

March / April 2001



Positively Aware

The Journal of Test Positive Aware Network

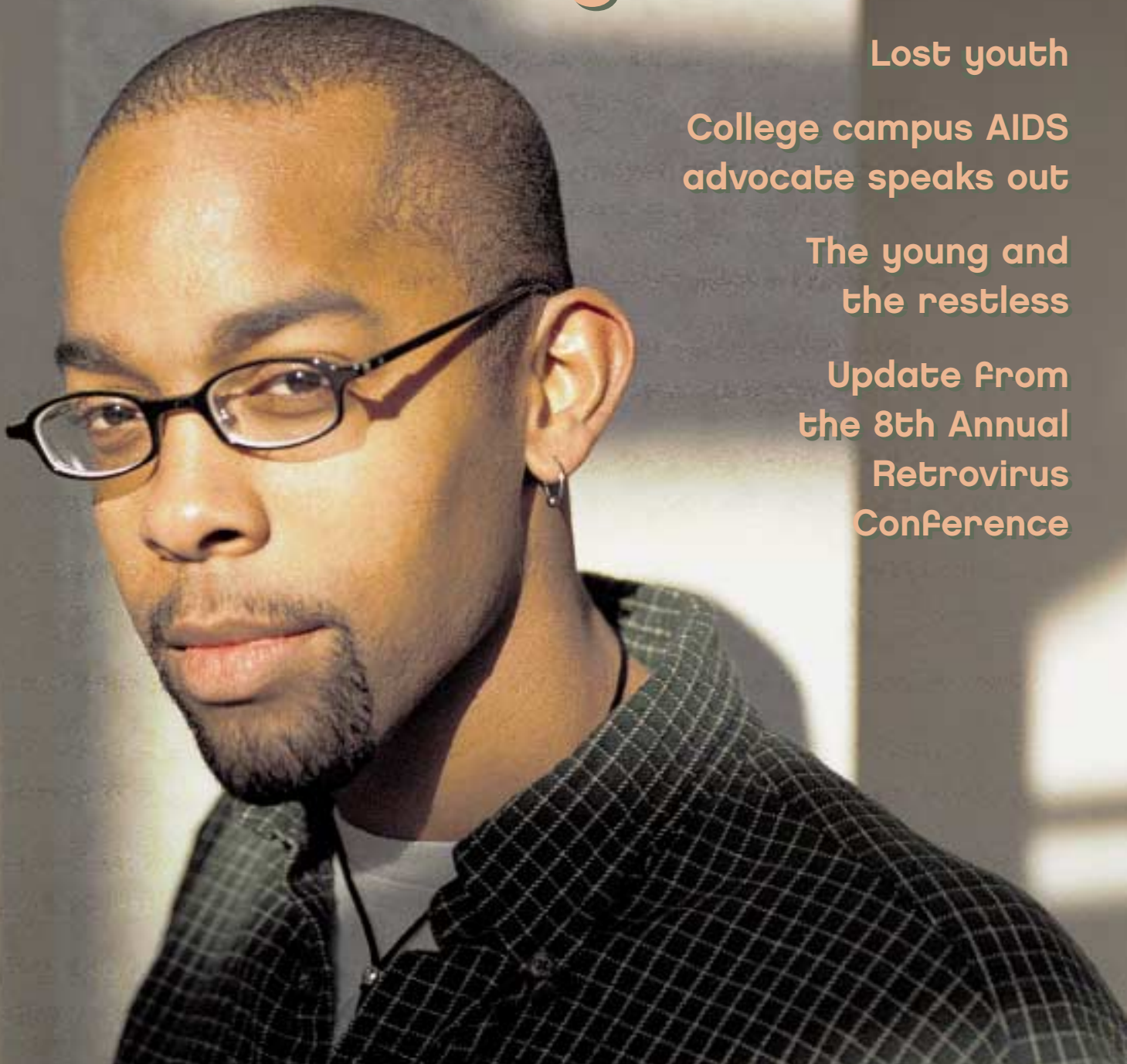
HIV: the next generation

Lost youth

College campus AIDS
advocate speaks out

The young and
the restless

Update from
the 8th Annual
Retrovirus
Conference



**BECAUSE
you have**

a lot to
THINK
about.

For the StatScript Pharmacy nearest
you, or to enroll in our home
delivery service, simply call:
800.869.6593

STATSCRIPT Pharmacy
HIV/AIDS SPECIALISTS FOR LIFE

**Serving the
HIV/AIDS
community in over
30 locations
nationwide!**

We provide:

**One source for all your
medications**

**Private one-on-one
consultations**

**Coordination and filing of
insurances**

HIV-certified pharmacists

www.statscript.com



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

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

Editor **Charles E. Clifton**

Associate Editor **Enid Vázquez**

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

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

Executive Director **Dennis Hartke**

Business Director **Rick Bejlovec**

Contributing
Reporters **Daniel S. Berger, M.D.**
Laura Jones
Bob Munk
Jim Pickett
Chris Bell
Glen Pietrandoni, R. Ph.

Art Directors **John Auterman**
Russell McGonagle
apparatus

© 2001, Test Positive Aware Network, Inc. For
reprint permission, contact Jeff Berry. Six issues
mailed bulkrate for \$25 donation; mailed free to
TPAN members or those unable to contribute.

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

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

Opinions expressed in *Positively Aware* are
not necessarily those of staff or membership or
TPAN, its supporters and sponsors, or distribut-
ing agencies. Information, resources, and adver-
tising in *Positively Aware* do not constitute
endorsement or recommendation of any medi-
cal treatment or product.

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

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

New Book Adds Muscle to the Fight Against HIV
by Michael Mooney and Nelson Vergel

The information contained in "Built to Survive"...helped me
stay alive. *Jeff Taylor, San Diego*

Favorite chapter: "Complementary Approaches to Treating
Lipodystrophy." *POZ Magazine, May 2000*

We suggest this book as a source of ideas that you may want to
discuss with your physician. *John James, AIDS Treatment News,*
March 2000



174 pages

Using this book's guidelines, most
people...just feel great. *Dr. Patricia
Salvato, a leading HIV physician in
Houston, Texas*

Perhaps by reading this book, you
don't need to lose health in the first
place. *Positively Aware May/June 2000*

Mooney and Vergel...separated out
the "wheat from the chaff."
*Karlis Ullis, M.D., Asst. Clinical
Professor, UCLA School of Medicine*

Michael and Nelson's message is: combine diet and exercise, and
hormones to get the healthiest body...immune system you can."
Charlie Smigelsky, R.D., Publisher, Nutrition for Life

To order call 800.350.2392 or visit **www.medibolics.com**

ALL NET PROFITS FUND HIV NON-PROFIT WELLNESS PROGRAMS

This space donated as a public service by Positively Aware

www.tpan.com

Table of Contents

March / April 2001 • Volume 12 Number 2

Departments		Articles	
	8 Editor's Note		22 Update from the 8th Retrovirus Conference <i>by Charles E. Clifton and Enid Vázquez</i>
	11 From TPAN		27 Lost Youth <i>by Undra C. Fulton</i>
	12 Readers' Forum		28 Scarlet Letter A: A College Campus AIDS Advocate Speaks Out <i>by Chris Bell</i>
	17 News Briefs <i>by Enid Vázquez</i>		31 The Young and the Restless <i>by Charles E. Clifton</i>
	40 Pickett Fences <i>by Jim Pickett</i>		34 One in 62: Young Injectors <i>By Laura Jones</i>
	42 The Buzz <i>by Daniel S. Berger, M.D.</i>		37 Here, Kitty Kitty <i>by Enid Vázquez</i>
	44 Dr. Sex <i>by Anthony "AC" Clark</i>		
	45 TPAN Programs		
	46 TPAN Calendar of Events		

Community AIDS advocate, Chris Bell appears on the cover of Positively Aware. Photo by Russell McGonagle.

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

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

Editor's Note

Endangered Species



In December of last year, while we were putting together the finishing touches on the HIV Drug Guide (Jan/Feb 2001), my partner's fifteen-year-old nephew committed suicide. On the surface, Ryan appeared to be a happy, energetic young man, with a bright future. He was active in his school, community and church. The mystery surrounding Ryan's suicide — Why?—left the family devastated. Particularly crushed by this tragedy was my partner, who struggled with very personal issues of being gay, obese, bulimic and suicidal when he was a teen.

This has been a difficult issue of *Positively Aware* for me to focus on, because every day those haunting questions resurface. What was Ryan going through? Why didn't anyone notice? How could this have been prevented? Prevention.

Young people, youth, street kids, and teenagers —whatever you want to label them—are an endangered species. Yes, we've all been there and done that. For many of us those years were a breeze, an experience we still look back on with fond memories. For some those years were filled with mental and physical violence. And far too many were forced to suffer in silence and invisibility.

Be they gay, straight, transgender, queer, bisexual or somewhere in between, black, white, brown, red or yellow...young people (under the age of 25) are quickly becoming the silent majority of new cases of HIV. What are these kids going through? Why didn't anyone take notice earlier? How can we prevent AIDS from devastating yet another generation?

This issue of *Positively Aware* examines HIV/AIDS prevention and education from the perspective of youth on the front lines. First-time contributor Chris Bell speaks of his experience of being an "out" HIV positive AIDS educator on a college

campus. Laura "Radical Red" Jones talks with a former drug injector about staying safe because of needle exchange programs. And I take a look at what is, and is not happening in prevention, and the growing number of HIV positive youth living on the streets. These three brief articles scratch at the scab of a deep, ugly wound. The bottom line is that more, much more, needs to be done, and could be done to prevent a second wave of HIV. What's in the way?

Every day that passes without such an effort is a missed opportunity. Ryan's death is a vivid reminder that youth, even those who on the surface appear to be at peace with their surroundings, may be troubled at their core. Ryan's memorial service was packed with friends his own age. It's scary to think that a person so loved could be so unhappy. It also demonstrates that no matter how supportive and protective we are as parents, as brothers and sisters, as aunts and uncles, and as peers, each child has a mind and will of their own.

This issue has caused me to reexamine my days of youth. As a proud "child of disco" I can look back on those days and truly give thanks that I was mature enough to enjoy the experience and lucky enough to still be here to reflect upon it. I am also thankful that my partner made it through his troubled teen and early adult years. For some unknown reason Ryan could not. We all miss him dearly.

Charles E. Clifton
Charles E. Clifton
Editor

Prevention—Let Your Voice Be Heard



The focus of this issue of *Positively Aware* is on youth and HIV. Ideally we would be reporting on scores of successful prevention programs being conducted. Ideally, we would be telling you of private funders and the government backing innovative, effective programs to give teenagers and young adults the knowledge, skills and support to minimize their risk of becoming infected with HIV. Ideally, we would be talking about lowered rates of infection for people under 25. Ideally.

The reality is quite different. While there are many prevention and education programs around the country, there are not enough. Prevention messages that were once nearly inescapable in gay communities around the country are now often hard to find, there or in the harder hit communities of African Americans and Latinos. Twenty years into the epidemic in this country, the major television networks will not allow advertising for condoms. Twenty years later, nearly 40% of Americans recently surveyed believe that one might be able to “catch” HIV by sharing a glass with an HIV positive person. Twenty years later, there is a dramatic and alarming increase in unsafe behavior and HIV infection rates among men and women under 25 years of age.

Why? How have we arrived at this point where prevention has assumed a poor, second-class status in our battle with HIV? There are many reasons. As treatments have improved, the perception has taken hold that becoming infected is “no big deal.” Many people, especially teenagers and younger adults, think current treatments make HIV just another manageable disease. Limited funds for HIV go towards direct services—housing, health care, mental health services, etc. Private funders no longer perceive HIV to be a crisis, and have shifted their funding to other issues. And “morals” have gotten in the way. The government generally has supported abstinence only or “just say no” campaigns, not ones that promote safer sex or access to sterile syringes.

Unfortunately, this bias is likely to become more pronounced with the Bush-II administration. Indications from the Bush-II White House are that the federal government will be returning to the policies more associated with the Reagan and Bush-I administrations. This means that the chances of prevention programs that go beyond “just say no” are slimmer than they were in the Clinton administration, which itself had a poor record in this area.

The tragedy of this can be seen in recent numbers from San Francisco, New York City, and elsewhere. There is a sharp increase in the number of new HIV infections, particularly among people under 25. In San Francisco, recent information released by that city’s health department indicates the rate of infection among gay males has more than doubled over the last three years.

We must have meaningful and substantial prevention messages and programs if we are to avoid another wave of HIV infections. Now is the time to let your legislators know the importance of comprehensive prevention education—prevention that goes beyond the simplistic “just say no” or that promote abstinence only. Write your legislators and tell them HIV prevention and education is a cost effective means to reduce the spread of HIV. Help them to understand its importance to the health of young adults.

Let us not have tens of thousands of more young Americans become HIV-positive simply because government officials wish to claim the “moral high ground” as it relates to sex and intravenous drugs. Prevention and education programs must be adequately funded to prevent this tragedy from happening. Help lawmakers to understand this.

Dennis Hartke

Dennis Hartke
Executive Director

photo by Russell McGonagle

Readers' Forum

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

Write to: Positively Aware,
1258 W. Belmont Ave.,
Chicago, IL 60657-3292
Fax: (773) 404-1040
E-mail: posaware@aol.com

OMISSION

The 2001 HIV Drug Guide in the January/February issue neglected to list the authors of the drug guide: Associate Editor Enid Vázquez and Glen Pietrandoni, R.Ph., of Walgreens pharmacy, with research assistance from interns Laura Martinez and Lynette Pho. The Walgreens staff, who work out of an HIV-specialty store in a community HIV organization and clinic, conducted an extensive amount of research, as did Ms. Vázquez. *Positively Aware* regrets the omission and apologizes to the authors.

THEN AND NOW

Today I went to the TPAN website and it wasn't there. What happened? I was going to respond to the 10th anniversary issue. I was among the 16 people who met with Chris Clason in the 1980s when I lived in Chicago. I now live in the San Francisco East Bay with my partner, David. I remember Bill Rydwels, along with Bob Hultz, Tony, and many other AIDS visionaries. I still have many of the old mimeographed newsletters from back then. I sometimes re-read them to show how far we really have not come. I was in ACTG [AIDS Clinical Trials Group] 016 (a granddaddy AZT study) in Chicago at Northwestern University in 1984. I took and believed in therapy for more than 16 years. All the drugs have failed me. I've been off HAART [highly active antiretroviral therapy] for more than three years now and my T-cells are under 150 and viral load is 40,000 and just stays about there. I'm lucky, we're lucky. I'd love to keep in touch with anyone who might remember those days or me.

Jay Segal, jaysegal@hotmail.com, Pleasant Hill, CA

Editor's Note: We were under reconstruction at www.tpan.com and are now back up on the web. As for the original 16, we (now!) know the whereabouts of eight of them.

ORIGINAL MEMBER

What a flash from the past! On my latest quarterly pilgrimage to my doctor I picked up your tenth anniversary issue. This couldn't be, I said to myself and "stole" a copy for myself to read. The editorial by Bill Rydwels and the stories about Chris Clason brought back many, many memories.

