



# AIDS ALERT®

The independent source for health care providers since 1986

## INSIDE

- **Names reporting:** A state-by-state review of current HIV infection reporting . . . . . 14
- **CDC guidelines:** A brief look at the new HIV surveillance guidelines . . . . . 17
- **Research results:** Testosterone therapy can help HIV-infected men . . . . . 18
- **Alternative therapies:** HIV/AIDS patients look beyond traditional treatment . . . . . 20
- **East meets West:** Complementary medicine requires integrating both approaches . . . . . 22
- **Compliance intervention:** Study will look at two different outcomes of adherence . . . 23
- **Common Sense about AIDS:** Understanding viral-load testing . . . . . Insert
- **AIDS Alert International:** Dont overlook transmission risks among HIV-negative pregnant women . . . . . Insert

FEBRUARY  
1999

VOL. 14, NO. 2  
(pages 13-24)

American Health Consultants® is  
A Medical Economics Company

## CDC wants all states to add HIV to current AIDS surveillance programs

*More accurate reporting system could increase funding for research*

The Centers for Disease Control and Prevention in Atlanta now recommends that all states and territories include HIV cases in their AIDS surveillance programs, a move that is expected to add 200,000 people diagnosed with HIV to the overall surveillance count. The change could prompt many more states to begin to collect the information within the next two years.

Thirty-two states already perform HIV surveillance using the same reporting system for both HIV and AIDS cases. Three of these have collected only pediatric HIV/AIDS information. The CDC's guidelines are recommendations, and states can decide for themselves whether to conduct HIV surveillance. There are no penalties for states that decide not to follow the recommendations.

"Most of the states will be expanding their existing AIDS surveillance infrastructure to include persons with HIV," says **Patricia Fleming, PhD**, chief of the HIV/AIDS surveillance branch division of the CDC's Division of HIV/AIDS Prevention.

The HIV reporting will come from hospital inpatient settings, private providers, and laboratories that conduct diagnostic and CD4 count tests.

CDC officials estimate the greatest initial impact will be that an additional 200,000 people diagnosed with HIV will be added to the HIV/AIDS surveillance count.

"We think that's a conservative estimate of the number of people who are infected with HIV and have been diagnosed," Fleming says.

States now report 300,000 are living with AIDS. And the states that perform HIV surveillance report that about 100,000 people are living with HIV, Fleming says. (See **HIV surveillance charts, pp. 14-16.**)

### *Reporting will provide a more accurate picture*

A more accurate reporting system could mean increased federal funding for HIV/AIDS research and a more detailed picture of how much the disease has spread. "This will allow us to target our efforts to reduce HIV infections and to reduce morbidity and mortality," Fleming adds.

## HIV State Surveillance Chart

### Current Status of HIV Infection Reporting

Updated as of December 7, 1998

Name-Based Reporting	Non-Name-Based Reporting*	Reporting Not Required
<p><i>Alabama</i> Arizona Arkansas Colorado Florida <i>Idaho</i> Indiana <i>Iowa</i> Louisiana Michigan Minnesota <i>Mississippi</i> Missouri <i>Nebraska</i> <i>Nevada</i> New Jersey New Mexico <i>North Carolina</i> <i>North Dakota</i> Ohio Oklahoma <i>South Carolina</i> <i>South Dakota</i> <i>Tennessee</i> Utah Virginia West Virginia Wisconsin <i>Wyoming</i></p>	<p>Georgia Illinois Kansas Kentucky Maine Maryland<sup>4</sup> Montana New Hampshire Oregon<sup>3</sup> Rhode Island Texas<sup>2</sup> Virgin Islands<sup>6</sup></p>	<p>Alaska California Connecticut<sup>1</sup> Delaware Hawaii Massachusetts New York<sup>6</sup> Pennsylvania Puerto Rico Vermont Washington<sup>5</sup> District of Columbia</p>
<p>1. Requires named reports of HIV infection in children &lt; 13 years of age. Reports of HIV infection not required for adults/adolescents 13 and older.                  2. Uses unique identifier system for HIV reporting. Requires named reporting of HIV infection in children &lt; 13 years of age.                  3. Requires named reporting only for HIV infection in children &lt; 6 years of age and in limited other circumstances.                  4. Uses unique identifier system for HIV reporting for persons 13 years of age and older. Requires named reporting of symptomatic HIV infection and AIDS.                  5. Requires named reporting of symptomatic HIV infection and AIDS.                  6. Name-based reporting passed by law, rule or regulation in 1998, but not yet implemented.</p> <p>*Maryland and Texas conduct HIV case surveillance using a 12 digit unique identifier (UI) and attempt to conduct follow-up activities to fill gaps in the information received. Providers, hospitals, and labs in the other states in this column send health departments individual-level HIV data using a variety of non-name-based identifiers, such as initials, a date of birth, or a test number. These states generally do not conduct any follow-up activities on this HIV case information and have not evaluated the usefulness or completeness of their HIV reporting systems.</p>		
<p>States in <i>italics</i> offer only confidential and not anonymous HIV testing.                  All other U.S. states and territories offer anonymous testing.</p>		

Source: AIDS Action, Washington, DC.

For example, AIDS data underestimate the infection rate of youths because the number of young people diagnosed with AIDS is much lower than the number of young people infected with HIV, Fleming explains.

“What states have found is that by having data on young people with HIV, they are better able to effectively target interventions, treatment, referrals, and prevention to young people,” she adds.

