

July / August 2001



Positively Aware

The Journal of Test Positive Aware Network

HIV ON LOCKDOWN

**Open Letter From a Prison Doctor
Positive Prisoners Speak Out
Prisoner Resource Guide**

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Committed to Living

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A model, photograph, or author's HIV status should not be assumed based on their appearance in *Positively Aware*.

You can view these (and other stories from previous issues) online at <http://www.tpan.com>

Cover: Illustration by Russell McGonagle

Editor's Note

Divide and Conquer



Gay men are having unprotected sex... *again*. Intravenous-Drug Users (IDUs) are sharing unclean works... *still*.

Sex workers are engaging in high-risk activities... *once more*.

Heterosexual individuals are “barebacking” (not using condoms) with numerous partners... *as usual*.

Everyone is engaging in practices that are considered high risk for transmitting HIV to unsuspecting partners.

We fault the FDA for delaying drug approval. We blame the pharmaceutical industry for developing anti-HIV medicines that are too powerful (yes, the drugs need to be improved, but the fact is that HIV therapy is basically a form of chemotherapy). We claim that the ads for these medicines are too misleading, because they don't accurately represent the reality of being on anti-HIV therapy.

I have friends who swear that when AIDS funding started drying up for the good ole boys here in the U.S., the good ole boys went global. Africa, Asia, Eastern Europe. They demand that pharmaceutical companies and the government package up these same anti-HIV meds, and ship them off, at discounted prices, to far away developing countries. But they still refuse to look into their own backyard and notice the “third world” rates of infection in rural areas, in prisons and communities of color.

Have you heard it? Have you read it? Attack, after attack, after counterattack—activist vs. advocate, women vs. men, heterosexuals vs. gays vs. bisexuals vs. transgender, positives vs. negatives, community based organizations vs. AIDS service organizations. I recently spent an entire day reading a seemingly endless stream of articles and e-mails that were pointing fingers in every-which-way and laying blame for the current day predicament.

Activist sell-outs. False prophets. Bankruptcy. Corporate greed. Traitors. Conspiracy theories.

Who the hell can we trust? Toss out your meds. Quit your support group. While you're at it toss out those damn HIV mags with them (this one too). And don't think you can trust those nifty little web sites or your doctor. Everyone's on the take.

Is there a divide and conquer conspiracy at work upon us? Has everyone gone crazy? What the hell is going on here? We sound like a bunch of hypocrites. Worst of all, we are behaving like a bunch of schizophrenics.

People living with and impacted by HIV in every part of the globe have a right to act up, act out by whatever means necessary. But after twenty years of struggle, twenty years of deaths, twenty years of new infections, twenty years of re-infections, more deaths and now an ultra-conservative White House...

Are we running scared and looking in every direction for a scapegoat?

Rather than acting out, are we acting in upon ourselves?

Seriously speaking, the reality of sex in the age of AIDS, staying negative or living positive, deciding on a treatment regimen that best fits your life(style) and building a productive life is a complicated and individualized process. The “fault” for increasing rates of HIV infection can not be simply laid at the door of pharmaceuticals, or defined by federal regulation, nor rationalized in a witty commentary.

What's real? People & HIV. And they continue to shoot up together with dirty works in New York's Spanish Harlem, and they are sexin' each other up in parks, bars and bathhouses in Seattle without protection or knowledge of their HIV status. And let's not forget that People and HIV are hookin' up in the low country of Georgia, in the Mississippi Delta, and state prisons.

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Take Responsibility



Prevention. Ten years ago it was the hottest buzzword. Back then, it was hot because we had virtually no treatments. Back then there was a clear, visible link between being HIV-positive and sickness and death. Today, prevention has become hot again. The connection between being HIV-positive and illness isn't as strong, thanks to new medications, but the underlying reason for prevention is the same. Prevention is needed to stop this plague, to stop the illness and to stop the death that still comes with it.

Today, basic education about HIV is still needed, including how it is transmitted. But other information is also needed. There needs to be an understanding that HIV is still a deadly disease. That the medications are not a cure, and in many cases, only a temporary barrier to disease progression. And most importantly, we must educate each other about our responsibilities and accept these responsibilities, whether we are HIV-positive or HIV-negative.

If you are HIV-positive, accept the fact that when you have unsafe sex or share a dirty needle with someone who is HIV-negative, you are putting that person at risk of getting a life threatening illness. Accept the fact that if you, and every other one of us who are HIV-positive, would practice safe sex, new infections would drop significantly. Realize that no matter what your viral load is, you are still able to pass the virus on to others. Understand that getting into medical care is good for you, and those who love you.

If you are HIV-negative, accept the fact that when you have unsafe sex or use a dirty needle you run the risk of becoming infected with HIV. Accept the fact that you have a responsibility for protecting yourself. Understand that HIV has not been cured, and is not pretty to have. Understand that the medications available today often have nasty side effects, are difficult to take correctly, and only slow the progression of the disease.

If you don't know your HIV status, accept the fact that you are hiding your head in the sand. Get to a clinic, a doctor, or a health department and get tested! Do it anonymously, and do it soon. Understand that you can be infected and not have any physical symptoms. Understand that if you are HIV-positive, the quicker you get into medical care (not necessarily on medications) the better your chances for a longer, healthier life.

All of us need to honestly look at our behaviors and see if we are putting ourselves or others at risk for infection. If we are, we need to look at why. Is it because of not wanting that hot girl or guy to say no when we insist that a rubber be used? Is it because we don't want to "break the mood" or "ruin the moment"? Are we afraid to even bring up the topic of HIV and safer sex for fear our prospective love partner of the moment will walk away?

Just as "it takes two to tango" so too does it take two to practice safer sex. Both people must accept their responsibility for insisting that they play safely and that their partner plays safely. Stopping this disease can be done. To start, each of us must understand and accept our responsibility for being part of the effort. Practice safer sex. And insist your partner does too.

A handwritten signature in black ink that reads "Dennis Hartke". The signature is written in a cursive, slightly slanted style.

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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PRISON DAMNED

I am currently incarcerated in the Riverbend Maximum Security Institution in Nashville. After reading Larry Harris' letter in the May/June issue, I wanted to tell you my experience in coping with HIV. Last July at Brushy Mountain Correctional Complex in Wartburg, Tennessee, I experienced character assassination. I've never in my life been suicidal, but that's how far the medical staff pushed me. My strong support system has helped me overcome those attacks, as we know having to cope with this disease is tough enough without also having to endure a daily regimen of harassment and intimidation and being denied medical care. The treatment I received in that facility, like Larry Harris said, it's gross exaggeration to label it "minimal" because it is the bottom of the barrel.

In 1997, at West Tennessee State Penitentiary in Henning, the problem extends far beyond the inadequacy of the medical care. There I was forced to live in a perpetually hostile environment where insults from correctional staff members far outweigh those from other inmates (it was the same at Brushy Mountain). I was assaulted several times in those two years by officers who in their fear and ignorance have chosen to respond to my condition with aggression and intimidation. I was attacked with a bedsheet put around my head, suffocating me, kicked and punched in the stomach and then they dropped me down on metal stairs with my hands behind my back and legs shackled, all because of a grievance. The medical staff labeled me a troublemaker because most correctional officers are their family members and lovers. It's very disturbing that a person with HIV/AIDS has to deal with such brutal assaults.

There is no counseling or literature about HIV here. I've learned a lot about different organizations and get on their mailing list. The resource material—that's compassion, what keeps an HIV/AIDS person like myself with strong support, especially for gay and bisexual men like myself.

Daren Payne,
R.M.S.I. #127306 #1-C-#207,
7475 Cockrill Bend Ind. Rd.,
Nashville, TN 37209-1048

I too am in prison, but my situation is not as bad as Mr. Harris'. I also read the Editor's Note, but in the prison I'm in you cannot get a job to make any money. These are taken mostly by guys who have been in for years and are never getting out. So that leaves me with no money but what I receive from the outside world. If I had it I would give it because your magazine is very informative and it helps me deal with the medical staff here.

Name Withheld,
Massachusetts

I couldn't let Mr. Harris' letter go without comment. I am a physician who works in the Illinois Department of Corrections, although not at the facility that Mr. Harris describes. I can't speak to his particulars, but I can assure your readers that our inmates get as good or better care for HIV/AIDS in prison than outside of prison. One has to remember that we are dealing with convicted felons, some of whom have significant mental disease, who were not always so concerned with their health before incarceration. We have available to us almost all the currently approved HIV medications as in the

"real world" and those that we don't have can be obtained if a good medical case can be made. Since we are a state institution and the health of inmates is dependent upon us, we are under frequent scrutiny. Routinely, we see each of our HIV patients every three months, usually with CD4 counts and viral loads each time. Genotypic assays are ordered as needed. Prophylactic antibiotics are ordered when the criteria demand it. For the most part, we do not use HIV "specialists," however, most of the MDs grew up with the HIV epidemic and are quite adept at providing the necessary medical care. Far from being "bottom of the barrel," the doctors providing care in the correctional environment have to be at the top of their game, because neither the institution nor the contracted health care provider will put up with frequent furloughs to the outside for conditions which could be handled onsite. However, when the need demands it, inmates can be sent to outside specialists.

Sometimes the inmates become disillusioned because they feel they need something that the doctor does not agree with. The art of being a doctor in a prison is to determine what the inmate actually needs for his medical condition, which is not always what the inmate thinks he needs. Sometimes life in prison can be difficult, but we make sure it does not interfere with medical care. Because of our frequent check-ups and adherence to standards, we can provide as good, or better care for our HIV inmates than they might get on the outside, left to their own devices.

William Rankin, MD,
East Moline, IL

HERE, KITTY KITTY

Thank you, Enid Vázquez, for an excellent article on the therapeutic benefits of pet companionship (March/April). This is the type of accurate and informative message that clients and caregivers need!

Lynn Beckmann, RN, DVM,
via the internet

REBEL'S GONE

Dear Enid, I'm very sorry to write to let you know that my treasure of 11 years, Rebel, died suddenly of kidney failure, about two weeks ago while I was out of town. I didn't get the messages about his hospitalization until after the fact from the vet. He didn't suffer from pain and I've been telling myself he didn't suffer from my not being there with him, but it's a hard act to convince myself. My anchor is gone; at least I'm not overmedicated, as I've been able to do a lot of crying. I've had his ashes back a week now and have scattered some with friends at different parks that we've walked at in different neighborhoods we've lived around in S.F. It's so quiet. No barking at the microwave bell or telephone. No greetings when I come home. I've tried to pet my Siamese beta fish, Pokey, alas, not really workable. Have attended an animal humane society pet loss grief support group and have many supportive friends. I'm glad I could tell my story to you and trust you received favorable feedback on the article. This is so hard. I guess I need to rediscover my personality separate from us; the whole was certainly greater than the sum of our parts. Such a wee spirit with so much love. Will I ever be blessed again with such devotion from someone or something? Life goes on, and so will I, sadder and more involved with others, for having been Rebel's guardian for all this time. Keep up your great efforts.

Jonathan Goldman,
San Francisco, rebelzdad@webtv.net

MOURNING ARCHIE

Jim, your article on the video journal you collaborated on touched my heart so much that I also cried for Archie. For about 10 minutes I could do nothing else but cry as I wondered if Archie had family or friends with him when he died. Was there a support net for him of some kind, or did he just die a lonely statistic. I cried because, like Archie,

I'm also African American and, like Archie, I was born in 1962. I'm gay and was diagnosed with AIDS in February of 2000. Right now my T-cells are at 280 (up from 38) and my viral load is undetectable (down from 40,000).

I was crying, in part, for myself, thinking as you did, "When will it be my turn to step out from the wings and get sick...walk with a cane...die?" But, mostly, I was just mourning for Archie. I know that support has meant a lot to me and without it I would not have progressed to where I am now (physically, mentally and, most of all, emotionally). And that was support from my family and my very good friends and partner of some years. Tell your mom and close family members (I'm sure they would be there to offer you their undying love and support too). I too have mourned for Archie, but I'm also celebrating life—my life. Best wishes for your health and well being.

Name Withheld,
Baltimore, MD

COLLEGE DEATH

The reason why this article (March/April) got my attention is that the Danny Brown story reminds me of a dear friend. I was more than a friend. I am also his cousin. I know that this exact story could not have happened to two people. I know the names were changed. It took a lot of courage to speak out about having AIDS and being gay, and I commend you [author Chris Bell] for that. I wish he would have been as brave as you. I always thought if he would not have kept what he was going through such a secret he would still be here or he would have not died that way. As close as he and I were I did not know he was gay and was HIV-positive until he came up missing. Actually the only people in our family who knew were his mother and sisters. I would like to thank you for speaking out and making people aware of HIV.

Name Withheld,
via the internet

[Correspondence determined that "Danny Brown" was indeed a pseudonym for the writer's cousin.]

CLARIFICATION

Chicago's "Beat the Heat" Youth Outreach program ("The Young and the

Restless," March/April) is a collaboration originated by The Night Ministry.

Barbara Bolsen
The Night Ministry

AFRICAN AMERICAN AIDS

Recently, I attended a regional training session held by NMAC [National Minority AIDS Council], where I received a copy of your issue covering the 13th International AIDS Conference. Awesome! I had not heard of this magazine before and thank God for showing it to me now! I read the whole magazine. What a learning experience that was. I am setting up an HIV/AIDS Initiative at my church in Silver Spring, MD, where surprisingly or not, there is still a lot of denial and ignorance about HIV/AIDS as a whole. As AAAPTI [African American AIDS Policy and Training Institute] Director Mr. [Phill] Wilson says: Our People, Our Problem, Our Solution. I have left the field of biomedical research to dedicate myself to the field of public health, while concentrating on HIV prevention in the urban setting. This summer our church will set out to South Africa, where we will help a group of women to rebuild a school and do HIV/AIDS outreach/education to families affected and infected with HIV/AIDS. This will be a tremendous experience. I commend you, Mr. Clifton (and all other staff members of TPAN), for your work in the battle against HIV/AIDS. Keep up the good work, you are a blessing to our community! and the world!

Ludmilla F. Scott,
via the internet

LOST YOUTH

I am an HIV educator for AIDS Community Resources in Syracuse, New York. I run a teen peer education program called Teen AIDS Task Force. On a monthly basis I put out a newsletter to the 37 schools we work with, as well as 550 other agencies and individuals. Recently I came across an article in your March/April issue titled "Lost Youth" by Undra C. Fulton. I am reprinting this article in my newsletter because I feel it would send a positive message to the youth I work with.

Marissa Bailey,
via the internet



News Briefs

by Enid Vázquez



PHARMACEUTICALS DROP LAWSUIT AGAINST SOUTH AFRICA

The pharmaceutical industry has dropped its lawsuit against the government of South Africa. The Pharmaceutical Manufacturers Association of South Africa, along with individual pharmaceutical companies, were trying to stop the country from importing and manufacturing generic versions of anti-HIV drugs. *The Guardian* newspaper, of Great Britain, reported that besides being a public relations disaster for pharmaceuticals, pursuing the lawsuit ran the risk of forcing them to detail business secrets surrounding their pricing, profits and source of funding for their research. In the United States, for example, a lot of tax-paid research through government agencies such as the National Institutes of Health (NIH) have helped bring HIV meds to market. The *Wall Street Journal* reported that five makers of the majority of the HIV drugs available in the U.S. (GlaxoSmithKline, Bristol-Myers Squibb, Roche, Boehringer Ingelheim and Merck) “pushed hard for a settlement” in an effort to avoid further harm to their reputation.

ONE TABLET SUSTIVA

The maker of Sustiva (efavirenz) has applied for Food and Drug Administration (FDA) approval of a 600 mg Sustiva tablet to be taken once a day. Right now, Sustiva is taken as three 200 mg capsules once a day. The new tablet is about the same size as the capsule. A 300 mg tablet formulation has also been applied for, allowing twice a day dosing (if you can tolerate it). The company is hoping to have the new tablets out early next year. Sustiva is a popular non-nuke drug that has been proven to be as effective as some of the protease inhibitors (see below). The most common side effects are nervous system symptoms (including abnormal dreaming, dizziness, insomnia, and impaired concentration) and mild to moderate rash.

MORE SUSTIVA

Sustiva continues to do better at lowering viral load than Crixivan in head-to-head competition, for three years now. “This is important because patients and physicians are looking for treatment regimens that are powerful and durable yet simple to take. A regimen including Sustiva fits this profile and we now have proof that it can sustain its power for a long time,” Madrid researcher Dr. José Arribas said in a company press release.

