



HIV Impact

A Closing the Gap newsletter of the Office of Minority Health, U.S. Department of Health and Human Services

Are We Communicating?

Improving HIV Care Through Healthy Patient-Physician Partnerships

By Linda Quander, Ph.D.

Some believe building an effective partnership with a physician affects the way a patient experiences HIV infection. A supportive relationship may hold the patient together physically and psychologically. But all too often, a patient living with HIV feels the sting of isolation and intolerance from others, including physicians.

In her poem "The Doctor's Office," Chardelle Lassiter, an HIV-positive patient, writes: "As I don't want to die, I must strictly comply, and follow the doctor's orders." A productive patient-physician relationship certainly does not require a blind, unquestioning allegiance to a doctor, but rather places value on open communication and the roles of both individuals.

A healthy patient-physician relationship allows the patient to make informed decisions throughout the disease course. Effective communication is especially important because of the frequency, severity, and variety of progressive illnesses associated with HIV infection. Treatment, which can require numerous medications, may result in multiple side effects and complications.

Here are seven steps to better patient-physician relations:

1. Encourage patient-centered approaches. While a disease-centered approach to the relationship focuses on symptoms of illness, a patient-centered approach considers the patient's unique experience of illness. The doctor should try to learn a patient's feelings about illness and the patient should express these feelings, especially fears.

Belynda Dunn, an HIV-positive AIDS activist and prevention educator at the AIDS Action Committee of Massachusetts, says, "Previous physicians were cut and dry with their physical exams. No one really looked into my eyes." But when she began her partnership with David Rind, M.D., an HIV Specialist at Boston's Deaconess Health Care Associates, she noticed a difference. He really looked at her, and he saw the fear in her eyes. He listened to her concerns about the toxicity of medications and her deepening depression due to a Hepatitis C diagnosis.

Why is the patient's point of view so important? Numerous studies show that when a doctor includes the patient's perspective, the patient's satisfaction with services improves, along with compliance with treatment and physical health. A patient's evaluation of the effects of illness on his daily duties, as well as expectations about treatment should be addressed.

2. Emphasize trust, respect and confidentiality. Long-term AIDS survivors often say their survival ultimately depends, at least in part, on their relationships with doctors. They stress the importance of mutual trust and respect between doctors and patients.

Researchers commonly find that gay male and bisexual youth are at high risk for HIV infection, but few reveal their sexual orientation. Many fear health care providers won't keep their secrets. Sexually-active minority youth also may be fearful of physicians and cautious about confidentiality.

The American Medical Association acknowledges these fears and anxieties, but tells patients that their conversations with their doctors are private. Doctors will not share any information with anyone else without the patient's permission.

3. Take a holistic approach. The physician should see the patient as a whole person through both physical and personal information. Doctors need to understand the patient's health within the context of his environment.

Darryl Lampkin, an HIV-positive treatment advocate with Motivational Educational Entertainment (MEE) in Washington, D.C., suggests that doctors be concerned not just about his biology, but about his life. He says, "HIV lives with me, and I live in the world. A physician needs to address the aspects of the world I live in. I'm not just a number in a lab report." Personal information a patient shares with a doctor may include sexual, cultural, or religious attitudes and beliefs that relate to lifestyle choices or illness.

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HIV Impact is a free quarterly newsletter of the Office of Minority Health, Office of Public Health and Science, U.S. Department of Health and Human Services.

The Office of Minority Health Resource Center provides free information on various health issues affecting U.S. minorities.

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PATIENT-PHYSICIAN RELATIONS

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4. Consider patients' access to resources. A patient-physician partnership should use personal, financial, and medical resources wisely. Both partners should work together to identify resources in light of health priorities. Convenience and cost issues affect the ability to comply with a treatment plan. They should assess the availability and accessibility of resources. For example, in *Not What the Doctor Ordered*, Margaret Chesney, Ph.D., Professor of Medicine at the University of California at San Francisco, says "Tailor the regimen to fit people's lives, not life to the regimen."

5. Recognize that physicians and patients can have differences of opinion and still seek common ground. Both partners should find and cultivate common ground. They should develop an effective plan to "manage" the patient's health, requiring mutual agreement and coordination. They should remember that finding common ground means understanding that it's okay to have different opinions. The key is to focus on negotiation and not confrontation.

Dr. Rind, Belynda Dunn's doctor, says it's important for both individuals to avoid preconceived notions. Deal with differences, he advises, in a "reasonable, not hostile way. In both directions, don't take it personally."

Even doctors disagree among themselves about "hit early, hit hard" (begin treatment early and aggressively) versus "hit late, hit soft" (begin treatment when the patient is physically and psychologically ready for more moderate treatment), so why shouldn't patients voice a variety of views?

6. Increase education about the importance of being an informed patient. The patient should approach the medical office visit like a reporter approaches an interview. He should use who, what, where, when, why, and how to ask questions about HIV care. It is the patient's right and responsibility to ask questions and to receive clear, comprehensive answers.

Before a visit ends, a patient should check his understanding of important information. Perhaps using notes taken during the visit, he should repeat or summarize what the doctor has said. Is understanding of HIV increased with printed or graphic information, demonstrations, or additional discussions with nurses, pharmacists, or others? "Yes," Darryl Lampkin says. The doctor "needs to go the extra mile...to find someone or some resource to help- even a peer counselor."

For example, MEE Productions provides a free videotape, "Life is what you make it. Live Life." It is an audiovisual investigation into the lives of adult per-

sons living with AIDS as they discuss the latest treatment regimens and work to maintain positive attitudes. For more information, call 877-633-7763 (toll free), or go to <http://www.meeproductions.com>.

7. Support minority health professionals with more education and training. A patient-physician partnership should use cultural sensitivity in collaborating and planning. Rani Lewis, M.D., an African-American HIV Specialist in Nashville, Tennessee, says that minority physicians are often more aware of and comfortable with cultural differences that affect HIV care. National groups like the Integrated Minority AIDS Network, Incorporated (IMANI) must attract more minority physicians to be a part of HIV care as well as research, she says.

Patricia Carter, manager of the Harvard AIDS Institute's Leading for Life Initiatives, adds that efforts like the Arthur Ashe Program in AIDS Care, established by the Kaiser Family Foundation, are essential in answering the desperate call for AIDS education and training for minority physicians.

As a joint initiative of the Harvard AIDS Institute and the National Medical Fellowships, Inc., this multidisciplinary training program for fourth-year, minority medical students builds AIDS-related clinical and cross-cultural skills while providing community outreach opportunities.

The Harvard-Tuskegee HIV and Bioethics Combined Fellowship is a parallel program sponsored by the Harvard AIDS Institute, the Tuskegee University National Center for Bioethics in Research and Health Care (TUNCBRH), and the Centers for Disease Control and Prevention (CDC). This program educates students on the bioethical issues surrounding HIV and diversity in the United States. Participants in this program share experiences and research with participants in the Arthur Ashe Program in AIDS Care. For more information, call 617-432-4400 or visit <http://www.hsph.harvard.edu/hai>.

Finally, the Health Resources and Services Administration (HRSA) increases the number of minority providers who care for HIV/AIDS patients through the National Minority AIDS Education and Training Center (NMAETC). NMAETC is a national network of historically black colleges and universities that trains healthcare providers who serve minority communities impacted by the HIV/AIDS epidemic. Howard University serves as its headquarters, with additional sites at Charles R. Drew University, Meharry Medical College and Morehouse School of Medicine. For more information on NMAETC, call 202-865-3300. 

Battling HIV/AIDS Among Hispanics

*By Lucille Roybal-Allard, M.C. Chair, Congressional Hispanic Caucus, and
Ciro D. Rodriguez, M.C. Chair, Congressional Hispanic Caucus Health Task Force*

As members of the Congressional Hispanic Caucus (CHC), we welcome the opportunity to share with you the views of our Caucus regarding the HIV/AIDS epidemic in communities of color, and specifically the impact in the Hispanic community.

