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AIDS ALERT

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Fear of disclosure and popular stigmas contribute to bad outcomes

CDC finds that 1 in 5 people stigmatize HIV

A number of new surveys show that public and even physician attitudes about HIV infection are surprisingly misinformed two decades into the epidemic.

These findings and another body of research about how HIV-infected workers continue to fear disclosure of their infection status despite protection under the Americans with Disabilities Act (ADA) may suggest that HIV stigma could have a negative impact on health outcomes because it affects decisions made by people with the disease.

"The reason people fear disclosure is revealed in a number of surveys done very recently looking at the issue of HIV and stigma," says **Catherine Hanssens**, a lawyer and director of the AIDS Project at Lambda Legal Defense and Education Fund in New York City.

A recent survey conducted by the Centers for Disease Control and Prevention in Atlanta found that 18.7% of 5,641 people questioned agreed with the statement, "People who got AIDS through sex or drug use have gotten what they deserve." **(See chart on CDC survey, p. 15.)**

The survey also found that one out of four people who stigmatized HIV infection and about 40% of all those surveyed believed that the virus could be transmitted through sharing a drink with someone who is infected or through an infected person sneezing or coughing.[1]

HIV-stigmatizing responses were more common among men, whites, people aged 55 or older, those with incomes below $30,000 a year, those with only

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AIDS Alert International

COMING IN FUTURE ISSUES

■ **HIV sometimes hits gut hardest:** New research could point the way to treatments that target the largest immune organ of the body

■ **AZT doesn't protect thymic function in young cats:** Research suggests more challenges in treating HIV-infected infants if goal is to improve immune response

■ **Oral rehydration solution:** ORS may be the best way to treat HIV-related diarrhea and wasting

■ **Race to unlock interleukin-2 secrets:** HIV investigators around the world are studying the use of IL-2 combined with antiretroviral therapy

■ **Youths and prevention:** Entering the third decade of the epidemic, what are some new strategies for targeting youths with HIV prevention messages?

a high school education, and those in poorer health.

This research demonstrates that the public continues to harbor as much misinformation about how HIV is transmitted as people did a decade ago, Hanssens says.

"This is complicated by the fact that studies also show that the general public has far less empathy for people with HIV than the general public did a decade ago," Hanssens adds. "Far more people believe that people with HIV who got infected got what they deserved."

The CDC study concludes that it's important for HIV-infected people to be diagnosed and treated early because this will lead to improved health and productivity, reduced hospitalization costs, and decreased incidence of transmission of HIV by infected people who do not know their HIV status.

Fear of stigma could affect health choices

"However, HIV-infected persons who fear being stigmatized are typically reluctant to acknowledge risk behaviors, avoid seeking prevention information, and may experience real or perceived barriers to prevention and other health-care services," the study states.

Another recent study highlighted how the stigma, which often is extended to gay men in general, even affects physicians.

Cornell University in Brooklyn, NY, asked 324 residents and faculty at a New York City teaching hospital whether they would be reluctant to perform mouth-to-mouth resuscitation (MMR) on various groups of people. This anonymous survey showed that 70%-80% of physicians said they would perform MMR on a newborn or child; 40%-50% would perform MMR on an unknown man; but only 20%-30% would perform MMR for a trauma victim or potentially gay man. A chief factor associated with MMR reluctance was a higher perceived risk of contracting HIV from MMR.[2]

"These are physicians who apparently are not aware of the fact that giving mouth-to-mouth resuscitation poses a barely measurable risk of HIV transmission," Hanssens says. "It's purely theoretical and has never been documented."

When surveys like this show how even physicians are vulnerable to homophobia and misconceptions about HIV transmission, then it's easy to

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HIV-Related Knowledge — Continued

TABLE 1. Percentage of respondents who gave stigmatizing response*, by demographic characteristics and knowledge of modes of HIV transmission — United States, 2000

Characteristic	No.†	(%)	(95% CI§)
Sex			
Male	2631	(21.5)	(19.7%–23.2%)
Female	2779	(15.9)	(14.4%–17.4%)
Race/Ethnicity			
White, non-Hispanic	4146	(20.8)	(19.4%–22.1%)
Black, non-Hispanic	557	(7.0)	(4.7%– 9.4%)
Hispanic	498	(11.2)	(8.1%–14.3%)
Other¶	243	(27.9)	(21.7%–34.2%)
Age group (yrs)			
18–24	571	(15.5)	(12.1%–18.8%)
25–29	522	(11.4)	(8.4%–14.3%)
30–34	583	(13.0)	(10.0%–16.0%)
35–39	652	(15.6)	(12.5%–18.6%)
40–44	659	(13.8)	(10.9%–16.8%)
45–49	630	(17.3)	(14.0%–20.6%)
50–54	533	(15.6)	(12.2%–19.0%)
55–64	582	(21.9)	(18.2%–25.6%)
≥65	902	(35.2)	(31.7%–38.7%)
Education			
<High school	504	(23.4)	(19.2%–27.5%)
High school	1732	(21.7)	(19.5%–23.8%)
Some college	1906	(16.8)	(14.9%–18.7%)
Bachelor's degree	1000	(15.4)	(12.9%–17.9%)
Graduate degree	465	(17.7)	(13.9%–21.6%)
Income level			
<$20,000	598	(21.8)	(18.0%–25.5%)
$20,000–$29,999	570	(25.0)	(21.0%–29.0%)
$30,000–$39,999	777	(18.0)	(15.0%–21.0%)
$40,000–$49,999	713	(18.4)	(15.3%–21.6%)
$50,000–$74,999	1342	(16.6)	(14.4%–18.8%)
≥$75,000	834	(18.0)	(15.0%–20.9%)
Health status			
Excellent	1065	(17.5)	(15.0%–20.1%)
Very good	2093	(18.8)	(16.9%–20.6%)
Good	1777	(17.3)	(15.4%–19.3%)
Fair or poor	694	(23.6)	(20.0%–27.2%)
Region**			
Northeast	924	(18.1)	(15.4%–20.9%)
Midwest	1177	(19.9)	(17.3%–22.5%)
South	1836	(17.9)	(16.0%–19.9%)
West	1295	(19.0)	(16.6%–21.4%)
Transmission knowledge			
Sharing a drink			
Misinformed††	2269	(25.1)	(23.1%–27.1%)
Informed§§	3355	(14.4)	(13.0%–15.7%)
Cough or sneeze			
Misinformed	2307	(25.4)	(23.4%–27.4%)
Informed	3318	(14.0)	(12.6%–15.3%)
Total	**5641**	**(18.7)**	**(17.5%–19.8%)**