But have the CDC’s guidelines arrived soon enough?

“We’ve been waiting for these recommendations for over a year, and the jurisdictions have been very frustrated that they haven’t been out even for comment until now,” says **Julie Scofield**, executive director of the National Alliance of State and Territorial AIDS Directors in Washington, DC.

Fleming says the CDC has been working on the draft of HIV surveillance guidelines since May 1997. CDC officials have met with public health groups and community groups to discuss the recommendations. The research on which the guidelines are based was started many years ago.

The CDC also has been criticized for recommending that states adopt name-reporting methods rather than non-name coding systems.

The Washington, DC-based advocacy group AIDS Action announced in December that the group opposes name reporting because it might cause some at-risk people to avoid being tested.

AIDS Action spokesman Steven Fisher publicly denounced names reporting, calling it a disaster: “Without better access to health care, names reporting is the Titanic all over again — we’re

## Characteristics of persons aged $\geq 13$ years with HIV, by disease status at initial diagnosis\* — 25 states<sup>†</sup>, January 1994-June 1997

Characteristic	Disease status at initial HIV diagnosis				Total
	HIV		AIDS		
	No. <sup>§</sup>	(% <sup>¶</sup> )	No. <sup>§</sup>	(% <sup>¶</sup> )	
<b>Sex</b>					
Male	37,996	(72)	16,866	(83)	<b>54,862</b>
Female	14,689	(28)	3,348	(17)	<b>18,037</b>
<b>Race/Ethnicity**</b>					
White, non-Hispanic	17,929	(34)	9,171	(45)	<b>27,100</b>
Black, non-Hispanic	30,229	(57)	9,127	(45)	<b>39,356</b>
Hispanic	3,581	(7)	1,660	(8)	<b>5,241</b>
Other/unknown	949	(2)	256	(1)	<b>1,205</b>
<b>Risk/Exposure Category</b>					
Men having sex with men	17,098	(32)	8,866	(44)	<b>25,964</b>
Injecting-drug user	9,671	(18)	3,959	(20)	<b>13,630</b>
Men having sex with men/ Injecting drug user	2,088	(4)	843	(4)	<b>2,931</b>
Heterosexual contact	9,279	(18)	2,428	(12)	<b>11,707</b>
Other/unreported	14,552	(28)	4,116	(20)	<b>18,668</b>
<b>Age Group (yrs)</b>					
13-24	7,200	(14)	653	(3)	<b>7,853</b>
25-29	9,384	(18)	2,239	(11)	<b>11,623</b>
30-34	11,916	(23)	4,503	(22)	<b>16,419</b>
35-39	10,030	(19)	4,608	(23)	<b>14,638</b>
$\geq 40$	14,159	(27)	8,210	(41)	<b>22,369</b>
<b>Total<sup>††</sup></b>	<b>52,690</b>		<b>20,215</b>		<b>72,905</b>

\* For persons who had not had an HIV diagnosis before being diagnosed with AIDS, their AIDS diagnosis date is considered their earliest HIV diagnosis date; for persons initially reported with HIV who subsequently had AIDS diagnosed and reported, they are presented by the earliest diagnosis date, which is their HIV diagnosis.

<sup>†</sup> Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.

<sup>§</sup> Numbers are estimates after adjustments for reporting delays. Point estimates are presented for reproducibility of the data.

<sup>¶</sup> Percentages may not total 100 because of rounding.

\*\* Persons of races other than black and white were included under "other/unknown" because estimates were too small for meaningful analysis.

<sup>††</sup> Column totals include missing/other for some categories (e.g., missing sex). Persons infected through receipt of blood or blood products are included under other/unreported risk.

Source: Centers for Disease Control and Prevention, Atlanta.

creating passenger lists without providing enough lifeboats."

The CDC is advising states to report HIV patients' names because evaluations have shown that names reporting systems perform well, Fleming says. "Some states may choose to adopt coded identifiers in lieu of names, and we'll work

with those states to try to ensure the level of performance is high enough to obtain accurate, high-quality data," Fleming adds.

Texas, New York, and Maryland had used unique identifiers, but Texas found that the system did not perform well and has changed its law to use names, beginning Jan. 1, 1999. New

## Estimated Incidence of AIDS and Deaths of Persons with AIDS\* , 1985-1997, United States

Source: Centers for Disease Control and Prevention, Atlanta.

York also is switching to using patient names this year, Fleming says.

The first state to begin HIV surveillance was New Jersey in 1991. The state has used names reporting from the very beginning, and officials have found that names reporting for HIV cases works very well, says **Sindy Paul**, MD, MPH, medical director of the Division of AIDS Prevention and Control of the New Jersey Department of Health and Senior Services in Trenton. People receive counseling with their HIV testing, and they're assured that their names will be kept confidential.

"We have a steel cage around our computer," Paul says. "We have criminal penalties for breaches of confidentiality by anyone, and that was put in before names were collected."

Since the state began names reporting of HIV/AIDS patients, there have been fewer New Jersey residents going to New York for HIV testing. So that trend obviously was not affected, Paul adds.

"The CDC has found that a concern with names reporting is rarely mentioned as a deterrent for people going for testing and counseling services," she says.

However, New Jersey residents who would like to receive anonymous testing may do so.

"We have an anonymous testing option, and people can go to a publicly funded site and be tested at no charge, and we'd receive an anonymous report," Paul says.

