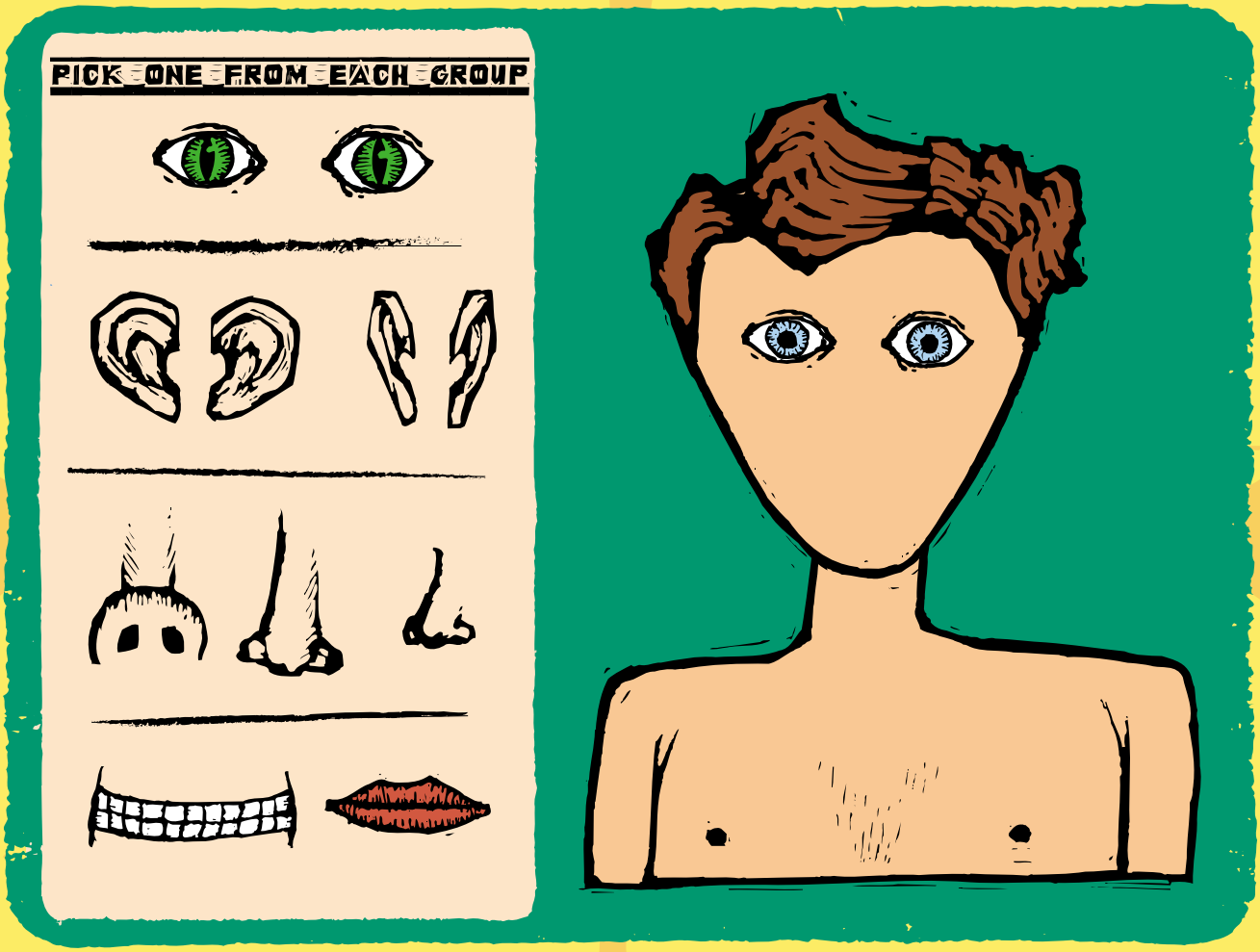
Positively Aware

The Journal of
Test Positive Aware Network

HIV Treatment and Health

July/August 2000

Consumer's Guide to Lipo Surgery



The Latest on Structured Treatment Interruptions

The Next Wave: Therapeutic Drug Monitoring

The Broad Benefits of HIV Research

Baby's Got the Red Ribbon Blues

Positively Aware
The Journal of Test Positive Aware Network
HIV Treatment and Health
July / August 2000 • Volume 11 Number 4

Table of Contents

Departments

Features

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

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

HIV/AIDS
Specialists for Life

StatScript Pharmacy provides the most effective HIV management available. In over thirty locations nationwide, we offer:

- One source for all your medications
- Private one-on-one consultations
- Coordination and filing of insurances
- HIV-certified pharmacists

For the StatScript Pharmacy nearest you or to enroll in our home delivery service simply call

1-800-869-6593

STATSCRIPT Pharmacy
www.statscript.com

Editor / Director of Communications

Test Positive Aware Network seeks a highly qualified individual for the position of Editor of *Positively Aware* and Director of Communications. This position is a key member of TPAN's senior management team.

Duties include editing of, and writing for, *Positively Aware*, a leading community-based national HIV treatment journal, supervision of magazine and public relations staff, budgeting, and managing agency communication efforts, including advertising and public and community relations. Desired qualifications include 2 years of editing, extensive writing experience, supervision, budgeting, and public relations.

Must have a strong commitment to peer-led services and self-empowerment of HIV positive persons.

People with disabilities, including HIV, people of color and women are strongly encouraged to apply.

Send cover letter, resume, writing samples, and salary requirements to Dennis Hartke, TPAN, 1258 W. Belmont Ave., Chicago, IL 60657. No phone calls or faxes.

test positive aware NETWORK

Test Positive Aware Network
1258 W. Belmont Ave.
Chicago, IL 60657-3292

phone: (773) 404-8726
fax: (773) 404-1040
e-mail: tpanet@aol.com
http://www.tpan.com

Interim Editor/ Associate Editor **Enid Vázquez**

Advertising and Distribution Manager/ Editorial Assistant **Jeff Berry**

National Advertising Representative **Rivendell Marketing 908-232-2021**

Executive Director **Dennis Hartke**

Business Director **Rick Bejlovec**

Contributing Reporters **Kelly Harmon, James Learned, Jim Pickettt**

Art Directors **John Auterman, Russell McGonagle, apparatus**

© 2000, Test Positive Aware Network, Inc. For reprint permission, contact Jeff Berry. Six issues mailed bulkrate for $25 donation; mailed free to TPAN members or those unable to contribute.

TPAN is an Illinois not-for-profit corporation, providing information and support to anyone concerned with HIV and AIDS issues. A person's HIV status should not be assumed based on his or her article or photograph in *Positively Aware*, membership in TPAN, or contributions to this journal.

We encourage contribution of articles covering medical or personal aspects of HIV/AIDS. We reserve the right to edit or decline submitted articles. When published, the articles become the property of TPAN and its assigns. You may use your actual name or a pseudonym for publication, but please include your name and phone number.

Opinions expressed in *Positively Aware* are not necessarily those of staff or membership or TPAN, its supporters and sponsors, or distributing agencies. Information, resources, and advertising in *Positively Aware* do not constitute endorsement or recommendation of any medical treatment or product.

TPAN recommends that all medical treatments or products be discussed thoroughly and frankly with a licensed and fully HIV-informed medical practitioner, preferably a personal physician.

Although *Positively Aware* takes great care to ensure the accuracy of all the information that it presents, *Positively Aware* staff and volunteers, TPAN, or the institutions and personnel who provide us with information cannot be held responsible for any damages, direct or consequential, that arise from use of this material or due to errors contained herein.

Editor's Note

What Price Beauty?

We're not talking about beauty. We're talking about normalcy. Our cover story on "plastic surgery" is actually about "reconstructive surgery." But the insurance companies don't see it that way. That means only the HIV positive people who have extra cash laying around can get the surgery it takes to make them feel normal again.

No one wants to feel ugly–or to look abnormal. We're so used to thinking in terms of "vanity" that we don't see surgery (or other tools) as something that can be constructive. We forget that real people have real pain, and that diminishing looks can be a true source of distress. It's not necessarily a matter of superficiality or spiritual vacuum.

This is more true when the diminishment comes from a life-threatening disease. When do we stop making excuses for medical indignities?

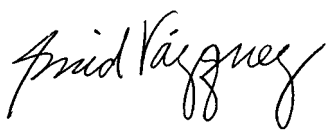
All along there were those in the health industry who chided people with HIV about drug side effects. The attitude has been, "You're alive, so what if your life is ruined by diarrhea?" Or maybe, "So your feet are extremely painful–would you rather be dead?"

Well, for many people, yes. And now the past several years have brought disfigurement from HIV medications. When will side effects be taken seriously?

When people with HIV began to discuss the wasting away of their face or the humps growing on their backs, so many people seemed to think this was petty.

It's not. Surgery is not easy. It's not fun. Some of the people I talked with loved their results, but most seemed saddled with some disappointment for their time and money, even when for the most part they were satisfied. You don't go back to looking the way you did before disease got to you.

But wearing AIDS on your face or your back could make you feel worse. So the question rises again as ever in medical care: when will insurance companies learn compassion?



Enid Vázquez
Interim Editor

HIV is the Cause of AIDS

"HIV is not the cause of AIDS." As hard as it may be to believe, there is a small, but visible (at present at least) group of people who believe this. Despite overwhelming evidence to the contrary, there are some "scientists," "medical experts" and "community leaders" who say HIV is not the cause of AIDS. Call them HIV "dissidents," "denialists," "non-believers," "right-wing fringe," "AIDS-phobic," or whatever else you like. I call people who believe this uninformed and gullible. I call the leaders of this farce crackpots, jerks and dangerous. What I'd like to call them is "gone." But unfortunately, with the President of South Africa giving them seeming legitimacy by appointing them to his panel on AIDS, they have once again surfaced on a national and international scale.

Scientific evidence, as well as plain old personal experiences, overwhelmingly proves the link between HIV and AIDS. Technology now allows portions of the actual virus to be isolated in persons who have tested positive for HIV antibodies ("the AIDS test"). HIV positive individuals who were extremely ill with depleted immune systems and one or more opportunistic infections (OIs) have had dramatic improvements in health after starting anti-HIV medications. In some cases, previously healthy individuals who were exposed to HIV-contaminated blood through accidental needle sticks have tested positive for HIV and later developed AIDS. HIV infection and AIDS cases that result from blood transfusions have nearly been eliminated now that blood is screened for HIV. All of these provide evidence of the link between HIV and AIDS.

Believing that HIV is not the cause of AIDS is dangerous as well as wrong. The danger comes in two forms–increasing the transmission of HIV and not seeking proper medical care. If one does not believe HIV leads to AIDS then the need to practice safer sex is no longer relevant as it relates to AIDS. While safer sex is important for reducing other sexually transmitted diseases (STDs), most of the increased use of condoms and other safer sex techniques are attributable to fear of HIV, not other STDs. If you do not believe in HIV, then it is not a huge leap to assume safer sex is a lower priority for you. After all, condom use was not very high before HIV came on the scene.

Another danger created by HIV "non-believers" is discouraging people from seeking proper medical care. Whether it is starting anti-HIV medications or simply regularly monitoring your health, proper medical care is vital. The single most critical factor in living with HIV is proper and timely medical care.

Do not be confused–HIV is the underlying cause of AIDS. While there are a number of factors that determine how fast the disease progresses, there is no doubt that HIV is the cause. But as tens of thousands of us who are HIV positive are proving every day, being HIV positive is not the end of life. Some of us are fighting HIV with the current drug combinations. Others are using "alternative" approaches, such as herbs, exercise, yoga and relaxation techniques. The approaches vary, but for many the result is the same–an active, productive life. The important factor is to remain "Committed to Living."

Dennis Hartke

Dennis Hartke
Executive Director

Readers Forum

Positively Aware will treat all communications (letters, faxes, e-mail, etc.) as letters to the editor unless otherwise instructed. We reserve the right to edit for length, style or clarity.

Write to: **Positively Aware,**
1258 W. Belmont Ave.,
Chicago, IL 60657–3292

Fax: (773) 404-1040
E-mail: posaware@aol.com

Sex work

I wanted to let you know that you guys are amazing. While I am continually impressed by your work in *Positively Aware*, I have to thank you for the feature article in the March/April issue, "Sex Work, Drugs and HIV." So many of the people I see on the Chicago Recovery Alliance syringe exchange van fit the self-description of Tony. I am looking forward to seeing how they respond to the article. Thanks for focusing so intimately on one person's life.

Karen, Chicago

Prison blues

I am writing to you because I would like to receive the journal of Test Positive Aware Network. I have been HIV positive for over 10 years and the information in the journal has been invaluable in helping both myself and other positive people stay alive and healthy. I am currently in prison for the next few years and although I do occasionally get the journal from some of my contacts, it sure would be helpful to have a subscription to ensure a steady supply of up-to-date, cutting-edge information.