Using a strict analysis of “non-completer = failure,” 52% of the people on Sustiva/Epivir/AZT (Retrovir) had less than 50 viral load, compared to 30% of the people on Crixivan/Epivir/AZT (Retrovir). However, Crixivan had to be taken every eight hours on an empty stomach, and that’s hard to do. Also, Sustiva has a long “half-life.” It lasts a long time in the body, so a missed dose is not as likely to lead to treatment failure. All of the people were taking anti-HIV drugs for the first time, and these people tend to do better at lowering viral load (the amount of HIV in their blood). Under NC=failure, anyone who stops taking medicine for any reason, such as moving out of the country, is counted as a failure for that regimen.

In a different study, more people were able to maintain undetectable viral load (again, less than 50) after switching to Sustiva from a protease inhibitor than the people who stayed on a PI. After an average of two years on a PI, 94% of people switching to Sustiva remained undetectable for another year, compared to 74% of the people who stayed on their PI. T-cell counts were the same. People may go off a PI because of side effects or rising viral load.

In a separate press release, Sustiva’s manufacturer noted that 94% of people taking Sustiva with two nucleoside drugs (such as AZT and Epivir) in one study had undetectable viral load out to 48 weeks. This compared to 100% of a comparison group of prisoners who took medication under directly observed therapy (DOT). Of the people on

photo by Russell McGonagle

the outside who were not taking a Sustiva combination, 70% had undetectable viral load. According to the release, "These data indicate the benefits of simple, but potent, regimens."

MORE TENOFOVIR

Tenofovir expanded access now has less strict requirements. The company has also applied for FDA approval. So those of you who get the drug for free will have to pay for it almost as soon as you receive it, but if you're desperate you don't have much choice. The once-daily drug is in a new class of HIV meds, nucleotide reverse transcriptase inhibitors. It can be hard to tolerate. Call 1-800-GILEAD-5 (445-3235) for more information.

"NEW" AIDS CANCER

National Cancer Institute researchers suggested in the *Journal of the American Medical Association* (JAMA) that three cancers should be added to the list of AIDS-defining illnesses. They reported that people with AIDS are 11 times more likely to have Hodgkin's disease, three times more likely to have lip cancer and twice as likely to have a type of testicular cancer. At this time, AIDS-defining cancers are non-Hodgkin's lymphoma, Kaposi's sarcoma and cervical cancer. NCI worked with the Danish Epidemiology Science Center on this study.

PERIPHERAL NEUROPATHY

There's now a sequel to the highly readable and enjoyable *Numb Toes and Aching Soles: Coping with Peripheral Neuropathy*. The new book is called *Numb Toes and Other Woes: More on Peripheral Neuropathy*. Author John Senneff digs deeper into pain treatments, with special emphasis on new clinical studies and drugs just coming out of laboratories. Both books are written for patients as well as for their care providers, including medical professionals. The sequel provides more information on nutrient supplementation as an alternative treatment for treating peripheral neuropathy, nerve damage that is common in HIV, both with the virus itself and with the drugs used to fight it. Visit www.medpress.com or call tollfree at 1-888-MED (633)-9898. The 280-page paperback is \$22.95, plus \$5 shipping and handling. We

can't emphasize enough: talk to your doctor right away if you're taking Hivid, Videx or Zerit and you experience tingling in your hands or feet. That innocent tingling can turn into debilitating pain every day for the rest of your life if you don't do something right away! Unfortunately, once PN is established (you didn't do anything to try to stop it early enough), treatments seem to provide only minor and temporary relief.

NEW-FILL POLYLACTIC ACID FOR FACIAL SURGERY

New-Fill polylactic acid is now available in the U.S. through DAAIR (the Direct AIDS Alternative Information Resources, a buyers club in Manhattan). The treatment, available in France but still experimental here, has been getting good reviews from HIV treatment advocates for AIDS-related facial surgery in people who've developed sunken cheeks.

Nelson Vergel of PoWeR (Program for Wellness Restoration) and co-author of *Built to Survive: A Comprehensive Guide to the Medical Use of Anabolic Steroids, Nutrition and Exercise for HIV+ Men and Women*,

Nelson reports that he's getting flooded with calls. Dr. Engelhard was trained in France. One person said his fees are high and noted there are better prices with a surgeon in the San Diego area.

Other U.S. doctors will soon be training for the procedure. For more information, contact Nelson at PoWeRTX@aol.com or see also News Briefs in the March/April issue. Visit www.daair.org or call them tollfree at 1-888-951-5433.

GROCERY SETTLES DISCRIMINATION LAWSUIT

A Missouri grocery store agreed to pay \$80,000 in back wages and damages to a former deli worker, who believed he was fired because he was HIV-positive. Store staff had also disclosed his status to other people.

MARIJUANA IN A BOTTLE

In light of the recent unanimous U.S. Supreme Court decision against medicinal marijuana, it's important to remember that an active ingredient of marijuana is still available in a capsule. The Supreme Court ruled that there is no "medical necessity" exemption to federal drug laws. As a result, medicinal use of marijuana is still illegal under federal law, even though it's allowed in several states. The prescription medicine is called Marinol—how easy is that to remember? Marinol's manufacturer conducted a national survey which found that 93% of the people they talked to knew

that marijuana is used for medicinal purposes, but only a third of them knew that there is a prescription drug available with a synthetic form of an active ingredient found in marijuana. Self-serving, true, but Marinol has a good reputation among HIV treatment advocates, who cite its pain relief, appetite stimulation and feel-good therapy. While some people respond



reported that Dr. Peter Engelhard in Miami is performing New Fill injections (like DAAIR, he also imports the product with an FDA investigational number). Dr. Engelhard's number is 1-305-534-7255, and

better to smoking marijuana, Marinol avoids the bacteria and fungus that may be present in the real thing and also avoids the lung damages of smoking. (Hence the beauty of baked brownies.)

FDA CRACKS DOWN ON HIV DRUG ADS

The Food and Drug Administration (FDA) sent a warning to HIV drug makers to change their ads. The FDA said ads should clearly convey that the drugs do not cure HIV, do not lower the risk of transmission and must be taken in combination with other HIV meds (with the “possible exception” of Trizivir, which is a triple combination in one pill). Also, many ads “show images that are not representative of patients with HIV infection,” such as “robust individuals engaged in strenuous physical activity to healthy-looking individuals giving testimonials.” In addition, “important limitations,” including side effects causing physical deformities, including facial wasting, are not mentioned. All together, these criticisms make for ads that are “misleading,” and are therefore in violation of FDA rules, the letter noted. The FDA gave pharmaceuticals three months to change their ads.

WOMEN’S T-CELLS

You would think that having less HIV in your blood would be an advantage. It ain’t necessarily so.

Different studies have found that women have lower viral loads than men do, but yet they have the same risk of developing AIDS.

The latest report on this topic comes from the March 8 issue of the New England Journal of Medicine (NEJM). Researchers found that women who later developed AIDS had a median starting viral load almost five times less than the level found in men who progressed to AIDS (17,000 vs. 78,000). Even in the people who hadn’t developed AIDS, the men started out with a viral load that was almost four times higher (41,000 vs. 12,000). T-cell counts for all of the men and the women, however, remained about the same from the beginning of infection to the development of AIDS.

So what does this say about women when looking at U.S. treatment guidelines, which specify that people should consider going on HIV meds when their T-cells drop to 350 or their viral load increases to more than 30,000 (bDNA, or the Chiron test) or

55,000 (RT-PCR, or the Roche test)? Doctors are wondering whether T-cells are more important than viral load in determining when to treat women. They’re also wondering about the role of sex hormones and other biological differences in the development of AIDS. Research is still underway to figure out what’s going on here.

The NEJM report came from one of the largest studies ever to examine gender-specific differences of HIV infection (although only 156 men and 46 women were involved). During the first years of HIV infection, women had significantly lower amounts of the virus in their blood than did men. “Despite early differences in viral load among men and women, as time went on, both men and women had a similar risk of developing AIDS,” says lead author of the study Dr. Timothy R. Sterling, in a press release. “In addition, men and women experienced a similar rate of loss of their CD4+ T cells, the immune cells that decrease as a result of HIV infection.” Researchers looked at a group of 200 men and women with a history of injection drug use who participated in a study called ALIVE (AIDS Linked to the Intravenous Experience), which began in 1988. ALIVE used the Roche test for measuring viral loads. Although 90% of the participants were black, the authors noted that neither race nor the route of acquisition of the virus has been found to make a difference in HIV progression. The often-cited study showing the risk of developing AIDS based on viral load levels comes from the Multicenter AIDS Cohort Study (MACS), a study of men.

The authors noted that

- “...a viral load cutoff value above which rapid progression to AIDS can be predicted has not been identified for either men or women.”
- “Later in the course of infection, when the risk of AIDS is greater, there is no longer a sex-based difference in the viral load.”
- “The CD4+ lymphocyte [T-cell] count is critical in predicting the risk of opportunistic infections and is a better predictor of mortality than is the viral load.”

HIV/AIDS SPECIALISTS

The American Academy of HIV Medicine (AAHIVM) has established criteria defining what it means to be a specialist among physicians and other health care workers treating people with HIV. According to an Academy press release, “The Academy’s definition emphasizes that the base line criteria for an HIV specialist is the ability to demonstrate Continuous Professional Development (CPD) in the area of HIV treatment. This differs from other organizations’ definitions that require only that an arbitrary number of patients are seen or units of Continuing Education are completed.” The organization’s minimum number of patients before being considered an HIV specialist is having treated 20 people with HIV within the past two years. It also announced that it expects to complete a list of “core competencies or ‘body of knowledge’ an HIV specialist should possess.” AAHIVM reported that its recommendations “are concurrent with research studies indicating that medical costs are lowered and better health care results when an experienced AIDS specialist physician is consulted in the care of HIV/AIDS patients.” For more information, visit www.aahivm.org. AAHIVM is located in Los Angeles.

YOUNG AIDS ACTIVIST LAID TO REST

Mourners on Saturday packed the funeral of Nkosi Johnson, a 12-year-old AIDS activist who died June 1. The downtown Johannesburg church in South Africa was filled to capacity with several hundred mourners, including former Zambian President Kenneth Kaunda. Banners showing a smiling Nkosi in a baseball cap asked mourners to “Let the love and courage of Xolani Nkosi Johnson fill your heart with determination to care for the infected and orphaned children of our land.” Nkosi was born with HIV. He stirred audiences with his pleas for acceptance of HIV-infected people, winning international fame last July when he addressed the opening of the UN’s 13th International AIDS Conference in Durban, South Africa. “We are all human beings. We are normal,” he said in that speech. Tributes to Nkosi were interspersed between hymns in Zulu, Xhosa and English, with some mourners dancing in the pews, clapping their hands as others wept.—CDC HIV/STD/TB Prevention News Update. ☞



couldn't help asking her, 'Do you need some help?' ...As a person who was informed, I could see and I knew what was happening to her, and it hurt that much worse, but anybody, even an untrained eye, could see that she was going to die. How did they release her from the hospital in this condition?"

“**T**he first woman that died on September 6, 1999, I had seen this woman running around for months. She had pieces of Tampax and Kleenex stuffed up in her nose to stop the flow of blood. Her stomach (she was a little skinny woman) looked like a basketball...”

Judy Ricci, an HIV-positive inmate at the Central California Women's Facility, knew that she was watching end-stage liver disease slowly kill a fellow HIV-positive inmate. Medical providers had failed to realize that the woman's co-infection with hepatitis C had reached a critical point. Ricci made the above statement at a state legislative hearing in October 2000, and went on to describe an encounter with the other inmate two days before the woman's death.

“Her eyes were literally the color of a pumpkin. I had never approached this woman, because while I knew what she had... I didn't want to break her confidentiality and I didn't want to offend her. But I

In many ways, HIV-positive women are already left with the dregs of this nation's healthcare resources. As the above testimony suggests, HIV-positive women who are incarcerated often get the dregs of the dregs. And providing prevention education to uninfected women who are incarcerated is a tremendous challenge.

Women who seek medical treatment for their HIV infection run the risk of being seen by doctors without any expertise in HIV care. Prison regulations often make it extremely difficult for inmates to comply with complicated instructions on when and how to take HIV medications. Thus they are at high risk for developing drug resistance. Also, inmates often are not educated about the potential side effects of the drugs. Some women are so alarmed by the severity of the side effects that they discontinue their regimens—an even faster route to drug resistance.

HIV
3 4 58 9

Incarcerated.
5 6 7 5 17 2 5 8 8 8 10 8 8 7

Women
0 17 83 4 58 36

by Kelly
Safreed
Harmon

**You need to be
'out' about having
HIV. Say, "I'm
HIV-positive, and
I'm getting
educated, and taking
care of myself..."**

Skeptical or indifferent prison staff are slow to respond to women's requests for medical care—even urgent requests relating to severe health problems. Incarcerated HIV-positive women and their advocates charge that when the women demand treatment or protest against policies that endanger their health, administrators retaliate with punitive measures.

On top of all this, incarcerated women often see their confidentiality violated when they test HIV-positive or when they seek medical care for HIV infection. Women who are known to be HIV-positive are subjected to derogatory remarks by their fellow inmates and by the staff. This verbal harassment can be devastating—Dr. Anne De Groot, co-chair of Brown University's HIV and Hepatitis Education Prison Project, recalls one woman who tried to scrub her skin off with a scouring brush after being told derisively that she "smelled like an AIDS patient."

SPEAKING OUT

It's no wonder that many HIV-positive inmates don't seek treatment, or that many inmates who don't know their HIV status refuse to get tested. But as dangerous as it

may seem for women to speak out about HIV-related issues, the perils of remaining silent must also be considered.

"It really is self-advocacy that gets anybody anything in the prison system," says Judy Greenspan, chairperson of the HIV in Prison Committee of California Prison Focus. "Men are so much better at it than women are."

Paulette Santos-Martinez of Oakland, who learned that she was HIV-positive not long before beginning a two-year prison term, urges HIV-positive incarcerated women to "take pen and paper in hand" and fight for their rights. Santos-Martinez, who repeatedly submitted grievances during her mid-1990s prison term, stresses, "You gotta make that fight for yourself."

Despite the potential for negative repercussions, De Groot's most emphatic message is, "You need to be 'out' about having HIV. Say, 'I'm HIV-positive, and I'm getting educated, and taking care of myself and my sis-

ters because I care.' There needs to be a sense of pride on the part of women inmates, a sense of 'I have this infection, and I'm going to take charge, not let it take charge of me.'"

FAMILY AND COMMUNITY

"I really believe that women are motivated by more than themselves. They're motivated by the communities in which they live, and by their responsibilities to their children and partners," De Groot says, naming a core issue for HIV-positive incarcerated women. "My patients want me to write down their T-cell counts and viral loads and explain to them what it means, so that when they call home, they can explain it to their family members."

When he is asked about this population's greatest concerns, Carlos Arboleda, Director of Treatment Education and Advocacy at the National Minority AIDS Council, says that many women are wondering, "What's going to happen to my children?"

Arboleda also notes that many HIV-positive mothers are intent on passing the lessons they have learned to their children. "When the children visit, [their mothers] want to make sure they're not having unpro-

ALARMING STATISTICS ABOUT INCARCERATED WOMEN

by Anne S. De Groot, M.D.

This text is excerpted from the April 2000 issue of HEPP News, which is published monthly by the Brown University HIV and Hepatitis Education Prison Project. The full article, including references, can be found in the HEPP News archives at www.hivcorrections.org.

Even though women are less likely to be incarcerated than men (one in 10 inmates in U.S. prisons and jails is a woman), incarcerated women are three times more likely to be HIV infected than incarcerated men. The proportion of inmates with HIV (U.S. prisons: 2.3% of men and 3.5% of women) is much higher than the proportion of HIV infected persons in the general population (U.S. free population: 0.6% of men, 0.1% of women). This

difference is amplified in the Northeast, where HIV prevalence among incarcerated men is 7% and 13% among incarcerated women.

In addition, the number of HIV infected women in prison has risen steadily since 1980, due in part to the steady increase in the total number of women who are incarcerated. The prevalence of HIV infection among incarcerated women rose 88% in 1995, while the rate among men rose 28%.

In most prison systems, the prevalence of HIV among women is two to three-fold higher than in men. Numerous studies have shown that the same behaviors that lead to incarceration put women at increased risk for HIV infection. Links between drug use, sex work, victimization, poverty, race and HIV explain the prevalence of HIV infected women behind prison walls.

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tected sex—they don't want it to happen to them.”

Unfortunately, making the transition from prison back to the outside world poses major challenges. Santos-Martinez suggests that getting involved in the AIDS community outside of prison is a useful strategy for HIV-positive women who are trying to take good care of themselves. But she observes that many HIV-positive women leave prison maintaining a state of denial about their health. “Some of them go right back to prostituting, without using condoms, and they *know* they're HIV-positive,” she says.

