

November / December 2003



Positively Aware

The Journal of Test Positive Aware Network

World AIDS

- Eastern Europe
- Vietnam
- Botswana

**More New Drugs
Managing Side Effects**



Combivir
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Volume 14 Number 6

ON THE COVER

Saigon, Vietnam 2003. 17-year-old who contracted HIV from sharing needles. He couldn't sleep well for weeks due to side effects.
Photograph by James Tuong Nguyen

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Saigon, Vietnam 2001

Photo by James Tuong Nguyen

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WHERE'S THE SILENT MAJORITY?

by Charles E. Clifton

For more than 1,000 days HIV prevention and care initiatives have been held hostage by the federal government. This national crisis has caused great distress to those of us on the front lines of the AIDS movement. Highly successful HIV prevention strategies targeting individuals and communities most severely impacted by HIV have been under constant scrutiny from the government. While thousands of individuals become infected with HIV and nameless others living with HIV and AIDS struggle to access a bankrupt healthcare system, the government continues to mischaracterize scientific facts to bolster political agendas in areas ranging from abstinence education and condom use to missile defense.

I for one am fed up watching advances in science and healthcare initiatives spiked with politics to justify conservative policies. I am sick and tired of seeing appointments to key scientific advisory committees given to people with political, rather than scientific credentials. AIDS is a complex disease that requires a sophisticated response. There are still far too many men, women and children who do not have access to comprehensive health care and lack adequate insurance coverage, too many are living with untreated mental health illnesses, too many are homeless and hungry, and far too many of them are still living in fear and isolation as the stigma attached to HIV disease continues to permeate families and communities nationwide. Diverting AIDS dollars to promote an ideological agenda and ineffective programs is a waste of scarce resources, and more importantly, a waste of lives.

But what is even more troublesome is the economy within the AIDS movement. Too many of us have become too comfortable with our "AIDS jobs", our "AIDS stipends", and our "AIDS subsidies". Once upon a time working for a community-based organization was about local volunteerism; about giving back to the community that had supported you in one way or another at one time. If you got paid to do this work it was a nice bonus. Yes, as we grow older our perspectives on life also changes, however, working at a community-based, non-profit organization is still about giving back, and sometimes giving back means sacrifice and doing without. While the non-profit arena brings a "relaxed" work environment, it's not glamorous. The hours are demanding, the job expectations are often unrealistic, and for the most part the pay sucks. I've seen many friends struggle with the decision of moving from the non-profit to private workforce during the last couple of years. But it's a decision we all have to eventually face.

This problem also extends into the community of individuals who survive and thrive because of "AIDS stipends". Far too many of us have become accustomed to, too dependent upon the benefits... the vouchers, the subsidies, the pantries, the AIDS Drug Assistance Programs, Medicaid and Medicare. We expect these benefits to continue rolling in month after month, indefinitely. And if there's a problem with delivery, we expect someone else to handle it.

Well, for those who haven't been paying close attention, the economy sucks big time and the government is cutting back on the Ryan White CARE Act and all the programs that have "supported" us over the last decade. Reports indicate that 43.6 million U.S. citizens were uninsured in 2001. That figure is up 2.4 million from the year 2000. Today more than 35% of Americans live without insurance. This condition has been brought on by higher unemployment rates and health care costs that continue to skyrocket. Small not-for-profit and for-profit businesses are making difficult choices of passing on escalating insurance premiums to employees or canceling coverage all together. As a result many individuals are making difficult decisions to live with an untreated illness, like HIV, or racking up bills they will never be able to pay.

While many of us have been asleep at the wheel, during the last three years, nearly three million domestic jobs have been lost and the number of men, women and children living below the poverty level continues to climb. Georgia, which already has a struggling ADAP, is looking at a 10% cut in HIV/AIDS funding for fiscal year 2004 and 2005. South Florida has seen its waiting lists expand as the number of HIV/AIDS patients seeking assistance grows faster than the federal Ryan White grants. An increase in domestic AIDS spending proposed in an amendment introduced by Senator Charles Schumer (D-NY) failed in Congress in September. With an increasing number of HIV positive individuals unable to afford the skyrocketing costs of antiretroviral therapy and management medicines, the planned domestic spending for HIV/AIDS care in 2004 displays a disturbing lack of concern for individuals living with HIV and AIDS in the U.S.

Far too many of us spend too much time making obscene references to being the "core" group of this organization or that movement; or pointing fingers and accusing "others" of taking their slice of the pie. Well, it doesn't matter if you're a gay man, a single mother of four, or a clean and sober ex-offender—it's five minutes to midnight, Cinderella. And it ain't gonna be pretty at

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CORRECTIONS

In the September/October issue of *Positively Aware*, a listing for the Bay Area Perinatal AIDS Center (BAPAC) was inadvertently left out of resources for couples wishing to have a baby. BAPAC is part of the University of California, San Francisco's Positive Health Program at San Francisco General Hospital. The center offers preconception counseling and infertility work-up to seroconcordant and serodiscordant couples (both partners are positive or only one is positive). It also conducts prenatal care to HIV positive women. Call (415) 206-8919. Visit <http://php.ucsf.edu/bapac>.

The description for SMART was also inadvertently omitted. SMART (Sisterhood Mobilized for AIDS/HIV Research & Treatment), in New York City, provides treatment and prevention education and support for women impacted by HIV/AIDS. Contact SMARTUNIV@aol.com or visit www.smartuniversity.org.

Left out among the few fertility centers that help HIV positive men conceive a child was the Jones Institute for Reproductive Medicine in Norfolk, Va., a division of Eastern Virginia Medical School (EVMS). The Jones Institute was the birthplace of the nation's first "test tube baby." Call (800) 51-JONES (800-515-6637) or (757) 446-7100. Visit www.jonesinstitute.org.

Also, sperm washing cannot cleanse "genes for disease." *Positively Aware* regrets the oversights.

SAME BOAT

The article was grrreat ("I get blessings, I get lessons," Positive Empowerment, July/August)! The man outlined in the article even greater... hats off to the success! I wonder what reversed the wasting? Was it the exercise? (I've always felt and done better when I've exercised a few times a week.)

He spoke of the difficulty exercising after a close call in the hospital. That's where I find myself at present. Our life stories are remarkably similar and I now find myself with a low count, low weight, low muscle tone and of course low energy (and I'll spare you the details of the side effects, especially those which rear their face in public).

Secondly: I don't believe I heard or read anything on T-20, so I've got some research to do. Thanks.

Name withheld, via the Internet

Editor's Note: Greg Braxton, author of the article, tells us that, "My doctor took me off T-20. No use to keep injecting. We're waiting for a new drug that comes out in the fall. But I've been feeling good, exercising and juicing carrots and stuff like that. That keeps my energy up." In his article Greg had reported good early success with Fuzeon (T-20), but his viral load later came back up.

GLOBAL AID

Thank you very much for your magazine, which I have been receiving regularly every two months. The publication is a source of enlightening and educative information on the devastating pandemic of HIV/AIDS. I am a retired medical/health worker in a resource-poor country, where the pandemic is claiming 700 lives daily and has reduced life expectancy to 45 years. Your journal is the only informative publication which I could readily lay hands on and share with my fellow community social workers among people with HIV and orphans. Please continue providing us with the journal, which is readable and beneficial, although we are unable to pay for it!

J.W. Makayoto, Kenya

NEW-FILL

I just had my first New-fill treatment last week in NYC. Wow, I got my "old" face back. What a huge boost to my morale. However it is starting to disappear just as the doctor said it would. I was kinda mad about that because even though I asked him endless questions about the product and what to expect, I guess the one question I did not ask was answered after he was through injecting the New-Fill and I had paid my \$800 (meaning he did not tell me it would disappear in a week until he was finished!). So I had my old face for about a week and now my "lipo face" is returning, which is very depressing. I am scheduled for several more treatments. Hopefully the effect will be "cumulative," as he assures me it will be—"It's like building a wall with bricks—you have to put up layers to see a good effect"—thus the need for multiple appointments. "We are building the foundation." My questions for Jeff Berry ("New-Fill for an Old Face," May/June 2002) are this—have the treatments you received improved your face? Has the effect (facial filling) lasted more than one week? Are sunken areas filling in? Has the effect been cumulative and lasting? I hate to waste money that I really don't have. Did you have lidocaine injected first? Or ice? I had neither and it was very painful. Thanks in advance for reading this and I hope you are able to respond to all my questions.

Name withheld, via the Internet

Jeff Berry responds: Thanks for your e-mail. First and foremost I would like to comment on your last questions: Absolutely I had lidocaine and ice, and I would think that it is standard procedure before injecting

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New-Fill (it was painful enough with those things, so I can't imagine what it was like without). Lidocaine obviously to minimize pain, and ice to reduce swelling. Be sure to bring it up with your doctor before he does another procedure. The four treatments that I received really did help, but after 3-4 months it reduced considerably. I did see improvement, although not as much as I had hoped (the effect was cumulative, it is normal for the first treatment to be absorbed in one week). I was supposed to go in for a booster shot around 12 months after my last treatment, but could not afford it. I am still paying for the treatments that I began receiving almost two years ago! I hope this helps, if you have any other questions, please let me know. Good luck!

I have been researching the availability of New-Fill or other alternatives for facial wasting and have come across many of your articles [by Dr. Daniel Berger]. I have been taking HIV medications for 13 years now with no opportunistic infections, with a T-cell count that has ranged between

170–450 and a viral load anywhere from 100,000–500,000. I have taken most medications available and currently have completed another phenotype test to determine yet another change. I live a very full, healthy life; am professionally employed and have a wonderful soul mate who I've known for 20 years and have lived with for the past four. Within the past year I have begun to notice my face changing and it bothers me for all of the self-esteem and associated reasons. I have just begun researching my options and came across your name. Would you be able to tell me the current status of New-Fill or any other facial wasting corrective alternative and the availability of treatment in the Hartford, Connecticut area. I am financially able and willing to travel anywhere in the U.S. Also, as I am in the process of switching my medications, could you clarify if there are any ones which are less related to facial or muscle wasting than others? I have read many statements which indicate Zerit as being the worst. Thank you for your time.

Name withheld, via the Internet

Dr. Berger responds: I believe that Zerit has contributed greatly to patients' facial wasting. Some patients are switching to tenofovir (Viread) or abacavir (Ziagen). They both are potent antivirals with better safety profiles than Zerit. There are other medications, and depending on your medical history, can be substituted for Zerit in your regimen. This alone may help your facial problems substantially, and at least retard the propensity for the lipoatrophy to worsen. There are various facial filling procedures, starting from fat transfer to various products that are being used to fill the face. If you have subcutaneous abdominal fat or a buffalo hump then those could be obvious places to remove fat and inject into one's face. Since it is your own tissue it has a low likelihood of causing problems. Various products include silicone, New-Fill, Radiance, etc., to name a few. I can't recommend one over another without discussing each in detail. Also some anabolic therapies can also be of some help. Thanks for writing. ☚

Editor's Note continued

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half past the hour. If you thought the last three years were tough, you ain't seen nothing yet.

The bottom line is that with cuts and flat funding for Ryan White CARE Act programs, an increasing number of uninsured, underinsured and poor individuals living with HIV will have reduced access to care and treatment.

Somewhere out there I know that there's a silent majority in this struggle against AIDS; a majority that feels the pinch of the economy, that questions the government's AIDS policy and wants to change the status quo. Unless more of us are willing to speak up and take action, in 2004 and beyond, community-based organizations will be expected to provide the same services with less funding and individuals living with AIDS and families impacted by HIV will be forced to make ends meet with less assistance.

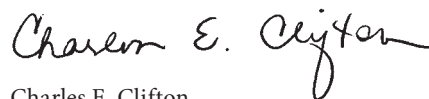
Now is the time, more than ever, that the voices of men and women living with and impacted by HIV and AIDS must be heard on a local, state and national level. You can no longer afford to sit on the sidelines and expect someone else to do it for you or to give

it to you. It's time to put an end to the "gimme syndrome" and the "pity party."

What can you do? What should you do? Get involved. Organize. Strategize. Mobilize. Vocalize. Vote.

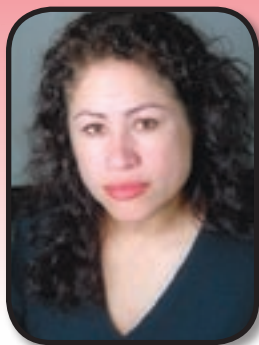
I challenge each of you to become involved in the AIDS movement—to further the ability of people living with HIV to have access to the services needed to live healthy and productive lives and maintain the personal rights and liberties that many of us take for granted. In the words of Margaret Mead, "never doubt that a small group of thoughtful committed citizens can change the world... indeed it's the only thing that ever has."

Be Strong. Stay Safe.



Charles E. Clifton
Executive Director / Editor

Send comments and reactions to ed@tpan.com



by Enid Vázquez

UPDATED HIV TREATMENT GUIDELINES

The U.S. Department of Health and Human Services in July updated its treatment guidelines for HIV. The DHHS panel simplified its complicated treatment regimen box that suggested picking one drug from Column A and two drugs from Column B. Now the guidelines direct people to start therapy with one of two regimens, a drug combination that includes either the protease inhibitor Kaletra or the non-nucleoside analog Sustiva. You still have a box with information about other combinations. There's also a separate box for drug combos following the initial regimen, along with a list of considerations for people who've already had anti-HIV therapy.

As always, remember that these are guidelines, not golden rules. With the number of HIV drugs on the market today, you can put together thousands of combinations. As one doctor said, "That would make a phone book."

The guidelines include information on the potency and durability of regimens, toxicities of the drugs, underlying medical conditions that might make someone more susceptible to these toxicities, side effects of the medications, dosing frequency and pill burden, or the number of pills a patient must take per day, and the potential for drug-drug or food-drug interactions. There's also a new table that lists the advantages and disadvantages of individual components of antiretroviral therapy, as well as suggestions for patients with few treatment options

Information on the use of resistance testing has also been updated. For a copy, call 1-800-HIV-0440 (1-800-448-0440) (international callers may dial 1-301-519-0459), or send an e-mail to ContactUs@aidsinfo.nih.gov. Visit www.aidsinfo.nih.gov.

PEDIATRIC GUIDELINES

The pediatric HIV treatment guidelines were also updated, in September. (Another update was expected in October after *Positively Aware* went to press.) Dr. Susan Coffey wrote a summary of the September changes for the AIDS Education & Training Centers (ATEC) National Resource Center. It can be found at the web address above.

