



**POSITIVELY AWARE**  
HIV Treatment and Health

# **SPECIAL 20TH ANNIVERSARY ISSUE**

**DAN BERGER:  
BIOGRAPHY OF  
AN HIV DOCTOR**

**DOES STARTING THERAPY  
EARLIER IMPROVE YOUR  
CHANCES OF SURVIVAL?**

**FORMER PA EDITORS SPEAK OUT**

**TREATMENT NEWS FROM  
THE 48TH ICAAC**

JANUARY / FEBRUARY 2009  
THE JOURNAL OF TEST POSITIVE AWARE NETWORK

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# TABLE OF CONTENTS

January / February 2009 Volume 20 Number 1



## DEPARTMENTS

- 6 **TPAN Programs, Meetings and Events**
- 7 **Editor's Note**  
*Creating Your Legacy*
- 12 **Readers Forum**
- 13 **PA Online Poll**
- 14 **News Briefs**  
*by Enid Vázquez*
- 20 **Ask the HIV Specialist**  
*This issue's Specialist:*  
*Michael Fingerhood MD, FACP, AAHIVS*
- 43 **The Buzz**  
*The Biography of an HIV Doctor*  
*A 20-year retrospective*  
*by Daniel S. Berger, M.D.*
- 46 **What's Goin' On?**  
*To Return to the Closet or Not?*  
*Embracing life outside of HIV*  
*by Keith R. Green*
- 47 **Pickett Fences**  
*TMI*  
*Many anniversaries of ranting and raging*  
*by Jim Pickett*



## ARTICLES

- 21 **HIV Treatment News from the 48th ICAAC**  
*A round-up of reports*  
*by Enid Vázquez*

### ON THE COVER:

*Dan Berger, M.D., see story page 43.*  
*Photo ©Russell McGonagle.*

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## ARTICLES CONTINUED

- 23 **Starting Therapy Earlier Found to Improve Survival**  
*Study raises the implications of more testing, less transmission*  
*by Enid Vázquez*
- POSITIVELY AWARE 20TH ANNIVERSARY**
- 26 **THE LAUNCHING OF TEST POSITIVE AWARE**  
*A revisited note from the founder*  
*by Christopher S. Clason*
- 27 **POSITIVELY AWARE TURNS TWENTY**  
*A former editor remembers our journey*  
*by Bob Hultz*
- 32 **THE BRIDGE TO SOMEWHERE**  
*A former board member reminisces*  
*by Michael Blackwell*
- 33 **20 YEARS OF COMMITMENT**  
*Positively Aware, then and now*  
*by Steve Wakefield*
- 34 **WITHOUT POSITIVELY AWARE, WHO KNOWS WHERE I'D BE?**  
*PA was only the beginning*  
*by Steve McGuire*
- 36 **TRANSITIONS**  
*Looking back, while moving forward*  
*by Charles E. Clifton*
- 38 **HEADLINES OF TOMORROW'S POSITIVELY AWARE**  
*The need for health care will always be universal*  
*by Brett Grodeck*
- 40 **ONE ON ONE WITH BARACK OBAMA**  
*The Politics of HIV*  
*Interview by Jeff Berry*

A model, photographer, 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 [www.tpan.com](http://www.tpan.com) and [www.positivelyaware.com](http://www.positivelyaware.com)

## TPAN PROGRAMS AND MEETINGS

- Support Groups
- Rapid HIV Testing
- Meditation, Reiki and Massage
- Needle Exchange Program
- Buddy Program
- Case Management
- Access Medical Clinic at TPAN
- PULSE, an HIV-positive Weekly Social
- Positively Aware Party at Hydrate
- POWER (Positive Outcomes for Wellness, Education, and Recovery)
- TEAM (Treatment Education Advocacy Management)
- SMART Sex—Prevention and Outreach Program
- Monthly Educational Forums and Trainings

For detailed descriptions of programs, including dates, times, and locations, visit [www.tpan.com](http://www.tpan.com) and click on Client Services, or call (773) 989-9400.

## TPAN EVENTS

- Chicago Takes Off  
Saturday, March 7th, 2009  
Two shows!  
(see ad on back cover)  
visit [www.tpan.com](http://www.tpan.com)
- Ride for AIDS  
June 6-7, 2009  
[www.rideforaids.org](http://www.rideforaids.org)



For detailed descriptions of these and other TPAN events visit [www.tpan.com](http://www.tpan.com) and click on Events, or call (773) 989-9400.



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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.

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## Creating Your Legacy



**T**his issue celebrates the twentieth anniversary of *Positively Aware* magazine, which first began publishing as *TPANews*, the agency newsletter of Test Positive Aware Network.

I was especially thrilled and deeply touched that each and every former editor of *Positively Aware*, along with many others who have been involved with TPAN and *PA* from the very beginning, was more than happy to contribute to this special issue. Together, their stories offer a brief snapshot of our history, and of the epidemic as a whole, as seen through the lens of *Positively Aware*.

Many people over the years have contributed to the growth and success of this publication, and have done so because I believe they understood the importance of providing accurate, unbiased information about HIV and its treatment. As it grew into the national voice of a peer-led, community-based organization, *Positively Aware* offered hope to many when there was none. Our mission of providing support and information to others infected and affected by HIV still remains to this day.

Unfortunately, there is just not room enough on these pages to thank everyone I'd like to thank, but I would be remiss not to mention two former editors, Steve Whitson and Charles Clifton, both who passed away quite suddenly while serving as editor. Steve and Charles were both incredibly gifted and talented individuals, each of whom I admired and respected, and each of whom brought their own unique qualities and abilities to their work. The dark days immediately following their deaths were indeed difficult times, but somehow we all pulled together, and we managed to get through them.

And that, to me, is the trademark of *PA* and TPAN, and will hopefully be our legacy—providing support and information, not only to the community at large, and to our readers, but also to each other. We must never lose sight of that ideal, because it is what we were founded on, what we are all about, and ultimately, it's what gets me through the day.

Recently I had the privilege of taking part in a World AIDS Day program put together by a group of students and faculty at Columbia College, my alma mater. Columbia holds a special place in my heart, because it was while attending Columbia nearly twenty years ago that I took my very first HIV test, which came back positive. Looking back now, I can honestly say that staying in school and working to finish and get my degree, even after receiving that devastating news, was a conscious choice on my part to remain

committed to living. I was not going to give up without a fight, and I was determined to seek out the help I needed, which eventually led me to TPAN.

As I stood and watched these young leaders of tomorrow, I was encouraged and heartened by their enthusiasm and commitment to raising awareness about HIV and AIDS using an artistic medium, whether it was through spoken word or music. Watching them reminded me that we all need to continually explore what it is that gives us passion, that which keeps us committed—whatever it is that gives us reason to hope. Because without hope, and without offering and extending that hope and help to others, no amount of information, education, or prevention is ever going to get us through the day, or guide us to a better tomorrow.

Thanks especially to the staff of *Positively Aware* magazine, Enid Vázquez, Keith Green, Sue Saltmarsh, Joe Fierke, and Russell McGonagle, and to the rest of the staff and crew at TPAN, for making each day a joy, and an adventure. And thanks to my family and friends for your faith in me, and to my partner Stephen, for putting up with me, and for your never-ending support and guidance.

And finally, and most importantly, I want to thank all of the many volunteers of *Positively Aware* magazine and TPAN, without whom none of this would have ever been possible. While words cannot sufficiently express my gratitude to you, it is only because of your tireless efforts and continued commitment to getting the work done that we are even still here.

So remember to search for and find your passion. Never give up hope. And reach out to others, whether it be through volunteering, or just taking the time to sit with a friend and listen. Step out of your comfort zone, if only for a moment, and begin to create your own legacy, and discover what “committed to living” means to you.

Take care of yourself, and each other.

Jeff Berry  
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# READERS FORUM



JOIN US ON MYSPACE AT

[WWW.MYSPACE.COM/POSITIVELYAWARE](http://WWW.MYSPACE.COM/POSITIVELYAWARE)

ADD US AS YOUR FRIEND AND CHECK OUT OUR COMMUNITY PARTNERS.

## A PERSONAL STORY

Thanks for sharing your story on The-Body.com [A Personal Story, September/October 2008] ... tears are rolling down my cheeks now! I am 37, and contracted HIV and was diagnosed within two weeks back in 2004. I live a very good life, and still no meds (which is cool). I was in a [long-term relationship] when I contracted HIV (one night of stupidity). While we stayed together and I thought we could get through all of this, he finally decided to leave me two months ago—14 years after we met. He's negative, 48 years old, and now quite bitter and angry. But there's not much I can do about that. This is for him to work through now. He's met someone else already. I recently met someone (on a plane) and we hit it off immediately. A week later, when it looked like we were going to get physical, I told him I had HIV. I expected to get thrown out of his hotel room and to never see him again, but he asked me to spend the night with him in his hotel and we held each other all night. It has restored my faith in humanity. He's young (27), successful, cute, and has his whole life ahead of him. I don't think we'll ever be more than great friends, and that's enough for me now. He's taught me a good lesson in life. I am so happy that I told him (I sometimes don't tell people, but never put them at risk). I just wanted to say thanks for sharing your story. I am

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E-mail: [readersforum@tpan.com](mailto:readersforum@tpan.com)

busy writing my own life story. I've called it "It can't happen to me," and hopefully once I finish it, I can get it published, since I think others can learn from my (and our) mistakes. Better get it onto the Oprah Book Club to fund the rest of my life!

Pete, via the Internet

*Kim Johnson replies: Thank you so very much for your kind comments. I am a strong believer in groups, so if there is any possibility of you becoming a member of a well-facilitated group of positive gay men, I recommend it. Good luck to you and your new friend. I know you'll find love—it comes when you least expect it.*

## GET TESTED

Currently I'm incarcerated in Metro State Prison (Atlanta, GA). If all goes well, I'll be going home in a couple years. During one of my chronic care visits I came across a *Positively Aware* subscription (January/February 2008) issue. I never heard of your magazine, but once I read through it, I was intrigued to want to learn more about my condition and all the useful information that comes hand in hand with the virus.

I've been positive and a drug user for well over 15 years; however I've been clean 6 ½ years. I found out about my condition after the 3rd year of my marriage. Strangely, my husband isn't positive. I'm grateful that I found out when I did and I encourage everyone to get tested, because we all seem to think, "It'll never happen to me!" Finally reality kicks in when it hits too close to home (a family member, close friend, etc.). I would've never thought to get tested, until I received a dreadful call from California telling me my brother was terminally ill and in the hospital. I at once flew out and brought him home. He was full-blown with less than six months to live. I was faced for the first time with this virus, yet I cared for him until he died. Thinking back on my addiction days, I knew I had to be tested. Low and behold, that's when I found out. I'm saying



## STAY CURRENT WITH PA E-MAIL UPDATES

Sign-up today for our *Positively Aware* e-mail newsletter and receive regular updates on HIV treatment news and information.

Visit [www.tpan.com](http://www.tpan.com) or [www.positivelyaware.com](http://www.positivelyaware.com) and click on Subscribe. Once you receive a confirmation e-mail, you can update your TPAN profile to include "Positively Aware Updates."

all this to say, don't wait until death walks into your home to be tested! People often tell me I'd rather not know than to live with knowing. I'm grateful I found out when I did, because at the peak of a slow death, you'll realize that had you known, you could've taken care of yourself and lived a lot longer. Now through your subscription I can learn more and help some of the women here. I would like to know if you are able to add my name and address so I can have friends I can relate to.

Pamela Morgan # 272052, Metro State Prison H-B, 1301 Constitution Rd., Atlanta, GA 30316

## GLAMOROUS

Keith Green had an article in the September/October issue of *Positively Aware* entitled "The Glamorous Life of HIV." I'm the person from downstate Illinois he references in the article. I'm really proud of the way that Keith handled the incident with DL and I'd like to repost it on my MySpace page. I emailed Keith about this as well. Thank you.

Phil, Downstate Illinois

# READERS FORUM



## VENTING

I just have to vent to someone who understands. I went to a doctor on Friday. I filled out my paperwork. The girl called me back. She asked me questions, such as why I was there. I answered and then I honestly admitted that I have been HIV-positive for more than 23 years, but I'm very healthy living with it. She only wrote down "HIV-positive over 23 years"—*that was all!* She then said the doctor will be in shortly. I knew at that point that my appointment was over. Soon enough another person came in and said that he wouldn't be able to help me. He wouldn't even come in the room! When I asked why, she said it was because the procedure I was looking to have done required an anesthesiologist, and the anesthesiologist wouldn't do it for me because of my high risk of infection. Well, I'm undetectable with a good T-cell count. They never even asked! I thought that in this day and age I needed to get over feeling discriminated against. I was fired from my job 23 years ago, so that pain still remained. After this, it was like I was kicked in the gut again.

I went home and cried, had a few beers, and went to bed.

I'm still in shock at his cold heartedness.

Name withheld, West Palm Beach, FL, via the Internet

*Jeff Berry responds: Thanks for your email. I'm sorry to hear about your recent encounter with an obviously uninformed provider. It is outrageous, as you say, in this day and age, but, unfortunately, not all that uncommon. I applaud your desire to disclose your status with your provider, because only when you are both armed with all the information you need can you and your provider make the best, informed decision when it comes to taking care of your health.*

*I would suggest you write a letter of complaint to the physician, and send a copy of your letter to the state health board. There is no reason that physicians and providers, when taking the proper precautions, should be at any risk of acquiring HIV. You are legally protected from discrimination based*

*on your HIV status under the Americans with Disabilities Act (ADA).*

*I would also strongly recommend that you find another more qualified physician. You can contact your nearest HIV community-based organization—in your area, the Comprehensive AIDS Program at (561) 472-2466, or the state AIDS hotline at 1-800-FLA-AIDS—and they should be able to refer you to someone. You really need to be in the care of an HIV specialist, and that would be someone who has a large HIV-positive clientele. You can also go to [www.aahivm.org](http://www.aahivm.org) and click on Find a Provider, to find a specialist in your area.*

*Basically when people act in this way, they are really acting out of fear and ignorance, and so it is our job, as HIV advocates, to try to educate people, so that they may become more informed, and ensure that something like this doesn't happen again to someone else.*

*Let me know if you need any more help, and good luck! ☒*

## PA ONLINE POLL

### JANUARY / FEBRUARY POLL QUESTION

**This month's question:**

**Have you ever had to stop or switch medications due to intolerable side effects?**

**VOTE AT  
[WWW.POSITIVELYAWARE.COM](http://WWW.POSITIVELYAWARE.COM)**

### NOVEMBER / DECEMBER POLL RESULTS

**The theme of this year's World AIDS Day (December 1) is leadership. What does leadership mean to you?**

### COMMENTS

- I believe true leadership is a combination of a curious mind, an innovative intellect, an open heart, the vision to see beyond the obvious, the courage to confront what's wrong, the tenacity to fight for what's right, and the understanding and patience to lead those who may have none of those things. I also believe the human condition makes us hungry for that kind of leader in a time when they are so rare—that's why this election was so important!
- A leader is someone who is not afraid to go outside of the box. In fact, I would think she or he would practically live there!

# NEWS BRIEFS



by Enid Vázquez

## U.S. GUIDELINES UPDATED

The U.S. HIV treatment guidelines for adults and adolescents were updated on November 3, 2008. The guidelines are written by a panel of experts, including advocates of people with HIV, through the Department of Health and Human Services (DHHS).

After finally reaching the “preferred” level for treatment of people taking HIV medications for the first time, the dual-drug Epzicom rode its wave of “success” for a very short time—until the next guidelines update. On November 3, Epzicom was downgraded to the “alternative” list of drugs. The popular Prezista/r (darunavir boosted with a small dose of Norvir, generic name ritonavir—hence the “r”) was moved on to the preferred list for first-time protease inhibitors. Kaletra once-a-day was added to the preferred list (except for pregnant women), instead of just twice a day as before on this list.

According to an update from the U.S. Food and Drug Administration (FDA), “Abacavir + lamivudine [Epzicom] has been moved from a preferred to an alternative dual-NRTI component because of concerns regarding an increased risk of myocardial infarction [MI, or heart attack] in patients with high cardiac risk factors, as suggested by large observational cohort studies, and concerns regarding virologic potency in patients with baseline viral loads greater than 100,000 copies/mL.”

