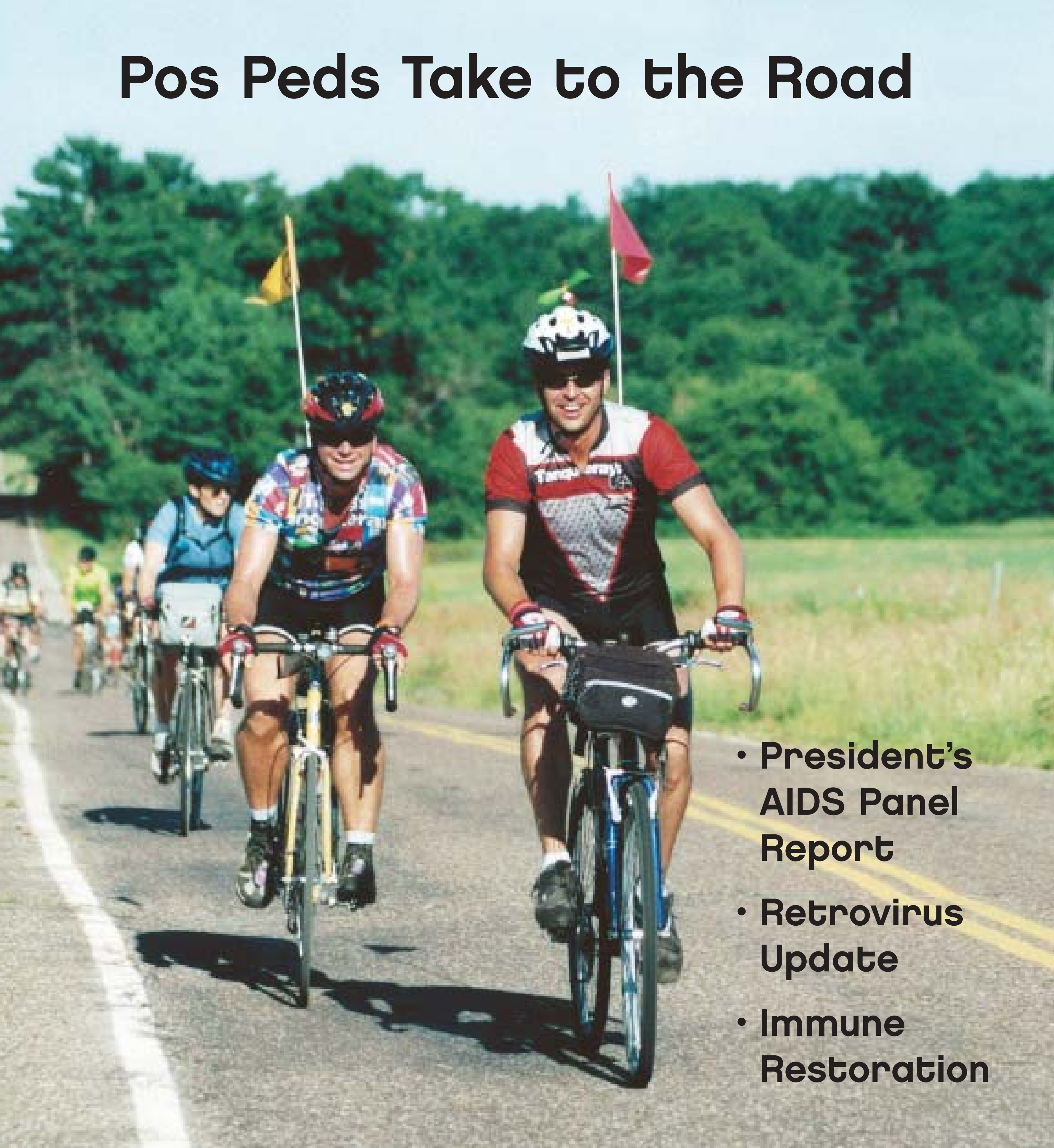
May / June 2002

Positively Aware

The Journal of Test Positive Aware Network

Pos Peds Take to the Road



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Cover photo by Miles J.McClelland

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

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Editor’s Note

Trailblazers

photo by Russell McGonagle

This year I watched in amazement as Denzel Washington and Halle Berry both won Academy Awards. As I sat at home on the side of my bed listening to their acceptance speeches, I cried. For me, it was a moment of huge historical significance. They were immediately labeled “trailblazers” by the media.

Ms. Berry dedicated her award, to “every nameless, faceless woman of color that now has a chance because this door tonight has been opened.” As I listened to Berry, I thought about the other brilliant performances given by African American women previously nominated in this category, Angela Bassett (1993), Whoppi Goldberg (1985), Diahann Carroll (1974), Diana Ross (1972), and Cicely Tyson (1972). The late Dorothy Danridge was the first African American woman nominated for best actress for *Carmen Jones*, 1954. Hattie McDaniels was the first black female to win an Academy Award. She won for best supporting actress for *Gone With The Wind*, 1939.

The promise (and burden) of being a trailblazer is complex. Thurgood Marshall. James Baldwin. Audre Lorde. Althea Gibson. Dr. Jocelyn Elders. Colin Powell. The promise of being a trailblazer is that barriers are being broken. To many, countless opportunities appear endless. The burden of being a trailblazer is being pigeonholed as the “spokesperson.”

However a larger problem exists. What is the significance of being a trailblazer if no one ever follows that path, or if it takes a lifetime for the path to be blazed again? It’s been 39 years between Sidney Poitier’s Academy Award win and Denzel Washington’s win. Will it be another four decades before another African American woman wins for best actress?

Is the situation different in AIDS policy making and advocacy? Arthur Ashe. Magic Johnson. Rae Lewis-Thornton. To some degree they are considered trailblazers in African American HIV/AIDS advocacy. But did they simply put a non-threatening African American face on the face of AIDS when nearly everyone was running scared? Did they serve a larger goal of raising the ambitions and self-expectations of others? When I was a teenager I certainly respected Ashe’s accomplishments on the tennis court and dreamt of imitating him one day as a professional bowler (don’t laugh). All of this occurred long before HIV/AIDS ever appeared on the horizon.

As an “HIV journalist” or “AIDS activist,” in recent years I have often found myself in an Ashe-like situation; being the only African American (not necessarily the first) at major scientific conferences or drug company updates. And I have to admit that initially I was a bit unnerved by the experience. But rather than focusing on the fact that I was the only African American at these meetings, I looked to the positive. There was representation. I also gained confidence from knowing that there were other African Americans, Saundra Johnson (GMHC), Charles Nelson (formerly with NAPWA) and Phil Wilson (AAHU), who had previously sat in the community chair where I am now seated. But if there is room for one, isn’t there room for four or five?

I recently had the privilege to meet Patricia Ware and Dr. Louis Sullivan at the Presidential Advisory Council on HIV/AIDS (PACHA) in Washington, D.C. Ware is the Executive Director of PACHA. Dr. Sullivan, whose achievements are too long to list, now serves as a co-chair of PACHA. Both are major players in HIV/AIDS policy at the federal level. They are also African Americans. And they are perceived as being supportive of conservative views on HIV prevention and care. Does it matter? No, not in terms of opening doors. Have they raised the ambitions of others? Yes.

While at the PACHA meetings, I also had the honor of meeting Lois Brown. I would suspect that no one reading this has ever heard of Ms. Brown.

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From TPAN

Random Musings

Miscellaneous thoughts (often politically incorrect) from behind the front lines.

Pinch me, I must be dreaming—Senator Jesse Helms is lobbying for *more* money to fight AIDS overseas. Isn't this one of the signs of the Apocalypse? It seems as he draws closer to his meeting with God, humanitarian spirits are stirring within him. (Note to Senator Helms: Based on the experience of your colleague Senator Thurmond, you may not be as close to that meeting as you may think.)

The Bush II administration has pledged $500 million to the Global AIDS Fund over the next two years. This has been widely criticized as too little support. This may be true, but how much was pledged under previous administrations?

It seems that if you are part of the federal government or are an agency or program funded by the federal government for HIV prevention you must be very careful what you say these days. Prevention messages are fine—as long as they say abstinence and abstinence only. However, if you are held in high regard by the public you can go on MTV and promote condom use without much criticism from the White House. (Ah, the power of polling numbers.)

Now that we are in the 21st century, isn't it reassuring to know that the United States government clings to old-fashioned ideals. Ideals such as sex education where you teach only "no sex." Ideals such as talking to teenagers about condoms will cause them to have more sex. Ideals such as protection of the father-(oops sorry) homeland from the thousands (millions?) of HIV positive people who want to *visit*. Of course if we did not have our immigration ban, hordes of HIV positive people from around the world would descend on this country, sneaking in as tourists, but fully intending to become residents so that they could use our public health system. Makes you wonder how the rest of the industrialized world (who *do* have socialized medical systems) have managed to withstand this mass-migration-for-medication.

And speaking of abstinence, is it really wrong or a "sell-out" for HIV prevention educators and providers to *add* abstinence to their programming? Should we not provide support and encouragement to individuals who believe in, or are leaning towards abstinence?

What are the long-term prospects for newer, better HIV treatments? Are the recent mergers within the drug industry good or bad? Do big companies have more resources to devote to expensive HIV drug research? Or are they now less inclined since the HIV portion of their total business is small. Has new drug development been hurt now that it is clear the only "profitable" markets are in North America and Western Europe? And what impact will an HIV vaccine have on anti-HIV drug development? If a vaccine is developed and therefore new infections stop, doesn't it seem likely that new treatments for those of us living with HIV will cease?

And finally, President Bush's announced nominee for Surgeon General is a high school drop-out who has made good through hard work and perseverance. Given our semi-war footing, it's not surprising Dr. Richard Carmona has experience in mass destruction and bio-terrorism planning. Too bad. What this administration needs is a voice advocating for prevention education. Just as *preventing* terrorism saves lives, so too does preventing diseases. Maybe we can count on Senator Helms.

Dennis Hartke

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Executive Director
Thoughts, comments, reactions? Write me at
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photo by Russell McGonagle

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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HIV Drug Guide Addition: Agenerase Warning

It is nice to see that *Positively Aware* publishes the 2002 HIV Drug Guide. It's very useful. Thank you. I am surprised, however, that for the medication Agenerase (amprenavir) the guide does not list other drugs that when mixed with this medication can cause death or life-threatening situations: Halcion, Hismanal, Propulsid, Versed and Vascor. Unfortunately, even hospital pharmacies are not aware of this, and they use Versed for many procedures. I was almost a victim of having Versed given to me for a procedure when it should not have been, even though I questioned the doctors, nurses and the hospital pharmacy. I just do not want to see any one else subjected to this type of stress.

Name withheld, via the Internet

Editor's Note: An important class warning for the HIV protease inhibitors is indeed left out of the Agenerase page. This warning, under "Potential Drug Interactions," states, "Do not take with rifampin, Versed, Halcion, D.H.E. 45, Migranal, St. John's Wort, or ergot derivatives (such as Cafetrate, Cafergot, Wigraine and Methergine, in any form—serious interactions seen with dilation during gynecological exams)." In addition, Orap (pimozide) should not be taken with Agenerase. As you mentioned, use of any of these medications may cause serious or life-threatening reactions. Thank you for your conscientiousness in bringing this to our attention.

Ergot derivatives are used for headaches and migraines, postpartum hemorrhage, and sometimes during gynecological procedures, while D.H.E. 45 and Migranal are used to treat migraines. These medications may stop blood flow when used with a protease inhibitor. Versed and Halcion are sedatives, and may cause over-sedation and extremely slow breathing. Both rifampin (used to treat tuberculosis) and St. John's Wort (an herbal remedy used for depression) may lower the anti-viral effect of Agenerase and lead to drug resistance (when Agenerase is no longer able to fight HIV). Using a protease inhibitor along with Mevacor or Zocor (to lower cholesterol) may lead to myopathy (muscle damage), although many HIV specialists still prescribe them and find no problems. Orap (used for Tourette's syndrome) may cause cardiac arrhthmias, or abnormal heart function. Vascor treats angina, or chest pains, and is used for cardiac arrhthmia. Hismanal, Seldane and Propulsid have been taken off the market.

Healthy attitudes

I have been HIV positive since 1993 and I have been taking meds for the last four years, with little or no side effects. I started with Retrovir/Epivir, and I now take Combivir/Crixivan, and I have been doing great. [*Editor's Note: Combivir is a combination of Retrovir and Epivir.*] I am in prison and about to be released. When I first got my time, my attitude was not very healthy, but over the course of time, I was introduced into the Louisiana prison's peer counselor program and support groups, and I was certified by the Louisiana Department of Public Health and Safety as a counselor for HIV/AIDS. I read "Living with Yoga,"[See Jan/Feb 2002 issue] and overall I would agree with it. Although I've never studied yoga, I have delved into other similar disciplines, and together with all the above, my unhealthy attitudes have for the most part vanished. I have also been receiving *Positively Aware* for four years now, and it has been a tremendous influence on my life, physically, mentally and spiritually. When I get out I will try to become involved in locally based organizations and continue to learn and teach, and do whatever else I can to further education and health. I thank you all there at TPAN for the unknowing support and influence you have given me through your magazine. Sometimes "thanks" doesn't seem enough, but it's all some of us have to give.

Danny, Winnfield, LA

Sustiva woes

I am writing to bring you up to date on my situation. I was charged with #203 (Drugs & Drug Paraphenalia) due to the consumption of Sustiva, one of the medications I take for HIV therapy. After I was forced to do the entire time in segregation, I was cleared of these bogus charges. Then, perhaps as a consolation, I was approved to be transferred to a lesser security facility. As the old saying goes, "We can forgive, but we could never forget." Personally, I doubt if I could even forgive them for their [prison staff] transgression. Because the fact that they were aware of the side effects makes turning the other cheek difficult to do. It's not entirely the fault of the staff here. The medical director, Dr. Elyea, refused to admit that he could be wrong, which resulted in his putting a gag order on the rest of the medical staff, his subordinates. This is why we were forced to suffer. I want to thank you for your support, keep up the good work. [See "Sustiva Dirty Drops," Nov/Dec 2001 issue]

Name withheld,
Menard Correctional Center, IL

I was released from segregation after nearly three months. My security level was changed from minimum to secure medium, which is nothing but a maximum security facility. This happened even though I've been found not guilty [of a dirty drop for marijuana, while on Sustiva] and had the incident report expunged from my records. I am trying to be transferred back to a minimum security facility.

Name withheld, Hill Correctional Center
Galesburg, IL

Uplifting

A friend of mine recently showed me an issue of your journal, and it opened my eyes to so many things about living with HIV that I was totally unaware of. I was told I tested positive for HIV on April 11, 2001. I was then, and am still, in prison. It was devastating news. Up until seeing your journal, I've had a miserable outlook on the future, thinking my life is wasted, and at best I'd live four to five more years healthy and then die. Your magazine—just the forum alone—lifted my spirits and made me realize that I can live a life still. I thank you dearly. Just this one issue made me believe that I can take the steps to live a healthy and perhaps fulfilling life! Keep up the good work. It's beautiful that there are people who truly care.

