IMAGN!

Increasing Minority Awareness of Genetics Now!

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The Genetics and Public Policy Center at the Phoebe R. Berman Bioethics Institute, Johns Hopkins University was established in April 2002 with a generous grant from The Pew Charitable Trusts. The Center is an objective source of information, research, analysis and policy options on human genetics for the public, policymakers and the media.

Monday, October 4, 2004
Marriott at Metro Center, Washington, DC 20005

9:00 a.m. **Welcome and Introduction**
Kathy Hudson, Ph.D., Director, Genetics and Public Policy Center
Associate Professor, Berman Bioethics Institute, Institute of Genetic Medicine at Johns Hopkins University

9:30 a.m. **What's In the Genes? – Genetic Variation and Race**
Introduction: Vence Bonham, Jr., J.D., NIH and IMAGN! Planning Committee
Aravinda Chakravarti, Ph.D., Henry J. Knotts Professor and Director of the McKusick-Nathans Institute of Genetic Medicine at Johns Hopkins University

10:30 a.m. **Lessons From The Past - Genes & Justice**
Introduction: Vence Bonham, Jr., J.D., NIH and IMAGN! Planning Committee
Troy Duster, Ph.D., Professor of Sociology at New York University and Chancellor's Professor at the University of California, Berkeley

11:15 a.m. **Survey of African American Attitudes Toward Genetics**
Kathy Hudson, Ph.D.

12:00 p.m. **Luncheon: Genes, Reproduction and the Black Community**
Invocation: The Rev. Brenda Girton-Mitchell, J.D., M.Div.

12:45 p.m. **Luncheon Address: Genes, Reproduction and the Black Community**
Introduction: Kathy Hudson, Ph.D., Director, Genetics and Public Policy Center
Dorothy Roberts, J. D., Kirkland and Ellis Professor
Northwestern University School of Law and Faculty Fellow at the Institute for Policy Research

2:00 p.m. **Panel Discussion**

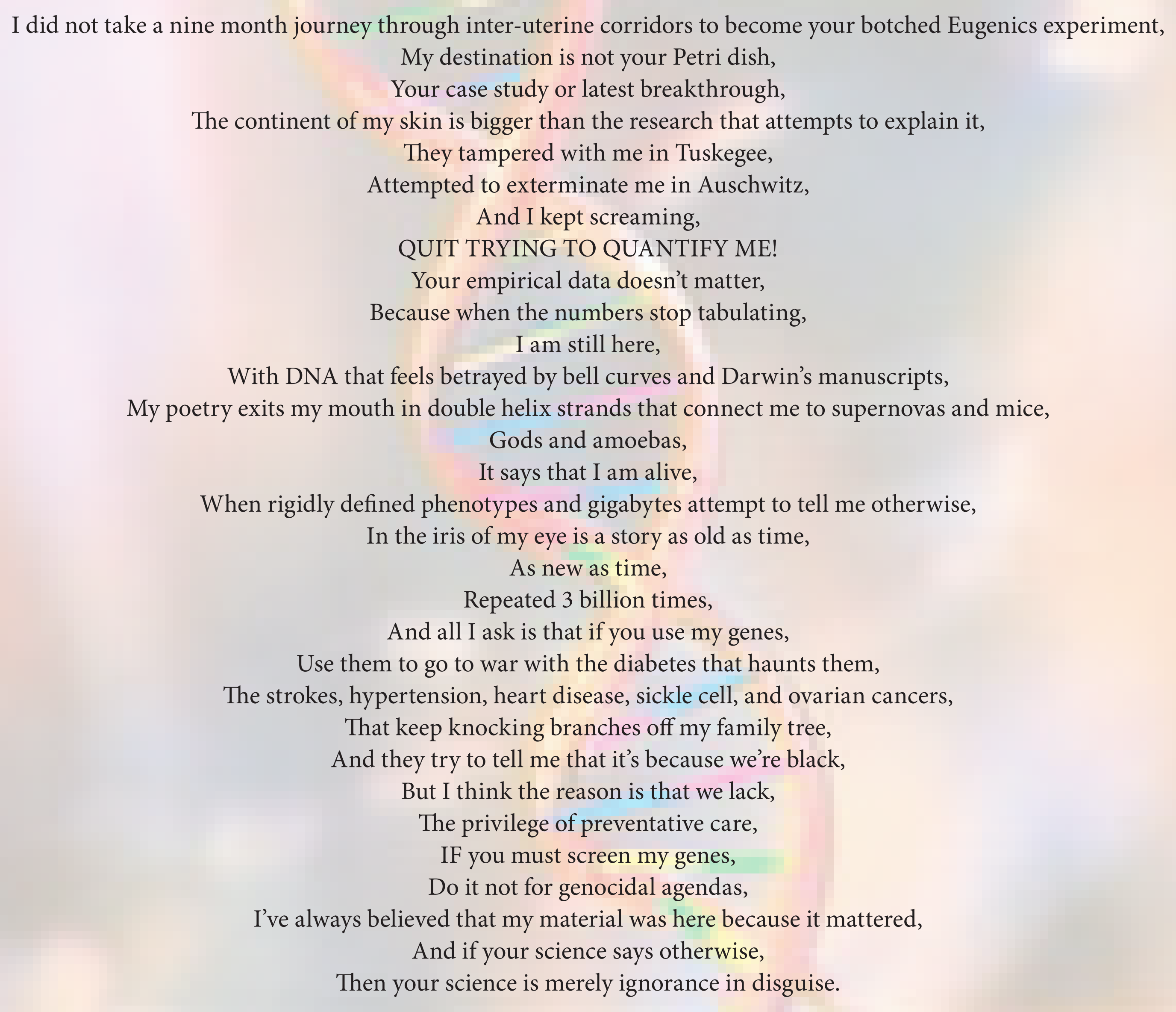
Moderator:
Tony Brown, Host, Tony Brown's Journal on PBS and PBS YOU and Dean of Scripps, Howard School of Journalism and Communications at Hampton University
Panelists:
Andre Davis, J.D., Judge, United States District Court for the District of Maryland
Francis Collins, M.D., Ph.D., Director, National Human Genome Research Institute
Georgia Dunston, Ph.D., Director, Molecular Genetics Research Program, Howard University
The Rev. Leslie Copeland Tune, Communications Officer at the National Council of the Churches of Christ in the USA
Maya Rockeymoore, Ph.D., Vice President, Research and Programs, Congressional Black Caucus Foundation, Inc.
Carol Swain, Ph.D., Professor of Political Science and Law, Vanderbilt University

