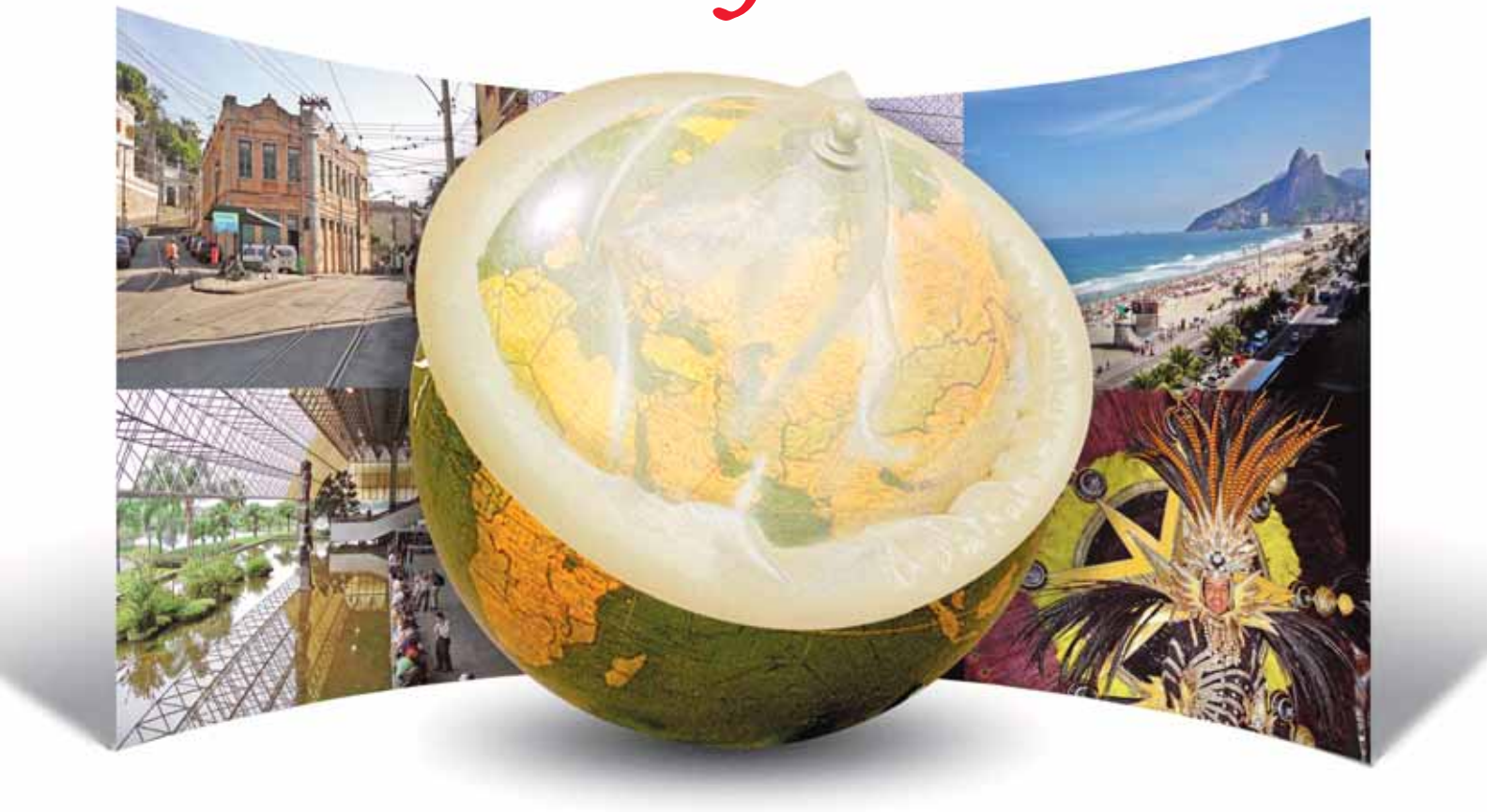
September / October 2005

Positively Aware

The Journal of Test Positive Aware Network

2005 IAS Conference Update From *Rio de Janeiro*



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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

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Departments

Photo © Jeff Berry

Articles

IAS 2005

Distribution of *Positively Aware* is supported in part through grants from GlaxoSmithKline and Abbott Laboratories.

Test Positive Aware Network (TPAN) presents

The 5th Annual Women Living Conference

October 22, 2005

at the
Ramada Inn Lake Shore

The goal for this conference is to gather leaders, HIV positive women, support networks and citizens within the HIV/AIDS prevention/care community to support and share information that is vital for any women living with, caring for or concerned about HIV and AIDS among women.

The program schedule includes:

- Workshops
- Prevention Updates
- Wellness Forums
- Resource Fair
- Networking Opportunities

Introducing the "Head-to-Toe" Fashion Show to recognize women living with HIV/AIDS by featuring significant life achievements that demonstrate internal and external beauty. A showcase of success stories and accomplishments will be featured as a collaborative beauty team performs full hair, make-up and clothing makeovers.

For information on attending, participation, or nominating a candidate for the "Head-to-Toe" fashion show please contact Alicia Ozier or Barb Marcotte at 773-989-9400.

These events are produced by

test positive aware NETWORK

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Test Positive Aware Network (TPAN) presents

MANALIVE '05

3rd Annual Gay Men's Health Summit

November 5, 2005

at the
Hyatt Regency Chicago
On the Riverwalk

The summit will provide a shame free space for gay men of all backgrounds featuring a keynote luncheon and 15 interactive workshops including topics on Gay Men's Health, HIV/AIDS, Alternative and Holistic Health, Nutrition and Exercise, Spirituality, Relationships and Dating.

Saturday, November 5, 9 am-4:30 pm

Featuring:

- Ron Stall, Ph.D University of Pittsburgh-Keynote Luncheon Speaker
- Resource Room with information from community based organizations
- Closing reception

Registration is free.

For more information and to RSVP

call 773-989-9400

The Power of Imagination

Imagine there's no countries
It isn't hard to do
Nothing to kill or die for
And no religion too
Imagine all the people
Living life in peace...

You may say I'm a dreamer
But I'm not the only one
I hope someday you'll join us
And the world will be as one

— John Lennon

I remember clearly that December day back in 1980 when John Lennon was killed outside his Manhattan apartment. I was a D.J. at the time. That evening, I opened the club with Lennon's song, Imagine. As I gazed at the record slowly spinning around on the turntable, I wondered silently to myself how something so tragic and senseless could be allowed to happen.

Now over 25 years later, tragedy and senseless acts of violence seem to be a regular, daily occurrence. We have become numb to the numbers, deaf to the death and desperation that are sweeping a continent and a planet. "Be a virus, see the world," is HIV's new slogan.

So last month I packed my bags and went to Rio de Janeiro, Brazil. Not to escape and get away from it all, although the thought was tempting. Instead, I went there to cover the 3rd International AIDS Society Conference on HIV Treatment and Pathogenesis.

I was truly honored to meet so many dedicated researchers, activists and workers who are on the front-lines of this epidemic, working tirelessly, day in and day out, who strongly believe in what they are doing, and are making a difference. Their intelligence and insight constantly blows me away, while their compassion and humor simultaneously move me to laughter and tears.

The entire experience over this last year, since Charles Clifton, the former editor of this publication, passed away has opened my eyes to a brave, new world of which I never aspired to be a part, yet leaves me humble and grateful, and yes—even hopeful.

Years ago, when I first started working with this magazine, I hate to admit I had some doubts as to whether readers were even that interested in HIV/AIDS outside of the U.S. It seemed to me at the time so isolated and distant, some nebulous virus that even had a different name—HIV-2—with routes of transmission and cultural issues that seemed so disparate and distinct from those in the U.S., that it was at times difficult for me to even make the connection.

Besides, I had enough problems of my own to worry about—thrush, kidney stones, diarrhea, shingles, falling T-cells, increasing viral load, eventually lipodystrophy. My health care costs were going through the roof.

But over time I began to realize how extremely lucky I am to live in a country where I can even afford health insurance, let alone receive the care, treatment and support necessary to keep this virus under control.

So I urge each and every one of you to count your blessings, take the next step, and to broaden your HIV horizons. Whether it be through volunteering, or joining a clinical study, or donating to an AIDS charity, or becoming involved with the AIDS Treatment Activist's Coalition (www.atac-usa.org), or the Campaign to end AIDS in Washington, DC in October (www.C2EA.org), or taking part in a support group—or any of the myriad other ways in which you can begin to effect change—do not hesitate, time's a-wasting.

The epidemic here in the U.S. is inevitably, inextricably linked to the millions of AIDS orphans in Africa. We all share a common denominator. We all suffer, and we all seek healing.

The doctors, activists, social workers, scientists, pharmaceutical representatives, orphans, mothers, positives, negatives, blacks, whites—we are all connected. And if we speak up now, our collective voice together will resonate so loudly, so clearly, that we cannot and will not be ignored. We must take the lead, and show the world that we value all life and all cultures. And the only way to show our fellow man and woman is to lead by example.

The World Health Organization's 3x5 initiative, to get 3 million HIV-infected people worldwide on treatment by 2005, was an incredibly lofty goal. And while that goal will not quite be reached, we have begun to see incredible change occurring, with one million people now on treatment. We must continue to advocate for universal access to treatment, care and prevention. Generic antiretroviral drugs must be manufactured and made affordable so that optimal treatment regimens are there for all who need them.

So begin to imagine a world in which we all have access to the most effective HIV drugs, medical care, counseling, testing and prevention, education, food, shelter and jobs. Imagine a world where babies have their parents into adulthood, and no longer weep. A world filled with hope and promise. And then imagine yourself helping to make this into a reality. You can do it, you must—there is no better legacy you could leave behind.

Take care of yourself, and each other,

Jeff Berry
Editor
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Photo © Russell McGonagle

test positive aware NETWORK

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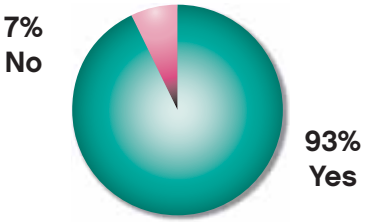
July/August PA Online Poll Results

Would you support a needle exchange program in your neighborhood?



Comment:

We had an NEP for 8 years that gave out over 100,000 syringes and kits the last year we were in operation. It was a lot like Chicago Recovery Alliance, but smaller. The political climate has not been so friendly here in Nashville, and is not so friendly at this time. However, over the last 3 months or so, another organization has begun to give out syringes—"any positive change".

September/October PA Online Poll:

Should the U.S. government take a more active leadership role in the care, prevention and treatment of HIV/AIDS in developing countries?

Give your answer at www.tpan.com

Peripheral neuropathy

I have had HIV for 10 years. I've had peripheral neuropathy for eight years. The only thing I could use for my PN was lidocaine jelly. My feet would get real hot and start burning real bad. My calves would have muscle spasms and cramping. My prison doctor took a chance and let me order something from a pharmacy at home, Maximum Strength Hawaiian Tropic Cool Aloe I.C.E. Burn Relief Gel with lidocaine. It has an instant cooling effect (I.C.E.) which is wonderful. Plus the lidocaine for pain and vitamins A and E, plumeria, mango, guava, papaya, aloe, passion fruit, taro and kukui nut. I don't know what the other extracts do, but the "cool aloe I.C.E." is perfect for relieving my PN. I hope you mention this to your readers.

Name withheld by request, Alto, GA

Guarded

I think Mr. Jones touched upon something when he wrote, "I know several serodiscordant couples in their thirties and forties between whom no transmission has occurred, and some of the couples have been together for over 10, 15, or 20 years. Serodiscordant couples are almost unheard of in the under-30 crowd."

I'm at that weird stage where I hang out with people in their 20s, 30s, 40s and older and I don't know if it's age as much as ignorance in all generations. People have forgotten the facts and rely on the worst-case scenarios like "we can't share drinking glasses."

This first-person article touched me as a straight woman in her early 30s. I was involved with a man who was HIV-positive this year and have had people tell me I'm also positive. It's not that they assume I'm positive, too. They tell me I'm positive. One man was in his 40s, another was a woman in her 30s.

I wasn't hurt because I've seen ignorance in many forms in my time on this planet but it does scare me that people can be so ignorant.

There seems to be a public awareness "kick" again and I hope it dispels some ignorance. Alas, I'm not hopeful.

Stephanie Flemin, Toronto, Ontario

The world is full of cruel people and some of them are not even aware of the pain they instill in others. Imagine one of those people who wrote about people being diseased and unclean—what if tomorrow that same person learns that he is HIV positive—he will be looking at the very same people he called diseased for support and help through the suffering he will find himself in.

What a wonderful thing it would be if all people would be considerate and careful when they open their mouths or their thoughts to the world and be able to put themselves in the shoes of those who are suffering and in need of help/support in any way possible. People who are suffering in any way need the healthy and the beautiful looking into their lives to "normalize" their existence, because today, when you are living with HIV/AIDS, people look at you as if you are abnormal, thus I use the word "normalize."

One important aspect in the lives of the positives is *family*. Not just any family but one that is supportive, open-minded, loving and understanding. People who have such a supportive base tend to live longer than those who do not have it. Now imagine yourself with a family that rejected you because of your HIV-positive status and all of your friends ignoring you also for the same reasons. No wonder people die so fast from this disease. The irony of it all is that the stress of worrying about such selfish people who cannot bring others into their

continued on page 44

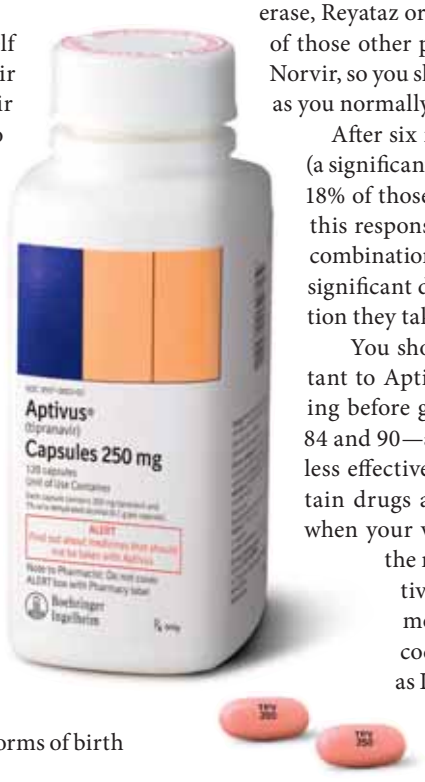
News Briefs

by Enid Vázquez

New HIV drug, Aptivus (tipranavir)

On June 22, the U.S. Food and Drug Administration (FDA) granted accelerated approval of Aptivus (tipranavir), an HIV protease inhibitor. Aptivus created excitement during its development by displaying greater power to cause large drops in viral load in people with drug-resistant virus, compared to people taking other protease inhibitors already on the market.

Unfortunately, it cannot be taken by itself but must be boosted with 200 mg of Norvir (ritonavir), twice a day. This is more Norvir than you take in other boosted regimens, so remember that Norvir has a lot of drug interactions. The Aptivus dose is 500 mg (two 250 mg capsules) and it should be taken with food. It is refrigerated prior to dispensing, and then must be maintained at 77ºF or lower. Like Bactrim and Lexiva, it is a sulfa drug, so watch the sun exposure.



In more than 3 out of 100 people taking Aptivus, the adverse reactions were diarrhea, nausea, fatigue, headache and vomiting. Common lab changes were elevated liver enzymes, cholesterol and triglycerides. Mild to moderate rash was observed in 14% of women and in 8-10% of men. In a drug interaction study in HIV-negative women on birth control, 33% developed rash. Be sure to check with your doctor or pharmacist if you are on oral hormones! Women taking estrogen-based birth control pills or patches should take additional or alternative forms of birth control.

There is a black box warning on the drug label, which basically means be sure to go back to see your doctor for follow-up labs after starting this medicine: "Specifically, Aptivus co-administered with low dose ritonavir has been associated with reports of clinical hepatitis and hepatic decompensation, including some fatalities. Extra vigilance is warranted in patients with chronic hepatitis B or hepatitis C co-infection, as these patients have an increased risk of hepatotoxicity."

Aptivus showed better results in clinical trials when it was taken along with Fuzeon (T-20), the only injectible HIV drug on the market. Fuzeon is still the only drug in a class called fusion inhibitors—these stop HIV from getting into cells. The approval of Aptivus is expected to help sales of Fuzeon, because it's difficult for people with advanced HIV disease to find two new drugs they can take together in a combination, and Fuzeon is one of the newer drugs. Plus it's one that people might hold off on because of its route of administration. Aptivus cannot be taken with Kaletra, Agenerase, Reyataz or Fortovase/Invirase, because it lowers the levels of those other protease inhibitors. (It also lowers the levels of Norvir, so you shouldn't see as many gastrointestinal side effects as you normally would with that drug.)