Name withheld, Midway, TX

Tired of tiredness

I picked up a copy of your fine magazine in the lobby of the San Francisco AIDS Foundation. I find it very informative. It gives an outlet to a group of people who, for whatever the reason, have lost temporarily or permanently their right to free association. It is true that we out here do not fully understand those incarcerated individuals, women, drug users or abusers. The fact remains that out here or in there, they have as much right to voice their concerns and are lucky to have found a media not afraid to give an outlet to their writing. Here or there, they are living with HIV. I have no idea who "the main core of readers" for your magazine is. I am a Hispanic immigrant living with HIV and other serious complications, due to either the medications or new devastating diagnoses, which compound my problems ten-fold.

Regarding the Editor's Note, [Nov/Dec 2001 issue] it has been a while since I have encountered such an empty display of *tiredness*. I too agree with you that dealing with this disease requires a great deal of compassion and understanding, not only of our concepts but of theirs. The need to change learned behaviors are at the root of the problem. As a longtime survivor (nearly 16 years), I am an educated gay male, who agrees 100% on many of the issues you raised. But to simply complain of these things seems wrong. I ask, is there a way we can expand the knowledge we have learned about this disease to those who for whatever reason find it harder to stick to our "med diets" or to the desire to stay healthy, even if it costs our lives to do so, or to the need to stay emotionally involved when the realities of our lives impedes us from doing this successfully? I am tired of the way those in a capacity to educate others with printed material to those of us who find ourselves in need of information choose to eloquently dress an entire sheet and say nothing at the same time. Perhaps it is a form of therapy to be tired of the status quo in our community, but to do nothing about it, other than to complain tiredlessly without giving an alternative solution to the same old issues, seems to me redundant.

Name withheld, San Francisco

HIV Activism

I applaud you for your story on HIV Activism [Editor's Note, Mar/Apr 2002 issue]. So many things in your article ring true right here in my community of Key West, Florida, which has a high HIV/AIDS population. I have become actively involved over the past year and a half and have met many obstacles along the way. Our Consortia is now called the Florida Keys HIV/AIDS Community Planning Partnership. I became a member and started participating about a year and a half ago. I have brought issues up at the meetings that concerned myself and others about the way we were being treated only to be belittled by many in the group, which consists mainly of Health Department employees and AIDS Help, Inc. employees. While our Planning Partnership is supposed to consist of one-third clients by law to have the required input, until recently it hasn't been the case. When I first started going to these meetings I noticed there were only one or two clients there including myself and, until recently, no real effort was put into better informing the clients that this group even existed.

Two other clients and myself came up with the idea of beginning some type of Wellness Program. In November of 2001, we met with a grant writer and a local gym owner with our ideas and now have a Wellness Program formed. We are in a three-month trial after raising the money needed to sustain it. We have had some luck. The head of the Monroe County Health Department has recognized the importance of our program and given us his support. He recognizes that not only will our physical appearance improve but also our mental state of mind and nutrition habits.

Because of this program we have gotten more clients involved in the community planning process. But there again lies the problem. The majority of the people at these meetings are still grasping on to the way things were done in the past and are critical of new ideas or change. Often clients are made to feel unwelcome at the meetings by the gestures of some members, which I find to be very inappropriate and disrespectful. And a lot of times we get choppy answers to our questions, as if there is something they don't want us to know. Often when we (clients) make comments or pose questions we are accused of trying to wreck the system or taking shots at it or someone, when all we are doing is becoming actively involved and making our observations known. I have not let this deter me from what I am doing, it has only made me stronger and try to pursue my goal of becoming an activist for my own health and also help others.

Any ideas on how to become more organized and how clients like me can push these organizations and agencies to change with the disease, like we are trying to, would be greatly appreciated. I think maybe some form of a chapter of the ATAC may be a good idea. I have written to them with my questions regarding becoming more of an activist. Thank you again for such a great article.

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News Briefs

by Enid Vázquez

photo by Russell McGonagle

UNDETECTABLE CUM?

Not quite, according to a report from the Center for AIDS Intervention Research of the Medical College of Wisconsin, in Milwaukee. They conducted a study with 44 HIV positive men. Of the guys who were undetectable based on the standard blood test for viral load, half had detectable HIV in their semen. This was true no matter what their disease or treatment history. The report was published in the December 10th, 2001 issue of *AIDS Research and Human Retroviruses*.

EAT AND WALK FOR LIPO

No, it's not a fundraiser. Once again researchers are reporting that eating right and exercising may help people with HIV-related lipodystrophy, a syndrome of body fat and cholesterol changes that's quite common. In this report, an "intensive" diet and exercise program helped a 44-year-old man. He had gained 30 pounds within two and a half years of HIV therapy (which has been associated with the changes). The fat on his arms and legs thinned, while his belly greatly increased and he grew "breasts." He was able to lose 14 pounds and lower his cholesterol, plus cut his visceral fat in half (which sits on the organs beneath the abdominals) after four months. Visceral fat has been associated with cardiovascular disease, among other serious illnesses. Three times a week he did cardiovascular exercise and strength training for 75 minutes and his daily diet consisted of at least 25 grams of fiber, 15% protein, 30% fat, with the rest of his calories from carbohydrates. The report was published in the February issue of *Clinical Infectious Diseases*.

SUSTIVA AND BIRTH DEFECTS

Sustiva is not supposed to be used by women hoping to become pregnant, because birth defects were seen in studies with monkeys. Italian doctors recently reported on birth defects in a baby born to a woman who had taken Sustiva, in combination with Retrovir and Zerit (two drugs that are not supposed to be used together because of antagonistic effects). After her periods stopped and a pregnancy test came back positive, she was switched to Epivir, Zerit and Viracept. The baby was born with a large mass outside its body near the base of its spine and had blockage of its spinal cord fluid. These conditions can be fatal, but the mass was successfully removed through surgery and the fluid drained. Viral load testing found that, thankfully, the child was negative for HIV. The case was reported in the medical journal *AIDS*.

VIRAMUNE FOR PREGNANCY

Don't panic. News that Viramune's manufacturer was "pulling it" from consideration for FDA approval in pregnancy may have given people the wrong impression. The company was applying for a new "indication" for the HIV med. An "indication" is what a drug is used for. In this case, the new indication for Viramune would be to reduce the risk of HIV transmission from a woman to her newborn. Research shows the drug is highly effective and safe at doing this, with only four doses around the time of labor (two for the mom and two for the child). Those research results are still valid. But the U.S. Food & Drug Administration (FDA) told the company that this research was not conducted in the way it needed to be in order to gain a new indication. Basically, the paperwork wasn't completely in order. For example, the FDA did not find it acceptable that one study submitted for the new indication used oral consent instead of written consent for the participants in the trial. However, unnamed FDA officials told the *Washington Post* that the issue was more than paperwork, but wouldn't comment further. Researchers from Johns Hopkins University and the National Institute of Allergy and Infectious Diseases, the organizations that conducted the Ugandan clinical trial in question, told the *Post* that safety concerns are not at issue. An application for the new indication is expected to be re-submitted in the future after the questions are resolved.

Children’s seizures

A report in *The Lancet* medical journal noted a doubled risk of “febrile seizures” in children born to mothers who had taken anti-HIV medications, compared to positive moms who had not. The seizures occurred with fever (which is what febrile means) between three to 18 months of age. The French researchers looked at 4,426 children. The vast majority (4,072) were HIV negative. Most of them (2,644) were exposed to treatment. Thirty children had a febrile seizure, and 24 of them had been exposed to HIV medications before, during or after birth. The seizures were little cause for concern, and usually occurred only once. According to the report, the longterm effect is unknown, and probably harmless, but the children’s cognitive (brain) and behavioral development should be monitored.

Babies and ethics

Since 1994, the ethics guidelines of the American Society for Reproductive Medicine have discouraged fertility treatment for HIV positive people. But this year the association has issued new ethics guidelines that say positive people should no longer be dismissed from such services. The society noted the success of HIV medications in cutting transmission from mother to child, although the risk is not down to zero. For positive men with negative women, sperm washing and testing reduces risk, but more research is needed in this area, according to the guidelines. Visit www.asrm.org.

Positive women and kidney problems

Kidney damage or failure in HIV positive women is most often correlated with having hepatitis C, being of African descent, or T-cell count below 200. Co-infection with hep C is common among people with HIV. Looking at the records of 2,057 women enrolled in the Women’s Interagency HIV Study (WIHS), researchers found that 32% had proteinuria at their initial evaluation. Protein in the urine is a sign of kidney damage or disease. Black women had a doubled risk for proteinuria. As for out-and-out kidney failure, risk factors included low T-cell counts, falling albumin levels (check your lab results), viral load above the detectable level, increasing creatinine levels (see labs), and high blood pressure, in that order. The findings were published in the January 2002 issue of *Kidney International*.

AIDS lawyers conference

The first-ever national gathering of lawyers and other advocates involved in the day-to-day representation of people with HIV is scheduled for May 17-19th here in Chicago. Keynote speaker Bennett Klein, director of the AIDS Law Project at Boston’s Gay and Lesbian Advocates and Defenders, successfully argued the case of *Bragdon v. Abbott* before the U.S. Supreme Court in 1998, which led to the landmark ruling extending full protection of the American with Disabilities Act to all individuals infected with HIV. The wide range of topics to be covered include employment discrimination, debtor-creditor issues, Social Security and public benefits, insurance, immigration, criminal justice and women’s issues. For more information, contact Michael Pates at the American Bar Association’s AIDS Coordinating Committee, at 1 (202) 662–1025 or e-mail at patesm@staff.abanet.org.

HPV in men

Of the many types of human papilloma virus (HPV), HPV-16 has been found to be associated with half of all cervical cancer cases. The U.S. Centers for Disease Control and Prevention (CDC) recently reported findings on HPV-16 in men. Of 83 men who have sex with men (MSM), 38% were infected with HPV-16, compared to 8% of heterosexual men and 19% of women. How the infection relates to anal and reproductive tract cancers is still unknown. The fact finding continues. HPV rarely has symptoms, although it can cause genital warts, which are easy to treat. Left untreated, the infection can lead to infertility as well as to cancer. The CDC made its report at the National STD Prevention Conference in San Diego in March. CDC researchers also reported on increasing rates of sexually transmitted diseases (STDs) among MSM, noting that, “Together with past indications, these findings continue to point to the danger of a possible resurgence in the HIV epidemic in this population and the urgent need for expanded prevention efforts.”

HIV cocaine

A study of mice injected with human cells found that cocaine doubled the number of cells infected with HIV, and increased viral load by 200 to 300 fold, when compared to placebo (fake drug). Cocaine also seemed to lower T-cells. How the drug is able to directly affect the virus is not understood. Researchers said the amount of cocaine given the mice was comparable to what people would use. The study by University of California Los Angeles was reported in the March 1 issue of *The Journal of Infectious Diseases*. ✚

CROI Update

by Enid Vázquez

Some news from the 9th Conference on Retroviruses and Opportunistic Infections (CROI), held in February in Seattle.

Liver transplants

A team of doctors found three reasons why HIV positive people may die shortly after a liver transplant: hepatitis C, HIV treatment intolerance and hemophilia. They looked at 23 HIV positive people from around the world. Of the seven people who died within a month after their transplant, all had hep C. This compared to only a little over half of the survivors (9 out of 16). Another difference was being able to tolerate HIV medications following the transplant, whether or not those medications were tolerated before the operation. Here the difference was more stark: all of the survivors, but none of the people who died, were able to tolerate their HIV treatment. Also, hemophilia was associated with a greater risk of death—five of the seven were hemophiliacs, compared to only two of the 16 survivors. Survival at the time of the report ranged from one month to 49 months, with a median (half below, half above) of 15 months.

Hepatitis B

The commonly used HIV drug Epivir (3TC) is also used to treat hepatitis B. With medications developing resistance after a while (they can no longer fight off disease), can another hep B drug work for people who develop Epivir resistance?

A small study of 35 people co-infected with HIV and hepatitis B found that after a year and a half, the majority continuously lowered their hep B viral load when using 10 mg a day of adefovir. None of them experienced a rise, and four of the people were able to clear their hep B altogether. However, there were four dropouts: two for adverse events (diabetes and insomnia), one for "noncompliance," and one for personal reasons. Fibrosis and liver function tests (ALT) also improved, along with liver inflammation in 14 people given biopsies. This study was conducted by adefovir's manufacturer, Gilead Sciences, and a hospital in Paris. One HIV specialist said doctors will be saving adefovir for use in people who are HIV negative.

Adefovir is an experimental drug. It had earlier been tested for HIV therapy, but was dropped when it became the first HIV med to fail to win FDA approval. Kidney damage was associated with the drug, but none was found in this study. The researchers noted that Epivir resistance is found in 90% of the people who've used it for four years. Epivir is also part of two other HIV drugs: Combivir (Retrovir, Epivir) and Trizivir (Retrovir, Epivir, Ziagen).

More hepatitis B

Gilead Sciences also makes Viread (tenofovir), an HIV drug (the newest on the market) that can also fight hepatitis B. In another study of co-infected people, researchers found that Viread lowered hepatitis B viral load, even in those who had developed drug resistance to Epivir. Researchers looked at the 14 co-infected participants in a Viread clinical trial. Twelve were given Viread and two received placebo (fake medication). All of them had taken Epivir at some point, and six remained on Epivir during the study. Liver enzymes (ALT) normalized in two Viread patients, and the hep cleared in another. Meanwhile, the hepatitis B viral load increased in the two placebo participants. The preliminary results came from 24 weeks of study. The report noted that Epivir resistance occurs in approximately 15 to 32% of people taking it for one year.

Newborns and lactic acidemia

We know that HIV medications in pregnant women help reduce transmission of the virus to the baby, and is quite safe, but the search for abnormalities is still necessary. Here doctors looked at 25 HIV negative infants whose moms used HAART (highly active anti-retroviral therapy) during pregnancy. They found that 92% of the infants (23 of them) had abnormally high levels of lactic acid, which were normal by the time they reached six months of age. These children had also received some Retrovir treatment (zidovudine, AZT) after birth to prevent infection. Half of the infants had also been exposed to cocaine, heroin or methadone in the womb. Most of the mothers themselves (17) had normal lactate levels by the end of their pregnancy.

The researchers looked at lactic acid because of abnormal levels found in HIV positive adults on therapy. Scientists are speculating that the nucleoside analogs in particular (Retrovir, Zerit, Videx, Epivir, Ziagen, Hivid, etc.) may be causing damage to the mitochrondria. These are "powerplants" that live in our cells, converting oxygen, fat and sugar into energy. It's believed that mitochondrial toxicity in adults is causing lactic acidemia, which in serious cases can lead to death. However, these researchers noted that as with adults, it's unclear what effect the abnormal levels of lactic acid had on the children.

TMC-125

If Sustiva or Viramune are no longer guarding the body against HIV, there's a promising non-nucleoside analog on the horizon. The potential of TMC-125 is that it may work when the other two drugs fail. That's an option that's needed in HIV therapy.

