

Positively Aware

The Journal of
Test Positive Aware Network
HIV Treatment and Health

November/December 2000

TPA News
The Monthly Newsletter of Test Positive Aware Network

Early Intervention Against HIV

The Eyes have it.
HIV, AIDS & the Eyes

MAGIC: ONE IN A MILLION

support drugs

sex
seeking health care

LIVING POSITIVE

10th Anniversary

The road ahead

indinavir ddC

SHE'S HAVING A BABY?
Why women with HIV consider pregnancy

visions, decisions
Is the future of sexual relations?

HIV Drug Guide

Sex work, drugs and HIV

Tomorrow's Promise?

- Science research
- New drugs
- Everyday realities

Memory Honor Hope

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Special Readers Forum for *Positively Aware's* Drug Guide

Positively Aware readers have been integral to its growth and
development. As the January/February 2001 issue will be
Positively Aware's Drug Guide, please send in letters about
your treatment choices. All letters should arrive by
Thursday, December 7, 2000.

Send to:
Readers Forum
1258 W. Belmont, Chicago, IL 60657
or e-mail TestPos@aol.com.



Transitions

Flashback to 1986...I was 27 years old, and in the eighth year of a relationship with the first love of my life. Antonio and I had it all—two wonderful dogs, Max and Tina, great jobs, a beautiful home, and our health. I was in total control, or so I thought. In April, Antonio took ill. I remember the exact afternoon, in the emergency ward at the hospital, when the doctor came out from examining Tony. He told me that Tony had AIDS. He said that Tony was going to die, and so would I. Following bouts of PCP, and after developing Kaposi's sarcoma and dementia, Antonio died on October 8, 1986, at 11:23 am. AIDS. There was no mono, dual or triple combination therapy. No poverty or malnutrition. No substance use, illegal drugs or "hedonistic" lifestyle. No alternative treatments. No genocide conspiracy. None of that. Straight up AIDS. And there I was, all alone, confused and scared. What did I know? Zero. Zip. Nada.

The sense of helplessness that I and others like me experienced during the 1980s eventually gave way to a generation of AIDS activists. They seized the streets in places like San Francisco, New York City, Chicago and Philadelphia, demanding treatment for people with AIDS and a cure for HIV. Remember the demands we made on the FDA and pharmaceutical companies for fast track approval for drugs? I do. Did anyone know what the long term side effects of these drugs would be? No. But anything was better than nothing...Right?

Well, here we are in the year 2000 in the world of HAART, the land of alternative therapies and on the horizon "Structured Therapy Interruptions." In the nearly five years that I've been a member TPAN I've seen friends who were near death respond to HAART therapy in nothing short of a miracle. There are individuals who choose holistic approaches to care. Some of them are also living healthy and productive lives. But then there

are those—the often lost faces of AIDS—who aren't able to tolerate the drugs and don't respond to alternative options.

I've watched the bodies of friends slowly shut down, for any number of reasons. The silver bullet that we once thought HAART was a few short years ago looks a bit tarnished today. The shine may have worn off somewhat, but that's no excuse to give up the struggle or worst yet, turn on one another as we seek new options.

This struggle against HIV/AIDS, like the civil rights, gay and women's movements, must continue as a collaborative effort. Many individuals who have been on the frontlines for years are frustrated and angry. Others joining the struggle more recently are suspicious and confrontational. Some still have their heads buried in the sand.

We all want answers. Where's a cure? What can be done to reduce toxicity? Why are ads for anti-HIV meds becoming more and more sexy? We all want a solution. Don't we?

This issue marks the 10th year of publication for *Positively Aware*. All of us at TPAN and *Positively Aware*, like everyone committed to the HIV/AIDS struggle, are in a transitional moment. We find ourselves asking new questions, seeking new strategies and alliances, and sadly still saying goodbye to dear friends, family members and partners. We continue to change with each passing day in order to better help ourselves and our readers understand this disease, to assist people living with HIV/AIDS make informed decisions on their treatment options, and cope with very personal feelings of loss. Everyone *living* with HIV/AIDS and *living* in the age of AIDS must change as the normal course of life. If we refuse to accept change then we and this movement will die.

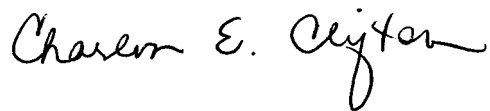
This is also the first issue of *Positively Aware* that has my signature on it as editor. I want to take a moment to thank Dennis Hartke, Enid Vázquez, Jeff Berry, the fabulous staff, volunteers and members of TPAN, and my MOCHA 2000 brothers (ya' all know who you are) for their continued support and encouragement.

Too often in this fight we tend to dwell on what isn't happening. In our work we rush from client to meetings, from conferences through articles, to protests and clinical trials. We often forget to acknowledge achievements. We tend to not take the time to celebrate life and the lives of those who paved the way, those who inspire and inspired us.

This 10th anniversary issue of *Positively Aware* takes a moment to acknowledge the transitions of our lives as people living with HIV/AIDS and living in the age of AIDS. Before we move forward we want to stop and reflect upon where we've come from, what we've been through, where we are at, where we hope to be in the future, and to remember a few individuals who have touched our lives.

On those few Saturday afternoons when I'm home and alone—listening to some classic Phyllis Hyman or Angela Bofill, I can feel Antonio's presence around me. There are days when my dog Carlisle reacts in a certain way, and I can't help but think that Max (1992) or Tina (2000) are there in the room. Some days I can still remember that day in 1986, when Antonio was standing at the door of our house, smiling and holding Max and Tina in his arms. Transitions.

Yours in struggle,



Charles E. Clifton
Editor



Since its inception in 1990, *Positively Aware* has become one of the nation's most widely read HIV treatment and information journals. In November 1990, *TPA News* changed its name to *Positively Aware*, "to attract more readers and send a strong, affirmative message about HIV awareness." In 1990, *Positively Aware* increased in press run from 10,000 to 17,000. In 1991, *Positively Aware* began a trial distribution in other cities, including Minneapolis-St. Paul, Detroit and Fort Lauderdale. In 1992, with substantial financial support from Burroughs Wellcome, 150,000 copies were distributed around the country quarterly. *Positively Aware* began its current bimonthly publication schedule in 1994. Included in this issue are covers that we believe to be significant, including Women, HIV, and AIDS (June 1991); Magic Johnson: One in a Million (December 1991); Whole Body Health (March/April 1997, our first four-color cover); and Stop the Drugs (May/June 2000). All of the covers chosen for this issue are representative of the many faces of HIV and reflect the growth of *Positively Aware* as a journal.

This issue of *Positively Aware* is dedicated to the memory of our departed friends, honor the work of those on the front-line and represents our hope for the future.



Some Things Change, Some Don't

The year 2000. I can remember in 1990 setting as my goal to live to the new millennium (let's not quibble over whether it was this year or 2001). At the time, I was three years into living with HIV and was having my first crisis. In nine months my CD4 cells had dropped from over 800 to 350. I was physically fine, but clinically in trouble. And with only low dose AZT to rely on, the future was less than bright. Even though I lived in a community of only 300,000 in Michigan, I had already attended a half dozen or more funerals and memorial services, including one for a lover.

The year 2000. Present day. I am now 45, continue to work full time, and am in good health. My CD4 count is in the 400 to 600 range and my viral load remains undetectable. Most of my health issues now seem to be more related to being 10 or 15 years older than I used to be. Yeah, I have some side effects from my drugs (Sustiva/Epivir/Zerit), but nothing too severe. In fact, on occasion the drug-induced dreams are interesting and amusing.

My HIV-related issues now are different from 10 years ago. Rather than waiting for the seemingly inevitable opportunistic infections (OIs) and decline in health, I monitor my viral load for the early signs of treatment "failure" so that I can switch to a new regimen. I watch closely for signs of side effects, including lipodystrophy and various nutritional and hormonal imbalances. And I deal with issues related to growing older.

But I go to my doctor when a "cold" doesn't get better in three or four days. Just to be sure. I still worry about a bruise if I don't remember running into the table. A chest cold still raises the specter of PCP. I still wonder if I will live another five years. I still wrestle with disclosure, particularly with a potential sexual part-

ner. And friends and loved ones still die of this disease. Some things haven't changed.

One constant for these past 10 years has been *Positively Aware*. From articles on compound Q and other "kitchen" remedies to the latest information on T-20 and other promising drugs, *Positively Aware* has chronicled HIV treatment and health issues. We have reported from numerous scientific and medical conferences and we have reported from the very personal perspectives of people living with HIV. This has been possible due in part to the talented, dedicated editors over the years—Bob Hultz, Steve Wakefield, Steve McGuire, Brett Grodeck, Steve Whitson, and now Charles Clifton. These individuals along with countless volunteers and staff of TPA Network and writers from across the country have produced this outstanding publication.

In 1990, I hoped to be alive to enjoy the new millennium. I can honestly say that I am here today, in part, because of this publication. Never in my dreams 10 years ago did I think I would be working in the HIV field. Never did I believe that I would be associated with such an outstanding publication.

My hope for 10 years from now is that we will not need to celebrate a 20th anniversary of *Positively Aware*. My hope is that by that time HIV will no longer be the world pandemic it is today. While only a hope, it is closer to reality than 10 years ago.

A handwritten signature in dark ink that reads "Dennis Hartke". The signature is written in a cursive, flowing style.

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**,
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E-mail: posaware@aol.com

Drug screening correction

The article on drug screenings in the Sept./Oct. issue stated that employers cannot request a drug screening until after a job offer has been made.

Actually, they can ask for one even before an interview, but if the potential employee refuses, the employer may not offer the position. This has not been tested in a court of law. You do not have to disclose your HIV status to the independent group conducting the screening, but I have been made aware that if you do not disclose the HIV meds to the independent screening service, and your potential employer finds out, you could be dismissed.

My apologies,
Glen Pietrandoni, author

Correct number

I wanted to let you know that a patient of mine sent along a copy of your article, "Consumer's Guide to Lipo Surgery." First, I wanted to thank you for mentioning my name in the article, because I know many people have a difficult time trying to find a surgeon who performs these procedures. You did, however, list my telephone number incorrectly. The number to my office is (415) 392-9800. Thank you.

Michael Echavez, M.D.,
San Francisco

Ten Years of Positively Aware

I started to read P.A. in May 1992 as a board member of our local AIDS task force. It helped me to know and respond to PWAs [people with AIDS] as I took them to hospital appointments. I have been County Jail Chaplain since March 1994 and always pass P.A. to prisoners who want to read it. Thank you.

Why do you continue to say that HIV causes AIDS? HIV *is* AIDS to a lesser degree. I see the distinction, though, for disability entitlement reasons.

John Cantrell
Washington, NC

Timely info

I'm looking at a friend's issue (Sept./Oct.) and would like to know if you would fax me pages 28 and 29. I have a concern as my husband was just prescribed Zocor. I'd like to show the doctor these pages and see if I can have him change to Pravachol or Lipitor. Your mag is very informative. I'll definitely be getting my own in the future. Thank you for caring.

Virginia,
via the internet

HIV "sluts"

Three cheers for Jim Pickett's article in the Sept./Oct 2000 issue, "Give Us Morality or Give Us Death." It's about time that someone spoke out about the "sluts" with HIV/AIDS, who just don't give a damn who they spread it to. My ex-lover knowingly and intentionally infected not only me with HIV, but at least seven other people. This was in Michigan in 1987-1990. Yes, there is an HIV law in Michigan and he was prosecuted under that law. He received a mere five years probation. It just about killed me to see activist groups defending him and protesting me for being a key witness in that case. Yes, people should have been educated about protecting themselves from HIV back in 1987, but in very rural northwest Michigan, it didn't happen. I have *always* accepted a percentage of the blame for my infection. However, I will always feel that the

largest percentage of *not* spreading HIV belongs to the person *with* the virus. They know that they have a deadly disease and know how not to spread it. I heard it from my ex-lover and many of my infected friends, "Not my problem if they catch HIV from me. It's up to them to protect themselves." Sure, in a perfect world that could happen, but in the real world, these uninfected people are only consenting to sex, *not death!* The HIV/AIDS people have absolutely *no right to murder people for their sexual pleasures!* I ask the infected, would you intentionally give your brother, mother, father, dog or cat HIV via a syringe full of your blood? Then *why* would you *murder* an innocent person by lying about your HIV status and infect them? If you were driving and got hit by a drunk driver with seven convictions for DUI, and lost all abilities to walk, see, hear and function on a daily basis (you're a human vegetable), but you'll stay alive and suffer for awhile—what do you think should happen to the drunk driver? Two months probation? Nothing? After all, he did say in court that he didn't care about the injuries that he caused you, nor will he say at the very least that he's "*sorry*." You were driving on the same road and the accident is your fault because you didn't *protect* yourself from *him* crossing the center line. Sounds crazy, right? This is what I see going on *all* the time. Blame somebody else for *your* lack of compassion, *your* lack of responsibility and *your* lack of humanity. It's no big deal to be honest about having HIV and to protect *both* parties while having sexual relations. It's the right thing to do and you'll be helping to stop the spread of HIV/AIDS. (That's a good thing.)

Patrick,
Redding, California

SS blues

I'm in the process of paying back Social Security around \$9,000 (over a period of three years) because I, too, thought I was following the rules. And I was, according to what I understood and was being told on a monthly basis.

Where did you come up the figure \$700? You state, "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." My SS office and manual in front of me (and at the time I was working part-time) says you can only make \$499 a month before taxes. Has this changed?

Also, after nine months, I called them every month asking them to evaluate my earnings to make sure I wasn't screwing anything up. Every month (for almost two years) I called and told them what I was making. Their reply was, "Don't worry about it. You're okay." Finally, I get a letter saying I had made around \$9,000 too much and they wanted it back—now. As I went to the office to discuss this and a payment plan, they even admitted it was their fault for not evaluating me and letting me know that I should not be working or making that much money. But I was still responsible for paying everything back. It's sad and a financial disaster. I'm scared to ever try to do anything again. Sad.

