

# AIDS ALERT.

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January 2001 • Volume 16, Number 1 • Pages 1-12

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### Clinicians may need to help patients with reproduction issues

HIV patients are living longer than ever, and some want to start families. No longer will HIV-infected couples assume they won't see their children grow up now that antiretroviral drugs have made HIV a manageable chronic infection for some. Now, more than ever, it's the role of HIV clinicians to offer guidance and advice to help patients reduce HIV transmission risk . . . . . Cover

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## Reproductive issues are a thorny problem for patients, clinicians

*New research offers hope for HIV-positive men*

One of the results of half a decade of successful antiretroviral therapy combinations is that HIV-infected men and women have more optimism that they will live for 20 or more years after they are diagnosed with HIV. Along with this optimism come the desires and problems that uninfected people experience, including the desire to have children.

The question that most clinicians did not want to answer until recently — and which many gynecologists are uncomfortable discussing even now — is how an HIV-infected person can safely reproduce and give birth.

Four years ago, **Stanley J. Bodner, MD, FACP**, associate professor of medicine at Vanderbilt University School of Medicine in Nashville, TN, gave a lecture on HIV and discussed how he was helping an HIV-positive woman become pregnant. Women in the audience were angry with him for even suggesting this. "They thought it was wrong," Bodner recalls. "But it's not wrong; people have a right to have a child."

Now that vertical transmission among pregnant HIV-infected women has been reduced to 1%-2% in the United States, there is slightly more tolerance for HIV-infected women who choose to have a baby, and it's likely clinicians will see increasing numbers of HIV-infected couples who make this decision. (**See story on strategies for preventing HIV transmission among couples who wish to reproduce, p. 4.**)

"Very few of us in the medical field are encouraging this group of people to try to achieve pregnancy,"

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**Program offers free info on talking to kids about HIV**

Although it's increasingly clear that the HIV epidemic cannot be halted without a stronger emphasis on prevention, controversy persists over school programs that teach youths about HIV and safe sex. While the dichotomy between abstinence-only advocates and those who believe in teaching children about condoms is unlikely to be resolved, there is one prevention program that has bridged the gap. The 12-year-old Parent HIV/AIDS Education Project at Cornell University in Ithaca, NY, has successfully taught parents and guardians how to teach their children about HIV and HIV prevention . . . . . 8

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**R. Scott Hitt**, MD, President of the American Academy of HIV Medicine in Los Angeles, discusses with *AIDS Alert* how the academy will certify HIV specialists and provide member services that include practice management support, networking, and being an advocate for better HIV funding. Hitt is the former chairman of the first Presidential Advisory Council on HIV/AIDS . . . . . 10

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says **Rani Lewis**, MD, associate professor of obstetrics and gynecology in the Division of Maternal Fetal Medicine at Vanderbilt University. Nevertheless, "HIV is no longer a death sentence," Lewis notes. "People are living with it for 10 to 20 years, and it's hitting men and women in the 25-to-45-year range, and that group of people is the group most interested in having families."

The widely publicized reductions in AIDS deaths and infants born with HIV in wealthier nations where antiretrovirals are readily available have convinced many HIV-infected people that they can lead normal lives, and this includes giving birth.

"We've convinced everyone from a public health standpoint that if you just take these medications, we'll decrease the likelihood that you'll transmit this virus to your unborn child," says **M. Keith Rawlings**, MD, associate medical director at Southeast Dallas Health Center of Parkland Health and Hospital Systems in Dallas.

"The truth of the matter is that one of the major accomplishments in the 1990s is the ability to reduce vertical transmission," Rawlings adds. "So if you are a 20-something woman, there may be a desire to have children, and that's not going to change because you're HIV-positive. We have in essence sold you a truism that you can be pregnant and deliver an uninfected child."

To suggest an HIV-infected man or woman give up the idea of having children is asking them to do something that's outside normal human experience, Lewis maintains.

**Rebecca Denison**, founding director of Women Organized to Respond to Life-Threatening Diseases (WORLD) in Oakland, CA, is an example of an HIV-infected woman whose desire to give birth was more powerful than her fear of the disease.

***HIV+ woman gives birth to twins***

When Denison tested positive in 1990, she was told she had about a 30% chance of transmitting the virus to her baby if she chose to become pregnant. Five years later, she was married and wanted to have her own children.

"My reasons were the same as any woman who wants to have children," Denison says. "My brain said, 'No, you're not going to do that,' and my heart would say, 'This is the only thing in life I really want.'"

Her heart won. She became pregnant with twins without high-tech assistance and gave birth to

healthy babies, who now at age 4½ years remain HIV-negative. While pregnant, she remained bed-bound by her physician's orders and took a short course of AZT, followed by a single dose of nevirapine an hour before delivery. She delivered her children via a scheduled cesarean section.

Denison notes that all of the methods she used to protect her infants from becoming infected with HIV have now been proven in scientific studies to be effective strategies.

WORLD provides pregnancy counseling to people with HIV, as do some HIV providers. For instance, the Southeast Dallas Health Center has a number of serodiscordant couples who wish to start a family, Rawlings says.

Because Rawlings believes this issue is outside of his area of HIV expertise, he asked Lewis to visit the clinic and to speak with couples about how to reduce the risk of transmission while attempting to fulfill their dreams of parenthood.

