Positively Aware
The Journal of Test Positive Aware Network
HIV Treatment and Health
September/October 2000

# The 13th International AIDS Conference


## Amandla!—Power to the people

## The transgender community at world AIDS

## Mbeki fails to break the silence

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

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

## Special Readers Forum for *Positively Aware's* 10th Anniversary

*Positively Aware* readers have been intregal to its growth and development. As the November/December issue will be *Positively Aware's* 10th anniversary issue, please send in letters about how the magazine has helped you or about your hopes for its future. All letters should arrive by Friday, September 29, 2000.

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# Cleaning your own house

Our tour guide stopped the van by the side of the highway in Capetown, South Africa. He pointed to a hut at the side of the road, off in the grass, not tall enough to stand up in.

There, he told us, teenage boys anywhere from ages 13 to 17 were recovering from circumcision, a tribal rite of passage to manhood that's done in cold blood, with the same blade used without sterilization from boy to boy. "What does that do for the spread of HIV?" our guide asked rhetorically.

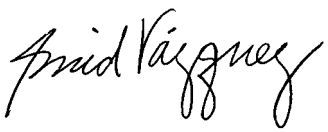
I thought this must be an urban legend, like alligators living in sewers. But a week later I saw a television documentary on Nelson Mandela's life, and he talked about going through this painful ritual. I talked with a Capetown woman who's living with HIV. She said–and I don't know where she gets her numbers–that of 10 boys undergoing the ritual, two come out with HIV, two are mutilated and maybe one dies. Yes, there are talks going on to change the practice, but it doesn't seem like things are changing soon enough.

I couldn't believe that a conscientious person like me hadn't heard of this ritual, especially since it clearly spreads HIV. I had heard of circumcision on young girls, also done in cold blood, and much more brutally. At the International AIDS Conference, I learned of a practice in another African country where the father of a groom, the groom's uncles or any other man who had contributed to a marriage dowry could have sex with the bride first. This, also, is found to spread HIV.

I'm a great respecter of culture. But cultures often need to change out of necessity. In so many ways, we are all alike. I've heard of so many men and women in the United States who don't tell their sexual partners that they have HIV. I've also heard of so many people who've been infected this way, some of whom were out and out lied to about their partner's HIV status.

We all have our ways of spreading HIV. Everyone–including South Africans–thinks South African President Thabo Mbeki is crazy for not supporting HIV therapy to fight the astounding epidemic in his country. But here in the United States, the government practices genocide by not supporting and funding syringe exchange for drug users.

Cultures need to change, wherever, however, they're killing people.



Enid Vázquez
*Interim Editor*

# If not now, when?

I have talked with a few people who attended the International AIDS conference in Durban, South Africa. Each of them tells a similar story–disappointingly little new information on treatments and a country, a continent, so ravaged by HIV and AIDS that it is almost impossible to comprehend.

The statistics from South Africa are numbing. One in five adults are positive, 1,700 new infections each day, nearly 600,000 newly infected people each year. More than half-a-million orphans. 50,000 deaths per year. And these are statistics for South Africa only. Not for all of Africa, just South Africa, a country of about 43 million people.

Look at those numbers again. One-in-five adults are positive. Think about that. Think about a office of 25 workers. In South Africa, five of them are likely to be positive. And given the lack of access to treatment, all five are likely to die before they are 40. 600,000 newly infected each year. That is equivalent to the entire population of Boston, Seattle, or Washington, DC becoming infected this year. 50,000 deaths each year. That is nearly equivalent to all United States soldiers killed during the Vietnam war. And 500,000 orphans, many themselves HIV positive. Nearly all with only a slightly older sister or brother, or aging grandparent, to care for them.

The numbers are overwhelming.

In the face of this, doctors, scientists, HIV activists and leaders from around the world gathered to share information and shine a spotlight on this ongoing tragedy. Speeches were made and papers were presented. Panelists from around the world shared their unique, yet common, experiences. Despite South Africa President Thabo Mbeki's unwillingness to part ways with the handful of people who do not think HIV causes AIDS, some good was achieved. For at least a few days, for at least the moment, sufficient attention was created to move governments and drug companies to pledge more support to South Africa and the entire continent. Hundreds of millions of dollars in additional aid have been promised from numerous drug companies as well as several governments. A global realization has started to be achieved that we are losing a generation of people in Africa, with Southeast Asia and Eastern Europe not far behind.

The breadth of the epidemic in Africa is overwhelming. Even with the millions of dollars in aid now promised, and the dropping of resistance by drug companies to locally produced generic drugs, the outlook is grim for Africa. The numbers of HIV positive people are enormous. The economies and health systems of the affected countries are often minimal and fragile. And the social norms of the populations often are in opposition to proven practices for reducing HIV infection. Yet it is wrong to simply turn away. Progress can be made, as proven by Uganda, where the HIV infection rate has been reduced. Education, working to change certain social norms, and the implementation of relatively low-cost treatment of HIV positive pregnant women to reduce the rate of infants born with HIV are all feasible.

An African proverb that I read in another magazine seems most appropriate. "The best time to plant a tree is 20 years ago. The second best time is now." The world cannot afford to let the HIV epidemic in Africa go unchecked for another 20 years. Action must be taken now.

Dennis Hartke

Dennis Hartke
Executive Director

# 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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### Wait and see

The focus of your May/June 2000 issue really struck a chord with me. I tested positive in December 1995, and in 1996, with T-cells of around 350, my doctor suggested I start AZT (the only thing available at that time). *(Editor's note: Dual therapy was being touted at the time, and triple therapy was established at the end of 1995.)* Fortunately I had already gotten involved with a support group and had heard too many horror stories of side effects and impossible scheduling, so I declined the offer. After all, I felt fine. (I firmly believe that I'd be dead now if I had started on that "merry-go-round" when first suggested.)

It wasn't until January of 1997 that I started taking drugs because of a high viral load (over one million!), but they were drugs I chose (d4T and 3TC [Zerit and Epivir]). They brought the load down to the low 1,000s (I don't believe undetectable is totally necessary). After three years I switched, but again, it was my choice of when and to what (lower dosage of d4T, ddI [Videx], and Viramune–no PIs [protease inhibitors] for me!). I had debated getting off the "merry-go-round" but decided to wait and see. After all, I feel fine.

Sincerely,
Rick VanVelkinburgh
Denver, Colorado

### Holiday hopes

I want to thank you for the article "Hoping for a Holiday: Structured Treatment Interruptions," by Tim Horn in the July/August issue.

I have been HIV positive for 18 years and on HAART [highly active antiretroviral therapy] for the past 10 years. My viral load would never go below 10,000 and as high as 600,000, my T-cells ranged from 13 to 200. Last year I was tired of all the side effects from taking almost 60 pills a day, and decided to try an STI.

I was off all my medications for nine months. During the first eight months, my counts remained around the same as when I was on HAART (viral load of around 50,000 and T-cells of around 150). In the ninth month my viral load increased to 750,000, so my doctor and I decided it was time to get back on medications. Although my viral load was high, I still felt the same as I did off medications, which was a lot better than the previous side effects.

After only four months back on medications (one new, and others that I had supposedly become resistant to) my viral load is down to only 69 (almost undetectable) and my T-cells have risen to over 325.

I am not sure if I had just gotten to a mental state before that prohibited the drugs from working because I was tired of it all, or if the STI really worked. Whatever the case, I'm happy and healthy. I have to admit that now that my viral load is as low as it is, I'm a little scared to try an STI again, at least as long as the drugs are working. Just because it seemed to work for me, I do not want to send the message out that everyone tired of taking medications should stop. But I appreciate your article about a topic that I'm sure will not get support from the pharmaceutical companies that could lose revenue if people were able to have STIs work.

Charles,
Houston TX

### HIV causes AIDS

I'm writing in regards to "From TPAN" by Dennis Hartke in the July/August 2000 issue. For a long time, the medical community could not conclusively prove that HIV was the sole cause of AIDS. So, through most of the 1980s and early 90s, open-minded researchers agreed to hold open at least the possibility that HIV may be only one cause in a chain of events that leads to AIDS.

This week, one of our clients with AIDS announced that he was stopping all of his HIV medications. He could not be persuaded to rethink his decision. He had heard all he wanted to hear when he read the president of South Africa's position that HIV doesn't cause AIDS, a position most notably propounded by the U.S. scientist Peter Duesberg.

This client's decision disturbs me greatly. He's not proposing a structured treatment interruption; rather, he's entering a period of HIV denial. Today, science has irrefutably proven HIV's fatal path. Where once we could only say that HIV infection was a common trait in people who died of AIDS, we have now proven that HIV is itself the cause of AIDS. Researchers

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now measure HIV directly, rather than trying to backtrack from the picture of immune system damage.

Viral load tests proved as early as 1995 that more HIV in a person's bloodstream is highly predictive of AIDS, and of mortality. Some people will argue that viral load tests are meaningless, because 99% of the virions measured are incapable of reproducing. But this doesn't change the proof that more is worse–even if all you chose to do was divide viral load readings by 100, the end result would still be the same; the patient with the higher viral load would fare worse.

Voices of dissent can advance research. However, advocates for alternative viewpoints should not become so wedded to their theories that they cling to them stubbornly when their foundations are soundly refuted. It is tragic that Duesberg cannot just take pride in having raised what was once a valid skepticism about the HIV-AIDS link, but continues to insist on his disproved theories. How many people will die sooner because they now ignore their HIV infection? How many teens will use Duesberg's theories as an excuse to abandon abstinence or safer sex practices, now that Duesberg has told them that HIV is no big deal?

Stephen J. Fallon, Ph.D.
Ft. Lauderdale, FL

*Editor's note: During the 13th International AIDS Conference in South Africa, spokespeople for the president continued to repeat that the president did not in fact say that HIV does not cause AIDS. Nevertheless, because of his continued defense of Duesberg, many people–including South African researchers–are waiting to hear him say that HIV* does *cause AIDS and that he supports HIV therapy.*

### Insensitive

I am an avid reader of *Positively Aware*, and am old enough to remember the original founding meetings of TPAN [Test Positive Aware Network]. I was also a friend of Chris', the founder of TPAN. I want to set the record straight regarding the article "Consumer's Guide to Lipo Surgery" in the July/August 2000 issue.

"Buchenwald" is not a generic word in German for concentration camp. Buchenwald was, in fact, an individual concentration camp during the holocaust, as was Dachau, Auschwitz, Bergen-Belson, etc. All of these were places of terror, unspeakable torture, starvation, inhumane medical experiments, gas chambers, ovens, and ultimately, for most, death. For a doctor to call the facial effects of antiretrovirals "the Dachau dimple" is utterly offensive. There were no dimples in Dachau; nothing was cute. There was only immaciation from starvation and slave labor. To say "Dachau dimple" is a deeply wounding joke for survivors of the holocaust, their families, and Jews in general. I wish people with AIDS today and those in the medical profession who are insensitive would take the epidemic seriously, and not joke their way out of it.

As one who has survived death three times during the crisis of the 80's and early 90's, I am still aware of the terrible loss of gay men back then, and still mourn for my friends and colleagues (well over 100) who were felled by the plague. There is a grayness in the world because of that loss. AIDS is still a plague and will continue to be a plague for uncountable years, despite the drugs which keep us alive, but which make many of us have sunken cheeks. There is no shame in this, no need for insensitive joking, neither by us nor by the medical profession. And, is there really a need for plastic surgery to hide "the look"? I wonder. Are people so ashamed of having AIDS? Has it come to this?

Keep up the wonderful work, support, and information of *Positively Aware*. It is an incredibly important voice of sanity in these insane times of misinformation, political entrenchment, and pharmaceutical company greed. There are few public voices that can be trusted in these times. *Positively Aware* is one of the voices I know that I can trust and count on to speak the truth. Thanks for your dedication and conscience.

Roger Goodman
Chicago, IL

*Author's note: In my article, the person with AIDS who had surgery likened his appearance to "the Buchenwald [concentration camp] look," and his doctor then came back with the "Dachau dimple" for alliteration. I took those statements to be expressions of the patient's sense of looking deathly ill and did not see them as insensitive. But after reading Mr. Goodman's comments, I can see his position and fully agree that the Nazi death camps should not be used as the basis of humor. My sincere apologies.*–Enid Vázquez

# News Briefs

*by Enid Vázquez*

News from the 13th International AIDS Conference, July 9–14, Durban, South Africa

## Children


The National Cancer Institute reported a very high rate of cancer in children with HIV–2.5% (124 out of 4,954 children whose records were reviewed). But a doctor in the audience noted that the figure was much higher–four times more–than was seen in any other published report, and noted that when he and other researchers looked at cases of cancer in HIV positive children, the majority of the cancer diagnoses could not be confirmed.

Other U.S. researchers noted that with improved HIV therapies, there will be greater concern over the potential for pain and other quality of life problems in people living with the virus, but that no one has looked at pain in children. PACTG 219 (Pediatric AIDS Clinical Trials Group) found in a survey that children with a CD4 percentage of less than 15% (severely immune suppressed) were almost three times more likely to report pain. (In children, CD4 percentage is more important than T-cell counts.) Overall, 20% (one in five) of the children experienced pain. The research is important because adults are frequently unable to notice pain in children.