### *AIDS cases differ from HIV cases*

HIV surveillance and names reporting have been tremendously helpful in finding accurate trends with regard to case demographics and infection rates, Paul says.

For example, New Jersey's AIDS cases listed through Sept. 30, 1998, indicate that 61% of the cases are men and 39% are women. However, the HIV cases listed for the same period show that 52% of the cases are women and 48% are men, Paul says. This type of statistical difference in case demographics can affect how state health officials target prevention efforts. The HIV data indicate that prevention efforts need to be divided equally between men and women.

New Jersey AIDS prevention officials evaluate prevention of perinatal HIV transmission through identification of HIV-positive mothers and their babies. By having the mothers' names, the state knows which mothers received AZT during their pregnancy or neonatal period. They

also can follow the child to find out whether the child became infected with HIV.

Paul says HIV surveillance data also can be used to target mutations and changes in the virus.

“You can identify from surveillance who would be a potential carrier, [and] who comes from a country where a particular strain is endemic,” she says. “We get the consent of the patient, and then we interview them and send specimens to the CDC.”

States also can use HIV surveillance, along with input from community planning groups, to develop a community prevention planning process. New Jersey used its HIV statistics to create a priority list of people to target for AIDS information.

New Jersey obtains its information from laboratories and medical providers, who send HIV/AIDS cases directly to the state health department. “We do active surveillance, in which our staff go out to providers, hospitals, and physicians to complete the report forms,” Paul says.

### ***Names reporting minimizes duplication***

The state verifies the completeness of its HIV reporting by matching its own statistics with other databases, such as AIDS drugs distribution program databases. Also, the state can minimize the number of duplications in its database with names reporting. “We match close to 90%,” Paul says.

For states that would like to conduct HIV surveillance and names reporting, the CDC’s guidelines could serve as a benchmark for how to conduct such programs. **(See summary of CDC guidelines, at right.)**

It will be difficult for the CDC to evaluate HIV infection nationwide without the states’ surveillance, Fleming says. “We think it is in the best interest of public health that we do this surveillance nationwide,” she adds.

Scofield asserts that states will need more federal funds to help them handle the increased surveillance efforts.

Current funding, which was \$53 million to all states and territories in 1997, is too little money, she adds.

“The overall CDC HIV prevention budget is over \$600 million, and \$53 million for state surveillance, which is the backbone of monitoring the epidemic, is a very small proportion,” Scofield says. ■

## **CDC recommends new guidelines for HIV tracking**

*Report covers surveillance, confidentiality*

The Centers for Disease Control and Prevention in Atlanta has recommended in guidelines released in December that all states and territories conduct case surveillance for HIV infection.

The CDC report also includes revised case definitions for HIV infections in adults and children younger than 18 months of age. It also has recommended program practices and performance and security standards for HIV and AIDS surveillance.

Here is a brief summary of the CDC’s AIDS surveillance recommendations:

- States and local programs should collect standard sets of surveillance data for all HIV and AIDS cases, including the following:
  - patient identifier;
  - earliest date of diagnosis for HIV infection;
  - earliest date of diagnosis of an AIDS-defining condition;
  - demographics, such as date of birth, race/ethnicity, sex, and residence at diagnosis;
  - facility of diagnosis;
  - date and place of death.
- Name-based HIV/AIDS surveillance systems are the most likely to meet necessary performance standards, and states should use the same name-based approach for HIV surveillance as is used for AIDS surveillance nationwide.
- HIV or AIDS surveillance should be used to identify rare modes of HIV transmission.
- HIV-infected people who are tested anonymously should be reported to HIV/AIDS surveillance only after they have been diagnosed by a health care provider and have test results that meet the reporting criteria.
- State or local programs should regularly publish HIV and AIDS surveillance data.
- Surveillance programs should conduct regular, ongoing assessments of the performance of the surveillance system.
- Surveillance systems must use reporting methods that provide at least 85% of case reporting with at least 66% within six months of diagnosis and have no more than 5% duplicate case reports. At least 85% of cases should have HIV risk information after epidemiologic follow-up is completed.

- Surveillance programs must conduct periodic evaluations that include the use of at least one appropriate population-based data source, such as the National Death Index, that is not used for routine case finding.

- The CDC will assist states conducting HIV and AIDS surveillance to evaluate current performance levels, institute revised program operations and policies as necessary, and reassess performance.

- The CDC requires that electronic HIV/AIDS surveillance data be protected by computer encryption during data transfer, and paper or unencrypted electronic case reports should be used to update the surveillance registry and then destroyed.

- The CDC requires that HIV and AIDS surveillance records be located in a physically secured area and that they be protected by coded passwords and computer encryption.

- The CDC requires that access to the HIV/AIDS surveillance registry be restricted to a minimum number of authorized staff who have been trained in confidentiality procedures.

- If states develop databases from cross-matching of HIV/AIDS surveillance data with other surveillance data, the HIV and AIDS records must not be used if the cross-matched databases do not have equivalent security and confidentiality protections.

- Appropriate institutional review boards must approve the use of HIV and AIDS surveillance data for any research purposes. States should make sure the release of data for statistical purposes does not result in direct or indirect identification of people reported with HIV and AIDS.

- States must investigate potential breaches of confidentiality and impose personnel sanctions and criminal penalties as appropriate.

- States should have a description of their security policies and procedures available for external review.

