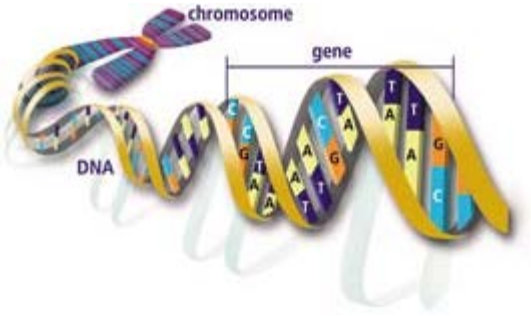

The Challenges and Impact of Human Genome Research for Minority Communities

proceedings from a conference presented by Zeta Phi Beta Sorority, Inc., National Educational Foundation
July 7-8, 2000, Philadelphia, PA

Contents

Acknowledgments

Dear Reader:

The Human Genome Project is one of the most important undertakings of our times. The changes which human genome research will make in our lives in the 21st Century will be significant.

The National Educational Foundation of Zeta Phi Beta Sorority has been privileged to have the opportunity to bring to minority communities information on the Human Genome Project (HGP) on the ethical, legal, and social implications of HGP research and findings.

The Foundation has planned and conducted two informational conferences on the Human Genome Project: one in April, 1999, at Xavier University, New Orleans, Louisiana, and the second in July, 2000, in Philadelphia, Pennsylvania. Both conferences had, as the primary target audience, members of the minority communities. These conferences provided information on the status of genetic research, avenues for greater involvement of minorities, and a vehicle for input by the minority communities on their issues and concerns.

The publication of the proceedings of the Philadelphia Conference is provided as a community service, for greater dissemination of this important information. The Foundation is grateful to the United States Department of Energy and the National Institutes of Health for grants and other support, and the March of Dimes and Merck Research Labs. It also wishes to thank the many presenters, panelists, and facilitators who were conference participants, and members of the community who served on the Conference Advisory Committees.

Special thanks to the following cooperating institutions: Xavier University of Louisiana, the New Orleans District Office and the Philadelphia District Officer of the Equal Employment Opportunity Commission, Directors Patricia Bivens and Marie Tomasso, respectively. Finally, our special thanks also to the Project Director of each conference, Dr. Rosalind Pijeaux Hale and Dr. Kathryn T. Malvern, and to Dr. Barbara West Carpenter, National President of Zeta Beta Sorority, Inc.

Sincerely,

Issie L. Shelton-Jenkins
Foundation Chair
July 1995 – July 2000

Introduction

The most profound phenomenon of year 2000 and at the beginning of the new millennium **has** to be the event of the Human Genome Project research and the near completion of the sequencing of the human genome.

Decoding the Book of Life has major implications for every human being and particularly minority communities. The raison d'être for Human Genome Project conferences, workshops and seminars for minority communities throughout the United States and abroad is to make those communities aware of this issue, so they may make informed health and daily life decisions, based on this impacting scientific technological research.

And so, the National Educational Foundation of Zeta Phi Beta Sorority, Inc. has produced its second and very successful HGP conference in Philadelphia, Pennsylvania, July 2000, the first being held at Xavier University in New Orleans, Louisiana in 1999.

This proceedings journal describes the entire event of the Philadelphia conference and has been produced for information dissemination as a community outreach service. However, it is important for you to know that imparting HGP information to minority communities did not cease on July 8, 2000.

Dr. Barbara West Carpenter, International President of Zeta Phi Beta Sorority, Inc., has made this project an international initiative throughout Zetadom. Regional, State and local conferences are currently being planned throughout the United States. The Foundation gives Dr. Carpenter special thanks.

The National Educational Foundation also gives special gratitude to the United States Department of Energy and the National Institutes of Health for grant funding, the March of Dimes and Merck Research Laboratories, Community Advisory Council, presenters, panelists,

facilitators and conference attendees. The Foundation looks forward to continued support.

Our very special thanks and gratitude are given to Community Coordinator Audrey Johnson Thornton, Barbara Henderson Resource Coordinator and past Regional Director, Valerie Hollingsworth Davis, Logistics Coordinator.

Issie L. Jenkins, Esquire, immediate past Foundation Chairman, who through her vision, brought the Foundation and Zeta to this genomic venture, receives the highest commendation.

It is hoped that this document will prove helpful in your understanding of the Human Genome Project research and its impact.

Sincerely,

Dr. Kathryn T. Malvern
Foundation Chairman
July 2000 - Present

Foreword

GREETINGS!

Zeta Phi Beta Sorority, Inc. is excited about the launching of "The Human Genome Project" through our National Educational Foundation. Once again, Zeta is blazing a new path into the 21st Century in an area that remains an age-old mystery. Our sorority is at the forefront of cutting edge research data that will allay some of the myths and fears that surround this project.

We have undertaken the responsibility to serve as a link between the scientific community and the general population – the people whom we serve in our local communities. It is especially important that the minority community is made aware of the impact that genomic research will have on our lives.

Whether from the perspective of health care, career interest, social and ethical implications, we feel very strongly that a case should be made in lay terms for the inclusion of the African American community in our country's exploration into genome research.

Commendations are extended to Sorors Dr. Kathryn T. Malvern and Issie S. Jenkins, Esq. for their dedication and commitment to the success of this very important work. We are delighted with their leadership as we realize this opportunity to devote some of our efforts to forces that will shape the future.

Our work with "The Human Genome Project" is just beginning. You will hear much more about it through our activities over the next two years.

Sincerely,

Barbara W. Carpenter, Ph.D.
International President
Zeta Phi Beta Sorority, Inc.

Zeta Phi Beta Sorority
National Educational Foundation

Purpose and Mission

The National Educational Foundation of Zeta Phi Beta Sorority, Inc. is created and operated exclusively for charitable and educational purposes. The principle activities and purpose of the trust are to award scholarship grants to worthy students for the pursuit of higher education; to conduct community educational programs which will aid in the educational and vocational improvement in individual and community living standards; to engage in activities which will aid in the educational development of all women; and to engage in any appropriate research related to the purposes of the Foundation.

Mission

The Foundation's programs have included an emphasis on community education. That is one of the goals set in the establishment of the Foundation. In keeping with this goal, the Foundation sought and received support to sponsor an information conference on the Human Genome Project for the minority communities in Philadelphia, Pennsylvania and surrounding areas on July 7-8, 2000.

The foundation believes that there is a continuing need in the minority communities for information on this important project, on the status of genetic research, for encouraging greater inquiry and involvement by minorities, and an appreciation of the societal implications of the knowledge gained from this research.

Even though a large share of both private and public research dollars are being devoted to study and research for mapping the genes, and related genetic research, the level of awareness in the minority communities remains relatively low. Moreover, the lack of involvement of significant numbers of minorities in genetic research and related sciences, is cause for concern and illustrates the need for creating greater career interest among minority students in the field of genetics, biotechnology, and related areas of research and business; and for providing more role models and mentors.

Outreach for conference attendance was made to all segments of the minority communities, including outreach in the Asian-American communities, the Native-American communities, the Hispanic communities, the African-American communities, and others who are interested.

Conference Objectives

The project was an Information Conference on the Human Genome Project: The Challenges and Impact of Human Genome Research for Minority Communities. This two-day conference was designed primarily for representatives of minority communities, including community

leaders, representatives of minority organizations, educators, collegiates, government officials, fraternal groups, religious organizations representatives, civic, medical, social, business and professional organizations. It was open to the public.

The project's broad objective was to raise the level of awareness, in minority communities, of the rapid strides being made in human genome research and the background of the HGP, its potential and value to minorities; particularly in the area of health care; to clearly identify issues that are important to the minority community and avenues for more involvement of this community; and to explore post-conference ways of continuing input from and update of minorities.

Through presentations, workshops and open discussions, the conference addressed the ethical, legal and social issues raised by human genome research; its impact on treatments for such health problems as cancer, sickle cell anemia, and other physical and mental health problems.

The conference agenda also addressed how to develop and enhance career interest (of younger people, in particular, and all in general) in genetics and related sciences and business development.

Research Plans

Specific Aims / Objectives of the Information Conference on the Human Genome Project (HGP):

- To present clear and understandable information to the minority communities regarding the Human Genome Project.
- To explore the ethical, legal and social issues raised by human genome research and the HGP, and their particular relevance for minorities.
- To review the present status of genetic research findings and the benefits anticipated in promoting better physical and mental health for our communities.
- To provide information on the present and anticipated positive results and benefits of genetic research and the HGP for minorities, and to examine possible adverse consequences and strategies for lessening any adverse benefits.
- To facilitate minority communities' input into the Human Genome Project as it develops, and explore mechanisms for keeping communities informed and updated on developments, and to facilitate the development of community networks to keep individuals and communities informed.
- To develop and enhance career interest in genetics and related sciences and business development.

Conference Program

Friday July 7, 2000

9:30-10:00 a.m.	**Registration**
	Welcome and Greetings
	Dr. Kathryn T. Malvern, Conference Project Director

	Foundation Board of Managers, Moorestown, New Jersey
10:00 a.m.	***Dr. Barbara West Carpenter***, International President, Zeta Phi Beta Sorority, Inc., Baker, Louisiana
	Marie Tomasso, District Director, Philadelphia District, Equal Employment Opportunity Commission, Philadelphia, Pennsylvania
	Keynote Speaker: The Human Genome Project
10:15 a.m.	***Dr. Aristides A. Patrinos***, Associate Director, Biological and Environmental Research, U.S. Department of Energy, Germantown, Maryland
	Genes and Genomes: Decoding the Book of Life
11:00 a.m.	***Dr. John Quackenbush***, Associate Investigator, The Institute for Genomic Research, Rockville, Maryland
	The Benefits of Genetic Research in Improving Health and Health Care
	Dr. Karen Nelson, Investigator, The Institute for Genomic Research, Rockville, Maryland; **Moderator**
11:30 a.m.	***Dr. Georgia Dunston***, Microbiology Department, Howard University Medical School, Washington, D.C.
	Dr. Robert F. Murray, Howard University Medical School, Department of Genetics, Washington, D.C.
12:30 a.m.	Lunch On Your Own
1:30 p.m.	**Genetic Problems in Clinical Practice and Biomedical Research** ***Dr. Mary Kay Pelias***, Biometry and Genetics Department, Louisiana State University Medical School, New Orleans, Louisiana
	Scientific and Folk Ideas About Heredity ***Dr. Fatimah Jackson***, Department of Anthropology, University of Maryland, College Park, Maryland
2:45 p.m.	**Private Industry and its Role in the Biological Revolution** ***Dr. Chris Adams***, Chief Executive Officer, Mosiac Technologies, Waltham, Massachusetts

3:15 p.m. Break

Workshop I

Genetic Screening, Genetic Testing, and Genetic Counseling: Issues of Importance to Minority Communities

Dr. Eunice S. Thomas, 19th International President. Zeta Phi Beta Sorority, Washington, D.C.
Facilitator

Panelists:

Deborah L. Eunpu, Director, Genetic Counseling Program, Beaver College, Glenside, Pennsylvania

Zora Kramer Brown, Chairwoman, Breast Cancer Resource Committee, Washington, D.C.

Dr. Mortimer Poncz, Professor, Department of Pediatrics, Division of Hemotology, Childrens' Hospital, Philadelphia, Pennsylvania, March of Dimes Representative

Workshop II

Expanding the Pool of Minority Scientists; Genomics and its Challenge in the Education of Minorities

Dr. Rosalind P. Hale, Chair, Department of Education, Xavier University, New Orleans, Louisiana, Foundation Board of Managers
Facilitator

Panelists:

Dr. Margaret Werner-Washburne, University of New Mexico, Biology Department, Albuquerque, New Mexico

3:30-5:00 p.m.