* Persons who strongly agreed or agreed with the statement, "People who get AIDS through sex or drug use have gotten what they deserve."
† Numbers differ because of item nonresponse. Chi-square tests indicated significant differences ($p<0.05$) among categories for each variable except region.
§ Confidence interval.
¶ Numbers for races/ethnicities other than black, white, and Hispanic were combined because, when analyzed separately, data were too small for meaningful analysis.
** *Northeast*=Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont; *Midwest*=Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin; *South*=Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia; *West*=Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming.
†† Transmission is very likely, somewhat likely, or somewhat unlikely.
§§ Transmission is very unlikely or impossible.

Source: Centers for Disease Control and Prevention. HIV-related knowledge and stigma — United States, 2000. *MMWR* 2000; 49:1062-1064.

understand how the general public has these same attitudes, Hanssens adds.

Stigma and fear of HIV-infected people extend to the workplace, where HIV-infected employees may be risking their own health in order to keep their HIV status a secret for as long as they possibly can.

"The workplace atmosphere is not institutionalized, and that poses a problem with HIV, because too many people are taking their disability leave early, and that hurts their immune systems, because as soon as people get up and have nowhere to go in the morning, depression hits and the body goes," says **James D. Slack**, PhD, professor and chairman of the department of government and public service and senior scientist in the Center for AIDS Research and the School of Medicine at the University of Alabama at Birmingham.

Some HIV patients wait too long for help

"HIV-infected employees would rather wait until they qualify for disability leave for six months or a year, and not say anything until then," Slack explains. "Then they take their disability leave, rather than seeking reasonable accommodations that would prolong their stay at work and their lives."

AIDS advocates say it's only natural that HIV-infected employees are wary of disclosing their infection status, given the apparent stigma and discrimination they might experience once people know they are infected.

"Stigma is a very real issue for people living with HIV and AIDS," says **Tanya Ehrmann**, director of public policy for AIDS Action in Washington, DC.

One study of HIV-infected women found that the women were more afraid of disclosure and stigma than they were of dying.[3]

"It's unfortunate that discrimination against people living with HIV / AIDS exists, particularly given all we know about transmission of the virus," Ehrmann says. "But it certainly is a very real problem."

Ehrmann says that rather than blaming people with HIV / AIDS for not disclosing their status, governmental, health, and community organizations should work on making it safe for people to make that disclosure.

Slack's research, which is expected to be published in 2001 in *Policy Studies Journal* and *Public Administration Quarterly*, suggests that workplace disclosure can even pose a challenge to HIV-infected employees in areas of the country that are generally seen as more tolerant and knowledgeable about HIV and AIDS, such as the San Francisco Bay area of California.

One HIV-infected California man Slack interviewed said it was harder for him to tell people at work about his HIV status than it was to tell anyone else in his life. When the man finally did tell his company's personnel director, he described how he felt as though he was going to black out during the discussion.

In other cases, employees told how they experienced harassment by management and coworkers after disclosing their HIV status. One man said his manager spread rumors about him at a national corporate meeting. Another man claimed to have been denied three promotions on the basis that his superiors felt that these positions would be harmful to his health.

The U.S. Supreme Court has upheld the rights of HIV-infected Americans to have some job protections under the Americans With Disabilities Act (ADA), but a pending case heard by the court and another ADA court decision have muddied the waters.

"We're waiting to hear from the court on whether the ADA is constitutional," Hanssens says. **(See story on the Supreme Court's decisions about ADA, p. 18; and story on how HIV-infected people may obtain ADA protections, p. 17.)**

It's difficult to make any general statements about workplace atmospheres based on anecdotal evidence, but it's apparent that the HIV stigma still thrives, says **Ben Klein**, an attorney with Gay and Lesbian Advocates and Defenders in Boston.

"While there have been some gains in terms of establishing legal rights, there has been only a marginal improvement, and in my view only a very slight decrease, in the stigma attached to HIV," Klein says. "It's really astounding how much it is still a feared and misunderstood condition on a widespread social basis."

References

1. Centers for Disease Control and Prevention. HIV-related knowledge and stigma — United States, 2000. *MMWR* 2000; 49:1062-1064.

2. Brenner BE, Van DC, Lazar EJ, Camargo CA. Determinants of physician reluctance to perform mouth-to-mouth resuscitation. *J Clin Epidemiol* 2000; 53:1054-1061.

3. Gray JJ. The difficulties of women living with HIV infection. *J Psychosoc Nurs Ment Health Serv* 1999; 37:39-43. ■

How much does the ADA protect workers with HIV?

Patients' health care may be at risk

The Supreme Court's decision is still out on giving workers a clear interpretation of their protections under the Americans With Disabilities Act (ADA).

However, AIDS legal experts say the ADA does offer protection to HIV-infected workers, and these employees should seek reasonable accommodation at their workplaces whenever possible and necessary. Despite this seemingly good news, there is evidence that at least some HIV-infected patients have postponed antiretroviral treatment or taken early leave from their work rather than be faced with disclosing their HIV status.

"When people are trying to decide whether to tell a boss or supervisor that they're positive, every situation is different," says **Ben Klein**, an attorney with Gay and Lesbian Advocates and Defenders in Boston. "It's based on their own status level and the environment of the workplace. Some people struggle with whether they need to disclose their HIV status in asking for reasonable accommodation."

HIV disability isn't self-evident

The ADA provides anti-discrimination protection to disabled employees.

"Most anti-discrimination laws don't require documentation [of disabilities] because they're self-evident," says **James D. Slack**, PhD, professor and chairman of the department of government and public service and senior scientist in the Center for AIDS Research and the School of Medicine at the University of Alabama at Birmingham.

