

March / April 2005



# Positively Aware

The Journal of Test Positive Aware Network



## The Straight Issue

- PEP—Not the Morning After Pill for HIV
  - Dating and Daring to Love Again
  - Online Resources for Straight Positives

# 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>

March / April 2005  
Volume 16 Number 2

## Departments

- 7 **Editor's Note**  
SUPPORT THE RYAN WHITE  
CARE ACT
- 11 **Readers Forum**
- 12 **News Briefs**  
*by Enid Vázquez*
- 38 **The Buzz**  
GIRAFFES AND HIV  
*Treatment interruptions  
with a twist*  
*by Andrew Zalski, M.D.*
- 40 **What's Goin' On?**  
SEX, LIES AND HIV: TRUTH HURTS  
*She knew I had sex with men,  
she didn't know I was positive*  
*by Keith R. Green*
- 42 **Pickett Fences**  
WORK YOUR ACTION  
*These are not days in which to  
be lazy, my dears*  
*by Jim Pickett*
- 44 **Livin' with it**  
POZDAR  
*Beyond gaydar*  
*by Tom Setto*
- 45 **Programs and Meetings**
- 46 **TPAN Events Calendar**

## Articles

- 17 **Dating and Daring to Love Again**  
*One woman's journey after becoming a young widow*  
*by Barb Marcotte*
- 22 **Guys and Girls—Interview with the Founder  
of NYC's Straight Social Group**  
*Support groups and educational forums are nice. Newsletters are great.  
But what about love?*  
*by Enid Vázquez*
- 25 **Online Resources for HIV-positive Heterosexuals**  
*Chat, post an ad, or meet at a conference*  
*compiled by Laura Jones*
- 26 **Small-town Living and Loving**  
*How one woman infected at 50 went on to find happiness*  
*by Enid Vázquez*
- 27 **New Protease Inhibitor TMC-114**  
*Preliminary 24-Week Late Breaker Results of the Phase II Trial*  
*by Daniel S. Berger, M.D.*
- 30 **The Nebulous Spirit**  
*On the path towards reclaiming your spirituality, expect some bumps  
along the way*  
*by Jeff Berry*
- 32 **HIV Treatment Series III  
Part Four of Five**  
LOWERING THE RISK OF HIV AFTER SEX OR OTHER EXPOSURE  
*by Tony Hosey, PharmD.*

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



## POSITION ANNOUNCEMENT: DIRECTOR OF PUBLICATIONS

Test Positive Aware Network, the Midwest's largest HIV support, information and empowerment organization for all people impacted by HIV, seeks a Director of Publications, to lead the Publications department, and serve as editor of *Positively Aware* and *Positively Aware en Español*. Also oversees department budget and administration; supervises Publications staff; edits, writes, solicits and assigns articles; determines editorial content, design and tone of publications; and manages all aspects of production and distribution.

Applicants should possess solid editorial experience and proven HIV/AIDS treatment knowledge and expertise, in addition to proven management ability; strong leadership, organizational, interpersonal and communications skills; ability to work in a deadline-oriented environment; understanding and ability to apply copyright laws; demonstrated ability to understand budgeting and resource allocation process and methods.

A degree in Journalism, English, Communications or other relevant field or commensurate experience, combined with at least three years of publishing and one-year of management experience is required. People of color and people with disabilities, including HIV, are strongly encouraged to apply.

A competitive salary and benefits package will be offered.

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.

Please submit cover letters and resumes in confidence, with full career and salary details, and clips to [editorsearch@tpan.com](mailto:editorsearch@tpan.com) or via mail to:

Editor Search, Test Positive Aware Network, 5537 N. Broadway Street, Chicago, IL 60640-1405.

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.



Test Positive Aware Network  
5537 North Broadway  
Chicago, IL 60640

phone: (773) 989-9400  
fax: (773) 989-9494  
e-mail: [tpan@tpan.com](mailto:tpan@tpan.com)  
<http://www.tpan.com>

INTERIM EDITOR  
Jeff Berry

ASSOCIATE EDITOR  
Enid Vázquez

INTERIM EXECUTIVE DIRECTOR  
Rick Bejlovec

DIRECTOR OF TREATMENT EDUCATION  
Matt Sharp

DIRECTOR OF ADVERTISING  
Danny Kopelson

CONTRIBUTING WRITERS  
Keith Green, Laura Jones, Carlos A. Perez,  
Jim Pickett, Tom Setto

MEDICAL ADVISORY BOARD  
Daniel S. Berger, M.D., Leslie Charles, M.D.,  
Thomas Barrett, M.D., Glen Pietrandoni, R. Ph.  
Patrick G. Clay, Pharm. D.

ART DIRECTION  
Russell McGonagle

© 2005, Test Positive Aware Network, Inc. For reprint permission, contact Jeff Berry. Six issues mailed bulkrate for \$30 donation; mailed free to TPAN members or those unable to contribute.

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

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

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

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

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

## SUPPORT THE RYAN WHITE CARE ACT



Several weeks ago, concerned activists and members of community organizations here in Chicago gathered to discuss reauthorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The event was co-sponsored by the Chicago Department of Public Health, Communities Advocating Emergency AIDS Relief (CAEAR) Coalition, Chicago Area HIV/AIDS Caucus, and Test Positive Aware Network.

The CARE Act was established by Congress in 1990, named after the young Indiana teen who died of AIDS. It comes up for renewal every five years, and the legislation that authorizes the Act will expire on September 30, 2005. According to the CAEAR Coalition, a national membership organization dedicated to meeting the critical needs of PWHIV through services provided by the CARE Act, the Act is the “largest discretionary investment in the care of people with HIV/AIDS in the U.S., [and] funds primary health care and support services for people with HIV/AIDS who lack health insurance and financial resources for their care.

“Each year, CARE Act programs reach more than 533,000 individuals with or at risk for HIV in all 50 states, the District of Columbia, Puerto Rico and the U.S. territories.

“Since 1990, CARE Act-funded services have:

- reduced AIDS mortality by 70 percent
- curbed mother-to-child transmission of HIV by 70 percent; and
- reduced HIV-related hospital admissions 30 percent nationally and up to 75 percent in some locales”

Included in the CARE Act are provisions for access to HIV medications for those who cannot afford them, otherwise known as the AIDS Drug Assistance Program (ADAP). This is a vital program, which unfortunately has waiting lists in many states due to lack of funding, and the rising cost of treatment.

While the CARE Act itself is up for renewal every five years, the actual funding of the Act is determined on an annual basis. The CARE Act has been funded essentially at a “flat” level over the past several years, resulting in an overall decrease in funding. Meanwhile, the need for services steadily increases along with new infections every year, while the cost of providing these services rises as well.

It is imperative that we let our elected officials know that the Ryan White CARE Act is making a crucial difference in the lives of the people they represent, and requires increased federal support. In so doing, Congress will send the message to the American

people that providing these much needed services to people living with HIV/AIDS in the U.S. is of the highest priority.

There are three potential amendments that could potentially be included in the reauthorized CARE Act, and are worrisome.

The first is mandatory testing for pregnant women. This could indirectly drive more people to not seek care, and raises additional issues regarding privacy.

The second is increased funding of abstinence-only programs. While abstaining from sex can and should be a part of a well-rounded sex education curriculum for youth, abstinence-only programs have not been shown to be effective in reducing the spread of HIV.

And finally, increased funding of faith-based programs is on the agenda. There are currently many organizations that are affiliated with various denominations, which already do some phenomenal work in HIV/AIDS. However, I believe it sets a dangerous precedent and sends the wrong message to mandate that a certain percentage of federal funds be tied to “faith-based” organizations. What percentage of Christian, Muslim, Jewish, and other organizations will qualify for these funds? What guidelines will they be required to follow? Which established, successful programs will be slashed to accommodate them? Are agnostics, or atheists, to be considered? And whatever happened to the separation of church and state?

The CAEAR Coalition has developed the Principles for Ryan White CARE Act Reauthorization:

- The Ryan White CARE Act works, and it must be reauthorized.
- People living with HIV, especially consumers of CARE Act services, must be a central part of the reauthorization process and provide continued input into CARE Act planning.
- The existing CARE Act title structure must be maintained to provide the ability to target policies and resources to diverse populations impacted by the AIDS epidemic.
- The CARE Act must address current, evolving and ongoing emergency needs of people living with HIV and AIDS and the organizations that serve them.
- Many people with AIDS are living longer.
- Many people living with HIV/AIDS need access to more treatment and medical support services.

*continued on page 39*

*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.

Write to: Positively Aware,  
5537 North Broadway  
Chicago, IL 60640  
Fax: (773) 989-9494  
E-mail: readersforum@tpan.com

## VIRAMUNE CORRECTION

The 9th Annual HIV Drug Guide (January/February 2005) incorrectly stated that Viramune is taken as one 400 mg tablet once a day. Viramune is only available in 200 mg tablets. Also, while it has long been commonly prescribed to be taken once a day (as two 200 mg tablets), that dose has not been approved by the U.S. Food and Drug Administration. The approved dose is one 200 mg tablet, twice a day. *Positively Aware* apologizes for the oversights.

## HI, GEORGE,

I felt inspired to reach out to you after I read your article [Waiting for a Transplant—One Man's Story] in the May/June, 2004 issue of *Positively Aware*.

I'm a 48-year-old white female in New Jersey, and have been a sober member of A.A. since April 1991. I owe my life to that fellowship, which drastically changed my life and gave me freedom from the drugs and alcohol that had been killing me for a very long time. I was diagnosed with HIV in June 1993. It's been a trip, to say the least. I was hospitalized twice with pneumonia, the first HIV-related in '97 (when I had two T-cells!) and the second not HIV-related in June 2001. Both of them were bad, but by the grace of God, I made it through and am okay to talk about it today. My last T-cell count was 318 and my viral load has been undetectable for a couple of years. I've been on meds since the first hospital visit in '97, and believe me, they've taken their toll on my body with lipodystrophy. I hate it, but I have to accept it and be grateful I'm alive and relatively healthy.

To add to the difficulties of living with HIV, I found out a year ago that I have hepatitis C. That really floored me. I never put a needle in my body, nor have I ever had a blood transfusion. I didn't think one could get hepatitis from sex, but obviously I was wrong. Anyway, I have it and it's scaring me to death. After living all these years with

HIV and coming to believe that I can live a long life, I feel like the rug has been pulled out from under me. The first viral load was 760,000, the second went up to 1,530,000, and the third one (two months ago) went down to 1,100,000. My liver functions that show up on my regular labwork are fine, but my doctor says that the only way to know if there's liver damage is to do a liver biopsy. She also tells me that eventually I'm going to have to do the treatment (the interferon thing), but I'm nowhere near ready. I'm scared to death of it. I'm scared of the treatment (because I know so many people who did it and got so terribly sick), and I'm scared not to do anything and run the risk of liver damage which can eventually lead to cirrhosis. I love my doctor, everything she's ever guided me to do has been good for me and worked well...I really do trust her, I'm just scared. I have a new fear now that it's not the HIV that's "going to get me," it's probably the hepatitis.

Sometimes I feel like it's all too much, and sometimes my faith instills in me a strength that tells me that I can get through anything...that I need to trust God and take the right actions. These last few weeks, however, I've been experiencing a lot of fear and sadness. I just want it all to go away, but that's not going to happen. It's here, and it's real. I know you understand...you've been through worse than me, yet you made it through. Thank you for the hope you gave me. You and so many people like you are my heroes.

Thank you, and God Bless,  
Debbie  
Via the Internet

## DR. BERGER

I came across an article that you wrote for *Positively Aware* in late 2001 about the product New-Fill. I have a couple of friends who traveled to New York (Dr. Frechette) about 24 months ago for the treatment with

amazing results. There is a clinic here in Atlanta conducting the procedure with the product under the name Sculptra. Unfortunately, since FDA approval, the Sculptra product and treatment is about three times the cost of the New-Fill treatment.

Do you know where I can obtain New-Fill at the lower cost? Is there anyone in the U.S. still using New-Fill, or can I obtain it from a buyer's club? I thought about contacting Dr. Jorge Tagle or possibly someone else outside the U.S., do you have any suggestions?

I am now ready to get this treatment (I estimate probably four treatments), but I am outraged by the cost since FDA approval. (If I obtain the treatments in Atlanta the total cost will be at least \$6,000.) Your assistance would be greatly appreciated.

Bill  
Atlanta, Georgia

Bill,

*I agree with you about the dramatic and outrageous cost difference—the pharmaceutical company should understand this is generally for use with HIV-positive patients stricken with a problem, and not for cosmetic use or higher-end affluent patients. But this would be expected here in the U.S. Jorge Tagle or direct from France may be less costly. Also Dr. Ken Stein in Chicago may be less expensive. (Editor's Note: see News Briefs on page 12 for information on Sculptra patient assistance.)*

Daniel S. Berger, MD 



by Enid Vázquez

## JIM PICKETT, AIDS MARATHON MAN

Writer, wit, policy maker and activist Jim Pickett (see Pickett Fences on p. 42), was among the AIDS Marathon runners who helped raise more than \$1.2 million for the AIDS Foundation of Chicago during the October Chicago Marathon. He came in with a time of 4:15:11, placing 14,320 out of 33,000 runners. Pickett wrote, “The male winner, Evans Rutto, came in at 2:06:16, so I got my work cut out for me next year. And hold on to your tiaras, *there will be a next year*. It was an amazing, tingly experience, the day was stunning, gorgeous, perfect, Chicago never looked better, and seeing many of you out there on the course (including my beautiful partner—Omar—who came in from Dallas to be Head Cheerleader, and later Human Crutch) made it that way.” Congratulations, my dear Pickles. And thank you again for all your efforts on behalf of the HIV community.

## NEW 500 MG INVIRASE

The U.S. Food and Drug Administration (FDA) in December approved a 500 mg film-coated tablet formula of Invirase (saquinavir mesylate). Like the other formulas of Invirase, it must be taken with a small dose of Norvir (ritonavir) and food. Both drugs are protease inhibitors. The new tablets reduce the Invirase dose from five pills to two, twice daily.

## SCULPTRA PATIENT ASSISTANCE

Nelson Vergel, an outstanding activist for the HIV community, presented this report on the facial filling product approved by the U.S. Food and Drug Administration late last year. “Sculptra is the new name for what used to be called New Fill (polylactic acid). We had a meeting with Dermik. They presented some of the details of the Sculptra Patient Assistance Program (go to [www.Sculptra.com](http://www.Sculptra.com) and [www.facialwasting.org](http://www.facialwasting.org) for more information on the product, and for a sample letter for payers). All doctors and patients wanting to participate in the program should call 1-888-SCULPTRA. For someone with no dependents, the product will be provided for free if income is \$40,000 or below. A sliding scale will be applied up to \$80,000 (with no dependents). After \$80,000 (no dependents) the full cost of the product is \$960 per kit (two vials, which is what most need for one session). Every case is different and will be handled by people answering the number. I think they, or your doctor, have to try to get through your third party payer first and get denied for you to qualify.

