DOE Award #: DE-FG02-05ER64020
President and Fellows of Harvard College, Harvard Medical School
Title: Race, Genetics and Medicine: New Information, Enduring Questions

Principal Investigator: Jonathan R. Beckwith

Final Report on Conference held on April 9, 2005 and its Sequelae

The Conference, "Race, Genetics and Medicine: New Information, Enduring Questions," was held on Saturday, April 9, 2005 in the Science Center, Lecture Hall D at Harvard University, Cambridge, MA. Approximately 150 people attended. The audience was composed mainly of college and graduate school science students and postdoctoral fellows, some science and medical school faculty, science teachers at various levels, journalists and interested members of the public.

The keynote speaker and the panelists reflected different academic disciplines (genetics, medicine, anthropology, sociology) and a CEO of a biotechnology company with background in medicine and law. They also presented different perspectives on the utility of race concepts in medicine and even on the use of the word "race." While the talks often involved descriptions of genetic approaches that were not simple to explain, the speakers did an effective job of getting across the gist of studies that have been carried out on these issues. Although no consensus was reached, the conference gave the audience the opportunity to understand the issues and to have the tools to follow the debates in the future. Our strongest feedback was from attendees who had heard of the race and genetics issues through various media, but did not have a sense of what they were really about. They reported to us that they now felt they understood the basis of these discussions.

Our post-conference activities have been successfully completed. While we had proposed to make available transcripts of the talks to the public through a Website, some of the speakers would not agree to have their presentations available in this way. Therefore, we asked permission from the DOE to use the funds to prepare classroom lesson plans for high school students to discuss the issues. These were prepared over a year-long period by the Genetic Screening Study Group Members with an educator, Ms. Ronnee Yashon, who teaches at Tufts University and who had long experience as a high school biology teacher. The lesson plans were then distributed for free to high school teachers attending the annual Conferences of the National Association of Biology Teachers and the National Science Teachers Association.

One of the participants in our Conference, Professor Evelynn Hammonds of Harvard University, subsequently initiated a study group comprising faculty from a number of different New England universities and colleges, who have been analyzing the issues raised at the conference. That group, of which I am a member, has published an article examining the issues in a recent issue of PLoS Medicine.

In summary, the Conference was successful in directly communicating to the public an understanding of these controversial issues, providing materials for teaching about the subject in schools, and stimulated others to involve themselves more deeply in the issues.

Included with this Report are a copy of the Program for the Conference and a copy of the prepared high school Lesson Plans.

PATENT CERTIFICATION

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JUNE 2005

U.S. DEPARTMENT OF ENERGY FINANCIAL ASSISTANCE PROPERTY CLOSEOUT CERTIFICATION

Award	Number
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Recipient (Name and address)
President & Fellows of Harvard College, 25 Shattuck St. Boston, MA 02115

The purpose of this report is to facilitate the closeout of the Award. Based on the records maintained by the Recipient in accordance

