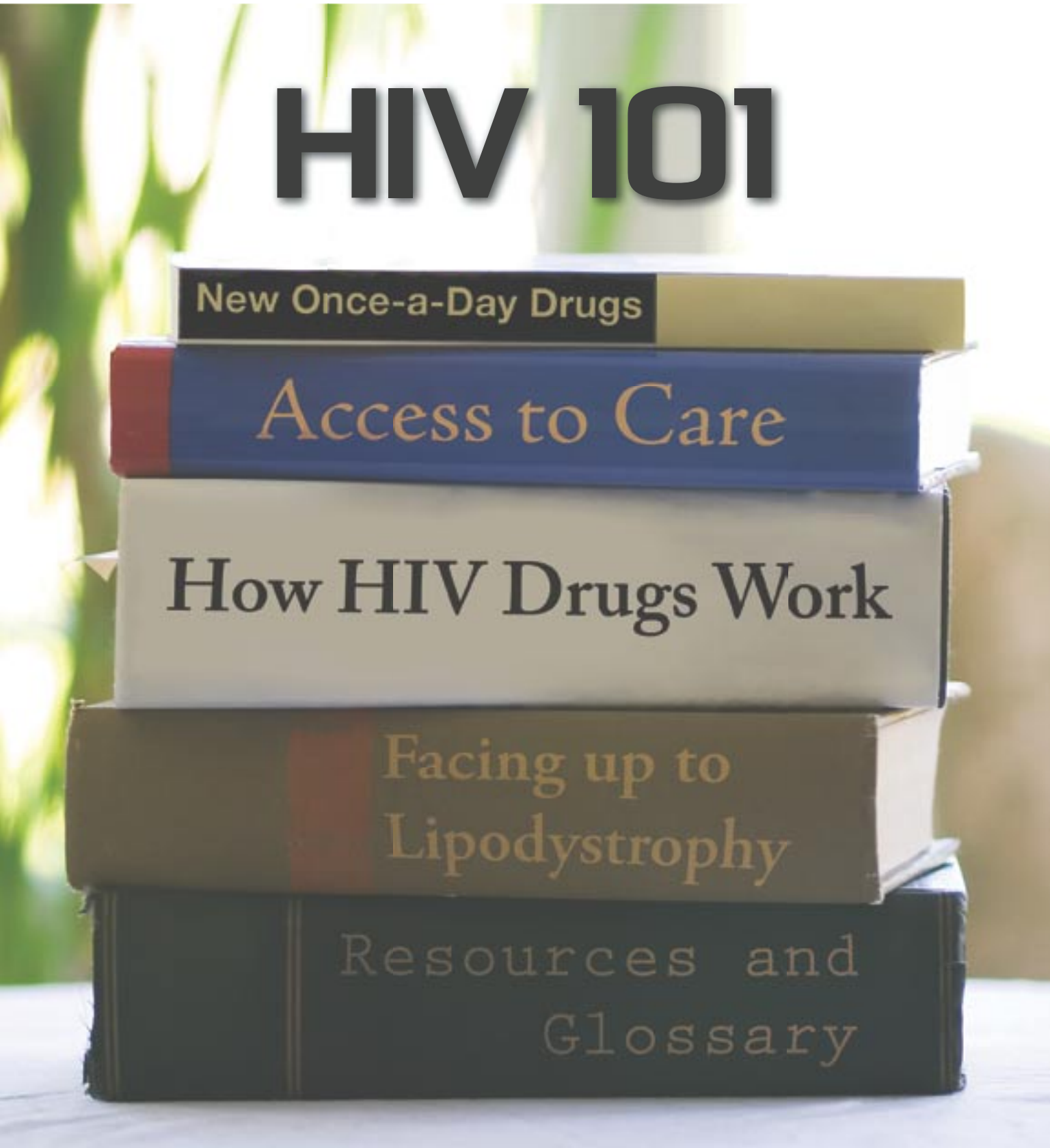
November / December 2004

Positively Aware

The Journal of Test Positive Aware Network

HIV 101



Truvada
Ad
Page
Here

Truvada
Ad
Page
Here

Truvada

P.I.

Page

Here

Table of Contents

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

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

November / December 2004
Volume 15 Number 6

Departments

Articles

Distribution of *Positively Aware* is supported in part through grants from the AIDS Foundation of Chicago, Illinois Department of Public Health, GlaxoSmithKline and Abbott Laboratories.

Position Available: Executive Director

Test Positive Aware Network is a leading HIV-related service organization in Chicago, and the publisher of two national HIV/AIDS treatment journals, Positively Aware, and Positively Aware en Español. We are seeking a suitably qualified person to administer the agency, including program development and management, fiscal and staff management, public relations, fundraising and board relations.

Test Positive Aware Network empowers people living with HIV through peer-led programming, support services, information dissemination, and advocacy. We also provide services to the broader community to increase HIV knowledge and sensitivity, and to reduce the risk of infection. Our client base is diverse across racial, ethnic, gender, gender-identification and economic lines.

The most attractive candidates will possess a Master's degree with emphasis in social work, business or health care from an accredited institution, at least eight years experience in a social services environment, demonstrated expertise in an HIV/AIDS specialty area, and a number of years of significant supervisory and administrative responsibility in a comparatively-sized not-for-profit organization. Strong leadership, organizational, interpersonal and facilitation skills are essential.

A competitive salary and benefits package reflecting the importance and level of responsibility attached to this position will be offered.

Please submit cover letters and resumes in confidence, with full career and salary details, electronically to edsearch@tpan.com or via mail to:

Executive Director Search Committee, Test Positive Aware Network, 5537 N. Broadway Street, Chicago, IL 60640-1405. For more information about the organization and the position, visit http://www.tpan.com/edsearch.html or send an email or a letter to the addresses listed. We regret that we cannot accept inquires via telephone.

Test Positive Aware Network is an Equal Opportunity Employer and an Illinois Not-for-Profit 501(c)(3) Organization.

Thank You For Making us Stronger!

Rivendell Media has, for many years, been a great friend to *Positively Aware (PA)* publications. Many years ago, when *PA* began distributing the publication nationally, (it was originally a local newsletter distributed in Chicago) Rivendell Media came on board to represent and to sell advertising for *Positively Aware*. Rivendell has represented *Positively Aware* for many years with our valued advertisers.

Because of Rivendell's support and the continued success and growth of *Positively Aware*, we have added a Marketing and Sales Director, Danny Kopelson to the *PA* publication staff. Beginning with the January/February 2005 issue of *Positively Aware*, Danny will be managing all of our advertising sales. We welcome Danny on board and thank Todd Evans and the terrific folks at Rivendell Media for their great support over the years.

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Those Who Can, Teach

Photo © Russell McGonagle

Fourteen years ago I walked through the doors of Test Positive Aware Network scared, lonely and afraid. What I found was hope, friendship, and the tools to help me survive with HIV. Back then the meeting rooms were packed with people, wall-to-wall, standing room only, people hungry for knowledge and fellowship. AZT, Louise Hay and Co-Q 10 were the buzzwords in treatment. Combination therapy meant going to a support group with your partner. Constant reminders of sickness and death were everywhere you looked, and memorial services were all too common.

But in the midst of all that, and out of that, grew what you hold in your hands today. And this issue gets back to the basics. In order to win the fight against HIV, you must first learn everything you can about the virus to gain the upper hand. It's like going back to school. You've got to eat, live and breathe HIV. You'll need to immerse yourself in your studies. You'll want to learn enough so that you can work with your healthcare provider to design a treatment program—one that you can live with, that you can adhere to, and that works for you. If you are not currently receiving care, accessing treatment and services is half of the battle. If you live in Chicagoland, the new 2005 Chicago Area HIV Services and Professionals Directory, published by Test Positive Aware Network and funded by the Ryan White CARE Act, is a great place to start. To find out more about services where you live, visit www.tpan.com. Whether you're negative or positive, you need to protect yourself and others not only from HIV, but also from other sexually transmitted infections. And if you are suffering from lipodystrophy or peripheral neuropathy, there are now new treatments available and on the horizon.

We've fought hard to get to where we are today. Armed with the right information, we can empower ourselves to take back control, and live longer, healthier lives. Thanks to the many activists, clinical trial participants, researchers, organizations and individuals who somehow found the courage to carry on despite the odds, you and I can reap the benefits.

One of those individuals in the struggle was Charles E. Clifton. Charles, the former editor of *Positively Aware*, died suddenly and unexpectedly on August 15th. I had spoken with Charles on the phone just a few days before he died. He was home recuperating from a recent hospital stay. I explained to him that his e-mail box was full, and I asked him if he could download the e-mail onto his laptop. I told him, "You don't have to read it," and he laughed. "Don't worry, I won't,' he said. And then, a very uncharacteristic "Ouch" came out of his mouth (Charles was never one to complain). And I never asked him, "What's wrong?" After we spoke a few more words, he said, "I'll see you on Monday." And then I said goodbye. I said goodbye to someone, who more than any other person in the fourteen years that I've been associated with TPAN, was a walking, living testament to what it meant to be self-empowered. Charles led by example, his door was always open, he had a contagious laugh, and a smile that made you want to smile back. I've lost both my mother and my father, and without ever realizing it, Charles was someone who had come into my life at just the right place and time. He made me feel not alone, he had faith in me, he trusted me, and he guided me. And through his example, I became more empowered and self-confident. He had that effect on so many of us, that's why his death has been especially difficult. But I know that his life, and his work, had meaning. And that's the most anyone could ask for, and the legacy I hope to leave as well.

We now know so much more about how this virus works, and there are so many more options in treatment, that we owe it to ourselves and those who have gone on before us to learn as much as we can, to take care of ourselves and each other, and to give something back in return. By volunteering at an AIDS service organization, joining a community planning group, or simply reaching out to someone in need, you honor those who have gone before you. Take charge of your life, act responsibly and share what you learn. Yes, with knowledge comes power. But with that power comes responsibility.

Jeff Berry
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Viracept
Ad
Page
Here

Viracept
Ad
Page
Here

Viracept

P.I.

Page

Here

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. Please advise if we can use your name and city.

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Crystal meth

Just wanted to say that I was very happy and touched to read Dr. Daniel Berger's article in *Positively Aware* on crystal meth and HIV (July/August 2004). I agree that our community needs to do more on educating each other as well as our youth. I believe that his article is a step in the right direction, and I thank him.

Name withheld,
via the Internet

Dear Dr. Berger,

I read your article "Crystal Methampetamine and HIV—A Catastrophe" while I was waiting for my son, who was seeing a psychiatrist at the Howard Brown Health Center in Chicago. My son lives in Chicago and I live out-of-town. I was there for a short visit.

Your article really hit home, as my son is 40 years old, was valedictorian of his class, has a master's degree and had a great career in fitness until about a year ago when he was let go at his job. It has been downhill from there. We found out then that he was addicted to crystal and had been using it regularly for about two years. I think he was using it a few years before that. He is gay and found out about two years ago that he is HIV-positive. He only told us about being positive about 10 months ago. Last week he got a job, but when it came time to start, he had a panic attack and couldn't go through with it.

We have watched him deteriorate, going on and off the drugs, taking many pills for anxiety attacks, depression, etc. I have to say I am very angry that, being a very intelligent person who has always been loved unconditionally by his family, he could get himself involved with drugs and practice unsafe sex when he was old enough to know better. I know I can't change the past, but what I am so frustrated about is how to help him. He keeps telling me that he is going to Alcoholics Anonymous or Narcotics Anonymous, but never does. For the most part, he is afraid to go out of his apartment and just stays there, practically living on the Internet. He tells me that right now he is not using drugs, but I really never know what to believe.

We have offered for him to come here to live with us and get help, but he refuses and would rather be homeless, if that is what it would come to. As a mother, I shudder to think of him homeless on a street corner in Chicago.

I know you have to be a very busy physician, but if you can just give me any advice, I would greatly appreciate it. Thank you.

Name withheld,
via the Internet

Dr. Berger replies: I am sorry to hear about your frustration with your son. I have to tell you this scenario is, unfortunately, not uncommon. Without knowing your son, you have given me a very telling description: been out of work for a year, then had a panic attack when re-starting work, afraid to go out of his apartment, etc. I suspect that he is still doing crystal and possibly on a daily basis. How he gets the money for this, without working, is a question for which the answer may be even more disheartening.

Your son is probably not living in a healthy environment and he obviously needs help. He may need in-patient treatment for his addiction, and I don't know if he has insurance. In Chicago, Rush University Medical School has a very good treatment program. Also, you may want to consider the Pride Institute, which has a gay-oriented program specializing in this area. If you know his physician, perhaps you may consider calling him and alert him about what is going on. Because patients usually lie to their physician in this situation, his doctor may not be fully aware of all the facts. Also, your son may not be able to make his own rational decisions, which may allow you to intervene.

As another suggestion, you may also consider visiting him, and trying to reason with him again. If there are other family members whom he trusts or may identify with, they may be able to more successfully persuade him to get aggressive help. Unfortunately, even with professional help, successful treatment will require a great deal of effort. Hope I was helpful. Thank you for writing to me and I wish you the best of luck.

PA help

I'm a prisoner who depends on *Positively Aware* for the main source of my info. It's helped me with a lot of decisions over the years. The biggest help was with a bad reaction to abacavir [Ziagen]. I was in agony. My back and side hurt so bad I could hardly walk and my skin was really sensitive. I went to sick call and was given Motrin. At first I thought I pulled a muscle, but it kept getting worse. I mentioned the abacavir and they said, "You have to expect some side effects from these meds."

But I knew it was more than that. By reading the side effects in the 2004 HIV Drug Guide (January/February), I quit taking my meds and it went away within a day or two. Then the next jail saw me and told me if I take it again I'd probably end up in ICU [intensive care unit] or dead. So thank you for doing a great job. I'm also grateful for receiving the magazine at no cost. I wish I could afford to donate because yours is the best of all the publications I read.

Name withheld,
Sommerset, PA

News Briefs

by Enid Vázquez

FDA approves two new drugs

In August, the U.S. Food and Drug Administration (FDA) approved two new HIV drugs, Epzicom and Truvada. See "The Buzz" on p. 38.

Agenerase

The HIV protease inhibitor drug Agenerase (amprenavir) will no longer be available in 150 mg capsules. The 50 mg capsules and the liquid formulation, however, will continue to be available. The new formulation of Agenerase, Lexiva (fosamprenavir calcium), was approved by the U.S. Food and Drug Administration (FDA) in late 2003 and it was expected that people taking Agenerase might switch over to the newer and easier-to-take Lexiva.

Don't take Crixivan with Reyataz

The FDA has made it official: you should not take Crixivan with Reyataz. When taken together, the two protease inhibitor medications might increase blood levels of bilirubin. This could indicate liver problems (although it hasn't been seen with Reyataz). Yellowing of the eyes and skin is a symptom.

Four infants with HIV

Four Chicago infants were born with HIV in the seven months prior to September 15, according to an informal flyer distributed by a health worker with the Illinois Department of Public Health. The flyer expressed concerns that medical providers did not follow state law outlining counseling and testing procedures for pregnant women. For information regarding that law, contact the state's Perinatal Elimination Program at 1-312-814-4846.

Attorney Chip Rowen skips town

A reader from Atlanta called *Positively Aware* about a lawyer who skipped town, leaving dozens of people with HIV stranded in their discrimination complaints or their fight for financial assistance. Chip Rowen was a founder of AIDS Legal Atlanta and well-known throughout the city for his private practice. Mary Lynn Hemphill, the Peer Counseling Program Manager for AIDS Survival Project in Atlanta, confirmed the problem. The Survival Project had regularly referred people to Rowen's private practice.

More updates from the 15th International AIDS Conference, held in Bangkok in July 2004.

Epivir during interruptions

Italian doctors had exciting news on HIV treatment interruptions. They found that Epivir helped keep T-cells up and viral load down during interruptions.

Instead of taking patients off all of their drugs, they had one group continue taking Epivir. The researchers found that the group of patients who continued to take Epivir (18 persons) lost half as many T-cells as the group which stopped all medications (22 persons). This was at six months. Moreover, the viral load of the Epivir group went up much less than in the stop group (at one point it was an increase of 7,000 vs. 80,000 for the no Epivir group).

Moreover, the HIV of the people on Epivir had less "replicative capacity," or the ability to infect T-cells. Basically, Epivir was crippling the virus. All of these patients had Epivir resistance (when the virus no longer responds as well to the drug). This study furthers supports the idea that Epivir resistance, the M184V mutation, does damage to the virus. The viral load may go up, but the virus is not as strong as it used to be.

Viramune and pregnancy

The good news that the HIV drug Viramune, with or without AZT, helps reduce transmission of the virus from a pregnant woman to her infant was followed by some negative news. Studies showed that women given two Viramune pills around the time of labor had a greater risk of developing resistance to the drug. In fact, they were less able to benefit from treatment with Viramune just months later.