After discussing new efficacy data on Epzicom (it did not work as well as competitor Truvada in people with more than 100,000 viral load in a large independent study, but worked as well as Truvada in a smaller study sponsored by Epzicom’s manufacturer; see more on page 21), the guidelines state, “Concern has also been raised regarding the potential cardiovascular risks of abacavir-containing regimens [Trizivir, Ziagen and Epzicom]. The D:A:D study group reported an analysis of myocardial infarction (MI) risk in a large, multinational, observational cohort that involved 33,345 participants and had 157,912 person-years of follow-up. Recent (within 6 months) or current, but not cumulative [total] or past use (last use more than 6 months ago) of abacavir predicted an increased risk of MI (relative risk [RR], 1.9; 95% CI, 1.5-2.6).” That’s nearly double the risk for heart attack. The guidelines immediately went on to say, however, that “The heightened risk of MI with recent abacavir exposure was accentuated in participants who had pre-existing cardiac risk factors.

“A second study also suggested an increased risk of MI associated with abacavir. An analysis of 2,752 participants in the continuous treatment arm of the SMART study indicated that abacavir use was associated with an increased risk of MI when compared with other NRTI [medications in the same drug class as abacavir] use (RR, 4.3; 95% CI, 1.4-13.0).” Again, the guidelines then explain that pre-existing risk factors are

involved: “Risk was concentrated in individuals with five or more known cardiovascular risk factors.

“In contrast to these two studies that suggested an increased MI risk among abacavir users, Cutrell et al [research sponsored by abacavir’s manufacturer] found no increased MI risk in a pooled analysis of 54 clinical trials, which involved 9,639 abacavir recipients, compared with 5,044 participants who received regimens without abacavir (RR, 0.9; 95% CI, 0.4-1.9).

“Although conflicting data exist regarding abacavir-based regimens, the combination of abacavir/lamivudine is now considered to be an alternative, rather than a preferred, dual-NRTI option. Pending additional data, abacavir/lamivudine should be used with caution in individuals who have plasma HIV RNA [viral load] greater than 100,000 copies/mL, as well as in persons at higher risk for cardiovascular disease.”

There were more updates to the guidelines, such as a discussion on simplifying therapy for treatment-experienced people. Pediatric and perinatal HIV guidelines were also updated. See all of the guidelines at [www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov).

## PREZISTA NEWS

Prezista 300 mg tablets are being phased out in favor of a new 600 mg tablet. The Prezista dose is 600 mg twice a day, and must be taken with a small booster dose of Norvir.

Prezista also received full FDA approval late last year.

Generally, new HIV drugs receive accelerated approval, a process pushed by advocates in order to bring badly needed meds to market as soon as possible. The manufacturer then has to complete the clinical study in order to receive full (traditional) approval. Prezista was also approved for people taking HIV medication for the first time. Newer drugs like Prezista, which was approved in 2006, are tested in treatment-experienced people, those who need a new drug the most.

## NEW ISENTRESS STUDY

The extremely popular new drug Isentress (raltegravir) is being studied at a once-daily dose. Currently Isentress must be taken twice a day. It is being studied in combination with Truvada. Anyone interested in participating in this study should consult their doctor. For more information, visit [www.benchmrk.com](http://www.benchmrk.com) and click on QDMRK.

## VIDEX-EC IN CHILDREN

The FDA expanded the use of Videx-EC to children weighing at least 20 kg (44 pounds). See the Dosage and Administration section of the drug.



Photo © Russell McGonagle



household. The findings will be published in the November issue of the peer-reviewed journal, *Pediatrics*.”

“We found that many of the worries were based on misconceptions about how HIV is spread,” said lead study author Burt Cowgill in the release. He is a staff researcher at the UCLA/RAND Center for Adolescent Health Promotion. “We also learned that HIV-infected parents had legitimate concerns about contracting infections such as a cold, flu, or chicken pox while caring for a sick child. This knowledge could help pediatricians to address children’s specific fears about HIV transmission as well as help clinicians who care for the HIV-infected parents.”

The researchers conducted interviews with 33 HIV-positive parents, 27 of their minor children (ages 9 to 17), 19 adult children, and 15 caregivers (spouses, partners, grandparents, or friends). They reported that although the families provided education on HIV, some fears were based on incorrect information and beliefs. Read the entire press release online.

## FAMILY FEAR OF DISCLOSURE

Writing from London for the November 2008 *HIV Treatment Update*, Edwin J. Bernard reports on the Don’t Forget the Children conference that recently took place in that city. Topics included untested children of positive mothers and the issue of children infected at birth who are not diagnosed or treated until they are adolescents. “When [Dr. Michael Eisenhut] asked the mothers why they had not tested their children, the most common response was the belief that because the child appeared to be well, it could not be infected. Other reasons included feeling unable to cope with a child’s positive diagnosis; a fear of confronting the child with the mother’s own HIV diagnosis; and a fear of feeling guilty if a child turned out to be HIV-positive.” See the report at [www.aidsmap.com](http://www.aidsmap.com). The conference website is [www.chiva.org.uk/news/dont-forget.html](http://www.chiva.org.uk/news/dont-forget.html).

## SYPHILIS AND ORAL SEX

The U.S. Centers for Disease Control and Prevention (CDC) is promoting education around syphilis in the gay community and large metropolitan areas. “A lot of my patients think they’re doing fine because they use condoms, but they don’t know they can get syphilis through oral sex,” said Los Angeles HIV specialist David Hardy, M.D. “Syphilis transmits very easily through oral sex. And it’s a very quiet disease.” *Positively Aware* asked Hardy at a recent conference what he thought the magazine should cover that would be helpful to his patients. This information is what he wants everyone to know.

According to the “Get Tested, Chicago” campaign, a collaboration between the city’s Department of Health and the CDC, signs of syphilis include:

- Sores or white patches on the genitals, anus, or mouth
- Rashes on palms of both hands or on bottoms of both feet
- Rash on any other part of the body
- Unexplained hair loss

“Don’t be fooled,” warns the campaign. “Syphilis often has no symptoms. Syphilis stays in your body even if sores go away. Only regular testing ensures your health.” The campaign recommends that people with multiple sex partners test for syphilis every six months. Visit [www.GetTestedChicago.com](http://www.GetTestedChicago.com) or call 1-800-243-2437.

## DISCOUNT ON GSK MEDS

GlaxoSmithKline (GSK), maker of several drugs used to fight HIV, recently announced the launch of a new Patient Savings Card designed to help improve compliance among eligible participants by reducing their out-of-pocket expenses for GSK HIV medications. Through this program, patients are eligible to save up to \$100 each month—for each of their GSK HIV medicines—for up to two years following their first use of the card. Patients can enroll in the program by visiting their doctor and asking about it. According to a GSK press release, “GSK has worked closely with leaders in the HIV community, the Fair Pricing Coalition among these, to improve access to HIV medicines since the beginning of the epidemic. Recently the community has voiced a significant need among those patients in the non-government program segment, who may

find paying their out-of-pocket costs an increasing challenge to adhering to their drug regimen.” Eligible individuals include patients who are paying out-of-pocket costs and whose prescriptions are not covered by Medicaid, Medicare, ADAP, or any other Federal or State assistance program.

The medications are zidovudine (brand name Retrovir); Eпивir; Combivir; Ziagen; Epzicom; Trizivir; and Lexiva. Some restrictions may apply, and more information about the program is available at [www.mysupportcard.com](http://www.mysupportcard.com). Read the entire press release online.

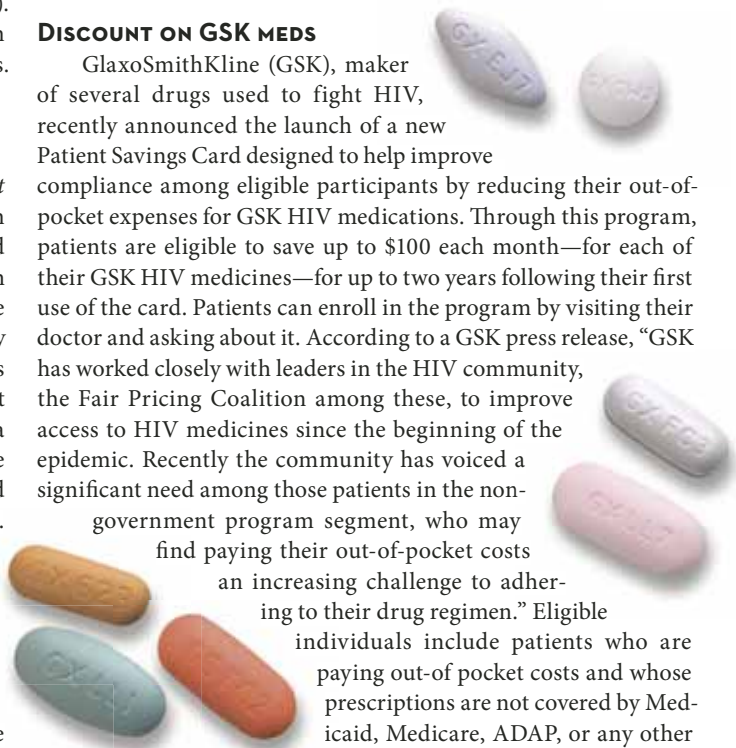


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## LONG-TERM COUPLES SURVEY

From friends of TPAN: “A long-term couple (30-plus years) is conducting research on how other long-term gay, male couples manage ‘outside’ sex, to see if there are any common elements and successful models that would be valuable to share with other couples. The study will look at how couples who have been together for eight or more years have navigated this issue, what ‘rules’ they find helpful, and the impact ‘outside’ sex has on their relationship.



“Interviews are conducted separately with each partner, and all information is considered confidential, including not sharing one partner’s responses with the other. Some demographic data will be collected such as age, race, and HIV status, but participants will be asked to provide only the information they are comfortable sharing, and may choose to use a pseudonym.

“Participants will be notified by e-mail at completion of the project and sent a report of the findings. Findings from the study will be shared with the LGBT community.

“For each couple participating, a donation of \$50 will be made to the LGBT or HIV/AIDS organization of their choice. For more information contact Lanz Lowen at [lanzlowen@aol.com](mailto:lanzlowen@aol.com) or Blake Spears at [dbspears@aol.com](mailto:dbspears@aol.com).” ☕

## LIPODYSTROPHY CONFERENCE COVERAGE NOW AVAILABLE ONLINE

Visit [www.positivelyaware.com](http://www.positivelyaware.com) for an update from the 10th International Workshop on Adverse Drug Reactions and Lipodystrophy, held in London in November 2008.



## 13TH ANNUAL HIV DRUG GUIDE

Look for the Positively Aware 13th Annual HIV Drug Guide in the upcoming March/April issue!



# Living with HIV doesn't

A white toilet is the central focus, with a tall stack of books balanced on its tank. To the right, a white hand sanitizer dispenser is mounted on the wall. In the bottom right corner, a white glass sits on the floor. The background is plain white.

**mean you have to live here.**

Ask your doctor if there are HIV medications  
with a low risk of diarrhea.

ASK THE  
AAHIVM  
HIV  
SPECIALIST™

This issue's Specialist:  
Michael Fingerhood, MD, FACP, AAHIVS



IS YOUR PROVIDER AN AAHIVM-CREDENTIALLED HIV SPECIALIST™?

If you are living with HIV, you have a lot of choices to make when seeking care and treatment. One of your most important choices is your health care practitioner—so why not choose someone who is knowledgeable about HIV and experienced in its treatment?

The American Academy of HIV Medicine (AAHIVM)'s HIV Specialist™ credentialing program is the first and only clinical credentialing program offered domestically and internationally to physicians (MDs and DOs), nurse practitioners and physician assistants specializing in HIV care. HIV care providers become designated HIV Specialists™ after meeting experience and education requirements, and successfully completing a rigorous exam on HIV-specialized care. Look for the letters "AAHIVS" after their name.

LOCATE AN HIV SPECIALIST™

Your search for an HIV Specialist™ is easy with AAHIVM's online Find-A-Provider directory at [www.aahivm.org](http://www.aahivm.org). Just click on the "Find-A-Provider" window on the homepage, key in your location and click on the search button for a list of HIV Specialists™ near you.

Due to space limitations, not all submitted questions can be answered in this column, but every effort is made to ensure you receive the information you have requested. For more information about AAHIVM, call 202-659-0699 or visit [www.aahivm.org](http://www.aahivm.org).

DEAR HIV SPECIALIST:

I am a registered nurse. I have a question about my HIV medications and I feel as if I am not getting an accurate response from my physician. Two weeks ago I started taking Atripla. On the 13th day of taking the medication I woke up with a head-to-toe rash, hives and extreme pruritus, almost unbearable. My M.D. said that it was the worst rash that she has seen with Atripla. She was certain that it is the Sustiva component of the Atripla, and gave me some samples of Truvada to see if it was the Sustiva component. I discontinued the Atripla and took the Truvada the following day, and I had an even worse outbreak of the rash. This time my lips became swollen, I had hives inside my mouth, and my eyes became swollen. My M.D. said to continue to take the Truvada and to take diphenhydramine routinely to reduce the hypersensitivity reaction. I have been taking Benedryl 75 mg every four hours routinely as well as Zyrtec daily, and hydroxyzine 50 mg every 4 hours, prednisone 40 mg daily, and I have had two shots of solumedrol IM 125 mg. My M.D. is certain that the rash will disappear but it seems to me that I am having a serious allergic reaction, and not a side effect of a rash! This is so annoying and I do not know what to do because I do not want to have mutations to the medications! Is there any way that allergy testing can be done to find out *exactly* which component of my HIV regimen that I am allergic to?

Signed, Super Sensitive

Dear SS:

The skin rash was undoubtedly related to the efavirenz (Sustiva) component of Atripla. In the original clinical trials, 27% of individuals receiving efavirenz developed a skin rash. However, in less than 1% of patients did the rash lead to blistering or become severe. The usual time to onset of rash is 7 to 14 days after starting efavirenz. The drug remains in the body for many days after stopping, so it is not unusual that the rash and symptoms worsened after you stopped the efavirenz component. The rash related to efavirenz is rarely life threatening and is usually treated with antihistamines, like Benadryl. Most individuals note improvement after a few days and are maintained on the drug. However, we do tell patients to stop efavirenz if there is blistering, significant fever, or a reaction with involvement of mucosal surfaces such as you had with swelling in your mouth and of your eyes. Your severe symptoms were treated appropriately with addition of prednisone and solumedrol. You should not receive efavirenz again, but you certainly can be treated with a regimen containing the other two components of Atripla (Viread and Emtriva, both contained in Truvada).  
✚

Michael Fingerhood, MD, FACP, AAHIVS  
Associate Professor of Medicine  
Johns Hopkins University  
Baltimore, MD

SUBMIT YOUR QUESTIONS FOR ASK THE HIV SPECIALIST TO [AAHIVM@TPAN.COM](mailto:AAHIVM@TPAN.COM)

## PREZISTA IN CHILDREN

The new-and-improved HIV protease inhibitor (PI) drug Prezista (darunavir), approved by the U.S. Food and Drug Administration (FDA) in late 2006, did well in treatment-experienced pediatric patients at one year of therapy. The study participants ranged from six to 17 years of age, with half of the 80 kids under the age of 14 and half older than that.

The most common side effects, found in more than 15% of these participants, were fever (pyrexia), cough, upper respiratory tract infections, and diarrhea. Most side effects were grade 1–2 (mild), but grade 3–4 adverse events occurred in one out of four patients (26%). These were not thought to be related to Prezista (which has to be boosted with another HIV PI, Norvir—generic name ritonavir). But six patients (8%) did experience grade 3–4 adverse events thought to be possibly related to Prezista/r (the “/r” is for ritonavir).

The participants had an average baseline viral load of 4.64 log (roughly 45,000). Half of them had less than 350 T-cells and half had a CD4 % less than 17%. They also had a lot of drug resistance in their virus.

After a year of therapy, 65% of study participants had a one log drop in their viral load (a significant amount, representing a 90% reduction). The percent of participants achieving less than 400 viral load was 59%, and a little less than half (48%) had less than 50 (undetectable). The average T-cell increase was 147.

The researchers wrote in their abstract that, “Darunavir/r was beneficial in this treatment-experienced, pediatric population based on the favorable tolerability, PK [pharmacokinetic, or how the drug works in the body] profiles, and virologic response rates [viral load results] at week 48.”

## A BETTER PROFILE

The ability to test HIV for its CCR5 or CXCR4 profile is important to the use of a new class of anti-virus drug, the CCR5 antagonists.

The only commercial test on the market for this, Trofile (from Monogram Biosciences), now has a more sensitive test available, Trofile (ES).

Looking at the blood samples of a study with the still-experimental CCR5 antagonist drug vicriviroc, Trofile (ES) was found to indeed be superior in predicting patient response to medication.

This kind of work needs to be done, but the fact is that the original Trofile assay is no longer even available.

