Despite nationwide progress in reducing HIV infection and preventing AIDS, rates of HIV infection have remained constant in the Asian American and Pacific Islander (AAPI) communities. While the number of reported AIDS cases among AAPIs remains small—about one percent of total cases reported in the U.S.—underreporting and a lack of detailed HIV surveillance about AAPIs may minimize the true impact of the AIDS epidemic on these communities.

“Many AAPI immigrants come from countries with increasingly high prevalence of HIV/AIDS, including China, Thailand, Viet Nam, the Philippines, and India, and often continue to travel back and forth between these countries and the U.S.,” said Denise Tang, associate director of community services at the Asian & Pacific Islander Wellness Center (A&PIWC).

“A&PIWC’s HIV Care Services provides free and confidential HIV treatment case management, mental health, and substance abuse counseling, on-site primary medical and psychiatric care, client and treatment advocacy, and group and individual support to AAPIs living with HIV/AIDS,” said Tang. “In addition, we provide support to their families, friends, and partners.”

Cofactors of HIV/AIDS, including tuberculosis, sexually transmitted diseases such as gonorrhea and chlamydia, and hepatitis B are well documented in AAPIs. “Many AAPIs suffer from high rates of poverty and low rates of education. Because of these factors, AAPIs continue to be at increased risk for contracting HIV,” Tang said. “But the greatest challenge in addressing HIV prevention in the AAPI community is the language barrier.”

“Even with a staff that speaks 18 languages, there are still many languages out there with no representative. For people who are monolingual, accessing care can be difficult,” Tang added.

AAPI cultures place a high value on medical providers and their words leave an impression. Health care providers are perhaps the first and only point of contact for many AAPI patients for health education and early intervention services, Tang explained.
“We place utmost importance on primary care services, and because of this our HIV Care Services program builds upon primary care as a means to increase AAPIs access to medical services and a means to improve their health and quality of life,” said Tang.

A&PIWC’s services are available at its home office or mobile—in the clients’ homes, in clinics, and outreach settings. “For example, Thai speakers go to Thai temples,” Tang explained.

The Center’s primary care services include a full range of care, including initial intake, episodic and urgent care, and continuity care. In addition to treatment and care, A&PIWC specifically focuses on HIV/AIDS prevention through several different programming efforts including community organizing and outreach, workshops and support groups, peer counseling, and prevention case management. “A&PIWC targets youth, men who have sex with men (MSM), transgender persons, and women, particularly those working in massage parlors,” Tang said.

Its HIV testing includes pre- and post-test counseling. The counseling is available in several Asian and Pacific Islander languages, including: Vietnamese, Tagalog, Ilokano, Thai, Lao, Japanese, Mandarin, Cantonese, Korean, and Visayan. In addition, interpretation services are available for other Asian and Pacific Islander languages. Tang said “A&PIWC has a diverse staff of HIV testing counselors, with immigrant, refugee, American-born, lesbian, gay, bisexual, transgender, and heterosexual representation.”

In addition, the Center hosts prevention workshops, rap groups, and socials, distributes brochures and palm cards promoting HIV testing, and maintains a comprehensive website. It launched “Paying Attention,” a column on sexual diversity in AsianWeek—the only national English language news weekly for AAPIs—and developed the California Statewide Treatment Education Program to bring its local training program which educates non-medical service providers to cities across the state.

“We also have a Research & Technical Assistance program that builds HIV prevention and capacity building in organizations and communities throughout the U.S. and its Pacific territories that work with communities of color, including AAPIs,” Tang said. To date, A&PIWC has provided technical assistance to nearly 50 community-based HIV/AIDS service organizations.

For more information about the Asian & Pacific Islander Wellness Center, visit the Web site at http://www.apiwc.org or call 415-292-3400.

Asian American and Pacific Islander Facts

Latest U.S. Census Bureau data show:

- 10.4 million Asian Americans and Pacific Islanders (AAPIs) live in the United States and U.S.-associated Pacific Island jurisdictions, comprising approximately 4 percent of the total U.S. population;
- AAPIs are the fastest growing racial/ethnic group in the United States, and are expected to reach 10 percent of the population by the year 2050; and
- 40 percent of AAPIs do not speak English fluently.

Asian Americans and Pacific Islanders are often viewed as a model minority with few health or social problems, however emerging data on AAPIs show significant disparities and barriers to health care and social service access.

- The poverty rate of AAPI families (14 percent) is higher than that of non-Hispanic White families (8 percent).
- AAPIs lack health insurance at a higher rate than the total U.S. population, with Korean Americans being the most likely racial/ethnic group to be uninsured. An estimated 2 million AAPIs are uninsured.
- AAPIs face tremendous cultural and linguistic barriers to health and social services.
- AAPIs suffer disproportionately high rates of hepatitis B, diabetes, cancer and tuberculosis.
- Infant mortality rates in the U.S.-associated Pacific Island jurisdictions exceed the U.S. rate, in some cases more than twice as much.
- Less than 6 percent of Tongans, Cambodians, Laotians, and Hmong have completed college; the high school graduation rate for Hmong is 31 percent.
A Dangerous Trend
Rates of Syphilis Increase for First Time in a Decade

Aimee Swartz

Rates of syphilis infections are on the rise for the first time in a decade, according to a report by the Centers for Disease Control and Prevention (CDC). The number of syphilis cases among White and Latino men increased by 63 percent and 50 percent, respectively from 2000 to 2001.

“This increase occurred only among men; the number of [primary and secondary] syphilis cases increased slightly in 2001,” wrote report author JD Heffelfinger, MD, in “Primary and Secondary Syphilis—United States, 2000-2001,” published in the November 1 issue of CDC’s Morbidity and Mortality Weekly Report.

Additionally, African American men were the only men in any racial or ethnic group to experience a decline. However, the 3.5 percent decline among African American men represents a significant slowing in the large decline reported last year (15 percent decline from 1999 to 2000).

Syphilis is a sexually transmitted disease caused by the bacterium Treponema pallidum. It is often called “the great imitator” because so many of the signs and symptoms are indistinguishable from those of other diseases. Its first symptoms are genital sores that go away without treatments; patients often do not realize they are infected. Six weeks to several months later, patients may experience a rash that will also go away untreated. The disease can then recur, possibly causing heart damage and blindness.