Back then the initial members [of Test Positive Aware Network] numbered themselves. I don't remember what number I was but it was in the low teens. I was one of the original group. It seemed like every week our numbers grew. I remember how scary it was for me when the numbers got up to 30 and 50. When it was decided to print the first *TPA News* I don't remember, but I was there. Chris had rented a Xerox machine and he had it installed in the basement of the apartment building he was living in. To this day I will never forget pushing the papers through the Xerox, Chris editing, me checking for spelling and a couple of others stacking and collating. That was the first issue of *TPA News*. The community was so hungry for news of any kind that it was only a matter of weeks before production became streamlined and the publication you have now was well on its way.

Back then there was also a gag order on all members. What was said in the meetings and who attended the meetings was in strict confidence. Everyone understood the social implications of this disease. It was not until many years later, when the Board of Directors lifted the gag order, did I ever tell any one of my friends that I was so much

involved in TPA and being a part of the first issue of *TPA News*. Now, today, as I look back on my life it is one of my proudest moments.

We were both scared and proud to be a part of our own cure. Chris always talked about the positive part of this disease. The meetings always ended up with the good-byes. They usually took the longest, were the hardest to endure, and the most therapeutic. You never knew who you would not see the following week.

When Bill Rydwels came to the group many of us looked upon him as the father of us all. I was one of the few who was fortunate enough to share in overcoming personal trials and discrimination. Bill was always an inspiration. I'm so glad you included him in your anniversary issue.

God has given me so many years of grace and excellent health. I have been so very fortunate. I have recently retired (something my doctors told me I would never see) and the future is full of wonderful plans for a life of leisure with my man. Those initial years at TPAN were hard years, but full of growth and understanding.

Bless you all for keeping up the legacy.
James D. Harris, Berkeley, Illinois

IN FOR THE LONG HAUL

I have read *Positively Aware* for many of your 10 years and I just wanted to let you know that I have appreciated receiving it and have found it most helpful. The personal reminiscences in your anniversary issue reflect both the frustrations and hopes of those of us who have been fighting HIV for many years—in my own case, 15. Luckily the simple combination of Sustiva and Combivir currently seems to be working for me. But I have struggled with extremely high blood pressure, kidney stones, a hip replacement,

ingrown toenails, the diarrhea, fattening of some parts and woeful thinning of others, high cholesterol and triglycerides, chronic pancreatitis, skin problems and a host of other physical ailments, most of which I think are related to my HIV status.

But I am also over 70 and glad to be a longterm survivor! I have outlived three support groups and the current one, bless it, now only meets biweekly with three or four attendees. Sadly, so many who should care about themselves (or others) no longer do. Perhaps some day *Positively Aware* will no longer be needed. But until then, keep up the good work.

Barc, Euless, Texas

REMEMBERING

I am writing to commend Jeff on his article in the November/December issue. It brought tears to my eyes. What I was reading was so like my own experience with learning that I was poz and the more I read the more I was moved by what he was saying. I thought that I was the only person who had an experience like that when so little was known about HIV at the time. I also was diagnosed 11 years ago, but was not offered any counseling or information on how to proceed with this new terrifying part of the rest of my life. Like Jeff, all I could do was cry and cry. I dare not tell anybody for fear of the stigma that comes with having HIV. But thank God that I have the support of a loving family and an excellent team of people who have the knowledge to treat people like us. Again, my thanks to Jeff for touching my heart so profoundly.

Michael (last name withheld),
via the internet

WHO MOVED MY CHEEKS?

I was on Crixivan long enough to have suffered some degree of the facial-lypo problems many have suffered, although I stopped it and changed to Sustiva as soon as I figured out what was happening. I wonder if Jeff knows about the new treatment that may soon be available which seems to be providing exceptional results. [See "Polylactic acid for facial filling" in News Briefs.] Test patients

examined physically and via ultrasound experienced increases of middle skin layer thickness of up to 151% after three months, and 196% over six months. Here is a website with before and after pictures I found: www.positivenation.co.uk/issue61_62/treatments/treatment%202/treatment2_61_62_2.htm.

Also, see www.medibolics.com/Facial-Wasting&Cosmetics.htm.

Anonymous, via the internet

ME, TOO

Jeff, your experience is very much like my own. Diagnosed in '89, I went on combo therapy in '97 and have been very successful with it so far. But the only downside that I am aware of is the destruction of a once adorable face. Living with it is better than being dead, or worse, gravely ill. But, oh, looking in the mirror is sometimes shocking. My body is fabulous. I'm taking testosterone and have put on a mass of muscle, but my face looks like someone has let the air out of it. I appreciated reading your very well written account of your personal experiences.

Name withheld by request,
via the Internet

COMPLEMENTARY

I've just read your January/February issue—great as usual! But under "Resources for Complementary Therapies and HIV," mention was not made of the following excellent resources: Direct AIDS Alternative Information Resources (DAAIR), www.daair.org, and monographs by Dr. Lark Lands, Ph.D., at www.vitetime.com. I am not aware of 3TC [Epivir] being used against hepatitis C, but it is used against hep B. [Editor's Note: You are right. Thank you for pointing out the typo.] Keep up the good work.

Name withheld, New York State

PICKETT FENCES

Where do I begin? I guess from the beginning. Jim Pickett's article "Slip Sliding Away" in the January/February issue blew me away. In all honesty, Jim, I had to put the magazine down and walk away sayin', "No dat bitch didn't!" Very profound words and

how true. I appreciated your pushing the envelope back into the faces of folk who usually just push envelopes. I often wondered how many of us working in the field of HIV/AIDS actually practiced what we preached, considering that we are human beings and aren't perfect. The experiences and thoughts depicted in your article are those that have run through my own mind and have been topics in conversation with peers who are also working in the field. I must admit that I had an almost moment for moment experience as you depicted that you had. I wanted to write about it, to share my thoughts, but for some reason I was feeling guilty. You've encouraged me through your writing to be more honest with mine. The key things that were pointed out were the need for continued communication for ourselves, partner(s) and our communities. HIV/AIDS is far from over and we do need to push for new methods of prevention. Thanks for making me reflect on this issue, Jim! And thank you for being man enough to put it in print.

Sanford E. Gaylord, Chicago

I was happy to see the article by Jim Pickett. This article explored a lot of the issues that poz men have been pondering for a long time...silently. Now that it is out of the "closet" I believe that it explores some of the questions a lot of us have been wondering about for a long time in our hearts, minds, and souls. I am so glad that someone is finally dealing with what is really going on in this world of HIV positive living. Now that the tides have changed, and PWAs [people with AIDS] are living longer, there is a much more diverse and complex set of issues that need to be addressed in the poz community. Sex or no sex? Protected or unprotected? Tell or not tell? All these issues deal with a host of ethical decisions and issues. I love the new face of the magazine, and appreciated the information found in this issue regarding medications and treatment. Keep up the good work.

Anthony King, Chicago ☩

by Enid Vázquez



OMISSION

In the annual *HIV Drug Guide* (January/February), Positively Aware inadvertently omitted the Merck & Co. statement on their HIV protease inhibitor drug, Crixivan (indinavir). The statement follows. Our sincere apologies to Merck & Co. and to our readers.

Crixivan was one of the first protease inhibitors on the market and in combination therapy provides highly effective therapy for the treatment of HIV. Crixivan in combination with antiretroviral agents is a powerful protease inhibitor that fights HIV and is among the preferred treatments for HIV in federal healthcare guidelines.

Crixivan can help reduce chance of illnesses and death associated with HIV; Crixivan can also help lower the amount of HIV in the body and raise CD4 T-cell counts, as shown in studies over a one-year period. As with all products some patients may not experience these effects and Crixivan is not a cure for HIV or AIDS. Crixivan must be taken every eight hours and adults should drink at least 6 glasses of water per day.

photo by Russell McGonagle

STOPPING PCP MEDS

Part of the good news that the use of HAART (highly active antiretroviral therapy) had brought to people with advanced HIV disease is that they were able to stop taking preventative medicine for PCP (*Pneumocystis carinii* pneumonia) once their T-cells were more than 200. The illness was a common cause of death in the early days of the epidemic. However, people who had already experienced PCP were not able to stop taking prevention because their risk of another bout of PCP was too high. Now a Swiss study published in the January 18 issue of *The New England Journal of Medicine* reports that this group can also stop taking PCP prophylaxis (prevention). Of a group of 325 people taking HAART whose T-cells were greater than 200, not one suffered a PCP relapse as of 13 months from the time they stopped taking PCP prophylaxis. The researchers concluded that stopping PCP prophylaxis is safe in this population. A different study in the same issue of *NEJM* again noted no finding of PCP in people whose T-cells had gone over 200.

HIV GUIDELINES NOW SAY "HIT LATER"

It's been years in the works. Doctors and HIV advocates had become increasingly concerned over the difficulties of taking HIV therapy, including side effects that may increase the risk of serious disease and deteriorate quality of life. Now it's a done deal: the new HIV treatment guidelines of the U.S. Department of Health and Human Services (DHHS, part of the National Institutes of Health, or NIH) suggest that people wait until their T-cells are down to 350 or their viral load above 20,000 before they begin HIV therapy. Before, the standards

were much higher: "In general, any patient with less than 500 CD4+ T-cells or greater than 10,000 (bDNA, the Chiron test) or 20,000 (RT-PCR, the Roche Amplicor test) copies [viral load] should be offered therapy." The changes represent more nails in the coffin of the "hit hard, hit early" school of HIV therapy. And although expected, the new official word is creating a buzz among HIV specialists about the continuously changing direction of treatment. For a copy of the guidelines, call 1-800-448-0440 or visit www.hivatis.org.

POLYLACTIC ACID FOR FACIAL FILLING

An experimental treatment successfully used in Europe for AIDS-related facial wasting is soon expected to be available in the U.S. The Direct AIDS Alternative Information Resources (DAAIR), a buyers club in New York City, offers a 3 ml bottle of New-Fill (polyactic acid) for \$177.50 plus shipping, with up to five refills. A prescription is necessary and several treatments are needed. A variety of materials are available for injecting during plastic surgery, including fat taken from other parts of the body and collagen. New-Fill is found to last longer than collagen and is expected to stimulate the body to form more of its own collagen. The material is thicker than most other injectibles, and must be injected with a smaller needle to get a smooth surface result. As with any experimental treatment, longterm side effects are unknown. DAAIR is providing a fact sheet on how to administer the treatments. Visit the manufacturer's website, www.new-fill.com, or contact DAAIR: e-mail info@daair.org, fax 1-212-689-6471, call 1-212-725-6994 or toll free outside New York state at 1-888-951-5433. Visit www.daair.org.

Facial wasting, the hollowing out of cheeks and temples, appears to be a side effect of HIV drug therapy and can be extremely distressing. Reconstruction surgery has been used by many to insert or inject a filling to round out the face again. AIDS reporter Emmanuel Trenado wrote to a U.S. internet list, "Polylactic acid has been used in France quite a lot. People who have been using it are pleased, but it seems that it does not last as long for some. The company which produces New-Fill answers to this by saying that you need a skilled doctor to inject the product (deep in the skin but not too deep). Also some people have bruises for a couple of days. The product was put on the market at the end of 1999, and it seems at least here in France for the moment the only interesting filling product that is temporary. Collagen and hyaluronic acid don't last very much. There's a brand new filling product called Outline and it will be in clinical trials soon."



MORE VIRAMUNE RASH FOR WOMEN

Researchers reported that women are seven times more likely to experience severe rash from the HIV drug Viramune (nevirapine) than are men. The side effect is potentially fatal. Women are also 3.5 times more likely to discontinue taking the drug because of rash. The researchers looked at people who had taken Viramune over a five-year period at several cities throughout the country. They found that nine out of 95 women had severe rash, compared with three out of 263 men. The results were reported in *Clinical Infectious Diseases*.

DON'T MIX CIPRO WITH METHADONE

A report in *The Lancet* medical journal of December 16, 2000 noted that a woman on methadone experienced toxic levels of that drug when she was given the antibiotic Cipro (ciprofloxacin) for a urinary tract infection. The interaction between the two medicines caused her to be hospitalized. Symptoms of toxicity from methadone can include drowsiness, confusion, low blood pressure and slowed breathing. An injection of the anti-narcotic drug Narcan (naloxone) helped her recover right away. Many people with HIV use methadone, a medicine to control cravings for drugs such as heroin. The doctors issuing this report noted that Luvox (fluvoxamine) and Prozac (fluoxetine) can also raise methadone blood levels.

ZERIT, VIDEX AND HYDROXYUREA

The story of a London man helps illustrate the point that the three drugs together may increase the risk of serious side effects. His doctors recently reported in the *British Medical Journal* that he took Zerit, Videx and Viramune for a year and a half before his viral load went up (the amount of HIV in his blood). His doctors then added hydroxyurea, a cancer drug that works against HIV. But he had to stop the hydroxyurea within two months, after experiencing pain in his upper abdomen. It was pancreatitis. Three weeks later the other three drugs also had to be stopped, after his condition became worse. In 1999 the manufacturer of Zerit and Videx had to add the following warning to Videx's drug label: "Patients treated with Videx in combination with stavudine [Zerit], with or without hydroxyurea, may be at increased risk for adverse events such as pancreatitis, peripheral neuropathy, and liver failure." Just a reminder.



EXPERIMENTAL DRUG PROBLEM

The *Washington Post* reported on December 18 that an experimental HIV drug which caused heart arrhythmia when it was tested in dogs, a problem that could lead to blackouts and death, is no longer allowed to be tested in large-scale studies in the U.S., but will now be tested in Mexico. The paper reported that Triangle Pharmaceuticals promised the Mexican government that it will closely monitor mozenavir. Trials in poorer countries are much less expensive to conduct, the report noted.

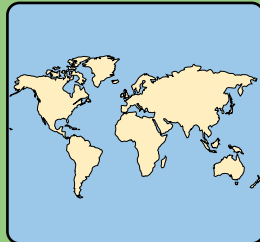
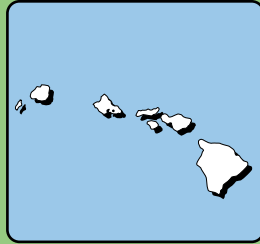


TREATING LACTIC ACIDOSIS

Lactic acidosis is yet another potentially fatal side effect of HIV drugs, and difficult to measure. Doctors in the Netherlands reported results from six HIV positive people with lactic acidosis (high levels of lactic acid in the blood). Symptoms include fatigue, abdominal pain, shortness of breath, and nausea. People with hepatitis B or C are at increased risk, as are women, especially obese women. The Dutch researchers infused their patients with a saline solution and twice-daily infusions consisting of 100 mg vitamin B1, 20 mg vitamin B2, 200 mg niacin (as nicotinamide), 20 mg of pantothenic acid, and 1,000 mg of L-carnitine. They reported that 50% of people with lactic acidosis die, but all six here survived. The results were published in *AIDS*.

MEDICINAL MARIJUANA FOR HAWAII

People with debilitating diseases who live in Hawaii can now legally have up to three ounces of marijuana and grow up to seven marijuana plants. A registration form must be obtained from a doctor and the marijuana is to be used for the treatment of pain. There are now nine states allowing the use of medicinal marijuana, but the U.S. Supreme Court is set to weigh those laws against the federal law prohibiting the use of marijuana.