"But with HIV, there is no way you can tell who is HIV-positive and who isn't, and hence it becomes a little more difficult to document that," Slack adds.

Therefore, employees who are HIV-positive may have to disclose their status to certain managers in their company so that if they are discriminated against based on their disability, they have proof that the managers knew of their disability. Managers also will need to know of a worker's disability if the worker wants managers to make changes to the individual's job to help the disabled worker better handle the job requirements.

Physicians may be called upon to verify an employee's disability. While this might sometimes mean confirming that the employee is HIV-positive, it doesn't necessarily have to mean disclosing the person's HIV status, Klein says.

Employers have a right to ask what the patient's disability is that necessitates the reasonable accommodation. But employees do not have to give employers every detail of their health condition, he explains.

"There are strategies people can think about using if they want to disclose that they have a health condition that would qualify as a disability under the ADA, but they don't want to specifically name their HIV status," he says. "If an employer insisted on knowing the nature of the disability, it would be sufficient if a doctor said an employee with a history of respiratory problems becomes fatigued because of his or her respiratory problems and needs accommodation."

This strategy won't work for all HIV-infected patients, because many are symptom-free, but it will work for some. It's up to doctors to help patients when they need some ADA protection but are fearful of disclosing their HIV status to their boss, Klein says.

If an employee fears disclosing his or her HIV status to an employer and is subsequently fired without a known cause, the employee has not necessarily lost all ADA protection, Klein says.

"In many situations, the employer may not have confirmation but may assume that someone is HIV-positive or has AIDS based on the employer's own perception of the disease," he notes. "They may think this person is a gay man and is losing weight or is taking a lot of medications, and so they jump to the assumption that the person has HIV."

When this happens, the employee could file a lawsuit against the employer and could make use of evidence that the employer was operating under the assumption that the patient had HIV, Klein says.

Still, this is more difficult course of action than forthright disclosure.

"The only way to force a company to consider accommodations is by standing up on that bus," Slack says. "If you don't, you are hoping for the best, and most people who do that tend to get sick quicker and fall into poverty much quicker, using their life savings to cover prescriptions that their health insurance policies

already cover, and they don't take sick days because they wait until they're really sick, so they tend to die sooner."

When advising HIV-infected people about when and how to disclose their HIV status, it really depends on the individual person's work setting, position, and personal views, says **Catherine Hanssens**, a lawyer and director of the AIDS Project at Lambda Legal Defense and Education Fund in New York City.

"There still are some highly paid professional men who wouldn't dream of disclosing it," Hanssens says. "And there are some people who will disclose and let the consequences be damned."

In many cases, the best approach is to disclose one's HIV status to management so that if there is discrimination, it can be proved that there's a connection, she adds. "But I'd be more cautious in advising someone who works on a construction site where he could be hit from three stories overhead by a dropped screwdriver."

Document positive reviews in writing

Whether they disclose or not, HIV-infected patients should document in writing all positive reviews and aspects of their work performance. They could write a supervisor who had verbally paid them a compliment and say, "I really appreciate the support, and the fact that you think I'm doing an excellent job really means a lot to me," suggests Hanssens.

"Just don't make it look like you're creating a paper trail," she says. "On the flip side, if you are not doing well on your job, then your HIV status or any disability is not going to protect you."

In some cases, perhaps the only reasonable accommodation an HIV-infected employee needs is to be able to refrigerate medication. Employees who fear disclosure need not say what the medication is for, but they should write a memo making the request, Hanssens says. It could read: "I have a disability that requires me to take medications regularly, and I need a refrigerator to do that."

HIV-infected employees should be realistic about their expectations for reasonable accommodation at work, Hanssens says.

For instance, for an employee who is self-directed and is not required to be present from 8 a.m. to 5 p.m., it might be reasonable to ask for various afternoons off to see a doctor.

But if the worker is a receptionist and the employer would have to hire someone to fill in whenever the employee took off, absences might not be considered reasonable, and that employee should consider finding a more flexible position, Hanssens says.

Slack conducted research of how reasonable accommodations were interpreted and used by employers of a small group of HIV-infected men and women in California. He found that several participants were permitted to use flextime and were given equipment that enabled them to work partially at home.

Some other ways their disability was handled include these:

- One person was allowed to work indoors during the winter months.
- Another man was given five-minute breaks whenever he needed them.
- One man could take paid time off for counseling sessions when he could fit this in his schedule.
- A cashier with neuropathy in his feet was given a bar stool to sit on.
- Several were allowed to take unpaid time off for medical reasons. ■

Here's a look at status of court rulings on ADA

First key decision involved HIV-infected person

The U.S. Supreme Court first issued a decision on HIV and the Americans With Disabilities Act (ADA) on June 25, 1998, and for AIDS advocates it was a high point in their efforts to provide legal protection to HIV-infected people.

However, there subsequently have been some disappointing ADA decisions by the nation's highest court, and while it's debatable whether these will affect HIV patients, it's clear they won't help.

The ADA requires individuals claiming its protection to show that they have an impairment that substantially limits a major life activity or that they are regarded as having such an impairment by the person discriminating against them.

Here's a look at the court's rulings with regard to HIV and the ADA:

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AIDS ALERT INTERNATIONAL

Worldwide AIDS statistics offer little reason for optimism

About 26 million infected in Africa

The latest statistics of world AIDS infections and deaths paint a dismal portrait of what life is like on planet Earth during what everyone hopes is the peak of the AIDS epidemic.

"In 2000, three million people died from HIV and AIDS, which continues to make it the leading cause-specific death in the world," says **Peter Piot**, MD, PhD, executive director of UNAIDS of Geneva, Switzerland. Piot discussed the latest trends and statistics at a telephone briefing held by UNAIDS and the World Health Organization (WHO) of Geneva in late November in conjunction with World AIDS Day.

Moreover, there have been 58 million people infected with HIV worldwide, a number that would encompass the entire population of France. And about 22 million people have died of AIDS. "This is more than we thought of [the number] of people who died of the other big epidemic of the 20th century, which was the Spanish flu," Piot says. **(See chart on worldwide HIV/ AIDS statistics, p. 20.)**

Even what could be seen as good news is not as hopeful as the numbers would first appear.