She writes that, "The Guidelines acknowledge controversy regarding treatment of asymptomatic infants and children and of children with mild-to-moderately advanced disease. They currently propose the following clinical, immunologic, and virologic criteria for treatment decisions. [See "Pediatric treatment" sidebar.]

"Treatment recommendations for initial therapy have been revised, based on current clinical trial and pharmacokinetic

data." Included in the guidelines is a table listing the advantages and disadvantages of different classes of HIV drugs and of the individual drugs themselves and a listing of the characteristics of antiretroviral drugs.

Resistance testing is recommended in virologic failure (when viral load is not controlled as it should be) before changing to a new drug regimen and before initiation of therapy in infants under 12 months of age, especially if the mother has known or suspected drug-resistant HIV virus.

PEDIATRIC TREATMENT

CHILDREN UNDER 12 MONTHS OF AGE

TREAT

If child is symptomatic (Clinical category A, B, or C) or has a CD4 percentage less than 25% (at any viral load).

CONSIDER TREATMENT

If child is asymptomatic (Clinical category N) and CD4 percentage is more than or equal to 25% (at any viral load).

CHILDREN MORE THAN A YEAR OLD

TREAT

If child has AIDS (Clinical category C) or has a CD4 percentage less than 15% (at any viral load).

CONSIDER TREATMENT

If child has mild-moderate symptoms (Clinical category A or B) or has a CD4 percentage of 15-25% or an HIV viral load greater than 100,000 copies/mL.

CONSIDER DEFERRING THERAPY

If child is asymptomatic (Clinical category N) and has a CD4 percentage greater than 25% and an HIV viral load of less than 100,000 copies/mL.

VIRAMUNE VS. SUSTIVA

Speaking of guidelines, the updated adult treatment version reviews the latest head-to-head data regarding Viramune vs. Sustiva (see “Does Viramune = Sustiva?” in the May/June *Positively Aware*). The updated guidelines clearly state that Sustiva is preferred over Viramune, except in pregnant women or those who desire to have a child.

COUNTERFEIT KALETRA

The U.S. Food and Drug Administration (FDA) in October warned that bottles of Kaletra may actually contain a different drug, the wrong expiration date or a counterfeit lot number. The warning came after 58 bottles of Kaletra had to be recalled because they contained a different HIV drug or had the other problems. The take-home message: if your drugs look funny to you, check with your pharmacist!

FOR WOMEN

The Well Project, an initiative designed by and for women living with HIV and AIDS, in September launched a comprehensive, woman-specific HIV website. The site offers the latest information on living with and managing HIV for HIV positive women, health care providers, and advocates. The mission of The Well Project is to improve the lives of all women living with HIV disease and the lives of those who care for them. Founder and CEO Dawn Averitt has provided woman-specific HIV information and advocacy for more than 10 years, and has been a source of inspiration for many. More recently, she was featured with her newborn daughter on the cover of *POZ* magazine (December 2002) as part of her story of finally overcoming HIV to have the child she always wanted.

TheWellProject.com includes fact sheets, data sets, summary slides, a searchable clinical trials database, a resource directory and a physician network for expert discussion on treatment. It is divided into five targeted sections—HIV: The Basics, Treatment and Trials, Diseases and Conditions, Living Well and a Women’s Center. Each section contains articles, links and related topics. Additionally, members will be able to participate in confidential and secure discussion boards, read about real people living with and successfully managing HIV, download advocacy tools, and receive a regular e-mail newsletter highlighting the most up-to-date information about women and HIV.

NEW NAME FOR PCP

PCP stands for “*Pneumocystis carinii* pneumonia,” an opportunistic infection that can flare up in people with a weakened immune system. It was for a long time a top killer of people with AIDS. However, “*carinii*” is a parasite, and it was more recently found that PCP is actually caused by an atypical fungus. PCP has now been renamed “*Pneumocystis jiroveci*” (or “*P. jiroveci*” for short). In the September issue of *AIDS Clinical Care*, Dr. A. Albrecht notes that the name change can cause problems with patients, such as explaining that prevention and treatment remain the same, and with recordkeeping. Dr. Albrecht says there’s reason to keep the acronym PCP, which is very well-known among people with HIV/AIDS, in that it can stand for “*PneumoCystis* pneumonia.” The change is helpful to patients, writes Dr. Albrecht, in that they no longer fear getting PCP from rat droppings or from pets.

HEART WOES

A survey taken by the International Association of Physicians in AIDS Care (IAPAC) shows that nearly 80% of physicians believe that HIV patients taking antiretroviral drugs are at an increased risk for cardiovascular complications. They cited smoking, antiretroviral use and family history as the top three risk factors for heart problems. Results of the survey of 600 physicians and patients were presented in a September 16 supplement to the Chicago-based association’s peer-reviewed publication, *JIAPAC*.

NEWS FROM THE 43RD INTERSCIENCE CONFERENCE ON ANTIMICROBIAL AGENTS AND CHEMOTHERAPY (ICAAC), HELD IN CHICAGO IN SEPTEMBER

THE VIREAD/ZIAGEN PROBLEM

Just because a drug combination seems like a good idea doesn’t mean it will work. That’s perhaps the most important conclusion from ESS30009, a trial comparing once-daily Sustiva and Viread, both combined with the once-daily, fixed-dose co-formulated Ziagen/Epivir. The study had to be stopped early because of poor results with the combination of Viread plus Ziagen/Epivir, a combination of three potent drugs that was expected to work well, but which failed miserably.

Researchers are investigating possible reasons for the failure of this triple nucleoside combination. One possibility is the similar resistance profiles of the three medications. Unless they’re completely suppressing viral load, HIV drugs put pressure on the

virus that cause it to mutate and become resistant. In most cases, the different drugs in a regimen cause different mutations, which means that it takes several mutations to become resistant to the combination. However, in the case of the Ziagen/Epivir + Viread combination, one mutation (K65R) can cause resistance to all three of the drugs.

Study presenter Dr. Joel Gallant, an HIV specialist at Johns Hopkins University, said that the low barrier to resistance may have been responsible for the failure of this combination. "On the other hand, we have drug regimens requiring only two mutations for resistance, such as Viread + Epivir + Sustiva, that are extremely potent and durable." Also, a third of the patients who failed on the Viread + Ziagen/Epivir combination did not have the K65R mutation, so it's not clear whether the resistance explanation is the answer.

Another possible reason for the failure of this regimen would be a drug interaction between Ziagen and Viread. So far, no one has found any evidence of such an interaction, but it's still possible that there might be some interaction taking place within the cell that hasn't been discovered. Intracellular pharmacokinetic interactions are now being studied.

Dr. Gallant said that other explanations for the failure of this combination were unlikely. For example, dosing Ziagen/Epivir once a day doesn't seem to have been the problem, since once-daily Ziagen and Epivir have worked well in other studies, including in the Sustiva-arm of ESS30009. And while the criteria for treatment failure in this trial were admittedly stringent, Dr. Gallant noted in the question and answer period that even with less strict criteria, the results would have been the same.

Dr. Gallant said the study "emphasizes the importance of basing practice on clinical trials rather than assumptions about what will work." Other doctors concurred. They noted that with all the HIV drugs on the market today and the number of combinations that can be put together, doctors and patients no longer need to try experimental concoctions the way they did in previous years. Today there are more options, and more knowledge to go with them.

ONCE-A-DAY ZIAGEN, EPIVIR AND SUSTIVA

Epivir and Sustiva are once-a-day drugs. Ziagen is on the market at a twice-daily dose, but there is data (mostly from the laboratory) showing efficacy with just a once-daily dose. An international team of researchers reported that all three medications taken together only once a day was highly effective out to one year (a significant amount of time). As the researchers noted, other combinations of once-daily drugs can be problematic because the medications cannot actually be taken together due to problems such as different food requirements.

The 770 participants in the ZODIAC study (Ziagen Once Daily in Antiretroviral Combination) took Ziagen either once-a-day or twice-a-day. At week 48, both combinations had similar efficacy. The majority of people had less than 50 viral load (66% once-a-day

vs. 68% twice-a-day). In as-treated analysis the figure was 86%. Participants also had an increase of around 200 T-cells. Half of the group had started out with less than 262 T-cells and 44% had more than 100,000 viral load at baseline.

Of the "few" participants with virologic, or viral load, failure (10%), half had a rebound to less than 500 viral load (almost undetectable). Although 9% of participants experienced Ziagen hypersensitivity, doctors noted that there was a very strict definition of this, so that even rash that might be due to Sustiva would be listed as the infamous Ziagen allergic reaction.

KALETRA MONOTHERAPY

Every once in a while startling information is presented at a conference. So it was that Dr. Joseph C. Gathe, Jr., an African American doctor from an inner-city clinic in Houston, presented a pilot study of 30 patients on Kaletra monotherapy. He noted that he received no funding (such as free drug from the manufacturer of Kaletra), and could not devote clinical staff time to "cajole" patients the way most studies do. Yet, the study participants had success with the treatment out to 24 weeks (still early results for a clinical trial). None of them had taken HIV therapy before, which makes them an ideal group for treatment.

He explained the rationale behind his tiny pilot proof-of-concept study: Kaletra has short-term activity similar to triple therapy (three week data). If the drug fails to work, there's a lack of resistance to other medications in people who are naïve to therapy. And it has a long half-life, that is, it stays in the body a long time. He called this "single-drug HAART" (highly active antiretroviral therapy).

At 24 weeks, using a strict intent-to-treat (ITT) analysis, 70% of the study's participants had less than 400 viral load (undetectable). ITT counts all patients, even those who dropped out of the trial (considered failure). Using an on-treatment analysis (OT), which looks at only those people still in the trial at the 24-week mark, 95% were below 400 (21 of 22). Half of the participants started out with less than 204 T-cells and more than 200,000 viral load. The clinic gave a higher dose to people weighing more than 154 pounds (70 kg), four capsules twice a day rather than the standard dose of three capsules twice a day.

Two people in the study were lost to follow-up (they stopped coming to the clinic), two people discontinued due to gastrointestinal upset, one person was non-adherent, one person had virological failure (viral load above 400) despite adequate blood levels of Kaletra, one person developed hepatitis B and one person was deported, but had been undetectable with a greater than two log drop in his viral load (highly successful treatment). One HIV specialist pointed out that this was a high drop-out rate (27%). In some studies out to a year, a drop-out rate of 30% is not acceptable, and this trial is still early.

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All in all, these are really small numbers, almost meaningless to the real world of medicine. Nevertheless, in this proof-of-concept trial, the concept has been proven.

STARTING ABOVE 350 T-CELLS

After years of a downward trend in when to start HIV therapy (below 500 T-cells, now below 350 or, according to British guidelines, 200), along come Italian researchers setting the clock back. The BASTA study looked at treatment interruptions. It found that people with lower T-cell nadir (lowest point ever) did less well than people with a higher nadir. Nothing new there. What was new was the Italian group's suggestion that perhaps people with HIV should begin therapy at a higher T-cell level in order to preserve their options for treatment interruption in the future. Many conference goers found the idea fascinating. One doctor pointed out that the data for waiting is based on the toxicity of older drugs.

The study found that people with a nadir of less than 200 T-cells had an average of 14 months off therapy before having to go back on (when T-cells went below 400) vs. 22 months for people with a nadir above 200. However, only one person with a nadir above 400 had to re-start therapy. The people with less than 200 nadir rapidly lost T-cells and the researchers said they would not recommend a treatment interruption for anyone in this group.

BASTA looked at people with less than 50 viral load and more than 800 T-cells. It compared 38 people being continued on therapy against 78 people whose therapy was stopped. The researchers said the option for prolonged structured treatment interruption in people with such good immune response to therapy should be preserved. They noted that there was also a great cost savings despite the intense laboratory monitoring of the study.

They concluded that "to preserve the option of longterm prolonged structured treatment interruption, the optimal time to start HAART should be re-considered and probably placed between 350–450 T-cells. Patients with a nadir above 500 can safely and steadily interrupt therapy."

SUSTIVA RESISTANCE

As if resistance wasn't difficult enough, now researchers are talking rare mutation patterns. One group looked at how a person's HIV gets resistant to Sustiva even though it doesn't have the standard mutations associated with Sustiva resistance. How does it do that? With rare mutations, of course. Mutations so rare they're not listed on the resistance tests your doctor can order. These resistance tests already come with difficult-to-read results information. Nevertheless, regardless of how difficult it is to analyze resistance tests, the research must go forward to find HIV mutations and try to understand how they develop. This in turn helps drug development.

ViroLogic, the maker of both genotypic and phenotypic resistance tests, looked at 18,034 samples. Of these, 8,673 did not have the Sustiva mutations. In analyzing these, ViroLogic came up with new mutation points that made HIV highly resistant to Sustiva, rendering it impotent against the virus. They concluded that, "Although rare, NNRTI [the drug class Sustiva is from] resistance in the absence of known mutations can be dramatic and is currently not reported by standard genotype [test]." The company recommended adding the following mutation points to NNRTI resistance results because of their strong negative influence on treatment: K101P and the combination of K103R and V179D.

DIABETES AND HEPATITIS C

The U.S. Veterans Administration found an increased risk of diabetes in people with hepatitis C, but the risk was greater for those who are HIV positive than in those who are negative. The Veterans Aging Cohort study compared 33,280 positive vets with 38,232 negative vets. The report said that, "In the post HAART era, HIV infection appears to increase the risk of [diabetes] associated with established risk factors including [hepatitis C] infection, age and minority race. The degree to which this association can be attributed to the effects of HIV itself or the effects of long term HAART therapy remains to be determined." They recommended that doctors screen for diabetes and avoid drugs associated with diabetes risk in the initial regimen of someone with high risk.

ANOTHER TEST FOR YOUR HIV

From what tropic is your virus? Is it CCR-5 tropic or X4 tropic? You'll probably know one day, and it could affect your therapy. An experimental test is looking at this in clinical trials.

Of the new drugs in development for HIV, there are five different types of HIV entry inhibitors. These are five different known ways to prevent HIV from entering a cell. One of these five drug types, the fusion inhibitors, is already on the market in the form of Fuzeon (T-20).

One of the other five entry inhibitors is the chemokine receptor inhibitor. Chemokine receptors sit on your CD4 T-cells and help HIV enter. Two chemokine receptors have been found: CCR5 and CXCR4. The cells are then called CCR5-positive or CXCR4-positive, depending on which receptor they have.

