?

x√ is "resistant" to a drug if it keeps multiplying rapidly while you are taking the drug. Changes (mutations) in the virus cause resistance.

HIV mutates almost every time a new copy is made. Not every mutation causes resistance. The "wild type" virus is the most common form of HIV. Anything different from the wild type is considered a mutation.

An antiretroviral drug (ARV) won't control a virus that is resistant to it. It can "escape" from the drug. If you keep taking the drug, the resistant virus will multiply the fastest. This is called "selective pressure."

If you stop taking medications, there is no selective pressure. The wild type virus will multiply the fastest. Although tests may not detect any drug resistance, it might come back if you re-start the same drugs.

Resistance testing helps health care providers make better treatment decisions for their patients.

#### DOES RESISTANCE HOW **VELOP?**

√ usually becomes resistant when it is not totally controlled by drugs someone is taking. However, more people are getting infected with HIV that is already resistant to one or more ARVs.

The more that HIV multiplies, the more mutations show up. These mutations happen by accident. The virus doesn't "figure out" which mutations will resist medications.

Just one mutation can make HIV resistant to some drugs. This is true for 3TC (Epivir) and the non-nucleoside reverse transcriptase inhibitors (NNRTIs). However, HIV has to go through a series of mutations to develop resistance to other drugs, including most protease inhibitors.

The best way to prevent resistance is to control HIV by taking strong ARVs. If you miss doses of your medications, HIV will multiply more easily. More mutations will occur. Some of them could cause resistance.

If you have to stop taking any ARV, talk to ur health care provider. You may have stop some drugs sooner than others. If you stop taking drugs while the virus is under control, you should be able to use them again.

#### TYPES OF RESISTANCE

There are three types of resistance:

- Clinical resistance: HIV multiplies rapidly in your body even though you're taking ARVs.
- Phenotypic resistance: HIV multiplies in a test tube when ARVs are added.
- Genotypic resistance: The genetic code of HIV has mutations that are linked to drug resistance.

Clinical resistance shows up as a higher viral load, lower CD4 count, or opportunistic infections (see Fact Sheet 500). Laboratory tests can measure phenotypic genotypic resistance.

#### PHENOTYPIC TESTING

A sample of HIV is grown in the laboratory. A dose of one ARV is added. The growth rate of the HIV is compared to the rate of wild type virus. If the sample grows more than normal, it is resistant to the medication.

Phenotypic resistance is reported as "fold" resistance. If the test sample grows twenty times as much as normal, it has "20-fold resistance."

Phenotypic tests cost about \$800. It used to take over a month to get the results. New phenotypic tests are somewhat quicker.

#### **GENOTYPIC TESTING**

The genetic code of the sample virus is compared to the wild type. The code is a long chain of molecules called nucleotides. Each group of three nucleotides, called a "codon," defines a particular amino acid used to build a new virus.

Mutations are described by a combination of letters and numbers, for example K103N. The first letter (K) is the code for the amino acid in the wild type virus. The number (103) identifies the position of the codon. The second letter (N) is the code for the "changed" amino acid in the mutant sample.

Genotypic testing costs about \$250. Results come back in about two weeks.

#### VIRTUAL PHENOTYPE

This test is really a method of interpreting genotypic test results. First, genotypic testing is done on the sample. Phenotypic test results for other virus samples with a similar genotypic pattern are taken from a database. These matched samples tell you how the virus is likely to behave. The virtual phenotype is faster and less expensive than a phenotypic test.

#### **CROSS-RESISTANCE**

Sometimes a mutant version of HIV is resistant to more than one drug. When this happens, the drugs are called "crossresistant." For example, most HIV that is resistant to nevirapine (Viramune) is also resistant to efavirenz (Sustiva). This means that nevirapine and efavirenz are crossresistant.

Cross-resistance is important when you change medications. You need to choose new drugs that are not cross-resistant to drugs you've already taken.

We do not totally understand crossresistance. However, many drugs are at least partly cross-resistant. As HIV develops more mutations, it gets harder to control. Take every dose of your ARVs according to instructions. This reduces the risk of resistance and cross-resistance. It saves the most options for changing medications in the future.

### PROBLEMS WITH RESISTANCE TESTING

Resistance tests are not available everywhere. They are expensive. However, they are becoming more common, faster, and cheaper.

The tests aren't good at detecting "minority" mutations (less than 20% of the virus population). Also, they work better when the viral load is higher. If your viral load is very low, the tests might not work. Tests usually cannot be run if the patient's viral load is less than 500 to 1,000 copies per ml.

Test results can be difficult to understand. Drugs that should work according to the tests sometimes don't work, and vice versa. Sometimes genotypic and phenotypic tests give conflicting results for the same patient. Some mutations can "reverse" or reduce resistance to some medications.

Recent research suggests that a genotypic resistance test should be done for every patient before they start taking ARVs. This saves money by avoiding putting someone on ARVs that will not work for them.

Revised May 12, 2007



PROVIDING HIV/AIDS CARE IN A CHANGING ENVIRONMENT - January 2007

# HIV Treatment and the Nonclinician: Getting Your Bearings

his past August, Ryan White Comprehensive AIDS Resources
Emergency (CARE) Act-funded grantees and providers
gathered in Washington, DC, for the biennial All-Titles
Technical Assistance Meeting. Veterans of previous All-Titles
conferences noted a significant increase in the number of young
professionals participating in the 2006 event, and registration data
showed that an incredible 46 percent of approximately 2,300
registrants were attending an All-Titles conference for the first time.

It is not known what proportion of the attendees are new to the field of HIV/AIDS services. Nevertheless, their presence in such numbers underscores that, as an older generation of providers retires or otherwise leaves the field, a new generation is entering.

And what a complicated field it is. People affected by the epidemic are often affected by many other challenges, too, such as a life-long struggle with poverty and poor access to health care. HIV service providers and their clients must contend with developments such as compassion fatigue, erosion in community support, the ever-present stigma of HIV/AIDS... and, always, the complexities of treatment.

Figure 1: Deaths in Adults and Adolescents With AIDS in the United States

5600 Fishers Lane, Suite 7-05 Rockville, MD 20857 Telephone: 301.443.1993

In this Issue

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Antiretroviral Drugs: Dosing and Side Effects-

HIV Treatment Resources-

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For More Information-

Publisher U.S. Department of Health and Human Services Health Resources and Services Administration HIV/AIDS Bureau

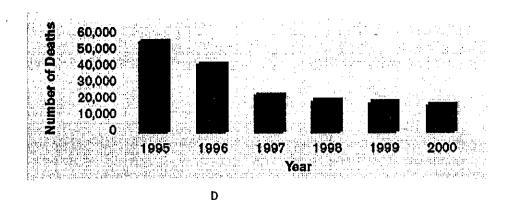
**Editor** Richard Seaton, Impact Marketing and Communications

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Please forward comments, letters, and questions to:

Health Resources and Services Administration, HIV/AIDS Bureau

Additional copies are available from the HRSA Information Center, 888.ASK.HRSA, and may be downloaded from the Web at http://hab.hrsa.gov/publications.htm



Source: Centers for Disease Control and Prevention (CDC). HIV/AIDS Surveillance Report. 2001;13(2):30. Table 21.

Entering the field of HIV/AIDS services as a nonclinician and wrapping one's brain around something as complex as highly active antiretroviral therapy (HAART) is no easy task—but it is an essential one. Nonclinician HIV/AIDS service providers are often pivotal in helping patients prepare for the rigors of HIV/AIDS treatment. They play equally important roles in helping their organizations build services that are culturally competent and reflective of the needs and challenges faced by people living with HIV/AIDS (PLWHA). They can do neither of those things effectively without at least a basic understanding of HAART. This issue of *HRSA CAREAction* is written to help them acquire that knowledge.

## **Having HAART**

Introduced in 1995, HAART "had an immediate and dramatic impact on the prognosis for HIV infection—[it was] one of the most impressive changes in any disease since the introduction of penicillin in the 1940s." After the introduction of HAART, AIDS-related deaths plummeted from 50,876 in 1995 to 18,028 in 1998 (Figure 1). They have since stabilized. The projected life expectancy of patients on antiretroviral therapy is 24.4 years, compared with 12.4 years for patients not receiving antiretroviral therapy.

HAART, to put it simply, is the use of a combination of different antiretroviral drugs. HAART is often referred to as "combination therapy" and, more colloquially, as a "drug cocktail." Typically, a HAART regimen has three different drugs, but it can have more. At least two of the drugs in a HAART regimen must come from different

drug classes—an important point because each class of drug attacks HIV in a different way.



Currently, more than 20 approved antiretroviral drugs from four different drug classes are available:

- 1. Nucleoside/nucleotide reverse transcriptase inhibitors (NRTIs)
- 2. Non-nucleoside reverse transcriptase inhibitors (NNRTIs)
- 3. Protease inhibitors (Pls)
- 4. Fusion inhibitors.

See the table at the end of this article for information on specific drugs.

HAART works because it suppresses HIV replication and, thus, reduces the amount of HIV circulating in the body (viral load). The reduction in viral load allows the body's immune function to improve, which can be measured by the CD4<sup>+</sup> T-cell count. (For the definition of this and other technical terms, see "Some Terms You'll Need To Know".) Figure 2 illustrates how the different classes of antiretroviral drugs work at each step of HIV replication.

For the nonclinician seeking to acquire an understanding of the challenges of HAART—or help a client deal with them—the three most important facts to understand are as follows:

- HAART is not a one-pill, one-time treatment, but a life-long commitment.
- 2. HAART can be laden with side effects.
- 3. HAART has strict and unforgiving adherence requirements.

All the HAART-related difficulties with which patients struggle descend from these three facts. If the first were not so—if HAART were a one-time treatment— facts two and three would not matter so much. However, because HAART is an ongoing, never-ending proposition, they matter a lot.

#### Some Terms You'll Need to Know

Adherence: Continuous maintenance of a drug regimen; the difficult work of not missing doses for as long as the patient is on

the treatment—which, for people living with HIV/AIDS (PLWHA), is for life.

Antiretroviral: An agent that suppresses the activity or replication of retroviruses, such as HIV. Antiretroviral drugs interfere with various stages of the virus's life cycle.

Asymptomatic: Living with a disease but having no symptoms.

CD4<sup>+</sup> count (also called T-cell count): The number of T cells in a small amount of blood; CD4<sup>+</sup> cell count is used to measure the strength of a PLWHA's immune system. When a patient's T-cell count is less than 200 per mm<sup>3</sup>, he or she is said to have AID5. CD4<sup>+</sup> cell count in persons not infected with HIV usually ranges from 600 to 1,200 cells per mm<sup>3</sup>.

CD4<sup>+</sup> T cells (also called T cells and T lymphocytes): A type of white blood cell that plays a vital role in the body's immune response. HIV enters and infects CD4<sup>+</sup> cells, disabling them and turning them into "virus factories."

**Co-formulation:** Combining more than one medication into a single pill to reduce pill burden and thereby make adherence easier.

**Drug resistance:** Changes in a virus or bacteria that make treatment ineffective.

**Genotypic testing:** A type of testing that identifies mutations associated with drug resistance.

HAART (highly active antiretroviral therapy): A combination of at least three drugs from more than one class of antiretroviral agents.

Phenotypic testing: A type of testing that measures the sensitivity of HIV to a specific drug; it reveals how much of a given drug is needed to suppress HIV replication.

Seroconversion: The point at which a person develops HIV antibodies.

**Sero-discordant:** A couple in which one person is HIV positive and the other is not. Treatment experienced: People who have been treated for HIV.

Treatment naive: People who have never received a particular treatment. When the term is used in regard to HIV/AIDS it is almost always referring to HAART.

Undetectable viral load: When the viral concentration in the bloodstream is too low for current technologies to detect.

Viral load: The amount of virus in a small sample of a patient's blood. It is a marker used to determine both when a PLWHA should begin HAART and how well he or she is responding to a HAART regimen. Ideally, viral load should be undetectable during antiretroviral therapy, meaning that the drugs are suppressing HIV replication to extremely low levels.

Viral replication: The process of a virus making copies of itself.

**Viral suppression:** Reducing the amount of virus in the blood by interfering with viral replication. Viral suppression is the goal of HAART.

Side effects from treatment can be mild, moderate, or severe. They can be occasional, frequent, or constant. In short, they vary according to innumerable factors. But almost universally, side effects can make people not want to take their medicine. For people on HAART, not taking one's medicine can cause trouble to develop at lightning speed.

The unhappy reality is that patients on HAART have to be much better at adhering to their treatment regimens than do most patients undergoing treatment for other diseases. Just 50 percent of people living with chronic diseases, including asthma, diabetes, and hypertension, take their medications as prescribed more than 80 percent of the time. That is not nearly good enough for people on HAART. Results of a study among primarily antiretroviral-experienced patients (i.e., people who had previously been on the kinds of

medicines included in HAART) showed that a greater than 95 percent adherence rate was necessary for 78 percent of patients to achieve an undetectable viral load.<sup>5</sup>

Figure 2. How HAART drugs work

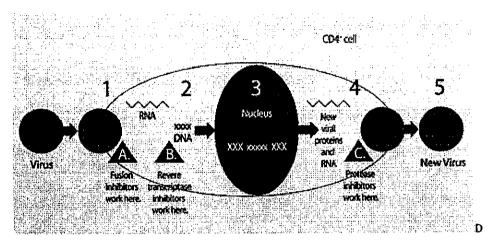


Illustration of (1) the virus entering the cell, (2) conversion of viral RNA to DNA using the reverse transcriptase enzyme, (3) incorporation of the viral genome into the DNA of the host cell, (4) viral proteins cleaved by protease for assembly of new viral particles, and (5) new virus particles budding from the surface of the host cell. It also shows the steps in the viral life cycle that are interrupted by (A) fusion inhibitors (B) reverse transcriptase inhibitors and (C) protease inhibitors. Source: National Institutes of Health. Available at www.niaid.nih.gov/publications/discovery/hiv.htm. Accessed September 20, 2006.

So why is adherence so important? Because HIV replicates rapidly—at rates as high as 10 billion copies per day. With replication rates like that, viral mutations (inexact copies) develop quickly. Some viral mutations confer resistance to a single drug. Others show resistance to an entire class of drugs.

Fortunately, meeting HAART's adherence demands has become easier during the past 10 years. One reason is that improvements in the drugs have reduced the side effects and long-term problems associated with taking the medications, making them much easier to take on schedule. The importance of this development has been trumped, however, by that of another: the dramatic decline in the number of pills that patients on HAART must take in a single day.

When HAART was introduced, daily pill burdens were measured in the dozens for some patients. In addition to the number of pills, there was the matter of dosing requirements: when to take the pills and

with what foods. Some pills were taken twice a day, others as many as six times daily. Some medications were to be taken with food, others to be taken hours before eating and still others made patients nauseous and never want to eat again. In those first years, being on HAART could seem like a fulltime job.

Today, a person on HAART may take as little as one pill per day since the Food and Drug Administration recently approved Atripla, the first once-daily combination of three drugs (Sustiva, Emtriva, and Viread) in a single tablet. Pill burden is also being reduced through an approach called pharmacokinetic "boosting." The essence of this strategy is to increase the concentration of a drug in the bloodstream and to increase the length of time that the drug stays there. This strategy is implemented by using one drug to increase the concentration of another or lengthening the time the drug stays in the bloodstream by slowing down metabolism.

In addition to reducing side effects and lowering the pill burden, other improvements in the administration of HAART have occurred. Viral load testing determines how active the virus is in the patient's body and, thus, helps clinicians assess the need for treatment and whether treatment is working. More recently introduced is genotypic and phenotypic resistance testing, which identifies the classes or types of drugs to which a person's virus has developed resistance and helps clinicians identify the best regimens for their patients.

Moreover, new agents that are active against drug-resistant virus have become available, and several promising new drugs from established and new drug classes are in the development pipeline.

Advances like these make HAART a much more effective treatment than it was 10 years ago.

In April 1998, the U.S. Department of Health and Human Services and the Centers for Disease Control and Prevention (CDC) issued the first comprehensive, evidence-based HIV treatment guidelines. The guidelines address a variety of issues, including the following:

- When to start HIV treatment
- Which drugs and combinations to start with, and which to avoid

- Short and long-term side effects and toxicities of HAART
- · How best to use resistance testing
- · How best to manage treatment-experienced patients
- How to address population-specific treatment issues.

Treatment guidelines have been updated regularly over the past decade, and guidelines for treating subpopulations such as children and women also have been developed. Several other tools and publications are available for helping patients, clinicians, and nonclinicians understand and administer HAART. See "HIV Treatment Resources" for information on obtaining treatment guidelines and other resources.