HIV prevalence in some sub-Saharan African nations is becoming stable, with slightly fewer cases of HIV infection than in 1998. In Uganda and Zambia, the slowing of new infections could be attributed to prevention efforts, but this is unlikely to be the case in other countries, such as Kenya and Tanzania, Piot says. Instead, there probably is epidemic fatigue at work in sub-Saharan Africa, where just about everyone at high risk for HIV probably has it, and therefore fewer people are available to become newly infected, he explains.

"The big question for Africa is what is going to happen in Nigeria, where we have a threshold, I believe, of 5% prevalence in the adult population," Piot says. "Will this go up or remain at that level?"

The infection rate in North Africa and the Middle East has increased dramatically in the past year. At the end of 1999, UNAIDS reported 220,000 people living with HIV / AIDS in that region of the world. At the end of 2000, the number had risen to 400,000. The new infection rate more than quadrupled from 19,000 in 1999 to 80,000 this past year.

UNAIDS officials also are worried about Eastern Europe, where the number of people living with HIV / AIDS climbed from 420,000 to 700,000. In Russia, it's estimated that the number of people living with the disease has more than doubled from the 130,000 infected at the end of 1999 to 300,000 at the end of 2000. **(See Q&A on the status of the HIV epidemic in Russia, p. 21.)**

"So there were more new infections [in 2000] in Russia than there were in all previous years combined," Piot says. "Something similar is happening in smaller countries in the region, namely Estonia and Uzbekistan."

Although UNAIDS has had some difficulty estimating HIV rates, particularly in countries where testing and surveillance are uncommon, Piot and other UNAIDS officials say they are confident in the accuracy of the current estimates. Also, they are cautious about predicting when this epidemic will peak because earlier predictions have been proven wrong.

"It's definitely true that the size of the epidemic was heavily underestimated in 1990," Piot says. "I think one of the big mistakes made was [the prediction] that there would be a peak occurring several years ago."

Not only has the world not yet reached that peak, but the number of AIDS cases is nearly twice as large as earlier estimates.

"No model predicted that on a countrywide basis one could reach the 35% infection rates like we have now in Botswana," Piot explains.

Regional HIV/AIDS Statistics and Features, End of 2000

Region	Epidemic started	Adults & children living with HIV/AIDS	Adults & children newly infected with HIV	Adult prevalence rate	% of HIV-positive adults who are women	Main mode(s) of transmission for adults living with HIV/AIDS
Sub-Saharan Africa	late '70s-early '80s	25.3 million	3.8 million	8.8%	55%	Hetero
North Africa & Middle East	late '80s	400,000	80,000	0.2%	40%	Hetero, IDU
South & South-East Africa	late '80s	5.8 million	780,000	0.56%	35%	Hetero, IDU
East Asia & Pacific	late '80s	640,000	130,000	0.07%	13%	IDU, hetero, MSM
Latin America	late '70s-early '80s	1.4 million	150,000	0.5%	25%	MSM, IDU, hetero
Caribbean	late '70s-early '80s	390,000	60,000	2.3%	35%	Hetero, MSM
Eastern Europe & Central Asia	early '90s	700,000	250,000	0.35%	25%	IDU
Western Europe	late '70s-early '80s	540,000	30,000	0.24%	25%	MSM, IDU
North America	late '70s-early '80s	920,000	45,000	0.6%	20%	MSM, IDU, hetero
Australia & New Zealand	late '70s-early '80s	15,000	500	0.13%	10%	MSM
TOTAL		**36.1 million**	**5.3 million**	**1.1%**	**47%**	

Source: Joint United Nations Programme on HIV/AIDS. December 2000. Geneva.

There is no example in history of an epidemic taking a course like HIV in sub-Saharan Africa, where there's been a dramatic explosion of HIV infection, says **Bernhard Schwartlander**, MD, chief epidemiologist for UNAIDS.

"The other question is where is this thing going," Schwartlander says. "As we were wrong 10 years ago, you may ask how certain can you be that our estimates are on the nose."

The key to the future of the epidemic lies in Nigeria, India, and China, he says.

If Nigeria follows the pattern of South Africa, the epidemic could explode in that large nation. This all depends on the extent to which HIV transmission spreads to the general population through heterosexual contact, Schwartlander says.

While there is a potential for that to occur, UNAIDS and WHO officials hope Nigeria will avert disaster by prevention efforts and making use of the world's knowledge about HIV / AIDS, he adds.

If even parts of India and China follow the trend of sub-Saharan Africa, there would be plenty of fuel to keep the epidemic burning for decades.

"We don't believe a whole country like India will have an epidemic," Schwartlander says. "But there are states in India where we have substantial spread already."

As the world has focused on the AIDS pandemic in sub-Saharan Africa, it has become increasingly clear that the disease has entirely different significance in poor nations where there is little or no access to antiretroviral therapies, testing, and treatment of opportunistic infections.

In eight African countries, about one-third of the youths who are now age 15 will die of AIDS. About 15% of all adults in these countries are infected with HIV. In South Africa, where one

out of every five adults has HIV, AIDS will wipe out the equivalent of $22 billion from its economy. In Botswana, where nearly 36% of adults are HIV-infected, AIDS will consume 20% of the government's budget and reduce the income of the nation's poorest citizens by 13%.

In sub-Saharan Africa, the number of deaths from AIDS is about 9.5% of the number of people living with HIV / AIDS infection. By contrast, in North America, the number of AIDS deaths is only about 2.2% of the number of people living with the disease.

"HIV shows very much the disparities between rich and poor," says **Elhadj Sy**, UNAIDS representative in the United States.

These disparities can be bridged through partnerships between the nations that have resources and those that do not, Sy says.

"We still have an epidemic, and the numbers and figures show that, but we can also say there is hope," he adds. "This hope, we believe, should be the basis for real partnership, for an expanding response, and for a direct response." ■

Russia's HIV epidemic spreads to heterosexuals

UNAIDS coordinator discusses current challenges

(Editor's note: ***Tatiana Shoumilina****, project coordinator for UNAIDS in Moscow, discussed the HIV epidemic's toll on Russia with* AIDS Alert *shortly after UNAIDS released its most recent statistics, showing that HIV cases have skyrocketed in Eastern Europe and particularly in Russia. Shoumilina's responses to this Q&A came via the Internet in late December.)*

AIDS Alert: The 2000 UNAIDS report says the Eastern European AIDS epidemic is fueled primarily by injection drug use. Are you currently seeing evidence that the epidemic is spreading to heterosexual and pediatric populations, and, if so, how bad is that problem?