I ask this not only for myself, but for the many others who I share your journal with. You see, I am also involved in peer education and quasi-clandestine advocacy for fellow HIVers. In fact, your journal has recently played a key role helping me to help an inmate here who recently found out he was HIV positive. He found out the hard way by coming down with a case of pneumonia and losing 50 pounds! He has recovered from the pneumonia, but must now learn to live with HIV. His confusion with his condition and his medications was complete, to put it mildly.

I rolled up my most recent prize, a copy of *Positively Aware*, January/February 2000 and smacked him on the head with it. I then said, "That's for not getting tested!" I then unrolled it and sat with him for over an hour explaining to him the HIV Drug Guide 2000, pointing out his medications and letting him know he was not alone. I want to thank you for that issue. The format was just what I needed to help him understand both his meds and the others that are widely accepted. I also wish to thank you for any consideration you may give this request for a subscription and I look forward to your reply. I cannot enclose a donation, however, I'm enclosing this poem that I wrote. It's the best I can do at this time.

Respectfully,
P. Y.,

Survivors
In our desire, zest and zeal for life we've come upon this dismal strife. Trespassed and violated the invader seeks to slowly steal away our life. With dismay this curse we dare not say for fear of driving everyone away. We manage to cope with grace and hope as we seek the courage to make it through another day.

So many never make it home, slowly shrinking to the bone, surrendering with each heartwrenching moan. They fall to the wayside in a race with death for a cure unknown.

It cuts so close that tears fill our eyes. We feel their cries! We see ourselves in the fading reflection of their faraway eyes.

News Briefs

by Enid Vázquez

Expanded access for kids

The liquid formula of Sustiva (efavirenz) non-nucleoside analog is now available through an expanded access program for HIV positive children and adolescents (ages 3 to16). The clear, strawberry/mint-flavored solution is taken once daily with or without food. Children have the same side effects as adults (primarily in the central nervous system), but experience more rash (40% in pediatric trial). Children also experienced diarrhea/loose stools (39%), fever (26%), cough (25%) and nausea/vomiting (16%). For more information, call (800) 334-4486 or visit www.sustiva.com.

Neuropathy drug

The AIDS Clinical Trials Group (ACTG) reported improvement in pain from HIV-related peripheral neuropathy with injections of recombinant human nerve growth factor (rhNGF). Peripheral neuropathy, damage to the nerves of the hands and feet, frequently begins as numbness or a sense of pins-and-needles, but then commonly becomes painful and permanently disabling. In a March *Neurology* report, the researchers noted that after 18 weeks of treatment, "17% of placebo recipients rated their neuropathy as 'improved' or 'much improved' compared to 33% of lower dose and 36% of higher dose patients." Current treatments for peripheral neuropathy are generally hit-and-miss, and sufferers are hard pressed to find relief.

Agenerase warning

Because of the potential for toxicity due to its content of propylene glycol, the liquid formula of Agenerase (amprenavir) protease inhibitor should not be used by infants and children, pregnant women, people with liver or kidney failure, and people who take Antabuse or metronidazole (including Flagyl), according to a new drug warning on the package insert. Signs of toxicity include seizures, stupor, tachycardia (rapid heart beat), hyperosmolality (an abnormally acute sense of smell), lactic acidosis, renal toxicity, and hemolysis (loss of red blood cells). Alcohol should be avoided during dosing. The manufacturer also reported that, "Certain ethnic populations (Asians, Eskimos, Native Americans) and women may be at increased risk of propylene glycol-associated adverse events due to diminished ability to metabolize propylene glycol; no data are available on propylene glycol metabolism in these groups." The warning does not apply to Agenerase capsules. For more information, visit http://www.fda.gov/medwatch/safety/2000/agener.pdf.

Vaginal thrush

Both clotrimazole (Lotrimin or Mycelex) antifungal tablets and *lactobacillus acidophilus* gelatin capsules reduced outbreaks of vaginal candidiasis by half, according to a conference abstract (summary) presented earlier this year. "This demonstrates that simple topical vaginal prophylaxis may be effective in preventing yeast infections and may be associated with a lower risk of fluconazole [Diflucon] resistance than systemic prophylaxis [prevention therapy]," noted Dr. Jean R. Anderson in *The Hopkins HIV Report* for May 2000.
Visit http://www.aegis.org/pubs/jhopkins.

Children's immune response

A small study of 25 HIV positive children taking antiviral drugs for the first time found a 3-log drop in viral load (for example, from 100,000 to 1,000) for up to a year on Viracept (nelfinavir) protease inhibitor with two nucleoside analogs. Their CD4 percentage also doubled. The researchers reported better immune system restoration with the children than is seen in adults. The study was published in *The Lancet*.

In a separate study from the Children's Hospital of Philadelphia, researchers also reported a better immune response from youngsters, this time adolescents on strong HIV drug combinations. In a press release, the hospital reported that researchers "found an unexpectedly higher number of CD8 naive T-lymphocytes in adolescents who had been infected with HIV, compared to uninfected adolescents." Naive T-lymphocytes are cells that have not been previously exposed to invading microorganisms, including HIV. 'The high levels of naive CD8 cells that we found suggests that these cells may be capable of mounting an immune response,' said the study's lead author, Steven D. Douglas, M.D., Chief of Immunology at Children's Hospital, who added, 'CD8 cells are major players in killing the virus.' T-lymphocytes are produced by the thymus gland, which gradually shrinks after puberty, becoming less active in immune function during adulthood. 'If the thymus continues to produce immune system cells in HIV- infected adolescents, the adolescent immune system may be stronger than previously thought,' said Dr. Douglas." The findings were published in the April issue of *Archives of Pediatric and Adolescent Medicine*.

HIV drugs and diabetes

Using studies in mice, researchers report that the HIV protease inhibitors Crixivan, Norvir and Agenerase block the body's ability to store sugar. This malfunction leads to diabetes. They expected the mechanism to be true of other HIV protease inhibitors. The development of diabetes has been noted in many people on HIV drug combinations, but the reason remains unknown. Excess abdominal fat, impaired glucose (sugar) tolerance and insulin resistance, all risk factors for diabetes, are also being seen. Washington University School of Medicine in St. Louis, where the research took place, noted in a press release that in one pilot study, 46% of people on a protease inhibitor had glucose intolerance and that an additional 13% of them developed diabetes within a year and a half, compared to 6% of the general U.S. population that develops diabetes during adulthood after years of problems with their glucose. The researchers reported that, "if our hypothesis is correct, insulin resistance should be maximal when *in vivo* protease inhibitor concentrations are maximal. Thus, depending on the dosing regimen and the pharmacokinetic characteristic of the protease inhibitor used, simple measurements of fasting glucose and insulin levels may be underestimating the true extent of insulin resistance that actually occurs."

Transgender TB

The U.S. Centers for Disease Control and Prevention (CDC) reported an outbreak of tuberculosis among young transgender persons in Baltimore and New York City, 62% of whom were also HIV positive. The CDC reported that, "Frequent travel and social network links identified among the Baltimore and NYC cases have raised concern that this strain of *M tuberculosis* may be circulating in other cities among young, mobile, transgender persons with HIV infection." For technical assistance in controlling this outbreak, health departments were asked to call (404) 639-8117.

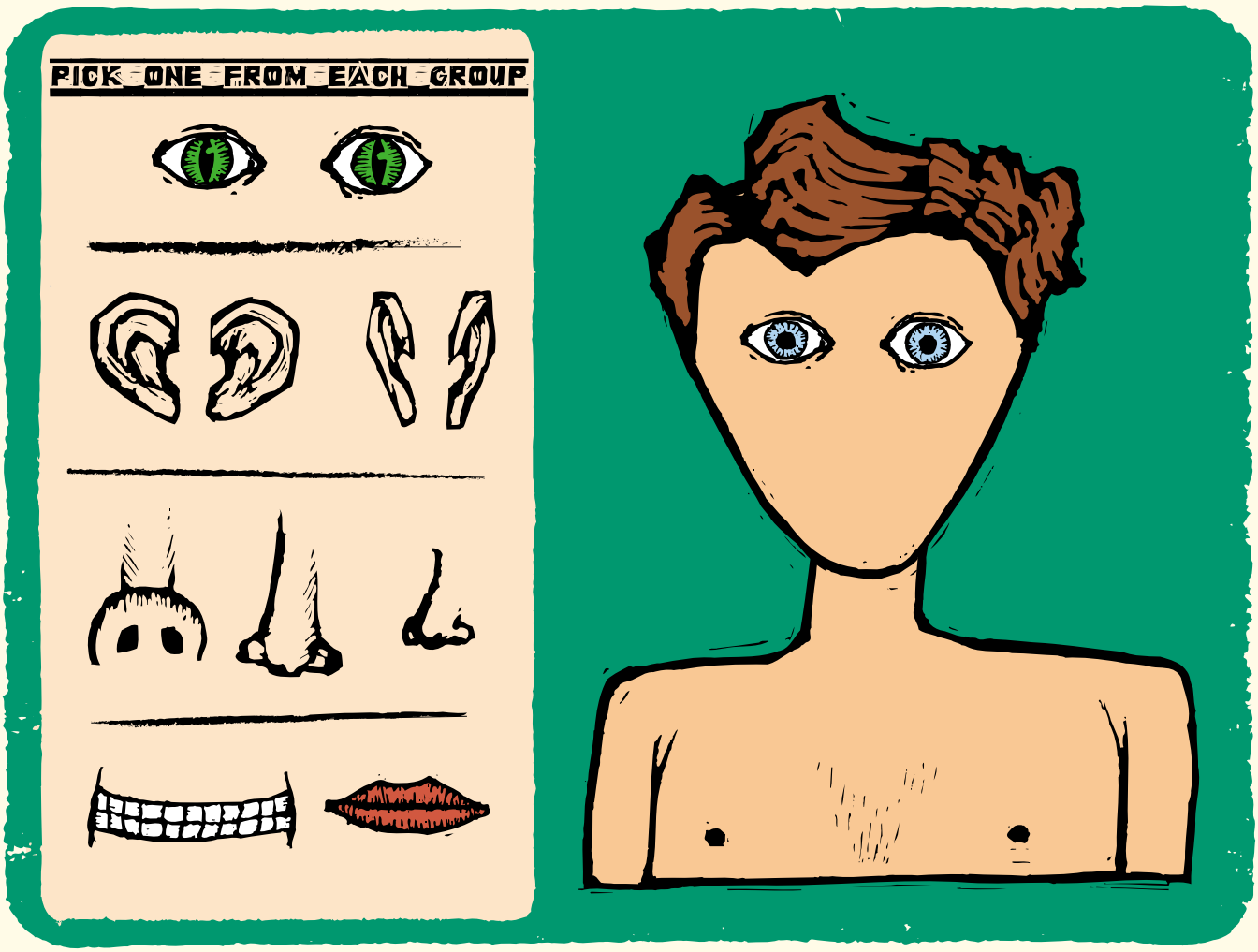
Bottled water

The American Water Works Association (AWWA), the people who clean the water coming from your tap, has asked the Food and Drug Administration (FDA) to improve the information consumers get about bottled water. The FDA should require better labeling, the association says, so that instead of just a toll-free number, buyers can also see the source of the water and the methods used to make it safe. People with AIDS, for example, need to drink water free of the parasite *cryptosporidium*. This requires a filtering method using a 1 mm microfilter.

Consumer's Guide to Lipo Surgery

Those Sunken Cheeks

by Enid Vázquez



"It's not surprising that some patients are disappointed and depressed at first." So warns the American Society of Plastic Surgeons in its factsheet on facelifts. After all, as the association also says in that document, "A facelift can make you look younger and fresher, and it may enhance your self-confidence in the process. But it can't give you a totally different look, nor can it restore the health and vitality of your youth. Before you decide to have surgery, think carefully about your expectations and discuss them with your surgeon."

All of which relates to those sunken cheeks frequently seen in people with HIV on antiviral medications. Of all the body changes being seen with the drugs, none are as distressing as the loss of fat in the temples and cheeks, giving a sickly look to an otherwise healthy person and sucking out the youth and beauty of their face. At the same time, this condition is the most difficult to treat with plastic surgery.

"I called it the Buchenwald [concentration camp] look," says one PWA [person with AIDS]. "My doctor called it the Dachau dimple [after the name of a specific Nazi concentration camp]. I appreciate the alliteration."