In turn—ta da!—there are CCR5 antagonists and CXCR4 inhibitors in drug development. People who have mostly CCR5-positive cells (called CCR5 tropic) do better than those who have mostly CXCR4 (X4 for short) virus. At some point, that balance can shift. Having a shift to mostly X4 seems to increase disease progression. "Tropic" comes from "tropism," the process of attachment to a co-receptor. ☒

Those who have worked in the area of HIV prevention in Eastern Europe and the former Soviet Union (fSU) have spent well over ten years talking about the social, economic, and human factors that make these countries susceptible to HIV. Now, in 2003, we no longer speak of what may be: HIV and AIDS have arrived and, as everywhere else, the virus is causing devastation.

For three years in a row UNAIDS has reported that HIV is growing faster in Eastern Europe and the fSU than anywhere in the world. Today, there are 235,000 registered HIV infections in Russia with the total number of people living with HIV estimated to be much higher—up to 1.5 one million.^[1] The situation is equally dire in neighboring Ukraine, where close to 1% of the adult population is estimated to have HIV.^[2] This is startling in a region where countries had few, if any, HIV/AIDS cases before 1995.

The meteoric rise in HIV/AIDS cases in this region began with an outbreak of HIV in Ukraine and Belarus in 1995, followed by outbreaks in Moldova in 1996 and the Russian Federation in 1998. Although case numbers remain relatively small in other European and fSU countries, growth rates have increased tremendously during the same time period. In 1999, Estonia reported 12 cases of HIV, by 2001 this number increased to 1474; in 1997 Latvia reported 25 new infections, in 2001 they reported 807.^[3]

Unlike in most other regions, HIV in Eastern Europe and the fSU is spreading primarily through injection drug use. Economic despair, social dislocation, and easy access to heroin and other opiates en route from Afghanistan have all contributed to an explosion of drug use in the region. For many of these countries, IDUs comprise the majority of registered HIV/AIDS cases. In the European Newly Independent States (Russia, Moldova, Belarus and the Ukraine) IDUs account for 88% of HIV/AIDS cases, while in the Baltic States (Estonia, Latvia, and Lithuania) they account for 80.1% of all cases. Even in countries with a longer history of HIV/AIDS, drug users continue to be among those most affected. In Poland, a country with one of the most mature HIV epidemics, drug users account for 62.5% of all cases.^[4]

Repressive drug policies in the region fuel the HIV epidemic. Injecting drug users receive little or no sympathy from the

general population and even less from governments that favor confinement over treatment. Drug users are sent to overcrowded prisons where needles are shared and HIV rates are surging at an even faster rate than among the population at large. In Russia alone, more than one-sixth of all registered HIV cases are people in prison.^[5] Potential for such pockets of infection among drug

preventing HIV transmission among injecting drug users.

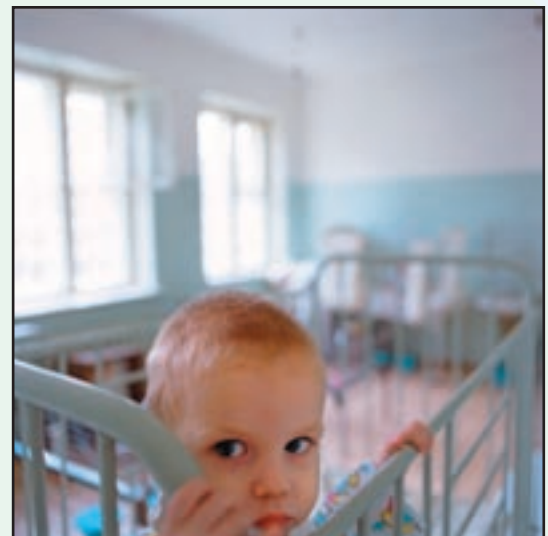
Treatment programs that offer methadone and other substitution therapies are another vital part of harm reduction efforts. Unfortunately, rigid and repressive drug policies in many countries mean that such programs are few and far between. In Russia, for example, substitution treatment

PREVENTION AND TREATMENT IN EASTERN EUROPE

users both in and out of prison are ripe. In Lithuania, a country previously regarded as having the lowest prevalence of HIV in Europe, 321 cases of HIV were detected between May 1 and August 20, 2002 almost doubling the number of previously recorded cases.^[6] Of these 321 cases, 284 were located in one closed prison facility.

Halting the spread of HIV among drug users requires entirely new ways of thinking. Clearly these pockets of infection must be addressed. National and local governments must implement flexible and caring health policies that focus on helping drug users, not punishing them. In the context of drug users, harm reduction is the most humane and realistic way to stem the spread of HIV.

One key element of most harm-reduction programs is needle exchange. Hundreds of studies around the world have shown that providing injecting drug users with access to clean needles greatly reduces needle-sharing and thus HIV infection. The World Health Organization (WHO), the American Medical Association, UNAIDS and many others consider provision of clean syringes to be an effective and necessary method of



The above two photographs: Moscow, Russia 2002. Misjakoetis—Children's Department at Orechovo-Zoejevo.

is not available. Ukraine, on the other hand, recently took a promising step when they registered methadone.

Along with HIV prevention we must also work with those already infected, including drug users, to provide treatment options. Treatment options in this region are scarce. In 2001, less than 1000 of the estimated 1 million people living with

AIDS in Eastern Europe and the fSU were receiving antiretroviral treatment.^[7] The situation is especially bad for HIV-infected drug users, who are often placed last on the list of those in line for antiretrovirals, are required to stop methadone in order to gain access to HIV treatment, or are denied antiretrovirals altogether.

In this bleak picture there are signs of

the hands of police, denial of public services, imprisonment that destroys health and breaks the spirit, so-called “drug treatment” that humiliates clients and their families... all of these human rights abuses experienced by drug users not only make for a repressive society but also fuel the HIV epidemic. If the world is unable or unwilling to turn its attention to this region and offer help in dealing with this looming disaster, the consequences will be horrific. ☠

BY KASIA MALINOWSKA-SEMPRUCH

PHOTOGRAPHY BY ILSE FRECH

Reprinted with permission from IATEC UPDATE, the magazine of the International Antiviral Therapy Evaluation Center, located at the University of Amsterdam, the Netherlands. Visit www.iatec.com. Malinowska-Sempruch is director of the International Harm Reduction Development Program for the Open Society Institute, in New York City.

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The above two photographs: Moscow, Russia 2002. Children's Home #7.

hope. In the first two rounds of proposals, grants from the Global Fund to Fight AIDS, Tuberculosis and Malaria have approved over US\$120 million in funding for the region. These funds will be used for the prevention, treatment, care and support of people infected and directly affected by AIDS and tuberculosis. Projects funded will increase access to health services; provide critical health products including antiretroviral drugs; train personnel and community health workers; conduct outreach and create community-based programs.

While Global Fund resources are much needed in the region, these resources are but a very tiny step in the right direction. Pilot programs are simply not enough. One methadone program in Bulgaria (where methadone has been legal for over five years) is not enough to stem an HIV epidemic. Large-scale interventions must be implemented.

There are no easy solutions to the AIDS epidemic in Eastern Europe and the former Soviet Union—or in any other region of the world. But this does not mean that people in the region or elsewhere can allow themselves to shy away from making difficult decisions—financially, culturally, or morally—about how to address it. Violence at



Finding a Voice in Vietnam

by Michael McColly

Photography by James Tuong Nguyen

Rice paddies, orderly and green, stretched out on either side of us as we bounced along a red clay road on the motorcycle belonging to the family of my traveling companion, a former student named Tuong Nguyen. Along the road, old women carried vegetables, children ran to school, teenagers three to a bike laughed and called out to us in fragments of English. All that morning, as we traversed the Vietnamese countryside, stopping at temples to light incense and at schoolyards to photograph crudely illustrated posters of needles dripping blood, meant to warn youths against the dangers of AIDS, I'd had a sense of *déjà vu*. Later, as we sat under a thatch roof eating fish and vegetables and drinking rice wine with the farmers my traveling companion once had worked with, I realized that, after teaching writing for 13 years to students for whom English was not their first language, this was the first time I had actually entered into one of their worlds.

Students often casually invite me to visit their countries, writing down names of siblings and cities to see. But most of them come

from places not exactly on the tourist route—dusty, drought-ridden villages, overcrowded barrios, working-class tenements, war-destroyed neighborhoods. Nevertheless, they would describe such places as if the world had begun there and make me appreciate just how far and how much they and their families had sacrificed to get to the U.S.

Often I would ask them to read their essays out loud, preaching to them that it had some educational purpose, but it was

really to hear the passion they infused into their memories of lands and languages that their children will most likely never understand. There was something in their voices, in their desperate immigrant's stammer, that made me listen as if I was being told something for me alone to understand. I was obsessed with their bittersweet tales of immigrant life. Perhaps I was selfish in the way I pried out their stories, unmindful at times of just how painful they were to set down in a second language. I was so affected by their narratives that I took students to poetry readings, bribing them with extra



Above: Saigon, Vietnam 2003. Young sex workers and 15 year old male drug user share lunch.

Above left: Saigon, Vietnam 2001. HIV positive woman attends an HIV/AIDS and drug use meeting (she died about three months later).



Saigon, Vietnam 2001. Man does shoe repair on the street.

credit if they would stand on stage and read their essays. I wanted to prove to them that they had important stories to tell, that they had more to offer than working in cardboard-box factories or daycare centers. I even published a little book of their essays.

I read and listened to my students' stories of survival—depictions of floating on the South China Sea or walking for weeks in the Sudanese desert to flee Ethiopian soldiers—because I needed to learn how to survive myself. Unbeknownst to my students and colleagues, I was swallowing a fist full of pills each morning and sitting in my car waiting for drug reactions to subside before my first class. I was HIV positive.

Yet, I shrank from telling students this fact of my life, even though day after day they revealed their personal lives to me, and even though my younger students, vulnerable 18-year-olds who feigned nonchalance while being bombarded by the sexual seductions of a merciless media and material culture, might have benefited from knowing my situation. But the time I came closest to telling them was not out of concern for them but out of one student's concern for me.

Tuong Nguyen had been coming by my office since I'd first had him in my class five years before; in fact, I'd had him twice, because he didn't pass the first time around. Often he came to show me his photographs. I admired him for daring to go into photography at a university where most students choose practical fields, particularly his fellow Asian classmates. One day he came to invite me to lunch, to pay me back for help I'd given him on a term paper for another class. I was annoyed, not so much with him, but with having to spend time "on the job" outside my duties as a teacher. I felt trapped and terrified that

I'd never find a position more in line with my interests as a writer. But my health, or more truthfully my health insurance, was making it nearly impossible to leave. When Tuong came in, he looked at me and simply asked: "You seem so sad, all the time. Are you all right?" I'd had to pay a therapist to ask me questions like that. Stunned, I reverted to my classic Midwestern stoicism. "Oh, I'm just a little tired, that's all." It was two more years before I told any students or colleagues.

What turned me around was the AIDS conference I attended in South Africa in 2000, where I was invited to give a yoga workshop for people living and working with HIV. The compassion and fearlessness of the activists I met at the conference transformed me: I began to see myself as part of a global movement rather than a victim. Nine months after returning from South Africa, I sold most of my things and took a leave of absence (without pay, but, thankfully with health coverage). My plan was to travel and meet as many people as I could in a year, to learn how different cultures (including those only blocks from where I lived in Chicago) were responding to the AIDS epidemic.

Tuong, with his facility with computers and photography, helped me put together my presentations, and while doing so I told him. He was quiet and respectful, asking me nothing. But after that he came to my office weekly, even called me at home sometimes, to make sure I was taking care of myself properly. And when I mentioned that I wanted to go Southeast Asia, he insisted that I come



Saigon, Vietnam 2003. Kids in a poor community where over 80% of women are sex workers, and most men are low-paid laborers, alcoholics or drug addicts.



to Vietnam at the same time he was planning to visit his brothers with several other members of his family.

By the time I'd arrived in Vietnam, I'd been in hospices in Northern Thailand where Buddhist monks cared for those infected and instructed them on how to die in peace; bars in Bangkok talking with advocates for the rights of sex workers; and clinics in south India where a doctor with HIV himself cared for terrified villagers who'd traveled up to hundreds of miles to see him.

I spent the first week in Vietnam with Tuong and his family in his brother's house, near the town of My Tho, in the Mekong Delta. After a decade of separation, the family had come back together: his sister, who did nails in downtown Chicago hotels; his brother-in-law, who worked for Motorola in Atlanta; another brother who lived 50 yards down a dirt road from the brother they were all staying with; and his parents, whose house was not many blocks from my university. Two worlds merged: Children played Nintendo on television; frog legs were frying in the kitchen; and men drank rice wine mixed with snake blood while singing Beatles' songs in Vietnamese. And there in the middle was the father, a veteran of the South Vietnamese army, imprisoned after the Vietnam War and tortured in a prison only a few miles away, now looking as if he couldn't quite believe that he and his family had survived.

According to the United Nations program on AIDS, the number of cases in Vietnam has risen sharply since 1990, when the first case was reported, and even though estimates are now at 150,000, (0.2 percent of Vietnam's adult population), the rise in drug use, sex work, and urbanization reflects the same looming crisis that exists in China and India.

In Ho Chi Minh City, I asked Tuong to accompany me into its burgeoning slums, a world he'd never entered himself, where

women prostitute themselves to pay for rent and food, where young boys and girls work the streets shining shoes or sifting through trash for scraps of metal to exchange for coins. We followed a social worker and a former sex worker into a slum along the Saigon River, where Tuong took photographs and I listened to the social worker, Pham Van, tell me how these women had come together to share work and look out for their teenage daughters. Police officers some-

times arrested the girls, blackmailing the parents for money or pushing the girls into prostitution rings or work camps.

On our last day, Mr. Van took us across the city by motorbike to a meeting he had organized for drug users with HIV. There, I sat in a circle with people whose lives had shrunk, as had their bodies, through drug addiction, lack of food, and HIV. Beside me sat a woman with needle marks on her bone-thin arms, who struggled with every inhalation. A man across the table looked almost invisible, ashen in a cloud of his own cigarette smoke. Tuong whispered their stories to me as they went around the table, describing their past week. One man told us he was worried that he would be jailed for not attending a required meeting for HIV carriers. None of them had access to treatment, as we'd learned the day before from a doctor who'd told us that, incredibly, less than a hundred people in all of Vietnam had access to antiretroviral drugs.

