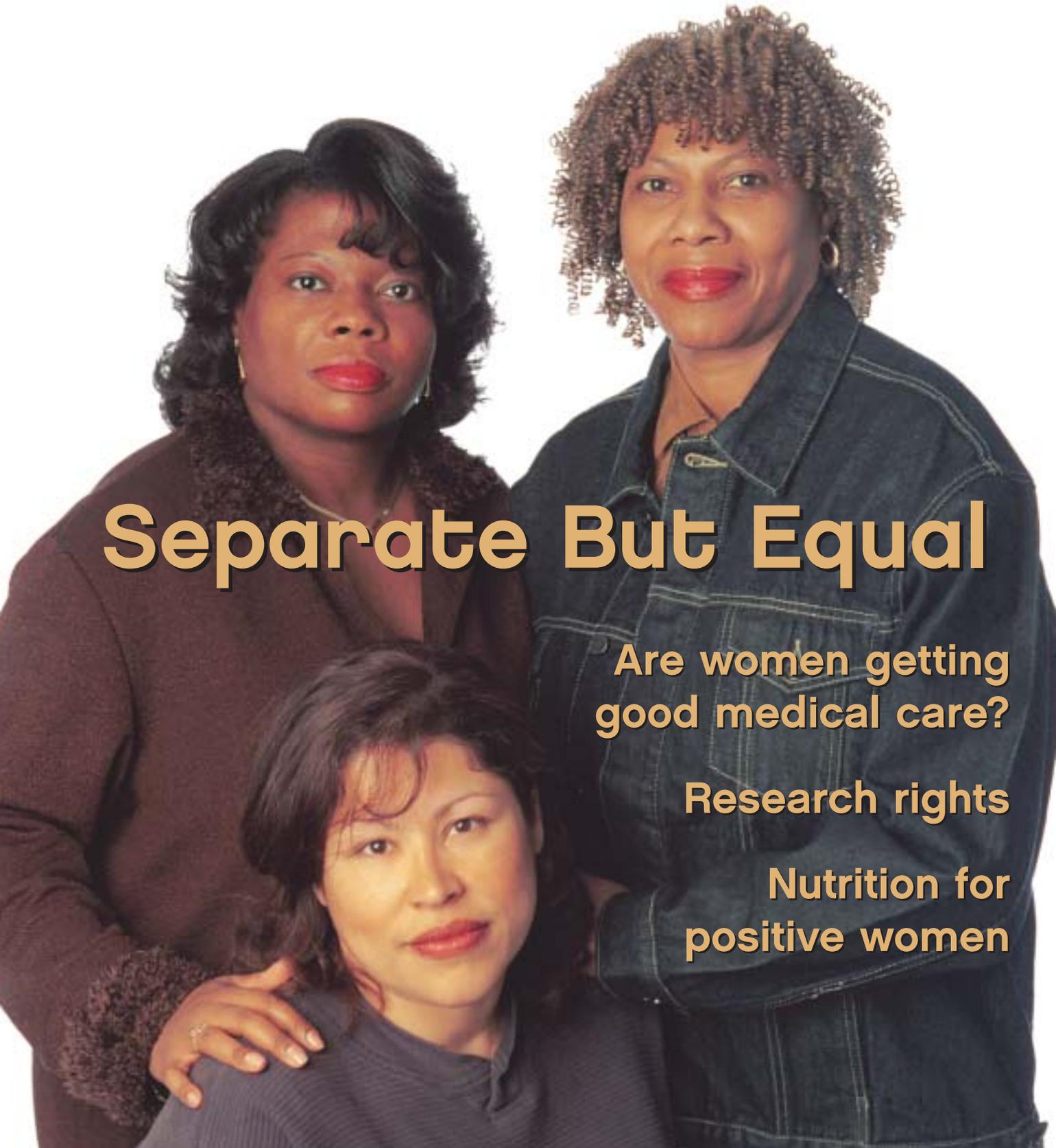


May / June 2001



Positively Aware

The Journal of Test Positive Aware Network



Separate But Equal

Are women getting
good medical care?

Research rights

Nutrition for
positive women

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Cover: *Leatrice Simpson, Earlene Hayden and Sylvia Vázquez O'Shaughnessy. Photographed by Russell McGonagle*

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TPAN recommends that all medical treatments or products be discussed thoroughly and frankly with a licensed and fully HIV-informed medical practitioner, preferably a personal physician.

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Editor's Note

Back to Our Roots



Per our mission, for its first 10 years *Positively Aware* has been provided free of cost to any HIV positive individual and distributed through community-based AIDS service organizations, regardless of their ability to pay.

The national distribution of *Positively Aware*, beginning in 1991, was made possible through a very generous five-year grant from GlaxoSmithKline (formerly Burroughs-Wellcome). In the ensuing years, the production and distribution of *Positively Aware* was supported primarily through bulk distribution (community organizations who supply the journal free of charge to their members and clients) and from the advertisements of HIV medicines by pharmaceutical companies.

While AIDS-related deaths have declined in the last five years, the incidence of reported new HIV infections have exploded among African American and Latino men who have sex with men, heterosexual women and incarcerated men; occurrences of sexually transmitted diseases (STDs) and new HIV infections have sharply increased in the gay ghettos, 'hoods and barrios of San Francisco, New York City, Chicago, Los Angeles, Miami and Washington, D.C.

The influx of new clients and the demand for multi-faceted services continues to outpace the capability of many service providers. An increasing number of community-based agencies are dealing with more HIV positive clients, fewer staff and slow government response to funding requests.

The pharmaceutical industry faces external pressure from AIDS activists and treatment educators to discontinue direct consumer advertising (the same type of ads that support *Positively Aware* and other HIV publications) and increase supplies of free or reduced cost antivirals domestically and internationally.

In the past year old-school, trickle down Reaganomics has taken a hold of *Positively Aware*.

On the demand end, subscriptions for *Positively Aware* from HIV positive individuals, their caregivers and community organizations continue to increase. On the supply end, advertising revenue for the journal declined substantially over the last year. And on the cost end, printing and distribution expenses associated with production of *Positively Aware* continue to increase.

Positively Aware and now *Positively Aware en Español* are created, edited and distributed by a staff of three—Jeff Berry, Enid Vázquez, and myself. It is only through grassroots efforts, dedicated volunteers and the strong cooperation of our agency's entire staff (just 15 in total) that Enid, Jeff and I are able to produce these two journals. We rely heavily upon these individuals to help with an assortment of tasks from writing articles, to unloading delivery trucks, to boxing up journals for shipments.

The bottom line right now is that we need your support. I am asking our readers, our friends and our supporters—anyone who's life has been touched by HIV/AIDS—to make a donation and support our efforts to distribute *Positively Aware* free to those individuals who need it most. HIV is a disease that affects all of us. AIDS is not over.

Please complete the donation/subscription form on page 41 of this issue and send in your contribution—today.

A handwritten signature in black ink that reads "Charles E. Clifton". The signature is written in a cursive, flowing style.

Charles E. Clifton
Editor

P.S. We could have mailed a separate solicitation letter or sent out subscription renewal forms, which we have never done. We could have provided a self-addressed, stamped envelope for donations. However, these efforts would have entailed additional costs.

HIV Priorities and Responsibilities



In the late eighties and early nineties there were many prevention efforts in gay communities across the country. All encouraged safer sex—“use a condom,” “don’t exchange bodily fluids,” “reduce the number of sex partners,” etc. And the efforts were successful. Infection rates dropped in gay communities and safer sex became acceptable, even if somewhat grudgingly.

Today the posters of hot men with rubbers, either in their hands or on their dicks, are hard to find, as are posters encouraging the use of clean needles only. Nearly as hard to find are individuals who demand that condoms be used. The expectation, even in the gay community, for safer sex seems to have disappeared. There is wide spread acceptance of an attitude of “don’t ask, don’t tell” as it relates to HIV status. Women and men, positive or negative, in far too great of numbers, have decided to ignore discussion of their HIV status with prospective sex partners. If there is no discussion about HIV status, then many people rationalize unprotected sex by thinking “If my partner is willing to have unprotected sex then they must be the same HIV status as me.” A convenient rationalization, whether you are positive or negative.

This return to not discussing and disclosing HIV status helps to fuel the rise in unsafe sex and other risk behaviors. Yet, there continues to be fewer prevention posters, ads and campaigns than in the past. And this is not just because of lack of funding. It is also the result of not being sure how to deliver prevention messages. Messages that ask people to have sex and shoot up drugs in a way that is not their favorite or most convenient. Messages that remind people, both HIV positive and HIV negative of their role and responsibility in limiting further HIV infection.

How do we reach teenagers and young adults to convince them to always insist that a condom is used before a dick goes in another person? How do

we help injection drug users to understand the risk from sharing works with a friend? How do we de-romanticize, de-eroticize “barebacking” (unprotected sexual intercourse)? How do we make safer sex the expected norm?

How do we do this without turning the issue into “us vs. them”? Positives vs. Negatives? How do we make people understand it is their responsibility to play safe and to use clean works? How do we remind both HIV negative and HIV positive people that they each have a responsibility in reducing HIV infections?

I don’t know. I suspect that a preachy, moralistic “just say no” approach will not work for many. But I’m not sure what the right message is. Will the approach of 10 years ago (posters of “hot” guys wearing rubbers) work? Will posters that show what it is like to live with HIV or what AIDS can, and does, look like for many, work? How do we do this in a way that places the responsibility on all involved parties—HIV positive and HIV negative, “tops” and “bottoms,” lovers and “tricks,” men and women? I don’t know.

What I do know is we need to make prevention a priority. We need to again widely, and openly, encourage some basic safer sex practices. We need to find the messages, and medium, to make safer sex not just acceptable, but expected. Our failure to do this today runs the risk of another wave of infections. And though the treatments are better now than 10 years ago, the cure is still nonexistent. In 2001 as in 1990, “Silence = Death.”

Dennis Hartke

Dennis Hartke
Executive Director

Thoughts, comments, reactions? Write me at tpaned@aol.com

Readers' Forum

Positively Aware will treat all communications (letters, faxes, e-mail, etc.) as letters to the editor unless otherwise instructed. We reserve the right to edit for length, style or clarity.

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OLDIE BUT GOODIE

I am in great need of your help. I had saved an article from years ago from *Positively Aware* that was I believed titled, "To Tell or Not To Tell." The article is at least six years old, I do believe. I had made copies to use and give to people who were in need of info on this matter. I have since run out and did not make any back-up copies. Is there any possibility that you can e-mail me a copy? I have a few guys here who can use this article at this time with their life right now. Anything that you can do would be greatly appreciated.

TJ, via the internet

Editor's Note: No problem. It's good to know we made such a difference.

PEP TALK

Life is beautiful. Even with AIDS, lupus, hep C, and whatever lurks in my body undetected. Pity sucks. I live, therefore, I am alive! Thinking is an option, not a necessity. I can opt to think about the interferon treatments [for hepatitis] that almost cost me my life, along with Zerit and Ziagen that did the same. But I opt to think about my kids, trees (yes, trees!), the ocean (any ocean), and the Higher Power that most definitely be. I smile, tell jokes, dance, roar with laughter and sometimes when I'm real lucky I have sex! Life is God's gift and He is the only licensed I-take-it-back gift giver. So I suggest all PWAs and HIV Lifers buy into my option plan. I guarantee you, "It does a HAART good!"

Peppi P. Davidson, Philadelphia

NEW READER

I just discovered *Positively Aware* and find it very interesting. I tested positive in 1995 with this deadly virus. While waiting

for a cure I take Sustiva, Zerit and Ziagen. No side effects as of yet! I go to support groups—too many at first. Now I have to stop going everywhere like a wild person. My children know I'm positive and deal with it in their own way. I want to speak out. I did not smoke or do drugs. All I can say is a person should get tested no matter what sexual activities they were in. All I can do is take my medications and live.

Name withheld, Newark, New Jersey

TWO TO TANGLE?

This letter is in response to one published in your Jan./Feb. 2001 issue, "Sex Ethics," which in turn, was in response to an article not named [see "Give Us Morality or Give Us Death," September/October 2000]. Let me first say that while it may take "two to tango," it only takes one to transmit, and therefore the original writer's premise is far from false. However, granting Mr. Carson's summation of human nature as wallowing in the need for "acceptance, love, kindness, dignity, and respect," I would add that those needs might certainly cause the uneducated, the unwary, or simply the uncaring, to exercise his or her "right to have unsafe sex." But, please, again being brutally honest, the consequences of that behavior are not just for the one or two to accept or not, but for the whole of society. We have seatbelt laws and strict drunk driving penalties, and because they work, we not only see fewer horrific casualties on the road, we have fewer grieving families, lower auto and health insurance rates, and our tax money can be used to fund health care for youth and the elderly, not intensive care for the reckless and impaired. And just as we as a society, through our legislators, reached an agreement on the rules of safe motor vehicle operation, as a society

of gay and straight people, we have an obligation to further the debate surrounding safe sex and to come to some universal conclusions. I am a pharmacist working as an HIV/AIDS specialist, and I can assure Mr. Carson that enormous effort and resources are being allocated to find better, faster, safer ways to kill the virus. But that solution may be years, even decades away. In the mean time, people suffer and die and the only way we can hope to get the upper hand is to simply prevent transmission, human nature being what it is and all. Does Mr. Carson think that the healthy gay population is just lucky? Does he think that his HIV status somehow confers upon him the wisdom to dismiss the ideal of responsibility toward our fellow humans? Or is it, as I suspect, his anger at the partner who infected him and then left him to face the consequences alone speaking? We haven't taken all the cars on the road to the crusher because a few unlucky souls perish in them, but we have made a concerted effort to make them safer, and to educate drivers about their responsibility when they get behind the wheel. Don't we owe the same level of concern to our partners, our lovers, and our children? Barebacking, circuit parties, party drugs, indifference and misinformation are the vessels carrying this virus, and as a case manager, Mr. Carson would be better serving his clients if he kept that mantra in mind.

Barbara Renthall, Phoenix, AZ

PRISON DAMNED

I am writing to you from the Dixon Correctional Center where I am an inmate, with AIDS, serving a 20-year sentence. I think your readers and young people with HIV/AIDS, who may be prone to incarceration, should be aware of the problems asso-

ciated with being in prison and having these diseases. People like us are double-damned.

The Illinois Department of Corrections operates a managed healthcare system that goes to the lowest bidder. It is a gross exaggeration to label it “minimal standards of health care.” The prison system is not obligated to treat or prescribe medication for illnesses not considered life threatening just to make you more comfortable. Because the medical and professional staff is contracted, the quality of the services is literally the “bottom of the barrel,” in other words, these people work here because they can’t work anywhere else. They have neither the commitment nor the compassion of private healthcare providers.

There are no specialists trained to work with HIV/AIDS patients even though a very large portion of the prison population is infected with these diseases. The doctors here who treat HIV/AIDS patients are what I have come to dub “country doctors,” ones who treat everyone for everything. It is pretty much like going to a General Practitioner for open-heart surgery. Not only are the medical services inadequate, there are no counseling and support services available to help patients. We are not even allowed to have peer counselors. Prisoners with these and other illnesses are on their own.

Due to the quality of the health care and the deliberate indifference of the medical staff, it is a daily battle just to get the minimum medication to prolong one’s life. Inmates have no voice in their treatment for HIV/AIDS or any illness. I was placed on a triple cocktail of Zerit, Ziagen and Sustiva. However, these drugs, in concert with the multitude of other drugs I must take, make me violently ill and in constant dire pain. The medical staff is unwilling to try different drug therapies or to prescribe medication for pain and side effects. Because of this, I recently discontinued all my AIDS medications. The quality and comfort of my daily life won out over the longevity of my life. This would be quite different if I were not in prison.