Still very curious where you come up with the \$700 figure.

Rick,
via the internet

Editor's Note: Social Security raised the amount for substantial gainful activity from \$500 a month to \$700 in July of last year.

Ribbon blues?

In response to "Baby's Got the Red Ribbon Blues" (July/August), when I wear a red ribbon here at Danbury Federal Prison, it is to tell everyone, "I'm willing and ready to talk about HIV." It may be tacky, with that I agree. It is also tacky to talk about sex, sexuality, politics, greed, racism, abuse, disease and even statistics.

I live in a population with one of the highest numbers of infected people in the U.S. Too many women don't talk out loud about HIV, and they should. We need to talk! My red ribbon says, "Please talk to me. I've been waiting for you."

Maybe one woman who is facing this challenge alone will take a chance and talk to me. Call me tacky, but please talk to me about HIV.

Jennifer Poteet,
Danbury, CT

Dear Jim:

Baby's Got the Red Ribbon Blues...
THANK YOU!

John,
via the internet

Lost in the twilight zone

The interview with Tony Palmisano and his girlfriend Tina (March/April) moved me to tears. I've had more than my own struggle with life, alcohol, sex, and depression. It all brought me to AIDS, also. I work at it all trying to find solu-

tions to all the craziness and try to move forward at the same time. I found the part in the interview where Tony tells about how he would retreat to that little corner in the back of his mind, a private, secret place where no one could enter and it felt safe—I can relate to that tremendously.

I ask God to hold them both close, keep a firm grip on their hand and gently guide them along their spiritual journey, watch over them and let no harm come their way. Their suffering was for a purpose of higher enlightenment. If you are in contact with them, tell them to keep seeking. God bless you all,

Rick,
Margate, FL

Steve Whitson

It's with shock that I opened my March/April issue, which I only received in October, due to my own fault, that I see the editor's page only to learn of the painful demise of my own mentor, Dr. Whitson. Sincerely accept my belated condolences and heartfelt loss, at this time when we are trying to bridge the gap in Africa and the rest of the world in our campaign for an improved quality of life for all those affected by HIV/AIDS. Take courage, those who personally knew him, especially Phillip (see page 36). It is very difficult to cope but you have all our hugs from those who knew Dr. Whitson through *Positively Aware*.

Milly Katana,
via the internet

Cocktails a crock

It is so insulting for me to read your magazine and other HIV-centered publications that constantly refer to the three drug regimen as "the cocktail." Do you know how many times I've had friends who ask me if I'm on the cocktail? I tell them absolutely NO! First of all, I don't drink and that bothers me to begin with. I tell them I'm taking antiretroviral chemotherapy, which is a more fair description considering the absolute horrible suffering I've experienced on the HAART routine. It is astounding because of the use of the word "cocktail" that people who are not infected are thinking about these very serious drugs like a simple cocktail gotten at a local bar. Please consider stopping referring to our medicine regimens as cocktails and use antiretroviral chemotherapy or HAART to refer to the medicines we take. You do not even fathom what disservice you are doing to those of us in the gay community by continuing to use the word "cocktail." Finally, in the many conversations with my friends about HIV, it appears that there is the idea that the war is over since these drugs exist. I want all non-infected persons to be forced to take vomit inducing drugs like ipecac for a week and see if they get the picture that the battle against HIV has only just begun. Maybe they wouldn't call it a cocktail after puking their guts out for a week.

Gary,
Chicago

We always say HAART, never "cocktail." We have also explained that HIV drugs are a form of chemotherapy. However, you noted

the word "cocktail" in the article "Defending the Castle." The author, Stephen J. Fallon, had this to say: "I agree that the term 'cocktail' implies something far more festive than the somber ritual of taking one's meds. I've never cared for the term. Still, I used this old term because the article is meant as a primer of sorts, and in my speaking, I keep getting blank stares when I use the term "HAART" before newly diagnosed groups. They're all familiar with the term 'the cocktail,' because it's been in vogue since 1997. During the course of my seminars (and the article), I inform patients that the newer term is HAART. However, my article was rather unwieldy in length, and I guess that section was one of the parts that got left on the editing room floor! I'll endeavor to push the HAART term even more in the future. Thanks for your feedback." -EV

Unfortunate error

In the Sept./Oct. 2000 issue you printed a letter from me entitled "Wait And See." An unfortunate mistake was made when stating the date when I first tested positive. That date should have read 19-EIGHTY-5, not 1995. The comment I had made about AZT being the only drug available at the time should have alerted the editorial department to notice something odd, since by 19-NINETY-5 there were many drugs available. This unfortunate 10-year discrepancy reduces the significance of my waiting as long as I had. To me, waiting two years before starting therapy hardly warrants a letter to the editor.

Sincerely,
Rick VanVelkinburgh,
Denver

Model prison care

After reading so many horror stories from HIV positive prisoners throughout the country, I can thankfully report one exception, the Suffolk County House of Correction in Boston. Sheriff Rouse should be commended for the staff he's put together and the treatment and programs they've implemented.

The HIV coordinator, Jeanne Internicola, organizes testing and programs like Risky Business, Health Matters and Peer Education that have brought the ignorance and intolerance level to near nil. She also sees everyone who's HIV positive has thermals to wear in the winter and helps with pre-release issues.

Nurse Hadi sees that our labs are done every three months, does her best to accommodate everyone's dosing requirements and keeps us scheduled with a great infectious disease specialist who visits weekly, Dr. Solman. All HIV medication is available right after FDA approval and the staff works with you to help make treatment strategy decisions.

The Recovery Unit headed by Joe Travis and Lana Steward has a substance abuse program that's second to none. After more than 20 years of substance abuse and doing time in 13 jails and prisons, S.C.H.O.C. is the only one to have a positive effect on my life. I owe everyone there a huge "Thank You!"

David O'Regan,
Boston ☩

by Enid Vázquez



Videx *not* once-a-day

Earlier this year the Food and Drug Administration (FDA) approved once daily dosing for Videx (ddI), but now the original twice-daily dose is being urged. The once-a-day approval was based on preliminary results of a study which later found that after a year, the dose was inferior. Although once-daily dosing is still approved and available, the FDA required the manufacturer to send out a letter to healthcare providers stating the trial results and noting that twice daily dosing is “preferred.” The letter says that the new dose should only be considered for people “whose management requires once-daily dosing of Videx.” The company points out that the Videx group was complicated by the need for a total of four separate HIV drug doses a day, compared to three doses for the competing drug regimen.

And HIV specialist Dr. Daniel S. Berger of Chicago, who also serves as medical consultant to *Positively Aware*, noted that, “For patients whose viral load is optimally suppressed on once daily dosing of Videx: should they be dictated to alter dosing to twice daily based on the results of one study? Twice daily dosing on an empty stomach is often impractical for patients trying to eat frequently so that they can avoid wasting, and perhaps fat depletion—not to mention having to take other meds with food or other meds on an empty stomach, like Crixivan.” For more information, call Bristol-Myers Squibb at 1 (800) 426-7644.

Those new drugs

T-20 at one year

This experimental HIV drug is not cross-resistant to the antivirals out on the market, because it’s in a brand-new class of drugs—fusion inhibitors. What’s most exciting about T-20 (generic name: pentafuside) is its study in people who have already been on lots of drugs and need new options. After a year of twice-daily injections, half the heavily-experienced people taking T-20 had a significant drop in viral load or were below 400 (“undetectable”). They took T-20 in addition to their HIV antivirals. Viral load came down from about 70,000 to around 10,000. On the minus side, only 40 out of 71 people who entered the study stayed on T-20 for the 48 weeks.

Kaletra (ABT-378/r) newly approved

Preliminary six-month results look good in heavily drug-experienced people. But this new three capsule, twice daily protease inhibitor—approved for adults and children in September—was taken with two nucleosides (like AZT/Epivir) *plus* a non-nucleoside (in this case, Sustiva). That’s a combination of every anti-viral drug class on the market, which limits even more options for future combinations. Then again, this was in people who don’t have much choice. Overall, 69% of people on the lower dose and 82% of those on the higher dose were able to achieve undetectable viral load (under 400 copies) at 24 weeks. Those results are hard to see in heavily pre-treated people, and this was under the strict intent-to-treat analysis. The higher dose of Kaletra (generic name lopinavir) is 533 mg lopinavir with 133 mg ritonavir (brand name Norvir, the manufacturer’s other protease inhibitor). The dose consists of three capsules, which are taken twice a day. The drug was called ABT-378/r during earlier clinical trials. This report came from a study of 57 people. Anyone planning to take Kaletra should prepare for the likeliness of nausea, diarrhea and muscle weakness.

When taken in combination with a different non-nuke, Viramune, results were also good, but for 72 weeks (a good, long time—making the results more reliable). People in this group had previously used at least one protease inhibitor, which stopped working for them. At 72 weeks with Kaletra, Viramune and two nucleosides, 57% were undetectable on an ultrasensitive viral load test (under 50). Altogether, 73% were undetectable (under 400 copies). T-cells went up by 154. Results are from 70 people, a small group.

Some critics say that the results of these “salvage” studies are difficult to interpret. Did good results come from Kaletra, the non-nuke or both, which could mean that you have to have a non-nuke to achieve the same results.

International conference news

More info from the 13th International AIDS Conference, held in Durban, South Africa in July. For more information, visit www.aids2000.com.

IL-2 by itself

The immune booster raises T-cells, but does it also raise HIV viral load? No, say London doctors who looked at people not on HIV antivirals. Everyone in the study (including the control group) started with at least 350 T-cells. IL-2 was given in three cycles eight weeks apart. At the end, the IL-2 group had gained 232 T-cells while the control group gained 13.

Viracept/Norvir

A “mini-dose” of 200 mg Norvir added to another protease inhibitor, Viracept, seems to make blood levels of once-daily Viracept similar to levels seen when the drug is taken at its usual twice-daily dose.

Viracept was given at 2,500 mg. That’s 10 tablets (plus two Norvir capsules), but a new Viracept formulation now in the works could reduce that to four tablets. However, fasting triglyceride (blood fat) levels were significantly higher after two weeks on the combination.

Sustiva side effects

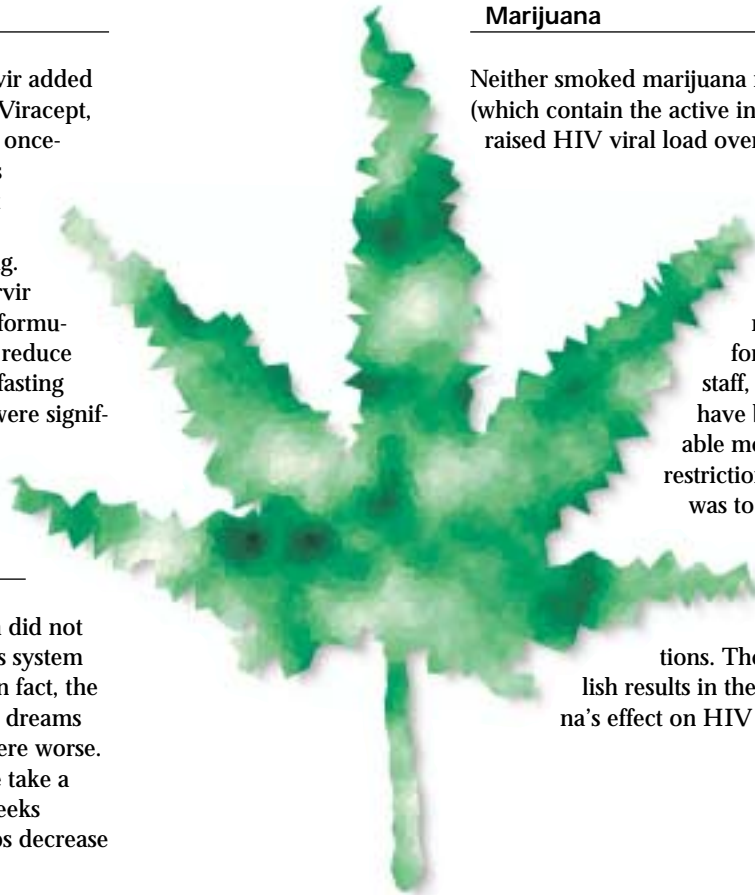
Unfortunately, dose escalation did not help lessen the central nervous system effects of Sustiva (efavirenz). In fact, the dizziness, insomnia, abnormal dreams and inability to concentrate were worse. Dose escalation, where people take a smaller dose for one or two weeks before going on full dose, helps decrease the side effects of some meds.

Hold off on prednisone?

Prednisone is used to treat rash caused by Viramune (nevirapine). Doctors took a look at whether it could therefore help to *avoid* rash (which can be serious and even fatal). One study found that using prednisone at the beginning of Viramune treatment actually doubled the incidence of rash and even made the rashes more serious, as well. But this was in contrast to an earlier study finding this to be a successful prevention effort. In fact, in the real world many people have successfully used prednisone. One clinic with a large HIV practice reported absolutely no incidence of rash when using 10 mg a day for the first four weeks of Viramune. (That’s amazing.)

Marijuana

Neither smoked marijuana nor Marinol capsules (which contain the active ingredient of marijuana) raised HIV viral load over a 21-day period, based on a small study of 63 people, who were on a Crixivan or a Viracept HIV drug combination. These results were a major accomplishment for Dr. Donald Abrams and staff, of San Francisco, who have been fighting unreasonable medical and government restrictions for years. Their goal was to help HIV patients deal with pain and wasting by doing research on the efficacy of marijuana for these conditions. They will continue to publish results in the future, such as marijuana’s effect on HIV drug levels.



Adherence: bad news, good news

Same old bad news: Unless you come close to perfection in taking your HIV meds, they will probably fail to keep your viral load undetectable. Canadian doctors reported that of people who took their doses correctly 95% of the time, 87% had less than 500 viral load “at least twice.” Only 64% of the people taking the drugs correctly 90% of the time achieved this. HIV drugs are horribly unforgiving. But remember: researchers have also reported that people still benefit even when their viral load is detectable. They may actually have better health and higher T-cells counts.