Prevention education programs give some female inmates an invaluable opportunity to learn how to protect against HIV, but these women run into difficulty when they try to implement their knowledge in the outside world. Felicia Davidson, a program coordinator at the Women's Project in Little Rock, Arkansas, hears a common story from clients returning to relationships with men. “Their concern is, ‘How will I know if he's been messing around on me?’” When the women ask their male partners to use condoms, Davidson says, the men often refuse, and some men respond with physical violence.

Women have also told Davidson about another common response. “The male partner asks them, ‘What have you been doing while you were incarcerated? You must have been fooling around with somebody in there.’ He throws the blame on her, and just keeps beating at her until she gives up. Since she's been in prison, she feels like she's not worth anything.”

The only advice that Davidson can offer is that women should persist in trying to protect their health. She recommends that both partners get tested for HIV, and that they practice safer sex until they have received accurate test results. Also, “be sure you're in a monogamous relationship before you take that condom off.”

PREVENTION WITHIN PRISONS

Prevention education programs also raise women's awareness about protecting themselves against HIV and other sexually transmitted diseases (STDs) while they are

incarcerated. Although female-to-female sexual transmission of HIV is thought to be extremely rare, it is certainly possible for HIV to pass from one woman to another through blood or vaginal fluids.

Female-to-female exposure to blood and vaginal fluids can occur when one woman puts her fingers or hand in her partner's vagina or anus, as well as when a woman “goes down on” or “rims” her partner, i.e. mouth-to-genitals or mouth-to-anus sex. (There are other female-to-female activities that can transmit HIV as well. Inmates who want more detailed information can request free copies of a brochure called “Woman to Woman: Sexually Transmitted Diseases” from the Whitman-Walker Clinic, 1407 S Street, N.W., Washington, DC 20009.)

Given the relatively high number of HIV-positive incarcerated women in prisons (see sidebar), women who have unprotected sex with each other are definitely taking a risk. And even though female-to-female intercourse doesn't provide the HIV virus with abundant opportunities to spread, it does provide a major gateway for other STDs, such as syphilis, hepatitis B, gonorrhea, human papilloma virus (HPV) and yeast infections.

Recent reports on the status of women inmates in the U.S. have revealed the following:

- 84% of the total U.S. female inmate population, or 65,338 women, reported a history of “ever” using drugs. 74% used drugs regularly.
- Most of the 84,400 women who were in prison in 1998 were incarcerated in state facilities (63,735). 37% of state women inmates were charged with drug-related offenses, while 72% of women in federal prisons were charged with drug-related offenses. Since 1980, the rate of incarceration of women for drug charges has increased three-fold, (11% to 34%), while the rate of incarceration for violent offense has declined by half (49% to 28%).

- Almost two-thirds of women in prison are women of color. Black women are twice as likely as Hispanic women and eight times more likely than White women to be in prison. HIV has disproportionately impacted women of color in recent years.
- According to self reported data, between one half and two thirds of incarcerated women have been physically or sexually abused before incarceration. These figures probably underestimate the prevalence of such histories among incarcerated women.

Incarcerated women frequently report histories of sexual and physical abuse. As many as two in three incarcerated women (33–65%) report prior sexual abuse and as many as two in five

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sometimes forcefully
and sometimes
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In many prisons, safer sex remains an elusive goal because supplies such as dental dams, condoms (which, although not ideal, can be adapted for female-to-female protection) and latex gloves are not permitted. Davidson's organization does HIV prevention education in an Arkansas women's prison, but she and her colleagues are not allowed to distribute supplies.

"For some reason, [administrators] don't think sex happens in their prison system," Davidson says. "But it happens, sometimes forcefully and sometimes without consent. There's a lot of homosexual activity in prison. [Women inmates] tell me sex is a God-given instinct, and just because you're incarcerated, your sex drive is not alleviated."

The measures suggested by Davidson's organization provide a disturbing illustration of the plight facing sexually active inmates. "We tell them to use bread sacks, cookie wrap paper, any kind of barrier to keep from sharing body fluids," Davidson says. The strategy: some protection is better than none at all. *(Author's note: latex barriers such as condoms, latex gloves and dental dams are the ONLY barriers recommended for reducing the risk of HIV transmission. Anyone who uses any other materials should keep in*

mind that alternatives to latex barriers could be significantly less effective.)

HIV-POSITIVE WOMEN TAKING CHARGE

As the prohibition against safer sex demonstrates, one of the most pervasive challenges facing prisoners is their lack of control over their circumstances. How can an HIV-positive woman living in such a tightly regulated environment exercise any influence over her well-being?

While the obstacles may be monumental, the fact remains that some HIV-positive women inmates are taking charge of their physical and emotional health to a surprising extent. Greenspan, who has worked with many HIV-positive women inmates in her long activist career, recommends a concrete strategy that is extremely important: use the available resources (such as the prison library and information mailed from outside) to learn as much as possible about HIV, so that you can become your own medical advocate.

"This means going in to the doctor knowing about everything from what your viral load means to what the newest drugs are," she says.

Greenspan illustrates her point by describing a California prison where HIV-positive women were being treated by a retired pediatrician with no expertise in the AIDS field. Time after time, the women who had done their HIV homework told him what they had learned—and this particular doctor listened. "By the time he left, he knew a lot about HIV."

Even in the absence of supportive relationships, Santos-Martinez maintains that there are still ways for HIV-positive women to protect their welfare behind bars.

"You can always do *something*," she says emphatically. If nothing else, she urges, "keep a positive mind, and be strong, and hold your head up. And when you get out of prison, go in the right direction." ✚

(19–42%) report a history of childhood sexual abuse. More than 80% of women in prison have experienced significant and prolonged exposure to physical abuse by family members or intimates. In contrast, in studies of women who are not currently incarcerated, approximately one in seven women reported a history of forced sex, one in five women (20%) report a history of childhood sexual abuse, and about one in four (25%) women report a history of physical abuse. (Note that these studies of women in "free living" communities did not explore histories of incarceration, thus there may be some overlap between the populations). The impact of prolonged sexual and physical abuse prior to incarceration on incarcerated women's health care, mental health care, and risk behaviors is thought to be profound.

SPECIAL WOMEN'S PRISON ISSUE

Activists Judy Greenspan and Beth Feinberg of the HIV in Prison Committee are co-editing a special edition of *Sinister Wisdom*, the nation's oldest lesbian literary journal, for an issue devoted to women loving women in prison. The edition is open to all sexual orientations (lesbian, bi, straight, two-spirit, queer, questioning) as well as transgender women. Submissions may be fiction, non-fiction, poetry, short stories, articles, artwork, cartoons, photographs, graphics, or any other paper-based medium. Written material should be limited to 10 hand-written or 8 double-spaced typewritten pages. Names can be kept confidential. Please send material to Judy and Beth c/o Sinister Wisdom, P.O. Box 3252, Berkeley, CA 94703. The deadline is September 15. This issue is open to all current and former prisoners, their lovers, ex-lovers, and other women on the outside.

HIV Prevention For Inmates

by Charles E. Clifton

In 1997, 22,518 state inmates and 1,030 federal inmates were known to be infected with HIV and 538 inmates died as a result of HIV disease. By the end of 1997, the rates of confirmed AIDS in prison (55 per 10,000 inmates) was more than five times the rate in the general population in the United States (10 per 10,000 U.S. residents age 13 or older).

The majority of positive inmates in the U.S. correctional system have no idea that they have HIV until they are incarcerated. For many being imprisoned provides their first access to healthcare. Michael, who served a five year sentence in the Mississippi State Prison at Parchman, was one such individual. "I thought I was the shit until I was busted. I came to jail 10 years ago. I tested positive 10 years ago. I couldn't believe that I was positive. I ain't gay. I wasn't shootin' up. But there

it was—19 years old, imprisoned for life and HIV-positive. Ain't that some shit."

Michael, who now lives in Jackson, Mississippi, states that he "ain't gay." However, prior to his conviction, Michael was sexually active with both men and women, exchanging sexual favors for money, cars, alcohol and drugs. "I lived the high life at an early age. Yeah, I got off on my smoke and drink, but you couldn't tell me nothin' back then. I knew it all."

Drug and alcohol abuse and addiction was implicated in the incarceration of 80 percent of the 1.7 million adults incarcerated at year-end 1996. This included those who violated drug or alcohol laws, were intoxicated at the time they committed their crimes, stole property to buy drugs, or reported using drugs regularly.

Michael, like many after learning that they are HIV-positive, sank into a state of

depression for the first two years of incarceration. "On top of that," he continues, "I lived in complete fear of others discovering my nasty little secret. Slowly I came around. I know I've only lived this long with this disease because I started to seek medical and psychological help. If I'm going to be around here for a long time, I have to take care of myself."

While it would seem logical to provide treatment to people while they are incarcerated, the reality is that few inmates received adequate substance abuse treatment. Billy Rose, a former inmate from Wisconsin, states that, "Sadly, many prisoners don't look for available help from the support groups already existing in the prisons. They isolate themselves until it's too late...until they have obvious signs of disease. Prison is a horrible place for anyone, but especially for HIV-positive individuals. It is 100% necessary for an

From a Positive Prisoner

by Kevin Lisboa

Cayuga Correctional Facility, New York



HOW ARE HIV MEDICATIONS GIVEN OUT?

Well, not on time. If you're on a HAART regimen [highly active anti-retroviral therapy] and you miss two to three days, you could get resistant. You put in for a refill and I've been weeks without it. It varies from jail to jail. The jail I was in before here was a joke, three weeks [wait] for my Videx and Viracept. See, I was on Sustiva. They took three weeks because they order from a pharmacy in Pennsylvania, so I grew resistant.

WHAT'S THE FOOD LIKE?

A joke. People (inmates) with HIV are treated just like crap, even worse. Special diets—forget it. You can't get Ensure [a nutritional supplement] unless you can show that you lost more than 10 pounds in one week. You get no preventive medicine. Yes, you get vitamins, but you must give blood in

order to get them. Sort of like, you give me and I give you. The blood is then sold to universities for studies. We're laboratory monkeys. If you get a rash or shit like that, you don't get any lotion. Everything has to be pre-approved. The doctor controls everything you do, from where you sleep to what you eat, and nine out of 10 of the doctors are unprofessional.

IS CONFIDENTIALITY A POSSIBILITY?

Zero. Nada. Once you come to jail your confidentiality is blown. They give you bags of medication in front of everyone. They talk openly about AIDS—your personal problems—in front of whomever. The officers make jokes. In March when I caught shingles, the officer got on the loudspeaker and said, "Get away from Lisboa. He's got the monster [AIDS]." Can I report him? Yes. Will

HIV-positive person to seek out support in order to survive.”

Many HIV-positive incarcerated individuals suffer from the horrors of childhood sexual abuse. The relationship between childhood sexual abuse and high-risk sexual activity as adults is a case history that isn't well documented. (See “Women incest survivors in prison.”) One HIV-positive inmate from California writes, “You see, as a child I survived sexual assaults by members of my family. I go through fits, flashbacks, nightmares, headaches, severe depressions, and extreme nervousness. I've been through a war...veterans are decorated...they get a Purple Heart. I'm wounded and mentally disable. I've been fighting for my dignity, personal power, safety and freedom since infancy.” Providing HIV prevention education while inmates are incarcerated may help them adopt safer behaviors and reduce their risk of acquiring and transmitting HIV.

Many correctional institutions are as large as, and operated like, small towns. And even though it is prohibited, drug use and

sexual activity do take place in correctional facilities and HIV can be transmitted through these activities. Larry Baker, an HIV advocate in the Louisiana State Prison, writes, “Angola [State Prison] is a city itself, covering 18,000 acres. It has its own Post Office, hospital, mental health hospital, and fire department, even its own State Police Department. It operates as the nation's largest prison ever in existence, housing 5,200 inmates, including Louisiana's only Death Row and location of executions carried out in the state. We not only have apartments for employees to sleep overnight in, but also even have a section for employees to live with their families. Like I said, Angola is a city itself.”

The primary concern in any correctional facility is security, which can result in a reluctance to collaborate with outsiders. However, correctional settings provide an opportunity to deliver prevention messages to individuals who can be very hard to reach once they are released. Many correctional facilities provide voluntary HIV counseling

and testing services, which is a unique opportunity to provide this service to a high-risk population.

According to the Justice Department's Bureau of Justice Statistics, the nation's prisons and jails held 1,860,520 inmates at mid-year 1999. If current growth trends continue, the jail and prison population will reach two million by the end of 2001. Correctional populations have higher rates of HIV/AIDS, as well as sexually transmitted diseases (STDs), tuberculosis (TB), and more risk factors for these diseases than the general population. Yet, the challenge of providing effective HIV prevention programs in correctional settings means that many inmates return to their communities without adopting safer behaviors. ☩

This text is partially excerpted from the September 2000 NASTAD HIV Prevention Fact Sheet, HIV in Correctional Facilities, which was published by the National Alliance of State and Territorial AIDS Directors, www.NASTAD.org.

anything change? No. See, once you complain about this or that, they isolate you. I've been in five different jails. In maximum security, you get just a little more of what you are entitled to. Medium security is a joke. They know you are close to your board [being released], so they won't give you what you need, and if you write to Albany (central office) they lock you up in solitary confinement. They will either find a razor on you or write a misbehavior report for anything.

ARE SUPPORT GROUPS AVAILABLE?

Varies with the jail. Some jails don't allow more than five inmates gathering because of gangs. So if you're HIV don't come to jail. It's like being in hell. You are humiliated constantly, laughed at. See, the officers here are mostly uneducated and they stereotype you. If you're HIV they say, “He's gay.” About four months ago, a C.O. [correctional officer] told me, “Hey, you like ass?” I said, “If it's your wife's.” Then I told him the

only meat I eat has to smell like fish and taste like chicken. He didn't lock me up. I never stay quiet. I do get what I'm entitled to, even if it costs me my TV or phone or yard privileges.

WHAT IS THE HEALTHCARE SITUATION?

Some guys get hep C. They tell you the meds are too expensive. Why spend money on you when AIDS is going to kill you? The state won't pay for hep C meds and you won't get them while in jail. To see an AIDS specialist they chain you and take you to another facility where you would wait eight hours to see a TV monitor—yes, a TV doctor. If you have an infection he can't see it on TV. He can't even touch you. He's 300 miles away. When I was on Crixivan I used to urinate blood from time to time. No kidney stones, just peeing blood. The nurse would ask, “Did you just masturbate?” No skills. Shit, if you jerk often and bleed, you must be a hell of a beater.

You don't get to see a doctor, only a nurse and LPN [licensed nurse practitioner], if you're lucky, a PA [physician's assistant]. God forbid you put down for sick call and you ain't really sick—\$5 and a ticket. See, it has to be what they say. If you have an emergency and they believe it's not, you get a ticket and \$5 [fine]. You pay those \$5 out of what your family sends you. The system is so screwed up and no one is doing nothing. The C.O.s get away with whatever. In '96, before I went home, two of my friends died in here. No family, no nothing. The times they were in the hospital they were not attended to.

I don't know what else to tell you. I could tell you so much, yet not tell you nothing. ☩

Kevin Lisboa is a prisoner in touch with the staff of Positively Aware. He never complains, and he always makes us laugh. You can write to him at Kevin Lisboa #98A5826, Cayuga Correctional Facility, P.O. Box 1186, Moravia, New York 13118 C-1 21B.

Death of Another Woman

by Judy Greenspan,
HIV in Prison Committee

In all of my years of prisoner advocacy, I have never had a more nightmarish and haunting night than my visit with women prisoners at the Central California Women's Facility in Chowchilla on Friday, December 15, 2000. Members of the HIV in Prison Committee of California Prison Focus (including myself) witnessed the seventh death of a woman prisoner since November 9th.

We undertook this visit to continue our advocacy efforts on behalf of women prisoners with HIV, hepatitis C and other serious illnesses. We visited with a woman who recently suffered a stroke after being forced to take the wrong medications by prison medical staff. We visited with women with hepatitis C who are not receiving any education, care monitoring or treatment for their disease. We visited with a woman living with HIV who recently survived an attack of AIDS-related pneumonia without receiving any medical treatment from prison staff. We talked with every woman about the six deaths that occurred since November 9—three of the women who died had HIV (and possible hepatitis C co-infection). (And, by the way, the local county coroner has a policy of not doing autopsies on HIV-positive women prisoners, so we will never know the real cause of medical neglect that precipitated their deaths.)

