

The AMERICAN ACADEMY of HIV MEDICINE

Winter 2009  
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# HIV SPECIALIST

PATIENT CARE, PRACTICE MANAGEMENT & PROFESSIONAL  
DEVELOPMENT INFORMATION for HIV CARE PROVIDERS

## WOMEN & HIV

SPECIAL  
CHALLENGES  
FOR HIV  
SPECIALISTS

10

The Eyes of  
an Intern

3

EMR & HIV

4

KS Case  
Studies

18

Patient  
Communication

20

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## CONTENTS

### FEATURES

# WOMEN & HIV

## 5 Feminization of an Epidemic

Women represent the fastest growing demographic of HIV infections worldwide and providers must understand the special issues involved so they can develop effective prevention and treatment strategies.

**BY SARASWATI IOBST, MD AND  
MONICA GANDHI, MD, MPH, AAHIVS**

## COVER STORY 10

# Special Challenges for HIV Specialists

In their own words, HIV specialists describe the unique challenges involved in treating female patients and some of the strategies they employ. Misplaced trust in partners, pregnancy, putting family ahead of their own care...just some of the issues involved.

**BY BOB GATTY, EDITOR, HIV SPECIALIST**

## DEPARTMENTS

### 2 FROM THE EXECUTIVE DIRECTOR

A Year of Progress

**BY JAMES FRIEDMAN, EXECUTIVE  
DIRECTOR, AMERICAN ACADEMY  
OF HIV MEDICINE**

### 3 ON THE FRONTLINES

Women & HIV:  
An Intern's Perspective

**BY BONNIE PROKESCH, MD**

### 4 BEST PRACTICES

Last in a Series:  
EMR & the HIV Practice

**BY RICHARD PROKESCH, MD, FACP**

### 18 AT THE FOREFRONT

Kaposi's Sarcoma in Treatment  
Naïve HIV Patients

**BY CAROLYN SAVINI, MSN, FNP,  
AAHIVS, BEVERLY HARRINGTON, MSN,  
FNP-C, AND SUSAN WILSON, ACRN**

### 20 QUICKPICS

Empowerment and  
Encouragement in  
HIV Care

**BY D. TREW DECKARD,  
PA-C, MHS, AAHIVS**

**HIV  
SPECIALIST**

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# Letter from the

## DIRECTOR

BY JAMES M. FRIEDMAN, MHA, EXECUTIVE DIRECTOR, AAHIVM

## A Year of Progress

**T**HIS ISSUE OF THE *HIV SPECIALIST* MARKS THE COMPLETION of the first full year of our unique, HIV provider-focused magazine. It has been quite a successful year for *HIV Specialist*. Each of the first four editions has addressed critical issues for HIV treating medical providers and their patients.

Congratulations are in order for the entire team that has helped bring this magazine to fruition. Dr. Jeffrey Kirchner, AAHIVM Board of Directors member, has chaired a dedicated Editorial Advisory Group (EAG) that has offered much time, insight and content to and for the magazine. AAHIVM Communications Director Rob Banaszak has been the linchpin to make each edition happen. Our managing editor, Bob Gatty, has helped take us deep into some of these key issues with provocative and informative cover articles. Advertising sales maven Jane Richardson has helped generate excitement with advertisers, while BonoTom Studio crafted our award-winning look. Together this team has helped us translate an idea into a professional magazine of which we can all be proud.

Likewise, 2009 has seen real progress in other areas of the Academy's work. AAHIVM Board of Directors Chair Donna Sweet, MD, MACP, AAHIVS testified before the Energy and Commerce Committee in support of the Ryan White Extension Act. Deputy Director Bruce Packett guided our educational programs and new and improved workshops. Director of Credentialing Peter Fox increased the quality and reach of our credentialing program. Director of Membership Ken South bolstered AAHIVM memberships, particularly among students. Assistant Director of Policy and Programs Holly Kilness oversaw our Ryan White Advocacy Network as well as the implementation of our cooperative agreement with the Centers for Disease Control and Prevention (CDC) to educate providers about the implementation of the CDC's 2006 revised recommendations on routine HIV testing. Finance and Administrative Director Aaron Austin has managed and maintained both our financial and administrative operations and helped keep AAHIVM running efficiently and effectively.

The Academy is looking forward to opportunities and challenges in 2010. There are several new and revised activi-

ties on the drawing board. We are working with the American Geriatrics Society to create a program to develop clinical guidelines for the care of aging HIV patients. We will be conducting a Role Delineation for HIV-focused pharmacists so that we can create a separate credentialing examination for them. We plan to expand our new HIV Referral Link, devel-

oped by the Academy working with the CDC, to several cities beyond the original six pilot cities. This Referral Link, which will be located on our web site, is a critical element of the HIV Routine Testing program. It will facilitate referral of those identified as HIV positive in a general medical setting to a choice of nearby HIV practitioners.

But our major focus — that cuts across all of our current and planned activities — is to get you, our members, more involved with the Academy. We need you to suggest new ways we

can better serve you, your practice and your patients. We encourage you to get more involved with your Academy chapter, to join a national committee, and yes, to give me a call or send me an e-mail with a new programmatic idea, or even a criticism. This not just an idle request, I really do want to hear from you. And I hope to meet more of you at our Membership Meeting to be held in conjunction with the CROI meeting in San Francisco in February 2010.

Finally I want to thank each and every one of you for the opportunity to work with such a wonderful and committed organization, board, membership and staff. **HIV**



James Friedman

Sincerely,

James M. Friedman, MHA  
Executive Director  
American Academy of HIV Medicine



On the **BY BONNIE PROKESCH, MD**

**FRONTLINES**

# Women & HIV: An Intern's Perspective

**A** **S I WALKED FROM ROOM TO ROOM** seeing my patients during my first week as an intern on the Special Immunology Service (the HIV service) at Grady Memorial Hospital in Atlanta, I could not help but think I had traveled back in time. For a moment I thought it was 1988, before antiretroviral medications had been invented, when people were presenting with multiple opportunistic infections, when HIV was a truly fatal disease. And then it hit me – if it really were 1988, I would be only 6 years old, and none of the patients on this service would be women.

Of course the service was primarily composed of men who had contracted HIV from their male sexual partners, but, as clinicians increasingly are seeing around the country, there were numerous women populating the HIV inpatient service. Ms. B., suffering from HIV dementia, told me she had become HIV positive after having sex with her boyfriend—although she knew he had HIV before she began dating him. Ms. T., who had PML, diarrhea, and candida esophagitis, said her children's father had infected her with the virus. She was unaware of his HIV status prior to engaging in sexual intercourse, and was extremely angry with him for giving her a virus that she was not prepared to handle mentally or financially.

What struck me the most about both of these women was their age. While they both looked as though they were over 60 years old, they were in their early 30s. They were both already living in nursing homes, unable to care for themselves or their children. They were like many of our patients: unin-

sured, from poor families with little education and support, and lacking the insight and resources to seek out and obtain adequate healthcare. These women were only a few years older than me and their lives were already over. In a different setting, they could have been my friends, my classmates, or even my siblings.

How can we better protect our women patients against a virus that no longer has to be fatal? In a world that remains patriarchal in many realms, including that of economic dependence and sexual protection (I know there is a female condom, but, honestly, do any of your patients use it?), how do we better educate American women regarding the dangers of unprotected sex and the resources available if they do in fact become infected with HIV?

As HIV becomes more of a woman's disease, as a young woman doctor, I see the need to better reach out to our female patients and ask the uncomfortable questions regarding sexual history and domestic safety that are often quickly rushed or even skipped by even some of the best clinicians. Every patient interaction is an opportunity to enrich a person's life and teach someone skills that can help her live a safer, healthier life and educate those around her. After all, isn't that why we all went into medicine? **HIV**



**About the Author:** Dr. Bonnie Prokesch is a first year resident in Internal Medicine at Emory University in Atlanta, GA.

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**AAHIVM MEMBERSHIP RECEPTION**  
**6:30 to 8 PM, February 18, 2010**  
**SAN FRANCISCO**

including remarks from  
Jeff Crowley, Director  
White House Office on  
AIDS Policy (invited)





**Best** BY RICHARD PROKESCH, MD, FACP

## PRACTICES

LAST IN A SERIES

EMR & the HIV Practice

# Implementation: One Step Back, Three Steps Ahead

**P**REVIOUSLY WE DISCUSSED the pros and cons of moving to an EMR system, system selection, and generalizations about implementation. Now let's address implementation of the clinical module.

### CHAMPIONS NEEDED

To improve chances of success, select a physician and medical assistant or nurse to initiate implementation, fine-tune the process; then train remaining physicians and staff.

I used our system for nearly a year before it was ready for roll-out. I first learned how to use it, then developed templates and efficiencies — which then were passed on to others.

You may wish to accelerate this process, but allow time for the champion to learn the system so he or she can lead full clinical implementation. Although trainers from the EMR vendor may be used, champions are essential to successful execution.

### HAVE A ROADMAP

It is difficult to implement the entire clinical module at once, so a timetable is needed for phasing in system functions.

The electronic chart usually is the first component implemented. The defining element, it can evoke both excitement and anxiety.

Do not expect to see the same number of patients when first implementing the system. To improve chances for success, the workload initially should be reduced by about half, and all documentation should be electronic. Designating a few patients for electronic charting and leaving the rest for paper charting can inhibit implementation because clinicians may slide back into the comfort of paper documentation. There will be moaning and groaning, but acceptance and even smiles should ensue.