HIV DRUG COMPANIES SUE SOUTH AFRICAN GOVERNMENT

An association of drug companies has renewed its lawsuit against the government of South Africa to stop the country from importing less expensive generic HIV drugs. In attempts to control its HIV epidemic, South Africa has passed a law challenging company drug patents, which give them exclusive rights to the sale of their medicines. However, the companies then set the price, which for HIV drugs are generally sky-high. Less expensive generic versions of many of the drugs are being manufactured around the world, most successfully in Brazil. It is these drugs that the South African government was trying to buy for its people when the drug manufacturers stopped them with the lawsuit. HIV advocates fear that U.S. president George Bush may reverse an executive order signed by Bill Clinton last year that allows poor countries to buy generic versions of drugs still under U.S. patents. An editorial in the British medical journal *The Lancet* in January urged drug manufacturers and governments representing their interests to change international laws that make it difficult for impoverished countries to fight the AIDS epidemic. As for the idea of drug discounts and giveaways, AIDS activists charge that these proposals are a public relations front for the drug companies with no plans in place for actually following up to provide the medicines.

CRIX STONES

Canadian researchers reported finding seven times more cases of nephrolithiasis (kidney stones or kidney sludge) from therapy with Crixivan protease inhibitor than the 4% incidence rate listed on the drug's product label. At 78 weeks, 43.2% of the 155 people they reported on had nephrolithiasis. These results are not surprising, given that there was nephrolithiasis in a third of the 33 people who took the drug for three years in one drug trial. The number of side effects associated with any drug tends to be greater out in the real world. The results were published in the December issue of *The Journal of Urology*.



drug photos by Russell McGonagle



UH, OH...PREGNANT WOMEN, LOOK OUT

The FDA and Bristol Myers Squibb, the manufacturer of the HIV meds Zerit (stavudine, or d4T) and Videx or Videx EC (didanosine, or ddI), issued a warning in January that pregnant women taking the two drugs together may be at increased risk of fatal lactic acidosis, as well as liver damage. The warning came after three pregnant women died of lactic acidosis while taking the drugs together along with other HIV antivirals. The FDA explained: "Lactic acidosis occurs when cells of the body are unable to convert food into usable energy. As a result, excess acid accumulates in the body and vital organs such as the liver or pancreas may be damaged. Severe lactic acidosis is an infrequent, but well-described complication of the class of HIV drugs known as nucleoside analogues. Pancreatitis is also a well-described complication of Videx and Zerit." The women were taking Zerit and Videx in combination with other drugs used to treat HIV, as is common with standard triple combination HIV therapy. Two of the cases were reported from HIV studies in South Africa and one was identified through worldwide post marketing surveillance. The FDA also noted that it "has received several nonfatal reports of lactic acidosis, with and without pancreatitis, occurring in pregnant

women receiving only Videx and Zerit. Although data have suggested that women may be at increased risk for the development of lactic acidosis and liver toxicity, it is unclear whether pregnancy potentiates [strengthens] these known side effects." The letter also noted that the two drugs should be prescribed for pregnant women only when the potential benefit clearly outweighs the potential risk, as when the women do not have other treatment options. Look out for symptoms of lactic acidosis as listed above in "Treating lactic acidosis," but don't get unnecessarily frightened. Pregnant women who are prescribed the two drugs should be closely monitored for clinical or laboratory signs of lactic acidosis and liver damage. Because lactic acidosis can develop quickly before abnormal lab values are seen, the FDA recommends that healthcare workers keep "a high index of suspicion when monitoring these patients." Adverse reactions to the two drugs can be reported to BMS at 1-800-426-7644. Contact the FDA by calling 1-800-FDA-1088, fax 1-800-FDA-0178, visit www.fda.gov/medwatch or send report to: MedWatch (HF-2), Food and Drug Administration, 5600 Fishers Lane, Rockville, MD 20857.

UH, OH...VIRAMUNE NOT FOR PEP

The U.S. Centers for Disease Control (CDC) in January said Viramune (nevirapine) should be avoided when trying to prevent infection after exposure to HIV, because of the potential for serious adverse reactions. This recommendation does not apply to treatment for people with HIV or the use of Viramune to prevent mother-to-infant transmission, which requires only two doses of the drug and has been shown to be safe. So-called post-exposure prophylaxis (PEP) consists of an HIV drug combination used for a few weeks and is commonly used by healthcare workers after accidents involving needles that have been used in people with HIV, or whose HIV status is unknown. But reports of adverse reactions following treatment with Viramune led the CDC to make its recommendation. One nurse needed a liver transplant two weeks after starting Viramune along with Retrovir and Epivir. A doctor was hospitalized with life-threatening fulminant hepatitis, also after taking that combination. All symptoms began within two weeks. At least six of the cases did not use a lead-in dose as called for when

taking Viramune. Still, Viramune can be used if necessary, as when the HIV source is resistant to other HIV drugs. The CDC points out that the risks of *all* the HIV drugs may be greater than the potential benefit of trying to prevent HIV when the risk of infection is very low to begin with. The complete *CDC Morbidity and Mortality Weekly Report* can be seen at www.hivatis.org/atisnew.html.

Recommended PEP regimens are outlined in the *MMWR* of May 15, 1998. See it online at www.cdc.gov/hiv/treatment.htm. For most exposures, Retrovir/Epivir (AZT plus lamivudine, also available in one tablet called Combivir) is recommended for four weeks. The two along with either Crixivan or Viracept protease inhibitor are recommended for exposures that may pose a greater risk for transmitting HIV (such as those involving a larger volume of blood or those involving a source with advanced HIV disease). The possibility of drug resistance in the source must be considered. For consumer inquiries, call tollfree 1-888-INFO-FDA.



AWARD TO MAN REFUSED TREATMENT

Neurosurgeons in Oklahoma were ordered by the U.S. Justice Department to pay \$50,000 to an HIV positive man for refusing to perform back surgery because of his HIV status. The successful lawsuit was brought under the Americans with Disabilities Act.

NONOXYNOL-9 INCREASES HIV RISK FROM ANAL SEX

The spermicide nonoxynol-9, found in many condoms and lubricants, may increase the risk of HIV transmission during anal sex. Recently the CDC issued a statement noting that the substance may in fact help increase the risk of transmission, rather than reduce the risk as had been hoped. The new report in the January issue of the journal *Contraception* said that nonoxynol-9 actually caused cells lining the rectum to peel off, thereby increasing the risk of transmission.

HIV SPECIALTY CENTER OPENS

AbsoluteCare, a center for HIV/wellness care, has opened in Atlanta. There are plans for more centers around the country through partnership with Absolute Wellness, a non-profit center open one year. Together they combine under one roof all the services that people with HIV need. Services include nutritional counseling, alternative healthcare, and minor medical procedures. A similar facility, the CORE Center, opened in Chicago in 1998. The center is run by Cook County Hospital and Rush Presbyterian-St. Luke's Medical Center.

AIDS LYMPHOMA STILL UP

by Daniel S. Berger, M.D.

Many infections and opportunistic complications in AIDS have decreased with new HIV therapies, but there are some concerns that lymphoma has not. Lymphoma is a cancer of the lymph node system, often referred to as "glands" or lymph glands. Lymph glands or lymph tissue are located in the neck and groin but also in many organ systems of our body, including intestines and lungs. Lymphoma is suspected when the lymph nodes swell to abnormally large size and often accompanies other symptoms such as fever, night sweats, fatigue and shortness of breath.



Changes in the course of AIDS-related lymphoma have recently been reported in the journal *Blood* (December 15, 2000, pages 4084-90). 369 patients from Los Angeles County Hospital diagnosed with, or who had treatment for lymphoma, were studied. Overall, the incidence of AIDS-related CNS (central nervous system) lymphoma (brain) has not changed, yet, there was a greater prevalence among women and minorities; the changing demographic of AIDS in general in the U.S. has also increased in women and minorities. Changes observed in this study were related to the specific type and pathology of lymphoma. The subtype "high-grade small noncleaved" lymphoma decreased from 55% in the years 1982-86 to 22% during 1995-98. However "diffuse large cell" subtype increased from 0% to 32% during the same time periods. Average survival for AIDS lymphoma in the study remained bleak.

However, despite HAART (highly active antiretroviral therapy) and the widespread use and availability of protease inhibitors, the median T-cell counts at the time of diagnosis of lymphoma was 177 cells during the time period of 1982-86 and decreased to

53 cells during 1995-98. One wouldn't expect that the average T-cell count would have decreased among HIV positive individuals, even those with lymphoma, if those individuals were taking effective HAART medications.

Many previous studies have demonstrated a reduction in opportunistic disease with marked increases in T-cells among patients on antiviral therapy. This study is different from that experience. The differences in this clinical trial may be due to the study being conducted in its entirety at one

institution, which sees a heavily indigent (poor) patient population and thus probably not representative of the overall population of HIV positive persons in the U.S. Additionally, one can not help but ask why would the average T-cell count decrease (from early '80s to the years 1995-98) in this population, despite widespread use of protease inhibitors and HAART, since this is in sharp contrast to what is commonly observed and published. The authors seem to rely on a less probable explanation for this disparity: "these patients may have simply lived long enough to eventually develop lymphoma as a long-term complication of HIV infection." Other explanations can be raised and include that the lower observed T-cells may indicate that these patients were not on treatment or their adherence to their drug therapy was poor. Perhaps treatment may not have started until too late or another possibility may be that the therapy chosen was not effective or tolerated. These reasons could easily explain differences that seem to be apparent from other treatment centers around the U.S. Lymphoma in our HIV-treatment center in Chicago still remains rare; we believe this is due to the availability and use of more potent antiviral therapies. ☒

Update from the 8th Retrovirus Conference

by Charles E. Clifton and Enid Vázquez

The new *Guidelines for the Use of Antiretroviral Agents in HIV-infected Adults and Adolescents* created a buzz among science investigators, AIDS treatment community advocates, and the press prior to the opening session of the 8th Conference on Retroviruses and Opportunistic Infections (CROI), held in Chicago in February. The new *Guidelines* recommend that HIV positive individuals and their physicians consider withholding antiretroviral therapy when a person's T-cell count is above 350 (previous *Guidelines* recommended therapy initiation when T-cell count fell below 500). The new *Guidelines* also suggest that treatment be considered when viral load exceeds 20,000 or 30,000 copies (previous recommendations were at 10,000 or 20,000 copies depending on which test was used).

"Although antiretroviral therapy has provided extraordinary benefits to many patients, we know that we cannot eradicate HIV infection with currently available medications," Anthony S. Fauci, M.D., director of the National Institute of Allergy and Infectious Diseases (NIAID) and co-chair of the panel that created the guidelines, noted in a press statement. "We also recognize that serious toxicities are associated with the long-term use of antiretroviral drugs. The new treatment guidelines provide patients and their doctors with evidence-based recommendations for initiating antiretroviral therapy that take into account both the benefits and potential risks of currently available treatment regimens." The *Guidelines* were developed by the Panel on Clinical Practices for the Treatment of HIV Infection, a joint

effort of the Department of Health and Human Services and the Henry J. Kaiser Family Foundation.

A rather larger body of AIDS treatment community advocates and activists met over two days to discuss long-term clinical efficacy and tolerability of anti-HIV therapy, the feasibility of conducting long-term antiretroviral therapy trials, and to establish a national coalition of HIV advocates. Reports from ongoing and proposed long-term effective research were submitted during day one. The overall goals of these studies are to evaluate strategies of drug free periods compared to continued therapy; to evaluate treatment strategies that both improve quality of life and delay progression of disease; and to evaluate the effect of mega-antiretroviral therapy (five or more meds) compared to standard antiretroviral therapy (usually triple combinations).

The treatment community appears to be at a crossroad, as new (and sometimes conflicting) data indicates that the highly touted "hit hard, hit early" treatment strategy initiated in 1995/96 may not have been the best strategy for the majority of HIV positive individuals. (See "Hit Later," page 17.)

However, in an effort to work more effectively and efficiently, treatment community advocates from around the U.S. agreed to establish an advocate coalition. The coalition will work towards improving relations and communications between community and pharmaceutical companies; establishing a national advocate training and mentoring network; and expanding international advocacy relationships with partners

from Canada, Europe, Africa and Latin America.

Given the news of the new *Guidelines* in treatment, it came as no surprise that the following questions dominated the four-and-a-half day conference. When to start antiretroviral therapy? When and how to change treatment regimens? What are the short-term and long-term effects of structured treatment interruptions (STI) or structured intermittent therapy (SIT)? Why are high-risk behaviors on the rise again? How are behaviors affecting HIV transmission rates? Who is at high risk for HIV infection, and why? What new drugs are on the horizon, and when will they be available? How are researchers and pharmaceuticals addressing concerns about toxicity and body-shape changes?

Robert Siliciano, M.D., Johns Hopkins University School of Medicine, presented data showing that while current highly active antiretroviral therapy (HAART) comes close to stopping the virus, viral reservoirs can exist and low levels of virus replication can take place in resting (dormant) T-cells of individuals who have responded well to HAART. Studies continue to determine whether a low viral load (as opposed to an undetectable viral load) results from or contributes to the emergence of drug resistance, in which case the drugs can no longer fight the virus.

Many labs reported from on-going studies indicating that short-term treatment interruptions or long-term treatment interruptions may be the direction of anti-HIV therapy, as it is highly unlikely that HIV can

be eradicated with current treatment availability. Because of the numerous short-term and long-term toxicities associated with HAART, a number of clinical trials are being pursued that may eventually reduce an individual's time of treatment (and influence the *Guidelines*). One option is a long-term structured treatment interruption, where HAART is stopped until the viral load or T-cells reach a pre-determined level. Once the pre-determined level is reached, HAART is re-started until viral load declines or T-cells increase; the cycle is then repeated. Several studies indicate that viral load and T-cells return to pre-interruption levels when HAART is resumed.

However, there are a number of factors to consider: length of time on HAART and level of adherence; risk of developing resistance or sensitivity to meds; and an increase in risk of virus transmission during an interruption. Moreover, what works for acutely (newly) infected individuals may not work for chronically infected individuals.

All of these interruptions are called "structured," meaning that individuals should never try this on their own. This type of treatment interruption is still in experimental stages, and should be closely monitored by a physician or in a clinical setting.

FOR OLD-TIMERS

Dr. Stephen Deeks and colleagues of the University of California at San Francisco answered a question that's on the minds of many, many people living with HIV: What happens to all those folks who took AZT monotherapy back in the 80's and went on HAART in the 90's, but never got to "undetectable"? Is therapy doing them any good?

They found pretty good results in a group of these patients, who had an average of 124 T-cells when going on HAART. The risk of disease was only 41% after four years, despite having detectable HIV in their blood. Dr. Deeks said this is "dramatically" better than what you would expect after four years with no treatment.

HEART ATTACKS?

Dr. Deeks had earlier reported that his patients were doing better with therapy even if they weren't undetectable. Another doctor following up on a previous report was Dr. Keith Henry of the University of Minnesota. He earlier shook up the HIV world by reporting on two young men—one only 29—who had had heart attacks while on HAART. Now Dr. Henry and colleagues were back with a presentation on whether HAART increases the risk of cardiovascular disease.