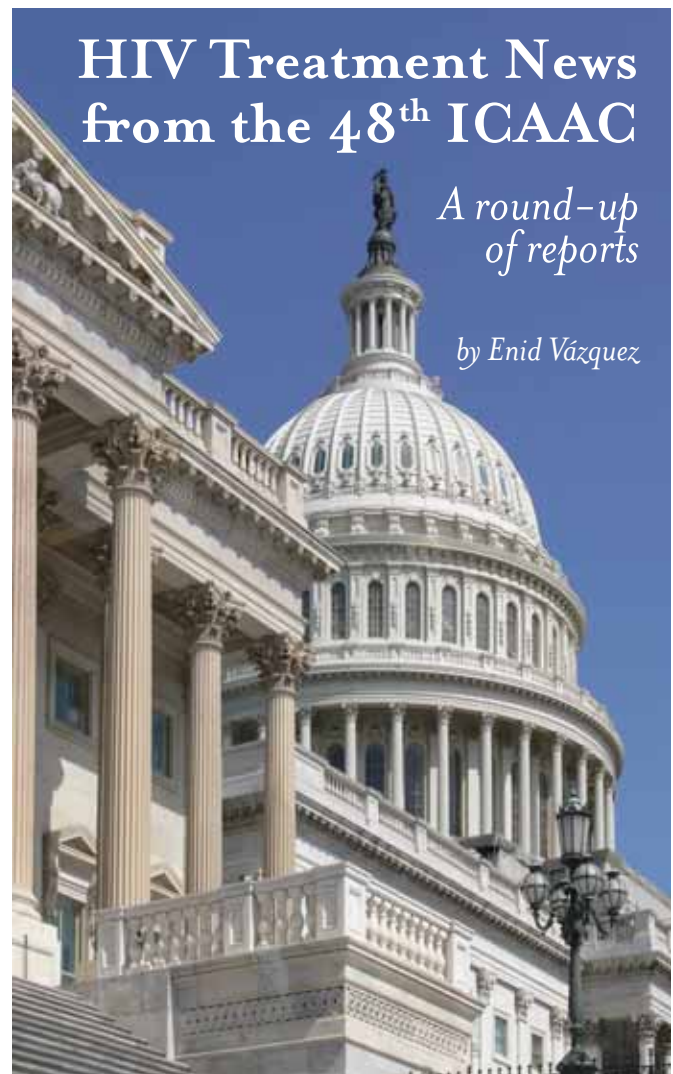
## ISENTRESS VS. SUSTIVA

An advanced stage (phase 3) study comparing Isentress to Sustiva found good results with both medications in people taking HIV therapy for the first time (called treatment-naïve).

Isentress (generic name raltegravir) is a very popular new drug from a novel drug class called integrase inhibitors. It was created for HIV treatment-experienced people whose virus has resistance to the older drug classes.

Sustiva, however, is also extremely popular, potent, and effective.

Looking at 48 week results, 86.1% of people on Isentress had achieved undetectable virus (less than 50 copies), compared to 81.9% of those on Sustiva. The Isentress group saw an average CD4 T-cell increase of 189, compared to 163 for the Sustiva group.



Drug-related adverse events were greater in the Sustiva group, 77% of the 282 individuals on it, compared to 44% of the 281 individuals taking Isentress.

## ONE DRUG ONLY: KALETRA

Patients of HIV specialist Joseph C. Gathe, M.D., in Houston, continued to do well after two years of HIV monotherapy—one drug only—with the protease inhibitor Kaletra (lopinavir with a booster dose of Norvir in it).

Dr. Gathe, who is African American, said years ago that he felt an urgent need to do something for his mostly black and Latino patients who did not have health insurance. For that reason, he designed this study with Kaletra monotherapy, which allowed him to obtain the medication free for the trial.

The experiment with a single-drug regimen—by this time a big no-no in therapy—was expected to succeed because of a combination of potency and Kaletra’s rare ability to avoid the development of drug resistance in HIV.

The 96-week results in the 39 study participants virtually continued the successful earlier 48 week findings—74% had less than 75 viral load (undetectable), compared to 79% for the first year. T-cells continued to increase throughout the two years, with half

of the participants seeing an increase of more than 310, and half less than that.

In the first year, the few (six) participants who experienced detectable viral load were found to be non-adherent, and counseling or intensification (adding other HIV medication) succeeded in bringing their viral load back down to undetectable for four of them.

In the second year, counseling helped bring viral load back down to undetectable in six of eight participants with low-level (but detectable) virus.

Happily, there was no development of PI resistance in the virus of the participants for whom Kaletra failed, or who had detectable virus on-and-off during the study. See more below.

those with HIV, understanding whether these changes affect time to AIDS or death is important.”

The NIAID researchers looked at a military cohort of 2,239 seroconverters from 1986 to 2006. There was confirmed syphilis in 9% of them (205 individuals) and probable syphilis was determined in another 3% of the group (66).

“Those acquiring syphilis were more likely to be older, African American, male, and co-infected with hepatitis B/C or other STDs. There was no difference in time from seroconversion to HIV diagnosis or in baseline CD4 or VL between those with and without syphilis.”

Syphilis is still a threat. Note the “access to healthcare” here, whether it’s free or not. See News Briefs on page 14 for more on this epidemic.

## WITH THE CONTINUED INCREASE IN SYPHILIS CASES AMONG THOSE WITH HIV, UNDERSTANDING WHETHER THESE CHANGES AFFECT TIME TO AIDS OR DEATH IS IMPORTANT.

### MORE ONE DRUG: KALETRA

At the same time, another poster presentation on Kaletra reported that, “After three years of follow-up, the OK-04 study shows that lopinavir/ritonavir monotherapy can maintain HIV viral suppression in a very large proportion of patients.” “OK” stands for “Only Kaletra.”

The Spanish researchers went on to report that, “Of the 100 patients initially randomized to lopinavir/ritonavir monotherapy, 71% remain on monotherapy with an HIV viral load of less than 50 HIV-RNA copies/mL at week 144. This result supports the durability of lopinavir/ritonavir and is consistent with the long-term follow-up of our pilot clinical trial in which 66.7% of patients randomized to lopinavir/ritonavir monotherapy remain on monotherapy and with HIV-RNA [less than] 50 copies/mL after four years of follow-up (*J Antimicrob Chemother.* 2008; 61:1359-61). Three-year results of OK-04 trial support long-term efficacy and a minimal risk of resistance of the strategy of lopinavir/ritonavir monotherapy with reintroduction of nucleosides [a different class of HIV drug] as needed.”

Importantly, these study participants were treatment-experienced and still maintained undetectable viral loads when put on Kaletra monotherapy. They were not, however, allowed to join the study if their HIV already had resistance to PI drugs.

### SYPHILIS AND HIV

There’s an epidemic of syphilis among gay men in the U.S. at this time. Some good news: NIAID (National Institute of Allergy and Infectious Disease, part of the U.S. National Institutes of Health, or NIH), reported that, “In a large, prospectively followed cohort [group] of HIV seroconverters [recently-infected individuals] with equal access to free healthcare, syphilis co-infection did not affect time to AIDS or death.”

According to the report, “Syphilis co-infection transiently decreases CD4 count and increases viral load (VL) in HIV-infected persons. With the continued increase in syphilis cases among

### EPZICOM VS. TRUVADA

Among the studies that have compared the two competitors was a British review of 12 clinical studies. The poster presentation reported greater effectiveness with Truvada.

“This systematic review of first-line clinical trials of 2NRTI [such as Epzicom or Truvada] plus boosted PI, with standard-

ized HIV RNA [less than] 50 copy efficacy data, using the [U.S.] FDA TLOVR algorithm [a type of statistical analysis], suggests higher efficacy for first-line use of a [Truvada] NRTI backbone, relative to use of [Epzicom]. This apparent difference in efficacy was seen for patients with baseline HIV RNA levels below and above 100,000 copies/mL. A similar difference in efficacy was shown in a systematic review of first-line trials of [Truvada/Sustiva] vs. [Epzicom/Sustiva] (Bartlett 2006).”

The report also noted that, “There is conflicting evidence on the relative efficacy of [Truvada] versus [Epzicom] from three direct head-to-head randomized trials. Two trials suggest higher efficacy for [Truvada], and one trial shows non-inferior efficacy for [Epzicom].” The first two studies were independent, while the last one was conducted by the manufacturer of Epzicom. See News Briefs on page 14 for more on this issue.

### HIV THERAPY AND BONE LOSS

There was ironic news from the large, international SMART trial. The same study that showed a greater risk of disease and dying for people who go on-and-off HIV therapy now shows that those who continuously take their antiviral meds have a greater risk of bone mineral density (BMD) loss. Still, the researchers noted that, “Intermittent [on-and-off] ART is not recommended due to increased risk of AIDS and death observed in the SMART study.” Results were from a sub-analysis of 214 study participants being followed in the SMART trial. The study report said the decline in bone mineral density could possibly lead to fractures. Bone fractures and even hip replacements have been seen unexpectedly in HIV patients, with medical providers scrambling to determine if medications were the cause and if so, which medications in particular. In this report, the researchers were unable to attribute loss in BMD to any particular drug or drugs. ☒

# Starting Therapy Earlier Found to Improve Survival

Study raises the implications of more testing, less transmission

by Enid Vázquez



It's been coming for years—a move to start HIV therapy earlier and earlier. Now, at this year's ICAAC (Interscience Conference on Antimicrobial Agents and Chemotherapy, held by the American Society for Microbiology), a report from a large study found a 74% higher risk of death in a group of patients delaying therapy.

The report raised a lot of implications—including the need for testing to learn that you're HIV-positive in the first place, and the potential to lower transmission if more people start therapy.

## NA-ACCORD

Mari M. Kitahata, M.D., of the University of Washington in Seattle, presented the results of the North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD) in a latebreaker session at the October conference, held in Washington, D.C.

"Our study indicates that initiating therapy rather than deferring HAART

[highly active antiretroviral therapy] with a CD4 count between 350 and 500 is associated with improved survival," Kitahata said in a press conference following her presentation. She said the study

bringing together the large numbers of patients needed for scientific power.

The researchers looked for individuals who were positive but did not have AIDS, had never taken HIV therapy, and had a CD4 count between 350 and 500. They looked at a 10-year time span, from 1996 to 2006.

**"IT SAYS THAT FOR THOSE WHO DON'T INITIATE THERAPY AT THE HIGHER CD4 CELL LEVEL, THEY HAVE A 74% INCREASED RISK OF DYING."**

was conducted because U.S. guidelines recommend treatment for otherwise healthy people who have less than 350 CD4 cells, but that the best time to start HIV therapy is unknown.

NA-ACCORD examined all HIV cohorts conducted in the U.S. and Canada,

Of the 5,926 individuals in this category, a third (32% or 1,921 individuals) began HAART. Using person-years of follow-up analysis, the study found a relative hazard (RH) of 1.74 of death in the 68% of people (4,005 individuals) who delayed therapy until their CD4s dropped below 350.

"It is a substantial and significant increase in the relative risk [relative to delay] of death," Kitahata said. "It says that for those who don't initiate therapy at the higher CD4 cell level, they have a 74% increased risk of dying."

Kitahata pointed out that the observational cohorts allowed for an examination of patients similar to those in the real world, rather than those seen in clinical studies, who generally receive care under superior conditions.

Moreover, research to date has looked at the question of when to start therapy by comparing people from different CD4 count levels or viral loads. Said Kitahata, "This is the largest study to date examining this question comparing head-to-head the same CD4 cell count level. And these data strongly support the use of antiretroviral treatment for patients of a CD4 count of 500 and below regardless of the presence of symptoms."

Speaking at the press conference along with Kitahata was HIV specialist Daniel Kuritzkes, M.D., of the Brigham and Women's Hospital and Harvard Medical School, who presented drug resistance data at this

Kitahata added that many studies only include patients who have already started HAART. "So they're not able to compare head-to-head patients who've initiated and not initiated therapy, which our study does."

NA-ACCORD worked through the International Epidemiology Databases to Evaluate AIDS (IeDEA), a global network of clinics funded in part by the National Institute of Allergy and Infectious Diseases (NIAID), part of the U.S. National Institutes of Health (NIH).

### TESTING, TESTING... DYING, DYING?

Kuritzkes said he believes the study is "a strong push" for U.S. recommendations to change, but couldn't say if the guidelines panel would act on the basis of one study, however strong that study might be.

He also talked about the problem of initiating therapy when so many HIV-positive people don't know that they're living with the virus.

"The average CD4 count of people who are beginning on treatment," said Kuritzkes, "similar to the people who are showing up for care, is in the mid-200s. At our center,

studies, you'd be comparing survival in people who started antiretroviral therapy at CD4s 350 to 500 to people who had started therapy below 350. But the only people who can start therapy below 350 are the ones who survived to start therapy below 350. And so you're missing all the people who died along the way."

He added that critics point out how well people do on HIV therapy even when they wait until they have a low CD4 count, saying that while that "generally tends to be true," it still does not consider the people who have already died during the wait.

### NEW AND IMPROVED

The writing has been on the wall for earlier treatment in part because HIV therapy is getting easier and easier to take.

"The older treatments, which were more toxic and less well-tolerated, often [led to treatment delay]," said Kitahata. "With the people included in this study, we found a significant survival with newer regimens taken these days that are easier to take, more tolerable, with less frequent doses."

"What we're seeing," said Kuritzkes, "is that the better regimens, because they're simpler to take and have fewer side effects, are also important to overall adherence."

### MORE MEDS = LESS TRANSMISSION

In response to a question about the public health impact of more people starting on therapy, and its relation to a decrease in HIV transmission, Kuritzkes said there are theoretical arguments about this relationship from study in couples where one person has HIV and the other doesn't.

"A lower viral load in the infected partner [has been associated with] a lower risk of transmission. ...So I think there could well be a public health benefit. In fact, the different models argue for different impacts," said Kuritzkes. "Some models suggest that most transmission occurs among newly infected people who have a high viral load and people at late stage disease who again have a higher viral load. ...It's a reasonable hypothesis that treating more people would reduce the community burden of viremia and reduce, therefore, the overall risk of transmission." ✚

*Editor's note: Listen to a taped recording of the press conference at TheBody.com.*

## THE WRITING HAS BEEN ON THE WALL FOR EARLIER TREATMENT IN PART BECAUSE HIV THERAPY IS GETTING EASIER AND EASIER TO TAKE.

year's ICAAC. "I think these are really very important data," Kuritzkes said. "There have been a variety of cohort studies that have shown differences in the time to AIDS and the time to death in patients who initiated therapy below 200 CD4 and then 200 to 350 CD4, which is where our current guidelines come from. But many of these cohorts, while they suggested transient favor in the role of initiating therapy for patients at earlier stages haven't had enough people—they lacked the power to really be able to find meaningful differences in the entire CD4 stratum. I think the importance of this study is that by aggregating all these North American cohort studies together, they really got enough patients to have the power to see this important difference."

a quarter of the people who find out they have HIV do so because they got hospitalized from illness."

He mentioned findings from the CDC (U.S. Centers for Disease Control and Prevention) which estimate that up to a third of people with HIV in this country do not know that they're positive. "That's because, [again,] people are still being tested far too late," Kuritzkes said.

"The point Dan made about who's taken into care is a critical one here, because in our clinic also we are seeing people presenting much later than we would like, and often pneumocystis is their first point of care as an opportunistic infection [advanced disease]," Kitahata said.

At one point, Kuritzkes returned to the question of waiting. "In the previous cohort



# MORE THAN JUST ANOTHER BRICK IN "THE WALL"

## WANT A PIECE OF TPAN?

TPAN is growing and we need your help! Not only are we expanding our variety of programs to include the new POWER (Positive Outcomes for Wellness, Education and Recovery) Program, as well as thinking ahead towards future growth, but we're also expanding our physical space into 5541 N. Broadway. There, we will have room for new staff members, a meeting room large enough for 75 people, modern equipment and facilities that will serve us well for years to come.

But, as you can imagine, all of that costs money. True to our long history of being peer-led, we are creating a grassroots campaign to support this growth. One of the large walls in the new space is made of bricks - we are inviting everyone to buy a brick in the wall at whatever level is right for them. In order to show our gratitude and acknowledge your ownership of TPAN's future, the bricks will bear the names of every contributor who wants their name, or the name of someone they donate in honor or memory of, to appear there. We believe that even the smallest donation deserves to be recognized for helping to make this exciting growth possible.