The more templates provided by the vendor or the champions, the easier conversion will be. It is the goal of every EMR to minimize typing or voice-activated dictation and maximize clicking.

This works well for the HIV patient where most follow up appointments ask the same questions; often the patients are doing well and the plan is similar for most. For the new patient, however, some free texting is necessary to optimize doc-

umentation. Consider using a voice-activated medical transcription program such as Dragon, which integrates with nearly all EMR systems, is user friendly and easy to train. Typing, another option, is generally slower.

EMR efficiencies will become apparent and usually the clinician will attain comfort with e-documentation and complete charts faster and more completely than with paper charting — once initial concerns are overcome.

After the e-chart is implemented, other modules can be phased in — including laboratory test result interface with the EMR, e-prescribing, electronic communication with other physicians, patient portal, etc.

Time needed for full implementation will vary and depend upon such factors as practice size, willingness and/or computer savvy of clinical personnel, and financial limitations.

### SMOOTH SAILING

A fully utilized EMR can significantly enhance the HIV practice. It will optimize patient care by improving documentation and enhancing communication with the patient, referring and/or consulting physicians, pharmacies and third party payers. Excellent documentation will optimize reimbursement by accurate coding and prevent fraudulent over-coding.

EMR is a powerful tool with unlimited uses. If there is a drug recall, electronic records can be rapidly searched to locate patients on that medication. Searches can be done for research purposes. If an antiretroviral agent in development comes to clinical trial and your practice desires participation, eligible patients can be ascertained with an electronic search.

Purchasing and implementing an EMR, while daunting and anxiety-provoking, is no longer optional, but a directive from the government. Move forward with a specific plan and with practice champions, and you will be successful and profitable. **HIV**



**About the Author:** Richard Prokesch, MD, FACP is in private practice in Riverdale, GA. He is chair of AAHIVM's Atlanta, GA chapter, and is on AAHIVM's Board of Directors.

BY SARASWATI IOBST, MD AND  
MONICA GANDHI, MD, MPH, AAHIVS

**W**OMEN REPRESENT THE FASTEST GROWING DEMOGRAPHIC OF HIV INFECTIONS WORLDWIDE AND PROVIDERS MUST UNDERSTAND the unique issues that affect women in order to develop effective prevention and treatment strategies. While research efforts have largely focused on HIV/AIDS in men, there are clear sex/gender-related differences that place women at higher risk for HIV and some of its complications.

## BACKGROUND

# WOMEN & HIV

## IN THE UNITED STATES

Of those infected with HIV worldwide, 46 percent are women, and 50 percent of all new infections worldwide are occurring in women ([www.unaids.org](http://www.unaids.org)). In the U.S., the proportion of all AIDS cases in women has increased from 7 percent in 1985 to 29 percent today,<sup>3</sup> with racial or ethnic minorities disproportionately at risk. The Centers for Disease Control and Prevention (CDC) reports that, among HIV-positive women in the U.S., more than 80 percent are either African American or Hispanic. HIV/AIDS remains the leading cause of death in black women ages 25-34 in the

## THE FEMINIZATION OF AN EPIDEMIC

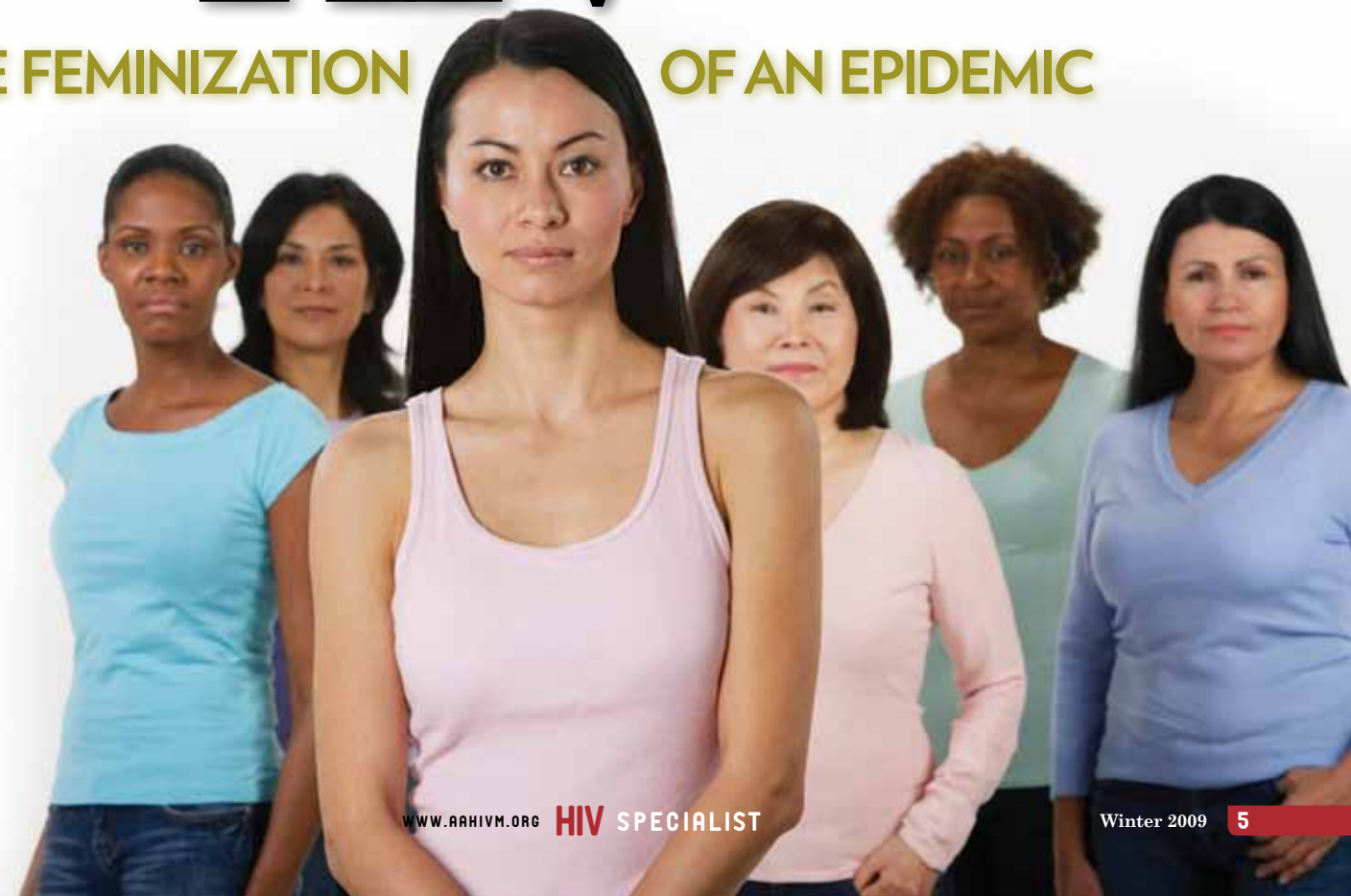


Photo: Jon Feingersh / Blend Images

# WOMEN & HIV IN THE UNITED STATES

U.S., whereas AIDS is the 10th leading cause of death in white women in the same age range. AIDS remains the third and fourth leading cause of death in black women in the U.S. ages 35-44 and 45-54, respectively.<sup>4</sup>

According to many studies, an increasing number of women are not aware of their risk factors for HIV acquisition. In the Women's Interagency HIV Study (WIHS), the largest cohort of HIV-infected women in the U.S., 48 percent could not identify how they had contracted HIV.<sup>5</sup> Other studies show similar results, indicating that some women in this country may not know the risk status of their male partners<sup>6</sup>, some of whom may be having secretive sex with other men and then unprotected intercourse with them.<sup>7</sup>

**TABLE 1: FEMALE-CONTROLLED METHODS OF HIV PREVENTION**

| Method                           | Current Status                                                                                                                                                                                 |
|----------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Female condom                    | Effective in reducing HIV transmission, but limitations include its expense, the fact that the female condom is not covert and the potential noise that the latex can make during intercourse. |
| Microbicides                     | Multiple trial failure; PRO2000 (0.5%) in preliminary studies shows up to 30% reduced risk of transmission                                                                                     |
| Diaphragms                       | No evidence of efficacy in reducing infection rates to women                                                                                                                                   |
| Oral tenofovir-based prophylaxis | In trials                                                                                                                                                                                      |
| Partner treatment                | Reduces risk of transmission to serodiscordant partners                                                                                                                                        |

Approximately 25 percent of people living with HIV in the U.S. are unaware of their infection status, with only 36 percent of adults reporting ever being tested.<sup>10</sup> Because U.S. women are often unaware of their risk factors for HIV infection, prevention efforts in this population must focus on increasing risk awareness in women, as well as early and routine testing. Hoping to strengthen HIV prevention efforts and maximize the efficacy of treatment for HIV-positive individuals, the CDC recommended in 2006 that all adults aged 13-64 be tested at least once for HIV in a medical setting and that people at higher risk be tested annually.<sup>11</sup> The guidelines recommend opt-out screening, where the patient

is informed verbally of the intent to test for HIV disease, instead of the previous policy of requiring written consent from the patient prior to testing. However, while California and other states have passed laws waiving the written consent recommendation for HIV testing, these guidelines have not been fully implemented throughout the U.S. Widespread implementation would be especially beneficial to women, given the lack of perceived risk factors for HIV in this group.