They found changes associated with increased risk for coronary artery disease in a group of 100 people taking Crixivan combination therapy. The risk factors were increased levels of triglycerides and total cholesterol, decreased HDL

Dr. Deeks said this is
"dramatically" better than what you
would expect after four years with
no treatment.

(the "good" cholesterol), and increased insulin resistance (found in 56%). The doctors recommended medical intervention for these conditions. Not quite new information, but it's good to know people with HIV have a solid watchdog in Dr. Henry.

ASPIRIN FOR PERIPHERAL NEUROPATHY

Another group looking for immediate practical information was the Community Research Initiative on AIDS (CRIA) in New York City. They gave 31 people an aspirin preparation to be placed directly on the skin where nerve damage was causing pain. Neuropathy is a common and often debilitating condition in HIV, resulting from either medications or from the virus itself. CRIA found significant improvement (25 to 30% better) with the use of topical aspirin in

diethyl ether (ASA/DE). They used 375 mg three times a day.

VIRAMUNE AND PREGNANCY

Viramune (nevirapine) is so effective at cutting transmission from a previously untreated mother to her newborn, using only two doses of the drug, that doctors looked at whether it can further cut transmission for women already on combination therapy. It can't. The international trial looked at 1,500 moms, 99% of them taking at least one HIV drug—half of them were on triple combination therapy. Whether or not you added Viramune, the transmission rate was 1.5%.

SUSTIVA AND TB

No, you don't get tuberculosis from taking Sustiva (efavirenz). But blood levels of the popular HIV drug goes down when people take rifampin for their TB infection. Spanish researchers suggested that your Sustiva dose be upped to 800 mg a day (four 200 mg capsules instead of three).

IN THE PIPE-LINE

ONCE-DAILY PROTEASE INHIBITOR

48-week results from a Phase II study of Bristol-Meyer Squibb's new once-daily HIV protease inhibitor, BMS-232632, indicates that higher doses of the new PI compares favorably against three times-a-day Viracept (nelfinavir). The safety and antiretroviral activity of three doses of BMS-232632 (200, 400, and 500 mg) was compared against Viracept at 750 mg; both were tested in monotherapy for 2 weeks and then in combination with Videx (ddI) and Zerit (d4T) for the duration, in 265 HIV positive individuals (38% women; 43% non-white) taking antiviral meds for the first time, who had viral loads greater than or equal to 2,000 copies. The most common side effects were diarrhea and nausea. It is recommended that BMS-232632 be taken with a light meal. There were no significant elevations in cholesterol, LDL-cholesterol (the bad kind), or triglycerides (fat in the blood) observed.

Phase III studies, also involving participants taking anti-HIV meds for the first time, have started.

FUSION INHIBITORS

Exciting possibilities in antiretroviral therapy are the experimental fusion or early inhibitors. Taken as a self-administered injection, these drugs are formulated to block HIV before it enters the T-cell. This is accomplished by interfering with stages of attachment and fusion between HIV and the cell.

T-1249, what Dr. Roy Gullick of Cornell University in New York City called “the son of T-20” (both drugs are made by the same company), was studied in people for the first time. The very early study looked at different doses of the drug taken by itself either once or twice a day, for a total of two weeks. Higher doses were better at decreasing viral load, and the data supports once-daily dosing. Adverse side effects: hypersensitivity reaction (oral ulcers, bumpy rash, fever) and grade 4 (serious) neutropenia (lowering of white blood cells). The most common side effects reported were injection site irritation (usually mild), headache, dizziness and diarrhea.

CHEMOKINE RECEPTOR INHIBITOR

Researchers are developing a new class of drugs that stop the virus from entering, or fusing into, cells. The chemokine receptors CCR5 and CXCR4 are identified as co-receptors on the T-cells required for HIV to enter

the cells. Initial data indicates that the compound SCH-C has excellent potency against a broad range of resistant virus; is compatible with existing anti-HIV meds; can reduce viral load (the amount of virus in the blood); and was well tolerated. A second-generation compound, SCH-D, with ten times more potency, is also being studied.

NEW PROTEASE INHIBITOR

A new type of protease inhibitor that works at lower concentrations and against resistant virus is in the works. One “femtomolar protease inhibitor” was reported on, TMC126. It has not yet been studied in people. Researchers are still looking at the chemical structure of these compounds and figuring out how they act in the test tube with multi-drug resistant virus. The researcher who made the oral presentation labeled TMC126 “a resistance-repellent PI” in his report. Cute, but don’t hold your breath.

NEW NON-NUKE

Then there’s TMC120 (made by the same company, as you can imagine from its name). This is a non-nucleoside (like Viramune and Sustiva) that is also supposed to work against drug-resistant HIV. At 50 mg or 100 mg twice a day in a small group of only 28 people, the drug showed significant viral load decreases after one week, with few side effects.

THE THIRD WORLD

Doctors and researchers are more and more thinking about what can be done to fight the HIV epidemic in developing countries, and the organizers of this year’s Retrovirus conference addressed this issue. HIV advocate George M. Carter of DAAIR (Direct AIDS Alternative Information Resources), in New York City, reported on this as well. “They framed this very intensively scientific conference with an economist, Jeffrey Sachs at the opening, and a physician, Anne-Valerie Kaninda, from Doctors Without Borders [at the closing] to discuss the absolute necessity for generic-pricing for AIDS drugs. While I can certainly argue some of the points made by Sachs, I think it is vitally important to recognize what an enormous leap this is toward that goal of breaking down the price barrier. Even a few years ago, the notion that politics, science and medicine were (sometimes hideously) intermeshed was an incomprehensible notion to many researchers and clinicians so enveloped by their own laser-like narrow beams of focus of their research.”

Additional reports and late breaking news from the 8th Annual Retrovirus Conference will also be included in the May/June issue of *Positively Aware*. ☒☒

Subscribe or get back issues now.

MA 2001

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

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

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

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

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

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

PHONE: _____ E-MAIL: _____

CHARGE MY: VISA MASTERCARD AMERICAN EXPRESS

CARD NUMBER: _____ EXPIRES: _____

NAME ON CARD: _____ SIGNATURE (REQUIRED): _____

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

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

Lost

youth

I'm presently incarcerated and I have AIDS. I have written a letter, "Me & AIDS," that might be of interest to *Positively Aware* readers.

AIDS has knocked 30 years or more off my young life. I don't want anyone to experience the heartache, pain, confusion and hardship that I have been going through in dealing with AIDS, drugs, alcohol and prison.

I feel that if I can reach one reader and persuade them to think twice before they use drugs or alcohol, or have unprotected sex, then my life won't be a total waste.

I have been HIV positive since 1989 and today I have full-blown AIDS. My immune system is practically gone, depleted! Everyone does what he believes is in his best interest. Today I am writing to you out of love and sincerity.

I am being subjected to an extreme and stressful environment with officers, offenders, and some staff members, and others who are sick mentally, hateful and evil within this unfair, double standard justice system at this prison.

Through it all, to have learned that I have the virus that causes AIDS living in my body drove me to the lowest and deepest level of negative and corrupt form of living. I became lost and confused in 1989 at the age of 22.

I told my family and friends that I had HIV in the hopes of getting moral support. I was wrong. Everybody turned their backs on me out of fear that I might give them HIV. Nobody wanted me around. I found myself homeless. I have eaten out of garbage cans. I have done things that I am too ashamed to speak of, just to survive on the streets.

I turned to alcohol and drugs to help me deal with and maintain what I felt was a sensible outlook on life. This led me to live a life full of hell, and full of crime. I seemed not to care about myself anymore. In the past, the best way

to handle my fears, loneliness and depression was to turn to alcohol to help me forget about myself and my problems, and that only led me to jail.

Growing up as a young adult in my teens, I was rebellious towards my mother and father. I would not listen when they tried to give me good advice concerning sex, drugs, alcohol and crime. As a result, at a young age I hung out with the wrong crowd, started smoking cigarettes and later, went on to drinking and staying out late at night.

I graduated from drinking and cigarettes to selling and doing drugs. This made me feel like I was cool. Today I realize I was a fool, not cool. I wanted to fit in with the crowd. I was mostly pressured by my so-called friends to do drugs and drink with them, and so I did.

I became a sexually promiscuous person. The alcohol and drugs led me to have unprotected sex with many women. The phrase, "When you have sex with someone, you have sex with everyone they ever slept with," is true!

AIDS is a powerful, painful and cunning disease. I have had painful, swollen glands in my neck, rapid weight loss, constant fatigue, persistent diarrhea, constant skin problems, sores in my mouth, shortness of breath, endless night sweats, recurring infections, and mental anguish. These are just some of the symptoms I deal with on a daily basis. It gets so bad that I wish I was dead. The medication is not working the way it should, so I prepare for the worse.

I am speaking out to the young adults, as well as to my peers, only to encourage them not to live as I once did. The sex, drugs, alcohol and rebelliousness is certainly not worth it. Please hear me out and take heed to what I'm saying, please.

By Undra C. Fulton, #983698, Pendleton Correctional Facility, P.O. Box 30, Pendleton, Indiana 46064, alliswel@netnitco.net ☒



by Chris Bell

I would like to share three stories, more specifically, one story involving three people. Billy, Danny and Chris. Similarities? All three were college students. They were all gay men. And they were young, very young and living with HIV.

BILLY VANCE*

I must confess I don't know much about Billy other than he grew up on a farm and majored in Biology. He also enjoyed writing poetry and after graduation, he applied to a graduate program in Creative Writing. Billy knew he didn't have the best qualifications for the program because as a Biology major, he'd only taken a few English classes. Nonetheless he had often been told his poetry was "pretty good," so he was hopeful. Much to Billy's delight, I would imagine, he was not only accepted into the program but awarded a fellowship as well.

When Billy met his professors and fellow graduate students, he confided in a select few. *I have AIDS*, I imagine Billy stating. *Not only that, I've had it for several years now and quite honestly I don't know if I'll be around long enough to complete my Ph.D.* Despite this realization, or perhaps because of it, Billy focused solely on his studies and his writing. He did little, if anything, to draw attention to his seropositive status. So when he grew sick a mere four months after his arrival and stopped attending classes, most of his professors and fellow students didn't know why. Indeed, it was only right before Billy died—a few days before the dawning of spring—that most people found out.

DANNY BROWN*

While Danny was in college, he seemed content. He joined the Black Student Union and was elected President for two years. He pledged a fraternity and was elected its President as well. He was the student selected to break ground for the university's multi-million dollar Black Culture Center. Danny was arguably one of the more well-known, well-respected students on his campus. But Danny had a secret. He was gay, and he found it extremely difficult to reconcile this fact with the person he wanted to be.

At some point in his academic life, probably his junior year, Danny tested positive for HIV. He told no one. Instead, he withdrew from the university, transferring to another school a few hundred miles away. When Danny felt comfortable, he told his mother and sister about his diagnosis. They offered their support. Not long after, Danny told his partner about his status and suggested he be tested. When Danny's partner learned he was also positive, he became convinced that Danny had "given him" the disease. He retaliated by beating Danny with a skillet.

One night, Danny received a phone call around midnight. After a brief conversation, he borrowed his sister's car and disappeared into the night. By sunrise, he hadn't returned. A few days later, the police found the abandoned car on the side of a highway. There were blood stains in the driver's seat.

Weeks passed; months passed. In a large city with a police force well-versed in missing person's cases, the mystery of Danny's disap-

pearance could not be solved. Finally, a year and a half after he vanished, two hikers and their young children discovered a skull in the woods six miles from where the car had been abandoned. It was Danny's. His murder remains unsolved.

CHRIS BELL

During my undergraduate years, I experienced a growing awareness of self, including the realization that I am gay. As I came out, I was intrigued by the seemingly non-plussed reactions of my close friends and family. While some of them were surprised, others were not. Regardless of their reactions, they all accepted me without reserve. I have always cherished that sense of acceptance.

I graduated from college a few weeks after my 21st birthday and began graduate school shortly thereafter. I had no qualms about being openly-gay in graduate school and experienced few, if any, negative repercussions. Halfway through my Masters coursework, I tested positive for HIV. As I sat in the student health center, pretending to listen to the doctor's counseling, I reflected on my life, particularly my undergraduate years, where people accepted me uninhibitedly. Since the people in my life had demonstrated their acceptance of me as an openly-gay person, I figured they could accept me as an openly-HIV-positive person. Thus, I knew I would tell others about my diagnosis; I just didn't know how or when.

Ironically, fifteen minutes later, I had an impromptu conversation with the president of the school's Gay, Lesbian, Bisexual and



photos by Russell McGonagle

Transgender (GLBT) student organization, the Triangle Coalition (Tri-Co). I decided to come out as positive to Tri-Co in the hopes that they would realize that, despite our tendency to think otherwise, HIV is a real facet of our lives. A few days later, the editor of the school newspaper, recognizing me as an AIDS advocate in the campus community, requested a quote for a story she was writing on college students' attitudes towards HIV/AIDS. I informed her that I'd tested positive a few days before. After embracing me, my editor friend stepped back, then asked if she could make me the focal point of her story. I said yes.

Consequently, nine days after my diagnosis, the university community picked up the school newspaper expecting to peruse coverage of that weekend's football game. (This was, after all, Homecoming weekend at

a Big 12 school.) Instead, the cover story was an in-depth explication of my HIV diagnosis. During the following weeks and months, I discussed HIV/AIDS issues with numerous classes and student organizations. To my surprise, countless strangers stopped to thank me for my frankness. In addition, several students informed me that reading the story had inspired them to get tested.

That's my part of the story.

Billy, Danny and Chris. Differences? First, the admittedly biased way I told the

story. You may have also guessed it by now, but just in case you haven't, you should know that the three of us attended the same university at the same time. The most striking difference to me is that two of them are dead and one is alive. Interestingly, the one who is alive is the one who, it could be argued, took the most palatable strides in speaking about HIV, the one who readily wore

the scarlet letter "A." But that doesn't make him the hero of the three.

AIDS ADVOCACY ON COLLEGE CAMPUSES

People have asked me: *Why did you do it? Why would you choose to reveal the intimate details of your health status to the university community?* In retrospect, receiving a positive diagnosis was a surprise for me. I hadn't been that shocked since 1980 when I learned Darth Vader was Luke Skywalker's father. But in addition to the surprise, I

viewed my diagnosis as a prime opportunity to:

Confront the apathy. On my campus, efforts at HIV prevention and education were largely overlooked. People simply did not want to contemplate the issues. One of the primary reasons for my openness was the desire for people to consider the ramifications of their lackluster attitudes towards HIV/AIDS. I knew I could do this by putting the proverbial face on the disease.

Break the silence. No one talked about it. For instance, when Billy Vance died, nothing was done; not in the immediate sense anyway. I remember walking through the English Department, hearing people discuss their upcoming comprehensive exams and the like. Not a word about the fact that one of our own had died. I'll never understand how those individuals could treat Death so cavalierly.

Counter the ignorance. It amazed me, as I undertook my speaking tour, how many students didn't know how HIV is contracted and spread; how many of them viewed AIDS as a "gay disease," and this almost three decades into the pandemic. Speaking out provided me the opportunity to correct the misinformation and prejudice, and, as previously stated, it galvanized some students to seek testing.