#### **HAART All the Time?**

The 1998 HIV treatment guidelines suggested an aggressive, "hit early, and hit hard" strategy, which was based on the theory that it was possible to eradicate HIV with HAART (i.e., to "cure" someone of HIV infection). It was soon discovered, however, that complete eradication of HIV is not possible with current therapies, even though some people may have no detectable virus in their bloodstream.

After HAART was widely introduced, reports quickly emerged of side effects. HAART-specific side effects include noticeable changes in body shape, increased diabetes rates, increased cholesterol, and bloating. Other side effects, such as chronic nausea, diarrhea, and peripheral neuropathy (pain, numbness, and tingling in the feet and fingers) are effects of HIV that were compounded by HAART. The side effects negatively affected quality of life and made challenging adherence requirements even more difficult.

Patients beginning treatment with CD4\* counts of less than 200 have poorer survival. Thus, "hit early, hit hard" was modified to the guidelines in place today: It is recommended that HAART be initiated in people whose CD4\* cell counts have fallen to between 201 and 350 per mm<sup>3</sup>.

## Resistance Testing: Genotype and Phenotype

A HAART regimen becomes less effective at suppressing viral

replication as mutant strains of HIV develop. Poor adherence to the regimen is a primary cause of viral mutations—but it is not the only cause. Mutant strains of the virus can be transmitted from one person to another. They also can develop over time, even before a person begins antiretroviral therapy, or emerge during treatment as a result of interactions between drugs or problems with the body's ability to absorb the drugs.

As mutations develop and drug resistance sets in, changing HAART regimens becomes necessary. But the strategy of changing regimens can be implemented only a limited number of times, because the number of viable regimens is finite. Additionally, once resistance develops, drug regimens become much more complicated. There is no "one pill once a day" regimen for highly resistant virus.

Viral mutations are public enemy number one for people on HAART, and they are occurring with increasing frequency. Single-drug and multidrug resistance has been detected in both newly infected and newly diagnosed, treatment-naïve PLWHA. In a 2002 report, Little and colleagues noted a rising incidence of antiretroviral drug resistance among 377 HIV-positive people, all of whom had never been on HAART. Over a 5-year period, resistance to a single drug class increased from 3.4 percent to 12.4 percent, and resistance to several drugs increased from 1.1 percent to 6.2 percent. Other studies have reported resistance rates ranging from 8.3 percent to 16.3 percent of untreated, newly infected, or newly diagnosed PLWHA in the United States. 7,8

The surge in treatment-resistant virus has made resistance testing a crucial clinical tool for optimizing anti-HIV therapy. Resistance testing results can be combined with patient preference and treatment history, clinician experience, and expert consultation to inform treatment decisions, particularly for treatment-experienced patients.

## **Complicated Matters**

The significant side effects and toxicities referred to above do more than negatively affect adherence. The list of potential long-term complications related to HAART is long and includes cardiovascular disease, renal disease, insulin resistance or diabetes, loss of bone density, and abnormal elevations in lipid (fat) levels (hyperlipidemia).

Lipodystrophy is one of the most talked about side effects of HAART in part because it is the most visible. Lipodystrophy (abnormal fat deposits that change body shape) is disfiguring; the "fat accumulation" type of lipodystrophy often appears as a hump on the upper back or a large potbelly, whereas the "fat loss" type of lipodystrophy—called lipoatrophy—results in hollowed cheeks and a generally gaunt face. These side effects are a significant concern for PLWHA and for the team of care providers working to support them. People who develop these complications often feel that their appearance reveals their HIV status, robbing them of the choice to disclose their status on their own terms. In this sense, they not only lose control of their own bodies but lose control over their identity and privacy.

In addition to their physical manifestations, lipodystrophy and lipoatrophy are sometimes accompanied by abnormally elevated triglycerides (fatty acids), cholesterol, and glucose (blood sugar). Lipodystrophy and lipoatrophy have been reported in people who have used Pis, NNRTis, and NRTis as well as in untreated PLWHA. Although a specific cause has yet to be identified, several additional factors have been linked, including genetics, longer duration of antiretroviral therapy, low CD4<sup>+</sup> cell count at HIV treatment initiation, older age at treatment initiation, and HIV disease itself.

Strategies for addressing lipodystrophy or lipoatrophy include lifestyle changes, pharmacological interventions, and switching antiretroviral agents. For example, abnormally elevated lipid levels can be managed by changes in diet, increased exercise, and smoking cessation. If those measures are not effective, lipid-lowering agents can be prescribed or treatment regimens can be changed.

Clinicians are still learning about the side effects of HAART and the effects of living with HIV/AIDS as a chronic disease. We do not know the long-term effects of HAART, nor do we know all the interactions between antiretroviral agents and other medications prescribed to



address ailments associated with aging. Thus, HIV/AIDS treatment remains a dynamic field, and everyone on the care team—nonclinicians included—has a role to play in ensuring that PLWHA reap the benefits of lessons learned.

### **HAART: Getting Ready**

The answer to the question "when to begin HAART" has changed over the years—and will likely continue to change as treatments for HIV improve. Many things have not changed, of course, and among them is the difficult decision for PLWHA of when to begin HAART.

That HAART can be an unforgiving taskmaster is no secret to PLWHA considering treatment. Its side effects and adherence demands make many people think twice about starting a treatment they will have to continue far into the future. Moreover, many treatment-naïve patients have watched HIV-positive friends and peers wrestle with tough questions that go beyond side effects and adherence: Who's going to pay for the drugs? Will it keep my other medications from working? How am I going to hide the pills from my mom and the other people who I don't want to know I'm positive? Add issues like those to the tough circumstances in which many PLWHA live, and it becomes clear why patients may say, "I just can't do it."

"We rarely have to discourage people who we believe cannot adhere from entering treatment," says Laura Cheever, M.D., chief medical officer in the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau. "But we spend an incredible amount of time getting people to a place that they can adhere—and to a place where they believe that they can adhere."

Cheever is known to many in the CARE Act community as deputy associate administrator in HRSA's HIV/AIDS Bureau. But she is also an active clinician who serves patients with a history of injection drug use in John Hopkins' Moore Clinic.

"When T-cell counts in my patients begin to fall toward the levels at which they need to begin HAART," Cheever explains, "we have a very open and honest discussion about their fears of HAART. The relationships that our patients and team members have established

provide the framework for that discussion."

Preparing patients for treatment is one of the most important services that organizations provide. The nurturing, confidence-giving relationships that develop outside of the doctor-patient interaction are a critical factor in making HAART viable for many patients. But the question of treatment readiness is not merely about patients and their relationship with caregivers; it also involves making sure the caregivers are prepared to help patients become ready. To that end, any serious strategy for preparing patients for treatment should include a team approach.

Addressing HIV/AIDS has never been a one-man or one-woman enterprise, and today, as much as at any time during the pandemic, the care and treatment of PLWHA require the collaboration of professionals from a variety of disciplines along with peers, social workers, and case managers. Without the broad knowledge base that only a team approach can provide, the impoverished, disenfranchised, multiply diagnosed people who are today's face of AIDS will neither have access to nor be able to reap the full benefits of life-saving HIV medication and treatment.

In many HIV/AIDS service settings, it is social workers, peers, and case managers who spend the most time with PLWHA. People in those roles have long been in pursuit of greater cultural competency and a better understanding of patients' challenges. In today's environment, this pursuit must include a quest for an understanding of HAART and its barriers and ramifications. Through providing services to and coming to understand the needs of their clients, HIV/AIDS service providers develop deep, nurturing relationships with their patients. Cheever explains, "These relationships become a source of self-confidence and determination for the patient, and they can help a person whose first response to HAART is to say 'I can't' rethink the issue and say, 'Well, maybe I can.'"

## What's in the Pipeline?

The antiretroviral pipeline is robust, and several drugs from new and

established classes of antiretroviral agents are currently in development.

Drugs from established classes may offer new therapeutic options for people who have become resistant to existing treatments. New drug classes include

- entry inhibitors (i.e., those that hinder HIV's entry into CD4<sup>+</sup> cells),
- integrase inhibitors (i.e., those that obstruct HIV's integration into cellular DNA), and
- maturation inhibitors (i.e., those that interfere with the final stages of HIV's reproduction and movement from cell to cell).

If new agents prove safe and effective, and if side effects and toxicities are minimal and therefore make adherence easier, the HiV treatment model may shift back toward earlier initiation of therapy.

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# Antiretroviral Drugs: Dosing and Side Effects

Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs) Class-specific adverse events: Lactic acidosis (an abnormal build up of lactic acid in the bloodstream) with hepatic steatosis (fat in the liver) is a rare but potentially life-threatening toxicity associated with use of NRTIs.

Agent (Generic/Brand/ Abbreviation), Approval Date, and Manufacturer	Dosing/Food Restrictions/ Pill Burden	Agent-Specific Adverse Events*	
Abacavir/Ziagen®/ABC December 17, 1998 GlaxoSmithKline	Once or twice daily, with or without food Total: 2 pills/day	Hypersensitivity reaction, which can be fatal. Symptoms may include fever; rash; nausea; vomiting; malaise or fatigue; loss of appetite; and respiratory symptoms, such as sore throat, cough, and shortness of breath. (Increased risk of hypersensitivity reaction has been reported with once-daily dosing.)	
Didanosine/Videx®/Videx EC®/ddl/ Generic didanosine, enteric coated Videx®: October 9, 1991 Videx EC®: October 31, 2000 Bristol-Myers Squibb Generic didanosine: December 3, 2004 Barr Laboratories	By weight; once or twice daily, depending on formulation; take Videx EC 1 or 2 hours after a meal; take tablets ½ hour before or 2 hours after a meal  Totat: ranges from 2 to 4 pills, or 1 capsule per day, depending on formulation (unless weight is under 133 lbs)	Pancreatitis; peripheral neuropathy (pain, numbness, and tingling in the hands or feet); nausea; diarrhea; vomiting; headache; rash	

Emtricitabine/Emtriva™/FTC July 2, 2003 Gilead Sciences	Once daily, with or without food Total: 1 capsule/day	Minimal toxicity; side effects include headache, diarrhea, nausea, rash.
Lamivudine/Epivir®/3TC November 17, 1995 GlaxoSmithKline	Once or twice daily, with or without food Total: 1 or 2 tablets/day (150 or 300 mg)	Minimal toxicity; nausea
Stavudine/Zerit®/d4T June 24, 1994 Bristol-Myers Squibb	By weight; twice daily, with or without food Total: 2 pills/day (unless weight is under 133 lbs)	Peripheral neuropathy; lipodystrophy; neuromuscular weakness (rare); pancreatitis; higher incidence of lactic acidosis with hepatic steatosis than with other NRTIs; hyperlipidemia
Tenofovir disoproxil fumarate/ Viread™/TDF October 26, 2001 Gilead Sciences	Once daily, with or without food Total: 1 pill/day	Asthenia (weakness); headache; diarrhea, nausea, vomiting, and flatulence; renal insufficiency; osteopenia (decrease in bone density rare)
Zalcitibine /HIVID®/ddC June 19, 1992 Hoffman-La Roche		Rarely prescribed; discontinuance pending due to toxicity and low potency
Zidovudine/Retrovir®/AZT/ZDV March 19, 1987 GlaxoSmithKline	Twice daily, with or without food Total: 2 pills/day	Nausea, abdominal pain, asthenia, headache, insomnia, bone marrow suppression leading to anemia (low red blood cell count) and neutropenia (low white blood cell count rare); muscle wasting
Coformulations		
Atripla™ (FTC/TDF/EFV) July 12, 2006 Bristol-Myers Squibb Gilead Sciences (Merck & Co. outside of the United States)	Once daily, on an empty stomach, preferably at bedtime Total: 1 pill/day	See emtricitabine, tenofovir disoproxil fumarate, and efavirenz
Combivir® (3TC/ZDV) September 27, 1997 GlaxoSmithKline	Twice daily, with or without food Total: 2 pills/day	See lamivudine and zidovudine
Epzicom® (ABC/3TC) August 2, 2004 GlaxoSmithKline	Once daily, with or without food Total: 1 pill/day	See abacavir and lamivudine
Trizivir® (ABC/ZDV/3TC) November 14, 2000 GlaxoSmithKline	Twice daily, with or without food Total: 2 pills/day	See abacavir, lamivudine, and zidovudine
Truvada™ (FTC/TDF) August 2, 2004 Gilead Sciences	Once daily, with or without food Total: 1 pill/day	See emtricitabine and tenofovir disoproxil fumarate

Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) Class-specific adverse events (rare; more commonly reported with NVP than other drugs in this class): Stevens-Johnson syndrome, a severe, potentially life-

threatening hypersensitivity reaction; rash				
Agent (Generic/Brand/ Abbreviation), Approval Date, and Manufacturer	Dosing/Food Restrictions/ Pill Burden	Agent-Specific Adverse Events*		
Rescriptor®/Delavirdine/DLV April 4, 1997 Pfizer	Three times daily, with or without food  Total: 6 pills/day	Elevated liver enzymes; headache, fatigue, upset stomach. This drug is rarely used.		
Efavirenz/Sustiva®/EFV September 17, 1998 Bristol- Myers Squibb	Once daily, on an empty stomach, at bedtime Total: 1 pill/day	Drowsiness, insomnia, vivid dreams, confusion, inability to concentrate, amnesia, hallucinations, euphoria, dizziness, nausea, stomach pain, fever, and elevated liver enzymes; associated with birth defects in monkeys; causes false positive drug test result for cannabis		
Nevirapine/Viramune®/NVP June 21, 1996 Boehringer Igleheim	Once daily for 14 days (200 mg), twice daily thereafter, with or without food Total: 2 pills/day; 1 pill/day during14-day lead-in	Hepatitis, which can be asymptomatic; in rare cases, fatal liver damage; headache; upset stomach		

Protease Inhibitors (PIs)
Class-specific adverse events: Abnormal distribution of body fat, hyperglycemia (abnormally high blood sugar levels), and possibility of increased bleeding among people with hemophilia are associated with PIs.

Agent (Generic/Brand/ Abbreviation), Approval Date, and Manufacturer	Dosing/Food Restrictions/ Pill Burden	Agent-Specific Adverse Events*
Amprenavir/Agenerase®/APV April 15, 1999 GlaxoSmithKline/Vertex Pharmaceuticals	Twice daily; avoid taking with high fat meal Total: oral solution, twice daily	Gastrointestinal intolerance (nausea, vomiting, stomach pain), rash, hyperlipidemia (lipid elevations), elevated liver enzymes, oral tingling or discomfort
Atazanavir/Reyataz®/ATZ June 20, 2003 Bristol-Myers Squibb	Once daily; take with food If treatment-experienced, or if using with TDF or EFV, boost with 100 mg RTV  Total: 2 pills/day if unboosted; otherwise, 3 pills/day (including ritonavir)	Increased bilirubin levels, headache, pain, tingling in arms and legs, nausea, diarrhea, rash, abnormal heartbeat (rare)
Darunavir/Prezista ™/TMC- 114 June 23, 2006 Tibotec Incorporated	Twice daily, in combination with 100 mg ritonavir; take with food Total: 6 pills/day (including ritonavir)	Diarrhea, nausea, headache, cold symptoms, mild-to-moderate skin rash
Fosamprenavir/Lexiva®/FPV October 20, 2003 GlaxoSmithKline/Vertex Pharmaceuticals	If treatment naïve, twice daily, or can be taken once or twice daily with ritonavir boosting; if treatment-experienced, twice daily with ritonavir boosting, with or without food	Rash, gastrointestinal intolerance, headache, hyperlipidemia, elevated liver enzymes

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	Total: 4 pills/day, (with or without ritonavir)	
Indinavir/Crixivan®/IDV March 13, 1996 Merck & Co	Three times/day, or twice daily with ritonavir boosting; if unboosted, take on empty stomach or with light, low-fat snack; if boosted, with or without food  Total: 6 to 8 pills/day, depending on dosing scheme (includes ritonavir)	Kidney stones, gastrointestinal intolerance, elevated bilirubin level, headache, insomnia, rash, back pain, weakness, dizziness, blurred vision, metallic taste, hair loss, low platelets, anemia
Lopinavir ritonavir/ Kaletra®/LPV/r September 15, 2000 Abbott Laboratories	Once daily if treatment naïve; twice daily if treatment experienced, with or without food Total: 4 pills/day (tablets) 6 pills/day (capsules)	Gastrointestinal intolerance, weakness, headache, elevated liver enzymes, lipid elevations, and pancreatitis (rare)
Nelfinavir/Viracept®/NFV March 14, 1997 Agouron Pharmaceuticals	Two or three times daily, with snack or meal  Total: ranges from 4 to 10 pills/day, depending on dosing scheme	Diarrhea, gas, rash, hyperlipidemia, elevated liver enzymes
Ritonavir/Norvir®/RTV March 1, 1996 Abbott Laboratories	Rarely used as single agent; dosing is three times/day. As a booster, dosing ranges from 100 to 400 mg/day, once or twice daily. If using as single agent, take with full meal.  Total: 12 pills/day	At full dose: gastrointestinal intolerance, numbness and tingling, weakness, hyperlipidemia, liver enzyme elevations, taste perversion
Saquinavir/Invirase®/SQV November 7, 1997 December 6, 1995 Hoffman-La Roche	Twice daily; must be ritonavir boosted; take with a full meal Total: 6 pills/day for invirase, (includes ritonavir)	Gastrointestinal intolerance, insomnia, headache, elevated liver enzymes, hyperlipidemia
Tipranavir/Aptivus®/TPV Boehringer Ingleheim June 22, 2005	Twice daily, must be ritonavir boosted take with a full meal Total: 8 pills/day (includes ritonavir)	Rash, gastrointestinal intolerance, fatigue, lipid elevations, hyperglycemia (rare: symptomatic hepatitis, liver failure) (possible: increased risk of intercranial hemorrhage)

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Agent (Generic/Brand/ Abbreviation), Approval Date, and Manufacturer	Dosing/Food Restrictions/ Pill Burden	Agent-Specific Adverse Events*	
Enfuvirtide/Fuzeon™/T20 March 13, 2003 Hoffman-La Roche/Trimeris	Two injections/day; must be mixed in advance	Injection site reaction: pain, swelling, lumps, hardened skin, bacterial pneumonia, and hypersensitivity reaction (rare; occurs in <1%)	



Note: No drugs in this table should be used as monotherapy (this is true for both treatment-naïve and treatment-experienced patients). Darunavir, tipranavir, and enfuvirtide are approved only for use in treatment-experienced people.