## RISKS & VULNERABILITIES

Women are biologically and sociologically more vulnerable to HIV infection than men, and at twice the risk of HIV infection through heterosexual sex simply because of an unequal exchange of genital secretions.<sup>12</sup> They may be at increased risk of infection during certain phases of the menstrual cycle (7-10 days following ovulation) because of hormonal interactions with the immune system.<sup>13</sup> Women are sociologically vulnerable to HIV infection through sex for many reasons, including issues of economic dependence, coercion, and an inability to consistently negotiate the use of male condoms.

HIV prevention efforts must, therefore, focus on providing women with female-controlled prevention modalities. The male condom is currently the most effective HIV prevention tool during heterosexual intercourse for women, but women have much less control over their use than men. Although the female condom has benefits in reducing HIV transmission, its acceptability has been decreased by a number of factors, including the visibility of the outer ring, the potential noise the latex produces during intercourse, difficulties with insertion and removal, and lack of ready availability in many settings. The female condom is more expensive than the male condom and is generally designed to be used only once, although there is increasing data on the possible reuse of the female condom.<sup>30</sup>

Microbicides and diaphragms would be ideal candidates for female-controlled methods of HIV prevention if proven effective given the covert nature of their use. However, diaphragms have been studied with lubricant gel in a randomized open-label controlled trial of 4,948 HIV-negative Zambian and South African women and showed no efficacy in protecting women against HIV transmission.<sup>14</sup> While most studies on microbicide products to date have shown disappointing results, a recent study offers some hope. The interim safety and effectiveness results of a study of a microbicide called PRO2000 (0.5%), a highly negatively-charged

molecule (a polyanionic polymer) designed to interfere with HIV entry into target cells, showed that it was at least 30 percent more effective than other means tested in the study in preventing new HIV infections. Larger studies on this microbicide are underway. Studies are also in progress to assess the efficacy of a once-a-day pill (tenofovir or tenofovir/emtricitabine) for HIV-negative people to protect against HIV infection (the pre-exposure prophylaxis or PrEP trials).

### TREATMENT ISSUES

Many issues may affect treatment strategies for women. A higher HIV viral load generally means more viral activity in the body, and a higher CD4 count means that fewer immune cells have been inactivated by viral replication. However, these assumptions and treatment guidelines were based mainly on studies on men; the immune system and HIV may interact differently in women. For instance, studies indicate that women have lower levels of HIV RNA in their bloodstream than men, even at the same CD4 cell counts.<sup>15</sup> This finding that men tend to have higher viral loads than women (perhaps as much as two to six-fold) has been reported mainly in patients at CD4 counts above 200 cells/mm<sup>3</sup>. Despite this difference in viral loads early on in infection, however, men and women seem to progress to AIDS and death at similar rates. Thus, women may be at increased risk of HIV progression when compared to men at the same viral load, especially early on in infection. Of note, the current treatment guidelines on when to treat HIV infection are based solely on CD4 count without consideration of viral load. Although the reasons for these sex-based differences in viral load are still unclear, these findings may have implications for considering the viral load level differently in men and women when initiating antiretrovirals.

Women also tend to have higher absolute CD4 cell counts than men, at least early on in infection. This does not necessarily translate to stronger immune systems in women, since women can still progress to AIDS as quickly as men despite this apparent CD4 cell count advantage. Some authors contend that, because women may have higher CD4 counts when they develop AIDS, they should be started on highly active antiretroviral therapy (HAART) earlier than men. Clearly, more research is needed to determine how to use viral loads and CD4 counts in women in determining when to start antiretroviral (ARV) treatment.

Despite the differences in CD4 counts and viral loads be-

tween sexes, recent studies have shown that HAART is just as effective in women as men. Early in the HIV epidemic, women with HIV seemed to progress faster to AIDS and death than men,<sup>16</sup> most likely due to sociological factors that included decreased HIV testing rates, access to antiretrovirals (ARVs) and HIV care, lower rates of medication adherence, and higher rates of substance abuse. Disease progression to AIDS and death between men and women seemed to equilibrate in the mid-1990s to early 2000s as more women were diagnosed with HIV and started on ARV treatment.<sup>17</sup> Current studies show a new trend towards women having better outcomes, in terms of AIDS progression and death, than men when controlling for access and adherence.<sup>18</sup>

The reasons for this recent trend vary and are not all well understood, although increased access to HIV testing and ARVs have contributed. Some studies have shown that women tend to have higher levels of the antiretroviral medications in their blood than men,<sup>19</sup> perhaps partially explaining the recent trend of improved outcomes among women as medications become more accessible. It is possible that drug-experienced patients on antiretrovirals may do better when they have higher drug levels in their blood. Many variables contribute to how different patients process medications, many of which are affected by gender and hormones. Some of this variability may result from women generally weighing less than men, leading to higher plasma levels of ARVs at a given dose. Estrogen affects protein production in the body, which will affect drug levels. Men may clear ARVs more rapidly than women due to differences in kidney and liver function, as well as differences in levels of metabolizing enzymes. Overall, however, the general trend observed in most studies is that women have higher levels of ARVs at a given dose than men.

### SIDE EFFECTS

Women experience more frequent and severe side effects from antiretrovirals than men,<sup>20</sup> an important issue for providers to address because these toxicities may affect women's quality of life, overall health, and place them at risk for stopping medications that they cannot tolerate, leading to devastating effects on HIV treatment.

Common side effects that seem to be worse in women are rashes, liver toxicity, fat distribution changes, and osteoporosis. Most rashes are mild, but some can lead to serious,

# WOMEN & HIV IN THE UNITED STATES

even deadly, complications. Studies have shown that non-nucleoside reverse transcriptase inhibitor (NNRTI)-induced rashes are more common and more severe among women.<sup>21</sup> For instance, a study of nevirapine (Viramune®) showed that 15.8 percent of women compared to 8.4 percent of men developed rashes and women were 3.5 times more likely to discontinue nevirapine as a result.<sup>22</sup> Studies have shown an increased risk of rash among patients with higher CD4 counts.<sup>23</sup> Most studies suggest pregnant women have either the same or a reduced risk of NNRTI-induced rash than non-pregnant women. A study of a new second-generation NNRTI, etravirine (Intelence®), also showed that women had an increased risk of rash compared to men (34 percent versus 18 percent).<sup>24</sup>

Women are also at increased risk of liver damage related to nevirapine. Reports from post-marketing surveillance data indicated that women with CD4 counts higher than 250 cells/mm<sup>3</sup> had a 12-fold increased risk of developing clinically significant liver damage compared to women with CD4 counts less than 250. This contrasts with men who had a five-fold increased risk of liver damage with higher CD4 counts (at greater than 400 cells/mm<sup>3</sup>) compared to men with lower CD4 counts.<sup>25</sup> In a study from South Africa of HIV patients on nevirapine, 20 percent of women compared to 12.8 percent of men had serious liver damage as indicated by blood levels of liver enzymes. Half of the liver damage among females occurred in women with low body mass indices.<sup>26</sup>

Antiretroviral medications are known for possibly contributing to fat redistribution syndromes, though these have been improving over time with the newer agents. Women normally have a higher percentage of total body fat than men, and HIV-positive women tend to have more central obesity. However, since women and men tend to have equal rates of fat loss from their extremities, this central obesity can seem accentuated. Further studies are needed to understand the specific fat redistribution effects of ARVs in women.

While women in general are at increased risk of developing osteoporosis after menopause, studies have shown that HIV infection alone increases a person's risk — male or female — of losing bone mineral density.<sup>27</sup> However, HIV-positive women are at approximately three times higher risk of bone thinning than HIV-positive men. Other risk factors for HIV-positive individuals and bone loss include older age, lower body mass indices, higher viral loads, and lower CD4

counts and traditional risk factors such as smoking.<sup>28</sup> Some studies have found that HIV-positive individuals on protease inhibitor (PI)-containing ARV regimens had higher rates of osteopenia and osteoporosis than HIV-positive individuals not on PI-containing regimens. Tenofovir (Viread®) has been associated with bone thinning, possibly related to phosphate wasting at the kidney level from this drug. Most studies show that HIV itself is a risk factor for bone loss, whether or not antiretrovirals are implicated. Studies have examined standard osteoporosis treatments with bisphosphonates and calcium/vitamin D supplementation in HIV-positive patients on ARVs and have found these to be safe and effective treatments for osteoporosis. The bottom line is that women with HIV need to be screened for osteoporosis regularly, and that treatment for both HIV and osteoporosis is warranted.

Women who could become pregnant require special consideration when deciding on the appropriate antiretroviral regimen because of the various effects of certain ARVs on pregnant women and the fetus. Efavirenz (Sustiva®, which is a component in Atripla®), has possible serious neurologic consequences in the fetus and should be avoided in pregnancy. Women should be on birth control if they are sexually active while on efavirenz. Other ARVs that should be used with caution in pregnant women include didanosine [Videx®] and stavudine [Zerit®] together, which can lead to serious metabolic and liver conditions in women. As above, women with CD4 counts above 250 cells/mm<sup>3</sup> have been shown to be at higher risk of life-threatening liver toxicity and rash when starting nevirapine, so this agent should also be used with caution in pregnant women.