Because most of Bob's surgery was picked up by his insurance company and he doesn't want them to have a change of heart, he had to speak anonymously about his experience. "It hits you hard. One day you wake up and it's there [the sunken look]. You don't notice your cheeks slowly going away. I think when people feel, 'Oh, I only have one or two or three years to live,' it doesn't matter as much. It was when I started feeling better and not being so sick that it bothered me more. It became a mark of AIDS, or of being sicker than I was." Bob was out on disability at that time and has since returned to his satisfying work, despite getting almost as much money on disability as he did while working.

Bob had slices of Alloderm inserted into his cheeks. He described Alloderm as a "human skin product that is like human collagen, which is deeper skin." You can also call it "purified cadaver skin tissue without cells," or tissue from dead bodies. The Alloderm treatment came out lumpy and he had to go in for a second surgery. This time his surgeon used finely cut (scalpeled) pieces of Alloderm. Still, his face did not become quite as full as he had expected.

Bob paid $3,000 out-of-pocket for both surgeries. The total cost was $10,000. Because Alloderm is used in skin grafts, his surgery was coded as a skin graft and his insurance covered most of the bill. Collagen would not have been paid for by the company, Bob says. Other wording used by his primary doctor and by the surgeon to ensure insurance coverage: "acquired deformity of face" and "patient's condition is terminal." The stark language startled him.

"When people feel, 'Oh, I only have one or two or three years to live,' it doesn't matter as much."

As for his okay results, he says he's come to realize that while others had made him aware of how he looked, he learned that ultimately he's much more sensitive about his appearance than other people are (a realization shared by other PWAs). After his surgery, many people told him they didn't think he had looked so bad before. Final word of advice: "Someone going into this should be aware that this may not be a one-shot deal."

That's true of all the facial reconstruction options , although some surgeons say they have found a permanent solution.

Facial options

To renew those sunken cheeks, you have basically four options: fat transfer; injections; insertion; and implants.

Fat transfer

The surgeon removes fat from your abdomen, groin or butt and injects it into your face. The procedure takes a few hours and you'll be home that night. One problem is that whatever is causing the fat loss in the face seems to be causing the fat loss in the areas best used for harvesting, so that many people with HIV don't have any or much fat to transfer. Also, fat seems to have a tendency to get re-absorbed by the body. There is concern that what caused your cheeks to become sunken in the first place will cause them to deflate again. However, Dr. Jeffrey Brande in Manhattan says that wasting has not reoccurred in patients who had fat transplants more than two years ago. However, he stresses that he harvests fat very, very gently and then injects tiny particles slowly and carefully using many passes.

Injections

Collagen comes from cows (it's not pleasant to think of). Collagen injections tend to last for less time than do fat injections (about three to nine months for either material). Like fat transfer, this is an out-patient procedure (in the doctor's office). Cost is about $800 to $1,200 per treatment. One customer reports, "I have been doing collagen for two years. It is not a permanent corrrection, but looks great while it lasts. It depends on how fast your body metabolizes the collagen. Up side is it's fast, safe and looks totally natural. Down side is the expense, $700 each visit, and my body metabolizes it in about six months, so that's twice a year." Newer injection materials are Dermalogen and Fascian, both from cadaver tissue that's been sterilized (again, not a pleasant thought).

Other materials

You can also get Softform, Goretex or Alloderm inserted. Softform and Goretex are made of polyethylene, the synthetic material used in raincoats. This material has been used in surgery for years. Softform consists of hollow tubes and may be more stable than Goretex because there's a tendency for facial tissue to bind to the inside of the tubes. You usually need more than one surgery to progressively increase the fullness of the cheeks.

Goretex and Alloderm come in flat sheets. Alloderm is organic. It's sterilized cadaver (dead body) tissue. Either material may move out of the location where they were placed. Goretex is easier to remove, if need be. Insertion of Goretex and Alloderm is an out-patient procedure.

Silicone implants

Unlike the other options, which can be performed as an office procedure, silicone cheek implants represent major surgery. However, the results last much longer.

Potential Problems

Any injected material can end up looking lumpy. You'll need another surgery to smooth it out–which costs more money, as well. In addition, repeated surgeries for new injections, if fat loss continues, also adds more expense.

People whose health is compromised can expect greater complications from surgery, especially if they're on medications. Beware of blood thinning products, such as aspirin, vitamin E and gingko biloba. Unless stopped for about two weeks before surgery, they can lead to excess bleeding. (Note that Agenerase contains a lot of vitamin E.)

Summarizing a workshop on surgery for lipodystrophy-related body changes held in San Francisco last summer, Dr. Harvey Bartnof wrote for HIVandHepatitis.com: "Any of the surgery procedures for fat loss in the cheek may not completely reverse the total fat loss appearance, but would be expected to improve it. The best improvement in one procedure is the implants. However, even that may not completely reverse the fat loss apppearance.

"Dr. [Michael] Echavez [of San Francisco] summarized the surgical approaches for fat redistribution by indicating that:

- The goal is complete restoration.
- The likely outcome is improvement, not complete restoration.
- No surgical procedure is ideal.
- Sometimes a combination of procedures works best."

(Sources include HIVandHepatitis.com and *POZ* magazine, January 1998 and June 2000.)

Old and improved?

Dr. Howell Tiller's plastic surgery practice in Miami Beach began seeing lots of HIV patients three years ago. "This is more than cosmetic," he says. "It's psychological. This is reconstruction. Most of my patients are insistent about it: the sunken face is a stigma of AIDS."

But there are a lot of problems with the options for facial reconstruction of sunken cheeks. "The more choices you have, the more it means none of them are perfect," he says. "You want to replace tissue with as like tissue as possible, ideally fat, but fat is notoriously unreliable." On the other hand, he says he's seen "wonderful results" with using fat, but it's frequently difficult to find enough elsewhere on the body of HIV patients to conduct the surgery. Also, he says he finds that many people opt for injections of fat or collagen because they're less expensive, but then opt for surgery when the results fade after a few months and the costs of more injections start adding up. Then they sometimes opt for surgery.

As for insertion of Goretex or Alloderm sheets, Dr. Tiller says these are not thick enough for what's needed by many people with HIV. That's not all. "I've taken out more Goretex than I put in. They harden." Silicone implants are thicker and firm, but he says he finds that they just don't look good in men, but do look good in women.

Instead, he says he's pioneering an old plastic surgery technique that he believes will give permanent results for HIV facial reconstruction. He inserts dermis, a layer of skin

Doctor, doctor

The following physicians have experience treating HIV drug-related body changes. To find a board certified plastic surgeon in your area or to learn more about reconstructive surgery, call toll free at 1-888-4PLASTIC or visit the American Society of Plastic Surgeons at www.plasticsurgery.org.º

Atlanta
Dr. Harold J. Brody
(404) 525-7409

Chicago
Dr. David Teplica
(773) 296-9900

Los Angeles
Dr. Harvey Abrams
Dr. Robin Schaffran
(323) 936-1245

Miami
Dr. Howell Tiller
(305) 534-9054

New York
Dr. Jeffery Brande
(212) 873-7302

Dr. Michael Lorin Reed
(212) 888-2260

San Francisco
Dr. Jeffrey DeWeese
(415) 397-1210

Dr. Michael Echavez
(415) 558-8200

Where the buffalo roam

by Enid Vázquez

Les went under Dr. Harvey Abrams' knife on a Tuesday and was enjoying a cruise of the Greek Isles by the weekend. His mom, whom he treated to the cruise, quickly and painlessly removed the stitches out of his back. He felt great.

You would think that because his buffalo hump came back within four months of his liposuction that he would be an unhappy customer. But he's not.

"Before, it was right on the back of my neck and more pointed, like a buffalo hump," says Les. "Now it's like a pad, and it's lower and more spread out. I feel that it's not normal, but it's not hideous like the old days before the surgery." It also used to be extremely hard, which made him feel like something horrible was in store for him. Now it's soft like normal fat.

It also helped that he was not expecting a cure, since his HIV specialist had pointed out before the surgery that until the reason for the hump is understood, it would probably come back since you can't treat something until you know what's going on.

Another big difference is his use of testosterone cream and gel to rub on his back. On an internet e-mail list for the discussion of HIV medications, PI Treatment, complementary treatment guru Michael Mooney talked about someone who found that his buffalo hump went away after rubbing testosterone cream on it.

Another member of the internet list did Les one better. He skipped the surgery and went straight to the cream. It went down by about 85%, within two months. According to his partner, HIV treatment advocate Bob Munk (who's written for *Positively Aware*), "Our [HIV] doctor says maybe it would have gone away by itself naturally. But I don't know of anyone whose hump went away by itself, do you?"

As someone who follows medical developments, Munk understands that individual reports are different from scientific proof. Says Munk, "There's no way to know if it's the testosterone cream. It isn't proof, but it's an interesting anecdote."

There was a different experience for yet another member of the PI Treatment list. Paul says he developed a buffalo hump after two years on a Norvir (ritonavir) protease inhibitor combination. "I pretty much took myself off the dating list at that point," he says. Paul tried a common tactic being explored in research and in the real world for the metabolic and body shape changes being seen with HIV medications: switching drugs. He also tried testosterone.

"Partially I did switch because of the hump. The other reason was the temptation of only having to take three pills once a day with Sustiva [efavirenz] and none of the eating/not eating requirements. I think the hump was the big motivator.

"I started Sustiva and the testosterone cream pretty close to simultaneously. I was on a lipodystrophy e-mail list and heard about the testosterone cream through them. It was purely anecdotal, but I was willing to give it a shot. Initially I was using the patches instead of the cream, and was definitely on Sustiva by the time I started with the cream. I think the testosterone helped control the growth of the hump more than anything. It is really hard to say. My neck size is down to about 17.5 (from 18.5, normally my size is 16.5), and the hump itself seems somewhat reduced.

As for his treatment experiment, he says, "My viral load has been undetectable since I started the ritonavir and has stayed that way with Sustiva thus far, about four years all together."

When considering surgery, smaller humps can be liposuctioned, while larger ones need surgery to be cut out. Some humps do not return. Humps are easier to get insurance coverage for, since they often disrupt the neck's mobility.

between the top layer of skin (epidermis) and layers of fat underneath. For this "dermal/fat graft," he uses dermis from the butt. "A lot of people want a buttock lift, so I use this material. It's placed under the facial dermis, where it fuses." (The buttock lift is not surprising, considering how often the butt disappears as part of HIV lipodystrophy syndrome. Even in the old days before combination therapy, there was so-called "AZT butt.") He says that in the past two and a half years, he has performed about 60 of these surgeries.

"It gives good augmentation and very natural-looking results," Dr. Tiller says. "The biggest complaints I've gotten are about scars at the site of harvesting [butt area]. It *is* more surgery–it's not like going into the fridge for a syringe of injectible." The cost is about $3,000 and includes general anesthesia. He reports seeing more cases of excess bleeding and more hemotomas (blood clots at the site of the surgery) in any surgery on people with HIV. (This can be expected in people with medical conditions.) Like Dr. Brande, he likes fat harvesting as well, and finds it can also give permanent results if harvested very gently.

AIDS Dissidents and Denialists

by Laura Jones

Something went wrong in South Africa this spring. Apparently President Thabo Mbeki, being a responsible political leader in the new 21st century, did what we might expect a responsible 21st century political leader to do: he went online to learn as much as possible about the horrible epidemic that's currently wiping out large portions of South Africa's population. And apparently he found some information that disputed the widely-accepted causal link between HIV and AIDS, as well as some scary information about the toxicity of AZT, an expensive medication he's been urged to supply. The information he found led him to contact Western scientists such as Dr. Peter Duesberg and Dr. David Rasnick, longtime opponents of the commonly accepted theory that HIV is the virus that causes AIDS. Contacting "dissident" Western scientists, and eventually including them in panel discussions concerning the cause of AIDS, caused many other Western scientists to cry foul–what is he doing? doesn't he know better?–and even propose boycotts of the World AIDS Conference being held in July in South Africa.

I've never questioned the causal link between HIV and AIDS, and didn't even know that anyone still did. So, asked to write an article on the scuffle and knowing very little about Dr. Peter Duesberg and Dr. David Rasnick, I did exactly what good President Mbeki did–I hopped on the ol' Internet to see what I could find.

What I found made me very, very glad that I am not responsible for coordinating health services and AIDS prevention strategies in South Africa.

There's more Internet malarkey surrounding HIV, AIDS, recreational drugs and sex, Koch's Postulates, polio vaccines, and genocidal government conspiracies than I ever thought possible. Some of it is blatant sex-and-drug phobic nonsense, like the "AIDSGate" website run by a thoroughly whacked-out Oregonian who spouts "scientific" data like, "Every single homosexual diagnosed with AIDS has also been a drug user…" and "clean" homosexuals do not get AIDS." (He also helped start the horrible "Up With People" group back in the '60s–a hanging crime itself, in my opinion).