Bodner has helped a variety of HIV-infected patients with reproductive issues, and he's currently participating on a committee of the Triangle AIDS Leadership Alliance Mid-America that is addressing the issue of improving reproductive care for HIV-positive women. The committee is developing guidelines for counseling and prenatal care involving HIV-infected women. (See story about HIV patient pregnancy guidelines, p. 6.)

The alliance was started by Triangle Pharmaceuticals in Durham, NC, as a way for the company to interact with physicians and listen to their concerns.

While the medical community readily acknowledges that the risk of vertical transmission can be greatly reduced through some acceptable medical strategies, there is no similar agreement about how an HIV-infected man can safely impregnate his HIV-negative mate.

"Couples in that situation need to understand there is a risk of transmission and there is no way to eliminate risk at this time," says **Ida Onorato**, MD, associate director for science at the Division of HIV/AIDS Prevention in the Centers for Disease Control and Prevention in Atlanta.

"So a couple should be given all of the information available on risks and benefits, and it's up to the couple as to what their decision should be," Onorato says. "Certainly, they should not try to attempt to conceive on their own, using some kind of natural method that they've read about, and they should not conceal from their provider what their situation is."

The CDC recommends none of the high-tech reproductive methods that are being used and studied by some physicians around the world because none of these have enough published research regarding their efficacy and safety, Onorato says.

Many urban HIV clinics deal daily with HIV-infected women who have become pregnant accidentally or who first learned of their HIV status when they became pregnant, so the issue of planning safe reproduction is a moot point.

### ***Most HIV pregnancies occur accidentally***

"When protease inhibitors were the new kids on the block, I think there was some theorizing in the community that there might be individuals wanting to become pregnant, but this group was never bigger than it was in the past," says **Roxanne Cox-Iyamu**, acting medical director for the Whitman-Walker Clinic in Washington, DC.

"We see five or six women become pregnant throughout the year, but very few planned pregnancies," Cox-Iyamu adds.

The bigger issue faced by Whitman-Walker patients is how single women with HIV can care for both their own health and that of their infants, Cox-Iyamu says. (See story on counseling HIV-infected women on what it will mean to bear and raise a child, p. 6.)

Likewise, the AIDS Action Committee in Boston has had few HIV patients who have planned pregnancies. Most cases have involved women who have had unplanned pregnancies, and some of these women opt to have an abortion. But reproductive issues do arise occasionally. In those cases, case managers may suggest clients meet with a gynecologist who can discuss the disease's implications for reproduction and what medications and other treatments might be necessary.

"What happens usually is someone from a foreign country has a different way of understanding HIV in general, and they think if their friend has a baby then they can have a baby," says **Claudine Guerrier**, bilingual case manager for AIDS Action Committee.

Guerrier briefly assisted an African woman who believed her HIV infection was caused by a curse from her mother-in-law. The woman had one daughter, and her husband, who was HIV-negative, wanted to have a second child. Guerrier gave the husband education about HIV, pointing out that he could contract the disease from his

wife if they had unprotected sexual intercourse. She also told him that by insisting on having another child he could be causing his wife additional stress because she would need to take additional medication.

“He said he didn’t care because he wanted a family,” Guerrier recalls. “I never saw them again.” ■

## Advances offer some hope for safer reproduction

*Discuss pros and cons with HIV clients*

There are no perfectly safe ways for an HIV person to reproduce and prevent transmission to either a partner or a baby. But medicine has improved considerably in recent years, and physicians may offer HIV-infected couples some hope that they could give birth to healthy babies without placing the uninfected spouse at undue risk.

“Usually the bigger problem is when there’s an HIV discordancy,” says **Rani Lewis**, MD, associate professor of obstetrics and gynecology in the Division of Maternal Fetal Medicine at Vanderbilt University in Nashville.

“When the female is HIV-positive and the male partner is not, then the issue is how she can become pregnant and minimize the risk to him and to the baby,” Lewis says. “That issue actually is a little bit easier.”

It’s when the man is HIV-positive and the woman is not infected that it becomes more difficult, Lewis says.

“In that case, we have a tremendous number of problems, because just in the course of ejaculation to get the sperm to the woman so that she can get pregnant, he’s also going to be spreading HIV in his ejaculate,” Lewis says.

While a reproductive specialist theoretically could fertilize the woman’s eggs by high-tech methods of inserting the sperm into the woman’s egg without the virus attached, this method has not been scientifically proven safe for use with HIV-infected patients, and it’s prohibitively expensive for most HIV-infected couples.

There is also a problem with even finding a specialist to do such a procedure for an HIV-infected person.

“Unfortunately, most of the reproductive endocrinologists and fertility subspecialists who assist people in getting pregnant are relatively uncomfortable with trying to inseminate someone with what they believe to be potentially HIV-positive sperm,” Lewis says. “They want to maximize the chances of a woman becoming pregnant in that specific instance where she and a partner will be healthy and able to take care of a baby.”

Here are some of the methods clinicians might recommend or that HIV-infected patients might try on their own:

- **Sperm washing:** Although sperm washing as an assisted reproductive technique is not new, it has rarely been used for the purpose of “cleaning” sperm of HIV. Where this technique is available, it has proven useful. However, it may not be an option in states where it’s illegal to knowingly expose someone to sperm from an HIV-infected man.

Also, the Centers for Disease Control and Prevention in Atlanta does not recommend this or any other technique purported to help serodiscordant couples achieve pregnancy.

