



# **AIDS in Blackface**

**25 YEARS  
OF AN EPIDEMIC**

**Black AIDS Institute  
June 2006**



*AIDS in Blackface: 25 Years of an Epidemic* edited by Kai Wright.

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FROM THE DIRECTOR

# My Life with AIDS

Here's a shocking fact: I'm a middle-aged man. I know it sounds like a pretty run-of-the-mill achievement, but it is not. I have been living on borrowed time for a quarter century.

You see, I was infected with HIV in 1981. This year, I celebrated my 50th birthday. I've lived with the virus so long now that I don't even remember what it was like not to have it.

The best medical knowledge had me on death's door by 1995. My first partner crossed over that portal in 1989; he's one of literally hundreds of friends, loved ones and colleagues whom I have watched die from AIDS over the last 25 years.

No, by all rights, I should not be here to see 50.

And yet, here I am. I could fill a lifetime's worth of reports and publications speculating on what blessings have sustained me all these years—and I'll spare you that. But I know one thing that's surely helped keep me going: My determination to beat this darned virus, not just in my own body, but in the communal body of Black America.

Like me, the AIDS epidemic has a shocking birthday this year. It was 25 years ago today—June 5, 2006, the date we release this report—that Dr. Michael Gottlieb diagnosed a strange illness among five of his white gay patients at University of California, Los Angeles. Since then, AIDS has become a defining issue of our time, particularly for Black folks.

The statistics, no matter how many times I speak them, are worth repeating: Nearly half of the more than one million Americans estimated to be living with HIV/AIDS are Black. We represent over 56 percent of the new AIDS cases among youth. We're nearly 70 percent of the new AIDS cases among women.

No one expected HIV to be around this long, any more than they expected it of me. And those two facts have me thinking about the next 50 years.

Some say middle-age is defined by the point in your life when you stop seeing just possibilities and start seeing a rising wall of the limitations—health, finances, time left on life's clock. Not so for me. Perhaps it's because of where I've been, but this



birthday has me thinking about nothing more than where my community and I are going.

Are we headed into another 25 years of this epidemic? Another 50 years? Will I allow that to happen, or will I do my part to stop the spread of this utterly preventable disease and to ensure wide access to the sort of quality healthcare that will allow everyone already diagnosed with it to live into their middle-ages and beyond?

For me, the answer is clear. I will continue to take care of myself. I will continue to refuse to put the people I love at risk. I will continue to refuse to live in shame about my HIV status or my sexual identity as a Black gay man. I will continue to speak my truth to power.

I will also continue to demand that my elected officials—from the school board to the White House—make this epidemic a priority. And I will continue to help my community and its leaders—from family to faith to politics—to do the same.

America's ability to defeat the AIDS epidemic will be determined by our ability to stop it in Black America. The only way to stop AIDS in Black communities is for there to be strong institutions with the infrastructure and capacity to make it happen. And the only way to build that infrastructure is for each and every one of us, including you, to do our part. Call your local Black AIDS organization, volunteer and make a donation. (You can also make a donation to my favorite AIDS organization: the Black AIDS Institute!) Contact your member of Congress, your senator and the White House. Tell them to adequately fund the Ryan White CARE Act and Medicaid, to lift the ban on federal funding for needle exchange programs, and to support aggressive, scientifically sound prevention.

Next Sunday, ask your minister to start an AIDS ministry and sponsor HIV testing at the church four times a year. Tonight at dinner, make a list of 12 things you will do over the next year to end the AIDS epidemic. If you can't think of anything else to do, at least get tested and take a friend with you.

In the pages of this report, you will read the testimonies of 25 African Americans who have found ways to take these sorts of steps. They are people who in ways both large and small have decided to change the course of the epidemic. It is my hope that these stories will motivate you to do the same. I was not supposed to still be here, but I am. AIDS is also still here and so are you. I'm looking forward to an amazing and challenging rest of my life—and to seeing the day when I finally out-live this epidemic. Wanna figure out a way to commemorate 25 years of the AIDS epidemic? Help make sure we don't have to commemorate 30 years?



# THE FOUR GETS

## FOUR STEPS YOU CAN TAKE TO FIGHT AIDS IN YOUR COMMUNITY:

**1 GET INFORMED.** What you don't know *can* kill you. Knowledge is a powerful weapon against HIV/AIDS.

**2 GET TESTED.** The vast majority of Black Americans infected with the AIDS virus don't even know it. You can't protect yourself or your partner if you don't know your status.

**3 GET TREATED.** 70 percent of HIV-positive people in America are not in proper treatment and care. AIDS is not the death sentence it once was. Early treatment can prolong your life.

**4 GET INVOLVED.** AIDS is spreading through our communities because not enough of us are involved in efforts to stop it. There are many ways to get involved in the fight:

- Volunteer
- Make a donation
- Become a regular contributor
- Join a board
- Deliver a meal
- Talk to your neighbors, friends and family about HIV/AIDS
- Write a letter to your Mayor, Governor, the President



**Black Voices  
ON AIDS**







## INTRODUCTION

# AIDS and Black America

It happened 17 years too late, but it happened: the federal government's first targeted effort at addressing HIV/AIDS in Black communities. Today, it's hard to understand how it took until 1998 for Congress to officially recognize the epidemic's disproportionate impact on African Americans—a reality that was plainly visible from the epidemic's opening moments. But then, that sort of delayed reaction may be the defining trait of America's first 25 years of living with AIDS.

In March 1998, the Centers for Disease Control and Prevention convened a group of Black AIDS service providers to talk about the rapidly hardening reality that America was facing not one, but two epidemics: one white, the other Black; one with access to care and life-saving information, the other isolated outside of the vast network of resources that had been set up to help stop the epidemic.

Just a couple of years earlier, African Americans had overtaken whites as the population with the largest share of AIDS cases diagnosed annually. The story of AIDS was rapidly and dramatically changing, as new drugs that hit the market in 1995 literally brought people back from death's door. But not only were the drugs massively expensive,

patients also had to be plugged into quality care to know about them—not to mention to manage the still-complicated treatment regimens they required. For those who met these requirements, AIDS suddenly stopped being a death sentence: HIV mortality in the U.S. dropped a staggering 70 percent between 1995 and 1998.<sup>1</sup> Among whites, deaths dropped from more than 22,000 in 1994 to just over 7,000 in 1997.<sup>2</sup>

But the picture for African Americans looked much different. Black death rates dropped too, but far more slowly. In 1996, for the first time, more African Americans died of AIDS than whites. By 2001, the annual Black death toll was nearly double that of whites.<sup>3</sup> Today, we're more than seven times more likely to die from AIDS once diagnosed with HIV than whites.<sup>4</sup>

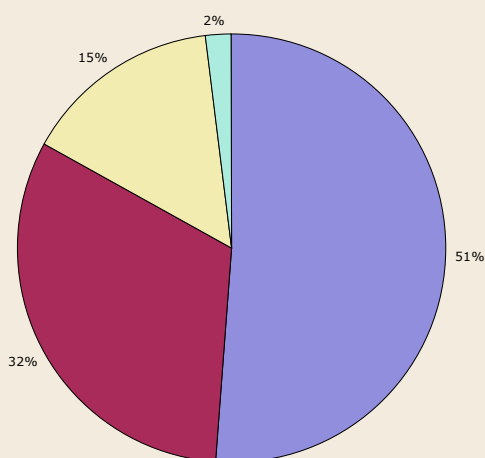
CDC officials saw all of this coming in spring of 1998, and shared their plans for addressing the divide with the Black AIDS leaders they convened in Atlanta that March. But the community leaders, equally shocked, sprung into their own action. In a joint statement, they declared HIV/AIDS had reach a "state of emergency" in Black America, and began making the rounds in Washington,



## A Black Epidemic

Among the 33 states that report to the CDC the names of people who test HIV-positive, African Americans make up an astounding share of new infections each year.

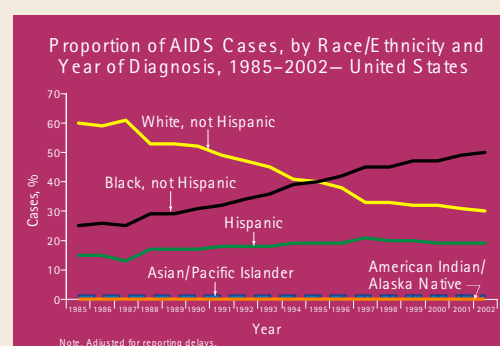
Racial breakdown of new HIV diagnoses, 2000-2003:



Black – 51 percent  
White – 32 percent  
Latino – 15 percent  
Other – 2 percent

Source: CDC. Media fact sheet. *The HIV and AIDS Epidemic Among African Americans*. June 2005.

All states and territories report diagnosed AIDS cases to the CDC each year. Since the mid-1990s, the number of cases has steadily dropped among whites; not so for African Americans.



Blacks account for a steadily increasing share of the epidemic—half since the end of 2002.

Source: CDC. *HIV/AIDS Surveillance by Race/Ethnicity L238 Slide Series*. Slide 2.

D.C., to see what could be done about it. The White House Presidential Advisory Council on HIV/AIDS endorsed the community declaration, and in April long-time Black AIDS leader Dr. Benny Primm presented it to the Congressional Black Caucus' (CBC) Health Brain Trust as well.<sup>5</sup> The CBC picked up the ball and ran with it. Finally, they declared, it was time for national lawmakers to directly address AIDS among African Americans.

The result was that in October 1998 Congress passed a program that has now become known as the Minority AIDS Initiative. The Initiative funnels money to AIDS service organizations specifically targeting minority communities. The goal is to build up those

often-struggling groups' capacity to deal with the massive challenge they face. In its first year, the federal government directed \$166 million to the Initiative.

It was hailed as a crowning achievement, and energized Blacks concerned about AIDS both inside and out of government. But the program has been plagued by lingering debates about how exactly the money should be spent—and who should be spending it. Some Black-run service providers complain that large, white AIDS organizations have crowded them out by developing programs that target minorities. Congress has tried to tailor the language to specify that grants should go to organizations based in minority communi-

ties, but some debate lingers about the legality of such rules, given recent Supreme Court rulings limiting affirmative action programs.

Moreover, in the grander scheme of the federal AIDS budget, the Initiative is a small pot of spoils to be tussling over. In 2004, federal funding for the Initiative topped out at \$404 million.

Nevertheless, the Minority AIDS Initiative and the community-wide support it drew was a welcome change for those advocating a head-on attack against AIDS in Black America. For too long, mainstream political, social and religious leaders had turned a blind eye to the epidemic's carnage. Now, with Black political leaders at the lead, the community appeared to be finally engaging an epidemic that had, by then, killed more African Americans than died in the Atlantic slave trade. CK

## In the Beginning

AIDS has been a uniquely Black problem from the start. In 1985, African Americans already accounted for roughly a quarter of all people diagnosed with AIDS; we were just 13 percent of the overall population that year. Since that time, African Americans have accounted for a steadily-increasing share of annual AIDS diagnoses: By the early 1990s, we were clocking in at nearly a third of cases diagnosed each year. In 1995, more Blacks were diagnosed with AIDS than whites for the first time; we boasted about 40 percent of new cases that year. Today, we're over half of new cases, and remain just 13 percent of the population.<sup>6</sup>

The simple reality of AIDS' disproportionate impact on African Americans from the onset was obscured by the fact that the first reports of it came out of the gay community—a segment of American society that has always been falsely stereotyped as uniquely white.

On June 5, 1981, the CDC published an ominous item in its weekly report on the

nation's health. The entry noted that five previously-healthy young men, "all active homosexuals," had turned up in Los Angeles hospitals in the previous six months with a rare pneumonia called *Pneumocystis carinii*, or PCP. This relatively weak protozoan—last seen in postwar European orphanages—lives in the air sacs through which oxygen passes from the lungs to the bloodstream. The modern immune system has long adapted to it, and normally beats it back long before it suffocates its host. Yet, two of the men had already died by the time the CDC report made it into print.<sup>7</sup>

"The fact that these patients were all homosexuals," the CDC's report read, "suggests an association between some aspect of a homosexual lifestyle or disease acquired through sexual contact and *Pneumocystis pneumonia* in this population."

The report would prompt doctors in New York City, San Francisco and major urban areas around the country to chime in with accounts of similar cases among young gay men. And it wasn't just PCP they were finding. A host of old, forgotten infections were suddenly killing people: a skin cancer last seen in elderly Mediterranean men, which had never been fatal; a herpes strain that should have been easily treated; a parasite, most often found in cat feces, that millions of people carry in their bodies without harm. The constellation of illnesses was originally dubbed "gay cancer" and "Gay Related Immune Disorder."

Scientists soon classified the condition as an immune disorder, and gave it the more appropriate name Acquired Immune Deficiency Syndrome, or AIDS. The official list of potentially affected populations broadened as well. In November 1982, the CDC published a follow-up report that listed four "groups with apparently increased risks of AIDS": gay men, hemophiliacs, Haitian immigrants, and intravenous drug users.<sup>8</sup> It would be 1984 before science identified HIV as the virus

causing all of this destruction.

Not until January 1983 did the question of race or heterosexual transmission arise, when another CDC report noted that female sex partners of injection drug users and diagnosed AIDS patients may also be at risk. The two cases the report noted involved a Black and a Latina woman who had been diagnosed with AIDS and had no other risk factors than their sex partners.<sup>9</sup> By 1988, Blacks accounted for half of all AIDS cases ever recorded among women.<sup>10</sup>

In an accompanying report, CDC discussed 16 prisoners in New York and New Jersey who had AIDS; seven of them were Black and two were Latino. In New Jersey, the report noted, six of the 48 AIDS cases documented so far were found in prisons. Also for the first time in 1983, the CDC began to breakdown its count of AIDS cases by race.

## AIDS

From the epidemic's start, however, African Americans living with AIDS—particularly Black gay men—were leaders among the grassroots activists trying to turn the nation's attention to the epidemic. In hard-hit cities around the country during the early 1980s, Black gay men spoke up and took action. Reggie Williams was among the most vocal of these pioneers—and a founder of one of the first Black AIDS organizations.

Williams had relocated from Los Angeles to San Francisco the same year as the first report of AIDS was published. There, he joined the gay community group Black and White Men Together (BWMT)—one of a burgeoning crop of groups seeking to organize gay men and build a visible, supportive community. As the city's gay men suddenly began getting sick and dying, Williams got involved in BWMT's AIDS work. He grew into a leading national voice, educating his peers and demanding that government and community alike wake up to the exploding epidemic.

BWMT would officially form an AIDS task force in 1985, which is now considered America's first Black AIDS organization.<sup>11</sup>

During these early years, Williams worked closely with his friend Phill Wilson (now founder and executive director of the Black AIDS Institute) to fight a dangerous misconception the pair discerned among their peers: that Black men couldn't get AIDS, unless they were sleeping with white men. Williams worked from San Francisco to document Black gay deaths around the country, while Wilson worked from Los Angeles to develop safer sex campaigns targeting Black men. They also began lobbying the CDC to direct money and prevention campaigns at Black gay men.

In 1988, with the rate of infection now noticeably quickening among Black gay and bisexual men, the lobbying effort by Williams and Wilson finally succeeded in prompting the CDC to make its first-ever grant for HIV prevention targeted at Black gay men.<sup>12</sup> The resulting activities launched the National Task Force on AIDS Prevention, which went on to serve as a lead agency for a coalition of groups working to stop HIV's spread among gay men of color until it folded in late 1998.

For many, Williams—who died from AIDS-related illnesses in 1999, after living 13 years with the virus—is emblematic of a brave legion of Black men whose contribution history has long forgotten. “One of the things that kind of pisses me off, frankly, is we always hear that white Gay men were the only ones organizing in the 1980s, and Gay men of color weren't there,” said Black AIDS activist Cornelius Baker, at the time of Williams' death. “Well, Reggie gives the lie to that.”

But Williams was hardly alone. As shown in this report's centerfold, honoring just a handful of the African American AIDS leaders we've lost to the epidemic, Black men were legion in an early AIDS movement that is too often believed to have been peopled



solely by white gays. Essex Hemphill and Marlon Riggs spoke passionately about the epidemic through their art. Local activists, like Thomas Gleaton in Washington, D.C., and William “Brandi” Moore in San Francisco, galvanized their communities. Their names have been largely left out of official histories, but their communities continue to benefit from their bravery.

Nor were Black gay men the only African American voices crying out for action. In November 1987, Debra Fraser-Howze—then a mother of three—left behind her work as director of teen services for the New York Urban League to take on the growing problem of AIDS. She founded the National Black

Leadership Commission on AIDS, a national organization that has coordinated and supported the AIDS work of Black community leaders around the country. Still running under her leadership today, the group remains a go-to source for national policymakers seeking information about the Black epidemic.

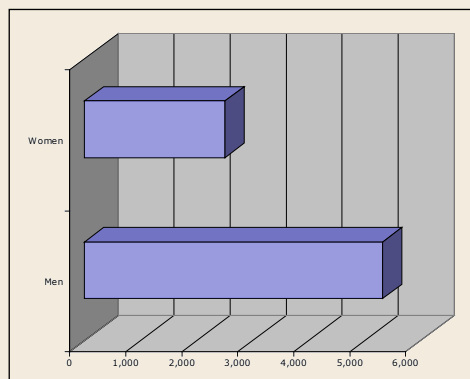
In cities around the country, local activists did the same for their communities. In 1985, the Philadelphia group BEBASHI may have been the first Black AIDS organization to spring into action, launching street outreach in Black neighborhoods. By 1988, the group had wrangled federal money to teach other organizations in the Mid-Atlantic states how to do the same sort of work, and today it provides a whole range of services to more than 15,000 people.

Just a year after BEBASHI, Sandra McDonald founded a similar group to serve Atlanta’s Black neighborhoods, Outreach Inc. In 1987, Georgia contracted Outreach to develop an AIDS education curriculum aimed at minority communities, and the organization has been a leading HIV educator throughout the Southeast ever since, particularly working with drug users and advocating for access to drug addiction treatment. “I’m a Southerner, so I’m a product of segregation,” McDonald said in explaining her early activism to the Institute’s journal *Kujisource* in 2001. “I grew up in a segregated city and, in that segregation, I learned the positive impact that people had on each other. Everybody on my street took responsibility for me. You could not escape that sort of love and correction.”

## A Killer, Still

Despite a growing belief that AIDS is no longer a lethal disease, African Americans are still dying from AIDS-related illnesses every year. Blacks who test HIV positive are seven times more likely to die from it than whites. And, as of 2002, AIDS remained the leading cause of death for Black women between the ages of 25 and 34—and ranked among the leading causes of death for all Black women.

Black deaths from AIDS in 2002:

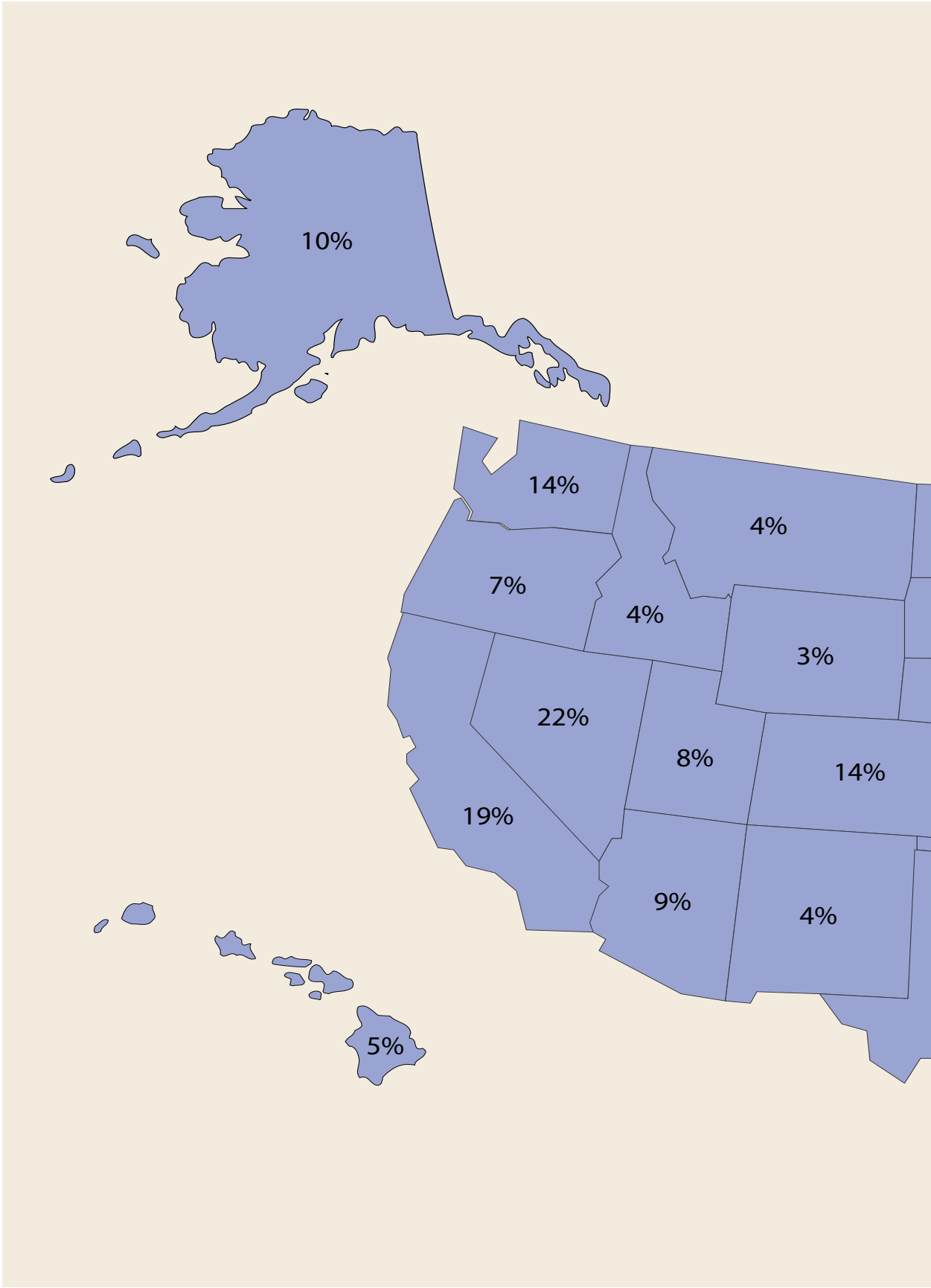


Source: U.S. Centers for Disease Control. Presentation before Black Media Roundtable on HIV/AIDS, Nov. 17, 2005.