### If you would like to donate, you can do so in several ways:

**By mail:** Use the form below and send a check or money order to TPAN at 5537 N. Broadway, Chicago, IL 60640.

**Online:** By credit card, go to [www.tpan.com](http://www.tpan.com) and click on "The Wall"

**In person:** forms and donation envelopes are available at reception

### There are four levels of giving:

**Bronze:** \$5-\$99; **Silver:** \$100-\$249; **Gold:** \$250-\$499; **Platinum:** \$500 and above. And, yes, your donation is tax deductible!

Additionally, there are other opportunities to become a conference or counseling room sponsor starting at \$1,500. Contact Ron Schnorbus, Director of Development, at 773-989-9400, ext. 229, for more information.

If you've ever felt that TPAN has helped you or someone you know to live a healthier, more informed, more empowered life, now is your chance to help us to continue to do that for all who enter here. Thanks for being part of TPAN's continued success!

In Memory of Alice

ILGA Bowling Team

eens David & Alex

M. R. E. K.

We miss you, Tommy

S.H.E.

Support

Group

## YES! I WANT MY PIECE OF TPAN!

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Is your donation in honor  or in memory  of someone?

How would you like your donation to appear on the "The Wall"? (please print legibly): \_\_\_\_\_

I prefer to donate anonymously.

**Bronze:** \$5 to \$99  **Silver:** \$100 to \$249  **Gold:** \$250 to \$499  **Platinum:** \$500 and above **Donation Amount:** \$ \_\_\_\_\_

Payment method:  Cash  Check/MO  Credit Card

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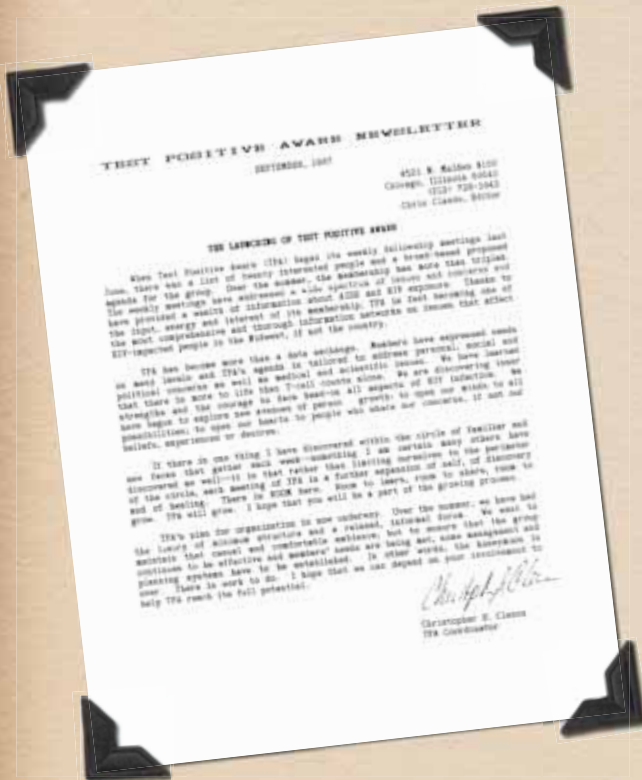


# POSITIVELY AWARE 20TH ANNIVERSARY

## THE LAUNCHING OF TEST POSITIVE AWARE

A revisited note from the founder

by Christopher S. Clason



*Editor's note: Chris Clason was the founder of Test Positive Aware Network (see the November/December 2000 issue of Positively Aware). This letter to the membership ran in the September 1987 issue of the Test Positive Aware Newsletter. His vision of growth has been realized. Chris Clason died in December 1991, but his spirit lives on in the organization he founded, and in the hearts of his friends and family, and even those who—like myself—never met him.—Enid Vázquez*

**W**hen Test Positive Aware (TPA) began its weekly fellowship meetings last June, there was a list of 20 interested people and a broad-based proposed agenda for the group. Over the summer, the membership has more than tripled. The weekly meetings have addressed a wide spectrum of issues and concerns and have provided a wealth of information about AIDS and HIV exposure. Thanks to the input, energy, and interest of its membership, TPA is fast becoming one of the most comprehensive and thorough information networks on issues that affect HIV-impacted people in the Midwest, if not the country.

TPA has become more than a data exchange. Members have expressed needs on many levels and TPA's agency is tailored to address personal, social, and political concerns as well as medical and scientific issues. We have learned that there is more to life than T-cell counts alone. We are discovering inner strengths and the courage to face head-on all aspects of HIV infection. We have begun to explore new avenues of personal growth: to open our minds to all possibilities; to open our hearts to people who share our concerns, if not our beliefs, experiences, or desires.

If there is one thing I have discovered within the circle of familiar and new faces that gather each week—something I am certain many others have discovered as well—it is that rather than limiting ourselves to the perimeter of the circle, each meeting of TPA is a further expansion of self, of discovery and of healing. There is *room* here. Room to learn, room to share, room to grow. TPA will grow. I hope that you will be a part of the growing process.

TPA's plan for organization is now underway. Over the summer, we have had the luxury of minimum structure and a relaxed, informal forum. We want to maintain that casual and comfortable ambiance, but to ensure that the group continues to be effective and members' needs are being met, some management and planning systems have to be established. In other words, the honeymoon is over. There is work to do. I hope that we can depend on your involvement to help TPA reach its full potential. ✚



Chris Clason pictured here in a video capture by Bob Hultz during an interview around 1992.

# POSITIVELY AWARE 20TH ANNIVERSARY



## POSITIVELY AWARE TURNS TWENTY

A former editor remembers our journey

by Bob Hultz

### DAYS OF DARKNESS, RAYS OF LIGHT

If you've ever lost your cell phone, along with it probably went your friends' phone numbers stored in memory. If your computer ever crashed, you know the chaos that follows when a virus hits your hard drive. All your data, photos, e-mail and contacts: gone.

Twenty years ago, a virus was erasing not just the phone numbers of our friends; it was erasing their lives. Lovers, intimate acquaintances, family members and friends were becoming critically ill and dying in rapid succession, one after the other, year after year.

When the darkness of HIV/AIDS first slithered across this country like some monster from an old sci-fi movie, many of us in Chicago responded by creating a new light. Together, we formed Test Positive Aware Network (TPAN) and *Positively Aware* (PA).

This article is about that decade and that time: when we changed lives with condoms, drug trials, pill timers, the stages of death and dying and the states of defiance and hope.

In an information vacuum, we gathered resources and learned from one another. We debated new cure quests: pharmaceutical drugs and Chinese herbs, bone-marrow transplants and blood swaps, egg yolks and acupuncture, drinking urine and blowing ozone gas up your ass.

We wanted to know everything about anything that might stop the devastating sickness and death. Because of our efforts, we were no longer isolated in fear and ignorance. And we carried that message to others nationwide: *You are not alone.*

### IN OUR BEGINNING

In the summer of 1987, when TPA Network was founded, Chicago had no open support group for people concerned about HIV and no local printed information concerning HIV and AIDS.

"Virtually fatal" and "incurable" was how U.S. Surgeon General, C. Everett Koop, described AIDS during his address to the first *President's Commission on AIDS* in September of 1987.<sup>1</sup> Another year would pass before 107 million copies of Dr. Koop's booklet, *Understanding AIDS*, would be distributed as the government's first mass-education campaign on the subject.

Like most of the rest of the country, those of us in Chicago relied heavily on resources produced regularly in the three cities hit hardest by the epidemic:

New York City — *Treatment Issues* from the Gay Men's Health Crisis (GMHC); materials from *Body Positive*; and publications from the American Foundation for AIDS Research (AmFAR).

San Francisco—Project Inform's *PI Perspective*; John James' *AIDS Treatment News*; and the *Bulletin of Experimental Treatments for AIDS* (BETA) from the San Francisco AIDS Foundation.

Los Angeles—The *Being Alive Newsletter* and numerous landmark publications of AIDS Project Los Angeles (APLA).

To help meet the Midwest's need for support and information about HIV/AIDS, Chicago activist Chris Clason founded Test Positive Aware Network (TPAN), holding its first meeting on June 19, 1987.

Three months later, Chris wrote and produced the first issue of *TPA News*, which eventually grew to become *Positively Aware* (PA). Monthly, for more than two years, he cranked out *TPA News* on an Atari game computer and a dot matrix printer from his apartment on North Malden street.

In July of 1989, production of *TPA News* moved from Chris' apartment to mine. As president of TPAN's second Board of Directors, I volunteered to handle the newsletter's writing, editing and production, an honor I held for 48 monthly issues.

Before I take you further into the history of our early years, take a look at the accompanying timeline to remind yourself about the decade when AIDS and HIV were first recognized and the years when TPAN and its publications began. [See sidebar.]

### GUIDING PRINCIPLES

Working with other dedicated volunteers and contributors, we steadily achieved higher levels of credibility and authority as an organization and as a publication. Our Editorial Committee helped maintain standards for balance and accuracy.

Experience in broadcasting and media gave me the skills to take on writing, editing and formatting the publication. An HIV-positive status and the loss of dozens of intimate friends to AIDS gave me drive and determination.

Type-setting and new page layouts made each issue more user-friendly. Contribution of my custom charts, graphics, and photographs helped to distinguish our monthly from all other monthly HIV/AIDS publications of the time.



Photo © courtesy of Bob Hultz



# POSITIVELY AWARE 20TH ANNIVERSARY



The combined result was a unique, credible news source that was enjoyable to read, authoritative and yet accessible to readers with a wide range of education. We worked hard to provide a publication that was true to our founder's goals, a tradition that continues twenty years later.

Month after month, we provided: informative reports and timely commentary; news of pharmaceutical treatments and complementary therapies; guest views and letters; listings of HIV/AIDS organizations, services and clinical trials; updates on legal and estate issues; "AIDS Basics" and glossaries; prevention information; and details of TPAN support meetings and social functions.

Above all, we championed our organization's theme: *Committed to Living*. We were determined to be a reliable, unbiased source of life-saving information and support without advocating for particular courses of action.

In the first years of our publishing, most of our funding was provided by mail subscriptions and grants. Our first major grant came from the Chicago Department of Public Health (CDPH). Foundation awards and fundraisers were the other source of continuing financial support for PA and TPAN. Our most significant

## THE EPIDEMIC'S EARLY DAYS

To understand the birth and growth of the publication you're reading right now, think back to the tumultuous decade in which TPA Network and *Positively Aware* were born.

In July of 1981, what we today know as "AIDS" (Acquired Immune Deficiency Syndrome) was first officially detected in the United States.<sup>3</sup> Nobody knew what was causing these rare cases of deadly cancer and pneumonia among gay men on either coast.

By July of 1982, 452 cases had been reported to the Centers for Disease Control (CDC) from 23 states.<sup>4</sup>

The collection of diseases still didn't have an official name. The CDC referred to it as "KS/OI Syndrome" (Kaposi's Sarcoma and Opportunistic Infections Syndrome).<sup>5</sup> Because it was seen among gay men, it was often called "gay cancer," "The Gay Plague," and "GRID" (Gay-Related Immune Deficiency).

But the same rare diseases were also devastating injecting drug users and people of Haitian descent. Further, AIDS was being discovered among hemophiliacs, in people who had received blood transfusions, in children of infected mothers and in heterosexual women.

In September of 1982, the CDC officially began using "AIDS" (Acquired Immune Deficiency Syndrome).<sup>6</sup>

## QUEST FOR A CAUSE

It was May of 1983 when French scientists, led by Luc Montanier, discovered "LAV" (Lymphadenopathy-Associated Virus), which they believed might be the cause of AIDS.<sup>7</sup>

The French researchers sent a sample of LAV to the U.S. National Cancer Institute (NCI) for study. Eleven months later, the U.S. government announced that NCI's Dr. Robert Gallo had isolated the cause of AIDS. He called it "HTLV-III" (Human T-Cell Leukemia Virus Type Three).<sup>8</sup>

In January of 1985, the U.S. Food and Drug Administration (FDA) licensed the first blood test to detect HTLV-III.<sup>9</sup>

By March of that year, researchers concluded that LAV from France and HTLV-III from the U.S. were the same virus.<sup>10</sup> But legal arguments continued over who should receive royalties for tests for the virus and which name it should be given.

In May 1986, the name dispute ended with an international agreement to adopt a new name: HIV (Human Immunodeficiency Virus).<sup>11</sup> The French later agreed to share proceeds from the HIV ELISA test with the U.S..

Paranoia about AIDS transmission exploded nationwide. Some churchgoers refused to drink communion wine from a common cup. Food trays were left in hallways outside the hos-

# POSITIVELY AWARE 20TH ANNIVERSARY



pital doors of AIDS patients. Ryan White, a 13-year old hemophiliac with AIDS, was barred from school in Indiana. People with AIDS faced discrimination in the workplace and in housing. Friends, families and neighbors rejected them out of fear of contagion. Rock Hudson and Liberace died. Magic Johnson had not yet disclosed that he had HIV.

By the end of 1986 the World Health Organization (WHO) estimated that 10 million people were infected with HIV worldwide.<sup>12</sup> Reported AIDS cases totaled 38,401 in 85 countries; 83% of these were from the Americas.<sup>13</sup>

## OUR FIRST YEARS

The Western Blot test was licensed in March of '87 as a confirmatory test for the less-reliable ELISA test to detect antibodies to HIV.

Senator Jesse Helms led passage of "The Helms Amendment," adding HIV to the list of diseases for which people could be excluded from entering the U.S. on public health grounds. (AIDS had been added a month earlier by the U.S. Public Health Service.)

AZT was approved by the FDA as the first and only drug to treat people with AIDS.<sup>14</sup> No approved treatments were available for those who "only" tested positive for HIV but had not progressed to AIDS. There are no cures or preventive measures for the more than two dozen AIDS-defining illnesses.

ACT UP (The AIDS Coalition to Unleash Power) demanded access to treatments and drug trials, to lower drug prices, raise public awareness and fight discrimination. Signs at their first mass demonstration at the New York Stock Exchange featured a pink triangle and the words "Silence=Death".

President Reagan made his first major speech on AIDS, calling for increased routine and compulsory HIV testing.

The Names Project AIDS Memorial Quilt began in California as gay-rights activist Cleve Jones stitched together the first AIDS Quilt panel to honor the death of his friend Marvin Feldman.

In August of 1989 results from a major drug trial showed that AZT could slow progression to AIDS in HIV-positive people who had no symptoms.<sup>15</sup>

Dr. Peter Duesberg published a scientific paper challenging the link between HIV and AIDS, leading a debate that would continue for years.<sup>16</sup>

Referenced footnotes available online at [www.positivelyaware.com](http://www.positivelyaware.com).



*ACT UP led demonstrations [against U.S. HSS Secretary Lewis Sullivan] at the opening of the 1990 IAC, protesting government inaction on AIDS and U.S. immigration policies restricting entry of HIV-positive people into the United States.*

*Photo by Bob Hultz.*

continuing fundraising was conducted by the volunteer organization *Bringing Our Hearts Together*, which eventually became the *Hearts Foundation*.

## EARLY PUBLISHING MILESTONES

In April of 1990, we began printing our monthly on a commercial web printing press, allowing us to print thousands of newsletters with color accents at a fraction of the cost of photocopying or offset printing. The lead story in that issue concerned aerosolized pentamidine, the first treatment approved to prevent *pneumocystis carinii* pneumonia (PCP), the leading killer of people with AIDS.<sup>2</sup>

November, 1990, marked the first issue of our news magazine bearing the new *Positively Aware* name and banner, created by Chicago AIDS activist Drew Badanish.

Three months later, we released our first "spin off" publication: a stand-alone 104-page *Directory of Chicago HIV/AIDS Clinical Trials*. Based on the consistently authoritative listings of HIV/AIDS clinical trials in our monthly magazine, TPAN obtained funding and source material for the project from AmFAR, the American Foundation for AIDS Research.

Sections were included in English and Spanish and the entire publication was made available on disc for customization and distribution by other HIV/AIDS organizations. *PA* continues to be a source of information about clinical trials locally and nationwide.

Another breakthrough publication was released the next year when TPAN published the first *Chicago Area HIV/AIDS Services*



# POSITIVELY AWARE 20TH ANNIVERSARY

*Directory*, a 62-page book funded by the CDPH.

By this time we had established a tradition of providing our readers first-hand reports and photographs from the annual International AIDS Conference (IAC). I and other reporters from *Positively Aware* covered the IAC beginning with San Francisco in 1990; these first-person reports continue today.

## PA GOES NATIONAL

In the spring of 1992, TPAN secured funding to expand *Positively Aware* from a local to a national publication. Working closely with Executive Director Steve Wakefield, I developed the concept and we successfully applied for a three-year grant from Burroughs Wellcome, manufacturer of AZT.