Then it was my turn. I knew Mr. Van wanted me to speak about how I'd learned to live with HIV. But I felt that it was cruel for me to even be there, exuding what these people couldn't have—health and hope. I tried. As Tuong walked around taking photos of the group, he translated for me, describing what I was doing and writing about. But that didn't satisfy them—they wanted the real

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Saigon, Vietnam 2003. 17 year old young man, HIV positive from drug use, says he would never give up life. Unlike many other young people with HIV, he works hard toward living, and that makes him stronger and healthier.

Botswana—The challenges of fighting HIV/AIDS

The continent of Africa has 29 of the world's 42 million people living with HIV/AIDS. Most of them live in sub-Saharan Africa, by themselves making up 70% of the world's total numbers. Today the scientists and medical providers of the wealthy nations race to Africa to fight the epidemic where it is hurting the most. There are not only lives to save and infections to prevent, but also medical knowledge to be gained. Political leaders and activists try to explain that the crisis of one country will affect other nations.

Dealing with AIDS in poor countries, however, is not a matter of simply giving out free drugs. To turn the pandemic around, several problems must be faced and resolved.

At the International AIDS Society meeting in Paris this past summer, Dr. Ernest Darkoh of Botswana highlighted some of the many issues that need to be addressed to effectively curb the epidemic in resource-poor countries. He put political will at the top.

"[HIV therapy] works—let's not debate that but provide models for treatment," Dr. Darkoh said. Most probably he was making a reference to the government of South Africa, which has stymied HIV care in every way possible, including turning down funds and free medicines. "History will remember us for how we act in this



moment," he went on. "If we do not act then we become the true enemy."

Dr. Darkoh was eloquent, but also forthright, in his plenary talk, "Challenges and Lessons Learned in Implementing Antiretroviral Therapy in the Developing World."

The talk detailed the work of Botswana's national HIV program, of which Dr. Darkoh is operations manager.

He did not hide the fact that one of the problems faced was with healthcare workers. Some of them did not want to work on HIV/AIDS and created stumbling blocks rather than promoting the government's new efforts. Many were simply uncomfortable discussing HIV.

This then became a matter of education and guidance—another problem to resolve. Dr. Darkoh said that one obstinate worker could put efforts months behind, and HIV programs must continuously look for people who are a hindrance.

But the greater problem is simply staff training and fast-track recruitment. Then there's the need for laboratory and clinical facilities. As he said, "Capacity is not something you achieve instantly. HIV/AIDS did not create the restraints we're facing. They were there a long time ago." The information and education needs alone were "massive," he said.

In Botswana, the government determined that 300,000 people have HIV and

by enid vázquez



Dr. Ernest Darkoh

roughly a third of them needed antivirals “immediately.” However, it could only provide medications right away to 10,000 people. People with less than 200 T-cells or an AIDS-defining illness were immediately eligible for antivirals, but the national program recognizes that all people with HIV need health monitoring. They also need psycho-social support and wellness care.

“People were coming to us late, with an average of 50 to 60 CD4 cells. Sickness made them overcome stigma,” he said. This was one challenge: people who do not come forward for health care until they are very ill will then need many resources. The lesson is to encourage routine testing. Botswana conducts an educational campaign to combat stigma and get people to know their status.

It also distributes posters to help people with HIV understand the infection: that medication must be taken correctly, that therapy can help make people healthy but is not a cure, that condoms still need to be used.

Dr. Darkoh called many of the different challenges “sliding bottlenecks.” The question of political leadership was “quite a challenge in itself.” Then there are macro-economic factors: “Most countries couldn’t tell you how many people need therapy or where to find them. You spend lots of time here in the heat of the epidemic.”

Not all of the work needs to be high-tech. “It could be, but could be someone on a bike, like the initiative in China,” he said. Adherence is promoted with a buddy system, along with pill counting and intensive counseling. And, as almost everywhere, there are experts from other countries helping to build Botswana’s program. Dr. Dar-

LESSONS FROM BOTSWANA

- Capacity-building is not linear.
- Each site experiences teething problems and can later help the sites coming after them.
- Public/private partnerships should be encouraged (the Botswana government works with the Bill & Melinda Gates and the Merck Company foundations, each pledging \$50 million a year for five years).
- HIV should be a national priority, not necessarily an individual priority—public motivation and mobilization are critical.
- Low knowledge of HIV status severely limits the ability to plan rapidly.
- ARV [antivirals] helps break cycles of denial and strongly facilitates prevention.
- Developed countries must take a leadership role.
- Individuals must take responsibility and come forward for care sooner in the course of their disease.
- Private companies have something to offer way beyond money—management skills and marketing knowledge.
- HIV/AIDS must be looked at in the context of the total healthcare delivery system.

koh himself is from the United States, born to Ghanaian parents, who earned a medical degree and a Master’s in Public Health from Harvard University and an MBA from Oxford. He was recently profiled in the *Christian Science Monitor* in a story on Africans and people of African descent returning to help the continent.

According to the article, published September 30, “In Botswana, 38 percent of adults are HIV positive and life expectancy has plummeted to below 40 from over 65. By 2010, [life expectancy] could sink to 29, predicts the United Nations Program on HIV/AIDS—a level not seen in developed nations since the Middle Ages.”

TO HELP AFRICA

Speaking before the annual meeting of the Midwest AIDS Training and Education Partners (MATEP) in Chicago in September, African American doctor Eric Goosby said, “I have a plea to all of the HIV healthcare providers here. I want you to put in your head that you can make an extraordinary contribution by coming in to these countries for six weeks. Working directly with healthcare providers in Africa would provide the best training possible for them,” he said.

Dr. Goosby is CEO for the Pangea Global AIDS Foundation, located in San Francisco. He was director of HIV/AIDS Policy for the U.S. Department of Health and Human Services under the Clinton administration. Dr. Goosby directed people to visit Pangea’s website at www.pgaf.org for information on how to contribute your service. He said healthcare providers can also recruit patients with home care service information to impart. ☒

Viracept
Ad
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I am a United States citizen, born in the South and raised in what has become known as the world's richest nation and only superpower by the start of the twenty-first century. Although I am a U.S. citizen, all of my life I have heard about rumors of war, taught about war in school, seen it firsthand and been part of war. In my childhood and youth I was instructed what to do in case of nuclear war, while coming of age during the Cold War.

One can never really understand the tragedy, horror, or the impacts of war unless you have been affected by it, lived it or were unfortunately a casualty of war. It can leave you riddled with scars mentally and physically that seem as though they will never go away. It can destroy relationships and haunt you to the grave.

In the last two decades of the twentieth century, we saw war televised live as the world was informed about HIV and the threat that it posed to humankind. The Persian Gulf War and Operation Desert Storm gave us minute-by-minute details of war twenty-four hours a day. Although that war was declared over in record time, I think that it kept simmering for another ten years as sanctions were placed over Iraq.

The 9/11 terrorist attacks caused a rippling effect throughout the U.S. and the world. Complacency and denial were shattered on that day, as well as the lives and households of many Americans and others across the globe. It was a time where testing positive had a new meaning. In America, for a brief moment in time, we went from AIDS to anthrax, although we had been at war with HIV for twenty years. With both diseases, we learned how it is transmitted. Many people were wearing latex gloves because they feared HIV the way they wear masks in Asia to combat and protect themselves from SARS today.

At nearly a million dollars a missile and *carte blanche* approval of funds to fight Operation Enduring Freedom, Afghanistan was bombed daily once America struck back and declared a global war on terrorism. Afghanistan was already a war-devastated country

and we still are not sure where Osama Bin Laden is to date. During this conflict, my concern grew that we might have lost focus with a war at home on U.S. soil that many of us in the trenches have been fighting since the very beginning.

There were severe thunderstorms here in Chicago the night that special broadcasts announced in all forms of media, throughout the world, that the U.S. and its Coalition was at war with Iraq. War ignited again this year due to alleged weapons of mass destruction. Thousands of million-dollar cruise missiles were launched

on Iraq. Operation Iraqi Freedom began at the cost of our own civil liberties and freedom we may take for granted.

Iraq is allegedly liberated now, in part because of another round of million-dollar cruise missiles and hundreds of millions of dollars spent for the campaign. The conflict is over but now Iraqi citizens and others who have been affected by the war will have to try to rebuild shattered lives. The world still waits to see evidence of weapons of mass destruction and if Saddam Hussein is alive or has perished.

The war that haunts me is the war with HIV. The bloodiest war for me is this one, because it is constant and there is no foreseeable end. As a young adult, I was drafted into a war that was declared on humankind over twenty years ago. I was placed on the frontline over thirteen years ago when HIV invaded my body. I saw the tragedies of war as I lost one friend after another to HIV and attended tearless funerals that had brimstone

overtones from the pulpit. I have gone from youth to middle age with HIV inside of me. A daily war that rages within that has me fighting for ground mentally and physically.

War is not a pretty thing. When you are at war, the last thing you would want to concern yourself with is being attacked by your allies or within your ranks. Under the Clinton administration, we were given tools that combatted homophobia to a degree and at least funds and acknowledgment that HIV/AIDS had become a



TALES OF WAR

BY SANFORD E. GAYLORD

Photoillustration © Russell McGonagle

critical issue. However, it took years after the discovery of the virus that we know as HIV to be acknowledged by President Reagan.

Flashback with me for a moment. Do you recall how it wasn't long after George W. Bush took the office of President that Chief of Staff Andrew Card informed the U.S. society that the Office of National AIDS Policy, that was created under the Clinton administration, would be closed? The announcement sent a message to the American people that AIDS was over and that was far from the truth, especially within communities of color.

George W. Bush, through his Press Secretary, Ari Fleischer, released a statement expressing that the office would continue under the Bush administration and that Mr. Card's statement was made in error. I never stopped wondering how much truth there was in the initiative to close the office in the first place. I also wondered what would have happened if activists hadn't gone on red alert and raised hell about the statement and implications behind such a move from a president with a fundamentalist Christian ideology.

This Spring, individuals working in HIV/AIDS prevention and research talked among themselves and online about rumors of old McCarthy era tactics and witch-hunts. The news eventually made *The New York Times* and other forms of media but we cannot forget about this particular attack because it has the potential to take us back to the dark days of the eighties when HIV declared war on humanity.

Many organizations that are involved in a variety of HIV prevention research and social service programs targeted to educate and prevent the spread of HIV are in essence under attack. Many of these organizations rely primarily on funding from the federal government. When you apply for federal funding, you have to be very specific and be able to produce data.

In the reports from *The New York Times*, the American public was informed that if you correspond with the National Institutes of Health you shouldn't use words like men-who-have-sex-with-men, anal sex, gay, lesbian or transgender without the risk of possibly being audited or failing to obtain grant funding. How can you

apply for money when you can't be specific about the population that is most affected? Must we live in gilded cages of shame?

All of war, with its major loss of life, dignity, justice, and civil liberties affects all of humankind. Is this a nightmare? Post-traumatic Stress Disorder, propaganda, or the truth shattering the denial that is thrown constantly at us to keep us numb and in some cases dumb? People of color are now at greatest risk globally for HIV/AIDS. I pray my nightmare about the end of races of people does not become a reality in my lifetime. There is no country on the planet that has reported a case of HIV that can say that they have stopped the spread, only slowed its advance on humankind.

Since the second war in Iraq concluded, the office of Homeland Security raised its terror alert to the second highest level because of renewed risk of terrorist attacks. What about having a security advisory system on HIV/AIDS? If there were, it would be at the highest level. Recent data from the Centers for Disease Control indicates that there are close to 950,000 individuals living with HIV in the U.S. and that a quarter of them may not be aware of their HIV status.

There is also an estimated 40,000 new infections a year and in these days, how many people don't know of at least one person who has been infected or affected by HIV/AIDS? What do we do as a superpower when we don't have men or women to fight for our freedom, our lives, and those of our children? What do we do when we need to liberate some oppressed people or continue the war on terrorism and can't because we've lost men and women with the War on AIDS on our own soil, maybe by our own hands?

All Americans, all of humankind needs to be united, not only against terrorism, we need to focus on the fact that we have already been engaged in a war for twenty years with HIV. We need to learn from our past to protect and ensure that there will be a future for all of humankind. ☸

Sanford E. Gaylord is an actor and writer based in Chicago. He is a contributing writer and columnist for Windy City Media Group's Blacklines and Windy City Times periodicals.

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Managing Side Effects

by Stephen J. Fallon

When allergy season rolls around, people reach for the medicine cabinet. Antihistamines will stop a runny nose, but may well leave a person sleepy or nervous. On the first sneezing day of the season, many people will gladly suffer through these side effects. If the allergies continue, though, people hesitate before reaching for that bottle. Can they afford to spend the whole season at work with dry sinuses but weary eyes?

People living with HIV (PLWH) don't have the luxury of making these choices. Antiretroviral medications extend lives, but only if they are taken consistently as prescribed. Since it's best to take medications before HIV erodes the immune system too much, PLWH may have to suffer through treatment side effects without enjoying the benefit of overcoming any noticeable bodily complaints in the early stages of their infection. Which side effects are merely bothersome, and which are serious? What is science doing to try to limit side effects? Can your choice of medications make any difference? This article will lay out some of the key challenges and changes relating to HIV treatment side effects. In some instances, the evidence is conflicting because there's often no way to know whether the development of progressive ailments is actually triggered by medications or is merely a natural occurrence of living longer.

PATIENT PREFERENCES

Many studies have surveyed patients about their treatment preferences for total number of pills, frequency of dosing, and side effects. No surprises here: people want to take fewer pills, less often, and with fewer side effects. But treatment wish lists are of little value if they do not ask patients to prioritize these preferences in real world trade offs. Would PLWH be willing to take pills more often if they produced fewer side effects? Or endure more side effects if the medications tackled HIV more effectively?

Patients living with other chronic diseases such as cancer have said that they would be willing to suffer through more side effects if the medications were known to extend life.^[1] To see if the same preferences would hold with HIV disease, Loren Millier's team at the UCLA Medical Center asked a small group of HIV positive patients to compare their preferences for treatment regimens according to four different criteria: side effects, pill burden, regimen inconvenience, and regimen potency.^[2]

Obviously, patients would not be willing to suffer more side effects, pill burden or inconvenience for a treatment plan that was actually less potent. So this last category was included to determine how much potency could offset the negative impact of the first three criteria. It should be noted that in the first category, Miller's team measured only "side effects that were bothersome but not severe enough to necessitate drug discontinuation." Generally, this meant things like headache, fatigue, nausea, and diarrhea, but not potentially life-threatening side effects like organ shock or heart disease.

