

A close-up photograph of a hand turning a brass doorknob on a white door. The hand is positioned on the right side of the frame, with fingers wrapped around the knob. The door has a vertical wood-grain texture. The lighting is bright, creating highlights on the brass and the skin.

# **EXIT** ENDING THE AIDS EPIDEMIC IN BLACK AMERICA **STRATEGY**

**THE STATE  
OF AIDS IN  
BLACK AMERICA 2012**

**BLACK AIDS INSTITUTE  
FEBRUARY 2012**

## Robi Reed

For information on this and other full page photos, see page 14.



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Jennifer Freeman

FROM THE CEO

# A New Chapter in AIDS

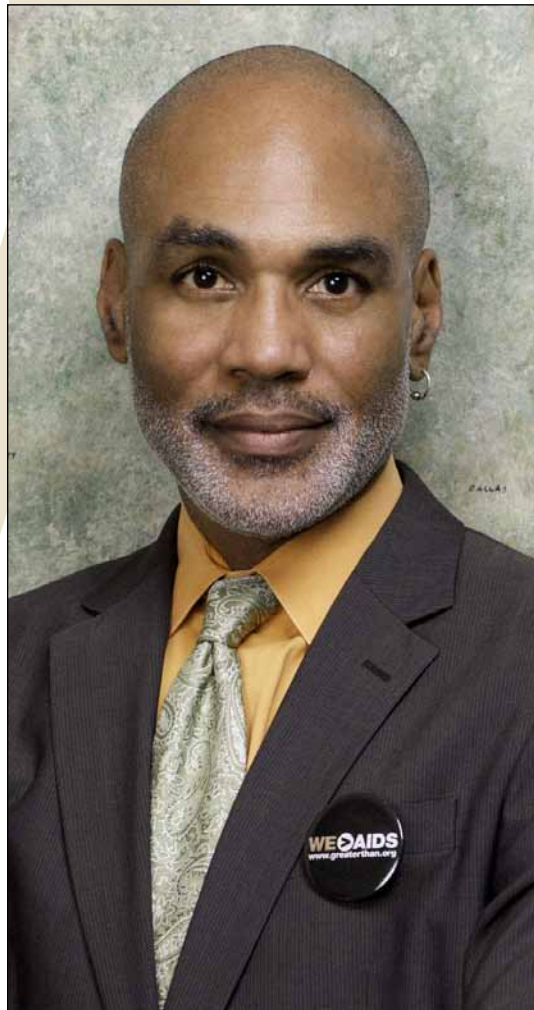
## Will It Be the Final Chapter? The Future Is in Our Hands

Welcome to *Exit Strategy: Ending the AIDS Epidemic in Black America*, the Black AIDS Institute's eighth annual State of AIDS in Black America report. It's hard to believe that I have been personally engaged in the fight against HIV/AIDS since the beginning. I was infected in 1980 just as the epidemic was emerging; I spoke at the first AIDS candle light vigil in Los Angeles in 1982; and I was diagnosed with HIV in 1986. I've lost too many friends and loved ones to count. I don't remember how many hospital rooms I've visited, death beds I've sat beside, or eulogies I've delivered. Through it all I've dreamed about and talked about the end of the epidemic.

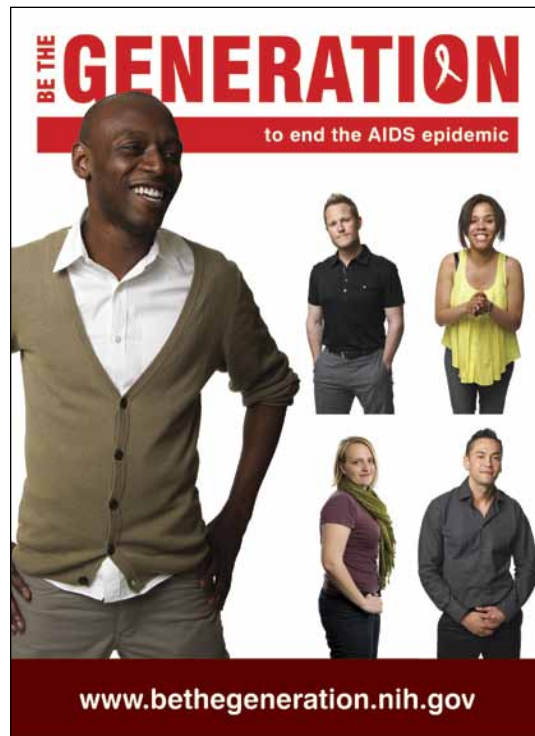
*"The day will come when this epidemic will be over. And when it does, it is important for them to know we were not all cowards. We were not all monsters. Some of us dared to care in the face of it. Some of us dared to fight because of it. And, some of us dared to love in spite of it, because it is in the caring, fighting and loving that we live forever."*

In the past, my admonitions about the end of the AIDS epidemic have been wistful, an ever-elusive prospect, the thoughts of someone to be remembered—dreams of a day I would never see.

But today, we have the means to end the AIDS epidemic. Research findings over the last



Phill Wilson



two years have ushered in new biomedical tools that are dramatically more promising than anything we've seen in the past.

The good news that this report summarizes and analyzes does not represent a victory achieved. Rather, it poses a challenge that lies ahead. Indeed, to put these new scientific tools to use, we must overcome formidable obstacles. But for the first time, we have the tools.

Until recently, the only way to stop new infections was through changing behavior—for example, using condoms for sex or clean needles for injecting drugs. These practices certainly helped and must be continued, but they were and will always be too little.

Now we know that taking effective antiretroviral drugs makes infected people much less infectious. If they're taking their medication, they are far less likely to infect their partners; even if the condom breaks or the heat of the moment causes them not to practice safer sex. So if we can get every HIV-positive person into good care—something we should do anyway to improve their health and keep them alive—keep them in care and suppress their viral load (the amount of virus in their body), we can also slow the torrent of new infections to a trickle.

This is called “treatment as prevention,” and it is the most important advance in over a decade. If we can deploy it effectively, we can turn

off the spigot of new infections and, over time, end the AIDS epidemic.

## A Four-Part Plan

This report sketches out a four-part plan for ending AIDS.

First, every Black American must know his or her HIV status. HIV testing needs to become a routine, frequent and fundamental component of health care for Black Americans. Testing needs to be aggressively promoted, and knowing one's HIV status needs to become a central social norm in Black communities.

Second, every person who tests HIV-positive must be connected to comprehensive medical care, including antiretroviral therapy. Doing so not only promotes good health for people who are living with HIV, but it also dramatically lowers the chance they will infect their partners. We need to deploy innovative strategies to keep patients in care and make sure they adhere to their regimens.

Third, prevention strategies must be expanded. Traditional approaches to HIV prevention such as condom promotion and behavior modification must be coupled with biomedical strategies that reduce the likelihood of acquiring the virus even if exposed to it, and transmitting the virus. The main strategy is treatment as prevention. In addition, some HIV-negative people might be able to take antiretroviral drugs to reduce the chances they will contract the virus, a strategy known as pre-exposure prophylaxis.

There is an urgent need for continued emphasis on HIV prevention and treatment research. While existing tools are capable of ending the epidemic, progress would be much swifter if we had a preventive vaccine or vaginal and rectal microbicides. And, of course, we need a cure; a goal many researchers believe is possible.

This agenda seems straightforward. But it will require dramatic changes in mindset and approach.

## A New Way of Thinking

We need a new understanding of “HIV prevention.” To date, we have almost exclusively invested in efforts to keep uninfected individuals from coming into contact with the virus. We still need those tools. But we need to combine them with new biomedical tools, such as treatment as

prevention, that lower the infectiousness of HIV-positive people.

In implementing this new combination prevention, we need do a better job of allowing evidence to drive our decisions about resource allocations and service priorities. We certainly need to continue advocating for more resources for prevention programs, but we need to be honest: resources are finite. We need to do a much better job focusing resources on geographic areas and populations where HIV incidence is highest.

We must also dismantle the arbitrary walls that have separated HIV prevention from HIV treatment. It is now clear that HIV treatment is HIV prevention. Going forward, every AIDS organization will need to be intimately linked to the delivery of health services.

At the community level, we need to dispense with the notion that science is something handled by others. Every community needs to embrace science, to learn and understand the science of HIV prevention and treatment.

These paradigm shifts are imperative for every community affected by HIV, but they are especially vital for Black communities. Black people make up less than 14 percent of the U.S. population, but they account for 44 percent of all new HIV infections.

Given the epidemic's disproportionate impact, fair or not, Black America needs to do better than other racial or ethnic groups. For example, we already know that Black people are notably more likely to have been recently tested for HIV than other groups. But we are still not testing enough. Black people account for a disproportionate share of people who are diagnosed late in the course of infection, a clear indication that we were not tested when we should have been. We need to boost our testing rates even higher than they already are.

Black AIDS service organizations and community-based organizations must reinvent themselves. The further downstream you are from a medical home, the less relevant you will be. Black AIDS organizations must become patient navigators and information translators and disseminators. They must also begin to connect the dots between HIV/AIDS and the overall health disparities in Black communities.

The incredibly good news about new HIV prevention tools has emerged at the very moment that decision-makers in Washington and state capitals across the land are slashing government spending. Government cannot defeat AIDS on

its own, but communities also can't win this fight without the active engagement of our political leaders and desperately needed resources.

Everyone—from governments to private households—understands the need to live within their means. But everyone also understands that every form of spending is not created equal. Some expenditures yield more bang for the buck than others. In the fight against AIDS, every infection prevented averts more than \$600,000 in future medical costs—not to mention productivity losses that are several times this amount. In short, our country can't afford *not* to do what it takes to put effective HIV prevention and treatment tools to use.

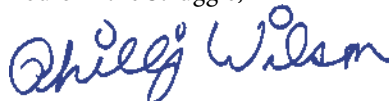
The challenge facing us is enormous. But anyone who has lived through the darkest days of the epidemic and managed to reach this moment of extraordinary hope has to be inspired.

We can do this. We must do this.

I encourage you to study the findings of this report and to take seriously the recommendations it makes. We owe it to the countless people who have died in this epidemic—and we owe it to future generations. I can think of no better way to remember my friends—gone too soon— than to focus on the future, to be as clear-eyed as possible about what we need to do to ensure that we seize this extraordinary opportunity.

Let's get to work.

Yours in the Struggle,



Phill Wilson  
CEO  
Black AIDS Institute



Anthony Burrell

## INTRODUCTION

# Setting the Course

## Political Decision-Makers and Community Leaders Step Up to the Plate

By the Honorable Barbara Lee

**This report by the Black AIDS Institute highlights a reality that would have been unthinkable not long ago. We now possess the tools we need to end the AIDS epidemic.**

Powerful tools—available for use in both HIV-positive and HIV-negative individuals—have the proven ability to dramatically reduce the odds of HIV transmission and acquisition.

From my personal experience in my own Northern California Congressional district—where the burden of HIV is among the greatest in the United States—to my travels in sub-Saharan Africa and other parts of the world, I'm acutely aware of the epidemic's seriousness. I'm also conscious of my duty as an elected representative to work across party lines to strengthen our ability to use the tools we have to end this health crisis.

### **New Momentum to Solve Old Problems**

At this moment of extraordinary opportunity, there is new momentum in Washington to do what it takes to bring AIDS to an end. A new Congressional caucus on AIDS has coalesced, including both Democrats and Republicans, with representation across the entire political spectrum.

But hard choices will need to be made if we are to succeed. In Washington, there is a lot of



**The Honorable Barbara Lee**

talk these days about fiscal austerity. The reality is that we have more than enough money to win the fight against AIDS. We certainly have sufficient funds to rescue entire private industries and to fight multiple wars of choice. At this pivotal hour, what we need most is not money but rather the political backbone to value people over profit.

In the United States today, we pay the highest prices for life-saving antiretroviral drugs of any country on earth. These high prices—combined with the failure of our political leaders to take reasonable steps to lower drug costs in this country—are an important reason why thousands of people living with HIV are on waiting lists for AIDS Drug Assistance Programs. Without ensuring that all who need antiretroviral therapy receive it, we will never realize the promise of treatment as prevention.

Black people are disproportionately affected by the weaknesses in our health system. More likely than other Americans to lack health insurance coverage or essential health information, Black people are more likely than other racial or ethnic groups in this country to be diagnosed late in the course of HIV infection, less likely to be linked to care, less likely to be prescribed life-preserving and prevention-promoting antiretroviral drugs and more likely to die of HIV-related causes.

Accounting for less than 14 percent of the American population, Black people represent 44 percent of all new infections. A Black woman in the U.S. is 15 times more likely to be living with HIV than a white woman her own age. In New York City, Black people living with HIV have an age-adjusted death rate more than twice as high as HIV-positive white New Yorkers.

## The Next Steps

This report focuses on the steps we need to take to reverse the epidemic in Black communities—ensuring the earliest possible diagnosis of HIV in all Black people, linking everyone who tests HIV-positive to high-quality care, taking steps to keep individuals in care, providing HIV-positive patients with the drugs they need to stay alive and avoid exposing others to the virus and supporting individuals in adhering to medication regimens.

In 2014, the Affordable Care Act is due to be fully implemented, bringing health coverage to more than 30 million people who currently

have no health insurance. This legislation offers perhaps the most important single strategy for putting powerful HIV-fighting tools to use.

But we need to be vigilant about implementation of health care reform. Too many forces, including many who see health care as a road to profit instead of healing, are aligned in an effort to defeat or undermine this major domestic achievement.

In the time until health care reform is fully implemented, we as a country need to take steps to aggressively promote HIV testing and deliver antiretroviral drugs to those who need them. That includes steps to lower drug prices and to eliminate waiting lists for AIDS drug assistance.

Other steps are urgently needed. For example, to support sexual risk reduction efforts, we need to ensure that every young person in the U.S. is provided with comprehensive sex education.

We also must stop taking stigmatizing, counterproductive actions that drive people away from needed services. I am especially concerned about the pernicious effects of laws that purport to criminalize HIV exposure or transmission. These laws do little, if anything, to prevent HIV transmission, but they perpetuate dangerous misconceptions about people living with HIV and deter individuals from learning their HIV status or seeking essential services.

## HIV Remains a Worldwide Problem

This report primarily focuses on our epidemic here in the U.S., but we always need to be mindful that our epidemic is but a part of a much larger global epidemic. Globally, as in the U.S., Black people are most heavily affected. Sub-Saharan Africa alone is home to more than two-thirds of all people living with HIV.

Our worldwide fight against HIV, like our response to the epidemic in the U.S., is also jeopardized by a failure of political leadership. Financial shortfalls at the Global Fund to Fight AIDS, Tuberculosis and Malaria—stemming in part from cuts in contributions by leading donor governments—threaten the ability of low-income countries to deliver essential treatment and prevention services. Here, too, the question is less one of money than of political will. Especially given the extraordinarily favorable returns on investments in antiretroviral treatment and other



**Rep. Barbara Lee, shown taking an HIV test, represents California’s 9th Congressional district. She has co-authored numerous pieces of HIV-related landmark legislation and she was co-founder of the Congressional HIV/AIDS Caucus.**

HIV strategies, political leaders need to step up to the plate and do what is needed to seize this historic moment of opportunity.

This report by the Black AIDS Institute not only analyzes our extraordinary opportunity to end AIDS, but also provides a roadmap for success. I encourage people from all walks of life—including but not limited to other political leaders—to take the time to study its contents and to heed its recommendations.

After more than 30 years of struggle, the

moment of hope we have all dreamed of has arrived. Science has done its job. Now let’s make sure that our political decision-makers and community leaders do theirs, as well.



Dennis Haysbert

## EXECUTIVE SUMMARY

# Exit Strategy

## Ending the AIDS Epidemic in Black America

**After more than 30 years of struggle against the most serious health challenge of our time, we now have the means to end the AIDS epidemic once and for all. Research results released in 2011 found that early antiretroviral therapy reduces by 96 percent the risk of HIV transmission within couples where one partner is HIV-positive and the other HIV-negative. In addition, three separate studies determined that administration of antiretrovirals is also useful in HIV-negative people, who are significantly less likely to become infected if they take the drugs prior to sexual exposure.**

Modeling exercises indicate that these tools, if used in combination with other prevention methods that already exist, could break the back of the epidemic in the next two decades. Were a preventive vaccine or other prevention breakthroughs to emerge in coming years, the timeline to end AIDS would be even shorter.