But some of it…well, it sure does read well. Gee, I didn't know there was a dispute as to whether HIV was ever actually isolated and grown in the lab. I didn't know polio vaccine was made from monkey kidneys. AZT was originally a potential cancer treatment that proved too toxic for common use? Are NIAID and the CDC, my reliable Hotline sources of HIV and AIDS information, really in league with the CIA? I mean, they are government agencies. The U.S. government does have a pretty checkered foreign policy record.

Ahhh! It's getting deep! Drag me out now, before I'm covered!

Given disparate information, cultural differences in policy-making, and perhaps a healthy dose of mistrust for pharmaceutical companies, I don't blame President Mbeki for his cautions. Open debate among disagreeing scientists makes a lot of sense in a country that has recently fought bitter battles for democratic self-rule, freedom of speech, and an end to decades of apartheid. I'm also not going to fault him for seeking second opinions before giving South Africa's pregnant women potentially toxic drugs they can't afford. However, we can take a hard look at the most frequently debated "dissident" arguments, and see why the majority of the scientific world believes that the HIV-causes-AIDS theory holds water.

Ahhh! It's getting deep! Drag me out now, before I'm covered!

Argument 1. In the U.S. and Europe, AIDS is caused by multiple sex partners and heavy use of recreational drugs. In Africa, malnutrition and diseases that have always existed in Africa cause AIDS. HIV is a harmless "passenger" virus and doesn't cause AIDS.

We all know this one's ridiculous, but let's take it right from the National Institute of Allergy and Infectious Disease (NIAID):

"… in a prospectively studied cohort in Vancouver, 715 homosexual men were followed for a median of 8.6 years. Among 365 HIV positive individuals, 136 developed AIDS. No AIDS-defining illnesses occurred among 350 seronegative [HIV negative] men despite the fact that these men reported appreciable use of inhalable nitrites ("poppers") and other

recreational drugs, and frequent receptive anal intercourse."

As for Africa:

"The diseases that have come to be associated with AIDS in Africa–such as wasting syndrome, diarrheal diseases and TB [tuberculosis]–have long been severe burdens there. However high rates of mortality, formerly confined to the elderly and malnourished, are now common among HIV-infected young and middle-aged people.

"In a recent study in rural Uganda, adolescents and young adults testing positive for HIV antibodies were 60 times more likely to die during the subsequent two-year observation period than otherwise similar persons who tested negative. In a study in Zaire, infants with HIV infection had an 11-fold increased risk of death from diarrhea compared with uninfected children. Elsewhere in Africa findings are similar."

Argument 2. The toxic effects of AZT and other anti-HIV medications cause AIDS, not the harmless "passenger" virus HIV.

Theories that AZT and other anti-HIV medications themselves cause AIDS are easily dismissed when one recalls all the nice people who died of AIDS before AZT became available in the U.S. and Western Europe in 1987, and all the nice people who are dying globally right now because they will never be able to afford expensive drugs like AZT. However, let's consult the NIAID Fact Sheet:

"Placebo-controlled trials have found that AZT and related anti-HIV drugs can benefit patients by prolonging, for up to a year or two, the onset of new AIDS-related illnesses in HIV-infected individuals. Significantly, long-term follow-up of these trials, although not showing prolonged benefit of AZT, has never indicated that the drug increases disease progression or mortality. The lack of excess AIDS cases and death in the AZT arms of these trials effectively rebuts the argument that AZT causes AIDS.

"In addition, many individuals who have never taken AZT or related drugs have developed AIDS, including people in the United States prior to the availability of AZT, and in Africa today where very few people receive AZT."

Argument 3. There are people with AIDS who don't have HIV, so HIV can't be the cause of AIDS.

Nicely summarized by Dr. Steven B. Harris, author of "The AIDS Heresies: A Case Study in Skepticism Taken Too Far":

"Previous to the epidemic of AIDS, of course, people did die of immune failure with low T-lymphocyte counts (including low CD4+ counts) for other reasons, and they continue to do so now…cancer, malnutrition, tuberculosis, radiation, chemotherapy, etc. These people do not have AIDS, because the historical epidemic of AIDS consisted of people with no T-lymphocytes, and yet no known reason for it.

"So let us simply collect all the people we can find with CD4+ counts remaining below 200 (for a few months) without known reason, and test them for HIV. When we do, we find that essentially all are HIV infected, and any who are not do not look at all like typical AIDS patients…Thus, at this point we have no evidence yet to directly contradict the simple theory that HIV causes 100% of our conservatively defined "AIDS." AIDS skeptics will need different definitions in order to find HIV-free AIDS."

hey, maybe one day we will discover that some people with HIV never develop AIDS—happy news.

(I sure do like Dr. Steven B. Harris. I also sure do like the fact that I found his terrific document via the previously cited nutty Oregonian's "AIDSGate" website, located at www.alive-andwell-eugene.dreamhost.com/aidsgate. The nutty one swears he's never received a single piece of e-mail disagreeing with any of his statements. Feel free to drop him a line–after all, he is "Up With People"!).

Argument 4. There are people with HIV who don't have AIDS, so HIV can't be the cause of AIDS.

It can take years, friends. Longer than we originally thought. And hey, maybe one day we will discover that some people with HIV never develop AIDS–happy news. Until that point, however, we need to realize that 20 years is not a very long time in the life of a complicated disease. We don't have all the answers yet, but we do have to use what we know.

Argument 5. If AIDS was caused by just one thing, everyone with AIDS would get sick in the same way, in the same amount of time. AIDS behaves differently in different populations, so AIDS must be caused by lots of different things instead of by HIV.

HIV doesn't cause the diseases associated with AIDS. People with AIDS get funky illnesses because their immune systems are mortally compromised, and people with compromised immune systems will get sick with whatever is floating around them. Different pathogens (disease-causing agents) lurk in different regions and communities, which explains why PWAs in Thailand may become ill with diseases not found in Sturgis, South Dakota, and vice versa. Opportunistic infections vary even by gender and age, due to differences in exposure to various pathogens.

Argument 6. HIV doesn't fulfill Koch's Postulates for an infectious disease, so it can't cause AIDS.

Duesberg's favorite, refuted several times over the course of AIDS history. Robert Koch discovered anthrax bacillus late in the 19th century and developed the standard determinants for the cause of any epidemic infectious disease.

Postulate #1: Epidemiological Association–Suspected cause of disease must be strongly associated with the disease.

HIV Fulfills Postulate: Antibodies to our RNA from HIV is found in the vast majority of persons with AIDS. Lack of HIV antibodies in less than 5% of cases fulfilling other criteria for AIDS (no other reason for immune system collapse) has been largely attributed to the insensitivity of early tests.

Postulate #2: Isolation–Suspected pathogen must be isolated and propagated outside the host organism.

HIV Fulfills Postulate: HIV has been cultivated in human T-lymphocytes, and cultured cell lines have been grown. (Dr. Duesberg himself agrees!)

Postulate #3: Transmission–Transferring suspected disease agent to uninfected host causes disease in new host.

HIV Fulfills Postulate: Most easily illustrated via the case of three lab technicians accidentally infected with HIV-1 through needle sticks. All three developed antibodies to HIV and experienced marked CD4+ cell depletion and/or opportunistic PCP (*Pneumocystis carinii* pneumonia) within five years.

There will always be people who will argue over the exact phrasing of Koch's Postulates, which have been modified over the years due to new technology and knowledge of infectious diseases. Defenders of HIV will continue to argue that other diseases–typhoid fever, leprosy, and tuberculosis–fail to meet strict Koch causality tests. In the meantime, however, HIV does a fine job arguing its case as the causative agent of AIDS.

Laura Jones is a sexual health activist and teacher, and is also a counselor for the Illinois HIV/AIDS and STD Hotline, operated by Test Positive Aware Network.

Therapeutic Drug Monitoring in HIV Therapy

by Glen Pietrandoni, R.Ph.

Have you ever wondered why a 210-pound man takes the same dose of a protease inhibitor as does a 110-pound woman, or questioned the difference between a dosage to be taken every eight hours versus one taken three times a day? Why do some drugs have to be taken with food and others on an empty stomach? Why do you have terrible side effects from your cocktail, but your friend takes the same drugs with no problems?

In the future, many of these contradictions will be resolved with the use of Therapeutic Drug Monitoring (TDM), the next big test to be used in HIV.

In order for anti-retroviral drugs to inhibit HIV replication, enough drug must be in the blood at all times to be effective, but not so much drug that it will cause side effects and possibly more serious long term problems. This is called the therapeutic range. We now use an average of levels found in clinical trials volunteers. The promise of TDM is that if we could determine the best blood level of a drug for a particular person, we could then customize an exact dosage for each drug for that patient's regimen. A blood test called a phenotypic assay (measuring drug resistance) could tell doctors which drugs may or may not be effective in suppressing viral replication in an individual.

From the results of the phenotypic test, a clinician could calculate the exact dose of that drug that would be necessary to be effective. This dosage would be designed to achieve that drug level for the correct amount of time, therefore optimizing the benefits of drug therapy and reducing side effects specifically for an individual. The dose will differ for every particular (drug) combination. A person's Crixivan dose for one combo would differ from his or her Crixivan dose in a different combo. All in all, we would therefore optimize the benefits of the combinations and reduce the risks of overmedicating.

TDM is used today in many other diseases with success. For example, treatments for asthma, epilepsy, and bacterial infections all use TDM to determine the correct dosage regimens and improve the desired outcome of therapy for an individual.

In order to understand how this all works, let's go over some terminology. When a drug is taken "by mouth," the amount of drug in the blood increases as it is absorbed in the body to the maximum concentration (Cmax), and then gradually is eliminated (metabolized) from the body over time (called the half-life, or T-1/2). Most anti-retroviral drugs, especially the protease inhibitors, are eliminated from the bloodstream by the liver and kidneys. The rate at which this clearance happens is very important because it affects the amount of drug in the blood and the length of time it is there.

The Therapeutic Range is the section of time where the drug level is above the amount needed to be effective and below the level that is risking side effects. TDM's goal is to keep drug levels in this range at all times, although the Therapeutic Range has yet to be determined in most of the anti-retroviral drugs we are using. For most research that is available about HIV Therapeutic Range at this time, concentrations used are the researcher's "best guesses." Moreover, the range is believed to be very narrow, with less room for error than seen with other medications. If you consider all the people who tested an HIV drug, you find that some of them achieved optimal blood levels of the drug and others didn't. Their level was above or below. The dosage that is finally approved is an average. For many of you, this dose is too high or too low. That's where TDM comes in.

The dosage that is finally approved is an average. For many of you, this dose is too high or too low. That's where TDM comes in.

Here is where it gets complicated.

There are challenges to using these concepts in practice.

- Bioavailability is the fractional amount of drug that eventually gets into the blood after taking an oral dose of medication as compared to the same dose of medicine that is injected intravenously. Bioavailability varies from drug to drug and is sometimes difficult to measure, and would make a significant difference in measuring

the Therapeutic Range accurately. Saquinavir HGC (Invirase hard gel capsule), for example, has a 4% bioavailability–96% does not make it to the blood. Reformulated saquinavir SGC (Fortovase soft gel capsule) is 20% bioavailable, giving much higher blood levels than the original formula.

- Genetics play a role, so everybody's different. Is there a difference in the amount of drug needed for a person with a high viral load versus a person who is undetectable? Variations exist in a patient's ability to absorb and metabolize medications. Different people have different abilities to absorb and metabolize medications, based on this and other differences. Differences can be seen between men and women, adults and adolescents, and among the races. Since most existing pharmaceutical research is done using adult white men, much more information is needed.

- Does every tablet or capsule that is manufactured in a particular batch dissolve at exactly the same rate? The FDA does regulate this very closely, but it is possible that the dosage form of drug products can affect drug responses.

- Impaired liver or kidney functions will definitely affect the measurement of Therapeutic Drug Monitoring. Co-infection with hepititis could be a factor as well.

- Let's not forget about everyone's favorite topic, adherence. The precise manner in which the anti-retroviral drugs are taken will still be critical when accessing Therapeutic Drug Monitoring. For example, nelfinavir (Viracept) will still need to be taken with food for better absorption, despite the availability of TDM.

- Drug interactions (both good ones and harmful ones) can drastically change the pharmacokinetics (a drug's action inside the body). Studies evaluating TDM have generally been done on individual drugs, not on drugs used in combination. The Therapeutic Range for Crixivan and Norvir together may be different than that of Crixivan and Norvir used separately.