Because I am a prisoner and suffer from a mild mental illness, along with AIDS and hepatitis C, prison officials infer that my life is not worth saving and certainly not worth the expense it would take to properly treat me, keep me out of pain and afford me a rea-

sonably comfortable quality of life. Their reasoning is, “Why should we when he’s going to die anyway?”

It is my fervent hope that anyone reading this letter will think twice before placing themselves in a situation where they have no control over their lives and where prison officials can withhold medical treatment as a means of behavior modification. I am in hopes that no one else becomes double-damned.

Please feel free to share this with your staff and readers. I enjoy your magazine very much and look forward to every issue.

Larry Harris, A61614, Dixon Correctional Center, 2600 N. Brinton, Dixon, Illinois 61021

“SLIP SLIDING INTO AN EARLIER GRAVE: A RESPONSE TO PICKETT FENCES”

I was disturbed by what I thought was an endorsement of “barebacking” in *Positively Aware*, published as it is with a national distribution and in two languages. How could an agency with such a long and dedicated service to the HIV community disseminate such a piece without offering, at the very least, an alternative viewpoint?

At the onset, I acknowledge that I admire Jim’s work, especially in his efforts around AIDS awareness and prevention. And this is not an *ad hominum* attack on him or his work. It’s a different point of view. That stated, let’s examine the facts of Pickett Fences.

His first near unsafe sex encounter occurred after being recently unpartnered—a time when most of us typically feel battered and needy. He also writes that the incident took place at the US Conference on AIDS, where being positive quickly loses its sigma and being positive doesn’t send potential dates running for the door. Finally, drugs are introduced. “We get high and silly,” Jim writes. Thus, the initial venial sin of not making a safe sex only negotiation upfront, was contextualized in a recreational drug atmosphere violating one of the first tenants of the HIV prevention cannon. Stated starkly, Jim may have been negatively impacted by his unpartnering, and presumably his isolation from being positive, met someone who brought temporary comfort, got high, and, what should have been an automatic action akin to lubrication, is then artificially

dropped. Emotionally vulnerable people mixing drugs and sex is what helped fuel this epidemic. Something we have known for a very long time.

Being part of the vanguard of the information age and aspiring to “achieve AIDS starlet-dom” as he terms it, Jim puts up an AOL profile to expand the sexual delivery system. He identifies himself as HIV positive and discovers that there are many responses to his posting, especially from men who want unprotected sex.

As if to make these actions somehow more acceptable from a prevention standpoint, Jim puts up two “boundaries—never doing it [barebacking] with a negative man and no one coming inside anyone else.”

Jim acknowledges a well documented suspicion that unprotected sex between two positive people probably contributes to drug resistant strains of HIV. What he remains silent on is that his boundaries will complicate treatment options (three drugs become four, sometimes five—with all its attending side effects—liver, kidney, pancreas, and coronary problems).

Additionally, he fails to point out that safe sex, namely, the condom use that he so readily eschews, helps control syphilis, gonorrhea, chlamydia, hepatitis, intestinal parasites and a whole host of other damaging infections. Again, treatment options become muddled and keep on chipping away at the quality of life, putting undue stress on already stressed organs.

Condoms are necessary nuisances—at least for now. This disease sucks; the drugs suck; the side effects suck; being deprived of that ultimate feeling of closeness with a loved one, sucks. Unfortunately, this is part and parcel of the disease.

I don’t think that he should be admonished for his article. Jim gives voice to all those who hate using condoms. He articulated that, given the right conditions, even the most strident of us can relapse. I think where he fails his readers is by not stating that his decision is clearly personal and that the scale is decidedly tipped in favor of condom use.

Richard Niemiec,
member, Test Positive Aware Network,
Chicago 🇺🇸

News Briefs

by Enid Vázquez



EXPANDED ACCESS

Run out of HIV drugs to choose from? You might consider the following free programs. Also see “The Buzz.”

T-20

This twice-daily self-injected (under the skin) drug is available to a small number of people who have multi-drug resistant virus and low T-cell counts. It is a fusion inhibitor, a new class of HIV drugs. T-20 is also going into Phase III clinical trials, which you may be able to join. Because no 800 number was provided, we suggest you contact one of the companies involved in developing T-20, Roche. Call (800) 910-4687 or visit www.rocheusa.com. Try also www.trimeris.com.

Tenofovir

This once-a-day drug is also in a new class of HIV medications, nucleotide reverse transcriptase inhibitors, and is also available in clinical trials, if you're eligible. Call (800) GILEAD-5 (445-3235).

KNOW WHAT I MEAN?

The San Francisco AIDS Foundation (SFAF) asks, “How do you know what you know?” That’s what they want gay men in the city to ask themselves about potential sex partners. Why? Because studies from a number of places, including the foundation and the Center for AIDS Prevention Studies out of the University of California, San Francisco (<http://hivinsite.ucsf.edu>), have found that many gay men figure a new partner has the same HIV status that they do. It’s that old concept found on other people’s health campaigns, where the guys are thinking, “He must be positive like me because he hasn’t asked about my status” or “He must be HIV negative like me because he hasn’t asked about my status.” SFAF will use billboards, bus shelter ads, and magazine ads, among other places, to get their message across. The organization will also encourage people to come in for counseling around making sexual decisions. Visit their Gay Life website, www.gaylife.org.

MORE GOLDEN GATE

The city’s health department conducted a survey at its clinic for sexually transmitted diseases which found that 62% of the people questioned believed that HIV drug ads may cause people to have unprotected sex. However, among men who have sex with men, only 25% of the ones with high exposure to HIV drug ads believed that the medications made HIV a less serious disease. The health department is fighting the dangers of unsafe sex by meeting with the FDA to try to control HIV ads and by contacting the drug companies directly. Visit www.hivandhepatitis.com for a report by activist Jeff Getty on this topic.

ORAL ULCERS

Low-dose thalidomide was previously found to work wonders in getting rid of oral ulcers in people with AIDS. Unfortunately, a new study found that the drug was not effective at preventing the ulcers from reappearing. In fact, it seemed that continuing to use thalidomide may create the risk of having ulcers return. The results of the AIDS Clinical Trials Group (ACTG) study were published in the January 15 *Journal of Infectious Diseases*.

STRAIGHT RETREAT

The Center for Positive Connections, a Miami organization for straight people living with HIV, is organizing a 7-day retreat for the HIV heterosexual community, in Montego Bay, Jamaica, October 18–25. The first deposit, for a third of your hotel stay, is due ASAP. The second is due June 11 and the final payment is due August 5. Hotel, meals, drinks and sports, depending on length of stay, cost \$555 to \$960. Discounted airfare available separately; contact Merry at 1-800-749-1900, ext. 165. Call Positive Connections at 1-888-POS-CONN (767-2666) or visit www.positiveconnections.org. E-mail pozconnect@aol.com. ☕

photo by Russell McGonagle

Are You Getting Good Medical Care?

By Debra Johnson, N.P., P.A.-C. and Kathleen E. Squires, M.D.

The beginning of the AIDS epidemic in the United States was presented as a disease that was primarily transmitted by men who have sex with men (MSM), and intravenous drug abusers (IVDA). In fact, women were essentially excluded from an AIDS defining diagnosis until 1993 when a CD4 T-cell count less than 200 cells/mm³, or a CD4 T-cell percentage of less than 14 and/or invasive cervical carcinoma became recognized (after years of community activism and pressure on the CDC). In 1995 greater than 59% of the women were diagnosed based on the addition of the new inclusion criteria added in 1993. As the faces of AIDS continues to change, with women representing more than 42% of the total cases reported in 1999, it would stand to reason that the health care system that had been developed to deliver clinical care services for men needs to redirect their care towards the specific needs of women.

This article would not be complete without a statement about how little is known regarding women who are infected with HIV disease. After 1993, the Food and Drug Administration (FDA) mandated the inclusion of women in Phase I clinical trials. Prior to the mandate most women were excluded from clinical trial participation because of their ability to reproduce. Currently women comprise less than 24% of the participants in clinical trials, therefore most of the data that is currently available continues to be gleaned from men.

BE AN ADVOCATE

Women activists need to continue their work with researchers to provide community input and direction towards the common goal of improving the quality and level of care that women who are HIV infected receive.

Most of the data currently available would suggest that a large disparity exists in access to health care for women. Women are traditionally the caregivers in the home, providing care for an infected spouse and/or children, and thus require much more energy to coordinate their perceived responsibilities and access to health care. Disparities also seem to exist in the ability to acquire transportation to health care appointments, as well as finding childcare resources. Until we, as an AIDS community, acknowledge these basic disparities, HIV positive women will continue to receive suboptimal health care, which in many cases may equate to no health care at all.

THE CLINIC VISIT

The clinical visit can sometimes consist of a very long time spent in waiting rooms that lack a supportive environment for women, including inadequate activities to keep their children occupied and a lack of GYN or contraceptive care. Many health care professionals have provided care to gay men with HIV/AIDS for so long, they may feel uncomfortable providing care for women and/or addressing the difference in women's health care demands.

During a woman's initial visit, usually between 50 to 100 mL (between 2–3 ounces or 4–5 tablespoons) of blood will be sent for routine laboratory evaluation such as CD4 T-cells, viral RNA, total blood count, chemistry panel (checking the liver, kidney and electrolytes), syphilis and a toxoplasmosis panel. Each woman will also have a baseline chest X-ray, urinalysis and a mantoux skin test (to check for tuberculosis). An appointment will be made for a return clinic visit



with the health care team where a history, physical examination and the laboratory results will be evaluated and discussed.

The initial physical examination should be conducted with a review of symptoms (to determine if anything is wrong), focusing on specific and common HIV-related symptoms including fevers, night sweats, weight loss, diarrhea, skin rashes or lesions, oral thrush or ulcerations, and changes in neurologic function (memory loss, tingling in your hands or feet).

Basic laboratory work (drawing blood) should be done during the first visit and then repeated every 3–4 months. The laboratory evaluation should include CD4 T-cell counts, viral load (vRNA) along with liver function testing, basic complete cell count and chemistry panels. Although there are a fair amount of data available that suggest resistance testing (genotyping and phenotyping) can help us decide the best and most successful antiretroviral therapy, these tests are not widely available.

STAYING HEALTHY

During the first several visits, women will receive an overview of how HIV is transmitted, how it affects the immune system and what they can do to stay healthy. All of the information may not be remembered, but a

list of questions that are felt by the patient to be important should be kept and brought to each appointment. Bringing questions to the clinic appointment helps to direct the health care team in addressing the individual needs

Until we, as an AIDS community, acknowledge basic disparities, HIV+ women will continue to receive suboptimal health care.

of each woman and can provide a rewarding experience for both the woman and her healthcare team. Becoming involved in community support groups will continue to enrich the women's understanding of HIV and its associated syndromes, and give them the opportunity to develop new friends thereby creating and strengthening a support network.

WHEN SHOULD YOU START ANTIRETROVIRAL THERAPY?

It is important to know that there are guidelines available (<http://www.hivatis.org> or call 1-800-448-0440) to help clinicians make decisions about what antiretroviral medications may be appropriate. However these are only guidelines and do not deal with individual or "life" issues. Starting antiretroviral therapy is almost never so immediately required that someone cannot take a couple of weeks to gather information, talk to a treatment advocate, read AIDS newsletters, talk about their options with their health care provider and make an educated choice!

Deciding when to start medications should not begin without a great deal of time spent on discussing the subject of adherence.

When to start taking antiretrovirals is really dependent on several factors. The first is to determine the viral load because the higher the viral load the more likely the CD4 T-cells are to start decreasing. (Note: viral loads may be lower in women than men with equal T-cells.) The second is to determine the CD4 T-cell count. T-cells are an important marker in knowing when to start taking antiretroviral therapy. As the virus damages the immune system, T-cell counts go down. Progression to an AIDS diagnosis is directly related to low T-cell counts.

But most importantly, adherence (taking medications regularly) is the real deciding factor of starting highly active antiretroviral therapy (HAART). Taking all of the medications as directed, as close as possible to the appropriate time, is extremely impor-

tant with antiretrovirals. Women who are 95% adherent (missing less than one dose a month) decrease the risk of developing resistance or eventual medication failure and thus disease progression. If a woman is not ready to take medications rigorously, then starting medications should wait until she feels that she can commit to adhering to a strict schedule. Health care is a team effort and each member has a responsibility to do his or her part in maintaining good health.

PREVENTION

Prevention care, or prophylaxis, really means trying to prevent infections instead of waiting until you become sick (<http://www.cdcnpin.org>). Guidelines include recommendations of when to start prophylaxis for opportunistic infection, immunizations, annual labs, PPD (screening for TB) and bi-annual Pap examinations and colposcopy if necessary. These guidelines suggest when preventive interventions should occur. Prevention is an important component of care; it helps to optimize health in women by minimizing illness.

Blood draws should be done on a regular basis—usually several times a year or when clinically indicated. During your regular blood draw, a toxoplasmosis IgG,

syphilis screening, lipid profiles, hepatitis screening, chemistry and complete blood cell count should be done. Annual flu vaccination should be utilized; this should occur during the end of September through the end of November. This allows the body enough time to respond to the vaccine by producing antibodies against the strain of influenza that may be expected during February through April. The flu vaccine does not lead to the development of influenza, but some individuals may be susceptible to developing an upper respiratory infection that may occur shortly after receiving any vaccination.

Current recommendations suggest that any HIV positive patient who is negative for hepatitis B (HBV) should be vaccinated. For those patients who are positive for hepatitis C (HCV) they should receive both HBV and HAV vaccinations. A pneumovax should be administered followed by a booster when CD4 T-cell increase >200 cells/mm³. A booster tetanus vaccination should be given if it has been greater than 5–10 years and/or again after CD4 T-cells are >200.

STDs

Routine screening of sexually transmitted diseases (STD) should be done every six months during the GYN exam and when clinically indicated. Currently, there is controversy over whether a colposcopy should be performed during a routine Pap smear or only



when the Pap results indicate that it is necessary. Mammograms should follow current guidelines (baseline between 40 and 50 years and annually over the age of 50 or if clinically indicated). Receiving GYN care from an experienced HIV/GYN clinician is extremely important when screening for CMV, HPV and HSV. In the next several months, the AIDS Clinical Trials Group (ACTG) will open a protocol (A5029) looking at the effect of highly active antiretroviral therapy (HAART) on genital secretions and effects on HPV (which can lead to the development of genital warts or invasive cervical carcinoma).

PREGNANCY

Pregnancy is an important discussion for some women. Discussing options regarding the best time to become pregnant and currently available information about fetal transmission should be a natural part of conversation with your health care team. If your intention is to become pregnant, it is extremely important to inform your health care team so that certain antiretrovirals that are thought to be unsafe in pregnancy can be avoided. Sustiva (efavirenz), Ziagen (abacavir, ABC) and hydroxyurea (HU) have been shown in animal models to potentially cause birth defects and should not be used in women whose intention is to become pregnant. Waiting until your viral replication or vRNA is below the lower limit of detection will also decrease the risk of transmitting HIV to your fetus.

WOMEN AND ESTROGEN

There is little information about women and estrogen replacement. Hopefully in the next year a clinical trial known as AT LAST will provide important information about the effect of hormones. Another trial scheduled for later next year will look at the contraceptive, Depo-Provera and any potential interactions with protease inhibitors. So, for now following the current guidelines on hormone replacement is the best recommendation. Discuss issues about hormone replacement and the use of contraceptives with your clinician and decide together what is best for you. Just remember that nothing takes the place of latex condoms (female or male) which should be used to protect against diseases, regardless of your other birth control choices.

TESTOSTERONE REPLACEMENT

Data on testosterone replacement in women may actually demonstrate an



increased risk of developing lipodystrophy. The bottom line is a good exercise program with a healthy diet decreasing fat intake. This is probably the least invasive and holds the most hope. It can be hard to start to exercise, so walk with a friend or your support group or push your child in a stroller. You do not have to join an expensive gym. Walking is a great way to build endurance and lose weight.