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### **HIV Treatment Resources**

#### **HIV/AIDS Treatment**

Advances in HIV care and treatment are highlighted in "HAART at 10," a special issue of Research Initiative/Treatment Action! published by the Center for AIDS Information & Advocacy. Available at www.centerforaids.org/rita/0805/contents0805.htm.

#### Treatment Guidelines

- The Centers for Disease Control and Prevention HIV/AIDS treatment guidelines are updated regularly to reflect relevant research results on management and treatment of HIV disease. The most recent Guidelines for the Use of Antiretroviral Therapy in HIV-1 Infected Adults and Adolescents was released on May 4, 2006. The guidelines, additional resources, and a patient-friendly companion brochure (HIV and Its Treatment: What You Should Know) are available at www.aidsinfo.nih.gov/guidelines/.
- Additional information is available at www.projectinform.org/fs/making.html (also available in Spanish)

#### **Drug Development**

Information on HIV drugs in development is available at

- www.aidsinfonyc.org/tag/tx/pipeline2006b.html
- www.thebodypro.com/treat/newdrugs.html

#### Resistance Testing

Information on resistance testing is available at

- www.aidsmeds.com/lessons/resistance1.htm (also available in Spanish)
- www.aidsinfonet.org/factsheet\_detail.php?fsnumber=126 (also available in Spanish)
- www.projectinform.org/fs/drugresist.html (also available in Spanish)

#### HIV Therapy and Management

- Information on complications of HIV therapy and their management is available in the Guidelines for the Use of Antiretroviral Therapy in HIV-1 infected Adults and Adolescents, Tables 11-14, 17a-c. Available at www.aidsinfo.nih.gov.
- Currently Approved Drugs for HIV: A Comparative Chart.
   Available at www.aidsmeds.com/lessons/drugchart.htm

#### Other resources include

- Anderson JR, Ed. A Guide to the Clinical Care of Women with HIV/AIDS, Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau; 2005. Available at: http://hab.hrsa.gov/publications/womencare05/index.htm.
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- Coffey S. Ed. Clinical Manual for Management of the HIV-Infected Adult. Newark, NJ: AIDS Education and Training National Resource Center; 2006. Available at: www.aidsetc.org/aetc/aetc?page=cm-00-00.

#### Additional general information is available at

- www.aids.gov/treatment/types/index.html
- www.aidsmeds.com/lessons/starthere7.htm (also available in Spanish)
- www.aidsinfonet.org/factsheet\_index.php?catnum=550 (also available in Spanish)
- www.i-base.org.uk/guides/side/index.html

#### Information on lipodystrophy and lipoatrophy is available at

- www.aidsmeds.com/lessons/lipo1.htm (also available in Spanish)
- www.aidsmeds.com/iessons/lipoatrophy1.htm (also available in Spanish)

#### Other valuable sites are

- www.aidsmeds.com/List.htm (also available in Spanish)
- www.aidsinfonet.org/factsheet\_index.php?catnum=400 (also available in Spanish)

www.i-base.org.uk/guides/index.html

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### For More Information

To obtain information on Medicare plan options and enrollment materials: www.medicare.gov. Toll free: 800-MEDICARE. (800-633-4227) TTY: 877-486-2048.

To locate Social Security Offices: www.socialsecurity.gov/locator.

Toll-free: 800-772-1213. TTY: 800-325-0778.

To find the nearest Medicaid office, contact the State Medicaid agency.

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# enter tox AIDS how does stigma affect HIV prevention and treatment?

## what is HIV/AIDS stigma?

HIV/AIDS-related stigma is a complex concept that refers to prejudice, discounting, discrediting and discrimination directed at persons perceived to have AIDS or HIV, as well as their partners, friends, families and communities.1.2

HIV/AIDS stigma often reinforces existing social inequalities based on gender, race, ethnicity, class, sexuality and culture. Stigma against many populations disproportionately affected by HIV has been present for a long time in the US. HIV has compounded the stigma of homosexuality, drug use, poverty, sex work and racial minority status.3

HIV/AIDS stigma is a problem in the US and throughout the world. Stigma has been expressed in a variety of ways, including: 1) ostracism, rejection and avoidance of people living with AIDS; 2) discrimination against people living with AIDS by their families health care professionals, communities and covernments; 2) mandatory UTV people fiving with AIDS; 2) discrimination against people fiving with AIDS by their families, health care professionals, communities and governments; 3) mandatory HIV testing of individuals without prior informed consent or confidentiality protections; 4) quarantine of persons who are HIV infected; and 5) violence against persons who are perceived to have AIDS, be infected with HIV or belong to "high risk groups."

## how can stigma affect prevention?

IV/AIDS stigma adds to the stress experienced by HIV+ persons. In addition, it leads to challenges for HIV prevention efforts.

HIV testing. Fear of negative social consequences of a positive HIV test result can deter some persons from getting tested. A study of men and women in seven cities in the US found that stigma-was associated with a decreased likelihood of being tested for HV. People who are HIV+ but haven't tested and don't know they are HIV+ are less likely to try to prevent transmitting HIV to others.5

Safer behaviors. Some HIV+ persons may fear that disclosing their HIV status or using condoms may bring partner rejection, limit sexual opportunities or increase risk for physical and sexual violence. A study of rural men who have sex with men (MSM), found that men who thought health care providers in their community were intolerant of HIV+ persons, also reported more high-risk sexual behaviors.6

Prevention programs. Stigma surrounding HIV, homosexuality, commercial sex work and drug use make it difficult for HIV prevention services to be offered in a variety of settings. While it is widely accepted that HIV prevention should be integrated into a broader Whale it is widely accepted that HIV prevention should be integrated into a broader health and community context, many community venues such as churches, businesses, health and community context, many community venues and businesses. jails, prisons and schools have resisted incorporating frank discussions of HIV?

## how can stigma affect treatment?

 ${
m HIV/AIDS}$  stigma can also negatively affect the health and well being of HIV+persons.

Treatment. HIV+ persons may not seek treatment or delay going to doctors due to real or perceived discrimination against them. A national study of HIV+ adults found that 36% reported experiencing discrimination by a health care provider, including 8% who had been refused medical service.8

Support. Some HIV+ persons don't have an adequate support network because they fear support. Some rily persons don't have an adequate support network because they lear that friends or family will abandon them or suffer the same stigma they do. One study of Asian and Pacific Islanders (API) living with HIV found high levels of internalized stigma. APIs avoided seeking support because they were afraid of disclosure and saw themselves as unworthy of getting support.9

Adherence. Experiences of social rejection, disapproval and discrimination related to HIV may decrease the motivation of HIV+ persons to stay healthy. A study of HIV+ men and women found that those who had experienced stigma were also more likely to miss HIV clinic appointments and lapse in adherence to their medication. 10

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## what's being done?

Stigma-reduction programs and trainings take place throughout the US and the world. However, it is difficult to measure the effectiveness of programs. As a result, there are few published studies of effective stigma-reduction programs. Most programs use multiple components to address stigma including education, skills building and contact with HIV+ persons on individual and community-wide levels.

A school-based program for inner-city high school students in Texas, featured HIV+ speakers to decrease negative attitudes towards HIV/AIDS. The speakers were popular with students and teachers and had a positive impact on attitudes in the short term. Combining HIV+ speakers with a multicomponent HIV prevention and education program produced a greater impact. 12

The South Carolina HIV/AIDS Council (SCHAC) instituted an anti-stigma program with three components. First, SCHAC held legislative town hall meetings focused on HIV issues within rural counties. Second, they produced an educational play on the realities of HIV stigma for communities and their local leaders. Third, SCHAC created a statewide marketing campaign to address HIV/AIDS stigma using public service announcements, posters and editorials.<sup>13</sup>

The New York State Department of Health AIDS Institute (AI) has used multi-level interventions to prevent HIV-related stigma and discrimination. On a policy level, the AI has worked to pass laws and enact policies to protect the rights of HIV+ persons and persons perceived to be HIV+, including confidentiality laws and naming HIV/ AIDS in the existing anti-discrimination law. They also provide forums and advisory councils for policy discussions, and set up an office for discrimination issues to handle complaints. On a program level, the AI provides diversity and confidentiality training for healthcare providers, leadership training for HIV+ persons and social marketing approaches for community-wide education and awareness. 14

## what needs to be done?

K nowledge about HIV prevention, transmission and care can offset the stigma that is caused by misinformation and ignorance. Education programs are still needed in many areas and populations, and will continue to be needed for successive generations of young people.<sup>5</sup>

Stigma exists not simply within individual actions, but within broad social and cultural contexts that need to be addressed in stigma-reduction programs. Organizations and communities must tackle the values, norms and moral judgments that contribute to the stigmatization of HIV+ persons by engaging faith-based organizations, key institutions and opinion leaders that help shape and reinforce societal values. Policymakers need to consider the potential consequences of laws to make sure they don't inadverdently increase HIV/AIDS-related stigma.

HIV+ persons must be involved in designing, running and evaluating stigma reduction programs. One approach is to train and support HIV+ persons to organize to advocate for themselves. <sup>16</sup> Prevention, coping and adherence programs for HIV+ persons should directly address stigma and its effect on HIV+ persons' health and well being.

Programs can also offer cultural competency, confidentiality and awareness training for healthcare workers, counselors and staff at social service organizations including drug treatment, housing, mental health services. Training is especially important in areas where stigma is high, such as rural areas and organizations where there may be few HIV+ clients.

HIV/AIDS-related stigma is unlikely to go away any time soon.¹6 While research is being conducted nationally and internationally,¹7 more research is needed to measure the effects of stigma and understand what types of interventions work best for which communities. Promising stigma awareness and reduction programs need to be evaluated and published so that effective programs can be widely replicated.

PREPARED BY MARIA EKSTRAND PHD, CAPS AND THE NATIONAL AIDS FUND

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## KANSAS CITY FREE HEALTH CLINIC JOB DESCRIPTION

Title:	
) Peer Educator  Division: HIV Primary Care	Status: Part-time/non-exempt
Number of Employees This Position Supervises:	Budget Size:
Reports To: LaTrischa Miles	<b>Date:</b> June 19, 2006

**General Summary:** 

The Peer Educators are integral to the Treatment Adherence Program and provide specialized services in a professional environment. Peer Educators work to encourage engagement into care and support adherence to treatment by providing client centered individual and group level skill building activities to achieve client goals.

## Minimum Requirements:

- Must have a high school diploma/GED;
- ♦ Must have 1 year of experience in this or a related field;
- Must have experience in providing HIV peer education, HIV related volunteer work or completion of a leadership training program;
- ♦ Must have good interpersonal skills with the ability to relate to diverse groups of people and people on all levels;
- ♦ Must have the ability to work independently and seek guidance when necessary;
- Must have the ability to work within a multi-disciplinary team approach to health care;
- ♦ Must have good interpersonal skills with ability to relate to diverse groups of people and people on all levels.

## **Essential Functions:**

- ♦ Maintain a client caseload of 5-10 HIV+ individuals
- Peer educators will provide individual contact with patients to identify and develop client directed treatment plan goals and monitor ongoing achievement of goals.
- Work collaboratively with primary care and case management staff to identify newly diagnosed patients who can benefit from peer support, by offering hope and living proof that living with the disease is possible
- ♦ Support patients in navigating the clinic system and community resources.
- ♦ Engage clients expected to start ARV regimens in an assessment of readiness for treatment, provide education on HIV medications, anticipated benefits/sides effects and importance of adherence. Assess patient needs upon onset of medication.
- Provide individual and group educational skill building opportunities to foster adherence to
  medications, identify strategies to improve adherence to health routines, communication with
  providers and additional issues to increase engagement in care and adherence to treatment;
- Enhance engagement in care and adherence by assembling next day appointment charts, complete patient reminder and DNKA calls per Protocol and Operational Activities Manual;
- Maintain appropriate records and collaborate with primary care and treatment adherence specialist on patient concerns

- ◆ Maintain the bulletin boards in patient exam rooms and re-stock with health promotion and disease prevention literature. Participate in continuing HIV/AIDS education.
- Mentor and educate new peer educators
- Supports the mission and vision of the Kansas City Free Health Clinic; follow all clinic policies and procedures; attend individual and group supervision meetings
- ♦ Must adhere to all confidentiality policies. It is a direct violation of Clinic policy to share the names or case facts concerning any client, patient or volunteer of the Clinic with any other person with the exception of those actually involved in the care of the patient/client. Any release of confidential information to any other entity shall be preformed by authorized personnel only and shall be accompanied by proper written authorization from the patient/client;

### Physical Demands/Working Conditions:

- Intermittent physical activity including walking, standing, sitting, lifting and supporting of patients.
- Incumbent will be exposed to virus, disease and infection from patients in working environment.
- ♦ Incumbent will be required to work at one of our two facilities and be responsible for their own transportation.
- Incumbent may experience traumatic situations including but not limited to psychiatric, dismembered and terminal patients.

My signature indicates that I understand that the above information is intended to describe the essential functions of the position and it is not intended to be an exhaustive list of all responsibilities, duties and skills required in order to perform the work required. I also understand that the Kansas City Free Health Clinic is an Equal Opportunity Employer and that the Kansas City Free Health Clinic is an "at will" organization and employment may be ended by either party with or without notice.

Signature and Date		
Supervisor Signature and Date		

## Looking for Mr. Right, Another View

#### Nucleoside Analogues

Type: Old reliable "Nukes" have been on the Scene for a decade or more and come with a well-known set of perks and quirks. Most anti-HIV cocktails start with a nuke or two.

Most likely to: Require a chaperone. Somewhat shaky at holding their own against HIV, nukes always go out in groups – generally with drugs in other classes. Most two-nuke combos tag along with protease inhibitor or a non-nuke. A few HIVers find bliss with a triple-nuke regimen

Personality Pitfalls: Works your nerves – literally – and can cause plenty of side effects including pain or numbness in the limbs (peripheral neuropathy), muscle aches and pains, headaches, low white and red blood cells and a long list of gut-related problems (such as diarrhea, nausea and vomiting).

#### Non-Nucleoside Analogues

Type: Great first date. Combos containing a PI are the most popular catch as a first-time treatment regimen, but lately those with non-nukes are giving them a run for their money.

Most likely to: Get jealous and compete with one another. Unfortunately, the three non-nukes on the market share the same hang-up: Developing drug resistant to all.

#### Possible Treatments

Personality Pitfalls: Easily hurt. For HIV to become resistant to the PIs, several changes (mutations) in the virus DNA must occur. With the non-Nukes, a single mutation will ruin the relationship. Instructions for taking a non-nuke must be followed to the letter. Side effects are also possible, from allergic reactions to sleep disorders and emotional disturbances like anxiety, anger and depression. Metabolic problems similar to those caused by PIs may pop up.

