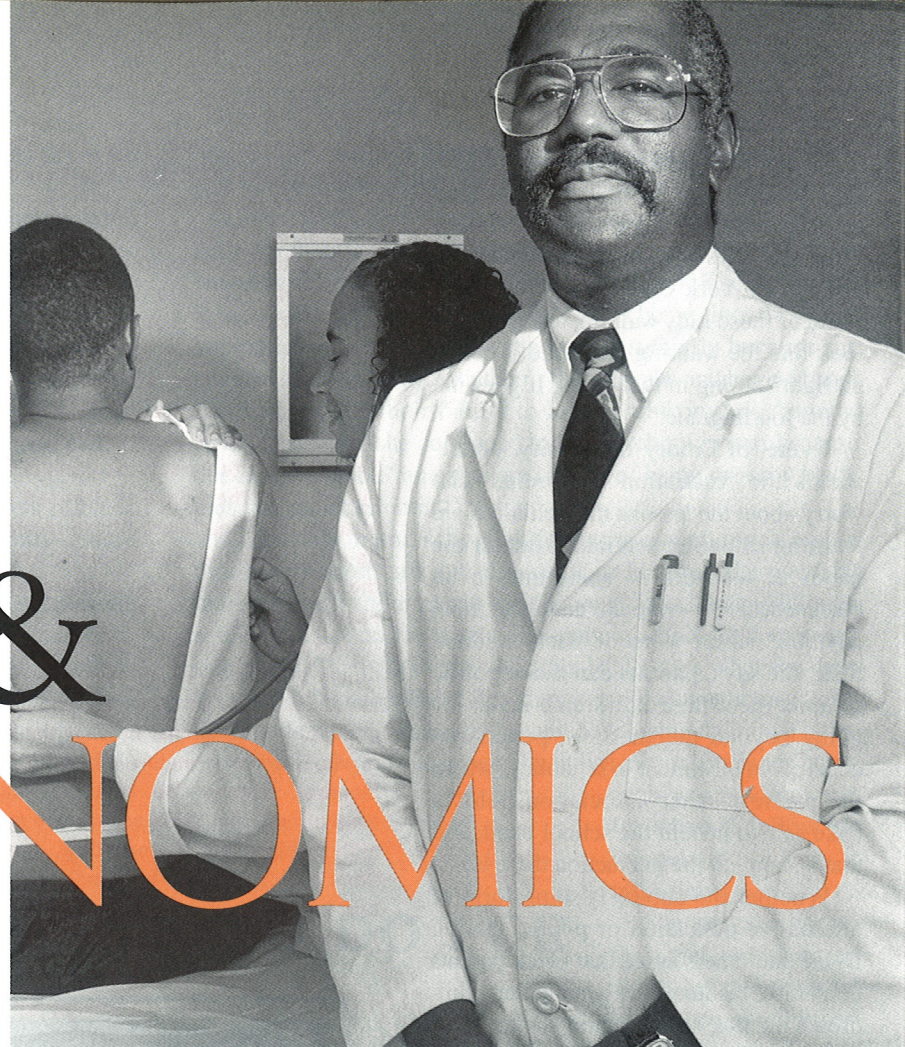


# Race, AIDS & ECONOMICS



Dr. William Alexander is director of the AIDS clinic at Atlanta's Southside Health Care Center.

By Shirley L. Smith

As the number of minorities infected with AIDS continues to increase at an alarming rate, there is a growing concern over the funding disparities that have existed since the epidemic was first noted in 1981.

Funding disparities can be found on every level -- from AIDS prevention and education to services, minority AIDS workers and physicians say. But nowhere is the disparity more evident than in the area of research.

There are very few minorities involved in research, particularly in the area of clinical trials. In 1993, clinical trials in humans constituted about \$176 million, or 38 percent of the National Institute of Allergy and Infectious Diseases' (NIAID) \$459 million research budget.

NIAID, the lead governmental agency for AIDS research, has three extramural programs that use trials to test new drugs and evaluate experimental therapies for AIDS and AIDS-related opportunistic infections and cancers. The largest of these trials are conducted under the AIDS Clinical Trials Group, a nationwide network of AIDS Clinical Trial Units (ACTUs) established at major academic institutions.

African-Americans have historically been underrepresented in such trials, both as active participants and as leaders in research. Of the 57 ACTUs, only four are at minority institutions: Howard University, Meharry Medical College, University of Puerto Rico and the University of Hawaii.

Minorities were also poorly represented in early studies of AZT, DDI and DDC -- the only licensed drugs used to fight HIV infection from 1987 to 1992. Another AIDS drug, D4T, was approved by the Food and Drug Administration in June. But, as with its predecessors, the test trial (privately sponsored by Bristol-Myers Squibb) that led to D4T's approval included few minorities.

