

July / August 2006



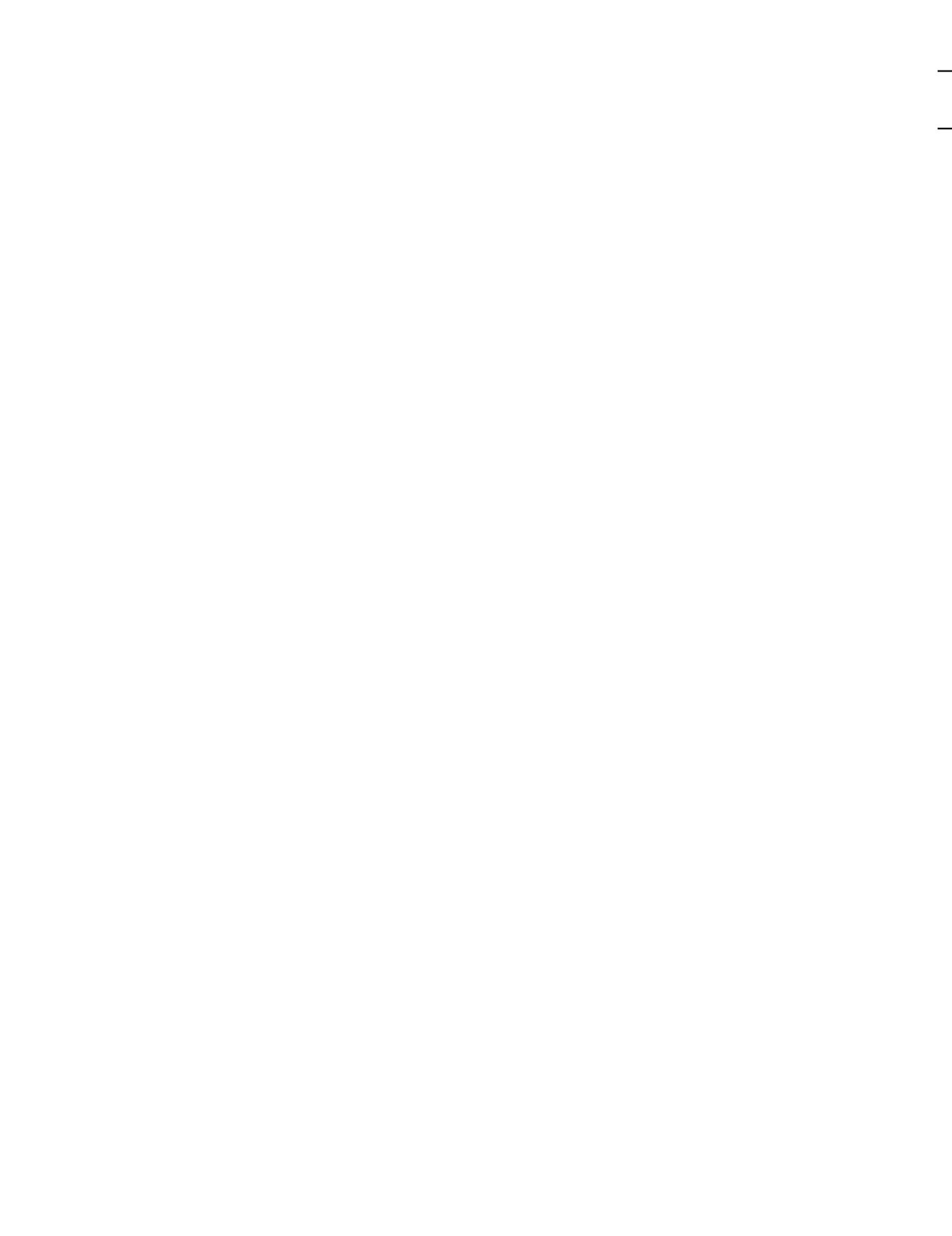
# Positively Aware

The Journal of Test Positive Aware Network

**VOICES OF HOPE — THE ROAD TO HOPE TOUR**  
**YOUTH & HIV**

**PLUS**

- **Transitioning—  
Moving into Adult Healthcare**
- **Care of the HIV-Positive Adolescent**



# Table of Contents

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July / August 2006  
Volume 17 Number 4

## Departments

- 6 **Programs and Meetings**
- 6 **TPAN Events Calendar**
- 7 **Editor's Note**  
TEACH YOUR CHILDREN WELL
- 8 **Readers Forum**
- 12 **News Briefs**  
*by Matt Sharp*
- 53 **What's Goin' On?**  
THE LITTLE VOICE WITHIN  
*by Keith R. Green*
- 54 **The Wholistic Picture**  
RESPONSE ABILITY  
*by Sue Saltmarsh*

## Articles

- 17 **Positively Aware Reader Survey**
- 19 **No Longer a Child**  
*Transitioning into adult care terrifies youth with HIV*  
*by Enid Vázquez*
- 24 **Voices of Hope**  
*A group of young adults, out to change the world, one step at a time*  
*by Jeff Berry*
- 29 **Having a Ball**  
*A look at an underground youth community that has taken HIV prevention and awareness into its own hands*  
*by Keith R. Green*
- 33 **"Live Fast, Die Young"**  
*Born with HIV, a young man's story of addiction and survival*  
*Interview by Enid Vázquez*

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>

## Articles continued

- 36 **HIV Treatment Series**  
CARE OF THE HIV-POSITIVE ADOLESCENT  
*Developmental stages and provider sensitivity play a special role*  
*by Margo Bell, M.D.*
- 40 **Dating, Youth and HIV—From Both Sides**  
*Teenagers try to make sense of it all*  
*Interviews by Keith R. Green*
- 43 **Every Hour**  
*A young person becomes infected with HIV in this country every 60 minutes*  
*by Enid Vázquez*
- 44 **Metabolic FAQ**  
*Frequently asked questions regarding metabolic syndrome*  
*by Carla R. Heiser, MS RD LD and James T. Barrett, MD*
- 48 **Kenya's Tale**  
*A short story for young people on courage, love and triumph over living with HIV*  
*by Keith R. Green*
- 49 **Politics and HIV: Statement from Representative Rahm Emanuel (IL-5)**
- 50 **How to Find a Doctor**  
*AAHIVM offers badly needed credentials*  
*by Howard Grossman, M.D.*
- 51 **AIDS Policy Update—2006 Ushers in the Era of "The Medical Approach"**  
*Whether the shift expands healthcare access or eases AIDS stigma remains to be seen.*  
*by David Munar and Jim Pickett*

Please fill out our reader survey on page 17, or visit [www.tpan.com](http://www.tpan.com)

On the cover, clockwise from lower left: Josh, Duane, Aaron, and William from the Road to Hope Tour

Photo © Russell McGonagle

# Programs and Meetings

## PROGRAMS AND MEETINGS AT TPAN

- Support Groups
- Rapid Testing
- Reiki and Massage
- Needle Exchange Program
- Individual Counseling
- Peer Support Network/Buddy Program
- Speakers Bureau
- Access Medical Clinic at TPAN
- PULSE, an HIV-positive Weekly Social
- TEAM (Treatment Education Advocacy Management)
- Positively Wired—A Free Basic Computer Skills Workshop

For detailed descriptions of programs, including days, times and locations, go to [http://www.tpan.com/client\\_services/clientservices.shtml](http://www.tpan.com/client_services/clientservices.shtml) or visit [www.tpan.com](http://www.tpan.com) and click on Client Services; or call (773) 989-9400

## TPAN Events Calendar

### TPAN EVENTS CALENDAR

- Educational Forums and Trainings
- Special Events

For detailed descriptions of upcoming TPAN events go to <http://www.tpan.com/events/events.shtml> or visit [www.tpan.com](http://www.tpan.com) and click on Events; or call (773) 989-9400



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

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## TEACH YOUR CHILDREN WELL



This issue of *Positively Aware* focuses on HIV, youth and young adults. Now, before you say to yourself, “I’m over 30,” and set us aside to reach for the newspaper or the remote, consider this: over half of all new infections occur in young adults between the ages of 15 and 24.

You may or may not have children of your own, but you probably have friends or a family member with kids. Many of you have nieces, nephews, grandchildren, or godchildren. You may know one of your neighbor’s kids. It’s possible you work with kids or young adults.

One thing is for certain—today’s youth are not getting the message that they may be at risk for HIV. So, it’s up to us to teach the children.

We are often told that we should lead by example, so even if you don’t think you have a relationship or a connection with a younger person who’s at risk, there is probably someone who looks up to you, or whom you have an opportunity to mentor in some fashion, either knowingly or unknowingly. If you’re online chatting with someone, they could be much younger than you, or could even be underage for that matter, you never really know for sure.

I still remember how it was in my youth, even though it’s becoming more and more of a distant memory. The raging hormones, the feeling of invincibility, your curiosity gets piqued, the sexual experimentation, the risk taking, the thrill seeking, drugs and alcohol, peer pressure, the desire to connect with another, and how any combination of the above can, coupled with a momentary lapse in judgment (*sans* condom), in a single instant, change one’s life forever, leading to a lifetime of pills, nausea, diarrhea, headache, sleeplessness, neuropathy, rash, lipodystrophy, bone mineral den-

sity loss, elevated lipids leading to increased risk of heart disease, liver malfunction, and kidney failure, not to mention the fear of rejection, diminished capacity to establish and maintain relationships (both physically and emotionally), loss of libido, cognitive impairment—*etcetera, etcetera, etcetera*.

It’s not pretty.

While living with HIV is possible, it’s certainly not preferable. It’s manageable, but it’s a lot of work. The drugs used to treat HIV are not a cure, and can be highly toxic. Most of them come equipped with a whole host of side effects. You may eventually become resistant to the drugs to the point where you can no longer construct a regimen that’s effective, even if you remember to take your drugs exactly as directed. And nowadays there is a good chance that those newly infected will acquire a strain of HIV that is already resistant to one or more of the drugs currently on the market, giving HIV the upper hand and keeping it one step ahead of the game. And the drugs continue to cost more and more every year and with each new drug, jeopardizing the financial stability of an already crippled healthcare system. At \$25,000 a head, and over one million in the U.S. alone, you do the math.

Think for a moment about how it was to be a kid. Think about how it was to have your whole future ahead of you. Then think about having it all taken away from you, or your partner, because you didn’t use a condom, or take the necessary precautions to protect yourself and your partner.

If each of us makes a commitment to help spread the word, to get out the message, and possibly help prevent even one new infection, it will make a difference.

So please, I urge you, give a young adult, or someone you know who has kids or has contact with at-risk youth, your copy

of this issue. Hey, we’ll even send you a replacement copy, free of charge. Or have them write to us, or e-mail us at [tpan@tpan.com](mailto:tpan@tpan.com) and we’ll send them a copy. As many copies as they want. No questions asked.

Spend a day mentoring a young adult, someone you know, someone you care about. Show them what it’s like to live with HIV, if only for a day. Have them spend a day at the clinic with you, or better yet, give them a peek at your medicine chest. Describe for them the side effects you experience. Tell them about the many lost dreams and opportunities, the stigma you may have experienced due to having HIV, or how it feels to lose your friends, your partner, or your looks.

If you’re a young adult, and know someone with HIV, ask them what it’s like living with it. Tell them you need to know, not only because you care about them, but because you want to stay informed and have to learn how to protect yourself and others *you* care about.

So protect yourself. Get tested. Stay informed, and reach out.

Our children’s lives, and the lives of their children, depend on it. It’s up to us, and the choices we make today will determine the course of the future, for generations to come.

Take care of yourself, and each other.

Jeff Berry  
Editor  
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## HOLISTIC WORK

My partner and I have recently been diagnosed (this week) as HIV-positive, and reading this article (The Wholistic Picture) helped to strengthen my belief that disease is so much a holistic phenomenon, that if we take care of the whole, we can overcome any obstacle. My partner teaches yoga and I practice as well, and am thinking about becoming a teacher too. I do hope to see more articles on the benefits of natural healing, i.e., yoga, energy work (such as cranio-sacral work, body talk, and Reiki), healthy eating and the like. Thank you.

Name withheld, via the Internet

## METABOLIC DIET

Thank you for this article [HIV Treatment Series: Early Interventions for Metabolic Complications of HIV, March/April 2006], which I find very informative and useful; can you please explain further why soy is a no-no, and especially why flax seed and lignans are a problem. I have tried a search, but cannot find any references.

Name withheld, via the Internet

*Carla Heiser responds: There are two well-designed research studies showing a negative impact of flax lignan on estrogen metabolism (affecting men and women's hormone balance). [View study abstracts online].*

It says in your article to avoid soy, but it never says why. This is the first time I've ever read this anywhere. I have become increasingly prone to problems with milk tolerance. I have a lot of HIV-related digestive problems (diarrhea, gas, etc.). I switched to soy milk about a year ago and feel much better. Any comments or suggestions? In the article it suggested rice milk instead of

soy. Is that what I should do? Thank you for your help.

Name withheld, via the Internet

*Carla Heiser responds: Data on health benefits of soy is not conclusive. There is a paucity of data from rigorously designed research studies, and published work of placebo-controlled studies represents small study sample sizes. Research shows that soy may have a negative effect on thyroid and other hormone balance. Another alternative for cow milk is low sugar almond milk. Goat milk and goat and sheep milk products may be okay if there is a sensitivity to cow milk. Sometimes people have sensitivities to goat and sheep milk proteins. The lab that we use for determining type of food sensitivity is U.S. Biotek ([www.usbiotek.com](http://www.usbiotek.com)). The test runs about \$390 to determine immediate and delayed sensitivities to 96 foods. Private insurance plans may cover this expense.*

## ANAL CANCER

I'm a four year survivor of 4th stage terminal anal cancer. I have HPV [human papillomavirus]. I was treated with 5FU and Cisplatin, was not expected to live, but I got through somehow. It was long and very painful, it took two years to heal from the radiation alone, and I had many side effects from the chemo. I just want to say that men having sex with men should have regular anal check-ups. Don't hesitate. It just might not be a hemorrhoid you're dealing with. That's what they thought I had, but luckily the doctor at the time thought I should see a colorectal doctor to make sure, and he was right, anal cancer is no joke. It has to be one of the more painful cancers to get, and there was not enough pain medication around to get rid of it, and even today on HAART medications I still have constant diarrhea, for which I have to take prescribed medication, so please get checked and be sure.

Name withheld, via the Internet

*Jeff Berry responds: Thanks for your e-mail. My partner also had anal cancer, so I know somewhat what you went through. The treatments are painful, but luckily the success rate is very high. He was in a lot of pain; only after a lot of complaining was he finally referred to a pain management specialist, who helped get his pain to a level he could deal with to get through the treatments. I'm glad to hear that you had success with your treatments, but I know that living with the after effects of chemo and radiation can be debilitating. Thankfully you had a good doctor, and I wish you all the best in the future.*

## CHILDREN

Carlos [Perez] hit the nail on the head [My Kind of Life, November/December 2005]! We need to start with the children. We as adults need to get over our hangups so we can protect our children. As director of a new community-based organization in the Lummi Nation Native American community near Bellingham, Washington, I have realized that to break the barrier of stigma here, we need to start with the youth. This will be a long-term goal. The change will not happen overnight. But with education we can begin to turn the tide. Education is key. HIV/AIDS is very secretive out here, but with the extremely common substance abuse, you know that HIV infection is also high. It is time to accept the fact and teach through education that we can learn how to protect ourselves and our children.

Hamen P. Ides, Ti-chee: Native American HIV Prevention, Education & Outreach, via the Internet

## POSITIVELY AWARE

As I sit wide awake, well rested and alive at 64, I am remembering the past 15 years and being aware of what it has taken for me to be alive and looking forward to being 65 next year.

Aside from God and my family's support, I am grateful to the wonderful doc-

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—



tor Joseph C. Gathe, Jr., for ongoing (even though slowly and not enough) research and developments, and to your publication. I am alive today with limited finances, but I am alive and eager to return to the ranks of the employed. I am positively aware of HIV disease.

Your positive approach and up-to-date information (and others) have liberated my mind to being more positive and has allowed me to always keep in my mind and thoughts and actions that HIV really means Hope Is Vital for living.

With all the positives and negatives, AIDS (As I Die Slowly, per some young folks) has never been my destination. I must live to see and help my two wonderful grandchildren grow and thrive. P.S. The donation is small but nowhere equal to what I've gotten.

Beneva Nyamu, MSW MPH, Houston, TX

#### SISSSTER CHRISSTIAN

I just read your [Jim Pickett's] most recent article in *Positively Aware* [March/April 2006], and I feel sick. I feel sick (and so tired) that you were uninvited to the "unless you look, believe, sound, and live just like us, you're not allowed to teach us" HIV prevention conference. It's so freaking ridiculous to me that these Christian groups, who claim to "love their neighbors as themselves," don't. They wear their crosses on their sleeves, and act like Judge Judy, and I hate it! I'm pretty sure Jesus hates it too. I guess I was especially enraged because I work at a Christian college, and I'm surrounded by this kind of hypocrisy each and every day. I stay here because I believe in higher education, and believe in being a safe space for students who, like me, fit outside the box (thank God). It's too bad that the community in "the interiors of Indiana" wasn't able to hear your presentation. You're brilliant and have so much goodness ("potty mouth" and all) to share with others. I wish I could simply say, "their loss,"

but so many others will lose out too. HIV prevention work is not for the squeamish or the judgmental. To be honest, I'd hate to be on the "receiving end" of their "work." Thanks for yours. Thanks for your writing. Thanks for kicking ass.

Lindsay Mitchell, via the Internet

Jim, I read this article and it doesn't surprise me at all that they made the right decision. Read the article you wrote! A lot of faith-based Christians are reaching out to those with AIDS and most don't fit your queer-minded framing of the subject. My wife and I run a children's orphanage in Haiti and down here and most of the third world, heterosexual misbehavior is killing children in droves. World Vision is exactly that. They work in a world you have no idea about. Go ahead and read your article and guess how many Christians would give you an ear. We need everyone in this fight. Even we who profess our love of Jesus Christ. Go ahead and *read your article*. I wish you God's blessing and guidance in your future writings.

With Christ's love, Ray Comfort, via the Internet

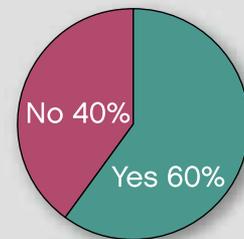
Is it your purpose to promote HIV/AIDS education or to compel conservative Christians to endorse your values and lifestyle as a precondition to providing HIV/AIDS education? As a self-styled "flaming vulgar queen" and "enormous homosexy fag," your religious, sexual and family values *are* inconsistent with the "vision" and "ethos" of World Vision International. Are you incensed because WVI used politically correct language in stating the obvious?

And pardon me, but have we not been desperately trying to make the point to these very conservative Christians that HIV is not a gay disease or a gay first disease? HIV/

*continued on page 14*

### May / June PA Online Poll Results

Have you ever undergone a treatment interruption under the advice of a doctor, or as part of a study?



Comments:

- Yes, while in the hospital and weeks afterward. Was infected in O/P Surgery. Three days later I was septic and developed pneumonia. Spent 14 days in the hospital. They changed meds daily, and took me off HIV meds for over two weeks.
- Yes, I chose to do it myself for 6 months. The results were mixed. While my Ts went down and VL up, the overall "good" feeling abounded. My MD/HIV oriented doctor asked me to return and the results, two blood draws later, were the best they've ever been.



July / August  
PA Online Poll:

At what age did you test positive for HIV?

Give your answer at  
[www.tpan.com](http://www.tpan.com)



by Matt Sharp

## DHHS TREATMENT GUIDELINES UPDATE

The Department of Health and Human Services (DHHS) has once again revised the *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*. This most recent version of the Guidelines was updated October 6, 2005 and released for publication May 4, 2006. A “living” document that provides guidelines but is not a mandate for treating HIV, the Guidelines are constantly updated to reflect recent clinical findings and current knowledge in HIV medication issues. The most significant changes in this 2006 update include HIV genotype resistance testing prior to initiation of antiretroviral therapy in people with acute or chronic HIV infection. Previously, the Guidelines only recommended resistance testing in the chronically infected. This change reflects the understanding that more people are becoming infected with resistant HIV strains and an initial genotype test can help to guide treatment decisions, making initial therapy cost effective.

In light of the hubbub over the stopping of the SMART treatment interruption trial, and more disappointing results with other treatment interruption studies, recommendations have been added in this revision, with discussions over the risks and benefits of planned long term treatment interruption in chronically infected people with suppressed virus. Information on the management of people with hepatitis B and HIV co-infection have also been updated.

The Guidelines represent the consensus opinion of the Panel on Clinical Practices for Treatment of HIV, which consists of leading researchers, clinicians, DHHS participants and community members. They reflect the most up-to-date information representing a “standard of care” for treatment of HIV in the U.S. This is the latest revision since the Guidelines were created in 1998. Visit <http://AIDSinfo.nih.gov>.

