

Along the Mississippi Delta, Citizens Mobilize Against Cancer

by Francis X. Mahaney, Jr. Photo by Bill Branson

Greenwood, Mississippi- Here where the Yalobusha and Tallahatchie Rivers meet to form the Yazoo River, a Confederate monument stands in the middle of town where 67 percent of the residents that reside here are black Americans--34 percent live below the poverty level. Cotton gins still drone much as they did 145 years ago, while the residents hope to revitalize the town with a lucrative cat fish industry.

But for the past two years, more than 500 black volunteers from the area have mobilized their community to inform them of better ways to prevent and treat cancer. Since then, more than 9,000 women have been enrolled in breast and cervical cancer programs.

These are the direct results of a program designed by the National Cancer Institute's Center to Reduce Cancer Health Disparities (CRCHD). The program is one of 18 CRCHD-funded projects which make up the Special Populations Networks. Its purpose is to bring cancer awareness among black Americans in a collaborative project with the University of Southern Mississippi. The Special Populations Networks is sponsored by the National Cancer Institute.



Local staff worker visits Delta families.

"It is one thing to hear descriptions of life in the Mississippi Delta, but it's another thing to see it first hand," said Frank Jackson of the CRCHD who visited Greenwood recently. "I walked away with feelings of both optimism and pessimism because the need of these people is so great. My thoughts now are directed to how we can implement the National Cancer Institute's commitment to relieve the burden."

He added, "Cancer affects all of us, regardless of race but especially in rural communities," where
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An Introduction to the Newsletter from the Center's Director



Dr. Harold P. Freeman

This is the first issue of **Equal Access**, the quarterly newsletter of the Center to Reduce Cancer Health Disparities of the National Cancer Institute (NCI). Let us introduce ourselves.

The Center was established two years ago as the cornerstone of NCI's efforts to reduce the unequal burden of cancer in our society. Center activities are designed to develop a better understanding of the causes of these disparities and to find strategies and actions that will reduce these disparities by
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Mississippi (from page 1)

resources are meager, Jackson said. It was only three years ago when US Rep. Bennie Thompson (D-Miss) introduced a bill that would eventually lead to the creation of the HHS Office of Minority Health. "That was the first recognition that minority health issues in this country should be put on the level with other

"The last thing you want to do is become sick..."

issues," Thompson said .

"Without the National Cancer Institute, the citizens of Greenwood would not know how to get mammograms, how to detect breast lumps and learn the early warning signs of skin cancer," said Freddie White-Johnson, director of the Deep South Network for Cancer Control, Greenwood , Mississippi.

The American Civil War ended almost a century and a half ago in the town of Greenwood, and yet working cotton plantations with Greek Revival Mansions still grace the landscape, and poor black farm workers still work on plantations living in run down shacks with inadequate heat, undrinkable water, and lack of adequate plumbing. Most of the cotton workers and nearby residents working at cat fish farms have no medical insurance, no sick leave and unemployment in the winter months. Most of the workers on the plantation receive less than \$6 an hour in wages or \$11,520 a year. There it is difficult to get a high school education, find a cancer specialist or get transportation to major cancer centers. People are out of work...more than 1,500 jobs have been lost since several large industries left town. People in Greenwood fear getting cancer from the pesticides that are dropped near the schools and homes here. "The pesticides fall on your car as thick as snow," White-Johnson said.

"The last thing you want to do is become sick because if you don't work, the family doesn't get paid and, at some plantations, the rent for a shack is \$60 a week," said White-Johnson.

"On the day of my father's funeral, the plantation owner asked us when we would leave. That's life on a

working plantation in 21st century Mississippi," Mrs White-Johnson said, staring out the window.

Just down the road in Sharkey County, Mississippi, there is no store and no doctor or medical providers.

"Its going to take the Holy Ghost to change some people's hearts in this town," she said.