Shoumilina: Yes, there is such evidence. Experts say sexual transmission of HIV in Russia is on a steep rise, especially in the Russian regions that have been experiencing outbreaks of the epidemic since 1996. The patterns and dynamics of the HIV epidemic emergence in different regions of the Russian Federation are more or less uniform, with initial outbreaks of HIV among injecting drug users (IDUs) followed by increasing incidence of sexual transmission.

For instance, in the Kaliningrad Region, sexual transmission of HIV constituted 32% of newly detected cases in 2000, vs. 3% in 1996. In the Rostov-on-Don Region, sexual transmissions of HIV reached 37.8% in 2000.

The number of children born to HIV-infected mothers is steadily growing. Though the absolute figure — 406, as of Nov. 1, 2000 — is not high, the dynamics show geometrical progression. Thirty-eight cases of mother-to-child transmission (MTCT) of HIV were detected in 1997, 71 cases were detected in 1998, and 178 MTCT cases were found in 1999. A majority of those mothers are injecting drug users who often reject their children.

AIDS Alert: UNAIDS has discussed the problem of injection drug use and HIV infections in Russia for the past couple of years. Has the Russian government or any of the neighboring nations tried needle-exchange programs or similar measures?

Shoumilina: You know most probably that Russian legislation relating to illicit drug use is not prepared to face the reality of the HIV epidemic. The existing legislation does not provide either for needle exchange or substitution therapy programs. The law enforcement bodies, in particular the Ministry of Interior and the Prosecutor's Office, initially were very strongly opposed to those law-violating measures. At present, the Ministry of Interior insists on the respective changes of the legislation so that practices do not contradict the law.

The first pilot needle-exchange programs were implemented in Russia starting in 1997. The international community has played and continues to play an important role in introducing the programs in Russia. Projects dealing with HIV prevention among IDUs, including harm reduction projects, are carried out in 30 regions of the Russian Federation. State institutions and nongovernmental organizations are implementing these initiatives in close collaboration. The Federal Ministry of Health and the regional authorities are supportive and encourage implementation of the initiatives. A few Russian regions, such as St. Petersburg (F.C.), the Astrakhan, Nizhny Novgorod, Tomsk and Tyumen Regions, and the Altai Territory are ready to pilot opioid agonist substitution therapy programs.

AIDS Alert: What type of treatment is available in Russia for HIV / AIDS patients? What are their major challenges to providing adequate testing, treatment, and prevention education?

Shoumilina: Upon testing positive, a person is expected to register with a territorial AIDS Centre, which is a public health institution, and receive follow-up care. Though the general policy is that all public health facilities should provide medical help — not related to their HIV status — in practice there is the risk of discrimination against people living with HIV / AIDS in accessing health services.

Currently, specialized care for people living with HIV is limited to a select number of specialized centers. According to Russian law, the state bears all expenses related to treatment . . . and these expenses are covered from the regional budgets. As the public health budget is very limited, the public health institutions of the regions are unable to provide the full range of necessary medications.

In this case, patients' access to free drugs for the treatment of opportunistic infections or free antiretrovirals is limited. Provided that there are indications for antiretroviral therapy, the patient's consent, and funds available, combined specialized treatment will include 2 or 3 antiretroviral drugs, a majority of which are imported from the USA, Switzerland, France, and Great Britain, and are very expensive. Antiretroviral monotherapy is not recommended. As a rule, injecting drug users do not receive antiretroviral therapy, as they are not able to strictly follow the medication schedule.

According to the findings of the UNAIDS-supported strategic planning process, the main challenges or core factors hindering the effective response to the HIV epidemic in Russia are as follows:

1. insufficient political and public awareness of the fast development of the HIV epidemic and its threat to national security and development in the short-term and long-term perspective;

2. lack of HIV-related national policy addressing HIV / AIDS as a complex social issue, which demands multisectoral approach and cooperation of all state, nongovernmental, private, and international actors;

3. lack of professional knowledge about HIV transmission and prevention on the part of many medical professionals and the majority of non-medical specialists dealing with HIV / AIDS-related social areas;

4. unsafe attitudes toward health and health protection remaining as a legacy from Soviet times;

5. lack of funds.

AIDS Alert: What age groups are primarily being affected by the epidemic in Russia, and what are the prevalence rates of the various age groups and genders?

Shoumilina: To date, the majority of HIV infections have been among males. While at the early stages of the epidemic the male / female ratio within the HIV-infected population was 4:1, at present the newly detected cases show it is 2:1. Increasing injecting drug use among women and sexual transmission of HIV, particularly among sexual partners of IDUs, has influenced the change in this ratio. The majority of newly detected HIV cases is among young people under the age of 25 years, with the proportion of younger age groups fast increasing. The highest prevalence is still in the age group 20-40 years, although the incidence is highest among the 17-23 age group. A total of 1,051 cases are registered in children under 15.

As of July 1, 2000, the cumulative number of registered HIV cases in Russia constituted 50,628, and of them, 39,516 were in men and 11,112 were women. A total of 925 cases were detected in children under age 15, with 11,201 in young people of the age group of 15-20 years; 30,159 HIV infections were detected in the 20-30 age group.

AIDS Alert: Why should the rest of the world be concerned about the HIV epidemic in Eastern Europe, and how is UNAIDS addressing those concerns?

Shoumilina: As infectious diseases — and AIDS as one of four leading killers — represent a serious threat to global security, it is important that the response to the threat is also global. As far as the countries in transition are concerned, the full-scale epidemic will enormously stretch the economy of such countries, and they will be much less able to effectively mitigate the epidemic's impact.