## NEW COMBO PILL FROM TWO COMPANIES

In the first joint company marketing of an HIV therapy, Gilead Sciences and Bristol-Myers Squibb announced the FDA filing of their once-daily tablet that combines Truvada (Emtriva plus Viread) and Sustiva. The collaboration of two competing pharmaceutical giants in the HIV field is unprecedented. Bioequivalence and the initiation of stability studies has been completed, paving the way for NDA (New Drug Application) submission with the FDA. The new once-daily tablet includes 600 mg of Sustiva, 200 mg of Emtriva and 300 mg of Viread, all three of which are drugs

that block the reverse transcriptase enzyme that is necessary for HIV replication.

Both companies will share marketing and publicity for the new product as well as support for promotion. In a joint company press release both companies “will receive revenues from future net sales at percentages relative to the contribution represented by their individual products that comprise the once-daily single tablet regimen.” Each individual drug will continue to be available separately. The new fixed-dosed combination should be available within a few months.

## ANOTHER COMPANY COLLABORATION: THE TROPISM ASSAY

Pfizer and Monogram Biosciences have entered into a collaborative agreement to make Monogram’s HIV co-receptor tropism assay globally available for patient use. The test is used to determine the path taken by a patient’s HIV to attach to his or her CD4 cells. In a new wave of science and technology, the development of therapies that target the CCR5 co-receptor on CD4 cells by Pfizer and other companies has led to the need for an assay to determine which co-receptor is most prevalent and therefore the best target for the appropriate antagonists. About 80–85% of people newly diagnosed with HIV have dominant CCR5 tropic virus. The number drops to 50–60% in those who have been on HIV therapy, and even lower for those with advanced disease.

Since the companies really “need” each other for their own interests, Pfizer has invested 25 million dollars in Monogram. The implications of providing tropism assay tests have not been validated, but if these drugs become approved (Pfizer’s maraviroc being the most likely first candidate, expected to be approved next year), the test will probably be widely used in order to determine the best use of the drug.

Pfizer also reported that the independent Data Safety Monitoring Board (DSMB) for maraviroc, the company’s CCR5 antagonist in research development, in April recommended that the four Phase 2b/3 studies for the drug continue as currently designed. In a press release, the company wrote that, “The DSMB further reported that they continue to see no evidence of maraviroc-associated hepatotoxicity [liver toxicity], including those patients receiving concomitant tipranavir [Aptivus]. Their review of HIV-associated malignancies such as non-Hodgkin’s lymphoma and Kaposi’s sarcoma, observed within the maraviroc Phase 2b/3 development program, found the incidence to be consistent with known rates of

Photo © Russell McGonagle

these malignancies in similar HIV-infected populations.” For more information about maraviroc studies, visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov).

#### **STUDENT GLOBAL AIDS CAMPAIGN STAGES INTERNATIONAL DAY OF ACTION**

In a dramatic international effort, several demonstrations targeting Abbott laboratories were held on April 28 in five U.S. states, Nigeria, Tanzania, Thailand and the UK. The demonstrations were sponsored by the Student Global AIDS Campaign (SGAC) and Doctors Without Borders (Médecins Sans Frontières). Activists claim Abbott Laboratories, with corporate headquarters outside of Chicago, is delaying access to a new stable form of Kaletra to the developing world, where 90% of AIDS cases are. The SGAC and MSF are demanding Abbott provide wider access to the countries that need the new Kaletra most by providing the drug at lower cost, and working to speed up the removal of regulatory barriers required by each country. Medical students, doctors, AIDS activists and passersby joined in the day of action and promised to make this a top priority in the coming months. Visit [www.fightglobalaids.org](http://www.fightglobalaids.org).

#### **PREZISTA, NEW TIBOTEC PROTEASE INHIBITOR FAIR PRICING CONSENSUS STATEMENT**

The Fair Pricing Coalition has initiated a new sign-on letter demanding that Tibotec’s new HIV protease inhibitor (PI) Prezista, previously known as TMC-114/darunavir, which is nearing the final approval stages, be cost neutral to Abbott’s Kaletra—its biggest competitor. This is not your normal AIDS drug pricing demand, because Tibotec’s new protease inhibitor represents an improvement over current therapies, as it appears to work well against PI-resistant strains. It also comes along in a time of higher drug costs, a crisis in healthcare, and growing competition from other HIV drug companies.

The consensus letter also demands that the Norvir boosting dose cost be included in the total cost of Prezista as it is with Kaletra. So far the company has agreed that the price will be “budget neutral,” but according to a study presented at the British HIV Association meeting in March, the price approximated in British pounds is twice as high as Kaletra. Prices set in Europe often predict the costs in the U.S., and if this bears out, the U.S. HIV community will need to mobilize and prepare for a new battle. See the entire letter and sign on at [www.champnetwork.org/index.php?name=tibotec-letter](http://www.champnetwork.org/index.php?name=tibotec-letter).

#### **RYAN WHITE CARE ACT**

A Senate health committee approved legislation to reauthorize funding for AIDS services through 2011. The Ryan White CARE Act, the largest federally funded AIDS services legislation of over 2 billion dollars annually, expired in September 2005 when legislators could not agree on its terms. The current form of the legislation has received bipartisan support, but still has to pass through the Senate and be signed by the president before it is enacted. The reauthorization process has been tenuous as other versions of the bill have been less than generous. This version is peeling back the layers of AIDS services in a less threatening way, but the writing is

basically on the wall that federal funding for AIDS care as we once knew it is all but over.

This latest version of the bill settled compromises on several key cutback proposals by conservative Senator Tom Coburn (R-OK), which would have limited services even more than the current bill proposes. This version is the lesser of two evils in the latest of our current administration’s efforts to thwart AIDS care in the U.S.

The new legislation increases the number of cities receiving funding from 51 to 76 and creates a tier system for those cities based on AIDS cases. New funding distribution formulas are still being negotiated at press time. One of the significant changes in funding is that 75% of services be allocated for “core medical services,” which will leave the categories of transportation and case management in jeopardy.

Activists are decrying the changes because the support services negatively affected by the new legislation enable people to access the “core medical services.” One person living with HIV exclaimed at a recent Chicago Ryan White community forum, “It’s like robbing Peter to pay Paul.” Final votes for passage into law should be in August 2006.

#### **LOCATE MERCK’S INTEGRASE STUDY SITES AT BENCHMRK.COM**

Merck’s Phase 3 integrase study is up and running. The drug, MK-0518, is the latest, brightest spot on the HIV research news front because it has shown to be very effective in studies to date (see May/June issue). To be in this one-year study you must have greater than 1000 viral load, failed antiretroviral therapy, and be on the same regimen for the past two months prior to enrollment. Check the interactive website for contact information for the site nearest you. Visit <http://benchmrk.com/secure/index.html>.

#### **HIV LONG-TERM NON-PROGRESSOR STUDY**

Researchers at the Partners AIDS Research Center of Massachusetts General Hospital in Boston are investigating how some people control HIV without medication. They expect their results to contribute substantially to the understanding of HIV disease and improved vaccine development. The study involves a simple blood draw. Travel to Boston is not required. Enrollment criteria are:

- HIV-positive without symptoms
- Age 18 to 75
- Viral load below 2,000 in the absence of medication on at least 3 determinations over a 12-month period; some measurements over 2,000 permitted as long as they are the minority of all measurements
- Past history of treatment may be acceptable—determined on an individual basis

For more information, call the study phone line, 1-617-726-5536, to speak directly with the study physician, Dr. Florencia Pereyra, or leave a confidential voice message. More information about the study may be found at [http://www.mgh.harvard.edu/aids/hiv\\_elite\\_controllers.asp](http://www.mgh.harvard.edu/aids/hiv_elite_controllers.asp).—Enid Vázquez

### MICROBICIDE ADVOCACY

The International Rectal Microbicide Working Group (IRMWG) issued a report during the Microbicides 2006 conference in Cape Town, South Africa, held in April. "Rectal Microbicides: Investments and Advocacy" is the first-ever report tracking rectal microbicide research and development expenditures. The group reported that, "Similar to a vaginal microbicide, a rectal microbicide may be formulated as a gel, cream or lubricant and would provide protection against HIV and other sexually transmitted infections (STIs) in the absence of a condom during anal intercourse. Studies show that up to 30% of the heterosexual population in many cultures engages in anal intercourse, making the development of a safe, effective rectal microbicide a desperately needed new prevention option for women, males who have sex with males, and gay men around the world." According to the report, funding for rectal microbicide research totaled US\$34 million between 2000 and 2006, showing an increase from US\$2 million in 2000. The U.S. public sector contributed 97.4% of these funds.

Convened by the AIDS Foundation of Chicago ([www.aidschicago.org](http://www.aidschicago.org)), the Canadian AIDS Society ([www.cdn aids.ca](http://www.cdn aids.ca)), and CHAMP ([www.champnetwork.org](http://www.champnetwork.org)), the International Rectal Microbicide Working Group is a coalition of more than 100 advocates, policymakers and scientists from five continents working to advance research and development. The Group also promotes new prevention technologies beyond microbicides, including pre-exposure prophylaxis (prevention), lubricant safety, and sexual harm reduction. Visit [www.lifelube.org](http://www.lifelube.org). —EV

### BUPRENORPHINE DRUG INTERACTION

A medication used as an opiate substitute, buprenorphine, has been related to a drug interaction with the HIV drugs Reyataz and Norvir. Doctors reported three cases in the March 21 issue of *AIDS*. One patient reported "daytime sleepiness" and "reduced mental function," a second reported feeling "doped out" and a third complained of dizziness and a feeling of being high. All side effects were controlled with dose adjustments. Buprenorphine is sold under the brand name Subutex, or combined with naloxone and sold under the name Suboxone. Its great advantage is that it can be prescribed by any doctor (training is required), and its withdrawal is mild to moderate and can usually be managed without the use of drugs. —EV

### FROM VIREAD TO TRUVADA

The U.S. Centers for Disease Control and Prevention (CDC) has expanded its research into the prevention of HIV using HIV medication. The study uses the HIV drug Viread to see if it prevents infection due to sexual exposure. It will now also test the HIV drug Truvada, which is a two-in-one pill combo of Viread and Emtriva. Recently reported results with monkeys found Truvada to be even more effective than Viread alone. Viread is being tested in Atlanta and San Francisco for prevention in men who have sex with men (MSM), and the CDC will add a third U.S. city (not yet identified) to study the use of Truvada for prevention among MSM. —EV ☒

## Readers Forum continued

*continued from page 11*

AIDS has devastated the gay male population of the United States. This fact is in large part a direct result of the high incidence of unprotected anal sex and low awareness of HIV status. Toss in crystal meth abuse, depression and fear of exposure, and the picture becomes quite bleak. About half of the gay African American population is HIV-positive. 57% of United States AIDS diagnoses among men in 2003 were men who have sex with men (MSM). These are sad facts, but only facts.

In the U.S., heterosexual transmission rates rose from 3% in the early '80s to 31% in 2003. The most common transmission route for women is heterosexual contact. Children born with HIV *are* innocent, Jim (or are you espousing that very un-Christian notion of visiting the sins of the parents upon the children?). You are free, I suppose, to sneer at the innocence of un-empowered women without the freedom to resist unprotected marital sex. And perhaps some will even commiserate with you over a missed opportunity to trash marriage as a risk factor for HIV transmission. Incidentally, heterosexual transmission is the number one transmission method in the

world. And yes, Jim, in Africa too. The gay white male who personifies the face of AIDS in the American psyche is arguably the single greatest obstacle in providing HIV/AIDS education, particularly to conservative religious groups.

So, suck up your personal rejection, create some headroom if you have no real room on your political agenda for people whose values differ from your own, and continue to educate about HIV/AIDS to those who are willing to listen to you. Perhaps, just maybe, this Christian group has already moved beyond "abstinence and being faithful" as preventative tools and has done so in a manner consistent with the shared values of its constituents. (Jesus did console the prostitute and deflate the moral superiority of self-righteousness: "Let he who is without sin cast the first stone.")

HIV is a human disease first and last. In your next diatribe, try not to lose sight of that fact. You did all HIV/AIDS educators a disservice by stating otherwise.

Name withheld,  
Collins Correctional Facility,  
Collins, New York ☒

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# Positively Aware Reader Survey

Dear *Positively Aware* Reader,

In an ongoing effort to improve the quality of *Positively Aware* for our readers, thank you in advance for taking a few minutes of your time to complete the Reader Survey.

We produce *Positively Aware* for you, our reader. This is why we need your valuable input and insight regarding the publication. There are no right or wrong answers, and you may choose to skip any questions you do not want to complete. The survey is completely anonymous, so please be candid with your responses as we value your honest feedback. This survey is also available online at [www.tpan.com](http://www.tpan.com).

Thank you for helping us to make *Positively Aware* an even more valuable resource for you, our readers.

Sincerely yours,  
The Publications Staff

*Please tell us about yourself.*

## AGE

- Under 18       18–24       25–29  
 30–39       40–49       50–59  
 60 and over

## RACE

- African American       Caucasian  
 Latino / a       Asian / Pacific Islander  
 Native American (American Indian)  
 More than one race       Other

## I IDENTIFY AS

- Male       Female       Transgender

## I IDENTIFY AS

- Gay / queer / lesbian / homosexual  
 Straight / heterosexual       Bisexual  
 Other / do not wish to disclose

## WHAT WAS THE LAST LEVEL OF EDUCATION YOU RECEIVED?

- Did not graduate from high school  
 High-school diploma / GED       Associates degree  
 College degree  
 Graduate / Professional degree  
 Post-graduate degree / Doctorate

## WHAT IS YOUR ANNUAL INCOME?

- Less than \$10,000       \$10,000–24,999  
 \$25,000–54,999       \$55,000–69,999  
 \$70,000–84,999       \$85,000–99,999  
 \$100,000 or more

## STATUS

- HIV-positive       HIV-negative  
 Unknown       Do not wish to disclose

## IF YOU ARE HIV-POSITIVE, HOW LONG HAS IT BEEN SINCE YOU WERE DIAGNOSED?

- Under 2 years (newly diagnosed)  
 2–5 years ago       6–10 years ago  
 11–15 years ago       16–20 years ago  
 20 years ago or more

## ARE YOU CURRENTLY TAKING HIV MEDICATIONS?

- Yes       No

## WHEN WAS THE LAST TIME YOU WERE IN JAIL OR PRISON, IF EVER?

- Currently in jail or prison       Less than one year ago  
 1–2 years ago       3–4 years ago  
 5–6 years ago       6+ years ago  
 I have never been in jail or prison

## WHERE / HOW DID YOU GET YOUR ISSUE OF *POSITIVELY AWARE*? (PLEASE CHECK ALL THAT APPLY)

- I'm a subscriber  
 A household member / friend / relative is a subscriber  
 Doctor's office / healthcare provider's office  
 Case manager / AIDS service organization's office  
 Online / Internet  
 Bar / restaurant / club  
 Other: \_\_\_\_\_

## HOW MANY PEOPLE DO YOU SHARE *POSITIVELY AWARE* WITH?

- None       1–2       3–4  
 4–5       6 or more

## WHAT ASSISTS YOU IN GETTING YOUR MEDICATIONS? (PLEASE CHECK ALL THAT APPLY)

- Medicare       Medicaid  
 ADAP (AIDS Drug Assistance Program)  
 Private Insurance  
 Other: \_\_\_\_\_

## HOW LONG HAVE YOU BEEN A READER?

- First time reader       Less than a year  
 1–2 years       2–3 years  
 3–4 years       4 years or more

## I HAVE USED *PA* TO HELP ME MAKE DECISIONS REGARDING MY HIV TREATMENT

- Frequently       Often       Sometimes  
 Rarely       Never

**I WOULD LIKE TO SEE MORE ARTICLES IN *POSITIVELY AWARE* FOCUSED ON (PLEASE CHECK ALL THAT APPLY)**

- Treatment Information
  - Alternative / Complementary Therapy
  - Opinion Pieces
  - Substance Abuse
  - Youth
  - Communities of Color
  - Access to Care
  - Clinical Trials
  - Research / Drugs in the Pipeline
  - Other: \_\_\_\_\_
- Personal Stories / Profiles
  - Hepatitis C Co-infection
  - Prevention
  - Aging
  - Women's Concerns
  - Safer Sex
  - Microbicides

**PLEASE LIST ANY COMMENTS OR SUGGESTIONS YOU HAVE FOR *POSITIVELY AWARE***

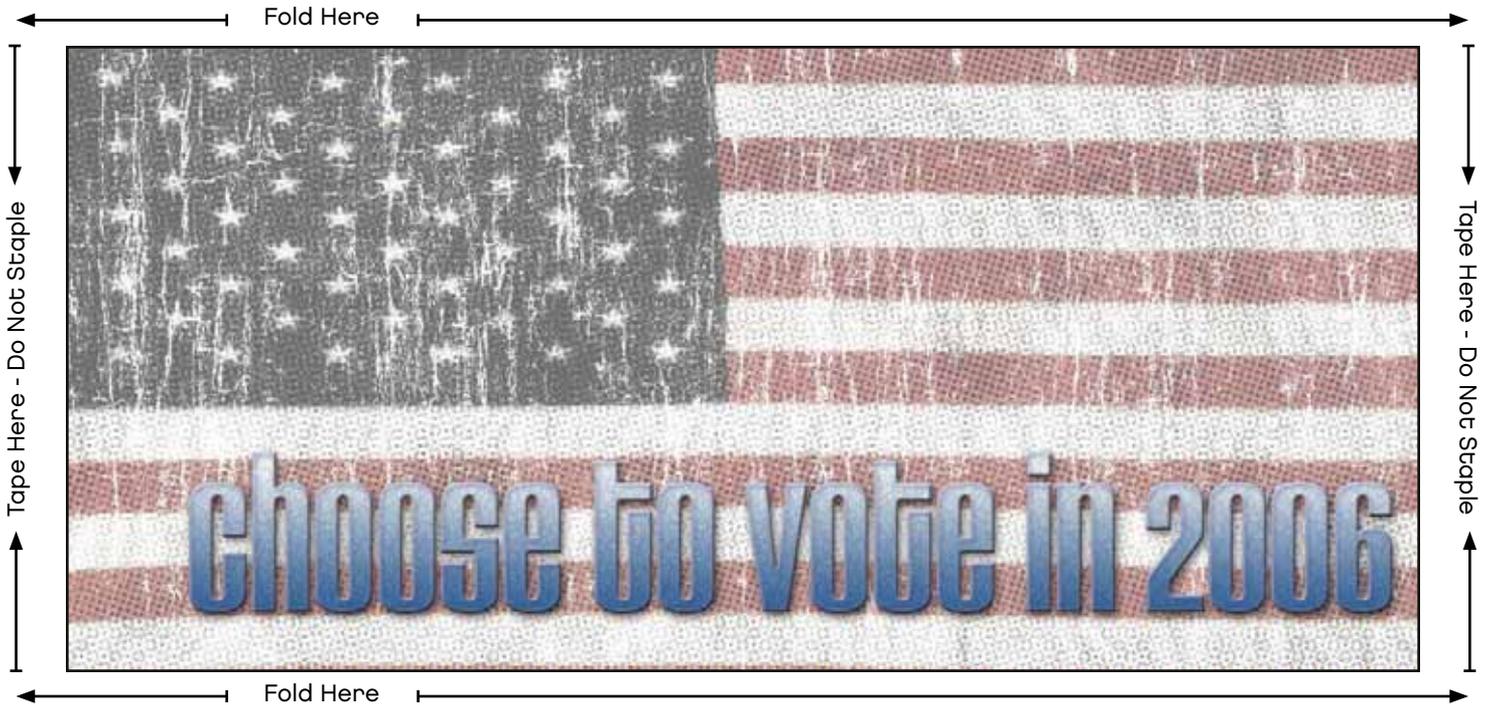
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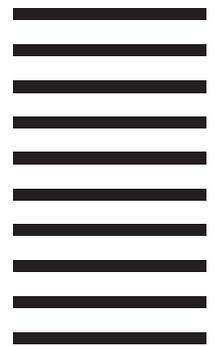
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# NO LONGER A CHILD

## TRANSITIONING INTO ADULT CARE TERRIFIES YOUTH WITH HIV

BY ENID VÁZQUEZ



Philadelphia William Brawner lists the three greatest problems of his life with HIV: “Stigma, side effects, and transitioning—absolutely. It’s an extremely difficult process.”

What is transitioning? It’s the process of forcing adolescents and young adults—many of them positive since birth—to leave behind the cocoon of their pediatric clinic and enter into adult healthcare.

Ruth Martin, Director of Social Work for Pediatric Infectious Diseases at the University of Chicago Children’s Hospital, sums it up as, “They don’t want to go.” And, she adds, a lot of the doctors don’t want to let them go.

“We used to have kids from zero to 21. Now it’s until 24. The other day I heard a doctor say 25. Okay, now, at 25 they’re fully grown,” says Martin.

Children born with HIV or infected later in their youth may be surviving and fully grown, but their move into adult care is a first in medical history. No other disease is as serious and as new for youth transitioning to adulthood. HIV is not like childhood diabetes or cancer or anything else, particularly with the stigma attached to the virus that complicates every aspect of living with it.

Says Brawner, “When you’re a child and no one knows your status, your healthcare workers become your family. They know everything and you don’t want to talk to anyone else. When you transition into adult care you have to find a new family.”