Researchers found that cases of primary and secondary syphilis in the United States rose by two percent between 2000 and 2001. According to the CDC, syphilis cases in New York City more than doubled, 282 in 2001 from 117 in 2000, marking the highest number of cases in seven years. Recent syphilis outbreaks have also occurred in Chicago, Los Angeles, Miami, and San Francisco. Agency officials attributed the increase to new infection in men who have sex with men.

According to the NYC Department of Health statistics, 93 percent of the city’s syphilis cases occurred among men and 81 percent involved men with male partners. More than half of the men surveyed also have HIV. “It sends another signal that there’s an increase in risky sexual behavior,” said Thomas R. Frieden, city health commissioner. “We’re seeing more and more cases of syphilis among men who have sex with men.” In 2001, 6,103 cases were reported, up from 5,979 in 2000.

Though the nationwide increase was slight, it nonetheless marks a definite setback in the agency’s effort to completely eliminate syphilis. In October 1999, the CDC, in collaboration with other Federal partners, initiated the National Plan to Eliminate Syphilis in the U.S. The syphilis rate was at its lowest since 1941, when the agency began keeping statistics on the disease, and CDC officials believed syphilis could be eradicated in five years.

The plan focused initially on reducing syphilis in African American communities and in the south, home to more than half of U.S. syphilis cases. Since its launch in 1999, efforts have met with much success. Syphilis infections in the south declined eight percent and infection among African American women fell 18.1 percent.

“These data clearly show that a targeted concerted national effort to eliminate syphilis can and will work,” said the CDC’s National Center for HIV, STD and TB Prevention’s deputy director, Dr. Ronald O. Valdiserri, in an October 31, 2002, interview with The New York Times.

In addition, Heffelfinger’s article notes, “The data suggest that, although efforts to reduce syphilis among women and African Americans appear effective and should continue, efforts to prevent and treat syphilis among men who have sex with men (MSM) need to be improved.”

The report points to the fact that many MSM are no longer practicing safe sex, a dangerous trend with implications not only for syphilis—which can be cured by an antibiotic—but for HIV/AIDS. Health officials said that because the risk behaviors for syphilis and HIV are similar, and because syphilis lesions increase risk of HIV transmission between two and five times, syphilis outbreaks among MSM could also signal a potential increase in HIV transmission.

“The syphilis rates are a red flag,” said Ronald Johnson, associate executive director of New York City’s Gay Men’s Health Crisis. “This increase in syphilis indicates that there are increases in the levels of unprotected sex.”

For more information about syphilis, call the CDC National STD/HIV Hotline at 800-227-8922.

HIV infection continues to increase at an alarming rate among young people, particularly within communities of color. This population is not only disproportionately affected by HIV/AIDS, but is particularly vulnerable to HIV infection because it lacks access to valuable health information, education, and services. Washington, DC’s Metro TeenAIDS (MTA) addresses this issue head-on with a variety of programming aimed at preventing new HIV infections among young people and improving the quality of life for young people already affected by, and infected with, HIV.

Early on in the AIDS epidemic, physicians, educators, medical experts, and citizens began to recognize the need for more HIV education and support services directed towards young people in the District of Columbia. To help meet this pressing need, the Washington Area Consortium on HIV Infection in Youth was founded in 1988. Shortly afterward, the Consortium was renamed Metro TeenAIDS.

Located in the heart of the city, MTA has been serving the District’s youth, ages 13-24, since its inception. In 2001, MTA made nearly 30,000 youth contacts through one or more of its programs. Most of the youth served by MTA are African American, ages 16-18.

Youth Helping Youth

“Young people are a diverse population with unique needs, realities, and preferences. There is no one right way to address HIV prevention with youth, which is why we have a variety of youth-focused services that tackle prevention,” said Adam Tenner, MTA’s executive director. “We know that youth have complicated and busy lives, just like adults. Youth have a lot going on and making HIV prevention a priority is not an easy task.”

Staffed by a team of outreach workers and youth volunteers, MTA provides outreach in schools, after-school programs, the streets, youth centers, and shelters. Outreach workers distribute educational materials, and make referrals to medical and social services. “Metro TeenAIDS provides peer-based outreach, which is proven to be the most effective way to change high risk behavior.” Tenner said. “All of our outreach workers are people of color and most of them are youth as well.”

MTA also has a team of educators that are trained to teach institutions, such as churches and schools, about health-related issues and how they relate to HIV infection. All of MTA’s programs are highly interactive, age-appropriate, and use the most current research to provide the highest quality HIV/AIDS prevention education.

MTA has a drop-in center open Monday-Friday, 4-8 p.m., and conducts activities for 10-30 youth, focusing on HIV education. “It’s cool here,” said James, a sixteen-year-old high school student. “The adults don’t seem like regular adults; they listen to you and when they talk to you about AIDS, it’s like we’re having a conversation, not like they’re giving a lecture.”

“There aren’t a lot of places in Washington, DC, for young people to hang out after school that are safe and provides these youth with good messages about themselves, reinforcing the importance of making positive choices about tough issues, such as HIV,” Tenner said.

James has been participating in MTA’s drop-in center as well as other activities for nearly 4 years. “It’s like my second family,” he said.

In collaboration with Washington, DC’s Latin American Youth Center (LAYC), MTA recently hosted a free HIV testing day for youth. Through the partnership, MTA was able to test nearly 50 youth. The testing day offered pre- and post- counseling in both English and Spanish, as well as referrals to care, if needed.

“Metro TeenAIDS and the LAYC partnered to offer youth-specific testing and counseling services so the youth would be more comfortable in the testing environment,” Tenner said.
We made sure testers were keyed into young peoples’ lives and that they were understanding of adolescent behaviors and environments.”

MTA and the LAYC passed out flyers at youth-friendly local businesses and other places where youth hang out. “But, the best way to spread knowledge is from youth to youth and word of mouth,” Tenner said.

“Considering that the number who showed up for testing is nearly double that during our drop-in hours, we think the testing day was a real success,” Tenner added.

“It’s the only way to know for sure,” said Stacie, a 17-year-old high school student who participated in the free testing day. “Then at least you know if you have to start doing things, like taking medicine, to take care of yourself.”

MTA is committed to ensuring that HIV-positive youth are connected to the medical care that they need. “We estimate that there are at least 2,500-3,500 HIV-positive youth that are infected in Washington, DC, but only 100 of those are enrolled in medical services,” Tenner explained.