“It’s possible that you could in some ways process semen to separate out sperm from the rest of the fluid and test for the virus, but we haven’t used this technique enough, and we don’t have data on it at this point as to advise people that it would be safe to use,” says **Ida Onorato**, MD, associate director for science in the CDC’s Division of HIV/AIDS prevention.

French and Italian researchers presented information about successful sperm-washing studies at an October meeting of the American Society for Reproductive Medicine in San Diego. French researchers used 101 blood and semen samples from HIV-positive patients and found that 59 of the blood samples and 20 of the semen samples tested positive. After processing the sperm through a sperm-washing technique, only 12% of the semen plasma samples were positive, and none of the sperm cells themselves were positive for the virus.

An Italian team led by investigator Augusto Enrico Semprini of Milan conducted a similar analysis with more than 500 semen samples from HIV-positive men and found that sperm washing could reduce the HIV-positive samples to a very low rate. However, the study also found that determination of HIV-1 nucleic acids in whole semen can give erroneous results and that clinicians should test all final spermatozoa

aliquots before using them for assisted reproductive technology.<sup>1</sup>

Semprini has announced more than 180 successful births after sperm washing for couples in which the men were HIV-positive and the women were HIV-negative. All of the women remained negative after they gave birth. Semprini mixes Percoll with sperm in a test tube and uses a centrifuge to force the infected semen through the fluid. The infected cells are eliminated, and the resulting sample is checked for HIV.

Japanese researchers have developed a variation on the sperm-washing technique by using Percoll gradient centrifugation followed by a “swim-up” method to separate virus from semen. This reduced proviral DNA to undetectable levels according to a polymerase chain reaction (PCR) test.<sup>2</sup>

There appears to be less enthusiasm for sperm-washing in the United States. While Harvard researchers have provided sperm-washing to some serodiscordant couples, there has been limited availability of the technique because of the high cost, which includes PCR testing, and other factors.

**Moher Downing**, MA, of the University of California at San Francisco, addressed the issue of sperm washing for HIV-positive men in a paper published on a UCSF Web site ([http://hivinsite.ucsf.edu/prevention/prev\\_contro/3098.0085.html](http://hivinsite.ucsf.edu/prevention/prev_contro/3098.0085.html)). Downing describes the sperm-washing technique as one in which the semen is layered over a more dense solution. Then it's placed in a centrifuge that separates the semen into three layers. Next, the sperm is washed twice in a chemical solution, and the washed sperm is divided in half, with one half frozen for later use and the other half used for PCR testing to detect HIV. If HIV is detected in any of the three parts, the sample is discarded. If it's not discarded, the sperm is combined with an artificial semen solution and used for fertilization.<sup>3,4</sup>

• **Intracytoplasmic sperm injection (ICSI):** This is the most costly technique used to help serodiscordant couples, with a price tag of about \$50,000. With ICSI, a reproductive specialist cleans the sperm and then takes one sperm and injects it into an egg cell that has been prepared, Lewis says.

“This is very high-tech in vitro fertilization,” Lewis says. “And it somewhat decreases the likelihood of transmitting HIV.”

**Mark Sauer**, MD, a professor of obstetrics and gynecology at Columbia University in New York

City, has begun a clinical trial to evaluate the safety of in vitro fertilization using ICSI in cases where the men are HIV-positive and the women are not. Further information about the trial can be obtained by calling (212) 305-4665.

Again, until there is a body of research supporting this method, the CDC cannot recommend ICSI, Onorato says.

“It's possible you can separate out the sperm, that is true, and you can test it and make sure there is no virus there,” Onorato says. “It is theoretically possible that these things can be done, but at this point, without an adequate number of people on which this has been tried and without adequate follow-up, it's hard to say whether or not it's effective or safe.”

• **Artificial insemination:** When the woman is HIV-positive and the man is HIV-negative, artificial insemination can eliminate risk of the man becoming HIV-infected. Because the easiest and least expensive method is what is commonly called the “turkey baster” method, couples often will opt for a home version of artificial insemination rather than using the services of a clinic or doctor's office, Lewis says.

“But before we'd recommend somebody do this, we would recommend they optimize the health of the woman who is HIV-positive,” Lewis says. “So we'd want to get her off of medications that are known to be bad for fetuses and preferably get her on an antiretroviral regimen that contains AZT or didanosine.”

### ***\$30 device might do the trick***

Bodner has helped HIV-infected women use an alternative form of insemination called an Algiospermia Cap, a device that enhances the likelihood that semen will inseminate or fertilize an egg.

“It gets a big quantity of semen to go into the uterus, and it's used when a man's sperm count is low,” Bodner says. “It's about like intrauterine insemination and puts the sperm at the beginning of the cervix.”

One of Bodner's patients used the \$30 device and gave birth to two children.

“If a woman is careful and knowledgeable and knows approximately when she ovulates, the chances of fertilization are excellent,” Bodner adds.

• **Alternative methods:** Many clinicians might be uneasy mentioning any of the alternative methods that a serodiscordant couple might use

to achieve pregnancy. But it's likely that any guidance from a clinician will be preferable to the couple attempting to get pregnant without taking any precautions.

Lewis once worked with a couple in which the man was HIV-positive and the woman was negative. They wanted to have a child but had very limited financial resources, and so assisted reproductive technology methods were ruled out.

"We came up with a plan of management that they could both live with, and it wasn't ridiculously expensive," Lewis recalls. "It involved maximizing her chances of becoming pregnant and treating him with antibiotics to decrease the number of white blood cells in his semen, because the white blood cells are the ones that carry HIV."