#### Protease Inhibitors

Type: Hot 'n' heavy. Pegged as the most eligible bachelors of 1996, protease inhibitors (PIs) quickly became the revolutionary heartthrobs of HIV treatment. They're designer drugs — the first compound on the market specifically designed to target HIV — and are one of the most powerful families of ani-HIV drugs around. They're proud of their pedigree, to a fault.

Most likely to: Be high maintenance. Treating these drugs right means taking them religiously and obeying

Most likely to: Be high maintenance. Treating these drugs right means taking them religiously and obeying dietary restrictions. Devotion does have its rewards, including an angelic viral load and a chorus of CD4 cells. PIs also require the support of other drugs most often nukes. It's not known which of the five currently available PIs is best. While they differ in side effects dosage and dietary restrictions they are quite similar with respect to resistance. Developing HIV resistance to one PI might spoil your changes with others, so deciding which PI to commit to first is a biggie.

Personality Pitfalls: Tendency to cause trouble down the road. Despite being a "designer" drug, they cause side effects just like the less-refined nukes. Nausea, vomiting and diarrhea are fairly common in HIVers not only during the first weeks or months but also long term. Liver problems can also occur over the long haul, also with metabolic problems such as elevated fat and sugar levels and body-shape changes.

#### **Entry Inhibitors**

Type: Calling out all the stops

Most likely to: Fuzeon acts like a piece of clothing that
gets stuck in the zipper as the HIV virus tries to insert and
dock at the CD4 cell it can no longer zip itself together to
dock. This completely halts the process of HIV fusing
with the CD4 cell. HIV cannot progress in your body.

Resistance is still a concern similar to other HIV drugs.

Personality Pitfalls: Requires self injection done twice a day. Side effects are skin reaction around the area where the drug is injected but only about 4 percent found it a problem enough to stop.

Borrowed from Treatment Choices, Meet Your Meds Matching up with anti-HIV drugs doesn't have to lead to a HAART-ache by Tim Horn, executive editor of the PRN Notebook, a quarterly for HIV physicians. POZ Special Edition, Fall 2000. Copyright 2000. All rights reserved. Reproduction of this booklet is encouraged as long as it is reproduced in its entirety and full credit is given to POZ.



## MEN OF COLOR WHO HAVE SEX WITH MEN AND HIV/AIDS IN THE UNITED STATES

Since the onset of the HIV/AIDS epidemic in the United States, HIV incidence has been highest among men who have sex with men (MSM). Most new AIDS cases for which MSM is the HIV exposure category are now among MSM of color, who face extraordinary barriers to HIV counseling and testing as well as to care. <sup>1,2</sup> Moreover, evidence suggests that AIDS surveillance data significantly underrepresent the rate of HIV/AIDS among men of color.

#### **SURVEILLANCE**

- In 2004, an estimated 31,024 men were diagnosed with AIDS in the United States. MSM was the HIV exposure category in an estimated 57 percent of those cases.<sup>3</sup> Men of color represented 52.7 percent of reported AIDS cases related to the MSM HIV exposure category.<sup>4</sup> Men of color also accounted for 55.2 percent of reported AIDS cases related to the MSM/injection drug use exposure category.<sup>4</sup>
- Evidence indicates extraordinarily high seroprevalence rates among some MSM populations. As part of the National HIV Behavioral Surveillance effort, the Centers for Disease Control and Prevention (CDC) surveyed MSM over age 18 who frequented certain venues in five cities; 25 percent of the study participants were HIV positive, and 48 percent were unaware of their serostatus.<sup>2</sup> Unrecognized seropositivity among the 217 MSM was 64 percent among Blacks and 18 percent among Hispanics, compared with 11 percent among Whites and 6 percent among multiracial groups.<sup>2</sup>

#### **CRITICAL ISSUES**

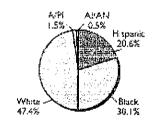
Like many racial and ethnic minorities, many minority MSM face poor access to health care because of poverty and lack of health insurance. In addition, MSM of color must cope with many types of stigma—for being a minority, for being an MSM, and for being HIV positive. MSM of color, therefore, may fear condemnation from many sectors: their family, community, and service providers.<sup>5</sup>

Many minority MSM do not self-identify as gay or bisexual. Thus, prevention and health outreach targeting sexual minorities may not be effective among this group—and MSM may be especially reluctant to seek services at organizations perceived to be gay oriented.<sup>5-7</sup> Many minority MSM identify with their racial identity more than their sexual identity; thus, messages aimed at the gay community often do not reach them.<sup>8</sup>

Minority MSM become infected at earlier ages than Whites and are more

#### This document is available in pdf format: Download PDF (76K)

MSM Reported AIDS Cases, by Race/Ethnicity, 20041 (N=15.538)



Estimated Proportion of Men Living With AIDS for Whom MSM Was the HIV Exposure Category, by Race/Esthnicity, 2004 (N=316.593)



A WN - American incremiAvence Net ve NP - As an Peoff of stander

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likely to learn that they are HIV positive later in the course of infection. Moreover, compared with Whites, a higher proportion of people of color have AIDS at initial diagnosis.<sup>2,9</sup>

Some MSM harbor misconceptions about effective HIV treatment. Many are aware of the advancements in medical technology and in the effectiveness of highly active antiretroviral therapy (known as HAART), but they overestimate its power. Others believe that HIV infection is inevitable and may do little to prevent it.<sup>6</sup>

#### MSM OF COLOR AND THE RYAN WHITE CARE ACT

Experiences of providers funded through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act have revealed program components that are key to reaching MSM. Providers must cultivate and then provide high-quality, nonjudgmental services that help MSM acknowledge their risk, get tested, and remain in care over time. The use of peer educators can be critical. <sup>10</sup>

In collaboration with the African-American AIDS Policy and Training Institute, the Asian and Pacific Islander Health Forum, Bienstar, and the National Native American AIDS Prevention Center, the Health Resources and Services Administration (HRSA) conducted a research project involving key informant interviews and structured roundtable discussions to identify barriers to care for MSM of color and develop solutions. The results of the publication Improving Care for HIV-Positive Men of Color Who Have Sex With Men: Barriers and Recommendations are shaping the process through which HRSA and the Centers for Disease Control and Prevention (CDC) are collaboratively responding to the epidemic among young MSM of color.

To increase access to quality care for minorities and respond to the need for additional minority providers of state-of-the-art HIV/AIDS care in underserved communities, the CARE Act funds the National Minority AIDS Education and Training Center program to expand clinical expertise in minority communities. More information is available at www.nmaetc.org.

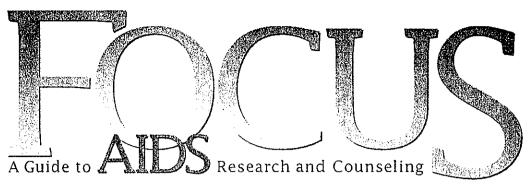
Capacity-building and planning grants have been targeted to underserved communities in order to expand the number of services available to vulnerable minority populations.

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U.S. Department of Health and Human Services - Health Resources and Services Administration - HIV/AIDS Bureau 5600 Fishers Lane - Room 7-05 - Rockville, MD 20857 - 301-443-1993 - www.hab.hrsa.gov





# Methamphetamine, the Brain, HIV, and Mental Health

Kristina Jones, MD

Recreational methamphetamine use is expanding among members of gay communities in the United States. Understanding the drug's mechanism of action and the short- and long-term psychiatric consequences of abuse offers insights into how methamphetamine affects HIV transmission behaviors among both HIV-positive and HIV-negative people, how it affects treatment-related behaviors such as adherence in people with HIV, and how it complicates the course of HIV disease.

#### Methamphetamine Drug Characteristics

Methamphetamine is classified as a stimulant (an amphetamine). Other drugs in this class include cocaine and MDMA (methylenedioxymethamphetamine; Ecstasy) and medications such as methylphenidate (Ritalin). Each of these drugs has unique effects on the brain and behavior. Methamphetamine can be thought of as a super-concentrated amphetamine in the same way that "crack" is a concentrated form of cocaine.

Medical practitioners discovered amphetamines in the 1940s and the drug was used by pilots during World War II to help them stay awake during long missions. The drug was initially prescribed for weight loss until it was recognized that it produces adverse personality changes, that weight was regained as soon as the drug was stopped, and that ongoing use could lead to heart attack and death.

Colloquially known as "crystal," "tina," "meth," or "speed," methamphetamine can be smoked, snorted, injected, or ingested. Some users report "booty bumping," inserting a solution of methamphetamine and water rectally with a syringe causing decreased sensation in the rectum—"freezing"—and

some absorption of the drug. Methamphetamine is apparently used for longer and more aggressive sexual encounters. Methamphetamine may be contaminated with other dangerous substances such as phencyclidine (PCP) and toxic ingredients that may alter the effects users expect to experience.

In the body, methamphetamine lasts about 12 hours. Users report "runs" or "binges," during which methamphetamine is used every few hours for several days at a time.

Subjective symptoms of intoxication include alertness, euphoria, and an increased sense of well-being. Many users report feeling more sexual desire, heightened self-confidence, and freedom from anxiety about HIV. As discussed below, however, methamphetamine can lead to a variety of serious psychiatric effects and physical dangers ranging from hallucinations and paranoia to heart attack and kidney failure.

Many of the worst effects of methamphetamine—physical, psychiatric, and HIVrelated dangers—can arise from casual or recreational use. That is, these effects do not occur only in the context of ongoing abuse.

#### Prevalence and Reasons for Use

According to the World Health Organization, amphetamine and methamphetamine are among the most widely abused illicit drugs in the world, second only to marijuana. More than 35 million individuals regularly abuse these drugs, while 15 million abuse cocaine.<sup>1</sup>

Recent studies have begun to define both the threat that the methamphetamine epidemic poses to public health and the reasons men who have sex with men use methamphetamine. For example, a New York study found a relationship between methamphetamine and transmission-related sexual behaviors. A San Francisco study found that in circuit party settings, the drug was used to initiate, enhance, and prolong sexual encounters, and that intoxication produced lapses in judgment leading to unprotected anal receptive intercourse.

#### Editorial: Just Say Mental Health

Robert Marks, Editor

It would be hard not to know by now that there is an amphetamine epidemic in the United States. Among gay and bisexual men, particularly in urban centers, methamphetamine use is fueling HIV transmission in ways that raise the specter of a more desperate time.

In a country that has inconsistently demonized and glorified the use of substances ranging from tobacco and alcohol to marijuana and heroin, that has accepted a "just-say-no" approach, and that has rejected the abundant evidence and scientific consensus on the value of medical marijuana, I have become wary of reports of the dire threat any substance poses to society. There is no

doubt, however, about methamphetamine. It is one nasty drug.

The articles in this issue of FOCUS should convince you, too. Kristina Jones, a psychiatrist who works on the front lines of the New York methamphetamine and HIV epidemics, offers a careful and clear description of the overwhelming risks that accompany methamphetamine use, an analysis that goes way beyond the paternalistic patter of just-sayno'ism. Los Angeles researchers Michael Campos and Steven Shoptaw discuss some evolving methamphetamine treatment options, but their hope is measured.

The treatment of addiction is never easy. We also know that men who have sex with men have higher rates of substance use than the general population, higher rates of depression, and higher rates of a history of child-hood sexual abuse. Methamphetamine is not the first substance to which gay and bisexual men—and heterosexual people too—have turned to self-medicate these ills. It won't be the last. But it may be the nastiest.

#### A Hit of Self-Esteem

To quote a line from an earlier draft of Jones's article: methamphetamine delivers "a hit of selfesteem in powder form." If there were ever a time to support programs that cultivate healthier paths to self-esteem, that time would be now. We know that just preaching "no" does not work. Offering drug treatment and mental health care and offering community support for people in sexual minorities does.

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A southern California study of HIV-positive gay men using methamphetamine found that in addition to reporting sexual enhancement, users said the drug "provided temporary escape from being HIV-positive," helped "manage negative self-perception and social rejection associated with being HIV-positive," offered "a method of coping with the specter of death," and made it easier to approach sexual partners and to have anonymous sex with multiple partners.

A Los Angeles study of gay and bisexual men seeking treatment for methamphet-amine dependence found that 61 percent of subjects were HIV-infected. Those with HIV were more likely to have injected methamphetamine and engaged in unprotected anal receptive intercourse with significantly more sexual partners than uninfected subjects.

#### Medical Complications and HIV Treatment

Medical complications of methamphetamine ingestion include tachycardia (rapid heart rate) hypertension, tachypnea (shortness of breath) hyperthermia (raised internal body temperature), and central nervous system excitation. Methamphetamine toxicity can also lead to rhabdomyolysis (the breakdown of muscle tissue leading to kidney failure). Methamphetamine can also lead to cardiovascular events such as heart attack and stroke.

Clinicians also report fatal interactions between protease inhibitors and both methamphetamine and Ecstasy. Protease inhibitors and methamphetamine each rely on a liver enzyme called CYP3A4 for their metabolism. When these substances are taken together, the enzyme's "receptor sites" are engaged by the protease inhibitor and cannot metabolize the methamphetamine. so the methamphetamine reaches the brain unchanged. This can result in a three- to tenfold increase in methamphetamine levels in the bloodstream and in the brain. An Australian patient taking a combination of stavudine, saquinavir, and ritonavir died after injecting methamphetamine. Two case reports also document fatalities following ingestion of ritonavir and Ecstasy.<sup>7</sup>

#### Psychological and Psychiatric Effects of Use

Methamphetamine use has serious psychological and psychiatric side effects, which may be long-lasting, continuing even after use has ceased. The effects of one-time use can include personality changes, most commonly suspiciousness or jealousy, paranoia, auditory hallucinations, restlessness, tension, irritability, aggressiveness (both sexual and physical), and appetite suppression.

Continual use of methamphetamine, with little or no sleep over a period of two to five days, can lead to extreme irritation and

paranoia. In approximately 10 percent of cases, heavy, chronic abuse can lead to psychosis, characterized by paranoia, impaired perception of reality, and vivid visual, auditory, and tactile hallucinations. Such amphetory, and tactile hallucinations.

tamine-produced psychoses mimic schizophrenia. Prolonged use can result in tolerance for the drug and increased levels of use, creating dependence.

Withdrawal symptoms, which occur 24 hours after last use of methamphetamine, resemble major depressive disorder. Symptoms include depressed mood, anhedonia (the inability to experience pleasure), fatigue, and suicidal ideation.

Quality clinical research data on long-term psychiatric consequences of methamphetamine use is sparse. People who use methamphetamine often also use other drugs such as alcohol, marijuana, cocaine, Ecstasy, gamma hydroxybutyrate (GHB), and ketamine. Each of these substances affects

the brain and behavior differently. Overall findings suggest that while acute psychosis tends to resolve, depressive symptoms tend to persist. California researchers studied 170 methamphetamine users two to five years after outpatient treatment. They found that of the 23 percent of the sample reporting paranoia at baseline, only 7 percent reported paranoia at follow-up, while 62 percent reported depressive symptoms at both baseline and follow-up. Twenty-eight percent of respondents reported violent behavior in the year prior to baseline.

#### The Role of Dopamine

The psychiatric and behavioral effects of methamphetamine are mediated primarily through the release of two neurotransmitters: large amounts of dopamine, one of the brain's key neurotransmitters, and smaller amounts of norepinephrine. Methamphetamine addiction can be understood as a two-part phenomenon: during intoxication, there is too much dopamine, and during withdrawal there is too little. It can take months or years to recover to normal dopamine levels, and sometimes normal levels are never attained.

Dopamine acts in regions of the brain that affect the experience of pleasure, such

as subjective sensations of euphoria, well-being, sexual desire, and confidence. It also influences the body's sleep clock. Further, dopamine is involved in reward behavior, the mechanism that causes people to repeat behaviors that are pleasurable. Most neurochemical models of addiction focus on this role of dopamine as a behavioral reinforcer, and addiction to most drugs, including heroin and tobacco, relies on dopamine to reinforce the substance's pleasurable effects.

The large amounts of dopamine that are released during methamphetamine use may explain some of the behaviors intoxication causes. Dopamine flooding the brain's amygdala accounts for some of the aggressive behavior reported by methamphetamine abusers. Excess dopamine is also probably responsible for the psychotic symptoms seen in some users, and treatment of methamphetamine-related symptoms such as agitation, paranoia, and auditory hallucinations includes conventional antipsychotic drugs, which block dopamine. Some theories implicate excess dopamine as the cause of schizophrenia. After months or years of methamphetamine abuse, the brain's supply of dopamine is probably depleted, resulting in depression, emotional flattening, and anhedonia.