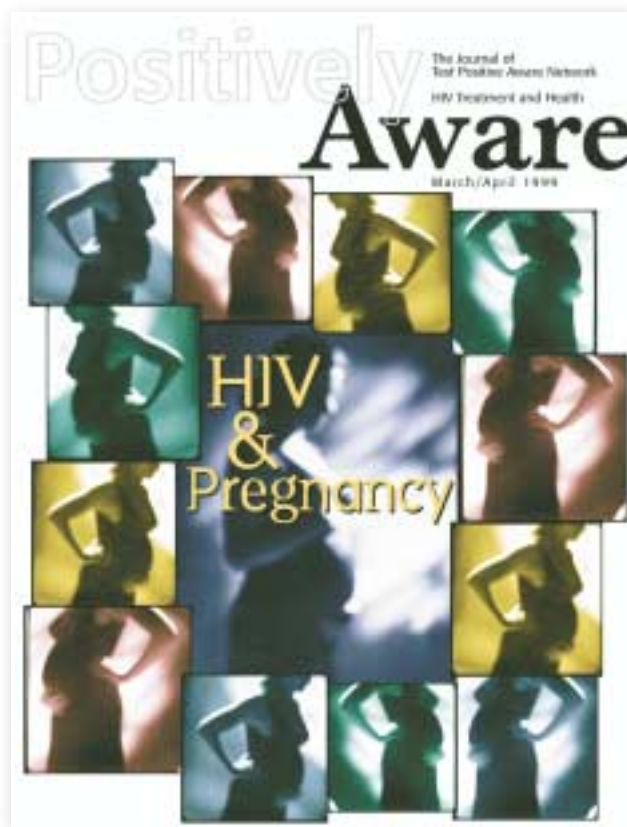
On the bright side, doctors reported good results with a compact yet powerful regimen. The AIDS Research Consortium of Atlanta gave Combivir (which is made up of two drugs, AZT and Efavir) and Ziagen (abacavir) to “under-represented populations” of ethnic minorities, women and injection drug users. Seventy-two percent of the people who took their doses correctly more than 70% of the time had less than 400 viral load, and 61% had less than 40 (the ultrasensitive test). But results were even better in the group who also received “educational intervention plus counseling”: at 24 weeks, 92% of them were undetectable (under 400) with only 70% adherence. The percent undetectable on the ultrasensitive test was strangely the same (62%).

Viramune in pregnancy

The last issue of *Positively Aware* (Sept./Oct. 2000) noted that Viramune (nevirapine) was found equal to a combination of Retrovir (AZT) and Efavir (3TC) for preventing transmission—and much more convenient and inexpensive—but did not mention another plus for the drug. In a separate study, Viramune was able to lower transmission by a third in breastfed babies after a year-and-a-half compared to AZT. The drugs were given at around the time of birth. The session moderator called this “tremendous news.” Breastfeeding may cancel the benefit of medicine to reduce transmission. Both African and U.S. doctors conducted the HIVNET 012 study in Uganda.

Potent drugs during pregnancy

In the U.S., where pregnant women have greater access to potent combination therapy, these medications were again found to reduce HIV transmission to infants regardless of the mother’s viral load. However, transmission does go up along with higher viral loads. The researcher noted that AZT, Efavir, Zerit (d4T) and Viramune are better at crossing the placenta than are protease inhibitors. Still, protease inhibitor combinations were better at lowering transmission than other potent combos (down to 1.1%, compared to 3.9%).



What to do for that fat stomach

Therapies that raise HDL cholesterol (the “good” kind) might help avoid the expanding stomach seen in so many people on HIV meds; such therapies include the statin drugs (like Pravachol), Cardura, exercise, omega 3 free fatty acids supplements and foods high in omega 3’s, and oral estrogen supplementation for post menopausal women. Nicotinic acid raises it the most (40%). A decrease in HDL helps increase brown fat. (Smoking decreases HDL.) Brown fat is more expansive than white fat, and there’s a lot of it in the stomach area (and so, the bigger belly). Another area with lots of brown fat cells, that can therefore also expand is the upper back, and hence, buffalo humps. Obviously, this area needs further research. For one thing, some researchers contend that only children have brown fat.

Other researchers found more fat redistribution in people who had used Zerit (d4T) and in people who had ever used a protease inhibitor, in this case Crixivan, for more than two years. Note: simply taking Crixivan and/or Zerit without non-drug risk factors being present didn’t add risk for the body fat changes. These non-drug risk factors were: having at least four

years since time of HIV diagnosis; living with AIDS for at least seven years; a BMI (body mass index) change of greater than two; and age over 40 (no surprise). BMI is determined by weight divided by height. The researchers were reviewing the records of more than a thousand people with HIV.

However, bioelectric impedance analysis (BIA) and anthropometric measurements are helpful in evaluating changes in body composition such as changes in lean body mass. Loss of lean body mass leads to AIDS wasting and should be monitored regularly. BIAs can be done for free. Visit www.medibolics.com/BIAcontacts.htm.

In addition, earlier this year different studies reported less body fat changes in Latinos and African Americans than in whites, and one study also found that people with a loss of at least 1 kg BMI were at greater risk for body changes. (More than 80% of them had been studied for three years, during which their BMI changed.) Another study found that men have more lipoatrophy (loss of fat) than do women.

Nonoxynol-9 bites the dust

There was evidence that a microbicide containing nonoxynol-9 may increase the risk of HIV transmission, rather than decrease it, as had been hoped. Nonoxynol-9 is added to many condoms and contraceptive foams, creams, and jellies, where it is used as a spermicide. Of 1,000 sex workers in Africa using either the microbicide or a placebo (fake gel), the ones using the microbicide were 50% more likely to become infected with HIV. They were also more likely to experience vaginal lesions, which also makes HIV transmission easier. Irritation from the substance is quite common and was reported years ago. The women were counseled to use condoms.

The U.S. Centers for Disease Control issued a statement: “Given that N-9 has now been proven ineffective against HIV transmission, the possibility of risk, with no benefit,

indicates that N-9 should not be recommended as an effective means of HIV prevention. . . . CDC has never recommended N-9 alone for HIV prevention, but current recommendations do emphasize the consistent and correct use of condoms, with or without a spermicide. While the level of N-9 used as a lubricant in condoms is much lower than the level found to be harmful in this study, CDC will re-evaluate this guidance as part of [an] upcoming consultation. In the interim, while N-9 will not offer any additional protection against HIV, a condom lubricated with N-9 is clearly better than using no condom at all.”

One healthcare worker specializing in HIV also pointed out that this study was conducted with sex workers, who use much more N-9 and will have more physical irritation.

Selenium deficiency may cause more HIV shedding

A team of Kenyan and U.S. researchers report that positive women with the mineral deficiency were three times more likely to have HIV shedding in their genital mucosa (lining), which may in turn make them more likely to infect someone else. This was after researchers accounted for other infections and for use of birth control pills.

More selenium info:

- less and less selenium is seen in the body as T-cells count drops
- people with HIV who also have selenium deficiency are 20 times more likely to die of HIV-related causes
- low levels of selenium are a greater threat to survival than low T-cells
- selenium deficiency poses more of a risk to survival than low levels of any other nutrient

This information comes from a literature review on selenium in the July issue of *The Lancet* medical journal, quoted by John S. James, publisher of *AIDS Treatment News*, in the July 28 *ATN* issue. The *Lancet* report stated that, "decline in selenium occurs even in early stages of disease when malnutrition or malabsorption cannot be a factor."

More drug stops

Warning: This item contains tantalizing but scientifically unproven information. There are no clear answers at this time.

Dr. Anthony Fauci, director of NIAID (National Institute of Allergy and Infectious Diseases), reported on two treatment interruption trials. He calls it "Structured Intermittent Therapy," or SIT.

One group that went on therapy for eight weeks, then off for four, continued to have lower viral load after each stop. But one of the seven people in the group didn't. All started out with less than 50 viral load and their T-cells didn't change. These results are from only two or three stops (interruptions).

Members of the second group remained under 50 viral load despite being on meds for one week and off for the next. Of seven people, only one experienced detectable viral load (above 500). This group also started with less than 50 viral load to begin with, and these results are from only 14 weeks.

Then there were Dr. Franco Lori's PANDAs, people treated with hydroxyurea and Videx. In his research abstract (summary), Lori reported that none of the nine PANDAs had viral load go up to 10,000 while off treatment, while 5 of 8 people in the study taking HAART did (Highly Active Antiretroviral Therapy). However, only one of the cute little critters had a viral load above 50 to begin with, while the majority (seven) of the HAART group

was above that. The stop-therapy was for eight weeks.

Among other conference reports on treatment interruptions was a Spanish report noting that 18 of 19 people off meds for three months reverted to wild-type HIV, which has no drug resistance. They all had some drug resistance before going off meds. The ability to go back to wildtype virus has been seen in other studies, and is a good thing.

PWA (person with AIDS) and advocate Jules Levin spoke from the audience at a session looking at treatment interruptions. "I'm very concerned about this. A lot of people are experimenting with this willy nilly." Researchers noted that viral load levels are followed very closely in studies and that a potential risk of this research is having drug resistance develop. Other concerns that have been raised include coming back to severe side effects all over again and the difficulty of going back on schedule with your meds (one Chicago doctor said some of her patients couldn't remember whether they were supposed to be on or off—a finding that was also found in yet another report at the conference).

The hope for interruptions is that they'll lessen toxicity and help the body's immune system kick in to fight HIV. One U.S. study presented found significant decreases in total cholesterol, "bad" cholesterol and triglycerides (fat in the blood) in people taking a few weeks off. But body fat distribution and insulin resistance did not change. ☒

Some Personal Confessions

by Christopher S. Clason

Thank God for founders and visionaries. I like to remember who came before us, what they did, and how we should follow in their footsteps.

When I look at the writings of Test Positive Aware Network founder Chris Clason, in little photocopied newsletters stapled in the corner, I'm amazed that he was prophetic. The ideas he discussed in the mid-80's are still relevant today.

I was privileged to see those "antique" newsletters because founding member Bill Rydwels, who writes in this anniversary edition, gave me a stack of them three years ago as I put together our local agency newsletter, tpanNOW. At that time, we were recognizing the 10th anniversary of the agency. TPAN started with 16 people in Chris Clason's living room after he ran an ad inviting others to come together

around their needs as HIV positive people. Back then, in 1987, services in Chicago were basically only for people with AIDS. These guys started a support group that later became many support groups, and an information service that grew from a 12-page typed-up newsletter to an offset printed magazine that today prints 100,000 copies and goes all over the world.

In Bill's words, "None of us would be here—or survived as well as we did—had it not been for Chris Clason." And remember Chris' own sign-off to each issue of Positively Aware's forerunner, TPA News—"Health and happiness." That's what he wished for all of us.

—Enid Vázquez

Some Personal Confessions

Editor's Letter, *TPA News*, March 1989

After 20 months of TPA Fellowship meetings, after cruising through books, newsletters and rams of reports and papers covering almost every known treatment or therapy related to HIV infection; after meeting and hearing from doctors, scientists, immunologists, alternative therapists, psychologists, acupuncturists, New Age therapists, yoga gurus, long-term survivors, short-term reactionaries and various tales from the 600-plus members of TPA, I can state without reservation I may be the most well-informed and the least-motivated person in Chicago on the subject of selecting therapies.

Although I've explored several therapeutic approaches (nal-trexone, hydrogen peroxide, acupuncture, isoprenizine) and have made some rather radical alterations to my personal habits regimen (quit smoking, gave up all liquids except water and herbal tea, introduced more fresh fruit into a basic McDonald's diet, cut way back on my sugar intake) I must confess that I'm finding myself in a position I'm not very pleased about. I'm not really doing much of anything at the moment to monitor my health or to bolster my immune system. One could argue I've found a sort of "normalcy" to my living with HIV infection. One could counter that by saying I was in a subtle form of denial: avoidance and procrastination.

My arguments and defenses have always been sound. For a long time I was making so little money I couldn't afford to take things like egg lecithin or Carrysin and as I had no insurance, visiting the doctor was a luxury I couldn't afford. (Lucky for me my day-to-day health has remained stable.) Today, money is not the problem it once was, although I still am not

insured to cover doctors' visits. Today, my defense is that I'm too busy: too many meetings to get to, too much reading to do, too many projects to finish and more to undertake, too many phone calls to answer.

I know, I know. It just doesn't make sense. If I don't put aside the barriers between me and my T-cell test, me and my diet and exercise program, me and my Chinese herb study and/or my experimental drug study protocol, or me and my antiviral/immunomodulator/prophylaxis treatment there may not be someone around to get to the meetings, finish the projects and answer the phone calls. As much as I hate to admit it, this is a form—albeit a subtle form—of denial. And I'm concerned enough about it to pose a question to others in [TPAN]—especially those who may have been members for quite a while—Are you experiencing some of these same things? Have certain therapies lost their appeal or positive effects? Have diet regimens become too complicated or expensive to maintain? Have we become desensitized to keeping up with new treatments or disinterested in trying new approaches? What should/can we do about it? [The author then invites readers to join TPAN for a support meeting where this topic would be discussed.]

Health and Happiness,
Christopher S. Clason
(signed Chris) ☒

Chris Clason died in December 1991.

Not Yet Satisfied

By Bill Rydwels

Tears, thanks, apologies, laughter, giggles, bingo, lectures, photos, hugs, massages, bonding, saying “hello” and “goodbye,” writing, stuffing envelopes, barbecues, sunny skies, planting flowers, sharing and hiding: these are just some of the things that Test Positive Aware Network (TPAN) offered to all of those who came seeking solace and knowledge in 1987.

of that day. Those who attended the meetings found a brotherhood within TPAN boundaries that served as a sounding board, a support base, an educational tool, an endless source of aid—both emotionally and physically—and a place where you’re never forgotten.