Reverend Dr. Deborah P. Wolfe, Past Education Chief, United States Congress, Professor Emerita, Queens College, C.U.N.Y., President New Jersey Baptist Convention, 14th International President, Foundation Board of Managers, Zeta Phi Beta Sorority, Inc., Cranford, New Jersey

Dr. Jeroo S. Kotval, University of Albany, State University of New York, School of Public Health, Health Policy and Management, Rensselaer, New York

Workshop III

Minorities in the Scientific Workforce; Career Development

Valerie Hollingsworth-Davis, Atlantic Regional Director, Zeta Phi Beta Sorority, Inc., Brooklyn, New York
Facilitator

Panelists:

Dr. Karen Nelson, Investigator, The Institute for Geomic Research Rockville, Maryland

Dr. Lashawn R. Drew, Acting Director, NIH Academy, National Institutes of Health, Rockville, Maryland

Betty Mansfield, Human Genome News, Oak Ridge Laboratory, U.S. Department of Energy, Oak Ridge, Tennessee

Dr. Lloyd Townsend, Aventis Pharmaceutical, Bridgewater, New Jersey Karen Graham, Manager, University Relations and Recruiting, BD Company, Franklin Lakes, New Jersey

Jamaal Murphy, Student, University of Pittsburgh, Pittsburgh, Pennsylvania

Saturday, July 8, 2000

8:30-9:00 a.m.	**Registration**
9:00 a.m.	**The Human Genome Project: A Recap, Video: The Human Genome Project**
	Workshop Summaries and Reporting
	Workshop I Genetic Screening, Testing, Counseling
9:30 a.m.	**Workshop II** Genomics and its Challenge in the Education of Minorities
	Workshop III Minorities in the Scientific Workforce; Career

	Opportunities
	The Human Genome Project: Ethical, Legal, and Scoial Implications for the Minority Communities
	Issie L. Shelton Jenkins, Esq., The Shelton Group, Sykesville, Maryland, Chair, Foundation Board **Moderator**
	Panelists:
10:00 a.m.	***Phyllis Epps, Esq.***, Health, Law, and Policy Institute, Houston, Texas ***Dr. Jenifer Smith***, Unit Chief, DNA Analysis Unit I, FBI Laboratory, Washington, D.C. ***Dr. Jeroo S. Kotval***, School of Public Health, Department of Health Policy and Management, University of Albany, Rensselaer, New York ***Dr. Pamela Sankar***, Assistant Professor, Center for Bioethics, University of Pennsylvania, Philadelphia, Pennsylvania
	Group Session
	Open Dialogue:
12:00 Noon	***MINORITIES AND THE HUMAN GENOME PROJECT: WHAT NEXT?*** Discussion and recommendations for greater minority involvement and awareness **Dr. Kathryn T. Malvern** **Conference Project Director** **Moderator**
12:30-2:00 p.m.	**Complimentary Wrap-Up -Luncheon Speaker** ***The Honorable Leanna Washington*** ***Pennsylvania State Representative***

Conference Summary

On July 7 and 8, the Zeta Phi Beta Sorority, Inc., and its National Educational Foundation held an information conference on the challenges and impact of human genome research for minority communities in the Philadelphia area. 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 symposium was arranged by the Zeta Foundation under the leadership of Chair Issie L. Jenkins, Esq., and Conference Project Director Dr. Kathryn Malvern. Sorority President Dr. Barbara West Carpenter involved the entire organization in helping to sponsor the event.

The conference was held several weeks after the President's announcement that 97% of human genome sequencing has 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 Human Genome Project (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 science education for minority students.

Conference Program

The Keynote Speaker was Dr. Ari Patrinos, Associate Director of Health and Environmental Research at the U.S. Department of Energy. He discussed the history and accomplishments of the HGP and provided background information on the President's announcement. Indicating that the HGP's outcome will dramatically affect the country's economy, Dr. Patrinos emphasized the importance of involving minority communities so that all can share in Project benefits and so related concerns can be avoided or responsibly addressed.

Other presenters included Dr. 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.

A panel discussion on the Project's implications for minority health issues included Dr. Georgia Dunston and Dr. Robert Murray, both of Howard University Medical School. In addressing recent programs that screen for genetically determined health disorders, Dr. 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 widespread genetic screening programs are put in place, according to Dr. Murray. He and Dr. Dunston agreed that, without protective measures, information from genetic screening could be used to stigmatize or discriminate against minorities. Dr. Dunston questioned the genetic samples being used in human genome research and whether the represent enough variation in population. Indicating that the genome study deals with the foundation of identity, she expressed concern that present knowledge is too limited.

Dr. 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, Dr. Pelias described how they are manifested in Louisiana's diverse population and how relevant historical developments and patterns of immigration can influence health issues.

Dr. Fatimah Jackson, anthropologist at the University of Maryland, emphasized that the African-American perspective on human genome research is critical, although it cannot substitute for that of other groups. Insights of African-Americans are important because they so frequently have been victims of "science" and "quasi-genetic inquiries. They were among the first to call for representative sampling in the Project, Dr. 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. Dr. Jackson pointed out that minorities can not assume inclusiveness at any stage of the HGP and that the pattern of sampling often reflects power relationships. Minorities will need to demand such inclusiveness.

On the second morning, Dr. Daniel Drell of the DOE Human Genome Program presented a review of the HGP and a recap of the first day's proceedings.

ELSI Panel

A panel on Ethical, Legal, and Social Implications of the HGP for Minorities included Phyllis Epps, Esq. (Health Law and Policy Center, University of Houston Law Center); Jenifer Smith (DNA Analysis Unit, FBI Laboratory); Dr. Jeroo S. Kotval (School of Public Health, New York State University); Dr. Pamela Sankar (Center for Bioethics, University of Pennsylvania); and facilitator Jenkins (Shelton Group).

Ms. Jenkins raised the issue of confidentiality of individual genetic information; uses to be made of such information; the potential for discrimination in health care, 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. Dr. Kotval spoke of ethical issues involved in a market-driven health care system and identified the following four principles as central: just distribution of health care, quality of care, cost-effective care, and trust. Each of these principles could be impacted by the new genetic tests and their implications.

Dr. Smith 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 serious crimes such as rapes and homicides. These profiles are compared to 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.

Ms. Epps spoke of recent advances in pharmacogenomics (the study of drug-responsive genetic variations) 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 by race for whatever reason.

Workshops

Three afternoon workshops covered (1) Issues of Importance to the Minority Communities Relating to Genetic Screening, Testing, and Counseling; (2) Expanding the Pool of Minority Scientists—Genomics and its Challenge in the Education of Minorities; and (3) Minorities in the Scientific Workforce: Career Development. These workshops led to a series of recommendations.

Workshop panelists and facilitators Dr. Deborah P. Wolf and Dr. Eunice Thomas, both former National Presidents of Zeta Phi Beta Sorority; Dr. Deborah L. Eunpu, Genetic Counseling Program Director, Beaver College; Zora Kramer Brown, Breast Cancer Resource Committee; Dr. Mortimer Poncz, Department of Pediatrics, Children's Hospital; Dr. Rosalind P. Hale,

Division of Education, Xavier University of New Orleans; Margaret Werner-Washburne, University of New Mexico; Valerie Hollingsworth-Davis, Atlantic Regional Director, Zeta Phi Beta Sorority; Dr. La Shawn Drew, NIH Academy Director; Dr. Lloyd Townsend, Aventis Pharmaceutical; Karen Graham, BD Company Recruitment Manager; Betty Mansfield, DOE Human Genome Management Information System; and Jamaal Murphy, University of Pittsburgh student.

Workshop recommendations and concerns included the following:

1. Monitor the status of health insurance coverage for genetic testing and counseling, an important issue for minority communities.
2. Create more training opportunities for veteran teachers in such scientific developments as genetics.
3. Create settings that will develop good scientific mentoring situations for minority students.
4. Increase minority student awareness of the large number and types of jobs and careers needed in the genomic, biomedical, and biotechnology industries.
5. Encourage minority students to volunteer, take part-time jobs and pursue internships in science and related fields.
6. Start minority students early (middle and high schools) in math and science courses; college is too late to begin.

Closing Session

In the Closing Session conducted by Dr. Kathryn Malvern, Project Director on "What Next?" for continued minority involvement in education about genomic research developments, suggestions and comments included the following:

1. Continue information sessions at or involving local churches.
2. Prepare and disseminate a summary of the conference proceedings
3. Break the silence about the HGP in minority communities; collaborate with other groups.
4. Begin a program to interest students in science by talking about it in schools in the lower grades.
5. On a larger scale, factual information written in layman’s terms should be disseminated at Black Expo and minority festivals and on videotapes. Develop information in cartoon form for children.
6. Form local HGP Awareness Teams to keep abreast of developments.
7. Provide easily understood examples of the Project’s benefits.
8. Develop Web site with short lists of benefits, positive and negative potentials
9. Develop career day presentations to encourage students to seek scientific careers in biotechnology, genetic research, and other related fields.
10. Conduct more research into minority issues and concerns.

Leanne Washington, member of the Pennsylvania House of Representatives, 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 statewide conference on the HGP in the fall of 2000.

The Foundation has 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 Conference was supported by grants from the Department of Energy and the National Institutes of Health through the Ethical, Legal, and Social Issues components of their respective Human Genome Programs. The U.S. Equal Employment Opportunity Commission, Philadelphia District Office, provided assistance as a cooperating agency sponsor. Funding also was received from the March of Dimes and Merck Research Laboratories.

Workshop I Summary
Genetic Screening, Genetic Testing, and Genetic Counseling: Issues of Importance to Minority Communities

Facilitator: Dr. Eunice S. Thomas

Panelist Deborah Eunpu, Director of Genetic Counseling first informed us that there are Master's programs available in Genetic Counseling. Genetics is about all of us and where we stand today. It's what we do / do not talk to our children about. It's about our family reunions. Genetic counselors are trained to specialize in the family's needs. They determine how to work / in hospitals and communities. All of us need to understand who should have genetic testing / screening. It means working with two to three generations of the family. Information is available on msge.com and other Websites and in health departments.

Many primary practitioners are not trained in genetics. Genetic counseling is done with "this is what we can do" and "this might be helpful." They want to train more counselors in the minority community. Genetic counseling must work to make information accessible. Genetic counseling is helping families understand if there is a genetic basis and how it affects the individual. She stated that genetic counseling must understand what it means to a family (will it require special equipment in the home?) Is there prenatal testing? Do I have children? What are the family values that need to be considered?

Panelist, Dr. Mortimer Poncz, Professor of Pediatrics. In 1955, Dr. Sanger described how to sequence human protein (hemoglobin) and sickle cell. He received the first of two Noble prizes. In the 1970's the gene for hemoglobin was characterized. He states that the DNA of sickle cell anemia has been studied for some time and because of his interest he began working with 300 sickle cell patients. Please note that in Africa, many children die before the age of three, because of sickle cell anemia.

Dr. Poncz also addressed Thalsamia, an Italian blood disease related to malaria. However, in contrast, this disease has decreased in Italy and Cypress. In Crete and Cypress no children are now born with Thalsamia. However, Dr. Poncz' sickle cell patients have increased from 300 to 600. He does not understand where the medical and local communities stand in advancing research programs to decrease and eliminate the number of patients with sickle cell anemia. If Thalsamia can be eradicated, so should sickle cell anemia.

Panelist Zora Kramer Brown, Chair Breast Cancer Committee. Twenty years ago, Mrs. Brown had a breast cancer and it is in her family. She had a good diet and exercised regularly, but was still diagnosed with cancer. However, it was an early diagnosis. Three years ago, she had a recurrence of cancer.

In July 1997, a niece was diagnosed with breast cancer. Consequently, Mrs. Brown wrote a grant and brought in genetic counseling and an oncologist over the weekend for her family

members for a retreat. One year later, the niece with breast cancer died. It propelled the other nine at the retreat to go with Mrs. Brown to Capitol Hill to speak out on this issue and also the issue of privacy. They met recently to discuss ways to pass on information of other family members. She preaches early detection and early prevention. Mrs. Brown "wants it out of the closet and into the headlines."

Questions and Answers

Q. How do we get the information from the industry to the community?

A. There are studies to find out how communities want to receive the information. The classroom may not be the best way. Information is put together on chips (in robotic fashion) for strokes, in order to determine risk factors. They will test for all stroke-related mutations (about 100 years hence).

Q. Are certain families predisposed to learning disabilities?
Need to know if they are boys or girls?
What are the environmental exposures?
Are those with learning disabilities on one side of the family or the other side?

A. A family history should be studied to see what the pattern is.

Q. Any issues on getting insurance or health care as a result of having breast care?

A. No, except her health insurance skyrocketed because she was predisposed to breast cancer.

Q. What is the theory for the rise in the number of Dr. Poncz' sickle cell patients?

A. Sickle cell is more dominant in certain parts of the country. It is also predominant in India and Saudia Arabia. Ten percent of the Black population carries the gene; only ½ % of population actually has sickle cell.

The increase in Dr. Poncz' patients may also be due to the good work [detection] his hospital is doing, and more patients are going there.

Then the discussion turned to testing during pregnancy. The question was asked, should a woman know of a predisposition to a disease. The pro's and con's were debated.

Incidentally, the disease Thalsamia declined, mainly due to a church program that counseled people with the disease and encouraged them not to marry and have children.

Q. Will insurance companies pay for genetic counseling?

A. It depends on the testing and diagnosis and reason for it. Carrier testing may not be paid for.

Dr. Eunice S. Thomas encouraged the members of Zeta Phi Beta Sorority, Inc. to write their

congresspersons to encourage payment for this testing.