- Money is always an issue. TDM is available here and in England now at a cost of about $50–$75 per patient, per drug. Who will pay for these tests? Will these lab tests be covered by Medicaid programs or state ADAPs (AIDS Drug Assistance Program)? Some suggest that the pharmaceutical companies should foot the bill, since they will benefit from the patient's ability to stay on their drug regimens for a longer period of time. Early reports seem to suggest that the drug companies have responded positively to that idea.

Therapeutic Drug Monitoring is no different than viral load testing was years ago and phenotypic and genotypic tests are today.

Let's imagine for a moment that we can work out all of these issues. We still have to deal with the logistical aspects of applying all of this new information at the clinic in real patients. In reality, Therapeutic Drug Monitoring is no different than viral load testing was years ago and phenotypic and genotypic tests are today. More information and time are needed to improve the technical skills of clinicians to use this new tool in clinical practice. We will be using Therapeutic Drug Monitoring in the management of HIV/AIDS; it's just a question of when.

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

A Look at Lactic Acidosis

by James Learned

Some of the long-term side effects that people with HIV experience are certainly due to mitochondrial damage caused by nucleoside analogs (the drug class that includes AZT and Zerit). Mitochondria, found inside all human cells, use oxygen, fat and sugar to produce energy for the cells. A single human cell can have thousands of mitochondria, depending on how much energy is required for the cell to function properly.

Mitochondrial damage caused by nucleoside analogs has been recognized since the introduction of AZT in 1987. Some of the resulting symptoms may have been under-diagnosed in the past, but as people have been on these drugs for longer periods of time, increasing attention is being paid to their role in metabolic and morphologic changes. The degree to which each of the nucleosides contributes to mitochondrial damage is unclear. Mitochondrial damage may be responsible for many of the common side effects of the nucleoside analogs: myopathy (inflammation of muscle tissue), peripheral neuropathy (nerve damage in the feet and hands), pancreatitis, and low levels of red blood cells (anemia), neutrophils (neutropenia), or platelets (thrombocytopenia).

Two particularly serious conditions can also result from mitochondrial damage–lactic acidosis and hepatic steatosis, or fatty liver. All of us are familiar with the aching muscles that often follow a physical workout. That soreness is caused by a buildup of lactate. Our bodies usually clear excess lactate, but mitochondrial damage can create very high levels of lactate in the blood, sometimes leading to lactic acidosis, a rare but potentially fatal condition. Symptoms of lactic acidosis are difficult to discern. They can include shortness of breath, abdominal pain, nausea, vomiting, fatigue and weight loss, subtle symptoms that can easily be ignored or mistaken for something else. If you experience these symptoms while on nucleoside analogs, see your doctor right away.

There are no simple blood tests to check lactate levels. However, serum bicarbonate levels are measured as part of routine blood work, and low levels are a sign that some kind of excess acid production is occurring. If you're taking a nucleoside and your serum bicarbonate levels are low, lactic acidosis should be suspected. Although riboflavin and coenzyme Q10 are sometimes used to treat lactic acidosis, there is no evidence yet to support the value of either. Usually, the only recourse is to stop nucleoside analog therapy or, if appropriate, reduce the dose.

At the recent 7th Conference on Retroviruses and Opportunistic Infections (CROI), a poster (printed report) from the Netherlands described four cases of fatal lactic acidosis. The four people had been on nucleoside-containing combinations (all with d4T, brand name Zerit) for six to 20 months, and all had previously experienced at least one nucleoside-related side effect. They entered the hospital with gastrointestinal and respiratory problems and died within three weeks.

The problems were identified early enough that no deaths resulted, and all 20 had normal lactate levels within seven to 176 days of stopping antiviral therapy.

A team from Johns Hopkins University looked at lactate levels in 509 individuals who had been on combinations that included two nucleosides and a protease inhibitor for varying lengths of time. Although these data are only suggestive, people on combinations that included d4T/3TC had significantly higher lactate levels than those on AZT/3TC (Retrovir/Epivir), d4T/ddI (Zerit/Videx) or AZT/ddI (Retrovir/Videx). The potential for these people to develop lactic acidosis is unclear.

Another poster discussed abnormally high lactate levels in 20 patients on nucleoside analog-containing regimens (again, all included d4T) at the University of California Medical Center in San Diego from July 1998 to September 1999. The problems were identified early enough that no deaths resulted, and all 20 had normal lactate levels within seven to 176 days of stopping antiviral therapy. Three of the 20 resumed antiviral therapy (without d4T), and still had normal lactate levels three months later.

A disturbing poster described the history of a child who developed extreme mitochondrial damage. At three months of age, he started AZT/ddI/nelfinavir (Viracept), which resulted in a good clinical response–undetectable viral load and rising CD4s. A year and a half later, however, he had unusual patches on his brain, elevated lactate levels, liver damage, severe atrophy of muscle and nerve fibers, and an astounding 79% depletion of mitochondrial DNA compared to HIV negative children his age. He was taken off antiviral therapy for three

weeks, during which time his viral load rebounded. Then he was started on a combination of ritonavir/nelfinavir/efavirenz (Norvir/Viracept/Sustiva) and his condition has improved. This is the first reported case of a child experiencing such severe mitochondrial damage, seemingly as a direct result of nucleoside analogs.

Early last year, investigators in France reported on two HIV negative one-year-olds who died of neurologic disease associated with mitochondrial damage and whose mothers had taken AZT/3TC during pregnancy. As more attention is directed at the potential for nucleoside analogs to cause damage to the mitochondria, an effort is underway in the United States to look at HIV negative children born to positive women who took nucleosides (primarily AZT) during pregnancy. Using databases from the National Institutes of Health and the Centers for Disease Control, this effort has so far focused on 227 HIV negative children who have died for any reason. Mitochondrial damage has not been found in any of these cases. The next step is to look for possible mitochondrial damage in the thousands of children who are alive.

This is the first reported case of a child experiencing such severe mitochondrial damage, seemingly as a direct result of nucleoside analogs.

Taken with permission from a longer article in the Spring 2000 CRIA Update. *James Learned is the National Technical Assistance Program Director at the Community Research Initiative on AIDS (CRIA) and a founding member of the Hepatitis C Action & Advocacy Coalition (HAAC).*

Subscribe or get back issues now.

JA 2000

Mail to:
Positively Aware
1258 W. Belmont Ave.
Chicago, IL 60657

❑ **Subscribe:** 1 year of **Positively Aware** for $25.
❑ **Subscription renewal:** My payment of $25 is enclosed.
❑ **Back issues:** Please send me the following back issue(s) at $2 per copy:

_____

*Subscriptions are mailed to those who are HIV positive for a small donation.

❑ **Donation:** *
❑ $25 ❑ $50 ❑ $100
❑ $250 ❑ $500 ❑ $_____
Thank you for your donation. Your contribution helps to provide subscriptions to people who cannot afford them. All donations are tax-deductible to the full extent allowed by law.

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

PHONE: _____ E-MAIL: _____

CHARGE MY: ❑ VISA ❑ MASTERCARD ❑ AMERICAN EXPRESS

CARD NUMBER: _____ EXPIRES: _____

NAME ON CARD: _____ SIGNATURE (REQUIRED): _____

Charges will appear on your credit card bill as *TPA Network*

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

Can you Work While on Social Security?

by Justin Hayford, AIDS Legal Council of Chicago

Se-cu-ri-ty \si-'kyur-e-tee\ n. Freedom from want or deprivation.

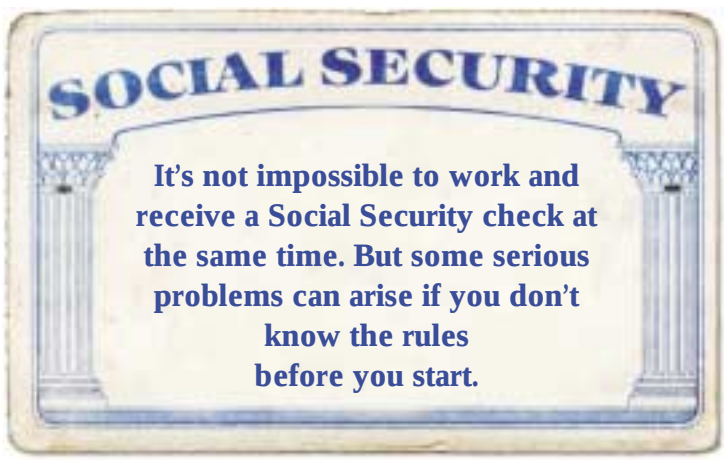
According to this definition, there's not much security in Social Security. If you're getting SSDI (Social Security Disability Insurance) anywhere in the nation, you're probably getting between $500 and $1200 a month. Ouch. And in Illinois, if you're getting SSI (Supplemental Security Income) you're receiving a maximum of $512 a month–that is, if you're living alone. If you're married, or living in someone else's household, you're getting only $341 a month. Yowch! Who, one wonders, can actually live on such amounts? For most people, being on Social Security means living in constant want and deprivation.

Of course states with more enlightened legislatures than Illinois (they're not hard to find) offer a supplement to federal SSI, increasing your monthly check. In Nevada, a standard SSI check for an individual is $548. In New York it's $599. And in California it's a whopping $692. Still, nobody on SSI receives a check large enough to get them above the federal poverty line.

So it's no surprise that lots of folks who receive Social Security benefits want to get some kind of part-time job to help make ends meet–or at least bring ends a little closer together. But can you work and receive Social Security benefits at the same time? Aren't those benefits supposed to be only for people who are disabled and cannot work? Will your check stop if you take a job? If so, how quickly?

People call me with these questions at least once a week. More often than not, they've already called Social Security repeatedly and encountered either a busy signal or an idiot. If I had a dollar for every caller who's been told the wrong information by a Social Security worker, I could afford my own island off the Amalfi Coast. So if you're wondering how a job will affect your Social Security check, remember one simple rule: never trust anything a government worker tells you. Check with a lawyer or legal advocate before you do anything.

It's not impossible to work and receive a Social Security check at the same time.



But some serious problems can arise if you don't know the rules before you start. And the rules are entirely different for SSI and SSDI. So let's all take a deep breath, think pleasant thoughts, and plunge into the nasty thicket of Social Security regulations.

Let's start with SSI, since the rules for returning to work from SSI really stink, and I prefer to get the depressing stuff out of the way as quickly as possible. The Wonderful Wizard of Social Security has invented something known as "instant budgeting," which in a nutshell means this: when you start making money, your pitifully small SSI check shrinks even further.

Here's how it works. First of all, SSI will not count the first $85 you make each month before taxes. In other words, you can make up to $85 dollars a month and it will not affect your check at all. Social Security regulations say that you must report any change of income within 10 days, even if it's less than $85. So you should let Social Security know you made some money, but if it stays under $85 a month your check will remain the same.

However, if you make more than $85 in a month–and how many people have jobs that pay less than $85 a month?–then your check starts going down, based on a two-for-one formula. For every two dollars you earn, your check goes down one dollar.

So let's imagine you're on SSI, and you earn $285 dollars in a month. You reported the income to Social Security within 10 days of receiving it, just like you were supposed to. How big will your check be the following month? Social Security will not count your first $85 of income, so they'll only count $200 of your earnings. And using their two-for-one instant budgeting, they'll take half of that amount–$100–and subtract it from your check. So your monthly check will shrink by $100, to $412. I guess you won't be buying that diamond tiara after all. (Your earned income may also affect your Medicaid eligibility, but the rules vary greatly from state to state. Check with a legal advocate in your area).

Okay, on to SSDI, where you've actually got some room to maneuver. Just like SSI, you are supposed to report any

change of income to Social Security within 10 days. But unlike SSI, your check won't be affected for quite a while.

If you're on SSDI, you are entitled to a "trial work period" so you can test your ability to hold a job. During your trial work period, you can make as much money as you want and your check won't be affected at all. This may be the one good idea the Wonderful Wizard of Social Security ever had. Your trial work period is nine months long, and those months don't have to be consecutive; any nine months over a five-year period can count.

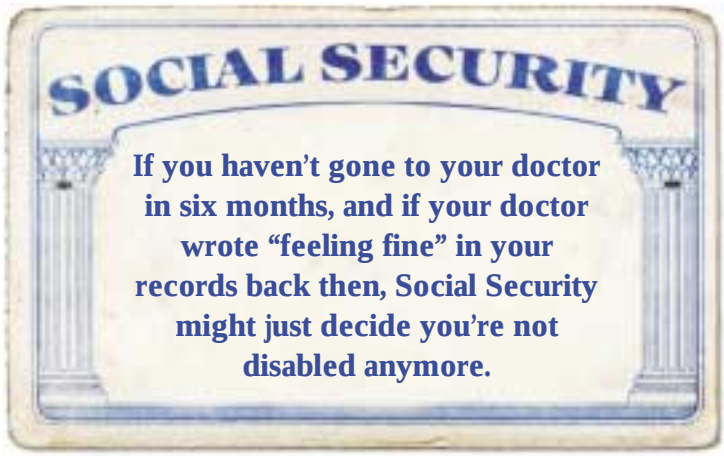
Any month that you earn more than $200 before taxes counts as a trial work period month. After you've earned more than $200 a month for nine months, your trial work period is officially over, although Social Security then gives you a three-month grace period, meaning that your trial work period is actually 12 months long. And remember, during your trial work period you receive your full SSDI check.

