

Genetics Information and the Minority Community

What you need to know



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Why does the minority community need to be informed about the Human Genome Project and the resulting developments in genetics research?

“It [The Human Genome Project] is the most expensive, most ambitious biology mission ever. The Human Genome Project at \$250 million and counting is biology’s moonshot. In the eyes of boosters, it promises to provide no less than the operating instructions for a human body, and will revolutionize the detection, prevention and treatment of conditions from cancer, to depression to old age itself.”

(Newsweek, April 10, 2000)

What should the minority community know about the Human Genome Project?

A genome is all of the DNA in an organism. The Human Genome Project (HGP) goals are to sequence the entire human genome and identify all human genes; to facilitate and accelerate research studies to characterize these genes, determine their function, and understand how diseases can result from errors in their functions.

What are some of the positive results already achieved from human genome research?

The genetic discoveries from this research have already resulted in development of DNA-based tests (gene tests) to diagnose disease, confirm a diagnosis, provide information about the course of a disease, and to some extent predict the risk of future disease in healthy individuals. Gene tests for diseases such as sickle cell anemia, breast, ovarian, and colon cancers, muscular dystrophy, cystic fibrosis, and Huntington disease, are already in use.

Use of DNA for identification has increased, and has resulted in identification of potential criminal suspects; exoneration of persons wrongfully accused of crimes; identification of victims of crimes and catastrophes; and establishment of family relationships.

What potential results can the minority community expect in the future from the continuing human genome research?

New therapies to treat diseases such as diabetes, arthritis, cancer, cardiovascular diseases, muscle diseases, blindness, and deafness, can be expected, as research continues. More available and affordable drugs, as well as drugs customized to an individual’s genetic profile, are predicted.

The minority community can expect the “new medicine” and its related technology to go a long way toward the elimination of the health disparities that currently exist.

What are the challenges and concerns of the minority community?

The HGP unofficially began in 1986 by the U.S. Department of Energy. It was officially launched in 1990. At its beginning the Scientists, officials, and policy makers were wise in making provisions for, and funding research into the ethical, legal, and social issues likely to be raised by human genome research. Many studies have been conducted in this area.

Zeta Phi Beta Sorority National Educational Foundation, as a part of its African-American Genetics Education Project, has conducted a number of information conferences for the minority community on the challenges and impact of human genome research. It has provided the community with information on human genome research, developments and issues of importance, as well as obtaining community input. Funding and support for these conferences have been provided by The U. S. Department of Energy, The National Human Genome Research Institute (NIH), the Consumer Health Foundation, Kaiser Permanente, the March of Dimes, and Zeta Phi Beta Sorority, Inc., as well as others.

Some of the issues that minorities have expressed concern about include:

- Privacy and confidentiality of an individual’s genetic information
- Fairness in access to new genetic tests and therapies, and their affordability
- Control over the access and use of individual genetic information by employers and insurers, and resulting potential for genetic discrimination
- Potential for stigmatizing an individual based on his or her genetic profile/genetic differences.
- Training of culturally sensitive genetic counselors.
- Availability of primary health care providers who have continuing education in new genetic information, tests, therapies, and technologies.

How can individuals in the community help in keeping minorities informed and part of the “biological revolution” resulting from genetics research?

- Stay informed and become involved.
- Be aware of your genetic information. Your genetic information is information about your genes, your gene tests results, and your inherited characteristics from your family members. Develop your individual family health history. Share it with your primary health care provider.
- Share information about genetic research with your neighbors and community members. Plan a meeting or workshop for your community, club, or other organization to discuss the research and its potential.
- Identify and discuss any related concerns or issues with the appropriate local officials or health providers.
- Encourage minority youth to pursue careers in the sciences, biotechnology, genetic counseling, scientific research, and related fields.



The audience listens will Dr. Georgia Dunston gives an amazing presentation.