Then Lewis started the man on antiretroviral therapy for several months to decrease the number of potentially infected white cells in his semen. The couple was told that they had two days in which to attempt pregnancy. After they had intercourse, the woman took a short course of antiretroviral therapy as a prophylactic measure.

The expense was low because the man's medications were covered by a third-party payer, the antibiotics were expensive, and the ovulation test sticks were inexpensive, Lewis notes. The short course of antiretroviral therapy also is relatively inexpensive.

"The idea is to not allow them to have indiscriminate intercourse at any time, but to maximize everyone's potential," Lewis says.

If an HIV-serodiscordant couple wish to have a child and they don't receive medical guidance, there's a good chance they'll figure out their own method of protection.

For instance, some couples in which the woman is HIV-positive have attempted using a condom with a hole in it during intercourse as a way to protect the man and still achieve pregnancy.

"There are a range of ways to protect the uninfected spouse," says **Rebecca Denison**, founding director of Women Organized to Respond to Life-Threatening Diseases in Oakland, CA. Denison, who is HIV-positive, is married to a man who is HIV-negative. They have twin daughters whom Denison conceived and delivered after she found out she was HIV-positive. The Denison's daughters remain HIV-negative after 4½ years.

"I know someone who had sex with an uninfected partner, using a condom, and when he was about to ejaculate they whipped off the condom,"

Denison says. "People try to look at their most fertile periods and get the viral load as low as possible before trying."

In other cases, the HIV-negative wife has said that she doesn't care about whether she becomes infected, and they've had unprotected intercourse, Denison adds. The drive to give birth is that strong, she notes.

"When I met my husband, the thing that made him not just a boyfriend but the person I wanted to spend the rest of my life with was the life I saw us building together with children," Denison explains. "I knew he'd be the most fabulous father in the world, and I knew I'd be a wonderful mother, and he is and I am."

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## Pre-pregnancy counseling critical for patients

### *Prospective parents should know all the risks*

One of the most important reasons clinicians should be open to assisting their HIV patients with planned pregnancies is that they can help patients reduce risk by providing counseling that clarifies all options and consequences.

"I just think the most important thing is to prepare HIV-positive women for the fact that there is always the potential for the child to become HIV-positive," says **Rani Lewis**, MD, associate professor of obstetrics and gynecology in the Division of Maternal Fetal Medicine at Vanderbilt University in Nashville, TN.

Before attempting pregnancy, HIV-infected women should consider improving their insurance

coverage, stop all risk behaviors (including drug use), and prepare for the difficulties that would arise with an HIV-infected infant.

“The thing that would change things the most for the couple is if the child becomes HIV-infected,” Lewis says. “Neonates have such a miserable immune system anyway, and HIV-infected neonates have a very short life span.”

On the other hand, if the infant is born HIV-negative, the HIV-infected parent or parents must face the possibility of not living to see their child reach adulthood. **Rebecca Denison**, who was diagnosed with HIV infection in 1990 and later gave birth to twins, says she often talks with HIV-infected women about the issue of whether they will live to raise their children. But she feels this issue is something all parents need to address.

“Every parent has a responsibility to think about what happens if I’m in a car crash tomorrow,” Denison says. “We need wills because we’re parents; the fact that I’m positive means that maybe I placed greater urgency and responsibility on doing those things.”

Denison has put together photo albums and audio tapes, including some in which she sings lullabies, for her daughters.

From a medical standpoint, clinicians need to advise HIV patients about strategies that will protect their own health and that of their child. If the pregnancy is unplanned, some physicians will suggest the woman have an abortion, but that shouldn’t be the knee-jerk reaction to every pregnancy an HIV-infected woman has, says **Stanley J. Bodner**, MD, FACP, associate clinical professor of medicine at Vanderbilt University School of Medicine in Nashville, TN.

Bodner has participated on a committee of the Triangle AIDS Leadership Alliance Mid-America that has developed guidelines for clinicians treating HIV-infected women who are or desire to become pregnant. The guidelines, titled “HIV Infection and Having A Baby Timeline,” are expected to be published in 2001.

According to Bodner, Lewis, and the guidelines, here are some of the steps clinicians should take when advising HIV-infected women about pregnancy:<sup>1</sup>

- **HIV management:** The first step is for an HIV specialist to be involved with prenatal care so antiretroviral treatment can be adjusted to accommodate the pregnancy.

- **Counseling:** The pregnant woman, her partner, and sometimes the larger family should be

counseled by an obstetrician and obstetric team nurse, and the obstetric team should be in early contact with the HIV specialist.

Initial counseling should give patients accurate information about HIV, including side effects of treatment, how to reduce the risk of mother-to-fetus transmission, and how the prospective mother might expect to live to see her child reach adulthood. Clinicians also may describe various scenarios to the prospective parents to help them see the situation realistically.

If the couple is serodiscordant, then they would be advised of various options for achieving pregnancy while reducing risk of transmitting the virus to the uninfected partner.

- **First-trimester care:** The team would include an obstetrician/gynecologist, an infectious disease expert, and a pediatrician. Each professional involved with the woman’s prenatal care would maintain strict confidentiality.

The team would plan how to use antiviral therapy and would monitor the patient’s viral load count and CD4 cell count.

### *Watch out for toxoplasmosis*

- **Second-trimester care:** Every three months, the team obtains the patient’s viral load and CD4 cell count.