After six months, Aptivus dropped viral load by one log (a significant amount) in 40% of people taking it. In contrast, 18% of those on other protease inhibitor combinations saw this response. These were people who had been on several combination therapies for HIV, so they're less likely to have significant drops in their viral load no matter what medication they take.

You should find out first if your virus is already resistant to Aptivus. Experts recommend drug resistance testing before going on it. Some resistance mutations (33, 82, 84 and 90—ask your doctor!) that occur may make Aptivus less effective. A treatment history can also help here—certain drugs are associated with certain mutations (mostly when your viral load starts going up while you're still on the medication). Aptivus is expected to be less effective for people with multiple mutations (three or more) (there'll be a letter in front and back of the codon number on your resistance test results, such as L82T). (These codons—also called amino acids—are known as PRAMS, for protease resistance-associated mutations). There are different letters that can wrap around these codon numbers, and some have shown tipranavir resistance while others don't. It's all still being figured out.

ATAC on new drug Aptivus

From the AIDS Treatment Activists Coalition (ATAC): A steady onslaught of "unreasonable, unacceptable, and unjustified" increases in the price of therapies to treat HIV has caused activists in the U.S. to accuse drugmakers of artificially inflating the market at the expense of people living with HIV/AIDS. As an example, activists point to the recent launch of the new drug Aptivus, a protease inhibitor developed by Boehringer-Ingelheim, which came in

Photo of Enid Vázquez © Russell McGonagle

at the highest price ever for this class of medication—more than $13,000 per year, which does not include the cost of other medications that must be taken in combination with Aptivus.

"We are approaching the point where a year's worth of HIV medications in the U.S. will cost anywhere from $30,000 to $50,000 a year. Every time a new medication is made available, it usually comes in at a new higher price than others in its class," stated Nelson Vergel, a member of the AIDS Treatment Activists Coalition. "The same thing happened with Reyataz, another protease inhibitor made by Bristol-Myers Squibb. It was the first once-daily medication of this kind, and the company priced it at an all-time high, with regular increases since then. It now costs almost $11,000 per year. This behavior is simply unreasonable, unacceptable, and unjustified."

Howard Grossman, MD, Executive Director of the American Academy of HIV Medicine notes, "Many insurance companies have focused on the high price of drugs to treat HIV. Healthcare providers are finding their choices increasingly limited as higher-priced drugs are taken off 'preferred' lists, in some cases raising patient copays from $20 to $75 or more per prescription. Anything that prevents doctors from prescribing the properly-indicated drugs reduces our chance of controlling HIV. High prices are driving this."

"Sadly, Boehringer-Ingelheim failed to realize that the size of the potential Aptivus market is directly tied to patients' access through publicly funded programs, and they just made that market a lot smaller," said Lei Chou, Director of Mobilization at the Community HIV/AIDS Mobilization Project (CHAMP). "State Medicaid Programs will delay coverage of the drug for months, AIDS Drug Assistance Programs will have to place access restrictions or may not cover it at all. This pricing decision will put Aptivus out of reach for the majority of patients who can benefit from it."

ATAC is a national coalition of AIDS activists, many living with HIV/AIDS, working together to end the AIDS epidemic by advancing research on HIV/AIDS. See the entire statement at www.atac-usa.org.

Generics approved by FDA

This past summer, the FDA granted tentative approval to several generic versions of HIV drugs—Sustiva (efavirenz); Viramune (nevirapine); Zerit (d4T, stavudine), Retrovir (AZT, zidovudine) and Combivir, which is made up of two HIV drugs: Retrovir and Epivir (lamivudine). With these approvals, the generics will be legally available for purchase by the President's Emergency Plan for AIDS Relief (PEPFAR). The program's refusal to buy any drugs without a U.S. patent has been controversial. It drives up the price, benefiting pharmaceuticals at the expense of greater drug access.

According to the FDA, "The agency's tentative approval means that although existing patents and/or exclusivity prevent marketing of a particular product in the United States, it meets all of FDA's quality, safety and efficacy standards required for marketing in the United States." Sustiva is a particularly powerful HIV medication that is popular in the U.S., but it cannot be taken by women wishing to conceive, due to its birth defect profile. The use of single-dose nevirapine for the prevention of mother to child transmission of HIV is permitted under PEPFAR. Zerit has long ago lost favor in the United States because of its strong association with facial wasting.

Kaletra now once-a-day …

… but only if you're taking therapy for the first time. U.S. HIV treatment guidelines from the Department of Health and Human Services were updated in July to add once-daily Kaletra for people who are treatment-naïve. This is a dose of six capsules, and has a significantly greater risk of causing diarrhea (16% vs. 5% for the twice-a-day dose in studies). A new formulation of Kaletra coming soon will probably make the once-a-day dose more tolerable. The once-a-day dose is not recommended for people who have already been on therapy, because it has not been studied in this group and because of a drop in the lowest level in the blood (trough). Nor is it recommended for people taking Sustiva, Viramune, Lexiva, or Viracept.

Also, the guidelines now state that the combination of Videx and Viread with a non-nucleoside analog (either Sustiva or Viramune) should not be given to treatment-naïve people.

Positively Aware teams up with IAPAC

Test Positive Aware Network (TPAN), the non-profit HIV service organization that publishes *Positively Aware*, has teamed up with the International Association of Physicians in AIDS Care (IAPAC) to produce educational materials for both people living with the virus and their medical providers. IAPAC, which like TPAN is also based in Chicago, has long published magazines and other materials for clinicians and patients. The partnership gives *Positively Aware* the opportunity to reach more medical providers, and to work with an international organization dedicated to treatment education and expanded drug access.

IAPAC produces numerous patient-related publications on a variety of HIV/AIDS topics such as mental health, metabolics, resistance, and antiretroviral therapy updates. It also produces guides and posters that feature guideline-based information through its Guidelines Regimen Information Program (GRIP).

The agreement covers a variety of activities, such as the inclusion of IAPAC materials into *Positively Aware* and the expanded distribution of *Positively Aware* to all IAPAC members nationwide.

Medicare's New Drug Program Creates Challenges

Part D is Part Drug Coverage, Part Difficult, Part Distressing

by David Munar,
AIDS Foundation of Chicago

A dizzying array of rules, options, and costs await the 41 million Medicare recipients under the new prescription drug program rolling out later next year.

For people with HIV, the program offers both a new opportunity to obtain prescription drug coverage and a maze of pitfalls and barriers that threaten to undermine continuous access to lifesaving medications—the hallmark of high-quality HIV/AIDS care.

Medicare is the nation's healthcare insurance program for retired seniors and disabled workers, which until now has only covered inpatient services (hospitalizations) and, for an additional monthly cost (called a premium), outpatient services. Oddly enough, the basic program has not previously offered prescription drug coverage, creating a serious gap for its millions of beneficiaries. To obtain their medications, many beneficiaries have purchased supplemental private coverage, if they could afford it, or turned to Medicaid (run by their state) if they are extremely low income.

With the 2003 enactment of the Medicare Modernization Act, that landscape is changing. Beginning in October (and through May), Medicare patients will have to choose prescription drug coverage through a complicated new program known officially as "Part D." Helping the estimated 85,000 people with HIV on Medicare navigate the new program and understand their options and obligations will be a monumental task for case managers, benefit counselors, and AIDS service organizations. It's worth noting that only those eligible for Medicare will be affected—essentially people who receive a monthly Social Security Disability Income (SSDI) check and not those who receive only a Social Security Income (SSI) check.

Part derby—history

The legislation that created Part D drew heavily on recommendations from influential pharmaceutical and insurance lobbyists and modeled the program to resemble insurance products sold in the private sector. In fact, the federal government is providing generous subsidies to health insurance companies to make prescription drug plans available across the country. Approved plans, to be announced on October 15, can decide what drugs to cover and how to structure their benefits, within the parameters established by the federal Centers for Medicare and Medicaid Services (CMS). Federal officials have stated publicly that plans will be expected to provide most HIV antiretroviral medications, which is welcome news. How plans differ in terms of extra costs and access to other needed medications will not be known until participating plans are publicly announced.

Most Medicare recipients will have until May 15, 2006 to enroll in Part D and must pick a plan offered in their area. They will have the option to change plans only once a year. Enrolling in Part D is optional, but a penalty (higher premiums) will be assessed on those who enroll after May 15, 2006, unless they already have prescription drug coverage "of equal or greater value."

Part daunting—out-of-pocket costs

An important way to measure the value of Part D for each beneficiary will be to assess both what the program will offer in terms of benefits and what it will cost. Congress devised a peculiar cost structure for beneficiaries. Most people will have to pay a monthly premium estimated at $37 a month (the cost will rise each year); the first $250 of their drug costs; 25% of their drug costs between $250 and $2,250; 100% of their drug costs between $2,250 and $5,100 (this is the so-called "donut hole"); and then 5% of drug costs beyond $5,100 for a given year. In other words, a beneficiary with high drug costs (like beneficiaries with HIV) will have to pay $3,600 out-of-pocket (not counting monthly premiums) before

Part D picks up 95% of drug costs. The cost calculator re-sets each year.

What does this all mean for the average person with HIV? The individual cost burden is higher for people with lower incomes and/or high drug costs.

Lisa

Consider, for example, Lisa's situation. Lisa is a retired nurse's assistant whose annual income from SSDI and investments is $28,716 ($2,393 per month). Her drug costs for Trizivir, Kaletra, and a cholesterol lowering medication are around $15,000 per year ($1,250 per month). Her annual out-of-pocket costs (including monthly premiums) would be approximately $4,539 (16% of her gross income). Out-of-pocket costs would rise to $1,287 in months three and four during the "donut hole" period (more than half her monthly gross income). She would pay $99.50 in months 6 through 12.

The financial burden becomes even steeper on individuals with lower incomes. If Lisa's income were $15,000 a year ($1,250 per month) and her drug costs remained the same, she would pay more than she receives in months three and four. The annual cost of the program would be 30% of her gross income.

Part deal—the low-income subsidy

Some very low-income beneficiaries will receive what is being billed as "extra help" so that out-of-pocket costs are lower. Beneficiaries with incomes below 150% of the federal poverty level ($14,355 for a single individual and $19,245 for couples in 2005) and limited assets (such as investments or savings) can qualify for the Low-Income Subsidy (LIS). People who qualify for LIS pay lower premiums, $1 to $5 per prescription, or none at all based on their income, and become exempt from the "donut hole."

People who are dually eligible for Medicaid and Medicare will be automatically enrolled in LIS. This includes people who receive Medicaid assistance to maximize Medicare benefits. All others must complete an LIS application form and meet eligibility criteria to receive the extra help. People who think they may qualify, and who are not dually eligible, will need to elect Part D, apply for LIS, and select a drug plan to receive Part D coverage.

Part dizzying—true out-of-pocket costs (TrOOP)

The architects of Part D designed the program to require "cost-sharing" so that beneficiaries bear responsibility for covering a portion of their drug costs. Cost-sharing is higher for individuals above 150% of poverty and lower—but not entirely eliminated—for the program's poorest members. For most recipients, cost-sharing is steepest in the donut-hole during which 100% of drug costs are borne by the beneficiary.

> The sum of expenditures needed to reach catastrophic coverage is known as TrOOP: True Out-of-Pocket Costs.

Beneficiaries receive the most generous coverage after surpassing the donut hole. At this level—called catastrophic coverage—the program pays 95% of a recipient's drug costs for the rest of the year.

The sum of expenditures needed to reach catastrophic coverage is known as TrOOP: True Out-of-Pocket Costs. Federal regulations define approved ways beneficiaries can receive assistance with meeting out-of-pocket costs that continue to count toward TrOOP. Beneficiaries may receive other forms of assistance but such expenditures do not count toward TrOOP.

What counts as TrOOP? Fully state-funded "State Pharmaceutical Assistance Programs" can help beneficiaries pay premiums, deductibles, and co-payments (including during the donut hole). All these expenditures count toward TrOOP. Other ways to meet TrOOP include when a family member, private organization (including charitable organizations), or even a Patient Assistance Program pays incurred drug costs.

What does this all mean for the average person with HIV? Beneficiaries need to explore whether their state has an approved assistance program, and if not, whether one can be created (federal regulations limit what states can do if they don't already have a State Pharmaceutical Assistance Program).

For example, Illinois has established a program to help low-income beneficiaries pay Part D premiums, co-payments, some of the deductible, and some medications during the donut hole. These expenditures help beneficiaries reach the catastrophic level where coverage is most generous. These strategies also help the state maximize scarce healthcare dollars and promote better healthcare.

Part dispiriting—ADAP

Many unanswered questions remain about the intersection of state AIDS Drug Assistance Programs (ADAP) and Part D. Earlier this year, CMS rejected calls by AIDS advocates to allow ADAP expenditures to count as TrOOP. While it appears ADAPs will be able to provide assistance to

Medicare beneficiaries, ADAPs will have little incentive to do so as such expenditures virtually guarantee that recipients remain in the donut hole (no drug coverage) for the rest of the year.

Allowing ADAP expenditures to count as TrOOP would have helped already cash-strapped programs further stretch their budgets and provide continuity of care for a highly vulnerable population. It would have also provided a powerful incentive for states to invest in their ADAP with state dollars.

As such, some states (especially those with waiting lists) are moving ahead to remove ADAP recipients who qualify for Part D—a dangerous move for the health of these individuals. Because most people assisted by or waiting for ADAP have incomes below 200% of poverty and high drug costs, their out-of-pocket expenditures will make Part D completely unaffordable.

With remarkable shortsightedness, federal officials indicated recently that they will require enrollment in Part D as a condition to receive ADAP (in states that don't exclude them altogether). This will essentially force a monthly premium upon one class of ADAP recipients and pave the way for new, arduous requirements to further diminish services to this vulnerable population.

In addition to ADAP appropriations advocacy, people with HIV/AIDS and their allies need to urge state officials to preserve ADAP benefits for eligible Medicare recipients, explore coverage for Part D premiums and deductibles, and enlist state support in advocacy to make Part D less onerous.

Part "devil's in the details"

It's not hard to imagine disabled and elderly recipients needing help understanding the program, their options, and how to avert a life-threatening gap in drug coverage. Because of the complexity of the program and the many variables for recipients at different income levels, Medicare recipients are encouraged to consult with a benefits specialist.

Medicare-eligible ADAP recipients and the dual eligible are especially encouraged to carefully plan their enrollment and use of Part D. Dual eligibles will be in a particularly precarious situation at the end of this year when their prescription drug coverage through Medicaid ends by law. They will need to rely solely on Part D for their medication needs.

Thankfully, their out-of-pocket costs will be lower than most Part D recipients and they will have the ability to switch plans at any time—an option not readily available to most recipients. Still, dual eligibles are among the poorest and sickest in the Medicare population and a gap in treatment could prove fatal.

Try the Project Inform Treatment Hotline for more information; call 1–800–822–7422.

Part darwinism

In the best of cases, Part D will evolve into a more comprehensive and less-Byzantine program that provides affordable benefits to retired and disabled workers. But this will happen only if we remain committed and vocal about its shortcomings, and continue to press government officials for real and immediate remedies.

David Ernesto Munar is the AIDS Foundation of Chicago's associate director. *Thanks to Tom Coburn of Health & Disability Advocates for help in preparing this article.*

Resources

FACT Sheet: Medicare and HIV/AIDS. Henry J. Kaiser Family Foundation (October 2004): www.kff.org/hivaids/7171.cfm.

FACT Sheet: Excellent fact sheet from Gay Men's Health Crisis in New York City. Request from Laura Caruso, laurac@gmhc.org. If you have technical questions about Part D that you would like to have answered by the Centers for Medicare and Medicaid Services, she suggests contacting Andrea Weddle at aweddle@idsociety.org. Visit www.taepusa.org/medicare_resources.html for advocacy tools around Medicaid and Medicare.

Policy and Politics: Medicare Prescription Drug Coverage. Article from the Bulletin of Experimental Treatments for AIDS (BETA), Summer 2005: www.sfaf.org/treatment/beta/b57/b57_medicare.pdf.

Tip Sheet: People with Medicare and HIV/AIDS. Centers for Medicare and Medicaid Services, July 2005: http://www.cms.hhs.gov/medicarereform/AIDS.pdf.

Medicare Part D Drug Benefit: What You Need to Know. American Academy of HIV Medicine: http://www.aahivm.org/medicare_drug_benefit_d.html.

