Protecting Our Communities of Color

Friend-to-Friend Network

Adverse Health Outcomes Among Black Americans

Microbicides: When, How and Why Care Now?


**TAKE ACTION**

**Letter Writing Campaign**

Ask Congress to Expand the Landmark Ryan White CARE Act

*Positively Aware* encourages readers to send personal letters to members of Congress urging rational legislation to extend and improve the Ryan White CARE Act—the nation’s flagship response to the domestic HIV/AIDS epidemic. The most recent law governing the CARE Act expired on September 30, 2005. While funded programs will continue to operate, Congress must draft new legislation (called “reauthorization”) to shape the program for the next five-year period. With an estimated 500,000 HIV-positive individuals in the U.S. too poor and under/uninsured to meet their basic needs—including housing, healthcare, and other essential services—a stronger CARE Act program is desperately needed.

Please send short letters to your U.S. House representative and two U.S. senators. Enter your address at www.vote-smart.org to find out who represents you. Short, personal, and hand-written letters are best, and should be sent to district offices as opposed to Capitol Hill offices, where mail service is delayed by bioterrorism screening efforts.

The Honorable John Doe
Address
Dear Rep. Doe:

I am deeply concerned about our nation’s ongoing HIV/AIDS crisis. I am writing as a constituent to ask for your leadership to enact rational legislation to reauthorize and strengthen the Ryan White CARE Act.

The CARE Act plays a critical role in helping low-income people with HIV/AIDS receive the vital medical and support services they need to continue to be productive, contributing members of society. The program is literally a lifeline for hundreds of thousands of Americans who are living with HIV/AIDS.

Please insert one or two sentences here about you. If you can, state what the care act does for you!

I am concerned for the estimated 500,000 people with HIV/AIDS in the U.S. who do not currently receive adequate HIV care, treatment, and support services. I also believe the Bush administration’s principles for CARE Act reauthorization fail to respond to these needs, and may make matters worse.

While our nation is faced with many challenges, it is urgent that we continue to focus on the growing HIV epidemic, especially among the poor and disenfranchised.

I look forward to your response.
Sincerely,

Your Name
List your full address—they may write you back
List your phone number

**Last Step:** Share your letters with *Positively Aware* by emailing (publications@tpan.com) or faxing (773-989-9494). Submitted letters may be reprinted with identifying information removed.

**Resources:** Learn more about CARE Act reauthorization and funding issues by connecting with any of the organizations listed below.

- AIDS Project Los Angeles: www.apla.org
- AIDS Foundation of Chicago: www.aidschicago.org
- Communities Advocating Emergency AIDS Relief (CAEAR): www.caear.org
- National Association of People with AIDS: www.napwa.org
- Project Inform: www.projectinform.org
- Ryan White Action Campaign: www.ryanwhiteaction.org
- San Francisco AIDS Foundation: www.sfaf.org
- Southern AIDS Coalition: http://southernaidscollection.org

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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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On the cover:
Dr. Margo Bell of the Friend-to-Friend Network, and general adolescent medicine doctor and pediatrician of the Stroger Hospital of Cook County, in Chicago, along with the staff of Friend-to-Friend.
Pho to © Russell McGonagle

A model, photograph, or author’s HIV status should not be assumed based on their appearance in Positively Aware.
You can view these (and other stories from previous issues) online at http://www.tpan.com

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Brain fog

I am on the mail list for TPAN, and read this article the day it arrived in my home [The Buzz, July/August 2005]. I was stunned, and at the same time totally puzzled at the seemingly simple proposed solutions. I seldom send internet links as most of the time they seem irrelevant. In this case, however, I am forwarding you this link to read about some of us who have been struggling with this issue for years now. Please feel free to read it, and if you feel so led, please register with the site, and give us any commentary you would like. These people are bright, attentive, and totally awake, so you might like the people in this discussion, and maybe, just maybe, there will be hope for clarity for us in the future. Personally, I am 58 going on 59, and have been living with the virus since ’83. Dr. Bob Frascino was my first HIV doctor, and by some miracle he is still in the work. Please feel free to get back to me, as I am dealing with concentration issues that have become very severe and debilitating at times.

Name withheld, via the Internet
http://aidsmeds.com/Fusetalk/messageview.cfm?catid=5&threadid=23654

From Dr. Dan Berger: Thanks for writing to me. I hope my article was helpful to you and your fellow e-mail buddies. I tried to write it as reader friendly as possible, and to avoid using terms that were unclear. For the others on the list who had trouble finding my article, I’ve posted the link at the end of this email that you can send to your list of members on AIDSMEDES. Also, I usually write for Positively Aware, my column is called The Buzz, which should be easy to find (www.tpan.com). I’ve read through the comments from the link you sent; most complain about similar cognitive neurologic symptoms that I have been seeing in our clinic for years. As an HIV specialist physician, it is frustrating to fully explain and watch, since many have undetectable viral loads, are otherwise healthy, but despite, continue to have what you all termed “brain fog” (I like the term, and may use it in the future). I have been seeing HIV-positive patients for something like 17 or 18 years, so I know that when a patient tells me something (and I know my patients fairly well), that this is a real problem. In fact, most have similar descriptions, and have much in common. One gentleman mentioned that he hopes no one at work discovers his handicap—this was all too familiar because I have had patients many times before.

We conduct many research protocols at our clinic (Northstar Healthcare, website is www.nstarmedical.com). But before putting a patient through this treatment, which we are currently studying, it’s important to make sure that there are no underlying factors. So, we rule out these possibilities first. We are currently studying “brain fog” as you call it, I am administering a specific cognitive testing process and then repeating it every three months while patients continue on treatment with minocycline. We’re using the testing to help monitor our patients more objectively. It’s too early to tell, but we’re hopeful that perhaps something can be done. Some patients have already reported benefit, but I’d be cautious about stating these results until we complete this project and analyze it closely.

I respectfully do not want to join your list, because of time constraints and hope that you are not offended, but am happy to answer your questions. Also, if you, or anyone on your list, is ever in Chicago, you are all welcome to visit us. If you want to participate in this study, you are also welcome to come in for testing.

Squat close to load

Jim,
Thanks for a great article written so well with humor and truth. [Pickett Fences—September/October issue].

I was actually the vendor at the conference that had sent 3,000 safer sex kits including both condoms and lubes to the conference for bag inserts and they ended up sitting in front of my booth at the start of the conference to be handed out for the next three days.

Thanks for all of your hard work and keep up the good fight.

Best regards,
Don Nelson
Client Services Manager
Total Access Group, Inc.
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What You Can Do

This issue of Positively Aware has been in the works for nearly two years. It seeks to address some of the multi-faceted issues surrounding HIV/AIDS in minority communities in the U.S., particularly among African Americans, the community in the U.S. most disproportionately affected by this virus.

More importantly, this issue of PA takes a look at what can be done to try to start to improve upon the grim outlook portrayed by some of the most recent, jarring statistics. Many of these stats you have already heard, and will read again throughout this issue, but some of them bear repeating here:

- African Americans represent 12% of the U.S. population, yet account for over half of new HIV infections.
- African American and Hispanic women together represent less than one-quarter of all women in the U.S., yet make up more than three-quarters of AIDS cases among women.
- Today, people under the age of 25 represent half of all new HIV infections each year, and 56% of those are African American.
- A recent Centers for Disease Control (CDC) study of gay and bisexual African American men in five major cities in the U.S. found that 46%—nearly half—were HIV-positive.

At a recent forum in Los Angeles, Carrie Broadus, executive director of Women Alive, noted that “a misperception still exists among some in the Black community that HIV only affects White men who have sex with men, commercial sex workers and injection drug users.” This belief contributes to rising infection rates among groups who may not think they are at risk.

Recent legislation passed in California and Illinois seeks to address the disproportionate impact of HIV/AIDS on the African American community by coordinating prevention and services in a more comprehensive manner, and thereby improve health outcomes for African Americans living with HIV/AIDS.

Join a clinical trial!

What can be done to stem the swelling tide of HIV flooding our communities of color? In addition to some of the innovative programs and inspirational individuals you will read about in this issue, you could consider joining a vaccine or drug clinical trial. The number of minority and women participants in trials are dismally low, typically around 10% or less, and unfortunately do not adequately reflect the changing face of HIV/AIDS. According to the CDC, in 2003 women constituted 28% of HIV/AIDS cases in the United States, and approximately 69% of those cases were among non-Hispanic Black women.

Women and minorities, African Americans in particular, are grossly underrepresented in many ongoing and completed trials, for reasons ranging from a historical distrust of the medical establishment, to poor recruitment and retention of minorities and women in clinical trials. In this month’s Treatment Series, Dr. David Malbranche examines this issue as part of his reporting on adverse health outcomes for Black Americans with HIV—nature vs. nurture.

Some women may think twice before joining a study due to some of the exclusionary criteria for the study itself. For example, some investigational agents may have interactions with hormones that are used for contraception or hormone replacement therapy; another possibility is that a woman who may want to become pregnant during the course of a two-year study will be excluded from that trial. However, it’s vital that women and minorities take part in these studies in real-world numbers, in order to safely and effectively measure how these drugs and vaccines will perform in these target populations. Visit http://www.acria.org/clinical/clinical_res_explained.html for more information or if you are considering joining a study.

Thankfully, many pharmaceutical companies and researchers are ramping up their efforts to recruit more women and minorities into studies. A recent investigators meeting for an upcoming trial clearly stated on the front of their pamphlet that the company needs more women in the trial, and encouraged investigators and trial sites to do their best to recruit more women.

And lest we forget, the need for new treatments and vaccines is as urgent as ever. We’ve recently lost several strong voices in our community, including Jeff Palmer, a treatment activist and the founder of Positives for Positives in Wyoming; and LeRoy Whitfield, who used to work with many of us here at TPAN, was a former writer and Associate Editor of Positively Aware, Senior Editor at POZ magazine, and more recently a regular contributor to HIV Plus, where he recounted his struggles of living with HIV. Jeff and LeRoy, we will miss you both.

I’d personally like to thank Associate Editors Enid Vázquez and Keith Green for doing such a fantastic job of putting together this important issue of PA.

AIDS continues to devastate our communities, and more and more, our communities of color. We all need to join together in the struggle, and fight to save not only ourselves, but all of our brothers and sisters as well.

Take care of yourself, and each other,

Jeff Berry
Editor
publications@tpan.com
SUSTIVA IN PEOPLE OF COLOR

The Adult AIDS Clinical Trials Group (AACTG) created quite a stir in 2004 when it reported finding a racial difference in treatment response in a substudy. African Americans participants were more likely (20% of them) to have a genetic basis for clearing Sustiva from their bodies more slowly than Whites (3%), and thus experienced more side effects. Might Sustiva—a very popular and effective drug—really be more toxic in African Americans as a group due to decreased clearance from the body?

Dr. Edwin DeJesus and colleagues reported no difference in side effect profiles between people of color and Whites. They conducted a post-hoc analysis of available 24-week results from an on-going 48-week study. None of the 86 White study participants dropped out due to nervous system symptoms (the primary Sustiva side effect), vs. two of the 59 Black participants and one of the 34 Latino participants. Discontinuation for any other reason was also similar between the three groups.

The VEST-QD (A1466-206) study switched people with undetectable viral load from a protease inhibitor regimen to a Sustiva-based one. There was also no racial difference in the people who remained undetectable after switching to Sustiva. The AACTG reported an association between the genetic marker and nervous system symptoms, but this association disappeared out to six months time despite the continued high blood levels of Sustiva. Dr. DeJesus reported his group’s findings at the International AIDS Society conference held in July in Brazil.

NEW KALETRA TABLETS

Also in the Rio conference, the maker of Kaletra reported on its new formulation of the protease inhibitor. The benefits of the tablet in development compared to the current gel capsule include a reduced pill count, no refrigeration needed, lack of a significant food effect, less pharmacokinetic (PK) variability, and—hurray—less diarrhea. Abbott Laboratories reported bioequivalence between the two formulations. The Phase I PK study provided a single dose of the tablet to 118 individuals, and multiple doses to 23 persons; all participants were HIV-negative (standard for PK work). The new formulation is particularly anticipated for use in resource-poor countries where lack of refrigeration is common.

GUIDELINES UPDATE

In October, the U.S. Department of Health and Human Services (DHHS) updated its “Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents.” To see the guidelines, visit www.AIDsinfo.nih.gov. Call 1-800-HIV-0440 (448-0440) or write AIDSinfo (or “Guidelines”), P.O. Box 6303, Rockville, MD 20849-6303 to request a free copy.

An edited version of the changes follows.

What Not to Use as Initial Therapy (Table 8):

- The Panel recommends that a regimen containing “NNRTI + didanosine + tenofovir” [Sustiva or Viramune plus Videx/ Viread] should not be used as an initial regimen in antiretroviral treatment-naïve patients due to reports of early virologic failure and rapid emergence of resistant mutations to NNRTIs, tenofovir, and/or didanosine.
- The Panel does not recommend the use of ritonavir-boosted tipranavir [Aptivus plus Norvir] in treatment-naïve patients [first time on HIV therapy] due to the lack of clinical trial data in this setting.

Management of Treatment Experienced Patients:

- This section has been updated to redefine the goal of antiretroviral therapy in the management of treatment-experienced patients with virologic failure [detectable viral load] and to review the role of more potent [Norvir]-boosted protease inhibitors such as [Aptivus] with or without enfuvirtide [Fuzeon] in these patients.

The Following Tables Have Been Updated:

- Table 7 – Treatment outcome data of once daily abacavir-lamivudine [Epzicom] and lopinavir-ritonavir [Kaletra] have been added to this table.
- Tables 12 & 13 – These tables have been updated with information on once daily [Kaletra] dosing and new information on characteristics of [Aptivus].
- Tables 16-21b – These tables have been updated to include information relating to [Aptivus]-associated adverse events and drug interactions.
- Table 26 – Suggested minimum target trough concentration for atazanavir [Reyataz] has been added to this table.
- Tables 28 & 29 – These tables are adapted from the USPHS perinatal antiretroviral guidelines with information on [Aptivus] use during pregnancy.
- Table 30 – This table has been updated with information for TMC-114 Expanded Access Program.

