Zeta Phi Beta Sorority
NATIONAL EDUCATIONAL FOUNDATION

June, 1999

FINAL TECHNICAL REPORT
DOE GRANT # DE-FG02-99ER62772
PROJECT TITLE: INFORMATION AND DIALOGUE CONFERENCE ON THE HUMAN GENOME PROJECT FOR THE MINORITY COMMUNITIES IN THE STATE OF LOUISIANA

Zeta Phi Beta Sorority National Educational Foundation, in cooperation with Xavier University of New Orleans, and the New Orleans District Office of the United States Equal Employment Opportunity Commission, held the **Information and Dialogue Conference on the Human Genome Project for the Minority Communities in the State of Louisiana** on April 16-17, 1999. The Conference was held on the campus of Xavier University in New Orleans. Community leaders, government officials, minority professional and social organizations leaders, religious leaders, persons from the educational and academic community, and students were invited.

Conference objectives included bringing HGP information and a focus in the minority community on the project, in clear and understandable terms, to spread the work in the minority community about the project; to explore the likely positive implications with respect to health care and related matters; to explore possible negative results and strategies to meet them; to discuss the social, legal, and ethical implications; and to facilitate minority input into the HGP as it develops.

The conference was planned with the assistance of an advisory group composed of representatives from the minority community and the cooperating organizations. In planning the conference, the Foundation also had input from the Louisiana Governor's Office on Indian Affairs, the Center for Environmental Programs, Xavier University, and the Deep South Center for Environmental Justice, Xavier University. Xavier University also contributed the refreshments and hosted the luncheon for conference participants.

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DISCLAIMER

In addition to bringing the information on the Human Genome Project to the Community, and providing an opportunity for discussion of the project's impact on the minority communities and the minority communities concerns, the Foundation also wanted to raise minority students awareness of the project, the career opportunities available in the biotechnology industry, and the educational and internship opportunities. To that end, students in the science/biology departments of Xavier University, Southern University, Dilliard University, Grambling University, as well as the University of New Orleans, Tulane, and Louisiana State University were invited.

Attached are copies of the conference program booklet which provides information on the conference program, the conference presenters, the advisory committee, and abstracts of some of the presentations and other relevant information.

Also attached is a copy of the press release that was used to publicize the conference. The press coverage of the conference was outstanding. The major New Orleans newspaper, the Times-Picayune, carried articles on Friday, April 16, 1999, and on Sunday, April 18, 1999 regarding the conference. Also attached are copies of the conference brochure.

Between the two days of the conference, there were 107 persons in attendance. They represented a cross-section of the communities. Because of lack of knowledge about the HGP and this entire area, interest in conferences of this type must be actively generated, requiring more than the usual advertising or notice. We believe from this experience, that personal meetings with groups prior to advertising the conference, to provide more of a background about the project, would create more interest in the minority community for attendance. One of the recommendations from conference participants was that more contact with lay persons, using churches and schools in the minority communities should be tried to stimulate interest.

Attached is a summary of the evaluation forms that were collected at the conference, and of some of the comments.

Participants Concerns, Issues, Recommendations

Some of the concerns, issues, and recommendations from the participants include the following:

1. That few if any minorities are major players in any part of the HGP or in genetic research; and that leaders in the field are used to talking to each other, and not to those

outside the field for input on policy and related matters.

2. That a concerted effort to educate the educators on the HGP so that they can bring information to students through Gnome workshops, science fairs, and career days.

3. Concern about lack of health insurance among minority groups (34.5% Hispanics, 21.5 % Blacks, 12% non-Hispanic Whites, and overall 16.1%, are without health insurance) and whether genetic testing information, if available to health insurers will make acquiring such insurance more difficult; concern about the cost of genetic testing, and the availability of genetic counseling to the minority community In addition, non-medical use of such information and disclosure issues were of concern.

4. Need to develop a Research Subject Bill of Rights; set a framework to make reseach fair and candid for the human subject used in any of the research; provide choices, provide consultation about risks, commercial value of any products developed; treat human research subjects as partners

5. Recourse available to those who are the victims of erroneous interpretation of their genetic tests.

6. Urged the development of a national policy on the ownership of genetic information and on its use.

7. There is a need to continue to talk about the project in the minority communities; to bring the information to the community in various venues where the average minority will attend; to emphasize that the issue is immediate and if there is to be minority input, it has to be now; to recognize that the title Human Genome Project is intimidating to many non-scientists, so using language that is less intimidating may be helpful in attracting minority attention.

