

# BIOTECHNOLOGY

By Sujatha Jesudason, PhD

## FACING FORWARD

### The Fate of Race and Genetics in the Twenty-first Century

In his landmark speech “A More Perfect Union,” delivered March 18, 2008 at Constitution Center in Philadelphia, Barack Obama said:

“I am married to a [B]lack American who carries within her the blood of slaves and slaveowners—an inheritance we pass on to our two precious daughters...[My] story...hasn't made me the most conventional candidate. But it is a story that has seared into my genetic makeup the idea that this nation is more than the sum of its parts—that out of many, we are truly one.”

Given that Barack Obama is probably the last man who would argue that his life has been predetermined by his biology and genes, why would he reference genetics this way? As human beings, we often use the language of blood and genes to tell our stories about families, communities and ourselves. It is a language that can unite families and communities or separate us from others. With visceral and physical power, this language reaches back in history and carries that history forward to the present and into the future. It links us to our individual identities, our families and our past in uniquely descriptive forms that we identify with on a non-verbal, gut level. This does not mean, however, that what we say should be taken literally. Racial groups are socially constructed categories reflecting politically structured hierarchies, different life experiences and a diversity of cultural, geographic and linguistic origins, but they are not scientific, biological or genetic categories of difference.

When Barack Obama spoke of the “blood” that he and Michelle are passing on to Malia and Sasha, he meant they are passing on a specific history and set of values deeply rooted in life experiences, family and community ties, and a particular worldview. He didn't really mean that the story “seared into my genetic make-up” is actually burned into his genes, that his experiences as a Black man in America raised by white grandparents and attending some of the best schools in the country are coded into his genes. He knows that his blood and his genes in this story are not the same as blood and genes in a scientific context, and still he uses those references to tell a vivid story because of their power.

Unless we are careful in this age of rapidly developing genetic discoveries and applications, any conflation between race and genes in a social context and race and genes in a scientific context can lead us to dangerous places. There has been a long history of efforts to align lived experiences and structural inequalities with biological categories of difference, of trying to map social hierarchies onto genetic differences, of using scientific justifications for unequal treatment and abuse. This includes ugly chapters when science—in the forms of scientific racism and eugenics—tried to weigh in on the sociopolitical debates about racial hierarchies. Many promising advances and benefits in science and technology can have a shadow side. Now, as discoveries and innovations in genetic science develop rapidly, we are faced again with the challenge of ensuring that this science not be used to justify or promote structural discrimination and inequality, particularly on the basis of race.

Governmental investment and leadership in the Human Genome Project, a 13-year program to decode and sequence human DNA, paved the way for a multibillion-dollar biotechnology industry in the United States and has supported a hopeful array of new developments in medicine and health. During the life of this project, a fair amount of attention was paid to social, ethical and legal issues in explicit recognition of the kinds of social and political concerns that can arise in research on the human genome. A central concern for advocates of racial justice in genetic research is that the despicable historical alliance between science and racism not take on a new genetic form. In the quest to understand the links between human genetics and health, the social,

environmental and structural causes of health disparities in communities of color must not get lost in an avalanche of weak claims about the genetically determined nature of racialized health disparities.

Most scientists, in their unflagging commitment to understanding the mysteries of human DNA and developing treatments for medical conditions, are not racists. They pride themselves on fighting the good fight for our collective wellbeing. However, this is a place where intent and impact can painfully diverge. In the quest to explore and understand genetic variation, social categories of difference can, intentionally or unintentionally, become entwined and mapped onto genetic differences. This conflation can imply that social differences are scientifically determined. Non-racist intentions can assume racist life in the form of genetic categories of race.

Given popular understandings of genetics, this could regress us back to forms of genetic determinism where racial and social hierarchies are justified by supposed group genetic variation. A few current examples of this relationship between race and genetic science include:

- FDA-approved race-specific medications like BiDil (intended to treat heart disease in Blacks) erroneously reinforce the unproven idea that there are medically relevant genetic differences between Blacks and other racial groups. The dubious claims of efficacy of this new breed of race-specific drugs may be a good marketing ploy, but it's bad science, lacking any credibility in sound research. A genetics-race focus on health shifts attention away from the social and environmental causes of health disparities toward predetermined genetic causes of disease and illness.
- Currently, DNA forensic databases contain disproportionately more profiles of Black and Latino people, a result of racial bias in arrests and the criminal justice system. As more states mandate the collection of DNA samples from people who are arrested—even if never convicted—this racial disparity is likely to grow worse. This increases opportunities for erroneous, coincidental or wrong profile matches and exacerbates existing racial biases in the system. Constructing genetic heritage and phenotypic profiles from DNA to catch crime suspects is based on little-tested, problematic science, conflating genetic profiles with social categories of race. The interest in using these databases to explore biological links to criminal behavior can lead to unfounded connections between race and crime.
- Assisted reproductive technologies are routinely used now to screen for and deselect specific genetic characteristics and conditions. As this science develops, will we also see people genetically select their children's eye color, hair texture, skin tone and "intelligence" characteristics currently imbued with racialized meaning? If assisted reproductive and genetic technologies develop to the point where we can design our babies, what racialized visions of perfection will be reinforced?

## **ENSURING THE FUTURE OF EQUITY AND EQUALITY**

In decoding the mysteries of human DNA, scientists have found that we are all 99.9% genetically the same; there is more genetic variation within any given human group defined linguistically, geographically or culturally than there is between any two groups of humans. Genetic variation is at the individual level, not at the group level. Given the amazing diversity in human lives, cultures and experiences, this is a powerful affirmation of our shared humanity and human variety—so long as we don't try to link those genetic variations to social categories and group hierarchies.