- For optimal security, data should be maintained on a single electronic HIV and AIDS surveillance registry.

- States should have policies that provide the flexibility to remove cases that were reported in error or that no longer serve a public health purpose.

- States should review their confidentiality statutes to determine whether additional protections should be put in place before HIV case surveillance begins.

- HIV case surveillance should not interfere with HIV prevention programs, including those that offer anonymous HIV counseling and testing services. The CDC requires states to provide opportunities for anonymous HIV testing and counseling as a condition of federal funding for HIV prevention, unless it is prohibited by state law or regulation.

- All HIV testing services should continue to be voluntary and preceded by informed consent.

- All people diagnosed with HIV infection should be referred to programs that provide HIV care, treatment, and comprehensive prevention case management services.

The guidelines may be modified, taking into consideration public comments received between Dec. 10, 1998, and Jan. 11, 1999. They will then be published in the *Morbidity and Mortality Weekly Report*.

For copies of the guidelines, call the CDC National Prevention Information Network at (800) 458-5231 or send a written request to P.O. Box 6003, Rockville, MD 20849-6003. The entire guidelines document is available on-line at [www.cdc.gov/nchstp/hiv\\_aids](http://www.cdc.gov/nchstp/hiv_aids). ■

## Testosterone therapy can improve mood, energy

*Motivation to comply with treatment is high*

Researchers at Columbia University report a significant improvement in mood, energy levels, libido, and muscle mass in HIV-positive men after they have been treated with testosterone therapy.

“People say they have more energy to face the day and that they’re more alert and interested and becoming engaged in daily activities,” says **Judith G. Rabkin**, PhD, MPH, professor of clinical psychology in psychiatry in the College of Physicians and Surgeons at Columbia University in New York City.

The therapy, which consisted of an eight-week trial for all participants and an additional four weeks for responders, also significantly improved muscle mass, especially if the men exercised, Rabkin says.

Rabkin is one of three researchers who have submitted a report on their findings, titled “Testosterone therapy for HIV+ men with and

without hypogonadism,” to the *Journal of Clinical Psychopharmacology* for publication this winter. The researchers also have written a paper on the “Effects of testosterone therapy on weight and body composition in men with HIV-related weight loss,” which is expected to be published this year in *Nutrition Research*.

The study, conducted from 1993 to 1995, consisted of 112 men who completed at least eight weeks of treatment with 400 mg intramuscular testosterone cypionate biweekly. Responders continued to take testosterone for another four weeks, and then they were randomized in a double-blind placebo-controlled six-week discontinuation trial.

“The first thing the men noticed was a loss of energy when they were put on a placebo,” Rabkin says.

No women were studied because testosterone is not indicated for use by women. The men, age 18 or older, had CD4 cell counts below 400 cells/mm<sup>3</sup>, and they had clinically deficient or low-normal serum testosterone levels of less than 500 mg/dl, with or without problems in erectile or orgasmic function.

They also reported a significant diminution of sexual desire and at least one additional symptom of low mood, low energy, or weight loss. They were screened by telephone and were evaluated with a psychiatric assessment, as well as social, sexual, medical, and family histories. They were given follow-up assessments and had blood drawn.

The study excluded men who had any of the following problems within the previous six months: substance use disorder; psychotic symptoms; significant suicidal risk; unstable medical condition including new onset or new episode of an opportunistic infection in the past month; or recent use of androgenic-anabolic steroids.

Researchers gave the men injectable testosterone because it’s inexpensive and effective. “There are testosterone patches, and some people prefer these if they don’t want injections,” Rabkin says.

“We did one study with patches that spare people the bother of getting an injection every two weeks,” Rabkin adds. “But the patches deliver a considerably lower dose and they are eight times as expensive, so for some people the dose is not enough.”

The study took place before protease inhibitor therapy was available, and the men studied were

very sick, with the majority having a life expectancy of less than one year, Rabkin says.

In a subsequent testosterone study conducted in 1998 to confirm the earlier results, the men were healthier and some even returned to work.

Rabkin often is asked about the ethical concerns surrounding administration of testosterone to men whom society may not want to be sexually active because of the nature of their sexually transmittable disease. She replies that the study included only men who had engaged only in safe sex during the last three months of sexual activity.

“We also asked them questions about risk behavior and offered them counseling if they wanted it,” Rabkin says.

For some of the men, their quality of life improved even if their only sexual activity was masturbation. For others, the improvement in libido could have made safe sex more likely, Rabkin says. “When men are having trouble with arousal, it’s harder to put on a condom because of a weak erection.”

The study showed that testosterone treatment increased the HIV-positive men’s feelings of overall well-being.

### **Positive results recorded**

The study reported a variety of other positive effects, as well. They are:

- **Mood.** The study assessed mood at baseline with a Structured Clinical Interview for DSM III-R, which stands for *Diagnostic and Statistical Manual of Mental Disorders — Third Edition Revised*.<sup>1</sup> Also, the study doctor administered the 21-item Hamilton Depression Rating Scale (HAM-D) at baseline and biweekly. Of 41 patients with major depressive or dysthymic disorders, 34 completed at least eight weeks of open treatment. Both clinician-rated and self-rated measures of depressive symptoms showed significant improvement over eight weeks. The HAM-D scale showed significant improvement as well.