During the early years information was disseminated at meetings and through

ing some of the suffering and some of the losses—but we, as well as the rest of the world, must understand that the pandemic has not stopped. People are still suffering from both the syndromes associated with HIV and the medications which are delaying the onset of AIDS. People are dying from AIDS and the medications are causing many bodies to slowly close down.

We, as well as the rest of the world, must understand that the pandemic has not stopped.

The job is not done and will never be done until we can look our brothers and sisters in the eye and tell them truthfully that the war with HIV and AIDS has ended. We cannot be done if we allow others to tell us that the epidemic is over when what is available does not kill the virus, but merely delays its actions. We cannot accept that AIDS today is equivalent to diabetes. Our job cannot be done when there are people out there getting infected because they either don’t care, or haven’t been educated about the virus.

Through meetings, literature-filled walls, conversations, therapies, and the newsletter that was to become *Positively Aware*, TPAN gave us the opportunity to expand our knowledge of ourselves, others and the medical and alternative therapies that would permit us to continue to hope for a cure and live until such a time that a cure was within our realm.

It is hard to believe that we have gone from the dark times of the first publication of *Positively Aware* to the “dark continent” of Africa to hear about the most recent developments in AIDS care and medicine. So many things, bad and good, have happened in the past 10 years. I just thought it might be useful to take a moment to reflect on what has happened and to be thankful of where we are, but also to acknowledge how much more needs to be achieved.

From the founding days of TPAN by Chris Clason, and for many years after, many frightened bodies came to the meetings and lectures, hoping that no person who they knew would discover that they were attending TPAN and thereby label them “one of the pariahs”

the grapevine so that many people in the Chicago and Illinois area could be up to date on such things as egg lecithin, aloe vera juice, acupuncture, massage therapy, newer drugs in the pipeline, crystals, and dozens of other means of staving off the grim reaper. But with time we came to realize that dear friends all over the country were anxious for the basic information that was readily presented and distributed within the membership of TPAN.

Though the hard work of Clason, Bob Hultz (editor), and many volunteers, the simple little TPAN newsletter became a national information source, *Positively Aware*, which allowed the organization to get the word out to communities in all 50 states.

For many years we saw our community being plague-ridden and lost valuable friends, brothers, sisters, mothers, fathers, children and unknown numbers of persons who, if they had lived, would have added to the sciences, culture, and development of a world slowly becoming smaller and more dependent. We are now seeing some movement in alleviat-

We have come far. Thirteen years ago when I first came to TPAN the only hope that I had was to live to the next holiday, whatever that was. Here I am today a person in relatively good health (except for the drug side effects). I remember the discrimination of yesterday, and feel the discrimination still associated with HIV and AIDS today.

Things have improved over the years, but we can not—must not—sit back and be satisfied. We must continue to educate each other, work towards finding a cure, fight against the epidemic, and those who would make us less worthy because of it. ☒

Bill Rydwels is a founding member of TPAN (1987).

May the Force Be with You!

By Steve Wakefield

Michael David Thurnherr was known throughout the United States for his tireless involvement in HIV/AIDS activism and advocacy. He was 28 when he died of complications due to AIDS. He joined TPAN as program coordinator in 1991 and was named executive director in 1995, a role he served until his death in 1996. Michael died with his life partner, Jon Norton, and his parents, Richard E. and Shirley H. Thurnherr, at his side.

Michael grew up—almost as if by fate—just a few miles from the energy and power of Niagara Falls. On my first visit to the falls, its powerful tons of rushing water made me understand words like omnipotent and unstoppable. For the first time in my life I knew incredible energy that could be only partially harnessed, only momentarily realized and that confounded me with a sense of the largeness of life.

Now and then we reach a moment in time when we realize that there is such a “force.” At such times, we may be fortunate enough to realize that, standing in the presence of that force, we can be keenly aware of its impact. Standing on the rim of the Grand Canyon, lying under millions of stars away from city lights, spying hundreds of brightly colored fish while snorkeling in a clear bay, I can easily realize that I am blessed to be engulfed by a special moment at a special place.

Not until Michael had moved on to whatever the next dimension holds did I realize that his touch on my life had been yet



another one of those moments. I've often taken pictures that I later show others to try to convey my sense of the world's majesty and beauty. Trying to convey the transforming effect of knowing Michael David Thurnherr feels a lot like holding a three-by-five photo and trying to communicate the essence of the intense experience I had when I took the photo.

Michael's work life led him to be thought of as an overachiever. Roommates say that in his home life he was the one who created a sense of celebration, play, and party. Jon and he shared a love life that could be understood only through Jon's eyes, although others envied what they observed. In his activist life, his perseverance and perspective changed other activists, while ensuring that the powers that be respond to the needs of people who often feel abandoned by the very institutions created to meet their needs. In each of these spheres of his life the people around Michael came to know him as a friend.

My friendship and discussions with Michael occasionally led to tearful moments from which each of us walked away. The object of these intense moments was to convince each other which opportunity would best lead to a new world. Rather than admit that we had touched each other's hearts, challenged the very fiber of each other's being, or opened a new vista of understanding, one of us would leave a candy bar or Diet Coke on the other's desk. Within a few hours, one of us would come to the other and say thanks. We both found it easier to thank the other for a treat than to tell a friend whom you admired, respected, and loved that his intelligence, acumen, and tenacity had profoundly changed you once again.

Like many of you, I had the privilege of knowing Michael and sensing the force through that experience. I go into each day knowing that I have been blessed. Many others will come through TPA, participate in a support group, take from a prescription bottle a life-saving treatment, have peace of mind because an insurance policy is continued, and in other ways enjoy a better quality of life because of Michael's activities. Few will realize that they are enjoying a blessing because Michael has left his imprint on us and lives on through his contributions to our community and to society as a whole. All of us recognize life's rich moments, brief acquaintances, and powerful friendships. Michael would want us to acknowledge them, revel in them, and celebrate them. He would urge us to bask in the sunshine of those things that make this day more bearable. In the words of the late poet Essex Hemphill, "Take care of your blessings—fiercely!" ✚

Steve Wakefield was executive director of TPAN from 1990 to 1994. He is now Director of Community Education for the HIV Vaccine Trials Network, in Seattle.

Photoillustration by John Auterman.

Diary of an HIV Doctor

Life During the Early Years of the Epidemic

by Daniel S. Berger, MD

ACT UP and other AIDS activists were often chaining themselves to various public buildings. They were frequently getting arrested while shouting and attempting to increase public awareness for AIDS. Two Republican presidents refused to demonstrate the slightest cognizance of the rapidly developing national emergency. It was commonplace to see individuals who looked like skeletons, many riddled with Kaposi's sarcoma lesions. We were desperate to help patients with opportunistic infections with little or no treatments.

Cryptosporidium, PML, toxoplasmosis, CMV encephalitis, CMV retinitis, cryptococcal meningitis and MAC. The year was 1984, 1985, 1986, 1987, 1988, 1989 or 1990.

During this era people like Martin Delaney were busy making drug runs across the border to Tijuana, Mexico to obtain ribavirin. Jim Corti was bringing in compound Q from Shanghai, China. Jim brought in, then illegal, clarithromycin (Biaxin) from Italy by request from me for my patients with MAC (later finally approved by the FDA). Several people in California and Texas were involved with the production of bootleg Hivid (ddC). A Philadelphia research lab was raided of its gp160 treatment vaccine. Also during this heart wrenching time period, Steve Wakfield, then the executive director of TPAN, was often busy visiting many members of the community at the hospital and providing education, support and other valuable services at TPAN. TPAN served an indescribably invaluable service during those days. It was not uncommon for "Ask the Doctor" night at TPAN to be attended by no less than 100 people. They were thirsty for any advice to result in their ability to help themselves feel better, let alone survive.

Was it really 10 or 12 years ago? Can many HIV-negative community members or the more recently and newly-infected individuals understand what life was like for someone with HIV or AIDS 10 years ago, let alone during the 1980's? How does one begin to attempt sharing with our readers this kind of experience? It may be said that it is unfortunate that most have little frame of reference for life during those times. One

could easily have been a Faust fan, selling one's soul to the devil in return for merely understanding the reasons behind the existence of this epidemic, the reasons why our community had to endure the loss of many of its closest friends and the disappearance of valuable talent.

But let's continue to put things in perspective. In 1987 there was nothing. During 1988 AZT was approved but still nothing available for CMV retinitis, the number one cause of blindness for persons with AIDS. In 1989 IV ganciclovir was approved. HIV doctors were constantly occupied with treating

the blood infections that resulted from infected central lines. Long term indwelling central catheters were needed for the administration of drugs to treat CMV retinitis. The ensuing hospitalizations and infections continued to weaken many HIV positive individuals. Life was all about hospitals for many of those infected with HIV.

There was the prevailing hopelessness and a conservative notion of what the standard of care should be. There were many nights of lost sleep, many days of preoccupation and worry. However, as a young HIV treating physician, I could not let my frustration and periods of depression show. I remained stubborn, putting on my most optimistic face mask so that one could continue to provide the necessary hope. I implored patients to obtain alternative sources of treatment.

We used AZT combined with bootleg ddC and a chemotherapeutic agent developed from a Chinese cucumber known as compound Q. While compound Q was found to kill HIV infected cells, it had to be administered intravenously. I could not provide Q through the medical office or clinic. Patients organized infusion groups (known as Q groups) at individual homes during many evenings. I needed to be present and supervise the infusions and treat the usual and frequent allergic reactions that may have occurred. I was sure this renegade treatment was effective since it raised T-cells, sometimes even doubling the count, and patients often reported improvement in HIV symptoms. Peter Jennings hosted a special television program on PBS devoted to compound Q treatment featuring

As a young HIV treating physician, I could not let my frustration and periods of depression show. I remained stubborn, putting on my most optimistic face mask so that one could continue to provide the necessary hope.

Martin Delaney and the late Larry Waits, MD. Project Inform issued a bulletin highlighting the effects and benefits of Q.

Therefore, compassionate track Videx (ddI), illegal ddC (later FDA approved) in combination with AZT and often with Compound Q, NAC or glutathione was more the norm in my practice during those early years. I endured the behind-my-back criticism by peers and other conservatives, but knew I was doing everything I could for a very bleak picture. Viral load testing was not yet discovered. In 1990, Drew Badanish, one of the founding graphic designers of *Positively Aware*, and another TPAN hero, Steve Whitson, who eventually became Editor of *Positively Aware*, were some of my heroic patients. They, along with many others who were taking these same combinations, made it to the era of protease inhibitors to talk about it. Many are currently working full time, their loved ones at their side. They can reflect on those interesting times and what was HIV drug therapy in 1990.

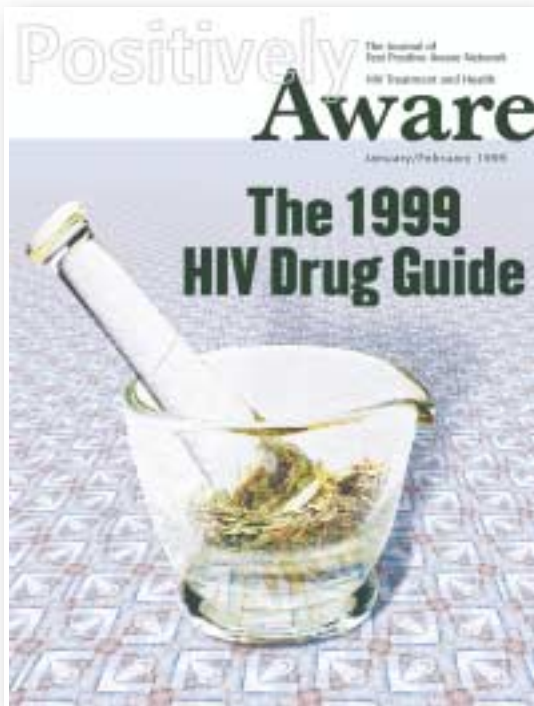
Eventually, Zerit (d4T) and Epivir (3TC) were approved, though we knew little of the optimum way of prescribing these new agents. Trials with thymus immune globulin and thymic humoral factors, as a treatment to stimulate T-cell growth and differentiation, came and went. Later we participated in clini-

cal trials for a new class of investigational agents known as non-nucleoside reverse transcriptase inhibitors (nevirapine or Viramune), protease inhibitors, interleukin-2 and Sustiva (efavirenz). As HIV drugs were being added to the national formulary, we saw less illness and less hospitalizations.

Slowly there was more hope.

There isn't a day that goes by when I don't think of those times and remember people not forgotten. I am thankful for the many who survived and made it to a new millennium. I am grateful for the support I received from many loyal patients and the same stubbornness and fortitude that many HIV positive individuals maintained through many hard times. I hope that lessons can be learned and safe sex may return to being *en vogue*. Many of you indeed understand; fortunately many of our readers have survived those tragic times. ☩

Daniel S. Berger, MD is Medical Director for NorthStar Medical Center, Clinical Assistant Professor of Medicine at the University of Illinois at Chicago and Editor of AIDS Infosource (www.aidsinfosource.com). Of recent, he is a medical consultant for Positively Aware and will feature a regular column entitled The Buzz.