Pediatric Norvir dose update

Also in October, the FDA approved dosing recommendations for Norvir for children ages one month to two years of age. “The recommended dosage of [Norvir] in children older than one month is 350 to 400 mg/m² twice daily by mouth and should not exceed 600 mg twice daily. [Norvir] should be started at 250 mg/m² and increased at two to three day intervals by 50 mg/m² twice daily. If patients do not tolerate 400 mg/m² twice daily due to adverse events, the highest tolerated dose may be used for maintenance therapy in combination with other antiretroviral agents, however, alternative therapy should be considered. When possible, dose should be administered using a calibrated dosing syringe.”
Findings from PACTG (Pediatric AIDS Clinical Trials Group) Study 310 in 37 children ages 2 to 14 years old and PACTG Study 345 in 41 children ages one month to two years old found that Norvir leaves the body faster than it does in adults. Therefore, the children had lower concentrations of the drug in their blood. The FDA also reported that side effects and adverse events in studies and in use once the drug came to market were similar to those seen in adults. “Vomiting, diarrhea, and skin rash/allergy were the only drug-related clinical adverse events of moderate to severe intensity observed in 2% of pediatric patients enrolled in Norvir clinical trials. The following Grade 3-4 laboratory abnormalities [moderate to serious] occurred with Norvir either alone or in combination with reverse transcriptase inhibitors: neutropenia [lowered white blood cell count] (9%), hyperamylasemia [an increase in amylase, a pancreatic enzyme that breaks down starches] (7%), thrombocytopenia [lowered platelets] (5%), anemia (4%), and elevated AST [liver enzymes] (3%).”

Generic Retrovir (AZT) for U.S.

In September, the FDA approved three generic formulations of Retrovir (zidovudine, AZT) for the U.S. With the expiration of Retrovir’s patent, these versions were given the green light: zidovudine tablets, 300 mg, manufactured by Roxane Laboratories of Columbus, Ohio; 300 mg tablets made by Ranbaxy Laboratories Limited of Guragon, India; and 300 mg tablets and 50 mg/5mL oral solution, manufactured by Aurobindo Pharma LTD. of Hyderabad, India.

Illinois passes African American HIV/AIDS Response Act

Illinois Governor Rod Blagojevich signed on to a first-of-its-kind bill in August that launches the state into a massive, government-wide initiative to address the AIDS epidemic among African Americans. AIDS activists say no previous federal or state law has included provisions for such a wide swath of public resources for work specifically targeting the Black epidemic.

Dubbed the African American HIV/AIDS Response Act, the new law follows a June U.S. Centers for Disease Control and Prevention report that estimated African Americans account for nearly half of all HIV infections in the country. In Illinois, where African Americans make up only about 15% of the population, they account for 51% of diagnosed AIDS cases.

The new legislation, which takes effect January 1, 2006, calls on the state to establish point people for the initiative in the Governor’s office, the Department of Human Services, the Department of Health, and the Department of Corrections. A panel consisting of representatives from each of these agencies and from three HIV/AIDS service organizations, along with two former prisoners, will develop an annual report for Governor Blagojevich on the state of AIDS among Illinois’ African American residents. The bill also mandates that “high-traffic” state agencies, such as the Department of Motor Vehicles and the secretary of state’s office, create space for community-based HIV/AIDS organizations to conduct rapid HIV testing.

But the aspects of the bill that have been called both its most ambitious and its most controversial seek to get a handle on the still-shadowy epidemic behind bars. According to the U.S. Department of Justice, the AIDS case rate in the nation’s jails and prisons is three and half times that of the general population. Illinois’ prison epidemic is more intense than any in the Midwest, with 1.3% of inmates known to be positive.

Under order of the new law, the Illinois Department of Corrections and county jails will be required to offer free voluntary testing and counseling to all inmates upon and during incarceration, as well as immediately prior to their release. Case managers will be assigned to help positive inmates transitioning out of incarceration and refer them to support services on the outside.

In addition, researchers at the University of Chicago will conduct a study to examine the correlation between incarceration and HIV infection. Prison health advocates nationally have long complained that correctional facilities rarely allow such research.

The law was originally developed by Illinois State Representative Constance A. Howard and Lloyd Kelly, who directs Howard’s “Let’s Talk, Let’s Test Foundation,” which helps raise money for Black AIDS groups throughout Chicago.—Keith R. Green, edited from BlackAIDS.org.

TMC-114 enters expanded access

Tibotec’s TMC-114 protease inhibitor (PI) expanded access program (EAP) began rolling out in late October, as this issue went to press. The purpose of this EAP is to gather safety data and to provide early access to a new PI to those whose treatment options are limited to none. Participants must have received treatment from three of the major classes of drugs, including two different PI-based regimens.

While the cut-off criteria for the EAP is 200 CD4s or less, company representatives have assured community members that exceptions can and will be made, and will be determined on a case-by-case basis. TMC-114 will be taken with other antiretroviral drugs and boosted with low-dose Norvir in this EAP. Physicians should call 1-866-889-2074 (within the U.S.), e-mail: TMC114-C226@i3research.com or visit www.tibotec.com. Visit www.clinicaltrials.gov for more info.—Jeff Berry

Until There’s a Cure Foundation awards grant to TPAN

Test Positive Aware Network was recently awarded a $3,000 general operating grant from the Until There’s a Cure Foundation. Until There’s A Cure is a national organization dedicated to eradicating HIV/AIDS by raising awareness and funds to combat this pandemic.

Their goal is to fund prevention education, care services, and vaccine development using The Bracelet as the tool. The Bracelet will serve not only as a bridge to unite people to fight HIV/AIDS, but to help people to recognize that anyone—man, woman, or child—can be infected and that everyone should be compassionate, understanding, and responsible. For more information about Until There’s a Cure or The Bracelet call 1-800-88-UNTIL or visit www. Until.org.
The Robert Taylor Homes are low-income housing projects located in the heart of Chicago’s South Side. With a long-standing reputation for a culture of drugs, violence and crime, it isn’t exactly the first place that comes to mind when you think of prevention education.

I entered the building at 40th and Dearborn, directly behind a young mother carrying one child across her shoulder and dragging the reluctant other by the hand. “This don’t make no damn sense,” she complained, releasing a heavy sigh of frustration as she headed towards the stairs.

Before I could ask what was going on, an older man, positioned in front of the elevator and soliciting people for spare change, looked at me and said, “It’s broke. You got a dollar?”

Not exactly enthused about the idea of hiking up eight long flights of stairs in this security-less fort of a building, I reached into my pocket for a dollar to give to the man and prepared myself for the dreadful trek.

The graffiti-covered stairway reeked of stale urine. I immediately began to feel badly for the young mother who couldn’t have possibly gotten her toddler up those stairs without him coming in contact with the filthy surfaces. The reality, however, is that hundreds, perhaps thousands of African American families in the Robert Taylor homes, and other housing developments throughout the city, live in such a state.

Not quite sure of exactly what to expect when I reached the apartment that was my destination, I hesitantly knocked on the door and was welcomed by a friendly older woman with a small baby boy in her arms. Pamela Carter is a babysitter and family friend to many of the children who live in the housing development. On that day, she was hosting the Friend-to-Friend Network, as she had many times in the past. Over the next half hour or so, several young African American adolescents began to fill her living room, anticipating their hour of uninhibited straight talk with Dr. Margo Bell of the Chicago HIV Risk Reduction Partnership for Youth (CHRRPY).

Dr. Bell, general adolescent medicine doctor and pediatrician at Stroger Hospital of Cook County, barely looks any older than her young patients. She and her colleagues at CHRRPY started what is now known as the Friend-to-Friend Network (F-to-F) in August of 2003.

Since its inception, the Friend-to-Friend Network has educated more than 1,500 young people in the city of Chicago about HIV and other STDs, in an environment that they choose, that is safe and comfortable for them. Primarily through word of mouth, the network has become so popular that there is currently a waiting list of young people who would like to host Dr. Bell and her staff for a training session with their peers.

“The demand is so great that we could be booked for five or six days a week,” says Dr. Bell. “But because of limited resources and funding cuts to HIV prevention programs overall, we have to limit the Network to a maximum of two or three sessions per week.”

Her staff consists of two paid outreach workers and Community Peer Educators who have sat through at least one session and expressed an interest in helping to organize and facilitate future groups. Each presentation lasts for about 45 minutes to an hour and includes discussion about HIV and STDs (with pictures), a condom demonstration, a peer HIV testimonial and the distribution of educational pamphlets and safer-sex kits. The dialogue is structured in such a way that it is real enough for young people to “get it,” without being so fluffy or technical that it goes in one ear and out the other.

“I am often amazed at how misinformed some of our young people today are,” says Dr. Bell. “But because of limited resources and funding cuts to HIV prevention programs overall, we have to limit the Network to a maximum of two or three sessions per week.”

Between 2001 and 2002, 11% of all HIV diagnoses in the city of Chicago were in young people ages 13 to 24. Within the adolescent division of the county hospital, one out of three youth diagnosed with HIV had already developed AIDS. Most of them were identified through another marker of risk for HIV, such as syphilis and pelvic inflammatory disease.

Frustrated with what seemed like a hopeless task of encouraging her young patients to make changes in their behavior, one adolescent medicine doctor decided to take HIV and STD prevention out of the clinic and into the hood.
Dr. Bell. “I had a young man in a session once who said, ‘You can’t give me no pussy! I only hit it from the back.’”

“We were all wondering what he meant and some people thought that he was implying that he was gay. But he was talking about protecting himself against HIV by only having anal intercourse with girls. I had to clear that up in a hurry, letting him know that anal sex is the riskiest sex there is.

“There are also lots of misconceptions about oral sex as well,” she adds. “Many of the kids don’t know that you can get infections such as chlamydia and gonorrhea from oral sex.”

Though some may consider Dr. Bell’s brutally honest approach to prevention to be a bit over the edge, many agree that her method is necessary. One African American pastor from Chicago’s West Side told her, “I don’t really agree with some of the things that you say, but I know you have to say them. My congregation needs to hear it. Our community has a problem.” His community, Chicago’s Austin neighborhood, has the highest number of HIV-positive youth in the city.

Through the Friend-to-Friend Network, Dr. Bell has come to understand the importance of developing relationships with her clients outside of a clinical setting.

“Young people need to know that we (doctors) are human,” she tells me on a Friday evening, way past regular office hours. “This is not just about HIV education, but it’s about establishing a relationship, which is extremely important. These kids call me about anything that is going on in their lives and I allow them the space to do that.

Unfortunately, some of them don’t get that kind of support from other adults in their lives.”

When asked to describe the biggest challenges to her work, Dr. Bell is easily able to identify two. The first she labels distractions.

“I was doing a session once and there was a guy in attendance who was a drug dealer and people were constantly knocking on the door for him,” she says, seriously. “But the interesting thing was that he kept telling them to come back because he was in the middle of something. Now, although that was a distraction to the group as a whole, it showed me just how necessary this project is. I may have never gotten him into my clinic. Through F-to-F, we are able to reach an underserved population that may not be able to access this information otherwise. For that reason alone, I can deal with the distractions.”

Dr. Bell also mentions that engaging the Latino community around HIV can also be incredibly challenging, primarily because of cultural beliefs concerning sexual behavior. “Catholicism is widely practiced throughout this community,” she explains. “It can be extremely difficult to introduce condom negotiation, for example, to people who are raised to believe that monogamous, heterosexual relationships between married couples are the only acceptable kind.”

However, Dr. Bell admits that the rewards that come from educating and empowering young people far outweigh the obstacles that she encounters. Her team has been able to test more than 200 people for HIV, identifying five HIV-positive youth and linking them to care.

“Unfortunately, we can’t test everyone who wants to be tested,” she says with a bit of frustration in her voice. “Our department is only funded to conduct a certain amount of tests and once we have reached that number…that’s it. Because we are more of a community service gesture than an actual research project, we are often turned down for funding that we request.”

But Dr. Bell is determined not to let funding be an obstacle. She is continuing to educate Peer Health Educators who can carry out the Friend-to-Friend Network on an even broader scale. She is also planning to transition the Network into a research project so that, hopefully, it can begin to receive the funding that it needs to achieve maximum effectiveness.

“It is really just an issue of time on my part,” she says. “As a doctor, I am required to wear so many different hats. Aside from this project, I also see patients in clinic three to four days a week and teach residents. It is really difficult, sometimes, to do all that is necessary to ensure that programs such as this one become as effective as they have the potential to become.”

Her goal for the coming year is to make the time to do the tedious work necessary to secure the financial means that F-to-F needs to achieve maximum effectiveness. With new HIV infections steadily increasing within communities of color, the Friend-to-Friend Network offers the hope for change that many in the community have been praying for.
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David Munar, a first generation Colombian American, was speaking at the 2005 National Conference on Latinos and AIDS, held in Chicago in July. As Associate Director of the AIDS Foundation of Chicago, an advocacy and services organization providing national leadership, Munar knows the statistics well—but he also works closely with communities affected by HIV.

Why should Latinos not be complacent? At last accounting, it’s true that they are affected by HIV out of proportion to their numbers in the U.S. population, but that the gap is not as large as it is in the African American community.

For the 32 states that report HIV diagnoses,
- Blacks made up 51% of all new diagnoses in 2000–2003, but only 13% of the population for those states
- Latinos made up 15% of the diagnoses for those states, but only 11% of the population

Those states do not include New York and California, two states with large numbers of Latinos and large numbers of people with HIV.

“People say, ‘It doesn’t affect us the way it affects African Americans.’ That’s not a good way to look at it. Here’s why.”

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“People say, ‘It doesn’t affect us the way it affects African Americans.’ That’s not a good way to look at it. Here’s why.”
highest in saying they leave the doctor’s office without understanding what the doctor said or getting all their questions answered. The highest rate is among non-English speakers. We don’t want to be in an uncomfortable situation and say we don’t agree, or we don’t understand. We’d rather be seen as polite.

**Immigration**

It’s true that we don’t have the incidence rate of the African American community, and for that we should be thankful. But at the same time, I believe it’s very likely that we’re undercounted. Two in five Latinos are foreign born, in common with Asian/Pacific Islanders. There’s discrimination, and there are large barriers of not knowing how things work. So everything adds up to lack of access to health care. So we’re not testing and those who are testing need to break down the stigma and get to it as a disease. There’s a real need for health assertiveness.

**Uncomfortable Conversations**

We have to figure out ways to talk to our young people, our mothers, and our aunts. In the AIDS community, we talk to each other a lot, but at the end of the day, what good does it do if we don’t talk to our families, especially our young people? We have to have uncomfortable conversations.

I’m not saying put a sign on the lawn—“Talk to me about AIDS.” But we have to go out of our comfort zone. Women are better at this, men suck at it. Women have the Tupperware model of health parties, where they learn about asthma, heart disease, pregnancy and STDs [sexually transmitted diseases], what to do if your child has a fever.