The infectious disease specialist should attend to both standard infectious disease concerns regarding pregnant women and special issues related to HIV opportunistic infections. This includes surveillance for perineal Group B *Streptococcus agalactiae* colonization, prior rubella and varicella exposure and immunization, maternal genital herpes simplex infection, and *S. agalactiae* vaginal colonization. HIV-infected women with CD4 lymphocyte counts under the 100-200 range who are not taking toxoplasmosis prophylaxis may have maternal risk of toxoplasma infection. All pregnant women who are HIV-infected should avoid cats and cat litter.

Lewis also recommends that HIV-infected pregnant women avoid having an amniocentesis because that could increase the likelihood of transmitting HIV to the infant.

“We would recommend they don’t automatically go to an amniocentesis, because interrupting the bag of water significantly increases the risk that the baby would get HIV,” Lewis says.

- **Third-trimester care:** At this point, the obstetrician discusses the importance of an elective cesarean section prior to labor for women who

have HIV-RNA levels of greater than 1,000 virions, to reduce the risk of infecting the infant. The infectious disease specialist should obtain a 35-37 week HIV viral load test.

The obstetrician also might discuss with the woman the possibility of sterilization, possibly to accompany the cesarean. The obstetrician also should advise the woman to use infant formula and avoid breast-feeding.

### ***Balancing health vs. bonding experience***

“Breast-feeding is very strongly associated with the baby becoming infected,” Lewis says. “In the United States, where we have alternate forms of nutrition for babies, I think increasing the risk to the baby’s health for the benefit of the maternal-infant bonding experience is probably not worth it.”

The pediatrician and other team members should plan to have the antiretrovirals zidovudine, lamivudine, and nevirapine present at the birth in oral infant pediatric syrup formulations. The obstetrician also should have intravenous zidovudine available to administer during delivery, and the ID specialist should provide a single 200 mg dose of nevirapine to the woman on the morning of the planned cesarean.

Lewis recommends alerting the patient to some potential birth complications, such as problems with a small gestational age or decreased amniotic fluid volume. “So as the amniotic fluid around the baby goes down, the chance that the baby can suffer interfetal demise goes up,” she says.

- **Newborns:** The birthing team should follow usual universal precautions and examine the newborn for mitochondria toxicity, birth defects, and other problems. The infant should be tested using a polymerase chain reaction (PCR) DNA test at six to eight weeks and again at five or six months. Because all babies born to HIV-infected women have positive ELISA HIV antibody tests, the PCR-DNA test is required, and the infant is considered negative after a second negative HIV test. All babies born to HIV-infected mothers should be prescribed sulfamethoxazole-trimethoprim for *Pneumocystis carinii* pneumonia prophylaxis until tests show that the baby is not infected with HIV.

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## **Cornell offers free info on talking to kids**

*Program has been duplicated internationally*

**A**lthough it’s becoming increasingly clear that the HIV epidemic cannot be fully halted without a more powerful emphasis on prevention, controversy continues to erupt over school programs that teach youths about HIV and safe sex.

While the dichotomy between abstinence-only advocates and those who believe in teaching children about condoms is unlikely to be resolved, there is at least one prevention program that has bridged the gap. The Parent HIV/AIDS Education Project at Cornell University in Ithaca, NY, has successfully taught parents and guardians how to teach their children about HIV and HIV prevention.

The project’s focus is on community-based programs, taught by peers to parents and guardians, called Talking with Kids About HIV/AIDS.

“This assists parents and guardians in being partners to their kids as they learn about HIV in school classes,” says **Jennifer Tiffany**, RN, MRP, director of the Cornell University Parent HIV/AIDS Education Project.

Because the program is directed to parents, giving them ideas of how to communicate prevention messages to their own children, it has an inherent buy-in among adults. Even if some of the parents disagree with the “safe sex” message, they at least can hear different opinions on the topic within a non-threatening group environment.

“In addition to that, it’s the parenting generation that’s dealing with the heaviest weight of AIDS diagnoses, really the 25-49 age group, the parenting years,” Tiffany says. “So at the same time we’re giving parents skills to teach their children, we’re reaching those parents and guardians with information that might help them make changes that would keep them healthier.”

A study of the program found that parents participating in the program were three times more likely to discuss HIV risk reduction with their children than parents enrolled in educational workshops, and they gave their children a broader scope of information.

Parents involved in the program had more conversations about HIV with their children, an

average of five in the past month, compared with one or two conversations among the control group. This proved to be important because when teenagers were asked what they wanted to hear from their parents about HIV, they often said that they didn't want it to be one big conversation and would rather their parents had a series of small conversations on the topic.

The likelihood that parents and children would discuss HIV risk behaviors increased due to the program; HIV testing increased among the parents; and the parents also were more likely to make behavioral changes themselves.

The program, available in English and Spanish, has been duplicated or modified and used over the years by various other groups, including a Tennessee Parent-Teacher Association, the National Development and Research Institutes in New York City, and by communities across the nation and the world. Peer volunteers have translated the program into various other languages, as well. Most recently, the program has been duplicated in Mexico City. (See **“Common Sense About AIDS” for a sample of what the program includes, inserted in this issue.**)

Here's how the program works:

### **1. Peer volunteer educators hold meetings for parents.**

The Cornell project recruits and teaches peer volunteers how to educate parents and facilitate group sessions within their communities. AIDS service organizations, churches, PTAs, and other groups could do the same.