The New Medicare Prescription Drug Law: Issues for Dual Eligibles with Disabilities and Serious Conditions. Kaiser Commission on Medicaid and the Uninsured, June 2004: www.kff.org/medicaid/7119.cfm.

Do You Speak Medicare Part D? Definitions of Selected Health Insurance Terminology Under Medicare Part D. Medicare Advocacy Center (July 2005): www.medicareadvocacy.org/AlertPDFs/07.21.05.PartDSpeak.full.pdf.

Taking healthcare around the globe

by Renslow Sherer, MD

photos courtesy of Project HOPE Annual Report

This story, written in Maputo, Mozambique, begins in Chicago at Cook County Hospital and ends in Project HOPE programs worldwide. It's fitting that it be told through Test Positive Aware Network, where so many stories of the terrible toll of the HIV epidemic in Chicago have been told, as have stories of remarkable individual resilience and community action.

I agreed to tell the story partly to present an appeal for support from TPAN readers. Your donation of $10, $100, or $1,000 to Project HOPE—at www.projecthope.org, or at 1–800–544–4673—could change the lives of people living with HIV around the world, like the women in the Xai Xai and Chokwe Districts of Gaza Province in Mozambique whom I've just met. Half of these women are caring for orphans—an average of two per household—and another half are caring for a dying family member…but I'm getting ahead of myself.

From local …

Much has been written about the early days of AIDS in the U.S. and in Chicago, the days before HIV. I write instead to note the lessons that we learned, and that we are still learning around the world. It's particularly for young people at risk of HIV, and for young doctors and nurses who didn't experience this terrible time. They need to hear how it was.

In those dark early days, AIDS was a fearful mystery that first killed gay men in the midst of a powerful silence of denial, even while the cases doubled every six months. AIDS shed equal light on the secrets of the gay community and a powerful homophobia. This was not news to the gay community, but it was a shock to see that the death and dying of gay men only intensified the stigma. It was hard to tell which of the epidemics—AIDS, or AIDS stigma and discrimination—was more painful, and more virulent.

Within a year at Cook County Hospital, from 1982–1983, we saw the early shape of the second wave of the epidemic of Chicago—AIDS in women and children, injection drug users, and increasing proportions of African Americans and Latina/Latinos. The brush of AIDS stigma broadened, and sometimes brought these diverse communities into conflict with one another.

The other lesson was action. Specifically, Gay community action, because no one else was acting, or even cared. And hospital action—at Cook County Hospital, Illinois Masonic Hospital, and the many others—because people with AIDS were suffering and dying. The rapidly escalating crisis demanded a response, and collaboration among responders—and, let the record show, the collaboration in Chicago was better than most cities. Chicago gained a reputation as the city that works among people who watched AIDS. This was no small matter when it came to competing with other cities for Ryan White funding.

It quickly became clear that the community, the city and county health departments, along with the hospitals, and the activists, would have to work together to care for the sick and dying, to prevent new cases through education, to support people living with AIDS and their friends and families, and to advocate for the civil and human rights of those affected and at risk.

These were the lessons: It takes a village to raise a child, and it takes a community to respond to AIDS. Effective AIDS responses are "all of a piece," so to speak. Human rights, stigma reduction, care and treatment, support, education and prevention, and advocacy each depend on the other to gain traction. And each depends on individual and collective action—of community leaders, health care providers, public health leaders, and government—in order to make painstaking, gradual progress in the fight against AIDS and HIV.

I can't think back to those days in Chicago without pausing to wonder, do young Chicagoans know the people who fought these AIDS battles, and what they did? Like John Hammill and Harvey Grossman at the AIDS Project at ACLU?

Or Joan Harris, Bill Young, Marshall Fields, Ron Sable, Marcia Lipitz, Karen Fishman, and others at the AIDS Foundation of Chicago? There are so many others, too many to list, like Tracy Baim at Windy City Times, David Blatt and David Moore at Illinois Masonic Hospital, KT Reddy and Chet Kelly at the Chicago Health Department, Cathey Cristeller at the Chicago Women's AIDS Project, Bill Mannion at Howard Brown Health Center, David Lye at Erie Family Health Center, Dan Bigg at the Chicago Recovery Alliance (needle exchange), Wayne Wiebel and Norman Altman at the University of Illinois School of Public Health, Carol Reese at the AIDS Pastoral Care Network, Nathan Linsk and Barb Schechtman at MATEC (Midwest AIDS Training and Education Center), Tom Tunney at Ann Sather's restaurant, Sam Clark at Meals on Wheels, and the clinical study units (ACTG and ARAC) at County, Rush, St. Joseph, Northwestern, the University of Chicago, and Children's Memorial Hospital. And the most powerful bonds of all were with my many friends, colleagues, and patients at County Hospital, like Ron Sable, Mardge Cohen, Jim Delacerda, Jim Lovette, Rogelio and Isabel Cadena, Edith "Nurse" Jackson, Robert Washington, Paul Hook, Ida Greathouse, Ginny Cohen, Mildred Williamson, Liz Gath, Jack Kowalski, David Siebert, Gigi Nicks, Paul Hook, Caroline Teter, Chuck Sternberg, Ruth Rodriquez, Joe Pulvirenti…the stories of their commitment and service deserve to be heard. Ask an old AIDS dinosaur about these folks sometime; you won't be disappointed.

While we struggled in Chicago and patched together a leaky but credible HIV service system, the virus spread silently in Africa, in Asia, and in most of the developing world—a story we all know too well now. The breathtaking reversal of the epidemic by HAART (highly active anti-retroviral therapy) in 1996 in the U.S. and Europe, dramatized the stark differences between the north and the south. During our period of international negligence and inaction, millions died, and millions more were infected.

Now, two thirds of cases are in sub-Saharan Africa. Half of the 1,800 daily new infections are in women, and half are in young people aged 15–24. And still the epidemic "is running faster than us all," as Peter Piot has said. One quarter of new cases are in Asia, and India now has more cases than any other country in the world. Nearly one million people in the developing world are on ART (anti-retroviral therapy), which is far below the 3 million target set by WHO, but far above recent levels. On the other hand, less than 5% of children with HIV in the world are on ART, which is a repetition of the lower priority placed on children in the U.S. when AIDS began. Women bear an increased risk that is out of their control, as well as the burden of caring for the sick, and for orphans and vulnerable children. Children are increasingly vulnerable, with orphan rates of 10–20% in sub-Saharan Africa, and rates of vulnerability of children exceeding 50% in many communities.

Project HOPE

So two years ago, after 25 years at Cook County Hospital, I left with a lifetime of experiences, lessons, hard knocks and great friends, and I took the job of Director of HIV/STI/TB at Project HOPE. My hope was to take the lessons from Chicago and put them to use in other parts of the world. At the same time, Caroline Teter, my friend and colleague, also came to Project HOPE as my associate.

Why Project HOPE? First, because Project HOPE has trained over 2 million doctors and health workers around the world for the past 47 years. Project HOPE started as a hospital ship that sailed from port to port providing care and training health workers. In 1972 Project HOPE became an international NGO (non-governmental organization) based in Northern Virginia. It currently has 46 programs in 32 countries around the world, and half include an HIV-related service. Project HOPE has superb technical expertise in infectious diseases such as TB and HIV, in pediatric hospitals, in maternal child health, in health systems management, in humanitarian assistance, and in physician education on such topics as cardiovascular disease and diabetes. From sophisticated hospital care to community-based primary care, Project HOPE's leadership in health provider education was a natural fit.

Since joining Project HOPE, Caroline and I have conducted health worker trainings on HIV with regional Project HOPE staff in China, the Western Balkans, Northern Africa, and Honduras. The most fully developed is a model program in Hubei Province, China, in partnership with Dr. Gui Xien of Wuhan University and the Hubei Province Centers for Disease Control. The ability to collaborate with local partners and respond to the invitations of the national health ministries is another Project HOPE trademark. In Wuhan, we used a "training of trainers" model with 20 Chinese "master trainers" with some experience in HIV care. Over the past year with this method we have trained more than 4,000 physicians and health care providers in the hardest hit counties in Hubei Province.

This strategy was dictated by the epidemiology of HIV in China; because of improper plasma donation techniques in Hubei Province in the 1990s, HIV spread in poor farmers in the villages and townships, with a secondary spread to their wives and children. For this reason, doctors and nurses in rural areas most needed training in HIV care, although trainings before 2003 were exclusively conducted in major cities, bypassing those who needed the training most urgently. Our trainings also coincided with the decision by the Minister of Health in Beijing to provide free HIV therapy to all people living with HIV and the arrival of generic nevirapine, zidovudine, didanosine, and stavudine. (Lamivudine has since become available.)

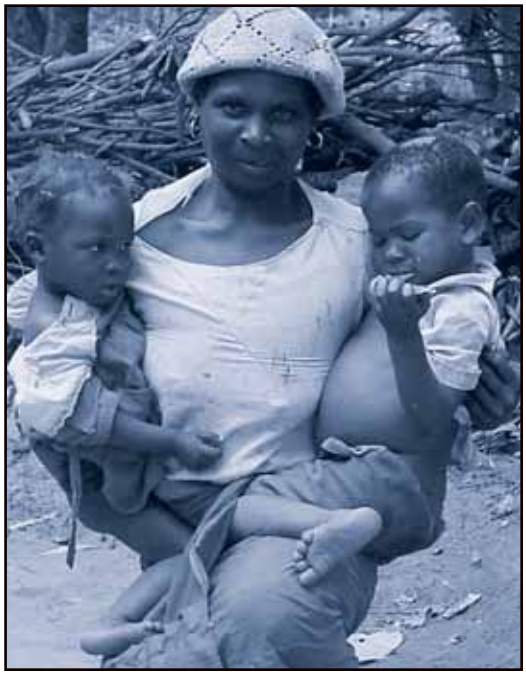
Over the past year with this method we have trained more than 4,000 physicians and health care providers in the hardest hit counties in Hubei Province.

Our approach to the urgent need for rapid scale up of anti-retroviral therapy and HIV care has been to train health ministry personnel who are embarking on small and large scale ART programs for the first time. This has allowed the emphasis to be on training, capacity building, and technical assistance rather than direct implementation. I believe this method to be the most cost effective. One of the lessons of the bold Gates-Merck ART initiative in Botswana has been that a high level model of ART care and support may not be sustainable when the external grant support runs out. Cost-effectiveness and sustainability are not just buzz words. The lives of people living with HIV depend on them.

Community programs

Project HOPE is also known and respected around the world for its work at the local level with families and communities. This

week in Mozambique, I met the women in Xai Xai and Chokwe who show the need for family support in the spectrum of comprehensive HIV services. I met them in their groups of 10–20 women in the Village Health Bank (VHB) program that caught my attention before I joined Project HOPE because of another lesson from County Hospital. AIDS isn't a very high priority for poor people compared to knowing where their next meal is coming from, or where your children can sleep at night. Poverty is a more immediate threat than AIDS, and it's pointless to throw money and drugs at people with AIDS—in Chicago or in Africa—while ignoring poverty.



The VHB is a micro credit and health education program that provides loans of $80–100 per family at four month intervals. The loans are managed by the groups of 10–20 women, including repayment of the loans with interest. Since these programs began in 1996, over 50,000 families have been served in eight countries on three continents, including Malawi and Mozambique, with 98% repayment of the loans. Among the demonstrated benefits of the VHB are increased income and savings, improvement in family nutrition, increase in retention in school for the children in the household, and empowerment of the members.

Project HOPE received a grant from USAID in April 2005 to use this intervention in the service of 75,000 orphans and vulnerable children in Mozambique and Namibia. The VHB program is being modified to provide health education, counseling, and referrals to partner organizations needed to meet the diverse needs of the children in these families.

There are many other programs in HIV and in other areas that I could describe. In Namibia, Malawi, and Mozambique, Project HOPE has conducted workplace programs on HIV that have received international recognition. Youth HIV prevention programs are in place in Thailand, Mexico, Russia, Ukraine, and Mozambique. Cross-border initiatives have addressed mobile populations—such as gold miners, truck drivers, and Roma—in Malawi, Mozambique, and the Western Balkans.

Project HOPE helped to build and operate two of the finest pediatric facilities in the world in Shanghai, China—the Shanghai Children's Medical Center—and in Krakow, Poland. Project HOPE has recently begun a campaign for its 50th anniversary in 2008 based on the development of Health Centers of Excellence around the world.

In several instances, Project HOPE programs have been adopted as national programs. In Russia, the HIV education program and curriculum in vocational and secondary schools have been adopted as national templates. In Honduras, the Project HOPE Home Based Care manual and program have been replicated at the national level. In the five Central Asian Republics, Project HOPE is the main technical advisor and implementer of tuberculosis control programs.

Project HOPE has a history of program development and capacity building followed by integration of the program into the region and then our withdrawal. Such sustainability is increasingly important as donor resources diminish. In the Dominican Republic, Project HOPE partnered with the Order of Malta to conduct a primary care clinic. Over time, the clinic generated revenues that allowed it to be economically self-sufficient, and both Project HOPE and the Order of Malta handed the clinic over to a local nongovernmental organization (NGO). In Ecuador, the largest VHB in the Americas became economically self-sufficient over a period of seven years, and formed an NGO to conduct its own financial affairs. In both cases, Project HOPE withdrew when the local capacity was established.

In each country in which it is active, Project HOPE has played an important advisory role to the Ministry of Health. Where there are HIV programs, Project HOPE staff have participated in the Central Coordinating Mechanisms for the Global Fund, and on national HIV planning bodies.

Chicago

I often talk about the lessons learned from Chicago and Cook County Hospital as I travel around the world. Much of the work is in stigma reduction and breaking the silence of AIDS and HIV, of homophobia and discrimination towards drug users, commercial sex workers, and others at risk of HIV. When it gets discouraging, and even surreal, to watch as the rest of the world struggles with so many of the battles that have been waged in the U.S. and Europe, I return to the early days at County, and call upon the spirits of Ron Sable and Gigi Nicks, and of Ida Greathouse and Jim Delacerda, and the many patients and colleagues who were on the front lines in the 1980s. It's a comfort and a powerful resource. We lived through it, and most of us are still here. It gives me hope that it can be done again, like before, with your help: www.projecthope.org, or at 1–800–544–4673.

In several instances, Project HOPE programs have been adopted as national programs.

Dr. Sherer is also with the Section of Infectious Diseases at the University of Chicago Hospitals.

Crystal Meth Recovery

A step-by-step guide

Compiled by Enid Vázquez

As *Positively Aware* went to press with the previous issue, which focused on harm reduction (July/August 2005), Jamie Turner and Will Halpin of the Fenway Community Health center in Boston presented a recovery model for crystal methamphetamine in a workshop for the 17th Annual National Conference on Social Work and HIV/AIDS, held in Chicago during Memorial Day weekend.

Since the harm reduction issue did not cover steps for recovery, this article discusses the model used at Fenway, which is a health clinic for gay men and women. The guide is based on slides from Turner and Halprin's presentation at the social workers conference.

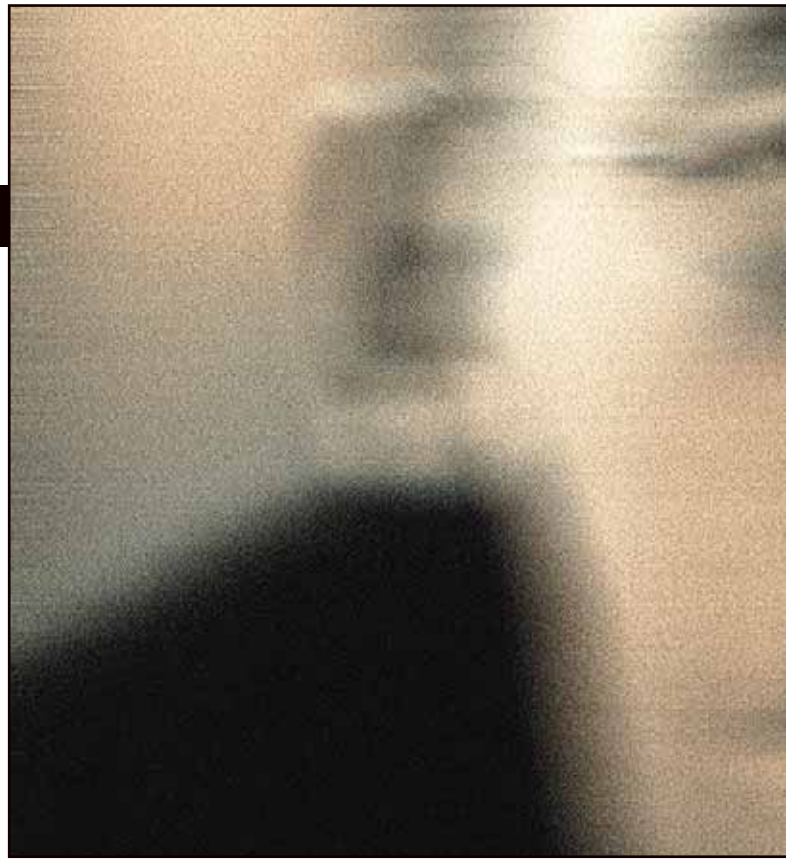
Most importantly, it should be understood that recovery from crystal meth is possible, says Halpin, a licensed social worker, despite the fact that the drug has more profound effects in the brain and the body than other illicit substances.