The Congressional Hispanic Caucus, an informal group of 18 Hispanic Members of Congress, is dedicated to voicing and advancing issues affecting Hispanic Americans in the United States and the insular areas. The CHC has nine task forces that tackle issues ranging from immigration to economic development. The CHC's Health Task Force addresses health of the Latino community.

Despite the progress our nation has made in addressing the AIDS epidemic, Latinos, like other communities of color, continue to be disproportionately affected by HIV/AIDS. Although Latinos represent 11% of the U.S. population, they represent approximately 20% of new AIDS cases. Considering that an estimated 110,000 - 170,000 Latinos are living with AIDS and that each week 250 Latinos in the United States are diagnosed with AIDS, much more needs to be done to battle the disease.

The CHC has made the impact of HIV/AIDS in the Latino community a top priority. We have advocated for increased funding of existing HIV/AIDS programs and continue to work with other members of Congress to highlight the needs of Latinos, African Americans, American Indians/Alaska Natives, Asian Americans, Native Hawaiians, Pacific Islanders and other highly impacted communities.

In order to raise awareness about the impact of diseases such as HIV/AIDS in the Latino community, the CHC sponsored Hispanic Health Awareness Week in September of 1999. During Hispanic Health Awareness Week, the CHC held hearings on diseases that disproportionately affect the Hispanic community, including HIV/AIDS.

The CHC report on the Hispanic Health Awareness Week findings was published in April of this year and has been submitted to the Congressional committees of jurisdiction, along with a list of recommendations and goals on how to address the health needs of

the Hispanic community. A copy of this report is also available through our website at: <http://www.house.gov/roybal-allard/CHC.htm>

The CHC report highlights specific findings and recommendations to tackle the HIV/AIDS epidemic. It shows that if we are to tackle diseases such as HIV/AIDS, we must meet broad challenges such as lack of health care, inadequate program funding, poor data collection, the low number of Latino health-care professionals, and culturally inappropriate information. In addition, the CHC has identified several barriers specific to HIV/AIDS which already exist in the Latino community.

These include: the community unwillingness to recognize that AIDS is a problem; lack of specific research on sexual attitudes, beliefs, behaviors and practices among Hispanics; cultural factors such as religion, views of homosexuality, established gender roles; and limited knowledge and misconceptions about HIV/AIDS and its treatment.

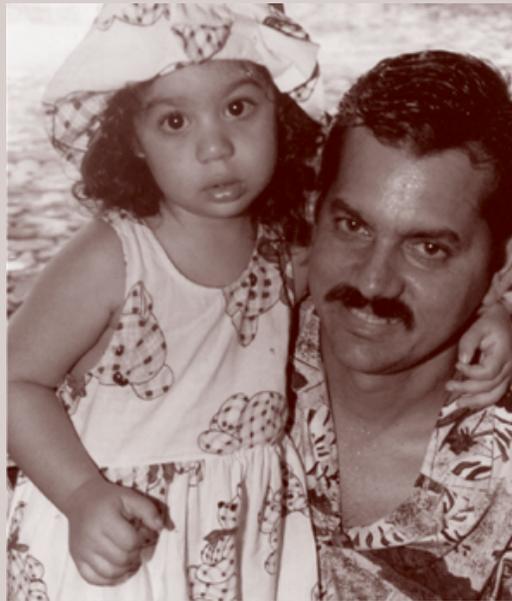
To address some of these barriers, we are currently working with the Surgeon

General on the Leadership Campaign on AIDS. Through this campaign, we hope to address the stigma associated with HIV/AIDS and tackle the negative perceptions of HIV positive individuals, injection drug users, and gay men in the Latino community. We will continue to work to confront these negative perceptions and eliminate the barriers that prevent those at risk from getting tested, disclosing their HIV status or seeking care.

By working on legislative remedies, advocating for increases in funding to existing programs, and coordinating our efforts with the different agencies within the Department of Health and Human Services, our members will continue to battle the HIV/AIDS epidemic in the Latino community.

The fight against HIV/AIDS in communities of color, and particularly in the Latino community, is and will continue to be a top priority for the members of the Congressional Hispanic Caucus until the crisis is alleviated.

For details on the legislative activities of the CHC, please call (202) 225-2410 or visit our website at: <http://www.house.gov/roybal-allard/CHC.htm> &



OMHRC Seeks Applications for Resource Persons Network

It's not news that many community-based organizations are strapped for resources. That's why the Resource Persons Network (RPN) is such an important part of the Office of Minority Health Resource Center's (OMHRC) mission. The RPN's slogan is "Connecting with Communities."

Under the leadership of Lisa E. Williams, OMHRC's new RPN Coordinator, the Network is undergoing some changes that will improve the current process of matching minority health experts with organizations.



Resource Persons Network
Connecting with Communities

Through the RPN, minority health experts volunteer to provide technical assistance to

community organizations across the country. Duties of RPN members vary, depending on an organization's needs. Typical activities include reviewing grant proposals; speaking at conferences and workshops; serving on committees and workgroups; serving as a subject expert for the media; providing advice on developing, implementing, and evaluating health programs; and offering guidance on preparing papers and speeches.

OMHRC is looking for volunteers with expertise in all areas of minority health, including HIV/AIDS. Network members must have a strong commitment to improving racial and ethnic minority health status, and proven experience with issues related to at least one of OMHRC's target populations: African Americans, Hispanics/Latinos, American Indians/Alaska Natives; Asian Americans, and Native Hawaiians and Other Pacific Islanders.

"Our RPN members volunteer out of a desire to make a difference in minority health," Williams says. OMHRC values members and supports them with additional benefits, including an RPN newsletter called *Minority Health Update*. This quarterly newsletter supports work in minority health by providing information on grants and awards, along with announcements on conferences. OMHRC also plans to offer a new electronic listserv that will encourage networking with colleagues.

OMHRC is a nationwide service of the Office of Minority Health, U.S. Department of Health and Human Services. To request an RPN application, please call our toll-free line, and ask to speak with an information specialist, 1-800-444-6472. 

HHS Awards \$794 million for High-Cost AIDS Medications for the Poor and Uninsured

HHS Secretary Donna Shalala announced in April that \$794 million in grants would go to 50 states, the District of Columbia, and U.S. territories to improve access to HIV/AIDS primary care, support services, and medications for individuals living with HIV/AIDS and their families. This award includes \$528 million targeted for state AIDS Drug Assistance Programs (ADAP). These grants will enable more than 78,000 low-income, HIV-positive individuals to have access to life-saving medications each month.

Grants are funded under Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which provides HIV/AIDS care to those who have low incomes, are uninsured, or are underinsured. The HIV/AIDS Bureau within HHS' Health Resources and Services Administration (HRSA) administers the CARE Act.

Title II formula grants are allotted in relation to the estimated number of individuals living with AIDS in the state or territory. Separate funds have been set aside under Title II to assist state ADAPs in purchasing drugs for those living with HIV/AIDS since fiscal year 1996. Since that time, states have received almost \$1.5 billion in ADAP funds. Approximately \$3.3 billion in Title II grants have been awarded since the CARE Act was originally funded in fiscal year 1991. 

Health Grants from the Robert Wood Johnson Foundation

Grants awarded by the Robert Wood Johnson Foundation (RWJF) support approximately 2,300 solicited and unsolicited projects in communities across the country. The RWJF uses nearly \$360 million of its assets a year to address the Foundation's goals. General goals are:

- to assure that all Americans have access to basic health care at reasonable cost;
- to improve care and support for people with chronic health conditions; and
- to promote health and prevent disease by reducing the harm caused by substance abuse—tobacco, alcohol, and illicit drugs.