TOP 10 THINGS YOU CAN DO TO FIGHT HIV/AIDS AT YOUR COLLEGE OR UNIVERSITY

10. Get tested. Everyone has an HIV status. You should know yours. How can you be comfortable not knowing?

9. Integrate HIV/AIDS issues into your classes. Write about it in English. In your Sociology and Women's Studies classes, discuss why women are disproportionately infected. Bring it up. Yell out "*WHEN ARE WE GONNA TALK ABOUT AIDS?!*", sit back down and see what happens. (And please, drop me a line and let me know.)

8. Students should get tested. According to the Centers for Disease Control and Prevention, college-aged adults have one of the most prevalent instances of HIV infection in the US.

7. Beware of AIDS propaganda. How many times have you attended a "red ribbon" event where an HIV-positive person materializes as the talking head, then disappears, never to be heard from again.

6. Get tested. Make sure your school provides venues for students, faculty and

3. Protect yourself. HIV/AIDS is preventable. You don't want it.

2. Get tested. It's free.

1. Move beyond the "red ribbon mentality." It's become a ritual for colleges and universities to present HIV/AIDS programs to commemorate World AIDS Day. At these programs, the audience proudly dons the ubiquitous red ribbons in a show of solidarity. Then, when the program concludes, they promptly discard them. This blasé, here today, gone tomorrow attitude is indicative of the "red ribbon mentality." Might I suggest you do the unexpected by moving beyond this mentality. Coordinate a program that does not coincide with World AIDS Day or rely on disposable symbols to convey empathy. Realize that people living with HIV/AIDS live with the disease 365 days a year. Develop programs and curriculum to reflect this. By doing so, you may find that beyond the red ribbon lies the true call to activism.



I'm considering returning to school next fall. In doing so, I

inevitably think of the trinity Billy, Danny and I created. Moreover, I can't help thinking we weren't the only ones; that at a university with a student population numbering over 20,000, there would *have* to have been more than three HIV-infected people. I'll never know who the others were, nor is there any particular reason why I should.

But I knew Billy and Danny. They weren't just faces in the crowd. Danny once sat in my living room watching music videos. For four months, I passed Billy in the hallways of the English Department. He died on my 23rd birthday. Because of this inextricable link I feel to Billy and Danny, they remain in my thoughts. For me, this story never ends. ☚

** Billy and Danny's names have been changed.*

Chris Bell receives email at tooferbell@yahoo.com.

staff to get tested. Not only that, work to break the mold of HIV testing. For instance, I went back to my school a few months ago to visit friends. While there, I learned that students are not obligated to go to the health center for testing. They can be tested in their residence halls and fraternity and sorority houses as well. In addition, the school's Black Culture Center, Women's Center and GLBT Resource Center have teamed up to offer monthly testing. During the month I visited, the Women's Center had run out of tests, providing sixty in one day.

5. Volunteer at the ASO of your choice. AIDS service organizations are always on the lookout for good volunteers. Spend some time at one and bring the knowledge back to your school via a program or training.

4. Get tested. It's easy.

The Young and the Restless

by Charles E. Clifton

We are all familiar with the numbers, but they need repeating every so often.

According to the Centers for Disease Control and Prevention, approximately 40,000 new HIV infections occur each year in the United States, about a 70% rate among men and 30% rate among women.

Of all these newly infected people, half are younger than 25 years of age. *Half.*

The HIV epidemic has taken a dangerous upturn among teens and young adults from coast to coast. In New York City, the highest rates of infection seem to occur among young, gay African American men, between 15 and 22 years of age, according to new health department data. The HIV seroprevalence among the 541 men who have sex with men (MSM) surveyed was 12.1%, the researchers determined. Visiting gay bars, video clubs, dance clubs and other well-known social centers of the gay community between December 1997 and September 1998, the researchers offered participants HIV testing, counseling and treatment (if necessary). They found that HIV seroprevalence among African-Americans was 18.4%, among men of mixed race it was 16.7%, among Latinos it was 8.8% and among whites, 3.1%. Nearly half (46.1%) of the men reported engaging in unprotected anal sex during the previous six months and 16.3% reported ever having had a sexually transmitted disease (STD).

In 1999, Houston Mayor Lee Brown declared an AIDS state of emergency after more than 2,500 new HIV cases were reported. Sixty-one percent of those cases were among African Americans, and 78 percent of

the cases among 13-19 year olds were in African American females.

These rates of infection among young people are staggering. Again we find ourselves at risk of losing yet another generation of leaders to AIDS. What are we doing wrong?

Since an amendment to the Welfare Reform Act of 1996 increased federal fund-

vaginal intercourse and abstinence is nothing more than holding hands is a discourse leading to disaster. Organizations and programs should be encouraged to and funded for providing a safe environment where teens and young adults can openly communicate about a whole range of sexual behaviors and issues.

In the Detroit neighborhood of Chene, at Neighborhood Service Organization, the Keepin' It Real program targets African American youth, ages 12-19, at high risk for HIV/AIDS/STDs. With these kids, the peer educators discuss a gambit of health related and social issues—from HIV/AIDS, sexually transmitted diseases, substance abuse and alcoholism, to developing positive relationships, communication and negotiation skills, and self respect.

The program activities include one-on-one risk reduction education, street outreach, workshops, and support groups.

The topics discussed are “a great tool when it comes to the youth, [who are] dealing with issues that other programs don't necessarily want to talk about.” Peer education group leader Dimetrez Griffin continues, “peer education is not a job where you just come to work for the money, you have to really want to be a part of the community” to effectively connect with the kids.

The goals of Keepin' It Real are twofold: first, to increase knowledge and education of HIV/AIDS/STD and substance abuse prevention in African American teenagers; and secondly, to increase social networks to enable and reinforce health enhancing behavior change through peer support. “It's still very difficult to get [our message] into the public school system,” in Detroit, says program coordinator Janice Cross. To get around road-

“The first time I ran away I was 13 years old, because my stepfather had beaten me. I left for good when I was fifteen...a friend dropped me at the [Chicago] Cook County emergency room one night because he thought I was dying...that's when I found out I had the HIV...that was about three years ago.”

—22 year old Matthew

ing for promoting chastity, the number of groups that are encouraging abstinence until marriage to combat the growing number of HIV/STD infections has grown. The new act also prohibits funded programs from promoting the use of condoms or contraception. But, are abstinence-based programs effective at curbing HIV/STD infections?

Statistics indicate that a growing number of teenagers and young adults, many of who declare themselves “virgins,” are engaging in oral and anal sex. A belief that anal and oral sex “is not really sex” and “a form of abstinence” and birth control is actually placing youth at risk for sexually transmitted diseases, which can be contracted through these acts.

These results indicate that parents and program developers need to take a broader view of sexual activity when talking about sex with young people. The view that sex is



blocks, outreach workers go to where the kids need the interventions most, outside of schools—on the streets, at clinics, community health fairs, and after school programs, or a counselor might call for a speaker to address a group that needs HIV and health education.

“We recognize the fact that a lot of times kids are listening to other kids...rather than adults. We train our peers [kids],” said Katherine Howard, an outreach worker at NSO. “We make sure that they have the correct information ... and have them deliver it in a language that’s common among their peers.”

Keepin’ It Real, is currently funded by the Substance Abuse and Mental Health Services Administration (SAMSHA); a demonstration grant providing first time joint substance abuse and HIV funding, under an initiative of the Congressional Black Caucus.

What makes the program successful is a commitment to peer-to-peer education, self-empowerment, and the dedication of the outreach staff. “We develop a rapport with the kids, we are there, they know us, they see us, and have this open atmosphere, so we’re able to interact with them...and give them information...We’re not there standing up like we’re teachers...we sit down and talk with them on a consistent basis and they know us and know about us,” Keyona Marsh, a nine-year HIV/AIDS advocate.

The reality is, however, that more youth than not across the U.S. are struggling with sex, sexuality and substance use without a peer support network. Case in point is Jason Karella.

Karella was 10-years-old when he figured out he was gay. At 17 he told his mother. She told him to get out. Jason struck out for San Francisco, in search of a gay com-

munity. Karella, now 24, an HIV positive drug user living in a shelter, is just one of many street kids who run to San Francisco every year in search of the elusive “gay community,” but instead discover homelessness and AIDS. In a CNN report, Karella said, “I ran to San Francisco because people told me this was the gay mecca. I came under false

“I’ve been on and off the streets since I was 16...I was living with a mate and the drugs just became a way of life...they make me forget...”
—19-year-old HIV positive female

pretenses. People said they would help me, and they didn’t.”

Homelessness is a major risk factor observed in many youth living with HIV. The National Gay and Lesbian Task Force estimates that 26% of gay teens are forced from their homes because of conflicts surrounding their sexual orientation. Most kids who find themselves in situations like Karella’s at one point or another try to go home. However, after short-lived reconciliation with families fail, many teens end up hustling to survive on the streets. Once on the streets, they are subjected to physical violence (including rape), drug and alcohol abuse, and prostitution in exchange for food, clothing and shelter.

Forty percent of homeless youth accessing the Larkin Street Youth Center’s LARK-Inn in San Francisco identify as gay, lesbian or transgender, and approximately 10 percent are HIV positive, mostly from drug use. The Larkin shelter serves about 3,000 street kids a year.

Located in the North Side Lakeview “Boystown” neighborhood of Chicago, Teen

Living Programs (TLP) has offered several programs, including housing, counseling and job assistance, to Chicago’s homeless and abused young people for more than 20 years. Since 1999, TLP has provided services to over 7,000 street kids through its outreach, counseling, shelter, independent living, education assistance and prevention programs and a 24-hour hotline (773-883-0025).

Lyndon Stallings and Angela Burnett are TLP’s two outreach workers. They work long hours in Lakeview and Uptown, hitting streets, stores, games room, hospitals and parks—“where street kids hang out”—to find out what’s

going on and to give young people information about how to be safe, find shelter and other assistance.

In the South Side neighborhood Grand Boulevard “it’s totally different,” says Stallings. “The kids bounce from house to house...so there’s usually somewhere for them to lay their heads [a friend’s house]. But on the North Side it’s different...you know the kids who are homeless...standing around, shaking a can, begging for money and sleeping on doorsteps.” When homeless youth are encountered on the streets, TLP is prepared to offer peer-led education and prevention counseling, anonymous HIV testing and treatment referrals.

Burnett and Stalling also coordinate “Beat the Heat” (summer) and “Kill the Chill” (winter). Burnett says that these two programs “allow the street kids [an opportunity] to eat, take showers, get clothing and referrals, and go into housing if they want.” The hope is that by getting a youth off the street, if only for a couple of hours, it will provide a chance for conversation, a few referrals, and build a layer of trust with the



NAMES Project Chicago has created a Youth Council designed to give youth the opportunity to create, develop and implement innovative programs promoting HIV/AIDS education and awareness using the AIDS Memorial Quilt (the Quilt).

Created in 1987 by Cleve Jones, the Quilt is a monument that memorializes people who have died from AIDS through three-foot by six-foot quilted cloth panels. Presently, the entire Quilt contains over 50,000 individual panels representing over 85,000 names.

Membership in the Youth Council is open to all City of Chicago and suburban youth between the ages of 16 and 21. All interested youth and groups should contact Jeff Allen, Program Manager, NAMES Project Chicago, for additional application requirements and materials, at 773-472-1600 or email Chgoquilt@aol.com

hope of eventually getting them off the streets permanently.

While important parts of an HIV prevention and treatment system for youth are available in some areas a great deal still needs to be done. Sandra Thurman, director of the Office of National AIDS Policy, released the "Youth and HIV/AIDS 2000: A New American Agenda" during the United States Conference on AIDS, held in Atlanta last October. This

report highlights the growing HIV epidemic in youth and the difficulty in providing appropriate services to young people. The reality of the situation is that far too many gay, lesbian, bisexual and transgender teens are living with HIV on the streets of America.

Listen up. Peer-to-peer HIV education and prevention programs work. ☑

Photos by John Auterman

HOTLINES:

Gay and Lesbian National Hotline: 1-888-THE-GLNH (tollfree)
 National Crisis Hotline: 24 hours, 1-800-999-9999
 National Runaway Switchboard: 1-800-621-4000
 National Domestic Violence Hotline: 24 hours, 1-800-799-SAFE
 RAINN (Rape, Abuse and Incest National Network): 24 hours, 1-800-656-HOPE
 Teens TAP National Prevention Hotline: 1-800-234-TEEN
 24 Hour National HIV/AIDS and STD Hotline: 1-800-342-2437

WEBSITES:

Sexual health for teens and young people

www.iwannaknow.org
 Get answers to questions about teen sexual health and HIV/STD prevention

www.advocatesforyouth.org
 creating programs and promoting policies that help young people make informed and responsible decisions about their sexual health

www.goaskalice.columbia.edu
 provides straight-forward and nonjudgmental information to assist teens in making informed decisions about their physical, sexual, emotional, and spiritual health

www.sxetc.org
 a cyberspace where teens can get accurate and up-front information about their sexuality

For young women and teens

www.ohsu.edu/women/teen
 a health site for a young woman's questions on physical, mental and sexual related health issues

www.chickclick.com
 has both information and discussions on everything from cloning to Xena to how to meet friends on the Internet

For gay and lesbian issues

www.youth-guard.org
 provides internet services and resources for gay, lesbian, bisexual, transgendered, questioning and supportive youth

www.outproud.org
 offers a wide range of resources, sponsored by the National Coalition for Gay, Lesbian, Bisexual and Transgender Youth

www.positive.org
 The Coalition for Positive Sexuality is a grassroots, not-for-profit, activist organization providing teens with candid sex education materials

For Parents

www.notmenotnow.org
 promotes abstinence among teens, also offers adults information on how to communicate with teens about sex and sexual health issues

www.teenpregnancy.org
 provides resources and links to parents and educators in efforts to reduce rates of teenage pregnancy, also available in Spanish

www.positiveorg/DiQueSi/index.html
 candid sex education materials in Spanish, provided by the Coalition for Positive Sexuality



Due to the usual limitations inherent in researching a population as “invisible” as injection-drug users (IDUs), the number of injectors under age 25 is hard to determine. However, it’s common knowledge among adolescent health workers and those operating syringe exchanges in large American cities that use of injection drugs among youth is high and rising. Rapidly increasing rates of injection-drug use have been found among homeless and transient youth—some studies indicate that IDU rates in these populations are close to 50%. But many young adult injectors also hold jobs and maintain regular living situations even while using drugs, and many school-age youth inject drugs, hormones, or steroids while living at home. Young injectors also live in rural or suburban areas that are not targeted for research. These young

Bigg estimates that there may be around 6,000 young injectors utilizing CRA services in Chicago and the surrounding suburbs, “based on 10% of those we see, and an estimated 60,000 injectors in the area.” He notes also that most of the young injectors he sees initially come from the suburban areas surrounding the city of Chicago, and that the younger injection crowd “is much whiter” than the over-24 IDUs who use CRA’s harm-reduction services.

JAE’S STORY

“It’s a part of my history that I’m trying to deal with but haven’t quite figured out or come to terms with.”