Progress and improvements in race relations in the United States and around the world come about only when we accept and acknowledge that race is a sociopolitical category based on structural inequities and cultural practices. There is no socially meaningful biological difference between human beings, and there is certainly no hierarchy in the small variations between us. Now is not the time to turn back the clock to unfounded and determinist visions for our world. In discourse and policies, we can prevent the perception and practice that race is a

biological and scientific category and focus instead on working actively to undo the very real structural inequities and practices that impact the health and well-being of so many communities of color.

Our challenge for the 21st century is to learn from the past and pay close attention to the ways we link race with genes in our daily lives, scientific research and consumer products. Our vision for the future is that we all enjoy those applications of genetic science that promote individual and social well-being without falling into the quicksand of scientific justification for social differences and exclusion. We want affordable, effective medicine and health care for all based on each person's unique needs. Universal accessibility needs to be built into research and development with an affirmative role for government to prevent race from becoming an unproven scientific category and to ensure affordability and accessibility in diagnosis and treatment. The benefits of the publicly funded Human Genome Project should not be privatized for the few, but shared by all.

Our goals for 21st century genetic science are twofold: eliminate any conflation between race and genetic variation, and promote the beneficial uses of genetic science for all. We already have the tools to help us achieve these goals.

First, to avoid this conflation, a multidisciplinary group of Stanford University faculty proposed ten guiding principles for using racial categories in human genetics. To encourage accurate, rigorous and disciplined uses of racial and ethnic categories, they explicitly remind us that there is no scientific basis for claims that human genetic variations support hierarchically organized categories of race and ethnicity, that sociopolitical racial categories change and shift over time and that there is more variation within than between human groups. In human genetic research, they specifically recommend that scientists:

- Recognize both cultural and geographical ancestry in addressing health disparities.
- Be explicit about how and why researchers are using racial or ethnic categories in the initial research design.
- Avoid overstatements of the contributions of genetic variation to phenotypic variation, especially in the media and in translation of research findings.
- Include historical and social scientific information in the teaching of genetics.
- Take a multidisciplinary approach to studying human genetic variation by including a broad range of experts from the humanities and social and life sciences.
- Avoid making naïve leaps to genetic explanation for group differences in complex traits, particularly behavioral traits.
- Avoid using race as proxy for biological similarities and instead focus on individuals rather than groups in clinical medicine.

Second, in order to ensure that all enjoy the benefits of human genetic research we should implement the use of Race and Equity Impact Assessments. These can be used to:

- Identify unwarranted racial impacts and inequities in access and affordability.
- Consider alternative means of achieving the health and public benefits of genetic science without reifying race, exacerbating existing racial inequities or creating new inequities.
- Facilitate adjustments that will maximize the beneficial effects and minimize any harmful effects on racial justice, inclusion and equity.

This tool can help ensure that intent and impact are consistent and aligned—that work in the area of human genetics advances a public and policy agenda of fairness and equity while addressing historic patterns of institutional bias and discrimination.

Impact Assessments would require public policy professionals and scientists to systematically expand the public debate on genetics and consult with stakeholders to assess the effect any existing or proposed policy might have on any particular racial group. This creates the possibility for public and policy dialogues on race and equity that acknowledge the existing assumptions about race and difference, and provides a way to reduce unfair and unjust disparities. It will help disentangle existing assumptions about race and biological variation in science and public policy.

### **PRESIDENTIAL TASK FORCE ON RACE, EQUITY AND ACCURACY IN THE GENETIC SCIENCES**

In order to promote the beneficial uses of genetic science for all and eliminate any conflation between race and genetic differences, we call on the new administration to issue an Executive Order to form a Task Force on Race, Equity and Accuracy in the Genetic Sciences that will develop protocols to promote responsible uses of racial categories in research and commercial product development; require Race and Equity Impact Assessments for genetic science at all levels of government; and develop recommendations for the institutional integration and incorporation of the Stanford guidelines, *The Ethics of Characterizing Difference: Guiding Principles on Using Racial Categories in Human Genetics*, at multiple levels. Impact Assessments would be required of government-funded research, institutional review boards, professional associations, and presidential and governmental agencies such as the Office of Science and Technology Policy, President's Council of Advisors on Science and Technology, the National Institutes of Health, Food and Drug Administration and the Department of Justice.

The protocols to be developed for the Race and Equity Impact Assessments should include:

1. Requiring the participation of a minimum number of community—not just industry or scientific—representatives
2. Developing a clear set of values to guide the process
3. Tracking, evaluating and reporting mechanisms to collect and document impact data
4. Developing and recommending policy alternatives to address and prevent unintended racialization or adverse equity effects

Because of our historical uses of science to justify the dehumanization of some peoples, we must pay close attention to balancing the benefits and risks of genetic science. Given the powerful relationship genes have to human understandings of ourselves—who is defined as family and how communities are constituted—unproven and little-tested claims about genetic differences that map onto social categories of race can have profound consequences. They can deeply divide us as a society or unite us in powerful ways.

The benefits of most scientific discoveries and innovations are easily balanced against potential disadvantages. In a commitment to ending the Bush Administration's neglect of and disregard for science, let us not blindly accept research claims that link genetic variation to social hierarchy. It will feed into another kind of agenda—perpetuation of a racialized and racially inequitable society—based on racist pseudoscience passing as legitimate science. Racism, however sophisticated in its trappings, must have no place in modern biotechnology, lest we forget the lessons of yesterday's eugenics movement. The rapidly advancing field of human genetic science holds great promise for benefiting all of us in many ways. As we stand on the verge of a new era in race relations in the United States, let us ensure that we reap the benefits of genetic science and avoid the dangers.