**Risk Groups**

MSM, IDUs, women—our risk groups are just not tell you about their behaviors.

MSM [men who have sex with men, who may not identify as gay] are part of our community. They’re at high risk of HIV and other problems. At the root is stigma and homophobia. That really stands out as a group that’s highly affected.

As a community, we need to look at what we can do to support and nurture our MSM, especially our youth. It’s not about pitting one group against another.

**What is HIV?**

Stigma in general is so big in our community. We don’t really pay attention to health, especially prevention. There’s a stigma around HIV, but it’s a disease. We need to break down the stigma and get to it as a disease. There’s a real need for health assertiveness.

**Not just a test**

What scares me is the misunderstanding there is around HIV. One of the pastors in a Black church told us about a conversation she had with a young man—and we’re very lucky to have a pastor talking about this subject. She asked him if he had been tested and he said yes, he was negative. She asked him when he was tested, and he said four years ago. She asked him if he had been at risk in that time and needed to get tested again. He was puzzled—why test again?

There’s such an emphasis on “get tested, get tested,” and we don’t emphasize behaviors. We need to talk about them.

People have to be careful to say it’s not just testing, but an on-going risk assessment and on-going testing and on-going awareness. It’s a commitment to being aware and being open to risk discussion.

It’s tough, I know it’s very tough. We can talk about pregnancy. It doesn’t affect MSM but our communities can talk about it. And sex—men, women, and teens are having it.

**The youth will lead**

This is where young people can break new ground. “I know my HIV status, do you?” “I have HIV—how does that make you feel?” Candidness. You see some in online chat rooms.

The next generation is always pushing the older one. I have a lot of faith that they can lead us in this new reality. It’s their future and their bodies. And it’s their lives and the lives of their children.

**The Blacks vs. the browns?**

We’re so racially divided. There’s so much distrust and so much pain. There’s racial tension in AIDS and we don’t talk about it. There’s a lot of distrust. People say, “Why are we only getting 11% of the money when we’re 12% of the population?” When we advocated for the African American [HIV/AIDS] Response Act, lots of people said, “Well, what are you doing for Latinos?” We have to make sure our response is constructive, and not paralyzing us, not splintering us.

AIDS advocates need to not fall into that trap. “I’m not Black, so it’s not my problem.” “You’re not Black, so you don’t understand.” I think we have to move beyond that “gay White male disease, now a Black/Latino disease.” The blame game is the only focus there. The world is full of “if onlys.” When are we going to own it?

Phill Wilson (see page 36) says it most eloquently: If you think it’s a conspiracy, fine. What are we going to do to survive? If it’s man-made, then we have more of a need to make sure we survive.

There’s always a temptation to say, “Who’s doing this to us? The Anglo? The gringo?” Well, what are we going to do for us? We have to move forward. Blame is going to distract us from doing the work that needs to be done.

We have to follow the epidemic, absolutely. But sometimes a lot of energy is wasted on who’s doing this to us. That’s a very defeatist attitude. For people who hate us, that’s exactly what they want—divide and conquer.
Microbicides:  
When, How and Why Care Now?

I f you are a regular reader of Positively Aware—or if you just live in the same universe as Jim Pickett (a regular contributor to this magazine) —you have undoubtedly heard of microbicides (mi-KRO-bi-sidz).

Wouldn’t it be great if there were something you could just buy over the counter in any drugstore—a lube, suppository, or gel—that you could insert to reduce HIV transmission risk during sex? Something to protect you in addition to condoms or when your partner isn’t using a condom? Something that would, at long last, enable you to protect yourself from infection or reinfection without having to discuss it with your partner if you didn’t want to?

You probably know that such products are under development. But maybe you’re not quite clear on the specifics like who will be able to use microbicides, how they will work, how effective they will be and how soon they will be available. This article offers an update on what’s up with microbicides, as well as some food for thought about why we don’t have non-condom prevention available already and what it will take to make that happen.

Who are microbicides being designed for?

Microbicides are designed primarily to provide protection to receptive sex partners: be they male or female, HIV-positive or HIV-negative. The first generation of microbicides (those that are farthest along in the clinical trials and likely to come to market first) are designed for vaginal use. But researchers and developers also clearly recognize that both men and women have anal intercourse. The much-promoted “ABC” model of HIV prevention says you can protect yourself if you Abstain from sex, Be faithful or use a Condom. But over half of all new HIV infections in the world are now occurring among women who become infected heterosexually—often by a husband or long-term partner. So how do the ABC’s protect that woman if she is already monogamous and can’t make her partner use a condom? The answer is, they don’t. That’s why we’re seeing about 8,000 women becoming newly infected with HIV every day. We desperately need an HIV prevention method for women who simply do not have the power in their sexual relationships to insist on abstinence, fidelity, or condom use and lack the social and economic resources to leave partners who put their health at risk. So that’s the public health/humanitarian reason.

2. The scientific reason for developing vaginal microbicides first is that they are actually less difficult to develop than rectal microbicides. The rectum and the vagina have very different structures and environments. The vagina, for example, is a closed pouch while the rectum is one end of a long, open-ended tube (the digestive tract). We know about how much gel or cream is needed to coat the inside of the vagina effectively but it is harder to determine how much product has to be inserted to make sure that all the rectal tissue exposed to HIV is adequately protected. The rectum also has more immune cells with CD4 receptors and more CD4 receptors per cell than the vagina. These make rectal mucosa particularly vulnerable to HIV infection. Finally, the rectal lining is more fragile than most of the tissue lining the vagina. These factors further enhance rectal vulnerability to irritation, tearing and infection during sex.

Because of these two considerations, it makes sense that vaginal microbicide research has been made the leading priority. Once we know which compound or compounds work as vaginal microbicides, they can be tested to see if they may also be usable as rectal microbicides. Meanwhile, other research is ongoing to establish the baseline data and clinical markers needed to measure the impact of a candidate microbicide in the rectal environment. With this information, researchers will be able to design effective rectal microbicide trials while suitable candidate products are being identified.

How will they work?

“Microbicide” is just a generic term applied to anything designed to prevent infection by HIV and other sexually transmitted pathogens when applied in the vagina or rectum. Since HIV and STI (sexually transmitted infection) pathogens can attack the body in multiple ways, an effective microbicide will have to stop this attack at one or more stages in the infection process.

Everything you need to know about this prevention product

by Anna Forbes

tpan.com  Positively Aware November/December 2005 19
About 20 candidate microbicides are now under development and no one knows yet which one or ones will prove to be both safe and effective. But each uses one or more of these five basic mechanisms of action:

1. **Killing or inactivating pathogens.** Some microbicides work by breaking down the surface or envelope of the virus or pathogen.

2. **Creating physical barriers.** Microbicides could provide a physical barrier between pathogens and vulnerable cells in the epithelium (cell wall) of the vagina or rectum.

3. **Strengthening the body's normal defenses.** The body has several naturally occurring defense mechanisms that a microbicide may be able to supplement or enhance. Lactobacillus, for example, is a naturally occurring, “good” bacteria that helps protect the vagina by maintaining its acidic environment. This natural acidity helps foster an inhospitable environment for many pathogens, including HIV. Thus, a microbicide that supports the lactobacilli in performing this function is one potential mechanism of action being explored.

4. **Inhibiting viral entry.** Some microbicides bind to viruses and bacteria to prevent them from binding to and infecting healthy cells.

5. **Inhibiting viral replication.** Some candidate microbicides are being developed from the antiretroviral drugs that HIV-positive people use to lower the amount of virus in their bodies. Formulated as gels or creams, these drugs may be able to suppress replication of HIV that enters the vagina or rectum during sex. If so, they could substantially lower the odds that the microbicide user will become infected or re-infected (if already HIV-positive).

Once we know which mechanisms of action are most effective, dual-action products will probably be developed that combine one or more of these approaches.

Microbicides may also be combined with physical barriers for greater effectiveness. Studies are already underway, for example, to see if just using a regular contraceptive diaphragm can help women reduce their HIV risk, given that the diaphragm blocks off the cervix which is more vulnerable to HIV infection than tissue on the lower part of the vagina. If this is true, then use of the diaphragm with an effective microbicide (once we have one) might give women better protection than either method alone. Needless to say, all candidate microbicides are tested for compatibility with latex to make sure that people can use condoms along with the microbicide if they want dual protection that way.

**When is the soonest we will have a microbicide?**

Five candidate microbicides have completed the safety-testing phase and are now in large-scale efficacy trials to determine whether they can substantially reduce the risk of HIV transmission. The effectiveness trials enroll thousands of women, all of whom receive intensive condom counseling, large supplies of free, high quality condoms and regular screening and treatment, if needed, for STIs. The women are encouraged to use condoms, whether they are given the active microbicide or not. A very large number of women (several thousand) have to be enrolled in the trial, in order to determine whether a reduced HIV infection rate (if one occurs) came about as a result of the microbicide, or because of condom use and other factors such as behavior change or prompt treatment of STIs.

Only when testing indicates solid evidence of both safety and effectiveness is a product presented for evaluation by regulatory agencies and, if approved, made publicly available. The soonest this might happen is around 2010—and that timeline will only be realized if one of the products now in Phase III trials turn out to be effective. If none of them work, it may take longer—especially given that the research pipeline is currently slowed down by lack of funding.

Meanwhile, the first rectal microbicide safety trials are expected to start in 2006. These trials will be essential to learning how rectal tissue may respond to some of the candidate vaginal microbicides. This information will help advance the process of developing rectal microbicides. It is also essential because adequate safety labels must be attached to any vaginal microbicides before they are marketed to advise users of the potential impact of using the product rectally (since some people may try to use it that way, even if it is labeled for vaginal use only).

**How effective will they be?**

“Partial efficacy” is the term used to describe a method that reduces, but does not eliminate, the risk of infection. The first generation of microbicides to reach the market are expected to be 50-60% effective against HIV, with the protection rate going up to 80-90% by the third generation as products are improved and new leads developed. Microbicides alone will probably never be as effective as correctly-used condoms, simply because it is generally safer to keep a virus out of your body than it is to try to stop it once it’s there. But even a partially effective microbicide will work far better than a condom left in the drawer.

The primary purpose of microbicides will be to provide a harm reduction alternative to people who cannot insist on condom use and who currently have no way to protect themselves from infection or reinfection. You can really see how huge this gap in HIV prevention is when you look at studies calculating the impact of even a partially effective microbicide. Mathematical modeling has shown that, if even 20% of women in contact with services in 73 lower income countries used a 60% effective microbicide in half...
the sex acts where condoms aren’t used, 2.5 million HIV infections could be averted over three years. ²

Given their partial efficacy, it will be critically important that the public health messages we develop around microbicides continue to encourage people to use condoms whenever possible. Microbicides will be a risk reduction approach to safe sex. The messages around using microbicides will need to be presented in a “hierarchy of risk” fashion—emphasizing that condoms provide the best protection and that microbicides can be used with condoms for additional protection and pleasure. But, for people for whom condom use just isn’t happening, microbicides could be a way of reducing risk by half or more—not an inconsequential benefit when your only alternative is no protection at all.

Why don’t we have microbicides already?

Right now, virtually all the research on microbicides is being done by non-profit and academic institutions or small biotech companies, using funding supplied by charitable foundations and government grants. These public funds also support the basic science, social and behavioral research, and the clinical trial infrastructure that contribute to microbicide research and development.

Large pharmaceutical companies have not invested significantly in this field, primarily because microbicides are a classic “public health good.” That means that, like contraceptives and treatments for diseases associated with poverty, microbicides are products that could yield a substantial social or public health benefit but that, nevertheless, fail to attract significant private sector investment. In short, the pharmaceutical industry doesn’t yet see them as money-makers.

Microbicide advocates calculate that a total of $142 million was spent globally on microbicide research, development, and advocacy in 2004. This amount is not adequate to move the product pipeline forward efficiently and under-funding is slowing the progress of microbicide development. Correcting this under-investment, they estimate, requires a doubling of total annual investment to $280 million per year, including $130 million for research; $120 million for clinical testing; $20 million for site development and $10 million for advocacy and policy. ¹³

Since microbicide development is funded almost exclusively by public money, the speed with which it progresses depends substantially upon the level of political will. It takes strong public demand to get governmental funding levels raised. Only one of the five Phase III trials now underway is fully funded through to completion. The others remain at risk of being unable to finish due to lack of money.

A healthy clinical trial pipeline is one in which dozens, if not hundreds, of candidate products move forward through the trial phases expeditiously, with unsafe or unsuccessful products being winnowed out rapidly so that resources can be used to move the more promising candidate products ahead without delay. In an under-funded pipeline, this cannot happen and progress is sluggish as products sit on shelves waiting for funding to become available before they can be tested.

Senate Bill 550, the Microbicides Development Act of 2005, was introduced by Senators Barack Obama (D-IL), Olympia Snow (R-ME) and Jon Corzine (D-NY) in the U.S. Senate on March 8. On September 21, Representatives Jan Schakowsky (D-IL), Danny Davis (D-IL) and Chris Shays (R-CT) introduced the Microbicide Development Act in the House of Representatives as HR 3854. If passed, this legislation that would boost the federal budget and federal commitment to microbicide research and development, thus helping to assure that testing moves forward efficiently.

No one strategy or technology will end the AIDS pandemic. What we need is an entire toolbox that includes existing prevention strategies such as behavior change, voluntary counseling and testing, STD diagnosis and treatment, broad access to male and female condoms, and antiretroviral treatment. To expand the prevention toolbox, we also need to add new options such as microbicides, vaccines and (if they are proven safe and effective) PREP and PEP (treatment before and after exposure). Each will fill a different need. As we learned from the birth control movement, offering a range of prevention options greatly increases people’s ability to identify and select options that fit their lives and that they can use consistently.

As a user-controlled (as opposed to partner-controlled) prevention tool, microbicides will give people who can’t or don’t use condoms a way of protecting themselves. But how quickly we get them depends, largely, on us.

Public education and advocacy are needed to pass the Microbicide Development Act and bring the first generation of microbicides to market as soon as possible. As advocates, we have to work to highlight the urgent need for user-controlled HIV prevention methods, educate those in a position to make a difference and pressure our elected officials to fund microbicide research and development at the level needed to eradicate delays.