## Silence Equaled Black Death

Despite the efforts of these grassroots trailblazers, much of the mainstream Black community leadership was woefully slow to respond to AIDS. Observers have wrestled



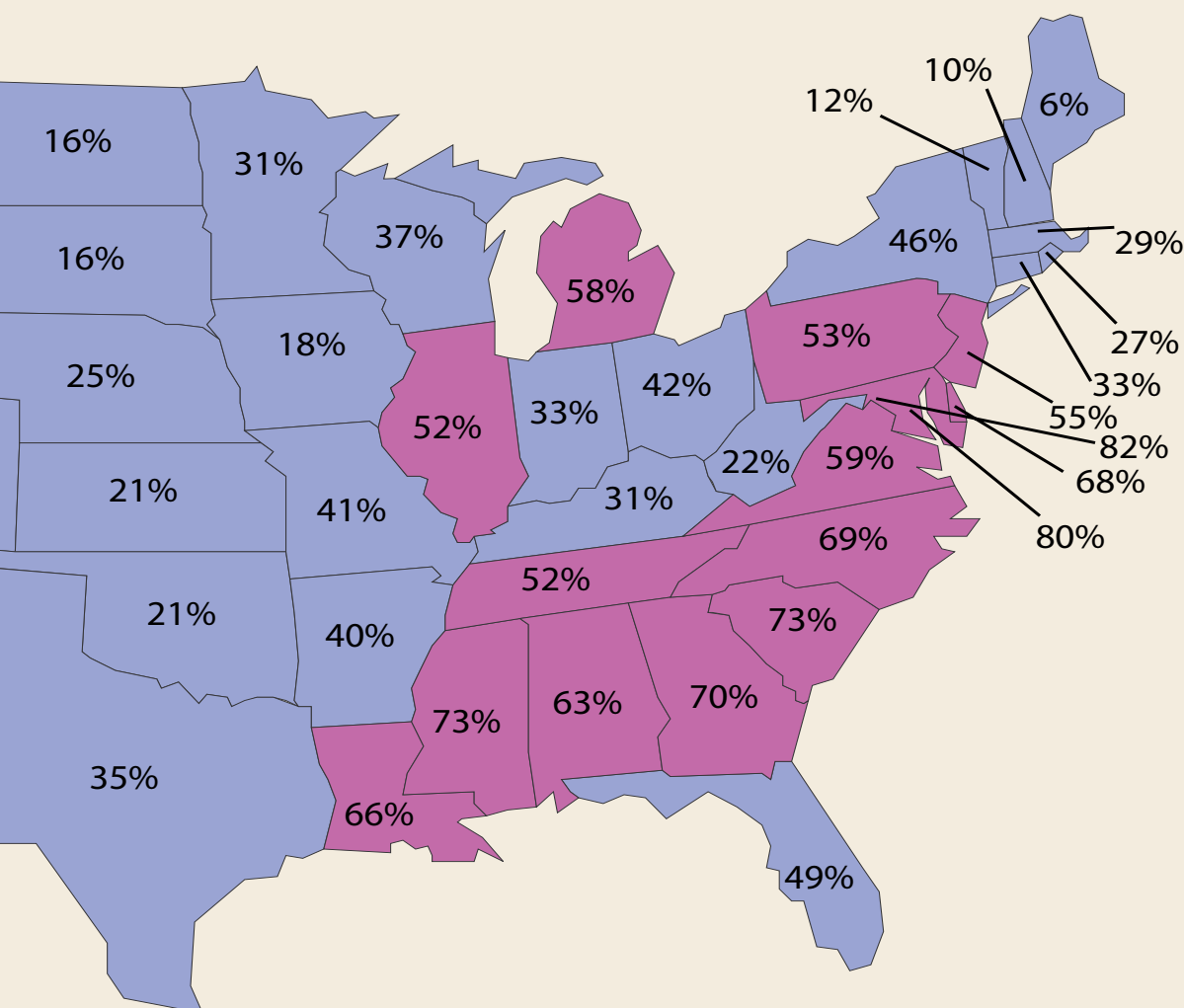




# The National Picture: Black AIDS State-by-State

Percentage of people living with AIDS in each state that is African American, as of 2004. In 15 states, more than half of the population of people living with AIDS is Black.

Source: *Statehealthfacts.org*. All percentages have been rounded.





# No Matter Where You Are, It's About You

## The National Picture, Black AIDS State-by-State

	% of AIDS Cases	% of Black Pop.		% of AIDS Cases	% of Black Pop.
Alabama	63%	26%	Missouri	41%	11%
Alaska	10%	3%	Montana	4%	<1%
Arizona	9%	3%	Nebraska	25%	4%
Arkansas	40%	16%	Nevada	22%	7%
California	19%	6%	New Hampshire	12%	1%
Colorado	14%	4%	New Jersey	55%	13%
Connecticut	33%	9%	New Mexico	4%	2%
Delaware	68%	19%	New York	46%	15%
District of Columbia	82%	57%	North Carolina	69%	21%
Florida	49%	15%	North Dakota	16%	1%
Georgia	70%	29%	Ohio	42%	12%
Hawaii	5%	2%	Oklahoma	21%	7%
Idaho	4%	<1%	Oregon	7%	2%
Illinois	52%	15%	Pennsylvania	53%	10%
Indiana	33%	8%	Rhode Island	27%	5%
Iowa	18%	2%	South Carolina	73%	29%
Kansas	21%	6%	South Dakota	16%	1%
Kentucky	31%	7%	Tennessee	52%	16%
Louisiana	66%	32%	Texas	35%	11%
Maine	6%	1%	Utah	8%	1%
Maryland	80%	27%	Vermont	10%	1%
Massachusetts	29%	6%	Virginia	59%	19%
Michigan	58%	14%	Washington	14%	3%
Minnesota	31%	4%	West Virginia	22%	3%
Mississippi	73%	37%	Wisconsin	37%	6%
			Wyoming	3%	1%

Sources: Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention-Surveillance and Epidemiology, Special Data Request, November 2005. Urban Institute and Kaiser Commission on Medicaid and the Uninsured. Estimates based on the Census Bureau's March 2004 and 2005 Current Population Survey (CPS: Annual Social and Economic Supplements).



with the nagging question of why that was the case. But it's worth stressing that African Americans were hardly unique: President Reagan didn't even speak the word AIDS publicly until 1986, and it was 1987 before he addressed the nation about the by-then raging crisis.

Nevertheless, as University of Chicago political science scholar Cathy Cohen has painfully documented, Black America sat silent for too long while its most vulnerable brothers and sisters died. Taking their cues from the nation's broader misunderstanding of the AIDS epidemic, most national Black political and community groups did not consider AIDS a problem for them to address in the 1980s and early 1990s. With few but notable exceptions, Black media overlooked the carnage unfolding. When Black publications did address the epidemic, they were unfortunately too often inaccurate or defensive—championing unfounded conspiracy theories and false “cures” or covering Black leaders' efforts to block AIDS services in their communities.<sup>13</sup>

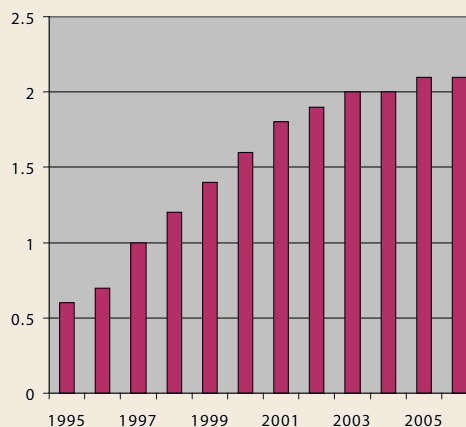
The ongoing debate over needle exchange provides a particularly damning example. In cities around the nation, Black leaders—besieged by open-air drug markets in their neighborhoods—held the line against establishing programs that would have taken HIV-contaminated needles off of the streets. In New York City, when Mayor Ed Koch pushed for such programs early in the epidemic, the *Amsterdam News* called for his resignation. Harlem Councilmember Hilton Clark labeled it a “genocidal campaign,” and Black Police Chief Benjamin Ward compared it to the infamous Tuskegee syphilis experiments. Koch still eventually set up a tiny test project, but Mayor David Dinkins—the city's first Black mayor—shut Koch's needle exchange project down as one of his first acts in office.<sup>14</sup>

Since that time, research has overwhelmingly established that needle exchange programs reduce the spread of HIV without

## Falling Behind

Since 2001, the federal AIDS care budget has failed to keep pace with the epidemic. The Ryan White CARE Act is the primary federal vehicle for funding AIDS care programs, supporting services ranging from support groups and mental health counseling to drug rehab. But while federal health monitors announced in 2005 that there are more Americans living with HIV or AIDS than ever before (over a million), Congress kept the Ryan White budget essentially flat for the fourth straight year. In five years, it has gone up by just under \$300 million.

Ryan White CARE Act funding, fiscal years 1995 to 2006 (in billions):



Sources: Kaiser Family Foundation. *Trends in U.S. Government Funding for HIV/AIDS, Fiscal Years 1981 to 2004*. Fig. 4. March 2004. And, U.S. House of Representatives, Appropriations Committee. *Highlights of the Fiscal Year 2006 Labor, HHS, Education & Related Agencies Appropriations Conference Report*. Nov. 16, 2005.

encouraging drug use, and may in fact also help drug abusers get into treatment. In fact, in 2005, CDC released new data showing that the needle exchange programs that New





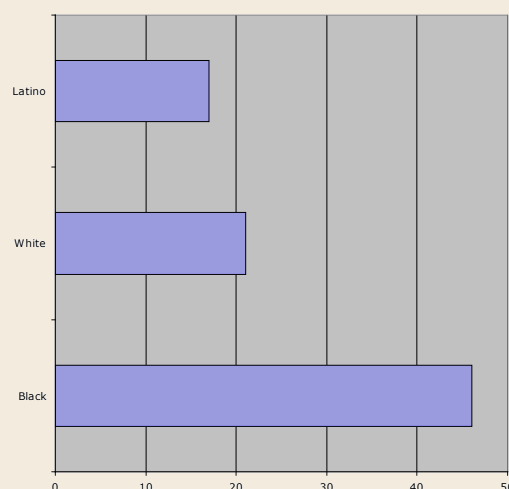
# 46%

In June 2005, CDC researchers announced that they had begun a multi-year survey seeking to identify behavior patterns among men who have sex with men that may put them at risk for HIV infection. The survey, to be repeated once every three years, includes over 14,000 men in 17 cities. While announcing the study, CDC released some early findings from it.

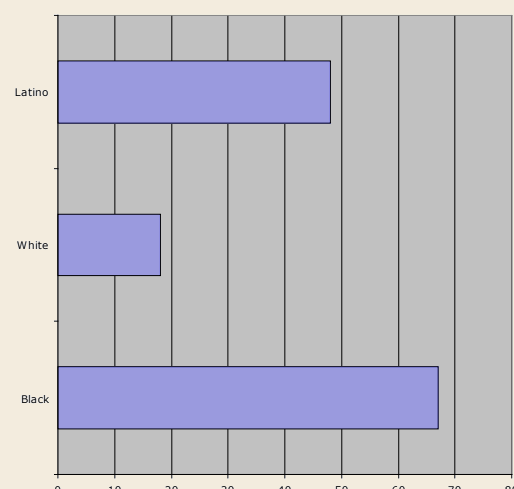
The preliminary results broke out data from five cities: Baltimore, Los Angeles, Miami, New York City and San Francisco. Of the 1,746 men tested for HIV in those cities, 25% were positive—of whom 48 percent were unaware of their infections. Undiagnosed infections were most pronounced among young men in the study: 79 percent of 18- to 24-year-olds and 70 percent of 25- to 29-year-olds who tested positive didn't know they had the virus.

But as dramatic as these overall findings were, the numbers are still more troubling when broken out by race.

Percentage of men in study who tested positive, by race:



Percentage of those who tested positive who were also undiagnosed, by race:



Source: Greenberg, Alan. CDC. *New Approaches to Tracking the HIV Epidemic in the United States*. Presentation to National HIV Prevention Conference. June 2005.

York City belatedly launched cut new Black infections in the city so dramatically that they helped drive a five percent annual decline in national Black infections between 2001 and 2004.<sup>15</sup>

There were, of course, stand-out examples of Black leaders breaking this trend. Civil rights icons and Black elected officials such as Rev. Jesse Jackson and the late Coretta Scott King, Congresswoman Maxine Waters and Congressman Carl Stokes were vocal

advocates for making AIDS a community priority from relatively early in the epidemic. *Ebony* magazine ran some of the first major stories in the Black press about AIDS, and *Jet* magazine ran dozens of stories in the late 80s—though most were of the sensational sort that typified media coverage of AIDS in general at the time. In 1994, *Essence* magazine boldly put an HIV-positive woman, Rae Lewis-Thornton, on its cover. HIV hotlines around the country reported a spike in calls

following the *Essence* cover story.<sup>16</sup>

In the end, it took the public disclosure—and in some cases death—of famous African Americans living with HIV and AIDS to begin getting the community's attention. Max Robinson, the first Black national news anchor, died at age 49 in 1988. Choreographer Alvin Ailey succumbed to the disease at age 58 in 1989. Tennis great Arthur Ashe would follow suit in 1993, at the age of 49.

But perhaps no event more helped change the Black community's willingness to see AIDS as its problem than Ervin "Magic" Johnson's 1991 disclosure that he had tested positive for the AIDS virus. Johnson—one of America's most recognizable and well-liked public figures—held an earth-shaking press conference on November 7 of that year, declaring that he was retiring from professional basketball because he had contracted HIV. "It could happen to anybody," he warned. Indeed, the CDC had documented it had been happening to more than 60,000 African Americans by then—and that not including those who had tested HIV-positive but did not have full-blown AIDS.

Four years later, rap icon Eric "Eazy-E" Wright would shock the hip-hop world in a similar way. In 1995, Wright, whose NWA rap group was credited with establishing the national popularity of "gangsta rap," announced he had recently been diagnosed with AIDS. Just weeks later, he died from the disease.

## A Black Epidemic

On the heels of Eazy-E's death, the American AIDS epidemic began to dramatically splinter. That same year would be the first in which more Blacks were diagnosed with AIDS than whites. The gap would grow by leaps and bounds from there.

Today, Blacks represent half of the more than one million Americans living with HIV.<sup>17</sup> Between 2000 and 2003, Blacks accounted for 69 percent of new diagno-

ses among women—with an infection rate 18 times higher than that among whites.<sup>18</sup> Among teens, Blacks are 66 percent of new infections.<sup>19</sup>

Meanwhile, the epidemic's frontline is quickly shifting from large, northern cities to the more dispersed communities of the South. Today, seven of the 10 states with the highest per capita AIDS rates are in the South, and 41 percent of people living with HIV are in the Southeast. It is a particularly Black epidemic: Eight of the 10 Blackest state epidemics are in the South.<sup>20</sup>

Perhaps most disturbing, however, is the path HIV is still cutting through communities of Black gay and bisexual men.

In June 2005, CDC released preliminary results from a study looking at HIV risk among 14,000 gay and bisexual men in 17 cities. The preliminary results broke out data from five cities: Baltimore, Los Angeles, Miami, New York City and San Francisco. Of the 1,746 men tested for HIV in those cities, 25 percent were positive, and 48 percent of those positive men were unaware of their infections. Undiagnosed infections were most pronounced among young men in the study: 79 percent of 18- to 24-year-olds and 70 percent of 25- to 29-year-olds who tested positive didn't know they had the virus.

But as dramatic as these overall findings were, the numbers are still more troubling when broken out by race. Of the 444 Black men tested in those five cities, nearly half—or 46 percent—tested positive. More than two-thirds of them—67 percent—had been previously undiagnosed.<sup>21</sup>

## Community in Action

But today, Black America is engaged on HIV/AIDS like never before. Since the CBC's 1998 clarion call, the community has sprung into undeniable action.

The Black media has begun to bird-dog the AIDS story, even as the rest of the Ameri-

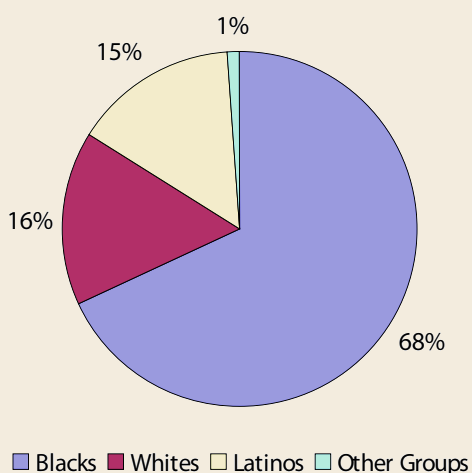


## The Good and the Bad for Black Women

The building head of steam on HIV prevention among Black women is showing results. In June 2005, the CDC announced that HIV infection rates among African American women dropped six percent between 2000 and 2003.

But the bad news is CDC also announced in November 2005 that Black women still account for a whopping two thirds of new HIV diagnoses each year.

Racial breakdown of new HIV diagnoses among women, 2001 to 2004:



Source: CDC. *Trends in HIV Diagnoses—33 States, 2001-2004. Morbidity and Mortality Weekly Report*. November 18, 2005.

can media moves on. A recent Kaiser Family Foundation study found that domestic AIDS stories in mainstream media declined by 57 percent between 1997 and 2002.<sup>22</sup> Not so for

the Black media. In January 2003, a host of broadcasters, publishers and Website producers with a combined audience of more than 40 million joined forces to launch the Drumbeat Project, in which they combined their forces to saturate Black audiences with messages about HIV. Today, the Institute records thousands of hits a month from the Black press.

Among civil rights groups, within fraternal and social organizations, and on college campuses around the country, Black community leaders are also finding new ways to talk about the epidemic and organize to stop it. In 2003, the NAACP, the Urban League, Rainbow PUSH, and the Southern Christian Leadership Council all made HIV a part of their agendas for their annual conventions. That same year, Delta Sigma Theta began dedicating a national “day of service” to HIV.

Hundreds of churches now participate in the annual Black Church Week of Prayer for the Healing of HIV/AIDS. Launched in 1989, the Week of Prayer is among the signature programs established by the pioneering group Balm in Gilead, which has been working for 17 years to engage the Black church on HIV. Today, the group links and supports hundreds of churches around the globe.

This collection of testimonials is meant to both inform and inspire more of just this sort of action. The 25 voices collected here come from varied walks of life, representing just a handful of the sectors of Black America that have begun to mobilize. Some are recognizable names, but most are everyday people who have found a way to get involved. None set out to become AIDS activists, they just found ways to make a difference through the work they were already doing.

And that is the message we hope readers will carry forward with these testimonials: that every contribution, big and small, counts. Whether it’s singing a song at the funeral of a loved one who died from AIDS, as one contributor describes, or launching



a massive HIV testing campaign in your church, as another recounts, you can make a change. For 25 years now, AIDS has been killing us one person at a time; we can beat it back with one brave act after another as well.

## Notes

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2. CDC. HIV Surveillance Report, V. 13, n. 2, table 32.

3. Ibid.

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7. CDC. Pneumocystis Pneumonia—Los Angeles. Morbidity and Mortality Weekly Report. June 5, 1981.

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12. Wright, Kai. "Activist Reggie Williams succumbs," *The Washington Blade*. February 12, 1999.

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16. Cohen. *Boundaries of Blackness*.

17. Greenberg, Alan. CDC. *New Approaches*

to Tracking the HIV Epidemic in the United States. Presentation to National HIV Prevention Conference. June 2005.

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19. Deas, Natasha. *Advocates for Youth*. Adolescents and HIV/AIDS fact sheet. January 2003.

20. All data in this graph is drawn from Statehealthfacts.org. HIV/AIDS data is broken out and tabbed to produce a range of up-to-date state rankings.

21. All details and data from this survey discussed here comes from: Greenberg, Alan. CDC. *New Approaches to Tracking the HIV Epidemic in the United States*. Presentation to National HIV Prevention Conference. June 2005.

22. Brodie M and others. Kaiser Family Foundation. "AIDS at 21: Media Coverage of the HIV Epidemic, 1981-2002." Published in the March/April 2004 issue of *Columbia Journalism Review*.

## TIMELINE

# 25 Milestones in Our Time with AIDS

### 1981

■ Centers for Disease Control and Prevention publishes its first notice of a rare, fatal pneumonia found in five previously healthy gay men in Los Angeles. Originally called GRID (Gay-Related Immune Deficiency) or “gay cancer,” the next year CDC would describe the condition as an immune disorder called AIDS, listing male homosexuality, injection drug use, Haitian origin and hemophilia as “identified risk factors.”

### 1983

■ CDC adds female sex partners of men with AIDS as a fifth group at risk, citing a Black and a Latina woman who developed the condition after having sex with men using injection drugs.

### 1984

■ Scientists identify the virus that causes AIDS and name it HIV, for human immunodeficiency virus.

### 1987

■ FDA approves AZT as the first drug for AIDS. Priced at as much as \$10,000 for a year’s supply, it’s one of the most expensive meds ever marketed. The recommended dosage of a pill every four hours, around the clock, is later found to be highly toxic.

■ President Reagan makes his first public speech about AIDS—he hadn’t mentioned the word at all before 1986.

■ Black AIDS activism explodes, with the founding of National Black Leadership Commission on AIDS and the National Minority AIDS Council. The National Task Force on AIDS Prevention would hold its first meeting the following year.

### 1988

■ CDC announces that as of December 1988, African Americans account for half of all AIDS cases ever reported among women.

## 1989

■ Dancer and choreographer Alvin Ailey dies from AIDS at age 58. While Rock Hudson and other celebrities had died from AIDS, Ailey's was the first high-profile African American death.



is still considered the watershed moment of the Black epidemic, when African Americans began talking openly about AIDS.

■ Red Ribbon is introduced as an AIDS awareness symbol during the Tony Awards.

## 1993

■ Wimbledon champ and tennis Hall of Famer Arthur Ashe dies from AIDS at age 49. More than 15,000 African Americans died from AIDS that year, rising toward a 1995 peak of nearly 20,000 deaths in a single year.