The RWJF funds unsolicited projects from the field, as well as proposals from competitive national programs. Grants to support unsolicited projects are made throughout the year. No specific application forms or deadline dates are issued for these projects. Grantmaking priorities include:

HEALTH

Alcohol and Illegal Drugs
Community Health
Health and Behavior
Population-Based Health Sciences
Tobacco

HEALTH CARE

Clinical Care Management
End-of-Life Care
Information/Tracking
Insurance Coverage
Safety Net
Supportive Services

Grantmaking priorities sometimes change, so for more information on the RWJF and other answers to frequently asked questions about applying for a grant, visit the website at <http://www.rwjf.org>. 

Educating Young People about HIV/AIDS

By Linda Quander, PhD



The reality of the AIDS epidemic in the new century is that it will strike at the very heart of our community—our youth, says Pernessa Seele, founder of the Balm in Gilead, a national organization that mobilizes African American churches to become community centers for HIV/AIDS education.

According to the Centers for Disease Control and Prevention's (CDC) *Young People at Risk: HIV/AIDS Among America's Youth*, it is estimated that at least half of all new HIV infections occur in young people under 25 years old.

Young African Americans are affected most, comprising 56 percent of all HIV cases reported between the ages of 13 and 19.

Experts say that better HIV/AIDS education is critical for young people at highest risk for the disease, including those who are sexually active, gay, incarcerated, homeless, or school drop-outs. Here are some key issues and resources to consider in HIV/AIDS education for youth.

Self-esteem

High-risk teens often lack self-assurance, negotiation skills, and an ability to express personal feelings about safe sex, according to *Dangerous Inhibitions: How America is Letting AIDS Become an Epidemic of the Young*, a 1997 report from the Center for AIDS Prevention Studies at the University of California, San Francisco.

Metro TeenAIDS, a community-based organization in Washington, D.C., addresses co-factors for adolescent HIV infection such as low self-esteem. One program, Sisters for Life, uses Kwanza principles and a sorority model, and it includes a series of workshops, lectures, and retreats to promote healthy decision making, academic achievement, and support for teens.

Family communication and support

A series of public health reports from the U.S. Department of Health and Human Services on health promotion for high-risk adolescents underscores the importance of family communication. In their youth focus groups, findings from teens identified love, home, family, and safety as positive influences on behavior.

A recent study by the Epidemiology Branch of CDC's Division of HIV/AIDS Prevention found that open and responsive discussions between mothers and children promoted communication between adolescents and their partners about sexual risk and condom use. This increased communication was associated with greater condom use during first and subsequent encounters.

Accurate information

Many young people lack accurate information about sexuality, risky behavior, and HIV/AIDS. Cornell University in Ithaca, N.Y., developed an award-winning program called "Talking with Kids about HIV/AIDS", which trains parents, guardians, and other adults to communicate accurate HIV-related information to children and teens. The program originally received seed money from CDC, and is now funded primarily by the New York State Department of Health's AIDS Institute.

"Talking with Kids about HIV/AIDS" involves many minority participants, including Spanish-speaking volunteers. Workshops provide basic information on HIV/AIDS, HIV risk assessment and reduction skills, and extensive parent-child communication activities. For more information, call Jennifer Tiffany at 607-255-1942 or visit <http://www.human.cornell.edu/pam/extesn/hiv aids/>.

Trust and confidentiality

When it comes to sexual health, many teens say they need someone to talk to that they can trust. Several studies show that young homosexual and bisexual men often feel isolated and alienated, making it difficult to communicate their views about safe sex. Many also worry that they can't establish an honest relationship with health providers because of stigmatization and fear of exposure.

The Risk Evaluation Program (REP) at the Montefiore Medical Center in New York recently formed the Gay and Lesbian Health Resource Center to address such issues. The program will train health providers about what it's like growing up gay or lesbian, and show how to help young people feel safer and more accepted. For more information, call 718-882-0232.

Youth-friendly approaches

Peer education has proven to be one effective way to reach youths with HIV/AIDS information. Under the Community Collaboration Project, the Second Baptist Church and the Fairfax County Department of Health in Virginia use peer education on HIV/AIDS to reach African American, Latino, and other minority youth ages 13 to 25. According to program participant Cherelle Gaines, youth are trained to be peer educators who are "real with one another, straightforward, and non-judgmental." For more information, call 703-533-3217.

Cultural beliefs

In many American Indian cultures, the extended family shares responsibility for the care of the children. Clan mothers are often those who share information about healthy behavior. Native American Community Services in Buffalo, N.Y., developed the HIV Reduction Curriculum to reinforce traditional beliefs and kinship structures. Cultural activities, which often involve elders, provide the context for prevention education. For more information, visit http://hivinsite.ucsf.edu/topics/native_americans/2098.2b51.html.

Also see *Youth Resources* on page 15.

Maintaining Financial Health When You're HIV Positive

By Linda Quander, Ph.D.

Many people living with AIDS (PLWAs) say there's a big difference between dealing with the illness when you have money versus when you don't.

Surviving critical illness causes unique and unexpected financial hardships, especially because problems related to HIV and AIDS often fall between the cracks of traditional insurance coverage. Some PLWAs find that strict and complex managed care guidelines mean insurance alone will not cover all expenses associated with HIV/AIDS services.

Disability insurance traditionally only covers approximately 60 to 70 percent of income, and not all workers can afford disability coverage. Life insurance provides financial support to family members as a result of the insured's untimely death, but most policies do not provide for financial assistance in recovering from a serious illness.

High costs of HIV/AIDS care

"The Care of HIV-Infected Adults in the United States," published in the *New England Journal of Medicine* in 1998, estimated that the annual cost of HIV-related care was approximately \$20,000 per HIV-infected adult each year. The cost of treatment was affected by the patient's stage of the disease.

The average cost per year for all HIV-positive patients was \$22,716, but the average cost for those with the lowest viral loads and highest CD4 counts was \$15,632. At the more advanced stages of the disease, the highest cost, \$24,708, was for those with the highest viral loads and lowest CD4 counts.

According to recent data from the Treatment Access Expansion Project (TAEP), of those PLWAs who do have some type of medical coverage, many have limited, inadequate pharmaceutical coverage. For other PLWAs without access to affordable health care and insurance, and already struggling to deal with other socio-economic pressures, their illness is only one of several concerns.

PLWAs are poorer and less likely to be employed or to have private insurance, according to findings from the *HIV Cost and Services Utilization Study (HCSUS)*, a national study of HIV-positive adults. And some minorities are not benefiting from new anti-retroviral treatments due to lack of access to services.

Short- and long-term strategies

Maintaining financial health for PLWAs should include both short- and long-term survival strategies. "Many of us have forgot-

ten how to dream, or simply assumed that our dreams could not be fulfilled, because we were going to die," says Tom Swift, an HIV-positive financial planner with San Francisco's Horton Investment Group. "Now is the time to re-evaluate our dreams and once we've done that, we can plan accordingly."

Here are some important questions and tips:

Q: What is the best way to start assessing finances?

A: To start assessing finances, experts recommend factoring in several areas—budget, employment, insurance, and tax issues—because they are connected.

For example, employment decisions can impact both income and health insurance coverage. As the Department of Labor's Pension and Welfare Benefits Administration (PWBA) puts it: "Work changes require health choices. Protect your rights."

Barbara Chinn, deputy executive director of the Whitman-Walker Clinic and Director of the Max Robinson Center in Washington, D.C., suggests that PLWAs "identify all necessary expenses such as housing, food, medication, clothing, and insurance," and then decide on eliminating unnecessary expenses.

Regional Town Meetings

Here's a chance to discuss your organization's needs. The federal Office of Minority Health (OMH), with Congressional support, is holding regional town meetings this summer in the following cities: **San Francisco, Miami, Washington DC, Houston, Chicago, New Orleans.**

If your organization provides HIV/AIDS services to African Americans, American Indians/Alaska Natives, Asian Americans, Hispanics/Latinos, and Native Hawaiians and Other Pacific Islanders, we encourage you to join us. This includes commu-

nity-based organizations (CBOs) and AIDS service organizations (ASOs) that offer HIV/AIDS prevention, education, outreach, care, counseling, and other support.