3:00 p.m. **Audience Comments & Questions**

4:00 p.m. **Summation**
Patricia King, J.D., Carmack Waterhouse Professor of Law, Medicine, Ethics, and Public Policy at Georgetown University Law Center

My DNA: Does Not Adhere...

by Natasha "Theory" Thomas,
Neo Griot Performance Collective



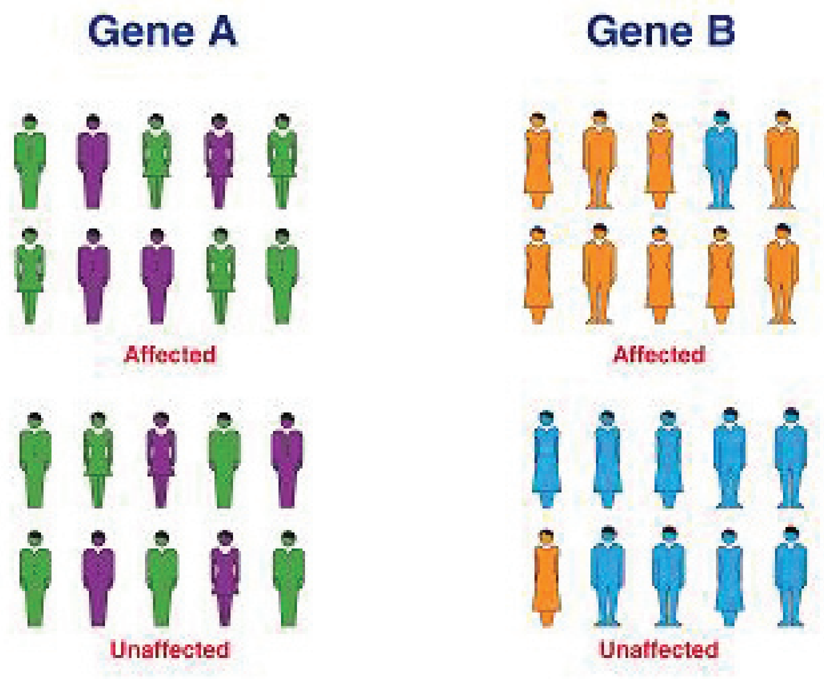
I did not take a nine month journey through inter-uterine corridors to become your botched Eugenics experiment,
My destination is not your Petri dish,
Your case study or latest breakthrough,
The continent of my skin is bigger than the research that attempts to explain it,
They tampered with me in Tuskegee,
Attempted to exterminate me in Auschwitz,
And I kept screaming,
QUIT TRYING TO QUANTIFY ME!
Your empirical data doesn't matter,
Because when the numbers stop tabulating,
I am still here,
With DNA that feels betrayed by bell curves and Darwin's manuscripts,
My poetry exits my mouth in double helix strands that connect me to supernovas and mice,
Gods and amoebas,
It says that I am alive,
When rigidly defined phenotypes and gigabytes attempt to tell me otherwise,
In the iris of my eye is a story as old as time,
As new as time,
Repeated 3 billion times,
And all I ask is that if you use my genes,
Use them to go to war with the diabetes that haunts them,
The strokes, hypertension, heart disease, sickle cell, and ovarian cancers,
That keep knocking branches off my family tree,
And they try to tell me that it's because we're black,
But I think the reason is that we lack,
The privilege of preventative care,
IF you must screen my genes,
Do it not for genocidal agendas,
I've always believed that my material was here because it mattered,
And if your science says otherwise,
Then your science is merely ignorance in disguise.

Race and Genetics

The Human Genome Project revealed that any two humans are 99.9 percent genetically identical to each other. Yet by looking around you, it's apparent that the 0.1 percent by which we all differ in our DNA can lead to significant differences in physical appearance. That our outward appearance can vary so dramatically has scientists wondering if our insides vary that much as well.