## 1990

■ Ryan White, an Indiana teen who contracted HIV as a hemophiliac, dies at 18. White's fight against his school's refusal to allow him to attend drew celebrity sponsors, including Michael Jackson. Congress names the bill creating today's system for funding AIDS care and treatment after White.

■ Kenyan President Daniel Moi ignites a firestorm of controversy by touting an AIDS "cure" developed by Kenyan scientists and marketed as Kemron. The declaration stoked conspiracy theories in Black neighborhoods that U.S. government had a cure for AIDS but was withholding it. No follow-up studies found Kemron to work.

■ Denzel Washington stars in the AIDS movie *Philadelphia*, for which Tom Hanks wins Best Actor Oscar.

■ FDA approves the sale of "female condoms" in the U.S. Today, researchers continue searching for female-controlled forms of HIV prevention to empower women in protecting themselves.

## 1994

## 1991

■ Los Angeles Lakers star Earvin "Magic" Johnson announces he has tested HIV-positive, warning "it could happen to anybody" and retiring from basketball. His announcement



■ HIV-positive activist Rae Lewis-Thornton is featured on the cover of *Essence*. AIDS hotlines report a large spike in calls from women who connect with Lewis-Thornton's story of a successful Black woman who didn't fit any AIDS stereotypes but nevertheless got infected.

## 1995

■ Hip-hop legend Eric "Eazy-E" Wright announces he has AIDS just weeks before

dying at age 31. If Magic's announcement grabbed Black America's attention, the rap star's sudden death finally jolted the hip-hop world into discussing AIDS.



■ FDA approves the first protease inhibitor drugs, which would be credited with suddenly beating back AIDS deaths—for those with access to the medicine. The following year would be the first year in which more Blacks died from AIDS than whites. Today Blacks are eight times more likely than whites to die from AIDS once diagnosed with HIV.

## 1996

■ Media celebrates the “end of AIDS,” with cover stories in *New York Times Magazine* and *Newsweek*, among others.

## 1997

■ Nushawn Williams is accused of deliberately exposing several white women in upstate New York to HIV and is jailed, sparking a media frenzy. It was never proven that any of the women contracted HIV from Williams.

## 1998

■ Congressional Black Caucus pushes Minority AIDS Initiative through Congress, creating a special stream of federal funding for addressing HIV/AIDS in communities of color.

■ Clinton administration acknowledges several previous government studies showing needle exchange stops the spread of

HIV and encourages addiction treatment, but refuses to lift ban on federal funding for such programs. Half of all Black female AIDS cases through 2003 were attributed either to injecting drugs or sex with someone using injection drugs.

## 2000

■ CDC announces Black and Latino men for the first time represent the majority of new AIDS cases among gay and bisexual men. By 2005, one CDC study would estimate infection rates among Black gay and bisexual men in some cities to be as high as 46 percent.

## 2005

■ CDC announces that African Americans account for half of all people now living with HIV/AIDS in America—and nearly half of all new infections.

## 2006

■ The AIDS epidemic turns 25 years old. No vaccine or cure exists, and none is predicted for the foreseeable future.

## CHAPTER ONE

# In the Spirit

## Voices from the Black Church

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### Rev. Jeremiah Wright

#### Trinity United Church of Christ Chicago, Illinois



When our first member to die of AIDS called me to his home to confide in me about his condition, and the conditions under which he was dying, I knew in my

heart and mind from that day that our church had to do something about AIDS.

“Herman” sat in his three-story, split-level home with nothing left but the carpet on the floor. His wife had packed up the children and all of their belongings while he was at work and left him with nothing in the home but his carpet. She did not want to be around

him because he had AIDS, and she did not want their children around him either.

“Herman” said to me: “Nobody should have to die like this, Rev!” He was absolutely right. He is still right!

I made up in my mind on that day that no person in our congregation who was living with AIDS would ever die like that again. We started our AIDS Ministry then and it has been up and running ever since.

I was not concerned about the stigma it might bring on our congregation. The United Church of Christ has been the “whipping boy” for the conservative, right-wing press and public when it decided to ordain homosexuals into the Christian ministry. That means that I have been the pariah of the Black church community and those outside of the Black Christian community since then. Since most of the persons who were affected by and infected by HIV/AIDS back in the ’80s were homosexuals, I knew that it would be “more of the same” in terms of the church community and the larger community branding us because of our decision to do work in this area. I do not do ministry, however, because of what the public thinks or the press

thinks. I do ministry, and we do ministry as a congregation, because of what the Prince of Peace thinks!

The Black community was slow to respond to the epidemic because the epidemic was branded as a white-male homosexual disease. And because many Black Christian families believe in their heart of hearts that AIDS is God's curse upon the homosexual, those churches and the larger community were slow to respond. Homosexuals were seen as "outside of the veil" of the Black community. Homosexuals within the church community and within the Black community were also viewed as "strange," "weird," "sissies," "faggots" and a whole host of other negative terms. So the Black community was slow to respond to the pandemic that has swept across this country for over a quarter of a century.

We are doing a little bit better now. We are not doing 1/100th of what we could be doing and should be doing, but the response now is much better. The response has gotten better since the pandemic has begun to affect heterosexual African American females.

If we're going to catch up, I think the religious community needs to do several things. First, it needs to educate its pastors and its members about the reality of HIV/AIDS. The reality is that HIV/AIDS is a biological problem, not a theological problem. It is a medical issue, not a moral issue. The religious community needs to make that message loud and clear across denominational lines and across interfaith lines.

The religious community also needs to hold quarterly workshops, seminars and teach-ins with its teenagers, its adults and even its seniors about sexually transmitted diseases and how HIV/AIDS is spread. One of the T-shirts that I saw back in the 1980s says it all:

"HIV/AIDS is spread three ways: By blood, by semen and by ignorance!"

So the religious community needs to stamp out ignorance among its constituents

and help them to come to grips with how this disease is transmitted. It also needs to teach preventive measures to cut down on the incidence of persons becoming infected.

Further, individual congregations need to form HIV/AIDS ministries to minister to families of persons who are infected, to minister to loved ones who are affected and to minister to persons who are living with AIDS and who are dying with AIDS.

And finally, the religious community needs to lobby the politicians just as it did back in the civil rights movement. It needs to lobby politicians to get the laws changed so that the poor and the needy can have access to anti-retroviral drugs at generic prices, just as they did in South Africa and in Brazil. Not everybody can afford the medications that Magic Johnson can afford! Until the religious community lobbies those senators who are in bed with the pharmaceutical companies to change those laws, then it is not doing what it did back in the civil rights days, when religious leaders lobbied the politicians to change the laws that kept people locked out of access to full participation in the American society.

Our church has had an HIV/AIDS Ministry since the beginning of the epidemic. We train persons who volunteer to work with this ministry before we turn them loose to work with families and individuals who are living with AIDS and/or affected by AIDS. Our training includes classes led by an epidemiologist, persons from the Chicago Board of Health, persons from the Centers for Disease Control in Atlanta, and chaplains who work with people living with HIV/AIDS. We also hear from people who are HIV-positive as well as persons who have full-blown AIDS.

Our AIDS Ministry has a house that serves as a "halfway house." We provide medications and minister to families who are affected and infected. And we help people learn about and take advantage of every social service that is available to them.



We also have annual seminars and workshops on safe sex. We have a Teenage Sexuality Ministry in our church, and sex is a constant discussion when it comes to the educational ministry of the church. We talk about it right from the pulpit.

Our theological approach comes straight from the Bible. God loves everybody. God says everyone who believes in God's Son shall have everlasting life. That includes people with HIV/AIDS, heterosexuals and homosexuals.

But the next step for all of us should be a fierce lobbying campaign of all of the politicians to get the laws changed, so that the poor have greater access to cheap anti-retroviral drugs! Of course there is the hard ground-work which the Balm in Gilead has been engaged in for over 17 years—that massive program of education for all of the historic Black church denominations. From the National Baptist Church to the African Methodist Episcopal Church to the Church of God in Christ or all of the non-denominational mega-churches in this country—we have got to get educated and get involved to stop this epidemic and heal our communities.

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## **Rev. Edwin Sanders II**

### **Senior Servant, Metropolitan Interdenominational Church Nashville, Tennessee**

We're a 25 year old congregation, and our beginnings were such that we have always been a congregation that puts a special emphasis on trying to respond to the spiritual needs of persons who have felt alienated, disenfranchised or separated from the church in one way or another. We always talk about ourselves as being a community of believers that represents a broad cross-section of folks,

cutting across all the lines of fragmentation and division—whether those lines be race, class, gender, ethnicity, nationality or anything else. We have always been committed to trying to respond to the needs of those who have been kicked to the curb of life—people who have found themselves being discounted, dismissed and left outside of the circle of inclusion within the faith community.

We do ministry in many areas. But a lot of the ways we do ministry is a direct byproduct of our commitment to trying to make real the teachings of Jesus, as we understand them. And we see those teachings as being radically inclusive to all and alienating to none. From the very beginning, the founding 12 members were a rich mix—in terms of being male/female, Black/white, Hispanic. Probably the only real point of diversity that did not exist among us was age, because we were a fairly young group at that time.

When we began, in 1981, we actually went for three and a half years without experiencing any deaths in our congregation. But the first death to occur was one of our founding members, and he died from what seemed to us then like a very strange disease: toxoplasmosis. We didn't know until six months after his death that it was one of the



opportunistic diseases that was starting to devastate persons whose immune systems had been weakened as a result of having AIDS.

When we became aware of that fact, we immediately began to try to educate ourselves. The general thought of the day was that this was a disease that was impacting gay white men. But our friend was an African American man, someone who

was very close to us, and we had no appreciation for his being vulnerable in this way. So it was on the occasion of his death that we began to educate ourselves, and in time that translated into us also starting to provide a prevention education within our community. And in time that translated into the delivery of direct services. Not long after that, when the Ryan White CARE Act was passed, we became major players in establishing the first community coalition to determine how those resources should be used in our community.

I think, initially, because there was such an atmosphere of demonization of those who were being impacted by the disease, for us to aggressively pursue ministry to persons who were infected was something that many of our counterparts in the faith community questioned. But we took the position that the teachings of Jesus, as we understood them, were clearly teachings that were framed by the spirit of redemption, reconciliation and inclusion. And for that reason, we felt strongly that persons who were being impacted by HIV/AIDS were clearly the people who Jesus would have been caring for, ministering to, and advocating on the behalf of.

So in terms of the larger faith community around us, there was initially criticism and there was reluctance in terms of the response. But it wasn't long before this disease began to touch the lives of folks in every congregation, and in a way that at least challenged them to try to frame the issues in a manner that allowed them to be honest about what was happening—and be responsive in a way that reflected the mandate for compassion and for service, especially to those who are most alienated from society.

What that meant initially, though, was that we simply became the referral source. It wasn't as though others suddenly bought into doing ministry in this arena, but rather we became the congregation that others looked to for help. When folks needed some guidance or input in terms of how to respond

when HIV came to their doorstep, very often they would seek us out for information, or in many instances just refer them to us. We were literally the only African American congregation, and one of only two congregations in the city of Nashville, period, that was openly embracing and dealing with people who were infected.

I think that some of the stigma and some of the misrepresentation of the truth about the disease perpetuated a period of denial and resistance, in terms of ministers and congregations being willing to address the issues rightly. In many instances there were those—and I'm sorry to say there are still some—who would talk about the disease as being a curse, especially since the association was always with homosexuality, drug addiction, and promiscuity. And because it was just so easy to categorize those things within the traditional church context as being sin, AIDS was easily talked about in terms of being God's wrath. I think that what we have seen over the last 25 years is some significant movement away from that kind of mindset.

I think what brought that movement was the honest facing of the fact that there were people sitting in our pews, people turning to our compassion ministries, and people's loved ones being affected in ways that they were simply not able to deny. And we were able to play a significant role, in that we were able to create forums and community-wide conversations that allowed the issues to be debated and discussed in a way that was, I think, consciousness-raising, liberating and transforming.

So to some degree we clearly were involved in the debate, but more than anything we were involved in ministry that demonstrated how to respond with sensitivity and compassion. So I think that what happened over time, especially as people would make referrals to us, is that they saw a ministry that was grounded in a spirit of unconditional love and was meaningful in some very pow-

erful ways to folks who came to our doorstep. And I think when there was not always understanding, when there was not always agreement, there was respect for the consistent posture that we were able to maintain in how we did the work with integrity and without compromise, in terms of whosoever came to our doorstep.

I always say to folks that I'm convinced we were given a prophetic insight into this disease. Because when you looked at the characterizing factors of persons who were being most disproportionately impacted, all you had to do was take the words "gay white male" out of the equation, and then the characteristics that you began to enumerate were very easily applied to who we were: people whose life experience has been so stigmatized that they have to deal with the dynamics of self-hatred, of low self-esteem, of denial about your truth, or lack of opportunity because of prejudice and bias as a result of who you were.

Today, even though I don't agree with all of the theology that leads folks to be involved and structures their responses to this disease, at least there is the general understanding that it is something we have to address. Early on, there was not even the understanding that this was something that needed to be addressed within the context of the church. So even though there might still be some disagreement, and there might be some bad theology in terms of how the responses are being shaped, it's not as though people are sitting back and saying this is not something that the church needs to be embracing and dealing with.

That's important because the church is still the institution in our community that has the greatest level of credibility, along with the ability to communicate effectively with the largest number of people on a regular basis. The voice of the pastor, minister, preacher, evangelist, teacher, prophet—whatever language best fits—that voice is still a criti-

cal voice, is still one that is respected and looked to. So what we find is we're not always able to move everybody to the theological posture that we would think of being Jesus's posture—that is, radical inclusion—but we do find that people understand enough public health to say you do need to know your status, and everybody needs to be tested. Or you find that people appreciate the fact that they might not have an AIDS ministry, but they can help ours by letting us use their vans, for instance, to transport people. Or they can help us in developing care teams, which do everything from helping families who are dealing with loved ones who are going through the disease to just being there in times of sorrow and grief.

So I think the church is better prepared to deal with all of this today, because I think some of the ignorance has been dispelled—and that's true across society, not just in the church. And I think a lot of the myths and fears that cause folks to be reluctant to even talk about the disease have started to erode. When there's conversation and there's openness to information-sharing, then I'm convinced you're postured to be a part of the solution instead of a part of the problem. If you remain ignorant, you're always going to be a part of the problem.

—As told to Kai Wright

## Elder Mamie Harris

### Heirs Covenant Church Cincinnati, Ohio



I was the wife of a pastor, Michael Harris, who had his own alcohol and drug ministry. I worked at the VA, but when I retired I got involved in that ministry.

Well, it's impossible to be involved with alcohol and drugs and not be involved with HIV. So in the process of looking for something to do with my time when I retired, someone suggested to me that I look into children who are infected with HIV. And in doing so I became aware of how African Americans are disproportionately affected.

I saw a video, *House on Fire*, that had been made by the NAACP. Someone loaned me a video of a 20/20 interview with a pastor whose son had been infected with HIV. He discussed how the church really rejected him and ostracized him, and how he had to resign his position. He couldn't even find a place for his child to go to Sunday school. As a result of seeing how the two communities were so opposite of each other—the church and the HIV community—I started to get involved in just trying to bridge the gap.

My desire was to get over the stigmas that surrounded the virus—such as homosexuality, adultery, the things that the church preached against—to begin to deal with the individuals who were being infected, and affected, and their need for love, support, understanding and compassion. In doing that, I got more involved, and the more I got

involved, well, the more I got involved. I decided that we should become an HIV testing site. I thought if we were testing as a religious community, it would open up the doors for the people in the churches to feel safe in at least acknowledging the need for the church to address these issues.

We educated the people of our church through the Red Cross, and then we put a survey out, asking, if we did this kind of ministry, would the church be willing to accept the people who came in. And we got a 100 percent “Yes.” Even though we didn't embrace all of the things we were educated in, we had an awareness of the need to open up our minds. We did not support being a church that would pass out condoms, for instance. But we knew we had to teach and educate for the use of them, because everybody isn't abstinent. Everybody doesn't think like me, so I couldn't go into HIV education and HIV testing assuming that everybody that came to me was going to embrace the same moral beliefs that I had. I had to be open to the point that when I educated about sexually transmitted diseases, I had to give the whole education. And even though I don't give you the condom, I had to be associated with people whom I could send you to. So I began to collaborate with organizations that pass out free condoms.

I really think going to the Black AIDS Institute's HIV University helped, and not just because of what I learned in class. I didn't realize that I was going to be staying with three other people—three complete strangers—for 30 days. One of my roommates was infected with the HIV virus. I didn't realize I'd be that closely associated with it. Then the first evening, I met people who had a transgender lifestyle. I was with people who were from the gay community. So I had to open up my eyes. I had 30 days that I could be there. Now, I could either get on the plane and come back home, or I could be really educated. So I had to learn to see that even though people don't

always think like you think, and don't embrace everything that you believe, you have to learn how to live with diversity and respect what other people think if you want them to respect who you are. It was a rude awakening. And everything I learned, I came back home and taught it to my church and I taught it to my husband.

They thought I was kinda crazy at first. And many people said, 'I bet they're infected, because no church would embrace this if one of the two of them wasn't infected.' So they said all kinds of things. It wasn't easy. But I honestly believe I was called by God to work in the ministry with HIV. So it gave me a special ability to look beyond the pettiness of people and be driven and goal focused on what I was doing. That became more important to me than the opinion of people. And I recognize that probably still today a lot of people say, 'Well, she's gotta be HIV-positive. Nobody can be that passionate about something unless it was affecting them personally.' I've learned to live with that.

I've also learned to live with the fact that a lot of people don't understand how I can come from the church community and some of my best friends are from the gay community. We've learned to love each other. They have a right to an education that's going to protect them, if we're to stop this virus—and if we're to stop all the things that are causing problems in the African American community, because it's not just HIV. We are suffering with all of the major illnesses, and I think it's because of lack of knowledge. So I want to be in a position where I'm open to knowledge in every area.

And that openness has allowed me to do amazing things. I even go to a home for pregnant young ladies and I'm able to talk to them about sexually transmitted diseases and even talk to them about the need for abstaining from sexual behavior as a mother, or embracing those things that are going to protect their children, and not be offensive. I'm able to go

into the gay community as a person from the church community and talk about all of the issues that we face and still come out with the respect of that community and the friendship of that community, yet having not compromised one bit of what I believe to be spiritually based.

We all have issues. So I do not go in with this self-righteous attitude that we're all right and everybody else is all wrong. Or that everything I believe makes me better than somebody else, because that's not true. I can't go in and beat somebody else up for not embracing every biblical principle when I have my own weaknesses. So I think when I walk in and I acknowledge that I'm not coming with all the answers, people are more apt to hear what I have to say.

After my husband passed away, we had to merge with another church, Heirs Covenant Church of Cincinnati. And now I'm in the process of trying to work in a new community and help them to not only want to support us financially, but also spiritually. But we've already had people in our church who have been able to stand up since we've been there and say, 'I'm infected with HIV.' And they've been embraced.

We've tested over 8,000 people. We started our ministry in 1998, and we started doing HIV testing in 2000. I've grown so much as a person, because I've touched 8,000 lives that I would never have reached sitting inside on the church pew. I've talked with people, I've ministered to people, I've educated people, I've learned information from other people that I would never have learned had I just sat in the church and never opened up my mind and heart. I've grown so much as a person as a result of the opportunity to serve. It's been a blessing to me, and I hope I've been a blessing to others.

—As told to Kai Wright

## Rev. Rickie G. Rush

### Senior Pastor, Inspiring Body of Christ Church Dallas, Texas



I think a lot of people started to participate in working against AIDS because of the approach and the appeal that was made by those who were pretty knowledge-

able about the subject. On the other hand, we started because we saw such a horrific trend happening around in the church; and we were unequipped and uneducated about what to do. I know it is still a mystery here. And I think we participated because people who educated us on it helped take the scare out of it. It is going to sound horrible, but it is almost as simple as a common cold. People who have it take the medication and they are OK.

So what we have been able to do is host town hall meetings here, and provide a lot of opportunities for people needing counseling. We guide them into other services. The church is not necessarily equipped as well as it probably should be to handle cases on a week-to-week basis. And sometime people are more sick than others, and the liability becomes an issue. But we are able to redirect them into areas where they are able to get help.

We were also able to present, for instance, to about 13,000 people at one time at Six Flags over Texas. We brought [Black AIDS Institute director] Phill Wilson in and had him do a presentation about AIDS—just to

say this is what it is, this is how it affects us. That was a great turnaround for the church in general, because everybody said, 'You know, some nice guys have this.'

The congregation in our church has been tremendous in responding to this work; the community has not been. The community would rather say right now, "Whatever, what are you going to do?" And everybody should be saying, "Whatever we have to do." But we don't know what "have to do" means. It is not like when you go to the church if you want some food, and you go to the pantry and they give you something to eat. If you come in there with AIDS, where are they going to take you? What are they going to do? What are they going to offer you? You need people who are equipped to handle it. Mainly now, we support those people with loving open arms, and they are part of our church. They need compassion. So the church started a program here. We just let it be known that we are a city on a hill and when they need help, we just guide them to where they need to go.

Of course, when you start talking about AIDS and trying to help people, it becomes a label that is put on your church, like everybody in your church has AIDS. As a leader, when you step out and do stuff like that, people tend to think maybe you have it. So people are afraid of it because it takes some things out of the closet that you want to keep in the closet. But I don't. It doesn't matter. It is like a hospital. You have to keep the doors open.

So now we're just trying to get more direction from people like the national Black AIDS Institute. We are available; we just need to know what we need to do. We are available, and we need to do something, but what is the "do something?" Mainly we stay available and willing to support, and that is what we do.

When I was asked to do the town hall meeting, I was honored, because in a growing church full of young people, the more awareness you bring to it, the more prevention you



help facilitate. It gives us a chance to make people more aware and to be a place where people know the subject can be talked about. We talk about it almost every week, in some form or another.