With the special bonding to a child facing a life-threatening disease comes the extra care that healthcare workers provide children and their families that adults are not privy to. “In pediatrics, you’re handheld through the process,” says Brawner, “and you know when you’re an adult you’re left on your own almost.”

“We are surrogate parents and caregivers of sorts,” says Martin. “They get a lot of wonderful attention, and they know when they go to an adult clinic they’re going to get treated like adults. People aren’t going to spend a lot of time with them. Now they have to go to a doctor and listen carefully to what they’re told. Before, they had a parent to reinforce what they were supposed to be doing.”

At 26, Brawner is on his third attempt at transitioning. Born in 1979, he suffered a severe burn to his leg from hot water (“that’s a whole other story,” he says) when he was one and a half that led

to a blood transfusion. When he was three, his mother received a call from the hospital where he was treated, informing her that the blood donor for his transfusion had died from GRID, or “gay-related immune disorder” as AIDS was then called, and that the disease had most likely passed on to her son. Brawner was found to have symptoms of illness (there was no HIV test at the time) and began to be seen at the immunology division of the children’s department of a large West Philadelphia hospital where he is treated to this day.

His first attempt at transitioning came at 16, when his clinic tried to transition him out of pediatrics and into adolescent care. He did not like the doctor and went back to pediatrics.

“I went to the doctor one time and didn’t feel comfortable,” he says. “It was too much of a process to open up. There was a lot of personal information I had to share during my visit, like adolescent issues, things my doctor already knew. To trust new people—it’s just a lot.”

Martin agrees. “Some of our patients were drug exposed. Some were in foster care. Many of them don’t know who their parents are or where they came from. Dealing with sexuality and disclosure—there are a whole lot of psychosocial issues that we’re working with.”

Brawner’s second attempt came when he left home to attend Howard University in Washington, D.C., where he earned a degree in sociology. But he did not like that doctor either and never went back.

“I would just see my doctor when I came home for breaks. I didn’t want to see another doctor, especially in D.C., where people might see me going in to a clinic and wonder what I have. I was only going to be there for four years, although I ended up staying for six. So during that time I wasn’t seeing a doctor as much as I should have,” Brawner explains.

This new transition is “totally by force,” he says. He needs adult services that his doctor cannot provide. The search for a new doctor took months of intense work for Brawner. “You have to figure out who’s good, what the hours are and everything else, and see the place in person, and in the meantime, you still want to see your pediatrician.”

One of the ironies of transitioning is moving from a children's hospital which is large by its nature to a much smaller adult clinic. The youth suffer over the possibility of trading their anonymity for the risk of being recognized as an HIV patient. "In a large hospital, nobody knows what you're going in for," says Brawner.

Martin says the worry about confidentiality the young patients of her clinic experience often evaporates. "It's like that worry about support groups—'Am I going to see someone I know?' I tell them, 'Then they're there for the same thing.' Or they say, 'I don't know anybody there.' They have a sense that the people in the new clinic won't care, but they don't know that unless they go."

She does recommend, however, that youth be introduced to at least one person at their future clinic "so there's at least one friendly person there they know."

She says the youth she works with sometimes find out their anxiety was needless when everything works out and they're happy with their new provider. "It's just not going to be the coddling and babying and calling 10 times for each appointment that they're used to," she notes.

She also recommends that the provider discuss transitioning at least a year before it takes place. Young people should also be told what other services and support are available in addition to medical care—"That would be encouraging." At the University of Chicago Children's Hospital, social work is provided for youth with HIV for a year after they leave. "Here they can also stay with the same case manager, so they're a little less reluctant to move on."

**"TO TRUST NEW PEOPLE—  
IT'S JUST A LOT."**

The difference between an adult clinic and youth care should be explained. "Let them know the follow-up isn't going to be as good," Martin says. "Here we have 115 kids up to 22 years old. The adult clinic has 600 patients and they have only one social worker and no case manager. They don't take as much time on anything, whether it's medical or social or anything else. Can you imagine with the great number of people they have trying to keep up with everyone? We can spend an hour talking about adherence and they can't. At the same time, the patients are growing up and they need to learn to take responsibility for their own health. They want to be emancipated at some point and live their lives the way we all do."

Martin admires the process at the CORE Center in Chicago, where a doctor or nurse practitioner from the adult clinic attends the visits of the youth patient for one year before transition takes place. "That's a great model," she says.

Brawner recommends that young people talk to other positive people for suggestions and that they interview doctors. "Ask around. Make some phone calls. Figure out what you want the most in a doctor and get the one who has the most from the list." Also, check the facility in person. "If you don't feel comfortable, you're not going to go there."

He offers simple suggestions for clinics that may nevertheless be a tall order. "Make sure your environment is patient friendly. Make sure your environment is clean. Make sure your front desk receptionist has a lot of patience and doesn't have a negative attitude. Have someone available who can be reached 24 hours a day, seven days a week—this is a 24-hour disease. Have materials on hand so they can learn. Be timely—I don't want to sit there for eight or nine hours. Have confidentiality. I don't want everyone to know that I'm walking into a clinic for HIV-positive patients."

"It's all a numbers game, a business," Brawner says, "but I want to be seen as a person." ✚

Visit Brawner's website at [www.williambrawner.com](http://www.williambrawner.com).

#### FREE CONDOMS

When I visited a friend in Colorado recently, she asked if I could bring condoms for a teenage girl she watches over. (TPAN provides condoms for free.) When I visited my young adult niece for a family get-together, she asked if I could bring her some condoms, especially the female ones, which are much more expensive than the male ones. And at last year's Gay Pride Parade in Chicago, teenage girls made up most of the people rushing TPAN's float for the condoms we were throwing out into the crowd.

I had never stopped to think about it—we push condoms for everyone, but at a cost of about eight bucks a pack for three male condoms, teenagers are at a distinct disadvantage for getting them. Then, as I worked on this issue, the *Washington Post* ran a story that began, "In Washington, D.C., where one in 20 residents are HIV-positive, an informal survey found nearly half the leading drugstore chain's stores, 22 of 50, lock up condoms."

It went on to report that stores in poor communities were most likely to keep condoms under lock and that a Planned Parenthood director said "the practice puts sexually active teens at risk." Teen girls told the agency staff that they were either too embarrassed to ask for condoms or were given dirty looks and lectured on being too young to have sex. The *Post* went on, "Many girls left the stores empty-handed and ashamed, but still likely to have sex, she said." A spokesperson for one drug chain said the added security was for preventing thefts.

But, teenagers, there are lots of free condoms out there! With luck, you'll be near some of these places and they'll have them.

- HIV service organizations (call 1-800-342-2437 for the one nearest to you)
- Gay bars (often, but not always, have free condoms)
- Gay pride parades, usually throughout the summer

It could be tricky, but figure it out.

You can also get a better price at places like Costco and Sam's Club.—*Enid Vázquez*



# Voices of Hope

A group of young adults, out to change the world, one stop at a time

by Jeff Berry



DePaul University is located in the trendy, upscale neighborhood of Lincoln Park in Chicago. It's an unseasonably warm, sunny spring afternoon in April, and there are large, red ribbons tied to the trees which line the streets of this picturesque campus of around 25,000 students. A large, non-descript RV rolls up in front of the student center, arriving 20 minutes late. Five young adults dis-

embark with their luggage, barely noticed by the dozens of students walking by.

Today is the Chicago stop on the Road to Hope Tour. Founded in 2004 by Todd Murray (see sidebar) and Danielle Rivera, the non-profit Hope's Voice orchestrates this annual speaking campaign which promotes HIV education and prevention amongst young adults.

Josh, 24, is the first one to step off the bus, and it's his last day on the tour. They all

seem a bit tired, and glad to be off the bus. "We sleep whenever we can," Josh says half-jokingly. "We just came from Iowa. It was really cool, we had over 100 people show up." He's on break from grad school and only heard about the tour three months ago, through a friend who did a stop last year.

Josh wants to be a guidance counselor at an elementary school when he finishes school. "I work with kids at a camp, kids with hemophilia and kids with HIV." Josh has hemophilia himself, and found out he had HIV at an early age. Although they've asked that only their first names be used in this article due to a string of recent threats, all the members of the group say that they are pretty open about their HIV status. Says Josh, "My whole community back where I live in upstate New York knows. It's kind of hard to scream out in New York City, 'I have HIV!'—but my friends do know. And as I meet more people, it's always a different way in how I try to tell them [about my HIV status]."

"It's a little crazy, because there's always something that happens [during the tour] that's not quite right, but it always falls together," states Aaron, 22, the group leader, and the only member of the group who is HIV-negative. "It never starts on time, and by the time it's over, it changes everyone's life in the room, including us. We learn something new about each other every time."

Aaron will be with the tour the entire five weeks—the other speakers generally sign up for shorter, one-week stints. The tour kicked off on April 3rd at George Washington University in Washington, D.C.

Photo © Russell McGonagle





and stops at college campuses along the way in places such as Waco, Texas and Lincoln, Nebraska, with the final stop in Williams College in Williamstown, Massachusetts on May 5th.

Today is only one of a series of weekend-long events that they are involved with in Chicago, including one tomorrow at a local GLBT (gay, lesbian, bisexual and transgender) youth drop-in center for at-risk teens. There they'll hang out with the kids, show the Road to Hope video (from last year's tour, which recently aired on MTV), answer questions, and just "chill."

**IT'S THE CONDOMS, STUPID**

Traci Ackron, 21, heads up the DePaul AIDS Project, which is run out of the University Ministry. She is on the Steering Committee of the Student Global AIDS Campaign, a national student-based grassroots AIDS organization, and this is the second year in a row that she has been involved with bringing the Road to Hope Tour to DePaul.

"We are not allowed to distribute condoms on campus," explains Ackron. "It's a Catholic institution, and they... see condoms solely as a form of contraception. You can talk about condoms, and demonstrate how to use them, you just can't distribute them." They are, however, allowed to bring in different organizations to conduct testing. Last week they tested 80 people during their AIDS awareness week through the Broadway Youth Center, a collaborative program of Howard Brown Health Center in Chicago, which provides free services for GLBT youth ages 12 to 24.



**I'M READY FOR MY CLOSE-UP**

As the group prepares for their photo shoot, Marvelyn, 21, wanders off. She's just finished a taping for the Tyra Banks show earlier in the day, and wants to find a television so she can view the episode.

I continue talking with the other group members during the shoot. There's Duane, 27, who runs a non-profit in Boise, Idaho called ALPHA (Allied Link for the Prevention of HIV and AIDS), an all-volunteer prevention and care organization. William is wearing a bright, orange T-shirt with the words "HIV+" and "Educate Yourself" boldly emblazoned across the front. Every-

one in the group received the shirt from the folks at Baylor Medical College in Texas during a recent stop.

William, who's 26, has had HIV since he was 18 months old, when he received a blood transfusion after being badly burned. I look, but can see no visible scars of the burns from his childhood.

**LET'S HEAR IT FOR THE GIRL**

That evening, the speakers gather in the lecture hall to share their stories with the audience. As people filter in, Marvelyn is positioned at a table outside the door, taking donations for Until There's a Cure bracelets, and for books and videos about HIV.

Marvelyn begins her story by talking about a boy she met who she thought was her soul mate. "He was 24, he had his own place, his own car, he looked good, he smelled good... I mean, he had it goin' on!" She thought he was everything. She bragged about him to all her friends. He told her he loved her.

One day, when he didn't have a condom, she said, that's okay. "I was happy. I felt privileged," she explains. "I had no problem seeing him as my baby's daddy!"

Weeks later, she thought she was pregnant, but found out instead that she had HIV. She was 19 years old. "I didn't have any initial reaction. I didn't cry. I didn't know anything about HIV." She desperately needed to talk to someone. She called and told her best friend, who said she'd be right over. "Then, I called another friend," continued Marvelyn, "And, she was like, 'Whoa! I'm sorry, Marvelyn, I know you're supposed to

be the godmother of my child. But you can no longer come around me or my child with HIV? I wish she would have told me that before I bought that crib and car seat!”

Marvelyn’s message is simple: You have to take responsibility for yourself. “I can’t blame him,” she says about the young man who infected her, “I can only blame myself. I put more trust in him than I did in myself. I trusted him to care about me, but no one can care about you but yourself. It’s not who you are, but what you do, that puts you at risk for HIV.”

#### SMALL TOWN BOY

Duane grew up in a small town, and the first thing he wanted to do was get out of that town. He moved to Phoenix to go to college. He got tested for HIV, and before the woman who gave him his results had even closed the door, he heard the word “positive.” “What do you mean, positive?” he asked. She told him, “The results of your test came back—you’re HIV-positive.”

“When they told me I had HIV, they might as well have told me I had AIDS and I was going to die,” says Duane. And he thought it was going to happen soon. He felt he needed to tell his family right away, before they found out later on, after he got sick, or maybe even died.

So he caught the first plane home, and it was Mother’s Day, “which was kind of a drag,” he says. His plan was to tell his family the next day, but it didn’t happen that way. His mom, dad, grandma, grandpa, and little brother were all there. “You guys have always been there to support me,” he told them, “and I hope that after what I have to tell you, you’ll still continue to be there for me.”

“I told them, ‘I have HIV.’ My grandma ran over, and she gave me a hug, and she said, ‘It’s okay, everything’s going to be alright, we still love you!’ My dad stood up and said, ‘Well, happy fuckin’ Mother’s Day.’ My mom cried hysterically, I’d never seen her cry like that before in my life. And my grandfather said that I had broken my father’s heart.”

“I didn’t know what to say, I mean, what do you say? I didn’t really expect them to react any differently, but since then, they’ve all kind of helped me in their own way.”

Duane has been positive for seven years, and things are going well in his life. “If you get HIV, you don’t have to give up,” says Duane. “You don’t have to crawl under a rock. You don’t have to turn to alcohol and drugs, which I did for a while. You can find hope. Your family, your community, some people they may or may not be there, but there will be people who will be there, and there will be more people eventually.”



#### PHILADELPHIA FREEDOM

William (see page 19) is from Philadelphia, and says that “being HIV-positive and being a young adult is the hardest thing in the world. You have to hide your medications, and you have to hide the fact that you’re positive.”

William never told anyone his status for 18 years. He was in denial, and fearful of the stigma attached to being HIV-positive and how it could affect him.

“Sometimes,” says William with a wry smile, “when sex crosses from the living room, to the bedroom, to the bathroom—the condom may not make it.” Once, after he and his girlfriend had finished having sex, he looked down, and the condom wasn’t there. He didn’t know what to do. He hadn’t told her he was positive, and he was too scared to tell her then. So he ran, and they broke up.

“If you are with a person, and you think you know everything about that person, you’re just kidding yourself,” says William. “HIV is just another secret. I was with my

girlfriend for one year and I never told her that I was positive. Most people in this room, if you were asked by your spouse or partner how many people you have had sex with—most of you are not going to tell the truth.

“So don’t assume that people are going to tell you the truth, they may be in denial, and they may fear rejection. The stigma attached to HIV may be the strongest thing on this earth.”

#### I LOVE NEW YORK

“I’m from the Big Apple—New York City,” begins Josh. “My life with HIV is pretty much all I know. It’s me. It’s who I am.” Josh was born with hemophilia, a blood clotting disorder. He found out when he was 4 ½ years old that he was HIV-positive. When he was nine, he got really sick, and he’s been taking meds ever since. “I thought life was going to get easier as I got older,” says Josh, “because people are more knowledgeable. As I got older, life got harder.”

Relationships, for Josh, are the hardest part. He says that life is about feeling like you’re somebody, like you’re worth something, like you’re worth having a friend, and about being accepted.

He had a best friend from when he was about 2 ½ years old until he was seven, and they were inseparable—they did everything together. But he lost his best friend because he was open about his status, and it wasn’t cool with his friend’s parents.

“It’s hard because I need a circle of people around me, to help me,” Josh says. “And at some point in my life I will find someone who will care about me and want to share my needs, and be there in my life.”

#### AND A CHILD SHALL LEAD THEM

Jasmine and her mom, Leslie, live in Lake County, Illinois. Jasmine is in the fifth grade, and found out about the Road to Hope Tour through Camp Kindle, a camp in California for kids with HIV. Many of the speakers on the tour become camp counselors for the kids, explains mom.

“After they meet them, they just can’t help it. Your heart goes out to them,” says Leslie. “For one week, the kids just get to be themselves.” Leslie is a long-time friend of Jim Pickett and Shelly Ebert, both of

AIDS Foundation of Chicago, and through them had an opportunity to meet recently with U.S. Representative Mark Kirk (R-IL), a “hardcore Republican,” helping to sway Kirk’s vote on pending legislation. “The best way to somebody’s heart and their purse-strings is through a child,” says Leslie, barely cracking a smile.

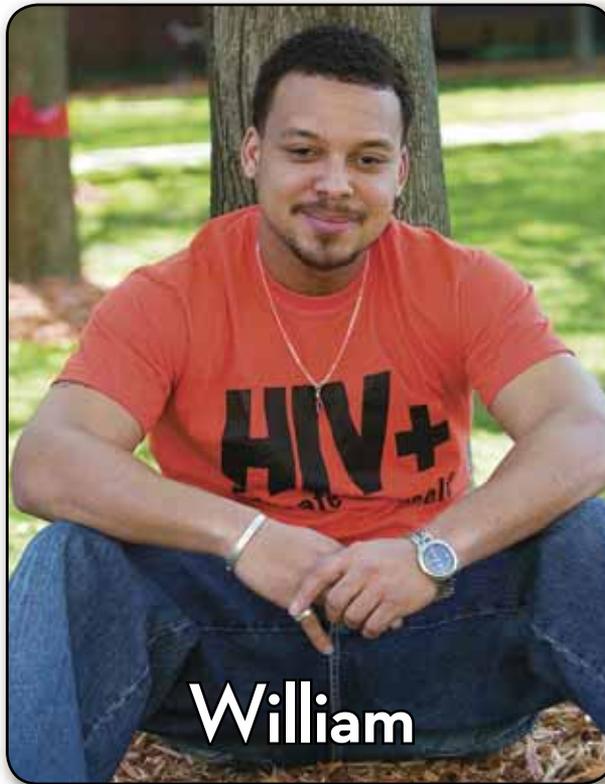
When Jasmine speaks to the audience, it’s difficult to hear her soft voice from where I’m seated in the lecture hall. She reads from a worn slip of paper, and I ask her mom later for a copy.

“Hi, my name is Jasmine, I am in the 5th grade at my middle school, and I have HIV!!! I am the only person in my school who has HIV. Once in a while I get sad because I can’t tell anyone in my school I have HIV, because they might laugh at me or their parents won’t want them to play with me or be around me. I am just like any other 5th grade kid. I like doing cartwheels and splits, I’m on the cheerleading squad and I get good grades.

You see, I was born with HIV. I got it from my mom. My dad also had HIV. I get scared sometimes that my mom might die. My dad died when I was four years old, and it’s been me and my mom since then. My mom has been giving me my medicine since the day I was born.

“My medicines used to make me very sick when I took them, but now I have a g-tube that’s in my stomach and they don’t make me sick anymore. I am lucky because I get my medicine. There are lots of kids in the world who don’t get medicine and they are dying. I am also very lucky because I get to go to Camp Kindle. I heard about camp at my doctor’s office. I was really excited to go to camp because I got to meet new people my age with HIV or AIDS or their parents have [it]. This will be my fourth year at Camp Kindle. While at camp I get to hang out with my friends and swim all day long!!! Camp Kindle gives me the chance to share my story through the SPEAK-OUT program, [which] stands for Sharing Personal Experiences and Knowledge: Our Unique Truths. When I share my story I get very nervous, but I like telling people about HIV and AIDS because we are no different than them. You don’t have to

be afraid of kids with HIV. They like rollerblading, bike-riding and just hanging out with friends. You can’t get HIV from being friends with them so remember: KIDS WITH HIV ARE JUST LIKE YOU. I am 11 years old and I have HIV and I am just like you, a kid that likes to have fun and make my mom mad. Thank you for having me here and hearing my story.”



William

#### LIKE DAUGHTER, LIKE MOTHER

Leslie, Jasmine’s mom, was born and raised in Illinois. “I’m the typical Jewish American Princess,” says Leslie in a gravelly voice that’s somewhere between Tallulah Bankhead and Brenda Vaccarro. Her story is anything but typical, but definitely from the heart. “My mother died when I was 17, by the time I was 17 ½ my father put me out on the street,” she continues. “After 2 ½ years of being in Chicago, I wound up in the penitentiary, and by the time I was 24, I was on my second jail term.

“You take the good with the bad,” says Leslie. “When I was in jail, I called my father, and he said, ‘How much money do you need?’” She told him she didn’t want his money. “I’m calling to tell you I’ve been diagnosed with HIV. I was informed not to call him until I was dying. I was 24 then, I’m 42 now—and the only thing I can tell him

is, ‘Sorry, you sonofabitch, but I’m gonna outlive you!’