The award was controversial because critics feared we would become a mouthpiece for the drug industry. To the contrary, we vowed to provide critically-needed, accurate, unbiased information to our readers—a promise *PA* upholds today.

The funding allowed us to acquire computers and production tools, furnish offices and hire staff to carry on the work that had been handled for years by me and other volunteers. Assistant editor Cesar Chavez, production editor Dave Thomas, writer Scott Williams, distribution coordinator Jeff Berry and other paid professional staff worked with me as Senior Editor. Together with dozens of volunteers and contributors, we achieved levels of production, reporting and circulation undreamed of just a few years earlier.

Our press run for *Positively Aware* expanded to nearly a million copies annually. Beginning in June of 1992, in addition to our monthly local edition, every three months we distributed more than 200,000 copies of *PA* to 245 HIV/AIDS organizations in more than 190 cities.

Additional to publishing “generic” versions without any city-based details, our staff worked with writers at community-based organizations to customize these quarterly editions for ten “second tier” cities. These ranked just behind the “first tier” cities of New York, Los Angeles and San Francisco as having the highest numbers of reported HIV/AIDS cases.

As the magazine developed in size and sophistication, our monthly mailing list grew from a few hundred in 1988 to more than 3,500 by 1993. Today, *Positively Aware* reaches readers in more



than 17 countries and in every state of the union.

## LETTING GO, HOLDING ON

Some personal reflections may help add perspective to the magnitude of TPAN’s accomplishments in creating and expanding *Positively Aware*.

Throughout much of the 1980s, I spent many hours with other TPAN members attending funerals and memorial services of friends

and loved ones who perished from AIDS. Even more hours were invested visiting the homes and bedsides of those who were dying of AIDS-related illnesses.

One night, I was sitting quietly in the hospital room of a dying TPAN member who was wheezing for breath, tortured with pain and terrified with panic. I watched as one of his visitors leaned over and whispered in his ear, “Let go. Just let go.”

This message of permission, calm and comfort was intended to communicate that it was all right to stop grasping for air, to relinquish control and pass in peace without regret for the past or fear of his final heartbeat.

Ironically, a day or so later, another visitor stood at my friend’s bedside with a message that defied the doctor’s prognosis, mixing faith, hope and denial.

She leaned over and, with quiet determination, urged him, “Hold on; hold on.” Her message was a valiant effort to impart strength and courage in the presence of certain death.

Such ironic twists constantly punctuated those years as we learned to face our own mortality with hope, realism and resolve.

## MORE THAN A MOTTO

Under the banner *Committed to Living*, we formed an organization to encourage, sustain and inform others in the face of an unprecedented, unknown disease that was rapidly killing us.

Some died within months or weeks of their diagnosis of HIV-related pneumonia, spinal meningitis or PML brain tumors. Many were disfigured from Kaposi’s sarcoma lesions on emaciated bodies that had previously been the envy of others in gyms, bars and clubs. Molluscum looked like clumps of cottage cheese on the gaunt faces of some. Others used canes to walk, having lost most of their eyesight to CMV (cytomegalovirus) retinitis or because their limbs

# POSITIVELY AWARE 20TH ANNIVERSARY



burned incessantly from peripheral neuropathy.

In addition to the many men and women I met through TPAN, dozens and dozens of my intimate and close friends have passed away from AIDS over the years. My first lover, Cliff Counts, died of PCP in San Francisco in 1983. My second life-partner, Tony Kiser, died of AIDS in 1993. He served with me on the Board of TPAN, supported my work at *Positively Aware*, and together, we attended fellowship meetings from the first months of the group.

In this unique support setting, we all learned how and when to “let go” with grace, to choose our battles carefully and fight them courageously. At TPAN and through the pages of *Positively Aware*, we studied the essentials of making a will, applying for disability, obtaining food and housing or enrolling in hospice.

We gathered each week to face unpleasant realities together. We calculated costs of cremation vs. burial. We took notes as Hemlock Society speakers explained how to take our own lives if we chose to let go under unbearable waves of pain.

## DRIVE AND DETERMINATION

At the same time, we embraced one another, dried each other's tears, found ways to laugh, learned to forget and remember, and encouraged one another. In countless ways on countless days we told one another to “Hold on.”

We were bound together by a hope that one day there would be better treatments or a cure—perhaps before our time was over. We were buoyed by each other's courage in the face of discrimination and rejection from society, employers, landlords and our own families.

Together we learned to meditate, exercise, eat better, try complementary and alternative therapies, take our meds and switch when they no longer worked. We donated our blood to drug trials so that we and others might benefit from our misfortune. We enjoyed yoga and massages from Hannah Hedrick and spiritual guidance from Rev. Brian Hastings.

We attended picnics and vigils. We biked, walked and marched for AIDS. We studied *Conversations with God*, *The Road Less Traveled* and the *Twelve Steps of AA*. We learned how to *simultaneously*



*TPAN member Danny Sotomayor, a Chicago artist and AIDS activist, helped keep our organization and publications current on HIV/AIDS political and prevention issues. He is shown at right at a 1990 local protest featuring the Gran Fury advertising campaign, “Kissing Doesn't Kill, Greed and Indifference Do” see: <http://creativetime.org/archive/?p=84>*

let go and to hold on, to fight as if we were going to live even though the odds then were against us.

Eventually, millions of readers around the country and around the world were able to share our determination to face the worst of HIV's realities with an affirmative spirit.

We were inspired and rewarded when letters of appreciation poured in

from readers at hospitals, schools, churches, prisons, substance-abuse treatment centers, and hospice facilities. Mothers and fathers, sisters and brothers, friends and lovers learned from us ways to hold on, ways to let go, and how to choose wisely between those seemingly opposite courses.

## CHANGING LIVES THEN AND NOW

The world is a better place and I am a better man for my work with *Positively Aware* and the members of TPAN.

Today, at age 60, I've lived far beyond my expectations during those early days of TPAN. I'm determined to hold on longer as a tribute to those I've loved and lost and as encouragement to others I've yet to meet.

I represent hope to those who test positive. And I try to bolster others with ways to stay negative while enjoying sex and life.

If someday I decide to let go, I can do so with the peace of having made a difference through my contributions to *Positively Aware* and its inestimable gifts to readers around the world.

I often wonder why I have survived more than two decades with HIV when so many millions of others have not. I believe that one reason is to be here today, bearing witness to you from all those, living and dead, who were a part of the early days at TPAN and *Positively Aware*. From me and them I say to you, “hold on.”

*Bob Hultz was Senior Editor of TPA News and Positively Aware from 1989 to 1993. Bob now lives in Los Angeles and may be contacted at [bobhultz@aol.com](mailto:bobhultz@aol.com).*

*Referenced footnotes available online at [www.positivelyaware.com](http://www.positivelyaware.com).*



# POSITIVELY AWARE 20TH ANNIVERSARY

## THE BRIDGE TO SOMEWHERE

*A former board member reminisces*

*by Michael Blackwell*



You've heard the saying: "You never know where your path will take you." Well, my path has always had a bridge attached.

Twenty years ago, I was living in Chicago, working as a freelance advertising writer. I

had a wide array of friends and participated in a very active arts community filled with painters, writers, dancers, and actors, all incredibly talented and promising individuals.

One of those people was my best friend, Patrick. He was an amazing graphic artist with a fast (and sometimes evil) wit but a generous heart to friends and strangers... and there were so many.

Of course, you know where this story is going. Yes, the day came when he found out that nagging cold was not just a cold, but pneumonia. And that pneumonia was more than HIV infection, but actually AIDS. This was in 1986. There were only alternative therapies then: Chinese herbs, acupuncture, body work and meditation. Did these therapies really work? They certainly didn't hurt Patrick. Back then, a person with HIV/AIDS would try just about anything to survive. There was fear but there was also a lot of hope, too.

One of the strongest and healthiest "therapies" Patrick depended on was a small, but determined group of HIV-positive men (and a few HIV-positive women and like-minded supporters) who came together to find comfort and education that had never existed before.

This was the birth of Test Positive Aware Network (TPAN) and *Positively Aware* magazine. (God bless founder Chris Clason.)

Every week, Patrick would go to hear the latest updates in HIV research, participate in the lively group discussions and always make the latest members joining the group feel welcomed. Many of Patrick's personal friends also became great supporters and volunteers at TPAN, myself included.

Unfortunately, within a year, Patrick's health was failing. Patrick was in and out of the hospital every few months... another bout

of pneumonia, then uncontrollable diarrhea and wasting and the final blow, spinal encephalitis that put him into a life-threatening coma. We felt helpless standing around his hospital room as we watched him struggle breathing. Hannah, a gifted meditation practitioner, sat at the head of his bed as we held hands in a circle, eyes tightly shut.

Hannah spoke, "Patrick wants you to know there's no need to worry. It's like a bridge. One moment, he says, he is standing here in this room; the next step he is in the arms of his loving mother, surrounded by friends." In my mind's eye, I saw him walk across that bridge, turn back and give us a playful grin. Later that day, Patrick passed away peacefully.

It was difficult to lose someone so close, so young. At that time, the NAMES Project was asking for quilt panels to "never forget" those who had left us. None of us really knew how to sew, but we knew we had a tribute to make: a bridge that would take us from this sad, sad place to a happier, more hopeful future.

Twenty years later, here I am. Fortunately, I left advertising; I went to work for several years in the non-profit AIDS community and then moved into the world of pharmaceutical sales and marketing. I had found my life's passion, once again helping others impacted by HIV/AIDS.

Now for the past eight years, I have worked in Southern California for Roche Pharmaceuticals. So today, when I talk to physicians or patients' groups about my company's HIV products, I find my mind wandering back to old times, distant places and one unforgettable, old friend.

It is true you really never know where your path will take you. But for me, I always smile when I see a bridge in the distance.

Congratulations to TPAN and *Positively Aware* magazine for providing 20 years of dedicated medical reporting and support to the HIV/AIDS community! 🏠

*Michael Blackwell served on the Board of Directors for Test Positive Aware Network in 1988 and 1990. He currently works as HIV Market Specialist for Roche Pharmaceuticals in Southern California. In previous lives he was an advertising writer; volunteered and then worked for Stop AIDS Chicago and AIDS Walk Chicago; and was co-founder of and playwright for the Tellin' Tales Theatre in Chicago.*



Photo courtesy of Michael Blackwell. Quilt image courtesy of The NAMES Project

# POSITIVELY AWARE 20TH ANNIVERSARY



## 20 YEARS OF COMMITMENT

Positively Aware, then and now

by Steve Wakefield

**T**here are a number of phenomenal events that seemed impossible to me as a child growing up in the suburbs of Chicago. A man on the moon. The fall of the Berlin Wall. The end of apartheid in South Africa. And today, 20 years after joining Test Positive Aware Network, I stand in awe of the number of lives it has touched, and of how my life continues to be enriched by the work of its volunteers and staff.

In February of 1989, it was my honor to serve as TPAN's first paid staff member. My best friend at the time suggested I should be committed. He really thought that perhaps there was a mental health institution that had a bed for me. In my clueless state, I replied that I *was* committed—that this group of men was going to find the secret to ending the AIDS epidemic. We had a banner in our main hall: "Committed To Living."

The organization moved from meeting in Shiel Park Fieldhouse to our own space on Belmont. Through donations, we furnished what became a place of comfort, hope, and wellness at a time when most persons diagnosed with HIV had less than a year to live. In times of sometimes unfathomable grief, the men and women of TPAN found ways to provide for each other. We had support groups and "Ask the Doctor" nights, but the real work took place as persons who had little in common found ways to be part of the fabric of each other's lives.

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

One such moment came when I was to moderate a public forum to welcome the new City of Chicago Commissioner of Health and help her work with the HIV community. Before the forum, Michael locked me in my office and told me to work on any report, but not to come out. Little did I know that on the other side of the door, members of ACT UP Chicago were preparing a demonstration. A few minutes into the forum, TPAN members Billy and Ida commandeered the microphones, chanting "Act Up! Fight Back! Fight

AIDS!" They took a break only to wonder out loud, "How can this flying nun support condom distribution?" Persons who were perfectly ambulatory that afternoon were wheeled into the room with IV poles. It was one of the best street theater demonstrations I witnessed

by a city known for radical organizing. Over 50 TPAN members helped ensure that the voice and commitment of people living with HIV would be heard by this new leader of the health department.

Today, I celebrate the spirit of those early pioneers of the TPAN family. But I would be remiss if I failed to share a more recent heartwarming moment in my life. One of my friends had been reluctant to routinely see his physician. As a friend, I expressed my anxiety, explaining that taking HIV drugs is not easy, but working with the right physician can really improve the quality of life. Despite his reluctance, we identified someone he could work with. After a recent doctor's visit, my friend called and asked if he could stop by my office and show me a magazine he picked up at the doctor's office. He had been reading it for a couple of hours, and it had provided him insight into living with HIV as well as great medical information. A few minutes later I was in tears as he reached in his backpack and pulled out the latest issue of *PA*.

My friends, you have a treasure. These are phenomenal times of hope and commitment. In a few days the country will move forward under new leadership. Success will depend on our ability to integrate new thought in a responsive manner to the existing infrastructure. Will there be a vaccine or a cure for HIV? Will there be a time when folks starting on HIV meds will only need to take one pill a month? I'm not sure. What I *am* sure of is that the spirit of TPAN members and staff will continue to improve the quality of my days. My desire is to continue to have each of you in my life, and for each of you to be a treasure in the lives of those who share your road of happy destiny. ✚

*Steve Wakefield served as Executive Director of TPAN from 1990–1994 and is currently Legacy Project Director for the HIV Vaccine Trials Network, working to increase participation of African Americans and Latinos.*



Photo: Tracy Baim - Windy City Times



# POSITIVELY AWARE 20TH ANNIVERSARY

## WITHOUT POSITIVELY AWARE, WHO KNOWS WHERE I'D BE?

*PA was only the beginning*

*by Steve McGuire*



In 1985, when I, along with several other volunteers at the Howard Brown Clinic (as it was then named), started the first newsletter about AIDS in Chicago, none of us imagined that

we would still be confronting this epidemic well into the twenty-first century. More than

two decades later, however, HIV remains a mainstay of my professional life—a reality that, in retrospect, was probably determined when TPAN's former executive director, Steve Wakefield, asked me to take on the job of editing *Positively Aware* in October 1993. I hemmed and hawed about giving him an answer for several weeks before deciding that this was something I needed to do.

I'd written about HIV/AIDS from time to time before that: for physicians, for patients, for policy makers, for grant makers, for general readers, but I often told myself that it was something I was doing until I could get back to my interests in public policy and nonprofit issues. In retrospect, *Positively Aware* turned that idea into yet another example of "the best-laid plans..."

What we did not have in 1985 are things that people with HIV largely take for granted today—a host of treatment options, the Internet, a variety of support networks, the experiences of others who have lived and prospered with HIV for years. Another thing that all too many people did not have in 1985 was a sense of hope. Happily, that also has changed, with many—maybe even most—HIV-positive folks, at least in the developed world, now able to look forward to something like a normal lifespan.

As some of my former colleagues may recall, I can't deny that I ended my career at *Positively Aware* with a burden of frustration, anger, and resentment. I like to think that such emotions don't influence my decisions so much these days. Still, probably the one constant in my professional—and maybe more in my personal life than some of my friends and family would like—has been a passion to offer up information and education that people can use to expand their knowledge, possibly improve their lives, and even share with others. Since leaving TPAN and *Positively Aware* in August 1996, I've had what looks like a rather checkered—though often interesting and even fulfilling—professional life:

- More than half of the years working as a freelancer for medical communications firms, public relations agencies, nonprofit organizations, pharmaceutical companies, software developers, and others
- A year and a half as scientific communications director at an international public relations agency—a surprisingly interesting gig
- A year or so at a medical education firm that proved to be probably the most dysfunctional place I've ever worked
- Finally settling into planning and managing continuing education activities for physicians, nurses, pharmacists, and other medical professionals.