Scientists believe that biology and genetics do play a significant role in disease susceptibility. The current research effort at the National Human Genome Research Institute called the HapMap Project aims to identify and study the 0.1 percent difference in the human genome with the goal of trying to figure out who is more likely to develop what disease. To do this, researchers are comparing the differences in genomes between people of three major continental groups: Asian, African, and European.

This intersection of genetics and race has a long and volatile history. From the American eugenics movement in the early 20th century, to the Holocaust, to the more recent Sickle Cell Control Act of the 1970s, studying the genetics of different populations often has led to discrimination. This new age of genetic medicine holds promise to predict, treat, and cure human disease better than ever before, but will we be able to avoid its misinterpretation and potential misuses?



Each individual person's genetic background affects his or her susceptibility to different diseases.

Increasing dialogue between scientists and community leaders may help avoid repeating history, while making the most of what genetic technologies have to offer. With funding from the National Institutes of Health and the U.S. Department of Energy, the Genetics and Public Policy Center, funded by The Pew Charitable Trusts at Johns Hopkins University, and the Congressional Black Caucus co-sponsored a conference to foster this type of dialogue. The one-day conference, entitled IMAGN! – Increasing Minority Awareness of Genetics Now! – brought together 150 political, community, business, religious and opinion leaders, mostly from the African American community, and scientists and policy leaders to discuss the impact of the new genetics on the black community. Participants were charged with addressing the following two questions: How can advances in human genetics be harnessed to improve the health and well-being of African Americans? And how can we protect against inequitable and unjust uses of genetic information?

The Morning Session

The morning session included three presentations: Aravinda Chakravarti, professor of medicine at the Johns Hopkins University School of Medicine; Troy Duster, professor of sociology at New York University and the University of California at Berkeley; and Kathy Hudson, director of the Genetics and Public Policy Center at Johns Hopkins University.

What's in the genes? Genetic variation and race – Aravinda Chakravarti

Chakravarti started off the morning describing how the variation in some human genes does, in fact, show geographic patterns, meaning that people from similar places are more similar in DNA sequence than people from different places. This supports the current theory that the earliest peoples originated in and migrated from Africa to populate the rest of the globe. However, human genetic variation is continuous, and there are no sharp genetic boundaries that correspond to geographical boundaries or traditional concepts of race. "If we are to divide humans in groups, where would we draw the line?" Chakravarti challenged the audience. Although humans do show diversity by geography, language and culture, Chakravarti asserted that, "race is an American invention."

"If we are to divide humans in groups, where would we draw the line?"

Chakravarti described the goals and progress of the HapMap project, a multinational project coordinated by the National Institutes of Health. The HapMap project is comparing 600,000 small genetic differences, known as haplotypes, in the DNA sequence across human chromosomes in three major continental groups of people: Africans, Asians and Europeans. By comparing haplotypes across different groups of people, said Chakravarti, "We can use genes as one way to understand the biological basis of disease."

Some human gene mutations or alterations show geographic patterns.

The ultimate goals of the project are improved and personalized medicines and treatments for disease. "Over the next decade we will identify genetic variations that contribute to both common and chronic human diseases," asserted Chakravarti. He adds that in addition to these goals, we also will learn more about human history, how populations have migrated and changed over time. We all have a stake in benefiting from the new genetics, he said. "Every human group will have its share of this genetic burden," said Chakravarti. "Our task is unfinished unless we find effective ways in identifying and addressing these differences, including societal and policy efforts."

Lessons from the past – genes and justice – Troy Duster

Following Chakravarti, Troy Duster discussed the interplay between non-medical uses of genetics and society.

In particular, Duster discussed the age-old "trouble at the bottom" problem, in other words, the lowest social classes. "Do you go inside the human body to talk about what's wrong with those people at the bottom or do you go outside the body?" asked Duster. He compared the current state of genetics and genetic information with the earliest attempts to classify groups of humans by Linnaeus in 1735. Before the discovery of genetics, scientists used physical traits to classify people and other living organisms, and to establish how they are related. In 1882, Herbert

Spencer classified different human cultures using a combination of both physical traits and behaviors that Duster argues still happens today; aboriginal people were thought not capable of thinking past a season while European city-dwellers all were believed to be capable of attending universities such as Oxford and Cambridge. The danger of these types of classifications, said Duster, is that they lump together traits that originate from "inside the body," as in genetic traits, with those he characterized as coming from "outside the body," or environmentally or socially influenced behaviors. Grouping these together implies that anything arising from "inside the body" cannot be changed or fixed at all. In contrast, "outside the body" problems can, in theory, be changed. If we attribute problems of poverty, crime, disease to lower classes and/or race, that implies that they are "inside the body" problems and "then there's no reason to transform social policies," said Duster. The "trouble at the bottom" is in danger of being attributed to genetics and therefore deemed impossible to fix.

To support his argument that society still wrongly classifies people by combining inside- and outside-the-body characteristics, Duster presented two non-medical uses of genetics: racial profiling and the DNA dragnet. Incarceration rates of black males over white males have increased from 2 to 1 in 1933 to 8 to 1 in 1995. "Why this rate?" demanded Duster, who presented data that showed in 1954 unemployment levels for black and white males were equal. Since then, according to Duster, American industry has moved from urban centers to the suburbs and overseas, now leaving the "trouble at the bottom" in inner cities. Racial profiling – police arrests based on race – and the high black male incarceration rate, asserted Duster, result from the high urban black male unemployment rate; according to Duster, this is a product of using modern genetic technology to wrongly associate race and socioeconomic situation to solve crime.