## SOCIAL, CULTURAL CONCERNS

Many social and cultural issues are also especially relevant to women and affect HIV treatment and prevention considerations. Only 60 percent of HIV-positive females who qualify for HAART in the U.S. are on this life-saving therapy, compared to 75 percent of HIV-positive men who qualify for therapy. Some of the reasons lie in community beliefs regarding HIV/AIDS.

Consider a 2005 survey in which 500 African Americans in the U.S. were asked about their beliefs regarding HIV (65 percent were women): 53 percent believed a cure for AIDS exists, but was being withheld from the poor; 44 percent felt that people taking new medications were “guinea pigs”; and 27

percent thought that AIDS was created in a government lab.<sup>29</sup> Clearly, conspiracy beliefs and suspicions regarding the medical establishment in the African American community will affect HIV-positive women more than men, given the disproportionate percentage of minorities among women.

Another reason women may be less likely to engage in HIV treatment or care is ongoing physical and sexual abuse. A history of abuse has been shown to decrease the likelihood that a woman will start and stay on an antiretroviral regimen. Female substance abusers are also less likely to start treatment for HIV. Then there is the overwhelming effect of stigma, which disproportionately affects women both internationally and domestically.

A national survey performed by the American Foundation for AIDS Research (AMFAR) and released in 2008 revealed the following regarding stigma against HIV-positive women: of almost 5,000 individuals polled, 70 percent would not want an HIV-positive female dentist; 60 percent would not want an HIV-positive physician or childcare provider; and 50 percent would not want an HIV-positive female food server. Only 14 percent of those polled felt HIV-positive women should have children.

However, there has been much progress in the U.S. in preventing mother-to-child transmission (PMTCT). The risk of HIV-positive mothers giving birth to HIV-positive babies has decreased from approximately 25 percent in 1993 to less than 2 percent today due to appropriate treatment and interventions. This decline is secondary to increasing HIV testing rates during pre-natal visits, increasing use of HAART in HIV-positive women during their pregnancies to prevent transmission to the fetus, and an increase in elective Cesarean-section births by HIV-positive women with viral loads that are detectable at delivery.

Worldwide, the number and percentage of women accessing PMTCT medications has also increased from approximately 10 percent in 2004 to almost 35 percent in 2007, although access rates are still woefully low.

The current guidelines in the U.S. for PMTCT are to start HAART in the second trimester if the mother is not already on therapy and to give intravenous zidovudine (AZT) to the mother during delivery. The options for the delivery mode are determined by the mother's HIV viral load. If the viral load is less than 1,000 copies/ml, vaginal delivery is as safe as C-section in terms of transmission rate to the baby. The baby receives six weeks of oral AZT after delivery. If no

treatment is started prior to labor, the mother and infant should receive treatment at birth and the infant should receive post-exposure prophylaxis [HIV medications used to prevent infection].

## CONCLUSION

HIV infection rates are increasing disproportionately among women in the U.S., especially in minority groups, and worldwide. Prevention of HIV in women needs to come from increased awareness of HIV through routine screening and through providing women with effective, safe, female-centered prevention methods. Of the little that is known regarding HIV treatment and women, we know women will do as well, if not better, on ARVs than men, perhaps in part due to higher levels of drugs found in women. These higher drug levels may also explain the higher levels of side effects on these medications in HIV-positive women and argue for dose ranging studies that focus on women.

Despite the improvement in HIV treatment outcomes in women, gender disparities, abuse, and stigma still remain significant barriers to HIV prevention and treatment in this population.

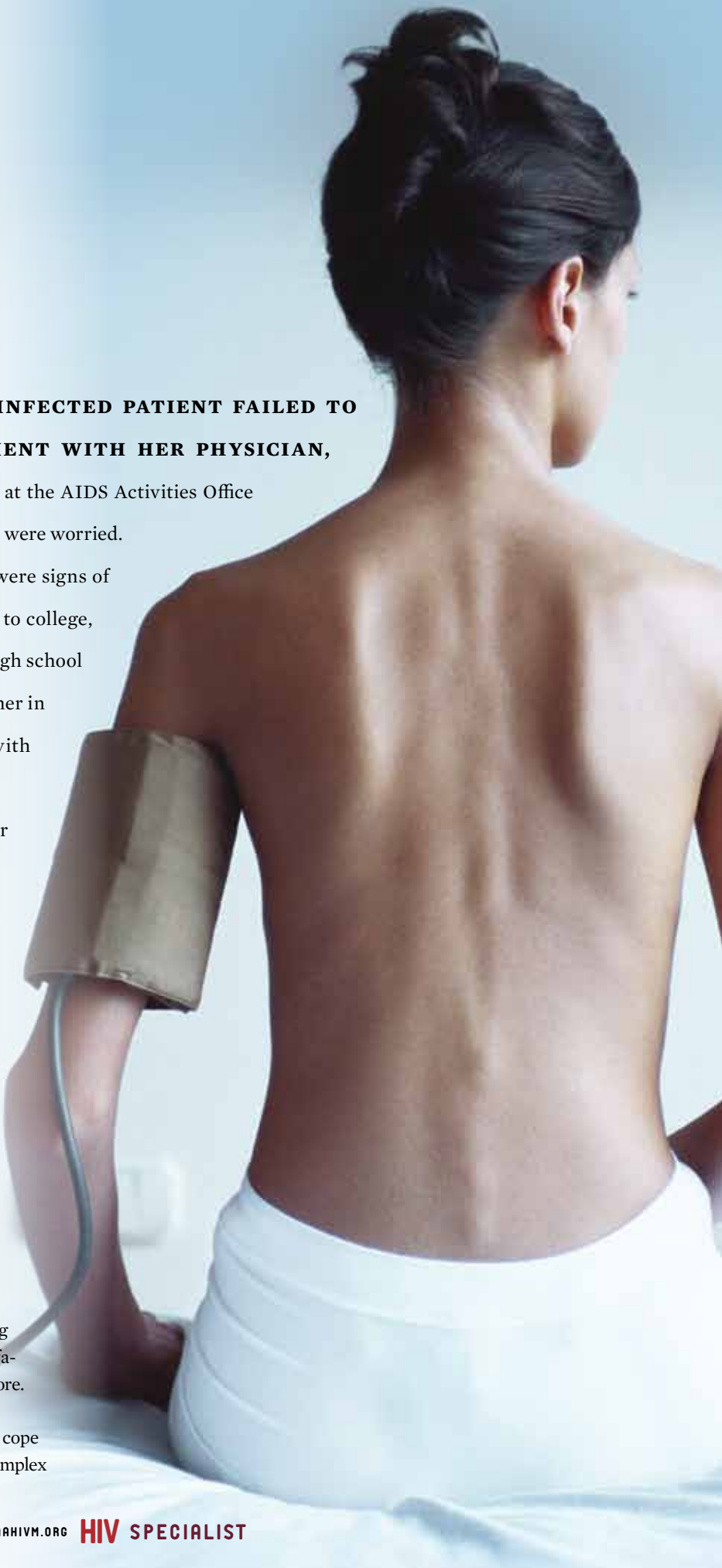
And finally, it is important to focus on PMTCT as a success story in the U.S. because it shows that, when significant research and program implementation efforts are instituted, amazing progress in HIV prevention and treatment is possible. This should serve as an example for increasing research efforts and special programs aimed at improving HIV prevention and treatment modalities in women. **HIV**

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**About the Author:** Dr. Monica Gandhi is an Assistant Professor of Medicine in the Division of HIV/AIDS at the University of California, San Francisco (UCSF). She specializes in the clinical care of HIV-infected women and directs the HIV inpatient consult service at San Francisco General Hospital. Her research career is focused on examining treatment issues for HIV-infected women in the Women's Inter-agency HIV Study (WIHS), a large prospective multicenter cohort study of HIV-infected women.

**Dr. Saraswati Iobst** is a second-year resident in the University of California Primary Care (UCPC) program at the University of California, San Francisco (UCSF). She graduated from the University of Pennsylvania, School of Medicine in 2007. Her career interests include HIV, primary care, and international health.

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**R**ECENTLY, A 16-YEAR-OLD HIV-INFECTED PATIENT FAILED TO SHOW UP FOR HER APPOINTMENT WITH HER PHYSICIAN, Margaret Hoffman-Terry, MD, AAHIVS, at the AIDS Activities Office clinic in Allentown, PA, and staff members were worried.

The patient had just delivered a baby and there were signs of trouble in her life. Although she had planned to go to college, those plans were history after she dropped out of high school to care for her child. Now, having lost her own mother in a bar room shooting several years ago, she lives with her baby's father and his family.

But there is a problem. She hasn't disclosed her HIV status to the child's father or his family, and is afraid to do so because she fears his violence, which she has experienced before, and worse, in her mind, possible rejection.

That causes a huge dilemma for Dr. Hoffman-Terry and the staff at the Ryan White-funded clinic at Lehigh Valley Hospital where she is an infectious diseases specialist. Most likely, her office will inform the local health bureau of the patient's HIV status. The bureau will then send the father a letter advising him that he may be at risk of HIV due to sexual contact and should be tested. They will not disclose the identity of the patient as the potential source for HIV.