The comparative choices were presented to patients in pictures, with larger or smaller drawings depicting better or worse side effects, pill burden, regimen inconveniences or treatment potency. The results? "Most though not all participants reported that they would want a regimen that was most effective at fighting HIV and prolonging life, regardless of side-effect severity, complexity, inconvenience



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or pill burden.” In other words, these PLWH are just like patients facing other chronic diseases: their top priority is getting strong treatments.

The study also found that the patients were less bothered by side effects than many physicians tend to believe. In interviews with patients, many reported that side effects were most severe when they had begun a new regimen. After a period of time, their bodies “had grown accustomed” to the meds, or else the patients developed strategies to minimize the side effects, such as timing the dose with or without food, drinking more water, or not taking doses as soon as they wake up.

However, side effects were still more troublesome to patients than were inconvenient dosing or higher pill burden. Patients “preferred regimens with fewer side effects to those that were more convenient” in dosing schedule. Preference for fewer pills was the lowest among the four domains.” The importance of pill burden may have declined because today’s regimens tend to be so effective that few PLWH have to suffer through a daily series of additional prophylactic pills to ward off specific opportunistic infections.

LIPODYSTROPHY

No treatment topic draws as much interest from patients and providers as lipodystrophy. Whenever lipodystrophy is the theme, dinner seminars are filled to capacity and conference sessions run out of handouts. The term lipodystrophy refers to the abnormal gain or loss of fat in certain areas of the body (and also within the body). This is different from wasting syndrome, which was once the telltale mark of AIDS. Wasting is the loss of fat throughout the entire body; in Africa, many communities referred to what we now know as AIDS as “slim man’s disease.”

Suspicious eyes have been cast towards protease inhibitors because it was soon after their development that doctors started reporting significant new cases of “protease paunch” and “buffalo hump,” bizarre accumulations of fat in the abdomen and neck regions. Around the same time, inexplicable fat loss began showing up in PLWH, a condition just as stigmatizing. Known as “lipoatrophy,” the condition leads to shrunken arms and legs, and sunken cheeks, even when overall bodyweight is unchanged.

As time went on, studies called into question the hypothesis that protease inhibitors are the culprits behind what true fat loss or fat accumulation does occur. Patients who had never taken PIs were found to develop the same bodily changes over time. That led researchers to speculate that all HIV treatments (not just PIs) may eventually cause bodily changes, due to the toxicities, or to the ways that the medicines interact with bodily hormones, disrupt cytokines, or trigger insulin resistance. This year’s d4T vs. tenofovir study (Zerit vs. Viread) implicated d4T in spurring fat accumulation, for example. Patients taking d4T lost over six pounds overall, and over 18 pounds of limb fat specifically, while patients in the tenofovir arm had negligible overall weight change and lost less than 12 pounds of limb fat.^[3] Another study compared patients taking only nucleoside analog drugs, one arm receiving AZT (Retrovir) and 3TC (Epivir) while the other took d4T and ddI (Videx).

Again, the d4T patients began losing limb fat sooner (and lost more limb fat overall).^[4]

However, a new study in the *Journal of AIDS* questions whether medications have been proven as the sole cause of lipodystrophy. The authors note that all previous lipodystrophy studies “have evaluated the time period after the introduction of highly active antiretroviral therapy (HAART) regimens.”^[5] As a result, the development of lipodystrophy might at least partially be a coincidental correlation with the advent of HAART, and not always be caused by it.

To try to answer this question more firmly, the authors drew on patients in the seven clinics nationwide that make up the HIV Outpatient Study (HOPS) cohort. Patients were examined in the fall of 1998, and then again in the summer of 2000. Of patients present for both surveys, 546 had no lipoatrophy during the first visit, but 13% had developed moderate or severe lipoatrophy by the second survey. This study also included data on patients as far back as 1994, allowing researchers to investigate other possible causes of lipoatrophy that they observed. Many factors seemed to correlate with risk of developing lipoatrophy. Not surprisingly, patients with low CD4 counts (less than 100) were at higher risk of developing lipoatrophy. The researchers came to the same conclusion for patients who had ever had what they defined as high viral load (more than 1,000). (The value of this correlation is uncertain since nearly all PLWH will have had viral loads more than 1,000 at some point in their infection, and those who appeared not to may simply not have had a measurement at the time when they actually had higher levels.)

However, when researchers accounted for differing CD4 counts in their patient comparisons, only three factors were shown to be independently significant. People at greatest risk of developing lipoatrophy were those who were white, had a low body mass index (BMI), or had bounced back from CD4 counts that were previously less than 50. The researchers could not explain why race would play a role in risk for lipoatrophy, and they noted that white race probably captures many other social and treatment dynamics that cannot be easily itemized.

The reference to low BMI, meanwhile, may seem surprising. Body mass index is the measure of muscle relative to overall body weight. People with less fat typically have higher body mass indices. So it may seem counterintuitive that the researchers noted low BMI (i.e. higher fat content) as a risk factor for abnormal and localized fat loss. Though the mechanism that causes this phenomenon is unclear, it may be the case that a moderate exercise routine could preserve not only muscle but also appropriate body fat. As for the correlation to rebounding CD4 counts, the authors postulated that either the severity of the illness itself or the mechanism of immune reconstitution could be responsible. The renewal of T-cells might inadvertently “produce unopposed proinflammatory cytokines (e.g. tumor necrosis factor alpha) that may” cause the loss of the body fat.

The study found no relationship between use of antiretroviral medications and the abnormal loss of body fat. Neither total time on medications, time of drug initiation, drug continuation, or drug

discontinuation presented any clear relationship to lipoatrophy. The authors did not completely rule out the possibility that medications may “exacerbate an underlying predisposition to lipoatrophy” but they concluded that, “HIV infection or factors associated with immune reconstitution may play a greater role ... than the use of any specific medication.” In fact, their findings suggest that beginning antiretroviral medications in a time when the disease is “less advanced” may stave off lipoatrophy by preventing either the excessive loss of CD4s or the possible side effects of immune reconstitution.

Meanwhile, a small Italian study this year suggests that the frequency of lipodystrophy problems may have been overstated. PLWH may judge their bodies harshly, and perceive lipodystrophy when none can be found through more objective measures.^[6] The authors compared patients’ and doctors’ often-conflicting assessments of body fat redistribution, either fat accumulation, fat loss, or both. The authors noted disagreement between the patients’ and physicians’ interpretations, and also pointed out that common tests used to define body fat redistribution (waist-hip ratio) are open to subjective interpretations. This does not mean that lipodystrophy is not a real and vexing problem, only that fears may be magnifying the reality of the problem.

PERIPHERAL NEUROPATHY

Neuropathy, which is numbness or pain in the arms, legs, hands and feet, actually arises for a number of reasons. The body’s autoimmune response may shut down certain nerves, causing numbness.^[7] Or neuropathy can result from damage caused by other viruses such as cytomegalovirus, certain herpes zoster viruses, or hepatitis B or C.^[8] But it is also related to toxic effects of antiretrovirals, particularly the “D” drugs (ddI, ddC, or d4T).^[9] Neuropathy caused by antiretrovirals is more likely to be painful, rather than of the numbing variety. Since the mid-1990s, numbing neuropathy has been in decline, as antiretrovirals have limited HIV’s debilitating effects, but painful varieties have increased. Unfortunately, having ever used any “D drugs” makes a person more susceptible to neuropathy, especially in more advanced HIV disease cases.

To control this debilitating side effect, physicians may prescribe numbing agents, such as 5% lidocaine gel, or anticonvulsant agents such as lamotrigine or gabapentin. Many PLWH also feel that acupuncture helps diminish neuropathy, though the scientific proof of this effect is dubious.^[10] Recombinant human growth hormone showed more evidence of reducing pain associated with neuropathy; yet this treatment did not impact the underlying nerve damage, and so is not widely used.^[11] With so many causes for neuropathy and so many manifestations, doctors struggle to find the tools to allow PLWH full mobility free of pain.

CORONARY HEART DISEASE

Nobody wants to gain years of life by slowing HIV if it also means risking their life to heart disease. Do HIV meds impact the heart and arteries negatively? One study at this year’s Conference on Retroviruses and Opportunistic Infections (CROI) implicated d4T in the development of angina, myocardial infarction and other cardiovascular events.^[12] To a lesser extent, 3TC use seemed to have some negative effect on heart health, too. The study did acknowledge that use of these meds was not as significant a risk factor as were age or history of hypertension. But the study’s effect was still chilling.

However, the risks have been challenged by other studies, including a much larger study of 36,766 veterans living with HIV, which was presented at last year’s CROI. In fact, that study found

that admissions to hospitals for cardiovascular events or deaths from heart disease dropped from 1993 to 2001.^[13] The Kaiser Permanente Medical Group conducted an observational study to see whether antiretroviral therapy in general, or protease inhibitors in particular, increased the rates of coronary heart disease. This study focused on over 4,000 HIV positive men old enough to have some chance of developing heart disease (35 to 64), but who had not yet personally had any coronary heart disease incidents. The patients on antiretroviral medications in general or protease inhibitors in particular were found not to be more likely to experience coronary heart disease during the four year follow up, though the authors acknowledged that differences might arise if a longer follow up was conducted. By comparing the 4,000 HIV positive patients to 40,000 HIV negative men of the same age and under care at the same

clinic, the study confirmed that PLWH do face higher risks of cardiovascular disease, just not that it’s related to their medications.^[14] Again, what health challenges facing PLWH may simply be the byproduct of the disease itself, and may have become more noticeable now that patients are living much longer—long enough for progressive heart disease to manifest itself. In fact, new data from the DAD study (Data Collection on Adverse Events of Anti-HIV Drugs) found that antiretroviral medications help prevent myocardial infarction. The study followed 17,600 patients over three years, and concluded that those who continued their medications faced a six-to-11 percent chance of death, while those who discontinued their meds faced a 22-29 percent chance.

HYPERLIPIDEMIA

As researchers try to determine why PLWH may suffer more cardiovascular events, many point to elevated cholesterol (called hyperlipidemia) as a possible cause. Two recent studies suggest that PLWH may be able to have the best of both worlds: potency

Unfortunately, having ever used any “D drugs” makes a person more susceptible to neuropathy, especially in more advanced HIV disease cases.

with minimum impact on lipids. Gilead's 96-week, double blinded study enrolled 600 PLWH who had significant viral loads (more than 5,000), and assigned them to take either d4T with efavirenz (Sustiva) and 3TC or to take tenofovir with the same base drugs. Patients in the tenofovir arm experienced only modest increases in triglycerides (5%) and cholesterol (30%), whereas patients in the d4T arm had over 100% climb in triglycerides and over 50% in total cholesterol.^[15] Another comparative study evaluated patients receiving either Combivir (AZT/3TC) with abacavir (Ziagen), Combivir with nelfinavir (Viracept), or d4T with 3TC and nelfinavir. After 48 weeks, patients in the d4T arm again experienced the highest mean increases in total cholesterol and triglycerides. Patients in the abacavir arm experienced the smallest increases.^[16] So, as PLWH can now expect to take their medications for many decades, physicians may need to select medications based not only on their anti-HIV potential, but also on their impact on other health indicators.

On the other hand, the significance of elevated cholesterol is not always apparent. Retrospective studies can point to heart problems patients developed, yet these studies may not prove that HIV medications caused high cholesterol, or that the elevated cholesterol was the cause of the heart disease. A recent study in the journal *AIDS* tried to settle these questions by tracking cholesterol levels in HIV positive patients, and then by comparing these levels both to those in HIV negative persons and amongst subgroups of persons taking different treatment regimens.^[17]

The patients taking antiretroviral medications were divided into groups: those taking only nucleoside analog drugs (nukes), those taking nukes plus a non nucleoside reverse transcriptase inhibitor (non-nukes), and those taking nukes and protease inhibitors. For the purposes of experimental control, the study did not examine patients who were taking both non-nukes and PIs, though such patients obviously exist and might potentially experience a multiplied impact of the side effects studied here.

The study concluded that patients taking either protease inhibitors or non-nucleoside reverse transcriptase inhibitors were more likely to show elevated total cholesterol, LDL-cholesterol, and HDL cholesterol as well as elevated triglycerides (for protease patients) or apolipoprotein A1 (for non-nuke patients).

So what does all of that mean? If you remember the butter vs. margarine debate of the 1980s, you know that all cholesterol are not created equal. Less than a third of the study patients reported to have elevated levels of total cholesterol also had elevated levels of the so called "bad" cholesterol, LDL. On the other hand, patients on any treatment showed significant increases in HDL cholesterol (the so-called "good cholesterol" that is believed to protect against heart disease). In fact, their HDL levels were generally higher than those in untreated HIV positive patients. So the study could not say that any class of medications, or any specific medication, was likely to promote heart disease. From a cholesterol standpoint, the increase in HDL attributed to treatment may generally offset the increases in LDL and total cholesterol that are common side effects of medications.

DIARRHEA, NAUSEA AND VOMITING

These three are the evil triplets of antiretroviral side effects. Nearly all HIV medications cause at least one of these effects. Nausea and vomiting are associated with all nucleoside reverse transcriptase inhibitors and all protease inhibitors, as well as with the non-nukes nevirapine (Viramune); the other non-nukes are associated with nausea, though not commonly with vomiting. Diarrhea is associated with nearly all PIs, and with abacavir and nevirapine.^[18] More than other treatment challenges, these three common side effects are most likely to directly interfere with day-to-day activities, and to induce shame and stigma.

Fortunately, these side effects also seem to be the most controllable. Most PLWH develop personal strategies that help mediate these effects. To control nausea and vomiting, some PLWH choose lighter meals with their dosing, while others find a weighty breakfast settles their stomach. Some do better if they drink a lot of water with their dose. One universally accepted rule about diarrhea: it's easier to prevent it than to stop it. Many PLWH regularly take a calcium supplement or a fiber bar to ward off diarrhea.

EVERYTHING FOR POTENCY?

In the early days of HAART (highly active antiretroviral therapy), many leading researchers advocated for the "hit it early, hit it hard" approach. Even if patients complained of intolerable side effects, the rationale held that the virus could be completely wiped out in just a few years with heavy protease-based treatment, so any suffering was worth this benefit. In recent years, the medical community has had to learn the hard way that HAART lacks the power to chase HIV out of the body, and even potent meds cannot deliver life-saving benefits if patients decide that they are intolerable and start skipping doses. Early protease inhibitors presented significant quality of life side effects (overwhelming nausea, diarrhea, gastrointestinal complaints, etc.) plus awkward pill burden and dosing requirements.