It's known that low-level drug resistance to one of the two older drugs will also lessen the chance of the other one working. As reported before, TMC-125 seems to work in people who have developed resistance to the two oldies. In this small study, 16 men substituted their Sustiva or Viramune for 900 mg of TMC-125, taken twice a day for one week. These guys already had high-level resistance to the non-nukes, plus resistance mutations to protease inhibitors and nucleoside analogs. At the end of the week, almost half of them had a very significant drop in their viral load of one log. Also, 75% of them had at least a half-log drop in viral load, the smallest drop that can be considered a significant benefit .

Other TMC-125 researchers noted that TMC-125 by itself dropped people's viral load as much as a five-drug combination, again, after one week on medication. These people were all taking HIV medication for the first time, when treatment tends to have the best results. The researchers compared the results of 12 people on TMC-125 with those of 13 people on the five-drug combo (Retrovir, Epivir, Ziagen [probably taken as Trizivir, one tablet twice a day], Viramune and Crixivan). The monotherapy group had a median viral load drop of 1.8 logs compared to a 1.55 log drop in the combo group. Bottom line: it's a potent drug. Changes in T-cells were not statistically significant. There was a rise in both groups.

DPC–083

Like TMC-125, DPC-083 is an experimental non-nucleoside that may work when the older non-nukes no longer can. It's made by the same company that manufactures Sustiva, and is considered a "second-generation" drug. The company switched failing Sustiva or Viramune with DPC-083 in 51 people. These people had extensive non-nucleoside resistance. Still, after eight weeks (not enough time to show durability, but enough to show potential) the majority of the participants (57%) had less than 400 viral load. They had all started out with more than 1,000—which is still pretty low. However, a goal of HIV is to have viral load below the level of detection (400 or 50, using an ultra sensitive test).

Positive Empowerment

by Beverly Henry

My name is Beverly. I am co-infected (HIV/hepatitis C), bisexual, African American, 52 years young and last of all, I'm in prison until 2009. My message is for every woman who is incarcerated and having a tough time living with the enemy (HIV/AIDS). When anyone is told they have any type of life-threatening illness, I believe a person becomes fearful of what to expect next. When you learn you are HIV/AIDS positive, all sorts of feelings surface and many of us prepare to die soon.

Learning about my positive status in 1994 (during a prior prison term) sent me reeling into depression, anger, guilt, shame and fear, just to name a few of the feelings I experienced. I was 45 years old at the time and my very first thought was I would die within a year or two. A couple of months passed by while I threw my own pity party, but then I decided to say my status out loud to every one who would listen.

I discovered a hidden quality within myself that suddenly surfaced to assist me in saving myself from self-destruction. This quality, courage, saved me in the form of self-disclosure. Not living in secret forced me to accept personal responsibility for my health, along with studying about my enemy and choosing who I care to include in my life today, as well as who I choose to share intimate moments with.

There may be a woman who reads this and thinks, "No way will I ever reveal my status." Well, please know countless women have passed away trying to live with these diseases secretly, not to mention the loneliness that tags along with being secretive. Courage to speak out can change how you think and feel about you!

Many of us women, prior to learning our positive status, had failed relationships, possibly due to addictions and abusive mates. Then you test positive and feel you will never have what means so much, a meaningful, healthy intimate relationship.

Being positive and having courage, and learning through trial and error, allow me to know that Beverly is deserving of intimacy and love in a healthy, meaningful relationship. I have choices today. Plus my courage allows me to never give up my desire for loving and being loved unconditionally. Do not allow anyone to make you feel bad about your serostatus. Do not allow yourself to accept verbal and physical abuse because you think your abuser is the only person in the world who will accept you now that you have HIV.

Check within yourself and apply the courage you find hidden inside you. Use it to the fullest, my sisters. There is love out there for you, and living with HIV/HCV is possible if you have the courage to go for it.

THIS IS WHAT COURAGE DEMANDS:

- Do not give up on yourself.
- Do not give up on your hope for being loved.
- Do not allow anyone to make you feel bad for being positive.
- Do not accept verbal or physical abuse because the abuser accepts your serostatus.

Beverly Henry is a member of the HIV in Prison Committee, an activist group that fights for adequate medical care and protests against abuses in Chowchilla.

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President's Advisory Panel Finally Convenes

by Charles E. Clifton

The newly appointed Presidential Advisory Council on HIV/AIDS (PACHA) met for the first time under the Bush administration in Washington, D.C. in March.

President Bush's top health advisors were on hand for the meetings. Health and Human Services Secretary Tommy G. Thompson imparted to members that we are "beginning a new chapter" in the struggle against HIV. He stated that "this isn't business as usual," but rather that the Office of National AIDS Policy is committed to "developing effective tangible steps to arrest the advance of AIDS."

PACHA Council member Caya Lewis, a manager at the National Family Planning and Reproductive Health Association, argued that allocations for treatment programs do not correspond to the spread of the disease in the U.S. Lewis stated, "I am deeply concerned about the lack of emphasis on prevention in this administration." Caya questioned the administration's commitment to curbing the increasing rates of infection within minority communities with flat funding for Ryan White programs.

Thompson proceeded to defend the administration's decisions on AIDS policy, including flat funding for Ryan White programs and funding emphasis on abstinence-only programs, for fiscal year 2002-03. He said that given the costs associated with the war on terrorism and homeland security, AIDS advocates are fortunate that current funding levels were maintained for prevention and treatment, and for increases for research. "You don't know how hard I had to fight to get flat funding," he informed the newly appointed Advisory Council. "The priorities are the international war and homeland security."

The administration's allocation for prevention funding is disappointing because it appears to directly counter the efforts of the Centers for Disease Control (CDC) and Prevention to improve HIV prevention.

> …the Office of National AIDS Policy is committed to "developing effective tangible steps to arrest the advance of AIDS."
> —Tommy G. Thompson

Many critics have also denounced Bush's proposed budget as devastating for many HIV-infected people who do not qualify for Medicaid and have no private insurance to cover their medications.

Stuart Burden, a Council member and Levi-Strauss and Company executive, questioned the administration's pledge to the Global AIDS Fund. The U.S. has promised $500 million for the Fund, estimated to need $8-10 billion. "There is a belief in the international community, given the size of our economy, that the United States has not done enough," Burden said. "What more are you [Thompson] prepared to recommend?" Thompson responded that "no other country has re-committed to the Fund" on the same level as the U.S. He noted that the U.S. pledge represents 25 percent of the total $2 billion in pledges, "a tremendous and generous contribution." Thompson restated that the international war, homeland security, and domestic concerns were priorities for the Bush administration and therefore overrides the Fund.

Thompson informed the Council that his office has commissioned a management review of all federally funded HIV programs. He stated that the goal of the review is to make them "more accountable, better coordinated and more efficient." These efforts have also raised concern among AIDS advocates who fear that this is simply the first step in the administration's plan to reduce HIV prevention programs or redirect money.

Dr. Joe O'Neill, the acting director of the Office of HIV/AIDS Policy, is overseeing the review process of HIV programs and funding. O'Neill stated that he only agreed to lead the process in order to "honor successes and identify problems," in other words, to improve the government's efforts. "I know there's a lot of concern this review will be either a whitewash or a witch-hunt," he said. "I want to put your minds at rest. The interest here is in doing a better job." He emphasized the fact that he is not trying to damage any programs, but finding a way of doing a better job of providing services to people living with HIV.

Dr. Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases at the National Institutes of Health, presented his agency's AIDS research for the Council. When asked about a possible AIDS vaccine, Dr. Fauci informed the members that an effective AIDS vaccine could be a decade or more away. "Do I think in five years we are going to have a vaccine that is going to prevent AIDS? Probably not," he said. However, Fauci pointed out that "some global health good" could come out of the vaccine clinical trials that are currently being conducted. He explained that in developing nations with the highest rates of HIV infection an AIDS vaccine with moderate effectiveness would have a lasting impact.

Data on Merck's highly anticipated experimental vaccine was presented at the Retroviruses conference held in Seattle this past February. The vaccine is only in the first stage of safety testing and if successful it will be at least another five years (and probably longer) before the vaccine would reach the general public. Many experts are of the opinion that a vaccine is the only way to stop the AIDS epidemic, which has infected over 40 million people and caused some 20 million deaths worldwide.

Comments from President Bush's gay AIDS czar, Scott Evertz, drew mixed reviews from those in attendance. What's the deal with him? In a scattered presentation, Evertz spoke briefly about the resolve of the Office of National AIDS Policy resolve to address HIV/AIDS, specifically in communities of color. Evertz's comments on efforts to reduce HIV infection rates (targeting National Testing Day), and engaging in early treatment for HIV infection, including reforming ADAP, Medicaid and Medicare regulations, drew praise from Council members. However, Evertz did not speak of specific policy initiatives. Although Evertz appears to be dedicated and committed to the work, his comments to the Council came across as being unprepared and not well thought out. Is this always the case? Evertz was also harshly criticized in an appearance in Atlanta in early March for his off-the-cuff remarks. One former board member of Atlanta Executive Network, a gay and lesbian business organization, stated that while he expected Evertz to deliver leadership, what he received was "a stand-up routine."

ADAP SHORTFALLS

Bill Arnold, the chairperson of the ADAP Working Group in Washington, D.C, told the Council that the AIDS Drug Assistance Program (ADAP) needs an $82 million emergency supplement to cover current shortages in the program. ADAPs accept some 600 new clients every month, and six or seven states now have waiting lists while others have unofficial waiting lists, Arnold said. States currently with waiting lists, client expenditure caps and/or drug access restrictions include Alabama, Georgia, North Carolina, Kentucky, South Dakota, Idaho, Wyoming, Maine and Texas.

Reports indicate that the southeastern region of the U.S. appears to be having the most difficulty with ADAP funding, with about 700 HIV/AIDS patients on several waiting lists to receive antiretroviral drugs. In addition, Arnold stated that these states have placed so many restrictions on who is eligible for anti-HIV meds through Medicaid that ADAPs have become the safety net for HIV positive individuals. AIDS groups in Florida have asked the legislature for an additional $5 million in ADAP funding. They say a drug waiting list in the state will be inevitable unless the state receives supplemental funding from the federal government. AIDS advocates remain hopeful that Congress will improve on the president's budget, as it has in the past. However, even during the budget surpluses of the Clinton years, the final funding was regularly short of what AIDS groups said was needed.

In a surprise move, Hank McKinnell, head of the drug company Pfizer, Inc. and a Council member, announced that his company is freezing the price of Viracept, a leading protease inhibitor used for HIV therapy. Pfizer is the parent company of Agouron, the manufacturer of Viracept. "We want all patients to have access to needed medicines," McKinnell said. AIDS activists have harshly criticized pharmaceutical companies in recent months for their pricing of AIDS drugs, the associated impact on state ADAP budgets and insurance premiums. In a move that will certainly place additional pressure on competitors, including industry leaders Bristol-Myers Squibb and GlaxoSmithKline, McKinnell promised that Pfizer would not raise the price of Viracept for two years.

PACHA CO-CHAIRS

The make-up of the Council has raised many eyebrows in the AIDS community. President Bush's decision to name former Oklahoma congressman Tom Coburn to co-chair the Presidential Advisory Council on HIV/AIDS created a firestorm among AIDS advocates. Co-chair Dr. Louis Sullivan was Secretary of Health and Human Services for the first Bush administration. Dr. Sullivan now serves as the President of Morehouse School of Medicine in Atlanta. While most are comfortable with the selection of Sullivan, Coburn is criticized for having difficulties separating his personal beliefs from proven science and public health policies.

Coburn is an obstetrician and gynecologist by profession. He also served as a Republican congressman from Oklahoma for six years until he retired in 2000. To his credit, Coburn was very instrumental in securing the reauthorization of AIDS treatment and research funding during his term in the House. He was the primary sponsor of legislation renewing the Ryan White CARE Act. However, Coburn maintains strong opposition to programs promoting condom use and safe sex. He advocates sexual abstinence and monogamy instead to reduce new HIV infections.

Coburn also opposes the distribution of clean syringes to injection drug users (IDUs) as a means to prevent the spread of HIV through contaminated needles. Despite evidence indicating that clean needles do not promote drug use and addiction, and do reduce the risk of HIV infection, Coburn maintains that clean-needle programs are an endorsement of further drug use. Under the Clinton administration, the PACHA advocated for clean needle programs in its reports.

In late January, Coburn issued statements stating that his personal views would not dictate the work of the Council, but he promised to challenge the national focus on condom use to prevent the spread of HIV. "We have a prevention strategy that's failed," Coburn said in an earlier interview. "We've spent hundreds and hundreds and hundreds of millions of dollars and HIV infection is going up." AIDS activists counter that while rates of infection are rising among certain groups, primarily in communities of color, overall the 40,000 new infections reported each year in the U.S. are well down from the 150,000 at the height of the epidemic.

To the surprise of many, Coburn took a low-key position at this initial meeting. He urged members to work towards "building a consensus" on recommendations. He spoke of his "visions" of a day with no more HIV infections, no babies being born with HIV, and when all HIV positive individuals, including IDUs, would have available to them the treatments and services required.

President Clinton, Vice President Gore, and Health and Human Services Secretary Donna Shalala established PACHA in 1995. The Presidential Advisory Council on HIV/AIDS provides advice, information and recommendations to the Secretary regarding programs and policies intended to promote effective prevention of HIV disease, and advance research on HIV disease and AIDS. The role of the Council is solely advisory in nature.

Early in the Bush presidency there was concern that the Council would not be renewed. At one point the administration suggested that the Council, as well as the Office of National AIDS Policy were unnecessary. However, after much criticism, President Bush and Secretary Tommy G. Thompson renewed the Council´s charter in July 2001.

There are 35 advisory council members, an interesting mix of corporate executives, AIDS advocates and people living with HIV. Six members are returnees from the Clinton-era council. The members who served during the Clinton administration are Stuart Burden, Caya Lewis, Joseph Cristina, Ronald Dellums, Philip Burgess and Ingrid Duran.

A full list of PACHA members and affiliations are available online at www.pacha.org, as are minutes from previous meetings. ✚

A Lad and His Dog

by Carlos A. Perez

Dickie 1991–1999

You may be aware of the studies that people who own pets have a better chance of living healthier lives. In many studies researchers have found blood pressure levels of pet lovers to be lower than "pet-less" people, as well as many other indicators of overall wellness. Well, I am here to tell you they are right.

I was going through some life challenging and altering events. These events are the direct results of the madness of being HIV positive. I was years into disability and not finding the right thing to do, I had not ventured into volunteering or doing anything meaningful with my time. I had thrombocytopenia, peripheral neuropathy, and of course, depression. I had figured out one thing about helping myself. I needed to have a reason to come home, every day. I needed a routine for myself that did not consist of pleasure 24/7 or, at least, cut back a bit and decrease my risk factors.