### ***Sessions held in various settings***

“We offer these sessions to parents in a wide range of community settings,” Tiffany says. “Peer educators have done creative things like negotiating with manufacturing plants to offer sandwich seminars, and they'll do a series of six or eight seminars.”

Employers have cooperated by extending lunch hours and allowing educators on site to conduct the seminars. Sometimes the volunteers even obtain small grants to pay for sandwiches and lunch food.

“These seminars will center around the issues of teaching kids about sexuality, HIV/AIDS, risk reduction, and other issues between kids and parents,” Tiffany says. “The overarching theme is to take it to the parents, maybe in an employment setting, prison, shelters for people who are homeless, and others.”

One unemployed volunteer even conducted mini-educational sessions while she waited in long lines at the unemployment office. “She would take her kit with her, and while in line she would offer some of the communication activities about learning about HIV/AIDS,” Tiffany says.

### **2. Use the Cornell program's standard curriculum.**

The Cornell curriculum includes information for three sessions of 2.5 hours each. It's available at no charge at the program's Web site ([www.human.cornell.edu/pam/extensn/hiv aids/](http://www.human.cornell.edu/pam/extensn/hiv aids/)) or copies may be purchased for a nominal fee.

“There's a lot of flexibility in how people offer the workshops, but we recommend they do it in multiple sessions, because a lot of learning happens in between the sessions,” Tiffany says. “Parents will initiate conversations with their kids, and the educators ask them to tell stories when they come back to the next session.”

This ongoing dialogue about what happens at home and what is being taught in the workshop is what facilitates behavioral changes and lasting education.

The self-explanatory curriculum is easy to use. Facilitators can adapt the material to suit their own group's needs.

“People do need to fold in local content, because the program looks at people's experiences with HIV/AIDS,” Tiffany says.

The program also includes illustrations and graphic details about condom use and other risk reduction strategies. A chapter on “How to Talk to Kids about AIDS” suggests that parents tell their toddlers, “This is your hand, this is your knee, this is your vulva/penis, this is your foot, this is your nose.” The idea is to bolster the child's comfort with and respect for the human body and build a foundation for talking about sexuality later.

“What you tell your kids about HIV is mediated by where they are in the process of growth and development,” Tiffany says. “But this is valuable, life-saving information, and everyone needs to know it whether or not they use it at this moment.”

The program has been well-received by parents and other participants over the years, Tiffany says. “I think the reason it's well-received is the process of talking about these things as a dialogue instead of having an expert lecturer talk to people.”

### **3. Give parents/guardians tools and incentive to discuss HIV with their children.**

Some of the program's activities help parents first become comfortable with discussing HIV/AIDS with other adults. For example, in one activity, the facilitator asks group members to discuss their own experiences of when they first heard about HIV/AIDS. They can further discuss what sort of impact it had in their community.

"When you have a small group of six to eight people talking about these things and saying, 'This is my experience,' and then talking as a group about AIDS, then you show that there has been an impact from the disease," Tiffany explains. "It's gone from being some distant disease that you blame others for to a more personal concern."

Some other activities give parents suggestions for discussing the disease with their children. These explain how the children might be at risk and what the children can do to reduce that risk.

Rather than have a polarized debate about the virtues of abstinence only and condom use, parents can talk about these strategies as part of a bigger continuum, each useful in its own time.

"It does a disservice to people's health to say that we have to back one and exclude the other," Tiffany says. "People who come to the workshops have the opportunity to say where they're coming from."

Sometimes participants will say, "I don't support the fact they are teaching XYZ in the classroom, and this is why," Tiffany says.

Then other parents in the group might comment, "Hmm, well, I think about it this way," she adds. "Sometimes people's hearts and minds are changed, and sometimes they're not, but the discussion is civil."

The important thing is for parents to learn how important it is for them to be involved in discussions about HIV with their children. Studies show that when parents discuss HIV comfortably with their children, the children are

more likely to be able to discuss risk behaviors with their sexual partners and also are more likely to delay first-time sexual activity and to use a condom for their first sexual intercourse experience, Tiffany says.

Some of Cornell's research about teenagers and parents suggests that teens want more dialogue and support from their parents, but they want to be recognized as people who are becoming more independent and responsible for their own actions, Tiffany says.

"They want parents who are good listeners and who are sources of information," she explains. "Teens also want their parents to not restrict their activities, but to recognize that they soon will be on their own and need to learn how to become independent." ■

## HIV specialists' academy will offer certification

*HIV patients can find specialists on Web site*

*(R. Scott Hitt, MD, President of the American Academy of HIV Medicine in Los Angeles, discusses with AIDS Alert how the academy will certify HIV specialists and provide member services that include practice management support, networking, and being an advocate for better HIV funding. Hitt is the former chair of the first Presidential Advisory Council on HIV/AIDS.)*

**AIDS Alert:** Why is this organization needed? What will be its specific purposes and goals?

**Hitt:** There currently isn't an organization whose main purpose is to represent the interests and concerns of HIV specialists. I think basically we want to gain greater access to quality care for all HIV patients. We want to establish and promote criteria to define what an HIV specialist is. Everybody has different opinions about what makes somebody an HIV specialist, and it really hasn't been standardized.

For instance, an insurance company may say that all of its HIV patients have access to HIV specialists, who are called infectious disease physicians. And we all know that some infectious disease physicians are good at HIV. But others passed their ID boards years ago, and they really don't take care of any HIV patients anymore. So they're really not HIV specialists.

