ETHNIC MINORITY DISPARITIES IN CANCER TREATMENT: WHY THE UNEQUAL BURDEN?

HEARING
BEFORE THE
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GOVERNMENT REFORM
HOUSE OF REPRESENTATIVES
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ETHNIC MINORITY DISPARITIES IN CANCER TREATMENT: WHY THE UNEQUAL BURDEN?

MONDAY, SEPTEMBER 25, 2000

HOUSE OF REPRESENTATIVES,
COMMITTEE ON GOVERNMENT REFORM,
Washington, DC.

The committee met, pursuant to notice, at 1 p.m., in room 2154, Rayburn House Office Building. Hon. Judy Biggert (acting chairwoman of the committee) presiding.

Present: Representatives Biggert, Horn, Norton, Cummings, and Kucinich.

Staff present: Daniel R. Moll, deputy staff director; S. Elizabeth Clay, professional staff member; Robert Briggs, clerk; Michael Canty and Toni Lightle, legislative assistants; Leneal Scott, computer systems manager; John Sare, staff assistant; Jon Bouker and Sarah Despres, minority counsels; Tania Shand, minority professional staff member; Ellen Rayner, minority chief clerk; and Jean Gosa and Earley Green, minority assistant clerks.

Mrs. BIGGERT. Good afternoon. A quorum being present, the Committee on Government Reform will come to order.

I ask unanimous consent that all Members' and witnesses' written opening statements be included in the record. Without objection, so ordered.

I ask unanimous consent that all articles, exhibits and extraneous or tabular materials referred to be included in the record. Without objection, so ordered.

Over the past 2 years, the Committee on Government Reform has held several hearings on cancer issues. We have examined the importance of early cancer detection and research, the role of complementary and alternative therapies, women's cancers, prostate cancer and the need to provide patients with their choice of treatment.

Today we are looking at the equally important topic of ethnic and racial disparity in cancer treatments.

Our colleague Mr. Cummings requested this hearing in order to raise the level of awareness of disparities in care, as well as to explore possible solutions to this problem.

We all know the devastating impact cancer has had on our society. One in four deaths in the United States is attributed to this terrible affliction, and one in three Americans also develop some form of cancer in their lifetimes. This year alone, some 552,000 Americans are expected to die of cancer.

Cancer is a disease that is color-blind. It strikes all socioeconomic, cultural and ethnic groups in America, but it often takes
the deadliest toll among minorities. Although many ethnic minority groups experience significantly lower levels of some types of cancer than the majority of the U.S. White population, other ethnic minorities experience higher cancer incidence and mortality rates.

Let us just look at a few of these examples. The incidence and mortality rates for multiple myeloma rose sharply in the United States from the 1950’s to the 1980’s, then leveled off. The rates for African Americans were twice as high as for Whites. Asian Americans are five times more likely to die from liver cancer associated with hepatitis. Vietnamese women suffer cervical cancer at nearly five times the rate of White women. Hispanics have had two to three times the rates of stomach cancer.

According to a UAW/Ford report, the overall mortality rates for African Americans in the five-county area around Kansas City is 63 percent higher than for Whites in the same area. In Wisconsin death rates from cancer for African Americans rose 3 percent, while death rates for Whites decreased by 2 percent. Breast cancer occurs less often in African American women than White women, but it is typically detected later. African American males develop cancer 15 percent more frequently than White males.

These are just a few examples of the racial disparities we see in cancer rates and deaths. They are complex and not well understood. They can be related to higher incidence of cancer, to later detection and to cancers not being treated as well. Research has shown that all three of these factors contribute to the disparity in mortality.

I am pleased that two of my colleagues are here today to talk about legislation they have introduced to deal with these issues. Congressmen Jesse Jackson, Jr., and Bennie Thompson have both introduced bills to elevate to a center the Office of Research on Minority Health at the National Institutes of Health.

I am pleased that Dr. Ruffin, the Associate Director for Research on Minority Health, and Dr. Ottis Brawley from the Office of Special Populations at the National Cancer Institute are joining us today to answer our questions.

Dr. Harold Freeman is returning to testify to the committee today on behalf of both the National Institutes of Health as well as the North General Hospital.

Last year an article published in the New England Journal of Medicine indicated that in early stage lung cancer, African Americans received less aggressive treatment than White individuals. The author of this research paper, Dr. Peter Bach of Memorial Sloan-Kettering Cancer Center, is here today to share insights from this research.

I am also pleased that we will hear from Dr. Linda Thompson of the Center for Community Partnerships for Children and Families in Baltimore, MD, and Dr. Elmer Huerta of the American Cancer Society.

The hearing record will remain open until October 10th.

[The prepared statement of Hon. Judy Biggert follows:]
Opening Statement

Acting Chair Judy Biggert (R-13IL)
Government Reform Committee

Ethnic Minority Disparities in Cancer Treatment:
Why the Unequal Burden?

1:00 pm
September 25, 2000

2154 Rayburn House Office Building
Washington, D.C. 20515
Over the last two years, the Committee on Government Reform has held several hearings on cancer issues. We have examined the importance of early cancer detection and research, the role of complementary and alternative therapies, women’s cancers, prostate cancer, and the need to provide patients with their choice of treatment.

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This year alone, some 552,000 Americans are expected to die of cancer.

Cancer is a disease that is color-blind. It strikes all socio-economic, cultural, and ethnic groups in America. But it often takes the deadliest toll among minorities.

Although many ethnic minority groups experience significantly lower levels of some types of cancer than the majority of the U.S. white population, other ethnic minorities experience higher cancer incidence and mortality rates.

Let’s just look at a few of these examples:
The incidence and mortality rates for multiple myeloma rose sharply in the United States from the 1950's to the 1980's, then leveled off. The rates for African Americans were twice as high as for whites.¹

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Vietnamese women suffer cervical cancer at nearly five times the rate of white women.

Hispanics have two to three times the rate of stomach cancer.

According to a UAW/Ford Report, the overall mortality rate for African Americans in the five-

county area around Kansas City is 63 percent higher than for whites in the same area.

- In Wisconsin, death rates from cancer for African Americans rose three percent, while death rates for whites decreased by two percent.²

- Breast cancer occurs less often in African American women than white women, but it is typically detected later.³

- African-American males develop cancer 15 percent more frequently than white males.

Those are just a few examples of the racial disparities we see in cancer rates and deaths.

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³ Schubert, C; Lung Cancer Deaths Offset Gains Elsewhere, Milwaukee Journal Sentinel, June 26, 2000
They are complex and not well understood. They can be related to a higher incidence of cancer, to later detection, and to cancer not being treated as well. Research has shown that all three of these factors contribute to the disparity in mortality.

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I am also pleased that we will hear from Dr. Linda Thompson of the Center for Community
Partnerships for Children and Families in Baltimore, Maryland, and Dr. Elmer Huerta of the American Cancer Society.

The hearing record will remain open until October 10.
Mrs. BIGGERT. Mr. Cummings, would you like to make an opening statement?

Mr. CUMMINGS. Thank you very much, Madam Chairlady. I want to thank you for chairing this meeting today, and I want to take a moment to thank Chairman Burton for convening this hearing at my request entitled, “Ethnic Minority Disparities in Cancer Treatment: Why the Unequal Burden?”

On June 8th, this committee held a hearing on the accessibility of complementary and alternative medicines for cancer treatments during which racial disparities in treatment were briefly examined through testimony given by Dr. Harold Freeman, who will testify today. However, as I requested, this hearing today affords us the opportunity to engage in a more exhaustive investigation of the disparity issue as it relates to conventional treatments for cancer.

I requested this hearing in response to a study published by the New England Journal of Medicine in October 1999, which reported that African American patients with early stage lung cancer are less likely than Whites to undergo life-saving surgery, and as a result are more likely to die of this disease. I’m pleased to see that one of the principal investigators of the study Dr. Peter Bach is here with us today to testify.

The treatment disparities revealed in the study were of great concern to me, particularly when considered along with other data regarding cancer incidence and mortality rates among minorities as compared to the majority population. In fact, disturbingly, the incidence rate for lung cancer in African American and native Hawaiian men is higher than in White men. Hispanics suffer elevated rates of cervical and liver cancer, and Alaska native and African American women have the first and second highest of all cancer and cancer mortality rates among females.

Cancer has also surpassed heart disease as the leading cause of death for Japanese, Korean, and Vietnamese populations. Further, while surgery is the treatment option for lung cancer in its early stages, only 64 percent of African Americans had surgery at this stage as compared to 76.7 percent of White Americans.

And paralleling recommended treatment options, cancer death rates among African Americans are about 35 percent higher than that for Whites, and in my district of Baltimore City, 251 African Americans per every 100,000 people die of cancer each year as compared to 194 of Whites.

These statistics are compelling and lead us to question why such disparities exist among races. Numerous studies have determined that race is not just a biological category. Race reflects the intersection of biological, cultural, socioeconomic, political and legal determinants. As such, to address the unequal burden in minority health, we must examine how all of these determinants individually and collectively play a role in creating existing health disparities. We must examine whether the trends in racial and economic differences in health are due to genetic factors, or socioeconomic factors such as income and cultural mores, including diet, have a significant impact, or, as Dr. Bach’s study suggests, do disparities result from racism and discrimination, which can lead to psychological stress and can restrict access to health care, education, housing and recreational facilities, all key components to a healthy
life. Is such racism and discrimination institutionalized within the medical industry such that preventive measures and treatment options are limited for minorities? The goal of this hearing is to explore these very questions and, further, to examine how such disparities can be eliminated.

I understand the key ways to address the issue include increased data collection and research toward the implementation of effective prevention, treatment and health programs, the appropriate levels of health and social services and nondiscriminatory access to health care. However, I look forward to hearing from our witnesses today on this issue.

I am particularly interested in the testimony of my colleagues, Representative Jesse Jackson, Jr., of Illinois and Representative Bennie Thompson of Mississippi, regarding legislation aimed toward these goals, and I thank them for their appearance here today, and I thank them for their concern.

Our Nation is in a race for the cure; however, we must be mindful that this race against cancer must be run by and for all Americans. The entry into this contest should not be dependent on your race, but must be based on your humanity. And winning the race for a quality, healthy life, must be a victory for every citizen no matter their race, ethnicity or socioeconomic status.

As we move closer to crossing that victory line, I will remain committed to the biotech ethical principles of justice, fairness which all call for one standard of health in this country for all Americans, not an acceptable level of disease for minorities and another for the minority population.

And with that I close, Madam Chairlady, and I thank you.

Mrs. Biggert. Thank you very much, Mr. Cummings, and thank you very much for requesting that we proceed with this hearing.

I might just mention that our chairman, Mr. Burton, is on the way, but he was delayed by traffic, and so he asked me to act in his stead, but he will be arriving later on in the afternoon, so I have the opportunity to do this.

Our first panel is the Representative from Illinois, Jesse Jackson, and Representative Bennie Thompson from Mississippi. On behalf of the committee, we welcome you here today, and if you would please proceed with your opening statements, and we'll start with you, Congressman Jackson.

STATEMENT OF HON. JESSE L. JACKSON, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ILLINOIS

Mr. Jackson. Thank you, Madam Chair, Ranking Member Cummings and members of the committee. I want to thank you for this opportunity to discuss health disparities and particularly an issue that I am concerned about, minority health research at the National Institutes of Health. I am very pleased to join my colleague Congressman Thompson on this panel to share ideas and concrete steps this Congress may take to address health status disparities in this country between African Americans and other ethnic minorities and that of the general population. I also want to take this time to thank Congressman Cummings for asking for this hearing and for working with me and Congressman Thompson on
advancing this very important issue and helping to ensure that no American is left behind.

I want to start by saying that the concept of elevating the Office of Research on Minority Health, Chairwoman Biggert, to center status and ensuring culturally competent curricula at medical schools is a first step, but an important step, in a long journey to end domestic health disparities. We still need to address the issues of access, of prevention and treatment in a comprehensive manner.

In this time of national economic prosperity and double-digit growth for the National Institutes of Health, I am disappointed to report that the health status gap among Blacks and other underserved populations is getting worse and not better. In fact, African American males develop cancer, as Congressman Cummings said, 15 percent more frequently than White males. For men and women combined, African Americans have a cancer death rate of 35 percent higher than that for Whites.

In addition, the incidence rate for lung cancer in African American men is about 50 percent higher than in White men. Moreover, several years ago the Chronicle of Higher Education wrote an article critical of the amount of dollars being spent on minority health research at NIH. The Chronicle article cited that 0.4 percent of extramural research grants were being awarded to African American researchers pursuing these studies. In my view, the National Institutes of Health could do more and should be doing more to address health care needs for all Americans.

At the beginning of the 106th Congress, I was pleased to be appointed to the House Appropriations Committee and to its Labor, Health and Human Services, and Education Subcommittee. Congressman Louis Stokes of Ohio made gigantic strides in improving minority health during his long and distinguished service on the Labor-HHS-Ed subcommittee, and I hope to make a similar contribution.

One of the many benefits of serving on the subcommittee is the opportunity to carefully review the program activities and the priorities of the Institute and to question the health care professionals and researchers that carry out such vital work. In fact, the Labor-HHS-Ed subcommittee held more than 40 days of hearings just this year alone, about 20 half-day sessions, which were dedicated to the oversight of NIH. I was privileged to attend almost all of those sessions this year.

In January 1999, I had the privilege of meeting with Dr. Louis Sullivan, the former HHS Secretary and current president of Morehouse School of Medicine. Dr. Sullivan shared with me the testimony he gave before the Senate Labor-HHS appropriations subcommittee concerning an Institute of Medicine study, an IOM study, that demonstrated a disturbingly low level of support for cancer research among minorities through the National Cancer Institute. The cornerstone recommendation made by Dr. Sullivan in his testimony was to elevate the existing NIH Office of Research on Minority Health to center status. He contended that the existing structure at NIH did not—I repeat, Madam Chair—did not adequately address or prioritize the issue of health disparities.

After asking scores of questions to the NIH Director and the Directors of the Institutes and Centers during last year's hearings
about these disparities, I became more convinced than ever that Dr. Sullivan was right, the Office of Research on Minority Health needed to be elevated to a center and to center status. Consequently, I worked with Dr. Sullivan and other health care professionals to fashion a bill that would do just that. The product of those efforts is H.R. 2391, which I introduced on June 30, 1999, and I am also pleased to see that Congressmen Thompson and Lewis have incorporated title 1 of their legislation, H.R. 3250, the Health Care Fairness Act, as essentially the essence of 2391.

Madam Chair, the bill in sum does this, as I prepare to close: No. 1, it provides the Director of the center a seat at the table, which they currently do not have, when NIH Institutes and Center Directors meet to discuss NIH policy and priorities. Currently the Director of the office does not even attend those meetings.

Second, it calls for the health status disparities to be prioritized at NIH through the establishment of an NIH-wide strategic plan for health disparities with the center playing a key role in such a strategic plan.

Third, it establishes direct grantmaking authority for the national center, guided by the work of scientific expertise of a national advisory council. Right now the office Director can’t spend his own budget unless an Institute Director allows him to fund a grant through his or her Institute.

And last, Madam Chair, it provides institutional support for those minority health professions schools which have a history and mission to serve and train minority health professions and conduct research on health status disparities. If we are ever going to solve the problem of health disparities, institutions which have a mission to solve these problems must be strong and viable.

Madam Chairman, I urge this committee to look seriously at the pieces of legislation that would elevate the Office of Research on Minority Health to a national center. Elevating this office will help save more lives and families from being sapped by illness and anguish. Together we can ensure that health care needs of all Americans are adequately addressed.

Madam Chairman, Ranking Member Cummings and members of the subcommittee, I thank you for the opportunity to present my views.

Mrs. Biggert. Thank you very much, Congressman Jackson.

[The prepared statement of Hon. Jesse L. Jackson follows:]
Statement for
Congressman Jesse L. Jackson, Jr.

September 25, 2000

House Committee on Government Reform

Concerning:

“Ethnic Minority Disparities in Cancer Treatment:
Why the Unequal Burden?”

H.R. 2391 - The Center for Research on Domestic Health Disparities

H.R. 3250 - The Healthcare Fairness Act
Mr. Chairman, Mr. Ranking Member and Members of the Committee, thank you for this opportunity to discuss health disparities, and particularly an issue that I am concerned about, minority health research at the National Institutes of Health (NIH). I am very pleased to join my colleagues on this panel to share ideas and concrete steps this Congress may take to address the health status disparities in this country between African Americans and other ethnic minorities and that of the general population. I also want to take this time to thank Congressman Cummings for asking for this hearing, and for working with me on advancing this very important issue and helping to ensure that no American is left behind.
I want to start by saying that the concept of elevating the Office of Research on Minority Health to center status and ensuring culturally competent curricula at medical schools is a first step, but an important step, in a long journey to end domestic health disparities. We still need to address the issues of access, prevention and treatment, in a comprehensive manner.

In this time of national economic prosperity, and double digit growth for the National Institutes of Health, I am disappointed to report that the health status gap among blacks and other underserved populations is getting worse, not better. In fact, African American males develop cancer 15 percent more frequently than white males. For men and women combined
African Americans have a cancer death rate about 35 percent higher than that for whites.

In addition, the incidence rate for lung cancer in African American men is about 50 percent higher than in white men. Moreover, several years ago, The Chronicle of Higher Education wrote an article critical of the amount of dollars being spent on minority health research at NIH. The Chronicle article cited that only .4 percent of extramural research grants were being awarded to African American researchers. In my view, The National Institutes of Health could and should be doing more to address the health care needs of all Americans.