“I am trying to come up with a way to get doctors listed in [facialwasting.org](http://facialwasting.org) who have been trained and are charging reasonable labor rates (under \$450 per session). Remember that there will be assistance only for product cost, not labor. You will still have to pay a doctor about \$300–\$500 a session for labor. Most people need 4–8 sessions of Sculptra, depending on the severity of their facial wasting. I hope one day we can get third party reimbursement for not only product but also labor cost (this will require lots of activism). With the help of others, I will generate a list of questions that all patients should ask the doctor applying this product to see if that doctor has received proper training. It will be no easy task to determine who is best qualified to apply this product besides number of prior patients and time using it.” To learn about people’s experiences with Sculptra and other facial restoration products, join a free Internet discussion group by sending a blank e-mail to [Pozhealth-subscribe@yahoo.com](mailto:Pozhealth-subscribe@yahoo.com).

## TREATMENT GUIDELINES UPDATED

U.S. HIV treatment guidelines for both adults and children were updated late last year. Pediatric guidelines now include two supplements, on managing both complications of HIV infection as well as adverse drug effects. There is also information added about Reyataz, Crixivan and Fuzeon.

For adult (and adolescent) guidelines, there were many more changes. People with more than 350 T-cells can wait to start treatment when their viral load is 100,000. The figure from previous guidelines was 55,000. The guidelines state that, “This is based on more recent data supporting HIV RNA level of greater than 100,000 copies/mL being a stronger predictor for disease progression than [above] 55,000, though even at these CD4 and viral load levels, the risk of disease progression is still relatively low. Most experienced clinicians will defer therapy with quarterly clinical and laboratory evaluation.” (Remember that recommendations change with circumstances; for example, therapy is recommended for anyone with an AIDS-defining illness or severe symptoms of infection, no matter what their T-cell count is.)

For initial therapy, Zerit has been moved from the “preferred” to the “alternative” list because of “increasing reports of [Zerit]-associated toxicities.” Added to the preferred list is the combination of Viread with either EpiVir or Emtriva as the backbone of a drug regimen. (Viread and Emtriva are also available in a new combination pill, called Truvada. However, the new combination pill of EpiVir with Ziagen, called Emtriva, was not added, probably because of

Photo © Russell McGonagle

potential toxicity with Ziagen.) Emtriva by itself was also added to initial therapy, on both the preferred and alternative lists.

Treatment considerations for special populations (adolescents, injection drug users, or people with either hepatitis or tuberculosis), were also added.

See guidelines for the complete list of changes. For a free copy, write to AIDSinfo, P.O. Box 6303, Rockville, MD 0849-6303 or call 1-800-HIV-0440 (1-800-448-0440). Visit [www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov).

#### NO CRIXIVAN DURING PREGNANCY

As a result of new data, Crixivan (indinavir) is not recommended for HIV-positive pregnant women. The package insert for the protease inhibitor has been updated to include information from a Pediatric AIDS Clinical Trials Group study, PACTG 358, showing substantially reduced Crixivan blood concentrations in women at weeks 30-32 weeks gestation.

#### VACCINE STUDY RECRUITMENT

The Aaron Diamond AIDS Research Center (ADARC) and the AIDS Vaccine Initiative (IAVI) have begun enrollment of HIV-negative persons ages 18-40 for an HIV vaccine study. The vaccine is ADMVA, based on Modified Vaccinia Ankara (if that means anything to you!). Vaccine studies are very technical, but one thing is easy to understand: we need a lot of bodies to get them studied, including people of color. Please pass the word to HIV-negative friends and family. For more information, they can call Elizabeth Londoño at 1-212-448-5125 or e-mail [aidsvaccine@adarc.org](mailto:aidsvaccine@adarc.org).

A much larger study—1,500 persons—is also newly enrolling. The National Institute of Allergy and Infectious Diseases (NIAID), part of the National Institutes of Health (NIH), working with Merck & Co., are studying “an experimental vaccine to stimulate HIV-specific cellular immunity, which prompts the body to produce T cells that kill HIV-infected cells. In previous smaller trials, this vaccine was found to be safe and to induce cellular immune responses against HIV in more than half of volunteers.” In a press release, NIAID director Anthony S. Fauci, M.D., says that, “This new study is the first time we have used such a large sample of people to test whether a vaccine that stimulates cellular immunity alone either blocks HIV infection, decreases the level of HIV early in infection or both,” says Anthony S. Fauci, M.D., director of NIAID. The researchers need HIV-negative volunteers between the ages of 18 and 45 who are at an increased risk of acquiring HIV. For more information on enrolling, visit [www.hvtn.org](http://www.hvtn.org).

#### VIAMUNE CHANGES

The prescribing label for Viramune (nevirapine) has been updated. The label now states that, “Based on serious and life-threatening hepatotoxicity [liver toxicity] observed in controlled and uncontrolled studies, Viramune should not be initiated in adult females with CD4+ cell counts greater than 250 cells/mm<sup>3</sup> or in adult males with CD4+ cell counts greater than 400 cells/mm<sup>3</sup> unless the benefit outweighs the risk (see Warnings).” Patients should also now be receiving a medication guide with every refill.

The potential for liver problems with Viramune are well known, and new patients especially should be monitored carefully.

The warnings section of the label goes on to state that, “The patients at greatest risk of hepatic [liver] events, including potentially fatal events, are women with high CD4 counts. In general, during the first 6 weeks of treatment, women have a three fold higher risk than men for symptomatic, often rash-associated, hepatic events (5.8% versus 2.2%), and patients with higher CD4 counts at initiation of Viramune therapy are at higher risk for symptomatic hepatic events with Viramune. In a retrospective review, women with CD4 counts greater than 250 cells/mm<sup>3</sup> had a 12-fold higher risk of symptomatic hepatic adverse events compared to women with CD4 counts <250 cells/mm<sup>3</sup> (11.0% versus 0.9%). An increased risk was observed in men with CD4 counts >400 cells/mm<sup>3</sup> (6.3% versus 1.2% for men with CD4 counts <400 cells/mm<sup>3</sup>). However, all patients, regardless of gender, CD4 count, or antiretroviral treatment history, should be monitored for hepatotoxicity since symptomatic hepatic adverse events have been reported at all CD4 counts. Co-infection with hepatitis B or C and/or increased liver function tests at the start of therapy with Viramune are associated with a greater risk of later symptomatic events (6 weeks or more after starting Viramune) and asymptomatic increases in AST or ALT.”

Visit [www.viramune.com](http://www.viramune.com), or ask your pharmacist for a copy of the package insert (also called “prescribing information”).

#### DROOPY EYELIDS

A true story, from a member of the Test Positive Aware Network staff, for others who may be experiencing the same problem. “My friend Dan was having vision problems, even though his eyesight had always been good. His mother mentioned to him that it looked like he had Droopy Eyelids. Long story short, he went to his doctor, then an ophthalmologist, who sent him to a plastic surgeon specializing in eyes only. The surgeon said that he has worked on a number of HIV-positive patients who had premature Droopy Eyelids. This means that the muscle holding the eyelid open becomes unattached and the lids sag, covering the eye and blocking vision. Plastic surgery can fix the problem and do a cosmetic eye lift too at the same time.

“Many of us have never heard of this, but apparently it happens to older folks and now to HIV-positive folks with lipatrophy. I had thought this might be a good thing to feature as many poz people like Dan may be walking around with poor vision and not having any idea what is happening to them. This could keep them informed and learn about how to solve the problem.”

#### NEW DRUG, ALINIA, FOR GIARDIA

The U.S. Food and Drug Administration (FDA) last summer approved Alinia (nitazoxanide tablets) for treatment of diarrhea caused by the parasite *Giardia lamblia* in patients 12 years of age and older. The suspension formula had previously been approved for treatment of *Giardia* and *cryptosporidium parvum* (crypto for short, another parasitic infection) in children ages 1 to 11. ☙



# Dating and Daring to Love Again

One woman's journey  
after becoming  
a young widow

by Barb Marcotte

**I**t was October 8, 1993. I was 26 years old. I remember that day like it happened yesterday. I had just spent a week watching my husband die. It was like a dream. I remember sitting on the porch, the sun shining. My father was with me, his strong hand on my back, soothing and comforting me. I realized that there was just one sound that I could hear and that sound was my own scream. The scream of my shattered dreams. The dream of a future that will never be, children, a house, vacations, and old age with a love that I had lost so abruptly because of HIV. My husband, Bill, was just 37 years old.

Today I am 37. I am living and loving again. If anyone tells you that dreams do not come true, then please read on. I am going to share my experiences with dating, disclosure and relationships from one HIV-positive woman's point of view.

First, let me tell you how it all began for me. It was the spring of 1990. I was happy, healthy and had my shit together. I had just graduated from college, gotten an awesome job (21 thou a year), and dumped an asshole of a boyfriend. I was certain that I had an excellent future ahead of me. When you are that age you feel like nothing can stop you.



But then, who ever expected as a woman that I would get HIV?

#### SOUL MATES

I was just starting to grow up and realize that my destiny was in my hands. I met Bill while out one night with some friends, listening to a band. It was right before Saint Patrick's Day and I am handing out leprechaun coasters, gummy bears and plastic monster women. (I loved giving out gag gifts from random yard sales.) This dude who resembles John Lennon approaches me. I hand him a coaster and he gives me his keys. At the time I did not realize that these were the keys to his heart. I proceed to ignore him for the remainder of the evening. He approaches me for his keys and I agree to return them along with my number. The next day Bill calls me. This is where it all starts.

I remember that summer as a growing experience. Here I am a little Catholic girl from Ohio who really had not been too many places outside of Ohio. Bill, a chef, was 10 years older and introduced me to so many things: French food, romance, culture and travel. A year later, we decide to be married.

We were just returning from a vacation in California. I was driving us home from the airport when Bill says to me: Diane (Bill's ex) called and she told me that she is positive; I got tested and I am positive too. He did not even use the word HIV or AIDS, but I knew.

All I could say and think was, Oh, my God, I don't want to lose you. How could God do this to me? I had found the person,

my soul mate, who I want to spend the rest of my life with and now You were going to take him away from me? I was angry. A while later I thought about my own status. Bill and I talked. I knew that I loved him and no matter what, I would not leave him. We would be married. But I was certain that my hopes and dreams for a future would end.

I tested positive for HIV in August 1991. I remember sitting at the health department with a friend and the test counselor who gave me my results and crying, crying,

**When I told Bill that my test had come back positive, he was angry.**

crying. I cried because I would never have children, a future or a life.

When I told Bill that my test had come back positive, he was angry. He was so angry that although normally a very quiet person, he went into the basement and broke everything he could get his hands on. My status—what Bill believed he had done to me—was something he struggled with. Bill felt that he had robbed me of life, of travel—of all the wonderful experiences he had already enjoyed.

The truth is, I never blamed Bill. If I blamed anyone, I blamed myself. I made a choice to have sex without using a condom. Before Bill died, I whispered in his ear, "It is okay for you to go. I will be okay and I promise that I will take care of myself."

#### PUTTING LOVE ON HOLD

Finding out that you are HIV-positive makes you think about what you want for your future. For many years after Bill's death, I did not think that I had one. I only thought about when I would die. I think I was actually expecting and looking forward to death. I was unhappy with life, myself and angry that this had happened to me. I did not feel attractive, interesting or fun. I felt stuck in a town and a job because of HIV. I was afraid that I would be unable to get medical insurance, so I had to stay in the same job, which I did for 13 years.

I never expected to meet anyone else I could love as much as I loved Bill. And even if I did, I never wanted to go through the experience of losing someone again.

I was just bitter and angry. I would go out with friends and

basically scare all of the men away with my angry attitude and looks. Any guy who would dare talk to me, I would be like, "What the hell do you want? Get away from me." I was not the most pleasant person to be around. And my girlfriends were not so pleased by my "cross to vampires" attitude.

But after a while without sex or intimacy with another person, a young girl's mind begins to wander beyond the toy in her drawer

I still had it in my head that I did not need or want a relationship. Maybe in some ways I did not think that I was worth having a good person in my life. At times in my life, HIV really made me feel dirty, ugly and just unhappy with who I was. I also had it



in my head that I would never ever again watch someone I love die.

This reflected in my life and my choices. I dated men who would never be relationship choices for me if I were “healthy.” I chose men who were still struggling with addiction, were unemployed or were “players.” My friends had a running joke that none of the guys I dated had a car, ’cause most of them were jerks.

#### STARTING OVER

Eventually I began to hope for more. I was not dead and I was still young. If I live, will I be living this life alone? Is that what I want? Is this really a death sentence? What about those hopes of a future and a family?

So if I date, then what do I do? I am positive! Do I tell the person? Will he run? What about meeting other HIV-positive men? What about having a child? All of these thoughts were in my head.

I was fortunate to have a good first dating experience about two years after the death of my husband. I met a guy who I thought was gay, so I was nice to him (as he posed no threat of possible date potential). Turns out that my “gaydar” must have been down that night. He asked me out and I felt that I needed to tell him. I just came out and said it, “I am HIV-positive.” He looked at me and said, “Okay, what do we need to do?” Now, I will tell you his response is not the usual straight boy response, but I was lucky to have it, because if I had not, I wonder if I would have had the courage or self-esteem to continue my dating ventures.

#### DATING VIA THE INTERNET

From my other HIV-positive female friends, I began to hear about the HIV heterosexual Internet dating scene. I had just gotten my first computer for a birthday present and thought that I would check some of the sites out. Today, the straight dating scene for a positive/positive relationship is much like Internet dating for HIV-negative individuals.

Many of these dating sites have great information and links. Some offer social activities for HIV-positive straight people

a conference, but rather a “hook up” social event, not what I had expected or wanted. I left there feeling like I had been placed back in the horrible years of adolescence where the boys only spoke to the prom queens and the cheerleaders. I did, however make some great new friends.

A big tip to folks using the Internet dating web sites: please try to be honest about what you want and what you are looking for. If you do not have the same desires or expectations, then let it be known. And if all you really want is a piece of ass, then say it. There are men and women out there looking for just that.

A word of caution, before you meet someone, remember, safety first. Meet in a public place, perhaps with a friend. One of the ways I checked on people before I met them was to ask the other women who I knew from the

**Many of these dating sites have great information and links. Some offer social activities for HIV-positive straight people to meet and get to know each other.**

to meet and get to know each other. But beware, and remember that HIV-positive men or women can still be the same as the jerks you may have dated in the HIV-negative scene.

I had heard of women and men who meet on these sites just jumping into relationships and marriage without really knowing the person. I think that many of us still have the idea that we do not have long to live and so we become involved with the first person who comes along. I hope that the men and women reading this can begin to realize that you can live with HIV, have children, marry and plan a future. (See resources on p. 25.)