8. Participants committed to share the information obtained at the conference with members of their individual communities.

As a result of the conference, several internship possibilities have been developed for minority undergraduates attending the conference.

Times-Picayune

NEW ORLEANS & the Metro area

SECTION B
A/B FRIDAY, APRIL 16, 1999

Retesters for magnet admission get a break

Secured seat can be held while child tries again

/ ANAND VAISHNAV
aff writer

In a concession to frustrated arents, New Orleans public hool administrators Thursday versed a magnet school ideline that would have forced udents to surrender a guarnteed spot at one magnet hool if they re-took the enance exam to try to get into an ven more selective school.

Students now can hold on to a seat at any magnet school where they're qualified until the retest results arrive. If they've been accepted at several schools, they may hold only one spot while retesting.

Though school officials overseeing the oft-delayed admissions process had hoped to know how many positions were taken by two weeks from today, that's unlikely with the policy change because no retesting date has been set. The change also forces students on a waiting list to wait even longer for the retested students to make up their minds.

Students still must notify schools where they were accepted by April 30 of their decisions to retest.

Board members emerging from a meeting in which they discussed the issue said the change is fair.

"Any kid focusing on going to school and being tested, we shouldn't hold them back and say, 'You can't go there,' " board member J. Berengher Brechtel said. "Why not give quality kids a choice?"

Before the change, magnet school applicants faced a tough choice. If they scored high enough to get into one magnet school, but not high enough for a more rigorous school, they could retake the entrance exam. But that meant they would have to give up all other seats, leaving them with no chance of attending a magnet school if they again missed the mark.

Rae Horton's daughter faced such a dilemma. The 13-year-old eighth-grader has been accepted to Eleanor McMain Magnet Sec-

See MAGNET, B-2

PEACE

y students Theresa Chardos,
ee Quadrangle at the univer
Albanian refugees suffering
Bible and e-mails from a Kos

Genetic research focus of seminar

Public to explore ethics of project

By LITTICE BACON-BLOOD
Staff writer

Etched into the sidewalk leading into the Norman C. Francis Science Building at Xavier University is a pair of twisted, parallel lines that also run along the floor and walls inside the complex.

To a casual observer, it may be an interesting oddity bringing to mind a wound ladder. To the informed, it's a DNA strand, what scientists refer to as our recipe for life because it contains our entire genetic program. Deoxyribonucleic acid contains information that determines such things as eye and hair color and influences the way we behave, and scientists believe it can help predict who is susceptible to certain diseases.

Beginning today, participants in a two-day workshop at Xavier will become familiar with the DNA strand as they learn about a $3 billion U.S. Department of Energy and National Institutes of Health project to map and decode the human genetic pattern.

Workshop participants will explore the ethical implications of disclosing a person's predisposition to a disease.

By 2003, scientists expect to complete a map of the genetic pattern that will let them determine the underlying causes of thousands of genetic diseases,

See GENES, B-2

cientists, ethicists debate impact of decoding DNA

perts gather Xavier campus

RONDA BELL
Writer

hile others are studying gal- far, far away, a group of tists and ethicists gathered avier University this week- to explore the genetic con- ations within the human and their implications on munities.

a $300 million-a-year pro- under way at laboratories s the country, scientists are he first time mapping the e genetic code: 3 billion bits formation contained in the n each human cell. The re- h will provide a road map to standing the physical and me extent, the mental char- istics of mankind as well as predispositions to certain ases.

ut some bioethicists are dering where that map will If, for example, prospective loyers or health care provid- know that someone carries gene for certain diseases, as breast or prostate cancer zheimer's disease — will discriminate against those carry the potentially lethal sequences? Those questions debated at the "Information Dialogue Conference on the Human Genome Project for the Minority Communities in the State of Louisiana" Friday and Saturday.

"In 1964, when the Civil Rights Act was passed, we never dreamed of what we'd be facing in 1999," said Keith Hill, regional attorney for the New Orleans Office of the U.S. Equal Employment Opportunity Commission. "This is truly new territory. And I'm not sure we're going to be able to keep up. Little did I know when I was reading Aldous Huxley's 'Brave New World,' we'd be living it."