Here's the tricky part. Once your trial work period starts, Social Security will schedule you for a "continuing disability review" (CDR). The point of a CDR is to determine if you are still disabled by Social Security's standards, based solely on medical evidence. In other words, they cannot use your income level or your work hours to deny you disability; they must instead evaluate whether you have had enough "medical improvement" to render you no longer disabled.

When your CDR is finished, one of three things will happen:

1. If Social Security determines that you are no longer disabled due to medical improvement, your SSDI check will stop.

2. If Social Security determines that you are still disabled, and you are earning less than $700 a month before taxes, your SSDI check will continue as before.



3. If Social Security determines that you are still disabled, and you are earning more than $700 a month before taxes, your SSDI check will stop.

So as you can see, it is awfully important to "pass" your CDR so that Social Security will find you to be disabled despite your ability to work. If you pass your CDR and your earn only $600 dollars a month, for example, your SSDI will continue as before. You're working and receiving full benefits, and hopefully your quality of life improves substantially.

Since the CDR is based on medical evidence, it's imperative that you see your doctor regularly during your trial work period–and even before you begin your trial work period–to tell your doctor every symptom and limitation you have. I advise my clients to keep a daily journal of all their health problems so that they don't forget just how lousy they felt three weeks before their appointment. And even if you've told your doctor about your diarrhea and your fatigue 10 times before, tell him again, and insist he write it down. If these symptoms aren't in your medical records every time you visit your doctor, Social Security may think the problems have resolved.

It's especially important to see your doctor regularly because you never know when Social Security is going to schedule your CDR. Typically they do it near the end of your trial work period. But they could do it during your first month of work. And if you haven't gone to your doctor in six months, and if your doctor wrote "feeling fine" in your records back then, Social Security might just decide you're not disabled anymore–and your check will stop immediately. Your trial work period is over after one month because Social Security says you're no longer disabled.

So as you can see, being on Social Security doesn't necessarily mean you can't earn any money at all. And now that you know the rules, perhaps you can make the system work to your benefit. That would be a terrific change, now wouldn't it?

Hoping for a Holiday: Structured Treatment Interruptions

by Tim Horn

Not too long ago, the idea of stopping anti-HIV therapy was a laughable notion. After all, possible eradication of the virus was at stake. But the hope of curing HIV using highly active antiretroviral therapy (HAART) has faded. Still, experts continued to warn against stopping therapy, including short-term drug holidays. There was a threat that nasty drug-resistant strains of the virus would emerge, along with the possibility that immune function would quickly decline and send patients' health spiraling downwards.

Preliminary results of several small studies reported at the recent 7th Conference on Retroviruses and Opportunistic Infections (CROI) suggest that not only may drug holidays be feasible and safe, but they may also be good for the immune system. While proving these suggestions will require a fair amount of additional research (none of the recent reports offer any guarantees) a dose of springtime optimism is certainly in the air.

Backgrounder

Let's face it. HAART is not all that its cracked up to be. For people who started therapy "early," that is, while their viral loads were low and CD4+ cell counts were high, popping pills every day in the face of side effects has been a herculean task. At the same time, there are also patients who desperately needed therapy to bring their high viral loads down and CD4+ cell counts out of the red. Now that many of these folks have been saved, that is, have seen their viral load stay undetectable and their CD4+ cell counts linger at healthy levels, a fundamental question remains: "Why do I need to stay on this stuff?"

It's not at all clear what comes next. There are a number of different possibilities, all of which will drive research over the next few years. Researchers might prove that all patients, once they've started therapy, should remain on it. Another avenue to explore is the possibility of treating HIV like many other chronic diseases, initiating therapy when the immune system shows signs of damage or when a patient experiences symptoms of HIV disease, then stopping therapy when their health improves. And let's not forget new treatments, including novel anti-HIV drugs and immune-based therapies, that may prove to be the magic bullet everyone is waiting for.

More commonly referred to as "drug holidays," STIs represent the first experimental approach to break with the current HAART model.

In essence, figuring out how to treat HIV remains in a constant state of uncertainty. Structured treatment interruptions, more commonly referred to as "drug holidays," represent the first experimental approach to break with the current HAART model. While drug holidays are by no means ready for the "real world" of HIV care (in other words, they are not yet considered to be safe or effective enough for patients to try them at home) they are definitely the research trend to watch in the coming months.

Structured treatment interruptions

While it would be nice to think that patients "sick of it all" were the driving force behind structured treatment interruption (STI) research, the scientific rationale can actually be traced back to a phenomenon seen in a single patient living in Germany. A few years ago, Dr. Franco Lori, a researcher with labs in Pavia, Italy and Georgetown, reported on the highly irregular circumstances of an unnamed patient who, after a series of interruptions in his drug therapy, appeared to have cleared HIV from his body.

The "Berlin Patient," as he has come to be known by the world, was participating in a clinical trial for recently infected patients. He entered the study approximately two months after an unsafe sexual experience which, as he feared, resulted in HIV infection. Once enrolled, he started a triple-drug regimen involving indinavir (Crixivan), ddI (Videx), and hydroxyurea (Hydrea), but went off of his drugs after two weeks due to a bacterial infection. He stopped his medication for three days, and predictably, saw his viral load increase. After restarting therapy, his viral load became undetectable. Four months later, he developed hepatitis A, causing his liver enzymes to increase dramatically, requiring that he go off therapy again. But this time, his viral load did not rebound; it stayed undetectable. While he opted to start therapy yet again after his hepatitis got better, he changed his mind and has been off therapy ever since and continues to enjoy an undetectable viral load.

Has he been cured? Dr. Lori says no. He still has a traceable amount of HIV in his lymph nodes. Instead, it appears as if the immune system of this very lucky patient has been able to keep his HIV in

check, much like other viral infections that are never totally eradicated from the body (e.g., varicella, the virus responsible for chickenpox).

While no one is sure why this happened, Dr. Lori and his colleagues have offered an intriguing hypothesis. HAART is designed to drastically reduce the amount of virus in the body. While this is definitely a good thing with respect to protecting the immune system from additional damage, it may prevent the immune system from doing what it should be doing in terms of fighting HIV. Perhaps with so little virus in the blood and the lymph nodes, the immune system "forgets" that HIV is there. In turn, it calls off cells programmed to search and destroy the virus. If HAART is stopped, the virus comes back with a vengeance. If HAART is not restarted, the amount of virus will grow considerably, often to levels that overwhelm the immune system.

The key, Dr. Lori argues, is to keep the amount of virus at a controllable level, just enough to keep the immune system active, but not enough to dominate it. This may have been what happened during the brief breaks, the structured treatment interruptions, in the Berlin Patient's therapy. During the first three-day STI, it's possible that just the right amount of virus was released and then controlled to spark the immune system. Then, upon stopping therapy the second time, the immune system was ready and waiting, able to control HIV on its own.

Fast-forward: New data

Unfortunately, the Berlin Patient is still a unique case. No other patient who has taken an STI, whether in a clinical trial or more discreetly with a doctor, has come close to achieving this level of success. But, in light of some new data presented at CROI in early February, STIs may still offer some benefits.

Dr. Lori presented one study that received a considerable amount of attention, this time involving a cohort of nine patients taking hydroxyurea in combination with ddI, a relatively weak regimen in comparison to the triple-drug therapies used by most people. For the sake of seeing what would happen upon stopping therapy, these patients were compared to a group of eight patients being treated with a protease inhibitor-based regimen (HAART) who also elected to do an STI.

Seven of the eight patients receiving HAART had undetectable viral loads while on therapy. Within six weeks after the STI, five of these patients saw their viral load increase to levels above 100,000 copies/mL. Among patients receiving only hydroxyurea and ddI, only one of whom had an undetectable viral load while on therapy, none saw their viral load increase to levels greater than 10,000 copies/mL during the six-week period off treatment.

Within six weeks after the STI, five of these patients saw their viral load increase to levels above 100,000 copies/mL.

In discussing these results, Dr. Lori suggested that hydroxyurea and ddI succeeded in keeping patients' viral loads low, but not undetectable. This allowed for small amounts of the virus to circulate in the blood and in the lymph nodes, keeping the immune system stimulated and ready to kick in once therapy was stopped. This might also explain why the HAART-treated patients saw a dramatic increase in viral load, along with a decrease in their CD4+ cell counts, after stopping therapy; keeping levels of the virus low allowed for the immune system to be caught off guard once therapy was halted.

In another study, Dr. Lydia Ruiz and her colleagues in Spain randomized 25 patients–all of whom had undetectable viral loads for more than two years while on HAART–either to continue on therapy or to undergo an STI. Therapy was interrupted for 30 days or until patients saw their viral loads increase to levels greater than 3,000 copies/mL, whichever came first. After 30 days off therapy, treatment was resumed for an additional 90 days followed by a second STI.

After the first STI, viral load failed to rebound in two of the patients during the 30-day drug holiday. Upon restarting therapy, all patients who took a drug holiday did so without any problems–their viral load went undetectable again and it did not appear that any had developed drug resistance while off therapy. Thus, while more data are needed to see what happens to the patients' viral loads and CD4+ cell counts during and after the second STI, these early results suggest that STIs may be safe. That is, there does not appear to be any immediate danger associated with STIs in patients who have undetectable viral loads upon stopping therapy, at least in these 25 Spanish patients.

Also of interest was a late-breaking report from an international team comprised of researchers in New York, Switzerland, and Spain. According to their report, ten HIV-infected patients treated with HAART for 52 weeks, all of whom had undetectable viral loads for at least 32 weeks, underwent three STIs (one month each) separated by six months of the same triple-drug therapy.

While therapy was stopped three times during this study, upon restarting therapy, all patients were able to drive their viral loads to undetectable levels each time. This helps to confirm Dr. Ruiz' finding that STIs may at least be safe for patients with undetectable viral loads while on therapy. But the news doesn't stop there. An interesting thing occurred in four of the nine patients during the second STI. While their viral loads increased significantly within a few weeks, the amount of virus in their blood samples began to drop all by themselves. What's more, CD4+ and CD8+ cells collected from these patients

during the second STI had taken on important HIV-specific characteristics that are not usually present in people who are either on HAART or have yet to start treatment.

Data from a study conducted at Massachusetts General Hospital in Boston have also added to the current level of optimism. Enrolled in this study were seven newly infected patients who were treated with HAART and willing to undergo two STIs lasting two months each. After the first STI, all seven patients saw major increases in their viral loads. But during the second STI, their viral loads failed to go any higher than 5,000 copies/mL. According to the presenters of these results, it seemed as if HAART followed by STIs during the earliest days of HIV infection could help preserve necessary components of the immune system needed to control the virus. Because these immune responses aren't usually seen in most HIV-infected patients, these results are of major interest.

The message to go

Now that the foundation has been laid–we have preliminary data suggesting that STIs might be safe for people who have been on HAART and have undetectable viral loads–it's time to do some heavy-duty research. It will be important to determine if STIs are safe for people who have been on anti-HIV therapy and have a detectable viral load upon deciding to temporarily stop treatment. As for the potential benefits of STIs, a number of questions remain:

Do STIs help patients recover from side effects, such as lipodystrophy?

Will STIs help boost the immune system's response to HIV for prolonged periods of time? Will these immune responses help slow HIV's destructive activity in the body?

> While therapy was stopped three times during this study, upon restarting therapy, all patients were able to drive their viral loads to undetectable levels each time.

Can STIs be used in combination with immune-based therapies to help boost the immune system responses to HIV even more and help patients live longer healthier lives without anti-HIV drugs?

It's not entirely clear if the data presented at CROI will convince anyone of anything. The results are preliminary and have yet to be duplicated by large clinical trials. Results of these studies are eagerly awaited. And while the race is on to address the uncertainties of STIs, the present message remains clear: do not try a drug holiday at home, at least not without the cooperation and direct supervision of a health-care provider.