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were dedicated to the oversight of NIH. I was privileged to
attend almost all of those sessions this year as well as last year.
In January of 1999, I had the privilege of meeting with Dr. Louis Sullivan, the former HHS Secretary and the current President of Morehouse School of Medicine. Dr. Sullivan shared with me the testimony he gave before the Senate Labor-HHS Appropriations Subcommittee concerning an Institute of Medicine Study (IOM) that demonstrated a disturbingly low level of support for cancer research among minorities through the National Cancer Institute. The cornerstone recommendation made by Dr. Sullivan in his testimony was to elevate the existing NIH Office of Research on Minority Health to “Center
status.” He contended that the existing structure at NIH did not adequately address or prioritize the issue of health disparities.

After asking scores of questions to the NIH Director and the Directors of the Institutes and Centers during last year's hearings about these disparities, I became more convinced than ever that Dr. Sullivan was right - the Office of Research on Minority Health needed to be elevated to “Center” status.

Consequently, I worked with Dr. Sullivan and other health care professionals to fashion a bill that would do just that. The
product of those efforts is H.R. 2391, which I introduced on June 30, 1999. I am also pleased to see that Congressman
Thompson and Lewis have incorporated my legislation as Title I of H.R. 3250, the Health Care Fairness Act.

The bill, in plain terms would:

1) Provide the director of the Center a seat at the table when NIH Institutes and Center directors meet to discuss NIH policy and priorities. Currently the director of the office does not attend those meetings.

2) Calls for health status disparities to be prioritized at NIH through the establishment of an NIH-wide
strategic plan for health disparities, with the Center playing a key role in the strategic plan.

3) Establishes direct grant making authority for the National Center, guided by the work and scientific expertise of a national advisory council. Right now the office director can't spend his own budget unless an Institute director allows him to fund a grant through his or her Institute.

4) Provides institutional support for those minority health professions schools which have a history and mission to serve and train minority health professionals and conduct research on health status disparities. If we are ever going to solve the problem of health disparities,
institutions which have a mission to solve these problems must be strong and viable.

Mr. Chairman, I urge this Committee to look seriously at these pieces of legislation that would elevate the Office of Research on Minority Health to a National Center. Elevating this office will help to save more lives and families from being sapped by illness and anguish. Together, we can ensure that the health care needs of all Americans are adequately addressed.

Thank you Mr. Chairman, Mr. Ranking Member and members of the Committee for the opportunity to present my views.
STATEMENT OF HON. BENNIE G. THOMPSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MISSISSIPPI

Mr. THOMPSON. Thank you, Madam Chairman, Ranking Member Cummings. I associate myself with the comments made by my colleague Congressman Jackson from Illinois.

I, along with Representatives Lewis, Watts, and Norwood introduced House Resolution 3250, the Health Care Fairness Act of 1999, on November 11, 1999, in order to address the glaring disparities between the quality of health care received by Whites and that received by minorities.

Madam Chairman, racial and ethnic minorities are not receiving adequate health care. Over the past few decades, we have made great advances as a Nation in science and medicine. However, all our citizens have not shared in the benefits of these advances. Minority populations have significantly higher rates of death from cancer and heart disease as well as higher rates of HIV/AIDS, diabetes and other severe health problems.

We know that poverty, lack of health insurance and other barriers to care are undermining the health of minority communities. However, we have not made the commitment necessary to understanding the genetic and behavioral differences that allow and affect health outcomes. In addition, recent studies show that bias in the health care system is another factor in racial and ethnic health disparities.

All of us are familiar with all the studies, Madam Chairman, that document consistently what problems we encounter. One that I think is glaring for this hearing is that Black men who contract prostate cancer are 133 percent more likely to die than White men.

Minorities are also underrepresented in medical education and in the health care delivery system. Although Blacks, Hispanics and Native Americans make up 24 percent of the U.S. population, only 7 percent of physicians, 5 percent of dentists and 6 percent of medical school faculty members are from one of these minority groups.

The Health Care Fairness Act includes an increased commitment to research on minority health, improved data systems and culturally competent health care delivery. These changes will increase our knowledge of the nature and causes of these disparities and improve the quality and outcomes of health care services for minority populations.

There is an inherent need to include minority health as a top legislative initiative. Just like Medicare reform and affordable prescription drugs for seniors, immediate and decisive action must be taken to address the disparate treatment minorities receive from health care providers. Already a number of health care studies have been released which clearly demonstrate the fact that minorities receive less and/or different treatment by health care providers.

Madam Chairman, we must make every effort to address these problems and reverse the extremely disturbing trend. My bill is a first positive step in that direction. H.R. 3250 has gained the sup-
port from both sides of the aisle along with several health-care-re-
lated organizations.

Again, I want to thank my colleagues for their support for this leg-
islation, and I urge that we as Members of Congress push for pas-
gsage of this bill.

Parenthetically, Madam Chairman, let me indicate that I rep-
resent a congressional district where all 24 counties are medically un-
dererved. We need all the help that we can get. It’s the third poor-
est congressional district in America, and I hope you can un-
derstand my passion for this piece of legislation and would encour-
ge the committee’s positive report on it. Thank you.

Mrs. BIGGERT. Thank you very much, Congressman Thompson.

[The prepared statement of Hon. Bennie Thompson follows:]
Mr. Chairman, I along with Rep. Lewis, Watts, and Norwood introduced H.R. 3250, The Health Care Fairness Act of 1999, on November 11, 1999 in order to address the glaring disparities between the quality of health care received by whites and that received by minorities.

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According to the Commonwealth Fund:

- Nearly two to five (39%) black adults report that they do not have a regular doctor, compared with one of four (26%) of white adults.
- More than one in three (35%) of black adults report difficulty paying for medical care, compared with one of four (26%) white adults.
- While about two-thirds (65%) of white Medicare beneficiaries were vaccinated against the flu in the past 12 months, about four of ten (43%) blacks received a flu shot in the past 12 months.
- Minority populations have significantly higher rates of death from cancer, stroke, and heart disease as well as higher rates of HIV/AIDS, diabetes, and other severe health problems.
Black men who contract prostate cancer are 133 percent more likely to die of it than white men.

Minorities are also under-represented in medical education and in the health care delivery system. Although Blacks, Hispanics, and Native Americans make up 24 percent of the U.S. population, only seven percent of physicians, five percent of dentists, and six percent of medical school faculty members are from one of these minority groups.

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Mr. Chairman, we must make every effort to address these problems and reverse this extremely disturbing trend. H.R. 3250 is the first, positive step in that direction. This bill has the gained support from both sides of the aisle along with several Health Care related organizations. Again I want to thank my colleagues for their support for this legislation and I urge that we as Members of Congress push for passage of this bill.
Mrs. BIGGERT. We'll have questioning now, and I'll begin.

Congressman Jackson, Congressman Thompson just mentioned that all of the communities in his area are underserved. Are there any existing programs in your district working to improve minority access to care?

Mr. JACKSON. There are a number of existing programs and a number of existing health care facilities in our district that are seeking to provide access and quality, high level of care to the underserved, but the fundamental issue that plagues NIH is not one that is relative to access or availability of care. It is that we have on the Appropriations Committee set out to double NIH's budget over the last 5 years. Now, the budget is roughly $88 billion, and the IOM study showed that 0.4 percent of extramural grants at NIH were not addressing fundamentally well-coordinated research across the $88 billion that we were spending on many of these concerns.

And one of the questions, for example, that came to mind during the course of our inquiry, Madam Chairman, was this. I remember in raising the question to the head of the National Institute on Alcoholism and Alcohol Abuse, and I asked the Director of that center was he aware of any studies that had occurred on the impact of 40 ounces of malt liquor on the hypothalamus or medulla oblongata, two very important regions of the brain, and he said at that time that he was not aware of any studies that the National Institute on Alcoholism and Alcohol Abuse had conducted.

I told him was he aware that malt liquor is predominantly a liquor that is sold in minority communities, African Americans and Hispanics. He said he was aware of that. At that time a member of his own panel then interrupted and said, Congressman Jackson, I'm also afraid and very disappointed to tell you that they are now marketing 64 ounces of malt liquor in African American and Hispanic communities.

Well, Madam Chairman, needless to say, without studies to study why malt liquor is marketed in our community—the hypothalamus and the medulla oblongata are the regions of the brain, for example, that remind you that you are married—so if people are consuming this alcohol in our communities, and people don't live in these communities, then who is to say whether or not the National Institutes of Health shouldn't be offering advisory warnings to corporations, don’t sell malt liquor in 40-ounce and 64-ounce containers. It maybe should be sold in a 12-ounce container and then consumed in only 12 ounces at a time.

So these are fundamental problems that need to be coordinated across NIH as this Congress seeks to double its budget, and many of these issues are not happening right now at NIH unless there's an office that specifically is aware of those concerns, Madam Chair.

Thank you for your question.

Madam Chairman, I am sorry it’s $18 billion. I think our entire labor HHHS bill is about $106 now, up from $88. Things change around here every minute.

Mrs. BIGGERT. Well, I certainly share your respect and admiration for the former HHS Secretary Dr. Lewis Sullivan, and when Dr. Sullivan advised you of his recommendation that the Office of Research on Minority Health be elevated to a center at NIH, did
he expand on why he felt this would be necessary, and was this his primary recommendation, and did he offer other ways to get at these disparities?

Mr. JACKSON. Madam Chair, when he testified before Senator Specter’s committee in the Senate, it became clear amongst the Senators who were participating in the panel that the lack of coordination upon our own inquiry in our Labor-HHS subcommittee further showed that there was a coordination problem on minority health disparities at the National Institutes of Health. Dr. Sullivan had no other recommendation other than the fact that he felt that this center should be treated like other centers, that it should not have to necessarily relate solely to the Director of NIH or get permission in a kind of paternalistic way, that it should be some center that somehow is housed in the Director’s office, but it should be treated like the other centers with the ability to offer research grants to those institutions that were passion-driven.

As you know, Madam Chair, research is a passion-driven subject, and so people who have lost parents and family members to various diseases who choose to pursue research are often driven by the passion of finding a cure for that which ails a personal family member or personally afflicts or affects their community. The absence of these research grants, these extramural grants, at these institutions that are being driven by this passion Dr. Sullivan suggested was the most fundamental problem, and that required its own coordination and its own center.

Mrs. B IGGERT. Thank you. My time has expired, so I’ll turn to Congressman Cummings.

Mr. CUMMINGS. Thank you very much, Madam Chairlady. Representative Thompson, I think you talked about in your testimony—I mean, in your legislation, rather, it addresses the issue of cultural competency in medical education. Can you help us with that and what the significance of that is? It sounds like that’s what also Representative Jackson is talking about.

Mr. THOMPSON. The passion.

Mr. CUMMINGS. Right.

Mr. THOMPSON. Absolutely. We have four African American medical schools in this country. When we started looking at the research for this bill, we found that in NIH only four-tenths of 1 percent of their money went to minority institutions. So we felt that given the minority population in this country, that was a problem.

One of the reasons we’re talking about creating this center is to get an elevation or, if you please, a standing that would give additional finance and credibility.

The other concern, to be quite honest with you, is everyone has been sympathetic to all these health concerns, but it seems to fall on deaf ears when it comes to research and actual dollars in support of it. So one of the reasons we have coined this bill, we also call it a civil rights bill, in that richest country in the world, it’s an absolute travesty that we have statistics for American citizens so glaring as what we have here today that we can’t in good conscience not support this bill, because it is the right thing to do, and that’s the cultural disparity.
Mr. CUMMINGS. Representative Jackson, the Office of Minority Research seems to—I guess they do some—would you agree they do accomplish some pretty good research?

Mr. JACKSON. Ranking Member Cummings, on our committee we’ve been very careful to use the language “good research.” They pursue good research. They don’t pursue minority research. They don’t pursue Black research. They don’t pursue substandard research, language that was used by some members of the committee. They pursue good research, and, for example, a classic example of good research, at Howard University School of Medicine, in one of their research departments, they have an African American woman who is preeminent in her field for the study of the human genome. They have other members of their faculty who have done outstanding work from the study of the human genome on back across to cancer research and a number of other issues that confront minority communities in terms of health research.

When many of these professors submitted papers to the NIH for grants and research funding from Howard University, they were denied. Well, one member of the faculty left Howard University and joined another Ivy League—essentially Ivy League—did not change one word in their research paper, resubmitted the paper to NIH, and the grant was awarded. So why it wouldn’t be awarded when that research professor was at Howard University, but when they then shifted to an Ivy League school, that research was rewarded with an award grant without one word being changed in the proposal is suspect, and that’s why you have to create a center at NIH that is specific and that honors and understands the impact and significance of addressing these health disparities where the passion research must occur.

Mr. CUMMINGS. And I take it that’s why you are promoting and pushing on this making authority that you talked about.

Mr. JACKSON. Yes, sir, I am, and I believe Congressman Thompson’s bill, a centerpiece of his bill as well is the ability of the center to provide research dollars to support good research on these questions.

Mr. CUMMINGS. Now, one of the things that we’re going to be addressing, some of the witnesses will be addressing later on in the hearing, is this whole idea—and Chairlady and I addressed it just a few moments ago, and I think you both talked about it—how you can have situations where African Americans may have less incidence of certain cancers, but yet—and still from a percentage standpoint and a number standpoint they die at greater rates? And I guess the older I get, I’m appreciating the concept of public health in that a lot of African American people and poor people—and poor people are dying long before their time, and I am just wondering how does this legislation, both of you—and this will be my last question because I see my time is up—how does your legislation address those kind of issues?

Mr. JACKSON. Mr. Chairman, as I began in my opening remarks, elevating the Office of Research on Minority Health at NIH to a center status, it is my humblest opinion, sir, it does not do that. This is about research amongst medical institutions, amongst research professionals to inspire and to encourage them to pursue research that might be available across NIH that might apply to all
Americans. But Congressman Thompson is right when he says his district is the third poorest district in America. That’s indicative of the absence of trained medical professionals in his district. It’s indicative of how rural his district is.

It is the same thing in Appalachia. If we weren’t sitting here as African Americans, access to health care, quality health care, doctors who can earn a reasonable living in that environment providing them with MRIs and CAT scan machines to be able to check for fundamental illnesses, and ability to pay are still the fundamental issues that confront our health care system.

And as Chairwoman Biggert indicated in her opening remarks, the ability to detect many of these diseases early is a significant factor in reducing health disparities, but in many of our communities, from African Americans to Latinos to those socioeconomic communities that are economically depressed, if they don’t feel comfortable going to hospitals and to doctors and to health care clinics because of the myriad of barriers that confront our own health care delivery system, then we find out these statistics at the tail end of their lives, which oftentimes reduces the life span of an American.

Mr. THOMPSON. Congressman Jackson is correct. You have to have that passion for the research. If you’re not interested in minority health outcomes, then it is a great possibility that you won’t give it the passion required to come up with good research and good data.

The other thing is most of the African American doctors in this country happen to graduate from African American medical schools. We have to enhance that opportunity. We have to give those schools the best resources possible to go back and practice in that medically underserved area. If we could do that, we could make a tremendous impact on the problems associated with inadequate health care delivery systems.

A number of grants and contracts, as my bill talks about, it’s very important. A lot of it has to do with resources. We have documented the problem. We’ve tried to offer legislation to address it. If we can get the support, bipartisan support, of our bills, I am convinced that over a period of time we can reduce those numbers so that it won’t be a racial disparity attached to health care in this country.

Mr. CUMMINGS. Just a last comment. As you were talking, both of you were talking, I couldn’t help but think about this morning in my district with—we have Johns Hopkins University and also University of Maryland, both with medical schools, but Johns Hopkins, you know, I was just thinking that Johns Hopkins receives hundreds of millions of dollars yearly for research, and I was just thinking if you gave Meharry just some of that, it would certainly enhance the school, would create a better environment for those doctors or students that are coming through there, and would give them an opportunity to do the very things that you all have talked about this morning, being giving service to those underserved communities and having some kind of cultural sensitivity at the same time.

I want to thank both of you. Really appreciate it.

Mrs. BIGGERT. We’ve been joined by Representative Kucinich.
Do you have questions?

Mr. KUCINICH. I just wanted to add my support for the legislation sponsored by Mr. Thompson and with Mr. Jackson’s participation. As someone who served as mayor of a major city and has seen the disparities that you’ve talked about in terms of the demand for health care that often is unmet, the point that you make here is so important, and I think that all of us in the Congress should be working very closely with you to make sure that these issues are addressed so we cannot only wipe out the disparities, but also, even more significantly, attack that very nature of why it is that people are getting cancer anyhow, let alone that they have it more than anyone else.

So I salute both of my colleagues for their work on this, and I look forward to working with you. Thank you. Thank you.

Mrs. BIGGERT. If there are no more questions, then we will thank you very much for coming, and thank you very much for your testimony, and we really appreciate the passion that you have for this. Thank you very much. We appreciate it, and if the next panel would like to come up.

If you would all like to stand, as the committee usually swears everyone in if you’re giving testimony or here to answer questions. So if you would like to raise your right hands.

[Witnesses sworn.]

Mrs. BIGGERT. Thank you, and be seated, please.

Let the record reflect that the witness responded in the affirmative.

On behalf of the committee, we welcome you here today, and I think we will begin with Dr. Freeman.

Dr. FREEMAN. Thank you, Madam Chairman.

Mrs. BIGGERT. And you’re recognized for an opening statement, which is usually about 5 minutes, then we will have 5 minutes of questioning by the committee here after all of you have testified. Thank you.
unequal burden of cancers among minorities, the poor and the underserved.

This spring Dr. Klausner, the Director of the Cancer Institute, asked me to consult with him on these issues, and later, particularly 24 hours ago, I was appointed as the Director of the new Center to Reduce Cancer Health Disparities, so I have been in this position for 1 day, including sleeping time.