Crystal meth is linked to the HIV epidemic because over the past several years it has been seen as causing many new infections among gay men.

The latest report came from this year's National HIV Prevention Conference, held by the U.S. Centers for Disease Control and Prevention (CDC) in Atlanta in July. Officials from the L.A. Gay & Lesbian Center reported that in their four-year survey of 19,300 HIV tests, almost one in three MSM testing positive in 2004 reported using crystal meth. Moreover, this was almost triple the rate of the MSM who tested positive in 2001. Overall, 10% of the gay and bisexual men who took an HIV test reported using crystal in 2004—double the rate in 2001.

Crystal makes achieving an erection difficult, plus the drug lowers inhibitions and pain. This makes gay men who would normally be the insertive partner become the bottom partner during sex, a much more riskier position for HIV infection. As always with illicit drugs, condom use decreases. The drug also increases sexual arousal and sexual pleasure. People can stay awake for days at a time, during which they can continuously seek to engage in sex.

For a community still struggling with the HIV epidemic, the destructive force of crystal meth is especially frustrating, and painful. People not only lose their health, but everything they've achieved in life—homes, jobs, relationships and careers.—Enid Vázquez



What follows is an outline of steps to take to recover from crystal meth.

The Matrix model

The Fenway Community Health center in Boston uses the Matrix Model of Stimulant Treatment. Books on this model can be bought from the Matrix Institute for $100 through its website, www.matrixinstitute.org. (The books are designed for staff members of addiction treatment programs.)

Relapse prevention

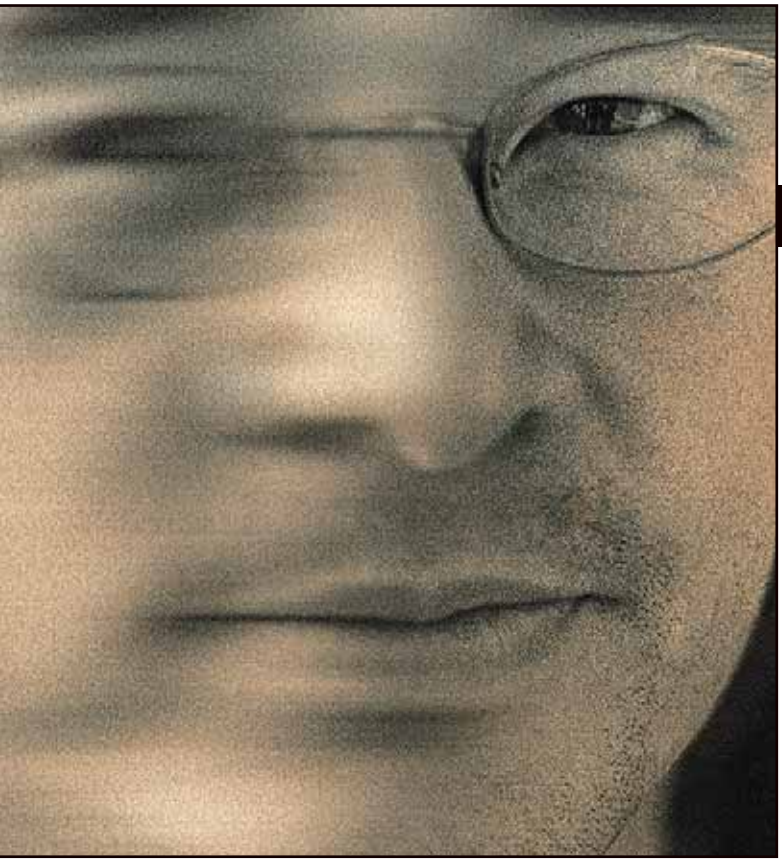
Relapse tends to happen gradually, but it seems to occur suddenly because small warning signs are ignored. Will Halprin of the Fenway clinic says it's like a ship drifting so slowly from where it's moored, that you don't notice it has moved.

Very specific actions keep people sober, but these need to be clear and decided upon ahead of time.

Fill up the time

First of all, keep a very tight schedule. Counselors recommend a daily schedule of activities from wake-up to bedtime. Put time slots on a sheet of paper and make copies. Know what you are going to do from the time you get up to the time you go to sleep. This is vital! An open slot gives you time to think about using and possibly drift back into it. A full schedule helps keep you busy and thinking about activities that would do you good.

Remember: the schedule must be written down. This calls your rational brain into gear. Ideas that you keep only in your head become fair game for your addicted brain, the one looking only for pleasure and excuses.



Things to try:

- Review your activity list to re-start things you used to enjoy or review new things you'd like to try.
- Talk to a confidant—can they give you suggestions?
- Re-commit to a schedule and to people.
- Do something for self-growth—boredom can come from not challenging yourself, and boredom helps trigger relapse.

Don't be bored

The next barrier to trip you up in recovery is b-o-r-e-d-o-m. People who stop using drugs often say that life now feels boring. This could be because:

- A structured, routine life feels different from an addict lifestyle.
- Brain chemical changes during recovery can make people feel flat or bored.
- Meth users often have huge emotional swings; normal emotions can feel flat by comparison.

Alcohol

Watch the alcohol. Think about these questions:

- Does feeling a certain way make you want to have a drink?
- Do you have friends who get together without drinking?
- Have you stopped drinking since entering treatment or tried stopping?
- Do you depend on alcohol for sexual or social reasons?
- Do you celebrate most occasions with drinking? Has that changed since entering treatment?
- Do you feel "less with it" when you are not drinking?
- What activities seem to go with drinking for you?

Drinking and using can go hand-in-hand. The important thing is to recognize your emotions and the activities that go with them (like drinking when you're feeling down or to have fun when you're bored).

Cravings

Identify what exactly triggers you back into drug use, avoid those triggers, and decide ahead of time what you will do if they come up.

It helps to remember all the times you would normally use: before, during or after sex; before going out; when carrying money or after payday; after passing through a certain part of town, etc.

Think, too, of the many emotions that can trigger use: feeling anxious, neglected, deprived, afraid, misunderstood, criticized, guilty, relaxed, excited, depressed, irritated, pressured, sad, embarrassed, etc.

Things to try:

- Create a new visualization—an image—in your mind to replace the thoughts of using; this is called "thought stopping."
- Breathe in and out slowly and deeply three times to relieve feelings of hollowness, heaviness or cramping in your stomach. These feelings are cravings.
- Call someone—get phone numbers of people you can talk to (visit www.crystalmeth.org for a list of Crystal Meth Anonymous groups; for group meetings not based on spirituality, visit www.smartrecovery.org, www.womenforsobriety.org, www.secularsobriety.org and www.rational.org).

Work issues

See if any of these apply to you.

- Employed in a demanding job that makes treatment difficult or impossible.
- Working in an unsatisfactory job.
- Working where it's difficult to stay away from drugs.
- Working with a schedule that needs to be changed so that treatment can work.
- Unemployed and needing to find a job.

Guilt and shame

"Guilt" is feeling bad about what you've done. "Shame" is feeling bad about who you are. Halprin says that "recovering cannot

A note about helping people on crystal meth

When faced with someone who has a problem with substance use, the role of a professional helper is almost the opposite of the role of a friend or a caring relative.

According to the Matrix Model of Stimulant Treatment (and most other therapy programs), a helping professional should remain non-judgmental. For example, if a client says, "I just got off a crazy party weekend," the social worker (or whomever) can say something like, "How was that for you?"

The idea behind this sounds simple but requires skill: you keep someone feeling comfortable as they work through the problems created by their substance use, until they can clearly see for themselves that they have a problem. This helps break down the denial system they've built up in their mind about being able to handle drug use, including the ways they minimize any damage that's done to themselves or others.

Says Chicago substance abuse counselor John Cebuhar, "If they come in and get beaten up [emotionally], they're not going to come back. Instead you start the thought process. That's all that outreach campaigns have to do, point the way. And then you say, 'There's hope.' That's the important part."

It may seem counterintuitive, but speaking in a manner that normalizes drug use helps maintain a dialogue with the drug user. For example, once a dialogue has been started, counselors can raise questions related to the drug use, such as getting the person to look at the significance of the environment in which they use drugs, perhaps with a comment to the effect that, "Many times, men use crystal for sex …." This type of conversation helps the drug user feel safe, and able to explore his concerns about his use.

A friend is something else. Cebuhar says that what friends and relatives can do is confront—"I see you killing yourself. You lied to me. You didn't pay back money you owe me." But, he says, you do this as calmly as possible, without hatred or rage.

You also set up boundaries. They haven't paid back money you lent them, so when they try to borrow more you say you're sorry, but you can't. "They'll say that you're attacking them, but you respond by saying that you just want them to stop," says Cebuhar. "You can continue to use—that's your choice, but there will be consequences, and they're not nice. For people with HIV, they're especially not nice."—Enid Vázquez

rely solely on willpower, being strong or trying to be 'good enough' to overcome these feelings."

Guilt is a healthy reaction, because you recognize that you did something which is against your own principles. Guilt over wrongdoing is common for anyone. Try to make peace with yourself. Sometimes that means making up for what you've done or said. Sometimes you realize that you've been feeling guilty unnecessarily.

With shame, you may have felt weak for not being able to stop. You may have felt stupid, or that you were a bad person. Recognize that what you did does not brand you forever. You can start over.

Motivation

List the reasons you began treatment. List the reasons why you continue in recovery today. Look at the differences between the reasons for stopping and the reasons for continuing. Remember that fear may get people into treatment, but fear alone won't keep them there.

Talk truth

Trying to be in treatment without being truthful will make you feel crazy. Do you ever let someone believe a partial truth, or tell them what they want to hear, or tell people what you wish were true, or avoid expressing what you're really feeling?

Not being truthful is part of addiction. It's hard to continue normal daily activities while using drugs, and lying helps cover the gaps and avoid problems. Being truthful now may be hard. It could be embarrassing or you might be afraid of hurting someone's feelings. But remember, truthfulness is part of recovery.

Sex

Meth affects the part of the brain that controls sexual pleasure. These reactions to meth use are common:

- increased sexual pleasure
- longer-lasting sex
- doing things you normally wouldn't
- meeting people becomes easier
- you feel less anxious in sexual encounters
- there's added excitement to an existing relationship

As addiction continues, negative experiences become common.

- Continued ability to prolong sexual activity, but with decreased pleasure.
- Increased activity beyond a person's usual limits.

- The thought of sex and drugs becomes more exciting than engaging in them.
- Difficulty achieving erections or orgasm.
- Doing drugs replaces sex.

Beware of the following:

- Cravings can be caused through arousal by sexy people, videos or cruising areas, creating a "1–2 punch" that's difficult to fight by the addicted brain, which focuses on pleasure.
- Bars, clubs and Internet chatrooms can be powerful triggers because people miss the social life previously created there.
- Alcohol dulls the rational brain and wins over the addicted brain, increasing vulnerability to cravings and old behaviors.
- Engaging in secretive sex can trigger addictive behavior because of the lying and cheating involved.
- "Impulsive" sex becomes a high in itself, as opposed to "intimate" sex that is part of a relationship.

The real red flags are feelings of loneliness, anger or deprivation.

"With patience and care, sex and drug use can be separated," says Halpin. Remember, impulsive sex can create a false sense of intimacy, in part because of chemical reactions in the brain that appear to be feelings of closeness.

"It takes a while after stopping meth to experience pleasurable 'normal' sex again," he continues. "Sometimes during 'the Wall' (four to six weeks into recovery), people can lose interest in sex."

Dealing with thoughts and emotions

Addictive thinking makes drug use seem okay: "They think I'm using, so I may as well use"; "I worked hard and deserve a break." This is the "stinking thinking" talked about in recovery groups. Other thoughts that contribute to drug use: "I need to control my weight," "I need it to meet people," "I can't enjoy sex without it," "I need the energy boost."

How about these thoughts? "I'm cured." "I'm strong enough to be around it." "I learned, I'll only use small amounts and only once in a while." "Everything's going great, I can celebrate." These thoughts revolve around the themes of being cured, testing yourself to see if you're stronger than the drug and celebration.

Emotional build-up is when feelings keep getting stronger, until they're unbearable. The most common emotions among people in recovery are boredom, anxiety, sexual frustration, irritation, irritability and depression. Relapse relieves these negative feelings. The real red flags are feelings of loneliness, anger or deprivation. How do you plan on dealing with these emotions? Do you even recognize them for what they are?

Plan actions you can take to deal with these thoughts and emotions. Writing in a journal helps you deal with them. Be especially aware of the physical signs of stress: sleep problems (too much or too little), stomach problems, headaches, illness, fatigue, irritability, difficulty concentrating, moodiness (up and down), and feeling overwhelmed or generally dissatisfied with life.

Behaviors

Recognize any of these compulsions? Working all the time, using prescription medicines, using other illicit drugs, drinking large amounts of caffeinated beverages, smoking, eating high-sugar foods, exercising to extreme, compulsive masturbation, gambling, spending too much money. Switching from using meth to one or more of these behaviors helps you deal with the discomfort of recovery, but ultimately, it's not doing you good.

Be most aware of the "Abstinence Violation Syndrome." This is the one where people feel that if they smoked or drank, or used some other drug, that they may as well use meth.

What can you do to better support yourself through recovery?

Real friends

Do you know the difference between an acquaintance and a friend? Where can you make some new acquaintances who can become friends? To whom are you a friend? Answering these questions may help you understand who you can count on for love and support.

Editor's note: Friends leave you feeling better. Think of someone who truly loved you—such as your mom or your favorite sibling—and think if they would ever say or do to you the things that some other people do. People who love you, like your friends, would not hurt you in any way or use you.

Dreams

Meth interferes with normal sleep, so when using stops, many people experience frequent and intense dreams. They can feel real and frightening. This is a normal part of recovery. Exercise seems to help lessen this problem. Be careful about relapsing the day following powerful dreams. Later in recovery, suddenly dreaming about using may be a warning of a relapse. Look at the problems you're having and what you can do about them.

Why HIV Drug Resistance Matters: An Overview

by James Learned

When we talk about HIV treatment, the issue of resistance almost always comes up. HIV drug resistance can seem to be a hopelessly complicated topic. But having a basic understanding of what resistance is, what causes it, and how it's measured can have a big impact on the success of antiretroviral treatment.

This overview is intended to help people better understand the basics of drug resistance (hopefully without being too complicated) in order to get the full benefit of treatment.

Drug resistance isn't anything new and certainly isn't limited to HIV. Most of us are familiar with drug resistance in situations outside of HIV. You may have experienced or read about widespread resistance to antibiotics, drug-resistant tuberculosis, or vaginal yeast infections that don't respond to conventional treatment.

The goal of any pathogen—or germ—is to survive and reproduce. Most medications are designed either to kill the offending germ or to stop it from reproducing, ideally resolving the infection. But if a germ continues to reproduce while you're on treatment, it may change—or mutate—so that the treatment can no longer kill the germ or stop it from reproducing. Over time, the treatment no longer works.

This is called drug resistance.

HIV replication

The goal of HIV treatment is to lower the amount of virus in your body (viral load) and increase your CD4 cell count so that the immune system is better able to deal with infections.

Many complex steps are necessary for HIV to make copies of itself. Two of these steps involve specific enzymes—reverse transcriptase and protease. All but one of the antiretrovirals approved by the Food and Drug Administration to treat HIV interfere with the virus's replication process by attaching—or binding—to one of these enzymes, effectively stopping HIV from replicating.

Without treatment, HIV usually reproduces very rapidly in the body, creating billions of new viral particles every day. Since HIV replication involves so many complex steps, the virus makes a lot of mistakes. And as sophisticated as HIV is, it's also a somewhat messy virus. It isn't able to correct mistakes it makes as it reproduces. These mistakes in HIV's genetic structure are called mutations.

Up to 90% of new viruses end up with a mutation (or mutations) that keep them from being able to infect a new CD4 T-cell or complete the replication process. Unfortunately, that still leaves millions of new viruses that go on to produce new copies of HIV. Many of these viruses also contain mutations, but they aren't harmful enough to interfere with HIV's ability to replicate.