I went to a “conference” held by one of the websites. I found it to be not really

Internet site if they knew of the guy. It is a small community and most people seem to know others or know of them.

But at the same time, take what you hear about folks with a grain of salt. Not everything you hear is the truth and you really need to form your own opinion. Take your time getting to know a person before you decide to meet and certainly before you decide to jump into a relationship.

It is particularly difficult to get to know someone who lives in another state. You need to spend time talking about interests, ideas and expectations. Meeting at a social event for HIV-positive heterosexuals is usually a safer venue. There are cruises, dances, conferences and social events all over the U.S. Many local AIDS service organizations



## TALKING 'BOUT YOUR STATUS

Disclosure, a hot topic. Do we tell, when do we tell, how do we tell and whom do we tell? Well, here is something anyone who is HIV-positive should know: Every state in the U.S. has generic criminal statutes that could apply to conduct that exposes others to HIV. Twenty-seven states have some type of law that specifically criminalizes the exposure or transmission of HIV. The AIDS Legal Council of Chicago says that often states without HIV-specific criminal transmission laws will find ways to prosecute HIV-positive individuals who do not disclose their status by charging them with assault, battery or attempted murder.

For more information on the specific laws in your state, you can see the HIV Criminal Law and Policy Project web site: <http://www.hivcriminallaw.org/laws/hivspec.cfm>.

I am sure we have all heard stories in the media of men and women being charged for not telling sex partners that they are HIV-positive. If I am HIV-positive and I just want to have sex or a one-night stand and that person consents, we use a condom and we both get a need fulfilled, am I any more obligated to tell him or her my status then they are to tell me that they have herpes or some other STD (sexually transmitted disease)? And what if they do not know their status or avoid getting tested because of not wanting to know—are they any more or less legally liable than I am? This is really a difficult topic for many.

Let's say you meet someone you are interested in—when is the best time to tell him or her your little secret? I can give you some examples of my experiences with this, but I am not sure that I have an answer for you. Each person needs to choose what is best for them and what approach makes them most comfortable.

When I first started dating again, I ran into someone I had known before I graduated from college. We had worked together and he had known me for three years. He asked me out one day and told me that he had been interested in me since way back then, but he had heard that I had gotten married. He asked me how my husband died and my common story was a "brain tumor." We went out a couple of times and I felt like I should just get it over with and let him know. I told him that I had HIV and that was really how my husband had died. His response was: "Were you a prostitute or did you shoot up?" He placed me in a stereotypical group for women with HIV, not unlike the stereotype of men with HIV being gay. At the time I was shocked, and made myself his HIV educator.

Today that kind of response would just piss me off. Why must HIV always be about a judgment of who I am? And does it really matter how I got it?

I handled the disclosure topic in many different ways, but most of the time I told men on our first date. Some I never heard from again, some I had to present the HIV 101 session to, some were cool and knowledgeable, or they took the time to do their own research. Some I sent to my friend Chuck, the HIV test counselor at the health department, and let him play the educator (like the guy from Bulgaria who was shocked to find out I had HIV—turns out he was running around on his wife). But, either way it was a relief to me. To have the issue out in the open and over with. I still worried about my disclosure getting back to people at my job or my friends who didn't know. It was an internal debate that was never simple for me.—Barb Marcotte

hold support groups or educational programs which also give you an opportunity to meet others with HIV. Some have specific heterosexual support services or events.

## SINK OR SWIM

I started speaking with a young man from Chicago whom I met through an Internet dating site in 1999. We became friends, we had a lot in common: music, food, laughter and strong wills. I met Steve after speaking with him for about six months. When I met him, I was a bit shocked and scared. He did not look healthy. He was thin, pale and had little energy. This was a memory that brought me back to one of my main reasons for not dating in the first place. I knew that Steve was a guy I could really care about, but I was determined to not allow myself to do this. You see, I could not, would not, should not, let myself do this again. I could not love someone so deeply again that they would leave me and take a part of me with them. I had done that once—hadn't I learned from the first time?

After meeting Steve, I tried not to stay in touch with him. I thought that would just be easier. But he would call and invite me to Chicago and we would go out to wonderful romantic restaurants and he would treat me like I was so special. HIV was not something I thought of with Steve. He was a guy I would be attracted to even if we were not positive. Laughter and mischief were always part of our times together. For the first time in my life, when I was with Steve, I felt like I was living again. And he had a car.

I did not tell my family or most of my friends about Steve in the beginning, because I was sure they would see how I felt about him and then it would make it more difficult for me to avoid those feelings.

Then he got sick, really sick. I talked to him while he was in the hospital. He was dying. I hung the phone up and screamed in my lonely, empty house. I vowed never to call him again. Then I called his father



to see how he was doing and if I could do anything for him.

A few weeks later, Steve called. He was getting out of the hospital. I thought this just could not be true, but still he was too much of a risk. We spoke over the next few months and Steve's voice sounded stronger each time. I started to think more about my life and what I wanted in my future (since I now realized I was going to be here). I became stronger by making a decision to start caring about myself physically and mentally. Maybe it was Steve who made me realize that if he was going to live, then I guess that I could too.

It was the summer of 2002. Steve asked if I wanted to go on a positive heterosexual camping trip planned in Ohio. It was close to my home and he thought that it would be fun. I was reluctant, but agreed.

When he arrived on my front porch, I was in shock. He had gained weight and he looked so healthy. I could see that his energy, vibrancy and health were returning. That was the weekend that my wall seemed to come crumbling down. When I took Steve to the airport, he left me with these words, "I would really like it if you could be more a part of my life." I got in the car and cried all the way home. How could he do this to me? He ruined my gloom and doom outlook on my life. I knew it.

Today, I live in Chicago with Steve; we have a home and a very naughty Siamese cat named Chet (he's also jazzy). We go on vacations, talk about having children and where we want to retire. We are strong, healthy and happy.

Life changes, and so do dreams and goals. I believe that I am a stronger and a better person because of HIV. I am blessed because of the people I have met during my journey with HIV.

Thirteen years after Bill's death, I realize that my life can go on. I told Bill that I would go on with life, and I think he would be happy with what I have been able to accomplish.

I know now that it is possible to love again. Each love will be different, but wonderful. I realize that even if people come into your life for just a short time, that time—no matter how long or short—is all worth it. I hope that others reading this article make a decision to take a chance on loving, because if we don't, we take the risk of losing out on something wonderful—living. ✚

*Barb Marcotte is Director of Programs at TPAN.*



**When he arrived  
on my front porch,  
I was in shock.  
He had gained weight and  
he looked so healthy.**



As a facilitator of support groups at New York City's Body Positive during the early '90s, straight boy Thorner Harris heard people say over and over that all social events for heterosexuals with HIV were largely limited to those living in the therapeutic community. Some felt unwelcome at the events, or they couldn't relate to people in recovery. Harris thought, Why not try to start a social group where the greatest cross-section of positive straight people could meet each other?

His idea was to have a group that was not based on a formal support group, where there are guidelines about keeping personal relationships equal with all members of the group. Harris envisioned this new group as "a social club or professional association," which allows—even encourages—people to have whatever level of personal involvement with which they're comfortable.

A few friends and a few hundred dollars later (including ads in Body Positive, the Village Voice and New York magazine), Guys and Girls began. Members happy with their experience gave flyers to their medical providers to pass on to other patients. The group's been going strong for 10 years now. With few—if any—exceptions, they're the only group of its kind in the country. They were so successful, gay men approached the group about starting one for them, and Nothing But Guys took off six years ago.

"We create a place of community, filled with friendship and camaraderie, where people with the virus can meet. It has normalized the experience of living with HIV," Harris says. "It gives people the opportunity to walk into this safe space and see other people with HIV who are living normal, well-adjusted lives. You see that HIV cuts across all groups. You walk in and see the librarian, the truck driver, the lawyer, or someone who's disabled, but you can't tell their profession by looking at them. People new to the group often remark how healthy people look, and this is very helpful and powerful for the newly diagnosed."

Participants are encouraged to reach out to potential new members, even if there's no sense of connection with them. They may connect with someone that person knows or that person may connect with someone else in the group.

"It's giving people a positive-positive sero-sorting option," says Harris, "not to make people lepers [by separating them out], but by taking away the stigma."

Harris says the group provides an important advantage over the Internet: face-to-face contact in a room full of friendly people. "We have a 'group date.' You can talk to someone and make an assessment. You don't have to buy them dinner and they don't have to buy you dinner." Plus, he says the problems of Internet photos and stories are well known.

While Guys and Girls has led to approximately a dozen marriages and several babies (and other people go AWOL after finding a special someone), Harris says that just as important is the ability of members to share their experiences in living with HIV. He says family and friends can empathize and give support, but don't have the understanding of what it's really like.

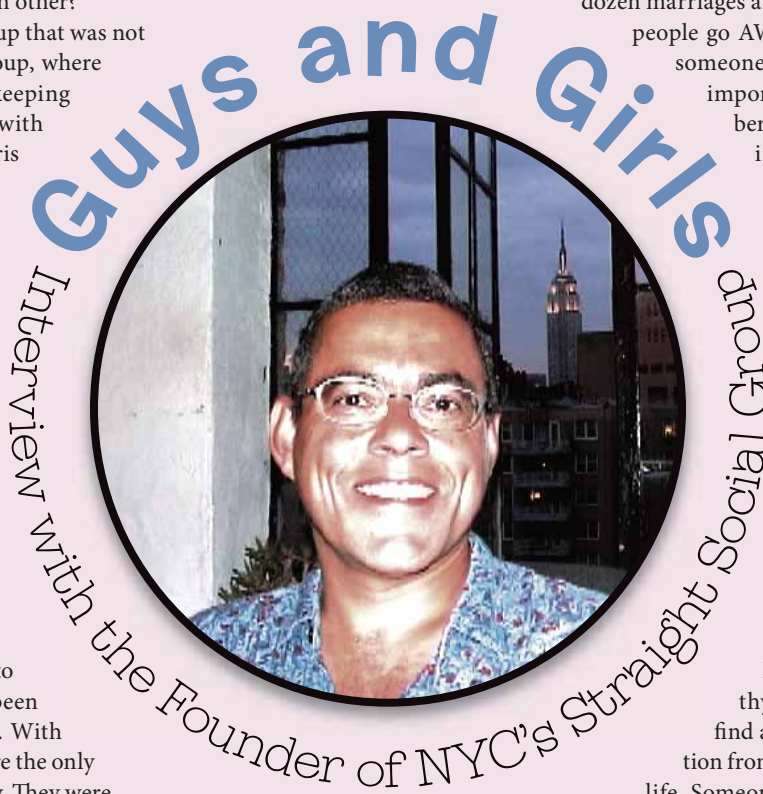
There's also medical care to discuss. Says Harris, "This virus, more than most other conditions, requires a great deal of medical knowledge. So a community like Guys and Girls becomes a professional association of sorts. People not only find empathy, but they are also able to find a source of medical information from others living a comparable life. Someone might talk about a medical procedure they had that your doctor is recommending for you."

Heterosexuals from around the country often reach out to Guys and Girls expressing the wish that they had as big a population as the one found in New York City with which to start their own association. Says Harris, "If you're committed as organizers, sensitive to the needs of your local community, and innovative to adapt to them, you too can make this sort of social networking association happen in your area."

Do, however, set up a written code of conduct before problems arise. Guys and Girls found the same problems popping up over and over, distracting the organizers and disrupting the function of the group.

Harris says that more than anything else, the group must serve the community, not its organizers.

For more information, call 1-212-462-9009, e-mail [guysgirls@aol.com](mailto:guysgirls@aol.com), or write to G&G, P.O. Box 251, New York, NY 10014. ☚



by Enid Vázquez

Online networking... everyone's doing it, including people living with HIV/AIDS. Below you'll find links to social and dating networks geared specifically for heterosexuals, or which provide space for HIV-positive heterosexual women and men in addition to the broader HIV/AIDS community. Basic safety rules apply in online dating, just as they do in real-life dating: Keep your personal information personal (phone, address, workplace, etc.), know your own motives and boundaries, trust your gut while getting to know someone, and don't be afraid to ask lots of questions. For more detailed information on online dating safety, check sites for articles specific to this topic.

**ApositiveOutlook.com:** According to it's keeper, "The Most Comprehensive Online dating and lifestyle resource for people living with HIV and AIDS". Free trial membership. <http://www.apositiveoutlook.com/>

**Chatmag.com:** "Comprehensive List of AIDS/HIV and Poz Chat Rooms on IRC and The Internet"—They're not all heterosexually-focused, but you'll find what you're looking for. <http://www.chatmag.com/topics/health/aids.html>

**HIVDate.com:** Personals ads and links to other sites maintained by Canada's own son, DaveyBoy. <http://www.hiv-date.com/>

**HIVSTRAIGHT:** Lots of general HIV info as well as links for social groups all over the country. <http://www.geocities.com/gene316/>

**Planet Poz:** New Mexico site with content for straight and gay HIV-positive people alike. Contact them if you'd like to contribute links, events, and other resources to the site. <http://www.planetpoz.org/index1.html>

**Positive Connections:** Very comprehensive site run by the Center for Positive Connections, geared towards heterosexual people living with HIV/AIDS. Chat, Personals, nationwide Buddy List and Support Group contacts, plus an annual cruise and retreats... check out the whole site. <http://www.positive-connections.org/>

**PositivePersonals.com:** HIV-positive personals ads, including heterosexual women and men. <http://www.positive-personals.com/browse.asp>

**PositiveSingles.com:** Dating site for folks with all manner of sexually-transmitted infections, including her-

pes as well as HIV. <http://www.positivesingles.com/>

**Positive Talk:** Heterosexual HIV-positive support and resources—our buddy Steve's site. Very useful for the Chica-goans! <http://www.geocities.com/positivetalk/>

**Poz.com chat:** Chatroom for HIV-positive heterosexuals. <http://hiv-aids.poz.ca/chat/hetero/>

**POZ.com:** New free online personals service from POZ Magazine. Contact POZ for more information: [personals@poz.com](mailto:personals@poz.com).

**PozMatch.com:** Personals ads from the Living Positive Community. Global! All-inclusive! Whee! <http://www.poz-match.com/index.php?page=index>

**TheBody.com:** Bulletin boards for all, including heterosexuals, in both English and Spanish. More information than dating focus, so mind the Guidelines. <http://www.thebody.com/bbs/forums.html>

**Wendy's Page:** Wendy has compiled quite the list of heterosexually-oriented weblinks, and maintains a great info page... thank you, Wendy! <http://n.domaindx.com/Positive/HIV/wendy.html>

**Yahoo HIV Chat:** I couldn't log on here, but you'll be able to navigate it if you're familiar with Yahoo chat groups. <http://chat.yahoo.com/?room=HIV/AIDS::1600326511>

Not up for dating, but still want to get your swerve on? Looking to expand those safer-sexual horizons with a partner? The following links will put you in contact with purveyors of quality sex toys (vibrators, dildos, sleeves, rings, and other sexual-pleasure aides), as well as erotica and sexual health books, videos, and other information sources. Masturbation is a healthy and pleasurable sexual expression for single and partnered people alike, and using toys with a partner can provide additional options for low- and no-risk intimacy that leave everyone feeling good.