At about 6:45 pm, we saw a group of guards and MTAs (Medical Technical Assistants) race to the back room behind the visiting room. While we could see only bits and pieces of what was going on, there was clearly a medical emergency happening. Not surprisingly, six deaths in a month made medical staff respond quite quickly to this emergency. An IV pole was brought in and MTAs were trying to perform CPR on a yet unidentified prisoner. We could see much of the motion but not the whole picture. Several of the women prisoners in the visiting room were standing on benches near the window so that they could see what was hap-

pening. There was a lot of commotion going on. One of the women who had a good view of the back room said that the woman on the floor wasn't breathing anymore.

We knew the woman was dead when guards forced the two women porters in the visiting room to go into the back room and don gowns, masks, goggles, and gloves to clean up the bodily fluids that the woman expelled all over the floor before dying. The guards just stood around without any expression—supervising. The terrified look in the eyes of those two women continues to haunt me. They were porters in the visiting room and never expected to have to clean up vomit, urine and excrement after a woman had died. Are there any international human rights sanctions against this callous abuse of women prisoners?

The death took about 45 minutes, during which time no prisoner was able to move in or out of the visiting room. At least 15-20 women prisoners also witnessed this death. I can only imagine how women inside CCWF are feeling right now—seven deaths, who is next?

We are demanding (even louder than before) an independent investigation into these deaths. We have asked California State Senator Richard Polanco, Chair of the Joint Subcommittee on Prison Construction and Operations, to conduct this investigation, and to bring in a panel of doctors and specialists to review these women's medical files. We have also demanded that the MTA system be suspended and competent medical staff be brought in from the public health sector to save the women's lives. This is a life and death situation for the women inside CCWF. If something is not done soon, many more women will die.

The women prisoners I was meeting with have seen a lot of death and dying inside the Central California Women's Facility, but even they are deeply affected by the current death toll. These seven deaths come in the wake of the dismissal of the Shumate case

(class action litigation challenging medical neglect and abuse at CCWF and another women's prison) and the historical two-day long legislative hearings held in October inside two California women's prisons.

I can only conclude that there is a war going on against our sisters at CCWF and they are losing.

Please call, fax or write to Senator Polanco today. The address is:

Senator Richard Polanco,
Chairperson
Joint Committee on Prison
Construction and Operations
Room 400 State Capitol
Sacramento, CA 95814
Phone: (916) 324-6175;
Fax: (916) 327-8817

We are working within a coalition of groups to stop the death toll at CCWF. Contact us [see Resources] to get involved and to get on our rapid response list. We will post events on our web page (www.prisons.org/hivin.htm) and also keep you informed. Keep in touch. We need to let the women inside know that they are not alone and that we support their right to live and to receive health care.

CHOWCHILLA PETITION

Women prisoners are fighting for their lives. Join the fight for adequate medical care for HIV-positive women at Chowchilla. Women with HIV receive substandard care. They are forced to stand in line outside in the raw valley weather once a day (for one to two hours) to receive their daily bag of HIV medicine. Women who are too ill to stand in the med line do not get their medications at all. Medications are still not renewed in a timely fashion. Opportunistic infections are often misdiagnosed due to the ignorance of medical staff. HIV-positive women feel that their confidentiality is continually violated by the med line. Women prisoners want consistent,

Prisoner



adequate and accessible HIV care. What you can do: Send a protest letter!
(Sample letter)

To: Warden Teena Farmon
P.O. Box 1501
Chowchilla, CA 93610
Fax: (559) 665-7158

I am deeply concerned about the mistreatment of HIV-positive women at the Central California Women's Facility. Forcing women to stand outside in med line in inclement weather does not guarantee consistent access to life-extending HIV medications. Women who are too ill to stand in line are not receiving their HIV medications. The confidentiality of HIV-positive prisoners is being violated on a daily basis on pill call line. Many women with HIV have already quit their HIV therapy due to the hardship of standing in line and the confidentiality violations. We urge you to provide consistent, adequate, confidential and accessible HIV care. Women prisoners deserve the dignity of taking their medication on their own in the privacy of their cells.

Sincerely,

(Your name and signature)

CC: Director C.A. Terhune,
California Department of
Corrections,
P.O. Box 942883,
Sacramento, CA 94283;
fax: (916) 322-2877

Show your support to the women inside by sending letters and stamps to Beverly Henry, W72830, 510-06-02L and Judy Ricci, W69939, 511-16-1L, both at P.O. Box 1508, Chowchilla, CA 93610. ☒☒

by Judy Greenspan,
HIV in Prison Committee

On October 11 and 12, 2000, women prisoners finally got the opportunity to tell state legislators about the abuse and neglect that they are suffering inside. The HIV in Prison Committee, along with other Bay area prisoner advocacy groups, participated in and helped to organize the October 11 hearing, which focused primarily on exposing the crisis in care at two of California's women's prisons: the Central California Women's Facility (CCWF), and Valley State Prison for Women (VSPW).

On October 11, HIP along with a coalition of other organizations (including Legal Services for Prisoners with Children, Justice NOW and the California Coalition for Women Prisoners) attended and gave testimony at a legislative hearing held inside. This hearing was called by Senator Richard Polanco's Joint Committee on Prison Construction and Operations in response to serious allegations of abuse and medical neglect by women prisoners and their advocates. Fifteen women prisoners braved possible retaliation to testify and expose all aspects of medical neglect, sexual harassment and abuse inside both prisons, which together house approximately 7,000 women and sit across the road from each other in Chowchilla, California—the largest women's prison complex in the world.

Some of the most moving testimony was given by three women prisoners who openly spoke about being co-infected with HIV and hepatitis C. These women testified on behalf of many others inside CCWF who are suffering daily due to the prison system's refusal to seriously deal with either of these two life-threatening diseases. Over the past two years, several co-infected women have died from hepatitis C-related liver failure. We hope that some of the policy recommendations are taken seriously and acted upon by Senator Polanco's committee. Clearly the lives of thousands of women prisoners (and men prisoners) depend upon it.

BEVERLY HENRY

I watched two women die on my yard. If I can see that the whites of their eyes are as yellow as a caution sign then why couldn't somebody else? I watched a woman's waist go from approximately 26 to 60 inches because her liver was cirrhotic. She could not wear shoes. She looked nine months pregnant and every day she asked me, "Am I going to die here? Do you think that is what is going to happen to me?" And there was nothing we could do about it. I know a compassionate release, at least, should be asked for these women. But they are not going to give it to them because you have to get the doctors to say that you have only six months left to live. They don't feel that is necessary because you are not laying flat on your back. I have approximately 10 years left in prison living with both of these diseases. I know 13 people died in 1999 and that scares me. How long will I remain asymptomatic?

I also have a problem with confidentiality at med line. No, I do not take meds and I made that conscious choice based on the knowledge that I have. For the women who have to take meds, these lines last a long time. They have to stand in extreme heat, they stand in severe cold weather just to get their regimen. In my personal opinion, these medications could be administered in their rooms. This is not Valium, this is not



Vicadin. These are antivirals that you take for HIV. If you are the only woman standing in line picking up a 3-med package every single day, someone is going to ask what are you taking. A lot of these women have come to us and told us that they don't want to go get their meds because they would rather take them in their room—why does everyone have to know?

HIV meds should be given in a monthly supply. I feel that women who are on these meds when their prescriptions run out, they should be expeditiously refilled. It is very important that treatment is adhered to. When a woman is positive the yard doctor should explain things to them because many of the women have no knowledge of their treatment. Someone just tells them, "I am putting you on this regimen and you take it." That's not enough. No one is telling her how important it is that she sticks to this regimen. No one is telling her what's going to happen when she takes these pills and her body starts experiencing side effects and she doesn't know what to do.

We have a lady on our yard who had a shingles outbreak. I knew exactly what I was looking at and I watched this woman be turned away and told that those were water blisters. An RN gave her some paper towels so that her underarms would not touch the sides of her breasts and told her to go back to her unit. It couldn't hurt that bad. She went back to her unit and tried to pop her blisters and those that she popped, of course they spread. This woman is now in the treatment center where she needed to be in the first place. I feel that when HIV-positive inmates and hepatitis C positive people come over to that med line and they are telling you their symptoms, someone needs to really pay attention because I know that they know who we are.

THERESA MARTINEZ

I have educated myself with the help of everyone else because CCWF doesn't take the time to take into consideration that some of us who do come into the prison in denial don't know the first thing about our diseases. One of my concerns is about peer counseling. We are not given any type of counseling. There is a peer counseling office and while we have just been assigned a new program by Centerforce, they have had nothing to do with the past two years that I have been here. But as far as counseling, it should not be up to an inmate to have to sit and figure out what my T-cell count is and what it means to me. They shouldn't have to figure out what the rash is on the side of my stomach. They shouldn't have to go into the bathroom when I have an outbreak of herpes in my vaginal area and counsel me.

Another issue that I would like to ask for help on is the special diets. CCWF has no special diets. I am on a protease inhibitor

called Viracept. I have not seen a raw carrot or raw celery since I have been there. There are no vegetables that are given to us that are not boiled and soggy. I am not asking them to put out a buffet for me. All I am asking is to help make my medication, my treatment, easier to work for me. I am trying to stay alive in prison.

JUDY RICCI

Since I have been here, I have met literally hundreds of women who are infected with hepatitis C. I met them because I am really open about my disease. I like to talk about HIV and hepatitis C. I like to learn about it because I believe my survival depends upon it. I like to share the information that I have with other women who may not be able to read it so that they can survive. I have met a lot of women who have been incarcerated 10 or 15 years and are just finding out this year or last year that they are hepatitis C positive. And guess what! It was in their file for 10 years. How do you let somebody run around not knowing that they have a life threatening communicable disease? What if that woman goes home and transmits that disease to someone else in ignorance? That whole idea breaks my heart. I don't want anybody to live with what I live with. I mean, I am healthy today. I am running around. I'm jazzy today. In two years, I could be falling apart and I wouldn't wish my disease on another person.

Something like 88% of our HIV-positive women also have hepatitis C because it was transmitted by IV drug use. So TB meds are really liver toxic. The second woman who died, I believe died because she was given TB medication. She never had TB. If a person is not having symptoms, they are not spitting blood, they don't have a fever, they don't have night sweats and you suspect that they have an active TB infection, then you isolate them. You should do a culture. This woman stayed for 14 days in isolation and when she came back her stomach was already distended. They offered to drain her stomach in our infirmary. Our infirmary has no emergency equipment. It's got a couple of gurneys and a curtain. She asked for a six-month chrono [for compassionate release] because it became apparent to her that she was going to lose her life. And this was denied. [She died on October 22, 1999.]

You know, 54% of our female population has hepatitis C. If we have 3,600 women, then 54% is 1,944 women. We are always hearing that we're just prisoners and CDC [California Department of Corrections] doesn't have money for hepatitis C treatment. How come they returned \$1.7 million dollars in 1998 that was designated for hepatitis C research and treatment in CDC? They didn't know what to do with it? ☘

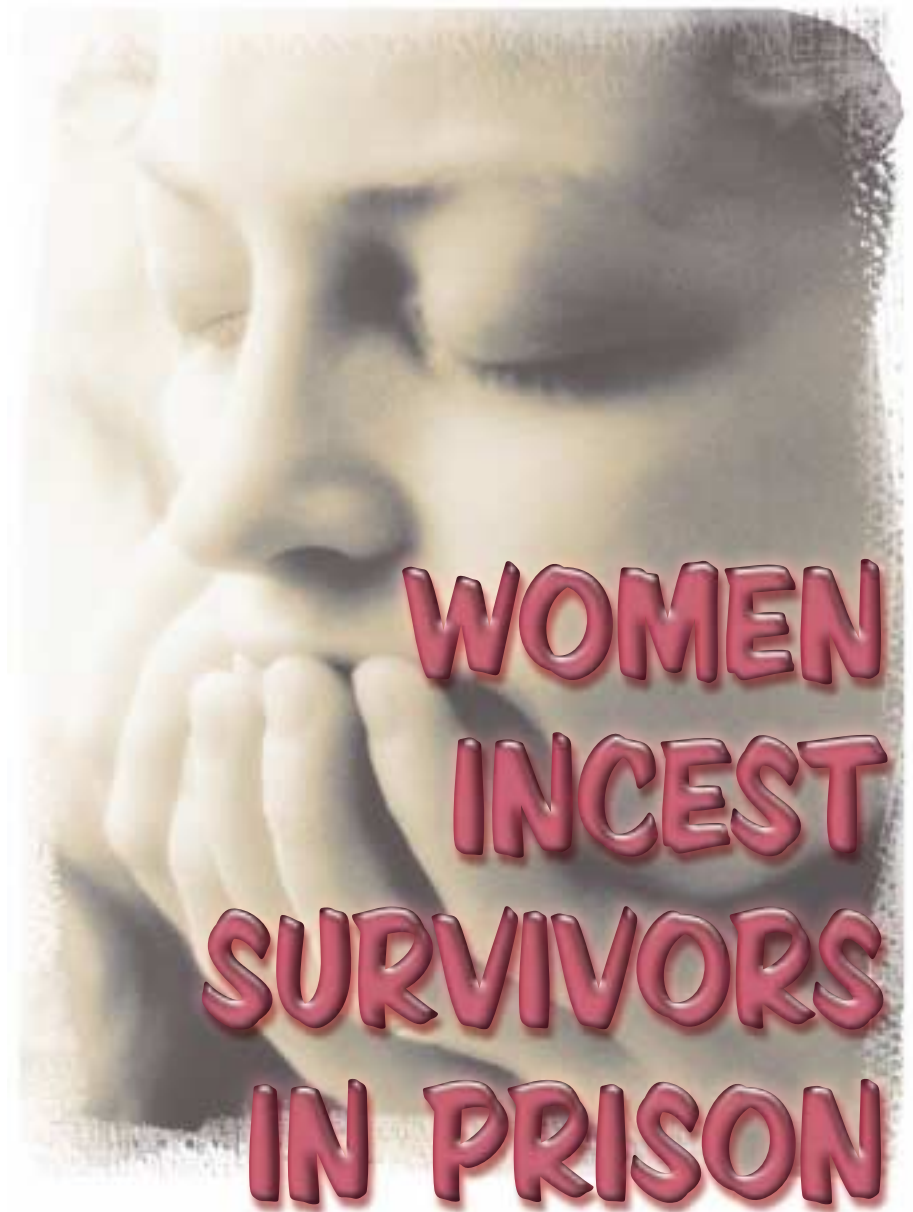
AN OPEN LETTER FROM A PRISON DOCTOR TO THOSE WHO CARE FOR WOMEN LIVING WITH HIV

by Anne S. De Groot, M.D.

I have been providing medical care to HIV infected women who are incarcerated at a prison in Massachusetts since 1992. Working with the HIV-positive women at that clinic opened my eyes to their struggles. I am amazed that they have been able to survive such difficult lives, and I have been deeply affected by their strength, their joys and their sorrows. I wrote this short piece on Friday night, July 28, 1995, after attending HIV clinic at the prison. Some of the details of this story have been changed, to protect my patients.

It is Friday night after HIV clinic. I am lying in bed holding my daughter in my arms. Her face is moonshaped and turned up to the light coming through the windows. She is beautiful, she is two, she is a small but precious vessel of joy. During the day time her joy spills over and over as she laughs and plays.

I cannot sleep. It is not because the heat is oppressive, it is not because the sprinklers outside are turning incessantly, it is not because the trees make scary shadows on the wall. I cannot sleep because I cannot forget what X told me about her father today. "When I went home at Thanksgiving he grabbed my breasts, and my ass" and "it happened again at Easter." She told me it started when she was three "but it was only oral sex" and it continued until she was 13. She said "he never penetrated me" ...except one time, he almost did, in the toolshed, and she doesn't remember exactly what happened, but it stopped after that. There was a divorce and a custody battle and she ran away to Florida to live a different kind of life when she was in her early teens. She returned to her father's house when she was seventeen, and one day, when her stepmother and stepsister had left the house, he tried to get her to do it again.



WOMEN INCEST SURVIVORS IN PRISON

He walked into the kitchen "you know, like that" (making a gesture to show a man who had nothing on below his waist). She said that she laughed nervously and said, "No, Dad, I really don't want to do that now" (I wish I could make you hear the voice that she used to say this last sentence, because it sounded so childlike and pleading and I felt that I was standing in the kitchen watching this happen) and he said, "Why not? You would do it if I paid you."

In my clinic today, she said "When I found out I had HIV I was happy, because I thought he would never touch me again." She said, "I thought if I got fat and really ugly, nobody would want to touch me." She told her father that she had HIV—she even

said she had AIDS, but it didn't make a difference at Thanksgiving.