vitl oer	the sone	Property Management standards set forth in the Award, the following data reflects the Recipient's closeout inventory of real and all property that was provided by the Department of Energy (DOE) or partially or wholly acquired with project funds.
	EQ	UIPMENT
		Federally-Owned: (Government Furnished Equipment): (10 CFR 600.133(a), 600.232, 600.322, or Federal Demonstration Partnership (FDP) General Terms and Conditions No. 33, as applicable): No Tyes (If yes, attach property inventory list that includes item description, manufacturer, model, serial number, original acquisition date, original acquisition cost and disposal condition code per the Federal Management Regulation 102-36.240)
	В.	Equipment Acquired with Award Funds where Title Vests in the Recipient with further obligations to DOE: (10 CFR 600.133, 600.134, 600.232, or 600.321, as applicable)
		⊠ No □ Yes
		If yes, does the equipment have a per unit fair market value of \$5,000 or more? No Yes
		(If yes , attach a property inventory list that includes item description, manufacturer, model, serial number, original acquisition date, original acquisition cost, disposal condition code per the Federal Management Regulation 102-36-240 and one of the disposition codes listed below)
		(1) The property will continue to be used for the purposes authorized in the Award.
		(2) The property is no longer needed for the purposes of the Award, and will be used on another Federally sponsored activity (List Activity and Federal Agency):
		(3) The Recipient wishes to retain the property and compensate DOE for its share of the current per unit fair market value.
		(Identify the fair market value on the attached property inventory list and describe how the value was determined).
		(4) The property is no longer needed for the purposes of the Award or other Federally sponsored activities and the Recipient
		requests DOE disposition instructions.
11.	SUF	PPLIES (10 CFR 600.135, 600.233, 600.324, or FDP General Terms and Conditions No. 35, as applicable)
	Doe	s the residual inventory of unused supplies exceed \$5,000 in total aggregate value? No Yes (if yes, check block below)
		The supplies will be used on another Federally sponsored activity (List Activity and Federal Agency).
		The supplies will be sold or retained for use on non-Federally sponsored activities and the Recipient will compensate DOE for its share of the sales proceeds (or estimate of current fair market value). Attach a list of the supplies and complete the following Worksheet:
		Sale proceeds or estimate of current fair market value
		Percentage of Federal participation
		Federal share
		Selling and handling allowance
		Amount to be remitted to DOE\$

U.S. DEPARTMENT OF ENERGY

FINANCIAL ASSISTANCE PROPERTY CLOSEOUT CERTIFICATION

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U.S. DEPARTMENT OF ENERGY FINANCIAL ASSISTANCE PROPERTY CLOSEOUT CERTIFICATION

To be completed by the Department of	of Energy:	
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☐ Real Property:		
Equipment:		
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15.		CERTIFICATION	
I certify to the best of my knowledge and belief that this report is true in all respects	AUTHORIZED	SIGNATURE	DATE REPORT SUBMITTED 10/12/2007
and that all disbursements have been made for the purpose	CERTIFYING	TYPED OF PRINTED NAME AND TITLE	TELEPHONE (Area Code, Number, Extension
and conditions of the grant or agreement		Min Xiao HMS Sponsored Programs Officer	(617) 432-6281

RACE, GENETICS AND MEDICINE



Organized by the Genetic Screening Study Group www.RaceGenMed.org

Harvard University
The Science Center, Lecture Hall C
One Oxford Street, Cambridge
Saturday, April 9, 2005
8:30 a.m. – 4:45 p.m.

Keynote Address - Troy Duster, University of California and New York University

"A Post-Genomic Surprise: The Increasing Significance of Race in Debates and Practical Applications of Human Molecular Genetics"

Session 1: Genetic Research: Ancestry and Race
Marcus Feldman, Stanford University
Jonathan Marks, University of North Carolina, Charlotte

Session 2: Genetics and Race: Applications to Medicine?

Esteban Burchard, University of California, San Francisco
Rick Kittles, Ohio State University

Session 3: Implications for Society
Evelynn Hammonds, Harvard University
Mary-Claire King, University of Washington
David Altshuler, Harvard University
Phillip Reilly, Interleukin Genetics

<u>Registration Fees (includes lunch and refreshments)</u>:

Individual Rate - \$40.00 Student Rate - \$25.00 Wheelchair accessible; real-time captioning with two weeks advance request

Some scholarships may be available. For information, please contact Catherine Ard at RaceGenMed@aol.com

Please make checks payable to Harvard University (credit cards not accepted) and send with name, address and e-mail address to <u>Laura Garwin</u>: Harvard University, Bauer Center for Genomics Research, Harvard University, 7 Divinity Avenue, Cambridge MA 02138

Race, Genetics and Medicine: New Information, Enduring Questions

Organized by the Genetic Screening Study Group

Harvard University The Science Center, Lecture Hall C One Oxford Street Cambridge, MA 02138-2901 Saturday, April 9, 2005