Professor Troy Duster on "Lessons From the Past - Genes and Justice"

The DNA dragnet, collecting DNA from all people that fit a suspect's profile within a certain distance from a crime scene, was first done in Britain. The largest dragnet to date occured in Germany, where 16,000 samples were collected; in both cases, the approach was successful and the suspect was caught with the dragnet. Duster described two examples of the DNA dragnet approach in the United States, the first in San Diego and the other in Michigan. In both cases, DNA samples were collected from black males and the dragnet failed to catch the suspect, Duster explained, because the dragnet approach "became racialized." Although suspects in both cases were caught, neither was caught from the dragnet.

Duster also raised concerns about the 1994 DNA Identification Act, which created CODIS (combined DNA index system), a DNA database that allows states to share and compare genetic information, out of the control of the owners of the DNA.

Duster then cited scientific papers in which researchers claim to be able to use a few DNA markers to infer ethnicity. To do this with as few markers as possible would streamline criminal investigations, according to some. However, Duster cautioned against this approach. “What I’m suggesting is, Linnaeus’s taxonomy, despite all the development in science [since 1735], is alive and well in forensic science. Why? We keep thinking in certain ways, and so do the police, and so do the victims,” said Duster. He urged people to become much better informed about the newest genetic technologies.

Survey of African American Attitudes Toward Genetics – Kathy Hudson

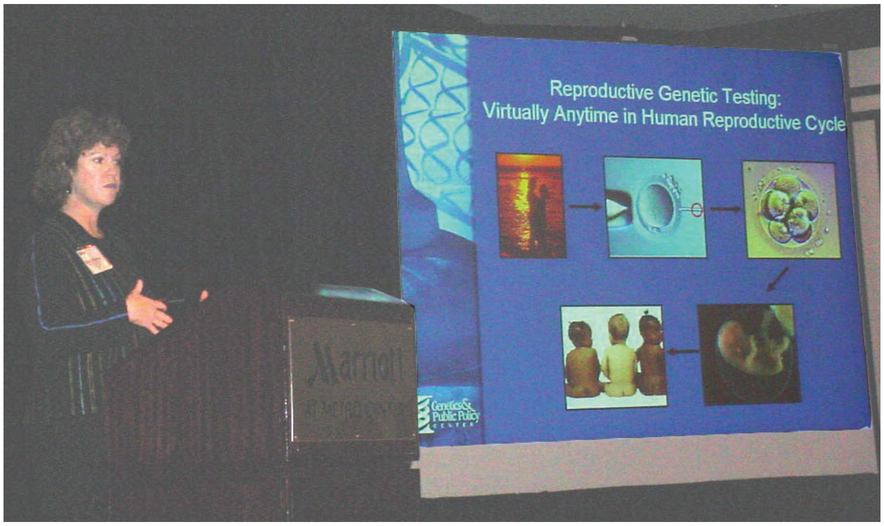
The Genetics and Public Policy Center provides tools needed by decision makers as they make science policy; one tool the Center views as valuable in this process is research and data on public opinion. Center director Kathy Hudson presented results from a survey taken of 4,834 Americans by the Center early in 2004 about American attitudes towards genetics, with a focus on reproductive genetic technologies, or “the use of genetics in baby-making,” said Hudson. The survey over-sampled non-Hispanic blacks (a total of 1,055 self-identified respondents) so that the number of survey responses from blacks could be used for detailed and statistically significant analysis.

Survey data about attitudes toward genetic technologies were examined to see if differences in view correlated with age, sex, income, education, religion, or race and ethnicity. The results from the survey were controlled for age, income, education, and religion, and compared to reveal statistically significant differences in attitudes.

Hudson discussed other recent studies that show a “black skepticism” towards genetic testing, asserting that the “received wisdom” in the field is that blacks are more skeptical of genetic technology and therefore may be less likely to use genetic testing. However, the Center’s survey results showed that blacks and whites equally are likely to approve of technologies such as prenatal genetic testing and preimplantation genetic diagnosis – genetically screening embryos created from in vitro fertilization – for health related uses, such as diagnosing fatal childhood disease. Hudson said, “you see very, very similar levels of approval of these technologies for health related purposes.”

“As genetics expands, there are more and more things that we can test for,” said Hudson. So the Center surveyed levels of approval of certain reproductive genetic technologies, including those that are not yet available or possible, such as selecting non-health related traits. Blacks and whites disapprove of genetic technologies when used for hypothetical non-health related, or enhancement purposes: selecting the sex of a baby, or for certain traits such as intelligence or strength (knowing that this type of selection is not yet possible). While there were slight differences between levels of black and white approval, “How much difference does this difference make?” asked Hudson. The differences between male and female approval levels, according to Hudson, actually were more significant than the differences between black and white approval levels.

The Center also asked respondents about attitudes toward scientific research and scientists, and found that blacks and whites equally are supportive of technological advances. This survey result is somewhat



Genetics & Public Policy Center Director Kathy Hudson on “Survey of African Americans Attitudes Toward Genetics.”

encouraging and provides evidence against the received wisdom of black skepticism. “I am actually very encouraged by this particular response: that it’s possible to control technology, that it’s possible to put into place the social structures and the regulations and the public policies that we need to maximize the good and limit the bad,” said Hudson. A difference in attitudes between blacks and whites did appear when asked about trust in scientists: Blacks significantly are less trustful than whites of scientists and what they will do with genetic information. “A sobering note for the scientific community, that about half of the [entire surveyed] population does not believe that scientists are mindful enough about the moral values of society,” said Hudson.