In short, an “exit strategy” for AIDS is in sight. The 2012 edition of the Black AIDS Institute’s annual report on the State of AIDS in Black America focuses on our historic opportunity to end AIDS in our lifetime. The report identifies how far we have to go to achieve success and what we need to do.

### Ending AIDS: The Challenge

Although the results on HIV treatment as prevention are extraordinarily good news, it hardly means that victory is around the corner. Antiretroviral therapy has been widely available in the U.S. for more than 15 years, yet the Centers for Disease Control and Prevention reports that we have made little, if any, progress in reducing new infections in recent years.

These discouraging results stem from the progressive loss of individuals at each stage of the HIV continuum. One in five Americans who are living with HIV are not aware of their infection; nearly one in four individuals who test HIV-positive are not linked to care; nearly half of those who make it into care drop out at some point; a considerable percentage of people in care do not receive needed medicines; and many who are on treatment do not fully adhere to prescribed regimens. As a result, only 28 percent of people living with HIV in this country have full viral suppression.

At each stage of the HIV continuum, results are worse for Black people than for other racial or ethnic groups. In the case of HIV testing, for example, the rate of undiagnosed infection is higher in Blacks than for other groups, with an estimated 116,750 Black Americans living with undiagnosed HIV infection. Lack of diagnosis not only prevents people from receiving the treatment they need, but it also leads to substantial unknowing exposure of others to the virus.

## Greater Than AIDS

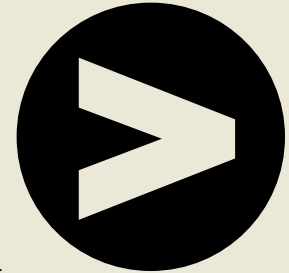
**I**mages of Black celebrities appear throughout this year's State of AIDS in Black America report. These are just a few of the more than 60 Black television and film actors, directors, producers and musical artists in Hollywood who have united with Greater Than AIDS to bring attention to the severe and disproportionate epidemic facing Black Americans and reduce the stigma surrounding the disease.

Coinciding with National Black HIV/AIDS Awareness Day on February 7, 2012, Greater Than AIDS debuted new public service ads and coordinated social media posts and other messages from artists and executives about the devastating effect of HIV/AIDS in the Black community.

This unprecedented response from Black Hollywood reinforces that HIV/AIDS is a deeply personal issue for many Black Americans. According to a national survey by the Kaiser Family Foundation, more than 60 percent—three in five—of Black Americans know someone living with HIV/AIDS or who has died from the disease; for most, it's a family member or close friend. Many of the participating talent speak about their own personal friends and family who have been affected by the epidemic, and throughout the year they will continue to support the campaign's themes of unity, hope and empowerment through their own social media platforms and personal appearances.

The celebrities featured in this campaign are all members of the Black AIDS Institute's Black Hollywood Task Force on AIDS, which works to engage the Hollywood community in an effort to fight HIV/AIDS.

Greater Than AIDS is an unprecedented collaboration among a coalition of public and private sector partners united in response to the HIV/AIDS crisis in the United States, in particular among Black Americans and other disproportionately affected groups. Through a national media campaign and targeted community outreach, Greater Than AIDS aims to increase knowledge and understanding about HIV/AIDS and confront the stigma surrounding the disease.



These weaknesses in the HIV safety net result in substantial harm in Black communities. Black people living with HIV are notably less likely to have viral suppression than white or Latino patients. And in New York City, the age-adjusted death rate for Black people living with HIV is more than twice as high as for HIV-positive whites.

Importantly, the comparatively poorer results for Black people at each stage of the HIV continuum are not the result of lack of awareness or commitment, but rather stem primarily from the epidemic's disproportionate effect on Black people. Accounting for less than 14 percent of the U.S. population, Black people represent 44 percent of all new infections. Black people are actually more likely to be tested than other racial or ethnic groups in the U.S., but these impressive testing rates are still not high enough to overcome the high background prevalence in Black

communities. In short, closing these gaps in order to capture the prevention benefits of treatment will require a higher standard of success in Black America than in other parts of the U.S.

Correcting the patterns that undermine efforts to control HIV in Black America will require new financial outlays. To deliver testing services to all who need them, for example, an estimated \$757 million will be required.

Yet these additional expenditures would more than pay for themselves. Each new case of HIV infection involves substantially more than \$600,000 in future treatment costs, as well as productivity losses that are several times greater.

## An Action Agenda for Ending AIDS

Several key steps are needed to accelerate the epidemic's end in Black America.

First, concerted, unprecedented action is needed to ensure that all Black Americans know their HIV status as early as possible. A new national initiative to promote and deliver HIV testing in Black communities is urgently needed. Testing needs to be effectively marketed through campaigns that take advantage of state-of-the-art learning and techniques from the marketing world. CDC recommendations for routine HIV testing in health care settings need to be fully implemented, and performance indicators for Medicare and other government programs should drive testing uptake. Black celebrities, opinion leaders, faith-based leaders, community leaders and grassroots activists should work toward establishing knowledge of HIV status as an essential community norm in Black communities.

Second, all people who test HIV-positive

should be ensured ready and timely access to comprehensive medical care, including antiretroviral therapy. New operational research is needed to inform efforts to ensure prompt and verifiable linkage of all people who test HIV-positive to high-quality medical care. The Affordable Care Act, also known as health care reform, should be fully implemented, and federal and state lawmakers must act to eliminate waiting lists for the AIDS Drug Assistance Program and prevent new waiting lists from emerging. Reducing unmet need for HIV care should become a heavily weighted consideration in the awarding of funds under the Ryan White CARE Act. Funders should prioritize support for community-based initiatives to build robust science and treatment literacy, and financing should be provided for peer-based programs to help patients remain in care and adhere to drug regimens.

Third, a new approach to HIV prevention is needed. Traditional efforts to reduce exposure to HIV (e.g., condom promotion and distribution, sexual behavior change programs, needle and syringe exchange programs) must be coupled with interventions that reduce the biological



**Michael Sidibé, Executive Director of UNAIDS, with Myron Cohen, M.D., who received the GAIA Vaccine Foundation's 2011 Hope is a Vaccine Award for his dedication to providing a scientific foundation for the Treatment as Prevention concept.**

likelihood of HIV acquisition. Demonstration projects for pre-exposure prophylaxis should be expanded, with particular attention to the diversity of populations in Black America affected by HIV. New pre-exposure prevention approaches—such as non-daily, or intermittent, prophylaxis—should be researched. Additional efforts are needed to ensure that limited prevention funds are targeted to the populations and geographic areas where the risk of new infection is greatest. And additional research is urgently needed on the development of new prevention breakthroughs, including a preventive vaccine.

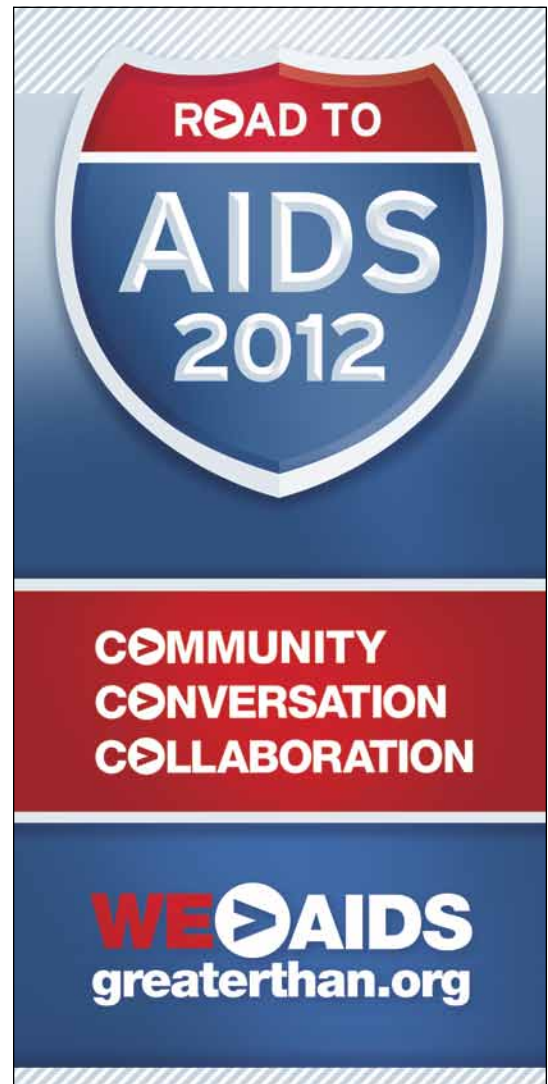
Although government at the federal, state and local levels will need to oversee many of these efforts, Black America has its own role to play. Strengthened leadership on AIDS is needed from Black people from all walks of life. Black organizations engaged in the HIV response need to establish strong and meaningful collaborations with medical homes to support scale-up of HIV treatment for prevention. Community organizations should undertake strategic reviews to prepare themselves to grasp new opportunities to end AIDS, with particular attention to the elimination of historic barriers between HIV prevention and treatment programming.

## AIDS 2012

AIDS 2012 in Washington, D.C., offers a unique chance to shine a global and national spotlight on the fight against AIDS in Black America. Not only will the conference occur in the city where the most important HIV-related political decisions are made, but the conference site also vividly illustrates both the challenges posed by AIDS in Black America as well as ways that Black communities are responding to these challenges.

Three percent of all Washingtonians are living with diagnosed HIV infection, with substantially higher rates among Black people than other racial or ethnic groups. The epidemic among Black people in Washington reflects the diversity of AIDS in Black America, involving men and women, young and old, and key populations, such as drug users, gay and bisexual men and the currently or formerly incarcerated.

Washington also reflects what communities can accomplish with sufficient commitment, creativity and steadfastness. Washington is the first city in the U.S. to deliver HIV testing services at a motor vehicle department office. The city has



embarked on a major new initiative to expand free HIV treatment, and a high-level mayoral commission is helping increase the visibility of the city's fight against AIDS.

Every two years, the International AIDS Conference serves as the most important HIV-related scientific meeting in the world. This year's conference—the first in the U.S. in more than two decades—is sure to highlight cutting-edge research findings and unparalleled opportunities for diverse stakeholders to network with each other. Program tracks will focus on leadership and affected communities, and a special series will provide skills-building sessions for those engaged in HIV-related work.

With such a unique opportunity to highlight the AIDS fight in Black America, robust participation by Black communities at this year's meeting is essential. The Black AIDS Institute is

contributing to this effort by sponsoring a delegation of Black journalists, working with Henry J. Kaiser Family Foundation to provide AIDS training to attending journalists, sponsoring Black treatment advocates to attend the conference and reporting each day to the grassroots on major happenings at the meeting.

Engagement in the International AIDS Conference is important to the goal of ending AIDS in Black America. As biomedical tools will be essential to efforts to reduce the spread of HIV and lower the incidence of HIV-related illness and death, Black communities need to build strong and durable science and treatment literacy to enable community members to understand and use AIDS-fighting tools. The conference also offers a unique opportunity for Black Americans involved in the HIV response to network with, and learn from, counterparts from other parts of the world, especially those working to fight AIDS in the worldwide Black diaspora.

## A Momentous Year: Looking Back on 2011

Although this year's report on the State of AIDS in Black America looks primarily to the future, it also takes an opportunity to review the key developments in the field in 2011. Indeed, last year was full of momentous events—on both the favorable and unfavorable sides of the ledger.

In June 2011, the world marked the 30th anniversary of CDC's first official report on what would become known as AIDS. The milestone



resulted in considerable media attention, with a notable focus on rising rates of HIV among young Black gay men. In part, the media focus on Black gay men stemmed from a report by CDC

concluding that young Black gay men were the only population in the U.S. to experience statistically significant increases in new infections from 2006 to 2009.

Funding for HIV programs remained relatively flat, although President Obama closed 2011 with a proposal for \$50 million in additional funding for HIV care and treatment programs, including the AIDS Drug Assistance Program. CDC's report in November 2011 on the low rate of viral suppression among people living with HIV merely underscored the need for intensified testing and treatment initiatives. On the testing front, there appeared to be some progress in reducing the number of people who are living with undiagnosed HIV infection, although, as reported above, one in five Americans with HIV has yet to test positive.

With respect to HIV prevention policy, both positives and negatives emerged in 2011. On the favorable side, CDC's innovative 12 Cities Project provided focused resources to intensify HIV responses in high-burden jurisdictions and demonstrated federal commitment to improved targeting of prevention funding. As 2012 dawned, however, federal lawmakers re-imposed a ban on federal funding for needle and syringe exchange programs, which the federal government's own scientists have found to be highly effective in preventing HIV infection.

In addition to research breakthroughs on HIV treatment as prevention, two studies reported in 2011 found that pre-exposure prophylaxis is effective in reducing the odds of HIV acquisition in heterosexuals. This good news supplements similar 2010 research findings in gay and bisexual men.

Less favorable was the premature termination of an arm of a major international HIV trial testing an antiretroviral-based microbicide gel. These trial results, which failed to find evidence that the gel was effective in reducing HIV acquisition, conflicted with a 2010 trial that had detected considerable benefit from use of a microbicide gel before and after intercourse.

Efforts to mobilize Black communities to respond more effectively to HIV/AIDS continued in 2011, with organizations such as the NAACP and the National AIDS Network demonstrating particularly vigorous leadership. However, evidence also emerged that fewer Black people report hearing a lot about AIDS in the prior year.



Nadine Ellis

# The Way Out

## New Opportunities and Major Challenges Lie Ahead

**Due to recent research advances, prospects for genuine, longstanding progress against HIV/AIDS have never been greater. Indeed, in what would have been an unthinkable statement not long ago, it is now clear that we have the tools to bring the AIDS epidemic to an end.**

Whether we do what it takes to end AIDS remains to be seen. Tough policy choices lie ahead, and these choices will need to be made in an environment of severe budgetary constraints.

This chapter describes the historic opportunity to end the epidemic, how current efforts are falling short and what needs to happen to terminate the most severe health crisis of modern times. A complementary chapter explores a key element of the effort to end AIDS in Black America—ensuring that all Black people know their HIV status and act on this information.

### A New Chapter in the History of AIDS

Clinical trial results released in 2010 and 2011 have transformed the AIDS landscape.

One major trial—HPTN 052—tested the hypothesis that antiretroviral therapy for people living with HIV reduces the risk that an HIV-positive person will transmit the virus to others. The trial enrolled 1,763 serodiscordant couples

(i.e., couples in which one partner is HIV-infected and the other uninfected), 97 percent of whom were heterosexual, in 13 sites in Botswana, Brazil, India, Kenya, Malawi, South Africa, Thailand, the U.S. and Zimbabwe. Couples were divided into those in which the HIV-positive partner received early antiretroviral therapy, and those in which therapy for the positive partner was not initiated until much later.

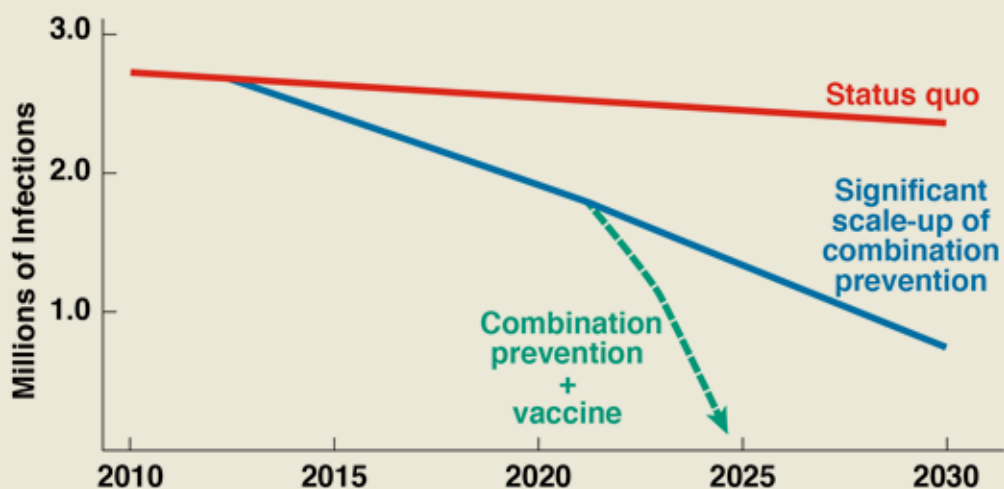
The results were striking, with couples in the early therapy group having a 96 percent reduced risk of becoming infected compared with couples in the later therapy group. The trial, which had been scheduled to continue through 2015, was terminated early due to the power of the findings.<sup>1</sup>

On one level, the trial results were not surprising. Epidemiological studies had long linked the likelihood of transmission with the infected individual's viral load.<sup>2</sup> As antiretroviral therapy dramatically lowers viral load, it had been thought that the ability to transmit the virus to another person would also be reduced.