The main thing that people are afraid of is the shame, I've learned. Shame is what makes an alcoholic not come out and say he is an alcohol. It is not the sin. It is not the alcohol. It is not the drinking. It's not the beating. It is the shame. He is ashamed. And he can't get past the shame of it. When God made Adam, Adam ran from God because of the shame, not the sin. He couldn't face it. He felt like he was shamed. When the guy with AIDS runs, he feels like he has shamed his family and shamed the people who trusted him. So we get them past the shame and the guilt and the condemnation leaves. We teach them that they that are sent here for a purpose and given a vision. They have to run with it and they have to accept the Lord in their lives, forgive themselves, and teach others to accept who they are. I don't know how anyone got AIDS. I was not there with them when it happened, so I would never really know. So how am I going to make one person ashamed because he got it from sex, the other from needles and the other from a blood transfusion? People don't need to get into how they got it. They need to get into how they get by with it. That's the part we don't want you to be ashamed of.

—As told to Sharon Egiebor

## **Jermaine D. Green & Michael Dorlando Oliver**

### **Unity Fellowship of Christ Church**

#### **New York, New York**

Jermaine: I'm 29 and I lead the youth ministry at Unity Fellowship of Christ Church, New York. I sit on the national young-adult ministry council, which encompasses the 16 different churches in the Unity movement. Basically, the young adult ministry is set up to instill and encourage discipleship in the young adults, and to encourage them to reach for their dreams, to understand who they are. Unity Fellowship is a ministry that is welcoming to all people. There is no separation of anyone. No religion will be a barrier—if you're a Muslim, Hindu, Hassidic, Catholic, Presbyterian—all religions are welcome to worship with us. If you're white, Black, Chinese, Latino, you are welcome to worship. If you are straight, gay, bisexual, transgender, you are welcome to worship. Even if you don't know what you label yourself as, you'll be welcome to worship.

We have come to understand that once a person enters the four walls of our sanctuary, that may be the only time that they hear from someone else that they are very special. That may be the only time they get a loving embrace. That may be the only time somebody says something nice to them, but while they're in the four walls of the sanctuary we make sure that those individuals feel welcome. And that they understand that God is spirit, a thing that can't be described, but that we know is there because It allowed us to wake up this morning in our right minds.

Michael: I'm 19 and am a peer educator for Unity Fellowship. What I do is talk to teens and youth of different ages. A peer educator is basically a person who is very

sexually aware and knowledgeable about what's going on in the world, and is trying to prevent other youth or teenagers from slipping in between the cracks by not having protected sex or having high-risk sex. We hold a basketball tournament to attract the younger audiences to our health fair. Basically, it's a health fair that is gonna allow people to get free rapid HIV testing, free STD screening, free counseling and information about safe sex.

I don't think it's weird work for the church. I think it's the next step up, because basically the church is here for the community. That's what the church is for. The church should be the place where people can go when they need help. And right now this church is reaching out to help the community.

Jermaine: I got involved in Unity because of the choir. Someone I knew invited me to come, and was like, 'We're having a choir.' And I thought, 'Choir? Church? Hmm, interesting.' And so when I came, that was the thing that got me hooked. But when the founder of Unity came and gave a sermon, that's when everything changed for me. Before I was just here. I was just present, I wasn't actively listening. I was clear in my head that my job was to sing, sit down, and shut up. Nothing else. But hearing his sermon I realized that I have a purpose, that I have a place in the bigger scheme of things and no one can outcast me because of who I am, or what I believe, or who I choose to go to bed with, or any health condition I have.

None of that will separate me from God. And God will still love me every single day, and nothing can separate me from that—no Pope, no preacher, no grandmother, no uncle, no grandfather. None of that can separate me from the love that God has for me. And when I heard that message clearly, that's when I became active. I started volunteering. I started working with the young adult ministry.

I didn't think "gay" and "church" worked

together, because of my past experiences with my grandmother's church. But now I realize I do have a seat at the table. By taking those voices out of my head about how I'm damned to hell and I'll never be nothing but damned to hell, regardless of anything I do, I realize that I have a seat at the table. I realized I am worthy of God's grace and mercy, not because I sleep with whomever I sleep with, but because I live. Because I am one of God's children.

Michael: I grew up in church. That's my main background. With all of the ins and outs that I've had, I've always found some type of stability in Christ, or in my faith. I started out in church in New York when I was three years old. And as I traveled, I didn't church-hop, but I found places where I was able to find some type of peace, outside of the home. And I've been going to church ever since.

I go to church with a lot of young people who are not too much older than me. My pastor back in North Carolina, where I lived before moving up here recently, is only about 10 years older than me. So I've been in a lot of churches where the ministry is run by a lot of younger adults. And in my church in North Carolina, a lot of the clergy work with HIV and AIDS facilities. So it's been kind of a heads up for me.

Jermaine: I tested HIV-positive at the age of 17. I was told by my doctor that I'd be dead at 18 and I'm now 29—God did that, I could not have healed myself that way. So I've worked with kids outside of the church with that issue. A lot of them who are HIV-positive and don't go to church believe that just because they are positive that it's a death sentence, and that they have no reason to live. I've helped them to realize that if I've lived this far, you can live as well. If you take care of yourself, if you realize that HIV doesn't have you but you have it, then you can do what you need to do to take care of yourself.

This sort of message and work has always been part of Unity Fellowship. When the

church started in Los Angeles, there were individuals whose parents would not bury them after they died from AIDS, and just left their bodies for the church to take care of. So it became known that the church would give the last rites and do the burial for individuals who were positive.

Michael: My friends wish they had the time to do what I'm doing right now, but unfortunately they have other things in life that they are reaching for, so they don't have time right now. Honestly, I'm quite amazed at the reactions I get from people about the work I'm doing in the church. For me, it's normal; it's like wearing my own skin. But people see me doing this and really commend me. I've gotten so many thank-yous and people saying "keep going" and really pushing me to keep doing what I'm doing. It's a pretty good feeling.

Jermaine: I make sure that I always stand on my truth, that I'm comfortable with my truth. That I can communicate and not be ashamed of all aspects of my personality and all aspects of who I am. Because I've come to believe that shame is really the thing that will kill individuals. They feel ashamed about something they did or about having HIV or that their mother's a "crackhead" or things like that. That shame can be very destructive, especially to a person who's HIV-positive. They sit there and become very depressed, because they feel they can't go to anybody and ask for help without that person trying to humiliate them or make them feel disgraceful.

For me, I had to go through the hard knocks of people separating themselves from me because of my status—folks didn't want to date me; so-called friends didn't want to be friends with me cause they thought they might catch something. And I realized that I had to feel within myself that there was nothing wrong with me. As long as I felt there was something wrong with me, then I would feel crushed and destroyed when other

people said hurtful things to me. But when I got to that space where I realized that there was nothing wrong with me—that it's just like having cancer or diabetes—then I was able to get comfortable. Regardless of how I got it, there's nothing wrong with me.

—As told to Kai Wright

## CHAPTER TWO

# In the Community

## Voices from Civil Rights and Neighborhood Organizing

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### Julian Bond

Chair, National Association  
for the Advancement of  
Colored People  
Washington, D.C.



We are the National Association for the Advancement of Colored People, and we say that colored people come in all colors. But the people whom we focus

most of our interests on are descendents of Africa—African Americans. And since the rate of AIDS infection is highest among African American women, and it's dangerously high among men and among children, it's a national scourge and an international

scourge, and something that just cries out for our attention.

We think the right to decent health is a civil right—and certainly people with AIDS and HIV don't have that right. African Americans are particularly afflicted by AIDS, yet, we're not included in clinical tests as often as we ought to be. We don't have access to the clinics in the same way that other Americans do; there are racial barriers. I don't think people are saying, 'Let those Black people have AIDS and die.' I don't think anybody's saying that. But I think there are racial barriers that are long-lasting. They are institutional in our society, and whether the issue is AIDS or housing or any of the things we think about, this is a civil rights issue.

It's absolutely true that African Americans have been slow to respond to AIDS, and I think there are many, many reasons for it. First, it was stereotyped as a disease of gay people. And I'm sorry to say there's a high level of homophobia in Black America—too often, sadly, coming from the pulpit where people certainly ought to know better. But this homophobia kept us from thinking about this as our disease.

Secondly, it's thought of as a disease of white men—gay white men, but white men nonetheless. We thought it didn't affect us. Of course, now we know it affects us more than it affects others. Plus, I think the typical method of transmission is through sexual intercourse, and we don't like to talk about sexual intercourse. It's something that we didn't want to talk about, that we felt embarrassed about.

Just a couple of weeks ago a prominent minister in Washington, D.C.—where I live—delivered what can only be thought of as a bigoted, ugly, homophobic sermon, trying to describe what “real men” were. And to him, homosexuals could not be “real men.” It was ugly. And luckily it was denounced by many, many people. But I think that attitude is more typical than we think. And it's a sign that we've not gone as far as we should in becoming an equal, open and trusting society.

For me, I really can't give you a date where some light dawned and I said, ‘Gee, this is important.’ I had a close friend, probably my closest friend in the world, who died from AIDS; this was in the 1970s. One member of my board of directors at the NAACP has AIDS. People I know in the world outside the NAACP have AIDS. And like everyone else I read the newspaper; I read the accounts of the rising death toll and the large numbers of women who now have this disease that we once thought was a man's disease. I mean, the evidence is all about us, and you'd have to be blind not to think this should be a major priority for many, many people.

I came up in the civil rights movement of the 1960s. Some of my civil rights companions were gay women, lesbians. They fought beside me. And I can't think of saying to them now, ‘Too bad, I don't care about you because of who you are.’ And I can't say to the larger number of straight people who have AIDS, ‘Too bad, I'm sorry.’ I'm not built that way. And the NAACP is not built that way. We have made a lifetime habit of standing up

for things that many people didn't think were right. Luckily, many people now do think what we stand for is right, but there're still people who do disagree. And I think there's always going to be some.

We are a civil rights organization. We're not a service provider. But when Katrina broke out we quickly responded, and did the things you would think only a Red Cross would do—and we did them very well. We spent a lot of money, and we raised a lot of money. So there are times when we know that service has to be part of our agenda. And that's the same with AIDS. We say to our local branches—there are 2,000 around the country—that you need to get engaged in this struggle.

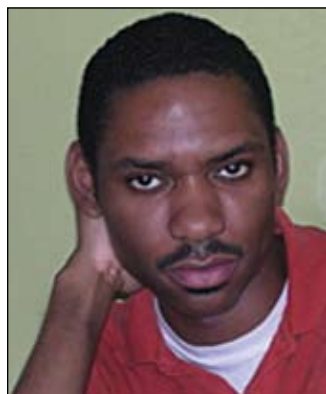
There are myriad things you can do. You can make sure that African Americans in your community have equal access to health clinics, to clinical trials, to all of the help that's available in your community. And if there's no health available, you can make sure that some becomes available, either through your private clinics or your public health department. You can fight against this homophobia—a terrible, terrible affliction in our community. I saw a study that said, among all Christians, African Americans register the highest level of homophobia. I hope that's not true. But if it is true, that's devastating, because we are the last people who should disparage other people—including ourselves. So, there are many, many things that individuals and groups like ours can do. But the most important thing is to have some consciousness that this is not a gay man's disease, it's not a white man's disease; it's our disease. And worldwide, it is afflicting more people that look like us than any other people.

—As told to Kai Wright

## Kenyon Farrow

### New York State Black Gay Network

### New York, New York



At age 31, I am one of the first generation of Black gay men who grew up in the time of HIV/AIDS. I have no recollection of the gay community or of sex with-

out the specter of AIDS. I do not remember a time when my Black gay body was not being associated with disease. As someone who has been an activist around LGBT youth issues, police brutality and “criminal justice” issues, I always have HIV/AIDS to contend with as a central issue to that work, simply because, as a Black gay man, it remains a constant theme in my personal biography.

As a child who always paid—perhaps a little too much—attention to the conversation of grown folks, I remember when Gay-Related Immunodeficiency Disease, or GRID, was named, and the conversations that circled around my family about its implications—conversations that only continued to incite fear and hysteria when GRID eventually gave way to Acquired Immune Deficiency Syndrome, or AIDS.

I remember my aunt getting sick in 1982. The doctors did not know what was happening to her. She died a few months later from a cancer now associated with AIDS, but because she wasn’t a gay man, doctors never thought to look for it. Perhaps because she was a poor Black woman with no health insurance, they had no will to look for it.

I remember growing up in the Cleveland, Ohio, A.M.E. church, where my great-uncle was the senior pastor. We had a gay choir director/organist, whose white lover came to church every Sunday, and sat in the first pew, as close to his lover as he could get without being on the organ bench. I remember the whispers of church sisters and brothers, who would be quietly alerting their neighbors as to which dishes were cooked by these men, so as to avoid AIDS by avoiding their dishes.

I remember my Uncle Roger, a good friend of the family. Roger hung out with my mother and my aunt, and would often stroll with them to the neighborhood bar at the other end of our housing project, in full drag. On Easter Sunday, 1986, when Roger’s brother found him dead in his apartment with five bullets in his body, friends and neighbors still found it in themselves to wonder if he had AIDS when he was killed. He did not.

I remember when Marlon Riggs’s film *Tongues Untied* aired on PBS my freshman year in high school. My mother made me and my two sisters sit down and watch it as a family. I was scared my mother knew something about me that I myself was terrified of, and it wasn’t until years later that I realized what an act of bravery that was on her part. We’ve talked about it since, and she did, in fact, know what she was doing.

I remember going to the hospital to donate blood for my father, who was dying from leukemia. We had never been close, but he asked me to live with him after I graduated from college until I got myself together. Four days after moving in, he was admitted to the hospital. Being a little naive, I decided to ask the nurse to “define sex,” since the form she gave me before drawing blood asked if I had had sex with a man since 1977 and, at that time (1997), I had only had oral sex. I was not allowed to donate blood and my father died three months later.

I remember friends testing positive and crying, screaming and laughing with them



through doctor's visits, hospital stays, and lovers—those who were understanding and those who acted cool, but stopped calling. I remember the confusion in their voices because a lover's response could not be gauged even if he himself were positive.

I remember every HIV test I have ever taken. I hate giving blood, and needles, and the waiting period—even the new 20-minute tests work my last nerve. I recognize that I ignore many other health issues I have. I am told that I should only worry about HIV. So diabetes, depression, or cancer—all of which run on both sides of the family—are almost non-issues for the Black gay man. As long as I “stay negative,” everything else be damned. Right?

I remember all these things, 25 years deep in the HIV epidemic. I continue to work with HIV in mind, sometimes directly confronting HIV in my work as an activist, community organizer and writer. Other times it is a part of the work I am doing, a contributing factor, but not the major player. But I am always committed to engaging it because I have to. It is part of my story. I cannot ignore it because it has not ignored me.

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## Tawain Kelly

### Benedict College Student Columbia, South Carolina

The fact is, the true face of HIV is not Ervin “Magic” Johnson.

It's my face. I can't afford my medicine; I can't pay for my hospital visits and everything that keeps me alive. I depend on organizations like the federal AIDS Drug Assistance Program, Medicare and all sorts of other government programs just to stay alive.

In the Black community, especially on a lot of campuses at historically Black col-

leges and universities, people still believe that Johnson is not HIV-positive, but he is. He is doing his part to stay alive.

So am I. There is no cure yet for AIDS. I know it will come one day, but until then, having the HIV virus is hell on earth: the crying, getting so sick until I can't move, the violent vomiting, the pills I have to take. The fact that my HIV is affecting my mom, my brother, my sister, my family, friends, my community and my little 8-year-old niece, who has to see her uncle slipping away, is almost unbearable at times.

HIV is a hard disease to manage and a hard one to see someone die of.

Four of my HIV-positive friends passed away last year, one from a simple eye infection. He slipped into a coma and two days later, he died. You start thinking about yourself when you are in a similar position, but life doesn't stop.

I tell myself that HIV can share my body, but it can't share my mind, my spirit, my hopes, my goals, my dream and my love.

The rate of HIV diagnoses has been dropping among Blacks over the past four years, but it remains alarmingly high, more than eight times the rate among whites, according to a U.S. government report.



I believe that the number of HIV/AIDS cases on historically Black campuses is much higher than generally thought, that some school officials may worry that re-

porting the actual number of people who are HIV-positive might lead to a drop in enrollment.

Some officials will not even admit that HIV exists on their campuses unless people

come forward, people like Jonathan Perry, a graduate of Johnson C. Smith University in Charlotte, N.C., who “came out” at his school, or others like myself, a student at Benedict College in Columbia, S.C., who came out to show the face of HIV.

I have chosen to stand on the shoulders of Black men and women who built this country: former slaves such as Nat Turner; heroes such as Booker T. Washington and Linda Brown, the little girl who became famous for fighting the Board of Education of Topeka, Kansas, and whose Supreme Court case, *Brown v. Board of Education*, helped all Black children get a better education. I stand with Ruby Bridges, who in 1960 became the first Black student to desegregate an elementary school. She had to be very brave to stand up to all the people who didn’t want her there. I admire Homer Plessey, who was arrested for being in the wrong part of the train. He fought against discrimination on trains in the famous Supreme Court case, *Plessey v. Ferguson*.

There were others such as Martin Luther King Jr., Rosa Parks and Malcolm X, and soldiers like Hydeia Broadbent, who was born with the virus but who has been a champion ever since in the fight against HIV/AIDS.

Their hopes and dreams will have been in vain if we don’t put a hold on HIV/AIDS in our communities. Until more people get tested and know their personal health status, the rates will continue to rise.

If no one tells you that your life is important, I am here to say it is. Without knowing you personally, I can say I love you and honestly care about your future.

Think about it: Would anyone tell you he or she is HIV-positive, just to be discriminated against and picked on at school? I didn’t ask for HIV to come into my life, but the sad part is I didn’t ask for it not to come into my life, either.

If it were true that you get HIV only through male-to-male sex, then I wouldn’t be HIV-positive. The woman who gave me the

virus in 1995 died before I found out I had it.

I found out in 1997. HIV can stay in your system for 10 to 20 years without being detected.

Last year, I went from 137 pounds to 62 pounds. I almost died. I had a mild stroke, went blind in my right eye and had feeding tubes inside me. I couldn’t walk. I was given intravenous tubes.

What I have that really matters is a college whose students, faculty and staff continue to pray for me. I have the prayers of my family, my church and positive people who circle around me and pray for my healing. I also have a praying mother. Never underestimate the prayers of a mother.

She told me that whether I live or die, everything will be all right. When I heard those words, I got it together. I buried the old me and celebrated the new one.

I will graduate from Benedict in May 2007, good Lord willing. HIV does not define me. We make choices every day on whether to go to class, what to wear and what to eat. How about making the choice to live and to be “Young, Black and Positive”? I have.

—*Reprinted from the Black College Wire*

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## Judith Dillard

### Community Activist Fort Worth, Texas

Let me tell you the story of a nice African American girl from Texas who didn’t think she could get HIV—but did.

It’s also the story of how she tried to kill herself over it. And it’s the story of how she found something to live for by fighting to stop the epidemic in her people—and by joining an amazing new AIDS activism movement called The Campaign to End AIDS.

Oh, by the way, it's my story.

My name is Judith Dillard. I'm 51 years old. I grew up in Abilene, Texas, in a close-knit family. Then I moved to L.A. with my husband. He worked for United Airlines and I was a sales associate for J.C. Penney in Culver City. But he left me for an ex-girlfriend.

I took it bad—but I reacted by finding a few boyfriends of my own. Of course, I didn't have safe sex with them. This was the 1980s—I thought HIV was something only gay white men got.

I needed back surgery in 1990, and the doctor told me that I'd need three pints of blood, but that I could use my own, so I went to the blood bank. Soon after, they let me know that I'd tested HIV-positive.

I was devastated. I thought I didn't know anything about the disease except that I was going to die. I couldn't deal with it and didn't want to tell anybody. So I did a complete about-face. I called work and told them I wouldn't be coming in anymore, left my whole apartment behind and got on a bus to downtown L.A. I checked into a cheap hotel and started smoking crack with people there. I just didn't want to live.

For seven years, I ran with homeless people and drug addicts on the streets of L.A.



I became one of them myself. Everybody I met would ask me, "What's someone like you doing down here?" Two years in, I confided to a girl that I had HIV—and she

told everybody on the streets.

Some folks treated me like I had the plague. I'm sure in that crowd, I wasn't the only one with HIV, but I was the only one who was out with it!

Occasionally I'd go to an AIDS agency, where they'd hook me up with a doctor and a supply of meds. I'd walk out of there and dump them in the garbage. I just didn't care.

Finally, in 1997, I got busted for crack possession. The judge said I could go to prison for three years or to drug rehab. I picked rehab, where they had a program that teaches you that drugs are just the surface problem of an underlying issue. For me, that issue was HIV. I looked forward to those classes every day. They made me accept that I had to learn to live with HIV and that drugs were not the answer. Now I've been clean for eight years.

After the rehab program, I went to a transitional housing program. That's where I decided to throw myself into HIV/AIDS activism. I got involved in L.A.'s planning council for the Ryan White CARE Act for treatment and services for people with HIV/AIDS, which decides how that money is spent in L.A. When I heard a well-paid "expert" say that one of the top three needs of women of color with HIV/AIDS in L.A. was pet care, it pissed me off.

I joined the Women's Caucus of HIV and AIDS, and together we made our real top priorities clear—housing, medical care, child care and transportation, thank you very much! Since then, I've worked as a benefits specialist, treatment educator and peer counselor for different AIDS services agencies in the L.A. area. I wanted to do as many things as possible to turn my life around.

I moved back to Texas after my dad died last year to be closer to my mom and family, but now I'm doing the most exciting AIDS activism of my life. I'm working on the Campaign to End AIDS.

C2EA is a nationwide coalition of people with HIV/AIDS and their supporters that formed early last year—thousands of us across the country, from gay white men in New York City and San Francisco who've survived the disease for 25 years to African Americans from all over the country—es-

pecially the deep South, where HIV/AIDS is hitting our people really hard. Right now, Black folks make up over half of all new infections in the U.S.—and I know most of my people can't afford to pay for HIV/AIDS meds and health care.

That's why I think HIV/AIDS has become a civil rights issue in the U.S. At the same time that the disease is hitting our people hard, our government is squeezing off funding for programs that keep us alive, like Medicaid and the AIDS Drug Assistance Program. One of C2EA's front-burner demands is full funding for programs like that—and not just for us African Americans, but for our brothers and sisters in Africa, who are dying left and right from this disease.

We also want the government to support HIV prevention based on science—like condoms and clean needles for drug addicts—instead of religious ideology, like abstinence-only sex ed classes. Our young people need to get all the facts if we're going to turn this epidemic around.