Researchers are working hard to overcome this problem, and one team reported some success. A team of doctors from the U.S. and South Africa found that resistance could be avoided by adding Combivir to the Viramune. (Combivir is a combination of two HIV drugs in one, AZT and Epivir.)

Half of the moms receiving only Viramune (9 out of 18) developed resistance, vs. 5% (1/20) of the women given

Rowen has fled to Alabama, although it's not sure why. The PA reader learned that his employer discrimination case had been dismissed by Rowen without his knowledge. The Georgia Bar Association has opened an investigation.

HIV hideaway

Government researchers have figured out part of the reason why HIV is able to hide out in the body, away from drugs that help stop it from multiplying.

In these "latent reservoirs," the virus is not multiplying but sitting around, waiting to do its damage. "The persistence of latent HIV reservoirs is one of the main barriers to the eradication of HIV infection," said principal investigator Steven Zeichner, M.D., PhD, in a press release. Finding a way to dump HIV out of these hiding places can give drugs a chance to get rid of the virus.

The doctors found several possible gene targets and two drugs to flush out HIV from the latent reservoirs, which current treatments do not affect. The work may also point to new possible targets for fighting the virus. The team from the National Cancer Institute (NCI), part of the National Institutes of Health (NIH), reported their results in the August 16 *Journal of Virology.*

Women's side effects

Drug treatment can lead to side effects, but not so fast. The Women's Interagency HIV Study (WIHS) reported that after looking at several side effects, all of them were associated with the virus itself. Moreover, the odds of experiencing any of the 14 symptoms looked at were the same for women not on therapy as for those on therapy. The WIHS team reported that, "The high prevalence of symptoms among HIV-negative [high-risk] women and HIV-positive women not receiving therapy demonstrates that caution should be used when attributing the occurrence of symptoms entirely to HAART." They also reported that, "Body fat redistribution and diarrhea were most consistently associated with therapy use, because these were the only symptoms associated with both changing and stable HAART regimens." Depression was difficult to account for because it is related to both HIV infection

Viramune/Combivir for four days and 13% (3/23) given Viramune/Combivir for seven days. (Why the women given an extra three days of therapy had more resistance instead of less is a mystery.)

Resistance tests were taken two weeks and six weeks after birth. The study is continuing, and Viramune will no longer be given by itself in the study.

These study results were from developing countries, where therapy is not widely available. (In the U.S., the risk of resistance should be lower if the woman is given adequate HIV therapy.)

Viramune and Diflucan

Use of the antifungal drug fluconazole (brand name Diflucan) increases blood levels of Viramune and leads to greater toxicity. Doctors in Cape Town, South Africa put 24 HIV-positive patients on fluconazole and 12 days later added Viramune. The fluconazole was continued for a total of 40 days. The participants were already taking AZT, Epivir and Ziagen (possibly as one combination pill, Trizivir). The fluconazole cut in half the clearance of Viramune out of the body. As a result, 25% of the participants developed severe liver problems, including hepatitis in two patients. The researchers said care should be taken when prescribing fluconazole with Viramune, and liver function should be monitored.

Women's heart disease

The Women's Intergency HIV Study (WIHS) looked for the number of heart attacks and heart failure in women on antiviral therapy. Like studies before it, this one found that heart problems result from some of the usual suspects: smoking and getting older. There was no difference between the women who took protease inhibitors and those who did not (the HIV drugs have been associated with a greater risk of cardiac troubles) and the control group of women who do not have HIV. Of the 1,564 women (1,224 positive and 340 negative), half were older than 41.7 years of age. The analysis was done for the years 2000–2002. But studies looking at risk for cardiovascular disease need to be long term to decide whether HAART and resulting cholesterol increases are indeed added risk factors.

New York, New York

Black people make up 25% of the population of New York City, but make up more than 40% of the city's population living

and HIV treatment, and has non-specific symptoms such as muscle ache, fatigue and headaches.

"Our findings confirm the need to closely monitor the clinical symptoms of women on [therapy]," the team noted. "Of particular concern were symptoms such as diarrhea, nausea and/or vomiting, body fat redistribution, myalgias (muscle aches), and paresthesias (nerve damage); these symptoms were associated with a change in the therapy regimen, the majority of which involved the discontinuation of HAART [highly active antiretroviral therapy] or a component of HAART." WIHS compared 364 HIV-negative women with 1,254 HIV-positive women reporting symptoms in one six-month period of time. The findings were reported in the August 16 *Clinical Infectious Diseases*.

Viracept in pregnancy

Researchers found that blood levels of Viracept were lower in pregnant women than in non-pregnant women, especially during the last trimester. The HIV drug is often used in pregnant women. Doctors from the Netherlands reported their results in the September 1 issue of *Clinical Infectious Diseases*. They noted that lower blood levels might lead to higher viral loads and therefore a greater risk of HIV infection to the infant, and theoretically posing a greater risk for development of drug resistance. They suggested that Viracept levels be monitored, and if there is not enough time to get viral load to undetectable, that the starting dose of the drug be higher: 1,500 mg twice a day.

with HIV/AIDS, and more than 50% of the deaths due to HIV/AIDS. For all groups, the prevalence of HIV/AIDS is

- Total population: 1 in 97
- Blacks: 1 in 54
- Latinos: 1 in 82
- Whites: 1 in 157
- Native American: 1 in 315
- Asian/Pacific Islanders: 1 in 972

The numbers for black men are worse: 1 in 39 are infected (it's 1 in 76 of black women).

Viread toxicity

It was thought that Viread could be toxic to the kidneys, but various reports found that renal toxicity was not common. The company-sponsored study that brought the drug to market reported no differences in renal function tests between the people taking Viread and the people in the study who didn't take it (each group had 296 participants). This was after three years of being on the medication. Also, none of the people in the Viread arm of the study dropped out because of kidney toxicity.

London doctors conducted an analysis of their patients with symptoms of kidney problems (those with a creatine level greater than 120 micro m/L). There was no difference in this group between the people taking Viread and the ones not taking it, no matter how long they've been on therapy. Moreover, of the 8% of Viread patients who did have increased creatinine (84 out of 1,058 individuals), 90% had kidney dysfunction because of some other reason.

African Americans, who tend to have more kidney dysfunction, did well with Viread for at least out to a year. This was according to a poster presentation from doctors in Houston at the University of Texas Medical School and at a private clinic. They compared 46 patients on Viread to 50 patients on AZT (Retrovir) and found no difference in kidney (renal) function. They conducted the analysis in part because, "Black race is a major risk factor for HIV-associated nephropathy (HIVAN) and other renal abnormalities seen in patients with HIV infection."

An analysis from five Kaiser clinics in California found a small increase in creatine in 199 people taking Viread, but no increase in protein in the urine.

German doctors, however, reported finding more kidney toxicity in people on Viread when using more sensitive measures. They compared 74 people on Viread with 84 people who never took the drug. None of the Viread patients, however, had kidney malfunction. Nevertheless, the researchers said care should be taken when prescribing Viread with drugs known to cause kidney toxicity.

A study reported earlier this year found renal function problems in patients on Viread followed for more than one year. The problems were associated with high blood pressure and diabetes, but not with age, sex, injection drug use or length of time on Viread.

Viramune
Ad
Page
Here

Viramune

P.I.

Page

Here

Remembering Charles

compiled by Jeff Berry

Following are excerpts from some of the many e-mails, letters, sympathy cards, press releases and news items regarding the untimely death of Charles E. Clifton. Charles, TPAN Executive Director and Positively Aware *Editor, died in Chicago on August 15th, 2004, of a pulmonary embolism. He was our leader, our colleague and our friend. We'll miss you, Mini.*

Charles was everywhere doing everything, all the time, and played many, many roles to many, many people, both here and across the country and the globe.

He was also one of the only executive directors I have *ever* known to be so unabashedly political and fired up. No mincing for him. He was never afraid to say what needed to be said. Loved him for that.

He will be missed from end to end and all points in between more than I am able to articulate.

Jim Pickett

Charles Clifton's tireless work, passion and generous spirit is indescribable. His approach was always informed, rational and immediate. This loss to Chicago and indeed the world will be immensely felt.

Lora Branch, Director of LGBT Health, Chicago Department of Public Health

The community has lost a great leader and many people have lost a great friend… you're all in our thoughts.

David Kern, Chicago Department of Public Health

A little over a year ago Charles discovered an article I had written about the plight of the Black community in the fight against HIV. The name of the article was "Dying in Silence" and it centered on the apathy about HIV/AIDS in Black communities across this country. Charles asked me could he publish the article, "This is something we should constantly bring to light," he said [see March/April 2003].

Charles was a special person. He was articulate, witty, thoughtful… there are just not enough adjectives. He and I have sat through many meetings together, his emphasis on care and treatment and mine on education and prevention made us a great team. I learned a great deal from Charles and I will truly miss him. He was the antithesis to the article I wrote. He was a strong Brother who knew that the silence in our Black communities about this virus was one of our greatest vulnerabilities. When we talked about the article I had written, he told me how *Positively Aware* deals mainly with care and treatment "but we have to find a place to put these words."

There is definitely a void which will be hard to fill with the passing of Charles. I do not say that only as a friend but also as an advocate in this fight. We have so much more work which needs to be done. Although he may be gone, his ideas, his passion and his sensitivity to the epidemic lives on through the many lives he has touched. Many we will never know. Many have read what he has written and have been inspired to fight on! He was a great man who gave of himself to help others, and that has to be the greatest gift. So once again, I will miss Charles, but I know he will always be with me in many ways. I will always hear his words of encouragement, I will always recall the passion he commanded in the struggle, and most of all I will always be comforted in the remembrance of someone who truly cared.

Charles W. Martin
Executive Director
Julius Adams AIDS Task Force, Key West

I had known Charles for a brief period when I was invited to serve with him and four others on the Retrovirus Community Liaison Subcommittee. I am sure my other colleagues will share my view that Charles was a fellow who made our work enjoyable to carry out. As the only member from Africa, I found Charles to be very supportive in helping me face some of the

challenging moments that came up during my tenure. I recall how with ease I instantly took to Charles when we first met in Chicago last year for our first working sessions. Again last year, Charles was there to bail me out when communication problems put me in a tight corner.

Before I heard of his death, I had been planning the 1st National HIV Treatment Forum here in Ghana. I was considering giving up the idea due to some challenges I was facing. But upon hearing of Charles' death, I have been rekindled to go ahead with the forum.

When I mount the platform as the first speaker, it will be in memory of Charles E. Clifton.

William Joe Adusei
Coordinating Director
Centre for AIDS Information Network

and an example of how one could be a leader without losing one's kindness, generosity, intelligence, and sense of humor. The work Charles did at TPA was an inspiration. He was an incisive writer and editor. Charles was one of the early activists to recognize the importance of building stronger new coalitions and he was key to the founding and development of ATAC [AIDS Treatment Activists Coalition]. Charles was a good listener and could often see the better sides of fellow activists, even in the midst of controversy. Most of all, Charles was a lot of fun. I will treasure the times we spent in Houston, in New York, and most recently in Bangkok, and I will feel sharply the pangs of never being able to enjoy his presence again. Charles, thanks for your contributions, your sense of justice, and your sense of fun. You are irreplaceable.

Mark Harrington, TAG (Treatment Action Group, NYC), and ATAC

The loss of Charles has stunned us. In our uncertain, chaotic world, we live under the illusion that someone like Charles will be around to show us the way through troubled, confusing times.

For a while the world will seem less bright and complete because he is no longer with us. But because he had such a powerful vision, his presence on this planet, even for such a short time, has made the world a better place for us all.

His articles in *Positively Aware* spoke to activists in fields far beyond HIV/AIDS. Until I read some of his pieces, the environmental community infuriated me. His insights and explanations helped put things in perspective.

Rarely does a leader combine intelligence, vision and compassion along with the ability to work with widely diverse groups of people. I loved watching him control conflict through subtle displays of disapproval. Seeing TPAN flourish under his direction must have both pleased and encouraged him.

Words can not heal the deep wounds of loss. Time and grief will run their course, and those who had the great pleasure of knowing him can experience the aura of his gifts.

With sympathy,
Judy and Dave Allen

I am overcome with grief at the loss of Charles Clifton. For me he was a hero

What can I say about the unexpected loss of Charles Clifton! I'm in shock! Many of us knew that he was in the hospital after experiencing complications from a diagnostic heart procedure. But we thought he was going to be okay.

This is a tremendous loss for the community. Charles was such a wonderful man. He had such a sweet and loving nature and was extremely smart and effective as an AIDS activist. I was so impressed with his remarks at our Abbott press conference at the last Retrovirus Conference in San Francisco. His words were well reasoned and right on the money. They also reflected a deep understanding of the entire issue and all its consequences.

Let's do what we can to honor his work and memory. We are all better for having known Charles.

Kaletra
Ad
Page
Here

Kaletra

P.I.

Page

Here

I hope that ATAC will think of a way to remember his gentle spirit and committed nature.

Lynda Dee, AIDS Action Baltimore, and ATAC

I'm deeply sorry to learn of Charles's passing. I'm at a loss for words to even begin to describe how much I liked him and respected him and all the work within the community he has done for many years. This is a tremendous loss personally and for the community.

Sam Soriano, ATAC

I had the pleasure of meeting Charles through my involvement with ATAC. I found him to be warm with a generous spirit and a great sense of humor. His presence as an activist will definitely be missed but his inspiration remains with us in the struggle.

Thank you, Charles, for the dedication and commitment you embodied. With your life and your work you have touched many lives.

Martell Randolph, Being Alive, Long Beach, and ATAC

I am very saddened to hear of the passing of Charles Clifton. As a positive person I was able to interact with TPAN and their wonderful staff, they were a credit to Charles' leadership. The thoughts and prayers of my wife and I, and all of our family are with all of you during this difficult time.

I truly feel that TPAN saved my life, and the staff were the first ones to tell me, "It will be okay, you can live with this, if you choose to…" I know that you will continue to touch the lives of so many of us struggling to make sense of this virus. Since my first visit to TPAN almost three years ago I got a great job; I got married to a beautiful, incredible (positive) woman; became a father to a beautiful (negative) baby girl; and most of all I *am healthy*, and living my life instead of waiting for it to end! Thanks to Charles and all of you at TPAN.

Name withheld, via the Internet

I just wanted to send a note to say that my thoughts are with you and everyone who knew and loved Charles. I still can hardly believe it, just too horrible for words to have lost such an incredibly wonderful human being. I'm going to miss him terribly, for the rest of my days.

Richard Jeffreys, AIDS Treatment Data Network (ATDN), and ATAC

Charles was a great guy and I love him. When I moved to Chicago and went to work for TPAN, I got not only a great "boss" (he was working on his degree and didn't have much time for bossing me around), but a friend with whom I've remained close since I moved back to California. He was so smart, and so funny—hilarious!—and fun to be around, whether we were talking politics, about HIV, or his "girls" [Llahsa Apso dogs]. I didn't get to see enough of him once I moved back, and I am so, so sorry about that. Charles was full of integrity and charm, and he worked so hard, but he always had time for anyone who needed him (okay, this was before he became the Executive Director, so I don't know what happened after that…)—Kurt, I'm so sorry for your loss.

Susan Forrest, Los Angeles

I only had the opportunity to meet Charles at the University of Chicago in the summer of 2001. We took a Spanish translation class together in order to prepare for an exam.

I enjoyed listening about his research on same-sex desire in historic Chicago. He was a scholar—willing to share his ideas and equally willing to listen to constructive criticism.

He was also funny, and he and I shared a few crazy looks and laughs as we worked on our Spanish translation that summer.

I didn't know him well, but I wanted to share that in addition to being a strong fellow Black brother, an activist, and being a kind and friendly person—Charles was a scholar.

My sincerest condolences to his family, friends and co-workers.

Sheldon Lyke

Access 101: Navigating the Rocky Waters of HIV/AIDS Healthcare

If you feel lost trying to figure out how to afford and obtain healthcare services, you are not alone. The checklist that follows is designed to help guide people with HIV/AIDS in their search for quality healthcare. Because programs and services vary dramatically state by state, this outline is the beginning of what will likely become a more detailed and specific list of what is available in your state and municipality.

Private health insurance

If you have private healthcare coverage, use it wisely and do all you can to hold onto it. Benefits vary dramatically depending on the type of plan you have and the insurance laws in your state. Pay special attention to your plan's prescription drug coverage (what's covered, how to use it, and what it will cost you), participating providers (doctors, hospitals, and healthcare facilities covered by your plan), required co-payments (your cost for each doctor's visit or service), deductibles (what you pay before the plan pays the rest), and lifetime limits (maximum amount the plan will pay).