However, what was shocking about the HPTN 052 results was the degree of protection afforded by treatment. In the world of randomized controlled trials, an intervention effect approaching 100 percent is exceedingly rare.

The implications of HPTN 052 hit like a thunderbolt. The level of protection conferred by antiretroviral therapy far exceeds the protection documented for any other prevention intervention.<sup>3</sup>

## Global HIV Incidence: Three Hypothetical Scenarios



Especially when combined with other proven prevention strategies, antiretroviral therapy has the potential to bring the epidemic to an end. For example, three separate trials in 2010 and 2011—two involving heterosexual adults, and one focused on men who have sex with men—found that HIV-negative individuals would directly benefit from taking antiretroviral drugs. These trials found that daily use of pre-exposure antiretroviral prophylaxis significantly reduced the likelihood that an HIV-negative individual would acquire HIV.<sup>4</sup>

As the accompanying figure illustrates, combining existing tools (including treatment as prevention) would sharply lower the global rate of new infections in coming years. If combined with a preventive vaccine, the epidemic's end would be tremendously accelerated.

### The End of AIDS: Testing Newfound Hope in the Real World

These groundbreaking results are cause for hope and optimism, but they need to be translated to the real world. Antiretroviral therapy has been widely available in the U.S. since the mid-1990s, yet our country has made little, if any, progress

in reducing the number of new infections during that period.<sup>5</sup>

To mark World AIDS Day 2011, CDC released research findings that illustrated why the prevention potential of treatment has yet to be realized. Analyzing available surveillance data, CDC researchers determined that more than 15 years since the emergence of Highly Active Antiretroviral Therapy only 28 percent of people living with HIV in the U.S.—slightly more than one in four—have achieved viral suppression.<sup>6</sup>

The CDC report described why such poor results have been achieved. The shortfall has nothing to do with available therapies, which are highly effective in lowering viral load. Rather, too few people obtain these therapies in a timely and continuous manner.

The effective delivery of antiretroviral drugs is actually the last stage in a multi-step process. Individuals must be diagnosed early in the course of HIV infection; people testing HIV-positive must be swiftly linked to care; antiretroviral treatment needs to be initiated in a timely manner; HIV-positive patients need to remain engaged in care; and those on treatment need to carefully adhere to prescribed regimens.

Unfortunately, the U.S. performance in this treatment spectrum is sub-optimal at each step. At each threshold, more patients fall through the cracks of the health care system, ultimately lead-

ing to the CDC's discouraging finding on the low rate of viral suppression.

First, CDC estimates that one in five people living with HIV have not yet been diagnosed<sup>7</sup>—a prerequisite for the initiation of treatment. Black Americans are more likely than other racial or ethnic groups to be diagnosed late in the course of infection. In 2010 in New York City, for example, 23 percent of newly diagnosed Black people received an AIDS diagnosis within one month of testing HIV-positive, compared to 17.9 percent of whites and 20.6 percent of Latinos.<sup>8</sup> Such a serious delay in testing means that many Black people live unknowingly with HIV for eight to 10 years, during which time their bodies fail to benefit from highly effective therapies and they may inadvertently expose their sex partners to the virus. (An accompanying article by Dr. David Holtgrave and his colleague Laura Wehrmeyer, from the Johns Hopkins School of Public Health, explores in greater depth the challenge of closing the HIV testing gap in Black America.)

Second, among individuals who test HIV-positive, nearly one in four (23 percent) are not linked to care within three to four months of their diagnoses, according to CDC.<sup>9</sup> Here, too, evidence indicates that Black people are less likely to be effectively linked to HIV care than other people who test HIV-positive. According to a study of nearly 2,000 HIV patients at a major clinic in Alabama, Black individuals are 2.5 times more likely to delay entering care after testing HIV-positive.<sup>10</sup>

Third, once linked to care, nearly half (49 percent) drop out of care at some point.<sup>11</sup> Again, evidence suggests that retention rates are poorer for Black patients with HIV than their HIV-positive counterparts from other races or ethnicities. In New York City, for example, Black patients were found to be twice as likely as whites to drop



**The CDC now recommends routine HIV screening in health care settings.**

## I Choose Life: Community Action to End AIDS

**T**he National Action Network's I Choose Life campaign is animated by the vision that Black America, given adequate information and assistance, will choose life—as expressed in measurable dignity-affirming, life-preserving and health-enhancing practices. The campaign aims to mobilize the Black community—through education and assistance—to respond personally and collectively to meet the HIV challenge.

The mission of I Choose Life and its partners is to improve the health of the Black community, using a grassroots and culturally competent approach to addressing health disparities in HIV/AIDS and other interrelated areas. Drawing on life-affirming, cultural values and internal resources, the campaign seeks to enable the community to become effectively informed, organized and engaged in a cooperative health care and prevention project focused on choosing life and rejecting ideas and actions which lead to health deterioration and death. I Choose Life meets people where they are, building on what they know and encouraging them to take individual and collective responsibility to fight HIV/AIDS.

out of care or to see their doctors sporadically.<sup>12</sup>

Fourth, patients who are enrolled in HIV care need to be prescribed antiretroviral therapy as soon as they are medically eligible. With available data increasingly pointing to the need to initiate therapy early in the course of infection, it is clear that treatment is warranted for the overwhelming majority of people living with diagnosed HIV. Again, Black patients are less likely than other people living with HIV to receive antiretroviral therapy. In 2008 to 2010, fewer Black people with diagnosed HIV infection were estimated to have received antiretroviral therapy, compared with Latino and white patients.<sup>13</sup>



**Rep. Maxine Waters (D-CA), Tony Wafford of the National Action Network and Steve Ross.**

Successful antiretroviral therapy often reduces viral load so much that HIV cannot be detected by standard virologic measures. This generates benefits to the individual, in that it prevents further progression of the disease and allows for reconstitution of the immune system, and also to his or her sex partners, who are less likely to be exposed to the virus.

Adherence to prescribed therapy is the single most important factor in treatment success. Yet treatment success rates are lower for African Americans than for other people living with HIV. According to CDC, 70 percent of Black patients on antiretroviral therapy have full viral suppression, compared to 79 percent of Latinos and 84 percent of whites.<sup>14</sup> This national pattern has appeared in local surveillance systems as well, with Black patients consistently having higher rates of persistent viral load than HIV-positive people of other races or ethnicities.<sup>15</sup>

The tragic end result is that Black people are more likely to die of HIV-related causes than other people living with HIV. In New York City, for example, HIV-positive Black people had an age-adjusted death rate more than twice as high as HIV-positive whites in 2009.<sup>16</sup>

With more HIV circulating in Black communities nationwide due to imperfections in our approach to treatment, it is hardly surprising that Black people continue to account for a

disproportionate share of new infections. Clearly, delivering effective HIV treatment in Black communities and taking steps to ensure the success of treatment interventions are critical to ending the epidemic—both in Black America and for the U.S. as a whole.

## **Delivering Treatment to Black Americans: What Needs to Happen**

Essential actions to end AIDS in Black America fall into two broad categories. First, steps must be taken to build comprehensive systems sufficient to deliver essential treatment and prevention services to all who need them. Second, innovative approaches are required to address the human dimensions of service utilization.

In particular, these dual approaches need to focus on four central aims. First, every Black American needs to know his or her HIV status, and regular testing needs to become a central component of routine health care for Black people. Second, every person who is diagnosed with HIV should have access to timely antiretroviral therapy. Third, traditional efforts to minimize exposure to HIV (through condom use, reduction in the number of partners and delayed initiation of sex for young people) should

be complemented by strategies that reduce the biological likelihood of HIV acquisition in the event of exposure. Anti-acquisition strategies include universal treatment for prevention; tailored use of pre-exposure prophylaxis for individuals at high risk of infection; and prevention of mother-to-child transmission. Fourth, continued research is urgently needed to develop new prevention tools, such as a preventive vaccine and both vaginal and rectal microbicides.

Knowledge of HIV status is essential to effective treatment and prevention. Through years of sustained investments, the U.S. has built a robust national network of HIV testing services. Yet more than 15 years since the emergence of highly active antiretroviral therapy, one in five people living with HIV remain undiagnosed. It is clear that, in addition to services, testing needs to be effectively marketed, with such initiatives addressing the documented factors that influence a person's decision whether to be tested.

The Affordable Care Act, commonly known as health care reform, represents a potentially transformative step in our country's long fight against AIDS. The program, which is being implemented in stages through 2014, will provide health coverage to more than 30 million people who are uninsured today. People living with HIV are overwhelmingly low income and unable to purchase health coverage on their own<sup>17</sup>, with Black Americans being more likely to be uninsured than whites.<sup>18</sup>

Having health insurance is associated with increased HIV testing and enhanced utilization of health services.<sup>19</sup> By expanding health coverage to millions who currently lack it, health care reform will help address many of the access gaps that currently undermine efforts to achieve universal HIV treatment coverage in the U.S.

In the run up to full implementation of health care reform and beyond, additional steps will be needed to build the systems needed to provide life-saving services to low-income people living with HIV. At least until 2014, many people living with HIV will continue to rely on the current patchwork of health programs, leaving many at risk of falling through the cracks in our health care system. As of mid-January 2012, for example, 4,600 people were on waiting lists for essential medicines provided by the AIDS Drug Assistance Program (ADAP).<sup>20</sup> The President has proposed an infusion of an additional \$35 million to address unmet demand for ADAP services in 2012, yet prior experience indicates

## An Action Agenda to End AIDS in Black America

- Ensure that every Black person knows his or her HIV status by making routine and repeated HIV testing a critical component of health care, aggressively marketing HIV testing and positioning knowledge of HIV status as a fundamental social norm.

- Link every person who tests HIV-positive to ongoing, comprehensive health services, including antiretroviral therapy. Clinical services should be supplemented with tailored, peer-based initiatives to improve treatment adherence and retention in care.

- Implement a combination of HIV prevention strategies that couples efforts to reduce HIV exposure (e.g., condom promotion and distribution, sexual behavior change programs, needle and syringe exchange) with tools that reduce the biological likelihood of HIV acquisition in the case of exposure (e.g., pre-exposure prophylaxis, prevention of mother-to-child transmission).

- Urgently continue and accelerate research on new prevention strategies, including a preventive vaccine, vaginal and rectal microbicides and new treatment breakthroughs (such as a complete cure).

that stop-gap funding measures are soon overtaken by continued demand for life-preserving medicines, underscoring the need for vigilance to ensure full funding for this essential safety net program.

In addition, implementation of health care reform should be leveraged to build HIV clinical capacity and preparedness in underserved communities.<sup>21</sup> The billions of dollars in special programs associated with health care reform—such as wellness initiatives, primary care worker training, capacity-building for community health centers and transitioning to electronic medical records—should be optimized to address



**Rev. T.D. Jakes takes an HIV test.**

the HIV-related clinical care needs of low-income communities.

Components of health care reform, and perhaps the entire Affordable Care Act, are potentially vulnerable to a legal challenge currently before the U.S. Supreme Court. Should the Court overrule all or portions of the legislation, law-makers should put aside partisan differences and unite to restore momentum toward the critical goal of achieving universal health coverage in the U.S.—a pivotal move to address all health problems but one that is especially urgent in the quest to end AIDS.

Other systems measures are urgently needed to address weaknesses in the HIV treatment continuum. For example, CDC now recommends routine HIV screening in health care settings, but available data indicate that most Americans have never had HIV tests recommended to them by their health care providers.<sup>22</sup> The federal government, state and local health departments, and professional medical groups, should collaborate to ensure that these CDC recommendations are effectively implemented in all clinical settings. Incorporating HIV testing in Medicare performance indicators will also help increase testing rates.

In addition to these and other systems reforms, additional steps are needed to adapt systems to the needs and desires of the flesh-and-blood individuals who use them. More than three decades' experience in the fight against HIV vividly demonstrates that building systems and funding services is not sufficient to ensure that individuals actually receive the services they need.

Clinical practice needs to be adapted to incorporate human interventions that maximize the effectiveness of clinical services. Many patients have difficulty communicating with their health providers and are often intimidated by clinical settings, reducing their motivation to keep clinic appointments or discuss important issues with their providers. Studies suggest that integrating peers into multidisciplinary care teams in clinical settings promotes enhanced health service utilization and medical outcomes for patients with chronic illnesses.<sup>23</sup>

For more than two decades, the Ryan White CARE Act has provided federal support for innovative care and treatment models, such as treatment-focused peer outreach, escorts to help clients keep their appointments, adherence

to support programs and clinical outreach in homeless shelters and drug treatment settings. With health care reform scheduled to be implemented by 2014, some have speculated about the future of the Ryan White program, suggesting that Congress may be less inclined to support a disease-specific program when near-universal health care is available. This would be a serious step backward in the fight against HIV, diminishing the ability of clinical programs to address the real-world needs of patients who struggle with multiple challenges, such as poverty, inadequate access to transportation, mental illness, substance abuse, or housing instability. The Ryan White HIV/AIDS Program needs to be strengthened, preserved and carefully integrated with health care reform to optimize both HIV treatment access and HIV-related medical outcomes.<sup>24</sup>

To maximize the impact of antiretroviral therapy and other biomedical HIV prevention tools, it is essential that the U.S. invest in community-based science and treatment literacy programs. This is especially vital in Black communities, given the epidemic's disproportionate burden in Black America and the sub-optimal outcomes experienced by Black patients at each step of the treatment continuum.

Strong science and treatment literacy is critical to increase awareness in Black communities of the importance of early diagnosis, medical care and treatment adherence. When people understand the science of HIV they are better able to protect themselves; more likely to get tested, enter care, stay in care and adhere to their regimens; and better positioned to influence HIV/AIDS policy.

## **Taking Action to End AIDS: A Smart Investment**

To end AIDS, additional funds will be needed. The accompanying article by Holtgrave and Wehrmeyer quantifies the additional funding needed to close the HIV testing gap. As more people are diagnosed with HIV, additional funds will be needed to link these individuals with ongoing care and to provide life-saving antiretroviral therapy.

At a time of fiscal austerity at federal, state and local levels, prudent decision-makers will certainly want to carefully examine new sources of spending, prioritizing only those approaches that provide an excellent return on investment.

Taking steps to end AIDS more than meets this common-sense and fiscally responsible test.

Every new HIV infection represents substantial economic liability for the U.S. Lifetime medical costs for a single case of HIV infection are estimated to be \$618,900.<sup>25</sup> Moreover, associated productivity losses as a result of HIV are estimated to be more than five times greater than medical outlays.<sup>26</sup> In any given year, new HIV infections amount to an ultimate bill of at least \$36.4 billion in treatment costs and future productivity losses.<sup>27</sup>

Investing in HIV treatment is both the humane and fiscally responsible thing to do. Delivering antiretroviral treatment achieves dual aims—reducing HIV-related illness and death in the foreseeable future, while dramatically reducing the further spread of HIV. Not surprisingly, studies have consistently found that taxpayer-supported programs to deliver HIV treatment are extraordinarily cost-effective.<sup>28</sup>

Beyond saving lives and money, taking the steps needed to end AIDS would honor America's more than three-decade-long fight to bring the epidemic under control. Pulling back now, when the opportunity to achieve ultimate victory is so clear, would undercut the long-term impact of our country's fight against AIDS.

While early diagnosis and prompt administration of antiretroviral therapy are central to ending AIDS, decision-makers and affected communities also need to recognize that antiretroviral treatment—while powerfully effective, both as a tool to save the lives of people living with HIV and as a primary HIV prevention strategy—is not a panacea on its own. Even if the U.S. took steps to achieve 90 percent success with respect to diagnosis of HIV infection, engagement in care, delivery of antiretroviral therapy and suppression of viral load, modeling indicates that more than one in three (34 percent) people living with HIV would still have inadequate viral suppression.<sup>29</sup>

Antiretroviral treatment must still be combined with other HIV prevention measures if we are to end AIDS in the U.S. In particular, traditional prevention methods (e.g., condom promotion, sexual behavior change, needle and syringe exchange) that aim to reduce the likelihood of exposure to the virus need to be complemented with initiatives that lower the odds of HIV acquisition if exposure occurs.

