The Fire This Time

After years of indifference, the nation's African-American leaders are finally tackling the epidemic in their midst.

January 1, 1999 By Esther Kaplan and LeRoy Whitfield

Last March, the federal Centers for Disease Control and Prevention (CDC) invited 33 leading African-American AIDS advocates to the lavish Wyndham Garden Hotel in suburban Atlanta. There they were offered an inside look at the CDC's latest African-American HIV initiative. It was a tough audience. Sandra Singleton-McDonald, for one, the founder and president of Outreach, a local Atlanta African American-run AIDS organization, had watched for more than 12 years as one CDC prevention strategy after another bottomed out on the toughest streets of Atlanta's black community. As the hours ticked by, marked by technical discussions of epidemiological reports and a distinct lack of urgency, Singleton-McDonald was underwhelmed. Finally she and the other frustrated participants called the dog-and-pony show to a close and headed for the door.

"We said, 'That's it, we can't do this,'" says Debra Fraser-Howze, president of the New York City-based National Black Leadership Commission on AIDS. "Our issues were far more urgent than those that we had been brought there to discuss." Within hours, Wyndham Garden was host to a second meeting about AIDS in the black community.

Huddled in the hotel lounge, seven of the dejected advocates worked late into the night drafting a list of demands for action from the federal government. Their "manifesto" was endorsed the next day by all 33 conference participants. At the top of the list was a meeting -- pronto -- with CDC acting director Claire V. Broome. And that wasn't all: They wanted the president of the United States to publicly declare AIDS in the black community a federal state of emergency.

To say such anger had been a long time in the making is an understatement. According to A. Cornelius Baker, executive director of the National Association of People with AIDS in Washington, D.C., himself an African-American PWA, "If you just look at the numbers, there's no question that there's long been a state of emergency." As far back as 1985, African Americans have accounted for at least a quarter of HIV infections, and that number is up to 40 percent now, despite the fact that African Americans make up only 12 percent of the U.S. population. African-American death rates have exceeded those of whites since at least 1983. *The New York Times* first took note of the black epidemic in 1985, and the first African American-run AIDS agencies began to emerge around that time. But ask Tracie Gardner, an advocate since 1987, when the public finally noticed the black epidemic, and she doesn't hesitate for a moment: "Magic Johnson." Gardner was at the Minority Task Force on AIDS in 1991, the year one of America's most famous basketball players

announced he had HIV, and “our phones were jammed” -- with not only media requests but many individuals scared out of their wits.

During these years African-American advocates had tough choices to make between following the money -- joining the staff of an established multimillion dollar AIDS service organization (ASO), founded and run mostly by white gay men -- or building a project from scratch in a resource-strapped community. Some, like Gardner, tried the former, only to throw up their hands and abandon such agencies for community groups where it seemed possible to integrate AIDS into a broader agenda -- not to create, in her words, “a black GMHC.”

Others launched AIDS organizations by and for local black communities. In 1987, Betty Smith founded Chicago’s South Side Help Center, which became the lone HIV service provider on the black side of this racially segregated city. Still, she says, “When it comes to funding in the African-American community, we have not been able to garner the dollars. When you look at the [predominantly white] North Side, there are services everywhere; in the South Side, there are none.” Her organization is notable for reaching, after 11 years, a million-dollar budget; the Howard Brown Health Center, the city’s main AIDS service provider, runs its HIV programs on more than five times that. On a local level, too few resources are stretched too thin. According to CDC rebel Singleton-McDonald, that’s one reason front-line providers “have not made the grass-roots push” to put AIDS at the top of the national black agenda.

From the beginning of the epidemic, few African Americans on the national scene did any better. Black elected officials, says California Democratic Rep. Maxine Waters, have been “under siege,” battling against drugs, teen pregnancy and unemployment, fighting for education, computer literacy and international aid all at once. “And we’ve had to stop two recent assaults on affirmative action,” says Waters. “We do all of that and then to take time to become [AIDS] experts and to try and mount a campaign to put pressure on is very difficult.”