If your plan is an HMO (health maintenance organization), be sure the physician you select specializes in HIV medicine, and become aware of your plan's "open enrollment" period, which is the time of year beneficiaries may switch to another physician within the plan. While co-workers and the benefits administrator at your place of employment may be helpful, remember that you are under no obligation to disclose your HIV status and you may well benefit from keeping this information private.

Studies show that patients receiving care from HIV specialists live longer than those who don't. Ask around for recommendations, contact an HIV service organization or contact the American Academy of HIV Medicine (www.aahivm.org) and the HIV Medicine Association (www.hivma.org).

If you leave your place of employment, work with a benefits counselor or lawyer to carefully plan the transition. Under the federal Consolidated Omnibus Budget Reconciliation Act, better known as COBRA, you have the option to purchase your existing health insurance coverage for up to 18 months after leaving your current place of employment (group health plans sponsored by employers with 20 or more employees), but you must abide by all the rules or risk being dropped from the plan permanently. You will have 60 days from the time you are notified to elect "COBRA continuation" coverage. You must elect continuation coverage in that period and begin paying the monthly premiums on time every month. If you fail to pay within the grace period, your coverage will be revoked. Individuals determined disabled by Social Security may extend COBRA coverage another 11 months at the completion of 18 months but may have to pay higher premiums. You must notify your prior employer within 30 days of Social Security's decision.

Some states offer people with HIV/AIDS or other low-income residents assistance paying COBRA continuation premiums and co-pays. Several states have laws making individual health insurance accessible and affordable for people with chronic conditions. Be sure you can afford the premiums and all the out-of-pocket costs before enrolling.

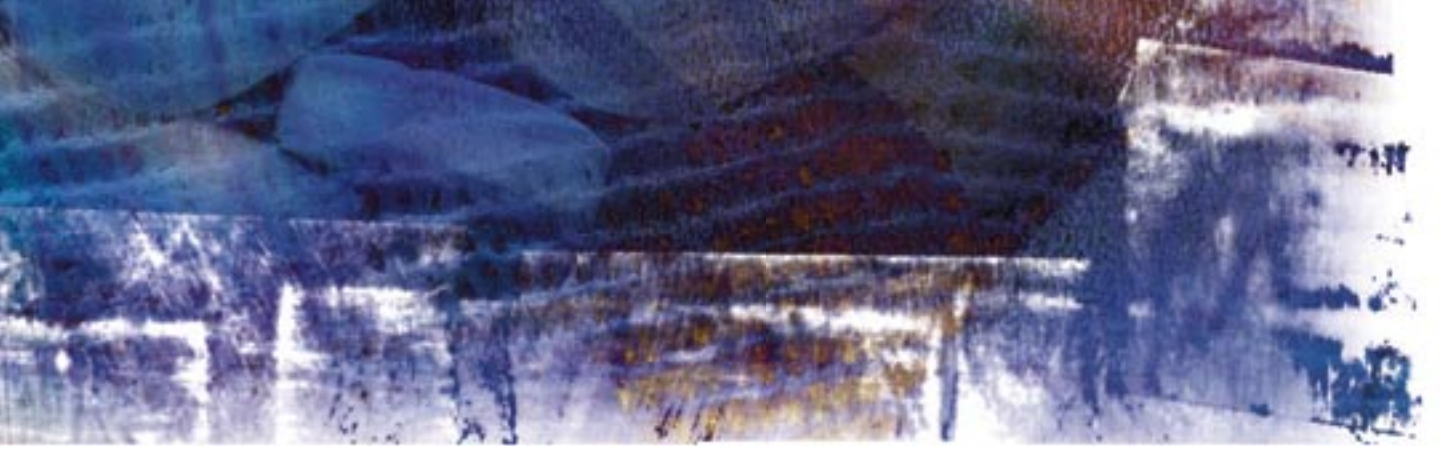
Beware of fraudulent health plans. Some advertise heavily on TV and are not health insurance at all, but drug discount cards marketed as comprehensive coverage. They may advertise extensive networks, low monthly premiums, and no enrollment exclusions. Read the fine print and contact your state's Office of Insurance if you suspect insurance fraud.

Ryan White CARE Act

The federal Ryan White CARE Act provides funding across the country for an array of HIV-related services, including health services, for people with HIV who are low-income and uninsured or underinsured. Call the National AIDS Hotline at 1-800-342-AIDS (342-2437) for the services near you. Ask the operator for information about local support groups and peer organizations, and request contact information for your state's AIDS Drug Assistance Program (ADAP) and HIV/AIDS case management offered in your area. When you meet with a case manager, ask him or her to assist you in applying for Medicaid and other government assistance programs, and to refer you to free or low-cost clinics. Help advocate for funding increases by joining groups such as Save ADAP. Join online at www.atac-usa.org/adap.html.

Medicaid

Medicaid is a federal/state heath insurance program for low-income people who are blind, disabled, or elderly. You must



BY DAVID MUNAR,
AIDS FOUNDATION OF CHICAGO

prove that you are too sick to "sustain gainful employment." This means that a physician will need to attest to the fatigue, lack of concentration, memory problems, and other impairments you experience, as a result of your disability, which keep you from working. Medicaid will also review your income and assets. Earned income and most forms of cash assistance, including Social Security Disability Insurance (SSDI), count toward the financial limits. Medicaid can pay for medications and services not available through the CARE Act, including non-HIV-related medications, in-patient services, and treatments for other diseases and conditions. Everyone who is low-income, uninsured and receiving CARE Act services should apply for Medicaid through their state's welfare agency. In most states, low-income pregnant women, low-income children, and individuals found eligible for Social Security Income (SSI) are considered for Medicaid on an expedited basis. Positive women should get early screening for breast and cervical cancer, and may qualify if they have precursors for these diseases.

Some states provide conditional eligibility to individuals who meet disability criteria but are found to have too much income to qualify for Medicaid. Earned income and most forms of cash assistance, including Social Security benefits, count toward the financial limits. Certain assets, such as a home and a vehicle used for transportation to and from medical appointments, are exempt from financial limits; personal savings are not exempt. Individuals granted conditional eligibility receive Medicaid coverage once they spend a set amount of their income (know as their "spend-down") on healthcare costs they incur for a period of between a month and six months (differs by state). It is important to know the rules and follow them closely so that you can be sure of continuous medical coverage.

Beware of fraudulent health plans.

Medicaid recipients may experience other barriers to quality healthcare such as "voluntary" pharmacy co-payments and required prior authorization for certain prescription drugs.

Medicare

Medicare is a federal health insurance program primarily for retired workers over age 65, although an increasing number of people under 65 with disabilities receive Medicare. People with HIV who have substantial work histories and receive Social Security Disability Insurance (SSDI) benefits qualify for Medicare after a two-year wait period. Because the program is complex and undergoing a significant restructuring, you should consult with a Medicare expert if you think you qualify or will qualify for Medicare in the near future.

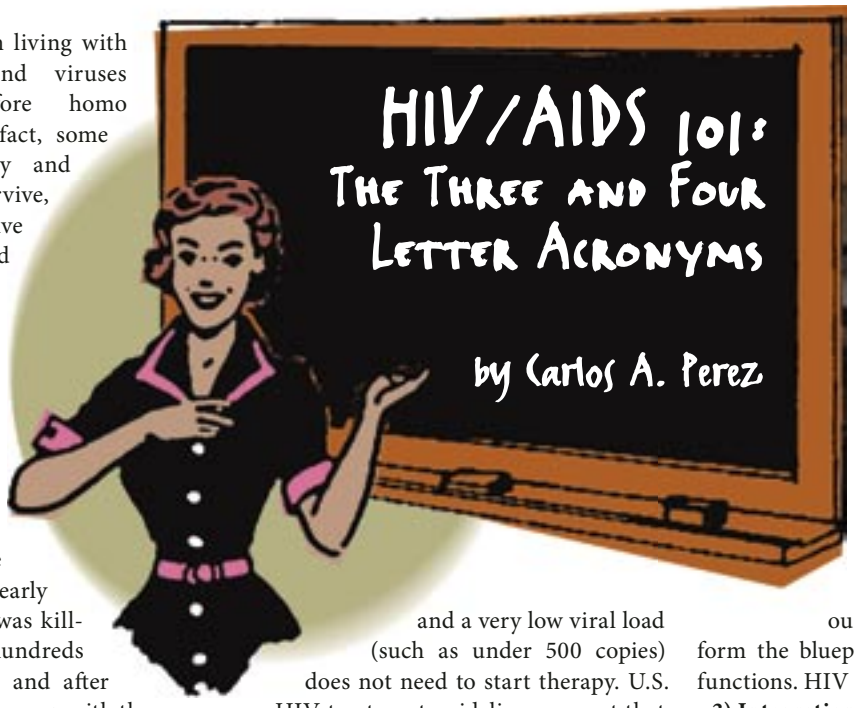
Medicare covers in-patient hospital care, skilled nursing facilities, and hospice (some deductibles and co-pays apply). Beneficiaries who pay a monthly premium may also receive coverage for out-patient medical care, home health, laboratory services, and medical supplies under a program know as Part B. People with HIV should always select Part B coverage because the outpatient benefits are better than those available through Medicaid. If your income is below the federal poverty level, the state Medicaid program should pay the premiums for you if you ask for assistance.

Because Medicare has historically not covered outpatient prescription drugs, many seniors supplement their coverage with private Medigap plans, if they can afford them, or Medicaid. Visit www.medicarerights.org.

Patient Assistance Programs

Virtually all pharmaceutical companies have programs for low-income patients who need their drugs but cannot afford them or cannot get them through another source.

Visit www.tpan.com for an expanded list of resources accompanying this article.



We have been living with bacteria and viruses since before homo became erectus. In fact, some bacteria are healthy and necessary for us to survive, like the ones that live in our stomachs and lower intestines that are helpful to our daily living.

Then we have the bad bugs. We have endured polio, Legionnaire's disease, West Nile virus, smallpox and the yearly flu, to name a few. However, in the early 1980's a new disease was killing people by the hundreds and then thousands, and after some years, science came up with the terms HIV—Human Immunodeficiency Virus—the name of the virus, and AIDS—Acquired Immunodeficiency Syndrome, the name of the condition that eventually ensues when HIV is left untreated.

What does AIDS Mean?

Acquired, which means you catch it, Immune Deficiency, which means your immune system is weakened and can no longer fight off bacteria and diseases, and Syndrome, a combination of symptoms that indicates a particular disorder. If left untreated, AIDS may lead to death. Nobody dies from AIDS itself, but from the illnesses that can develop due to AIDS.

What if I test positive for HIV?

If you have a positive result for HIV, take a deep breath and be glad that it is 2004, because there have been many advances in treatment and it is no longer a death sentence. It used to be. In the early 1980s when patients tested positive all they were given was an amount of time to prepare for death. And unfortunately, even today some people find out that they are HIV-positive only when they end up in the emergency room of a hospital, and have come down with one or more of the opportunistic infections brought on by a weakened immune system and are less likely to respond to treatment. Many people these days test positive and do not need to go on medications because science is now more sophisticated, and we know that a person with over 500 T-cells and a very low viral load (such as under 500 copies) does not need to start therapy. U.S. HIV treatment guidelines suggest that a person consider starting HAART (highly active antiretroviral therapy) when their T-cell count is below 350, or their viral load is above 30,000 by the bDNA test or 55,000 by the PCR test. If someone knows they are HIV-positive, their health and quality of life can be manageable if they empower themselves to learn about the virus, how it works and how it impacts their body.

How does HIV work?

There are five basic steps to the life cycle of HIV. These are the steps scientists use to develop drugs—fighting HIV every step of the way, as it were.

1) Attachment, Fusion and Entry

HIV attaches itself to the body's CD4 cells (also called T-cells). The virus does this by using receptors on the surface of the cell. Next, HIV fuses (or melts) into the surface of the cell. When all the separate steps of fusion take place, like arms reaching out and completing a handshake, HIV is pulled inside the cell. (By the way, the virus also infects other cells of the body, such as the lymph nodes or the brain. Sometimes it just sits there instead of going through the steps below. But the CD4s, which are immune system cells, are its favorite target.) There are several key receptors that affect cell attachment and fusion. Science knows of two types of receptors, the CD4 receptor and the chemokine co-receptor.

2) Reverse Transcription

Once inside the cell, HIV uses its transcriptase enzyme to change itself in preparation for becoming part of the body's genetic code. When that happens, the body will be forced to produce HIV like it does anything else—tears, new liver cells, etc. Because HIV works backwards compared to most viruses (making it a "retrovirus"), this is called a "reverse transcriptase" enzyme. (Enzymes are proteins that cause substances to change.) The RT enzyme changes HIV's genetic material from RNA to DNA. (To put it simply, RNA and DNA are part of our genetic structure, which form the blueprints for all of the body's functions. HIV has its own genetics.)

3) Integration

The HIV DNA then enters the nucleus, the command center of the cell. Once inside the nucleus, HIV uses another enzyme, integrase, to re-program the cell, integrating the virus with the cell's DNA.

4) Cutting and Assembly

Every time the T-cells become activated due to an immune response—for example, you catch a flu virus and T-cells come to fight the flu out of your system—spare parts of the HIV DNA separate and form what is called a messenger RNA. The messenger RNA leaves the center of the cell and forms a long chain of instructions to make new HIV particles, like a parent would leave a list of instructions for a babysitter. Then an enzyme called protease comes to play. This is why we have protease inhibitors, which inhibit this part of the HIV life cycle. The protease enzyme cuts the long list of instructions into separate parts that assemble and come together to form a new HIV particle.

5) Budding

The new HIV particle moves out of the cell through a process called budding, because its action is like a blooming flower. The HIV particle pushes through the cell wall, taking parts of the cell's covering to form the new coat of HIV. The HIV particles are constantly maturing and growing, or blooming, from the time it becomes the messenger piece of information to the time it buds from the cell.

Opportunistic Infections 101

by Enid Vázquez

What's an opportunistic infection? It's a disease that preys on people with weak immune systems. That's what makes it an opportunist.

Fortunately, people with HIV who are taking therapy can go a long time before they suffer the immune damage that allows an opportunistic infection (OI) to rise up. Even people who have an AIDS diagnosis but respond well to HIV therapy can avoid an OI.

Unfortunately, there are still many people who don't even know they're infected until the virus develops into AIDS and an OI lands them in the hospital—sometimes killing them. The U.S. Centers for Disease Control and Prevention (CDC) estimates that one out of four people living with HIV in this country don't realize that they have it. Tell your friends and family to get tested!

A set of guidelines for preventing and treating opportunistic infections in people with HIV is available from the U.S. Public Health Service (USPHS), in conjunction with the Infectious Diseases Society of America (IDSA). If you have an opportunistic infection, I urge you to get a copy of the guidelines. See the end of this article for ordering information. The following is some of the updated information from the guidelines since our last story on OIs, which included transmission and symptoms (see "The Stalker Awaits," Sept./Oct. 2001 on-line or write to PA for a copy).

- The importance of screening people with HIV for hepatitis C is emphasized.
- Children born to mothers who have both HIV and hep C infection should be tested for hep C, since women with both viruses are more likely to pass on the hepatitis than women without HIV.
- People co-infected with HHV-8 (human herpesvirus 8) are at risk for developing a rare cancer, Kaposi's sarcoma (KS). If they already have KS, the cancer may become more aggressive. Safer sex avoids infection with this herpes virus, but keep in mind that it can be transmitted through deep kissing. Sharing needles also shares the virus. Unfortunately, there is no blood test available at the doctor's office to see if your partner has HHV-8.
- It's been shown that taking rifabutin or clarithromycin helps protect against cryptosporidiosis, a serious diarrheal disease that results from a parasite found in water. Unfortunately, the data on people taking those medicines do not allow for a recommendation to be made.
- Doctors should consider repeating the tuberculosis skin test in people whose T-cells go up above 200 after taking HIV therapy.
- Beware that two-month daily tuberculosis treatment with rifampin and pyrazinamide has been associated with severe and even fatal liver injury. It would be good to avoid the pyrazinamide.
- Drug treatment information for tuberculosis MAC (*Mycobacterium avium* complex) has also been updated.
- Vaccination information has been updated for both children and adults.

