



# 30 Years Is ENUF!

**The History of the AIDS Epidemic  
in Black America**

**Black AIDS Institute  
June 2011**



# Table of Contents

4	<b>From the CEO</b>
8	<b>Forward</b> by Rosalyn Brock and Benjamin Todd Jealous
10	<b>Executive Summary</b>
20	<b>The History of the AIDS Epidemic in Black America</b>
	What is AIDS?
	Still Standing After All This Time
	We Have Survived
40	<b>AIDS Timeline</b>
52	<b>Viral Generation</b>
	They've Got SWAG
78	<b>Leadership Matters</b>
	The 30 Most Influential Black AIDS Leaders
	People You Might Not Know, Whom You Should!
	Leaders to Look Out For
88	<b>We Have the Tools</b>
100	<b>Presidential Report Cards</b>
106	<b>Recommendations</b>
114	<b>Appendix 1: Glossary of Terms</b>
124	<b>Appendix 2: Glossary of Acronyms</b>
128	<b>About the Institute</b>

**SHERYL LEE RALPH**  
Hero in the Struggle



FROM THE CEO

# AIDS: 30 Years Is Enuf!

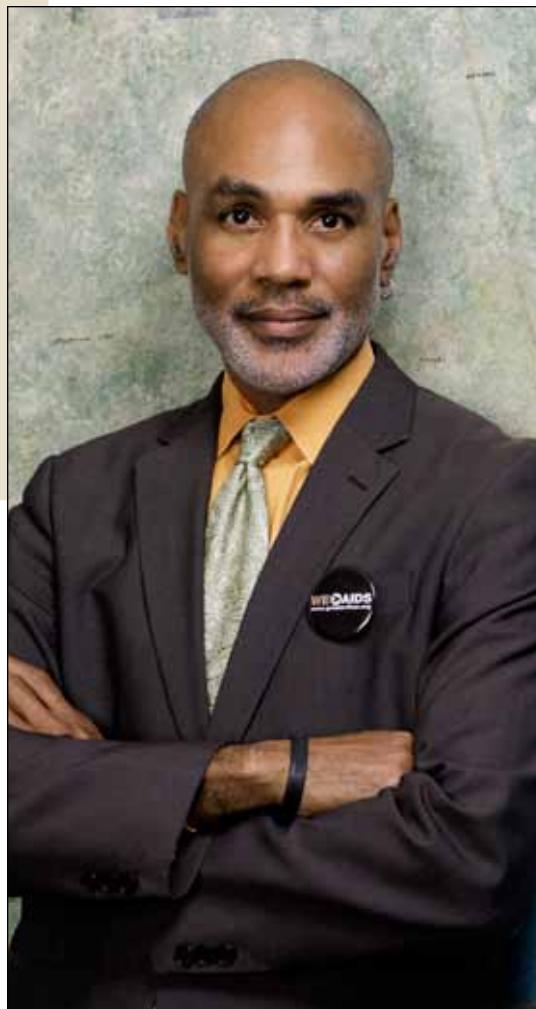
## The History of the AIDS Epidemic in Black America

**Marking the 30th year of the epidemic brings to the surface so many powerful and conflicting emotions for me personally that I find it difficult to make sense of them all.**

I'm acutely aware of how lucky I am and how improbable it was when I was infected that I would be alive today. But here I am, the personification of what can happen when people with HIV have the love and support of family and friends and the care and treatment we need. Hundreds of thousands of Americans living with HIV are alive today because of scientific breakthroughs. This milestone provides a moment to reflect and give thanks.

Yet I'm also mindful of all that has been lost. More than half a million people have died of AIDS in this country. Worldwide, the death toll is over 25 million. They aren't here to witness the end of the epidemic's third decade. I remember Reggie, Marlon, Essex, Belynda, Rory, Roger, Craig, Brandy, Sylvester, Assotto, and the countless friends, loved ones and cherished colleagues gone too soon. No amount of scientific advances will bring them back, but their memories comfort me when I'm feeling lonely and inspire me to keep fighting until it is over.

Thirty years since the first official report of AIDS among six white gay men at UCLA medical center in Los Angeles, I'm also buffeted by conflicting emotions regarding how much we have failed to do. I'm mindful of the extraordinary opportunities we now have, but also beset by



**Phill Wilson**



concern that we won't do the right thing.

In May 2011, federal health officials announced that a major clinical trial demonstrated that early initiation of antiretroviral therapy sharply lowers the risk of HIV transmission. According to study results, HIV-negative partners of HIV-positive individuals who started treatment early were 96 percent less likely to become infected than uninfected partners of individuals who waited later to begin therapy.

In 2010, we also received strong positive evidence from a clinical trial regarding the effectiveness of a vaginal microbicide. Last year also witnessed the release of major new find-

ings that daily use of pre-exposure prophylaxis significantly reduces the risk of transmission among gay and bisexual men.

These results are nothing short of earthshaking. Especially when combined with the expanding array of other prevention tools, antiretroviral therapy holds the potential to make new HIV infections exceedingly rare. Indeed, these study results make it reasonable—indeed, imperative—to begin discussing a possible “end game” to the epidemic.

In fact, these findings merely underscore the realistic prospects for achieving the vision set forth in the National HIV/AIDS Strategy: “The United States will become a place where new HIV infections are rare and when they do occur, every person regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.”

It's impossible not to rejoice at these new findings. Yet as my spirits soar at the prospect of bringing this three-decade-long struggle to an end, I'm reminded of how many times we've frittered away critical opportunities. This failure to act when historic progress was possible has had especially devastating consequences for Black America.

From the epidemic's earliest days, it was ap-

parent that Black Americans were disproportionately affected by the epidemic. Yet the epidemic in its early years was consistently portrayed as a problem for white gay men. Neither our national leaders, nor Black America itself, responded as they should have to the clear signs of an emerging health crisis among Black people. Few programs were put in place to address the HIV-related needs of Black people in the epidemic's early years.

Only during the third decade of AIDS was the epidemic considered to pose a “state of emergency” in Black America. By this point, Black people were more than seven times more likely than whites to become infected.

In 1996, approval of a new class of antiretroviral drugs, protease inhibitors, presented a second historic opportunity to act. When used in a combination cocktail with other antiretroviral classes, these new drugs proved to be powerfully effective in stopping HIV in its tracks. Nationally, AIDS deaths plummeted.

But when the treatment revolution came, Black America again was unprepared. Too few Black people recognized the threat posed by AIDS or the extraordinary promise of the new medications. Far too many of us continued to be diagnosed late in the course of infection, after HIV had already severely damaged the body's immune system. The robust community-based treatment education initiatives for which the AIDS response was rightly hailed were largely located in white communities, and precious few programs were created to address the impediments that many Black people face in adhering to demanding antiretroviral regimens.

The eventual result has been as tragic as it was predictable. In the HIV treatment era, racial and ethnic disparities in HIV medical outcomes have actually widened in the U.S. Since the mid-1990s, well-resourced communities have thrived on HIV medications, while low-income communities of color have failed to reap anywhere near the same degree of benefit. In the wealthiest and most powerful nation on earth, we have failed to ensure that the fruits of modern medicine are provided to those who need them the most.

So in 2011, as we appear to be on the cusp of a new era in the long fight against AIDS, I can't stop the sad history of missed opportunities from dampening my new-found hope.

Will our country—and especially Black America—be prepared this time to seize this deciding moment? What needs to happen to ensure

that we rapidly progress toward the long-hoped-for “end game” for AIDS?

What is crystal clear is that we must be bold, courageous and radical in our thinking. “Business as usual” simply will not suffice.

The first thing we must do is get serious about HIV testing and treatment services. Our passive approach to service delivery—in which a network of services is created, with the expectation that people who need the services will find them, let alone use them—must urgently give way to a seamless, more proactive approach. We need to aggressively market HIV testing and treatment, make it easy for people to use needed services, and create a variety of incentives for both patients and providers to maximize utilization of needed services.

We also can't assume that patients will, or even know how to, adhere to prescribed regimens. Most Americans, regardless of health condition, don't faithfully take their meds as prescribed. And many people living with HIV, especially those in poverty, confront real-world barriers to good health. We need well-resourced, evidence-based programs that address patients' individual needs and offer critical support for treatment adherence.

With recent historic biomedical breakthroughs, we also can't give up on AIDS research. We need well-designed studies to identify optimally effective methods for promoting and delivering testing and treatment services. We must lower the per-patient costs of treatment and re-emphasize the search for a cure and a preventive vaccine.

The silos that have been created for prevention and treatment must be dismantled and replaced with an approach that recognizes that prevention and treatment are part of a single continuum. The historic approach to planning, funding and implementing AIDS programs—in which the Centers for Disease Control has been responsible for HIV prevention and testing, while others in the Department of Health and Human Services have taken the lead on HIV treatment and care—must rapidly be replaced with a unified approach with streamlined oversight and a single locus for accountability. At the level of local service delivery, the HIV/AIDS workforce is woefully undertrained. Prevention workers need to become treatment experts, while clinical settings need to integrate the behavioral expertise of the HIV prevention world.

And last—but certainly not least—if we are

serious about avoiding the pitfalls of the past, we must make massive new investments in HIV treatment literacy in Black communities. Black America needs a robust, nationwide network of Black treatment advocates and educators, who can help spread the word about the promise of HIV treatment, promote saturation testing and treatment coverage in Black communities, and help patients navigate accessing and adhering to treatment. To make treatment-as-prevention work, Black Americans need to become treatment-savvy, understanding the value of early testing, collaborating with their doctors to address their health needs, taking care to avoid drug resistance if they are infected, and standing up against stigma and denial.

It's been said that the definition of insanity is doing the same thing over and over again and expecting different results. Since the epidemic began, we've tried “business as usual.” It hasn't worked in the past, and it most certainly won't work now. Treatment-as-prevention holds the promise of transforming our fight against AIDS, but it offers little room for failure, demanding a level of comprehensiveness and achievement in service provision that we have never achieved.

As AIDS enters its fourth decade, there could be no more fitting tribute to the hundreds of thousands who have perished from this disease in the U.S. than to demonstrate that we've learned a lesson or two over the last 30 years. In 2011, we have an extraordinary new opportunity to conquer AIDS. Only bold, wise action will get us where we need to go.

We have no time to waste. Let's get moving!

Yours in the Struggle,



Phill Wilson  
CEO  
Black AIDS Institute



**DR. MARJORIE J. HILL**  
Hero in the Struggle



FORWARD

# We Have the Tools

By Roslyn Brock  
and Benjamin Todd Jealous

**Exactly 30 years ago this month the Centers for Disease Control and Prevention identified the nation's first diagnosed case of AIDS. Over the past three decades, HIV/AIDS has become an important focal point of our national and global debate—even more so for Black communities, which are the epicenter of the epidemic in the United States.**

Both the United States and Black America are experiencing a historical and urgent moment, documented by this new report from the Black AIDS Institute. Thirty years after that first incident, HIV-related health disparities for African Americans remain staggering. If the United States were its own country, the epidemic in Black America would be the 16th largest in the world. In fact, Black America accounts for about 12 percent of the national population but for nearly half of all people living with HIV. African Americans are eight times more likely to be diagnosed with HIV than whites and experience the highest rate of AIDS-related deaths. Today approximately 1.1 million people live with the virus in the U.S, including more than 500,000 Black Americans.

We have reached a deciding moment. Exacerbated by our nation's economic crisis, our national investment to the HIV/AIDS crisis continues to fall far short. Concerns over "spending" are translating into fewer dollars and fewer service deliverables—while more than 8,000



**Roslyn Brock, Board Chair, NAACP**



**Benjamin Todd Jealous, President and CEO,  
NAACP**

people are waitlisted for AIDS Drug Assistance Programs nationwide. We cannot balance our budgets on the backs of those most vulnerable.

The report shows that major investments are needed in HIV prevention and treatment education across Black America. Blacks make up more than 56 percent of all so-called “late testers,” people diagnosed with AIDS within one year of an HIV diagnosis—a sobering statistic.

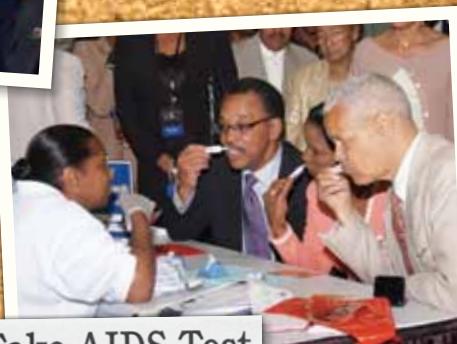
Many of the states cutting back on their HIV infrastructure are in the South, which has experienced the nation’s highest growth in HIV/AIDS. This region is the nation’s poorest, has the highest percentage of Black residents and has seen the greatest spread of HIV among Black women.

Yet as these issues threaten our nation’s progress, the HIV prevention toolbox has begun to “explode” with new prevention technology options, from aggressive anti-retroviral “treat-

ment as prevention” to pre-exposure prophylaxis. None of these interventions will be possible if our communities do not mobilize against conservative threats to cut HIV/AIDS spending—and to defund health care reform.

This report also asks frank questions—and offers equally frank recommendations—on Black America’s response to the crisis. A new dialogue must begin around stigma, discrimination and homophobia, which have fueled the epidemic in our community. The NAACP is engaging faith leaders to normalize the conversation about HIV/AIDS in our churches—and we’re calling all our faith community to action.

Thirty years into the epidemic and we finally may have the tools to aggressively fight HIV/AIDS in Black America. This report by the Black AIDS Institute helps lay out the path forward.



## NAACP Execs Take AIDS Test

Nation's Oldest Civil Rights Organization Vows to Lead Fight Against the Epidemic in Black America



TEST: Executives practice what they preach and test for HIV. From left: Rev. Sharpton, NAACP president & CEO, sitting left; Rev. Dr. Jules Charles, NAACP Board member; Rev. Dr. John Lewis, NAACP Board member; Cheryl Lee Ralph, actress; Phil Wilson, NAACP executive director; and Pamela Bond, Jules Charles' wife.

WASHINGTON (July 15, 2006)

The president and CEO of the National Action Network, the nation's oldest and largest civil rights organization, has tested for HIV yesterday.

The move came during the organization's 9th annual national convention and follows his participation in a panel discussion that turned the spotlight on HIV and AIDS.

"AIDS is killing our community," said NAACP president Bruce S. Gordon, "but I'm clear I'm not talking about the problem of AIDS. I've been there. I'm talking about the problem right outside of this convention if you walks right out of this convention at the end of this week and you have not been tested. If you have not been tested, you have failed to do your duty to your community and to this nation."

Then, he practiced what he preached.

Gordon joined by his wife, Pamela Bond, and Rev. Dr. Jules Charles, Rev. Sharpton, tested on an on-site HIV testing center sponsored by the U.S. Department of Health and the Black AIDS Institute. Sited out several blocks from the convention, a quick HIV test, and returned 20 minutes later for the confidential results.

The testing, designed to raise awareness about the importance of HIV testing, was a part of a ribbon cutting ceremony to mark the opening of the 37th NAACP Convention and Industry Show.

"It is still a big deal to have high profile people acknowledging the disease and being tested," said Rev. Sharpton. "The Black AIDS Institute in Los Angeles, who has long been working to get Black Americans to get involved."

On June 5, 2006, NAACP

Activists tested the move, saying it has been a struggle for Black Americans to get involved in battling epidemics that may be national to the Black community.

From a national level, we've been die

hardly to the AIDS epidemic, and so that's why we're coming together to reduce the stigma of AIDS in the Black community.

The year things about changed.

The year's convention, attended by thousands, opened with a health symposium titled "The Black Community Owns Grace."

The HIV/AIDS Crisis in the Black Community," followed

an HIV/AIDS awareness and a performance piece on AIDS by actors and actresses.

It was the first time at the Annual NAACP convention that HIV

and AIDS prevention services were made available as a part of the NAACP Health and Wellness Program.

According to the CDC, the African American community has the highest rate of new HIV/AIDS diagnoses, per capita, in the nation.

And, HIV/AIDS related deaths are the leading cause of death

in the U.S. according to the CDC.

In February, the NAACP re-

leased "The Way Forward," a national report subtitled "The Black AIDS Crisis: The State of the Epidemic."

Developed with the guidance of the Black AIDS Institute, the report highlights the staggering statistics among five white gay patients at University of California, San Francisco, and the defining issue of our time, and its disproportionate impact on Black Americans.

The report included critical recommendations for government, foundations, and individuals.

She told the hundreds of people gathered that basketball star Magic Johnson got his HIV test because he wanted to get treated right away.

"He looks as healthy as anyone you have seen," she said.

and individuals, institutions and foundations to develop strategies and activities that match their unique niches and strengths.

According to federal re-

search, 66 percent of African Americans living with HIV/AIDS are Black. Black Americans represent more than 54 percent of the total AIDS cases in the United States. AIDS is the leading cause of death for African Americans.

A CDC study by the CDC showed that 46 percent of Black gay men in America may already be HIV

positive.

For the last few days, Gordon led thousands of members to California to lobby

and to push for more funding for HIV research and prevention.

"It's a crisis we should have seen coming," he said. "We were slow to respond."

Wilson said during the panel discussion, "It's time for a new sense of urgency in Black America, so that no one accepts AIDS as a death sentence."

HIV and AIDS are inevitable," he continued.

"We will not stand before you

and blame others for our condi-

tion. Our obligation is to take

action to control our

destinies and our futures."

We may not have all the power

and resources, but we have

the power that we need.

All we have to do is use

that. That's all it takes."



TEST: Rev. Sharpton, Vanessa Williams and Rev. Dr. Jules Charles take an HIV test.

Photo: AP/Wide World

## Black A-List Actors Take HIV Test

Regina King, Jimmy Jean-Louis, Samaki Walker among Those Tested as Sharpton Speaks to AIDS among African Americans



TEST: Henry Simmons, Vanessa Williams and Rev. Dr. Jules Charles take an HIV test.

Photo: AP/Wide World

black AIDS diagnosis. "While we can't eradicate the virus in five years, we can certainly reduce the rates, increase the percentage of Black people who know they have HIV, and increase the percentage of people who are in appropriate care and treatment, and reduce the debilitating stigma that crippled us during the epidemic."

There are an estimated 600,000 Black Americans living with HIV and AIDS, out of the estimated 1.3 million Americans with HIV/AIDS.

"The only way to end the AIDS epidemic in Black America is for Black folks to get involved in the movement," said Rev. Sharpton, who was in Los Angeles to speak at the 2007 BET Awards, pledged his organization's support for the campaign.

"We are excited about this campaign and will keep publishing stories on Black Americans living with HIV and AIDS, out of the estimated 1.3 million Americans with HIV/AIDS," he said.

Several other celebrities who were present at the BET Awards, including Rev. Sharpton, actors Jimmy Jean-Louis and Samaki Walker, stepped up Monday to take an HIV test, as part of the "I'm in a Million" campaign.

Henry Simmons, Vanessa Williams and Rev. Dr. Jules Charles also took a public HIV

King said.

The Screen Actors Guild (SAG), the American Federation of Musicians, the National Basketball Association, the Black AIDS Institute, Artists for a New South Africa, the National Black Justice Coalition, the National Black Leadership Roundtable and the NAACP

Artists for a New South Africa, also spoke at the news conference and committed his organization's support to the "I'm in a Million" campaign.

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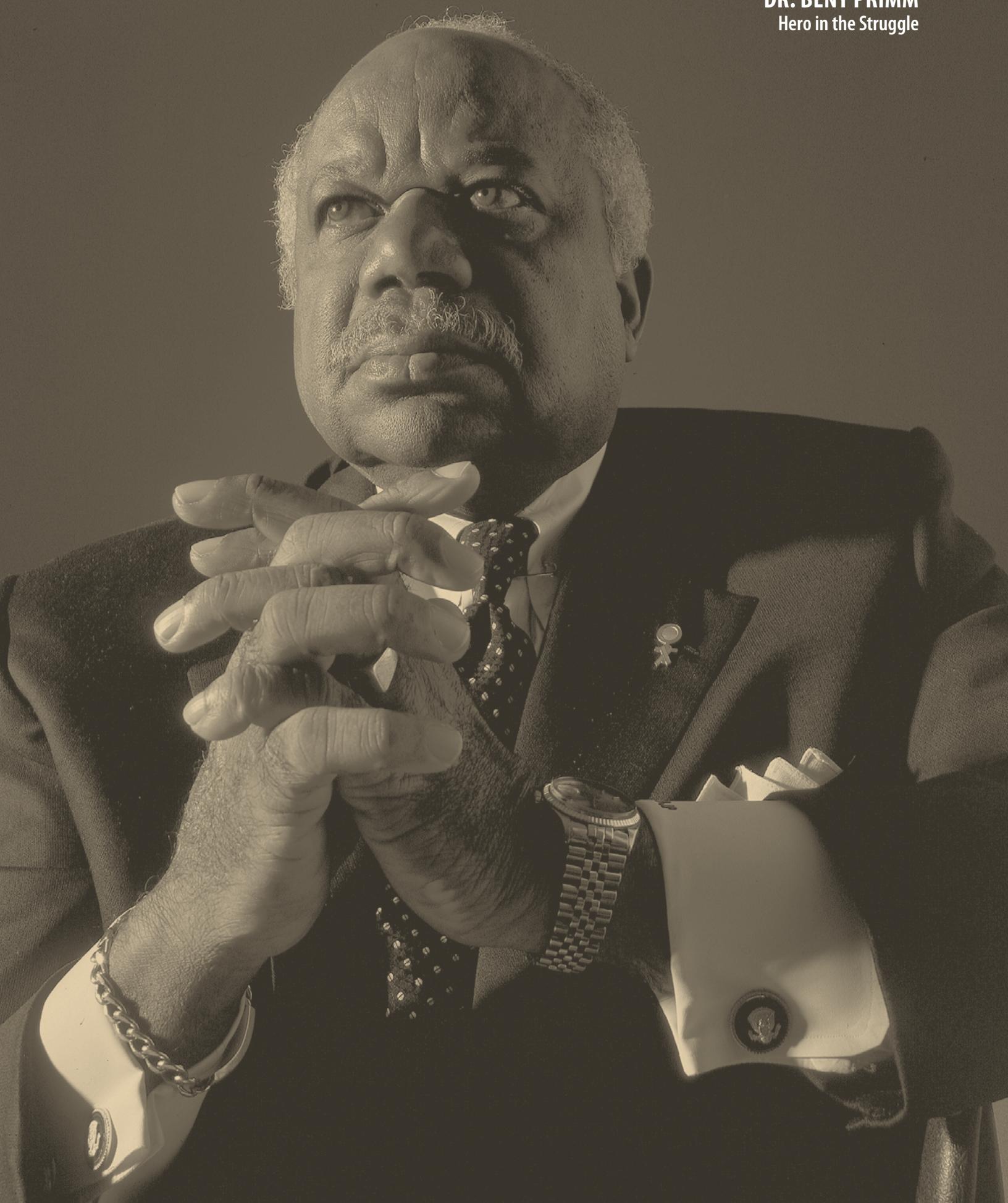
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**DR. BENY PRIMM**  
Hero in the Struggle



## EXECUTIVE SUMMARY

# AIDS: 30 Years Is Enuf!

## The History of the AIDS Epidemic in Black America

This report by the Black AIDS Institute marks the 30th anniversary of the first official report on the emergence of the HIV/AIDS epidemic. Over three decades, AIDS has radically altered our world, reshaping entire regions of the world, changing people's relationship with their own sexuality, dramatically accelerating social and cultural change, and producing some of the most important scientific advances of the last century.

No single report can possibly address all the various ramifications of the epidemic's first 30 years, and this one certainly does not attempt to do so. Rather, this report aims to provide a degree of context to our understanding of the epidemic, using the 30th anniversary as an opportunity to reflect on what we have experienced and to understand both the challenges and the opportunities that will face us in the future.

The report includes a brief historical overview of the first 30 years of AIDS, including a timeline of key events and a report card for the American presidents who have overseen our national response. Personal essays explore some of the ways that AIDS has affected both our world at large and our own individual life experiences. Looking to the future, the report profiles current and emerging leaders in Black America's response to AIDS, includes HIV-themed essays from 30 people under age 30, and highlights major new scientific advances that may hold the key to eventual efforts to end AIDS. The report ends with a series of urgent recommendations to ensure that this historic moment of opportunity is not wasted.

### Looking Back: 30 Years of AIDS

Although June 1981 is typically assigned as the start of the global AIDS epidemic, marking the publication of the first official report by the Centers for Disease Control and Prevention, HIV had existed long before 1981. The history of AIDS is one of extraordinary personal and collective courage and vision, as well as one of hysterical fear, ignorance, official apathy, and missed opportunities.

From what originally (and erroneously) appeared to be a problem concentrated among gay men in urban populations in the U.S., AIDS has grown into a global phenomenon and one of the most serious health challenges facing our world. In the U.S. alone, nearly 600,000 people have died of AIDS, with more than 60 million infections having occurred worldwide.



Contrary to popular belief, AIDS has disproportionately affected Black America since the very beginning of the epidemic. Today, Black America represents nearly one-half of all people living with HIV in the U.S. and nearly half of all new HIV infections. Black people in the U.S. are more than seven times as likely to become newly infected with HIV as their white counterparts.

Although a handful of municipalities began responding to AIDS in the early 1980s, the federal government was slow to the fight, in large measure because it was perceived that the epidemic did not imperil “normal” people. Only in 1987 did President Reagan, under whose watch AIDS first emerged, officially address AIDS. Congressional AIDS champions spearheaded passage of the Ryan White CARE Act and the Americans with Disabilities Act in 1990, which provided targeted funding for HIV care and treatment and barred HIV-related discrimination, respectively. The domestic AIDS response gathered steam under President Clinton, who supported robust funding increases and over-



saw the launch of the Minority AIDS Initiative, but it subsequently lost energy under the second President Bush, who nevertheless exhibited vision by pushing for U.S. leadership in the fight against AIDS in Africa. Under President Obama, America launched its first comprehensive, target-driven National HIV/AIDS Strategy; repealed many of the most problematic national AIDS policies (such as the prohibition on federal funding for needle exchange program); and enacted sweeping health care reform legislation.

AIDS has resulted in major scientific breakthroughs. In addition to early epidemiological investigations that rapidly characterized the modes of HIV transmission and laboratory testing that isolated HIV, U.S.-funded research has resulted in critical advances in methods to prevent and treat the disease. Especially noteworthy is the development of Highly Active Antiretroviral Therapy (HAART) in the mid-1990s, which has dramatically reduced AIDS deaths in the U.S. and is beginning to do so in low- and middle-income countries, where drugs have only become available in the last several years. In addition, implementation of proven prevention methods has reduced the number of infants newly infected with HIV by more than 90 percent since the early 1990s. These advances are continuing, with several important new prevention methods having emerged toward the end of the epidemic's third decade. HIV testing technologies have also greatly improved, including the development of rapid tests, home-based tests, and oral technologies.

Far too often, however, scientific learning has not been put to effective use. This has especially proven to be true with respect to efforts to prevent new infections, which have been impeded by prevailing discomfort with issues of sexuality and drug use. For example, a mammoth body of evidence has long demonstrated the effectiveness of needle exchange programs in reducing HIV transmission as a result of drug use, but until very recently federal funds could not be used to support this life-saving approach. This has had particularly devastating consequences in Black America, which accounts for 55 percent of all people living with HIV acquired as a result of injection drug use.

Other factors also inhibit optimal use of scientific knowledge to fight AIDS. For example, while Black America has certainly benefited from treatment breakthroughs, racial and ethnic disparities in HIV-related medical out-

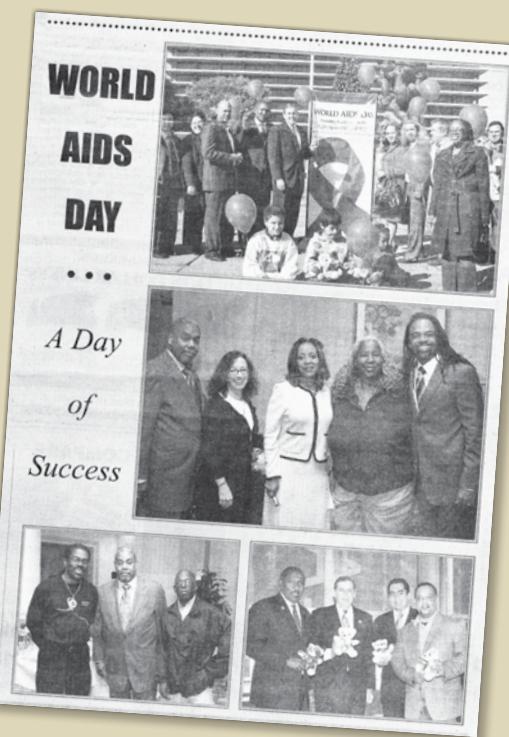
comes have actually widened during the HAART era. Key factors that impede favorable medical outcomes among Black people living with HIV include late diagnosis of HIV infection, inadequate health care access, discontinuity of care, and a high prevalence of conditions that interfere with treatment adherence.

Since the epidemic began, communities led the way in the AIDS fight here in the U.S. Although the earliest community-based AIDS organizations were founded in largely white gay communities, Black America also responded to the epidemic. Several organizations dedicated to the fight against AIDS in Black America—such as the National Black Leadership Commission on AIDS and the Balm in Gilead—were founded in the 1980s. More recently, leading national Black political, civic and cultural organizations have become engaged in AIDS work.

Evidence suggests that awareness of, and concern about, AIDS is higher in Black America than among other racial and ethnic groups. However, media interest in AIDS has sharply declined, with the percentage of Black Americans who report hearing a lot about AIDS in the last year falling by nearly half from 2006 to 2009.

The essays included in this report vividly illustrate the epidemic's impact on individuals and communities. Among those diagnosed in the epidemic's early years was the Founder and CEO of the Black AIDS Institute, Phill Wilson. In his essay, Wilson recalls the many friends and loved ones lost to AIDS, his own struggle to stay healthy, and the reasons why he left the business world to become involved in the fight against AIDS.

The report also includes a summary of key findings from a consultation that the Black AIDS Institute sponsored for several long-term survivors of HIV infection on May 21, 2011. Telling their stories and how AIDS has affected them, these long-term survivors describe what their lives were like in 1981, when they first heard about AIDS, how they are experiencing the process of aging with HIV, how surviving with AIDS has opened new opportunities, and the greatest achievements and biggest disappointments in the AIDS response. These stories capture both the extraordinary wisdom and resiliency of people who have lived with this disease for 25 years or more, and they underscore how the legacy of missed opportunities in the fight against AIDS continues to undermine efforts to combat the disease.



## Looking Forward: Building on Our Successes, Seizing New Opportunities

**A**s a new decade in the AIDS fight dawns, prospects have never been brighter for an actual end to the epidemic. In 2010, a South African research team reported results from the first study to find that a vaginal microbicide was effective in reducing women's risk of becoming infected. Results from a separate study also found that pre-exposure prophylaxis significantly reduces the risk that gay men will become infected, with especially strong protection seen in men who carefully adhere to the daily prophylactic regimen.

In May 2011, it was announced that a federally-sponsored trial found that early antiretroviral therapy reduced the likelihood of HIV transmission by 96 percent in comparison to later initiation of treatment. These results provide the most emphatic evidence yet that antiretroviral treatment is a critical component of effective HIV prevention.

Altogether, these recent results suggest that it is reasonable—indeed, imperative—for us to begin thinking about an “end game” for AIDS. However, it’s equally critical that we acknowledge



while a separate essay by his twin sister recalls both her concern when her brother told her of his infection as well as her admiration of his decision to devote himself to HIV work. A popular television personality explains why he decided to use his public platform to help educate people about AIDS.

Perhaps above all, these essays describe the human stakes of the choices that key decision-makers and Black leaders will make in future years in the fight against AIDS. "My struggle has taught me that—as a woman—I am the architect of my destiny," writes one 27-year HIV-positive Black woman. "HIV shattered my dreams but it also helped me rebuild them." Marking a major historical landmark, this report by the Black AIDS Institute is dedicated to the belief that we can prevent HIV from shattering more lives and simultaneously ensure that those living with the disease have the means to thrive.



## Recommendations for Action

After 30 years, it is time to get truly serious about ending AIDS. Now, for the first time, we actually have the tools to move to the "end game." To this end, the Black AIDS Institute offers the following priority recommendations:

### Build strong and durable treatment capacity in Black communities.

- Make major investments in HIV treatment science education in Black communities.
- Create a national network of AIDS treatment advocates in Black America.
- Establish a national network of HIV centers of excellence in Black communities.

### Sustain and strengthen the national AIDS response to capitalize on historic new opportunities to end AIDS.

- Maintain and increase funding for AIDS.
- Take immediate steps to eliminate all AIDS Drug Assistance Program waiting lists.
- Ensure that AIDS funding follows the epidemic by targeting spending to those who need it.
- Fully implement the Affordable Care Act.
- Take immediate steps to introduce new prevention tools.
- Invest in operational research to inform implementation of innovative new programs to capture the potential of treatment-as-prevention.
- Continue and strengthen investments in HIV prevention and treatment research.

### Create a single, comprehensive service continuum for HIV.

- Merge the federal response into a truly unified approach, integrating prevention and

treatment with streamlined reporting as a single focus for accountability.

- Planning for treatment and prevention services must be merged at the local level.
- Innovative operational funding and capacity-building support should encourage cross-fertilization of expertise and best practices among local service providers.
- Health care providers should be adequately reimbursed for a comprehensive array of prevention interventions, including HIV testing and counseling as well as diverse uses of antiretrovirals.
- Monitor HIV results.

#### **Pursue innovative strategies to market and promote HIV testing and treatment.**

- Undertake mass marketing campaigns to promote HIV testing and treatment.
- Mandate that all testing providers have strong and demonstrated links with HIV treatment settings.
- The offer of a voluntary, confidential HIV test should be made routine in a range of health, educational and service settings.

#### **Ensure strong leadership on AIDS—nationally, and especially within Black America.**

- President Obama should deliver a major address specifically dedicated to the fight against AIDS.
- Every Black institutions in the U.S. must develop and implement an AIDS strategy.
- Cultivate future AIDS leaders.

A black and white studio portrait of a person, likely a woman, dressed in a flight suit and a beret. The flight suit is heavily decorated with patches, including a peace sign, a skull, and a small American flag. The beret has a similar emblem. The person is standing with their hands on their hips, looking directly at the camera. The background is plain white.

# Getting Real

## Black Women Taking Charge in the Fight Against AIDS

By Hilary Beard  
Black AIDS Institut  
December 2005

## Amaechi gives NBA anti-AIDS weapon

Because of two recent acts — one of courage, the other of hate — the National Basketball Association has an historic opportunity to combat AIDS in

in "Homeboy" major. Among this, that the itself

stand he is not homosexual, my standing up and telling the truth about who he is, Amache also stood up for a healthy Black America. He struck a blow against the stigma and shame that keep too many in our community — gay, straight and anything in between — from talking openly about their sexuality and their sexual health.

all new HIV infections occurring among African Americans, we can no longer afford sexual silences of any sort.

back to the NAACP, which needs to come together to protect itself from the devastation of HIV/AIDS.

recent interview, Wilson, one of the NBA's most vocal critics of Black, was coming to grips with his own views on AIDS (the ways Black "should" last summer, Wilson boldly positioned himself among the leaders in supporting the new, more

against this epidemic. However, an unprecedented gathering of Black leaders and activists convened at the AIDS conference in Atlanta and pledged conference attendees to "end the silence and they counted themselves a deadly stigma surrounding sexuality and AIDS that they do list. However, some in our community still haven't gotten the message and former Mayor Hudspeth appears to be one left out of the know. His Saturday Day radio appearance

to demonstrate the opportunity and willingness to lead on the issue and to save lives. We call on you to do so. —DAN

The image shows the front cover of the magazine 'Kujisource'. At the top, the title 'Kujisource' is written in a large, stylized, orange font. Above the title, the text 'THE PEOPLE - GOD PREPARED - AAT SALVATION' is printed in a smaller, all-caps font. Below the title is a black and white photograph of Nelson Mandela, smiling and wearing a suit and tie. To the left of the photo is a green map of Africa with a green box highlighting South Africa. Inside this box, the text 'SPECIAL DURBAN EDITION' is printed in white. Below the map is a small illustration of a flower. On the left side of the cover, there is a column of text in a blue box. At the bottom left, there is a smaller photo of a man in a suit, with the caption 'Voices from Durban' and 'Felix Fallen Warrior'. The bottom right corner features the text 'AIDS SHADOWS BLACKS, LATINS' and 'MANDELA SLAMS AIDS 'RHETORIC''. The center of the cover has the text 'IN THIS ISSUE' and 'March For Treatment' followed by a list of names. The number '10' is printed in the bottom right corner.

**WILLIS EDWARDS**  
Hero in the Struggle



# The History of the AIDS Epidemic in Black America

When the Centers for Disease Control and Prevention issued its first report on mysterious clusters of profound immune suppression among gay men in Southern California in June 1981,<sup>1</sup> it was believed that the era of pandemic infectious disease had passed. At that time, most health experts believed, the principal health challenges that the U.S. would face would be rising rates of chronic diseases associated with affluence and increasing life expectancy.<sup>2</sup>

AIDS scrambled all such expectations, and many more. AIDS prompted many Americans to rethink sexuality at a time when conventional wisdom held that the results of the so-called “sexual revolution” of the 1960s were permanent. AIDS gave rise to a host of patient empowerment movements for different diseases, prompted major changes in processes for testing and approving new drugs, and resulted in the largest federal program ever implemented for managing a single disease.

The epidemic has also had dramatic effects in Black America, which has been more heavily affected than any other racial or ethnic group in the developed world. Thirty years after the first report on AIDS, that challenge continues for Black America, which accounts for 12 percent of the national population but for nearly half of all people living with HIV.