Let me point out that profound advances have been made in biomedical science over the last several decades. Many Americans have benefited, but some have not. And there are some groups of people who experience a heavier burden of cancer mortality and incidence, particularly certain minorities, the poor and the underserved. I believe that the unequal burden of cancer in our society is a challenge to science and is a moral and ethical dilemma for our Nation.

Health disparities have been framed historically as racial and ethnic differences, and clearly some races and ethnic groups don’t do as well, but the fact of the matter is, as you have pointed out, Congressman Cummings, is that races are not biological categories. They are social and political categories which we need to keep in mind.

The consequences of racism, however inherent in racial classifications, have for some racial and ethnic groups been associated with several negative factors. For example, fewer social and educational and economic opportunities associated with racism, greater exposure to stress and unsafe environments and reduced access to quality health care.

I would like to point out in another role that I have as a member of the President’s Cancer Panel, last year, in 1999, we reviewed the National Cancer Institute’s history, current status and evolution. We made one major conclusion, that whereas we had made tremendous progress in the war against cancer since 1971 when Richard Nixon declared that war, research has advanced greatly during that time, but we believe—the panel believes that there’s a critical disconnect between what we discover in America and what we deliver to the American people. Barriers that prevent the benefits of research from reaching all of our populations, particularly those who bear the greatest disease burden, must be identified and removed.

In my own work I have thought a great deal about this, and I have reduced these considerations to three major considerations that cause disparities. No. 1 is poverty itself, which has a universal effect. Poor people have substandard living conditions. Poor people are less educated, have frequently a risk-promoting lifestyle and lower access to preventive health care.

Poverty has a universal human effect, but it is disproportionately reflected in certain groups such as African Americans. A third of African Americans are poor. African Americans make up only about 12 percent of our population.

The second factor I think is very critical is culture, including communication systems, belief systems, values, traditions, lifestyles, attitudes and behaviors which need to be understood. Now, culture, Madam Chairman, is not equal to race. There are many cultures within a race, but I think in our research we need to un-
derstand what it is about various culture of our society that may lead to excess, incidence and sometimes mortality.

The third factor which we’re here to talk about today is social injustice, and social injustice is reflected in studies that we’re examining here today, particularly the example given by the fact that Black Americans presenting with early cancer of the lung, colon, breast and prostate are less likely to get the curative treatment. Dr. Bach will elucidate this further.

What are the reasons that this could happen in America? Correcting for socioeconomic status and whether people have insurance or not, these conditions still hold. So we need to look at what it is in America that could allow a person or a group of people to present with early cancer, curable cancer, and not get treated in the same way as others.

In my own view, the answers have to be in two categories. No. 1, what is the attitude and the bias of the health care givers? This seems to be an element that needs to be further explored. No. 2, what is the level of distrust of the people who are being treated? We’ve had a Tuskegee incident here, and I think there’s still concern among Black people that they may be experimented on. So these two elements need to be further explored.

I believe that the issue goes very deep. The issue has to do with how American people in one group perceive each other, value each other and behave toward each other, so that the question of social injustice, the short arm of it is what’s happening today. The long arm of it is what has happened over nearly 400 years in America with respect to social injustice with slavery and legalized segregation.

I’d like to end, because I believe my time is probably up, with a general statement. I believe that we are in a very critical time in America. We have made great advances in science. Those advances are not being evenly applied across our population. Poverty seems to be a determining factor, but also social injustice has a bearing. And so I believe that in our studies to come, we must learn more about these differences in populations, whether they’re intrinsic within the population’s culture or whether they’re extrinsic, related to how people are being treated in our society.

One thing that we need to do is to create standards of care for all American people and know what they are. We need to monitor those standards to see that everyone is treated in the same way. And we need to develop a country that has health providers that are very diverse, that reflect the country that we really are so that the issue of sensitivity of how people are getting treated in our society will somewhat be improved.

Thank you very much.

Mrs. BIGGERT. Thank you very much, Doctor.

[The prepared statement of Dr. Freeman follows:]
Testimony

Ethnic Minority Disparities in Cancer Treatment: Why the Unequal Burden?

Harold Freeman, M.D.

Director, Center to Reduce Cancer Health Disparities
The National Cancer Institute
National Institutes of Health
Department of Health and Human Services

Hearing before the House Committee on Government Reform
Monday, September 25, 2000 at 1:00 pm
2154 Rayburn House Office Building
Good afternoon, Mr Chairman and distinguished Members. I am Dr. Harold Freeman, and I am pleased to have the opportunity to speak with you this afternoon about the disparities in the diagnosis and treatment of cancer and the unequal burden of cancer among minorities, poor and underserved. This spring, Dr. Richard Klausner, Director of the National Institutes of Cancer (NCI), asked me to consult with him on these issues and asked if I would consent to become Director of NCI’s new Center to Reduce Cancer Health Disparities. My experience as director of surgery at Harlem Hospital for twenty-five years (1974-1999) and as national president of the American Cancer Society (1988-1989), as well as my continued commitment to examining health disparities in cancer treatment were deciding factors in accepting this appointment.

Profound advances in biomedical science have occurred over the last several decades which for many Americans have contributed to increased longevity and improved quality of life. Despite this progress, a heavier burden of disease is borne by some population groups, particularly the poor and underserved. The unequal burden of disease in our society is a challenge to science as well as a moral and ethical dilemma for our nation. The scientific evidence is compelling - the incidences of cancer do vary among race and ethnic groups - but the number of those dying of cancer vary at higher rates among certain races and ethnic groups. The urgency for action to address these disparities is critical.

Ten years ago, I co-authored an article in the New England Journal of Medicine entitled “Excess Mortality in Harlem”, in which we documented that a black male in Harlem had less chance of surviving to age sixty-five than a male in Third World Bangladesh. I regret to have to report that too little has changed during the past ten years for many members of the minority populations. Poverty, because of its many effects on resources, environment, behavior and attitude remains to this day to be a major driving force of excess mortality among minorities in this country.
In 1997, the President’s Cancer Panel convened a meeting to discuss the meaning of race in science. We invited a number of nationally recognized scholars across many disciplines including scientists, philosophers, sociologists and psychologists. The group confirmed, what many of us had suspected, that race is a social construct which, as applied to humans, is no longer acceptable and has no legitimate place in biological science.

Racial distinctions in science can provide us with evidence of significant variation in health and disease but this evidence must be interpreted, by examining the social, economic, cultural, and environmental factors in order to understand the underlying causes of the unequal burden of disease among groups.

To begin to examine this complex question let us look at some examples of high quality peer reviewed studies published over the last two years.

In October, 1999, the New England Journal of Medicine published the results of a study that examined racial differences in the treatment of early-stage lung cancer. If discovered at an early stage, non-small-cell lung cancer is potentially curable by surgical resection. However, two disparities between black patients and white patients with this disease were noted in the study.

First, blacks were found to be less likely to receive surgical treatment than whites; and second, blacks were likely to die sooner than whites from this condition. The study further concluded that those black patients who did receive the surgical resection had a survival rate similar to white patients.

Subsequent studies published in the Journal indicated similar treatment disparities with respect to renal transplantation. Black patients were found to be less likely that whites to have been evaluated as candidates for transplants that have been shown to extend survival time and improve quality of life. Moreover, this past spring, an NCI-supported
study published concluded that both black and Hispanic patients were less likely than white patients to be able to obtain commonly prescribed pain medications, because pharmacies in predominately non-white communities often do not carry adequate stocks of opioids.

Black Americans have a higher overall incidence of cancer, and a higher rate of death from cancer than any other racial or ethnic group. The findings of the study lead us to believe that in addition to these burdens, blacks are also inadequately treated for pain from cancer.

Dr. Klausner and I expect that the new NCI Center to Reduce Cancer Health will be at the forefront of our collective efforts to reduce disparities in health. We are grateful for the generous support Congress has provided NCI so the Center can move forward with its work.

Because minority communities carry an unequal burden of cancer-related health disparities, NCI is working to enhance its research, education, and training programs that focus on racial and ethnic populations in need. In my new position, I will have the unique opportunity to direct the implementation of NCI’s ongoing efforts to reduce cancer-related health disparities, and find new ways to translate biomedical research discoveries into practice to reduce these disparities.

Even before I was appointed by Dr. Klausner as Director of the Center, the President’s Cancer Panel began to tackle this problem. The Panel has undertaken a series of regional meetings across the country, with representation from every state, to explore in detail the obstacles which prevent us from getting the best available, state-of-the-art cancer care to all people, regardless of their racial or ethnic background.

In 1999, the Panel conducted a series of meetings survey the history and status of the National Cancer Program. Among the most important findings arising from that effort
was the discovery that a crucial disconnect existed between the research and delivery enterprises associated with modern medical care. Programs of prevention and treatment that are recognized as effective were not being incorporated consistently into routine medical practice in all the diverse populations and neighborhoods of America. Correcting that shortcoming is vital to improve overall cancer care, access, delivery and quality.

Our Panel’s forthcoming regional meetings, each with representatives from nine to twelve states, will include local community members with stories to tell; cancer survivors, employers, health providers, Medicaid officials, and others involved with cancer care will add immeasurably to our store of knowledge. We believe that much of what we will learn at the local and regional level will provide tools for us to address these disparities at the national level as well.

Among other things, we want to find out just who specifically are the under-served for cancer prevention and care in particular areas. Who are the vulnerable populations in each state or region? What factors are preventing patients with treatable cancers from receiving the most appropriate and up-to-date care? Why are people dying from treatable cancers, and who are they? What do states and communities need to do to provide proven interventions for cancer prevention and control? What policy and legislative changes need to be addressed to ensure that all people get appropriate cancer treatment services?

The unequal burden of health disparities among minorities will continue to be a vexing problem. We believe that through the efforts of NCI’s Center to Reduce Cancer Health Disparities, working with all areas of the Institute, the President’s Cancer Panel, and Members of Congress we will be able to focus national attention on developing policies to address this complex problem.

This concludes my remarks and I will be pleased to take any questions you might have.
Mrs. Biggert. We'll proceed then to Dr. Bach.

Dr. Bach. Thank you very much.

Although cancer incidence rates are only 13 percent higher in Blacks than in Whites in the United States, mortality rates from cancer in Blacks exceed that of Whites by 33 percent. Lung cancer ranks No. 1 amongst these cancer killers and claims the lives of more than 150,000 people each year. Just as in cancer overall, we have known for a while that lung cancer disproportionately affects Black Americans.

Today when compared to White Americans, Black Americans are disproportionately affected by lung cancer in two ways. First, they're at an increased risk of developing lung cancer. Second, they have a far shorter survival after they are diagnosed with lung cancer.

Our research group based at Memorial Sloan-Kettering Cancer Center in New York and at the National Cancer Institute here in Bethesda conducted a study that was published in October 1999 to examine this latter problem, specifically why is survival shorter for Black patients than for White patients after a diagnosis of lung cancer. Our focus was on the survival of Black and White patients who were diagnosed at a potentially curable stage, because we knew that even among these patients, Black patients have much poorer survival than White patients.

To illustrate this point let me give you some survival statistics from the patients we studied, Black and White patients 65 years and older who have potentially curable lung cancer. During the years of our study, we saw that 34 percent of White patients who began our study were alive 5 years after diagnosis, while only 26 percent of the Black patients in our study were still alive.

We thought for a number of reasons that this difference in survival between Blacks and Whites with potentially curable lung cancer might be due to Black patients receiving inferior treatment relative to that received by White patients, so we designed a study to address two questions: First, are Black and White patients who are diagnosed with potentially curable lung cancer equally likely to get the best available treatment, specifically surgical removal of their cancer? Second, if treatment rates are unequal, then to what extent do differences in treatment account for the overall lower survival rates that we see in Black patients?

Our study had some special features I'd like to point out. First of all, we addressed our questions by analyzing the National Cancer Institute's SEER data base. This comprehensive cancer incidence data base is the primary source for most cancer statistics.

Second, we limited our analysis to patients who were over— who were 65 years or older, and, therefore, all of the patients in our study had Medicare insurance at the time that they were diagnosed. Therefore, we knew that any differences in treatment that we observed would not be due to differences in insurance coverage.

With the caveat that our findings only report on results for patients 65 years and older, we found two things. First, while 77 percent of White patients underwent surgery for their lung cancer, only 64 percent of Black patients underwent surgery, and this difference was highly statistically significant.
Second, although overall there were the large survival differences between Whites and Blacks that I’d mentioned a little earlier, we saw that those Black and White patients who were treated equally also had equal survival.

The consequence of these two findings put together is that differences in treatment are responsible for a large part of the difference in survival that exists between Black and White patients with early stage lung cancer.

I should emphasize that this difference in treatment was not due to differences in insurance coverage, as I’ve already mentioned. All of these patients had Medicare insurance. Also, this difference in treatment was not due to differences in socioeconomic status. Even among those White and Black persons who were within the lowest income quartiles in our study, we saw that 71 percent of poor White patients would have surgery for lung cancer, while only 63 percent of poor Black patients underwent surgery, and this difference also was highly statistically significant.

We cannot determine from the study why Black patients receive inferior treatment. Our study does provide an estimate for the magnitude of the difference in treatment received by Blacks and Whites and also documents that this difference in treatment is responsible for some of the observed survival differences that we see in lung cancer.

At Memorial Sloan-Kettering we are continuing our efforts to understand and improve the treatment of Black persons with lung cancer. We have formed a partnership with North General Hospital in Harlem in collaboration with Dr. Freeman to expand the screening and treatment services that we are able to offer for persons in need.

In addition, the American Lung Association in New York City and the National Cancer Institute have both continued to provide our research group with funds so we can continue our inquiry into the disparities we see in both cancer treatment and survival.

Thank you.

Mrs. BIGGERT. Thank you very much, Doctor, for your insight.

[The prepared statement of Dr. Bach follows:]
Although cancer incidence rates are only 13% higher in blacks than in whites in the United States (incidence rates 455.2/100,000 vs. 401.9/100,000), mortality rates from cancer in blacks exceed that of whites by 33% (age adjusted mortality rates 271.6/100,000 vs. 166.7/100,000). Lung cancer ranks number one amongst these cancer killers, and claims the lives of more than 150,000 people each year. Just as in cancer overall, we have known for a while that lung cancer disproportionately affects blacks. Today, black americans are not only at an increased risk of developing lung cancer, but also have a shorter survival after diagnosis than do white patients.

Our research group, based at Memorial Sloan-Kettering and at the National Cancer Institute, conducted a study that was published in October 1999 to examine this latter problem — why is survival shorter for black patients than white patients after diagnosis? Our focus was on the survival of black and white patients who were diagnosed at a potentially curable stage, because we knew that even among these patients, black patients have a much poorer survival than white patients. (see Figure below)
We thought, for a number of reasons, that the difference in survival between blacks and whites with potentially curable lung cancer may be due to the fact that black patients were receiving less good treatment for their cancers than were white patients after they were diagnosed. So, we designed a study to address two questions:

1) First, are black and white patients who are diagnosed with potentially curable disease equally likely to get the best available treatment – specifically, surgical removal of their cancer?

2) Second, if treatment rates are unequal, then to what extent do differences in treatment account for the overall lower survival rates that we see in black persons?

Our study had some special features. First of all, we addressed our questions by analyzing the National Cancer Institute's Surveillance Epidemiology, and End Results (SEER) database. This comprehensive database captures information on all patients who are diagnosed with cancer in 10 geographic regions of the United States, and is the primary source for most cancer statistics. Our analysis focused on those patients who were diagnosed between 1985 and 1993. Second, we limited our analysis to patients who were over 65, and therefore had Medicare insurance at the time that they were diagnosed with lung cancer. Therefore, we knew that any differences in treatment that we saw would not be due to differences in insurance coverage. Lastly, because our data included hospital discharge information from the Medicare program, we were able to determine if patients had other serious illnesses that might have kept them from having surgery.

With the caveat that our findings report only results for patients over 65, we found two things. First, black patients were substantially less likely than white patients to have their lung cancers surgically removed. Second, when treated equally, the survival was also equal (see Figure next page), meaning that differences in treatment explained a large part (somewhat more than half) of the difference in survival that exists between black and white patients with early stage lung cancer.

We were concerned that the different rates of treatment that we observed might be due to differences in socio-economic status, degree of burden of other illnesses, or type of Medicare insurance, rather than due to a fundamental difference in the treatment that is received by blacks and whites. We therefore re-examined the rates of surgery for different groups of patients. What we found was that for every grouping, black patients were less likely to undergo surgery than were similar white patients (see Table on next page).

We cannot determine from our study why blacks and whites receive different treatment. Our study does demonstrate that blacks and whites do not receive equal treatment, and this difference in treatment is responsible for some of the observed survival disparity that we see in lung cancer. At Memorial Sloan-Kettering, we are continuing our efforts to understand and improve the treatment of black persons with lung cancer. We have formed a partnership with North General Hospital in Harlem to expand the screening and treatment services that we are able to offer for persons in Harlem. In addition, the American Lung Association of New York City, and the National Cancer Institute have both provided our group with research funds so that we can continue our inquiry into the disparities we see in cancer treatment and survival.
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<td>73.7</td>
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<tr>
<td>Stage of disease</td>
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<td>I</td>
<td>6,052</td>
<td>64.1</td>
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<tr>
<td>II</td>
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<td>43.7</td>
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<td>0.81</td>
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<td>SIFER enrol.</td>
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<td>79.6</td>
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<td>69.6</td>
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<td>0.88</td>
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<td>Concomitantly</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of hospitalizations in previous year</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>6,975</td>
<td>64.0</td>
<td>77.6</td>
<td>0.84</td>
</tr>
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<td>72.3</td>
<td>0.83</td>
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<td>≥ 3</td>
<td>178</td>
<td>56.9</td>
<td>70.7</td>
<td>0.80</td>
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<tr>
<td>Highest Roman–Chisholm index in previous year</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>764</td>
<td>59.7</td>
<td>81.6</td>
<td>0.72</td>
</tr>
<tr>
<td>1</td>
<td>272</td>
<td>58.3</td>
<td>67.3</td>
<td>0.82</td>
</tr>
<tr>
<td>≥ 3</td>
<td>579</td>
<td>54.7</td>
<td>63.1</td>
<td>0.87</td>
</tr>
</tbody>
</table>

*Relative data set of underlying surgical procedure for black patients as compared with white patients. CI = 95% confidence interval.