For more information

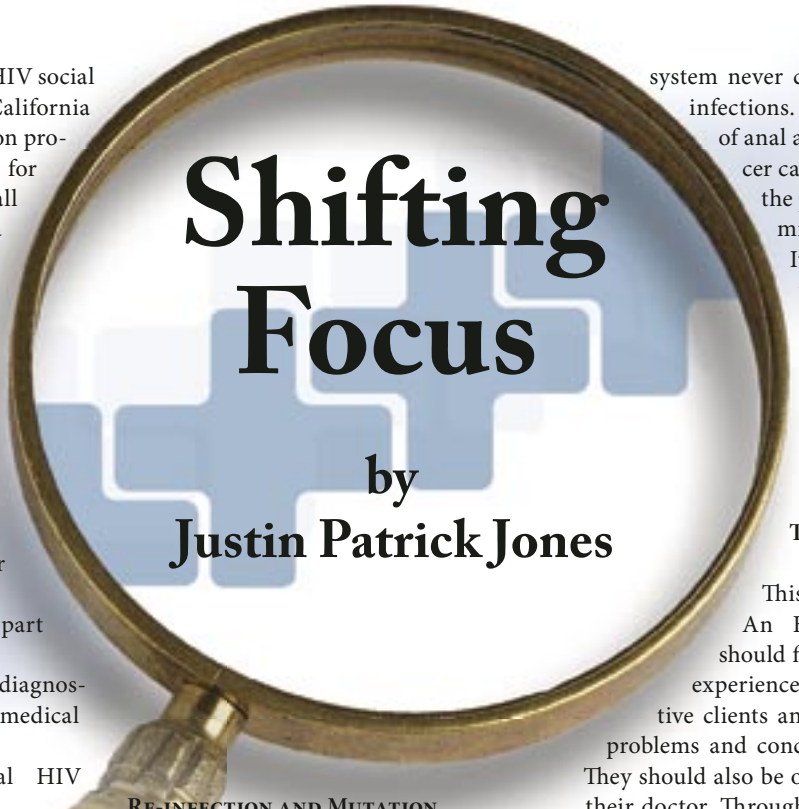
You can order a copy of the Guidelines for the Prevention of Opportunistic Infections in Persons with HIV by contacting the U.S. Department of Health and Human Services (DHHS). The document is written for medical providers, but is pretty straightforward and broken down by each OI. DHHS also has very easy-to-read brochures on many of the OIs. The toll-free number is 1-800-HIV-0440 (448-0440). Write AIDSinfo, P.O. Box 6303, Rockville, MD 20849-6303. (You can write "DHHS Guidelines" instead of AIDSinfo.) Visit www.aidsinfo.nih.gov.

Opportunistic infections

1. *Pneumocystis* pneumonia (PCP), officially called *Pneumocystis jiroveci*
2. Toxoplasmic encephalitits
3. Cryptosporidiosis
4. Microsporidiosis
5. Tuberculosis
6. Disseminated infection with *Mycobacterium avium* complex (MAC)
7. Bacterial respiratory infections
8. Bacterial enteric (intestinal) infections
9. Bartonellosis
10. Candidiasis
11. Cryptococcosis
12. Histoplasmosis
13. Coccidioidomycosis
14. Cytomegalovirus disease (CMV)
15. Herpes simplex virus disease
16. Varicella-zoster virus disease
17. Human herpesvirus 8 infection (Kaposi's sarcoma-associated herpes virus)
18. Human papillomavirus infection
19. Hepatitis C virus infection

Shifting Focus

by Justin Patrick Jones



A few years ago, part of the HIV social service community in California developed a new prevention program. They called it "Prevention for Positives." (Here at TPAN, we call it "Prevention with Positives," a minor change, but without some of the assumptions and stings of the original.) The CDC heard about it. They studied and discussed the merits and downfalls of the program. Finally, they developed a nationwide prevention initiative which they now highly encourage prevention programs to embrace.

The new initiative called for four key strategies.

1. Make HIV testing a routine part of medical care.
2. Implement new models for diagnosing HIV infections outside medical settings.
3. Further decrease perinatal HIV transmission.
4. Prevent new infections by working with persons diagnosed with HIV and their partners.

At its core, prevention with positives follows a harm reduction model. It integrates prevention and care. Many positives believe that unprotected sexual acts and sharing needles with other infected people carries with it minimal or no risk. Through Prevention with Positives, they begin to understand that "sero-sorting" (only engaging in risky behaviors with other HIV-positive people) does not always guarantee safety for themselves or their partners. Properly implemented, the program communicates risk, but no judgment. The program discusses abstinence, but does not push it. The program imparts scientific knowledge, but it relies on the client to use the knowledge.

In order to achieve these tasks, agencies across the country have begun to implement educational programs for their clients following guidelines set by the CDC, but they modify these guidelines to fit the face of their community. TPAN developed an 18-hour class called TEAM—Treatment, Education, Advocacy, Management—which is presented to clients and providers six times a year. Many important issues surrounding the healthy lifestyle of an HIV-positive person are discussed. They include, but are not limited to, re-infection, co-infection, and treatment.

Re-infection and Mutation

While originally a theory, well documented cases of re-infection have now been reported. Essentially, re-infection means that another strain of the virus takes hold in your body. This can be potentially disastrous to a person's health. If an HIV-positive person receives a new strain that no longer responds well to treatment, that person runs the risk of treatment failure, or at the very least, he or she may limit treatment options for themselves. This phenomenon is somewhat rare, but barriers (e.g. condoms) during sex with an HIV-positive partner should be used in order to minimize the risk.

Co-infection and STDs

Taking unprotected risks with HIV-positive partners sometimes puts a positive person in danger of receiving another infection. While many STDs such as gonorrhea, chlamydia and syphilis can be treated with antibiotics, others cannot be successfully treated, or they are significantly more difficult to treat. Hepatitis C is a common co-infection that affects and infects those who take both sexual and intravenous drug use risks. Interferon has proven to be an effective treatment; however, according to the latest data, it only works in about 30-40% of cases in HIV-positive people (60% in HIV-negative cases). HPV and herpes have treatments to control the infections, but in most cases the body's immune system never completely clears the infections. With certain strains of anal and vaginal HPV, cancer can result, especially in the presence of a compromised immune system. It should be noted that condoms do not always provide an effective barrier against HPV and herpes; however, they do minimize risk of exposure.

Treatment

This is not theory. This is not conjecture. An HIV-positive person should find a doctor who has experience treating HIV-positive clients and who listens to the problems and concerns of their clients. They should also be open and honest with their doctor. Through a good relationship with an educated doctor, a person can make informed decisions regarding their health. Feeling empowered over a situation that often makes people feel powerless provides the upper hand in the battle to defeat this disease.

In my work in HIV prevention and education, I hear the community's concerns. Many of them fear that Prevention with Positives stigmatizes positive people by putting all the responsibility of healthy decisions on them. While some individuals promoting this program see it that way, many of us see it as an opportunity to empower people living with HIV to live happy, healthy, long lives with minimal added stress to what is already a stressful situation. Others believe that the prevention focus should not be shifted from negatives to positives. After all, prevention failed the positives we already have, therefore why should HIV-positive people carry all the burden of the disease and of their partners? I understand this point of view, but I do not agree with it. I also do not agree that the focus should be completely shifted away from negative individuals. Through concentrated educational efforts towards both negative and positive populations, perhaps the tide will finally shift against this pandemic.

HOW HIV drugs work

by Steve Meyer, R.Ph.

There are currently five categories of HIV antiviral drugs available that have FDA (U.S. Food and Drug Administration) approval. These categories are:

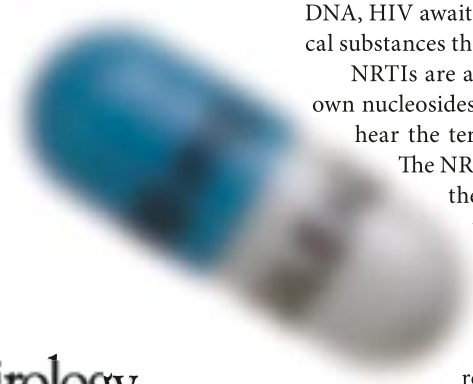
- nucleoside reverse transcriptase inhibitors (NRTIs)
- nucleotide reverse transcriptase inhibitors (NtRTIs)
- non-nucleoside reverse transcriptase inhibitors (NNRTIs)
- protease inhibitors (PIs)
- fusion inhibitors

Fusion inhibitors work outside the CD4 cell by inhibiting HIV from joining, or fusing, with the cell. Nucleosides, nucleotides and non-nucleosides all work to stop HIV from infecting CD4 cells. Protease inhibitors stop infected cells from reproducing the virus.

NRTIs

Nucleoside reverse transcriptase inhibitors, commonly referred to as NRTIs or nukes for short, inhibit reverse transcriptase, an enzyme that HIV needs in order to infect CD4 cells. Retroviruses, such as HIV, use the enzyme reverse transcriptase to convert their RNA into DNA, the structure that contains all of a person's genes. Without the ability to create the DNA inside the nucleus of a healthy cell, HIV cannot infect that cell. The HIV DNA then integrates with the DNA of cells (the CD4 cells, also called T-cells) in the body. A category of drugs called "integrase inhibitors" are in development to work at this stage of the virus.

Once proviral DNA has been integrated into the body's natural DNA, HIV becomes a lifelong infection. HIV drugs provide the body with a strong defense against the reproduction of HIV; however, they do not kill the virus. Generally HIV converts into proviral DNA within 72 hours after infection. Once inside the cell's DNA, HIV awaits activation by cytokines and chemokines, chemical substances that tell cells what to do.



NRTIs are analogs because they are imitations of the body's own nucleosides, which HIV uses to infect cells. Hence, you will hear the term "nucleoside analogs" used to refer to NRTIs. The NRTIs trick the HIV reverse transcriptase into using these imitation nucleosides, incorporating the imitation nucleoside into the HIV DNA chain. The virus thinks it's inserting the cell's nucleoside into its DNA chain, but it's actually inserting the drug. This breaks the viral DNA chain.

Drugs in the NRTI category include Retrovir (AZT), Zerit (d4T), Hivid (ddC), Epivir (3TC or lamivudine), Videx (ddI), Ziagen (abacavir), and Emtriva (FTC or emtricitabine). Combinations of these drugs are also available, such as Combivir (Retrovir and Epivir together in one pill) and Trizivir (Retrovir, Epivir and Ziagen). Epzicom, which was just approved by the FDA, is a once-daily combination of Epivir and Ziagen. Side effects to beware of with NRTIs include

pancreatitis, rash, flu-like symptoms, and peripheral neuropathy (a type of nerve damage).

Nucleotides

Viread (tenofovir) is the first drug (and so far, the only one) in the category of nucleotide reverse transcriptase inhibitors (NtRTIs) to be approved by the FDA. NtRTIs are very similar to the NRTIs, but are chemically pre-activated, to quickly convert to the actual form of drug in the body, allowing the NtRTIs to enter the HIV's DNA more rapidly than the drugs in the NRTI class. Viread and the NRTI Emtriva are now available in a combination once-daily tablet called Truvada.

NNRTIs

Like the NRTIs, the non-nucleoside reverse transcriptase inhibitors (NNRTIs or non-nukes) also keep HIV from infecting cells by interfering with the virus' reverse transcriptase. However, they do this in a slightly different way. The NNRTIs attach themselves directly to reverse transcriptase so that the RNA cannot make DNA, thus preventing further replication of the virus. The downside to this class of drugs is that NNRTIs are highly cross-resistant to one another (see "Resistance" below).

Though the protease inhibitors are considered to be the most potent of the HIV drugs, they are not without problems.

The NNRTIs provide a choice for people who are intolerant of protease inhibitor side effects, those who want to save the protease class for future use, or for those whose protease inhibitor therapy failed them. Drugs in the NNRTI class include Rescriptor (delavirdine), Viramune (nevirapine), and Sustiva (efavirenz). Sustiva has been placed in the "preferred" category in the current federal guidelines for those starting HIV treatment. Viramune and Sustiva are also both easy to take. Viramune requires two tablets daily (one twice a day) while Sustiva requires just one tablet daily, usually taken at bedtime.

Rash is a side effect that all NNRTIs share in common, and is one of the more prevalent side effects in the class. Other common side effects, usually associated with Sustiva, include confusion, abnormal thoughts, vivid dreams and impaired concentration. These side effects, though, usually disappear after two to four weeks of therapy.

Protease inhibitors

Protease inhibitors (commonly called PIs), inhibit protease, a digestive enzyme that breaks down protein. HIV protease is only one of several enzymes that the virus uses to reproduce itself. The HIV protease works by cutting up long chains of the virus' proteins into smaller pieces that go on to infect new cells. By blocking HIV protease, these drugs keep the virus from making copies that can infect cells. Thus, these drugs keep immature non-infectious virus particles from becoming mature infectious particles, which cannot infect any other cells.

There are currently nine PIs on the market, making it the largest category of HIV drugs available. Protease inhibitors are generally thought to be the most potent or the "heavy–weights" of the HIV drugs, and Kaletra is considered, so far, to be the undisputed champion of the heavy weights. Kaletra is the other drug, along with Sustiva, to be placed in the "preferred" category in the current federal guidelines for HIV treatment. It has proven to be a very durable drug and has become the most-prescribed drug in the protease inhibitor class.

Other PIs in the class include: Agenerase (amprenavir), Invirase (saquinavir hard-gel), Fortovase (saquinavir soft-gel), Crixivan (indinavir), Norvir (ritonavir), Viracept (nelfinavir), Lexiva (fos-amprenavir) and Reyataz (atazanavir). Lexiva and Reyataz, the two newest PIs, can be dosed just once daily and both are usually boosted with Norvir, an older PI, which raises the levels of the drugs in the body. Norvir is also contained in Kaletra and is used to boost the other ingredient of the drug, lopinavir. Norvir is also used to boost Crixivan and Fortovase. Another PI, Viracept, is now available as a 625 mg tablet. This reduces the dose to only two 625 mg tablets twice a day, as compared to the original dose of five 250 mg tablets twice a day.

Though the protease inhibitors are considered to be the most potent of the HIV drugs, they are not without problems. PIs can cause blood glucose levels to rise in people with diabetes and can even bring on new cases of the disease. PIs can also increase the levels of cholesterol and triglycerides in the blood, putting you at risk for a heart attack. Other side effects include: kidney stones with Crixivan, diarrhea with Viracept, hyperbilirubinemia with Reyataz, and all of them can cause nausea and diarrhea.

Tipranavir will likely be the next PI to be approved by the FDA. It is in the latter phase of clinical trials and will be the first non-petidic protease inhibitor (NPPI) available to treat HIV infection. A new 500 mg tablet of an older PI, Invirase, is also expected to be approved this year.

Fusion inhibitors

While the NRTIs, NtRTIs, NNRTIs, and PIs are all working inside the infected CD4 cell to treat HIV, fusion inhibitors fight HIV outside the CD4 cell by blocking fusion of HIV before the virus enters the cell and begins its replication process. Fuzeon is the first (and thus far the only) in this class of drugs to be FDA approved. Administration by twice daily subcutaneous injection and its high cost have limited the use of this drug. The most common side effect of Fuzeon, due to its route of administration, is injection site reactions. To help avoid this side effect, rotation of injection sites is recommended.

Adherence to HIV medications

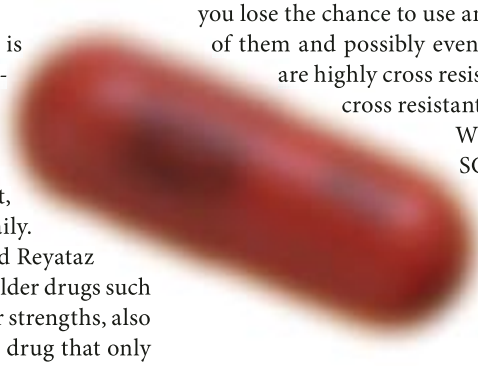
What exactly is adherence when talking about HIV medications? Simply put, adherence is sticking to your program—taking the medications you're supposed to take, on time, every time! Whether you've been on HIV medications for 10 years or are just starting out, it takes a strong personal commitment to take your medications on time, every time. Non-adherence is the number one reason why HIV treatments fail. These medications work—but they can't work if you're not taking them! So, here are some tips and suggestions to help you achieve adherence with your HIV medications.

1. **Make sure you're mentally ready to start taking HIV medications.**
   Not sticking to your regimen makes it very easy for the virus to mutate and develop resistance to the medications, and then you may have wasted the regimen. Don't start taking the medications until you are totally committed to taking them right on time, every time!
2. **Keep your medication regimen simple.**
   Nowadays, simplifying your HIV regimen is often easily done, thanks in part to combination drugs such as Trizivir, Truvada, Combivir, and Epzicom. These drugs combine two or three drugs into one tablet, which reduces pill burden and makes dosing simpler. In fact, Truvada and Epzicom are only taken once daily. Newer protease inhibitors such as Lexiva and Reyataz can also be taken just once daily. Plus, some older drugs such as Sustiva and Viracept are available in higher strengths, also reducing pill burden. Sustiva is also another drug that only has to be taken once daily. Talk with your physician about keeping your regimen simple and easy. Reducing the pill burden and using once daily regimens can greatly increase medication adherence.
3. **Use reminders.**
   Some people use timers or pagers set to go off when it's time to take medications to help them remember to take their meds. Other people take an activity they do every day and link that activity to taking their medications, such as before, with or after meals, before or after showering or brushing teeth or first thing in the morning or right before bedtime. A basic seven-day pillbox is also one of the most useful tools to help with adherence. The pillbox can be stacked with meds once a week with the meds being put in the correct day and time slot. Many pillboxes also are made so that each day can be popped out of the holder and taken with you.
4. **Get help from family and friends.**
   Family and friends can help you stick to your regimen, so don't be afraid to rely on them. Let them know exactly what you're supposed to take and when. You can also ask them to help you remember to take your drugs, which can be easily done with just a simple phone call!