The meetings will give you a valuable opportunity to discuss your organization's challenges and needs. OMH is committed to following up this needs assessment with a one-day Regional Technical Assistance Training for ASOs and CBOs in each of the six regions. We will focus on capacity building to support your work in serving minority populations.

The assistance will relate to such areas as:

- ⇒ access to resources
- ⇒ board/staff development
- ⇒ cultural competency
- ⇒ effective HIV interventions
- ⇒ finance management
- ⇒ partnership development
- ⇒ program evaluation

To obtain more information or reserve your place at the table call 1-800-444-6472, ext. 235 or 301-230-7874. 

Chinn says AIDS service organizations (ASOs) may provide free financial planning services. “It is important to meet with an intake coordinator in order to identify basic financial issues. Depending on what a client needs, referrals to case managers, legal services, or other resources may follow.”

Q: How can HIV-positive patients cut costs on food and housing?

A: Tyrone, an HIV-positive networker with the HIV Community Coalition in Washington, D.C., challenges individuals to “cut some corners by being creative.” Diagnosed with HIV in 1993, he is a long-term survivor who coaches PLWAs to “save money on one end in order to spend it on the other.”

For example, he suggests using community food banks such as Food and Friends in Washington, D.C. Food supplements are also available through the federal Women, Infants, and Children (WIC) nutrition program of the Department of Agriculture. See its website at <http://www.fns.usda.gov>.

Tyrone finds help with utility costs through community programs like Building Futures and federal benefits through the HOME Energy Assistance Program (HEAP). The federal Housing Opportunities for Persons With AIDS (HOPWA) program and other Department of Housing and Urban Development (HUD) programs provide Tyrone with ways to cut housing costs. HOPWA is administered through local agencies such as public housing authorities, Ryan White CARE Act affiliates, and not-for-profit AIDS Service Organizations.

Housing aid programs may provide certificates, vouchers, or other partnerships to assist with or reduce housing costs. In addition, Shelter Plus Care is a HUD program that provides temporary and permanent housing aid for homeless persons on a group-home or individual-unit basis. For more information, visit the Department of Housing and Urban Development’s website at <http://www.hud.gov>.

Examples of local organizations that can help:

- Residing in Group Housing Together (RIGHT) provides holistic support to PLWAs and their families in Washington, D.C., 202-581-0900.
- Housing Works is a minority-controlled, community-based, not-for-profit corporation in New York City that provides housing, health care, job training, clothing, and other support services to homeless PLWAs, 212-966-0466, <http://www.housingworks.org>

Q: What resources are available to help pay for medication?

A: Deciding whether to pay the rent or to take their medications is not a decision that HIV-positive patients should have to make. AIDS Drug Assistance Programs (ADAP) are administered by the states to provide access to the drugs used to treat HIV/AIDS and to avoid AIDS-related opportunistic infections for low-income PLWAs who do not have adequate private or public health insurance.

The 50 states, plus the District of Columbia and Puerto Rico, receive federal funds through the Ryan White CARE Act. Some states contribute supplementary funding. Each state sets its own income and eligibility requirements and determines which drugs will be covered and how they will be purchased and distributed.

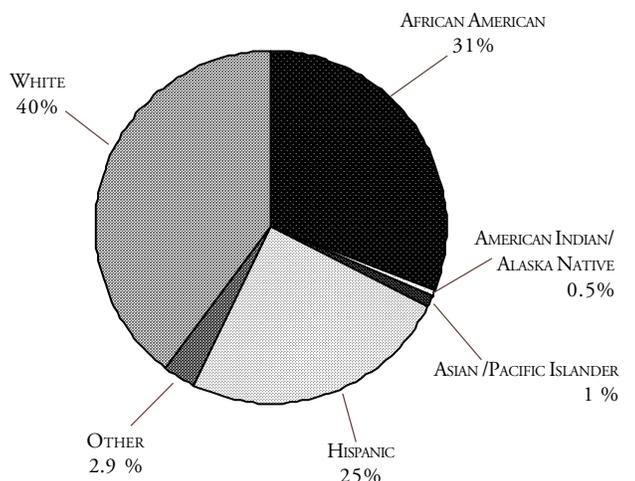
Most ADAPs use a pharmacy reimbursement system similar to Medicaid, which permits patients to go to a participating pharmacy, show their enrollment cards and have prescriptions filled. Some ADAPs directly purchase and distribute medications to patients.

In addition, some prescriptions are available free-of-charge from drug companies that have special programs for those who cannot afford to pay for their medications. Examples include Abbot Laboratories, Bristol-Myers Squibb, Hoffman-LaRoche, and Glaxo Wellcome. A case manager or pharmacist can help patients identify and participate in appropriate programs.

The Medicine Program is an organization that helps eligible patients enroll in one or more of the many patient assistance programs sponsored by drug manufacturers. These programs provide prescription medications free-of-charge to individuals in need, regardless of age, if they meet the sponsor’s criteria. For more information, call 573-996-7300, or visit <http://www.themedicineprogram.com>.

Opportunities also exist for involvement in the testing of selected, free drug treatments through clinical research trials at companies and federal agencies such as the National Institutes of Health (NIH) (See clinical trials article on page 12-13.)

Race/Ethnicity of June 1999 ADAP Clients



Source: National ADAP Monitoring Project: Annual Report • March 2000. Available from the Henry J. Kaiser Family Foundation, <http://www.kff.org>

HIV/AIDS and Minorities in Prison

By Linda Quander, Ph.D.

Just as in the general community, infectious disease, substance abuse, high-risk activities, and other health-related problems disproportionately affect minorities in the correctional system, says John Miles, special assistant for corrections and substance abuse at the Center for Disease Control and Prevention's (CDC) National Center for HIV, STD and TB Prevention. He adds that prisons should not be considered a breeding ground for disease, but rather an opportunity for public health intervention.

HIV in prisons

According to the National Commission on Correctional Health Care, an organization that develops nationally recognized standards for health care in correctional systems, the HIV infection rate in prisons is, on average, five times higher than in the general American population. Key findings from the most recent collaborative report from the Centers for Disease Control and Prevention (CDC), National Institute of Justice (NIJ), and Bureau of Justice Statistics (BJS) indicate:

- HIV and AIDS are more prevalent among Hispanic and African American inmates than among white inmates.
- Among state prisoners, African American non-Hispanic inmates are twice as likely as white non-Hispanic inmates to report being HIV positive.
- Among local jail inmates, an estimated 2.6 percent of black inmates compared to 1.4 percent of white inmates said they tested HIV positive.
- Among male jail inmates, African Americans are nearly twice as likely as whites to report being HIV positive.
- Among male jail inmates, Hispanics have the highest HIV-positive rate.

The BJS notes a link between drug use prior to incarceration with HIV infection rates in prisons. But high-risk behaviors for HIV transmission—consensual sex, sexual victimization, drug use, sharing of injection materials, and tattooing—do occur in correctional facilities, according to the collaborative report from CDC, NIJ, and BJS.

Some prisoners do not understand safer sex practices, and others are discouraged by the ban on condoms in many prisons. The majority of correctional systems prohibit inmates from having condoms. But many health officials worry that HIV-positive prisoners will not practice safe sex upon their release if they have not had access to basic precautionary measures in prisons.

The danger of denial

According to Deya Smith, former lobbyist for the National Minority AIDS Council and an editor for politically black.com, "Most men who have been incarcerated and participated in same sex activities during that time will justify the sex as something that only occurred as a result of their situation. And when they get out, one of their first priorities often is to have sex with their wife, girlfriend, or whoever is available. At least for the first encounter, a condom is less likely to be used... and the woman usually feels it is safe because he has been locked up..."