"Sometimes (people) have been mistreated by the system, and sometimes they are locked out," said Dr. Lovetta Brown of the Northwest Mississippi Public Health District.

"But there remains optimism in the Mississippi Delta that you have to admire, the dedicated people who strive to effect meaningful change," Jackson said. "That's why we must help them." ♡

U.S. Census Classifications Based on 'Perceptions, Not on Science' Says Scholar

by Neil Swan, Staff Writer

Racial categories are not static or stable because they are based largely on perceptions, not science, according to a leading scholar of ethnic studies at Berkeley.



Dr. Michael Omi

And while racial and ethnic classifications, as used by the Census Bureau, are distasteful to many, it is highly unlikely that the U.S. can or should totally abandon the use of such categories in the foreseeable future, according to Dr. Michael

Omi in a lecture in March sponsored by the Center to Reduce Cancer Health Disparities.

A key message of the Center is that leading scientists have determined that race and ethnic classifications have been socially and politically determined and have no basis in biological science. The Center seeks to reduce the unequal burden of cancer in our society by removing barriers

– particularly racial and ethnic perceptions – that prevent medical research benefits from reaching all populations equally.

While the idea that race has no biological basis is now endorsed by leading scientific organizations, it is still an “issue that won’t go away,” said Omi, pointing to a headline in the previous week’s *New York Times* about two articles in the March 20 issue of *The New England Journal of Medicine* that take opposing views on whether race is a meaningful factor in medicine.

Debates about racial classification have raged for years, said Omi, who is professor of ethnic studies and acting director of the Institute for the Study of Social Change at the University of California at Berkeley. He is co-author with Howard Winant of *Racial Formation in the United States*, now considered a classic work in scholarly studies on race and ethnicity.

Omi has used Census Bureau data and its racial and ethnic classifications drawn up by the Office of Management and Budget as a barometer of the issue. “These census definitions have had the unintended consequence of shaping the very discourse of race and the distribution of vast resources,” he said.

“Race and ethnicity are more a matter of perception...”

But attitudes change, and policies change. Official racial categories were altered nine times in the past 10 U.S. census tabulations, Omi pointed out. Self-identities change, too, as in the case of a 27-year-old Ohio-born man living as a member of a German-ancestry family who changed his self-selected census identity from “white” to “Chicano” after he spent time with his mother’s family in Mexico.

Race and ethnicity are more a matter of perception than reality, Omi suggested. Media portrayals of American Indians in more romantic images (compared to old cowboy movies) in recent years led to a self-selected 25 percent increase in the Indian population between 1980 and 1990. A mere wording change in the 1990 census form produced a whopping 6,000

percent increase in those who call themselves Cajuns.

Determinations of race made by others can lead to baffling cases of Americans who are “born in one race and die in another race,” said Omi. This last-minute race-switching phenomenon is perhaps because it is morticians who make the final determination when filling out death certificates. Often, it may be a hasty check-off decision that “switches” a person’s race after death.

“Some people say we need a racial awareness campaign among the nation’s funeral directors,” Omi commented wryly.

The director of NCI’s Center, Dr. Harold P. Freeman, asked whether younger Americans are more willing than their elders to accept multiracial concepts. Generally yes, replied Omi, but many variables come into play. For example, a study of attitudes in two California high schools, one with a primarily white enrollment and one with a racially diverse enrollment, showed contrasts. In the white school, students showed much greater freedom in selecting offbeat lifestyles and attire – such as “rappers” or “cowboys” – than the white students in the diverse-race school, who probably felt more confined by their racial identity as perceived by others, he said.

There has been a movement to create a multiracial census category. But leading civil rights organizations opposed the multiracial category, fearing it would diminish their numbers and undermine the “protected status” of non-whites. In response, the OMB told the Census Bureau to allow multiracial Americans in 2000 to “mark one or more” racial categories when identifying themselves.