27-year-old Jae* began injecting drugs in 1990 at the age of 17, while working as a political activist in Seattle. In 1993, she left

experience everything I could and this was a chance I couldn’t pass up.

“So, of course, blah blah blah, flash three years ahead to me, totally strung out on heroin, having done (many times) each and

One in 62: Young Injectors

by Laura Jones

people will not be counted in research focusing on “street injectors,” even though their numbers may also be high.

YOUTH INJECTION

Dan Bigg doesn’t need numbers to “prove” more and more youth are injecting drugs—he sees them regularly through his work with the Chicago Recovery Alliance, an organization providing legal syringe exchange and other harm-reduction services to IDUs in the Chicago metro area. Bigg notes that the number of young injectors taking advantage of CRA’s services “has increased steadily over the last nine years.”

“Over the years, working with young injectors to reduce risk has been a progressively larger part of our work,” states Bigg. “Most of all the under-24 injectors are white, and around half female.” While some young injectors also shoot cocaine, speed and other substances, heroin is still the most commonly injected substance in this age group.

Seattle and returned to the East Coast, where she stopped using injection drugs. She is now a graduate student, married, and the mother of a preschool-aged child. “I haven’t used needles since I left, in 1993. I nursed my daughter for longer than I shot heroin. I still have scars on my arms, however, from shooting up many times a day.”

While Jae doesn’t fit the profile most people associate with injection-drug users, her story would come as no surprise to those knowledgeable of youth injection trends throughout the United States.

“I come from a middle-class background, with educated parents. I went to good public schools, management programs, was a National Merit Scholar in 10th grade—then I dropped out of school to travel around the country with a Greenpeace job. I ended up in Seattle, and soon had a new roommate, a guy in his mid-twenties who urged me to try shooting cocaine. After a week of deliberation, I decided it was my mission in life to

every thing I had sworn I would never stoop to, 20 pounds too skinny, with everything I owned in my backpack.”

During her time as an injection-drug user in Seattle, Jae’s injection peer group consisted of “mostly white twenty-somethings, about 2/3 male, a few older black and Latino men, and some mid-teenage street kids. Most of the people I hung out with were involved in some way in...the intellectual hippie/punk scene.”

Also contrary to popular opinion, Jae and her peers were not primarily “initiated” into injection-drug use by older, hardcore injectors. “Most of the people I knew sought it out for themselves...I think most often someone would hint at their own needle use and the people who were interested in that would follow through by pursuing that person...the boyfriend/girlfriend element, when it occurred, really increased the pressure.”

She adds “the young people I hung out with were really into exchanging needles—not the case with the older folk—but not safe sex.”

In addition to an age-specific enthusiasm for needle exchanges, Jae also noticed a generational difference in comfort level with injection, as well as specific youth-culture and gender issues that contributed to her injection use. “The older people I knew who did dope were either out-and-out junkies or dead set against needles—mostly against,” she states. “The young people I knew, even those who didn’t use weren’t too freaked out by needles. They looked at it as a clinical, exact way to get really high. We definitely romanticized [poet William S.] Burroughs and all the dead rock stars and the whole nihilistic fuck-everything junkie image. Also, shooting up was as *bad* as you could get...so, especially for the teenagers, there was that *badness* appeal....And for me, as a young woman, I liked showing how tough I was, I mean, I wasn’t scared of *anything*.”

Jae has repeatedly tested negative for both HIV and hepatitis C, and considers her access to syringe exchange services the main reason she was able to avoid infection. “At first I would never have shared needles—being an educated person, I knew how dangerous it was. Later, by the time I was 19 or so, I cared so little about my life that I’m sure I would have used dirty needles if the needle exchanges had not been so available and convenient. As it was, I had new needles every week, always had plenty of bleach, and never had to use a dirty needle.”

THE IMPORTANCE OF NEEDLE EXCHANGE

The Centers for Disease Control estimate that the percentage of cumulative AIDS cases directly attributable to IDU in youth under age 25 are around 9% for males 13-19, 14% for males 20-24, 20% for females 13-19, and 31% for females 20-24. The percentage of cumulative reported cases of HIV infection directly attributable to IDU in that age group is 5% for males 13-19, 6% for males 20-24, 7% for females 13-19, and 12% for females 20-24.

These figures do not take into account young people infected through sexual contact with an HIV positive injector, nor can they predict the number of HIV positive youth who are infected but either have no access to HIV testing or choose not to test.

Research during the 1990’s yielded a great deal of data showing that syringe exchange programs can dramatically reduce the rates of new HIV and hep C infection in IDUs, and younger injectors in particular appear anxious to take advantage of available exchange programs. Organizations such as the American Medical Association, American Academy of Pediatrics, and the World Health Association all support making such programs available throughout the United States. But so far, federal policy has not been enacted to establish such programs. Currently, syringe exchange programs in the United States receive funding from their state, city or county governments, as well as donations from private organizations and individuals, and only under the heading of research. All programs are subject to the restrictions their state places on programs providing syringes and other “paraphernalia” for the purpose of injecting drugs

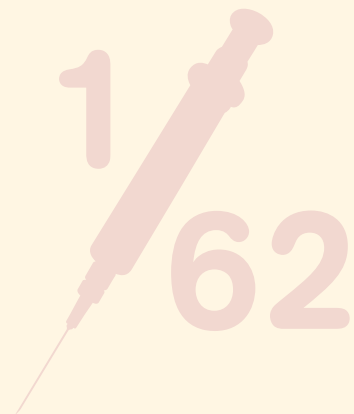
Dan Bigg sees a link between the perceived IDU population and the slow turn-about in establishing a nationwide policy of syringe exchange, and wonders if the increasing visibility of young injectors will have an effect on national syringe-exchange policy. “There are many effective ways to reduce the harm from heroin injection which have been slow to be adopted to date—seemingly because of the race and class of the majority of users. As heroin use is increasingly seen as a more white and suburban kid kinda problem it may be society will be willing to take

effective action to reduce sickness and death associated with heroin use.”

Jae doesn’t care what provokes the change. Like many who have clearly benefited from syringe exchange and other harm-reduction services, she is outspoken about the need for such programs.

“I’ve been incensed by the local movements against needle exchange—how can you be against something that saves lives? And I feel compelled to share my story if there’s a chance I can help people. I mean, there are bad junkies, and pretty much all junkies do creepy things, but a lot of them are also smart and funny and kind and utterly human.” ☒

* Jae’s name has been changed.



WEBSITES:

Chicago Recovery Alliance (Chicago metro area) (773) 471-0999

<http://www.anypositivechange.org>

Narcotics Anonymous IL: (708) 848-4884

National: (818) 773-9999

<http://www.na.org>

The Night Ministry (outreach and services to street people)

(773) 935-8300

<http://www.thenightministry.org>

Outside In (services and harm-reduction for street youth in Portland, OR—additional West Coast information)

(503) 223-4121

<http://www.outsidein.org>

CAPS Publication: Needle Exchange Report

<http://www.caps.ucsf.edu/capsweb/publications/needlereport.html>

LIFE, YOUR CHOICE

TUNE-IN FOR

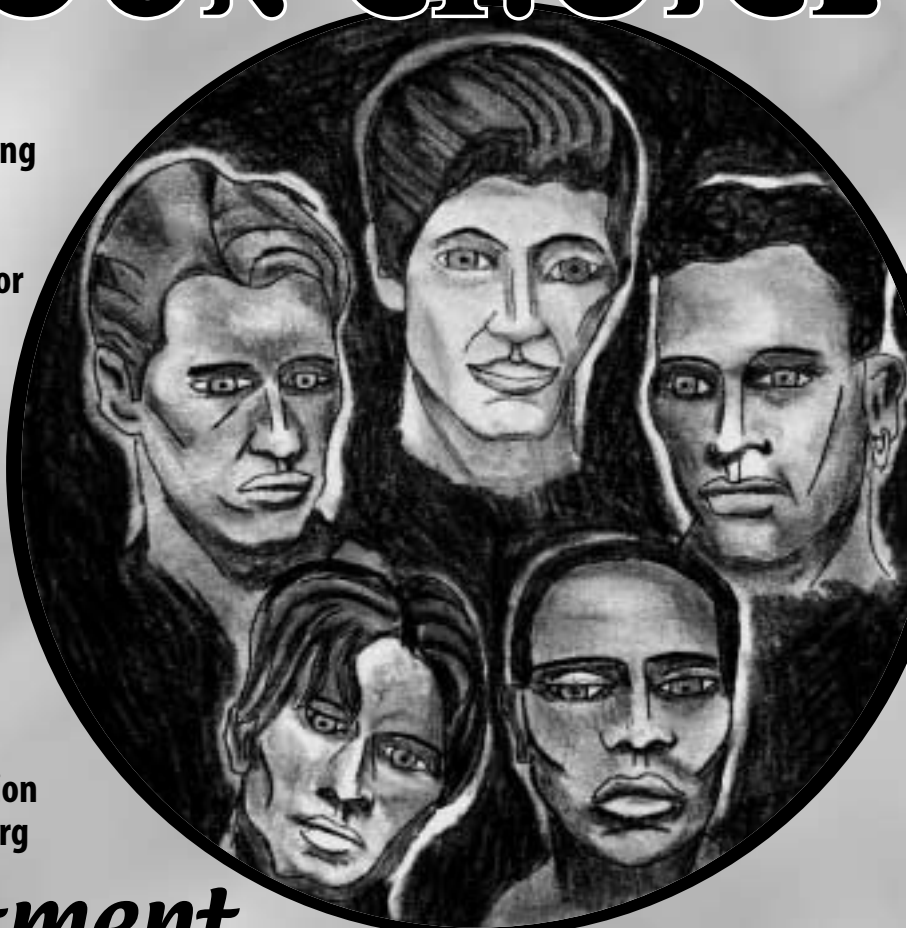
Strategic HIV Drug Sequencing
AND
Structured HIV Therapy
Interruptions: Pipe Dream or
New Treatment Reality

Beginning
March 17, 2001

ON:



For local broadcast information
Visit www.awaretalkradio.org



HIV Treatment,
It's always Your Choice!

GET THE FACTS

- ★ For a FREE cassette of *HIV Treatment Strategies: What Are Your Options?*,
- ★ A FREE *National HIV/AIDS Resource Guide*,
- ★ A FREE *MAKING CHOICES Brochure about HIV Therapy*,

CALL AWARE TALK RADIO AT

312-541-8255

or visit **WWW.AWARETALKRADIO.ORG**

THIS MESSAGE IS SUPPORTED BY AN UNRESTRICTED EDUCATIONAL GRANT FROM AGOURON PHARMACEUTICALS

Here, Kitty Kitty

Why pets are good for you

by Enid Vázquez



photo by Russell McGonagle



One week before he died, AIDS activist and writer Stephen Gendin left very detailed instructions about the care of his beloved little dog, Zoom.

What is this strong bond that so many people feel for their pets—a passion even? Animal lovers say that everyone gets sick and tired of you at some point or another, but pets give you absolute, unconditional love.

But can they also make you healthy? Chicago nurse Keren Hahn, the inspiration for this article, strongly believes that people with HIV should have a pet. “I’ll tell folks, ‘Oh, my God, your T-cells went up really high.’ And they’ll say, ‘Oh, I got a new dog!’ Or, ‘I’m in love.’ Somebody needs to do a study,” she says. (Maybe later we’ll look at falling in love.)

Before, when serious disease was much more common in people with HIV, people with AIDS were often told—incorrectly—to get rid of their pets for the sake of their health. Today, that still happens too often.

The most knowledgeable sources counter the ignorance. From the top of a Centers for Disease Control webpage for people with HIV, are these words: “You do not have to give up your pet.” The CDC goes on to say, “Most people with HIV can and should keep their pets. Owning a pet can be rewarding.

Pets can help you feel psychologically and even physically better.

Ken Gorczyca, a veterinarian and co-founder of PAWS (Pets Are Wonderful Support), a non-profit organization for pet owners with HIV, has written that, “For the severely ill patient, animal companions can offer an important source of pleasure, affection, and even a reason to live. In a study of patients with cardiac disease, pet ownership made a significant difference in survival regardless of the severity of the cardiac disease or the type of pet. For elderly patients and patients with disabilities, animal-assisted therapy has affected physiological and psychological improvement. Studies indicate watching fish in an aquarium or petting a dog can lower blood pressure, even among healthy individuals.”

“A lot of my clients will say their pet is the reason they’re alive,” says Ilana Strubel, who like Gorczyca, is a volunteer veterinarian with PAWS in San Francisco. “A lot of people say, ‘If it weren’t for my pet, I would have no reason to live.’ The benefits of pet companionship far outweigh any risk to your health. The human-animal bond motivates people to take care of themselves. One study found that people with HIV who have pets

were better at taking their medications and following their doctor’s advice.”

Strubel said the health benefits of pets, or animal companions, has been well-established over the past 10 years, including benefits to the immune system, and that much more research is underway to tease out the hard numbers.

For example, research from the Multicenter AIDS Cohort Study (MACS) has found that people with HIV were less likely to suffer from depression if they’re pet owners, especially if they did not have a lot of human support.

SAMMA, WOLF AND SAMANTHA

Test Positive Aware Network Executive Director Dennis Hartke is one of the healthiest people I know living with HIV. That’s probably part genetics. But Dennis says he doesn’t know how he would have gotten through the death of his partner Jimm from AIDS more than 15 years ago had it not been for their two dogs and their black cat. Very few people knew that they were partners in life or that they had the AIDS virus. In the midst of this severe isolation, it was Samma, a German Shepard mix, Wolf, a Golden Retriever, and Samantha the cat—all rescued animals—that continued to bring warmth to his life after Jimm died.

"I did not have a support network in place," says Dennis. "Pet owners love to talk to their animals. Sometimes they listen well. And even when they don't, they pretend." He says the companionship and continued routine of having to take care of their three pets helped him stay strong. "It was some place to focus my loss and my need for attention.

"I really do believe in the research that shows petting a dog lowers your blood pressure. Pets are very relaxing, except when they're doing things they shouldn't be doing," he jokes. "It's really that unconditional love that's been bought over the years with food. And even when you don't feed them, they still pay attention to you—maybe

that's why." Be that as it may, Samma, Wolf and Samantha were important enough to attend Jimm's memorial service and funeral. "They were like family," says Dennis.

REBEL

Jonathan Goldman's beloved Yorky, Rebel, also attended his partner's funeral. "Pets are part of your family," Goldman echoes.

One researcher reported that during experiments comparing how women respond to pressure when in the presence of either their best friend or their dog, dogs were better every time. Five widows had exactly the same stories to tell about how

their pets helped them get through the death of their husbands. The researcher, Karen Allen, Ph.D., was amazed at the identical circumstances. Each woman said she appreciated the consolation of friends and family, but most wanted to be alone with her dog. Each one thought about their pet and carried something that belonged to it close to them in a pocket (such as a dog toy or collar) during the funeral service where the dog could not be brought.