"But if she has been his only partner, he will know, and that may put her in danger," Dr. Hoffman-Terry said. "It is a very difficult scenario. She lives in secrecy and is not getting treated because she is scared of what will happen if the father finds out. She doesn't have parents of her own any more. She really has nowhere else to turn."

Unfortunately, this case is not atypical. HIV specialists cope every day with these and additional unique, difficult, and complex

## COVER STORY

# WOMEN & HIV

## SPECIAL CHALLENGES FOR HIV SPECIALISTS

BY BOB GATTY

challenges that arise as they treat increasing numbers of female patients. In addition to medical specialists, they must become defacto counselors, social workers, and confidants as they strive to provide an atmosphere of comfort and support designed to encourage female patients to be tested, continue care, and adhere to the prescribed regimen of medication – regardless of the difficulties and obstacles that may confront them in their lives.

HIV specialists find themselves challenged to help patients as they struggle to care for their families, to keep them from putting themselves last on the list and to pay attention to their own medical needs. It is a problem described over and over again by providers interviewed for this article.

“Competing priorities, childcare, work, caring for others—often all of this means they don’t have time to care for themselves,” Dr. Hoffman-Terry said. “We have a large number of female staffers, and we also run individual support groups; some are for women only, and they help them deal with multiple risks that they face. We try to get them to believe they are valuable, and that their health is important, saying that if they don’t take care of themselves, they won’t be around to care for their loved ones.”

Providers must find a way to help patients whose partners refuse to use condoms, some of whom are involved in “down low” – secretly having unprotected sex with other men – even though the patient may believe, or want to believe, her partner is monogamous.

“Many women trust their partners and don’t use protection,” said Dr. Hoffman-Terry. “Many have been with one continuous partner, and often that partner is not faithful, even though the woman thinks he is. Heterosexual sex is the number one risk factor, but not in the minds of many women, so they don’t use protection.”

Providers must make certain that they prescribe proper regimens of medication, sometimes avoiding otherwise preferred drugs for sexually active female patients who may become pregnant, in order to avoid harm to the fetus.

Cervical cancer is a serious problem for many female HIV patients, and providers often face difficult and complex challenges as they seek to avoid the deadly consequences that can result from the cancer going undetected for too long, finding ways to encourage patients to have the proper tests and procedures that could save their lives.

Many HIV patients as they age, are now confronting osteoporosis, a common problem for many aging women – as they



Margaret Hoffman-Terry

# WOMEN & HIV

## SPECIAL CHALLENGES FOR HIV SPECIALISTS

live longer because of the advances in medication and treatment. Because osteoporosis can be worsened by some of the life-saving medications normally prescribed for HIV, providers must be cognizant and take special care here as well. According to Dr Hoffman-Terry, it would help if they had better information.

“The population of HIV infected women is aging, though we have no data on menopausal changes, osteoporosis, arthritis, etc. in women with HIV,” she said. “We need more studies to determine what it means to a population that already is more likely to get osteoporosis to be on medication that may make it worse. Most studies are 70 to 80 percent men, but that doesn’t reflect the population of my clinic. We need drug studies that include women, especially minority women, to know how these drugs are going to affect woman who are living for decades with HIV. A lot of those things vary, and we have primarily male information.”

In her practice, Dr. Hoffman-Terry sees a growing number of perinatally infected children who are now in their mid-teens to early 20s and are having difficulty transitioning from pediatrics into the adult care world, with the situation often complicated by their own pregnancy.

“In the last year,” she said, “I have had three perinatally infected patients ages 15-16 become pregnant. We are getting a lot of young girls who are HIV positive since birth who are now having babies. There are all kinds of problems associated with poverty and growing up with low income; and with that extra overlay of HIV, it is very difficult to get them to take their medication and to continue in care. When you are 16, how do you tell your partner that you have HIV?”

“We’ve had 15 teens in the past five to six years who have moved from pediatrics to us. They just don’t take their medication. They are tired of taking it their whole lives. Now, many are choosing not to be compliant with those meds. We’ve been having meetings trying to figure out what we can do. There are no easy answers.”

Then, of course, there is the age-old problem of stigma – especially difficult for many women, one that can even put them in danger. Somehow, providers must find ways to help with that, as well.

### METHODOLOGY

To prepare for this article, AAHIVM surveyed members and asked them to describe the top five challenges or issues that they face in treating HIV/AIDS in women. The Academy re-

ceived more than 330 responses, and according to the survey, nearly 34 percent of patients are women, with 60 percent of respondents indicating that figure has changed at least somewhat over the past five years.

Those trends dovetail with data from Centers for Disease Control and Prevention, showing that women are increasingly being affected by HIV/AIDS, although the epidemic historically has affected more men than women. Since 1985, CDC reports, the proportion of estimated AIDS cases diagnosed among women has more than tripled, from 8 percent in 1985 to 27 percent in 2003.

CDC also says the epidemic has increased most dramatically among women of color, noting that although black and Hispanic women together represent about one fourth of all women in the U.S., they account for more than three fourths of estimated AIDS cases diagnosed to date among U.S. women.

Although each year more men than women become infected with HIV, CDC says the gap is slowly closing, noting that data from reporting states show that new HIV diagnoses in men declined 27 percent from 1994 through 2003.

Transmission routes differ by gender as well, notes CDC. Among men, HIV transmission is estimated to occur 63 percent through sexual contact with men (MSM), 14 percent through injection drug use, and 17 percent through sexual contact with women. But among women, transmission is estimated to occur 79 percent through sexual contact with men, many of whom are intravenous drug users (IDUs) or also have sexual contact with men, and 19 percent through injection drug use.

Those statistics, although several years old now, track with the experiences reported by AAHIVM members who participated in our survey, and were discussed in more detail during telephone interviews. Here are their stories:



Polly E. Ross

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### POLLY E. ROSS, MD, AAHIVS

WNC Community Health Services, Asheville, NC

“Ours is a rural clinic that serves patients in 17 rural counties in western North Carolina. It is a Ryan White funded clinic, as well as a community health center serving people both with and without HIV. We are in Appalachia; the buckle of the Bible Belt, as we like to say. Our HIV patients are mostly white, but of the 30 percent who are women, the majority of them are African American.

“After working with HIV patients for the past sixteen years, it is more the norm than the exception that the female patient with HIV also has a mental health issue like depression or an Axis II personality disorder. There is a high rate of PTSD with about 60 percent of our female HIV patients having experienced some type of trauma; either sexual, physical or emotional abuse.

“The minute that I recognize that a mental health issue has to be addressed, I try to hook them up with a counselor and get them on the right mental health medications. Nine times out of ten, then things get better for them. If I didn’t do that, and if we did not address their mental health needs, then patients wouldn’t come in, wouldn’t adhere and their HIV would remain uncontrolled. The difficult thing though, is getting the patient to believe that treating their emotional pain will help their physical pain.

“For example, maybe the patient has had trouble with authority in the past or is fearful of being around authority figures. So when you come into the exam room, they are fidgety, nervous and not very focused. So you ask them to sit in a chair instead of up on the exam table, and I sit next to them. I am trying to provide them with some parity. Small things like that can go a long way. But it takes time to learn what is an emotional manifestation of other deeper mental health issues. It takes time to learn, and it’s difficult to do that sometimes with the short amount of time that you have with your patients.

“Also, our female patients have conflicting priorities. There is the caregiver role that women play, often putting their needs behind the needs of others. There is the issue of disclosure: ‘will my partner still want to be with me if they find out that I have HIV?’ When women disclose, they are set up for abuse. That’s a constant issue for many. Often it’s more desirable to have a male partner who is abusive or who willingly transmits HIV to you than to be alone. Status in the community is based on who’s your man.

“The first thing you need to provide to your HIV positive female patients is a safe place in your office. They need to know that they can be open and honest, so let them know that you are not going to look down on them or judge them for anything that they share with you. You’ve got to take time to listen, and to give consistent messages over time. Sometimes you can gently lead them and ask, ‘Have you tried this? What did they say when you told them this?’ and give them options in the future instead of a negative attitude about not disclosing or not using a condom.”



Travis Sherer

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**TRAVIS SHERER, PA-C, AAHIVS**

*Montefiore Medical Center, The Bronx, NY*

“I am at the Center for Positive Living, an HIV clinic, and a primary care provider. I have a lot of HIV patients in my in-patient role, too, because there are a lot of HIV positive people in the population here.

“I am a brand new HIV provider. I just started in the last three months, and as somebody new, I’ve already noticed it is much more difficult to manage the HIV and co-morbidities in women than in men – specifically regarding pregnancy issues.

“The realities of care are different from the textbook answers.

I expect patients to say, ‘I plan on getting pregnant’ – or not. But they don’t give definitive answers regarding pregnancy. They say they are sexually active and are using birth control, but on further exploration it’s clear they might not always be using birth control, and that’s not necessarily covered in the textbook.

“A woman came in the other day. She was on Atripla. She loved it. She wanted that one pill once a day, and she resisted doing anything else. But she is sexually active and it’s unlikely that she’s using

condoms and birth control 100 percent of the time. So it’s a quandary as to what to do. I explained to her the contraindications with efavirenz and pregnancy, but even though it was important to me, it wasn’t her top priority. She is in a shelter. She needs housing. She needs to pay her bills. I can talk to her about her medication, but that’s not what she wants to talk about and it understandably wasn’t her most pressing issue. In reality, she has other things going on; other things much more serious as far as she’s concerned. Again, navigating those complexities is not always covered in the text books.”