HIV drug resistance

Simply put, HIV drug resistance means that an antiretroviral drug—or combination of drugs—can't prevent or reduce HIV replication. Our main concern is the mutations that affect currently available antiretrovirals. Specific mutations that stop a drug from being able to bind to either the reverse transcriptase or protease enzyme can make the drug less effective. This can have a negative effect on how well treatment works.

Reverse transcriptase inhibitors and non-nucleoside reverse transcriptase inhibitors bind to HIV's reverse transcriptase enzyme. Protease inhibitors bind to the protease enzyme.

Drug resistance doesn't happen because HIV is smart. The virus doesn't have a brain and can't think about how to get around a drug. Mutations that cause resistance occur naturally and randomly. We sometimes think of HIV as intelligent and cunning, but, in fact, it survives simply because it can. It uses what it needs to replicate—white blood cells (usually CD4 cells), certain enzymes, and other materials it brings with it.

Drug resistance before starting treatment

Mutations in the genetic structure of the reverse transcriptase and protease enzymes can occur before you begin antiretroviral treatment and, more often, when you're on treatment.

When HIV enters your body, it makes both perfect copies of itself—called wild-type virus—and copies with random mutations. As both the wild-type and mutated HIV continue to replicate, populations of mixed viruses develop in your body.

Wild-type virus is the most fit and best able to replicate, so most of the HIV in your body is wild-type virus. Even though mutations continue to randomly occur, most of them are harmless and will have little or no effect if and when you begin treatment.

Unfortunately, many people who have never been on treatment have HIV that's resistant to one or many HIV drugs. If you're HIV-negative and engage in risk behaviors with someone whose virus is resistant to one or more antiretroviral, you could be infected with your partner's drug-resistant HIV.

Recent data show that 10-30% of new infections (generally defined as having been infected over the past three years) involve HIV that's resistant to at least one drug. As many as 10% of new infections involve HIV that is resistant to at least *two* drugs. And a recent study found that 3% of new HIV infections involved strains of HIV that were resistant to drugs in three classes of antiretrovirals (reverse transcriptase inhibitors, non-nucleosides, and protease inhibitors).

It's also possible for someone with HIV to be infected again, with drug-resistant HIV, possibly HIV that's resistant to many drugs. This is called superinfection. We don't know how often superinfection occurs, but there are several reports showing that it's possible.

If you're infected with drug-resistant HIV—either initially or through superinfection—you have fewer treatment options even before you start therapy. This could affect the likelihood of treatment being successful.

Drug resistance while on treatment

Most mutations that can influence the effectiveness of combination therapy happen while you're on treatment. When you first start antiretroviral treatment, the amount of HIV in your body goes down dramatically.

No combination completely stops HIV from reproducing, but treatment significantly lowers levels of *all* viral populations in the body, both wild-type and mutated virus. Just as wild-type virus is the most fit and most able to replicate, it's also the most sensitive to antiretroviral treatment.

When you have a viral load test soon after you begin treatment and see a dramatically lower number, most of that decrease is due to the affect of the drugs on your wild-type virus.

The flip side of wild-type virus's sensitivity to antiretrovirals is that any HIV in your body with certain mutations in the reverse transcriptase or protease enzymes has a survival advantage. Depending on the mutations, the drug can't bind to the enzyme and can't interfere with HIV's replication process.

This is called selective pressure. Drug-resistant virus is able to replicate despite the presence of the drug.

Even though there's less HIV in your body, the virus with the relevant mutation(s) can become the dominant strain over time. As the mutated virus continues to replicate, it makes copies of HIV with that same mutation and other mutations can also develop.

The Xerox machine

The HIV replication process is a bit like using a Xerox machine. You start with a nice, clear original of your document (the wild-type). You make a copy of the original and, in the process, you may copy a speck of dirt (a mutation) that's on the glass of the copier.

When you make a copy of the copy, that speck of dirt is copied, too. As you go on to make copies from each copy, the mutation continues to show up—along with many others. After a while, your original document has become an unreadable blur, complete with many Xeroxed specks of dirt (multiple mutations).

As discussed above, most mutations harm the virus, making HIV unable to complete the replication process (an unreadable blur). But other mutations severely limit a drug's effectiveness. The drug can no longer bind to the enzyme that HIV uses to replicate. As a result, the amount of drug-resistant virus increases and so does your viral load.

Drug resistance would usually happen very quickly if you took only one antiretroviral. For example, only one mutation (called the M184V) in the reverse transcriptase enzyme makes HIV completely resistant to both Epivir (3TC, lamivudine) and Emtriva (emtricitabine). If you took either of these drugs alone, your virus would develop resistance within just a couple of weeks.

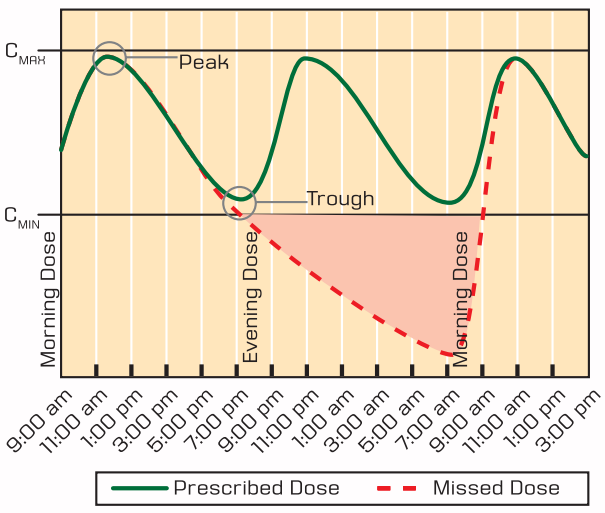
Resistance to the non-nucleosides is similar. One mutation (the K103N) in the reverse transcriptase enzyme can cause HIV to become highly resistant to all three non-nucleosides—Viramune (nevirapine), Sustiva (efavirenz), and Rescriptor (delavirdine). This is an example of cross-resistance. Depending on the mutation, if HIV develops resistance to one drug, it can be resistant to other drugs in the same class because of the same or similar resistance patterns—even if you've never taken those other drugs.

Some antiretrovirals require more than one mutation in the relevant enzyme to cause resistance to that particular drug. This is especially true with protease inhibitors.

Each antiretroviral is associated with at least one mutation—called the primary mutation—that causes the most drug resistance. Other mutations—called secondary mutations—sometimes make HIV less sensitive to a drug, but they don't usually cause complete resistance unless the primary mutation is also present.

As more mutations—both primary and secondary—occur, the likelihood of HIV becoming resistant to a given antiretroviral increases. The concept of multiple mutations can be difficult to

Peak and trough levels



- This graph shows levels in your body of an antiretroviral that's dosed twice a day.
- The first dose is taken at 7 am.
- The amount of drug quickly rises to the highest level (peak) and then slowly begins to fall, reaching the lowest level (trough) before 7 pm—time for the next dose.
- C_{max} is the maximum concentration of the drug in your blood. The C_{max} should be low enough to keep short-term side effects like nausea or headaches from being intolerable.
- If drug levels rise above the peak (C_{max})—because you took more than the prescribed dose, for example—the side effects can be serious.
- C_{min} is the minimum concentration of a drug in your body between one dose and the next.
- If drug levels fall below the trough (C_{min}), the drug may not be effective. If drug levels drop too low, HIV can replicate freely and may develop resistance to the drug.
- When doses are taken at the right time, drug levels stay within the therapeutic range—between the C_{max} and the C_{min}—ensuring that there is enough drug in your body to slow down or stop HIV from reproducing.
- But if you miss your 7 pm dose (dotted line), the trough level gets way too low (see the colored area).
- The chance of developing resistance to the drug increases greatly, since there isn't enough drug in your body to control HIV replication.

understand. This is about when many of us throw up our hands in surrender. Some people dutifully track the primary and secondary mutations of every available antiretroviral and those that are in development, but it isn't necessary for everyone to do that.

You don't need all of that information in your head in order to make informed decisions about treatment or to develop treatment strategies. Coming up with good questions to ask your healthcare provider and knowledgeable advocates can be as valuable as memorizing the mutations that keep a drug from working.

Now some good news. Having resistance to a drug doesn't necessarily mean that it can't still be useful. A drug that your virus is resistant to may still work for you, just not as well as it used to. There are varying degrees of resistance—partial and complete. And although mutations like the ones described above can cause complete resistance to one (or more) drug, mutated HIV is almost always sensitive to the other drugs in a combination. That's why we use multiple drug regimens.

HIV with specific mutations may be resistant to one of the drugs in your combination, but the other antiretrovirals in the regimen bind to the protease enzyme or to a different part of the reverse transcriptase enzyme and successfully stop HIV replication.

The bottom line concerning the development of drug resistance is that the less virus there is (the lower your viral load), the less likely it is that HIV will develop mutations.

Adherence, absorption, and pharmacokinetics

Often, a combination stops working no matter how adherent a person is. This doesn't usually happen quickly—certainly nowhere near as quickly as it would if you took only one or two drugs. But it can still happen. When it does, some healthcare and service providers assume that the individual isn't adhering to his or her regimen. That's sometimes the case, but other things can also contribute to the development of resistance while you're on treatment.

If the amount of drug in your body falls below therapeutic levels—for any reason—you won't have enough of the drug in your system to stop or slow down HIV replication. The drug may inhibit wild-type virus from replicating, but it won't have an effect on HIV with mutations that keep that drug from binding to the relevant enzyme. This allows the mutated HIV to continue to reproduce, creating more viruses with that same mutation.

Poor adherence can cause drug resistance to develop. Adherence means taking your medications on time, taking the prescribed dose, and taking them the correct way (with or without food, for example).

After you take a dose, levels of the drug quickly rise to the highest level (peak) and then slowly begin falling, reaching the lowest level (trough) before you take the next dose. Skipping doses or not taking a drug correctly can cause the trough level to get too low.

When the amount of drug in your body falls below the trough level, the chance of developing resistance is increased since HIV can reproduce more freely and accumulate more mutations. (See graphic.)

Some people who are meticulous about adherence get very nervous if they miss even one dose, afraid that their HIV will immediately become resistant to their regimen. Missing the occasional

dose isn't a big problem. Resistance develops when you regularly miss doses.

According to estimates, you need to be up to 95% adherent in order for your regimen to be most effective. This degree of adherence is very high. For example, if you're on a twice-a-day regimen, it means missing fewer than four doses a month. And if you're on a once-a-day regimen, it means missing one dose a month—at most. Poor adherence can cause drug resistance and, possibly, cross-resistance, too.

If you have trouble sticking to your schedule, be honest with your healthcare provider about it. He or she may be able to prescribe a simpler regimen or help you come up with strategies that work for you. If not, in the long run it may be better for you not to be on antiretrovirals until the reasons for your difficulties with adherence have been addressed.

Poor absorption can also affect levels of a drug. If a drug isn't properly absorbed into your bloodstream, drug levels can be too low. This would allow HIV to reproduce without interference and, in the process, accumulate drug-resistant mutations.

If you vomit or have diarrhea shortly after taking your dose, for example, the drug you just took could be expelled from your gut right away, reducing or eliminating the amount of drug absorbed.

As mentioned above, some antiretrovirals have food restrictions, most of which are necessary for the drugs to be absorbed properly. If these food restrictions aren't followed, drug levels can become too low to be effective. Most antiretrovirals don't have any food restrictions these days, but some do. For example, both Kaletra (lopinavir/ritonavir) and Viracept (nelfinavir) should be taken with a meal or light snack. Reyataz (atazanavir) should be taken with food, ideally a complete, nutritious meal.

Drug absorption can also be reduced if you have an intestinal infection. So if you're having nausea, abdominal pain, constipation, diarrhea, or any other symptoms of a possible infection, have it checked out.

Pharmacokinetics—the way that a drug is absorbed, distributed, metabolized, and eliminated from the body—can also affect the development of HIV drug resistance.

Some people process drugs faster or slower than other people do, which can speed up or slow down the rate at which a drug clears your body. So if two people take the exact same dose of a drug, the level of drug may be higher in one person than it is in the other one. Factors that can contribute to this include weight, height, age, and, possibly, race and gender.

We all know that people metabolize food differently—some of us eat as much as we want and stay thin, while other people carefully watch their diet and continue to gain weight. These differences in metabolism are similar to the way we process other substances, including drugs.

The prescribed dose of an antiretroviral is based on the dose that was found to be safest and most effective in clinical trials for *most* trial participants. Some people may be able to take a lower dose and keep their viral load low or undetectable, while others might need a higher dose to get the same response. There's a lot we don't know about this issue, including how to figure out who may need a dose that's lower or higher than the one that's prescribed.

Finally, many over-the-counter and prescription medications, illegal drugs, herbs, vitamins, and supplements interact with a lot of the antiretrovirals and shouldn't be taken together. Many antiretrovirals also interact with each other. Interactions are complex. Some lower antiretroviral drug levels, which could allow the development of mutations. Pay attention to possible interactions and tell your provider about everything that you're taking.

Drug resistance when stopping treatment

People sometimes stop treatment—because of toxicity, because another health problem requires a treatment interruption, because they've been responding well and decide to discontinue therapy for a while, or because they're just plain tired of taking medication. If you stop treatment for *any* reason, work closely with your healthcare provider. Careful planning is important.

Depending on your regimen, if you stop all of your antiretrovirals at once, your virus could develop resistance to one or more of the drugs you were taking. This is most likely to happen if one of your drugs has a long half-life, meaning that drug levels stay high in your body for a long time after you take a dose.

For example, it can take up to three weeks for Sustiva (efavirenz) to be eliminated from your body after you stop taking it. If you stop Sustiva at the same time as you stop taking other antiretrovirals with shorter half-lives, it's like being on Sustiva by itself for a while. This gives a survival advantage to any virus in your body with the mutation that makes it resistant to Sustiva. During that short time after stopping your drugs, much of your HIV could become completely resistant to Sustiva and become resistant to Viramune and Rescriptor, too.

If you plan to stop a regimen that includes Sustiva, it's probably safest to stop the Sustiva one or two weeks before stopping the other drugs in your combination. It may also be possible to switch from Sustiva to a drug with a shorter half-life for a while before stopping everything.

Most antiretrovirals have relatively short half-lives—including most of the ones that are dosed once a day. But the half-life of Viramune, for example, is also long enough to require careful planning with your provider to avoid the development of resistance if you're stopping a regimen that includes that drug.

Figuring out if your HIV is drug-resistant

Regular viral load testing is the quickest way to tell whether treatment is working. If your viral load doesn't reach very low or undetectable levels within a few months after you begin treatment, it's a sign that something's off. Similarly, if an undetectable viral load becomes detectable and continues to go up while you're still on treatment, it's a sign that your regimen isn't working properly.

Viral load tests can't tell why your regimen isn't working. A detectable or increasing viral load doesn't necessarily mean that drug-resistance has occurred. But it could mean that you're at risk of developing drug resistance because there's more HIV replication going on. It's important to find out what's happening.

Viral load tests can't tell whether your HIV is resistant to one drug or, perhaps, your whole regimen. They can't tell which drug or combination may be most effective for you in the future, either.

This is where drug resistance testing comes in.

Resistance Testing

There are two types of drug resistance tests. Genotype tests look for specific mutations in the genetic structure of your reverse transcriptase and protease enzymes that could cause drug resistance. Phenotype tests measure the sensitivity of your HIV to specific antiretrovirals.

If your regimen isn't working, genotype and phenotype tests can help you and your provider figure out which drug or drugs your virus is resistant to and which ones you're most likely to respond to. This information can help you put together a new regimen that's likely to be effective.

Resistance tests are recommended in many situations. The Department of Health and Human Services' *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* suggest that HIV drug resistance testing should be done:

- If you're switching regimens because your current regimen is failing;
- If your viral load doesn't drop significantly shortly after beginning treatment;
- Before starting treatment during acute (initial) HIV infection if the test is done within a few weeks after infection; and, possibly,
- Before starting treatment if you may have been infected with drug-resistant virus.

Avoiding HIV drug resistance

There are many ways that you can slow down the development of drug resistance:

- The more you know about antiretrovirals, the better prepared you'll be to make treatment choices that can help you avoid drug resistance.
- The first regimen you take may be your best chance to suppress HIV the most and prevent drug resistance from developing.
- It's also important to take your medications as prescribed. Missing doses, not taking the right number of pills, not taking them at the right time, or taking medication on an empty stomach if it's supposed to be taken with food, can cause viral load to increase and drug-resistant mutations to develop.
- A good relationship with your healthcare provider can help with all of this. Communicate honestly with your provider. Ask questions, talk about any problems you're having, and tell him or her everything you're taking—including over-the counter medications, herbs, and any other legal or illegal drugs.