While it is impossible to define racial categories that are valid, measurable, and reliable over time, “we simply cannot dispense with the use of racial and ethnic categories,” Omi concluded. Without categories it would be impossible to monitor racial inequality and discrimination in society – for example, racial “profiling” by police or bias in the issuance of homebuyer loans. ❖

Scientists Urged Not to View Health Disparities Through Artificial “Prism of Culture”

Despite tremendous medical advances made since the discovery of the secret of DNA 50 years ago, the Nation is still struggling to overcome lingering unscientific conceptions about race that result in social injustice and disparities in health and health care, leading scientists and geneticists were told at a symposium marking the 40th anniversary of the discovery of the structure of DNA.

“There is no genetic basis for racial classification. Race is based on social and political considerations, not science,” Dr. Harold P. Freeman told the meeting of distinguished scientists and policymakers in April. Scientists must now strive to insure that DNA-based advances in health care help society to overcome outdated concepts and thus reduce health disparities and injustice, he said.

Freeman spoke at a symposium entitled *From Double Helix to Human Sequence – and Beyond* sponsored by the National Human Genome Research Institute, part of the National Institutes of Health (NIH). The CRCHD is a component of the National Cancer Institute, which is one of 17 institutes comprising NIH. The symposium was part of NIH’s 50th anniversary celebration of the discovery of the double helix structure of DNA, the genetic “blueprint” for reproduction of all life forms. Dr. James Watson, Noble prize winner and co-discoverer of the DNA double helix structure, spoke at the symposium. The two-day event ended with remarks by Freeman, followed by several other speakers, addressing the issue of “Race, Science and Genomics.”

Freeman noted that Charles Darwin, the father of the theory of evolution, “did not think much of race.” In fact, Darwin wrote in 1871 that the “variability of all the characteristic differences between races cannot be of much importance.” His reasoning was confirmed by recent genetic advances building on DNA studies

that show there is more genetic variation (95 percent) within a group that is called a race than between so-called racial groups (5 percent), Freeman noted.

The so-called One Drop Rule, which holds that any American who has one black ancestor (or one drop of black blood) is an African-American, despite physical appearance, is still widely observed and remains a problem in the U.S., he said. DNA-based studies can determine scientific categories of variations among humans that are valuable when studying the causes of disease, as well as developing treatments. For example, the region of the world where a genetically definable group of humans originated is an important research factor in studying diseases. “But the one-drop rule is hardly a scientific basis” for such studies, he noted.

“Scientific truth must always be wedded to social justice,” said Freeman. “Scientists working in their labs must stay connected to human beings” to see that the benefits of genetic and other scientific discoveries are used to reduce health disparities and social injustice, he added.

Poverty drives health disparities more than any other factor, but “poverty is reflected through the prism of culture,” wrote Freeman, in a recently published* elaboration of his symposium remarks. “Culture and cultural values, including those concerning race, may be a kind of baggage that virtually all people, including scientists, bring to their professional endeavors and social interactions,” he wrote.

“We see, value, and behave toward one another through a powerful prism of culture,” he continued. “This prism can create false assumptions that may result in serious harm to members of some racial and ethnic groups.”

Continued use of racial classifications is necessary not for scientific reasons but as a means of monitoring and eliminating race-based discrimination, he said, adding, “We must move away from saying that being in a group is itself the cause of disparity, unless it is because of how people are treated according to fairness issues.”

Freeman noted, both in his speech and his article, that the renown physicist Albert Einstein, author of the theory of relativity, years ago summed

up the concept of how viewing the world through the lens of race leads to distortions. Einstein said: what you see depends on where you stand. ♡

*Freeman, H.P. *Commentary on the Meaning of Race in Science and Society*, *Cancer Epidemiology, Biomarkers & Prevention* Vol. 12, 232s-236s, March 2003 (Suppl.)