This chapter describes the epidemic’s impact on our world, telling the history of AIDS from different vantage points and particularly focusing on America’s domestic epidemic and its effects on Black America. Unfortunately, while progress has been made, we appear nowhere near the end point of the epidemic’s history. Indeed, the many twists and turns in the last 30 years underscore

the certainty that additional surprises are in store in future years. In the case of AIDS, ongoing vigilance is not just wise; it is essential.

## The Epidemic Itself

**A**lthough 2011 marks the 30th anniversary of the first official report, the history of AIDS is actually much longer. Testing on stored plasma samples indicates that individuals were infected with HIV in Africa as early as the 1950s.<sup>3</sup> Epidemiological estimates by UNAIDS suggests that considerable HIV transmission was occurring in the U.S. before 1981, although the epidemic remained unrecognized.

HIV is a global phenomenon. As of December 2009, an estimated 33.3 million people were living with HIV, including 2.6 million people newly infected in 2009.<sup>4</sup> Since the beginning of the epidemic, UNAIDS estimates that more than 60 million people worldwide have been infected with HIV and more than 25 million have died of HIV-related causes.

Because public health surveillance systems were much stronger in high-income countries

in the early 1980s than in the developing world, HIV in its early years was thought primarily to be a problem in North America and Western Europe, with heterosexual transmission in Central Africa first documented in 1983. In reality, HIV



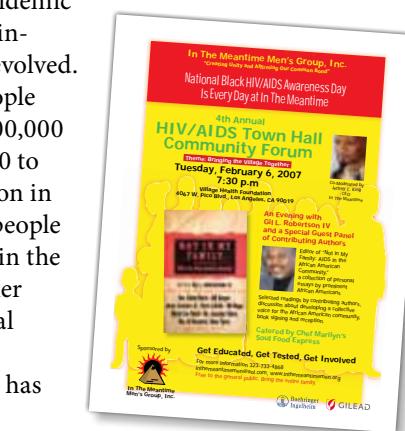
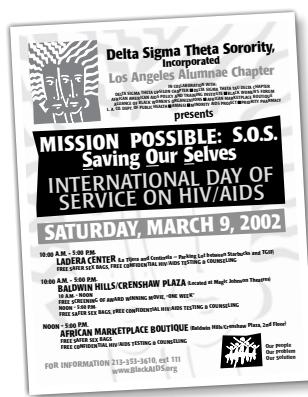
become plain that most people living with HIV resided in low- and middle-income

African countries.

In the U.S. alone, nearly 600,000 people had died of AIDS as of December 2009.<sup>5</sup> AIDS deaths in the U.S. peaked in 1994, when 47,636 people with AIDS died.<sup>6</sup> Globally, AIDS deaths peaked much later (2004), largely due to the fact that life-preserving antiretroviral drugs were not available in most low- and middle-income countries until recent years.<sup>7</sup>

The magnitude of the epidemic in the U.S. has progressively increased as the epidemic has evolved. The estimated number of people living with HIV rose from 400,000 to 450,000 in 1984, to 650,000 to 900,000 in 1992,<sup>8</sup> to 1.1 million in 2006.<sup>9</sup> An estimated 56,000 people are newly infected each year in the U.S., a rate considerably higher than was believed only several years ago.<sup>10</sup>

The epidemic in the U.S. has



undergone profound changes over time. In the late 1980s, Black people surpassed whites in the annual number of new HIV infections.<sup>11</sup> By 2006, Black people were 7.3 times more likely than whites to become infected.<sup>12</sup>

One of the enduring myths of the epidemic is that AIDS almost exclusively affected white gay men in the U.S. during its early years. In reality, AIDS had a disproportionate effect on Black America from the very beginning. Representing just 12 percent of the U.S. population, Black people accounted for 26 percent of all AIDS cases reported in 1981-1983.<sup>13</sup>

Outside sub-Saharan Africa, only four countries have HIV prevalence as high as the conservative estimates of the HIV burden in Black America. Indeed, were Black America its own country, it would have the 16th largest number of people living with HIV, with levels of infection rivaling numerous countries in Africa.<sup>14</sup>

Epidemiological patterns in the U.S. have changed since AIDS first appeared. In the late 1980s, the number of incident infections among injection drug users surpassed the number among men who have sex with men. Beginning in the early 1990s, however, this pattern reversed itself, as the number of new infections among drug users sharply declined while HIV incidence among gay and bisexual men began a steady increase that continues still.<sup>15</sup>

Throughout the epidemic, HIV has overwhelmingly affected men. However, for a brief moment in the late 1980s, the number of new infections among women approached the number of incident infections among men. Thereafter, the gender divide among people newly infected widened again, in large measure due to the steady increase in incident infections among gay and bisexual men over the last two decades. Currently, men now represent nearly three out of four new infections.<sup>16</sup>

## Public Awareness

**W**ith the risks associated with HIV now firmly ingrained in the public consciousness, one might be excused for believing this had always been the case from the epidemic's initial appearance. Sadly, America

# What is AIDS?

By Chris Brownlie

**I**t is a whimper, and a scream. It is the brush of a branch on the screen of your window, a rustle, a rattle. It is being in your center, and being so far from your center that you don't know if you'll ever find your way back. It is relentless. It is daunting, a great mountain which you MUST climb.

It is sweating, bleeding, puking and shitting in ways you never have before. It is pain you never imagined. It is fear you never dreamed. It is grief you never guessed. It is the frenzy of medicine. It is too many visits to the outpatient clinic, the two days in the hospital for tests, the weeks for the treatments. It is the doctor's kindness, the nurse's caring, the phlebotomist's apology. It is the doctor's prodding, the nurse's poking, the phlebotomist's piercing.

It is the manic need to make your mark, to leave some worthwhile trace of yourself behind. It is shattering denial every time the symptoms of another infection begin to mount. It is the loneliness, like the whistle of a train passing in the dark night of your soul.

It is caring for your friends in a way you never have before. Intimate ways, horrible ways, ways that take more of your love than you knew you had. It is being there when the coma comes, and it is begging in your heart for some little piece of mercy. It is going to the church, or the park, or the beach to say farewell and Godspeed, beloved one.

It is waking up wet, so wet, wetter than you were at birth. It is having your skull split

by its swollen lining. It is changing your pants again because at the critical moment you couldn't tell the difference between gas and excrement. It is changing your sheets because the stench woke you up.

It is anger, weird, quirky anger that knocks you off your pins and makes you doubt your own judgments. It is not knowing the difference between your needs and your desires. It is being disoriented by the force of the great emotional wind which is constantly blowing within you.

It is the fighting back. It is the building of places to care for the living and for the dying. It is courage, it is honor, it is integrity. It is people joining forces in a time of great need. It is hope, it is sharing the burden. It is people caring for their own and finding love, and surviving, and believing in the future even when we are hurting more than we have ever hurt before.

It is bearing the unbearable, enduring the unendurable, and hoping in the face of hopelessness. It is the haunted look in your lover's eyes when a new crisis begins. It is mourning together. It is mourning alone. It is holding him in your arms and in your heart. It is crying because your heart is breaking over leaving him behind. It is the sweet pain of knowing that you are dying, and the overwhelming sadness for those who will kiss you into their dreams.

It is a wail. It is a howl. It is beyond our grasp. It is awful. It is awesome. It is AIDS.

**wasted nearly a decade in the fight against AIDS, allowing the disease to grow into a full-fledged health crisis.**

The AIDS epidemic emerged while President Ronald Reagan was in power. With the exception of a brief mention of AIDS research at a 1985 press conference, Reagan never addressed the AIDS crisis until 1987. By the time Reagan formally addressed the AIDS challenge, hundreds of thousands of Americans had become infected and the number of AIDS deaths was increasing exponentially.

In the early years, AIDS was typically depicted as a uniquely "gay plague." Indeed, the first official name for the disease was Gay-Related Immune Deficiency (GRID) syndrome. After it became clear that injection drug users and hemophiliacs were also vulnerable to the disease, the name was changed to Acquired Immune Deficiency Syndrome.

Typical of the early media coverage of AIDS was a December 1985 article in *Discover* magazine, which contrasted the supposedly "vulnerable rectum" with the "rugged vagina." Accord-

## Still Standing After All This Time

by Phill Wilson

In 1981 I was living in Chicago. I had finally finished school. I had a job that my banker mother was proud of. "Phill is a marketing director with AT&T," she would tell her friends. And she had every right to be proud. She and my truck driver father had made tremendous sacrifices to make sure I got a great education. I lived on the 24th floor of Doral Plaza, a luxury apartment building on the Chicago's Gold coast—Tom Joyner was one of my neighbors. It was a long way from the Altgeld Gardens, the housing project on the south side of Chicago where I grew up. I was 25. Earlier that year, I discovered that I was gay. And, I was in love. Then it happened.

His name was Chris. He was 30. We met at the Club Baths. I had never met anyone like him. He had this mane of Black curly hair. He was skinny with bow legs—it was 1981 and skinny was in. He was funny, smart and a communist. Needless to say, our politics could not have been more different. But he made me feel safe. When I was with him I had no fear.

Chris had this cough that would not go away. He was always skinny, but he started to lose weight. He came home from a doctor's appointment one day. "So, what did he say?" I asked. "I have swollen lymph nodes." He responded. "OK, but what about the cough and the trouble breathing?" I asked. "Well, he wants to do a lymph node biopsy. There's this thing going around among gay men in New York and Los Angeles that has something to do with swollen lymph nodes," he said. "Well, I have swollen lymph nodes." I said. He looked weird, worried. "Maybe, I should have my lymph nodes biopsied too? We can do it together." I wanted to make him feel better. The biopsies came back abnormal. That's all they could tell us.

Chris and I found ourselves in Los Angeles in the spring of 1982. By the end of the winter of 1981, I was over Chicago winters. I went into my office to request

a transfer to California. My boss said they weren't doing any transfers. We were in the middle of the breakup of the Bell system. I said to him with the bravado only a 25-year-old full of himself could muster, "You don't understand. In two weeks the movers are coming to move me to California. The question is, when I get to California, will I work for AT&T or MCI. If I were you I'd prefer to have me on my team rather than the competition." Three weeks later, our car was packed and we were on the road.

Shortly after arriving in California, Chris and I attended a community meeting about this strange new disease at the Department of Water and Power in downtown Los Angeles. By then, it was called Gay Related Immune Deficiency Syndrome (GRID). By then, we had already lost our first friend, Armando, a member of our softball team back in Chicago. Some of our friends were already sick. I think we knew that Chris was already sick but we couldn't think about that. I needed to feel safe for a little while longer and he couldn't bear the thought of leaving me alone.

Chris and I started Black Is More Than Beautiful, a small giftware manufacturing business and started to volunteer, give money, and pretend to not notice that Chris was always sick. As the years progressed more friends grew ill and we learned a virus caused AIDS. In 1986 California placed Proposition 64—a proposal calling for the forced quarantine of all people with AIDS—on the election ballot. Both Chris and I volunteered to work for committees opposing the passage of Prop 64. We decided that I would take a leading role in the main "No on 64" Campaign. Chris would focus on the more radical "Stop AIDS Quarantine committee."

We defeated Prop 64, but by the time of the elections, Chris was really sick. My job in our company was to travel around the country doing the marketing. Given Chris' failing health and the amount of time we found ourselves working on the ballot initia-

tive AIDS related projects, we decided to close down our giftware business. I went to work for Stop AIDS Los Angeles. We went on to co-found the AIDS Hospice Foundation, which eventually became the AIDS Healthcare Foundation.

In 1987, I became concerned that AIDS was too easily being ignored in the Black community. By then, it was clear to me. AIDS was not just about white gay men. Black people were already 25 percent of the new AIDS cases. In 1986, 50 percent of the AIDS cases among women in the United States were Black. AIDS was never just a white gay disease. There was no place for Black Gays and Lesbians to go to talk about AIDS and get the skills needed to build the kind of community infrastructure we needed to fight the disease. In an effort to change that, we founded the National Black Gay and Lesbian Conference and one year later the Black Gay and Lesbian Leadership Forum (BGLL).

Chris died in 1989. As he had done from the first day I met him, he took care of me. He made sure I was ready before he went. He made sure I had time to figure out who I was and what I was meant to do.

I've seen a lot over the last 30 years. I've been there every step of the way. I've seen

the wins and the misses. I've lived with AIDS almost my entire adult life. I don't remember what it was like not to have HIV.

We are at a deciding moment. There has been an avalanche of scientific breakthroughs in the last two years—microbicides, new antibodies, Post-Exposure Prophylaxis (PEP), Pre-exposure Prophylaxis (PrEP), viral mapping, vaccine development, “treatment as prevention.” In addition, we finally have healthcare reform—of sorts—and a national HIV/AIDS strategy in this country. We have the tools to end the AIDS epidemic. We owe it to Chris, and Reggie, and all of our friends and loved ones lost to this disease to use these tools to put an end to this thing. We owe it to my nephews and nieces, to Kali Villarosa, a 14-year-old girl in Brooklyn who is already an AIDS activist, and young people everywhere to not leave them with this mess.

I'm scared. Not of the virus any more. Actually, I was never really scared of the disease. I always figured my dying would take care of itself. It didn't need my help. My job was to take care of living. I'm afraid we won't do our part. I'm afraid, when asked, “What did you do during the plague years?” The answer will be not enough.

ing to the article, “AIDS isn't a threat to the vast majority of heterosexuals . . . It is now—and is likely to remain—largely the fatal price one can pay for anal intercourse.”<sup>17</sup>

The fact that such assertions flew in the face of scientific fact did not diminish their impact on public perceptions. As early as 1983, CDC had documented the transmission of HIV during heterosexual intercourse.<sup>18</sup> By 1983, a full-fledged epidemic of heterosexually transmitted HIV had been confirmed in Africa.<sup>19</sup> Between 1984-1987 and 1988-1990, the annual number of heterosexually acquired HIV infections in the U.S. more than doubled, and today heterosexual transmission is second only to male-male sex as a leading source of new infections.<sup>20</sup> Black people account for more than 64 percent of all cases of heterosexually acquired HIV in the U.S.

Although facts would rapidly overtake the idea that AIDS was only a “gay problem,” the perception of AIDS as a gay disease would un-

dermine efforts to increase awareness of the full spectrum of risks associated with the virus. In particular, popular misconceptions about HIV-related risks long impeded efforts to increase AIDS awareness in Black America.

The strategies used by public health authorities to track the epidemic often compounded these difficulties. Beginning in the early 1980s, most state and local health departments kept track of AIDS diagnoses rather than positive HIV test results. Because roughly a decade or so



typically transpires between a new HIV infection and a diagnosis of AIDS in the absence of treatment, these AIDS case reports failed to detect emerging infection trends. Thus, the dramatic

rise in new infections among Black Americans in the 1980s only became apparent the following decade when these infection patterns were reflected in AIDS case reports.

These weaknesses in epidemiological monitoring proved especially damaging to efforts to call attention to HIV-related risks experienced by Black gay and bisexual men. Even as AIDS was regarded as a primarily “white gay” disease in the 1980s and early 1990s, infection rates among Black gay men were spiraling out of control. Only when CDC and various state and local health departments sponsored

HIV surveys of gay and bisexual men did the disproportionate risks to Black gay men become plain. In one five-city study by CDC, 46 percent of Black gay men were found to be HIV-infected in 2004-2005.<sup>21</sup> While this and other comparable studies dramatically increased public awareness of the extraordinary HIV burden among Black gay men, this spike in attention occurred only after tens of thousands of men had become infected.

Courageous leadership has played an important role in building public awareness. Even while belonging to an administration for which AIDS barely registered as a priority, former Surgeon General C. Everett Koop took the initiative to develop an official report on AIDS. In 1988, Koop sent an AIDS informational mailing to every household in the U.S.

Leaders on AIDS emerged from unexpected quarters in the epidemic’s early years. Especially noteworthy was the role played by the actress Elizabeth Taylor, who worked tirelessly on behalf of the American Foundation for AIDS Research (now amfAR) to draw attention in the 1980s to



the rapidly expanding crisis. Revealingly, Taylor had little success in the 1980s in recruiting other Hollywood celebrities to contribute to the AIDS fight.

The AIDS-related death of actor Rock Hudson in 1985 shocked the country and dramatically increased AIDS awareness. A similar effect resulted from the AIDS diagnosis in 1988 of tennis great Arthur Ashe, one of only two Black men to win a Grand Slam tournament. Before his death in 1993, Ashe established a private foundation to fight AIDS.

Public awareness of the AIDS crisis, especially in Black communities, underwent a sea change in 1991, when basketball great Earvin “Magic” Johnson announced that he had tested HIV-positive. After his announcement, HIV testing rates in Black communities skyrocketed, as many Black Americans awoke to the reality that AIDS was not only a problem for gay men. The Magic Johnson Foundation continues to contribute to the AIDS fight, providing HIV medical services to more than 1,200 people in communities of color, testing nearly 30,000 people, and providing grants to community organizations.

Over the years, complications related to AIDS would claim the lives of leaders from all walks of life in Black America, bringing growing attention to the health threat in Black communities. Black luminaries who died of AIDS-related causes included ABC News anchor Max Robinson, dance legend Alvin Ailey, gospel recording artists James Cleveland, and writer Essex Hemphill.

As the epidemic’s third decade draws to a close, evidence indicates that AIDS awareness is highest in Black America. While Americans overall do not rate HIV as one of the country’s five most serious health problems (according to 2009 survey data), Blacks consider HIV the second most serious health problem, following cancer. Blacks are significantly more likely than Americans as a whole to fear contracting HIV, and 80 percent of Black parents of children 21 or younger worry that their child may become infected.<sup>22</sup>

However, there are disturbing signs that public concern about AIDS is declining. Even among Black Americans, the most heavily affected racial or ethnic group, the percentage of people who report having heard a lot about HIV in the past year fell from 62 percent in 2006 to 33 percent in 2009.<sup>23</sup>

## Scientific Knowledge About HIV

**P**erhaps more than any other major health problem, AIDS highlights the extraordinary potential of scientific knowledge. Unfortunately, scientific knowledge has not always been put to use in responding to AIDS.

When AIDS first emerged in the early 1980s as a frightening new disease, CDC investigators rapidly determined how the disease was transmitted.<sup>24</sup> CDC was swiftly able to assure the public that transmission through casual contact was impossible, although misperceptions regarding the disease would endure.

In 1983, French scientists isolated HIV as the cause of AIDS. Two years later, the first test to diagnose the disease was licensed. Over the epidemic's three decades, HIV testing technology would continually improve, permitting infection to be diagnosed within days or weeks of initial exposure. One important result of these advances was the near-eradication of HIV transmission as a result of blood transfusions or other blood products, a major source of infection in the epidemic's early stages. Improvements in testing technologies include the development of rapid tests and the emergence of oral testing.

Progress in treating HIV was too slow to save millions worldwide, but advances have nevertheless been steady. In the epidemic's early years, the primary cause of HIV-related death was pneumocystis pneumonia. A common pathogen that poses little risk to people with healthy immune systems, pneumocystis deprives the body of oxygen in severely immune-compromised individuals. An early advance in reducing the risk of HIV-related death was the development of pneumocystis prophylaxis with pentamadine. Since that time, other prophylactic and therapeutic developments have occurred, rendering death as a result of pneumocystis rare in the U.S.

During the early years of AIDS, government researchers and pharmaceutical companies began testing an array of compounds for their activity against HIV. The first drug approved to treat HIV infection itself was AZT, or zidovudine. AZT therapy produced favorable early

results in many patients, although resistance tended to develop quickly in most patients. In 1993, a major international study found that early initiation of AZT did not extend life for people living with HIV.<sup>25</sup>

After the approval of AZT, additional antiretroviral drugs were licensed by the Food and Drug Administration for the treatment of HIV. Like AZT, these antiretrovirals attacked various stages of the viral replication process. However, also like AZT, use of these drugs, either singly or in combination with another drug, was rapidly overwhelmed by resistant virus.

In the mid-1990s, a transformative event occurred. An entirely new class of antiretroviral drugs, protease inhibitors, emerged. By combining multiple classes of antiretroviral drugs, doctors were able to attack the viral replication process from several angles, sharply slowing the emergence of resistance. For those able to obtain the drugs, combination antiretroviral therapy, or Highly Active Antiretroviral Therapy (HAART), represented a lifeline. In the U.S. and other high-income countries, AIDS death rates plummeted as a result of the new medicines. As HAART was expanded to developing countries in the last decade, similar results have been achieved.<sup>26</sup>

Black America

**Black AIDS Institute strategies plan on ending AIDS epidemic in Black America**

Sen. Barack Obama last week became the second presidential contender to show bold leadership by calling for a national AIDS plan to guide America's response to the domestic epidemic. Obama released his AIDS platform on his Web site on Oct. 16 and listed as the top priority the development of a national strategy to target resources, a call that echoes John Edwards' platform, released last month.

The Black AIDS Institute urges every candidate in both parties to join Obama and Edwards in both publishing an AIDS platform and committing to the development of a national AIDS plan if elected president.

The United States wisely insists

that any country seeking foreign assistance for its AIDS effort first develop an overall plan for directing those resources. More than 26 years into the epidemic, however, the U.S. still does not have its own blueprint for ending AIDS domestically—an epidemic that is larger today than ever, with nearly 1.2 million Americans living with HIV/AIDS, according to federal health monitors.

America's AIDS epidemic is uniquely Black. Nearly half of all people living with HIV/AIDS in America and over half of those newly infected every year are African Americans, though we represent just 13 percent of the U.S. population. And despite an annual AIDS budget of more than \$2 billion, America continues to log an estimated 40,000 new infections a year. Thousands of people—disproportionately African Americans—continue to die from AIDS every year. Local safety net programs all over the country have collapsed, forced to turn away poor people in search of treatment and care—at least four people died in South Carolina in 2006 while awaiting access to the publicly-financed AIDS drug insurance program.

Meanwhile, racial disparities continue to widen in every corner of the epidemic. Whether you measure infections by gay men, heterosexual women, youth or any other population, African Americans are vastly overrepresented. Clearly, the resources need to better planned and targeted.

As a result of all of this, a coalition of traditional African-American institutions, ranging from civil rights groups like the NAACP to faith leaders like Bishop T.D. Jakes, have banded together to develop a community-wide plan of action. Each organization is now crafting a strategic plan for folding the fight against AIDS into its broader work.

In addition, the Black AIDS Institute is also demanding that the government support the effort. The first step in doing so is having the same sort of strategic plan that our community is developing for itself.

*To learn more, visit [BlackAIDS.org](http://BlackAIDS.org)*

has benefited from treatment breakthroughs but not to the same extent as whites. Indeed, evidence indicates that Black-white disparities in HIV-related medical outcomes have actually widened in the HAART era.<sup>27</sup> The sub-optimal HIV

## We Have Survived

### Reflections of Six Long-Term Survivors

**D**uring the darkest days of the epidemic—the 1980s and early 1990s—a positive HIV/AIDS diagnosis often included a prognosis of just months to live. Yet under the era's devastatingly adverse conditions—AZT toxicity, bouts of pneumocystis pneumonia (PCP), losing partners, friends and loved ones—some people not only survived but thrived. Today, many Americans with HIV/AIDS live for decades, in no small part because of their advocacy work.

Infected over 30 years ago, Black AIDS Institute president and CEO Phill Wilson has had HIV/AIDS since his early 20s. In late May he moderated a virtual roundtable discussion with other Black long-term survivors, all of whom have lived with HIV for over 20 years.



**Cornelius Baker**

Chairman of the Board, Black AIDS Institute  
Member of the Presidential Advisory Council HIV/AIDS  
Diagnosed in 1986



**Hydeia Broadbent, 27**

Motivational speaker  
Born HIV-positive in 1984



**Vanessa Johnson, 53**

Executive Vice President, National Association of People with AIDS  
Diagnosed in 1990



**Jesse Milan Jr., 54**

Vice President, Altarum Institute  
Chairman Emeritus, Black AIDS Institute  
HIV-positive for 29 years



**Ron Simmons, 61**

Executive Director, Us Helping Us  
Diagnosed in 1989



**Rae Lewis-Thornton, 49**

Pastor and Motivational Speaker  
Diagnosed at 23

**PHILL: Who and where were you in 1981?**

JESSE: I graduated from law school that June and moved to Philadelphia. I was starting my professional career and my independent personal life as an openly gay man.

VANESSA: I was 23 and had just graduated with a degree in marine biology. I was working for the New York State Senate.

RON: I was 31 and had moved to Washington, D.C., that August to start my doctorate at Howard University. I was working on one of the first Black gay magazines in the country.

RAE: I'd just turned 20. I was doing political organizing on my college campus, registering students to vote and very active in the Free South Africa Movement.

HYDEIA: In 1981? I wasn't even born yet!

PHILL: Hydeia that is exactly why it is so important to have you here. So that young people can understand that some people have been involved in the epidemic from the very beginning—and others for literally all of their lives.

**PHILL: Where were you when you first heard about HIV or AIDS—or as it was called then, "Gay Related Immune Disorder," or GRID?**

RAE: It was 1983 and I was working at Operation Push as an intern. At the end of each staff meeting, we would pray and Rev. Jesse Jackson would say, "Let's keep Keith in our prayers." I turned to someone and said, "Who's Keith? And they said, "Shhh!"

After the staff meeting, I was told that Keith was PUSH chairman Reverend Willie T. Barrow's only son, and he had AIDS. The irony was that I was already infected; I just didn't know.

VANESSA: I was working for the New York State Department of Health. I heard about it as GRID. I was stunned because they started showing pictures of folks who were basically ... emaciated. It was scary.

JESSE: I read about GRID for the first time in the fall of 1981. I thought it was localized in the gay community in San Francisco. I thought there was probably something going on there and I didn't need to worry about it.

HYDEIA: I was born HIV-positive. My mother told me. We would speak about it at the dinner table. It wasn't a secret. It was like being Black and being a girl. It's something that you know you are.

**PHILL: What's the hardest part about getting older with HIV?**

HYDEIA: Learning to handle my own medical care. That was the hardest part because my mom did everything. Now, I have to fight for insurance and worry about my medications.

JESSE: Knowing the virus is still in my body and that there is nothing on the horizon that is going to eliminate it from my body.

RON: I just cannot see any negatives to it. It's such a blessing to get older and have HIV.

**PHILL: What's the best part about getting older with HIV?**

HYDEIA: I love saying my age because it's a celebration. I'm reaching a fabulous 27 this year.

RAE: I expected to be dead by now. To wake up in the morning and being aware that I am a part of God's earthly plan, it's just a wonderful thing.

VANESSA: I'm alive. They told me when I was diagnosed in 1990 that I had seven years. That was 20-plus years ago.

**PHILL: What have you accomplished that you would not have been able to accomplish if you weren't HIV-positive?**

VANESSA: Having a meaningful relationship with my son. Once I made up my mind that I was gonna live with this disease, I was able to be a mother to him rather than run away from my responsibilities.

CORNELIUS: Letting go of any fear of death. Everything becomes just a full embracing of the present and being in that moment.

RON: Once you lose that fear of death, life takes on a whole new meaning.

JESSE: When I was informed of my diagnosis, I never thought I would live for 29 years with the virus. That is an

accomplishment.

RAE: God gave me a new plan. I couldn't have imagined that God would take something as ugly as what the world has said AIDS is—and done something awesome with my life with it.

**PHILL: How have you survived and what would you say to others is the key to surviving HIV?**

RAE: Letting go of the shame. The secret was going to kill me quicker than the disease. It was unbearable weight to have to take medicine in the bathroom, tear the labels off my pill bottles—before I threw them in the trash because I didn't want anyone to see.

CORNELIUS: You have to have a purpose. For me, it's been based on making sure that we, as a people, get through this and enjoy all the rest of life. Experiencing the gifts and graces.

VANESSA: We've found ways to use our anger and to project it for positive outcomes. Many things have been accomplished towards fighting the AIDS epidemic with the intense anger that many of us have experienced. I also had to start thinking about the role I played in things that kept repeating in my life and take some responsibility and control.

HYDEIA: God allows me to survive. Just keeping myself motivated, not having anger, not being bitter. I've never been angry or bitter about having AIDS. My mom always told me everything that lives must die. Just enjoying my life.

PHILL: I was infected when I was 23; I am now 55. I decided that my life was not a democracy; it was not a parliamentary process. It was a monarchy, and I was king of it—nobody else had a vote. I had a right to make every single decision and a responsibility to get the best advice that I could. If I was going to have to die on my own, then I might as well take control of the living process.

RON: I decided that I was going to live my life for my life. I was diagnosed in 1989, when the average lifespan was like six months. If you lived 18 months, you were really doing well. The doctor said, "If you take

AZT, you'll live two or three years." My attitude was, "I'm not looking for two or three years. I'm looking for 20 or 30 years."

**PHILL: Are you on treatment? If so, what kinds?**

RON: I'm taking Atripla and I've been on treatment since 2003.

JESSE: I was in a clinical trial for 10 years. That may have been a useful part of my long term survival. In August of 2009, I went on triple combination therapy, Norvir, Sustiva and Reyataz.

HYDEIA: I've been on different types of treatment my entire life—intravenous, pills, all kinds of things. I take Truvada, Norvir and Reyataz right now.

VANESSA: I have been off and on treatment since 1990. I was in a Crixivan clinical trial in 1995. Now I'm on Truvada, Aprivir and Reyataz.

RAE: I'm first generation AZT. I've been on treatment since, oh, I don't know, 1989. I'm currently on Isentress, Emtriva, Norvir and Ritonavir.

PHILL: I was on the AZT clinical trial when you had to take it every four hours [LAUGHTER]. But I am currently on Norvir, Reyataz and Truvada. So, Hydeia, you and I are teammates.

**PHILL: I want to touch upon the importance of Black people being involved in clinical trials—from researchers to technicians to volunteers.**

RON: I have two feelings. One, it is important for Black people to be part of clinical trials because, given the burden we have of the disease, whatever they come up with, we have to know it works for us. That was one of the mistakes about AZT—that Black people were not in the original AZT trial.

At the same time, given the entire healthcare pharmaceutical industrial complex, I'm not ready to join any kind of trial. I simply am not going to help Big Pharma make more money. They have made their billions and watched people die and couldn't care less. I'll be damned if they're gonna use me as a guinea pig to come up with their next moneymaker.

JESSE: I think it's important for Black people to be involved in clinical trials. But the decision to participate should be based on whether you trust the medical person recommending you for that clinical trial. If you don't trust that person, then I wouldn't do it.

About researchers and other aspects of clinical trials, I think Black people should definitely be involved. But the fundamental question for a patient is, "Do you trust the medical provider who's recommending this?"

**PHILL:** *What were the major policy "misses" over the last 30 years, the opportunities where we could have moved forward but didn't? How could we have prevented many AIDS-related deaths?*

JESSE: We waited much, much too late to help the African American community understand that they were at risk for HIV.

PHILL: Right. Black people get AIDS.

RAE: Ditto.

RON: Yep, I agree.

HYDEIA: I agree.

**PHILL:** *Living with HIV/AIDS can be a roller coaster. What was your lowest point and how did you get through that experience?*

VANESSA: I was diagnosed in 1990. That was probably the worst emotional experi-

ence in my life. How did I get through it? One day at a time. My family was very instrumental: They kept feeding me information that indicated that seven years could turn to 12 years, could turn to 15 years.

RON: Probably when I had HIV and tuberculosis in 1996. Being in my apartment all by myself and too weak to get out of bed. Thinking that I could die and it would be days before anyone noticed. Unity Fellowship Archbishop Carl Bean called me and said, "You've been at the top of the mountain for a while now. It's time for you to walk through the valley." And it dawned on me that I really had been blessed. Now it was time for me to go through a hard part. And that really helped me hang in there.

JESSE: When my late partner died. I had to go into a very spiritual place—understanding that it was his time to go and I had no control over that. It was his time to die not mine.

RAE: My lowest point was after my third bout of PCP. I just knew that I was gonna die. What got me through the most was a sense of purpose for my life. I kept pushing through the pneumonia. I could see death stare at me in the face. But God is the keeper.

**Rod McCullom,** a writer and television news producer, blogs on Black gay, lesbian, bisexual and transgender news and pop culture at [rod20.com](http://rod20.com).





**President Barack Obama**

outcomes experienced by Black Americans stem from a combination of late diagnosis of HIV, inadequate health care access, discontinuity of care, treatment adherence challenges, and a higher prevalence of other serious co-morbidities.<sup>28</sup>

Scientific knowledge about preventing HIV has also expanded since the epidemic first appeared. An impressive body of data has emerged regarding effective prevention strategies, including behavior change programs, sex education for young people, condom promotion, and needle exchange and other measures to prevent drug-related transmission.<sup>29</sup> Unfortunately, squeamishness about human sexuality and drug use has inhibited these tools from being used as effectively as they could be. According to a national survey of more than 10,000 gay and bisexual men in the U.S., only 15 percent have ever participated in an individual program to build sexual risk reduction skills.<sup>30</sup>

Beginning in the 1990s, research sponsored by the National Institutes of Health found that strategic use of antiretrovirals could sharply reduce the odds that a pregnant woman would transmit HIV to her newborn. Over time, additional studies have expanded the knowledge base on prevention of mother-to-child transmission, identifying optimally effective regimens and approaches. As a result of these breakthroughs, the number of infants who become infected with HIV each year in the U.S. has fallen by more than

90 percent since the early 1990s.<sup>31</sup> These advances have had particularly beneficial effects in Black communities, as Black women account for more than 60 percent of all women living with HIV in the U.S.

The knowledge horizon for HIV prevention continues to expand. In 2010, researchers in South Africa found that a vaginal microbicide containing an antiretroviral reduced the risk that a woman would become infected during sexual intercourse by 39 percent.<sup>32</sup> Also in 2010, researchers reported that a daily oral combination of the antiretrovirals emtricitabine and tenofovir reduced the risk of HIV acquisition among gay and bisexual men by 44 percent, with significantly higher protection found among people who carefully adhered to the daily regimen.<sup>33</sup>

In recent years, there have also been emerging signs that treatment itself plays an important role in preventing new infections. By reducing viral load, often to the point that it becomes undetectable under standard tests, antiretroviral therapy is believed to reduce the infectivity of people living with HIV. In San Francisco, a 40 percent drop in community viral load earlier this decade was associated with a 45 percent reduction in new HIV infections.<sup>34</sup> The prevention potential of antiretroviral therapy was underscored in 2011, when NIH study results found that early treatment reduced the likelihood of transmission within serodiscordant couples by

96 percent.<sup>35</sup> (A separate article appears in this report highlighting the importance of these new research findings.)

Progress towards the development of a preventive vaccine has been slow yet real. After disappointing results from large-scale trials of candidate vaccines, a large randomized trial in Thailand of a combination vaccine found evidence of modest efficacy.<sup>36</sup> Although the level of efficacy found in the Thai trial is not believed to warrant steps toward licensing the vaccine, the results nevertheless indicate that vaccination against HIV is likely to be feasible. Identification in recent years of antibodies that appear to neutralize HIV has generated increased enthusiasm over prospects for developing a safe and effective vaccine.

## Government Action to Fight AIDS

**I**n the epidemic's early years, government action to address AIDS remained rare. With the exception of a handful of local governments, such as San Francisco, authorities largely watched while the epidemic rapidly worsened. In New York City, the epicenter of the U.S. epidemic, then-Mayor Ed Koch refused for years even to meet with gay leaders to discuss AIDS.

Early steps by CDC to respond to AIDS included the establishment of an information line in 1983 and an AIDS clearinghouse in 1987. However, the agency did not truly begin to invest in community-based prevention programs until the late 1980s and early 1990s.<sup>37</sup>

NIH's early steps on AIDS were also somewhat meager. In 1982, when new AIDS cases and AIDS deaths were increasing exponentially, total NIH spending on AIDS research was \$8 million. By way of comparison, this is half the amount currently spent by NIH on research on otitis media, an inner ear problem that typically heals on its own.<sup>38</sup> Since its early low-level focus on AIDS, NIH has become the world's most important funder for AIDS-related research, allocating more than \$3.4 billion towards AIDS research in Fiscal Year 2010.<sup>39</sup> Indeed, NIH is largely responsible for many, if not most, of the scientific breakthroughs on AIDS.

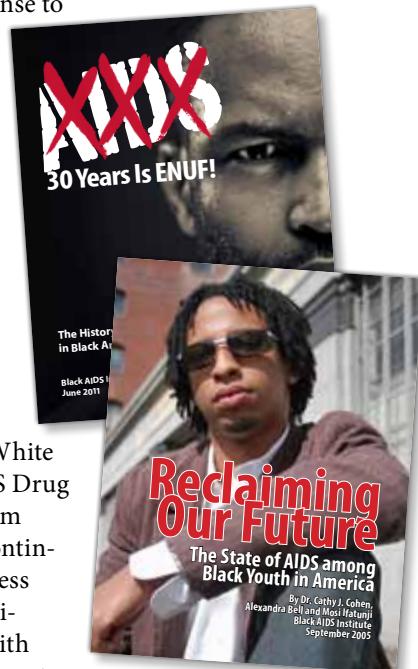
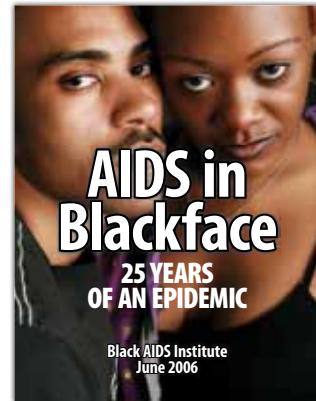
By the end of the 1980s, America's lethargic response to AIDS had become a national embar-

rassment and a potential political liability for the President. Under President George H.W. Bush, the National Commission on AIDS was established in 1989. Assessing the national response to AIDS, the Commission issued biting reports that called for greater political commitment and urgent attention to the AIDS challenge.<sup>40</sup> President Bush met with leaders of the National Commission but largely ignored the group's findings and recommendations.