Although the government admits there have been some clear disparities in minority participation in clinical research, officials at NIAID say progress is being made. "We are by no means where we would like to be," says Dr. George W. Counts, who headed up the agency's Clinical Research Management Branch for five years. But, he says, NIAID is making more of an effort to reach out to minorities.

Of the 14,499 people who participated in clinical trials for new AIDS drugs in 1993, African-Americans and Hispanics accounted for 42 percent of the patients. This is a marked

improvement from 1987, when the trials began with only 18.7 percent minority participants, 7.4 percent of whom were African-Americans.

Dr. Counts believes the relative lack of minority participation in the '80s reflected the demographics of AIDS at the time. "In 1985, '86 and '87, we were falling off the legacy that this was a gay disease." Hence, the trials consisted mostly of gay white men.

But some AIDS-treatment advocates and physicians contend that there were reports early in the epidemic that AIDS was spreading in black populations, but the government did not respond to those reports.

"AIDS was misidentified early in the epidemic as somehow related to homosexuality, and funding decisions were made to funnel all the money in that direction," says Dr. Abdul Alim Muhammad, director of the Abundant Life Clinic in Washington, D.C. As a result, he points out, minorities were not included

**"PEOPLE HERE live in RAT-INFESTED environments and they can't PAY RENT, and YOU'RE TALKING about getting involved in CLINICAL TRIALS."**

in critical studies and very little money was pumped into our communities for prevention and AIDS-related services.

If minorities had been informed of their risks from the beginning, we would have been able to mobilize and organize early in the epidemic like the white gay community, says Alonzo Fair, president of D.C.'s United Response to Black America's Needs (URBAN), a research and technical assistance firm that focuses on health care and social issues affecting people in the inner city.

The global demographics of AIDS was never characterized by homosexuality, Dr. Muhammad asserts. "The whole public health policy surrounding AIDS has been flawed from the beginning. It's a very clear pattern of racial discrimination that has existed."

As early as 1983, African-Americans and Hispanics were reported as making up 40 percent of the AIDS cases, according to data compiled by the Centers for Disease Control and Prevention in Atlanta. The majority of these were homosexual and bisexual men.

Current CDC statistics reveal that homosexual contact is still the main mode of transmission for HIV infection in the United States, but the highest rate of increase in AIDS cases reported in 1993 was among heterosexuals. In this group, African-Americans represented 55 percent of the men infected and 50 percent of the women.

African-Americans and Hispanics are also disproportionately represented in the total number of U.S. AIDS cases. Of the 339,250 cases reported to the CDC as of October 1993, African-Americans accounted for 31 percent, even though we make up only 12 percent of the population. The numbers for Hispanics are just as alarming. People of Hispanic origin make up about 9 percent of the population, yet they account for almost 17 percent of reported cases.

One of the major obstacles health officials say they encounter when trying to treat minorities infected with HIV or recruit minorities into clinical trials is the deep-rooted mistrust of medical research and the government. "We have a long history that has to be overcome," Dr. Counts says.

"The legacy of the Tuskegee experiment is still present, and people view research with a jaundiced eye," says Dr. Wayne Greaves, referring to the Tuskegee Syphilis Experiment, a government study conducted from 1932 to 1972 in which hundreds of rural black men with syphilis were monitored -- but never treated.

Dr. Greaves, who runs the AIDS Clinical Trial Unit at Howard University, is the only black person leading an ACTU study. Even though Howard is a black institution, it has experienced difficulties recruiting minorities because of the legacy of the Tuskegee study, he says.

Another big obstacle that hinders recruitment efforts is eco-

nomics. The majority of the university's trial patients are African-Americans who fall in the low-income bracket, he says.

"People here live in rat-infested environments and they can't pay rent and you're talking about getting involved in clinical trials," Dr. Greaves says.

AIDS is often one of many problems facing African-Americans who live in urban areas. "In addition to being a medical facility, we find ourselves in a social-service capacity," says Viktoria Trimmer, research coordinator of the ACTU at Howard. "Our patients don't have any money. We find ourselves trying to access money to pay for rent, buy groceries."

The desperate need for health care in these communities has forced Howard and other minority institutions to put their emphasis over the years on care rather than research, Dr. Greaves says. Because the commitment was not there for research, the facilities don't exist and the schools did not attract minority researchers. Consequently, minority institutions often don't have the infrastructure they need to compete for federal dollars to do research.

