

Exploring the Impact of Genetics Research on Minorities

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One of the goals of the National Educational Foundation of Zeta Phi Beta Sorority, Inc., is to emphasize education in minority communities. In keeping with this goal, the foundation has planned and conducted three major informational conferences on the challenges and impacts of the Human Genome Project (HGP) within the last 3 years: New Orleans in April 1999, Philadelphia in July 2000, and Atlanta in July. Follow-up meetings and training sessions all over the country have been carried out by members of the educational foundation. Following is a summary of the Philadelphia meeting, held July 7 and 8, 2000.

The 250 attendees included representatives of minority organizations, civic and religious groups, health communities, government, student groups, and the public. Because the conference was held in conjunction with the sorority's national meeting (July 9–14), minority representatives from states across the country also were present.

The conference took place several weeks after President Bill Clinton's announcement that a rough draft of the human genome sequence had been completed and that differences had been resolved between private and public sectors in the sequencing race. Meeting objectives were to make minority communities more aware of the HGP and its status, to inform them of the project's benefits, and to provide a forum for minority input. Other topics were implications and concerns raised by HGP research, including ethical, legal, and social issues (ELSI). The symposium also addressed the need to expand the pool of minority scientists and the challenge of interesting minority students in science.

Conference Program

The keynote speaker was DOE Associate Director of Biological and Environmental Research Ari Patrinos. He discussed the history and accomplishments of the HGP and provided background information on Clinton's announcement. Indicating that the HGP's outcome will dramatically affect the country's economy, Patrinos emphasized the importance of



Pictured left to right: Kathryn Malvern (Zeta Phi Beta Sorority, Inc.), Ari Patrinos (DOE Office of Biological and Environmental Research), Issie Jenkins (Zeta Phi Beta Sorority, Inc.), and Daniel Drell (DOE Human Genome Program).

involving minority communities so that all can share in project benefits and related concerns can be avoided or responsibly addressed.

Presenters included John Quackenbush (The Institute for Genomic Research), who spoke on "Decoding the Book of Life" and how genomics will influence approaches to a variety of problems in modern biology. The challenge for the future, he said, will be to identify specific genes, determine their functions, and explore genetic changes that can lead to disease.

Panels

A panel discussion on the project's implications for minority health issues included Georgia Dunston and Robert Murray (both at Howard University Medical School). In addressing recent programs that screen for genetically determined health disorders, Murray spoke of ethical and legal conflicts that can arise when the disorder will not be manifested for a number of years and intervention is unknown or of questionable value. He indicated that such problems often arise when a person is merely placed in a category of increased risk for developing the condition; this situation is more likely to have serious negative consequences for members of minority groups. Finding a solution to this dilemma is imperative before any widespread genetic screening programs are put in place, according to Murray. He and Dunstan agreed that, without protective measures, information from genetic screening could be used to stigmatize or discriminate against minorities.

Dunston questioned the genetic samples being used in human genome

research and whether they represent enough variation in populations. Indicating that the genome study deals with the foundation of identity, she expressed concern that current research could be too limited.

Mary Kay Pelias (Louisiana State University Medical School) spoke on genetic problems in clinical practice and biomedical research. Using hereditary traits and diseases as illustrations, Pelias described how they are manifested in Louisiana's diverse population and how relevant historical developments and patterns of immigration can influence health issues.

Fatimah Jackson (University of Maryland) emphasized that consideration of the African-American perspective on human genome research is critical, although it cannot be used as a substitute for those of other groups. Insights of African Americans are important because they so frequently have been victims of "science" and "quasigenetic" inquiries. This group was among the first to call for representative sampling in the HGP, Jackson said, and for the inclusion of African-American genetic sequences in the human genome's template. If all groups were not included in the baseline template, some might not be considered by the big pharmaceutical companies intent on making commercial drugs linked to specific genotypes. Jackson pointed out that minorities cannot assume inclusiveness at any stage of the HGP and that the pattern of sampling often reflects power relationships. Minorities may need to demand such inclusiveness.

Daniel Drell (DOE Human Genome Program) presented a review of the HGP and a recap of the first day's proceedings.