NUTRITIONAL COUNSELING

Nutrition is becoming a much more important component in HIV care with information slowly trickling into the mainstream about women's risk of being vitamin deficient. Several small studies suggest that women may be low in vitamin B12 and vitamin A. The information is not strong enough to recommend replacement, but an inexpensive antioxidant and a multivitamin once a day is advised. Talk to your health care team about a nutritional evaluation either at your clinic, if it is available, or through one of the community based organizations. Eating healthy makes good sense and it is preventive.

SUPPORT

Becoming involved in a support group may be one of the most important things that you do. Getting together with other women to validate how you feel is necessary! Support groups also will assist you in obtaining all of the benefits you may be entitled to, including, at times, free transportation to clinic appointments.

Talk to your health care team, the nurse manager or the administrator of your clinic and make suggestions about things you think would be important to help you make your visit to the clinic more comfortable. If you do not make suggestions, changes may or may not occur. We need to start ensuring that our issues, as women, are addressed because we are important! Many men with HIV/AIDS are skilled in advocating for themselves and their male friends. Women with HIV need to develop these skills to ensure that their needs are being met.

CONCLUSIONS

More information is necessary to improve the quality of care that women currently receive. Health care facilities need to seek out the barriers that impede the care of women infected with HIV disease, such as transportation, child care and women-specific services.

Get involved! There are all levels of involvement. Expect the best from the clinic and if it does not meet your needs, suggest constructive ways that the clinic can meet the needs of women. We need to capitalize on the services that are available, and ask questions and demand appropriate answers as to why some services that are available to men are not available for women. Get involved, be an activist. Become an equal partner in your health care. ☒

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One On One

Earlene Hayden

By Charles E. Clifton

I recently sat down and spoke with Earlene Hayden, an HIV prevention specialist and outreach worker with South Side Help Center in Chicago. Over the course of our two-hour conversation, we laughed, cried and shared jellybeans. It was like catching up with an old girl friend. Earlene works primarily with sex workers, injection drug users (IDUs), and homeless women in shelters; and coordinates positive support groups. She also serves as the co-chair elect of the city's HIV Prevention Planning Group for 2001. We would probably still be chatting if her husband hadn't called to see how her day was going.

ON SUBSTANCE USE AND TREATING HIV:

"The system, in many regards, is set up to fail. Why give HIV medication to a homeless person, who is still doing IV drugs? They ain't gonna stop doing drugs to take HIV meds on a regular basis. You have to arrest the addiction, then take care of the housing situation, then find out if they are ready for medication. What about the interaction of methadone, alcohol addiction, hep C, and HIV meds? There's a whole lot of work that still needs to be done."

ON HOW HIV SILENTLY DEVASTATES A COMMUNITY:

"Let's say one person has a thing of water...we got high...we all shared it...as long as one person had a bottle of water and an outfit and a cooker... that meant that you could go cop, turn each other on, and didn't have to share with nobody in the shooting gallery. This bottle of water, say me and you use it, I get high with somebody else, then we bring in somebody else, so before the night is over more than 20 people been in that one bottle of water. But it don't end there. So long as water is in the bottle, you close it up, and start all over again the next day."

ON LACK OF HOUSING:

"Where is an HIV positive woman with three children supposed to go? It [the lack of shelters for women with children] keeps a lot of them on the street. Many women will trade unprotected sex for shelter...with men who will put them out in the streets at three or four o'clock in the morning, if they don't trick with them, or all the other men in the house."

ON THE ROAD TO RECOVERY:

After years of hustling on the streets, using IV drugs and denying her HIV status, Earlene checked herself into a hospital for three days of care. A stranger in a restaurant gave her carfare to get there. While in the hospital a 28-day bed opened up, and she pleaded for the bed, because she knew that if she went back on the streets she would die. The doctor gave her the bed and told Earlene, 'You better not let me down.' Earlene took the bed, and she has been sober since—eight years and counting. "I always wanted to be sober, but I was homeless and strung out for years." It wasn't until Earlene obtained sobriety that she was able to face the fact that she was HIV positive and then she began to treat the disease.

ON HIV STIGMA AND DENIAL:

"Women have a tendency to dress up their virus," to deal with the stigma attached to HIV/AIDS, according to Earlene. What she means by that is that T-cells and viral loads become weapons in certain situations. 'Girl, I got 900 T-cells,' a woman claims. 'So and so got AIDS, I ain't there yet'—thereby distancing herself from others living with AIDS. Earlene believes that line of defense is a barrier that prevents effective treatment and education opportunities. "We are all infected. My virus is no different from yours."

Earlene observes that many women are also in denial about the status of their relationships and the sexual activities of their husbands or partners. "Women call [into the office] and say, 'I just tested positive. I've

been with this guy for 17 years and he's been my only partner. I guess when I was younger, when I was promiscuous, I must have acquired HIV. They told me that the virus can lay dormant for up to 20 years. I don't want my husband to leave me. I don't know how to tell him, that I may have infected him."

To counter this line of reasoning, she asks clients: How many sexual partners have you had who have told you that they were an IV drug user, or bisexual? None. "I'm a living witness. When I was out there in the world, looking normal, getting high, I met men from all around the world. We'd do what we had to do, and move on. I didn't wear a sign that I was an IV drug user."

ON THE (MIS)EDUCATION OF POSITIVES:

The very basics of communication is a huge factor contributing to the confusion surrounding the disease, Earlene pointed out. A woman in a clinic recently asked Earlene if she was still HIV positive, to which Earlene answered, yes. "You still HIV positive?" the woman asked again, as if surprised. "Well, they told me I have AIDS and I just found out," she continued. "How come you still got HIV?" Here was a woman living with AIDS, who didn't understand the connection between HIV and AIDS.

It's an extremely difficult situation for an individual diagnosed with AIDS, which is the reality of most women that Earlene deals with. "They don't know what led them to AIDS. The doctor might say, 'You have 100 T-cells and 650,000 viral load' and in the same breath say, 'but we're not into numbers.' The

damage is already done,” Earlene explains. One of the many challenges Earlene and others in her field face is that they are encountering individuals living with AIDS on complex antiretroviral therapy, who really don’t understand the basis of HIV and AIDS.

One of the most frustrating aspects of Earlene’s work is the fact that when many women find out that they’re positive, the doctors and clinics are through with them. In many instances there’s no additional education. “They hand you a bunch of pills and expect you to be adherent. Everything is for the next person. We need more interventions for the positives,” she states. “How is a positive woman suppose to live with her husband? Does she know how to take care of herself or her partner?”

Earlene was misdiagnosed with a pelvic inflammatory disease (PID) in the ER. Two weeks later when she saw her primary physician, Earlene discovered that a cyst had ruptured. For two weeks she was taking antibiotics that in her words, “were tearing down my immune system.” No ultrasound was performed in the emergency room.

What’s a person to do? “We go to the doctor. We tell the truth [about our HIV status]. We get mistreated. We go to the doctor. We lie. We take a chance on them killing us. It’s a no-win situation, but it’s what we fight so hard for.”

ON HIV AND MENOPAUSE:

“We need to have some more information on this. When a woman is going

ON THE NECESSITY FOR PREVENTIVE CARE FOR HIV POSITIVE WOMEN:

“Overall, across the board, regardless of race, women suffer from a lack of care... some women have never even had a pap smear or a mammogram. MRIs should be a part of a regular yearly examination. We all should take an MRI...that should be implemented into primary care...because things are coming now [side effects from long-term HIV antiretroviral therapy].”

Although Earlene has been an AIDS advocate for years, it wasn’t until 1996 that the reality of living with HIV hit. “It wasn’t until I had to start medication myself that it hit. I really did have HIV. It was a wake up call. Women have to pay attention, you have to take care of yourself, eat right, dress right.”

When I was out there in the world, looking normal, getting high, I met men from all around the world. We’d do what we had to do, and move on. I didn’t wear a sign that I was an IV drug user.



ON TEMPORARY SETBACKS:

In January 2001, Earlene was rushed to the emergency room with a stomach ailment. “In the 13 years I’ve been positive I have not been sick. I never even had a viral load,” Earlene recounts. In this instance, she went to the emergency room, where all her confidentiality was broken.

While Earlene was left waiting in the emergency room in severe pain, the paramedics were running around and yelling that they had “an HIV positive African American woman,” and as she remembers, “all the other people in the waiting room started scrambling to get as far away from me as they could.”

through menopause a lot of hormones, estrogens and things are changing. We don’t know what it is. Is it a side effect of the medication? Or are we really going through menopause? A doctor told me two, three years ago that I was going through menopause. I wasn’t. Thyroids give off the same symptoms as menopause. Hot flashes. Sweating. Irritability. We need some clearer guidelines for women. There are so many restrictions on placing women in studies [clinical trials.]”

Earlene learned early on that the best tool for living a healthier life with HIV is to empower oneself. “Educate yourself on the disease. Women need to come together. Stop isolating ourselves. We are all dealing with similar issues. We need to take control of our lives.” Indeed. ☒

One On One

Sylvia Vázquez O'Shaughnessy

by Charles E. Clifton

I chatted briefly with Sylvia Vázquez-O'Shaughnessy, facilitator for TPAN's support group for HIV positive women, following a recent Chicago HIV Services Planning meeting. Day and night, good health or bad, Sylvia's always there for her clients. She's a dynamo, a powerhouse, and sometimes a holy terror. In every sense of the word, Sylvia's a patient advocate. I managed to get Sylvia to sit still for a bit just as she was preparing to visit with her parents in Puerto Rico—with her new husband Arthur—for a well deserved rest.

ON TREATMENT ACTIVISM:

"I'm an activist," Sylvia proudly proclaims. "I love putting my foot up somebody's ass for someone else." When she's not busy with her full-time responsibilities as a program and support group coordinator with TPAN, Sylvia serves as a member of the HIV Positive Action Coalition (HIV-PAC) and on the HIV Services Planning Council. "This is HIV positive people working for other HIV people, representing and advocating for them."

"Sometimes I don't think I make sense. I don't think that people understand, because I get so frustrated, I just want to get it all out." Not one to bite her tongue, she maintains, "I'm not afraid to ask questions until I fully understand what the situation is. Wait a minute. Stop. I don't understand." Because of her sheer forcefulness, sometimes people get the wrong impression of Sylvia. "I think people hate me and people love me. I see it. The clients and people I work closely with appreciate the advocacy work I do. I just do what I love doing. Helping."

ON HIV STIGMA:

Her advocacy work began in 1991. "I was really a big mouth, with picket signs and everything." However, she pulled back from HIV/AIDS activity in part because of the stigma attached to HIV and the toll it took on her previous marriage. "I was married to a man who didn't want everyone to know I was HIV positive. And he didn't want people to assume he was positive, because he wasn't," she states. "He was in the penitentiary...and in the penitentiary if you're HIV they outcast you. He didn't want to have to go through that. But when that marriage dissolved, I was back full force, doing what I like to do."

ON MISEDUCATION AND CULTURAL BARRIERS TO UNDERSTANDING HIV:

HIV became a permanent fixture in Sylvia's life around the end of 1983. Her first husband had been sick on and off for months. "I got tired and frustrated with him going in and out... and there was never a diagnosis. Well, it wasn't that there wasn't a diagnosis, it was the fact that he wasn't telling me. He had full blown AIDS."

She continues, "It wasn't that he didn't tell me. But I don't think he understood the doctors, because he spoke Spanish." Sylvia and her husband both understood English at the time, but didn't understand the seriousness of his illness.

"I had just had [my last child]," she explains, and her husband told her he had cancer. "Well, he did have cancer," she remembers. "He had *Kaposi* sarcoma." The doctor eventually pulled Sylvia to the side and advised her that her husband had Acquired Immune Deficiency Syndrome.

But for a young Latina, who at the time read at a third grade level, the explanation was meaningless. Sylvia adds, "She told me that gay men and intravenous drug users get it [AIDS]. And your husband is both... bisexual and an IV-drug user."

"I couldn't understand [when] she told me that I needed to get tested. I said, 'Why? I'm not gay. I don't use drugs.' I didn't understand how me having sex with my husband would make me ill, when he was the one shooting up drugs and was bisexual."

The ability to read is often taken for granted in HIV prevention campaigns, but Sylvia was basically illiterate until the age of 27. "Reading is still tough for me," she adds.

ON HER EXPERIENCE WITH TESTING FOR HIV:

"I was sitting down in the [city clinic]. I don't know if he was a nurse, counselor or a doctor. I don't know what the hell he was. He never introduced himself."

What she remembers distinctly were those three little words: "You have AIDS." She continues, "Wow, I got AIDS and my husband has this big thing—Acquired Immune Deficiency Syndrome." Sylvia still hadn't made the connection between AIDS and Acquired Immune Deficiency Syndrome. Sylvia (and I) can chuckle about it today, but it wasn't funny to her some 16 years ago.

In a very serious tone she tells me the counselor said, "You're gonna die. Do you know that?" And near tears, Sylvia adds, "I nodded my head. I never opened my mouth to say a word. Then he asked if I had any questions. What the hell kind of questions was I going to ask? You'll telling me I'm gonna die. I don't know what the hell is going on. All I'm thinking about is my babies...in an orphanage. Then he said, 'Have a good day.' That was it."

"I got up, walked out the room, and closed the door behind me. My whole world collapsed."

ON THE ROAD TO SELF-EMPOWERMENT:

Like many newly diagnosed individuals, Sylvia's path to self-empowerment was frightening, frustrating, and not without detours. First, she had to deal with having her infant tested for HIV. "I didn't want to hear that. But we did test him, and they told me he was positive." Once that bomb was dropped, Sylvia withdrew from all medical advice. As she explains, "I didn't need to go

to the doctor anymore. I was gonna go home and take care of my baby.”

When her child entered school, his condition was reported to his teacher, who told the principal, who informed the school nurse. The next thing Sylvia knew, a freaked out nurse was at her door. “She was telling me that [my child] chews on his pencil and there’s saliva all over the place. And I looked at her and my daughter. It was like, ‘What is her problem?’ We already knew we couldn’t get it [HIV] from saliva. We had some clue.”

Sylvia finally found a doctor she felt comfortable with, and told him she had AIDS.

ON SUPPORT NETWORKS:

“My kids gave me support, since they were little. Always. They said go mom. They were the only ones who could have stopped me from doing what I do. From that point on I became a sponge—observing and learning.” Sylvia has a solid support network – her children, her husband, her family, and her sister, Enid Vázquez.

Sylvia maintains that she’s “still learning a lot,” and sometimes she gets scared. “A lot of things change [in regards to therapy], but a lot of things haven’t [in taking care of yourself].”

African-American or Caucasian...it’s the same. Prevention and treatment messages go in one ear and out the other. Educating women is my primary concern.”

“Women have a lot of strength, but don’t get recognized for that...holding down a home, working and raising kids. We don’t even get credit for that. I have to pay rent, clothe the kids and put food on the table. Because we don’t take credit, because society doesn’t really value the work of women, we don’t see the value in it. I tell women, ‘take care of yourself, stay strong, and speak up.’”

Women have a lot of strength, but don't get recognized for that because society doesn't really value the work of women, we don't see the value in it.



This doctor helped her to understand how HIV was transmitted, but more importantly how to take care of herself and her children.

With great hesitation, Sylvia took her son back to the hospital for additional tests. “I didn’t want to hear what I was going to hear again. So when we got his results and they told me he was negative, I said, ‘No, no, no. You’ve got the wrong paper.’”

“That’s when they explained to me about how a child is born with the mother’s anti-bodies and then he builds his own immune system. And that’s when I grew furious. And that’s when I started to learn about this disease. And that’s when I sat my kids down and said, ‘I’ll be damned. I’m gonna teach these people about this disease.’ I told them that I was going to start talking about this disease and kids weren’t going to want to play with them because their parents are gonna to say, ‘No, they’re the family with AIDS.’”