To address this issue, MTA has partnered with Children’s Hospital to increase youth access to medical treatment and care, as well as HIV testing and pre- and post-counseling.

“We want to make sure that if these young people need services that they are getting them. A lot of infected youth don’t even know they’re infected. It is a complicated process. We try to understand the young person and all the issues they are facing,” Tenner concluded.

MTA is also developing comprehensive programs that address co-factors of youth HIV infection, such as drug and alcohol abuse, and low self-esteem.

For more information about Metro TeenAIDS, call 202-543-9355 or go to http://www.metroteenaids.org

The Key
Participant Protection Can Increase Minority Enrollment in Clinical Trials

Aimee Swartz

One of the greatest challenges facing AIDS researchers today is the enrollment of racial and ethnic minorities in clinical trials. As the virus continues to ravage communities of color, now more than ever, minority representation is needed in clinical trials to ensure that the results of HIV and AIDS research is applicable to all populations affected by the disease.

Participation in Research and Access to Experimental Treatments by HIV-Infected Patients, a recent study conducted by Allen Gifford and a team of researchers at the Veterans Affairs San Diego Healthcare System, found that African American and Hispanic patients, infected with HIV, are less likely than Whites to participate in clinical trials. Using results from the nationally representative data of the HIV Cost and Services Utilization study, researchers found that while African Americans make up 33 percent of adults receiving HIV care, they constitute only 23 percent of clinical study participants.

Though a broad range of barriers contribute to low participation of minorities in clinical trials, perhaps the overriding reason is government mistrust. From the Tuskegee scandal to more recent medical errors, the public in general is fearful of participating in clinical research.

“It is understandable that the public has come to perceive that research institutions put more emphasis on insulating themselves from liability than on protecting people from harm,” said Daniel Federman, MD, Harvard Medical School, at an October 3, 2002, public briefing in Washington, DC.

Federman recently chaired the Institute of Medicine’s Committee on Assessing the System for Protecting Human Research Participants, whose report, “Responsible Research: A Systems Approach to Protecting Research Participants,” recommended broader Federal oversight to ensure increased protection of health and safety of people who are enrolled in all clinical trials, whether public or private.

“There is no single cause for the errors and mishaps that unfortunately have resulted in the deaths of some research participants in recent years,” Federman said. “It’s a combination of stresses, weaknesses, and a lack of accountability that strains the current hodgepodge of protections to the point where fundamental changes are needed to protect all participants and keep public trust from being irrevocably eroded.”

New insights in rigorous controlled studies with human volunteers are needed, Federman explained.

“No research effort is utterly without risk,” said Federman. “Our committee believes that the promise of biological and social research can be fulfilled, but research can be done only with appropriate safeguards for participants, whose presence is indispensable to the progress that beckons us all.”

“By volunteering to participate in research, many people have provided scientists with unprecedented opportunities to better understand human disease. In some studies, these volunteers assume great risks, though their personal benefit is slim or nonexistent. Because of this, they deserve society’s deepest gratitude.”

The report was developed at the request of the U.S. Department of Health and Human Services following the death of 18-year-old Jesse Gelsinger, a participant in a 1999 clinical study on gene therapy at the University of Pennsylvania. This incident, in combination with recent adverse events at other research centers, highlighted issues such as conflicts of interest, inadequate monitoring and oversight, and in-
Dining out is a thing of the past. Grocery shopping has become a stressful chore. Misreading the label on a bottle of water can be a matter of life and death. The nutritional concerns for people living with HIV/AIDS (PLWHA) can make life extremely uncomfortable. Fortunately, people are taking control of HIV and AIDS by choosing wisely what they eat.

“We can make better choices than white bread, a bagel, or a Pop Tart,” said registered dietician and nutritionist Marcy Fenton, AIDS Project Los Angeles (APLA), at the sixth annual United States Conference on AIDS (USCA).

“Nutrition and immunity go hand in hand. Cook rather than just relying on fast food, supplement bars, or something that’s packaged. Food and water born diseases can be eliminated by safe food and safe water practices,” Fenton said.

“It’s hard. There are a lot of obstacles. We need to figure out how to do it because the problems are not going away.”

The HIV virus exposes the human body to a variety of opportunistic infections due to a suppressed immune system and secondary diseases. There is a growing appreciation among the HIV community that nutrition is an important component in medical care for PLWHA. Proper nutrition is important in building and maintaining the immune system and preventing malnutrition, nutrient deficiencies, and weight loss.

After being diagnosed with cryptosporidium, the result of a parasite possibly transferred from tap water or uncooked food, Gregory Valenzuela of La Mirada, CA, was recommended by his dietitian to eat smaller portions of food and maintain a high-fiber diet. “A lot of us who are dealing with the nutritional part of it [HIV/AIDS], it’s a difficult thing to accept because you’re constantly saying ‘wow, my body is changing,’” said Valenzuela, who participated on a nutrition-related panel of PLWHAs at the USCA.

“You don’t want to accept that you have to change your whole lifestyle. I had to come to the acceptance that I was tired of beating my body. That’s when I got to the point where I said ‘OK I got to do something for me.’” Valenzuela said. “The doctors ordered a bland diet, so that’s what I eat: a bland diet. That’s how I keep myself nutritionally balanced.”

To reduce the risk of opportunistic infections, maximize the effectiveness of medical treatments, and reduce the risk for onset or complications of co-morbidities such as diabetes, cardiovascular, kidney, and liver disease, PLWHAs are forming close relationships with their dietitians for nutritional counseling, education, and, in particular, HIV medical nutrition therapy (MNT).

**Saving Lives: Medical Nutrition Therapy (MNT)**

MNT is defined as specific nutrition procedures, assessments, and interventions in the treatment of an illness, injury, or disease. Communication between the primary care provider and the dietitian is established through MNT, in aspects of planning, evaluation reassessment, and outcome measurements. Participating patients can be screened by a registered dietitian, a dietetic technician, or other healthcare professionals.