Study Confirms PSA Test Reduces Prostate Cancer Deaths in Blacks and Whites

Patterns of incidence, survival, and mortality support the contention that increased PSA testing has resulted in earlier detection of prostate cancer, thus reducing the prostate cancer death rate in both black men and white men in the U.S., according to a new study. Cancer statistics support the notion



Dr. Kenneth C. Chu

that PSA testing locates cancer in the prostate before it has a chance to metastasize, or migrate, to other locations in the body where it leads to fatal tumors.

PSA blood tests detect increased levels of a substance called prostate-

specific antigen (PSA) that are a warning of possible prostate disease. Prostate cancer can be cured, if diagnosed early, before it spreads.

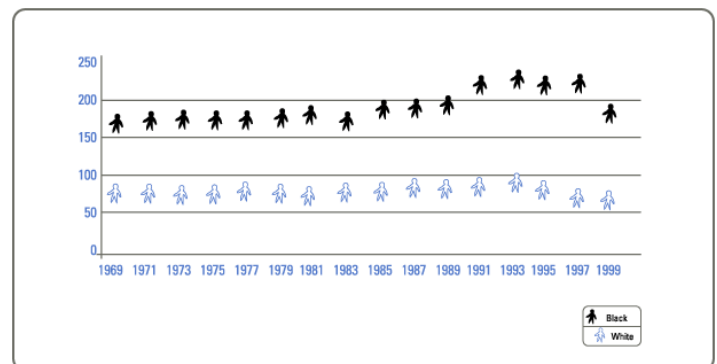
“Tumors that, without intervention, would be diagnosed in the lethal, distant stage are being detected early by PSA testing, so that men are diagnosed in the localized or regional stage; the resulting marked improvement in prognosis leads to decreasing mortality rates,” according to an examination of mortality data by researchers at the National Cancer Institute.

Prostate cancer mortality rates in both white men and black men currently are at their lowest levels in several decades for many age groups, the researchers noted. Since this study can not prove PSA is beneficial, discussion of the pros and cons of PSA testing are needed. These discussions are critical because black men in the U.S. still have some of the highest prostate cancer rates in the world.

The study, *Trends in Prostate Cancer Mortality among Black Men and White Men in the United States*, was authored by Dr. Kenneth C. Chu, CRCHD Health Scientist Administrator; Dr. Harold P. Freeman, director of the CRCHD; and Robert E. Tarone, NCI’s Biostatistics Branch. It is published in the March 15, 2003 issue of the journal *Cancer*.

Stat Byte

Prostate Cancer Death Rates Decrease After PSA Testing Is Introduced



Prostate cancer mortality rates in the U.S. declined after 1991 in white men and after 1992 in black men. The cause is increased detection of prostate cancer before it migrates away from the prostate to produce fatal tumors, researchers suggest. Increased use of PSA testing for prostate cancer after 1986 may explain the mortality decreases, which came while there were large increases in the number of men treated for prostate cancer since 1986. Black men in the U.S. still have some of the highest prostate cancer rates in the world. ♡

Introduction from the Director

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integrating proven cancer-related interventions and research findings into health care delivery systems.

Cancer health disparities are a concern for all Americans, not just racial or ethnic minorities. Disparities – or inequalities – occur when members of certain population groups do not enjoy the same health status as other groups. Disparities are most often identified along racial and ethnic lines – showing, for example that African Americans or Hispanics have different disease rates and survival rates than whites. But disparities also extend beyond race and ethnicity. For example, cancer health disparities can involve biological, environmental, and behavioral factors, as well as differences based on income, education, access to care or health insurance coverage.

The goal of our newsletter is to introduce awareness and disparity-reducing strategies to a broad range of interest groups: cancer patients and their families; health care practitioners; community and interest groups representing the poor, the medically underserved and a spectrum of racially- and ethnically-based groups; churches and religious groups; medical researchers; state and local health agencies; opinion-leaders at various public agencies and policy makers at the Department of Health and Human Services (HHS); public health experts and organizations, both public and private; independent research organizations or “think tanks.”