These medications work—
but they can't work if you're not taking them!

Resistance to HIV medications

If the anti-HIV drugs are not kept at a steady level in your body, HIV can quickly make copies of itself and that leads to resistance. Resistance is when HIV is able to resist the effects of the anti-HIV drugs in your body. When that happens, the drugs will not work as well—or even not at all—in stopping HIV from spreading throughout your body. If HIV becomes resistant to a medication, the virus can sometimes become resistant to other medications in the same drug class. This is called "cross-resistance." When this happens, you lose the chance to use another drug from that class, or several of them and possibly even all of them. The NNRTI class drugs are highly cross resistant to one another. Some PIs are also cross resistant to one another.

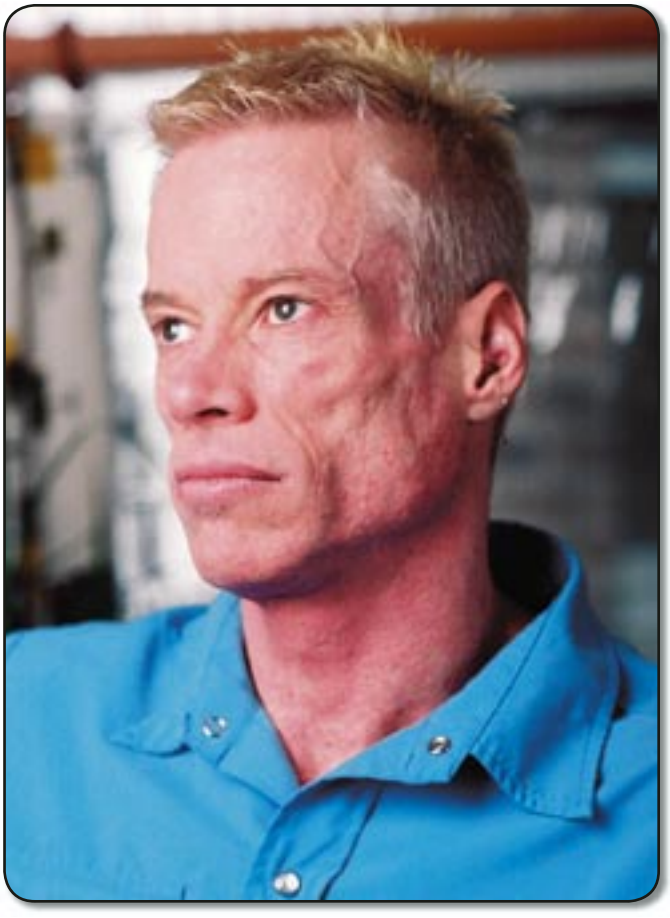


With new drugs such as tipranavir and SCH-D in development, people who are already resistant to other anti-HIV drugs will get another opportunity to continue drug therapy in the battle against HIV.

Steve Meyer is a registered pharmacist with Pharmacare Pharmacy, located at 3337 N. Broadway in Chicago. Steve also assisted with Positively Aware's *first two annual HIV Drug Guides, in 1997 and 1998.*

Facing Up To It

by Matt Sharp



Our faces are the windows of good health. The face, along with body weight, is often the barometer of how most people judge a person's overall health. People with HIV are sometimes told that we look tired, thinner, or stressed out because of a gaunt face. But we are familiar with "the look" attributed to AIDS from the early years when wasting syndrome was often the scarlet letter. And while successful antiviral therapy has changed the outcome of people's health for the better, it unfortunately has left a new symbol of AIDS on our faces, despite how well we feel or how well HIV is being controlled.

The scarlet letter today is a metabolic syndrome called *lipodystrophy* (see sidebar "Lipodystrophy"). Having been diagnosed with wasting syndrome in 1995 and later lipodystrophy, I am very familiar with body shape changes. I have been researching any way to restore my own face with several types of fillers and implants that are being used to reconstruct faces. I have known several people who have used New-Fill (see sidebar on *Sculptra*), microdroplet silicone, fat grafting and collagen, but all have their specific problems including side effects, expense, availability and long-term effectiveness. Most of the products have been used before in some capacity, but only Sculptra has been approved for HIV.

One product garnered my interest when I read that it is a permanent filler, can be removed and is relatively easy to implant. It's called Bio-Alcamid or polyalkylimide, and is available in a clinic in Tijuana called Clinic'estetica. Bio-Alcamid is a biopolymer, made mostly of water and is stable and non-toxic. In studies this far it does not cause granulomas, a cancerous tumor. In those who have used it thus far, Bio-Alcamid appears to be safe and long lasting, however it is not yet widely used, probably due to its expense—approximately $4500—and the fact that it is also not approved in the U.S.

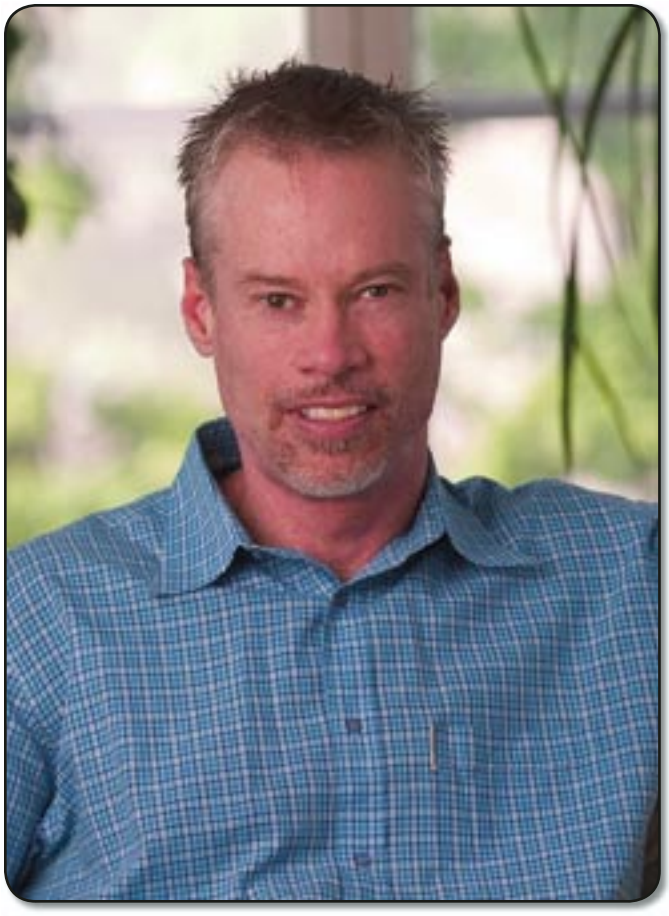
Bio-Alcamid is owned by Polymekon, an Italian company, and has been used in Europe for several years. Because of its biochemistry, it can be used in high volume and can also be removed in cases of overfilling. One to three sessions are required depending on the severity of the lipoatrophy. Several studies in HIV negative reconstructive and cosmetic surgery have been performed in Europe and show positive and lasting results. Other larger trials in HIV facial lipoatrophy are ongoing in Los Angeles and London.

I realized my face was getting bad because I was literally getting double takes in the supermarket. Friends and family who hadn't seen me in awhile were always saying how bad I looked (not in front of me of course). Quite frankly, I knew at times my face looked hollow, but I just wrote it all off as getting older. Despite the fact I couldn't afford it, I came to the realization that it was

Lipodystrophy

Lipodystrophy is a condition that causes several health problems including lipid abnormalities—elevated cholesterol and triglycerides, body fat redistribution and thinning of the limbs and face (more specifically called *lipoatrophy*). Sometimes these symptoms coexist, and most likely they are multifactoral. Lipodystrophy is one of the most common complications seen in HIV. Reporting methods vary, but cases are estimated at 50% of people with HIV.

The good news is that there has been relative progress in treating lipid abnormalities in people with HIV, and some people have been able to control trunk fat associated with protease inhibitors. The bad news is that there have been no advances in treating facial lipoatrophy. Sadly, the look of AIDS persists for those who have sunken cheeks and hollowed temples and therefore stigmatization still exists for those with an otherwise healthy outlook. And unfortunately, some people make the choice between looking good and having to take antiviral therapy.



time to take action. Then, an offer came to *Positively Aware* from Clinic'estetica in Tijuana. The agreement was to trade a written article in the magazine for an actual facial filling with Bio-Alcamid in hopes of reaching out to those who had not heard of the product. I jumped at the offer, made the necessary arrangements and packed my bags for the border.

In May I flew to San Diego and on a warm smoggy morning I met Anna Love, the director of Clinic'estetica. Together we drove with her husband Nick across the border in their SUV. I was somewhat apprehensive about the upcoming procedure, but Anna made me feel at ease as we talked about her history with facial reconstruction in AIDS, and her belief that Bio-Alcamid was the product to beat. Anna is a petite, attractive woman whose background has been in holistic health and plastic surgery—something I subsequently learned was not mutually exclusive. Although living in San Diego, Anna operates Clinic'estetica across the border in Tijuana. And despite not being a physician, she has been performing facial reconstruction for several years at the clinic in AIDS patients who were fortunate enough to afford the luxury. Through her vast experience, Anna is so assured of the quality and effectiveness of Bio-Alcamid that she owns the license to the American subsidiary of the Italian company and has begun the extensive FDA deliberations for approval in the U.S.. Her medical director, Dr. Luis Casavantes, is an M.D. and dermatologist and performs most of the Bio-Alcamid procedures at the clinic. He has authored the studies performed at the clinic and speaks about his experience to medical doctors. Together, Anna and Dr. C, as he is affectionately known, are quite a confident team with excellent bedside manner, and made me feel I was doing the best possible thing for my face. Out of approximately

Sculptra

By Bob Munk

Sculptra (also known as New-Fill) is the first treatment approved by the FDA for lipoatrophy related to HIV disease or treatment. Facial wasting can include a sinking of the cheeks, eyes and temples caused by the loss of fat tissue under the skin. The FDA expedited review of the product because of its importance to people with HIV/AIDS. Sculptra is an injectable form of poly-L-lactic acid. It is a biodegradable, biocompatible synthetic polymer that has been widely used for many years in dissolvable stitches, bone screws, and facial implants.

Sculptra can produce significant increases in skin thickness, adding volume to facial tissue and restoring shape in areas of the face with fat loss in patients with HIV-related facial fat loss. Studies reported an improvement in the quality of life among those treated, including less of the anxiety and depression often associated with lipoatrophy. Each session of Sculptra application involves multiple injections of small volumes of product.

If you search the Internet for "New-Fill" you'll find a lot of European cosmetic surgery clinics. Their ads describe New-Fill as a product that has been used in plastic and reconstructive surgery for over 20 years, and is now available for cosmetic use, especially filling in wrinkles, making the skin appear smoother and firmer. Not surprisingly, you'll see a lot more pictures of Greek statues than of people with facial wasting.

Sculptra was presented to the FDA by Dermik Laboratories, the U.S. dermatology arm of Aventis Pharmaceuticals. According to the FDA advisory panel, the presentation was very weak in terms of data on exactly how the product works. Dermik had recently acquired the product and the clinical trials data, which were not standardized in terms of who was studied, exactly what was measured, for how long, and with how many treatments. At the FDA hearing, several people with HIV who had used Sculptra brought their own "before and after" pictures. They made a compelling case that Sculptra helped them regain self confidence and, in some cases, remain employed.

The panel members unanimously recommended approval of Sculptra, restricted to HIV-related facial wasting. There was concern that the manufacturer, Dermik, would use this FDA approval as the "foot in the door" to start extensive sales and use of Sculptra for cosmetic purposes. However, there's no effective way to prevent "off-label" use of an FDA-approved product, although the manufacturer cannot legally promote off-label uses.

In the studies presented to support Sculptra's approval (two from Europe, and two from the U.S.), patients typically

had several treatment sessions. FDA approval of Sculptra was based on data from 277 HIV-positive patients with severe facial wasting. They were all being treated with antiretroviral drugs, and were primarily white males, mostly ages 41 to 45. Patients were given Sculptra in three to six sessions at two-week intervals, and were followed for two years.

In the U.S., New-Fill is difficult to get—and harder to get paid for. According to the manufacturer's website, Sculptra is available in over 40 countries. Its use to treat facial wasting is reimbursed only in France, and with restrictions in Sweden and the United Kingdom. German people with HIV are suing to force reimbursement for New-Fill. People in the U.S. expected the cost situation to improve following FDA approval but were disappointed. The price of Sculptra more than doubled from what it had been through personal importation through a buyers club (no longer an option), and the physician's fee has to be added. The cost of a restored face? At an estimated $1,400 to $1,500 per session, we're talking about $5,000 to $10,000, with no reimbursement in sight.

After an initial treatment series, repeat treatments may be needed to maintain the correction; most of the product literature mentions that Sculptra corrections can last "a year or more."

Third-party payers are likely to automatically reject claims for what they will call a cosmetic procedure. Efforts are underway to draft a standard "Letter of Medical Necessity" for Sculptra restoration of HIV-related facial wasting. Best chances for reimbursement are in California, where legislation requires coverage of reconstructive surgery. The difference between "cosmetic" and "reconstructive" is a critical one. In the California law, reconstructive surgery is performed to "correct or repair abnormal structures of the body to improve function or to create a normal appearance." Cosmetic surgery is performed "to alter or reshape normal structures of the body to improve appearance."

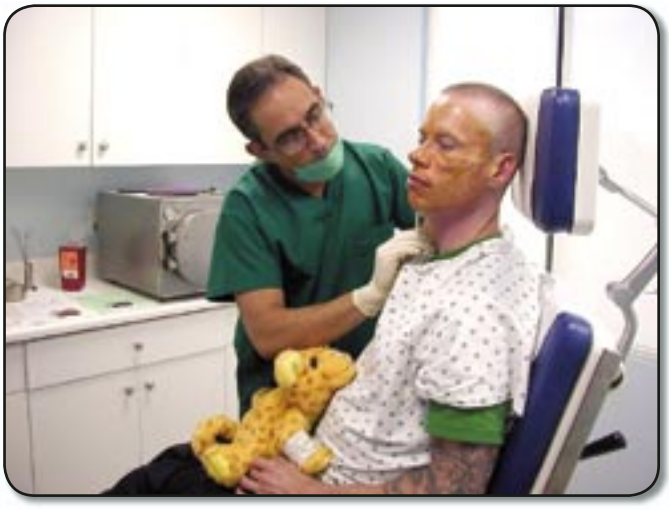
Where from here? Dermik Laboratories is considering a patient assistance program. Details have not yet been worked out. Also, as a condition of FDA approval, Dermik has agreed to conduct an open-label registry study of 100 patients for five years to evaluate Sculptra's long-term safety. The study will include at least 30 females and 30 people with dark skin types. Sculptra is currently available from physicians who participated in the U.S.-based trials, including Peter Engelhard in Miami Beach, Doug Mest in Hermosa Beach, Patrick McNamara in Houston, and Gervais Frechette in New York City. Additional physicians will certainly be instructed in Sculptra use and make it available in their practices. So there is an approved method of dealing with facial wasting—but it's expensive, at least for now.

HIV treatment advocate Bob Munk represented consumers on the FDA advisory committee to review Sculptra. Bob is the Coordinator of the New Mexico AIDS InfoNet.

500 people with HIV who visit the clinic, thousands of fillings with Bio-Alcamid have been performed.

After coffee and more interviews, I was brought into the clinic and told to wash my face thoroughly in preparation. One thing I noticed immediately was the cleanliness of the clinic. After signing a detailed consent form, I posed for the "before" photographs with Anna's boisterous assistant, Ellen. Ellen is an HIV-positive woman who was so happy with her Bio-Alcamid reconstruction at Anna's clinic, she moved from Texas to San Diego to work for Clinic'estetica and promote the procedure to people with HIV. She's a true believer who arranged the procedure for *Positively Aware* so we could report on and experience the benefits first hand. I was ushered into a very sterile exam room with a reclining dental chair, complete with a stuffed animal to grab on to. I had taken no pain medication, since I had expected there to be little pain.

Anna and Dr. C explained that I was a "5"—the most advanced facial fat loss. It would take two or three trips to the clinic to finish the job. Even then, because of HIV, my lipoatrophy might progress in the months after the filling. As I watched the nurse prepare the lidocaine needles for numbing, Dr. C carefully explained in detail each step of the procedure and reassured me that I was going to look terrific.