It has long been established that antiretroviral prophylaxis significantly reduces the likeli-

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hood that an HIV-positive woman will transmit the virus to her newborn during pregnancy, delivery or breastfeeding. New data indicating that antiretroviral regimens protect against sexual acquisition demand immediate policy and programmatic attention. In particular, we need to learn as much as possible—as soon as possible—from demonstration projects to determine how best to implement pre-exposure prophylaxis for individuals at high risk of HIV infection. In particular, focused efforts to facilitate access to pre-exposure prophylaxis are urgently needed for communities with a high background prevalence of HIV, such as Black gay and bisexual men and Black heterosexual women.

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Alimi Ballard

INTERVIEW

# Dr. Anthony Fauci

## The Tools to End the AIDS Epidemic

*Dr. Anthony Fauci, director of the National Institute of Allergy and Infectious Disease, has helped lead the federal HIV research effort since 1981. In January 2012, the Black AIDS Institute spoke to Dr. Fauci about his work and what he saw ahead.*

**In 2011, you stated in *Science* that we now have the “wherewithal, even in the absence of an effective vaccine, to begin to control and ultimately end the AIDS pandemic.” What has led you to this conclusion?**

By having the tools we need to end the AIDS epidemic, I mean a combination of proven prevention modalities used together at the right scale. Treating people with HIV, reducing their viral load, not only saves their lives but also reduces the risk of transmission. According to study results this past summer, people on antiretroviral treatment are 96 percent less likely to pass HIV along to their sex partners. We also know that male circumcision has a profound and desirable effect, reducing the odds of infection by between 55 percent and 65 to 68 percent; and we know that this protective effect lasts at least five years, according to available data. We also know from numerous studies that it is possible to significantly reduce the risk of mother-to-child transmission. Taking these tools together, it is clear you can turn around the trajectory of the epidemic, even without a vaccine. And if we had a vaccine, we could do this even more rapidly.

**In the United States, antiretroviral therapy**



**Dr. Anthony Fauci, Director, NAID**

**has been widely available for more than 15 years. Yet last year CDC reported that little, if any, progress has been made in reducing the annual number of new infections. If treatment is also effective HIV prevention, why haven't we made more progress in lowering HIV incidence?**

There are several factors that account for this. Probably most important, it is estimated that 21 percent of the 1.1 million people who are infected do not know they are infected. The majority of new infections likely come from individuals who are not aware they are infected. This compromises the ability of treatment to

have an optimal prevention effect.

**The 2011 study on treatment as prevention largely enrolled heterosexual couples. And the studies on male circumcision were conducted in Africa and focused solely on female-to-male sexual transmission. In the United States, we have a much different epidemic than in Africa. Is your conclusion that we have the tools to end AIDS applicable to the U.S. epidemic?**

Yes, I believe that recent breakthroughs are applicable here in the U.S.

We have a unique situation in the U.S. due to



**The economic situation in many communities undermines efforts to deliver treatment and prevention.**

the incredible heterogeneity of our epidemic. We know, for example, that while African Americans account for 12.5 percent to 13 percent of the population, they make up 44 to 50 percent of all people who are infected with HIV. Among African American men, we know that the vast majority who are infected are men who have sex with men. These are phenomenal disparities.

While I believe that these research breakthroughs are applicable here in the U.S., it is clear we have to do a better job of getting these breakthroughs to disenfranchised populations. However, this is a challenge to achieve among disenfranchised populations given the imperfections in the American health system. The economic situation in many African American communities undermines our efforts to deliver treatment and prevention to those who need them. And there is considerable stigma that also impedes our efforts to use the tools we have. I truly believe we can end AIDS in the African American population, but this will take a major effort on our part.

**To turn the epidemic around in Black America and move toward the epidemic's end, what needs to happen?**

There needs to be strong and effective leadership at several levels. The political will to take action must exist at both the national and local levels. We need to see strong leadership from the clergy, from affected communities and from political leaders.

People who are trusted in African American communities need to be beating the bushes to encourage people to get tested. We can't just rely on advertisements. Things are getting better when it comes to encouraging more testing, but so far there has been a deficit of leadership in the African American community on AIDS issues.

**You said the "imperfections in the American health system" undermine our ability to use treatment as prevention by making it difficult for people living with HIV to receive the care they need. Do you think health care reform could strengthen our fight against HIV by addressing some of these imperfections?**

It is clear that increasing the availability of health care improves our ability to respond to the epidemic. If you fix the health care delivery system and increase health care availability, then you are able to bring those who are outside the

health care system into care. It adds to the tools we have to fight AIDS.

**You have helped lead America's fight against HIV since the very beginning of the epidemic. And perhaps more than any other person, you're responsible for the incredible research breakthroughs that have transformed HIV treatment and prevention, saving countless lives. Personally, how does it feel—after more than 30 years of working in this field—to be able to say that we now have the tools to end AIDS?**

It is a complex and complicated feeling. On the one hand, I am feeling really good about where we are as a field. But I'm also feeling cautious about it, because I want to make sure we don't declare victory before we have actually achieved victory.

I've been involved in the federal government's response to HIV since the very week the CDC made its first official report on AIDS in 1981. Over the years, we have been through some very dark periods. But today, it feels really good to have genuine hope. It gets you energized to keep fighting. The finish line is there to see.

But I'm not one who counts the chickens before they hatch. The good news we have had is not a reason to diminish resources or commitment. I'm very adamant about that. We have to keep up our efforts until we reach the finish line.



Orlando Jones

# How Many Don't Know?

## Ensuring That All Black Americans Know Their HIV Status

By David R. Holtgrave, Ph.D., and Laura Wehrmeyer, M.M.

**New research findings on the powerful prevention effectiveness of antiretroviral treatment have generated optimism that the HIV epidemic can be brought to an end. Capturing the prevention potential of HIV treatment requires timely diagnosis of HIV and swift linkage to ongoing, high-quality care for people who test HIV-positive. Delayed diagnosis not only undermines optimal use of HIV treatment for HIV prevention, but also contributes to unknowing transmission of the virus to others.**

This chapter explores the critical importance of HIV testing, including what we know about how to improve testing rates. Encouraging widespread knowledge of HIV status is especially important for Black Americans, who are at substantially greater risk of becoming infected than any other racial or ethnic group in the country.

### What are the numbers?

Black Americans continue to carry a disproportionate HIV disease burden in the United States. As of 2008, the Centers for Disease Control and Prevention estimates that there are 1,178,350 people living with HIV in the United States, of whom 545,000, or 46 percent, are Black.<sup>1</sup> Although Blacks make up only 14 percent of the United States population, they represented an

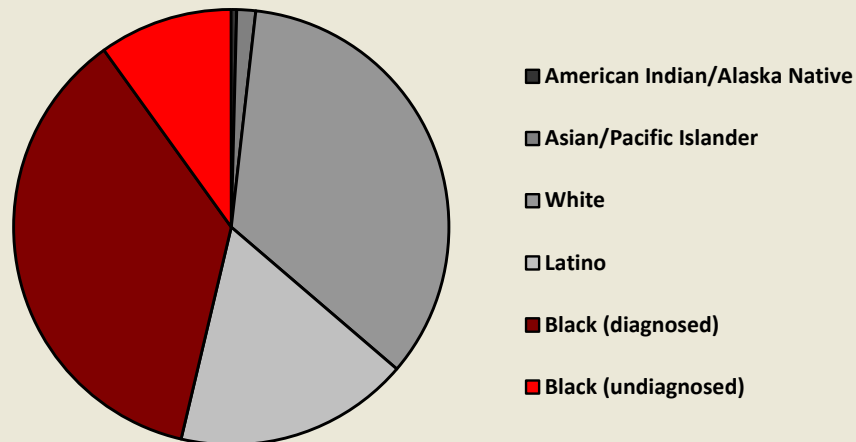
estimated 52 percent of new HIV infections in 2009.<sup>2</sup> The rate of new HIV infections among Black men in the U.S. is estimated to be six and a half times higher than that of white men, while the rate of infection among Black women is approximately 15 times higher than that of white women. Furthermore, the CDC estimates that one in 16 Black men and one in 32 Black women will be infected with HIV in their lifetime.<sup>3</sup>

Recent evidence indicates that roughly 116,750 Black Americans are HIV-positive and unaware of their infection.<sup>4</sup> Based upon these data, the percentage of Black Americans living with HIV who are unaware of their infection is approximately 21.4 percent. This percentage is higher than the CDC's estimate of 20.1 percent of people of all races living with HIV who are unaware of their infection, and notably higher than the 18.5 percent of white Americans living with HIV who are unaware of their infection.<sup>5</sup>

Recent CDC data indicate that within the Black population, approximately 69 percent of new HIV infections are among Black men, and roughly 31 percent are among Black women.<sup>6</sup> Based on the same data (see figure), an estimated 75 percent of new Black male infections in 2009 (52 percent of total infections among Blacks) were among men who have sex with men (MSM).<sup>7</sup> In fact, young Black MSM were the only group with statistically significant increases in new HIV infections from 2006 to 2009.<sup>8</sup> Awareness of infection among young Black MSM is particularly low. A 2005 survey found that

## People Living with HIV, 2008

Estimated number of people living with HIV, 2008, by race (n=1,178,350)



Source: Centers for Disease Control and Prevention. HIV Surveillance—United States, 1981–2008. MMWR 2011 60(21); 689–693.

among young Black MSM who tested positive for HIV in six U.S. cities, 91 percent were unaware of their HIV infection.<sup>9</sup>

### Why Does Lack of HIV Diagnosis Matter?

Clearly, if someone living with HIV doesn't know it, then it is impossible to get treatment for the disease. This is extremely important because treatment advances over especially the last 15 years have dramatically improved the life expectancy of persons living with HIV.<sup>10</sup> Treatment regimens have been simplified in the past several years,<sup>11</sup> and adverse effects appear to be improving as well. Of course, the cost of HIV care is still very high in the U.S.<sup>12, 13</sup> and not everyone who knows they are living with HIV and needs care can get it.<sup>14</sup> For these reasons, in 2004, the Institute of Medicine conducted an extensive study and concluded that HIV care should be guaranteed in the U.S. so that treatment can begin as early as clinically appropriate for everyone living with HIV.<sup>15</sup> Thankfully, with the advent of the Affordable Care Act to be fully implemented in 2014, the potential of universal access for HIV care will be a reality in the U.S.

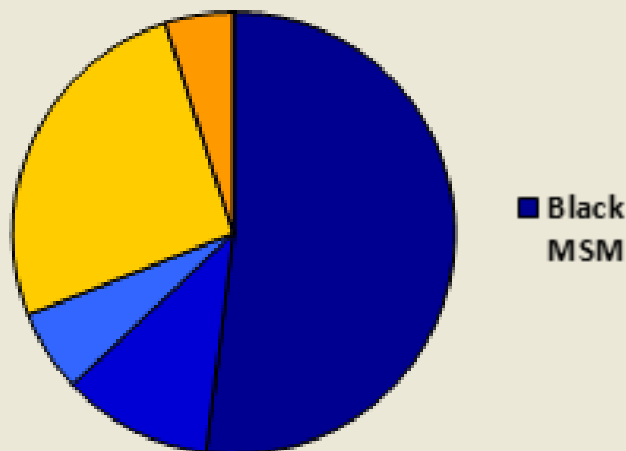
Certainly, there are clinical benefits of

HIV treatment; but there are also public health benefits. In a study that *Science* recently called the breakthrough of the year,<sup>16, 17</sup> researchers found that when combined with counseling and condom availability, early HIV treatment can reduce transmission of the virus by up to 96 percent among couples in which one person is HIV-positive and the other is HIV-negative. This is a finding that had been long suspected to be true,<sup>18</sup> but it was never so clearly and dramatically demonstrated until recently. Because of the promise of this new finding, people—including and notably President Obama—are now talking about the beginning of the end of AIDS<sup>19</sup>. This is a wonderful, overdue and welcome sentiment. But to achieve it we must ensure that everyone who needs and desires care is able to obtain it.<sup>20, 21</sup> An essential step toward the goal of universal HIV treatment access is to ensure prompt diagnosis of all people who are living with HIV. (Another chapter in this report describes the important steps that must be achieved after awareness of HIV infection—from linkage and retention in care, to prescription of antiretroviral drugs, to successful suppression of the virus.)

Indeed, the fact that so many Americans are HIV-infected but unaware has a direct effect on the spread of HIV. To illustrate this effect, researchers from CDC and their university col-

## New Black HIV Infections, 2009

Number of people newly infected with HIV, 2009, by subpopulation



Source: Centers for Disease Control and Prevention. HIV among African Americans, November 2011

leagues estimated the HIV transmission rate for persons living with HIV to their HIV-negative partners (this work was done even before NIH 052 was published). The HIV transmission rate is the number of HIV transmissions from 100 persons living with HIV to their HIV-negative partners in one year's time in the U.S.<sup>22, 23, 24</sup> Overall, the most recent published estimate of the HIV transmission rate (based on 2006 data) in the U.S. is 5.0 (meaning there were about five HIV transmissions per 100 persons living with HIV in a year; or in other words, less than 5 percent of people living with HIV in the U.S. transmit to another person in a given year—already an outstanding achievement). We can break this out further for persons aware and unaware that they are living with HIV. For persons aware that they are living with HIV, the transmission rate is estimated to be approximately 3.3; for persons who are unaware it is roughly 11.4.<sup>25</sup> This large difference is due to a combination of two factors; first, that persons who learn that they are living with HIV change HIV-related risk behavior very substantially on learning of this news so as to protect partners; and second, that treatment (for those who can get it) has the effect of lowering viral load and thereby the possibility of transmission. Therefore, awareness of HIV infection is critically important from a prevention viewpoint.

There is at least one more reason why the diagnosis of HIV matters: unless and until the major racial differences in lack of awareness of HIV seropositivity are addressed, the social injustice of disproportionate burden of HIV incidence in Black America sadly will continue. In fact, given the disproportionate numbers of Black Americans living with HIV who do not know it, and given that the transmission rate for persons unaware that they are living with HIV is 3.5 times higher than for persons who are diagnosed, it might be anticipated that not only will the health disparity of HIV in Black America stay the same, it could potentially continue to worsen. Clearly, improving the diagnosis of HIV among Black Americans is a matter of medicine and public health, but also a matter of ethics, civil rights and social justice.

### What Can Be Done?

The principal means to awareness of HIV infection is obviously HIV testing. A 2008 study conducted in Massachusetts found that 33 percent of Black MSM at risk for HIV had not been tested for HIV in the two years prior to the study.<sup>26</sup> Additional studies have shown that major barriers to testing among Black MSM are the lack of a primary physician and lack of access to health

care.<sup>27</sup> CDC estimates that 20 percent of Black Americans lacked health insurance as of 2007, compared with 10 percent of white Americans. This lack of access to health care may translate to a lack of access to testing and awareness of infection.<sup>28</sup> Therefore, it will be important to increase HIV testing in health care settings as well as in community-based and outreach settings outside of the health care system.

But at what scale will these efforts need to be delivered? Above, we saw that roughly 116,750 Black Americans are living with HIV and do not know it. What would the scale of an HIV testing program have to be that would address this unmet need, and what would it cost? In its Expanded HIV Testing Initiative (ETI) that focused heavily (though not exclusively) on HIV diagnosis in African American communities, from the year 2007 to 2010, CDC tested 2.7 million persons and saw a new HIV diagnoses rate of 0.7 percent. (The rate of new diagnoses among Black participants was a bit higher but one could not field a testing program that turned away persons of other races and ethnicities, so the overall new diagnostic rate was approximately 0.7 percent.<sup>29</sup>) That is approximately 143 tests for every person newly diagnosed. CDC also estimates<sup>30</sup> that on average, each test costs about \$45.35 (including the test, its administration, necessary lab work and related costs, as expressed in 2009 dollars).