- **Muscle mass.** The muscle mass of HIV-positive men is important to watch because an HIV-positive person’s muscle mass may be depleted even if the body weight remains unchanged or increases.<sup>2</sup> The report’s findings involved 52 men, each of whom had less than 90% of their normative body cell mass. Of the 52, 44 (85%) completed 12 weeks of testosterone treatment. After the 12 weeks of treatment, the average weight gain was 2.4 kg, with a range

from a loss of 5 kg to an increase of 9.5 kg. All measures of body composition, except for total body water, increased significantly from the baseline to the 12th week, including body-cell mass and fat-free mass. The men also reported stronger appetites.

"It helps if they exercise," Rabkin says. "In the beginning, they may not have the energy to exercise, but those who did gained more weight."

- **Energy.** The study showed that at baseline, 87 men (79%) reported low energy and fatigue. After testosterone treatment, 61 (70%) had clear-cut improvement, according to what the men reported and physician assessment based on CGI ratings and a 10-point visual analog scale.

Overall, the study's findings backed up the men's self-reports of how much better they felt with the testosterone treatment.

There are side effects to using testosterone; the most common one in this study was irritability. The men gave examples of having an increased likelihood of complaining if pushed in the subway or if someone cut in front of them in the grocery store line. The study concludes that this type of behavior is often within the range of normal behavior.

"The most annoying side effects for the men we treated have been acne and hair loss, and some people just don't want to continue with the treatment," Rabkin says.

Hair loss was reported by 6% and acne by 7% of the men. Of 124 patients, 49 (40%) reported at least one side effect at one of the four times during the first eight weeks of treatment. But none of the side effects were persistent except for acne and hair loss.

"All the side effects are reversible if you lower or stop the dose," Rabkin adds.

### **Therapy guidelines**

Rabkin suggests that clinicians who consider testosterone therapy for HIV-positive men should consider these guidelines:

- Test the patient's serum testosterone levels at regular intervals to make sure the treatment is working. "If patients say they are not getting much of an effect and the serum levels are low, that would be an indication to raise the dose," Rabkin says.

- Monitor the serum testosterone levels to make sure the dose doesn't bring the levels up to more than double the top of the normal range. "If it was more than double the top number, we reduced the

dose," Rabkin says. "We also used larger doses than endocrinologists use because we didn't get any effect with lower doses."

- Watch for irritability that falls outside of normal behavior.

- Don't give testosterone treatment to men with bipolar illness because of the possibility of the men developing an irritable mania.

- Consider having the patient take testosterone therapy for as long as needed. "It's worth stopping it to see if the patient doesn't notice a difference, because then the patient doesn't have to keep getting injections," Rabkin says.

- Some patients can learn to self-inject testosterone.

- Older men should be screened for prostate cancer, because the one medically serious side effect of testosterone is possible exacerbation of prostate cancer.

- For patients who are clinically depressed, the clinician might want to go the conventional route and try giving the patient Prozac first, and then use testosterone adjunctively if there are still residual problems with energy, libido, and weight loss, Rabkin says.

### **References**

1. Spitzer RL, Williams JBW, Gibbon M. *First MB. Structured Interview for DSM-III-R (SCID)*. Washington, DC: American Psychiatric Association Press; 1990.
2. Kotler DP, Tierney AR, Wang J, Pierson RN. Magnitude of body cell mass depletion and timing of death from wasting in AIDS. *Am J Clin Nutr* 1989; 50:444-447. ■

## **Doctors should coordinate use of alternative therapies**

*Physicians need to be knowledgeable, open-minded*

It was clear to **Donald Abrams**, MD, that a patient he was treating at an AIDS clinic was reacting to something he was taking, but the man's medical records indicated he was not on prescription medication. Abrams asked if he was taking any vitamins. Yes, the patient was taking five or six different vitamins. Herbs? Yes, he was taking a half-dozen herbs, as well. Abrams asked why he had never told any other doctor about it. The patient replied that no other doctor had ever asked him before.

The use of alternative medicine in the general U.S. population has increased from 33.8% in 1990 to 42.1% in 1997.<sup>1</sup> Although significant numbers of people are turning to various forms of alternative therapies, researchers suggest that the reasons are poorly understood.<sup>2</sup>

Not so for HIV/AIDS patients, say the clinicians interviewed for this article.

“In spite of the fact that we have good control of the virus now with antivirals, there are areas where we still don’t have good available treatments,” says Abrams, an oncologist and assistant director of the AIDS Program at San Francisco General Hospital. “In those areas — such as the new body alterations [fat accumulations in the abdomen and on the back of the neck from protease inhibitors, or loss of total body fat] that we’re seeing in HIV patients, or with building back immune systems — people are turning to alternative interventions.”

Patients with chronic illnesses for which there are few or no conventional curative treatments are the groups most likely to use alternative therapies, says Abrams, who estimates that from 40% to 70% of HIV/AIDS patients seek some kind of complementary or alternative intervention.<sup>3</sup>

### ***Physicians must learn to ask questions***

The widespread use of alternative HIV/AIDS treatments presents a couple of concerns.

“Physicians need to learn how to ask their patients whether or not they’re using them,” Abrams says. “The major problem is that they don’t know how to ask. Physicians need to be not only open-minded and nonjudgmental, but they also have to know how to ask the questions.”

Learning about commonly used alternatives such as herbs and understanding their actions through research on the Internet and other sources can help doctors communicate with their patients.