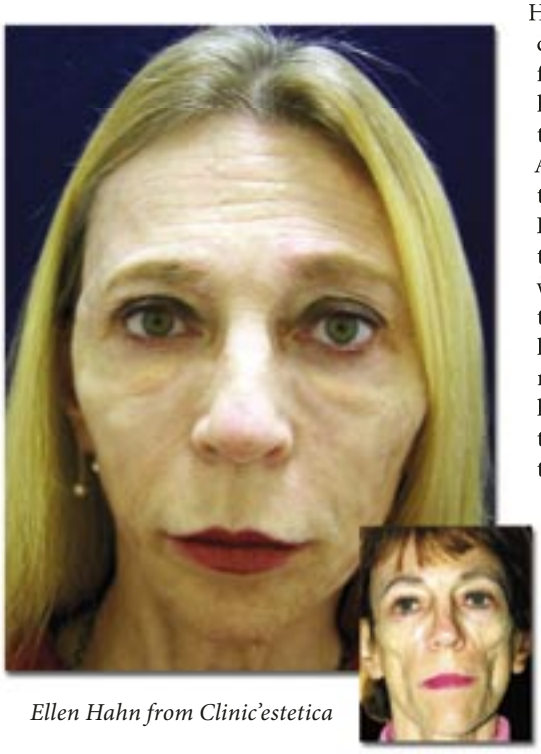
Then he began injecting about seven or eight times in different quadrants of my face to numb me for the Bio-Alcamid. It was an intense "pinching" that burned wherever the lidocaine went in, and probably the worst part of the entire process. In a few minutes I was unable to whistle, which was a sign the drug had taken effect to numb my face.

Dr. C then carefully felt the hollows of my face that needed the Bio-Alcamid. He determined the best place to inject and began by saying, "Here we go!" If the needle went in I didn't feel it, but after the sixth or seventh injection I felt an intense pressure under the skin. Then Dr. C pressed and molded the injected fluid to the form of my face like a wax sculptor. The whole procedure took a little over an hour. Despite the ease of the procedure I was relieved when it was over.

The assistant gave me a mirror so I could witness the immediate results. My face was red and slightly puffy, but the hollows were definitely filled. There was a distinct difference despite the swelling. I felt a sense of relief besides a headache that had developed. I knew the days of lipoatrophy were all but over.

I was given some antibiotics, an anti-inflammatory drug, and some Diflucan to prevent any fungal outbreak. Ellen slapped two ice packs on my swollen gopher cheeks to reduce the swelling. I then left with her to drive back across the border.

Within two days the swelling had subsided and I basically felt no physical difference but felt an improved self confidence. When I returned to Chicago most people reacted subtly to the procedure. Those who knew I had gone to Tijuana for the filling were nicely surprised by the results. Those who didn't know knew something had changed but weren't quite sure what it was. I think the fact that it was such a subtle change—that it was reconstructive, and not so much cosmetic—was definitely a positive outcome. Anna and her team had performed another successful procedure and I had a new face and new outlook on life!



Ellen Hahn from Clinic'estetica

I had a second procedure in early August to complete the job. The "after" pictures you see are reflective of both fillings. I was less apprehensive with the second trip to Tijuana. I came prepared with pain medication and had an overall easier time. Now my face is done and I am feeling like a new man. Despite the traveling I would definitely recommend Bio-Alcamid and the care of Anna's team to anyone.

I spoke with two other men who went to the clinic. Glenn had had several botched fillings with other products, which led to him to Bio-Alcamid. He claims the results have been "amazing" and only wished he had learned of it before he had the other procedures done. "It would have been much easier and saved a lot of money," Glenn said of his outcome. "The confidence and improvement to my self image have been the greatest part. No one looks at me anymore and wonders what kind of horrible disease I have because I don't look sick anymore."

I ran into Dan from Chicago at Clinic'estetica while I was there. He explained that he wanted the procedure because he was a "walking billboard for AIDS" and wanted to feel good about himself so he could date again. A long-term survivor who had been in the first AZT trials, Dan was a little frightened to do the first of three procedures with Bio-Alcamid, but because he was going to be starting a new business where he will be visible to customers, he decided to go ahead. During the procedure Dan had pain medication and said he didn't remember the whole experience. When he returned to work he had similar reactions to mine. Smiling, he explained that the outcome is not like a "night and day" difference but subtle and "most people don't pick up on it."

Today while more people are benefiting from Bio-Alcamid and other procedures for lipoatrophy, the fact remains that the products will only be available for the privileged few who have the cash or those who may get into clinical trials. Even now with the approval of Sculptra there is uncertainty about reimbursement from third party payers. One thing seems clear, however, that products like Bio-Alcamid are raising the standard for good lasting results in reconstructing fat loss that will help us to enjoy a better quality of life into the future.

Resources

by Enid Vázquez

In the age of the Internet, some of the organizations here can be reached only through the Net. Contact the CDC Hotline for HIV service organizations located near you. Visit www.tpan.com for an expanded list of resources.

Hotlines

African Americans

RAP-IT-UP is the HIV awareness campaign of BET, 1–866–RAP-IT-UP (727–4887). The campaign includes presentations at high schools. Visit www.RAP-IT-UP.com. Also write to the **Black AIDS Institute**, 1833 W. 8th St., Ste. 200, Los Angeles, CA. 90057. Call 1–213–353–3610; visit www.blackaids.org.

AIDSInfo

Run by the U.S. Department of Health and Human Services (DHHS). Central resource for HIV treatment guidelines. You can also track down clinical trials. Call 1–800–HIV–0440 (448–0440). Write AIDSinfo, P.O. Box 6303, Rockville, MD 20849–6303. (You can write "Guidelines" instead of AIDSInfo.) Visit www.aidsinfo.nih.gov.

AIDS Treatment Data Network (ATDN)

The New York City organization offers treatment information and counseling in Spanish and English, 1–800–734–7104.

CDC (Centers for Disease Control and Prevention)

National AIDS Hotline: 1–800–342–AIDS (342–2437). For Spanish call 1–800–344–SIDA (344–7432). Open 24 hours a day, seven days a week. The center also offers an e-mail list. Under President Bush, the CDC has sacrificed science to religion, so be careful about CDC advice. (No matter what they're forced to tell you, remember that condoms are a good thing.) Visit www.cdc.gov.

Gay Men's Health Crisis

The New York City agency offers peer counseling and support at 1–800–AIDS–NYC (243–7692). Write GMHC, The Tisch Building, 119 West 24th Street, New York, NY 10011.

Prisoners

The activist group **HIV/Hepatitis C in Prison Committee (HIP)** is at California Prison Focus, 2940 16th St., #B–5, San Francisco, CA 94103. Visit www.prisons.org/hivin.htm. **The Osborne Association's AIDS in Prison Project** sends out health information. Write 809 Westchester Ave., Bronx, NY 10455. Prisoners can call the APP hotline collect on Tuesday, Wednesday and Thursday from 2:30–8 p.m. Eastern Time, but must first be added to their institute's telephone list; 1–718–378–7022.

Project Inform

The agency's National HIV/AIDS Treatment Hotline is 1–800–822–7422. The hotline also mails out treatment information packets. International calls or those from the San Francisco area can be made to 1–415–558–9051. Write to Project Inform, 205 13th Street, #2001, San Francisco, CA 94103. Visit www.projectinform.org.

Women

The **Sister Connect** national warmline is operated by the New Jersey Women and AIDS Network. Includes referrals for pregnancy care and birth control services. Call 1–800–747–1108. The **Sisterhood Mobilized for AIDS/HIV Research and Treatment (SMART)** provides treatment and prevention education. Write to PMB #117, 217 E. 85th Street, NY, NY 10028. Call (917) 593–8797. Visit www.smartuniversity.org. HIV-positive women operate the hotline of **Women Alive**, 1–800–554–4876. Calls can be taken in English and Spanish. Write them at 1566 Burnside Ave., Los Angeles, CA 90019. Visit www.women-alive.org.

The Internet

You can get truly simple-to-understand information on everything HIV from **AIDSinfonet.org**. Tons of great articles are available at **http://hivinsite.ucsf.edu** (that's the correct address—no www.) The **Adult AIDS Clinical Trials Group (AACTG)** also has no www in their address: visit **http://aactg.org** for lots of basic information and a list of their studies.

Other outstanding websites are: **AIDSmeds.com**, **TheBody.com**, **AEGIS.com** and **kaisernetwork.org.** Writer and advocate **Jim Pickett** also posts articles related to HIV and gay rights, plus, information on signing petitions and contacting government representatives. Drop him an e-mail: JimberlyPickett@aol.com. **The Well Project**, an initiative by and for women with HIV, has a comprehensive website: **TheWellProject.com**.

Visit the **AIDS Treatment Activists Coalition (ATAC)**, **atac-usa.org**. At **CHAMP, the Community HIV/AIDS Mobilization Project**, prison issues are a primary concern. Write them at 594 Broadway, Suite 700, New York, New York 10012. Call 1–212–966–0466 ext. 1226. Visit www.champnetwork.org.

Visit **powerusa.org**, and take note of the organization's **facialwasting.org** website.

HIV & AIDS Glossary

compiled by Jeff Berry

Acquired Immunodeficiency Syndrome (AIDS): the late stage of the condition triggered by infection with HIV. According to the official definition by the Centers for Disease Control (CDC), a person receives an AIDS diagnosis when he or she has a CD4 cell count of less than 200 and/or certain opportunistic infections common with advanced immune deficiency.

Acute HIV Infection: the first few months after HIV infection. This initial infection precedes seroconversion and is sometimes characterized by fever, sore throat, headache, skin rash and swollen glands. Also called Primary Infection.

Adherence: the degree to which a patient sticks to a schedule for taking medicines. Non-adherence may lead to drug resistance. Also called "compliance."

AIDS Drug Assistance Program (ADAP): ADAPs serve people with HIV/AIDS who are uninsured or underinsured, including those who are not disabled and, therefore, ineligible for programs like Medicaid. ADAPs are authorized by the Ryan White Care Act. Federal funding goes to states, which use a portion of the money to provide HIV/AIDS drugs, including prophylaxis and treatment of opportunistic conditions, to those who cannot otherwise afford the medications.

Antibody: a disease-fighting protein created by the immune system, also known as immunoglobulin. Antibodies coat, mark for immune destruction, or render harmless foreign matter such as bacteria, viruses or dangerous toxins. Antibodies also tag virus-infected cells, making them vulnerable to attack by the immune system.

Antigen: a foreign substance, usually a protein, that stimulates an immune response. An antigen may have several subunits called epitopes that are targets of specific antibodies or cytotoxic T lymphocytes.

Antiretroviral (ARV): a substance that stops or suppresses the activity of a retrovirus, such as HIV. Nucleoside analogs and protease inhibitors are examples of antiretroviral drugs

Asymptomatic: without signs or symptoms of disease or illness.

B Cell (B Lymphocyte): a type of lymphocyte that is a precursor to plasma cells. During infections, individual B cell clones multiply and are transformed into plasma cells, which produce large amounts of antibodies against a particular antigen on a foreign microbe. This transformation mainly occurs through interaction with the appropriate CD4 cells.

BID: abbreviation for *bis in die*, a Latin phrase meaning "twice a day." A drug prescribed this way should be taken every twelve hours.

Bioavailability: the extent to which an oral medication is absorbed in the digestive tract and reaches the bloodstream.

CD4+ Cells: Special white blood cells that coordinate the immune response to fight bacterial and viral infections. In HIV medicine, the CD4+ count is a marker for measuring immune-system health—normal CD4+ count is between 500 and 1500 per cubic milliliter of blood. HIV infection plus a CD4+ count below 200 is considered an AIDS diagnosis.

Chemokines: Proteins released by cells that stimulate activity between cells. Chemokines are intracellular messenger molecules secreted by CD8+ cells, whose major function is to attract immune cells to sites of infection.

Clinical Trial: a study done to test an experimental drug or procedure in human beings to see whether it is safe and effective, as well as to determine its proper dose.

Compassionate Use: a process for providing experimental drugs on an individual basis to very sick patients who have no treatment options, despite the fact that there is insufficient data on the drug's effectiveness. Often, case-by-case approval must be obtained from the FDA for compassionate use of a drug.

Complete Blood Count (CBC): a screening of the most important cellular components of the blood. A CBC includes the total white blood (leukocyte) count, counts of specific types of white blood cells, red blood cell count, hemoglobin level and platelet count.

Highly Active Antiretroviral Therapy (HAART): anti-HIV treatment, often including a combination of a protease inhibitor or non-nucleoside reverse transcriptase inhibitor and two reverse transcriptase inhibitors, whose purpose is to reduce viral load to undetectable levels.

Human Immunodeficiency Virus (HIV): a retrovirus that is believed to cause AIDS. HIV can be transmitted sexually, by blood-to-blood contact, and perinatally (from mother to child).

HIV-1 is the most common version around the world, while HIV-2 is closely related to HIV-1, but is not as virulent as HIV-1 and is epidemic only in West Africa.

Immunosuppression: weakening of the immune response that occurs with HIV infection as well as with some antiviral or anticancer treatments.

Immune system: The body's complicated natural defense against disruption caused by invading foreign agents (e.g. microbes, viruses). There are two aspects of the immune system's response to disease: innate and acquired. The innate part of the response is mobilized very quickly in response to infection and does not depend on recognizing specific proteins or antigens foreign to an individual's normal tissue. It includes complements, macrophages, dendritic cells and granulocytes. The acquired, or learned, immune response arises when dendritic cells and macrophages present pieces of antigen to lymphocytes, which are genetically programmed to recognize very specific amino acid sequences. The ultimate result is the creation of cloned populations of antibody-producing B cells and cytotoxic T lymphocytes primed to respond to a unique pathogen.

Interferon (IFN): one of a number of antiviral proteins that modulates the immune response.

Lipodystrophy: a disturbance of fat metabolism that involves the absence of fat and/or the abnormal distribution of fat in the body. Currently, "lipodystrophy" is not clearly defined and the term is used to refer to a variety of sydromes, including wasting in the face and extremities, an accumulation of abdominal fat, and breast enlargement. The cause is unknown, but it could be a result of HIV infection and/or antiretroviral therapy.

Lymphocyte: white blood cells that mature and reside in the lymphoid organs and are responsible for the acquired immune response. The two major types of lymphocytes are T cells and B cells.

Macrophage: A large immune cell that devours invading pathogens and other intruders. Stimulates other immune cells by presenting them with small pieces of the invader. Macrophages can harbor large quantities of HIV without being killed, acting as reservoirs of the virus.

Pathogen: any disease-provoking microorganism or material.

q8h: an abbreviation used on prescriptions that means "take every 8 hours."

qd: an abbreviation used on prescriptions that means "take once a day." From the Latin *quaque die*.

Resistance: reduction in a pathogen's sensitivity to a particular drug. Resistance is thought to result mainly from genetic mutation. In HIV, such mutations can change the structure of viral enzymes and proteins so that an antiviral drug cannot bind with them as effectively.

Seroconversion: development of detectable antibodies to HIV in the blood as a result of infection. It normally takes several weeks to several months for antibodies to the virus to develop after HIV transmission. When antibodies to HIV appear in the blood, a person will test positive in the standard ELISA test for HIV.

Structured Treatment Interruption (STI): a planned treatment interruption, typically under medical supervision. The purpose of an STI varies; for example, it can be used to see whether a patient's immune system can control HIV after it has been undetectable for years, or it can be used in an attempt to get a person's viral population to revert from resistant to wild type.

TID: a term used on prescriptions meaning "take three times a day," from the Latin phrase *ter in die*.

Toxicity: the harmful side effects of a given drug.

Undetectable: (Limit of Detection) refers to the sensitivity of a quantitative diagnostic test, such as the viral load assay. The limit of detection is the level below which the test can no longer accurately measure the amount of a substance, such as HIV RNA. If a person has an "undetectable" viral load, it does not mean that HIV is no longer present, but rather, that the test is not sensitive enough to measure the amount. Also called the "limit of quantification."

Viral Load: Amount of measurable HIV virus found in blood or other body fluid sample.

Virus: a noncellular pathogen composed essentially of genetic material (DNA or RNA) surrounded by a protein envelope. Viruses can reproduce only within living cells into which they inject their genetic material. The viral genes then subvert an infected cell's normal chemical processes to create new virus particles, usually killing the cell in the process.

Wild Type Virus: naturally occurring HIV with an optimal genetic makeup and no artificially or lab-induced mutational defects. This term also refers to HIV that has not been exposed to antiviral drugs and therefore has not accumulated mutations conferring drug resistance.