3:30	Registration
9:00	Welcome and Introductory Remarks Peter Conrad, Genetic Screening Study Group and Brandeis University
9:10	Keynote Address Troy Duster , University of California and New York University: "A post-genomic surprise: The increasing significance of race in debates and practical applications of human molecular genetics"
9:50	Session I: Genetic Research: Ancestry and Race Marcus Feldman, Stanford University Jonathan Marks, University of North Carolina, Charlotte Moderator: Laura Garwin, Genetic Screening Study Group and the Bauer Center for Genomics Research
11:10	Coffee Break
11:30	Session II: Genetics and Race: Applications to Medicine? Esteban Burchard, University of California Rick Kittles, Ohio State University Moderator: Joseph Alper, Genetic Screening Study Group and the University of Massachusetts
12:45	Lunch Break
2:00	Session III: Implications for Society Evelynn Hammonds, Harvard University Mary-Claire King, University of Washington David Altshuler, Harvard University Philip Reilly, Interleukin Genetics Moderator: Jonathan Beckwith, Genetic Screening Study Group and Harvard Medical School
4:00	Discussion and Closing Remarks
4:45	Reception

The Sponsors: Harvard Departments: History of Science, Social Medicine and African and African American Studies, Harvard's Program on Science, Technology and Society, the Bauer Center for Genomics Research and the National Writer's Union.

Financial Support comes from the United States Department of Energy, New England BioLabs, Novartis Institutes for Biomedical Research, Biogen IDEC, The Bauer Center for Genomics Research, and the Pettus-Crowe Foundation.

The Speakers:

Troy Duster, Professor Sociology, New York University and author of *Backdoor to Eugenics* (Routledge, 2nd Edition, 2003). http://sociology.fas.nyu.edu/object/troyduster.html

Marcus Feldman, Professor of Biology, Stanford University and co-author of Genetic structure of human populations. Rosenberg, N.A., Pritchard, J.K., Weber, J.L., et al. *Science*. 2002 Dec 20;298(5602):2381-5. http://www-evo.stanford.edu/marc.html

Jonathan Marks, Professor of Anthropology, University of North Carolina at Charlotte and author of *What It Means to Be 98% Chimpanzee* (University of California Press, 2002). http://personal.uncc.edu/jmarks/

Esteban Burchard, Assistant Professor of Medicine at the University of California at San Francisco and author of Burchard, R., Ziv, E., Coyle, N., et al. Importance of race and ethnic background in biomedical research and clinical practice. *New England Journal of Medicine*. 2003; 348(12):1170-74 http://pulmonary.ucsf.edu/faculty/burchard.html

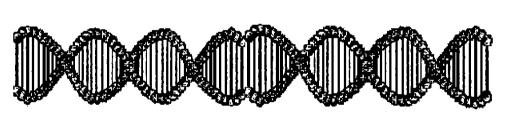
Rick Kittles, Associate Professor in the Department of Molecular Virology, Immunology and Medical Genetics at Ohio State University and author of Kittles, R.A., and Weiss, K.M. Race, ancestry, and genes: Implications for defining disease risk. *Annual Review of Genomics and Human Genetics*. 2003; 4: 33-67. http://pulmonary.ucsf.edu/faculty/burchard.html

Evelynn Hammonds, Professor of History of Science and African-American Studies at Harvard University and author of *The Logic of Difference: A History of Race in Science and Medicine in the United States*, 1850-1999 (forthcoming from the University of North Carolina Press). http://www.fas.harvard.edu/~afroam/Faculty/Evelynn M Hammonds/evelynn m hammonds.html

Mary-Claire King, American Cancer Society Professor of Medicine (Medical Genetics) and Genome Sciences, University of Washington at Seattle, and author of. King, M.C., and Motulsky, A.G. Mapping human history. *Science*. 2002. 298;2342-2343. http://depts.washington.edu/~kingweb/

David Altshuler, Associate Professor of Genetics and Medicine at Harvard University, Director of Medical and Population Genetics at the Broad Institute and co-author of Smith, M.W., Patterson, N., Lautenberger, JA., et al. A high density admixture map for disease gene discovery in African Americans. *American Journal of Human Genetics*. 2004; 74:1001-1013. http://genetics.mgh.harvard.edu/PublicWeb/faculty/altshuler/index.html

Philip Reilly. Chief Executive Officer and Chairman of the Board of Interleukin Genetics. Author of *Abraham Lincoln's DNA and Other Adventures in Genetics* (Cold Spring Harbor Laboratory Press , 2002). http://www.ilgenetics.com/interleukin.htm



"Race", Ancestry & DNA: Where do we come from?