According to one case report presented at CROI, an STI can go terribly wrong. The report came from researchers at the University of Alabama in Birmingham and involved a patient who secretly stopped therapy due to financial reasons on the same day he received a vaccination against the flu. Even though the patient had an undetectable viral load and a CD4+ count of almost 750 cells/mm3, his viral load shot up to more than 1 million copies/mL and his CD4+ count dropped to 164 cells/mm3 within three weeks. What's more, the patient required hospitalization due to flu-like symptoms. While the reason for this lightening-fast progression of HIV disease has not been fully evaluated, it's likely that the flu vaccine had a lot to do with it (vaccines have been shown to have a strong effect on viral load in patients not taking anti-HIV therapy). Still, this case report warns that STIs are by no means fail proof, and may in fact be dangerous in some cases.

Reprinted with permission from the spring issue of CRIA Notes. *Visit* www.criany.org. *Tim Horn is the executive editor of* The PRN Notebook, *published by Physicians' Research Network in New York, and a member of CRIA's Research Advisory Committee.*

Drug holidays should not be weekend getaways

It is important to understand that Structured Treatment Interruption (STI) is not the same as taking a weekend "holiday" from your meds. Medication interruptions under STI are for longer periods of time, usually a month or more. Taking a weekend off from your medications is not a good idea. Brief interruptions in taking anti-HIV medication can lead to developing a resistance to one or more of the medications, making them unable to control the virus. Additionally, stopping only one or two of your medications can cause problems, not only for the medicine that is stopped, but for the ones you continue to take. In short, drug holidays are not something to try on your own or for brief periods of time. If side effects are getting to be too much, consult with your healthcare provider, or a knowledgeable source to decide your best response. Do not just take a few days' break–it may end up costing you the effectiveness of the drugs.

–Dennis Hartke

AIDS Activism Benefits Us All

by Kelly Saffreed Harmon

Some good is coming out of this horrible epidemic. Our response to AIDS is helping to strengthen the entire American health care system, and could even have significant benefits for many developing nations.

Consider the issue of universal health care. At the local, state and national levels, dozens of groups are steadily working to provide more Americans with access to affordable health care. The cost of health care is such an enormous problem that it would garner a spot on the American political landscape even if there had been no AIDS epidemic. But what savvy AIDS activists have done is add some very loud voices to the growing demands that the U.S. healthcare system heal itself.

Chuck Bell of Consumer's Union, the non-profit publisher of Consumer Reports, gives high marks to the AIDS activists who have added their muscle to the push for health care reform. He calls attention to developments in New York state, where a strong consumer coalition has worked for changes that have earned the state a reputation as a leader in health care reform.

"AIDS activists have played an integral role in the coalition," Bell says. "They bring a wealth of knowledge and expertise from their involvement in other policy issues. They have a sense of what's possible, and what types of pressure need to be brought to bear."

Similar dynamics are impacting the issue of making medicine more affordable. A recent issue of Time magazine contained a six-page series of stories about growing consumer resistance to the high cost of pharmaceutical drugs. A dramatic full-page photo showed a woman angrily waving a bag of prescription drug bottles at a recent demonstration at U.S. House Speaker Dennis Hastert's Illinois office. AIDS wasn't mentioned once in the article, but anyone familiar with AIDS activism is well aware of its place in this battle.

A related issue is the inability of developing nations to pay the high cost of drugs that are only available from U.S. manufacturers because those manufacturers hold the patents. AIDS activists pushed this issue to the forefront several months ago by dogging Vice President Al Gore on the campaign trail. Their specific charge was that he was helping the U.S. bully AIDS-ravaged South Africa out of producing or procuring its own more affordable versions of AIDS drugs.

Two years ago, citing humanitarian reasons, the South African government had passed legislation that would provide an end-run around U.S. patents. But this end-run was stalled by the U.S. government, which sided with aggrieved American drug manufacturers–with Gore playing a key role in a diplomatic show of force intended to persuade South Africa to back down.

The efforts of the AIDS activists have sent a clear message to the U.S. government: it cannot put corporate profit above humanitarian need without facing the possibility of being publicly called on the carpet by its own citizenry.

Enter the American AIDS activists, whose highly visible protests of Gore's position led to coverage in the Washington Post, the New York Times, and Newsweek. Last September, AIDS activists won a significant victory when the U.S. and South Africa reached a compromise that enabled South Africa to work on more specific legislation.

South Africa's plan to produce drugs is still in limbo as the complicated international trade negotiations drag on. However, the efforts of the AIDS activists have sent a clear message to the U.S. government: it cannot put corporate profit above humanitarian need without facing the possibility of being publicly called on the carpet by its own citizenry. While the current struggle is specifically about AIDS drugs, the implications are far-reaching. AIDS activists are, in effect, calling for the United States to be a more altruistic member of the world community–to put saving lives ahead of making money. If this precedent is clearly set in the AIDS arena, it might have a positive impact on how world powers deal with developing countries on a wide range of issues.

The grassroots response to AIDS has also provided a model for Americans dealing with other types of health problems. The most striking example is breast cancer activism. In the last decade, breast cancer activists have pushed for and won significant increases in federal funding for research, as well as greatly increasing awareness about the benefits of early detection.

To say that AIDS activism made this possible would be an overstatement, as well as a discredit to other sources of inspiration for the breast cancer movement, such as the women's health movement of the early 1970s. But it's obvious that AIDS activism has been an important factor.

Dr. Steven Miles of the University of California-Los Angeles AIDS Institute, who has been treating people with AIDS and HIV since his residency in the early years of the epidemic, observes, "Initially there was much more rancor in AIDS activism—people were doing things like going into [pharmaceutical companies] and spilling pigs' blood. The companies said, 'Come be a part of the process.' The AIDS activists won themselves a place at the table. After that, other groups became more emboldened."

Even the language that the HIV/AIDS community uses may be providing a model for others. Miles points out that the common convention of PWAs (People With AIDS) to talk about how many years they have been "living with AIDS," in other words, casting the struggle in less negative terms than they would if they talked about how long they had been ill, has a significant parallel. It's not uncommon for women stricken with breast cancer to identify themselves as "breast cancer survivors," he observes, and for those who regain good health to mark the number of years that they have been free of cancer.

HIV positive people's efforts to educate themselves about their options and to make their own decisions, instead of blindly following doctors' orders, have taken the concept of "patient empowerment" to a whole new level, changing how people with other kinds of needs relate to health care providers.

This phenomenon is part of the larger issue of how people with certain health care needs define themselves and their relationship to health care providers. Again, people with AIDS and HIV are setting a great example. HIV positive people's efforts to educate themselves about their options and to make their own decisions, instead of blindly following doctors' orders, have taken the concept of "patient empowerment" to a whole new level, changing how people with other kinds of needs relate to health care providers. While this trend has been slow to spread, it is definitely becoming more noticeable in other disease fields, particularly cancer.

Furthermore, the American psyche has long harbored a bugaboo that is finally being addressed more directly in the face of the AIDS epidemic: sexuality. There are still far too few discussions about how to have physically and emotionally healthy sex, but AIDS has compelled some people to try harder than they did before. "The epidemic has brought sexuality out of the closet," says Mark Hannay of ACT UP (AIDS Coalition to Unlease Power) New York. While contemporary candor about sexuality has its roots in the sexual revolution of the 1960s, Hannay suggests that the emergence of AIDS has led to new health-related developments such as "a much franker discussion about substance abuse and sexuality."

U.C.L.A.'s Miles agrees that AIDS has contributed to more open discussions about once-taboo issues. He believes that there's a connection between the AIDS epidemic and a growing trend that he sees in the cancer field. "People are beginning to discuss sexual functioning post-mastectomy or post-prostectomy with their doctors," he says. "Physicians fully expect patients to ask about this now."

Developments in the AIDS community have also had an impact on some more general health care issues, such as preventive care. People with AIDS and HIV are helping to call attention to the concept of maintaining wellness, instead of only seeking health care when illness occurs. Ditto the concept of holistic health care—addressing a person's medical needs in the context of that person's emotional makeup and socioeconomic status.

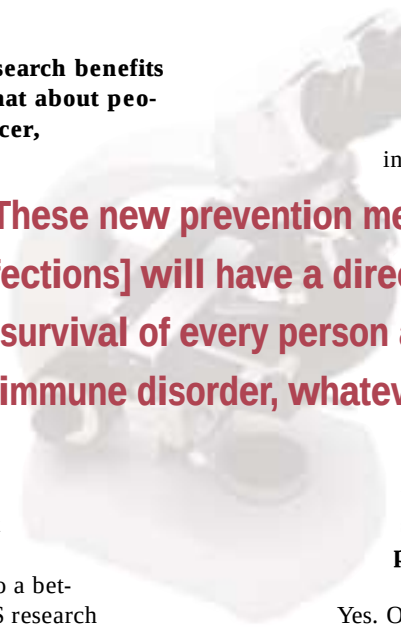
These are only some of the possible beneficial outcomes of our experiences in the AIDS epidemic. We won't be able to fully comprehend what we have accomplished until we have gained the perspective that comes with time.

The Broad Benefits of AIDS Research: An Update

by the American Foundation for AIDS Research (amfAR)

Fundamental discoveries made in one area of biomedical research often benefit a wide variety of human diseases. Nowhere has this concept been more apparent than in the quest for a cure for AIDS. AIDS research has been a testing ground for new concepts and technologies in drug development, diagnostics, and prevention. Some findings have been immediately translatable, yielding new drug therapies for old diseases, including hepatitis and cancer. Others will require more time and applied research before their benefits can be realized broadly. Following is a summary of how research on HIV and AIDS is helping us all.

1. I know how support for AIDS research benefits people with AIDS and HIV, but what about people with other diseases, such as cancer, heart disease, hepatitis, and Alzheimer's? Will the continued funding of AIDS research help people with those and other often life-threatening conditions?



These new prevention methods [for infections] will have a direct impact on the survival of every person afflicted with an immune disorder, whatever its cause.

AIDS has a single underlying cause–a virus, HIV. This makes it easier to target than disorders with multiple and largely unknown causes. But AIDS research doesn't exist in a vacuum. Just as it was the federal virus-cancer program of the 1970s that paved the way to a better understanding of HIV, so has AIDS research become a gateway to the diagnosis and treatment of many diseases. For example, it has already led to a new drug for hepatitis B, the leading cause of liver cancer worldwide; for hepatitis C, a rapidly emerging, additional cause of chronic liver disease; and possibly for liver cancer. And it promises a great deal more. In "Cancer and AIDS," a recent article published in *The Scientist*, A.J.S. Rayl notes that "HIV/AIDS research has blazed trails empirically, politically, and even philosophically. Since this disease took hold some 15 years ago, new insights and understanding in immunology, antiviral research, vaccine development, and gene therapy have emerged from HIV/AIDS research laboratories and crossed over to cancer research," as well as to many other fields.

2. What are some specific examples of those benefits?

Recent therapies developed to combat HIV have had a profound impact on the quality of life of people with HIV/AIDS and, in many instances, have prolonged their survival. Less well known is how these drugs may be critical in the treatment of other diseases. For example, lamivudine (3TC, Epivir), a drug that is similar to zidovudine (AZT, Retrovir) in its anti-HIV activity, has been found to block the growth of the hepatitis B virus. Now it is used to treat patients with chronic hepatitis who were untreatable by any other means. Adefovir, a very recent anti-HIV drug, also has been found to have marked anti-hepatitis B and anti-herpes virus activity in patients. Similarly, the success of the HIV protease inhibitors has spurred the development of similar inhibitors for use in treating other infections, such as hepatitis C and influenza, that rely on their protease enzymes to cause cell damage. In addition, several drug companies are developing protease inhibitors for use in treating bone loss, or osteoporosis–a problem for a vast number of elderly people–and in limiting the heart muscle damage that results from a heart attack.

3. What about breast cancer? It's a major cause of death among women, and current therapies have had only minimal impact on survival. Has AIDS research benefited patients with breast cancer?

Yes. One promising experimental therapy for advanced breast cancer is high-dose chemotherapy, followed by a bone-marrow transplant. However, the profound immune suppression necessary for a successful transplantation often leads to devastating, even fatal, opportunistic infections, including cytomegalovirus (CMV), other herpes viruses, and *Pneumocystis carinii* pneumonia (PCP). These conditions are common in AIDS, too, and new drugs against CMV and other herpes viruses have come directly from AIDS-targeted research. New methods of preventing infections such as PCP, CMV, and toxoplasmosis, which threaten people with HIV, as well as those who are immune-suppressed because of organ transplants, cancer, severe autoimmune diseases, steroid treatment, or genetic disorders, have also come from AIDS research. These new prevention methods will have a direct impact on the survival of every person afflicted with an immune disorder, whatever its cause.