Though research shows that HIV MNT reduces morbidity, health care costs, and patients’ length of hospital stays, lack of coverage by health care plans is a barrier for PLWHAs and others who need access to MNT. However, a
Right now there’s a big gap and it’s just work that can be done in the area of HIV, said Asarian-Anderson. “There is a lot of want information to be more available nationally and internationally. We need nutritionists throughout the U.S. bilingual listserv that links nutrition specialists with PLWHA. APALA, are in the process of creating a department of Health Services and the HIV and nutrition, the L.A. County Department of Health Services. “It’s difficult. We need nutritionists to be trained and bilingual nutritionists are in high demand. Training for nutritionists specializing in HIV/AIDS is very difficult and it’s ever changing. Medications are changing and treatments are changing,” she added.

In an attempt to raise awareness of HIV and nutrition, the L.A. County Department of Health Services and the APLA, are in the process of creating a bilingual listserv that links nutrition specialists throughout the U.S. “We want to establish communication nationally and internationally. We want information to be more available and translated in Spanish and in English,” said Asarian-Anderson. “There is a lot of work that can be done in the area of HIV. Right now there’s a big gap and it’s just not being filled. The listserv is just the first step. We’ll see where it goes from there.”

To spread the word on a local level that a nutritionally balanced diet for PLWHAs is not impossible, Fenton distributes to her clients a guide developed by God’s Love We Deliver, a New York City-based meals provider for PLWHAs that also provides patients ways to track their culinary practices and lists of restricted foods. Tailored to the language and practices of the community being served, the food guide meets cultural, ethnic, and linguistic needs, providing choices that reintroduce people living with HIV/AIDS to the joy of eating. “The food guide was really kind of cool because when you start circling [the food on the list] you find out you’ve got so many more food [choices] that provide the vitamins A and C,” said Shelley Singer of Tarzana, CA, and PLWHA panelist at the USCA.

“You really start finding how much [food] is available and so instead of restricting you, this opens it up. I hate to be told what I can and can’t eat. I can have sushi and I can have a dippy egg. I can have meat tartare. I can do what ever I want. It might kill me, but that’s my choice. So I have to choose and this guide gives me a choice,” said Singer.

Unfortunately, difficulty lies in trying to incorporate nutrition into programs that service people living with HIV. As a resident in a home for people living with HIV/AIDS, Long Beach, CA’s Kent Speirs encountered numerous difficulties with the full-time cook, who provided a high-sugar and high-fat diet. After multiple meetings between Speirs’ dietician and the house manager, proper dietary needs were finally met.

“I haven’t had anything fried in that house for a month,” said Speirs. “Now I’m going to be thrown into independent living, which is what I want to do very much. I’m as healthy now as I’ll ever be, so I need to make that move.”

Although difficult at times, nutritional solutions for people living with HIV/AIDS are obtainable with research, education, and a little creativity. According to Fenton, the solution lies in five simple steps: nutrition, activity, sleep, self-esteem, and loving yourself unconditionally.

For more information on HIV and nutrition, go to any of the Web sites listed in the HIV & Nutrition Resources box, or call the Office of Minority Health Resource Center at 800-44-6472.
Latinos living in the United States continue to be disproportionately affected by the HIV/AIDS epidemic. The AIDS case rate among Latino adults per 100,000 people was almost four times greater than the rate for Whites in 2001, according to the Centers for Disease Control and Prevention.

“Now that Latinos have become the largest minority population in the United States, it is imperative that a national effort to prevent HIV/AIDS in their communities be established. It is vital that those working in health and human services recognize the unique issues facing Latinos,” said Dr. Britt Rios-Ellis, project director, National Council of La Raza’s Latino Families HIV/AIDS Prevention Project, and associate professor of health sciences at California State University, Long Beach.

In 1999 NCLR launched the “Latina HIV/AIDS Needs Assessment,” later to be renamed as the “Latino Families HIV/AIDS Prevention Project,” following a grant provided by the Department of Health and Human Services’ Office of Minority Health. This project, in its earlier stages, aimed to determine Latinas’ HIV infection risk, barriers to prevention, exposure to media messages and HIV prevention education, as well as the needs of HIV-positive Latinas.

“There is a lack of understanding and information regarding Latinas and HIV infection. Because of this fact, we undertook a large-scale data collection effort with Latinas and their families to be better assess their needs,” said Rios-Ellis.

Over a three-year period, Rios-Ellis and her team collected qualitative data from 322 Latino men and woman at 14 sites throughout the United States (Miami, FL; San Juan, Puerto Rico; Paterson, NJ; Hartford, CT; New York City, NY; Harlingen, San Antonio, and El Paso, TX; Los Angeles and San Ysidro, CA; Boston, MA; Washington, DC; Durham, NC; and, Hattiesburg and Jackson, MS.) These men and women ranged in age from 15-71 and were from Puerto Rico, Mexico, Cuba, El Salvador, Dominican Republic, Honduras, Guatemala, Ecuador, Colombia, Panama, Costa Rica, Peru, Bolivia, Venezuela, and the U.S. Eighteen focus groups and in-depth interviews with high-risk and at-risk populations were conducted with HIV-positive Latinos and Latinas. The following themes were explored: gender, power, traditional male/female roles, machismo, family, communication, violence, religious, poverty, discrimination, barriers to risk reduction, recall of media message, preferences for prevention methods, change in risk upon immigration, infidelity, bisexuality, sex work, and disclosure.

Over 100 demographic questions were posed, including: age, income, marital status, educational status, preventive health behaviors, condom use, likelihood of future condom use, family size, personal contact with AIDS, language use in personal and social contexts, time in the U.S., place of birth, residence, and availability of a telephone.

“This project is a landmark effort to increase the understanding and information regarding Latinas and HIV infection,” said Carlos Urgarte, NCLR’s deputy vice president for health. “No study like this has ever been done and the findings it produced blew all of us away.”

“During the first two years of the data collection, we interviewed only Latinas. Through our dialogue, it became apparent we needed to expand the scope of the project in the third year to include HIV risk among Latino men and Latinas’ experience of HIV risk through sex with their partners,” Rios-Ellis said. “The women identified several risk behaviors for HIV infection, but they all said the same thing: ‘If you want to talk to us about HIV and AIDS, then you must talk to our husbands.’”

“When we interviewed the men, we were surprised to hear them speak so candidly, corroborating everything the women had said. The men confirmed a number of HIV risk behaviors, such as a reluctance to use condoms, infidelity, and failure to disclose HIV infection,” Rios-Ellis said. Other risk factors included the veil of silence surrounding sex in the Latino community, Latino men’s frequent sex with men regardless of self-identification as a homosexual or a bisexual, and the language barriers in accessing HIV/AIDS-related medical care.
“All of these behaviors really put Latinas at risk because the men are bringing home the disease. We have found that Latina housewives are at an extremely high risk of HIV infection, despite having only one sex partner and not using drugs,” Rios-Ellis said. “What this tells us is that Latino men must be included in any and all prevention messages.”