For more information and to find out what you can do to help, please check out the Global Campaign for Microbicides website at www.global-campaign.org, e-mail us at info@global-campaign.org or call us at 202-822-0033 (Europe: +32 2507 1221). <

Anna Forbes, a widely published writer, community organizer and activist, has worked in HIV/AIDS since 1985 and in women’s health care and human rights advocacy since 1977. An outspoken advocate for the development of non-condom HIV prevention tools since 1992, she now serves as Global North Programs Coordinator for the Global Campaign for Microbicides. Anna’s writing has appeared in the AIDS and Public Policy Journal, AIDS Policy and Law, Harvard Health Policy Review, the New York Times, Newsweek and other journals and periodicals. She has also contributed to anthologies including Our Bodies Ourselves and is the author of eight children’s books on HIV/AIDS.

Footnotes

1-3 Footnotes available at www.tpan.com
Marilyn McBride needed information and she needed it quick. A former substance abuser, ex-offender and African American woman living with HIV, she was as desperate for knowledge as she had once been for crack cocaine and not ashamed to admit it.

Marilyn’s husband, the love of her life, was dying. Her quest to learn all she could about the deadly virus that was eating away at him led her to TEAM (Treatment Education Advocacy Management), a peer-led training program conducted by Test Positive Aware Network.

“TEAM put it out there for me in the raw,” Marilyn says of the program she credits with changing her life. “And that was exactly what I needed.”

TEAM provides participants with a basic understanding of the body, the immune system, the HIV lifecycle, antiretroviral treatment as well as associated issues including side effects, adherence, opportunistic infections, STDS, nutrition and complementary therapies.

Worley also points out that the TEAM program especially has made me whole again.”

Consisting of 18 initial hours of training and six, three-hour update sessions, TEAM provides participants with a basic understanding of the body, the immune system, the HIV lifecycle, antiretroviral treatment as well as associated issues including side effects, adherence, opportunistic infections, STDS, nutrition and complementary therapies.

“TEAM taught me the technical stuff I didn’t know and didn’t realize I was going through...I wasn’t whole anymore. I was broken,” Billy Coats, who currently works as a support group for women living with HIV.

“I am the happiest that I have ever been in life,” she says with a warm smile that reflects her peaceful spirit. “Coming to TPAN and going through TEAM turned my whole life around.”

And she is not alone. Marilyn is one of many success stories that the TEAM program boasts. Since its inception in the spring of 2003, more than 125 people from all walks of life have completed the TEAM curriculum.

Marilyn’s husband, unfortunately, died just shy of her completing the program. But the wealth of knowledge and the network of support that she gained from her peers and the TEAM staff have led her on a journey of self-empowerment that she never dreamed she would embark upon. Today she is a consumer advocate with Access Community Health Network and facilitator of S.H.E. (Strong Healthy and Empowered), a support group for women living with HIV.

“TEAM taught me the technical stuff that I needed to better understand the complexities of living with both hepatitis B and HIV,” says Martinez. “More and more people today, especially people of color, are facing co-infection as their reality. For us, accurate knowledge about both of our diseases is the key to living a longer, healthier life.”

Funded by the Ryan White CARE Act and the Minority AIDS Initiative, TEAM places a special emphasis on educating people of color. “We represent an incredibly large portion of the HIV burden in this country and around the world,” says Montre Westbrook, graduate of the Black AIDS Institute in Los Angeles and co-creator of the TEAM program, along with Director of Treatment Education Matt Sharp. “I believe that this is largely due to a lack of education within our community about HIV and AIDS. The more we know, the better equipped we are to make educated decisions and behavior changes that can save our lives and the lives of our partners.”

Billy Coats, who currently works as an administrative assistant at BEHIV (Better Existence with HIV) in Chicago, credits his TEAM for renewing his sense of hope about life. “I was a whole person before HIV came into my life and then all of a sudden I wasn’t whole anymore. I was broken,” Billy says. “My experience at TPAN and in the TEAM program especially has made me whole again.”

“I don’t live as much in fear as I did before,” he explains. “I have the self-confidence to live with HIV and to accept the things that I don’t have control over and to take control over the things that I do.”

Though TEAM has meant different things to different people, there is one thing that is clear. The life-altering effect that it has had on the lives of those who have been a part of it is undeniable and far-reaching.

For more information on TEAM, contact Derek Worley at (773) 989–9400.
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Men who have sex with men (MSM) bear a greater burden of HIV than any other group in the U.S. We account for an estimated 45% of people living with HIV, compared to 27% infected through heterosexual contact, and 22% infected through injection drug use.

In June, the Centers for Disease Control and Prevention (CDC) released a study showing a stunning 46%—nearly half—of the Black homosexual and bisexual men surveyed in five major cities were already HIV-positive (more than twice the infection rate among men of other races).

To make matters worse, more than two thirds of the HIV-infected Black men in the study were unaware of their infection. That’s right. Half of us may be infected and, of that half, two thirds don’t know it and so almost certainly aren’t doing anything about it.

The factors contributing to the spread of HIV among Black gay and bisexual men are complex and vary from person to person. While some men do not yet recognize the level of risk they face, others are making complex decisions about sex and relationships based on perceptions about their partners’ serostatus, old myths, and plain misinformation rather than real knowledge and open communication. There is a perception that AIDS is not as bad as it was, and of course there is an understandable desire among many of us to just enjoy relationships and have plain fun. Many of us are just tired of talking about how we are all going to die. But that fatigue will kill us. Disease does not have to overshadow our lives, but we must remain aware enough of it to protect ourselves.

Forty-six percent isn’t a catastrophe. It’s genocide!

But, where is the outrage? As far as we can tell, following the CDC’s announcement no Black or gay media organizations ran front-page stories. No civil rights organization marched in the streets or called on policy makers to take action. No Black celebrities sponsored relief concerts. There wasn’t even a call to action issued by a Black gay and lesbian organization!

Now, we could make charges of racism and homophobia (and some of us have). And, we might be right. But those charges would not be helpful and may be beside the point. A Black LGBT group founded to advocate for civil marriage rights sponsored a town hall meeting on “The State of Black LGBT America” during the annual Black Gay Pride event in Los Angeles in July. AIDS was not even on the agenda. Nearly 50% of Black gay men in America may already be infected with HIV, and AIDS is not on our agenda? How can that be? While equal rights, including the right to marry, are certainly worthwhile goals, they are not very useful to us if we are dead. Keeping us alive long enough to enjoy the rights we deserve should at least be on the list.

This is not the first time the alarm has been sounded. An eye-opening 1994 study put the HIV prevalence among Black homosexual and bisexual men at 21%. We did virtually nothing in response. That study was followed by a CDC study in 2000 in which—surprise, surprise—the prevalence rate among Black MSM had increased to over 30%. And again, after calling on the CDC to do more, we did virtually nothing. Now we’re looking at 50%.

What will it take? How many Black gay men have to get infected, get sick and die before we—not CDC, not the Congressional Black Caucus, not the large AIDS organizations, but us—mobilize and take action?

Following CDC’s prevention conference in June some Black gay and AIDS activists grumbled about the amount of attention crystal meth is getting. Please, White gay men are doing exactly what they should be doing. They are forcing each other to take responsibility, be accountable and attack a threat that is attacking them. Meanwhile, we’re dancing from pride event to pride event while this threat is barreling down on us.

We have to start a national public discourse among ourselves about this new AIDS reality. We must create a cultural shift to where knowing your HIV status is the norm, where those of us who are negative are committed to stay that way and where those of us who are positive refuse to engage in behavior that might expose our brothers to the virus. We must all support each other in our collective and individual campaigns to end the epidemic. Nothing short of an all-out mobilization is acceptable. We must not allow any of the institutions or businesses that we support to fail to do their part in ending this epidemic. Most importantly, we must increase our visibility and demand our rightful places in our communities.

There is a role for all parties to play—government, the larger Black community, the White LGBT community, our society as a whole—but we must be willing to hold ourselves accountable and responsible for our own survival. How can Black gay and bisexual or same gender loving men ask others to respond if we continue to be so complacent in the face of our own genocide?

HIV is currently ravaging the Black community in the United States. It is estimated that one out of every 50 Black men is HIV-positive, and a recent CDC study with Black men who have sex with men (MSM) found an HIV prevalence of 46% in five major metropolitan cities. Black women, while only comprising 12% of the entire female population in the United States, make up approximately 70% of all female HIV/AIDS cases.

While primary HIV prevention issues have been at the forefront of the American public health agenda for years, stressing the secondary prevention needs for Black Americans currently living with HIV is equally important. Despite the availability of over 20 FDA-approved antiretrovirals (ARVs), African Americans are still suffering from disproportionate HIV-related morbidity and mortality rates when compared to their White and Hispanic counterparts. The reasons for the racial disparity are multi-factorial, but are often categorized into two distinct camps of thinking: one suggests that inherent genetic racial differences account for the disparity, while the other emphasizes the role of broader environmental and social issues. So which is it?

As HIV has progressed so rapidly among both African and African American populations worldwide, medical officials have postulated that there may be genetic factors influencing this current trend. On the HIV prevention front, researchers have been pursuing a couple of interesting leads with regards to susceptibility of individuals to HIV infection. CCR5 receptors are receptors on the surface of the CD4 cell (T-cell) and are one of the receptor types that HIV attaches to in order to gain entry into the T-cell. Enhanced CCR5 receptor expression or a lower number of CCL31 protein gene copies (which are proteins that block CCR5 receptors) are possible factors that may contribute to enhanced HIV-1 susceptibility among people of African descent.1,2

The thought of genetics factoring into responses to medication and HIV morbidity and mortality rates is also taking shape. A recent ACTG study, A5095 & A5097s, found that a greater percent of African Americans than Whites have changes in their cytochrome P450 system (the enzymes which aid in liver metabolism of medications), called polymorphisms CYP2B6 and CYP3A4.3 These polymorphisms lead to slower clearance of ARVs in the liver (in this case, Sustiva), increased blood levels and body exposure to Sustiva, and increased side effects among African Americans. The authors concluded that these differences “may” help explain the HIV racial disparity in treatment outcomes seen among African Americans. While the study found no direct relationship between genetic subtypes and discontinuation rates or adverse events among study participants, the findings do suggest that these decreased clearance rates of Sustiva among African Americans may influence adherence patterns and ultimately, resistance profiles and outcomes.

The results from the Sustiva study may not necessarily surprise anyone living with HIV or who has been doing clinical work with HIV for years. Darkening skin and nail discoloration among African Americans with medications such as AZT, Bactrim, and
Americans is compelling. African Americans with HIV/AIDS are... How’s environment got to do with it?

What’s environment got to do with it?

While the genetic argument for adverse health outcomes is developing steam, information supporting the role of social influences on the poor HIV morbidity and mortality rates of African Americans is compelling. African Americans with HIV/AIDS are often diagnosed at more advanced stages of HIV, and utilize less outpatient and more inpatient care than their White counterparts, even when controlling for socioeconomic status and insurance. This is to be expected, as an emphasis on emergency medical treatment utilization instead of primary care services has long been a staple of healthcare access patterns in the Black community. However, when you consider studies demonstrating that heavy reliance on inpatient and ER facilities lead to worse HIV outcomes, and increased outpatient HIV support leads to improved medication adherence, clinic retention rates and lower hospital admission rates, one can see where this mode of accessing health care services is like shooting ourselves in the proverbial foot.

Access

So what are the reasons for the patterns of healthcare access and utilization that may be impacting the morbidity and mortality rates among HIV-positive African Americans? At first glance, many would cite the high rates of poverty, lack of insurance, poor access and inadequate transportation as the main culprits of this public health dilemma. Moreover, policy barriers such as Medicaid requirements for legal immigration status and residency, limits on Medicaid eligibility based on disability requirements, and state-imposed income and benefit limits on ADAP also represent larger structural forces at work. While these factors are surely the major external “barriers” to improved HIV care for African Americans, would the HIV outcome disparity among African Americans be resolved if everyone had money, insurance, a car, and access to a healthcare facility at every corner? Maybe, maybe not. Addressing these broader structural factors is definitely a start, but there are also interpersonal, institutional and individual behavioral and cultural factors driving this racial HIV outcome disparity.

Black doctors

While the overall prevalence of HAART use has increased among HIV-positive individuals since the mid-1990s, African Americans and those with an injection drug use risk factor are less likely to receive HAART. While these findings can be partially explained by problems with insurance and access, studies have demonstrated that the interpersonal provider-patient interaction has influence on this dynamic as well. Physician perceptions of African Americans as less educated, less intelligent and less pleasant influence their expectations of these patients to engage in risk behavior and follow advice. Specifically, one study found that physicians’ predictions that Black men are less likely to adhere to HAART influenced their treatment decisions. However, another study found that HIV-positive Black men’s perceptions of physician competence and support may influence their adherence to protease inhibitors. These findings underscore the fact that statistics of low HAART use among African Americans may also be influenced if patient and medical provider are not of the same race, or if there is individual provider or patient bias, and lack of cultural competency and effective communication between both parties.

Stigma

Institutional factors within clinical settings can also potentially affect HAART adherence among African Americans. In focus groups conducted with Black MSM in New York a few years ago, participants were asked to detail their experiences with medical institutions and providers. In addition to stories of overt racial and sexual discrimination experienced by these men in medical facilities, they also told of specific institutional barriers to health care. The social stigma associated with going to a certain clinic known for HIV care, long waiting times for providers, problems with patient confidentiality and the impersonal approach of healthcare staff were all factors influencing how often the men in this study accessed healthcare services, the level of communication they had with providers, and their adherence to medical advice.
These clinic variables, both interpersonal and systematic, create an environment that can potentially affect the manner in which HIV-positive individuals decide on how to communicate with healthcare providers and access services. This, in turn, may have a direct impact on adherence to medications, development of resistance, and rapid progression of disease.

**Beliefs**

Medical and public health officials have also speculated about specific cultural and individual behavioral factors that may influence healthcare utilization, adherence patterns and other variables influencing HIV morbidity and mortality among African Americans. These factors include, but are not limited to: religiosity, beliefs regarding complementary and alternative medicine practices, mental health status and substance abuse. Perhaps the most widely discussed variable that has not yet been adequately measured involves the pervasive distrust of medical and public health messages and personnel, combined with widespread support of HIV conspiracy theories. These factors have been put in context in medical literature, and a recent random telephone survey with 500 African Americans found that stronger Black genocide conspiracy beliefs were significantly associated with negative contraceptive beliefs. Believing that contraception methods such as condoms and birth control are social genocide provide a strong counter-argument against current HIV public health messages emphasizing safer sex.