I can't get this out of my head tonight. X had just finished a post-incarceration drug abuse recovery program, and had returned home for Thanksgiving, when her father touched her again. She had just finished the program, she felt safer and stronger, she thought she was protected by her HIV, and he invaded her space anyway. After Thanksgiving she started eating to keep from using drugs again, and purging to get clean, and eating and purging. She didn't pick up drugging again, even though her self esteem had hit rock bottom. Her father tried to touch her again at the next family reunion.

Just a few weeks later she went along with some friends who had decided to start using drugs again, and she ended up back in prison, where I saw her looking huge and not at all HIV-positive but bruised and ashamed to be back inside. She couldn't say, at that time, why she came back (now she says that she was still "too much inside of it"), even though I tried very hard to learn from her where the weakness lay in someone I knew to be resolved to recover and dedicated to avoiding reincarceration. Today, after she finally told me about her reasons for returning, she said that she felt a huge weight leave her. I asked her if I could write it all down, especially this part that just happened, so that we could use her story as a tool to change this terrible world.

How do I keep X safe from her father? How do I repair the damages that have been done to the women who share their stories with me? Questions fill my head. How do I keep my children safe from this? How can I keep it from happening to the child next door, to the child across the street, to the children in my city? I lie awake listening for cries and tears around me, feeling powerless to keep this harm from happening. Tonight, in the heat and in the dark, the danger to women and children overwhelms me. I sit down at my computer to write it out, to bring it into the light, to purge it from me. I don't know where this writing will go. This is X's story, and my own. If we bring our fears and our wounds out into the light, will writing these stories make a difference in women's lives?

And how did this conversation with X come about today?

Some people think I go dredging for these stories. In this case, I had asked her to see the dietitian to talk about her eating disorder. I

sent her to the dietitian for two reasons—to find some way to draw attention to her bulimia and to get some assistance with it, and also to illustrate to the prison dietitian the complexity of the dietary issues involved in caring for HIV seropositive women. Many, too many, of the women I see in my clinic

have eating disorders: how am I to be sure that they get their HIV medicine if it is purged with their food? My experience at work confirms what is known about eating disorders: bulimia has been linked to childhood sexual abuse.

Today X told me that the session with the dietitian was helpful, because she actually confessed that her bulimia was worse during the past winter, and because she finally realized the connection between her father's actions and her reincarceration. To tell me this, she had to tell me that her father had abused her again, and that is how the whole story came out. We talked at length, and she smiled through her tears as she left my clinic. Her terrible sadness, fear, and anger, remained with me.

So what does all of this have to do with running an HIV clinic for women? Nothing at all, if you ask prison officials and prison health care corporations. Nothing at all, if you ask my medical colleagues who wonder why I don't do "my work" and stop seeking answers to my questions. But I can't separate listening to these stories and seeking to understand my patients from my work. If my work is to "take care" of HIV infected women, then understanding why these women use drugs, do sex work, don't go to their HIV clinic appointments that I set up for them on the outside, and end up coming back to see me in the HIV clinic at the prison is part of the work that I have to do. Understanding why my patients have eating disorders will enable me to intervene effectively, so that the medications they are taking for their HIV disease are absorbed.

Which intervention will save the life of my patient?

A case in point: Y returned to prison at the same time as X. Y was also a recent graduate of the post-incarceration drug recovery program. The story that she lives with, the story that was untold until she came to my clinic the first time, is this one: her son is also her brother. Her relationship to her son/brother has never been discussed within her family. Is it a surprise that she left home at an early age and spent many years on the street drinking, drugging, and doing sex work to support her habit? Why did she tell me and no one else her story? Because I asked her why (not how or when) she started using drugs. I have learned from my experience at the prison that many of my patients left home as teenagers because of childhood sexual abuse, turning to drugs for comfort and sex work to support their drug habits. Unless the cycle of abuse is broken, these women will never be free to choose a healthier lifestyle—whether they are already living with HIV or at risk of becoming infected.

Y spent many hours talking about her son/brother with me at the clinic, and in sessions with counselors in the drug recovery program. As part of her drug treatment program after she was released from prison, she wrote down all of the things her father did to her. She says now, after returning to prison for using drugs again, that telling her story at the drug treatment program made her feel strong enough to go home to see her son, at last. She thought she might tell him that she was HIV-positive, but wasn't sure that she could tell him the truth about their kinship. He still

***How do I keep X safe from her father?
How do I repair the damages that
have been done to the women who
share their stories with me?***

Learning more about my patients helps me set priorities: is it more important to find safe housing, away from an abusive spouse, or start a new anti-viral drug? Is it more important to re-unite them with their families, than to urge them to move to a city where they might have access to HIV care?

thought she was his sister, and she didn't think that he was ready to learn the truth she had been living with every day, all 17 years of his life.

When she returned home, she found that her son had a newborn son, and that she was now a grandmother and an aunt all at once. Her son had named this new child after his father, her abuser. She spent many hours that weekend holding the baby. Then she went off to find her friends, so that she could get high and forget about the whole thing.

Another case in point: Z is 25. Last year, Z moved back to her mother's

house after her husband died of AIDS, and her mother moved her stepfather back into her room with her. That was the way they lived when she left home at 16. She says that she protested, that she ran out into the yard crying about incest, but they sat her down at the kitchen table and told her that it couldn't be incest because he was not her real father. I try to imagine this scene in my head—I see the kitchen table, the stepfather, the mother. How can this be? I ask her why her mother does this to her. She says her stepfather doesn't care that she is HIV-positive, he doesn't wear a condom when he sleeps with her, and she thinks that her mother is "getting him back" this way. She wears her hair long, in two big ponytails set high on her head like a little girl. She talks in a little-girl voice and won't look me in the eye when she tells me that she has to go home when she gets out, to her mother and stepfather, because she has no other place to go.

For so many of the women I take care of, there is no safe place to go. X tells me about "running away" from her father; running from room to room, and running away from home. Running from the hero of her life. The stories the women tell are all differ-

ent but all the same: The abuser is always the person they love the most. Recovery involves calling the abuse by its name and losing that

is valid: we must not tolerate sexual abuse of children. There must be no acceptance, no excuse, for valuing the lives of women and

...we must not tolerate sexual abuse of children. There must be no acceptance, no excuse, for valuing the lives of women and children less than sexual pleasure.

love. For some, this loss is the largest one, bigger even than the initial loss of trust. And for women who are HIV seropositive, the urge to return home to find comfort can be heartbreaking. There is no other place to go, no safe place to find love.

I am told that incest has been a part of human behavior for a long, long time. Through my work at the prison, I am learning the terrible consequences of incest. Women who have been forced to have sex as children, who have never been able to speak about their experiences, bear the scars forever. For women who have no access to professional counseling and psychotherapy, drugs and alcohol numb the pain and diminish the terror of sexual intimacy. Blame is internalized, and self-esteem is destroyed. The links to drug use and sex work are clear; and now HIV has entered the equation. These links, between childhood losses, failure of support systems, lack of access to means of recovery from abuse, drug use, sex work, and HIV infection, are illustrated over and over again by the women who come sit with me in my HIV clinic at the prison and speak to me about their lives. Because I ask them about their lives and because I choose to spend the time listening, I have learned that every other woman who comes through my doors at that prison clinic is a survivor of childhood sexual abuse.

I ask: What comes before? How does it start? What unhinges that taboo, allows men to begin to damage their daughters, their granddaughters, their nieces, and their sisters? I don't know the answer. What can we change about our society to prevent this from happening to women? A student of mine wrote me the one answer that I think

children less than sexual pleasure. I have come to know the newest consequence of childhood sexual abuse: to damaged self esteem and troubled hearts is now added the burden of HIV. For my child, I don't know which way the danger lies, and that is why I sit here writing, wondering if I will be heard, wondering how I can protect my moonlit daughter, wondering how I can change women's lives. ☩

Previously published in Friends for Life The stories of patients X, Y, Z have been changed, to protect their identities. Any resemblance to any one individual's life story is coincidental. This work would not be possible without the support and encouragement of S. Zierler, CCJ Carpenter, Ken H. Mayer, and APT; and my directors Joe Cohen and Rochelle Scheib at the Lemuel Shattuck Hospital, Jamaica Plain, Massachusetts.

Dr. De Groot is Assistant Professor of Medicine and Community Health at Brown University AIDS Program Brown University, Providence, Rhode Island and a member of the HIV/AIDS Program Staff at Lemuel Shattuck Hospital. She is also an editor of HEPP News. More information can be found in Anne S. De Groot and Debi Cuccinelli, "Put her in a cage: Childhood sexual abuse, incarceration, and HIV infection," in The Gender Politics of HIV in Women: Perspectives on the Pandemic in the United States, J. Manlowe and N. Goldstein, eds., New York University Press. Also see Jessica Stevens, Sally Zierler, Virginia Cram, Diane Dean, Ken H. Mayer, and Anne S. De Groot, "Risks for HIV infection in incarcerated women," Journal of Women's Health, Volume 5 (4) 1-7, 1995.

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At a minimum, the facility’s primary care physician should evaluate asymptomatic [having no symptoms of disease] HIV-positive patients every three to four months. Between regularly scheduled visits the inmate may present to the nurse for multiple issues, including acute [new] signs or symptoms, medication issues, etc.

Adherence to complex pharmaceutical regimens has become a critical component of the nurse’s role as educator and motivator. In some correctional systems the case manager may initiate adherence checks, which may be [called for] in the following instances:

SESSION 2

- Required routine laboratory tests
- Routine clinic visits
- Willingness to take medication
- Willingness to adhere to medication

SESSION 3

- Antiretroviral medication regimens
- Side effects
- How to take medications correctly
- How to re-order medication
- How to pick up medication if in KOP [keep-on-person] program
- Discharge/aftercare planning issues

Establishing community linkages is mandatory and might require face to face meetings. State Departments of Health are useful agencies for providing resource manuals of current AIDS service agencies available in the local areas.



1. Inmate did not show for clinic appointment
2. Inmate did not re-order medication on time
3. Inmate did not pick up medication on time
4. Viral load is increasing despite appropriate therapy

Because it is common to move inmates from facility to facility, nursing case management should be established system-wide. With a system-wide approach, inmates can be incorporated into a new facility’s procedures without being “lost to follow-up.” The following three intensive education sessions may be used by nurse case managers with a newly diagnosed HIV-positive inmate.

SESSION 1

- Overall disease process
- Acceptance of HIV diagnosis

A signed release of information form must be obtained prior to release of any information to outside community resources... Continuity of care is especially critical for patients receiving antiretroviral [drugs] and for those vulnerable to [opportunistic infections] due to low CD4 [T] cell counts.

Prisoners should be given medications and/or prescriptions to be filled in the community upon release. The critical issue of continuity of all antiretroviral agents should be stressed to the inmate and to the provider/organization providing post-release care. If therapy must be interrupted, it is often best to stop all antiretroviral agents. [Remember that Sustiva and Viramune must be stopped two days before the rest of the HIV medications are stopped, since it lasts longer in the body and should not be alone in your system, because you may develop resistance.—EV]

In many correctional health care systems it is the primary care provider who decides when and if antiviral therapy will be offered.

This decision, the [drugs] selected and other management decisions regarding HIV care should be based on recommendations of the DHHS or IAS-USA [see Resources for how to obtain a free copy] or other authoritative sources.

Dietitians should be available to advise inmates with HIV about nutritional aspects of wasting syndrome, lipodystrophy [high levels of triglycerides or cholesterol] and gastrointestinal intolerance of meds [such as nausea, vomiting and diarrhea].

[Housing and work] segregation may [lead people to] unscientific beliefs about HIV transmission.

The security staff, primarily the correctional officer (CO), plays an important role in case management. Many times it is the CO who recognizes early signs or symptoms of HIV disease progression. Similarly, COs learn which inmates require medications on a regular basis and can encourage inmates to be adherent. In addition, the health care staff must rely on the security staff to bring the inmate to the medical facility. The success of this depends largely on how informed the security staff is. [Editor's Note: According to the HIV Education Prison Project, in a report on mental health, "Inmates with

support services... Many of the pharmaceutical companies have made free medication available for inmates leaving prison for some defined period until they have sources of funding for their medications, but this availability still does not address the issue of the assignment of providers of care. [Check with advocacy groups.]

- A frustrating but oft-repeated scenario is the inmate who receives state-of-the-art care for his [or her] HIV while in prison, is released, and presents again later to the prison with resistant virus from inconsistent medication adherence post release due to incongruous medical care.
- It has now become increasingly apparent that clinicians should avoid initiating antiretroviral therapy that cannot be continued post release if release is anticipated relatively soon.
- Programs that deal with the psychological and social aspects of HIV disease (and other chronic diseases) have been shown to

Recommendations For Positive Inmates

unrecognized cognitive impairment as a result of HIV may be emotionally [unstable] and behaviorally unpredictable, inviting attacks from other inmates and punishment/retaliation from correctional officers who fail to understand the behavioral impetus. They may receive punishment for rule infractions that they were never entirely capable of understanding or remembering.”]

PRISON INFORMATION

- Some states and the federal system have instituted co-payments for some health services.
- Even when Medicaid funding is available, the inmate may have to wait 30 days to a year after release to become eligible.
- Ryan White Care Act funds specifically target the inmate population and should be contacted regarding medical care and

reduce recidivism [returning to prison]. In general, recidivism [is related to] sub-optimal self care and increases the likelihood of poor disease outcomes.

- Attempts to reduce drug addiction and recidivism have been generally disappointing. An exception is in Delaware where a “therapeutic community” (TC) model of substance abuse treatment and intervention with treatment during and after incarceration demonstrated durable reduction of recidivism in that state (Prison J 1999; 79:294)... Another potentially useful but controversial method of HIV intervention is to base medication administration for HIV around a methadone-maintenance program. ☒

HIV Treatment In Prison

by
**Enid
Vázquez**

We can't list everything you may need to know on these few pages, so check out the resources listed on page 35. Don't forget to let your health care workers know of the organizations which will provide HIV information to them, including a treatment hotline. And by the way, prison health advocates maintain that treating yourself treats the outside community, as well. People coming in and out of the corrections system need treatment and education to help avoid spreading illnesses when they're out.

TESTING

Prison staff cannot take the word of an inmate that he or she has HIV. You may have to be re-tested to confirm your status, or have your health records forwarded.

People who don't know their HIV status, but believe they may have been at high risk of getting HIV, may want to get tested and if positive, take medication. This may keep them from getting seriously ill while locked up. The last place anyone wants to be when very sick is in a prison. Remember, many people feel fine until their immune system is so badly battered that they find out they have HIV at the point that they have developed AIDS. In fact, many of these peo-

ple—primarily people of color—die at the time of their AIDS diagnosis. Ironically, only prisoners have a right to free health care in the United States, and practically every prison provides standard-of-care HIV drug combinations.

DRUG COMBINATIONS

You can get a "regimen," but it may not be the HIV drug combination you want. Also, not all HIV drugs are available in every institution.

CONFIDENTIALITY

You know better than we do what goes on in your institution. What we can say is that there is no national plan or advocacy drive to change prison procedures for clinic visits or handing out medications. Again, you can seek help from advocacy groups. A letter from them to the staff can really help. However, one prisoner advocate points out that there's really no such thing as confidentiality in prison. Word gets out. (If you think you can keep your confidentiality, remember that there's one HIV triple drug combination in one tablet, taken twice a day: Trizivir, as in tricycle. See Retrovir, Epivir and Ziagen in the 2001 Drug Guide for the three drugs that make up Trizivir, to see if this med might be good for you.)

SIDE EFFECTS

Ask your health care provider what side effects are associated with the medications being recommended and get tips for how to deal with them if they occur. You can request

a prescription to treat some common side effects before going on your meds (such as a sleeping aid to help with Sustiva or Imodium to help with other HIV drugs—write to us for a copy of the annual HIV drug guide from *Positively Aware* for more suggestions). Remember that you may not experience any side effects at all, so don't jinx yourself. Psych yourself up instead. Then, too, remember that many side effects often go away within a couple of months. Some quick tips:

- Make sure you're taking your meds correctly! You could be overdosing yourself. Also, some meds cannot be taken together. Remember, health care providers make mistakes, too. Check the bottle and package insert, the drug guide or whatever you can. Drugs that cannot be taken together are called "contraindicated."
- Taking medications with food helps prevent nausea. But Videx and Videx-EC must be taken on an empty stomach, and Crixivan may be taken with a very low-calorie, no-fat meal (no cream in that coffee, no butter on that toast), unless you're taking the Crix along with Norvir or Rescriptor.
- Remain sitting or standing up after dosing. Lying down right away may promote nausea.