**Good Vibrations:** San Francisco's premier woman-owned sex toy emporium also runs "Down There Press", the independent publishing company responsible for The Good Vibrations Guide to Sex. Excellent for toys, books, videos, and more! <http://www.goodvibes.com>

# Online Resources for HIV-positive Heterosexuals

compiled by Laura Jones



**Toys in Babeland:** Also woman-owned, with a fine selection of toys for both women and men. Reliable information on toy use and safer sex in general, too. <http://www.babeland.com>

**Early 2 Bed:** Chicago's finest sex shop. Stop in and say hello to Searah, Early2Bed's friendly and knowledgeable proprietor. <http://www.early2bed.com>

**MyPleasure.com:** Men's and women's toys, but a primarily male staff... you can contact them for toy recommendations and sexual-health information. Good source of online sexuality education, too. <http://www.mypleasure.com/> ☒

When nurses came up to Janet\* during a recent hospital stay and whispered, "How did you get *that?*," she said, "In a fun way!"

Which goes to show that she's a much different person from the woman she became after learning she had HIV at the age of 56, almost 10 years ago. At that time, she was devastated and afraid, and became withdrawn.

She believes she was infected when she first started seeing her then-boyfriend six years previously. She was divorced and, "wanting to better myself," she attended a college evening class. That is where she met her boyfriend. They started "going together" and found out that they had a lot in common. Not much later, they purchased a house together and began a new life.

But after a few years of being together, he got very sick and was put in the hospital. His doctor her that he had AIDS and that Janet should be tested right away.

Janet was HIV-positive. Her boyfriend had only 20 T-cells, she had 800. He died two years later after a long illness.

"The thing is, he knew all along, because he had risky behavior and the other person had died of AIDS a month before I met him. But he was in denial. I believe he would be alive today if he had gone to get tested and started meds." Because of that experience, Janet urges people to test for HIV as early as possible. "You can have a long and productive life even with HIV."

Janet felt she would be alone for the rest of her life. She didn't even think she was going to live much longer. But in reaching out to community organizations and social groups for help in dealing with her HIV and depression, she began to come out of her shell and overcome her fears.

Still, after her boyfriend's death in 1997, she thought she would never find another love again. "I didn't want anyone. I felt like I had been cheated—why did this happen to me?" But she was meeting wonderful people, most of them gay men. They became her fast friends and a very important source of support. Then, in 2000, on a field trip with her social group for people with HIV, she met Robert.

"We met in the planetarium, and he always says 'it was in the stars.' We had lunch and he sat with some other men. I thought he was so very handsome. It was my job to send out membership materials to people, so I always went up to newcomers to introduce myself and welcome them. I went up and talked to all of the men at the table. Later, under the sky show, in the dark, he sat next to me. He said, 'I just wanted to hold your hand.'

"The next day, a Monday, I sent everyone a letter thanking them for coming to the event and telling them about the next trip, asking them to join us for that and to call me if they had any questions. On Friday he called and asked me out for Saturday. He came over on Saturday and every weekend after that. It was wonderful."

Although they hit it off, Janet says, "I think what he liked was having someone interested in him, and I liked having someone interested in me too. I never thought I would ever find anyone who would want me and he felt the same way."

That was November 2000. They were married in March 2001. "I asked him to marry me because I wasn't about to let him go. He was mine. Not only was he goodlooking, but he was kind and gentle, loving and generous. He did things that endeared him to me."

Although they met in a big city, Robert was from a chapter of the social group out in a rural area. They bought a home there, in a small town of 5,000 people, close to a larger town with HIV social events.

"We enjoy being together and doing things together. He is my very best friend, and I am thrilled to be with him. We love our home and what life has to offer us. We're surrounded and comforted by our family, children and grandchildren.

"They keep me busy and give me my biggest reason to keep healthy. Between my children and my husband's children, there's lots of love flowing. I can't worry about HIV—I just get up everyday and enjoy life.

"I have joined a women's HIV group in the city, a very small, intimate group. There's a real variety of women and their histories of drug and alcohol addiction, prostitution and jail. I feel blessed that this never happened to me. I am so amazed at everything they have overcome."

Janet believes, "We can all get compassion and understanding from other people who feel the way we do. No one can understand except those who live with the same thing. Along the way, you may even find someone to share your life.

If you come out to events, it makes you feel good and you can speak openly with no fear of stigma. But remember, people still need to be educated on this disease. I know that even if you don't find a partner, there are good people who want to be your friend. Talking about your meds and how they make you feel is very helpful. Find a good doctor and follow your medicine routine—you don't have to die of AIDS."

Janet is the only white woman attending her women's group, and there's only one other white man besides her husband attending groups. She believes there must be other white women with HIV in the area, perhaps too wrapped up in stigma to take advantage of support groups, for themselves or maybe to help someone else.

"I wish women would come out more because we can talk about our issues. I think women need to know that their life isn't over. They need to know they can still have a valuable life. I think some women hide. I did too. I gave away everything I had because I thought I was going to die.

"I'm happy, and I want people to know, you can have a good life. There is a chance for you to find love. You don't have to be alone." She hopes that others with HIV will come out and find friendships with people who can share their hopes and dreams. ✚

## Small-town Living and Loving

How one woman infected at 50  
went on to find happiness

by Enid Vázquez

\*Names have been changed.

**D**eveloping medications effective against HIV resistance is a challenge, but has become a very important priority for pharmaceutical companies.

Drugs without therapeutic advantages, or without additional treatment niches, will eventually lose their usefulness over the coming years because of the slow, steady climb in the pervasiveness of resistant mutations among the HIV-positive population. TMC-114 is a new protease inhibitor being developed that should have great application due to its ability to answer a tremendous unmet need in treatment-experienced patients.

#### LATE BREAKER

At the 12th Conference on Retroviruses and Opportunistic Infections (CROI), held in Boston in February, the first interim results of the Phase II studies with TMC-114—C202 (conducted in the U.S.) and C213 (conducted outside the U.S.)—was highly newsworthy and was presented as a “late breaker”.

The study was carried out in the U.S., Europe and South America. Three-hundred patients were enrolled in each study; however, data from the study participants who reached the timeline for this analysis was presented here (497 patients). Having participated as a lead investigator in this Phase II trial, I have great confidence in describing these results.

#### BACKGROUND

Uniquely, in the laboratory, TMC-114 has shown to be sensitive to almost all protease inhibitor (PI) mutations. It also binds to the protease substrate (chemical ingredient) evenly across the volume of cleavage sites so that it becomes embedded in the substrate. Moreover, it does so at higher magnitudes than other PIs, so that it stays within the substrate like glue.

#### THE PHASE II STUDY

Among the patients in the study, 89% were male with an average of 44 years of age; 74% were Caucasian and 14% were African American. All had triple class HIV drug experience, and their HIV had resistance mutations from each class of antiviral. The most frequent protease inhibitor used during the failed regimen at baseline was Kaletra, with many of the participants having previous Kaletra use.

Also, 17% of patients showed no sensitive drugs from all of the three main HIV classes—that is, there were not any drugs that could be expected to work well for them. There was an even distribution of mutations in each treatment arm, with 40% having greater than three primary PI mutations and 66% having resistance to all PIs. Participants who had prior T-20 (Fuzeon) usage made up 16% of all participants, and 8% had prior tipranavir use (another protease inhibitor in development).

Thus, to summarize the type of patient population in this study, the participants were among individuals with the fewest treatment options.

#### STUDY DESIGN

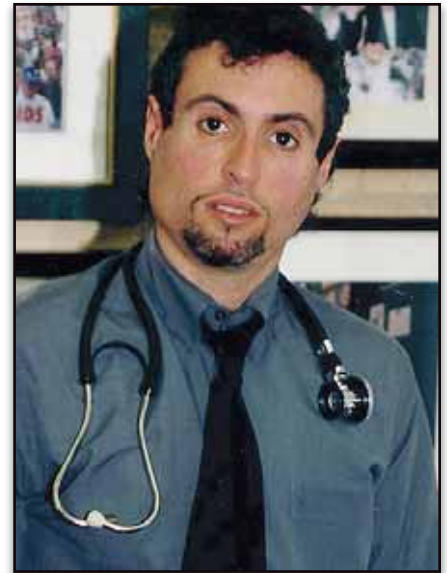
The study was designed so that patients were randomized to receive one of four doses of TMC-114, either once daily or twice daily. Every TMC-114 dose, within each arm, was boosted with ritonavir (Norvir). The fifth arm served as a control, meaning that the physician picked the best regimen from already available antivirals. The background antiviral agents were all chosen by the physician based on genotyping and treatment history, to provide the most optimum therapy.

#### RESULTS

At 24 weeks of treatment, the results showed significant improvements in all TMC-114 arms compared to the control. Looking at the control group first, 71% were on single boosted protease inhibitors and 27% on double boosted; viral loads only decreased by 0.27 logs. This is not a significant drop.

In contrast, of the TMC-114 treatment arms, the lowest dose (400 mg, once daily) demonstrated a highly significant 1.28 log drop. The 800 mg once-daily and 400 mg twice-daily doses resulted in a 1.4 log decrease in HIV-RNA, while the patients on the 600 mg twice-daily administration demonstrated a 1.85 log decline in viral load.

Also, patients taking the 600 mg dose twice daily demonstrated a rise in 75 CD4+ T-cells versus a 15 cell increase in the control arm. Approximately 47% of the patients in the study were also were taking T-20, which was evenly balanced throughout each treatment arm. (T-20 is the only approved drug in the latest class of HIV antivirals, fusion inhibitors.)



## New Protease Inhibitor TMC-114

### Preliminary 24-Week Late Breaker Results of the Phase II Trial

by  
Daniel S. Berger, M.D.

#### UNPRECEDENTED

As an experienced clinician, it is unexpected for individuals who have previously been aggressively treated and have already derived the biggest possible bang out of their regimen, to realize this kind of further viral load decrease. The occurrence of a further 1.85 log suppression and significant

*continued on page 41*



# The National Conference on Latinos and AIDS

*A National Forum on HIV/AIDS for Health  
Professionals Who Provide Care for Latinos*

**July 25th and 26th  
Holiday Inn Mart Plaza  
Chicago Illinois**

*CME Credits Available for Physicians and Nurses*



**To Register call 866-901-6267,  
fax 410-772-7915 or visit  
[www.minority-healthcare.com](http://www.minority-healthcare.com)**

**Sponsored by Minority Health Care Communications, Inc.**



# The Nebulous Spirit

by Jeff Berry

**Nebulous**—Lacking definite form or limits; unclearly identified or established; vague.

**Spirit**—That which is traditionally believed to be the vital principle or animating force within living beings.

The times in my life when I have been most afraid, I've been able to draw upon an inner strength, a voice within myself, to help guide me through the darkness.

I can remember sitting in the doctor's office when I was having my blood drawn for my HIV test. It was September 13th, 1989. I hadn't come that day to take the test, but here I was, sitting in a chair waiting to have my blood drawn. Suddenly I became very afraid, and a palpable fear fell over me. It was unexplainable, but nonetheless very real. It was a feeling of dread, of what was to come, of what the future held in store.

As the nurse began to draw my blood, an image popped into my head, of Jesus sitting next to me, holding my hand. Now, please understand, I'm not religious, by any stretch of the imagination. But at that moment a sense of peace washed over me, and a feeling as if everything was going to be alright. And it got me through that office visit.

## GIMME SOME OF THAT OLD-TIME RELIGION

As I was growing up in Michigan, our family belonged to a Protestant church. My father directed the choir, which my mother

also sang in, as did I and other members of my family. My brother, sisters and I all went to Sunday school, and attended services on a regular basis. But I never really felt like I belonged to that church, and I always felt out of place. Most of the members of the congregation were from "upper-class" families from a much wealthier side of town, while we were a working, "middle class" family. And as I got older, many times I would feign illness just to get out of having to go to church.

But I think it was important to both my parents that their children learned a certain "moral code", the "golden rule", and that we learn the importance of treating others with respect, while honoring our differences, and "religion" was just one of many ways of instilling those values in us. Both my mother's father and her grandmother were Methodist ministers, so "religion" ran in the family.

## ALL GROWN UP

I practiced yoga and meditation as a teenager, but as I grew into adulthood, I stopped attending church, and began exploring my sexuality. Back then, I guess spirituality and sexuality seemed incompatible to me. I remember at one point coming to the realization that, indeed, I had devoted much of my life, up to that point, to getting in touch with the spiritual side of myself. Now, I was making a very conscious decision to explore my more "human" side.

And so I did, and with a zest and enthusiasm that sometimes surprised even me! I moved to Chicago to deejay at Dugan's Bistro, which was our "Studio 54". I hobnobbed with celebrities, and indulged in all the excesses of the times, and had a blast—at least what I remember of it.

When I tested positive for HIV, I suddenly was forced to re-examine everything I thought I had come to learn about life, relationships, why I was here, where I had been, and where I was headed. It was as though, all of a sudden, I had been sent back to the drawing board. The things that had seemed so incredibly important to me, now no longer held the same allure or appeal.

Many of us, when faced with a life-threatening illness, are forced to re-examine our lives, look at some of the choices we have made, and perhaps wipe the slate clean and start over.

When I tested positive, I had already begun to make some definite changes in my life. I had gone back to college several years earlier, after taking a 10-year hiatus. I was still "spinning" records in the clubs, while working towards getting my degree, and was in a long-term relationship.

When the doctor gave me my positive test result, he referred me to the HIV clinic at Northwestern hospital, because he felt that they could provide the kind of specialized care and treatment that I required. I was actually kind of surprised. It was like breaking up with a lover. I hadn't anticipated losing my doctor, but he explained he didn't have any experience in HIV, and so I agreed to go to the clinic for treatment.

And I'm glad I did. At the clinic, they offered me the option of seeing a psychologist. I felt it might be a good idea to be able to talk to someone about my diagnosis, as my partner had tested negative. I began to meet with the psychologist on a weekly basis.

And that man literally saved my life.

#### HEALING

I was already "out" as a gay man to my family, having come out many years before, and they had always been extremely supportive. So although my psychologist repeatedly assured me that I did not have to disclose my status to them, and that there was certainly no rush, I felt empowered to do so, mainly because of the love and support of my family.