Therefore, we might estimate that very roughly, a program that costs \$757 million would be necessary to address undiagnosed HIV infection in Black America (116,750 persons undiagnosed implying a need for 16,695,250 tests at \$45.35 per test). Certainly this is only a rough approximation of the cost of the unmet need, but it provides a sense of scale required to address this critical issue; by comparison CDC's entire HIV prevention budget for fiscal year 2011 was \$800.4 million. It is clear that to increase awareness of serostatus among Black Americans living with HIV, it will require the political will to substantially increase resources.

Some may say that with these very difficult economic times, the country lacks the ability to invest further in HIV testing initiatives. While it is true that our economic times are challenging, the argument that there is no further money for testing is shortsighted. Consider the return on HIV testing investments. If the HIV transmission rate for persons who are unaware that they are living with HIV is 11.4 and for persons aware it is 3.3, then for each 100 new diagnoses, we

may crudely estimate that we would prevent 8.1 HIV transmissions. If we were able to diagnose 116,750 infections, we might expect to avert 9457 infections (116,750 divided by 100 times 8.1).

This prevention dividend would translate into extraordinary economic returns on our national HIV testing investments. CDC has estimated that the net present value of medical care costs saved each time we avert an infection is \$367,134.<sup>31</sup> If we could avert 9,457 transmissions, we would save society over \$3.4 billion in downstream medical care costs. Given that about 75 percent of persons living with HIV need public assistance to pay for HIV care,<sup>32</sup> this \$3.4 billion in societal savings would imply \$2.6 billion in savings to American taxpayers. Even if these numbers are imprecise in some way(s), it is clear that the public sector savings from an investment in targeted HIV testing can well more than pay for itself. And conversely, to argue that we cannot invest in such prevention efforts is to assert that as a nation we are willing to accept more HIV infection, more health disparities and *higher* downstream medical costs. Indeed, a failure to invest is to express a desire to pay more to see more lives impacted by HIV. This is not only bad clinical practice, it is a civil rights travesty and public health error of the first degree.<sup>33</sup>

In his July 2010 speech to release the National HIV/AIDS Strategy, President Obama stated: "So the question is not whether we know what to do, but whether we will do it. Whether we will fulfill those obligations; whether we will marshal our resources and the political will to confront a tragedy that is preventable."<sup>34</sup> In the case of HIV testing, it is remarkably clear what needs to be done, but less clear if we will marshal the effort to make manifest achievement of our goals.

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Robinne Lee

## INTERVIEW

# Dr. Kevin Fenton

## Effective, Appropriate and Comprehensive Strategies for Individuals and Communities

*Dr. Kevin Fenton is the director of the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention at the Centers for Disease Control and Prevention. In January 2012, the Black AIDS Institute spoke to Dr. Fenton about the end of the AIDS epidemic.*

**In the last several months, a lot of people have said we now have the tools to end the AIDS epidemic. Do you agree?**

I do. We are at an amazing time in the course of the HIV pandemic. We now have an expanded HIV prevention toolkit, with a wide spectrum of effective interventions to reduce HIV incidence and to reduce HIV risk behaviors. The key thing to remember, however, is that we still have no “magic bullet” to end the epidemic. What these new tools tell us is that for maximum benefit we must continue to combine the most effective prevention approaches, both for HIV-positive and HIV-negative individuals, and scale up our prevention efforts, to end the epidemic in the U.S.

**Were you surprised by the results from the HPTN 052 trial?**

No, I was not surprised. In fact, I was very pleased to see this magnitude of impact from antiretroviral treatment confirmed by the study. We have had the results from a number of trials over the last 18 months which have examined the use of antiretrovirals for prevention for both HIV-positive and HIV-negative individuals. The results



**Dr. Kevin Fenton, Director, NCHHSTP**

suggest that consistent and correct use of antiretroviral treatment may be an effective prevention tool for some populations when combined with other prevention approaches, and are very encouraging. Now that we have this information on the role of antiretrovirals to prevent HIV transmission and acquisition, some key questions remain: How do we use these drugs most effectively? How do we ensure that we provide access to those who need them? How do we combine these biomedical approaches with other proven methods, such as preventing sexually transmitted diseases, promoting condoms and changing risk behaviors to have the greatest impact on the epidemic?

**As we think about what it takes to end AIDS, what do you see as CDC's role?**

CDC was an active partner in the development of the National HIV/AIDS Strategy. The strategy provides a bold, new operational framework for what we are trying to do and achieve in the U.S. as far as ending the domestic epidemic is concerned.

At CDC, we have been very proactive in moving very quickly to change the way we do business when it comes to HIV prevention in response to the Strategy. Evidence of this is the release of a new strategic plan from our Division of HIV/AIDS Prevention; new funding opportunity announcements that are changing way we fund health departments and community-based organizations; improved targeting of resources; and new campaigns to ensure that we are leveraging evidence from new prevention research. We are now poised to take advantage of these new opportunities to focus on funding high-impact interventions at the right scale for the right communities, to have the greatest impact on the U.S. epidemic.

**How far are we from doing what we need to do to end AIDS?**

There is no easy answer to that question. Undoubtedly, we now have powerful prevention tools at our disposal, but much remains to ensure that we are maximally benefitting from them. In a number of recently published *Morbidity & Mortality Weekly Reports* (MMWRs) CDC has showed that we have substantial work ahead of us to put these new tools to use, including treatment as prevention. We are not having the level of coverage for our most effective interventions to have the impact that we need to see. From looking at our efforts to scale up HIV testing here in

the United States, to increasing the proportion of HIV-positive Americans on treatment who are virally suppressed, to expanding the proportion of gay and bisexual men who are reached by effective HIV prevention approaches, we are not where we need to be, and need to do more.

Ending AIDS demands that we use our resources efficiently and effectively. That is why we are focusing on high-impact prevention—ensuring that we have the right resources to support the most effective interventions, targeted to the right populations in the right geographic locations to have the greatest impact on the epidemic.

**Can we realistically expect to end AIDS without additional funding?**

The first thing we need to do is ensure that we are using available resources as effectively as possible. We also need to look at all of our assets—human, fiscal and others—that can be brought to bear to end this epidemic, through expanding existing partnerships, bringing new partners to the table and focusing on the task at hand. Ultimately, it is critical that we work together to ensure that the levels of investment are commensurate with the severity of the epidemic in the U.S. We may need to look at new investments in HIV prevention in the U.S., and there have been new investments in HIV prevention recently—for example, new funding for HIV testing, and new opportunities through the prevention and public health fund. Ultimately, HIV is everybody's concern, and the solution will require the engagement, resources and commitment from multiple sectors.

**The National HIV/AIDS Strategy places great emphasis on improving the coordination and working relationship among diverse federal agencies. What steps has CDC taken to improve coordination with its federal partners?**

We have always worked across organizational boundaries to focus on HIV prevention, and support HIV treatment and care. CDC has longstanding partnerships with the Health Resources and Services Administration, the Substance Abuse and Mental Health Services Administration, the National Institutes of Health, the Indian Health Service and many other agencies to help extend the reach and impact of our prevention efforts.

I will say, however, that the publication of the National HIV/AIDS Strategy and new

scientific developments including treatment as prevention, have underscored the importance of improved inter-agency coordination. Today, we need a seamless continuum of HIV services that educates, empowers and protects individuals regardless of their HIV status. At CDC we have a vested interest as the nation's prevention agency in ensuring that people who are in care remain in care and are virally suppressed. We need to work with treatment agencies to integrate prevention into treatment, using the best evidence-based approaches. CDC brings our expertise in prevention, monitoring and evaluation to enhance the effectiveness of clinical service provision. Conversely, CDC also has much to learn from our clinical partners about ways in which healthcare services can be better leveraged to support prevention, especially prevention with HIV-positive individuals, as well as to improve access to disenfranchised communities.

**As you know, Black America has been more heavily affected by HIV than any other racial or ethnic group. When we think about ending AIDS, how might our efforts differ with respect to Black America?**

Our approach has to differ with respect to Black America because the impact of the HIV epidemic in the African American community is so severe. We must recognize HIV in Black America as a crisis, and act accordingly. African Americans make up 14 percent of the population but nearly half of all people living with HIV. Rates are especially high among young Black men who have sex with men and African American women. In addition to looking at specific interventions targeting African Americans, we need to look at unique approaches that are relevant and appropriate for this community. We need to be honest about the complex factors that drive the epidemic, including stigma, homophobia and other forms of discrimination; and other structural determinants, such as poverty, incarceration and poor access to quality healthcare. We need to be honest about high levels of STDs that facilitate transmission and acquisition of HIV at an individual level. We also need to have honest conversations about the role of personal responsibility for one's sexual health—taking care of our own health and also the health of our loved ones.

In dealing with the HIV epidemic in Black America, we also need to focus on community assets and the factors that promote resiliency for individuals and communities across the coun-

try. We need to think about mobilizing African American businesses, civil rights organizations, faith communities, local governments and media. We should look to the pillars within the African American community and work with those groups to ensure that our efforts have more impact. CDC has been strengthening, through the Act Against AIDS Leadership Initiative, the ways in which we engage with longstanding and historic organizations within the African American community. Leaders from every walk of life within the Black community will need to play a part in disseminating the prevention message.

We need to make sure that our efforts are focusing on communities at highest risk. Within the African American community, the situation for Black gay and bisexual men is quite grave. In the U.S., the only population sub-group that has seen significant increases in new HIV infections since 2006 is young Black gay men. We should look at new approaches to deal with the epidemic in this population. CDC has developed new social marketing campaigns, and we are changing the way we are funding organizations that serve Black gay and bisexual men to bring the most effective interventions to scale for this population. Similarly, Black women have substantially higher rates of disease than women of other racial/ethnic backgrounds, and we need to expand our efforts to ensure that our programs address the drivers of the epidemic among Black women, as well as accelerate efforts to promote awareness, testing and care.

**Ensuring that every Black American knows his or her HIV status is obviously an urgent necessity. How do we do this? Black Americans are already more likely to be tested than other racial or ethnic groups, but studies suggest that Black Americans represent a disproportionate number of those who are diagnosed late.**

The testing picture does, indeed, represent a paradox within the African American community. African Americans have higher rates of testing than other racial/ethnic groups but they also have higher background prevalence or levels of disease within the community. Because of this greater burden, getting ahead of the HIV epidemic in the Black community will require higher rates of testing; more aggressive linkage to and maintenance in care, and optimal treatment outcomes with antiretrovirals. We also must address those social and structural factors

which result in delayed testing and late diagnosis, including stigma, fear of HIV testing and poor access to prevention, testing and treatment services. CDC's efforts to scale up HIV testing have been focused especially among African Americans, Hispanic/Latinos and gay and bisexual men of all races, in some of the hardest hit areas of the country. We are committed to doing our part to address the barriers to HIV testing in the Black community and improve testing access and uptake, to more effectively address the late diagnosis issue. Of course, this is an area where our partners can play an important role too.

**You've mentioned social and structural drivers of the epidemic. What do we need to do to address these effectively?**

No single agency will end this epidemic on its own. The complex nature of the domestic HIV epidemic means that we need to have effective, appropriate and comprehensive strategies targeted at the individuals, communities and the wider society for maximal impact.

For us to effectively address the social and structural issues, we need to work across organizational boundaries, and identify partners who have the appropriate competencies and resources for action. For example, we are working with the Department of Housing and Urban Development to tackle homelessness issues as well as the provision of stable housing for those with HIV, because stable housing is HIV prevention. We are working with the Bureau of Prisons to look at effective HIV prevention policies and practices for incarcerated populations. And we are working with our counterparts at SAMHSA to look at ensuring that we better integrate drug and behavioral health issues into prevention programs.

In addition to developing impactful partnerships to address the social and structural drivers of the epidemic, I believe that agencies also need to have explicit strategic commitments to tackle these issues. CDC has produced our strategic plan to improve health equity and address the social determinants of HIV and other STDs. We are one of the first agencies to do so, and we are convinced that this strategic approach is needed to guide a more comprehensive and effective prevention response. Our strategic plan outlines key activities for CDC and our grantees and we are now implementing various actions in the plan.

Finally, we need to prioritize research to better understand the social and structural drivers and their effect on HIV health outcomes. We



must expand the range of tools that can be used to effectively intervene at the social and structural levels to reduce HIV incidence. We must understand how best to combine these social and structural approaches with other effective individual-level approaches for greatest impact. Continued research is therefore needed, but the seriousness and scale of the epidemic means that we need to move quickly, deliberately and pragmatically in building the evidence and implementing best practices.

**How do we move forward to reach the goal of ending AIDS?**



We have a vision for ending the epidemic in the U.S. and now, for the first time, we have a national strategy that requires coordinated action to achieve this goal. Moving forward, I believe that developing robust partnerships will be key to ending AIDS.

Strategic partnership development for HIV prevention is a major focus for us at CDC and also a key theme of the National HIV/AIDS Strategy. At CDC, we are committed to taking partnerships to a whole new level by working with our existing partners and bringing new stakeholders into the fight against HIV at home. We are especially excited about new partners

that have emerged to join us in our prevention efforts—the business sector, philanthropic agencies and educational agencies to name a few. But more needs to be done to ensure that we engage the hearts and minds of an even broader coalition of stakeholders moving forward. We especially have to think about how we reach young people, especially in this highly technological and networked age, to ensure that we are reaching youth where they live, learn, work and play more effectively. Effective, accountable and focused partnerships will be key towards creating an AIDS-free generation.



Brian White

# AIDS 2012

## A Unique Opportunity to Shine a Spotlight on AIDS in Black America

**In July 2012, the International AIDS Conference returns to the U.S. for the first time in more than two decades. With new policy-makers, researchers and advocates uniting around the vision of turning the tide together and bringing an end to the AIDS epidemic, the conference will occur at a deciding moment in the history of HIV/AIDS. As more than 20,000 delegates are expected to converge on Washington, D.C., for the meeting, the conference promises, as always, to serve as the world's most important HIV-related scientific gathering and as a critical opportunity to renew and strengthen national and global resolve to do what is needed to end the epidemic.**

AIDS 2012 is an important marker in many ways. It will be the first to be held since release of results from the clinical trial HPTN 052, which definitively demonstrated the potential for anti-retroviral therapy to stop HIV transmission in its tracks.<sup>1</sup> The return of the conference to the U.S. is the result of historic leadership at the federal level to end the longstanding ban on entry into the U.S. of foreigners living with HIV.

The decision to have the conference in Washington, D.C., is also historic. The U.S. is by far the leading provider of international HIV assistance, with HIV-related disbursements by the federal government exceeding more than four-

fold the closest donor government (the United Kingdom).<sup>2</sup> But with Congress poised to slash the federal budget, future American leadership on the response is potentially in doubt, rendering Washington's decision-makers critical to the world's ability to bring HIV/AIDS under control globally.

Washington as a conference locale also offers a unique opportunity to train a national and global spotlight on the epidemic in Black America. Washington's epidemic, concentrated among Black Washingtonians, is especially severe, with HIV prevalence more than twice as high as in New York City. But mobilization by Washington decision-makers and community partners is leading the way toward new solutions, offering a potential roadmap to strengthen the AIDS response in other Black communities as well.

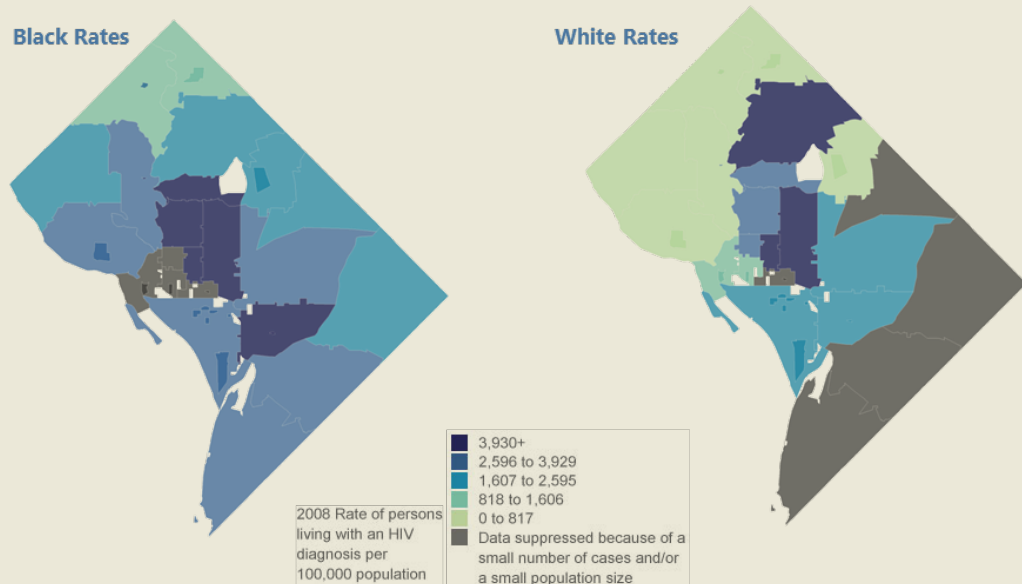
This chapter describes why this conference is so important to our future ability to respond effectively to the epidemic. It also describes how it is being planned, what is likely to occur at the meeting and how Black leaders and activists can become involved in this historic gathering.