SIFER includes the Surveillance, Epidemiology, and End Results program. Only data from the states that contributed more than 5 percent of the total data are listed.

Data were missing for 5 black patients and 61 white patients.

Data category includes only the patients who were 65 years of age or older and who had indemnity insurance coverage at the time of diagnosis.

The Roman–Chisholm index was calculated only for the patients who were hospitalized in the 13-month period before the diagnosis.
RACIAL DIFFERENCES IN THE TREATMENT OF EARLY STAGE LUNG CANCER

PETER B. BACH, M.D., LAURA D. CRASHER, Sc.M., JOAN L. WARREN, PH.D., AND COLIN B. BEGG, PH.D.

ABSTRACT

Background: If discovered at an early stage, non-small-cell lung cancer is potentially curable by surgical resection. However, two disparities have been noted between black patients and white patients with this disease. Blacks are less likely to receive surgical treatment than whites, and they are likely to die sooner than whites. We undertook a population-based study to estimate the disparity in the rates of surgical treatment and to evaluate the extent to which this disparity is associated with differences in overall survival.

Methods: We studied all black patients and white patients 65 years of age or older who were given a diagnosis of resectable non-small-cell lung cancer (stage I or II) between 1985 and 1993 and who resided in 1 of the 10 study areas of the Surveillance, Epidemiology, and End Results (SEER) program (10,894 patients). Data on the diagnosis, stage of disease, treatment, and demographic characteristics of the patients were obtained from the SEER data base. Information on coexisting illnesses, type of Medicare coverage, and survival was obtained from linked Medicare inpatient-discharge records.

Results: The rate of surgery was 12.7 percentage points lower for black patients than for white patients (64.0 percent vs. 76.7 percent, P < 0.001), and the five-year survival rate was also lower for blacks (26.4 percent vs. 34.3 percent, P < 0.001). However, among the patients undergoing surgery, survival was similar for the two racial groups, as it was among those who did not undergo surgery. Furthermore, analyses in which adjustments were made for factors that are predictive of either candidacy for surgery or survival did not alter the influence of race on these outcomes.

Conclusions: Our analyses suggest that the lower survival rate among black patients with early-stage, non-small-cell lung cancer, as compared with white patients, is largely explained by the lower rate of surgical treatment among blacks. Efforts to increase the rate of surgical treatment for black patients appear to be a promising way of improving survival in this group.

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choose a setting and design that mitigated the effect of the confounding factors. We proposed two hypotheses: that black patients would receive surgical treat-
ment less frequently than white patients and that dif-
ficulties in survival between black patients and white patients would be substantially explained by the dif-
ference in the rates of surgical treatment.

METHODS

Sources of Data

We tested our hypotheses with the use of data from the Sur-
veillance, Epidemiology, and End Results (SEER) cancer regis-
ters that have been linked with data on Medicare hospitalizations. The SEER–Medicare data base has been used extensively to as-
sess patterns of care for persons with new diagnoses of cancer.16 The SEER registries, sponsored by the National Cancer Institute, list all incident cases of cancer in five metropolitan areas (San Francisco–Oakland–San Jose, Detroit, Atlanta, Seattle, and Los Angeles Counties) and five states (Connecticut, Utah, New Mexico, Iowa, and Hawaii) and cover approximately 14 percent of the pop-
ulation of the United States.17 These data contain information on each new, diagnosed case of cancer; including the month and year of the diagnosis, the location, histologic type, nodal involvement, and spread of the tumor; and the type of treatment provided within four months after diagnosis (e.g., surgery or radiation). The size of the cancer is coded in the SEER data as the Interna-
tional Classification of Disease for Oncology, 2nd edition (ICD-O-2).18

The Medicare program, which provides health care coverage for 97 percent of persons 65 years of age or older, million dollars for all services covered by the program. Information about hos-
italizations is included in the Medicare Provider Analysis and Review (MEDPAR) files, which contain information on all hos-
pital admissions since 1984. Medicare also maintains files that doc-
ument the dates of death of beneficiaries and whether they were covered by a traditional indemnity program or by a health mainte-
nance organization (HMO). The SEER and Medicare data bases have been linked in order to perform population-based studies of health outcomes. The data on 94 percent of persons included in the SEER files who are 65 years of age or older have been successfully linked to Medicare records.19 Focusing on the group of people who were eligible for Medicare or to the exclusion of the 44 percent of persons in the SEER data base who received diagnoses of lung cancer before the age of 65 years, but this allowed us to adjust for confounding con-
trols, the survival outcomes were reported by the SEER data base.

Study Participants

The subjects were persons with a form of lung cancer for which surgical resection has been shown to confer a definite ben-
etic stage I or II (all non-small cell lung cancers).15 We includ-
ed all patients classified as non-Hispanic white or black who were 65 years of age or older, who resided in 1 of the 10 SEER areas, and who were given a diagnosis between 1988 and 1993 of pri-
mary cancer of the lung, non-small-cell histologic type (SEER codes 132, 133, 134, 135, and ICD-O-2 morphology codes 8020 to 8940, 8260 to 8267, 8260 to 8267, 8230 to 8232, 8232 to 8234, 8240 to 8249, 8250 to 8257, 8280 to 8289, and 8961); there were a total of 81,665 patients.

From this group we excluded patients who had not undergone a complete evaluation to determine the stage of disease; that is, those who were not evaluated or examined by a surgeon, a specialist, or a radiologist in the SEER data base (21,006 patients [31.4 per-
cent]). We then identified patients with stage I or II disease (12,927 patients) according to the staging system of the American Joint Committee on Cancer,20 using the information in the

SEER data base on site, spread, and nodal involvement of the tu-
ror. The definitions of these stages were constant throughout the study period. We then excluded patients for whom diagnoses were obtained from death certificates or at autopsy (127 patients [1.0 percent]) and those in whom a second cancer was diagnosed within two months of the primary lung cancer (1,789 patients [15.9 percent]), leaving a cohort of 10,994.

Surgical Treatment and Survival after Diagnosis

Patients were considered to have undergone surgical resection if the record for one specific surgery in the SEER data base in-
dicated that the procedure that was curative in intent had been per-
fomed. Such procedures included local resection, wedge resection, segmentectomy, lobectomy, sleeve resection, partial pneumone-
y, and radical pneumonectomy (SEER codes 10 to 79). The men and year of diagnosis were documented in the SEER data base. For analytic purposes, we assumed that the diagnosis was made on the first day of the month. Dates of death were retrieved from Medicare, which receives this information from the Social Security Administration. All records of death are complete through December 31, 1994, which was therefore chosen as the date of death censoring for patients who were last known to be alive.

Characteristics of the Participants

Demographic Characteristics and Coexisting Illnesses

Information on sex of the patients was obtained from Medicare records, and information on race and age at diagnosis was obtained from the SEER data base. The demographic status of each patient was estimated on the basis of Medicare data on the median income for the ZIP Code of the patient's residence. This variable was especially a measure of income, as opposed to a factor that reflected socioeconomic status on an individual basis. We constructed two measures: one concerning the patients who resided in the lowest quartile of median income, and the other concerning the remaining population.

The hospitalization data were determined with the use of MEDPAR records through an examination of all hos-
pital admissions occurring within the 12-month period before the

month of diagnosis. We calculated two indices of coexisting illness for each patient according to the method suggested by Ro-
mano et al.,21 in which the Charlson comorbidity index was calcu-
lated on the basis of diagnostic records during this period and the other according to the total number of hospital admissions during this period. In order to calculate these two indices, we needed one or more Medicare claims for hospitalization for persons in the SEER data base. Before diagnosis, we therefore calculated the comorbidity index and conducted the adjusted analyses only for patients who had at least one Medicare claim for hospitalization during this period.

Access to Care

All patients were insured by Medicare. We assigned each patient the percentage (HEMO or indemnity) that he or she paid during the month in which the diagnosis was made. To assess the local avail-
ability of care, we used the health care service areas defined by the Health Resources and Services Administration. These areas represent regions with certain characteristics of health care availability, and they have been used in other studies of the availability of health care.22 The areas range in size from parts of a city to sub-
stantial portions of rural population. The health care service areas corresponding to each patient's area of residence were ascer-
tainned in the SEER data base; our 10,994 study participants resided in 89 health care service areas. To determine whether some of our findings could be related to variations in the local availability of health care services, we looked for heterogeneity in our find-
ings with respect to the health care service areas and SEER areas.
RESULTS

Characteristics of the Study Participants

There were 10,984 patients in this study, 860 (8 percent) were black, and 10,124 (92 percent) were non-Hispanic white (Table 1). There were no substantial differences between the two groups with respect to the stage of disease, type of insurance, number of hospitalizations in the 12 months before the diagnosis, or the Roman-Carcinoid comorbidity index. Black patients were slightly younger and somewhat more likely to be men. The most important disparity between the two groups was that black patients were substantially more likely to reside in a ZIP Code area with a low median income. Also, the distribution of patients among the SEER areas differed between the two groups.

Resection Rates and Association with Survival

Black patients and white patients who underwent surgery had roughly similar rates of survival at five years — 35.1 percent among black patients and 42.5 percent among whites ($P=0.10$) (Fig. 1). Those who did not undergo surgery also had similar five-year survival rates (4 percent among blacks and 5 percent among whites, $P=0.25$) (Fig. 1). However, 76.7 percent of the white patients underwent surgery, whereas only 64.0 percent of the black patients received this treatment ($P=0.001$) (Table 2). The combination of discrepant resection rates and similar survival rates after treatment contributed to a substantial difference in the overall survival rates, as shown in Figure 2.

TABLE 1. CHARACTERISTICS OF BLACK AND WHITE METASTATIC BONE-MARROW AS ASK AGE OR OLDER WITH STAGE 1 OR 2 II NON-SMALL CELL LUNG CANCER, 1985 TO 1990.

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>BLACK PATIENTS</th>
<th>WHITE PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yr)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td>210 (42)</td>
<td>3,522 (35)</td>
</tr>
<tr>
<td>65-74</td>
<td>180 (36)</td>
<td>2,591 (32)</td>
</tr>
<tr>
<td>75+</td>
<td>106 (21)</td>
<td>2,381 (31)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>583 (68)</td>
<td>2,566 (62)</td>
</tr>
<tr>
<td>Female</td>
<td>277 (32)</td>
<td>3,039 (38)</td>
</tr>
<tr>
<td>Stage of disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>682 (79)</td>
<td>2,603 (79)</td>
</tr>
<tr>
<td>II</td>
<td>179 (21)</td>
<td>2,321 (21)</td>
</tr>
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<td>Median income in ZIP Code of residence</td>
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<td></td>
</tr>
<tr>
<td>Lowest quartile</td>
<td>385 (42)</td>
<td>1,907 (42)</td>
</tr>
<tr>
<td>Highest quartile</td>
<td>385 (42)</td>
<td>6,914 (68)</td>
</tr>
<tr>
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<td>1,310 (12)</td>
</tr>
<tr>
<td>SEER area</td>
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<td></td>
</tr>
<tr>
<td>Atlanta</td>
<td>122 (14)</td>
<td>730 (7)</td>
</tr>
<tr>
<td>Conner</td>
<td>69 (8)</td>
<td>1,662 (26)</td>
</tr>
<tr>
<td>Detroit</td>
<td>277 (44)</td>
<td>1,792 (28)</td>
</tr>
<tr>
<td>Los Angeles County</td>
<td>83 (18)</td>
<td>189 (4)</td>
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<tr>
<td>San Francisco-San Jose-San Mateo</td>
<td>168 (19)</td>
<td>1,395 (16)</td>
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<td></td>
</tr>
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<td>73 (9)</td>
<td>964 (9)</td>
</tr>
<tr>
<td>Medicare</td>
<td>780 (91)</td>
<td>8,112 (90)</td>
</tr>
<tr>
<td>Not determined</td>
<td>5 (1)</td>
<td>51 (1)</td>
</tr>
</tbody>
</table>

| Total no. | 712 |
| Hospitalizations in previous year | 8,979 |
| Number of hospitalizations | | |
| 0 | 320 (72) | 6,458 (76) |
| 1 | 162 (19) | 1,408 (17) |
| 2 | 41 (5) | 568 (6) |
| 3 | 18 (2) | 150 (2) |
| Highest Roman-Carcinoid index | 3,522 (35) |
| Never treated | 277 (32) | 6,914 (68) |
| 1 | 72 (9) | 803 (9) |
| 2 | 54 (7) | 126 (9) |

*Because of rounding, all percentages do not total 100. SEER data from the Surveillance, Epidemiology, and End Results program. Only the patients from the areas that contributed more than 5 percent of the black cohort are listed.

The Roman-Carcinoid index was calculated only for the patients who were hospitalized in the 12-month period before the diagnosis.

These participants continue the cohort for which comorbidity scores could not be calculated.

The remaining 23.3 percent of patients who did not receive surgical treatment survived for that long. Thus, overall, 341 patients (54.1 percent) were alive at five years. In contrast, of the 1000 black patients, only 264 patients were alive at five years — 77.7 percent lower than the white cohort. Two factors are responsible for this difference: the lower rate of resection among blacks (64.0 percent, vs. 76.7 percent among whites) and the slightly (though nonsignificantly)
lower five-year survival rate after surgery among blacks (39.1 percent vs. 42.9 percent). If black patients had undergone surgery at a rate similar to that for white patients, we estimate that 308 black patients would have been alive at five years, a number only 3.3 percent lower than that for whites. These figures suggest that of the 77 more deaths per 1000 black patients, the majority (44) can be attributed to the failure to provide surgical treatment for a curable disease.

Stratified and Adjusted Analyses

We performed a number of stratified and adjusted analyses to test the robustness of these results. The pivotal disparity in rates of resection was evaluated in several important subgroups (Table 3). The results show that the lower resection rate among black patients was consistent. In addition, we found no evidence that the disparity in resection rates differed according to the health care service area (P=0.85) or SEER area (P=0.64) or that the overall resection rate or the disparity in resection rates varied during the years of the study (P=0.62) (data not shown).

The disparity also persisted in two multivariable logistic-regression analyses in which we controlled for age, sex, stage of disease, median income in the ZIP Code of residence, and coexisting illness, as measured by either the Romano–Charlson index or the number of hospitalizations in the previous year. On the basis of these analyses, the odds ratios for undergoing surgery among black patients, as compared with white patients, were 0.54 when the Romano–Charlson index was used as a measure of coexisting illness and 0.53 when the number of hospitalizations was used — findings that were consistent with the unadjusted odds ratio of 0.52. The results of all the analyses support the hypothesis that race is an important independent factor in determining the likelihood that a patient with early-stage, non–small-cell lung cancer will receive surgical treatment.

The observed similarities in survival among black patients and white patients after either receiving or not receiving surgical treatment were also evaluated in analyses adjusted for factors previously identified as affecting survival. These analyses showed a slightly increased risk of death among black patients after surgery (relative risk, 1.10; P=0.18) and a slightly decreased risk of death for black patients who did not undergo surgery (relative risk, 0.74; P=0.02) (Table 3). The analyses also confirmed that in this cohort, residence in an area with a lower median income, male sex, older age, a higher stage of disease, and more coexisting illness all conferred an increased risk of death, regardless of treatment.

DISCUSSION

The optimal treatment for early-stage, non–small-cell lung cancer is surgical resection — a treatment with a substantial cure rate.5,9,10 In this study, we determined whether the rate of surgical treatment for stage I or stage II non–small-cell lung cancer was lower for black patients 65 years of age or older than it was for white patients in the same age group. Then we compared the survival rates between black patients and white patients who had undergone surgery and between black patients and white patients who had not undergone surgery. Using several analytic techniques to control for the confounding effects of disease stage, type of insurance coverage, avail-
### Table 2. Rate of Rejection and Relative Risk According to Race.