Getting the Message Out

According to Rios-Ellis, many people ask why HIV/AIDS rates continue to increase when messages are being translated and people are becoming more savvy as to HIV/AIDS and related risk behaviors.

“We wanted to know why Latinos are at risk. Perhaps the most important finding in our needs assessment is that the participants could not recall one HIV/AIDS prevention message targeting the Latino community,” Rios-Ellis said. “Not that we expect that any one message will dramatically affect HIV risk behavior, but our findings demonstrate that the few messages that are available are not reaching the population at all. Prevention efforts must be multifaceted and affect the context of HIV risk behaviors within the lives of Latinos.”

“Despite the fact that resources have been invested in preventing HIV in the Latino community, these findings show us this is not the case,” said Urgarte. “A ‘one-size-fits all’ media campaign approach is definitely not the answer to preventing HIV among Latinos.”

Through the needs assessment, the NCLR identified several recommendations made by the community to help develop HIV prevention programs. These recommendations include developing peer education and family sex education programs; creating culturally and linguistically appropriate and literacy-level-specific programs; linking other issues impacting HIV risk, such as substance abuse and poverty; involving men and families in HIV prevention; addressing the needs of HIV-positive Latinas; and creating HIV prevention television messages that involve men and family.

“These findings create a solid foundation on which to build new direction for HIV prevention in Latino communities,” Urgarte said. “We’ve gotten our marching orders from the community. They have told us what needs to be done. Our first step is to go out and raise the resources to support a large-scale HIV-prevention project in the Latino community.”

According to Rios-Ellis, NCLR is applying the information learned in the assessments to the creation of synergistic prevention programming and examining all of the findings and recommendations to decide what HIV prevention strategies to pursue moving forward.

Currently, NCLR has disseminated four prevention brochures, each one available in both English and Spanish, which target HIV-affected families, at-risk Latinas, Latino youth, and Latino men who have sex with men. To date, they have distributed nearly 50,000 brochures and are evaluating them at over 300 affiliate community-based organizations throughout the country.

The brochures cover topics such as “How to Communicate with Your Partner About Sex,” “How HIV/AIDS Affects Latino Families,” and “How to Talk to Your Family About Sex,” and draw on quotations gathered through the assessments.

NCLR is also working with It’s a Gas! in an effort to develop public service announcements with Latino artists to spread the message of HIV prevention within the Latino community and has started a dialogue with MTV Latino, BMI Recording, and BMG Recording, all of whom have expressed an interest in harnessing the power of celebrities to increase HIV prevention efforts in the Latino community.

For more information about the “Latino Families HIV/AIDS Prevention Project,” contact Dr. Britt Rios-Ellis at 562-430-0044.

*Statistics are from the CDC’s Year-End HIV/AIDS Surveillance Report, Table 8. HIV infection cases by sex, age at diagnosis, and race/ethnicity, reported through December 2001.
Many African American women, who live in rural areas of the United States, do not consider themselves at high risk for HIV, according to a new study, HIV-Associated Histories, Perception, and Practices Among Low-Income African American Women: Does Rural Residence Matter? As a result, these women often engage in more sexually risky behaviors than their urban and suburban counterparts, said study author Dr. Richard A. Crosby of the Rollins School of Public Health at Emory University in Atlanta.

In the U.S., the incidence of HIV infection and AIDS diagnoses is increasing rapidly among African American women. Compared to Hispanic women and White women, African American women are, and have been since the beginning of the AIDS epidemic, disproportionately affected by HIV/AIDS.

Though women infected with HIV by and large reside in urban epicenters and their surrounding suburbs, HIV transmission is increasing at rapid rates in rural counties throughout the nation, where messages about HIV prevention often take a backseat to the daily struggles of rural life. Unemployment, poverty, teenage pregnancy, sexually transmitted diseases, inadequate education, and little or no access to health care all contribute to the increase in HIV infection in rural counties.

Rural residents are also burdened by geographic isolation. Patients may be spread out over hundreds of miles. Many don’t have cars or access to other transportation to get to the doctor. For those who do, rugged topography, harsh winters, and long distances between towns can make traveling for medical care or social services an all-day effort.

Moreover, rural residents often lack health insurance and sufficient education to understand and adhere to complicated drug regimens. Thus, in many cases, patients keep their HIV status a secret for fear of being ostracized.

Researchers found that rural women were twice as likely as urban or suburban women to say that they did not have a preferred way to protect themselves against HIV and other STDs.

Rural women were also twice as likely to report never having used condoms or not using condoms because they believed their partner to be HIV-negative (despite their partner not having been tested for the virus). Rural women were also twice as likely to report that their past or current partner had not been tested for HIV.

Rural women were about half as likely to report that they had ever been diagnosed with syphilis or gonorrhea and were twice as likely to report not having received counseling about HIV during their last pregnancy.

Because the belief that their partner’s HIV status was based on something other than an HIV test, rural women may be more likely than non-rural women to take their partners’ word that they are HIV-negative, the authors added. Researchers suggest this discrepancy in HIV beliefs and prevention practices between urban and rural women may exist because rural African American women do not perceive HIV as a salient threat.

Getting the Message Out in Rural New York

The Catskill Rural AIDS Services (CRAS), located in Oneonta, New York, is working within upstate New York’s rural community to ensure that residents are informed about risk factors for the transmission of HIV/AIDS. “There are a lot of people whose perception of risk is a lot lower than reality,” said Chuck Christoffers of CRAS.

CRAS provides support and HIV-prevention services for Delaware and Otsego Counties, two of the most rural counties in New York state. “Because this area is so rural, all of our services are aimed at keeping people connected and informed about the disease,” said Christoffers. “It’s important that people know and remember that AIDS is out there.”

CRAS is currently providing support services, including dinners, social events, or an annual retreat weekend, to about 30-40 people infected or affected by HIV/AIDS. CRAS serves a diverse mix of people, including Caucasian, African American, and Hispanic men and women.

In addition to support services, it also focuses on education. When CRAS was organized in 1997, the founders added a
sufficient communication with study participants, and underscored the need for an in-depth review of the clinical trial process.