“I went on every medication there was when I found out I was pregnant. I didn’t drink any alcohol, I even quit smoking while I was pregnant,” Leslie states proudly. “I just knew my baby was going to be born negative—I did everything I was supposed to do.” But it didn’t work out that way, and Jasmine was born HIV-positive.

Leslie says there is a reason for everything that happens in this world, there is a purpose. “My reason for getting HIV was to have a beautiful, beautiful daughter who could go out and speak to people, and educate them.

“People don’t realize that the person sitting next to them could be HIV-positive,” Leslie tells the audience. “It doesn’t matter if you’re old, young, gay, straight, black, white, green or purple. All that matters is if you didn’t put a condom on. So 26 years from now, *you* could be standing up here telling the story of how you got HIV, because you forgot that condom,” she tells them. “Or, you could use a condom, and get yourself tested.”

#### ON THE ROAD AGAIN

The speakers stay onstage afterwards for a brief Q&A. William, when asked where he sees himself in 10 years, says he’ll be finished with his Masters degree and head of his own non-profit organization. Josh will have his Masters and hopes to be married. Duane says he’ll be married, with kids. “I’ll be a daddy,” he says with a smile.

During the train ride home that evening, I think about all of the different people I’d met that day, and discover a common thread woven through each of their unique stories. The desire to make a connection with others, to find a way to give back something to their communities and to their peers, and to strengthen their resolve to never give up hope for a better future.

As Josh says, “HIV is the card I’ve been dealt—and I’m going to use it to teach.” ☞

*To find out more about Hope’s Voice and the Road to Hope Tour, visit [www.hopesvoice.org](http://www.hopesvoice.org). For more information on Camp Kindle, visit [www.campkindle.org](http://www.campkindle.org).*

## THE HISTORY OF HOPE'S VOICE

*Interview with Todd Murray*



*Jeff Berry: Can you give a brief history of how Hope's Voice was founded?*

*Todd Murray:* Hope's Voice was founded in 2004 while attending the Ryan White National Youth Conference. I did a speech on young people living with HIV and AIDS using their voices and faces to educate and end stigma for all those living with HIV and AIDS. After making the call for action, several young adults approached me about doing this type of work year round. The passionate, driven and inspiring young adults I met needed an agency that handled press, contracts, accounting, and let them do what they do best... educate their peers on HIV and AIDS. Hope's Voice was born.

*How do you select speakers for the Road to Hope Tour?*

We are always interested in finding new speakers. Our key demographic is young adults, and we accept speakers within the age range of 18-28. However, we do make exceptions from time to time. What we typically look for is someone who has the ability to relate to young adults, and is comfortable speaking in public settings and sharing their experiences living with HIV or AIDS. Part of our program is peer-to-peer education and giving the audience a personal connection to the disease, and we look for those who are comfortable disclosing their status. Speakers for Hope's Voice not only speak on the Road to Hope Tour, but year round.

*Do you ever encounter resistance to your work on campuses?*

For the most part we do not encounter resistance on campuses. Hope's Voice programs are brought to campuses by stu-

dents, which can improve acceptance for our program and communication on HIV and AIDS. Students advocate for our program and are doing the logistics on their campus and community. Hope's Voice and this message still face resistance on a national level and at many religious institutions. We address this problem by not telling students what to do, but just simply telling our story and letting our peers make their own conclusions. This form of peer-to-peer education allows us to get into institutions that wouldn't allow this type of education in the past.

*How did the documentary come about?*

The Road to Hope Tour documentary came together at the last minute. I wanted to show young people the process, frustrations and joys of building a non-profit, showing them that we can make a difference and that difference can come from a drive and passion towards a cause. I also wanted the documentary to serve as an introduction to a group of young people living with HIV and AIDS, each telling their story and showing the "behind the scenes" of the tour. It allowed those who couldn't attend a tour stop to still get an HIV encounter. The documentary is being used by education institutions and health departments across the United States.

*Where is a good place for youth to go for more information on HIV and AIDS?*

It depends on what they are looking for. Hope's Voice has a student center that has links to resources on education and testing, and a reminder service that the visitor can use to send routine reminder e-mails to get their STD tests. There are so many resources out there that if a young person is looking to get educated and can't find it in their home, school or community, use the Internet.

*What do you think is the most important thing our readers should know about youth and HIV?*

Readers need to know that communication is key in fighting this epidemic. We need to create an open, safe and comfortable environment for young people to talk about their concerns, get correct answers to their questions, and get educated on HIV and AIDS. With half of HIV and AIDS infections in young adults under the age of 25, it's time to start looking at new approaches to address the epidemic. ☒

# Having a Ball

A look at an underground youth community that has taken HIV prevention and awareness into its own hands

by Keith R. Green      photos by Frank Leon Roberts

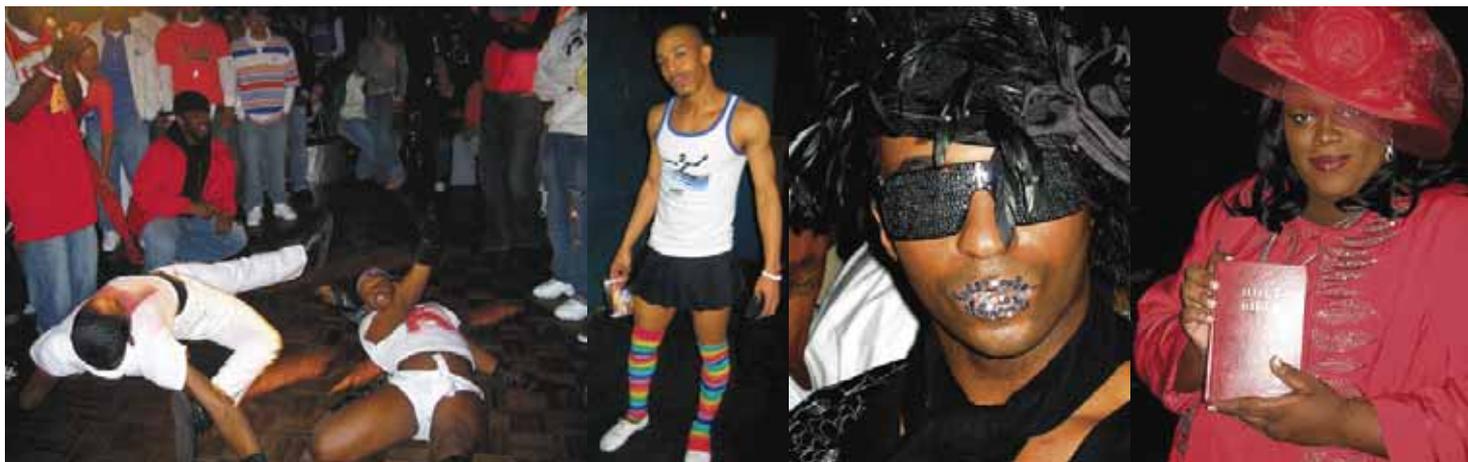
In a world where the influence of hip-hop dictates one's sense of style, speech and masculinity, many Black gay youth have a difficult time finding their way. Safe spaces where they can explore their gender and sexuality are few, far and in between, likely contributing to the extremely high prevalence of HIV and STDs among this marginalized group of young people. Hundreds, if not thousands, turn (or are pushed away) from their traditional families and are forced to fend for themselves in order to survive.

Many, however, find refuge in a small community that celebrates self-expression and encourages them to explore and define who they are for themselves. Here, they are given the tools they need to create their own realities and to live fully inside of their own truths.

center, there are sizeable ball communities in several major cities across the country, including Chicago, Atlanta, Detroit, Philadelphia, and Los Angeles.

Though it is derived from a highly competitive institution, the ball community is more about social networking than it is about competition. It is made up of more than 35-50 nationally recognized and active houses, each named after a different fashion designer extraordinaire (House of Chanel, House of Escada, etc.).

Houses serve as makeshift families for many GLBT (gay, lesbian, bisexual, and transgender) youth who would otherwise do without the support and nourishment provided from "traditional family households."



## HISTORY

The ball scene dates back to as early as the 1920's. The first balls were basically drag pageants, organized and thrown inside of grand ballrooms in Harlem. They were competitive in nature, with structures similar to other events in the Black cultural tradition—such as cotillions, step shows, and carnivals.

Balls as we know them today are centered around several aesthetic categories, including Face, Body, Realness (which is often a play on Black masculinity), Fashion and Vogue (made popular by the classic Madonna hit by the same name). Cash prizes and trophies are the most common rewards. However, any ball kid (as members of this community refer to themselves) will tell you that the ultimate goal of competition is community recognition and status.

## COMMUNITY

In order to understand this concept, one must first become familiar with the ball community—which is slightly different from the ball scene. While New York City is still recognized as its epi-

## A TRUE HOME

Each house consists of a house mother and a house father, usually both male and not necessarily defined by degrees of masculinity (or the lack thereof). The roles of house parents are similar to those of "traditional family households," where the mother lays down the laws and the father enforces them. Both exist to ensure that their "children" have everything they need to grow and develop into healthy, productive human beings.

"Belonging to a house really entails membership, and is, in and of itself, about belonging," says ball kid and scholar Frank Leon Roberts. Roberts, also known as Frank Mizrahi of the House of Mizrahi, has been actively involved in the ball community and scene since early 2002. At 23 years old, he is a doctoral candidate at New York University, in the Graduate School of Arts and Sciences and the Tisch School of the Arts.

"Houses are basically social networks similar to fraternities or sororities," he explains. "People network within their houses for jobs and resources that they are often otherwise refused."

Roberts goes on to explain that many of the kids actually live with their house parents, because they have been ostracized by their biological families for being gay or transgender (or sometimes simply for questioning) and have no place else to go.

“You will often find very young kids—12, 13, 14 years old—who are questioning their sexuality or their gender,” he tells me with wisdom way beyond his years. “It is often the only place where transgenders can celebrate their gender transition free of judgment.”

While many social service agencies make attempts at outreach to the ball community, its underground nature and transient population make efforts done out of good intention oftentimes unfruitful. Roberts describes it as a marginalized community within a marginalized community that many people, including other Black gay men, just don’t get.

“The scene comes out of the community. Therefore, you can’t just do the work at the balls, you have to do the work within the community,” Roberts says matter-of-factly. “You have to be connected to the ballroom community. It has to be hand in hand.

“The work that the ballroom scene does, in and of itself, is that it provides a self-affirming space for Black gay men to be themselves and to play with gender, and to affirm their gender ideas and sexual identities. It provides a recreational space that truly is intervention on the ground level. It is the only place where these types of gender performances are celebrated.”

While he believes that traditional outreach is necessary and that people should be encouraged to practice safer sex and use condoms, Roberts also stresses that outreach to this population has got to be considerably more involved. “The problem with telling people to put on a condom and protect themselves is that you assume that they have a positive sense of self worth and identity,” he says. “But if you have been systematically taught to devalue your life and your body, then why the hell are you going to protect yourself?”

#### CHI-TOWN HOME

The agenda of a Sunday evening family meeting at the Chicago chapter of the House of Omni absolutely supports this theory.

House father Kenny Omni has been involved in the ball community since 1989. He has seen firsthand the devastation that HIV and AIDS has inflicted on Black gay men, both young and old. Having only recently been able to have any type of productive dialogue with his own mother regarding his sexuality, he does not take his role as house father lightly. He understands that his influence is oftentimes the only parental guidance that many of his “kids” will ever know.

“This house is different from most other houses in the ball community,” he says seriously. “I don’t push the balls on my kids. Don’t get me wrong, I enjoy the balls and love for my house to be recognized within the community,” he explains. “But more important than that, to me, is seeing to it that my kids succeed in life and realize their potential to be whatever they want to be.” And, based on the level of success that many of Omni’s members have attained thus far, Father Kenny Omni is achieving his goal.

Darren Omni recently produced remixes for the Kanye West and Brandy hit *Talk About Our Love*, and Natalie Cole’s *Tell Me All About It*. While he refuses to share his real age with anyone in the group, Darren has been a member of the House of Omni for more than eight years. He says that he got involved strictly for the social aspect of it, not necessarily for the balls. “I enjoy the camaraderie

that I have with my brothers and sisters,” he says. “I have never really been interested in walking in the balls.”

The exact opposite is true for 20-year old Bambi Omni, who is a professional dancer with Deeply Rooted Productions (a dance troop based out of New York and Chicago). “I don’t live for the balls,” he says. “But the balls live for me.” His animated remarks cause his house brothers to burst into laughter as he demonstrates the unique way in which he works the runway. “I give it to the children.”

Though he fully enjoys being a part of the ball scene, Bambi’s life is a perfect example of what it means to not get caught up in it. He walked into today’s meeting with news that he has been selected from thousands of dancers to perform in the opening and closing ceremonies for the Gay Games, to be held in Chicago in July. He is also an honor student at the American Intercontinental University, where he majors in business administration.

He moved out of his parents’ home at the age of 16 and has never looked back. “When I came out to my family, they called a family meeting and folks I hadn’t seen in years [came] from all over the country... to exorcise the ‘demon’ from me,” he shares. “I sat there with my Louisville Slugger clutched under my arm and dared those girls to try it. From then on, this community became my family.”

#### GROWING UP

Sex and sexuality are discussions that are constantly on the table for the House of Omni. Father Kenny Omni is a member of the Friend-to-Friend Network (see November/December 2005), and requires that his “kids” not only participate in educational sessions about safer sex practices and HIV, but also has an unspoken rule that they be involved with community events to raise awareness and money to support the efforts of AIDS service organizations in the GLBT community.

“We had 12 members participate in the AIDS Walk last year,” says Fred Omni, who is a prevention case manager for a local HIV/AIDS organization in Chicago. “Not that we were resistant, but we weren’t given much of a choice in the matter,” he jokingly explains.

“In other words,” Bambi chimes in. “Kenny was going to put us out of the house if we didn’t show up.” The entire room bursts into laughter again, but Kenny Omni doesn’t crack a smile.

“I take this very seriously,” he says. “This is such a serious issue that affects all of our community. If we don’t do something about it, who will?”

The House of Omni also takes a serious stand as it relates to underage drinking and substance use/abuse among its members, another hot topic that draws lots of negative attention to the ball scene. “We have a zero tolerance policy on matters such as these,” he says sternly. “There is no place for any of that in this house.”

When asked his perspective on the substance abuse issue that exists within the ball scene, Frank Leon Roberts had this to say: “I don’t know if substance abuse is any more of a problem within the ballroom scene than it is in any other queer recreational space.

“Whether it’s the club scene or the sex party scene or whatever recreational scene it is, drug use is a problem in the gay community in general,” he adds. “But because no one is doing that work and doing that research and doing those surveys with the ballroom community, the entire scene gets stigmatized. Regardless of the situation, however, it is still no excuse for resources to be denied, which is often what happens.” ☚

# “Live Fast, Die Young”

Born with HIV, a young man's story of addiction and survival

Interview by Enid Vázquez

**A**rlo Andrade is 19. He was born with HIV and found out he had it when he was seven. When he was diagnosed with AIDS a year later, he began speaking in his school about HIV to educate other kids about the virus. As a result, he was beaten up, although most of the other children were supportive. He was also struck with stigma that followed him up through high school.

Andrade fell in love with movies for their ability to take him away from his pain for a short time. A creative writing class in seventh grade also eased his pain, and he still writes short stories and poems. But as an adolescent, he found that drugs were the easiest way to take away all of his emotional pain, and he became an addict. Two years in a treatment facility helped him recover and today he has goals for his future. He's a beautiful, bright, and articulate young man. These are his words.—*Enid Vázquez*

## POETRY AND SHORT STORIES

I only write about addiction and not HIV. The people who know me know that's where it comes from. I hated life and I wanted to take everything I could get my hands on.

## THE MOMENT

The day I found out, I remember it clearly. I was seven years old and my mom was dropping me off at school. When I got out of the car, I turned around and said, “What do I have? I know I'm sick.” There is no way to back off from a question like that.

The reason I asked is that I was taking all these medications. It wasn't talked about a whole lot. I had physical pain from taking ritonavir [Norvir], full dose. It killed my stomach.

She told me I had HIV. I knew what it was, but not really.

That's when I became depressed, when I realized I wasn't a normal kid where I could go out and just have fun.

## BULLYING

A year later I got an AIDS-defining illness. That's when other kids found out. I had a PICC line. People know you're sick, you can't hide it. I talked about it, wanted to educate other kids. When I came back from my month away from school due to being sick, most everyone supported me coming back and welcomed me back with get well cards and so many hugs. I felt really loved, but still didn't fully understand why I got so sick.

During my fourth or fifth grade, a kid called me “AIDS boy” and I beat the hell out of him. Even my friends got picked on. They got called “faggot” and things like that.

I was on the Oprah show when I was eight [he read from a book he wrote for Chicago's Children's Memorial Hospital to help kids deal with HIV]. After that—surprisingly enough—I didn't get picked on. If anything, I guess the kids grew up emotionally and were happy for me. But then my picture was in a book called “The Faces of AIDS” [produced by the Chicago Department of Public Health] when I was 12, and that got me beat up.

## A NEW SCHOOL

In junior high, I had a creative writing class and I learned to write about my pain. I ended up graduating with honors from eighth grade, and I never thought that would happen.

But the kids who moved on to junior high

with me opened their mouths, and from there it went on to high school. Oak Park [a middle-class suburb on the Western edge of Chicago] is a small town and in the teen world everybody knows everybody's business. Nothing's secret.

As a teenager living with this, kids don't realize how important it is to keep confidentiality. It's nobody's business. If they talk,



I can meet someone down the road who will judge me off of that. I can't tell them and explain it.

#### ADDICTION

When I got older I decided I didn't have a future and I was just going to have fun. At the 8th grade dance, I got drunk. After that, going into freshman year, I started to drink more heavily and started smoking weed. Then I went on to Codeine, Special K, Xanax, Valium—to name a few. I was losing reality. At the time I didn't know that's what I was doing. I wasn't feeling my pain any more. In my first year I started doing heavy drugs.

In 2002 I snorted heroin. I never slammed it. I'm so scared of needles. I know that's ironic for someone who has regular blood draws and 11 tattoos.

Heroin is the best high of your life. But it ruins your life.

#### DROPPING OUT

I didn't make it through even one year of high school. If you tell the teachers, it makes the harassment even worse. That's why you have things like Columbine. If things had gotten worse and I had stayed in my school for all four years, I would have done something to my high school.

I don't remember a whole lot because I drowned most of it out. I was just thinking I want to have fun. [Andrade has a tattoo that says, "Live fast, die young."]

Hanging out in the park I was accepted. It felt good being a part of something. I could talk and hang around them [other kids] and not worry about being harassed.

#### TREATMENT

My problems got bigger than they were to begin with. In December '02 I went into treatment for almost two years, at two different places. Before that, I was hospitalized for the same reason. My way of life wasn't working for me. It isn't working for anybody.

The people in treatment [in Knoxville, Tennessee] were incredible. They gave me another family that will always have my back. Whenever I go back to visit it feels just like a second home. Thank you, all you cats in Knoxville, for helping me get my shit back together.

They also got me to look at parts of my life that I didn't know existed. Subconsciously I'm angry at my father and angry at my mother. I knew I was angry at my dad,

but I didn't realize I was angry at my mom. [Andrade's father died before he turned two, and he doesn't remember him. He has a tattoo with his father's date of birth and "Mexico"—Andrade's mother is of European descent, including Russian.]

My underlying root is my health. I have no idea what my life would be like if I hadn't been born positive. I have no idea. Sometimes I think about it, but I know it's no use.

#### RELAPSE

I got too comfortable at the treatment center in Knoxville. I didn't want to leave. Meds twice a day. Three meals a day. I learned everything I could there. I went to another treatment center [in League City, Texas] and left against medical advice. I hated it. They didn't even bother to put me in the best program they had. I was watching TV about quitting cigarettes and

*I have no idea  
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I have no idea.*

I had been snorting three bags of heroin. I said screw this.

I went back to heroin, but then I was sober for six months, until I fell in with a party crowd. I wanted to go back to my way of life.

#### SUICIDAL

I was using cocaine and Ecstasy, and drinking a lot. I stopped that because I was in a suicidal depression.

I was staying with some people in a studio apartment on the North side [of Chicago]. One day, very early in the day, around three or four in the morning, I decided that I'm either going to go to AA or I'm going to kill myself. I didn't know how to use the El [subway] but I got on the train and got to Forest Park [where the AA club is located, a suburb 15 minutes away from his home].

#### RECOVERY

I had attended an AA meeting in Forest Park when I had a home pass from the treatment center [in Knoxville] and I went back. It's been helpful. What I learned in rehab has also helped me. I had a better head on my shoulders. I knew that what I was doing was wrong.

Dwelling on [your pain] is what gets to people. That's what gets you back to drugs.



#### THE VIRUS

This disease is fatal. But it also can be controlled. It's not something you have to fear. "Oh, my God—HIV. I'm going to die." "He's going to give it to me." "I can't drink from his soda." It's serious and it's not serious. You can share a soda, you can share a fork, you can share a toilet.

Sex is serious. You have to use a condom. My friends just want to get laid. (Well, I want to get laid too, but I know that you need to be careful.) You're playing with a

bullet. If you're doing drugs, the odds of you grabbing a condom don't look good.