“Usually clients come to me with concerns about a bad interaction with someone. Or they tell me something that was told to them, which was totally inaccurate. What I say is that you have to ask questions. The only dumb question is the one you don’t ask. If you feel that what someone is telling you is not right... then ask someone else. You have to take care of yourself.”

ON WOMEN AND HIV TREATMENT:

“Women in particular... are raised to believe that the husband and children come first. My generation and before, the husband handles everything, the wife takes care of the kids. Everything comes before the woman’s health. Doesn’t matter if you’re Asian,

ON INNER PEACE:

“I want people to see that I’m doing this because... I found God from within. It’s really difficult to describe everything that has happened to me, everything I’ve been through... people think I’m crazy. But when I learned to love Sylvia unconditionally, and learned to accept myself as I am... I was able to give to others and love people for who they are. Women need to remember to concentrate on themselves, but that’s difficult thing for a woman to do when she has other responsibilities. But we’re fighters. We’re survivors.” Indeed. ☩

One
Of
One

Leatrice Simpson

by Enid Vázquez

Despite many frustrations, Lea's been successfully able to both prevent cervical cancer from developing, and to treat it when it did.

That takes regular check-ups and follow-up on abnormalities. Lea's great about getting good health care.

Her Pap smear abnormalities began when she was a teenager, long before she had HIV, and she had them taken care of every time. Abnormalities are not so strange, since human papilloma virus (HPV), which can lead to cancer of the cervix, is a very common infection in women.

But if left untreated, abnormal cervical cells—no matter what causes them—may become cancerous. A Pap smear looks for abnormalities in the cervix, the lower part of the uterus that leads into the vagina. Every woman over the age of 18 should have one done every year. Thanks to Pap smears, cervical cancer has decreased by 70% over the past several decades.

For women with HIV, all the problems seen with the cervix are more complicated than in HIV negative women. Positive women are much more likely to have abnormal cell growth and other conditions,

shape of a cone). Then a year later she had a LEEP, another cutting off process (see "Treatments"). A year later, again abnormal tissue. This time she had a hysterectomy (removal of the uterus). Ironically for Lea, who has a T-cell count of 860 and undetectable viral load, the incidence of serious problems has been shown to increase when a woman has less than 200 T-cells, as you would expect. Obviously there's still a risk with good numbers, as with all negative women.

But now abnormal cells are back. At this point, her treatment is that old standby, "close monitoring." Her doctor has upped Lea's Pap smears from once every six months to every three months. Her option now is 5-FU, which she was told is "a messy, burning cream" that takes off the abnormal cells. But it's painful, and she would need a prescription for a painkiller. Or she would need more surgery.

If there are any suspicions whatsoever, go to the doctor. And don't be afraid to ask questions.

including serious abnormalities. They're also much more likely to be infected with HPV.

As a result of her exams, Lea's had eight surgeries, four of those before she was positive. Most of these treatments can be performed on an outpatient basis (no hospitalization). Thanks to her regular exams and follow-up, she remains cancer-free. And because HIV medicines are shown to reverse certain conditions that can lead to cancer, her drug combination may be helping to keep cancer away.

For now, the only treatment gynecologists have for preventing cervical cancer is to freeze, burn off, or just plain cut out abnormal cells.

Lea started out with cryotherapy (or freezing, a process that's no longer recommended for positive women) at age 18. Later she had laser surgery (destroying abnormal tissue by zapping it with a laser). Then she had a cone biopsy, a surgical procedure in which part of the cervix is cut off (in the

Lea advises women to continue monitoring for problems. "Be prayerful," is her first advice. Then, "If there are any suspicions whatsoever, go to the doctor. And don't be afraid to ask questions. And last, don't be afraid to have the doctor examine you. Women get so sick of these gyne exams. But there's that good catch phrase doctors use, 'At least we caught it in time and we can do something about it.' That's always good to hear."

Dr. Mardge H. Cohen, director of the Women's Intragency HIV Study in Chicago, agrees. "The point is that careful monitoring is important. Low-grade lesions need attention. Most people with high T-cells and undetectable viral load do like everybody else who are uninfected and do better. HPV is common, more so in HIV infected women. They need to be encouraged to connect with their health care provider so that we can give appropriate treatment. There are no progressions to cancer, if appropriate therapy is instituted." ☒



Pap smears for survivors of sexual abuse

by Pamela Dole, M.D.

The following article, with minor changes, is taken from the June 1999 HEPP News, a newsletter of the HIV Education Prison Project (www.hivcorrections.org). While references to prison remain, most of the points made in the article remain applicable to all women.

It is important to provide

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Pamela Dole has worked in corrections in both New York State at Bayview and works with nurse practitioner students at York Prison in Mystic, Connecticut. She realized some of her patients had difficulty keeping or completing appointments due to fear and anxiety from past or recent experiences of sexual victimization. The correctional setting, according to Dole, poses an especially difficult problem for victimized women because it increases their feelings of invaded privacy and loss of control.

Dr. Dole is participating in a landmark forensic project (the medical examination of death and injury when the cause is not known, especially when criminal activity is suspected) to decrease violence against women by educating nurses in Kimberly, South Africa. She feels further research is necessary to fully comprehend the impact of interpersonal violence on health seeking behaviors. Dole believes the key to caring for traumatized women is making the gynecologic exam a process in which the woman herself can work with the medical providers. "It can't be something done to them... it comes down to working from our hearts or places of compassion." Following is Dr. Dole's article for *HEPP News*.

As many as 60% of incarcerated women have histories of sexual abuse. It is therefore important to keep these histories in mind when approaching the examination of women in prison. Some of the issues that interfere with medical care, as reported by sexually abused women, include trust, authority, control, disclosure and not wishing to have her body touched during examinations. [In a different issue of *HEPP News*, the editors explain "control" as "wishing to control the time and place of the gyne exam," adding that, "Insensitive gynecological providers can become a major barrier to obtaining the routine gynecological screening that is so critically important for this high-risk population."] Given these themes, incarcerated women pose unique challenges to health care providers, who should not miss this opportunity for education, healing and health care in sensitive ways.

The first step in caring for sexually traumatized incarcerated women is to get them to keep gynecology appointments. A patient's desire to remain in control and her fear of the examination will often lead her to refuse care. As a result, refusals of gynecological care need to be brought to the attention of the medical director or nurse manager, as persistent refusals can lead to progression of underlying disease. Refusals may be viewed as an invitation

Avoid revictimizing

the patient

by a rough and

insensitive exam.

for education, which is the first step in creating a caring and trustful relationship with the patient.

If she will remain within the facility for several weeks before being reassigned, the provider should begin with an interview only and reschedule the examination. This approach can be extremely beneficial in increasing trust and adherence over time [the patient's ability to follow through with her medical care]. Patients will feel respected for their feelings while becoming acquainted with the provider in a non-threatening situation.

The initial interview and history should include a routine OB/GYN history (child-bearing and sexual organs) as well as information about incest and childhood molestation, sexual assaults and domestic violence issues. Often women have never been questioned regarding sexual abuse and may initially deny these experiences. However, questioning may cause them to experience flash-

backs after a woman has left the clinic. Asking questions about sexual abuse during a second visit often produces an emotional release from years of shame and secrecy, allowing the patient to make her first disclosure of sexual victimization. It is important to provide reassurance that anxiety about gyne exams and the embarrassment surrounding the secrets of their childhood or adult sexual abuse are common feelings. Whenever possible the health care provider should avoid doing a gyne exam when a patient is suffering emotional stress and instead empower her to choose a time when she is ready to participate in the gynecological examination. This provides the possibility for increased communication and trust while helping the patient to begin the healing process.

Some women may not be ready to disclose their "secrets." Telltale signs and symptoms may provide clues to the provider. Some of these may include histories of the

Pap Smear Primer

by Enid Vázquez

RECOMMENDATIONS FOR POSITIVE WOMEN

HIV positive women often need more frequent Pap smears. Remember not to douche (douching is not good for any woman, anyway, see "Douching is Bad For You," September/October 2000), use a tampon or have intercourse for 48 hours before an exam. Also, the test cannot be done during your menstrual period. A Pap smear should be done at the time of HIV diagnosis and then again in another six months, and if still normal, annually thereafter. Some women will also be offered anal Pap smears because of an increased incidence of rectal HPV (a long cotton swab is used, not a speculum!). An adequate exam will include an interview with questions about your medical history, including any childhood sexual abuse or sex work, and other questions that seem nosy, but are only asked because these situations are associated with some physical problems and behaviors that health care providers should be paying attention to.

Health care providers conducting a Pap smear should know that a curved brush obtains seven times more samples than a spatula; contamination of the sample with lubricant should be avoided; the Pap is to be collected before a physical examination or samples for STD testing; an ectocervical sample should be obtained before an endocervical sample; clumping or air-drying of the sample should be avoided; and if using spray fixative, the spray should be held at least 10 inches away to prevent disruption of cells by propellant. (See reference listed in the box below.) Nurse practitioner and advocate for positive women Risa Deneberg recommends that health care workers be prepared to address fears women have about disease and provide reassurance. In particular, they should realize that women often take findings of abnormalities to be a diagnosis of cancer. They should discuss potential treatments *before* results are known, especially if the woman will be referred somewhere else.

following, in the absence of disease: chronic pelvic pain (stomach and genital area); dysmenorrhea (painful menstruation); menorrhagia (abnormally heavy menstrual bleeding) or gastrointestinal illness. Other signs include eating problems, substance abuse, failure to maintain good women's health care screening (making sure everything is okay), and anxiety disorders (which can include panic attacks—feeling overwhelmingly frightened, such as the feeling that you're going to die although nothing is threatening you). During an examination the provider may observe the following: the patient taking a long time to take off her clothes, statements like “how long will this take?” or “I hate these exams,” twitchy toes during the examination, pulling back while the speculum is being inserted, arching of the back, and disassociation from the exam itself (separating herself, as if she wasn't there). Should these signs occur, the provider may want to stop the exam, allow the patient to sit up and

cover herself, and then ask whether she would be more comfortable talking about her discomfort with the exam and reschedule the exam for another day.

At the time of the second exam, it is often helpful to have the patient sit on the table in her hospital gown, ready for the exam, and discuss how she is feeling. At this point it is also beneficial to let the patient decide whether or not to continue with the exam. Rarely does it take more than three visits to complete the exam.

Once a patient has chosen to have the gynecological exam completed, it is important to help her in remaining relaxed and to prevent disassociation. The most common mistake clinicians make is to tell the patient to relax instead of providing her with specific ways to do so. One method is to ask the patient to count her breaths. The provider can also ask the patient to tell a story, or to blow bubbles, which help her to breathe. Laughing together is a marvelous way to

reduce stress. Other techniques may include guided imagery (talk her through a series of images, such as being in a forest with the sounds of birds chirping, the feeling of thick leaves underfoot, etc.), centering and the use of classical music (avoid music with words).

It is important to avoid revictimizing the patient by a rough and insensitive exam, during a gynecologic exam especially, when women feel vulnerable and embarrassed. Slow, gentle and supportive pelvic exams are essential. The patient may wish to be examined by a female health care provider. Women who develop a rapport (feeling comfortable and able to talk) with their health care provider are more likely to participate in their own health care, which reduces disease and long-term costs. ☛

Notes: References listed in the original. To find a sensitive gynecologist, Planned Parenthood clinics are probably the best place to start.

RISK FACTORS

Risk factors for pre-cancerous and cancerous changes in the cervix include smoking. For positive women, having less than 200 T-cells seems to increase risk. One of the most common risk factors, for both positive and negative women, is human papilloma virus (HPV), a very common sexually transmitted infection. HPV also causes genital warts. For more information, visit www.cervicalhealth.org, www.ashastd.org and www.niaid.nih.gov.

PAP SMEAR RESULTS

- Normal
- ASCUS (atypical cells of undetermined significance—it's not known if it's normal or not; usually normal in HIV negative women, but should be followed up with a colposcopy for positive women)
- SIL (squamous intraepithelial lesion), also called dysplasia (abnormal cell tissue); an older term was CIN (for cervical intraepithelial neoplasia)
 - Low-grade SIL (LSIL), or mild dysplasia
 - High-grade SIL (HSIL), or moderate and severe dysplasia; also includes carcinoma *in situ*, cancer that hasn't spread and can just be taken out
- Invasive cancer
- “squamous” refers to the thin flat cells of the cervix, “intraepithelial” refers to cells that lie on the surface of tissue

Women's News

by Enid Vázquez

Following are summaries of some of the research findings on HIV positive women over the last few years from WIHS (Women's Interagency HIV Study). This study was started in 1994 and follows women with HIV and women at high risk of HIV every six months. See other stories in this section for definitions of words in *italic* letters.

CERVIX WOES

There is conflicting data about the relationship between vitamin A deficiency and *cervical cancer*. A look at HIV positive women found that vitamin A deficiency was associated with abnormal *Pap smears* (the first step towards cervical cancer). It didn't matter if the women had low T-cells or *HPV* (human papilloma virus), both of which are more likely to be present in positive women with abnormal Pap smears. The vitamin deficiency by itself was an independent risk factor. It was also related to injection drug use and low income. (1999)

"Even in the face of HIV infection, relatively immunocompetent women can eliminate *squamous cervical lesions*," researchers reported. The likelihood of abnormal cytology [cell findings] among women with HIV was high. Two out of three positive women had abnormal test results, compared to one out of three negative women. However, the so-called "cumulative risk" (over time) of *HSIL* (*high-grade squamous intraepithelial lesions*) and cancer was not high. (2000)

Comparing a group of 2,000 positive women with 500 HIV negative women, researchers found that 38% of the positive women showed abnormalities in their Pap smear vs. 16% of negative women. Positive women were also twice as likely to have high-grade (significant) abnormalities (2.3% vs. 1.3%). The researchers reported that while infection with HPV most predicts Pap smear abnormalities, other predictors included low T-cells, younger age (under 30), and ever having had tuberculosis. (1997)

In a different report, the same group of researchers noted that positive women were twice as likely to have HPV (58% vs. 27% of the negative women). Since then, four HPV types have been most strongly associated with leading to cervical cancer. One group of

positive women were twice as likely to have HPV (58% vs. 27% of the negative women)

researchers found that women with HIV and HPV who developed abnormal cervical cells had equal numbers of low-risk and high-risk HPV types. In contrast, 80% of the negative women with cervical abnormalities had the high-risk strains. Therefore, even the "innocent" strains of HPV can cause problems for positive women. (1997)

But there is really good news for women in the HAART era! For women with Pap smear abnormalities, those who began on highly active antiretroviral therapy (generally a triple combination of HIV drugs) were less likely to continue having abnormalities. They were also less likely to have HPV even if they had it before going on medication, no matter what their viral load or T-cell count. "[HAART] appears to have a beneficial effect on coincident HPV infection and disease," researchers concluded. (2001)

"Preliminary evidence suggests that immune reconstitution following HAART impacts HPV-associated disease," researchers noted. They found that women on HAART were more likely to have a lack of progression in abnormal cervical cells. They even had regression of disease. (2000) HAART use significantly reversed cervical abnormalities to normal or to less severe. (2001)

Pap smears alone missed precancerous changes in a third of positive women tested. Even using a higher level of examination, a *colposcopy*, still missed precancerous abnormalities in a third of positive women. Comparing these women's findings of abnormalities further with a biopsy, in which a piece of cervical tissue is taken off and examined, is what identified the seriousness of their condition. "Liberal use of biopsy is essential for proper management of women with abnormal smears," researchers reported. (See also "Controversies," page 30.)