Workshop II Summary
Genomics and its Challenge in the Education of Minorities

Facilitator: Dr. Rosalind Pijeaux Hale

Panelists: Reverand Dr. Deborah Partridge Wolfe, Dr. Margaret Werner-Washburne, and Dr. Jeroo S. Kotval

Recommendations:

1. Create settings that will develop good mentoring situations for minorities.
2. Develop a working committee to continue to find solutions.
3. Create a network of young people who have completed various programs.
4. Develop the teaching force that is knowledgeable about these topics and that encourages minorities to pursue these fields.
5. Capitalize on government funds for teacher training and for student scholarships.
6. Use curriculum specialists to develop the curriculum needed.
7. Involve a variety of community groups to discuss these issues and help (churches, sororities, fraternities, etc.)
8. Increase the awareness of the large number of careers needed in the Genome Project besides scientists: Social Workers, Sociologists, Psychologists, Anthropologists, Genetic Counselors, Theologians, Public Relations, etc.
9. Increase the awareness of teachers concerning the curriculum areas involved.
10. Require Federal Agency Institutional training grants to include:
    - Adequate minority representation
    - An infrastructure in place to make it work
    - An evaluation process
12. Support leaders who take risks that indicate an understanding of these issues.
13. Develop more training opportunities for veteran teachers (summer, internships).
14. Provide meaning as to why minorities should select these careers. They bring cultural factors that would otherwise be excluded.
15. Become more knowledgeable about the various sources of information available.

Remember: It takes a community to raise a child. Therefore, everyone must be involved in the success of minority students in these fields.

Workshop III Summary
Minorities in the Scientific Workforce: Career Opportunities

Facilitator: Valarie Hollingsworth-Davis

Dr. LaShawn Drew, Acting Director of the NIH Academy, indicated that minorities in the United States have poorer medical health outcomes than majorities. Diagnoses for conditions such as cancer, diabetes, and high blood pressure may come later in disease progression, so the average prognosis is less favorable than for majority populations whose chronic diseases

may be diagnosed earlier.

In the 1980s, AIDS was considered a homosexual white male disease; now HIV is 10 times more prevalent among African Americans than whites. What is happening?

U.S. minority populations have a shorter lifespan, on average, than majority populations. Health care is not as good in minority communities for a number of reasons; one is that minorities may distrust medical professional due to past history, and some are reluctant to seek care. Despite notable progress in the nation's overall health, disparities continue in the burden of illness and death experienced by minorities compared to the U.S. population as a whole.

As a part of the Race and Health Initiative by 2010, President Clinton committed the nation in February 1998 to eliminating disparities in six areas of health status experienced by racial and ethnic minorities. These disparities were called to the nation's attention by Dr. Louis Sullivan and Rev. Jesse Jackson, Jr., U.S. Representative from Illinois.

Dr. Drew discussed a new NIH post-baccalaureate research and training program to help eliminate domestic health disparities by developing a diverse cadre of biomedical science researchers. The one-year program, recent college graduates, will convene its first class of 8 to 10 students in September 2000. The class will emphasize research-based training along with educational components such as seminars and workshops on topics related to health disparities. Skills development and general knowledge-building workshops also will be included.

Betty Mansfield, Managing Editor of *Human Genome News*, which is sponsored by the Department of Energy at Oak Ridge National Laboratory, told the audience that *the new genetics* soon will affect almost everyone as medical consumers, job holders, or both.

Expectations from genomic applications are high, and it is a special challenge for the nation to ensure that these benefits are realized by everyone regardless of race, citizenship, or national origin. Experts believe that if more minorities work in good jobs and careers in the medical sectors—especially those related to genetics—the healthcare-deliver system will have more credibility and trust among minorities.

Recommendations for Jobs in the Bioscience Industry

To obtain more information on the wide range of bioscience careers, Mansfield continued, students should use public libraries, surf the Internet, and read newspapers and trade and technology journals. They should contact their state's biotechnology-industry organization and find its "Careers" section on the Web (the URL for the national umbrella Biotechnology Industry Organization is www.bio.org).

Students also should communicate with professionals working in fields in which they are interested. Showing interest opens doors for new opportunities.

Some specific careers in or relying heavily on bioscience:

- Biomedical laboratory research
- Medical, pharmaceutical, and biotechnology industries
- Agricultural research and production
- Wildlife management
- Computing: databases, data analysis, supercomputing
- Engineering
- Toxic waste cleanup: bioremediation

- Creation of new energy sources
- Business: bioscience investment specialist, marketing and sales, banking
- Legal and justice system: patent specialists, genetics lawyers, and DNA forensics
- History and anthropology
- Military
- Space exploration
- Bioscience communication

In the past six years, the biotechnology industry doubled in size and is expected to triple in the next 10 years. The number and diversity of bioscience careers, therefore, is expected to increase dramatically.

Cross-disciplinary training in bioethics as well as science or technology (including biology, chemistry, physics, engineering principles, and computer and information science) is seen as important in securing good positions in the growing biosciences industry.

Value of Experience

The meeting panel concluded that students who have jobs, internship positions, or volunteer work in their planned fields have an advantage after graduation—whether the degree being sought is a 2-year, 4-year, M.S., or Ph.D.

Karen Graham, Manager of University Relations and College Recruiting at BD Company, indicated that such experience on a resume would carry more weight than work in unrelated fields and could help offset a less-than-optimal GPA.

Ms. Graham enumerated the traits she looks for in hiring students from college:

- Good communication skills
- Ability to work in teams
- Ability to adopt company objectives and purpose
- Willingness to understand how an individual's work fits into the big picture and how it is translated into a product
- Potential for future company leadership
- Willingness to take risks, take action, and make decisions
- Willingness to learn continuously

Ms. Graham said that, in her experience, most companies are on an ethnicity-diversity kick; they are struggling to get more diverse candidates into their organizations.

Dr. Lloyd Townsend of Aventis Pharmaceutical began his presentation by discussing a study published in the *Journal of Women and Minorities in Science and Engineering.* The study indicated that by 2008, the United States will experience a shortfall of about 2000 Ph.D. –level scientists. This 1992 study was conducted before the genome project kicked the biotechnology industry into high gear. The estimate probably is low, and the shortfall of scientists may be even more pronounced.

Earlier in the session, Dr. Drew said that less than 15% of Ph.D.'s each year go to minorities, who make up about 30% of the U.S. population. The panel and members of the audience concluded that we should be reading the publication mentioned above. Certainly school boards and guidance counselors would benefit from this information as well.

Dr. Townsend said that educators must work diligently to encourage middle and high school students to take more math and science courses. He emphasized that waiting until students are in college to focus on science and math is too late.

Advice to Students

Finally, the audience heard the insights of **Jamaal Murphy, a student representative** who is a recent college graduate and is now enrolled as a student in physical therapy. After obtaining this degree, he plans to go to medical school and become a pediatrician. He offered the following advice to students: never give up and always practice excellent time-management skills. In reference to past discrimination against minorities, he said we must change with the times, get over past hurts, and pursue careers of choice. At the end of his talk, he acknowledged his mother in the audience, "without whose genes I wouldn't be here."

Keynote Speaker

Aristides Patrinos, Ph.D.
The Human Genome Project: What Minority Communities Need to Know

As you read this, the first phase of the Human Genome Project (HGP) will have just about been finished, its first major milestone achieved. A nearly complete, "draft" version of the entire human genome, all of the chromosomes containing the 3.2 billion base pairs of DNA, will have been determined and deposited in publicly accessible databases for anyone to view and use. Scientists will know almost all of the human DNA sequence, containing the essential information for all the "parts" that make up all of the approximately 10 trillion cells in an adult human body and carry out all the functions inside each of those cells. Biologists will have begun to identify all the basic genetic building blocks, some 120,000 genes and will be computationally exploring what they do. Perhaps 30% of those genetic "parts" will be tentatively "annotated," that is, assigned a reasonably certain biological function and purpose. Technologies for DNA sequencing will have progressed to the state that a highly organized and well-equipped sequencing center can determine on the order of 30,000,000 base pairs of DNA sequence in a day, equivalent, if printed, to a 1600 page phone book. With this complete "parts list" in hand, and using modern DNA manipulation and analysis technologies, a scientist in her or his lab can find the location of any gene in the vast human genome and amplify, study, and characterize it. The promise from this ambitious effort is huge and the outcomes will dramatically affect the economy of the United States. In part as a direct consequence, these DNA technologies and the resulting information will have many impacts on other aspects of society.

In 1986, scientists in the U.S. DOE started the HGP as a way to explore newly developing DNA analytical technologies that might better assess mutations from radiation. (Mutations had been understood since the work of Watson and Crick as abased n changes in the sequence of the four bases that comprise DNA. Thus sequencing the human DNA in its entirety would provide a reference for evaluating the effects of radiation-induced mutations.) DOE'S network of National Laboratories, its experience with large projects (e.g., particle accelerators), and the availability of both interdisciplinary teams of scientists and powerful computational facilities, all made DOE a logical, if unexpected, agency to begin a massive effort to sequence the human genome.

Each of us is a unique individual. Each of us has a genome, consisting of some 3.2 billion DNA bases inherited from our mother, plus an additional and very similar 3.2 billion inherited from our father. Each of us differs in DNA sequence by about 1 base in every thousand, for a total of between 3 and 6 million differences. While these differences underlie our uniqueness and

individuality, it should be clear that we are about 99.9% the same as anyone else and this is true regardless of any distinctions based on ethnicity, race, gender, or anything else. However, while this 0.1% difference accounts for much of what makes us individuals, there are other contributing factors as well, man of them non-genetic (such as the environmental input). Numerous studies of identical twins have shown that identical twins genetically identical from conception, are not identical for various traits and diseases. The are often observed to be more similar than either non-identical siblings or random individuals, but still very often non-concordant.

The importance of this observation is that while we can expect to learn much from studying a person's genome, there is a limit to what it can tell us even when we "know" it in its entirety. After all, what better genetic test can there be than to have a identical twin to observe? So it is necessary to be extremely cautious and alert to "genetic determinism," the trap of assuming that more is due to genetic inheritance than in fact is.

At the outset of the HGP, several people recognized that ethical, legal and social issues (abbreviated "ELSI" would be challenges. Much of the initial credit goes to Dr. James Watson, co-discoverer of the structure of the DNA molecule, and first director of the Genome Office at the National Institute of Health. In 1988, Watson noted the concerns about ELSI and set aside some funding to study the issues that would arise from the HGP. DOE soon followed suit setting aside funds from its genome research budget and participating in joint coordination activities between the two agencies' programs. A non-exhaustive list of some of these issues includes:

- Identification of individuals, whether in criminal courts or in the context of paternity disputes.
- Insurance issues, e.g., as more information about an individual's future health status is known or knowable, it may be harder to obtain insurance and an insurance company, answerable to its investors, may elect not to underwrite "high risk" individuals.
- Employment issues, e.g., should an employer be able to learn of an employee's potential genetic susceptibilities so the employer can assign her or him to work where exposure to a hazard is less likely?
- Personal injury litigation, e.g., can one party to a dispute request genetic information about the potential longevity of the other party with the intent of seeking reduction of potential damages due to a genetically-shortened life span? Commercial transactions: (should a bank or loan agency be able to request genetic information from a borrower to ensure she or he will survive long enough to pay back the loan?)
- Domestic relations, e.g., adoption or child custody cases.
- Educational settings., e.g., can a school require genetic information about students in order to sequester or even refuse any student thought to have a predisposition to disruptive behavior?
- Criminal justice issues, e.g., can a defendant argue that "my genes predisposed me to this behavior" and thus seek mitigation of punishment post-conviction with the equivalent of a "not guilty by reason of genetic inheritance" assertion?

Presently, most of these questions represent untested social and legal scenarios that also presuppose much highly questionable science. Ultimately, they will only be resolved by courts. An additional major concern is that the impacts of many of these applications of genomics may affect minority communities disproportionately; while there is little (if any) evidence of this today, it remains something we must all guard against.

The genome program will elucidate the fundamental parts list and instruction manual for a human and it will be a reference for every human on the planet. The HGP has taken great care

to make it as difficult as possible for anyone to learn who are the donors of the DNA that is being sequenced by the effort. After being carefully counseled, and voluntarily giving informed consent, the donors themselves do not know if their DNA is being used, nor do the researchers know which donors provided the DNA being sequenced for the HGP. Truly this effort is for all of us, not only the medical benefits to come from it, but also the new industries, the new opportunities, and the new insights into our relation to the other residents of the world around us.

John Quackenbush, Ph.D.
Genes and Genomes: Decoding the Book of Life

The Human Genome Project recently reached a milestone with the completion and public release of a first draft version of a reference human DNA sequence in June of 2000. This achievement represents not only the accomplishment of one of the primary goals of the nearly decade old Genome Project, but also stands as the culmination of a great tradition of scientific research in the fields of genetics and molecular biology. The "genome" is the collection of all of the DNA within an organism, and the discovery of the "genes" contained within the genome can allow us to begin to understand both much about ourselves, our development, and factors that can effect our health and welfare.

In some sense, the history of genetics and genomics can be traced back to the work of Gregor Mendel, who analyzed the transmission of traits in plant hybrids in the late 1800's. Mendel discovered that traits (or what he calls "genes") pass from one generation to the next with precise mathematical relationships, a discovery that laid the basis for our current understanding of genetics and heredity. However, the mechanism by which genetic information is stored and transmitted was not understood and required significant additional scientific investigation. Charles Darwin provided other crucial insights in the development of genetics when, in "On the Origin of Species," he postulated that genetic changes could arise spontaneously and that these could be passed from one generation to the next.