During the administration of the first President Bush, a major achievement that transformed the national response to

AIDS was passage in 1990 of the Ryan White CARE Act. The Ryan White program provides grants to hard-hit cities and all 50 states to support care initiatives for people living with HIV. One of the most important features of Ryan White has been the AIDS Drug Assistance Program (ADAP), which continues to provide access to life-saving medicines for people with HIV who lack adequate health coverage. Funding under Ryan White has increased over time, reaching more than \$3.4 billion in FY2010, including \$858 million in funding for ADAP.<sup>41</sup>

Upon assuming office in January 1993, President Bill Clinton took steps to strengthen the national response to AIDS. A White House Office of National AIDS Policy was established, and a high-level presidential advisory council was appointed to make recommendations. Funding for AIDS programs increased, a national effort to discover an AIDS vaccine was launched, and the



AIDS research program at the NIH was reorganized to increase coordination and strategic focus.



million in 1998 to \$421 million in 2010. Although President Clinton brought new enthusiasm to the AIDS fight, he rejected the advice of his health officials and refused to permit federal funding for needle exchange programs to prevent new infections.

The national response lost energy under President George W. Bush. Whereas Ryan White had benefited from healthy annual increases during the Clinton administration to enable the

program to meet growing demand, domestic AIDS funding generally flattened during the second Bush administration.<sup>42</sup> As a result of funding shortfalls, numerous states created waiting lists or restricted eligibility for life-saving ADAP drugs.

One important bright spot during the second President Bush's two terms was U.S. leadership on global AIDS issues. In particular, President Bush created the President's Emergency Plan for AIDS Relief (PEPFAR), the largest single program to tackle a specific disease.

Through September 2010, PEPFAR had supported antiretroviral treatment for 3.2 million people in developing countries and averted 114,000 new infections in

infants as a result of scaled-up services to prevent vertical transmission.<sup>43</sup>

As a presidential candidate, then-Senator Barack Obama vowed to create the country's first comprehensive strategy to combat the domestic AIDS epidemic. In 2010, President Obama made good on his promise by unveiling the National HIV/AIDS Strategy.<sup>44</sup> The strategy includes concrete targets for the national response, including a 25 percent reduction in the number of new infections by 2015, ensuring that 90 percent of all people living with HIV know their HIV status, and concrete reductions in HIV-related health disparities.

President Obama also took additional steps to strengthen the country's fight against AIDS. The President reinvigorated the White House Office of National AIDS Policy, reconvened the Presidential Advisory Council on HIV/AIDS, and approved the use of federal funding for harm reduction programs for drug users. (The President also lifted the longstanding ban on immigration of people living with HIV, a measure discussed in more detail below.)

Throughout the country's fitful three-decade response to its domestic epidemic, one notable feature has been the low priority accorded efforts to prevent new infections. In 2010, only 4 percent of federal HIV-related funding was allocated to HIV prevention programs.<sup>45</sup> President Obama's proposed budget for Fiscal Year 2012 calls for a 7.6 percent increase in funding for CDC prevention programs.<sup>46</sup>



## The Mobilization of Communities

**A**ffected communities have led the way in responding to AIDS in the U.S. The earliest prevention programs were created and delivered by community volunteers in urban gay communities,<sup>47</sup> and AIDS service organizations emerged in cities across the U.S. in the early 1980s.<sup>48</sup>

Throughout the three decades of AIDS in the U.S., the empowerment of people living with HIV has remained a central feature of the national response. In 1983, people living with AIDS gathered in Denver, articulating a set of principles and founding what became known as the PWA Empowerment Movement. The Denver Principles insisted that people with AIDS were

entitled to participate in all decisions affecting their lives. These principles were incorporated in the mandates of the Ryan White CARE Act, which require that local planning councils for HIV services include robust and meaningful participation of people living with HIV.

An empowered patient population radically changed American attitudes and practices regarding health care. Not content to wait for new treatments to emerge from industry, communities banded together to lobby for increases in federal HIV research spending, to create buyers' groups to provide patients with access to unapproved but promising drugs, and to establish treatment information resources to help patients participate in their own care. People living with HIV soon became arguably the most organized and educated of all patient groups, developing approaches that have been enthusiastically emulated by advocates for breast cancer and other diseases.

With few treatment options available in the early years of the epidemic, activists joined together to create AIDS Coalition to Unleash Power, ACT UP. Although the group would run out of steam in a few years—with the exception of some local chapters, such as ACT UP Philadelphia, which has remained active—it played a critical role in the late 1980s in focusing national attention on the need for a stronger AIDS research effort. Early ACT UP leaders also worked with congressional leaders during the early years of the Clinton administration to redesign the country's research and drug approval process, which arguably accelerated progress toward subsequent treatment breakthroughs.

Most of the early activism on AIDS was centered in largely white gay communities in New York, San Francisco and other cities. In 2011, many of the same organizations created in the epidemic's early years continue to provide the backbone for AIDS services and advocacy, even though the face of AIDS in the U.S. has been transformed over the years.

However, Black communities also began mobilizing in the epidemic's early years in response to rising rates of HIV infection. Led by longtime activist Reggie Williams, the National Task Force on AIDS Prevention was founded in 1988 to lead HIV prevention efforts among Black gay men. The National Black Leadership Commission on AIDS, founded in 1987, aimed to educate, organize and empower leaders in Black communities across the U.S. to lead the fight against AIDS. The

Balm in Gilead has undertaken extraordinary efforts to mobilize faith leaders in Black communities to lead the AIDS fight.

These early national groups were followed by countless community organizations across the U.S. that supported AIDS programs and activities in Black communities. In comparison to the major AIDS service and advocacy organizations created by gay men in the early 1980s, many Black community groups have long remained poorly funded.

The Black AIDS Institute, the only national think tank specifically devoted to HIV issues in Black America, was launched in 1999. The Institute has focused on mobilizing and building the capacity of traditional Black institutions. This approach recognizes that unlike gay communities, which generally had weak community infrastructures when AIDS first appeared in the early 1980s, Black America has a robust network of prominent political, cultural and educational organizations. For example, NAACP

began to increase its visibility on AIDS issues in the late 1990s, with former chair Julian Bond playing a particularly active role in promoting AIDS awareness in Black America. At the 2006 International AIDS Conference in Toronto, more than 20 leading figures in Black America gathered to pledge greater action to fight AIDS in Black communities.

Over the last several years, the Institute has worked with 16 leading national Black organizations to build their institutional focus on AIDS. Each of these organizations has developed their first-ever national AIDS strategies and action



plans, and hired focal points to oversee AIDS-related work. This approach benefited greatly from the CDC's Act Against AIDS Leadership Initiative, launched in 2009. The CDC initiative has provided funding to leading Black organizations to support their efforts to engage their constituents in the AIDS response.

## Stigma, Discrimination and AIDS Hysteria

**S**ince AIDS appeared, the disease has been accompanied by an epidemic of fear, ignorance and social isolation. In part, AIDS merely followed in the footsteps of other stigmatized diseases of the past, such as cancer, syphilis and tuberculosis. However, the link in the public mind between AIDS and homosexuality arguably exacerbated the stigma associated with AIDS.<sup>49</sup> In the 1980s, Congress enacted legislation proposed by the late Sen. Jesse Helms to bar federal HIV prevention funding for any program found to "promote" sexual activity.

Surveys during the epidemic's early years consistently detected a high prevalence of negative social attitudes toward people living with HIV in the U.S.<sup>50</sup> People diagnosed with the disease lost their jobs, were kicked out of their homes, had their health insurance terminated, and were ostracized by their families. Some health insurers that provided ample coverage to people with other health conditions imposed onerous lifetime coverage caps for people living with HIV. In many parts of the U.S., health care workers refused to care for people living with HIV. The Ray family in Florida, with three hemophiliac brothers who contracted HIV through blood products, had their house burned and were refused admission by local schools. Ryan White, an HIV-positive American teenager living in Indiana, was expelled from school because of his infection during the epidemic's early years.

Unfortunately, government policies in the early years often served to magnify, rather than alleviate, stigmatizing attitudes toward people living with HIV. While generally avoiding support for prevention, treatment and care programs for people living with HIV, the Reagan administration turned to mandatory HIV testing as its principal AIDS strategy. During the Reagan years, mandatory testing was implemented in

a number of federal programs, including the military, the foreign service, and the U.S. Job Corps, with those testing positive deemed to be ineligible for service or benefits. This approach suggested to the public that people with HIV were dangerous sources of infection and were to be shunned and isolated. In addition, with the military and the U.S. Job Corps disproportionately attracting Black participants, mandatory testing in these programs had particularly severe negative impacts in Black America.

In the 1980s, the U.S. implemented rules barring the entry of foreigners infected with HIV, even though a broad range of medical and public health professionals decried the discriminatory and baseless nature of this approach. In particular, the immigration restriction, which was repealed only in 2010, suggested that people living with HIV were dangerous sources of disease. Ironically, HIV prevalence tended to be higher in the U.S. than in most foreign countries, theoretically placing foreigners at greater risk of becoming infected from an American citizen than vice versa.

Early epidemiological reports on AIDS classified Haitians as a separate risk category.<sup>51</sup> This practice, which was eventually abandoned as baseless, deepened the social isolation of this population and contributed to discriminatory treatment of Haitian-Americans.

In 1990, with the support of the first President Bush, Congress passed the Americans with Disabilities Act (ADA) of 1990, which proved to be a watershed in the fight against ignorance and fear. As a result of the ADA, people living with HIV for the first time enjoyed broad national anti-discrimination protections. In particular, ADA nullified many of the most heinous restrictions imposed by private health insurers on coverage of HIV-related treatments.

As the epidemic persisted and more and more Americans knew a person living with HIV, negative social attitudes declined. However, they did not disappear. As late as 1999, one in three Americans surveyed said they had negative feelings toward people living with HIV.<sup>52</sup> Misconceptions about the disease and judgmental attitudes toward those affected continue to impede rational, effective responses to the problem.

Although there is little evidence that homophobia is more severe in Black America than among other racial or ethnic groups, anti-gay attitudes in Black communities have nevertheless served as an important impediment to a sound,

compassionate response to the epidemic's disproportionate impact on Black gay and bisexual men. In particular, the discourse on the "down low" phenomenon, which suggested that secretly bisexual men posed a major risk of transmission to Black women, resulted in considerable anxiety in Black communities and encouraged the stigmatization of Black bisexual men as dangerous vectors of infection.<sup>53</sup> Extensive studies have failed to find a link between "down low" identity and unprotected sex,<sup>54</sup> although this has not prevented the periodic appearance of sensational and baseless media stories on the supposed dangers of men on the "down low."

During the epidemic, waves of AIDS panic and hysteria have periodically washed over the public, undermining efforts to mitigate negative attitudes about AIDS. Early evidence that HIV could be transmitted by blood or blood products generated widespread public anxiety and led CDC to impose strict screening requirements on blood banks.

A high-water mark for AIDS hysteria occurred in the early 1990s, when testing suggested that a young Florida woman, Kimberly Bergalis, had contracted HIV from her dentist. CDC initially proposed an approach that some argued would result in the exclusion of health care workers living with HIV from medical practice, but the agency eventually backed away from this approach under heavy criticism.

Over time, signs have emerged that Americans are increasingly prepared to deal more rationally with HIV as a health problem. As of 2009, 53 percent of non-elderly Americans reported having been tested for HIV, including 19 percent who were tested in the previous year.<sup>55</sup>

With respect to Black America, there is compelling evidence that Black people have grown considerably more comfortable with AIDS as a health issue. Black Americans are more likely than other Americans to discuss HIV with their physician. In part, the greater comfort level experienced by Black Americans may stem from the fact that Black people are considerably more likely to report knowing someone living with HIV than other racial or ethnic groups.<sup>56</sup>

\* \* \*

Although much has changed since AIDS first emerged three decades ago and substantial progress has been made, AIDS remains one of the country's most pressing health issues. Each year,

more than 16,000 deaths occur among people diagnosed with AIDS.

The fight against AIDS is especially critical to the health and well being of Black America. In 2008, the AIDS death rate for Black Americans was more than nine times the rate among whites.<sup>57</sup> Despite the enormous progress made in the fight against AIDS, the disease remains one of the 10 leading causes of death of Black Americans.<sup>58</sup>

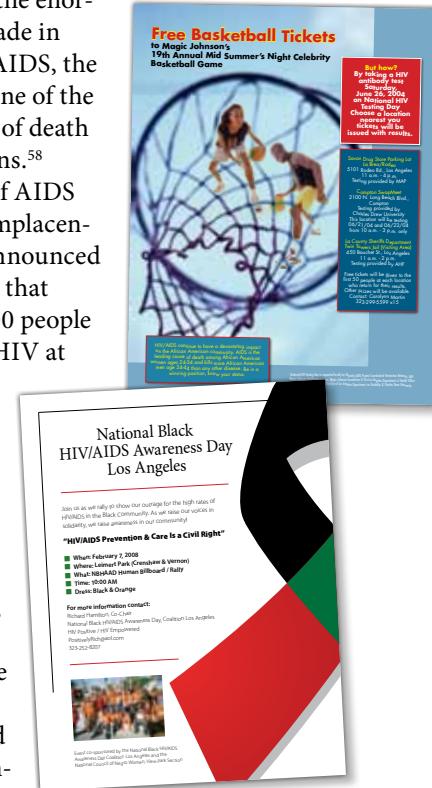
The history of AIDS warns against complacency. When CDC announced in the early 1990s that 650,000 to 900,000 people were living with HIV at the time, the new estimate represented a substantial scaling-back of earlier estimates. AIDS, it was believed, had begun a long, inevitable decline. That decline never occurred, as evidence would eventually demonstrate that the rate of new infections was always much higher than had been believed.

Likewise, when rates of new infections plummeted among gay men in the 1980s, it was assumed that the AIDS problem in gay communities would become a thing of the past. Yet today, the number of gay and bisexual men newly infected with HIV each year is roughly 50 percent higher than in the early 1990s, with especially high infection rates among young Black men.

In short, the history of AIDS repeatedly demonstrates the critical importance of vigilance. As AIDS enters its fourth decade, renewed energy and commitment are needed to avoid still more surprises in the history of the disease.

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**BISHOP T. D. JAKES, SR.**  
Hero in the Struggle

## THE TIMELINE

# AIDS: 30 Years Is Enuf!

## The History of the AIDS Epidemic in Black America

1981

CDC reports on an unusual cluster of cases of severe immune suppression among gay men in Los Angeles

### RARE CANCER SEEN IN 41 HOMOSEXUALS

Outbreak Occurs Among Men in New York and California —8 Died Inside 2 Years

By LAWRENCE K. ALTMAN  
Doctors in New York and California have diagnosed among homosexual men 41 cases of a rare, often fatal, early form of cancer. Eight of the victims died less than 24 months after the diagnosis was made.

The disease is unknown and there is as yet no evidence of contagion. But the doctors who have made the

CDC reports that GRID has been diagnosed in hemophiliacs and Haitians. The phrase 3Hs—Hemophiliacs, Haitians and Homosexuals—is coined

1982

86 Black people diagnosed with AIDS in the first 12 months after the CDC's initial report on the epidemic

**Gay Men's Health Crisis** formed becoming the first AIDS service organization in the U.S.

First news story on AIDS is published in the *New York Times*

New disease is known as **Gay Related Immune Deficiency (GRID)**



CDC and others adopt the name **Acquired Immune Deficiency Syndrome**, identifying four "risk factors" for the disease (male homosexuality, injection drug use, Haitian origin, and hemophilia)

New AIDS reports increase exponentially

1983

787 cumulative AIDS diagnoses among Blacks

French scientists isolate HIV



U.S. Health and Human Services Secretary **Margaret Heckler** predicts that a preventive vaccine for HIV will be available in two years

Heterosexual transmission is documented

HIV documented among children

CDC reports that Black people account for 26 percent of all individuals diagnosed with AIDS in 1981-83

People with AIDS gather in Denver, articulating principles and giving rise to the AIDS empowerment movement



**National Association of People with AIDS formed**

CDC warning to blood banks triggers national furor on the safety of the blood supply

CDC officially declares that female partners of men with AIDS and children born to infected mothers are at risk

Epidemiologists document the epidemic in Central Africa

First articles on AIDS appear in Black newspapers but do not focus on racial disparities

**1984**

**1,898 cumulative AIDS diagnoses among Blacks**



Actor **Rock Hudson** announces he has AIDS

San Francisco takes steps to close gay bathhouses

First needle exchange program established in the Netherlands

An estimated 400,000 to 450,000 people are living with HIV in the U.S.

**1985**

**4,004 cumulative AIDS diagnoses among Blacks**

First antibody test for HIV is licensed

First International AIDS Conference is held in Atlanta



Teenager **Ryan White** is denied admittance to his

school in Kokomo, Indiana

**Rock Hudson dies**

**Haitians** formally dropped from list of "high-risk" groups

American Foundation for AIDS Research founded



**Rev. Carl Bean** founds Minority AIDS Project

The **Larry Kramer** play—*A Normal Heart*, about the early years of AIDS—appears for the first time at New York City's Public Theatre

**1986**

**7,224 cumulative AIDS diagnoses among Blacks**



Surgeon General **C. Everett Koop** sends HIV

prevention information to every U.S. household

**Black Coalition on AIDS** is founded

California defeats Proposition 64, the Lyndon LaRouche AIDS quarantine initiative

U.S. Justice Department advises that employers are able to ban workers with AIDS from the workplace

**1987**

**12,508 cumulative AIDS diagnoses among Blacks**

**Blacks surpass whites** in total number of new HIV infections in the U.S.



Food and Drug Administration approves AZT, or zidovudine, for treatment of HIV infection

FDA approves Western Blot test to confirm positive HIV test results



**Debra Fraser-Howze** founds the National Black Leadership Commission on AIDS

**National Task Force on AIDS Prevention**

is founded by Reggie Williams, Phill Wilson and Steve Feeback as a project of NABWMT

**AIDS Coalition to Unleash Power (ACT UP)** is created following a fiery address by activist and playwright Larry Kramer



President **Ronald Reagan** formally addresses AIDS for the first time

AIDS quilt is launched to memorialize those lost to AIDS

President **Reagan** ramps up mandatory HIV

testing policies by requiring testing of immigrants and prisoners

CDC holds first national conference on HIV and communities of color

FDA formally endorses condoms for use to prevent HIV transmission

**1988**

21,929 cumulative AIDS diagnoses among Blacks



ABC News broadcaster **Max Robinson** dies of AIDS-related causes



Health and Human Services Secretary **Louis Sullivan**

declares AIDS to be "public health emergency"



Disco diva and soul singer **Sylvester** dies of AIDS-related complications

Educational pamphlet on AIDS is mailed to 100 million U.S. homes

CDC announces that Blacks account for half of all AIDS cases ever reported among women

International health experts announce that women outnumber men among people living with HIV in sub-Saharan Africa

Arthur Ashe diagnosed with AIDS

**1989**

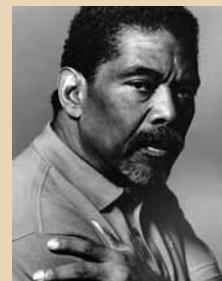
31,198 cumulative AIDS diagnoses among Blacks

More than twice as many Black people are newly infected with HIV as whites,

as the infection rate surges in Black America



Activist **Pernessa Seele** founds the Balm in Gilead to engage Black churches in the fight against AIDS



Dance legend **Alvin Ailey** dies of AIDS-related causes

**NAACP** publication *The Crisis* publishes first article on AIDS

National Institutes of Health launches parallel track program to provide people not enrolled in clinical trials access to experimental treatments

# 1990

45,446 cumulative AIDS diagnoses among Blacks; 28,576 cumulative AIDS deaths among Blacks

CDC issues a report on the possible transmission of HIV from provider to patient during a dental procedure, igniting a national furor

Congress enacts the **Ryan White CARE Act** to provide grants to hard-hit cities and all states for HIV care and treatment services



President **George H.W. Bush** signs into law the Americans with Disabilities Act, which effectively becomes the first national law prohibiting HIV-related discrimination

Kenyan research team announces it has found a cure for AIDS, stoking conspiracy

theories in Black communities that the government is withholding this medical breakthrough

More than 15,000 Black people in the U.S. die of AIDS in a single year

First conference on women and AIDS is held in Boston

**Ryan White** dies

# 1991

60,037 cumulative AIDS diagnoses among Blacks; 38,264 cumulative AIDS deaths among Blacks



Gospel recording artist **Rev. James Cleveland** dies of AIDS-related causes

The red ribbon is first used as the international symbol of AIDS awareness

CDC issues guidelines on HIV-positive health care workers but subsequently backtracks



Basketball legend **Earvin 'Magic' Johnson** announces he is living with HIV

**Housing Opportunities for People with AIDS** is established

death in U.S. men ages 25-44

FDA approves first rapid HIV test

The first anti-retroviral cocktail appears, although its effectiveness is limited



The first part of the **Tony Kushner** play *Angels in America* premieres in Los Angeles

# 1992

73,686 cumulative AIDS diagnoses among Blacks; 50,253 cumulative AIDS deaths among Blacks

CDC estimates that 650,000 to 900,000 people are living with HIV

**Magic Johnson** joins with other Black celebrities to produce the AIDS prevention program "Time Out"

114,868 cumulative AIDS diagnoses among Blacks; 68,651 cumulative AIDS deaths among Blacks



A comprehensive study commissioned by CDC concludes that needle exchange programs are effective in

AIDS becomes the leading cause of

preventing HIV transmission



Tennis great **Arthur Ashe** dies of AIDS-related causes

FDA approves the Reality female condom

Large Concorde trial demonstrates that early AZT does not extend life



**Philadelphia**—a major motion picture starring **Denzel Washington** and **Tom Hanks**—appears to critical acclaim, winning two Academy Awards the following year



President **Bill Clinton** signs HIV immigration ban into law

## 1994

146,285 cumulative AIDS diagnoses among Blacks; 84,549 cumulative AIDS deaths among Blacks

A landmark serosurvey of gay and bisexual men in San Francisco and Berkeley finds that Black men are more than twice as likely to be infected as whites and Latinos

FDA approves first oral test for HIV



Activist **Rae Lewis-Thornton** is

featured on the cover of *Essence*

AIDS becomes leading causes of death among all people ages 25-44

The number of AIDS cases in the United States doubles again, surpassing 400,000

## 1995

174,715 cumulative AIDS diagnoses among Blacks; 102,361 cumulative AIDS deaths among Blacks

First **National HIV Testing Day** is held



**Bill & Melinda Gates Foundation** is formed

New AIDS cases among Blacks surpass those among whites

White House convenes African American National Clergy Summit on HIV/AIDS

The U.S. National Institutes of Health requires grant applicants to include women and minorities in clinical trials



**Eazy-E** dies of AIDS-related complications 12 days after publicly announcing his condition



**Joint United Nations Program on AIDS (UNAIDS)** is created

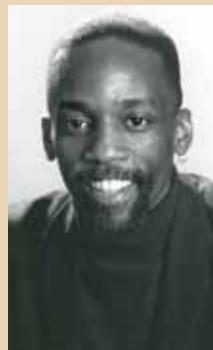


Los Angeles Dodger slugger **Glenn Burke** dies of AIDS-related complications

Annual AIDS deaths in Black

America peak at 18,813.

Food and Drug Administration licenses the first of a new class of antiretroviral drugs, protease inhibitors



Black gay writer **Essex Hemphill** dies of AIDS-related causes

White House holds conference on AIDS

**1996**

203,189 cumulative AIDS diagnoses among Blacks; 119,538 cumulative AIDS deaths among Blacks

**Harvard AIDS Institute** launches "Leading for Life" campaign to mobilize Black leaders

Presentation of data on morbidity and mortality reductions resulting from antiretroviral therapy electrifies

International AIDS Conference in Vancouver



**Novella Dudley** dies of AIDS-related complications

International AIDS Vaccine Initiative is launched

Although AIDS is no longer the leading cause of death for people in the U.S. ages 25-44, it remains the leading cause of death for Black Americans



Brazil launches free antiretroviral therapy through the public sector

**1997**

230,029 cumulative AIDS diagnoses among Blacks; 132,221 cumulative AIDS deaths among Blacks

More than twice as many Black people are newly infected

with HIV as whites, as declines in new infections among whites are matched by increased infection rates in Black America



Prosecutors bring charges against **Nushawn Williams** for deliberately exposing several white women to HIV

AIDS deaths in the U.S. decline by more than 40 percent



UNAIDS launches pilot projects in Uganda and Côte d'Ivoire, which will ultimately demonstrate the feasibility of introducing HIV treatment in developing countries

# 1998

21,515 new AIDS diagnoses among Blacks; 141,607 cumulative AIDS deaths among Blacks

Black AIDS activists declare AIDS to be "state of emergency" and demand national action, a cause taken up by the Congressional Black Caucus



NAACP leaders pledge to raise AIDS awareness

**National Medical Association** declares "war on AIDS"



BET inaugurates Rap-It-Up campaign.



National convention of **Delta Sigma Theta** sorority approves resolution affirming its commitment to

AIDS prevention and education

**Minority AIDS Initiative** is created, with \$166 million in funding

President **Bill Clinton** acknowledges effectiveness of needle exchange but declines to allow federal funding for needle exchange programs

**Treatment Action Campaign** is launched in South Africa to make HIV treatments more affordable and accessible in the country with the largest number of people living with HIV

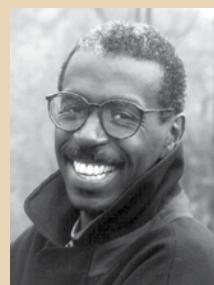
# 1999

21,900 new AIDS diagnoses among Blacks; cumulative deaths among Blacks pass 150,000

**National Conference on African Americans and AIDS** produces action steps to strengthen the AIDS response



Rep. **Maxine Waters** (D-CA), chair of the Congressional Black Caucus, challenges Congress to provide \$349 million in emergency funding to address AIDS in communities of color



**Reggie Williams**, a founder of the **National Task Force on AIDS Prevention**, dies

**Black AIDS Institute** is founded as the nation's only think tank exclusively devoted to HIV in Black America

The first national Black AIDS newsletter is

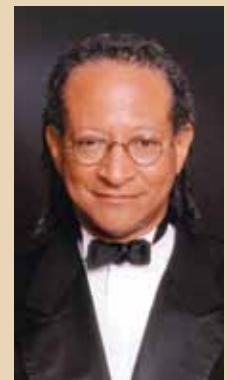
launched by the predecessor organization of the Institute

Globally, more than 1.5 million people die of AIDS-related causes

# 2000

19,783 new AIDS diagnoses among Blacks; 7,401 new AIDS deaths among Blacks

For the first time, more Black and Latino gay men are diagnosed with AIDS than white gay men



**Dr. Walter Shervington**, AIDS researcher and former National Medical Association President, dies

Black clergy convene in Tuskegee to study ways to strengthen the AIDS response

**UNAIDS** negotiates

agreement with five major pharmaceutical companies to reduce prices for antiretroviral drugs in poor countries

International AIDS Conference in **Durban, South Africa**—the first ever held in the global South—generates calls to expand HIV treatment access in developing countries

**United Nations Security Council** holds a special session to focus on the security implications of the global epidemic



Rev. Jesse Jackson hosts town hall meeting on AIDS at the Rainbow/PUSH convention

**The Black Treatment Advocates Network** is launched

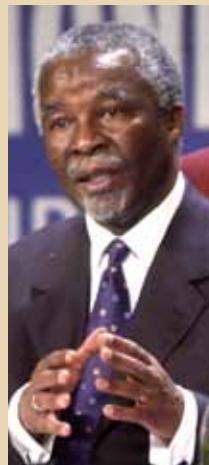
Globally, more than 30 million people are living with HIV

## 2001

21,031 new AIDS diagnoses among Blacks; 8,915 new AIDS deaths among Blacks

First annual **National Black HIV/AIDS Awareness Day** is held

Global leaders gather at the first-ever UN General Assembly Special Session on HIV/AIDS where agreement is reached on intellectual property rights allowing developing countries to take innovative steps to expand access to essential medicines for priority diseases



Even as South African President **Thabo Mbeki** embraces AIDS denialists, the Pretoria High Court

orders the government to roll out prevention of mother-to-child transmission

Caribbean leaders launch a major regional initiative on AIDS

## 2002

21,106 new AIDS diagnoses among Blacks; 8,566 new AIDS deaths among Blacks



**The Global Fund to Fight AIDS, Tuberculosis and Malaria** is launched as a major new funding mechanism for HIV and other health programs in developing countries

AIDS becomes the leading cause of death worldwide for people ages 15-59

Botswana launches the first national AIDS treatment program in Africa, with support from Merck and the Bill & Melinda Gates Foundation



**Belinda Dunn** dies of AIDS-related complications

FDA approves **OraQuick** rapid HIV test using a finger prick

## 2003

21,214 new AIDS diagnoses among Blacks; 9,048 new AIDS deaths among Blacks



President **George W. Bush** launched **U.S. President's Emergency Plan for AIDS Relief (PEPFAR)**, the largest health program ever

focused on a single disease

First clinical trial of a preventive vaccine yields disappointing results

**Clinton Foundation** secures major reductions in prices for AIDS drugs in developing countries

## 2004

Cumulative AIDS deaths among Black Americans surpass 200,000



AIDS activist **Keith Cylar**, co-founder of Housing Works, dies



Journalist **Gwen Ifill**, moderating a Vice Presidential debate between

Republican nominee Dick Cheney and Democratic nominee John Edwards, asks a question about AIDS in Black America, exposing each candidate's ignorance of the topic



**Oral rapid HIV test** approved by FDA

Globally, AIDS deaths peak at more than 2 million

## 2005

20,187 new AIDS diagnoses among Blacks; 8,562 new AIDS deaths among Blacks; nearly 30,000 new estimated HIV infections among Blacks

CDC announces that Black America accounts for roughly half of the U.S. epidemic



Noah's ARC, written and directed by **Patrik-Ian Polk**, about four Black gay friends dealing with everyday life premieres on Logo

CDC reports that a five-city study finds 46 percent of Black gay and bisexual men surveyed are living with HIV

French researchers report that adult male circumcision reduces the risk of female-to-male sexual transmission by 60 percent

## 2006

17,960 new AIDS diagnoses among Blacks; 7,426 new AIDS deaths among Blacks

Black leaders convene at the International AIDS Conference in Toronto to issue a declaration of commitment

CDC recommends routine HIV testing for adults,

adolescents and pregnant women in health care settings

A delegation of Black leaders calls for a national Black AIDS mobilization at the International AIDS Conference in Toronto

Global community endorses goal of universal access to HIV prevention, treatment, care and support

## 2007

17,507 new AIDS diagnoses among Blacks; 7,124 new AIDS deaths among Blacks

A major trial of a vaginal microbicide produces disappointing news

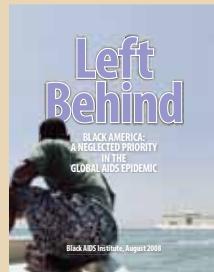


Merck discontinues testing of what was believed to be the most promising candidate vaccine following disappointing trial results

Black clergy meet to explore the church's role in the AIDS fight

# 2008

CDC estimates that 545,000 Black people in the U.S. are living with HIV, including 21.4% with undiagnosed infection



A special report by the **Black AIDS Institute**—Left Behind—reports that Black America would have the world's 16th largest population of people living with HIV were it a country on its own

CDC estimates that 56,000 people—including 45 percent who are Black—are newly infected with HIV each year—roughly 40 percent more than previously believed



**Barbara Lee**  
(D-CA) calls for a national AIDS strategy at the International AIDS Conference in Mexico City

CDC estimates that 1.1 million Americans are living with HIV, including 46 percent who are Black

CDC estimates indicate that new infections among gay and bisexual men increased by roughly 50 percent between 1991 and 2006, with especially high rates reported among young Black gay men



Two French scientists, Françoise Barré-Sinoussi and

Luc Montagnier, receive the **Nobel Prize** in medicine for their discovery of HIV

First-ever decline in global AIDS death is reported

# 2009

Cumulative AIDS deaths among Black Americans approach 250,000



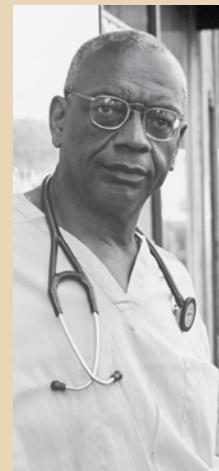
**President Barack Obama** reinvigorates White House Office of National AIDS Policy by naming Jeffrey Crowley as new ONAP director



President Obama takes steps to rejuvenate the Presidential Advisory Council on HIV/AIDS, appointing **Dr. Helene Gayle** as

its new chairwoman

CDC launches the **Act Against AIDS Initiative**, providing core HIV funding to several traditional Black institutions



Internationally acclaimed HIV clinician **Robert Scott** dies of pulmonary embolism

Clinical trial in Thailand finds that a combination vaccine is modestly effective in protecting against HIV infection—the first such positive sign in a clinical trial

Disappointing trial results are reported for what is believed to be the most promising microbicide candidate



Polling by **Henry J. Kaiser Family Foundation** indicates that American concern about AIDS has sharply declined, including among Black Americans

**2010**

Obama Administration ends 20-year-old travel restrictions on foreigners living with HIV

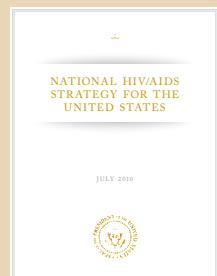


South Africa's new leader, President **Jacob Zuma**, breaks with his predecessor to pledge a major national effort to combat AIDS



South African researchers **Quarraisha and Salim Abdool Karim** report that an antiretroviral-based vaginal microbicide significantly reduces women's risk of becoming infected

International AIDS Society announces that International AIDS Conference will be held in the U.S. in 2012 for the first time in more than two decades



President Obama unveils new **National HIV/AIDS Strategy**

Multi-country clinical trial

demonstrates that pre-exposure prophylaxis significantly lowers the risk that gay or bisexual men will contract HIV

Ban on federal funding for needle exchange programs is lifted



The Black AIDS Institute joins with the Henry J. Kaiser Family Foundation to launch the Greater Than AIDS campaign

Discovery of numerous antibodies that neutralize HIV raises hopes for vaccine development

Congress passes, and

President Obama signs into law, comprehensive health care reform legislation that will extend health coverage to more than 30 million uninsured individuals

**2011**

NIH trial finds that early initiation of antiretroviral therapy reduces the likelihood of HIV transmission with serodiscordant couples by 96 percent in comparison to delayed therapy

The number of people on waiting lists for AIDS Drug Assistance Programs approaches 8,000

# Viral Generation

## ISO Real Connections on HIV/AIDS

By Julian Breece

**Those of us born after 1981 share a unique duality. For the most part, we're known as the Millennials or Gen Y—children of the Information Age, raised in a world of mass media, digital technology and wireless communication. We are the most educated and tech-savvy generation in history, and the first to incorporate social media and Internet technology into every facet of our lives. But what also distinguishes Millennials, and seems to be increasingly over-looked, is that we represent the first generation of Americans born in the era of AIDS. Our formative years were in lockstep with the rise of the HIV infection, which killed more Americans than any war in modern history, and is still etched into our cultural narrative.**

That said, Black Millennials' relationship to HIV/AIDS is especially complex. In the mid-'90s, the U.S. began to see steep declines in new HIV infections and AIDS related-deaths—a downward trend that continued into the new millennium. However, even as advances in treatment and prevention have stabilized the disease among the greater U.S. population, infections among Black Americans continue to rise. We represent roughly 14 percent of the U.S. population, but account for nearly half of the people in our country living with HIV. According to a 2010 CDC report, Black Millennials seem to be especially hard-hit, with estimates showing that one-third of all new infections among Black Americans occurred in young people aged 13 to 29. Infections among young Black women in that age group are “11 times as high as that of young white women and four times that of young Hispanic women.” Perhaps most alarming are disease estimates on Black gay and bisexual men aged 13 to 29, with a 2008 study reporting that as many as 21 percent of the men in this population are already infected with HIV.

I explored the latter statistic in my short film *The Young & Evil*, which follows a day in the life of a sexually active Black gay teen. I wrote the film after reading similarly disturbing CDC estimates. At the time, I remember feeling an inexorable sense of dread regarding HIV. As gay young man who grew up during the AIDS crisis, I knew that sex was a potentially fatal enterprise before I even understood how it worked. Even today, at 30, my sexuality continues to be informed by the need to remain negative. It's part of the reason I didn't understand why so many of my peers were becoming infected despite sharing a similar awareness.

I got closer to an answer in 2009, as *The Young & Evil* began to travel the country. During that time, I came in contact with young activists, health care advocates and academics that were equally concerned about the ongoing crisis in our community. The insights that struck me the most came from a 27-year-old youth counselor from Kansas City who I'll call “Marcus.” We met at the Creating Change Conference in Denver. At that point, Marcus had been working with

at-risk youth and focused much of his work on HIV testing and prevention. As our conversation progressed, I was surprised when Marcus revealed that he had contracted HIV the year before. Despite an acute knowledge of prevention, Marcus had found himself at an emotional low point at the time that he became positive. He said that he felt isolated and was desperate for a “real connection.”

When I started working on this collection, which presents my generation’s response to HIV/AIDS, that notion of “real connection” came up and again and again, and emerged as a thematic link between the selected essays and interviews. I began to realize that my generation’s need for connectivity isn’t an entirely technical concern, but rather an extension of the impulse that guides humanity. When Marcus described his need for “connection,” it seemed to have little to do with unprotected sex, but that he’d simply found himself on a desperate scramble for validation—for proof that he existed and that he belonged. In the pages that follow we’ll examine the disconnect between HIV prevention and the young Black generation, and meet 30 young representatives from the group who are determined to bridge the gap.