### **An International Conference in Our Nation's Capital**

Washington is not only the center of political power in the U.S., but it is also an epicenter of the HIV/AIDS epidemic in Black America. More than 3 percent of Washington residents—and

## Black and White Living with HIV, 2008

Rates of Black and white people living with HIV, 2008, Washington, D.C., by zip code.



Source: AIDS Vu Project, 2012.

almost one in 20 Black Washingtonians—are living with HIV.<sup>3</sup>

The concentration of HIV among Black Washingtonians is striking. HIV prevalence among Black people in Washington is more than twice as high as among Latinos and more than three times as high as for whites.<sup>4</sup>

The epidemic among Black Washingtonians reflects the diversity of the epidemic in Black America generally. Nearly one in three Black Washingtonians living with HIV in 2009 are believed to have contracted HIV during heterosexual intercourse; more than 29 percent of HIV-positive Black people are men who have sex with men (MSM), and one in five are people who inject drugs. The HIV/AIDS case rate is more than 18 times higher among Black women (2826.4 per 100,000 population) than among white women (153.4). Black Washingtonians also account for almost 96 percent of children living with HIV in the district.<sup>5</sup>

Several factors contribute to the severity of the epidemic among Black Washingtonians. These factors include poverty, substance abuse, social exclusion, limited health care access and widespread incarceration. In Washington, for

example, the median income of Black households is less than 40 percent of what white households earn.<sup>6</sup> The percentage of people living in poverty is nearly four times higher for Black Washingtonians than for their white counterparts.<sup>7</sup>

Washington, in short, vividly reflects the HIV-related challenges faced by Black America as a whole. While grappling with a substantially more severe epidemic than in any other racial or ethnic group, Washington's Black community has fewer financial resources with which to respond. Unlike the U.S. as a whole, which has low HIV prevalence and a concentration of infections in discrete populations, the Black population of Washington (like Black America as a whole) is experiencing a generalized epidemic, with high levels of HIV across diverse demographic categories.

Yet Washington is not only a useful lens for understanding the severity of the HIV challenge in Black America. Washington also shows what can be accomplished with determined action and a mobilized community.

Confronting the HIV challenge in Washington, Mayor Vincent Gray in 2011 appointed a Commission on HIV/AIDS to develop new HIV

prevention and treatment strategies. Reflecting the broad array of stakeholders needed for a robust response, the Commission includes medical providers, faith community leaders, the private sector and the local government. The mayor himself is chairing the Commission, underscoring the seriousness of purpose that defines efforts to strengthen the HIV response in the District of Columbia.

Washington has taken steps to strengthen the health care safety net for people living with HIV. Beginning in 2011, the city began work to create a system to offer treatment on demand for all people who have tested HIV-positive. New procedures have been put in place to ensure continuity of care for HIV-positive people who are discharged from correctional settings back to their Washington communities. The city also embarked on an initiative to improve HIV clinical training for all the city's health care providers.

There are other signs of progress in Washington's fight against HIV. The number of people

receiving public HIV testing services nearly tripled from 2006 to 2010. Indeed, Washington is a national leader in innovative testing models, becoming the first city in the U.S. to offer HIV testing at department of motor vehicles offices. Treatment of HIV has also expanded, as the number of HIV-positive Washingtonians receiving free HIV medicines rose nearly three-fold from 2007 to 2010.

The number of people diagnosed with HIV in Washington fell by almost 50 percent from 2007 to 2009. Although testing data do not necessarily reflect actual trends in new infections (as many people may wait years after initial infection before getting tested), the fact that the decline in diagnoses occurred during a surge in testing utilization suggests that new infections may in fact be on the decline. Washington is one of 12 cities nationwide participating in a groundbreaking federal initiative to strengthen the effectiveness and integration of HIV prevention, testing and care programs.

In short, Washington has much to teach



**Walter E Washington Convention Center, site of AIDS 2012.**



**Rhon Reynolds, Michel Sidibe, Wangari Tharao, Amanda Lugg and Valerie Pierre-Pierre at the Global Village at AIDS 2010 in Vienna.**

the HIV field and those who will be following AIDS 2012 proceedings in the media. Not only does Washington underscore the challenge facing Black America, but it also shows what can be done when communities join with the local government and other partners in a common endeavor to prevent new infections and care for those who are living with HIV.

## What to Expect at AIDS 2012

The International AIDS Conference began in 1985, when the first such meeting was hosted in Atlanta just as the global dimensions of the epidemic were first becoming apparent. Since then, the confer-



ence has grown to become one of the most important scientific gatherings in the world. Beyond its earlier scientific focus, the conference has assumed political dimensions, attracting global leaders such as former South African President Nelson Mandela, former U.S. President Bill Clinton, Bill Gates, Bono and a host of celebrities and opinion leaders.

Held every other year, the conference also generates intensive media attention. In part, this is due to the release of groundbreaking scientific information and the coalescence of new HIV movements. At the Vancouver meeting in 1996, scientists released definitive proof that antiretroviral therapy dramatically slows HIV disease progression and reduces the risk of illness and death among people living with HIV. Four years later, in Durban, South Africa, the first stirrings of a global consensus for universal treatment access became plain. In 2010 in Vienna, South

African researchers reported that a major study had found an antiretroviral-based microbicide gel reduced women’s risk of becoming infected.

More than 190 countries are expected to be represented at this year’s International AIDS Conference. In addition to an estimated 20,000 delegates, at least 2,000 media representatives are likely to attend. At least 150 organizations and companies are expected to have their own exhibition booths at the conference.

The conference is expected to include 680 speakers, including those speaking in plenary and thematic sessions. Hundreds of additional data presentations will appear in poster formats that conference participants may review. Dead-

line for submission of abstracts is February 15.

As its name suggests, the **Community Program** will focus on the role of affected communities in a strong and effective HIV response. The community program will reaffirm the centrality of human rights in efforts to end the epidemic and underscore the importance of meaningful involvement of people and communities affected by HIV. Issues addressed by the Community Program will include strategies for mobilizing needed resources, ensuring equitable access and addressing social and economic issues that affect the HIV response.

The **Leadership and Accountability Program** aims to revitalize global, national,

## Previous International AIDS Conferences

Year	Location	Participants	Theme
1985	Atlanta, Georgia, USA	2,000	
1986	Paris, France	2,800	
1987	Washington, D.C., USA	6,300	
1988	Stockholm, Sweden	7,500	
1989	Montreal, Canada	12,000	The Scientific and Social Challenge of AIDS
1990	San Francisco, USA	11,000	AIDS in the Nineties: From Science to Policy
1991	Florence, Italy	8,000	Science Challenging AIDS
1992	Amsterdam, Netherlands	8,000	A World United Against AIDS
1993	Berlin, Germany	14,000	Time to Act
1994	Yokohama, Japan	10,000	The Global Challenge of AIDS: Together for the Future
1996	Vancouver, Canada	15,000	One World One Hope
	<i>Protease Inhibitors presented, radically reshaping AIDS treatment, and extending the lives of millions</i>		
1998	Geneva, Switzerland	15,000	Bridging the Gap
2000	Durban, South Africa	12,000	Breaking the Silence
	<i>African activists demand global attention for the epidemic in Global South, igniting a wave of political action and economic investment</i>		
2002	Barcelona, Spain	18,500	Knowledge and Commitment for Action
2004	Bangkok, Thailand	18,500	Access for All
2006	Toronto, Canada	26,000	Time to Deliver
2008	Mexico City, Mexico	20,000	Universal Action Now
2010	Vienna, Austria	19,000	Rights here, Right Now

## Plenary Sessions: Planned Themes and Speakers

### **Monday, July 23—Ending the Epidemic: Turning the Tide**

Ending the HIV Epidemic: From Scientific Advances to Public Health Implementation  
Anthony S. Fauci, National Institute of Allergy and Infectious Diseases

The U.S. Epidemic  
Phill Wilson, Black AIDS Institute

Turning the Tide in Affected Countries: Leadership, Accountability and Targets  
Sheila Tlou, UNAIDS

### **Tuesday, July 24—Challenges and Solutions**

Viral Eradication: The Cure Agenda  
Javier Martinez-Picado, AIDS Research Institute (Spain)

Implementation Science: Making the New Prevention Revolution Real  
Nelly Mugo, University of Nairobi (Kenya)

What Will It Take to Turn the Tide?  
Bernhard Schwartlander, UNAIDS

### **Wednesday, July 25—Turning the Tide on Transmission**

Bart Haynes  
Duke Human Vaccine Institute

Turning the Tide for Women and Girls  
Geeta Rao Gupta, UNICEF

Turning the Tide for Children and Youth  
Chewe Luo, UNICEF

### **Thursday, July 26—Dynamics of the Epidemic in Context**

Turning the Tide for MSM and HIV  
Paul Semugoma, Global Forum on MSM and HIV (Uganda)

The Tide Cannot Be Turned Without Us—HIV Epidemics Among Key Affected Populations  
(Public Health, Human Rights and Harm Reduction)  
Cheryl Overs, Monash University (Australia)

Expanding HIV Testing and Treatment  
Gottfried Hirnschall, World Health Organization

### **Friday, July 27—HIV in the Larger Global Health Context**

TB and HIV—Science and Implementation to Turn the Tide on TB  
Anthony Harries, International Union Against Tuberculosis and Lung Disease (France)

Intersection of Non-Communicable Diseases and Aging in HIV  
Judith Currier, University of California, Los Angeles

Optimization, Effectiveness and Efficiency of Service Delivery—Integration of HIV and Health Services  
Yogan Pillay, National Department of Health (South Africa)

organizational and personal commitment and responsibility for ending the epidemic. The program seeks to nurture and highlight leadership excellence in the HIV response, with the goal of engaging new, non-traditional and existing leaders in efforts to advance measurable progress against HIV/AIDS.

The **Scientific Program** will highlight new scientific findings on HIV/AIDS. Through scientific presentations, the program aims to accelerate the scale-up of evidence-informed, rights-based, combination approaches to HIV prevention, treatment, care and support. The Scientific Program will address the full gamut of scientific issues, including basic science, clinical, epidemiological, prevention, social, human rights, political, implementation, health systems and economic research. Presentations will also examine the epidemic's impact on individuals, communities and societies.

In addition to these basic programmatic areas, the conference will include 60 workshops focused on professional development. Designed for small audiences, these workshops aim to promote and enhance opportunities for knowledge transfer, skills development and collaborative learning. The professional development workshops will span the various disciplines involved in the HIV response, with each of the above-noted conference programs designing five different workshops. An additional 40 workshops will be selected from among those proposed by other parties.

As in prior conferences, the 2012 Washington meeting will offer numerous opportunities for community members to network with each other and to share information and perspectives. The Global Village will include marketplace booths, exhibition booths by non-governmental organizations, space for community dialogue, award presentations, cultural activities, performances and daily live plenary broadcasts, as well as opportunities for debates and workshops. Based on experience in previous conferences, it is expected that the Global Village will be a highlight of the meeting for conference attendees.

Special activities will also be undertaken for young people attending the conference. A youth pavilion will provide space for sessions and workshops specifically designed for young people. A pre-conference meeting for young attendees will be held, and networking areas for young people will be provided.

## Why Black America Has a Stake in the 2012 Meeting

Black Americans have historically had difficulty engaging with the International AIDS Conference. As the conference has happened in other regions of the world for more than two decades, travel costs have been prohibitive for most Black activists. Fees for conference registration are also steep, and the limited number of scholarships that have been offered for prior conferences has been largely restricted to attendees from developing countries.

This year offers a critical opportunity for Black Americans to become involved in this most important of all global HIV scientific meetings. Because it is occurring in the U.S., costs associated with participation are significantly lower than in previous conferences and there are special scholarship programs to increase American participation. And because a number of U.S. organizations, including the Black AIDS Institute, are helping plan the conference program, the chances are much greater that key sessions will include Black speakers.

But why should Black America care? Does another AIDS conference make a difference, even if it is occurring here in the U.S.?

The truth is that the upcoming conference is happening at a deciding moment in the history of the HIV response in Black America. Earlier conferences have shined global media attention on HIV issues specific to the host country—the lack of treatment access in South Africa at the 2000 Durban meeting; backsliding on HIV prevention by Thai leaders at the 2004 Bangkok meeting; Latin American HIV issues at the 2008 Mexico City conference; and the role of injecting drug use in the spread of HIV in Eastern Europe at the 2010 Vienna conference. Similarly, this year's conference—occurring in our nation's capital, where Black people represent the overwhelming majority of prevalent and incident infections—provides a unique chance to focus attention on what needs to be done to end AIDS in Black America.

The fact that Washington is the city where the most important AIDS policy decisions are made underscores the importance of AIDS 2012. If we are to reverse and eventually end the AIDS epidemic in the U.S., Black America itself will need to be joined by Washington lawmakers from across the political spectrum. Robust en-

## Black American Members of AIDS 2012 Governance Committees

### Conference Coordinating Committee

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### Track C: Epidemiology and Prevention Science

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### Track D: Social Science, Human Rights and Political Science

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gagement by Black America is critical to ensure that this message is heard at each end of Pennsylvania Avenue.

There are other important reasons why Black Americans should become actively involved in AIDS 2012. The meeting has long served as an important platform for articulating and advancing the AIDS agenda—both globally and here in the U.S.

The conference also provides a valuable platform for learning about best practices from programs in other parts of the world. Whether it comes to mobilizing communities, introducing new prevention tools, or addressing the particular HIV-related needs of key populations, stakeholders in the U.S. have much to learn from people in other countries. The substantive sessions and multiple networking opportunities afforded by AIDS 2012 can help build capacity and creativity for the AIDS response here at home.

But there is perhaps an even more important reason why engagement in this upcoming scientific meeting is so vital. With new biomedical tools offering the greatest hope to end the AIDS

epidemic in our lifetimes, future success will depend in large measure on broad-based scientific literacy in affected communities.

To capture the prevention potential of anti-retroviral treatment, Black communities across the U.S. must become sufficiently aware of the need for all Black Americans to know their HIV status. All Black people need to know that medical treatments are available that make it possible to live a long and full life with HIV. Black communities must understand the importance of keeping medical appointments and adhering closely to prescribed regimens. Concepts such as viral load need to extend beyond the clinical setting and enter the consciousness of affected communities. In short, community-based knowledge and awareness must be robust enough to overcome enduring fear, misinformation and stigma about HIV.

The predominantly white mainstream gay community has demonstrated the power of treatment education. With an HIV-aware and educated community, white gay men have become prepared to take advantage of the extraordinary

treatment advances that have revolutionized medical management of HIV.

A similar treatment revolution is needed in Black communities. To bring this treatment revolution to pass, Black communities need to engage with scientific issues, becoming intimately familiar with key concepts pertinent to HIV treatment and prevention.

Playing an active role at AIDS 2012 is an important step toward building scientific and treatment literacy in Black communities. Strong participation in the conference will also help prepare the way for a major reorganization of the Black AIDS response, ensuring that community organizations are linked with medical homes and have a role to play in promoting and delivering HIV testing and treatment.

The Black AIDS Institute is working with other partners, including the Black Treatment

Advocates Network, to ensure a strong Black community presence at the Washington meeting. The Institute will be sponsoring a delegation of Black reporters to the conference and will also sponsor Black treatment advocates to attend the meeting and convene a two-day science and treatment institute prior to the conference. Each day during the conference, the Institute will report to the field on key data presentations and developments at the meeting, helping ensure that those who are unable to attend the meeting can still benefit. Attendees of the meeting will benefit from daily breakfast updates, and the Institute will sponsor conference updates at venues across the U.S. after conclusion of the meeting.