For a more extended glossary, please visit http://www.gmhc.org/health/glossary.html, or call 1-800-HIV-0440 for a free copy of the Glossary of HIV/AIDS Related Terms.

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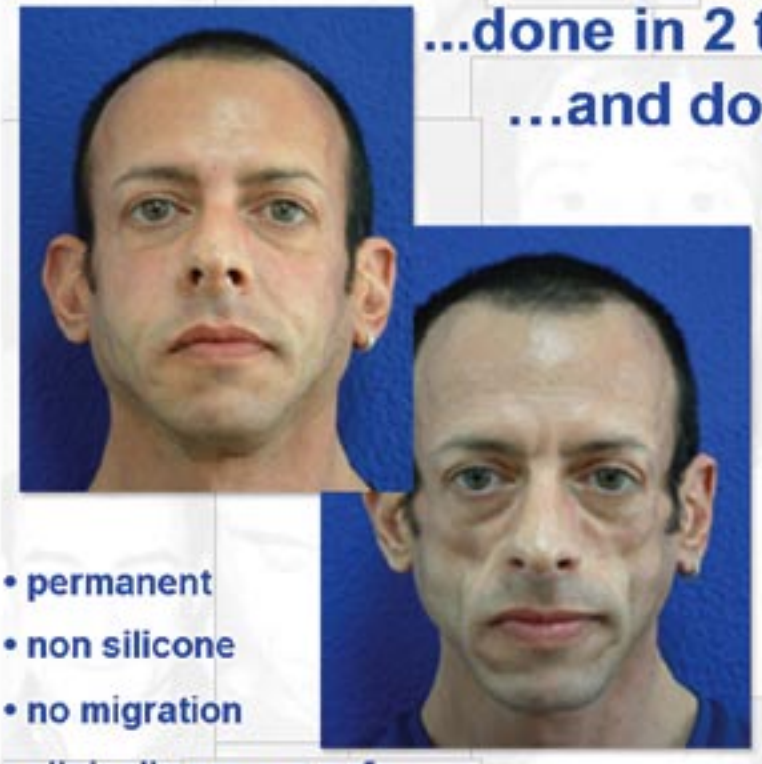

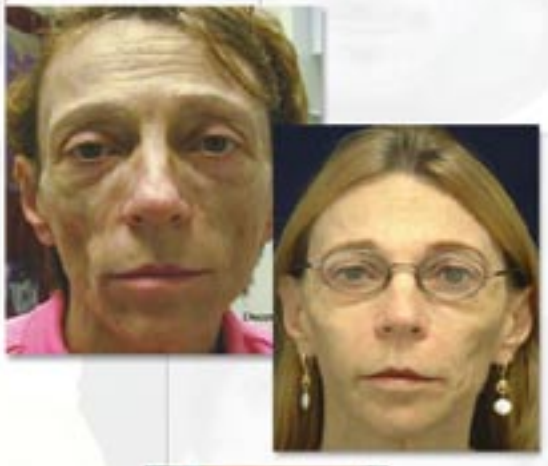

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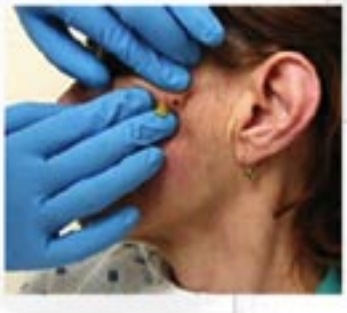

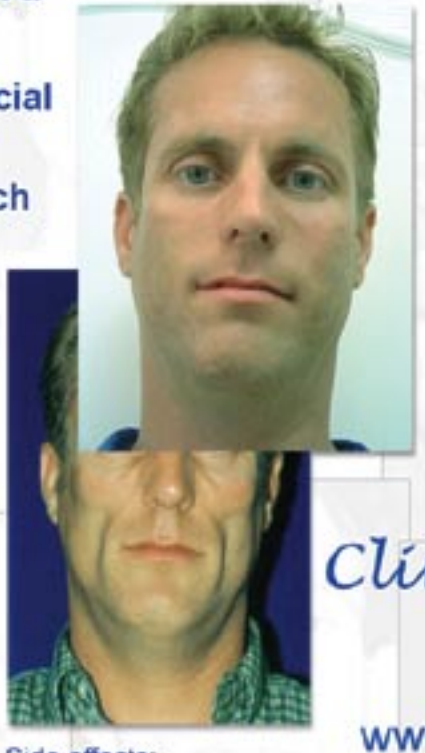

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New Once-a-day Drugs: Truvada and Epzicom

by Daniel S. Berger, MD

Two sexy new once-a-day drugs have appeared ahead of schedule and with much fanfare. Gilead Sciences gained approval for Truvada, a combination pill of Viread and Emtriva. GlaxoSmithKline (GSK) combined Epivir and Ziagen into one pill, Epzicom.

Both Epivir (3TC, lamivudine) and Ziagen (abacavir sulfate) have long track records, originally administered as twice-daily drugs. Viread (tenofovir DF) was uniquely developed as the first nucleotide HIV drug and is administered as one pill, once daily. It was observed to be effective against Epivir-resistant virus. Approval of Emtriva (emtricitabine) followed last year, another once-a-day pill. Emtriva is a drug that is similar to Epivir, but with the advantage of having a more favorable pharmacokinetic (PK) profile (see below). Once-daily Emtriva compared with twice-daily Epivir showed a more potent viral load drop after 11 days of treatment, although the Epivir had a significant and similar decrease as well (-1.7 log compared to -1.45).

All four drugs generally have a low risk of side effects, including a low risk of lipodystrophy. Ziagen, however, can cause a severe allergic response called a hypersensitivity reaction (HSR). Ziagen HSR manifests as flu-like symptoms with at least two of the following: rash, fever, body aches, malaise, headaches, abdominal symptoms or shortness of breath. This HSR only occurs in 5-9% of patients, usually within the first three weeks of treatment. Once a person experiences this HSR, they can never attempt to take Ziagen again. This warning applies to Epzicom and Trizivir, another combination drug that has Ziagen in it.

Experienced physicians following the progress and research regarding these agents should understand the scientific attributes of each and tailor regimens to specific individual patient needs.

Blood levels

Pharmacokinetics (PK) refers to the way a drug works in the blood. A favorable PK generally refers to the longevity of drugs. Medications should be sufficiently potent and be present long enough in both the blood and the cells to allow for effectiveness without causing overwhelming toxicity, ideally while maintaining easy dosing schedules.

For this class of HIV medications, the nucleoside reverse transcriptase inhibitors (NRTIs), drugs must be phosphorylated intracellularly (chemically altered within the cell) before they can become active. Thus, a drug effect is dependent on its dose, its half-life in the plasma (blood) and in the cells, and its rate of intracellular phosphorylation. Newer methods of studying PK plus studies showing efficacy made it possible to consider reducing the dosing frequency of Epivir and Ziagen to once daily (although Ziagen continues to be one tablet twice a day).

As illustrated in Table 1, Ziagen has an intracellular half-life (longevity within the cell) of 12 to 19 hours, while its serum half-life (longevity in the blood) is only 1.5 hours. Epivir has an intracellular half-life of it active (phosphorylated) form of 11 to 16 hours; its activity in plasma is only 3-6 hours. Both components of Truvada have much longer longevity. Viread has an intracellular half life (intracellular longevity) of more than 50 hours and serum half life of 17 hours; Emtriva intracellularly is 39 hours and serum half life is 10 hours. Patients are human and may miss a dose by several hours from time to time. Drugs with longer half lives, while also remaining longer within body cells, may remain effective for a longer time.

Importantly, research supports once-daily dosing of Ziagen and Epivir. It was as effective as twice-daily dosing (each with Sustiva) with no increased side effects observed in the once-daily group.

Once A Day Keeps the Doctor Away

Adherence means taking all medication doses as prescribed, and good adherence is required to achieve the best therapeutic results. New formulations like Truvada and Epzicom are a welcome addition to our treatment landscape and should be convenient for both new patients starting on treatment as well as treatment-experienced patients.

There are studies showing that once-daily drug combinations resulted in better adherence. As more data from large randomized trials become available, once-daily HAART (highly active antiretroviral therapy) may show better durability in treatment. Yet, putting individuals on once-daily drug regimens may have other implications. Drugs that do not provide full coverage for 24 hours in a once-daily combination can potentially be a danger for subtherapeutic blood levels. In twice-daily regimens, one missed dose a week translates to one out of 14 doses, or 8% missed. One missed dose of a once-a–day regimen translates to one out of 7 doses, or 15% missed. In this situation, more time without antiviral coverage means suboptimal HIV suppression. This usually results in lowered antiretroviral plasma (blood) levels, leading to development of resistant strains of the virus.

Despite the missed dosing drawback, it is generally agreed that once-daily dosing is more practical and patient friendly; ultimately it should improve durability through better adherence. Because there are other factors that influence adherence, seasoned HIV physicians understand that there is no magic answer for all patients.

Who's on first

There exists much controversy regarding the sequencing of the new Truvada and Epzicom. When we refer to sequencing, we are describing a chess game. When making each move on a chess board, you need to keep in mind your partner's next move against you. Likewise, choosing an HIV drug regimen mandates an awareness of potential resistance to those medications that can develop later on and have a plan for treatment options ahead. The medications prescribed the first time an individual goes on HIV therapy can be crucial later on to that person's therapy because HIV mutates itself to get around drugs. The HIV mutations represent what we call "drug resistance"—HIV is resisting (fighting) that medication. The individual may then have to switch to a new drug or drugs. Resistance and sequencing is complicated and there is much we are still learning. Some mutations pop up more quickly than others. Some cause resistance to other medications that the person has yet to take.

Various mutations are associated with resistance to specific antiviral agents. For example, the M184V mutation is associated with Epivir resistance and the K65R mutation can be associated with Ziagen, Videx or Viread. If Epivir resistance develops during treatment with Epzicom (M184V mutation), then later treatment with Viread continues to remain a treatment option. However, if Epzicom selects for the L74V mutant, a recent study showed this to potentially result in the eventual emergence of K65R, which can potentially block the option of later treatment with Viread.

Two Gilead studies in which Viread was given to highly treatment-experienced patients found that the infrequent presence of K65R was associated with only low-grade resistance to Viread. The few patients in these trials who had this mutation also had a history of Ziagen or Videx treatment, which was implicated as the cause of the K65R. Moreover, the K65R mutation is associated with a low-grade resistance to Ziagen and Videx, and moderate resistance to Epivir. In real world clinical experience, resistance to Viread occurs relatively infrequently and patients who have the K65R often respond to Viread treatment. In my clinic, we find that in phenotypic resistance tests (in which the patient's virus is pitted against a drug in a test tube), Viread is still effective against HIV despite the presence of K65R.

To make things more complicated, if a patient takes Truvada and develops both K65R and M184V, there is the potential to eliminate later options for treatment with Ziagen, Trizivir and Epzicom. However, if one developed resistance with AZT or Combivir (a combination of AZT and Epivir), the mutations might also block one's options with Viread as well as other agents.

Thus one can see how complicated drug sequencing becomes, especially when newer treatments come to market. We usually don't have all the answers in the beginning.

Summary

The arrival of the two new formulations have made it simpler for patients, but there are still unanswered questions and clinicians debate which drugs are best for patients beginning therapy. The patient's needs along with details such as pharmacokinetics, sequencing and resistance all need to be measured. Epzicom and Truvada both can be combined with other single-dosed antivirals to construct true once-daily regimens. They can also be combined with other dosing regimens to reduce pill burden. Furthermore, fixed-dose combination pills of three antivirals (like Trizivir) are being developed.

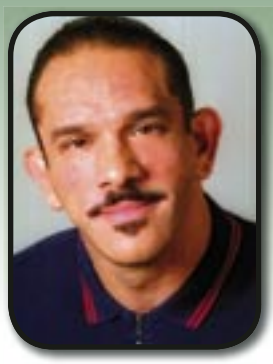
Table 1

Half lives of the Epivir + Ziagen (Epzicom) and Viread + Emtriva (Truvada).

Longer half lives may be more practical and forgiving, especially for patients who have difficulty taking daily medications promptly, every 12 hours.

Drug	Intracellular Half-life	Serum Half-life
Ziagen	12-14 hours	1.5 hours
Epivir	14-18 hours	3-6 hours
Viread	More than 50 hours	17 hours
Emtriva	39 hours	10 hours

Daniel S. Berger, MD, is Medical Director of Chicago's largest private HIV treatment and research center, NorthStar Healthcare and Clinical Assistant Professor of Medicine at the University of Illinois at Chicago. He serves on the HIV Medical Issues Committee for the Illinois AIDS Drug Assistance Program, the Board of Directors for the AIDS Foundation of Chicago and the Editorial Board of Contagion, Reports, Cases, and Commentaries in HIV and Infectious Disease Research. Dr. Berger can be reached at DSBergerMD@aol.com or (773) 296-2400.



Peripheral Neuropathy

by Carlos A. Perez

I had PN (peripheral neuropathy) for about three years, and with hindsight I can say that it was one of the complications of HIV and its medications that held me deep in depression for a very long time. PN is caused by damage to the nerves that serve the peripheral extremities such as hands and feet. HIV itself can cause PN, however, most people feel its painful wrath sometime after taking certain HIV medications. I was taking ddI (Videx), d4T (Zerit) and 3TC (Epivir), back in the early '90s.

The neurologist I was seeing added prednisone to my regimen and amitriptyline to see if these two additional medications might ease the pain. When all else fails, if it's a mammal give it some prednisone! These drugs helped somewhat—amitriptyline when taken at high doses helped quite a bit—but the side effects were making me feel like a zombie.

You know what eased the pain? Marijuana, that terrible, gateway drug that America must win the war against. Sorry, enough about failed war efforts. When I smoked half a joint the pain went away as long as I kept off my feet. When I had to get up and move my carcass around, no matter what I had popped or smoked, the PN came back. But the pot did help keep the pain at bay for a longer period of time than the "white man's drug." What finally worked was switching off the infamous "d" drugs I was taking.

Now let's get real about this pain. When you read the medical establishment's definition of PN it usually talks about throbbing, tingling and aching—sometimes they get a little real and mention a burning sensation. But I'll tell you what it's like. It is like frostbite. I've never really had frostbite, but have read about it and I have played too long in the snow and gotten to the point when my feet got so cold that they were numb and hurt something awful.

I'll tell you what else it's like. It's like walking slowly over hot coals. Never done that either but I don't have to, to know it's going to burn like hell. A friend of mine who has never kicked PN and who went to work on crutches for a while due to the severity of the pain told me it's like someone is digging red, hot pokers into the bottom of his feet. His description reminds me all too well of what my pain was like. The pain is excruciating and debilitating.

> The pain is excruciating and debilitating.

I have read about Lidocaine and Capzasin-P being used as a topical ointment that may ease the pain and may work with some who only suffer mildly from PN. Another temporary relief may come from Neurontin, an anti-seizure medication used in diabetics with PN, although I've read it works temporarily and best at night. Lamictal, an anti-spasmodic, has been somewhat successful for some who suffer from PN, but it may have possibly severe side effects for those who are pregnant or suffering from liver disease, and there is also a hypersensitivity side effect that may cause some serious reactions.

There is a procedure called anodyne therapy that's been around for three years. It works by emitting infrared photo energy to increase circulation and temporarily reduce pain to the affected area. The diodes emitting the energy are placed directly on the skin where the pain exists. A diode is an electron tube having a cathode and an anode, basically a semiconductor that flows current in one direction. It can be applied to the feet as well as the hands. Clients report the therapy feels warm and soothing and others say they feel tingling and pulsing; this is normal as blood returns to the area. It is covered by most insurance plans and Medicare and there are no reported side effects when properly used and monitored.

I went to the Greater Chicago Foot & Ankle Associates Clinic with a buddy of mine who has terrible PN. The client takes off his shoes and rests his feet on black rubber mats that hold the diodes. My friend says he felt relief after his fourth session. After the session that I came along to watch, he said he immediately felt relief and that it would probably feel painless for about 24 to 48 hours, until the next session. The effects are cumulative, and usually after 12 sessions should only have to be repeated once every three to four months.

Dr. Christopher Staehling D.P.M.—whose clientele is 50% HIV-positive—said that it does take several sessions to feel improvement because "we are dealing with nerve damage, which used to be thought of as permanent damage." One of his HIV patients never experienced PN again. It took my friend 10 minutes for him to feel the warmth coming through the soles of his feet, and I did notice a jump in his stride on the way out. We won't know for sure if this is the cure for PN, but it certainly looks like a painless, drugless, side-effect free alternative.

Photo © Russell McGonagle

Fuseon Refuse to Settle Ad Page Here

Marathon Man

by Jim Pickett

On October 10, in exactly two weeks, I will run 26.2 miles in the Chicago Marathon.