**Conspiracy Theory**

I often field questions from my patients regarding how effective ARVs are against HIV, whether HIV is truly the causative agent of AIDS, and if I think the pharmaceutical companies are holding out the cure to HIV to get more Black people dependent on their medications. While some medical providers would scoff at these questions, they are legitimate questions founded in historical context. Given the United States’ infamous history of medical experimentation on Black people, ranging from heat tolerance testing of slaves in the 1800s to the Tuskegee experiments from 1940 to 1972; it shouldn’t be difficult for others to appreciate the current climate of distrust of medical institutions among African Americans today. In fact, while recently doing a radio show on HIV and the “down low” on a local Atlanta radio station, the majority of Black men who called in had questions and concerns regarding the truth of HIV being the causative agent of AIDS, not about so-called “down low” men. Survey instruments measuring levels of distrust and support of conspiracy theories and their relationship with unprotected sex rates among African Americans are sorely needed. Moreover, disbelief in HIV as the virus that causes AIDS can influence healthcare utilization practices, medication adherence, and overall open communication and discussion with medical practitioners. These factors, unfortunately, may also collectively contribute to the current adverse health outcomes for African Americans living with HIV/AIDS.

These social and environmental factors I have described are undoubtedly present in the equation leading to poor health outcomes among HIV-positive African Americans, yet they present a difficult challenge when measuring direct associations with health outcomes due to their subjective nature. How do you measure distrust or how one experiences discrimination? It’s as difficult as mapping a gene nowadays. Nonetheless, these forces are vital to our consideration of the complex overlap of variables influencing these poor outcomes.

**Genetics and Environment: Not mutually exclusive?**

**Hypertension**

In a study examining the prevalence of hypertension among seven populations of West African origin, researchers found a linear increase in prevalence among Black people living in West Africa (16%), the Caribbean (26%) and the United States (36%). They argued that by standardizing blood pressure measuring in geographic locations that traced the path of the African Diaspora, the increase in mean blood pressure going from West Africa to the United States suggested that high blood pressure among African Americans was a reflection of social conditions rather than due to specific racial genetic traits. In other words, Black folk developed this tendency to have high blood pressure as a direct result of forced and traumatic passage and acculturation to the United States. Since 90% of hypertension is said to be “essential,” or genetically inherited, it is plausible to speculate that over generations, Black people living in the United States and exposed to adverse social conditions that contribute to high blood pressure (racism, stress, poor diet, lack of exercise, obesity) developed over time a genetic “predisposition” that reflects chronic exposure to these conditions.

**Circumcision**

Similarly, the role of circumcision in the susceptibility to HIV provides an example of possible biologic/genetic traits and environmental forces interacting to drive the epidemic among African Americans. A study by Australian researchers examined biological traits of the foreskins from 30 men who had recently undergone adult circumcision or were recently deceased. They found that the inner aspect of the foreskin had less keratin than other areas of the penis, but just as many Langerhans cells that express CD4 and CCR5 receptors to which HIV can attach. HIV binds to these receptors and the Langerhans cells migrate to regional lymph nodes, transporting HIV to resident T-cells. The authors concluded that circumcision may provide a protective effect against HIV as it removes the main site for HIV entry into the penis.

Additionally, results from a recent prospective study following over 3,000 men outside of Johannesburg, South Africa found that over 1½ years, men who were circumcised were 65% less likely to contract HIV than those who were not circumcised. If Black men are less likely than White men to be circumcised in the United States, it is possible that this culturally-based preference may aid in the perpetuation of HIV among the Black community. To date there are no comparative studies between the genetic makeup of Black and White men with regards to biologic keratinization of foreskin or relative presence of Langerhans cells that influence HIV susceptibility, but these recent findings on circumcision dem-
onstrate a potential intersection of genetics, biologic and cultural factors influencing disease susceptibility that warrants further exploration.

**Putting it all together**

Given the results of the studies on hypertension and circumcision with primary HIV susceptibility, it is apparent that the answers to the disproportionately adverse HIV morbidity and mortality rates among African Americans likely involve both genetic and environmental explanations. And these seemingly separate and distinct entities are likely in a constant state of influencing and informing one another. We know that traumatic events among HIV-positive gay men and attributing negative experiences to self can predict faster CD4 decline and progression of disease.22,23 The broader environmental and institutional social conditions (racism, poverty, trauma) impacting African Americans can influence individual behavioral choices regarding healthcare utilization and adherence and health behaviors that drive other medical conditions such as hypertension and diabetes, but may also directly impact the immune system’s status and subsequent HIV disease progression. Whether this constellation of forces directly impacts the expression of genes that influence responses to particular HAART medications, such as cytochrome P450 polymorphisms that influence the clearance of Sustiva, is not known. But what research has demonstrated thus far suggests how environmental forces and genetics influence one another and is a subject that is worth further investigation when it comes to the health outcomes of HIV-positive African Americans.

**Confronting the HIV Racial Disparity—Individual Suggestions**

There are many challenges that lie ahead in addressing the reasons behind the adverse health outcomes of HIV-positive African Americans. It is apparent that genetic factors may be influencing issues surrounding medication clearance, susceptibility and side effects to certain AIDS-related complications (such as HIVAN). Yet it is also clear that social conditions and stressors may be driving individual health behavioral choices and rapidity of HIV disease progression. Research on the intersection of genetic and social determinants of racial HIV disparities should continually be at the forefront of the academic agenda. Racism, sexual prejudice and HIV-related stigma and discrimination are not going to disappear overnight, and at least until 2008 federal HIV policies will be unsatisfactory. And cultural competency programs in medical training facilities are more common now, but medical culture still has a long way to go with regards to sensitivity and effectiveness issues of those living with HIV. So, what can I suggest to my brothers and sisters living with HIV in this maze of issues in the meantime? Here are a few ideas:

- **Read, read, read!** The more you know, the more informed you will be. Whether you read *Positively Aware* for your biomedical treatment/medication updates or consult with a local herbal specialist, keep up to date with what’s current in how medications and supplements may be interacting with your body so that you can understand potential benefits and side effects.
- **Be persistent with your provider**—When you notice bodily changes that may be medication-related, no matter how insignificant you may think they are, mention them to your provider. If they can’t give you an answer, ask them to refer you to someone who can, or get a second opinion on your own. This way you’ll know soon if you need to change medications or if a side effect is something you can tolerate.
- **Be honest with your word**—Honesty with yourself as far as what your actual needs are from a clinic, clinic staff and your provider, and honesty with the staff and providers regarding who you are as an individual so they can work with you to provide an appropriate and acceptable treatment plan. Lying to yourself or keeping secrets from providers leaves you in a position to blame no one but yourself if anything goes wrong.
- **Embrace healthy skepticism**—Yes, some pharmaceutical companies can be very money-hungry and probably wouldn’t benefit from a cure for HIV. Yes, medical providers can be impersonal, insensitive and flat-out racist at times. Yes, God has a plan for all of us and we can’t control everything. And yes, there are alternative theories to HIV origins and treatment that you could consider. But don’t let these realities prevent you from making informed choices about what is best for your mental, spiritual and physical health.
- **Don’t let stress get the best of you**—regardless of whether you are on ARVs or not, your reaction to environmental stressors is key to your living healthy with HIV. Pay attention to your body in times of personal and professional stress, and seek help when you need it. Whether you take a private moment to yourself, or consult a trained psychological counselor, your local pastor, or a friend or family member—reach out when you need to. You and your body will be glad you did.

**Conclusion**

Whether its genetics or environment, the responsibility falls on all of us as people of African descent to love ourselves enough in our approach to HIV (and life in general) to modify the social conditions that we can change, and adapt to the genetic realities we cannot. *Loving ourselves*—now there’s a social condition worth passing on to our future generations until it becomes a genetic trait.

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**Footnotes**

1-23 Footnotes available at www.tpan.com
Black People and the Search for an HIV Vaccine

A vaccine advocate gives us the low-down
by Steve Wakefield

What exactly is a vaccine? It’s a substance, usually injected, that teaches your body to fend off a virus that might invade before the infection actually occurs. That way your body’s already prepped for the fight if you’re ever exposed. Some people get a flu shot every year, for instance. Most people get shots as a child so that they never have to worry about polio or measles. Studies known as “clinical trials” are being conducted to find one that works to protect us from HIV, too. It’s also possible that a vaccine could slow down the disease’s progression in people already infected with HIV.

So far, over 20,000 people have helped test more than 30 potential vaccines, but we still don’t know which one will work. That means many more people are needed.

**Myth:** You can catch HIV by volunteering for vaccine research.  
**Truth:** No. It is impossible to get HIV infection or develop AIDS from experimental vaccines, because they are not made from live HIV, killed HIV, weakened HIV, or HIV-infected cells of any sort. It just can’t happen.

The people working to find an HIV vaccine are the same people who found the drugs we use to treat HIV and AIDS today. Strict rules governing medical research prevent them from testing a product that has any chance of giving someone HIV.  

**Myth:** Medical researchers can’t be trusted, especially those funded by the government.  
**Truth:** Our community has certainly had problems with medical researchers. Tuskegee anyone? But today’s HIV vaccine studies are closely monitored by several watchdog groups, and their research teams include representatives from the communities in which the studies are taking place.

There are also local groups called Community Advisory Boards, or CABs, which take a hard look at what each study is doing to protect volunteers and help those volunteers to understand the research taking place. CABs include people who have been in other studies, nurses, college students, journalists, parents and others who understand the science and can voice community concerns.

**Myth:** Black people can benefit from whatever vaccine they find without participating in the research.  
**Truth:** I’m afraid not. If Blacks don’t participate in large enough numbers, we will not know if the vaccine works for our lives and bodies too.

Some other vaccines are showing that gender makes a difference, perhaps race does as well. We need to develop a vaccine that will work in the context of everyone’s actual day-to-day life. Do diet, exercise patterns, stress levels, the presence of other illnesses or any host of factors that vary between racial and economic groups matter? The only way to know is to do the studies with enough Black men and women participating.

**Myth:** When they find a vaccine AIDS will be over.  
**Truth:** If only it were so. A vaccine is not a cure. And it will not single-handedly end the AIDS crisis. People already infected—that is, people living with HIV today—will still need better treatment and better care. And even with a vaccine, condom use, abstinence and other ongoing HIV-prevention efforts will still be important tools for stopping the virus’ spread.

For more information about vaccine research, or to find study sites near you, visit the website of the HIV Vaccine Trials Network.

Steve Wakefield, a former executive director of Te8 Positive Aware Network, is associate director for community education of the HIV Vaccine Trials Network and a regular science contributor to BlackAIDS.org. This article was reprinted from BlackAIDS.org.
As a youth peer advocate for Circle of Care in Alameda County—home of Oakland, California and across the bay from San Francisco—Lizette Green goes into high school classes to educate teens about the prevention of HIV and other sexually transmitted diseases.

“I’ve been certified in a million things, but I don’t talk that medical mumble jumble,” says Green, 25. “Teens are having sex at a younger and younger age, and they don’t know what they’re doing.

“I always ask, ‘Should a female smell like fish?’ There’s always two or three kids who raise their hands. I say, ‘Okay, that’s a sign that you have to step away from that cat, because that cat’s not right.’ ”

Green says, “I do not tell them to have sex. I tell them that if they are going to have sex, to protect themselves and respect themselves. I tell them that there are consequences.”

Last year Green did not disclose that she is HIV-positive. This year she did and talked about how she was infected, at the age of 15. She said “even some of the boys cried. I was younger than anyone in the class when I was infected.”

Transmission
The most common question I get is like, “Can I get it if I get into a fight?” They don’t understand transmission.

Forget risk assessment. Throw that risk assessment bullshit into the garbage. Have you had unprotected sex? Then you’re at risk. When I was infected 10 years ago, I was not considered to be at risk.

If it Smells Like Fish, That Cat’s Not Right
Infected with HIV at 15, a young peer educator tells it like it is to teens
Interview by Enid Vázquez

Oral sex
Kids don’t think oral sex is sex. I tell them, “You want to see a picture of gonorrhea of the throat?” They say, “You’re kidding. You can’t get gonorrhea in the throat.” I say, “You guys, it ain’t pretty. The pictures of syphilis and herpes—they ain’t cute.”

“Regular” sex
Kids ask if they can get HIV through “regular sex.” I ask them what “regular sex” is. I tell them, “What’s regular sex to you may not be regular sex to me.” They’re talking about vaginal sex. They don’t think “regular sex” is dangerous.

Transmission
The most common question I get is like, “Can I get it if I get into a fight?” They don’t understand transmission.

Forget risk assessment. Throw that risk assessment bullshit into the garbage. Have you had unprotected sex? Then you’re at risk. When I was infected 10 years ago, I was not considered to be at risk.

Anal sex
At the same time, some young people think anal sex is the way to avoid HIV. They also think it’s a way to remain virgins. It’s really true. It’s really true. If they have not had vaginal sex, given or received, they think they’re still a virgin.

Like a virgin
Kids will say, “Oh, yeah, I’m a virgin.” Then you ask them what they have. They say “vaginitis.” You ask them what kind. They say, “Trichomonas vaginitis.” Well, you didn’t get that by yourself.

Teachers
Teachers are a bunch of old people who teach prevention because it’s mandated, not because they think [HIV infection] might actually happen.

Parents
The parents really want to protect their kids and keep them out of danger, but they’re not talking to them. They don’t want to think that their 14-year-old girl is having sex. They don’t want to know that their son is gay.

Medical providers
Medical providers who are not in touch with today’s reality and statistics, they’re saying you’re not at risk. That’s what happened with me. Granted, that was 10 years ago, but it’s still happening today.
GIVE ME A BUBBLE
I feel for these young men and women. I wish I could just take them all and put them in a ball, so they wouldn’t get hurt… but I can’t do that. Our house is made out of glass and HIV is the stone.

DOWN-LOW
I see so many kids on the down-low. They’re having sex with men and then going back and having sex with a girlfriend who they can put in front of their families.

LATIN LOVERS
Girls feel safe when they’re in love, especially Latin women. We were taught to be with one man forever and ever. That’s how I got infected.

That’s what we see so much in our community. This man of our dreams is bringing things home to us, including HIV and other STDs.

ALL LOVERS
Expectations have changed. They’re not what they were 20 years ago. The whole virgin thing is out the window, so be honest about what’s going on. Thinking that a young girl is going to stay a virgin until marriage is not realistic. People don’t want to see it until it’s in their face. They don’t want to think that HIV is in their community.

BOYS ONLY
Society says, “Alright, guys, be responsible and wrap it up,” but society doesn’t say that to the girls.

GIRLS ONLY
If a girl asks a guy to use a condom, he thinks that she must be having sex with a whole lot of guys. It comes back to your reputation. Girls can’t carry condoms because they’re not supposed to be having sex and having a condom means you’re having sex.