## Notes

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**Jesse Milan, Jr., Board Chair Emeritus, Black AIDS Institute, member of AIDS 2012 Central Coordinating Committee**



Essence Atkins

# Leadership Matters

## Ending AIDS in Black America

**With Black America more heavily affected by HIV than any other racial or ethnic group, Black people have a greater stake than any others in recent scientific advances that have made it feasible to begin thinking about the end of AIDS.**

There is a role for government to play in supporting new research—promoting early diagnosis of HIV infection, linking all who test HIV-positive to ongoing care, and combining prevention and treatment tools to maximize impact. But government action won't occur on its own, and it alone won't be sufficient to bring AIDS to an end. The emerging AIDS "exit strategy will need Black leadership to be effective.

To write the final chapter of the epidemic, Black America will need to act on its own behalf. Only strong and genuine leadership will get us where we need to go.

### Attributes of True Leadership

The word *leadership* is used a lot. But in the case of AIDS in Black America, what does it mean?

True leadership is *visible*. In the first decade of the epidemic, AIDS activists coined the phrase, "Silence = Death." In the case of AIDS, truer words have never been spoken, and they remain as true today as they were more than 20 years ago when the slogan was first coined.

For a long time, there was a disturbing and paralyzing silence about AIDS in many Black communities. In recent years, that has begun to change, as leading Black political and civic organizations, the clergy and community leaders have worked to raise AIDS awareness.

But we are seeing some disturbing trends in Black communities. As the next chapter in this report summarizes, surveys have found a sharp reduction in the percentage of Black people who report having heard a lot about AIDS over the last year.

This is a recipe for disaster and will certainly not help us bring AIDS to an end. People from all walks of life in Black communities—including family members, acquaintances and community leaders—need to speak openly and often about AIDS.

Particular attention is needed to encourage all Black people to know their HIV status. A positive HIV test is one of the most important pieces of information any person can receive, as it opens the door to life-saving treatment. Knowing your HIV status helps pierce the denial and silence that often surrounds the fight against AIDS in our communities.

There is yet another attribute of leadership—one that is also relevant to the recent trends in public discussion about HIV. Genuine leadership is *steadfast*. True leaders don't lose interest or declare victory before it has been achieved and we don't walk away from unfinished business just because we are tired.



**Black community leaders at AIDS 2006 in Toronto.**

We stand at a deciding moment in the fight against AIDS. New tools offer the real prospect of ending the epidemic and ushering in an AIDS-free generation. But the fight will not be easy, and victory will not occur overnight. If we seek to lead the effort to end AIDS in Black America, we need to prepare ourselves for a long, arduous effort.

True leadership is *courageous*. The unfortunate reality is that our collective response to this most serious of health problems has been undermined by the fact that many key issues—including homosexuality and drug use—make a lot of people uncomfortable.

Being uncomfortable is not a crime, but it warrants censure when it keeps us from acting to address a crisis as serious as HIV/AIDS. Every Black person affected by HIV is a part of our family, our community, our collective history. All of us—from the most humble to those who occupy the highest office in the land—need to summon the courage to transcend our discomfort and speak openly about the need for community-wide action on AIDS. Inclusion, compassion and tolerance need to trump division, prejudice and discomfort in our response to the epidemic.

Effective leadership on AIDS is *demanding*.

Black America hasn't accomplished the substantial, if still uneven, progress toward full equality by politely asking for special favors. Our greatest leaders have spoken truth to power.

Nothing less than this will be needed to end the AIDS epidemic in our communities. When those who value profit over people seek to repeal or undermine health care reform, we need the courage to say no. When the media, government decision-makers and other powers-that-be want to focus on "other issues" because AIDS is "old news," we must actively resist these instincts. And when the small-minded suggest that stigma and discrimination are more effective HIV control strategies than evidence-based prevention and treatment, we need to oppose them.

Last, but certainly not least, leadership is *accountable*. For the first time in our nation's history, we have a comprehensive National HIV/AIDS Strategy, with clear, measurable, time-bound targets. We need to hold our national representatives accountable for achieving these results.

At the state and local level, accountability is also essential to long-term success. In states across the land, thousands of people who need life-preserving HIV drugs are on waiting lists for AIDS Drug Assistance Programs. It's true that

many states and cities are experiencing severe fiscal constraints due to continuing economic difficulties. But we must insist that budgets not be balanced at the expense of those who are most vulnerable.

Above all, we need to hold ourselves accountable. The end of AIDS is possible to achieve. We now have the tools. But will we use those tools expeditiously, effectively and compassionately?

## **It's Up to Us**

We hold the future in our own hands. If we fail to do what is needed, we will only have ourselves to blame.

For more than 30 years, our communities have been devastated by HIV. With such an extraordinary opportunity staring us in the face to end this crisis once and for all, let's not let history say that we failed.



**President Barack Obama in the White House Oval Office.**



Camille Winbush

# AIDS in 2011

## Important Progress, Disturbing Trends Typify a Pivotal Year in the HIV Response

**The year 2011 may well be remembered as a milestone in the AIDS response. New research breakthroughs offered the first real hope for ending the epidemic, CDC estimates suggested some progress in promoting knowledge of HIV status and the U.S. government made bold new moves to strengthen its global leadership on AIDS.**

Yet at the same time, important challenges emerged. The political climate in Washington threatened our ability to put proven new prevention methods to effective use, and new epidemiological evidence documented a frightening rise in new infections among young Black gay and bisexual men. At the beginning of 2012, Congress passed legislation that undermined our country's ability to prevent new infections among people who use drugs by re-imposing a ban on federal support for proven needle and syringe exchange programs.

This chapter reviews the major AIDS-related developments in 2011. As the summary below reveals, the challenge confronting the U.S. in 2012 is whether the country will muster sufficient political commitment to grasp the extraordinary opportunities that now exist to move toward an "end game" for the national AIDS response.

### Ending AIDS: Treatment as Prevention

In mid-2011, research findings released by the National Institutes of Health struck the world like a thunderbolt. As summarized in a separate chapter of this report, a U.S.-sponsored study found antiretroviral treatment to be powerfully effective in reducing the risk of HIV transmission.<sup>1</sup>

The striking findings led leading experts to declare that we now have the tools to end the AIDS epidemic.<sup>2</sup> However, as another chapter in this report explains, we are a long way from realizing the promise of treatment, as nearly three-quarters of people living with HIV do not have suppressed virus.<sup>3</sup>

Capturing the promise of treatment as prevention will require concerted efforts to close these health care gaps. *We now have the ability to end AIDS, but whether we do so will depend largely on national commitment and wise policy choices.*

### 30 Years of AIDS

June 2011 marked the 30th anniversary of the first official report on AIDS by the Centers for Disease Control and Prevention. Extensive media attention marked the beginning of the epidemic's fourth decade, with stories examining the history of the AIDS response and exploring current and future challenges posed by the epidemic. Com-



## Black AIDS Treatment Advocates Network Brings 'Treatment Revolution' to Black America

**W**hen Highly Active Antiretroviral Therapy emerged in the mid-1990s, it was rightly hailed as a “treatment revolution” for people living with HIV. Sadly, this treatment revolution never reached many Black communities, as Black people are consistently less likely than other people living with HIV to receive needed medicines and adherence supports.

The Black Treatment Advocates Network (BTAN) is the only collaboration of its kind that links Black Americans with HIV to care, strengthens local and national leadership on treatment issues, mobilizes peer advocates for treatment education and increases HIV science and treatment literacy in Black communities. BTAN has created a national network of Black AIDS treatment advocates, guided by a steering committee of more than 30 leading national HIV experts and activists. Since 2010, BTAN has focused intensive efforts on building local treatment advocacy networks in six cities—Atlanta, Chicago, Houston, Jackson, Los Angeles and Philadelphia. Three new cities—New Orleans, Miami and Oakland—will be brought on-line in 2012.

BTAN provides intensive HIV science and advocacy trainings during two three-day sessions, helping build an army of treatment educators and advocates in Black communities across the country. Since BTAN’s launch, more than 250 advocates have been trained through national and local BTAN programming.

ing only a few days after the NIH release of data on the effectiveness of antiretroviral treatment for HIV prevention, the anniversary prompted considerable media attention about historic new

opportunities to slow the epidemic’s spread. Framed in part by the Black AIDS Institute’s release of a major report, *AIDS—Thirty Years is Enuf!*, substantial media coverage focused on

the epidemic's disproportionate impact on Black America.

Popular culture took note of the 30th anniversary of AIDS. On Broadway, for example, a revival of Larry Kramer's *The Normal Heart*, which told the story of early AIDS activism in New York City, played to sold-out audiences and quickly became the hottest ticket in town.

Also marking the 30th anniversary, a national survey by the Henry J. Kaiser Family Foundation revealed cause for concern with respect to the future of the AIDS response in the U.S.<sup>4</sup> According to the survey, only 7 percent of Americans rank HIV/AIDS as the number one health concern—down from nearly two-thirds in 1987. Black Americans remain far more concerned about HIV/AIDS than other Americans, with nearly four times as many Black Americans (40 percent) as whites (11 percent) saying they were “very concerned” about becoming infected.

## Epidemiological Trends: Disturbing News on Black Gay/Bisexual Men

To mark the 30th anniversary of AIDS, CDC released new HIV prevalence estimates for the U.S., determining that 1.2 million people were living with HIV as of December 2008.<sup>5</sup> In a separate report, the CDC found that the country made little, if any, progress in reducing the number of new HIV infections from 2006 to 2009.<sup>6</sup>

Black America remains more heavily affected by HIV than any other racial or ethnic group. Accounting for less than 14 percent of the U.S. population, Black Americans represent 46 percent of all people living with HIV and 44 percent of new HIV infections in the U.S.

Trends are especially disturbing for Black men who have sex with men. Nationally, Black gay and bisexual men ages 18 to 29 are the only population in which there was a statistically significant increase in HIV incidence from 2006 to 2009. In 2009, 48 percent more Black gay and bisexual men became infected than in 2006.

## HIV Funding

With the nation's budget deficit at historic levels, Washington policy-makers were consumed by efforts to reduce federal spending. After rejecting a so-called “grand bargain” with the White House that would have balanced

spending cuts with revenue increases, the Republican House majority reached agreement with Democrats to impose more than \$2 billion in federal spending cuts over 10 years. The failure of a Congressionally mandated bipartisan commission to agree on spending reductions triggered a process that will lead to automatic spending cuts across a broad range of federal programs. Although defense spending and entitlement programs are slated for some automatic cuts in future years, the spending triggers in the budget legislation are expected to place particular budget pressures on such discretionary programs as the Ryan White CARE Act, CDC-funded HIV prevention and housing assistance for people living with HIV.

Federal spending on domestic HIV-related activities rose modestly in 2011, to \$20.5 billion from \$19.6 billion the previous year. This slight uptick in spending resulted from increased Medicaid and Medicare outlays for HIV-related care, as most discretionary HIV programs for care, housing, prevention and research were flat-funded.<sup>7</sup>

Funding shortfalls represent a particular threat to national efforts to promote the health and well-being of people living with HIV and to capture the prevention potential of antiretroviral treatment. As 2011 drew to a close, it was

## Bringing Surveillance Data to You

A new project at Emory University is working to enhance the dissemination and usefulness of the wealth of surveillance data collected on HIV. The AIDSvu project provides dynamic, pictorial maps that vividly communicate the concentration and distribution of HIV.

These maps—several of which are highlighted in this report—not only aid in communication of basic epidemiological trends, but will also support state and local efforts to target limited resources where they are most needed. AIDSvu resources—which will be expanded and updated throughout the year—are available at AIDSvu.org



**Black gay and bisexual men ages 18 to 29 are the only population in which there was a statistically significant increase in HIV incidence from 2006 to 2009.**

estimated that more than 6,500 people in need of life-saving HIV treatment were on waiting lists for the AIDS Drug Assistance Program (ADAP). The total number of Americans on ADAP waiting lists peaked in September at 9,298. This number has been declining in subsequent months, but not necessarily because people are getting the drugs they need. Some states are shrinking their waiting lists by simply restricting eligibility or closing the lists, effectively depriving some waitlisted individuals of access to the program at all.

On World AIDS Day, President Obama announced plans to allocate an additional \$50 million for HIV care and treatment programs. In addition to providing an additional \$35 million for ADAP, the Obama administration pledged to increase funding to link people living with HIV to specialized HIV medical clinics.

## HIV Testing

Some signs of progress were visible on national efforts to promote widespread knowledge of HIV status. In 2011, CDC estimated that 20 percent of all people living with HIV in 2008 had yet to be diagnosed<sup>8</sup>—down from an earlier 2006 estimate of 24 percent.

However, even though one in five people with HIV remains undiagnosed, a national survey in 2011 found that HIV testing rates in the U.S. have remained flat since 1997.<sup>9</sup> Black Americans are more likely to be tested for HIV, with 43 percent of non-elderly Black people reporting a recent HIV test, compared with 24 percent of non-elderly Latinos and 15 percent of non-elderly whites.

Black America continued its work to build support for HIV testing in 2011. Marketing campaigns such as “Testing Makes Us Stronger,” which focused on Black gay and bisexual men, and “Keep It 100,” which targets Black heterosexual men in New York City, worked to position knowledge of HIV status as a social norm in Black communities.

In 2011, the Greater Than AIDS campaign continued to urge increased testing. A joint project of the Black AIDS Institute and the Henry J. Kaiser Family Foundation and supported financially by the Ford Foundation, the Elton John Foundation and M-A-C AIDS Fund, Greater Than AIDS promotes testing, among other HIV-related messages, connecting the fight against AIDS to Black America’s historical legacy of collective action. Greater than AIDS continued to be the largest national social marketing effort targeting Black Americans.

CDC recommendations for routine HIV screening in health care settings remain imperfectly implemented. Although the number of non-elderly Americans reporting that their doctor has recommended an HIV test increased from 19 percent in 2009 to 29 percent in 2011, more than 70 percent of adults have not had HIV testing recommended by their health care provider.<sup>10</sup>

Federal policy on HIV testing continued to evolve in 2011. For the first time, competitive awards for Ryan White funds for HIV treatment and care services in heavily affected cities placed substantial weight on local efforts to promote knowledge of HIV status and link individuals to care and treatment services.

## HIV Prevention Policy

At the beginning of 2012, Congress took a major step back in the fight against AIDS by reinstating the ban on federal funding for needle and syringe exchange programs. Previously, President Obama had shown courage, leadership and commitment to science in lifting the longstanding funding ban. In reinstating these funding restrictions, Congress ignored both the overwhelming scientific evidence that needle exchange programs prevent new HIV infections without encouraging increased drug use, but also the advice of the federal government's leading scientific experts.

In 2011, CDC began implementing its groundbreaking 12 Cities Project, which seeks to intensify integrated programs for HIV prevention, treatment and care in the localities most heavily affected by HIV.<sup>11</sup> These cities—Atlanta, Baltimore, Chicago, Dallas, Houston, Los Angeles, Miami, New York, Philadelphia, San Francisco, San Juan and Washington, D.C.—together account for 44 percent of all AIDS cases in the U.S. An important element of the federal government's implementation of the National HIV/AIDS Strategy, the 12 Cities Project builds on CDC awards for Enhanced Comprehensive HIV Prevention Plans under the Affordable Care Act. Each of these 12 jurisdictions have used additional CDC funding to articulate plans to strengthen HIV prevention, focusing resources on the populations and geographic areas most heavily affected by the epidemic.

Efforts to promote sound HIV prevention policy continue to be undermined by inadequate funding. In 2011, prevention programs accounted

for only four cents of every dollar spent on HIV-related services by the federal government.<sup>12</sup>

## Mobilizing Black Communities to Fight AIDS

There was a notable upswing in grassroots organizing on AIDS in Black communities in 2011. Building on momentum from the Act Against AIDS initiative, numerous groups punched up their activities in 2011, including the Black Treatment Advocates Network, Black Gay Men's Network, National Black Gay Men's Advocacy Coalition and National Black Justice Coalition. As always, the Black AIDS Institute remained visible at key community events, such as the Essence Music Festival, the NAACP's national convention and Black Gay Pride events around the country.

Although many Black organizations and institutions are becoming more active in the AIDS fight, there are signs that the visibility of HIV/

## NAACP Leadership on AIDS

**I**n 2011, the NAACP intensified its leadership on AIDS. The organization convened focus groups of faith leaders in 10 high-burden cities to explore new ways to strengthen community efforts on HIV/AIDS. At the annual NAACP convention, more than 200 participants attended a symposium on HIV and other health issues, which included the three living Black Surgeon Generals, Vice-Admiral Regina Benjamin, Dr. Joyce Elders and Dr. David Satcher.