Willie Byrd, an HIV-positive outreach advocate for the HIV Community Coalition in Washington, D.C., adds "Infected inmates or ex-inmates may 'burn' or infect a female partner, and she will pass it on. This may happen not because she means to but because she may not know that she has been burned."

Byrd says the stigma of AIDS, fear of disclosing HIV-positive status, and crowded conditions both within prisons and minority communities all contribute to the growing AIDS epidemic.

Editor's Note: This article is the first in a two-part series. The second part, which will cover HIV/AIDS outreach in prisons, will appear in the Fall 2000 issue of HIV Impact. ☞

The Prison Population

In April 2000, the U.S. Department of Justice's (DOJ) Bureau of Justice Statistics (BJS) reported a continuing climb in incarceration figures, with nearly 1.9 million people in prisons and jails by midyear 1999. The nation's inmate population is expected to reach 2 million by late 2001.

According to the BJS report, minorities are the majority in correctional facilities. Black non-Hispanics comprise 41.5 percent, Hispanics 15.5 percent, and Asians, Pacific Islanders, American Indians, and Alaska Natives 1.7 percent of all local jail inmates. Approximately 11 percent of black males and 4 percent of Hispanic males in their twenties and early thirties were in prison or jails by midyear 1999.

Similar racial and ethnic disparities appear among female incarceration rates in all age groups. Among black non-Hispanic females, the rate is highest among those 30-34 years old. This rate is almost as great as the highest rate among white males.

According to a 1999 BJS report, on any given day, approximately one in 25 American Indians 18 years old and older is under the control of the U.S. criminal justice system. This number is 2.4 times the rate for whites.

The number of American Indians per capita confined in federal and state prisons is about 38 percent above the national average. Additionally, the rate of confinement for American Indians in local jails is nearly four times the national average but about half the rate for blacks. ☞

Testing Policies for HIV in U.S. Prisons, 1998

Jurisdiction	ENTERING	ALL INMATES IN CUSTODY	UPON RELEASE	HIGH-RISK GROUPS
Federal System *			X	
<i>Northeast</i>				
Connecticut				X
Maine				
Massachusetts				
New Hampshire	X			
New Jersey				
New York				X
Pennsylvania				
Rhode Island	X			
Vermont				
<i>Midwest</i>				
Illinois				X
Indiana				X
Iowa	X			
Kansas				X
Michigan	X			
Minnesota				X
Missouri	X		X	
Nebraska	X			
North Dakota	X			
Ohio	X			X
South Dakota				X
Wisconsin	X	X	X	
<i>South</i>				
Alabama	X		X	
Arkansas	X	X		X
Delaware				X
Florida				
Georgia	X			
Kentucky				X
Louisiana				
Maryland				
Mississippi	X			
North Carolina				
Oklahoma	X			
South Carolina	X	X	X	
Tennessee	X			
Texas				X
Virginia				X
West Virginia	X	X		
<i>West</i>				
Alaska				
Arizona				
California				
Colorado	X			
Hawaii				
Idaho	X			
Montana				
Nevada	X		X	
New Mexico				X
Oregon				
Utah	X			
Washington				
Wyoming	X			

* The Bureau of Prisons tests a random sample of inmates on alternative years. The complete table and report can be reached at <http://www.ojp.usdoj.gov/bjs>

After Prison: The Challenge of Tracking Behavior

Correctional counselors and other staff persons are charged with specialized pre-release planning for HIV-positive inmates. Parole/probation supervisors are supposed to track the health-related activities of these individuals in the community. During meetings such as the last National Conference on Correctional Health Care, concerns were raised that because of increasing case loads, necessary arrangements and follow-up do not always occur.

John Miles, special assistant for corrections and substance abuse at the Centers for Disease Control and Prevention's (CDC) National Center for HIV, STD and TB Prevention, believes the challenge to government is to involve communities of color in a continuum of care. He says, "We have to be proactive in working with community-based organizations in providing health care, housing, jobs and other support services which allow inmates to return and to stay in their communities."

The National Minority AIDS Council (NMAC) also believes community-based organizations can aid prison health officials in providing information and services to HIV-positive inmates both during and after their release. NMAC developed a Discharge Planning Kit which contains:

1. a Discharge Planning Flow Sheet and a Discharge Planning Check list to direct correctional health personnel in providing newly diagnosed inmates with the necessary information, treatment and care;
2. a listing of State AIDS Hotlines for all 50 states ; and
3. a series of Information Sheets such as *Being in Charge, Is Case Management for You?, Do You Need to Take Meds?, and Thinking about HIV?*

For more information, contact the Treatment Education Division of NMAC at 202-483-6622, ext.314 or e-mail tbrown@nmac.org

CDC Awards \$7 Million for HIV Prevention in Prisons

The Centers for Disease Control and Prevention (CDC) awarded \$7 million in late 1999 to 11 state and city health departments to create HIV prevention programs in areas that contain 56 percent of the total prison population; 83 percent of all HIV-infected inmates; and almost 75 percent of all AIDS cases among African Americans.

The Correctional Demonstration Projects, a collaborative effort with the Health Resources and Services Administration, aim to provide inmates with prevention and treatment services during and after their incarceration. Only 10 percent of state and federal prison systems and 5 percent of city and county jail systems provide comprehensive HIV prevention. Services will include HIV prevention education, treatment for chemical dependence, HIV counseling and testing, and HIV treatment and care.

For more information, visit CDC's National Center for HIV, STD & TB Prevention at <http://www.cdc.gov>

Updated HIV Treatment Guidelines Available on the Web

The HIV/AIDS Treatment Information Service (ATIS) has posted an updated version of the "Guidelines for the Use of Anti-retroviral Agents in HIV-Infected Adults and Adolescents" on its website at www.hivatis.org.

According to Anthony Fauci, M.D., director of the National Institute of Allergy and Infectious Diseases (NIAID) and co-chair of the Panel on Clinical Practices for the Treatment of HIV Infection, the guidelines are drawn from the latest research findings and provide recommendations on the optimal use of many anti-retroviral medications and laboratory tests.

The guidelines were developed by the Panel on Clinical Practices for the Treatment of HIV Infection, a collaborative effort of the Department of Health and Human Services (DHHS) and the Henry J. Kaiser Family Foundation.

The updated guidelines contain recommendations for clinical practice use of recently developed tests which assist in determining if the virus a patient is carrying has developed resistance

to one or more anti-retroviral drugs.

Primary goals of anti-retroviral therapy are discussed, including suppressing plasma viral load to below detectable levels for as long as possible; restoring and/or preserving the patient's immunologic function; improving the patient's quality of life; and reducing HIV-related illness and death.

Tools to help obtain these goals are presented, including maximizing patient adherence to a regimen; selecting user-friendly regimens when possible; prescribing drugs in a rational sequence in order to maintain future treatment options; and utilizing drug resistance assays when treatment fails.

A new hypertext link to information on the use of anti-retroviral drugs in pregnant women has been added. Updated "Guidelines" are available at <http://www.hivatis.org>. You may also call 1-800-448-0440 or send an e-mail request to atis@hivatis.org to order single copies. &

NIH Minority Health Initiative Web Site

The Office of Research on Minority Health (ORMH) of the National Institutes of Health (NIH) recently launched a new web site to offer the public and scientific community information about the NIH Minority Health Initiative (MHI).

This multi-year program supports biomedical and behavioral research aimed at improving the health of minority Americans. The program is designed to increase the number of underrepresented minorities in all aspects of biomedical and behavioral research.

For patients and the public, the new ORMH web site will provide information about ORMH programs, clinical trials, and NIH health radio programming. Scientists, health care providers, and students will be able to access information about the NIH grants and contracts, employment, and other resources. Visit the new ORMH web site at <http://www1.od.nih.gov/ormh> &

Adolescents Benefit from Early Treatment with Aggressive Drug Therapy



According to researchers at The Children's Hospital of Philadelphia, HIV-positive adolescents respond well to early, aggressive treatment with anti-HIV medications due to a strong immune response system.