Allen wrote about this finding: "The feeling was that, with the dog, no social pretenses were necessary, and no one was judging her ability to 'bear up.' These women all said that the dog provided the desirable qual-



PET TIPS

- While there are a number of diseases that can be caught from animals, cases of people with HIV/AIDS who have contracted infections from their pets are rare.
- Remember that some cats can be very affectionate.
- Puppies and kittens (less than nine months old) should be avoided because they have a tendency to harbor more infections. Also, puppies may be too much work for someone with advanced disease. Plus, with older animals, you can see whether their size and temperament agree with you.
- Most birds pose a minimal risk for transmitting disease.
- PAWS recommends that people at risk do not keep or handle reptiles.
- Although caution should be exercised when changing cat litter boxes, people with HIV disease are more likely to be exposed to toxoplasmosis from ingesting undercooked meat or through contact with oocyst (egg)-contaminated soil than from contact with litter boxes. In fact, HIV positive people contract infections more often from contaminated food, water, soil, or even other people than from pets.
- Precautions apply for children as well as adults. However, children may want to snuggle more with their pets. Some pets, like cats, may bite or scratch to get away from children. Adults should be extra watchful and supervise an HIV positive child's handwashing to prevent infections.
- San Francisco has a certification process for people with disabilities whereby pets can be considered "animal companions." As such, they are akin to seeing eye dogs and must be allowed in housing otherwise off-limits to pets. They can also be taken

along on public transportation, among other privileges. Check your local laws if this idea interests you.

- Volunteers at the Pet Loss Hotline help you grieve for your pets. Call 1-509-335-5704 or e-mail plhl@vetmed.wsu.edu. Due to lack of funding, phone calls are returned collect. Hours are generally during the school semester on Mondays through Thursdays from 6:30 to 9 p.m., and Saturdays from 1 to 3 p.m., Pacific Time.

PET SAFETY

- Feed your pet a commercial diet that is designed for your animal and his or her stage of life.
- Don't feed your pet raw or undercooked meats or unpasteurized milk. Keep in mind that microwaving may not heat the meat sufficiently to kill organisms in it.
- Never let your pet eat their own or another animal's feces. Do not allow birds to fly freely, in order to avoid droppings.
- Provide plenty of clean, fresh water. Don't let your pet drink from the toilet or root through the garbage.
- Prevent your pet from hunting or eating other animals.
- Have all new animals examined by a veterinarian.
- Take your pets to the veterinarian for a check up at least once each year and keep vaccinations current.
- Have your pet's feces checked by a veterinarian periodically for parasites. Have your cat (particularly a new cat or an outdoor cat) checked for the Feline Leukemia Virus (FeLV) and Feline

ities of a best friend (for example, listening, physical contact, and empathy) without any undesirable evaluative ones.... Perhaps certain situations call for specific types of social support, and pets provide a unique type that cannot be duplicated by a person.”

Goldman and his partner Roger had gotten Rebel when Roger was bedridden due to AIDS, in 1990. He died later that year. “Just having a dog alongside next to you when you’re napping is very comforting,” says Goldman, a volunteer with PAWS in San Francisco. Today Rebel, now 12-years-old, comforts Goldman when he becomes ill from one HIV problem or another. And he encourages him to get out of the house for walks.

Rebel, who’s only six-and-a-half pounds, has marched with Goldman in San Francisco’s gay pride parade for the past 11 years under the PAWS banner. He’s the “official” pet of the National AIDS Update Conference held by AmfAR (American Foundation for AIDS Research) each year in San Francisco. He’s there to be petted and adored, and of course, help the conference goers feel better.

As a PAWS volunteer, Goldman has many pet stories to tell. He remembers one man with non-Hodgkin’s lymphoma whose doctor encouraged him to give up his two birds. He gave them up, then died six months later. “He was heartbroken the entire six

months,” Goldman says. Another man who had had his cat for 18 years at the time of the cat’s death was thinking of looking for a boyfriend to keep him occupied, until a friend asked how many of his boyfriends lasted for 18 years. He went out and got *two* cats.

“In my mind the epidemic really is an equal component between physical health and mental health. Now that it’s more of a chronic illness, we need a shift to dealing with mental well-being, of which pets are a part,” says Goldman. “Mental health pushes the physical health. And I believe research will find some magical, mystical substance in dog saliva that we benefit from when they lick our face.” ☒



Immunodeficiency Virus (FIV). These cats are more susceptible to infections.

- Keep your animal’s toenails trimmed to minimize the risk of your being scratched. If necessary, ask your vet about rubber caps that can be placed on your cat’s nails.
- Use good flea control. A clean environment is important. Keep your pet’s living and feeding areas clean. Wash your pet’s bedding regularly.
- Stay away from animals that have diarrhea.
- Neuter pets to avoid roaming and discharges.
- Keep the litter box away from the kitchen and eating areas.
- Change the litter box daily. It takes the toxoplasma parasite at least 24 hours to become infectious. If possible, have someone do it who’s not at risk.
- Use disposable plastic liners and change them each time you change the litter.
- Don’t dump! If inhaled, the dust could possibly infect you. Gently seal the plastic liner with a twist tie and place in a plastic garbage bag for disposal. Use rubber gloves. Remove disposable gloves inside out to avoid spreading germs.
- Disinfect the litter box at least once a month by filling it with boiling water and letting it stand for five minutes. This will kill the toxoplasma organism.
- Always wash your hands after cleaning the litter box (soap up for at least 30 seconds, use warm water).

- Wear rubber gloves when cleaning an aquarium or when handling fish. Fish suspected of having *Mycobacterium* or any fish showing unusual lumps should be killed and the aquarium should be disinfected before new fish are introduced.
- Rinse a bite wound or scratch right away with plenty of cool running water. Wash the area with a mild soap or with a tamed iodine solution such as Betadine solution (not Betadine soap) that has been diluted with water. After this first aid, always contact your physician.
- Always wash your hands well with soap and water after playing with or caring for animals, or their care items, and especially before eating or smoking. In the event of an accident, clean up the mess with a disinfectant (an ounce of bleach in a quart of water works nicely to kill many infectious organisms), then wash your hands thoroughly. Better yet, wear gloves, or have someone not at risk clean it up.
- Don’t let your pet lick your mouth or a wound on your face or body. You never know where that tongue has been.

Taken primarily from *Safe Pet Guidelines* by Pets Are Wonderful Support and *HIV/AIDS & Pet Ownership* by Tuskegee University College of Veterinary Medicine. The suggested donation for each PAWS brochure is \$1, including the ones on different animals. Contact PAWS Education Department, 3248 16th Street, San Francisco, CA 94103; (415) 241-1460; e-mail: pawssf@dnai.com or visit www.pawssf.org. Also visit the website of the Gay & Lesbian Veterinary Medical Association, www.lgvma.org, which includes a link to the Healthy Pets, Healthy People website, established for immunocompromised people.

Pickett Fences

Day and night, night and day and night

by Jim Pickett

It is the day after my 35th birthday. It is five-and-one-half years since I tested positive for HIV.

It is nearly one year since I kicked my triple combo to the curb.

It is minutes after watching, for the first time, a video journal I collaborated on three years ago. My dear, darling friend William was working on his masters in Art Therapy at the time, and part of his thesis entailed creating a video journal of images and music supplied and inspired by three men living

me into anaphylactic shock, turned purple. Sick as Old Yeller. Pills, pills, everywhere pills. My relationship was in tatters, and my sex life consisted of jacking off to *Machismo* and the entire family of *Inches* magazines. And not that I understood this then, but I was compensating for the lack of control in my life by cleaning my apartment constantly. I was forever sweeping and wiping, polishing, straightening, and tidying up behind myself and anyone else who displaced a dust particle. When I wasn't streamlining the house-

I laughed. It was actually funny. God, I was a weirdo.

Then comes Orlando. The music is a hypnotic, instrumental jazz piece, kind of Pink Panther-ish. And much of the focus is on him getting around his apartment, and elsewhere, in a wheelchair. He's 35. He has some loss of capability in one of his arms and hands. He has long fingernails. I wonder if he is able to cut them himself, or if he wants them like that. The segment is quiet, sad and oddly soothing at the same time.



with HIV/AIDS. I was one of those men, a 32-year-old Caucasian homosexual, in addition to "Orlando," a 35-year-old Latino heterosexual, and "Archie," an African American bisexual male, 36-years-old. William brought me a copy of the video just a couple days ago.

The journal opens with my segment. I felt very uncomfortable seeing this at first, being whisked back to a more neurotic me, rather depressed, and sort of obsessive/compulsive. I had just started on a triple combination at the time, so many pills, and had been recently released from the hospital after pulling a Code Blue—some allergy shots sent

hold, running to doctor and clinical trial appointments, or working, I was smoking a lot of medicinal pot and spraying Windex. A lot. The video captures images that recall all this, lots of pills and one-hits and hits on the asthma inhaler, supermodel Linda Evangelista, *The Planet of the Apes*, sleazy bars, brooms, and more, set alternately to East Indian chanting, George Michael's "Freedom," and the song featuring the refrain "I think I'm going out of my head"—because I thought I was going crazy, see.

Viewing this three years later, cozied up in chaos and clutter, tripping over dustballs,

Then comes Archie. It's apparently cold outside as he's all bundled up, several layers and gloves, walking down a city street, a narrow alley. Similar to the other segments, you cannot see his face. He is careful and deliberate, using a cane to make his way, each step barely the length of one of his feet, and he sits, tired, on the edge of a bus bench, and his head hangs. The trees have no leaves, and there is an empty water bottle and other debris on the ground. He is 36, but I'd guess 80 from that slow shuffle, that cane. The music is a blues number, and a man is singing, "It's been too hard livin' but I'm

afraid to die. I don't know what's up there beyond the sky."

Archie died shortly after taping his images.

I watch Archie's segment over and over.

I had started out laughing at this video, like HIV is just a goofy sitcom episode starring a hapless Caucasian homosexual. Then, with Orlando, I became melancholy, and now, with Archie, I am crying. Sobbing. The blues'll do that. "It's been a long, long time coming, but I know a change is gonna come,

witty one-liners, a couple zingers and some real doozies, and it has allowed me to vent a lot of rage. But beneath the raucous laughter and the strident shrieking, I'm still grappling with what it's doing to me emotionally, with the enormous effort it takes to not let it flatten me, and with what it is bound to do to me physically. Sometime unknown.

I feel sorry for myself.

I am 35, and it is hard for me to think back to the time, the many times, before HIV

such great numbers. So I went on a drug holiday. My last regular lab work revealed a T-cell count in the 400's and a viral load around 40,000–60,000. Being that 350 in the T-cell department is the new magic number indicating the optimum time for treatment, I am resigned to starting back on meds in March. I will have gotten an entire year off, which I am grateful for. Yet, still, I feel sorry for myself. I really wish I didn't have to face a new drug regimen.



oh yes it will." I never met Archie, but I am crying for him. I am crying for a life that reduces a 36-year-old man to relying on a cane. I am crying for a life that is over too young. And I am crying for me.

Is this a window into my future? Where am I on the time line?

I feel overwhelmed by the enormity. I'm exhausted from the fight, and I haven't even gotten in the ring yet. For crying out loud! I've been sitting on the sidelines, watching it all go by with me in the third person, still merely an understudy for a secondary role, waiting and waiting. Meanwhile, HIV has provided me an opportunity to write a lot of

so rudely barged in. It's not that I can't remember, it's that it hurts. It still hurts.

I am 35, I have been infected going on six years now, and still, still I can't tell my mom, or the rest of my family. This thing that is public knowledge, this thing that strangers know intimate details of, I cannot bring myself to disclose to the people I have known the longest, people with whom I share the most history, people with whom I share blood. Oh, the agony of this irony.

I am 35, and one year ago my T-cells were over 1000 and my viral load was undetectable. I felt like hell most of the time, thanks to the handfuls of pills that gave me

Will I be able to ever take a break like that again? Will the Sustiva dreams be sweet or scary? Will I be nauseated and have diarrhea every day, like before? Will I feel compelled to start scrubbing the bathtub again? And when will it be my turn to step out from the wings and get sick... walk with a cane... die?

Will I always be a bridesmaid?

Will it ever stop hurting?

One thing I do know. I will always try to laugh. ☘

In memory of "Archie"

1962-1998

by Daniel S. Berger, M.D.

FASTER APPROVAL OF HIV DRUGS FOR PATIENTS WITH RESISTANCE

It is finally apparent to government policy makers that an increasing number of HIV positive people are in need of more options to combat resistance to available therapies. The U.S. Food and Drug Administration (FDA) recently held a meeting in Washington, D.C. to consider setting new guidelines for HIV drug development. The FDA heard testimony from HIV clinicians and research experts who addressed the growing need for treatments that would be helpful to those patients dealing with resistance to current HIV drugs. Often antiviral medications fail to suppress HIV replication, ultimately leading to rising viral loads. In other words, medications may no longer remain effective because of the virus' ability to change into mutant HIV strains resistant to the effect of the medication.

Combination therapy for HIV disease has saved countless lives, however, many more individuals with high levels of mutant virus have resistance to many common treatments. It is these individuals that are at greater risk for HIV progression and complications, and they are often excluded from research studies involving the new more effective therapies. In other words, patients that are in the most need of new treatment do not have access to them. In our practice, there is a growing number of people who are on their second, third, or fourth regimen. These are the individuals who most urgently need access to new drugs.

The FDA indicates a readiness to examine the possibility of allowing faster approval

of drugs that are potentially helpful to patients with fewer options. The agency is now considering approval of drugs that demonstrate antiviral effect through the use of shorter clinical trials. This would promote the quicker availability of drugs to patients, especially those who need drugs to stay alive.

By reducing the length of time of research trials, drugs can potentially become available to patients with the greatest need much sooner. However, at the meeting's conclusion it was still unclear whether the agency has made any decision in regards to this issue. There is uncertainty as to when a decision will actually be made regarding these potential changes in the approval process. But the AIDS Chief, Heidi Jolson, was quoted as saying a decision may be ready next year.

Dr. Heidi Jolson, the director of the Division of Antiviral Drug Products (FDA AIDS Chief) is leaving the FDA. She supports AIDS treatments for approval while appropriately evaluating safety issues. She also supports the various compassionate track pathways. We hope that a suitable individual is found to replace Dr. Jolson upon her departure and that the issue of promoting a faster approval process for HIV drugs to the sickest patients does not get delayed.

HIV VACCINE STUDY: CONFLICT WITH A PHARMACEUTICAL MANUFACTURER:

Does Remune Have Clinical Utility as a Treatment for HIV Positive Patients?

The prestigious *Journal of the American Medical Association (JAMA)* recently pub-

lished a controversial article regarding the results of a large-scale clinical trial using an HIV treatment vaccine called HIV-1 Immunogen (brand name Remune). The article described the results of a large multicenter study of 2,527 HIV positive participants. Patients with CD4 counts between 300 and 549 cells received either Remune or placebo (fake medicine). The idea for a treatment vaccine is to boost the immune system of HIV positive individuals by exposing them to viral antigens (HIV proteins). The body's own immune response against these proteins would hypothetically assist in one's control of HIV. The study was not a success and was terminated earlier than scheduled by the Data Safety Monitoring Board, an independent group that oversees clinical trials. According to the authors of the *JAMA* article, the results failed to demonstrate that the addition of the vaccine conferred any effect on HIV progression-free survival and was also associated with a lack of clinical improvement.