Some results in the scientific literature suggest “that there may be a big race gap in terms of optimism in viewing genetic technologies, and that may lead to lesser pursuit of using genetic testing and genetic technologies based on race,” said Hudson. “Our findings do not really support that.”

The Luncheon Address

Genes, Reproduction, and the Black Community – Dorothy Roberts

The greatest potential for the beneficial use of genetic knowledge today can be realized through reproductive technologies, according to Dorothy Roberts, professor of law at Northwestern University. With the help of reproductive genetic technologies such as prenatal genetic testing and preimplantation genetic diagnosis, people can have children with a far better chance of leading a healthy life. Specifically, Roberts challenged the audience to think about how the experiences of the black community, especially its history of racial discrimination and unique perspective on science and social justice, might help shape the national debate about the ethical uses of reproductive genetics. After all, "just as there are no natural black and white racial categories, there are no black and white answers to the thorny questions posed by reproductive genetics," said Roberts.

Historically, blacks have been left behind in all aspects of healthcare and similarly are in danger of being left behind in this newest set of reproductive genetic technologies. Whites currently benefit disproportionately from reproductive genetics allowing them to have the children they want – taking advantage of reproductive genetic technologies for in vitro fertilization and prenatal screening against fatal diseases – whereas reproductive technologies for blacks usually are welfare-based and generally aim to limit child bearing. The most pernicious uses of genetics, according to Roberts, always have involved race and reproduction. At the height of the American eugenics movement in the early twentieth century, more than 2000 sterilizations were performed per day. "Given the potential for inequitable access to reproductive genetics to exponentially intensify the current disparities in health status, justice demands that genetic information and technologies be distributed equally to the black community," said Roberts.

> *"Just as there are no natural black and white racial categories, there are no black and white answers to the thorny questions posed by reproductive genetics"*

The effort to justify racial inequality in biological terms rather than social or political terms has affected American science for the last 300 years, and still operates today, charged Roberts, echoing Duster's point from the morning session. Roberts warns that this will affect every aspect of reproductive genetics, so she suggested that social justice become the center of the discussion, to have family planning come hand in hand with better overall healthcare for black Americans. She also cited the need for a new vocabulary that doesn't place good or bad value judgments on reproductive genetics and race; in having these discussions, we should avoid devaluing disabilities and ascribing social advantage to certain traits. The tricky part of this discussion is to avoid reinforcing our current unjust system that values some traits over others.

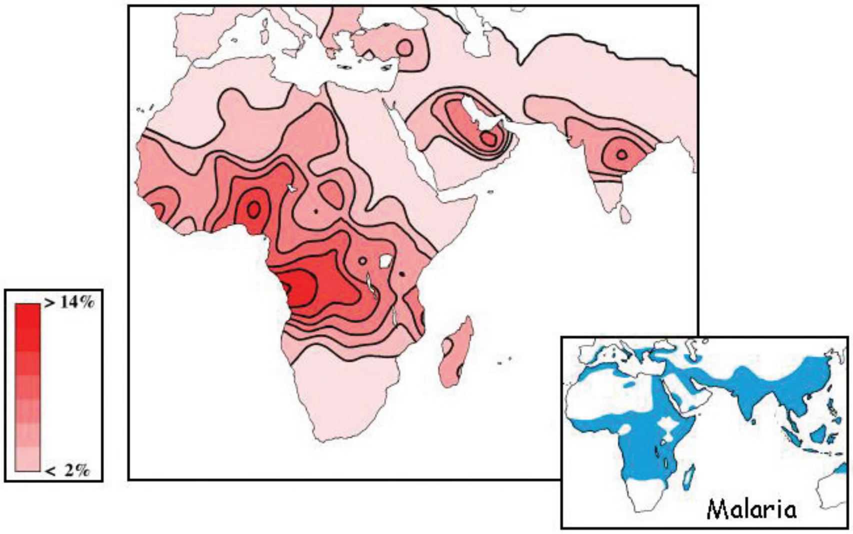
Since any program that ties race to genetics risks reinforcing notions of the biological basis of race and thus further could marginalize groups, Roberts distinguished the ways in which reproductive genetic testing could be implemented: government mandated testing, similar to the Sickle Cell Control Act of the 1970s, versus testing demanded by individuals who then have control over the test results.

Luncheon speaker Professor Dorothy Roberts

Roberts suggested that the African American community implement its own testing program, similar to what the Ashkenazi Jewish community has done in the last 30 years. The Ashkenazi community program has been extremely successful in reducing by 90 percent the incidence of Tay Sachs, a fatal childhood disease carried predominately among those of Ashkenazi descent. Community driven genetic testing efforts are less problematic than government controlled ones, said Roberts, especially since black skepticism about genetics is based not on ignorance or irrational fear of the technologies, but on who demands the tests and who controls the test results.