The study, reported in the *Archives of Pediatric and Adolescent Medicine* (April 2000), was co-sponsored by the National Institute of Child Health and Human Development (NICHD), the National Institute of Allergy and Infectious Diseases (NIAID), the National Institute of Drug Abuse (NIDA), the National Institute of Mental Health (NIMH), and the Health Resources and Services Administration (HRSA).

Blood samples were drawn from adolescents at 16 clinical sites participating in the Adolescent Medicine HIV/AIDS Research Network, established by the National Institutes of Health (NIH) and HRSA.

Steven Douglas, M.D., Chief of Immunology at Children's Hospital, says the adolescent immune system may be stronger than previously thought because they found a surprisingly higher number of CD8 naive T lymphocytes in HIV-positive adolescents as compared with uninfected adolescents. (Naive T lymphocytes are cells which have not been exposed to invading microorganisms such as HIV; CD8 cells are major factors in killing the virus.)

Bret Rudy, M.D., who directs the Adolescent AIDS Initiative at Children's Hospital and is co-author of the study, says because of the vigor of the adolescent immune system, they may be the best candidates for highly active anti-retroviral therapy (HAART).

With early, aggressive use of current medications, these researchers believe that they may be able to rebuild immune systems in HIV-infected adolescents. Findings from this study indicate that it is essential that adolescents become aware of their infections before symptoms appear, because early treatment offers the best opportunity for a strong response. &

Resources on Patient-Physician Partnerships

FOR PATIENTS

Communicating With Your Doctor, American Medical Association (AMA), AMA Health Insight On-Line Health Information for Everyone, April 1999, <http://www.ama-assn.org/insight>.

Consumer Bill of Rights and Responsibilities, President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, July 1998, <http://www.hcqualitycommission.gov>

Now You Have A Diagnosis: What's Next? Using Healthcare Information to Help Make Treatment Decisions, Agency for Healthcare Research and Quality and the Kanter Family Foundation, December 1999, <http://www.ahrq.gov/consumer/diaginfo.htm>

Taking Part in Research Studies: What Questions Should You Ask?, HIV/AIDS Brochure, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention, August 1998, <http://www.cdc.gov/nchstp/hiv-aids/pubs/brochure>

FOR PHYSICIANS

AIDS & the Soul of the Physician, N. Michael Murphy, Journal of the International Association of Physicians in AIDS Care, June 1996, <http://www.iapac.org/clinmgmt/practice.soul.html>

Confidentiality vs. The Duty to Warn: Ethical and Legal Dilemmas in the HIV Epidemic, Lawrence Gostin, Journal of the International Association of Physicians in AIDS Care, September 1995, <http://www.iapac.org/policy/advocacy/confidential.html>

Doctors: It's Your Responsibility, Health Care Financing Administration (HCFA), March 2000, <http://www.hcfa.gov/hiv/>.

Not What the Doctor Ordered: Challenges Individuals Face in Adhering to Medical Advice/Treatment, Congressional Briefing, April 16, 1999, Consortium of Social Science Associations, <http://www.cossa.org>

Predicting Antiviral Compliance: Physicians' Responsibilities vs Patients' Rights, Mark Senak, Journal of the International Association of Physicians in AIDS Care, June 1997, <http://www.iapac.org/clinmgmt/avtherapies/predictms.html> 

The Need for More Support

Born and raised in a nurturing community in North Carolina, Belynda Dunn was accustomed to African American community members reaching out to each other, especially when people were in need. But she found little support when first diagnosed with HIV, and says "HIV is pushing people apart from their traditions."

"When I first tested positive, not a lot was known and there were no support groups," says Dunn, an AIDS activist and prevention educator at the AIDS Action Committee of Massachusetts. "There was no support, not from the black community or the church. As an African-American heterosexual female at forty plus, I was ostracized. The only community I was accepted by and received support from was the gay community."

Phil Wilson, an HIV-positive AIDS activist and founder of the African-American AIDS Policy and Training Institute (AAAPTI) at the University of Southern California, encourages racial and ethnic minority communities to "break the silence" and remove the stigma surrounding AIDS. We have to break barriers in the community if we ever hope to reduce communication barriers in healthcare services, he says. 

HHS News Briefs

- **OMH/AAIP Cooperative Agreement Addresses HIV/AIDS Awareness:** In its latest newsletter (February 2000), the Association of American Indian Physicians (AAIP) announced that it will provide HIV/AIDS awareness and education to American Indians/Alaska Natives (AI/AN) with a focus on youth. The project is under a cooperative agreement between AAIP and the HHS Office of Minority Health (OMH). The newsletter reports that HIV/AIDS among Native Americans has doubled since 1992 in reported cases, and that open and frank discussions concerning the use of condoms, non-use of needles, and HIV/AIDS are rare. AAIP plans to use its trusted and professional relationships with AI/AN communities, tribes, tribal colleges, AI/AN education programs, and other health care providers to increase awareness for those in high-risk categories. AAIP invites participation in its HIV/AIDS prevention efforts. For more on AAIP, visit <http://www.aaip.com> 
- **Ryan White Program Has Cut AIDS Deaths:** Systems of care developed from Ryan White CARE Act funds are largely responsible for recent drops in illness and death from AIDS, Surgeon General David Satcher told a Senate committee on March 2, 2000. Dr. Satcher addressed the Senate Health, Education, Labor and Pensions Committee during a hearing on reauthorization of the CARE Act. Since the creation of the act a decade ago, the number of new HIV infections has stabilized to about 40,000 annually, and the development of full-blown AIDS cases and the number of deaths have declined. Satcher noted that continued success in treating AIDS may be entering a more difficult phase as the epidemic shifts toward harder-to-reach populations, including people of color, women, and young people. 

Advancing AIDS Treatment through Clinical Trials

By Keith Crawford, R.Ph., Ph.D.

Faculty in the Department of Pharmacology, Howard University College of Medicine, and
Research Associate for the National Institute of Diabetes, Digestive, and Kidney Diseases, National Institutes of Health

Seventeen years ago, the human immune deficiency virus (HIV) was isolated as the likely cause of AIDS. At that time, major risk groups included homosexuals, intravenous drug users, Haitian immigrants, and hemophiliacs.

The response from the public at large and the medical community reflected attitudes of homophobia, racism, disenfranchisement of the poor, and failure to recognize substance abuse as a medical problem. The growing epidemic in Africa was hardly, if at all, discussed.

The prevalent view was that the disease was uniformly fatal. With no cure or treatment in sight, activists from the gay community demanded that the medical community respond to the epidemic. The federal government was targeted to make research funding available. With few options and great desperation, any treatment that offered promise in slowing and reversing immune deficiency quickly had its fill of study participants.

Now in the year 2000, there are 15 approved drugs with demonstrated efficiency in treating this disease. Mortality rates have decreased dramatically. More and more, HIV is considered as a chronically-manageable disease like diabetes and hypertension. Potent combinations of drugs have reduced viral loads to undetectable levels in thousands of patients.

So with such effective treatments readily available, why should anyone consider clinical trials? Because even though we've discovered drugs that have a profound impact on the disease, our discoveries have generated more questions. Consider these issues:

- Some patients are never able to achieve total viral suppression despite numerous attempts with various drug combinations.
- The potent drugs are far from benign. What are the best strategies for coping with the many adverse drug reactions that have emerged through the use of highly-active anti-retroviral therapy (HAART)?
- Understanding the limitations of available drugs, when is the best time to start therapy, and which combinations provide the most durable response?

These are just a few of the pressing issues needing answers to improve our management of AIDS. It is easy to see that most HIV patients fall into one of the above categories. Certainly, one can envision a patient with total viral suppression and no drug toxicities taking an interest in a study that investigates approaches to totally eradicate the infection.