Moreover, the strategy for this mode of treatment is a controversial one. HIV infected patients already possess very high turnover of virus in the blood, which should be enough to stimulate an immune response against the virus. Administering more viral proteins in the form of a vaccine to the already present viral burden of an HIV positive person is not a proven way to fight HIV.

The results published in the *JAMA* article concluded with the lack of substantial effect of the vaccine and was followed with much drama and criticism of the authors by Remune's manufacturer, Immune Response

Corporation. The pharmaceutical company has filed a claim with the American Arbitration Association seeking millions of dollars in damages from the University of California at San Francisco, the affiliation of the lead author of the study. According to Dr. Ronald Moss, vice president of Medical and Scientific Affairs for Immune Response Corp., the purpose of the suit was to have a third party arbitrate and hopefully cause the *JAMA* authors to incorporate other data that would dispel the already negative view of the product. The University of California has filed a counter-claim against Immune Response, however.

Allegations were made by the manufacturing company that certain details and findings may have been excluded and may have been more positive to their product. These details included data from a subset of 250 randomly assigned patients who had virologic testing done every three months, as opposed to the every six months monitoring done for the more than 2,000 other patients under study. According to Immune Response, of this smaller subgroup of patients, there was some data indicating the presence of HIV specific immunity that was associated with greater decrease in viral load. However, the *JAMA* authors were not persuaded by Immune Response's arguments and felt the subset virologic data was not consistent with any significant changes. Additionally, many believe that in a large study of 2,500 people,

if the drug was indeed successful it would have been demonstrable in this large patient group.

Other company complaints were the unexpected presence of low HIV-related illnesses and the high rate of changing antiviral therapy occurring during the study, not planned for, nor were guidelines set in the study design, which Immune Response claims altered the results. However in a letter

Individuals that are at greater risk for HIV progression and complications, are often excluded from research studies involving the new more effective therapies

to me dated November 30, 2000, the *JAMA* authors clearly state they did not leave out any data that should have been published in this manuscript and eventually concluded that the treatment vaccine was ineffective; their objective in presenting the manuscript was to present an accurate assessment of the study. They were also concerned that "new patients were enrolling" in further studies with this agent and "were concerned that selective data improperly analyzed from the study was being sent to investigators to justify the ongoing or newly planned studies."

Other criticism came from some study investigators and clinicians who did much of

the work; the authors James Kahn, *et. al.*, failed to recognize these individuals in the manuscript (the authors claim that the company did not provide the names and the company says that isn't true). In addition, some of the investigators disagreed with the *JAMA* authors' conclusions and interpretation of the study. Consequently, a second manuscript submitted by other lead investigators in cooperation with Immune Response has been accepted for publication in an attempt to refute the present conclusions and offer an additional interpretation of the study. Current *JAMA* authors plan to also do further analysis of the data. There is much corporate and pharmaceutical money at stake here and so it appears that the controversy will be never ending.

Too often pharmaceutical companies exert much censorship on publication of research because of industry money concerns. There are strong feelings harbored by many physicians that medical research can often be compromised because of the "bottom line." ☒

Daniel S. Berger, M.D. is Medical Director for NorthStar Medical Center, Clinical Assistant Professor of Medicine at the University of Illinois at Chicago and editor of AIDS Infosource (www.aidsinfosource.com). He also serves as medical consultant and columnist for Positively Aware.

The Joys of Safer Sex

by Anthony "AC" Clark

To me condoms always seemed to be someone else's problem. I mean being young and gay in the early 1980s meant not having to worry about getting some girl pregnant. Syphilis and gonorrhea were the only major STDs that I tried to avoid. Oops, I forgot about herpes, but who hasn't had a cold sore on their mouth.

Having lost my virginity to both sexes, my idea of sexual lubrication was K-Y jelly, Vaseline or spit. If I were really excited then I hunted for that motion lotion. By accident one drunken lusty night I used some icy hot, and learned for the first time the many uses of the aloe vera plant.

As my sexual drive increased, so did my risk behavior, until I heard the words "Acquired Immune Deficiency Syndrome (AIDS)." I was one of those who thought that AIDS only happened in the big cities, real cities, like New York and San Francisco. Or worst that it was happening only in the white gay community. I didn't even know people who had colds, let alone who were dying. However, slowly but surely I started using condoms and started finding out more information on this new thing called "Safe Sex".

Somewhere during the course of my personal journey, HIV and then AIDS became a new life-partner with me. The days of flesh upon flesh and the mingling of fluids came to an abrupt end. But I was determined that I would continue to have a healthy sex life. Hell I was using the military's "Don't ask-Don't tell" motto years before they even coined the phrase. See, if you didn't ask if I had AIDS, I wouldn't tell you I had AIDS.

I just held firm to the idea, "No Glove-No Love." I created all types of interesting

ways to pull the vital sexual behavior information from my sexual partners, while steering clear of those acts that could put us at risk. I asked, "What kinds of things do you like to suck? How many sexual partners have you been freaky with? You use that tongue really well, don't you? A buddy of mine says he's not worried about Hepatitis, are you?"

As long as I used safe sex, I could live my life. Safe sex to me meant using latex condoms and lube, not Vaseline. Overtime, I began to limit the types of things that I did sexually with another person. I really didn't like condoms at this point in time, but I felt that they were a necessary evil. I wasn't into oral sex. I didn't kiss. I wouldn't let my sexual partners touch me in any way, shape or form unless we were alone or unless we were located where prying eyes could not see us. The strange thing about this is that I wasn't really happy. I felt totally restricted, but at least I wasn't being abstinent. I can't speak for others but personally being abstinent was not an option. In my mind abstinent meant that my life was over, and I was no longer desirable. Remember this is my stuff, my own personal issues, but that's another article.

I asked myself, "Is this all that I need in order to have a "normal" life?" After going through the motions, with several partners, I felt that it was time to reevaluate my personal position on sex. Finally, I decided that I would be proactive about sex. The first step was being honest with all of my sexual partners. Yes, I feared the rejection and the stigma that I believed would follow, once people in the community found out about my status. However, I moved forward and discovered that it was ok. I was not some sexual

leper, in fact many of my partners had new respect for my honesty. Of course, there were those who reacted negatively, but I felt that if they couldn't deal with my honesty then they didn't need to be in my life anyway. I knew that if I loved myself, was honest with myself, and respected myself, everything would be fine.

I decided that I needed to learn more about "safer sex" and opted to talk with several people who were giving "eroticizing safe sex" workshops. This opened my eyes to many misconceptions I had about safe sex and personal intimacy. I knew what types of condoms and personal lubrication should be used, but I didn't know how to really incorporate it into a truly intimate setting.

I realized that I was often in such a rush when it came to sex, that I would miss the opportunity to really enjoy myself and experience intimacy. So, I took a mental inventory of the things I truly enjoyed sexually. I loved touching and caressing. I found out that a full body massage is actually a great place to begin one's sexual journey. Kissing, licking and sucking were other things I really enjoyed. I came to the realization that my oral fixation wasn't limited to suckers and cigarettes. But all of these types of interactions take time, that is if you really want to fully enjoy the experience. I slowly began to apply some of my new skills. I eventually discovered that I enjoyed being held, and I enjoyed holding another person in my arms.

Just think all of these wonderful new experiences... [to be continued]. ☞

AC is the director of Men of Color HIV/AIDS programs at TPAN.

Programs and Meetings

All meetings held at TPAN offices unless otherwise indicated: 1258 W. Belmont Ave., Chicago.
Office hours: Monday–Thursday, 9 am–8 pm. Friday, 9 am–6 pm
phone: (773) 404-TPAN • fax: (773) 404-1040 • e-mail: tpanet@aol.com • www.tpan.com

Discussion and Support Groups (Call 773-404-8726)

Beyond Basics: Getting on with Life

A group for those who have lived with HIV for several years. Thursdays at 7:30 pm.

Brothers United in Support (BUS)

A group for HIV positive gay and bisexual men of African descent. Thursdays at 7:00 pm.

Chicago Help

A group for those infected with an STD or their partner. Focus on education, support, and resources. Second Thursday at 7:00 pm. Call Chicago Help (773) 660-0416.

Family AIDS Support Network (FASN)

A group for family, friends, and caregivers. Call Betty Stern at (773) 404-1038.

Living Positive

HIV positive gay men discuss how being positive affects relationships and deal with the impact of HIV as single men. Tuesdays at 7:30 pm.

Newly Diagnosed

A group for newly diagnosed individuals. Mondays at 7:30 pm.

Negative Partners

The Negative Partners of Positive People group meets every 2nd and 4th Tuesday at 7:30 pm. The group is dedicated to helping those who are dealing with issues surrounding the HIV positive status of their significant other as well as their own HIV-negative status.

Positive Progress

A group for HIV positive people in recovery. Tuesdays at 7:30 pm.

Straight Talk

A group for HIV positive heterosexuals. Wednesdays at 7:30 pm.

TPAN Daytimers

A group for people with HIV who prefer to meet during the day. Mondays and Thursdays at 10:30 am.

transDiva

transDiva is a transgender “safe space” for youth and young adults (ages 13–24) to get together and discuss issues important to them. Fridays 5:00 pm–9:00 pm.

transGenesis

A group for HIV-affected transgender individuals. Mondays at 6:00 pm.

T.R.I.B.E.

An educational discussion group for Gay Men of Color focused on maintaining a healthy lifestyle. 2nd and 4th Monday at 7:00 pm.

Women’s Group

A group for HIV positive women. Women supporting each other in dealing with HIV and overcoming other issues. Created for positive women by positive women. Call Sylvia for more information.

Health and Fitness

Medical Clinic

Free medical care provided by a physician’s assistant. This program is in conjunction with the Needle Exchange Program and is offered by Access Community Health Network. Call for an appointment. Wednesdays 3:30 pm–7:30 pm. Fridays 2:00 pm–5:00 pm.

Needle Exchange Program

Free, anonymous, legal syringe exchange and HIV/AIDS prevention. Every Wednesday 5:00 pm–7:00 pm at TPAN offices. In association with Chicago Recovery Alliance.

Wellness Wednesday

Free alternative therapies (massage, Reiki, Shiatsu, Structural therapy). This program is offered by AIDSCare. Wednesdays 12:00 pm–3:00 pm. Call for an appointment.

Yoga

Wednesdays at 7:30 pm.

Resources

Speakers Bureau

Individuals are available to community groups and organizations to educate on HIV, safer sex, harm reduction and experiences of living with HIV. Call Sylvia or Keith.

Chris Clason Resource Center

Find the latest news in the Chris Clason Resource Center. Open Monday through Thursday 9:00 am–8:00 pm., Friday 9:00 am–6:00 pm.

Social

Berlin HIV positive Social Hour

Berlin, 954 W. Belmont, Chicago. Thursdays from 6:00–10:00 pm.

Buddy Programs

Peer Support Network

Provides one-on-one support for recently diagnosed individuals. Volunteers provide support, information and referrals. Call Angelo to get a buddy!

Positive Buddy

Provides individuals living with HIV/AIDS one-on-one emotional/physical support. Volunteers provide the support that each HIV positive individual has often lost. Call Angelo to get a buddy!

Legal issues

HIV-Related Legal Clinic

First and third Thursdays, 4:00–6:00 pm at 1258 W. Belmont Ave.; by appointment only. Call Katy at (773) 404-8726.

TPAN Calendar of Events

March 2001

All events are held at TPAN offices unless otherwise indicated.

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
				1	2	3
9 am Sunrise AA						
4	5	6	7	8	9	10
9 am Sunrise AA				11:30 am * North Side HIV Coalition meeting		
11	12	13	14	15	16	17
9 am Sunrise AA		7 pm TPAN Board of Directors meet- ing; TPAN members invited				
18	19	20	21	22	23	24
9 am Sunrise AA			9 am HIV Prevention Planning Group (HPPG) meeting. for more infor- mation call: (312) 747-9661	7 pm Brothers United in Support, Social for HIV positive gay and bisexual African American men		
25	26	27	28	29	30	31

* For additional information on these events please contact Keith Waltrip, Program Director at (773) 404-8726.

April 2001

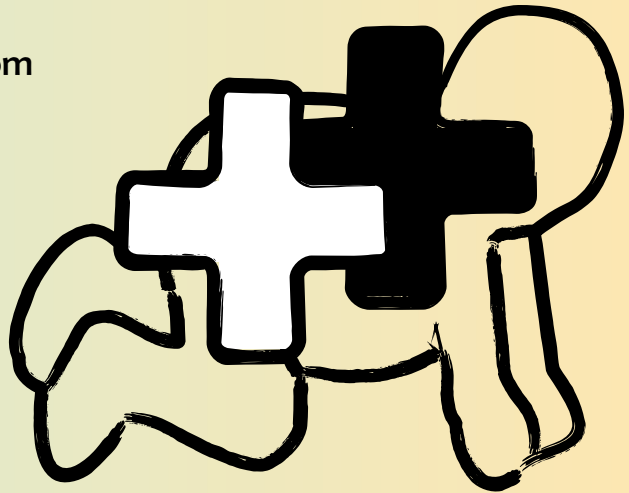
All events are held at TPAN offices unless otherwise indicated.

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
9 am Sunrise AA 1						
9 am Sunrise AA 8		5 pm * HIV Research Update— Structured Treatment Interruptions 10				
9 am Sunrise AA 15		7 pm TPAN Board of Directors Meeting; TPAN members invited 17				7 pm Straight Talk, Social for HIV positive heterosexuals 21
9 am Sunrise AA 22			6 pm TPAN Benefit and Bar Crawl 2001 Kick Off at Circuit, 3641 N. Halsted 25			
9 am Sunrise AA 29		<p><i>Save the Date:</i> <i>Staying Alive—A PWA Conference</i> <i>August 16–19, 2001 Chicago</i></p>				

* For additional information on these events please contact Keith Waltrip, Program Director at (773) 404-8726.

**TPAN
Spring
Benefit
and
Bar
Crawl
2001
Kick
Off**

April 25, 2001
6:00 pm – 9:00 pm
Circuit
3641 N. Halsted
\$20 donation to
support TPAN
programs
requested



Join us as we introduce TPAN's newest program and our bi-weekly fundraiser that will take us up to Pride Weekend!

C I R C U I T

donations may be sent
directly to:

TPAN
c/o Spring Benefit
1258 W. Belmont Avenue
Chicago, IL 60657

To order tickets or for more
information, call Patrick at
773.404.8726 visit
www.tpan.com.

**CONGRATULATIONS ON
A MOST SUCCESSFUL
FIREBALL 2001!**

ON BEHALF OF ALL INDIVIDUALS WHOSE LIVES HAVE BEEN IMPACTED BY HIV AND AIDS, THE STAFF AND MEMBERS OF TEST POSITIVE AWARE NETWORK EXTEND A SINCERE THANKS TO THE HEARTS FOUNDATION, THEIR BOARD OF DIRECTORS, AND THEIR MANY VOLUNTEERS FROM THE COMMUNITY. THE CONTINUED FINANCIAL AND MORAL SUPPORT PROVIDED BY THE HEARTS FOUNDATION AND ITS SUPPORTERS IS VITAL TO THE CONTINUED PREVENTION AND EDUCATION EFFORTS OF TEST POSITIVE AWARE NETWORK.