4. Are there HIV-related advances that are useful in treating cancer itself?

Absolutely. AIDS researchers have discovered antibodies and drugs that inhibit the activity of specific growth factors, or cytokines, which are the natural body hormones that promote the activity of HIV. Many of these hormones also accelerate the growth and spread of cancer cells. Inhibiting the essential cell receptors for such hormones, for example, EGF (epidermal growth factor), prevents certain cancer cells from spreading. This strategy, which was used first in the experimental treatment of Kaposi's sarcoma, a cancer found in HIV-infected patients, is also being tested in bladder, vulvar, and breast cancers. Furthermore, small proteins and drugs that can block the growth of new blood vessels (which is critical to the survival of tumor cells) were developed to treat Kaposi's sarcoma, but are now being tested in many other cancers as well. Yet even as strategies to inhibit cytokines are being developed, their ability to promote the growth of certain normal body cells has focused interest on their potential for having a positive impact on specific conditions unrelated to AIDS. EGF-like molecules, for example, are being tested as treatments for spinal cord injuries and strokes.

5. What about immune-based therapies for cancer and autoimmune disorders?

Research on AIDS and HIV has stimulated interdisciplinary studies into the development of new treatments for both conditions. HIV positive individuals often develop evidence of an autoimmune problem, such as a lupus-like blood abnormality, Sjogren's syndrome, rheumatoid arthritis, or psoriasis. For these autoimmune diseases, treatments developed in the context of AIDS should be directly applicable to the same conditions when they occur spontaneously, that is, apart from any association with an identifiable stimulus.

At the same time, treatments developed for other diseases have been applicable to AIDS and HIV; it is a reciprocal relationship. For example, the immune hormone IL-2 was first used almost a decade ago for the experimental treatment of malignant melanoma, a particularly devastating form of skin cancer, and for the treatment of kidney cancer. Now it is used to boost the T-cell counts of people with HIV disease. Likewise, other hormones designed to modify immune cells in AIDS and now being tested–the most recent being IL-12 and TNF (tumor necrosis factor)-alpha inhibitors, such as thalidomide–may also boost the immune systems of cancer patients. In those patients, the hormones assist in destroying the last vestiges of cancer, after most of the tumor has been removed surgically or reduced in size by radiation or chemotherapy. The TNF-alpha inhibitors may, in addition, be useful in combating the "body wasting" that accompanies AIDS, severe tuberculosis, and some forms of cancer.

Identifying the causes of various types of cancer is the only way to develop other new mechanism-based treatments. "We will probably learn more from HIV about indirect mechanisms that influence cancer than we have ever learned from combined research in all medical history," said Dr. Robert Gallo, who spent 20 years on "pure cancer research" before beginning his landmark work on AIDS.

6. We hear a lot about testing procedures for HIV and for other infections associated with AIDS. Can these procedures help to improve the diagnosis of other diseases?

Great effort has been expended in the development of better diagnostic tests for antibodies against HIV and for HIV itself. These tests are vital for following both the course of infection and the impact of various therapies. Extraordinarily sensitive techniques, capable of locating less than one molecule of HIV genetic material (DNA and RNA) among millions of particles of extraneous material, are now available and are known as PCR (polymerase chain reaction) and RT-PCR (reverse transcription PCR). Such techniques have made it possible to measure otherwise undetectable levels of cancer cells in individuals, who clinically appear to have been "cured," so that new therapy can be initiated or ongoing treatments continued, not inappropriately discontinued. Similar techniques applied to the rapid diagnosis of infectious diseases, such as tuberculosis, are also being perfected. Also of great importance is a capacity to search for the causes of cancer and other diseases and to detect at an early stage the probable emergence of new, unknown infectious diseases. The discovery of HHV-8, a herpes virus linked to Kaposi's sarcoma, was made possible by a new application of PCR. This technique is now being used worldwide to seek possible infectious causes for diseases of unknown origins.

The ability to rapidly screen small quantities of blood for changes that are associated with resistance to specific antiviral drugs has enormous potential for use in HIV and, as new uses are developed, in biology and medicine.

The first medical application of an emergent technology, the "DNA microchip," is the detection of drug-resistant mutations in HIV. The ability to rapidly screen small quantities of blood for changes that are associated with resistance to specific antiviral drugs has enormous potential for use in HIV and, as new uses are developed, in biology and medicine.

7. What impact does AIDS research have on Alzheimer's research?

Alzheimer's may attack as many as one in ten individuals over the age of 80, and the incidence of this terrible disease will grow as the population continues to age.

Alzheimer's disease is a progressive, global dementia of unknown cause. There are many theories as to how it occurs, including the autoimmune destruction of brain cells; the deprivation of nutrients to nerve cells secondary to the proliferation of a fibrous substance known as an amyloid; the growth of a unique infectious agent known as a prion; and others. Profound dementia is also an important component of AIDS in its late stages. Research has shown that HIV can cause dementia by interfering with the activity, nourishment, or interconnection of nerve cells and accessory cells of the nervous system through a process of cell injury known as apoptosis, or programmed cell death. AIDS dementia provides a test system, reproducible in monkeys infected with the simian AIDS virus (SIV), for studies of Alzheimer-like diseases. Drugs that are successful in ameliorating nerve damage and dementia in AIDS may thus have salutary effects in Alzheimer's.

8. Aren't you reaching a bit when you talk about AIDS research benefiting patients with heart disease?

Not at all. A substantial portion of HIV positive children and adults suffer heart attacks and strokes. HIV appears to affect small blood vessels in the heart and the brain, rendering them vulnerable to spasm, blood clots, and early atherosclerosis. The small arteries of a two-year-old child with AIDS often resemble those of a fifty-year-old man. It appears that in HIV infection, apoptosis–the same condition mentioned above in regard to dementia–injures the cells that line the small blood vessels of the heart. This same injury occurs in HIV negative people with atherosclerosis, where its origin is thought to be certain infections of the blood-vessel wall. Thus, the discovery of the means to block the apoptotic process may not only benefit those with AIDS, but everyone.

9. One hears a lot about "AIDS activism." Has it helped anyone besides AIDS patients?

Definitely yes. AIDS advocates have focused national attention on the high cost of new drugs and on the traditionally slow and cumbersome way in which drug development is regulated by federal agencies. The Food and Drug Administration has responded constructively to the urging of AIDS advocates and has instituted "fast track" procedures to review new treatments for all life-threatening conditions. Fast tracking has already been applied in the approval of drugs for treating Alzheimer's, AIDS, and other diseases, including cancer.

10. What about costs? Should we compare the costs of different diseases? How cost-effective are AIDS treatments?

If one simply counts deaths, then the number of people dying annually from either cancer or heart disease surpasses those dying from HIV disease. But statistics show that most of those dying from cancer or heart disease are much older than the average person dying from AIDS. In terms of years of productive life lost (in other words, when death occurs before age 65), AIDS is a much bigger threat and a much larger economic burden on society as a whole. As one standard by which the cost-effectiveness of treatments can be measured, medical economists use $50,000, the cost each year of a life saved by kidney dialysis. Using this standard, the antiviral treatment of HIV/AIDS is an economical investment in life. It also compares well with some generally accepted interventions, such as heart surgery (e.g., coronary artery bypass) and blood screening for prostate cancer, each of which costs about $113,000 per year of life saved.

In terms of years of productive life lost, AIDS is a much bigger threat and a much larger economic burden on society as a whole.

In summary, HIV disease and AIDS need not–and must not–be viewed as distinct from other diseases. Education and "safer sex" messages, together with efforts to promote the treatment of substance abuse, will help to control current epidemics of sexually transmitted diseases and injection drug use. Basic and clinical research in AIDS, a disease for which the cause is known, is providing insights into immune, infectious, and cancerous diseases, their causes, and their treatments. Programs in immune system restoration, better diagnostic methods such as PCR, newer prophylactic antibiotics and drugs, and new therapies for infectious diseases and cancer–all developed in the course of AIDS research–are having a major impact on countless lives.

Visit www.amfar.org

Baby's Got the Red Ribbon Blues

by Jim Pickett

It's the end of March, and I am enjoying a glass of mellow red wine on the patio of an enormous convention hotel located in downtown Los Angeles, with all the smokers. You can't smoke inside anywhere in that silly town. Getting a breath of fresh air usually means stepping into a cloud of Newport, but, truth be told, I'd search out the smokers anyhow. They're usually cooler, despite their toxic tastes and stinky fingers.

I'm "doing" LA (hey, isn't that the restaurant from "Pulp Fiction"?) thanks to the Chicago Department of Public Health, which has graciously sent me, and more than twenty others from Chicago's HIV Prevention Planning Group, to a national leadership summit on HIV prevention. It feels like the big time, and it is, more than 1,000 participants, all the heavy hitters, big wigs from the Centers for Disease Control (CDC), everybody who's anybody on the national HIV prevention scene.

And me. Just soaking in it. Tres glam.

All day long for five days a packed schedule of (mostly) dynamic sessions focused on the important and exciting work of prevention–workshops, round tables, institutes, plenaries–and after all of that, each day I'd meet up with the gang and whoever on the patio just as enthused as can be. I'd want to share what I had learned–about implementing interventions on the Internet from a couple of guys from the health department in Lexington, Kentucky (of all places), about the development of microbicides (which is really where it's at), products similar to spermicides but designed to kill HIV and other microbes that cause sexually transmitted diseases, about the targeting of HIV positive people for prevention initiatives, which made all the sense in the world to me–every new infection requires one, after all. Everybody else would talk about their knowledge gains, too.

Interesting stuff to be sure, but as it happens at these things, a lot goes on outside the realm of workshops and speakers and "affinity sessions" that is also very informative and mind expanding. I met a fascinating woman from upstate Washington, for instance, who does prevention work in small, rural towns. I met Sister MaryMae Himm, one of the famed

Sisters of Perpetual Indulgence, which is a group of gay men from San Francisco who wear nun drag to spice up their advocacy and fundraising work. I imbibed expensive hotel drinks with wonks from the CDC, with fellow Chicagoans I'd never met 'til I flew a couple thousand miles away, with people whose names I didn't catch but who made for good conversation.

Was it all fascinating? All friendly? Did everyone I meet find me irresistibly provocative and charming?

Believe it or not, no.

So it's one of those late afternoons, early evenings on the patio in LA. We're all sitting around, talking shop, drinking expensive hotel drinks, when this guy breathlessly relates how his state has just made it so you can get a red ribbon stamped on your license plate. "Isn't that fabulous, isn't that wonderful?" And, "What a great thing!"

I was like, "What's the big deal?"

There was a kind of hush. All the twitterings, silenced. All eyes, deering out in the headlights of my loud, obnoxious voice. Hating a vacuum, I filled the void.

"Yeah, I mean, who really even sees the red ribbon anymore? What does it mean? Nothing! It means nothing, it's vapid. Its grotesque ubiquitousness has rendered it utterly meaningless," I said. Or something like that. Dissed it but good. "There's a ribbon for everything now. Who cares?"

The guy tried to break in, but like a train out of the station I could not stop and kept going, picking up speed. "Putting a fleckin' red ribbon on the license plate of somebody's Duster is not going to stop someone from getting HIV." So there! And for my finale, I pronounced something along the lines of, "Like the pink triangle and the rainbow flag, the red ribbon has just turned into something really, really stupid."

Well, not only had I offended the license plate aficionado, I also managed to piss off a couple of my compatriots, one of whom wears a red ribbon pin on his jacket, and has for years. He takes it seriously and thinks of it as a way to honor those who have passed, and those who still suffer. Which I failed to remember when I was embarking on my dismal harangue.

I'm not big on symbols that have long since outworn their usefulness.

But do you see my point? I'm not big on symbols that have long since outworn their usefulness. For me, slapping a red ribbon on something or someone has lost all relevance, it has become disconnected from its original significance–just as one does not think of all the homosexuals persecuted by Nazis when placing their cosmopolitan on a pink triangle beverage coaster, just as one does not think of the beautiful diversity of our gay brothers and sisters when they see a factory-crafted rainbow votive display on sale in the local crap shop. What they see–okay, what I see–is just a bunch of tacky shit.

And tacky shit does not enlighten, nor does it save lives. Tacky shit, even if it is diamond encrusted, even if it is made from the finest silks, is simply tacky shit. What that state should be putting on their license plates is the image of a condom. Or a sterile syringe. Or the phone number of an AIDS hot line.

Call me cranky and antagonistic, but I was also unimpressed, and practically just as red-ribbon-annoyed, at the free slinkies given to all conference attendees in our big bag of goodies. They were made from blue plastic and had the brand "Viracept" stamped on them. Very weird. Does that mean taking Viracept is like a "wonderful toy," "fun for a girl and a boy?" No one else found this twisted or deeply disturbing. But I did.

Yet, I still have mine. Just to keep me in touch with my exasperation, and besides, it is fun to play with.