Trials to evaluate investigational drugs

When a pharmaceutical company has developed a drug to the point where it has been tested for toxicity in three different animal species, the Food and Drug Administration (FDA) may grant the compound Investigational New Drug status. This allows the company to begin testing the drug in humans. Based on the results of a series of closely monitored phases of testing, the FDA may authorize approval of the drug for marketing.

Phase I Clinical Trials

This type of trial is a dose-escalation study to determine safety and toxicity endpoints (outcomes). The clinical efficacy of the drug may be assessed as well, but this is not the primary function of the study. When these trials are initiated, there may be no clinical evidence of therapeutic benefit as of yet, but only in vitro studies (lab studies) or animal studies suggesting the drug should be effective.

Even if the drug is effective, the study participant may be randomized to a sub-therapeutic dose or to a toxic dose. These studies are monitored closely so that potential toxicities can be detected quickly and the drug can be discontinued before serious damage occurs.

Though these trials are critically important, I recommend them only for those with limited options and after researching the study substances extensively. Ask your physician about the drug. Oftentimes, information on investigational drugs is not readily available. In this case, contact the Drug Information Center at a research hospital or the National Institutes of Health (301-496-3436.)

Phase II Clinical Trials

Having established dosing parameters from phase I studies, the researchers may be allowed to advance to phase II clinical trials. These trials are often placebo (inactive substance)-controlled and specifically assess the clinical effectiveness of the drug in question. In diseases where it may be inappropriate to have patients on placebo (life-threatening diseases like cancer and AIDS where there are effective treatments available), the investigational drug may be compared with a regimen known to be effective.

Phase III Clinical Trials

These are expanded, controlled trials that attempt to reproduce the benefits observed in the phase II trials in a larger study population. Satisfactory responses to phase III trials may provide the necessary data for the FDA to grant approval of the investigational drug for clinical use. 

Are Clinical Trials Right for You?

All trials are not “good trials” or of potential benefit to you. Researchers associated with the study may not always provide unbiased information. If you’re considering participation in a clinical trial, here are some questions you should ask.

1. How can I expect to benefit from this study? Better control of the virus? Reduction in adverse effects? Possible eradication of the infection? Reduced risk for opportunistic infections? Help scientists better understand the disease?

2. What are my risks? Unknown or known toxicities? Loss of control of the virus? Risk of disease progression?

Read the informed consent form for the study thoroughly and ask questions if you don’t understand. The informed consent document is designed to inform potential participants of the purpose of the trial and possible risks. It’s written in plain language without confusing medical terms. Don’t be frightened by the informed consent form because it must list ALL known possible adverse effects; even those that occur very rarely.

3. What are the chances that I will receive the treatment of interest to me? There are open-label studies, where participants know what treatment they are receiving. However, more rigorous studies randomize the participants to a treatment group, and they are often blinded (a term that means the participant and/or researcher don’t know what treatment is being given.) These measures—randomization and blinding—are designed to eliminate bias that can affect the outcome of the study.

Find a physician who is knowledgeable about clinical trials and supportive of patients who are interested in clinical trials. Your physician should be willing to consult with clinical study personnel, and to do some research and represent your best interest.

Consider that a physician may not adequately advise you because of failure to research the trial strategy or drugs being investigated. That’s why it’s important to do your homework. Use the Internet, other health professionals, and HIV patient advocacy groups such as the American Foundation for AIDS Research (202-331-8600) and Project Inform (1-800-822-7422; <http://www.projectinform.org>)

Because of the changing nature of this epidemic, it is critical that more women, people of color, intravenous drug users, and other at-risk groups actively participate in clinical trials. This is the only way that we can establish guidelines that are effective in managing disease in these populations.  --K.C.

NIAID Seeks Research Volunteers

The National Institute of Allergy and Infectious Diseases (NIAID), National Institutes of Health, is looking for volunteers for biomedical research studies. These studies are conducted by the NIAID and the NIH Clinical Center in Bethesda, Maryland. Contact the appropriate coordinator below for each study, or go to <http://www.niaid.nih.gov/hivclinic>

- **ESPRIT Interleukin-2:** This is an open label, phase III international trial to determine if IL-2, combined with anti-retroviral therapy, prolongs the health of people with HIV-infection. Contact Doreen Chait at 1-800-772-5464, ext. 58008.
- **Lymphapheresis:** This study seeks HIV-positive volunteers with CD4 (a type of T-cell involved in protecting against infection) counts over 200. Volunteers will participate in a 45-minute apheresis procedure that involves removal of some white blood cells from the circulating blood. The study is recruiting participants in the Washington, D.C., Maryland, and Virginia metropolitan area. Financial compensation is provided. Contact: Linda Ehler at 1-800-772-5464, ext. 5-7687.
- **Use of Combination Anti-retroviral Therapy to Delineate the Persistence of HIV Infection:** This study will try to identify and define potential reservoirs (sites in the body) of HIV-1 that permit the maintenance of persistent HIV-1 infection. It will examine whether antiviral therapy can reverse the effects of HIV-1 infection. The study seeks HIV-positive men and women with CD4 counts in all ranges. Contact: Christian Yoder at 1-800-772-5464, ext. 5-7745.
- **Once Daily Dosing/HAART Regimen Study:** People with HIV who have not been treated with any anti-HIV medication may be eligible to participate in a study of a once-daily regimen of medication for HIV treatment. Study visits and medication are free. Participants will come to NIH in Bethesda, Maryland. Contact: Mary McLaughlin at 1-800-772-5464, ext. 5-8001.
- **APL 400-003, a Candidate HIV Vaccine in HIV-Negative Volunteers:** This is a phase I study to evaluate the safety, tolerance, and immune response of APL 400-003, a genetic vaccine. Participants must be HIV negative, in good health, and not previously immunized with vaccines directed against HIV. Contact Grace Kelly at 1-800-772-5464, ext. 5-7744. 

U.N. Identifies AIDS As a Threat to World Security

In recent remarks to the United Nations Security Council, U.N. Secretary-General Kofi Annan said that high AIDS mortality rates among Africa's elite and public servants threaten some countries' capabilities to govern themselves.

Exacerbating the problem are high infection rates among police and armed forces according to Annan. Health and education services are deteriorating, Humanitarian assistance is even obstructed in some cases.

Annan asked the council to coordinate efforts so that more conflict does not spread AIDS nor prevent United Nations agencies and others from controlling it. He also asked wealthier nations to increase their contributions to fighting AIDS.

The U.S. is especially concerned about the impact of AIDS in Africa and India. As life expectancy decreases in these areas, AIDS is erasing the gains from development efforts. Africa has 70 percent of the world's total HIV or AIDS cases with 23.3 million Africans infected. As reported in the last issue of *HIV Impact* (Spring 2000), 200,000 Africans were killed as a result of wars in 1998, but 2.2 million died of AIDS.

In India, the world's second largest country, patterns of HIV infection are changing. No longer is infection limited to drug injectors or urban sex workers, but rural areas are suffering. Villagers, constituting 73 percent of the country's population, like city dwellers are affected. The virus, along with other sexually transmitted diseases, is rooted within the general population, including among women whose only risk behavior is having sex with their husbands. 

HIV/AIDS Increasing in Latin America and the Caribbean

In Latin America, HIV infections are concentrated among individuals who inject drugs and share needles and men who have unprotected sex with other men, according to the UNAIDS Joint United Nations Programme on HIV/AIDS and the World Health Organization.

For example, in Argentina and Brazil almost half of drug injectors may be infected. In Mexico as many as 30 percent of men who have sex with men may be infected. The trends concerning the spread of HIV are similar to the United States with an increasing number of infections occurring among heterosexuals, especially in Brazil.

Heterosexual transmission of HIV is significant in the Caribbean, perhaps striking 2 percent of the countries' populations. According to a recent report in *The Economist*, 12 percent of those in urban areas in Haiti are infected; in the Bahamas, Dominican Republic, and Guyana, tests show that more than three percent of blood donors and pregnant women are infected.