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**BEN NASH, MD, AAHIVS**

*Department of Pediatrics, University of Mississippi Medical Center, Jackson, MS*

“Stigma – limiting access to care and affecting adherence to medications is the number one concern. There is a lot of community stigma that drives women away from testing and if diagnosed, impacts their attendance at the clinic. They have to explain where they are going and why they have these medicines. Some try to hide it.

“That gets into disclosure. Those who don’t disclose to somebody who can encourage them tend to do less well. They come to their appointments less often. They adhere less to their meds.

# WOMEN & HIV

## SPECIAL CHALLENGES FOR HIV SPECIALISTS

"My patient base is 100 percent pregnant women. I'm a family physician, but on the faculty in the pediatrics department as assistant professor and director of the perinatal HIV service. Most every referral for HIV in pregnancy comes here, but we've set up a network of obstetrical providers who help, which eases transportation concerns for many patients. But they come here for their initial labs and medication. Statewide we have a loose association of HIV providers, but there are still pockets in the state that don't have even minimal provider coverage.

"I am always concerned about the psychological status of the newly diagnosed patient who is pregnant and finds out she has HIV. We have to work through that and get through the pregnancy, and we have to treat her for the protection of the baby. We are scrambling for resources to deal with homelessness, drug abuse. The most common root of failure is cocaine use.

"But most women who follow a treatment plan through their pregnancy, labor, and delivering the baby do pretty well.

"Another concern is assuring appropriate contraception for women of child-bearing potential on efavirenz."

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### SUSAN LELACHEUR, MPH, PA-C

*Whitman Walker Clinic, Washington, DC*

"I've been working in AIDS/HIV since 1987, and while I'm on the PA faculty at George Washington University, I continue to see patients at the Whitman Walker Clinic in Washington. Since '87, my clientele has shifted. Many of our female patients are Ethiopian or from other African countries. Currently all my female patients are either African American or African.

"Social supports for female patients tend to be more difficult, especially when there are children involved. They have to have a home and food on the table, and it becomes more critical when they have kids. Women can't think about adherence to medication or deal with their own HIV issues until the needs of their children are met.

"That means I need a referral system that works. We have social support and people who can help address those issues. I send patients to our own case management team and they place them.

"The one-pill-a-day regime is pretty much off limits for women who become or may become pregnant. So they have to be on three pills or more a day. So these things get kind of difficult. There are specific infections that women get as well. Cervical cancer is a big problem that we have to address, but since

we have hired an in-house specialist to handle culposcopy and HPV follow-up, that has helped."

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### ELIZABETH E. HUDSON, DO, MPH, AAHIVS

*Attending Physician, Division of Infectious Diseases, Kaiser Permanente, Panorama City, CA*

"Patients not having insurance or losing coverage is a big problem. A lot of women have part-time jobs and don't have insurance, or many have lost what they had as a result of the economic downturn. Many women get coverage through their spouse, so if there is divorce or the spouse dies, they lose their coverage.

"When people tell us they are going to lose their insurance, they want to know what we can do to help them. Continuity of care is crucial. At Kaiser, we have an integrated team and we work every way possible to get them coverage. Any time we can keep people on treatment, it makes their lives better and saves money for everyone in the long run.

"Many patients are not getting tested soon enough and are coming in with AIDS. The good news for women is that the American College of Gynecology and the CDC recommends that women have an HIV test when they get a Pap or get pregnant. That helps. But the lack of insurance coverage feeds into many patients not getting tested.

"We know that African American women are at heightened risk. AIDS is the leading cause of death among African American women ages 25-34. That relates to the inability to negotiate the use of condoms in a relationship. We know that different cultures also make that more difficult. Partners say, 'You don't trust me.' Women don't want their partners to think that. A

lot of older women, post-menopausal women, don't think about getting pregnant so they are not using condoms. They don't think they are at risk.

"So we have to find ways to help all women understand the importance of condom use. Often when we are in dire economic straits, as the country is now, there can be a shift in relationship dynamics. As the focus becomes more on day-to-day survival and less on the balance in a relationship, women can lose their power to negotiate condom usage.

"Many patients fear their diagnosis. When they find out they



*Elizabeth E. Hudson*



*Susan LeLacheur*

are positive, they are afraid how their family will react. Are they going to lose their home and their kids? If they die, who will take care of the children?

“As a provider, we have to take testing of HIV to the point that it is done every day, like cholesterol or testing your sugar level. It has got to be the norm so people understand that HIV does not mean the end of life, that they can lead a completely normal life just like someone with high blood pressure or blood sugar problems.

“Stigma interferes with a patient’s willingness to take medication. They try to hide their meds from their significant other. They worry the partner will find out. They are worried about side effects, such as weight gain and rashes.

“What do I do? We just have to have lots of communication with our patients regarding what the meds are, what the side effects are, and reassure them that these are not the bad old days.

“Yes, we are seeing more women getting tested during pregnancy. That’s wonderful because we can make sure HIV is not passed on to the children.”

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**ALYCIA DICKENS, RN, MSN, FNP, AAHIVS**

*Eastern Virginia Medical School, The Center for Comprehensive Care of Immune Deficiency, Norfolk, VA*

“I cannot begin the conversation about HIV in women without including the impact of HIV on the African American community. In our clinic, the demographics of new HIV infections are among the poor and uninsured, women, youth, African Americans, Hispanics and formerly incarcerated individuals. The vast majority are African American youth and females.

“The disparities in poverty, employment and education are prevalent. Poverty has driven some of our patients to exchange sex for basic needs such as food and shelter. Poverty also contributes to the HIV/AIDS rates because of limited access to health education and prevention services. According to the 2006 Census, 25 percent of Blacks live in poverty as opposed to 8.2% of Whites. Fatalism is an attitude that often prevails with many African Americans living in poverty. It means feeling powerless over your own destiny.

“As a female African American healthcare provider, I spend a lot of time instilling hope and telling patients that low expectations trap them in mediocrity. I want them to understand that how they think is how they live. Once some of these patients accept the fact that all is not lost, then I will start to hear, ‘I’m

starting community college or I’m getting my GED.’

“For those fortunate enough to be employed, it’s a challenge to even come to appointments. Many patients lack transportation; thus their healthcare needs are not “high” priority. Often, employers do not understand taking time off, even for health reasons. This is especially seen with some of the minimum wage jobs in the service industry.

“Gender ratios in the African American community are unbalanced and contribute to the HIV/AIDS epidemic. Concurrent partnerships are common with African Americans, with many having multiple sexual partners that overlap in time. This is very prevalent with Black women because of low marriage rates related to the ratio of men to women. The imbalance occurs mainly because of violence, incarceration, men being gay or unavailable to women secondary to joblessness, drug and/or gang activity. Unfortunately, this concept is a very important factor in fueling the HIV/AIDS epidemic in the African American community.

“There is stigma associated with disclosure. Many HIV+ women fear not being loved. Sadly, many often equate sex with love. Many women have difficulty communicating and negotiating condom use. For some, they fear losing their source of support or even violence for insisting that their partner use a condom. Many of these women feel like they have to accept this behavior because ‘no one else will want me.’

“As an HIV Specialist, I see about 12 patients per day in our clinic. We have a physician assistant, two other nurse practitioners and seven medical doctors in our clinic. We use the one-stop shopping approach and have on-site case managers as well as a medication adherence RN and triage nurse. I love being an HIV Specialist. It is more than a job; it is a ministry of love. You have to be passionate about this work to be effective in this role. This is hard work. I have been doing this since 1999, and would not want to do anything else!”



*Alycia Dickens*

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**MONA GAHUNIA, DO, AAHIVS**

*The Moore Clinic for HIV Care,  
The Johns Hopkins Hospital, Baltimore, MD*

“The most common issues unique to women in HIV care are pregnancy, dealing with conception through pregnancy and post-partum issues, cervical cancer, and sexual practices.

“With pregnancy, we have to choose antiretrovirals that will not cause harm to the fetus. We have to try to educate the

# WOMEN & HIV

## SPECIAL CHALLENGES FOR HIV SPECIALISTS

patient about the necessity of having undetectable viral loads before trying to become pregnant.

“I have seen a lot of c-sections because physicians don’t understand that if the viral load is undetectable at the time, data shows no benefit vs. a vaginal delivery.

“Most women are good about adhering to meds before pregnancy, but post partum they fear they are not going to live to see their kids, and that affects adherence. Psychological factors play into it. That’s what we are seeing.

“Sometimes it’s hard to get across to women with HIV that they have a higher risk of cervical cancer. It is a challenge to make sure they get screened. But if we can pick it up early, that’s a good thing. But I’ve seen some horrible cases in patients when that doesn’t happen. I have a patient now who did not have early testing and her cervical cancer has spread into her abdomen. It’s such a shame, because the cure rate is so high – if it’s caught in time.

“Even when male partners are negative, or think they are negative, they still don’t want to use protection. And female condoms are not as widely available. It’s a matter of the female partner feeling she does not have power, even if she has a good understanding of why they should use protection. We try to make female condoms available, but they are just not as commonly understood.