## Correction

In the October 2000 issue of *AIDS Alert*, it was incorrectly stated on page 128 that research at the Pennsylvania Medical School in Philadelphia "supports a theory that HIV-infected adolescents have functioning thyroid tissue . . ." It should have read that the research "supports a theory that HIV-infected adolescents have functioning thymic tissue. . ." ■

That's why it's important to establish and promote the criteria of what an HIV specialist is. For instance, there was a law that was passed in California about a month and a half ago. It mandates that health carriers make sure their HIV patients are seen by HIV specialists. This means we need a definition for what an HIV specialist is.

**AIDS Alert:** How are you going about defining that?

**Hitt:** We've done a couple of things. We would define a specialist as a licensed MD, DO, PA, NP, or PharmD. We are not talking about just doctors. We recognize that nurse practitioners and physician assistants can be HIV specialists. They are currently caring for at least 20 HIV patients and they show a continuous professional development. There are different ways they can show that. If they passed their infectious disease board certification in that year, then that qualifies as continuous professional development. For non-ID doctors or for ID doctors who have not passed their boards that year, the other way they can do it is to complete 30 units of HIV-related CME each year. But if they don't want to do that many units, because that's an awful lot of continuing education in one subject, the third way is they can complete 15 units of HIV-related CME and pass what we're calling a maintenance of HIV competency examination. It's an open book, take-home, Web-based concise assessment that shows that they're up to date.

What makes HIV so unique is how fast everything is changing. If I passed my boards three years ago, I may not know that if somebody had a hypersensitivity reaction to abacavir they shouldn't be put on trizivir. That's a simple thing that some people don't know. So there has got to be a way of saying, "Look, if you're in the field today, you should know that information." That criterion means you have to do some homework.

One of the things we're doing is we've put together a core curriculum committee, and their task is to develop a core curriculum that defines HIV specialty competency. They are going to suggest what defines competency in HIV. Then we're going to certify some update programs for HIV specialists to see if the classes actually meet the core curriculum.

We're going to use that same core curriculum to develop the annual maintenance of HIV competency exams. We're also going to develop a self-directed HIV medicine study guide.

**AIDS Alert:** Are there any other types of functions that your organization will serve?

**Hitt:** One of the things we've put together already is an Internet referral database where patients or physicians can go to a map, click on their city, and up pops a list of certified HIV specialists in their area. When they click on that doctor's name, they actually will get information on doctors' office hours, what insurance they take, what hospitals they go to, and a little bit of information about them. This is a personal profile of that doctor, or PA, or NP. Many AIDS services organizations in the country all keep separate

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Editor: **Melinda Young**, (828) 859-2066.

Vice President/Group Publisher: **Brenda Mooney**, (404) 262-5403,

(brenda.mooney@ahcpub.com).

Editorial Group Head: **Glen Harris**, (404) 262-5461, (glen.harris@ahcpub.com).

Production Editor: **Brent Winter**.

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### Editorial Questions

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

lists of specialists. We're going to have an updated list of who is the certified specialist in their area. That's one benefit we're offering.

We're also offering a lot of tools to help manage HIV practices. For instance, on the Web there will be handouts that specialists can use. Our Web site will list upcoming conferences. But also we're going to be mailing out to all of our members an 80-page book called "The HIV Specialist's Guide to Reimbursement." This will cover things we need to know in managing our practices, including what are the issues with Medicare, Medicaid, or private payment. It will include information on coding, how to upcode, and details on items that have been found wrong with coding. We will be supplying our members with several other practice management tools, as well.

We certainly will also be involved also in the legislative arena in a couple of areas. We're trying to get official recognition of HIV specialists, but we're also working hard on expanding the definition of Medicaid to include those who are HIV-positive and not disabled. Of course, we'll work on obtaining better funding for ADAP, Ryan White, etc.

**AIDS Alert:** There are some rural areas, particularly in the South, that have no one to specialize in HIV. What will you do about that problem?

**Hitt:** We want to improve access to quality care for all patients, and that would include seeing that they receive quality care in rural areas. One of the things we'd like to do is try to focus on what education a rural provider would need to become a specialist. Right now, it might be a little overwhelming. They can't go to all the conferences. So we say, "Here's what you need to do if you want to learn how to be an HIV specialist. But if you don't have the time to be a true HIV specialist, let's link you up with an HIV specialist in the nearest city who you can call when there's a significant decision to be made."

That's on the Web site. If you live in Macon, Georgia, and you want to find the closest HIV specialists who are certified, you can go on the Web site and do that. They can also find out information about various HIV classes on the Web site.

*[Membership in the Academy costs \$50 per year for primary, associate, and affiliate members, who also will receive the newsletter. The organization's address is: American Academy of HIV Medicine, 836 North La Cienega Blvd., Suite 303, Los Angeles, CA 90069. Telephone: (520) 962-9009. Web site: <http://www.aahivm.org>.]* ■

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## 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. ■

# Common Sense About

# AIDS®

## Conversations with kids about HIV/AIDS

*Editor's note: What follows is a guide to teaching children about HIV/AIDS prepared by the Cornell University Parent HIV/AIDS Education Project. The project offers its training and teaching materials free on the program's website at <http://www.human.cornell.edu/pam/extensn/hiv aids/>. AIDS Alert reprints this chapter of the program with permission from the project.*

Any conversation about sex or drug use or disease may feel uncomfortable at the beginning, because these are topics that are rarely discussed between adults and young people in our society. Many adults don't even talk about these topics with other adults! Sometimes adults hide behind factual information when dealing with controversial subjects. Facts are important, but they are impersonal. Facts alone are not likely to change someone's behavior or to form the sole basis for their future decisions. Research

has shown that young people who know all the right answers about AIDS still do risky things. To be effective, education must address both the factual and emotional aspects of charged issues such as AIDS.