DEATHS

The Centers for Disease Control and Prevention (CDC) and WIHS both reported findings that active drug users who were HIV positive had a substantial rate of death from non-HIV causes. The CDC in 2000 reported that in one group, many of the women were not using strong combination HIV drugs available to them. Only one out of four of the women with less than 200 T-cells were on HAART. In this group, a third of the deaths not related to HIV resulted from illicit drug use, and the CDC cited the need for hepatitis vaccinations and better drug treatment options.

WIHS reported similar findings in 1999. "A substantial minority" (one out of five of the deaths with known cause) were due to non-AIDS related deaths. These included deaths from liver failure, murder, suicide, and overdose on illicit drugs. "While the number of deaths from AIDS has significantly decreased, the number of deaths from non-AIDS causes has remained constant, and in the HAART period make up a higher proportion of deaths among women with HIV. These causes of death need to be addressed if we are to continue to reduce mortality," WIHS concluded.

THRUSH

Researchers looked at the effectiveness of weekly intravaginal application of

Lactobacillus acidophilus gelatin capsules or clotrimazole 100 mg tablets. There was a significantly longer time to the first episode of vaginal thrush with clotrimazole, but not with the acidophilus. Still, they reported that, “Both interventions reduced the number of episodes by half. Vaginal yeast infections can be prevented with local therapy and prophylaxis [prevention] should be offered to HIV infected women as part of routine primary care.” Elsewhere, a gynecologist, and HIV specialist, reported that in her clinical experience, she had found that boric acid suppositories prepared by pharmacists had cleared some yeast infections. (2000)

PERIOD WOES

WIHS and other investigators reported on menstrual abnormalities in women with HIV compared to those without HIV. After adjustment for demographic differences (age, ethnicity, etc.), body mass index and substance abuse, it was found that being HIV positive increased the odds of having both a very short menstrual cycle and a very long menstrual cycle. Being HIV positive did not increase the odds of having a moderately long cycle, or affect average cycle length and variability. Although HIV may slightly increase the possibility of very short cycles, HIV serostatus has very little effect on amenorrhea (the absence or stopping of menstruation), menstrual length or variability. Among HIV positive women, higher viral loads and lower CD4 T-cell counts were associated with increased cycle variability. (2000)

LUNG WOES

Researchers found twice the rate of lung infection in positive women as in high-risk negative women. Eighty-five percent of all the women smoked cigarettes and 50% used injection drugs. (2000)

ANEMIA

WIHS reported that women who used HAART for at least 18 months had a reduced risk of developing anemia. There was also resolution of anemia for those who had it before starting meds and increased their T-

“Anemia is an independent risk factor for decreased survival in HIV positive women.”

cells or those who used HAART for more than 18 months. However, women who continued to use Retrovir (AZT), which can cause anemia, did not see an improvement.

The researchers noted that, “Anemia is an independent risk factor for decreased survival in HIV positive women.” It is common in positive women, more so with higher viral load levels (HIV in the blood), lower T-cells, clinical AIDS, Retrovir use, low mean corpuscular volume (MCV, the size of their red blood cells), and African American ethnicity. (2000)

HAPPINESS

“Feeling bad lately”? You might if you believe that, “There is nothing you can do [about getting sick] if you don’t have good health care.” On the other hand, those women who believed “a person can have HIV but never get sick” reported having more “excellent health” and “feeling happy.”

Women who said their health wasn’t so good were more likely to agree with the statement, “It is not worth following a difficult health plan/regimen.” The women who

Severe inflammation

Evaluate for infection; repeat Pap preferably within 2–3 months.

Atypical (not typical) or ASCUS

Follow-up Pap without colposcopy (may even do colposcopy with one Pap with ASCUS); repeat every 4–6 months for 2 years until three exams are negative; if two ASCUS findings in a row, do a colposcopy.

LSIL

Colposcopy with or without a biopsy.

HSIL and carcinoma *in situ*

Colposcopy with biopsy.

Invasive carcinoma (cancer)

Colposcopy with biopsy if there is a lesion, or conization; treat as appropriate with surgery or radiation.

Taken from the 2000–2001 Medical Management of HIV Infection by Drs. John G. Bartlett and Joel E. Gallant. The authors also note, “Newer methods of cytologic evaluation [looking at cells] using liquid-based collection and thin-layer processing may enhance sensitivity but have not yet been evaluated in HIV infected women.”

disagreed were more likely to say that they *did* enjoy good health. (1999)

DEPRESSION

Depression leads to lower T-cells and greater risk of death in positive women. The findings add to knowledge that depression is a risk factor for death for positive people, male and female. (2001)

TRANSMISSION

The presence of STDs (sexually transmitted disease) is known to increase the risk of becoming infected with HIV. A study with Kenya women found that the presence of vaginal trush and trichomonis lead to greater shedding of HIV in their vaginal secretions, which may increase the risk of transmission to their partner. (2001)

Another, very tiny, study found that cervical inflammation and genital ulcers also increased HIV shedding. (2001)

DIABETES

Although new cases of diabetes were rare, they happened twice as often in women using a protease inhibitor (3% vs. 1.3%). Even improvements in viral load did not help this trend. Nevertheless, these was an even greater risk of developing diabetes for those women on a protease inhibitor whose viral load did not decrease. (1999)

BREAST CANCER

Researchers reported unusual cases of breast cancer seen in positive women, at an early age. The report needs follow-up

research to determine how significant this finding may be. (1997)

CHILDHOOD ABUSE AND DOMESTIC VIOLENCE

A WIHS study of more than 2,000 positive women and 500 negative women found that two-thirds of the women had a history of domestic abuse, including physical, emotional or sexual abuse. The study also noted that, "A history of childhood abuse may identify women at increased risk for sexual and physical victimization as adults. Further, childhood abuse is related to increased participation in behaviors identified as high risk for HIV infection." (1997) ☒

Taken primarily from the WIHS website. Visit www.statepi.jhsph.edu/wihs/index.html.

TREATMENTS

These treatments require local anesthesia and can be done as an outpatient procedure (except the hysterectomy). Choice of treatment depends on the location and size of the abnormal cervical tissue and the extent of the disease being treated, among other factors.

Chemical treatments: use of trichloroacetic acid (TCA); Podophyllin; Podofilox; 5-fluorouracil cream (5-FU); interferon alpha; and Aldara (imiquimod). These treatments are toxic.

Colposcopy: Examining tissue with a tiny microscope.

Biopsy: Taking a tissue sample. Can cause some bleeding, cramping and, rarely, infection.

Cone biopsy (also called conization): Cutting off a section of precancerous or cancerous tissue, done in the shape of a cone. General anesthesia may be used. In addition to being a treatment, this procedure can also show whether cancer has become invasive. This procedure can be done with a knife or with an electrical loop (see LEEP).

LEEP (Loop Electrical Excision Procedure): a biopsy done with an electric wire loop to slice off a thin, round piece of tissue; can also use LEEP to perform a conization.

D and C (dilation and curettage): Stretching the cervical opening and using a curette (a small, spoon-shaped tool) to collect tissue samples from the uterus. General anesthesia may be used.

Cryotherapy (freezing): destroys tissue, including warts, with an instrument called a cryophobe, the tip of which has been cooled by carbon dioxide or nitrous oxide gas. No longer recommended for HIV positive women.

Cauterization (burning, also called diathermy): destroys tissue, including warts, by using a heated instrument, an electric current, or a caustic substance.

Laser surgery: cutting with a very thin beam of light.

Hysterectomy: removal of the uterus, with or without the ovaries. Causes periods to stop.

CONTROVERSIES

Doctors swear by the Pap smear as the best method of detecting cancer early. Just get one on schedule like you're supposed to. But problems with the test have made media horror stories, showing women dying unnecessarily from cancer that wasn't found early. Problems include negligent labs that try to read too many smears a day and therefore whiz by dangerous cells. Now there are new methods that can improve on the Pap smear. But, of course, doctors are showing their conservative stripes with the old "it isn't proven" line. The HIV docs, in turn, are saying, "it isn't proven to help women with HIV."

A Pap with speculoscopy is a standard Pap smear followed by a vinegar wash. Then a chemical light on a microscope is used to look for abnormal cells. It's not much more expensive than the Pap, but the difference is not paid by insurance. It is available at many Planned Parenthood clinics. It's as sensitive (as good at catching abnormalities) as a colposcopy with biopsy. That's an improvement over the standard Pap, but abnormal findings from a speculoscopy will still need to be followed up by a colposcopy with biopsy for confirmation. There's also a different type of Pap smear, in which the handling of the cells differs. Instead of being smeared right onto a slide, the cells are first put into a tube with liquid that helps sort out mucus and other contaminants, and avoids clumping. The sample is then put on a slide as usual. These Pap tests are called "ThinPrep." It allows for HPV testing, as well, to see if you have strains that are highly associated with cancer. There are also computerized readings of slides that may pick up abnormalities not seen by cytologists (the people reading the slides). The ThinPrep people say a computer program can't pick up abnormalities that aren't there because of a bad sample collection. The speculoscopy people say a sample collection can't pick up the abnormalities that haven't shed, but which the speculoscopy light can see.

Special thanks to Dr. Mardge H. Cohen, director of the Women's Intragency HIV Study in Chicago, for reviewing pages 24-30.

NUTRITION IN THE HIV POSITIVE WOMAN

By Tami Jones Mackle, RD

Proper nutrition plays an important role in overall health care. For the HIV-infected woman, adequate nutrition is critical, and efforts must be made to optimize nutritional status. Since women in today's society are pulled in so many different directions by taking on many roles, playing homemaker, mother, caregiver, wife, and career women all in the same day, often we neglect ourselves. Part of that neglect may be in our diet habits. Reasons such as too busy, too tired, and forgetting to eat are some of the more common phrases used to explain why proper diet is often lost during the day.

Eventually something serious occurs, most obviously presented by unexplained weight loss. This is a visible indication of what has already been a progression of body changes from HIV disease itself.

HIV-infected women are all at risk for poor nutrition status. Women who play "superwoman" and do not take care of their health may be at increased risk for compromised nutritional status. Unfortunately, unless there has been some significant weight loss, we may not know what's going on inside the body. It is not until this time that a woman thinks about her diet and food intake.

Unintentional weight loss is called wasting. In the context of HIV disease, it can be considered AIDS-related wasting. The cause of wasting can be complex and varied. Researchers believe that aside from the changes in food intake, absorption, and metabolism all playing a role in wasting, hormonal changes may also contribute to the difference in body wasting in women.

Wasting in a woman appears different than in a man. Women tend to lose fat tissue, whereas men appear to lose lean tissue quicker. It is important not only to monitor



weight and to measure what the body is made of, or your body composition (body fat, body cell mass), but we must preserve body cell mass, and preserve a certain amount of fat to

live and function. Be sure to ask your registered dietitian to test and monitor your body composition. Although some women initially may be somewhat excited about some weight loss, it is not something to be taken lightly. Weight loss may indicate an infection or other problem, and can become life threatening.

What can we do to help prevent wasting? Aside from visiting your doctor regularly, nutritionally you can do a number of things. First, you can eat a variety of foods. Use the food guide pyramid to make sure you are getting enough vitamins and minerals, calories, and protein daily, which recommends the following:

- Breads and cereal group: 6 to 11 servings
- Meat, poultry, fish, egg, or alternative: 2 to 3 servings
- Fruits and vegetables: 3 to 5 servings each
- Milk/Dairy: 2 to 4 servings
- Fats, sweets, and oils: sparingly

If you need to gain weight, or to keep from losing weight, eat the higher number of servings for extra calories.



Because women are more susceptible to osteoporosis, it is essential we get enough calcium. Calcium is a mineral responsible for bone health. Lack of adequate calcium can lead to loss of bone mass and tissue. Calcium is found in dairy foods, and can also be found in calcium-enriched juices and cereals, sardine (with bones), salmon (with bones), collard greens, broc-

coli, and turnip greens. Women need 1000 mg daily of calcium, 1200 mg for pregnant women and the elderly (51+years). This is equal to 3 cups of milk or calcium-fortified orange juice.

When cooking, preparing, and/or handling foods, your primary goal should be to avoid food infection. It is critical that hands are washed with hot soapy water before and after handling any type of food, whether you are cooking or eating. Keep foods at a safe temperature—cold foods should be cold, and hot foods hot. Food left at a temperature between 40–140 degrees F are in the "danger zone," where bacteria may grow. Heat leftovers to at least 140 degrees F. Check food labels—do not use packaged food past the recommended date on the label. Finally, avoid eating raw foods, including eggs, fish, and meats. Check to be sure milk products and juices are pasteurized because not all milk and juice is. If the item has not gone through the pasteurization process it may contain harmful bacteria. Food safety is especially important in the immune compromised patient, as it can be hard to fight infection. Symptoms of food borne illness can include nausea, vomiting, fever, diarrhea and dehydration, and can lead to hospitalization.



Women must learn to make their own mental and physical health a priority. Without good health, we are putting family, job/financial security, and ourselves on the line. Kids want and need healthy moms, and co-workers need healthy colleagues. Proper nutrition is one way to help obtain and keep good health. It is a crucial part of the overall healthcare of the HIV-infected person, and should be taken seriously. ☒

Tami Jones Mackle, RD is a Registered Dietitian, and works in the Infectious Disease Clinic at the University of Medicine and Dentistry in Newark, NJ.

Research Rights and Responsibilities

by Jeffrey Zurlinden, RN, MS, ACRN

Research entices people infected with HIV by offering potentially safer and better medications. But before you jump to join a new study, know your ethical rights to say “Yes” and “No.” And remember that joining makes you responsible for keeping up your end of the bargain by being honest.

YOUR RIGHT TO SAY “YES!”

Always know your research opportunities, and if you find a study that may help you, push to learn about it in detail. You have an ethical right to volunteer to join a research study. You should not be prevented from joining for reasons that have nothing to do with the study. In the past, women, injection-drug users, foreign-language speakers, and even people without phone numbers have been summarily excluded from medical research.

Before you sign the consent, you are entitled to a full explanation in words you understand. Ask questions. For example, if the researcher claims that your identity will be protected, ask how. If the explanation sounds fishy, then walk away.

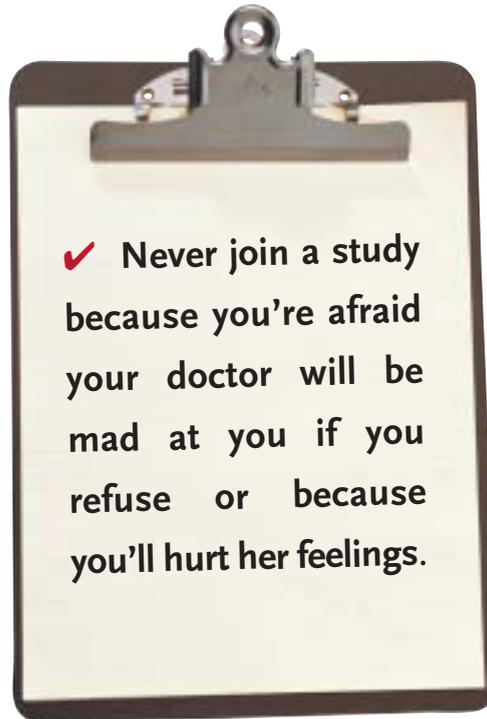
Fully understand exactly what’s expected of you. Be honest about your ability and willingness to do what you’re told. Most details of the study are set in stone and can’t be changed, while certain technicalities can flex. For example, you might be required to have your blood drawn every three weeks, a difficult schedule to fit into your work routine. The number of blood draws can’t change, but ask if you can schedule your appointments in the evenings, early in the mornings, or on Saturdays.

Ask about expenses. Who pays for lab work, doctor visits, and medications?

After the study ends, assuming the drug works, how long will the new medication be provided free?