“I have a patient now who is post-partum. During her pregnancy, her viral load was undetectable and she did really well. Then, post-partum, we didn’t see her for a year. We finally got her back into care. Her viral load is 50,000 and her CD4 count dropped below 200. We see this a lot. Is this an element of post-partum depression, or are they so wrapped up in taking care of baby and family that they are not taking care of themselves?”

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### CLAY ROSCOE, MD, AAHIVS

*The Wellness Center, Boise, ID, a Ryan White clinic*

“Sometimes our female patients feel a bit marginalized. They are a minority in our clinic, and we struggle to develop support groups that are tailored to their needs, which are often very different from the needs of our male patients.

“Timely preventative screening for cervical dysplasia, breast cancer, colon cancer, BMD, etc. is a major concern. We would like to see no-show rates for these evaluations to be lower. Arranging for follow-up colposcopy for abnormal Pap smears, for example, can be a big challenge. Abnormal results occur more frequently in HIV-positive women, and multiple colposcopies

in a single year are not that unusual. You know patients can get more than a little bit worn out starting as a new patient in another office. And it is also the nature of the procedure that reduces compliance. We can always do a better job of ensuring that patients come in for routine screening tests.

“I’m a board-certified family medicine doc, and my training includes prenatal care and fertility counseling. We have several patients trying to get pregnant now. That’s something new, having a routine appointment with an HIV-positive woman where the topic of discussion is fertility. It’s a positive thing, and testimony to the success of the newer antiretroviral drugs and how they keep the patient and their potential pregnancy healthy. We see several deliveries a year with HIV positive women, many at this point are still unplanned, but planned fertility for HIV-positive women is a new trend; and a potential success story. It’s very rewarding to work with a patient while she is pregnant, co-manage the pregnancy, and see a healthy baby be born that is HIV-negative.

“Most of our patients are in their early 20s through their 60s. In fact, our oldest female patient is 71 and she is doing great. To see so many of my patients in their 60s and 70s, it can feel like a new era in HIV care.

“Our clinic has a number of female refugee patients from Africa and Southeast Asia, as well as a few individuals from eastern Europe. Many come from a place and a mentality that told them, absolutely, they were going to die from HIV. After some time on treatment, especially after they have seen the effect the medications can have on their body and the infection, some of these women now say to me, ‘I believe you, and I want to have a baby.’ My African patients, especially, are often very motivated and share with me and the staff their desire to have ‘an American baby’.

“I trained in Idaho, but have also worked in Namibia in Southern Africa. In Namibia, I learned a lot about HIV care in more resource-limited settings and some of my patients even came to Idaho from a refugee camp in Namibia that I worked at while there. This experience has given me a few tools to help me work more effectively with my refugee patients, especially those who are coming from Africa.

“One other challenge with our female patients involves trying to determine their true risk to HIV, which is often only the risk factors of their male partners. This can be especially challenging with our Latina/Hispanic patients, who often were unaware of



Clay Roscoe

their risk for exposure until they tested positive for HIV.

“To get the word out about HIV risk, and affect changes in behavior to reduce the risk of HIV infection is a very big challenge and we need to do a better job with education, prevention and universal testing.”

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**SHAWNA APPLIN, ARNP, CNM**

*Community Health Care Clinic, Tacoma, WA*

“In the last year, newly diagnosed patients have been coming in later in the disease, and they are much sicker. The women who I treat are largely in denial that they could get this from their partner, or they are involved in substance abuse.

“I don’t have a lot of women that are actively doing prostitution, but the concept of the down-low, either denying their partners are involved in MSM or they truly don’t know and think they are being monogamous, is a major factor.

“Between myself and our HIV nurse, we spend a lot of time talking with patients about how HIV spreads; about the concept of down-low and the importance of taking care of themselves and asking patients about their partners. We also try to get them into a group setting so they don’t feel so alone.

“A second challenge is getting them on the right meds in preparation for pregnancy. But we can encourage them to have children if that is what they want, because there has been a lot of progress, and in our state, we haven’t had an HIV positive baby in several years. But they have to pick the right regimen that won’t hurt the baby.

“In our county, until I started doing deliveries of HIV positive moms, they were sent to Seattle. That was a barrier for pregnancy care, and a major cause of morbidity. Now, there are a couple of obstetricians who will take HIV positive women, but I’m the catch-all because, essentially, no one else will take them.

“Active substance abuse keeps many women from coming in for regular care. There are mental health issues to deal with, and I also provide primary care, managing people with diabetes, helping them manage their insulin, etc. It’s kind of stretching me.”

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**MARY K. MILLER, PHARM.D, MD, HIV GYNECOLOGIST**

*Center for AIDS Research, Education & Services;  
Clinical Professor, OB/GYN Clinic Medical Director,  
UC Davis, Sacramento, CA*

“Many patients are single heads of household, the breadwinners, taking care of the children. Many times appointments around the first of the month are not kept because the check from the state agency is used for food. They will sacrifice to take care of their children, and not take care of themselves.

“We also have women with insurance, but they can’t afford even the \$10 or \$15 co-pay. They are trying to count their pennies.

“We have patients who have a fear of procedures, especially those who have been treated elsewhere without adequate anesthesia. I really hate pain, so I will do whatever I can do to help – use a numbing gel or a cervical block. For some of these ladies, it may be the first time they meet me and I have to convince them that I am serious about reducing their pain. It’s important to relieve them of their fears as much as possible.

“Gaining their trust is very important.

When you do, you can help them through the other areas that they may face. Many patients may not need repeated biopsies, but many do. With all of these patients, we have to gain their trust.

“Wearing my pharmacist hat, many of our patients are on complex regimes. My HIV colleagues are wonderful. They figure out which meds they need to be on to keep their CD4 counts up and their viral loads down, so patients are living longer and more normal lives. But that means they have the same problems as all of us as they age – pregnancy, menopause, so there are potential drug interactions (hormones, oral contraceptives, etc.) to be concerned about.

“We have to take time to talk with their HIV provider and make sure we’re not adding a routine GYN drug that interferes with our patient’s antiretroviral regime. If a patient is on a salvage regime, I don’t want to mess that up. Communication between providers is critical.

“This virus does not discriminate. It does not care. It continues to become resistant and puts all of us on alert, and we have to be able to respond with the right treatments. But we’re not giving up. We’re still devoted.” **HIV**



*Shawna Applin*



**About the Author:** Editor of *HIV Specialist*, Bob Gatty is a Washington, DC-area health policy writer and publications professional. He is founder of G-Net Strategic Communications and can be reached at bob@gattyedits.com.



At the

FOREFRONT

BY CAROLYN SAVINI, MSN, FNP, AAHIVS; BEVERLY HARRINGTON, MSN, FNP-C, AND SUSAN WILSON, ACRN

# Kaposi's Sarcoma in Treatment Naïve HIV Patients

**D**URING THE EARLY YEARS of the HIV/AIDS epidemic, Kaposi's sarcoma (KS) was a common malignancy responsible for significant morbidity and mortality. As treatments for HIV infection markedly improved in the mid to late 1990's, there was a dramatic decrease in AIDS-related malignancies including KS.<sup>1</sup>

KS is a disorder characterized by proliferation of spindle-shaped cells, neo-angiogenesis, inflammation, and edema.<sup>2</sup> In the HIV-infected patient it may be indolent or aggressive in presentation and disease course. Cutaneous violaceous lesions may be present on the extremities, trunk, or face. In the pre-HAART, Fauci, et al. reported 10 percent of HIV-KS subjects would die as a consequence of this condition.<sup>3</sup>

At the epidemic's onset, KS was primarily seen in homosexual and bisexual men and it became an AIDS-defining condition as designated by CDC criteria.<sup>4</sup> Although postulated causes included amyl nitrate (poppers), genetic factors, HIV, and multiple sexually transmitted infections, it was determined in the mid 1990's that Human Herpes Virus 8 (HHV-8) was the causative factor KS.<sup>5</sup> Risk factors for development of KS include immune deficiency and transmission of HIV infection through male-to-male sexual intercourse.

In our rural HIV clinic in Southern Delaware, we manage over 350 patients and average an additional 60 new HIV patients per calendar year. Over the past six months, we have seen a surprising increase in patients entering into care with initial presentation of KS. This recent trend has led us to present three cases of KS in newly diagnosed patients with HIV infection. These patients entered our clinic during the first six months of 2009 and represent 10 percent of newly diagnosed patients. Prior to this, the last time a new patient presented with KS into our system was 2005.

**Case 1:** A 36-year-old Caucasian male presented with violaceous lesions on his maxilla and mandible. He reported the lesions had been apparent for the past four months. Six years ago he tested HIV negative, but recent HIV testing was positive with a baseline CD4+ T cell count of 213 cells/mm<sup>3</sup> (14%) and HIV RNA of 69,278 copies/ml. Physical examination revealed soft, violaceous lesions on his face, a hyper-pigmented lesion

on his soft palate, perirectal lesions, and cervical and inguinal nontender lymphadenopathy. Biopsy of the facial lesions confirmed KS. The patient reported a history of multiple, unprotected same sex partners, anal condyloma, and use of multiple recreational drugs, including "poppers."