So that Thanksgiving, I revealed to my family that I was HIV-positive. And as we all stood in a circle, holding hands, I knew I had made the right decision. I thought then that it was the most difficult thing I would ever have to do, but little did I know—I was on a "spiritual" roll.

During the course of my therapy I opened up to my psychologist about the sexual abuse I had experienced as a child. It was a

pivotal moment for me, because I had vowed to myself to never tell another soul, and had kept the secret buried for some 20 years. As I uttered the words aloud, unable to look him in the eyes, the emotions welled up within me, and a release sprang forth from the depths of my soul. I felt a huge weight being lifted off of my shoulders.

Over the following weeks and months, I increasingly gained more self-confidence, and began to let go of the feelings of guilt that had hounded me most of my life. Suddenly, for the first time, I felt like I was taking back control. I had begun to let go of a secret that was eating away at me, body and soul. Finally, I was able to start to work through some of those feelings, and to begin the healing process.

And so, little by little, I began to let go of the things in my life that no longer seemed quite so important. I quit my job as a deejay, hung up my headphones, and walked away from the whole lifestyle. It just seemed like it was time for me to move on to something new. And I embarked upon a lifelong journey of self-discovery and self-awareness.

#### SPIRITUAL GROWTH

I started to read everything I could get my hands on about HIV and spirituality. I bought books by Louise Hay and Michael Callen, and devoured them voraciously. I began to study "A Course In Miracles", and attended a weekly study group. I began to get my feet wet with alternative, or complementary therapies, such as Tai chi, yoga, acupuncture, and massage. I sought out HIV support groups, which ultimately led me to volunteer at *Positively Aware* magazine. And most importantly, I started to get outside of myself, and my own self-absorbed little world, and began to reach out to others.

I also began the difficult process of re-examining my old belief systems, and attempting to look at things from a different perspective. I started to realize that, while I cannot change the past, I am able to choose how I look at it, as well how I perceive the present. And this has brought, at times, tremendous peace into my life, and has allowed me to more freely trust my own instincts. I am less afraid to look within, to really look at myself, for fear of what I might see. Because I like who I am now, and I realize that I'm not that different than anyone else.

And that's truly all I ever really wanted, was to belong.

This is not to say that it's all been easy. It's not all peaches and cream once you make a choice to look at life in a different way. In fact, it can be more difficult in many ways, because when you eventually veer off the path, and you do, trust me, it can be even harder to get back on course. But I've learned, for me, the trick is to not be so hard on myself. I've come to realize that, just as I try not to judge another for his perceived "shortcomings", it is equally important not to judge myself for my own. As someone once said, we are all spiritual beings having a human experience. And you just never know where someone else is on his or her own spiritual path.

I do know, in my heart, that we are all in this together, and that whether we realize it or not, we are all on a spiritual journey. ✚



I started to  
read everything  
I could get my  
hands on about  
HIV and  
spirituality.

# Lowering the risk OF HIV after sex or other exposure

by  
Tony Hosey, PharmD.



The HIV Treatment Series  
is sponsored in part by an unrestricted grant from  
Abbott Virology.

Post-exposure prophylaxis—or PEP for short—has long been used to minimize the chance of HIV infection among health-care workers exposed to the virus (primarily through accidental needlestick injuries) [1, 2, 3]. It is also generally available in the emergency room to sexual assault survivors.

“Prophylaxis” is treatment used for the prevention of disease. For example, Bactrim or Septra is used as a prophylaxis against PCP (a type of pneumonia).

For HIV, anti-HIV drugs are used [4]. A combination of HIV drugs must be given within 72 hours (three days) of exposure and taken for 28 days. PEP is not a cure—it is not guaranteed to prevent infection. Moreover, its use, especially in the community (or non-occupational setting), remains controversial.

As wonderful as the concept sounds, anyone familiar with HIV drugs can quickly see potential problems—among them toxicities and the costs of the medications. In 2001, it was reported that a phlebotomist in Chicago had to undergo a liver transplant two weeks after beginning a PEP regimen, due to one of the HIV medications used. As for cost, a month’s worth of only one HIV drug will cost no less than \$300, and insurance is not likely to cover what is still an experimental treatment strategy. PEP is not to be taken lightly.

At the same time, opportunities for extending the benefits of PEP out to the community are to be welcomed. In January, as *Positively Aware* prepared this article for press, the U.S. Centers for Disease Control and Prevention (CDC) updated the guidelines for PEP following sexual exposure.

As Dr. Ronald O. Valdiserri, the Deputy Director of the CDC’s National Center for HIV, STD and TB Prevention, said during a press conference call introducing the guidelines, “Far too many Americans are becoming infected every year. Prevention is the most effective strategy, but the severity of the problem requires that we use all available interventions.”

This article will examine the concept of PEP and non-occupational post-exposure prophylaxis (nPEP), its advantages and its limitations, and will explore how nPEP may eventually impact the spread of new HIV infections in the community setting.

## NOT “THE MORNING AFTER” PILL

PEP is never a one-time pill. It is not the “morning after pill” equivalent for HIV [6]. Nor is it a cure for the spread of HIV infections in the United States.

Prevention efforts that protect against any possible exposures to HIV are still the mainstays to prevent HIV transmission and infection. The CDC guidelines state, “the most effective methods for preventing ...HIV infection are those that protect against exposure to HIV. Preventive behaviors include sexual abstinence, sex only with an uninfected partner, consistent and correct condom use, abstinence from injecting-drug use, and consistent use of sterile equipment by those unable to cease injecting-drug use.” [4, 7].

However, PEP is an interesting treatment concept for helping to minimize the chances of HIV infection when a non-HIV infected person has accidentally been exposed to HIV-containing

blood or bodily secretions (such as semen or vaginal secretions) [4], especially after having taken precautions [8].

In the healthcare setting, accidental exposures can occur when the healthcare worker comes into blood-to-blood contact with HIV-infected fluids. This often occurs as accidental needle-stick exposures, or even as a result of human bites, from a known HIV-positive person or someone at very high risk of HIV. When PEP is properly administered, the risk of HIV infection has been clinically shown to be reduced by greater than 80%, in the healthcare setting [2].

It can be argued that the risks of HIV infection in healthcare settings can be similar to the risks of HIV infection in non-healthcare or community settings (such as in sexual contact, intravenous drug use (IDU), or other exposures) [4] despite limited data [8] (See Table 1).

The risk of HIV infection from an accidental needle stick exposure is between 0.2%–0.4% per exposure for healthcare workers. The risks of HIV infection in the community setting range from 0.01% to less than 3% per exposure, depending on risk behaviors [1, 2, 4]. *It has been known, however, for infection to occur after a single exposure.*

An important difference between the healthcare setting and the community setting is the timing or access to treatment and the ability to confirm the HIV status of a highly suspected source prior to treatment initiation.

In the healthcare setting, healthcare workers have instant access to antiretroviral treatments (usually within one to two hours) and have a unique ability to confirm the source patient's HIV status prior to initiation of PEP. In the community setting, the confirmation of serostatus may be very difficult to obtain. Also, access to treatment may take longer, especially if the post-exposure patient does not have an established healthcare provider, or a healthcare provider comfortable with prescribing antiretroviral treatments, plus knowledge of a pharmacy able to provide antiretrovirals at a moment's notice. Studies have demonstrated the median time to access PEP treatment is approximately 33 hours from time of exposure [8], even when established PEP resources for treatment are already in place.

#### RESEARCH FINDINGS

There have been many studies showing the advantages of PEP.

Initial studies occurred in animals. Research performed in both mice and primates have demonstrated the effects of PEP in minimizing the chances for HIV infection [2, 9].

In these studies, we have learned that antiretrovirals provide their protective effects by helping to block the uptake of HIV from dendritic cells in the body, thus helping to prevent their uptake into the lymphatic system. This effect usually occurs in the first 24 to 48 hours of HIV infection [1,9].

In animal studies, it was learned most of the protective effects of PEP occurred if administered within the first 24 to 48 hours, but also showed the effects diminish if given after 72 hours from time of exposure. Also, these studies have demonstrated that antiretro-

viral therapy needs to be administered for not less than four weeks of treatment [1, 2].

From early on in the use of PEP, AZT (Retrovir, also called zidovudine) used by itself has shown a greater than 80% reduction in minimizing the chances of HIV infection in healthcare workers [2]. This has been the basis for PEP in the healthcare setting.

Studies have shown the additional benefits in reducing the chances of HIV infection with antiretrovirals during pregnancy. Studies have clearly demonstrated HIV infection can be prevented after birth in babies born to HIV-infected mothers (known as vertical transmission), with treatment initiated in the first few days of life. This further supports the notion that it is possible to prevent HIV transmission in humans after potential exposure [2].

Recent data performed in the community setting has shown a benefit in reducing the chances of HIV infection with PEP. In California, the San Francisco PEP study looked at the effects of antiretroviral combination therapy in minimizing the rates of HIV seroconversion in mostly gay males having been exposed or potentially exposed to HIV after a high risk sexual or injection drug use exposure.

The nPEP regimen consisted of either lamivudine (3TC, Epivir) and zidovudine (AZT, Retrovir) in the fixed dose combination pill (Combivir), alone or in combination with the protease inhibitor Viracept (nelfinavir mesylate). Viracept was only used when the source partner's HIV status was known, or highly suspected, to be positive and with a detectable, or uncontrolled, viral load. Also, as a secondary measure, lamivudine (3TC, Epivir) and stavudine (d4T, Zerit) or stavudine and didanosine (ddI, Videx) were allowed as combination therapy if participants were not tolerating Combivir well. The study showed a 1% risk of seroconversion when treatments were administered within 72 hours of exposure and when adhered to for a 4-week treatment regimen [8].

#### CONTROVERSIES SURROUNDING PEP IN THE COMMUNITY SETTING

If we had treatments which could decrease the chances of HIV infection in the community setting, would this be a license for people to practice unsafe, high-risk sex? Data from the San Francisco PEP study showed that the likelihood for gay men to practice unsafe, high-risk sex was not increased when participants were given nPEP. Only 12% of those having received an initial course of nPEP returned for a second round of nPEP treatment.

These rates have also been demonstrated similarly in other studies [3, 7, 8]. The majority of nPEP participants who practiced unsafe sex or IV drug use reported a momentary lapse in judgment when requiring their initial nPEP treatment. However, are the community programs for HIV prevention and awareness different in San Francisco than in other parts of the country? Many believe they are, with California having unique prevention and outreach programs already in place [5, 8].

Also, many critics of PEP in the community setting feel there is simply not enough information to use nPEP as an effective tool for HIV prevention [4, 5, 7]. When used appropriately, it has been demonstrated that nPEP, along with behavioral modifications of sexual

or other high-risk practices, can decrease the chances of HIV infection when momentary lapses in judgment have occurred [8].

And what about the cost of rolling out such programs? With combination antiretroviral therapies ranging from approximately \$800–\$2,400 per month of treatment, would community HIV PEP place too much of a strain on already dwindling resources?

A theoretical analysis of 96 metropolitan cities nationwide was conducted using the information gained from the San Francisco PEP study. In the analysis, it was determined that the cost of administering a course of nPEP treatments to minimize the chances of seroconversion when sexual precautions were already in place or when momentary lapses in judgment occurred during high-risk behaviors, nPEP was more cost effective than a lifetime cost of antiretroviral treatments and medical costs incurred if seroconversion did occur [5].

However, when looking at the costs of rolling out an nPEP program in the community setting, it is also important to look at the resources available for such a program. Unlike San Francisco, many cities may not have resources in place to ensure participants can receive care within 72 hours from time of exposure. The San Francisco PEP study also demonstrated the importance of combining different areas of medical care to achieve maximum outcomes.

Such areas of medical care consisted of psychosocial services to modify and instill safe sex behaviors among participants and to reduce high-risk behaviors. Also, in-depth educational services on antiretroviral therapy and adherence to antiretroviral therapy were given to all participants in the PEP study. Constant and consistent monitoring to prevent or decrease side effects and minimize toxicities to antiretroviral therapy were also administered. The costs of

having such medical resources available may be too much for many cities across the country.

And what of the success rate of the PEP program itself? In the San Francisco study, approximately 700 participants were studied, with 1% of participants seroconverting. Would those numbers increase with an increase in study enrollment? Would those same numbers be achieved in other geographic areas outside of California? These and many more questions have yet to be answered regarding the true benefits of PEP in the community setting.

Currently, there are studies being conducted across the country and internationally looking at the benefits of using nPEP as a secondary HIV prevention tool. With more information about using PEP in the community setting, we may gain more insight into the potential benefits of PEP in reducing HIV transmission.

#### MAKING IT WORK

In order to make nPEP work, many resources need to be available. As research has illustrated, access to PEP needs to be readily available. People seeking PEP need access to medical providers within the first 72 hours after potential high-risk exposure. After that, it may be harmful to start PEP treatment, as antiretroviral therapy at this stage may blunt cellular responses the body may invoke against HIV infection [1, 9].

Not only do people need to seek help from medical providers, but the healthcare workers need to have an active working expertise in HIV. Due to the unknown risks involved with PEP, an educated HIV provider is the best resource to navigate any potential dangers associated with PEP therapy. This in and of itself may present some additional barriers to PEP in some cities.

Knowing the behaviors that are associated with an increased risk for HIV exposure is also important for the person seeking nPEP. Not all behaviors carry the same risks for possible HIV transmission [1, 10, 11, 12]. Also, the risks associated with potential HIV transmission from a known HIV-positive source are only estimates based on per exposure data. These risks may increase as the number of exposures increase. (See Table 1.)

Also the risks do not account for differences in the status or stage of HIV infection of the known source. Factors such as high viral load, low CD4 T-cells, present opportunistic infections, or even additional sexually transmitted diseases may exponentially increase the risks associated with the per exposure risk of HIV transmission shown above [10, 11, 12].

Because of these factors, and the unpredictable nature of HIV transmission, it is essential for all precautions to be taken prior to any sexual or other high-risk acts, to eliminate the potential for HIV transmission. *Remember, HIV transmissions have been documented to occur from a one time, single exposure.* Therefore, any act stated above or otherwise that presents the potential risk to HIV transmission, no matter how small of a risk, with a known or unknown HIV-positive source, is considered a high-risk behavior [4, 10].