Abrams also warns that most of the herbs and supplements patients are taking have not undergone testing similar to prescription drugs.

“We don’t know if there are interactions with prescribed drugs,” he says. “People should be careful, but if they have a condition they feel they is being benefited by one of these interventions, I’d like to further test it. My belief has always been, if it’s out there and may have some benefits, let’s test it. If it’s out there and it may do some harm, we’d better know that as well.”

However, testing alternative therapies is no easy matter. Abrams has been investigating alternative treatments for nearly 20 years and collaborated with an Asian medicine practitioner in publishing the first placebo-controlled clinical trial of Chinese herbs in patients with symptomatic HIV disease. The study showed some reduced symptoms in subjects taking herbs, but concluded that larger trials of longer duration were needed.<sup>4</sup>

With keen competition for scarce federal dollars, obtaining funds for further research of alternatives such as herb therapy has been problematic. In addition, those studies can be difficult to conduct. For example, Abrams says he learned that the Chinese herbs study really didn’t resemble an actual Chinese medicine intervention, in which each patient would be given an individualized treatment based on a traditional Chinese medicine diagnosis that differs greatly from the Western medical model. (See **related story, p. 22.**) Also, an authentic Chinese medicine treatment would include acupuncture, and the herbs would have been consumed as a tea, not in pill form.

Investigators at the AIDS Research Center of Bastyr University, a naturopathic college in Kenmore, WA, also are seeking federal funds for research into alternatives. **Carlo Calabrese, ND, MPH**, the center’s co-director, says recent research has shown that the number of therapies being used by HIV-positive people is “unexpectedly large.”<sup>5</sup>

Another Bastyr study aims to determine whether patients who use both conventional and alternative medicine have different outcomes from patients who use only conventional medicine. Researchers are collecting data every six months from 1,500 HIV-positive men and women who are using alternatives.<sup>6</sup>

About half the participants use acupuncture. Initial results focusing mainly on acupuncture and the use of Chinese herbs could be published this year, and Calabrese says only that some outcome parameters show positive results while others do not.

“I am not looking at an AIDS cure, but I am seeing some significantly positive results, and I’m also seeing some [conditions] which acupuncture does not help,” he states.

Research is necessary to “separate the wheat from the chaff,” Calabrese says. “We want to know if there are therapies that are beneficial, and at the same time if certain [therapies] are

# East clashes with West in approach to HIV treatment

*Focus on patients vs. battle against virus*

Many alternative interventions used for HIV/AIDS originate from traditional Chinese or ayurvedic medicine, both Eastern healing systems. Resistance or outright hostility to alternatives among many practitioners of Western medicine often are based on a narrow view of knowledge and science, according to the author of an extensive report on complementary medicine for HIV/AIDS.<sup>1,2</sup>

Western medicine has developed along more empirical lines, while Eastern medicine is based on theoretical systems that have developed over centuries, explains **Richard C. MacIntyre**, PhD, RN, associate professor and division chair for health sciences at Mercy College in Dobbs Ferry, NY.

“The problem in Western medicine is that we started thinking of Western medical science as a paradigmatic form of knowledge or truth, and that real truth resides only in the way we do science in the West. That thinking has so dominated that it has become almost dogmatic and doesn’t admit any ideas outside of that belief system,” he says.

But MacIntyre points out that “many different forms of human knowledge exist,” and empirical evidence is only one of them. Complementary therapies such as Chinese medicine, although “grounded in sophisticated theoretical systems,”

can appear less than credible when viewed “piecemeal” by other cultures.

While Western HIV/AIDS treatments are aimed at battling the virus, Eastern therapies focus more on the condition of the host and on bolstering and maintaining the patient’s immune system so HIV doesn’t overwhelm it, he says.

Another difference is that Chinese medicine programs are tailored to each patient, while Western therapies are aimed more at the disease than the individual.

Complementary medicine involves integrating both approaches, but for many Western practitioners, that requires a more open-minded attitude, MacIntyre states.

“Open-mindedness and doubt in one’s own knowledge of the world used to be the hallmark of science, and we’ve lost a lot of that,” he says. “We’ve instituted a standard by which all knowledge is judged, which is itself myopic. That’s not to say that everything should go, but the intellectual basis for how we develop knowledge in Western medicine needs to be re-examined by a greater number of researchers and practitioners.”

## References

1. MacIntyre RC, Holzemer WL, Philippek M. Complementary and alternative medicine and HIV/AIDS. Part I: Issues and context. *JANAC* 1997; 8:23-31.
2. MacIntyre RC, Holzemer WL. Complementary and alternative medicine and HIV/AIDS. Part II: Selected literature review. *JANAC* 1997; 8:25-38. ■

harmful, we ought to caution the public. We also advocate medical doctors keeping an open mind about what their patients are doing.”

Although advances in drug treatment for HIV/AIDS seem promising, many patients are attracted to alternative or complementary

therapies based on a need for “empowerment, . . . a sense of connectedness between their thoughts, diet, and medical regimen on the one hand, and their view of HIV on the other,” reports a recent study of complementary medicine and HIV infection.<sup>7</sup>

## COMING IN FUTURE MONTHS

■ Latent virus hides in bloodstream

■ New drug helps HIV patients with herpes

■ Urine test reveals HIV where blood tests do not

■ HIV in genital tract responds to HAART therapy

■ Gene variation speeds up progression to AIDS

Author **Richard A. Elion, MD**, a Washington, DC, family practitioner specializing in HIV/AIDS, combines both conventional and alternative medicine for about 70% of his patients.