However, it was the publication of the structure of DNA by James Watson and Francis Crick in 1943 that truly ushered in a new era in biology, setting the stage for the molecular understanding of genetics cellular physiology, metabolism, and evolution. Watson and Crick's structure provided an intellectual framework in which one could understand both how hereditary information could be reliably passed between generations while also allowing a mechanism by which changes in the "code" could arise, giving rise to variation. Further, DNA, and sister molecule RNA, allowed an explanation for how the information stored in genes (regions of the DNA) could be turned into proteins. As proteins serve as the primary building blocks of organisms and their cells, one could then understand how changes in DNA could lead to heritable changes in organisms, leading to the variation that Darwin observed.

DNA consists of four basic nucleotide sub-units, or bases, Adenine (A), Cytosine (C), Guanine (G), and Thiamine (T), linked together as a linear polymer. DNA, however, rarely occurs as a single polymer. Rather, it occurs as a double stranded molecule in which two "complementary" strands pair together such that As from one strand always pairs with Ts from the second (and vice versa) while Gs and Cs always pair. Although DNA consists of only a four-letter alphabet, linear combinations of As, Cs, Gs and Ts can encode a tremendous quantity of useful

information, including the instructions that cells need to make proteins. Watson and Crick's discovery led to a rapid series of discoveries, including a detailed understanding of transcription and translation, the mechanism by which the DNA blueprint is first converted into RNA, and the RNA message is used to make a distinct protein. What is fascinating about this process is that both the basic mechanisms, as well as the "code" that is used to convert the DNA blueprint into a protein, are nearly universal among all forms of life on earth.

This observation, and the data on genes and genomes that we have generated has allowed us to learn a number of important lessons both about our shared genetic heritage with all life on earth as well as how closely related all humans are to each other. Empirical data now tells us that the difference in the DNA sequence between any two individuals – regardless of race, sex, national origin – is less than 1 base per thousand. The fact that we are 99.9% similar at our most basic level (in our genes and DNA) may seem surprising given the apparent diversity of human morphology (differences in height, sex, hair color, skin color, and body shape.) However we can easily understand this if we consider that we can all eat the same food, breathe the same air, have children together, and even exchange blood or transplanted organs.

In the 1970's, Fredrick Sanger and the team of Alan Maxam and Walter Gilbert independently discovered means of sequencing DNA, or reading off the series of As, Cs, Gs, and Ts that make up the genetic code. With this technique, one could envision reading the sequence of one gene, or many genes, or even the entire DNA complement, or genome, or an organism. Other novel techniques for the molecular analysis of DNA, RNA, and proteins have followed rapidly. These rapid developments in laboratory techniques, coupled with advances in computational approaches to data analysis, resulted in the creation of a new science know as "genomics." The goal of genomics is to rapidly sequence the entire genome of an organism to provide a starting point for further investigation. The first genome sequence of a first free-living organism. *Haemophilus influenzae* (a bacteria that causes ear infections in children, was completed in 1995 by Robert Fleischman, J. Craig Venter, and some of my other colleagues at TIGR. Since then, there has been an explosion in the number of unicellular prokaryotes (bacteria and archaea) and more complex eukaryotes (organisms, like humans, whose cells contain nuclei) that have been fully sequenced. Indeed, the announcement this summer that a working draft of the human genome had been completed was a clear signal that genomic science had reached maturity.

One might ask how and why genomics is important. To answer those questions, we have to first understand the importance of the role DNA plays. As mentioned previously, the DNA contains a blueprint that the cells use for making proteins. Changes in that DNA blueprint can lead to changes in the proteins that are made, and these changed proteins may not properly carry out their functions, leading to the development of a disease. For example, in sickle cell anemia, a single nucleotide change in the beta-globin gene leads to a form of the beta-globin protein that, under conditions of oxygen stress (low oxygen concentrations due to stress or exertion), can deform, causing the normally round blood cells to "sickle," impeding blood flow and causing severe pain and in some extreme cases, even death.

Part of our goal as scientists is to develop techniques that allow us to identify genes that play roles in disease with the hope that we can first provide information to people at risk so they can, for example, change their lifestyle to lessen their risk. Later, we hope that information will allow us to understand the mechanism responsible for the disease and allow us to develop treatments.

However finding disease genes has been a difficult task. The human genome contains approximately 3,000,000,000 base pairs of DNA (in two copies, for a total of 6,000,000,000 base

pairs. To put this in perspective, 3,000,000,000 is approximately the number of seconds in 95 years. Within that sequence, we first have to find one of 30,000-100,000 genes within the 46 chromosomes (22 autosome pairs plus the X and Y chromosomes) and then identify the "normal" and "mutant" forms of the gene. This is complicated by the natural variation (polymorphism) in the genome that distinguishes individuals. Fortunately, we have developed techniques that allow us to "zoom into" the genome, building maps of higher and higher resolution, until ultimately, we discover the DNA sequence and the gene involved in the disease.

As an analogy to the techniques we use, consider how an alien species might try to find, for example, the New York Knicks basketball team. Upon arriving in the solar system, they would first learn that the Knicks play somewhere on earth. As they approached earth, they would be able to make simple maps of the earth, but those maps would get better and better as they got closer to the earth. Eventually, the aliens would learn that the Knicks were somewhere on the island of Manhattan near Central Park, where they could then land and begin a detailed search.

Finding disease genes is similar. First, we identify on which chromosome the disease gene lies, often through studies of families in which the disease is prevalent. We then establish landmarks on the chromosome, building a simple map. As we gather more information our maps become more detailed, until we find a convenient landmark that is closely associated with the disease. We can then focus on that area of the genome, ultimately obtaining the DNA sequence and identifying the gene.

While scientists have been searching for disease genes, one at a time, using these techniques for years, it was only in the late 1980's that we began to realize that finding genes would be easier if we could complete all of these steps for all human genes at once. The Human Genome Project was born at the Department of Energy (which has a long history of studying genetics), and later joined by the National Institutes of Health and by organizations around the world. The first goal of the Genome Project was to build comprehensive maps of the human genome, placing useful landmarks along the chromosomes. Having accomplished this task, the sequencing of the genome began with the goal of producing a completed genome by 2003. Spurred on by competition from the private sector, the schedule for completing the task was pushed forward and due to the efforts of scientists around the world, we saw the announcement of the completion of the "first draft" of the human genome sequence in the summer of 2000. Although much work remains to be done to fill the gaps and finish this sequence, we now have a tremendous resource for gene discovery that will provide the starting point for much of the biology and medicine of the future.

The Human Genome Project has, in essence, provided us with our first glimpse of the "Book of Life." Our tasks now are no less challenging. We want to "mine" the DNA sequence for the presence of genes. We have to identify the functions of these genes. We want to use our tools and resources to map genes that play a role in human disease. We want to find the same genes in animal models such as a mouse and a rat so that we can continue our studies of gene function. Be we also have to address a number of complex social, ethical and legal issues associated with genome data.

Our primary tool to address these issues is education. For example, many genes involved in disease are found by studying inheritance patterns in populations where a particular disease is prevalent. The discovery of a mutated gene in such a population is often misinterpreted as implying that that finding is only relevant to that particular population, or that that mutation is somehow linked to that group of people. In fact, what we should learn from genomics is that genes are universal and that the same mutation is likely to contribute to the disease in many other people.

We not only have to educate ourselves, however. It is important that we educate our legislators and government policy makers. The genetic information is extremely private information about each individual and we must work to assure that our privacy is respected and that genetic information is not misused. We can already identify people who are at risk for developing certain diseases that have a strong genetic component. We have to now make sure that such information is not used to deny those individuals, employment, job training, or medical insurance. These responsibilities are shared by all of us. Through our continued efforts to educate ourselves, to reach out to our communities, and to communicate our fears, needs, and responsibilities to government policy makers, we have our best opportunity to have genetic and genomic information used to its greatest potential to provide a better quality of life for all people.

Georgia M. Dunston, Ph.D.
The Implications of Human Genome Research for Minority Health Issues: The Benefits of Genetic Research in Improving Health and Health Care

As the awesome technological feat of sequencing the human genome nears completion, the more daunting task of deciphering the genomic text (i.e., the language of life) is just beginning. The emergence of the Human Genome Project at this juncture in the evolution of western sciences is not only impacting the way "we view" biology, but also how "we do" biology. Community education in genome science is the most compelling and potentially the most transformative challenge to 21st century science and society. DNA sequence data coming forth from the Human Genome Project challenges prevailing constructs of human populations, which partition humanity into bounded ethnic and/or racial groups. Because natural variation in the human genome is the ultimate measure of biological relationship, it is a determinant of individual, family, population, and human identity.

The Human Genome Project is unique among the leading edge sciences in having as part of its initial core, a component to anticipate and address ethical, legal, and social issues emanating from the advancement of knowledge gained from the science. Because of inherent variation in the genome, the Human Genome Project challenges science to expand, (i.e., make more inclusive) the contest or measure of humanity in order to better understand the content of the human biology.

The Human Genome Project is forcing a paradigm shift in biology from the phenotype to the genotype, or from an "outside" to an "inside" view of biology and life. The transition from structural genomics to functional genomics focuses less on sequencing and more on understanding the significance of sequence variation. The importance of population variation in the genetic diagnosis, treatment and management of complex diseases cannot be marginalized or ignored.

The population that is used as the reference to locate abnormal (i.e., mutations) and natural variation (i.e., polymorphisms) is relevant to the identification and proper application of information emerging from DNA sequence variation. The African American genome is perhaps the most comprehensive single population resource for exploiting DNA sequence variation in the genetic dissection of complex diseases. As medicine becomes increasingly more customized, made to order, designer medicine, a more refined definition of the individual and population-based disparities in health will be required.

Let me preface my comments by commending Zeta Phi Beta Sorority for having planned such a well-timed conference. With the recent news on the cover of Time magazine, announcing the near completion of a ‘’Working Draft’ of the human genome, nothing could be timelier than this conference addressing the challenges and impact of human genome research for minority communities, specifically the benefits of genetic research in improving health and health care. As the awesome technological feat of sequencing the human genome nears completion, the more daunting task of deciphering the genomic text (i.e., the language of life) is just beginning. The organizers of this conference have shown great insight in planning a program that recognizes the major triumphs of the Human Genome Project (HGP) along with the sobering implications of how knowledge gained from this sciences is impacting society in general and minority health issues in particular.

Because so much of the current attention in human genome research is on the success of sequencing, I especially appreciate the recognition and attention that this conference directs to community education on genetics research and its relevance to minority health. As stunning and awesome as is the sequencing of 3 billion nucleotides in the human genome, community education in genome sciences is the most compelling and potentially the most transformative challenge to 21st century science and society. Informed, educated, and activist communities will ultimately determine whether the billions of dollars expended in sequencing the human genome will usher in a new era of human liberation from the tyranny of disease, disability, and death due to complex diseases, such as diabetes, cancer, and heart disease – or whether the HGP will be remembered as the most expensive, self-promoting and exploitative venture in the history of western science and technology.

In addressing the topic of this panel, I want to focus your attention on the potential benefits of genetic research in improving health and health care by underscoring the links between human genome research, self-knowledge, and minority health issues. In my opinion, the formal beginning of the U.S. Human Genome Project in 1990 represents a defining moment in western science and human history.

My reasons for making this statement are twofold. First, the HGP perhaps like no other leading edge of western science, challenges scientist to expand, (i.e., make more inclusive) the context or measure of humanity, in order to better understand the content of human biology. Second, with regard to human history, sequence data emerging from the HGP challenges prevailing constructs of human populations which partition humanity into bounded ethnic and/or racial groups. At this, the dawn of the 21st century, the HGP has extended the probing of biomedical science to the ultimate level of biological identity (i.e., unique DNA sequence variation).

Moreover, exploration of the human genome has introduced new prospects for understanding molecular processes underlying disease and disease susceptibility. Attention is now focused on DNA sequence variation and the challenges inherent in distinguishing sequence variation of biomedical interest (i.e., mutations) from the tremendous amount of natural variation (i.e., polymorphisms) of biological interest. Because natural variation in the human genome is the ultimate measure of biological relationship, it is a determinant of individual, family, population, and human identity. Studies on DNA sequence analysis show that populations differ in the frequency of both mutations of biomedical interest and polymorphisms of biological interests. Thus, the population that is used as the reference to many mutations and polymorphisms is relevant to the identification and proper application of information emerging from DNA sequence variation.

Let me direct your attention for a moment to the historic and evolutionary significance of

completing the human genome sequence for humankind. I say historic, because completing the human genome sequence marks this moment in history as the ceremonial beginning of a new era of biomedical science, genomic medicine and the paradigm shift in biology to DNA-sequence based diagnosis and prevention of disease. I say evolutionary because – with the completion of the human genome sequence, comes a new knowledge-base for biology and biomedical science. A knowledge base that is as old as the origins of humanity and yet as new as the most recent gene discovery. This knowledge base connects all life and has the capacity to transform our most basic concepts of self and human identity. Thus, sequencing the human genome is not only applicable to biomedical science in the identification of genes of both clinical and non-clinical interests, but also to more fundamental questions of human identity and integrity. One of the major implications of human genome research for minority health issues is its potential impact on how we define ourselves.