**TABLE 1 - SUMMARY OF HIV TRANSMISSION RISK BY TYPE OF NON-OCCUPATIONAL EXPOSURE**

Type of exposure (from a source known to be HIV positive)	Risk of HIV transmission per exposure
Accidental needlestick injury	0.2%-0.4%
Mucosal membrane exposure	0.1%
Receptive oral sex	From 0 to 0.04%
Insertive vaginal sex	≤ 0.1%
Insertive anal sex	≤ 0.1%
Receptive vaginal sex	0.01%-0.15%
Receptive anal sex	≤ 3%
IDUs sharing needle	0.7%
Transfusion	90-100%

Source: Euro-NONOPEP Project Group. Table 1. Summary of HIV transmission risk by type of non-occupational exposure

**TABLE 2 - ANTIRETROVIRAL REGIMENS FOR NONOCCUPATIONAL POSTEXPOSURE PROPHYLAXIS OF HIV INFECTION**

Preferred regimens	
NNRTI†-based	Efavirenz‡ plus (lamivudine or emtricitabine) plus (zidovudine or tenofovir)
Protease inhibitor (PI)-based	Lopinavir/ritonavir (co-formulated as Kaletra) plus (lamivudine or emtricitabine) plus zidovudine
Alternative regimens	
NNRTI-based	Efavirenz‡ plus (lamivudine or emtricitabine) plus abacavir or didanosine or stavudine§
PI-based	Atazanavir plus (lamivudine or emtricitabine) plus (zidovudine or stavudine or abacavir or didanosine) or (tenofovir plus ritonavir [100 mg/day])
	Fosamprenavir plus (lamivudine or emtricitabine) plus (zidovudine or stavudine) or (abacavir or tenofovir or didanosine)
	Fosamprenavir/ritonavir¶ plus (lamivudine or emtricitabine) plus (zidovudine or stavudine or abacavir or tenofovir or didanosine)
	Indinavir/ritonavir¶, ° plus (lamivudine or emtricitabine) plus (zidovudine or stavudine or abacavir or tenofovir or didanosine)
	Lopinavir/ritonavir (co-formulated as Kaletra) plus (lamivudine or emtricitabine) plus (stavudine or abacavir or tenofovir or didanosine)
	Nelfinavir plus (lamivudine or emtricitabine) plus (zidovudine or stavudine or abacavir or tenofovir or didanosine)
	Saquinavir (hgc† or sgc†)/ritonavir‡ plus (lamivudine or emtricitabine) plus (zidovudine or stavudine or abacavir or tenofovir or didanosine)
Triple NRTI	Abacavir plus lamivudine plus zidovudine (only when an NNRTI- or PI-based regimen cannot or should not be used)
<p>† NNRTI = non-nucleoside reverse transcriptase inhibitor; NRTI = nucleoside reverse transcriptase inhibitor; sgc = soft-gel saquinavir capsule (Fortovase); hgc = hard-gel saquinavir capsule (Invirase).                      ‡ Efavirenz should be avoided in pregnant women and women of child bearing potential.                      § Higher incidence of lipodatrophy, hyperlipidemia, and mitochondrial toxicities associated with stavudine than with other NRTIs.                      ¶ Low-dose (100-400 mg) ritonavir. See Table 4 for doses used with specific PIs.                      ° Use of ritonavir with indinavir might increase risk for renal adverse events.</p>	
<p><b>Source:</b> U.S. Department of Health and Human Services. <i>Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents</i>, October 29, 2004 revision. Available at <a href="http://www.aidsinfo.nih.gov/guidelines/default_db2.asp?id=50">http://www.aidsinfo.nih.gov/guidelines/default_db2.asp?id=50</a>. This document is updated periodically; refer to website for updated versions.</p>	

**WHICH MEDS TO TAKE**

The new CDC guidelines highlight the study data we currently have and also make suggestions on the antiretrovirals medical providers may wish to use for nPEP treatments [7]. The antiretrovirals used in nPEP are to be given either as a two or a three-drug combination (see Table 2 [7]).

For a free copy, write to AIDSinfo, P.O. Box 6303, Rockville, MD 0849-6303 or call 1-800-HIV-0440 (1-800-448-0440). Visit [www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov).

The CDC points out that each course of PEP or nPEP prescribed should be a decision between the prescriber and the patient, and determined on a case-by-case basis [7]. This means that each regi-

men prescribed should be individualized according to the needs of the patient as well as the situation which occurred.

Two-drug combinations may be prescribed if the known or suspected HIV-infected source has an undetectable viral load. A three-drug regimen should be prescribed if the source has a detectable or uncontrolled viral load, especially if experiencing while on a protease-based regimen.

However, there is no medical evidence that a three-drug regimen is any more effective than a two-drug regimen from the available information on nPEP we have to date [7, 8]. The rationale for using a three-drug regimen is based on the assumption that a triple-

combo highly active antiretroviral regimen (HAART) is more suppressive to HIV replication.

Also, the cost and complexity of the regimen prescribed should be considered, to ensure that the individual will be able to successfully complete the course prescribed. Again, there is toxicity and cost for the individual to weigh. Potential barriers to treatment should be addressed before starting PEP or nPEP treatments.

Because the antiretrovirals used as treatments in nPEP are the same antiretrovirals used in treating HIV, the side effects and the adherence issues are the same. Therefore, when people are seeking nPEP, it is important to know what to expect when taking the medications.

Potential side effects common to antiretrovirals include nausea, vomiting, diarrhea, and increases in cholesterol and blood glucose. Liver impairments, rare allergic reactions and other serious side effects may occur when HIV antiretrovirals are taken.

#### ADDITIONAL INFORMATION [6]

##### NATIONAL RESOURCES

*For physicians who are willing to provide nPEP:*

##### AIDS Survival Project

1-404-874-7926

##### HIV/AIDS Treatment Information Service

1-800-HIV-0440

##### National AIDS Hotline

1-800-342-AIDS

##### National HIV PEP Registry

1-877-HIV-1PEP (medical providers only)

##### LOCAL RESOURCES

*nPEP is offered at:*

##### Whitman-Walker Clinic

Washington, DC  
1-202-332-AIDS

##### Fenway Community Health Center

Boston, MA  
1-617-927-6450

##### San Francisco City Clinic

San Francisco, CA  
1-415-514-4PEP

##### Beth Israel Medical Center

New York City, NY  
1-212-420-2000

##### Howard Brown Health Center

Chicago, IL  
1-773-388-1600

#### ALL THE PILLS, ALL THE TIME

Also of importance is the way in which the antiretrovirals need to be taken. Many antiretrovirals need to be taken in doses of multiple pills taken multiple times a day, rarely just one pill, once a day. This means that following and completing the course exactly as prescribed (called “adherence”) may be difficult for some to accomplish. However, strict adherence is required to ensure the maximal response to diminish the chance of HIV infection from occurring.

Most prescribed antiretrovirals in an nPEP regimen would be dosed either once every 24 hours, once every 12 hours, or a combination of the two, depending on the medication(s) prescribed. As with HIV treatment, it can be reasonably assumed that treatment for prevention of possible infection should be followed just as strictly (if not more so) with little room for error in missing doses or even the timing of doses.

#### NOT JUST PILLS

In addition to taking the antiretrovirals for nPEP treatment, many studies have shown the true successes of nPEP treatment come from the integration of both medical education and behavioral counseling [8]. Teamed together, medical education and behavioral counseling techniques have shown to be detrimental not only for prevention of the current exposure to HIV, but for preventing other possible future exposures from occurring.

Most studies have shown accidental re-exposures to HIV to be minimal; however, most studies have also included in-depth education on both the prescribed medication regimen and education on improving current behaviors to prevent another accidental exposure from reoccurring.

Since antiretroviral regimens are complex, medication education is a requirement. This helps ensure those taking antiretrovirals are knowledgeable not only on how to incorporate taking the medications into their daily lives, but also on managing the side effects as they occur to help ensure adherence for the entire course, to ensure maximal success in prevention.

#### BE INFORMED

As with any medical information, it's important to know all the facts and to be as prepared as you can be. HIV knowledge and prevention is needed more now than ever before. HIV infection rates have been on the rise worldwide with over 40,000 new HIV infections occurring in the U.S. each year alone.

Arming ourselves with information on prevention and treatment techniques are the only tools currently available to help prevent the spread of infection [4, 7]. Post-exposure prophylaxis (either PEP or nPEP) is only to be used when all other precautions to prevent HIV exposure in the first place have failed.

When deciding to engage in sexual practices or other activities which may place one at risk for HIV exposure, it is also important to make the decision to be regularly tested for HIV. Without regular HIV testing and knowledge on preventing exposures to HIV, we may never prevent the spread of this virus with currently available tools.

## PREP—PILLS BEFORE SEX

Another treatment concept in minimizing the chances of HIV infection is PREP (pre-exposure prophylaxis). This is not to be confused with PEP or nPEP.

PREP is the use of antiretroviral therapy prior to unintentional or accidental exposures to HIV infection. Data from animal studies used to support the therapeutic effects of PEP will be put to the test in a large, placebo-controlled, multi-centered international HIV prevention study sponsored by the CDC to test the effects of using PREP.

Also known as Project T, this study in San Francisco will look at using tenofovir (Viread) as a once-a-day treatment to prevent or minimize the spread of new HIV infections. Participants as well as researchers will both be blinded (meaning neither will know who is receiving the actual drug or the placebo). For this and many reasons, participants will be counseled on the importance of practicing safe sex and using safer techniques to minimize the chances of new HIV infections. Participants will also be reminded that unless such practices are used, they may not be protected from HIV infection [13].

The effects of this study will not be known until the study is completed a few years down the road. Until any results are revealed, we will not have any answers on whether such a treatment concept will even work. And until such results are in, it will be important for people to understand this concept should not be tried outside of a study.

## CONCLUSIONS

nPEP is an interesting treatment concept in helping to reduce the chances of HIV infection, particularly when all other precautions have been taken. It is a concept that has been studied in animals, has been shown to potentially work in humans, and may one day be another tool in helping to prevent the spread of new HIV infections.

However, to date, there is limited data to demonstrate the true effects of PEP in the community or non-healthcare setting. PEP is not a cure for the spread of HIV infections. It is not 100% effective. It is not even a substitute for true prevention measures, such as preventing the spread of HIV through practicing behaviors that protect against exposure to HIV.

But when all other precautions have been taken, nPEP may be a helpful tool to minimize the chances of HIV infection when an accidental, high-risk exposure has occurred. Although promising, without more data on PEP in the community setting, we do not know the full impact of nPEP in helping to reduce the spread of new HIV infections. ☞

*Tony Hosey, PharmD, is an HIV specialty pharmacist who serves as the Pharmacy Manager for StatScript Pharmacy in Chicago and on the Adjunct Faculty of the Chicago College of Pharmacy. E-mail [thosey@chronimed.com](mailto:thosey@chronimed.com).*

## REFERENCES

- 1) Almeda J, Simon B, Gerard M, Rey D, Puro V, Thomas T; Euro-NONOPEP Project Group. Proposed recommendations for the

management of HIV post-exposure prophylaxis after sexual, injecting drug or other exposures in Europe. *Euro Surveill.* 2004 Jun 1;9(6).

- 2) Henderson DK. HIV postexposure prophylaxis in the 21st century. *Emerg Infect Dis.* 2001 Mar-Apr;7(2):254-8.
- 3) Koh HK, DeMaria A, McGuire JF. Clinical Advisory HIV Prophylaxis for Non-Occupational Exposures. Commonwealth of Massachusetts Department of Public Health. 2000 Oct. Medical Letter.
- 4) Centers for Disease Control and Prevention. Management of possible sexual, injecting-drug-use, or other nonoccupational exposure to HIV, including considerations related to antiretroviral therapy. Public Health Service Statement. *MMWR Recomm Rep.* 1998 Sep 25;47(RR-17):1-14. Review.
- 5) Pinkerton SD, Martin JN, Roland ME, Katz MH, Coates TJ, Kahn JO. Cost-effectiveness of HIV postexposure prophylaxis following sexual or injection drug exposure in 96 metropolitan areas in the United States. *AIDS.* 2004 Oct 21;18(15):2065-73.
- 6) Wilder, TL. What you should know about...PEP! *The Body.com* 2001 Feb. [www.thebody.com](http://www.thebody.com) Date Accessed: Jan 9, 2005.
- 7) Centers for Disease Control and Prevention. Antiretroviral Postexposure Prophylaxis After Sexual, Injection-Drug Use, or Other Nonoccupational Exposure to HIV in the United States. Public Health Service statement. *MMWR Recomm Rep.* 2005 Jan 21;54(RR02):1-20. Visit <http://aidsinfo.nih.gov>.
- 8) Kahn JO, Martin JN, Roland ME, Bamberger JD, Chesney M, Chambers D, Franes K, Coates TJ, Katz M. Feasibility of post-exposure prophylaxis (PEP) against human immunodeficiency virus infection after sexual or injection drug use exposure: the San Francisco PEP Study. *J Infect Dis.* 2001 Mar 1;183(5):707-14. Epub 2001 Feb 01.
- 9) Vernazza PL, Eron JJ, Fiscus SA, Cohen MS. Sexual transmission of HIV: infectiousness and prevention. *AIDS.* 1999 Feb 4;13(2):155-66. Review.
- 10) Vittinghoff E, Judson DJ, McKirnan JF, MacQueen K, Buchbinder SP. Per-contact risk of human immunodeficiency virus transmission between male sexual partners. *Am J Epidemiol.* 1999 Aug 1;150(3):306-11.
- 11) Pinkerton SD, Layde PM, DiFranceisco W, Chesson HW; NIMH Multisite HIV Prevention Trial Group. All STDs are not created equal: an analysis of the differential effects of sexual behaviour changes on different STDs. *Int J STD AIDS.* 2003 May;14(5):320-8. Abstract.
- 12) Galvin SR, Cohen MS. The role of sexually transmitted diseases in HIV transmission. *Nat Rev Microbiol.* 2004 Jan; 2(1): 33-42.
- 13) Russell S. Antiviral Drug Used To Treat AIDS To Be Tested As Vaccine. *San Francisco Chronicle Online.* 2004 Dec 1. <http://www.sfgate.com/cgi-bin/article.cgi?file=/chronicle/archive/2004/12/01/MNGRMA48351.DTL>. Date Accessed: December 10, 2004.
- 14) ARVs to prevent sexual transmission of HIV. *Aidsmap.com* [www.aidsmap.com](http://www.aidsmap.com) Date Accessed: Dec 31, 2004
- 15) Henry K. HIV JournalView. *The Body Pro.com.* 2004 Jul. [www.thebodypro.com](http://www.thebodypro.com) Date accessed: Dec 10, 2004.



## GIRAFFES AND HIV

*Treatment interruptions with a twist*

by Andrew Zalski, M.D.

*Editor's Note: Dr. Zalski is filling in for Dr. Daniel S. Berger for this issue.*

With the recent New Year came the usual resolutions, including improving one's fitness. We're all familiar with the new crowds at the health clubs that time of year that include many people who are obviously less fit.

Wouldn't it be great if we were able to make HIV less fit, less likely to be able to replicate itself efficiently? Would having a less fit HIV virus be advantageous in managing HIV disease? Can viral fitness be measured and selected for? These are all very interesting questions, and as usual with HIV care, not all the answers to these questions are clear.

First of all, we should define some terms.