In order to provide a framework for our conversation, I called upon several rising Black intellectuals to provide an overview of the social and political factors stoking the ongoing crisis of Black AIDS. In his incisive polemic, NYU scholar Frank Roberts, 29, indicts the “structured leadership” of the Black community, charging them with “irresponsible vilification” of non-marital and non-monogamous sex despite a liberal discourse on sexuality in the Black mainstream. In an interview, political activist Maya Marcel-Keyes, 26, takes his point a step further, and suggests that sexual stigma drives HIV/AIDS prevalence, because it’s directly preclusive to sexual education and sexual health.

As I compiled and edited essays, I was drawn to several brave testimonials from young people living with HIV. Celebrated activist Hydeia Broadbent, 26, was born with HIV, and shares her story as “proof that an HIV diagnosis does not equal death.” Author Marvelyn Brown, 27, was diagnosed positive in 2003, and tells us how she transformed her life from one “plagued with uncertainty, loneliness and stigma” to one of “self-love and self-acceptance.” In his essay, outreach worker Tree Alexander, 24, details the heartbreak he experienced upon learning that he

had contracted the virus from his monogamous partner. In a separate interview, Tree’s twin sister Sonya Herriot, 24, describes the day that Tree confided in her about his status, and how that conversation strengthened their bond.

In the Black community, gay and bisexual men continue to feel the greatest impact from the Black AIDS crisis. In an in depth interview, community leader, Venton Jones, 27, discusses the unique challenges facing Black men who have sex with men and how those challenges increase their vulnerability to HIV infection. Prevention worker Greg Wilson, 29, examines the effects of internalized homophobia in his piece and stresses the importance of targeted community outreach.

Despite the need for honest dialogue between Black men and women on HIV, there are related concerns that affect each group uniquely. In her statement, best-selling author Nancy Redd, 30, says, “Black women need to learn about sexual health from other women who can address the importance of self-respect and self-protection.” Thirty-year-old William Brawner, details the struggles he faced coming of age with HIV, and calls on other HIV positive straight men to release themselves from shame and stand up in the fight. .

We also spotlight young people who are “making the connection” on HIV awareness via new media platforms. Media consultant, Luvvie Ajayi, 26, founded The Red Pump Project, which, this past year organized 1,200 bloggers to participate in National Women and Girls’ HIV/AIDS Awareness Day. Popular singer and Internet personality Steph Jones tells us that he promotes HIV prevention to fans by sending tweets whenever he gets tested and chatting about the disease on U-Stream.

The young people in this collection come from different parts of the country, represent a range of perspectives, and have each been touched by the AIDS epidemic in different ways. They represent a generation of Black Americans who haven’t known a world without the disease, but they’re bonded in the assertion that 30 years is, indeed, enough.

***Julian Breece is a writer and filmmaker. His debut film, The Young & Evil, addressed the rise in HIV infections amongst young Black gay men and was an Official Selection of the Sundance Film Festival in 2009. Breece is also the creator of BET’s hit comedy series Buppies, and the upcoming drama series American Skin.***



FRANK ROBERTS  
Co-Founder  
National Black  
Justice Coalition  
Age: 29  
New York, NY

## FRANK ROBERTS

The AIDS epidemic in Black America is the result of a powerful set of political, historical, and socio-cultural forces that are at work multilaterally, inside and outside of the Black community. On one hand, the continued rise in HIV infections among Black men and women can be attributed to Black America's longstanding and contumacious unwillingness to have candid, open, and non-judgmental conversations about our relationship with power, sex and sexuality. Black America continues to suffer from a stifling paradox: while our sources of popular entertainment (hip-hop, cinema, radio, and Black television) are saturated with images of non-marital, non-monogamous sex, our structured political leadership (i.e. the ministers, elected officials, and community organizers who are influencing public policy) is characterized by an irresponsible vilification of sexual identities that exist outside the confines of marriage, heterosexuality, and monogamy. Thus, while the discourse on sexuality within the realm of Black popular culture has become more varied and liberal as of late, the institutions that make up our formalized political structure are still characterized by stigmatizing, moralistic, and anti-productive dialogues. In this context, Black America's AIDS epidemic is largely the result of its own internal shortcomings and prevailing ideological dogmas.

On the other hand, the crisis of Black America's AIDS

epidemic is the result of a larger set of structural inequities that are fueled and manufactured externally: a prison industrial complex that has become a breeding ground for HIV infection; a federal government that devotes inadequate funding and pays insufficient attention to the health and wellness of Black constituencies; and an HIV prevention industry that has been slow to address the racial disparities that are plaguing the epidemic.

The daunting challenge ahead for the emergent cohort of young Black leaders will be to figure out how to simultaneously probe, reverse and undo these internal and external dilemmas; and if we're ever to do so, several paradigm shifts must occur:

First, the end of AIDS in Black America can only take place by and through a series of aggressive political transformations that must include altering the culture of the Black church (by demanding that its leaders be held accountable for the deadly effects of their egregious sexual conservatism); increasing the political might of the Black electorate (by forcing our elected officials to finally translate Black constituent concerns into legislative policy, or risk losing the Black base of the Democratic party); politically empowering those voices in the Black community that have been systematically silenced (particularly single Black mothers, gay men, and substance abusers) and assisting in the creation of a greater number of HIV agencies that are run by, for, and within communities of color.

America, we will also have to engage in a complete recon-

figuration of how we do "HIV prevention." First, let us be honest: many of us are suffering from condom fatigue. The field of HIV prevention is in desperate need of a revival. The awareness campaigns coming out of the prevention industry have increasingly made condom usage feel like more of a "chore" than a source of erotic pleasure. Indeed, in the eyes of the general public the only thing that the HIV prevention industry has been good at preventing is pleasure. Condoms continue to be associated with preventing rather than heightening sexual pleasure, which is precisely why there is so much resistance to using them. In spite of the tremendous gains the prevention industry has made over the past 30 years, the field has failed to devote sufficient attention to a fundamental dilemma that still fuels most people's desire to want to have unprotected intercourse: sex without a condom feels better.

The time has come for us to organize our prevention efforts around what I like to call the "pleasure principle" (i.e. the understanding that the more we are able to enhance people's experiences with condoms, the more likely they will be to use them). Therefore, in my mind, our greatest challenge ahead will be figuring out how to significantly increase the pleasure that can be derived from latex prophylactics. Though small strides have been made in recent years (by way of ribbed condoms, ultra-thin brands, and the vaginal condom) ultimately our outcomes in this area have been meek at best. As we look ahead, our generation will have to commit to more aggressive research, time, and

funding towards broadening the range of prophylactics people have at their disposal.

Ultimately, it is only when all of these grand-scale transformations occur simultaneously—a decline in our mainstream Black community's systematic homophobia; an increase in the number of "home-grown" HIV agencies situated within communities of color; a greater governmental concern for the lives of Black people; and a reconfiguration of the field of HIV prevention—that our generation can finally witness the fall of AIDS in Black America.

**Frank Roberts is a Ph.D. candidate at New York University, where he is the recipient of the Ford Foundation Diversity Fellowship. Visit [frankrobertsonline.com](http://frankrobertsonline.com).**

## LUVVIE AJAYI

The Red Pump Project was launched two years ago, when Karyn Watkins and I decided to commemorate National Women and Girls' HIV/AIDS Awareness Day (NWGHAAD) on March 10th. Our idea was to have bloggers dedicate posts to the epidemic as it affects women and ask their female readers to put on their favorite pair of red shoes on NWGHAAD. The goal was to have 100 bloggers participate and display our custom red pump on their sidebars. On March 10, 2009, 135 bloggers talked about HIV/AIDS and its impact on women, displaying the red pump badge on their pages. In 2010, 250 bloggers "Rocked the Red Pump" for NWGHAAD. Red Pump's 3rd annual campaign, which

## HYDEIA BROADBENT

**I was given a death sentence at age 3.  
I was told that I would not live past the age of 5.  
This year, I turn 27.**

**I**n the mid-80s, there wasn't much hope for children born with HIV. But now—30 years later—there is hope, and those living with the virus should use my life as proof that a positive test result does not equal death.

That said, some people think that because I was born with HIV, my story doesn't apply to their lives. But the fact is that the same disease I'm living with and almost died from is a disease you can contract through unprotected sex. For that reason, I ask people to use my testimony as a warning, because even though there's hope for people living with HIV/AIDS, there are also serious difficulties. Because death is no longer in front of our faces, we've stopped warning younger generations of the dangers that come from not protecting themselves. Did we forget that this is a costly disease and at the end of the day there is still no cure? Did we forget that people are still dying from complications?

When the AIDS epidemic started we only saw images of gay white men suffering from it and that's the image that stuck. Now, in 2011, HIV/AIDS has become an epidemic among African Americans. Our community is being hit harder than any other, yet we have moved slower than any other to stand up and fight.

As we commemorate 30 years of AIDS, let's use this as an opportunity to raise awareness, remember those who've passed on, and celebrate victories like increased access to treatment and prevention services. At the same time, we have to challenge individuals to step up and work together in the continued fight against this ongoing epidemic. I personally challenge people to talk about HIV to their families, co-workers and friends. You don't have to be rich or famous to educate people about the disease; you just have to care.

**Hydeia Broadbent was featured as one of "100 African Americans Making History in 2011" by NBC News and TheGrio.com.**

wrapped on March 10, 2011, had 1,200 blogs participate!

Red Pump has not only established a presence online, but we've hit the ground running with awareness events around the country to ensure that women are empowered with knowledge about HIV/AIDS and the issues surrounding it.

The Red Pump Project is now a national nonprofit organization that raises awareness about the impact of HIV/AIDS on women and girls.

**Luvvie Ajayi is a social media strategist. Co-founder of the Red Pump Project, she holds a degree in psychology from the University of Illinois.**



**HYDEIA BROADBENT**  
Speaker & Activist  
Age: 27  
Las Vegas, NV



**LUVVIE AJAYI**  
Co-Founder  
The Red Pump Project  
Age: 26  
Chicago, IL



## MAYA MARCEL-KEYES

*Much of your work as an activist has been focused on the plight of homeless queer youth, many of whom are homeless as a direct result of “coming out” to their families. Why is this issue of personal importance to you and how does it intersect with the continued fight against AIDS?*

The issue of homeless queer youth has been a very personal one for me, because LGBT youth are at high risk of homelessness, due in large part to the ostracism they can face from families that don’t accept them. Growing up, I saw a number of friends get rejected by their parents and end up on the streets—eventually, I was even one of them. I watched people go through some really terrible things out there, and I lost people I cared about deeply. Seeing all that really spurred my desire to do something to help the situation.

Homeless youth are at higher risk than other youth of contracting HIV—possibly as much as 2-10 times higher than their peers. There is definite intersectionality between the struggles of homeless youth and the struggle against AIDS, and I think it would be to our detriment to ignore any one issue in favor of another.

*Has HIV/AIDS personally touched your life? If so, how?*

Yes, I have lost very close friends to AIDS. It sucked.

*Considering the overall progress we’ve seen in America with regard to HIV awareness and prevention, are you*

*surprised by the paradoxical rise in infection among Black men and women?*

I wouldn’t say surprised, no. Communities of color are often hit disproportionately hard by all kinds of ills, for any number of reasons—poor access to safe sex education, the lack of proper health care in poor communities, more cultural stigma around discussions of sexuality. If we continue to avoid proper conversation on matters of sexual health, and fail to provide the resources needed to tackle this issue, infection rates will continue to rise.

*You’ve been a strident voice in the fight for marriage equality, while some Black queer activists have expressed their disillusionment, alleging the larger community’s abandonment of issues that disproportionately affect poor LGBTs and LGBTs of color. Does the marriage fight complement the continued fight against AIDS?*

While I am not certain how much of a direct relation there is between the marriage fight and the fight against AIDS, I definitely do think that one influences the other in an important way. I believe that some of the prevalence of HIV in certain cultures can be attributed to the stigma surrounding issues of sexuality, which works to prevent people from gaining access to the education and resources they need to be in control of their sexual health. The fight for marriage equality has been a large part of the overall fight for LGBT equality and acceptance, and I think making strides in that regard

will go a long way toward de-stigmatizing communication about sexuality, which in turn will help the fight against AIDS.

*Why have older generations been unsuccessful in communicating messages of sexual health and prevention to Black youth? And how can young people step in and change the tide?*

I think in older generations there is a higher prevalence of conservative attitudes when it comes to matters of sexuality. This has obviously been a hindrance when trying to talk openly and without stigma about matters of sexual health. Changing the tide, I think, requires a comprehensive approach to the situation. As long as there are higher incidences of poverty and inequality in the Black community, there are going to be higher incidences of all kinds of health and social ills.

To me, I think the most important thing Black youth can do is get involved in their communities in whatever way seems most important to them, as long as it is helping to uplift the community. The issues that plague the Black community and any minority community are all intersecting; they don’t happen in a vacuum. If young people work together to combat inequalities on one level, the situation overall will be improved.

Most importantly, I think, being proactive in taking leadership roles in the fight and reaching out to peers will be more effective than allowing ourselves to be talked at by people who might not have the same perspectives.

*Maya Marcel-Keyes has served on the board of the National Youth Advocacy Coalition, and was awarded the Emery Award from the Hetrick-Martin Institute for outstanding work on behalf of homeless LGBT youth.*

## JERMAINE SYLVESTER

In January of 2008, I stumbled upon the FUSION Program in Houston, Texas—a community organization dedicated to providing a safe space for Black gay/bisexual young men. It was through this program that I realized I wasn't alone in my sexuality, but part of a family larger than the one I'd grown up with.

That year I also had the unique privilege of attending Houston's first YMSM (Young Men Who Have Sex with Other Men) Summit where Dr. Mark Columb gave me a rude awakening to the devastation that HIV has wrought in my newfound family. He gave me a history lesson with statistics and shared personal stories that rubbed me in all of the wrong ways.

I left that summit raw and afraid for the lives of my sisters and brothers. From that day forward, I refused to stand idle and watch something as weak as HIV wreak havoc on my community. In the end, we are all one family, and where HIV is concerned it takes a village to change the tide. While I remain HIV-negative, my status has not been maintained alone, but also by the support of those around me who cared enough to hold the mirror of reality to my face.

## MARVELYN BROWN

**I** found out that I was HIV positive in 2003. By then treatments had advanced to the point where you could choose to live with the disease, while a decade earlier it was something you'd most likely die from. Despite the fact that I had lifesaving medicines available to me, I was torn between accepting treatment and wallowing in my own denial and shame.

Suddenly, the life that I'd envisioned for myself—one that included romance, health and family—was plagued with uncertainty, loneliness and stigma. For a long time I pushed my dreams aside, believing that one couldn't live a full life with HIV. But eventually I worked through my shame, and the strength I gained allowed me to create new dreams.

Today I am healthy and living with HIV in an open, humble and confident way. Each day, I work hard to empower young women who naively believe that Prince Charming will protect them and keep his word—women who, generation after generation, put themselves at risk only to end up raising children alone, struggling to pay bills, and facing life's challenges without the skills needed to compete.

My struggle has taught me that—as a woman—I am the architect of my destiny. HIV shattered my dreams but it also helped me rebuild them. Since my diagnosis, I have learned the importance of self-love and self-acceptance. For me, HIV was the beginning of the end: it was the end of shame, self-hatred, and irresponsibility, and the beginning of a new life.

Over the past 30 years, many brave people living with HIV and others fighting on our behalf have created a new reality—one in which I can proudly say that I am a confident, independent and loving woman with a real T4 cell count of 1,274 and an undetectable viral load.

*Marvelyn Brown is the author of *The Naked Truth: Young, Beautiful and (HIV) Positive*.*



MARVELYN BROWN  
Author  
HIV Consultant  
Age: 27  
New York, NY



JERMAINE SYLVESTER  
Intervention Specialist  
Age: 26  
Houston, TX



SONYA HERRIOT  
Tree Alexander's  
Twin Sister  
Age: 24  
Chicago, IL

## SONYA HERRIOT

*You were the first person that your twin brother, Tree, confided in after learning that he tested positive for HIV. How did he tell you?*

First he called me on the phone. He said we needed to sit down and talk, so the next day we met up for lunch. As soon as we sat down he said, "I have something important to tell you, so please brace yourself for it." Then he looked down and started looking all over the place. That's when I told him, "Whatever it is, it can't be that bad. And if it is bad, you already know I'm here to support you." That's when he told me that his boyfriend had gotten sick and when they took him to the hospital they found that he had HIV. Then he told me that he also got tested and found out he's HIV-positive too. I was shocked when he said it, but I didn't show it; I didn't freeze up. I just hugged him because he started crying. I held him and told him it was going to be alright and we were going to get through it together. I told him I was going to every appointment with him and that I was there for him 100 percent.

*Were you scared at all?*

I was. I'm not gonna lie, I was nervous, because at the time I didn't know how bad it was or if it was too late for him to get treatment.

So, I was a little scared and nervous because my brother is my best friend and I didn't want to lose him. After that conversation, I called him and told him I loved him every day. I even cried at night. He didn't know it but I did.

*What were your feelings toward Tree's boyfriend at that point?*

I was furious. Pissed off. Because he hurt my brother really bad. I couldn't stand to look at him. HIV isn't something you can take some medicine and get rid of. It's permanent, like a tattoo. He tried to talk to me and beg for forgiveness, but I was just disgusted.

*What was your reaction when Tree decided to stay with his boyfriend for a brief time after that?*

I was upset, but I told him if that's what he needed to do, I'd support him. I didn't like it, but that was his decision and I respected it.

*Would you date someone who is living with HIV?*

I get asked that question all the time and I freeze up on it because... I don't know. I know that a person can take the proper meds to the point where the HIV in his or her body is undetectable. I know how everything works but... I honestly don't know.

*When Tree started to tell others about his status did you have to protect him from people who were ignorant about the disease?*

I told people that it wasn't his fault and not to judge him. I'm very protective of my brother and people know that I'll take offense really quickly if they say something bad about him. There were a few people who I had to tell basic stuff, like they couldn't get HIV from casual contact like hugging, kissing or a fiber of clothing. If people ask me questions about it I tell them to do their research before jumping to conclusions.

*How has Tree changed since his diagnosis?*

He's grown so much. I'm so proud of him. He's out there speaking up and letting people know what's true and what isn't. He tells other people with HIV to fight for their medicine, to fight to stay alive and I love that about him. He does motivational speaking about safe sex, hate crimes, gay rights—everything. I love that he refuses to hide in a shell because of his condition. He inspires people to open up and live without fear. And he inspires me because of his strength. He's so confident and strong and it's something I really admire.

## B. SCOTT

*Why has it been important for you to use your popularity to spread awareness about HIV/AIDS?*

In 1995, my sister died from AIDS, so for me the issue has always been deeply personal. I grew up in a small town called Ahoskie, North Carolina and AIDS had always been portrayed as something that only gay people could get. Everyone believed that and as a teenager that's what I believed as well. When my sister contracted it and passed away, it was a shock and the disease instantly became very real to me. Now I try to use the platform I've built to educate people about AIDS, because I know that a lot of my love muffins are going through similar situations.

*When you were growing up, did the stigmas attached to AIDS affect how you viewed your sexuality?*

Definitely. When my sister passed away I wasn't "out" yet. Deep down I think I always knew I was gay, but my mother was a devout Christian and taught us that homosexuality was wrong so I suppressed it. The stigmas surrounding HIV added to that because people in our community believed that the disease was a direct punishment for being gay.

*Over the past 30 years, we've seen HIV infections among gay white men decrease significantly, while rates of infection among gay Black men are estimated to be as high as 46 percent. How does that make you feel?*

It makes me very sad, but

I think we know why that's the case. There's a lot of hurt and pain in the Black gay community and it stems from the ostracization we've felt from the larger Black population. If there were more acceptance in our community and less rampant homophobia, Black gay men would have more self-love and be more likely to protect themselves. I'm not saying that there isn't homophobia in the white community, because they aren't where they need to be either, but white gay men seem to experience a level of acceptance that Black gay men don't.

*Some people argue that white communities are just as homophobic as Black communities, but white gay men have been more likely to leave and build spaces for themselves.*

Right, so in the Black gay community we need to do a better job of working together and supporting each other, because we're not united. We're very pocketed and cliquish and it's just unfortunate. I really think it's time that we start working together for the greater good instead of mimicking the homophobia that we receive from the straight community. We have to stop degrading each other for being "too gay" or "too feminine." We get that enough from people outside of the community and we can't afford to do it to ourselves.

*Interesting that you bring that up, because a recent study out of Johns Hopkins found that Black gay men contract HIV more than other races because of a sexual preference for "masculine men" and a misperception that those men are less likely to*

*be infected with HIV than gay men that are more feminine.*

I'm not surprised because we're hung up on that. And I know that kind of thing affects the self-esteem of those of us who are more feminine and gender non-conforming, because on top of being Black and gay if you aren't "masculine enough" you get degraded by other Black gays. And then we wonder why AIDS is so rampant in our community. If someone doesn't feel supported by others like him he's less likely to love himself and protect his own life; and if he's not protecting his own life why would he reveal his status to someone he's sleeping with? It just creates an endless cycle of destruction.

*Are you hopeful that in 30 years Black AIDS will be a thing of the past?*

Yes, I'm very hopeful because the Black community has had a long history and legacy of survival, so I have no doubt that we'll overcome this. I'm also hopeful because I'm seeing more and more people like myself sending out a positive message about what it means to be Black and gay and gender non-conforming—telling people that no matter what, it's okay to be you.



**B. SCOTT**  
Television and  
Radio Personality  
Age: 30  
New York, NY



TREE ALEXANDER  
HIV Case Worker  
Age: 24  
New York, NY

## TREE ALEXANDER

I moved to the North Side of Chicago when I was 18. I was introduced to the gay clubs and bars, the late nights and early mornings, the alcohol and the sex. I began working, partying and enjoying life on the North Side. I was now in a neighborhood that was accepting of me.

During the summer when I turned 19, I was working in a clothing store on Halsted and Roscoe streets. I saw this guy come in and he was cute. He looked over and when I asked him if he needed any help, he gave me a smile. After that, he smiled at me the entire time he was in the store. He began to leave, so I stopped him and asked, "After all that, you not going to ask for my number?" In a quick reply he said, "Nope, but I will take it if you give it to me." We laughed and exchanged info before he left.

He called me every day, and every day I was busy working two jobs, so I told him to call back. That went on for about a month. He then started to show up at the store and tried to take me out for lunch, which never happened. I think it was because I saw him in the parking lot across the street watching me. So another three months went by, he gave me a call, asked me out for a dinner date, and I said "sure."

By December of that

year, after only being together for three months, we were living together. I became ill with a cold, something I haven't had since I was two-years-old. I didn't know how to deal with it and it seemed to get worse. He was there to take care of me for almost three weeks, and then I was back to work. He wasn't working at the time and spent a lot of time at home (so he said). Another six months passed and he started to get sick. But this was more than a cold or "flu-like" symptoms. He began to get weak, lose weight, got a Black spot on his tongue and more.

I tried to get him to the doctor, but he wouldn't go. There was always some excuse. He said, "There's too many people in the ER and everyone is dirty. That will only make me more sick." He started to spend most of the day in the bed. This went on until one day when he couldn't move any part of his body. After being rushed to the hospital, doctors said that if I didn't bring him in he wouldn't have made it through the night.

We found out his status after three days in the hospital, and I went to get tested that same day. The ER redirected me to the Ruth M. Rothstein CORE Center, which is a clinic for the prevention, care, and research of HIV/AIDS. He later told me that he'd thought he

had "IT," but was afraid.

When the time came for me to pick up my results, so many things were running through my head. I wanted a negative result but I knew the chances were slim. I remember thinking, "They say it only takes one time for the little swimmer to catch you." I prayed that one time hadn't happened. After seeing him in that hospital bed with his face thin and ribs visible, I started to count money. I know how much of an insurance policy my mom had on me, so I was planning her pockets. I didn't feel sick or like I was dying but I didn't have much of a drive to continue living. I knew that if I were to pass away my mother would have a financial boost.

Now it's my turn to go into the back room and talk with the tester. "I'm sorry to tell you, but you're HIV-positive," she said with a straight face. I took a deep, deep breath and replied with a straight face, "OK." She asked me if I was really OK about five more times. I was truly in denial and my thoughts were focused on getting home and drinking nothing but orange juice for the next two weeks. Then I wanted to boost my vitamin C intake so that I could return and show them that the first test was indeed wrong.

My career has changed a bit. When I found out I was HIV-positive I was working

as a fitness trainer. Now I have committed myself to HIV/AIDS care and prevention. This came about when I would attend groups and hear all the horror stories of disclosure. I also thought back to my high school's Sex Ed. Class and just remember hearing how to get tested and that HIV leads to AIDS. I also remember that picture of that guy with the gonorrhea in his eye, that picture of the penis with warts the size of Reese's peanut butter cups, and more. That's what made me use condoms up until my ex convinced me that we both were negative and "faithful," whatever that means. So where were the pictures of HIV?

You can say "one million people die from AIDS complications" all you want but it's not real to someone until you tell them that 75 of those people are in your city, 15 of which are in your neighborhood and two from your high school, and so on. I think we need more education on HIV/AIDS worldwide, especially with youth, and the only way to do that is to show them a picture. Show people that HIV really does exist; it's not just something from T.V. or from the distant past. It's right in your backyard.

## AARON THOMAS

**W**hen I think about HIV/AIDS I feel frustrated. I'm frustrated because the national conversation about prevention has all but ceased to exist; because when I turn on the news there's hardly any discussion about the soaring rates of infection in certain populations. I'm frustrated because no one is talking about the virus and what it is medically—how it's constantly evolving and changing. I'm frustrated that instead of banding together in this time of crisis, the Black community has resorted to the blame game, demonizing people instead of educating. I'm frustrated that we still treat people living with HIV as if they're lepers. I'm frustrated that people are still having unprotected sex without knowing their status and the status of their partners. Lastly, I am incredibly frustrated that people are still testing positive because they lack a basic understanding of disease transmission and prevention.

## ASHLEY LOVE

**D**ue to a lack of human rights protections from the government and understanding from families and society, many Americans born transsexual and/or intersex, or that have a transgender identity, find themselves in very vulnerable and dangerous situations. Because of this alienation some people in these communities engage in unsafe behavior as a way to cope and survive, making them vulnerable to infection with HIV. I have lost

two people close to me because of this disease. One of them was a woman who was born with a transsexual medical condition. She wanted love so much that she trusted the wrong man and, instead of protecting herself, took a risk that proved fatal.

A lot of work needs to be done to educate society about transsexual, transgender and intersex issues. The unhealthy stigma and dehumanization of these communities is what leads to situations where they contract the disease. Low self-esteem caused by people's prejudice against human diversity is what causes many in these communities to fail to safeguard their health.

If any of my sisters are reading this, know that your life is a beautiful gem. Cherish yourself and your temple. We all want love, but we have to love ourselves first and foremost if we are to receive authentic love from someone else. Regardless of the misguided fear and toxic hate in the world directed at people who are born different, don't believe the lies that say you are unworthy. You are a child of God just the way you are. Treat yourself kindly, because you deserve it.

*Ashley Love is the founder of Media Advocates Giving National Equality to Transsexual & Transgender People and a popular contributor to the Huffington Post.*



AARON THOMAS  
Legal Assistant  
Age: 26  
Columbus, OH



ASHLEY LOVE  
Transsexual and  
Transgender Rights  
Advocate  
Age: 30  
New York, NY



**JONATHAN LEWIS**  
NAACP Regional  
Field Fellow  
Age: 23  
Baltimore, MD

## JONATHAN LEWIS

**A**s I waited for the nurse to bring my results into the counseling room, chills ran down my spine. I couldn't believe I'd waited that long to get tested. I'd enjoyed a fairly "risky" lifestyle in college, and even though protection was a top priority, I'd had the occasional slip-up and as I waited for my HIV test results those incidents played over and over in my mind.

When the nurse finally walked in, she sat in front of me and read my results: "Negative for HIV." At that moment, I couldn't hear anything other than those words. Hearing that I was HIV-negative lifted a weight from my shoulders and I vowed to never put myself in a situation like that again.



**GREG WILSON**  
Manager  
REACH LA  
Age: 29  
Los Angeles, CA

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## GREG WILSON

**“B**ut I just talked to him yesterday!" This is what so many of us say when yet another member of the Ball community dies from HIV/AIDS related complications. The Ball Community is a sub-culture of the gay Black community that's been alive since the early '80s.

Within this culture gay "houses" serve as extended families and support systems for queer youth and compete against one another in vogue "Balls" for fun, awards, cash prizes and status. I have been a part of the Iconic House of Ultra Omni for nine years and the experience of losing my peers to AIDS has become more and more frequent. So many of the kids in our community have been rejected growing up, disowned by family and forced to go through life feeling as if they aren't worthy of love. For this reason many of them are also reluctant to get tested for HIV, fearing that a positive result might lead to further ostracization. Because I understand the different barriers and challenges that the members of our community face, I've been blessed with the opportunity to help make a difference. Last fall my organization, REACH LA, hosted a "20 Days of Testing Event" to encourage members of the Ball Community to learn their status before our "Ovahness 5 Ball" in November. Through our efforts, 14 young men were newly diagnosed and carefully guided through the treatment and care process.



**MALCOLM VARNER**  
Outreach  
Coordinator,  
Family AIDS Clinic  
and Education  
Services  
Age: 27  
Columbus, OH

## MALCOLM VARNER

**I**n the early 90s, I had my first encounter with the devastating reality of AIDS when my Uncle Mike succumbed to the disease. He was emaciated and sick with pneumocystis pneumonia and my family and I stood by his bedside until he was finally freed from suffering.

As I grew older I noticed the silence surrounding his death and sexuality—subjects that remained taboo in our family. When I came out as a gay man, I was forced to navigate the silence and discomfort that my family had regarding homosexuality and their fears about me becoming HIV-positive like my uncle.

My second encounter with HIV/AIDS came when I learned that my mother was HIV-positive. At the time we'd only begun to build a relationship. She was doing time in a prison outside of New York City and we hadn't even had a chance to meet yet. I was in my freshman year of college when I received a letter from her, disclosing her HIV status. The news was shocking and a lot to absorb. I don't know whether she was infected by a sexual partner or through intravenous drug use, but she made me promise that I would never use drugs. Substance abuse had cost my mother and father a great deal; and for my mother, it's possible that HIV was an added consequence.

*Two years after receiving that letter, my mother passed away.*

## QUINCI MOODY

One thing is clear: It's time for women in our community to take control of their health. I live in Washington, D.C.

where HIV is skyrocketing among Black teen girls—most of whom don't even know they're at risk. With the young women I mentor, I make sure to instill the importance of self-reliance when it comes to

their reproductive health and sexuality.



QUINCY MOODY  
Founder of Women  
Achieving Visionary  
Excellence  
Age: 30  
Washington, DC

## KALI VILLAROSA

The topic of HIV came up in my ninth grade health class this year. As one of my classmates wrote the letters H-I-V on the board, my teacher asked if anyone knew what these letters stood for. A few hands quickly shot into the air and, someone stated: "Human Immunodeficiency Virus." Nodding his head, my teacher turned back to the board and began furiously scribbling statistics and facts about HIV/AIDS, things that we had all heard before. It was not until my teacher turned around and said,

"You better write this down because there is going to be a test," that people actually took out paper and pencils and begin copying the notes.

Suddenly a boy in the back of the room picked up his head and asked, "If someone with the virus sneezes on you, does that mean you get AIDS?" The room exploded with laughter as if that was the stupidest thing they had ever heard. But it soon quieted down when it became clear that he was completely serious. My teacher calmly began going through the ways the virus can be transferred: vaginal secretion, blood-to-blood contact, semen, and breast milk.

Sitting there in my high school health class, I was surprised by how little my peers knew about HIV. We were writing down the facts being thrown at us in order to do well on our next exam, but the disease didn't plague in the way it haunted those who came before us.

My generation takes HIV for granted. For many of us, it's not as personal as it was for our parents and others who watched loved ones die from it.

In health class we also learned how to protect ourselves from sexually transmitted diseases. Despite the warnings and reminder "to use a condom every time" no one seems to be following the rules. A very popular show among my peers is *16 and Pregnant*. The title is pretty self explanatory, but the show involves girls having unprotected sex and having to deal with getting pregnant at a young age. Those girls could just as easily be getting infected with AIDS. And even as we learn that exchanging blood spreads HIV, we live in a world obsessed with young vampires. The *Twilight* series, a huge teen phenomenon, is all about a bunch of beautiful blood-sharing creatures. Is this supposed to be a metaphor for HIV? If it is, it's

over most of our heads. What we see is the thrilling fantasy of teen love. The main character in the series even ends up getting pregnant, thinking that she could have unprotected sex with a vampire without consequences. Yet again we are exposed to matters of sex, pregnancy and known consequences, but for most, a breathtaking vampire seems worth the risk.

HIV doesn't feel like it kills. I know people who are living with the disease, and they seem fine. They take their medication and function like everybody else. Magazine advertisements for HIV drugs show happy couples going out to lunch or riding bikes. None of these advertisements show someone who is sick or even dying from the once deadly illness. My cousin has HIV. I've known her my entire life, but just recently learned that she's been living with the virus. She looks and acts like everyone else, so I never would have guessed if I hadn't been told. I have not yet had a chance to discuss the disease with her but I would like to. I want to know how she lives, how she feels, and what medications she takes, because I don't want to be one of those people who take HIV for granted.



KALI VILLAROSA  
High School Student  
Age: 14  
Brooklyn, NY



**JONATHAN PERRY**  
Community Organizer  
Age: 25  
New Orleans, LA



**TASHA COLEMAN**  
College Student  
Age: 23  
Savannah, GA

## JONATHAN PERRY

**I**t wasn't until I was 23 and joined the Peace Corps that I actually met someone who was openly HIV-positive. As a Peace Corps Volunteer in Africa, I was stationed at a small clinic in a rural village and charged with mobilizing the community around HIV. In Botswana, the country in which I'd been placed, nearly 1 in 4 adults was HIV-positive. With infection rates this high, it was impossible to hide from HIV. Everywhere you looked, HIV was there. Everything you did, HIV was there. Everyone was either infected or affected. The only disease that mattered was HIV. Cancer, Diabetes, High Blood Pressure and every other disease all took back seats to HIV. Every week brought a new funeral to a village of only 3,000 people. In Botswana, I saw the many faces of HIV. It was not a gay disease; it was a national disease. I saw grandmothers who were positive and struggling to raise their deceased son's children. I saw boys born positive to infected mothers who struggled with the thought of telling their future partners their status. I saw men who were positive and turned to alcohol as a solution.

When I finished my Peace Corps service and returned to the U.S., I wanted to continue working with HIV-infected and affected

individuals. Since the U.S. is one of the most developed nations, I expected to see a world of difference compared to Botswana. I expected HIV to be a problem still mainly for gay men. I expected those who were HIV-positive to have access to medical care and medicine. I expected HIV to be a disease that was on the decline. I expected the type of work to be different. In Botswana, there was a definite need for community mobilization. I didn't think that need would exist in the U.S.

To my surprise, my expectations were completely wrong. The HIV epidemic that I knew growing up in New Orleans had transformed into a different, much larger beast. No longer was HIV a problem for gay men but rather a national problem. No longer was the disease invisible, it had a face—the same as in Botswana. Once again I saw the faces I thought I had left behind in Africa. I saw the grandmothers who were positive and struggling to raise their grandchildren, the boys born positive to infected mothers who struggled with telling their partners, and the positive men who turned to alcohol.

The reality is that HIV is just as bad here in the U.S. as it is in Botswana; and like Botswana, the disease is entrenching itself in the Black community.

## TASHA COLEMAN

**I**'ve heard people give all kinds of reasons for why they don't feel the need to get tested. I recall one conversation in particular when I'd asked a male associate of mine if he planned to get tested. He said, "no" and explained that he'd already been tested once before and since then all of his partners had been "clean" so he didn't need to bother getting tested again.

## NANCY REDD

My generation grew up with multiple faces of AIDS, but I can't remember a single one being the face of a Black woman. We watched special broadcasts in school, announcing the deaths of Eazy-E and Ryan White. The gritty indie film *Kids*, depicted the virus being transmitted within a group of white teenagers, and the Oscar-winning film *Philadelphia* humanized the plight of gay men affected by the epidemic. Throughout the 90s the media offered more and more real-life stories of Americans struggling with HIV, but ignored the issue as it related to Black women contracting the virus through heterosexual intercourse.

Sadly, this failure of representation continues in the present, at a time when Black women are among the fastest-growing populations infected with the disease. The only way to curb this trend is to demand honest dialogue surrounding sexual and reproductive health in our schools and churches. We have to promote a culture where women can have healthy attitudes about sex and sexuality and feel a sense of ownership over their bodies. Instead of taking cues from men, Black women need to learn about sexual health from other women who can address the importance of self-respect and self-protection.

*Nancy Redd is a New York Times bestselling author and speaker who has appeared on Good Morning America, The Today Show, Oprah & Friends.*

## WILLIAM COUNCIL II

I remember when my fraternity brother found out that his real brother had full blown AIDS. His brother was 27-years-old at the time and contracted the virus through unprotected sex he had with a woman he met in a club. Ten months later, he was diagnosed with full blown AIDS. The virus opened him up to a host of infections that left him bedridden and reliant upon family members to help him perform basic body functions. He passed away several months later. Not only did this experience show me how destructive HIV can be to a person's body, but it also showed me how the virus can devastate one's family and community.

## TERRANCE GILBERT

At 16 years old, I came out as a gay Black man in the heart of the Bible Belt. That same year I became sexually active and even though I knew the dangers of unprotected sex and had been told to use a condom, I was never shown how to properly do so. I was well aware of STDs but it never clicked in my head to use protection each and every time. I left my mid-sized suburban-rural hometown for college, and that's when discussions started to take place about HIV/AIDS and its painful effects.

In 2010, I took a job with the University of California at San Francisco's Center for AIDS Prevention Studies working on a research intervention focused on young Black men who have sex with men between the ages of 18-29. I am now in the process of conducting a research study focused on ways to mobilize, treat, and prevent the spread of HIV/AIDS through social networking.