The idea of a puppy was on the back burner. It sounded great but it was almost like committing to a relationship. Been there, done it, bought the tee shirt, didn't fit. One day my brother told me about a doggie, a Pit-Bull doggie. I was deep in depression, I thought it can't hurt and my brother's company is always action-packed, to say the least. We went to the "hood" where a beautiful bitch had a litter of pups. They were all adorable but one just gravitated towards me. I checked him out and it was definite. I was wearing Dickies overalls and I placed the pup in the front large pocket. We drove away and I started pretending like I liked the dog but I was depressed, I didn't know what to feel. After a couple of turns he puked on my Dickies. That's what I named him.

Dickie was my guardian angel. Besides the fact that he was a blast—acting like a spastic Tasmanian Devil—he made me laugh when I felt like I couldn't cry anymore. This animal was so glad to see me. This dog lived for me. I see it like this: they watch you produce food and water for them, they believe you're God. And you know what God spelled backwards is.

He was the reason I needed to be at home at least twice a day. I tried to go with early morning and late afternoons, you know, mimic society at large. I was still going out. That was my thing. I was on the "government cheese" and I still saw myself as an HIV victim instead of an HIV survivor. So the clubs were the answer. Besides, they still predicted we were dying of AIDS in "x amount of time" and I believed in "going out with a bang." I went out to bang just about every night. Dickie helped me get out of banging and get back in the house. I fell into a routine. I added regular visits to the gym. I started cooking more at home, thanks to Open Hand. I started meditation and one day while walking Dickie I met my partner. Did I mention this routine kept me away from the risk factors?

Little by little I began to realize that Dickie loved me more than the "tricks" did. I fell deeper in love with Dickie. He always wanted to stay with me the following morning just like every other second of the day. He wanted to stay around when my neuropathy hurt so bad I could only lie on the couch and he would lie there beside me. He stayed there with me when I cried in confusion just looking at me with those almond eyes, looking sideways, blinking, understanding me more than the "quickies" did.

We had to put Dickie down after he was about eight years old. He had cancer and to add drama his symptoms were AIDS-like. His lymph nodes were enlarged, his platelet count was very low, and his white cells were out of whack. It was a great loss. I was devastated.

The irony here is that there was one night during my bad spell when I came pretty close to giving up on waiting to die from AIDS. Dickie was there, nobody else. I remember sobbing because I thought I was giving up on him. I put him in his crate and he knew I was not right. He was barking and whining at me. He didn't have to speak words. It was clear to me that he was telling me to "get over it!" I didn't listen to his barks of wisdom and just drank and drank and did a "Judy Garland bender." Major hangover.

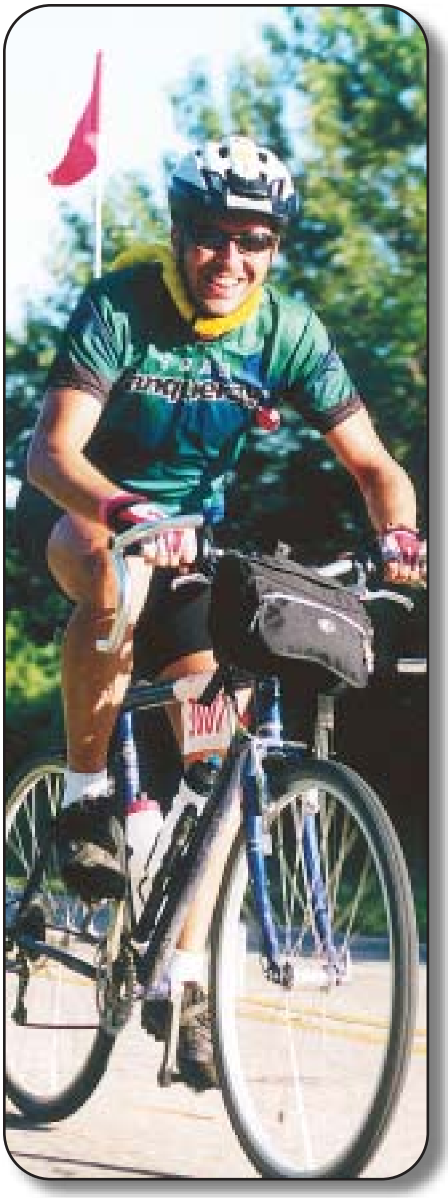
The next morning when I came out of my stupor I immediately realized the poor dog had not been out in hours, I mean like twenty-four of them! He was in his cage, which was clean as a whistle, and he looked so happy to see me. We were outside in no time. He was walking proudly, like Pits do with their chest flared and their butt shimmying from side to side and I had to smile. Dickie had pulled me through one of my darkest times and put me back on my routine. It worked for me. I have another angel now—another Pit-Bull, named Papi.

Cats, ferrets and Savannah monitors will do as well, I'm just a doggie-kind-of-guy. But believe me they can help. There's nothing like having to care for another living thing when you're not yet sure how to care for yourself. ✚

Carlos Perez is the editor of the Chicago Area HIV Services Directory *and Information Services Coordinator at Test Positive Aware Network.*

I Ride Because I Can —A Pos Ped Perspective

by Jeffrey Allen



photos by Miles J. McClelland

I ride because I can. I ride for those who cannot. I ride because too many won't. This is a common sentiment among AIDS Ride Positive Pedelers, or Pos Peds. We are a group of riders who come together from all walks of life and choose to participate in one or more of the many AIDS Rides around the country, fully disclosing our HIV positive status by wearing special jerseys and bright orange flags on our bicycles.

San Francisco rider Jonathon Pon founded the Positive Pedelers several years ago. Pon had a vision of HIV positive riders supporting each other throughout training, fundraising and along the ride route. As visibility of Pos Peds grew in California, its tradition spread to AIDS Rides around the country. Each AIDS Ride now has a Pos Ped team recognized with the jerseys and flags, and participation in the Opening and Closing Ceremonies. Jonathon passed away last year and leaves a legacy in the Pos Peds for all rides dedicated to raising money and awareness for AIDS. For that I thank him.

Over the past few years I have felt fortunate to participate in the Heartland AIDS Ride as a member of Pos Ped. I have been inspired and hopefully inspired others. What I do know is that I've joined others in making a powerful statement about how we view HIV.

This was not always the case though. The first year I rode in an AIDS Ride, I discovered how I could be "stopped" in the face of fear and judgment. In 1998, I arrived in Minneapolis for my first AIDS Ride experience. I was terrified yet exhilarated as I had trained for months, raised the needed donations to participate and now only had to prove to myself I could ride a bike from Minneapolis to Chicago. At the registration site, I saw a table for the Pos Peds and suddenly my fears and what I would later interpret as selfishness arose. I recall telling a friend that I could never do that, I mean why would I ever want to ride a bike through rural Wisconsin waving a flag screaming "I'm infected—come look at me." I felt that I didn't need to be an activist on the ride. I had done my share of lying on Capitol steps, confronting politicians, and demanding better access to services and funding. Why would I need to do that on the AIDS Ride?

By Day Three of the event I learned the error of my thinking. I saw the Pos Peds riding with their flags and jerseys. They were not being confrontational by waving their orange flags in peoples' faces. Nor were they demanding attention or monopolizing other riders' time with their ideals. Nor was there shame in riding through central Wisconsin with visible symbols disclosing positive status. Most importantly though was my impression of grace and bravery in sharing with the ride community and the world that there is power in openness. I learned that day that with a very simple gesture I could contribute to an entire community. I learned that in a sense, I had made a choice to be selfish about who I am. I realized that I was participating in the ride with a selfish intent, one of proving to myself that I could ride my bike from Minneapolis to Chicago. My focus on the ride was on the specifics I could get out of it rather than being part of an experience shared by the entire ride community.

This realization opened up possibilities that I couldn't imagine. After proving to myself that I could do the ride, I had a feeling I could accomplish anything I put my heart and mind to completing. I could take on the world without selfish intent, sharing myself fully; clearly available to what others in the world had to offer. I chose to take on the ride again. This time without regard for myself, but really doing the event for others—helping other riders along, helping the beneficiaries provide services to their clients, being part of an event that knows no emotional boundaries and is only limited by the actions and beliefs of those participating.

I arrived in Minneapolis the next year with a new sense of freedom. My first stop that year was the Pos Ped table where I joined the team. Admittedly, it was a little scary, but also comforting to know that I was joining a team of other riders who undoubtedly have similar experiences as my own and go through many of the same fears and stopping points as I do. As I signed my name and picked up my jersey and bright orange flag, I felt a feeling of joy knowing that I was going to ride as a flag waving Pos Ped cheerleader. I was a force of nature rather than a selfish victim of circumstances. I was unstoppable in my conviction to make the ride as empowering for others as it had been for me the previous year.

As I reunited with old friends, some from the last ride and others from long before in college, I suddenly faced the fear of disclosure. I realized this was the first test. I had to not only face the issue of telling old friends I am positive, but also I had to face the fact that I felt like a selfish jerk the year before. As we were going through registration lines, I remember hearing from Anna, an old friend from college who had also done the ride the year prior, "That's a great jersey, where did you get it?" As beads of sweat started building on my forehead, I told her it was a Pos Ped jersey. After a very brief moment of silence she responded with indelible warmth and just said, "I love you, Jeff." Others around us in line started asking about the Pos Peds and I was suddenly rushed with such unbelievable support from complete strangers that I started to understand what the AIDS Ride community is about. I was surrounded by people who, for whatever their reason, are driven by the possibility to make a difference in the world. I understood that without even knowing me, they cared for me, my well-being, and my presence on the ride.

As the ride continued that year, selfishness and insecurity decided to rear its ugly head again. Was this another test? After riding for hours in a torrential downpour of rain, following a night of virtually no sleep because of rain, I decided I couldn't go on for one more turn of the wheel. It was sheer misery. As I was struggling with each pedal stroke, I knew it was perfectly OK to give up. Anybody would agree that being positive, I probably should not be out riding in pouring rain and strong winds, basically freezing my ass off. Just when I was ready to pull over and wait for a sag wagon, another rider came up behind me, looking as exhausted and "over it" as I was, and told me that if I could do it he could too. Together we rode in a downpour for another ten miles until we reached the next pit stop. Again I was given a chance to move beyond my own limits while supporting another rider in expanding his horizons.

The generosity of all the riders and crew continued in what has become the reputation of kindness on the AIDS Rides. People simply go out of their way to help others. I frequently took the opportunity to cheer riders up steep hills, visit with children selling lemonade along the ride route, talking with spectators about why I do the AIDS Ride and how important the Pos Peds are both for me as an individual and for the entire ride experience. We provide a source of information on HIV and AIDS as well as giving a face and personality to the disease.

Last year on the AIDS Ride, I met a young woman who was riding for the first time. She was riding for her brother who had passed away from AIDS the year prior. Doing the ride was her way of trying to let go of her brother, as her knowledge of the details of his illness was very minor. As we spoke while riding through the rolling hills of Wisconsin, she gave me the gift of remembering her brother as the active wild person she knew. She told me how I reminded her of her brother. I don't know, perhaps it was the heat or humidity or something, but I felt a unique connection to her. As we rode, she seemed to realize that her anger toward her brother's HIV infection was more sadness over her loss. She thanked me for being so open about being positive, how it does and doesn't impact my life. After all, with the exception of a few circumstances caused by meds, my life has only altered where I have allowed it to or caused it to.

The impact of riding as a Pos Ped is different for everyone. For many like myself, it is a place of freedom where the fear of discrimination is replaced by respect and compassion. It is an opportunity to give something back to the world. For others it is a form of activism and visibility; a chance to have our collective voices be heard. Whatever the case, Pos Peds has given me the gift of moving beyond my perceived selfish limitations and the opportunity to open myself to the compassion offered by others, for others.

Jeffrey Allen is the Events Coordinator at Test Positive Aware Network. For more information on Pos Peds, please contact him at jeffrey@tpan.com.

Immune Restoration

by Jo Ann Berg

"The way to prevent AIDS," said Dr. Beatrice Hahn of the University of Alabama in Birmingham at the recent 9th Retroviruses Conference in Seattle, "is to become more like chimpanzees." She hypothesized that when chimps—and the 16 species of African monkeys found so far to be naturally infected with SIV, the simian equivalent of HIV—were initially infected with SIV thousands of years ago, they suffered the same dire consequences as humans now suffer from HIV. But over time their immune systems have adapted to live with their virus. "The trick is to figure out how the chimp's [immune system] decides what to do and when," concluded Dr. Hahn.

In his talk, Dr. Marc Feinberg of the Emory University School of Medicine in Atlanta explained that these animals harbor just as high viral loads as humans with chronic or even full-blown AIDS. But they rarely get sick, he hypothesized, because their immune responses to SIV are much less aggressive, and therefore there is much less collateral damage to the cells by the immune system itself. Indeed, he believes that chronic immune system activation may be the primary mechanism driving the depletion of CD4 T cells and not the virus itself. (However, the virus is certainly toxic, and Dr. David Ho of the New York Rockefeller University's Aaron Diamond AIDS Research Center emphasized in his talk his belief in the primacy of the virus in destroying CD4 T cells.)

Dr. Alan Landay of the Rush-Presbyterian Medical Center in Chicago has said the "new" emphasis on immune restoration, and immune hyperactivity in particular, is really an example of another swing of the proverbial HIV treatment pendulum. He has pointed out that back in 1983 and 1984, before the introduction of HAART or even AZT, there were attempts to dampen the immune responses against HIV. But likely because the agents used then depressed too much of the immune system, they failed. Today's means of manipulating an overactive immune response against HIV are both more targeted and more varied in their approaches, as evidenced by the following preliminary but promising studies presented at the 9th Retroviruses Conference.

At his poster presentation, Dr. Northfelt of the University of California in San Diego described a product called Cytolin that he believes stops the CD8 cytotoxic T cells

Retrovirus Conference Update

by Patrick G. Clay, PharmD

The 9th Retroviruses Conference held in Seattle provided useful information about drug interactions and pharmacokinetics. At this meeting as well as upcoming ones, it is imperative to learn more information about how the various medications interact and what levels are obtained.

An assessment of how increasing the dose of ritonavir (Norvir) changes the body's level of GlaxoSmithKline's pipeline protease inhibitor 908, was presented. Non-HIV infected persons were given 908 with ritonavir and efavirenz (Sustiva). The dose of 908 and efavirenz remained the same (700 mg and 600 mg, respectively). The dose of ritonavir was 100 mg for one group and 200 mg for the other. The researchers found no significant increase in the plasma concentrations of 908 when a higher dose of ritonavir was given. This is important as this is helping to decide how much ritonavir is going to be given in clinical trials and, likely, the expanded access program with the new protease inhibitor.

Examining how delavirdine (Rescriptor) is affected by amprenavir (Agenerase) was reported. There are those who believe that delavirdine, given its potent liver metabolism inhibitory properties, could be used in the place of ritonavir in boosting levels of other agents. Eighteen non-HIV infected persons were given delavirdine or amprenavir for 10 days, had levels checked and then given the other drug for another 10 days and had levels checked again. It was found that the delavirdine levels were significantly dropped. The levels of amprenavir, however, were increased "favorably." The investigators may be planning on examining this further to find out what may be the optimal combination of medications.