Prevention of the full-scale epidemic is the only cost-effective response to the spread of the disease in countries which are not yet badly affected by HIV / AIDS. Strategic planning of the response to HIV / AIDS in the countries of Eastern Europe is one of UNAIDS' priorities in the region. The Russian Federation has just completed the strategic planning exercise supported by UNAIDS. The Joint Response to the HIV / AIDS Epidemic Initiative that addresses the proposed strategic priorities was introduced to the international donor community on Nov. 16, 2000. Similar processes were supported in other countries of the region.

One of the strategic priorities is the establishment of the high-level National Committee on HIV / AIDS in the Russian Federation. UNAIDS will support this activity through its Programme Acceleration Funds. ■

(Continued from page 18)

• **Bragdon v. Abbott:** This June 1998 decision was about a Maine dentist, Randon Bragdon, who refused to fill a cavity for Sidney Abbott because Abbott was HIV-positive, a fact that was listed on her intake form. A federal trial court ruled in Abbott's favor, as did the First Circuit Court of Appeals. Bragdon petitioned the U.S. Supreme Court to review the case, and the court agreed to do so.

The court examined three issues, including whether asymptomatic HIV is a disability under ADA, whether reproduction is a major life activity under the ADA (Abbott claimed that her HIV infection impaired her ability to have children), and whether courts should defer to a health care professional's judgment about the direct threat a particular patient might pose.

Court: HIV is always an impairment

The Supreme Court ruled in a 5-to-4 vote that HIV is always an impairment under the ADA, and they held that medical professionals are not entitled to special treatment in discrimination cases. Although the court's ruling pertained to a woman who claimed protection under the ADA because her impairment would limit her major life activity of having children, it did note that "reproduction and the sexual dynamics surrounding it are central to the life process itself." This suggests that any person who is experiencing impairment of sexual activity due to HIV infection might be covered under the ADA.

This case has resulted in consistent lower court decisions that conclude that HIV-infected individuals are protected under the ADA, says **Ben Klein**, an attorney with Gay and Lesbian Advocates and Defenders in Boston, which was involved in the case.

• **Albertsons v. Kirkingburg; Sutton v. United Airlines; Murphy v. United Parcel Service:** In June 1999, the Supreme Court issued some additional ADA rulings that would appear to limit the act's scope. These decisions basically said that individuals who have mostly eliminated the impact of their impairments through mitigating measures are not disabled enough to be covered by the ADA.

For example, in the Albertsons v. Kirkingburg decision, a Portland truck driver was fired due to of his monocular vision. He had an excellent driving record, but his employer argued that his vision impairment was too serious to permit him to work but not serious enough to be covered by the ADA.

In Murphy v. United Parcel Service, the case involved a mechanic named Vaughn L. Murphy who was required to drive commercial vehicles. He had high blood pressure and was granted certification and began to work, despite the Department of Transportation's health certification requirement that commercial drivers have no current clinical diagnosis of high blood pressure that would likely interfere with the person's ability to drive safely. Murphy's blood pressure is controlled by medication. Later, UPS let him go, citing his inability to meet certification requirements, so he sued under the ADA.

The Supreme Court ruling said, "Again, assuming without deciding that these regulations are valid, petitioner has failed to demonstrate that there is a genuine issue of material fact as to whether he is regarded as disabled." The ruling further states that UPS fired Murphy because of a physical impairment that the company believed would prevent him from obtaining DOT health certification and not because the company regarded Murphy as disabled.

Klein says while these decisions may be bad news for certain disabled people, including those who have diabetes or other conditions that can be successfully mitigated, they shouldn't affect court decisions about HIV patients.

These rulings were completely inconsistent with Congress' intent and the language of the ADA, says **Catherine Hanssens**, a lawyer and director of the AIDS Project at Lambda Legal Defense and Education Fund in New York City. Lambda participated in friend-of-the-court briefs in all three cases.

"But I think they are likely to have far less negative impact on people with HIV than those with other disabilities," Hanssens explains. "In the Bragdon v. Abbott decision, the first ADA case and the first HIV case the Supreme Court reviewed, even the more conservative members of the court seemed to recognize there is a stigma around HIV," she says.

• **University of Alabama v. Garrett:** This case, which was still pending as of the end of 2000, involves two state employees, Patricia Garrett and Milton Ash, who lost their jobs at the University of Alabama. Garrett was a nurse who was encouraged to leave her job after the university found out she had cancer. She took an unpaid leave of absence, and when she returned she was

demoted. Ash, a security guard who has severe asthma, asked the university to enforce a no-smoking rule in his security booth and to maintain a truck he drove so that he wouldn't get sick from the smoke and fumes. Both plaintiffs won in the 11th Circuit, and the Supreme Court heard their arguments on Oct. 11.

"The question the Supreme Court has considered in this past term is whether Congress violated the Constitution when they imposed the requirements of the ADA on the states," Hanssens says. "How the court rules will be particularly important in southern states where alternative remedies against state government discriminators are not as generous as they are in some of the Northeastern states and other parts of the country."

Lambda Legal Defense and Education Fund filed an amicus curiae brief in this case on behalf of civil rights and AIDS organizations. But whether this decision will affect HIV-infected workers will depend on what the court says when it finally rules on the case, Hanssens says. ■

Prison study shows a transmission first

Finding supports need for consistent meds use

A study of HIV infection among Texas inmates has identified one patient who was infected while in prison and then within one year of infection had acquired nine HIV drug mutations although he had never received antiretroviral treatment.

"So this is the first report of transmission of highly resistant virus during primary infection in prisons," says **William A. O'Brien**, MD, professor of medicine, pathology, and microbiology and immunology at the University of Texas Medical Branch and Division of Infectious Diseases in Galveston.

O'Brien accessed plasma samples from inmates in 1998, looking at resistance patterns among HIV-infected prisoners who had viral loads of 5,000 copies or more.

"Our center takes care of patients in the Department of Justice as well as in the university setting, so I analyzed about 700 samples, about half in prison and half in the university, to make a comparison of the two different populations," O'Brien says.

He found that people who have more than 5,000 viral copies showed a lot of resistance in both patient populations. The resistance mutation that emerged most significantly was the one associated with the use of the antiretroviral drug 3TC.

Prison population showed more resistance

The chief difference between the two populations was that there was significantly more mutation associated with 3TC among the prison population, with resistance approaching 80%, vs. 50% among the university health center patients.