NANCY REDD  
Author and Speaker  
Age: 30  
Santa Monica, CA



WILLIAM COUNCIL II  
College Student  
Age: 24  
Green Cove Springs, FL



TERRANCE GILBERT  
Researcher  
Age: 25  
Dallas, TX



PATRICE J. WILLIAMS  
Journalist  
Age: 28  
New York, NY

## PATRICE J. WILLIAMS

**H**I can affect you even when you're not infected. I've been living with HIV for the last 16 years. Though my status is negative, I've spent days in the hospital for it. It's affected my sex life, and it has caused endless anxiety and heartache.

I was nine years old when Magic Johnson announced he was HIV-positive. My best friend asked me if I knew what HIV was. I said yes, although I really didn't. The wannabe-know-it-all in me just changed subjects. We rode our bikes to the park and never mentioned HIV again.

Three years later, I would eventually become all too familiar with the virus. Johnson announced his status to a roomful of reporters on Nov. 7, 1991, and my father announced he was HIV-positive one Sunday after church in 1994. Unlike Johnson's press conference, there were no cameras, flashing lights or rapid-fire questions. My father was admittedly promiscuous and rarely used condoms. Though I didn't realize it at the time, I was angry with him. Furious. How could he be so reckless? Was unprotected sex more important than being around to watch me grow up? At the time, I still didn't fully understand the meaning of HIV, but judging from my father's unusually serious demeanor and my older cousin's tears, I knew it was serious. She

cried, so I cried, too. My mother was no stranger to my father's wandering eye, and she assured me that she'd tested negative.

My parents separated when I was a toddler, and although I had no recollection of there ever being any love between them, I could tell that my mom was just as devastated with the news as I was. But up until that point, my only frame of reference was Johnson, who was healthy and strong. My 12-year-old self thought everything was going to be OK. Three little letters couldn't snuff out my Superman.

After my father's announcement, the virus came to mean something more to me than what was briefly mentioned in health class. I would ask my teacher questions about life expectancy and T-cell counts, when previously I had never said a peep. Suddenly they weren't just talking about some illness in class; they were talking about my father—the man whose pug nose I had, who I shared inside jokes with, and who loved to recount the time he rushed me to the emergency room when I knocked my tooth out attempting to jump from the couch to the table.

One thing I did learn was that HIV affects everybody differently. Magic Johnson wouldn't be the model for what my father's status looked like. "I'm going to go on. I'm going to beat this, and

I'm going to have fun." That's how Johnson ended his press conference in 1991. And he's done just that. Of course, he hasn't beaten HIV, but his life has gone on and he has thrived. Nineteen years later, he looks healthy and has gone on to be a *New York Times* best-selling author and have great success with his entrepreneurial endeavors.

My father didn't "go on" or "have fun." He was admitted to the hospital for multiple stays. The man who was fiercely independent had to rely on the help of others for little tasks that now required energy he didn't have. While I was preparing to send out college applications, his virus progressed to full-blown AIDS. He eventually dropped to 120 pounds. Eight years after being diagnosed, he passed on a Thursday morning during the beginning of my spring semester.

**I** wasn't the one with HIV, but the disease affected me without my being infected. My life was changed in ways I had never expected. My father had antiretroviral drugs to fight off the attack to his body, but I was left to fend for myself. There was no drug to help my pain, or at least not one that I was offered. As a teenager, I wanted to be carefree and feel naively invincible, but my father's HIV status constantly reminded me of life's shaky ground. There was no thought of what I'd wear

to the prom or crushing on boys. My heart was too heavy for those trivial teenage affairs.

Anyone who's ever been in the caregiver position knows the toll it takes. Living with my mom and being away at school gave me a respite from the 24-7 care (that heavy burden fell on my aunt), but weekends and visits home involved preparing meals, accompanying him to doctor visits and giving him his two dozen pills a day. It changes you emotionally to see someone you love struggle. I felt weak watching my father. He was only in his 40s but had the body of an old man. My Superman had found his kryptonite.

I didn't know how to navigate being the child of someone with HIV. If the subject of my father ever came up, either I received the sympathetic head tilt or people wanted to drill me with 20 questions. Of course there was the occasional person who made me realize that no matter how much information is available on HIV, some folks are still ignorant and mean-spirited.

During a heated argument I had with my college boyfriend, he told me that my father must have been a "f-ggot," and that's why he died of AIDS. This wasn't new to me. There was also a guy I briefly dated who thought that because my father had AIDS, then I must

have it also. For days after I told him about my father's passing, he drilled me on my status. Questions about my HIV status don't offend me. Actually, it was the norm for me to do the same with anyone I was sexually involved with. "When was the last time you were tested? How many partners have you had or are you currently with? Do you want to get tested together?" But these questions seemed to make some men uncomfortable. Talking about HIV was a turnoff to them but necessary for me. Long before I was even sexually active, the thought of HIV and AIDS loomed in the back of my mind. I was never fearful of sex, but I grew up understanding the repercussions that can come along with it. Unless people know my story, they don't understand why HIV is so important to me. But it's serious, and so am I about prevention, testing and education.

It's been 16 years since HIV came into my life. I think about it every day that my father's not here. I would never minimize the struggle that those stricken with HIV or AIDS go through, but there are other victims as well—those without a voice, who are changed forever because of those three loaded letters.

*Patrice J. Williams is a journalist whose work has appeared in InStyle, CosmoGIRL!, and The Root.com.*

## BRENDA SENYANA



BRENDA SENYANA  
Researcher  
Age: 24  
New York, NY

**A**t the age of seven, I left Minnesota, the only place I'd ever called home, and ventured to Uganda, the land where I was born. It was 1994 and the AIDS epidemic in Sub-Saharan Africa had reached unimaginable heights. It seemed like everyone around me was either infected with the disease or knew someone who was. I also noticed that people's fears of contracting HIV and its looming death sentence perpetuated an ethos of secrecy and shame.

Today, in both Uganda and the United States, infections among Black women are rising at alarming rates. For many years and throughout many societies, women have been oppressed and treated with inequity in sexual relationships. To this day they're predisposed to biological, cultural and socio-economic factors that make them disproportionately vulnerable to sexually transmitted diseases, including HIV.

As women we need to put ourselves first at all times and actively protect ourselves against HIV/AIDS. We need to feel empowered to say NO to things that put us at risk and disregard who or what we'll lose in the process.



WILLIAM BRAWNER  
Founder  
Haven Youth Center,  
Inc.  
Age: 30  
Philadelphia, PA

## WILLIAM BRAWNER

**A**t just 18 months old, I had to undergo a blood transfusion following abuse I'd suffered at the hands of a family friend. The transfusion was successful and I survived, but a few months later my mother learned that the donor whose blood I received had recently died from GRID (Gay-related immune deficiency)—the original name for HIV. The doctor explained to her that there was no cure for this little-known disease and I probably didn't have much longer to live. Four years later my mother received a phone call informing her that treatment for my condition was finally available. After that call, she revealed to me for the first time that I was HIV-positive. Even though I didn't understand what that meant, I could tell that it was something that hurt my mother very deeply. In order to protect her feelings, I kept my emotions bottled up for years and suffered in silence.

When I turned 12, I attended my first support group meeting and finally had the opportunity to share what I was going through,

from the horrible medications I had to take to the debilitating side effects that were keeping me up at night. For years that support group was the only place where I felt comfortable opening up about my experience living with HIV. To the rest of the world I was energetic, charming, handsome Billy, and I never discussed my disease status. This worked for a while, but things got complicated when I started to become attracted to girls.

Because of my reluctance to disclose my HIV status, I didn't become sexually active until I turned 18. When I finally revealed my status to my girlfriend at the time she handled the news well. We were together for an entire year after that and broke up on what seemed like good terms soon after I left for college.

But two years later the president of my university called to inform me that the school had received an anonymous letter alerting them to my HIV status. I knew immediately that my ex-girlfriend was behind it, because she was the only person I'd ever told. It took years of counsel-

ing and prayer to recover from that betrayal. When I finally built the courage to disclose again, a lot of people insisted that I "had to be gay" because they didn't believe that a heterosexual could live with HIV as long as I had and be in such good shape.

After a while it seemed like those I encountered were more interested in debating my sexuality than learning about the disease. What people fail to realize is that heterosexual Black men make up a large portion of those infected with HIV in our country. Unfortunately, many of these men don't disclose their HIV status for fear of being labeled and their silence is killing our community.

Because of my experience, I've dedicated my life to the fight against HIV/AIDS, but I can't do it alone. It's time for other HIV-positive straight Black men to take responsibility and stand up in this fight as well.

***William Brawner is the Founder & Executive Director of Haven Youth Center, a non-profit, providing services to HIV-positive youth in Philadelphia, PA.***

## STEPH JONES

*You've been vocal about the importance of HIV testing and even "tweet" your fans via Twitter whenever you get tested. Is that you leading by example?*

Definitely. My Twitter is like my reality show and it's interactive so my followers join in. Whenever I say "I just got my HIV test back and I'm good," at least a hundred of my followers hit me back and tell me they're going out to get tested that day. When people get that sort of message from someone they relate to or someone they respect they're more likely to consider it for their own lives.

*How else have you used social networking to promote HIV awareness?*

One of the things I like to do to get close to my fans is get on Ustream live and talk about real things that are going on with real people. I also like to use YouTube for that because a lot of my followers aren't just coming for the music; they're coming for the message, too. I like to talk straight from the heart about whatever's on their minds and whatever's

## JURNEE SMOLLETT-BELL

**J**t's one thing to read statistics and another to know people with the disease. Hydeia and I met 12 years ago and have since become best friends. HIV/AIDS is never far from my mind because she and another close friend of mine are living with the infection. They're both talented, intelligent, young African Americans who have never been sexually promiscuous nor used intravenous drugs. You would never know by looking at them that a potentially deadly virus lurks in their bloodstreams. But it does. Thankfully, they're each getting medical care that keeps them healthy. They live their lives, have fun, pursue their dreams, have relationships and are careful to not pass the virus on to anyone else. They're proof that HIV/AIDS doesn't have to be a death sentence, if you know your status.

Most of my life I've volunteered with Artists for a New South Africa, a nonprofit organization working in the U.S. and South Africa to combat HIV/AIDS, assist children orphaned by the disease, educate and empower youth, and build bonds between our nations through arts, culture, and our shared pursuit of social justice. Regardless of the country, what frustrates me most is the lack of informative dialogue within our community, churches, homes, and schools. That very silence is killing us, but it can be broken if we speak out and take action.

*Jurnee Smollett-Bell currently stars in the CBS series The Defenders and in the NBC series, Friday Night Lights.*

important. Of course, HIV is one of those things.

*Has HIV/AIDS touched your life personally?*

When I was a kid, my uncle Duane died from AIDS, so I knew from an early age that it's nothing to play around with.

*Did you find out that he had AIDS before or after he died?*

After. I've never said this but I think my family was ashamed that my uncle died from AIDS. They called it pneumonia and kinda covered it up like that. It's something that they didn't like to talk about. But to me it's what you

do talk about so that you're educating the nieces and the nephews, and the daughters and the sons about the disease so they know which route to take in their lives. Another thing my family didn't talk about was the fact that Duane was a gay man. I didn't know what that meant when he was alive. All I knew was that he was my favorite uncle. He was just so free and happy all the time. And the thing is, if our family had been open with us about Duane's life and what happened to him I would've loved him the exact same way.

*Follow Steph Jones on Twitter @stephjonesmusic.*



JURNEE SMOLLETT-BELL  
Actress and Activist  
Age: 24  
Los Angeles, CA



STEPH JONES  
Singer and Songwriter  
Age: 27  
Los Angeles, CA



## MAYO MCCLINTON

*When you learned that you were HIV-positive what was your doctor's treatment recommendation?*

When I was diagnosed in July '05 my doctors told me that I didn't need to start antiretrovirals because my body was fighting off the virus pretty well on its own. They just advised me to slow down on things like drinking and to stay away from drugs, but I wasn't doing that anyway. I was told to focus on healthy eating habits, which meant I had to cut out fried foods and bake or broil the food I cooked. I also started eating lots of salad and vegetables. It was hard in the beginning, because I wasn't used to eating that way, but it's something I appreciate now. At that point I just had to be smart about what I was putting into my body.

*When were you started on HIV medications?*

I did a research study in the fall of 2006, and that was my first experience with medication. My doctors wanted to see how my body would respond to antiretrovirals.

*Was treatment necessary at that point?*

No, I didn't have to start it right away, but they told me to sign up for the study to see how I would do on treatment. I guess they wanted to train me before I actually needed it.

*Did you start a different regimen after the study?*

No, I still didn't need medication at that point

because my CD4 count was good. I didn't start treatment again until I "aged out" at that clinic and entered adult care somewhere else. The doctor there told me that my CD4 had dropped and recommended that I start an antiretroviral regimen.

*What was the process of finding the right treatment program?*

What made it hard for me is that I have trouble swallowing pills. Since most HIV medications come in pill form my doctor had to find a regimen that came in liquid form. I had a lot of side effects with the first medications I was on. Mainly diarrhea, headaches, body aches, feeling nauseous at times. Kaletra and Truvada are the ones I really had problems with.

*Were you ever tempted to stop taking the medication your doctor put you on?*

Once I started having really bad side effects, I did stop.

*On your own? Or did you make the decision with your doctor?*

I told her I'd stopped. Her response was, "You need to continue the treatment to remain healthy." I understood that but the side effects were ridiculous. It felt like the medication was making me sicker than I already was. I told her, "I hear what you're saying, but you're not the one living with these side effects. You have no idea how this is making me feel."

*When you stopped treatment did you notice a difference in your health?*

Around the time I stopped taking the medication, I also lost my insurance and the doctors stopped seeing me, so I fell out of care for a while. After some time passed I started to lose weight and I was getting sicker than usual. My friends noticed the physical change and got really worried. One of them introduced me to a really good clinic in Baltimore called Chase Brexton. The care I got there was great because the people there assist you with everything. They don't just tell you what to do; they actually walk you through every step of the treatment process.

*How was Chase Brexton different from the previous clinic?*

When I got to Chase Brexton they immediately knew how to correct the side effects I was having on those other treatments. They made sure that I had my insurance together and it felt like they wanted to do everything in their power to keep me healthy. At the other clinic their position was, "You're an adult, so we shouldn't have to hold your hand." But they didn't understand that I'd just transferred from a youth clinic and everything was still new to me. They were telling me to go down and sign up for medical assistance, but I didn't know how. I'd never done it before. And when I'd ask for help they'd brush me to the side.

At Chase Brexton, on the other hand, I got one-on-one assistance through that whole process. They gave me the information I needed and even called the medical assistance office to make sure they knew how to help me when I got there.

*Based on your experiences, what steps should HIV-positive young people take to make sure they're getting the best possible care?*

The first thing you have to do is find a clinic where you feel comfortable. You can't go to just any clinic and expect to get what you need. You have to find a place where you feel safe opening up and telling people exactly what you need, because they can't help you otherwise. And don't be afraid to ask questions. If you don't understand something your doctor says, tell him you need it explained. I linked into some good support groups that helped me and I think that's very important for young people as well. Also, you have to find the right social worker. I didn't have a good social worker at first, but the one I have now makes sure that I'm doing everything I need to do. She really goes the extra mile and I know she cares.

*You were recently selected to be a national spokesmodel for the "HIV Stops with Me" campaign. Do you think being open about your status has helped others grow comfortable with theirs?*

Yes, and that's the main reason I wanted to be a part of the campaign. The young people where I come from don't feel comfortable opening up about their status because they don't see other people out there that they can relate to. I felt like this was an opportunity to be that for people who feel like they're in this alone. Ever since I started the campaign and put it all out there, I've had so many people come to me and open up about their status or tell me about how they're finally

getting treatment. I know other people who were afraid to get tested before but finally went and found out their status. I think they saw me and realized that no matter what the result was, they'd be okay.

*For more information on Mayo and "HIV Stops with Me" visit [hivstopswithme.org](http://hivstopswithme.org).*

## JUSSIE SMOLLETT

**A**IDS. It's murdered three friends, four associates and millions of people whom I haven't met, but respect and love. The disease continues to threaten our friends, lovers and family members. My question is why?

I've volunteered with Artists for a New South Africa and the Black Aids Institute for almost half my life. Over 30 million people worldwide are currently living with this disease and half a million of these are African Americans, so as a man... a Black man... a human being... I'm forced to keep my eyes open and my voice raised.

Black conservatives say it's the Black men on the "dl" (a term I hate) bringing it into the community. White conservatives still believe it's a gay thing. I say, regardless of these old school, antiquated beliefs, the disease still exists, so what are we going to do about it? We can't simply throw galas with rooms full of money and feel it's good enough. Nothing's good enough until the disease is gone.

*Jussie Smollett's debut album, The Poisoned Hearts Club, will be released Summer 2011.*

## TIA HINES

**I**remember the day someone close to me revealed that she was HIV-positive. Talk about the world shutting down. I didn't know which one of us was more hurt. There is so much that comes with the disease that people don't understand. It's not a walk in the park, no matter how much counseling and support people have access to these days.



**JUSSIE SMOLLETT**  
Singer/Songwriter/  
Activist  
Age: 28  
Los Angeles, CA



**TIA HINES**  
Writer  
Age: 30  
Boston, MA



**VENTON JONES**  
Activist & Community Leader  
Age: 27  
Washington, DC

## VENTON JONES

*When did you find out that you were HIV-positive?*

There's a lot to that story, so I'll start at the beginning. Around April 2007 I became very ill, and it got so bad that I took myself to the emergency room several times. But instead of looking into it, the hospital staff kept sending me home with packets of Motrin. Finally, I went back and laid it all out on the table and told the attendant, "I'm Black, I'm gay, it's possible that I've been exposed to HIV and I need to be tested." At the time I'd just graduated with a public health degree and knew that the high fever, night sweats and swollen glands I was experiencing were textbook signs of Acute Retroviral Syndrome (or Acute HIV). They ended up keeping me in the hospital for two days and when my HIV test came back the result was negative so the doctor sent me home.

*At the time were you satisfied with the "negative" result?*

Completely. I was relieved because it was a period in my life when I needed a fresh start anyway. After college I'd planned to go back home to Dallas and work in public health with a focus on Black LGBTs but we were at the start of the recession and there weren't any opportunities. I've always had an intense need to serve, so after my hospital experience I signed up for the military hoping to become an army nurse. After I went through the enlistment process, I received a letter telling me that the Army physician needed

to see me regarding a "serious and private medical condition." When I read that line, I already had a feeling I knew what it was. I immediately went to a nearby clinic and got an HIV rapid test. This time the test came back positive. At first, I was confused because I hadn't had sex since the last time I tested; after I left the hospital sex was the last thing on my mind. Later I found out that I'd tested negative at the hospital because I was still in the "window period" between infection and seroconversion, but I had the virus the entire time.

*Do you think health care professionals in Black communities need to be more vigilant about identifying patients that might be experiencing Acute HIV?*

Without question. Doctors need to be educated on the early symptoms of the virus and hospitals need to be equipped with the tests needed to properly rule out HIV as a diagnosis. In my situation, an ELISA wasn't the test I needed. I should've been given an RNA test, which detects the virus itself, not antibodies which develop weeks later. What's upsetting is that people with no real knowledge of HIV go into emergency rooms with these symptoms and get misdiagnosed, only to find out months or years later that they're HIV-positive.

*How did this experience influence the work that you do now?*

I'd worked with HIV in the past, but when I became positive and saw first hand what needed to change, I felt a

responsibility to take that work to the next level. And it wasn't just me—there were so many people in my circle of friends who became positive that year too, and I just became more and more aware of the gap in infections rates between Black and white men who have sex with men (MSM).

*Do you know how you contracted the virus?*

Through unprotected sex. The person I contracted it from is someone I'd been in a relationship with in the past and we'd recently resumed a more casual relationship.

*Knowing the risks involved, why did you decide not to use condoms?*

I'm going to tell you this, because it's something that was true in my life and I've noticed it in my clients' lives as well. As you get older it's easier to engage in safe sex with someone you've just met, especially since those are the rules. But as you get to know a person more those rules lag more and more everyday. It becomes a stronger temptation each time. In my situation, the person I was sleeping with is someone I'd used condoms with when we were together, but didn't use them when we started up again. We weren't in a relationship at that point but we had a history and "trusted" each other. Obviously that was a mistake.

*Did you talk to him after you found out you had tested positive?*

I called him and told him I tested positive. He was just silent the whole time because I believe he knew before I even said it.

*Do you think he was already aware that he was positive?*

I know he was.

*What were your feelings toward him at that point?*

I didn't feel negatively toward him because I don't think he intentionally gave it to me. We weren't in a relationship at the time and what he did when we weren't together was his business. I can honestly say that I wasn't tricked. I wasn't deceived. A lot of people have that story but that's not what happened in my situation. At the end of the day, the responsibility comes back to me and the choices I was making at the time. I was going through a very difficult period with the whole job situation, and on top of that I'd just come out to my family, which did not go well. I'd also just started really dating and was—for lack of a better term—"being grown." In order to cope with everything, I started partying a lot and I wasn't making the best decisions in general.

*How did you learn about sex growing up?*

Honestly? Online. I think anybody in my generation learned it the same way. Online, chat lines. I learned from the guys that I made friends with there and we'd talk about our sexual experiences. My mom talked to me about sex, but the lesson she conveyed wasn't about STD prevention, it was about not getting girls pregnant, which is something I didn't have to worry about.

*When you started having sex how much of it was protected?*

None. And that was mainly due to the inaccessibility of condoms. I remember getting my first HIV test at 15. I had to search online to find a place and they didn't even have condoms out. I couldn't go to my parents, because when they'd ask if I was having sex of course the answer was "no." Safe sex just wasn't a conversation that the people around me were having.

*Have you discussed your HIV status with your family?*

It happened this past Thanksgiving actually. I only told my grandmother, but I'm sure everybody else'll start finding out because I was featured in the Washington Blade recently and discussed my status in print for the first time. Before that I'd taken time over the past three years to get comfortable with my diagnosis and learn to love myself with it. I needed to be sure that—even in a worst case scenario where everyone I told was to turn their backs on me—I was strong enough to hold my head up, be myself and live the rest of my life. I often hear gay men who survived the first wave of AIDS talk about how they used to go to a funeral every day. What they don't realize is that those funerals are still going on, but the difference is that, in 2011, young Black people are the ones dying. We don't hear their stories because even in death we're afraid to discuss their HIV status. Even people living with HIV who take care of themselves feel the need to shroud themselves in silence and some hold onto that secret for the rest of their lives. It prevents them from becoming close to people because they're scared of being pushed away if

they disclose. I refused to live with that fear, and if I was going to help others I had to be open and come to terms with my status.

*How big of a role do socio-economics play in the growing HIV prevalence among Black MSMs?*

In our field we tend to rest on socio-economics but in reality disenfranchisement comes in many forms. It's not just Black gay men from poor backgrounds that are vulnerable or those who have low levels of education. I had a college degree when I became positive and I've encountered many others who did as well. The commonality I find in those who seem to be most vulnerable is that they don't have spaces where they can engage in honest and constructive dialogue about themselves, their sexuality and their every day struggles.

*Prevention campaigns targeting the larger gay community have opened a dialogue on the relationship between recreational drug use and HIV prevalence. Is that a conversation that needs to be prioritized in the Black gay community as well?*

Absolutely, because the young Black people dying from the disease aren't the ones who take care of themselves, it's the ones with histories of substance abuse and they aren't your typical IVUs (intravenous drug users). They're using ecstasy, cocaine, meth—the party drugs we don't like to talk about. We also need to be clear about the fact that alcohol abuse is, indeed, substance abuse. The outlets that gay men have to

acknowledge each other are often covered in drugs and alcohol, whether it's the bars and clubs or online where men can post that they like to "party and play." Because of the high concentration of HIV in our community we can't ignore the relationship between recreational drug use and high-risk sexual behavior. It's something that young people in particular need to be aware of.

*Why is the visibility of gay Black leaders essential to the fight against Black AIDS?*

Because young people with positive role models and impacts are more likely to avoid the virus and those already infected are more likely to lead productive and healthy lives. Right now I have the most amazing mentors and friends around me and it truly makes all the difference. I didn't have

that when I was younger and going through my struggles, but I'm working to make sure that the next generation of Black gay men can't say the same.

**Venton Jones is a Senior Program Associate for The National Black Gay Men's Advocacy Coalition and an alumni of The Black AIDS Institute's African American HIV University.**

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Together We Survive

## They've Got SWAG

By Adrian Fussell

**N**EW YORK—Forgiveness was the day's Word of Wisdom, and Elery George sat next in line. "I forgave the person that gave it to me," he said, "My boyfriend at the time. He was 30 and I was 19."

The group looked on, silent as Elery paused to gather himself, taking the hand of his close friend Andre, whose lipgloss sparkled in the afternoon sun. "Everyday I think about it, but I'm not what I used to be. I used to cry about it all day long, but I'm stronger now," said the 24-year-old Borough of Manhattan Community College student, holding back tears, lifting his head to reveal a wide smile.

A silver and gold medallion hung from a chain around his neck, spelling out SWAG, for Sexy With A Goal, like an inner city badge of honor. All but recent additions to the eponymous support group wear the necklace, an accessory that matches their manicured fingernails and stylish haircuts. Yet for Elery and most of the other young men in the room, this membership comes with a lifelong fee: HIV.

SWAG is one of several new groups in New York City providing a peer-to-peer forum on sexual health for a community of young gay men badly in need of help. Men who have sex with men—or MSM—still



make up a majority of those newly infected with HIV in the United States, but over the past several years, a significant shift in the demographic most at risk has heaped growing pressure on the youngest generation of the gay community. For the first time, HIV transmissions among gay Black men have outpaced those of gay whites, the most recent reports from the Centers for Disease Control and Prevention show. Among gay men in New York City, Black men aged 13-29 lead all other demographics in new infections, according to New York Department of Health statistics released in 2010.

**S**WAG evolved out of its parent organization, the AIDS Service Center New York, or ASCNY, as a safe space where the youth could come together and learn to educate their friends, peers and siblings. In late 2010,

activists at ASCNY realized that their support services for gay men with HIV were not working. Programs at the center had been effective at teaching older men already living with the virus how to cope with the side effects of their medicine cocktails and how to live a healthier life. The youth participants needed something different, a place where they could be themselves while coming to terms with their newly HIV-positive status. While they meet in Greenwich Village, they now take their awareness of HIV/AIDS back to distant parts of Brooklyn and the Bronx, hoping to erase the stigma of being young, Black, and gay in the epicenter of the epidemic.

HIV is spreading in the young MSM community for a number of complex reasons say health officials, but one of the primary factors is the stigma of gay sexuality among Blacks, a cultural barrier preventing many from

getting tested. "Just walking in for care is a big issue. The issues around being Black and gay are very different than being white and gay," said Dr. Birnbaum, founder and director of the Brooklyn-based HIV prevention organization HEAT, for Health & Education Alternatives for Teens. HEAT has now shifted its target demographic from young heterosexual women to the young gay men of East New York, Bed Stuy, and Brownsville in just the past two to three years. "The epidemic follows the A and C subway lines," said Dr. Birnbaum. "That's just where they live."

**D**evon Boyd, a 23-year-old SWAG member, knows of the issues well. His ride home from the SWAG meetings ends at the last stop on the C train, Euclid Avenue in East New York, where he was born and raised. Nearly all of Devon's friends are positive.

"Every time I turn around, a friend calls me and says, 'Oh I tested positive.' And I'm like, what? We just went through, we've just been through this." He sees the stigma around HIV testing and gay sexuality as a community's way of dealing with adversity, passed down through generations. "We are taught to be strong. You don't talk about things like that, you internalize it. Our mothers and grandmothers were taught that anything like that, you just push it aside."

Boyd was awaiting the results of his own HIV test in February 2011 when Gary Sneed, a counselor from the AIDS Service Center who helped found SWAG, walked into the exam room, introduced himself, and talked Devon into visiting the group.

"My first meeting was that Friday. It was raining that day, I'll never forget it," said Boyd, an accounting and finance student at Monroe College. Devon's HIV test was ultimately negative, but he still made the group a part of his life. "I make it to every meeting now. I feel more comfortable around them than I do with practically my own family," he said.

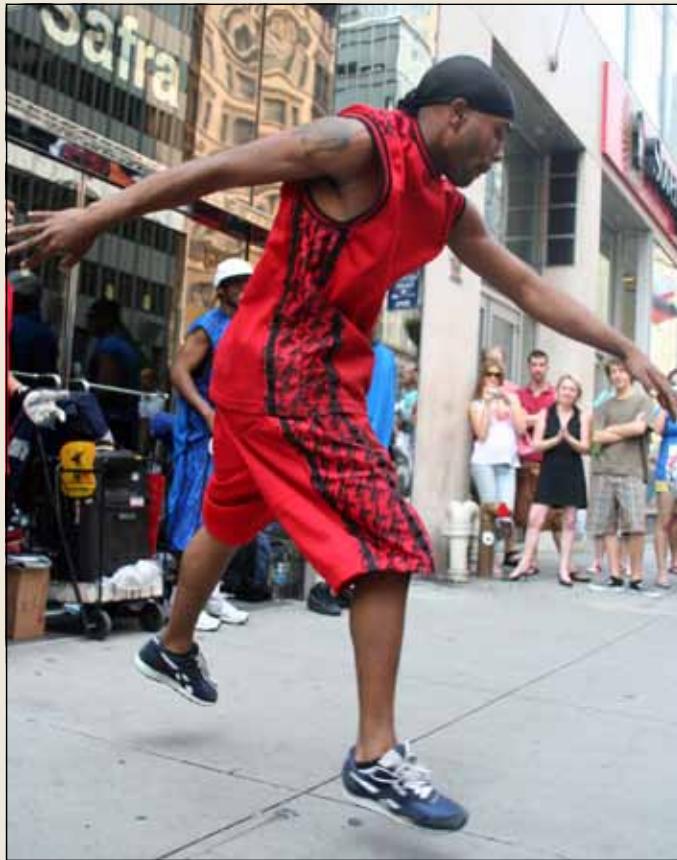
Devon sometimes walks with his 21 year-old brother in the ballroom voguing scene, a combination of dance and homemade runway fashion born in New York during the 1960s and '70s. The HEAT program sponsors balls throughout the year, pairing the events with free HIV testing, but Dr. Birnbaum's organization will soon be forced to cut back on the balls and other outreach events because of funding shortfalls.

Health officials citywide are struggling to build programs that resonate with the young men and encourage testing and prevention as funding cuts loom in a post-recession economy. "There's certainly a money issue," said Dr. Jeffrey Parsons, the founder and co-director of CHEST, the Center for HIV Educational Studies and

Training. The testing and outreach services at CHEST are primarily funded by the National Institutes for Health, which announced on April 25 that due to a \$260 million budget cut, the size of nearly all of its research grants would decrease. "There's a combination of factors: the general economy and the reduced philanthropic giving in general, but then certainly this perception that HIV is not as big of a deal that it used to be," Dr. Parsons said.

**H**IV/AIDS is no longer known as a death sentence, as anti-retroviral medicine can often keep an HIV-positive person alive for a normal lifespan if the patients adhere to their regimens. To alert the young gay community, the New York City Department of Health and Mental Hygiene has tried to jolt them out of complacency. In similar fashion to its contentious anti-smoking and anti-obesity campaigns, the Dept. of Health released an ominous video in late 2010 titled "It's Never Just HIV." It showed brief snapshots of anal cancer and cracked bones from osteoporosis.

HIV prevention organizations in New York City and nationwide criticized the campaigns as needlessly fear-mongering. In a statement, Gay Men's Health Crisis and the Gay and Lesbian Alliance Against Defamation called the video "Sensationalistic and stigmatizing," saying that it unfairly portrayed



gay men as disease carriers and public health risks.

In February, scenes from the N.Y. Dept. of Health commercial moved from YouTube to subway cars. The grim ads inside the trains sharply contrasted with a different kind of awareness campaign adorning the subway stations themselves. On one of the posters at the 125th Street and Lexington Avenue Station, a young, healthy looking man named Tree stands before a New York night scene, grinning while beneath him read the words "Get Tested," or "Positive Since —."

It's Tree Alexander, 24, an outreach specialist for the Brooklyn AIDS Task

Force, or BATF. As the poster informs passing commuters, he has been HIV-positive since 2006. Alexander and the BATF saw the need for a youth oriented group for young men with HIV. In February 2011, he helped create Brooklyn Men's (K)onnect, an online forum organized through social media for young men who might be uncomfortable with stepping forward in person for help with living HIV-positive. "For me personally, being infected and having been homeless, I know how it felt, I know what that's like, being alone, being without resources," the Chicago native said.

As organizations like

HEAT and CHEST will soon be forced to treat a growing number of young gay men with fewer resources, Dr. Parsons believes that creating more programs like SWAG and Brooklyn Men's (K)onnect will prove crucial in stopping the epidemic. "The rates will continue to rise until we develop more programs that are going to particularly resonate with young people, particularly for the young men of color," he said. The future of youth outreach in Brooklyn is equally tenuous. "We're going to continue to have problems," said BATF's Tree Alexander. "In the next couple of years, there will be a continuous HIV rise in the MSM community."

**T**hrough the peer support groups and message boards, the line between socializing and learning about HIV has been intentionally dissolved, and the methods are working. For Elery George, the SWAG group has become a second home. His own apartment is bare save for a mattress, a pile of textbooks, and his pocket-sized dog named Amber. "Growing up, I wanted to go to school and I didn't finish. Now I'm able to be a kid," said Elery, thumbing through his African studies notes before an upcoming exam. "With my HIV diagnosis, I took lemons and made lemonade," he said, now teaching others to do the same, very much the adult helping to save his own generation from itself.

**CORETTA SCOTT KING**  
Hero in the Struggle



# Leadership Matters

## Who's Leading the AIDS Response in Black America

### The 30 Most Influential Black AIDS Leaders

**Leadership matters. Three decades after AIDS was discovered it has become a Black disease with Black-Americans bearing the brunt of new HIV diagnoses, people living with the disease and annual AIDS related deaths. The Black community was slow to mobilize early in the epidemic and infection rates soared. But today, Black America is more active than ever in the fight against HIV and AIDS. Black leaders in various arenas have taken ownership of the disease and are working to prevent the spread of HIV, fight stigma, and increase access and utilization of appropriate care and treatment. Black America is now viewing the AIDS epidemic with a sense of urgency and the high number of Black people in decision-making positions across the country reflects that. In this chapter we've attempted to identify 30 of the most influential Black Americans in the fight against HIV/AIDS.**

### Government

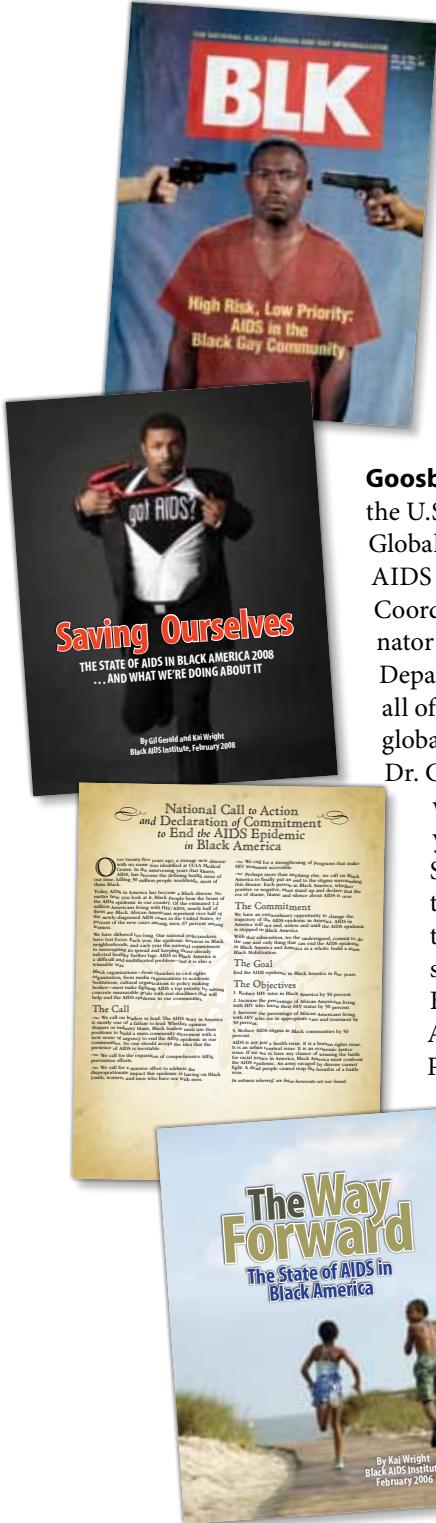
#### Team Obama: **Melody Barnes and Valerie Jarrett**

In the past two years President Barack Obama's administration has pushed forward to advance AIDS policy domestically. Last year the administration released the nation's first and only national AIDS strategy which aims to address several facets of the disease including investing in prevention,

making sure people who are infected get better care, eliminating disparities and reducing new HIV infections 25 percent by 2015. In 2010 Obama also spearheaded the effort for monumental changes in health care with the passage of the Affordable Care Act. White House Domestic Policy Council Director

**Melody Barnes** has been involved in the development of the national AIDS strategy. **Valerie Jarrett**, senior adviser to President





Congresswoman **Barbara Lee** got involved in the fight against HIV/AIDS when she arrived in Washington. She has provided needed support for every major piece of AIDS legislation drafted in the recent past including

Obama, is also the chairwoman of the White House Council on Women and Girls, which has addressed HIV/AIDS disparities among women.

**Dr. Eric**



**Goosby** is the U.S. Global AIDS Coordinator at the State Department and heads all of the United States' global AIDS initiatives. Dr. Goosby was

working as a young doctor in San Francisco in the 1980s when the AIDS epidemic started to surface. He served as HIV/AIDS advisor to President Bill

Clinton. Dr. Goosby was the first director of the Ryan White Care Act and served as the chief executive officer of the

Global Fund to fight HIV/AIDS which established a \$15 billion global AIDS initiative and the President's Emergency Plan for AIDS Relief. Lee, a past Congressional Black Caucus chairwoman, also leads the Minority AIDS Initiative.