Researchers believe that methamphetamine can cause brain damage, because the drug pushes out huge amounts of dopamine from nerve cells. This flooding can be toxic to nerve cells and to the whole group of cells where dopamine is clustered and stored in the brain. Animal studies show that methamphetamine damages dopamine and the serotonin nerve structures. Human studies have provided hard evidence from scans of the brain that methamphetamine use leads to a reduction of dopamine transporter levels, a marker for dopamine function in the brain. showing that dopamine is absent or missing from the proteins that move dopamine around the brain.

#### Dopamine and HIV Dementia

Dopamine also plays a role in the brain's ability to process information, that is, moving information from one brain cell to the next. The precise chemical mechanism of HIV dementia and HIV-related cognitive impairment is poorly understood. Research suggests, however, that impairment is caused by a metabolic alteration in brain chemistry that involves both brain cell loss and neuronal dysfunction, probably involving dopamine neurons. Some studies have found that HIV viral proteins are toxic to the dopamine neuron.

The psychiatric effects of methamphetamine are caused largely by the release of dopamine; the medical complications are due primarily to the release of norepinephrine.

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#### Authors

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The danger for HIV-positive methamphetamine users is that methamphetamine may amplify the neuron-damaging effect of HIV. Some researchers have inferred from this that the combination of HIV infection and methamphetamine abuse can increase the chances of cognitive impairment.9

#### The Role of Norepinephrine and Serotonin

Many of the medical complications of methamphetamine are due to the other component of the drug, norepinephrine, which is chemically related to adrenaline. Norepinephrine is primarily responsible for methamphetamine's physical effects of increased heart rate and blood pressure, hence, its cardiovascular complications. The norepinephrine component may explain why methamphetamine abusers get high blood pressure, heart attacks, and strokes. Large amounts of norepinephrine may also account for the anxiety that users experience and for some of the weight loss.

In contrast, Ecstasy exerts its effects primarily through release of another neurotransmitter, serotonin. Serotonin is implicated in the regulation of mood, sleep, appetite, and libido, and is the key ingredient in most antidepressants. Unlike excess dopamine, excess serotonin does not usually result in psychosis, violence, or sexual behaviors that can lead to HIV transmission. In high doses, however, the excess serotonin released during Ecstasy use can cause hallucinations, paranoia, seizures, rhabdomyolysis (muscle breakdown leading to kidney failure), and death.

#### **Psychiatric Treatment**

The acute psychotic symptoms associated with methamphetamine can be treated with standard neuroleptic (antipsychotic) medication and sometimes with hospitalization. Drug rehabilitation for methamphetamine addiction aims at inpatient detoxification. treatment for depression with antidepressants, and harm reduction counseling for people who choose to continue use.

Since there is no evidence to guide medication use for methamphetamine recovery, methamphetamine treatment is modeled after cocaine treatment. However, randomized controlled trials of the dopamine "agonists"—substances such as bromocriptine and pergolide that promote dopamine's effects and which are used for cocaine recovery—have shown no efficacy in methamphetamine recovery.

Many drug abusers conclude that they need stimulants to recover. But a study of cocaine users in recovery found that methylphenidate, a stimulant and an indirect dopamine agonist, did not decrease cocaine use (although it did decrease dropout from drug treatment). 10 While drug users, including methamphetamine users, may present for psychiatric care demanding Ritalin or other stimulants, there is no data to support this approach. Finally, while psychiatrists may use the antidepressant buproprion (Wellbutrin; Zyban) to treat depressive symptoms in methamphetamine users, this drug does not work during acute stimulant withdrawal.

#### Conclusion

Methamphetamine use, epidemic in many gay and bisexual communities, has serious adverse physical, psychiatric, and psychological effects, and the drug may interact with HIV medications to produce increased toxicity or death. Neurological complications resulting from dopamine depletion can lead to irreversible neuropsychiatric symptoms and may compound HIV-related cognitive impairment. Psychiatric consequences include acute psychosis and paranoia during intoxication, and long-lasting depression even after addiction has ended. At a time of continued, if measured, success in HIV treatment, burgeoning methamphetamine use threatens hope as well as health.

#### Clearinghouse: Crystal Meth and HIV

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# **Evidence-Based Treatments for Methamphetamine Abuse**

Michael Campos, PhD and Steven Shoptaw, PhD

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Methamphetamine use was once primarily observed in the western United States and Hawaii, however, its use and production are on the rise across the United States. Data from the Drug Abuse Warning Network show increases in amphetamine/methamphetamine-related emergency room admissions across the nation from 1995 to 2002. This article briefly reviews the efforts of the drug treatment community to develop evidence-based methamphetamine treatment.

The National Institute on Drug Abuse has funded evaluations of potential medications for methamphetamine withdrawal, craving, and associated cognitive deficits. Recent work has focused on evaluating the efficacy of drugs that enhance serotonin (sertraline); enhance serotonin, dopamine, and norepinephrine (buproprion); inhibit serotonin (ondansetron); enhance the neurotransmitter GABA (baclofen and gabapentin); and enhance cognition (aripiprazole, which partially enhances dopamine; rivastigmine, which inhibits acetylcholinesterase). Modafinil, which has shown promise as a cocaine pharmacotherapy, is another medication that has attracted interest as a methamphetamine treatment.

None of these medications, however, has yet proven its efficacy. By contrast, behavioral therapies have proven effective in helping methamphetamine abusers to recover and also reduce HIV-related sexual behaviors. The most effective interventions fall into two categories: cognitive-behavioral therapy and contingency management.

#### Cognitive-Behavioral Therapy

Cognitive behavioral substance abuse

therapy is a short-term, focused approach that can be administered individually or in groups designed to initiate abstinence and avoid relapse. There are three broad phases of cognitive behavioral treatment.2 The first phase is designed to gain initial control of drug use. Specific techniques include teaching participants to identify high-risk situations and methods to deal with thoughts about use. The second phase addresses more psychosocial substance-related problems including social isolation and unemployment. The third phase teaches internal coping skills, for example, managing triggers to relapse such as craving, and interpersonal coping skills, for example, drug refusal skills training.

The Matrix Model, a cognitive-behaviorally based outpatient treatment originally developed to treat cocaine dependence, incorporates many of these elements. Matrix treatment aims to stop drug use, teach issues critical to addiction and relapse, provide education for family members affected by addiction and recovery, help clients become familiar with self-help programs including 12-step programs, and provide weekly monitoring of urine and breath samples for drug and alcohol use.<sup>3</sup>

An eight-site, randomized outpatient trial, compared the Matrix Model to "treatment as usual," which consisted of individual counseling sessions, groups, and 12-step participation. Researchers found that Matrix participation led to increased retention in treatment, increased program completion, and longer periods of sustained abstinence compared to treatment as usual. Matrix also resulted in comparable, but not statistically different levels of drug-free urine while in treatment. By six month follow-up evaluations, all participants benefited equally from treatment as measured by greatly reducing methamphetamine use from baseline levels.

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See also references cited in articles in this issue.

#### **Contingency Management**

Contingency management treats methamphetamine abuse by systematically delivering immediate reinforcement in response to a client's success in remaining drug free, as documented by biological samples such as urine. Contingency management can be used as a primary treatment or an adjunct to treatment for cocaine, opiate, and nicotine addictions and has been shown to be effective in the treatment of methamphetamine addiction.<sup>4-6</sup>

Contingency management understands drug abuse as an "operant" behavior, that is, behavior that is maintained by powerful reinforcers. It theorizes that alternative, non-drug reinforcers should decrease drug use if these reinforcers are sufficiently powerful and if they are incompatible with drug use. In many studies, vouchers for prosocial goods or services are the alternate reinforcer. The vouchers become increasingly valuable with provision of consecutive urine or breath samples that document continued abstinence. Provision of a sample that shows recent drug use does not earn a voucher for a participant and sets the value of the next voucher back to the initial value. Voucher values vary among studies, but the maximum that can be earned has ranged from about \$200 to about \$1,300 over a four-month period.

A recent trial, undertaken by researchers at the University of California, Los Angeles reported on outcomes of 162 methamphetamine-dependent gay and bisexual men who were randomly assigned to one of four 16-week behavioral drug abuse treatments: Matrix Model (40 participants), contingency management (42 participants), combined Matrix and contingency management (40 participants), and a version of the Matrix Model culturally tailored to gay issues (40 participants).6 Researchers observed outcomes including methamphetamine use, as measured by urine testing, and self-reported sexual risk behaviors. Sixty percent of study participants

were HIV-positive.

The study found statistically significant differences in retention and in the longest period of consecutive urine samples negative for methamphetamine metabolites in the contingency management and the Matrix plus contingency management conditions versus either of the other conditions that used the Matrix Model alone. The gaytailored version of the Matrix Model also significantly reduced unprotected receptive anal intercourse during treatment when compared to the basic Matrix Model. At one-year follow-up, however, reductions

from baseline in drug use and sexual risk behaviors were maintained similarly across all four groups.

#### Conclusion

The combination of contingency management and cognitive-behavioral treatment constitutes a particularly powerful in-treatment and post-treatment approach. Contingency management appears to be an effective method for initiating abstinence, and the structure of reimbursements for drug-free urine samples is designed to reward sustained abstinence. This is important because individuals with periods of sustained abstinence while in drug treatment may benefit more from treatment than participants who have shorter in-treatment abstinence periods.

Cognitive-behavioral treatment offers training to develop coping skills related to maintaining abstinence after treatment. It gives clients the opportunity to process and learn from relapse, plan for high-risk substance-related and HIV-related situations, and learn new interpersonal skills.

The establishment of abstinence is vital not only because it improves treatment outcomes, but also because it allows for the natural recovery of normal cognitive function in methamphetamine users. While methamphetamine addiction may lead to long-term problems that extend into abstinence, many of these cognitive and psychological problems may resolve within a year if abstinence is maintained.

The rise in methamphetamine use throughout the United States underscores the need for enhanced public education, increased law enforcement efforts to disrupt methamphetamine manufacture and trafficking, the development of evidenced-based treatment resources, and continuing work to evaluate medications to address methamphetamine-related craving, withdrawal, and cognitive deficits.

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Steven Shoptaw, PhD is an Associate Research Psychologist at UCLA Integrated Substance Abuse Programs and a Principal Investigator with Friends Research Institute, Inc. Dr. Shoptaw also is Director of the Intervention Core of the UCLA Center for HIV Identification, Prevention, and Treatment Services and Executive Director for Safe House, a residential facility for people with HIV who have cooccurring mental illness or chemical dependency.

#### Comments and Submissions

We invite readers to send letters responding to articles published in *FOCUS* or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals. Send correspondence to rmarks@itsa.ucsf.edu or to Editor, *FOCUS*, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884.

#### **Recent Reports**

Substance Use and Sexual Behavior Colfax G, Coates TJ, Husnik MJ, et al. Longitudinal

patterns of methamphetamine, popper (amyl nitrite), and cocaine use and high-risk sexual behavior among a cohort of San Francisco men who have sex with men. *Journal of Urban Health*. 2005; 82 (1, Suppl. 1): i62–i70. (San Francisco Department of Public Health; University of California, Los Angeles; and University of California, San Francisco.)

A large San Francisco study of HIV-negative men who have sex with men found that episodic use of methamphetamine, poppers, or sniffed cocaine—even intermittent use—was associated with unprotected anal intercourse with serodiscordant partners.

Between January 1999 and February 2001, researchers recruited HIV-negative men who had engaged in any anal sex—protected or unprotected—with one or more men in the prior year. Men were excluded from the sample if they had been in a monogamous rela-

tionship for two or more years with an HIV-negative male partner. Of the 736 men, 69 percent were White, 7 percent were African American, and 16 percent were Latino. Fortytwo percent of the men were between the ages of 26 and 35, and 31 percent were between the ages of 36 and 45. Researchers collected at baseline and at six-month follow-up intervals (for a total of four vears) data on alcohol and drug use, sexual behaviors, and depression symptoms.

Latino men were significantly less likely than White men to use methamphetamine, poppers, or sniffed cocaine. Men who were 25

years or younger were more likely than men who were 45 years or older to increase their drug use from one visit to the next.

At a mimimum of one follow-up session, 52 percent of participants reported engaging in unprotected anal sex with a partner who was HIV-positive or whose status was unknown. Compared to other participants, those who had serodiscordant unprotected sex had lower levels of formal education, and were more likely to be depressed, to report multiple sex partners, and to report use of methamphetamine, poppers, or sniffed cocaine.

After the data were controlled for current depression levels, participants were significantly more likely to report serodiscordant unprotected sex during the six-month periods characterized by higher levels of drug use. However, above a certain level of use, there was no statistical difference in behavior, suggesting that "no level of use of these drugs should be considered 'safe."

Methamphetamine Use among Gay Men Halkitis PN, Green KA, and Mourgues P. Longitudinal investigation of methamphetamine use among gay and bisexual men in New York City: Findings from Project BUMPS. *Journal of Urban Health*. 2005; 82(1 Suppl. 1): i18–i25. (New York University.)

HIV-positive men differ from HIV-negative men in both the contexts of, and reasons for, methamphetamine use, according to a longitudinal study of gay and bisexual club-drug users.

Researchers analyzed data from the Boys Using Multiple Party Substances (BUMPS) study, a longitudinal investigation of 450 club-drug-using gay and bisexual men recruited in New York City between February 2001 and October 2002. Participants had to self-identify as gay or bisexual and report that they had used club drugs—any combination of GHB, ketamine, MDMA, methamphetamine, and powdered cocaine—six times in the prior year.

The sample included 293 methamphetamine users and 157 non-users. The average age of methamphetamine users was 33. The sample was 51 percent White, 20 percent Latino, 15 percent African American, and 5 percent Asian-Pacific Islander.

African American men were less likely than White men, Latino men, and Asian-Pacific Islander men to report methamphetamine use. At both baseline and 12-month follow-up, significantly more HIV-positive than HIV-negative men had used methamphetamine at sex clubs and sex parties. HIV-positive men were also more likely than HIV-negative men to report using methamphetamine to deal with social pressures, to avoid conflict with others, and to avoid unpleasant emotions.

Stimulant Use Among Gay Latino Men Diaz RM, Heckert AL, and Sanchez J. Reasons for stimulant use among Latino gay men in San Francisco: A comparison between methamphetamine and cocaine users. *Journal of Urban Health*. 2005; 82 (1 Suppl. 1): i71–i78. (San Francisco State University.)

A San Francisco study of gay Latino men found that those who used methamphetamine were more likely than those who used cocaine to be HIV-positive, unemployed, and highly acculturated to U.S. society.

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Researchers recruited a random sample of 300 men entering bars, sex clubs, and public sex environments, and participating in Internet chat rooms and phone sex services. Subjects had to have reported stimulant use in the prior six months. Acculturation was based on reports of frequency of use of the Spanish language among friends.

The average age was 30, and 90 percent of the sample were between the ages of 18 and 39. Participants were classified as methamphetamine users (52 percent), cocaine users (43 percent), or crack users (5 percent) based on the stimulant they reported most frequently using. Twenty-seven percent of methamphetamine users were HIV-positive, compared to 12 percent of cocaine users.

Methamphetamine users were more likely to report reasons for use related to sexual enhancement. Cocaine users were more likely to report reasons related to social connections. Among both groups, however, the most frequently reported reason for stimulant use was energy increase.

#### Neuropsychological Impairment

Rippeth JD, Heaton RK, Carey CL, et al. Methamphetamine dependence increases risk of neuropsychological impairment in HIV infected persons. *Journal of the International Neuropsychological Society*. 2004; 10(1): 1–14. (University of California, San Diego; San Diego State University; and Veterans Affairs San Diego Healthcare System.)

A cross-sectional San Diego study found that the combination of HIV infection and methamphetamine dependence was associated with neuropsychological impairment.

Researchers split the sample of 200 participants into four groups: HIV-positive and methamphetamine dependent (22 percent); HIV-negative and methamphetamine dependent (24 percent); HIV-positive and methamphetamine nondependent (25 percent); and HIV-negative and methamphetamine nondependent (30 percent). The sample was 73 percent male, and the average age was 37. Sixty-eight percent of subjects were White, 12 percent were African American, and 17 percent were Latino.

Participants received a neuropsychological assessment, physical and neurological exams, a psychiatric and substance use interview, and a medical history. The neuropsychological evaluation assessed seven cognitive domains: speed of information processing; learning; recall; abstraction/executive functioning; verbal fluency; attention/working memory; and motor skills.

A "global deficit score" for each patient reflected an objective summary score of neuropsychological impairment. The three

groups that were HIV-positive, methamphetamine dependent, or both had significantly higher global deficit scores than the group of participants who were HIV-negative and methamphetamine nondependent.

Further, the HIV-positive and methamphetamine dependent group had significantly higher global deficit scores than the two groups with only one of the risk factors. When compared to the other three groups, the HIV-positive and methamphetamine dependent group had scores indicating greater problem severity in the learning, recall, and motor skills domains. Finally, the three groups with at least one risk factor had significantly higher depressive symptom scores than the HIV-negative and methamphetamine nondependent group.