Things have got to change, Dr. Greaves says. "All the things we know about black folks, about this disease, have been written by white researchers and white institutions. It's time that we now move to the next rung of the ladder. Because the disease affects us a lot, we need to be players and policymakers in the field."

Prior to the enrollment of the four minority schools into the ACTU program in 1993, white establishments monopolized all the research funds.

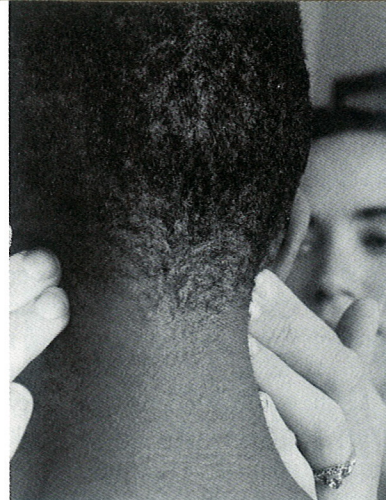
"Not one of the black schools, with the exception of Howard, has the resources to carry out a program independently," explains Dr. Rudolph Jackson, a professor at Morehouse School of Medicine and director of the Association of Minority Health Professions Schools AIDS Research Consortium.

In an effort to increase minority participation in clinical

research, NIAID awarded infrastructure grants to Howard University, the University of Hawaii and the University of Puerto Rico. The purpose of these grants was to develop the infrastructure of these universities so they could successfully compete for federal research money. No infrastructure money was awarded to Meharry, but it was able to enter the research program because it teamed up with Vanderbilt University.

In 1992, NIAID also attempted to bridge the gap by requiring each ACTU to establish a Community Advisory Board. The board is responsible for making sure the needs of the affected population at the respective sites are addressed, Dr. Counts says. NIAID also increased funding to existing ACTUs to help them reach out to communities of color, and it is collaborating with the National Institute on Drug Abuse to recruit inner-city drug users for trials.

In addition, NIAID is providing money to the consortium of minority medical schools headed by Dr. Jackson. The consortium consists of eight schools that have pooled their resources to build a foundation so they can better compete with white institutions for funding. The goals of the consortium are simple -- to



which have more access to private funds and more support systems to turn to, says Robert Vazquez, program director of the Minority AIDS Coalition, a nonprofit organization in Philadelphia.

The coalition, formed in 1992 by grassroots organizations in the city's African-American, Latino and Asian communities, provides technical assistance, training and funding to about 20 community-based organizations. Prior to its development, the coalition contends that the government only gave out a few token grants during the first decade

of the epidemic to agencies that specialized in HIV prevention activities. But no state, city or federal money was spent on building the capacity of minority organizations to provide direct HIV/AIDS services to minorities in Philadelphia. Today, obtaining local funding for HIV-related activities remains an uphill battle for minority organizations in Philadelphia, Vazquez says.

"People of color have traditionally been shut out," he says. "The funding is essentially controlled by a government which is essentially controlled by white men. When we try to access these funds, we have to deal with race and class issues.... We don't look like them or think like them."

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increase the number of minority researchers and the number of minorities with access to care and education and prevention programs. Since its inception in 1988, the consortium has recruited 69 new investigators into AIDS research and has published more than 40 papers in medical journals.

The consortium is also working with other universities to form partnerships, like the one between Meharry and Vanderbilt, that will allow them to become ACTUs. The partnerships will not give minorities the kind of leadership role they desire, but right now it's the only feasible solution, Dr. Jackson says.

Some AIDS-care providers say institutional racism is at the root of minorities' struggle for federal dollars. They say minorities have long been ignored by the government in the area of health care and education, and that the government has taken action only when compelled to. AIDS is no different.

The infrastructure within minority institutions, for example, is weak because the government has not committed much federal money to these institutions in the past, they say. The same goes for minority community-based organizations that provide education, prevention and services. They are all trying to play catch-up.


Minority organizations generally have smaller budgets and staffs, which puts them at a disadvantage when they have to compete for federal funds with larger white organizations, many of

A lot of grassroots minority organizations don't have the training or expertise to develop grant proposals or to weave their way through the complex funding application process, Vazquez adds. And, because AIDS often hits the most vulnerable members of minority communities, health-care providers often have to contend with other problems -- such as homelessness, teenage pregnancy, drug abuse and poverty -- that stretch their limited resources.

To overcome these barriers, Vazquez says, "We need to educate ourselves to the way the system works and learn to work the system. We can do that in larger coalitions. There is power in a group. We need to set up information networks." However, Vazquez points out, the key to the problem is money.

If the government is truly committed to stemming the AIDS increase within communities of color, it will put more money into minority institutions, says Dr. Greaves of Howard University.