“Our report calls for making sure that all people enrolled in research studies, whether public or private, should be adequately protected and that research institutions’ leadership should continually ensure that participant protection are consistently being followed,” said Federman.

The committee found three core issues around which its analysis was focused. First, the common finding was widespread dissatisfaction with the current system and significant doubt exists regarding the current process. Second, institutional review boards, currently responsible for determining research ethics, are overburdened and in need of reform. Third, the existing regulatory framework cannot adequately address the ever-changing research environment.

“No research effort is utterly without risk,” said Federman. “Our committee believes that the promise of biological and social research can be fulfilled, but research can be done only with appropriate safeguards for participants, whose presence is indispensable to the progress that beckons us all.”

For more information about the report, contact the National Academy of Sciences’ Office of New and Public Information at 202-334-2138. Reports will be available later this year by calling 202-334-3313 or by visiting http://www.nap.edu

Major Recommendations

Daniel Federman, MD, Harvard Medical School, outlined Responsible Research: A Systems Approach to Protecting Research Participants recommendations at a public briefing late last year [October 3, 2002]. These included:

- All research staff should be educated in the ethical principles of responsible research;
- Patients and community representatives from all backgrounds should be recruited to help in the design, review, and conduct of clinical trials;
- Three types of review of proposed studies should occur before moving forward: an in-depth review of the scientific basis for research and possible risks, an evaluation of possible financial conflicts of interest of the investigators, and a comprehensive review by a research ethics review board;
- Obtaining informed consent should be an ongoing, rather than a finite, process, and the document used to obtain consent should be written in simple and objective language;
- All studies involving more than minimal risk should be monitored with prompt reporting of adverse events;
- Reasonable compensation should be provided to people who are harmed as a result of their participation in clinical trials; and
- Participant protection programs should strive for constant improvement.

Improving continued from 5

prevention mandate as a role secondary to providing support services to people infected with HIV. “We understand the importance of working to reduce the stigmas still attached to HIV/AIDS while at the same time ensuring that people who are not infected with the virus have the facts that will help them avoid getting infected,” Christoffers said.

To raise awareness of HIV/AIDS, CRAS has an active speakers’ bureau of people who are HIV-positive or living with AIDS. The speakers’ bureau travels throughout the region, presenting real-life stories to students, women’s groups, and nurses’ training days. “Though it can be somewhat anxiety-provoking to speak-out about an AIDS diagnosis, sharing a personal story is a sure fire way to raise awareness,” said Christoffers. “AIDS is hardly mentioned at all here—not in the newspapers, radio or television—and that really reinforces the myth that it does not exist.”

CRAS is also running an extensive public relations campaign in local media. “We have raised enough money to run weekly ads for our hotline in the free shopper-newspapers that circulate in both counties,” said Christoffers. “We also submit press releases about HIV and our organization to area newspapers and radio stations.”

In addition, CRAS has produced a public service announcement aimed at the rural population with the basic message that “AIDS is here,” Christoffers said. Because no one newspaper, radio station, or television station reaches the entire area, it is has been difficult to disseminate the message. In spite of this, CRAS has experienced a significant increase in calls to their hotline.

“I think our visibility is lifting the veil of silence around HIV/AIDS,” Christoffers said.

For more information about Catskill Rural AIDS Services, call 800-976-2727.◆
Bad Taste, Big Pills, and Side Effects Helping Kids Take Their Meds

Aimee Swartz

In the 1980s, the number of babies born with HIV was increasing at an alarming rate. These infants, often dubbed “AIDS babies” by the media, were the children of HIV-positive women, many of whom were still injecting drugs. Most of them were very ill and were either given away or taken away from their mothers. They were not expected to live until the age of five.

By the early 1990s, HIV-positive births began to decline thanks to the administration of anti-HIV medicine before, during, and after birth. According to the Centers for Disease Control and Prevention (CDC), offering AZT during the perinatal period to infected women during pregnancy and delivery, and to the infant after birth, resulted in decreases in mother-to-child transmission of HIV from 20-25 percent in the 1980s to 5-10 percent today. Before perinatal, or mother-to-child preventive HIV treatments were available, an estimated 1,000-2,000 infants each year were born in the U.S. infected with HIV.

The Incarnation Children’s Center (ICC) in Brooklyn, New York, has cared for many of these children, acting as surrogate families for children whose mothers are otherwise unable to care for them. Since its inception in 1989, the ICC has served hundreds of children, with stays ranging from several weeks to several years.

“Some of the children at the ICC have literally grown up here,” said Dr. Catherine Painter, ICC’s medical director. “When it first opened its doors to the AIDS community, the ICC was New York City’s only residence exclusively for this population. Since then we have served hundreds of children living with HIV.”

The ICC provides outpatient diagnostic and medical care for HIV-positive children, respite care for children whose natural and foster parents are temporarily unable to provide care, residential transitional care with 24-hour nursing for chronically-ill HIV infected children who do not need hospitalization but require round-the-clock care in a home-like setting, and access to clinical trials for new medications.

The ICC is a joint venture of the Catholic Home Charities, Columbia University’s Department of Pediatrics, Harlem Hospital’s Pediatric AIDS Program, and the Samuel and May Rudin Foundation. House in a four-story former convent in Manhattan’s Washington Heights neighborhood, the ICC’s bedrooms, play rooms, and backyard garden help to create a home-like atmosphere. A staff of nurses, doctors, social workers, and child care staff not only provide 24-hour medical attention, but also residential care for the Center’s 18 children living with HIV and AIDS.

The majority of children the ICC serves are African American or Hispanic, with ages ranging from birth to 19 years old. For the most part, the ICC develops long-term relationships with children who stay at the center for six months to a year and are having treatment adherence and compliance difficulties.

“At the beginning of the AIDS epidemic, the ICC saw a lot more infants and toddlers because there were a lot more pediatric infections at that time,” Painter said. “Now that these children are growing up, our population is largely skewed to adolescents.”

“The ICC has a unique combination of expertise and support that provides the child and his or her family with multidisciplinary services that are designed to meet the challenges of pediatric HIV/AIDS and to minimize its effects on their quality of life,” Painter said. “Often the biggest challenge are the many issues that affect treatment adherence.”