A big question: do children born to mothers on HIV drugs get hurt by the medications? Most research shows that they don't. But researchers from the Netherlands reported immune system damage and blood cell malfunctions (such as much less CD4 T-cells) in negative children of positive moms. The report started a storm of controversy in the audience. Among the issues raised was the fact that this was a one-time look at the umbilical cord blood at birth; the researchers are still looking at how fast the children's immune system recovers; and that these may be transient problems (the presenter said they will look at that).

Brazilian researchers found a high level of blood lipid changes (51%) in children and adolescents on anti-HIV drugs (as is found in adults). Those with a longer history of symptomatic disease had a greater risk of lipid problems (more cholesterol or triglycerides, a type of fat). Actual changes in physical appearance was greater in the kids taking a protease inhibitor (five out of 29, compared to one out of 37 using only two nucleoside analogues–such as Zerit and Epivir). "Protease inhibitors seem to play a significant role in the development of abnormal body fat distribution," the presenter said.

Researchers reported good preliminary results in children, even those who previously took medications (a group that tends to show less benefit), with the newest protease inhibitor, lopinavir (formerly known as ABT-378/r), expected to be approved by the FDA (Food and Drug Administration) soon. After four months, undetectable viral load (less than 400) was seen in 57% of kids who had previously taken a protease inhibitor, 77% of kids who had taken a nucleoside analog, and 79% of kids who had never taken anti-HIV therapy before. The children's starting viral load was not given. The PI-experienced children received Viramune in addition to lopinavir and two nucleoside analogs. A doctor in the audience said that much higher doses of the manufacturer's current protease inhibitor, Norvir, had to be used in infants because the company didn't have enough research to provide adequate pharmocokinetics (how the drug works in the blood) in that population. He cautioned that since very few children here were less than two years old, and only one was less than six months old, the pharmacokinetic data may again end up being different once the drug is on the market. In response to a question, the presenter said the drug is not very palatable (tasty), but can be

easily masked and that children, who are now a year into the study, no longer complain about taste.

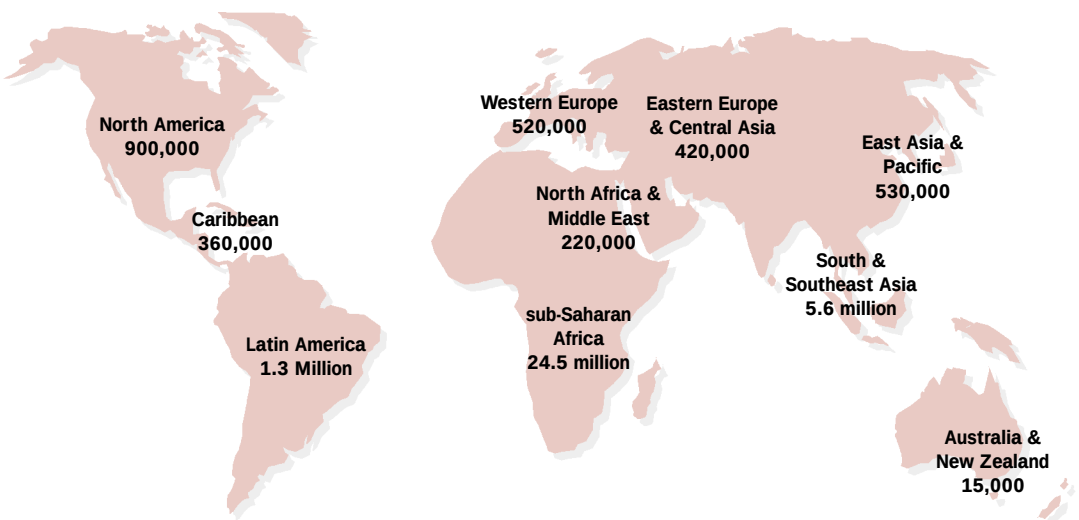
Mexican researchers found good results with the use of the cancer drug hydroxyurea (Hydrea) in 24 children. They had greater weight gain, growth, increases in T-cells and CD4 percentages, less viral load and less disease after nine months on hydroxyurea (30 mg/kg a day) with Videx and Zerit. The researchers reported good tolerance (plus, no cases of pancreatitis) and noted the lower cost of using hydroxyurea than using one of the potent HIV drugs, an issue raised by other doctors at the conference in terms of adult therapy.

## Pregnancy

The most exciting news for preventing transmission from mother to child came from a study finding that three doses of Viramune (nevirapine) was similar to a more expensive and inconvenient combination of AZT with Epivir. (In the U.S., AZT monotherapy is minimum standard of care for preventing transmission, but at least a triple drug combination is preferred, both because it's a higher standard of care for the mother and because it reduces transmission more effectively than just using AZT.) In the SAINT Study (South African Intrapartum Nevirapine Trial), more than 1,000 pregnant women were given therapy while in labor. They received either one tablet of Viramune during labor and one tablet within 24–48 hours of giving birth (with the babies receiving a single 6 mg dose of Viramune within 24–48 hours of birth), or the women were given a 600 mg dose of AZT upon entering labor, with 300 mg every three hours thereafter, plus Epivir twice a day during labor, and then both drugs twice a day for seven days after birth (with the babies getting 12 mg AZT and 6 mg Epivir twice a day, also for seven days). There were no serious drug-related side effects. There was a 7% transmission at birth, which increased 42 weeks after birth to 13.3% for Viramune and 10.2% for AZT/Epivir (no statistical difference). Forty percent of the mothers breastfed, although they were offered infant formula at cost. The findings caused a stir of excitement among delegates, especially those from developing countries–including the doctors, because of the ease and inexpensiveness of the highly effective Viramune regimen (a total of less than $10 for the three doses).

Also comparing well with AZT in short-course therapy was Zerit, Videx and a combination of Zerit/Videx. (Short-courses are studied in an attempt to decrease the cost of the original, longer U.S. trial with AZT that set the standard for preventing transmission.) In this study (also in South Africa), the drugs were given from the 34–36th week of pregnancy, but not during labor. The drugs were also given to the infants for the first six weeks of life. Baby formula was provided. Overall, there was a 3.6% transmission in more than 200 babies. Researchers said all drugs were safe and well-tolerated, and the "d" drugs (Zerit is d4T and Videx is ddI) had as much anti-HIV activity and decreases in transmission as did AZT. There were almost no drug related side effects.

In another study, breastfeeding was found to negate the benefits of AZT. In an analysis of two clinical trials that used short-course AZT in the sub-Saharan countries of Cote d'Ivoire and Burkina-Faso, there was no statistical difference in transmission at 24 months after birth between the women who used AZT (9.4%) and those who were given placebo (fake drug, 8.6%). Researchers noted that women with greater HIV viral load (the amount of virus in their blood) had a greater risk of transmission. It is preferrable for HIV positive mothers to breastfeed in developing countries if the families have no access to infant formula or clean water.




**Adults and Children living with HIV/AIDS—total: 34.3 million**

*Source: UNAIDS*

### Stop

German researchers took a small group of people off their meds for four to six weeks, then back on for six months. In the group with less than 50 viral load (HIV in the blood, considered undetectable here), only 58% were again undetectable after six months. Overall, they had a median rise of 0.4 log in viral load, which is statistically significant (not good). During the interruption itself, the increase was a scary 2.4 logs. They also lost an average of 11 T-cells at the end of six months. However, their lipid profile improved. They had lowered their triglyceride and cholesterol levels.

In the U.S., four people were put through three cycles of interruption, with four weeks on therapy followed by four weeks off. All started out with undetectable viral loads (considered under 400, in this case) and more than 400 T-cells. After 20 weeks, two of them did not show an increase to above undetectable (called "rebound") after one interruption, but did after the second and third (for a maximum of 14,000 and 25,000 viral load). The other two had a rebound during all three interruptions, with a maximum of 86,000 and 135,000. Viral load came back down with therapy for all four people, but not always to undetectable.

*The following News Briefs are not from the International AIDS Conference.*

### Ziagen kills

It's pretty well known that an allergic reaction to Ziagen (abacavir) can be fatal if people stop taking the drug and then go back on it. Recently the manufacturer had to add previously unrecognized symptoms of hypersensitivity (respiratory problems) to the drug's warning label. But now the warning has been strengthened. Allergic reactions either were not being recognized or mistaken for other conditions, and people have died as a result when they started taking Ziagen again after an interruption. Sometimes the interruption had nothing to do with a reaction to the drug, as when someone stops taking anti-viral medications while another condition is brought under control. And if that person or the doctor didn't recognize a hypersensitivity reaction before, or took it for something else, like bronchitis or pneumonia–well, you see the problem. The person goes back on the drug and, usually within hours, suffers a severe or even fatal reaction. Once again, respiratory warning signs include cough, difficulty breathing and sore throat. Other warning signs are fever, fatigue or malaise (overall ill feeling, as with a flu), and gastrointestinal symptoms (nausea, vomiting, diarrhea or stomach pain). Rash is sometimes, but not always, a symptom. For more information, call the Glaxo Wellcome Customer Response Center toll-free at (1-888) TALK2GW (825-5249).

### Social Security

New changes for people who work begin in September. The following is from a press release issued by the Social Security Administration (visit www.ssa.gov/pressoffice/ADA.htm). The "substantial gainful activity" (SGA) level will be raised for the first time ever, based on any annual increases in the national average wage index. (Blindness is excluded.) Currently, the SGA is monthly earnings of $700 or more, at which point people are ineligible to continue receiving benefits. Minimum monthly earnings for a Trial Work Period (TWP) go up from $200 to $530, and maybe more later on (also based on the wage index). The maximum monthly earned income exclusion for students receiving Supplemental Security Income (SSI) will increase from $400 to $1,290, and the yearly exclusion increases from $1,620 to $5,200.

### New protease inhibitor

The newest protease inhibitor may be in pharmacies soon. Lopinavir (formerly known as ABT-378/r) was recently submitted for FDA approval. Each capsule includes a small amount of the manufacturer's current protease inhibitor, Norvir (ritonavir). The brand name is Kaletra. A previously reported brand name was rejected because it was too close to that of an existing drug. The FDA doesn't like this because people have died after getting the wrong drug when the correct name was misread on a prescription.

# Amandla!—Power to the people

*by Charles E. Clifton*


*City Hall, Durban, South Africa. Photo by Charles Clifton*

The motherland. Africa takes you there and then some. I can't speak for all the brothers and sisters of African descent who find themselves scattered about the Americas, however, the opportunity to attend the 13th International AIDS Conference also represented a homecoming of sorts. A return to where it all began for my ancestors, for all our ancestors for that matter.

I knew before traveling to Africa that the rates of HIV infection are the highest in sub-Saharan Africa. Nevertheless, until you actually come face-to-face with the reality of AIDS in Africa I don't believe one can actually comprehend the devastation HIV/AIDS is causing.

- 24.5 million adults and children living with HIV in sub-Saharan Africa (out of 34.3 million worldwide)
- 4.2 million South Africans living with HIV
- 500,000 AIDS orphans in South Africa
- 550,000 newly infected South Africans each year

While in Capetown, I visited the Langa township. In this community constructed for 80,000, but currently home to 250,000 people, I saw the legacy of apartheid (abolished in 1994) and learned of the devastation of AIDS. As I examined the numbers, statistics and figures I wondered: How did this happen? What can be done at this point? Slavery, colonialism, apartheid and now AIDS–what's a continent to do to get a break? However, despite hundreds of years of oppression and with less than ten years of freedom and democracy, I also felt from these people a willpower to triumph over adversity.

Against this backdrop, for the first time, the world traveled to a developing nation to renew its International AIDS Conference. It could not have come at a better time. The primary focus of the 13th International AIDS Conference held in Durban, South Africa was to address questions surrounding the explosive rate of HIV infections in sub-Saharan Africa.

In the southern cone of the continent, at least one adult in five is living with HIV. One in five. And for the most part there is no incentive in most of Africa to test for HIV. There is no protection of individual rights; access to treatment and care is basically nonexistent in most impoverished and rural communities. Not including funds required for antiviral treatment, it is estimated that upwards of three billion US dollars would be needed every year to support effective prevention programs that would include treatment of mother-to-child transmission, condoms, educational programs, treatment of sexually transmitted diseases and blood safety programs. Where do you begin to overcome such insurmountable odds?

South African HIV and AIDS community leaders and activists used this once-in-a-lifetime opportunity to demand a new, diverse and globalized response to an epidemic that is producing 1,700 new infections per day in South Africa. For treatment advocates the conference was not only an opportunity to break the silence on HIV/AIDS (the theme of the conference), but also a chance to remind visitors of the recent history in the country. The people of South Africa built a resistance struggle based on grass roots activities that empowered a population of

*Langa Township, Capetown, South Africa. Photo by Charles Clifton*

ordinary men, women and children with the strength and courage to overthrow apartheid. They know that their struggle to implement effective measures against HIV will require the same level of commitment and courage.