- The wild type virus is essentially HIV without any significant mutations.
- Mutations are changes in the viral genome. They occur as the virus replicates. Some of these mutations lead to "resistance" to HIV medications.
- The viral genome is the genetic code that determines the type of virus that is produced.
- Selective pressure refers to an outside force, such as an HIV medication, which pressures the virus to select for specific and characteristic mutations. With these mutations, the virus can resist or elude the effect of antiviral medicines, thus ensuring its own (viral) survival.

The classic example from evolutionary theory is the giraffe. Giraffes with longer necks were more likely to survive because they were able to eat the fruits higher up on trees, while the giraffes with shorter necks could only eat low-lying fruit. Eventually, only the giraffes with long necks would survive, although the number of giraffes would at least initially be less.

So do giraffes have anything to do with HIV management? Hardly, because if we continued the analogy, it would be better (for the fruit on the trees) to completely wipe out the population than to select for long-necked giraffes. However, these giraffes, because of their size, are not as efficient in reproducing, and thus are fewer in number. The end result is that there are fewer giraffes and more fruit. Similarly, in HIV, there might be less fit virus and more T-cells, at least for a period of time.



**A lower viral fitness may mean that the virus is weaker.**

Replication capacity of the HIV virus can now be measured by genotypic and phenotypic testing. Replication capacity is thought to be a measure of viral fitness. A lower viral fitness may mean that the virus is weaker and less likely to replicate (make copies of itself) efficiently and less likely to cause immune system and T-cell deterioration. This would be the equivalent of selecting for the short-necked giraffe that has decreased survival capacity.

How does all this impact HIV care? The gold standard of care has been undetectable viral load and increased T-cells. There are many people with HIV who have been able to maintain undetectable (or nearly undetectable) viral load for many years.

However, some become tired of taking medications (pill fatigue), or wish to take a holiday from having to take medications, or may have developed significant side effects from the medications whereby it has direct effect on their quality of life. Some of these factors may make it medically advisable to take a treatment interruption.

## Editor's Note continued

*continued from page 7*

Finally, on occasion where individuals have developed multiple resistance mutations, a treatment holiday is advised to encourage wild type virus to re-emerge; thus re-establishing susceptibility to antiviral medications. Would it be better for these patients to take a break from their triple medication regimen and only continue on a single (one) HIV medication which would primarily promote the selection to a less fit virus?

There is an intriguing study of patients from Italy that suggests just that. In a study designed by Antenella Castagna, M.D., patients whose virus had a M184V mutation (selected for by 3TC or FTC—brand names Efavirenz or Emtriva) were randomized to two groups. The first group stopped all their HIV medications while the second group was continued on only 3TC (Efavirenz). After 24 weeks, the group that continued 3TC had lower viral loads and higher T-cells than the group that had stopped all HIV medications. The 3TC group continued to select (remember selective pressure) for virus that had the M184V mutation that rendered the virus "less fit."

It is important to note two facts. First, 3TC causes only a M184V mutation and no other significant mutations. Continuing an HIV medication, which selected for more than one mutation, would lead to resistance to other HIV drugs. Second, all the participants in the study already had a virus that had the M184V mutation. We would not want to select for the M184V mutation in patients whose virus does not already contain this mutation because the presence of this mutation might make the virus less susceptible to other HIV medications in the future.

Only time and further studies will let us know whether this is a useful strategy. We only have very preliminary, 24-week results which are encouraging. Further, we do not know what long-term effects may occur nor guarantee a long-term response. This may represent a reasonable strategy for those who would need, or have been medically advised to take a break from treatment and whose virus already contains the M184V mutation.

It goes without saying that this should not be attempted without discussion with your HIV care provider. In the meantime, continue to be true to your resolutions to become more fit, hope for a less fit virus, and be aware that giraffes and HIV are still quite prevalent. 🦒

*Andrew Zalski, M.D., practices as an HIV specialist at NorthStar Healthcare in Chicago. He is an Assistant Professor of Family Medicine at Rush University Medical Center.*

- Community planning, coordination with health care systems and local decision-making are central to the success of CARE Act programs.
- A comprehensive range of services should be supported, including HIV testing, treatment and supportive services, which must be available in sufficient quantities, appropriate to local need.
- CARE Act funding and program guidance must continue to take into consideration that HIV/AIDS is a life-threatening infectious disease that is an ongoing public health emergency.
- The CARE Act must commit to:
- Strengthen and re-energize the Planning Councils and Consortia
- Address geographic variability and stabilize necessary and effective systems of care
- Reinvest in maintenance and expansion of service capacity, targeted education and training of health care providers (AETCs), including continuing medical education and systems improvement projects.
- The AIDS Drug Assistance Program must remain an essential component of the CARE Act.

### SO WHAT CAN YOU DO?

First, get involved! Let your representatives in the U.S. Senate know that the Ryan White CARE Act must be reauthorized, and increased funding is essential. If you don't know who your Senators at the national level are (there are only two for every state), go to [www.aidsvote.org](http://www.aidsvote.org) and find out! Also, visit [www.caear.org](http://www.caear.org) for more information about the CAEAR Coalition.

Second, let your friends, family and co-workers know that they need to contact their representatives in Congress. Every person who contacts their senator represents hundreds, if not thousands, of constituents to that elected official.

Make your voice heard, and your vote count!



Jeff Berry  
Interim Editor  
[publications@tpan.com](mailto:publications@tpan.com)



## SEX, LIES AND HIV: TRUTH HURTS

*She knew I had sex with men, she didn't know I was positive*

*by Keith R. Green*

I hadn't had sex with a woman in several years. I was attracted to Angela (not her real name) the first time that I saw her and she knew it. But at first, neither of us entertained it. We would flirt with each other from time to time. We would write and read poetry to each other. We'd go out to clubs together (both gay and straight ones) to drink like fish and dance the night away. The friendship that we were developing, similar to that of a brother and sister, was unique and special. Because I was not ready to deal with the reality of HIV in my life, I didn't really discuss it at all in those days. And since there was no intimacy between us, I didn't feel the need to do so at that point. So I didn't.

I don't think that either of us would call what we were doing dating. We had become really good friends in a really short amount of time and she had even become a part of my family in such a way that my mother would invite her to family functions without asking me. Her 5-year-old son and I were developing a really good bond that still exists today.

She and I had met at a specialty (African American) bookstore that she owned, which I helped her to manage for a year or so. Everyone called her the "neighborhood Oprah," because women came in to discuss all of their problems with her.

Angela knew that I enjoyed sex with men. She knew everything that there was to know about me. Well, almost everything that is.

On one unseasonably warm, autumn evening, after a long day of work for the both of us, we decided to go back to her house for a glass of wine. I remember her lighting this really sweet, exotic-smelling incense. She always burned the best incense. We laughed and talked for hours, enjoying what was, at the time, Sades' first new CD in 10 years.

I'm not sure exactly when our good time turned sexual, but it did. Perhaps it was after the third or fourth glass of wine, or maybe during the second joint, but at some point or another, it did. One thing that I am very sure of, however, was that we had used condoms and that I was the one who had insisted that we do.

When I left her house the next morning, I was totally disgusted with myself. To this day I don't know why I didn't have the courage

to tell her that I was HIV-positive before we had sex. I would like to blame it on the alcohol and the marijuana, but I am not quite certain that even if I had been sober I would have done anything differently. Even knowing that we had used protection, I still felt entirely horrible about myself and vowed that nothing like this could ever happen again. I am extremely sad to admit that it did.

Neither of us spoke a word about that night for a long time afterwards and it was almost a year later when it happened again (under almost the same circumstances). Whenever she would light her mood-altering incense in the store, I would always give her a devilish grin and say "alright now" in a sly tone.

Our friendship grew deeper than I think either of us imagined that it would and soon we began to express the true feelings that we had been harboring for one another since we met. No matter how deep our relationship grew, however, I could not bring myself to let go of the secret that I had been keeping deep within. That secret may have cost me a life with one of the few women I ever really romantically loved and one of my dearest friends.

The summer of 2002 was a rocky one for me. I had been living in North Carolina but came home to visit my mother and grandmother for Mother's Day and ended up staying for a couple of months. I think that I stayed because I knew then that there was something seriously wrong with me.

I had been HIV-positive for eight years at that point and had been virtually symptom free until then. I was violently yanked from denial of that fact when my body began to show signs of what I knew were HIV-related illness. I would wake up several times throughout the night, drenched with sweat. My regular bowel movements turned to loose stools, which then turned into constant, explosive diarrhea. Because of that, I had very little energy and was tired all the time. I began to lose a lot of weight, fast.

At that point, I made a conscious decision to face the truth and stop lying to myself and to others. I sought out medical attention and then vowed to come clean to everyone close to me about my HIV status. That meant that I had to tell Angela.

Even knowing that we had used protection, I still felt entirely horrible about myself and vowed that nothing like this could ever happen again. I am extremely sad to admit that it did.

I remember that day like it was yesterday. I didn't want to tell her over the phone, but the conversation that we were having that afternoon opened the door for it and I walked right in. She listened in silence. There was a long pause after my spill that let me know that she had heard every word and was taking it all in. In a very shrill and distant voice she managed to say, "I gotta go," and it wasn't for about two years that we actually had an in-depth conversation about that experience.

"My biggest issue with you, Keith, is that you did not value our friendship enough to just come out and tell me your truth," Angela said. "For almost two years we had been practically inseparable and I truly thought that I meant more to you than that." I could hear the pain in her voice as she spoke. She was holding back tears; I couldn't.

"Not only did you take away my right to choose whether or not to be intimate with you, which I probably would have still done, but you also took away my ability to be there for you as a friend. I would have wanted to be there for you and done everything that I could have to make sure that you remained as healthy as possible." After we joked about hoping that that didn't mean me eating her cooking, she said, "But seriously, that is what hurts me the most. It makes me wonder if I could ever trust you again, as a friend. I have forgiven you, and still love you like a brother, but I will never be able to forget the hurt that I feel from your deception and how you put my life and future in jeopardy."

Angela has been tested for HIV twice since learning about my status and, thankfully, she is HIV-negative. She now hopes that our near tragic story will be an example for people, especially women, all over the world. "We as women have got to learn to ask questions. And not just ask questions, but make him follow it up with some proof! If he tells you that he is HIV-negative, make him prove that to you." Federal regulations are in place to protect the confidentiality of any individual who tests positive for HIV, therefore, a testing counselor cannot share anyone's test result, positive or negative, with anyone else. However, if your partner has nothing to hide from you, there may be a waiver of rights that can be signed to confirm the results with you.

"A huge part of being open with one another about sexuality is acceptance," Angela claims. "So many men fear disclosing their bisexual nature to their girlfriend or wife because of the way that they think she will react to them, and that fear is not unfounded. As women, we have to be more open-minded if we are ever going to put a stop to the spread of HIV. We have to accept people for who they are and where they have been and move on. Even if you cannot continue to pursue a relationship with a man who tells you that he is bisexual or that he is HIV-positive, continue to show him love. Be honest with him about your own feelings and then be the most supportive friend that you can be."

The recent birth of Angela's daughter Mariah has made me take a closer look at the choices that I make in my life for myself, and how those choices affect the people who choose to be a part of it. My choice to withhold vital information from Angela could have altered her dreams of having a baby girl. Thankfully, that didn't happen. Unfortunately, however, not everyone is as fortunate as I am.

There are many men, women and children whose lives have been altered because of a choice that someone else made for them, without their permission. Don't allow yourself or those you love to be victims of those circumstances. Live in the truth, no matter how hard that may seem. Know that it is a choice that you must make every single day for yourself and that you are the only one who can make it. It will never be easy. Trust me, I know. Ask questions and know "what's goin' on." Then be open-minded enough to receive whatever truth may come to you. Make a conscious effort to love harder and to be a better friend to those you have chosen to befriend. Until next time, play safe and love even harder.

Peace! ☸

## New Protease Inhibitor continued

*continued from page 27*

improvement in T-cell count in this very experienced HIV population is enormous.

### SIDE EFFECTS

Regarding observed side effects and adverse events in this study, there was no dose relationship or dose response changes; this means that taking higher doses of TMC-114 did not increase any side effects. Nor were there any differences observed compared to the patients in the control arm. Additionally, no liver-related grade 3 or 4 adverse events were reported. There was a small incidence of elevated (blood fats) cholesterol (4.8% versus 2.0% in the control) and triglycerides (17% versus 23% in the control) but again, there was no dose response with these blood fat abnormalities.

### SUMMARY

Thus, in summary, TMC-114 was studied in a patient population at great need. The patients had a very high degree of resistance to most available antivirals. Despite this, the study participants derived significant benefit with a dramatic decline in viral load and increased CD4+ T-cells.

During the study, many treatment-experienced patients witnessed their viral loads decrease to undetectable levels for the first time. When contrasting these results to other salvage-type trials, including the T-20 Fuzeon (TORO I and TORO II) and the tipranavir (RESIST) studies, it appears that preliminary treatment with TMC-114 has shown an unparalleled and extraordinary benefit. Continued study with this exciting compound for long-term safety and effectiveness is ongoing and other studies are being planned. ☸

*Daniel S. Berger, MD, is Medical Director of NorthStar Healthcare in Chicago. He can be reached at DSBergerMD@aol.com or 1-773- 296-2400.*



## WORK YOUR ACTION

*These are not days in which to be lazy, my dears*

*by Jim Pickett*

I am writing this in early January 2005, in the thick of dissent within the AIDS community and I'm feeling quite dismayed, as many do, with the latest shenanigans from the Washington, DC AIDS lobby group called AIDS Action.

The organization's executive director had signed on to be a host of an inaugural fundraiser saluting President Bush and celebrating Republican electoral success. The proceeds of said event will go to the AIDS Responsibility Project (ARP), essentially a big pharma front group that works to keep generic drugs out of the hands, and bodies, of sick and dying people with AIDS in third-world countries. In Bangkok this past summer, ARP staged counter-demonstrations against activists calling for greater generic access with signs bearing the slogans, "GENERICS KILL" and "CAPITALISM WORKS." They also took out a full-page ad in the Bangkok Post attacking generic drugs.

Writer/activist Doug Ireland broke the story about this foul fiesta around Christmas, and the howling began. An enraged group of advocates and activists forced AIDS Action, "the national voice on AIDS," to disassociate itself from this revelry. AIDS Action indicated they had no idea the invite would be so partisan. Uh, yeah. WHAT-evah. Interestingly, they indicated NADA about their affiliation with ARP, or why they would choose to support a fundraiser for such a group.

Speaking of muck, I've more tidbits about ARP. Its executive director is Abner Mason, the international committee chair of the Presidential Advisory Council on HIV/AIDS who wrote a column titled, "Why Bush's win is a victory for gays" in the December 21 issue of *The Advocate*. Work your Google for more info on that piece of work.

How many of us felt AIDS Action had our back? How do you feel now? Whose back do you think Abner Mason has?