Ending the epidemic—for our people and for all people—won't be easy, but if we keep the faith and speak as one, we can make those in power take steps to lick AIDS. Take it from me—I know a little bit about beating the odds.

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## **Carolyn Puyol**

### **Community Activist**

### **Dallas, Texas**

I decided HIV needed to be part of my organizing work when my daughter contacted it back in 1990. She was 34 years old, and she died in 1996.

I assumed she was infected. She was on the drugs, and I took her to Parkland Hospital. They put her on the AZT. She did really

well for a while, by her being drug addicted, she went back to the drugs and by 1995 she became full-blown. By 1996, she decided she didn't want any more of the medication. From that point on, I decided to look into the cause of AIDS. I did a lot of reading up on it, and I talked with one my fellow nurses that I used to work with. He had it too and was doing a lot of research into it. I wanted to know what caused it. At the time, you heard all these alerts about the toilet seats and kissing, but I found a lot of that was myth.

I was doing the research while she was infected and at home. During her passing, I took off from work. I took all that time caring for her, with the help of my other kids and my sister. I took a month off and it was devastating. The following year, 1997, is when I started giving speeches. Different people from AIDS organizations would call me to speak to the youth or whoever. I also started selling insurance for the AIDS clients. I got in touch with a lot of them and met a lot of them. A lot of them became my godchildren. I explained to them about my daughter, shared how we celebrated her.

The first client I had an encounter with was Tina. Tina had full-blown AIDS. Her family didn't understand her. They pushed her away. Her skin had broken out. Tina got AIDS from her husband; he was what they call a "down low" brother. On his deathbed



he left her a letter, saying he had a lover and that he knew he was inflected. Tina had three teenage girls. She would say, "Why did he do that to me? He knows I had

to raise these three girls?"

I went to clinics and all the appointments

with her. I stuck by her and got attached. I became the mom; my sister, who works very closely with me, became the aunt. Tina got very attached to her. My children became her children's sisters and brother. We became the alternative family.

Her husband wrote a letter that said, "I'm sorry, but my best friend is my lover." If he had worn a condom, she would have become suspicious. After he was dead and buried and she got the letter, she was full-blown. He had someone mail the letter to her. At the time, Tina was married too. She met a guy who knew she was infected. He loved her right until the end. It got real bad. It was hard for him to accept that she was dying.

I just turned 65, but I feel like I just got started—if it wasn't for the grace of God—I believe it is my calling. Emotionally, a lot of time, I feel like it gets to me, but more and more it is what I have to give them. The only thing I have to give is love. When my daughter was on drugs, I would go into those broken-down buildings. I would say, "I love you, I love you." It was a strain.

When you have people to help you—like my sister, my husband—that helps. They create alternative families for some of the patients. Too often the patient's immediate family just doesn't understand that you can hug them and you can kiss them. Tina's grandmother wouldn't let her bring her a glass of water because she was afraid she would pass HIV on.

Before my daughter died, the Lord had me taking pictures of her from the time she was sick up until she took her last breath. I don't know when it started, maybe two or three years before her death. I started using them when I spoke about AIDS. That started with the youth in our church. I would show them the beginning when she was looking good with meat on her bones and until she got thin. I show the picture and see the reaction. They would cry and say, "I don't want that to happen to me." The pictures are not nice to look at.

Wherever the Lord leads and whatever chance I get, I want to be there to speak out. I get a rush from it. I can tell somebody else to love your people, to find out about the disease and just love them and take care of them.

—As told to Sharon Egiebor

# Voices We've Lost

## A Black AIDS Memorial

Tens of thousands of African Americans have died at the hands of HIV/AIDS in the last 25 years. They were our brothers and sisters, parents and children, neighbors and lovers. Some were public figures, others known only to those lives they touched. Too many of them died in silence, their struggles shrouded over by the paralyzing stigma of the disease. Others shouted from the rooftops to their dying end. All of their deaths were needless.

Here, the Black AIDS Institute names just 25 of those whose lives, and deaths, shaped the course of the Black epidemic—some deliberately, others inadvertently. These 25 names could and will be augmented by scores of other lost leaders, both national and local. Indeed, they mark merely the first entries in a memorial log of African Americans lost to AIDS that the Institute has begun to compile.



**JOSEPH HOLMES**

Dancer and choreographer  
died 1986







**MAX ROBINSON**

First Black network news anchor, ABC News  
1939—1988



**CRAIG HARRIS**

Writer and activist  
1958—1992



**ALVIN AILEY**

Dancer and choreographer  
1931—1989



**KATRINA HASLIP**

Prison AIDS activist  
1959—1992



**JOSEPH BEAM**

Writer and activist  
1954—1989



**ARTHUR ASHE**

Tennis legend  
1943—1993



**JAMES CLEVELAND**

Gospel singer  
1931—1991



**CLIFFORD RAWLINS**

AIDS activist  
1950—1993





**WILLIAM "BRANDY" MOORE**

AIDS activist  
died 1994



**ESSEX HEMPHILL**

Poet  
1956—1995



**MARLON RIGGS**

Filmmaker and activist  
1957—1994



**ERIC "EAZY E" WRIGHT**

Rap star  
1964—1995



**ASSOTTO SAINT**

Poet  
1957—1994



**NOVELLA DUDLEY**

AIDS activist  
1952—c. 1996



**GLENN BURKE**

Openly gay professional baseball player  
1952—1995



**PERRY WATKINS**

Soldier who fought ban on gays in military  
1949—1996





**REGGIE WILLIAMS**

Founder of early Black AIDS organization  
1951—1999



**CHARLES CLIFTON**

AIDS treatment activist and journalist  
died 2004



**RAYMOND DUMAS**

AIDS Activist  
1948—2000



**KEITH CYLAR**

AIDS activist  
1958—2004



**BELYNDA DUNN**

AIDS and Hep C treatment activist  
1951—2002



**GIGI NICKS**

AIDS activist  
1942—2004



**JOE BOSTIC**

Prison AIDS activist  
died 2004



**LEROY WHITFIELD**

AIDS journalist  
1969—2005



## CHAPTER THREE

# In the Arts

## Voices from the Creative World

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### Danny Glover

Actor, Activist

Los Angeles, California



I happen to be part of a generation that came up in San Francisco at an important time in the world. We saw ourselves as part of a community with a commitment

to ideas that would change the world. That resonated with me as a child and as a young student. I spent six years doing community development work in San Francisco. Those kinds of things you don't dismiss or put aside.

That history drives all of my activism. And it's certainly what drives my AIDS activism. When people hear about AIDS, a lot of them think of Africa. After all, the media has inundated us with photographs and stories of

AIDS orphans, mother to child transmission, the lack of access to drugs, the disproportionate number of persons infected by the HIV virus, and so on. All of this is true and we should continue to fight the AIDS pandemic in Africa, yet we need to realize that the AIDS epidemic is not over in America, and it is especially not over in Black America.

AIDS is the leading cause of death for Black women between the ages of 24 and 34 and continues to be a leading cause of death for Black men of all ages. Why aren't we alarmed? Why isn't the media reporting this and getting the word out so that we can protect ourselves?

People here and around the world think, based on what they hear from our government and the media, that the incidence of HIV and AIDS is considerably lower now than it was in the 1980s. That is true. But lowering HIV incidence and prevalence in some communities is not the same as ending the epidemic in all communities. Nearly half of the estimated 1.2 million people living with AIDS in America today are Black. Fifty-four percent of the new HIV infections in the United States are in Black communities. Yet, the silence is deafening.

We've got to work on the stigma. We cannot allow so-called "traditional values" to allow large segments of our communities to be marginalized. If we want to end the AIDS pandemic, either at home or abroad, we have to confront intolerance wherever we find it. If you open your heart, you open your mind. If you open your mind, you also open your heart.

I remember the day that my brother told me that he had AIDS. I was scared and angry. I was even speechless because I didn't know how I could comfort him. Although I had already lost countless friends to AIDS since the 1980s, there was nothing that could have prepared me to hear those words come out of his mouth.

My brother is not gay. I say that not because that would matter to me, but because in our community, we think AIDS is only a gay issue. This misperception has undermined our ability to adequately confront the disease in our communities. Black churches and traditional Black institutions stayed away from even talking about AIDS in the beginning. As a result, it spread like wildfire in our neighborhoods because of drug use, the lack of awareness, insufficient prevention efforts, and an absence of any mass Black mobilization. Today, AIDS in America is a Black disease, and everyone of us has been touched by it in some way. Even though it is a hard subject to bring up with family and friends, we need to talk about it with our children and with each other.

A lot of my AIDS work was born out of my work in Africa. The African AIDS pandemic is really a part of the larger systemic social and economic problems facing the planet. In some ways, the HIV/AIDS pandemic is showing us the ultimate result of sustained systemic poverty. If you don't have enough hospitals, you can't treat the numbers of people who come to you. If you don't have enough medical supplies or needles, you will use needles multiple times, increasing the

probability of HIV transmission. If the AIDS medications are not made in-country or the prices reduced to make them affordable, the cycle can only get worse.

Many Africans get that, and are taking action. One of the things we've sought to do with the UN campaigns I've worked on is to demonstrate what Africans are doing about the AIDS crisis. They are not sitting idly by. Whether at the local village level or as a part of the national plans, there are countless stories of Africans using whatever they have to fight this disease and to save themselves.

But where are our leaders in the United States? Where are our educators? Where are our ministers? We have to take control of our own lives, our own bodies. And we have to fight this pandemic from all sides. We have to get involved for ourselves and our children. That is why I'm involved and why I will be involved until the AIDS pandemic is over. If my visibility as an actor creates a kind of space where these kinds of discussions can be out on the table and other people can be part of that dialogue, so be it. That's what I'll lend my name to.

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## Sheryl Lee Ralph

Actress, Singer, Songwriter  
Los Angeles, California



In December of 1981, I opened on Broadway in what has become the iconic musical of the 1980s, *Dreamgirls*—also known as the Drag

Queens Review. For many reasons, it was the best and worst of times for me. The worst being when up and down the Great White Way—that's what they call Broadway; I have never liked that phrase, but that's a whole 'nother issue—gay men started dropping dead of some mystery disease. They would get sick one day and be dead the next. Then the whispering would start about the gay men's cancer, that gay disease.

Your friends took ill, and if they were lucky enough to have a home to return to they would quietly leave New York for parts unknown, like Kentucky, Kansas, Nebraska—back to places and people they had run away from. Many of them never came back. But if you were lucky, their people would sometimes send messages saying that they had died of pneumonia, cancer, bronchitis ... anything other than, shhhhhhhh, that gay disease.

The silence was the real killer.

I remember such an ugly time in America, when to be diagnosed with HIV/AIDS was an immediate death sentence, with the immediate knowledge that you would be ostracized and stigmatized. Such an ugly time when people disposed of their infected family members like garbage. When doctors and nurses refused care to those so obviously in need. When good Christian people found comfort in pointing fingers and passing judgment on others. Forgetting that bit of wisdom: "There but for the grace of God go I." Such an ugly time in America.

I remember when the mystery disease was called GRID, for Gay-Related Immuno-deficiency Disease, which eventually became HIV, for Human Immunodeficiency Virus. A big difference between the G and the H: "Gay" became "Human."

I remember around 1989, when I had lost another dear friend to this silent disease and had to cross their number out of my phone book. I realized then that I had to do more. I called up a few of my girlfriends and asked

them to lend their voice in song against this deadly disease. In 1990, "Divas Simply Singing!" was born. It's like no other show you've seen—the lights, the mic, and *divas* simply singing! For 15 consecutive years, the most talented women in the entertainment business (the divas) have come together to raise their voices in song and commitment to HIV/AIDS awareness and prevention.

Also in 1990, as a memorial to the many friends and family I had lost to HIV/AIDS, I created the Diva Foundation. A national not-for-profit charitable organization, the foundation focuses on generating resources and coordinating activities to create awareness of and combat against HIV/AIDS. The Diva Foundation utilizes music and entertainment as a vehicle to inform, educate and erase the stigma attached to this deadly disease.

After 25 years it is still hard to accept that there are so many people who don't remember those times, or who don't even know that HIV and AIDS are two very different things. You'd be surprised how many people don't know that HIV is the virus that causes AIDS. They don't know what it means. It means that you can be HIV-positive and not necessarily contract AIDS. It means you can be positive and be perfectly healthy.

Think 1991. Magic Johnson—not a gay man—announces he has the HIV virus, not the disease. But Magic looks so good, he can't have AIDS! He doesn't, he has the virus that causes AIDS. He also has access to platinum health care.

"Nearly 90 percent of the people who take the powerful drugs within a few months of being diagnosed HIV-positive have undetectable levels similar to Johnson's condition," said Dr. Jeffrey Laurence, an AIDS researcher at Cornell Medical Center and a consultant to the American Foundation for AIDS Research.

The messed-up part is that most people with HIV don't tell people they have HIV because they don't know they have it. They have no access to healthcare of any kind, so



by the time they get any help and start taking any drugs, HIV has become AIDS.

Rap star Eazy-E, for instance, died of AIDS; not the virus, the disease. An article in the *Washington Post* of March 27, 1995 written after he passed away, stated that rapper Eazy E, whose real name was Eric Wright, died on Sunday from AIDS-related complications at the age of 31. Wright's pioneering "gangsta" rap group N.W.A. helped bring inner-city rap to the suburbs. In announcing that he had AIDS on March 16, Wright said he did not know how he got the disease, but that he wanted to warn his friends and their families. "I've learned in the last week that this thing is real and it doesn't discriminate," Wright said in a statement. With HIV and care you can manage a life; with final-stage AIDS and no care you die.

Eight years later, in the summer of 2003, my friend, Phill Wilson, founder of the Black AIDS Institute, called me and asked me to accompany him on some speaking dates across the country to talk about HIV/AIDS in a few cities that don't usually make front-page AIDS stories—especially not the rising infection rate in Black American women. That summer I heard so many stories from so many well-kept, otherwise silent women infected and affected by HIV/AIDS. It became obvious to me that with the growing rate of infection in women, soon the burden of HIV/AIDS would be borne by women—and that upset me since life is usually born of women. Life!

I have always felt that if sex could be death for men, then women couldn't be far behind. With women come children. There is a natural connection between us men and women, male and female. I may not be your lover, but I am definitely your mother, and we are now all in this AIDS thing together.

Recently, I wrote a one-woman show, *Sometimes I Cry*, to tell my sisters' AIDS stories. I wrote it because it seemed that the rebel voices that dared to speak up and act

out in the 1980s, demanding help, are silent now, particularly as it pertains to Black women. So I had to use my voice to speak up, out and loud!

AIDS! Twenty five years old and growing strong!

It didn't have to get like this.

Jeremiah 8:14-22: *Why do we sit still? assemble yourselves, and let us enter into the defenced cities, and let us be silent there: We looked for peace, but no good came; and for a time of health, and behold trouble! When I would comfort myself against sorrow, my heart is faint in me. Behold the voice of the cry of the daughter of my people because of them that dwell in a far country: Is not the LORD in Zion? is not her king in her? The harvest is past, the summer is ended, and we are not saved. For the hurt of the daughter of my people am I hurt; I am Black; astonishment hath taken hold on me. Is there no balm in Gilead; is there no physician there? Why then is not the health of the daughter of my people recovered?*

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## Patrick-Ian Polk

### Producer, Director, Writer

### Los Angeles, California



I'm the creator and executive producer of *Noah's Arc*, a television show about Black gay men in Los Angeles. I saw a lack of representation of gay people of color

in entertainment media, and being a Black gay man, that's an area that interested me. So

I just stopped waiting around for Hollywood to decide to really portray our community and tried to make a series on my own terms that explores who we are as Black gay men.

It's an obvious thing that HIV is an important subject when you're talking about the Black gay community. And I knew it was something I wanted to address in some way. I had done a movie a few years before called *Punks*, where we dealt with it. One of the lead characters was HIV-positive and was dealing with it. Another character was dealing with getting tested and going to a clinic to get counseling about it.

So it's been something that's been on my mind and in my work for a while. And as the epidemic continues to be such a huge problem, with the numbers we've heard over the last few years, I wanted to find a very organic and interesting way to incorporate HIV information and messages into *Noah's Arc*, without being too preachy or melodramatic. So rather than even having a lead character who was HIV-positive, I decided to have a character who worked in the field of HIV prevention and treatment.

The basic idea I modeled, really, after Phill Wilson and the Black AIDS Institute. One of the main characters, Alex, is working for a more mainstream gay health organization and trying unorthodox ways of getting the messages out there to gay people of color. But his methods are met with resistance from the powers-that-be within this organization, who are trying to toe the line of the conservative administration. And so, frustrated with that experience, he quits his job and opens his own organization called the Black AIDS Institute. And we see the organization from the beginning—when it's just a dilapidated storefront with rats. He enlists the help of his friends to spruce it up and decorate and help to raise money. And then it's a fully operational clinic, that's offering free STD screenings and counseling and advice.

And Alex has a doctor character whom

we introduce later in the season, who helps facilitate the medical aspects of the clinic's business. And the doctor ends up in a relationship with one of the other main characters, Ricky. But it turns out that the doctor is HIV-positive himself. So, that was a way to weave in the issue of dating someone who is HIV-positive.

So my task was to find interesting ways to layer in HIV, so that it's not just about getting sick and dying. It's about living with it and dating with it, and dealing with the health system and the medical system and all these things. It's a hugely complicated issue to deal with, and I wanted to explore that in the show. In the past, HIV/AIDS in film and television has been this melodramatic, death sentence story line. It's always this tragic character who's going to die; we've seen it time and time again. Now, because we've had the medical advancements that we've had, it's become for many people, who have access to regular health care and follow the treatment regimens, largely a manageable condition. So I really wanted to show that, because we haven't seen a lot of that.

Any time you can create characters that an audience can relate to and care about in other ways, weaving in story lines about HIV can only be more affective. When you feel like you know someone or you can relate to someone, and you're suddenly going through something serious with them, then it means more to us as viewers. So that's what's nice about being able to weave story lines into a television series. It's not just about the fact that they're HIV-positive or that they're working on HIV; it's about so much more. And the person who felt like, "Oh, I could never date someone who's HIV-positive," when they see Ricky on the show dealing with this situation and falling in love, trying to decide if he can go out with this person he loves but who has HIV—it opens the viewers' minds too. They might change their minds about it and maybe they can date someone

with HIV. Or someone who's HIV-positive might get the message that, "You know, life is not over for me and I can still have a career and have relationships and be healthy and happy."

I'm always concerned about being too heavy-handed or being preachy. But I think as long as story lines are presented in a realistic and interesting way, in a way that we don't expect, then we avoid the dangers of people being turned off. It's only when people feel like they're being preached to or talked down to that they get turned off. The trick is not to deal with this like an after-school special, but to treat it in a very realistic way.

—As told to Kai Wright

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## Gordon Chambers

### Songwriter, Producer, Singer Brooklyn, New York



I've just released an album. It's called, "Introducing Gordon Chambers." It's a mature R&B album, and it's an album about love. After having written for over 70

recording artists, I just wanted to explore my own singing voice, and put together a suite of songs that I thought spoke to people's yearning for love.

As a child I was always writing songs. The first song I wrote, I was like 9 or 10. I had dreamed of writing a song for Gladys Knight, because I grew up in a family with a lot of Gladys fans. And so eventually I did write for Gladys and for Chaka and Whitney

and Aretha and the many artists that I grew up idolizing. And I also wrote for a lot of new artists that went on to become platinum, like Beyoncé and Usher, Angie Stone and Carl Thomas. So I've been gratified by my career, because I feel like I've been part of both the best of what I was inspired by growing up and the best of my contemporaries.

I think that the music industry is kind of a trendy industry. And I think at some point during the 1990s, AIDS activism sort of became a trendy thing, and the AIDS benefit became the thing to go to. But who knows where it is right now. I was just in South Africa, and to learn about the HIV statistics in South Africa was really frightening. So I think that Black America needs to get into the global conversation about AIDS. The conversation needs to be globalized.

I'm not sure what the recording industry can do to make that happen. There're the obvious things like charity performances and recordings—we've seen how that machinery can work with other issues. But I think the entertainment industry needs to make AIDS sexy again, and I don't think it's particularly sexy right now. I mean, I don't think Americans are thinking about anything particularly deep right now. We have a completely unjust war and people are not revolting. People are just deadened, thinking about fashion and what's cool and iPods and middle-class euphoria. So I think, if you can't beat 'em then join 'em. The AIDS and HIV statistics need to be reframed in this new technological, fashion-driven world.

Is it something I'm thinking about every single day: oh, what can I do about AIDS today? No. It's not on my mind like that. I don't have any friends who are dying in the hospital. I have certainly known people who have died of AIDS—who hasn't? But it hasn't hit home like that in my lifetime, thank God. I think I've been pretty blessed. But I'm certainly down to participate as a creative person. That's what wakes me up every morning.

I'm at a time in my life where I really just love to sing. I'm an artist; I love to express myself.

I often think about that when remembering the one close friend who has died. He got ill and called me one day to say that he was in the hospital. I hadn't heard from him in months, but he called to say he was in the hospital. He didn't say what was going on, but I kind of found out. And so I and two other friends of his said we were going to visit him. And we called on such and such a day and said we were going to visit, but then he got all pissed and said don't come. So we said maybe we should just let it go. Well, he died two months after that. And, of course, I had gotten busy and I didn't think he was going to die. I was thinking he'll get better and get over this temper tantrum and we'll move on. When he passed, you know, the feelings of guilt came over my mind: should I have gone to visit? I didn't like that the last conversation we had was a spat.

Well, there was a song that I had written called "Touched by an Angel" that I had tried to write for Anita Baker, but to this day, the song hasn't been published. But Billy Porter actually sang the demo of it, and the demo was wonderful because Billy Porter is an amazing singer. My friend used to just love that song! Every time we'd get together he would say, "Can you play 'Touched by an Angel'?"

About two months after he passed, he was buried in North Carolina, where he's from. You know, there's always so much silence around people when they die of this illness. They go home and they're buried by their families—families that they don't know and that don't know them. That's the way it goes unfortunately, because there's so much silence around it. So a couple of months after he passed, one of his other friends called me and said, "We're doing a memorial, would you like to come?" I met different friends of his whom I had never met, because they were friends from different times of his life. And they were wonderful people. We gathered and

held hands in a circle. Some said, "Gordon, Steve asked if this moment ever came that you would sing 'Touched by an Angel'?"