NAACP joined with experts at Harvard University to host an historic two-day meeting on the "forgotten epidemic" of HIV among African Americans, which included a day of Capitol Hill visits to remind decision-makers of the need for action on AIDS. In addition, NAACP awarded grants to seven community organizations for HIV education, screening, prevention, testing and awareness initiatives.



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

AIDS is declining in Black America. According to a national survey in 2011, the percentage of Black people who report having seen, heard or read “a lot” about the epidemic in the past year declined to 26 percent, from 62 percent in 2004.<sup>13</sup>

Misunderstandings about HIV potentially undermine Black America's ability to respond effectively to the epidemic. Among Black people surveyed in 2011, nearly one in three believed that a cure or a preventive vaccine is currently available. One in five Black Americans report being uncomfortable working with someone who is HIV-positive, and Black people are notably more likely than whites or Latinos to express discomfort having food prepared by someone who is living with HIV.<sup>14</sup> These findings underscore the continued need to invest in community awareness and HIV science literacy programs in Black communities to build a strong foundation for a robust and sustainable AIDS response.

## Protecting Women: The Latest on Microbicides

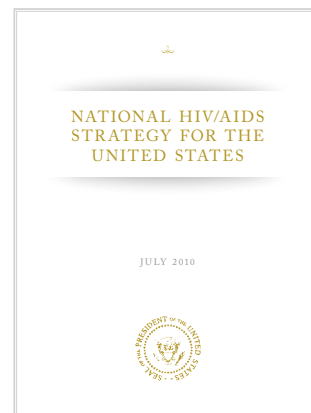
A major shortcoming of HIV prevention efforts has been the shortage of prevention tools that women can control and initiate on their own. The need for a wider range of proven prevention methods for women is especially critical in Black America, as Black women account for 57 percent of all diagnoses of HIV infection among females in the U.S.<sup>15</sup>

Hopes for development of a safe and effective vaginal microbicide gel to prevent HIV transmission among women surged in 2010, as South African researchers reported that an antiretroviral-based topical microbicide reduced the risk of HIV transmission by 39 percent in a cohort of African women.<sup>16</sup> In November 2011, however, one arm of a major international study of a daily antiretroviral-based microbicide gel was halted after study data failed to find evidence that the product was effective in reducing HIV infection.<sup>17</sup>

While expressing disappointment with the results, scientific experts and microbicide advocates insisted that the 2011 trial results did not represent the end of the line for microbicide research. Additional studies, including a major trial in South Africa, are ongoing to assess various microbicide products and diverse delivery methods. In addition, the trial that terminated the microbicide component is continuing to study oral administration of antiretrovirals to determine whether women are protected from infection.

## A New Prevention Tool: Pre-Exposure Prophylaxis

In 2011, two separate studies found that pre-exposure administration of antiretrovirals significantly reduces the risk of HIV transmission in heterosexual couples.<sup>18</sup> These findings follow 2010 study results documenting a significant reduction in transmission among men who have sex with men with pre-exposure prophylaxis.<sup>19</sup> In 2011, CDC issued interim guidance on use of pre-exposure prophylaxis among men who have sex with men.<sup>20</sup>



Although these research results prompted considerable excitement in the HIV field, important questions remain regarding the ultimate impact of this research advance. Pre-exposure antiretroviral prophylaxis is considerably more expensive than the typical HIV prevention method, and it is

widely recognized that its universal use is unfeasible. For which groups would roll-out of pre-exposure prophylaxis be most appropriate? Will it be possible to convince healthy people to take a pill on a daily basis to avoid infection? Will users of pre-exposure prophylaxis adhere to the daily regimen? Who will pay for the intervention?

To answer some of these questions, pilot projects are being rolled out in San Francisco and Miami.<sup>21</sup> Given the extraordinarily high risks of transmission experienced by young Black gay men, it is critical that pilot projects assess efforts to roll out this new prevention intervention in this heavily affected population. Involving Black communities in efforts to promote and deliver pre-exposure prophylaxis is essential.

In the meantime, research is ongoing to explore the possibility of intermittent (or non-daily) pre-exposure antiretroviral prophylaxis.

## **Implementation of the National HIV/AIDS Strategy**

The Obama administration continued efforts to implement the country's first-ever comprehensive HIV/AIDS strategy. In addition to hosting regional consultations that attracted hundreds of AIDS advocates around the country, the administration proposed in its Fiscal Year 2012 budget to reallocate 1 percent of all domestic HIV spending to create a \$60 million fund to support collaborative initiatives to advance the goals of the National HIV/AIDS Strategy. This proposal was rejected by Congress.

A major change in the administration's leadership team for implementation of the strategy was announced in late 2011, when Jeffrey Crowley disclosed that he was leaving his position as director of the Office of National AIDS Policy. In his nearly three-year term, Crowley oversaw the development of the National HIV/AIDS Strategy and key departmental operational plans, bringing thoughtful and dynamic leadership to the job and working hard to involve all parts of the AIDS community. At publication time, the administration was still searching for a replacement for Crowley.

## **Moving Toward Universal Health Coverage**

In 2011, the country continued a step-by-step implementation of the Patient Protection and

Affordable Care Act, otherwise known as health care reform. The legislation, which is projected to bring health coverage to more than 30 million Americans who are uninsured, is due to be fully implemented by 2014.

However, a number of challenges to the legislation have emerged, including a legal challenge to the law that the Supreme Court is set to review later this year. The Supreme Court will decide whether the law's individual insurance mandate is constitutional and, if so, whether the entire health care reform bill must be invalidated. It is anticipated that the Supreme Court's decision, arguably the most important it has issued in decades, could emerge this summer, in the midst of the Presidential election.

In the meantime, the Obama administration has moved forward to implement health care reform. In addition to implementing regulations and offering guidance on coverage requirements for health insurance policies under the legislation, the administration issued waivers to more than 1,000 companies, giving them a one-year reprieve in implementing certain of the law's insurance requirements.

All people living with HIV—and especially HIV-positive Black Americans—have an important stake in the ultimate fate of health care reform. Seventy percent of people living with HIV are low-income and typically unable to purchase health coverage on their own.<sup>22</sup> Black Americans and other people of color are more likely than whites to lack health coverage.<sup>23</sup>

New findings on the extraordinary HIV prevention benefits of antiretroviral therapy merely underscore the importance of universal health coverage. People living with HIV need ready access to affordable, high-quality medical care—not only for their own health, but also to minimize the risk of onward HIV transmission.

## **The Global AIDS Response**

The trend toward recent declines in the annual number of new HIV infections worldwide has appeared to stall, as UNAIDS and the World Health Organization reported in December 2011 that 2.7 million people were newly infected in 2010.<sup>24</sup> There was good news to report, however, as the number of AIDS deaths fell to 1.8 million, down from 2.2 million in the mid-2000s. An estimated 6.6 million people in developing countries were receiving antiretroviral therapy as of December 2010, and coverage for services

to prevent mother-to-child transmission approached 50 percent.

In 2011—one decade after the global community united to embrace the first set of time-bound targets in the HIV response—countries convened again at the United Nations to adopt a new set of goals. The U.S. joined with other countries around the world to pledge action to reduce sexual transmission of HIV by 50 percent by 2015, to eliminate new HIV infections in children and to ensure that within four years 15 million people are receiving antiretroviral therapy.<sup>25</sup>

However, funding uncertainties threaten the ability to continue, and to build on, recent successes. In 2011, global HIV spending flattened at \$16.6 billion, and international HIV assistance actually declined.<sup>26</sup> Especially disturbing was the decision by the board of the Global Fund to Fight AIDS, Tuberculosis and Malaria to cancel a planned 11th competitive funding round for 2012, which resulted from an acute funding shortfall.

U.S. financing for global HIV programs remained stable in 2011. Speaking on World AIDS Day, President Obama declared, “Make no mistake, we are going to win this fight. But the fight is not over—not by a long shot.” The President pledged that PEPFAR would reach at least 6 million people with antiretroviral treatment by the end of 2013—2 million more than are currently served by the program—and support 4.7 million male circumcisions to prevent HIV transmission in sub-Saharan Africa.

The new targets unveiled by the President followed the launch by Secretary of State Hillary Clinton in November 2011 of a new PEPFAR prevention strategy that prioritizes HIV treatment for HIV prevention, scale-up of adult male circumcision and elimination of mother-to-child transmission. The new strategy will not involve substantial new funding but instead rely on reallocation of resources in PEPFAR-supported countries.

## Looking Toward AIDS 2012

Planning began in earnest in 2011 for the upcoming International AIDS Conference in Washington, D.C., the first in the U.S. in more than two decades. Convened by the International AIDS Society, the conference is expected to draw more than 20,000 participants and serve once again as the most important HIV-related scientific gathering in the world.

A committee of local partners is helping guide conference planning. Local partners for the conference include the D.C. Department of Health, the White House, the Black AIDS Institute, the U.S. Positive Women’s Network, the National Institutes of Health and the HIV Medicine Association of the Infectious Diseases Society of America, among others. (A separate chapter in this report specifically focuses on the conference and why strong participation by Black America is essential.)

## Women’s Health Policy

HIV has highlighted the health system’s shortcomings with respect to women’s health, as a disease that was initially almost exclusively concentrated among men has posed an increasing burden on women and girls. Globally, half of all people living with HIV are women.

Important women’s health policy matters took center stage in 2011. The Obama administration announced that health insurers would be required under the Affordable Health Act to provide free coverage for birth control and other health tests for women. In December 2011, Health and Human Services Secretary Kathleen Sebelius took the unprecedented step of overruling the Food and Drug Administration, barring FDA from permitting over-the-counter sales of the emergency contraceptive Plan B.

## LGBT Rights

It has long been clear that advances against AIDS require progress toward ensuring equal rights and non-discrimination for lesbian, gay, bisexual and transgender people. 2011 turned out to be a landmark year in the history of gay rights.

In the summer of 2011, New York became the largest state to extend married rights to gay and lesbian couples. Also in 2011, a federal judge invalidated California referendum results that overturned a California Supreme Court decision permitting gay marriage. The Obama administration came out in favor of repeal of the Defense of Marriage Act, which allowed states to disregard marriages of gay couples performed in other states, and also said it would no longer defend the legislation against legal challenges.

AIDS advocates have long decried the role of institutionalized homophobia in undermining a sound, effective response to AIDS. In 2011, a major source of institutional discrimination

was removed, as the U.S. military dropped the so-called “Don’t Ask, Don’t Tell” policy, openly welcoming gay and lesbian people to serve in the military.

Confronting the growing concern of AIDS advocates regarding official homophobia in many countries heavily affected by the epidemic, the Obama administration announced its intention to prioritize gay rights in its international diplomacy. In a speech in Geneva that surprised the diplomatic community and delighted advocates for a rights-based AIDS response, Secretary of State Hillary Rodham Clinton called for the LGBT community to be given full and equal recognition and protection under international human rights protocols.

\* \* \*

In looking toward 2012, the record from 2011 offers both unprecedented opportunities and extraordinary challenges. We now have the tools to end the AIDS epidemic, and the country continues to advance toward the long effort to expand health coverage to those who lack the ability to pay. But federal budget-cutting threatens to undermine our ability to put new HIV-fighting tools to use, and legal challenges potentially imperil national efforts to reform our broken health care system. As an election looms that will place these issues front and center on the national agenda, it is clear that 2012 will serve as an important milestone in the national fight against AIDS.

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Carlton Jeffery

# Ending AIDS

## Priority Recommendations for Urgent Action

**Mindful of the historic opportunity to end AIDS through strong, evidence-based action, the Black AIDS Institute submits the following recommendations and urges their immediate implementation:**

**Concerted, unprecedented action is needed to ensure that all Black Americans know their HIV status as early as possible.**

- A national emergency initiative to close the HIV testing gap should be implemented, with at least \$757 million dollars in new funding allocated to this effort.

- CDC should collaborate with pharmaceutical companies, media companies and affected communities to implement a major community effort to market HIV testing to Black communities and other communities most heavily affected by HIV.

- CDC should intensify outreach and collaboration with professional medical associations and state and local health departments to increase adherence to recommendations for the routine offer of HIV testing in medical settings.

- As part of the above-noted national testing initiative, intensified support should be provided to non-clinical venues for free and rapid HIV testing, such as motor vehicles offices, other public agencies, community centers and the like.

- Medicare performance indicators should be established for hospitals and other health care

sites to increase HIV testing rates.

- Black celebrities, opinion leaders, faith-based leaders, community leaders and grassroots activists should work toward establishing knowledge of HIV status as an essential community norm in Black communities.

### At a Glance: Priority Recommendations for Urgent Action

- Concerted, unprecedented action is needed to ensure that all Black Americans know their HIV status as early as possible.

- All people who test HIV-positive should be ensured ready and timely access to comprehensive medical care, including antiretroviral therapy.

- A new approach to HIV prevention, coupling measures to reduce HIV exposure with interventions to reduce the odds of HIV acquisition, should be immediately implemented.

- Black communities need to take steps to serve as essential partners in the quest to end AIDS in Black America.

**All people who test HIV-positive should be ensured ready and timely access to comprehensive medical care, including antiretroviral therapy.**

■ CDC should collaborate with its other federal partners and with state and local health departments to undertake priority operational research to identify improved strategies for verifiably linking people who test HIV-positive to ongoing medical care.

■ The Health Resources and Services Administration should accord substantial weight to reductions in HIV-related unmet need for primary care in making awards to states and localities under the Ryan White CARE Act.

■ The Affordable Care Act should be fully and timely implemented.

■ Immediate steps should be taken to eliminate all waiting lists for AIDS Drug Assistance Programs, ensuring access to antiretroviral therapy for all HIV-positive people with CD4 counts of 550 or below. Warning criteria should be put in place to flag potential



**Marvelyn Brown**

funding shortfalls, and appropriators at the federal and state levels should take immediate action to prevent any individual from being placed on an ADAP waiting list.

■ Through Ryan White and/or new funding opportunities associated with the Affordable Care Act, substantial new funding should be made available for peer-based retention-in-care and treatment adherence programs.

■ Priority should be given to enhanced funding for community-based initiatives to build strong, durable HIV science and treatment literacy in Black communities.

**A new approach to HIV prevention, coupling measures to reduce HIV exposure with interventions to reduce the odds of HIV acquisition, should be immediately implemented.**

■ Demonstration projects for pre-exposure prophylaxis should be rapidly expanded, with particular focus on diverse Black populations (including heterosexuals and men who have sex with men). Results from these projects should inform the development and implementation of focused efforts to bring pre-exposure prophylaxis to those who need them.

■ Research needs to be vigorously pursued on diverse avenues for pre-exposure prophylaxis, including intermittent (i.e., non-daily) administration and topical application.

■ Building on lessons learned from its 12 Cities Project, CDC should intensify efforts to require state and local health department grantees to target scarce prevention resources to the populations and geographic settings most heavily affected by HIV.

■ The Obama administration and Congress should collaborate to approve substantial new funding for evidence-based HIV prevention services.

■ Congress should immediately repeal its recent reinstatement of the ban on needle and syringe exchange.

■ Following through on the spirit of the National HIV/AIDS Strategy, the administration should ensure smooth and seamless coordination and collaboration between diverse federal agencies involved in the HIV response, with the goal of establishing a single, results-driven continuum of HIV services.



**Black communities need to take steps to serve as essential partners in the quest to end AIDS in Black America.**

■ Black AIDS organizations should immediately establish strong and meaningful collaborations with medical homes to prepare to support efforts to optimize treatment as prevention.

■ Black organizations engaged in HIV/AIDS work need to undertake immediate strategic organizational reviews, with the aim of re-tooling to intensify expertise and

preparedness to support HIV testing, linkage to care, treatment access, retention in care and treatment adherence.

■ Black leaders from all walks of life—from the grassroots level, to churches and other Black institutions, to Black media, to elected representatives—should strengthen leadership and commitment on HIV/AIDS, recognizing the critical moment of opportunity to end the AIDS epidemic through concerted action.



Jason George

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 focuses on training, mobilizing and networking. The only collaboration of its kind, it links Black Americans with HIV with 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 stu-

dents 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.



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