Okay, enough trash talk. Let's chat about the polar opposite—Senator Barack Obama—for a hot second. This newly elected hottie from Illinois, the only African American in the U.S. Senate, is being hailed across the nation as the second coming, our progressive savior who will fight for all of us who care about social justice, education, access to healthcare, trees and the birds and the bees. He's dazzling our popular culture and dominating our headlines, capturing our imaginations like few ever have.

So we don't have to worry. Mr. Obama has gone to Washington. He's gonna take care of business. He's got our back.

Moving on, allow me to appear self-indulgent and self-aggrandize for just a moment. It's all about appearances after all,

aint it? Perhaps you are aware that I operate a national listserv that focuses on HIV/AIDS, gay men's health issues and progressive politics. Perhaps not. Anyway, a couple thousand subscribe, and I've heard from more than one that they are thankful for the information I provide and are glad "I got their back."

Yeah, I got their back. Feel real good about that. Doncha worry. I'll dig up all the information ya'll need.

Clearly, a side-by-side evaluation of these different entities and personalities is like comparing rotten tomatoes and moist, succulent fruits. The common theme here is the sense we have that other people are watching out for us, that organizations and people in power and obnoxious, sleep-deprived overly-caffeinated queens with big mouths will advocate for our interests, will represent us, will have our backs. Some of the above will have our backs most/all of the time. Some will some of the time. Some will get tired, some will forget who they're advocating for. And some will give the appearance of having our back as the knife plunges in, over and over...

The desire to be protected and looked out for is a very human, but rather infantile trait. Grow up. You gotta work your own action. I'm not suggesting you shouldn't put your faith into institutions and people in whom you trust and may have connections and abilities you don't. But never, ever rely on them to do it all for you. Never, ever feel like it's unnecessary to engage. Never, ever kick back on your Jennifer Convertible and say, "They got my back. Gimme the remote."

We must empower ourselves. And that's a job we cannot delegate.

These are not days in which to be lazy, my dears. We're immersed in a morally repugnant war that is draining the nation's treasury. Social Security and Medicaid are on the chopping block. The Ryan White CARE Act, which provides many of us with medical and supportive services, is up for reauthorization and it's unclear how that may play out. Funding for domestic AIDS programs has been cut two years running while the need continues to grow. Meanwhile abstinence-only programs are receiving more money than ever, with curricula that teach that sweat and tears are potential vectors for HIV transmission, and that girls can get pregnant by touching a boy's wee wee. The CDC has dangerously narrowed its prevention focus, and actively worked to disparage the efficacy of condoms. Prevention programs for gay men are under attack.

Faith is trumping science every time, the flat earthers are going back for seconds and thirds at the buffet while millions go hungry.

*Photo © Russell McGonagle*

We must inform  
each other and our  
communities. Surf it,  
Google it, look it up.

More people are living in poverty, more people than ever have no health insurance.

We must get involved. We must engage. WE do. We must inform each other and our communities. Surf it, Google it, look it up. Join a group, go to a meeting, go to lots of meetings, sign on to a committee, plan a protest. Call and e-mail Barack and our elected officials at every level. We gotta show up at their district offices and in our state capitals and the nation's capital. We gotta work our action!

You bettah work... I have a couple dates to lipstick into your planner. Plan to participate where and when you can. Engage. Have your own back.

April 12-13, 2005—Caring for Our Communities-HIV/AIDS Advocacy Days in Springfield, Illinois. More info at [www.aidschicago.org](http://www.aidschicago.org).

May 2-5, 2005—An expanded super-sized AIDS Watch (co-sponsored with the National Association of People with AIDS)

training and advocacy days in Washington, DC. This is the first installment of the Campaign to End AIDS. More info at [www.napwa.org](http://www.napwa.org), [www.aidsmarch.org](http://www.aidsmarch.org) and [www.aidschicago.org](http://www.aidschicago.org).

August 19-21, 2005—Staying Alive, annual conference by the National Association for People with AIDS, in Los Angeles, CA. More info at [www.napwa.org](http://www.napwa.org).

October 8-12, 2005—Five days of Action to End AIDS, with caravans of activists from around the country and PWAs from around the world convening in Washington, DC for an historic mobilization that will build political power for the AIDS movement for years to come. This is being organized and planned even as you finish this phrase, and you can join the efforts NOW. Check out [www.aidsmarch.org](http://www.aidsmarch.org) for more info.

Finally, as ONE way to HELP stay informed, sign up for my free listserv. Send an e-mail to [jimberlypickett@aol.com](mailto:jimberlypickett@aol.com).  
Work it out! +

Work it out! +

## Subscribe or get back issues now.

- Subscribe:** 1 year of **Positively Aware** for \$30.\*  
 **Subscription renewal:** My payment of \$30 is enclosed.  
 **Back issues:** Please send me the following back issue(s) at \$3 per copy:  
 **Jan/Feb 2005** Qty. \_\_\_\_\_  **Mar/Apr 2004** Qty. \_\_\_\_\_  
 **May/Jun 2004** Qty. \_\_\_\_\_  **Jul/Aug 2004** Qty. \_\_\_\_\_  
 **Sep/Oct 2004** Qty. \_\_\_\_\_  **Nov/Dec 2003** Qty. \_\_\_\_\_

\*Subscriptions are mailed free of charge to those who are HIV-positive.

- Donation: \***  
 \$25  \$50  \$100  
 \$250  \$500  \$\_\_\_\_\_

Thank you for your donation. Your contribution helps to provide subscriptions to people who cannot afford them. All donations are tax-deductible to the full extent allowed by law.

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

PHONE: \_\_\_\_\_ E-MAIL: \_\_\_\_\_

CHARGE MY:  VISA  MASTERCARD  AMERICAN EXPRESS TOTAL \$ \_\_\_\_\_

CARD NUMBER: \_\_\_\_\_ EXPIRES: \_\_\_\_\_

NAME ON CARD: \_\_\_\_\_ SIGNATURE (REQUIRED): \_\_\_\_\_

Charges will appear on your credit card bill as TPA Network

MA 2005

Mail to:  
Positively Aware  
5537 N. Broadway  
Chicago, IL 60640

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



## POZDAR

*Beyond gaydar*

*by Tom Setto*

“I’ve been noticing something for over a year now. It’s kind of weird. I haven’t said anything about it because I wasn’t sure if it really was happening or if it was just me.” Gary broke a short period of silence the other day at our weekly breakfast at the Montrose Diner with this latest gem.

“What are you talking about?” Ken usually is the one of us that is the least tolerant of the way Gary kind of backs into a story through the side door.

“I started seeing it around here, but I brushed it off thinking that people here know who I am. I may not know them personally, but they know me from my days of bartending. They know who I am, that I’m gay and that I’m HIV-positive.

“But last summer when I was visiting some friends in New York City, we were walking down the street in the Village and a guy walking toward us smiled and nodded at me.”

“You were in the Village, for God’s sake, he was cruising you,” Miguel said with a touch of impatience.

“No, wait, let me finish,” Gary interrupted. “You know my friends in New York are all gay too. They said the same thing, but that’s not what I felt. There was nothing sexual about it at all.”

“You just found a friendly person in New York City,” I said

“It happened again later that day. We were going to see a show. We were out of the Village and up in Times Square. You know how touristy that area has become. The same group of us was walking together and a guy who was also with a group of people looked me in the eye and smiled. He had a camera around his neck so there was a good chance he was from out of town also.”

“Okay, you have a friendly face,” Jerome said. “What’s so earth shattering about all this? There better be more to this story.”

“There is,” Gary said. “After this I noticed that it was happening more than I realized. Later in the summer, I was in Philadelphia, the same thing. Whether I was in a gay neighborhood, a tourist area, wherever, I keep getting these warm knowing smiles, sometimes a little nod, a wink. Then finally I figured it out. These guys were all HIV-positive and they knew I was too.

“I know how you guys sometimes think that I am a little out there when I start talking about souls and the strength of the human spirit, and I knew you all would treat this with more than a little cynicism, but I truly believe that even subconsciously we are always in search of kindred spirits, people who understand what we are going through.

“We all know about gaydar. I think those of us who are living with HIV are developing a form of gaydar, sort of a pozdar. Some-

times there are physical things that make someone stand out as HIV-positive and those of us who live with it can see it much better than people who aren’t as familiar with the side-effects, but there’s more. Because HIV is such a huge part of my life and long time ago I decided to accept it and not keep it tucked away inside, I think others who have done the same can feel that. They understand and it makes them feel a little more normal.”

“I agree,” I added, “we don’t necessarily have to tattoo our status on our foreheads, but we really do need to understand that being HIV-positive is a part of our very being. We probably think about it more throughout the course of a day than anything else. So why not make it part of our persona? If we do, others will pick up on it. We don’t have to start a Positive Pride campaign, although that might not be such a bad idea, but we need to open ourselves to others who need the reassurance that they are not alone.”

Jerome was nodding. “Gaydar came into being so that gay people could find each other without wearing our gayness on our sleeve. Even in the gay community there is still a stigma attached to being positive, so I guess we’ve had to develop a way of sharing without screaming ‘I’m positive.’ ”

“I wonder,” Miguel asked, “if this is happening with all people who are positive? I don’t think I would feel it with, say, a woman who is positive because even though I know many positive women, it is not something I think about when I meet a woman or even a straight man. It must be much more difficult for straight people to develop pozdar. I hope it happens because I know I feel so much better when I realize the person standing next to me is positive and out there living a regular life. Jerome, you said there still is a stigma in the gay community, but HIV is such a big part of gay life. We look at guys and turn on the gaydar to figure out if they are gay and now we’ll add the pozdar. It seems like the natural succession.”

“Of course, because some of us prefer sex with other positives, we will use our pozdar when looking for sex, but I hope it becomes more than that,” Gary said. “I hope it is used for reassurance, that we use it to let other positive people know they are not alone. Those of us who have accepted—and in a kind of weird way embraced—our ‘positiveness’ can share it with other positive people and not necessarily say a word.”

“Once again, Gary, in your own convoluted way, you make sense.” Ken shook his head. “And hell, if your pozdar malfunctions, what harm can giving another person a warm friendly smile hurt?” ☩

# 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](mailto:programs@tpan.com) • [www.tpan.com](http://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.

## 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–4 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

### INDIVIDUAL COUNSELING

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

### PEER SUPPORT NETWORK/BUDDY PROGRAM

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

### SPEAKERS BUREAU

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

### TEAM (TREATMENT, EDUCATION, ADVOCACY AND MANAGEMENT)

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

## 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](mailto:livingpos18to24@aol.com)

# TPAN Events Calendar

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

## March 2005

DATE	TIME	EVENT
Wednesday 2	7:00 pm	Committed to Living: HIV Advocacy and Action—Jim Pickett and David Munar, AIDS Foundation Chicago. Location TBA. RSVP (773) 989-9494.
Monday 7	9–5 pm	TEAM training
Tuesday 8	9–5 pm	TEAM training
Wednesday 9	9–5 pm	TEAM training
Tuesday 15	6–8 pm	TPAN Community Advisory Board
Thursday 24	9 pm–12 am	Super PornFest, Lucky Horseshoe

## April 2005

DATE	TIME	EVENT
Wednesday 6	7:00 pm	Committed to Caring: 12th Retrovirus Conference Update Matt Sharp and Enid Vázquez. RSVP (773) 989-9400.
Tuesday 19	6–8 pm	TPAN Community Advisory Board
Wednesday 20	7–9 pm	TEAM Update—HIV Drug Development and Clinical Trials
Thursday 21	9 pm–12 am	Super PornFest, Lucky Horseshoe

### AFFORDABLE COST



**GETTING SUPPORT FOR HIV AND TAKING CARE OF YOUR HEALTH SHOULDN'T BE A HASSLE. NOW THEY BOTH JUST GOT A LITTLE EASIER.**

- HIV Specialty Care
- HIV & Syphilis Testing
- HEP Testing & Vaccination to IVDU

Monday 10 am–6 pm  
Tuesday 9 am–12 pm  
Thursday 12 pm–8 pm  
drop-in or by appointment  
call 773.989.9400

We accept Medicaid, Medicare, KidCare, and most major health insurances. Title I, Title III and Title IV funding is also available for eligible patients. If you are uninsured, we offer a sliding fee scale based on ability to pay.

offered by Access Community Health Network



test  
positive  
aware  
NETWORK

Because I Can  
Make A Difference

# Ride *for* AIDS<sup>®</sup> C H I C A G O

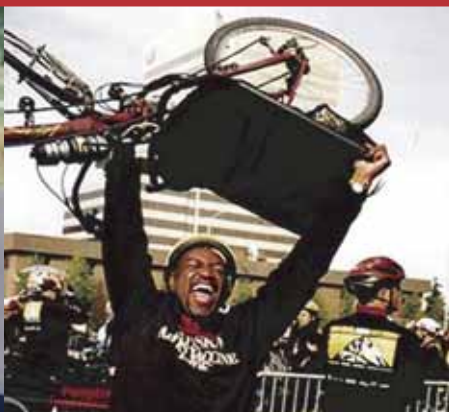
A Two-Day Bike Ride to Fight HIV/AIDS

June 4<sup>th</sup>-5<sup>th</sup>, 2005

Committed to returning 100% of pledges to TPAN and BEHIV to support HIV/AIDS services in Chicagoland.

visit **rideforaids.org**

▼ Aaron Freeman, journalist, stand up comedian, avid cyclist, rider and Official Spokesperson for the Ride for AIDS Chicago. (aaronfreeman.com)



Sponsored by:

cable positive

Comcast



Chicago in Bloom  
Floral & Events

STATSCRIPT PHARMACY  
CHRONIMED



Columbia  
COLLEGE CHICAGO



EVANSTON  
CMC

WHOLE  
FOODS

PLAQUE PUNCH

To register or learn more, visit [rideforaids.org](http://rideforaids.org) or call 773-989-9400

Ad design: Rick Aiello: rick@rcktman.com



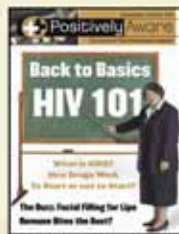
# Knowledge

## Your Best Protection

**If only it came in a bottle.**

Learning about HIV/AIDS takes time and effort. Knowing about your treatment options can help you take control of your health and life, help you improve your quality of life and advocate for yourself. It can also provide hope for a better future.

To learn more about HIV/AIDS treatment options, subscribe to *Positively Aware Magazine*. Subscriptions are free to those who cannot afford to pay. Or visit [www.tpan.com](http://www.tpan.com)



## Be Positively Aware!

Test Positive Aware Network and *Positively Aware Magazine* bring this public awareness message to you. For more information, visit [www.tpan.com](http://www.tpan.com).

design: Kevin Putz, Toolbox Inc. [www.toolboxinc.com](http://www.toolboxinc.com)