Amphetamine Use and Seroconversion Buchacz K, McFarland W, Kellogg TA, et al. Amphetamine use is associated with increased HIV incidence among men who have sex with men (MSM) in San Francisco. AIDS. In press. (U.S. Centers for Disease Control and Prevention; San Francisco Department of Public Health; and University of California, San Francisco.)

HIV incidence among amphetamine users was significantly higher than among non-users, according to a study of almost 3,000 men who have sex with men testing at anonymous HIV test sites in San Francisco.

HIV incidence among users was 2.1 percent among non-users, 6.3 percent among amphetamine users, and 7.7 percent among people who had sex while using amphetamines. After controlling for other substance use, age, and ethnicity, the association weakened but the difference remained statistically significant.

#### Next Issue

HIV prevention test counseling is a hybrid of many approaches that has evolved over 20 years. In the August issue of *FOCUS*, **Jaklyn Brookman**, **MFT**, a consultant to government and non-profit agencies and long-time HIV test counselor trainer, confronts some of the current challenges in counseling technique as she explores the art of risk reduction counseling.

Also in August, **David Huebner**, **PhD**, **MPH**, an Assistant Professor of Medicine at the UCSF Center for AIDS Prevention Studies, reviews the recent data on the effect of treatment optimism on motivations to engage in HIV risk reduction.

# MIND-BODY MEDICINE AND HIV/AIDS

by Jeffrey Leiphart, Ph.D.

MIND-BODY MEDICINE IS A NEW WAY OF UNDER-STANDING HEALTH AND DISEASE WHICH RECOGNIZES THAT EMOTIONAL AND PSYCHOLOGICAL ISSUES INFLUENCE WHETHER WE ARE SICK OR HEALTHY.

Mind-body research has shown that our emotions, beliefs, relationships with others and behavior habits can influence our immune system, making it stronger or weaker, and thus move us towards sickness or health. For example, we now know that severe stress and continued grief and depression can weaken the immune system, and that the support of friends, being self-assertive and physical exercise all contribute to strong immunity and health.

Researchers in mind-body medicine have studied how the mind-body connection works in HIV/AIDS since the mid-1980s. They have looked at why some people get sick and die from HIV, while others remain free of symptoms and healthy. Here are some specifics, based on medical research:

- (1) Believing that you must die from being HIV-infected can trigger fear, decreases in immunity, avoidance of health-promoting behavior and ultimately result in a shorter lifespan.
- (2) Stress: being stuck in "survival stress" for many months where you feel somehow unsafe or threatened can wear down immune system functioning and speed up the progression to developing AIDS.
- (3) GRIEF: feeling grief is normal after a significant loss of an important person, pet or cherished goal. If that grief is "held in" and not expressed for many months, it can trigger a decrease in immunity and speed up the progression of disease.
- (4) Self-disclosure to Trusted Support: science has learned that talking about your problems honestly with someone you trust provides a boost to immune system functioning.
- (5) LIFE PURPOSE AND GOALS: research studies on HIV+ people who remain healthy for long periods show that these HIV+ folks typically have "reasons to live," whether they are general purposes ("I want to enjoy my friends and family") or specific goals ("I want to take a cooking class next month"). It appears that "reasons for living" provide a boost to the immune system and survival.
- (6) Self-assertiveness is defined as the ability to say "no" to something you really do not want to do, and "yes" to something that you want or like. Medical research shows that being self-assertive promotes the strength and quantity of Natural Killer (NK) cells of the immune system. This is important because NK cells can kill HIV in the body and can do so in people with very low CD4 counts.

I am healthy.
I have a future.



(7) Body Care is defined as making sure that you are doing the right things on a regular basis to keep your body healthy. This includes being aware of your breathing patterns and correcting any problems (like shallow breathing or unconscious breathholding). You should be drinking a minimum of eight glasses of water every day and having good nutrition and eating patterns so that all of your body, including immune cells, gets the nutrition it needs. Getting regular sleep that allows you to wake up "feeling rested" most mornings is also important. Finally, you should be getting regular (3 times per week), moderate physical exercise. An example of moderate exercise is a 20-minute brisk walk that gets you to breath a little harder and perhaps some sweat on the forehead. Remember Natural Killer (NK) immune cells from above? Exercise also promotes the strength and quantity of these HIV-fighting NK cells.

How can you use this new information about the mind-body connection to enhance your HIV+ health? For each of the issues mentioned above, rate yourself on how well you are doing: good, OK or poor. Then, make a list of the issues rated "poor" and pick someone to talk honestly with about each problematic issue. You may want to pick different people for different issues. After the discussion, create a plan for improvement for each "poor" issue and begin working on your plan.

For more information on this topic, please check out the L.I.F.E. Program website at www.Shanti.org.

Jeffrey M. Leiphart, Ph.D. is a health psychologist and Director of the L.I.F.E. Institute at Shanti in San Francisco.

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#### Questions to ask your doctor when starting a new medication?

#### Starting a new medication? Here are a few questions to ask your doctor:

- ✓ What are the possible side effects of the drug?
- ✓ Which side effects am I most likely to experience?
- ✓ When will the side effects start?
- ✓ How long will they last?
- ✓ What should I do if I have a side effect?
- ✓ Can I do anything to prevent certain side effects from happening?
- ✓ Are there any dangerous side effects I should know about: If so, what should I do if I start having them?

There are also some questions you might want to ask yourself. Figuring out answers to these questions can help you and your doctor determine which medication is right for you.

- ✓ Which side effects do I have the hardest time dealing with? For example, some people have an easier time dealing with nausea than diarrhea.
- ✓ Am I willing to take other drugs or complementary therapies to help control the side effects?
- ✓ Do I have family or friends I can call on if my side effects are bad?
- ✓ How long am I willing to put up with a particular side effect?

Adherence: Barriers and Strategies

# Taking Our HIV medicines: How's it going?

HIV medicines can help save your life, but they also can be hard to take. These questions can help you work with your healthcare provider if you are having a hard time taking your medicines as should. There

make your HIV treatment easier.

If you miss a dose, is it in the morning, evening, or middle of the day?    Morning	Very easy	Easy N	ot too bad	Sometimes diff	icult I	Diff
Morning						
Do you ever go a day without taking your HIV medicines?    Yes; why?		-		•	skip doses	
Do you ever have any of these possible side effects?    How many times a month?	Do you ever skip a dose	because the medicines	make you feel ba	d? □Yes	□No	
Do you ever have any of these possible side effects?    How many times a month?	Do you ever go a day w	ithout taking your HIV m	nedicines?			
Side effect  How many times a month?  How long have you had this side effect?  Feeling sick to my stomach  Vomiting  Diarrhea  Headache Feeling tired  Rash Shortness of breath Trouble sleeping  Change in skin color  Bad dreams Nervousness  Has your energy changed since you started taking your current HIV medicines?  Mark an X on the line below.  Less energy  Same energy  More en  Are you concerned that the HIV medicines you are taking now might cause either of these side effect  Meight loss in the arms, legs, buttocks, or face  Meight gain in the upper back and neck, breast, or trunk  Mould you be interested in talking to your healthcare provider about whether a change to your					□No	
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## **VIRAL LOAD TESTS**

#### HAT IS VIRAL LOAD?

The viral load test measures the amount of HIV virus in your blood. There are different techniques for doing this:

- (polymerase The PCR reaction) method uses an enzyme to multiply the HIV in the blood sample. Then a chemical reaction marks the virus. The markers are measured and used to calculate the amount of virus. Roche and Abbott produce this type of test.
- The bDNA (branched DNA) method combines a material that gives off light with the sample. This material connects with the HIV particles. The amount of light is measured and converted to a viral count. Bayer produces this test.
- The NASBA (nucleic acid sequence based amplification) method amplifies viral proteins to derive a count. It is manufactured by bioMerieux.

Different test methods often give different results for the same sample. Because the tests are different, you should stick with the same kind of test to measure your al load over time.

viral loads are usually reported as copies of HIV in one milliliter of blood. The tests count up to about 1 million copies, and are always being improved to be more sensitive. The first bDNA test measured down to 10,000 copies. The second generation could detect as few as 500 copies. Now there are ultra sensitive tests for research that can detect less than 5 copies.

The best viral load test result is "undetectable." This does not mean that there is no virus in your blood; it just means that there is not enough for the test to find and count. With the first viral load tests, "undetectable" meant up to 9,999 copies! "Undetectable" depends on the sensitivity of the test used on your blood sample.

The first viral load tests all used frozen blood samples. Good results have been obtained using dried samples. This will reduce costs for freezers and shipping.

#### HOW IS THE TEST USED?

The viral load test is helpful in several areas:

- For medical researchers, the test proved that HIV is never "latent" but is always multiplying. Many people with no symptoms of AIDS and high CD4 cell counts also had high viral loads. If the virus was latent, the test wouldn't have found any HIV in the blood.
- The test can be used for diagnosis. because it can detect a viral load a few days after HIV infection. This is better than the standard HIV (antibody) test, which can be "negative" for 2 to 6 months after HIV infection. (See Fact Sheet 102 for more information on HIV antibody testing.)
- For prognosis, viral load can help predict how long someone will stay healthy. The higher the viral load, the faster HIV disease progresses.
- For prevention, viral load predicts how easy it is to transmit HIV to someone else. The higher the viral load, the higher the risk of transmitting HIV.

Finally, the viral load test is valuable for managing therapy, to see if antiretroviral drugs are controlling the virus. Current guidelines (see Fact Sheet 404) suggest measuring baseline (pre-treatment) viral load. A drug is "working" if it lowers viral load by at least 90% within 8 weeks. The viral load should continue to drop to less than 50 copies within 6 months. The viral load should be measured within 2 to 8 weeks after treatment is started or changed, and every 3 to 4 months after

#### HOW ARE CHANGES IN VIRAL LOAD MEASURED?

Repeated tests of the same blood sample can give results that vary by a factor of 3. This means that a meaningful change would be a drop to less than 1/3 or an increase to more than 3 times the previous test result. For example, a change from 200,000 to 600,000 is within the normal variability of the test. A drop from 50,000 to 10,000 would be significant. The most important change is to reach an undetectable viral load.

Viral load changes are often described as "log" changes. This refers to scientific notation, which uses powers of 10. For example, a 2-log drop is a drop of 102 or 100 times. A drop from 60,000 to 600 would be a 2-log drop.

#### VIRAL LOAD "BLIPS"

Recently, researchers have noticed that the viral load of many patients sometimes went from undetectable to a low level (usually less than 500) and then returned to undetectable. Careful study suggests that these "blips" do not indicate that the virus is developing resistance.

#### WHAT DO THE NUMBERS MEAN?

There are no "magic" numbers for viral loads. We don't know how long you'll stay healthy with any particular viral load. All we know so far is that lower is better and seems to mean a longer, healthier life.

US treatment guidelines suggest that anyone with a viral load over 100,000 should be offered treatment.

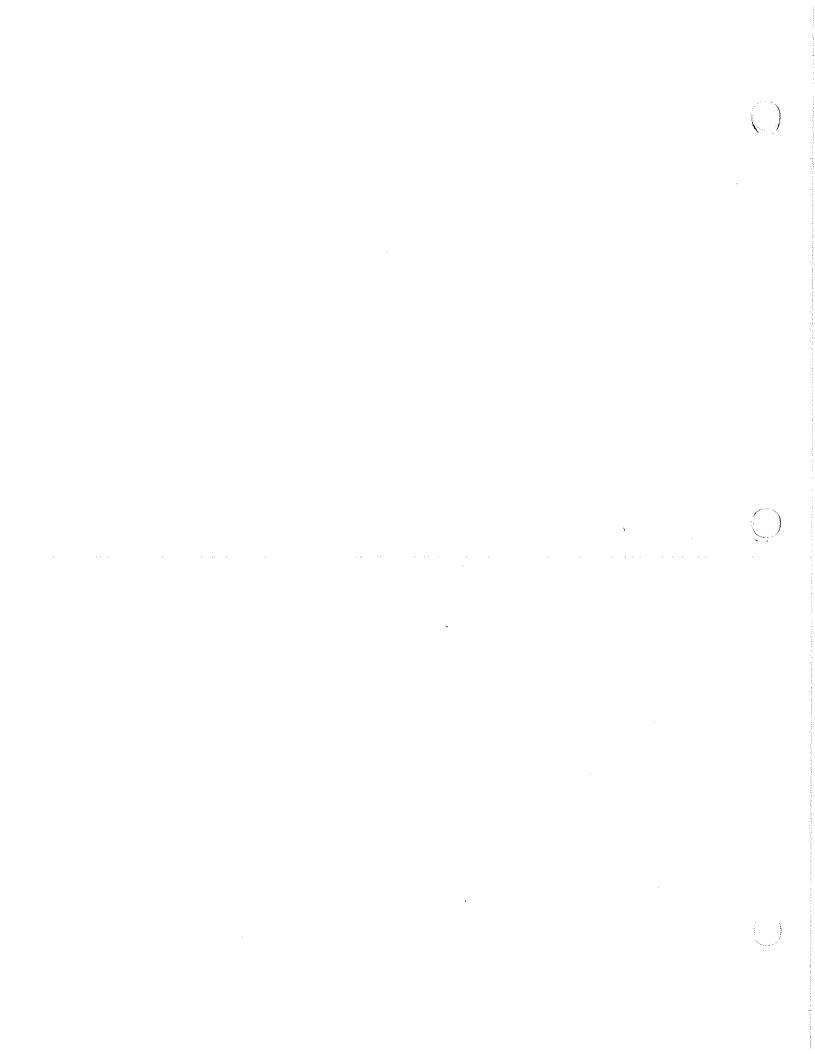
Some people may think that if their viral load is undetectable, they can't pass the HIV virus to another person. This is not true. There is no "safe" level of viral load. Although the risk is less, you can pass HIV to another person even if vour viral load is undetectable.

#### ARE THERE PROBLEMS WITH THE VIRAL LOAD TEST?

There are some concerns with the viral load test:

- Only about 2% of the HIV in your body is in the blood. The viral load test does not measure how much HIV is in body tissues like the lymph nodes. spleen, or brain. HIV levels in lymph tissue and semen go down when blood levels go down, but not at the same time or the same rate.
- The viral load test results can be thrown off if your body is fighting an infection, or if you have just received an immunization (like a flu shot). You should not have blood taken for a viral load test within four weeks of any infection or immunization.

Revised September 5, 2006





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**WOMEN ALIVE** 

Ask the Experts

#### What Are HIV-Positive Persons' HIV **Prevention Needs?**

By Unknown

Spring 2003

#### Why Prevention for HIV-Positive Persons?

Every new HIV infection involves an HIV-positive person. The Centers for Disease Control and Prevention (CDC) estimate that there are 600,000-900,000 people living with HIV in the U.S. Yet very few prevention interventions have been directed to HIV-positive women and men. People who are HIV positive deserve to have interventions to help them stay safe and play an active role in stopping the epidemic.

In the past few years, advances in the treatment and care of HIV-positive persons have helped many people enjoy increased health and longer life. For many, this allows for a renewed interest in sexual and for some, drug using activity. More sexually active and drug using HIV-positive persons means the possibility of more new infections.

#### Why Haven't We Done More of This?

In the past, prevention efforts had not been directed toward HIV-positive persons for fear of "pointing the finger" or blaming HIV-positive persons for the epidemic. Although AIDS has become less stigmatized in the U.S., in some communities there is still serious stigma experienced by HIV-positive persons. AIDS activists and HIV-positive persons have also feared laws criminalizing sexual risk behaviors and further prosecution of injection drug users (IDUs).

Prevention efforts for HIV-positive persons have focused on protecting one's own health from the possibility of reinfection with untreatable strains of HIV. Few efforts have addressed altruis -- the responsibility of HIV-positive persons to not transmit the virus to others and the opportunity for HIV-positive persons to actively contribute to ending the epidemic. Prevention efforts need to address both issues: taking responsibility for one's own health and the health of one's partners, children, other family members and community.

ARTICLE TOOLBOX

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#### Why Would Someone Infect Another?

Most HIV-positive persons are concerned about not infecting others and have made efforts to prevent transmission. Yet there has not been much support for HIV-positive persons to gain the necessary skills and tools to adopt new, safer behaviors. Couples where one partner is HIV positive and the other is HIV negative often wrestle with issues such as how to maintain sexual satisfaction and trust. For some couples, the risk of losing commitment and intimacy in a relationship is more threatening than the risk of transmitting HIV.