INTRODUCTION

Although most people would feel comfortable defining the word "race", they might be surprised to learn that the definition of "race" has changed numerous times since the term was coined less than 400 years ago. Early definitions of race used the word interchangeably with "nation," such that the first dictionary definition of race described it as a group of men originating from the same country that shared physical characteristics. In the late 19th century, the association of race with nation was lost, as slavery and colonization forced the assimilation of many cultures such that Europeans considered certain groups as "inferior" and functionally homogeneous.

The first scientific definition of race was made by Carolus Linneeus, who was the first to define *Homo supiens* as a species. He subdivided *Homo supiens* into four categories largely based on geography (Americans, Asians, Africans, and Europeans). However, the basis for his classification extended beyond physical differences, such as skin color, to behavioral traits that were inferred with little or no scientific evidence.

As a result, in the late 19th century, scientists believed that races represented fixed biological entities, despite failing to agree upon the taxonomic classifications used to group humans. This belief was undermined when sequencing of the human genomes of a number of individuals differing in geographical origin revealed that two people from anywhere in the world shared 99.9% of their DNA sequences. This prompted numerous scientists associated with the Human Genome Project to declare that "race" had no scientific basis.

Within a few years of this dramatic statement, however, a number of researchers found that certain regions of people's chromosomes, termed "markers," often differed between geographical groups when sorted for differences using computer programs. Given that physical differences exist between populations, the existence of subtle genetic difference was not surprising.

Nevertheless, since certain common health conditions - like high blood pressure, prostate cancer, and Type II diabetes – are more prevalent in one "racial group" relative to another, some scientists have suggested that genetic differences related to ancestral origin might underlie some medical conditions. On the other hand, numerous studies have shown that environmental factors - like poverty, nutrition, toxic environments and racism - contribute significantly to health disparities in minority populations.

Thus, racial classifications do not adequately describe the distribution of genetic variation in humans, even though scientists can cluster genetic differences among populations into broad geographic regions. Although race is a useful social concept, there is little or no scientific support for a genetic basis for race.

Case Study #1

Mary Anderson had always felt different. She looked around in her school and noticed how, while most students could identify their race by looking in the mirror, she did not feel as though her appearance placed her solidly in any specific group. Some people even made fun of her. She didn't feel as though she belonged to any group.

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Her father, James, an African-American accountant, bad met her mother while he saw his time he saw his come. It had been deficient in James and always said the first time he saw his

served in the army. He had been stationed in Japan and always said the first time he saw his wife, Yoshi, he was in love. They married in Japan and came back to live in California where James had grown up.

James' mother, Mary's grandmother, always told her that her great grandmother had been Indian, a Sloux, one of the first indians to be educated.

Mary had never met her Japanese grandparents until last year when her grandfather died and they all went to the functal in Japan. Her grandmother was so nice to her, even though she didn't speak English. But, the Japanese looked at her strangely, she thought. Her father said she was imagining it.

On the return flight Mary was reading a magazine and saw an article about Oprah Winfrey. Oprah had just returned from a trip to Africa and confessed that she had her DNA tested to find out her African origins. The company she used offered tests to African Americans to see which of the 400 ethnic groups in African they are related to. These tests can also prin point what percentage of European, African or Asian ancestry a person has.

Mary thought, this would help her find out more about her ancestry. In her biology class she learned about DNA testing for disease genes but not race. She looked over at her father wondering if she should ask him about the test.