Congresswoman **Maxine Waters**, then the chairwoman of the Congressional Black Caucus and an early HIV/AIDS pioneer, led the effort to develop and later fund the Minority AIDS Initiative with other members of the Congressional Black Caucus. The Minority AIDS Initiative grew from a 1998 CDC meeting with Black leaders and HIV prevention specialists, who were moved to action after discussing the devastating impact the AIDS epidemic was having on communities of color.



## The Caregivers

**Dr. Wilbert C. Jordan** established the Oasis Clinic in 1979, which became the first clinic to serve the needs of Black people with HIV/AIDS. Since the Los Angeles clinic opened its doors at least 3,000 patients with HIV/AIDS have been treated.



**Dr. David Malebranche**, a physician and an assistant professor of medicine at Emory University's School of Medicine in Atlanta, has conducted an extensive amount of research on gay Black men, and their HIV risk and their behavior.



**Dr. Beny Primm** is a global expert on AIDS and drug addiction. Primm is the founder and executive director of the Addiction Research Treatment Corporation, one of the country's largest minority drug treatment programs.



## The Policy Makers

**Dr. Helene D. Gayle** is one of the early soldiers in the fight against HIV/AIDS. She worked at the Centers for Disease Control and Prevention for 20 years, mostly combating AIDS. Dr. Gayle directed the HIV, TB and Reproductive Health Program at the Bill & Melinda Gates



Foundation. She has been appointed by the Obama administration to serve as chair of the Presidential Advisory Council on HIV/AIDS. Dr. Gayle now leads CARE USA, one of the world's top humanitarian organizations.

## The Messengers

Veteran journalist **George Curry**, former NNPA editor-in-chief, is the AIDS coordinator for the NNPA partnership. Curry writes stories about the epidemic for Black newspapers. Curry has covered the International AIDS Conferences in Mexico City, Toronto and Bangkok.



### Team CNN

During her critically acclaimed CNN Black in America series **Soledad O'Brien** examined the alarming AIDS and HIV rates among Black women and how they are coping with the epidemic. **Don Lemon**, weekend anchor at CNN, often reports on how the AIDS epidemic affects African Americans. Whether it



is new data on HIV/AIDS or new drugs released, Lemon always finds a way to relate how the story is important to Black America by interviewing Black experts, advocates and people living with the disease.



**Sonya Lockett** has led, Rap It Up, an HIV/AIDS awareness campaign targeted to Black youth, for a decade. The campaign pushes culturally relevant HIV education and prevention information using young Black people and the language they speak. Rap It Up dispels myths about AIDS, urges youth to get tested and works to demystify stigma surrounding the disease.



**Bev Smith** host of *The Bev Smith Show*, which airs on the American Urban Radio Networks, has raised her voice and others' consciences about HIV/AIDS in the Black community. As a broadcaster she's told various stories about the ways AIDS touches the Black community including stigma, myth and how the epidemic impacts groups such as inmates and women. Smith has also raised money for AIDS charities.



**Matters of Opinion**

### Lead by example: Get tested for HIV

Public health advocates have spent 20 years and millions of dollars trying to get more Black folks tested for HIV. But as I'm constantly reminded, nothing works better than old fashioned role modeling and leadership by example. Take James, my 19-year-old nephew. He's heard all the arguments - a quarter of all people living with HIV don't know it; early detection not only stops the virus' spread but gets you life-saving treatment. And he knows he's at risk, since half of the estimated 40,000 new HIV/AIDS cases diagnosed every year are found among African-Americans. I mean, I'm his uncle after all. But what got James ready to learn his status is something simpler: Actress Regina King's doing it, too.

King's one of a bevy of A-list Black celebrities who are taking public HIV tests in association with the June 27th National HIV Testing Day. The massive display of

Phill Wilson  
Special Commentary

million Americans are living with HIV and don't know it, according to U.S. Centers for Disease Control and Prevention estimates. Not only are those people unable to protect their sexual partners, they are also decreasing their chances of surviving with an HIV infection by delaying medical attention.

African-Americans accounted for 38 percent of all people killed by AIDS as of 2004, and HIV infection remained the second leading cause of death among 25- to 44-year-old Blacks as of 2002. This carnage comes at least in part because we are more likely to find out we are positive only once we get seriously ill - and that's the point at which treatment is much less likely to work.

Celebrities have a huge role to play in turning those numbers around, but they are not the only ones who can lead by example. We all have the potential to be HIV-prevention role models for those we love - particularly our youth, who accounted for a

stunning 70 percent of new HIV infections among teens in 2004.

And taking the test today is easier than ever: Most testing sites now use "rapid testing," in which you simply swab your gums with a device similar to a Q-Tip and wait roughly 20 to 40 minutes to get the results. Finding a testing site is just as easy: Just log onto the Internet at [www.BlackAIDS.org](http://www.BlackAIDS.org) to locate one in any zip code you choose.

There's an old saw about the wisdom of getting tested: The life you save might be your own. That's true. But given the power of leadership-by-example, you might also save the life of someone you love.

Regina King saved Sandra Bullock's life in *Miss Congeniality 2*. She may very well have saved my nephew's life by taking an HIV test. For that I will be forever grateful. *Phill Wilson is an NNPA columnist and is founder and Executive Director of the Black AIDS Institute. The Institute is a training and mobilization center focused exclusively on Black people.*

## The Activists

**A. Cornelius Baker** is the senior communications advisor with the AED Center on AIDS & Community Health. He heads the HIV Vaccine Research Education Initiative for the National Institutes of Allergy and Infectious Diseases where he partners with community leaders and arms them with information for their communities about HIV vaccine research.



**Magic Johnson** founded the Magic Johnson Foundation in 1991, the same year he announced he was HIV-positive. The beloved basketball giant's foundation and the AIDS Healthcare Foundation have partnered and opened five HIV/AIDS treatment centers in

low-income communities of color across the country. At least 1,200 people annually receive medications including anti-retroviral drugs at those clinics. The foundation also awards community grants to groups working to promote AIDS education and reduction.



**Frank J. Oldham Jr.** is president and chief executive officer of the National Association for People with AIDS. He advocates for policy, funding and treatment of people with HIV/AIDS. Oldham, the author of two books, also headed AIDS service organizations in Chicago and Los Angeles. Oldham's photo exhibit, The Faces of AIDS, chronicled the reality of the lives of people living with HIV/AIDS.



**Phill Wilson** is the founder and President of the Black AIDS Institute. He is also a member of the PACHA and a member of the coordinating committee for the 2012 International AIDS Conference in Washington DC.



## Industry

**Debra Fraser-Howze**, who founded the National Black Leadership Commission on AIDS in 1987, is the senior vice president of government relations at OraSure Technologies. She partners with legislators to institute HIV testing and ensures that communities in need of testing have materials they need to make HIV testing possible.



## Entertainment

**Danny Glover** has used his star power to bring attention to the HIV/AIDS epidemic as it affects people of African descent across the globe. As a UNICEF Goodwill Ambassador he brought attention to the epidemic in Tanzania. Glover also narrated the *Tiny Tears* documentary about children living with AIDS.



**Hill Harper** is famous for his acting roles but he's also active in the fight against HIV/AIDS. He is a national spokesperson for National Black HIV/AIDS Awareness Day. Harper contributed to the book, *Not in My Family: AIDS in the African American Community*. He also played an inmate who was living with AIDS in the film *The Visit*.



**Sheryl Lee Ralph** has been raising her divine voice for AIDS for the past 20 years. The actress and activist has hosted the Divas Simply Singing event which gathers top entertainers to raise awareness and funds to end the stigma surrounding AIDS.



## The Advocates

**Marjorie Hill** is the chief executive officer of the Gay Men's Health Crisis in New York City. Her group advocates for the health of gay men and also provides health care. The group also supports policy and research into the health issues gay men face.



**Marsha Martin** is the director of Get Screened Oakland. The organization, based in Oakland, California, teams with clinics, commu-

nity agencies and hospitals to seek the best ways to get communities tested for HIV while addressing their social, economic and cultural status.

**Pernessa Seele** is the founder and chief executive officer of The Balm in Gilead Inc. which takes a faith approach to combating HIV/AIDS. The Balm in Gilead has helped 20,000 faith houses institute health programs. The group also promotes Black Church Week of Prayer which encourages Black churches across the country to use prayer to fight HIV/AIDS and the stigma around it.



**Tony Wafford** is the director of the National Action Network's "I Choose Life" campaign. He was the founder of the Test One Million campaign and has used the sweet sounds of R&B music to get people tested for HIV by giving out tickets to major artists' concerts after getting an HIV test.



## The Faithful

**Bishop Charles E. Blake**, who presides over the West Angeles Church of God in Christ in Los Angeles, is the chief executive officer of Save Africa's Children. The group has helped more than 300 grassroots projects in sub-Saharan Africa assist more than 90,000 children affected by AIDS.



**Rev. Calvin Butts** is the chairman of the National Black Leadership Commission on AIDS. Butts, pastor of the Abyssinian Baptist Church in New York, helps to unite and organize Black leaders around the epidemic to advocate for AIDS policy and care on the behalf of Black people.



**Rev. Jesse Jackson**, founder and president of the Rainbow/PUSH Coalition, established the PUSH for Life HIV/AIDS program 11 years ago. Rev. Jackson advocated for AIDS policy as a candidate during the 1984 presidential campaign. He was the first national civil rights leader to publicly get tested for HIV.



**Bishop T.D. Jakes, Sr.**, pastor of The Potter's House church in Dallas, has done more than just pray for HIV/AIDS to go away. He participated in the National Conclave on HIV/AIDS Policy for

Black Clergy that mobilized Black religious leaders. He also led his church's It's Time to Step Up campaign that promoted HIV/AIDS awareness and testing.



**Rev. Ed Sanders** established the Nashville's Metropolitan Interdenominational Church. Since one of its founders died in the early 1980s the church has been working since 1984 to treat people living with HIV/AIDS.



## Civil Rights

**The NAACP**: Today under the leadership of Chairwoman Roselyn Brock, and President and CEO Benjamin Todd Jealous, the NAACP is setting the bar on how Black institutions can respond to the AIDS epidemic. Julian Bond, former chair of the NAACP, helped get the civil-rights organization on board to address AIDS. Bond kicked off the 2006 national convention with a plea to members to get involved, get informed and get tested. Willis Edwards is the chair of NAACP's AIDS Committee



# People You Might Not Know, Whom You Should!

**There are Black Americans all over the country, who are providing leadership in ways both large and small. Some of them you may never hear about. Some of them you might hear or read about and not pay attention, but the work they do saves lives every day. Maybe even yours. These are people you should know.**

## Team Health and Human Services

The center of the HIV/AIDS response in America is the Department of Health and Human Services. Today many of the decision makers at HHS are Black. They are responsible for administering HIV prevention strategies, care and treatment formulas, housing initiatives for people with HIV/AIDS and the implementation of minority health initiatives.

**Christopher Bates** is the executive director of the President's Advisory Council on HIV/AIDS. **Dr. Kevin**

**Fenton**, the director of the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB

Prevention with the CDC, develops and directs research projects and forums related to HIV/AIDS and sexual health. **Dr. Garth Graham** is the deputy assistant secretary for minority health in the Office of Minority Health at the Department of Health and Human Services. Dr. Graham's office drafts and facilitates health policy, including addressing health disparities that affects communities of color.

**Debra Parham Hobson** is the associate administrator for HIV/AIDS in the U.S. Department of Health and Human Services' Health Resources and Services Administration.

She oversees the \$2 billion Ryan White HIV/AIDS Program which funds medical care and support services for people without insurance who are living with HIV.

**Dr. Gregorio Millett**, now at the CDC, was the senior policy advisor in the White House Office of National AIDS Policy. Millett oversaw the office's research, prevention and policy. In that role, Millett was a



major contributor to the development of the National HIV/AIDS Strategy.

**Dr. Ada Adimora** is a physician and epidemiologist whose HIV/AIDS research work has focused on African Americans and particularly women. She is a professor in medicine and epidemiology at the University of North Carolina School of Medicine.



**Dr. Mindy Fullilove** is a psychiatrist and professor who has researched the connection between AIDS and where people live. Fullilove's work on "the psychology of place" has shed light on how issues such as violence and urban renewal affect people's mental and physical health.

**Marlene McNeese-Ward** is the bureau chief of the Bureau of HIV/STD and Viral Hepatitis Prevention in the Houston Department of Health and Human Services. She heads the city's efforts to reduce HIV diagnoses by providing counseling and testing for the city's 3.7 million residents.

**Rudolph H. Carn** is the founder and CEO of the National AIDS and Education Services for Minorities Inc. in Atlanta. The organization works to educate the Black community on HIV/AIDS and provides long-term and transitional housing for people living with it. The group also sponsors the National African American MSM Leadership Conference on HIV/AIDS and other Health Disparities conference.

**Dázon Dixon Diallo** is the founder and president of Atlanta-based SisterLove, Incorporated, a women's HIV/AIDS organization founded in 1989 to advocate for HIV/AIDS education and treatment for women



of color. Diallo is also adjunct faculty in women's health at Morehouse School of Medicine's Master of Public Health Program.

**Robert E. Fullilove**, is the associate dean for Community and Minority Affairs at the Columbia University Mailman School of Public Health. Fullilove, a professor of clinical sociomedical sciences and the co-director of the Community Research Group, has explored connections between addiction and HIV/AIDS. He also served on the Advisory Committee on HIV and STD Prevention at the CDC as a member and as its chairman.

**Dr. Kimberly Smith** is a global expert in HIV/AIDS and people of African descent. She has presented her research in Brazil and South Africa. She is an associate professor at the Rush University Medical Center in Chicago.



**Dr. Monica Sweeney** is the assistant commissioner in the Bureau of HIV/AIDS Prevention and Control, New York City Department of Health and Mental Hygiene. In that role she has led condom use and HIV testing efforts in New York City.



**Steve Wakefield** is the Legacy Project director at the HIV Vaccine Trials Network in Seattle. He works to combat the lack of trust people of color have against the medical system and the government and increase their participation in HIV vaccine trials.



**Hydeia Broadbent** was born with HIV to a mother who was addicted to drugs. Since she was about six years old she's been a profound speaker who has raised awareness about the impact of AIDS on children. For the past two decades she has continued to inform people across the globe about AIDS. Now at 27 she lectures frequently and continues her activism.



**Marvelyn Brown**, often called the accidental activist, learned she was infected with HIV at age 19. Brown's fear spurred her to action. She wrote about her experience being infected



by her teenage sweetheart and alienated by her community in the book *The Naked Truth: Young, Beautiful, and (HIV) Positive*. Brown, now 27, runs her own global HIV/AIDS consulting agency, Marvelous Connections, which she founded in 2007.

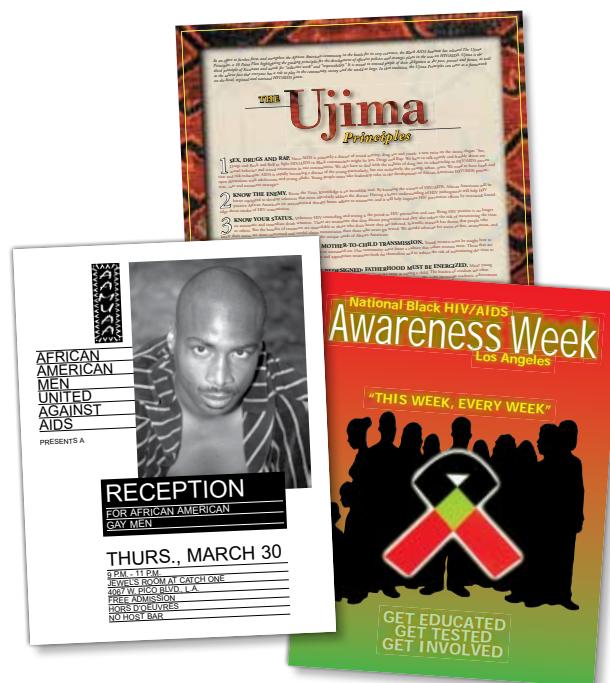
### Team NNPA

**Danny Bakewell Sr., Dorothy Levelle.** The Black press helped in the fight for civil rights last century. Now they're taking up the fight against the spread of HIV/AIDS this century. In 2009 the National



Newspaper Publishers Association, a trade group of 200 Black newspapers, joined the Obama administration's Act Against AIDS Leadership Initiative which informs the Black community on the AIDS epidemic. Medically sound information is dispensed about the epidemic's impact on the Black community. Danny Bakewell Sr., chairman of the NNPA, and Dorothy Lavelle, president of the NNPA Foundation, are supporting the effort to get the Black press more involved in spreading information on AIDS on Blacks.

**Ernest Hopkins** is the director of federal affairs at San Francisco AIDS Foundation. Hopkins oversees HIV funding, policy, and legislative activities at the federal, as well as state and local levels for San Francisco AIDS Foundation.





**Valerie Spencer** is co-developer and co-facilitator of the Transgender Leadership Academy, a collaborative effort of the Los Angeles Transgender Youth Consortium and the FTM Alliance. She created Los Angeles County's first curriculum addressing transgenderism from a people of color perspective.

**Kai Wright** is the editorial director at Colorlines.com. Wright's work, including reports from Africa, has revealed the intersections of politics of sexuality, race and gender as they relate to health, especially HIV/AIDS. He is the author of *Drifting Toward Love: Black, Brown, Gay and Coming of Age on the Streets of New York*.

**Toni Young** is the executive director of the Community Education Group in Washington DC. Young is also a member of Mayor Vincent C. Gray's host committee for the International AIDS Conference to be held in D.C. next year.

**Sandra Evers-Manly** is the vice president of corporate responsibility for the Northrop Grumman Corporation and the president of the Northrop Grumman Foundation. She oversees Northrop Grumman's philanthropic contributions including those to HIV/AIDS agencies and charities.

**Linda Villarosa** is a journalist who has been writing about the AIDS epidemic and its impact on the Black community and Black women since the early days of the disease. She is working on a profound documentary about AIDS in Black America, *The Age of AIDS*, with filmmaker Renata Simone. The film has been described as *And the Band Played On* for Black America and *Eyes on the Prize* for AIDS. Previews of Villarosa's anticipated film are emotional, insightful and informative.

**Archbishop Carl Bean**, who leads the Unity Fellowship Church, is the founder of the Los Angeles-based Minority AIDS Project.

# Leaders to Look Out For

**These Black Americans are providing leadership within professions in areas that cover the spectrum from mass-market entertainment companies to community-based non-profit organizations. They are dedicated to the cause and work diligently to educate and serve the African American community. Be on the look out for these exceptional women and men.**

**Shavon Arline:** director of health programs, NAACP

**Lisa Fager Bediako:** project coordinator, Congressional Black Caucus Foundation's ACT Against AIDS Leadership Initiative

**Steven C. Bussey:** chief executive officer, Harlem United Community AIDS Center

**Rashad Burgess:** chief, Capacity Building Branch of the Division of HIV/AIDS, Centers for Disease Control and Prevention

**Dr. Yvette C. Burton:** chief executive officer, Arcus Foundation

**Ebony Johnson:** North American community liaison, International Community of Women Living with HIV/AIDS

**Keith Green:** director of federal affairs, AIDS Foundation of Chicago

**Jeffrey C. King:** executive director, In the Meantime Men's Group, Inc.

**Kali Lindsey:** senior director of federal policy, Harlem United Community AIDS Center

**Amanda Lugg:** director of advocacy and mobilization, African Services Committee

**Leisha McKinley-Beach:** HIV prevention program manager, Georgia Department of Community Health

**Robi Reed:** vice president of talent and casting, Black Entertainment Television

**Waheeda Shabazz-el:** community organizer and trainer, Community HIV/AIDS Mobilization Project

**James Wellons:** president and chief executive officer of the GLBT cultural event Fire Island Blackout

**Patrick Wilson:** researcher and professor at Columbia University who focuses on research related to HIV risk and prevention, ethnicity and sexuality among gay men

**African-American Leaders Issue Call To Action And Declaration Of Commitment To End AIDS Epidemic In Black America**

Executive Director of the Black AIDS Institute, "The only way for AIDS to be over in America is for AIDS to be over in Black America, and the only way to stop AIDS in Black America is for Black people to take ownership of the disease and mount a mass Black mobilization."

Over a million Americans are living with HIV today – nearly half of them are Black. Yet, national policymakers have lost focus. Federal funding for domestic AIDS care programs has remained largely flat since 2001.

Approximately 54% of the new HIV/AIDS cases diagnosed in the U.S. are Black.

Along with Glover,



**CORNELIUS BAKER**  
Hero in the Struggle

# We Have the Tools

## An Expanding Biomedical Prevention Toolkit

**As the epidemic's third decade draws to a close, we appear to have entered an unprecedented era of medical advances in the prevention of new infections. These developments, which punctuate the end of the epidemic's 30th year with an exclamation mark, suggest that we are on the cusp of extraordinary new opportunities to achieve long-term success against one of the most serious health threats of our era.**

While historic breakthroughs on HIV treatment long ago transformed the medical management of HIV infection, progress in preventing new infections has been much slower. Clinical trials have documented the efficacy of programs to promote safer sexual behavior, but these research results have been difficult to replicate in the real world.<sup>1</sup> Condoms may be highly effective in preventing transmission, but many people don't use them.<sup>2</sup> And early optimism on the development of a preventive vaccine has given way to recognition that the search for a safe and effective vaccine will be long and difficult.

Many factors have contributed to disappointing results in HIV prevention. Far too often, decision-makers have failed to aggressively implement proven prevention strategies.<sup>3</sup> In 2010, only four cents of every dollar spent by the federal government on HIV were allocated for HIV prevention.<sup>4</sup>

As serious as the lack of political support for HIV prevention, has been the shortage of effective prevention tools. Most notably, the prevention toolkit has lacked approaches that offer lifelong protection. Key risk reduction strategies, such as condom use, require individuals to

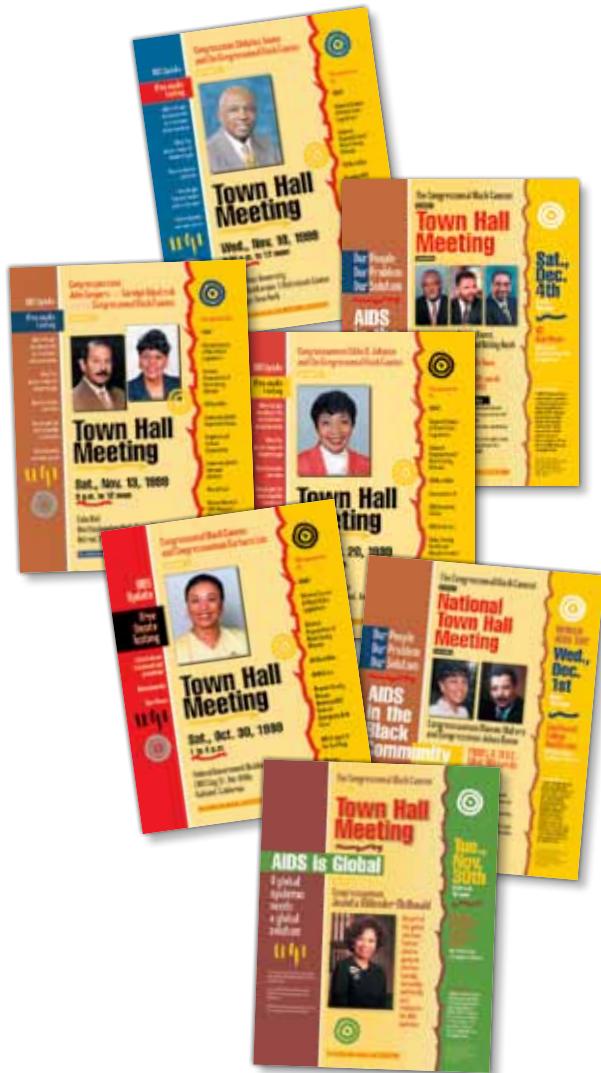
take steps to avoid transmission each time they engage in potentially risky behavior. And there are critical gaps in our prevention continuum; for example, although women are more physiologically susceptible to transmission during penile-vaginal intercourse than men, they have lacked access to a prevention method they could initiate and control on their own.

Yet in rapid succession in the last several years, researchers have demonstrated the powerful efficacy of a range of new prevention tools. Some of these new approaches offer long-lasting protection against infection, avoiding the reliance on user-dependent approaches. Others address key gaps in the prevention toolkit.

As this article explains, some of the recent advances are so radical that they upend many historic assumptions about how to address AIDS. Indeed, to capitalize on these new tools, it will be necessary to adopt entirely new approaches to controlling the epidemic. As we enter the epidemic's fourth decade, an AIDS response that has become institutionalized and set in its ways confronts the urgent need to rethink long-held practices.

## Treatment as Prevention

Perhaps the most radical of recent developments is the growing recognition, based on a rapidly expanding body of evidence, that treatment itself has a central role to play in efforts to prevent new infections. In May 2011—less than a month before the 30th anniversary of the first official report of AIDS—researchers for the National Institutes of Health announced that a multi-country study of antiretroviral therapy for HIV prevention had been terminated four years early due to overwhelming evidence of efficacy.<sup>5</sup> According to the study involving more than 1,700 couples residing in four different continents, starting antiretroviral therapy early appeared to be 96 percent more effective in preventing transmission to an uninfected partner than waiting to initiate therapy until the infected



individual's CD4 count fell below 250 cells per cubic millimeter.

The NIH study (known as HPTN 052) was merely the latest and most emphatic piece of evidence that antiretroviral therapy reduces the infectivity of people living with HIV. The fact that treatment dramatically lowers viral load (i.e., the amount of virus circulating in the blood) inevitably led to the expectation that therapy could reduce the odds of transmission. Studies have consistently correlated the likelihood of transmission with the infected partner's viral load.<sup>6</sup> More recently, studies in Vancouver<sup>7</sup> and San Francisco<sup>8</sup> have found an association between reductions in community viral load due to treatment scale-up and declines in incident HIV infections.

Although the NIH study is the most compelling evidence to date for antiretroviral treatment as prevention, it leaves a number of questions still outstanding. Given that nearly all the couples enrolled in the study were heterosexual, the applicability of the findings to gay and bisexual men remains unclear. Although one would expect the mechanisms of action of antiretroviral therapy to be the same in gay men as in heterosexuals, the fact that the likelihood of transmission during anal intercourse is substantially greater than with vaginal intercourse raises questions about whether gay men would reap the same degree of protection as the straight couples enrolled in the NIH trial.

In addition, to have a meaningful impact on the epidemic's trajectory, these research findings will need to be translated to the real world. Currently, the U.S. falls far short of what will be required to capture the prevention benefits of treatment. Due to key gaps in our approach to HIV—including late diagnosis of infection, inadequate linkage to quality care, and sub-optimal treatment adherence—federal health officials estimate that only about one in four (26 percent) of people living with HIV are currently in care and experiencing successful viral suppression.<sup>9</sup> The fact that little, if any, progress has been made in reducing new infections in the 15 years in which Highly Active Antiretroviral Therapy has been available in the U.S. merely highlights how far we are from realizing the potential of treatment as prevention.<sup>10</sup>

The latest NIH findings suggest that radical changes are needed in the country's response to AIDS. For starters, it will be essential to revisit

national guidelines on when to initiate therapy. As more evidence has become available regarding the benefits of early treatment—and as treatment regimens have improved over time, with fewer side effects—federal health officials have recommended earlier initiation of treatment, with current guidelines calling for initiation once the patient's CD4 count falls below 500.<sup>11</sup> However, the most recent NIH study used a so-called "test and treat" approach, with therapy initiated as soon as an individual tested HIV-positive, including in individuals with CD4 counts as high as 550.

These new results suggest that early initiation of therapy could significantly slow the rate of new infections. According to mathematical modeling undertaken by experts at the World Health Organization, a test-and-treat approach in sub-Saharan Africa would sharply lower the rate of incident infections and potentially permit the region to transition toward the ultimate elimination of HIV.<sup>12</sup> However, a test-and-treat approach potentially raises important ethical and logistical questions, calling for individuals to be prescribed powerful medications not for their own health but rather for the benefit of others. Trials are currently underway both to ascertain the population-level effects of treatment as prevention and to identify the optimal time at which antiretroviral therapy should be initiated. Were these studies to find that therapy is medically beneficial at any stage of HIV infection, some of the ethical questions surrounding test-and-treat could be resolved.

The NIH results also indicate that major changes are needed in the way testing and treatment services are administered. Currently, the U.S. relies on a largely passive approach to service delivery, reflecting a mindset of “build it and they will come.” Yet while the U.S. has established an impressive national network of testing and treatment services, the reality is that many people who need these services are not using them. This is especially true for Black Americans, who disproportionately experience access barriers and deterrents to service utilization. For example, in a recent CDC-sponsored 21-city study of gay and bisexual men, Black men were significantly more likely than other men to have undiagnosed HIV infection.<sup>13</sup>

Closing the holes in the HIV safety net that presently inhibit realization of the full potential of treatment as prevention will demand a much more proactive and aggressive approach. Test-

ing services must not merely be made available, but they must be routinized and aggressively promoted. Linkage to care will need to depend less on referrals and



more on rigorous follow-up after a positive HIV test result. And patients on antiretroviral treatment, especially those who confront multiple life challenges, will require more than information on the importance of treatment adherence, but evidence-based, client-centered support services to overcome adherence barriers.

The need for seamless care and treatment also raises questions about the optimal uses of public health surveillance. Currently, HIV-related information collected by state and local health departments, such as positive HIV test results or AIDS case reports, help inform policy development and programmatic targeting. However, the growing number of jurisdictions that also track viral load results possess important information regarding breakdowns in the delivery of care and treatment services. If surveillance data reveals that a patient that previously had suppressed virus is showing signs of treatment failure and viral rebound, should the health department contact the treating physician to determine if appropriate action is being taken? These and other difficult questions will need to be considered if the U.S. is to ensure full realization of the promise of treatment as prevention.

The cost implications of treatment as prevention will also need to be tackled. Already, AIDS

## The Syndrome of Kaposi's Sarcoma and Opportunistic Infections

### An Epidemiologically Restricted Disorder of Immunoregulation

**I**n June and July of 1981 the Centers for Disease Control (CDC) reported to the medical community the alarming and unprecedented occurrence of Kaposi's sarcoma, *Pneumocystis carinii* pneumonia, and other severe opportunistic infections among apparently previously healthy homosexual men in the United States, with a concentration of cases in New York and California (1, 2). Soon thereafter more detailed reports appeared in the literature clearly documenting this unique pattern of disease (3-6). The number of cases being recognized is increasing, with at least one case per day being reported to the CDC. The current total is 290 recognized cases, making this illness a public health problem of essentially epidemic proportions for a particular segment of our society.

The common denominator in these patients seems to be a profound immunosuppressed state, particularly among the patients with severe opportunistic infections (4-6). Virtually all the patients studied have manifested a severe acquired immunodeficiency that was selective; cell-mediated immune function, as measured by in-vivo (delayed cutaneous hypersensitivity) and in-vitro (T lymphocyte function) testing, was selectively impaired, whereas humoral immune responses appeared to be intact by both in-vitro testing and the presence of normal in-vivo antibody titers. One study (4) found that inducer or helper subset of T cells was selectively impaired with a resulting reversal of the ratio of inducer/helper T cell subset to suppressor/cytotoxic T cell subset in favor of a selective predominance of suppression. The types of opportunistic infections that these patients developed indicated the selective impairment of cell-mediated immunity; of particular note were infections with *P. carinii*, *Cryptococcus neoformans*, *Candida albicans*, *Mycobacterium tuberculosis*, *Mycobacterium avium-intracellular*, and several others. Cytomegalovirus and herpes simplex virus infections were strikingly predominant, both with regard to documented infections and serum antibody titers indicating recent exposure.

Cytomegalovirus has been thought to be the primary causal agent in the induction of the immunosuppressed state (4), with

subsequent infections or Kaposi's sarcoma resulting from the underlying immunosuppression originally caused by cytomegalovirus. This hypothesis is not unreasonable because cytomegalovirus can cause transient immunosuppression in normal hosts (7). The likelihood of frequent re-exposure and reinfections with cytomegalovirus among persons with a high degree of sexual promiscuity within a confined group could conceivably lead to a state of profound and apparently permanent immunosuppression directly related to recurrent viral infection, as opposed to the clinically insignificant degree and duration of immunosuppression usually seen in hosts with a single exposure. However, a counter-argument can be made that patients who are immunosuppressed for other reasons, such as iatrogenesis, also have a high incidence of cytomegalovirus infections (8). Therefore, it is possible that the immunosuppressed state is caused by other factors and cytomegalovirus infection is merely a consequence of this immunosuppression. Similarly, it is likely that the other opportunistic infections as well as Kaposi's sarcoma are secondary to the immunosuppression. Thus, the primary cause of the immunosuppression in this syndrome is currently unknown.

In this issue, four additional reports (9-12) give insights into the further ramifications of the syndrome. The finding of a selective depletion of the inducer T cell subset

is consistent in all four reports. Whatever agent or agents—acting independently, in combination, or synergistically—are responsible for the noted immunosuppression, the remarkable feature of the defect is the apparent selectivity for a specific immunoregulatory T cell subset. Because the inducer T cell subset is responsible for the induction of antibody responses to T-cell-dependent antigens (13), there is an apparent paradox noted in the current reports (9-12) and in previous studies (4-6): Unexpectedly antibody responses are preserved. This finding, however, should not be surprising because even within the inducer subset of T cells, there are likely to be subsubsets of cells that selectively induce cell-mediated versus humoral immunity. Thus, it is quite conceivable that a person can have selective impairment of the ability to induce a cell-mediated immune response with relative sparing of the inductive function for humoral responses. Furthermore, suppressor-effector function of the suppressor T cell subset (OKT8) requires induction by an inducer (OKT4) subset of cells (13). Even certain suppressor cells need an intact inducer T cell subset for normal expression of suppressor function. Although most studies up to this point (4-6, 9, 10, 12) have indicated a predominance of immunosuppression in this syndrome, the report by Morris and colleagues (11) on the occurrence of autoimmune thrombocytopenic purpura among homosexual men in the absence of opportunistic infection or Kaposi's sarcoma raises an interesting alternative possibility. Their patients who have relative increases in numbers of phenotypically identified suppressor cells may have ineffective suppressor cell function related to a deficiency of the OKT4 inducer of the OKT8 suppressor cell, thus leading to or perpetuating an autoimmune state. The authors' suggestion that the syndrome should be termed a defect in immunoregulation rather than strictly an immunosuppressed state is appropriate.

The complexity of the syndrome becomes even more apparent from the study of Friedman-Kien and colleagues (12) who report a significant elevation of the frequency of the HLA-DR5 haplotype in homosexual as

well and nonhomosexual men with Kaposi's sarcoma. This finding suggests that the common denominator of the syndrome is indeed a severe disorder of immunoregulation, the underlying cause of which is unclear. Depending on the severity of the immune defect, the precise genetic profile of the host, as well as a number of other unrecognized factors, a given person may develop Kaposi's sarcoma without other associated infections, opportunistic infections in the absence of Kaposi's sarcoma, autoimmune disease, or a combination of all of these. In this regard, it is highly likely as more cases are reported and carefully studied that a wider spectrum of associated diseases will become apparent.

Despite the important new information made available in the four reports in this issue, critical questions remain unanswered. Paramount among these questions are those relating to the epidemiologic aspects of the syndrome: why homosexual men and why occurrence or recognition only as recently as 1979? With regard to the latter point, it now appears that beyond question this syndrome is truly a new disease. Monitoring of cases of *P. carinii* by the CDC (14) as well as careful documentation of cases of Kaposi's sarcoma render it virtually impossible for more than an extremely small number of cases to have gone unrecognized before 1979 (14). Some recent change, therefore, seems to have occurred within the unique epidemiologic confines of the male homosexual population that has been expressing itself only over the past 2 to 3 years. Is there a new virus or other infectious agent that has expressed itself first among the male homosexual community because of the unusual exposure potential within this group? Is this an immunosuppressed state due to chronic exposure to a recognized virus or viruses? Is this illness due to a synergy among various factors such as infectious agents, recreational drugs, therapeutic agents administered for diseases that are peculiar to this population such as the "gay bowel syndrome," or is this illness due to a combination of all of these factors?

Of note is the geographic clustering of cases with almost half of all recognized cases being reported from New York City, and the

vast majority of cases reported from New York, Los Angeles, and San Francisco (14). If this clustering represents a real phenomenon, then it is likely that risk factors for the syndrome are not randomly distributed in the nationwide homosexual community (14). In this regard, it is unclear whether the predominance of this syndrome in these three cities relates to the unusual lifestyle of the homosexual men in these locations or to the presence of common sources of possible primary infectious factors. Still, the questions of why now and why this group remain unanswered. The CDC Task Force on Kaposi's Sarcoma and Opportunistic Infections currently is examining a broad range of epidemiologic, virologic, toxicologic, immunologic, and genetic factors in an attempt to shed light on these questions. Precise delineation of risk factors for the syndrome (such as sexual practices, drug usage, and virus exposure history) may be difficult because individual cases are now being recognized that lack one or all of these features. In fact, not all patients are homosexual and not all of them are even men. The CDC Task Force has been informed of at least 27 heterosexual men and 10 women with the syndrome. However, several of the heterosexual men and most of the women were users of illicit drugs. Determination of the factors or combinations of factors (whether drugs, virus, or others) that link homosexual men with these other groups will obviously be critical to the understanding of the cause of the syndrome.

Furthermore, because the predominant and immutable feature of this syndrome is the striking selective and persistent immune dysfunction in virtually all patients, it is imperative to determine the overall baseline immune status of the population of homosexual men who do not have the syndrome and to identify risk factors for the development of immune dysfunction before

the onset of clinical disease.