Critical to preventing transmission of HIV from mother to infant is the assurance that adequate levels of drugs are maintained in both mother and infant. Two posters examined the levels of medications in these populations. One study looked to see the levels of nelfinavir (Viracept) in women before, during and after labor as well as in their infants. The study had 23 HIV-1 infected women. The authors report good levels in the women, but that in 28% of infants, levels were less than desirable. Both groups tolerated the medications well. The adjacent poster was evaluating ritonavir in women and children. The ritonavir was given before, during and after labor as well. The infants received one dose of ritonavir between 8–12 days after birth. The investigators reported that the dose used for the infants did not produce adequate blood levels. More studies are clearly needed to ensure that adequate dosing of these agents are achieved in this population of highly preventable transmission.

Abbott presented information about using their new protease inhibitor, lopinavir/ritonavir (Kaletra), once daily ver-

(CTL's) that kill HIV-infected CD4 cells from also killing CD4 cells that are not infected with HIV. He explained that many CTL's contain an adhesion molecule called LFA on their surface that helps the CTL's interact with CD4 cells by binding with a "sister" molecule (called ICAM) on the surface of CD4 cells. While those CTL's that contain LFA will kill CD4 cells that are infected with HIV, they may also kill CD4 cells that are not infected with HIV. Cytolin is an antibody to LFA that blocks the ability of LFA to function, and hence seems to stop the initial overkill by CTL. Dr. Northfelt explained that this drug "sort of got lost for awhile" because it went into an underground system where patients were treating themselves with it without any real clinical science being done to determine whether it was safe or effective. He said that in the mid-1990s about 300 people in Los Angeles were treated with it regularly. Because of a number of anecdotal reports of dramatic improvements in health with Cytolin, a company was formed specifically to try to develop this drug as a legitimate pharmaceutical product. He presented preliminary results showing that in the first organized trial of Cytolin, where it was given along with HAART, it seemed to be well tolerated and to both decrease viral loads and increase CD4 counts above those seen on HAART only. One of its problems, however, is that the antibody is made by using mouse cell cultures, so it looks foreign to the body and if the immune system is still capable, it tries to eliminate it. Therapeutic antibodies used in cancer and rheumatoid arthritis have had this same problem, but many of them have recently been humanized. Dr. Northfelt said that ways to also humanize Cytolin will have to be found if it is to be more broadly applicable.

Another approach to dampening and/or redirecting an out-of-control or badly regulated immune response may be to "re-boot" the immune response by stimulating the innate or first line, non-specific responses. Long treated as the Cinderella of the immune system, researchers felt the innate immune system's only job was to non-specifically hold germs at bay until the more specific cells of the adaptive response kicked in. But now scientists believe the strength or type of innate immune response also helps determine or direct the type of adaptive immune response that will take place. At ICAAC (Dec. 2001), in Chicago, the results

sus the approved twice daily dosing schedule. Thirty-eight HIV positive persons were given either four capsules twice a day or eight capsules once daily. Three weeks later, the blood concentrations were assessed. These same concentrations were checked again over the next 48 weeks. They found much greater variance in the amount of drug in the plasma at the end of the dosing times in the once daily compared to the twice daily regimen. They also stated the amount of drug needed for good outcomes was achieved. The researchers compared the percent of patients with viral loads less than 50 copies/mL at week 48 and found no difference between the two arms. This data raises a number of questions about targeting once daily regimens as the ultimate goal of pharmaceutical company development. Many studies have found that, from an adherence standpoint, once daily offers no improvement compared to twice daily. Yet, this type of regimen may allow for dosing in special populations (e.g., incarcerated, marginally housed) persons with new evidence that the amount of drug being given a person is not being compromised.

Lastly, a session at the conference, appropriately entitled, "Controversies in HIV Therapy" given by David Back, PhD, provided insight into the direction being taken by investigators utilizing Therapeutic Drug Monitoring (TDM). Dr. Back discussed at length the studies completed to date, both those showing evidence to support as well as refute the need to conduct TDM in clinical practice, which measures drug levels in individuals. His points included the need to conduct TDM to be incorporated into practice as a complementary and not stand alone nor replacement tool for others. This was driven home by the review of data in which using the inhibitory quotient (IQ) versus resistance assays or TDM alone proved more predictive of outcomes. He then went on to point out that IQ itself is still a research tool and controversies still surround it.

The abstracts I have chosen to summarize here represent only a snapshot of what was presented at CROI and a miniscule amount of what is available in the literature. TDM continues to be evaluated as a component of clinical practice, but from the data presented in this conference and others, it is not quite ready for "prime time."

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from two encouraging animal trials involving the stimulation of innate immune cells called dendritic cells were presented, one on animals with end-stage disease and the other on those with CD4 counts above 500.

At her poster presentation, Dr. Judith Lisziewicz of the Research Institute for Genetic and Human Therapy in Washington, D.C. presented "very exciting and surprising" results of a DNA vaccine used on very sick Rhesus Macaques. These monkeys are from Asia, and unlike the African species mentioned earlier, have not been infected with SIV for thousands of years. Like humans, they have only recently contacted their virus, either when housed with African primates or more likely when injected with a form of it by researchers. Also like humans, and unlike the African monkey species, their viral load is a good measure of disease progression. Normally, they survive only 14 months or less after being infected with a potent form of SIV. But two of three monkeys in her study given a vaccine containing most of the genes for SIV are still alive after two years. (The one monkey that died had the lowest viral load and was the one most expected to survive, but died of kidney failure.)

Other DNA therapeutic vaccines, or vaccines for those already infected and that contain genes, as opposed to proteins or bits of proteins, from SIV have been tried but not in end-stage disease nor with any success. Indeed, this is the first demonstration that a therapeutic vaccine works in monkeys. The difference, surmised Dr. Lisziewicz, is that this vaccine, called DermaVir, is a topical (applied directly to the skin instead of being injected) immunization that primarily stimulates innate immune cells in the skin called langerhans cells. These cells then migrate to lymph nodes where they mature and become known as dendritic cells. As dendritic cells, their function is to present parts of the virus that they captured in the skin (whether from a vaccine or the virus itself) to helper CD4 T cells that are specific for SIV (or HIV), thus inducing them to in turn stimulate virus-specific antibodies and CTL's.

The most remarkable finding is that DermaVir was only used in very sick, end-stage monkeys. The monkeys were so sick that Dr. Lisziewicz said they had trouble getting permission to even attempt their experiment, as their supervisors wanted to end the monkeys' suffering by putting them to sleep. In other words, this is the first clear evidence of the ability to reconstitute an HIV-specific immune response in end-stage AIDS (assuming, as is most likely, that SIV operates in the Rhesus Macaque as HIV does in humans). Dr. Lisziewicz's group is hoping to begin a human study in September, if they can find a way to reformulate the monkey vaccine into a human-adapted vaccine by then. She is also hoping the vaccine will work at earlier stages of HIV disease.

Another poster demonstrated the trial results of a product that enhances the innate defense in early HIV disease when CD4 counts are above 500 and patients are not yet on HAART. The product is called Murabutide (MB), and at an earlier conference, results were presented that showed it increases the CD4 cell count in end-stage patients who are failing HAART. But at the 9th Retroviruses Conference, Dr. X. De La Tribonniere of ISTAC Biotech in Lille, France presented a pilot study highlighting MB's ability to also increase the CD4 count in patients naïve to HAART. Dr. De La Tribonniere described the results of MB as "like those of a vaccine." Since MB is a synthetic version of a bacterium's cell wall, it likely stimulates the skin langerhans cells similarly to DermaVir. This is because langerhans cells are in the skin precisely because they want to pick up bacteria; this is what they normally do. By targeting innate cells, both MB and DermaVir may, by restarting an innate immune response against HIV, allow the innate cells to redirect the adaptive response to one that isn't "out of control."

A fourth way to perhaps help contain an overactive immune system is through the consumption of anti-inflammatory foods and/or supplements. Unfortunately, this information was not provided at this conference, but nutritionists and literature on nutrition can be helpful. However, there was one intriguing study showing that just as too much virus or too much of an immune response can be dangerous, so too can too much of a supplement. The study showed that "for unknown reasons, vitamin A supplementation may have deleterious effects on pneumonia in some [African] children." It concluded that since the immune markers associated with lower vitamin A levels "would all assist in anti-HIV immunity, moderately low vitamin A levels might actually be preferable to the currently defined 'normal' levels."

Finally, instead of trying to dampen or otherwise regulate the immune response, some immune-based therapies aim at correcting the results of a poor immune response against HIV, i.e., a low CD4 count. So far the foremost agent used to increase CD4 cell counts has been Interlelukin-2 or IL-2, a cytokine or kind of natural hormone that causes CD4 cells to grow and divide. This conference featured numerous accounts of IL-2 trials, but the basic question of whether the improvement in CD4 cell count seen with IL-2 therapy results in a better prognosis has not yet been solved. Rather, these accounts mainly centered on safety results, showing that after more than three years of IL-2 therapy no untoward effects (other than those temporarily experienced while taking the IL-2 injections) have been seen. Two very large studies are in progress to finally answer the question as to IL-2's usefulness, but because the studies are blinded, no results were yet forthcoming. One interesting poster presented by Dr. Jay Levy's group at the University of California in San Francisco examined IL-2 added to HAART in the very earliest stage of HIV disease, called primary HIV infection. It found that used in this way IL-2 increases CD4 cell count and "enhances anti-HIV immune responses." [For more complete info on IL-2 and/or to learn how to enter an IL-2 trial, See: www.aidsmeds.com/drugs/Proleukin.htm.]

The few lectures and posters on immune reconstitution at this premier scientific conference on HIV were dwarfed by the many studies there on chemotherapeutic antiretroviral strategies and their side effects. But each year more immune-based studies are appearing at this conference, lending hope that a two-pronged, virologic and immunologic approach will result in our someday being "more like chimpanzees." This "new" emphasis on immune reconstitution should also spur our efforts to save our nearest and very endangered relatives from extinction. Dr. Hahn did mention that the chimp population today is under 70,000, down from over a million just ten years ago.

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One-on-One: Christopher Brown

by Charles E. Clifton

Christopher Brown, who likes to go by Chris, is the new Assistant Commissioner of the Division of STD/HIV/AIDS Public Policy and Programs with the Chicago Department of Public Health. Chris moved from Phoenix, Arizona to Chicago in September of 2001.

Background:

As a kid, Chris lived in a suburb in Virginia, just outside of the Washington, D.C. area, but he moved to Arizona in 1971. He has been in public health since 1983. He started with a county health department in Tucson, AZ. He was there for 11 years in the HIV/STD division. Eventually, he took a job with the state health department in Phoenix, and was there for 7 years. In this position Chris headed the HIV/STD, and in the latter part of his tenure there the Hepatitis C program. "It's almost hard to remember for me a time before all of this. Almost my entire adult life I've been around it [HIV]," he states. That's nearly twenty years of working in HIV. "Thanks for reminding me," Chris laughs.

Why Chicago?:

"A bigger urban area… urban feel. A stronger gay community… more visible, and more unified." As Chris stated, "I was looking for a new challenge and opportunity when the position in Chicago became available." He and his partner talked about it and they agreed that they would go for it.

Chicago's Division of STD/HIV/AIDS has "a larger, more diverse program… housing HOPWA, larger Ryan White budget, Title I as opposed to Title II." Chris also found the difference in the HIV epidemic in Chicago intriguing. "I certainly have been reading for decades now on the differences in the epidemic across the country. The epidemic here, of HIV, is slightly different from what's going on in Arizona." While the MSM population continues to drive the epidemic across the country, Chris added that, "injection drug use is much more of a risk factor in Chicago and the East coast, than in Arizona."

Biggest challenge to date?:

"Learning what's happening in Chicago has been one of the biggest challenges, meeting folks, meeting the people in the community that are doing the work. Learning what they are doing and trying to get a handle on what their programs are about. I'm thankful for my background in HIV, so that I don't have to learn the subject matter, because it's certainly challenging enough to have to learn what's happening in the city."

Immediate goals for the department:

"I'm really in an assessment mode. I have to say that what I'm seeing, given my background and experience in this field is some pretty good stuff going on. I'm not going to try to jump in and make radical changes, right now. I'm not so certain that there needs to be. Clearly there's room for improvement, but in general, the systems are pretty well intact. And I'm thankful that it seems that the relationship between the community and the department appears to be really strong. My biggest challenge right now is assessing what's going on, talking with folks, and trying to get an idea for where they believe the problems are and working with the communities to try and solve those problems.

Living with HIV:

I first met Chris when he was introduced to the Chicago Area HIV Planning and Prevention Group in October 2001. At this meeting, and barely one month on the job, he voluntarily disclosed that he was HIV positive. Chris found out he was HIV positive in 1985 and is public about his positive status.

"[HIV] has basically been a part of all of my adult life. But, I've been blessed with very good health, and have never been on antiretrovirals." Chris recognizes that his experience with HIV has been, for the most part, different than most long-term survivors. He explains, "there are times when I've felt guilty about that. I went to a support group years ago when I was living in Tucson, and listened to what people were going through [with their meds]. And when it got to me I realized that I was sort of embarrassed to say I hadn't been on any meds. It was different." Chris adds that his immune system is in pretty good shape, and that his viral load continues to hover around undetectable.

Resolutions:

One of Chris's resolutions for the new year is to get out and see more of Chicago. "It's a great city. There's so much to do. I want to take 2002 and get out and see the city… do some touristy stuff." Chris shares his life with his partner of 10 years and their 3 kids (a Labrador and two Rescue dogs). All are adapting well to their new home and the weather, but with the demands of the new job and settling in to their new home, Chris hasn't had as much of a chance to see that much of the city.

New-Fill for an Old Face

by Jeff Berry

Monday, September 10, 2001

God, I'm nervous! Is this the right decision? I'm not sure if I should go through with this.

I arrive at the doctor's office five minutes prior to my appointment for my first treatment of New-Fill (polylactic acid) injections. I've always hated needles, and they want to stick them in my face? I don't think so! Well, I'm here, and I've already ordered the kit from DAAIR. I can't afford to waste $500. I had to take out a loan against my life insurance to pay for the treatments, which will run me about $3000 for four treatments, which includes the price of two kits of New-Fill.

My plastic surgeon (I've always wanted to say that), Dr. Kenneth Stein, puts me right at ease. A very nice man with a superb bedside manner, he tells me that while the results from my first treatment will be instantaneous, they will pretty much fade after one week. I'll have some initial swelling, but that should be gone by tomorrow.

Well, that doesn't sound so bad. Let's see, $750 for my first treatment, seven days…"In just seven days, I can make you a ma-a-a-a-an"…that's about one hundred dollars a day. The scariest part, at this point, is, what if I like the results, I mean, really really like them, and then it's gone after seven days and I'm back to my old face? How will that affect me psychologically? I'd discussed this several times at length with my partner, Stephen, who was concerned about that very issue. But I had to try this, if I didn't, I would never know. I was willing to take the risk. I mean, I miss my old face.