A precondition of reducing your risk is knowing you're HIV positive and getting help. There are an estimated 200,000-250,000 Americans unaware that they are infected with HIV. It is imperative to help HIV-positive persons get tested before they unknowingly infect others. Finding out HIV status can also allow early access to life-prolonging treatment and services.

#### Disclosure

Incorrect assumptions and denial of responsibility between partners can lead to risky behavior. Many HIV negative persons are unaware of their partners' status or risk behaviors and may make assumptions that they are not at risk for HIV because they are married, in a relationship, their partner looks healthy, or simply because their partner did not ask to use a condom. HIV-positive persons may make the same assumptions that their partner is also HIV positive because the partner didn't ask about serostatus or suggest using condoms. Likewise, there may be a difference of opinion on who's responsible for keeping safe, the HIV positive person, the HIV negative person, or both.

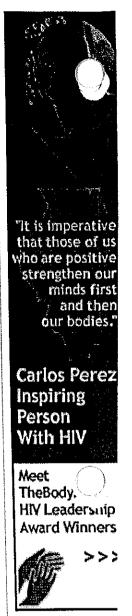
Disclosure can be a way of beginning a discussion about safer sex or drug use. Yet disclosure of one's serostatus is difficult for many HIV-positive persons, especially women, who may fear stigma, rejection or violence from their partners.

Practicing safer sex with all partners and always using clean needles is one way of preventing transmission without having to disclose status. However, in many communities where this is not the norm, simply using a condom can disclose HIV-positive status, even without saying it.

HIV is a disease that is often mistakenly associated with careless sexual behavior. However, many HIV-positive persons become infected within a loving relationship. In one study of HIV-positive men and women, 41% reported becoming infected by a spouse, significant other, or long-standing friend. Research has shown that people are often more comfortable disclosing and practicing safer sex with partners outside of their main relationship.

#### What Are Barriers to Prevention?

Often, the same factors that led someone to become infected are also barriers to preventing transmission. Many HIV-positive persons face complex issues that can affect their ability to engage in safer sex or drug-using behaviors. Depression, substance use and abuse, history of violence and abuse and sexual compulsivity are all issues that may need to be addressed. Many of these issues cannot be addressed in a prevention program and may require referral to longer-term counseling or other social services.



Legal, political, and environmental factors can be barriers to HIV prevention among HIV-positive persons. For example, the lack of access to sterile syringes and needle exchange programs, as well as laws prohibiting possession of syringes, hamper the ability of IDUs to engage in safe behaviors. Fear of arrest for carrying drug paraphernalia has been associated with sharing syringes and other injection supplies.

#### What's Being Done?

In 1998, the CDC funded five Health Departments to create demonstration projects providing primary HIV prevention for HIV-positive individuals. California, Los Angeles, San Francisco, Maryland, and Wisconsin have begun a variety of programs that address a wide audience including: HIV-positive women, men of color who have sex with men, IDUs, youth, female sex and needle sharing partners of IDUs, and incarcerated men and women.

Interventions include: HIV, STD and TB counseling, testing and treatment; referral and linkage to care; prevention case management; HIV-positive peer "buddies"; outreach via social networks; mass media and internet marketing; partner counseling and referral services; skills building; and community level forums and social events.

#### Campaign

AIDS Action Committee in Boston, MA, created an ad campaign that targets HIV-positive gay men with messages aimed at opening discussion about transmission and promoting responsibility. Posters with messages such as "Ask. Tell." "Let's stop new infections now." and "If you're positive, think about transmission." were placed over urinals in gay bars and sex clubs. A survey of men leaving the bathrooms found that 70% could recall two or more of the messages.

#### Couples

Couples counseling for sero-discordant couples (where one partner is HIV positive, the other HIV negative) has proven highly effective at reducing new HIV infections. One program for heterosexual women and men provided couples counseling in combination with social support. As a result, condom use increased and no new HIV infections were reported among the couples. Couples counseling can help ease communication and provide support for both the HIV-positive and HIV-negative partner in straight and gay/lesbian relationships.

#### What Needs to Be Done?

HIV-positive persons are a unique population in that they require both care and prevention, which requires better coordination between these two worlds.

 Health care providers need to be trained to deliver HIV prevention, as seroconversion can provide a strong motivation to change risky behaviors.

- HIV prevention programs need to address HIV-positive persons and include STD, hepatitis and TB screening and treatment as well as referrals to drug treatment, family planning and mental health services.
- HIV-positive persons' partners, children and families must be included with support and education.
- We need more effective HIV testing and counseling strategies.

#### Don't Know

There is currently an unacceptably high number of persons who do not know they are HIV positive unknowingly infecting others. The social network approach (encouraging HIV-positive persons to provide information and outreach to peers who might be positive) is one way to create a more efficient and targeted approach to HIV testing and counseling for those at greatest risk.

There are many things we don't know about the relationship between new anti-HIV drugs and HIV transmission. How much do they affect a person's infectiousness and how does that affect transmission? Is reinfection or super-infection a valid concern? These questions need to be researched, and the answers disseminated widely so that HIV-positive persons can make informed decisions about preventing transmission of the virus.

If you have tested HIV positive, reach out and get some help. If you don't know your HIV status, take the test -- it's free and confidential.

If you need a prevention for positives program to help you reduce your chances of transmitting virus to others, please call the Women Alive Coalition at 323.965.1564. Ask for Gina!

Back to the Women Alive Spring 2003 contents page.

This article is a part of the publication Women Alive Newsletter.

Our thanks to Women Alive, which provided this article to The Body.

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#### What's PK got to do with it?

#### The main ways the human body handles drugs are:

Step 1. Drug absorption:	This is how the drug enters the blood – usually from tablets or capsules in the stomach and intestines. This is where "food requirements" come in or why some drugs have warnings not to take antacids along with the drugs.
Step 2. Drug distribution:	This is how the drug travels in the blood-stream and how it goes into and comes out of other areas of the body. Did you know that some areas of the body, like the brain and reproductive organs, are specifically protected from chemicals? It is hard to measure drug levels in those areas.
Step 3. Drug metabolism:	This is how the body chemically changes a drug — usually in the intestines and liver. Metabolism involves breaking a drug down or adding a chemical that makes it easier to pass it into urine or stool.
Step 1. Drug elimination:	This is how the body gets the drug out — usually by passing the drug into the urine (via the kidneys) or stool (via the liver). Sometimes people have kidney or liver illness. In these people blood level of some drugs may build to very high levels if the drug dose is not reduced.

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#### WOMEN AND HIV/AIDS IN THE UNITED STATES

Women continue to account for a growing proportion of reported U.S. AIDS cases, an extraordinarily high number of which are among racial and ethnic minorities. In addition to facing the challenges of living with HIV disease and adhering to treatment, women living with HIV often are primary caregivers for children and aging parents.

#### SURVEILLANCE

- Of the 42,514 estimated new AIDS cases in 2004, 26.9 percent were among women, up from 26.4 percent in 2000.<sup>1</sup> The estimated number of AIDS diagnoses among women increased 9.9 percent from 2000 through 2004, compared with a 7.1 percent increase among men.<sup>2</sup>
- Black women accounted for the highest proportion of estimated female AIDS cases in 2004 (64.0 percent); Hispanic and White women accounted for 17.6 percent and 16.6 percent, respectively.<sup>3</sup>
- One in 4 reported AIDS cases among women are among those age 29 and younger; in contrast, 1 in 6 cases among men are in that age range. The difference can be explained, in part, by the fact that reproductive health needs bring young women into contact with health care providers; young women thus have more opportunities for HIV testing and detection. Sexual relationships between older men and younger women dramatically increase the risk of exposure to HIV and other sexually transmitted infections (STIs).
- Estimated AIDS mortality from 2000 to 2004 decreased by 10.3 percent for men but remained the same for women.<sup>4</sup>
- The primary exposure category for women living with AIDS in 2004 was heterosexual contact, which accounted for 63.7 percent of cases.
   The proportion of cases attributable to heterosexual contact increased by 52.3 percent from 2000 to 2004.<sup>5</sup>

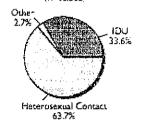
#### **CRITICAL ISSUES**

Women with HIV/AIDS have a harder time accessing treatment and health care than men do. According to one study, however, more men (24 percent) than women (19 percent) consider HIV/AIDS the most urgent national problem.<sup>6</sup>

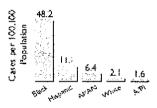
Minority women are particularly vulnerable to HIV infection: A study of 13,998 adolescents reported that Black adolescent girls are at greater risk (1 in 5) for STIs than White adolescent girls (1 in 10).7 Minority women in particular lack access to preventive health care services. In addition, they underestimate

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Estanated Number of Women Living With AIDS, by Exposure Category, 20041 (N=93,565)

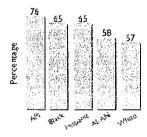


Estimated Number of Female AIDS Cases, by Race/Edinacity, 2004;2



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Women Living With AIDS Identifying Heterosexual Contact as Exposure Category, by Race/Eshnicisy, 2004<sup>17</sup>



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- 2 CDC, HIV/AIDS Surveillance Report. 2004;16(1):12. Table 3.

their risk of STIs by overestimating how safe their partners are. 7.

Women with HIV/AIDS report barriers to care when seeking HIV/AIDS services. Those barriers include provider insensitivity and health care workers' lack of knowledge.<sup>6</sup>

In addition, male-to-female transmission of HIV is between 2 and 4 times more efficient than female-to-male transmission. Women are especially vulnerable to HIV disease in relationships in which HIV status is not discussed and prevention methods are not incorporated. Beliefs about gender roles, knowledge of sex and sexuality, level of education, and employment all play important roles in determining risk factors and risky behavior. 9

Most women who are HIV positive live in poverty and were already poor when they learned their serostatus. <sup>10,11</sup> The socioeconomic status of women negatively influences access to health care. When women face unmet subsistence needs (e.g., for housing, food, and child care), they have little time or resources to devote to their own health. The impact on their lives and on the lives of their children—and on older adults who may be in their care—can be catastrophic.

#### WOMEN AND THE RYAN WHITE CARE ACT

Women accounted for 31.3 percent of clients receiving services funded by the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. All CARE Act programs serve HIV-positive women, and the legislation mandates that women be served in proportion to their representation in the epidemic. In addition, the CARE Act Title IV program funds grants specifically targeting women, infants, children, youth, and families.

The Health Resources and Services Administration (HRSA) has published *A Guide to the Clinical Care of Women With HIV*, the first text providing comprehensive information about the clinical care of women living with HIV disease. Free copies are available at 888-ASK-HRSA.

The experience of CARE Act providers is that comprehensive and coordinated care—medical treatment, case management, support services, and care for the entire family—is crucial if HIV-positive women and their families are to remain in care over time. Comprehensive care for pregnant women has been shown to be equally critical in reducing perinatal transmission rates, which at some Title IV sites is now zero.

For more information about HIV/AIDS and women, see the December 2004 issue of *HRSA CAREAction*, available at <a href="www.hab.hrsa.gov/publications">www.hab.hrsa.gov/publications</a>.

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U.S. Department of Health and Human Services - Health Resources and Services Administration - HIV/AIDS Bureau 5600 Fishers Lane - Room 7-05 - Rockville, MD 20857 - 301-443-1993 - www.hab.hrsa.gov

#### **Working With Healthcare Providers**

Winter 2004/2005

The following is adapted from the curriculum that ACRIA uses in workshops to discuss the often complicated is between individuals and their healthcare providers:

#### So -- What's the First Step?

• Get involved with your care!

#### **Educate Yourself**

- It's pretty easy to find information about HIV and basic treatment options:
  - · Through treatment newsletters.
  - Through the Internet. Learn how to use the Internet and find places where you can go online -service organization, the library, etc. (See the Spring 2004 issue of ACRIA Update for a list of or
    newsletters, and websites that provide HIV treatment information -- it's available online at www
- In today's world of healthcare cuts and managed care, doctors rarely have the time to properly educatpatients on the complexities of combination therapy.
- Do your homework -- know as much as you can about HIV and your treatment options.
- Get subscriptions to treatment magazines and newsletters -- most are free!
- Go to your local AIDS service organization and talk to the treatment specialist or enroll in a treatment program.
- Talk to other HIV-positive people who are experiencing some of the same things that you are.

#### Considerations When Choosing a Doctor or Other Healthcare Provider

#### Qualifications:

- Clinic providers are often infectious disease (ID) or internal medicine doctors.
- Does the provider have at least two years of HIV experience?
- Does the provider see many HIV patients?
- Do they keep up to date? Do they read journals, attend conferences and seminars, and participate in o HIV-specific medical education?
- Nurse Practitioners (NPs) and Physician Assistants (PAs) who are specifically trained in HIV care are als choices for care.

Location: How far do you have to travel? You may not have a choice.

Personality: Sensitivity to your particular issues -- drug use, gender, sexual orientation, religious or spiritua

Relationship: What kind of relationship do you want to have with your healthcare provider? There are variou

- The provider is in control. He or she tells you what to do, and you follow orders. You rely on him or what is best for you.
- A collaborative effort. The two of you make decisions, and you are partly responsible for your care.
- You make all the decisions. The healthcare provider is more of a consultant. In this case, you have

educated on what treatments are available and how to use them.

Word of mouth: Ask other people who their healthcare provider is and how they like the service they get.

Finding the right setting: Depending on your circumstances (Medicaid, private insurance, uninsured), you i different choices regarding where you can get your care -- a private physician, a private clinic, or a public clir

- If you'll be going to a clinic, make sure that you'll be able to see the same provider each time you go.
- Continuity of care is important. You don't want to have to start from scratch with a different provider e and you shouldn't have to.

#### Making, Keeping, and Preparing for Appointments

- If you receive your healthcare at a clinic, make sure that your provider will be there to see you on the appointment.
- Office visits are usually short -- maybe a half-hour or only 15 minutes. Make it count! The first visit shollonger -- 45 minutes to one hour.

#### It's Your First Visit - Bring Your Medical History

- If you can get your records from your previous provider, it makes things easier.
- You have a legal right to copies of all your medical records.
- Keep a copy of all of your records.

#### Take Some Time Before Seeing the Provider

- Make a list of everything you'd like to ask about. This way, you won't forget the important things or the
  that have been bugging you.
- Check the list with a friend before you go to make sure that your questions are clear.
- You probably won't get the chance to ask everything, but think of it as a wish list.
- Check off five things that you really want to ask about, so that you're sure to get to them. Things like:
  - New symptoms or recent illness you may have had.
  - Medications, natural, over-the-counter remedies, or vitamins you're taking.
  - Lifestyle changes, like changes in your diet, your living arrangements, your job, or your activity
  - Let your provider know about any emergency room visits.
  - Questions you have about your medications or new medications you've heard about.

#### Make a Plan for Talking With Your Healthcare Provider

- For example, if you don't usually talk with your provider much, let him or her know that you want som different to happen this time.
- Start with something like: I know we haven't talked much in the past, but I really want to ask you som. I've written some things down ...

#### Don't Hesitate to Stop Your Provider the Moment You Don't Understand Something

• Lots of times, things snowball -- the provider starts saying something and you're not really sure wha

you're a nice person, so you nod, and the provider keeps talking, and suddenly you realize that you rewhat they're talking about at all.

#### Take Notes

- If you find it hard to listen or hear what your provider says (and who doesn't?), bring paper and pen to down.
- Keep notes of the important points of your visit.
- You can bring a friend or family member to help you remember what the healthcare provider said. You bring a tape recorder (although the tape recorder might make the provider nervous).
- Ask your provider to write treatments or instructions down on paper.

#### Keep Copies of Your Lab Results

- File your lab results by date.
- Pay close attention to any unusual changes in lab results.
- Discuss any changes with your healthcare provider.

#### **Ask About Your Medications**

- What is the name and the purpose of the medication?
- Will there be any interactions with any other medications you're taking?
- What is the dosage of the drug and how often should it be taken?
- Are there any dietary requirements you should know about?
- What are the possible side effects? And how can you manage them if you experience them?
- Is there written material about the drug that you can take home with you?

#### Get the Names of Other People Who Are Part of Your Medical Team

- Social workers and nurses at the clinic.
- Get to know the receptionist -- he or she can be a huge help to you in the future!

#### Waiting for the Visit

- Providers almost always run late, sometimes as much as two or three hours.
- Keeping you waiting this long isn't acceptable -- find care elsewhere (if possible).
- Clinics are sometimes the worst in terms of the amount of time spent waiting.
- Be patient, bring a magazine, maybe a treatment newsletter. If the provider is always very late, menti
  a later or earlier appointment would help.

#### Bring Information to Your Healthcare Provider About Subjects You Want to Discuss

Providers like it when you're prepared.