Beware of false claims. These are research drugs because no one knows whether they’ll work, or what all the side effects might be. Some of the side effects are known from earlier small studies, but no one can predict whether the drug will make you personally feel better or live longer.

Avoid high-pressure sales tactics. This is a big decision, in some cases, a life-or-death decision. You’re entitled to think it over before signing up. Each year there are more and better drugs to test. Joining one study may prevent you from joining others. Ask how your participation in the current study will influence your participation in future studies.



YOUR RIGHT TO SAY “NO!”

You can’t be forced to join a study, or receive fewer services because you refused to join. Never join a study because you’re afraid your doctor will be mad at you if you refuse or because you’ll hurt her feelings.

You always have the right to drop out at any time, for any reason—in fact, you don’t even have to give a reason—and to refuse further contact with the researcher. But after you leave, you can’t make your past participation disappear. The study sponsor, as well as certain government agencies and hospital committees, continue to have access to the information you already provided and your medical record.

Remember that HIV medication is very big business. In 1999, Glaxo Wellcome sold

about \$500 million worth of Combivir, Agouron sold almost the same amount of Viracept, and Bristol-Meyer sold a little over \$300 million of Zerit.* Other companies sold additional millions of dollars of drugs to people infected with HIV. Most of the money was well spent, but the next blockbuster drug will make millionaires, as well as healthier people.

The New England Journal of Medicine recently criticized all medical experiments, not just HIV studies, because too many researchers are too cozy with drug companies. The prestigious journal condemned the practice of doctors owning stock or holding decision-making positions in the drug companies whose products they test. Some doctors steer patients to join the study with the biggest jackpot for the doctor, not the patient.

YOUR RESPONSIBILITY TO BE HONEST

Always tell the truth—not just what you think the doctor or nurse will want to hear. The information you give could decide whether a drug is eventually used by millions of people.

Always stay in touch and keep your appointments. The proof of a drug’s safety and effectiveness may hinge on only a handful of people who have the same dangerous side effect or the same healthy response.

Remember, no one cares more about you, than you do. If the study drug does more harm than good, your doctor may have regrets, the drug company may be disappointed, and the hospital or the government may have to stop the study. But you’re the only one who gets hurt.

HIV research offers tremendous opportunities, but only if you ask questions, do what’s required, and take a selfish interest in your own health and happiness. ☒

*Latner, A. The Top 200 Drugs of 1999. *Pharmacy Times*. (2000 April). pgs. 16-32.

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The Ups and Downs of Drug Levels

By Bob Munk

Antiviral medications have a much harder time getting to work than you do. Sure, you have to deal with buses or subways, or traffic on your commute. But take a look at what your meds have to deal with! First they get swallowed and dumped into a pool of acid in your stomach. They get absorbed, mostly in the small intestine. From there, they go to the liver, which breaks down (metabolizes) and removes foreign substances from your blood. This process is called “first-pass metabolism.” Some drugs make it through the liver untouched, but only a tiny fraction of other drugs get past this hurdle and into the bloodstream.

The amount of drug that makes it into your bloodstream, compared to the amount that you put into your mouth, is called “bioavailability.” If a drug has low bioavailability, it means that a lot of the drug is destroyed by stomach acid, or is not absorbed in the small intestine, or is removed by first-pass metabolism in the liver. The dose you take has been increased to compensate for this.

Once drugs are in the bloodstream, they get carried throughout the body in about one minute. But they’re still not ready to go to work. They have to move out of the bloodstream and into infected cells. Before this happens, they have to get past still more barriers.

The next hurdle is protein binding. Proteins in the blood (albumin and alpha-1 acid glycoprotein) latch onto most of the drug. This is a distribution system in the body. For example, adrenalin is produced in the kidneys. Without protein binding, it all might get absorbed in your gut. But blood proteins carry it around the body so that some of it gets to your heart and brain and it can have its full effect.

Protein binding is like a fleet of vans that load up most of the available drug supply and drive it to locations all over the body. The drug that’s not loaded in the vans is called the “free fraction,” and that’s the only amount that can leave the bloodstream and go to work. As the free fraction gets used up, the blood proteins gradually unload more of the drug. If a drug is “highly protein bound,” it’s possible that less than 1% of the amount that makes it into the bloodstream will be available for work.

Some areas of the body are “high security.” For example, the “blood brain barrier,” a tightly-woven network of blood vessels, protects our brain and spinal cord and keeps most antiviral drugs out. Another area of the body that drugs have a hard time penetrating is the genital area.

To get into infected cells, drugs have to get through the cell membrane, past the chemical “guards” that make sure only the right things get in. The nukes (nucleoside analog reverse transcriptase inhibitors) have an easy time getting in, because they look like the building materials that the cell needs in order to divide. Chemical “hands” pull them into the cell. Once inside the cells, the nukes have to go through three steps of chemical processing (phosphorylation) before they are ready to get to work.

Other antiviral drugs—the NNRTIs and PIs—have a harder time getting into cells. They don’t look like anything the cell needs. They push their way in, but some of the drug gets pushed back out by a chemical “bouncer” called P-Glycoprotein.

DO WE HAVE ENOUGH?

With all of these barriers, as much as 99% of the medication we swallow might never get to fight the virus. So it’s critical that we have enough drug in our bloodstream to start with. That’s why drug companies study pharmacokinetics (far’ muh ko kih NEH’ tix), or PK.

PK measures the ups and downs of blood levels of drug in your body. For example, when you take a dose of a medication, the drug level goes up quickly. In a little while, it reaches its peak. This is called C_{max} , the maximum concentration. As the drug gets removed from your body by the liver or kidneys, the blood level drops. Just before a new dose gets into your bloodstream, the blood level is the lowest. This is the “trough,” or C_{min} , the minimum concentration.

Another PK measurement is how long a drug stays in the bloodstream. This is calculated as the amount of time it takes for drug levels to fall by 50%. This is called the “half-life” of the drug.

If you draw a graph of drug levels in the blood, you will see that they rise quickly to the C_{max} after a dose is taken, then fall off over time until the next dose. This graph can be used to determine your total exposure to the drug. This is called the “area under the curve,” or AUC, because it’s calculated by measuring the area under the curved line that charts the peak and trough levels of a drug.

Drug levels are different in different people. We all know some people who can eat a lot and stay thin, and others who seem to just look at food and gain weight. It’s similar with drug levels. Some people “process” drugs quickly and have lower blood levels, while others have higher levels with the same dosing. PK results are based on the average for the people who were studied. Still, it’s possible that you should use a lower dose if you don’t weigh very much, or if you have a slow metabolism. If you have a large body or a quick metabolism, you might need a higher dose. Your doctor might want to check your blood levels if a drug doesn’t seem to work the way it should.

HOW IS PK USED?

PK studies help drug companies choose a dose for a new drug that will be effective without causing too many side effects. But first, we need to set some limits on drug levels in the blood. We can draw two horizontal lines on our PK graph. The upper line represents the blood level where people start to develop serious side effects. The lower line represents the minimum drug levels that provide good control of the virus. This is usually the drug concentration that cuts down viral replication by 50%. This is called the “inhibitory concentration (50)” or IC_{50} . We want to keep drug concentrations above the IC_{50} , but below the level that will cause serious side effects. The zone

between these two lines is called the “**therapeutic window**,” the range of drug concentrations where it’s doing more good than harm.

Each PK measurement puts some limits on the dosing:

- The **C_{max}** is related to short-term side effects like nausea or headache that hit after each dose. The **C_{max}** has to stay low enough to keep these at a reasonable level.
- The **C_{min}** relates to control of the virus. If the **C_{min}** drops too low, HIV can multiply and maybe develop resistance to the drug. The higher the **C_{min}**, the better the viral control. Most manufacturers want to see the **C_{min}** stay several times higher than the **IC₅₀**.
- The half-life of the drug helps decide how often you have to take it. Drugs with a long half-life stay in the blood longer, and you might only have to take them once or twice a day. If a drug has a short half-life, you might have to take it three or more times a day.
- The **AUC**, which measures total exposure to the drug, is often related to control of the virus. The higher the **AUC**, the better the control. It can also be related to the amount of long-term side effects.

Let’s say that a drug was approved based on three doses a day. Then the manufacturer wants to make it easier for patients to take, so they try to design a twice-daily dose. To do this, they will rely on PK data.

- They’ll need to put more medication in each dose. Will that make the **C_{max}** too high, and cause too much nausea and headache when each dose is taken?
- Instead of about 8 hours between doses, it will now be 12 hours. If the drug has a long half-life, there won’t be a huge difference in the minimum blood levels (**C_{min}**). How does the new **C_{min}** after 12 hours compare to the amount of drug needed to control the virus?
- What’s the **AUC** (area under the curve) using the new twice-daily dosing? If it’s equal to or higher than the old **AUC**, then the new dosing is probably going to be just as powerful against the virus.

With a wide therapeutic window, it’s easier to make some of these changes. There’s more room to increase the dose without causing bad side effects, and more room (time) to let the blood level drop before it gets too low. With a narrow therapeutic window, there may be just one choice for dosing.

THE BEST CURVE IS A STRAIGHT LINE

The ideal situation would be a constant level of drug in the body: enough to control the virus, but not enough to cause a lot of side effects. Instead of a graph showing peaks and troughs, we’d have a flat line. This will never happen if we swallow pills, because we get a large amount of drug with each dose. The only way to get constant drug levels is with an intravenous (IV) infusion, or with a pump like

some diabetics use to take insulin. These methods of taking medication are more expensive and complicated than taking pills. Because they break the skin, there is a risk of infection.

There is another way, however, to “smooth out” drug levels in the blood. Blood levels drop when the drug is metabolized by the liver and removed from the body. If we slow down this process, less drug is removed from the blood. The concentrations stay higher and the drug’s half-life gets extended.

The protease inhibitor ritonavir (Norvir) has this effect. For example, if the protease inhibitor indinavir (Crixivan) is used by itself, it has to be taken on an empty stomach, three times a day, once every eight hours. The “trough” levels are not much higher than the levels needed to stop the virus. But if indinavir is combined with a small amount of ritonavir, the trough levels of indinavir stay much higher, and you can take it just twice a day, with food. Ritonavir has a similar effect when it’s combined with other protease inhibitors. These “ritonavir-boosted” regimens haven’t been approved by the FDA yet but are getting a lot of attention from researchers.

Pharmacokinetics gets pretty technical, but it’s important for manufacturers to study drug levels to be sure that we can control the virus without too many side effects. ☒

Bob Munk is the Coordinator of the New Mexico AIDS InfoNet at www.aidsinfonyet.org, and is a frequent writer on AIDS treatment topics. He tested HIV positive in 1987.

GLOSSARY

AUC: Area under the curve, a measure of total exposure to a drug over a 24-hour period.

Bioavailability: A measure of how much drug makes it into the bloodstream, compared to how much we swallow.

C_{max}: The maximum concentration of drug in the blood. It occurs shortly after taking a dose.

C_{min}: The minimum concentration of drug in the blood. It occurs close to the time before the next dose is taken.

Half-life: A measure of how long a drug stays in the blood. The length of time it takes for the blood concentration to drop to 50% of **C_{max}**.

IC₅₀: Inhibitory concentration (50), the concentration of drug that cuts viral replication by 50%.

NNRTI: Non-nucleoside reverse transcriptase inhibitor, a type of antiviral drug. Examples are nevirapine (Viramune) and efavirenz (Sustiva).

Nuke: Nucleoside analog reverse transcriptase inhibitors, a type of antiviral drug. Examples are AZT (Retrovir) or d4T (Zerit).

Pharmacokinetics: The study of how drug levels change over time in the body.

PI: Protease Inhibitor, a type of antiviral drug. Examples: indinavir (Crixivan), nelfinavir (Viracept).

Protein binding: A process that inactivates some of the drug in the bloodstream and carries it throughout the body.

Therapeutic window: The difference or gap between the lowest drug concentration that is helpful (controls the virus), and the drug concentration that is harmful (causes too many side effects.)

Fungus Among Us

by Frank Pizzoli

With names like *aspergillosis* (the name of an old girlfriend), *candidiasis* (a famous French play), *coccidioidomycosis* (Gezzhunte!), *cryptococcal meningitis* (what killed Boris Karloff in the Mummy), and *histoplasmosis* (that's when you bomb a history test), it's a wonder HIV infected folks don't die from just saying these fungal infections.

Essentially, the body's health is defended by its immune system. When "germs", such as viruses, nasty bacteria, parasites—and fungi—arrive on the scene, our white blood cells known as lymphocytes (B cells and T cells) protect the body. Our protective armor is weakened and eventually destroyed by HIV as the virus breaks down the body's immune system. The good news is that the threat of fungal infections, at least for some individuals, has lessened with the advent of newer HIV drugs.

In a set-for-publication article on fungal infections by William G. Powderly, MD, and Nicholas E. Haddad, MD, (The Changing Face of Mycoses in Patients with HIV/AIDS), they point out that the "current era of effective antiretroviral therapy has led to a marked reduction in opportunistic

infections (OIs) in those countries where such therapies are available. Opportunistic fungal infections (FIs) are no exception, and the incidence of such infections is now 20-25% of that seen in the mid-1990s."

In fact, infections associated with very advanced HIV disease, such as azole-resistant candidiasis and aspergillosis are also rarely seen, according to the doctors' research. The rare occurrence of these two FIs reflects an improved immune function. "The most common issue now is whether patients who have had a systemic mycosis require life-long therapy as used to be recommended. Preliminary data from small studies suggest that, like is seen with other OIs, it may be possible to stop suppressive therapy in patients whose CD4 lymphocyte count rises with antiretroviral therapy," Powderly notes.

So what are these fungal invaders with the awful sounding names?

ASPERGILLOSIS

Aspergillosis is formed from a fungus found in soil and decaying plant life, and, luckily, is somewhat rare with HIV. More commonly, cancer patients on chemothera-

py and transplant patients on immunosuppressive therapies may contract the fungus. For the most part, aspergillosis affects the lungs and sinus. Prominent symptoms include cough, chest pain, shortness of breath, facial pain, fever, and night sweat.

The danger zone is when an individual has a CD4 count of less than 100 cells/mm, although infections do occur in people with higher CD4+ cell counts. Anecdotally, reports indicate that among people with AIDS who first are treated for bacterial pneumonia or PCP, aspergillosis may follow. Doctors think that these other infections weaken the lungs, making it easier for the fungus to take root.

Typical treatments are amphotericin B (AMB, IV) and itraconazole (oral).

CANDIDIASIS

Formed from a mold called *Candida albicans*, candida is the most common HIV-related fungus infection expressing itself in the human body as "thrush" or a yeast infection, especially in women. There are at least four other "species" of the fungus: *Candida glabrata*, *C. parapsilosis*, *C. tropicalis*, and *C. krusei*.

The threat of fungal infections, at least for some individuals, has lessened with the advent of newer HIV drugs.

When infected, patients experience discomfort in the mucous membranes around the mouth, vagina, esophagus, and skin. Typical symptoms are white humps, dry mouth, difficulty swallowing, and an altered sense of taste. Candida in its many manifestations is an AIDS-defining illness, according to the Centers for Disease Control (CDC), when it appears in the mouth or when the yeast infection is found vaginally and is persistent, frequent, or responds poorly to therapy. An infected person with virtually any level of CD4 count is at risk, but individuals with counts less than CD4 200 are at greater risk.

It isn't really clear if preventative measures are more effective than treating thrush after it appears. For vaginal yeast infections, yogurt containing *Lactobacillus acidophilus* cultures decreases infection rates. Drugs used to treat candida depend on where and how in the body the fungus shows itself. For oral thrush, doctors often prescribe fluconazole, clotrimazole, ketoconazole, and nystatin. If the fungus appears in the esophageal area (the swallowing tube) fluconazole, ketoconazole, and itraconazole seem to work. Vaginal yeast infections can sometimes be treated with over-the-counter antifungal remedies like clotrimazole or miconazole.