**Community Indaba—"Coming together, sharing"**

In an attempt to understand how activists in South Africa are dealing with HIV/AIDS, I decided to follow the community and activist track of the conference. It's gonna take a village, a community and then some–Indaba. The theme of the Community Indaba was "Community Voices–a Call to Action." This conference was an opportunity for South Africans to directly communicate and learn from community activists and colleagues long engaged in struggle for better treatment and care for HIV and AIDS related illnesses. Shaun Mellors, an HIV positive South African AIDS activist, in a passionate voice that generated shout outs of solidarity from the audience, Amandla! (power to the people), stressed the need for breaking the silence on "inclusion" and "accountability." He challenged people living with HIV to expand their notion of community in this struggle and create a movement of solidarity that is inclusive of infected and affected populations. Mellors challenged all South Africans to take responsibility for the country's current situation in the AIDS epidemic, to be proactive in this struggle and in a search for local and global solutions.

The highlight of this opening session was the three first-person narratives: an HIV positive gay man from Australia, an HIV positive black mother from South Africa and an HIV negative drug user from India. Each individual spoke of how HIV has impacted their life, strengthened their commitment to the struggle and gave them the resolve to break the silence on HIV and AIDS. Musa Njolo, an HIV positive mother of an eight-year-old boy, was visibly frustrated and angered by the state of AIDS politics in South Africa. Njolo blasted government policy that continues to severely restrict treatment and care to people living with HIV, especially poor women and children.

Statistics released by the Kaiser Family Foundation and the American Medical Association show that in South Africa there was a 34% rise in HIV infected pregnant women in 1998 and a 64% rise in prevalence in pregnant teenage girls. The refusal of the government to support the use of anti-HIV treatment

*City Hall, Durban, South Africa. Photo by Charles Clifton*

during pregnancy, proven successful, is in Njolo's words, "a government that does not want to extend the life of a child whose mother will eventually die of AIDS."

Break the silence on the unequal distribution of wealth and power, on political inaction, on gender inequality, on access to care/treatment, on options to educate impacted communities, on information dissemination and tools of negotiation, on discrimination, racism and human rights abuses.

### Community activists take to the streets of Durban

"Cheap AIDS drugs save lives. Affordable treatment NOW!" "Let me start by accepting what has recently become less obvious," Winnie Madikizela-Mandela declared at the AIDS protest march. "AIDS exists and HIV causes AIDS." Winnie Madikizela-Mandela, Pan-Africanist Congress MP Patricia de Lille and Anglican Archbishop Njongonkulu Ngundane joined Treatment Action Campaign (TAC), ACT UP (the old school version!) and Health GAP Coalition in a march in Durban to protest government and pharmaceutical inaction. "If we struggle against HIV/AIDS the same way we struggled against apartheid, we can turn back time." Mrs. De Lille added, "the drug companies must know that HIV positive people are a powerful force."

TAC members and people living with HIV/AIDS (PWHAs) are frustrated and rightly so by what appears to be the complete absence of a comprehensive HIV/AIDS care and treatment strategy for South Africa. Activists and community organizers used the demonstration to bring attention to the need for the South African government to make affordable medicines, including anti-retroviral drugs available to PWHAs. They demand the immediate distribution of Viramune (nevirapine) and AZT to pregnant women with HIV. AIDS activists ask: If the government's core focus is prevention, why doesn't it try to prevent all these children from becoming orphans in the first place by providing anti-retroviral treatment to keep parents alive and unborn babies HIV negative? They promise to increase pressure on the government including, if necessary, demonstrations of a magnitude not seen since the struggle against apartheid.

TAC organizers are also critical of major international pharmaceuticals and UNAIDS. International activist group ACT UP maintains that the drug pricing policies are outrageous and appalling. Mark Milano, speaking on behalf of ACT UP and acting in collaboration with TAC, stated that "lower drug prices were promised for a long time with no results" from either the pharmaceutical companies or action on the part of UNAIDS. Activists went on to criticize pharmaceutical companies' promotional spending practices and donations to poor countries. Dr. Peter Piot (UNAIDS) estimates that $3 billion is needed annually to effectively fund HIV prevention programs in Africa. In a separate presentation at the AIDS 2000 Conference, Dr. Richard Laing, School of Public Health at Boston University, reports that U.S. pharmaceutical companies allocated $5.9 billion to promotional spending in 1998. With millions of people dying worldwide, how is that level of promotional spending justified?

The solution to the treatment dilemma in South Africa, according to TAC and ACT UP, is not donations and promotions, but rather lower prices, the introduction of generic drugs, and a real commitment to research and development. During the conference, Viramune producer Boehringer Ingelheim offered to provide the drug free to the government for five years. The representatives from Merck and Glaxo Wellcome restated their commitment to lower prices.


*Protestors at the 13th International AIDS Conference.*

### AIDS=death

It is estimated that 95% of all people living with AIDS in Africa do not have access to any drugs to fight the disease. South African High Court Justice Edwin Cameron, a person living with AIDS, in a keynote address to delegates acknowledged that, "I exist as a living embodiment of the inequity of drug availability and access in Africa…I am male…I am proudly gay…I was born white. My presence here embodies the injustices of AIDS in Africa." Cameron stated that he pays $400 a month for his medication, while 290 million other Africans survive on less than $1 a day. He said that he is alive today simply because, when he took ill in 1996, he was able to

*Langa Township, Capetown, South Africa. Photo by Charles Clifton*

afford a combination of the drugs AZT, Epivir and Viramune. He said that it is "shocking and monstrous" that some should be living while others are left to die simply because they are poor. Cameron applauded the Treatment Action Campaign on its direct action demonstrations and demands for the government to implement an immediate program of anti-retroviral treatment to reduce mother-to-child transmission of HIV. Cameron slammed President Thabo Mbeki's speech at the opening ceremony and his "flirtation with those who…dispute the etiology of AIDS." Cameron stated that Mbeki's policy is unsound and "has created an air of unbelief amongst scientists, confusion among those at risk of HIV, and consternation amongst AIDS workers."

### Living with HIV

"LOVE Life–Talk about it" is the largest and most comprehensive national HIV prevention effort dealing with the threat of HIV/AIDS to youth (15–20 year–olds) ever in South Africa. The campaign using innovative radio ads, TV programming, website, newspaper and teen hotline is piloted by four local youth who engage in frank conversations about their lifestyles and the effect of HIV/AIDS on their lives to bring an awareness to South African youth.

The truth is that South Africa is making progress in primary HIV prevention, but there must be a long-term commitment to frontline intervention in order to obtain a consistent and significant reduction in HIV in youth, as obtained in Uganda. In Uganda, successful peer-education prevention programs such as "True Love" (monogamy in marriage) have cut the HIV infection rates in half among youth.

A few times during the week the mounting reports of deaths, rates of infection and the sheer lack of care and treatment of the HIV/AIDS epidemic in Africa dismayed me. What could I do to make sure that this struggle is not forgotten? How could I help facilitate change? More than once I sat dumbfounded, contemplating a situation that felt hopeless, in the comfort of my hotel (29 floors above the harsh realities of Durban overlooking the stunningly blue waters of the Indian Ocean). And as I pondered my own existence, I knew that in a few days I would be on a plane, on my way back to the U.S. and a health-care system, which though not perfect is accessible to the vast majority.

Another South African group I spoke with, the National Association of People Living With AIDS (NAPWA), made me remember how and why I became involved in the HIV/AIDS movement. This conversation forced me to reexamine my way of thinking about the current situation in Africa. Our talk was devoted to the ways that affected communities–with little or no financial resources–come together and create workable solutions to HIV/AIDS. Can anyone remember how the gay and lesbian communities in the U.S. responded to the disease in the 1980s? Have you noticed the change in how African-American and Latino/a communities are responding to HIV today? Grassroots organizing.

A woman involved with the Sinosizo home-based care program, who I spoke with briefly, described the situation of children aged nine to 14 who are now the primary caregivers for their parents dying of AIDS, as well as for younger brothers and sisters. Many of these households have no income. Children are forced onto the streets to beg, steal and trade sex for money and/or food. Most are malnourished. There are no beds in many homes. Parents are often sent home from the hospital two or three days before death and often children are the only caregiver available to cleanse and lift their parents to and from toilets. In addition, these children have to cook on open fires, carry smaller siblings around on their backs, wash clothes and fetch drinking water from long distances. The

Sinosizo provides home-based training for children, not because they believe children should be caring for dying parents, but rather because there are no other options available.

There is a township not far from Durban where a group of women have created an orphanage to ensure that the children orphaned by AIDS have at least the basic necessities of life. The community center was created after it became apparent that AIDS affected the majority of the households, and that there would no one left in these homes to look after the children. The center is entirely dependant on volunteers, who take responsibility for making sure the children are cared for. They try to provide one meal a day and some basic education, but mainly the center is a place for the children to play and sleep.


*One of the many "LOVE Life" buses in Durban, South Africa. Photo by Charles Clifton*

The significance of a support system for "AIDS orphans" in Africa goes beyond our conceptualization of HIV and AIDS related deaths in the United States. In South Africa there are nearly 500,000 AIDS orphans and estimates indicate that these figures will more than double by 2005. These children come from homes where virtually every potential caregiver and/or provider is sick or has died from AIDS and/or the child was abandoned because of the stigma and discrimination associated with AIDS. Without the protection of family, children lose even their basic human rights. These women and NAPWA are breaking the silence on AIDS; dealing with it openly and honestly as a community; and using their African culture and family traditions to find solutions for the people affected and infected. Isn't that what gays and lesbians did in the 1980s, and what communities of color are doing today? No, it was not and still is not perfect, but if we waited for perfection–1,700 new infections daily.

**HIV and violence against women**

Violence against women remains one of the most overlooked factors driving the HIV pandemic. An address by Dr. Geeta Rao Gupta, International Center for Research on Women, focused on gender, sexuality and heterosexual transmission of HIV. Gupta noted that the cultural specific constructs of gender roles, norms and expectations in many societies have positioned men in positions of power and in control of female sexuality and reproductive rights. Because men operate from an absolute position of power in these societies, they dictate sexual practices, the number of and choice in sexual partner(s), who obtains sexual pleasure and when, and who controls procreation. The 5 P's of gender relations are power, practices, partner, pleasure and procreation. Gupta maintains that the unquestioned image of masculinity creates notions of male invulnerability and self-reliance. Consequently, men do not acquire the necessary information to reduce their own risk for HIV. They engage in multiple sexual relations, while maintaining sexual domination over women and deny sexual activity with other men. In most societies there is no discourse on sex and sexuality. All of these factors place heterosexual women at a higher risk for HIV than their heterosexual male partners. Gupta advocates for the following changes in gender relations: 1) decrease in gaps in education 2) improved economic access for women 3) improved political participation for women and 4) decrease in sexual violence against women. She maintains that demanding changes in gender roles does not compromise multi-culturalism and diversity. Gupta concluded that a society that empowers women does not disempower men.

Other studies from countries in southern Africa confirm that various forms of violence against women are practiced, including physical/sexual abuse and rape. The fear of violence or the

experience of violence may interfere with a woman's decision to seek voluntary testing and counseling, as well as asking their sexual partner to use condoms. All of these factors place women at a higher risk of violence (emotional and sexual) as well as increasing their risk for HIV when forced into unprotected sex with partners, husbands and trading sex for money with multiple partners.

*Mural detail, African Market, 13th International AIDS Conference. Photo by Enid Vázquez*

One day, the young girl (maybe 18 years old) who works in the store I stopped in every morning to buy bottled water said hello. She wanted to know about the "AIDS Conference." What is HIV? How do you know if you have it? What does AIDS look like? She had so many questions. I wished South African president Thabo Mbeki could have heard her. As simply as I could I explained the importance of HIV testing, treatment and care. However I could see that she was still confused. No one had ever explained HIV to her or her friends.

### To treat or not to treat

The general consensus to arise during this conference was that the costs of medicines are and will continue to be harmful to the improvement and development of adequate healthcare infrastructures in developing nations. Can we simply dismiss treatment of HIV/AIDS in Africa on the grounds of non-existent infrastructure? I think not. As one delegate asked: "Where on earth is there no healthcare infrastructure?"

It is true, the majority of the continent suffers from a dilapidated, outdated, and over-utilized healthcare system, but it does have healthcare. It can be changed. It can be improved. These things must happen. However, with the prevailing pricing structure in the pharmaceutical industry there exists little or no incentive for changes to current healthcare system in countries such as South Africa. Why improve the system if you can't afford the drugs? South Africa has a first-world private sector and within that sector there exists a first-world healthcare system. Where is the debate that questions a two-tier health care system? Why is the focus simply directed at what is not available? Why aren't we questioning the inequities of the existing private healthcare sector and a market that forces pharmacists, physicians and HIV specialists to join the private sector in order to practice, rather than providing public healthcare services? An argument that dismisses the possibility of treatment and care due to cost is a decoy of pharmaceuticals who refuse to address the high cost of anti-retrovirals and a deceptive ploy of a government that refuses to address its own mismanagement and lack of leadership in the HIV epidemic.