<table>
<thead>
<tr>
<th>Variables</th>
<th>No. of Patients</th>
<th>Rejection Rate (%)</th>
<th>Relative Risk [95% CI]*</th>
<th>p Value</th>
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</thead>
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<tr>
<td></td>
<td>BLACK PATIENTS</td>
<td>WHITE PATIENTS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>10,984</td>
<td>64.9</td>
<td>76.7</td>
<td>0.83 (0.79-0.85)</td>
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<tr>
<td>Age [yr]</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65-69</td>
<td>3,978</td>
<td>73.7</td>
<td>85.4</td>
<td>0.86 (0.81-0.92)</td>
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<tr>
<td>70-74</td>
<td>2,541</td>
<td>64.3</td>
<td>80.2</td>
<td>0.80 (0.73-0.86)</td>
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<td>≥75</td>
<td>3,565</td>
<td>65.6</td>
<td>64.2</td>
<td>0.71 (0.61-0.82)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6,447</td>
<td>64.8</td>
<td>76.7</td>
<td>0.65 (0.60-0.70)</td>
</tr>
<tr>
<td>Female</td>
<td>4,537</td>
<td>62.1</td>
<td>76.6</td>
<td>0.62 (0.57-0.69)</td>
</tr>
<tr>
<td>Stage of disease</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>8,841</td>
<td>64.1</td>
<td>77.0</td>
<td>0.83 (0.79-0.88)</td>
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<tr>
<td>2</td>
<td>2,143</td>
<td>65.5</td>
<td>75.5</td>
<td>0.84 (0.79-0.89)</td>
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<tr>
<td>Median income in ZIP Code of residence</td>
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<tr>
<td>Lowest quartile</td>
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<td>70.7</td>
<td>0.88 (0.83-0.93)</td>
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<td>78.0</td>
<td>0.87 (0.82-0.92)</td>
</tr>
<tr>
<td>Not determined</td>
<td>1,421</td>
<td>66.3</td>
<td>78.2</td>
<td>0.81 (0.74-0.86)</td>
</tr>
<tr>
<td>SEER area</td>
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</tr>
<tr>
<td>Nevada</td>
<td>942</td>
<td>59.7</td>
<td>70.4</td>
<td>0.79 (0.70-0.88)</td>
</tr>
<tr>
<td>Colorado</td>
<td>1,731</td>
<td>65.0</td>
<td>79.5</td>
<td>0.88 (0.75-0.102)</td>
</tr>
<tr>
<td>Denver</td>
<td>2,167</td>
<td>69.2</td>
<td>73.1</td>
<td>0.88 (0.76-0.91)</td>
</tr>
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<td>Los Angeles County</td>
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<td>65.9</td>
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<td>0.83 (0.71-0.97)</td>
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<tr>
<td>No. of hospitalizations in previous year</td>
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<tr>
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<td>419</td>
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<td>50.0</td>
<td>66.2</td>
<td>0.80 (0.65-1.01)</td>
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<td>Hispanic–Romano–Chowon index in previous year</td>
<td></td>
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<tr>
<td>0</td>
<td>766</td>
<td>59.7</td>
<td>81.6</td>
<td>0.73 (0.65-0.80)</td>
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<tr>
<td>1</td>
<td>673</td>
<td>58.3</td>
<td>67.3</td>
<td>0.87 (0.71-1.06)</td>
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<tr>
<td>≥3</td>
<td>579</td>
<td>54.7</td>
<td>60.1</td>
<td>0.91 (0.73-1.13)</td>
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*Relative risks are of undergoing surgical resection for black patients as compared with white patients. CI denotes confidence interval.

SEER denotes the Surveillance, Epidemiology, and End Results program. Only data from the states that contributed more than 5 percent of the Black cohort are utilized.

Data were missing for 5 black patients and 51 white patients.

**This analysis excludes only the patients who were 65 years of age or older and who had adequate insurance coverage at the time of diagnosis.

The Hispanic–Romano–Chowon index was calculated only for the patients who were hospitalized in the 12-month period before the diagnosis.

The ability of care, socioeconomic status, age, and coexisting illnesses, we found that black patients were less likely than white patients to undergo surgical resection (a difference of 12.7 percentage points). Both unadjusted and adjusted analyses showed that black patients who underwent surgical resection had a five-year survival rate similar to that of white patients who underwent resection, and we estimated that the 77 more deaths per 1000 black patients, the majority (64) could be attributed to the lack of surgical treatment.

If black patients were to undergo surgery at a rate equal to that of white patients, their survival rate would probably be substantially improved and would adopt that of white patients. Given equal rates of resection, we estimate that there would be a 3.3 percent discrepancy in survival at five years (343 survivors among 1000 white patients vs. 308 among 1000 black patients). The survival curves shown in Figure 2 for black patients and white patients after surgery suggest a similar conclusion; given equal treatment, black patients will have a survival rate that is only marginally lower than that of white patients. The small disparity in survival between black patients and white patients with equal resection rates is not surprising, even if surgery confers an equal benefit in each group.
The actuarial data (deaths due to all causes) in the same population show a larger gap on average, a 73-year-old black person has a 76 percent likelihood of survival for five years, as compared with 81 percent for a 73-year-old white person.

These results should be viewed with caution. We focused on Medicare beneficiaries who were 65 years of age or older, and it is not clear whether there is similar variability in the care provided to younger patients with lung cancer. In addition, in all the patients in our study, the diagnosis of non-small-cell lung cancer and the stage of disease had been established, which meant that all the patients had had extensive involvement with the health care system. Our study did not address the care received by patients who present with advanced disease or those in whom the stage of disease has not been determined. Two other factors that we did not investigate also increase mortality due to non–small-cell lung cancer in black persons. The annual incidence of non–small-cell lung cancer in this population of people who are 65 years of age or older is higher among black persons.
per 100,000 population) than among white persons (294 per 100,000).2,22 Also, among persons 65 years of age or older in whom the stage of disease is determined at the time of diagnosis, the SEER data show that black patients are less likely than white patients to have resectable (i.e., stage I or II) disease (27 percent vs. 31 percent) (unpublished data).

In this study, we were also limited in our ability to make adjustments for two factors that might have influenced the interpretation of our results. We used an aggregate measure of income as a surrogate for the socioeconomic status of each patient. Some investigators have argued that our aggregate measure is an adequate surrogate marker for socioeconomic status,23 but others have argued that the optimal socioeconomic variable is at the level of the patient, not at the level of the community.24 Therefore, we cannot be sure that we have separated the effects of race from those of socioeconomic status.

In addition, we could not ascertain the Romano-Charlson comorbidity index for the 76 percent of our patients who were not hospitalized in the year before the diagnosis. However, it seems unlikely that this lack has led us to make incorrect conclusions, for three reasons. First, in the 24 percent of patients in whom we could evaluate coexisting illness in terms of the Romano-Charlson comorbidity index, the disparity in treatment was consistent. Second, most clinicians would agree that, barring the presence of severe pulmonary disease, a patient who had not required hospitalization for a year could probably tolerate a thoracotomy and partial lung resection.25 Third, we can predict that the bias we may have introduced by using this measure of coexisting illness would, if anything, have led us to underestimate the disparity in treatment between black and white patients. Specifically, for chronic diseases that are responsive to outpatient management, such as chronic obstructive pulmonary disease, blacks are more likely than whites to be hospitalized for the same degree of illness, thus increasing our estimate of the burden of coexisting illness among blacks.25,26 Variations in the care of patients with similar diseases have been observed since Wennberg and Gittelsohn first called attention to the phenomenon in 1973.27 Unlike the treatments under scrutiny in many other studies, the optimal strategy for the treatment of early-stage, non-small-cell lung cancer is unambiguous: surgical resection confers a meaningful probability of cure, whereas other therapies do not. We cannot determine from our data why black patients have a lower rate of resection than their white counterparts, but we can conclude that the difference in treatment has a substantial effect on survival. Others have argued that the preferences of black patients may differ from those of white patients or that black patients may weigh the risks of surgical therapy differently.28,29 An alternative explanation is that black patients are offered optimal treatment less frequently than their white counterparts.30 These are certainly issues worthy of investigation in future studies.

REFERENCES

RACIAL DIFFERENCES IN THE TREATMENT OF EARLY-STAGE LUNG CANCER

Mrs. Biggert. Dr. Thompson, if you would like to proceed.

Ms. Thompson. Madam Chair, Ranking Member Cummings, and the rest of the committee, thank you for asking me to talk about what we're doing at the University of Maryland to reduce disparities. I would like to just highlight some of the things we're doing for African American males and some of the community level interventions we're doing at the University.

Faculty and students at the School of Nursing reach out to communities in Maryland by providing direct primary health care services to medically and geographically underserved populations in a number of innovative models.

Faculty and students operate a community-based health center which brings low-cost health care services to an inner-city community in Baltimore City, as well as manage and staff 14 school-based and school-linked clinics throughout the State.

Other examples of initiatives that we do is we offer— we conduct six mobile health units that are staffed by the School of Nursing and faculty. These services are mobile health services to vulnerable populations in the State.

We also train lay workers to conduct outreach education and support in high-risk communities throughout the State of Maryland. Hundreds of individuals thought of as hard to reach are touched by these services. Lives are being saved through these primary health care initiatives.

For years, my colleagues at the University of Maryland have researched the problems facing African Americans in this country. We have worked to better understand African American males, their cultural beliefs and practices and how they are impacted by public health.

The result of clinical studies show that lack of accurate knowledge about cancer and cultural misconceptions are major barriers to increasing the number of African American men who participate in early screening and treatments.

Our research has also shown that encouragement by loved ones and friends can encourage healthy life-styles. More research is needed, however, to better understand these factors and their impact on behavior and to design more culturally specific innovations that can motivate African American men to seek early cancer screening and care.

Through funding from the National Cancer Institute, the Maryland Special Populations Cancer Network partnered with community-based organizations to address Black male cancer disparities in Baltimore City, MD's Eastern Shore and southern Maryland.

In July, the University held a cancer prevention workshop within the State; and we reached hundreds of people who spoke candidly about the cancer prevention needs of minorities and lack of educational resources that are available to meet their needs.

At the University of Maryland-Baltimore, researchers are looking at ways to reduce costs as we continue to try to provide quality health care service. We believe that prevention is the moral and cost-effective course to take.

We are convinced that effective reduction in cancer incidence and mortality among African American men requires community-based education and public health efforts specifically tailored for them.
We know from data from the World Health Organization that availability, accessibility and acceptability of resources determine access to preventive health care interventions.

Lack of any health insurance remains a critical problem to trying to serve high-risk communities.

Preventive cancer screening is critical, and we need to develop workable strategies in order to reach people throughout the country.

I have seen in my practice many men who come in for care who work every day and are unable to get the services they need until they're disabled. We do need to try to reduce this disparity because it increases the burden of health care costs.

I am convinced that with increased Federal funding we would be able to provide targeted primary health care services to the community. The strategies we seek in order to reduce the disparity—to provide more direct primary health care services to high-risk minority communities, nurse practitioner clinics and accessible mobile vans—are strategies we have seen that could be used to reach high-risk communities. The use of lay workers is also an effective way to out reach to communities. If we are to successfully eliminate minority health disparities we must make every opportunity to reach African American men.

Thank you.

Mrs. Biggert. Thank you very much, Dr. Thompson.

[The prepared statement of Ms. Thompson follows:]
Witnesses Appearing before the House of Representatives
Committee on Government Reform

Linda Thompson, Dr.PH, RN FAAN
Associate Professor and Asst. Dean of Nursing, UMAB
Accompanied by
Keith Plowden, Ph.D., RN, Assistant Professor

Statement by Dr. Linda Thompson
September 25, 2000

Mr. Chairman and Members of the Committee:

I would like to thank the Committee for your interest in the disproportionate burden of cancer on minorities and, especially, for your support for the elimination of the cancer disparities that unduly afflict minority Americans, especially African-American men.

My name is Dr. Linda Thompson, and I am accompanied by Dr. Keith Plowden. We represent the University of Maryland, Baltimore School of Nursing and Maryland Special Populations Cancer Network at the School of Medicine.

At the University of Maryland, Baltimore we have worked diligently on reducing health disparities among minority groups through research, service, and education. I would like to highlight the cancer issues facing Blacks, with a special emphasis on Black men, and some of the community-level interventions that we have seen work at our institution.

While this country has the most advanced medical science in the world, many Americans of color have limited access to that system, mainly due to lack of resource availability.

- Nearly 24 percent of African American adults are uninsured compared with 14 percent of white adults.

- Nearly 4 of every 10 African American adults report that they do not have a regular doctor.
Faculty and students of the School reach out to communities in Maryland by providing direct primary health care services to medically and geographically under-served populations in a number of innovative nurse-managed models.

Faculty and students of the School operate a community-based health center, Open Gates, which brings primary and preventive health care to an inner-city community in southwest Baltimore, as well as manage and staff 14 school-based and school-linked wellness centers in Baltimore and several surrounding counties.

Other examples of innovative initiatives include the Governor’s “Wellmobiles,” six mobile health units staffed by School of Nursing faculty and students, that take preventive and primary care directly to the vulnerable populations of the state.

Hundreds of individuals who are thought of as hard to reach are touched by these services. Lives are being saved through these primary and secondary prevention interventions.

For years, my colleagues at the University of Maryland have researched the health problems facing Blacks in this country. In particular, we have worked to better understand African American male cultural beliefs and practices - as they affect public health - and to develop programs that will save more lives.

The results of clinical studies show that lack of accurate knowledge about cancer and cultural misconceptions are major barriers to increasing the number of African American males who participate in the early screening and treatment that can save their lives.

Our research has also shown that encouragement by loved ones and friends can encourage healthy lifestyles. More research is needed, however, to better understand these factors and their impact on behavior and to design culturally specific interventions that will better motivate African American men to seek regular cancer screening and care.

Through funding from the National Cancer Institute, the Maryland Special Populations Cancer Network currently is partnering with community-based organizations to address Black male cancer disparities in Baltimore City, Maryland’s Eastern Shore and Southern Maryland.
In July, the University held a cancer prevention workshop for the state that reached hundreds of people who spoke candidly about the cancer prevention needs of minorities and the lack of educational and related resources available to meet those needs.

Cancer Burden

The burden of cancer has disproportionately fallen upon Black men. Nationally, they are at least 50% more likely to develop prostate cancer than men of any other racial or ethnic group. Black men also are more likely than any other group to be stricken with invasive cancer.

Perhaps the most disturbing evidence about the burden of cancer on African Americans males, however, is that they are more likely than Caucasians to reveal advanced, more deadly cancers at the time of initial detection.

As a result, the 5-year survival rate for cancer is 10% lower for Black men than for White men (SEERS, 1996; Haas & Sakr, 1997).

Specifically, for the years 1990-1996, the age-adjusted incidence of invasive cancer was 598/100,000 for Black men compared to 480/100,000 for Caucasian men.

The mortality rate for all cancers is higher among Black men (208/100,000) compared to white men (138.6/100,000).

Esophageal cancer was 13.5/100,000 for Black men compared to 6.3/100,000 for White men.

Lung cancer was 112.3/100,000 for Black men compared to 73.1/100,000 for white men.

Late diagnoses may be linked to a lack of awareness of early warning signs; poor availability of screening, inadequate outreach or other educational efforts; cultural factors, such as fatalism and pessimism; the absence or inadequacy of health insurance; and other factors that pose barriers to early diagnostic care.

Most of the specific cancers I have mentioned are generally affected by lifestyles. For example, 70% of most lung cancers are related to cigarette smoking; and we know that
Blacks tend to smoke cigarettes higher in tar, which greatly increases their risk.

With respect to most cancers, the availability of timely, quality health care significantly increases one’s chances of remaining cancer free and surviving cancer when it does occur. Even when cancer is not prevented, survival can greatly be influence by early detection and treatment.

The burden of cancer falls not only on individuals but also upon society as a whole. The American Cancer Society estimates national cancer care costs at $107 billion annually, with prostate and lung cancer accounting for most of those costs.

Saving lives is not incompatible with saving the public’s tax dollars.

Public policy should compare the human and economic costs of public interventions that reduce smoking among Black men with the significant national expenditures for lung cancer surgery. We should examine more closely the cost of providing screening for prostate cancer as those costs compare to the cost of a radical Prostatectomy.

At the University of Maryland, Baltimore, researchers are looking at ways to reduce costs while continuing to provide quality services. We believe prevention is the moral and cost-effective course to take.

Social and Economic Factors Associated with the Higher Cancer Mortality Experienced by African American Males

We are convinced that effective reduction in cancer incidence and mortality among Black males requires community-based education and public health organization efforts specifically tailored for them.

We know from World Health Organization data, for example, that the availability, accessibility and acceptability of resources determine access to preventive health care interventions.

As noted, lack of health insurance remains a critical problem that we must address if we wish to improve cancer survival rates. Although efforts are being made to expand health care services into minority communities, people must be able to afford them.

Preventive cancer screening is a critical component of any workable strategy to reduce
cancer mortality among African American males, but additional resources are needed to support follow-up diagnosis and treatment.

I have seen in my practice many men who are working every day and still are unable to afford the health care services that they need. Many men with chronic illness are only eligible for health assistance when their medical problems progress to the point of disability, increasing the burdens on our health care system.

Upon close examination, I am convinced that you will find that increased federal funding targeting primary and secondary cancer prevention within African American communities will cost-effectively reduce the burden of disability among Black males.

Even when resources are available, however, closer attention must be paid to how these men are treated when they do have access to health care.

A growing body of evidence demonstrates that ethnic minorities are less likely than whites to receive aggressive therapies and treatments for cancer and other potentially mortal diseases.

In 1996, for example, Geiger et al. documented studies showing that minority patients, particularly African Americans, are less likely than whites to receive appropriate clinical treatment, even when controlling for income, education, insurance status and other factors.

Shulman et al. (1998), found that physicians were less likely to prescribe an appropriate treatment for African Americans than for whites, despite the fact that the patients displayed the same symptoms of heart disease and were controlled for age, gender and other factors that may affect clinical judgment.

Bach et al. (1999) reported that Black patients were less likely than white patients to receive surgery for early lung cancer, concluding that a lower survival rate among Black patients was largely explained by the lower rate of surgery.
Expanded Community Based Education and Health Care Services Will Reduce Cancer Mortality Among African American Men

The University of Maryland, Baltimore has been successful in reaching hard to reach individuals through our community-based primary care approach.

We suggest more funding be directed toward primary care facilities that serve minority communities with a special focus on prevention and early interventions.

Nurse managed clinics and other accessible health care services such as mobile health units are essential to meeting the cancer threat where it arises - in the community.

While efforts have been made to address the issue of minority participation in research, more work is needed. We suggest more funding and training for investigators (especially minorities) with both an interest in reducing disparity and the training to design public health interventions that will better address the existing disparity in cancer mortality among Black men.

If we are to successfully eliminate minority health disparities by the year 2010, far more effort must be made to address the specific health care needs of African American men.

In this age of advanced medical technology, no one should die needlessly in America.

Thank you.
Mrs. BIGGERT. Now Dr. Huerta.