COCCIDIOIDOMYCOSIS

Coccidioidomycosis is a fungus found mainly in soil in the southwestern parts of the US, in Mexico, in Central America, and in parts of South America. During one part of this nasty germ's life, it is airborne—and that's when it is most dangerous. Those with coccidioidomycosis have inhaled the fungus, making the lungs the most commonly affect-

ed part of the body, although the fungus can also invade the kidneys, lymph system, brain, and spleen. When it infects the lungs, the fungus is likely inhaled.

Typical symptoms are cough, weight loss, and fatigue. If left untreated, meningitis is a commonly associated complication. The CDC also considers this fungus an AIDS-defining illness. HIV-infected individuals are considered to be at risk when their CD4 T-cell count is less than 100.

There have been no studies on preventing coccidioidomycosis. Typically, treatments include amphotericin (IV) and fluconazole (oral).

CRYPTOCOCCAL MENINGITIS

Cryptococcal meningitis is a yeast-like fungus infection found in soil around the world, especially in soil contaminated by bird droppings. This disease usually affects the brain and lungs and advance stages can involve almost any organ. Patients are most at risk when their CD4 T-cell count is less than 50.

Because the disease is so deadly, the CDC recommends patients consider using fluconazole for those with CD4 T-cell counts less than 50. Be advised that sometimes this preventative treatment isn't indicated because this type of meningitis is rare and the treatment is expensive. Infected individuals who accept preventive treatment may end up with fungi that are resistant to treatments for cryptococcal meningitis. Another factor may influence whether or not individuals take preventive steps: the preventive drugs may interact with other important treatments.

Typically, this infection is treated with amphotericin B, flucytosine, and fluconazole. Once infected with this fungal invader, long-term treatment (maintenance therapy) is almost always needed to prevent a relapse.

HISTOPLASMOSIS

Histoplasmosis is a yeast-like fungus infection found in the southern parts of the US and South America in soil contaminated by bird dung. Infection occurs by inhaling the fungus, which means the lungs are almost always infected, although histoplasmosis can affect other internal organs. This is an AIDS-defining illness, according to the CDC.

Symptoms include fever, skin lesions, breathing problems, weight loss, and liver enlargement. Patients are most at risk when their CD4 T-cell count is less than 100. Itraconazole is sometimes used as a prophylaxis preventive for those with very low CD4 T-cell counts who live in southern parts of the US.

Treatments include amphotericin B (IV), and itraconazole (orally). Once infected with the fungus, long-term maintenance therapy is usually needed.

Although sticks and stones can break one's bones, and normally words won't hurt someone, HIV-infected individuals should consult their physicians on how best to combat fungal infections. ☩

Freelance writer Frank Pizzoli is founder and executive director of Positive Opportunities in Harrisburg, Pennsylvania, an HIV-employment service and wellness and prevention program. E-mail fpizzoli@aol.com.

Pharmacy Considerations for Pediatric HIV

by Glen Pietrandoni, R.Ph.

In many ways, we have come a long way in understanding HIV disease and the drugs we use in controlling its progression. Many millions of dollars have been spent in researching chemical compounds in the hope that safe and effective drugs could be developed from them. Until recently, most of the research involved mostly adult male subjects.

So when clinicians use drugs in women and children, they sometimes have to use an educated guess in determining the drug's dosages and effectiveness. Using laboratory testing (which is not as effective as studies in people), pharmaceutical companies have come up with standard doses of all HIV medicines for use in children.

Just as the treatment of HIV/AIDS is recognized as a specialty area of medicine, pediatric HIV/AIDS care can be thought of as a specialty within a specialty. You can go one step further to make the distinction between caring for newborns, children, and adolescents. A newly infected adolescent would be treated differently than a child of the same age who has been living with the disease from birth.

Since a young child does not have the verbal skills and ability to communicate as an adult, the art of a medical diagnosis can be very difficult. Medical providers are dependent on the adults caring for the child to obtain information needed to make decisions. HIV disease manifests itself differently in children and laboratory results are interpreted specifically for them. Drugs work differently in infants and children than they do in adults. Maybe the most important point that makes the care of children unique is that their care is entirely in the control of a parent or guardian, not themselves. Giving medications, scheduling and keeping provider visits and appointments for lab tests must all fit the caregivers' abilities as well as the patient's.

Education of parents and caregivers is critical. They should remember that a pharmacist may have more time to discuss medicines and side effects than a doctor might. The pharmacist can also tell you what to mix with the medicine to cover its bad taste. As with adults, there are a limited number of options available in drug combinations. The risk of viral resistance—when the drugs can no longer fight HIV—can be decreased with good adherence, which is the art of taking the drugs correctly. That means taking doses on time under the right conditions, such as with or without food. This can become even more complicated than it already is if the caregiver must manage disease or addiction themselves.

As in adults, adherence is the key to successful viral suppression. Adherence in children with drug regimens containing large capsules is complicated by their ability to actually swallow them. Depending on the age and health of the child, this problem may require doctors to install a shunt (a tube for administering medications that leads from the outside directly into the stomach). This avoids struggling with the children and insures that a proper dose is administered. Quality of life improvements have been documented in the patients and the caregivers alike. Liquid formulations of most antiretroviral drugs are available and are approved for treatment of HIV infection in children when indicated. If you have ever fed an infant or toddler, you can imagine how actually getting the medication into the child could be very challenging. Some liquid formulations are not that easy to take, as we learned with Norvir liquid. Zerit, Epivir and Agenerase liquids, for example, have formulations that seem to be much better tolerated.

U.S. guidelines recommend that all HIV positive infants less than a year old and any older children showing symptoms of infec-

tion or a weakened immune system should be treated regardless of their age or viral load. This is because there is evidence that treatment may be able to keep an infant's immune system normal. In older children, treatment can reverse developmental problems and serious illnesses. Providers may choose to defer treatment in children over 12 months old with normal immune status or low viral load, the amount of HIV in the blood.

The goals of therapy in HIV infected children and adolescents are similar to those in adults: reduce viral load, preserve immune function, and delay the progression of the disease. In addition to monitoring with traditional laboratory tests, children must also be monitored for failure to grow normally and for normal development of the nervous system.

When possible, only those providers who are experts in the field of pediatrics and HIV should be treating infants and children. If this is not possible, it is suggested that the providers be in contact with such specialists on a regular basis. Young people cannot be thought of as just small adults. Experts in caring for HIV-infected children, family members of these children, and government agency representatives publish *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection* on an ongoing basis. For a free copy call 1-800-448-0440 or visit www.hivatis.org.

In addition, the HIV Telephone Consulting Service operated by the Community Provider AIDS Training (CPAT) project answers questions from healthcare providers. The number is 1-800-933-3413. Parents and guardians can talk with other caregivers—try the Just Kids Foundation in New York City at 1-800-341-1880 or the National Pediatric AIDS Network Hotline at 1-800-646-1001, founded by the father of a positive child. ☚

Pickett Fences

Rising above the pain

by Jim Pickett

I have *always* said, “If I ever stoop to giving cheap advice in my column, take me out back like Old Yeller.” I have also *never* been one to engage in shameless self-promotion. It’s not that I don’t adore masturbation, but, you know, if I have my druthers, I prefer other consenting adults toot tooting my horn. Okay? Hey, beep beep! Alright? So please don’t be alarmed and dig out that shotgun you save for special occasions (like Thursday) when it appears that what follows is both the cheap advising and the masturbatory tooting I purport to loathe. Because it’s not. Because I said so. And really, I’d like to spin this more as an exercise in “sharing” and/or “caring.” I’m confident Ari Fleischer would be on board with that.

For the last millennia I have been working on a project developed by the Chicago Department of Public Health called “The Faces of AIDS—Personal Stories from the Heartland.” The Faces of AIDS is a series of books (the second is due out the end of May), and a companion traveling photo exhibit. As the title implies, the project documents people’s voices, stories and experiences “from the compelling to the commonplace, always honest and human” living with or impacted by HIV in the “Heartland,” a sort of modified Midwest.

It’s been the greatest privilege to be one of the writers collecting these stories. The strength and beauty I’ve witnessed, the insights I’ve gained, and the opportunity for understanding I’ve been given I can never be thankful enough for. From Tulsa, Oklahoma to Topeka, Kansas, from Lincoln, Nebraska to Springfield, Illinois, the same sets of themes kept appearing.

Church, spirituality, doing for others, and attitude, “making the best of what could be tragic and devastating,” these are as important to health and survival, perhaps more so, than rigid drug compliance, doctor visits, or even eating right.

The strength and beauty I’ve witnessed, the insights I’ve gained, and the opportunity for understanding I’ve been given I can never be thankful enough for

“It’s a blessing, HIV has changed the type of person that I am,” says Mia in St. Louis. “It made me a totally compassionate person, because I was a bitch, big time. You could have your heart falling out of your chest in sorrow, and I’d be, ‘So? This has what to do with me?’”

“I have osteoarthritis and a lot of other things that go along with being 50, with neuropathy and all these little combined side effects,” explains Mike, who lives in a town called Ardmore, Oklahoma, not far from the Texas border. “I was coming back from the altar rail [in church] once and almost fell. It was like I passed out, I stood up too fast. But I never touched the ground. There were so many hands to catch me. Where else could I find that?”

Father Jim, a gay, HIV positive priest in Tulsa, makes his point succinctly. “The peo-

ple who survive are the ones who don’t just sit and say, ‘Oh I’ve got AIDS, come and feed me, come and take care of me.’ They are the ones who get up and take care of each other. The joy of being able to do that sort of fills in the anguish of being sick.”

Trever lives in Norfolk, Nebraska and speaks about his HIV and drug and alcohol addiction to upwards of 4,000 youth a year. He’s had doctors refuse to work on him because of their religious beliefs “Trever is gay, and that’s a conflict of interest.” Sharing his story, doing something, fills in the anguish Father Jim mentions. “Every time I share my story it reminds me of where I was,” he states, “and helps me to realize where I am now. Today I have people calling and asking for me to speak. I have a God that I understand and that loves me for who I am, that doesn’t hate me like I always thought. I’m rich. Being rich is not about having 50,000 dollars in the bank. Riches are making a difference in people’s lives.”

JoAnne in Chicago says, “You make lemonade. This is the hand you’re dealt, you deal with it. I’ve learned to be happy with what I have.”

And Laura in Oklahoma City sums it up. “Instead of why me, I turn that question around and say, why not me? I’m willing to take a stand and say, ‘I’ve got HIV, and this is how you can prevent yourself from getting it.’ I use myself as an example. If I wasn’t able to turn that around, I’d wallow in self-pity. It keeps me sane. Attitude has a lot to do with your physical being. If I didn’t have this outlet, I probably would have tried to kill myself. Ya know, there are days when it’s painful to walk because of my neuropathy. But because I have a purpose, I can rise above that pain.” ✚

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The Importance of Sequencing in Treatment Options

Daniel S. Berger, MD

Physicians should constantly consider the sequence for which they use antiviral drugs in their patients (sequencing therapies). HIV positive individuals are living longer with the help of effective treatment, but an increasing number of patients are developing resistance to their regimen. If a patient develops resistance to his or her regimen, the next regimen, one that is not cross resistant and allows for further options, should be well thought out. Thus, the *raison d'être* for properly sequencing HIV drug treatment allows for the maximum number of options and alternatives to be available for the long term. With the probability of keeping patients on treatment for 20 or more years, antiretroviral drugs must be properly sequenced.

Physicians may need to change a patient's therapy perhaps as early as 18 months into treatment. While newer drugs become available, sequencing should encompass the specific resistance characteristics of all antiviral agents. For example, patients who have had long experience to the nucleoside class (nukes, or NRTI) and whose virus is resistant to, for example, 3TC may have resistance to other nukes, such as abacavir or Ziagen. Those with high resistance to this class of drug may alternatively be very susceptible to the non-nuke class (NNRTI) or have increased susceptibility to tenofovir (an experimental drug). However, individuals developing resistance to their new NNRTI will likely have cross-resistance to other NNRTIs. Likewise, various protease inhibitors bear cross resistance within their family of drugs. However, using them in a particular order may allow for further use in salvage regimens and in various dual pro-

tease inhibitor regimens (two protease inhibitors in the same drug regimen).

For these reasons, changing therapy should be well thought out, not done haphazardly. For highly experienced patients newer drugs should be reserved whenever possible. A basis for changing to another regimen includes treatment failure, but toxicities or intolerance to the current antiviral regimen are also grounds for switching an existing regimen. Pharmaceutical companies are attempting to develop newer drugs, acutely aware of the urgency and marketability of drugs effective against resistant virus. A new protease inhibitor recently approved, Kaletra, is being used in salvage regimens. Three other agents from differing drug classes are in development and key in on resistant virus; they include tenofovir DF, T-20 and DPC-083. These significantly improve our options for patients who need alternatives.

Kaletra (lopinavir/ritonavir or ABT-378/ritonavir) has only been available and on the market for a relatively short period of time. It has been studied in naïve and protease-experienced patients in combination with non-nucleosides. The data holds up regarding the advantages of using this protease inhibitor in certain situations. Being new, Kaletra has not been studied as extensively as other drugs, and regarding sequencing protease inhibitors, it is not quite clear as to where Kaletra should fit in with the overall treatment scheme of individual patients. Questions regarding its appropriate use as first line treatment, and the proper sequencing of this drug because of cross-resistance to other protease inhibitors have been raised. However, it is well tolerated and has become

a useful addition to the antiviral armamentarium. Like most new drugs coming to market, the reported studies were designed to get the drug FDA approved. Later studies and further clinical experience will add to our understanding.

Abbott Labs has promoted Kaletra and a post-marketing switch protocol (FDA approved) called PLATO. A switch study generally denotes discontinuing an existing drug therapy and changing to the promoted product. This particular study involves switching patients who are intolerant to other therapies to Kaletra. During the study, Abbott provides Kaletra free-of-charge to the patient, afterwards it becomes the patient's responsibility to pay for the drug.

While observed for a period of only eight weeks, patients are evaluated for quality-of-life changes. While touted as a "quality-of-life" study, PLATO disregards side effects impacting this very issue, such as lipodystrophy and metabolic complications. While lipodystrophy changes usually arise later, when they do occur, they can have huge quality-of-life consequences. Studies of Kaletra have shown that the drug is associated with hyperlipidemia (increased cholesterol and triglycerides) which are often associated with lipodystrophy. Other symptoms can appear later than eight-weeks of treatment which may affect quality-of-life. But Abbott's Medical Director of Global Antiviral Marketing Product Development denies that the study was done as a marketing vehicle, simply to get people on their drug, claiming there are "probably cheaper ways to market drugs, such as starter packs and coupons." However, it is widely known that starter samples and coupons are rarely

used for HIV prescriptions of antiviral drug therapy. Many physicians and treatment advocates believe the scientific value of studies are improved by designing conventional longer-term projects that seriously delve into the important issues of quality of life and metabolic complications.

Tenofovir DF (developed by Gilead Sciences) is part of a new class of drugs called nucleotide reverse transcriptase inhibitors. Its active metabolite (duration of drug lasting in the blood stream) has a half life between 10–30 hours and the intracellular half life is equal to or greater than 30 hours, therefore it can be given at convenient once daily dosing. *In vitro* (test tube) toxicity studies show tenofovir having little effects on the mitochondrial enzymes and not limiting the mitochondrial DNA, predictors of mitochondrial toxicity. Most current schools of thought believe that it is this toxicity to mitochondria that causes lipodystrophy complications in HIV disease.