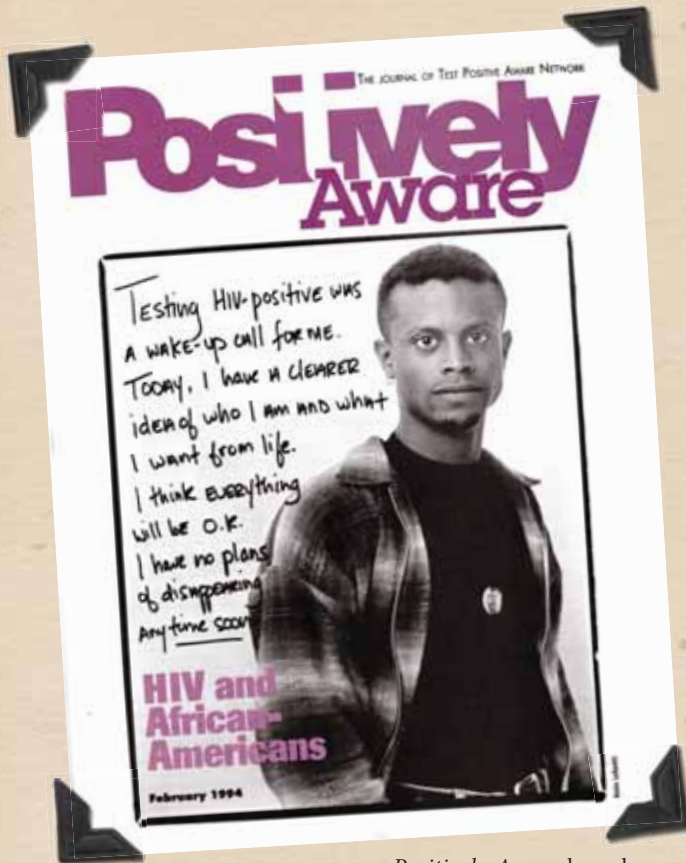
Although I would not have guessed it at that time, I have little doubt that most of this work has come my way as a result of the experience and connections that began in my years of working in communications and development at TPAN. In fact, this seeming grab bag of a career might even have become almost inevitable after editing *Positively Aware* for some three years (along with serving on various related boards and committees).

Digestive disorders, cardiovascular disease, nervous system problems, infections most people have never heard of, and the list could go on—in the 1980s and 1990s, all of us involved in whatever way with the epidemic became all too familiar with HIV's excess baggage. The unfortunate reality that people living with HIV disease have often found themselves having to deal with such a broad range of health issues gave me the familiarity and adaptability to work with a diversity of topics and audiences. In the fall of 1993, I never would have imagined that directing a community-based HIV treatment publication would have enabled me to work with such a variety of people, issues, and communications types. And that experience provided the training ground that has let me list publications and projects on my resume that range across antibiotics, gastroenterology, hepatitis, influenza, migraine, neurology, ophthalmology, and so on.

One of the long-term projects with which I have had the privilege to be involved, and am most proud of, is Chicago's CORE Center, where I began to serve on the community advisory board while still working at TPAN and later wrote the content for COMET, the Center's exceptionally comprehensive patient Intranet.

Photo © courtesy of Steve McGuire

# POSITIVELY AWARE 20TH ANNIVERSARY



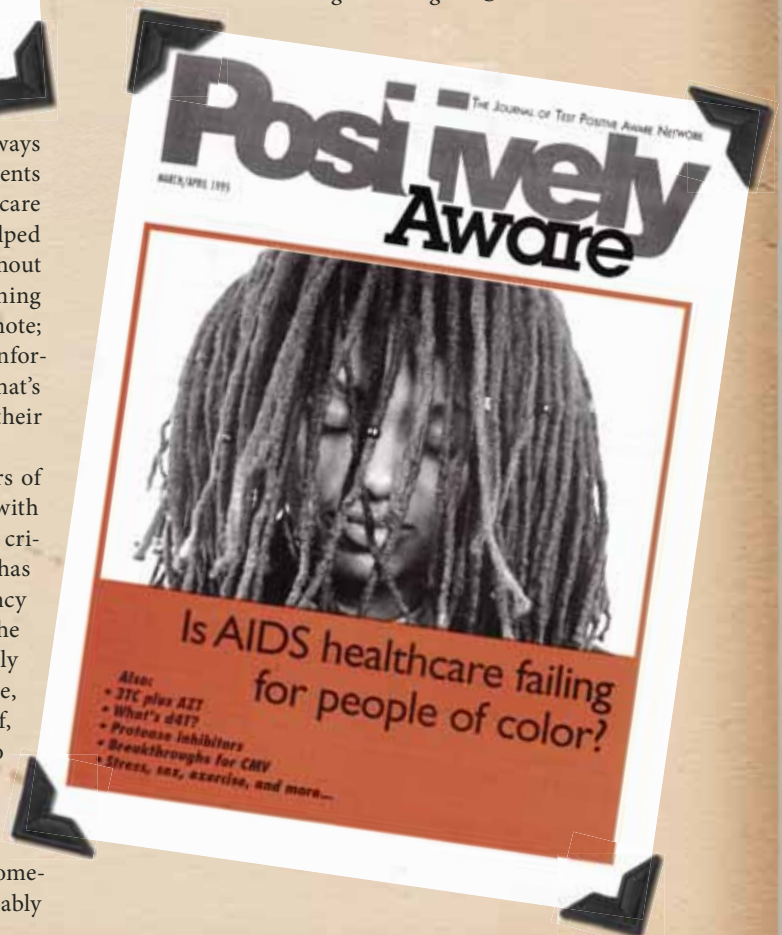
*Positively Aware* has always served as a key information source, not only for HIV patients and members of their support systems, but also for many healthcare providers themselves. Writing for such a wide readership helped prepare me for the spectrum of readers I've addressed throughout my career: explaining HIV and its treatment to patients; training pharmaceutical representatives about the products they promote; providing doctors, nurses, and pharmacists the data and information to do their jobs better; helping patients understand what's going on in their own bodies and how they can work with their healthcare providers to maintain and improve their health.

It is unfortunate that so few of us from the earlier years of TPAN and *Positively Aware* seem to have remained in touch with each other. For good or ill, this is often what happens during a crisis—sharing an intensely personal experience that feels as if it has created a deep bond. But the passing of the years and the urgency of other concerns can strain and often break such bonds. In the case of the HIV crisis, this may be a very good thing. Highly effective, increasingly tolerable treatments became available, and many people living with HIV infection, including myself, found themselves in the unexpected situation of being able to focus on matters of career, family, and—for some of the longest survivors—even retirement.

Most of the time, I'm a calmer sort of guy now, or at least I keep telling myself that. And a couple years ago, I became something I never imagined I'd be—a suburbanite, though in probably

the most urban of Chicago's suburbs, Evanston. For those of us who have lived with and worked in HIV for many years, the one constant in our lives may be change—something I long ago decided had to be accepted and not resisted if there was to be any hope of succeeding in the endless ebb and flow of circumstances, people, and events that carry all of us along. If my words have reached any of you with whom I've been out of touch for some time, I'd be glad to hear from you. And for everyone—I hope the next 20 years can be as eventful as the last—minus some of the traumas, missteps, and losses.

*Steve McGuire served as Editor of Positively Aware from 1993 to 1996, and is now managing editor for HIV at Clinical Care Options, LLC. He can be reached at [gstevenmcguire@aol.com](mailto:gstevenmcguire@aol.com).*





# POSITIVELY AWARE 20TH ANNIVERSARY

## TRANSITIONS

*Looking back, while moving forward*

by Charles E. Clifton



*Editor's note: Charles Clifton served as Editor of Positively Aware from 2000 until his death in August 2004, during which time he also served as executive director of TPAN for three years. The following column was taken from the November/December 2000 issue, which was his first as editor.*

tive treatments. No genocide conspiracy. None of that. Straight up AIDS. And there I was, all alone, confused and scared. What did I know? Zero. Zip. Nada.

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

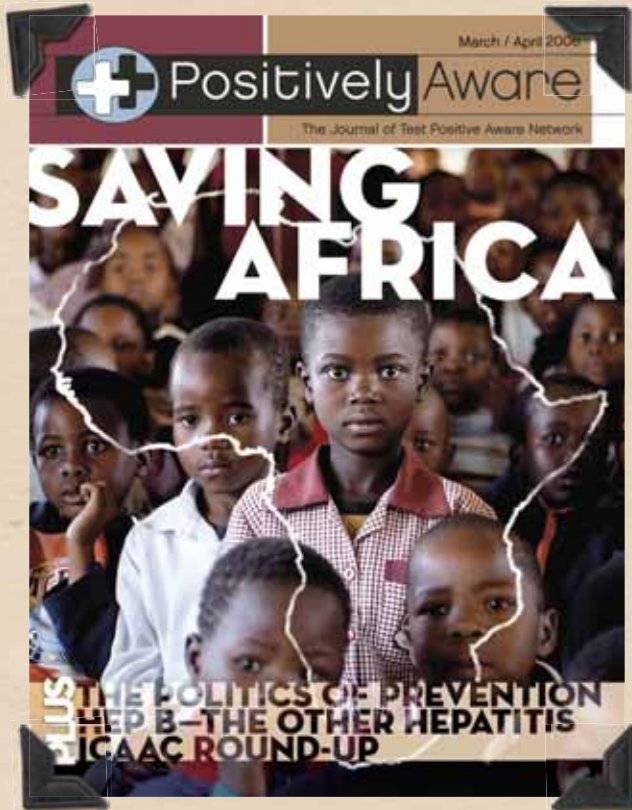
Well, here we are in the year 2000 in the world of HAART, the land of alternative therapies and on the horizon "Structured Therapy Interruptions." In the nearly five years that I've been a member of TPAN, I've seen friends who were near death respond to HAART therapy in ways nothing short of a miracle. There are individuals who choose holistic approaches to care. Some of them are also living healthy and productive lives. But then there are those—the often lost faces of AIDS—who aren't able to tolerate the drugs and don't respond to alternative options.

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

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

**F**lashback to 1986... I was 27 years old, and in the eighth year of a relationship with the first love of my life. Antonio and I had it all—two wonderful dogs, Max and Tina, great jobs, a beautiful home, and our health. I was in total control, or so I thought. In April, Antonio took ill. I remember the exact afternoon, in the emergency ward at the hospital, when the doctor came out from examining Tony. He told me that Tony had AIDS. He said that Tony was going to die, and so would I. Following bouts of PCP, and after developing Kaposi's sarcoma and dementia, Antonio died on October 8, 1986, at 11:23 am. AIDS. There was no mono, dual or triple combination therapy. No poverty or malnutrition. No substance use, illegal drugs or "hedonistic" lifestyle. No alterna-

# POSITIVELY AWARE 20TH ANNIVERSARY



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

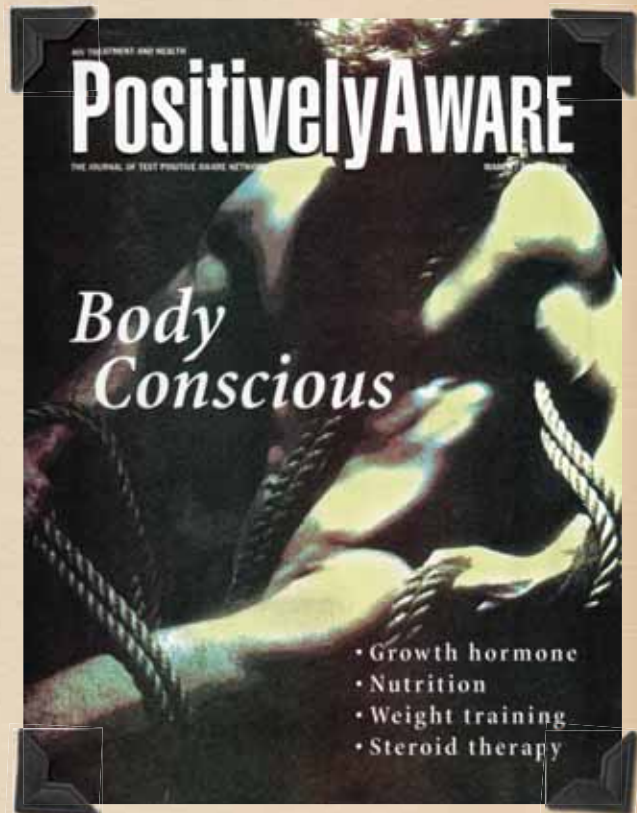
On those few Saturday afternoons when I'm home and alone—listening to some classic Phyllis Hyman or Angela Bofill, I can feel Antonio's presence around me. There are days when my dog Carlisle reacts in a certain way, and I can't help but think that Max (1992) or Tina (2000) are there in the room. Some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

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

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

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

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



Saving Africa cover photography by Charlotte Raymond, BMS photographer



# POSITIVELY AWARE 20TH ANNIVERSARY

## HEADLINES OF TOMORROW'S POSITIVELY AWARE

*The need for health care will always be universal*

by Brett Grodeck

**E**veryone at the computer software company where I worked got the same e-mail: layoffs were coming. This time, I had a bad feeling. In fact, I wore a clean shirt to work last Friday in the event I got the axe. At 10:30 am that day, my boss called and I got the axe. By noon, I was being shooed out of the glass and aluminum office building with a backpack and a Trader Joe's bag filled with papers, a few books, and a plastic cereal bowl.

Later that afternoon, I discovered that my health insurance had been terminated as well. To me, that was far more devastating. I depend on my health insurance to pay for my HIV medicine. If I had to buy the medicine on my own, it would run about \$1,500 a month or about \$18,000 a year. That's a lot of money.

Having HIV isn't cheap. I've had it 20 years now. For the first ten years, I didn't have health insurance. Just out of college, I worked part-time writing for magazines and part-time as a waiter. Neither job offered health insurance. At one point, I needed an emergency surgery. Without many options, I resorted to surgery at a public hospital that accepted patients without health insurance. To me, the experience was a little barbaric.

When I finally needed HIV medicine, I couldn't possibly afford it myself. I was scared and didn't know what to do next. That's when I discovered a publication called *Positively Aware*. Thumbing through the pages, I remember finding two Illinois state programs that were lifelines until I could find a job that offered health insurance.

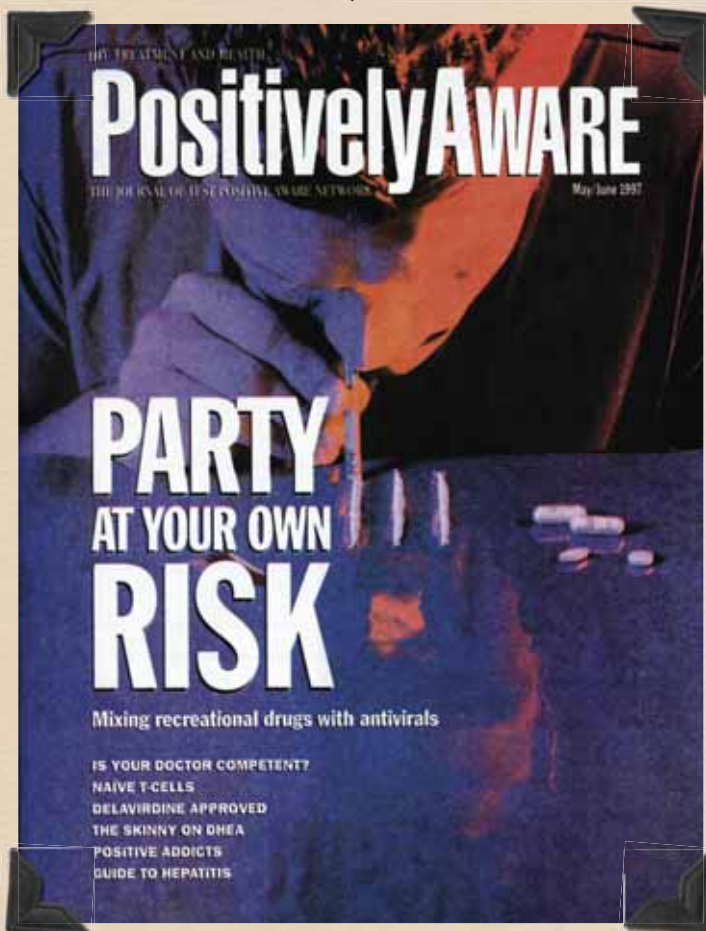
One program provided private health insurance that covered everything but medications. The insurance wasn't cheap, but it would cover doctor visits, lab tests, and any emergency surgeries. The other program was the AIDS Drug Assistance Program, also known as ADAP. It covered all HIV medicine plus a few others.

With good health care, my health improved. Feeling better, I was able to work. Needing work, I contacted the editor of *Positively Aware* back then, Steve McGuire. He hired me as associate editor. Now, I can say that the position was both fascinating and satisfying. I was paid to write about science and medicine just when my life depended on it.

Back then, *Positively Aware* focused mainly on preventing the symptoms of HIV, the long list of horrifying opportunistic infections that included purple skin cancer, blindness, and madness. Years later when I was the editor of the publication, we were lucky to be able to cover many major advances in HIV medicine by scientists and doctors. At last, it was possible to fight the true cause of AIDS: the human immunodeficiency virus.