But even if a successful reproductive genetic testing program can be implemented in the African American community, it will not correct the current health disparities, warned Roberts. “We should not let our faith in genetics to improve our children’s future replace improving social conditions in general,” she insisted. Relying on technology to “solve” the problems of racism does not work. Since most diseases arise from complex genetics combined with complex environmental factors, Roberts contended that even if blacks are more susceptible to certain diseases, genetics do not account for the current racial health disparities in the United States. “The future of most black children in America hinges on the kind of society they are born into and not the genetic traits that they are born with,” said Roberts.

Regulation of and education about reproductive genetic technologies to avoid their use in re-inscribing a biological definition of race and a biological explanation for racial inequities is critical, said Roberts. “The danger of ‘in the gene thinking’ is this kind of thinking can let society off the hook from fixing racial discrimination,” said Roberts; “we cannot let advances in reproductive genetic technologies divert attention and resources from social change that is far more critical to the future of the black community and every community in America.”



The geographic variation in the prevalence of the sickle cell mutation as compared to the incidence of malaria.

The Afternoon Session

The afternoon session took part in three segments. The moderator, Tony Brown, first asked one question of each panelist. Then, Brown opened the floor to the audience for questions. Finally, Patricia King, professor of law, medicine, ethics and public policy at Georgetown University Law Center, closed the meeting with a summation.

> *“If you understand that you have 40,000 genes and only six of those give you skin color, you will know that the difference between a black person and a white person is nothing more than a genetic sunburn”*

Tony Brown introduced the session by warning that the dated concepts of genocide, slavery, and oppression have the potential of resurfacing in the new era of genetics, especially if people remain in the dark about the subject of genetics. “The uninformed will not know what hit them,” said Brown. Therefore, it is imperative that everyone is educated, and he asked the panelists to be especially thoughtful in answering questions. Charged Brown, “The emerging trouble in this country will demand your command of the information,” along with the ability of community experts to know and understand the dynamics of society. The purpose of the afternoon session, said Brown, was to inform and settle the large topic of genetics and race into a manageable one so that everyone could begin to understand its social implications.

“If you understand that you have 40,000 genes and only six of those give you skin color, you will know that the difference between a black person and a white person is nothing more than a genetic sunburn,” said Brown. Getting this idea straight, according to Brown, will solve many problems because those problems stem from the false construction of race, “because when we say ‘race,’ we’re really referring to color.” Brown emphasized that there is only one race: the human race.

Panelists:

- Judge Andre Davis, United States District Court Judge in Maryland;
- Dr. Francis Collins, director of National Human Genome Research Institute at the National Institutes of Health;
- Dr. Georgia Dunston, director of the National Human Genome Center at Howard University;
- Dr. Carol Swain, professor of political science and law at Vanderbilt University;
- Reverend Leslie Copeland Tune, communications officer for the National Council of Churches of Christ;
- Dr. Maya Rockeymoore, vice-president of research and programs at Congressional Black Caucus Foundation.

Center Director Kathy Hudson introducing Tony Brown.

Brown outlined three issues to be covered by the panel: (1) genetics and its relevance to our concepts of race; (2) assuring that genetic tests and future genetic medicines benefit everyone; and (3) how DNA and our understanding of genetics may be used and potentially misused outside of the medical context.

Brown: Dr. Dunston, what

do we know now and what are we likely to learn about genetic differences and similarities within and between racial and ethnic groups?

"Who we say we are is not only related to the health of our bodies, but is related to the stability of our communities, and the integrity of our world"

Dr. Dunston stated that the use of 'races' to describe humans is incorrect because ethnic human groups are genetically very similar. Each individual is genetically unique and it is impossible to separate genetics from environment. The differences in health disparities are due to an interaction between genetics and the environment. The variation in humans shows the tremendous adaptive ability of the human genome. "Who we say we are is not only related to the health of our bodies, but is related to the stability of our communities, and the integrity of our world," said Dunston.

Brown: Dr. Collins, how does the understanding of genetic similarities and differences influence our understanding of race?

Dr. Collins said we are learning a lot about how we're related to each other. "We are all Africans by origin," he said. The genetic variations that make up the 0.1 percent difference, said Collins, were present in the original "founder" group of about 10,000 people who lived 100,000 years ago. Most of the genetic variations can be found in people all over the world – some are more prevalent in some populations than others, and most are "bland variations of no significance," said Collins. While it's true that it may be possible to guess the ancestral origin, given a random piece of DNA, one must be careful not to overstate that certainty. Race, emphasized Collins, "is not a biological construct, it is a social construct." There is some connection between genetics and self-identified race, but it's a "blurry surrogacy relationship," he said. When it comes to health disparities, Collins echoed Dunston's assertion that this will require studying both genes and environment. He said that race is a lousy way to group people for disease risk and we should move toward looking at genetic and environmental causes of human diseases in order to better treat them.

"We are all Africans by origin"

Brown: Dr. Swain, will healthcare be compromised and will some fall through the cracks and not get appropriate testing in a race-based genetic context?

Social class is the problem, not race, said Swain; it's the poor communities that are at risk, not just the black community. The bigger risk is that people will be misinformed, or incompletely informed when it comes to test results or medical advice. Swain expressed concerns stemming from young pregnant black women being convinced to undergo sterilization while in labor and delivery in the 1970s and regretting that 'decision' years later, because they weren't given adequate time or information to best make that decision.