Now that eradication theory has been soundly disproved, providers and PLWH need to communicate as partners devising a manageable plan. For years, many PLWH were voting with their dosing—secretly skipping doses of medications they found were not palatable. Yet everyone knows the importance of medication adherence; a study at last year's *International Conference on AIDS* showed that PLWH who took more than 90% of their medications on time were nearly four times more likely to live through the decade than were patients who took less than 90% of their prescribed doses.^[19]

First generation protease inhibitors faced a major challenge: the body cleared them out (through the liver's P450 enzymes) before they could complete their task. To counter this natural bodily response, pharmaceutical companies had to produce treatments with heavy and frequent doses, which only increased patients' side effects. Ritonavir (Norvir) was particularly singled out for unpalatable side effects in its full dose formulation. But then researchers discovered that ritonavir not only inhibits HIV's protease, but also inhibits the P450 enzyme, allowing for a more steady stream delivery of another protease inhibitor into the bloodstream. Many second generation PIs are now "ritonavir-boosted," combin-

ing a lower dose of ritonavir with another PI. The first formulation to deliver two PIs in the same pill was Kaletra, which adds lopinavir to low dose ritonavir. Initially this drug was used almost entirely as a salvage option for patients who had suffered failure on other PIs, though now physicians recognize that the drug has durability to support its use as an initial treatment. Today, many medications are prescribed with a ritonavir boost, as the strategy allows for reduced dosing (once or twice daily instead of three times daily) and reduced overall pill burden.

As new treatment options continue to improve life expectancy for PLWH, the issue of side effects becomes more important than ever before, because patients need regimens that they can tolerate during ever-longer lives. ☩

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WAITING IN THE WINGS!

MORE NEW DRUGS

BY MATT SHARP

2003 was a banner year for HIV drug approval despite the fact that some of the drugs are very similar to what already exists. Improvements in medical treatment come slowly and incrementally, but lately there seems to be a wave of new treatments that in conjunction with new approved therapies may improve quality of life and benefit those with fewer treatment options. The newer drugs are from existing classes that are improvements on their predecessors, some are easier to take, and some are entirely new classes never used before, targeting other points in the HIV lifecycle. Cumulatively, they may end up representing a new treatment era in HIV.

The following are a few of the drugs furthest along in development.

REPEAT PERFORMANCE

Lexira (or 908/fos-amprenavir as it is currently known) is the fourth in line for approval this year. It is a new “pro-drug” formulation of amprenavir (or Agenerase) an older, mostly unpopular protease inhibitor. Out of all protease inhibitors, amprenavir was only 5% of the market due to the fact that it required eight horse pills twice a day. The new compound has been reformulated to be easier to take; one tablet twice-a-day, and will metabolize so that more drug gets into the bloodstream.

More data from clinical trials are shedding light as to the effectiveness of this drug. The NEAT study looked at 908

compared to Viracept with a background regimen of Ziagen and Epivir in treatment naïve participants. In those with initial viral levels of greater than 100,000, 71% (908) versus 35% (Viracept) saw their viral load drop below 400. The SOLO study also looked at treatment naïve participants with 908 boosted by ritonavir (Norvir). (As with other protease inhibitors, this drug may be more effective with a ritonavir boost.) The study compared once-daily boosted 908 to twice daily Viracept with a background regimen of Ziagen and Epivir. Again, those with higher baseline viral loads had a better viral load result.

One trial called CONTEXT looked at people who had failed one or two protease inhibitors and compared boosted 908 once daily or twice daily to Kaletra twice daily with a nucleoside background. No non-nucleoside reverse transcriptase inhibitors (NNRTIs) were allowed in this study. 48 weeks of data showed little difference in viral outcomes between the two arms, however based on a different analysis the study was able to show that 908 was really worse than Kaletra.

908 has not yet shown cross resistance to other protease inhibitors in laboratory studies, however, and according to the efficacy results thus far it most likely will be

better as a first line treatment. Common side effects for 908 are gastro-intestinal and there are significant drug interactions with other medications commonly used in HIV. 908 represents the HIV treatment era we find ourselves in today. While every effort has been made to make an easier drug to take it is probably not any better than what is already available.

Another protease inhibitor in final stages of development is tipranavir, which has shown to be a promising drug for those who are resistant to protease inhibitors. Tipranavir requires up to 20 mutations to become resistant. A Phase II study in protease resistant participants showed a sustained virological suppression for up to 48 weeks. There are two large Phase III studies underway looking at tipranavir with a ritonavir boost in highly protease resistant participants. It is dosed as 500 mg twice daily with a 200 mg ritonavir boost. All indications show tipranavir a useful protease inhibitor in those with multiple resistant PI mutations but the Phase III studies will put to rest any doubt that the drug will be effective in this difficult to treat population. The most common side effects seen were diarrhea. Tipranavir will be next in line for approval.

Another new protease inhibitor that was designed exclusively to work in those with PI resistance is called TMC-114. A Phase II dose finding study in 50 multiple-experienced participants showed that despite multiple resistance to protease inhibitors, all three doses selected showed a median drop of 1.35 log in viral load after 14 days. Again TMC-114 was boosted in this study but it may be effective without the ritonavir. GI side effects were seen in about a third of participants, but that may be due to the ritonavir.

CURTAIN CALL

The three approved non-nukes—Sustiva, Rescriptor, or Viramune—are highly cross resistant to one another, but high technology is making it possible to develop new NNRTIs which should not be cross resistant to them. Capravirine is a NNRTI that is nearing Phase III studies. After a significant intermission due to vasculitis in dogs seen in early studies at higher doses than would be used in humans, research in capravirine has restarted and larger studies are being planned. Early indications from Phase II studies involving NNRTI resistant participants show that it may be effective

in this group of people, but larger studies and more time will determine if this is true. One good thing is that the rash commonly associated with the older NNRTIs was not seen in early studies.

TMC-125 is a novel approach for those resistant to the current family of NNRTIs because it is a unique compound that is flexible and can fit into various binding pockets of HIV. In one short open label study of 16 HIV participants with a wide range of NNRTI mutations, TMC-125 was effective in suppressing HIV. Again, larger studies need to be performed to fully elucidate the effectiveness of this new drug in those who need a new NNRTI.

There are several other companies looking into novel NNRTI compounds. We need new drugs in this class!

MAKING A BIG ENTRANCE

Entry inhibitors have stepped into the spotlight for people who have used all the older anti-HIV drugs. This progress has led the way to more exciting research, and definitely gives those whose viral load levels are climbing and T-cells falling a degree of excitement and hope. Certainly T-20, now known as Fuzeon, the first approved entry inhibitor, was a milestone in creation of this new class of HIV drugs. Its cousin, T-1249, has showed impressive results in a small preliminary study looking at those who had failed Fuzeon. A median log drop of 1.26 was seen after eleven days of therapy. Participants switched out their Fuzeon for T-1249. It was shown that those who had used Fuzeon for a longer period of time didn't do as well. But the longer people were on T-1249 they continued to see viral load drops. Unfortunately, Roche is moving painfully slow with development of this new drug.

Like an arm holding a key to open a door, another clever way HIV uses to attach and infect T-cells is by using cell co-receptors. One of the co-receptors most prevalent in HIV is called CCR5. This co-receptor is associated with the early stage, slower progression of HIV. Another co-receptor called CXCR4 is associated with rapid progression and quick destruction of T-cells. Since CCR5 is more common, several companies are looking at drug candidates to block this co-receptor. In fact, two candidates are already moving into Phase II studies. At least one CXCR4 compound is in very early studies.

UK-427,857 has been tested in HIV negative people and was found to be safe. This kind of study is necessary in new drugs that have not been widely tested to establish safety. A second short term, monotherapy placebo controlled study looked at HIV positive people who were screened for the CCR5 receptor. The study tested several doses of the drug and saw a 1.42 log reduction in viral load after eleven days of 100 mg twice-daily. This was in seven patients. An eighth patient was later found to be dual tropic at baseline (had both CCR5 and CXCR4 cells), and the drug was ineffective for this patient.

The higher dose also had a higher saturation of CCR5, more than 90%, compared to less than 80% for the lower dose.

The drug seems to be safe in this small, short study. Now, larger studies can be designed to compare to existing HIV drugs, and to further evaluate how safe this CCR5 compound is.

SCH-D is another CCR5 attachment inhibitor in the treatment pipeline. Since some complications developed with the sister compound in early studies, this newer drug is now moving in a similar development path as the UK-427 drug mentioned above.

One major hurdle to overcome in co-receptor research is that if a person is treated with a CCR5 antagonist, will their virus "switch" to the more dangerous CXCR4 virus. In early studies this has not been seen, but more work needs to be done to be sure.

There are four different mechanisms that allow virus entry into a human T-cells. Research is now looking at ways to target each of these mechanisms alone and in combination. This discovery in entry inhibition has opened the door to a whole new era in HIV research.

However, as with any drug research there are many obstacles to overcome, and more clinical trials will paint a fuller picture as to whether or not they will play a role in the future of HIV treatment. What is encouraging is that just a short time ago there were very few promising drugs for people with HIV drug resistance. Now, the time is ripe for a whole new generation of drugs. Encore, encore! 🍀



TUBERCULOSIS: NOT A THING OF THE PAST

BY DOROTHY MURPHY, RN, MSN

Tuberculosis (TB) in certain communities of Chicago continues to pose a potential threat for re-emergence. In fact, there are 14 communities in Chicago that continue to have TB rates that are higher than the national and local rates. The majority of these communities are on the south side of Chicago; some of these communities are Grand Boulevard, Englewood, South Shore, and Roseland.

The Metropolitan Chicago Tuberculosis Coalition of the American Lung Association (MCTC), which emerged from the work of the Chicago Department of Health (CDPH)/ Cook County Tuberculosis Task Force, was established in 1992 to address the re-emergence of the tuberculosis (TB) epidemic in the late 1980's. MCTC was comprised of representatives from public medicine, public health and private entities.

Taking its lead from the Centers for Disease Control (CDC) in Atlanta, Georgia and its principles espoused by international agencies for tuberculosis elimination, MCTC set about the business of oversight for TB control in metropolitan Chicago. Led by some of the most noted infection control, pulmonology and public health experts in the area, the TB problem in Chicago over the past decade has been greatly impacted, with significant declines in TB rates. In spite of these efforts, a community health risk remains.

The goal of MCTC is to continue to create, coordinate and mobilize a variety of resources to focus on the elimination of TB in Chicago and metropolitan Chicago. With this in mind, two years ago, MCTC began hosting a series of community symposiums.

The ultimate desire was to "keep TB on the radar screen" in order to avoid another epidemic. A variety of community-based organizations were invited to come together to plan strategies to support MCTC and CDPH in its continuing efforts. Such agencies included churches, homeless shelters, local health and social service providers, as well as forums held by consumers and elected officials. After the South Side symposiums held in Grand Boulevard, additional symposiums were held on the west side and north side of Chicago. All planning groups are actively addressing the TB problems within their jurisdictions.

Aldermen Ed Smith and Arenda Troutman took the political lead and greatly increased MCTC's ability to access the affected communities. The HIV community has also greatly supported the community efforts of MCTC, including funding support. The South Side efforts have received support from the administration staff at St. Bernard and South Shore hospital through meeting space and infection control nurses support.

HOW TB WORKS

Unlike some other communicable diseases where person-to-person physical contact is needed to acquire the disease, TB is an airborne illness, which may be contracted when one breathes the same air of an active contagious case for prolonged periods. With

HIV, for instance, one can choose their sexual partner. That's unlike TB, where one is not always aware of the air space they're sharing.

TB is contracted when one shares the air space with an active infectious person who is talking, coughing, singing or otherwise exhaling germs into the environment. Most persons who come into contact with an active case will not develop one themselves, but may develop a latent form of the disease of the disease called latent TB. Of those who develop the latent form of the disease, approximately 10% will develop active disease later in life.

Those persons with impaired immune systems which occurs with HIV/AIDS, diabetes, cancer chemotherapy and other susceptible conditions are more likely to develop the active form of the disease. Once someone has active TB, they will require a minimum of six months of treatment or more, depending on whether they contract a drug resistant form or if they have an immune-compromised disorder. Those with latent TB can avoid an active case later in life by taking treatment.

PREVENTION

There are some preventive measures that everyone can take for TB control and some of these include:

- Covering one's mouth and nose when coughing (keeping tissue handy in your place of business).
- Recognizing the signs and symptoms, which include: a cough lasting more than two weeks, weight loss, night sweats, loss of appetite and bloody sputum. Anyone with these symptoms should have a medical work up for TB.
- Annual TB screening.
- Assuring that there is a TB screening program in your work place for clients and staff.

TB rates are found to be higher in some risk groups, such as those with HIV/AIDS, intravenous drug users, the medically compromised, the incarcerated and in some foreign-born populations. While one may argue that they have little contact with persons listed, please bear in mind that TB is airborne and individuals in these groups are mobile and so TB remains a public health risk. Speaking of the incarcerated, in 1992 in New York City, more than 30 inmates and two correctional officers died from a drug resistant form of TB.

If you would like to have more information about TB, including a TB 101 course for your staff, please contact Judith Beison, coordinator of TB programs at the American Lung Association, at (312) 243-2000. ☒

Dorothy Murphy is co-chair of the Metropolitan Chicago Tuberculosis Coalition of the American Lung Association.

HCV/HIV Co-infection II— A Patient's Perspective

by Gerald Moreno

Editor's note: Gerry Moreno first wrote for Positively Aware about living with hepatitis C virus (HCV)-HIV co-infection in September/October 2001 and again in March/April 2002. Last year he underwent a year-long treatment for hepatitis C and kept a journal from which this article is taken. The first part of this story details what he felt as he underwent therapy, and the second part relates how he feels now, along with his advice for other people living with these two viruses.

THAT WAS THEN

Living with HCV/HIV co-infection is like preparing a three-course meal. Not only do you have to learn the ingredients of each dish (HIV and HCV), but also the preparation (life-style changes) and of course the clean-up (which would be treatment). I feel as if I have been preparing this meal for the last 20 years, as the recipe keeps changing, and more ingredients must be added. I was hoping that one of the main courses would be completed, and the dishes put away, but that doesn't seem to be the case.