#### SEX

I can't just go out and have sex. The obligation of telling a girl I have it is scary as hell.

What I see in my age group is that sex is just a game. Who can sleep with [the most] people. Who can be the biggest whore, in other words. Casual partners. One night stands. Those are nice, but yet they are very dangerous.

That's what boggles my mind. You have a friend who has it. You know it's in your community.

Yes, I'm jealous. I can't go out there and do that. But it's dangerous. There are people out there who will have sex with you and not let you know.

I'm protective as hell with my friends, guys and girls, especially the girls, because I know how guys think. They see a cute girl and they think, "I want to get with her tonight." And I'll just stand there trying my best to be intimidating. Even with how short I am—5'2"—I still can come off threatening if needed. "Don't mess with her." Sometimes they get mad at me [the girls].

#### GIRLS

I don't talk to them because I don't have a high self-esteem. My friends tell me go talk to her. I know I look good because my friends tell me I do. But I'm self-conscious. If they do [flirt with me], I'm oblivious to it.

I have hit on girls. I was always on drugs. Every girl I dated I was on drugs. I was always upfront about it. If I meet a new girl, then it's a problem. It's kind of hard to say something. If it's a group of friends, then they know. It's just that taking the chance of getting rejected because I have HIV is hard.

I'll ask a question. How do you feel about this or how do you feel about that, just to get a clue about whether to say something or not. I'm pretty blatant: "How do you feel about people with STDs or HIV?" I make sure it's not an awkward time. I always ask one-on-one, not in a group. "I'm cool with it" or "I've got no problems," that's usually the response I get. Usually they are. But sometimes they say they're okay with it and they're not.

I hate when they say, "Oh, I'm sooo sorry!" You know what? Get the fuck out of here. I don't need your pity shit.

Or when they say, "I understand." Really? Do you? Do you understand? Do you take meds that tear your stomach apart? Do you take medications that yeah, they save your life, but if you don't take them, you could die? That's why I refuse to talk with a therapist who says they understand when they've never had an addiction.

#### THE MOVIES

You lose yourself for a couple of hours. You just have fun for a little time. I loved *Saw 1* and *2*. I could relate it to myself in a sick way. The *Jigsaw* killer didn't kill anyone. He put his victims in a position where they could see how advantaged they were and to not to take life for granted. *Jigsaw* was a cancer patient. These people were assholes cheating on their spouse, drug addicted, a voyeur. They didn't have to take medications every day and deal with a life-threatening disease. I think that about other people. They're living a healthy life. Here I am with a ticking time bomb. I could get a cold and get very sick.

As I continue in my recovery, I see more that I do have a good life. I have two parents. Yes, one is a stepparent, but he loves me as much as he loves his four kids. My stepdad's oldest son was my best friend. That's how my parents met, driving us back and forth. I have four great step-siblings. Why should I feel sorry for myself?

#### GOALS

I want to start a tattoo shop. I want to get married and have kids. Then some little thing gets me down.

I'm not on psychotropic drugs, but I see light at the end of the tunnel. That's a cheesy way of putting things, but it's true.

I'm registering for business classes and working on starting the shop.

People who lose someone go in to get a memorial. [Andrade has one for a friend who overdosed on cocaine: "Spencer—Rest in peace."] It's healing. They'll look at it and remember the shop and say, "Yeah,

they helped me get through this time in my life." Or even just the pure pleasure of giving someone a piece of art that they want for whatever reason and in doing so making someone happy. There is no greater joy for me than to see people happy and if I can be the one to help make them happy, then it's all good.

I learned there's other ways of feeling good, other than being high. I don't regret anything I've done in my life. I think there's a difference between feeling bad and having regret. There's a difference between guilty and feeling bad because you did something wrong. If you have a conscience, you should feel bad. But there are only so many times you can say, "I'm sorry."

#### TODAY

I see myself as having a good state of mind. I'm not okay. I'm still

depressed. I'm still anxious, but with my addiction managed. I am back on my medications for HIV and still have the same struggles with those. But I see it this way: I have a life I want to live now. In the past, I didn't want to live or I feared the future. I am facing life head on. I *will* succeed in my dreams of having a tattoo shop and having a family with a wife and kids. I will be successful!

#### SURVIVAL

Doctors shouldn't tell people they're not going to live. A doctor told my mother that I wouldn't live for very long. My mother smothered me. I'm almost 20—it's time to let go. ☠

*Arlo Andrade received a Mustang from his parents recently, but the light of his life is his five-year-old bulldog, Toro, who goes practically everywhere with him. Andrade's mother, Eva Janzen Powell, was chairperson of the Community Constituency Group of the Pediatric AIDS Clinical Trials Group, a volunteer position, and is active in the struggle against HIV/AIDS. Andrade can be reached at [shorty\\_tattoo313@yahoo.com](mailto:shorty_tattoo313@yahoo.com) or online at [www.myspace.com/distortedstateofmind](http://www.myspace.com/distortedstateofmind).*



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## Care of the HIV-Positive Adolescent

Developmental stages and provider  
sensitivity play a special role

by Margo Bell, M.D

As I was leaving the stigma workshop sponsored by the National Minority AIDS Council in St. Louis in May, it was obvious that we physicians don't perceive ourselves the way others perceive us. Enlightened by a group of non-physicians about why patients don't feel comfortable talking to many physicians and how we perpetuate some of the stigma associated with HIV care, I was reminded of the recurrent theme that occurs in adolescent healthcare.

We (adolescent docs) have been trying to help physicians become comfortable with adolescent healthcare for years, yet the fact remains that many doctors never acquire a level of comfort in dealing with this group and thus choose to turf their care to us regardless of the level of intensity of the problem. With the ever-increasing rate of HIV infections in young people, physicians have to become familiar with taking care of them and implementing age-appropriate services to address all of their needs.

### THE NUMBERS

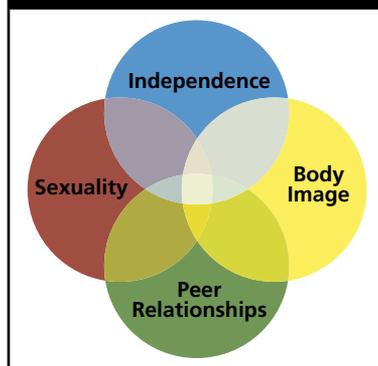
Statistics from the Youth Risk Behavior Survey (YRBS) conducted on 15,000 students in the United States in 2003 revealed that more than 60% of high school students have had a sexual encounter by their senior year, while condom use declines from ninth to 12th grade. A consistent theme exists in that youth today don't seem to think they are at risk of sexually transmissible infections (STIs) any more than they did in years past. Of the approximate 12 million new cases of STIs reported each year in the U.S., two-thirds occur in adolescents and young adults less than 25 years of age. Pus-producing and ulcerative STIs increase the risk of HIV transmission by four and nine times, respectively.

Half of all new HIV infections in the U.S. occur among 13–24 year olds, primarily due to sexual transmission, while AIDS is the sixth leading cause of death for young people 16–24 years old. Sex coupled with homelessness, abuse and other circumstances, especially lack of understanding of the needs of this population, puts them at risk. Adolescents in communities of color, just like adults, are disproportionately represented by this epidemic. Young ado-

lescent women and young men who have sex with men (MSM) are at greatest risk of infection. Since the beginning of the HIV/AIDS epidemic, MSM have consistently been found to have the highest rates of HIV infection in the U.S., while adolescents of color, especially African American adolescents, have shown a steady increase in HIV infection.

The demographics of Chicago's HIV epidemic share this pattern. According to the Chicago Department of Public Health (CDPH), MSM account for *over half* (52%) of the 20,850 AIDS cases in Chicago, and 43% of the 2,346 newly diagnosed HIV infections. Youth between 13–24 years account for approximately 11% of newly diagnosed HIV infections in Chicago, with young MSM of color leading the numbers of cases (65% are African American and 19% are Latino). In 2001–2002, young MSM accounted for 73% of all recently diagnosed adolescent males in Chicago.

FIGURE 1. TASKS OF ADOLESCENT DEVELOPMENT



### THE ISSUES

Young minority men who have sex with men (YMMSM) face multiple social difficulties in dealing with being both minority members and MSM within cultures that marginalize both groups. Various mental health and emotional challenges disproportionately affect MSM, which may lead to developing inappropriate coping skills and detrimental behaviors. These behaviors include the abuse of both disinhibiting and/or intravenous (IV) drugs; dropping out of high school; and high rates of depression and suicide. YMSM have consistently reported engaging in high-risk behaviors, including drug use (58%), chemical

dependency (17%), and suicide attempts (43%), all behaviors that put youth at exceptionally high risk for HIV transmission. Seventeen percent (17%) of young gay men report having engaged in prostitution, and 45% have a history of STIs. High levels of ignorance of how STIs are transmitted, in part due to the unwillingness of YMSM to talk to their families, health providers, or partners about issues of sexual health, also contribute to growing infection rates.

Young women, particularly minority youth, are vulnerable to HIV due to their partners being age discordant. Adolescent females often date men 20 and older, allowing for power inequalities to take

# HIV Treatment Series

place, such as condom negotiation. Many older male partners present a greater HIV risk as well due to the likelihood of having had multiple partners and of not knowing their HIV status. Adolescent females are more biologically vulnerable due to their large cervical ectropion. This is different from prepubescent females and older women.

## STAGES OF DEVELOPMENT

In order to understand the entities required to provide healthcare to adolescents, one must first understand their developmental tasks, as depicted in Figure 1. Adolescence can be a time of intense change. Adolescents transition from being concrete thinkers to becoming abstract thinkers (Figure 2) along a continuum. In the Early stage, independence-dependence struggles are heralded by rapid physical changes with the onset of puberty. The Middle stage is characterized by an increased scope of feelings, and increased importance of peer group values and more risk-taking behaviors. The Late stage represents emerging adults who have successfully transitioned into accepting responsibility for their behaviors. If their developmental task is interrupted (by things such as problems in the home, dropping out of school, substance use, or acquiring a chronic illness), that continuum is arrested or delayed, and they may never complete their developmental tasks or may have extreme difficulty in completing their tasks. The healthcare provider plays a vital role in helping the adolescent complete their developmental tasks, especially in the face of chronic illnesses. An understanding of this developmental pattern, though it may not be exactly the same in every adolescent, helps the healthcare provider evaluate an adolescent's behavior as it applies to their health.

## A MODEL OF SERVICES

In our Adolescent Medicine at Core (AMaC) program, a program primarily geared towards the care of HIV-positive adolescents and young adults, we employ the following principles of healthcare (See Figure 3).

- **Youth require adolescent-specific HIV services.** Service-system models must be adolescent specific and developmentally appropriate, taking into account youth's maturational processes both biologically and physically.
- **Youth need support during engaging and stabilization.** The basic needs of youth for food, housing and clothing must be met before medical care for HIV or any other issue can be effective.
- **Services must be comprehensive, seamless and integrated.** Case finding involves outreach, HIV CT (counseling and testing), and transition into care. Secondly, on-site (one-stop shopping) clinic services, medical primary care, mental health assessment and treatment, access to youth-friendly substance services, access to research, and case management. These services are linked so that there is the accurate perception of provid-

ers working together within one program, with each other and with the consumer.

- **Youth must be supported as they transition into care.** Actively link identified HIV-infected youth at outreach sites in the community to clinics and offer case management services.

**FIGURE 2. STAGES OF ADOLESCENT DEVELOPMENT**

	Puberty	Early Adolescence	Middle Adolescence	Late Adolescence
Females	8-11 years	12-14 years	14-17 years	18-21 years
Males	9-11.5 years			

**Figure 3. Entities involved in the transitioning process into healthcare**

CASE FINDING & PRIMARY HEALTHCARE (AMaC, CHRRPY, PACTG, ATN)*			
		CHRRPY	AMaC
	Unidentified HIV Infected Youth	←○	
↓	Outreach	↕	
	HIV Education		
	Trust Building		
	Referrals		
	HIV Counseling & Testing	←○	
↓	Age Competent Providers	↕	
	Engagement and Stabilization		
	Risk Reduction		
	On-Site HIV Testing		
	HIV Identified	←○	
↓	Engagement and Stabilization	↓	
	Risk Reduction		
	Transitioned into Care		←○
↓	Engagement and Stabilization	↓	↕
	Escorting into Medical Setting		
	Buddy System		
	Primary Care		←○
↓	Medical Services	↓	↕
	Mental Health Services		
	Case Management		
	Nursing		
	Retention, Adherence, Compliance		
	Buddy System		
	Access to Research		←○

\*AMaC-Adolescent Medicine at Core  
 CHRRPY-Chicago HIV Risk Reduction Program for Youth  
 PACTG-Pediatric AIDS Clinical Trials Group  
 ATN-Adolescent Trials Network

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## SUPPORT

Often after initial diagnosis of HIV, adolescents may not enter care for many months. Although parental involvement in HIV healthcare is a desirable goal, it is not mandatory and therefore consent by the adolescent is sufficient to provide evaluation and treatment for HIV infection. YMSM face being displaced from their home if they disclose their status, which they feel may out their sexuality as well.

One thing to keep in mind is that youth face many barriers that may occur at any point in the transitioning and care process (Figure 4). Hurdling those barriers is often more than the adolescent patient can handle alone. A multidisciplinary team can best

address these issues along with the adolescent. We know that youth are an important resource in responding to the HIV epidemic and we must therefore assist them to the point of being able to contribute to the process of finding solutions to the problem. It is not possible to treat adolescents unless they are part of the evaluation process, thus enrolling them in clinical trials is a must.

## RESEARCH

Initially, little definitive research was conducted with HIV-positive adolescents. Barriers to research don't start at the research level but are present at different stages of transition, starting with HIV counseling and testing, with the stigma of getting tested as a major factor, identifying youth-friendly testing sites and overcoming stigma associated with HIV, such as fear of the life-threatening implications of an HIV diagnosis. In addition, many adolescents are inexperienced in manipulating the healthcare system and may not trust healthcare professionals. Young MSM are a population that encounters significant barriers due to homophobia.

Although most clinical trials have been open to adolescents, they were not focused on adolescents. Enrollment had therefore not been a priority and as a result was poor. In 1994, the Pediatric AIDS Clinical Trials Group (PACTG) (also funded by the National Institute of Child Health and Human Development, or NICHD) developed the Adolescent Medicine HIV/AIDS Research Network to encourage participation by more adolescents in clinical trials. The initiative was formed to plan and conduct research on the medical, biobehavioral and psychological aspects of HIV and AIDS in young people. The network, composed of funds from NIAID, NICHD, NIDA, NIMH and HRSA, entitled its first study Project REACH (Reaching for Excellence in Adolescent Care and Health), in which 16 programs in 13 cities were granted funding, including the present AMaC program with Dr. Lisa Henry-Reid, chairman of the Division of Adolescent and Young Adult Medicine at Stroger Hospital of Cook County (the public hospital of Chicago), as the principal investigator for this site. This was the first large-scale disease progression study of HIV-positive adolescents infected through sexual behavior or injection drug use. Outcomes of the REACH study that looked at recruitment and retention of participants showed that the five most important factors for the participants were:

- (a) quality medical care,
- (b) caring staff,
- (c) health education,
- (d) privacy/confidentiality and
- (e) altruism.

Items that were deemed least important by participants included social activities, compensation, transportation and food/meals. It was found that both satisfaction with care and adaptive coping were associated with level of depression in HIV-infected adolescents. Another outcome of adolescent-focused research revealed that psychological factors may affect the success of implementing a research study for adolescents, while other research targeting adolescent girls and young women demonstrate special needs for promoting retention and adherence to research. Exposure to violence and potentially traumatic events and mental health issues required special attention. These factors served as potential hindrances to the research. In order to combat these potential downfalls, adolescent females were provided case manager's pager numbers, had

**Figure 4. Barriers to Primary Healthcare**

BARRIERS TO PRIMARY HEALTHCARE (BARRIERS IDENTIFIED BY YOUTH FOCUS GROUPS AND ADOLESCENT MEDICINE STAFF)	
Unidentified HIV Infected Youth	
↓	Lack of Knowledge
↓	Environmental Factors
↓	No Perceived Vulnerability
HIV Counseling & Testing	
↓	Insensitive Providers
↓	Structural Barriers
↓	Legal Barriers
↓	Requirements of Daily Living
HIV Identified	
↓	Personal Barriers (fear of testing to Post-Test Counseling)
↓	Requirements of Daily Living
Transitioned into Care	
↓	Requirements of Daily Living
↓	Structural Barriers
↓	Psychological Barriers
↓	Social Barriers
Primary Care	
↓	Insensitive Providers
↓	Legal Barriers
↓	Requirements of Daily Living
↓	Structural Barriers
↓	Psychological Barriers
↓	Social Barriers
Access to Research	
↓	Insensitive Providers
↓	Requirements of Daily Living
↓	Psychological Barriers
↓	Social Barriers
↓	Availability of Adolescent Specific Research/Clinical Trials

# HIV Treatment Series

arranged taxicabs and bus tokens, and a place to vent and express fears and emotions.

AMaC, under the guidance of Dr. Jaime Martinez, Director of HIV adolescent services for The Division of Adolescent and Young Adult Medicine and an adolescent care provider at Stroger Hospital, is the largest clinical research site for adolescent HIV in the Midwest. Presently, our program is a funded site of the Adolescent Trials Network (ATN). In 2005, we were involved in 11 youth-specific research protocols (ATN 009, 015,021, 022, 023B, 024, 025, 026, 048, 052 and 056), and one community-based research protocol (ATN 016a & b - C2P). Twenty-six youth were newly enrolled in youth-specific research protocols in 2005, with a total of 142 youth enrolled cumulatively for the year (not inclusive of the youth involved in Protocol 16b, which is a community-based research initiative through our C2P program). We retained all but seven youth in these studies. Hence, our retention rate for youth enrolled in clinical trials from AMaC is 95%. In 2005 there were 52 youth educated about and referred to our research projects prior to enrollment.

Clients are informed about research opportunities and the benefits of research during a new client's first or second visit to AMaC. The study coordinators (Research Nurse Practitioners) are introduced to each new patient as working with the primary care team (assigned clinician, psychologist, and case manager). The nurse practitioners, two of whom are ATN study coordinators, educate clients on available research opportunities. We have a video on HIV/AIDS clinical trials that patients can view in our resource room (the teen room). Peer educators who have participated in research are also available to educate the client on research opportunities and answer any questions. In addition, every four to six months, we present all of the clinical trials that our community partners and we conduct to the youth Community Advisory Board (CAB).

All of our patients, including those involved in research protocols, require supportive services. The AMaC clinic offers integrated mental health, case management, nutrition, complementary therapy, and a comprehensive array of medical care services as depicted in Figures 3 and 5. Our wide spectrum of services enables us to meet the supportive needs of patients before, during and after participation in research. In addition, each youth's investment in time and effort to participate in research protocols is respected and adheres to the guidelines established by our Hospital Investigational Review Board (IRB). Thus, they are compensated for their participation in any research protocols, which includes support for transportation, food

and babysitting. Respecting and reimbursing youth for their time is the practice of all sites working with the Adolescent Trials Network, as is often the practice in adult research protocols.

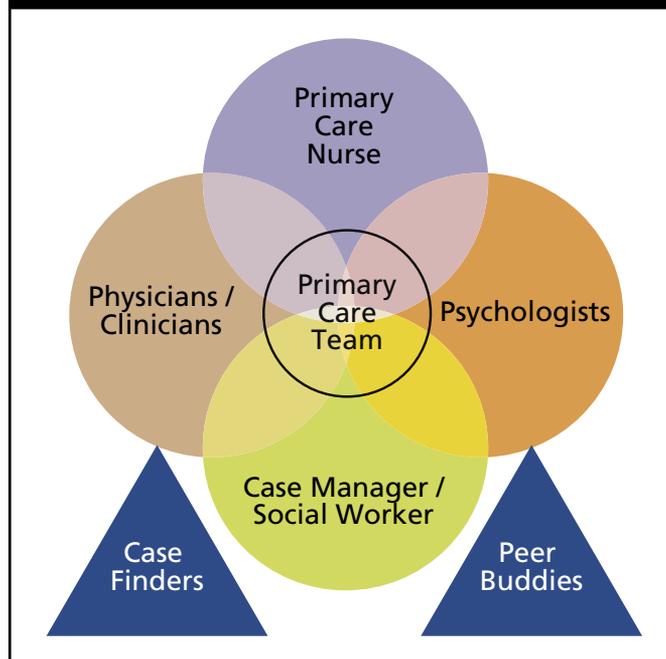
Our retention of youth in research for 2005 was 95%. This success in retention is achieved through a multidisciplinary approach where each client is assigned a primary care team. If the client has any healthcare needs outside clinic hours, the research nurse practitioners are available for walk-in visits Monday through Friday. The flexibility of this approach assists in the retention of youth in research protocols. It would be difficult for a patient to enter and be retained in research without these supportive services. We believe that 100% of the patients who have entered research protocols would not have done so without the aforementioned supportive services.