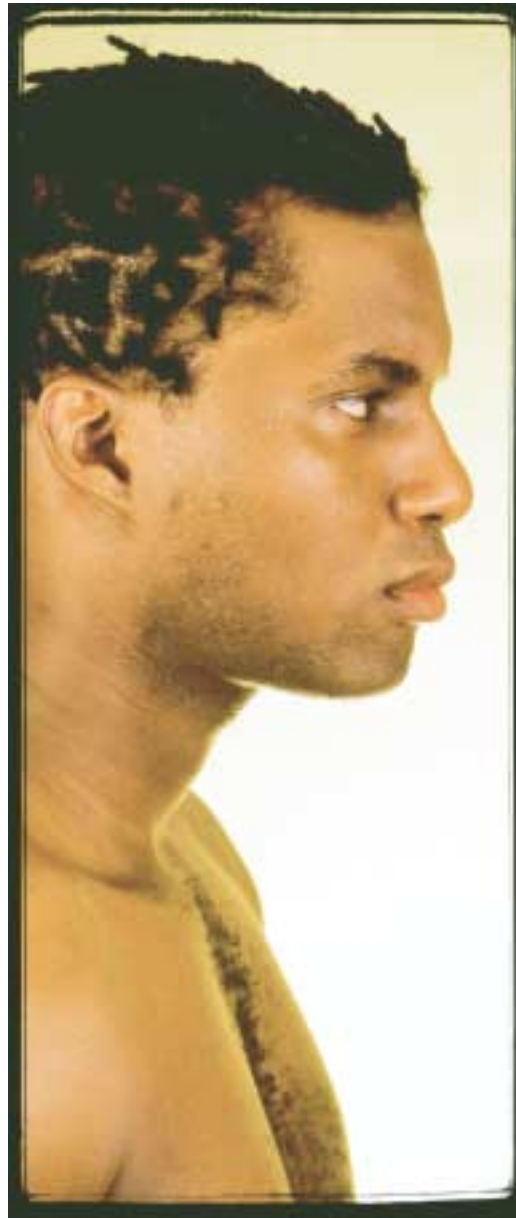
Evolution

By LeRoy Whitfield

If it's true that the first step to recovery is acknowledging that you have a problem, then the black community's sobriety about AIDS has begun. The 1990s began with a reality check: On November 7, 1991, baller Magic Johnson dropped a bombshell about his HIV diagnosis and inadvertently created the largest AIDS awareness campaign targeting blacks in the history of the disease. Although African Americans have accounted for nearly a quarter of HIV infections since 1985 and have exceeded whites in AIDS deaths since 1993, Johnson brought AIDS from the fringe of African American concern and entered it into our dialogues at barbershops and beauty salons in 'hoods across the nation.

Listening to all of the talk that ensued about how to stay negative, however, seemed too late for me. I'd already beaten Magic to the pos punchbowl over a year earlier. But if Magic's disclosure wasn't enough to persuade blacks that AIDS was partly our problem, the death of tennis pro-turned-human rights activist Arthur Ashe five months later reinforced the message. A year later, as I danced my worries away at a nightclub, a new for-charity remix by rap queens Salt-N-Pepa swapped lyrics from their hit song "Let's Talk About Sex" to "Let's Talk About AIDS." On the strobe-lit dance floor, folks shook their rumps all the same as the prevention message penetrated our collective conscious.

By March 1995, gansta rapper Eazy-E shocked the hip-hop community when he announced that he had AIDS before dying of the disease later that month. If a hardcore rapper with a bulletproof public persona fell to this disease, I wondered, how am I still here? A handful of Eazy's fellow hip-hip artists—a genre that



had been notorious for AIDS-phobic lyrics—joined Red Hot Organization to produce the under-appreciated rap album "America Is Dying Slowly" about safer sex. When I heard rapper Method Man spit: "Wu Tang on that AIDS thang," I knew nothing would be the same again. The AIDS landscape was transforming all around me—for better

and worse. My friends who used to chatter about folks that they knew with HIV were now chatting with me about their own positive status. I began understanding the magnitude of the problem when the number of people I knew with HIV grew from a couple to a full-flanked posse. But a grassroots push was still lacking.

By 1996, with African American devastation dominating nearly every major AIDS category, few could deny the need for organized community-based action. By May 1998, after many phone calls and much arm-twisting by a handful of black AIDS advocates, African American leaders finally mobilized against the disease. The Congressional Black Caucus led the charge on Capitol Hill, wielding their influence with President Clinton, and eventually secured over \$400 million to target the problem.

With the cash, longstanding black AIDS organizations, like the Balm In Gilead in New York City, are better-positioned to engage black churches seeking to start AIDS ministries. Black Gay organizations, like New York's Gay Men of African Decent, have been empowered to begin an AIDS off-shoot to carry forth forward-thinking safer sex messages snuffed by the loss of filmmaker Marlon Riggs in 1994 and poet Essex Hemphill in 1995. As for me, I've found the courage to disclose to my family and community, whose ideas about AIDS acceptance have improved over the last decade. And our evolution continues. ☒

LeRoy Whitfield, former Positively Aware Associate Editor, is now Senior Editor of POZ magazine.

Who Moved my Cheeks?

by Jeff Berry

Change.
Change is good.
Change is inevitable.

Everything changes...nothing stays the same.

Change is sometimes painful.

Change is definitely something I have experienced a lot of over the last 11 years. When I was first diagnosed with HIV in 1989, AZT monotherapy was my best option. That would now be considered substandard care, but at the time it gave me hope. I had by then lost dozens of friends, and would continue to lose more in the years to come. I can remember specifically one beautiful, warm, summer evening in 1989, sitting on the rooftop of the apartment I lived in at the time, gazing up at the stars and thinking how lucky I was not to have "caught it." Thanking God, and wondering why I had been spared.

I was in for a big change.

In September I went in to my doctor for a routine checkup, and he suggested I get an HIV test. I had never had one before, but I figured it would be a good idea. I was at the time in a monogamous relationship, but that had not always been the case. I wasn't showing any symptoms, but decided to err on the side of caution, and got tested.

A week later, I went alone to get the results. It was a warm, sunny day of autumn. My doctor, while a very good doctor, didn't have a lot of experience with HIV patients. It was obviously difficult for him to tell me I had a potentially life-threatening illness, and after giving me my results, referred me to the HIV clinic at Northwestern Memorial Hospital in Chicago. I mumbled thank-you, numbly walked out of the office and made my way home. Everything looked different, and nothing would ever look the same again. Anyone who's been there knows what I'm talking about.

When I got home I plopped myself down in the chair and cried and cried, until I couldn't cry any more. Actually I wailed. Sobbed. Felt sorry for myself. Why me? So much for being spared. And later that evening, I had to tell my lover over the phone, while he was at work (I'm not a good liar, although I sometimes wish I was) that I was positive. I'll always remember the look in his eyes when he came home from work that evening, and the words "I'll always be there for you" and how much they meant to me.

You have to remember, back in 1989 there wasn't a lot of hope for those of us diagnosed with HIV. There was some hope, certainly more than our brothers and sisters had in the early and mid 80's, but it was way before the time of protease inhibitors. I remember thinking to myself, I had to make it to the year 2000, because I had always wondered since childhood what my life would be like in the 21st century. So that was my goal. And I made it.

But I've changed.

And so have the treatments for HIV. When I joined TPAN as a member in 1990, there still weren't a lot of options. AZT, ddI, and ddC were the "alphabet" drugs. Many of the other drugs at the time were those used to treat or prevent opportunistic infections such as KS, CMV or PCP. Today there are so many more options and drug therapies to help battle this virus. I probably would not still be here if it weren't for combination therapy and protease inhibitors. By my own calculations, at the time I tested positive, I had to have already been



positive for at least 2 years, probably longer. My T-cells were at 500 when I started AZT, but they gradually dropped over the years, once dipping below 200. (Oh my God—I have AIDS!) Protease inhibitors changed all of that, and for several years my viral load was undetectable, my T-cells up to 800. I actually looked and felt better than I had my entire life. I began taking better care of myself, working out, working on my inner-self, watching my diet.

But I've changed.

My numbers are still pretty good, T-cells at 800, percentage at 28, and viral load, while not undetectable (it usually isn't on the second protease) is still relatively low at 2900. I still look and feel great, but lipodystrophy has started to take its toll. No paunch, no hump, just lots of veiny arms and legs and that hollowed out look in the face. But I could deal with all of that. The veins were eyed enviously by body builders at the gym, and the high cheekbones gave me that gaunt look that was sought after by Calvin Klein and the rest of Madison Avenue.

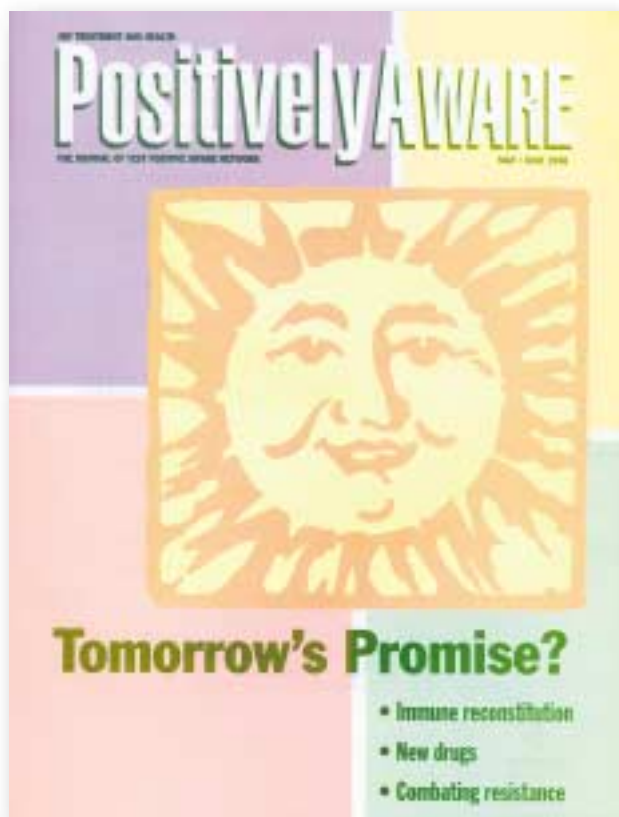
But the naso-labial folds that I've started to get around my mouth just make me look old. And I've always been told I look younger than I am. Now I'm starting to look my age. So, what, in two years when I'm 44, will I look 60? I never anticipated having to deal with looking sick, especially when I don't feel sick. But it really fucks with your head, and for the first time in my life I'm considering plastic surgery. Go figure.

So is this where I thought I would be in the year 2000? No, but I'm glad to be here. Working at TPAN these last eight years has been the most wonderful, fulfilling, scary, chaotic time of my life, and I wouldn't change it for a thing. I've helped to get information about HIV into the hands of those who need it most. People like me who are living with this disease, individuals who are incarcerated and denied treatment, those living in rural areas who have to teach their doctors about HIV, people in Africa who can't afford a subscription to the magazine because it's equal to one month's wages. Real people. Not prisoners, not patients, not clients, but people. I want to help give other people the hope that I've been given.

Because some things never change. ☒

Jeff Berry has served as Positively Aware distribution manager and editorial assistant since 1992.

**The veins were eyed
enviously by body builders at
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A True Champion

by Phil Matthews

(TPAN Executive Director, 1996–98)

Before I reflect on the past 10 years of *Positively Aware*, I would like to first congratulate Charles Clifton on being named the next editor of this terrific HIV treatment publication. I worked with Charles when I served as the executive director of TPAN from 1996-98. I have always been impressed with his intelligence, work ethic and his knowledge of the issues that affect people living with HIV. More importantly, Charles has compassion and commitment to making a difference in the HIV community. He is an ideal choice to guide *Positively Aware* as it enters the next millennium. Congratulations, Charles!

When Charles invited me to submit an article commemorating the 10th anniversary of this outstanding journal I agreed without hesitation. After all, experience has given me a unique voice regarding this issue. My personal journey of 18 years as a gay man living with HIV closely parallels the growth of *Positively Aware*. My experiences as executive director of the agency, and finally, my personal relationship with Steve Whitson, the late editor of *Positively Aware* (and my lover of three years) gave me a direct view of the intelligence, energy and commitment necessary to produce a quality publication issue after issue.

I know when I became infected with the HIV virus and I even know the man from whom I contracted the disease. It was the spring of 1982 and I was a junior in college. I had not yet ventured far beyond the safe confines of my childhood home, a small town of 35,000 people. I was young and beginning to fully explore my sexuality. Of course, no one had yet started to stress the behaviors of "safe sex"...no one knew it would become our sexual reality for years to come. I would not test for the virus until 1987, by which time I was living in New York City. At that time, organizations like Test Positive Aware Network and NYC's Gay Men's Health Crisis were just beginning to become a necessary part of the HIV landscape and there were no HIV treatment publications to read. We were flying blind and grasping for answers that did not exist.

As HIV and AIDS threatened the community, activists began to organize and people living with HIV started sharing their stories, experiences and knowledge. The self-empowerment movement was born and community-based organizations

started distributing pamphlets and newsletters, providing the foundation from which publications like *Positively Aware* would be created.



Positively Aware has seen amazing growth and development. Each editor has brought a special talent to his job and each person's contribution is essential to elevate the magazine to where the magazine stands today—one of the most widely read and highly respected HIV treatment publications available. Steve Whitson began working on the publication in 1997. As editor of *Positively Aware*, he was the happiest he had been in his life. At the time Steve was a tenured professor at DePaul University. He was first and foremost a teacher, and he used those skills to guide one of the most respected HIV journals in the

country. He gladly accepted the challenge of educating people about HIV, and was dedicated to providing the most up-to-date treatment information, ultimately, giving people the tools to make knowledgeable choices about their healthcare.

Steve explored the personal side of HIV by reporting on issues that affect a rich and diverse community regardless of race, gender or sexual orientation. He was fiercely loyal to, and protective of, the HIV community. His size and stature intimidated people, but he was truly a kind and gentle soul. He was blessed with a rare gift to be equally comfortable speaking with researchers and physicians as he was at taking time to talk with a complete stranger about the problems they may be having with their current medications.

Steve's wisdom and compassion touched many lives. Many of you reading this magazine are healthier today because of his commitment to making the complex world of HIV a little easier to understand...and hopefully, not quite so overwhelming and frightening. I miss him a great deal and the community lost a true champion of its cause.

Positively Aware has maintained a vital voice in the HIV community by being the voice of all people living with the disease. Congratulations on the last 10 years helping everyone affected by HIV live healthier lives. Keep up the important work! ☒

To Die For

by Jim Pickett

Confronting my own mortality is the hardest thing being positive has thrown at me.