Bette Davis once said, "Fasten your seat belts, it's going to be a bumpy night," and that is exactly how I have been feeling on HCV treatment. I started treatment in January of 2002, after many months of preparation and meditation. I decided that everything else in my life will take a back seat, and treatment would become my priority for this year. I wanted to give treatment my best shot. I feel that mental preparation, and being aware of the difficulties that treatment can present, is the most important factor to a successful course of treatment. My mantra for this year is "One Day at a Time" and I am relying heavily on my recovery program and my higher power for the strength and courage to complete this course of treatment.

The therapy for chronic hepatitis C has evolved steadily since alpha interferon was first approved more than 10 years ago.

At the present time, the optimal regimen appears to be a 24- or 48-week course (depending on the HCV genotype) of the combination of pegylated alpha interferon and ribavirin. My genotype is 1A, so the course of treatment is 48 weeks. That includes one injection per week (under the skin) plus ribavirin (pill) at 400 mg two times per day.

I decided to give myself my injection on Fridays, so that I would have two days to recuperate before returning to work the following Monday. Six hours following my first injection, I started to feel all the classic side effects that are associated with interferon therapy. These included flu-like symptoms such as fever, headaches, nausea, muscle and body aches, loss of appetite, and fatigue. I remember waking up in the middle of the night and thinking, "Oh, my God, now I know what they are talking about," because it felt like the flu, but was more intense.

During the course of the weekend I stayed in bed, curtains drawn because the sunlight hurt my eyes, and slept. I started to feel better by Sunday evening, but did not return to work until the following Tuesday. During the week that followed I actually felt quite good, and continued my life as I normally do (work, gym, and hobbies), and I remember thinking that maybe this will not be that bad, but I spoke too soon. I

consider myself an optimist, but the weeks that followed tested my limits.

After the second injection I was bed-ridden with the usual side effects, the only difference was my nausea had increased, my energy level decreased, and I had shortness of breath. I recognized the latter two symptoms as potentially being anemia, so I made an appointment to see my physician. After a series of lab tests I was diagnosed with anemia (no surprise), and also lactic acidosis (mitochondrial damage), which was a big surprise. All medications were immediately stopped, and that included both my HIV and HCV treatments, and I started the treatment for anemia (Procrit). I remember feeling like a failure, and got very depressed because I thought that I would not be able to re-start HCV treatment again, but three weeks later I re-started peg-interferon without the anemia-causing ribavirin.

During the following month (February) I was doing fine, *sans* HIV medication and ribavirin, and my first HCV viral load confirmed that. My viral load dropped from 550,000 IU to approximately 40,000 IU, and that was without the addition of ribavirin. We re-introduced ribavirin back into the treatment plan a month later at a lower dose of 600 mg a day, and a month after that at 800 mg a day. I'm tolerating it nicely today. In fact, I only need to give myself Procrit when needed, and that hasn't happened in a while.

During the month of March I was beginning to get used to the routine, and side effects, when I got an urgent call from my doctor. He asked me if I wanted to hear the good news first, or the bad; and I chose the good first. My HCV viral load came back at undetectable (eight weeks), but my white count is very low, and I either need to lower my interferon dose (not an

option), or begin Neupogen (which stimulates production of white blood cells). I chose the Neupogen, and currently give myself two injections per week. For a person who has 12 years of sobriety from injection drug use, I am reminded everyday how far I have come, and how grateful I am for the support my recovery program has given me.

As I am writing this article I am at week 27. Everyday is a new experience, and everyday brings new surprises. I am responding very well (still have undetectable HIV at six months) and have yet to re-start my HIV medications. I hope to stay off them during the course of HCV treatment.

My mental and emotional health is like a roller coaster. I did not want to go on antidepressants, and waited until the very last minute to do so. I am discovering that whatever dysfunctional behaviors you may possess, they are magnified on interferon therapy. I belong to a support group, have a therapist, and am surrounding myself with love, especially from my partner, who bares the brunt of my emotions.

THIS IS NOW

My treatment goal was to land on the moon; I didn't quite get there, but I know that I picked up a few stars along the way. This is how I feel, today, about my treatment experience. If you had talked to me a few months ago, my answer would have been quite different.

I responded to treatment quite well; my HCV viral load went to undetectable levels within three months and my liver function tests were perfectly normal. With every passing month my hope for clearing



the HCV virus grew stronger, as I became more convicted toward completion. At the end of treatment I continued to be HCV undetectable, but I was also feeling a variety of emotions. This was the hardest obstacle that I have ever endured in my life. This experience taught me "one day at a time" much better than many of my recovery experiences. I was elated and exhausted at the same time, but now the next stage of treatment was about to begin: the wait.

The following 60 days, after treatment, went very well; I even continued to stay off all my medication. I had stopped my HIV medication due to a contraindication with my HCV treatment. Since I have been taking HIV meds since the early days of AZT, to be completely drug free was a treat.

After 30 days I re-started HIV meds without any difficulty. Everything was looking great, and I was trying not to get my hopes up, but I could not help it when

all my liver markers were perfectly normal.

At 60 days post-treatment everything continued to look good and my hopes continued to strengthen, even though I tried not to think about it. Then the phone call came. Everything that I had visualized, everything that I had hoped for, ended with eight words, "You relapsed. Your HCV viral load is back."

When I heard those words I got such a stomach ache that I could not speak. I was in shock, and the disappointment that followed was nothing that I had experienced before. I was at work, so I had to excuse myself and take a walk around the block, and cry. I know that I am at fault for having expectations, but I could not help it. Everything looked so good! All I wanted to do was scream out

to my higher power, "What did I do wrong, why did you let this happen?" So I did, down an alley; loud enough for a lady to open her window and ask if I was all right.

Her words felt so comforting, and I felt so safe, that I spent the next ten minutes sobbing. I kept repeating "What did I do wrong" and you know what, I could not think of anything. I am so grateful that I gave treatment 150 percent, because if I hadn't the guilt would be over-powering, and I would be beating myself up. When I returned to work I felt numb and I shared the information with my co-workers, and I received so much support. I am fortunate that I work in such a supportive environment; and this taught me that having a strong support system is crucial before, during and after treatment.

The weeks that followed were filled with many emotions, but the emotion that dominated was anger. I was so angry, not

at myself, but at my higher power. This is a new experience for me, but I am giving myself permission to walk through this process in my own time.

I am coping with this by staying very close to my support network, exercising and doing yoga, having fun, and by working my 12-step program.

The knowledge that I received histologic benefit (liver improvement) from treatment, even without viral clearance, aided in the comfort. Seven months post-treatment I requested a liver biopsy. I wanted to know if I actually did receive some benefit, so I could plan not only my future treatment strategies, but also my life. I am very happy to report that the results in medical jargon are “impressive” and in lay terms “f--k--g great.” Minor inflammation, no fibrosis, and no activity are the post-treatment results. This is a big improvement from pre-treatment; which showed that I had some activity accompanied with fibrosis.

I should have been on treatment longer. My doctor now says co-infected people may need to be on hepatitis treatment for 18 months. There’s a better interferon, that’s stronger and has less side effects, coming out from another company, as well as new HIV drugs on the market today. But my

viral load is back up to where it was, 1.5 million, which is low for hepatitis C (two million or less). My liver enzymes and everything else are perfect. My T-cells have been 350 since I can remember, and now they’re 550. I feel great now.

This is confirmation for me, and I hope for all of you who are contemplating treatment, that even if you are not successful in evicting the HCV virus, containment and improvement are a big possibility. My vision for the future will definitely include re-treatment; but now I have the luxury to wait a year or two. I will serve another eviction notice; it is now just a matter of when.

I definitely feel that patients should not start both HIV and HCV treatment at the same time. They also need to look at their emotional and mental health, and if they are going through some stressful situations, they may need to wait until they are in a better place. Above all, they need to discuss this with their health team! I also believe that HCV/HIV support groups are very positive, and can really help while people are on treatment. I have started one at our site, and it is working very well. We have speakers, as well as success stories, sharing and answering questions. I also supply mas-

sages and free videos to help them (pampering is good, especially on treatment).

Living with co-infection presents us daily with many challenges; but I encourage you to take them one at a time. Take good care of yourself, and remember that pampering is a positive thing. Go out and get a massage, facial, or just take a hot bath; you will be surprised at how good you will feel. “Reward” should not be a foreign word to you, and it should happen daily, even if it is just a positive affirmation. All these things should be two, three, and four on your priority list; leaving the number one slot to support. Develop a support network that will include professionals, peers, and most importantly, loved ones who will be there 24-7.

Life should be lived to the fullest, and there is no reason that we should be left behind. ☸

Gerald Moreno is the Health Educator with the University of California San Diego Antiviral Research Center. UCSD is a research facility that is currently conducting clinical trials for people living with HIV and HCV. For information on current and on-going trials, please call Gerald Moreno at (619) 543-8080 x237.

FINDING A VOICE IN VIETNAM CONTINUED

continued from page 22

story: how I’d contracted HIV, and how I was facing the prospect of my own death.

I grabbed hold of my chair and stared at the floor, embarrassed and afraid of what I had to tell them. Looking at their faces, dying people who had become trapped in the cycle of poverty and addiction, I knew that I had to tell them the truth.

But of course it wasn’t me who told them. It was Tuong, a student who failed my class and then gladly took it again. I watched as he expressed my story, his lips quivering as he tried to explain in Vietnamese the anger I felt when I first discovered I was HIV positive. My words, now his, rose and fell in singsong diphthongal Vietnamese, telling them about how I had my own problems with drugs, about the despair that went with addiction.

Most difficult of all for me, and now for Tuong, too, I had to admit to them that I had contracted the virus by having sex with another man. I also spoke about how I used yoga and meditation to help me feel more in charge of my health. That seemed to fascinate them, and they began a debate about the nature of yoga. As I listened to Tuong’s voice, I felt oddly liberated, knowing that someone else could take the story of my own life and tell it with perhaps more truthfulness than I could.

Last fall I returned to Chicago and my former teaching position. And between my teaching duties, I keep the memories of my

travels fresh in my mind as I work on a book chronicling the stories of those I met in Vietnam and elsewhere in Asia and Africa. I struggle to keep their faces from blurring. But Tuong continues to sharpen my gaze with his photography and his compassion. Since his graduation he returned to Vietnam to work with Mr. Van and photograph the conditions of the urban poor in his country. And sadly, while he was there, he discovered that his own nephew had contracted HIV from drug use—a 16 year-old boy. ☸

Michael McColly teaches Writing and English as a Second Language at Northeastern Illinois University and is working on a memoir based on his travels in countries affected by HIV/AIDS.

James Tuong Nguyen has a degree in Fine Arts in photography and computer graphic design from Northeastern Illinois University and is working on a portfolio of a documentary photograph series that records the social conditions of Vietnam’s poor. He had revisited Vietnam and traveled to Cambodia and Korea to study Vietnamese people working and living in those countries. He can be contacted at tnghuyen60640@yahoo.com.

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MAKING THE ADJUSTMENTS

by Deneen Robinson

As sure as I am a woman, I have had to make adjustments simply for HIV. You would think that HIV and I could reach some sort of compromise, like I would only have to make a certain number of changes and once I reach the maximum number, I wouldn't have to make any more. Well, it does not work like that. Living with HIV is full of adjustments. That is, if you want to continue having some quality of life. Or you could be like this woman I met on a retreat.

She loved onions and pickles. The onions and pickles did not love her. As she got sicker with HIV, the onions and pickles loved her even less. I remember her telling me that every time she ate them, she would get sick and she did not know why. I thought that maybe she just needed someone to help her see the relationship between the constant vomiting and nausea and the pickles and onions. Seeing the relationship, I thought, would help her make the adjustments she needed to make. The designated educator for this trip, I explained to her that there was a relationship between her diet and the nausea and vomiting that occurred afterwards. I talked to her about how the gut carries a large number of lymphatic cells, which hold HIV. Therefore, the gut is sometimes very sensitive. I suggested that she look at eating less of these items or substituting something else in their place. She was not prepared to make the adjustments. She said, "I gotta have 'em. I can't give 'em up." And she did not. The last time I saw her, we were sitting in the cafeteria at a campsite; eating barbecue. And yes, she was eating her pickles and onions.

Shortly afterwards, someone was holding her head over a trash can in the middle of the dining room full of strangers. She was throwing up her dinner, because she did not want to give up pickles and onions. She died shortly after that.

I remember asking some of the other women how she was doing. They told me some really great things about her. Unfortunately I have no memory of those things. My memory of her is the picture of seeing a woman in her mid-forties sitting in a wheelchair, bent over a trash can, held at her waist in a room full of more

than 200 strangers watching her throw up. I will never forget feeling so angry that someone did not say "no" to her and help her make a different choice. There is no dignity in being bent over a trash can in a crowded cafeteria full of strangers. Making change is not easy. However, it is necessary. The adjustments you make can help improve the quality of your life.

I love ice cream. Especially Haagen Dazs Chocolate. It does not love me. It hates me! For a long time I would continue to eat it and suffer the consequences. I would have chronic diarrhea and cramps for at least three days afterwards. As I have grown in my understanding of how HIV works in the body, I realize that I am hurting

myself if I continue to eat food that makes me sick. I am certainly not improving my quality of life. I have since given up this ice cream and am eating Haagen Dazs Chocolate Sorbet. It tastes just like ice cream without all the milk, cramps and diarrhea.

It took me a long time to make that adjustment. Sometimes, I falter and eat ice cream. The important

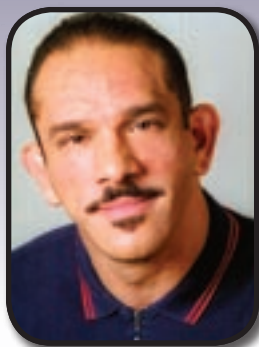
point is that I do not continue to do this. I try to get back on track as soon as possible because the consequences are grave.

The best way to find out how HIV manifests itself in you is to listen to your body. Your body will tell you if you are eating things you should not. Your body will tell you if you are not getting enough rest, need more energy, etc... If you listen, you will have the information you need to make any necessary adjustments to help improve your quality of life.

Making adjustments does not mean you are giving in to HIV. It means that you are participating in your healthcare and taking charge of the things you can control. It is very empowering to say, "I am not going to eat that anymore because it makes me sick." And then don't eat it. What you find is that you do get better. Your quality of life improves. I personally want to revisit my earlier discussion with HIV and ask, "Hey, I am reaching my limit with these adjustments. Can you help me here?"

Take care of yourself and your blessings. ☪

The best way to find out how HIV manifests itself in you is to listen to your body. Your body will tell you if you are eating things you should not.