## SUMMARY

Providing care to adolescents is a multifaceted process in that no two adolescents are the same, but they all require sensitive, flexible, culturally and developmentally appropriate care. Identifying and transitioning HIV-positive adolescents into care requires a team approach to be successful, including the time and willingness of the provider to become a part of the process. Ultimately, adolescents should be encouraged to participate in research protocols that will help to minimize the virus in this population just as it has become minimally existent in the pediatric population. In order to increase prevention of HIV in the adolescent population, behavioral research must be escalated beyond its present point. At every avenue that means acknowledging that adolescents are sexually active and need to be easily included in research that is pertinent to addressing this issue. Clinical research should continue to be encouraged in order to determine means by which we are able to decrease the detrimental effects of the virus to youth, including decreasing viral load and increasing CD4 counts. In reality, however, clinical research cannot be conducted without understanding what makes it successful... and that means understanding adolescent behavior. ☒

*Dr. Margo Bell is an Adolescent Medicine subspecialist and a pediatrician at Stroger Hospital of Cook County and the Ambulatory Care Health Network of Cook County. She is the director of Adolescent HIV outreach services and the principal investigator of the CHRRPY (Chicago HIV Risk Reduction Partnership for Youth) program, and the director of the LEEP (Living, Eating, Exercising and Problem Solving) program for overweight teens.*

**FIGURE 5. PRIMARY CARE TEAM STRUCTURE OF THE AMaC CLINIC**



# Dating, Youth and HIV—From Both Sides

*Teenagers try to make sense of it all*

*Interviews by Keith R. Green*

**D**ating is hard enough at 16. But when you factor in HIV, you instantly shift from the innocence of sneaking a kiss in the hallway between classes to serious matters that most grown ups aren't even ready to deal with. There are lots of young people, however, who are dealing with it in one way or another.

I recently spoke with one remarkably brave young woman about how HIV affects her relationships with family, friends and, of course, boys. Raven Lopez is her name and she was born with HIV. Though her life has been filled with intensely dramatic ups and downs, it is her connection to other people and the support that she receives from them that keeps her walking tall with her head up.

**KG: HOW ARE YOUR RELATIONSHIPS WITH YOUR FAMILY AND FRIENDS?**

**RL:** Well, my family is excellent. No matter what, they love me. You know, I'm their niece. I'm their granddaughter. Nothing has changed. With my friends... yes, I lost a couple of friends in school. But that was in elementary school—now I'm in high school and I have all of my friends. When I was in junior high, when I was growing up, yes... people used to make fun of me. Now that I have grown older, I know how to deal with it.

**KG: HOW DO YOU DECIDE WHETHER OR NOT TO DISCLOSE YOUR HIV STATUS TO SOMEONE?**

**RL:** If I see that you're very close and you're nice and you're not the type of person who will tell everybody, "Listen, that girl has the monster," I will probably pull you to the side and tell you up front, like, "Let me tell you one thing right now. I'm HIV-positive and either you want to be my friend or not." But some of my friends, they are like, "Oh, Raven, you are just saying that to make me feel sad for you." And I'm like, "No, it's really true." So I'll bring in a *POZ* magazine, and they will see for themselves and be like, "Oh, wow," and they get emotional and all that kind of stuff.

**KG: HOW SAFE DO YOU FEEL TELLING PEOPLE ABOUT IT?**

**RL:** Um, I do get scared, because I don't know how they're going to react. Sometimes I think they might say, "Uh, Raven, get out of here. We don't want to be your friend no more." And I think that it will go around the school. But then again, I know how to deal with stuff like that now.

**KG: WHAT IS THE BEST RESPONSE YOU HAVE EVER GOTTEN FROM TELLING SOMEONE?**

**RL:** All of my friends I told, they all got emotional and they all started crying. But all of them, they said, "No matter what, Raven, we will still love you and you will always be our friend."

**KG: WHAT IS THE WORST RESPONSE TO TELLING SOMEONE?**

**RL:** Oh, when I was in Catholic school, one of my teachers asked my mother if they had to wear rubber gloves in class. And kids used to make fun of me. One time a girl said, "You can't sit on that chair, 'cause we are going to catch it through your clothes." It used to be so much drama that I couldn't take it no more, and that's why I had to leave Catholic school.

**KG: WHERE DO YOU GO FOR SUPPORT?**

**RL:** I get support from my friends, my family... from everybody. Like when I'm down or depressed or whatever, all my friends—they always have my back. They're like, "Listen, Raven, we understand." I have a loving family and friends.

**KG: DO YOU ATTEND CHURCH? HOW DOES YOUR CHURCH ADDRESS HIV?**

**RL:** Our pastor, she's a lady. When I first told her... well, it was my mom who told her... she took it okay. She started praying for us and stuff, because at that time I was dealing with a little sickness. So, you know, she prayed and did spiritual baths for us and stuff like that.

**KG: DO YOU FEEL ACCEPTED AS A PERSON WITH HIV THERE?**

**RL:** Yes, they were very supportive.

*Kids used to  
make fun of me.*

**KG: HOW HAS DATING BEEN FOR YOU?**

**RL:** Well, I just got over this guy not too long ago... last year. I disclosed that I was HIV-positive to him. At first, he had a suspicion because I told him how my mother got it. He used to always ask me, "Raven, do you have it?" And I always used to tell him no, because I did not want to lose him. But on New Year's night—the New Year's that just passed, but last year—he came to my house and I told him. And it was like all of the emotions just came out of him. He started crying, I started crying. And like, he was scared that he had it at first. But my mother told him that he won't have it because, you know, this and that. And, yes, we did have sexual intercourse, but we used protection. But... it was a lot of stuff that was going on between me and him, not just because of [HIV]. He didn't really know what to do with himself, so I said, "Whenever you're ready to come back in, you can come back." But right now he's dating another girl, so, I don't know. That's it.

**KG: HAVE YOU FACED MUCH REJECTION FROM POTENTIAL PARTNERS?**

**RL:** No, not really. All of my partners I go out with now, I tell them from the beginning. I tell them, "Hey, I'm HIV-positive. Either you want to be with me or not." And sometimes they don't believe me. They be like, "Raven, you're lying. You

just don't want to be with me." And I tell them the truth like, "Seriously, yes I am."

**KG: DO YOU HAVE A POLICY ABOUT IF OR WHEN YOU TELL A POTENTIAL BOYFRIEND THAT YOU ARE POSITIVE?**

**RL:** No, because I will never go out with another boy at my school. Everybody in my school... once you do something or go out with somebody, the whole entire school knows. I didn't think that he [former boyfriend] would do something like that, because he always told me, "No matter what, Raven, even if we hate each other, I would never disclose your business to someone else."

**KG: WAS HE OLDER OR THE SAME AGE?**

**RL:** No, older. I was 14... he was 17.

**KG: HOW DO YOU TELL SOMEONE WHO YOU WANT TO DATE THAT YOU'RE HIV-POSITIVE?**

**RL:** I sit down and talk to them. I always ask them, "If you had a girlfriend you really loved and then she told you that she had HIV, what would you do?" And at first, I hear how they act, like, "Oh, I wouldn't go out with her... I wouldn't talk to her." And I'm like, "All right... I know not to tell this person." And sometimes they are like, "Oh, if I really love her, I would stay with her." So then, right there I know that I could tell him—and that's when I tell him.

**KG: DO YOU FEEL THAT IF YOU PRACTICE SAFE SEX, IT IS NECESSARY TO TELL A SEX PARTNER THAT YOU ARE POSITIVE?**

**RL:** Yes. Because, God forbid, if something happens and he finds out before you even tell him... so I think you should tell him.

*Editor's note: The above interview is taken from a longer version in TheBody.com.*

**WHEN A YOUTH FALLS FOR SOMEONE WITH HIV**

**A**aron Parker (not his real name) is the son of one of my classmates. His mother pulled me to the side one day and told me that he was dating a girl who is HIV-positive and she was concerned. I asked her if she'd like me to talk with him and she loved that idea. After speaking with him, however, I was sure that she had nothing to worry about. At 16, Aaron is smart, sensitive and unmoved by the pressure that most teenagers his age face to put as many notches on their belts as they can before settling down. Following are some of the highlights from our conversation.

**KG: SO TELL ME ABOUT YOUR EXPERIENCE DATING SOMEONE WHO IS HIV-POSITIVE. HOW DID SHE TELL YOU?**

**AP:** Well, one day we were talking and it seemed like something was wrong, but she didn't want to tell me what it was. And then she told me. She said, "You don't know what it's like being me because I have HIV." And then she felt really bad and embarrassed and she didn't think that I would talk to her any more.

**KG: HOW DID YOU RESPOND?**

**AP:** Well, this happened before we even started going out. But that didn't bother me. We still went out.

**KG: WHAT DID YOU SAY TO HER?**

**AP:** I actually felt really bad because at the time we were sort of fighting because I knew something was wrong and she just wouldn't tell me what it was. But I had no idea that it would be something this big. So I felt really bad and I said sorry about a gazillion times.

**KG: DID YOU HAVE ANY FEAR ABOUT DATING HER AFTER YOU FOUND OUT SHE WAS HIV-POSITIVE?**

**AP:** No, not really. I knew that we weren't going to do anything or have to worry about that stuff right away. At the beginning of relationships, I don't just jump into things. So, I figured that I would worry about it later... when the time came.

**KG: SO, IF YOU GUYS WERE STILL DATING FIVE YEARS FROM NOW AND IT WAS GOING STRONG AND YOU WERE OLD ENOUGH TO CONSIDER MARRIAGE AND ALL OF THOSE KINDS OF THINGS, DO YOU THINK THAT IT COULD HAVE LED TO THAT? COULD YOU HAVE BEEN DEEPLY INVOLVED?**

**AP:** Yeah, I think that it could have led to that. And I would have been okay with it. There are other ways to have children besides sex, so we could still be safe and have a family. But I can't really talk a lot about marriage because I don't really know a lot about that stuff. I'm only 16 and in high school.

**KG: SO ARE YOU HOLDING OUT ON SEX FOR MARRIAGE?**

**AP:** Um, not necessarily all the way until marriage, but at least until I am older.

**KG: WHAT DO YOU KNOW ABOUT HIV?**

**AP:** I know that eventually it will lead to AIDS and that there is no cure for HIV or AIDS. I know all the basic "health class" stuff that you learn in school, like how it weakens your immune system and how it's not actually HIV or AIDS that kills you, but other diseases that your immune system can't fight off.

**KG: HOW DO YOU AVOID THE PRESSURE FROM YOUR PEERS IN HIGH SCHOOL TO HAVE SEX?**

**AP:** Well, you take health classes once or twice in junior high and then you have to take one in high school to graduate. So,

*One day we  
were talking and  
it seemed like  
something was  
wrong, but she  
didn't want to tell  
me what it was.*

I took all of those classes and I knew the ways that HIV is transmitted and I knew that I didn't want to get that because it can ruin your life. So I made a decision not to go that far until I'm ready.

**KG: WHAT ABOUT YOUR GROUP OF FRIENDS? WHAT'S THEIR TAKE ON SEX?**

**AP:** I have friends who are all across the board. They're like yeah, go out and party... have all the girls and stuff like that. And then I have friends who are like, "No, I'm waiting for the right person or the right time, or for marriage."

**KG: WOULD YOU SAY THAT THE MAJORITY OF FOLKS YOUR AGE ARE ALREADY SEXUALLY ACTIVE?**

**AP:** The majority of my friends aren't, but I know that most of my school is.

**KG: DO YOU THINK THAT THEY ARE AS AWARE AS YOU ARE ABOUT HIV AND OTHER STDs?**

**AP:** Well, there are a lot of really ignorant people in my school. But I guess I can't fairly answer that because I really don't know.

**KG: WHAT WAS THE CONVERSATION LIKE WITH YOUR MOM WHEN YOU TOLD HER THAT YOU WERE DATING SOMEONE WHO IS HIV-POSITIVE?**

**AP:** At first she was really shocked. I told her that April (not her real name) was

going to an HIV convention to learn more about it. And first she was like, "Oh, her mom is a nurse so she needs to know about it for her HIV-positive patients, right?" And I said no. But before I could elaborate she says, "Well, her mom has HIV." And I'm like no. And she says, "She has HIV?" And then she stopped, and then after a while she just got to a point where it wasn't that she didn't really like April, but she was just worried for me. She felt more relieved when we broke up.

**KG: WHAT KINDS OF THINGS DID YOU GUYS TALK ABOUT?**

**AP:** Well, we had the talk that every parent has with their kid. You're not supposed to have sex... you're too young... that kind of stuff. And she just explained to me again the severity of HIV and what it could do to me.

**KG: SO SHE WAS PRETTY OPEN WITH YOU ABOUT IT?**

**AP:** Yes. And she said that if at any time I had any questions, to come to her.

**KG: HAVE YOU TALKED TO ANYBODY ELSE ABOUT IT?**

**AP:** I talked to some of my friends, but it's not really my business to share with them what she has. But April and I have some of the same friends and some of them know, so I was able to talk about it with some of them. They understood how hard the whole thing was for us.

**KG: WHAT WAS THEIR REACTION LIKE?**

**AP:** Well, I had one friend who I'm not sure if he was completely truthful to my face and gave me one thing and then behind my back was like, "Man, I can't believe that he is dating her because she has that." I don't know if he was suspicious of me because he thinks that I have HIV or what. But my other friend who knows, who is also friends with April, we talked about it and he was cool. ✚

**F**or half of the 20,000 new HIV infections a year in the U.S. to be among youth ages 13 to 24 means that a young person is infected in this country every hour.

"I find this stunning at this stage of the epidemic," said Dr. Donna Futterman as she made a presentation to the North American Sessions of the International Association of Physicians in AIDS Care (IAPAC) in May in Chicago. Her slides declared that "AIDS is NOT over for youth."

Futterman, director of the Adolescent AIDS Program for the Albert Einstein College of Medicine in the Bronx, told the audience of doctors and other medical providers, "People talk about condom failure, but they don't talk about abstinence failure. The young people who make an abstinence pledge and fail are less likely to use a condom."

"Abstinence is important to talk about," Futterman continued, "but we can't start and end there."

Her clinic staff try to get doctors at the hospital to test for HIV when they treat sexually transmitted infections (STIs) in teens and young adults, but Futterman says that doctors ask her why they should do this. One doctor treating a teenage girl for pelvic inflammatory disease (PID) told her, "What do you mean that you think my patient did something to get HIV?" Futterman said, "It's just an STD like PID."

"The kids can be doing the same things kids are doing in Iowa, but they're more likely to run into the virus [in the Bronx]," she says. "Doctors internalize their patients and become defensive for them, but now we have to go beyond the patient in front of us to the general public and what we can do to protect against the spread of the virus."

Unfortunately, young people rely heavily on the "visual AIDS test." "I can look in his eyes and tell." "He looks fine." "I know he's okay, and plus he told me he's negative." These quotes—which Futterman has heard many times in her 20 years of treating youth with HIV—ran in *Newsweek* magazine the week of her presentation (May 11).



by ENID VÁZQUEZ

## Unfortunately, young people rely heavily on the "visual AIDS test."

- Communication (readiness, decision-making)
- Abstinence
- Outercourse (another way to experience pleasure)
- Condom use

Everyone needs to understand that there is a link between sex, STIs and HIV, and that there's a link between prevention and testing. The counseling that comes with testing can help clear up misconceptions, and any positive test results can help keep people from transmitting the HIV they didn't realize they had. On the negative side, she acknowledges that condom use is not easy.

And sadly, research has shown that one of five teenagers infected sexually also have an HIV-positive parent. Futterman said this is due to the socioeconomic factors the families live in—poverty, drug use, and lack of access to healthcare and information.

Her clinic works with the "Connect to Protect" national research partnership that designs posters and other materials to grab the attention of teenagers. Messages appear

under headings like "Gettin' busy?" and "Doin' it?"

"The success of the gay community was in mobilization and awareness, not just individual behavior," she said. ☒

"As shocking as it is to think that this is the youth assessment," said Futterman, "it's more shocking that this is the provider [healthcare worker] assessment. What you did doesn't matter—you either have HIV or not. It's what you do in the future that counts."

Her clinic created the A.C.T.S. project—Assess, Consent, Test, Support. A "concise yet comprehensive" laminated pocket guide to testing youth for HIV is given to hospital staff. "We've made it as simple as it could be and it still is not taken up as much as it could be."

And yet, Futterman points out that, "You can't expect kids to tell you what they're doing, or adults tell you how many hamburgers they ate."

She listed "reality-based prevention" that runs on a safer sex continuum:

Visit [www.adolescentaids.org](http://www.adolescentaids.org).

# Metabolic FAQ

## Frequently asked questions regarding metabolic syndrome

by Carla R. Heiser, MS RD LD and James T. Barrett, MD

In a follow-up to “Early Intervention for Metabolic Complications of HIV,” which appeared in the March/April issue of *Positively Aware*, the authors answer some questions they are frequently asked about metabolic syndrome.

### WHAT IS METABOLIC SYNDROME?

Metabolic syndrome, until recently known as Syndrome X, is a triad of metabolic abnormalities. The metabolic abnormalities are defined as high cholesterol, high blood pressure, and high blood sugar or insulin resistance. Patients with metabolic syndrome also have waist circumferences greater than 40 in. In HIV we use the term metabolic syndrome to refer to the same set of metabolic abnormalities.

### WHAT IS INSULIN RESISTANCE?

Insulin is required for processing of blood sugar. Specifically insulin is used to get sugar from the blood into the cells where it is required for fuel (energy production.) The condition of insulin resistance opposes proper blood sugar control at the cellular level—more insulin is needed to get sugar from the blood into the cell or the amount of insulin available over-regulates blood sugar control resulting in episodes of high blood sugar followed by low blood sugar levels.

### WHAT ARE ACE INHIBITORS?

ACE (angiotensin converting enzyme) inhibitors are a class of drugs that cause blood vessel widening (vasodilation) and are used to treat hypertension (high blood pressure) and heart failure. ACE inhibitors

block the body’s production of angiotensin, a vasoconstrictor (a chemical which stimulates constriction of blood vessels), and thereby improve the opening of blood vessels. ACE inhibitors help lower blood pressure and help protect the kidney by blocking this conversion to angiotensin. They are commonly used to treat symptoms associated with high blood pressure, diabetes, and HIV associated kidney disease (HIVAN).

### WHAT IS HIVAN?

HIVAN is HIV-associated nephropathy (kidney problem). It is a syndrome causing loss of protein through the urine and decreasing renal (kidney) function. Proven clinical practice is to treat all diseases that may cause kidney problems, such as diabetes, and to intervene in HIV disease if a patient starts to develop HIVAN. ACE inhibitors are helpful in protecting the kidneys in diseases such as HIVAN.

### DO ALL HIV-POSITIVE PATIENTS GET METABOLIC SYNDROME AND FAT REDISTRIBUTION?

Not all HIV-positive patients experience metabolic and body composition changes. The occurrence of these complications is dependent on several factors. Most of the causes are not well understood. However, there are several studies that show associations with genetic predisposition, HIV itself, certain HIV medications, HAART (combinations of HIV medications), how long patients have been on HAART, the use of protease inhibitors and the lowest CD4 count. Fat redistribution is felt to be a syndrome of fat loss (lipodystro-

phy: sunken cheeks, skinny arms and legs) or fat accumulation (belly, neck and back fat). Lipodystrophy and lipoatrophy may or may not occur together. These characteristics are not always associated with metabolic syndrome. Proper nutrition and exercise have been shown to help prevent and ameliorate fat redistribution and metabolic syndrome.

### IS MY RISK OF HEART DISEASE INCREASED BECAUSE I HAVE HIV?

Researchers think risk for heart disease is increased in HIV disease. The ongoing D:A:D trial shows a small but increased risk of heart disease associated with HIV disease. The trial is still early and the true increase in risk, or not, may be detected with ongoing monitoring. Our aggressive treatment of cardiac risk factors in HIV-positive patients is due in large part to this study and others like it.

### WHAT ARE THE MOST POTENT NUTRITIONAL STRATEGIES FOR OPTIMIZING METABOLISM AND CO-TREATING METABOLIC SYNDROME?

1. Balance meals and snacks by including a source of protein, “good fat” and dietary fiber-rich carbohydrates.
2. Especially, eat a protein and “good fat” containing breakfast.
3. Eat over the course of the day avoiding long delays with meals.
4. Try to include 4–6 small meals/snacks.
5. Vary the types of good fat included with meals and snacks by getting a variety of olive, fish and flax types of

oils and other foods containing these types of nutrients.