Dr. Huerta. Buenas tardes. Good afternoon. My name is Elmer Huerta. I’m the founder and director of the Cancer Risk Assessment and Screening Center of the Washington Cancer Institute at the Washington Hospital Center here in Washington, DC.

I am the founder of a clinic that has a theme. It says, if you are sick, this is not a place for you. This is for healthy people only. Over 7,500 people crossed our doors in 5 years. You can’t imagine how much I shiver every time I have an uninsured person come in for cancer screening. I wonder to myself how this wonderful and powerful country can allow its citizens to have this bad time.

I’m pleased to appear before you today as a member of the National Board of Directors of the American Cancer Society. As you might know, the American Cancer Society is the Nationwide, community-based, voluntary health organization dedicated to eliminating cancer by preventing cancer, saving lives and diminishing suffering from cancer through research, education, advocacy and services.

Most of my work as a physician has focused on providing care to those in greatest need. My dedication has been to my community, which primarily represent Latinos and African Americans in the greater Washington, DC, area. Allow me to share a little bit about them.

Many of my Latino patients have origins outside of these borders, our borders. They are Americans nonetheless who are exploding in numbers and make up an increasing number of the U.S. work force.

As for my African American patients, some of them are native Washingtonians whose ancestors helped build this wonderful city known as the Capitol where decisions are made daily that effect the lives of all Americans. Despite the history and the many contributions made by these populations, they are not pictures of health. Too many of them are uninsured, unemployed and at an increased risk for cancer and other chronic diseases.

We all know people—friends, neighbors and beloved ones—who are surviving cancer today in greater number than before. The evidence of decreasing cancer mortality is encouraging and presents a compelling argument for prevention, early detection and scientific research. However, the higher cancer incidence and death rates among minorities suggest that not all Americans are equally benefiting from scientific breakthroughs and cancer prevention and control efforts.

So we ask ourselves, why do these disparities exist and how can we address this problem?

For starters, let me give you a snapshot of this crisis. As a Nation, we have spent $1 trillion each year on health care, yet only 1 percent of that goes to population-based prevention efforts. That translates into less than a penny a day per person. Sergeant General David Satcher emphasized this fact at the launching of Healthy People 2010. Primary prevention strategies such as tobacco control, nutrition and physical activity do save lives and do reduce the social and economic costs of cancer and other diseases.
It seems to me that most of our medical establishment is very interested in Mrs. Smith’s tumor. What I request from you is that we must focus on Mrs. Smith herself.

The American Cancer Society has identified several areas of promise that will help us tackle these challenges, some of which are captured in the Institute of Medicine Report on the Unequal Burden of Cancer. I respectfully urge the committee to consider the following recommendations. I can assure you that the American Cancer Society stands ready to assist you in any way.

First, we must sustain and expand the proven research programs that have enabled us to pursue a path of scientific excellence and discovery in cancer research, while also seizing extraordinary opportunities to further the progress made by our previous research success.

Second, we must focus on strategies that involve communities in creating and delivering the programs that will reduce and eliminate that unequal burden of cancer, with government providing the support and resources critical for success.

Next, we must place a greater focus on prevention and early detection efforts. That means bringing cancer screenings to the people, instead of waiting for them to come to us. We must continue our efforts to build awareness through creative approaches utilizing channels such as the media, radio, our schools and churches. Resources need to be directed toward development of programs that will better reach and serve medically underserved populations.

We must continue to fund research. We must certainly apply what we know about cancer prevention, early detection and treatment equally to all communities to ensure that all Americans benefit from the progress we have made in the 20th century. Eliminating disparities is critical to the success of our national cancer program and to improving the lives of all American families.

Thank you.

Mrs. BIGGERT. Thank you very much, Doctor.

[The prepared statement of Dr. Huerta follows:]
TESTIMONY ON BEHALF OF THE AMERICAN CANCER SOCIETY

ELMER E. HUERTA, M.D., M.P.H.
NATIONAL BOARD MEMBER

BEFORE THE UNITED STATES HOUSE OF REPRESENTATIVES
COMMITTEE ON GOVERNMENT REFORM

"ETHNIC MINORITY DISPARITIES IN CANCER TREATMENT: WHY THE UNEQUAL BURDEN"

SEPTEMBER 25, 2000
1:00 PM

Contact
Elisa D. Quarles
American Cancer Society
National Government Relations Department
Phone: 202-661-5708
Fax: 202-661-5750
Email: equarles@cancer.org
INTRODUCTION

Buenas Tardes. Good afternoon. My name is Elmer Huerta, M.D., founder and director of the Cancer Risk Assessment and Screening Center of the Washington Cancer Institute at the Washington Hospital Center in Washington, D.C. I am pleased to appear before you today as a member of the National Board of Directors of the American Cancer Society. The Society is grateful for the interest of this committee on an issue of utmost importance to our organization and to me personally. It is a central priority of the American Cancer Society to reduce the burden of cancer among minorities and medically underserved populations. Today, I’d like to share with you what our organization is doing to fight the war on cancer and paint a picture -- all too common in American – of how communities of color and poor Americans often face the greatest barriers to quality health care.

As you may know, the American Cancer Society is the nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer through research, education, advocacy, and services. Nationwide, more than 18 million volunteers and supporters, many of who are cancer survivors, contribute their time and resources to the American Cancer Society to help meet our goals. I am proud to say I am one of those volunteers.

Most of my work as a physician has focused on providing care to those in greatest need. My dedication has been to my community, which primarily represents Latinos and African Americans in the Greater Washington DC area. Allow me to share a little about them. Many of my Latino patients have origins outside of our borders. They are
Americans nonetheless who are exploding in numbers and make up an increasing number of the United States' workforce. As for my African American patients, some of them are native Washingtonians whose ancestors helped build this wonderful city we know as the Capitol, where decisions are made daily that affect the lives of all Americans. Despite this history and the many contributions made by these populations, they are not pictures of health. Too many of them are uninsured, unemployed, and at increased risk for cancer and other chronic diseases.

As documented, cancer is the second leading cause of death in the United States, accounting for more than 550,000 deaths each year – more than 1,500 people a day. One in four Americans will die from cancer. Those who die of cancer may have been our family members, our neighbors, and our friends. However, let us not forget those we don’t often see, those who may be the less fortunate. They are the people we stumble past every day as we cross the street, or the woman who works night and day to make ends meet to feed her family. They, too, are the real people who make up this very real number.

As a nation, we have made tremendous progress in the battle against cancer. When the American Cancer Society was founded in 1913, cancer was a poorly understood disease that killed the great majority of the people it touched. Over time, we have learned more about cancer and how environmental agents – such as tobacco – cause disease. This basic knowledge about the nature of cancer is providing us with critical insights into how we can prevent and detect cancer more effectively. And it is giving us the opportunity to improve treatments that lead to longer survival and improved quality of life.
WHY DISPARITIES EXIST

We all know people — friends, neighbors and loved ones — who are surviving cancer today, in greater numbers than ever before. The evidence of decreasing cancer mortality is encouraging and presents a compelling argument for accelerating our national investment in prevention, early detection and scientific research. However, the higher cancer incidence and death rates among minorities and medically underserved populations suggest that not all Americans are equally benefiting from scientific breakthroughs and cancer prevention and control efforts. Allow me to give you some examples. African Americans overall are more likely to develop cancer than persons of any other racial and ethnic group and are twice as likely to die of cancer than Asian/Pacific Islanders, American Indians, and Hispanics. Also, death rates from prostate cancer among African American men are almost twice those of white men. Among all women, Alaska Natives are 30% more likely to die from cancer and the incidence of cervical cancer in Hispanic women has been consistently higher at all ages, although African American women hold the title for the highest death rate from cervical cancer. Lastly, rates of rarer cancers such as stomach cancer, are substantially higher among Asian Pacific Islanders, including Native Americans. This data shows that minority and poor Americans have a disproportionate risk of being diagnosed with, and dying from, certain types of cancer. I stand before you as one provider who has witnessed the darkness of cancer and the lives it has claimed.

So we ask ourselves today, why do disparities exist and how can we address this problem?
For starters, let me give you a snapshot of this crisis. As a nation we spend $1 trillion each year on health care, yet only one percent of that goes to population based prevention efforts. That translates into less than a penny a day per person. Surgeon General David Satcher emphasized this startling fact at the launching of Healthy People 2010. Primary prevention strategies such as tobacco control, nutrition and physical activity do save lives and reduce the human, economic, and social costs of cancer and other diseases.

Existing tools to fight cancer are working. But, unfortunately, they are not being used or are unavailable to all Americans. If our investments are increased and efforts are targeted to make the biggest impact at the community level—particularly in medically underserved communities—we can reduce death and suffering, by preventing cancer from occurring in the first place or, if cancer occurs, detecting it at its earliest, most treatable stage.

Other key reasons for the reality that some communities are not experiencing declines in cancer deaths and incidence include access to care and health insurance coverage. One in seven Americans lacks health insurance. This creates a significant barrier to getting medical care of any kind.

Less obvious, yet equally important barriers to receiving quality health care include geography, language, fear and distrust of health care providers, and difficulties navigating our health care delivery system. We believe that ensuring access to care is a large part of preventing premature cancer deaths. Access is the door through which all Americans must pass to become empowered, informed, and healthier individuals.
NATIONAL ADVOCACY EFFORTS

The needs of these very real people with real problems will go unmet unless we play an active role in developing real solutions. As a part of our mission, the American Cancer Society's advocacy efforts are integral to our day to day operations. We take pride in being a leader in helping to craft and influence public policies that positively impact the lives of cancer patients and their families. Our soldiers are bringing the message to those who make decisions on our behalf -- be it on a federal, state, or local level. However, the fight for all families, particularly those most distant from the health care system, never ends and always needs more support.

The American Cancer Society recognizes the importance of partnerships and collaboration with traditional and non-traditional partners. We know that our efforts would be fruitless unless we empower others who have traditionally been overlooked by the cancer community. Our relationship building and partnerships include organizations like the Intercultural Cancer Council (ICC), the NAACP, the National Medical Association, the National Council of La Raza, the Interamerican College of Physicians and Surgeons, and the National Asian Women's Health Organization to name a few. We have encouraged them to be part of our agenda-setting process and asked them to take action on important legislation that affects every American. As a result, we have made new cancer fighting allies and have honed our focus on the realities of being a minority or medically underserved person in America.

Achieving equity with regard to cancer incidence and mortality is not solely the responsibility of the government, it is a responsibility we all share. I am here today because all of us must take the responsibility for turning our dreams into reality not a dream deferred. Our commitment to defeat this terrible disease is what brings us all
together today. Here, in this city of political wrangling and partisan posturing, cancer crosses all traditional lines. We are here as a community sharing a common vision for winning the war against cancer.

The American Cancer Society has identified several areas of promise that will help us tackle these challenges some which are captured in the Institutes of Medicine Report on the Unequal Burden of Cancer. I respectfully urge the committee to consider the following recommendations. I assure you that the American Cancer Society stands ready to assist you in any way.

- First, we must sustain and expand the proven research programs that have enabled us to pursue a path of scientific excellence and discovery in cancer research while also seizing extraordinary opportunities to further the progress made by our previous research successes.

- Second, we must focus on strategies that involve communities in creating and delivering the programs that will reduce and eliminate the unequal burden of cancer, with government providing the support and resources critical for success.

- Next, we must place a greater focus on prevention and early detection efforts – that means bringing cancer screenings to the people, instead of waiting for them to come to us. We must continue our efforts to build awareness through creative approaches utilizing channels such as the media, radio, our schools and our churches. Resources need to be directed towards development of culturally competent programs that will better reach and serve medically underserved populations. These approaches have been successful in improving the access of populations to cancer prevention; early detection, treatment and continuing care services.
• Additionally, we must improve cancer data collection and surveillance efforts that continue to be the backbone to our cancer control and prevention efforts. Data on all Americans, diverse as we are, is critical to mapping our course to success. Data will give us the information to target our interventions where the need is greatest. Now is the time to invest in this data infrastructure – no other successful industry in this country operates without strong R&D and good data – we must have the same framework for our cancer research and control efforts.

• Finally, we urge Congress to pass the Health Care Fairness Act (H.R. 3250), an emerging piece of legislation that seeks to enhance the federal government’s commitments to improving the health of minorities and medically underserved populations principally through the work of the National Institutes of Health. We encourage Congress to take the action to strengthen the federal government’s commitment to the conduct and support of research on issues related to health disparities among racial and ethnic minorities. Moreover, this legislation takes important steps to assure that the federal government funds studies and efforts to address cultural biases in health care access and delivery, promote effective interventions in minority communities, and develop outcome measures to assess and improve health care quality for minority communities.

CONCLUSION

The decline in cancer death rates is promising news for all of us, but we must not take this progress for granted. It must be sustained and broadened to reach into all communities. We cannot mask the reality that exists for millions of Americans who continue to live each day with cancer that goes undetected. We must build the fortress that will protect us all from unnecessary loss of human life.
We must continue to fund research. We must certainly apply what we know about cancer prevention, early detection and treatment equally to all communities to ensure that all Americans benefit from the progress we've made in the 20th century. Eliminating disparities is critical to the success of our National Cancer Program and to improving the lives of all America's families. We are confident that through our efforts — national, state, and local — we can seize the opportunities and win the war against cancer.
Mrs. BIGGERT. We’ll now turn to the questioning, and at 5 minutes—the other two witnesses are going to answer questions that we might have.

In fact, I will—we’ll begin by asking Dr. Ruffin, I think that, as you know, the National Institutes of Health has traditionally opposed the creation of any new centers. So what is the NIH position on the two bills that have been introduced by Congressman Jackson and Congressman Thompson to elevate the Office of Research on Minority Health to a center?

Dr. RUFFIN. Madam Chairman, if you would permit me to make one sentence before I get to the answer of your question.

But I wanted to say, in light of much of the testimony that has been provided here, that my office, the Office of Research on Minority Health, was created 10 years ago during the tenure of then Secretary Louis Sullivan; and I must say to you that over that 10 year period of time I have had the opportunity to go to various parts of this country and listen to testimony, much the way you are listening to it here today. We’ve held hearings around the country where more than 1,000 people have testified; and individuals who are survivors of various chronic diseases, not just cancer but heart disease and diabetes, scientists as well as politicians and others have come before the committee.

I think today you’ve heard a number of concepts and terms that have been mentioned to you, that when we look at outcome, much of this may be due to biology, some of it may be due to socioeconomics, some of it may be due to legal and political poverty and racism, all in terms of what the health outcome is going to be eventually.

I think in a nutshell I must say to you that much of what we’ve learned from many of the hearings around the country is in fact that these outcomes are due to all of the above. They have all played a special role in some form or fashion.

The point is, we must get to the point in this country where we stop passing the buck. With those who are in the box that has to do with biology, say that, no, it’s not mine, it’s really about the socioeconomic, it’s about—all about poverty. It’s about all of the above, and until partnerships are built between the boxes then we will be here talking about this for a long, long time.

To your specific question, I think yes is the answer. There’s no denying of the fact that in the early going at the National Institutes of Health there was some skepticism about what would happen if, in fact, a Center for Research on Minority Health was created at the NIH. I think there is absolutely no doubt about it, that we’ve come a long ways and that that thought no longer persists. The National Institutes of Health is convinced that the elevation of the office to center can play a very, very important role in the solution to this great problem.

Mrs. BIGGERT. Thank you very much.

Before I forget to do some housekeeping, it appears that Chairman Burton’s plane has been further delayed by the weather. If you’ve looked outside the last couple of hours, you would know that that has happened. So he has asked that his statement be included in the record. So, without objection, that would be so ordered.
I think I'll then turn to Dr. Brawley and ask you about what are some of the projects that the National Cancer Institute has sponsored to date to look at the ethnic and racial disparities in cancer care.

Dr. BRAWLEY. Madam Chairwoman, the Institute a few years ago established what was called the Office of Special Populations Research, which I revived; and we have looked at a number of studies that have been done by the Institute over the last decade and that actually show by race equal treatment yields equal outcome. There are also a number of studies—Dr. Bach's being the latest and perhaps the best done—that indicate there is not equal treatment in the United States.

So the Cancer Institute has really been doing both the work to demonstrate that equal treatment yields equal outcome as well as try to get a little bit more word out, if you pardon me saying that, that there is not equal treatment. This includes things such as the Special Populations Networks which Dr. Thompson has 1 of the 18 grants with Dr. Claudia McKay at the University of Maryland, as well as several other leadership initiatives working with our cancer information service.

Mrs. BIGGERT. Thank you.

My time has expired. I think we'll probably have several rounds of questions, but, unfortunately, I have to go to the floor to do something else on government reform. So we've been joined by Representative Horn, who is the chairman of the Subcommittee on Management, Information, and Technology, who will take the chair. Thank you.

Mr. Cummings, do you want to proceed?

Mr. CUMMINGS. Thank you very much, Madam Chairlady. Unfortunately, I will have to join you on the floor shortly.

I have a bill on the floor, and I don't know how much you all know about that, but when you have a bill that's your bill that you sponsored you have to go to the floor. But I will get in as much as I can.

You know, I guess, Dr. Bach, I'm just wondering, after you all did your research at Sloan-Kettering and you saw this disparity, did that change your policies at all? Did you do things any differently than what you were doing them? After all, you could clearly see from your own testimony that people were probably dying early. And I was just curious, did you all do anything differently?

Dr. BACH. As I mentioned, we were concerned about the results of the study and thought it offered a great opportunity for improving the patients for lung cancer. If Blacks were to receive surgery at equal rates to White patients, we should virtually eliminate the gap. The study that I was discussing was a national study located in 10 geographic locations in the United States. New York wasn't one of them, so we do not know much about patterns of study, about patterns per se. We know and attempt to provide the best care to all of them.