At the panel on HGP ELSI for Minorities, facilitator Issie Jenkins (then foundation chair) raised the issue of confidentiality and uses of individual genetic information; the potential for discrimination in healthcare, health insurance, and employment; the potential for use and misuse of genetic data in the criminal justice system; and the benefits of minority participation in clinical trials. Jerroo Kotval (School of Public Health, New York State University) spoke of ethical issues involved in a market-driven healthcare system and identified the following four principles as central: just distribution and quality of healthcare, cost-effective care, and trust. Each of these principles could be impacted by the new genetic tests and their implications.

Jenifer Smith (DNA Analysis Unit, FBI Laboratory) explained how law enforcement officials use DNA evidence and the Combined DNA Index System (CODIS)—a collection of DNA databases from forensic laboratories around the United States. CODIS includes DNA profiles of individuals convicted of such serious crimes as rapes and homicides. These profiles are compared with those collected in other cases waiting to be solved. All states have legislation allowing the collection of DNA samples from convicted offenders. Questions were raised about the use of such evidence with respect to minorities.

Phyllis Epps (Health Law and Policy Center, University of Houston Law Center) spoke of recent advances in pharmacogenomics (drug targeting to a patient's genetic makeup) that have revealed drug-metabolism differences linked to race, ethnicity, and gender. As a result, drug manufacturers, researchers, and physicians will have legitimate reasons to consider race in judging the effectiveness of medicines. Given past history, patients will regard race-based treatment with suspicion, and the medical community will find it a great challenge to balance the benefits of different treatments against the risks inherent in classifying persons for whatever reason.

Workshops

Three afternoon workshops led to a series of recommendations and concerns that included the following:

- Monitor the status of health insurance coverage for genetic testing and counseling, an important issue for minority communities.
- Create more training opportunities for veteran teachers and encourage mentors for minority students in such scientific developments as genetics.
- Develop career-day presentations to increase minority student awareness of the large number and types of current and future opportunities in the genomic, biomedical, and biotechnology industries.
- Encourage minority students to volunteer, take part-time jobs, and pursue internships in science and related fields.
- Interest minority students in math and science courses in middle and high school; college is too late to begin.

Closing Session

The closing session was conducted by Kathryn Malvern (now foundation chair) on "What Next?" for continued minority involvement in education about genomic research developments. Suggestions were made to continue information sessions at or involving local churches, prepare and disseminate conference proceedings and collaborate with other groups.

Attendees also recommended disseminating factual information written in layman's terms at Black Expo and minority festivals and on videotapes.

Information in cartoon form should be developed for children.

They also saw a need to form local HGP Awareness Teams to keep abreast of developments; provide easily understood examples of the project's benefits; develop a Web site with short lists of benefits and positive and negative potentials; and conduct more research into minority issues and concerns.

Leanne Washington (Pennsylvania House of Representatives member) was the closing luncheon speaker. She spoke of state involvement and of the important need for information in minority communities. She committed to sponsoring a state-wide conference on the HGP.

The foundation received many favorable comments on the informative conference. A number of participants expressed the desire to keep abreast of developments and contribute to policy and legislative decisions regarding genetic research and the use of genetic information. The proceedings of this meeting are on the Web (www.ornl.gov/hgmis/publicat/zetaphibeta/) [Issie L. Jenkins, Esq.]

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¶ Minorities and the Human Genome Project

The book *Plain Talk About the Human Genome Project*, edited by Edward Smith and Walter Sapp, is a compilation of talks presented during a 3-day conference at Tuskegee University in September 1996 [*HGN* 8(2), 9–10]. Distinguished leaders, scientists, ethicists, educators, and students spoke on wide-ranging topics related to the Human Genome Project's promise and perils, matters of race and diversity, and education about the project and its implications. 292 pp., 1997. [Ordering Information: http://agriculture.tusk.edu/Genome2/Plain_Talk_HGP/Plain_Talk.html]

The Human Genome Project and Minority Communities: Ethical, Social, and Political Dilemmas, edited by Raymond Zilinskas (Monterey Institute of International Studies) and Peter Balint (University of Maryland) addresses the divisions between minority groups and the scientific community, particularly in the area of medical and genetic research. The book consists largely of talks by distinguished speakers at the conference, "The Human Genome Project: Reaching the Minority Communities in Maryland," held in June 1997 at the University of Maryland at Baltimore [*HGN* 9(1–2), 19–21]. In an essay that was not part of the conference, the editors argue that, although minorities tend to be skeptical of medical research in general and genetics research in particular, the Human Genome Project has the potential to make dramatic positive contributions to the health of all people. 144 pp., 2000. [Available through bookstores, including online suppliers.] ◇