On the other hand, "doing the right thing" can be complicated. As Phill Wilson of the African American AIDS Institute (U.S.) stated, "there is an obligation not to harm…as we enter into different countries and cultures…in regards to resistance and compliance." Do we [developed nations] want to be seen as "pill pushers"? What are the ramifications if we jump the gun? Is distributing pills too narrow of a focus when it comes to care and treatment? What about testing, monitoring and counseling? An equitable treatment program will require safe, effective and wide distribution of anti-retroviral medicines. People living with AIDS and those providing care in Africa will need to monitor treatment of opportunistic infections, plus provide psychological support and financial protection (from illness and disease). We also need to support treatment that includes clinical and laboratory competence, and assurances that a continuous drug supply will be available. What will hap-

pen if we get these nations "hooked" and additional medications are not available when changes in drug-regimens are required? Who is going to deal with treatment failure, toxicity, development of resistance, and the possibility for increased treatment access inequalities? It's not perfect, but if we wait for perfection–550,000 new infections every year.

So it's agreed that the cost associated with anti-retroviral therapy should be decreased; an equitable and reliable distribution system needs to be implemented; access to treatment and clinical support will always be a problem, as will poverty (food), sanitation (water supply), and homecare. But with six new infections every minute in South Africa, do we wait for the perfect drug and the perfect system? Absolutely not. The infrastructure system will be improved through doing, not by waiting.

### Amandla!—Power to the people

Nelson Mandela, the founding father and first president of South Africa's democratic era, closed the 13th International AIDS Conference. Mandela was released from Robben Island Prison in February 1990 after serving 27 years. He belongs to the nation. His work is the work of South Africa. In his address, Mandela eloquently and indirectly called for an end to the recent conflict between President Mbeki and AIDS experts around the world.

"Now, the ordinary people of the continent and the world," Mr. Mandela said, "would, if anybody cared to ask their opinions, wish that the dispute about the primacy of politics or science be put on the backburner and that we proceed to address the needs and concerns of those suffering and dying." Mandela never mentioned the issue by name, however everyone in the audience knew exactly what he was talking about, Mbeki's association with HIV denialists. "In the face of the grave threat posed by HIV/AIDS," Mandela continued, "we have to rise above our differences and combine our efforts to save our people. History will judge us harshly if we fail to do so now, and right now."


*Langa Township, Capetown, South Africa. Photo by Charles Clifton*

*Langa Township, Capetown, South Africa. Photo by Charles Clifton*

With his white hair shining in the spotlight, Mr. Mandela looked and sounded like a prophet. He spoke to nearly every single issue I (and many thousand in the audience) had hoped for Mbeki to address at the opening ceremony. Mandela mentioned safer sex, abstinence and condom use as necessary steps to prevention "about which there can be no dispute." And in a list of "bold initiatives" that are necessary in the struggle against HIV/AIDS Mandela included "large-scale actions to prevent mother-to-child transmission." The South African government thus far has not approved a national program to prevent HIV infection through anti-retroviral treatment of mothers and newborns.

Drawing cheers and applause from nearly every completed sentence, Mr. Mandela condemned ongoing discrimination and stigmatization of people living with HIV/AIDS. He called for an aggressive treatment of opportunistic infections and for assistance to families and communities devastated by the disease. "We have a duty to give support and love to people who have acquired this disease not because of any bad behavior on their part," stressing, "especially children."

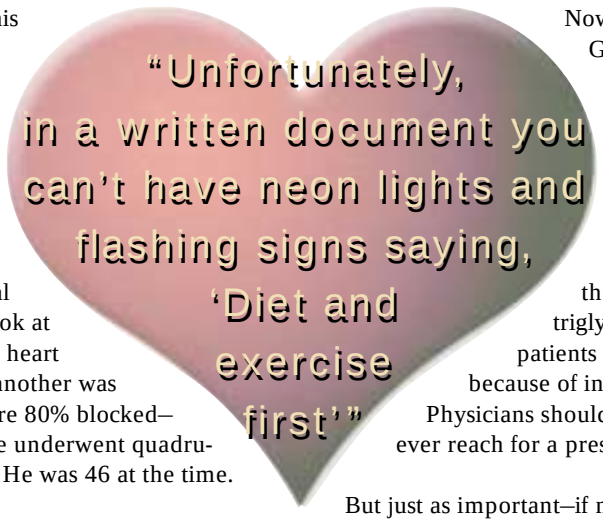
*Charles E. Clifton is the new editor of* Positively Aware *and Director of Communications for Test Positive Aware Network.*

# HIV lipid guidelines good for your heart

*by Enid Vázquez*

Gene Coughlin, *Positively Aware's* cover boy for July/August 1996, started having difficulty walking two years ago. Or as he puts it with his usual dry wit, "The little old ladies were outpacing me." Coughlin couldn't go a block without stopping to breathe. At first he thought he was recovering from pancreatitis, which had laid him up in the hospital for a month.

But after two months of breathing difficulties, he mentioned the problem to his HIV specialist. His doctor, conscious of cardiac problems in people with HIV taking protease inhibitors, had him come in right away for a stress test. Not four minutes passed before the treadmill was stopped and a chair placed on it so that Coughlin could rest. He was admitted to the hospital on the spot. The next morning, a look at the four main arteries leading to his heart found that one was 100% blocked, another was 90% blocked, and the other two were 80% blocked–a heart attack waiting to happen. He underwent quadruple bypass surgery a few days later. He was 46 at the time.




Coughlin was never careless about his diet or about exercising, because he had two major risk factors for heart disease: he always had high cholesterol levels and he had a family history of cardiac woes. Although no one knows for sure what's causing the high levels of sugar, cholesterol and triglycerides (fat) in the blood seen in many HIV positive people taking antiviral medicines, people with pre-existing risk factors like Coughlin's are at greater risk for these abnormalities. In HIV negative people, these conditions can cause heart disease. One leading HIV specialist with a special interest in this area says that everyone with HIV who's on medications should be treated like a 50-year-old heart patient.

Now the Adult AIDS Clinical Trials Group (Adult ACTG) has released guidelines for controlling dyslipidemia, as they're calling it ("dys" for impaired and "lipid" for fat). Lead author Dr. Michael P. Dubé, of Indiana University, says, "If nothing else, the guidelines would be a success if people begin using the right drugs to control their triglycerides and cholesterol. I see patients on drugs they shouldn't be on because of interactions with antivirals. Physicians should look at interactions before they ever reach for a prescription pad."

But just as important–if not more–is to control risk factors by making healthy changes, such as getting regular exercise and watching your intake of saturated fat. "Unfortunately, in a written document you can't have neon lights and flashing signs saying, 'Diet and exercise first,'" says Dr. Dubé. "Everyone should be doing the lifestyle changes that are good for

**Highlights from the ACTG lipid guidelines**

Dyslipidemia is common among HIV positive people taking antiretroviral therapy.

Although the implications of dyslipidemia in HIV is not known, the frequency, type, and magnitude of lipid changes in people with HIV are expected to result in increased cardiovascular disease.

People with HIV should undergo evaluation and treatment based on existing guidelines for dyslipidemia in HIV negative people, with the caveat that avoidance of interactions with antiretroviral agents is paramount.

Abnormalities of lipid metabolism in HIV positive people were seen long before the use of HAART (highly active antiretroviral therapy). Still, significant increases in triglyceride and cholesterol (both LDL and VLDL cholesterol) concentrations have been associated with all the available protease inhibitors (PIs). Lipid elevations have also been reported in patients receiving non-nucleoside reverse transcriptase inhibitor (NNRTI) therapy (Rescriptor, Sustiva, and Viramune).

It is possible that HIV treatment-related dyslipidemia may have a particularly atherogenic (artery damage) tendency when combined with other HIV-associated and treatment-associated metabolic abnormalities such as insulin resistance (which causes loss of control over sugar in the body) and visceral adiposity (central fat lying on top of the internal organs, like the liver and stomach).
–Enid Vázquez

longterm health, but at the end of my talks on this subject, 90% of the questions are, 'OK, what drug do we use?' That's very frustrating, because like [HIV specialist] Carl Grunfeld said, if you quit smoking, that cuts your risk more impressively than a 20 or 30-point drop in cholesterol with use of a statin drug."

Both physicians and people with HIV should be aware that there may be a problem and make sure risk factors are examined and treated, says Dr. Dubé. So far there's no clear increase being found among people with HIV, but this kind of data takes time to collect, he notes, and besides, "There's abundant evidence that there are increased risk factors for cardiovascular disease. There's also reason to believe that high cholesterolemia may affect people with HIV more because of insulin resistance and other problems they're having. For now, I wouldn't recommend anything for HIV that wouldn't be recommended for someone without HIV." The guidelines were published this summer in the journal *Clinical Infectious Diseases*.

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*The following is taken almost word-for-word from the AACTG lipid guidelines.*

### Effects of switching antiviral therapies

One published study suggests that in people who've never taken an NNRTI, substituting Viramune (nevirapine) for PI [protease inhibitor] therapy can improve the lipid profile. The substitution of Sustiva (efavirenz) for a PI has not consistently had a beneficial effect in several studies that have been presented in abstract [summary] form. Trends for improvement in lipid levels have also been reported with the substitution of Ziagen (abacavir) for a PI in several abstracts. High rates of increased viral load with substitution of an NNRTI or Ziagen for PI have not been reported in these small studies. In practice, however, many people will have already received NNRTI therapy or are extensively NRTI-experienced and the long-term viral load benefit of switching is unknown. At the present time, there are no studies that compare the effects of treatment switching to those of adding lipid-lowering agents to ongoing successful therapy. Clinicians will need to weigh the risks of new treatment-related toxicities and the possibility of virologic relapse when switching from a PI-based regimen to an NNRTI-based or Ziagen-based regimen to the risks of potential drug interactions and new treatment-related toxicities from lipid-lowering agents added to PI-based regimens.

### Measuring lipids

Evaluation of serum lipids should be performed after fasting for a minimum of eight hours, and preferably 12 hours. While total cholesterol and HDL cholesterol [the "good" cholesterol] are not markedly altered when tested in the non-fasting state, measurement of triglycerides and thus the calculation of LDL cholesterol [the "bad" cholesterol] must be performed while fasting. In general, the standard screening lipid profile should include measurement of total cholesterol, HDL cholesterol, and triglycerides, with calculation of LDL and VLDL cholesterol. It is recommended that a fasting lipid profile be obtained prior to therapy. This should be repeated within 3-6 months following the initiation of HAART. For individuals with elevated triglyceride levels at baseline, it may be preferable to repeat a lipid profile sooner, within 1-2 months of initiating HAART.

Fasting triglyceride levels will exceed 400 mg/dL in a substantial proportion of HIV positive PI-treated individuals and will make calculation of LDL cholesterol unreliable. Direct measurements of LDL cholesterol may not be readily available in some clinical laboratories. In these individuals, initial intervention decisions can be based upon the total cholesterol level, HDL cholesterol level, and triglycerides. The treating clinician must keep in mind that with high triglyceride levels, total cholesterol levels can be misleading, especially if used as a surrogate (substitute) for LDL cholesterol treatment.

Patients should be routinely screened for other cardiovascular risk factors such as family history, smoking, hypertension, menopausal status, physical inactivity, obesity, and diabetes. In addition, those with dyslipidemia should be screened for potential exacerbating factors such as excessive alcohol use, hypothyroidism, renal disease, liver disease and hypogonadism. The clinician should also consider the effects of glucocorticoids, beta-blockers, thiazide diuretics, thyroid preparations, and hormonal agents such as androgens [testosterone, Anadrol and Oxandrin, among others] and estrogens, on both cholesterol and triglyceride values.

### Cholesterol treatment

Non-drug therapies should generally be instituted first and given a thorough chance before instituting drug therapies. Dietary needs are frequently competing in the HIV positive population, where the need for lipid lowering and weight gain may co-exist in patients who often experience prominent gastrointestinal problems. In many patients it will be preferable to address their wasting prior to their dyslipidemia. Attention must be given to other correctable risk factors for CHD (coronary heart disease), such as cigarette smoking, obesity, physical inactivity, diabetes, and hypertension.

Drug therapies for hypercholesterolemia in people taking PIs are problematic. The HMG-CoA reductase inhibitors, or statins, have been used extensively for first-line therapy for hypercholesterolemia in other diseases. Considerable evidence demonstrates their beneficial effects in both reducing the risk of CHD in patients without prior CHD (primary prevention) as well as reducing the progression of coronary artery stenoses and risk of recurrent CHD events (secondary prevention).

Most statin agents can provide similar LDL cholesterol lowering, even though to a modest extent Zocor, but particularly

Lipitor, can more substantially influence these cholesterol levels. Pravachol may be the statin least susceptible to interaction with CYP3A4 inhibitors. A recent abstract reported that, in HIV negative people, the median 24-hour concentration area-under-the-curve for Pravachol co-administered with Norvir/Fortovase decreased a median of 0.5 fold while there was a 4.5-fold increase for Lipitor and 32-fold increase for Zocor.

Potential problems include significantly increased skeletal muscle toxicity due to increased levels of statins caused by CYP3A4 inhibition by HIV PIs and lower levels of PIs (possibly leading to virologic failure–increased viral load) caused by p450 induction [liver function] by statins. Elevated levels of statins have been associated with the development of rhabdomyolysis [a muscle disorder], such that the FDA has issued warnings about using these medications in patients known to be taking an agent which inhibits their metabolism. Similarly, interactions between statin agents and the CYP3A4 inducers Viramune and Sustiva may occur, possibly resulting in lower serum levels of statins.