Morehouse's Dr. Jackson agrees. "I think minority institutions are better able to reach out to minority populations," he says.

However, NIAID has no current plans to fund another minority infrastructure program, Dr. Counts says. Agency officials say they are working with the institutions they have already helped to see how successful they will be at conducting trials. 

*Shirley L. Smith is an Atlanta free-lance writer.*

## Life on Trial: 'I Was Determined to Do Anything I Could to Survive'

By Shirley L. Smith

In 1992, one year after he was diagnosed with having HIV, the virus that causes AIDS, Gregory Hutchings enlisted himself into a clinical trial.

"The way the prognosis is with AIDS, you are going to die," the 38-year-old says. "If I can participate in something that could possibly prolong my life or someone else's, it empowers me."

Unfortunately, Hutchings' perspective is somewhat unique. A lot of African-Americans shy away from clinical trials for fear that the past will repeat itself.

People have vivid memories of the infamous 40-year Tuskegee Syphilis Experiment, which used hundreds of poor black men in Alabama as guinea pigs for a government study on syphilis. The researchers studied the men, many of whom were illiterate, to monitor the long-term effects of the venereal disease. Although penicillin was discovered as an effective treatment during the course of the study, the men were denied treatment.

The experiment ended in 1972 in a wave of controversy, but it is still talked about, and stories -- some of them distorted -- are passed on from generation to generation. Education and health officials say when it comes to AIDS, they have to continuously deal with the Tuskegee question. It has become a major obstacle not only in recruiting minorities for studies but in getting them to take much-needed drugs to treat the disease. It has also given credence to the belief by some African-Americans that HIV was developed by white scientists as part of a genocidal plan.

As the number of AIDS cases within minority communities continues to increase at a disproportionate rate, minority participation in trials is crucial, says Dr. Wayne Greaves, a professor at Howard University and the only African-American running an AIDS Clinical Trial Unit (ACTU). Clinical trials are necessary for the development of new drugs and therapies to fight HIV infection and the opportunistic diseases that accompany the disease. It also is the first step in developing prevention vaccines.

Although the number of minorities involved in clinical trials has improved to better reflect the demographics of the disease, much of the new data involving minorities has not been analyzed yet, says Viktoria Trimmer, research coordinator of the ACTU at Howard University.

There is no evidence of biological differences between the races that makes it necessary to include different ethnic groups in trials, but previous studies have shown that certain drugs used to treat other ailments have not worked as well for black people as they have for whites.

For example, Trimmer says, "the drug minipres, an anti-hypertensive [used to lower high blood pressure], was studied for years in white males, and they found that the drug was not as effective in blacks." The inclusion of minorities in studies is necessary to detect such differences, she adds.

Hutchings, who lives in Washington, D.C., says his reservations about participating in a clinical trial were overcome by his will to survive. "I went through a period of anger and depression. Then there was a longing for survival, and I was determined to do anything I could to survive."

The trial he participated in was conducted by Fujisawa phar-

maceutical company. Unlike government trials, which do not pay, he was paid \$1,500 for each six-month period of the trial.

"Lining yourself up with a clinical trial will help you get effective care for your HIV problem that might not otherwise be available," says Dr. George W. Counts of the National Institute of Allergy and Infectious Diseases. People in trials have access to free medical care, the latest drugs and doctors who are experts in the field.

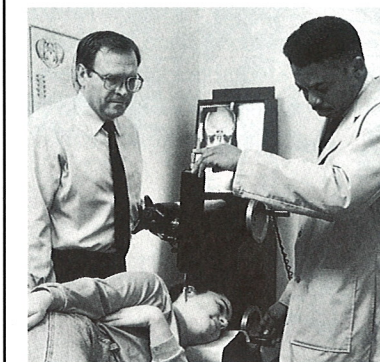
Many of the government trials are blinded studies, which means the researchers don't know which patients are getting the placebos or which ones are getting the actual drugs. The only people who know who's getting the actual medication are the pharmacists, Trimmer says.

This practice contributes to some minorities' skepticism, but researchers say it is necessary to prevent biases.

Before entering the trial, Hutchings says he made sure he was well-informed. He also maintained a private physician throughout the trial to monitor his care.

Having your own doctor outside of the clinical trial is important, he says, not just for an unbiased opinion but to continue your care after the trial since the current system does not connect research with treatment. "Generally, when you're finished with the clinical trial, they are finished with you."

**People interested in participating in trials can call the AIDS Clinical Trials Information Service at 1-800-Trials-A, also dialed as 1-800-874-2572. Hotline provides information on government and private trials 9 a.m. - 7 p.m. EST Mondays-Fridays.**



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