The human genome is unique in that it is the fundamental level and expression of life. It contains all the information required for the construction, assembly, and operation of the human body. Thus, it is both a type of manufacturer's Handbook and owner's Manual. Because the genome is in all nucleated cells of the body and the body is encoded in every genome, the genome and the body are inextricably one.

The human genome is not only the most complex information system known to mankind, but also an unfathomable communications system, in which the four-lettered DNA sequence code is translated into "flesh" and dwells among us. As the "Book of Life," the genome contains the record of every human being that ever was and is and will ever be. It encodes both the laws of life and of creation. The knowledge contained therein is indeed unique. One wonders if science is not the instrument for revelation of this knowledge in our time.

The sequencing of the human genome has shifted the orientation of human knowledge from the outside appearance of things to the inside reality of life expressed at the molecular and cellular, or microcosmic levels. The HGP project also shifts the definition humankind from a population-based to a DNA sequence-based science. The characterization of DNA sequence variation in the human genome is not only applicable to human biology, but also to human identity.

The most salient feature of human identity at the sequence level is variation. Human genome sequence variation dispels the myth of a majority. At the level of the genome, every genome is unique; the norm is variation not uniformity, and the norm is best defined as a range of variation. As medicine becomes increasingly more customized, made to order, designer medicine, a more refined definition of humanity and the individual will be required. It remains to be determined how DNA sequence-based knowledge of self and group identity will impact minority health issue. Biological anthropologists and population geneticists are already mining the rich resources of natural variation in the human genome to reconstruct population history. Although no known biological product is encoded by much of the natural variation in the genome, it is nonetheless transmitted from generation to generation through the genome much like the genes that code for proteins, the functional products of genes. Natural variation in DNA sequences is a very rich source of information on family and population history. The results of research in areas of molecular evolution on gene genealogies in human populations are challenging old ways of characterizing racial and ethnic groups, which traditionally have been based on phenotypic, linguistic, and/or cultural differences. Anthropologists have estimated that less than 1% of the total gene pool code for the phenotypic characteristics widely used in the western world to classify human populations. In other words, the genes for physical appearance, such as skin color, eye color, and hair texture are an extremely small fraction of the approximately 3 billion nucleotides that make up the human genome. If DNA sequence based biology is to be science

driven then scientists and the general public must better understand the public health significance of the vastly greater stretches of unexpressed DNA sequence variation. The genome era is also forcing a paradigm shift in biology. A shift that is not just a change, but rather a transformation in the way we define ourselves; the way we see ourselves; the way we see our world, and how we see ourselves in relationship to our world.

As an African American woman and trained human geneticist, I am aware of the narrow Eurocentric context in which much of human biology has heretofore been cast and of the history of exploitation and exclusionary practices of western science and biomedical research in communities of color. As part of the African American community and a member of the academy, I am convinced that the active participation of communities of color in general, and African Americans in particular will be a major factor in whether knowledge gained from sequencing the human genome will contribute to widening the gap or eliminating national and global health disparities between socio-economically and politically advantaged and disadvantaged people. I am therefore committed to realizing the benefits of genetics in public health and to the importance of connecting research, education, practice and community.

While the alleviation of disease is the prime motivation for the HGP, this conference focuses on the implications of human genome research for minority health issues. If health is recognized as "more than" the absence of disease, then human genome research must go beyond a focus on disease to a greater understanding of the "more than " implicit in health. Because an individual's concept of identity frames his or her reality, I hypothesize that the study of disease in individuals and between groups cannot be uncoupled from an individual's and/or group concept of identity. Studies of DNA sequence variation challenge the truth of perceived and believed links between human identity and biology that is inculcated in the U.S. culture. The social implications of uncoupling individual and group identity from biology are enormous. It remains to be determined whether attention to emerging knowledge of DNA sequence variation may effect a paradigm shift in our understanding of individual and group identity. Knowledge gained from the human genome is unique in it capacity to liberate science and society from constructs of biology based on a very limited and incomplete picture of the human identity. If sickness and disease results from incomplete and distorted concept of human identity – then it remains to be determined whether wholeness and health would follow after a more comprehensive construct of biology based on more complete knowledge of the human genome.

It is now, that America is challenged nationally to close the gap in health status between majority and minority populations. There is indeed much to be learned, when we see human variation as a gift and not an aberration. It is noteworthy that knowledge of population differences in profiles of variation in the human genome, coupled with knowledge of the broader spectrum of natural variation in the genome of African people, underscores the critical importance of the population reference in human genome research. Understanding the "language of life" encoded in DNA sequence variation is indeed the braved new frontier of whole genome science, genomic medicine, and public health. Genomic research in African Americans and the African Diaspora offer unique resources for understanding human genome variation. Because the African American genome brings together the depth and breadth of DNA sequence variation resident in African populations with evolutionarily more recent profiles of variation contributed by admixture with Europeans and Native Americans. The African American genome is perhaps the most comprehensive single population resource for exploiting DNA sequence variation in the genetic dissection of complex diseases.

Let me close by commenting briefly on Genomic Research in African-American Pedigrees (G-RAP). This is a concept for human genome research initially proposed by investigators at

Howard University contemporaneously with the beginning of the first five years (FY 1991-1995) of the U.S. Human Genome Project. G-RAP focuses on DNA sequence variation as the foundation of biology and biomedical science.

The long-range goal of G-RAP is to improve the health status of African-Americans through research on DNA sequence variation and the application of knowledge gained from research to better understand the biomedical significance of gene-based differences already known to exist among populations in immune response to organ transplants, susceptibility to diseases such as diabetes, sensitivity to drugs, cancer, and the influence of environment on health. G-RAP provided a research foundation for the newly formed National Human Genome Center at Howard University. The purpose of this National Center is to bring multicultural perspectives and resources to an understanding of human genome variation and its implications for health and life.

Our mission is knowledge driven – to explore the science of and teach the knowledge about DNA sequence variation in the causality, treatment, and prevention of diseases common in African Americans and other peoples of the African Diaspora. By addressing population variability in the human genome, the NHGC brings a depth perception to the linear perspective of human biology. The implications of this more enriched construct of human biology in improving health and health care will be determined not so much by the science as by the scientists and not scientists in isolation but in community.

Mary Kay Pelias, Ph.D., J.D.
Genetic Problems in Clinical Practice and Biomedical Research

The exponential growth of our knowledge of the human genome has confirmed what man has known intuitively for eons: genetic factors in health and disease affect all human groups in countless ways. Most of our genes contribute to "normal variation," or the spectrum of characteristics that make all of us human, yet all unique. The concept of normal variation includes such traits as intelligence, color, and stature and body form, all of which are difficult to define and quantify. While we all know that genes are very much involved in the determination of these characteristics, we also know very little about exactly how many genes are involved or what those genes actually do. In addition to all of our normal traits, genes also contribute to characteristics related to health and disease. Some health problems are directly controlled by single genes that are really identifiable, while other health problems are controlled by complex interactions of many genes throughout the human genome. Some hereditary health problems are deadly, while others are amenable to medical treatment, or surgical treatment, or even to dietary or other environmental manipulations. As we continue to explore our genes, we are learning that we will realize immense benefits from the new genetic technologies and the development of new treatment protocols.

As a prototype of how specific genetic problems affect specific human groups, the populations of Louisiana offer several excellent examples. At least 6 populations have been documented as relatively closed groups. These "isolates" include the Scotch-Irish of the Central Hills and the Delta Blacks I the north, the Ten Milers in the center of the state, the Scotch-Irish of the Florida parishes, the Houmas Indians in the south, and the French Acadians. Each of these groups is characterized by the unique incidence of specific genetic problems that reflect the genealogical and genetic history of the original settlers in separate geographical areas. The populations of Louisiana represent a microcosm of populations around the world, each with its own genetic

endowment.

The scope of hereditary health problems is immense. These problems reflect the adage that "anything that can go wrong will go wrong," because every physiological process and every biochemical conversion is subject to malfunction. Many problems are caused by mutations that affect the membranes of cells in various tissues and organs so that nutrients or hormones can no longer attach to cells or be transported across the membranes to the places where they should function. Other genetic diseases are the result of mutations that affect the synthesis or the activity of enzymes that drive the thousands of biochemical conversions that characterize normal metabolism. Such enzyme deficiencies may result in the a accumulation of substances that can be toxic to the system if they are present in greater than normal amounts, as we see most dramatically in the array of "storage diseases" that occur more frequently in some ethnic groups than in others. In addition to a plethora of enzymopathies, the synthesis and function of structural proteins is subject to mutational changes, with the result that the normally strong fibers of muscle, tendons, ligaments, bone, and connective tissue may be weak and prone to collapse. Proteins associated with blood and oxygen transport are likewise subject to deleterious mutations that are expressed in a variety of anemias and other deficiencies. Genetic changes are also implicated in a vast number of sensory deficits that result in blindness, deafness and the ability to sense pain. Finally, we are rapidly learning that genes account for cancer and a spectrum of behavioral and psychiatric traits. The array expands daily, as does our potential for relieving the burden of genetic disease and disorders.

Over the past half century, research in human and medical genetics has focused on finding and characterizing genes that determine our normal traits as well as those hereditary variations that may lead to serious compromise of health and personal function. Numerous approaches to finding our genes are described as gene mapping, which entails family studies that show how a gene is transmitted through successive generations of large families. One approach to these studies involves tracking the "unknown" gene as it is transmitted with another gene whose position in the genome is already known. Once the chromosomal location of a gene is determined, various molecular techniques permit the detailed examination of DNA in the region until the gene itself is identified and is molecular sequence of nucleotides is elucidated. This sequence is then examined to determine the nature of the protein that is coded in the DNA nucleotides, with every three nucleotides coding for one of the 20 amino acids that determine protein structure. Once the amino acid sequence of the protein product is determined, the protein can be examined for its normal function and any alterations in structure that result from mutations, or changes, in the nucleotide sequence of the DNA.

With the molecular basis of DNA and protein delineated, new clinical approaches may be sought to treat – or even cure – some genetic diseases. One approach to treatment is to supply the gene product to the patient whose body is unable to produce the product. The isolation of the gene that codes for the structure of human insulin, for example, permitted the insertion of that gene into bacterial cells, which then became microscopic factories for producing human insulin that could be concentrated and administered to patients with diabetes. Another molecular approach to treatment is insertion of the isolated gene into the cells of a patient so that these cells can then produce the product that the patient was unable to manufacture because of a particular inborn genetic deficiency. This approach has been dramatically successful in the treatment of severe combined immune deficiency, or SCID, when bone marrow cells of patients are removed from the body and engineered to contain the gene that the patient lacks. Once the engineered cells are returned to the patient’s body and produce the formerly absent protein product, the patient may experience a dramatic upswing in immune function and general health. These are but two examples of the progress that clinical genetics and biomedical research are

now offering to the human population, and many more can be expected in the not too distant future.

In spite of the great advantages that the Human Genome Project is conferring on man, our efforts are tempered by deliberation and caution among clinicians and laboratory scientists. Geneticists think carefully about the potential pitfalls in the applications of the new genetic technologies. They are dedicated to bringing advantages to the human population, while they simultaneously grieve the negative consequences of unexpected experimental outcomes. They continuously search for benefits in health and health care, while they simultaneously abhor the use of the new technologies for purposes of vanity or genetic enhancement. Geneticists seek advantages for man across all human groups, while they simultaneously guard our genetic legacy and our genetic future.

Fatimah Jackson, Ph.D.
Scientific and Folk Perspectives on Heredity

Good afternoon. I'd like to thank the ladies of Zeta Phi Beta for organizing this very important conference. It is a significant step toward educating the community about the Human Genome Project so that the people can maximally benefit from this major endeavor.

Molecular genetics is having an impact on virtually all aspects of life. I've been asked to speak today briefly on the topic of scientific and fold perspectives on heredity. This is, of course, a huge subject. What scientific and folk perspectives both have in common, however, is that that are both rooted in preexisting integrated sociocultural constructs.

Scientific insights have a folk background and folk perspectives often have some element of scientific veracity to them. My own training is at the interface of biology and anthropology, of the study of (biological) scientific perspectives and the study of folk perspectives. I am at that interface identified earlier by Dr. Patrinos that promises to yield great insights well into the 21st century.

[joke about still waiting to get 2 salaries for being trained in two fields]

This afternoon we have seen visual depictions of what can go wrong when the genetic information is not faithfully replicated within an individual or between parents and their children. Dr. Pelias has presented this aspect of variation in vivid detail and yet what you have seen is just the tip of the iceberg. Every human group has its share of variation and diversity. Some of this variation will be pathological, as you have seen in the previous speaker's slides, while most of the variation with a group will be nonpathological. This latter diversity will not significantly make a difference in one's health or well being. It is simply "noise."