- What should Mary do?
- If Mary told her father, should be allow her to take the test?
- Some people are afraid to send their DNA or genetic information to companies and think that insurance companies or police might have access to it. How do you think this might be avoided? Why would insurance companies or the police want access to DNA samples? What might these organizations do with the DNA?
- Draw Mary's family pedigree.
- When Mary finds out what her ancestry is, list three things that might happen and how this might change Mary's perception of herself.
- Watch the video, African American Lives, to see how these tests were done on Oprah and other celebrities. Would you like to have these tests done on you?

 Research some of the companies doing these tests. Include the following informal tests.
- Research some of the companies doing tiese tests. Include the national state of the companies doing tiese tests.
 Some companies determine the percentage of a customer's genome that derives
- 8. Some companies determine the percentage of a customer's genome that derives from different geographical regions. If Mary were to find out that she was 30% African, 50% Asian, and 20% European and she met somebody else who had the same distribution of "racial" origins would this mean that they shared the same ancestry?
- 9. What if Mary was told by the testing company that no Native American markers had been found in her genome? Do you think that this should change the way that Mary perceived herself, her family, or how others perceived Mary?
- 10. Each human being shares about 99.9 % of their DNA sequence with any other human. Why should we care about the differences? What do they mean?

Case Study #2

It was all over the newspapers. After much public discussion and argument, a famous landmark in the heart of the city was being demolished. To get various groups against the demolition to agree, one of the city's anthropologists was to be present during the demolition, and, could halt the demolition if she believed that something unexpected and of historical interest was found during the demolition.

As the workers dug below the foundations of the original building, they were amazed to find a skeleton. The city anthropologist hatted work on the demolition project. The skeleton was carefully excavated from the building site and removed to the lab of Dr. Ama Demarco, a foreasic anthropologist at the city's university, where the bones were studied and a DNA sample taken for analysis.

The press wanted to know more about the skeleton. At a press conference, Dr. Demarco and her colleagues answered their questions, like "what was the sex of the person?" and "how old is the skeleton?"

Dr. Demarco responded by saying that, "we can tell from the bone structure that this was a male, Radiocarbon dating and pottery fragments found near the skeleton suggest that the skeleton is around 1000 years old."

Finally, someone asked the question that Dr. Demarco never liked but was always asked - "What was the race of the skeleton?"

Aithough Dr. Demarco's thought that this question was less relevant than to ask about the ancestry of the skeleton, she answered, "While race is an important concept in current U.S. society, it has no real meaning in the scientific sense. What we can determine from a DNA sample is only where a person's ancestors came from and, even then, with less than 100% accuracy. Nothing certain can be determined."

The reporters persisted, "Okay, so what is the geographic origin of the skeleton?"Dr. Demarco sighed and said "Look, the information doesn't tell you where this person is from, only where their ancestors came from."

LGive three reasons why Dr. Demarco was anxious talking to reporters about the differences between race and geographic origin?

- 2. If the DNA tests are not necessarily accurate, should we use them? Why or why not ?
- 3. There are many different ways to determine geographic origins, and they do not necessarify give the same results. Does this affect your thinking about such a test?
 4. After the skeleton is removed, list three things (legal and political) that might happen involving the construction company.
- 5. After the skeleton is removed, Native American groups demanded that the skeleton be returned to them under the Native Graves and Repatitation Act for appropriate burial. Dr. Demarco and her colleagues wanted to keep the skeleton to study because they believed that it could reveal much information about how people livee in the past. Who should get the skeleton? Do some research on the topic and give three reasons for your answer.
- 6.If this argument were to go to the courts, what might they suggest as a middle mound that avoid eatiefy everyone?
- ground that would satisfy everyone?
 7.1f Dr. Demarco revealed that the DNA testing showed the skeleton to be about 9,500 years old, before the recorded presence of Europeans in North America.
- would this change your mind? Why or why not?

 8. After more testing, Anna found that, according to her DNA testing, the skeleton has more genes in common with the Ainu of Japan than with Native Americans or Siberian native peoples (who are believed to be important ancestors of Native Americans). Does this change the interpretation of the forensic evidence? Why or why not?