**Case 2:** A 35-year-old Caucasian male, presented to the clinic with biopsy-confirmed KS after testing HIV positive. He reported being tested six months prior for HIV and was allegedly negative. However, his baseline CD4+ T cell count was only 27 cells/mm<sup>3</sup> (3%) and his HIV RNA was 75,646 copies/ml. Physical examination revealed multiple violaceous lesions on his face, back, chest and upper and lower extremities with thick white plaques adherent to buccal mucosa. He had shotty cervical, submandibular, submental and supraclavicular lymphadenopathy. He reported a history of multiple, unprotected same sex partners and a history of syphilis and gonorrhea. He also admitted to past and current recreational drug use, including "poppers," marijuana, and "crystal meth."

**Case 3:** A 46-year-old Hispanic male was referred by an otolaryngologist to our clinic after a biopsy confirmed KS from a lesion on his hard palate. The patient indicated he had not been previously tested for HIV. His baseline CD4+ T cell count was 257 cells/mm<sup>3</sup> (14%) and his HIV RNA was 295,288 copies/ml. Physical examination confirmed the KS lesion on his hard palate and also revealed lymphadenopathy in the right inguinal area and multiple violaceous lesions consistent with KS on the posterior thorax and left thigh. Subsequently, he was diagnosed with *Pneumocystis jiroveci* pneumonia confirmed by bronchial lavage. He reported a history of gonorrhea and multiple, unprotected same sex partners. Unlike the first two patients, he denied current or past recreational drug use.

The cases above demonstrate three patients with biopsy-confirmed KS who also had multiple risk factors for acquiring HHV-8 in the presence of an immune system compromised by HIV leading to clinical manifestations of KS disease. Martin et al's review of sexual transmission of HHV-8 notes a greater risk of disease in men who contracted HHV-8 with a history of a large number of sexual partners and sexually

transmitted infections. His paper also suggests the acquisition of HHV-8 precedes the clinical disease and onset of KS.<sup>6</sup>

Current treatment guidelines for KS include initiation of HAART and/or chemotherapy. The lesions of KS may decrease in size or even resolve after initiation of HAART and restoration of immune competence suggesting that HAART may have a direct, anti-viral effect against HHV-8.<sup>7</sup> Currently, there is no supportive data demonstrating that a protease inhibitor (PI) or non-nucleoside reverse transcriptase inhibitor (NNRTI)-based regimen is more effective for KS treatment.

The three patients described above are currently being treated with varying PI or NNRTI-based regimens specific to their genotypes. All were referred for oncologic consultation. One has been treated with both systemic chemotherapy (doxorubicin q28 days times 8 cycles) and local radiation to a large lesion on his arm. These treatments produced a notable decrease in size and appearance of his multiple cutaneous KS lesions.

Although recent observational studies report an increase in non-AIDS defining cancers in HIV patients, clinicians should be reminded that KS continues to occur in the post-HAART, especially in patients who present late for testing and care. In addition, there have been recent reports of KS in people with undetectable HIV RNA and higher CD4+ T cell counts as well<sup>8</sup>. The best initial treatment for cutaneous KS is anti-viral therapy, although some patients may need systemic chemotherapy, particularly those with visceral disease.<sup>9</sup> Immune reconstitution inflammatory syndrome (IRIS) may cause an apparent initial worsening of KS after initiation of ART<sup>10</sup>. Clinicians must continue to emphasize clear prevention messages at every encounter, reminding them that like other STDs, HHV-8 can be acquired through unsafe sexual practices. **HIV**

*For a complete list of references for this article, please visit [www.aahivm.org](http://www.aahivm.org).*

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### TIPS & TACTICS ABOUT:

# Empowerment & Encouragement in HIV Care

**IN RECENT YEARS**, clinicians who provide HIV care have increasingly sought to incorporate prevention into the medical care of their patients. Many articles and trainings on the subject emphasize strategies to help us facilitate conversations with patients about HIV transmission. Of these strategies, one of the most important is building rapport and trust with patients through meaningful conversations about their sex lives and factors that risk HIV transmission. With a foundation of trust, patients feel encouraged by me to seek the support they may need and empowered to take care of all aspects of their health.

### How do you encourage your patients to build trust with you and others in their lives?

I actively encourage my patients to be honest with everyone in their lives. Nondisclosure expends energy and leads to anxiety, which can affect the patient's overall health. I encourage my patients to have some kind of psychotherapeutic relationship: A counselor-patient environment is one in which a patient can have discussions they might not have elsewhere. To facilitate trust in me, I broach questions about their sex lives in as routine a matter as possible, so that discussing sex and HIV transmission risk becomes similar to talking about other aspects of health. In fact, questions about sexual behavior are integrated on the patient intake form along with other routine questions about a patient's medical history. Questions such as "How many sex partners have you had during the past year?" or "Are you sexually active with men, women, or both?" become as standard as asking about smoking history or other components of behavioral health.

### What is your approach to empowering patients to disclose their HIV status to potential sex partners and to negotiate condom use?

I believe that empowerment comes through education. I educate my patients about the short- and long-term effects of HIV (in-

cluding comorbidities) and about specific HIV transmission risk factors. Part of my responsibility is to remind patients about the ramifications of infecting another person and the effects of HIV infection on their community. I ask my patients if they recall specific choices they made that may have put them at risk for infection. This question can be used as a valuable teaching tool, as many believe that some of their choices did not put them at risk. By reflecting in this way, patients often realize which choices can be made in the future to decrease the probability of transmission to a seronegative person or a superinfection to a person who is already infected. Indirectly, these one-on-one choices can decrease the rate of transmission within the larger community. Having this information can produce strategies which can foster condom use and safer sex — behavior that I encourage my patients to maintain through whatever techniques work for them. Some patients find that prayer and spirituality, meditation, exercise, and engaging in social groups for people with HIV help them remain committed to safer sex strategies and to living healthy lives.

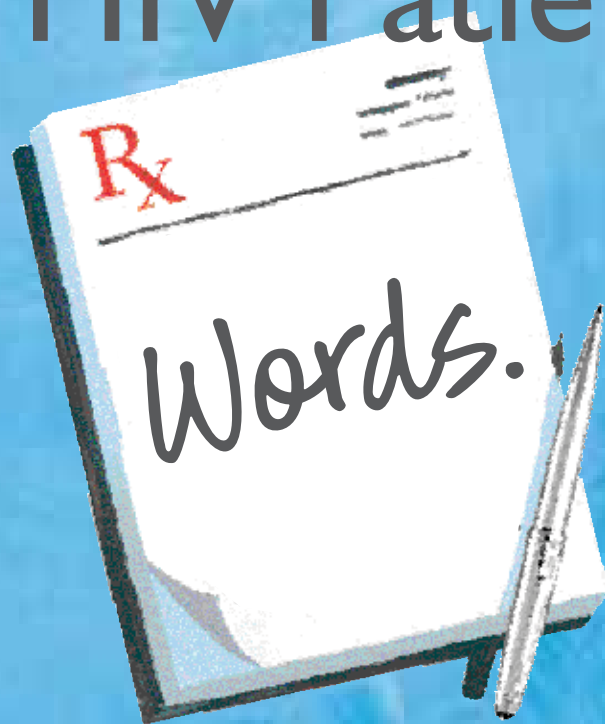
Another very important way for patients to feel empowered to live happy, healthy lives is by participating in AIDS service organizations. I have one patient who identified a need for long-term survivors of HIV to have a place where they could learn about and discuss issues that challenge long-term survivors, e.g., hepatitis B and C, renal disease, mental health, malignancies, and cardiovascular health. Many of my patients have benefited from groups such as this one.

In closing, the healthiest provider-patient relationship is one where both patient and provider respect each other and are engaged in ongoing, long-term relationship development and sharing of information about the latest developments in HIV care. **HIV**



**About the Author:** D. Trew Deckard is a Physician Assistant in Internal Medicine with the practice of Steven M. Pounders, MD, PA, in Dallas, TX, and is AAHIVS credentialed. He has worked with HIV impacted persons since 1984.

# The Latest Approach to Caring for HIV Patients?



## DISCUSSING PREVENTION HELPS PROTECT YOUR PATIENTS AND THEIR PARTNERS

Although people living with HIV often adopt healthy behaviors upon initial diagnosis, many revert back to risky behavior after time. Risky behaviors can lead to acquiring an STD, which can jeopardize a patient's health; and untreated STDs increase the risk of transmitting HIV to partners. Research shows that integrating brief prevention transmission discussions into each patient visit helps reduce risky behaviors. The Centers for Disease Control and Prevention created the *Prevention IS Care* campaign and Web site to support providers who treat people living with HIV. **To receive FREE materials that translate scientific**

**evidence into practical tools for providers and patients, visit**  
**[www.cdc.gov/PreventionISCare](http://www.cdc.gov/PreventionISCare) or call 1-800-CDC-INFO (232-4636).**

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## COMING IN THE SPRING 2010 ISSUE:

### *HIV Testing and Prevention*

It has been more than three years since the Centers for Disease Control and Prevention published *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings*.

These guidelines urged medical providers in all health care settings — including hospital emergency departments, urgent care clinics, inpatient services, substance abuse treatment clinics, public health clinics, community clinics, correctional health-care facilities, and primary care settings — to make HIV testing a regular part of the routine health care for everyone in the United States ages 13-64.

We will examine the success of these recommendations; how they have been implemented and integrated into regular care; what some of the barriers for routine HIV testing faced by providers; how HIV specialists can help educate the public and promote to non-HIV health care providers the importance of routine testing and its relationship to preventing new HIV infections.

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