Fibrates are alternative agents for hypercholesterolemia when it is accompanied by elevated triglycerides. A 32% reduction in total cholesterol level occurred in 25 HIV positive people treated with Lopid (gemfibrozil) 600 mg twice a day. Clinically significant drug interactions with PIs are unlikely. Although they generally have a greater effect on lowering triglycerides than on LDL cholesterol, many patients will also have hypertriglyceridemia and low HDL cholesterol, which tend to improve with use of fibrates. Concomitant use of fibrates and statin agents may increase the risk of skeletal muscle toxicity, and they should be used together only with caution.

An alternative to Lopid (gemfibrozil), Tricor (fenofibrate), was recently introduced in the US after many years of use in Europe. While Tricor may have potential advantages over Lopid such as more favorable effects on LDL cholesterol and greater ease of administration, at the present time there is no compelling reason to prefer Tricor to Lopid in HIV patients.

Because it causes insulin resistance even in non-diabetic individuals, niacin should be avoided as first-line therapy in patients receiving HIV PIs. Bile sequestering resins (cholestyramine, colestipol) are discouraged because their use can be associated with increased triglyceride levels, and their effects on antiviral drug absorption have not been studied.

**Table 1**

**National Cholesterol Education Program (NCEP) Treatment Decisions Based on LDL Cholesterol**

| | Initiate dietary intervention | Consider drug therapy | LDL-C goal |
|---|---|---|---|
| **Without CHD and less than 2 risk factors*** | ≥160 mg/dL | ≥190 mg/dL | < 160 mg/dL |
| **Without CHD and with 2 or more risk factors*** | ≥ 130 mg/dL | ≥160 mg/dL | < 130 mg/dL |
| **With CHD** | ≥100 mg/dL | ≥130 mg/dL | < 100 mg/dL |

* Risk factors include age (men ≥ 45 years, women ≥ 55 years or premature menopause without estrogen replacement therapy), family history of CHD, or coronary heart disease (first degree male relative with CHD before 55 years of age or first-degree female relative before 65 years of age), current cigarette smoking, hypertension, low HDL cholesterol (< 35 mg/dL), diabetes mellitus. In the presence of high HDL cholesterol (≥ 60 mg/dL), subtract one risk factor.

None of the statins are known to be strong inhibitors or inducers of CYP3A4, although data are limited in this regard. If this is indeed the case, it is unlikely that the statins would significantly lower or raise levels of PIs. However, there exists a possibility for clinically significant drug interactions resulting in decreased levels of the active metabolite of Viracept. Given the potential interactions, it is reasonable to recommend the use of low initial dosages of either Pravachol (20 mg daily) or Lipitor (10 mg daily) in HIV patients who require drug therapy for hypercholesterolemia and who are taking PIs. Lescol and Baycol are acceptable alternative agents, but no data on interaction with PI's have been reported. Mevacor and Zocor should be avoided.

### Isolated elevation of LDL cholesterol

Based on their efficacy in other groups of patients, statins represent the most reasonable initial choice. Until more detailed pharmacokinetic data is available, either Pravachol (20 mg/d initial dose) or Lipitor (10 mg/d initial dose) is recommended, along with careful monitoring of virologic status [viral load] and creatine kinase values. Baycol and Lescol are reasonable alternative statin agents. A fibrate, either Lopid (600 mg twice a day) or micronized Tricor (200 mg once daily) are reasonable alternative agents when statins are not appropriate, or when patients fail to respond to adequate doses of statins.

**Table 2**

| Agent | Considerations |
|---|---|
| Mevacor (lovastatin), Zocor (simvastatin) | Extensively metabolized by CYP3A4, toxicity likely when combined with PIs. |
| Lescol (fluvastatin) | Metabolized by CYP2C9, interaction with Viracept (nelfinavir) likely. |
| Baycol (cerivastatin) | Newest agent, relatively limited published data on drug interactions. May have low likelihood for interactions. |
| Lipitor (atorvastatin) | Some CYP3A4 metabolism, small amount of anecdotal and research experience in HIV. Modest increases in AUC (area under the curve), a measure of when co-administered with Norvir/Fortovase (ritonavir/saquinavir). |
| Pravachol (pravastatin) | No significant p450 [liver] interactions, primarily renal [kidney] excretion. Minimally decreased AUC when co-administered with Norvir/Fortovase. |

There exists the possibility of increased risk of myopathy (muscle damage) when a fibrate such as Lopid is combined with a statin.

### Hypercholesterolemia with hypertriglyceridemia

Fibrates represent the cornerstone of drug therapy for hypertriglyceridemia (Table 3). Treatment is with Lopid (600 mg twice a day, 30 minutes prior to the morning and evening meals) or micronized Tricor (200 mg once daily). Significant drug interactions with common agents used in HIV treatment are unlikely to occur, but these have not yet been studied.

**Table 3**

| | First choice | Second choice (or if additional treatment is needed) | Comments |
|---|---|---|---|
| **Isolated high LDL** | Statin | Fibrate | Start with low doses of statins and titrate upward. Patients on PI may have increased risk of statin-induced myopathy. |
| **Combined hyperlipidemia (high cholesterol and high triglycerides)** | Fibrate or statin | If starting with fibrate, add statin. If starting with statin, add fibrate. | Combining statin and a fibrate may increase risk for myopathy [disease of the muscles]. |
| **Isolated Hypertriglyceridemia** | Fibrate | Statin | Combining statin and a fibrate may increase risk for myopathy. |

Many HIV positive patients will fall under this classification of combined hyperlipidemia. Either Lopid or Tricor or a statin agent (see above) represent reasonable initial choices for management.

### Hypertriglyceridemia

Non-drug therapies should be instituted first and given a thorough therapeutic trial. Smoking cessation and regular aerobic exercise are general health measures that will reduce triglycerides and improve the overall cardiovascular risk profile. Weight reduction should be strongly encouraged if obesity is present. Fat intake should be decreased, but a concomitant increase in carbohydrate intake may raise triglyceride and lower HDL levels. If this occurs, replacing some of the saturated fat with monounsaturated fat, which will not raise LDL cholesterol, may be valuable.

Because of its propensity to cause insulin resistance, niacin should be avoided as first-line therapy in patients receiving HIV PIs. Preliminary data suggest that Lipitor is safe and effective for lowering triglyceride levels in patients receiving PIs. However, only small numbers of patients were studied, thus further data are needed before the use of this agent can be routinely recommended. As a class, HMG-CoA reductase inhibitors are not generally recommended as first-line therapy for isolated hypertriglyceridemia. If the use of a fibrate results in inadequate triglyceride lowering, or if LDL levels remain elevated, a cautious trial of adding a statin agent should be considered.

*The AACTG guidelines are available at http://aactg.s-3.com/pub/docs/lipid_guidelines.htm. For more information, also see*

# Back to work drug screenings

*by Glen Pietrandoni, R.Ph.*

Well, you think you feel good enough to go back to work. That's great! Your health is good, you have managed the HIV drug regimen and side effects and you are raring to go! Here is something that you probably have not thought about–*pre-employment drug screening.* As a pharmacist, I get a lot of questions from HIV positive people regarding drug tests and how to prepare for them. It is important to understand how the test works, what employers are looking for, and what to do when it's time for your test.

Pre-employment drug screenings can be given to any prospective job applicant only after an offer of employment has been made. You do have a right to refuse to take the test, but you will probably not get the job. Please be aware that this differs from a random drug screening that is given after you are hired. An employer has the right to give a drug test that is not announced on a routine basis, or if there is suspicion of drug or alcohol abuse on the job. If you refuse to take these tests, you may be terminated from the job. Most employers use independent laboratories to conduct a drug screen. They will in turn give the results of the test to your employer.

The most common type of pre-employment drug test is a urine test. It is the easiest and least expensive test to give, and is used by most companies to screen employees for use of illegal drugs. It usually can detect use of drugs for the past few days to a week. Chronic users can expect their urine to detect drugs even 30 days after the last dose. Don't assume you are in the clear if you take a few days off from your recreational drugs. Many variables affect the presence of drugs in the urine, including metabolism, frequency of use, potency of the drug in question, and hydration of the individual. Depending on the employer and the type of position you are applying for, a blood or hair test can also be given. These tests are expensive, but can detect a larger variety of chemicals and for a longer time period.

Drug screens do not measure how much drug is in the urine, simply if a drug is present or not. Only these drugs are tested for in a standard drug screen:

- Marijuana (cannabis, hash)
- Cocaine (crack, benzoylecognine)
- Opiates (heroin, opium, morphine)
- PCPs (phencyclidine)
- Amphetamines (speed, methamphetamines)

Tests are not given to determine the presence of any other compounds. The test will not know if you are taking anti-retroviral medication so do not stop taking anti-retroviral medica-

tion because of an upcoming drug screen!!!

Expanded tests can look for barbiturates, benzodiazepines, methadone, and propoxyphene. Sometimes, alcohol is tested for, but usually during tests given after you are hired, or if there is a question of your sobriety, not for pre-employment. Few companies test for LSD, MDA, mescaline, or inhalants.

Your future employer wants to know if you are using illicit drugs, not if you are taking medication prescribed by a doctor. If you test positive for any of these drugs you will be asked by a Medical Review Officer (MRO) who performs the test to show proof of a legal prescription. This will be reported to the employer as a *negative* result. You must be honest with the Medical Review Officer, but you do not have to disclose your HIV status or HIV medications. If you take Sustiva, certain urine tests will show a positive result for marijuana in error. If this occurs, ask the MRO to confirm the test with another brand of urine test. (False positive tests occur only with the CEDIA DAU Multi-level THC assay.)

Examples of prescription drugs that can cause a positive test are drugs for pain, sleeplessness, anxiety, neuropathy, and others. Acetaminophen (Tylenol) with codeine, alprazolam (Xanax), diazepam (Valium), lorazepam (Ativan), Marinol, tincture of opium, hydrocodone (Anexsia or Hydrocet) and methadone all will cause positive test results. Again, be honest with the MRO. It is your responsibility to clear up any positive results of the drug test. Positive results resulting from a prescribed drug are reported as *negative* to the employer. Copies of prescription receipts or medical records will be very helpful to the MRO. A pharmacist can easily give you copies of prescription receipts if you need them.

If you think you have a foolproof way to "trick" the tests into giving false negative results, you might be fooled yourself. I am certain the MROs have heard and seen everything. The McDonald's poppy-seed bun trick is not going to work! There are products on the market in health food stores and on the internet sold for this purpose. It is possible to dilute the urine with herbs and teas. Results of tampered urine will almost always come back as *inconclusive* rather than positive or negative. This is a red flag to the MRO, who will have to repeat the test. After a similar result on a subsequent test, the MRO will have no choice but to report this to the employer, and the job may not be yours after all. There are websites devoted to this topic that may assist you in your search for information (www.cleartest.com).

Some doctors may be sympathetic to the common use of marijuana to alleviate nausea and increase appetite in their patients living with HIV/AIDS. If you have a good, open relationship with your physician, it may be possible for your physician to assist you in explaining a positive test result for marijuana. Speak to your physician before you go to have the test performed about their willingness to help.

When it's your turn for the drug screen, be honest with the MROs and do not stop taking your anti-retroviral medication. Be prepared with proof of prescription drug records and remember it is your responsibility to clear up any positive results before they are sent to the new employer.

*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.*

# Cutting edge research

## Includes chemotherapy and transplant drugs

*by Frank Pizzoli*

"There was a time when all the body's members rebelled against the belly," declared a group of men in Shakespeare's Coriolanis, his tumultuous play on democracy. HIV is a democratic invasion of the body that leaves no major organ or system untouched. However, the rebellion against its presence in the lymph node system, and maybe tonsils, has begun.

Cutting-edge research eventually may allow doctors to cleanse HIV reservoirs from the lymph node system, where, after infection, the virus replicates then flushes out into the blood stream. Once circulating in our blood, Highly Active Antiretroviral Therapy (HAART), for some, is effective in reducing viral load and preserving, sometimes increasing, precious CD4 cells. Total eradication of replicating "viral pools" in major body systems is the next logical step.

"We must find ways to eradicate HIV from the body," says Duke University's John A. Bartlett, MD. With assistance from Midge Silberman, RN, Bartlett recently added his tenth human subject to a National Institutes of Health (NIH) clinical trail known as ACTG 380. The study focuses on a potential method of viral eradication: the effects of chemotherapy combined with HAART on HIV DNA present in the lymph node system.

Specifically, Bartlett uses Viracept (nelfinavir) plus Zerit plus Epivir and combines that drug combination with the chemotherapy drug cyclophosphamide in a low-dose regimen. Three chemotherapy treatments are administered (by infusion into a vein) six weeks apart in escalating does. Each infusion requires a 36-hour hospital visit. Investigators want to learn if this particular HAART combination plus cyclophosphamide has any effect on eliminating HIV hidden in lymph nodes, tonsils and blood. Normally, these deep HIV "reservoirs" are not adequately reached by oral HAART regimens alone. All clinical trial subjects must be antiretroviral naïve, according to Bartlett, adding, "That's not always easy to find in patients."

"We're looking to assess if the combined effects of this particular HAART combination when combined with cyclophosphamide can reach those otherwise hard to reach HIV reservoirs," Bartlett says.