I began training for this day in April, via the AIDS Marathon Training Program. This program, which exists in Washington, DC, Los Angeles, San Francisco, and sweet home Chicago, trains participants to run a marathon and in exchange we agree to raise money for HIV/AIDS services in our area. In Chicago as of this writing, we have raised nearly 1.2 million unfettered dollars that will go to the AIDS Foundation of Chicago's grant making program.

On every level, this has been the challenge of my life. I've never enjoyed, nor been particularly good at fundraising and up until this program, I never really saw myself as athletic. Because I wasn't, Blanche, I wasn't athletic.

I've always maintained an intense aversion to any sort of hitting, throwing, kicking or catching of any sort of cylindrical object. Anything that required some sort of hand-eye coordination? Umm, I don't think so. The torment, the humiliation, always picked last for any team… While I was a decent swimmer and had actually competed as a young boy, by high school I had become completely mortified by my own body—especially but not limited to my pale, hairy Planet of the Ape stick legs—and the thought of willingly spending hours in a Speedo around lots of other people was about as appealing as turning my head and coughing in the doctor's office with my mother in the room. No. I think I'll pass, thank you.

I was also a burgeoning big time sissy, whether I was fully aware of that or not, and spending lots of time around other boys in Speedos probably wasn't the best idea. Though today it sounds fabulous, among boys my own age (or at least the legal age of consent) of course!

So, I went out for track in my freshman year of high school. Why? I felt the pressure to do some kind of sport. All boys did sports, and I was a boy. Hello. Well, I lasted all of one infinitely miserable day. The asthmatic wheezing, the limping, the shooting pains, the inner screaming and sobbing—and that was just the warm up—encouraged me never to return. I'd stick with theater, natch.

So earlier this year, when I willingly signed up for a program that culminated with the running of a frickin' marathon, I was taking a leap of faith into an abyss fraught with painful self-doubt, a plethora of neuroses, bad memories and the very real potential of extreme physical, mental and emotional trauma.

Sometimes denial is a good thing.

I listened to those discouraging, naysaying voices, both in my head and around me. "Don't do it, you can't do it, you're crazy for doing it. And what about your knees???" I ignored them. Sometimes being a stubborn SOB is a good thing too.

The combination of highly disciplined physical training—run 3x/week, cross train 3x/week—and raising funds for a cause that is at the center of my life both personally and professionally, has given me more rewards on every level than I ever could have imagined.

Despite being "not good" at fundraising, I have brought in over $4,000 to date. Despite being an "un-athletic" sissy, I have thrived on the physical training and become a very respectable runner, if I must say so myself. I have already run 26 miles, okay? Despite being someone who avoided competition like a plate of liver and onions ("Christina, eat your meat!"), I have run three races this summer, two 5k's and one 10k. Never done anything like that before. While I went into each thinking, "Oh, I don't really care about how fast I run, I just want to experience being in a race," I found myself really pushing and, dare I say it, actively competing with myself and the other participants. Fast and hard, woo hoo!

A benefit to all of this running and training that was completely unanticipated is the overall feeling of confidence I gained in my body and what my body could do. The level of comfort I have with myself, my abilities, and my potential increased as well.

I mean, I willingly played Frisbee with my boyfriend this summer. Scary but true, it was my idea. Now this may seem like nada to you, but lest you forget, Frisbee involves throwing, catching, and eye-hand coordination. While I am not going to be asked to be the captain of any Olympic Frisbee team, I actually enjoyed it and wasn't absolutely awful, neither.

After 38 years, I finally feel like Baby Jane Hudson, after she has dragged her poor, half-dead sister onto the hot beach and says, "You mean… after all these years we could have been friends?" That's the feeling I have with me and my body. Eliminating all that psychic garbage has been the greatest gift. And now more than ever, I feel like I can meet the challenges HIV might, and most likely will, throw my way.

Incidentally, my T-cells shot up over 100% this year. The start of 2004 they were around 600. Last count, 1,291. My doctor, who had been, shall we say, un-thrilled about me and my knees doing a marathon, exclaimed, "Must be all that running you are doing!"

Smell them sweaty socks.

Click www.AIDSMarathon.com for more info.

Take Note.

That sore could be a symptom of syphilis.

If you're sexually active, make syphilis testing part of the routine. For more information about symptoms, testing and treatment — syphilis is curable — visit our new and improved web site **www.GetTestedChicago.com** or call a counselor at the state's STD/HIV hotline at **1-800-243-2437** (Illinois only).

SYPHILIS TESTING

Just part of the routine.

Silabha

by Keith Green

Since Charles' passing, I have dreaded sitting down to write this column. It is, after all, a work in progress… under his direction. I think often about the last conversation that I had with him and, truth be told, my whole life is a work in progress… under his direction. In that conversation, he made it clear that I was to put school first and TPAN second ("This will be here… school is most important for you right now"). He shared his vision of expanding the agency with me and we were beginning to lay the groundwork for the role that I would play in that expansion. He had brought me back a T-shirt from the International Conference on AIDS that simply read "Silabha". I had asked him what "Silabha" meant but he didn't have time to share with me at that moment so with that loving smile that I will miss so much he simply stated, "I'll get back to you." The smile that he gave me let me know that he had something up his sleeve.

I knew that there had to be something significant about "Silabha" and that there was a reason why he had chosen that shirt for me. I looked forward to him sharing that reason with me and the inspiration that I knew would follow. Charles was just that kind of man… inspiring in everything that he did. About a week after his passing as I fumbled through my closet for something to wear to work, I came across that shirt. As I stared at the single blood red word traced in gold, printed across the front of an all black T-shirt I began to weep uncontrollably. I cried until I no longer needed to iron the shirt because of wrinkles, but to dry it from the soaking that my tears had given it. My eyes became so clouded that the words on the shirt looked as if they had begun to bleed. Although Charles's passing was not a bloody one, it was certainly violent. Another of our great African American leaders lost. I cried for Charles. I cried for Malcolm. I cried for Marvin. I cried for Tupac. I cried for Martin. I cried for my grandfather whom I watched being slowly eaten away by lung and prostate cancer. I just cried, hysterically. When I had cried until I could not cry anymore I put on my shirt and headed into cyberspace, searching for "Silabha" and ultimately, Charles. As I began my Google search, an overwhelming sense of comfort came over me and I suddenly got the strangest feeling that I was not alone. When I located the definition of "Silabha" I knew without a doubt that I wasn't. There was Charles. There was Malcolm. There was Marvin. There was Granddaddy. There was Tupac… and there too was Martin.

An overwhelming sense of comfort came over me and I suddenly got the strangest feeling that I was not alone.

"Silabha" is the Thai word for all things to do with art and culture. Culture is at the heart of everything that we do—it shapes our ideas, behavior, expression, and perception of the world around us. The "Silabha" Art and Culture Program, presented at the XV International AIDS Conference brought together a range of extraordinary artistic and cultural events and people from all over the world to share and express ideas and experiences relating to HIV/AIDS in creative ways—bringing the issues which affect all of us out into the open and helping to build greater understanding. The violent deaths of all of those wonderful leaders before us can all be traced to our lack of "greater understanding" and not just as it relates to HIV/AIDS. As a people, whether black, white, brown, gay, straight, lesbian, transgendered… whatever, we lack an understanding of true love and acceptance for one another. This program suggests that through "Silabha" there can be a cure. Maybe not a literal cure for AIDS, but a cure for all that ails us as a human race. Perhaps through art and culture we as a people can get a clearer picture of the extremely diverse lives that we each lead individually and gain the understanding that there is no real division among us. We are all human with basic human needs and desires. We all need compassion. We all need security. We all need love. I believe that when we all gain an understanding of the fact that these elements are just as relevant to our universe as earth, wind or fire, then a cure for AIDS will surface. Fathers won't kill their sons… or vice versa. There won't be a real need for leaders… let alone their assassins. There would be a "Marvin Gaye featuring Tupac Shakur" hit! Our brothers would not be gunned down in the streets. I would be able to sit in my Granddaddy's lap and listen contently to our family history. And Charles would still be here to continue to direct this work in progress. But you are reading this… so maybe he is.

Photo © Russell McGonagle

TPAN Events Calendar

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

November 2004

Date	Time	Event
Tuesday 2	All Day	Election Day - VOTE!
Wednesday 3	7:30 pm	Committed to Living Series – Understanding Labs with Dr. James Sullivan. Support provided by BMS Virology.
Saturday 6	4–6 pm	See Eyewear Anniversary Party to benefit TPAN. 2531 N. Clark.
Wednesday 10	7:30 pm	CTL South – The TPAN HIV Treatment Education Series heads to Chicago's southside. Please check www.tpan.com for time and location details. Support provided by BMS Virology.
Thursday 11	6–10 pm	PULSE Military Party. The weekly social event for Chicago's HIV community recognizes Veterans Day with a special military uniform party. Prizes will be given for best uniform, Berlin, 954 W. Belmont.
Thurs 25 & Fri 26	All Day	TPAN Offices Closed For Holiday.

December 2004

Date	Time	Event
Wednesday 1	All Day	World AIDS Day
Wednesday 1	7:30 pm	Committed to Living Series – Clinical Trials and Pipeline Treatments. Support provided by Boehringer Ingelheim.
Tuesday 7	6–8 pm	TPAN Holiday Party and Volunteer Awards at Sidetrack, 3349 N. Halsted.
Thursday 16	6–10pm	PULSE Holiday Party – Spread the seasonal cheer with the gang at PULSE, The social event for Chicago's HIV community, Berlin, 954 W. Belmont.
Fri 24 & Mon 27	All Day	TPAN Offices Closed For Holiday.
Friday 31	All Day	TPAN Offices Closed For Holiday.

We hear you, and we're making some changes!

- *Positively Aware's* yearly subscription rate of $30 is completely optional. Please look for the subscription order form on page 33 or visit www.tpan.com.
- Copies of *Positively Aware* are available in bulk to all AIDS and community service oganizations in the US, regardless of an agency's ability to pay.
- Results of our 2004 Reader Survey will be published in an upcoming issue. PA will be making some changes based upon your great suggestions.
- Look for upcoming special issues of *Positively Aware*. These special issues will be more of an in depth exploration of specific issues of concern and interest to those living with HIV.
- During 2005, look for the "Be Positively Aware" HIV Awareness campaign. The campaign has been developed to increase awareness about HIV/AIDS and to prevent the further spread of HIV.

Programs and Meetings

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

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

Monday

Medical Clinic

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

TPAN Daytimers

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

Reiki

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

HEALTH

Support group for people co-infected with HIV and hepatitis. Meets from 7-9 pm.

Couples Group

Support group for couples affected by HIV. One or both partners may be HIV-positive. Meets 7:30–9 pm.

Crystal Meth Anonymous (CMA)

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

Spirit Alive!

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

Tuesday

Medical Clinic

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

Yoga

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

Positive Progress

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

Living Positive

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

Wednesday

Reiki

See description on Monday. Wednesday by appointment only.

Test Aware

TPAN's new rapid HIV counseling and testing program. Learn results in around 20 minutes. Wednesday 10 am-6 pm. or by appointment.

Needle Exchange Program

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

Poz Leathermen

Support and social group for HIV-positive leathermen and friends. Meets from 7:30–9 pm.

SHE (Strong, Healthy and Empowered)

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

Thursday

Yoga

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

Medical Clinic

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

TPAN Daytimers

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

Needle Exchange Program

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

BUS (Brothers United in Support)

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

Positive Now

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

Pulse at Berlin

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

Friday

Needle Exchange Program

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

Scheduled By Appointment

FASN (Family AIDS Support Network)

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

Individual Counseling

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

Peer Support Network/Buddy Program

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

Speakers Bureau

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

TEAM (Treatment, Education, Advocacy and Management)

Peer-led program integrating secondary prevention and treatment education to provide individuals the training and knowledge to more successfully support other individuals impacted by HIV. Call Montré at (773) 989-9400.

Miscellaneous

livingpos18to24@aol.com

An AOL chat room for young adults (ages 18–24) who are HIV-positive. Monday through Friday from 3–5 pm. Contact email livingpos18to24@aol.com

Test Positive Aware Network thanks all of it generous sponsors, talent and donors for their support of the Aware Affair.

THE TEST POSITIVE AWARE NETWORK GALA
AWARE AFFAIR
SEPTEMBER 10, 2004

Thank you for being aware!

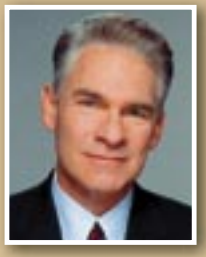
The 2004 TPAN Gala

Friday, September 10, 2004

Hyatt Regency Chicago

Hosted by

Mary Ann Childers
CBS Anchor and Medical Editor



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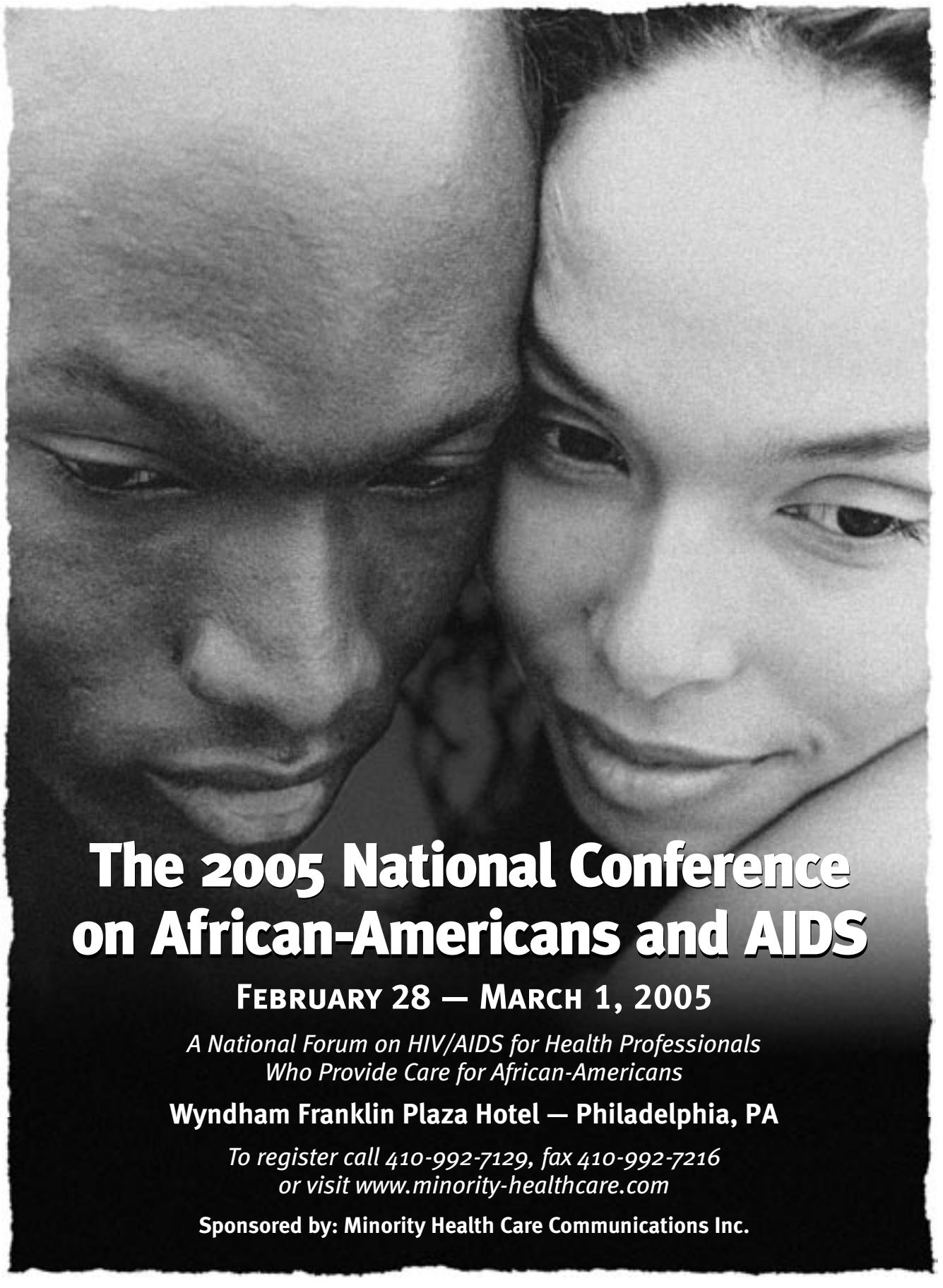

The 2005 National Conference on African-Americans and AIDS

February 28 — March 1, 2005

A National Forum on HIV/AIDS for Health Professionals Who Provide Care for African-Americans

Wyndham Franklin Plaza Hotel — Philadelphia, PA

To register call 410-992-7129, fax 410-992-7216 or visit www.minority-healthcare.com

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