Dr. Stein goes back to work on his earlier patient, who is also getting a treatment of New-Fill. I don't hear any screaming or moaning coming from the other room, so that's a good sign. He comes back, takes some pictures, you know, for before and after shots, and then he draws on my face with a marker. He explains that the procedure should only take about thirty minutes, I have my vitals taken, then I'm given icepacks to place on my face for a few minutes, to constrict the blood vessels and help keep the swelling and bleeding (hey, nobody said anything about blood) to a minimum. I'm supposed to hold them to my face as long as I can, and pull away when it gets too cold. Have you ever eaten something cold too fast, and you get that terrible headache? Multiply that by about ten times and, well, you get the idea.

First he'll numb my face, and then he's going to concentrate on four areas of each side of my face, including the temples. He tells me that the lower part of my jaw, around my mouth and lower lip (fill 'em up, doc, while you're at it!) would probably be the most sensitive (he was right). If the pain is too much, I'm supposed to tell him, and he will administer more lidocaine, but too much and I will be drooling for half the day.

I probably get around four or five injections in each site, for a total of about 40-50 needle sticks. Since I am numbed up, mostly I just feel pressure in the area of injection, but maybe 20 percent of the sticks are uncomfortable, and about 5 percent *really* hurt. But only for a few seconds. And keep in mind, *I hate needles*. I have to look the other way when they draw my blood. You'd think I'd be used to it by now, I've been doing it every few months since 1989! So, I'm probably a little more sensitive than your average Joe.

During the entire procedure my doctor keeps reassuring me that I am doing really good, and that it's looking great. And then, all of a sudden, he's done!

"That's it?" I hear myself say aloud.

"Yes, that's it, we're done," he replies.

He wipes my face clean, sterilizes, and then the moment of truth. He hands me a mirror.

"It looks great, don't you think?" asks Dr. Stein.

I swallow hard. "Yeah, It looks great," I lie. I smile. A misshapen, swollen, blotchy face contorts back at me, and I hardly recognize that it's me. What the hell have have I done?

I step out of the exam room, Steve says, "It looks great, honey." I feel loopy, I walk to the receptionist to pay my bill, first stopping in the bathroom to get another look at the grotesque creature in the mirror. As I try to smile at the receptionist, he remarks, "It looks great!" I wish everyone would please stop saying that…why are they all lying? I want my old face back.

As I walk out the door. I turn to Steve and say, "Wait, I have to put on my sunglasses, just like in the movies." We joke, he takes me for a chocolate malt at an ice cream shop in Lincoln Park. That helps. "I think I want to go home," I remark to Steve.

"I thought you were going back to the office?" Like this, I think to myself? But Steve encourages me to go, as originally planned, and I'm glad I did. After about an hour I start to see how wonderful the results really are. The blotchiness is gone, the raised lumps have lowered, and although still a bit swollen, bruised, and with a few needle marks, it looked pretty damn good.

Tuesday, September 11, 2001

It's an unusually warm, sunny September morning, and our two cats, Missy and Zach, are enjoying the sun along with me on the breakfast porch as I sip my coffee and catch up on Sunday's *Chicago Tribune*. The phone rings. Steve, calling from work. All I can utter is "No, no" in disbelief as he recounts the events of the morning. It's unreal. And as I watch the twin towers collapse on television, the horror unfolding before my eyes, the surreal images on the tube—it helps put the previous day's experience in perspective for me. My concerns and fears about the treatment seem so trivial now.

End Results

My second treatment in October seems to go a lot quicker, and while the pain isn't any less, there seems to be fewer injections. My biggest "problem areas" are my temples (who knew?) and cheeks, so the remaining treatments focus more on these areas.

While it is exciting to get my face back, my old face, it is difficult to see it all go away in a week. But with each successive treatment, there is a cumulative effect, and the results last longer. At the end of the fourth treatment, in December, Dr. Stein says, "Now, when you come in for your next treatment, I want to use a whole kit just on your cheeks."

"My next…a whole…You want me to come back for another treament? You think I should?" I asked.

"I think it would help," he replied. And I knew he was right. With the results I have seen, two kits, right in the cheeks, would be the icing on the cake. But, I didn't have another $1,000 budgeted. I finally just got reimbursed from my FSA, money I had set aside from my paycheck last year for unreimbursable medical expenses. They didn't want to give it back to me, *my own money*, because it's viewed as a "cosmetic procedure." Yeah, about as cosmetic as when my mother had reconstructive surgery after two radical mastectomies. I'm hoping someday that these types of treatments will be viewed as medically necessary and covered by health insurance. Until then, there are some studies coming up soon, and other treatments on the horizon. [See new-fill.com]

Before

After

Would I do it all over again? Yes, in a heartbeat. But here are some tips that might help if you are considering facial injections:

- Make an informed decision. Ask your doctor lots of questions, and don't be afraid if you think they sound stupid.
- Don't expect miracles. Do you own stock? Do you like to gamble? It's a lot of money, and the results aren't guaranteed.
- Look at all the options, discuss them thoroughly with your doctor, and choose one that's best for you and your budget.
- Get plenty of rest before your treatments.
- Try stress-reducing techniques, such as visualization and deep-breathing, before, during and after the treatments.
- Take vitamin C. It helps in the production of collagen.
- If possible, talk to someone who has had the treatments and ask them about their experience.
- Think about what it will be like to have your old face for only a few days, and then lose it all over again. Are you ready for that?
- Realize that you may just be getting older. Those lines in your face make you look distinguished, lend authority, and are attractive to many people. ✚

Jeff Berry is the Web Site, Advertising and Distribution Manager at Test Positive Aware Network. He first wrote about his lipodystrophy in the Nov/Dec 2000 of Positively Aware, *"Who Moved my Cheeks?"*

Twenty Years of Women Living with HIV: Past, Present and Future

by Terri L. Wilder

Since the beginning of time, women have had to fight for recognition. Women had to fight to vote. Women had to fight to work for pay to support themselves and their families, or to stay at home if they chose to do so. Women even had to fight to wear the clothes they liked.

Twenty years ago, women were fighting off unusual symptoms. Twenty years ago, women were fighting to be diagnosed. Twenty years ago, women were fighting to stay alive.

When I gasp in repulsion over the lack of female sensitivity and study in HIV/AIDS research today, I know that I shouldn't be surprised. But I am. I keep thinking that twenty years of this illness should have taught a lesson in inclusiveness and pro-activity. Today, women are fighting to be recognized in the AIDS epidemic as if it were 1981.

I invite you to read this humble history of Women and HIV and decide what you can do to add to the history of HIV and Women. As you process your vision of the future, keep in mind that the final paragraph of this story should include the following words: cure, women, AIDS, and forever.

1981

The first cases of GRID, which will later be referred to as AIDS, are reported. Five women are among those diagnosed.

1982

Women are sick and dying, falling through the cracks.

Women diagnosed with this illness are classified under the risk category of "prostitutes." An article in the *Wall Street Journal* states that male and female drug users are being affected by GRID.

Mary Richards Johnstone, a wealthy woman from the affluent suburb of Belvedere, receives twenty units of blood from Irwin Memorial Blood Bank in San Francisco. She is later diagnosed with AIDS.

1983

Liz Smith is the first popular columnist to write about AIDS.

Barbara Fabian Baird, of the National Institutes of Health (NIH), becomes one of the first nurses to conduct AIDS research.

The Women's AIDS Network is established.

The CDC adds female sexual partners of men with AIDS as a "risk group."

The *New York Post* headline reads "L.I. Grandma Dead of AIDS." The story goes on to describe how Lorraine DeSantis dies from AIDS after receiving a blood transfusion in 1980.

1984

Health and Human Services Margaret Heckler announces that Dr. Robert Gallo has found the cause of AIDS. She also announces the development of a diagnostic blood test to identify the virus and suggests that a vaccine against AIDS could be produced in two years.

Caitlin Ryan, a social worker, becomes the first executive director of AID Atlanta. AID Atlanta is the oldest AIDS Service Organization (ASO) in the Southeast.

1985

Elizabeth Taylor and Dr. Mathilde Krim co-found AmFar (the American Foundation for AIDS research). Elizabeth Taylor hosts the first Hollywood AIDS fundraiser.

San Francisco AIDS Foundation produces their first brochure about women and AIDS. Bette Midler and Barbara Streisand appear in a sold-out fundraiser for the San Francisco AIDS Foundation.

Mother Teresa visits AIDS patients at George Washington University after receiving the Medal of Freedom from President Reagan.

A reporter from the *San Francisco Chronicle* publishes a front-page story about Silvana Strangis, a sex worker living with AIDS.

For the first time, a woman is admitted to the AIDS ward at San Francisco General Hospital (Ward 5B).

Frances Borchelt, an older adult from San Francisco, dies from AIDS after she received three pints of infected blood during surgery in 1983. Her family files a negligence lawsuit against Irwin Memorial Blood Bank.

1986

Women represent 7% of U.S. AIDS cases.

Women and AIDS Resource Network (WARN) is formed by several women living with and affected by HIV. Marie St. Cyr, a Haitian-born social worker, becomes the first director of the New York-based organization.

Silvana Strangis dies after battling cryptococcosis.

Caitlin Ryan is hired to co-author *AIDS: A Public Health Challenge*, the first book on AIDS policy. This book is distributed to all members of Congress, governors, mayors, and key public officials and served as the basis for many of the recommendations of the first Presidential Commission on AIDS.

1987

13.5% of NIH money is dedicated to women's health issues.

ACT-UP begins.

Women are excluded from HIV trials unless on the birth control pill or IUD; no childcare, transportation or GYN care is available. Trial inclusion/exclusion criteria read: "No pregnant women and no non-pregnant women" allowed.

Surgeon General C. Everett Koop urges any woman considering pregnancy to be tested for HIV.

Princess Diana opens the first specialist AIDS hospital ward in England. The fact that she did not wear gloves when shaking hands with people with AIDS was widely reported in the press and helped change attitudes towards people with AIDS.

Madonna throws her first AIDS benefit concert and later records a song, "In This Life," about friends who had died from the disease.

St. Louis University School of Medicine produces *Strong Women, Positive Choices*, an award-winning documentary on the lives of HIV positive women.

1988

The New Jersey Women and AIDS Network is founded.

Revised NIH guidelines suggests "by gender" analysis of data being collected in clinical trials however does not establish clear standards for women's inclusion.

Cosmopolitan Magazine article written by a psychiatrist tells women that they can have unprotected vaginal intercourse with an HIV positive man if they have healthy vaginas. The article also reports that "most heterosexuals are not at risk" and further states that it is impossible to transmit HIV using the "missionary position."

Women named fastest growing population with HIV.

San Francisco AIDS Foundation develops a Women's Services Program.

An affluent 22-year-old New Yorker, Alison L. Gertz, is diagnosed with AIDS. Alison's mother Carol comments, "Alison had gotten sick that summer, and they tested her for everything: lymphoma, Hodgkin's, you name it. But they never tested her for AIDS because nobody thought a heterosexual woman who's not a drug user would get it. We subsequently learned that she'd gotten it from a good friend, who she'd only slept with once."

Dawn Averitt is diagnosed with HIV. She later becomes a national AIDS treatment advocate and the founder of WISE (now Project WISE at Project Inform).

Elizabeth Glaser, Susan DeLaurentis and Susan Zeeger co-found the Pediatric AIDS Foundation after learning that Elizabeth, her daughter Ariel and son Jake are living with HIV.

1989

Rebekka Armstrong, former Playboy Playmate, tests HIV positive.

NIH publishes further guidelines on inclusion of women.

Bruce Lambert writes an article on Alison Gertz. In later years, a movie is made about her life.

Television star Amanda Blake ("Miss Kitty" on Gunsmoke) dies from AIDS.

Sisterlove, Inc. is founded by Dazon Dixon as the first and oldest organization in Georgia to focus on the needs of women living with and at risk for HIV.

BABES is founded by HIV positive women in Seattle, under the philosophy that HIV positive women are uniquely qualified to understand and encourage one another.

1990

The First National Women and HIV Conference is held.

ACT-UP spearheads a massive protest at the Centers for Disease Control in Atlanta to expand AIDS definitions to include women-specific diseases. Women with AIDS lead the demonstration; 94 are arrested.

An estimate of women worldwide with HIV is at 3 million.

Cook County Hospital (the only hospital with an AIDS ward in Chicago) refuses to admit women stating they have no women's AIDS ward. Gay and Lesbian activists set up a ward in the street in front of the hospital; 35 are arrested. Two days later, the hospital admits women with AIDS for the first time.

National "Speak Out" by women with AIDS is held in Washington, DC to protest the Social Security definition of disability, which discriminates against women and people of color.

On March 7th, the CARE bill was introduced into the Senate and House. During a Budget Committee that same day, Elizabeth Taylor speaks forcefully in support of the bill during her testimony, playing a vocal and visible role in its introduction.

Elizabeth Glaser, a woman living with HIV, speaks at a House subcommittee hearing on pediatric AIDS, where she is praised for convincing the formerly unresponsive Ronald Reagan to do a public service announcement on pediatric AIDS.

1991

Kimberly Bergalis says her dentist infected her with HIV and requests that Congress mandate testing of healthcare workers. Kimberly writes the American Medical Association (AMA) requesting mandatory testing of healthcare workers. She dies by year's end.

WORLD (founded by Rebecca Denison) publishes their first newsletter, by and about women living with HIV.

Mary Fisher, a prominent woman in Washington circles, is diagnosed with HIV.

Women Alive is founded in Los Angeles by and for women living with HIV.

Mother's Voices, a group founded by five mothers who had lost a child to AIDS, is founded by Suzanne Benzer.

1992

Mary Fisher addresses the Republican National Convention as a person living with AIDS and stated "I don't know what kind of reception my speech received. It was like an out-of-body experience. People told me afterwards that the room got completely silent while I spoke, which is unheard of at a convention. Afterwards, President Bush said I'd done a wonderful thing."

Elizabeth Glaser gives a speech to the U.S. Democratic National Convention as a person living with AIDS. A full-page ad in the *New York Times* reads "Women Don't Get AIDS. They Just Die From It." Over 300 grassroots groups sign the ad.

The CDC expands the definition of AIDS to include bacterial pneumonia, TB and stage III cervical cancer. Recurrent vaginal candidiasis (yeast infections) was also added as a symptom of HIV. This is a victory for women living with HIV.

AIDS Survival Project creates the first support group for women living with HIV in Atlanta. Three women attend the first group.

1993

The "female condom" is approved.

Kristine Gebbie is appointed as the first national "AIDS Czar," director of the Office of National AIDS Policy.

In response to protest by ACT-UP's Lesbian Caucus, Health and Human Services Secretary Donna Shalala forms a Lesbian AIDS Task Force.

Gena Corea's book, *The Story of Women and AIDS: The Invisible Epidemic*, is published.