One of the best things about working for *Positively Aware* and Test Positive Aware Network was the affordable group health insurance that the organization offered to its employees. This coverage allowed me to quit the state programs, which hopefully provided another person with HIV the same lifeline. Since that time and over the years, I've worked in many different jobs, all with excellent health insurance. In some ways, I've been lucky.

But as I toted my Trader Joe's bag away from the glass office building, I realized how quickly things change. One day, I have a sta-



# POSITIVELY AWARE 20TH ANNIVERSARY



ble income and health care for \$166 a month. The next day, I don't have an income and health care now costs \$467 month. That's how much I will pay to continue my health insurance through a federal program called COBRA, another lifesaving program for anyone with a chronic health condition.



On one hand, I'm worried about paying the bills. On the other hand, I'm grateful to have good health these days. I figure with good health—both physical and mental—anything is possible. It won't be easy, but I'm confident that I'll be able to navigate the unknowns of unemployment and health insurance.

For twenty years, *Positively Aware* has written about the never-ending unknowns for people with HIV. So what might fill the pages of *Positively Aware* for another 20 years until it celebrates its 40th anniversary in the year 2029?

A cure would be great, but there's debate about what exactly defines a cure. Without the ability to eradicate HIV after infection, the next best option is to improve HIV medicine over time. Perhaps some day, HIV treatment will be a pill that's taken once a week or once a month. Perhaps a treatment will come out of the blue, such as bone marrow replacement with gene therapy. Who knows?

What I know is that with any advance in HIV treatment, regular people need access to it. Regular people need access to affordable and flexible health insurance that actually helps when you need it most, during the inevitable bad patches of life.

The good news is that President Barack Obama is committed to signing universal health care legislation within four years.

This legislation would ensure that all Americans can get high-quality and

affordable health care coverage.

That's a lofty goal, sure, but it's worth pursuing. HIV or not, if you have a chronic health condition or depend on health insurance, now is the time to make your voice heard.

The pages of *Positively Aware* in the future have not yet been written.

We—readers, people with HIV, society as a whole—have the ability to influence the head-

lines of the future. What we think about today, we can bring about tomorrow. So I urge you, start thinking about living in a country where good health care is available and affordable to all.

*Brett Grodeck served as Editor of Positively Aware from 1997 to 1998 and is the author of The First Year—HIV: An Essential Guide for the Newly Diagnosed.*



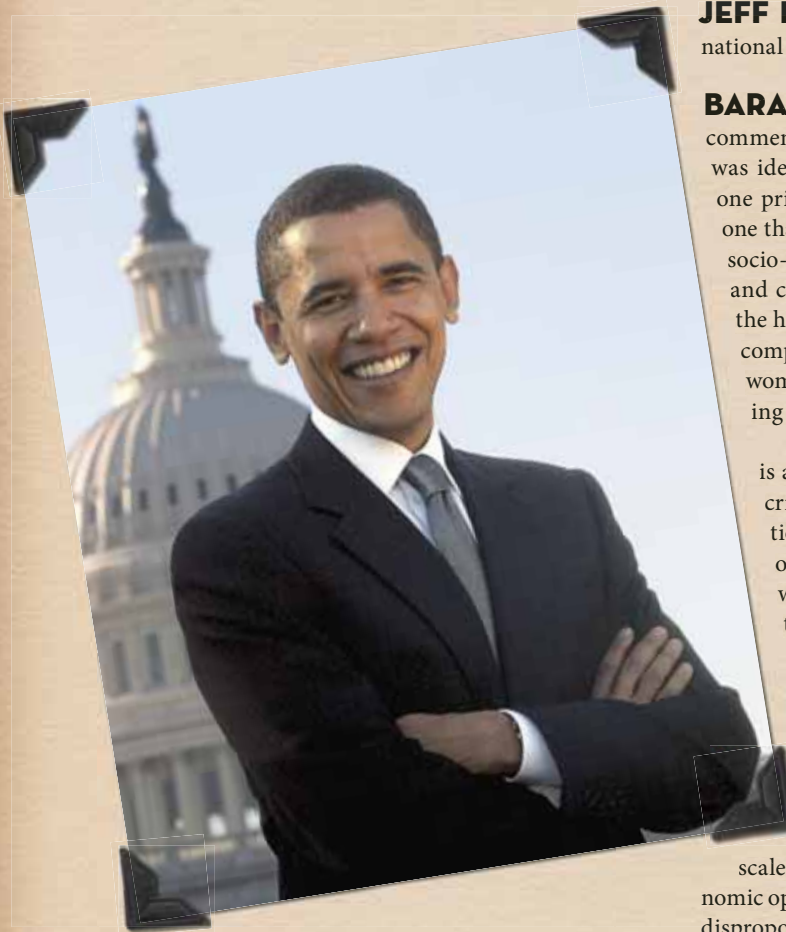


# POSITIVELY AWARE 20TH ANNIVERSARY

## ONE ON ONE WITH BARACK OBAMA

*The Politics of HIV*

*Interview by Jeff Berry*



*President-elect Obama first spoke with us back in the September/October 2006 issue of Positively Aware magazine, months before he announced his bid to run for the presidency. We thought it only fitting to reprint the interview here, in its entirety, during the month of his inauguration. His views on needle exchange, harm reduction, prevention and HIV/AIDS policy are even more relevant now than they were when he was just a young senator from Illinois. One interesting question we asked then was, "Who would be your choice for a pro-AIDS care president?" I guess we now know the answer!*

**JEFF BERRY:** What are your priorities on your agenda for national HIV/AIDS issues for 2006?

**BARACK OBAMA:** This past June, the world paused to commemorate the passing of 25 years since the first AIDS case was identified. Over this time, the epidemic has evolved from one primarily afflicting the white, homosexual community to one that impacts all populations, regardless of race, ethnicity or socio-economic status. The epicenter is shifting towards women and children, and African Americans continue to experience the highest rates of new infections and deaths from HIV/AIDS compared to all other patient groups. For African American women aged 25-34 in the United States, HIV/AIDS is the leading cause of death.

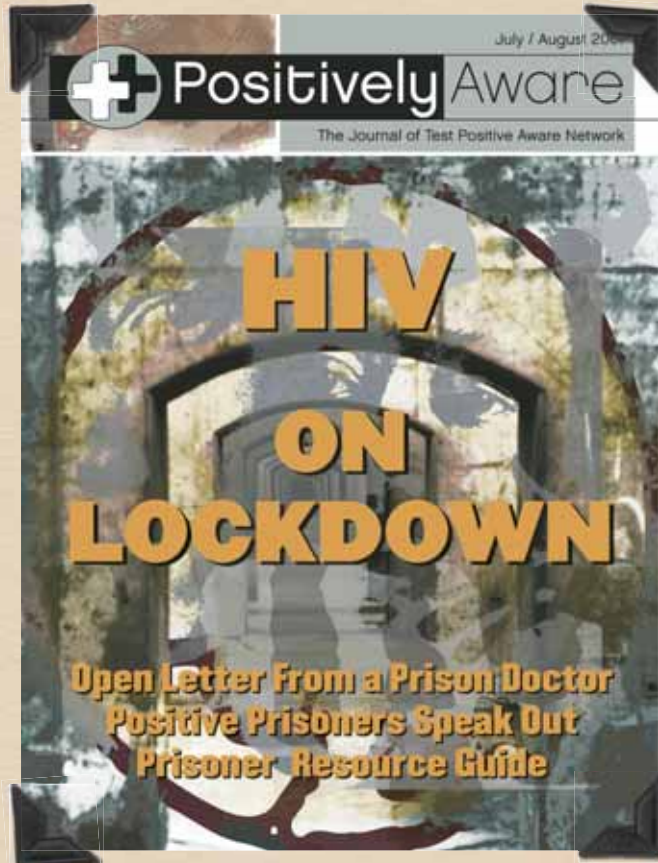
The tragedy and irony of these statistics is that HIV/AIDS is a preventable disease. To that end, I believe that the most critical AIDS issue facing our nation is the need for prevention. We have not adequately educated ourselves and each other about this disease, nor have we identified effective ways to empower individuals to change their sexual practices to protect themselves from HIV infection.

Until we have an open and honest dialogue about what we need to do, or do better, we will not be able to stop the silent but deadly spread of this disease. This is not an easy task, and given that the HIV/AIDS epidemic continues to evolve, what may seem logical today may not be a top priority tomorrow. Additionally, successful eradication is unlikely without a comprehensive, large-scale societal investment in improving the educational and economic opportunities of our most vulnerable populations, which are disproportionately affected by this disease.

That being said, the following are some of the general policy priorities for my HIV/AIDS agenda.

*Expansion of coverage for HIV/AIDS treatment and services.* A number of programs, particularly those offered under the Ryan White CARE Act, have been instrumental in getting individuals the care they need to remain healthy and live longer. Yet too many individuals continue to fall through the cracks, and the overall federal investment is inadequate given the scope and magnitude of the epidemic. And the care we do provide must be comprehensive. Having the correct medications will not be of much benefit to an individual battling AIDS who lacks a decent meal and a place to sleep.

# POSITIVELY AWARE 20TH ANNIVERSARY



*Promotion of screening for HIV/AIDS.* Studies indicate that about one-fourth of Americans infected with HIV are unaware of their status. If we expect these individuals to make healthy decisions, seek care, and discontinue activities contributing to the transmission of this deadly infection, these individuals first need to be educated and tested. And if we expect to gain ground on the epidemic, we need to educate the public about prevention. While there have been several national public education campaigns in the U.S., many would argue that our efforts have been surpassed by those in other countries. For example, walking down the streets of Kenya, you cannot help but notice the prevention advertisements. The U.S. should follow in the steps of other countries in which public advertisements regarding education and testing are popular, prominent, and effective. Until we do, fear, stigma, ignorance, and transmission will persist.

*Strengthening of the public health infrastructure.* The federal government's investment in prevention is minimal compared to its investment in medical care and treatment, and is yet another example of this Administration being "penny-wise and pound-foolish." We must increase our investment in the federal and state public health agencies, as well as in our community-based organization partners—the foot-soldiers in this war against AIDS.

*Support for treatment and drug research.* HIV has continued to mutate, hampering vaccine development efforts and rendering many current treatments ineffective. The federal government must expand and accelerate research for the development of effective medications and treatments. In particular, we must act expeditiously to support the development of microbicides, which hold tremendous promise for HIV prevention for women.

*Provision of comprehensive sex education.* Promotion of abstinence from sex outside of monogamous relationships must be part of any successful HIV prevention strategy, but it cannot be the

entire strategy. Raising awareness of the virtues of abstinence cannot be a substitute for providing truthful, medically accurate, and age-appropriate information about contraception, sexually transmitted diseases, and reproductive health in general. Information about condoms and other effective tools must be made readily available. We are losing the battle against the HIV/AIDS epidemic, and we cannot allow partisan politics to trump sound, scientific policies.

**BERRY:** What is the current state of affairs with support for HIV/AIDS care and prevention today and how do you see it becoming affected in mid-term 2006 and general 2008 elections?

**OBAMA:** I believe that health care issues on the whole will receive greater attention during the election seasons, and that has the potential to be a very good thing. I am constantly disappointed that the issues my Illinois constituents tell me they are most concerned with—issues such as health care, energy costs, and education—get put on the back burner in favor of divisive social issues such as gay marriage or a constitutional amendment to ban flag burning. My hope is that the elections will fuel sound debate on health issues on the Hill, which will translate to greater action on HIV/AIDS care and prevention concerns.

**BERRY:** What is your policy on harm reduction and what is your perception of the crystal meth problem?

**OBAMA:** There is no denying the link between HIV transmission and injection drug use. I believe that harm reduction and law enforcement are not mutually exclusive methods of reducing drug abuse and its health consequences. In April 2005, the U.S. Department of Health and Human Services reported that 18% of users shared their needle with others after use and 13% used a needle



# POSITIVELY AWARE 20TH ANNIVERSARY

they suspected or knew someone else had previously used. Only 56% of users claimed to use needles purchased from a pharmacy or provided through a needle exchange program.

I understand the controversial nature of implementing harm reduction methods on a national level. However, this is not a novel concept. Many developed nations rely on harm reduction as part of the solution to control the spread of HIV/AIDS. We can either acknowledge the potential public health benefits of harm reduction, while continuing to strengthen law enforcement efforts in the war on drugs, or we can choose to allow the drug world to be a breeding ground for HIV/AIDS, hepatitis, and so many other preventable diseases.

Crystal meth use in Illinois and across the nation is skyrocketing, with no signs of improvement. According to the 2004 National Survey on Drug Use and Health conducted by the National Institutes of Health, 12 million Americans have tried methamphetamine. Abuse of crystal meth leads to a host of serious problems, including high-risk sexual behavior which increases risk for HIV/AIDS. As a U.S. Senator, I have fought for more funding for law enforcement efforts to combat meth use. However, this is not only a law enforcement issue but also a health and public health issue. A greater investment in prevention, treatment, and rehabilitation programs is long overdue. In Illinois, we have several programs, including those sponsored by the Women's Treatment Center and the Haymarket Center, which have been quite effective at using family-centered models to treat women with meth addiction, helping them to stay out of jail and with their families, and assisting them with employment training and other needs. We should support similar programs on a national level.

**BERRY:** Who would be your choice for a pro-AIDS care president in 2008?

**OBAMA:** As I stated earlier, I expect health care to be one of the major issues in the 2008 Presidential campaign. I will not support any candidate who has not demonstrated a serious commitment to improving health and health care broadly and combating the HIV/AIDS epidemic more specifically.



**BERRY:** Where do you see AIDS research funding in 2006? Are you committed to continued funding for OAR (Office of AIDS Research)?

**OBAMA:** Federal agencies will spend approximately \$21.1 billion this year on HIV/AIDS programs. Of this funding, only 14% is directed for research. The President requested \$22.8 billion for FY07 [Fiscal Year 2007] HIV/AIDS activities. Despite the 8.3% overall increase requested by the President, funding for research was reduced by 0.05% to \$2.6 billion. While we certainly should not reduce funding for prevention, treatment, and international efforts, I think most would agree that continued investment in HIV/AIDS research is critical to making progress against this epidemic.

The Office of AIDS Research has been quite effective in directing HIV/AIDS related research at NIH, and should continue to receive full support.

**BERRY:** Are you committed to being a leader in keeping the CARE Act strong and intact for the future?

**OBAMA:** The Ryan White Care Act (RWCA), which is up for reauthorization, has provided vital support for those suffering from HIV/AIDS. An important component of this statute is, of course, medical treatment. However, comprehensive and effective care must include housing, transportation, and food. RWCA was crafted with multifaceted care in mind, and that is the reason for its success. During reauthorization, we must be certain to strengthen, not jeopardize, this comprehensive approach. Additionally, in order to provide this comprehensive care, Congress must allocate adequate funding. We cannot put service providers in a position of providing care to a greater number of clients with fewer resources.

A number of contentious issues are still being discussed and negotiated by House and Senate members, including determining a fair proxy method for funding allocation, defining "core medical services," and balancing the needs of urban and rural populations, just to name a few. I have and will continue to voice my support or concerns regarding the proposed legislation, and hope the Congress will work through policy and political differences to pass a good bill this year. ++



## The Biography of an HIV Doctor

A 20-year retrospective

by Daniel S. Berger, M.D.

It's been more than 20 years of an unflinching, uninterrupted, and unwavering practice of medicine, seeing patients afflicted with the HIV infection, treating them from near the beginning of the epidemic and throughout the gamut of changing therapeutic standards. In the beginning, there were little or no effective treatments for HIV disease and its complications. In this brief account, I will attempt to contrast personal and difficult challenges that I faced, and managed to endure, during the first 10 years, with the present, but completely changed, lifestyle taking me through the unexpected directions my life has gone while immersed in the HIV field.

Twenty-one years ago, approximately the same time that I began seeing the first HIV-positive patients, most of whom had AIDS, Test Positive Aware Network (TPAN) was launched, and it now celebrates 21 years of dedication to the community. Back then there was only one approved treatment for HIV infection, and people were taking their own home remedies or the treatment du jour, changing sometimes weekly, and most were worthless for halting the disease. The weekly meetings at TPAN were often attended by no less than 100 people, everyone very anxious to get information about how they could help themselves during very dire circumstances. Not until 1987 did AZT become approved, but only for patients with a CD4 T-cell count below 200. At that time, imagine, there was no treatment for CMV retinitis, the number one cause of AIDS-related blindness, which affected about 10% of people with HIV/AIDS. Today, we simply don't see many of these problems, due to the improved treatment for HIV infection.