### HIV and non-Hodgkin's lymphoma

Willis Navarro, MD, of the University of Califirnia at San Francisco, hopes to use cyclophosphamide and other drugs and existing interventions for different reasons. "I want to apply the standard of care for non-HIV non-Hodgkin's lymphoma patients to HIV positive individuals," he explains.

HIV negative patients who are given a diagnosis of non-Hodgkins lymphoma and then relapse or are at high risk of relapse are considered as candidates for "autologous stem cell transplant." Stem cells are undeveloped cells that first must be harvested and then transplanted back into patients after they undergo two separate courses of chemotherapy treatments. The "stem cells" will replace bone marrow destroyed by the harsh chemotherapy drugs needed to kill off the lymphoma. Normally, the first-line treatment for this type of lymphoma is chemotherapy alone. The stem cell transplant is a second, more aggressive treatment.

Willis was originally looking for HIV positive patients with a *de novo* (or new, recent) diagnosis of non-Hodgkin's lymphoma, but after conducting an open study for one year he found only one patient with the needed characteristics. "My referral sources are telling me they don't see as much HIV-related lymphoma as before," he says, possibly due to HAART's general improvements to the immune system. "I'm revising the study to enroll HIV positive patients with existing diagnosis of non-Hodgkins lymphoma or patients who have relapsed or who are at high risk of relapse," Willis says.

**The clinical scenario for treating non-Hodgkins lymphoma is complicated**

The clinical scenario for treating non-Hodgkins lymphoma is complicated. Adding HIV creates an even more complex logarithm. The study's first purpose is to see if intensive chemotherapy combined with stem cell transplant is safe and well tolerated by individuals with AIDS-related lymphoma. The treatment itself is not new and is the accepted standard of care for non-HIV, non-Hodgkins lymphoma.

Viral eradication of HIV through chemotherapy and effective treatments for non-Hodgkins lymphoma may signal a time when all the body's parts may stop rebelling against the treatments.

*Note: For more information on these and other HIV clinical trials, call (800) TRIALS-A.*

# Defending the castle

## How HIV attacks, and how medicines fight back

*by Stephen J. Fallon, Ph.D.*

Most of us have heard that HIV creates complex chemical reactions to fool our white blood cells into producing new baby HIVs (that is, virions). Our white blood cells make up our immune system, which is the invisible armor that protects us from colds and other diseases. Following are some illustrations that describe how HIV takes over. (I'll put the technical description in italics, *like this*, after each section).

Since our immune system's white blood cells shield us from the full effects of most pathogens, imagine that our bloodstream is filled with white fortresses, or castles, which protect us from enemies. Castles are designed to be sturdy, and our castles are just that: they can stand up against almost any disease we might come up against. But our deadliest enemy, HIV, has figured out how to beat our castles. How? Through four basic steps.

### Step 1

If any enemy wanted to attack a castle, what would be his very first objective? Well, he'd have to make it across the moat (the deep water that surrounds a castle, keeping enemies from running up to the door). HIV knows how to get on a raft to get across our moats (*in other words, it fuses and attaches to our cells, using the T-cell co-receptors, such as CKR-5 and CXR-4*). Now, if an enemy makes it across the moat, has it won the war? Of course not. You've seen movies that show how armies secure their castle doors. Picture faithful soldiers pouring boiling oil onto an enemy who is trying to break down the door to a castle. Your body can also kill off HIV that is still crossing the moat. But it's a race to see whether HIV will sneak in before the troops can catch it.

### Step 2

What if an enemy that makes it across the moat also has a key to the castle's door? HIV does, and it can turn the key to get in the door (*it turns its RNA into DNA in the cell, through a process called reverse transcriptase. RNA is just a piece of information; DNA is the operating code for cells*). If an enemy makes it through your castle's door, has he won? No, you still have a sturdy castle, but your castle is more vulnerable now, as the enemy can start causing havoc inside.

### Step 3

Once inside the castle, a smart enemy would know that he's outnumbered, so he'd want to mess up the castle's defense system. So an enemy might sneak down to the castle's map room, and pin a phony map up on top of the one that is supposed to correctly direct the troops in the event of attack. Then he would sound the alarm, and watch all the soldiers running the wrong way. In effect, the enemy would turn the soldiers against the castle they're supposed to defend! (*At this point, HIV integrates its new DNA into the cell's nucleus, using an enzyme called integrase. This step overtakes the cell's primary function, and directs the cell to start producing strips of new material to make future virions*). In other words, the enemy fools the castle into actually sending new soldiers out to battle other castles, rather than the castle's enemies.

### Step 4

But the enemy's work still isn't done. Not only does the enemy want to take over this castle; it wants to take over all of the castles in the "kingdom" of your body. So it sneaks down to the weapons room, to arm itself for battle in this and other castles. It does this by cutting up pieces of "metal" to make new weapons. (*Or, more exactly, HIV cuts up virion strands, using its protease enzyme. Until these strips are separated, like pieces of a model car, they can't be made into new HIV particles*). The enemy would then put on the special war gloves needed to carry these new, sharp weapons out to battle. Then he breaks out of the castle to go attack other castles fully armed (*that is, HIV packages new virions using zinc fingers, and then buds from the cell. The new weapons are in reality new HIV pieces, which break out to infect new cells*).

Medicine first worked at trying to stop HIV at the castle door, Step 2, in its overall attack plan. Medicines like AZT basically try to fake out HIV, by putting a phony keyhole on the door,

so that it won't turn its key in the lock. (*they set a decoy so that HIV can't turn its RNA into DNA through reverse transcriptase; this class of drugs is called nucleoside analogues*).

These drugs work fairly well, especially if two are combined. A newer strategy to holding HIV outside the door tries to gum up the lock, in order to stall HIV even if it does luck out and place its key in the right hole (*these drugs are called NNRTIs, or non-nucleoside reverse transcriptase inhibitors*). The newest defense of all at this step tries to bend HIV's key itself, making it harder for HIV to turn the RNA into DNA. (*These drugs are called nucleotide analogues—not nucleoside. Though quite potent, they are proving difficult to make in a way that is safe.*)

These days, most people are talking about "the cocktail," which is a daily drug combination made up of three or more different medicines taken during the course of a day (but, unlike a real cocktail, you don't actually mix them in a glass). There are actually many cocktails, because there are many combinations that you could take. Cocktails are also called HAART (highly active anti-retrovial therapy). The earliest cocktails typically featured two nucleoside analogue RTIs and one protease inhibitor (PI). Today, some include two PIs, while others use potent NNRTIs instead of PIs. Another uses the newest nucleoside analogue, Ziagen, for a total of three RTIs.

Powerful protease inhibitors have helped many patients lower their virus below detection (though we know virus is still there, hiding out). Unfortunately, these meds can also bring the worst side effects some patients have ever experienced: kidney stones, anemia, neuropathy, nausea and vomiting, and even lipid redistribution ("protease paunch" and "buffalo hump"). In addition, PIs have a weakness of cross-resistance. The tricks that HIV pulls to outsmart one of the drugs seem to give it an advantage against other similar drugs later (*HIV develops cross-resistance*). Non-peptide PIs (like the coming tipranavir) may help thwart cross-resistance.

For a while, some scientists thought that cocktails might push HIV out of a person's body. We now see that this probably won't work. These days, doctors are talking about "remission," rather than "eradication." We've

**Undetectable?**

Viral load tests typically look for HIV in the bloodstream, which you might think of as being the "highways" of the body. When we can't find any HIV traveling those highways, that's a good sign. But there could still be lots of HIV hidden away in the "buildings" of the body (such as the lymph nodes, the spleen, the liver, the brain, the testes, etc.). Typically, about 98% of the HIV in a person's body resides in the tissues and organs, not in the bloodstream. The good news is that medicines that work in the bloodstream usually have some effect in the tissues as well. The bad news is that they don't always reach everywhere they need to go (for example, they may not effectively cross the blood/brain barrier). As such, patients with undetectable viral load may still shed drug resistant HIV through their sexual fluids. HIV positive persons can speak frankly with their partners about the possible risk of "undetectable, yet transmittable" HIV.

—Stephen J. Fallon

learned that it may not be necessary to hold the virus completely below the limits of detection. Our bodies have some ability to recover their immune systems, if the virus is brought down to fairly low (but still detectable) levels.

Scientists also continue to work on a new drug from another new class, integrase inhibitors. Unfortunately, so far, tests suggest that these drugs are difficult to make, and don't work as well as hoped.

Early in the years of our war on HIV, scientists tried to stop HIV at Step 1, before it crossed the moat. Some of the medicines looked good in test tube studies, but then failed when we tried them in live patients (the anti-oxidants in our blood absorbed the medicines). Science moved to working on protecting the door, because it was easier to develop medicines at this step.

Then three years ago, researchers were startled to discover a few individuals who were virtually immune to traditional modes of HIV transmission, despite numerous exposures to the virus. *These people don't have a boat in their moat!* They were born with pieces missing in their immune system. Normally, this would be a bad thing, but scientists learned that the missing part was just what HIV uses to get across the moat to the castle's door. Less than 1% of persons tested lacked a boat (*or a CC-CKR-5 co-receptor*).

The discovery that people could live without the boat turned scientists on to new ideas, and new ways to try to slow HIV down at its first step. Scientists want to learn how to create this "defect" in other people, so that HIV will be stopped at the moat. It will take many years to figure out how to program our bodies to lose its boats. We're working on gene therapy, which would pull the boats out of every moat surrounding every new castle your body produces (*forcing the body to produce CD4 white blood cells that are "born" without the CKR-5 co-receptor*). In the meantime, medicines such as T-20 (pentafuside) and T-1249 try to block HIV's fusion and attachment in slightly different ways.

Taking whatever combination of medicines works well for you can buy time. By taking your medicines correctly now, you make it more likely that your castle will still be intact when medicine finally develops new reinforcements to bring to the battle.

*Stephen J. Fallon is director of education for CenterOne in Fort Lauderdale.*

**Skipping pills**

Many patients are trying very hard to take their meds as scheduled, so that the drugs will keep working. Unfortunately, drug failure rates now reach 50% in urban populations. HIV can eventually develop resistance on its own, even if you don't skip any pills. But you don't want to help HIV win any sooner. The lesson is simple: fighting HIV requires commitment and a wise strategy.

Recent studies show that patients miss doses of their medicines frequently, either due to forgetfulness or intolerable side effects. Missing doses, though, gives HIV time to "regroup." One study found that 56% of patients miss doses, and of those who take all of their pills, only 43% take them on time. This is dangerous because HIV can begin mutating around some protease inhibitors in just an hour and a half if patients miss a dose! A new study shows that skipping 5% of your pills leads to a one-in-six chance that your meds will fail within a year. If you miss 10% of your pills, the risk doubles to a one in three chance. And if you skip 20% of your pills, your chances are three-out-of-four that HIV will break through your medicines.

Now, you might think that with so many medicines available, failing on one combination is no big deal. But remember that doctors can't just pick any two, three, or four anti-HIV medications off of the shelf. Certain drugs do not work well together, while others work only in concert with certain others. That means that there are only so many possible ways to combine the available medicines.

In a disturbing recent study, researchers used a computer model to predict what would happen if a patient did not adhere well to medicines, and was thus forced to switch to new combinations frequently. This patient "exhausted her choices of AIDS drugs fairly early in her disease." On the other hand, if you take your pills exactly as scheduled, and with the right food considerations, we've seen patients hold their virus to undetectable levels for many, many years.

–Stephen J. Fallon

# The transgender community at world AIDS

*by Lorraine Sade-Baskerville*

The XIII International Conference on HIV/AIDS was held in July in Durban, South Africa, in the Kwa-Zulu Natal province. The theme of the AIDS Conference was "Breaking the Silence." In the spirit of this metaphor, the Community Indaba pre-conference session on Transgenders and Sexual Health, which I facilitated, was an important opportunity for the global transgender community to begin to find a voice to speak out about all the transgender individuals who die in silence from HIV/AIDS, die in silence because of barriers to health care and education, and die in silence from social and psychological pressures to renounce the legitimate expression of their gender identity.

At the Indaba, one of the panelists was a 40-year-old transsexual who is also HIV-positive. Jacqueline described how Brazilian STD prevention campaigns have been targeted towards sex workers for many years; for this reason, many transgender sexual practices have been recognized in current HIV/AIDS prevention campaigns produced by the government and community organizations. However, there is little public understanding of the trans phenomenon–even within the gay community. The Brazilian government has adopted a very limited acceptance of trans people. Sex reassignment surgery is provided free by the government, but only on the limited basis of engaging in a scientific study of transsexuality; consequently, there is a long waiting list. However, Brazilian law does not permit a name or sex change on any official identification documents, even after a person undergoes reassignment surgery.

Another Indaba panelist was Khartini, a transsexual from Malaysia and a senior manager with their Pink Triangle Gay/Lesbian/Bisexual/Transgender (GLBT) health and counseling organization. She recently conducted the first ever survey of attitudes and knowledge about HIV/AIDS among Malaysian transsexuals. As she described her own personal experience, she finds general public acceptance of transgender people in the Malaysian population, but very strong condemnation among segments of their Muslim religious community. After her talk, a member of the audience described a very different, and positive, degree of acceptance among the Muslim religious community in Turkey.