Well-meaning people will say, well, any one of us can get hit by that ubiquitous bus at any time. None of us is guaranteed the next day, the next minute, the next second—regardless of serostatus. We all live, we all die. That is very true. But the day I tested positive for the virus that causes AIDS, a little over five years ago, I was forced to contemplate my own death in a way that I never had before. No longer was it an abstraction. It was very real to me, and very frightening.

And frankly, the chances of me dying due to AIDS is greater than my chances of getting hit by a bus, or being gunned down in a drive-by. Let's be honest.

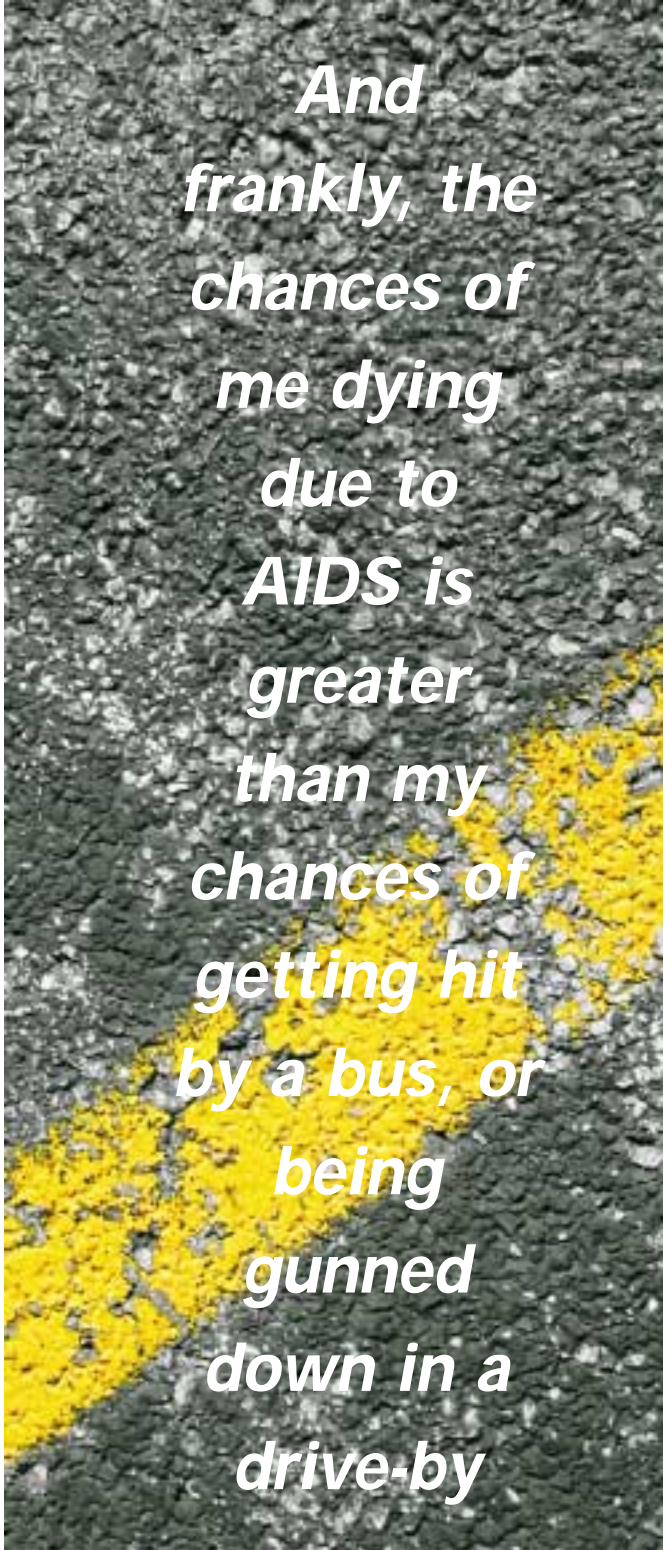
Before I was infected, I was able to operate under a very comfortable layer of denial and invincibility. I could deal with dying in my eighties or beyond. A long, long time from now. Not now. Not anymore. Death is all up in my face—despite being “healthy.”

But a problem I have is that no one wants to talk about it. We're doing better than the earlier days of the epidemic. The “crisis is over.” More and more we're “living with AIDS,” thriving even, rather than dying. “AIDS is manageable.” Or so we'd like to believe, we need to believe.

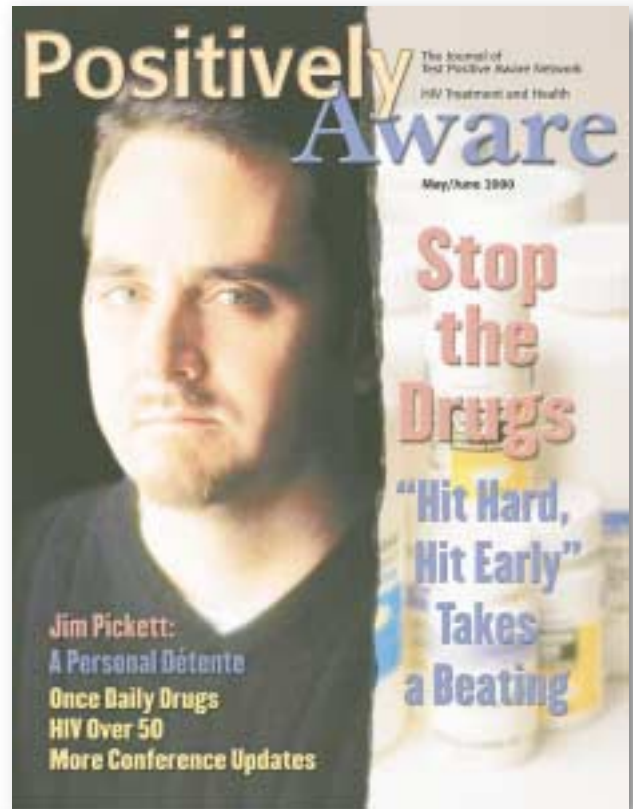
Yet, we are still dying. That's not negative or pessimistic or a drama queen's sniff. We are still being taken out in obscene ways at obscenely young ages. When long-time activist and writer Stephen Gendin died this past summer it really hit me... again. He was in his early thirties, had been at the front lines of treatment forever, and had kicked up a lot of shit over the years. He was funny and provocative. I never knew him personally but admired him—his honesty and his work.

He did not get hit by a bus. His death slapped me back into reality. News flash—AIDS will kill you, and could very well kill me. I'm scared. I don't want to die.

I've dealt with my fears over these past few years by writing. I write about my own experience and I try to laugh at it, make it into something funny and ridiculous, which it often is. Give me three snaps in + formation. Okay? Sassy! I express sarcasm and rage, disappointment and ennui. I scream and yell, giggle, snicker, guffaw and carry on. Writing about it in all its lack of glory has removed me from it in a way. The process protects me, takes it outside of myself. Yet...I know it is a cover for my feelings of helplessness and terror and mortal dread.



And
frankly, the
chances of
me dying
due to
AIDS is
greater
than my
chances of
getting hit
by a bus, or
being
gunned
down in a
drive-by



Because I'm scared and I don't want to die. Does anybody?

I am afraid of dying alone. What's more, I am afraid of dying with people around me. I do not want anyone to see me all a mess. I don't want anyone to wipe my ass. I don't want anyone to feed me. I don't want anyone to see me broken and beaten. I don't want to be gross. I don't want to be a burden. I don't want to be weak and pathetic. I don't want to die, I don't want to!

I don't want to be alone, I don't want to be with people—a bit of problem. I will not be pleased!

PBS recently ran a fantastic series by Bill Moyers called “On Our Own Terms.” It sensitively and beautifully explored end-of-life issues with terminal patients. Issues like palliative care, hospice, hastened death, the physical, emotional, and spiritual components of dying, the financial aspects, and how we as a society can do it all better. We know how to keep people alive, “cure” them, but we don't have a real good handle on helping people to die, which, after all, is a defining experience of the human condition. We don't know how to help people die peacefully and with dignity. Dying is seen as a failure. A scary, awful failure.

Each night the series ran, I cried, and I cried hard. It was painful and extraordinarily difficult to watch, as much as it was lovely, and absolutely necessary to watch. It made me realize I need to think about how I want to die before I get to that point, before I am in a crisis and can't think about it clearly.

After the second night's installment ended I was bawling—from the stories portrayed, and for myself. So I called my ex-lover in Washington, DC in mid-sob. We had ended our relationship as boyfriends a month previous, and I was still grieving, am still grieving, the end of that phase of our connection. But I felt like he was the only one who I could stomach thinking of being around me at my worst, the only one who I wouldn't be ashamed and horrified to see me at my worst. I asked him if he would still be there for me when I get sick, when I get *really* sick, when I need someone to take care of me, when I'm a pathetic, weak mess and can't wipe my own ass.

“Of course, Jim. I will be there for you...I want to be.”

I cried some more, from the relief his warm and open heart gave me, from the thankfulness welling inside me. Dying is never easy or pretty, but knowing someone will walk beside you through the process makes it transcendental.

Not that I am unafraid, but maybe just a little less. +



Lipodystrophy Review

by Bob Munk, Ph.D.

Three years ago, *Positively Aware* was the first treatment magazine to publish an article on lipodystrophy. Back then it was called Crix-belly. People with HIV were very disturbed by unexplained changes in their body shape. Researchers disagreed on how frequently these symptoms were being seen, whether they were linked or separate, and what might cause them.

Fast-forward to today. The body shape changes are still occurring. From a few scattered reports at major research conferences three years ago, we now have entire conference tracks, and even an international conference in its second year devoted to metabolic side effects of HIV medications.

What are we dealing with?

In some ways, we haven't made much progress at all. There is still no accepted definition for the syndrome (or syndromes). Without a definition, there are no standard measurements. Some studies still use patient self-report to define lipodystrophy. In a recent talk, Dr. Donald Kotler of New York summed up the problem, saying, "we may not know how to define it, but we certainly know it when we see it." Problem is, not every patient who has "it" looks the same. Some people have both metabolic changes (increases in the levels of blood sugar, cholesterol and triglycerides) and morphologic (body shape) changes including loss of fat from arms, legs, buttocks and cheeks and fat gain in the belly, breasts, or behind the neck. Others have just one type or the other. Women and men seem to have a different mix of symptoms. Women are more likely to report fat gain, and men are more likely to show fat loss and increases in cholesterol and triglycerides.

Without a standard definition, it's difficult to know how many people are affected. Estimates of the prevalence of lipodystrophy have ranged from a low of 2% to a high of 83% of patients studied. More recent studies, including several large studies, identify rates of lipodystrophy that cluster around the range of 40% to 50% of patients.

"At least people now generally believe lipodystrophy exists. We're through the denial and anger, despite some intense skepticism on the part of various players."

Researchers don't even agree on what to call the syndrome. The term "lipodystrophy" has been used as a catch-all to cover both metabolic and morphologic changes. Some people call it fat redistribution, which implies that body fat is actually moving from one location to another—and there is no evidence that this is happening. Diabetes seemed to be a major problem three years ago when the FDA issued a warning that protease inhibitors could cause it, but later research has not supported this risk. However, lipodystrophy is associated with insulin resistance, the decreased

ability of insulin to move sugar from the blood into the cells. Possibly related symptoms include dry skin, brittle hair, and ingrown toenails. During the last three years, the list has gotten longer, with reports of heart disease, osteoporosis and even partial bone death that might be related to the syndrome.

For patients, the psychological impact of body shape changes can be serious. Many people with HIV worry that once again there is a "look" that identifies them in public as having AIDS. Case managers at several large AIDS service organizations report that clients are stopping their antiviral therapies because of body shape changes, or are refusing even to start taking them for fear of these side effects.

What causes it?

Three years ago, researchers were focusing on protease inhibitors and particularly on Crixivan (indinavir) as causing lipodystrophy, despite published reports of metabolic and morphologic changes in people who had never used protease inhibitors. Today, it seems clear that no one drug or class of drugs is to blame for lipodystrophy. In fact, data from one study, the HOPS cohort, showed that several non-drug cofactors, including age, duration of HIV infection, degree of immune recovery, baseline body mass index (BMI), gender, and white race, are highly associated with lipodystrophy.

Kotler warns us against reading too much into associations between individual drugs and lipodystrophy. He notes that both Crixivan and Zerit (d4T) were in wide use at the time that much of our current data was collected, and could just be "catching the blame" if, for

example, total time on medications is really the culprit.

On the other hand, different drugs may well contribute to various aspects of the syndrome. Norvir (ritonavir) was studied in HIV-negative patients, and within two weeks, they showed significant increases in cholesterol and triglycerides.

The fact that lipodystrophy tends to show up in people who are successfully controlling the virus led Kotler to suggest that the syndrome might somehow be due to improvement of the immune system. Little work has been done on this concept, although the degree of immune restoration has continued to show an association with body shape changes.

Dr. Andrew Carr and his research group in Sydney, Australia proposed that lipodystrophy might be caused by protease inhibitor molecules binding to two proteins involved with fat transport and metabolism: the Lipoprotein Receptor Protein (LRP) and Cis-Retinoic Acid Binding Protein type 1 (CRABP-1). However, there is not yet a lot of data to support this proposal.

Another hypothesis that has gotten a lot of attention was proposed last year by Dr. Kees Brinkman of Amsterdam. He believes that the nucleoside analog drugs may be causing many of the lipodystrophy symptoms because of their known ability to interfere with mitochondria, small structures within our cells that produce energy. Mitochondrial toxicity can result in peripheral neuropathy, myopathy, pancreatitis, lactic acidosis (high blood levels of lactic acid) and hepatic steatosis (fatty liver). Many researchers are trying to confirm the mitochondrial toxicity hypothesis. This may be a difficult challenge: a recent meeting of experts agreed that mitochondrial toxicity can cause a wide range of problems, but none of them include fat wasting.