Mr. CUMMINGS. If that were done at your hospital, do you think you might have a similar result?

Dr. BACH. I don't have any information about that.

Mr. CUMMINGS. Dr. Thompson, you know, one of the things we have noticed in Baltimore is that some people tend to believe when
they’re cut—I have heard this so many times—then when they’re cut and they have cancer that the cancer will automatically spread and lead to their deaths. I don’t know if any of you all have heard that. People really believe that. And I’m just wondering, have you heard those kind of statements and how do we deal with those when you’re talking about addressing the issue of cancer?

Ms. THOMPSON. I have heard that anecdotally from patients.

I know when we held the forum, with hundreds of people throughout the State coming to tell us what they wanted, people generally wanted more information. They needed and they asked for education so that they would know what to do, where to go for treatment. What were the signs and symptoms?

We really need to do a better job in educating the public and educating African Americans about cancer, cancer disparities and then what to do if they have certain symptoms. Because that’s what we have found from research. People tend to wait. People are afraid that if they go into certain facilities for care they might be guinea pigs. So there is some misconceptions there.

We have also seen some misconceptions on the health care providers’ side not saying that they do not know how to reach out to people, one. The second thing they say is, maybe African Americans are not interested in participating in research and clinical trials. And that’s also not true because, from the research, we know that they are interested.

So there needs to be a way that we can begin to bring together our knowledge with the people in need and have some way of having a balance between those two. Because if we’re not able to do that then we’re going to tend to continue to not reach people, and this information that people have about what cancer may do if you have surgery, this is going to happen. We really need to get good information out to the public.

Mr. CUMMINGS. Dr. Ruffin, the results of Dr. Bach’s test, does that surprise you with regard to that study in lung cancer?

Dr. RUFFIN. Not really. I think that one of the things that concerned me—and to comment to some extent on what Dr. Thompson just said—is that the solution to much of this also resides in the relationship—doctor/patient relationship.

There is no question in my mind when I talk to some of my majority friends who have had to face major decisions about their health and had to choose in some instances between radiation and surgery and I have asked them what was the major factor in your deciding one way or the other and let me tell you that the major factor was doctor/patient relationship, the fact that they had a good relationship with their physician.

All of us sometime walk into a doctor’s office with misconceptions. But if we do not feel comfortable and if the doctor doesn’t feel comfortable with us, if we go in there with misconceptions, we come out with misconceptions.

So there has to be a way—and sometime when we’re talking about health issues and you hear us talking about training, people talk about these two issues as if there is a major separation, but there is a close connection between when we talk about research and when we talk about training. We have to figure out a better
way of training our physicians so that that cultural competence that is needed will be there.

Mr. CUMMINGS. Just one followup question.

Mr. HORN [presiding]. Please.

Mr. CUMMINGS. A few years ago when we started moving more and more toward managed care in my district, and I'm sure in districts throughout the entire country, you can find people who—particularly elderly or middle-aged people that worked with doctors just about all their adults lives, and then suddenly, for various reasons, maybe their doctor wasn't on the list, and they found themselves with new doctors. And just following up on what you just said, I imagine that could play a part too. You move. You have a new doctor. You're unfamiliar with that person. And that person is telling you something is one thing, but that person who you've been with for the last 25 years telling you is a whole other thing. So you think the trust factor is very significant.

Dr. RUFFIN. There is no doubt in my mind. Those individuals sitting at the table who see patients on a regular basis may be able to comment on that a little more, but from my experience I would think that would be a factor.

Mr. CUMMINGS. Thank you.

Mr. HORN. Thank the gentleman.

Dr. Freeman, I would like to ask you a few questions. I gather that you recently accepted a position as the Associate Director for Reducing Health Disparities for the National Cancer Institute. Will that position bring you to Bethesda full time?

Dr. FREEMAN. No, it will not. It is not a full-time position.

Mr. HORN. Have you had a chance to look at the proposed budget for the National Cancer Institute and what about the aid that they can provide to this very question? What is your feeling on that?

Dr. FREEMAN. My job started yesterday.

Mr. HORN. I expect you to have all the problems solved by tomorrow.

Dr. FREEMAN. I have a general feeling, in speaking to Rick Klausner who hired me into this position, that he considers this a very, very important issue and will give the fullest support.

It's going to take a while, I think, to determine how money should be spent. But I'm looking at four different things at this point.

No. 1, I think we have to have a research division that will do research related to these issues—not just to special population research that is going on now but larger than that.

I think, No. 2, we need to have a communications division, because culturally targeted communication is so critical to preventing disease and to instructing people how and when they should come in for a certain test.

Third, I think that, ultimately, a huge effect will come related to creating health care related policies in our Nation which are compatible with the problems that we must be facing. So, for example, if we're discovering things in our discovery system but we're not delivering them appropriately to all of our population, this is a policy issue. So we're going to have a division that is going to be kind of a think tank division to deal with policy so you can be well instructed about the substance of the problems that we face.
Mr. HORN. This is a good time for you to get your proposals in, because September is when all government agencies have money to reprogram. And in the going out of this fiscal year, it's a good opportunity to start pilot projects and get that money so you can use it. And, as I remember, the National Institutes of Health overall can move money around between some of the Institutes. Also, within the National Cancer Institute I would assume they could move money around, also. We shouldn't have to wait a year for you to have what you bring to the table. We shouldn't have to do that. So we'll need to get moving now.

Dr. FREEMAN. Thank you.

Mr. HORN. What specific programs do you think are needed to reduce these disparities? When I was on the Civil Rights Commission, we had studies on this throughout the country; and that was 30 years ago.

Dr. FREEMAN. Well, one question that we have is to try to determine what the precise variables are that cause disparity. We have groups according to race and culture, but we do not know enough about what the precise variables are that cause people not to do as well.

For example, how much of this is related to lack of knowledge and resources? How much of it is related to the life-style factors that we all live within that we call culture. How much of it is related to what we're talking about here today, the matters of social injustice? How can we separate, disentangle the meaning of race as we use it in society from the meaning of class and culture? These are some of the early questions.

Another question is, what about parts of the country that we already know how to identify where people are dying at a higher rate, geographically and culturally delineated areas of excess mortality.

In 1989, I published a paper in the New England Journal that showed, for example, that Black Americans, particularly males in Harlem, have less of a chance of reaching age 65 than males growing up in Bangladesh, which is a third-world country. We need to look and learn from the community of America what we should do for the most distressed communities; and this is one of the areas, lines of research that I will take.

Mr. HORN. What about the research of minorities in the military where they move around and they aren't in a ghetto here in the domestic United States? Is that worthy of research?

Dr. FREEMAN. It is. There is a recent paper, and there is more than one recent one, in May, which looked at the veterans hospital—I mean, the people in the service, women who developed cervical cancer who were the wives or perhaps they were soldiers themselves. And when they have looked at the results they found, as Dr. Brawley has said, that when people of any race are treated with the same treatment at the same states of disease the outcome is the same. So our military model is one perhaps we need to look at very closely because, apparently, the access is the same for people who are in the Army or Navy, and so America can learn. So we need to look at those military models.

Mr. HORN. Obviously, one's socioeconomic status does have something to do with this.
Dr. Freeman. May I just point out this, that in a study which I authored—and I'll give you this to keep—The Effect of Poverty Related to Race, a paper published in 1989 based on an American Cancer Society's 2-year study trying to understand the effect of poverty on cancer outcome. We concluded that when one corrects for socioeconomic status the disparities in cancer outcome between Blacks and Whites are to a large extent but not completely corrected. So poverty with its effect on living conditions, lack of education, nutrition, access to preventative care and life-style factors has a major influence on these disparities, but poverty is a universal condition. It effects all people who are poor.

Mr. Horn. I would think in some cases, though, that it isn't just the socioeconomic status. As you mentioned, you want to call it cultural, the food they have eaten as little kids they might still like, and we know fats and other things certainly do not help matters.

Dr. Freeman. That's true. And before you came in we spoke of the meaning of culture, the life-style, attitudes and behavior of groups of people who have similar life-styles. The Seventh-Day Adventists, to give you an example, have the lowest cancer death rate in America and the longest lifespan. Even when they are poor they don't smoke cigarettes, they eat vegetables, and they do not drink alcohol. So there is something about life-style that is very critically important across race.

Mr. Horn. Well, thank you very much, Dr. Freeman.

Let's ask Dr. Ruffin a question or two. What's the ratio of minorities going into medical and nursing schools and how is that different from the White population?

Dr. Ruffin. I don't have those statistics before me, but I could provide those to you for the record.

Mr. Horn. Without objection.

Dr. Ruffin. Pardon me?

Mr. Horn. Without objection, it is put in the record at this point.

Dr. Ruffin. Yes.

But let me answer it this way. Those numbers are very, very low in terms of number of minorities that are going into those professions; and we have many, many programs at the National Institutes of Health that we put in place to try and get those numbers up.

Mr. Horn. Do we know that the cancer treatments differ for Asian Americans, Hispanics, Native Americans, Native Hawaiians, Native Alaskans? What do we see there?

Dr. Ruffin. I think we will see some of these across the board when we look at some of the statistics, particularly when we start examining different groups.

For example, if we were looking at Asian Americans, I am aware of the fact that, as it relates to cancer in general, that, for example—I think Dr. Freeman may know a little better the current statistics on this, but that there is an increase of colon cancer among Japanese Americans when they leave Japan and come to the United States.

By the same token, as I understand it, stomach cancer, for example, which is relatively high in Japan, but when those individuals come to the United States there is a decrease in stomach cancer. So that suggests to me that there are environmental factors, too,
that must be examined as we examine these broad scenarios of health outcomes.

Mr. HORN. Well, I stepped beyond my minutes; and I now yield to the gentleman from Maryland, Mr. Cummings.

Mr. CUMMINGS. Thank you very much, Mr. Chairman.

Dr. Huerta, I just want to know what your thoughts are on the impact of including funding for cultural competency in medical education. I think Representatives Jessie Jackson, Jr., and Bennie Thompson talked about that, and I was just curious as to your feelings on how would that effect the population you serve.

Dr. HUERTA. Thanks for the question, Mr. Cummings. It would tremendously effect the quality of service we can provide to our patients.

As an anecdote, I had a patient with pancreatic cancer some years ago. He used to be from the—he was from the Dominican Republic. So I diagnosed the cancer. And the next day he came with 11 members of his family. But the amazing thing is that when the family came to see me they didn’t let him get inside my room. The family wanted to talk to me before that, and they pleaded with me not to tell him the truth.

So I’m from Peru. I’m recently arrived to this country. In Peru, if you tell a patient that the patient has cancer, you are considered an inhuman doctor. That’s culture. That’s incomprehensible for many Americans. But that is culture.

So if a doctor here doesn’t know that, subtle changes in the culture of people, how can we treat with quality an Asian American person, a Latino person, a middle Eastern person or an African American person? We all have different qualities.

And medical schools now they lack this kind of training. I think we have to allow our medical students to open their eyes, open their minds that this society of ours is becoming increasingly multicultural. Medicine reflects society, in my opinion. Quality of care is not reflecting those changes in our demographics.

Mr. CUMMINGS. Now, Dr. Brawley, you know, when you think about this whole idea, I keep going back to Dr. Bach’s study where you have those 65 people, people 65 and older. Am I right, Dr. Brawley?

Dr. BRAWLEY. Yes.

Mr. CUMMINGS. And for some of them to get surgery and others not, and apparently surgery does make a difference, I mean, what conclusions did you come to, if any, in regard to that?

Dr. BRAWLEY. One can look at virtually every major cancer. I personally wrote the literature on prostate cancer and find the same finding that Dr. Bach had.

Breast cancer, which I’ve become very interested in, is a good example of looking at this. In the military, by the way, Black women have a much lower breast cancer mortality then Black women in the United States as a whole. Partially because of cultural differences between Black women who were either married to a soldier or in service themselves, partially because they have access to care, they have access to convenient care, and they have access to good care, which is the other factor.

There are also some hospitals like Henry Ford Hospital or the University of Chicago that published their series over the last 20
or 30 years and find that Blacks and Whites treated at those places have equal outcome if you look at them in 5, 10 and 15 years. This is especially important because, in 1980, Black and White women had the same death rate in the United States. But since 1980 the death rate has gotten wider and wider, Blacks going up and Whites going down.

Ultimately, how people get quality—how people get their care, care in county hospitals or in other facilities where sometimes perhaps they say, no, I don't want the treatment; other times, they were denied the treatment.

I have actually been to one hospital in the Midwest—it's a county hospital. They are giving radiation off a cobalt machine which has been obsolete for 30 years. This is where people who are poor go to get their medical care. To them, a mastectomy is the only treatment for breast cancer. Lumpectomy and radiation is not an option because that machine can't give the powerful radiation you need for that care.

Sometimes it's because people have to wait in line or wait all day to see a doctor. They just get fed up, and they leave. I actually found this out because we've done studies at the NCI to show that there are areas in the country where 1 out of 20 Black women diagnosed with breast cancer did not get treated. They had enough access to care that they got a biopsy of the breast to be diagnosed, but they ultimately did not get the tumor removed. Now that is research that was completed in 1890 that is not being applied in the year 2000.

Mr. CUMMINGS. Dr. Thompson, one other question, have you seen situations with people, because of age, who just want to give up? They have—find out they have cancer, and they just want to give up. They just do not want to continue, although doctors want to say otherwise.

Ms. THOMPSON. I have a close friend whose mother just died of cancer, and they just gave up because they don't want to go through the treatment. That was a choice. So that's one person that I know of personally who made that choice of not getting care because they didn't want to live with the consequences of having to go through a certain type of surgery.

I'm sure other people have had those experiences, too, where you give information to a patient and tell them what they need to do in order to survive, and they make that choice.

Mr. CUMMINGS. Thank you, Mr. Chairman.

I see Ms. Norton is here, but I have a few other questions. Let me ask you this. I won't be long.

When we look, Dr. Ruffin, at this whole question of elevating the office, the research office, do you think it will have the kind of—you heard the testimony of Congressmen Jackson and Thompson, do you think it will have the kind of impact that they're hoping for, in other words, if it is elevated? And what differences would you project?

Dr. RUFFIN. I think so, and I think for two reasons. One is that it would be the first time that the National Institutes of Health would attempt to put in place a strategic plan; and that strategic plan would be a plan that is trans-NIH, which means that it involves all of the institutes and centers, not isolated. So the next
time, perhaps, when you hold a hearing like this, you will have all of NIH sitting at this table at one time to defend one document that we have put together to say this is how we're going to do it.

Second, as you know, anybody who has worked with a strategic plan, a strategic plan brings with it another component. That component is an evaluation, something to hold the agency and those individuals who are responsible for that strategic plan accountable. So I think the fact that there would be a strategic plan and accountability attached to that plan, that results would surely come.

Mr. CUMMINGS. Finally, Dr. Bach, just going back to the injury study, because it was one of the major factors that brings us here today. Do you think that—I mean, when you look at those differences with regard to the folks with the lung cancer, you would believe that that's going on all over the country. You would have those kind of findings, if you were to guess. First of all, how did you come up with the 10 sites that you came up with?

Dr. BACH. The last question I'll try to answer first.

The 10 sites constitute the National Cancer Institute's ongoing cancer surveillance network called Surveillance Epidemiology and End Results, nicknamed SEER. It's the ongoing data base we use for virtually all cancer statistics, and many of the statistics you've heard cited here are from that data base. So that sample, although it's not a random sample, constitutes a cross-section of the United States.

I would say, on average, the results that we've found likely would hold true in most geographic regions of the United States that we did not sample. And although I don't have the numbers in front of me, I can tell you that we looked in individual geographic regions that are captured by that data base, and we found this: consistent findings that Black patients were less likely than White to undergo surgery.

Mr. CUMMINGS. The thing that concerns me more personally than anything else is, when I look at the obituary page of the Baltimore Sun, what I see are a lot of African Americans dying from cancer from 35 to 55 and/or heart disease. I started looking at the obituary page a few years ago, I think, after my 35th birthday so I could value life a little bit more every day.

But in your study you're dealing with 65 years and older. Would it change for that population, say the 35 to 55, and would they make perhaps different decisions? Because one of the factors I guess that comes into play is, if somebody is going to get surgery, they have to look at the shape of their body, what kind of health—whether they're healthy and whether they can withstand surgery. Because I'm not a doctor, but I understand surgery can have an impact on your body. So I'm just wondering if that would change these figures a bit, you think?

Dr. BACH. As I mentioned, we didn't look directly at the younger populations. We did that for a special reason, which is that we wanted to control—what we use in the epidemiologic lingo—control for insurance status. In other words, we wanted to be sure if you weren't having the surgery it wasn't because you were uninsured.

In terms of the comment of the risk of surgery and what it can have on your body, we were able, because of the structure of this data base that's maintained by the NCI, able to ascertain whether
or not people were too sick to have surgery. We used the term “co-
morbidity” to describe that.

What I can tell you is when we looked at Black and White pa-
tients who had very low level, medium levels and high levels of co-
morbidity comparing within those different groups in every case
Black patients were less likely to have surgery than Whites.

To address the question you began this with, as I said, we have
examined this data, but there was a study published approximately
6 months before ours which examined the rate of surgery for Black
patients of all ages using the same data base but without the bene-
fit of the insurance information we had; and in that study also it
was shown that the younger Black Americans were less likely than
the younger White Americans to have surgery.

Mr. CUMMINGS. Thank you very much, Mr. Chairman.
Mr. HORN. We thank you for all your good questions.

We now yield 5 minutes to the gentlewoman from the District of
Columbia, Ms. Norton.

Ms. NORTON. I thank you, Mr. Chairman.

I regret very much that I was not able to attend the entire hear-
ing as this is a very special interest of mine.