Taking these steps can help avoid drug resistance from getting a chance to develop and leave you more options in the future.

James Learned was Director of Treatment Education at AIDS Community Research Initiative of America (ACRIA) until June of this year. He writes for various community-based publications and conducts trainings on HIV and viral hepatitis treatment issues. E-mail James_Learned@prodigy.net.

Letters & numbers

When we read about mutations that cause resistance to HIV drugs or look at the results of a genotype test, mutations are listed as a letter followed by a number and then another letter. This way of describing a mutation may seem confusing, but it's really very straightforward.

HIV is made up of proteins, and proteins are made up of amino acids. A codon tells us which amino acid is found at a specific spot in a protein chain. The reverse transcriptase and protease enzymes are protein chains made up of codons. The amino acids in a protein chain are numbered starting at one end of the chain.

With reverse transcriptase, for example, the 184th amino acid in the protein chain is called position 184. A mutation in reverse transcriptase means that a different amino acid has replaced the one that would be located at that place in wild-type virus. Each mutation is given a specific name to tell it apart from other mutations.

The first letter in a mutation stands for the amino acid that's found at that position in wild-type virus. The number in the middle is the codon, where the mutation is located. And the final letter stands for the amino acid that's there instead of what we'd find in wild-type virus (the mutation).

Some examples:

- M184V is the mutation that makes HIV resistant to both Epivir and Emtriva. M184V tells us that there's a mutation at codon 184 in HIV's reverse transcriptase enzyme. At that position, the amino acid methionine (M) has been replaced by valine (V), another amino acid.

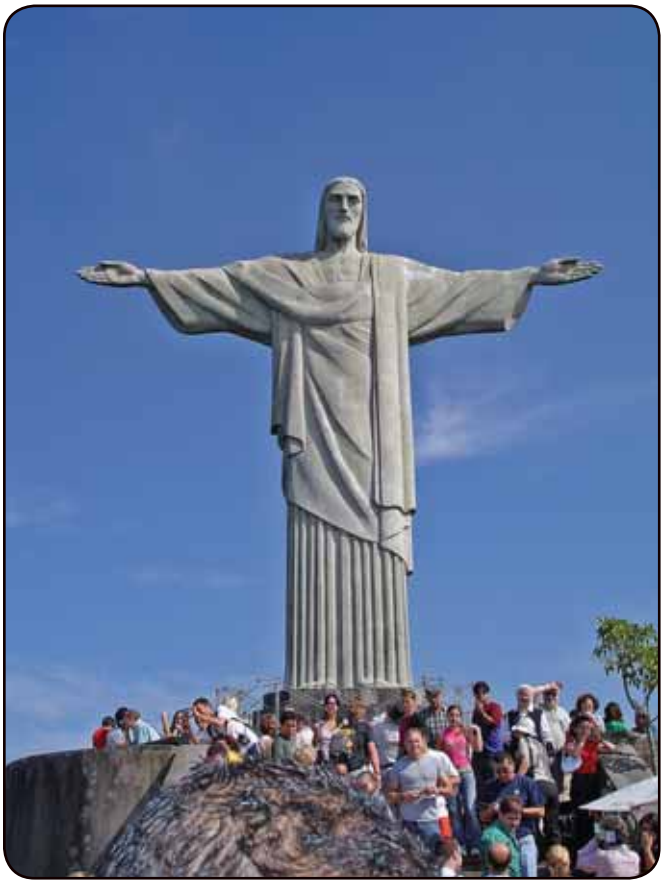
- K103N is the mutation that can cause resistance to all three non-nucleosides. K103N tells us that there's a mutation at codon 103 in the reverse transcriptase enzyme. At that position, the amino acid lysine (abbreviated as K) has been replaced by asparagine, another amino acid (abbreviated as N).

- D30N is the most common mutation in the protease enzyme that can cause resistance to the protease inhibitor Viracept (nelfinavir). This mutation alone doesn't cause cross-resistance to other protease inhibitors. D30N means that there's a mutation at codon 30 in the protease enzyme. At that position, aspartic acid (abbreviated as D) has been replaced by asparagine.

2005 IAS in Rio de Janeiro

by Jeff Berry, Keith R. Green, Matt Sharp and Enid Vázquez

Photos by Jeff Berry



Over 5,000 scientists, researchers, physicians and community advocates from around the globe gathered in Rio de Janeiro, Brazil from July 24-27 for the 3rd International AIDS Society (IAS) Conference on HIV Pathogenesis and Treatment. 2,060 abstracts were submitted for presentation at the conference in 17 categories, giving cause for both hope and concern in a variety of fields, including basic science, research, prevention, access to care, co-infections, complications and drug resistance.

During the opening ceremonies on Sunday, Stephen Lewis, UN Envoy on HIV/AIDS in Africa, delivered a moving speech and a call to action. In his opening remarks, he stated, "I have spent the last four years traveling through Africa, primarily southern Africa, watching people die. I think I understand, better than most, why your collective scientific and academic work can be said to be the most important work on the planet.

"But precisely because the work you do speaks to the rescue of the human condition, you carry an immense public and international authority. I beg you never to underestimate that authority. And I beg you to use it beyond the realms of science.

"What we desperately need in the response to AIDS today are voices of advocacy: tough, unrelenting, informed. The issues are so intense, the situation is so precarious for millions of people, the virus cuts such a swath of pain and desolation, that your voices, as well as your science, must be summoned and heard."

Lewis remarked that the recent G8 Summit was a disappointment. He supports the cancellation of debt and the increase of foreign aid to 18 countries, 14 of which are in Africa. Many economies face imminent collapse due to the devastation caused by AIDS.

Additionally, Lewis called for "a major, multilateral organization to represent the needs and rights of the world's women," referring to the failure to intervene on behalf of women "the greatest single international failure in the response to HIV/AIDS."

He reminded the audience that the "proliferation of orphans has become a deluge; it's absolutely overwhelming in country after country. Governments are beside themselves: no one has any firm grip on how to handle these millions of frantic children."

He closed with an appeal to all of us to become advocates. "We can subdue this pandemic, but it will take the uncompromising voices of principle and outrage to make it happen. It will, in other words, take your voices."

Following is a brief summary of some highlights of presentations from the 3rd IAS Conference in Rio. For full conference coverage, including webcasts and transcripts of selected presentations, visit www.kaisernetwork.org/rio. See also www.ias-2005.org.—Jeff Berry

Round-up

by Jeff Berry

Microbicides and Prevention trials

A poster presented by Dean Hamer of the National Institutes of Health looked at using live microbes (a genetically engineered strain of E. coli) *in vitro* and in mice, that could prove to be useful in developing a durable (lasting weeks to months) and inexpensive microbicide.

Another poster supports the development of microbicides in combination for the prevention of sexual transmission of HIV-1 and other STDs. Cellulose acetate 1,2-benzenedicarboxylate (CAP), a polymer that blocks HIV-1 entry by targeting gp120 and gp41, and UC781, a tight-binding HIV-1 reverse transriptase inhibitor (RTI), had significant synergistic and complementary effects against HIV-1.

TMC-120, a non-nucleoside reverse transcriptase inhibitor (NNRTI) which Tibotec stopped development on in 2003, is now being looked at as a promising microbicidal candidate, showing no toxicity at therapeutic levels.

One trial of 20 HIV-uninfected men measured the acceptable volume of a placebo microbicidal gel during receptive anal intercourse (RAI), and found that 15 out of 18 would use 35 ml of a microbicidal gel during RAI. Two individuals were lost to follow-up during the study.

In the "Believe it or Not" category, male genital tissue obtained by consent from gender reassignment and "other" surgical procedures, was used to develop a model that could help characterize the mechanisms of HIV-1 infection of male genital tissue and to evaluate future candidate microbicides.

Microbicides now being studied include Buffergel, Pro2000, C31G, cellulose sulfate and Carraguard—all are in early phases and it will be some time before results are available. Ongoing prevention trials include oral acyclovir for herpes prohpylaxis (to reduce the risk of acquiring HIV); PREP (pre-exposure prophylaxis) with Viread (tenofovir) daily oral use (although some of these trials have been stopped or interrupted); and antiretroviral therapy (ART) as prevention in discordant couples. Future prevention trials will likely include microbicides containing antiretrovirals, new cervical barriers, and combinations of cervical barriers and mircrobicides.

Male circumcision as prevention?

A large, randomized 21-month trial conducted by a team of researchers led by Dr. Bertran Auvert of France looked at more than 3,273 sexually active South African men aged 18-24. These were men who were uncircumcised and wishing to be circumcised. It found that adult male circumcision had a 65% protective effect against HIV.

Participants were randomized into two groups; half were circumcised and half remained uncircumcised. The number of HIV infections was three times lower in the first group than in the second (18 of the circumcised men contracted HIV, compared with 51 of the uncircumcised men). All study participants were given condoms and prevention counseling. Due to the findings the trial was stopped upon recommendation of the trial's Data Safety and Monitoring Board (DSMB), and all participants were offered circumcision.

It should be noted that the trial only looked at heterosexual men acquiring HIV from infected women through sexual transmission, and should not be applied to male-to-male, or male-to-female transmission. Further studies

are needed, and additional trials are underway in Uganda and Kenya, with results expected in early 2007. And male circumcision, even if it is found to effectively reduce the risk of acquiring HIV, would be part of a larger "package of interventions" including condom usage and behavior change.

Lipodystrophy and switching

Several studies presented in Rio looked at the effects switching therapies has on lipodystrophy and lipid profiles.

In a small observational study, replacing a protease inhibitor (PI) or NNRTI with Reyataz (atazanavir) significantly reduced total triglycerides, total cholesterol and non-HDL cholesterol levels after 24 weeks. HDL cholesterol (the good one) was not significantly decreased, while viral load and T-cell count remained stable.

In a 45 patient RAVE substudy, switching from a thymidine anologue NRTI (either Retrovir or Zerit) to Viread (tenofovir) or Ziagen (abacavir) resulted in a significant improvement in facial lipoatrophy after 48 weeks. Inclusion criteria included those with moderate-to-severe lipoatrophy, no history of tenofovir or abacavir use or resistance, undetectable viral load and on stable antiretroviral therapy for greater than or equal to 24 weeks. The control group included 17 individuals who had received collagen injections. The study saw no significant differences between changes in the tenofovir and abacavir groups. Total cheek volume for all patients at week 48 was comparable to those receiving collagen injections.

Similarly, a prospective, open-label single-arm substudy, GS 903e, demonstrated that a switch from Zerit (stavudine, d4T) to Viread in those on stable initial antiretroviral therapy showed significant improvements in triglycerides, cholesterol, and LDL (the "bad" cholesterol), and a significant increase in limb fat, while some small decreases in bone mineral density were seen.

Biojector for Fuzeon

Injection Site Reactions (ISRs) are the most frequent reported side effect for those currently injecting Fuzeon (T-20) using a needle. A study of the Biojector injection system, a needle-free, gas-powered injection system found that after 24 weeks ISRs were significantly reduced using the Biojector, and patients reported increased ease of use with the Biojector over the standard needle. Plasma levels of Fuzeon did not differ between the needle and the Biojector. Two of the 32 patients in the study (6%) stopped due to Biojector-specific adverse events (bruising and numbness). Longer-term safety and efficacy evaluation of the Biojector for Fuzeon administration is ongoing.

""Supervirus" loses its superpowers

Reports of a potential unusually virulent and highly drug-resistant strain of HIV found in a New York City man earlier this year (see "Superbug or Superdud?", May/June issue) now appear to be unfounded. According to Richard Jefferys, Basic Science and Vaccine Project Director of Treatment Action Group in New York, researchers are looking at whether dual infection could be to blame. Dual infection is when a person contracts viral strains from two different people before they develop immune responses. Superinfection is when an HIV-infected individual becomes re-infected years later; superinfection and dual infection may occur in up to 10% of newly infected individuals, and both are associated with rapid progression to AIDS.

Dr. Gary Blick presented at the conference and suggested that rapid disease progression in the New York patient could be due to heavy use of crystal methamphetamine. The poster abstract refuted the concept of a new aggressive HIV strain, while suggesting host factors may best explain the rapid progression to AIDS in the New York City patient. The patient is now responding well to treatment.

Current Drugs

by Enid Vázquez

Yea for Epivir

Encouraging early results were followed by success in the final outcome of the E –184V study, which used Epivir (3TC, lamivudine) during treatment interruptions.

The development of drug resistance to Epivir—the M184V mutation—is rather common. Fortunately, however, the resistance can have treatment benefit.

Italian researchers designed a study for patients with a failing drug regimen that included Epivir, who had Epivir resistance. Of 50 patients who requested a treatment interruption, half went off all their medications and half stopped everything but Epivir. Epivir is not only extremely well-tolerated, but it is also only associated with one HIV mutation. Therefore, Epivir monotherapy in people who already have the drug's resistance mutation is not going to lead to more drug resistance.

After a year, the Epivir group had a smaller drop in their T-cell counts, but it was not statistically significant. They did, however, have less of a drop in CD4 percentage, and this was statistically significant. So was the smaller rise in their viral loads. They also had a greater drop in viral load when everyone was put back on therapy at the end of a year.

The difference in clinical benefits was also statistically significant. The people continuing to take Epivir had less AIDS-defining illnesses. Researcher Dr. Adriano Lazzarin told Medscape.com that "patients love this solution." He said many patients weren't very comfortable going off therapy completely.

The study also found less "replicative capacity" in the people who continued to take Epivir. That is, the HIV in those people had a reduced ability to multiply.

Doctors everywhere are excited about the results of this study, which helps point to a new option for HIV management. More research is still needed. (See "The Buzz," March/April 2005.)

Kaletra only

The OK study (which stands for "Only Kaletra") from Spain was s'alright. After one year on Kaletra by itself, people did just as well as those in the comparison group, who were given a more traditional, three-drug regimen. They received Kaletra with two nucleoside drugs (for example, Combivir).

Viral load and T-cell changes between the two groups were not statistically significant – both of them did very well.

A viral load over 500 was considered a treatment failure. Of the three out of 21 patients on Kaletra only with viral load failure, all went back below 50 when two nucleosides were added to their regimen. Their viral load at the time of failure was 564; 1,270; and 3,600. One person decided to discontinue the monotherapy, and this was also considered a failure for Kaletra only.

The other good news was that none of them had a primary resistance mutation for protease inhibitors. Drug resistance, which can render treatment ineffective, is almost unheard of with Kaletra.

Watch for Kaletra only, plus resistance

Then there was the report of a man in Germany who did develop resistance to Kaletra, and in turn, resistance to other drugs in its class (protease inhibitors). Still to Kaletra's credit, such reports are so rare that the authors of this report noted that this is only the third one.

The German man had been on Zerit and Epivir for years, with a low viral load. After a treatment interruption of two weeks, his viral load increased to 49,000. He had no resistance mutations to the HIV protease inhibitors and was put on Kaletra monotherapy.

At three months, his viral load had been re-suppressed to less than 50, but at 10 months, it had rebounded to 49,000. He was found to have several mutations rendering him resistant to protease inhibitors, including the L76V mutation associated with Kaletra.

It's rare, but it can happen.

Four years with Viread

Viread is one of the "newest" HIV drugs on the market, so it's good to hear longer term data.

More than 90% of the 82 people starting HIV therapy for the first time still had less than 400 viral load after 192 weeks on Viread. They were also taking Epivir and Sustiva. The average change in T-cells was an increase of 391.

Some more good news: the bone mineral density loss that was seen in the first year of therapy did not progress. Only one person discontinued therapy because of an adverse event (Grade 3 amylase/Grade 4 lipase).

Experimental Drugs

by Matt Sharp

CCR5

It's truly hopeful that there is so much interest in looking at drugs to inhibit HIV by blocking a crucial CCR5 co-receptor on the host CD4 cell. Three compounds that block CCR5 were presented in Rio and appear to be in a near dead heat race. The "viroc" class, Pfizer's Maraviroc, Schering Plough's Vicriviroc and GSK 873140, are all looking to be the next promising antiviral drug class being astonishingly similar in development, safety and antiviral activity thus far.

A data overview of five Maraviroc studies was presented that showed the drug to have a significant antiviral effect at a 300 mg dose once or twice daily. So far the drug is safe. Larger Phase II studies are currently underway.

Vicriviroc is Schering's bet for a winning CCR5 antagonist. Studies in Rio showed the drug to have similar potency (up to 1.6 log drop in viral load) as the Pfizer compound, where a smaller dose is required to achieve adequate blood levels.

GSK 873140 appears to have a very similar effect as the former drugs in very similar studies so far.