Along with the unfathomable benefits that lie ahead for medicine, there is the usual quagmire of civil rights concerns as protective laws are not keeping up with the pace of scientific discoveries.

"This is going to affect the individual, the family, the community, the region and the nation and beyond," said Valerie Setlow, deputy director of the Tulane/Xavier Center for Bioenvironmental Research. "As a technological society, we're very capable. But as a human society, we're amateurs at charting the course for the implications of technology.

"Knowing about this is a social obligation," Setlow said. "All of what I learned as a microbiologist in college is either gone or no longer true. It is imperative that we keep up with the times."

For minority communities in which some members may have predispositions to certain diseases, such as sickle cell anemia, which mostly afflicts African-Americans, and Tay-Sachs disease, which affects those of Jewish descent, the project can have far-reaching implications that will help scientists further understand the maladies. Eventually, researchers said they will be able to use gene therapy to cure or treat the diseases that are the result of misplaced genetic sequences.

Scientists already know that all humans share 99.9 percent of their genes regardless of ethnicity with minuscule differences between members of different races. In fact, among members of separate groups, for example, those of African, Asian and European descent, the genetic variation is greater than it is from group to group, scientists said.

"We're more alike than a lot of people think," said Betty Mansfield, managing editor of the U.S. Department of Energy's "Human Genome News." "Most of the differences between ethnic groups are not significant from a medical perspective."

The Genome Project, sponsored by the National Institute of Health and the U.S. Department of Energy, will also provide information on how genetic differences may follow geographic populations. In Louisiana, for example, with its gumbo of ethnicities that have often mixed, the genetic differences may be even smaller from group to group, experts said.

Although the genetic map will be completed by 2003, the solution to the DNA puzzle and what its pieces mean will be far from complete. Scientists by then will know the code but will only know a tiny fraction of how the sequences translate into certain traits and health issues.

Conference participants urged minorities to become aware and get involved in the project. Diversity is needed in the genetic research, they said. And the exponentially budding field has endless opportunities for employment in medical research and computer technology, two fields that are sorely lacking in minority representation.

"This is part of our shared future, whether we get actively involved or don't," said Issie L. Shelton Jenkins, a chairperson of the Zeta Phi Beta Sorority National Education Foundation, which co-sponsored the conference with Xavier and the Department of Energy. "We need to be actively involved."

More information on the Humane Genome Project is available at www.ornl.gov/hgmis on the Internet.

CENTER FOR BIOENVIRONMENTAL RESEARCH

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April 23, 1999

TO: Rosalind P. Hale, Ph.D.
Conference Chair, and
Chair, Education Department
Xavier University

Mrs. Issie Jenkins,
Conference Program Director, and
Chair, Board of Managers
Zeta Phi Beta Sorority National Education Foundation

From: Valerie Petit Setlow, Ph.D.
Deputy Director
Center for Bioenvironmental Research

Subject: Note to Dan Drell, Department of Energy

Just a note to share a copy of my message to Daniel Drell, Biologist with the Department of energy. I was very impressed with the conference and spoke to a number of Tulane university faculty who expressed regret for not being there.

I hope you have seen the newspaper article about the conference. Mrs. Jenkins final closing comment sums up the message from the conference: we all need to be actively involved.

Thanks for putting up with me and for inviting me in the first place. I do hope that you will consider the next steps and move ahead to build on this successful event.

Mime-Version: 1.0
Date: Fri, 23 Apr 1999 13:17:33 -0500
To: daniel.drell@science.doe.gov
From: Valerie Setlow <vsetlow@mailhost.tcs.tulane.edu>
Subject: Zeta Phi Beta human Genome Conference

Dan:
I just wanted to tell you how well the Zeta Phi Beta/Xavier University conference on "Information and Dialogue on the Human Genome for Minority Communities" went. I was one of the presenters of an extraordinary panel of persons. I am certain that Dr. Hale and Mrs. Jenkins will provide you with details of the event and copies of the subsequent news coverage in our local newspaper.

It was great to see that the issues of national significant have an opportunity to be translated to the local level and to see the interest and expertise of the local community rise to debate the impact.

It was thoughtfully done, and well organized. Everyone's only regret was that there were not more persons in attendance. However those that were present were very much engaged in the issues. I was pleased to be a part of it.

Keep it touch.