Aggressive therapeutic approaches to the infections in these patients have in many cases been frustrated by the recurrence of infections and death in an extraordinarily high proportion of patients (4, 6, 9, 10). Unfortunately, the immune defect in patients with this syndrome seems to be persistent even after they recover from the opportunistic infection that brings them to the attention of a physician. Thus, the question arises concerning therapies for the persistent immune defect. Foremost among these therapies would seem to be immunologic reconstitution with normal immunocompetent cells. However, the difficulties that accompany transplants of nonhistocompatible lymphoid tissue (such as bone marrow) currently render this approach impractical for extensive use.

Clearly, this extremely important public health problem deserves intensive investigation, and the CDC is to be commended in rapidly deploying a task force to investigate this problem. Important information of scientific interest may ultimately result from study of this syndrome, such as a more precise delineation of the relation between immune defects, viral infection, and oncogenesis. However, the immediate goal that must be recognized and vigorously pursued is the designation of resources and energy to the solving of the mystery behind this extraordinary disease, which currently seems to selectively affect a particular segment of our society. The population that currently is affected deserves this effort. Furthermore, because we do not know the cause of this syndrome, any assumption that the syndrome will remain restricted to a particular segment of our society is truly an assumption without a scientific basis. (Anthony S. Fauci, M.D.; National Institutes of Health, Bethesda, Maryland)

Drug Assistance Programs (ADAPs) are struggling, as demand increasingly outstrips funding. As of May 2011, nearly 8,000 patients were on ADAP waiting lists, with 14 states having taken steps to restrict drug access since 2009.<sup>14</sup> Expanding eligibility for antiretrovirals beyond the

current 500 CD4 cutoff will merely add to budget pressures for ADAP programs, at a time when fiscal austerity is being promoted by both political parties.

Moreover, there are potential questions about whether third-party payers would actually

cover early initiation of antiretroviral therapy in the absence of evidence that early treatment actually confers a medical benefit on the HIV-positive individual. Historically, “medical necessity” has been the standard for determining whether public sector payers have an obligation to reimburse a particular treatment. Medicare, for example, is required to pay for services that are “reasonable and necessary for the diagnosis or treatment of illness or injury to improve the functioning of a malformed body member.” A specific statutory mandate may override the medical necessity test in particular cases, but this would require congressional action.

As the universe of individuals eligible for antiretroviral drugs expands, the need to reduce per-patient treatment costs becomes ever more urgent. American health consumers pay the world’s highest prices for pharmaceutical products, in part due to the lack of sufficient bargaining power by the public sector to drive down costs. While the enormous profits reaped by big pharma from American consumers enabled drug companies to offer sharply lower prices in developing countries, which facilitates treatment scale-up in the countries most heavily affected by HIV, the increased use of antiretrovirals for preventive purposes will inevitably call into question the ability of U.S. public programs to continue to pay top-dollar prices for these medicines.

Perhaps the greatest “paradigm shift” that will be needed in the AIDS response is to transcend the historic silos of HIV “prevention” and “treatment.” Since the epidemic’s first decades, prevention and treatment have been regarded as separate domains. CDC has been primarily responsible for funding HIV testing services and prevention programs, while treatment and care have been the responsibility of other agencies, notably the Center for Medicare & Medicaid Services and the Health Resources Services Administration. Coordination between these agencies has often been poor or non-existent.

Likewise, at the level of service planning and delivery, coordination seldom occurs. Under legislative and regulatory mandates, most states and localities have separate processes for planning prevention and treatment services. Treatment programs use a highly clinical, physician-intensive model in which preventive interventions

are infrequently integrated. And many prevention workers in community-based agencies are either surprisingly ignorant of medical facts about HIV or do not consider promotion of treatment linkages as their responsibility. Meanwhile, the enormous insights that prevention workers have gained over the last three decades in understanding how to change human behavior are seldom applied in treatment settings, even though treatment success depends in large measure on human behavior (e.g., seeking early testing, seeing one’s doctor regularly, or taking one’s medicines as



prescribed).

The HPTN 052 results underscore the anachronism of this arbitrary bifurcation between prevention and treatment. It is clear that effective treatment is also effective prevention, and that a reduction in the number of new infections is conversely essential to preserve the long-term viability of treatment programs. These results suggest that the organization of the AIDS response needs to be radically rethought, and that prevention and treatment planning should be merged or closely linked, using desired outcomes (e.g., reducing the number of infections, reducing the number of AIDS deaths) rather than funding streams as the starting point for strategic planning and accountability.

For Black America, the HPTN 052 results



have potentially profound implications. To date, most HIV treatment education and advocacy programs have been located in white communities, yet data on late diagnosis, health care access, treatment literacy and treatment adherence suggest that Black people living with HIV are at particular need for such initiatives. To achieve the level of success required to capture the prevention benefits of antiretroviral therapy, major new investments will be needed to increase HIV treatment literacy in Black communities. Social marketing campaigns are needed to increase awareness of the benefits of HIV testing and treatment, as well as the importance of treatment adherence. Peer support should be provided to help Black people living with HIV adhere to treatment. Social support services need to be readily available to address the factors that make adherence difficult for many patients. And a national network of Black treatment advocates is needed to educate their peers and help patients navigate their way through the treatment process.

With the HPTN 052 results, the AIDS response enters the epidemic's fourth decade confronting the horizon of a brave new world.

The question now is whether stakeholders in the AIDS field will have the courage to make the changes needed to capture the promise of recent scientific advances.

## Prophylactic Uses of Antiretrovirals

**I**n addition to the powerful indirect prevention benefits of antiretroviral therapy, recent years have witnessed major advances in the use of these compounds for prophylaxis against infection. As in the therapeutic use of the drugs, antiretroviral prophylaxis undermines the viral replication process, preventing infection from taking hold following the body's exposure to HIV.

Although progress in the preventive uses of antiretrovirals has accelerated in recent years, the latest advances represent the continuation of long-term trends. As early as 1990, CDC recommended that health care workers who experience a blood exposure immediately initiate a four-week antiretroviral to reduce the risk of becoming infected.<sup>15</sup> As evidence for post-exposure prophylaxis accumulated, this recommendation was extended to non-occupational exposures, such as sexual intercourse or needle sharing.<sup>16</sup>

In 1994, an NIH-supported study found that administration of antiretrovirals to pregnant women and their newborns significantly reduced the risk of mother-to-child transmission.<sup>17</sup> As a result of additional research as well as extensive real-world experience, evidence regarding the optimal timing and drug regimens for prevention of mother-to-child transmission has expanded.<sup>18</sup> Recent studies indicate that use of antiretrovirals significantly reduce the likelihood of mother-to-child transmission as a result of breastfeeding.<sup>19</sup> In the U.S., the number of newborns infected annually with HIV has fallen by 93 percent since the early 1990s as prevention methods have been routinely implemented in prenatal care settings.<sup>20</sup>

In the 30th year of AIDS, dramatic new progress was reported in the use of antiretrovirals to prevent HIV infection. In 2010, the husband-wife research team of Salim and Quarraisha Abdool Karim presented findings from their study of a vaginal microbicide gel in South Africa that contained the antiretroviral drug tenofovir. Applied topically to the vagina, the gel reduced the risk of HIV transmission in female study

participants by 39 percent, with considerably greater protection (54 percent) reported among women who carefully adhered to the prescribed regimen, which required users to apply the microbicide 12 hours before and 12 hours after sex.<sup>21</sup> If confirmed by trials that are presently ongoing, these results could help close a major gap in the prevention continuum by providing women with their first discreet prevention option that they themselves may initiate and control.

In late 2010, researchers reported that a multi-country study had found that daily pre-exposure prophylaxis with the antiretrovirals emtricitabine and tenofovir reduced the risk of infection by 44 percent in men who have sex with men, with a prevention benefit greater than 90 percent for study participants whose blood tests indicated careful adherence to the daily protocol.<sup>22</sup> In April 2011, a trial of the same pre-exposure regimen involving nearly 2,000 women in sub-Saharan Africa was terminated due to lack of evidence of efficacy.<sup>23</sup>

Although exciting, the results from the 2010 trials nevertheless leave a number of questions unanswered. In addition to the need to confirm these initial results, uncertainties remain regarding costs associated with the interventions, especially for PrEP, as the study suggests that careful adherence to the daily regimen by HIV-negative people is required to maximize the protective effect.

## Other Potential Prevention Approaches

**B**eyond antiretroviral drugs, several other new prevention strategies have emerged in recent years. For example, three clinical trials in sub-Saharan Africa found that adult male circumcision reduces the risk of female-to-male sexual transmission by 60 percent.<sup>24,25,26</sup> Although these findings have prompted numerous African countries to begin efforts to introduce medical circumcision services, the applicability of the results to the U.S. context remain unclear. In addition to the fact that circumcision prevalence is higher among Black American men and other groups of males in the U.S., studies to date have failed to generate convincing evidence for a protective benefit to gay and bisexual men in this country.<sup>27</sup>

Meanwhile, the search for a preventive vac-

cine continues. In 2009, results from the trial of a combination preventive vaccine in Thailand found that the product conferred modest reduction (about 26 percent) in the risk of HIV transmission among study participants who were vaccinated.<sup>28</sup> Recent laboratory discoveries of antibodies that appear to broadly neutralize HIV further suggest that development of a preventive vaccine is likely to be feasible, injecting new excitement into the vaccine field.

In addition to new biomedical tools for HIV prevention, there have been promising advances in efforts to address the social determinants of HIV risk and vulnerability. In study results reported in 2010, girls who received regular cash payments to remain in school resulted in a 60 percent decline in new HIV infections compared to the control group.<sup>29</sup> In a separate study, providing cash payments to young men and women to avoid unsafe sex resulted in a 25 percent decline in new diagnoses of sexually transmitted infections.<sup>30</sup> Although these preliminary results need to be confirmed, the findings strongly suggest that targeted efforts to address young people's economic vulnerabilities and to forge innovative incentives that encourage safer behavior may have a role to play in HIV prevention.

\* \* \*

After years of disappointment on the HIV prevention front, recent advances have the potential to transform the fight against AIDS. Indeed, these gains are so profound that it is now possible to imagine an “end game” against the



epidemic. Whether this opportunity is seized will depend in large measure on our ability to muster sufficient wisdom, commitment and fortitude to translate these scientific advances into the kinds of policies and programs needed to move toward the elimination phase of the epidemic. In contrast to earlier stages in the epidemic, when a shortage of needed tools stymied progress, the question now is whether governments, affected communities and other stakeholders have the will to do what is necessary to end the epidemic.

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# Presidential Report Cards

## Which Presidents Make the Grade

Over the past 30 years, five U.S. commanders-in-chief have led the nation's response to the HIV/AIDS epidemic. Who gets good marks? From 1981 to the present, we assess each president's leadership.

## Ronald Reagan (1981-1989)



**Biggest Hits:** Allowed Surgeon General C. Everett Koop to send a letter to all Americans about AIDS.

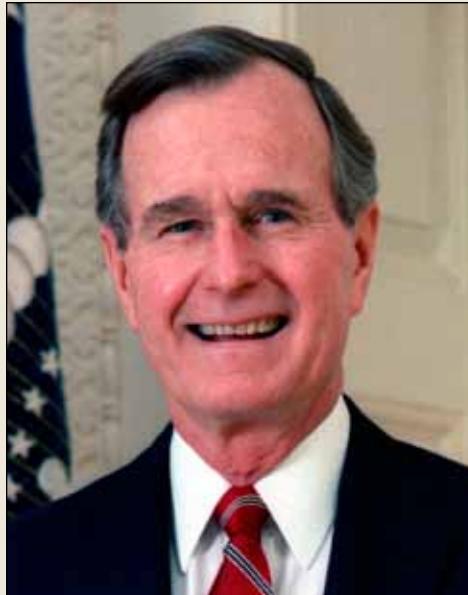
**Biggest Misses:** Ignored the disease for years. Failed to rally public awareness and support. Imposed mandatory HIV testing in numerous federal programs.

**Grade: F**

**T**he AIDS epidemic arose during his first year in office, yet no U.S. president demonstrated less leadership about the disease or a greater lack of concern for its sufferers than Ronald Reagan. Strongly influenced by the so-called Moral Majority, which believed that AIDS was God's punishment to gay men and IV drug users, the Reagan administration failed to mount a meaningful public health response at a time when aggressive action might have curbed what would become the greatest public health catastrophe of the 20th century. Ignoring the overwhelming opinion of medical and public health experts, Reagan pursued mandatory HIV testing in federal programs as the centerpiece of his AIDS policy.

While the Reagan administration allocated some funding for research, it wasn't until 1986 that Reagan's Surgeon General C. Everett Koop—aided by a small team that included Dr. Anthony Fauci, the head of AIDS research at the National Institutes of Health—effectively executed an end run around the rest of the administration. Dr. Koop published a Surgeon General's report that not only explained AIDS, its risk factors and how to prevent the disease to the American public, but that also included information about condoms and sex education that differed from the administration's more conservative approach. (In 1988 Dr. Koop also sent a mailing about AIDS to every household in the U.S.) Ironically President Reagan, nicknamed The Great Communicator, didn't give his first speech on AIDS until 1987. By then over 36,000 Americans had been diagnosed with the disease and 20,000 people had died, including his dear friend Rock Hudson. Shortly after speaking out he established the President's Commission on the HIV Epidemic, whose findings activists say, he largely ignored.

## George Herbert Walker Bush (1989-1993)



**H**e was Vice President when the Reagan Administration failed to launch an effective approach to the burgeoning epidemic. And while he never implemented a comprehensive strategic response of his own, President Bush did take two very important steps that provided much-needed services to people living with HIV/AIDS (PLWHA). First, President Bush signed the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, providing \$882 million in federal grants to the hardest-hit cities and all 50 states to care for people living with HIV/AIDS (PLWHA) and their families. Second, President Bush signed the Americans with Disabilities Act, prohibiting discrimination against people with disabilities, including PLWHA.

**Biggest Hits:** Signed Ryan White CARE Act and Americans with Disabilities, and met with the National Commission on AIDS.

**Biggest Misses:** Refused to support full funding for Ryan White. Largely ignored the recommendations of the National Commission on AIDS.

**Grade: C**

## William J. Clinton (1993-2001)



**Biggest Hits:** Supported robust funding increases for AIDS treatment and Ryan White services. Rallied public support for the fight against AIDS. Supported creation of the Minority AIDS Initiative as part of the Ryan White programs. Approved notable funding increases for global AIDS at the end of his second term.

**Biggest Misses:** Failed to approve federal funding for needle exchange. Failed in his effort to achieve comprehensive health care reform.

**Grade: B**

President Clinton failed in his 1994 attempt to achieve national health coverage through a universal health care plan. But he succeeded in bolstering the country's response to the AIDS epidemic, elevating AIDS to the level of a White House office by establishing the Office of National AIDS Policy and creating the President's Advisory Council on HIV/AIDS (PACHA). Funding for AIDS programs increased on his watch, including to the Minority AIDS Initiative directed towards communities of color. His administration also initiated outreach to educate Black leaders about AIDS' disproportionate impact on their constituents.

The Clinton administration launched the national effort to discover an AIDS vaccine and reorganized the AIDS research program at NIH. As well, that reorganization improved coordination and strategic focus. In 1995 President Clinton signed the Family Medical Leave Act, allowing employees to take unpaid leave for a pregnancy or serious medical condition. And after killing the first version of the bill, he eventually signed the Children's Health Insurance Program, providing health coverage to low-income children and pregnant women.

The global impact of what was rapidly becoming an HIV/AIDS pandemic began to be felt during the middle of his term. By then the president's effectiveness was hampered and he failed to fund needle exchange programs to prevent new infections because he believed "politically the country wasn't ready." Since leaving office President Clinton has become one of the most effective HIV/AIDS ambassadors in the world. Through the William J. Clinton Foundation, he has played an integral role in convincing heads of state and industry leaders to focus on HIV/AIDS and negotiating price reductions in antiretroviral medications for millions of PLWHA worldwide.

## George W. Bush (2001-2009)



**Biggest Hits:** Created the largest global health program in history to tackle a single disease, delivering life-saving antiretroviral therapy to millions of people in poor countries and transforming the global AIDS response.

**Biggest Misses:** Paid very little attention to domestic epidemic, watching while waiting lists for AIDS Drug Assistance Programs emerged and particularly shortchanging prevention programs. Limited the prevention impact of U.S. global AIDS programs by favoring unproven abstinence-only programs and by imposing restrictions on organizations serving sex workers.

**Grade: C**

While his father strengthened the domestic response after years of inaction under President Reagan, the second President Bush largely turned his back on the domestic epidemic. Not only did he barely convene PACHA, the Bush administration's investment in the domestic epidemic was lackluster at best, barely keeping pace with inflation. For every dollar the Bush administration spent on AIDS domestically, it spent only 4 cents on prevention. He also failed to implement meaningful reform during the prescription drug plan, which many say turned into a giveaway to pharmaceutical companies.

But while Bush II failed to carry out a vision at home, globally he showed significant leadership in the form of his landmark 2003 legislation the President's Emergency Plan for AIDS Relief (PEPFAR), a \$15 billion, 5-year strategy to fight the epidemic in 15 severely affected African nations. Renewed by the Obama administration, to date PEPFAR claims that nearly 33 million people have been counseled and tested, 3 million people have started on treatment and in 2010 alone 114,000 mother-to-child transmissions have been prevented, worldwide. Although PEPFAR has literally changed our world, some of the Bush administration's policies limited its effectiveness. In particular, the administration prioritized abstinence-only funding over comprehensive prevention measures, an approach that critics contend allowed Uganda's epidemic to rebound after years of success. In addition, the administration required recipients of PEPFAR support to pledge their opposition to sex work, undercutting the effectiveness of efforts to engage sex workers in prevention programs.

Meanwhile the virus devastated Black communities in the U.S. By 2009 Black America was suffering the equivalent of the world's 16th largest AIDS epidemic, which would have qualified it for PEPFAR had that program existed at home. President Bush also vetoed two attempts to expand funding for the SCHIP program.

## Barack H. Obama (2009-present)



**Biggest Hits:** Launched National HIV/AIDS Strategy. Achieved comprehensive health care reform. Lifted longstanding HIV immigration ban and previous bar on federal funding for needle exchange. Revitalized PACHA and Office of National AIDS Policy.

**Biggest Misses:** Failed to ensure that domestic AIDS funding keeps pace with need. Supported only modest funding increases for global AIDS spending.

**Grade: Incomplete**

**B**efore he entered office our nation's first Black president had already spoken at length about the need for personal and professional leadership on AIDS. He'd also walked the talk by getting tested publically. Once in office he moved fairly quickly on two fronts: repealing the ban against PLWHA traveling to the United States and ending the federal prohibition against needle exchange in Washington, D.C.

He also maneuvered through political landmines, orchestrating the passage of the Affordable Care Act (ACA), which majority whip James Clyburn, the most powerful Black member of the U.S. House of Representatives, called "the Civil Rights Act of the 21st century." Although now being vigorously fought by its detractors, the ACA will ensure health insurance coverage for 32 million uninsured Americans, close the drug assistance donut hole, prevent insurance companies from denying coverage to those with "pre-existing conditions," and prohibits lifetime caps on the amount of health care an insurance plan will provide.

But the publication of our country's first National HIV/AIDS Strategy in the 30-year history of the epidemic ranks as perhaps the most notable HIV/AIDS-related accomplishment by any U.S. president in the 30-year history of the epidemic. With its goal of reducing new infections 25 percent by 2015, the NHAS sets forth aggressive goals and accountability for all departments in the federal government.

Still, the NHAS must be carried out in the worst economic climate since the Great Depression—one that has blown holes in state ADAP budgets. (The administration did provide \$25M in emergency funding.) In our opinion the president's FY2012 budget came up a little short, with no increases to the Minority AIDS Initiative and too few dollars allocated to drive the nation toward its 2015 prevention goal. Still, we're cautiously optimistic.



**JULIAN BOND**  
Hero in the Struggle

30 YEARS IS ENUF!

# Recommendations to End the AIDS Epidemic in Black Communities

## Build strong and durable treatment capacity in Black communities.

It will be impossible to seize the opportunities of treatment-as-prevention or other promising ARV-based prevention methods without dramatically increasing HIV treatment literacy in Black America.

### **Recommendation 1:** Make major investments in HIV treatment science education in Black communities.

Educational efforts should include focused training and capacity-building support, use of peer-based educational models, and extensive marketing of the benefits of HIV testing, prevention, treatment, and adherence.

### **Recommendation 2:** Create a national network of AIDS treatment advocates in Black America.

Funding by federal, state and local governments and by private industry and philanthropies should support the establishment of a strong community-based platform for treatment advocacy. Black treatment advocates should prioritize initiatives to address specific impediments to

favorable medical outcomes in Black communities, including late HIV testing, inadequate health care access, interruptions in health services, and sub-optimal treatment adherence.

**Recommendation 3:** Establish a national network of HIV centers of excellence in Black communities. In recognition of the urgent need for holistic, client-centered services to address the HIV-related needs of Black people, national leaders should ensure that every Black person living with HIV has meaningful access to a comprehensive HIV center of excellence. These centers should offer or provide linkages to a continuum of HIV prevention and treatment services, including wraparound services to help Black patients overcome access barriers and impediments to treatment adherence.

## Make the appropriate investment to end the AIDS epidemic now.

Ending the AIDS epidemic is not just about money. But proper resources matter. As



concern about federal spending has mounted, policy-makers are increasingly arguing for fiscal austerity. It's reasonable for Americans to expect their government to live within its means, but it's equally imperative that we avoid sacrificing the nation's public health in the name of budget-cutting. AIDS shouldn't be yet another political football.

**Recommendation 1:** Maintain and increase funding for AIDS. Historic new opportunities to end AIDS will slip through our fingers if we nickel-and-dime the national response. Spending the money needed now to transition toward the elimination phase of HIV will pay health and economic dividends for generations.

**Recommendation 2:** Take immediate steps to eliminate all AIDS Drug Assistance Program (ADAP) waiting lists. It will be impossible to capture the prevention potential of antiretroviral treatment if thousands of people living with HIV remain on ADAP waiting lists. ADAP not only preserves the lives of the more than 140,000 people living with HIV who depend on the program for essential medicines, but also

significantly reduces the risk of onward transmission.

**Recommendation 3:** Ensure that AIDS funding follows the epidemic by targeting spending to those who need it. Mismatches between AIDS spending patterns and available evidence of the disease burden in different communities must be eliminated. Timely, reliable monitoring mechanisms must be put in place to track AIDS spending by demographic group and geographic setting, and both incentives and penalties must be put in place to ensure that policy-makers act rapidly to correct the mis-targeting of AIDS spending.

**Recommendation 4:** Fully implement and adequately fund the National HIV/AIDS Strategy. With a comprehensive, target-driven framework now in place to drive effective action on the domestic epidemic, the President and Congress must work together to ensure that the strategy is effectively implemented. Regular reports are needed to monitor progress toward the targets set forth in the strategy.

**Recommendation 5:** Fully implement the Patient Protection and Affordable Care Act. Moving toward universal health coverage is critical to capturing the prevention potential of treatment. Studies consistently correlate lack of health coverage with sub-optimal utilization of testing and treatment services. As the Congressional Budget Office has found, health care reform will help reduce the federal deficit over the long run.

**Recommendation 6:** Take immediate steps to introduce new prevention tools. The Food and Drug Administration should expedite the follow-up studies required to ensure licensure of the recently validated vaginal microbicide for use as an HIV prevention method that women can control and initiate on their own. Demonstration projects

should be put in place to inform the introduction of pre-exposure prophylaxis (PrEP) for gay and bisexual men, and additional studies should be pursued to ascertain the effectiveness of PrEP for heterosexual populations.

**Recommendation 7:** Invest in operational research to inform implementation of innovative new programs to capture the potential of treatment-as-prevention. Community organizations, state and local health departments, and other stakeholders urgently need information on optimal methods for promoting HIV testing, linking individuals who test HIV-positive with care, ensuring the continuity of HIV care and treatment, and promoting treatment adherence.

**Recommendation 8:** Continue and strengthen investments in HIV prevention and treatment research. Research is urgently needed to identify less costly methods to achieve favorable treatment outcomes for people living with HIV. It is also critically important that the National Institutes of Health continue supporting research toward a cure as well as toward development of a safe and preventive AIDS vaccine.

## Create a single, comprehensive service continuum for HIV.

Recent research findings from HPTN 052 make clear that prevention and treatment are part of a single continuum. Now, more than ever, the historic dichotomy between prevention and treatment is an anachronism that needs to be jettisoned.

**Recommendation 1:** Merge the federal response into a truly unified approach, integrating prevention, treatment, research, and evaluation with streamlined reporting and a single locus for accountability.

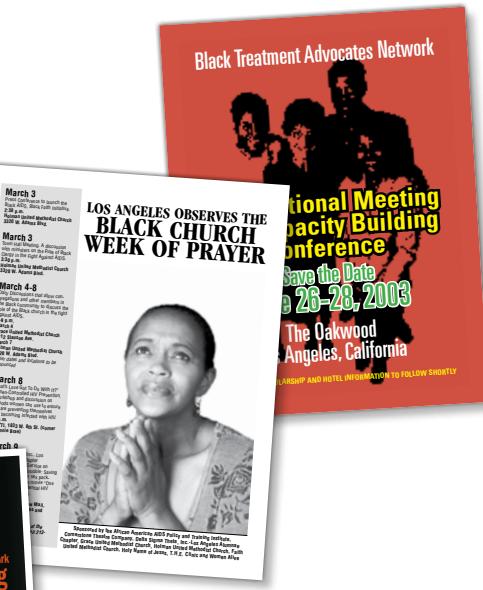


Innovative bureaucratic solutions should be considered, including the merger of all elements of the federal response into a single federal agency. At the very least, all components of the federal government must be directly accountable for a single set of outcome and performance indicators. To capture the potential of new opportunities, the historic protection of turf within the federal AIDS response must give way to an optimally strategic, coordinated and coherent effort that transcends bureaucratic hurdles.



### Recommendation

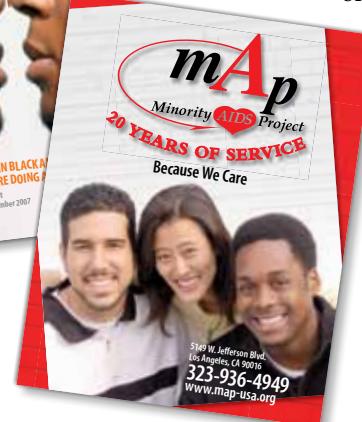
**2:** Planning for treatment and prevention services must be merged at the local level. All state and local health departments should have a common planning process for all elements of the AIDS response, with planning outcomes determined not by arbitrary funding



streams but by desired outcomes (e.g., reduce HIV infections, reduce AIDS deaths, etc.). Where needed, federal regulatory obstacles to merged planning for prevention and treatment should be removed. Within state and local health departments, prevention and treatment programs should be overseen and administered by the same office.

**Recommendation 3:** Innovative operational funding and capacity-building support should encourage cross-fertilization of expertise and best practices among local service providers. Prevention service providers must become fully versed in HIV treatment issues. Conversely, especially in light of the importance of treatment adherence, regular clinic attendance, and patient self-care, clinical settings must be able to benefit from the expertise of prevention

providers in changing individual behavior and forging new social norms.



**Recommendation 4:** Health care providers should be adequately reimbursed for a comprehensive array of prevention interventions, including HIV testing and counseling as well as diverse uses of antiretrovirals. One reason why medical providers place such little emphasis on prevention is that third-party payers are stingy in paying for such interventions. If the promise of recent research breakthroughs is to be realized, this counterproductive approach must be rejected. As part of the implementation of health care reform, the federal government should mandate adequate coverage for essential prevention strategies, including testing and counseling, pre- and post-exposure antiretroviral prophylaxis, wraparound services to promote health care continuity and treatment adherence, and vaginal microbicides.

**Recommendation 5:** Monitor HIV results. Consistent with the National HIV/AIDS Strategy, the federal government must carefully monitor and report annually on HIV-related outcomes (e.g., incident infections, AIDS deaths, treatment adherence, knowledge of HIV status, community viral load, etc.). Where sub-optimal outcomes are reported, policy changes must be implemented to address such problems.

## Pursue innovative strategies to market and promote HIV testing and treatment.

Passive approaches to service delivery—in which services are created, and low-income people, including those with multiple health challenges, are left to their own devices to access these services—must be replaced by a more aggressive and proactive effort. Treatment-as-prevention leaves little room for error. If the promise of this new breakthrough is to be realized, all people living with HIV will need to be diagnosed

early, immediately linked to care, and supported in adhering to treatment regimens.

**Recommendation 1:** Undertake mass marketing campaigns to promote HIV testing and treatment. Campaigns should be particularly targeted toward Black America. Too many Black people remain hesitant to learn their HIV status, in part because they are unaware of the enormous advances that have been made in treating HIV and that it is possible for a person living with HIV to have a normal lifespan. Extensive marketing should be used to position HIV testing as a fundamental social norm in Black communities and to increase awareness of the availability of HIV treatment services.

**Recommendation 2:** Make HIV testing a Medicare Performance Indicator. Providers should receive enhanced payments for successful innovation in promoting and delivering HIV testing services.

**Recommendation 3:** Mandate that all testing providers have strong and demonstrated links with HIV treatment settings. Although it's often

## Performers getting HIV tests to raise awareness

NEW YORK (AP) — Regina King, Howard Hesseman and Jimmy Jean-Louis of NBC's "Heroes" are among a group of performers getting HIV tests next week to raise awareness of the spread of the virus in black communities.

They will be screened Monday in front of cameras at the Screen Actors Guild headquarters in Los Angeles as part of a new campaign called "1 in a Million." The goal is to motivate 1 million black Americans to get tested for HIV/AIDS by Dec. 1, 2008.

"Actors are blessed with the gift of voice, and people listen to what they have to say," SAG president Alan Rosenberg said Friday in a statement. Rosenberg hopes others will take the "message to heart" and follow their lead.

Other celebrity participants include Hill Harper ("CSI: NY"), musical stage star Sheryl Lee Ralph, Gloria Reuben of the HBO movie "Life Support" and former "Fresh Prince of Bel-Air" star Tatyana Ali.

According to the statement announcing the campaign, AIDS is the leading cause of death for black women between the ages of 25 and 34, and up to 46 percent of black gay men are estimated to be HIV-positive.

"AIDS in America today is a black disease," said Phil Wilson, founder of the Black AIDS Institute.



Associated Press/Mark J. Terrill

Regina King arrives at the Women In Film 2007 Crystal + Lucy Awards in Beverly Hills, Calif., in this photo from June 14.

that, and nobody wants to own that. That silence is killing us."

Besides SAG, the American Federation of Television and Radio Artists, Artists for a New South Africa and the Black AIDS Institute are involved in the "1 in a Million" drive.

### On the Web:

[www.sag.org](http://www.sag.org)

said that knowledge is power, too often knowledge of HIV status has not proven to be powerful enough to ensure use of needed health services. While aggressively promoting HIV testing, it will be equally important to ensure that all people who test HIV-positive are immediately linked to follow-up care. Testing providers should be required to monitor service linkage for people who test HIV-positive, and future funding should be conditioned on demonstrated success in linking positive testers to follow-up care.

**Recommendation 4:** The offer of a voluntary, confidential HIV test should be made routine in a range of health, educational and service settings. The vision of routinizing HIV testing in health care settings remains unrealized in many communities, underscoring the need for urgent action to ensure that all individuals who use health services are offered the chance to be tested for HIV. Students entering high school or college should be offered HIV testing and encouraged to learn their HIV status. Welfare offices and social service settings should similarly offer meaningful, low-threshold opportunities for clients to be tested. Consistent with existing confidentiality and anti-discrimination protections, testing should in all cases be voluntary and confidential, with individuals being tested retaining sole control over the disclosure of their HIV test results.

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## Ensure strong leadership on AIDS—nationally, and especially within Black America.

AIDS is no longer a new problem. But it is not going away, especially in Black America. With a comprehensive national strategy now in place to guide and strengthen the AIDS response, strong leadership will be critical to future progress against the epidemic.

### **Recommendation 1: President**

Obama should deliver a major address specifically dedicated to the fight against AIDS. Building on recent research advances and on the future directions set forth in the National HIV/AIDS Strategy, the President should build American commitment to take the necessary steps to end the epidemic.

### **Recommendation 2: Every Black**

institution in the U.S. must develop and implement an AIDS strategy. No stakeholder in Black America is able to take a pass in the fight against AIDS. With new opportunities to move toward the “end game” on AIDS, this fight needs to be taken up by every institution in Black America—at local, state and national levels.

### **Recommendation 3: Cultivate future**

AIDS leaders. The 30 young people under age 30 who are profiled in this report demonstrate the passion and insights that young people bring to the AIDS fight. Far too often, though, they receive little support or mentoring on the path toward future leadership. This needs to change. Government and private funders need to prioritize leadership development initiatives for young people, and organizations and institutions within Black America need to take steps to support leadership and decision-making by young people.

A close-up portrait of a man with dark skin, short dark hair, and a well-groomed mustache. He is wearing a bright red, short-sleeved button-down shirt and a white lanyard with a small tag. The background is blurred, showing what appears to be an indoor event or conference.

**14 July**  
**BlackAIDS.org**  
The OnSite Daily Newsletter of the Black AIDS Institute at the XXI International AIDS Conference

**RASHIDAH ABDUL-KHABEER**  
Hero in the Struggle



# APPENDIX 1

# Glossary of Terms

## A

### **ABC**

The ABC approach to behavior change promotes the adoption of the following three behaviors as central to HIV prevention efforts:

A—Abstaining from sexual activity or delaying the age of the first sexual experience

B—Being faithful or practicing mutual monogamy with an uninfected partner

C—Correct and consistent condom use

### **Abstinence**

Refaining from sexual activity. In the context of HIV/AIDS, this term also refers to delaying the age of first sexual experience or sexual debut.

### **Accidental Exposure or Accidental Transmission**

This usually refers to HIV exposure or transmission that occurs in the health care setting. Transmission can occur from patient to provider or vice-versa.

### **Acute HIV Infection**

The first stage of HIV infection, this is the period immediately following infection with HIV. The

length of the acute stage can last anywhere from a few days to several weeks. HIV multiplies rapidly and can be transmitted to others during this time. Acute HIV infection is also known as primary HIV infection (PHI).

### **ADAP—AIDS Drug Assistance Program(s)**

AIDS Drug Assistance Programs are U.S. federally funded, state-administered programs. They provide HIV-related medications to people with HIV/AIDS with limited or no health insurance coverage.

The programs vary widely across the country as eligibility for ADAP is determined on a state-by-state basis, as are the drugs that are covered.

### **Affected Community**

Persons living with HIV/AIDS, and other related individuals including their families and friends, whose lives are directly influenced by HIV infection and its physical, social and emotional effects.

### **AIDS**

Acquired Immunodeficiency Syndrome (AIDS) is the stage at which an individual's immune system is weakened by HIV to the point where they develop any number of diseases or cancers. People who haven't had one of these diseases or cancers, but whose immune system is shown by a laboratory test to be severely damaged, are also considered to have progressed to an AIDS diagnosis.

## AIDS-Defining Illness

These include a variety of conditions that occur at late stages of HIV disease and that signal progression to AIDS. According to UNAIDS, many individuals first become aware of their infection at this stage.

### AIDS Dementia Complex (ADC)

AIDS Dementia Complex, also known as HIV Dementia, is a condition caused by HIV that affects the brain and causes a person to lose their mental ability. Symptoms include loss of coordination and interest in one's surroundings, mood swings, and mental dysfunction. Memory loss and limited mobility can also develop. ADC usually occurs after a person has developed serious opportunistic infections, but can also occur at an earlier stage. ADC can be prevented and treated with antiretroviral therapy.

### Antenatal

Occurring before birth (as in HIV exposure or transmission from mother to infant during pregnancy).

### Antibodies

Molecules in the body that identify and destroy foreign (unfamiliar) substances such as bacteria and viruses. Standard HIV tests identify whether or not antibodies to HIV (HIV antibodies) are present in the blood.

A positive HIV test signals that antibodies are present.

### Antiretroviral Therapy (ART)

ART refers to any of a range of treatments that include antiretroviral (ARV) medications. The drugs that are used in the treatment of HIV, a retrovirus, are designed to interfere with the virus' ability to replicate itself and, therefore, slow the progression of the disease.

### Asymptomatic

A person with HIV is asymptomatic if they do not show signs and symptoms of the disease. This is also the second stage of HIV disease progression and can last for many years after infection. The virus can be transmitted during this stage.

## B

### Burden of Disease

A comprehensive demographic and epidemiological framework used to assess the comparative importance of diseases, injuries, and risk factors in causing premature death, loss of health, and disability. The World Health Organization (WHO) and other partners carry out the Global Burden of Disease (GBD) Project to develop global estimates of burden.

## C

### Care, Treatment and Support

Care, treatment and support encompass the range of interventions necessary to take care of people living with HIV/AIDS, including antiretroviral therapy, treatment and prevention of opportunistic infections, nutritional support, psychological and community and home support. Care, treatment and support are increasingly seen as being inextricably linked to each other.

### CD4 (T4) Cell Count

These cells control the body's immune response against infections and are the primary targets for HIV.

HIV multiplies within these cells and eventually destroys them. As a result, the immune system becomes progressively weaker. CD4 cell count is used as one measure of HIV disease progression. The lower a person's CD4 cell count, the more advanced the HIV disease and deterioration of the immune system.

### U.S. Centers for Disease Control and Prevention (CDC)

The United States Federal agency responsible for protecting individuals' health and safety. The CDC's activities emphasize disease prevention, control, health education and health promotion. The CDC also conducts international prevention activities for HIV, TB, malaria and other diseases.