At this point in time it is difficult to see much difference other than dosages in these three co-receptor antagonists. According to monotherapy studies the drugs appear to have similar rates of half lives, or what is being referred to as "occupancy", where the agent sticks to the co-receptor for a long time after the drug is administered. Schering and Pfizer spoke of doing or planning extensive drug interaction studies, especially with some of the brand new drugs. However, Vicriviroc and GSK 873140 will move forward in clinical trials with a Norvir boost. Fasten your seat belts, the race is on.

Reverset

Reverset is a new drug from an older class moving forward in a larger Phase II study. The hope for this nucleoside analog is that it will work against nuke resistant virus. A 3 phase study looking at treatment experienced individuals showed a modest reduction of virus levels (between .6 and .8 log drop depending on number of baseline mutations). Videx (ddI) will not be recommended for use with Reverset due to elevations of lipase and three cases of pancreatitis using the two therapies in combination. Also, due to drug interactions, Reverset cannot be taken with Epivir or Emtriva. Large Phase III trials will be opening soon.

Tibotec therapies

TMC-114 is a new protease inhibitor that is showing strong potent antiviral activity in people who are treatment experienced. A 24 week analysis of the drug showed substantial antiviral response and CD4 increases compared to an optimized background regimen. 114 will most likely be the next protease inhibitor approved and will be a welcome new option for people with protease resistant virus. An added benefit of using Fuzeon was also shown in combination with 114, the newly approved Aptivus or Kaletra. (See "New Protease Inhibitor TMC-114" in March/April 2005.)

New non-nucleoside drugs TMC-125 and 278 were also presented in several pharmacokinetic and interaction studies in Rio. Newer oral formulations are being studied as well the effect with food. Larger studies are underway and in planning stages to look at effectiveness. So far these compounds should work against non-nucleoside resistant virus, an important problem with this antiviral class. AIDS activists have lobbied for a first of its kind combination trial with two new investigational agents manufactured by the same company. TMC-114 and 125 will begin enrolling in this fall. The company is also studying a topical microbicide candidate that

is very early in development. These agents represent potential hope for treatment and prevention of HIV.

Maturation inhibitor

A new drug class that targets a later stage of the HIV lifecycle is slowly gaining attention. In Rio further analysis of the single dose study presented at CROI in Boston showed a long half-life of PA-457 in the bloodstream, and also showed appropriate pharmacokinetic parameters. Watch for a larger Phase II study.

Immune based therapy?

Human growth hormone got some significant attention in Rio and this time it was not for weight gain. Two separate studies showed increases in thymic mass and total and naive T-cells compared to HAART (highly active antiretroviral therapy) alone or in combination. One study also showed an increase in IL-7, an important immune signaling protein. Study participants received 1.5 mg a day for 48 weeks, or their HAART regimen by itself for 24 weeks, followed by the addition of 3 mg human growth hormone for 24 weeks, taken as once-a-day subcutaneous injections. So far IL-2 is the only immune based therapy that has made it to Phase III studies. Much more work needs to be done to prove human growth hormone will be useful for immune modulation, which could lead to new focus in research.

Summary

There were several posters and oral presentations of novel classes and mechanisms against HIV that are all in the basic science phase of research. One thing is true—the field of HIV research for drugs that may be effective for those in need of new options is here, although it may be years before we will see them at the pharmacy.

Crisis in Zambia (maybe)

by Keith R. Green

Reading through conference abstracts on the flight to Brooklyn for the Black Gay Research Summit, I stumble upon an interesting study done in the poverty stricken African nation of Zambia.

Although the details of the study mentioned in the abstract leave a lot to be questioned, many of the statistics in it alarm me. There is one stat in particular that practically jumps right from the page and onto my lap.

It isn't that 73% of the men in the study reported that they believe that anal sex is safer than having vaginal sex with a woman.

Nor is it the fact that more than 40% of the men who reported having sex with other men by choice also said that they only do it for money.

It isn't even that almost 95% of these men do not know that condoms are used in anal sex, either.

As alarming as those statistics may sound, believe it or not, there is something else in this study that is far more frightening. Of all of the men who reported having sex with other men in Zambia, none of them reported having ever been exposed to MSM (men who have sex with men) prevention or advocacy programs. Not one!

In fact, as the author of the study would later reveal, funds that have been allocated for such programs have been redirected towards other projects, such as prevention for female sex workers, because "HIV is not considered to be an exclusively MSM problem in Zambia."

The author also points out that though sex work is illegal in Zambia, as it is in most parts of the United States, there are still many programs that are directed towards female sex workers. And, although many men cross over into the sex work industry as a means for survival in that country, as we see from the 40% in the study who report only having sex with men for money, there are still no efforts being made at outreach for this incredibly high-risk population.

It is not mentioned whether or not any of the men in the study are HIV-positive or if they have ever been tested for HIV. However, it is estimated that more than 16% of the population of Zambia is known to be infected with the virus and, as is the case in the developing countries, heterosexual contact is cited as the most common mode of transmission

As I head to the "Big Apple" to gather with other African American men to discuss the state of the Black gay population in this country, I think about the progress that has been made at acknowledging the prevalence of homosexual behavior among Black men.

I think about how the lingering effects of denying such a truth have ultimately led to some 50% of Black gay men becoming HIV-positive.

The potential for an even greater tragedy awaits the people of Zambia, and many other countries across the globe, if the masses remain in denial about homosexual behavior and ignorant to the factors that put oneself and others at risk for HIV.

Why I Ride

Ride for AIDS Chicago raises funds, and awareness

by Sherman Johnson

One thing about being diagnosed HIV-positive and always faced with the possibility of death is that it led me to make some badly needed changes in my life. Up to the point when I was diagnosed with HIV in 1991, I hadn't accomplished a great deal with my life. I finished high school, but that was it. I spent many nights partying or looking for one.

I went to college and I obtained some degrees, and I started addressing the substance abuse problem that I had. I never really dealt with being HIV-positive except to see the doctor on a semi-regular basis and to get my medications. I wanted to look and be normal. The medications accommodated that.

Internally, my way of addressing my HIV status could not have been very healthy. I did not talk about it with anyone except my doctor. It was my dirty secret. I guess that that's what made Test Positive Aware Network (TPAN) so appealing when I saw the classified ad for a position that was offered there. Minorities and persons who were HIV-positive were encouraged to apply.

TPAN has many great attributes, but the one that I liked the most is that it is peer-led. This means that most of the staff who are employed here are HIV positive or living with AIDS. Now I could talk about my fears and think positively about the future. TPAN has also been a source of a lot of information. I learned, in detail, what HIV means, the latest treatment strategies, how to advocate for myself as a person who is HIV-positive and how to better manage my health. As a social services agency, TPAN seems to appreciate that there is more to living with HIV/AIDS than the medical aspect. The social aspect of being positive is addressed as well. We talk about relationships and sex, and we hold events to bring people who are impacted by HIV/AIDS together.

The Ride for AIDS Chicago was one such event.

Ride for AIDS Chicago was an event to raise funds for TPAN and another AIDS service organization, Better Existence with HIV (BEHIV). It was a bike ride over two days and 160 miles, from Chicago to Lake Geneva, Wisconsin and back. As soon as it was announced, I signed up. I signed up in part because I bought a bike the year before and I had been riding it and appreciated the challenge. Moreover, it was a way to give back to agencies that had been fighting for me before I knew how to or appreciated fighting for myself.

More than 50% of all new infections are in people of color. As a person who is in recovery, I know that drugs and alcohol greatly increase the risk of transmitting HIV or becoming infected, because it lowers your inhibitions and you're more likely to engage in risky behaviors. Lastly, those who are incarcerated are twice more likely to be infected. I am no stranger to the criminal justice system.

I must continue to do my part to spread the word that HIV/AIDS is a war that must be waged on many fronts. My part includes those things that I may do to keep the faces of HIV/AIDS visible. I am remiss in my responsibility if I keep quiet. So, I ride. I advocate.

The physical ride was long and arduous. Many times, I wanted to give up. For people who live with HIV/AIDS, giving up means death. Therefore, it is not a viable option. I finished the ride, but I continue riding.

Sherman Johnson is Buddy Program Coordinator and Information Referral Specialist for Test Positive Aware Network

Ride For AIDS Chicago

TPAN and BEHIV received more than $80,000 in net proceeds from the Ride for AIDS Chicago 2005, held June 4th and 5th. The rider registration fees, sponsorships and in-kind donations allowed TPAN & BEHIV to return 100% of the riders' pledges to the charities. Special thanks to our 90 riders and 31 crew members who participated in the 160-mile, round-trip ride from Northwestern University in Evanston to Lake Geneva, Wisconsin.

The 2006 Ride For AIDS Chicago will mark the 25th year of HIV/AIDS. Ride registration has already begun. The first person to register again was crew member Elvina Moen—going strong at 87! For further information on the Ride, visit www.rideforaidschicago.org.

Haiti—The Intersection of Race, Poverty and HIV

A doctor describes the impact of an epidemic on his homeland

by Keith R. Green

In the early 1980's, before HIV had been identified or AIDS was officially named AIDS, one poverty-stricken nation was thought to be the epicenter of the disease that was wreaking havoc on the lives of gay, white men abroad.

In an effort to identify high risk groups for this mysterious plague, the United States Centers for Disease Control and Prevention (CDC) placed Haitians on their list of "H's", alongside homosexuals, heroin injectors and hemophiliacs. In fact, early studies even suggested that HIV had originated in Haiti, and that people of Haitian descent carried a particular trait that gave them a predisposition for the disease.

The infant mortality rate in Haiti is the highest in the Americas and life expectancy, at approximately 52 years, is the lowest in the Caribbean. This small, famine-stricken nation also holds the title for the second-lowest per capita caloric intake in the world, with an average household income of $230 per year. As a result of such poor living conditions, crime, violence and prostitution became the way of life for many within the lower class majority.

In the late 1970s, inexpensive vacation packages drew many tourists to the Caribbean, to Haiti in particular. It is thought by many that the high prevalence of sex trade that took place between citizens trying to survive in their homeland and tourists seeking a better vacation yielded a plethora of sexually transmitted diseases, including what we now know as HIV.

In an effort to obtain a better understanding of the effects of such a dramatic series of events on an already fragile people, I sought out the wisdom of Dr. Fritz Lolagne, who was once a private practitioner in Haiti.

Dr. Lolagne and I became fast friends during an interview I conducted with him for TheBody.com, a comprehensive HIV treatment education website. He was a recipient of their 2005 HIV Leadership Award for his work in prevention education at the Center for Multicultural Wellness and Prevention in Orlando, Florida.

I credit him for being the first person to truly open my eyes to the extent of devastation that Black people, and not just those in America or in Africa, but Black people all over the world are experiencing from AIDS.

"For people who live in poverty," says Dr. Lolagne, "there are very few options for entertainment, so sex becomes a big deal. People can't go to the movies or watch television or listen to CD's, so what do they do for recreation? They have sex.

"The number one mode of transmission for HIV in Haiti is reported as heterosexual contact," he explains. "In my own private practice, largely due to our culture, not many people would admit to being gay or to having sex with anyone of the same sex. Homosexuality is completely taboo in Haiti."

Although the people of Haiti live in great denial and silence about the existence of homosexual behavior, the exact opposite is true for Haitians about their HIV status.

"The people of Haiti feel that if they spread the word, they can garner support and, therefore, their fight will be much easier," says Dr. Lolagne. "Hiding creates stigma and stigma creates separation. Our situation is far too intense to isolate anyone."

It is estimated that nearly 5 percent of the population in Haiti is infected with HIV (15 times the rate of infection in the United States). According to Dr. Lolagne, achieving adequate healthcare for the masses is a task that appears to be virtually impossible. "Our resources are very limited. We have some great people there doing some really great things, but I am afraid that it just isn't enough."

A dispute between the administration of Haiti's president, Jean-Bertrand Aristide, and the small non-Haitian coalition of powerful entities that oppose him have caused some $500 million in approved international loans and grants to be blocked. "There are resources available," Dr. Lolagne says in desperation. "But it appears, at times, that for one reason or another, the entire world has turned a deaf ear to cries of the people of Haiti."

One major effort that Dr. Lolagne speaks highly of is Zanmi Lasante (Creole for Partners in Health), located in Cange, Haiti. Zanmi Lasante is headed by Paul Farmer, an American doctor from Harvard Medical School. Aside from providing healthcare to more than 1,500 Haitians living with HIV, Zanmi Lasante also runs schools, makes sure that the local water is safe to drink, and helps to provide jobs for hundreds of people.

Partners in Health has been successful in reducing the cost of antiretroviral therapy down to $1,000 per year per patient from about $10,000 (roughly the average cost for anti-HIV medication in the U.S.). Amazingly, they have also been able to ensure, through private donations from non-governmental agencies, that all of their patients who are in need of medication receive it.

But even with such great progress being made, there remains a huge deficiency in overall healthcare in Haiti, especially for those living with HIV. At times, there are literally hundreds of people who sleep outside of the Zanmi Lasante clinic, awaiting their turn to see a doctor. And because clinics such as this only exist in urban areas throughout the country, the devastation brought on by the epidemic in rural areas is magnified.

"I am really saddened at times by what I see when I return home," Dr. Lolagne says. "I try to gather as much knowledge and material as I can so that I can share it with my colleagues back in Haiti."

Dr. Lolange strongly believes that the road out of poverty and disease for the people of Haiti is paved with education. "When people are poor or sick or hungry, education is the furthest thing from their minds," he explains. "We must somehow provide them with the resources they need to educate themselves and take control over their own destiny."

Passing the Torch

Charles Clifton and Gigi Nicks honored by new program

by Keith R. Green

From Kelvin Johnson's perspective, there is something seriously wrong in the African American HIV community. As co-chair of the Chicago Area Ryan White HIV Services Planning Council and a 44-year-old Black gay man living with HIV, Johnson bases his theory on the latest statistics made available by the Centers for Disease Control and Prevention (CDC) regarding African Americans and HIV.

According to recent studies made public at this year's HIV Prevention Conference, African Americans, who make up only about 13% of the country's population, now account for nearly half of its HIV infections. One study also suggests that roughly half of all black men who have sex with other men are HIV-positive. As many Black professionals within the HIV/AIDS community scratch their heads for a viable solution. Johnson is directing his drive for resolution towards a very personal and meaningful endeavor.

Last year in August, Johnson lost two of his most cherished mentors and friends, both of whom happened to be incredible forces in the HIV/AIDS community. He credits one of them, *Positively Aware's* beloved editor and executive director, Charles Clifton, for helping him to realize his potential to become an effective community leader.

"I was whining and complaining about my life and he said, 'What are you going to do to help someone else?' I was shocked. Me? A former substance abuser? I remember him saying, 'You know you are smart…you need to get up off of your ass and help somebody else,' " Johnson says with a warm smile that reflects the fond memories he holds of his mentor and friend, who passed away in August 2004 of a blood clot that traveled to his lungs. "Nobody had ever said anything like that to me in such a real way and with such love, what else could I do besides take his words to heart."

From there, Johnson went on to volunteer in various capacities and soon became outreach coordinator for Test Positive Aware Network (TPAN). Two years ago Johnson enrolled in TPAN's TEAM (Treatment Education Advocacy Management) program, an intensive, year-long training commitment that is designed to educate both those living with HIV and the people who provide services to them.

Upon receiving his certification from TEAM, Kelvin was encouraged by another of his mentors, the late Gigi Nicks, to put his newfound knowledge to use in direct service to people living with the virus. He took on the role of Prevention and Education Peer Counselor, beside Nicks, at Chicago's CORE center, and became a member of the Planning Council, of which he is currently the co-chair.

> "If we are going to beat this thing," says Johnson, "we have got to do what Gigi and Charles did for me."

Now, more than ever, following the CDC's big announcement in June, Johnson can feel the huge void that exists in the HIV community from the passing on of these two heroes. "We need leaders," he says, with a trace of sadness in his voice. "Not that we could ever replace Gigi or Charles, but somebody has got to pick up the torch and run with it."

In an attempt to do that and to honor his role models at the same time, Johnson has teamed up with the CORE Foundation of Chicago and other major players in the HIV/AIDS community to create the T.O.R.C.H. institute. T.O.R.C.H. (which stands for Teaching, Organizing and Reaching Community HIV Advocates) is a living tribute to the leadership and advocacy work of Charles Clifton and Gigi Nicks. Expected to launch in the fall of 2005 in Chicago, the T.O.R.C.H. institute is a leadership and advocacy training program designed to identify and strengthen a team of community advocates at the local, state and national levels who will assume the role of community leaders.