I was in shock, because I had not remembered that he really loved that song. And so I sang, and everybody was in a circle singing along. And I was like, "How do you all know that song?" They said because when he was in the hospital, that's the song he just played over and over again. So now when I think of that song I think of him. And I'm still determined to get that song published.

I think the moral of this story is life is a gift, and as one who believes in God, I believe that God grants us all very special gifts that make the universe a more harmonious place. It can be a carpenter who has an eye to build homes. It could be a fashion designer who has a way with a needle and thread. It could be someone who hears melodies dancing in their head and can go to a piano and create a song. We all never know how long we have and as long as we're here on earth, we should just utilize those gifts from God to add a little more beauty to the world. That's what I dedicate my life to every day.

So I live my life trying to create and spread love.

—As told to Kai Wright

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## Michelle Lynne Coons

### Filmmaker

### Los Angeles, California

*Let's Talk* is the name of my short film. And it's basically about a sista and a brotha who have been dating each other, and they're starting to feel that sexual tension and are ready to move to the next level. So the sister in the film, Essence, decides to take Maurice away for the weekend. She wants the timing to be right to ask him to go to get HIV tested.

When she brings up the topic, he's kind of shocked, because they've discussed this before. He's been tested and she's been tested, but she wants them to go get tested together. And her whole point is, the only person who you know what they're doing 24 hours a day is you.

So it's trying to get people to think about not just taking other people's word for it. We love other people, and I'm a big advocate of love and loving others. But you need to advocate for yourself as well, and feel comfortable with that. So it was very important for me to select a sister to play this role who was very comfortable with herself and with her sexuality, because that was the character I needed her to portray. For some people it can be a very difficult topic to talk about. But I wanted to show people how easy it can be.

I had actually written a script a while back that was a feature—which I didn't complete—about a sister who becomes HIV infected. But *Let's Talk* comes from the fact that I consider myself pretty conscious and pretty safe, and I always ask men that I'm dating if they've been HIV tested, but I hadn't gone with someone to the clinic to get tested together. A lot of people don't even know you can do that. In writing the script I started doing research, calling around to see what clinics do offer this. And it isn't offered ev-



everywhere, and is new to some clinics and places. So it was a really interesting journey.

For me, it is important to be authentic as a filmmaker and a storyteller. I asked myself,

"How am I going to be advocating for people to do this and I haven't done it myself?" So I went with my current boyfriend and we went

to this place called THE Clinic, here in Los Angeles. We went down there and we were tested by this brother who was just an everyday brother from around the way. He looked like Ice Cube or something. And it was nothing like what we perceive HIV testing to be a lot of times. So I really wanted to portray that in the film. And you'd be surprised how many people react to that scene: Wow, it's really that easy? Wow, you can really test orally? So that was really important for me.

When I wrote the other script a while back, what prompted me was just that people are suffering. We are all connected, and what affects my brother and sister across the seas or next door, it's going to affect me too. A lot of people, especially in the African American community, think this disease looks like something—looks white, or looks gay, or something else. And I really wanted to show how beautiful you could be—the lead character in that film had only slept with one person, wasn't promiscuous. I wanted to relate with that film that there's no look to this, and that you can just have sex one or two times and get this disease.

I am also a teacher and am in graduate school, getting my Masters in Education. When I was going back to get my Masters, my sister was like, 'Why don't you focus on film?' But my whole thing is it's all connected. My only purpose in life is to send love and positive energy into the world. And whether I do that in a conversation one on one, or doing spoken word poetry, or in a classroom teaching or filmmaking, the only purpose is to send some positive love and energy. And if I can inspire others along the way, then that's wonderful.

—As told to Kai Wright

## CHAPTER FOUR

# In the Capital

## Voices from the Political Arena

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### Congresswoman Maxine Waters

U.S. House of  
Representatives  
Los Angeles, California



I started working on AIDS in the 1980s. I was elected to office in 1990, and I've been working on this prior to coming to Congress, since sometime in the late 1980s. I was

a member of the California State Assembly. I was approached by a minister, Rev. Carl Bean. He first approached me because he was trying to collect some money to start a national program. I was instrumental in helping to get a donation from a group I was associated

with, called the Black Women's Forum. And I talked with some other 501(c)(3)s at the time about contributing and giving him some support.

The defining moment was when they put on a fundraiser and asked me to come to a place called Catch One. Catch One was a bar frequented by gays and lesbians on Pico Boulevard in Los Angeles. And they did this fundraiser in the yard of the bar on a Saturday. I saw all of these young Black men who were mostly gay and already infected. And I heard the stories at that time and they told me that they didn't have any place to live and that their families had disowned them. It was a time when people were ignorant of AIDS and their families didn't support them. They were afraid of AIDS.

It was a riveting experience that brought me face-to-face with the real devastation of HIV and AIDS. Not only were their health conditions absolutely devastated, their entire lives were too—no place to live, no income, no program that was connecting them to health care services. We had a community that had fallen far behind the gay community in addressing this issue. They needed help.



They desperately needed help. The Black community was slow, the public policy makers were slow, the ministers and churches were absolutely uninvolved at that time. I was originally attacked by Black ministers. Basically, what one minister said was that these were people who were involved in drugs and that I was involved with drug addicts and drug dealers. Then we would hear rumblings about sinners and God's wrath taking place on sinners and all that kind of stuff.

But I fight on cutting-edge issues for my community and for my people. I am never deterred by attacks or threats. I just don't get intimidated if it is the right thing to do. It was obvious that people were dying, people were affected and lives were being destroyed, and that public policy-makers obviously needed to address these issues.

So I decided that I would make AIDS a priority, as a public policy-maker. I became the point person in the California State Assembly who fought for funding. It has been a constant struggle fighting for funding, both with the State of California and the country, to make sure we get the money and get it where it needs to go.

When I came to Congress, I held the first meeting about AIDS at the Capitol—the first among the Black elected officials, the Congressional Black Caucus. Then I went on to become the chair of the Congressional Black Caucus by 1998. And there was a meeting held here in the capital that was sponsored by the Health Brain Trust of the Congressional Black Caucus. I attended that meeting. It was focused on the HIV/AIDS crisis in the minority community, particularly in the Black community. There was a speech given by Dr. Benny Primm, who is a leader in the HIV/AIDS community out of New York. He said it was of epidemic proportion and there should be a state of emergency declared in the African American community.

I took that up as a priority for the Congressional Black Caucus, because I was the

chair then. We met with Donna Shalala, Secretary of Health and Human services, and I asked her point blank if she thought the situation was in a state of an emergency in the Black community, if it had gotten to that point. She hesitated, and then said yes. So I called on her to declare a public health emergency around the HIV/AIDS crisis in the minority community. That is when it got extremely political.

We had to do a lot of work to try to get an emergency declared. I took the CBC members, all of us, to Baltimore on a tour to look at the high incidence of HIV/AIDS among African Americans. We visited HIV/AIDS programs at Johns Hopkins; we visited a syringe exchange program and a program that was targeted at African American women. Also during that time, there was a Harvard scholar named Mario Cooper, who published a kind of editorial and said that the CBC members were not doing enough to address the HIV/AIDS epidemic among Blacks. That too was a defining moment, because I thought we were doing everything we could. But the perception out there was that we were not doing enough.

We brought 20 AIDS activists from all over the country and met with Congressman Louis Stokes, the senior member of the Congressional Black Caucus with a high-ranking position on the Appropriations Committee. I met with him and again with Secretary Shalala. The Clinton administration wanted to respond to our request, but in terms of legal language, when you declare a public health emergency, it required a lot of other stuff. It required a lot of data and a lot of legal hoops that you had to jump through.

Dr. Shalala and the Clinton administration agreed that we needed to have additional money to address the crisis, even if we didn't have everything required to declare an emergency. On Oct. 28, 1998, the CBC held a press event and we rolled out the Minority AIDS Initiative. The event featured the participa-

tion of President Clinton, Secretary Shalala, Congressman Stokes, Congresswoman Donna Christian Christianson (who was our Brain Trust Chair; she is a physician who is a member of Congress), myself and representatives of AIDS organizations from all over the country.

What we had accomplished was a Minority AIDS Initiative that received \$156 million (money above and beyond Ryan White, particularly for minority AIDS), and that grant was to provide grants to community-based organizations and health care providers serving African American, Hispanic, Asian and Native American communities. Basically, the idea was to enable health care providers serving minority communities to expand their capacities to deliver culturally- and linguistically-appropriate care and services.

The appropriation grew each year thereafter. But now what is happening is this administration has leveled off this funding. For 2005 and 2006 we are at about \$399 million. They call this “level-funding.”

As of May 1, 2006, I have requested \$610 million for the Minority AIDS Initiative. I’ve got a record 119 members who have signed my letters requesting increased funding. We’re still trying to build capacity in the minority community. We still need to do a lot more work in terms of designing how the money is spent in the minority community. We need more money. It has been disappointing that whatever we have done has not been good enough: The infections rates are much too high. African American women are close to 70 percent of all new AIDS cases.

So we have to continue to fight for money for outreach and education, and we’re going to have to examine all of the strategies that have been used to deal with this issue. I think the African American community is going to have to step back from some of the older strategies and come up with new strategies.

—As told to Sharon Egiebor

## Rep. Constance A. Howard

### Illinois General Assembly Chicago, Illinois



I represent the 34th District of Illinois, with 105,000 people. But when it comes to certain kinds of issues, I’ve taken over trying to represent the entire state, especially

in the African American community. Several years ago, I began to notice how people in my community were being extraordinarily impacted by HIV. I was beginning to see that other groups were coming to grips with the problem, but in the communities that I represent, this was not happening. So, as a person who tries to solve problems, I began to see the need to solve this problem.

Early on I began to hear things, and I was invited to some conferences. At one of them, we were told that HIV was beginning to devastate the Black community, especially Black women, and we became alarmed about it. I had also been involved in Congressional Black Caucus events. I would hear people talk about what was happening to our community, and I didn’t really see the sort of effort that I thought should be going into trying to solve this, or at least getting a handle on it for our community. So, I began to talk to people and tried to reach out for some help.

We began to work on a number of things that we thought would help—sort of very simplistic things like having a seminar or bringing people together, telling them which end is up and hoping that they would then

pass the word. Well, those things that we thought were going to do the job just did not. We invited people to come to these seminars and workshops, and had more people making presentations than coming to get the information. I began to say this is not working and we need to figure out some other kinds of ways.

Lloyd Kelly, director of the Let's Talk, Let's Test Foundation, came to me early on and said, "I want to help you with this." So I made him my point person, who would help me, because I am not someone who has all of the knowledge about the intricacies of what AIDS is all about. But Lloyd was someone who had all the knowledge. So I became the facilitator for the kinds of things that he believed we could do. And we began to work on making sure that more people knew what was negatively impacting our community, including the establishment of an annual walk.

The African American HIV/AIDS I Need You to Survive Walk takes place every year in May; this year is our fourth. And we walk throughout the communities—the south and west side of Chicago—and we try to get people to come and help us raise funds and make people aware. We start at one park, march five miles, and arrive at the second park, where we have entertainment, testing and literature. We also get the participation of celebrities who draw attention and help us get our message out.

We've also, as part of the Let's Talk, Let's Test Foundation, established at Chicago State University an institute for doing research and policy study. It's the African American HIV/AIDS Policy Institute. We are trying to figure out how it is that we can say what's necessary—do what's necessary—to make sure our people understand it. We are operating from the premise that HIV is totally preventable; it's a matter of people knowing better so they can do better.

We're also sponsoring legislation. Lloyd generally is the idea person—the person who

does all the brainstorming about the kinds of legislation that we should pursue. The first piece of legislation that we were successful in getting signed last year is the African American HIV/AIDS Response Act, which lets the state of Illinois recognize that AIDS in the African American community is something that's distinct from the overall problem. In our state, we always point out that 13 percent of the population is African American but a larger percentage of those who have the disease and of new cases are from our community.

One of the things we've tried to do with our studies at Chicago State is to determine if there really is a correlation between the numbers of our people who are imprisoned and the high incidence of HIV in the community. One of the things we tried to do with our legislation was to have condoms distributed in prisons. But that was knocked down because they say having sex in the prisons is illegal, therefore they cannot be given condoms there. The powers-that-be that run the corrections system just insisted that they cannot allow us to talk about having condoms distributed, because they believe that you're not supposed to have sex in prison. And while we know that there is sex going on, they didn't want to admit to that. So we couldn't get them to understand. But we're going to continue to try to push that. There are ways that you can check to make sure that condoms can't be used to bring things into the facilities that shouldn't be there. There is a way that can be done and we're going to continue to pursue that.

In all of this, I've never had any kind of problem getting the Illinois legislative Black Caucus to understand the need, because they represent the same kinds of communities that I represent. But even when we stand shoulder to shoulder, we cannot represent the votes that are necessary for anything to pass. So it is incumbent upon us to go to our colleagues and try to convince them. There's been a lot

of horse trading, so that finally we were able to get the Response Act passed and signed by the governor.

Now, this year, we wanted to go a little further and we are now waiting for the governor to sign the response fund. Because we know that anything that we want to have done must have some kind of dollar amount attached to it. We got substantial support. Now we are waiting for the governor to sign it.

I think that if you talked to my colleagues, they would say that Connie Howard has three passions. One of them is helping ex-offenders get a second chance. Two is trying to eliminate the digital divide. And, of course, there's HIV/AIDS in the African American community. So they know when somebody says HIV, they point to me. I do other things as well—people come to me from the other side of the aisle, and regarding all kinds of issues. But they know that this is the kind of thing that they can always look to me for. I'm willing to do whatever I can to help all of the segments of the HIV community. I don't have any reservations. I ask the question, and if you say no I'll try to give you a few minutes to breathe and then I'll come back.

And certainly we have had difficulties in trying to convince some in our own community. There was a point when the faith-based community was completely uninterested. They wanted to talk about the sins and gays and etc, etc. So we've had to get by that. But what people are seeing now is it's not just the gay community that's being impacted by this. Women are dying. And at some point they had to begin to raise the question that perhaps we need to make sure that we're part of the solution.

—As told to Kai Wright

## Mayor Ron Oden

### Palm Springs, California



I am in the third year of my four-year term as a directly-elected mayor, and I've been an elected official for 11 years. So prior to becoming the mayor, I

was a council member for eight years. And I announced in March my candidacy for California State Assembly 80th district.

But before all of this I was in the ministry. In 1978, I entered the ministry, and was ordained in 1981. Shortly after my ordination, I started receiving calls asking me to go and visit men who were ill and who wanted someone to administer last rites or pray with them. They would call me because I was on the chaplain's list for most of the hospitals. And I began to ask, "Why aren't the other ministers going?" And there was a lot of mystery surrounding the illness of these men. It wasn't until a few years later that they actually put a name on this mysterious gay plague. So even before I understood it, I found myself in my active pastorate trying to address this unknown issue.

It wasn't until the mid-1980s that a friend of mine became ill. I was living in New York and he was living in California. But during my college days and early days of experimentation, we were good friends—and I should say that would be sexual-orientation experimentation. He was a married man, had several children, and we were just the best of friends before I went into the ministry. His name was Jesse, and Jesse had more personality in his baby finger than most people had

in their whole bodies. Jesse could walk into a room and just light it up. And even though we were separated by distance, there was still a thread that connected us. We were never intimate, just friends.

A few years later, I remember he got all these rare problems. No one ever said what was wrong until he was dying. I had just moved back to California and I got a call from my family that said Jesse had passed away, and I think it was my mother who said he died of AIDS. It just broke my heart, because I loved him so much. And my life was so different at the time—it bothered me that I didn't know who he talked to, who assisted him through that period of darkness in his life. And I wondered about that experience for a man who brought so much life and energy and beauty in the lives of other people. It had a profound effect on me.

At that time, I had gone back to school and did not go back into the active pastorate. Shortly after that, I went through a divorce and, after a few years of introspection, my sexual orientation changed. After my divorce, I ended up involved with guys and eventually came out as gay—but that's my personal story.

As a political advocate, it was important to me to do everything that I could. In my community we have the Desert AIDS Project—a service-oriented program that assists people with medical care for HIV and AIDS. I think we have some of the best medical care here. I think by concentration, we probably have one of the highest concentrations of people living with HIV and AIDS in the state here in Palm Springs, primarily because by percentage we're probably the gayest city in America. At least a third of our population is identified as same-sex household or same-gender-loving people. So politically it is a must that we address this issue, because a significant portion of my constituency is affected by HIV and AIDS. But this is a burden that's placed upon my heart. So no matter

where I go, or what I do, it's a part of my life.

—As told to Kai Wright

## Rep. Laura Hall

### Alabama General Assembly Montgomery, Alabama



I was elected in 1993, and I'm 62 years old now. But I'm planning on being around in the general assembly for a while. I really do enjoy it, and want to believe

that I make a difference.

My son was diagnosed in 1988. My husband and I suspected something, because he could never get rid of this cough. Eventually we got him to go to the doctor one day. He was 22 at the time—he died at 25. We got the results the Monday after the Sunday we had buried my dad, and he was here visiting. We tried to talk about it, but he just said, "I don't care what you do. I don't want to talk about it anymore. As a matter a fact, I'm not even going home with you guys. I'm going back to Atlanta." He went through some difficult times after that. He started using drugs, and doing so many things out of character for himself.

We kept it a secret for a long time. But when they finally told everyone, it was heart-warming. My uncle's statement was, "You know, we're family, and families stick together. Families just don't leave each other." So it was heart-warming to have that response. But meanwhile, in his own family, his son was dealing with the same disease. And his sister,



she didn't know her son was also dealing with the same disease. So over a period of three years, we had three deaths, and none of us had talked about it. I'm sad to say, not enough has changed today, because I am very suspicious of another little cousin's condition.

By the time of my son's death, though, he had come to insist on openness about his infection. He insisted on an open casket and he made a tape that he asked us to play.

In that tape, he asked everybody who was there to put whatever they had in their pockets in a basket, because a collection was being made to give to an AIDS agency. He really taught us how to die with dignity.

There's a lot of work still to be done in our Black community here in Alabama. We're more sensitive to the fact of AIDS's existence, and we're willing to discuss it. But there's nobody out there saying, "Oh, we need to rally around this." There's still that fear factor—the fear of being ostracized. It's difficult. I lived through that fear, so I guess I want to think that 13 years later we wouldn't have to deal with that. But it is so overbearing. People who are where we were in our family are always worried about what people are going to think. If they are going to be there for you. I have a god-child who is HIV-positive; I know only because her mother has told me. She's 25. Now, we've been in several settings where I have gone in thinking she would say something to me. Nope. She has not shared; not one time.

So I make sure that I deal with this issue in my role as an elected official. I talk about it whenever I can, and I try to bring my colleagues together to pass legislation that combats this epidemic. In my last election, Republicans even charged that's all I do, is talk about AIDS. I said I make no apologies for my position. And if you choose not to elect me because I'm very outspoken and upfront about this disease that has impacted my family, then so be it. That means I'll spend 100 percent of my time working on this issue.

Never heard another word.

—As told to Kai Wright

## Honorable Marilyn Mackel

### Superior Court Los Angeles, California



Why get involved in HIV/AIDS work? But for the grace of God, there go I.

The question ought to be: How can any "professional" be uninvolved in

supporting the work of AIDS activists?

We in the African American community lost thousands of young men and women to the fiasco of the Vietnam War; we annually loose thousands more to addictions, mental illness, and the multiple other malaises that can appropriately be called "post-traumatic slavery disorder." Now, we have lost and continue to lose some of our greatest artists, athletes and performers to the HIV/AIDS epidemic—Rev. James Cleveland, Alvin Ailey, Essex Hemphill, Arthur Ashe and Max Robinson—to name just a few. These lost voices represent open holes in our community's heart and create imbalances in our social order, because the intergenerational continuity of excellence—of mentoring for the artist, and particularly of the artist-activist—is broken.

Now we face the loss of millions more on the African continent. What does that mean for a planet of humans, generally, and for people of color specifically? Africa has al-



ready lost too much of its intellectual wealth to colonial strife and its aftermath. The continent has lost, and continues to lose its populations, cultures, and its natural resources to the ravages of outright theft, chemical warfare, and the civil strife and genocide that imperialism has left behind. It can ill afford to lose yet another generation to AIDS.

And so, we must be involved. If one cannot count on the so-called “professional” to support those who do the day-to-day work of combating AIDS, we are in trouble. Education and information are needed to awaken this professional class to the mounting crisis. There is no single professional—whether in business, the arts, politics or any other field—who can afford to be uninvolved in supporting HIV/AIDS work. If there are those who do shirk this responsibility, as a community we must “out” their failures.

In electoral politics, we must ask our representatives what they are doing to fight AIDS—and vote them out of office if we are not satisfied with the answer. When recommending professionals to others, and when seeking the professional services of another, the first question ought to be: What non-profit work do you support with your treasures? If you are not satisfied with the answer, move on!

There are things in life that we simply cannot afford to sit back and say, “Let others deal with it.” HIV/AIDS is one such reality, which must be tackled with the commitment of every professional everywhere—doing so is what makes us so-called “professionals.” We can and must be present, and our presence can take many different forms. To whom much is given, much is expected.

## CHAPTER FIVE

# In the Press

## Voices from the News Media

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### Debra L. Lee

**Chairman and CEO  
BET Holdings, Inc.  
New York, New York**



*"Our lives begin  
to end the day  
we become silent  
about things  
that matter."*

—Rev. Martin  
Luther King, Jr.

Silence has been a deadly weapon in the spread of the HIV/AIDS epidemic in the African American community. Since 1998, BET has worked to be an active and vocal partner in the fight against this disease.

Statistics show that over half (53 percent) of Black adults get information about HIV/AIDS from the media—including radio, TV and newspapers. Only 15 percent said

they got information from friends and family and only 14 percent said they had received information about HIV/AIDS from their doctor. For African American youth the role of media is even stronger, with 79 percent of African Americans aged 16-24 saying they get their information about HIV/AIDS from TV, magazines and websites.

The media's potential to reach millions of people on a daily basis puts it in a very powerful position to raise awareness. That's where networks like BET come in.