Then they’re going to a party or a friend’s house and having sex. Hormones take over. If they don’t have anyone to turn to and have a support system, they’re going to get infected.

It freaks me out. I’m already talking to my nine-year-old about getting her period. I’m totally stressed about this.

PERMISSION FOR SEX
I tell them, “The only person responsible for you is you.” They say, “Our parents are responsible for us.” I ask them if they’re asking their parents for permission to have sex and they say no. I ask them if they’re asking their parents for permission to buy condoms and they say no. Well then, you’re responsible for yourself. That makes them stop and listen.

I make them own their responsibility.

HOW’D THAT HAPPEN?
When people test positive, they’re dumbfounded. They don’t know how it happened. I ask them if they had unprotected sex. “Yeah.” Well, that’s what happened.

They have what I call “Superman syndrome.” They just don’t think it can happen to them. HIV is our community’s Kryptonite. Our communities—African American and Latino—this is killing us off.

STRAIGHT TO AIDS
It’s not just people testing positive. They’ve been positive for years and years and didn’t know it. What could be just one quick swab of the mouth [OraSure HIV test]—we don’t want to do it, because ignorance is bliss.

We have young guys 19, 20 years old who have AIDS when they test positive, because they didn’t take care of it. When they’re real sick and can’t ignore the symptoms anymore, that’s when doctors test them.

GOT AIDS?
They test positive for gonorrhea or Chlamydia, but don’t get encouraged to test for HIV. And that comes back to the medical profession. The lack of awareness is everywhere.
Give me HIV
People think the weirdest things. Some kids think that if their partner has HIV, they can get it and HIV won’t affect them anymore. “If I’m infected, I won’t get sick.” They think it’s like a vaccine.
I can’t tell you how it’s justified in their mind. Young ladies tell me, “He didn’t come inside me.” It’s in pre-cum as well. Everyone has their own justification.

The missing link
It’s about talking to your kids. It’s about talking to your friends. But those of us who are informed about all this aren’t talking. That’s the missing link.

It’s your body
It’s not talked about to them. They’re having sex and they don’t know what’s going on with their bodies. Young girls don’t know that they’re at most risk because the cells of their cervix are still developing. Their cervix hasn’t fully matured, and is more vulnerable to HIV infection.

He loves me
“He loves me,” or I love him. Or he’s got a fly body or he looks “clean.” Why would you want to face the reality of somebody you care about who could kill you? Who wants to see the reality that they’re cheating on you?
People think their partner has only been with them. They don’t think about the other people their partner has been with.
Someone putting on a condom is not like saying “I love you” and handing you a rose. Kids also just get caught up in the heat of the moment.
Ignorance is bliss, so you don’t want to hear negative stuff.
I tell them I’d love to be stupid. I’d love to not be aware of this. I’d like to wake up and take a couple of antibiotics and it would be gone. But it’s here with me forever.

It’s her fault
Lots of guys don’t feel guilty if they infect a girl. They say, “She slept with me, so why should I care what she gets? Why should I feel guilty?” If you just deny [your responsibility], you justify what you’ve done.

It’s a gay thing
In 2005, Latinos and African Americans and youth and women have high rates of HIV, but many people see it as a gay man’s disease. There are so many myths around transmission.

Seatbelts
Would you drive a car without a seatbelt? [EV: A lot of people do.] Well, not at a hundred and fifty miles an hour. You wouldn’t jump into a race car and not put it on. Maybe that’s like putting on a condom. People think, “Not this time, I’m just going a couple of blocks to the store.”

Routine testing
I don’t support routine testing. You really need well-trained staff to provide counseling, support and information. I can just hear the test results: “Oh, by the way, you’re positive. Good luck with your life.”
But I do think testing should be offered more.

The love of my life
I was so sure I had met the love of my life. I was 15 going on 16. I’m Puerto Rican and White and he was Mexican. We started living together and I got pregnant. In the state of Washington, that makes you a common-law marriage.
I had always tested for HIV, because I was not a saint. That was my justification. I wasn’t doing what I was supposed to be doing according to my family—not having sex.
Two weeks later I got a call that I needed to come in to the clinic right away. When I got there, they were calling other patients to clear my doctor’s calendar that day. That’s when I knew. This was in 1996 and people are still fighting for an HIV test today.
My husband developed AIDS within four years, and he died that year, from other complications. We were already divorced. I never got to ask him how he got it. I never wanted to know just because at that point it didn’t matter anymore. There was nothing I could do about it, so at that point, why bring on extra agony for myself?
He bled a lot when he had needle draws, and I know now that it’s a sign of trauma to the vein, from lots of use of needles. I thought his brother had died of cancer, but he had died because of AIDS and injection drug use. I never knew that. His brother was his best friend.

Green had two children with her husband and now has a third child. They are all HIV-negative. She is on Combivir and Viramune, a drug combination she tolerates well and calls “no fuss.”
Phill Wilson, founder and director of the Black AIDS institute, is a leader in the fight against HIV/AIDS in the Black community. Globally known and respected for his "tell it like it is" approach to combating the epidemic in Black America and abroad, Wilson sat down for a One-on-One with Associate Editor Keith Green to share his views on the plight of this disproportionately affected and infected population. What follows are highlights from that dialogue.

KG: What is your perspective on the state of African Americans as it relates to HIV/AIDS?
PW: In many ways, the issue around HIV/AIDS in Black America is a tale of two cities. On one hand, most of the data and information about HIV/AIDS as it relates to Black people in America is bad. No matter how you look at it, people of African descent in the United States represent a disproportionate amount of the HIV burden. We are roughly 12% of the U.S. population, yet we are nearly 50% of people living with AIDS in America today.

It is estimated that there are currently over a million people living with AIDS in this country. Over 50% of the new HIV/AIDS diagnoses in America are Black. When you look at the epidemic along gender, sexual orientation or age lines you find that, there again, Black people are being decimated by HIV/AIDS. Among women, 69% of the new HIV/AIDS cases are Black. Among young people, two-thirds of adolescent cases, between the ages of 13-19, are Black. The CDC recently released data suggesting that possibly 46% of Black men who have sex with men in America may already be HIV positive. So, from that lens, the news is bad.

There are glimmers of hope, however, in that Black institutions are beginning to mobilize around HIV/AIDS in ways that we have not seen before. We have an increasing number of Black churches that are developing HIV/AIDS ministries. Black civil rights organizations are developing AIDS programming. Historically Black colleges and universities are beginning to teach HIV 101 on their campuses. Black fraternities and sororities are establishing activities to address HIV/AIDS. And women's organizations across the board are tackling this issue. So, the Black community is really poised to attack this problem full force and that's the good news.

KG: What factors play into those statistics?
PW: There are a number of factors that contribute to how African Americans are being impacted by HIV/AIDS. 

One is obviously the economic disparities that exist in the U.S. that are based on race or manifest themselves along racial lines.

Number two is the under-utilization and under-access of medical care by African Americans.

Number three, obviously and probably the most important reason, is that the African American community was slow to respond to the epidemic, and as a result the virus had a chance to take hold in our communities, yielding a higher prevalence than in other communities. This slow response also resulted in the infrastructure and capacity of our community being totally insufficient to deal with this epidemic.

KG: Is there a unified response or plan of action?
PW: There is no unified response or plan, yet. However, developing a unified plan is critical and there are efforts being made to create one.

KG: What would that look like?
PW: I think that it would have to involve a number of components. First, there would have to be a cultural shift in our attitudes about HIV/AIDS. Meaning we have to establish a cultural norm where engaging in risky sexual behavior or risky drug use is just unacceptable.

We have to create an environment where people who are HIV negative have made a commitment that they are going to stay negative and people who are HIV positive have made a commitment that they are not going to engage in any behavior that would possibly transmit their virus to another person. Then we have to create community structures to support those kinds of commitments. That's number one.

Secondly, our institutions have to all include HIV/AIDS in their agendas...the civil rights organizations, the fraternities and the sororities...no matter what they are doing, AIDS needs to be a part of that agenda, because AIDS is so much more than just a health issue. It is a civil rights issue, it's an economic issue, it's an urban renewal issue, and it's a gender issue. So there are all of these other issues that are impacted by HIV/AIDS and, therefore, these other organizations need to take that on.

We also need to be aggressive in confronting stigma wherever we see it and let it be known that it is not acceptable. We need to make sure that people have the information that they need about HIV/AIDS. That they are encouraged to find out their HIV status and that they have access to the latest testing technology. People who are HIV positive must have access to care, minimally...access to information about care options.

KG: What role does the Black church play in combating the epidemic?
PW: The Black church has always been an important institution in Black communities and I think that that is no different on this issue. Probably the area where the Black church can play the biggest part is in fighting stigma by not contributing to it either on the basis of sexual orientation, which undermines prevention efforts, or HIV status.

Churches can show compassion, which can go a long way in creating a less judgmental environment where people are not afraid to deal with their HIV status. Also, churches should not back away...
from their traditional role of providing sanctuary, shelter, food and support for people in need.

KG: What are the major obstacles that prevent us from turning the statistics around?

PW: Clearly, the biggest obstacle is a lack of resources. The vast majority of organizations who are best positioned to turn those statistics around are wholly under-resourced. When I say resources I am speaking of both capitol and technical. Not just technical in terms of computers and such, but technical in terms of epidemiology and those kinds of things.

KG: What about the Black gay men are currently the hardest hit population in the country. What factors do you think play into that?

PW: Certainly, I think that stigma, demonization and marginalization contribute greatly to it. However, when you look at health indicators overall, Black men (Black gay men included) fare worse than any other population.

Even when you compare indicators by education, income and access to insurance, and then you compare young Black men to young Black women, you find that young Black women are doing much better than young Black men in all of those areas. And in the case of Black gay men, the lack of an infrastructure to really address the HIV/AIDS needs of young Black men speaks volumes about why we are having the problems we are having among this population.

The truth is that there is a community in our midst that is being devastated in ways that we are not seeing anywhere else on the planet!

KG: The CDC recently pulled together Black gay leaders from across the country in Atlanta to address this issue. What came out of that?

PW: Well, a number of recommendations have been made, not just to the CDC, but to all levels of government and to the community. There is a call for the President to focus on this issue by delivering a World AIDS Day speech on AIDS and Black men who have sex with men. There is a call for the President's HIV/AIDS commission to take up this issue at their next scheduled meeting.

There is a call for [Health and Human Services] Secretary Mike Levitt to convene an African American summit to talk about the issues of Black MSMs (men who have sex with men) and rising AIDS case loads. We are also calling on Secretary Levitt to create an interagency task force so that all of the federal agencies can look at and figure out strategies to turn this number around. There is a call on the part of Congress to hold a Congressional hearing about this problem, led by the Congressional Black Caucus. We are urging the CDC to make a commitment to cut the incidence of HIV among Black men who have sex with men in half by 2010. So, there are lots of recommendations, but the question is who is going to hold the administration, the divisions, the departments and our elected officials accountable.

KG: How is the Black AIDS Institute addressing this issue?

PW: Two years ago BAI started Black gay men's programming, in an effort to mobilize Black gay men in the private sector to do things in their field. That program actually is starting to really take momentum. One of the things that we did in response to this data released in June is that we led the release of an open letter that was signed by over 50 Black gay leaders from around the country. What was important about that letter is that it wasn't just AIDS activists who signed it, but there were people who are involved in the arts, in entertainment, in business and in government, so that every aspect was represented in that letter. We had 50-plus Black gay men sign this letter and then distributed it broadly and advocate for Black institutions to pay attention to this issue, and not just as it impacts women and children.

KG: Over the next year or so what are some of our critical next steps as a people in general and, more specifically, as Black gay men at combating this epidemic?

PW: Well I think that the biggest thing is that we have to come up with a plan. A plan that is separate from whatever the government comes up with. That plan should lay out what role the government should play and, certainly in that mix, what role different agencies and levels of government can play. Right now the biggest next step is to get the word out, to raise awareness about the current state of affairs around AIDS in Black communities. Unfortunately, across all communities in the United States, people think that the AIDS epidemic is over. We need to find ways to "dis-infuse" them of that notion and to get them engaged in realizing the truth.

KG: Where do you see us as a people, 10 years from now as it relates to this epidemic? And if where you see us is not the same as where you would like to see us, give me some insight into that as well.

PW: Where do I see us? Well...(long pause)...unfortunately I don't see that we will have solved the AIDS problem by then, but what I would hope is that we have a robust infrastructure so that we are making steady progress towards stopping new infections and increasing access to and utilization of care, as well as being well on our way to establishing a culture where everyone knows their HIV status. 

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Positively Aware November/December 2005
In a recent article pointed out to me by my bright colleague, Keith Green, Phill Wilson (see page 36) writes, “We are each responsible for keeping ourselves healthy, for keeping our communities engaged and for keeping our leaders vigilant. We may not know much about this epidemic, but we know this: If we all demand accountability of ourselves, we can make a change.”

Which brings me to the issue of Power and, especially, in keeping with the theme of this issue, power for people of color. Before any of you look up to the corner of the page and think, “Huh, she looks pretty damn White to me—wonder what she thinks she’s talking about,” let me just own that I’ve asked myself that question more than once. What business is it of mine? I would like to think it’s my business the way it was John Kennedy’s business to validate and support the fight of Martin Luther King Jr. and all those who fought for civil rights. I am human and so it is my business to see to the welfare of those of my species, regardless of their color or their language or the country of their origin.

That said, my years of working in the HIV/AIDS community have left me occasionally feeling a bit hopeless. Though Righties like to identify sinful and/or illegal behavior as the cause for the rampant spread of this disease in minority communities, it seems more insidious than that to me.

It seems to start at a basic, foundational lack of Self. Too often Power is identified as wealth, violence, the ability to get what you want no matter who gets hurt. Role models like Nelson Mandela, Maya Angelou, Rae Lewis-Thornton, Barack Obama, Nancy Shearer, Alondra de la Parra, Luis Gutierrez, Chrystos, Leonard Peltier and Ronald Rowell are eclipsed by the immediacy of the thugs on the corner who threaten the safety and security of everyone in their scope, by the abject poverty, by drug and alcohol abuse.

But I am wondering how the communities of color that I see and interact with can begin to turn back the tsunami wave of hundreds of years of negative messaging and how and why did they accept it to begin with?

As much as I’d like to, and as much as I try to accomplish this through my work, I can’t just say, “Come on! Feel good about yourself! Have some dignity and self-respect! Make choices that defeat negative expectations instead of proving them right!”