Phill Wilson

Phill Wilson is the director of the AIDS Social Policy Archive at the University of Southern California,

a longtime associate of Waters and easily LA's most outspoken African-American PWA. "Have black legislators dropped the ball?" he asks. "Absolutely. But by and large their constituencies haven't been asking them to do this. The people who have dropped the ball, criminally so, are the civil rights organizations."

Indeed the NAACP, the nation's premier civil rights organization -- with the power to set the community agenda -- was, until recently, out of touch with the epidemic. Emphasizing its role as a "rights" organization, not a service provider, the NAACP has passed a series of statements and resolutions about AIDS since the late '80s, asking most recently, in 1997, according to current chair Julian Bond, "that there not be a stigma associated with AIDS." But with a lone paid health staffer at a national office wracked by leadership scandals and yawning debt, there has been little money and less will to back up such pronouncements. Among its few dubious accomplishments was a 1993 teen prevention pamphlet whose just-say-no message included such lines as "There's no such thing as safe sex."

By 1994, Mario Cooper, then chair of the AIDS Action Council, a national lobbying group in Washington, D.C., felt something had to be done to "calibrate up the response, to claim ownership of this epidemic in the black community." When Cooper, a Washington insider, began to make his rounds -- to African-American pols and major civil rights groups such as the NAACP and the Urban League -- "the response was horrible." "We're very concerned," he was told again and again, "but this isn't really our issue." Cooper, a black PWA himself, recalls the tension that would invade meetings when he disclosed his status. "I left more than a couple with tears in my eyes," he says. "It was a reality check on where some of our leaders were."

Yet Cooper kept at it and, within 18 months, had obtained a Kaiser Family Foundation grant and a home for his new organization at Harvard University. Leading for Life, founded to make noise about AIDS among African-American leaders nationwide, was launched in October 1996. The opening conference boasted intellectual celebrity Henry Louis Gates of Harvard's W.E.B. DuBois Institute along with the CDC's HIV prevention director Helene Gayle and then-CDC head David Satcher, the two top African-American health officials in the country. In his opening remarks, Gates let loose: "This is an historic gathering and a call to arms against a disease that is ravaging our community," he said. "AIDS is our generation's war."

Within a month of last spring's CDC blow-up, the advocates -- dubbed the "Palm Sunday Group" after the date of a key meeting -- had solicited the help of the Congressional Black Caucus, the 39-member political force on Capitol Hill whose inner-city constituents reflect the bulk of AIDS statistics. Enter fiery Black Caucus chair Maxine Waters, who would soon find herself well-positioned to wield influence on a distressed Clinton administration. Though still denying in late spring that he had an affair with "that woman," the president was soon to become notably dependent, in the wake of the Starr report, on the support of Democratic Judiciary Committee members like Waters and on the Black Caucus' very public loyalty. Waters, for whom the epidemic hits close to home -- her sister in New York City, she says, is "very ill" from AIDS -- "took this issue and put force and power behind it," says Singleton-McDonald. "She wasn't ever going to back down."

By May 11, the Black Caucus had advanced -- but also softened -- the Palm Sunday Group's demands. At a high-profile Washington press conference, Waters ratcheted down the call for Clinton to declare AIDS in the black community a "state of emergency" to a request that Health and Human Services Secretary Donna Shalala announce a "public health emergency." (Such a decision is not completely without precedent: In 1987, for example, $30 million was dispersed from a "Public Health Emergency Fund" to pay for AZT medication for Americans who couldn't afford it.) Additional work by Waters and long-time Ohio Democratic Rep. Louis Stokes led to AIDS topping the agenda at the Black Caucus' annual legislative conference in September.

What had provoked so bold a move from the once-timid caucus? Cooper's Leading for Life had played a part by raising the profile of AIDS in the community, gathering together a high-profile steering committee including sports stars Magic Johnson and Alex English, academics Gates and Alvin Poussaint, and leaders of the NAACP, the Urban League and the National Medical Association (the black doctors' group). The determination of those whom Cooper calls "the heroes working at community organizations, out there alone, without support" was essential, as was the shock of steadily rising AIDS statistics among people of color at a time when the mass media were crowing about the end of AIDS. In fact, AIDS continues to be the leading cause of death among all African Americans aged 25 to 44. "As [elected officials] walk their districts now," says Cooper, "they have to see it." But it took an unlikely force for the issue to reach critical mass. The national black church organizations, as Cooper says, may "have failed to lead on this issue," but local African-American churches had begun to move.