Like the United States, the epidemic among the young is worsening with AIDS as the leading cause of death for young men in English-language Caribbean countries. AIDS has deprived the Caribbean of six percent of its potential earnings due to fewer workers, greater dependency on those who do work, larger medical expenses, and lower savings according to World Bank statistics.

Although Cuba previously had low HIV infection rates, numbers are now rising. Mandatory testing and involuntary quarantines within sanatorias were previously indicators of a strict HIV screening and reporting process. However, a shrinking public health budget and cash-poor economy have had a negative impact on prevention and control efforts.

Drug use and prostitution are increasing while quality condoms are scarce. Basic medical supplies, including disposable syringes, are in short supply. According to International Association of Physicians in AIDS Care reports, medications are costly, and new HIV/AIDS combination therapies are few. 

African Health Ministers Meet to Discuss AIDS Pandemic

Government ministers from across Africa gathered on May 7-9, 2000, to address the staggering challenges posed by the HIV/AIDS pandemic in their continent. Organized by United Nations agencies, this Organization of African Unity (OAU) Ministers of Health meeting was held in Ouagadougou, Burkina Faso.

The goal was to identify strategic approaches to meet Africa's needs within resource constraints, while adopting strategies to mobilize funds and strengthen international partnerships.

Conference participants also developed recommendations on the framework document of the International Partnership Against HIV/AIDS in Africa, a recent initiative of UNAIDS, the UN's inter-agency programme on AIDS. Visit the UNAIDS web site at <http://www.unaids.org> 

African Life Expectancy by 2010

COUNTRY	LIFE * EXPECTANCY YEARS	
Namibia	Without AIDS	70.1
	With AIDS	38.9
Zimbabwe	Without AIDS	69.5
	With AIDS	38.8
Botswana	Without AIDS	66.3
	With AIDS	37.8
Swaziland	Without AIDS	63.2
	With AIDS	37.1
Malawi	Without AIDS	56.8
	With AIDS	34.8
Zambia	Without AIDS	60.1
	With AIDS	37.8
Lesotho	Without AIDS	65.9
	With AIDS	44.7
South Africa	Without AIDS	68.2
	With AIDS	48.0
Tanzania	Without AIDS	60.7
	With AIDS	46.1

Source: World Bank, WHO, UNICEF, USAID

* Life expectancy from birth

Organization Websites

Youth Outreach

AIDS Action
<http://www.aidsaction.org>

Advocates for Youth
<http://www.advocatesforyouth.org>

American Academy of Child and Adolescent Psychiatry
<http://www.aacap.org>

American Red Cross AIDS Education Office
<http://www.redcross.org>

Association for the Care of Children's Health
<http://www.acch.org>

Kaiser Family Foundation
<http://www.kff.org>

Mother's Voices
<http://www.mvoices.org>

The National Parenting Center
<http://www.tnpc.com>

National Prevention Information Network
<http://www.cdcnpin.org>

National Youth Advocacy Coalition
<http://www.nyacyouth.org>

Pediatric AIDS Foundation
<http://www.pedaids.org>

Clinical Trials

Adult AIDS Clinical Trials Group
<http://aactg.s-3.com/index.htm>

AIDS Clinical Trials Information Service
<http://www.actis.org>

HIV InSite- USA HIV Clinical Trials Search
<http://hivinsite.ucsf.edu/tsearch>

Pediatric AIDS Clinical Trials Group
<http://pactg.s-3.com>

Publications

Youth Outreach

AIDS Prevention Guide: For Parents and Other Adults Concerned About Youth. Centers for Disease Control and Prevention (CDC). This guide, available in English and Spanish, defines HIV and AIDS, discusses methods of transmission, and presents answers to common questions. Available from: CDC Business and Labor Resource Service, CDC National AIDS Clearinghouse, P.O. Box 6003, Rockville, MD 20849-6003. Call 800-458-5231.

Children, Parents and HIV. This brochure gives parents the facts they need to know in order to discuss HIV/AIDS with school-age children. A section on facts to share with teens and preteens helps parents to present important topics. Available from: American Red Cross, National Headquarters, Office of HIV/AIDS Education, 811 Gatehouse Road, Falls Church, VA 22042. Call 800-375-2040.

Teenagers and HIV. This brochure emphasizes that taking risks can be fatal. It explains safer and unsafe sexual behavior. Available from: American Red Cross, National Headquarters, Office of HIV/AIDS Education, 811 Gatehouse Road, Falls Church, VA 22042. Call 800-375-2040.

Clinical Trials

Clinical Trials: Improving Health Care for African Americans. This publication discusses issues concerning minorities in clinical trials. It lists contacts and telephone numbers to use in order to join clinical trials. To obtain a free copy, write to: American College of Radiology (ACR) Publication Sales, P.O. Box 2348, Merrifield, VA 22116. Call 703-648-8900.

HIV/AIDS Clinical Trials. This fact sheet presents critical information about HIV/AIDS clinical trials and treatments. To obtain a free copy, write to: National Council of La Raza, 111 19th Street, NW, Suite 1000, Washington, D.C. 20036. Call 202-785-1672.

Outreach Notebook for the NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research. This notebook contains advice on inclusion criteria. It gives an overview of key elements in the outreach process and suggests practical applications. Available from the National Institutes of Health by calling 301-496-5787. 

DEPARTMENT OF
HEALTH & HUMAN SERVICES
Public Health Service
Office of Minority Health Resource
Center
P.O. Box 37337
Washington DC 20013-7337

BULK RATE
POSTAGE AND FEES PAID
DHHS/OPHS
PERMIT NO. G-280

Official Business
Penalty for Private Use \$300

HIV Impact

Upcoming Conferences

JULY

16-19: International Conference on Emerging Infectious Diseases 2000. To be held in Atlanta, GA. Sponsored by the American Society for Microbiology. Contact: 202-942-9257; Website: <http://www.asmtusa.org>.

19-21: Hispanic Health: Visions for the 21st Century. To be held in Washington, D.C. Sponsored by the National Association of Hispanic Nurses. Contact: 202-387-2477

19-21: 5th Annual National Prevention Institute: Passion for Prevention. To be held in San Diego, CA. Sponsored by the Comprehensive Health Education Foundation. Contact: 206-824-2907.

AUGUST

3-8: Association of American Indian Physicians' (AAIP) 29th Annual Meeting and National Health Conference. To be held in Tucson, AZ. Contact: 405-946-7072; Website: <http://www.aaip.com>.

10-12: Gay and Lesbian Medical Association's (GLMA) 18th Annual Conference. To be held in Vancouver, British Columbia. Contact: 510-843-8048; Website: <http://www.glma.org>.

12-17: The National Medical Association (NMA) Year 2000 Annual Convention & Scientific Assembly. To be held in Washington, D.C. Contact: 202-347-1895; Website: <http://www.nmanet.org>.

16-20: National Black Nurses Association's (NBNA) 28th Annual Institute and Conference. To be held in Washington, D.C. Contact: 301-589-3200.

SEPTEMBER

7-8: Spotlight on Workplace Solutions for HIV and AIDS Conference. To be held in Washington, D.C. Sponsored by the Centers for Disease Control and Prevention (CDC). Contact: 800-458-5231; Website: <http://www.brta-irta.org/spotlight.htm>.

OCTOBER

1-4: United States Conference on AIDS (USCA). To be held in Atlanta, GA. Sponsored by USCA. Contact: 202-483-6622, ext. 343.

21-25: 3rd National Harm Reduction Coalition Conference- Communities Respond to Drug Related Harm: AIDS, Hepatitis, Prison, Overdose, and Beyond. To be held in Miami, FL. Sponsored by Harm Reduction Coalition, Advocates for Recovery through Medicine, AIDS Action Council, American Foundation for AIDS Research. Contact: 212-213-6376, ext.31; Website: <http://www.harmreduction.org>.