“The vast majority of children we see have had HIV since birth. As adults, HIV affects every organ of the body. The difference in children is that their immune systems are not as mature as adults living with HIV, so the affects of the disease on their body can be more challenging,” Painter explained. “I cannot stress enough the importance of treatment adherence in the long-term health of these children.

Many children have a hard time taking their medications for a host of reasons, including their bad taste, big pills, and side effects, Painter explained. “There are also a lot of mental health and psychosocial reasons the kids aren’t taking their medicines, and that is where the real challenge comes in. We work with the families to understand what’s going on in the home environment that might be having a negative affect on the child’s treatment adherence. While the children are here, we’re actually living with them so we can see how they react to having to take their medicine.”

The ICC uses a model of directly observed therapy (DOT), to ensure that the child takes his or her medication at the right time and in the right way. DOT refers to the taking of medications in the presence of a medical provider, so the provider can actually watch the pills being swallowed.

“Some of these families might be grappling with substance abuse or poverty or mental health issues, which makes it really hard to adhere to a complex medical regimen of taking several medications at the same time and in the right way,” Painter said. “Or sometimes, it’s just a matter establishing some consistency.”

“In a lot of families, medicating has become a battleground,” Painter said. “So we work to break that routine, allowing the

Adherence continued on 13
HIV/AIDS in the Workplace
Maintaining A Supportive and Productive Work Environment

Aimee Swartz

While much progress has been made in erasing the stigma facing people infected with HIV, living with AIDS, or impacted by the disease, many proactive measures still need to be taken to ensure quality of life for those directly or indirectly affected by HIV and AIDS.

The workplace is often the scene of prejudice, discrimination, and harassment for people infected or affected by HIV and AIDS. However, the workplace also offers many opportunities to change attitudes, provide support to HIV-positive people, and raise awareness about the disease.

HIV and AIDS are considered disabilities under the Americans with Disabilities Act. This law prohibits employment discrimination against a person who has HIV infection or AIDS, or against a person perceived as having HIV infection or AIDS. This applies to all conditions of employment, including hiring, advancement, and compensation.

In addition, the ADA requires employers of disabled people to make “reasonable accommodations.” This can include flexible work schedules, generous leave policies, reassignment to vacant positions, and part-time work.

To this end, many companies have created HIV/AIDS policies to define their positions and practices as they relate to employees with HIV infection. HIV/AIDS policies set the standards of behavior expected of all employees, establish compliance with all Federal, state, and local laws, and provide additional resources. Companies with effective policies in place are more prepared to manage AIDS in their workplace.

Creating Corporate HIV/AIDS Policies—Where to Begin?

The Centers for Disease Control and Prevention’s (CDC) Business Responds to AIDS and Labor Responds to AIDS Programs help large and small businesses and labor unions meet the challenges of HIV/AIDS in the workplace and the community. These programs partner with businesses and labor unions, as well as trade associations, public health departments, AIDS service organizations, and government agencies to promote the development of comprehensive workplace HIV/AIDS programs.

These CDC programs work to support leadership and create resources not only to eradicate the HIV/AIDS epidemic, but also to address its social and economic consequences, particularly within the workplace. The program accomplishes this through technical assistance and the implementation of HIV/AIDS workplace programs that combat prejudice and fear and foster community activism, volunteerism, corporate philanthropy, and leadership.

These programs recommend five components for implementing comprehensive HIV/AIDS programming: (1) HIV/AIDS policy development; (2) manager/labor leader training; (3) employee education; (4) education for employees’ families; and (5) community service and volunteerism.

Likewise, the American Red Cross’s Workplace HIV/AIDS program was created to help businesses maintain a supportive and productive work environment for everyone and helps businesses meet the need for reliable, factual information about HIV and AIDS.

The Red Cross not only provides a “Your Job and HIV” brochure and “America at Work: Living with HIV” video, but has also created a modular program for a variety of workplaces. The program:

- Provides to employees and employers reliable information about HIV and AIDS, including facts about transmission and prevention;

Adherence continued from 12

children to become active participants in their own medication.” The ICC works with the children to establish medication schedules that are comfortable. This gives them more responsibility as they get older and learning to self-medicate.

“We might start by giving them a beeper, so they know when to come to take their meds. Then we might give them a watch, so it’s on them to look at the time to go get their meds,” Painter explained. “The last step of course is getting them to the point where they can actually take the meds themselves.”

“Adolescents are unique because as they grow up they become more aware and more responsible. At the same time, they are grappling with their diagnosis. With that comes very complex issues that intersect, for example, with disclosure or control,” Painter said. “Let’s say they just lost a parent and the one way to have control over their life is to stop taking their medicine. Having to take medicine also reminds them of something they don’t want to think about.”

“We cannot underestimate the affect of mental health on treatment adherence, just as we cannot underestimate the affects of treatment adherence on keeping the virus at bay,” Painter said. “Our goal is that discharge from the ICC will enable their adherence and compliance to continue, eventually saving their lives,” Painter added.

For more information about the Incarnation Children’s Center and their program, call 212-928-2590. ◆
Encourages discussion about topics including employee and employer rights and responsibilities, legislation such as the ADA, medical confidentiality, and reasonable accommodation;

Helps employees understand that they can work safely, without fear, alongside people living with HIV or AIDS;

Promotes a compassionate environment for workers living with HIV, or those whose family members, friends, or partners may be HIV-positive;

Includes a special interactive module for managers and supervisors that prepares them for the unique challenges presented by HIV/AIDS in the workplace; and

Identifies local resources and services.

In addition, the Global Business Coalition on HIV/AIDS, established in 1997, is a rapidly-expanding coalition of international businesses dedicated to combating the AIDS epidemic through the business sector. As part of its mission, the coalition encourages business to adopt HIV/AIDS friendly work environments. Membership consists of nearly 100 international companies, from Exxon Mobil to Coca-Cola to Levi Strauss, who are committed increasing HIV/AIDS awareness.

The Global Business Coalition on HIV/AIDS has established an advisory working group of representatives from leading companies and partner organizations to provide guidance on the development of the Workplace Protocols and Best Practices.

The policy will provide detailed advice to company managers wishing to implement comprehensive employee HIV programs, particularly those operating in resource limited settings. It will include in-depth descriptions of interventions including risk assessment, non-discriminatory policies, prevention and awareness programs, condom distribution and treatment of sexually transmitted diseases, voluntary counseling and testing, care support and treatment, and monitoring and evaluation.