- To control nausea, try accupressure. Locate the indentation on the inside of your wrist (measure about two fingers down from the palm of your hand). Apply fingertip pressure for three minutes on each side.
- Get a prescription for an anti-vomiting or anti-nausea medication (such as Compazine, which also treats vomiting). Double check that the medicine does not counteract against your HIV drugs.
- For diarrhea, get an anti-diarrhea medicine, cut back on your fat and sugar intake, and try fiber supplements or Tums. Tums contain calcium, which has been shown, in some people, to reduce the number of loose stools from treatment with Viracept. For both vomiting and diarrhea, don't forget to drink extra water and juices, and also have soups. The nutrients you are losing need to be replaced so that you can avoid illness.

To DOT or NOT TO DOT?

In directly observed treatment (DOT) a health care provider watches you take your medicines. On the one hand, you may lose confidentiality, plus the opportunity to learn how to take your meds correctly and the ability to control your doses, such as saving them for dinnertime or breakfast. DOT is also authoritarian. On the other hand, you may have a better chance at lowering the amount of HIV in your blood (your viral load). A recently reported study of 50 inmates in Florida found that after a year of DOT, 100% of them had undetectable viral load. In contrast, 81% of the participants in a comparison group outside the prison was undetectable.

MEDICATION DELAY

"All or none is a good message," says a leading HIV specialist who's a prison doctor. In other words, temporarily stopping your meds is better than spotty doses. To a large degree, HIV medications are about, "Every dose, on time, under the right conditions." The idea generally hasn't sunk in with all prison administrators and correctional officers.

If you can't take your entire HIV drug combination, don't just take the ones that are available. Stop taking them all until you can be sure that you can take each and every dose. If your viral load is undetectable, you have a good chance of being undetectable again when you go back on all the meds.

If your viral load is detectable, you're still better off stopping all the meds at the same time. Taking only some of your drugs can make your virus develop resistance, which might make the drugs ineffective. You also increase the risk of transmitting resistant virus to someone else. This limits treatment options for a newly infected person.

You may want to set aside all your doses for the first few days you're supposed to be starting your combo, to save them in case the prison runs out of one. It's not legal, but there you go. Lots of people use this trick.

Remember that Sustiva and Viramune last a lot longer in the body than the other meds. They should be stopped two days before the other meds are (although there's still no conclusive evidence that this will actually help). Stopping them early, of course, may not be within anyone's control in a prison. All in all, the common delays in giving medications is "a scary situation," says the prison doc.

TELEMEDICINE

Telemedicine allows the prison's primary health care provider to communicate with an HIV specialist, or the specialist to "see" a prison patient, without costly and time-consuming travel to each other's clinic. It involves the use of "electronic information and communications technology," such as computers, telephone consultations and interactive video cameras. This area of medicine is still being developed.

TB

Tuberculosis disease in the lungs might be mistaken for other causes of pneumonia.

The TB skin test and the chest x-ray used to diagnose TB can be falsely normal in people with HIV. A sputum test is recommended when there are respiratory symptoms in HIV-positive inmates, even if they were previously found to have negative tests for TB. TB symptoms include fatigue, weight loss, fever, night sweats, chest pain, coughing up blood and a cough that doesn't go away.

Rifabutin should be used instead of rifampin for people taking protease inhibitors (Agenerase, Crixivan, Fortovase, Kaletra, Norvir and Viracept) or non-nukes (Sustiva, Rescriptor and Viracept) to treat TB. Rifabutin dose must be cut in half with Agenerase, Crixivan or Viracept, and it should not be given with Norvir or Rescriptor. Centers for Disease Control and Prevention (CDC) recommendations call for using a four-drug combination with rifabutin for the first two months. After two months, if there is no drug resistance the treatment can usually be decreased to two drugs. (However, the CDC recently warned the public again about the rare potential for hepatitis with the two-drug regimen of rifampin and pyrazinamide). Healthcare workers can check the March 1999 *HEPP News* for tables listing different regimens and dosages to use. Pregnant women cannot take the oral drug pyrazinamide (PZA) or the intramuscular injection drug streptomycin (SM). Isoniazid should be given with pyridoxine to reduce the risk of neurotoxicity. Treatment of active disease should never be delayed because of pregnancy. Prophylactic (prevention) treatment for those who are infected but do not have active disease can be delayed.

DEPRESSION AND STRESS KILLS

Both inmates and people living with HIV have higher rates of depression than the general population. Prisoners also have higher rates of mental illness, especially those with substance abuse. Substance abuse, for

ACTIVIST VICTORY ENDS MISSISSIPPI SEGREGATION

In April, the Corrections Commissioner of Mississippi, Robert L. Johnson, agreed to adopt the recommendations of the HIV/AIDS Task Force he appointed last year. No longer will inmates with HIV be barred from participation in educational, treatment and vocational training opportunities. Alabama now stands alone as the only state that continues to deny access to programs for positive prisoners and allows segregation (including housing). Congratulations to the prison activists and advocates who worked for this major progress, which included the folks at the American Civil Liberties Union HIV Prison Project.—EV

anyone, is highly related to untreated underlying illnesses such as anxiety disorders, and is also related to post-traumatic stress disorders, such as surviving childhood physical and sexual abuse. Some even argue that in fact, the U.S. uses prisons as poor substitutes for mental health and substance abuse care.

The anti-depressants in the class of selective serotonin reuptake inhibitors (SSRIs) has few interactions with HIV meds. These drugs include Zoloft, Paxil, Prozac and Wellbutrin. The tricyclic anti-depressants (Elavil or amitriptyline) tend to suppress cognitive function (thinking and analyzing abilities), and people with HIV may already have their cognitive functions under stress. Health care providers should look for underlying cognitive problems in order to avoid a misdiagnosis of depression or other condition, since neurological problems overlap

with mental health difficulties. Inmates with these problems may be subject to retaliation from other inmates or prison staff because they fail to understand or remember rules, and they may exhibit erratic behavior.

DRUG USE

It's estimated that three out of four people in prison have drug or alcohol problems. People who continue to use when released have a greater risk of returning to prison. They also have a greater risk getting reinfected with hepatitis C, which may have already cleared their body.

Inside prison, check out drug treatment if you can get it. If you continue to use, try not to share equipment. You need to try to avoid hepatitis C as well as new strains of HIV. Again, this may not be in your control, since condoms, dental dams and bleach are

contraband in the vast majority of prisons, and methadone is not always available. (Remember that full strength bleach is needed to clean needles, with lots of rinsing—four shots of bleach, each shaken and then rinsed.)

RELEASE

If your system doesn't help plan for your health care after release (see "Recommendations for Prisoners"), start planning on your own several months before your parole date. Contact the advocacy groups in listed in "Resources." ☞

Special thanks to Dr. Joseph Bick, Director of HIV Treatment Services for the California Medical Facility, California Department of Corrections, and an editor of HEPP News, for reviewing this article.

Hep C—an epidemic in itself

It's been estimated that about a third of the people in the U.S. with hepatitis C have gone through jail or prison. About 20% of prisoners have chronic hepatitis C virus (HCV), 10 times more than the 2% found in the general population. That 2% is more than double the percent of people living with HIV. According to an article in *HEPP News*, "Much of the controversy around HCV testing and treatment in corrections is related to delayed recognition of the important role incarcerated individuals play in the transmission of hepatitis in the communities after they are released." Other problems are the high cost of what is often an ineffective therapy, and the fact that while HCV is found in more than 80% of people with a history of injection drug use, many drug users will continue to use drugs after leaving prison and therefore continue to get infected with hep C. Most of the following information is taken from *HEPP News*. For more information on hep C in prison, see resources on page 35.—EV

- Inmates should be routinely tested for hepatitis (Centers for Disease Control and Prevention recommendation).
- If positive for HCV, get hepatitis C viral load and genotype (the strain of hep C) and do liver function tests (LFTs). LFTs measure AST, ALT, LDH and GGT. Elevated levels indicate liver damage.
- Be aware that unlike HIV viral load, HCV viral load is often in the millions. Genotypes 2 and 3 respond best to treatment, but 70% of the U.S. infections are genotype 1.
- People with hep C should be vaccinated against hepatitis A or B. The first HBV shot alone provides about 50% protection. Although the three shots are to be completed within four months, their protection is still good if extended beyond that time.
- Liver biopsy is the best way to determine the extent of liver damage. Unfortunately, doing a liver biopsy is expensive and often impractical under prison conditions. (However, the State of Florida makes them routine for monitoring prisoners with hepatitis and gets them done for \$200 each.) Therefore, even though the other tests (viral load and LFTs) are not accurate predictors of liver damage, some prison health advocates believe these tests should be used to determine treatment.
- People should be prepared for the difficult side effects: fatigue, muscle aches, fever, chills, nausea, headaches, weight loss, reduced white blood cell and platelet counts, irritability, depression and even suicidal thoughts. They should be checked for depression and anemia within the first two weeks of treatment.
- People co-infected with HIV and HCV have a 12 to 300 times greater risk of developing liver cancer.



inmate's Resource Guide

AMERICAN CIVIL LIBERTIES UNION (ACLU), NATIONAL PRISON PROJECT

733 15th St., NW, Suite 620
Washington, DC 20005
Tel: 1-202-393-4930
www.aclu.org
E-mail: jwalker@npp-aclu.org

Referrals to city and state programs across the country. Resource center, including free copies of "Play It Safer," a booklet on STDs (sexually transmitted diseases), and HIV/AIDS magazines. Works with correctional support groups and peer education programs. Quarterly subscription rate to the *NPP Journal* is \$2 for inmates.

THE FORTUNE SOCIETY

53 W. 23rd St., 8th Floor
New York, NY 10011
Tel: 1-212-206-7070
www.fortunesociety.org

Although not HIV-specific, the highly-readable newsletter *Fortune News* presents a wide range of articles of interest to inmates. Many articles written by current and former prisoners. Free for inmates.

HIV/AIDS TREATMENT INFORMATION SERVICE (ATIS)

P.O. Box 6303
Rockville, MD 20849
Tollfree: 1-800-448-0440
www.hivatis.org

Free literature, including U.S. guidelines on HIV treatment from the Department of Health and Human Services (DHHS).

HIV IN PRISON COMMITTEE (HIP)

California Prison Focus
2940 16th Street, #307
San Francisco, CA 94103
Tel: 1-510-665-1935 (voicemail and fax)
www.prisons.org/hivin.htm
E-mail: hipcomm@excite.com

Activist group organizing to make medications and harm reduction tools (such as condoms and syringes) available, end prison discrimination, advocate for compassionate release, and provide education for interested persons and organizations.

LATINO COMMISSION ON AIDS, ALLIANCE FOR INMATES WITH AIDS

80 Fifth Ave., Suite 1501
New York, NY 10455
Tel: 1-212-675-3288

Legal and medical advocacy, peer education and support. Referrals. Accepts collect calls from inmates.

NATIONAL HEPATITIS C PRISON COALITION

P.O. Box 41803
Eugene, OR 97404
Tel: 541-607-5725
Fax: 541-607-5684
www.hcvprisonnews.org
E-mail: hepcaware@aol.com

Brings together organizations and individuals to support and raise awareness among prisoners suffering from hepatitis and HIV/HCV co-infection. Offers seminars and support groups inside and outside of correctional facilities. Free newsletter and hepatitis C info packets for prisoners.

NEW YORK CITY COMMISSION ON HUMAN RIGHTS, HIV PRISON PROJECT

40 Rector St., 10th Floor
New York, NY 10006
Tel: 1-212-306-7544

Advocates for the rights of city and state prisoners, parolees, ex-offenders, and their families. Responds to a wide range of medical complaints due to AIDS-related discrimination within the criminal justice system. Distributes free brochures related to AIDS discrimination in Spanish and English. Accepts collect calls from inmates Monday–Friday, 9 am–5 pm; call 1-212-233-5560.

OSBORNE ASSOCIATION, AIDS IN PRISON PROJECT

809 Westchester Ave.
Bronx, NY 10455
Tel: 1-718-842-0500

Conducts research and makes policy recommendations regarding positive inmates and persons on parole. Operates HIV/AIDS clearinghouse, bilingual hotline and inmate support groups. Staff and peer counselors provide HIV prevention and treatment information and discharge planning. Inmate hotline accepts collect calls Tuesdays, Wednesdays and Thursdays from 3 pm–8 pm; call 1-718-378-7022.

PRISON BOOK PROGRAM

110 Arlington
 Boston, MA 02116
 Tel: 1-617-423-3298

Sends donated legal, health, educational and political books free to prisoners nationwide. Spanish-language books available. Provides help in starting Books for Prisoners projects.

PROJECT INFORM'S NATIONAL HIV/AIDS TREATMENT HOTLINE

Tollfree: 1-866-HIV-INFO (448-4636)

Accepts collect calls from inmates: 1-415-558-9051. Can also mail out materials. Operates Monday–Friday, 9 am–5 pm and Saturday 11 am–4 pm, California time.

FOR HEALTHCARE PROVIDERS**AIDS TRAINING AND EDUCATION CENTER (ATEC)**

Tel: 1-301-443-6365
www.aids-ed.org

Coordinated by the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA). Training for all healthcare providers, including correctional staff. Check for nearest training center.

ALBANY MEDICAL CENTER

Tel: 1-518-262-4674
www.amc.edu/patient/HIV/hivconf.htm

Management of HIV/AIDS in the Correctional Setting: A Live Satellite Videoconference Series.

HIV EDUCATION PRISON PROJECT (HEPP)

Brown University Medical School
 Providence, RI 02906
 Tel: 1-401-863-2181
 Fax: 863-1243
 Tollfree: 1-800-748-4336
www.hivcorrections.org
 E-mail: HEPP@corrections.net

Excellent monthly treatment newsletter, *HEPP News*, via fax or e-mail. CME credit available.

HIV TELEPHONE CONSULTING SERVICE

Community Provider AIDS Training
 Tollfree: 1-800-933-3413

Answers questions from health care providers.

FOR SERVICE PROVIDERS**NATIONAL MINORITY AIDS COUNCIL (NMAC)**

1931 13th St., NW
 Washington, DC 20009
 Tel: 1-202-483-6622
www.nmac.org

HIV and Corrections program produces a newsletter, brochures and regularly updated resource list.

MEDICAL MANAGEMENT OF HIV

by Drs. John G. Bartlett and Joel E. Gallant
 Johns Hopkins University School of Medicine

Corrections edition is no longer available in print, but the comprehensive chapter on correctional health care is available online at <http://hopkins-aids.edu>. It includes detailed suggestions for tele-mentoring and telemedicine.

PUBLICATIONS FOR PEOPLE LIVING WITH HIV/AIDS PROVIDED FREE TO POSITIVE INMATES**A GUIDE ON THE INSIDE: WOMEN TALKING TO WOMEN ABOUT HIV.**

Free brochure.
 Information is good for men, as well.
 HIV Health Library
 131 Clarendon St.
 Boston, MA 01226
 AIDS Action Committee of Massachusetts
 Tel: 1-617-450-1432

POSITIVELY AWARE AND POSITIVELY AWARE EN ESPAÑOL

1258 W. Belmont Ave.
 Chicago, IL 60657
www.tpan.com
 E-mail: posaware@aol.com

POZ

P.O. Box 1279
 Old Chelsea Station
 New York, NY 10113

WORLD (FOR WOMEN)

P.O. Box 11535
 Oakland, CA 94611

Excellent monthly newsletter with personal stories and easy-to-understand medical information. If you are not a woman living with HIV, please send a donation. ☕

Get Me Some Self-esteem

by Laura Jones

I've been hearing a lot of people lately talking about the problems they're having in providing care and services for HIV-positive women, or women at risk for infection. Women, it seems, don't take care of themselves very well. They don't show up for appointments. They aren't very compliant with medications. They run themselves ragged taking care of the family and the house...they never take time off for rest and relaxation...and they still aren't very good at that "consistent condom use" thing, even after all these years! These "challenges," we're told, have a lot to do with women's low sense of self-worth and assertiveness in taking control of their lives. Over and over again, we hear clinicians, social workers, and prevention people declaring, "Someone has got to get women some self-esteem! Women have got to start taking better care of themselves!"

And you know what? This is absolutely true—women do need greater self-esteem, and we do need to start taking better care of ourselves. Unfortunately, we still have a shitload of work to do while we're developing this self-esteem, and we still have a lot of institutionalized sexist tree stumps blocking our path to improved self-care. So before we get that self-esteem, can we try a little anger?

...women do need greater self-esteem, and we do need to start taking better care of ourselves. Unfortunately, we still have a shitload of work to do...and we still have a lot of institutionalized sexist tree stumps blocking our path to improved self-care.