### Circumcision

The procedure, in which the foreskin of the penis is removed, has been shown in randomized con-

trolled trials to reduce the risk of HIV transmission from women to men. In 2007, the World Health Organization and UNAIDS recommended that circumcision be considered “an important intervention” in reducing the risk of heterosexually acquired HIV infection in men. The health organizations view the procedure as one part of a comprehensive prevention program.

### **Clinical Trial**

A scientific study designed to evaluate the safety, efficacy and medical effects of a treatment (e.g., antiretroviral therapy, vaccine). A treatment must proceed through several phases of clinical trials before it is approved for use in humans.

### **Co-Infection**

Refers to the condition of an organism or individual cell infected by two pathogens, or infectious agents, simultaneously, such as HIV and tuberculosis.

### **Combination (Anti retroviral) Therapy**

The use of two or more antiretroviral drugs in combination. The use of three or more antiretroviral drugs is often referred to as HAART or Highly Active Antiretroviral Therapy.

### **Complementary and Alternative Therapies**

Treatments that are outside the scope of Western medicine. The effectiveness of these therapies in combating HIV infection has not been proven.

### **Concurrent Sexual Partnerships**

Having more than one sexual partner at a time. The practice raises the risk of contracting HIV and is increasingly recognized as a significant factor in the high prevalence rate of HIV in Africa.

### **Cross Resistance**

The phenomenon where HIV resistance to one drug (see drug resistance) prompts resistance to other drugs in the same drug class. An example of this is nevirapine resistance resulting in resistance to efavirenz.

## **D**

### **DDT**

DDT (dichlorodiphenyltrichloroethane) was the main insecticide used during the 1950s and 1960s in the World Health Organization’s (WHO) global campaign to eradicate the mosquitoes that carry malaria. DDT has a history of being a highly controversial insecticide. It has been banned from agricultural use in almost all countries. Currently, WHO recommends use of DDT for malaria control through indoor spraying. Through WHO’s efforts, malaria was successfully eradicated from North America and Europe.

### **Down Low**

A term that has been used to refer to men who have sex with men but do not necessarily identify as gay or bisexual and may not disclose this information to others. They may also be having sexual relations with women.

### **Drug-Drug Interaction**

A situation where a drug changes the way another drug works in the body, also known as a synergistic effect. This can result in increased or decreased effectiveness of either drug. Drug-drug interactions can also lead to unintended side effects.

### **Drug Resistance**

The ability of HIV to reproduce despite the presence of anti-HIV drugs. Drug resistance results from mutations that arise during HIV replication.

### **Dry Sex**

Refers to the practice of women using various agents to “dry out” the vagina before sexual intercourse. This practice is often based on cultural beliefs, but inadvertently can increase the risk of HIV transmission because condoms break more easily from the friction and a dry vaginal wall can lead to tears and lacerations during intercourse.

## **E**

### **Efficacy**

The measurement of a drug’s or treatment’s ability to heal, regardless of dose. For example, the efficacy of an antiretroviral drug is the most benefit

that the drug can cause without considering how much of the drug is taken.

### Endemic

The constant presence of a disease or infectious agent within a given geographic area or population group; can also refer to the usual prevalence of a given disease within such area or group.

### End-stage Disease

The four stages of HIV disease are acute infection, asymptomatic, chronic symptomatic and AIDS. Although AIDS is the end-stage of HIV disease, it is possible to live for years after an AIDS diagnosis given appropriate drug therapy.

### Epidemic (types—low, concentrated, generalized, hyperendemic)

The occurrence of more cases of disease than expected in a given area or among a specific group of people over a particular period of time.

There are different ways to describe the distribution of an HIV epidemic in an area:

- Low-level—HIV prevalence is low across the general population and is still low among higher-risk sub-populations
- Concentrated—HIV prevalence does not exceed 1 percent of the general population but does exceed 5 percent of some sub-populations (e.g., among sex workers, IDU, MSM)
- Generalized—HIV prevalence exceeds 1 percent of the general population
- Hyperendemic—HIV prevalence exceeds 15 percent of the general population

## F

### Feminization

The word used to describe the increasing impact the HIV/AIDS pandemic is having on women. In South Africa, for example, far more women than men are HIV-positive. Globally, approximately half of those living with HIV are women.

### First-Line Drugs

Therapeutic agents that are the immediate drug

of choice used to treat a particular condition (as opposed to second-line drugs). See also second-line drugs.

### Fixed Dose Combination (FDC)

Fixed dose combination treatment refers to a combination of two or more drug products, such as antiretrovirals, in a single pill. An example of FDC is the single-pill combination of stavudine, lamivudine and nevirapine.

## G

### Gender Inequality

A phrase typically used to describe the second-class status women hold in many societies affected by the AIDS epidemic. This is important to consider in the context of the AIDS epidemic because the inequality often leaves them unable to negotiate sexual situations, which increases their risk of contracting HIV. Gender inequality is increasingly seen as a major driver of the AIDS epidemic.

### Generic

A drug that is identical, or bioequivalent, to a brand name drug in dosage, safety, strength, how it is taken, quality, performance, and intended use. The generic name of a drug is the common name of a drug, which is not protected under any manufacturer's copyright. It is the more commonly used format when referring to a drug in medical literature. In addition, generic sometimes refers to less expensive, but chemically identical, medications manufactured by companies that did not invent the drug. In some countries, generic drugs come on the market after a patent on the drug has expired. In other countries, generic drugs are manufactured and sold even before a patent expires.

### GIPA (Greater Involvement of People Living with HIV/AIDS)

The phrase reflects the recognition that people who are HIV-positive must be involved in every aspect of responding to the epidemic ranging from HIV prevention, testing and counseling to participating in policy forums. The principle was adopted at the Paris AIDS summit in 1994, establishing that GIPA is, in the words of UNAIDS, "critical to ethical and effective national responses to the epidemic."

## Global Fund

The Global Fund to Fight AIDS, Tuberculosis and Malaria was created in 2001 at the urging of then UN Secretary General Kofi Annan. The Global Fund is a partnership among governments, the private sector and affected communities. It is an independent grant-making organization whose purpose is to raise and provide funding to developing countries fight AIDS, tuberculosis and malaria.



ing majority of global infections, whereas HIV-2 is less widespread and primarily found in West Africa.

## Human Rights-Based Approach (HRBA) to HIV

The general recognition that human rights must be promoted and protected in the context of dealing with the AIDS epidemic. The UN's International Guidelines on HIV/AIDS and Human Rights underscore the links between the protection of human rights—such as gender equality and non-discrimination—and providing an effective response to the epidemic.

## H

### Highly Active Antiretroviral Treatment (HAART)

A course of treatment that involves the use of three or more antiretrovirals.

### HIV Test

The standard HIV diagnostic test looks for the presence of HIV antibodies in the blood or in oral fluid. HIV antibodies are molecules produced by the body once it detects the presence of HIV. The production of HIV antibodies does not happen immediately after exposure to the virus. The period after infection, but before production of antibodies, is called the window period. During the window period, an HIV test may be negative. It is possible to test negative despite the presence of HIV in the body. There are several different kinds of HIV tests used to screen for the presence of antibodies.

### Human Immunodeficiency Virus (HIV)

The virus that causes AIDS. HIV can be transmitted through infected blood, semen, vaginal secretions, breast milk and during pregnancy or delivery. There are two types of HIV: HIV-1 and HIV-2. Both are transmitted through the same methods/manners and result in progression to AIDS. HIV-1 is responsible for the overwhelm-

## IDU

Acronym for Injecting Drug User(s), and refers to individuals who use needles/syringes to inject drugs. This is a major risk for HIV infection in many parts of the world.

## Immune System

The body's system of defense against foreign organisms such as bacteria, viruses or fungi.

## Immunodeficiency

A state where the immune system cannot defend itself against infection. HIV progressively weakens the immune system and causes immunodeficiency.

### Immunosuppression

A state where the immune system cannot function normally because it has been weakened. This can arise from drugs and medical treatments (chemotherapy) or diseases (HIV). An immune system that is immunosuppressed may also be referred to as immunocompromised.

### Incidence

The number of new cases of a disease in a population over a specific period of time (e.g., annual number of new HIV cases in a country).

### Incubation Period

The period of time between HIV infection and the onset of symptoms.

## M

### Malaria

Malaria is a disease caused by parasites that are transmitted to humans via mosquito bites. Symptoms of infection may include fever, chills, headache, muscle pain, fatigue, nausea and vomiting. These symptoms usually appear between 9 and 14 days after a person is bitten by an infected mosquito. In severe cases, the disease can be life threatening.

### MDR TB

Acronym for “multidrug resistant tuberculosis,” a strain of tuberculosis that is resistant to two or more anti-TB drugs. MDR-TB usually arises when people take only enough medication to feel better, but not the full amount prescribed by a physician. The weaker bacteria are killed, but the stronger bacteria survive and reproduce. These stronger bacteria, when fully grown and causing sickness again, cannot be killed with the same treatment and require larger doses of the drug or an entirely new, stronger drug. MDR-TB is a large problem in developing countries, where continual supervision of treatment and access to health care are not always possible.

### Microbicides

Microbicides are products designed to reduce the transmission of microbes. Research is underway to determine whether microbicides can be

developed to successfully reduce the transmission of sexually-transmitted diseases, including HIV. Microbicides would be applied topically, either in the vagina or anus and could be produced in many forms, including films, creams, gels, suppositories or as a ring or sponge that releases the active ingredient over time.

### Mother-to-Child Transmission

This refers to transmission of HIV from an HIV-positive mother to her child during pregnancy, labor and delivery or breast-feeding. Transmission from mother to child is also referred to as perinatal and vertical transmission.

### MSM

Acronym for “men who have sex with men.” For assessing disease risk, use of the term “MSM” is often used instead of “gay”, “homosexual” or “bisexual” because it refers to a risk behavior, rather than an identity that may or may not be tied to a behavior. In many countries and cultures, men who have sex with other men may not perceive themselves as gay or bisexual.

### MTCT

This stands for “mother-to-child transmission.”

### Multidrug Resistant Tuberculosis (MDR-TB)

See MDR-TB.

### Mutation

A change in an organism’s genetic structure that arises during the process of multiplication. HIV multiplies quickly and changes form during the process. These changes allow for the formation of drug resistant strains of the virus.

## O

### Opportunistic Infection (OI)

Diseases that rarely occur in healthy people but cause infections in individuals whose immune systems are compromised, including by HIV infection. These disease organisms are frequently present in the body but are generally kept under control by a healthy immune system. When a person infected with HIV develops an OI, they are considered to have progressed to an AIDS diagnosis.

## Orphans

A child who has lost a parent to HIV/AIDS. UNAIDS estimates that about 15 million children under the age of 18 have lost one or both parents to HIV/AIDS. Use of the phrase “AIDS orphans” is discouraged as it stigmatizes these children and also suggests they are HIV-positive when that may not be the case.

## P

### Pandemic

A worldwide epidemic; occurring over a wide geographic area and affecting an exceptionally high proportion of the population.

### Pathogen

An organism or virus that causes disease.

### PEPFAR

The President’s Emergency Plan for AIDS Relief (PEPFAR) is a US\$15 billion, five-year initiative, initially announced in 2003 by U.S. President George W. Bush to address HIV/AIDS, TB and malaria in developing countries.

### Perinatal Transmission

Transmission of HIV from an HIV-positive mother to her child during pregnancy, labor and delivery or breast-feeding. Perinatal transmission is also known as mother-to-child transmission or vertical transmission.

### Placebo

A substance that resembles a real medication but has no medical effect.

### PMTCT

PMTCT stands for “prevention of mother-to-child transmission.” UNAIDS outlines a three-part strategy to prevent HIV transmission from an HIV-positive mother to her child.

- Protect females of child-bearing age against HIV infection.
- Avoid unwanted pregnancies among HIV-positive women.

- Prevent transmission during pregnancy, delivery and breast-feeding by providing voluntary counseling and testing, antiretroviral therapy, safe delivery practices and breast milk substitutes when appropriate.

### PMTCT Plus

PMTCT is “prevention of mother-to-child transmission” of HIV which is described above. The “plus” refers to providing anti-retroviral treatment to the mother even after the recommended course of therapy for prevention of transmission to the child has ended.



### Prevalence

Prevalence is a measure of the proportion of the population that has a disease at a specific period in time (e.g., number of people living with HIV).

### Prevention (primary, secondary)

In the context of HIV, prevention activities are designed to reduce the risk of becoming infected with HIV (primary prevention) and the risk of transmitting the disease to others (secondary prevention). Prevention services include voluntary counseling and testing, condom distribution, disease surveillance, outreach and education, and blood safety and harm reduction programs for intravenous drug users.

### Primary HIV Infection (PHI)

The first stage of HIV infection, this is the period immediately following infection with HIV. The length of this stage can last for several weeks. HIV multiplies very often and can be transmitted to others during this time. PHI is also known as acute HIV infection.

### Prophylaxis

Prophylaxis refers to the prevention or protective treatment of disease. Primary prophylaxis refers to the medical treatment that is given to prevent onset of an infection. Secondary prophylaxis refers to medications given to prevent recurrent symptoms in an existing infection.

## PLHIV / PWA / PLWA / PLWHA

Acronyms for “People living with HIV,” “People with HIV/AIDS,” and “People living with HIV/AIDS,” PLHIV is the preferred description, according to UNAIDS, because it “reflects the fact that an infected person may continue to live well and productively for many years.”

## R

### Risky Behavior

This refers to any behavior or action that increases an individual’s probability of acquiring or transmitting HIV. Some examples of risky behaviors are having unprotected sex, having unprotected sex with multiple partners and injecting drugs with contaminated equipment. Alcohol use has also been linked to risky behavior because of its effect on an individual’s ability to make decisions and negotiate safer sex.

## S

### Scale Up

Refers to the concept of achieving a sufficient level of coverage, uptake, intensity, and duration of an HIV intervention to enable the intended effect.

### Second-Line Drugs

Therapeutic agents that are not the first drug of choice (called first-line) used to treat a particular condition, but are generally used to treat those who have developed resistance to first-line treatments. See also first-line drugs.

### Sexually Transmitted Disease/Infection (STD/STI)

Any disease or infection that is spread through sexual contact.

### Social Marketing

An approach or technique that refers to the adaptation of commercial marketing techniques to achieve social goals and encourage the adoption of healthier behavior. Social marketing has been used to promote a range of HIV-related prevention techniques including condom use.

## Stigma and Discrimination

Stigma and discrimination toward HIV-positive people, and those perceived to be HIV-positive, are recognized as obstacles to achieving full access to prevention, treatment and support services. The stigma and discrimination that those at risk, and those living with HIV, may face from governments, communities and families make it less likely the at-risk will seek out care and information.

## T

### Tuberculosis (TB)

Tuberculosis is a bacterial infection caused by *Mycobacterium tuberculosis*. The disease usually affects the lungs but can spread to other parts of the body in serious cases. An individual can become infected with TB when another person who has active TB coughs, sneezes, or spits. Not all people who become infected with TB develop symptoms. Those who do not become ill are referred to as having latent TB and cannot spread the disease to others.

## U

### UNAIDS

Acronym that refers to the Joint United Nations Programme on HIV/AIDS. It is a part of the UN and was established to coordinate its response to HIV/AIDS. Currently, UNAIDS comprises 10 UN organizations and a Secretariat.

### Universal Access

The ability of all people to have equal opportunity and access to prevention, care, treatment, and support interventions from which they can benefit, regardless of their social class, ethnicity, background or physical disabilities. One example in the field of global health is universal access to HIV treatment, a belief that all individuals living with HIV/AIDS should have access to HIV treatment.

### Universal Precautions

Infection control measures used in health care settings aimed at preventing the transmission of

HIV (and other blood-borne pathogens). These measures include the use of gloves and other protective gear, and the safe disposal of needles to prevent exposure to blood and other body fluids.

## V

### **Vaccine**

A substance that contains a deactivated infectious organism designed to stimulate the immune system to protect against subsequent infection from the active organism. A preventive vaccine preempts infection from that organism. A therapeutic vaccine improves the ability of the immune system of a person already infected with the organism to defend itself.

### **VCT**

“Voluntary Counseling and Testing” programs are a critical component of both HIV prevention and treatment activities. VCT is an internationally accepted intervention designed to enable people to learn their HIV status and receive counseling about risk reduction and referral to care if they are HIV-positive. Voluntary HIV testing approaches have relied on both client-initiated or opt-in testing (where the client asks to be tested) and provider-initiated or opt-out testing (where a provider offers testing to a client). Recently, there has been a move to provider-initiated testing to encourage more people to get tested and to make testing a more routine procedure in the health care environment.

### **Vertical Transmission**

Transmission of HIV from an HIV-positive mother to her child during pregnancy, birth or breast-feeding. Vertical transmission is also referred to as mother-to-child or perinatal transmission.

### **Viral Load**

The amount or concentration of HIV in the blood. There is a correlation between the amount of virus in the blood and the severity of disease—the higher the viral load, the more progressive the HIV disease. A viral load test is an important tool for doctors in monitoring illness and determining treatment decisions.

## **Vulnerable Populations**

Populations that are at increased risk of exposure to HIV due to socioeconomic, cultural or behavioral factors. Vulnerable populations include racial and ethnic minorities, refugees, poor people, men who have sex with men, injecting drug users, sex workers, and women where gender inequality is pronounced.

## W

### **World Bank**

The World Bank is a development bank that provides loans, policy advice, technical assistance and knowledge sharing services to low- and middle-income countries to reduce poverty. The World Bank is a co-sponsor of UNAIDS and a significant donor to international HIV/AIDS efforts.

### **World Health Organization (WHO)**

The WHO is the United Nations agency for health. It is governed by 192 member states and aims to help all individuals achieve the highest possible level of health. It is internationally recognized as one of the leading organizations dedicated to global health, including the prevention and treatment of HIV.



**MARLON RIGGS and ESSEX HEMPHILL**

## APPENDIX 2

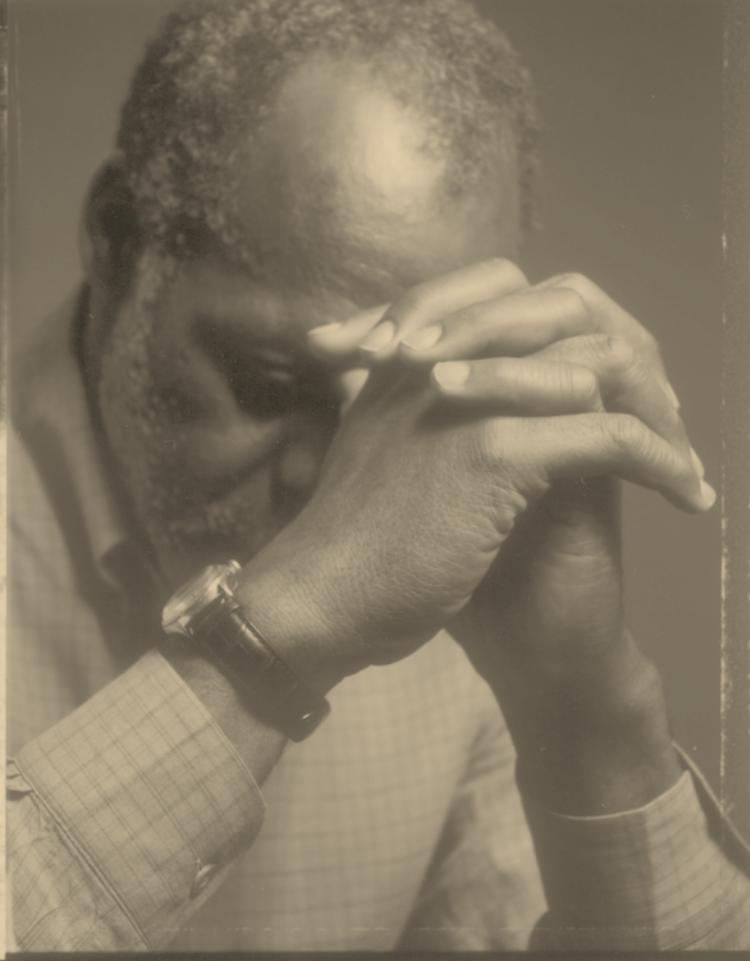
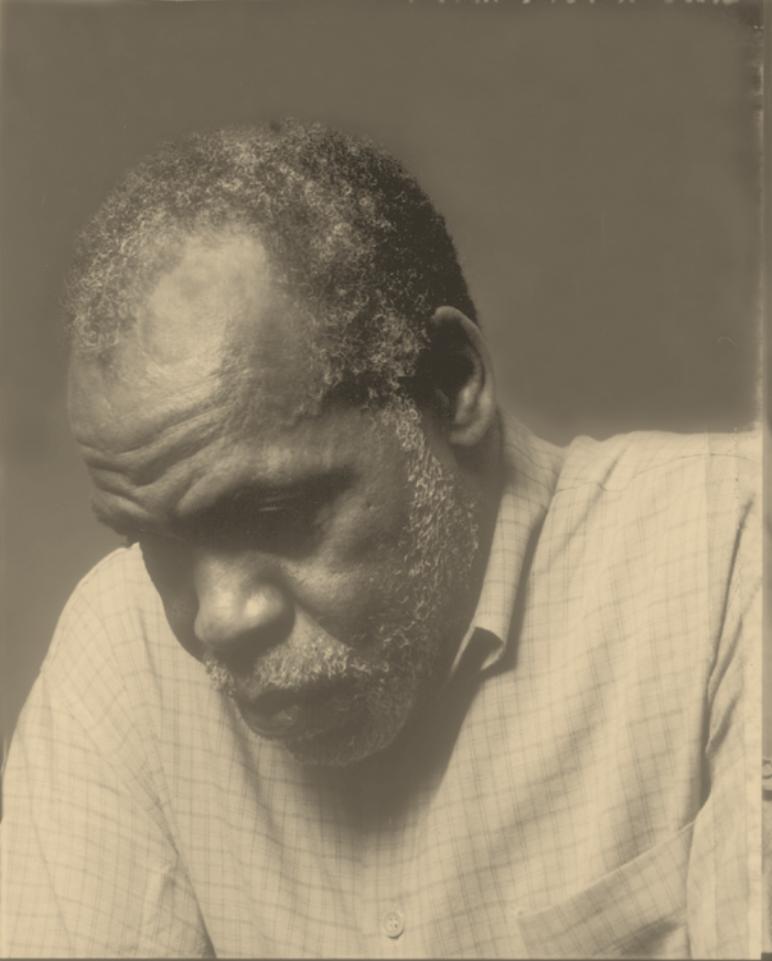
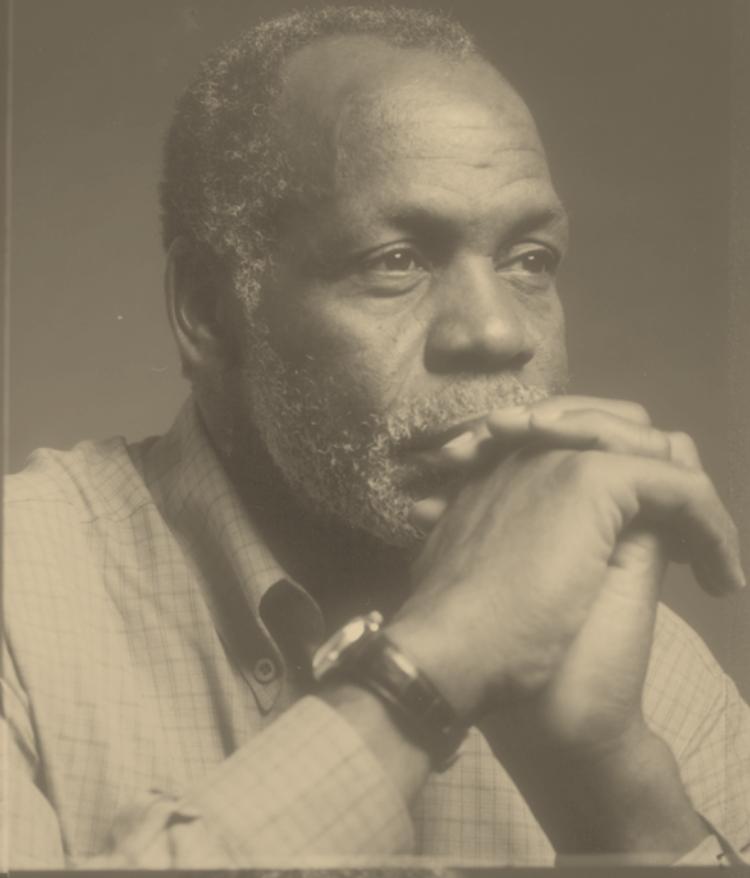
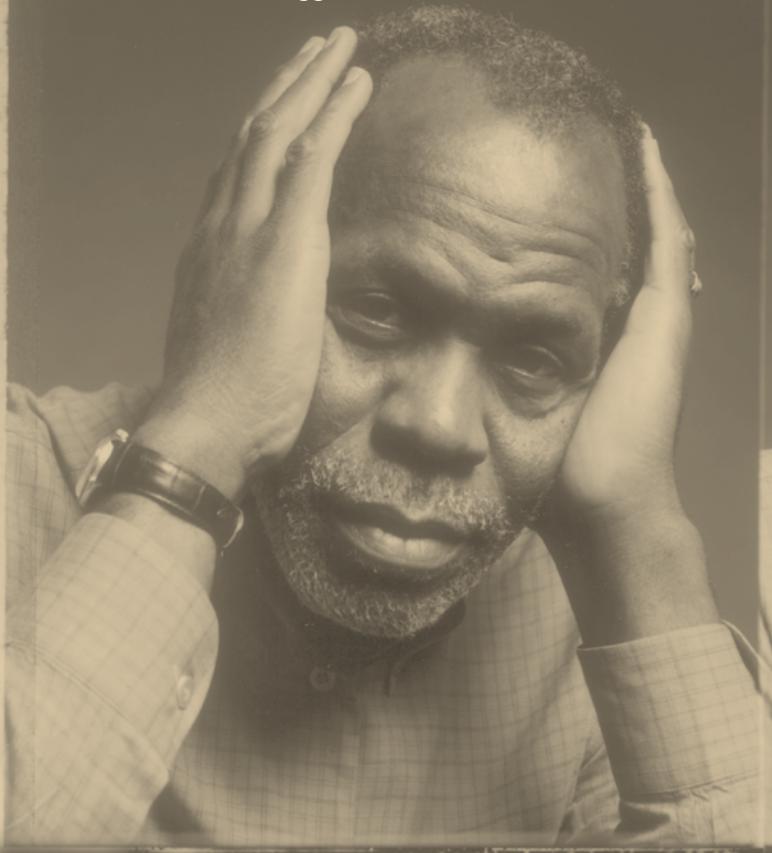
# Glossary of Acronyms

ABC	Abstinence, Be faithful, Condom use
ACA	Affordable Care Act
ADAP	AIDS Drug Assistance Program, HRSA
ADC	AIDS Dementia Complex
AETC	AIDS Education and Training Center(s), HRSA
AHRQ	Agency for Healthcare Research and Quality
AI/AN	American Indian/Alaska Native
AIDS	Acquired Immune Deficiency Syndrome
A/PI	Asian/Pacific Islander
ART, ARV	Antiretroviral Therapy, Antiretroviral(s)
ASL	Assistant Secretary for Legislation, HHS
ASPE	Assistant Secretary for Planning and Evaluation, HHS
ATTC	Addiction Technology Transfer Center(s), SAMHSA
AZT	Zidovudine
BCRS	Bureau of Clinician Recruitment and Service
BOP	Bureau of Prisons, DOJ
BPHC	Bureau of Primary Health Care
BHPr	Bureau of Health Professionals
CBO	Community-Based Organization
CDC	Centers for Disease Control and Prevention
CFAR	Center(s) for AIDS Research, NIH
CHAT	Curbing HIV/AIDS Transmission Among High Risk Youth and Adolescents
CHC	Community Health Center(s)
CMS	Centers for Medicare and Medicaid Services
CNN	Condoms, Needles, Negotiation
CTG	Community Transformation Grants
CTN	Clinical Trials Network, NIH
CVL	Community Viral Load
CY	Calendar Year
DASH-ID	Deputy Assistant Secretary for Health, Infectious Disease
DEBI	Diffusion of Effective Behavioral Interventions, CDC
DOE	Department of Education
DOJ	Department of Justice
DOL	Department of Labor
DOTS	Directly Observed Treatment or Therapy Short-Course

ECHPP	Enhanced Comprehensive HIV Prevention Planning, CDC
EHR	Electronic Health Records
ELISA	Enzyme-Linked Immunosorbent Assay
EMEA	European Medicines Agency (EU)
FDA	Food and Drug Administration
FDC	Fixed Dose Combination
FI	Fusion Inhibitor
FOA	Funding Opportunity Announcement
FPC	Family Planning Clinics
FQHC	Federally Qualified Health Center
FTCC	Federal Training Centers Collaborative
FY	Fiscal Year (October 1—September 30)
GIPA	Greater Involvement of People Living with HIV/AIDS
Global Fund	The Global Fund to Fight AIDS, Tuberculosis and Malaria
GMAI	Global Media AIDS Initiative
GNP+	Global Network of People Living with HIV/AIDS
GPRA	Government Performance and Results Act
HAART (ART)	Highly-Active Anti-Retroviral Therapy
HAB	HIV/AIDS Bureau
NCCC	National Center for Cultural Competence
HCCN	Health Center Controlled Networks
HHS (DHHS)	Department of Health and Human Services
HIRE	Health Improvement for Re-entering Ex-offenders
HIV	Human Immunodeficiency Virus
HOPWA	Housing Opportunities for Persons with AIDS
HRBA	Human Rights-Based Approach (to HIV)
HRSA	Health Resources and Services Administration
HUD	Department of Housing and Urban Development
IAS	International AIDS Society
IAVI	International AIDS Vaccine Initiative
IDU	Injection Drug Use(r)
IGA	Office of Inter-Governmental Affairs
IHS	Indian Health Service
ISC	International Steering Committee for People with AIDS
L2L	Linkage to Life
LGBT	Lesbian, Gay, Bisexual, Transgender
LIFE Initiative	Leadership and Investment in Fighting An Epidemic Initiative (U.S.)
MAI	Minority AIDS Initiative
MAP	Multi-Country HIV/AIDS Program (World Bank)
MCHB	Maternal and Child Health Bureau
MDR-TB	Multi Drug Resistant Tuberculosis
MOU	Memorandum of Understanding
MSA	Metropolitan Statistical Area
MSM	Men who have Sex with Men
MTCT	Mother-to-Child Transmission
NAPWA	National Association of People With AIDS (U.S.)
NARCH	Native American Research Centers for Health
NEP	Needle Exchange Program
NHAS	National HIV/AIDS Strategy
NIH	National Institutes of Health
NNRTI	Non-Nucleoside Reverse Transcriptase Inhibitor
N RTI	Nucleoside Reverse Transcriptase Inhibitor
OAA	Office of the Associate Administrator
OAH	Office of Adolescent Health, OS
OASH	Office of the Assistant Secretary for Health, HHS
OGAC	Office of the Global AIDS Coordinator (U.S.)
OHAP	Office of HIV/AIDS Policy, OS
OI	Opportunistic Infection
OMB	Office of Management and Budget

OMH	Office of Minority Health, OS
ONAP	Office of National AIDS Policy, The White House
ONC	Office of the National Coordinator for Health Information Technology, OS
OPA	Office of Population Affairs, OS
OpDiv	Operational Division
ORHP	Office of Rural Health Policy
OS	Office of the Secretary, HHS
OWH	Office on Women's Health, OS
PACHA	Presidential Advisory Council on HIV/AIDS
PAHO	Pan American Health Organization
PAL	Program Assistance Letter
PCA	Primary Care Association
PCO	Primary Care Office
PEP	Post-Exposure Prophylaxis
PEPFAR	President's Emergency Plan for AIDS Relief (U.S.)
PHI	Primary HIV Infection
PHS	Public Health Service
PI	Protease Inhibitor
PIA	Performance Improvement Activities
PLHIV	People Living with HIV
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
PrEP	Pre-Exposure Prophylaxis
PSA	Public Service Announcement
PSPC	Patient Safety & Clinical Pharmacy Services Collaborative
RBM	Roll Back Malaria
RRNP	Regional Resource Network Program
RW	Ryan White CARE Act, HRSA
SAMHSA	Substance Abuse and Mental Health Services Administration
SAPTBG	Substance Abuse Prevention and Treatment Block Grant
SBIRT	Screening, Brief Intervention, and Referral to Treatment
SEP	Syringe Exchange Program
SPNS	Special Projects of National Significance
SSA	Social Security Administration
SSP	Syringe Service Program
STD (STI)	Sexually Transmitted Disease (Sexually Transmitted Infection)
TAC	Treatment Action Campaign (South Africa)
TB	Tuberculosis
TIP	Treatment Improvement Protocol
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VA	Department of Veterans Affairs
VCT	Voluntary Counseling and Testing
WFP	World Food Programme
WHO	World Health Organization
WTO	World Trade Organization
ZDV	See AZT

**DANNY GLOVER**  
Hero in the Struggle



# About the Black AIDS Institute

**The Black AIDS Institute, founded in 1999, is the only national 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 leaders, 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."

### African American HIV University

Aimed at strengthening Black organizational and individual capacity to address the HIV/AIDS epidemic in their communities, the African American HIV University is the comprehensive training and capacity building fellowship program developed by the Black AIDS Institute.

### Black AIDS Weekly

Black AIDS Weekly is the Institute's e-newsletter of national HIV/AIDS related news, interviews and commentary relevant to Black Americans.

### Black Gay Men's Network

The Black Gay Men's Network promotes the active participation of self-actualized Black gay men in all aspects of community life. It provides opportunities for career development, social connections, loving relationships, educational outreach, skills-building, leadership development, physical and mental health, financial wealth and spiritual wellness. [www.thebgmnetwork.com](http://www.thebgmnetwork.com)

### Black Hollywood Task Force

An initiative to bring together Black members of the entertainment industry to use their voice and influence to promote HIV/AIDS awareness in the Black community. The Institute

engages them to participate in public service announcements, make personal appearances and integrate HIV/AIDS messages into their projects and performances.

### Black Treatment Advocates Network

The Black Treatment Advocates Network focusses on training, mobilizing and networking. The only collaboration of its kind, links Black Americans with HIV into care and treatment, strengthens local and national leadership, connects influential peers, raises HIV science and treatment literacy in Black communities, and advocates for policy change and research priorities. [www.BlackAIDS.org/btan](http://www.BlackAIDS.org/btan)

### CitySheet Series

The CitySheet Series is a set of fact sheets that provide background, statistics and resources related to HIV/AIDS in local and regional Black communities. It is an invaluable resource for community stakeholders who want local information and potential partners in one succinct document.

### Greater Than AIDS

Greater Than AIDS, a collaboration between the Black AIDS Institute and the Kaiser Family Foundation, in collaboration with the U.S. Centers for Disease Control and Prevention, and in partnership with the Elton John AIDS Foundation, the MAC AIDS Fund and the Ford Foundation, is a media campaign built around the message that, as Black Americans, we are greater than any challenge we have ever faced. We are greater than AIDS. [www.greaterthan.org](http://www.greaterthan.org)

### Heroes in the Struggle

Heroes in the Struggle is a photographic tribute to African Americans who have made outstanding contributions in the fight against HIV/AIDS. The Heroes In The Struggle exhibit has traveled around the country, raising awareness, challenging individuals and institutions to get involved in their communities, and generating critical conversation about HIV testing and treatment. [www.heroesinthestruggle.com](http://www.heroesinthestruggle.com)

### Ledge

*Ledge* is the nation's first and only HIV/AIDS awareness, general health and lifestyle magazine

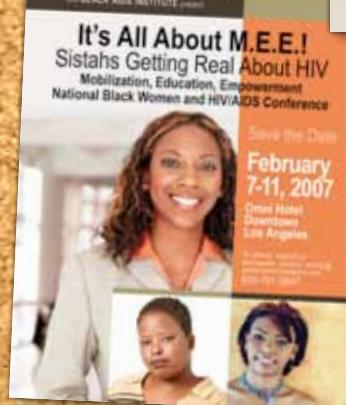
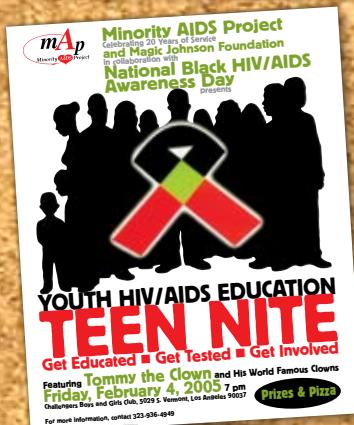
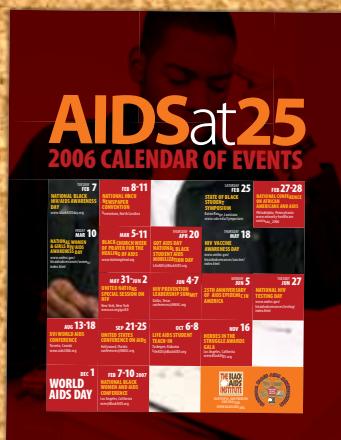
written by and for students at historically Black colleges and universities. [www.ledgemagazine.com](http://www.ledgemagazine.com)

### LIFE AIDS

Leaders In the Fight to Eradicate AIDS (LIFE AIDS) is a collegiate mobilization initiative whose mission is to educate Black college students on the causes and effects of HIV/AIDS, and to create comfortable dialogues about sex and sexuality.

### State of AIDS in Black America

The annual State of AIDS in Black America report comprehensively assesses the national picture of AIDS in Black communities from epidemiological, political, and cultural perspectives, and offers recommendations for policymakers and Black leaders. Each report assesses the progress made towards ending the AIDS epidemic in Black America and holds accountable those institutions and individuals which have advanced or hindered such progress.





For more information or more copies of this report, contact:

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