#### Missing an Appointment

If you miss an appointment, always call beforehand and cancel, if possible, or at least call later.

#### Communication Skills/Conflict Resolution

- Open Up: Don't feel embarrassed about bringing up sensitive health issues. If your provider makes youncomfortable when you discuss your lifestyle or a particular issue, you may need to find another provider.
- **Be Honest:** Don't be tempted to tell your providers what they want to hear -- for example, that you a medications regularly and in the correct way when you're really not.

#### Communicate Treatment Requests in a Spirit of Mutual Respect

- Some providers don't feel comfortable discussing unapproved or unfamiliar medications -- especially or therapies.
- Prepare yourself to discuss them with your provider.
- Know as much as you can about the treatments you want to talk about so that the discussion will be presented.
- Of course, your opinions may still differ.
- Remember that even if you disagree with your healthcare provider's opinion, his or her opinion may sti

#### Be Prepared for the Emotional Content of the Visit

- New health problems or a new diagnosis can be emotional.
- Getting too emotional will distract you and your provider.
- If you need more time to make a decision about something, tell the healthcare provider that you need things and will call later to make another appointment -- or schedule another appointment before you

#### Ask for Things in a Friendly but Firm Way

- If the healthcare provider disagrees with your request, ask why. There might be a good reason.
- Ask questions -- repeatedly if necessary. If things still aren't clear, ask for a simpler explanation.

#### When You Find a Healthcare Provider Who's Good, Let Him or Her Know

Like anyone else, providers like praise.

#### Tell Friends That You've Found a Good Healthcare Provider

Recommend him or her to others.

#### What to Do When Your Provider Isn't Available

- When you call the clinic or the doctor's office, your provider usually isn't there or isn't able to take you
- Depending on what you're calling about, you can often get help from the nurse, the PA, or someone elethere. That's one reason why it's a good idea to know the names of everyone on the medical team.
- If it's a serious problem and you must speak with your doctor, be clear that you'll be waiting for a retu be sure to be available at the number that you leave.

#### Healthcare Providers Are Human

- They make mistakes, too.
- When problems arise between you and your provider, discuss them politely.
- If you don't think that the provider adequately addressed or solved the problem, ask again.
- Being an aggressive, inquisitive advocate for yourself is not rude or hostile.
- Most providers can handle disagreement as long as it does not get personal.
- A good healthcare provider is one who will fight for you:
  - Try to get you access to particular medications, even if your insurance or payer doesn't cover th
  - Get you into a clinical trial if it is right for you.
  - Refer you to a specialist if the need arises.

#### Firing a Doctor or (a Better Term) Switching

- Find a new one first.
- Sometimes a relationship just doesn't work for a variety of reasons.
- Give it a lot of thought before switching.

#### **Special Issues**

- If clinic providers are always changing, ask to see the same provider each time you go.
- If the provider has moved to another location, find out where he or she is.
- Some women may want to visit a women's clinic so that they can get all their care in one place.

#### Getting a Second Opinion

- Maybe see another doctor if you aren't satisfied with your regular provider's opinion about an importan
- Seeing another doctor may be particularly helpful when you're confronting a significant decision about options.
- Think about enrolling in an information-gathering trial in which you can get free blood work.

This article evolved from a fact sheet originally created by Sally Cooper and the staff of the PWA Health Group expanded over time by ACRIA's treatment education staff with input from ACRIA's Community Advisory Board clients with whom we work.

#### Healthcare Providers Don't Receive Any More Training Than the Rest of Us in How to Be Human B

- Some are kind, some aren't so smart, some are malicious, and some are really great people.
- They may be nervous and hate that they sometimes don't really know what to do.
- They hate that they don't have a cure to offer you.
- They rarely try to cause harm.
- They're often overwhelmed, but rarely admit it. They carry their arrogance mostly to protect themselves, not
- As in any other relationship, calling them on their stuff can sometimes help communication.

- If it's not working, move on if you can!
- Never forget that the healthcare provider works for you. It's your body, your health, your blood tests, your HI
  paying the provider's rent for him or her every time you walk in the door.

#### **HIV Specialists**

Some states have specific requirements in order for a healthcare provider to be designated a specialist ir New York State, for example, providers must have the following experience and knowledge to qualify as Specialists:

- Direct care of at least 20 HIV-positive people during the past year, including managing antiretroviral therapy patients;
- Ten hours of CME (Continuing Medical Education) each year that includes information on the use of antiretrov
- The latest information about HIV disease and treatments;
- State-of-the-art diagnostic techniques, including viral load measures, resistance testing, and immune system
- Management of opportunistic infections and diseases;
- Expertise in the management of HIV-positive patients with common co-morbid conditions, including tuberculo B, hepatitis C, and syphilis;
- · Access and referral to clinical trials;
- Proper referrals to other providers for specialty care (oral, ophthalmologic, obstetrics, gynecology, dermatolog drug treatment, etc.);
- Strategies to promote treatment adherence;
- Patient education, including risk reduction/harm reduction counseling;
- Post-exposure prophylaxis protocols and infection control issues;
- An understanding of counseling for women of childbearing age, including knowledge of contraceptive methods prepare for a healthy pregnancy.

Back to the ACRIA Update Winter 2004/2005 contents page.

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Our thanks to AIDS Community Research Initiative of America, which provided this article to The Body.



#### YOUTH AND HIV/AIDS IN THE UNITED STATES

An estimated one-fourth of all HIV infections occur in people age 21 and younger—a segment of the population that is among the most medically underserved. Experts estimate that only 11 percent of HIV-positive youth in the United States receive adequate health care. Most HIV-infected youth are asymptomatic, do not know they are infected, and are not enrolled in treatment.

#### **SURVEILLANCE**

Given the power of today's treatments and the average time from HIV infection to progression to AIDS, AIDS surveillance data do not reveal the scope of the epidemic among adolescents. Available data, however, reveal past trends in the epidemic.

- Only a small proportion of estimated AIDS cases have been among people in their teens. Given the time lapse from seroconversion to progression to AIDS, it is certain that a large number of people in their 20s—and some in their 30s—became infected with HIV while in their teens.<sup>4</sup>
- In 2004, there were 2,114 estimated AIDS cases among people ages 15 to 24, an increase of 30.5 percent since 2000.<sup>5</sup>
- Approximately one-half of new HIV infections are in people under 25 years old.<sup>6</sup>
- HIV diagnoses are disproportionately higher among women and non-Hispanic Blacks. Blacks ages 13 to 24 account for 56 percent of HIV diagnoses.<sup>6</sup>
- Large proportions of young adults, particularly minorities ages 18 to 29, report that they know someone with HIV/AIDS or someone who has died from AIDS. In one national survey, 61 percent of African-Americans said they knew someone infected, compared with approximately 42 percent of Latinos and 34 percent of Whites.<sup>7</sup>

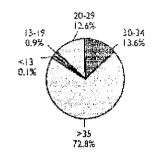
#### CRITICAL ISSUES

Although parents of youth age 21 or younger are concerned about their children becoming infected with HIV, young people ages 18 to 29 are more likely than older people to call HIV/AIDS the most urgent health problem facing the Nation.<sup>7</sup>

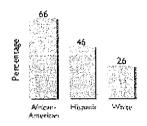
African-American adolescent males are more likely than youth in any other racial or ethnic group to become sexually active at a young age, have multiple

This document is available in pdf format: Download PDF (76K)

> U.S. AIDS Cases, by Age at Dagnosis, 20041 (N=42.515)



Parental Contern about Children Contracting HIV, by Race/Ethnicity, 2004/



Race/Ethnicity

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partners, and engage in high-risk activities. This behavior increases the risk for contracting and spreading sexually transmitted infections (STIs), a risk that African-American adolescent girls greatly underestimate, according to a study of 13,998 adolescents. Minority girls in particular lack access to preventive health care services. They also underestimate their risk of STIs by overestimating how safe their partners are.

People age 24 and younger constitute the most uninsured population in the United States.<sup>8</sup> Consequently, they are likely to lack preventive health care or access to important information about their health.

#### YOUTH AND THE RYAN WHITE CARE ACT

Youth ages 13 to 24 constituted approximately 7 percent of all Ryan White Comprehensive AIDS Resources Emergency (CARE) Act clients in 2004, a year in which CARE Act programs reached approximately 533,000 people. Many CARE Act-funded providers are reaching out to young people. For example, through the Title IV Program for Women, Infants, Children, Youth, and Families, 16 grants totaling \$72.7 million were funded in 2006 as part of the Title IV Youth Initiative.

The CARE Act Special Projects of National Significance Program funded an initiative in which grantees received funds for developing innovative models for reaching HIV- positive adolescents not in care. Results from those activities have been disseminated across the country.

Lesbian and Gay Youth: Care and Counseling, by Donna Futterman and Caitlin Ryan (Columbia University Press, 1998), is the preeminent text on health care and well-being for sexual minority youth. Development of the publication was supported with funding from the Health Resources and Services Administration (HRSA).

HRSA conducted a nationwide conference call on youth and HIV disease called *Reaching HIV-Positive Youth: Models That Work*. Subsequent to the event, a report that provides information on an array of resources available to organizations serving youth at risk for HIV disease was made available at www.hab.hrsa.gov/.

For more information on young people and HIV/AIDS, see the May and July 2004 issues of *HRSA CAREAction*, available at <a href="https://www.hab.hrsa.gov/publications/news.htm">www.hab.hrsa.gov/publications/news.htm</a>.

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U.S. Department of Health and Human Services - Health Resources and Services Administration - FIIV/AIDS Bureau 5600 Fishers Lane - Room 7-05 - Rockville, MD 20857 - 301-443-1993 - www.hab.hrsa.gov

### Glossary

Acquired Immunodeficiency Syndrome (AIDS) – A result of human immunodeficiency virus (HIV) infection, which makes the immune system less able to fight infection. 2. AIDS refers to the late stages of the disease of a person who is infected with the virus called HIV. A CD4 count below 200 and an opportunistic infection must be present before a person is said to have AIDS.

Adherence: how closely you follow a prescribed treatment regimen.

Affective Learning: Change in attitudes and/or behaviors.

Aggressive: interacting with others without respect for their rights and feelings.

Alanine Aminotransferase (ALT or SGPT) is by contrast, normally found largely in the liver. This is not to say that it is exclusively located in liver but that is where it is most concentrated. It is released into the bloodstream as the result of liver injury. It therefore serves as a fairly specific indicator of liver status.

Antibodies: a substance in the blood that forms when disease agents such viruses, bacteria, fungi and parasites invade the body. Although antibodies usually defend the body against invading disease agents, HIV antibodies, over time, give no such protection. 2. are a type of protein that is produced by your body when a virus enters your body.

Antiretroviral Agents: drugs that slow the pace of HIV infection by suppressing the ability of HIV to replicate. 2. are substances used against retroviruses such as HIV.

Aspartat Aminotransferase (AST or SGOT) - is normally found in a diversity of tissues including liver, heart, muscle, kidney, and brain. It is released into serum when any one of these tissues is damaged. For example, its level in serum rises with heart attacks and with muscle disorders. It is therefore not a highly specific indicator of liver injury.

Assertive: expressing what we want or believe in and is an important part of clear communication.

CD4 T-Cells: A type of white blood cell essential to the body's immune system. 2. Important cells in mounting the body's defense against infection. These "helper" cells not only fight infection, but recruit other immune cells to the site of infection to help kill infection-causing bacteria and viruses. The HIV virus uses the CD4 T-cells to make more HIV viruses. By doing this, HIV destroys the CD4 cell. Without CD4 T-cells, the body is not able to defend itself against bacterial and viral infections.

Cognitive Learning: Introduction of new facts, concepts and skills.

Combination therapy: treatments, sometimes called "drug cocktails," involving a combination of three or more antiviral drugs that can dramatically inhibit HIV replication. 2. refers to two or more drugs or treatments used together to achieve the best results against HIV infection and/or AIDS.

**DNA (Deoxyribonucleic Acid):** the chain of molecules in genes, which carries genetic information that helps cells reproduce. DNA is the main ingredient of chromosomes, which transmit genetic information.

**Host:** used to describe where a germ lives. For example, a person who has HIV is the host for the virus. 2. The animal or cell that another organism lives in. In HIV human CD4 T-cells are the host for HIV virus.

**Health Resource Services Administration (HRSA):** Funding source of the Federal Government.

Health Insurance and Portability Act (HIPAA): The federal government Act maintained to protect the rights and interest of the customer.

Human Immunodeficiency Virus (HIV): the virus that causes AIDS. HIV weakens several body systems and destroys the body's immune system, making it easier for life-threatening opportunistic infections and cancers to invade the body.

MARS-A strategy used to enhance learning. Motivation, Association, Repetition and Sense

Mycobacterium avium complex (MAC): a disease caused by mycobacteria. Appears in people whose immune systems are badly damaged and causes fever, weight loss, weakness and sometimes diarrhea. 2.is a common opportunistic infection caused by Mycrobacterium avium and Mycobacterium intracellulare, which are two very similar mycobacterial organisms found in soil and dust particles. It is a serious bacterial infection that HIV+ people can get. MAC is related to tuberculosis. MAC is usually found only in people with fewer than 50 T4 cells. The symptoms can include weight loss, fevers, chills, night sweats, swollen glands, abdominal pains, diarrhea and overall weakness. MAC usually affects the intestines and inner organs first, causing liver test to be high. Swelling and inflammation also occur.

Multi-Disciplinary Teams: groups of professionals from diverse disciplines who come together to provide comprehensive assessments and consultation for a common goal.

Nucleus: The core of CD4 T-cells, it contains human DNA.

Opportunistic infections: a variety of infections, such as Pneumocystis carinii pneumonia, that occur in people whose immune systems are weak for various reasons, including disease, such as HIV infection.

2. illnesses caused by different organisms,

some of which usually do not cause disease in people with a normal immune system. Opportunistic infections of the lungs, brain, eyes, and other organs can develop in people with HIV infection.

**Peer Educator Training Site (PETS):** A project that will build the capacity of organizations and Peers to develop and replicate HIV Peer Education programs.

**Peer Educator:** Someone who shares characteristics of his or her peers receives special training to provide support and education in various health fields, such as HIV/AIDS, Teen Reproductive Health, Mental Health, Cancer and Substance Abuse.

Passive: repress the emotions, feeling and thoughts that a person may have.

**Prejudice:** Preconceived judgment of members of a certain race, ethnicity, gender, religion, or group.

Protease inhibitors: (PIs) a new class of antiviral drugs. These drugs suppress HIV by blocking infected cells from making copies of HIV, which are capable of infecting other cells. 2. is a class of antiretroviral drugs that bind to and block HIV protease to prevent the production of new infectious viral particles.

RNA: a nucleic acid found in the contents of a cell surrounding the nucleus. Some retroviruses, such as HIV, carry RNA instead of the more usual DNA. 2. The chemical make-up of living things. RNA contains only 1 copy of information and needs another copy to replicate.

Racism: Discrimination or mistreatment of an individual due to their belonging to a particular race or ethnic group.

Resistance: HIV will multiply rapidly while taking medication.

**Retrovirus:** A type of virus that has RNA instead of DNA as its genetic material. It uses an enzyme called reverse transcriptase to become part of the host cells' DNA. This allows many copies of the virus to be made in the host cells. The virus that causes AIDS, the human immunodeficiency virus (HIV), is a type of retrovirus.

**Stereotype:** A belief that all members of a group possess the same characteristics or traits exhibited by some members of that group.

Stigma: Negative feelings, beliefs, and behavior directed toward an individual or group due to a particular label or characteristic.

**Toxoplasmosis:** is an infection caused by Toxoplasma gondi, a parasite. The parasite is carried by cats, birds, and other animals, and is found in soil contaminated by cat feces and in meat, particularly pork. The parasite can infect the eye, heart, pancreas, liver, colon and testes. If the immune system becomes severely damaged, as in HIV-infected

persons. T. gondii can begin to multiply and cause severe disease. In HIV-infected persons, the most common site of toxoplasmosis is the brain.

Viral Life Cycle: Life cycle of HIV and how it works.

Viral load test: a marker that measures the amount of HIV RNA in the blood. Used by doctors to help make decisions about treatment.

Virus: a germ, much smaller than a bacterium, whose survival depends on cells in the host. A virus, such as HIV, often destroys these cells. 2. Ultramicroscopic infectious agent that replicates itself only within cells of living hosts; many are pathogenic; a piece of nucleic acid (DNA or RNA) wrapped in a thin coat of protein.

Western Blot: confirmatory test

Source: American Red Cross HIV/AIDS Facts Book (Glossary), 2003. Bristol-Meyers Squibb Company (HIV Glossary), Princeton, New Jersey July, 2001.