**WHAT LABORATORY TESTS DO YOU USE IN YOUR PRIVATE PRACTICE TO EVALUATE METABOLISM AND MEDICAL NUTRITIONAL STATUS?**

- Chemistry panel
- Complete Blood Count (CBC)
- Lipid panel (Total-Chol, LDL-Chol, HDL-Chol, Triglycerides)
- Hemoglobin A1C (HgA1C)
- Thyroid Stimulating Hormone (TSH)
- Free and total testosterone
- 3 hour oral glucose tolerance test with insulin response to glucose (Insulin and glucose levels at time 0, 1, 2, 3 hours)

**IN ADDITION TO PUBLISHED CRITERIA (CUT OFFS) FOR DIAGNOSING METABOLIC SYNDROME, WHAT OTHER CLINICAL INDICATORS CAN HELP ME UNDERSTAND MY METABOLISM?**

The following appear to be predictors of metabolic complications now or down the line:

- Acne, skin or hair changes
- Baldness, male pattern or hair thinning
- Carbohydrate sensitivity or food cravings
- Emotional issues such as depression, anxiety, forgetfulness or fogginess
- Facial hair, increased (especially in women)
- Family history of diseases such as diabetes, cardiovascular disease or symptoms, obesity, infertility
- Fatigue/malaise
- Insomnia

Also, blood sugar levels in the lower range of normal or a low HgA1c may be an indicator of insulin resistance or metabolic syndrome. Work with a clinician trained in evaluating the trend with laboratory measures of insulin and blood sugar measurements, and how these evaluations correlate to a physical exam and symptoms.

**WHAT IS A GLUCOSE TOLERANCE TEST?**

A glucose tolerance test is a test that measures the body's response to glucose (sugar) after a period of fasting and over a certain amount of time after drinking a beverage that contains a measured amount of sugar.



The test is given in a lab or doctor's office in the morning before the person has eaten (usually after an eight hour fast). A first sample of blood is taken from the person at time point 0. Then the person drinks a liquid that contains a measured amount of glucose (sugar). Subsequent blood samples are taken at hours 1, 2, and 3. The object is to see how well the body deals with clearing blood sugar over time. Corresponding insulin levels can be obtained to gauge insulin response to glucose load. The test should be performed as described by WHO (World Health Organization), using a sugar load containing the equivalent of 75 g anhydrous (dry powder) dissolved in water.

**WHAT ARE PROPER BLOOD SUGAR LEVELS?**

- Fasting Plasma Glucose (FPG): <100 mg/dl
- 2-h post load glucose: <140 mg/dl

**WHAT IS HYPOGLYCEMIA OR LOW BLOOD SUGAR?**

The low end of normal for blood glucose is defined as 65 mg/dl. Often low blood sugar may not be regarded as clinically relevant. Ask again, especially when symptoms are present. In our office we look for tighter blood sugar control, i.e., FPG 85-95 mg/dl.

**WHAT ARE THE CRITERIA FOR DIAGNOSING BLOOD SUGAR ABNORMALITIES?**

1. Impaired fasting glucose or "pre-diabetes"

- FPG 100-125 mg/dl
  - 2-h post load glucose 140-199 mg/dl
2. Provisional diagnosis of diabetes
    - FPG  $\geq$  126 mg/dl
    - 2-h post load glucose  $\geq$  200 mg/dl
  3. Diagnosis of diabetes mellitus
    - Casual (any time of day without regard to meal time)
    - Plasma glucose  $\geq$  200 mg/dl plus symptoms of diabetes

**WHAT ARE THE CLASSIC SYMPTOMS OF DIABETES?**

Classic symptoms of diabetes include frequent urination (polyuria), excessive hunger (polydypsia) and unexplained, unintentional weight loss.

**WHAT ARE PROPER INSULIN LEVELS?**

In our practice we find that fasting insulin levels more than 5 micro IU/ml may be associated with symptoms of metabolic syndrome. Additionally, hours 1, 2, and 3 insulin levels may not appear unusual but when you evaluate these markers alongside of blood sugar levels and patient presentation, a story unfolds that points to sugar and insulin sensitivity as the root of metabolic complications. At our practice we have the input of a specially-trained endocrinologist to offer insights with possible medical co-therapies and understanding how to interpret the continually emerging set of data alongside metabolic syndrome and how the body processes sugar for fuel.

**IN ORDER TO CONSERVE RESOURCES AT MEDICAL CLINICS, WHICH MARKERS WOULD YOU CONSIDER USEFUL TO SCREEN FOR METABOLIC COMPLICATIONS AND INSULIN RESISTANCE?**

- Basic chemistry panel
- Lipid profile
- HgA1c

Most importantly, we also listen intently to our clients and use clinical presentation in structuring medical nutrition and lifestyle treatment options.

**WHAT IS HgA1C?**

HgA1c is a measure of how well blood glucose is controlled for the previous three to four months before the test. Glucose binds to hemoglobin (red blood cell) through a process called glycosylation. The higher the blood sugar the more glucose binds to the hemoglobin. This blood test

measures the amount of glycosylation that has occurred revealing the average blood glucose levels.

#### **WHAT IS THE TARGET LEVEL FOR HgA1C?**

The published normal range for HgA1C is 4% to 5.9%. The low end of normal for blood sugar is often overlooked as a clinical marker. Low HgA1C values may not be regarded as clinically relevant. Ask again, especially when symptoms are present. In our office we look for tighter control, i.e., HgA1C 5.2–5.7 mg/dl.

#### **WHAT IS THE DIFFERENCE, METABOLICALLY, BETWEEN AEROBIC AND RESISTIVE EXERCISE?**

Aerobic (with oxygen) exercise represents exercise with a low enough intensity to facilitate adequate oxygen transfer to the muscle cells so that no buildup of lactic acid is observed. This type of exercise may be useful for improving cardiovascular (heart) health, reducing insulin levels and lowering blood glucose. Anaerobic (without oxygen) is resistive exercise which includes weight training, weight machine use, and band workouts. Isometric or muscle building benefits are also realized with yoga, pilates and other forms of calisthenics.

#### **WHY IS RESISTIVE EXERCISE SO IMPORTANT?**

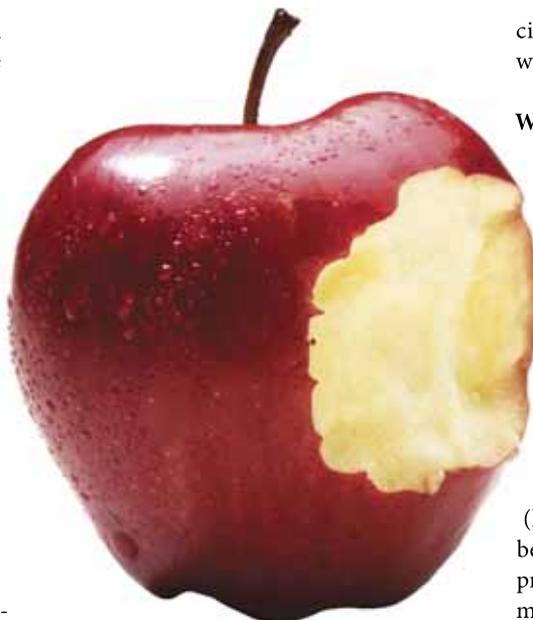
Resistance training will increase strength, muscular endurance, and muscle size, while running and jogging will not. Resistive exercise maintains and builds muscle which improves metabolism. Muscle burns stored body and blood fat more efficiently.

#### **WHAT IS AN ADEQUATE AMOUNT OF DIETARY PROTEIN PER DAY?**

The daily requirement of protein is 0.8 to 1.5 grams per kg (1 kg = 2.2 pounds) of protein a day for healthy to moderately depleted adults. Dietary protein facilitates muscle building as part of a healthy diet and exercise plan. For individuals with renal (kidney) impairment, lower protein may be necessary.

#### **WHY ARE SOME FATS “GOOD” AND SOME FATS “BAD” FOR YOU?**

Good fats reduce insulin, inflammation and blood fat levels (olive, flax and fish oil types). “Bad fats” like chicken skin,



bacon, visible meat fat, processed fats (trans and hydrogenated) increase blood fat levels and promote inflammation.

#### **IS BUTTER A “BAD” FAT?**

In the debate over butter versus margarine, butter wins. Butter and other dairy products do contain saturated fat. We are advised to control our intake of saturated fat daily. It should be noted that the type of saturated fat contained in butter and other dairy is different than the saturated fat from chicken or meat skin.

#### **WHAT IS THE DIFFERENCE BETWEEN BUTTER FAT AND VISIBLE MEAT FAT OR CHICKEN SKIN?**

The difference between butter and other animal fat is the type and amount of saturated fat that these items contain. As a general rule, saturated fats are those fats that are hard at room temperature. Animal fat stays hard at room temperature, whereas butter fat softens. Butter is processed for fuel more efficiently than the type of fat found in chicken skin or visible meat fat. Also, about one-third of the fat in butter equals the type of healthy fat found in olive oil.

#### **GIVEN THE UPSIDE TO “GOOD FATS,” CAN I EAT AS MUCH AS I WANT TO?**

Dietary fat is twice the caloric value of protein and carbohydrates. Overdoing fat intake can result in weight gain. It is also important to consider the health benefits of proper nutritional strategies and exer-

cise with regard to maintaining a healthy weight.

#### **WHAT IS THE DIFFERENCE BETWEEN SIMPLE AND COMPLEX CARBOHYDRATES?**

Simple carbohydrates are converted to sugar quickly and complex carbohydrates, usually containing higher fiber, convert to sugar more slowly.

#### **WHAT ARE THE BENEFITS OF LIMITING SUGAR?**

By limiting sugar and replacing refined carbohydrates (high glycemic value) with complex carbohydrates (high fiber, low glycemic value) the body is better able to process carbohydrate for fuel, providing a more efficient “burn” rate. Too much sugar at a given time gets converted to body fat or blood fat (i.e., cholesterol or triglycerides).

#### **DOES LIMITING SUGAR AND REFINED CARBOHYDRATES MEAN THAT DESSERTS OR SWEETS ARE NEVER ALLOWED?**

Desserts or sweets can be incorporated by reducing portion sizes. Avoid eating or drinking sugar-containing foods or beverages on an empty stomach. Increase exercise to maximize and maintain effective carbohydrate utilization.

#### **WHAT SWEETENER DO YOU RECOMMEND?**

In our practice we recommend Stevia. Stevia is a natural sweetener which is 400 times sweeter than sugar. There are other purported health benefits to Stevia including its role as an antioxidant and blood pressure-lowering agent. Stevia is not approved by the FDA as a sweetener, although it is available as a dietary supplement.

#### **WHY IS SKIM MILK HIGHER GLYCEMIC THAN LOW-FAT OR WHOLE MILK?**

Skim milk is a higher glycemic carbohydrate-containing beverage (more quickly converts to sugar) than low fat or whole milk because it lacks dietary fat. Fat acts to blunt blood sugar response after eating a carbohydrate containing meal.

#### **WHY ARE CORN FLAKES OR CHEERIOS HIGH GLYCEMIC IF THERE IS NOT ADDED SUGAR OR A ZERO SUGAR VALUE?**

Although Cheerios and Cornflakes do not contain added sugar, they are rolled or processed, which results in the body converting these refined carbohydrates for fuel

more quickly, causing a faster increase in blood sugar levels. These cereals are low in dietary fiber which may contribute to faster sugar uptake. Dietary fiber has a blood sugar-lowering tempering effect. Most cereals are high glycemic. Low glycemic cereals generally provide 8 g of fiber or more per ½ c serving. These include All Bran, Fiber One, Arrowhead Mills Steel Cut Oats, and Nature's Way Multi Bran Fiber.

**WHAT ARE THE CLINICAL BENEFITS VERSUS POTENTIAL SIDE EFFECTS OF CHROMIUM?**

**Dose:** The estimated safe and adequate daily dietary intake (ESADDI) for chromium is 50 to 200 micrograms daily.

**Benefit:** Chromium may have blood sugar-regulating activity. It may also lower cholesterol and reduce artery clogging activities.

**HOW DOES CHROMIUM WORK?**

The mechanism of chromium's possible blood sugar regulation activity is not well understood. Chromium may enhance insulin activity and sensitivity. Chromium may improve the liver's role with insulin and blood sugar regulation. The mechanism of the possible cholesterol lowering activity of chromium is unknown. This effect may be due to the impact on blood sugar and insulin.

**POTENTIAL SIDE EFFECTS OF CHROMIUM**

Chromium supplements are generally well tolerated. There are a few reports of bad reactions particularly with use of chromium picolinate. There is one report of a 24-year-old body builder who developed rhabdomyolysis (muscle breakdown) after ingesting 1,200 mcg of chromium picolinate. A rare skin rash was also reported to be associated with the use of chromium picolinate. A case of interstitial nephritis (kidney problem) was reported to occur five months after a subject received a six-week course of 600 mcg chromium picolinate daily. Another report described anemia, thrombocytopenia, hemolysis (blood disorders,) liver and kidney problems and weight loss after the use of 1,200-2,400 mcg of chromium picolinate daily for four to five months.

**WHAT ARE THE CLINICAL BENEFITS VERSUS POTENTIAL SIDE EFFECTS OF NAC?**

**Dose:** Supplemental intake ranges from 600 milligrams once to three times



daily. Those who supplement with NAC should drink 6 to 8 glasses of water daily in order to prevent renal (kidney) stones.

**Benefit:** N-acetyl cysteine (NAC) is a delivery form of L-cysteine, an amino acid (protein building block) which serves as a major precursor (building block) to the antioxidant glutathione. A major role of glutathione is the maintenance of liver health. Specifically, it is thought that NAC may protect cell membranes. NAC is also shown to reduce insulin levels and sugar uptake.

**HOW DOES NAC WORK?**

The effectiveness of NAC is due mainly to its activity as an antioxidant.

**Work with a clinician trained in evaluating the trend with laboratory measures of insulin and blood sugar measurements, and how these evaluations correlate to a physical exam and symptoms.**

**POTENTIAL SIDE EFFECTS OF NAC**

There are no reports of over dosage with oral, supplemental NAC. Adverse reactions reported with oral NAC include nausea, vomiting, diarrhea, headache (especially when used along with nitrates) and rashes. There are rare reports of kidney stone formation.

**WHY DON'T YOU RECOMMEND SOY?**

It seems like the jury is still out on the upside versus the downside of soy. Limited placebo-controlled trial data is available. Soy may have a negative effect on thyroid metabolism and other hormone balance, including proper insulin and estrogen metabolism.

**WHY DO YOU SUGGEST LIMITING WHEY-CONTAINING PROTEIN BARS?**

Some people have a hard time digesting milk proteins which include whey and casein. ☒

*Carla Heiser, MS RD LD, is President and founder of Heiser & Associates, PC, The Center for Functional Nutrition. She received her nutrition training at the State University of New York College at Oneonta and Masters of Nutrition and Dietetics at New York Medical College (Valhalla, NY). Heiser worked under the auspices of leading cardiovascular and endocrine researchers at Columbia University (New York, NY) and Medlantic Research Institute (Washington, D.C.). She has 20 years of clinical nutrition and research experience.*

*Currently, she specializes in women's and men's health from a metabolic and hormone balance perspective. Blending nutrition with cutting-edge medical approaches to optimize health outcomes is a hallmark of her clinical practice approaches. She loves to cook and to make healthy food taste delicious. Teaching clients and colleagues is a passion as she continually strives to strengthen her skills. Heiser aspires to translate forward-thinking and research approaches into practical, "can do" strategies.*

*Dr. Tom Barrett is an HIV provider at the Howard Brown Health Center and Triad Health Practice in Chicago, Illinois. Barrett is on faculty at Northwestern University Medical School in Chicago and is primary investigator on several HIV associated research studies through Howard Brown Health Center.*

# KENYA'S TALE

A SHORT STORY FOR YOUNG PEOPLE ON  
COURAGE, LOVE AND TRIUMPH OVER  
LIVING WITH HIV

By KEITH R. GREEN  
ILLUSTRATION BY ADONIS OMNI

The cloudy, wet day only added to Kenya's mood. The anthill that she had spent hours playing with yesterday would surely be gone today. She'd stumbled upon it along the side of the big red brick house that she now called home. It was her third home in two years, and she was pretty sure that it wouldn't be her last.

She had arrived there early yesterday afternoon, so the stares from the other kids were still fresh in her mind. The stares were something that, like moving from place to place, she was beginning to get used to. The stares, the giggles, the whispering behind her back when they thought she couldn't hear them. As much as she wished that she couldn't, she did. And everything she heard made her sad.

Kenya is a caramel-brown-skinned nine-year-old girl who has never been told how beautiful and special she is. She has never really had a family to call her own because she's spent most of her short life being shifted from foster home to foster home. At one point, about three years ago, she came really close to being adopted.

The young husband and wife had come several times to the foster home that she lived in, bringing a special gift for Kenya when they came. She was actually beginning to like them and looking forward to going to live with them permanently, as their daughter. The affection they showed her was the best (and only) that she had ever known.

The couple also had a nine-year-old son of their own. His name was Joey, and he would come along with his parents on their weekly visits. Joey and Kenya got along as if they were brother and sister already. They enjoyed watching cartoons together, especially *Arthur*, and were both really big fans of Usher.

About a month before the adoption process was complete, the young couple had a change of heart. Kenya had become ill with a cold that she just couldn't seem to get rid of. It had lasted for weeks and she eventually had to be hospitalized before it finally went away. The young couple came to visit her in the hospital and what they saw frightened them. Kenya was connected to several tubes that went in through her arm and there was even one that had been placed in her nose to help with her breathing.

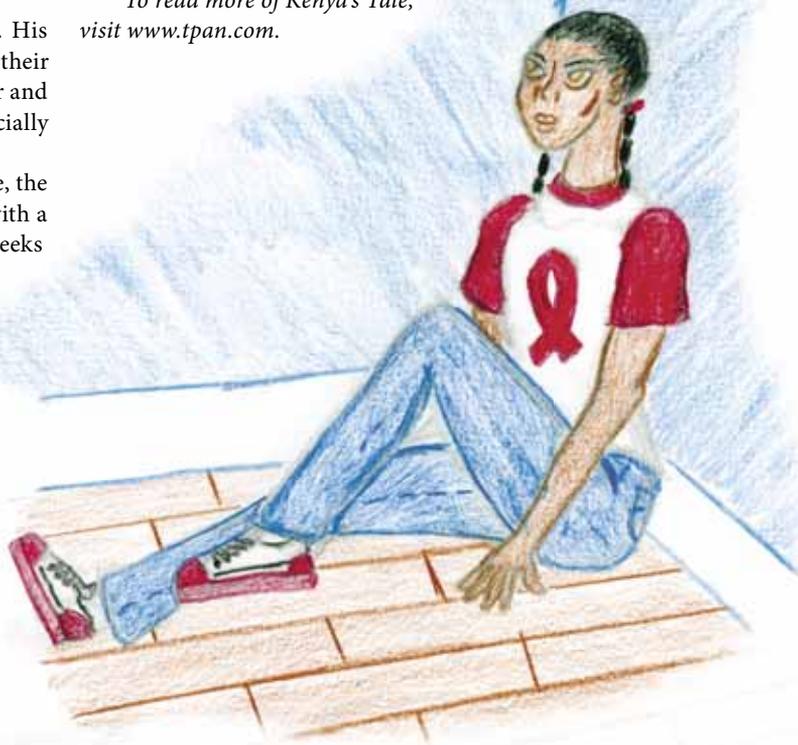
The young woman broke down in tears as soon as they entered the room. As her husband comforted her, she sat staring at Kenya through horrified eyes. He was able to keep her calm long enough to speak to Kenya, but just barely. The tears, however, flowed from her eyes the entire time that they visited. Aside from consoling his wife, the young man barely spoke two words to Kenya. It was the only time they had visited her during her two-week stay in the hospital.

She soon got better and came home only to learn that the young wife didn't feel that she was up to caring for such a sickly child. The couple had changed their mind about adopting her. Kenya was so sad that she went to her room and cried herself to sleep. She vowed never to get her hopes up about anything again, especially about being adopted or having a real family. She vowed this despite the fact that it was the only thing that she had ever dreamed of for as far back as she could remember.

Kenya was born inside of a prison hospital. Her mother, Keyana, was pregnant with her when she went to jail for doing some very bad things. Keyana was only 19 years old, and had become addicted to drugs while experimenting in high school. She dropped out of school at 16 and had been living on the streets ever since. To support herself and her drug habit, she had done many bad things. She lied, she stole, and even sold her own body so that she could get the drugs that she so desperately needed. She did not know that she had HIV until she was about to give birth. She didn't even know when or where she got it from and, at that time in her life, she really didn't care.

Because her mother was made to spend three years in prison, Kenya was sent to live in a foster home when she was strong enough to leave the hospital. The people there did not care very much about her, and only opened up their home to foster children to receive the government money that comes along with taking them in. Sure, they took care of Kenya well enough so that the monthly check would keep coming, but they never gave her the love and attention that a girl her age truly needs. When the responsibility of taking care of a child with HIV (constant doctor visits, medication several times a day, and occasional unexplained illness) became more than what the foster family felt the check was worth, they turned Kenya back over to the state authorities and off to another foster home she went. ☩

To read more of Kenya's Tale,  
visit [www.tpan.com](http://www.tpan.com).



# Politics and HIV:

## Statement from Representative Rahm Emanuel (IL-5)

*In our continuing coverage leading up to the November elections, Illinois Representative Rahm Emanuel speaks out. We still haven't heard back from any Republicans—any takers?*

I am committed to ending the global occurrence of HIV/AIDS. I greatly support increased funding for research, prevention, healthcare and housing to combat the suffering resulting from AIDS in the United States and abroad. Additionally, I believe that the Ryan White CARE Act is vital to our efforts to fight HIV and AIDS, and I will continue to work to reauthorize and strengthen this important legislation.