Remember that you can have many types of conversations about AIDS with young people. Some may mostly involve listening, some may involve sharing feelings and discussing facts, some may focus on information you are passing on to your child, and some may focus on solving problems and planning what you or your child will do. All of these types of conversations are very important, even if each has a different style. It is also possible to have your child leave each type of conversation feeling accepted, valued, and supported in learning how to cope in a world with AIDS.

Once you have learned some basic facts about AIDS and ways of reducing the spread of HIV, you are

ready to talk with your child. Make sure that you and your child both have an understanding of the clinical and slang words each of you uses to discuss sex and drugs. It may help if you teach children the correct terms for all their body parts in a matter-of-fact way when they are young. Parents can tell infants and toddlers, "This is your hand, this is your knee, this is your vulva/penis, this is your foot, this is your nose." This will build the young child's sense of comfort and respect for the human body. It will help to build the foundation needed for talking about sexuality later on.

Two common situations in which you may talk with your child about AIDS are 1) when you have made a special plan to have a conversation about AIDS, and 2) when a special opportunity for talking with your child about AIDS just happens. The building blocks for either talk are the same.

**Conversation building block  
number one:  
Know your child**

First, you need to think about your child: age, questions or concerns about HIV, what information your child already has about AIDS, where the information came

from, and whether that information is correct. You need to think about any special circumstances your child might face in terms of AIDS: Does your child know or love anyone who has HIV? Is a child with HIV enrolled in the school? If your child has hemophilia, does he or she feel afraid or face stigma related to AIDS? Is your child sexually active? Does your child fear that you may be at risk? Also, think about times and situations when you and your child have had good talks. What went into making those talks comfortable and effective?

**Conversation building block  
number two: Accurate  
HIV/AIDS information**

Next, think about the information you know about AIDS and HIV. Do you need to know more to feel secure in presenting the information? What pieces of this information does your child need to know now? Some information might resolve unrealistic fears your child might have about AIDS. Other information might be important for your child to have to change risks he or she may be taking. Your child may be too young to understand some of what you know about AIDS, so think about what informa-

tion you can save to teach your child later on. Does your child have a grasp of the vocabulary and concepts that will enable her or him to understand the information you wish to present? Make a plan of what you want to say.

**Conversation building block  
number three:  
What are your values?**

Third, think about your beliefs and values in relation to the information you want to share. Examine your values and try to determine where they have come from. Make a plan for what values you want to teach your child. Be aware of the impact of your values on the information you tell your child about AIDS. Do you have personal difficulties with any issues related to AIDS? Try to present a balanced point of view and admit that some of the topics are controversial and hotly debated. Sometimes it may be difficult to talk with your child about something very important, because you fear finding out that your child is doing something that goes against your values. For example, I may feel very strongly that shooting cocaine is wrong -- so I avoid frank conversations about drug use with my teenager. I may disapprove

of premarital sex-so I avoid talking with my sexually active son about condom use. I may feel that vaginal intercourse is right and natural and may not talk with my college-aged daughter about the risks it presents for transmitting HIV. Research has shown that education about sex and drugs does not increase sexual activity and drug use. The effect of educational efforts is to increase the level of safety precautions taken by those who are already sexually active or experimenting with drugs. Think about ways to share your values with your child at the same time as you tell them the facts about HIV transmission and risk reduction.

**Conversation building block number four:  
Affirm your child**

Think about several ways you can affirm your child during your conversation: by listening to them, by praising them, by telling them you care.

The fact that you are talking with them about AIDS shows that you respect and care about them.

**Conversation building block five: Good times and places to talk**

If you are planning a special conversation about AIDS and HIV, think about a good time and place to have it. Make sure that the groundwork has been laid and that a climate of open communication about issues of

sexuality has already been established. AIDS should not be the topic of a first talk with your child about sexuality. Think about how much time the conversation will require and plan for enough time. Plan something fun and relaxing to do before, after, or during the talk.

**Teachable moments**

This kind of thinking will also help you take advantage of teachable moments - opportunities for talking with your child about AIDS and HIV that arise naturally. All of us are most interested in learning when we have an immediate need for information or when something happens that makes us seek answers to specific

questions. Gifted teachers sometimes have a special ability to recognize teachable moments and to respond to them. You can take advantage of a variety of teachable moments in relation to AIDS. Your child may come home from school with questions about AIDS or see a show about AIDS on television. Your teenager may ask to go to a party and imply that some of the kids planning to be there are sexually active. You may learn that someone in your family or neighborhood has HIV or AIDS. Your child may simply ask you a question about AIDS out of the blue.

How you reach your child about HIV/AIDS depends on

the child's questions and concerns, level of understanding, age, prior knowledge, learning style, and your communication style. ■

To the health care worker: *Common Sense About AIDS* is written especially for your patients and other laymen. It explains important issues concerning AIDS in a thorough, yet easy-to-understand style.

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