Elion tells *AIDS Alert* it's important for physicians to know what their patients are taking because of any potential interactions, but it's also important for physicians to be able to offer patients alternative therapies that work. He advocates using "integrative therapies" such as acupuncture, Chinese herbs, vitamin supplements, antioxidants, and amino acids.

### ***HIV offers unique opportunity for integration***

While drug treatment can help suppress viral loads, alternative medicine better addresses restoration and maintenance of immune function, he says. It is not surprising, then, that HIV-infected patients often seek both types of treatments.

In fact, "this trend may very well establish HIV infection as the model condition for a natural integration of allopathic medicine with the emerging sciences of energy medicine, meditation, nutrition, and herbal therapies," Elion's report states.

Nevertheless, patients' use of alternative therapies should be coordinated by physicians, "but sometimes physicians are not competent to supervise that," he notes. "They should have a dialogue with the alternative practitioner so there can be a team approach and so the patient isn't in a position of trying to manage it themselves."

### ***References***

1. Eisenberg DM, Davis RB, Ettner SL. Trends in alternative medicine use in the United States, 1990-1997: Results of a follow-up national survey. *JAMA* 1998; 280:1,569-1,575.
2. Astin JA. Why patients use alternative medicine: Results of a national study. *JAMA* 1998; 279:1,548-1,553.
3. Abrams DI. "Alternative Therapies for HIV." In: Sande MA, Volberding PA, eds. *The Medical Management of AIDS*. 5th ed. Philadelphia: WB Saunders; 1996. pp. 143-158.
4. Burack JH, Cohen MR, Hahn JA, et al. Pilot randomized controlled trial of Chinese herbal treatment for HIV-associated symptoms. *J Acquir Immune Defic Syndr Hum Retrovirol* 1996; 12:386-393.
5. Calabrese C, Wenner CA, Reeves C, et al. Treatment of human immunodeficiency virus-positive patients with complementary and alternative medicine: A survey of practitioners. *J Alt Comp Med* 1998; 4:281-287.
6. Standish LJ, Calabrese C, Reeves C, et al. A scientific plan for the evaluation of alternative medicine in the treatment of HIV/AIDS. *Altern Ther Health Med* 1997; 3:58-67.
7. Elion RA, Cohen C. Complementary medicine and HIV infection. *Primary Care* 1997; 24:905-919. ■

# Study to track benefits of compliance intervention

*Effects of habit training, problem solving sought*

One of the main reasons people who live outside of a medication-controlled setting are failing HIV treatment is lack of adherence to their prescribed treatment regimen. Results of an upcoming 4½-year study may give caregivers new tools for increasing compliance rates.

**Judith A. Erlen, PhD, RN**, associate professor at the University of Pittsburgh School of Nursing, has received a grant from the National Institutes of Health's National Institute of Nursing Research (NINR) to test the effects of habit training, problem solving, and intervention on patient adherence to protease inhibitors.

**AIDS Alert**<sup>®</sup> (ISSN 0887-0292), including **AIDS Guide for Health Care Workers**<sup>®</sup> and **Common Sense About AIDS**<sup>®</sup>, is published monthly by American Health Consultants<sup>®</sup>, 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. Periodical postage paid at Atlanta, GA 30304. POSTMASTER: Send address changes to **AIDS Alert**<sup>®</sup>, P.O. Box 740059, Atlanta, GA 30374.

This continuing education offering is sponsored by American Health Consultants<sup>®</sup>, which is accredited as a provider of continuing education in nursing by the American Nurses Credentialing Centers Commission on Accreditation. This continuing education program does not fulfill State of Florida requirements for AIDS education. American Health Consultants<sup>®</sup> is accredited by the Accreditation Council for Continuing Medical Education to sponsor CME for physicians. American Health Consultants<sup>®</sup> designates this continuing medical education activity for 18 credit hours in Category 1 of the Physicians Recognition Award of the American Medical Association.

### **Subscriber Information**

**Customer Service:** (800) 688-2421 or fax (800) 284-3291. **Hours of operation:** 8:30 a.m.-6:00 p.m. M-Th, 8:30-4:30 F EST. **E-mail:** [custserv@ahcpub.com](mailto:custserv@ahcpub.com). **World Wide Web:** <http://www.ahcpub.com>.

**Subscription rates:** U.S.A., one year (12 issues), \$399. Approximately 18 nursing contact hours or Category 1 CME credits, \$449. Outside U.S., add \$30 per year, total prepaid in U.S. funds. One to nine additional copies, \$200 per year; 10 or more additional copies, \$120 per year. Missing issues will be fulfilled by customer service free of charge when contacted within 1 month of the missing issue date. **Back issues**, when available, are \$67 each. (GST registration number R128870672.)

**Photocopying:** No part of this newsletter may be reproduced in any form or incorporated into any information retrieval system without the written permission of the copyright owner. For reprint permission, please contact Karen Wehly at American Health Consultants<sup>®</sup>. Address: P.O. Box 740056, Atlanta, GA 30374. Telephone: (404) 262-5491.

Opinions expressed are not necessarily those of this publication. Mention of products or services does not constitute endorsement. Clinical, legal, tax, and other comments are offered for general guidance only; professional counsel should be sought for specific situations.