I am extremely proud of the contributions that BET has made to the fight against HIV/AIDS through our Rap It Up campaign. Rap It Up, a partnership with the Kaiser Family Foundation, is an extensive public education campaign that seeks to inform young people about sexual health issues, including HIV/AIDS and other sexually transmitted diseases.

Since the launch of the campaign, BET has produced a total of 24 different full-length specials covering issues ranging from sexual identity to HIV testing and relationships and over 75 PSAs thousands of times. In 2004, BET, in conjunction with the Black

AIDS Institute, introduced its Rap It Up/Black AIDS Short Subject Film competition, a screenplay competition for aspiring writers. This year BET teamed up with Scenarios USA to create a scriptwriting competition for 13- to 18-year-olds, asking contestants to describe what it has been like growing up in the age of AIDS.

Each year, BET and Kaiser develop a set of new public service announcements regarding sexual health information to reach BET viewers. These messages are meant to inform viewers of the risks of HIV, encourage safe sex practices and testing. To date, a total of 45 PSAs have aired on BET. Each PSA and on-air program is tagged with a toll-free hotline number (866-RAPITUP) and website ([www.rap-it-up.com](http://www.rap-it-up.com)) for viewers seeking additional information. Through these services, viewers can receive a free informational guide and they can talk to counselors at the CDC's HIV/STD hotlines or a local Planned Parenthood. To date, over 1.1 million people have called the hotline and over 402,000 sexual health information guides have been distributed.

The campaign launched a grassroots initiative to complement the on-air and on-line components. Program elements include teen forums and HIV testing events that take place throughout the country. Rap It Up has also developed curricula tailored to middle and high school students on issues around HIV/AIDS that are available at no charge to teachers and health educators.

The success of Rap it Up is undeniable; but there's still so much more work to be done. A recent survey by the Kaiser Family Foundation found that Rap-It-Up's public service ads, full-length specials, news pieces and integration into top-rated shows was seen by more than nine out of ten African American 18- to 24-year-olds, with most seeing a variety of content multiple times.

The most exciting findings are what young people are doing because of the campaign. Eight in 10 young people who said

they saw some part of the campaign on-air said it made them more likely to take their sexual relationships more seriously. Three out of four said it made them more likely to use condoms during sex. Over half (58 percent) took at least one action to protect their own health after seeing the ads or shows—including getting tested for HIV and using protection. Half said they were moved to talk to their partner about safer sex by the ads or shows they saw.

No media campaign alone can be the “silver bullet” that changes behavior as personal and sensitive as sex. Such a campaign can, however, help to increase awareness about HIV/AIDS and how to prevent it, encourage testing, and address the role that stigma and discrimination play in the spread of the disease. Media can do all of this in a variety of formats that can appeal to a variety of audiences.

There are important roles for many different parts of the community to play in addressing HIV/AIDS, including government, parents, health providers, religious institutions, grass-roots organizations and schools. The media is but one part of a multi-pronged, nationwide effort to address the crisis of HIV/AIDS in the African American community. If used correctly, the media can be a powerful player.

At BET, we are committed to continuing the fight in the struggle to combat HIV/AIDS

## George Curry

### Executive Director, National Newspaper Publishers Association Washington, D.C.



The number of newly-diagnosed HIV infections among African Americans has declined an average of 5 percent a year for the past three years. Usually,

such as drop would be viewed as good news. But it's not.

Consider this: More than 368,000 Blacks have been infected with AIDS since the disease was first diagnosed almost a quarter of a century ago. That's larger than the population of either Miami, St. Louis, Pittsburgh, Tampa, Greensboro, N.C. or Baton Rouge, La. Blacks are 12.3 percent of the U.S. population yet account for 40 percent of AIDS cases diagnosed.

Also consider this: By the end of 2004, according to the CDC, more than 200,000 African Americans with AIDS had died. That's larger than either Spokane, Wash.; Augusta, Ga.; Little Rock, Ark.; Salt Lake City, Utah; Knoxville, Tenn.; Huntsville, Ala. or New Haven, Conn.

Numbers get tossed around so frequently that there is a tendency to be numbed by all the figures. But we're not talking numbers—we're talking about people. Real people. Enough to form a mid-size city.

But even numbers need to be placed in perspective. Overall, the rate of AIDS diagnosed for African Americans in 2004 was al-

most 10 times the rate for whites and almost three times the rate for Latinos. But when you compare the statistics by gender, the gap is even more startling.

Of women diagnosed with HIV from 2001-2004, more than two-thirds—68 percent—were African American; whites were 16 percent and Latinos 15 percent. The CDC found that 78 percent of Black females contracted HIV through heterosexual activities.

Among men diagnosed with HIV during that same period, 45 percent were Black, 37 percent white and 16 percent Latino. Almost half of African American men—49 percent—contracted HIV through sex with other men. And 67 percent of them were unaware that they were infected, according to the CDC.

The CDC cites an array of factors—poverty, limited awareness of HIV status, disproportionate rates for sexually transmitted diseases, mistrust and limited access to healthcare—that help explain the glaring gaps in the numbers.

At some point, however, while acknowledging that those are all legitimate factors, African Americans must realize that not enough is being done to lessen the likelihood of Blacks contracting HIV. And when African Americans do contract HIV, they are late finding out, meaning that they run a higher risk of death because of delayed treatment.

Black religious and political leaders must move beyond lip service and consistently organize testing programs. The community must offer realistic sex education for our young people. To support abstinence only programs for teens when almost half of them acknowledge being sexually active is, in some instances, signing their death certificates. The issue is not whether teens should abstain from sex—few disagree with that notion—but what to do about those who do not.

If we're serious about curbing this epidemic, we must aggressively promote the use of condoms. A report by Population Action International in Washington, D.C. stated,

“The condom is the only technology available for protection from sexually transmitted HIV.” It noted, “Public health experts around the globe agree that condoms block contact with body fluids that can carry the HIV virus and have nearly 100 percent effectiveness when used correctly and consistently.”

When I attended an international conference on AIDS in Bangkok, Thailand last year, I noticed how some countries are not squeamish about distributing condoms. They pass them out at major public events, enlist the assistance of taxi drivers and make them easily available in public places without stigmatizing users. Yet, in the U.S., where sex is used to sell everything from automobiles to vacations, we are timid about discussing condoms. Actually, we’re not talking as much about condom use as we are about saving lives.

The federal government must play an important role. Elected officials shouldn’t be allowed to get away with saying they are interested in HIV and AIDS programs while slashing funds for them. And nor should corporations and foundations.

The Black AIDS Institute in Los Angeles does more than any other organization in the Black community to keep this issue before the public. But Phill Wilson, executive director of the organization, says this year his group has had its income reduced by 50 percent, causing him to cut his small staff. Evidently, in the national rush to help victims of Hurricane Katrina, many contributors are shifting funds away from other worthwhile programs.

This is no time to abandon anti-AIDS activists or to become complacent.

—*Reprinted from GeorgeCurry.com.*

## Bev Smith

### Host, the Bev Smith Show American Urban Radio Network



I host a nationally syndicated show—the only nationally syndicated show hosted by an African American woman—for the American Urban Radio

Networks. I’ve been in this business for 40 years or more, and my theme is definitely: Get involved. For the last 40 years I’ve put this phrase forward and even made it into T-shirts: Stand up, be counted, get involved.

Why? Because first of all, I’m not just your average talk show host. I’m an activist. I come from a family of activists. So it’s very difficult for me not to be able to use my platform—and this is what I believe my talk show is: it’s a platform—to make changes in the lives of people. It’s not just to sit around and talk, but to make changes in the lives of people. That’s what I’m all about. And thankfully, I’ve been able to do that.

I’ve been able to use my show to save young children who have been abused. I’ve been able to use my show to get foster children adopted. I’ve been able to use my show to raise money for babies who were born crack-addicted or with AIDS. I’ve used my show to deal with children killing children over drugs and violence in the nation’s capital. I’ve used my show to raise money for slaves in Sudan—it’s an interesting term to use, but that’s exactly what it is. And just recently I used my show to raise money to

help people caught up with the situation with Katrina. So I am an advocate. And being an advocate means that each talk show has a purpose, and that purpose for me is to make a difference in the lives of people.

I've always been involved in the HIV issue, but I can say probably my awareness came with Randy Shilts's book [called *And the Band Played On*]. I was doing a talk show in Miami—as the first Black in Miami with a talk show. I began to get involved because I couldn't believe that the Centers for Disease Control could put out a theory that said a green monkey bit a man who went to San Francisco and had sex, and went from San Francisco back to New York, and that's how it spread. [For a full explanation of U.S. government-funded research on the origin of AIDS visit [www3.niaid.nih.gov/news/news-releases/1999/hivorigin.htm](http://www3.niaid.nih.gov/news/news-releases/1999/hivorigin.htm).] It just sounded like I oughta be singing “doo-da, doo-da.” And that's when I became involved, because I thought that was asinine. So I became involved in investigating the origin of AIDS.

But what really did it for me—and I'll never forget it—was: I was sitting on my deck in beautiful Rockville, Maryland, drinking a vodka gimlet with one of my best friends. He was talking about all the work that I had done with AIDS. He said, “Oh Bev, you don't know how this work is going to change lives.” Now, he had always been interested in my show, but not like this. This was different. We got quiet, and we were just enjoying living in suburbia and I was thinking how blessed I was. Then he looked at me and he said, “I have AIDS.” I broke down and I cried. I made up my mind I would make a difference in the lives of not only him, but anybody touched by this disease. That's how I began.

I lost Ricky, as I lost Jack from New York, as I lost Flynn from Washington, D.C. These are people who had beautiful hearts and souls and spirits, whose families had abandoned them. And there was Gregory whom I worked with in Washington, D.C., who we

thought was gonna beat it, and he died. So this disease is always living with me because there is not a day that goes by that I don't miss Ricky and wish I had him in my life. And as long as I live I will do whatever I can to stop this disease from ruining lives.

I think the Black community's still ignorant about AIDS. I think that there is a hidden silence. The hidden silence says: Don't talk about it and it will go away. Don't mention that you have a gay friend. Don't mention that there are gay people in the pulpit, gay people in the White House. Don't talk about it, and it'll go away. The people who do talk about it are generally those who have sons or brothers or someone like that who has HIV or AIDS. For the most part I think the Black community is just ignorant about it and fearful that it will be one more negative stereotype of our community.

That I would like to see changed, because we still don't get how widely this impacts us. No matter how many young college women I have on the show who say, “I just went with him one time”; no matter how many wives who say, “My husband came home from prison and I contracted the disease.” In the Black community they still see this as the gay disease and, as a result, are not able to connect with it. We have senior citizens with AIDS! Yet, our churches are still too judgmental—but God will deal with them.

Still, I'm going to talk about it no matter what the audience's reaction. I'm straight up. So if you don't like it, turn the channel. When there's a problem, I don't care whether it's racism or George Bush or whatever, I'm going to address it. When I first started talking about George Bush, I stopped getting invited back on the air in certain places. When I talked about the Palestinian people needing a country, I lost advertisers in Washington, D.C.—but they came back, 'cause I named them. So, I'm not afraid.

But I've never had a problem. Maybe I'm just blessed. Maybe the Lord just says, “I'm



going to take care of this fool.” But if you don’t stand up for something, you’re going to fall down for everything.

—As told to Kai Wright

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## Frankie Edozien

### Reporter, New York Post New York, New York



I am a newspaper writer and I live in New York City. I also write for magazines from time to time, and I am the editor of *The African* magazine. My life is sort of

this dual existence: I straddle my African world and my American world. I’m from Nigeria, and every time I go home I come to grips with people who don’t have the advantages and benefits I have as a journalist living in America.

I’m reminded of one year in which balancing these two worlds became particularly difficult. That year, when I was just getting out of college and doing one of my first jobs, at ABC Primetime, one of my American gay friends was dying of AIDS. He unfortunately passed on, but that’s because he had received treatment very, very late. This was during the time when they were beginning to record success with the cocktail treatment, but he never took advantage of that treatment. In that same year, there was a cousin of mine back home who also died of AIDS. But that cousin had no access to treatment whatsoever. In my village, there was no AIDS medicine, period.

So I had this situation where a dear friend of mine in America had died, and I was very angry at him for a long time. Because I felt like there was all this stuff available to him that he didn’t take advantage of. And at the same time, I had this cousin who absolutely would have done anything to prolong her life, but couldn’t. So it was at that point that I started thinking that I had to find ways to try and do stories from time to time on the impact of HIV in people’s lives.

A lot of times I feel that I’m a worker for hire; I basically do what my editors tell me. But I do have control over the stories that I pitch to them. And for every nine HIV stories I pitch to them, at least one gets accepted. Some might worry about getting pigeonholed by advocating for a particular topic’s coverage that way. But I cover government and politics. So in the course of what I do, I’m churning out a lot of work product. To my supervisors I’m doing more than my share of work, and I work very hard for them. So I have not been branded the HIV reporter for the paper—although, when they have a question they tend to ask me, because I’m the one who’s the most enthusiastic about it.

I’m a Black journalist, and in my newsroom, there’s not many of us. So I think that a lot of times we as Black journalists worry about being labeled as something—the this reporter, the that reporter—and we don’t want to be seen as the angry Black person. But the reality is, sometimes, if you don’t do those things, nobody else will. So I have to consider for myself, for the ideas that I pitch, have I done the best that I can do?

For my own magazine, which is *The African* magazine, it’s very small and I control all the content. The challenge there for me is to simply make sure there is HIV content in every issue, and that we’ve been able to do that and not make it boring or hit people over the head with it. The magazine’s audience is quite targeted. It’s for people who are really interested in Africa, or for Africans them-

selves. And I don't think there's a bigger issue on the continent than AIDS—it's bigger than debt relief, it's bigger than getting clean water. So the thing I can do is remind people—because my readership for the most part is in the U.S.—just remind people their brothers and sisters are dying, their babies are dying. It should not always take a Bono or somebody famous to remind people that, even though Americans are dying, they still have access to drugs, while there are thousands and thousands of Africans, even with everything Clinton is doing, who still don't have access to drugs. So what I can do is to write those stories, whether it is a heavy story or a light story, and at least there's something in the magazine about the scourge of HIV. And for me it's just a way of saying, if you pick up this magazine and you read it all the time, with everything else we give you, you will know that HIV is still there.

In my newsroom at the paper, it doesn't have that sense of urgency it once had. It's not 20 years ago, where it was a great-white-homo disease; it's moved to people of color, and it doesn't have that sense of urgency, unless there's a crisis like last year, when they thought they had this "superbug." When it's not that crisis situation, it's a struggle to get stories in. But the least I can do is ask. I just got turned down yesterday as a matter of fact.

The problem is, I cannot do news feature stories on HIV. They're just not interested. I've got to find real news, something to take the story forward, something more than that it's out there. So generally I try to approach it from the dollars and sense, public health area: The city has spent more money to do this, or the city has done that. Or federal officials are descending on New York to study something, or city officials have traveled abroad to present a paper on people in Chelsea. That gets into the paper. But saying that next week is the 25th anniversary of HIV is a tougher sell, even though I think that's important.

But, you know, I will do a story on the

anniversary too—I just don't know what my news hook will be! And they may let me do a story, but without a news hook I move from page two to page 18 or 19. And while I'm always grateful when I get an AIDS story in the paper, it's much better if it's more prominent. But, being at the back of the paper is better than not being in the paper at all.

—As told to Kai Wright

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## Alice Thomas-Tisdale

### Editor, The Jackson Advocate Jackson, Mississippi



Just recently I wrote an article about a 35-year-old white female living with HIV. The story is compelling. She battles with drug addiction, her mother committed

suicide, and her husband died two weeks after being diagnosed with AIDS. Unfortunately, there are thousands of untold stories of African Americans living with HIV/AIDS. Today, I write about these as well. But with the epidemic running 20-plus years, here's my confession: I haven't been writing them long enough.

As a seasoned journalist of 25 years with the *Jackson Advocate*, I have spent only the last six years writing about the AIDS pandemic. Our duty as journalists is to make sure America doesn't become immune to the plight of those who are HIV-positive as we fight for a cure.

I say I was predestined to keep HIV/AIDS on the front page of the *Jackson Advo-*

cate. I met Sandra Varner, an AIDS advocate, in May of 2000. I saw her again in June 2000, and I told her our meetings were God-driven. She agreed, and invited me to cover the 14th International AIDS Conference in Barcelona, Spain, in 2002. Sandra owns a public relations firm in Oakland. She has worked with several physicians in the Oakland community and coordinated Congresswoman Barbara Lee's trip to the Barcelona world AIDS conference. Sandra had written for the *Jackson Advocate* years ago. So our experiences at the *Jackson Advocate* brought us together to educate people about HIV/AIDS through the newspaper. We made a commitment to use our skills to help reduce stigma and ignorance, and to increase community support for education, prevention, intervention and research. We have both kept that commitment over the past six years.

When I returned to Jackson from Barcelona, I enrolled in a Red Cross HIV/AIDS training course and received certification to teach HIV/AIDS education to community groups. I continue to attend conferences to receive information in our quest for empowering communities to be comfortable with battling HIV/AIDS.

The *Jackson Advocate's* readers have embraced the information we provide through the newspapers, and have come to expect coverage of anything—I mean anything—that has to do with HIV/AIDS. They expect to see it in the newspaper and for events related to HIV/AIDS to be advertised to give them an opportunity to participate.

Meanwhile, the city council and the mayor also look to me for updates on HIV/AIDS. I have given them a full report each time I have attended the International AIDS Conference. They consider me an expert in the field of advocacy, and the state of Mississippi's Health Department, its STD/HIV division, makes sure they alert me to meetings to attend and new data to share with our readers.

So it has been very rewarding to become

this sort of go-to source for the community on this important topic. I will continue to be prayerful in my work as an HIV/AIDS advocate, and applaud the work of people like Sandra Varner—who got me involved in the first place.

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## James Dunn

### Managing Editor, BlackPlanet.com Brooklyn, New York



Twenty-five years ago I was a 13-year-old boy. My world was full with junior high school, backyard softball games and Sunday roller skating parties.

I remember watching *Nightline* as Ted Koppel reported about the mysterious illness striking at the heart of America's white gay ghettos, mainly in New York and San Francisco. At this time, HIV/AIDS seemed far away from the daily reality of life for my family and friends in Baltimore.

Today the world is quite different. I am a grown man now. The face of HIV/AIDS has changed drastically: The faces are disproportionately Black and brown. The bodies infected by the disease are increasingly heterosexual females, and the number of infected Black gay men has reached stupendous proportions.

Let's face it. Public perception about HIV/AIDS has been shaped mainly by the media and by fear. Oftentimes the news is produced by people who don't look like

us and who don't understand the cultural intricacies of Blacks. The changing face of HIV/AIDS calls for a new paradigm shift where the media does a better job of reporting on the intersections of race, sex, class and homophobia and its affect on the epidemic.

Unfortunately, the media has failed to ask some of the important questions of the day, not only in its HIV/AIDS coverage, but also in many of the peripheral issues associated with the disease, like poverty and inadequate health care. Instead much of the coverage about HIV/AIDS has focused on stories mired in anonymous statistics and clinical analysis.

Quite simply, I have made covering HIV/AIDS an editorial priority because it is a matter of life and death for Blacks, especially for our young people. My job as a media maker is to cover stories that inform and foster discussions about issues that affect the African American community. This task is not always sexy and it's certainly not always fun—but it's the job I've chosen.

My goal: Give people the information they need to make good healthy choices for themselves and their families, for ultimately knowledge is power. My hope is that I'll be able to expose the different real-life circumstances around which people have to make choices about the disease. These stories must be told in order for us to get a better understanding of the complexities of the HIV/AIDS epidemic.

So my job is about reaching people where they are, not where I wish them to be. Part of that editorial outreach involves producing content that is relevant to the audience—anything from stories about condom negotiation between Black men and Black women to a frank discussion about men who have unprotected sex with men. HIV/AIDS is one of the greatest crises affecting Black people all over the world, from America's inner cities to sub-Saharan Africa.

I consider my work an act of love. My

niece and nephew are 14 years old—almost the same age as I was when HIV/AIDS came to national prominence. I want them to be armed with enough knowledge to make good choices about what to do with their bodies.

Sometimes it seems African Americans are being bombarded from all sides; it feels like we need a miracle for our sake and for the sake of our children. I remember going to church with my mother when I was a child and listening to the choir sing, "I Don't Feel No Ways Tired," by the late Rev. James Cleveland—who also died of AIDS. The hymn tells us, "I don't feel no ways tired ... for I have come too far from where I started from. ... Nobody told me the road would be easy ... But I don't believe He brought me this far just to leave me." Simply put, African Americans have come too far to be beaten by HIV/AIDS. We have a legacy of survival. Let's not end it now.

## HISTORY

# AIDS Trailblazers

## Black Groups that Led the Way

It is often said that Black America was slow to respond to the AIDS epidemic; this is undoubtedly and tragically true. There were, however, brave and bold advocates and service providers who understood the scope of the challenge we faced from the beginning. Here, we highlight three of those early organizations and activists who went to work in the 1980s on issues that would prove, years later, to lie at the eye of Black America's AIDS storm.

The Balm in Gilead realized the Black church's crucial role—its awesome power to be either a force for positive change or crippling stigma—and got started doing the slow, steady education that laid the foundation for today's blossoming AIDS ministries. The Minority AIDS Project and Rev. Carl Bean understood the need for direct, unapologetic prevention campaigns targeting people of color, particularly African Americans—a necessity that took much of public health far too long to appreciate. And the group Us Helping Us saw the need for intensive outreach among Black gay and bisexual men, among whom studies now find infection rates on par with sub-Saharan Africa.

Each of these organizations blazed trails that we must all now march down.

### The Balm in Gilead



Don't tell Pernessa C. Seele that Black churches don't want to respond to AIDS. For 17 years, the non-profit organization she founded has been mobiliz-

ing and educating what she calls "the most important institutions owned and operated by Black Americans." And judging by her group's endorsements and accomplishments, her efforts are paying huge dividends.

In 1989, Seele founded The Balm In Gilead with the belief that education and prayer have brought Black Americans through the toughest of times. The organization's name comes from the biblical Book of Jeremiah

(8:22), which refers to healing in a time of sickness. The name is also the title of a traditional African American spiritual which is sung as an expression of faith and comfort.