"There are a number of explanations, and one of the best is that because it's such a well-tolerated and easy-to-take drug, people in prison can continue to get this drug even after they fail their regimen that contains this drug," O'Brien says. "So this is a value of resistance testing."

If prison physicians used resistance testing among patients who were failing their therapy, they would have known that this mutation was present and could have avoided the drugs that were associated with the mutation, he adds.

While conducting the research, O'Brien came across one patient who had high-risk sexual behaviors for HIV infection and had several negative HIV tests while incarcerated. Then, in early 1997, the man had his first positive antibody test. He was not placed on antiretroviral therapy. Eleven months later, the man's blood tests showed that he had nine HIV mutations associated with drug resistance. These same mutations were found again a little more than a year later, although he had never received antiretroviral drugs.

"What makes this case even more interesting is that there are a number of reports that show that resistant virus can be transmitted with HIV infection, and there have been reports of multidrug-resistant virus," O'Brien says. "But the resistance mutations usually fade away over time if patients are not treated, because the virus without mutations may be able to grow a little better."

That's why it was so unusual to find an untreated patient with nine drug-resistant mutations existing a year or more after they were transmitted, O'Brien says.

"So this suggests that resistant virus can be transmitted to people who are already infected," O'Brien says. "I've been cautioning patients for

15 years that even if they already have HIV, it's theoretically possible they could get a virus that's worse than the one they already have."

The study also suggests that clinicians should consider obtaining a resistance test of HIV patients before beginning therapy when those patients have high-risk behaviors that would make it likely they've been exposed to drug-resistant virus, O'Brien says.

Inmates may wish to hide HIV status

Drug-resistant virus may be more common in some prison settings because inmates may be unwilling to subject themselves to the hassle of following a strict medication regimen. Those who start therapy may be inconsistent in taking medications, and others may decline to take drugs altogether because they don't want to be identified as an inmate who has HIV, O'Brien says.

"If a young man goes to the prison's pill window two or three times a day, everyday, then he's identified as having HIV infection," he says.

O'Brien's continuing research will focus on providing routine resistance testing and following patients' drug regimens to see whether resistance testing is providing a benefit in their therapy.

"We will look at which drugs are selected and what their viral load response is," O'Brien says. "Interpretation will be made by doctors at our center and made through direct observation of prison patients when they come to our center." ■

When gonorrhea rates rise, can HIV be far behind?

CDC's latest STD report notes disturbing trend

There were at least two significant infectious disease trends in the early 1980s. One of those was the advent of HIV infection. The other was the beginning of a long decline in gonorrhea rates.

Perhaps due in part to the safe-sex practices made popular because of the risk of HIV infection, gonorrhea rates continued to decline throughout the 1980s and the 1990s until 1999. However, gonorrhea rates among HIV-infected men who have sex with men more than doubled to 19.7% between 1995 and 1999 in Denver. This finding, reported by the Centers for Disease Control and Prevention in Atlanta, was yet another indicator that fewer men who have sex with men are engaging in safe sex practices.

"For the first time in two decades, we're seeing increases in gonorrhea rates in the United States," says **Ronald O. Valdiserri**, MD, MPH, deputy director of the National Center for HIV, STD, and TB Prevention at the CDC. Valdiserri spoke at the National STD Prevention Conference held Dec. 4 in Milwaukee.

Three factors are contributing to the trend of increased gonorrhea cases:

- There are increased screening activities, because the test for gonorrhea is being administered at the same time as the test for chlamydia.
- There are more sensitive diagnostic tests and improved reporting.
- More people, particularly men who have sex with men, are becoming infected.

It's the latter factor that worries public health officials and HIV advocates.

Rising gonorrhea rates signal unsafe sex

"First, an increase in gonorrhea cases is evidence of multiple acts of unsafe sex, which are probably resulting in the transmission of other STDs, including HIV," says **Susan Wang**, MD, of the Division of STD Prevention of the National Center for HIV, STD, and TB Prevention.

"Second, infection with gonorrhea increases the infected person's likelihood of acquiring HIV if she or he isn't infected with HIV, or of transmitting HIV if he or she already is infected with HIV," Wang adds. "If more people are infected with gonorrhea, those gonorrhea infections will facilitate HIV transmission in the population."

AIDS advocates also express concern.

"Any time we see an increase in a sexually transmitted disease rate, it indicates we may well see an increase down the road in HIV rates," says **Tanya Ehrmann**, director of public policy for AIDS Action in Washington, DC.

"This is not only because it indicates people are not having safe sex, but because of the vectors of transmission and increasing one's risk of HIV," Ehrmann adds.

In recent years, prevention efforts and the fear of HIV have held new HIV infection rates at about 40,000 per year in the United States. This and the ready availability of antiretroviral medications have led to decreases in AIDS cases. But the increase in

gonorrhea rates may be an early signal that prevention efforts are failing, despite the recent renewed focus on targeting youths and minorities.

One solution to this problem is for health care providers to take a more aggressive and active interest in providing STD counseling to youths, says **Judith Wasserheit**, MD, MPH, director of the Division of STD Prevention of the National Center for HIV, STD, and TB Prevention.

CDC research shows that many high school students do not discuss STDs or pregnancy prevention with their physicians during routine check-ups.

"Of high school students, about two-thirds had an appointment with a health care provider in the prior year, and less than half of those individuals had their provider actually talk with them about STD prevention or pregnancy prevention," Wasserheit says. "Many teens are sexually experienced; in these data, about half of the high school students were sexually experienced, and by grade 12, 65% are sexually experienced."

The study also shows that about one in five teens have more than five partners.

Gonorrhea rates, like HIV rates, have hit the African-American community hardest. The gonorrhea rate among blacks is close to 3,500 per 100,000 population and about 3.5% of African-American teens.

"That's a huge number," Wasserheit notes.

There have been recent outbreaks of gonorrhea rates among men who have sex with men in Washington, DC, in the Pacific Northwest, and on both coasts, Valdiserri says.