Jeremiah Wright, pastor of Chicago's Trinity United Church of Christ, is one of a handful of clergy nationwide who responded to the epidemic early on when it hit their congregations. He recalls sitting on the floor of a congregant's empty apartment in 1982 after the man's wife had left with the children and the furniture upon learning he had AIDS. He says, "At that point, we formed an AIDS ministry."

In the years that followed, Wright says, "theological differences, homophobia and denial" combined to prevent any collaborative efforts among local African-American churches. He recalls one pastor who, when asked whether he had an AIDS ministry, answered, "No. And I don't have an adultery ministry either. Or a ministry for liars." Another pastor told Wright that he could have laid hands on an HIV positive congregant and healed him not only of his AIDS but of his homosexuality. To that, an exasperated Wright could only respond, "Can I heal you of your blackness?"

Julia Walker, communications director of the faith-based AIDS organization The Balm in Gilead, says that Wright is one of the all-important progressive ministers who have chosen to push the issue within their congregations. Others, she adds, have had to be pushed. Balm in Gilead, based in New York City -- but with 26 affiliates nationwide -- was started 10 years ago when founder Pernessa Seele, then a Harlem Hospital immunologist, noticed a problem on the wards. Unlike those gravely ill with cancer or heart disease, PWAs were dying with no pastor at their sides. Seele set out with a list of Harlem's 350 churches and didn't stop knocking on doors until she had contacted every one.

Balm in Gilead now distributes HIV-related liturgy and educational materials, and organizes a national “Week of Prayer for the Healing of AIDS.” The staff there knows that “seeing what their idols are doing” is what channels nervous clergy, and so they distribute audiotapes of AIDS addresses by the likes of Reverend James A. Forbes, of New York City’s historic Riverside Church, and evangelical powerhouse Bishop T.D. Jakes of Dallas. In 1994, the group got dozens of major national church groups to sign on to its “African-American Clergy Declaration of War on AIDS.”

Balm in Gilead has done all of this without some of the nation’s most prominent black clergy on board. “The Southern Christian Leadership Conference [the religious home base of the civil rights movement of the ’50s and ’60s],” Walker says delicately, “under the noble leadership of this important young man, Martin Luther King III, has been slow.” When King finally commented on the epidemic last July, he said it was not among his top priorities -- though he did note that “the only way is abstinence.” When asked about Clinton family spiritual adviser Jesse Jackson, Walker laughs. “He has not really been at the forefront,” she says. Of the nation’s best-known black clergy, Walker says Cornel West has been the most outspoken on AIDS.

The Nation of Islam (NOI), too, has had a mixed record on AIDS, including its controversial endorsement of the experimental drug Kemron. Although the NOI’s attention to the epidemic has been high-profile, many community leaders have faulted the group’s advancement of conspiracy theories about HIV infections and conventional treatments, as well as Minister Louis Farrakhan’s open homophobia. (King, Jackson and the NOI did not return phone calls from *POZ.*)

Still, Balm in Gilead, and local ministers like Wright in Chicago and Reverend Carl Bean, founder of the Minority AIDS Project in LA, have been encouraging clergy to take a stand. “When [black elected officials] see a minister speak out on the issue, it opens up some space for them to be out front on it,” says Cooper.

“One thing we say all the time is when you talk about mobilizing the black community, you’re talking about mobilizing the black church,” says Walker. “And when we get someone like T.D. Jakes to say AIDS is an important issue, that counts a lot.”

If African-American AIDS advocates were angry going into the Black Caucus’ much-hyped September 16 legislative conference, they only felt worse afterward. Shalala, citing “scheduling conflicts,” failed to appear, and Satcher, now surgeon general, followed suit. With an audience of nearly 1,500 African Americans, including civil rights movement legend Rosa Parks, and a live broadcast to historically black colleges nationwide, the HHS secretary appeared only via pretaped video, speaking down from a pair of towering screens to polite applause. This may have been an easy out, given that her talk was so long on solidarity and so short on action: No public health emergency was declared for the black community (“this is a crisis for every American,” she said), and only $4.9 million was offered up to black AIDS programs for fiscal year ’98.