1994

The ACTG 076 study finds that pregnant women taking AZT reduce the risk of HIV transmission to their unborn child by two-thirds. The Public Health Service recommends that HIV positive pregnant women use AZT to reduce mother-to-child transmission.

Elizabeth Glaser, co-founder of the Pediatric AIDS Foundation, dies.

Jocelyn Elders is fired by President Clinton for saying that masturbation should "perhaps be taught" as part of sex education.

Rae Lewis-Thornton, an African American woman living with HIV, is featured on the cover of Essence magazine.

1995

Actress Sharon Stone becomes AmFar's celebrity spokeswoman.

Elizabeth Dole, president of the American Red Cross and wife of Bob Dole (then the front-runner for the 1996 Republican presidential nomination) halts publication of a highly anticipated HIV/AIDS training manual for 1600 Red Cross chapters nationwide when her "special team" of advisors from outside the organization convinces her its contents are too explicit and controversial.

President Clinton appoints Dr. Alexandra M. Levin to the Presidential Advisory Council on HIV/AIDS. Dr. Levin's research includes HIV-associated lymphoma, women and HIV, and the development and testing of a therapeutic AIDS vaccine.

1996

The annual incidence in women diagnosed with AIDS begins to decline because of the success of antiretroviral therapies in the U.S.

Rebecca Denison (founder and editor of WORLD) delivers twin girls, becoming one of the first HIV positive women to talk publicly about her decision to become pregnant.

1997

Women account for more than half of HIV cases worldwide.

In March, The NAMES Project Foundation presents a month-long online Quilt display on its World Wide Web site featuring panels made for women who have died from AIDS, in honor of National Women's History Month. 75% of cases are in women of color.

Sandra Thurman, former Executive Director of AID Atlanta, is named AIDS Czar. Therapist Penny Chernow starts the first support group in San Francisco for older women with HIV.

The National Conference on Women and HIV takes place in Pasadena, CA and chants of "Do Research to Save Women's Lives!" echo the conference halls. The *Los Angeles Times* publishes an article on the conference.

Princess Diana, one of the first public figures to urge compassion for people living with AIDS, dies in an automobile crash.

Poet River Huston's book, *Portraits of Women Living with HIV*, is released. The book's idea was stimulated by River's own HIV diagnosis and the lack of images of women living with HIV in society.

Catholic World News reports that Mother Teresa plans to start a new AIDS Ministry in the United States. Her religious order, The Missionaries of Charity, currently runs five hospices for persons living with AIDS.

1998

In South Africa, Gugu Diamini, an AIDS activist, was beaten to death by her neighbors after revealing her HIV status on Zulu television.

45% of the cumulative HIV cases reported among Asian and Pacific Islander adult/adolescent females acquired HIV through heterosexual transmission.

A cumulative total of 109,311 adolescent /adult females have been diagnosed with AIDS in the U.S. 63% of newly reported female AIDS cases are African American women. African American women are three times more likely to die from AIDS than Caucasian or Hispanic women.

Of the 6,051 new HIV cases reported in women, 8% (461) were among Latinas.

The Global Campaign for Microbicides is founded at the XII International AIDS Conference in Geneva. The creation of the Microbicide Campaign came about from key members of the women's health and HIV community deciding to work together to focus world attention on the critical need for new HIV prevention options, especially for women.

AIDS researcher Dr. Mary-Lou Clements-Mann is killed in the crash of Swissair flight 111.

Kate Shindle wins the title of Miss America under the platform of HIV/AIDS education. She travels all over the country on a national speaking tour entitled "On the Way to a Cure: Preventing HIV transmission in America." She also moderates a panel discussion on Women and AIDS at the 12th annual world AIDS conference in Geneva, Switzerland at the invitation of Health and Human Services Secretary Donna Shalala.

1999

Mary Fisher makes primetime news announcing that she is stopping combination therapy due to the side effects.

Of new cases of AIDS reported in women, 68% were in ages 30-49, 18% were in ages 20-29 and 12% were in ages 50 and over. Overall, heterosexual transmission accounts for an estimated 62% of AIDS cases diagnosed among women between July 1999-June 2000.

The National Conference on Women and HIV is held in Los Angeles, CA. Over 1,000 women attend. This event is documented as the largest gathering of HIV positive women in history.

Worldwide, over one million women died of AIDS, the highest number so far in a single year.

2000

In the southern United States, more women with AIDS report their exposure as heterosexual contact than injecting drug use. Approximately 3-4 times more cases are reported from the South than from the Midwest and West.

45,000 women 15-44 years old are reported to be living with AIDS in the United States. Sixty-three percent of women reported with AIDS are African American.

Ofra Haza, Israeli singer, dies of AIDS.

Coretta Scott King launches the AIDS Memorial Quilt to black colleges and universities. One of four pregnant women in South Africa are living with HIV.

The FDA (Food and Drug Administration) passes the Clinical Hold Rule. This allows the FDA to delay or suspend any clinical trial that's found to exclude women (or men) because of it's "reproductive potential." This dramatically increases the opportunity for women with HIV to take advantage of drug trials and other treatment research.

Valerie Reeder-Bey along with her granddaughter Annisha Monic Wilburn publish *My Grandma Has AIDS: Annisha's Story*. Valerie has been living with HIV since the late 1980s and is the co-founder of Heaven In View, Inc. "A Positive Force."

2001

UNAIDS found that in India, women are often blamed by their parents and in-laws for infecting their husbands or for not controlling their partners urges to have sex with other women.

At a conference in Chicago, conference attendee Judy Delmar states, "This disease does not necessarily behave the same way in both genders. It's just a different disease in women." The statement was made in response to the need for women to be included in clinical drug trials and other AIDS-related research.

An article written by Jane P. Fowler on persons over 50 living with HIV, is published in *Positive Living*. Jane is a woman living with HIV who was diagnosed at the age of 55 and is the co-chair of the National Association on HIV over Fifty.

Dr. Mathilde Krim, Founding Chairman and Chairman of the Board of the American Foundation for AIDS Research (amfAR), receives the African-America Institute's Award for Individual Vision and Achievement.

Mothering Magazine cover page article is "HIV Positive Moms Say No To AIDS Drug; Special Report: HIV, Families & Medical Justice." Articles describe the stories of several HIV positive women who chose not to use anti-HIV medications during pregnancy in order to avoid the possibility of side effects and toxins that could affect their unborn child. Another article describes one HIV positive woman's fight to breastfeed her child despite her doctor's protest.

Blood Ties-The Stories of Five Positive Women, edited by Salli Trathen, is available in print. This book describes the lives of five Australian women who are living with HIV/AIDS.

After six years as the director of the National Center for HIV, STD, and TB Prevention with the Centers for Disease Control in Atlanta, Dr. Helen Gayle resigns to become the Bill and Melinda Gates Foundation's senior advisor on HIV.

U.S. Department of Health and Human Services releases *A Guide to the Clinical Care of Women with HIV*, the first manual specifically written about the medical care for HIV positive women.

Korrin Krause, a 16-year-old living with HIV, is fired from her job at the Quality Foods IGA in Wisconsin. A store representative stated that he did not want other store workers "to take this (HIV) home to our families." The Equal Employment Opportunity Commission has sided with Krause in May; however, a settlement has not been reached.

2002. Women, Cure, HIV/AIDS, forever.

✚

Terri L. Wilder, LMSW is a licensed social worker who has provided social services for persons living with HIV/AIDS for the past twelve years. She can be reached at tlwilder@mindspring.com. Terri invites women who are interested in adding information to this history to contact her. Terri apologizes for any oversights in our history.

The history is dedicated to the countless powerful women who are living with and affected by HIV including: Kellie, Ilyse (who is the CEO of her own company), Jane P. Fowler, River, Marguerite G. Wilder, Regina Ann Goldsworthy Stott, Susan, Eva, Valerie Reeder-Bey, Annisha Monic Wilburn, Lois C. and yes, Cara.

Medicine Chest

Ten Ways to Mess Up Your Meds

by Glen Pietrandoni R.Ph.

When you have worked in a pharmacy for as long as I have, you hear some very odd things over and over again. I thought I would share some of these comments (embellished a little for dramatic effect) with the readers. Even though they may seem humorous, they are important educational opportunities for pharmacists to help clients with the overall success of their treatment.

10) "I missed my drugs this weekend, so I guess I was on a Drug Holiday since Thursday."

A true "Drug Holiday" is prescribed by your doctor, on a specific schedule, with a therapeutic goal in mind. Drug Holidays are not when a patient decides to take a few days off of drugs and enjoy the weekend. This is how drug resistance occurs and will reduce the effectiveness of your therapy.

9) "I don't know the name of my medicine, but I think it was round and white and looks like an aspirin tablet."

It is very important you know the names of the medications you are taking and what they look like. I can't stress this enough! So many medications look alike and sound alike. You may not always be in the care of an HIV expert. Believe me, there are a lot of medical professionals who do not see HIV patients on a regular basis and are more confused than many of you about these drugs. You have to protect yourself and double-check everything.

8) "The prescription label says 'take three times a day,' so I took all three at once."

Unfortunately, the drugs used in HIV must be taken exactly as prescribed, with very little wiggle room. If the prescription says to take "twice daily," it usually means very close to every 12 hours (8 am and 8 pm, for example). The hardest one is "three times a day." Those drugs should be taken every 8 hours (8 am, 4 pm and midnight). Because this is sometimes hard to do, some people try to squeeze those doses together to 8 am, lunch and dinner. In this example, the patient has three doses between 8 am and 6 pm (10 hours) and no drug again until 8 am the next day (14 hours later). Over time, this may allow for resistance to develop to the drug.

Many drugs are now, or soon will be available as once-a-day dosing. This is great news, but please be careful to note that they may or may not be able to be dosed at the same time. Some drugs are still "empty stomach" and other "with food." Even though they are both once a day doses, the two drugs may have to be taken at different times during the day. This is the case once a day Videx EC (take on an empty stomach) and Viread (take once a day with food). Please check with your provider or pharmacist if you need help with the scheduling of your medication.

7) When refilling prescriptions, the pharmacist gives the customer another bag full of drugs and he/she says, "I have enough of these protease inhibitors, you gave me a whole bottle last month."

Usually, a pharmacist gives you a 30 day supply of medication. When 30 days pass, and if you took all of your doses correctly, your bottle should be empty. If you find you have pills left at the end of the month, the pharmacist is concerned that you have missed doses or taken the medication incorrectly. If you can, give the pharmacist a few minutes of your time to help you. Pharmacists can be a great resource of information and tips about adherence and side effect management. We are not the *drug police*, we are trying to help you.

6) "The bartender I always go to is Thor. Nobody touches my hair except for Fredrique. I just go to any pharmacist because it doesn't matter who fills my prescriptions."

A lot of people get their medications in the mail and others go to large pharmacy chains where you are never sure who the pharmacist is that day. That's no problem if you can try to speak with the same person each time you need them. Find a pharmacy and pharmacist that you are comfortable with and then get their name. When you have questions for them, introduce yourself and ask to speak with the same pharmacist each time. Before you know it, you will be fast friends!

5) "My viral load was undetectable last month, even though I missed a

few doses, so I guess it is okay if I miss a couple doses once in a while.”

Even though you may get great results from your doctor, the goal of drug therapy is to have the viral load as low as possible for as long as possible. A few missed doses should not be a problem, but repeated adherence problems may shorten the *duration* of the regimen’s effectiveness. A change in the drug regimen may have to occur sooner than you would like when there is poor adherence.

4) “I went to the health food store and bought all kinds of herbal products that the clerk told me would help my immune system.”

Be careful with over-the-counter medications, including herbal products, because we don’t know enough about how these agents affect HIV or the drugs used to treat HIV. We already know that there are some drug interactions, like St. John’s Wort and protease inhibitors. Tell your doctors and pharmacists about these items you are taking. Be honest with your providers about anything you take prescribed from other doctors or that you buy on your own, including the use of alcohol and recreational drugs.

3) “I have a few days of medication left, so I will wait until this weekend to go to the pharmacy and get refills.”

Sometimes the pharmacist has to reach the doctor for refill authorization or fix an insurance problem. If you wait until the last tablet is being swallowed on a Friday afternoon, it may take a few days to resolve these problems. Plan ahead so you and your pharmacist will be a lot happier! Usually a phone call to the pharmacy is all that it takes to get the ball rolling.

2) When trying to get prescription refills, the pharmacist tells you that your insurance coverage has changed, and you say “I got a letter from the insurance company, but I didn’t pay attention to it.”

It seems like insurance plans change all the time, and it is very important to keep up-to-date on this. It may be as simple as a change in the ID number, or it could be a complete change in coverage. Pharmacists spend about half of their time with insurance companies and billing for medications. If there is a change in your plan or benefits, please let us know so you don’t get stranded out there without pharmacy coverage. We don’t want the insurance companies to be the cause of any missed doses. Be a step ahead of them and read your insurance papers and notices.

1) “I’m going out of town for a year and an half, so could you give me all 18 months of my refill medication today?”

Usually insurance companies pay for one month’s supply of medication every 30 days or so. Sometimes they will allow up to three months, but that depends on the insurance company’s agreement with your employer or the agency giving the insurance benefit. Be careful if you have a plan for medication paid for only in the state you live in, or through specific pharmacies. This is especially true with Medicaid and ADAP programs. Theses benefits are usually not transportable to other states.

Don’t forget to take advantage of a pharmacist’s knowledge of drugs. It is usually free and most pharmacists are available at any time to help you with any problems that you may have. ✚

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. Contact: Glen.Pietrandoni@walgreens.com.

Editor’s Note continued

continued from page 11

She is a brave and beautiful HIV positive African American woman living in a small community in Virginia. Lois just learned that she was HIV positive a year ago. She knew nothing about the virus, or about AIDS. With the help of her sister, she has spent the past year educating herself about HIV. They drove to D.C. to attend the PACHA meetings and learn more. She stood before the Council and spoke of the lack of adequate care and availability of treatment information for persons like herself. Lois Brown is a true trailblazer.

I suppose in a way we’re all trailblazers. And we need trailblazers at every level, from every walk of life. For us to eventually succeed in this struggle against AIDS, it will ultimately be more important to focus on the many things we have achieved as a community on this path, and not on the ones we have not.

Charles E. Clifton

Charles E. Clifton
Editor
Send comments and reactions to publications@tpan.com

The Buzz

The Disconnect Syndrome: A Controversial Dilemma

by Daniel S. Berger, MD

It is not uncommon for patients to have increasing viral loads while on treatment. However, patients can have a “disconnect”: they may have detectable viral load and yet still be deriving benefit from their “failing” regimen. Their CD4 T-cell counts are not plummeting and are often still increasing. Overall, their general health remains well. These individuals continue with their daily life and routine, without any clinical consequences. The discordance between T-cells and viral load is often referred to as the Disconnect Syndrome. It is not a new disease, just an observation of the difference between viral and immunologic lab measures (viral load test vs. T-cell count).