As for the many people who are actively concerned about our low self-esteem, I'm sure folks won't mind rising to the occasion in order to help us out. So while all the world's HIV-positive and at-risk women go on a big Paths-To-Wellness Retreat for a few days, we'd like everyone else to address some of our more noticeable "challenges." We limited it to a random five (didn't want to overwhelm anyone), so here you go:

1 Help us with child/elder care, home maintenance, and transportation. Yes, many women do take care of everyone and everything else before taking care of themselves. We do this because families require a lot of care-taking, and we're trained

from infancy to take on the bulk of this work. It's going to take us a while to break down generation upon generation of conditioning—and in the meantime, our children still need to be played with, meals need to be prepared, laundry and shopping needs to be done, elderly parents require care, and money needs to be earned to support ourselves and our families. Some of us have partners and family to help us with these responsibilities, but many of us do not. So please: Come over! Stay with our kids and elders while we go to doctor's appointments, drug/alcohol rehab, support groups, and desperately-

needed mental health retreats. Come by and do our shopping or clean our bathroom when we're sick from our meds. If you have a car, drive us to appointments or go pick up our medications from the pharmacy. Revive the "Buddy" programs, especially as they pertain to childcare, elder care, and transportation assistance.

2 Give us information we can understand and apply to our daily lives. Given the difficulty many of us have even going to doctor's appointments, we need quality educational materials we can use at home—including materials printed in the languages we understand, especially if our doctors do not speak our language.

Women's self-esteem will grow when the people with the greatest power to affect change start acting like women matter—like women are human beings whose life realities are to be taken seriously and addressed.

Nutritional information must reflect the foods we eat at home, not the foods most commonly eaten by the people who make nutritional pamphlets. Additionally, we need materials for those of us who don't read in any language, especially regarding our medications—it's hard to be compliant when you don't know how to take your meds, or which side effects are dangerous vs. merely annoying. We're working on this among ourselves, but we generally don't have as much time and money as do hospitals, clinics, universities, and pharmaceutical companies...so please feel free to help us out.

3 Men who have sex with us must accept responsibility for condom use. Even the most empowered, self-loving woman in the world cannot force a man to wear a condom. Guys, you need to quit giving us a hard time about protecting ourselves. You need to quit acting like cavemen when we try to put the "No Glove, No Love" rule into practice, and you need to stop dishonest portrayals of monogamy if you're having sex with other people. If you're going to lie, outright or through omission, protect yourself so we don't pay the price for your fun. We don't have the power to control your behavior, and you don't have the right to hurt our health. Ditto for drug use.

Plus, you never know if we have something we could pass to you...self-care goes both ways, boys.

4 Fund microbicide development. "Consistent condom use" aside, I hope that by now everyone acknowledges that most of the world's women don't have a lot of control over when they will and will not have sex. Therefore, insisting that we develop enough "self-esteem" to control our male partner's actions (i.e. condom use) is a remarkably cruel avoidance of medical

responsibility to women. We need woman-controlled methods of HIV and STD protection—including methods that will allow us to conceive children, if we want them. Microbicides will also allow us to help protect our partners and children from infections. So please, consider microbicide development a Family Value.

5 Quit abusing women verbally, emotionally, physically, sexually, and economically—especially when we are children. Developing and maintaining self-esteem is difficult for all of us, but immeasurably more so if we're encouraged to believe that we're powerless pieces of crap. Abuse in childhood is particularly damaging to self-esteem and leads many of us into dangerous behaviors in adolescence and adulthood—sexual risk-taking, drug and alcohol misuse, dependence on romantic relationships and/or motherhood for a sense of self-worth, and lack of confidence in our ability to learn and to sustain ourselves economically. Sexual abuse can also make it difficult for us to seek out health care when we need it, especially sexual-health and gyne care.

If you abuse women or girls, knock it off and get some help. If you see girls or women being abused in any of the above-mentioned ways (and if you don't see it at least once an hour, you're not looking very hard), do something! If you are a man, examine both your own actions towards women and your interactions with other men when talking about and interacting with women. Refuse to support "male-bonding" activities that

involve disrespect and/or violence towards women and girls. If you are a woman, examine the image of womanhood you reflect to other women, especially girls. Refuse to support aspects of "femininity" that bring down our self-esteem, including acrimony among women. We need to help each other be strong, not tear each other down...

...and anything we can get for ourselves here needs to be expanded to include women everywhere, or we won't have the right to feel very good about our "progress." We all deserve safety and good health, no matter where we live or what we look like.

Women's self-esteem will grow when the people with the greatest power to affect change start acting like women matter—like women are human beings whose life realities are to be taken seriously and addressed. Telling women to "get some self-esteem" and "take better care of themselves" without acknowledging our reality is like telling closeted gay men to come out in a roomful of God Hates Fags disciples, or suggesting that people starving in a famine-stricken area really just need to plant more crops.

But anyway...when we come back from our retreat, bursting with self-esteem and all the tools we need for proper self-care, we expect to see at least these five realities addressed and corrected (you'll notice that we left off the really complicated ones like access to health care, clinical trials, economic self-sufficiency, and complete overthrow of patriarchy). And who knows? If y'all can fix these five for us, maybe we can harness enough collective self-esteem to take care of everything else. ☸

Laura Jones is the Hotline Coordinator for the Illinois AIDS/HIV & STD Hotline.

Medicine Chest

Understanding Prescription Benefits

by Glen Pietrandoni, R.Ph.

For people living with HIV/AIDS, prescription drug benefits are an important part of care necessary for success of any treatment regimen. Drugs must be affordable, accessible, and available without interruption. As a community pharmacist, I get lots of questions about insurance coverage. Believe me when I say it is confusing to providers as well as the patients! Let's try to sort out some of the facts.

Because the insurance industry, Medicaid, Medicare, AIDS Drug Assistance Programs (ADAP) and Social Security are all regulated by state or federal government agencies, there are variations on benefits and restrictions from one state to another. For example, an ADAP program in State A may only pay for antiretrovirals, while State B also allows drugs for opportunistic infections, lipodystrophy, and lipid control.

Prescription drug benefits given by employers are the most complicated. In general, the pharmacy portion of health insurance provided by employers is a small part of an entire package of benefits. For the majority of the public who may only need a couple of prescriptions filled a year, medications are not a big priority. Those living with HIV/AIDS need at least five or six prescriptions every month. You are usually locked into a program for a year, or until there is an "open enrollment" opportunity to change policies. It is important to understand your plan so there are no surprises at the pharmacy.

Co-pay is the amount that the patient must pay for each prescription. It is usually a fixed dollar amount. Sometimes there are two co-pays: a higher one for brand name drugs, and a lower price for generic drugs. Co-pays must be paid at the time the prescriptions are picked up. These co-pay fees are slowly getting higher and higher. It is not

unusual to see a \$30 co-pay on each prescription. With many prescriptions a month, it really adds up. Some policies have percentage co-pays rather than a fixed amount, usually 10% or 20%.

Formulary plans only allow you to get certain drugs using your insurance; other drugs would have to be purchased at the full price. At this time, I know of no formulary plan that excludes any antiretroviral, but I have seen these plans exclude drugs for other conditions such as opportunistic infections and depression. A list of drugs covered by insurance is provided when you enroll. Ask your doctor to look over the drug list. Keep a copy of it in your medical records and give one to the physician so that it can be used when prescribing new drugs. This will save you (and me) a lot of time and aggravation at the pharmacy. Providers writing prescriptions for those with HIV/AIDS have to be concerned about drug interaction with the antiretrovirals, especially the protease inhibitors. The "recommended" drug that is offered on the formulary may not be the correct choice for you, requiring you to pay the full retail price for the best choice.

Mail order options are offered to patients receiving "maintenance drugs" or drugs that are needed for long periods of time, as opposed to prescriptions that are needed and used immediately. This can save money because of lower co-pay amounts. The drawback is that you have to be organized to plan ahead to place orders and have refills placed by the physician. This option does not allow for face-to-face consultations with the pharmacist, but a pharmacist can be contacted through a tollfree telephone number.

Most prescriptions are filled for 30 days, with a couple of days leeway. Some insurance companies are very strict about allowing early

refills, as when planning a vacation. Mail order prescription plans allow for 90 days of supply to be dispensed for fixed co-pays.

When drugs are "not covered" by an insurance company, a **prior authorization** can be obtained to by-pass this ruling. This usually requires the physician to write a letter or submit a form to the insurance company to explain the need for the drug. It usually takes a few days to even weeks to get this accomplished.

Some policies specifically exclude **injectable drugs**. Testosterone, human growth hormone, and maybe the new fusion inhibitors could possibly be excluded under this restriction.

Under **limited access**, you may be required to use only certain pharmacies to obtain refills.

Discount plans are not a good option for HIV-positive patients. Instead of paying the full retail for a three-drug regimen of about \$1,000, the discount may only be 10%, leaving \$900 still due from you.

Reimbursement plans could be a problem as well. Even though the insurance company may pay 80% for example, it requires the patient to pay the total pharmacy bill up front and wait for the insurance company to send a check. Some pharmacies may agree to take an **assignment of benefits**. The pharmacy will charge the patient the deductible (20% in this example) and then will wait for the check to be sent directly to the pharmacy from the insurance company. Pharmacies can charge vastly different prices under this plan, so do your shopping! ☒

Glen Pietrandoni is director of Clinical Pharmacy Services for the Walgreen Specialty Pharmacy, focusing on HIV, located in the Howard Brown Health Center of Chicago.

Pickett Fences

A Crisis Obscured

by Jim Pickett

Yes, mami, sexy antiviral ads do lead to risky sex. Okay. It's not as if a hot young stud, let's say me, sees an ad for a delightful new protease inhibitor featuring busty, glistening hardbodies workin' their Thigh Masters and says, "Hey dude, I got a hankerin' for a little un-negotiated, un-safe sex. Where's my lip gloss?"

It's not that direct, it's not that cause and effect. But pharmaceutical ads which consistently portray unrealistic images, and highly sexualized images, help create an environment in which HIV is made to look fun and challenging, a way to pick up dates.

Zerit—I make you sexy good time, yes.

Take me, daddy. And don't waste a drop.

Of course everything in our society is sold to us by means of unrealistic, sexually-charged imagery. And of course we have those lovely ads of women skipping through posey fields to shill pills snuffing the sniffles, burying the blues, giving them their lives back. Direct-to-consumer marketing of any pharmaceutical is highly problematic. But it's more than problematic in the case of anti-HIV medications. HIV is not about a drippy nose or suburban ennui. HIV is a vicious, ugly, disgusting, demoralizing and always fatal contagious disease, and a fully preventable one.

Prevention relies on human behavior, and human behavior is all about perceptions. HIV drugs that sell us a vision of Baywatch (may it rest in peace) or a joyful commitment ceremony don't tell us "urgency," or "crisis." They don't tell us the "horror show" awaiting us. They don't bring to mind

HIV is a vicious, ugly, disgusting, demoralizing and always fatal contagious disease, and a fully preventable one.

lipodystrophy, neuropathy, heart attack or kidney failure.

They shout everything is coming up roses! They normalize HIV. And there ain't nothing normal about it. Admittedly, it's not just the advertising of the drugs but their efficacy that sends this message. The slick imagery coupled with the drugs' success at slowing viral progress augment, enhance complacency and denial—not only very human conditions but VIP guests with first row seats at many sexually risky encounters and instances when needles are shared as well.

Frankly, most people are educated, and know how to protect themselves. That goes for sex addicts, drug addicts, me and you, Betty and Bob and the octuplets. Advocates who yammer on and on about "just getting the information out there" are only partly there. Yes, we must do consistent, continuous education. Yes, condoms must be made available. But we must go further. We know smoking cigarettes is dangerous to our bodies. And yet we light up. Everyone knows about HIV. And yet we get fucked without a how are ya? or a condom.

It's not that we don't know we're putting ourselves at risk. Somehow we are making

decisions that ignore what we know, that are about perceptions, or misperceptions for that matter.

Of course, human behavior is multiply influenced. Twenty years into the epidemic, and we're just tired of being scared, and we're just tired of being safe, and we just want to be like other kids, to just fit in. Besides, hello! HELLO! The big problem is in Africa. Those poor people! We need to worry about Africa, we

need to be concerned about Africa, what can we do to help Africa?

What is in the subtext here?

Twenty years into the epidemic and the Bush administration proposes under-funding for AIDS programs, with a few puny increases and unbelievably, flat funding for the Ryan White CARE Act, a lifeline to hundreds of thousands of us with HIV/AIDS. There are 40,000 new infections every year in the United States, 20,000 of those under the age of 25, and more and more people are living with the disease than ever. Why flat funding? Why a few tiny increases akin to me flipping you a nickel and you a dime? What is in the subtext of that?

Twenty years into the epidemic, and while most people know a helluva lot about it, many still think it doesn't apply to them.

Twenty years into this madness and HIV is a "lifestyle."

Evil pharmaceutical companies are not the only ones who manufacture the illusion. Recently HIV/AIDS-savvy MTV ran a marketing campaign I first noticed on a huge billboard while cruising the Kansas interstate and then back home on Chicago public transit.

Editor's note cont.

continued from page 9

There are individuals living with HIV in the U.S., on complex antiretroviral therapy, who still don't understand the basics of HIV and AIDS. Hell, there are people living right here in the U.S. who don't access healthcare or HIV therapy. Just imagine the work ahead of those engaging HIV in Africa.

Yes, we are flawed. Yes, we are angry, and full of fear, superstitions, and frustrations. And rightfully so, but rather than feeding shamelessly on each other, let's try something new, let's try something old. Let's reaffirm our commitment to do something constructive. Write a letter to the President, or your representative in Congress declaring your support to increase funding for domestic HIV/AIDS prevention, care, housing and research; join a protest to express your outrage at pharmaceuticals' practices and federal government policies; or volunteer at a local agency and help someone living with HIV. Don't cost ya' nothin'.

Let someone know you still care, that you still remember, in this the twentieth year that the first cases of AIDS were reported.

Charles E. Clifton

Editor

Send comments and reactions to posaware@aol.com

It was a general awareness campaign for the network. "Talk to your partner about MTV," advised one billboard, featuring a close-up of a couple in black and white.

"People need to know about MTV," said another. "Many people with MTV still lead happy and productive lives."

I'm itchy. Do I have MTV?

What's going on here?

Hmmmm, could it be a very creative and well-executed spoof of HIV awareness and prevention messages?

What's in the subtext there?

What's in the subtext of the viatical ad featuring that guy with the ripples and nipples? Besides a clear yummy and delicious?

HIV is not a threat. It has a sense of humor. And it's a good lay.

There are almost a million people in this country infected with HIV. Most of them can tell you about the great jokes HIV tells, and the incredible erotic potential of "moderate" diarrhea. Well, maybe "most of them" is a bit of a stretch because actually, one third of that million can't articulate their exciting HIV adventure. They don't know they're having one. They haven't been tested. Or they've been tested and they haven't gone back for their results. Or it's not about them. Or what's to worry about?

It's a bike ride. It makes me giggle. And it gets me horny, baby.



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JA 2001

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Test Positive Aware Network (TPAN) is a not-for-profit organization dedicated to providing support and information to all people impacted by HIV.

Dem Bones—Reports of Abnormal Changes in HIV

by Daniel S. Berger, MD

Body habitus and metabolic abnormalities in HIV- infection continue to get great press and headlines—and they should. The alterations in fat redistribution are sometimes gruesome and include various combinations of manifestations, including posterior neck fat pads (buffalo hump), increasing visceral fat (abdominal paunch), loss of fat from extremities, face and buttocks, and increasing breast mass. If one is bored of reading repeated reports of metabolic problems that emphasize insulin resistance and diabetes as well as elevations in cholesterol and triglycerides (and don't forget the elevations of lactic acid in the blood, a byproduct of biochemical pathways occurring as tissues deprived of oxygen), there is something new to contemplate. Bone mineral loss has been emerging as a new metabolic concern in patients who are HIV infected. Several reports of HIV-positive HAART (regimen) treated patients with bone disorders have come to the surface. One such disease of bone that results in death of bone tissue due to circulation problems is called avascular necrosis. The second reported disorder is osteopenia, or bone thinning that may result in spontaneous bone fractures.