Distinguishing between pathological and nonpathological genetic variation is very difficult without linking particular genetic sequences to specific morphological changes. We are still a long way from understanding these relationships as it is clearly not the case that having an unusual gene automatically mean production of a defective protein and expression of a clinically significant condition. As Dr. Dunston referred to in her presentation this morning, the new molecular genetics is forcing us to rethink many of the old models. We are moving away from linear thinking and away from binary approaches. Molecular genetics is forcing us to think in new, integrative ways.

Tremendous variation exists among African Americans. This variation, which has historical and

ecological roots, lay the foundation for the unique insights, inclusive thinking, and increased tolerance that characterizes many African American cultures. Our perspectives on heredity are shaped by historical forces such as the "one drop rule" that meant having only one African ancestor among many non-African ancestors still mandated that one was African American. Our perspectives on heredity are shaped by the diversity of African and non-African (European and Native American) ethnic groups that are part of our ancestral gene pool. Diversity in African origins, in particular, has increased our social and cultural tendency toward inclusiveness and away from exclusiveness.

It is not surprising then that African Americans have tended to view exclusiveness as a step toward disenfranchisement. While African American perspectives do not substitute for other groups, African American insights regarding genetics are important because African Americans have so frequently been the victims of "science" and "quasi-genetic inquiries."

My purpose this afternoon is to give you a population perspective, a cross-cultural orientation to the discussion. African American responses are extremely critical because our responses have tended to highlight areas that remain underemphasized by most academic bioethicists (whose values tend to reflect the folk and scientific perspectives of North Atlantic European Americans.) Academic ethicists have traditionally focused on the individual while African Americans have tended to focus on society and community. Dr. Murray, whom you heard from this morning, has made outstanding contributions in introducing African American-centered ethics and population thinking to the historical examination of sickle cell anemia.

[Give example of group vs. individual dilemma as exemplified in the recent tennis competition of the Williams sisters and the questions posed by the media to the winning sister.]

Regarding the Human Genome Project, African Americans were among the first to call for representative sampling. Dr. Dunston was among the early proponents of the inclusion of African American derived genetic sequences in the template for the Human Genome. Back in the early days of the Human Genome Project, Dr. Dunston and I were afraid that the absence of African Americans from the baseline genes for the Human Genome Project could produce binary models with the potential to concretize an official "human norm". This model would not only represent only a narrow slice of our diverse species, it could end up designation normal African American variation (that fell outside the narrow "norm") as pathological, defective, and in need of genetic remediation.

African American concerns are not a proxy for other ethnic and regional groups, yet they (African American perspectives and issues) serve as an invaluable window into some of the problems associated with American biomedicine. Some of American biomedicine has definitely been part of the "dark side" as Dr. Patrinos spoke of.

In January 1994, a small group of African Americans met to put together a Manifesto on Genomic Studies among African Americans. The six key points on this Manifesto are presented in the handout I brought for your review. This is a recent publication of mine entitled "African American Responses to the Human Genome Project." There are extra copies of this paper on the back table and here are a few reprints up here as well.

African Americans were not the only non-European peoples concerned with the Human Genome Project and will to produce a Manifesto in response. However, unlike the Manifestos of other groups (mainly Native American and other indigenous groups), African Americans were the only groups asking for inclusion in genomic diversity studies. We were asking for the engagement of African Americans at all levels of the research process. We were asking for

reciprocity and a genomic research program that would address meaningful health and educational goals among African Americans.

We were not blind in 1994 and we are not blind now to the fact that groups, whose sequences are not represented in the Human Genome Project, are not part of the baseline template, and will not be addressed by the emerging field of pharmacogenomics. Intervention is the real reason for the Human Genome Project. Those missing African American sequences will not be considered by the big pharmaceutical companies intent on making commercial drugs linked to specific genotypes. This morning, a gentleman in the audience asked whose genome is being sequenced and this was treated as a trivial question. It was not and it is not trivial. It matters very much who comprises the Human Genome Project sampling base because these sequences will become the template for pharmacogenomics, toxicogenomics, and other new applied scientific fields dependent upon a sequenced human genome. The mission of the Human Genome Project was never just to sequence an "average" human genome. As I have pointed out many times in my publications, the Human Genome Project was sold to the U.S. Congress as a worthwhile and fundable project because of its direct implications for applied science. To state otherwise is to misrepresent the actual intent of the project. Believe me, the U.S. Congress is not paying for "science for the sake of science."

When we compare the position of African Americans as articulated by the Manifesto with the manifestos developed by other peoples around the world, we see other important differences. Our Manifesto call for the establishment of a National Review Panel – a watchdog organization to monitor genetic research to increase the probability that the genetic research conducted on African Americans is consistent with the needs of the African American community. For some outside our community, the idea of being monitored is disturbing. My position is that self-definition and self-control is (respectively) our right and our responsibility. We must educate ourselves about this project so that we can demand of it the information that it is capable of generating. Again, this is one more reason that this conference is so important.

Over the years, as an outside observer of the Human Genome Project, I have noted some important trends that we, as a people, should keep in mind as we seek to understand and have impact on this mega project. The Human Genome Project is a story with a rich and long history. The project is continually transforming and redefining itself in response to external pressures and events. Here are some points I'' like all of us to keep in mind as we reflect on the presentations already given and those that will follow mine.

1. Genomic studies can be analyzed at many different levels. Things that are true at the molecular level do not necessarily translate into public health issues. We have to be able to distinguish what genetic variation is an important health concern for the group and what is an important individual health concern and what is just "noise in the system."
2. Inclusiveness cannot be assumed at any stage in the scientific endeavor. Exclusiveness is often the rule in American biomedicine and the pattern of sampling often reflects power relationships. For this mega project to reflect our concerns and priorities, we must make the demand for, as the great orator and abolitionist Frederick Douglass once said, "Power concedes nothing without demand, it never has and it never will…"
3. Representativeness (in the Human Genome Project database or otherwise) is not guaranteed by shared financial backing or even clear scientific merit. Scientists are products of their culture. If the culture (which is driven by folk perspectives) does not mandate the inclusion of Black people, then the science generated by members of

that culture will not necessarily consider including African American genetic sequences either. For example, consider the case of Celera. Celera, in its race with the Human Genome Project to sequence the human genome, relied on only one individual sequenced three times. Representativeness was clearly not even a consideration! Science is full of imbedded cultural assumptions. Sometimes (actually quite often) folk perspectives drive scientific interpretations. The only way that I know to get around this is to increase the number of "others" doing science. Cross-cultural, multi-ethnic, interdisciplinary dialogue is essential to get around the bias that all of us have.

4. Open competition and private enterprise (associated with the "race to sequence") can have some beneficial effects and can encourage a certain clarity of purpose. As long as there is no competition, the real purposes of mega efforts often become clear. Remember from your geometry, it takes two points to make a line. This competition has allowed us, on the outside, to see more clearly which direction molecular genetics is headed.
5. Institutions often misrepresent themselves when under scrutiny. This is why we need to be engaged as a people in the Human Genome Project and any other project that demands so many resources from all of us. Our engagement can help keep everybody honest and our presence at the table can keep our issues on the research and policy agenda.
6. Finally, we should realize that even highly touted mega projects like the Human Genome Project can make omissions and can shift directions. For years, Dr. Dunston has lobbied our colleagues in both the Human Genome Diversity Project and the Human Genome Project to include African American sequences in their baseline databases. These efforts were not successful at this level, but they did secure the investment, at Howard University, of a National Genome Center that promises to make our issues and our concerns a priority.

Human variation is a paradox. We are diverse, but often not in the ways that we imagine. There is fundamental diversity within our subspecies, but there is also overwhelming essential unity. To suggest that we share 99% of our genes with chimpanzees misses the point. We share 26% of our genes with petunias! All life on this planet is interconnected and shows the signature of a single Creator God. Our task in the 21st century will be to try to understand what both the diversity and similarity of each of us means. We will need the new technological tools of functional genomics and interaction biology but we will also nee fresh perspectives. I believe that these perspectives will benefit from African American insights, honed over generations of overcoming disenfranchisement.

Thank you.

Questions from the audience.

Christopher Adams, Ph.D.
Personalized Drug Medicine

There are approximately 34 million African Americans in the U.S. population. African Americans represent a unique gene pool in that the predominance of the population originated from the West African coast beginning 400 years ago. Since that time the gene pool of African Americans has been subject to a variety of environmental and racial influences. Due to such influences the African American population is not homogenous and is ethnically more diverse than it was centuries ago. The remaining common genetic factors offer a significant opportunity

to identify and treat a variety of diseases that affect this population.

Diseases that affect African Americans are many and include diabetes and cardiovascular disease. In cardiovascular disease the most serious symptom is high blood pressure. High blood pressure in turn leads to stroke and heart attack. This presentation will focus on the incidence of high blood pressure in African Americans, the likely genes that cause it and targeted strategies that can be used to achieve effective pharmaceutical intervention. The future of health management will be to identify the genetic traits associated with disease and then allow individuals to be tested for such traits, e.g., high blood pressure. Once identified, individuals can be matched to the appropriate drug that offers the best therapeutic benefit for their genetic profile. The genetic model represents personalized medicine. In contrast today's drug therapy is a one size fits all model.

Rosalind Hale, Ph.D.
The Biological Revolution: Genomics and Its Challenges in the Education of Minorities

In the past, teaching was considered a very lucrative career choice for a person of color. Today, this is not the case. Low teacher salaries, poor teaching situations and severe problem students are all reasons minorities and others have selected different career paths. However, one of the main reasons people of color are selecting other careers is because the choices have expanded. Jobs such as lawyers, doctors, nurses, accountants, and many others are open to minority groups more now than in the past. Still, in order to qualify for these job opportunities the individuals must be academically ready!

This reduction in the number of individuals selecting teaching as a career choice has created a shortage of teachers for the 21st Century. There is an enormous amount of literature that supports the fact that the supply of teachers will not meet the demand in the coming years. Figures from 2 million to 2.5 million to as many as 2.75 million are quoted in various sources (Bureau of Labor Statistics, 1999; National Center for Education statistics, 1999). Within the teacher shortage there is a critical need for more minority teachers in the areas of mathematics and science. If the goal is to increase the number of students prepared for careers in gene research, the pool of mathematics and science teachers must first be increased.

Increasing the number of qualified teachers in mathematics and science is only part of the solution. An additional need is to enhance the training of all teachers in the areas of mathematics and science. For instance, in the state of Louisiana the National Assessment of Educational Progress (NAEP) reported that only thirty-seven percent of eight graders are capable of demonstrating basic mathematics skills compared to a national average of fifty-eight. Frightening results from the Third International Mathematics and Science Study (TIMSS) also indicate the need for improving the achievement level of students in mathematics and science. The study further reported that teachers in top performing countries teach for understanding of concepts rather than "how to" as in schools in the United States.

Early emphasis in the areas of mathematics and science should be incorporated in all teacher education programs. No longer should secondary mathematics and science teachers be the only individuals knowledgeable in these areas. Elementary and middle school teachers should also be cognizant of the skills necessary. Once the skills are taught, these youngsters will be ready for the jobs available in gene research.

Is this the final step? No, teachers and counselors must know about these new career paths for minorities. Thus, conferences like this one are needed throughout the United States to inform the public. The challenge in education of minorities in Human genetics begins with having an adequate supply of well-trained minority teachers in the areas of mathematics and sciences.

Then the students must be made aware of educational opportunities in higher education to further develop their skills in the area of Human genetics. Attached is a list of universities that have graduate and postgraduate training programs in Human Genetics. It is our responsibility to inform minority students of these opportunities.

Margaret C. Werner-Washburne, Ph.D.
The Biological Revolution: Genomics and Its Challenges for Minority Education

The changes in perspective brought about by this new information have led to completely novel avenues of scientific investigation and a revolution in the way science is done. The accumulation of orders of magnitude more data has required that biologists work with computer scientists and mathematicians. The need for new technology has led to increasing interactions between biologists and engineers, physicists and chemists. The ethical questions brought about by this new biology, has brought biologists into collaborations with sociologists, educators and political scientists. The potential financial value of discoveries in this area has led to more interactions with industry and law. Thus, genomics can be viewed as a thread – a revolutionary thread that is connecting the patches of our academic quilt more firmly than ever before.

As an area of scientific research, genomics is growing rapidly and represents a revolution in technology and its applications. The market for the fruits of genomics can be counted in the billions of dollars in the pharmaceutical industry alone. Major changes in agricultural practices are occurring at the minute, with the use of genetically engineered seeds that may reduce the use of pesticides and herbicides and change the sociology of farming. Discoveries in human health, the environment, and evolution are being made daily. Entirely new job markets have been created, such as in the area of computational biology, where salaries are extremely competitive and the number of students we are training simply cannot meet the demand.