“I can tell you right now,” said panelist Fraser-Howze, “that’s a $4.9 million allocation to a $4.9 billion problem.” An anxious Rep. Stokes quickly noted that money negotiations with HHS were still in progress.

A month later, what was more remarkable than the fact that an impeachment-obsessed Congress passed a 1999 budget at all was a historic allocation for AIDS contained within. Cobbled together from general appropriations monies and HHS discretionary funds, $130 million -- over and above the $4 million already allocated for AIDS -- was earmarked specifically to expand HIV prevention, substance abuse programs and treatment access in African-American communities for 1999. Fraser-Howze, for one, was floored. Finally a significant federal commitment had been won. “Never in the history of the epidemic has anybody successfully negotiated $130 million like this,” she said. “This is the start of a revolution.”

Fraser-Howze’s remark may seem a bit breathless in retrospect, but even a sober activist like Wilson believes that, due to intensive closed-door work by black AIDS advocates, most of those millions will make it into the hands of black-run groups -- a significant windfall. Equally important in the months between the Black Caucus’ first big May press conference on AIDS and the October victory, there were signs of a growing community response. At the NAACP’s national convention in Atlanta last July, with the Black Caucus conference fast approaching, Bond, the group’s chair, stated that the NAACP would step up efforts in the fight for equal distribution of AIDS services. “We have a history of activism against AIDS...but much, much more needs to be done,” he said in a July speech before 3,500 NAACP members. “AIDS has become a black epidemic.” Then, in a letter to *The New York Times,* NAACP President Kweisi Mfume pointed to his group’s recent “Outrage over AIDS” march, saying efforts like this have “set the direction” for programs at each of their more than 2,200 branches.

In August, both the National Medical Association and Delta Sigma Theta, a black sorority, issued statements vowing more action on AIDS. Perhaps most promising, less than two weeks after the close of the Black Caucus’ September conference, the CDC announced, for the first time, a cooperative agreement (a partnership that conveys both prestige and funding) with an African-American AIDS organization -- Balm in Gilead.

Singleton-McDonald, measuring the amount of money against the scale of the epidemic, calls it only “a beginning step.” It has become almost received wisdom that, as she says, “white gay males did a good job of mobilizing quickly” around the epidemic, and African Americans did not. But the black community won this financial commitment -- upped to $156 million (some of which will go to Latino groups as well) on October 28 by Clinton at a press conference where he said, “We must use all our power to end the growing disparities in HIV and AIDS” -- in a year when mainstream AIDS organizations, even behemoths like GMHC and AIDS Project Los Angeles, suffered declines in both donor giving and overall budgets.

According to Daniel Zingale, a white gay man and the executive director of DC’s AIDS Action, “The strongest leadership in the fight against the epidemic is now coming from the black community.”

Local leaders like Wright are poised to take advantage of the moment. With little prompting, he spouts off an action plan as if he’s rehearsed it many times: “Local leadership should work collaboratively to present forums, seminars and workshops once or twice a year. In addition to churches, civil rights organizations need to have it front and center at every single one of their

meetings. Traditional leadership need to be the ones to raise it with the school boards, principals and local school councils. And our sports and music figures and radio personalities need to publicly come out to educate people." The impatience in his voice has been years in the making.

Waters, too, has grown tired of hearing, "Why don't you do something about AIDS?" She is tired of people "who don't feel a sense of their own power" sitting around and "waiting for Jesse Jackson. If we took our individual power and pooled it, we could really do a lot," she says. "If we had thousands of people who are involved in the AIDS issue faxing Donna Shalala and the president while I'm in the back room cussing people out, then we'd get something done."

Wilson, speaking on the afternoon of President Clinton's self-congratulatory announcement of the funds, agrees: "No one has yet found a way to energize the community itself. There have been a gazillion 'moments'" like this Black Caucus victory, he says. "But it's only a big deal if there's a force to continue it. We need to always be asking the question, 'What's the next step?'"

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