Case Study #3

The Human Genome Project has been a big success. As a result, it is becoming possible to test fetuses, children or adults for many genetic disorders. People can request and pay for these tests themselves or see whether insurance will cover the cost. Some treatments for human genetic diseases are available and others are being explored.

Genetic testing can also be used to evaluate which geographical areas of the world your ancestors came from. This information may be helpful in finding gene mutations contributing to diseases that are associated with particular ethnic groups.

Before becoming a congresswoman for her home state, Melinda O'Bryant worked with scientists as a patent lawyer. After reading about these studies, she wonders if more information about genetic factors contributing to disease might be obtained by taking blood from every newborn and testing it for disease genes and ancestry. She begins working on a bill for Congress that mandates the removal of a small DNA sample (either blood drop or saliva) from every newborn in the U.S. These samples would be tested for disease genes and ancestral origins, and the regults would be released to parents and also placed in a database to be kept for research.

You are a Congressperson and asked to vote on this bill.

- . How would you vote? Why?
- List three problems you see with this bill.
- List three good things that might come from the passage of this bill
- Should parents have a right to refuse this test?
- List three things you would include in the bill to protect the children and parents being tested.
- One example of a condition being studied is high blood pressure. This condition is more common among African-Americans than among other populations in the United States. Researchers have found that a mutation in a gene is tied to high blood pressure among African-Americans whose ancestors came from West Africa. After testing Nigerians, they found a similar gene mutation in many of them but they do not have high blood pressure. List some possible causes of the differences observed. How might you test your hypotheses for the underlying cause(s) of the difference?

How to Use the Case Studies

	How to Do it
Group Work	break students into groups (teacher should choose or students can pick their own groups)give them the case study to read and questions on a separate sheetstand back and watch the interactionwalk around and watch and listen to the groups steer them along if you have to.
Individual Work	Assign students to read case studies as homework or in class time. Ask students to answer questions at end of the case studies. Make sure they write their answers fully. When grading: do not grade right or wrong give positive encouragement ex: write "good idea" or "clever" grade on creativity keep an eye out for clever, out of the ordinary answers.
Group Discussion	Wait until students have done one or more case studies either in groups or alonehave students read case studiesbegin with each question in the case study separatelyEither ask for opinions or assign students to talk.

INFORMATION FOR TEACHERS

Other activities for students

- Students can develop a pedigree of their family and ask parents about their backgrounds.
- about their ancestry. Students can write a case of their own about a student who finds out
- Students can act out any of these cases.
- Develop an art project that will allow students to show their feelings about ethnic diversity.

Websites for research

- PBS website for their program "African American Lives"
- www.pbs.org/wnet/aalives
- Brownshopops or a
- to purchase a copy of the video Genetic Screening Study Group website: www.racegenmed.org

Videos

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Man, a well-preserved, 9,000-year-old human skeleton found in Washington State in 1996. It attempts to answer the question: Does Race Americans who through DNA testing find out their heritage. It show wonderful graphics of the science of DNA testing as well as reactions ments the discovery and ensuing controversy over the Kennewick The Mystery of the First Americans, PBS Nova. The film docuof those people tested. African American Lives, Hosted by Henry Louis Gates, Jr PBS Home video, Kunhardt Productions, \$34.99 This PBS sponsored two part television show looks at famous African

Articles

Exist? Available at shoppbs.org

- 1..Harmon, Amy. "Love You, K2a2a, Whoever You are." New York Times 1/22/06/ Section 4 page 1.
 2. "Genes and Family, "What Science can Tell you About your History" Newsweek Magazine. Feb

Books

- 1. Human Genetic Variation, BSCS (1999). Curriculum guide for
- Biology Teachers Avaliable at www.bscs.org
 2. Beckwith, Jon. Making Genes, Making Waves; A Social Activist in Science, Cambridge, MA; Harvard University Press, 2002.

CAMBRIDGE MA

SPONSONED BY

THE GENETIC SCREENING STUDY GROUP