Yet minorities are not yet a part of this revolution. At a time when the distance between the "haves" and the "have nots" of genomics is increasing exponentially, there is not agreement at the national or local level what significant measures are needed to bridge this gap. At a time when scientists in the area of genomics are interested in studying the genetic makeup of isolated minority groups, there is not enough discussion of the importance of having minorities not just as subjects but also as researchers. We need to address what it will take to enable a student from a predominantly minority or rural school to want to participate in this revolution, or what it will take to train and support the teachers to teach these students. Families and communities may believe that by being scientists and engineers that their children are choosing to move away from them. Minority students in middle and high school frequently do not see science and math as education that enhances who they are or that empowers them within their communities.

The genomic revolution can be seen as a challenge and an opportunity for minority

communities. For children form underrepresented groups to have the opportunity to participate in and contribute to an increasingly technologically sophisticated world, communities need to be able to work together, to communicate across ethnic lines, to determine what the needs and the possibilities are. Genomics is a challenge for us, we need to understand this revolution on order to have a voice in it. We need to work with our children to understand that scientific literacy is a valuable way to learn about the economic development of our communities. There are many important ways in which genomics is going to touch our lives and many different kinds of jobs that are possible in this area. The doors are wide open for students who are academically prepared and empowered. The big question is what can and needs to be done to ensure that the children from your community and all of our communities can take advantage of the moment for themselves, their children and us?

Rev. Deborah P. Wolfe, Ph.D., Past Grand Basileus, Zeta Phi Beta
Professor Emerita, Queens College, City University of New York

We couldn't have picked a more timely subject! This week's *Newsweek* headline reads, "A Genome Milestone." *Time* writes, "The Race is Over."

The great genome quest is officially a tie and *U.S. News and World Report* claims, "We've only just begun: Gene map in hand, the hunt for proteins is on."

And so it is!

It took more than a decade of constant effort, it cost $3 billion in federal funds, and it fueled fierce battles between government and corporate scientists, but at last it is done. This week researchers will announce that they have successfully mapped the human genome, the famous DNA strand of more than 3 billion chemical "letters" that spell out instructions for how to build a human being.

Yet, despite the grand aura of the double helix, knowing its code is really only a means to a greater end. To learn what makes the human body thrive or falter, scientists will now brave an endeavor that dwarfs the genome project. Welcome to the world of "proteomics," which is the study of proteins, the most complex of all known molecules. Proteins are in essence everything that DNA blueprints call for: workers that build the body and keep it in good repair, and warriors that battle invaders. By watching what goes right or wrong as proteins attempt to carry out genetic instructions, scientists hope to finally attain some of the highest aims of medicine, such as the prevention of breast cancer and the cure for heart disease.

It is difficult to know which is more impossible, the work of proteomics or its purported benefits. Each of the body's genes carries the code to create as many as ten different proteins, and each of those proteins links with hundreds of other proteins, sometimes creating still more proteins in the process. All in all, the body may have 2 million or more distinct proteins. A single protein is so complex that IBM plans to spend the next five years deciphering how just one particular protein forms its unique shape. To do that, the company will need to create a computer five hundred times as powerful as any in existence today and four times as fast as today's forty fastest machines working in concert.

Though the challenge is daunting, nearly every major biomedical entity is rushing in. P.E. Corp-Celera genomics Chief, J. Craig Venter, guru of the private genome-mapping efforts, raised

nearly $1 billion to create a new proteomics center and promised to "dominate the field." New announcements arrive daily from pharmaceutical firms launching proteomics teams in search of hitting pay dirt with novel protein-altering drugs.

You know better than I the struggle between the Department of Energy and the National Institutes of Health as the government's representatives in the Human Genome Project and private industry's representative for the current announcement to be made.

All humankind is grateful that these groups agreed to come and "reason together" for the good of all. It is impossible to overstate the significance of this achievement. Armed with the genetic code, scientists can now start teasing out the secrets of human health and disease at the molecular level—secrets that will lead at the very least to a revolution in diagnosing and treating everything from Alzheimer's to heart disease, cancer, and more. In a matter of decades, the world of medicine will be utterly transformed, and history books will mark this period (the week of June 20 – July 4, 2000) as the ceremonial start of the genomics era.

So we have just begun!

And now I come to my role in this discussion. Since, as you know, I did not participate in bringing about this great discovery, and since I really know so little about the details of the study, all I can do as a teacher, as a preacher, as an interested citizen is raise questions to you who are specialists.

First:
To be certain that I really understand and my good sorority sisters and friends understand: what is the Human Genome Project? Who directed the Human Genome Project?

Second: Which U.S. laboratories and investigators were involved? Were other countries involved?

Third: What are the major benefits resulting from the study?

Fourth: In what ways may the findings present ethical problems and questions?

Fifth: Are there legal questions that should be raised? Why was such a small percentage of the project budget (3% to 5%) set aside to examine such important issues?

Sixth: In what ways will these findings affect social behavior?

Seventh: How will these findings affect the teaching of science in elementary schools, middle schools, high schools, and in higher education?

Eighth: What person or group is currently devising curricula to include these new findings? How soon will such curricula be available?

Ninth: What should we teach children and youth about DNA?

Tenth: Where can we access maps of genes? Why is it important?

Eleventh: What is DNA sequencing? Why is it important? How is it done?

Twelfth: Why is model organism research important?

Thirteenth: Why should we fear undue cloning?

Fourteenth: What efforts are being made to include sociologists, psychologists, theologians, and others in further research?

Truly, we have just begun! What a timely discussion!

What a wonderful challenge! Let's get on board!

The Human Genome Project Information Conference: The Challenges and Impact of Human Genome Research for Minority Communities

Jeroo S. Kotval, Ph.D.
Genomics and Market-Driven Health Care: Ethical Concerns

The United States has embarked on an unprecedented experiment in the financing and delivery of health care. It is called market-driven health care. At the center of this system is the investor owned, for-profit institution: the market-driven managed care organization which is both the insurer and the provided of health care, which raises capital through offering stock, and which uses a variety of cost-saving and cost-shifting strategies to control expenditures.

Strategies for cost-savings and cost-shifting used by insurers include: risk-rating (medical underwriting); policies with exclusion clauses; restrictions on coverage; selective marketing; co-payments; deductibles; capitated or discounted payments to health providers; and utilization review, which can occur before, during, and after care; and disease management.

At the same time, advances spurred by the Human Genome Project allow the prediction – now and in one's future – of human disease conditions and an individual's response to drugs and other pharmacological agents. These tests can provide insurers with advance information about future health care costs. Persons seeking health insurance in the individual markets are subject to risk rating – where the premiums charged are based on the likely health care costs for the individual. Some of the new genetic tests provide the most accurate methods of predicting costs available currently.

Institutions are not moral agents, and make decisions impersonally in order to further institutional objectives – which in the case of market-based institutions is to capture market share. This is done by under-cutting one's competition, showing a profit to their stockholders, and providing bargain prices to their clients (e.g., private employers and government).

There is concern that trust, which is a bedrock principle in the physician-patient relationship, would suffer – especially with respect to underserved communities and communities with historic experiences of institutional bad faith – as persons fear that their genetic test results would be misused for the purposes of cherry-picking healthy clients or to 'redline' entire communities in the interest of cost-savings. This would result in persons refraining from taking advantage of the fruits of the Human Genome Project to truly advance their health, and could further aggravate already existing differentials among minority communities and the majority population with respect to health care access. This would defeat the goal of achieving equal access, which is absolutely necessary to a just health care system.

Market mechanisms for distributing quality care are dependent on the purchasing power of the

consumers or the bargaining power of those who represent the interests of minorities and underserved communities. Minority communities have traditionally suffered in such circumstances since they are disproportionately represented at the lower end of the socio-economic status scale and do not have the same social and political influence as majority populations.

Another ethnical concern about investor-owned companies providing health care is that earnings provided by the patients to obtain health care are not returned to the system in toto to provide quality care for increasing numbers of persons or better care for those who are already in the system, but are channeled to the stockholders. In this sense, use of genetic tests by a market-driven health care system, to cherry-pick healthy consumers in order to further the reward to stockholders is implicitly unfair to those who need ca re but cannot afford it.

I identify four ethical principles as central to any health care system: the just distribution of health care, concerns about quality of care, cost-effective care or efficiency, and trust. Genomic information available to a market driven institution intent on cost-savings for its survival raises concerns related to each of these ethical principles.

Betty Mansfield, Human Genome Management Information System
Bioscience Careers Fueled by Genome Research in the Biology Century

The large, multidisciplinary Human Genome Project (HGP) – the effort to find all human genes and characterize a reference genome—promises to revolutionize the future so profoundly that this has been dubbed the "biology century." Almost everyone will be affected by applications of information and technologies derived from the HGP era of the late 20th century. Entirely new approaches will be implemented in biological research and the practice of medicine and agriculture. Genetic data will provide the foundation for research in many biological subdisciplines, leading to an unprecedented understanding of the inner workings of whole biological systems. The benefits of genomic research are, or soon will be realized in such areas as forensics and identification science, ecology and environmental science, toxic-waste cleanup, creation of new bioenergy sources and more efficient industrial processes, and understanding the mysteries of evolution, anthropology, and human migration.

Among the fields that HGP research will impact are engineering, computer science, mathematics, counseling, sociology, ethics, religion, law, agriculture, education, pharmaceuticals, instrumentation, nuclear medicine, forensics, bioremediation, biofuels, and journalism. Cross-disciplinary students with solid backgrounds in science and in one or more other fields such as journalism, law, and computer science will be needed to tackle the issues and applications arising from the HGP.

Commercialization of numerous applications in genomic science is fueling the burgeoning life sciences economic sector. Legislation and litigation increasingly will be concerned with genetics and the intellectual-property issues pertaining to genetic information and technologies. Educators, the media, students, and the public need a good understanding of the "new genetics" and its implications to communicate, teach, and help others make related career and personal decisions. Democratizing access to genetic science information should help maximize HGP benefits while protecting against misuse of the data. Every effort must be made to ensure that everyone, regardless of race, citizenship, or national origin, enjoys the benefits of genomics research and its subsequent applications, including life improvements and excellent career possibilities. Society simultaneously must be protected from such possible negative impacts as the failure to preserve the privacy of individual genetic information.

People who pursued careers in fields such as business that traditionally did not require life sciences training are increasingly finding that, at the very least, they need a working knowledge of the principles of biology and life science research and development. Presented below are some traditional and new bioscience career possibilities, followed by some educational strategies for pursuing such careers.

Possible Career Areas in Bioscience

Note: The biotechnology industry has doubled in the past six years. In 1999, there were 437,400 U.S. jobs in the field (150,800 direct; 286,600 indirect), and more opportunities are expected in healthcare, food production, and environmental cleanup (Ernst & Young, May 2000, www.bio.org). In regard to the burgeoning drug industry based on genomics, the spring 1999 issue of the Consulting Resources Corporation's newsletter for biotechnology professional said, "We expect the growing family of new genomics, proteomics, and bioinformatics technologies to dominate the next decade's developments in therapeutics by greatly improving the efficiency and speed of the entire drug discovery, testing, and approval process."

Medicine

- Medical genetics, genetic counseling, genetic nursing
- Gene testing, gene therapy
- Organ transplantation, fertility, and reproduction
- Public health
- Pharmaceutical industry and suppliers
    - -Pharmacogenomics
    - -Chemical, vaccine, medicine development and production
    - -Database development, operation, use
    - -Communication, work with regulatory agencies

Agriculture and Wildlife

- Genetic modification of foods and seeds
- Biopesticide and neutriceutical development
- Wildlife management: Identification, protection of endangered species
- Authentication of consumables, such as, wine, caviar.

Computing and Bioinformatics requires experts in both biology and computing)

- Databases, analysis, modeling, data transfer
- Supercomputing
- Mathematics, statistics, actuarial field

Engineering Disciplines

- Bioprocessing chamber, vat design and production
- Toxic-waste cleanup
- Instrumentation development
- Creation of new energy source via engineering, life science research
- Biomedical engineering.

Business

- Investment in biosciences industry
- Marketing and sales
- Banking

Legal and Justice

- Education
- Patent specialities
- Specialties in ethical, legal, and social issues
- Gene and paternity testing
- DNA forensics, laboratory and legal

History and Anthropology

- Use of genetics to study population, migration patterns
- Study of inheritance over evolutionary time

Military

- Soldier identification
- Pathogen identification
- Biological and chemical warfare protection
- Radiation-exposure assessment

Space Exploration

- Research into space effects
- Search for other life forms, evidence of life

Bench Science

- Sequencing of many organisms, including human
- Data analysis, computation
- Functional genomics
- Proteomics
- Human variation in health and disease
- Microbial genetics
- Environmental studies
- Education

Bioscience Communication

Audiences: public, media, judiciary, legal and medical professionals, consumers, Congress, researchers, educators and students

- Reporting, writing, editing
- Website development, maintenance
- Science, ELSI information distribution
- Public relations
- Marketing
- Special events

Preparing for a Career in the Biosciences

- Gain experience in the biosciences industry through internships, volunteer work, work-study, and co-op programs.
- Pursue a cross-disciplinary education. Biology problems are too big to be solved by people trained in only one discipline. People need science and technology basics, training in computer use and information technology, and education in bioethics to anticipate and present options for solving prickly social issues. Community and four-year college training is offered in biology and related disciplines, including integrated science and technology programs that incorporate computer science, information technology chemistry, biology, engineering principles, and bioethics. More specialized M.S., Ph.D., and M.D. degrees are not offered.
- Surf the Internet and use library resources to read newspapers, technical magazines, and trade journals.
- Contact your state's biotechnology industry organization or find its careers section on the Web.
- Talk to professionals from a wide array of disciplines. Don't be shy; showing your interest will open doors.