Understanding the HIV/STD relationship

"There's been a lot of focus and attention on this issue within the context of HIV transmission," Valdiserri adds. "The factors involved include the fact that high-risk sexual behavior no longer carries the extreme consequences it once did because of improvements in HIV treatment."

Also, many gay and bisexual men do not understand the relationship between HIV and other STDs, he says. "And sometimes substance abuse has been involved in these outbreaks," he notes.

The message nationwide is that outbreaks of gonorrhea infection often have gay and bisexual men as a common denominator, and this may be due to their misconception that unsafe sex is no longer as risky as it once was, Valdiserri says. ■

Study: HAART less costly than treatment for AIDS

Annual health care cost lowered by 31%

Even with the high cost of medications prescribed as part of highly active antiretroviral therapy (HAART), it's cheaper to treat HIV-infected patients and keep them from developing AIDS than it is to take care of them once they have the full-fledged disease, new research shows.

"It's more costly to treat a patient who has AIDS than to treat a patient with HIV medications," states **Judith O'Brien**, RN, senior researcher and vice president of Caro Research in Concord, MA. Caro Research is an independent health care consulting firm.

'You have to look at in the whole context'

"The biggest point to be made is there is always the issue of HAART being very expensive, and while that may be a valid point, you have to look at it in the whole context of treating HIV patients and preventing them from crossing the threshold to AIDS," O'Brien says. "And looking at the broader picture, you get a better sense of how even though one's therapy may be thought of as costly, in the long run it's probably more cost-effective in treating patients."

O'Brien's research, presented at the fall Interscience Conference on Antimicrobial Agents and Chemotherapy meeting held in Toronto, examined hospital admissions for AIDS in Massachusetts both before and after antiretroviral therapy came into widespread use.

The findings were as follows:

- Of 13,100 hospital discharges of HIV patients who had not advanced to AIDS and 49,000 patients with AIDS, there was an average annual cost of $17,600 per patient who had HIV without AIDS vs. an annual cost of $24,900 for patients with AIDS. The cost difference per patient was $7,300.
- Patients with AIDS who are hospitalized have an average of 1.8 admissions per year and mean annual hospital costs of $13,277 in 1998 dollars, excluding physician costs.
- The number of reported AIDS cases in Massachusetts rose by 78% between 1995 and

1998 . But the rate of hospitalization declined in the same period from 85% to 31%.

• The cost of inpatient care declined from $8,100 for an average hospital stay for AIDS care in 1995 to a mean of $7,500 in 1998. These costs included medications taken during the hospital stay.

• The average length of stay for AIDS patients fell by 1.3 days between 1995 and 1998.

• The inpatient case fatality rate dropped from 6.7% to 4.6% during that period.

• There was no apparent cost-shifting to post-acute settings among this population. The referral rate to post-discharge services dropped by 8.6% between 1995 and 1998. ■

Are Native Americans next brush fire in HIV epidemic?

The virus has not hit this group so far

The public and governmental response to rising HIV infection rates among minority populations in the United States, such as Hispanics or African-Americans, may have been a little late. The virus had already caused a high rate of infection among this population before various groups began focused and consistent prevention and testing campaigns.

This is why the public and government should begin now to reach and teach native Americans about HIV prevention, says **Eric Goosby**, MD, director of HIV / AIDS Policy for the U.S. Department of Health & Human Services and deputy director for the Office of National AIDS Policy in Washington, DC.

Community displays high-risk behaviors

"Native Americans have participated historically in behavior patterns that are of high risk for transmitting HIV: alcoholism and injection drug use," Goosby says.

Native Americans have high rates of sexually transmitted diseases (STDs) and teen pregnancy, both indicators of unprotected sexual activity. In 1997, the rate of gonorrhea among Native American males was 67 per 100,000 population. This is compared with 19.5 per 100,000 white males. Among Native American females, the gonorrhea rate was 131.4 per 100,000, compared with a rate of 32.3 per 100,000 among white females.

Syphilis infection rates also were close to four times higher for Native American men and women than they were for white men and women.

Data from the Centers for Disease Control and Prevention in Atlanta show that more than 2,000 American Indian / Alaskan Natives in the United

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States and its territories were diagnosed with AIDS as of 1999. This figure is a 24% increase over the number of AIDS cases among Native Americans only two years earlier. The cumulative HIV infection cases had increased by 33% to 632 in that same period.

AIDS deaths among Native Americans totaled 1,035 through December 1998.

"All you're waiting for is the introduction of the virus to that situation," Goosby says. "The only thing that has prevented a rapid seroconversion in Native American communities is that the virus has not been introduced to any great degree, and that's why this is a special opportunity."

Goosby spoke about the risk of HIV infection at a meeting with Native American tribal leaders in November. His talk was given at the 57th Annual Session of the National Congress of American Indians (NCAI), the largest organization of tribal governments in the United States.

Goosby says the NCAI, which he describes as being like a United Nations with each tribe being a sovereign entity, was interested in the HIV discussion and surprised by the information Goosby presented.

Targeted prevention messages are needed

"They understood that when you put those high-risk elements together with HIV, you run the risk of rapid transmission," Goosby says. "They have HIV literature, but we need to provide them with targeted prevention messages."

It's crucial that Native Americans, particularly youths, learn how to eliminate their high-risk behaviors before HIV is introduced, because once that happens, it could spread very rapidly and become a crisis, Goosby says.

"Our office has taken the lead in establishing the response to minority disparity in HIV infection," he says. "We've gone to 16 epicenters where there are disproportionate numbers of minorities with HIV and have worked with city public health departments to target minorities."

Goosby says his office also worked with black churches to help make their prevention efforts more effective.

"We are attempting to engage the Native American leadership along those lines," he adds. "And we're doing our best to get coordinated prevention efforts into the Native American, Pacific Islander, and Hispanic populations." ■

CE objectives

After reading this issue of *AIDS Alert*, CE participants should be able to:

- identify the particular clinical, legal, or scientific issues related to AIDS patient care;
- describe how those issues affect nurses, physicians, hospitals, clinics, or the health care industry in general;
- cite practical solutions to the problems associated with those issues, based on overall expert guidelines from the Centers for Disease Control and Prevention or other authorities and/or based on independent recommendations from specific clinicians at individual institutions. ■