I LOVE MY ANDROGEL

by Carlos A. Perez

What I really love about my Androgel I can't write about in a family magazine, but my editor demanded to know. Alright, when I have leftover Androgel at the end of the month, I rub it on myself and my partner and we go into a frenzy. We have a great time in the bedroom.

One of HIV's most popular affect on our system is hypogonadism, which is the medical term for a low testosterone level. The statistics say maybe as many as 30-50% of HIV positive men have low testosterone counts.

that same night. Before long your energy level may be back to a place you may not remember because it was sometime way before the HIV infection occurred. There can be side effects, as with any other drug, which may manifest as headaches, hypertension, acne or prostate disorders. There are also concerns for people with heart, kidney and liver disease, and it is not recommended for pregnant women. Aside from a small percentage of those who fit this criteria, testosterone is very well tolerated by most people, especially HIV positive men who need this hormone.

would take during a controlled cycle monitored by your doctor.

Testosterone replacement may help you feel better, therefore making it easier for you to get to the gym or start jogging. It's not just about the ego. Depression has a sly way of slipping into your life. A few days turn into a few weeks then winter comes and you look at yourself one day and shriek in horror because you've been locked up all winter waiting for your disability payments and now you can't fit into last years' jeans. Testosterone replacement therapy may be the kick you need in your jeans.

Some people receiving testosterone injections feel aggression or anxiety or experience mood swings. This is from the spike of testosterone hitting your blood stream. Imagine your testosterone level being at a low and suddenly you're fully charged. It can make you feel like an angry AIDS activist acting out in San Francisco's City Hall! I experienced some "roid rage" while taking the injections and I didn't care for the way it made me feel. I was feeling great for the first time in a long time, my energy and libido was back and the other benefits started to show as well, which is the burning of fat and the enhancement of lean muscle tissue. However, I found that I became angry and easily frustrated. On a few occasions I was ready to punch out that idiot driver in front of me... how dare he drive like an imbecile! I discussed this with my doctor and we figured the surge of testosterone was causing an urge.

Then my doctor suggested a cream that was made with testosterone but you had to get it by mail order from a women's clinic in Wisconsin. It had a lower concentration of testosterone so I would apply it daily instead of the weekly intra-muscular shot. They literally crushed it up in a pestle and mortar

Androgel is intended for people with below normal levels of testosterone.

Symptoms of low testosterone may include fatigue, depression, inability to concentrate and (gasp!) erectile dysfunction or decreased sex drive. If left unchecked for a long period of time there is the possibility of losing bone mass leading to osteoporosis, loss of hair and loss of muscle tissue.

Luckily there is hope, and it's cheap and simple with hardly any bad side effects. Testosterone injections are an option and work just fine for many. However, some people, like *moi*, cannot handle the sudden surge of testosterone and there are others who just hate an extra needle stick in their bun.

Most people who go on testosterone replacement therapy notice an improvement in their energy level overnight. Some notice an improvement in their bedroom

People hate side effects and most people cringe when they hear steroid or hormone because we cling to the negative and sensational stories we've heard. There was bad news when athletes like wrestling super hunk Kyle Hazard died from steroid abuse years back and then there were the many scandalous stories of Olympic champions caught cheating while "on the juice." The Olympics brings up the bar on the hysteria factor because it's an international event.

These stories are blown out of proportion. These people either were caught because they used the substance to cheat in an athletic performance or worse yet they overdosed. Those who overdose are sometimes taking thousand of milligrams per injection, which may be more than you

to your doctors' order. The original intent of the cream was to control symptoms of menopause. Since there was no other choice on the market I tried it. I had to lather it on my scrotum and then wait, sort of hanging there, and let it absorb through the skin. It was icky but it worked like a charm. Within the first week I was able to pop out of my house and I started feeling like my old, or should I say younger, self again.

In June of 2000 Unimed Pharmaceuticals brought Androgel to market. I think I had my doctor write the script in June 2000! It is one of the best innovations in medicine and my chosen option instead of that shot that can sometimes leave you limping for hours. The gel is so easy to apply, you just rub it on and it instantly dries. You may rub it on your shoulders, thighs, or abdomen. Make sure to thoroughly wash your hands after applying the gel because you do not want to forget and then rub your eyes (ouch!), and if you have any finger food it will taste very wrong.

Androgel is intended for people with below normal levels of testosterone. By applying one packet per day you should expect to see a positive result in your blood work by the next time you see your doctor. It is not meant to be an anabolic supplement. Do not expect to apply a few packets and start bursting out of your shirts. To deal with wasting syndrome you would need to take higher dosages of testosterone and probably combine it with other anabolic steroids, in controlled cycles as prescribed by your physician. With time, however, the daily applications will have a very positive effect on your figure, so if you can faithfully apply the gel and go to the gym regularly you will burn fat and gain lean muscle tissue. After all, testosterone is what makes "the mens" a man.

It is not
meant to be
an anabolic
supplement.

Androgel is a great product. It comes in handy little packets that deliver 50, 75 or 100 milligrams of testosterone through your skin and into your wonderful bloodstream. You get all the benefits from testosterone replacement without the added trips to the doctor's office for the shot. You also get smoother delivery of the drug because you are applying a smaller amount of it daily instead of getting a weekly shot that will cause a sudden spike in your circulatory system. It is covered by insurance as long as it's prescribed and it's a breeze to use. It should be applied when you do not expect to shower since you should allow up to four hours for full absorption. You should not apply anything before the gel like moisturizing cream as this will create a barrier and not let the testosterone be fully absorbed.

Keep in mind that our body's natural release of testosterone peaks around 6 to 8 in the morning so it would be advantageous to get your shower done by this time so you

can apply your gel and still mimic your own body's cycle of testosterone. Even individuals with hypogonadism release some testosterone during early morning, however, not enough to sustain day to day life.

There are two other types of testosterone replacement therapies. Testim made by Auxilium Pharmaceuticals was approved in October 2002. Testim works great, it is much the same as Androgel. It is absorbed even faster than Androgel, thus, requiring only a two-hour period for maximum absorption before showering. Once applied Testim gives you an almost instant rush of energy. The drawback is it comes with a very 70's musk oil fragrance that was too strong for me. The reason for the scent is not from adding fragrance but from pentadecalactone. This oil is used as an emollient that helps with better absorption and it moisturizes too! And this oil has a sweet, powdery, musky, woody odor, which is why I was getting all the weird looks at the gym.

This is a great product and if you don't mind the smell ask your physician about it. Auxilium has an information packet, which you may request directly from them or your doctor that can even save you some cash on the co-pay end of the prescription.

The next type of testosterone replacement therapy will be a "buccal tablet" which delivers the testosterone transmucosally. It will be developed so it dissolves underneath your tongue or inside your cheek. The buccal tablet is further down the pipeline of testosterone replacement therapies, but at least we have more options to get the juice back into you with or without that needle stick. ☩

TPAN Events Calendar

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

November 2003

DATE	TIME	EVENT
Tuesday 4th	12:00-2:00 PM	Metabolic Issues with HIV, lunch provided. Sponsored by Serono Laboratories. RSVP with Jennifer Roe at (888) 839-9657
Wednesday 5th	7:30-9:00 PM	Committed to Living - HIV Reinfection - Dr. Roberta Luskin-Hawk dinner provided
Thursday 20th	6:00-10:00 PM	PULSE End of the Month Party at Berlin
Thur. 27th - Fri. 28th		TPAN Closed for Thanksgiving holiday

December 2003

DATE	TIME	EVENT
Monday 1st		World AIDS Day - Please visit www.tpan.com and www.aidschicago.org for Chicago area events
Monday 1st		2004 Chicago HIV Services Directory to be distributed, agencies should contact Carlos Perez to request copies
Monday 8th	6:00-8:00 PM	TPAN Annual Holiday Party - Sidetrack - 3349 N. Halsted
Wednesday 17th	7:00-9:00 PM	T.E.A.M. Update - Accessing HIV Information Resources
Thursday 18th	5:00-10:00 PM	Hairspray The Musical - Preshow reception at Marshall Fields on State St.
Wed. 24th - Wed. 31st		Please check for TPAN open hours during holidays

Getting support for HIV and taking care of your health shouldn't be a hassle.

Now they both just got a little easier.

- HIV Specialty Care
- Full Service Clinic
- Free HIV & STD Testing



Monday & Wednesday
10:30 am - 6:00 pm
drop-in or by appointment
call 773.989.9400

offered by
Access Community
Health Network



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–6 pm

phone: (773) 989–9400 • fax: (773) 989–9494

e-mail: programs@tpan.com • www.tpan.com

Support groups sponsored by the
Chicago Department of Public Health

Peer Support and Buddy programs sponsored by the
AIDS Foundation of Chicago

Monday

MEDICAL CLINIC

HIV/STD screenings and full medical care for HIV positive clients is available. Program is offered by Access Community Health Network. Call for an appointment. 10:30 am–6 pm.

TPAN DAYTIMERS

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

HEALTH (HIV EMPOWERMENT AND LIVING TOGETHER WITH HEPATITIS)

NEW support group for people living with HIV and hepatitis. HEALTH focuses on therapy and treatment concerns of people who have experienced HBV/HCV/HIV co-infection. Meets Monday 11/3, 11/17, 12/8 and 12/22 from 7:30–9 pm.

SPIRIT ALIVE!

Through a collaborative effort of AIDS Pastoral Care Network (APCN) and TPAN, Spirit Alive! fosters discussions on topics such as hope vs. despair or strength in times of adversity. Meets from 7:30–9 pm.

Tuesday

YOGA

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

POSITIVE PROGRESS

A peer-led group for HIV positive individuals in recovery. Special emphasis is placed on sobriety as a priority to effectively living and dealing with HIV. Meets from 7–9 pm.

LIVING POSITIVE

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

Wednesday

MEDICAL CLINIC

See description on Monday. Call for an appointment. From 10:30 am–6 pm.

Wednesday continued

NEEDLE EXCHANGE PROGRAM

Through a collaborative effort of Chicago Recovery Alliance and TPAN, a free, anonymous, legal syringe exchange and HIV/AIDS prevention is 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 1st, 3rd and 5th Wednesdays from 7:30–9 pm.

POZ LEATHERMEN

NEW support and social group for HIV positive leathermen and friends. Meets from 7–9 pm.

YOGA

All levels of yoga are welcome. Meets from 7:30–8:30 pm.

Thursday

TPAN DAYTIMERS

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

NEEDLE EXCHANGE PROGRAM

See description on Wednesday. Thursdays 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.

POSITIVE NOW

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

PULSE AT BERLIN

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

Friday

NEEDLE EXCHANGE PROGRAM

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

SAFE PASSAGE

A support group for young adults (ages 18–24) who are HIV positive. Meets from 7–9 pm.

Scheduled By Appointment

FASN (FAMILY AIDS SUPPORT NETWORK)

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

INDIVIDUAL COUNSELING

Licensed professional provides individuals with one-on-one counseling on Mondays. Call Joe Flint at (773) 394–7063.

PEER SUPPORT NETWORK/BUDDY PROGRAM

Trained volunteers provide individuals living with one-on-one peer, emotional support. Call Jim 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)

This peer-led program integrates secondary prevention and treatment education to provide individuals the training and knowledge to more successfully support other individuals impacted by HIV. Call Montréal at (773) 989–9400.

REIKI

Energetic healing practice that utilizes hands-on touch and focused visualization. Meets Tuesdays and Thursdays by appointment only from 2–5 pm.

Miscellaneous

LIVINGPOS18to24@AOL.COM

An AOL chat room for young adults (ages 18–24) who are HIV positive. Monday through Friday from 3–5 pm.

CABARET CHICAGO—2003 TPAN GALA

The Test Positive Aware Network benefit gala, Cold Gin Hot Jazz—Cabaret Chicago, held on September 5, 2003 at the Hyatt Regency Chicago, raised \$50,000 for TPAN programs and services. 400 people in attendance enjoyed the voice and comedy of emcee Jeff Roscoe and performances by Michael Thompson, members of the Chicago Gay Men's Chorus, the Joel Hall Dancers, and the Chad Willets Band.

TPAN presented its annual awards at the dinner. Earlene Hayden received the Chris Clason Committed to Living Award, AIDS Foundation of Chicago received the TPAN Visionary Award, and Jeff Berry received the TPAN Award of Excellence.

Many special guests attended Cabaret Chicago including Illinois State Rep. Larry McKeon and Chicago Alderman Tom Tunney, as well as candidate for U.S. Senate Blair Hull. Attendees representing the offices of IL State Comptroller Dan Hynes, U.S. Congresswoman Jan Schakowsky, IL State Sen. Carol Ronen, and Cook County States Attorney Dick Devine were also present. TPAN wishes to also thank IL State Gov. Rod Blagojevich, Chicago Mayor Richard Daley, IL Secretary of State Jesse White, IL State Treasurer Judy Baar Topinka, IL State Sen. John Cullerton, IL State Rep. Sara Feigenholz, IL State Rep. Harry Osterman, Chicago Ald. Mary Ann Smith and Michael Leppin for their support of Cabaret Chicago and the mission of Test Positive Aware Network. ☒



TPAN Executive Director Charles E. Clifton (right) with candidate for United States Senate Blair Hull.



Equality Illinois political director Rick Garcia with Mary Kay Dawson and Blair Hull, candidate for United States Senate.



Photographs by © Catherine Sikora 2003



Joel Hall Dancers perform at the TPAN annual gala, Cabaret Chicago.



Jeff Berry accepts the TPAN Award of Excellence.



Charles Clifton presents Mark Ishaug, Executive Director of the AIDS Foundation of Chicago, with the TPAN Visionary Award.



Earlene Hayden accepts the Chris Clason Committed to Living Award.



Jeff Williams, Andrew Foster and Equality Illinois political director Rick Garcia.



Jeffrey Williams, Ruby Fong, Illinois State Representative Larry McKeon and Father John Schmidt.



Lesbian Community Cancer Project Executive Director Jessica Halem, Joel Hall, and friends.

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YOUR SEATS
NOW!**



hairspray

• BROADWAY'S BIG FAT MUSICAL COMEDY HIT •

Join us at a Hair Hoppin' benefit for
Test Positive Aware Network

Tickets are \$175
includes main orchestra seating
Private reception before the show
with Hostess Miss Fozzie

Thursday, December 18
Ford Center for the Performing Arts
Oriental Theatre

SPACE IS LIMITED, SO RESERVE YOUR SEATS NOW!

Tracey Turnblad and Link Larkin will be there. WILL YOU?

*Sponsors
Include*



Call Jeffrey Allen at
773-989-9400
to reserve your seats