After the Indaba, I met Peter, a young trans person from Zimbabwe, who reported that trans individuals are regularly put in jail and "become property of the government." Most trans hide in isolation because of the harsh punishment if they are found out. They are called Chingetanai, a Zimbabwean word which translates as "queens." Zimbabwe also suffers from economic and political isolation, making it difficult for "outsiders" to reach those people in need.

*The author at the 13th International Aids Conference.*

I am a proud African American transgender sister who is advocating for the rights of transgender people. It is ironic that the devastation of HIV/AIDS, and the world wide response to this catastrophe, has not only shaped my life but also provided the occasion for me to travel to my "motherland," the continent of my origin. My interest in the personal and social consequences of the African slave trade colored my visit with feelings of joy and inspiration at standing on the soil where my ancestors may have stood, feelings of great sadness at the historical disruptions of slavery and apartheid, and feelings of hope for the future after meeting African sisters and brothers of all ethnicities and cultural backgrounds and observing their great spirit and determination. I am personally committed to strengthening the international contacts I made during this journey.

*Lorraine Sade-Baskerville is founder and executive director of transGenesis, in Chicago. For more information, contact transgenesis@mailcity.com or call (800) 805–4052.*

# Douching is bad for you

*by Laura Jones*

For a lot of us, douching (rinsing out the vagina with water or a special solution) is a regular part of our lives as women. We may douche after our menstrual period, before or after sexual intercourse, or when we have a vaginal infection or that infamous "not-so-fresh" feeling. If we grew up seeing the women in our family use douches, we may have started using them too when we first began our periods. Many of us have heard that women need to douche, that douching is necessary to keep ourselves clean and smelling nice. But douching disrupts our body's natural protective cleansing system and rinses away the bacteria and yeast that are always present in our vaginas. The resulting irritation can make it easier for us to get STDs, bacterial and yeast infections, and HIV infection. Women with HIV are already at greater risk for gyne problems; douching can complicate the vaginal infections common to women living with HIV/AIDS, possibly leading to serious health problems or an increase in viral load. Douching can also rinse away the vaginal secretions that can give us information about our overall health, especially where our hormonal cycles are concerned. For women who have HIV, this can mean losing out on clues which may be helpful in determining how HIV disease and/or medications are affecting their immune system.

Since many women associate douching with cleanliness and good hygiene, it may come as a surprise to learn that douching can actually be dangerous. But the truth is, we're not dirty, and our vaginas can take care of themselves. The best thing to do for our health is to leave our vaginas alone and let our natural system work. There's supposed to be stuff in there–left to their own devices, they keep each other from overgrowing and promote healthy vaginal pH balance (strong enough for a man, but made by and for a woman!). And there's supposed to be stuff coming out of us, too–different stuff throughout our menstrual cycle. In fact, vaginal secretions can actually help us know when we're in good health, if we know what to look for.

**Douching on top of vaginal dryness is doubly dangerous for women of all ages and HIV status!**

### The dangers of douching

The dangers of douching are threefold. First of all, douching can cause irritation and inflammation of vaginal tissues, which make it easier for STDs and HIV to set up shop in our bodies. Secondly, douching can actually cause an infection by disrupting the natural balance of bacteria and yeast in the vagina. Infections lead to an immune response, which for women with HIV could in turn lead to increased viral replication. Women who have irregular cycles because of hormonal changes or medications may also find that they experience more vaginal dryness, which can also lead to irritation, tears, and an increased risk of STDs, HIV, or vaginal infection. Douching on top of vaginal dryness is doubly dangerous for women of all ages and HIV status! So if your vagina feels dry or intercourse is uncomfortable, throw douches out the window and pile on the water-based lubricants–they help keep you safer, and they're more fun!

Thirdly, douching can complicate an existing infection, perhaps even to the point of serious health risk. If you notice an unusual vaginal discharge, do NOT douche! The discharge may be a sign that your vagina is trying to re-balance itself, and washing it away could slow down your body's healing process. If the discharge is caused by an infection, douching could push the germs causing the infection up into the cervix or uterus, increasing the chance of PID (pelvic inflammatory disease, a serious infection of the uterus, fallopian tubes, and/or ovaries). Women with immune systems weakened by HIV/AIDS are at special risk for developing PID, which may be more difficult to treat and more likely to cause long-term damage in HIV positive women than in women without HIV. If you think you might have a vaginal infection–especially if you have low abdominal pain, pain with intercourse, or abdominal pain with fever and chills–go to a doctor or clinic to have your symptoms properly diagnosed and treated.

But if a woman's been douching since she started menstruating, she may not be familiar with her normal secretions. So where do we start? How do we know what's healthy, and what's not?

# HIV rights for teens

*by Justin Hayford,*
*AIDS Legal Council of Chicago*

It's difficult enough for teenagers to get accurate, comprehensive information about safe sex. Every time I peruse a pamphlet geared toward educating young adults about their sexual health, I'm convinced that public health officials won't be happy until everyone under the age of 20 is completely terrified or ignorant of sex.

So I can only imagine the difficulties teenagers face trying to learn the facts about their legal rights, especially once HIV enters the picture. Unlike a discussion about sexuality, which can be cloaked in comforting metaphors to minimize the embarrassment to adults who can't imagine teenagers with fully functioning genitalia, an explanation of the law must be frank and to the point. So let me get started answering some of the more important legal questions which may be in the forefront of many teenagers' minds.

**Do I need permission from my parents or guardians to get tested for HIV?**

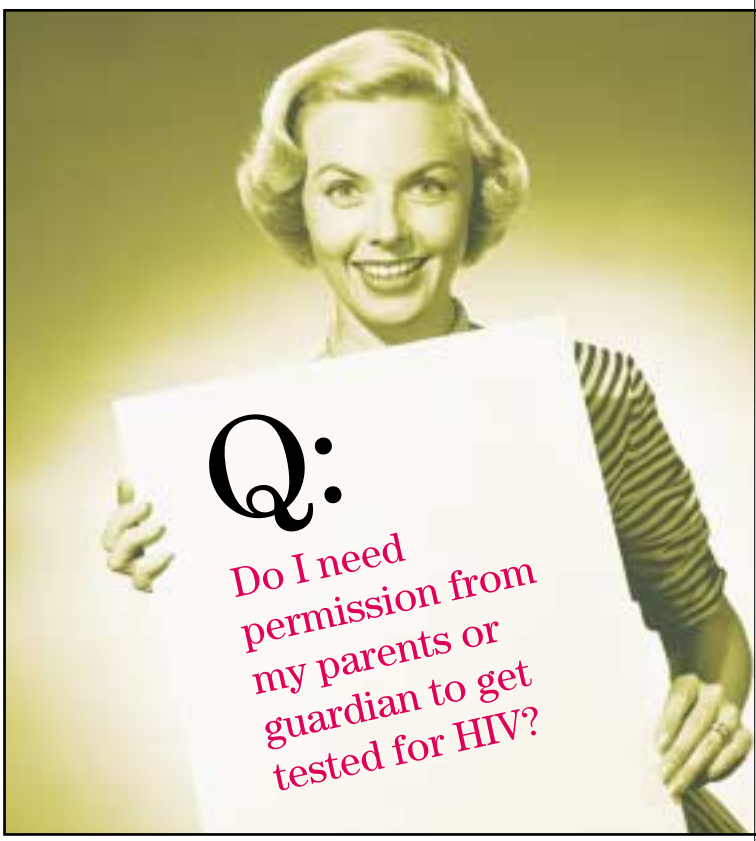
No. If you are 12 years of age or older, you don't need anyone's permission to get an HIV test, or to get tested or treated for any sexually transmitted disease. So if you go to get an HIV test and the doctor tells you that you need your parents' permission, that doctor is wrong.

Of course, getting an HIV test can be a frightening experience. It takes a lot of courage to prepare yourself in case the test comes back positive. It's often a good idea to find a responsible adult to help you through the process, whether it's a parent, teacher, minister or friend.

**Do I have to give my name to get an HIV test?**

No. Illinois law says that every person has the right to an anonymous HIV test. You can get an anonymous test at most public health clinics. [Check with the AIDS legal council nearest you for the laws in your state.]

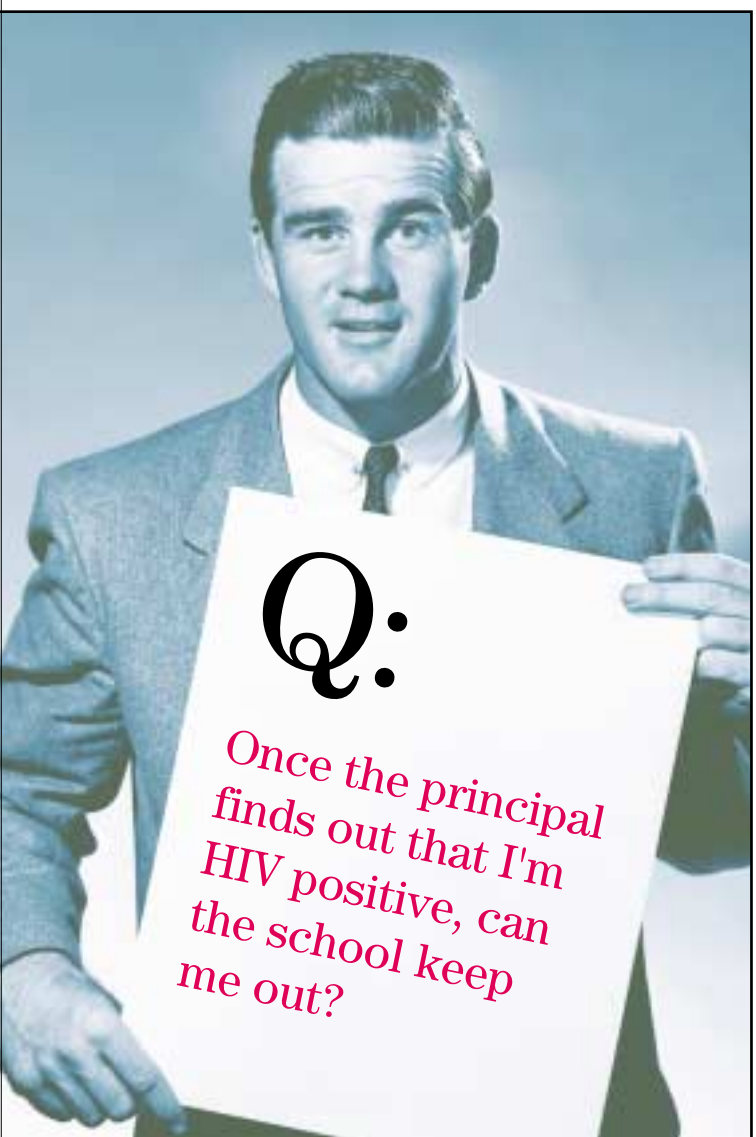
However, if you go to your regular doctor for an HIV test, the law does not require him to do it anonymously, even if you ask him to. So if anonymity is important to you, make sure that you ask about it before the doctor draws your blood. If the doctor says he won't do the test anonymously, you have the right to stop the test from continuing, even if your blood has already been drawn.




**If I test HIV positive, do my parents or guardians have to be told?**

Usually. If you are under 18 and you test HIV positive, the Illinois public health code says that the health care worker who gave you your test result must first encourage you to tell your parents or guardian. If a reasonable amount of time passes and the health care worker has reason to believe you have not informed your parents or guardian of your HIV status, then the health care worker must make an effort to tell them.

However, if the health care worker believes that it is not in your best interest to tell your parents or guardian that you are HIV positive, then he or she must not do so. For example, some young adults have been abused or kicked out of their homes once their parents discovered they are HIV positive. If you believe your parents or guardian will do something like this to you if you test positive, be sure to tell the person taking your HIV test.




**If I am a student and I test HIV positive, will my school be informed?**

Yes–or at least the law says that your school is supposed to be informed. According to Illinois law, whenever a student aged 3 to 21 tests HIV positive, the department of public health must notify the principal of the school that student attends. The principal must then inform the superintendent. These are the only two people who must be given your name. And in case you're wondering, this is a stupid, pointless, nonsensical law.

This stupid, pointless, nonsensical law goes on to say that the principal may inform your school nurse, your classroom teachers and those people who are required to decide placement or educational programs for you–so long as those people have a need to know. If you can figure out why your algebra teacher or your music teacher would ever need to know your HIV status, let me know, because I'm still scratching my head.

It's important to realize that you don't have to inform the school about your HIV status. Neither do your parents.

It's also important to realize that you do not have to inform any of your fellow students about your HIV status.

**Once the principal finds out that I'm HIV positive, can the school keep me out?**

No. You have just as much right to be in school as any other student. The only time the school could temporarily keep you out would be if you pose a "direct threat" of infecting other students. It's very unlikely that any HIV positive student would ever pose a direct threat, since HIV is not spread through casual contact.

**If I test HIV positive, does my doctor have to tell my employer?**

Absolutely not. Most people who test HIV positive don't want their employer to know, because they worry that their employer will discriminate against them. Your doctor has no right to tell your employer about your HIV status unless you say it's all right. And you don't have to tell your employer, either.