Brown: Dr. Rockeymoore, genetic tests are expensive and genetic medicines are likely to be very costly. Will genetics exacerbate access issues in medicine?

Afternoon session panelists from left to right: Judge Andre Davis, Dr. Georgia Dunston, Dr. Carol Swain, Dr. Francis Collins, Reverend Leslie Tune
Not pictured: Dr. Maya Rockeymoore

Yes, said Rockeymoore, who reiterated Swain's previous statement that healthcare already is compromised in today's race-based society. Although it's nice to say that there's only the one human race, Rockeymoore pointed out the reality that the sociological, cultural, and political phenomena of race manifest in specific ways that add to the current healthcare disparities. Additionally, income, education, technology, and economic gaps all exist now; adding genetics to the mix would lead to "a perfect storm where Tuskegee would be nothing but a footnote," warned Rockeymoore. In order to equalize outcomes and opportunities for everyone, all of these current gaps need to be closed, said Rockeymoore.

Brown: Judge Davis, is DNA sampling a valid science and is it a good tool for solving crime or is it an example of racism in law enforcement?

Davis emphasized that the science is "important, significant and valuable, and being put to good use in the forensic criminal justice arena." But many involved in criminal and civil justice have deep concerns – not that anyone should be against solving crimes – about these new technologies taking resources away from other areas. "What is worse and more frightening, is the idea of predicting criminality," said Davis. DNA has exonerated quite a few people on death row. But throwing resources at this new beloved technology that would otherwise go to fix poverty will only further entrench the impoverished. Davis said he believes that in a market society, anything can be commoditized. So he warned against the dangers of commoditizing DNA and genetic information. Lastly, he stressed that it's everyone's responsibility to prevent the misuse of genetic information.

Brown: Dr. Tune, is there a spiritual, a religious dimension to the new phenomenon of genetic advances? Do we have to worry at all about "playing God" and did God lead us to the new discoveries? Where should our faith and religious institutions position themselves in terms of delivering the best medical care to the maximum number of people and alleviating pain among those people who cannot afford medical treatment?

Dr. Tune cautioned against playing God. Her organization has put together a committee to determine how genetics affects people in the pews. "Are children with certain kinds of diseases not still a blessing?" asked Tune. She questioned how a god could make us genetically so similar but look so different. According to Tune, religion is struggling with the questions of stem cell research and the role it plays, but there is no clear-cut answer as to where religious institutions should position themselves on the issue of genetics.

IMAGN! conference participants ask probing questions of race and genetics.

Audience Comments and Questions

The audience asked questions covering a vast range of topics. A common concern voiced by many members of the audience was escaping current race-driven societal forces. The panelists suggested changing the rhetoric to deal with social inequalities in a race-specific manner. The audience and panel became very animated over the politics of current social policies as well as planning future social policies. While some argued that genetics will "level the field" as far as racial disparities are concerned, others argued that the only way to bring African Americans to an equal level of healthcare access, education, and income will be to implement policy in a race-specific approach.

The audience also raised questions about how genetic information will affect justice. Since racial forces do shape who is criminalized and how policing is done, how will we prevent the misuse of DNA and genetic information? Collins pressed for the passing of genetic non-discrimination legislation, which passed in the Senate last year but has not been dealt with by the House of Representatives at all. [1]

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[1] Editor's Note: The House did not vote on The Genetic Information Nondiscrimination Act before the end of the legislative session. It was reintroduced in 2005, passed unanimously in the Senate and is again awaiting House action.

Summation

Patricia King, Professor of law, medicine, ethics, and public policy, Georgetown University Law Center

"First of all, I want to be clear about what I'm supposed to do here. I'm not answering any questions. My charge was to try to summarize; I have already decided that was impossible if you listened carefully to the extent of discussion that we had today. When offered the opportunity to step outside the room to see if I'd like to pull my thoughts together, I declined, because I found what was happening in the room so fascinating.

"I think that Dr. Hudson and her associates did not know what they were doing when they set out to increase minority awareness about genetics. As we have seen, increasing awareness of genetics provides an opportunity to talk about genetics and to talk about many other things as well. So if I had one way of trying to summarize most of what I heard today, it boils down to putting genetics or genomic information in its place. And we had different views or understanding about what 'in its place' means, all of which were important.

"Putting genetics in its place is to take account of the fact that genomic knowledge is dumped literally into a society that has many divisions: race and ethnicity, class and socioeconomic, different levels of education; a society that already has its biases and its stereotypes. How the information will be used or not used is in part a function of what we understand about the society that exists. So part of putting genomic information in its place involves understanding how it contributes in terms of making a society better, and its potential for misuse which would make our society worse. Unfortunately we have a long enough history with respect to the use of genetic explanations for social problems to know that there are some risks attached to that.

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"Another way of putting genetics in its place is to go back to something that Dr. Duster said this morning, and that is, it is a mistake to understand this as a society versus science problem. The two are very much integrated and most of our work has to go with understanding that integration and if possible, make it work in beneficial ways rather than not. The beginning of trying to put genetics in its place is to follow Dr. Rockeymoore who said that if we are to try to translate any new area into beneficial uses rather than not, the outline is education, organization and action.