The bony skeleton is an integral part of the human anatomy. Besides the obvious characteristics of movement and support, bone is dynamic, constantly turning over with bone formation and resorption (bone remodeling). Bone also acts as a mineral reservoir, and regulates calcium and phosphate metabolism. When bone is being resorped, calcium is extracted and the bone matrix is destroyed. Conversely, bone forma-

Bone mineral loss has been emerging as a *new* metabolic concern in patients who are HIV infected.

tion requires normal levels of calcium, phosphate and vitamin D. Various hormones (calcitonin and parathormone) and several organs (kidney, intestine and brain) are also involved in this process. Up to 15% of our total bone mass turns over each year. A peak in bone mass occurs between ages 20 and 30 years. Equal rates of formation and resorption continue to maintain stable bone mass until near 50 years of age. Thereafter resorption increases over formation and bone density decreases slowly. Certain diseases and certain medications can disrupt this process and results in a loss of bone mass. As of recent, HIV or HIV-negative related therapy is now being called into question as a possible cause for increased bone turnover and/or bone disorders.

Various reports of bone abnormalities being observed began recently. Several studies have been presented at international conferences and in medical journals. One such meeting, the Second International Workshop on Adverse Reactions and Lipodystrophy in HIV, met last fall in Toronto. While the meeting primarily discussed the research relating to fat redistribution, and its associated metabolic complications, several reports of bone demineralization and related bone disorders were presented. Researchers from Washington University School of Medicine presented evidence of elevated bone

turnover and an additional study evaluated evidence of the inhibition (stopping) of conversion by protease inhibitors of vitamin D to the more active form [1,25(OH)₂ vitamin D₃], which is needed for bone formation. Additionally, Dr. David Nolan from the Western Australia HIV cohort showed

higher rates of osteopenia (bone thinning) and osteoporosis (increased bone softening and loss of bone tissue) in individuals on protease inhibitors.

In the area of avascular necrosis (death of bone tissue associated with circulation problems), a small group of 14 patients with this disorder was found to have the association of previous *Pneumocystis carinii* pneumonia infection, prior corticosteroid use (not anabolic steroid use) and low CD4 T-cells (less than 50).

Lastly, Dr. Pablo Tebas recently published a report in *AIDS* (2000;14:F63-F67) of a study of 112 patients: 64 received protease inhibitors, 36 HIV-positive patients were not exposed to protease inhibitors and 22 HIV negative persons were used as controls. Various tests were performed to assess bone density, including a specialized x-ray scan (DEXA) to detect bone density reduction. The results of the study showed that 50% of the patients from the group of protease inhibitors use had lower bone mineral density. This was compared with the 6% of the HIV negative controls and 11% of the other HIV-positive patients with no prior protease inhibitor use who showed reduced bone density. While the rates of bone disorders reported here are shocking, one should question how the patients were selected for the study. Most HIV treatment clinics have not wit-

nessed bone disorders this high, but do not routinely test for bone density.

Presently and for patients who are on antiviral therapy, there is no cause for alarm. There is no evidence to suggest a need for changing one's antiviral therapy or regimen. Although there are increasing numbers of patients being reported with bone disorders, most HIV treaters are not observing these complications at these alarming numbers. Also, a cause and effect relationship to antiviral therapy has not been demonstrated, nor do we know of any mechanism for which protease inhibitors can cause bone mineral loss or turn over.

Moreover other causes and factors are associated with bone loss. Avascular necrosis is associated with alcohol abuse, hyperlipidemia (elevated cholesterol and triglycerides), sickle cell disease, systemic lupus erythematosus and the use of anabolic steroids and testosterone. Osteopenia (bone loss) has been associated with prolonged bed rest, severe weight loss, disorders of the parathyroid and thyroid hormone axis as well as medications that include corticosteroids, pentamidine, phenobarbital and ketoconazole. Thus one must take into account these other factors when examining the rates of bone disorders, as well as individual patients.

Thus far, it is not indicated to routinely check for bone densities



in HIV-positive patients on treatment. However, if signs or symptoms occur that suggest the possibility of a bone disorder, such as bone pain, which means weakness in a particular bone structure, then appropriate X-rays, MRIs and bone density testing should be done. To be proactive, weight bearing exercises and calcium supplements can be considered, but should be discussed with one's physician. Lastly, a relatively new class of drugs called biphosphonates reduce bone resorption and are being increasingly used for certain bone thinning diseases, such as osteoporosis.

There is much that needs to be examined to improve our understanding of this relatively new reported complication of HIV. Large controlled studies should be undertaken to better explore the risks of bone loss in HIV-related disease in our patients, as well as studying HIV negative controls on antiviral therapy. Other work should look into the etiology (cause) and possible relationship to various antiviral agents. ☩

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

It's All About Communication

by Keith Waltrip, LPC

This article is an extension of a letter I wrote to the editorial section of a local paper and it addresses the difficulty around communication and disclosure of status. My intention is not to place blame or shame on anyone, but to help individuals understand how their actions affect others, and take responsibility for themselves.

The first issue concerns couples (emphasis is on couples and not tricks or one-night stands) in which one person is HIV-positive and the other is negative. The partner who is positive is fully aware of his/her status and does not disclose this to the partner or lies and states they are negative. Now let me add another layer to this; the couple has been together for some time. With that there is a sense of trust in which condom usage may decrease or not used at all—which is understandable. Now add that the person who is HIV-positive is exchanging bodily fluids with their partner. What formula do we have here? A perfect formula for an infection.

I have been told a number of reasons for this behavior including fear of rejection or losing the person they love. While these reasons are understandable, be aware that if you love someone then be honest with them. Placing them at risk without their knowledge is life threatening and even criminal. Being HIV-positive and sharing that information can be difficult. However, there are plenty of organizations across the U.S. that can help someone learn ways to share their HIV status with a loved one.

The best example I have of this is when I tested a woman of color for HIV in her 50s. She stated she just found out her boyfriend of five years was HIV-positive and never told her. I asked if they used protection and she stated, "Why would we use protection when

we were in a relationship and living together?" Made sense to me. I then informed her that if she wanted to press charges she could. She stated she could not do that and I stated I understood. She then said, "No you don't. He died three days ago from AIDS and that is how I found out." Guess what—she came back positive.

My point with all of this is communication. Telling a loved one your status is hard—I understand. What is even harder is trying to explain to that person why you did not tell them or lied to them. In the case of the woman I counseled, her communication ended and was buried. She was left alone with no answers and no support from her "loved" one.

The second issue has to do with tricks/one-night stands. I again have worked with individuals in which they did everything right. They asked the person who was going to be the insertive partner/top to use a condom. The person obliged and put a condom on. The insertive partner/top at some point took the condom off and ejaculated inside the receptive partner/bottom. If someone does not like using condoms—then the individual should be honest from the beginning and share that information. Don't mislead someone.

My example for this case was that after my original letter to the editor was published, I received a thank you card from a gay man in his early 20s. He stated that he took home a trick and saw the person put on a condom. He stated after they were done he noticed the person no longer had the condom on. He asked the person what happened and he replied that he did not like condoms and took it off. Guess what—he came back positive. He stated that when he tried to talk to his friends about this and warn them, they

did not believe him. For him my letter was now proof that this happens. This person did what was right—he asked for a condom. (For those of you who are saying it could have been someone else that the infection happened from—it was not).

My suggestions for addressing these issues are fairly simple: when entering a relationship test for HIV/STDs together, discuss the results in the presence of an HIV counselor. Have a discussion about condoms, whether the relationship is going to be exclusive or open (I often heard, "How could I be positive? I am in a monogamous relationship.") or how to maintain open communication about sexually difficult issues. During sex, check occasionally to make sure the condom is still in place, has not broken or was removed. My belief is that everyone is responsible to take care of himself/herself. Waiting for someone to tell you their status (or be truthful about it) may not happen. I advise people that if you do not know the person—get it in your mind that he/she is HIV-positive regardless of what they say, look like or do and act accordingly. Until you can test together—take care of yourself first. It really all comes down to a matter of basic human dignity, trust and respect. ✚

Keith Waltrip is Director of Programs at TPAN. He can be reached at TPANProgrm@aol.com.

TPAN Calendar of Events

For Additional information on these events please contact Keith Waltrip, Program Director, at (773) 404-TPAN (8726)

JULY 2001

Date	Time	Event
Sundays	9:00 am	Sunrise AA (held at TPAN offices)
10th	6:30 pm	Client Advisory Board (CAB) Meeting
11th–13th		The Chicago Coalitions Project Retreat
17th	7:00 pm	TPAN Board of Directors Meeting; TPAN members invited
20th	9:00 am	HIV Services Planning Council, contact Andrea Densham at (312) 747-8815
25th	9:00 am	HIV Prevention Planning Group (HPPG), contact Laird Peterson at (312) 747-9661
28th		Women & HIV/AIDS Conference, Chicago, for HIV-positive women free registration—limited space available

AUGUST 2001

Date	Time	Event
Sundays	9:00 am	Sunrise AA
14th	6:00 pm	HIV Research Update, The Female Connection: HIV Research For Women
16th–18th		Staying Alive: Conference for People Living with HIV/AIDS, Chicago
17th	9:00 am	HIV Services Planning Council, contact Andrea Densham at (312) 747-8815
17th	7:00 pm	TPAN Board of Directors Meeting; TPAN members invited
29th	9:00 am	HIV Prevention Planning Group (HPPG), contact Laird Peterson at (312) 747-9661

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 (8726) • fax: (773) 404-1040 •

e-mail: tpanet@aol.com • www.tpan.com

Support groups sponsored by the Chicago Department of Public Health
Peer Support and Buddy programs sponsored by the AIDS Foundation of Chicago

MONDAY

TPAN DAYTIMERS

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

MEDITATION

Mondays at 7:00 pm

NEWLY DIAGNOSED

A group for newly diagnosed individuals. Mondays at 7:30 pm. 2nd and 4th Mondays includes HIV 101 education.

NEGATIVE PARTNERS

The Negative Partners of Positive People. 3rd Monday at 7:30 pm.

TUESDAY

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 massage Wednesday 12:00 pm–3:00 pm. Call for an appointment. Program offered by AIDSCare.

MEDICAL CLINIC

See description in Friday's listing. Wednesdays 3:30 pm–7:30 pm.

STRAIGHT TALK

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

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.

MEDICAL CLINIC

See description in Friday's listing. Thursdays 2:00 pm–5:00 pm.

NEEDLE EXCHANGE PROGRAM

See description in Wednesday's listing. Thursdays 2:00 pm–5:00 pm.

BROTHERS UNITED IN SUPPORT (BUS)

A group for HIV-positive gay and bisexual men of African descent. Thursdays at 7:00 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 nurse practitioner. This program is in conjunction with the Needle Exchange Program and is offered by Access Community Health Network. Call for an appointment. Fridays 2:00 pm–5:00 pm.

NEEDLE EXCHANGE PROGRAM

See description in Wednesday's listing. Fridays 2:00 pm–5:00 pm.

SAFE PASSAGE

A group for young adults (ages 18–24) who are HIV-positive. Fridays at 7:00 pm

SCHEDULED BY APPOINTMENT

FAMILY AIDS SUPPORT NETWORK (FASN)

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

WOMEN'S GROUP

A group for HIV-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 Derek at (773) 404-8726 to get a buddy!

POSITIVE BUDDY

Volunteers provide individuals living with HIV/AIDS one-on-one emotional / physical support. Call Derek at (773) 404-8726 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.

MISCELLANEOUS

HIVPosYOUTHCHI AT AOL.COM

AOL Chat room for young adults (ages 18–24) who are HIV-positive. Hosted by TPAN's Young Adult Program. Go to AOL town square. Monday through Friday 3:00 pm–6:00 pm, except Thursdays 4:00 pm–6:00 pm.

4th Annual

Staying Alive: A Survival Training for People Living with HIV/AIDS and THRIVE expo

Registration Form Hoja de Inscripción

Chicago, IL August 16-19, 2001 / 16 al 19 de agosto del 2001

Please type or print all information/Escriba en letra de molde:

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 Other/Otro _____

Demographic Information (Check all that apply) / Información demográfica (Seleccione todas las que apliquen):

Health Department Official/Dept. de Salud
 Planning Council - Consortia/Concilio de Planificación
 AIDS Service Organization/Organización de Servicios de SIDA
 Community-Based Organization/Agencias de base comunitaria
 Person Living With HIV/Persona viviendo con el virus
 Community Prevention Group/ Grupo de Prevención
 Community-at-risk Member/Comunidad de alto riesgo
 Ad-hoc, Advisory Council, or Committee Member/Comité asesor Comunitaria
 Other (specify): _____

(The following questions are OPTIONAL/Estas preguntas con opcionales)

Gender/Género:

Male/Masculino Female/Femenino Transgender/Transgénero

Sexual Orientation/Orientación sexual:

Gay/gai Lesbian/lesbiana Heterosexual Bisexual

Ethnic group/Grupo étnico:

African American/afroamericano Caucasian/caucásico
 Asian/Pacific Islander/Islas del Pacífico-asiático Latino/a
 Native American/nativo americano Other/otro (please specify/especifique): _____

Age/Edad:

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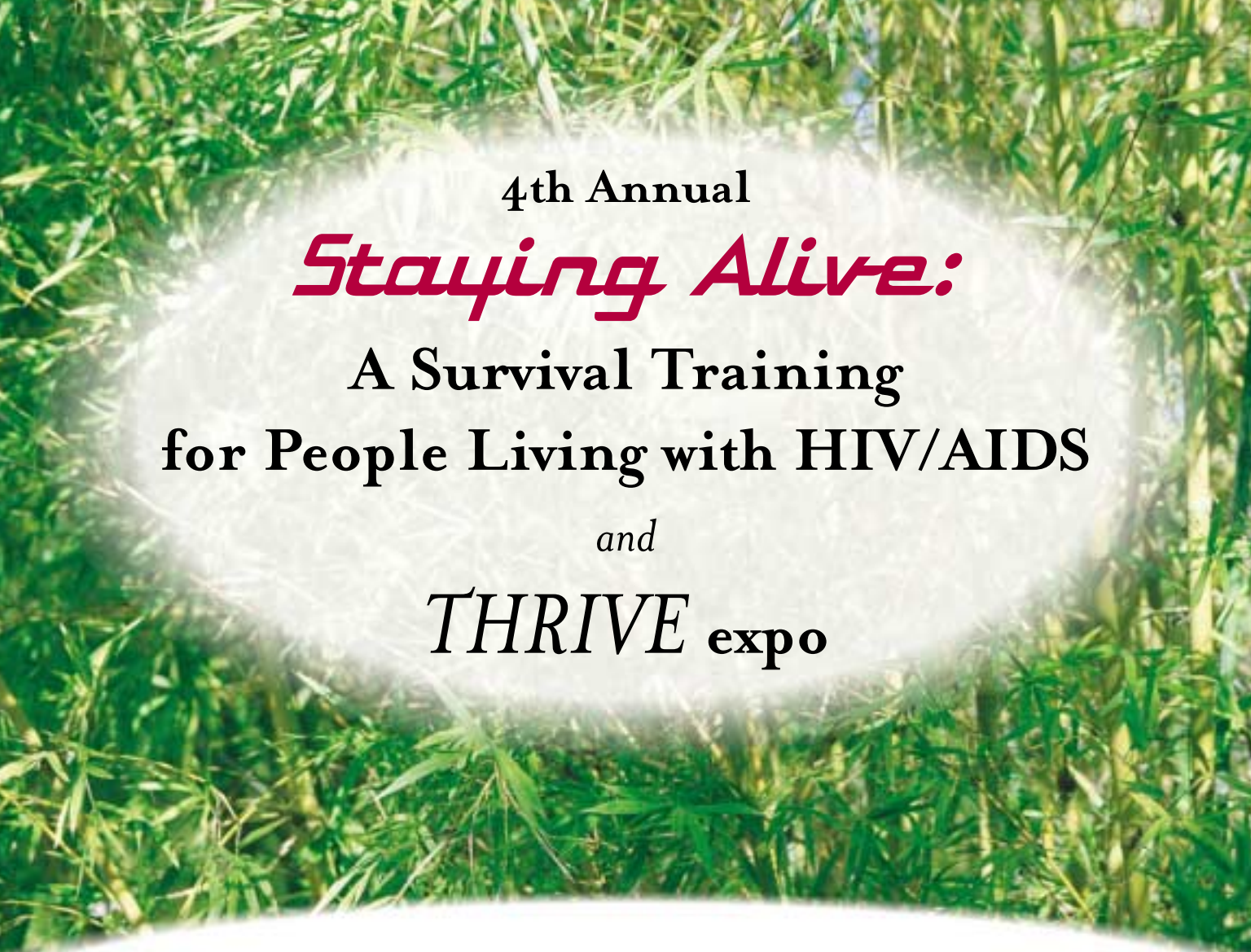
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For more information contact Charles Debnam at NAPWA (202) 898-0414 ext 127
or Keith Waltrip at TPAN (773) 404-8726