In order to do that, to make that kind of sea change in your life, you have to find and use your true Power. This kind of Power has nothing to do with money, race, religion, where you live or who you know. It’s about finding the Truth and Purpose of your life and standing by that Truth and Purpose no matter what the challenge. It’s not about begging for handouts or seeing how much you can get for free or asking God to save your ass. It’s about looking at yourself with no illusion and recognizing that, yeah, you may have made some mistakes and you may have been hurt and you may not have the money, food and shelter of the next guy, but the only one who’s responsible for changing that is you.

It’s about saying, “No,” not only to the people and circumstances that would keep you in the victim mentality, but also to those in your family, your church, your prison, your school, your ‘hood/barrio/reservation who tell you there’s no use, that you’re not worth shit and you never will be, that you better just get drunk or high and forget about the rest. It’s about listening to Senator Obama—not just what he says but how he says it—reading the poetry of Maya Angelou, hearing the symphony that Alondra de la Parra is conducting, and seeing that they all said no to the forces of limitation, discrimination and degradation. It’s about not just reading and understanding, but also feeling the power of MLK saying, “Above all else, we must retain our dignity.” All those people have found their Power and have decided to shine their light bright and strong so we can be inspired by it. Rae Lewis-Thornton, Nancy Shearer and Ronald Rowell are bright stars for us to follow in the fight against AIDS. Not only have they struggled with racism and discrimination, but they’ve done it while also being on the front line of the AIDS war.

As much as I resist it, it seems like the bottom line here is a matter of personal choice. When someone tells you you are worthless or powerless or going to Hell, you must choose whether to accept that or to dispute it or, even better, prove it wrong. Of course that is a gross simplification, but why not start from that simplicity?

As we gather together in support groups and clinics and political meetings, we must be conscious of addressing not just medications, symptoms, new treatments, quality of life issues, program funding, education and prevention, but we must also be thoughtful and aware of not perpetuating the negative. Make a conscious choice not to be truer to what another group may expect you to be than you are to who you really are. And if you don’t know who you are, figure out who you aren’t and build from there.

Power is an amazing healer, a force of joy and satisfaction, a true Guide to making this life count. In the language of the work I do, it is also rich golden yellow, a color that looks good on us all.

Photo © Russell McGonagle
Indication and Important Safety Information for VIRAMUNE

VIRAMUNE is indicated for use in combination with other antiretroviral agents for the treatment of HIV-1 infection.

VIRAMUNE does not cure HIV or AIDS, and has not been shown to reduce the risk of passing HIV to others through sexual contact or blood contamination.

VIRAMUNE can cause severe liver disease and skin reactions that can cause death. These reactions occur most often during the first 18 weeks of treatment, but can occur later. Ask your healthcare provider about how to recognize these problems. Stop taking VIRAMUNE and do not restart it if you have these reactions. Call your healthcare provider immediately.

Any patient can experience liver problems with VIRAMUNE but women and patients who have higher CD4 counts when they begin VIRAMUNE treatment have a greater risk. If you are a woman with CD4 >250 cells/mm³ or a man with CD4 >400 cells/mm³ you should not begin taking VIRAMUNE unless you and your doctor have decided that the benefit of doing so outweighs the risk.

The dose of VIRAMUNE for adults is one 200-mg tablet daily for the first 14 days, followed by one 200-mg tablet twice daily. The 14-day lead-in period is important because it can help reduce your chances of getting a rash.

Other side effects that patients have experienced include nausea, fatigue, fever, headache, vomiting, diarrhea, abdominal pain and myalgia. Changes in body fat may occur in patients receiving antiretroviral therapy.

Please see Medication Guide for VIRAMUNE on following page for more detail on these side effects and other important information.

* A viral load less than 50 or 400 copies depending on the test used.
† A 14-day lead-in period of VIRAMUNE once daily has been shown to reduce the frequency of rash.
VIRAMUNE is a medicine used to treat Human Immunodeficiency Virus (HIV), the virus that causes AIDS (Acquired Immune Deficiency Syndrome). VIRAMUNE is a type of anti-HIV medicine called a "non-nucleoside reverse transcriptase inhibitor" (NNRTI). It works by lowering the amount of HIV in the body ("viral load"). VIRAMUNE should not be taken with other anti-HIV medicines. When taken with other anti-HIV medicines, VIRAMUNE can reduce viral load and increase the number of CD4 cells ("T cells"). CD4 cells are a type of immune helper cell in the blood. VIRAMUNE may not have these effects in every patient.

For more information about VIRAMUNE, you can ask your pharmacist or doctor for information about VIRAMUNE that is written for health professionals, or you can visit www.viramune.com or call 1-800-542-4257 for additional information.

Boehringer Ingelheim
Ridgefield, CT 06877 USA

This Medication Guide has been approved by the US Food and Drug Administration.
Promoting Unity and Love in the Black Gay Community

A challenging but not impossible task

by Keith R. Green

“The question isn’t whether or not Black gay men can be saved. The question is whether or not we believe that we are worth saving.”—Dr. Ron Simmons (from the Black Gay Research Summit in Brooklyn, NY—August 2005)

Dr. Simmons’ statement brought an eerie chill to the room. With over 100 Black gay men convened to discuss and develop a research agenda concerning a group of Americans that have been labeled an “endangered species,” the naked truth of the matter had just been exposed.

We could talk until we were blue in the face. We could create endless amounts of culturally competent, totally measurable programs and then lobby for millions and millions of government dollars to support them. We could even march on Washington or “Act Up” in the streets of our respective cities. But at the end of the day, when all is said and done, our efforts would be in vain if the very people we are trying to save do not themselves realize that they are, in fact, worth saving.

The bigger issue, then, becomes how did we get in this position.

I can remember the first time I really paid attention to the use of the word “faggot.” I was a young boy of about 7 or 8 years old. The family next door to mine had an uncle named “Tommy” who came to visit from time to time. Everybody knew that “Uncle Tommy” was a “faggot” and people used a lot of other remarkable words to describe him, like “bitch” and “pussy.” Words that were, oddly enough, also used to describe Black women and their anatomies.

I don’t remember when I knew exactly what a “faggot” was or when I first came to understand that it was associated with homosexual sex, but I do remember when I knew that I myself was indeed what some would call a “faggot.” And I hated it. I did everything that I could to curb my feelings towards men. I dated and slept with several women. I got deeply involved in the Pentecostal church, hoping to pray it away. I even considered attending a seminary and giving my life over to the church totally, if God would just make this sick and disgusting feeling that I had towards men go away. But it wouldn’t leave.

And I was not alone. There are thousands of Black men just like me who would give their lives to make the feelings go away. For many of us, denial and a lack of self-love drive us to make bad decisions that ultimately lead to HIV.

Startling news recently came from the national Centers for Disease Control suggesting that half of Black men who have sex with men in this country may already be HIV positive. News that, if we were talking about whales being harmed by fisherman fishing for tuna in the Atlantic, would cause outrage throughout our nation. Instead, there has been silence.

But who is to blame for that? The Centers for Disease Control? The government? Racist White people? Homophobic Black people?

After countless hours of thought and conversation with many who are concerned about the plight of Black gay men in this country, I have come to a conclusion that is sometimes hard to accept. Although all of these parties may be partially responsible for our current condition, the main perpetrator is, in fact, Black gay men ourselves. If we do not care enough about ourselves to take ownership of the epidemic that is devastating our community, why on Earth should anyone else?

With that said, I have stopped feeling sorry for myself and for my people and I have dedicated my life to provoking change. More importantly, I am learning what it means to be totally in love with the man I was created to be, which also means fully embracing the complexities of my sexuality.

I have stopped looking outside of our community for solutions to our crisis, rather, I am beginning to look within it, aligning myself with others who are committed to restoring a sense of hope and self-worth to the lives of Black gay men.

Taking action…

Locally, I am involved with the Chicago Black Gay Men’s Caucus. Our primary focus is the overall health and well-being of Black gay men in the city of Chicago. Membership consists of representation from the Chicago Department of Public Health, Black gay business owners and promoters, community-based organizations, political activists as well as members of academic institutions, all of whom have made a conscious decision to lay aside their own personal agendas and come together to promote unity and love within the Black gay community.

In an effort to do that, we also realize the significance of forming alliances with other organizations throughout the nation, who have as their mission a focus similar to ours. Following are examples of four such allies who are committed to improving the quality of life for Black gay men in America.

The Black Gay Research Group

Established in the spring of 2001, the Black Gay Research Group consists of 21 Black gay men from across the country of...
The real reason why we are obsessed with Atlanta, and activist Keith Boykin, author What’s Goin’ On? continued

Black AIDS epidemic,” declared Boykin. Brooklyn. Spearheaded by the Brooklyn-based AIDS service organization People of Color In Crisis, the summit served as a bridge between the Black gay research community and the various service organizations in place to address the unique needs of Black gay men. Research on and about Black gay men was presented, discussed, analyzed and then framed into constructs that the group hopes will help to influence governmental policy, community-based interventions and future research undertakings.

Keynote addresses were made by Dr. David Malebranche (see page 26), a Black gay researcher and assistant professor at Emory University’s School of Medicine in Atlanta, and activist Keith Boykin, author of the controversial best-seller “Beyond the Down Low.” Both men emphasized a need for more extensive research to be done on and about Black gay men.

“We are more than walking HIV statistics,” proclaimed Dr. Malebranche. “We must conduct research that adequately addresses every aspect of our lives, both qualitative and quantitative.

“Statistics don’t tell the whole story and neither do interviews with 10 or 12 people,” he argued.

Boykin, more recently known for his efforts at setting the record straight about the infamous “down low” phenomenon, stressed the fact that the “down low” discussion is but a distraction from the real issues at hand.

“The down low is not the cause of the Black AIDS epidemic,” declared Boykin. “The real reason why we are obsessed with women who are infected by men who are on the down low is because we don’t want to deal with the reality that Black gay men are the greatest victims of this disease.

“Rather than talk about the tragedy among Black gay men, we create an illusion about straight Black women. It is much easier to talk about sympathetic straight Black women who are being infected by stereotypical deceptive and predatory Black men than to address what is really going on.”

The group has issued a list of recommendations to address HIV infection rates among Black men who have sex with men, for consideration by governmental officials in critical positions with responsibility for curtailing the epidemic in the United States. A published report of the findings of their collective research will follow.

The Unity Fellowship Church Movement

In 1982, when the mystery of the AIDS epidemic was fueling a fire of fear and segregation for the gay community at large, one Baptist minister in Los Angeles decided to take a stand. Rev. Carl Bean, nationally known for his vocals on the Motown club classic “I Was Born This Way,” organized a bible study for the families and supporters of African American gay men who had been rejected by the churches they had served in for years.

Rev. Beans’ bible study grew into what is now known as the Unity Fellowship Church Movement, with 12 established churches throughout the nation. The primary work of Unity Fellowship is to proclaim the sacredness of all life, thus focusing on empowering those who have been oppressed and made to feel shame. The movement’s motto is “God is Love and Love is for Everyone” and its membership includes worshipers from all walks of life, both gay and straight, Black and White.

I personally came to know the Unity Fellowship Movement while living in Charlotte, North Carolina. I had relocated there in hopes of getting a handle on both my sexuality and my HIV status. Pastor Tanyia Rawls and her partner, Elder Gwen, selflessly opened up their hearts to me and made me a part of their family. I credit the love and support they gave me with transforming me into a Black gay man who is free of shame and doubt about the man God created him to be.

“I believe that the faith community can completely change the flow of efforts in reference to Black gay men and HIV/AIDS,” says Pastor Rawls. “Jesus was led by the human condition. Whether we get it or don’t get it…whether we like it or don’t like it, there is a segment of our community that is dying and at risk and we must do all that we can as a church to help make sure that our community lives.”

According to Rev. Rawls, the church is still the greatest institution within the Black community. “The church is in a position to give people permission to live,” she says, boldly. “We can do things from a faith-based perspective to show African American gay men that we not only love them, but that we honor them and we need them to survive.

“I don’t know how many Black men hear that and I definitely don’t know how many Black gay men hear that. Can you imagine what would happen if from pulpits across America on Sunday morning, instead of the ‘Black gay bash, you’re going to hell sermon’, some preacher gets up and says ‘I love you as you are, Black gay man and we need you to survive and will do everything in our power to help you do so…because God loves you and so do we’. Do you know what kind of drop we would see in the infection rate?”

For more information on the Unity Fellowship Church Movement, visit www.ufc-usa.org.

Us Helping Us

Off the top of her head, Pamela Johnson, Assistant Director of Treatment Education and Advocacy for the National Minority AIDS Council, could name two agencies...
nationwide whose primary focus is Black gay men. Just two. The frightening reality is that while estimates indicate that nearly 50% of this population may already be HIV positive, institutions whose focus is prevention, support and treatment of HIV/AIDS in the Black gay community are virtually non-existent. However, one of the agencies that she was able to name has been reaching out to this disproportionately affected community for 20 years.

Us Helping Us was started in 1985 by a small group of HIV-positive, Black gay men. Collectively, they were interested in researching a more holistic approach to maintaining their health—incorporating mind, body and spirit into the healing process. This small group developed into a larger one, which then branched off into smaller groups throughout the Washington, D.C. area. From their meetings and research emerged a 12-week workshop, which also served as a training ground for other men interested in hosting a group of their own.

This network morphed into the full service agency that we know today as Us Helping Us, with programming that reaches into Maryland, Virginia and as far as West Virginia. With 19 full-time staff members and a two million dollar budget, UHU continues to set the pace nationally for prevention and support services geared towards Black gay men. Aside from basic services such as rapid testing, counseling and case management, UHU does a considerable amount of work at combating stigma and homophobia within the Black community at large.

“I think that it is really important that we support and educate the families of young Black men who are beginning to identify with their feelings towards other men,” says Dr. Simmons, executive director of Us Helping Us. “A kid who is curious about his sexuality will, unfortunately, encounter homophobia years before he encounters a Black gay man, or anyone else for that matter, who will tell him what the lifestyle is really all about. Families are in a unique position to break that cycle.”

Us Helping Us also does a great deal of work with the transgender community, a population that is arguably the most underserved community as it relates to HIV services and prevention. “At least people view Black gay men as people even if they do consider us to be an abomination to society,” says Dr. Simmons. “I don’t think that people even view transgender people as people and we have to stop that.”

When asked his opinion on the future of Black gay men in this country, Dr. Simmons stalls for a moment and then expresses what sounds like a glimmer of hope. “The real issue is that, right now, I don’t think that we really see ourselves as a viable community. However, I’m encouraged when I see our young people express and address some of our issues in ways that us old folks never have before,” he explains. “I get excited by the energy that I see in a lot of the young Black gay men today. It gives me hope.”