More Information on the Web

Human Genome Project Information: Careers in Genetics and the Biosciences

Guide to North American Graduate and Post-Graduate Training Programs in Human Genetics

Solving the Puzzle: Careers in Genetics

Genetics Careers on the Genetic Professionals Website

Biology Careers for the Next Century from Carolina Biological Supply

Careers in Biotechnology from the Access Excellence home page

Functional Genomics Careers from *The Scientist*

Science Careers from *Science* Magazine

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Issie L. Jenkins, Esq.
Moderator, The Human Genome Project: Ethical, Legal, and Social Implications for the Minority Communities

Genetic discoveries resulting from the Human Genome Project will undoubtedly have major impacts on our society. While attention has become more focused on the Human Genome project during the past year with the race to complete the sequence of the human genome and gene identification, our need in the minority community is to heighten our awareness of both the benefits that can be expected, the issues that are of concern to our communities, and strategies for addressing those issues. The Human Genome Project will unquestionably provide enormous health benefits. Genetic Research is providing information on some of the most serious diseases that affect the minority community, such as sickle cell anemia, prostrate cancer, tay

sacks disease, and mental disabilities. The prospect of individualized medical treatment with drugs based on a patient's particular genetic make-up is considered just around the corner, as well as the use of gene therapy. There are significant legal, ethical, and social issues that must be resolved with these new discoveries. How confidential will individual genetic information be; what privacy safeguards? Will persons of all economic classes have access to genetic counseling? Will it be affordable? What about genetic tests results, who will use them? How will they be used? Are minorities involved in clinical trials? are disclosures adequate concerning risks; are there adequate protections? What are the disadvantages of noninvolvement? What safeguards are available for the use of DNA evidence in the criminal justice system? What about genetic information and racial identification; what about discrimination based on genetic make-up; are there protections? Will there be a "genetic underclass"? Is there danger in overemphasizing genetics as opposed to environmental influences in social behavior, etc.? These are a few of the areas that must be addressed.

Health officials, lawmakers, government regulators, and private industry will be addressing the social, legal, and ethicalquestions raised by the discoveries resulting from the Human Genome Project and related genetic research. Minority communities need to make their voices heard as policy decisions are made, laws passed, and regulations promulgated to address the issues raised. We must first define the issues and have input into the resolution of them, so that our interests are served along with those of the majority. Past history has shown that we must be vigilant and timely in advocating that interest.

In the area of protection from discrimination in sharing in the benefits of new discoveries, it is important to urge affordable genetic testing, counseling, and therapy for everyone. Protection against discrimination in health insurance benefits based on genetic factors will be needed, as well as protection from employment discrimination based on genetic makeup. Are federal and state laws adequate to prevent health insurance companies from using genetic information to deny health insurance coverage? Will Title I of the Americans with Disabilities Act provide adequate protection against employment discrimination, as genetic testing becomes more widespread?

In the criminal justice system, where African-American males are disproportionately, represented what uses of DNA evidence will be made? Will minorities have the same access to post-conviction relief based on DNA evidence as others in the criminal justice system? Will DNA profiling replace the use of fingerprints? Since minorities, in particular African-Americans, are arrested in larger numbers thantheir proportion in the general population, would DNA testing of all arrestees have an adverse impact on African-Americans.

Are we concerned about the ethnical issues involved in genetic engineering? Should our genes be treated as commodities for researchers and biotechnology companies to profit from them? How do we reconcile societal values, economic incentives needed to spur research and development, and our religious values.

Phyllis Griffin Epps , Esq.
White Pill, Yellow Pill, Red Pill, Brown Pill: Pharmacogenomics and the Changing Face of Medicine

Recent advances in genetic research offer a glimpse into the future of pharmaceuticals. The relatively new fields of pharmacogenomics and pharmacogenetics leave not doubt that drug

manufacturers will develop tomorrow's medicines with individuals and specific groups of people in mind. Given finite resources available for research and development, the questions for drug manufacturers are "Who will they have in mind?" and "Who will be left behind?" in new drug development. Whether the answers are palatable to health care consumers is another question entirely.

Increasingly, researchers can identify specific genes and polymorphic markers of an individual's ability to metabolize a drug. Pharmacogenomics refers to the entire spectrum of genes that determine drug behavior and sensitivity. Pharmacogenetics, a subset of pharmacogenomics, is the study of differences in drug response between individuals based on inherited variations in genes, and the enzymes and proteins produced by such genes. Persons with a particular genotype, or genetic characteristic, may suffer adverse responses to a drug and such responses may be traced through families, ethnic groups, and geographic clusters. Pharmacogenetics also promises to identify the most efficacious drugs for individuals.

Advances in pharmacogenomics will reduce the number of people who die from adverse drug reactions each year. Drugs that prevent diseases to which a person is genetically predisposed may become common. Several pharmaceutical companies have formed alliances with genomic research firms to facilitate the translation of data on the sequencing of genes into the development of new drugs. For drug manufacturers, the focus will shift from the development of drugs that are safe and effective for the greatest number of people to the development of drugs for specific, genetically identifiable subgroups of the population.

To date, all pharmacogenetic polymorphisms, or relatively stable variations of the genes involved in drug metabolism, differ in frequency among ethnic and racial groups. For this reason, race must be considered in studies intended to discover whether specific characteristics are associated with disease risk or drug toxicity. For any given malady, drug manufacturers may find themselves dedicated to the task of developing a drug for use by a specific racial or ethnic group. Alternatively, individuals could find themselves precluded from using a drug that has been proven effective for one or several racial or ethnic groups, but ineffective and even dangerous for another. Such exclusion, while medically justified, may cause negative social repercussions unless addressed in a timely and sensitive manner.

Pharmacogenomics is undeniably a positive development for drug safety and effectiveness, but will it benefit everyone? In the United States, the typical large drug manufacturer will endeavor to produce a drug that will sell well enough to recoup the costs of the expensive development process and generate a profit. Where the audience for a drug is relatively small, market forces dictate a higher price for the drug. The smaller may be defined by a particular genotype that occurs in a smaller number of persons whose need for a drug to treat asthma or arthritis, for example, is no less real. Where a smaller market is defined not only as persons who share a genetic characteristic but also happen to share race as well, the chances are greater than a higher price will act as a barrier to access and treatment. Nevertheless, the cost to produce a drug for a smaller number of people will be no less than the cost to produce a drug for either a larger population or a population more likely to afford the drug. Absent incentives to the contrary, a drug manufacturer in the United States will pass the costs onto the consumer in the form of higher prices. That is, if the drug manufacturer decides to develop the drug at all. How will pharmacogenomics affect the criteria for deciding which drugs to develop and for whom? In a country with such strong traditions of racial and ethnic discrimination, what forces, if any, will ensure that all segments of the population are included in the drug development strategies of drug manufacturers?

Assume that pharmacogenomic research produces a drug to treat diabetes, which occurs

across racial lines. The new drug is particularly effective in Hispanics, who are at risk for severe side effects from the drug used by the mainstream population. The new drug, while safest for Hispanics, costs more than the more widely used drug. Will HMOs and other managed care organizations and third-party payers be more or less likely to support the prescription of the drug best suited for each patient when the best drug may well cost more? Absent insurance coverage for prescription drugs, an Hispanic person will pay more to be treated for the same condition. The result is consistent with science and economics, but how well will it sit with consumers? From a broader perspective, how will the health insurance industry respond to a scenario in which different ethnic minorities require more expensive care than their white counterparts?

The trends in drug development have not escaped the notice of federal regulators. The Food and Drug Administration (FDA) requires drug manufacturers to disclose effectiveness and safety data for gender, racial, and age subgroups, but does not require drug sponsors to conduct studies, much less include persons from specific subgroups in such studies. Through the Orphan Drug Act, the government offers tax credits, research grants, exclusive marketing rights, and other valuable incentives to companies to encourage research on rare diseases. Biotechnology companies that labor under the Act are able to set their own prices; the FDA does not regulate the pricing of the final products. The law has made orphan drugs a popular area of research and a moneymaker for the industry. Similar incentives may become necessary to encourage the production and distribution of drugs that benefit larger but neglected sub-populations.

In a free market, the prospect of economic gain should be sufficient motivation for producers to distribute goods and services to all consumers. Many private institutions in the United States still have to be forced by law to drop policies that discriminate against persons based on their race and ethnicity, even when the illicit policy is contrary to sound business practice and the pursuit of profit. Will racial politics sustain a system in which drug companies market higher-priced drugs to specific minority communities? How do we balance the higher economic costs associated with targeting a group with genetic similarities against commitments to equitable social treatment of all persons without regard to race?

With the growth of pharmacogenomics, race could play a legitimate role in the clinical treatment of illnesses. Whereas attempts toward equality have emphasized the absence of meaningful differences between races, society must confront the reality that immutable genetic differences among individuals of various racial and ethnic backgrounds may require separate treatment for the same conditions. Moreover, society must decide how best to promote equality in this context. The creation of a pharmaceutical apartheid, in which the price and availability of a needed drug are a function of genetics and race, must be avoided.

Kathryn T. Malvern, Ph.D.

Minorities and the Human Genome Project: What Next?

Did any of us ever believe that this new century and new millennium would bring with it the greatest age of discovery, "A Map of the Book of Life?" Researchers in the field of genomics must have had some idea of the enormity and approximate completion data of the human genome sequencing breakthrough. However, the average lay person, and particularly the minority communities, most likely know little or nothing about the Human Genome Project. With so much media exposure concerning this phenomenal research and the breakthrough announcement by President Bill Clinton, extolling the fact that the genetic code has been broken, many people have heard about the research. However, it can be assured that most do

not have an understanding of what scientists currently know.

Thus, we are here today, with scientists, ministers, anthropologists, lawyers, educators, business persons, students and legislators, who will be in conversation, giving the explanation of the genome and the research findings implications for mankind. We are now at the threshold of a new era in biotechnology, which brings us to a crossroad, a crossroad that brings us to a crucial point where serious questions must be asked and answered. We are at a fork-in-the road. The question is, which road will lead to the "Betterment of the Human Condition?" Today we will hve conversations such as: What is the genome? Will the findings revolutionize the detection, prevention and treatment of diseases such as cancer, diabetes, Alzheimer's disease, Parkinson's disease, sickle cell anemia, etc.? Will this "power to heal" make life better for all, not just a few? What about ethics and privacy? Could medical privacy be invaded in such a way that insurance and employment will be negatively impacted? What does this all mean for minority communities?

After today's conference, what is the next step? Because every minority individual cannot be in conversation with us today, it is imperative that each person in attendance becomes an ambassador for his or her community.

Our minority communities must be brought to a very high level of awareness as to what these medical research findings mean to each individual. We expect that this informational conference will not end today, but will continue for at least one year or as long as necessary, via community liaison coordinators and committees as well as all forms of media. The purpose will be to provide awareness and any new information on the human genome research findings and its implications.

At this Informational Conference, you will be provided time for input in deciding the possibilities and direction to be taken in determining the level of awareness needed and how to adequately provide this information to the minority communities. Conference participants, you are requested and urged to be a part of this new century, new millennium biological research information dissemination to our minority communities! Please join us in partnership.

Kathryn T. Malvern, Ph.D.
Minorities and the Human Genome Project: What Next?

IN THE CLOSING SESSION ON "WHAT NEXT?" FOR CONTINUING INVOLVEMENT OF MINORITIES AND EDUCATION AND INFORMATION ON GENOMIC RESEARCH DEVELOPMENTS, CONDUCTED BY DR. MALVERN, THE FOLLOWING WERE AMONG THE WRITTEN SUGGESTIONS / COMMENTS:

- Continue information sessions at or involve local churches.
- Prepare and disseminate a summary of the conference proceedings.
- Break the silence in the minority community about the Human Genome Project; collaborate with other groups.
- Begin a program of getting students interested early by beginning to talk about genetics in schools at an early age.
- On a larger scale, information should be disseminated at events like Black Expo; Minority

festivals, Videotapes, using factual information written in laymen's terms. Develop information in cartoon form for children.
- Form local HGP Awareness Teams to keep abreast of developments.
- Provide more examples of the benefits from the project that can be easily understood.
- Develop website with short lists of benefits; positive and negative potentials.
- Develop career day presentations to encourage students to seek scientific careers; careers in biotechnology, genetic research, related fields.
- Conduct more research into minority issues and minority concerns.

The Foundation received many favorable comments on the information received at the conference and many participants expressed the desire to continue to keep abreast of developments and have input into policy and legislative decisions that will be made with respect to genetic research and the use of genetic information.

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