I am very hopeful, I must say, about cancer. Only a few years
ago I only—literally, I don’t think people were talking about people
living with cancer. It’s almost like AIDS. People now live with
AIDS. People live with cancer.

The elevation of the NIH Office of Research on Minority Con-
cerns to an NIH center is, it seems to me, minimally necessary if
we’re serious about tackling these disparities. I am told that if this
is not done by Congress it may be done administratively, that there
may be the authority to do so. I certainly hope that does not be-
come necessary. I think it would send a very bad message if some-
how, given these disparities, we were not able to get this done
through the Congress. And I’m certain that everyone in the Con-
gress understands and is sympathetic with the need here.

I would just like to say a word, since I did not hear the testi-
mony, about my major concern, which is prevention. We know in
some instances there is more cancer; we know in some instances
there is less cancer. We are convinced that some of these are not
human differences but ethnic differences. Until we find out, we will
not have a good way to get at these disparities. There will be a lot
of continuing good guesswork on the part of physician and health
care professionals. I think we owe the minority community better
than that.

I am particularly interested that there is less breast cancer
among African American women, for example, but more cancer
death; and now everyone goes to the obvious, that is—of course,
that there is less access to health care. But I would say to you I
think we have an equal obligation to go to prevention here if there
are fewer cases of breast cancer or if they occur less often. Then
it seems to me we have a better chance of preventing breast cancer
among African Americans than among Whites.

One of the reasons we don’t do so is because they don’t have ac-
cess to preventative care. But another reason is that the preventa-
tives that are now becoming known to middle-class people and edu-
cated people are not wide enough known in the minority communities.

I have a bill that I think is going to become part of an appropriation on obesity that is going to be passed as a part of the Labor-HHS appropriation. That marks the first time that the Congress will come forward with a large appropriation to combat obesity in the country.

Now that is an across-the-board problem in this country, every age group from the littlest children to the oldest people and every ethnic group. But I have to tell you that, by sight, I see many people on the street in my community that are headed for all kinds of problems on the basis of obesity, and we certainly think that cancer is one of them. We can talk about all the health care access we want to, but I am a whole lot less interested in pouring money at health care professionals to try to cure something than I am preventing a terrible disease like cancer.

I would like to see a lot more emphasis put on explaining to young people the link between all this fat food and all this stuff that would lure anybody on the television, all this lack of exercise and where it all ends up in the final analysis.

I did not hear testimony—I was not privileged to hear your testimony, so I do not know whether you were able to discuss prevention, but I would, if I'm not causing you to be redundant, like to hear what you have to say about ordinary preventative matters, not simply being able to go to the doctor to get your annual treatment. If we're going to wait for that, we're going to wait for a long time for Blacks and Hispanics to be equal.

I want to get straight through that and get the message through that cancer is preventable, just like a lot of other diseases are preventable, but not if you're going to eat yourself to death until you're 50 and then expect that everything is going to come out all right because your grandma lived to be 95. Somehow we have to break through the folklore and the mythologies of our respective communities, and I wonder what the medical and health care people have to say about prevention as a way to go at cancer.

Dr. HUERTA. I would like to address your question with a practical example of my work at the Washington Hospital Center here in Washington, DC.

Eleven years ago, I started a radio show. It started on December 4, 1989, and that show has been on the air every single day since then until today for 11 years. It's broadcast three times a day.

In the 5th year of doing this radio show, I opened a clinic that has a theme that says, this place is only for healthy people. If you're sick, you go see your primary care doctor. If you want to talk about cancer prevention, you want to get screening, come here.

The administrators in the hospital told me, good luck. You want healthy people, No. 1, and then you want them to pay out of pocket. Because I knew my community was uninsured so I put a very low fee. In 3 weeks, we were booked for 6 months; and so far we have seen 7,500 people crossing our doors.

Eighty-five percent of these people, they are completely healthy, asymptomatic. Ninety percent are the Latinos. They are the people cleaning your houses, gardeners, waiters. And 90 percent of the people have less than a high school education. Why is that? Be-
cause the message has crossed their minds every single day three times a day for 11 years.

This is one side of the coin. Preventative health that you’re asking for can be solved using the media with four premises.

No. 1, the message needs to be consistent. Consistent in my opinion means every single day. Can you imagine your 11 o’clock news without sports? Probably not. But there are many 11 o’clock news without health.

No. 2, the education needs to be comprehensive. There is no point in talking only about breast cancer or only about prostate cancer. It needs to be about obesity, cigarette smoking, seat belts, maternity health—the whole comprehensive health education.

No. 3, we have to use the channels that the community uses. Some people love radio; others like television. People are on the internet already. Some people like to read. We have to produce materials for all of them every day.

No. 4, messages needs to be delivered by someone the community trusts and identifies with. So with this moral that we have been able to attract all of these thousands of people for preventive care.

The other side of the coin, in my hospital I do ask—and this is new data that I will publish. I asked my cancer control person in the hospital to please get me a list of all the advanced cancers that went to the hospital over the last 5 years. I was interested in breast cancer, prostate cancer, cervical cancer, and colorectal cancer—preventable, detectable. As you know, she came up with a list of 200 people. All of them, 95 percent of them, lived in the zip code 20010 and 20011 which all cross my hospital. Stages three and four advanced, incurable cancers.

Guess what? Ninety-eight percent of these people are fully insured—Medicare, Medicaid, commercial health insurance. That’s the other side of the coin. Why are these people waiting at their homes letting their tumors grow?

So this is the kind of thing that I meant when I said that our medical establishment is much more interested in finding the molecules, the genes, about the lady’s tumor. I think we should be interested also in the lady herself. Why is this lady waiting so long?

Ms. NORTON. Thank you very much. I must say that was itself a lesson in prevention.

Thank you, Mr. Chairman.

Mr. HORN. Well, thank you for asking the question.

I have seen various academic relationships with working hospitals where sometimes the person is simply a case number when the students come in, instead of saying, good morning, Joe, or good morning, Susie, how are you doing today? So I think we have that breakdown that is needed in medical school that was mentioned. What else would you have the—we don’t have interns anymore, we have residents. But while they’re in medical school, what do you think they should be taught to be sensitive to patients especially of different races and ethnicity? Yes.

Dr. HUERTA. Thank you for your question, Mr. Horn.

I think they should be sent to—obligatory to inner-cities, to community clinics that serve multicultural populations. They should not graduate from medical school if they don’t have that kind of training. I would do that.
I have students in my little clinic, they are 2nd year and 1st year medical students, so they haven’t really gone through the whole medical studies; and they, when they have my Latino patients, when they have my poor African American patients, they really—at the beginning, I can see their eyes. They are kind of seeing different people, different cultures. But at the end of the rotation, which is 3 months, they can talk to them. I can see their eyes. They were lighting because they have learned something, how to see different kind of cultures.

I would be very tough. No graduation if you do not have training in treating multicultural people.

Mr. HORN. I think that is an excellent suggestion. As a former university president, that’s what I had the School of Education do. Don’t put them out in the suburbs. Put them out where you will meet real people in the inner-cities.

Dr. Bach, this essentially goes to you. Do individuals in different backgrounds or races react differently to chemotherapy and radiation treatment? And do some fare better under those chemotherapy and radiation treatments?

Dr. BACH. I—actually, I may have to pass this question to one of the oncologists sitting to our right.

Our study looked at a large population of people using administrative claims data. I can tell you that my impression as a clinician—I’m a practicing pulmonologist at a cancer center—is that people of all ethnicities tend to withstand or benefit from treatment to an equal extent, regardless of their ethnicity.

It may be that some of the oncologists on my right can further fill this in.

Dr. BRAWLEY. If I may, sir, as a medical oncologist, discuss this sort of thing, there is really no difference among the races in terms of chemotherapy or radiation. There are differences in terms of older people versus younger people, but not between Blacks and Whites or Hispanics.

There will sometimes, however, be cultural differences in people complaining. Certain cultures, for example, are much more accepting of pain and not voicing it, for example.

Mr. HORN. Dr. Bach, in your article on early stage cancer you note about African-American patients not receiving the more effective treatment of surgical resection.

As part of this study, did you talk to the doctors? If not, have there been any physician interviews to determine if racial bias is a problem in medicine?

Dr. BACH. In response to your first question, our study was based, as you mentioned, on administrative claims data, so we were not able to either interview the patients involved or the physicians.

The primary goal of the study was to get a population-based estimate of the extent to which both disparities in treatment existed and their impact on survival.

By taking that approach, we had a tradeoff. We believed that our estimates are accurate, but we lost the ability to get a good sense of why it was that there were treatment differences.

I should tell you, there is a great deal of research into the doctor-patient relationship that is attempting to explore this issue. As I
mentioned a little earlier, the National Cancer Institute has supported our research or continued to support our research into this area. We hope that part of the outgrowth of this finding will be better information based on patient and physician interviews.

Mr. HORN. Thank you for that.

Are there any other comments any of you would like to make?

My next question is to Dr. Thompson.

Do you have some thoughts on this, Dr. Thompson?

Dr. THOMPSON. On the question?

Mr. HORN. On that question, right. I have a different one for you.

Dr. THOMPSON. No, sir.

Mr. HORN. There was a news announcement over the weekend that a new recommendation is expected on when to begin PSA testing for all men, and in particular, for African-American men.

Would you explain why this is so vital to catch it early, and if so, well, a lot of people don’t take annual physicals seriously until maybe they are about 30 or 35 and they sense that they are aging rapidly. So what would your advice be?

Dr. THOMPSON. One of the things we know from the literature is prostate cancer, based on what we know, is a little bit more lethal in African-American males.

I know when I talk with people about the problem of prostate cancer, many men are not aware of the issue. They don’t get PSA testing, they don’t get rectal exams.

So we really do need to figure out a way to get the message out as early as possible and really teach early screening and treatment at an earlier age for all men dealing with issues of testicular cancer, prostate cancer, all of those, just to make them aware of the problem like we do with women with breast self-exams, and the whole idea of getting early treatment for breast cancer; educating the public, making them aware of the problem, telling them what to do, and encouraging them to talk with their doctor about getting the testing and getting the screening.

Mr. HORN. Well, thank you.

Dr. Huerta, I believe earlier in this month I know now thousands of people looked at the PBS series on end-of-life care.

Is there difference in the preferences and access to hospice care based on ethnicity?

Dr. HUERTA. The question is if there is a difference between people that choose different hospitals based on their ethnicity?

Mr. HORN. On hospice care based on ethnicity.

Dr. HUERTA. Yes, there are some differences. There are some cultures, for example, the Latino or Hispanic culture, they do not like to put their elders in hospices or nursing homes. They believe that they are “dumping their families” and they are not taking care of them. The same thing happens with Asian-Americans.

There are definitely differences in cultures regarding the use of these kinds of health facilities.

Mr. HORN. Thank you. I am going to close this out and thank the staff, but before doing that, is there something that has come to your mind that a colleague has said that you would like to comment on?

We will start with you, Dr. Ruffin. Do you have anything to add to the record?
Dr. Ruffin. Most of the questions have centered around, to some extent, the elevation of the Office of Research on Minority Health to center status. Much of Mr. Jackson’s testimony also had much to do with that same subject.

I think the only thing that I would say for the record is that it be clearly understood that this is not something new for the National Institutes of Health. In many instances where issues have come to the forefront and where compelling data warrant it, we have responded in a similar manner.

We need only look to the Genome Institute now as guidance to that. We will see that a few years ago we were talking about a genome center which was elevated to institute status.

Just last year, alternative medicine became of interest to us in this country. Alternative Medicine, which was an office just like the office that I now run, is now a center. Nursing was a center, which is now an institute.

So in most instances at the National Institutes of Health when we recognize the importance of an issue, we have elevated that issue in many instances by elevating the status of that unit.

So I just wanted to make it clear that this is not groundbreaking. This is not a new idea for us, but a model we have followed with many of the other entities in the National Institutes of Health.

Mr. Horn. Thank you.

Dr. Freeman, anything to add?

Dr. Freeman. Yes, Congressman, three points related to the discussion on prevention raised by Congresswoman Norton.

Primary prevention is believed to be able to prevent at least two-thirds of cancers. A third of cancers are due to smoking, another third are related to diet, and some others are due to exposure to the sun.

Then there is secondary prevention. For example, it is believed, although currently 55,000 American people die of colon cancer every year, disproportionately poor and Black, it is believed that we can prevent—most or at least half of those cancers can be prevented by what is called secondary prevention.

If everyone at a certain age, perhaps 50 years old, had a total colonoscopy, we could make a big dent into colon cancer deaths, this is an important application of secondary prevention.

No woman should die of cervical cancer. We still have 5,000 deaths a year. We can diagnose and treat that cancer before it becomes invasive.

Breast cancer is now frequently being surgically removed on at the point before it becomes invasive.

So this is one set of things. Prevention is critical. I appreciate your comments.

The second thing is that not only are Dr. Bach’s findings important in the lung, but over the last 7 years since 1993 we have had about a dozen peer-reviewed papers that show racial differences in the treatment of cancer and other diseases, and in the treatment of pain.

There are two studies that show that Hispanic and African-American people in emergency rooms who present with long bone fractures, which are very painful, are less likely to be treated with pain medications compared to others.
There is another study from Harvard that has shown that Black American people are less likely to be referred for renal transplantation when they are in renal failure, at the same economic status and insurance.

There are studies that show that Black Americans are less likely to be worked up fully for symptoms that might mean they have life-threatening coronary heart disease.

So I want to put it in perspective that we are not only talking about one problem, we are talking about a societal set of issues that affect Black Americans.

A final thing, I think that in prostate cancer—you raise the question about the PSA. I have two concerns. No. 1 is that we don't have all of the scientific answers as to which prostate cancer will progress and which will remain dormant, so the question of the treatment—there is a lively debate about how to treat this disease: Radical prostatectomy versus radiation in its two forms and watchful and waiting.

We had a mayor in New York who waited about 3 months after diagnosis and before treatment because he had to think it over. What happens in poor communities, poor Black communities, when there is no counseling? The men in these communities don't know these options, they are not explained. So if we bring in screening in a poor community, we should bring in counseling along with it.

Mr. HORN. Thank you, Dr. Freeman.

Dr. Brawley.

Dr. BRAWLEY. Thank you for the opportunity, sir.

Dr. Freeman has been wonderful in explaining that this problem is not just in cancer, and I can focus directly on cancer and tell you that there are studies in the literature in colon, breast, prostate, cervix, and lung cancer that show that there are disparities in treatment.

There are also studies in the literature that show that equal treatment yields equal outcome in all of those cancers, sometimes by looking at a specific hospital that for some reason or another is actually able to offer that good therapy, and other times looking at systems like the military.

What it boils down to, to me, is not just access to care, which is what we frequently worry about when talking about poor people, but also susceptibility to care.

Nancy Breen at the National Cancer Institute, for example, published a study that showed that one out of five Black women with breast cancer gets less than optimal care. They get care, but less than optimal care. It is actually one out of eight White women who get less than optimal care.

So where people get their care and is that care optimal, is that care acceptable, are real issues.

I cannot overstate the fact that there are hospitals where people actually go and start getting care and literally walk away because of inconvenience. Sometimes it is because of the faculty being not sensitive. Sometimes it is because of basic issues of having to wait for 4 or 6 hours to see a physician.

Mr. HORN. Thank you.

Dr. Bach, any last thoughts?
Dr. Bach. I only want to thank you for considering the results of our study.

I would say that we certainly hope that it leads to progress and improved treatment for people with lung cancer, as well as the other conditions that have been mentioned.

Mr. Horn. Thank you.

Dr. Thompson, any thoughts?

Dr. Thompson. Sure. Thank you.

I just wanted to make a comment about the professional nursing. Someone made a comment earlier about the number of African-American nurses. We only have 4 percent of nurses who are African-American in this country, so we really do need to figure out a way to increase that number.

The other comment I wanted to make is this whole idea of sustaining programs that work. There are many studies that have been conducted and demonstration pilot programs that have been placed in communities, and the funding—they only go on as long as the funding is available.

We know things work and that it is having an impact on reaching people and reducing problems, especially in relationship to prevention, so we really need to figure out better ways to take those programs to scale and sustain them, instead of the funding that currently happens only looking at a demonstration for 3 to 5 years.

Mr. Horn. Thank you.

Dr. Huerta, your last words?

Dr. Huerta. Thank you. I would like to talk about prevention that Ms. Norton talked about.

There is a wonderful program from CDC, for example, called the Breast and Cervical Cancer Early Detection Program which I am employed to do here in the District. There is a wonderful program called WISH, Wish Women Into Staying Healthy, which is a CDC program. I am a member of that.

But you know what, we call women, we lure women, “Come here, please, it is for free. For your mammogram, your Pap smear, come here.” Well, I have seen 6,000 Latino women and 200 African-American women and I have found already three cancers among the African-American women, but that is not the point. The point is that this program has no treatment component.

So when I diagnose these cancers, I am between a sword and the wall, because on one side my patient is telling me, “Why did you call me here?” And on the other side, my hospital is saying, “Dr. Huerta, we have to pay for this? Are you doing this kind of business to us?”

In other words, I am being punished for being a good citizen.

Mr. Horn. That is a sad situation, to say the least.

I want to thank each of you. It has been a very good hearing in terms of getting things on the record.

Let me thank the staff for both the majority and the minority. On my left, your right, is Beth Clay, the majority counsel. Back of her is T.J. Lightle, the legislative aide.

Our clerks for the majority are Bob Briggs and Mike Canty, and then for the minority counsel it is Sarah Despres, the minority legislative aide is Tania Shand, and the minority clerk is Jean Gosa,
and our faithful court reporters are Colleen Lynch and Leanne Dotson.
We thank you all.
With that, we are adjourned.
[Whereupon, at 3:15 p.m., the committee was adjourned.]