For more information on Us Helping Us, visit www.ushelpingus.com.

The International Federation of Black Prides

Contrary to popular belief, Black gay pride celebrations are more than weekend-long circuit parties. If fact, the first “official” Black Pride, which took place 15 years ago in the District of Columbia, was a one day event to raise money for HIV/AIDS service organizations within the African American community. Since then, more than 20 cities throughout the country have established Black Prides as affirming spaces for Black gay men and lesbians to meet and network with others like themselves.

In 2001, in an effort to organize the 20-plus Black Prides in the United States and abroad, the International Federation of Black Prides (IFBP) was formed. The primary goal of the federation is to develop sponsorship strategies and to provide technical assistance, networking, mentoring and support for its members. Each year, the group comes together to set a detailed agenda to determine what issues their respective prides should address. HIV/AIDS is always at the top of that list.

“Collectively, we come in contact with close to a quarter of a million Black gay men every year,” says Earl Fowlkes, president of IFBP. “Most of these men are outside of the radar when it comes to HIV prevention. They come out for these weekends and then return to their low-key sexual networks.”

In many cities, such as Chicago, AIDS service organizations actually head up their city’s Black Pride in order to take advantage of the opportunity to outreach to this otherwise invisible, at-risk population.

“We [Black gay men] don’t have a means of mass communication, per se,” says Fowlkes. “We don’t have a television network or a radio station or even a national magazine for that matter. So outside from the clubs, Black Pride becomes our primary mechanism for reaching out to one another.”

Currently, the IFBP is researching ways to conduct a more concerted effort as it relates to HIV/AIDS prevention. Fowlkes, though, is quick to point out that the collective is not interested in “one-shot deals,” rather they are seeking to establish more intimate relationships with their attendees.

“I don’t have anything against traditional outreach efforts,” Fowlkes explains, “but outreach has got to be about more than just handing someone a condom and some literature without having some mechanism for follow-up in place. This is where our collaboration with local community-based organizations (CBOs) becomes critical.”

The Federation hopes that through these collaborations, they can assist CBOs with identifying various subpopulations within the Black gay community, and implementing measurable prevention interventions that will reduce the HIV prevalence among Black gay men.
Since HIV is mainly transmitted either sexually or by sharing needles and since admitting that one uses illicit drugs is reason enough to be deported or locked up, why in the world would anybody admit to sharing needles? You can holster all you want about confidentiality and privacy but when it comes to sex and drugs America has done such a swell job of creating the most fearsome stigma attached to these behaviors that one would not even admit it to God in the confessional.

So how do we take care of our communities of color that are already dogged, stigmatized and racially profiled every day by our society just for being beautifully colored? We have to do it for ourselves and for each other because no one else will; they’re all too busy with their own agendas and closets full of their own skeletons.

The sooner that everyone in our communities of color admits that HIV has hit us hard, the sooner our healing can begin. Let’s forget about who is having sex with who and if it is an abomination or a deviation or a denial. Let’s focus on the fact that your children can understand sexuality and the psyche. If you do not teach your kids about the “reality” of life then whom do you want to train your kids for you? Jugs, Hustler, Honcho or porno flicks? They may receive their sex education from the latest fallacies and myths going around the schoolyard or the street or worse yet, by trial and error. I am focusing on the children because that is where we need to start. If we can change the thinking and behavior of the children by arming them with accurate and scientific-based information on human sexuality and sexually transmitted diseases, we’ll have half the battle won.

Meanwhile, the adults out there running around poking each other without condoms, sharing needles and sniffing or smoking anything that’s white are going to be very hard to reach, especially if the other people in their community don’t reach out to them. How do we get our communities of color to adhere to some simple rules? By destigmatizing their behavior and removing the importance of the gender of whom they are having sex with. Let’s leave that factoid in the closet for now—pun intended—and let’s just focus on the facts and the fact that having unprotected sex or sharing needles can lead to ill health at the very least and death at worst. People only hear the labels and feel the stigma, therefore they tune the message out and do not seek testing and counseling.

One of the most troublesome problems is admitting that some of us beautifully colored people have sex with the same sex. “Not in my family!” I’ve heard this as a youngster from my elders and have heard it proclaimed from other families’ elders. As long as these deviants are from another family or better yet another race entirely, then a conversation about men who have sex with men may be possible but still “not in my colored community!” So why don’t we just stop it!

The Ryan White CARE Act expired on September 30, 2005. What will our communities of color do if we keep on keepin’ on and find ourselves in lines waiting and praying that we get help before AIDS kills more members of our community?

You need help talking about these sexual, uncomfy issues with your partner or family? First search within yourself and see if you can handle talking about it with yourself, try it in front of a mirror. Can’t go there? Call the Red Cross and ask them for information on HIV basics and when you can attend their next free training. You can also contact Test Positive Aware Network and ask about their TEAM (Treatment Education Advocacy Management) curriculum, an in-depth training covering HIV and AIDS from how the infection works to learning how to take care of yourself or others impacted by HIV/AIDS. Pick up a copy of the Chicago Area HIV Services Directory or go online at www.tpan.com and look under education or information. It is out there and it is free. If anything about sex makes you feel uncomfortable, talk to a therapist, they are also free for you and your family, again in the Directory. Better use these services while they’re still available.

So I don’t want to hear any more babbling about not in my family, not in my school, not in my hood and not in my church. I want to hear complete acceptance and caring for one another by us teaching one another. We do not need to be tolerated; we need to be helped and respected.

That means that we’re going to start acting like we care for one another. Love is the message. This means you take responsibility for yourself and the person you are going to have sex with. Do not let yourself be penetrated by anyone who is not wearing a condom. That’s not love—love for yourself. If you ask someone are you HIV-positive and they say no, you do not act like a fool and have unsafe sex with them as if they just gave you their Western Blot test results. Don’t forget about the tests’ inability to check for antibodies until three to six months after exposure.

If we don’t teach love and scientific facts, the numbers of HIV infections in our beautifully colored communities will truly be an epidemic of gargantuan proportions.

Hey, take care of yourself and your community too!

by Carlos A. Perez
I t’s been a while since I’ve totally gone off on a rant. And there’s this little incident, actually pretty minor in the grand scheme of things, that nonetheless has just been working my last frayed nerve since it happened. So I’m gonna scratch that bitch. I know you’ll understand, we’re all family here.

Now, I have allowed myself to become something of an HIV posterboy, and as any posterboy will tell you, there is a lot that comes with the territory. Which is cool, I get it. Kinda like prostitution, not exactly, but close. Kinda hot, but not really. I often find myself standing in front of large groups of total strangers unpacking the psychic, slightly battered baggage of my HIV infection, in full fluorescent glare, and I sift through all the mementos, travel-sized toiletries, receipts, condoms, free lube samples, odd scraps of paper and dirty underwear that have been stuffed inside. Like any demented “celebrity,” or posterboy worth his Saltines, I kind of get off revealing all my issues and lifetime subscriptions for an audience, because at the end of the day, I do believe it is effective in humanizing the disease and helping people understand their own issues when it comes to things like sexual behavior, prevention and risk-reduction decision making.

So I ain’t mad about my posterized status. Like I said, I let it happen, and continue to seek it out. It helps me make sense of a disease that creates such senseless despair and destruction, it helps me to help others, it helps me to talk about it—and all that surrounds it—as if it is separate from me. It empowers me as it disempowers HIV. And after all, I work in AIDS Inc. as a policy director—this is what I do, this is my schtick. It’s kinda hot.

But you’re waiting for the rant...

Not long ago, I was asked to give a two-and-a-half minute speech for several hundred people around HIV issues. No big deal. It was a motivated group that had sacrificed a great deal of time and energy to raise money for AIDS services—I was happy to do it. While I wasn’t thrilled with the time constraints—I usually have more than a couple minutes worth of anything to say—but hey, I’m a willow, I would give them what they wanted. So there is someone who speaks before me, the director of the organization that has recruited and nurtured this large group of people. He goes on and on, “blah blah blah.” When he introduces me, he doesn’t give my job title, my work affiliation, or even use my last name.

“And now we have someone who would like to say something... Jim?”

That was the intro. The ultimate posterboy introduction. I am not a professional in the field, no, not with a certain level of expertise, or of credibility, nope to that too. I don’t even have a last name for that matter. I am just “Jim”—ain’t that special. And I have a little something I’d like to say. “Awwww, would you look at that!” The tone of voice he used was all soft and sing-songy, you know what I’m talking about, like “we have someone VERY SPECIAL with us today... Jim?” And he had that “special look” one employs when one is not a titch condescending, when one is telegraphing P-I-T-Y in neon. It was a very “Jerry’s Kids,” “Tears of a Clown” moment. Take a look at this thoroughly pathetic creature, “awwww, the poor thing.” As in, “let us all listen with earnest expressions and moistened eyeballs for two-and-a-half minutes while this ‘Jim’ makes us feel so lucky for being negative, for being healthy, for not being him. And let us all revel in self-satisfied smugness for helping him and his poor, wretched kind make it to their next dismal day thanks to our super glorious efforts.”

All of that went through my brain stem as I walked to the microphone. And as I gave myself the introduction I deserved—name, title, affiliation, thank you—behind the scenes I was letting this dude have it, dragging him down to the seventh ring. Hell hath no fury like a provoked Pickett.

Uh, I don’t think so, Sister, I thought, even as I spoke about national HIV statistics and the desperate need for adequate funding. The last thing I am is some pitiable creature to be looked down on, to feel sorry for, to immortalize in velvet. You can smudge your mascara on someone else’s watch, shed those John Wayne Gacy crocodiles elsewhere. They are not required or requested here. I’m running my second marathon in a week, in what way does this make me weak? I don’t deserve some clueless, miserable, trifling, objectifying freak trotting me out like the poz Gay Mare in front of hundreds of people in a bizarre display attempting to demean and diminish me, rob me of my strength, my essence, my humanity. I’m no victim, hon, I want no one’s pity, least of all yours.

HIV does not define me. It does not make me pathetic or turn me into an object for your pity lust. I will not be humiliated and abused in this way. While I am revolted you tried, you must know you failed. Being clueless or “well-intentioned” is no defense, you’re still guilty.

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

Programs and Meetings

**Monday**

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

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

**Crystal Meth Anonymous (CMA)**
Support group for individuals for whom crystal meth has become a problem. Meets 7:30–9 pm.

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

**Tuesday**

**Medical Clinic**
See description on Monday. Call for an appointment. From 9 am–5 pm.

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

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

**Wednesday**

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

**Test Aware**
TPAN’s new rapid HIV counseling and testing program. Learn results in around 20 minutes. Wednesday by appointment.

**Medical Clinic**
See description on Monday. Call for an appointment. From 9 am–5 pm.

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

**SHE (Strong, Healthy and Empowered)**
HIV-positive women discuss needs, concerns and issues facing women with HIV. Meets from 7:30–9 pm. Socials every 4th Wednesday.

**Thursday**

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

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

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

**Needle Exchange Program**
See description on Wednesday. From 2–5 pm, or by appointment.

**BUS (Brothers United in Support)**
Support group for HIV-positive gay and bisexual men of African descent. Monthly socials and speakers on occasion. Meets from 7–9 pm.

**Thursday continued**

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

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

**Friday**

**Medical Clinic**
See description on Monday. Call for an appointment. From 9 am–4 pm.

**Needle Exchange Program**
See description on Wednesday. From 2–5 pm, or by appointment.

**Scheduled by Appointment**

**FASN (Family AIDS Support Network)**
A group for family, friends and caregivers. Call Betty Stern at (773) 989–9490.

**Individual Counseling**
AIDS Pastoral Care Network (APCN) provides spiritual support. Can provide information for one-on-one counseling, chaplains and help with liturgies. Ask for Sherry at (773) 826–7751.

**Peer Support Network/Buddy Program**
Trained volunteers provide one-on-one peer, emotional support to individuals living with HIV. Call Brad at (773) 989–9400.

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

**Team (Treatment, Education, Advocacy and Management)**
Peer-led, 18-hour training program integrating secondary prevention and HIV treatment education to people living with HIV and those affected by HIV. Call Derek at (773) 989–9400.
### November 2005

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<thead>
<tr>
<th>DATE</th>
<th>TIME</th>
<th>EVENT</th>
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<tbody>
<tr>
<td>Wednesday 2nd</td>
<td>7–9 pm</td>
<td>Committed to Living Educational Forum: “Healthcare Disparities in People of Color”—Speaker: Bethsheba Johnson, APRN, BC</td>
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<tr>
<td>Saturday 5th</td>
<td>9 am–4 pm</td>
<td>ManAlive Health Conference</td>
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<td>Hyatt Regency Chicago on the Riverwalk</td>
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<tr>
<td>Friday 18th</td>
<td>12–2 pm</td>
<td>Committed to Caring, a series of forums designed for case managers, CME letters of attendance available. Co-sponsored by MATEC (Midwest AIDS Training &amp; Education Center). “Recognizing Methamphetamine Abuse for Physicians”—Speaker: Dan Berger, MD</td>
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<td>Thursday 24th</td>
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<td>No PULSE</td>
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<td>Thursday 24th – Friday 25th</td>
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<td>TPAN Closed – Happy Thanksgiving!</td>
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### December 2004

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<tr>
<th>DATE</th>
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<tbody>
<tr>
<td>Thursday 1st</td>
<td>TBA</td>
<td>World AIDS Day Commemoration</td>
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<td>Monday 5th</td>
<td>TBA</td>
<td>TPAN Annual Holiday Party</td>
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<td>Wednesday 7th</td>
<td>7–9 pm</td>
<td>Committed to Living Educational Forum: “Depression and HIV” Speaker: Tony Hollenbeck</td>
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<td>Monday 26th</td>
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<td>TPAN Closed – Happy Holidays!</td>
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<tr>
<td>Thursday 29th</td>
<td>6–10 pm</td>
<td>PULSE Holiday Party: Christmas in Toyland</td>
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<td>Berlin Nightclub – Chicago, 954 W. Belmont</td>
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Test Positive Aware Network (TPAN) is a not-for-profit organization dedicated to providing support and information to all people impacted by HIV.
I take my meds, work out, watch my diet, manage my stress, have a great relationship, family and friends...

Why would I mess it all up with drugs and alcohol?

If you’re concerned about drug or alcohol use, you are not alone. Talk openly and honestly with your physician or local HIV/AIDS service provider. There is help.

Be Positively Aware!

Test Positive Aware Network and Positively Aware Magazine bring this public awareness message to you.

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