Editor: **Melinda Young**, (828) 859-2066.  
Publisher: **Brenda Mooney**, (404) 262-5403,  
([brenda.mooney@medec.com](mailto:brenda.mooney@medec.com)).  
Executive Editor: **Susan Hasty**, (404) 262-5456,  
([susan.hasty@medec.com](mailto:susan.hasty@medec.com)).  
Managing Editor: **Coles McKagen**, (404) 262-5420,  
([coles.mckagen@medec.com](mailto:coles.mckagen@medec.com)).  
Senior Production Editor: **Brent Winter**, (404) 262-5401.

Copyright © 1999 by American Health Consultants<sup>®</sup>. **AIDS Alert**<sup>®</sup>, **AIDS Guide for Health Care Workers**<sup>®</sup>, and **Common Sense About AIDS**<sup>®</sup> are registered trademarks of American Health Consultants<sup>®</sup>. The trademark **AIDS Alert**<sup>®</sup> is used herein under license. All rights reserved.

### **Editorial Questions**

For questions or comments, call **Melinda Young** at (828) 859-2066.

Erlen, who also is associate director of the Center for Research in Chronic Disorders and an Associate Professor in the Center for Medical Ethics at the University of Pittsburgh School of Nursing, says the current study plan is for researchers to deliver a 12-week telephone intervention followed by a 12-week maintenance program, then follow subjects for an additional six months. Adherence will be defined as taking medications within one hour before or after the prescribed time.

The purpose of the study is to determine if there will be sustaining effects of the intervention over the year's time. Erlen's group will collect baseline data at the end of the three-month intervention period, again following the maintenance program, and finally at one year. She has received funding for the study and expects to begin recruiting about 220 subjects in early February.

The Center for Research in Chronic Disorders is an NINR-sponsored center. "Through the center, we've advanced the science in quality of life," Erlen says. "We're looking at adherence, functional status, and cognitive functioning, and we're looking at the various phenomena across populations. We've done some previous work with quality of life and hope to move forward with these studies, building the kind of measures we want into them. It's a unique opportunity for those of us who are doing research to be able to look at not only what we're doing in our own particular population [but] to learn if other chronic populations have similar or different kinds of problems and outcomes.

"This will be a very systematic, structured kind of intervention, first teaching subjects how to develop a habit and then teaching them how to deal with their problems related to taking their medication," Erlen says. "Other studies have been done that have used a similar approach for habit training and problem solving, but the maintenance piece has been the piece that has not been done in the way we're going to do it."

The study will look at two different outcomes of adherence: quality of life (a subjective measure) and the clinical measures of viral load, CD4 count, number of opportunistic infections patients have had, and whether or not they have been hospitalized. "People can be, at least by all laboratory indicators, doing very poorly, with a high viral load and low CD4's, and yet they'll tell you that their quality of life is fine," Erlen says. "You need to have that whole picture in order to understand something about what the patient's health is and their quality of life and their ability to function." ■

## EDITORIAL ADVISORY BOARD

Consulting Editor: **Anthony Braswell**, MBA, MHA  
Executive Director, AID Atlanta

**John G. Bartlett**, MD  
Chief  
Division of Infectious Diseases  
The Johns Hopkins University  
School of Medicine  
Baltimore

**Bernard Bihari**, MD  
Clinical Associate Professor  
State University of New York  
Health Science Center  
Brooklyn, NY

**James A. Cotrone**, DMD, MS  
Professor and Director  
Division of Oral  
Diagnosis & Oral Medicine  
Department of Dental Diagnostic  
Science  
University of Texas  
Health Science Center  
San Antonio, TX

**Theodore C. Eickhoff**, MD  
Professor of Medicine  
Division of Infectious Disease  
University of Colorado  
School of Medicine  
Denver

**Julie Gerberding**, MD, MPH  
Director  
HIV Counseling and Testing Service  
San Francisco General Hospital  
Associate Professor of Medicine  
University of California  
San Francisco

**Aaron E. Glatt**, MD  
Chief  
Division of Infectious Diseases  
Catholic Medical Center  
of Brooklyn and Queens  
Jamaica, NY

**Lawrence O. Gostin**, JD  
Professor of Law  
Georgetown Center for Law and  
Public Policy  
Georgetown University  
Washington, DC

**Jeanne Kalinoski**, RN, MA  
Director of HIV  
Health and Human Services Planning  
Council  
Office of the Mayor  
AIDS Policy Coordination  
City of New York

**Laurene Mascola**, MD, MPH  
Chief, Acute Communicable Disease  
Control Unit  
Los Angeles County  
Department of Health Services  
Los Angeles

**Kenneth Mayer**, MD  
Director  
Brown University AIDS Program  
Providence, RI

**Cliff Morrison**, MS, RN  
Deputy Director, AIDS Health Services  
University of California  
Institute for Health Policy Studies  
San Francisco

**Douglas Richman**, MD  
Chief, Virology Section  
Veterans Administration of San Diego  
Professor of Pathology and Medicine  
University of California  
San Diego

**Mark Smith**, MD  
President and CEO  
California Healthcare Foundation  
Oakland, CA

**Michael L. Tapper**, MD  
Chief, Section of Infectious Diseases  
and Hospital Epidemiology  
Lenox Hill Hospital  
New York City

**Melanie Thompson**, MD  
President and Principal Investigator  
AIDS Research  
Consortium of Atlanta  
Atlanta

## 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, 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. ■