However, without available treatment during the early years, buyers clubs for HIV medicines sprang up in several U.S. cities. Their practices were not always legal; they were proponents of activism and helped provide some treatments that were effective but not yet available. One of these was ddC (Hivid, now discontinued), a then useful

antiviral which several buyers clubs were synthesizing themselves in homemade labs. It was not until September, 1989 that ddI (Videx) became available by compassionate track program for only those patients who could not take AZT. I had started putting many patients on a combination of these drugs, constructing my version of an early "cocktail" for my patients. For many reasons, it was apparent to me that two or three antiviral drugs were better than one alone. Understand that what is now known as the treatment cocktail did not come about until 1996. And although I presented my

who was sick in the intensive care unit of a Chicago hospital. Because of irrational panic among the house staff, the nurses at this ICU began calling in sick or striking, for fear that they would contract some infection from my patient. The hospital did not stand by me, nor was it supportive of my intense focus on caring for people with AIDS, nor was the physician who was then the chief of medicine at this institution (which I shall not name here), who was my associate. I was forced to transfer my sick patient, who was on a respirator, to another medical center.

**THE TIME WAS DESPERATE  
AND I HAD FELT THAT EXTREME  
MEASURES WERE SOMETIMES  
NEEDED TO SAVE LIVES.**

research data of combination AZT/ddI at the World AIDS Conference in 1992, I was heavily criticized, by many more conservative community physicians who believed that treating HIV was hopeless and perhaps damaging. As a doctor who believed in activism, I had to battle a Chicago community newspaper that once criticized me heavily for opening up a private research clinic and taking action. I was employing nutrition and conducting the first studies to fight AIDS wasting, the number one AIDS killer. The extensive and in-depth immune system testing I performed was also challenged by others, but since viral load tests did not yet exist, this was a useful marker from which to monitor patients.

Taking us back to those days, I'd like to recall a story about one of my patients,

It was not an easy time being an HIV doctor. Admitting that this was my field to other physician peers was not uncommonly met with a sneer. But the difficult times and endured sadness were paralleled by a strong mindset of being on a mission, which helped me overcome common prejudice and challenges. The time was desperate and I had felt that extreme measures were sometimes needed to save lives. There was no time to sit back and wait for the "system" while others were dying. I began studying a variety of immune system modulators in clinical trials. I was not a conservative doctor but was constantly under attack for trying newer approaches to a disease for which patients and friends were between a rock and hard place.

Needless to say, there were many sleepless nights and the environment one had to put up with, during the earlier years of the epidemic here in Chicago, was not of my choosing. However, it made me tough and what slowly emerged was strength.

graphic artist for *Positively Aware* and is credited for helping transition TPAN's newsletter into a dynamic magazine. He called himself an AIDS warrior and fought the disease with enviable stubbornness. He, along with others, was instrumental in

apy. How to achieve treatment success and construct effective therapy was learned and extended to a broader category of primary care doctors in urban areas. It's important to take note that now we've even observed the development of a one-pill, once-daily cocktail, Atripla, which newly-infected patients can take advantage of if not infected with resistant virus. More technological breakthroughs have resulted in more choices for HIV treatment. Toxicities and side effects from older drugs have been greatly reduced with many of the newer agents.

Fast forward to 2008. To date, at Northstar Medical Center in Chicago, we're conducting more than 150 HIV clinical trials. A team of research staff helps coordinate the various research projects currently ongoing. Like the space age and Star Wars, we're comparing two integrase inhibitors in one trial and studying several new but intravenously administered antiviral medications in other studies. In my daily routines, doing multi-directional research feels surreal. Amongst the weekly cacophony of seeing patients and conducting research, there's also the constant flow of e-mails and communications, requests and questions from various research-sponsoring companies throughout most days. These usually need to be answered promptly while still seeing patients.

Patient visits have changed as well. They now require confronting issues such as HIV with hepatitis C co-infection (the rates have soared), and HIV complications often now involve syphilis and MRSA infections, as well as crystal meth drug addiction. My schedule also constantly gets altered due to travel so that I can provide lectures to physicians around the country. There are frequent research-related manuscripts, articles, or abstracts that need work or review. Finally, running a demanding clinic means that there are always management issues that need immediate attention. In a word, the work is often exhilarating and challenging, but often too much.-

## THIS INFORMATION EMPOWERED PATIENTS, AND ALLOWED THEM TO MAKE INFORMED CHOICES REGARDING THEIR TREATMENT.

### STRENGTH WITH POWER

During the days of AIDS activism, the world was awakened by an outpouring of news stories and heartbreaking accounts combined with many spirited ACT UP protests. AIDS survivors chained themselves to government buildings, and public "die-ins" were in vogue. Eventually compassionate track programs for early access to HIV medications were instituted due to these protests. This was the first time in U.S. history that this provision became the rule for any life-threatening disease. It was a major accomplishment by very courageous AIDS activists.

Many early AIDS service organizations, such as Project Inform, Test Positive Aware Network and Gay Men's Health Crisis were actively getting information out about investigative approaches to treating HIV disease. Community newsletters were read by hungry PWA's (people with AIDS, a common term used at the time) pursuing information to help themselves feel better, let alone survive. Educationally, they offered possible treatment approaches, and explained how and where to gain access to new medications and clinical trials being conducted for investigative approaches. This information empowered patients, and allowed them to make informed choices regarding their treatment. A close friend and patient, Drew Badanish, was then the

shaping my philosophy of treating patients. Martin Delaney, the founding director of Project Inform, was another important individual who challenged the bureaucracy. Together, we held yearly community forums in Chicago, often attended by more than 300 people, further educating individuals about research and treatment.

I don't know where we'd be today without countless individuals who gave their lives at that time. Also, some physicians began implementing research projects, their cohort studies providing clues and insight into potential directions for treatment. Many of these earlier studies were presented at national and international conferences in the form of abstracts and posters; I often found them to be the pearls of these conferences.

In summary it was like a machine where all the components—the treatment activists, educators and physicians—all worked together. It added strength to the struggle, and became an organized and powerful functional movement.

### THE SECOND TEN YEARS

1996 saw the beginnings of what became known as the treatment cocktail; the use of protease inhibitors became pervasive. I began to spend less time making rounds at the hospital, since I had very few patients needing in-patient testing or ther-

HIV treatment conferences are important to attend; new research results get unveiled, many prior to publication in medical journals. The International AIDS Conference held this year in Mexico City and the Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC), held in Washington, D.C., had varying themes this year that demonstrated how the field of HIV has changed. However, there are currently 36-39 million people around the world infected with HIV. The vast majority do not receive treatment. Infection rates have continued to skyrocket.

New debate occurred this year. Low viral loads correlate with reduced HIV in genital secretions and may result in lower probability of HIV transmission by HIV-positive persons on treatment having undetectable viral loads. This strategy may be an important tool for slowing infection rates. We have yet to develop an HIV vaccine or effective microbicides.

Other current issues revolve around the many long-term survivors who developed resistance to older treatment. However, new technological advances have resulted in true second generation agents in the classes of protease inhibitors (Prezista) and non-nucleoside reverse transcriptase inhibitors (Intelence). Medications from entirely new drug classes were developed, such as fusion (Fuzeon), integrase (Isentress) and entry inhibitors (Selzentry). Patients will have many antiviral choices for the future to continue maintaining full viral suppression.

Management of HIV disease in all its facets and components has become an art and complicated science. Sadly, there are fewer doctors from the early days of the epidemic who remain in the field seeing patients while continuing to participate in clinical research. Many have left and gone to industry. I often feel like a dinosaur. But as one who once dealt with daily difficul-

ties due to ineffective treatment and ugly politics, I now find myself in the midst of the big blast of progress. I remain an HIV doctor fulfilled. ☒

*Dr. Daniel Berger is a leading HIV specialist in the U.S. and is Clinical Associate Professor of Medicine at the University of Illinois at Chicago. He is the founder and medical director of Northstar Medical Center, the largest private HIV treatment and research center in the Greater Chicago area. Dr. Berger has published extensively in such prestigious journals as The Lancet and The New England Journal of Medicine and serves on the Medical Issues Committee for the Illinois AIDS Drug Assistance Program and the AIDS Foundation of Chicago. Dr. Berger has been honored by Test Positive Aware Network with the Charles E Clifton Leadership Award. Dr. Berger can be reached at DSBergerMD@aol.com.*

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

# WHAT'S GOIN' ON?



## To Return to the Closet, or Not?

*Embracing life outside of HIV*

by Keith R. Green

**R**ecently I came to the startling realization that working at TPAN for the past six years has sheltered me from the world outside of HIV. There aren't many work environments on earth where conversations around the water cooler can range from the joys of homosexual sex to the blues of medication-related diarrhea, without in any way being considered strange or inappropriate.

**FOR THE FIRST TIME IN SEVERAL YEARS, I FEEL AS IF MY LIFE IS NOT DEFINED BY EITHER MY HIV STATUS OR MY SEXUAL ORIENTATION.**

Upon arriving at TPAN, I was living much of my life in darkness. Not too many people knew how I identified sexually, and only my immediate family and a small number of close friends knew that I was living with AIDS.

As clandestinely as I had been living my life, the atmosphere at TPAN encouraged me to be an open book. I immediately felt comfortable enough to throw my sexuality on the table and I never for a second felt I should hide my HIV status from anyone.

Being there, I developed the courage to "come out" in almost every aspect of my life. I began speaking publicly about my experience as a young, bisexual African American man living with HIV, becoming somewhat of a "poster boy" for prevention and treatment education.

My personal world became consumed by HIV and, for a time, I believed that there was no need to really consider the world outside of it. I believed it would most certainly be the thing to take me out, so it made perfect sense to me to devote the rest of my days to the work and study of it.

Even when it became apparent that I wouldn't be dying anytime soon, somehow, I wasn't completely internalizing all of the knowledge that I was gaining about living a "normal, healthy life" with HIV. It should then come as no surprise that my arrival at the University of Wisconsin-Madison this past August was a bit of a culture shock.

After settling into the city, classes, and my internship at the state mental health institution, it occurred to me that nobody in this town really knows anything about me. The statement of purpose that I wrote when applying to UW expressed my interest in social research related to HIV, but contained none of my personal experiences with the virus.

Except for a couple of "need to know" experiences, and the process of finding a doctor to provide my health care here, I haven't had "the conversation" with anyone. And, because I also "pass" rather easily, only a select few of my new friends have a clue about my sexual orientation.

For the first time in several years, I feel as if my life is not defined by either my HIV status or my sexual orientation. In some ways it's almost as if I've walked back into the closet, but in others, it feels like this is part of a natural progression and growth for me. Have I made a choice, consciously or not, to assume the position of "don't ask, don't tell" in order to construct a new academic and professional image for myself, or is that construct becoming a healthy part of my evolving Truth?

As it always has, a conversation with my mother helped me to put some of this into perspective by challenging me to look at my situation from a different angle. Considering that I have chosen a clinical track

for my graduate studies, she questioned whether or not it would actually be healthy or productive to continue to allow myself to be defined in the way that I have been for the past five years. Reflecting on my experience with grad school so far, I couldn't help but seriously consider what she asked.

My internship at the mental health institution is split evenly between two units. One is a minimum-security forensic unit for adult males who have committed crimes but have been found not guilty by reason of mental illness or defect. The other is a civil unit for adolescent males who, for various reasons, have been deemed dangerous to themselves or to others.

As a clinical social work intern, part of my training requires me to become very involved in the most intimate details of our patients' lives. Outwardly, many of them appear to be tough as nails. Internally, though, I'm learning that there is a common thread of vulnerability and deeply rooted pain that links them.

For many of them, opening up to anyone is nearly impossible. With that in mind, I realize that the more I keep my personal stuff off the table, the better able I am to establish productive therapeutic relationships that allow their stuff to be at the center where it belongs for progress to be made.

Looking at it through this lens, it would make sense for me to keep my personal life personal. Not that I would be hiding anything from anyone, or that I wouldn't bring up certain elements that would be beneficial to the outcome of the clinical experience, but that I wouldn't be allowing it to become a barrier or distraction.

Though I miss the freedom of an environment like TPAN, I am learning to balance my personal and professional lives so that I can feel free to be most productive at what I feel I was put on this earth to do—help others. It feels rather uncomfortable and a bit awkward in the moment, like a baby bird leaving the nest for the first time, but I am hopeful that it will prove to be the beginning of quite a flight.

Please keep me in your prayers! ✚

Photo © Russell McGonagle

# PICKETT FENCES



## TMI

Many anniversaries of ranting and raging

by Jim Pickett

It's sort of hard to believe that 10 years ago I wrote my first piece—“I'm Dancing as Fast as I Can”—for *Positively Aware*.

I am sitting here looking back at all the columns I've written and I have to say, and, ya know, without even reading them, just looking over the titles, I feel a little embarrassed, a bit over-exposed, and a lot TMI. It's like—DAMN, PICKETT! Have you no shame? Is there nothing you won't run off at the mouth—or the keyboard—about? And can we talk opinionated? How many things can you go off about?

And now you are referring to yourself in the third person—can any one human being be more insufferable?

I blame it all on Associate Editor Enid Vázquez—and you can too. I first met Enid (affectionately known to me as “La Vaca”) at a 1999 community forum on barebacking that was held at a local Chicago bathhouse with the very queer (not in a good way) name of The Unicorn Club (since morphed into Steamworks). I was a speaker on the panel representing the opposition... stridently against the mere idea of barebacking, taking a very hard line, Nancy Reagan approach. Yep, that was me. I had been on meds for a couple of years by then and was nauseated, poopy and very, very cranky. How could anyone be so stupid and selfish and insane as to want to bring on that kind of misery to themselves?

My thoughts and opinions on this topic, like so much else, have evolved over time, thank Goddess. And while I wouldn't say I am a bareback advocate, I also am not a histrionic finger-wagging judge and jury on the issue anymore. There are other things for me to be cranky about. I totally *get* why people don't want to use condoms—it is natural sex after all—and I totally *get* that unlike the bad and dirty fags, the royal we doesn't go ballistic on heterosexuals pushing baby carriages for the *raw juicy bareback sex* they *obviously* engaged in. I mean, I only go off on people with baby carriages if they

are ramming into me with those annoying double-wides. Then all bets are off, baby.

So, back to La Vaca. I suppose it was the obnoxious spouting off that attracted her to me. Birds of a feather. She approached me after the forum was over and gushed over my writing (for a local gay rag) and said I should think about writing something for *Positively Aware*. I did, and have kept on doing ever since. Thanks for inviting me into the flock, Enid!

sions—vaginal and rectal microbicides. Thank you for giving me this bully pulpit to go after the purveyors of a phony cure for meth abuse (Prometa), and to draw attention to the abhorrent inequalities faced globally by gay men and men who have sex with men with regard to the genocidal lack of HIV/AIDS prevention services.

Thanks for not editing out the “fucks” and the “shits” and other vulgarities that regularly pepper my rantings.

**THANK YOU FOR ALLOWING ME TO BE AN ADVOCATE, AN EDUCATOR, A SCARED LITTLE BOY, AN ANGRY QUEEN, A HORNDOG, AND A BITCH.**

And thanks, *Positively Aware*. Thank you for allowing me to write about anything and everything. Thanks for letting me go off on World Vision for being homophobic, say “no more” to red ribbons, share my HIV coming out story to my family, complain about getting fat, and chronicle my first marathon. Thanks for letting me talk about sexual encounters at AIDS conferences and bathhouses, about stopping my meds, about re-starting my meds, about how it sucks to have HIV, and about how it doesn't suck to have HIV.

Thank you for providing me a soap box from which I have been both adored, and despised.

Thanks for letting me go after the hands that feed this publication—namely the pharmaceutical industry—when I thought they deserved it.

Danke for letting me detail how I shit my culottes on a summer day in the D.C. metro.

I'm ever grateful for the times I have been able to write about one of my obses-

Gracias for allowing me to process the schizophrenic ride that is HIV, highs and lows, the rage, the delight, the hopes, and the fears... sometimes colliding in one column.

Thank you for allowing me to tell my story these last 10 years, with all its inconsistencies and flip-flopping. Thanks for allowing me to be a patient and an activist, to be mentally ill and spiritually engaged, to be in love and so outta love, and back in love again. Thank you for giving me the space to breathe, to vent, to argue, and persuade. And to cry. I only hope readers of this column got as much out of all of this as I have.

Thank you for allowing me to be an advocate, an educator, a scared little boy, an angry queen, a horndog, and a bitch. Most of all, thank you for letting me be a big, messy, contradictory human being, and to have it all on record for anyone and everyone to witness.

Not! (LOL)

Here's to another 10? ☘

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