We will strive to reach this broad range of readers with timely information that helps the Center fulfill its mission, utilizing three key strategies:

- **Closing the Gap Between Discovery and Delivery:** A critical disconnect exists between research discovery and delivery of care to cancer patients. This disconnect is a key factor leading to the unequal and unjust burden of cancer in our society. Closing the gap will

reduce cancer health disparities.

- **Removing Barriers that Prevent the Benefits of Research from Reaching All Populations:** Identifying and removing a number of barriers that limit or prevent access to cancer care will produce immediate benefits in reducing cancer health disparities. Other barriers that arise from cultural or racial differences, and biases these differences produce, must also be eradicated to eliminate social injustices.
- **Uniting the Drive to Reach Scientific Truth with Social Justice:** The Center will become the focal point within NCI for uniting, leading, coordinating and fostering innovation in research-based efforts to reduce health disparities. It will demonstrate to diverse audiences that, until health disparities are ended, the Nation is failing to meet a key element of the center’s founding creed: **Equal treatment for all.**

We intend for the newsletter to become a focus of a broadening recognition of cancer health disparities, as well as a means of explaining and dramatizing some of the Center’s corrective strategies. In this way, we will help fulfill the Center’s mission by:

- advancing understanding of the cause of health disparities
- developing and integrating effective interventions to reduce or eliminate these disparities.

Our news and feature articles will spotlight the Center’s unique and innovative outreach and research efforts via its research grants to large multi-site projects, as well as other projects that target one or more counties, tribal nations, or population subgroups.

We hope to become the focus of interest in exploring ways to support interdisciplinary research initiatives on disparities in care, including the establishment of collaborations between NCI- and

NIH-supported researchers, the development of innovation partnerships with Federal, state, and local agencies.

We will strive to make **Equal Access** a lively publication, with vivid photos of activities in the field and articles that are written in a simple, easy-to-read, “friendly” style. We want to become the “voice” of the Center in its outreach to a broad range of audiences, spotlighting the personalities and hopes of the researchers and others who are carrying out this outreach.

And we want **Equal Access** to be a two-way communication system, welcoming suggestions and comments from readers. Contact us at crchdnewsletter@mail.nih.gov. ❖

Disparities Summit Spotlights Researchers’ “Best Practices”

Investigators and staffers from 18 research coalitions comprising CRCHD’s Special Populations Networks (SPN) attended the Cancer Health Disparities Summit 2003 sessions in Washington on July 13-15, reported on their progress and shared their outreach advances and emerging research insights.

The sessions highlighted how the various SPN research projects are functioning as community-based cancer control partnerships, now actively engaging their communities in a range of pilot research activities and moving forward to become peer-reviewed and funded cancer control and cancer prevention research and demonstration projects.

SPNs, with the 18 projects in 15 states, seek to build relationships between large research institutions and community-based programs and to find ways of addressing critical questions about the burden of cancer in minority communities.

Presentations by the various SPN researchers spotlighted the “Best Practices” demonstrated in programs targeting the various SPN racial-ethnic

groups. Selected Best Practices highlighted included “Novel Outreach Approaches,” “Innovative Tracking Methods,” “Leveraging Resources and Partnerships,” and “Training and Mentoring.”

The major goal of the SPN is to establish a robust and sustainable infrastructure to promote cancer awareness within minority and medically underserved communities and to launch from these communities more research and cancer control activities aimed at specific population subgroups.

Dr. Andrew C. von Eschenbach, M.D., director of the National Cancer Institute, spoke at the Summit. ❖



Dr. Andrew von Eschenbach, left, Director of the National Cancer Institute, addresses the 2003 Summit of the Special Populations Networks in Washington, D.C. He was introduced by Dr. Harold P. Freeman, CRCHD Director. Report on Summit activities will be featured in the Fall issue of *Equal Access* newsletter.

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Equal Access

Closing the Gap between Discovery and Delivery

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