"If we are going to beat this thing," says Johnson, "we have got to do what Gigi and Charles did for me. It is important to not only recognize a new breed of community leaders, but also to equip them with the knowledge and resources that they need to be effective and to do the work."

Like his mentors who have gone on before him, Johnson also understands the importance of using a diverse group of players on the field. "Right now, HIV is impacting African Americans at an alarming rate, and I agree that Black people have to take ownership and responsibility for ourselves," he says. "But when my house is on fire, I am not going to sift through firefighters until I have rounded up all of the Black ones to have them to put it out! I would put every willing and able body to use in order to save my house."

The steering committee for the T.O.R.C.H. institute, which is presently hard at work developing its curriculum and infrastructure, is a direct reflection of this mentality. Hand-picked by many who have worked closely with both Clifton and Nicks, the members represent an overall balance of demographics, geography and expertise within the HIV/AIDS community.

"Working on this project helps me to get through this (my loss)," says Johnson. "It makes me okay. I feel like I am giving something back to the legacy of two people who dedicated their lives to helping others, and that makes me feel good."

For more information, contact Matt Sharp at Test Positive Aware Network, m.sharp@tpan.com.

How I Became My Doctor's Free Continuing Medical Education Provider

For one, Oxandrin does not equal Excedrin

by Carlos A. Perez

I recently lost my position as Editor of the HIV Services Directory that TPAN published for 15 years, basically due to Bush's cuts. I was blessed and found another job during January 2005, as manager at one of the Rapid HIV Testing Programs for Access Community Health Network.

For healthcare coverage I chose the HMO (Health Maintenance Organization), because I couldn't afford the PPO (Preferred Provider Organization).

I know there are people at Northstar Medical Services saying "I told you so," but this choice was based on the pocketbook. Believe me, my HMO does not have the handsome and gay-friendly doctors who know HIV inside and out and gorgeous patients in the waiting area that Northstar is known for (sigh).

HMOs require that I see an Internal Medicine or Family Practice doctor before I can see an Infectious Disease Specialist.

The first time I saw an internist, Dr. So-and-So says, "I am 50 years old and have had this practice all my life and I run a tight ship around here, and I am not going to have my office shut down by prescribing some of these medicines."

I looked at him and said something like "what?" He was treating me like I was some fat, hypocrital, Republican-butt-kissing radio host. I told him that most people with HIV experience nervousness, anxiety and depression, and that's just a few of the mental side effects.

It was back to the HMO doctor-finder. As soon as I uttered "HIV" to the new internist, he said, "You don't belong here. You need a PPO so you can get the care you need. Do you know how much work it is within this HMO to get you to your specialist?"

"Umm, no, I was under the impression that I see you and you refer me to the Infectious Disease doctor and if I show signs or symptoms of any HIV-related illness you can use another type of referral that will let me see the specialist on a regular basis." "Who told you that?" "The customer service people at the 800 number," I replied. "Yeah, well, what they tell you and what really happens are two totally different things," he replied, looking rather upset.

"That's like marijuana," he whispered, as if the DEA was tapping his phone line.

A few days passed and I needed some refills. He called to tell me he had a problem prescribing Oxandrin. He said, "This is a steroid and I do not feel comfortable prescribing steroids." I told him that Oxandrin has been approved by the FDA and has been in use for many years by HIV specialists for their positive patients, especially long-term survivors like myself. "But these steroids are not good for you, haven't you heard the stories about athletes dying from taking steroids?" He sounded very serious and I was thinking, How could he be so ignorant?

I responded, "Yes I have, but these athletes are taking injectable steroids and they are self-administering them in huge dosages equal to more than what an HIV-positive person takes in Oxandrin in one week!" He queried further. "What would happen to you if you stopped taking the Oxandrin? Wouldn't you look and feel okay and maybe be just a little less buff?" I could not believe my ears.

"If I stop the Oxandrin I will start to feel tired in about two days and in about two to three weeks I would lose a lot of my muscle mass, and within six months there is a very good chance that I would lose my lean muscle and then start to lose weight little by little." I paused. "Oxandrin is used to stave off wasting." He did not sound convinced. "I'm going to have to ask the Infectious Disease specialist about this before I approve this prescription. And the Marinol…" "Uh huh?" I responded. "That's like marijuana," he whispered, as if the DEA was tapping his phone line. "What do you use that for?"

I use it to help me with the nausea and vomiting that can frequently occur as a side effect from my HIV combination therapy. "But there are other drugs you can take for that; have you tried Compazine or Pepto Bismol when you feel nauseated?"

At this point I knew I should be getting paid for all this "free" continuing medical education. "When I feel nausea from the HIV meds, I could take Compazine or Pepto Bismol, but I guarantee you that I will vomit that up with the rest of the

Photo © Russell McGonagle

contents of my stomach, including my last dosage of HIV meds that made me upchuck in the first place." He sounded grossed out. I wished I could puke on his shiny patent leather MD shoes.

"I will have to confer with your Infectious Disease specialist about these two drugs," he said. Both drugs were finally approved and I quickly signed up for the three-month prescription service by mail.

I recently visited his office for a routine check–up and he left the room with my chart on the desk opened up to the day's notes. Naturally I perused my files. I found his letter to my specialist in which he was asking about the Oxandrin and Marinol. I was really impressed with the specialist's reply; he really knows his stuff and I wish I did not have to go through the HMO red tape and hoops of fire to get to the doctor who understands my medical condition, but I did not make the rules. The best part was how the HMO internist spelled Oxandrin. What he spelled out was Excedrin! I laughed out loud, but quickly gagged myself thinking they'll think I'm mad.

So sign up for your CME courses right here with Carlos A. Perez, because it's my kind of life in your kind of world!

Readers Forum continued

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lives is the reason most people die—not forgetting the loneliness brought by shame that is made visible by those who make you feel inadequate and less human just because you are HIV-positive—not sick, not realizing that you did them a favor by disclosing your status to them, that alone is love at its best—otherwise you would have infected them all by being silent and taking out your frustrations on them, but yet you did the opposite. All you need is love, not judgment. Keep on being strong and don't lose the faith, Justin. May the good Lord help you find the right man for you, dear. That's what all of us are looking for—the right person who can love us unconditionally.

Name withheld, via the Internet

I wrote a poem recently, shortly after testing positive. I have been struggling with the old "death sentence" mentality and have been trying to adjust to this new reality. I have been having the same feelings as Justin shared in his article. I really enjoyed it. I hope you will forward my poem on to him.

R.J. Sloan, New York

View this poem online at www.tpan.com

Great Issue

Jeff, Enid, and the crew

I have to say that the July/August issue is your best yet. One compelling and informative article after another. Keith's interview with Tim'm west, Jeff's article about the CRA van, Eddie Young's Crystal Meth story, and Derek's about the needle exchange program were highlights, but it was all worthwhile reading.

Keep up the good work. Thank you.

Ann Hilton Fisher
Executive Director
AIDS Legal Council of Chicago
www.aidslegal.com

Squat Close to the Load

When safety really matters

by Jim Pickett

Every one of the 3,000-plus participants at the 2005 National HIV Prevention Conference received a safety manual, aptly titled "Safety", stuffed into their conference goodie tote bag. Including yours truly.

And I for one had a reaction that went something like, "thank goodness." The world is a dangerous place filled with all manner of risk equations that we must constantly assess and calculate and come up with the best answer to minimize the potential harms that could very well befall us had we not recently perused "Safety." The 14-page booklet was filled to the rim with safety guidelines that really came in handy as I scampered between plenaries and workshops and press conferences, dodging researchers and outreach workers and public health administrators networking madly throughout four intense days in Atlanta. Oh, the horrors I averted! Oh, the bad things that didn't happen!

The guide wasted no time at getting to the nitty gritty, opening up with a whole section on falls, with tips like "close drawers completely after every use" and "avoid excessive bending, twisting, and leaning backward while seated." If there is one way to get in trouble, it's excessive bending, my dears. Been there. Modified that behavior and don't want to go back.

Following the final "avoiding falls" intervention—"roll, don't reach"—began a section on strains and overexertion.

"Is this too heavy for me to lift or carry alone?"

"Am I trying to impress anyone by lifting this?"

These important practical and psychosocial self-assessments were addressed with a number of "safe lifting steps." The one that I identified best with was the simple and elegant "squat close to the load." It's a modus operandi that will surely come in handy in the months and years to come. I have decided to include the phrase in my daily affirmations. "I am valuable. My life has meaning. The world is my oyster. Squat close to the load."

A section on the application of good work practices included a number of those "wow, I wish I had thought of that" suggestions. For instance, placing your computer monitor so that it is directly in front of you is preferred. And you might want to tilt your computer monitor slightly downward to avoid glare. See what I'm saying? It's such a simple intervention, it's genius. Things needn't be complicated or convoluted to be effective, that's how I look at it.

Telephonic concerns? Well, let me share that the proper method one should employ while holding a telephone does not include "cradling" said object between head and shoulder. The guide hits the mark on this one. I think it's pretty clear why that's a bad idea. Follow the science. But let's be honest here. How many of us are guilty of engaging in this improper technique at one time or another? I'm not trying to get on a soapbox or get all up in your face about this, I just think it's an area where we all could stand to improve, me included. Telephones should not be cradled, period.

Electrical safety, fire prevention strategies, elevator entrapment and severe weather threats were all given their due.

Here's one that needs no introduction or explanation. "Move between different postures regularly; don't stay in one position for long periods of time."

Okay? Hello! Don't need to tell me that twice.

"Take mini-breaks to rest the eyes and muscles." I hear that! I was most pleased, as an over-performing Type A professional born and raised into a strong Midwestern work ethic, to read the second part of this strategy, "A break does not have to be a stop of work." Maintaining productivity while concurrently giving oneself a break—brill. I love it!

Electrical safety, fire prevention strategies, elevator entrapment and severe weather threats were all given their due.

Pretty comprehensive. I am sure lots of bad lifting was prevented at the conference. I feel safe in surmising that cradling incidence was most likely down and that "rolling and reaching" prevalence was up—both good things. I pondered this road safely traveled as I dug deep into the conference tote, searching among the pens and pharma-sponsored mints and assorted crap for…hmmm, it must be here somewhere.

What, no condom? No lube? No condom, no lube at an HIV PREVENTION conference with 3,000 sexual beings talking about unprotected receptive anal intercourse all day?

Nowhere to be found. Heard through the grapevine that a condom distributor in the exhibitor hall had offered to stuff all the bags with these types of goodies and was told by the conference organizers, "No thanks." Not in my Bush (Administration). This is a government-run conference, by the watch-out-for-condoms Centers for Disease Control and Prevention (CDC).

No condoms, but 14 pages of squatting close to loads. Whatever.

Photo © Russell McGonagle

Programs and Meetings

All meetings held at TPAN unless otherwise indicated:
5537 North Broadway, Chicago.
Office hours: Monday–Thursday, 9 am–8 pm. Friday, 9 am–5 pm
phone: (773) 989–9400 • fax: (773) 989–9494
e-mail: tpan@tpan.com • www.tpan.com

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

Monday

Medical Clinic

HIV and Syphilis testing and full medical care for HIV-positive clients is available. Program is offered by Access Community Health Network. Call for an appointment. From 10 am–6 pm.

TPAN Daytimers

A support group for people with HIV who prefer to meet during the day. Meets from 10:30 am–12:30 pm.

Reiki

Energetic healing practice that utilizes hands-on touch and focused visualization. Monday by appointment only.

Crystal Meth Anonymous (CMA)

Support group for individuals for whom crystal meth has become a problem. Meets 7:30–9 pm.

Spirit Alive!

A collaborative effort of AIDS Pastoral Care Network (APCN) and TPAN. Meets from 7:30–9 pm. Socials every other month, on 3rd Monday beginning in November.

Tuesday

Medical Clinic

See description on Monday. Call for an appointment. From 9 am–12 pm.

Positive Progress

A peer-led group for HIV-positive individuals in recovery. Meets from 7–9 pm.

Living Positive

HIV-positive individuals discuss how being positive affects life and relationships. Socials and speakers on occasion. Meets from 7:30–9 pm.

Wednesday

Reiki

See description on Monday. Wednesday by appointment only.

Test Aware

TPAN's new rapid HIV counseling and testing program. Learn results in around 20 minutes. Wednesday by appointment.

Needle Exchange Program

Through a collaborative effort of Chicago Recovery Alliance and TPAN, a free, anonymous, legal syringe exchange and HIV/AIDS prevention are offered Wednesdays from 5–7 pm, or by appointment.

SHE (Strong, Healthy and Empowered)

HIV-positive women discuss needs, concerns and issues facing women with HIV. Meets from 7:30–9 pm. Socials every 4th Wednesday.

Thursday

Yoga

All levels of yoga are welcome. Meets from 10–11 am.

Medical Clinic

See description on Monday. Call for an appointment. From 12 pm–8 pm.

TPAN Daytimers

See description on Monday. Meets from 10:30 am–12:30 pm.

Needle Exchange Program

See description on Wednesday. From 2–5 pm, or by appointment.

BUS (Brothers United in Support)

Support group for HIV-positive gay and bisexual men of African descent. Monthly socials and speakers on occasion. Meets from 7–9 pm.

Thursday continued

Positive Now

Support group for newly diagnosed HIV-positive individuals who seek support, education and the opportunity to share their experiences in a relaxing, empowering environment. Meets from 7–9 pm.

Pulse at Berlin

A weekly social for HIV-positive individuals and friends. Meets from 6–10 pm at Berlin Nightclub, 954 W. Belmont, Chicago.

Friday

Needle Exchange Program

See description on Wednesday. From 2–5 pm, or by appointment.

Scheduled By Appointment

FASN (Family AIDS Support Network)

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

Individual Counseling

AIDS Pastoral Care Network (APCN) professionals provide individuals with one-on-one counseling on Mondays. Ask for Sherry or Betsy at (708) 681–6327.

Peer Support Network/Buddy Program

Trained volunteers provide one-on-one peer, emotional support to individuals living with HIV. Call Sherman at (773) 989–9400.

Speakers Bureau

Individuals are available to community groups to educate peers on HIV, safer sex, and harm reduction. Call Matt at (773) 989–9400.

TEAM (Treatment, Education, Advocacy and Management)

Peer-led, 18-hour training program integrating secondary prevention and HIV treatment education to people living with HIV and those affected by HIV. Call Derek at (773) 989-9400.

TPAN Events Calendar

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

September 2005

Date	Time	Event
Wednesday 7th	7-9 pm	Committed to Living Educational Forum: "Holistic Health and Complementary Therapies" - Speaker: Gary Bucher, MD
Saturday 10th	6 pm	The Aware Affair: TPAN's Annual Gala, Hyatt Regency – Chicago, 151 E. Wacker
Thursday 15th	7:30-9 pm	H.E.A.L.T.H. – an HIV/Hepatitis C co-infection monthly support group meeting
Thursday 15th	9 pm	Porn Fest, The Lucky Horseshoe - Chicago, 3169 N. Halsted
Saturday 17th	10 am	AIDS Run and Walk Chicago, Grant Park
Wednesday 21st	7:30-9 pm	Legal Clinic: "Confidentiality in Employment"
Thursday 29th	6-10 pm	PULSE Monthly Party, Berlin Nightclub – Chicago, 954 W. Berlin

October 2005

Date	Time	Event
Wednesday 5th	7-9 pm	Committed to Living Educational Forum: "Making HIV Vaccines a Reality" Speaker: Edd Lee, AIDS Vaccine Advocacy Coalition
Friday 7th	6:30-8:30 pm	TPAN Volunteer Training - Topic and speaker to be announced
Tuesday 11th	6-8 pm	TPAN Community Advisory Board Meeting
Tuesday 11th	7-9 pm	Fuzeon Empowerment – North Contact Barb at 773-989-9400 ext. 237 for more information
Saturday 15th	10 am – 8 pm	Shopping Works Wonders - Bloomingdale's – North Michigan Avenue, Chicago
Thursday 20th	9 pm	Porn Fest, The Lucky Horseshoe - Chicago, 3169 N. Halsted
Saturday 22nd	9-5 am	Women Living, Ramada Inn Lake Shore RSVP to Barb at 773-989-9400 ext. 237
Tuesday 25th	7-9 pm	Fuzeon Empowerment – South, The Little Black Pearl Workshop Contact Keith at 773-989-9400 ext. 252 for more information
Thursday 27th	6-10 pm	PULSE Monthly Party, Berlin Nightclub – Chicago, 954 W. Berlin
Friday 28th	12 -2 pm	Committed to Caring (a series of forums designed for case managers, CME letters of attendance available). Co-sponsored by Midwest AIDS Training and Education Center (MATEC). Topic: "Co-morbidities of Living With HIV" Speaker to be announced.

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