The Balm's mission is to work through Black churches to stop the spread of HIV in the African American community and to support those infected with and affected by the virus. At first, that might seem like a plot for the next installment of *Mission Impossible*, but Seele believes differently.

"There is no doubt that the link between HIV/AIDS, drug abuse and sexual activity has been a stumbling block for churches that feel that such behavior is contrary to their tenets," says Seele. "Fortunately, increasing numbers of churches are realizing that providing AIDS education and social services is consistent with the teachings of Jesus Christ. Clearly, Jesus's actions on behalf of the sick show us how we should behave during this age of AIDS."

Seele also cites the alarming increase of AIDS cases among Blacks as high motivation for more and more churches to seek ways to integrate AIDS education into their work.

The idea of churches responding to the wake-up call is made more potent with organizations like The Balm, which answers that call through a variety of well-placed missives against ignorance and inaction. Recognizing that traditional methods of promoting AIDS awareness may not work among Black Americans, The Balm has developed new ways of making AIDS messages relevant. Those methods include providing churches with training, networking and education, and operating the Black Church HIV/AIDS National Technical Assistance Center in conjunction with the Centers for Disease Control and Prevention. The Center provides guidance to churches, nonprofits, schools and individuals in matters involving HIV. The Balm also offers training conferences throughout the year which assist churches in addressing AIDS.

Another important facet of The Balm's

work is The Black Church Week of Prayer for the Healing of AIDS, which begins the first Sunday in March and engages more than 5,000 churches in a week of prayer and educational activities. As the largest AIDS awareness program in the country aimed at Black Americans, the event is based on traditional church revivals and emphasizes compassion in healing the ravages of AIDS within the community.

The Balm's efforts have not gone unnoticed. The group is the only AIDS service organization endorsed by all major historically Black church denominations and caucuses, including the eight-million-member National Baptist Convention USA and the four-million-member African Methodist Episcopal Church. It also has earned the endorsement of Bishop T. D. Jakes, who draws millions of viewers to his weekly television program. These endorsements give the organization the potential to bring AIDS information to over 20 million Black Americans through their religious affiliations. The Balm also works internationally to support church-based HIV activities in Africa and the Caribbean.

Keeping in step with our high-tech world, The Balm is also making its case on the Net, creating the first web directory of Black churches that are active in AIDS prevention and care activities. Its website ([www.balmingilead.org](http://www.balmingilead.org)) contains many of the latest interactive Internet features, including video clips and downloadable HIV resources and information tailored to Black church audiences.

"When we talk about mobilizing the Black community, we are in effect, talking about mobilizing the Black church," says Seele, and it's hard to argue with her assessment. Approximately 23 million African Americans (about 80 percent) belong to a church. As a result of the efforts of groups like The Balm in Gilead, an increasing share of those millions have gotten lifesaving information while there.



## Rev. Carl Bean and the Minority AIDS Project



Archbishop Rev. Carl Bean doesn't mince his words, and about the following point, he is absolutely clear. "Love," he explains, "saved my life." Growing up in 1950s

Baltimore, Maryland, Rev. Bean saw no reason to conceal the fact that he was gay. That decision sent him down a tough road, and at age 15, he attempted suicide. In the hospital, a nurse told him she couldn't and wouldn't try to "cure" him—as his parents wanted—but could help him accept who he was.

Today, he credits that experience with launching a spiritual journey. Since then Rev. Bean has won acclaim as a gospel music singer, founded a national fellowship of Black churches that embraces sexual minorities, and built what is now the nation's oldest AIDS organization designed by and for people of color.

In the late 1970s, his gospel career having moved him to Los Angeles by then, Rev. Bean decided to record a song for Motown Records in which he celebrated his sexual orientation. It was during production of that song, released as "I Was Born This Way," that Rev. Bean realized his calling would go beyond the music career he had already built. Colleagues urged him not to do the project, fearing he would destroy himself by being so publicly gay. But the bishop tentatively pushed ahead. "I knew the path was determined," Rev. Bean recalls, "but I didn't know what it was."

A few years later, in 1981 and 1982, when he started getting calls from all over the country about gay friends in the business

who were dying, that destiny came into focus. "People would just say so-and-so is 'sick.' At that time they didn't understand," he explains. "Everything that I had learned in my life said to me, 'You must act upon this.' I knew better than anyone that the church was going to be silent." For him, that wasn't an option. "It was my friends," he sighs. "And I just could not be silent."

After learning of this mysterious illness's disproportionate impact on African Americans, Rev. Bean became even more alarmed. "I said, 'I know my people don't know about this.'" He placed a cold call to the *Los Angeles Times* and offered himself as a profile: an openly gay Black minister who wanted to help others like himself, people who were falling ill and had no one to turn to.

The ministry that grew from that article eventually became the Unity Fellowship Church Movement and the Minority AIDS Project. Targeting Central and South Central Los Angeles, MAP today serves over 1,200 clients, primarily Blacks and Latinos. The agency's work not only includes HIV prevention and treatment programs, but encompasses a range of services tackling the stresses of urban life that often complicate efforts to fight the epidemic. MAP's case managers and volunteers help clients navigate government bureaucracy in accessing public benefits, offer counseling, make employment and housing referrals, and provide rental assistance, among other things.

But Rev. Bean recalls the early days of the epidemic, when his AIDS ministry largely meant simply being the one willing to sit in a hospital room with a dying patient. He remembers seeing food trays piled up outside patients' rooms, lingering from one mealtime to the next as attendants refused to carry them in for fear of becoming infected. "All I knew," he says, "was that everything I had learned in my spiritual journey said love is what will take care of this."

Today, the bishop adds, the love most

needed is the sort which that nurse back in Baltimore instilled in him at age 15: a love for ourselves. He believes too many African Americans have internalized American culture's negative messages about the worth of a Black life. "If that kind of oppressive thought thrives in the psyche of a human being, it is very difficult to say to them that they have to save their own lives," Rev. Bean explains. "You cannot save people who don't believe they have a right to live." The bishop believes that MAP's success has come from its willingness to counter the broader culture's lessons of self-hate and division. He speaks with pride of the way visitors marvel at the mosaic of clients who feel comfortable at MAP—from gay men to gang members to single mothers. "We really are the same," he concludes. "That other stuff is made up. If you offer love to a Crip, a Blood, or a drag queen—you see the transformation before your very eyes."

## Us Helping Us



Black gay men in the nation's capital discovered a great source of empowerment when it comes to dealing with HIV: themselves. Who better to turn

to for information on what works or doesn't work for fatigue or depression? Who better to relate to while dealing with the terror of becoming sick or the grief of losing a friend or lover? Who else in America has the unique perspective of being Black and gay and affected by HIV?

It's that kind of thinking that gave birth to Us Helping Us, People Into Living, Inc., which first began meeting in a popular Black gay nightclub in Washington, D.C., back in

1985. It's the success of those meetings and the continuing need for HIV resources that have kept the group going and made UHU the Washington, D.C., area's only organization geared specifically toward providing HIV-related services to Black gay and bisexual men.

"I think Us Helping Us has a special foundation to it," says Dr. Ron Simmons, UHU's executive director. "Most of the ideas come from the people we serve."

One of those services, the use of holistic therapies for treating HIV, sets the group apart from many more-traditional AIDS organizations. UHU offers classes that teach participants natural, holistic methods for maintaining good health, including proper diet and nutrition, internal cleansing, vitamin, mineral and herbal therapies, stress management, physical exercise and spiritual development.

Us Helping Us is nothing if not well-rounded in its approach. One of its key services over the years has been peer-led support groups, many of them targeting specific demographics, including men living with HIV/AIDS, mature men (40 years of age and older), transgender individuals, and men taking protease inhibitors. "We're an agency that gives Black gay men hope," says Simmons. "Not just around HIV, but about being homosexuals."

In reaching out to the non-infected population of Washington, D.C., UHU has become a visible entity at events such as the Black Lesbian and Gay Pride Weekend, the Capital Pride Festival and Kwanzaa celebrations, where the goal is to promote HIV prevention and safer sex. And on any given night in the D.C. area, gay men out for a good time might find themselves the recipients of one of over 1,300 condom kits distributed weekly in bars, nightclubs and anonymous sex areas frequented by Black gay and bisexual men.

With a yearly budget that went from \$8,000 in 1992 to over half a million in 1998,

the relatively small agency has managed to both build resources and do a lot with a little over the years. It remains one of the country's most engaged AIDS service agencies today.

"I'm really excited about the future," Simmons beams. "It's a good time—despite HIV."

—*Randy Boyd*







# Ujima Principles

## 1. Sex, drugs and hip-hop.

Since AIDS is primarily a disease of sexual activity, drug use and youth, a new twist on the sixties slogan “Sex, Drugs and Rock and Roll” might be “Sex, Drugs and Hip-Hop”. We have to talk openly and frankly about sex, sexual behavior and sexual orientation in our communities. We also have to deal with the realities of drug use, its relationship to HIV/AIDS prevention and risk reduction. AIDS is rapidly becoming a disease of the young—particularly, but not exclusively, the young, urban and poor. We need to have frank and open discussions with adolescents and young adults. Hip-hop, often accused of being a negative influence on young people, is a powerful medium. If used properly, it can be used to inspire and motivate young people to protect themselves and take leadership roles in the development of HIV/AIDS prevention, care and treatment strategies.

## 2. Know the enemy. Know the virus.

Knowledge is an incredible weapon in the war against AIDS. The more we know about HIV/AIDS, the better equipped we are to develop prevention, treatment and research solutions that more effectively address the disease in our communities. When we understand the science of the disease, we are better able to protect ourselves from the virus; more likely to get tested and seek treatment; better equipped to adhere to the medical regimens, when positive; and better positioned to influence public policy.

## 3. Know your status.

Voluntary HIV counseling and testing is the portal to HIV prevention and care. Being HIV-positive is no longer an automatic and immediate death sentence. There are treatments that slow disease progression and they also reduce the risk of transmitting the virus to others. But the benefits of treatment are

unavailable to those who don't know they are infected. Scientific research has shown that people who know their status are more concerned and careful about transmission than those who never get tested. We should advocate for access to free, anonymous, and voluntary HIV counseling and testing designed to meet the unique needs of Black America.

## 4. Empower women.

Young women must be taught how to protect themselves and be supported in saying no to unwanted sex. Our community must foster a culture that values women more. Those that are pregnant should have access to early prenatal care and appropriate treatment both for themselves and to reduce the risk of transmitting the virus to their unborn child. We must advocate for comprehensive AIDS prevention strategies for both young women and young men, inclusive of abstinence, delayed gratification, sexual responsibility, safer sex practices, condom use, and risk reduction.

## 5. Black masculinity must be redesigned.

Black men are disproportionately represented among America's incarcerated population. These men return to Black communities, often with HIV. Correctional health facilities must provide appropriate counseling and treatment to inmates, and help in integrating them back into society armed with the knowledge and skills to care for themselves, and prevent further infection. The burden of condom use is often placed on women. This must change. We must expand Black male role models beyond sports and music and encourage academic achievement among Black men. We must teach young Black men that protecting their partner is their responsibility.

## 6. Provide health care.

Too many African Americans must use emergency rooms as primary care facilities. HIV care requires access to primary care physicians and specialists. Health services targeting African Americans must also include supportive services. HIV occurs in Black communities against a backdrop of an inadequate health delivery system. We are now facing multiple epidemics of STDs, hepatitis and TB. We must develop Black health promotion messages and public awareness campaigns that acknowledge the relationship between sexually transmitted diseases, hepatitis, tuberculosis and HIV/AIDS.

## 7. Stigma must stop.

In the face of derision, fear, and sometimes even hostility, people won't get tested and seek treatment for HIV. In the face of homophobia and anti-drug hysteria, people won't disclose their risk factors. To fight the stigmas that perpetuate this epidemic, people living with HIV/AIDS are an invaluable source of information and leadership. By sharing their stories, and giving a face to a nameless epidemic, they can inspire hope and promote prevention.

## 8. Vaccines must be found.

The ultimate weapon against HIV will be a vaccine. A preventative vaccine is especially critical for Africans, African Americans and other communities of color who are already disproportionately impacted by other chronic illnesses. This is especially true for individuals, communities, and countries that cannot afford expensive HIV therapies; preventive and therapeutic vaccines are essential. Only a vaccine has the potential to eradicate an



illness from the face of the earth. To this end, African Americans must participate in vaccine development, trials and readiness. We must prepare our communities for HIV vaccines by educating them about the benefits of vaccines.

## **9. You gotta have faith.**

The faith community can be an invaluable source of support in the fight against HIV/AIDS in Black America. We must remind faith leaders that “we are all God’s children.” We must demand that our churches be sanctuaries for the least of us. Black clergy and lay people must be included in the development of Black HIV/AIDS policies. Black churches must be called upon to provide services, encourage testing and support prevention messages.

## **10. Mobilize, mobilize, mobilize!**

We must build a national mass Black response to the AIDS epidemic in America. As Coretta Scott King said, “Anyone who sincerely cares about the future of Black America had better be speaking out about AIDS.” AIDS will not be over in Black America unless and until Black people develop the capacity and commitment to stop it. Every Black organization in America must make HIV/AIDS a top priority. Black leaders—from traditional Black ministers and civil rights leaders to hip-hop artists and Hollywood celebrities—must join in a national call to action and declaration of commitment to end the AIDS epidemic in our communities immediately.

# Recommendations

Black America can no longer afford to trifle with the politics of America's culture wars, whether they come from the left or the right. It is time for Black people to take ownership of the AIDS epidemic and responsibility for ending it. Individuals, community organizers and policymakers must all begin to hold ourselves accountable.

As individuals, two things are clear. First, every Black person in America who does not know his or her HIV status has the responsibility to find out. Free, confidential, and fast HIV testing is available in every part of this country. Go get tested for HIV. And take someone you love with you.

Second, every one of us who know we are HIV-positive has the responsibility to make sure we are not a link in the insidious HIV infection chain. Similarly, everyone who is negative has the responsibility to stay that way, by protecting yourself from infection.

Community organizers who have rightly taken the lead in HIV prevention must accept a new reality. We can no longer afford to spend limited resources on initiatives that just make us feel good. Prevention campaigns must be accountable to scientific standards; if

we can't show they work, then we need to put resources into efforts that can.

But accountability doesn't stop there. Individuals and communities need support in their efforts, and policy makers—at local, state, and national levels—must be far more responsible partners than they have been in the past. From the school board to the White House, AIDS is relevant. We must hold our elected officials and community leaders accountable.

Religion and politics rather than science continue to guide the federal government's role in prevention. Politicians must get out of the way and let science rule the day, and we must hold them accountable when they don't.

We have dithered too long. Each year, the epidemic worsens in Black neighborhoods, and each year the national commitment to interrupting its spread and keeping those already infected healthy further lags. AIDS in Black America is a difficult and multifaceted problem—but it is also a winnable war. It's time for all of us to take responsibility for stopping this slaughter.

For Black America, the moment of truth has arrived. If we are to survive the AIDS

epidemic, we are going to have to gather all of our resources and marshal them for the political struggles that lay ahead. With that mandate in mind, the Black AIDS Institute calls on all sectors of Black America—from individuals to political, religious and cultural leaders—to commit to taking action against HIV/AIDS by engaging in a coordinated campaign to renew our national commitment.

Over a million Americans are living with HIV today; nearly half of them are Black. Yet, our national policymakers have lost focus. Federal funding for domestic AIDS care programs has remained largely flat since 2001. As a community, we must engage HIV not only as an individual health concern, but also as a political and social struggle.

## Recommendations

Leaders must lead. Those who have come into leadership roles in Black America, whether as opinion shapers or industry titans, must use their positions to help build a mass community movement to end HIV/AIDS. From local heroes to Hollywood stars to trailblazers in business and politics, our leaders must lead. And those who are already educated about the epidemic must reach out to those leaders to give them the knowledge they need to carry the message forward.

## Reject defeat.

We must build a new sense of urgency in Black communities, so that no one accepts the idea that the presence of HIV and AIDS is inevitable.

## Demand expansion of proven prevention work.

We must no longer allow politics and sub-

jective notions of morality to stand in the way of stopping the virus's spread. We know beyond a doubt that needle exchange stops HIV's spread among injection drug users, and thus their sexual partners as well; the ban on federal funding for these programs must end. We also know that comprehensive AIDS and sex education works. Prevention money is being directed towards unproven initiatives driven by subjective morality rather than hard science. Schools must uncompromisingly teach young people about both abstinence and delaying sexual activity and protecting themselves if they do have sex. We must demand that Congress and federal agencies support aggressive, targeted prevention programs that give people all of the information they need to protect themselves. We must also insist that the programs which have a proven track record of reducing the transmission of HIV—programs like needle exchange—be adopted and funded across the country. We can no longer allow those with little investment in Black communities to limit the information young Black people receive in schools and community-based programs.

## Protect access to treatment.

We must demand Congress and the White House maintain and strengthen the network of programs designed to make healthcare affordable and support the AIDS safety net. Congress must also reauthorize Ryan White and fund it adequately, so that people with HIV/AIDS have access to life-saving services no matter what region of the country they live in.

Medicaid, which is the largest payer for AIDS treatment, is collapsing for lack of resources and short-sighted reforms. We must demand that Congress not only prevent the current program's collapse but come up with genuine reforms that protect our nation's

commitment to providing healthcare to the most vulnerable in our society. The effort to shift Medicaid costs onto poor families must end, and Washington must partner with state governments to develop a fair and sustainable solution to financing the program.

## **End the debilitating stigma that helps HIV spread.**

Perhaps more than anything else, Black America must finally put an end to the stigma surrounding this virus. It cripples efforts to both prevent the virus's spread and treat those who are infected, particularly in the South and among gay and bisexual men. It fuels distracting and debilitating conspiracy theories. And it renders us incapable of defending ourselves in crucial policymaking battles. Worst of all, it rips at the souls of individuals and families struggling to build a healthy future in the face of HIV's attack. It must end. And that begins with each person in Black America, whether positive or negative, being willing to stand up and declare that the era of shame and silence about HIV is over. We must make our homes, schools, churches and neighborhoods sites of open and honest discussion about what sometimes can be uncomfortable topics—sex, drugs, poverty and culture. The survival of our communities depends on this.

Black America must acknowledge that it is a community, inclusive of a wide and beautiful range of people. That community includes gay, lesbian, bisexual, transgender people, and people living with HIV/AIDS, and they must be not only accepted but supported. Black LGBT people must come home and share in the responsibility for building this unity by refusing to live in shame and secrecy, by standing up within the community, being willing to be held accountable, and demanding to be counted.

## **See the Big Picture.**

We must understand that the fight against HIV and AIDS is actually a broader fight against an environment in which poverty, homelessness, unemployment, incarceration and violence exacerbate the risk young African Americans face daily, including their risk for HIV and AIDS.

In the final analysis, this epidemic isn't terribly complicated: When we allow politics, subjective notions of morality and profit-driven health economics to reign over public health, the most vulnerable in our society are left for HIV to prey upon. When we make a genuine commitment to meet people where they are, with the resources they need to chart a healthy path and stay on it, we find success. When we have the courage to act we make progress; when we don't we lose ground.





# About the Black AIDS Institute

The Black AIDS Institute, founded in 1999, is the only HIV/AIDS think tank in the United States focused exclusively on Black people. The Institute's mission is to stop the AIDS pandemic in Black communities by engaging and mobilizing Black institutions and individuals in efforts to confront HIV. The Institute conducts HIV policy research, interprets public and private sector HIV policies, conducts trainings, builds capacity, disseminates information, and provides advocacy and mobilization from a uniquely and unapologetically Black point of view.

## What We Do

- The Institute develops and disseminates information on HIV/AIDS policy. Our first major publication was the **NIA Plan**, which launched a national campaign to stop HIV/AIDS in African American communities by formulating and disseminating policy proposals developed through collaboration with federal, state and local government agencies, universities, community-based organizations, healthcare providers, opinion shapers and

“gatekeepers.”

- **The African American HIV University (AAHU)**, the Institute's flagship training program, is a two-year fellowship program designed to increase the quantity and quality of HIV education in Black communities by training and supporting peer educators of African descent.

- **The International Community Treatment and Science Workshop** is a training and mentoring program to help people who are living with HIV/AIDS or who are working with community-based and non-governmental AIDS organizations to meaningfully access information presented at scientific meetings.

- **The Drum Beat** is the Institute's Black media project designed to train Black media on how to report accurately on HIV/AIDS and tell the stories of those infected and affected. **The Black Media Task Force on AIDS**, a component of the Drum Beat Project, currently has over 800 Black media members.

- The Institute publishes original editorial materials on the Black AIDS epidemic. Our flagship publication is a monthly news-



letter, **Kujisource**, which has a distribution of 25,000. Our web site **www.BlackAIDS.org** attracts nearly 100,000 hits a month. The **Drum Beat** newspaper is a semi-annual tabloid with a distribution of 300,000. It is distributed to Black conventions, barbershops, beauty parlors, bookstores and doctors' offices. The Institute's newest publication is **Ledge**, a magazine produced by and for Black college students and distributed on the campuses of historically Black colleges and universities around the country.

■ **Heroes in the Struggle**, an annual photographic tribute to the work of Black warriors in the fight against AIDS, is currently traveling to Black universities, museums and community-based organizations throughout the United States, providing information on HIV/AIDS.

■ The Black AIDS Institute and BET, in association with the Kaiser Family Foundation, also sponsors the **Rap-It-Up Black AIDS Short-Subject Film Competition** to highlight the issue of AIDS and HIV infection within the African American community. The 2004 Rap-It-Up winner, first-time filmmaker Tracy Taylor, has been nominated

for an NAACP Image Award. Taylor's film, *Walking on Sunshine*, aired on BET and will be screened at film festivals throughout the year.

Rap-It-Up is designed to provide a voice and visual outlet for the thousands of African Americans living with or caring for those with HIV and AIDS, and/or fighting AIDS in Black communities. By showcasing examples of heroism from within Black communities, we can galvanize African Americans to refocus and recommit to overcoming this epidemic.

■ The Institute provides **technical assistance** to traditional African American institutions, elected officials and churches who are interested in developing effective HIV/AIDS programs, and to AIDS organizations that would like to work more effectively with traditional African American institutions.

Finally, nearly 30,000 people participated in AIDS updates, town hall meetings or community organizing forums sponsored by the Institute last year.



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