Also, tenofovir has activity against HIV with various Retrovir (AZT), Videx (ddI), and Hivid (ddC)-associated mutations and shows increased activity against HIV with Epivir (3TC) resistance. Indeed, an earlier study (study 902) demonstrated antiviral effect of this agent; 94% of the study patients had NTRI resistance mutations prior to study. The most recently reported study (study 907) enrolled more than 550 treatment-experienced patients. There was significant viral load reduction observed in this group, who had tenofovir added to their existing drug regimen and 45% achieved viral loads below 400 copies. Thus, once available, tenofovir appears to be an attractive choice for use in antiviral regimens.

Tenofovir is currently available on a compassionate program to patients with CD4 T-cells below 100 count who are failing their regimens (two protease inhibitors or one protease inhibitor and a non-nuke) and for patients with recent (within 90 days) opportunistic complications, the CD4 cells can extend to 200 count for eligibility. Gilead Sciences is on track for submission of its New Drug Application to the FDA by mid-year.

A second-generation non-nuke, **DPC-083**, developed by DuPont Pharmaceuticals, is continuing in clinical trials. Phase II studies are being conducted in Europe and at only five sites around the US, one being here at NorthStar Medical Center in Chicago. This particular protocol is studying individuals who are failing their first regimen containing a non-nucleoside and is still open for enrollment. As a non-nucleoside, DPC-083 has similar potency to Sustiva (efavirenz) against wild type virus, however it has other significant advantages: the drug is effective for virus that is potentially resistant to Sustiva or Viramune (nevirapine), including against the infamous K103 mutant, and is two to eleven times more potent than Sustiva against other potential resistant virus. It has a long half-life, and is administered once daily. Thus far the drug has been found to be well tolerated and side effects have been found to be of minor severity and of short duration.

DuPont Pharmaceuticals is currently up for sale. We hope that a pharmaceutical company experienced in HIV drug development acquires DuPont and will show the same commitment and ability to develop further antiviral options, and continues to support the HIV community.

T-20 is another novel agent in a new drug class called fusion inhibitors. T-20 blocks the ability of HIV to combine or fuse with the CD4 receptor (T-cell). Preliminary studies have shown that T-20 is effective in patients with resistance to other antiviral agents. Cross-resistance is unlikely due to the unique mechanism of action. Because the chemical structure of this agent is a chain of amino acids, it is easily broken down by stomach acids. Thus the drug needs to be administered by subcutaneous injection. The drug, developed by the small biotech company Trimeris, sold marketing rights to Roche. This larger pharmaceutical company will definitely aid in its faster development and production. T-20 will also become available on a limited compassionate track program (see *News Briefs*).

New antiviral agents are being developed with resistance in mind. With more drugs becoming available and as we expect to see our patients living to old age, effective drug sequencing becomes even more crucial and we'll need to conserve as many options for treatment as wholly possible. ☩

Daniel S. Berger, MD is Medical Director for NorthStar Medical Center; Clinical Assistant Professor of Medicine at the University of Illinois at Chicago and editor of AIDS infomsource (www.aidsinfomsource.com). He also serves as medical consultant for Positively Aware.

The Joys of Safer Sex...continued

By Anthony "AC" Clark

Self-examination is a hard thing to do. Accepting that you have bags under your eyes is a very difficult thing to acknowledge. But of course I'm not talking about myself. Most of us find many faults with our physical appearance. Inside of our heads we say such things as "I'm not muscular enough." "I'm too fat." "I'm losing my hair." or "My hips are too wide." Yes ladies, men notice their wide hips and big butts, too.

I wasn't happy with my appearance and because I wasn't happy with my appearance, I didn't feel good about myself. And because I didn't feel good about myself, I took unnecessary chances in my sexual encounters. Sound familiar? It's called low self-esteem.

Let me explain myself. I needed to have physical sexual contact because it was the only thing that made me feel alive. I didn't care if it was just a one night stand. I didn't stop to think if a casual encounter would be good for me. I didn't care about my future. I only knew that I felt hurt and I felt lonely. I needed to feel needed, if only for just that moment.

With reckless abandon, I searched and did things that later I professed was due to drinking too much. You've heard that line before. Even when I had achieved my goal and had consumed the person sexually, I still felt horrible. I was an emotional wreck. Low self-esteem clouded my judgement and made me feel that I wasn't desirable or lovable. I'm sure many of you understand and can relate to this scenario.

There were times when I felt overwhelmed with everything in my life. I felt like a failure, lacked assertiveness, and avoided anything new. I was more dependent on

other people than myself. I dwelt in the negative. I was always putting myself down.

I made the classic mistake of internalizing the negative messages that I had heard all of my life. "You'll never be worth anything." "You can't do anything right." "Why do you mess up the simplest things?" "You're not smart enough." "You're so lazy."

Self-esteem refers to how you feel about yourself, your self-confidence, self-respect, pride in your self, your independence and your self-reliance. These were all of the things that I needed, but lacked, to believe in myself.

My first step was accepting myself for the person who I am. In part, accepting yourself means that you are willing to act in your own best interest. From there it was possible to consider modifying my sexual behaviors. That's exactly what I did.

I took a good look at my body and I made changes. One day when I was "Home Alone," I took off my clothes. I took the large mirror off the wall and placed it on the floor, so I could see myself. Remember, I was still into self-examination.

I began to touch myself...to feel my entire body. I realized that I would never be a great safer sex partner if I weren't in touch with my own feelings; if I didn't know or understand the things that aroused me. I once read somewhere that we don't like looking at ourselves in mirrors. I would like to take that a step further and say we don't enjoy touching ourselves, either. In safer sex, foreplay is an important part of the sexual experience. A lot of sexual foreplay involves touching, grabbing, holding, scratching, tickling, licking, spanking and massaging.

Eventually I needed help with my self-exploration, so I asked an intimate friend to

come over and help out. I mean there are certain parts of the body that I just can't reach. I'm not that flexible. Finally, my company arrived. I made it crystal clear that I wanted us to have fun, to just experience each other without getting into the serious sex. My companion was also aroused at the thought of us just touching and exploring each other's body.

Once we both were fully naked I held on tightly. I closed my eyes and felt a smile spread through my whole body. That hug felt like a lifetime.

I reflected upon something that my therapist once said and it rang true to me in this special moment. "Let the child in you play, and just have fun and you will experience a joy from the past right in the present." I was happy to have created an opportunity to not only learn something about myself but to put into practice my new safer sex skills. We took turns massaging the body and finding those erotic spots that make you giggle.

As we lay on the bed playing with the large mirror and several small ones, I remembered the many safer sex presentations I had previously attended and realized they were so sterile, compared to real life. Those presentations give you the basics, but to really enjoy safer sex one has to let one's imagination run wild.

Later, I was feeling kind of hungry, so got up and went into the kitchen. As I grabbed snacks, I thought, "How many ways can you use cheese whiz on a body?" 🧀

Programs and Meetings

All meetings held at TPAN offices unless otherwise indicated: 1258 W. Belmont Ave., Chicago.

Office hours: Monday–Thursday, 9 am–8 pm. Friday, 9 am–6 pm

phone: (773) 404-TPAN • fax: (773) 404-1040 • e-mail: tpanet@aol.com • www.tpan.com

MONDAY

TPAN DAYTIMERS

A group for people with HIV who prefer to meet during the day. Mondays and Thursdays at 10:30 am.

NEWLY DIAGNOSED

A group for newly diagnosed individuals. Mondays at 7:30 pm.

NEGATIVE PARTNERS

The Negative Partners of Positive People. Mondays at 7:30 pm. The group is dedicated to helping those who are dealing with issues surrounding the HIV positive status of their significant other as well as their own HIV negative status.

TUESDAYS

T.R.I.B.E.

An educational discussion group for Gay Men of Color focused on maintaining a healthy lifestyle. 2nd and 4th Tuesday at 7:00 pm.

LIVING POSITIVE

HIV positive gay men discuss how being positive affects relationships and deal with the impact of HIV as single men. Tuesdays at 7:30 pm.

POSITIVE PROGRESS

A group for HIV positive people in recovery. Tuesdays at 7:30 pm.

WEDNESDAY

WELLNESS WEDNESDAY

Free alternative therapies (massage, Reiki, Shiatsu, Structural therapy). This program is offered by AIDSCare. Wednesdays 12:00 pm–3:00 pm. Call for an appointment.

MEDICAL CLINIC

Free medical care provided by a physician's assistant. This program is in conjunction with the Needle Exchange Program and is offered by Access Community Health Network. Call for an appointment. Wednesdays 3:30 pm–7:30 pm. Fridays 2:00 pm–5:00 pm.

WEDNESDAY, CONT.

NEEDLE EXCHANGE PROGRAM

Free, anonymous, legal syringe exchange and HIV/AIDS prevention. Every Wednesday 5:00 pm–7:00 pm at TPAN offices. In association with Chicago Recovery Alliance.

STRAIGHT TALK

A group for HIV positive heterosexuals. Wednesdays at 7:30 pm.

YOGA

Wednesdays at 7:30 pm.

THURSDAY

TPAN DAYTIMERS

A group for people with HIV who prefer to meet during the day. Mondays and Thursdays at 10:30 am.

BROTHERS UNITED IN SUPPORT (BUS)

A group for HIV positive gay and bisexual men of African descent. Thursdays at 7:00 pm.

BEYOND BASICS: GETTING ON WITH LIFE

A group for those who have lived with HIV for several years. Thursdays at 7:30 pm.

BERLIN HIV POSITIVE SOCIAL HOUR

Berlin, 954 W. Belmont, Chicago. Thursdays from 6:00–10:00 pm.

FRIDAY

MEDICAL CLINIC

Free medical care provided by a physician's assistant. This program is in conjunction with the Needle Exchange Program and is offered by Access Community Health Network. Call for an appointment. Wednesdays 3:30 pm–7:30 pm. Fridays 2:00 pm–5:00 pm.

SCHEDULED BY APPOINTMENT

FAMILY AIDS SUPPORT NETWORK (FASN)

A group for family, friends, and caregivers. Call Betty Stern at (773) 404-1038.

WOMEN'S GROUP

A group for HIV positive women. Women supporting each other in dealing with HIV and overcoming other issues. Created for positive women by positive women. Call Sylvia at (773) 404-8726 for more information.

SPEAKERS BUREAU

Individuals are available to community groups and organizations to educate on HIV, safer sex, harm reduction and experiences of living with HIV. Call Sylvia or Keith at (773) 404-8726.

PEER SUPPORT NETWORK

Provides one-on-one support for recently diagnosed individuals. Volunteers provide support, information and referrals. Call Angelo at (773) 404-8726 to get a buddy!

POSITIVE BUDDY

Provides individuals living with HIV/AIDS one-on-one emotional/physical support. Volunteers provide the support that each HIV positive individual has often lost. Call Angelo to get a buddy!

CHRIS CLASON RESOURCE CENTER

Find the latest news in the Chris Clason Resource Center. Open Monday through Thursday 9:00 am–8:00 pm., Friday 9:00 am–6:00 pm.

HIV-RELATED LEGAL CLINIC

First and third Thursdays, 4:00–6:00 pm at 1258 W. Belmont Ave.; by appointment only. Call Katy at (773) 404-8726.

TPAN Calendar of Events

May 2001

All events are held at TPAN offices unless otherwise indicated.

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			6:30 – 8:30 pm ** Salvage Therapy Speaker Dr. Malte Schutz			May 5–8 AIDS WATCH Washington, DC
		1	2	3	4	5
9 am Sunrise AA May 5–8 AIDS WATCH – Washington, DC for more information, contact Jean-Michel Breville, NAPWA, (202) 898–0414 ext. 124			2nd Annual Chicago Medical Conference on HIV/ AIDS and the Latino Community call Hispanocare (773) 296–7157			
6	7	8	9	10	11	12
9 am Sunrise AA		7 pm TPAN Board of Directors meeting; TPAN members invited		11:30 am * North Side HIV Coalition meeting		
13	14	15	16	17	18	19
9 am Sunrise AA			6:30 – 8:30 pm ** The Survivor Workshop: Manage Side Effects, Live Strong and Healthy		May 25–27 International Mr. Leather (IML) 2001, Chicago Palmer House, call Angelo at TPAN to volunteer	
20	21	22	23	24	25	26
9 am Sunrise AA May 25–27 International Mr. Leather (IML) 2001			May 30– June 1 2001 AIDS in the Heartland Conf. Midwest regional conference on AIDS. Call (773) 388-1019		May 25–27 <i>Bear Pride, Chicago</i> Call (773) 509-8172	
27	28	29	30	31		

* For additional information on these events please contact Keith Waltrip, Program Director at (773) 404-8726.

** Event will be held at Theater Building, 1225 W. Belmont, Free, please contact Keith Waltrip, Program Director at (773) 404-8726.

June 2001

All events are held at TPAN offices unless otherwise indicated.

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
<p><i>Save the Date:</i> <i>Staying Alive—A PWA Conference</i> <i>August 16–19, 2001 Chicago</i></p>					<p>May 30– June 1 2001 AIDS in the Heartland Conference</p>	
					1	2
<p>9 am Sunrise AA</p>		<p>6–8 pm * Community Advisory Board Meeting</p>				
3	4	5	6	7	8	9
<p>9 am Sunrise AA</p>		<p>6–8 pm * Clinical Research Update</p>		<p>7–8:30 pm *Panel–Positive or Negative: Who's Responsible for Disclosure. Steamworks - 3246 N. Halsted</p>		
10	11	12	13	14	15	16
<p>9 am Sunrise AA</p>		<p>7 pm TPAN Board of Directors Meeting; TPAN members invited</p>			<p>TPAN's Annual Backyard Picnic. Contact Patrick for more information.</p>	
17	18	19	20	21	22	23
<p>9 am Sunrise AA</p> <p>Chicago's Gay Pride Parade. Contact Katy or Patrick for more info</p>						
24	25	26	27	28	29	30

* For additional information on these events please contact Keith Waltrip, Program Director at (773) 404-8726.

TPAN

Spring

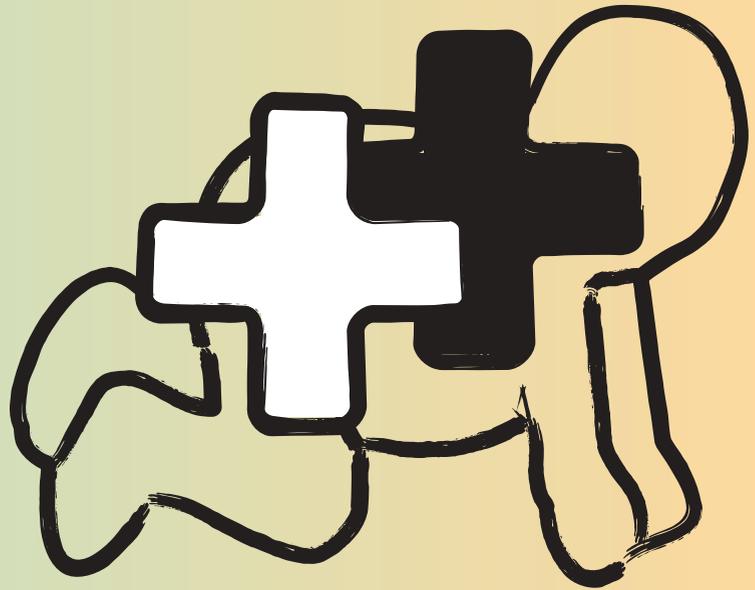
Benefit

and

Bar

Crawl

2001



We would like to thank all of the generous sponsors and hosts who helped make TPAN's Spring Benefit and Bar Crawl 2001 possible

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« Bar Crawl Hosts »

CIRCUIT



« Bar Crawl Dates »

Berlin
954 W. Belmont
Thursday, May 3 6-9 pm

Sidetrack
3349 N. Halsted
Friday, May 18 6-9 pm

and
Grand Finale
Thursday, June 21 6-9 pm

Big Chicks
5024 N. Sheridan
Sunday, May 3 6:30 - 8:30 pm