Other factors have been suggested for research, including environmental factors such as the patient's diet and nutri-

Lipo lowdown

by Enid Vázquez

It's fat, it's thin, it's thick—it's lipodystrophy. Fat on the stomach, breasts and back; thinness in the face, arms and legs; and thickening fat in the blood (not to mention cholesterol). Doctors no longer doubt that these changes result at least in part from HIV therapy. Why and how they come about is the question. Their exact impact on developing heart disease is also unknown. The following comes from abstracts (research summaries) published by the 40th Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC).

- Spanish researchers found more lipodystrophy among people using protease inhibitors (56%) than in people using only nucleosides (39.4%). However, fat wasting (thin arms and legs) was more frequent in the group taking only nukes (52.5% vs. 35.5% for the PI group). The nukes include drugs like AZT and Videx. The results came from 443 people throughout Spain.
- Some of the same Spanish researchers found significantly more lipodystrophy in people using Zerit than in those using AZT (Retrovir). None of the people had taken protease inhibitors.
- Italian researchers noted a greater risk of lipodystrophy with longer time on therapy, older age, being a woman, and maximum therapy (4 drugs vs. 3 vs. 2 vs. 1/none). They looked at 2,258 people, 44% of whom were taking protease inhibitors.
- A Beverly Hills clinic took a close look at the HIV positive patients who came in during a one week period. They found that half of the 141 people had body fat changes. Of this group, three-thirds had facial wasting. Increased risk of lipodystrophy was found with an AIDS diagnosis, longer time on therapy, and Zerit use. In an attempt to reverse these abnormalities, a third of the group chose to change their combination to one that doesn't include a protease inhibitor.
- A U.S. look at how different drug combinations affect people found similar results as the Spanish group. In the CHORUS observational study of more than 4,000 people, those taking protease inhibitors were more likely to experience lipodystrophy. Risk factors again included older age, an AIDS diagnosis, and use of Zerit. For example, there were significantly higher numbers of people with lipodystrophy among those taking Crixivan with Zerit/Epivir than among those taking Crixivan with Retrovir/Epivir.
- German doctors looked at people who started HIV meds at the same time. After three years, a third of the 221 people had some type of

continued on page 42

tional status, and genetic factors that might make some people more likely to develop lipodystrophy.

Can lipodystrophy be treated?

Three years ago, there were no suggestions for people with lipodystrophy. We still have no clear way to treat the syn-

drome, although there are several ways to deal with individual symptoms. The first treatment was to switch drugs, avoiding Crixivan or all protease inhibitors, and more recently switching away from Zerit. Results of these studies have been inconclusive. Switching off of protease inhibitors generally leads to lower blood cholesterol and triglycerides, but body shape changes have shown little or no improvement in studies lasting up to a year.

Fat gain: Exercise and diet are the first-line approaches to dealing with abdominal fat gain. Testosterone may help, especially in men whose levels are subnormal. Human growth hormone (Serostim) has been shown to reduce abdominal fat and buffalo humps, but the drug is extremely expensive, has unpleasant side effects, and may actually increase the loss of fat in arms and legs. Researchers also report that the high dosages used for treating wasting are too high for treating lipodystrophy. Liposuction is not an option for internal abdominal fat, but only for subcutaneous fat. Some patients have also used liposuction or surgical removal for buffalo humps, and in a few cases, the humps have returned. Rubbing testosterone cream or using a patch on humps has helped decrease them, according to individual reports.

Fat loss: We know the least about how to deal with the loss of subcutaneous fat. Patients who can afford it are using plastic surgery or injections to fill in their sunken cheeks. No therapy has yet been shown to restore subcutaneous fat in the arms and legs.

High cholesterol and triglycerides: Removing protease inhibitors from your antiviral regimen can result in lower cholesterol and triglycerides. Before changing your regimen, you may want to apply the standard treatments for high blood lipids from the National Cholesterol Education Program (NCEP) Guidelines (see www.americanheart.org/Heart_and_Stroke_A_Z_Guide/ncep.html). The first line of treatment involves diet. If the diet options are not effective by themselves, then exercise, smoking ces-

sation, and weight loss for obesity should all be tried. If that's not enough, there are medications.

The standard cholesterol-lowering drugs, the "statins," interact with protease inhibitors through the cytochrome P450 liver pathway. This can cause excessive blood levels of the statins. These interactions appear least serious with pravastatin (Pravachol) and atorvastatin (Lipitor), although not all drugs in this class have been tested yet. Another class of drugs, the fibrates (Lopid and Tricor), are effective in lowering triglycerides. Although niacin is sometimes used to lower cholesterol, it can also increase insulin resistance.

High blood sugar or insulin resistance: It's important to note that insulin resistance can occur even when blood sugar levels are normal. Insulin resistance is a known risk factor for heart disease and diabetes. The first responses to insulin resistance should be to increase physical activity, stop smoking, reduce obesity, and reduce high blood pressure. Preliminary studies suggest that Glucophage, a drug used to treat diabetes, can reduce weight, blood pressure, and abdominal fat in people with lipodystrophy. However, it can also cause lactic acidosis, so it should be used with caution.

Mitochondrial toxicity: The mitochondrial toxicity hypothesis has yet to be proven, but some patients are trying to prevent it by using supplements of elements that the mitochondria use to produce energy. These include riboflavin (vitamin B2), coenzyme Q10, L-carnitine or L-acetyl carnitine, and the vitamins B1 (thiamine), B12, and K.

The state of the art

Some things haven't changed. There are still many physicians who consider body shape changes to be nothing more than a cosmetic concern, and are so focused on viral loads and T-cell counts that they don't adequately deal with other health issues such as cardiac risk factors and diabetes. Very few clinics routinely perform bioelectric impedance analysis (BIA—see page 21) to track overall body

composition, and even fewer are equipped to perform CAT scans, MRI scans, or dual x-ray absorptiometry (DEXA) studies that can measure regional body composition and differentiate, for example, fat gain in the abdomen from fat loss in the arms and legs.

Major research efforts are underway, including reviews of historical data looking for evidence of symptoms of lipodystrophy and prospective studies that will follow large numbers of people as they begin taking antiviral therapy. A collaborative group is defining an ideal set of data to collect for monitoring metabolic and morphologic changes. An international study has the goal of developing a standardized definition of the syndrome. Unfortunately, we will have to wait several years for results from some of these efforts.

Where does that leave us? Carr sums it up this way: "At least people now generally believe lipodystrophy exists. It's kind of like the Kübler-Ross stages of dealing with death. We're through the denial and anger, despite some intense skepticism on the part of various players. Now we're down to serious pathogenesis, getting a better handle on risk factors. We still don't have a clue about what to do about it, but it has become a factor in when and how to treat. We've gone from 11 posters three years ago to an international meeting with 400 people. That says it all."

Grunfeld feels that metabolic issues "have to be part of any treatment decision. HIV treatment probably should start when there is a high risk of damage to the immune system, instead of when CD4 counts hit some magic number. Ideally, HIV docs will pay more attention to cardiovascular risk factors for all of their patients and treat them appropriately. They will balance the antiviral value of each drug against its potential for causing metabolic or fat redistribution problems. I don't think it will be too long before we can recommend an initial HAART regimen that won't cause too much trouble."

We all hope so. ☛

lipodystrophy. The study noted two risk factors: ever having had less than 200 T-cells and using Zerit for more than a year. The use of a non-nucleoside (Rescriptor, Sustiva or Viramune) combination for more than a year, without a protease inhibitor, was found to lower risk of lipodystrophy, but protease inhibitor use itself was not found to be related one way or another.

- On the other hand, contrary to most of the research above was another group of doctors from Spain who reported no difference in lipodystrophy between people taking Zerit or those taking AZT. (HIV drug therapy generally includes one of these two agents, but never both.) They looked at 98 people, 23 of whom had taken AZT at some point. Blood levels of sugar, insulin, cholesterol, etc., as well as body changes were examined.
- Canadian doctors also reported no effect from protease inhibitors. They looked at the relationship between body fat changes and insulin resistance in what they call “HIV/HAART associated lipodystrophy,” or HAL. (HAART stands for highly active anti-retroviral therapy.) A high level of sugar in the blood indicates insulin resistance, when the body doesn’t use insulin well (in fact, resists it) and therefore can’t control sugar levels. Impaired glucose tolerance (in other words, impaired ability of the body to use up sugar) is often seen with insulin resistance; fasting blood sugar or single glucose check may not expose the existence of insulin resistance in many individuals, unless a glucose tolerance test is done. This in turn can be associated with other metabolic changes that may include excess of fat around the middle, something long seen in HIV-negative people, especially with certain diseases, such as alcoholism.
- Of 62 men with either fat wasting or fat gain, 26 had the wasting and 36 had both. As for insulin resistance, it was found to be associated with increases of both fat depletion and fat accumulation. The researchers noted that this shows certain predispositions to lipodystrophy among some people, despite receiving treatment similar to others who don’t suffer from it.
- The COMBINE study comparing Viracept to Viramune found significantly higher levels of total cholesterol and LDL cholesterol (the “bad” kind) along with a decrease in HDL cholesterol (the “good” kind, which you don’t want to drop) among the people taking Viracept. This was after six months. No body differences were seen. The researchers reported that their “preliminary data suggests a trend to a more atherogenic (causing artery damage) lipid profile in those treated with [Viracept] compared to patients on [Viramune].”
- Because the nutritional supplement L-carnitine is often mentioned in HIV community groups for fighting lipodystrophy, German doctors set out to test its effect. They gave 1,000 mg twice a day to 12 men with HIV-associated lipodystrophy. All of them had central fat with wasting in the face, arms, legs and butt. There was no improvement after 12 weeks, but total cholesterol levels dropped significantly, from around 250 to around 219 (still in the danger zone, but better controlled). LDL also dropped significantly, from 177 to 132. There was no change in HDL or triglycerides. This is great news for cholesterol, but not necessarily the death-nell for lipodystrophy, since supplements often take a long time to show a beneficial effect.
- Italian researchers examined the role of nucleosides in lipodystrophy by starting 335 people on dual nukes in 1998 (doesn’t seem ethical in the era of triple combination therapy). Increased risk of high levels of triglycerides (fat in the blood) was associated with use of Zerit (vs. AZT) and also with therapy lasting more than a year. Risk of high levels of cholesterol was associated with more than a year on therapy, while excess blood sugar (hyperglycemia) was associated with age. Men tended to have more blood level changes than did women, but the difference was not statistically significant. But women were significantly more likely to experience body fat changes. Lastly, the risk of blood lipid changes was not higher in those people with body fat changes.
- Then again, Chicago doctors did a chart review that found no relationship between therapy and high triglycerides. “Based on this retrospective analysis in our population, the predominant hypotheses that hypertriglyceridemia is primarily associated with antiretroviral drugs may be overly simplistic,” they reported. Nevertheless, those people with increased tri’s were more likely to be older, have HIV longer and have a lower nadir T-cell count (their lowest point) than the control group with normal levels. ☒

Notes from ICAAC

By Charles E. Clifton and Enid Vázquez

Following are some of the HIV highlights from the 40th Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC), organized by the American Society for Microbiology, held this past September in Toronto.

Sustiva vs. Viramune

In head-to-head competition, the two drugs did just as well at lowering viral load. Unfortunately, these were early results from a small group of 50 people. "At the last visit" (anywhere from six to 14 months), 76% of the Viramune group and 80% of the Sustiva group had a viral load of less than 50.

Sustiva received well-earned fame in 1998 when it beat out the then-gold standard HIV combo of Crixivan, AZT and Efavirenz. It did well even in people with a high viral load, more than 100,000. The thrill behind this well-conducted study is that Sustiva (as well as Viramune) are in an HIV class of drugs, the non-nucleoside analogs, that was considered to be less potent than protease inhibitors like Crixivan. The once-a-day Sustiva has continued to do well since then.

But Viramune is an older non-nucleoside that while popular, just wasn't studied at a time of advanced HIV knowledge that newer drugs like Sustiva were able to benefit from. A big question in HIV therapy has been whether or not Viramune is as potent as Sustiva.

The two drugs have already both been shown to be equivalent or even superior to Viracept protease inhibitor. Viramune worked just as well as Viracept even in people who started therapy with a viral load above 100,000 (although these results are only as of 24 weeks, which is preliminary). At this conference, one study showed that they were also able to keep viral load undetectable in a vast majority of people switching from a protease inhibitor (not new information, but always good to confirm with more recent data).

Pump up those T-cells

A group of researchers from the National Centre in HIV Epidemiology and Clinical Research, Sydney, Australia, reported that "the greatest response to antiretroviral therapy in patients with long-term suppression of viral replication appears to occur early after treatment is started, with smaller

increases in CD4 cell counts seen later in the course of treatment." In a study of 63 participants, the greatest increase in CD4 cell count was observed during the first three months of treatment. Two-thirds of these patients reached "normal" CD4 cell counts (greater than 500 cells) after two to three years of highly active antiretroviral therapy (HAART).

Treat me right

Results of the DPC-006 study at Chelsea and Westminster Hospitals, London, England indicate that current treatment guidelines recommending a viral load less than 50 copies at 24 weeks is most realistic in individuals with baseline HIV levels below 100,000 copies to begin with. Individuals with an initial viral load above 100,000 copies were found to require at least 36 weeks before a viral load of less than 50 copies was achieved. This was a study of mainly treatment naïve persons. One group of 157 people was randomly treated with AZT + Efavirenz (3TC) + Sustiva (efavirenz).