"It seems to me that today what we started is to try to do some of the minimal groundwork that one can do with respect to education. With respect to education, the first thing we could do is fully appreciate how much genomic information will permeate all aspects of our society. Sometimes this gets lost because we spend so much time talking about medicine or the criminal justice system; those are two great big systems. But genetics and genomic information will affect us all. It's not just reproductive technologies, which Dorothy Roberts talked about at lunch; it influences how we conceptualize our family. It


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influences our understanding of family relationships. It influences what makes a family as distinct from some other grouping in the society. It influences what happens to us in the workplace. For good reasons, I think, we didn't dwell on genetic discrimination in the workplace but there is a history of that as well. And it is most prominent in the sickle cell context where people were discriminated against because they carried the sickle cell trait. This also happened in education where people were labeled and went through school with genetic traits or genetic diseases. So one of the things I think we need to appreciate is the breadth and depth of what genomic information will mean.

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"I say that because you don't have to turn yourselves into geneticists, genetic action groups – you can if that's what you want – my point is, each and every one of you can find some place where genetic information has some relevance with what you do every day. So we don't have to throw our hands up and say that it's someone else's problem. This is an issue large enough to take care of us all. And each of us has a role. Someone asked Aravinda [Chakravarti] this morning about his role and responsibilities as a scientist. I want to stand up and say: 'What are each and every one of our roles with respect to what we do with genomic knowledge?' It's just not enough to sit back and ask others what they will do; we have to find how to make it relevant in our own lives.

"There are some cross-cutting themes that I would really like to emphasize, that I think applies to use of genetic or genomic information in various fields. One was mentioned by Judge Davis when he talked about commodification of information. Whether we're talking about medicine or the criminal justice system, it seems to me this is a big issue, and an issue that we have to be quite suspect of, not of making money, but how the money is made.

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"I read recently a powerful piece by Jonathan Kahn in the Yale Journal of Health Policy, Law and Ethics, an article entitled, 'How a drug becomes ethnic.' In August of 2004, NitroMed announced that it was ending its clinical trial of BiDil in which all participants were African American because the drug was having such a positive effect in the patients that they decided it was unethical to withhold the drug from the control group. This is not in any peer-reviewed journal yet, but it's on track for FDA approval so I'm sure in 2005 we will see it being approved for sale.[2] The interesting thing about BiDil is it has the prospect of being our first black drug for black diseases because that is the society into which this drug will be introduced. The reason why I found this article to be so insightful is Kahn traces for us how we move from a drug that had no connection with African Americans at all to a drug that is now only connected to African Americans, and the transition is in large part due to commercialization of this drug. It was an opportunity for a company to reposition itself to go public and sell. We did indeed come very far in getting this drug approved with the potential labeling of 'efficacious for African Americans,' whoever African Americans are. Because as we all know, we are many things. Barak Obama said it best, being of Kenyan and Kansan descent, he calls himself an African American because that's the way he's treated. He's a wise man, but it goes to the questions of 'who is African American?' and 'how did we bring ourselves to this place?'

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[2] Editor's Note: In June 2005, the Food and Drug Administration approved BiDil for treatment of heart failure. The BiDil label will say the drug is for self-identified black patients, but many cardiologists believe the drug will work for people of other races as well.

"How did we get here? There is also a patent connected with this drug and the patents are considered the first ethnic patents. So a major theme, as we walk through genomic information, is how to implement what we're trying to do without benefiting others, or diminishing the benefit that we would like to receive. How, in other words, to avoid or minimize the possibility of misuse?

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"The other theme that I heard today was, 'is it possible to use race to help African Americans?' where genetic information shows that there is no such thing as race. This is a very difficult subject, one that requires walking very carefully through what we might do with genomic knowledge. We would like to use race and ethnicity when we're trying to describe what our problems are. We like to use race when talking about the fact that hypertension, diabetes, and heart disease are serious problems in the African American community. On the other hand, we shy away when we want to connect genetic variation to predominance of a disease or condition among African Americans and no others, as is the case with sickle cell disease. Because that can reify race and lead to other adverse social consequences as well. And so the second theme, 'are there appropriate uses of race? What are they?' is a difficult one and one that has to be confronted in a range of activities, not just medicine. My own rule of thumb for that is, that my history tells me that African Americans have done better when those in power have understood that they were affected along with us …You gain to the extent that your problem is perceived as the problem of a broader group. That's not always possible. I want to make that clear. But to the extent that it is possible and at the same time benefits African Americans, then it's worth trying.

"I saw this meeting as mostly an optimistic one in the sense that we realize that genomic information, knowledge, provides opportunities for changing our situations even in small ways. And as an opportunity, it shouldn't be ignored. And as an opportunity, we shouldn't complain, nor should we talk so much about all the other problems that we are confronted with which are also real. But there's an opportunity here to try to make a small difference. My husband is fond of saying 'you take it day by day' every person makes a difference, you don't think you do, but you do, and you have to have a long range vision and a belief that getting up everyday, working on an issue every day will in time get you somewhere. And that's the message that I want to leave here with. I don't want anyone to ask me 'Well, Professor King, what are we going to do next?' that's my question for you. And it's my question for me, personally, to figure out what I'm going to do next that involves genomic information that I can get my hands around and perhaps move the ball just a little bit forward. I am asking the exact same thing of you. Thank you."


Carol Swain and Troy Duster speak with a conference participant.