**If I test HIV positive, do I have to tell anyone I have sex with?**

Yes. Illinois law says that if you engage in "intimate contact"–which means anything that might transmit HIV–without first disclosing your status, then you are breaking the law. You don't have to actually infect someone to break this law. Just putting someone at risk is enough.

As you can probably tell, this law is extremely broad. To protect yourself legally, the AIDS Legal Council of Chicago recommends you disclose your HIV status before engaging in any kind of sexual activity.

# Salvage conference highlights

*by Enid Vázquez*

The 3rd International Workshop on Salvage Therapy for HIV Infection was held in Chicago in April. It's when you hit that third group of drugs that you're considered to be on "salvage" therapy. (The second combination of meds is being called the "second-line regimen.") Following are highlights from the conference.

### LAC improves neuropathy

Let's start with side effects–the reason many regimens fail in the first place. A tiny study of four people taking 1,500 mg twice a day of L-acetyl carnitine (or LAC, not to be confused with regular carnitine supplements) found it improved their peripheral neuropathy. Patients reported relief in symptoms of numbness, tingling and pain in the hands and feet caused by this common HIV condition. (The symptoms don't sound like much, but neuropathy tends to be extremely painful and permanently disabling.) The self-reported improvements were confirmed by laboratory testing. One person was even able to stop taking narcotic painkillers after several months on LAC (the average time it took for people to see improvements). The only side effect noted was mild diarrhea. Dr. Michael Youle and colleagues from the Royal Free Center for HIV Medicine in London conducted this trial to follow up on another small study finding neuropathy improvement with LAC. There are now about 60 people in the clinic taking the drug.

**One person was even able to stop taking narcotic painkillers after several months on LAC…**

### See an HIV specialist

Two reports confirmed earlier findings that the more HIV patients doctors have, the more experience those doctors have, and the better their patients do. HIV is a complicated disease that's best not left to amateurs.

### The Norvir boost

The odious little drug (okay, lots of people take it without trouble, but it's infamous for nausea, diarrhea and regurgitation) looks pretty good in small amounts for boosting the levels of other protease inhibitors. The conference organizing panel ended up deciding they want to see more data before determining Norvir's usefulness for this job. Naturally, since doctors like to be careful. Because low-dose Norvir is getting so popular, even observational databases would be helpful, they said.

What they saw here was that 800 mg of Crixivan boosted by 200 mg of Norvir–both given twice a day–resulted in half the people on this salvage regimen measuring undetectable (using 400 copies viral load) at 12 weeks. The 41 men had previously taken an average of three protease inhibitors and on average had gone through six regimens. Their median starting baseline viral load was 30,015 and median T-cells was 258. The results are from a retrospective chart review and not as scientifically strong as would be found in a controlled clinical trial. Also, the number of participants is small and the results short-term (48 weeks is ideal). There were two drop-outs, one due to hair loss (Crixivan, undoubtedly) and one to nausea/vomiting (Mr. Odious, himself, undoubtedly). Good news is there are no food restrictions as there generally are with Crixivan alone, but you still need to drink lots and lots of water to avoid painful kidney stones.

Norvir also helps people manage to take Agenerase protease inhibitor with Sustiva, a non-nuke. Otherwise, the two drugs shouldn't be taken together because Agenerase levels are greatly lowered. Jean-Louis Vilde and colleagues, from Paris, prescribed Agenerase at 450 mg and Norvir at 100 mg, both twice daily, with Sustiva at its standard dose of 600 mg once a day (three capsules). The standard dosing of Agenerase horse pills (they may be soft-gelatin capsules, but that doesn't help much) is 1,200 mg twice daily. Viral load results were good in the seven people taking the five-drug regimen (including two nucleoside analogs, such as AZT).

### TDM

Therapeutic drug monitoring (TDM) is expected to become the next big test for HIV. It measures your blood levels of different drugs. However, there are lots of complications that need to be figured out. It is also still experimental for HIV (but used in other diseases).

According to HIVandHepatitis.com, Dr. Richard Hoetelmans from Slotervaart Hospital in Amsterdam made the following points during an oral presenation on TDM: there is good predictability between protease inhibitor blood levels and undetectable viral load for salvage patients, but not for people taking meds for the first time (however, he expects that to change so that you can predict success in this latter group, as well); it's the opposite for the non-nukes–you can predict success for the so-called "treatment naive" group (the first-timers), but not for the non-nuke experienced; and there is no association at all for the nukes (the AZT class of drugs).

# Give us morality or give us death

*by Jim Pickett*

HIV is being spread by HIV positive people.

Admittedly, this is no news flash, but it seems as though we forget this very basic fact regarding this very infectious disease. It takes two to have sex, it takes one to pass along the lovely and enchanting virus that causes AIDS. Of course, before you start to screeching, it takes two to be responsible and safe during sexual activity, it takes two to make smart decisions, or dumb ones.

But it only takes one to infect. *It only takes one.*

We all need to take ownership of safe sex. It is, or should be, of paramount concern to all of us regardless of serostatus. But, still, the fact remains, that two negatives cannot infect the other. A positive must be in the equation.

**…being moral doesn't mean being a Sex Nazi or a Good-Time Gestapo.**

Sadly, HIV prevention work has sorely overlooked the targeting of positives, for a couple of reasons. One being that, well, once you're positive, there ain't no more prevention happening for you, my dear, and two, the whole issue of stigmatization, demonization, and blaming that might and probably will happen. Well, screw stigma! Target me! Target me and every other positive person on earth–it's the only way we'll contain this disease, if not end it. I'm tough, I can take it. And ya know, it's not about blame, it's about practicality, it's about facts, however cold and hard they may be. Remember, there is no cure. Remember, the treatments are often worse than the disease itself. Remember, it takes a positive person to infect–it will take a positive person, it will take positive people, to stop infecting. Stop neglecting us.

The Centers for Disease Control and Prevention estimate that close to 900,000 people in the U.S. are HIV positive, and that approximately one-third of that number, 300,000 or so, do not know their status. Mildly put, that's highly problematic. Everybody needs to get their ass in for testing–for their own health and for the health of others. Studies are proving that people who know their status have more responsible, more safe sex. That means less infections.

What really disturbs me, however, are the people who do know they're positive and continue to have unsafe sex. Yes, it takes two. But, again, it takes only one to infect. We justify our behavior, saying, "Well, he didn't want to use a condom, he must be poz too." We say, "Well, if he's so stupid, if he's so foolish, let him get it, and let me get mine." We say, "Well, things were moving too fast, and before we knew it…" I am talking about gay men, for that is what I am and that is what I know, but I suspect these rationalizations and excuses cut across all sexual boundaries.

Where is our compassion, our human compassion for another living being? We would not knowingly run over someone with our car, why would we knowingly participate in sex that would put another person, another living being, at risk for a harrowing, deadly (and totally preventable) disease? There are so many reasons. We need to examine them, closely, and we need to start a dialogue, many dialogues, and keep them going *ad nauseum.*

This brings me to those two nasty words so many of us are afraid of, and indeed, loathe–morals and ethics. We need to reclaim them from the right-wing horror shows that have bastardized them and made them these big, bad bugaboos. Morals and ethics need not be about hate and judgment, for they are simply about the distinction between right and wrong, about objectively defined principles regarding human conduct–about doing the right thing, about treating another as you would have them treat you, about being nice to each other in coffee shops, and in the bushes.

Hey, being moral doesn't mean being a Sex Nazi or a Good-Time Gestapo. I can have loads of anonymous sex in bathhouses and bushes and truck stops, tons of sweaty, hot, delightful, animal, grunting, heaving, lusty sex, with complete and total strangers, and do so morally and ethically. Yes, I can. How? *By protecting the warm body I am enjoying. By protecting the warm body that is mine.* I do that by insisting on safer sex. If the person does not want to go along, sorry, no hot sex in the city tonight. But ya know what? It's the right thing to do, the moral, ethical thing to do. What is immoral is the callous disrespect of another.

A friend, a gay PWA (person with AIDS) who has worked in prevention for many years in California, says, "Yeah, but fact is that changing community norms happens slowly, over time. Imagine how difficult it would be to reclaim something as tainted as the concepts of 'moral' or 'ethical.' As soon as someone hears it, their first thought is 'judgment' and then they shut down."

Yeah, but…sounds like a battle I am willing to fight.

# Mbeki fails to break the silence

*by Charles E. Clifton*

*Charles Clifton on Robben Island, where Nelson Mandela was imprisoned for 27 years. Photo by Enid Vázquez*

In Durban, South Africa, where the 2000 International AIDS Conference convened, the gap between the rich and poor, the haves and have nots was tragically exposed. The HIV epidemic in South Africa is one of the fastest growing in the world.

- Between 25–40% of all pregnant women attending public health clinics in 1998 and 1999 were HIV positive.
- There are approximately 4.2 million South Africans living with HIV today. One in five adults (20%) is HIV positive.
- UNAIDS estimates that blacks may become the minority in South Africa because of AIDS. If the HIV infection rate continues as it is now, the agency also estimates that more than half of all the 15-year-old boys in the country today will die because of AIDS by the time they're 40.

The theme of the conference was "Break the Silence" on HIV/AIDS, but this conference may eventually be remembered for breaking the silence on the global inequities surrounding treatment and care for all people living with HIV and AIDS.

However, this highly anticipated conference was burdened recently by controversy, from the fallout accompanying President Thabo Mbeki's dabbling in medical science and on the internet. Mbeki has been harshly criticized for using the scarce resources his country can allocate to HIV research to rehash questions and theories surrounding HIV long ago dismissed in accredited scientific communities. In the name of Africans seeking solutions to African questions, Mbeki asks, "Does HIV cause AIDS? Is AZT an effective treatment in preventing mother to child transmission of HIV? Is the Elisa test reliable in detecting HIV?" The government's special panel of international experts included the highly respected Helene Gayle, M.D., director of the CDC's National Center for HIV, STD and TB Prevention, as well as discredited "dissident" American scientist Peter Duesberg, whose denial of the link between HIV/AIDS was long ago dismissed. The contradictions in Mbeki's statements and actions are apparent. As one South African reporter wrote, "Why invite discredited international experts to help find an 'African solution'? How does the insistence that 'we won't be dictated to by outsiders' square with the inclusion of foreign nationals prominent only for their own outsiderhood within internationally reputable HIV/AIDS medical science?"

Instead, President Mbeki failed to break the silence around HIV/AIDS in South African government policies in his opening ceremony address to the conference. Mbeki effectively dashed all hopes that he had reconsidered his controversial opinions on the epidemic. In his speech Mbeki not only repeated many of his doubts about the effectiveness of AIDS drugs, but also questioned the effectiveness of the entire meeting. He stated: "Perhaps in thinking that your conference will help us to overcome our problems as Africans, we overestimate what the 13th International AIDS Conference can do." And unfortunately, Mbeki may have actually caused further controversy with his statement to the 10,000 stunned spectators gathered at the stadium, "...it seems to me that we could not blame everything on a single virus."

Responding to building criticism of his recent comments, Mbeki said, "As an African speaking at the conference...I believe we should speak to one another honestly and frankly, with sufficient tolerance to respect everybody's point of view, with sufficient tolerance to allow all voices to be heard." But instead of listening to the words of more than 500 scientists from around the world who painstakingly drew together the

evidence that HIV leads to AIDS, Mbeki and his cabinet took the Durban Declaration as an attack.

To his credit, Mbeki raised critical questions about the disturbing level of ill health and suffering around the world, caused mainly by the "unacceptable disparities in wealth" between developing and developed nations. He stuck closely to the HIV/AIDS and STD strategic plan for South Africa 2000–2005 that states "the underlying causes [of HIV/AIDS] include socio-economic factors such as poverty, migrant labor, commercial sex workers, the low status of women, illiteracy, the lack of former education, stigma and discrimination."

However, his attacks on "a [global] value system based on financial profit and individual material reward" were largely overshadowed by what he did not say. HIV causes AIDS. He also side-stepped the issue of anti-retroviral therapy and the issue of making treatment accessible to millions of pregnant women, saying that HIV drugs may be potentially more toxic than beneficial. But studies around the world, including South Africa, show that the drugs are safe and well-tolerated in pregnant women and their newborns. At the conference, South African doctors, researchers and people living with HIV promoted the safety and efficacy of AZT and other drugs for preventing transmission, and you could hear the anguish and outrage in their voices over the president's lack of commitment and the need to change state policy.

This conference, in this place and at this time, provided the people and President Thabo Mbeki of the Republic of South Africa a historic opportunity to showcase the result of six years of freedom and democracy, and the reality of black and white working together to build a future, but most importantly the chance to see, feel and hear how the country would effectively cope with HIV/AIDS without the discrimination, prejudice and stigma that has plagued the United States. This conference gave President Mbeki a forum to raise new and necessary questions associated with the inequalities of making HIV medicines and treatments available to all people, regardless of class, race, gender, sexuality, religious affiliation–and most importantly ability to afford the astronomical cost associated with HIV drugs. This conference provided Mbeki a podium from which to challenge world leaders, governments, pharmaceutical companies, financiers, and world health organizations on their humanitarian rhetoric and the politics of AIDS.

Mbeki failed to break those silences and many others. He failed to end the silence on the global mismanagement and inequitable distribution of medicines and treatment options available to all poor people and particularly to the millions of people of color living with HIV.

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