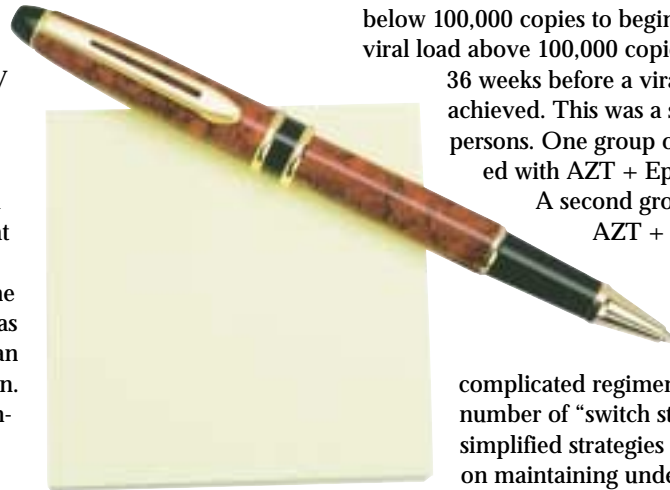
A second group of 96 people was treated with AZT + Efavirenz + Crixivan (indinavir).

I'd rather fight than switch

Community concerns about the toxic side effects and complicated regimens of therapy has encouraged a number of "switch studies" to deliver alternative and simplified strategies to treat HIV, with an emphasis on maintaining undetectable viral loads and avoiding or reversing adverse side effects.

Preliminary data from switch studies reveals that for most individuals a switch in therapeutic regimens does not result in a viral load increase. To date, the majority of ongoing switch studies involve protease inhibitors (PIs), since they seem to be responsible for most of the toxicities, and nucleoside reverse transcriptase inhibitors (NRTIs), due to the metabolic side effects recently acknowledged.

Results from early studies indicate that the metabolic irregularities are often reversible upon switching from a PI to a non-nucleoside RTI (NNRTI) or to a third NRTI (often Ziagen). In addition, reductions in triglyceride levels and insulin resistance were also observed. The effects on cholesterol differed depending on which drugs were used. Cholesterol levels remain high with Sustiva. The discontinuation of a PI did not have a significant effect on the reversal of or improvement in fat redistribution, although an improvement in lipoatrophy (thinning) was noted in a small study in which an alternative NRTI was substituted for Zidovudine (d4T).



Examples of switch studies:

- A study of patients on a successful PI-containing HAART to a more simple triple NRTI regimen; patient's viral load was below 50 copies for 6 months or more prior to switch with no 215 resistance mutation at baseline; patients in the 48 week study were switched to Ziagen (abacavir) (300 mg twice a day) + Combivir (150 mg Efavir + 300 mg Retrovir, twice a day). This study revealed a slight increased risk of viral load failure in a simplified therapy (11 of 84 participants), as opposed to the group continuing with PIs (5 of 79). However, the viral increase in the switch group was observed in patients with prior mono or dual therapy prior to HAART.
- Results of a 24 week study on 207 patients (mean age 41 years, 91% male, 70% white, 20% black, 8% Hispanic and 2% other); Sustiva 600 mg was substituted for PI, where all nucleosides were maintained; viral load was successfully maintained at less than 50 copies and a minimum increase in CD4 cells (medium change +40) was observed up to 24 weeks.

All individuals considering switching their regimens should carefully discuss all medical treatments and products with a physician. This can not be over emphasized. Each individual should have her or his treatment history carefully assessed for detection of resistance or intolerance before switching. ☒



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White Girls Don't Get AIDS

by Laura Jones

"In 1998, the most common cause of AIDS among women was heterosexual exposure to HIV, followed by the use of injection drugs. A large percentage of women who became infected heterosexually did so through sexual contact with injection-drug users. For this reason, reducing the HIV infection rate among women will require combating substance abuse as well as reducing HIV risk behaviors." *HIV Frontline*, Issue 40, Jul/Aug 2000.

Last time I checked, the Centers for Disease Control estimated that there were between 120,000 and 160,000 women and adolescent girls in the United States living with HIV infection, including those who already had an AIDS diagnosis. From 1985 to 1998, the proportion of reported AIDS cases in women and adolescent girls rose from 7% to 23%. 77% of these reported AIDS cases are in African American and Latina women and girls, who account for less than 25% of the U.S. female population.

These figures are unacceptable.

But what is also unacceptable are the numbers that are missing—namely the other 75% of the female population, who I'll wager aren't doing so well either, but don't know it yet. Remember: if you don't get tested, you don't know you have HIV. If you don't think you can get HIV, you don't get tested. Counties with low numbers of actual diagnosed AIDS cases are not necessarily counties with low rates of HIV infection—they're just counties that have fewer reasons for pulling their heads out of the sand.

Given the state of health in sub-Saharan Africa, Southeast Asia, and U.S. minority communities, I'm not expecting anyone to open a vein and bleed for the plight of white suburbia (though I do think more blood, and certainly more money, should be shed for Americans of all ages and races living in economically-depressed rural areas). Money alone will not change the high level of denial that saturates suburban and small-town culture. It won't stop the emphasis on keeping up "respectable appearances," to not behave like "trash," that prevents open communication and dissemination of much-needed educational materials. Some outer-city people may have more financial resources at their disposal, but that doesn't mean they're pouring it into HIV/AIDS prevention and health services; it certainly doesn't mean they're any less mired in the cultural propaganda that continuously reinforces the notion that HIV/AIDS is something that happens to "other people."

Let me illustrate with a story:

In 1994, I left the Twin Cities—one of the nation's bastions of liberal niceness, with state-sponsored health coverage, an excellent

network of community clinics, and one of the highest literacy rates in the United States. I left for a lot of reasons, but a big one was the need to get away from a drug scene that was rapidly consuming way too many of my peers. I'd moved there from Sioux Falls, South Dakota in 1988, and started doing sexual health activism in 1990. From then until the time I left, my social group consisted largely of people like me: middle-class or rural working-class young folk with at least a high-school diploma and the opportunity to go to college; people between the ages of 15 and 27 who had come to Minneapolis and St. Paul from mid-western suburbs, small towns and farms. We weren't all white, but those of us who were not were often uncomfortably "white-

Remember: if you don't get tested,
you don't know you have HIV.
If you don't think you can get HIV,
you don't get tested.

identified"—Koreans and Vietnamese adopted as children by white parents, black youth who had grown up in mostly-white towns, and others of mixed ethnicities who felt excluded by their racial communities. Injection drugs—primarily heroin, but also methamphetamine and cocaine—

were all the rage at the time, and while the "scene" definitely supported such self-destructive activities, drug use in general was new to only a few of us. People looking for an escape valve without leaving their neighborhood will choose the same options in outer-city areas as they will in the inner city. My friends got high a lot in the late '80s and first half of the '90s, more and more often via the needle.

Oh yeah—we had sex a lot, too. That was easy, and our crowd was right-on with same-sex experiences as well. Not that most of us waited on that before we got to the Big City either. For example, there was a very popular telephone pole in downtown Sioux Falls where the interstate truckers and other men of any age could post their sexual-partner requests, complete with meeting times and places. Less sophisticated than the options in larger cities, true; but my male friends who knew they were queer didn't have to wait until they were 18 and living elsewhere, and most of them didn't. Neither did us breeder kids, as the teen pregnancy rate did show.

How many HIV/AIDS outreach programs do you think were targeting smalltown women between the ages of 15 and 27 in the early 1990's? Mainstream America had only decided to worry about AIDS in 1985—do you think we heard about HIV in "family life" class in places like Preston, Iowa and Allouez, Michigan? In particular, how many I.V. drug intervention programs do think targeted that demographic at that time?

How many are targeting them today?

In 1988, I graduated from high school. In 1990, the city of Sioux Falls finally overcame community opposition long enough to build a Planned Parenthood. *Positively Aware* got started the same year residents of the largest city in South Dakota gained access to birth control methods from somewhere other than their family doctor's prescription pad.

Need I say more?

Even though most people nowadays acknowledge that women of all ages and backgrounds have sex, there's still a lot of ignorance surrounding the high level of I.V. drug use among women in general, and among certain women's partners. This was certainly true of my demographic, even though many of us—or the people we dated—were in bands where the popular look was pale, lanky, androgynous and sleepy. Boys and girls so bony you wanted to drag them offstage and feed them nourishing soups, if they could stay awake long enough to eat them. My own long-term boyfriend was in one of those bands, though they were definitely more healthy-looking than most of their colleagues. He was also a bartender in one of the most popular music venues in town, with constant access to all the perks of said job: women,

men, drugs, totally justifiable reasons for rolling home in the wee morning hours long after I'd gone to bed, etc. We'd been together so long that we didn't use condoms anymore.

My gut rolls over when I think of how much trust I placed in him—trust that fortunately was merited (either that or he really read all those outreach pamphlets I kept stacked in his storage cabinet). Many, many women I know weren't that lucky.

Women weren't lucky in other ways, too. Our gay friends knew and believed that safe sex was hot sex (they'd seen that unsafe sex could leave you permanently cold), but in the early '90s you didn't even hear much about women and AIDS. If you did, the women you heard about were generally "drug addicts," "homeless," or "prostitutes"—which we were not, since A) we only used drugs sometimes, and B) we just had sex with the friends and friends-of-friends who let us sleep on their couches and eat their food when we were between jobs or too young to get an apartment. We didn't do it for actual money; we weren't hookers or anything. Anyway, we weren't going to get AIDS because we came from towns, farm counties, and suburbs, not big places like New York City. Oh, we knew we could get it—in theory. But it didn't really sink in for a lot of us. And my girlfriends were no more skilled than any other young women in negotiating condom use with partners, despite our high literacy rate and liberal politics. We could easily get our hands on a copy of "Our Bodies, Ourselves"—and that access to information is, unfortunately, still a privilege—but that alone didn't mean we were empowered enough to put what we read into practice. I personally saw all too many of my friends and acquaintances use and abuse the Unclean Way, and based on the number of times I supported women friends during home pregnancy tests and gave STD tutorials and referrals to the area's excellent low-cost clinics, I can say quite honestly that there was safer-sex Trouble in our own little River City.

But most of us were, you know, white. And everyone knows white girls don't get HIV.

We were morons, is what we were. But we didn't have too many people telling us otherwise—just like women today. In fact, a lot of healthcare providers are more than happy to reinforce these stereotypes for us. I know plenty of young women who have been told by their doctor, gynecologist, or pre-natal care provider that they're "not at risk" for HIV, as though because they're white women who've had a few college-level courses they do nothing in the sack but discuss "Beowulf" with their always-monogamous, always-hetero, always-straightedge lover (note the singular form: "nice" girls may have sex now, but we still never have more than one partner at a time. We never do



drugs either, and we certainly never shoot up or let our boyfriends shoot us up with communal syringes at after-hours parties. But you knew that already). I know plenty of young women who “confessed” to fictitious high-risk activities during pre-test counseling because they’d been denied HIV tests so often that they knew lying was the fastest—and sometimes only—way to get one. From what I hear, this is still as true in 2000 as it was in 1990. People from my background are always more than happy to believe that the people they think are the least like them are definitely at risk for all sorts of things, including HIV and AIDS. When I visited my mother’s family in downstate Illinois this summer, for example, they were so pleased to hear that I’m doing “good work” for the “underserved” in the big city. They’d never heard of the state STD and HIV hotline I work for, nor apparently did they consider southern Illinois “underserved,” even though any of them would have had to travel two counties over to get services if they were HIV positive, or even had an embarrassing infection.

As a friend of mine said recently, “If 50% of youth live in large cities, where do you think the other 50% live?” I can tell you this: they do not live in places that provide them with the health information and services they need, especially when it comes to HIV.

It’s true that many outer-city kids lead comparatively more privileged lives than most inner city youth (though not all do, especially youth from rural boom-and-bust economic regions). Unfortunately, their “privileges” also include ignorance and isolation, along with hefty doses of culturally-endorsed denial.

The risk factors my friends and I engaged in 10 years ago haven’t dissipated; if anything, they’ve increased. What hasn’t increased during that time are services for non-city people with HIV/AIDS, or prevention services for the next generation of rural and near rural kids. There’s no needle exchange in Decatur, Illinois. There’s no young-injectors HIV/AIDS awareness campaign in Clancy, Montana (heck, there’s none in Chicago, either). And now that we all know abstinence-only sex ed programs are the greatest things since sliced bread and we can rest assured that all America’s youth won’t even think about having sex until their mutually heterosexual life-long monoga-

mous marriages take place, there’s really no need to even talk about these “issues” anymore, is there?

No, they’ll just do what everyone before them has done: become infected, and then infect others before they get into rehab or fall sick and find out why. Because everyone knows AIDS only hap-

pens to gay men. Or inner city Black and Latino women. Or those “backwards” people in Africa and Thailand. Or anywhere else but “here.”

I’m not in touch with most of my old crowd anymore. Most of them are on the West Coast now—Seattle, Portland, San Francisco—and hopefully they’re doing better out there than they were the last time I saw them. The ones I know of from the grapevine have mostly gone through rehab or overdosed; there are quite a few successful rehab stories, which is a great blessing. The one good friend I still know from that time tested negative for HIV,

though she lost most of her cervix to aggressive treatment for early cervical cancer at the age of 31 (we didn’t hear much about HPV or other STDs either). The old “scene” seems to have quieted down as well, or maybe it just migrated west with a lot of the scenesters.

Or maybe I’m just out of the loop now, and it’s the same as it was a decade ago.

Because I don’t know where they are, I don’t honestly know how many of the Old Crowd came up HIV positive. Maybe the numbers are as small as we’re led to believe. Maybe there weren’t enough of us infected at that time to spread HIV within our circle of friends. Maybe our communities were more insulated than we thought, or more of us adapted our behavior before things got really bad. Maybe we did get lucky. If not, those of us who never felt the need to test should start figuring that out any day now, given that 8-to-10-year incubation period. All I can say is we were definitely “high-risk,” despite our age, race, gender and background.

We were so much like women and girls today, coming from the same backgrounds, the same suburbs and small towns, and the same experiences.

Again: Need I say more? ☩

I know plenty of young women who “confessed” to fictitious high-risk activities during pre-test counseling because they’d been denied HIV tests so often that they knew lying was the fastest—and sometimes only—way to get one.