Usually, patients on antiretroviral treatment demonstrate a drop in viral load (often to undetectable levels) while improving their immune system with an accompanying T-cell rise. The disconnect syndrome of rising viral load along with stable or improving immune markers such as T-cells is more common among patients who have a longer history of being on several antiviral regimens. Viral drug resistance, which is associated with decreased efficacy of treatment, is not uncommon for these patients. They have fewer options than patients on their very first antiviral regimen.

Usually, patients with an overtly failing regimen need to undergo changes in their antiviral treatment. This is a basic tenet of care for the chronically HIV-infected individual. This is done to halt progression of HIV disease, to preserve immune system function and to avoid further resistance development.

THE DILEMMA

However, in the unique situation of the disconnect syndrome, a question may be posed: Does every discordant patient merit a change in antiretroviral therapy? Sometimes a clinician may consider the fact that the viral load (HIV RNA) has not reached levels high enough to merit exposing their patient to further antiretroviral drugs. Many patients in this disconnect situation have already been exposed to multiple antiviral agents. Since undetectability does not mean one is cured, one must weigh the risks and benefits of modifying the regimen in order to lower the viral load.

There exists a dilemma when considering altering a regimen in this unique situation. New antivirals to reduce viral load may forestall the emergence of more resistance mutations. On the other hand, one must consider that changing to yet another new regimen will reduce options for the future. This is critical in situations where new options for specific and heavily treated patients are not plentiful. Realistically, formulating a regimen for a heavily treated patient is often challenging because of the presence of multiple resistance mutations. Therefore the likelihood or durability of fully suppressing viral load with a new regimen is in question.

Thus management of patients who are highly treatment experienced and who have a discordant response is a real quandary. It is believed that continuing the failing regimen further selects for resistance mutations, therefore further limiting future therapeutic options. But when there is stability in the elevated viral load together with increasing CD4 counts going yet higher, patients are obviously still deriving clinical benefit. No large prospective clinical trial has been performed to help provide insight for this situation.

THE INFAMOUS 184V MUTATION

Patients who manifest a disconnect do not have undetectable viral loads, so by definition they generally have mutations or resistance. [These mutations occur in the virus itself, usually in response to drugs used against it. The mutations in turn allow HIV to develop drug resistance. This means what it says: HIV can resist the drug or drugs, therefore making the medications less effective in fighting the virus.]

Individuals with a discordant response usually exhibit high numbers of mutations against the nucleoside drug class, which often includes the M184V mutation. This specific mutation of M184V (refers to a change in the amino acid switch in HIV’s viral gene strand) is most known for being the tell-tale sign of 3TC (Epivir) resistance. But having the 184V resistance mutation has also been associated with sustained responses to antivirals, confirmed in several studies. [Generally, cross-resistance would be a concern. Mutations that resist one drug may also resist another, especially one in the same drug class. This may lower the efficacy of new drugs which a patient has never taken before.) However, if one has the 184V, without other nucleoside mutations, it does not confer resistance to other nucleosides such as ddI, d4T, ddC or abacavir (Videx, Zerit, Hivid or Ziagen). Also, the M184V seems to result in re-sensitization of the virus to AZT (Retrovir) in patients who previously developed resistance to AZT. Finally, the presence of 184V in highly experienced patients is associated with a better antiviral response to the newest HIV agent, tenofovir (Viread).

The discordance between T-cells and viral load is often referred to as the Disconnect Syndrome.

Mechanisms & Theories

A complex interaction of viral and other factors are at play in discordant responses to HAART (highly active antiretroviral therapy). These include drug resistance mutations, replicative capacity and immunologic aspects.

The initial status of the patient, including CD4 T-cell count and presence of the 184V mutation before antiviral treatment, is predictive of responses to HAART and development of discordance. A lower CD4 count is more predictive of discordance. The more damaged one's immune system has become prior to treatment, the more difficult it may be for the immune system to assist in suppressing viral load later.

Often, T-cells remain stable or rise despite not obtaining optimally suppressed viral loads because HIV (though resistant) becomes [weakened] by antiviral drugs, impairing its ability to replicate. Thus the immune system is able to continue its restoration process. In other words, the antiviral treatments cause a decreased replicative capacity of the virus. In fact, there is a firm relationship between the high numbers of mutations and decreased replicative capacity of [virus from people with] discordance.

The disconnect syndrome can be explained in an alternative way. The M184V and other mutations may result in the virus becoming less fit than wild type. (Wild type is virus that has not mutated, seen usually in non-treated individuals.) [The less fit the virus, the less able it is to overcome the effects of other antivirals. Additionally, the reverse transcriptase enzyme, which HIV uses to reproduce itself, is also crippled despite the presence of resistance, and thus becomes less able to help make copies of the virus. HIV can not process its DNA strand (viral gene), and is therefore unable to replicate.]

Finally, development of increased mutations does not interfere with immune recovery during HAART. Measured by immune cell proliferation and response to interleukin 15 (a specific cytokine, protein produced by immune cells used for research purposes to measure immune response), researchers found that discordant patients had responses similar to fully respondant patients (Stephano Vella and colleagues, 9th Retroviruses Conference, Seattle, February 2002).

Conclusion

Without attempting to advise whether patients in a disconnect situation should change or continue their treatment, the questions invoked here are placed on the table. The presence of primary resistance mutations can oddly enough be associated with the provision of some beneficial effects. However, developing resistance or discordance is not the preferred outcome. When a patient is facing this discordant predicament, the next path may not be always clear. Phenomena are occurring in the disconnect syndrome that are below the surface. A patient's decisions are often complicated by various confounding issues.

This is compounded by the fact that data regarding the long-term outlook of patients continuing in this disconnect pattern is sorely lacking. Some researchers have demonstrated higher progression rates while others concluded that the immunologic deterioration is delayed by an average of three years (Stephen Deeks and colleagues, University of California at San Francisco). However large trials of "disconnected" patients who continue to maintain good clinical immunologic response to HAART for a specified duration would provide greater insight into the risks. It seems that patients manifesting a disconnect who continue their treatment are stable clinically and not developing opportunistic infections. However, with the ongoing epidemic of resistance, it would be helpful to understand what it all means to a patient's health and longevity.

Daniel S. Berger, MD is Medical Director for NorthStar Healthcare; 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. *Inquiries are welcomed by Dr Berger; he can be reached at DSBergerMD@aol.com or 773.296.2400.*

Pickett Fences

Act the Fuck Up!

by Jim Pickett

I awoke from my denial as someone who has been sleeping a long time and is really warm, comfortable and cozy does. That is to say, bleary-eyed, pissed off and craving desperately to crawl back under the covers. A year and a half ago, the night George W. Bush and the fiendish cast of freaks that make up his family and friends stole the American presidential election, I sobbed uncontrollably. I sat here in my little apartment and cried like I did when I found out I had tested positive for HIV. I was that distraught. I felt that much grief. I felt that hopeless.

And then I sorta forgot about all of it. The wracking, heaving, and wailing turned into more of a tired, cynical sniping about how dumb poor W is. Not like I had gotten a major hard on for Gore or anything. At most he inspired in me only semi-wood, and I know had he won the election (wait a minute, he did win the election) I would have spent a lot of time cringing when he talked, in that embarrassed way you have for people who are smart and mean well but are just so geeky. Ya know, and let's be clear, I certainly wouldn't want to, like, have him over for tabouleh. But he isn't stupid. And I'm pretty sure he wouldn't have surrounded himself with scary right wing ideologues hell bent on destroying me.

So, okay, time is of the essence my dears, so let's get on with my awakening. I'll tell you a little story. Recently, the Community Planning Leadership Summit for HIV Prevention had it's big annual conference here in Chicago. It's funded by the Centers for Disease Control and Prevention, and put on with the help of the National Minority AIDS Council, the North American State and Territorial AIDS Directors, and the Academy for Educational Development. I was on the Chicago Host Committee, and when the organizers said they wanted a dance company to entertain at one of the big plenary lunch sessions, I thought, "I know just who to get!"

There is a dance troupe here called The Sex Police who have been doing HIV prevention work in our high schools for 10 years. How perfect, what a match, this was going to be cool. I approached them, they had time on their schedule (to donate their services by the way), and it seemed like a done deal. Fabulously done! Well, here is where the problems began.

It was requested by the Executive Committee for the Summit that the group send in the lyrics of the music they were intending to use for their performance. Our federal partners were hyper concerned about the content because of the truly harrowing climate we are in. A frigid climate where a group called The Citizens Against Government Waste releases a report called "Through the Looking Glass—AIDS Programs: An Epidemic of Waste," which basically calls for the dismantling of all our programs, and on the prevention side, specifically targets interventions directed towards gay men.

Check it out for yourself, it was released on Valentine's Day 2002. A Big Brother climate where the new leader of the Presidential Advisory Council on HIV and AIDS, Patricia Funderburk Ware, is a rabid proponent of abstinence only education, publicly states time and again that condoms aren't effective, and believes sex should be had only within the sanctity of marriage. A climate where all of us doing prevention work are being scrutinized like never before, and our culturally appropriate messages are being taken out of context and twisted and distorted dangerously by right wing fascists who would prefer to see baby fags die.

But I digress. Let me share with you a few of said lyrics to the Sex Police's theme song:

Sex Police, we're the Sex Police
we have a warrant for your sex;
Sex Police, Sex Police
we're here to serve and protect (repeat chorus)
When it gets too hot for the senses,
keep your cool, you're not defenseless;
a flash of light, a funky sound,
the Sex Police will turn you around
in our black shields of steel.
Your mind's confusion it's for real
is it voodoo, is it a hex
what you say, it's about sex.
If it's black or bright moon light,
you make the choices about what's right.
Don't take chances, don't roll the dice;

It's not just sex, it's your life.
Feel the heat of the street
take the lead of the beat.
Don't let your love pay the price
it's your future don't think twice.
In the heat, the heat of passion
Sex Police will jump into action.
Know in your mind to be cool is cool,
It's your responsibility to be in the rule.
You're the one playing the game,
life's a struggle, ain't it a shame.
Losing ground
what a shock
remember this, you ain't no bum
Who's on the street to protect us,
no heroes left to honor and respect
But who's keepin' the beat,
hippin & hoppin',
it's the Sex Police.

Guess what? The Sex Police, who have performed to this song for thousands and thousands of high school students, were summarily disinvited. Specifically, the line "We have a warrant for your sex" was deemed too provocative for a room of 1,500 adult HIV prevention professionals. The organizers were afraid (rightly I'm afraid) that a line as innocuous as that could be taken out of context and turned into ammunition for fascist freaks like Pat Funderburk Ware and the Citizens Against Government Waste. The Axis of Evil indeed.

Sure, we can listen to women have orgasms as they condition their hair during the commercial breaks for the nightly news, aspirational dressing for six-year-olds is less enchanted princess and more porn starlet, we are saturated in sex and sexual images from the time we get up (excuse the pun) to the time we get down (couldn't resist)… but "We have a warrant for your sex" is just too naughty.

What does this mean in terms of the work we are doing? The insistent push for abstinence only education (which is seeing increased funding by the way), coupled with the "sex only for marriage" mantra and the inability to say even the most innocuous things about sex, is going to spell GENOCIDE for gay men, who are, HELLO ladies, still the population most likely to get infected by the virus that causes AIDS.

Well, as fellow Chicago activist Tyrone Pittman so eloquently put it, "HIV and AIDS are letters that kill. Don't let W be another."

Silencio = Muerte.

We will not be silenced.

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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.

TPAN Calendar of Events

All events held at TPAN unless indicated otherwise.
For additional information on these events please contact Michael Barnett at (773) 989-9400.

May 2002

Date	Time	Event
Tuesday, 7th Speaker: Pat Staszak	7:30 PM	Committed to Living Series: Exercise
Wednesday, 8th Speaker: Kurt Zackrison	9:00 AM	Navigator to pilot training
Tuesday, 14th	6:00 PM	Client Advisory Board Meeting
Tuesday, 21st	7:30 PM	TPAN Board Meeting

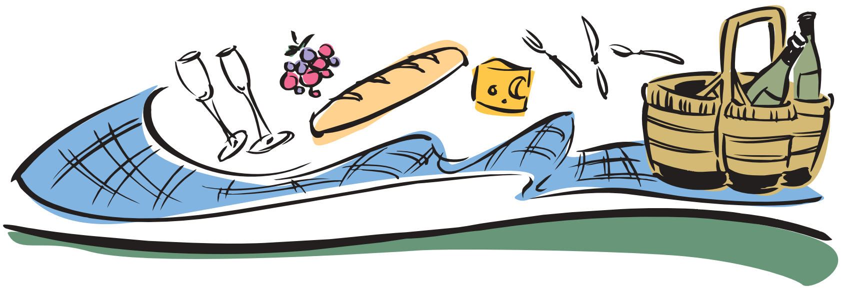
june 2002

Date	Time	Event
Tuesday, 4th Speaker: Carla Heiser	7:30 PM	Committed to Living Series: Nutrition
Wednesday, 5th Speaker: Kurt Zackrison	6:00 PM	Road to Wellville
Tuesday, 11th	6:00 PM	Back to Basics: HIV 101
Tuesday, 18th	7:30 PM	TPAN Board Meeting
Thursday, 27th	2:00 PM–5:00 PM	National HIV Testing Day

Join us for TPAN's Annual Backyard Picnic

June 28th 5 pm–8 pm

Celebrating 15 years of commitment and support
For more infomation, contact Jeffrey Allen at 773–989–9400



test positive aware NETWORK

Test Positive Aware Network
5537 North Broadway
Chicago, IL 60640
phone: (773) 989-9400

Programs and Meetings

All meetings held at TPAN offices unless otherwise indicated:
5537 North Broadway, Chicago.
Office hours: Monday–Thursday, 9 am–8 pm. Friday, 9 am–6 pm
phone: (773) 989-9400 • fax: (773) 989-9494
e-mail: programs@tpan.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.

NEWLY DIAGNOSED

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

TUESDAY

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 from 7:00–9:00 pm.

WEDNESDAY

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.

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.

POSITIVE PROGRESS II

A group for HIV positive people in recovery. Fridays 2:00–4:00 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. 2nd and 4th Fridays at 7:00 pm.

SCHEDULED BY APPOINTMENT

FAMILY AIDS SUPPORT NETWORK (FASN)

A group for family, friends, and caregivers. Call Betty Stern at (773) 989-9490.

WOMEN'S GROUP

A group for HIV positive women. Call Sylvia at (773) 989-9400 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 at (773) 989-9400.

PEER SUPPORT NETWORK

Provides one-on-one support for recently diagnosed individuals. Volunteers provide support, information and referrals. Call Derek at (773) 989-9400 to get a buddy!

POSITIVE BUDDY

Volunteers provide individuals living with HIV/AIDS one-on-one emotional / physical support. Call Derek at (773) 989-9400 to get a buddy!

MISCELLANEOUS

CHICAGOPOS18TO24 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.

Having both HIV and Hepatitis C increases the risk of liver damage

For additional information
and other Internet links
visit www.tpan.com

test positive aware NETWORK

For further information about the hepatitis C
virus call the CDC National HIV/AIDS,
STD Hotline 800-342-2437