I believe that it is necessary for the United States to take action to prevent the spread of this deadly disease, and that government action is essential. During the 108th Congress, I voted in favor of H.R. 1298, the U.S. Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act, which was passed by the House on May, 23, 2003. This bill, known as the AIDS Assistance Bill, authorizes funding for international

HIV/AIDS programs, focusing on nations in the Caribbean and in Africa that have been seriously afflicted with this illness. I also voted to pass H.Con.Res.30, a bill supporting the goals and ideals of National Black HIV/AIDS Awareness Day.

My deep concern for this issue has led me to co-sponsor a number of bills regarding HIV/AIDS. In the 108th Congress, I was an original co-sponsor of H.R. 3859, the Early Treatment for HIV Act (ETHA), which would allow more people who are HIV-positive to receive earlier access to treatment. I was also a co-sponsor of H.R. 4792, the New United States Global HIV Prevention Strategy to Address the Needs of Women and Girls Act of 2004, which called for the establishment of an efficient and effective HIV prevention strategy to be used for each country that the United

States assists in battling HIV/AIDS, with an emphasis on the needs of women and girls. Last year I co-sponsored H.R. 1409, the Assistance for Orphans and Other Vulnerable Children in Developing Countries Act of 2005, and H.R. 1413, the Women and Children in Crisis and Conflict Protection Act of 2005. The former, among other things, provides HIV/AIDS care assistance for those children, while the latter legislation helps protect these populations by providing them with health services that include the prevention of sexual violence and reduction of HIV transmission. I will continue to support programs such as these that provide vital services for individuals living with HIV/AIDS as well as initiatives that seek to prevent the spread of the disease. ☒

**I believe that it is necessary for the United States to take action to prevent the spread of this deadly disease, and that government action is essential.**





# How to Find a Doctor

AAHIVM offers badly needed credentials

by Howard Grossman, M.D.

*Editor's note: Due to space considerations, in the last issue of Positively Aware we left out Dr. Howard Grossman's call for medical credentialing in his reflection on 25 years of the epidemic. Grossman is the executive director of the American Academy of HIV Medicine and a longtime HIV specialist. We run his comments here now.—Enid Vázquez*

ing more providers about HIV. We have also developed a credential, the AAHIVM HIV Specialist (AAHIVS) designation, to help people living with HIV identify dedicated providers who have taken medical education courses and passed our exam. This should help to identify the best providers for patients. Ask your provider if he or she is credentialed by AAHIVM." Visit [www.AAHIVM.org](http://www.AAHIVM.org).

**“W**e face a crisis in the provision of care for those with HIV. With few exceptions, HIV providers have never made as much money as our colleagues. There were other compensations, however. In the '80s there was no ready group of senior clinicians—we were the 'young turks,' boldly moving forward in a field that most providers didn't want to touch. Professional advancement was easier. We also got to learn each new drug and new test one at a time, while feeling we were on the cutting edge of medicine.

*From the Editor: At a recent meeting of the International Association of Physicians in AIDS Care, one HIV specialist noted that new doctors are not taking on HIV care due to the poor reimbursements provided by managed care. Small clinics find it hard to meet expenses when large numbers of patients with HIV are seen. He reported that in one state, a clinic with five outstanding HIV specialists closed—and all of them refuse to see new HIV patients in their new practice. Another doctor reported that when interns were asked what they thought healthcare reimbursement would be for various treatments, they vastly overrated the amounts. She said young doctors need training in finance to prepare them for HIV care.—EV*

*In the '80s there was no ready group of senior clinicians—we were the 'young turks,' boldly moving forward in a field that most providers didn't want to touch.*

“Today's young providers face an AIDS establishment full of rapidly aging senior clinicians. They also have to learn everything immediately that we had 20 years to learn. As in most primary care areas, but perhaps more so, there is a growing shortage of young providers willing to go into the field.

Another doctor reported that when interns were asked what they thought healthcare reimbursement would be for various treatments, they vastly overrated the amounts. She said young doctors need training in finance to prepare them for HIV care.—EV

“The American Academy of HIV Medicine is trying to change that. With our Study Guide and Update Workshops we are educat-

Note: The International AIDS Society-U.S.A. also offers educational sessions for providers. Visit [www.iasusa.org](http://www.iasusa.org).

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# AIDS POLICY UPDATE— 2006 USHERS IN THE ERA OF “THE MEDICAL APPROACH”



WHETHER THE SHIFT EXPANDS  
HEALTHCARE ACCESS OR EASES  
AIDS STIGMA REMAINS TO BE SEEN

BY DAVID MUNAR AND JIM PICKETT

Catapulted by enormous advances in HIV medicine, local and national policymakers increasingly favor physician-led interventions to solve the nation's and the world's ongoing HIV/AIDS crisis.

And who could blame them? Little more than a decade ago, modern medicine offered barely any reliable treatments for people with advanced HIV disease. Despite a handful of experimental medications—including a toxic new drug called AZT—and treatments for opportunistic infections such as bacterial and fungal pathogens, rare cancers, and blinding microbes, doctors could not effectively control a torrent of HIV replication, which slowly but effectively destroyed the immune system of virtually everyone it infected.

When saving lives became elusive, AIDS workers, doctors, and volunteers strived to help people die with dignity.

All that changed in 1996. For hundreds of thousands of people living with HIV/AIDS in the Western Hemisphere (and elsewhere in instances of personal wealth, charity, and government action), powerful, new drug combinations began to stop death in its tracks. Initially lauded as “the end of AIDS,” combination therapies, along with revolutionary new ways to diagnose and measure HIV, are nothing short of a modern miracle. In the last decade, big pharma

and government scientists have developed more than 20 antiretroviral agents and dozens of sensitive, new diagnostic tools to detect even trace amounts of HIV and effectively monitor its presence in the blood.

People living with HIV/AIDS who stand to benefit from these rapid medical advances have rallied industry, their governments, and anyone else who would listen in order to counter the status quo and save their lives.

But, to the dismay of many, prioritizing medical care is a far cry from actually guaranteeing healthcare for all who need it. Moreover, the push toward medical interventions is casting doubts upon the relative importance of government-offered support services and long-cherished patient rights, such as medical privacy, counseling, and informed, written consent to testing.

## RYAN WHITE CARE ACT REAUTHORIZATION

Nowhere is the trend more evident than in political machinations over the future of the Ryan White CARE Act—the nation's flagship response to the domestic HIV/AIDS crisis. As *Positively Aware* goes to press, fierce negotiations are underway in the House and Senate over arcane but critical legislative provisions governing how future CARE Act dollars will be shared among states and territories, urban centers,

early intervention clinics, and 57 beleaguered AIDS Drug Assistance Programs (ADAP) across the country. While actual funding amounts are determined annually through a bruising political process known as “appropriations,” Congress will shape the next five years of the CARE Act program through the rules and requirements it includes in its “reauthorization” legislation.

The stakes are especially high this year because pressure on the program has never been greater. At least 1.1 million people are living with HIV/AIDS in the U.S.—more than ever before. According to the Institute of Medicine, only about half of the nation's HIV-positive population receives regular healthcare services. Factors such as poverty, lack of insurance, depression, housing instability, homelessness, substance abuse, and other chronic medical conditions, such as hepatitis, affect large numbers of CARE Act clients. Meanwhile, federal funding available to the CARE Act has steadily declined over the past five years, with the exception of ADAP. But even ADAP remains woefully under-funded with nearly 1,000 clients in nine states languishing on waiting lists. At least nine other states have needed to institute cost-containment measures.

With conventional wisdom on Capitol Hill predicting even leaner funding years ahead, in-fighting has erupted among some HIV/AIDS advocates, with rivalries forged along rural vs. urban interests, state vs. city interests, medical providers vs. support service providers, etc.

Recommendations released in 2005 by the Bush administration call for a concentration of CARE Act funds (75%) on “core medical services,” ostensibly signaling waning support for critical transportation, housing, case management, and other non-medical services. The plan would diminish the role of consumer input by making Title I planning councils optional, and would deduct funding from states with Title I cities in order to boost Title II grants to less populous states. The plan seems to presume that the CARE Act is already adequately funded but that dollars are overly concentrated in big states. At the very least, the plan predicts no significant funding increases in years to come. In February 2006, U.S. Senator Tom Coburn, MD (R-OK), introduced legislation codifying the administration's plan into legislative language.

Thankfully, a less draconian proposal has emerged from a delicate negotiation brokered by a bipartisan group of House

and Senate members who control health legislation. House and Senate votes on this bill are expected by August or September, with a final draft going to President Bush by the end of 2006.

Clients of CARE Act services will notice differences in the program by the end of 2007. The new law will require local and federal officials to concentrate CARE Act funding on “core medical services,” which will undoubtedly shrink the availability of funds available for support services, such as food and legal. Planning councils will be required in only 20 cities with the largest HIV/AIDS epidemics (51 councils exist currently).

Less populous states, including states that currently have ADAP waiting lists, should receive desperately needed funding increases, which is the good news. Without significant new funding (highly unlikely), other jurisdictions will shoulder funding reductions. In fact, the bill caps annual funding increases for the CARE Act at no more than 4%, well below the rate of medical inflation.

In addition, all states will be required to provide a minimum list of antiretroviral medications to clients as part of their ADAPs. Without assurances adequate funding will follow, states and local communities will likely be forced to ration healthcare, including access to drugs, and significantly scale back support services.

#### TESTING AND REPORTING

Meanwhile, the Centers for Disease Control and Prevention (CDC) is preparing to roll out new HIV testing guidelines, timed to coincide with National HIV Testing Day on June 27, which will recommend HIV testing for everyone who interacts with the nation’s healthcare system, with or without consent.

The routine offer of HIV testing, as part of a basic healthcare visit, is a laudable goal and one that has been widely endorsed by community groups and advocates for years.

Of concern to advocates, however, are recommendations to forego pre-test counseling and informed written consent to HIV testing. The CDC will instead recommend that providers include HIV testing in their standard consents for healthcare or obtain oral consent to testing. Many of the nation’s physicians who specialize in HIV medicine are likely to adopt the recommendations in responsible ways by expediting counseling

and consent, and assuring that everyone tested is aware they are being tested and afforded an explicit chance to decline. One fear, of course, is the opportunity for abuses, particularly among healthcare providers without sensitivity to HIV issues who may not bother or care if people know they are being tested for HIV.

CDC argues that routine, uninformed testing procedures are needed to overcome barriers to testing acceptance. Officials also say routine offers of testing will lessen the stigma surrounding HIV.

One can easily imagine more people being tested if counseling and informed consent were eliminated. It’s not clear that talking about HIV or eliciting consent inhibits anyone from accepting testing, but

tories of clients served by HIV prevention organizations. For people living with HIV, who may receive counseling on disclosing HIV status and adopting risk-reduction behaviors, answering such sensitive questions carries the added risk of self incrimination. Sexual contact without disclosure is a criminal offense in many states; provider charts could be subpoenaed in criminal proceedings.

The CDC has also prevailed in requiring states to adopt name-based HIV surveillance systems or risk losing millions in federal funds, including CARE Act funds. Alternate code-based systems, developed to give clients added assurances to accept HIV testing, have been maligned by CDC as cumbersome and ineffective.

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both requirements may likely inhibit some healthcare providers from offering it. In fact, informed written consent and pre-test counseling is required in many states by law or regulation.

While routine testing may likely decrease stigma associated with HIV testing, persistent HIV/AIDS stigma—unfortunately—is likely to prevail for some time to come. In addition, stigmatizing attitudes, behaviors, and beliefs feed on ignorance and misinformation. Failure to educate people on the basics of HIV/AIDS—including the fact that HIV is not transmitted through casual contact—may expand instead of contract stigma in our society.

Ironically, as the CDC recommends less HIV/AIDS talk in healthcare settings it is expanding the battery of questions HIV prevention providers are required to ask and record every time they interact with a client.

A controversial new system called Program Evaluation and Monitoring System (PEMS) is being implemented to track minute details about the sex and drug use his-

#### RAPID MEDICALIZATION: WHAT DOES IT MEAN FOR PEOPLE LIVING WITH HIV/AIDS?

We all hope and pray for a day when HIV/AIDS is treated just like any other disease or condition, but that day has yet to come.

Unfortunately, people continue to lose their jobs, housing, and support networks from authorized and unauthorized disclosures of HIV status. Because of persistent stigma, HIV remains as much a social disease as a medical condition. Our global responses to HIV must remain comprehensive and tailored to address both the social and physical manifestations of the pandemic—and continue to involve people living with and at-risk for HIV in every facet of a united response.

A *real* plan to fully cover the care, treatment, and support service needs of people living with HIV/AIDS would go a long way in reducing stigma and reversing the course of the pandemic. ☒

## THE LITTLE VOICE WITHIN

*A youth with HIV learns to trust life*

by Keith R. Green



A couple months ago, I stumbled upon an interesting revelation. Not that I've never thought about it before, but approaching my 30<sup>th</sup> birthday somehow makes it all the more real. As I poured out my life story in front of a group of young, vibrant high school students, it suddenly occurred to me that I've lived my entire adult life with HIV.

Though it's been more than 12 years since I received the diagnosis, I can remember the events that led to it as if they had transpired last week. As a member of the senior boys council at my high school, I had helped to organize a blood drive as part of our community service requirement. I never had any intention of donating blood. The very thought of it made me ill and I was way too cool to let anybody know that (or see me fall out, which is what I thought would surely happen).

This led to a heated argument between me and my long-term girlfriend. She couldn't understand how I could be such a hypocrite, helping to organize the blood drive and then not donating. I told her that I had done my duty and that was that. She didn't see it that way. Needless to say, as was usually the case, she won. On the day of the drive I found myself in the designated area drinking orange juice and eating graham crackers, praying that that lightheaded feeling I was experiencing would go away before I stood up.

When I didn't pass out, I thought the worst was over. There were, however, a couple of questions that the nurse asked during the initial screening that disturbed me. In particular, the question about whether or not I had ever had sex with a man was unnerving. What in the world did that have to do with me giving blood, and, who on Earth would ever admit that out loud?

After a couple of hours, I had forgotten all about the whole experience. I hadn't made a complete ass of myself by passing out. The blood drive had been a success. My girl was proud of her community leader-type boyfriend. And the secret that I held

about having slept with a man was still safe, secure and very much in the past. Or so I thought.

A couple of weeks later, I received a phone call from Life Source, the company that had conducted the blood drive. The representative was relatively nice, but not as equally helpful. She informed me that I needed to make an appointment with one of their staff right away and, in the meantime, not to donate any more blood. I asked her what the problem was, but she kept blabbing about their company policy not allowing her to release any information over the phone and would not let up until I finally made an appointment.

A million things ran through my mind between the time I hung up that phone and the day of that dreadful appointment. What in the world could be wrong? Sick cell anemia and diabetes run in my family, so maybe I had tested positive for one of those. Or maybe they had done a drug screening and detected that I had smoked marijuana... on more than one occasion. I couldn't put my finger on exactly what could have been the problem, but those awkward questions that the nurse had asked me before she took my blood began to replay in my head like a broken record.

I vaguely believed that I had potentially put myself at risk for HIV by having sex with a man, but just vaguely. It wasn't like that made me gay, or promiscuous for that matter, and only gay or promiscuous people could get HIV. Besides, I was way too young. HIV was something that only happened to old people—people who were 21 and older. I was only 17 and there was just no way that I could be infected with a virus that would take me out before I had the chance to grow old.

I had too much planned. I was on my way to college to major in audio engineering. I was going to be the man who made Janet Jackson sound as beautiful as she looks. I was going to get married, have children, and live long enough to spoil my grandchildren the way that my granddaddy had

spoiled me. I had way too much planned to be infected with HIV.

But, as I learned the hard way, things don't always happen as you plan them.

The funny thing is that every time I tell this story, I am even more convinced that the little voice that I heard on my way home from receiving the devastating news was real. Now that I'm older, I recognize it as my "God voice." I also believe that each of us has one within, but it is up to us to choose to listen to it.

On this particular day, that voice told me that everything was going to be alright. In spite of everything that I knew (and didn't know at the time) about HIV, I had this strange feeling that somehow I would survive. And, by the grace of God, I have.

In many respects, I cannot complain. I'm healthy. I have loving, nurturing relationships with my family and friends. I'm building a career for myself in a field that I love. And I have a connection to that little voice that keeps me grounded and constantly walking in my own truth. From the outside looking in, my life is pretty good.

But, as I approach the big 3-0, there's a sadness deep inside that not many people know about. More often than anyone would think, I sit and wonder what my life would have been like without HIV. I wonder about the family that I might have had. What kind of father I might have been. What my career would be like. And what I would be doing now if HIV had not changed the entire course of my life.

That little voice, however, constantly tells me to be patient. And, for some reason, I trust it. I have absolutely no reason not to. The path that trusting it has led me on has been one filled with blessings and miracles. My only concern is what's next! ✚



## RESPONSE ABILITY

*Responding to others, responding to yourself*

*by Sue Saltmarsh*

I started thinking of the issue of lack of response when I was channel surfing a few months back and caught a snippet of Oprah talking about the Katrina victims and then a bit of Charlie Rose discussing the genocide in Darfur. Much was made of how people have responded with open, generous hearts to the victims of hurricanes and earthquakes, to “natural” disasters. And yet, there was no focus on the lack of response to human-generated catastrophes like genocide, poverty, war. Has human arrogance gotten to the point where we think of *ourselves* as equal to the forces of Nature? Have we become so corrupt that we think our actions are no more under our control than a tsunami? Do we really not see that the harm we cause originates with someone’s *choice* to do that harm?

I truly believe we are all a part of the Whole and within our individual beings we have not just the right and the power, but also the responsibility to make a positive contribution to that Whole. It is so easy to become insulated and segregated by our own problems, fears, and expectations that we, as a species, have moved away from that Wholeness. So we do not respond. Whether it’s someone being attacked at a subway stop, an entire country’s population being massacred, or a world leader committing war crimes in the name of “democracy,” we watch, but we do not respond. We accept wrongness as if it’s a reasonable price to pay for being alive.

I’m sure many of you have experienced the phenomenon of a doctor telling you that that buffalo hump or the neuropathy are okay because, after all, you’re alive, aren’t you? Your T-cells are higher, your viral load lower—hey, it’s the price you pay, baby. I venture to guess that many responded to that kind of mindless, heartless, soulless proclamation by hanging their heads and sighing because that doc was right. Many of you went on to encourage your fellow AIDS survivors to think of it that way, to not let yourselves focus on the negative side effects, no matter how greatly they impact your life. Your *life*—at least you have one, right? So you didn’t even respond to yourself.

What are you supposed to do, you wail? There is an endless list of *wrong* being wrought in our world today and the only way we can begin to change that is to listen to our *own* law, our *own* morality and say, “No. This is *not* alright with me.” The elections are our most lethal weapon at this point, though we must be vigilant and intolerant of vote fraud. If all that is going on is alright with you, then go right ahead and keep the Republican mess we’ve got.

But if it makes you feel a little queasy when you see the way the people of Iraq are having to live and the way the people of Darfur are having to die; if you’re one of the thousands who’ve been wiped out by medical bills you can’t pay and who now will not be able to declare bankruptcy; if your home and your job were wiped out by Katrina and Amex is still finding a way to get that credit card statement to you with the late and over limit fees intact; if you’re living with HIV/AIDS and faced with losing your medication or your housing or your treatment programs; if you’re a Syrian/Arab/Iranian-American who could find yourself imprisoned with no right to an attorney and no charges being filed for years simply because your name is “funny”; if you’ve got a loved one in the military who’s in Iraq or, worse, not coming home at all; if you’re a 16-year-old mother who just left her newborn in a dumpster because that abstinence-only thing didn’t exactly work and no one at the free clinic was *allowed* to tell you that you have the right to terminate that pregnancy; if you’re a Republican who still has a shred of personal integrity, honor and decency; if you’re just a normal, everyday person who just wants to live your life and make a positive contribution to the Whole, *step up*.

I urge you to join me and the millions of others who aren’t letting themselves just shut up and take it. *Respond* to the wrong by speaking out, write your politicians, cast informed votes—don’t choose your politicians just because they’re Black or White or Hispanic or male or female or Republican or Democrat, but because they’re the best *person* for the job. Join the Campaign To End AIDS effort, write letters to the editor, get on the MoveOn email list. *Respond* to yourself by making your doctor look you in the eye and spend more than 3 minutes with you or find another who will. Ask questions, become an investigator and find your way to the Truth. *Respond* to others by dropping the labels—you are, as we all are, first and foremost, a *human being*. Start there and make sure that no matter what other words you use to define yourself, they honor that humanness in yourself and others. *Respond* to bigotry and stereotyping by proving it wrong. Be greater than what small minds expect you to be.

We cannot do without your voice, your ideas, your vote, your knowledge of right and wrong. We all have the ability to respond—it’s up to each of us to choose to do so. End the complacency. End the silence now. Understand the truth of “The only thing required for Evil to triumph is for good men to do nothing.” ☩

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