For more information about the Business Responds to AIDS and Labor Responds to AIDS Programs, visit http://www.hivatwork.org

For more information about the American Red Cross Workplace HIV/AIDS program, visit http://www.redcross.org/services/hss/hivaids/work2.html

For more information about the Global Business Coalition on HIV/AIDS http://www.businessfightsaids.org

Organizations

AIDSinfo
P.O. Box 6303
Rockville, MD 20849-6303
800-HIV-0440 (800-448-0440)
http://www.AIDSinfo.nih.gov

American Red Cross Workplace HIV/AIDS Program
431 18th Street, NW
Washington, DC 20006
202-639-3520
http://www.redcross.org/services/hss/hivaids/work2.html

Asian & Pacific Islander Wellness Center
730 Polk Street, 4th floor
San Francisco, CA 94109
415-292-3400
http://www.apiwc.org

Business Responds to AIDS and Labor Responds to AIDS Programs
P.O. Box 6003
Rockville, MD 20849-6003
800-458-5231
http://www.brta-lrta.org/

Catskill Rural AIDS Services (CRAS)
66 Chestnut Street,
Oneonta, NY 13820
607-436-9554
http://www.catskill-aids.org/

Global Business Coalition on HIV/AIDS
1515 Broadway, 45th Floor
C/o Viacom
New York, NY 10036
212-846-5893
http://www.businessfightsaids.org

Incarnation Children’s Center
142 Audubon Avenue
New York, NY 10032
212-928-2590
http://www.icc-pedsaids.org/

Metro TeenAIDS
P.O. Box 15577
Washington, DC 20003-5577
202-543-9355
http://www.metroteenaids.org

National Academy of Sciences
The National Academies
500 Fifth Street, NW
Washington, DC 20001
202-334-2000
http://www.nas.edu
Resources

2002 Abbreviated Guide to Medical Management of HIV Infection
The Abbreviated Guide to Medical Management of HIV Infection is intended for bedside clinical management decisions. The parent text, Medical Management of HIV Infection, provides the scientific foundation for recommendations.
This Guide provides complete recommendations but without the background data and references of the parent text; the Guide came out 6 months later, so it is more up to date; and it has new features in the drug section.
For more information, go to the Johns Hopkins AIDS Service Web site at http://hopkins-aids.edu/publications/abbrevgd/abbrevgd.pdf

This directory is a compilation of HIV/AIDS primary care, testing & counseling and support services providing care to rural areas in the United States. Program service descriptions as contributed by providers are included.
For more information, contact the National Rural Health Association at 816-756-3140 or go to http://www.nrharural.org/providers/HIV-Dir.html

APIs in CPGs: a Manual for Asians and Pacific Islanders Who are New to the Community Planning Group Process
This manual contains basic information on: the CPG process overall; stereotypes about APIs and how they may affect participation on CPGs; what to expect at your first CPG meeting; behavioral science and epidemiology; epidemiologic profiles and conducting needs assessments; prioritization process; recruitment; coalition and alliance-building; and leadership.
For more information, contact the Asian & Pacific Islander Wellness Center at 415-292-3400 or http://www.apiwellness.org

An Introduction to Clinical Trials
Choosing to participate in a clinical trial is an important personal decision. This online source’s frequently asked questions section provides introductory information about clinical trials. In addition, it is often helpful to talk to a physician, family members, or friends about deciding to join a trial. After identifying some trial options, the next step is to contact the study research staff and ask questions about specific trials.
For more information, go to the ClinicalTrials.gov Web site at http://clinicaltrials.gov/ct/gui/info/resources

Physicians Guide to Working with Asians and Pacific Islanders Living with HIV
This guide from the Asian and Pacific Islander Wellness Center looks at treatment goals and interventions to address cultural factors of Asians and Pacific Islanders living with HIV.
For more information, contact the Asian & Pacific Islander Wellness Center at 415-292-3400 or http://www.apiwellness.org/v20/physician/clinicianguide.pdf

What Are U.S. Latinos’ HIV Prevention Needs? (17ER)
This fact sheet provides the prevention needs, barriers to prevention, and cultural barriers for U.S. Latinos.
For more information, call the National Prevention Information Network at 800-458-5231 or go to HIV InSite at http://hivinsite.ucsf.edu/prevention

HHS Briefs

Caribbean Project
The Health Resources and Services Administration’s HIV/AIDS Bureau (HAB) has funding available for the Special Project of National Significance-Models of Comprehensive Care for Caribbeans Living in the United States (SPCCL).
The funding is to develop and evaluate peer support interventions targeted towards HIV infected persons of Caribbean origin residing in the U.S., and to support development of human and organizational clinical capacity in the Caribbean.
Letters of intent are due March 3, and the application deadline is April 18, 2003.
For more information on this grant, go to http://hab.hrsa.gov/grants/Caribbean2003.htm

Prisoners and Hepatitis C
In the January 24, 2003, Morbidity and Mortality Weekly Report, the Centers for Disease Control and Prevention (CDC) urged states to test all prisoners with a history of intravenous drug use for hepatitis C. The CDC reported that of the one million hepatitis C infected inmates released annually, it is unknown how many are aware of their infection. Somewhere between 16-41 percent of inmates are infected, depending on the state.
Federal law requires states to treat sick inmates, but some prison officials argue that money is not available for tests and treatments for hepatitis C. CDC’s recommendations spell out the education and care prisons should give inmates with the disease and say targeted testing would find most cases.
For more information, go to http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5201a1.htm
Conferences

March 30 - April 2, 2003

15th National HIV/AIDS Update Conference
American Foundation for AIDS Research
Miami, FL
Contact the National HIV/AIDS Update Conference (NAUC) at http://www.nauc.org for more information.

April 27 - May 1, 2003

16th International Conference on Antiviral Research
Savannah, GA
Contact the International Society for Antiviral Research (ISAR) at http://www.isar-icar.com for more information.

May 1-5, 2003

Voices 2003: The National Conference on HIV/AIDS and Children, Youth, and Families
Washington, DC
Contact the AIDS-Alliance at 202-785-3564, ext. 34, or at lhorton@aids-alliance.org for more information.

May 18 - 20, 2003

AIDSWatch 2003
Washington, DC
Contact National Association for People With AIDS at aidswatch@napwa.org or http://www.napwa.org/aidswatch.htm for more information.