Val
Valerie Petit Setlow, Ph.D
Deputy Director
Center for Bioenvironmental Research
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and Clinical Associate Professor
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TIGR
THE INSTITUTE FOR GENOMIC RESEARCH

June 4, 1999

Mrs. Issie L. Jenkins Esq.
Chairperson
Board of Managers
Zeta Phi Beta Sorority
National Education Foundation
1734 New Hampshire Avenue. N.W
Washington DC 20009

Dear Issie,

I would like to take the opportunity to tell you how successful your recent meeting on the Human Genome Project and reaching the Minority Communities of Louisiana was. It was particularly informative from my point of view as both an attendant and a speaker, and I believe it went beyond achieving the goals that were initially set out. Many students who were in the audience have since been in touch with me about getting involved in the Human Genome Project, through jobs or internships with The Institute for Genomic Research in Rockville, Maryland.

I hope we will endeavor to pull together more meetings of this type in the near future, as there is a need to convey the importance and significance of the Human Genome Project and the need for minority groups to be involved. We have been working together for almost two years now, and I will continue to make every effort to participate in these meetings whenever the need arises.

Thanks again, congratulations on the success of your first meeting, and looking forward to working with you again soon.

Sincerely

Karen Nelson

Karen E. Nelson.

Human Genome Project Conference

An Information and Dialogue Conference on the Human Genome Project for the Minority Communities in the State of Louisiana

Friday, April 16, 1999

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Saturday, April 17, 1999

Xavier University of Louisiana
New Orleans, Louisiana

Supported By:

- Zeta Beta Sorority National Educational Foundation in cooperation with Xavier University of Louisiana
- U.S. Equal Employment Opportunity Commission
- A Grant from the U.S. Department of Energy

PROGRAM

Friday, April 16, 1999

Student Center (Gold Rush Room)

1:00 p.m.	Registration
2:00 p.m.	Conference Call to Order
	Welcoming Remarks
	Issie L. Shelton Jenkins, Chairperson Zeta Phi Beta Sorority National Educational Foundation
	Patricia T. Bivens, District Director U.S. Equal Employment Opportunity Commission
	Mr. Love Collins, III, Vice President Institutional Advancement and Development Dillard University, New Orleans, Louisiana
	Welcoming Remarks and Introduction to the Conference
	Dr. Rosalind Pijeaux Hale, Conference Director Chair, Division of Education at Xavier University of Louisiana Vice-Chairperson, Board of Managers, Zeta Foundation
2:30 p.m.	**Overview of the Human Genome Project:** **What Is It?** *Betty Mansfield,* Managing Editor, *Human Genome News* Oak Ridge National Laboratory, U.S. Department of Energy
3:15 p.m.	**Genetic Research - Changing Our World** **Genetic Research in the State of Louisiana**
	Dr. Mary Kay Pelias Department of Biometry and Genetics Louisiana State University Medical Center
4:15 p.m.	**The Biological Revolution: Genomics and its Challenge for Minority Education**
	Dr. Margaret C. Werner-Washburne, Program Director Microbial Genetics, National Science Foundation Arlington, Virginia
5:00 p.m.	**Comments and Questions**
5:15 p.m. - 6:15 p.m.	**Reception**

Saturday, April 17, 1999

Norman C. Francis Annex Building (Rooms 102, 103, 104, 105)

8:00 a.m.	**Conference Registration** (continued) (*NCF Annex Atrium*)
8:30 a.m.	**Conference Opening/Recap** *Dr. Rosalind Hale* Chair, Division of Education, Xavier University Conference Project Director *Betty Mansfield,* Managing Editor, *Human Genome News* Oak Ridge National Laboratory, U.S. Department of Energy
8:45 a.m.	**The Genetics of Behavior and IQ;** **Scientific and Folk Ideas about Heredity** *Dr. Jonathan Marks* Department of Anthropology University of California at Berkeley
9:15 a.m.	**The Implications of the Human Genome Project for Minority Health Issues** **Panel Presentation:** Hereditary Diseases and the implication of Gene Therapy; Genetics and Mental Retardation *Dr. Karen Nelson,* Assistant Investigator Institute for Genomic Research, Rockville, MD *Dr. Sharon Davis,* Director of Research and Program Services The ARC, Arlington, Texas
10:00 a.m.	Break
10:15 a.m.	**The Human Genome Project: Ethical, Legal, and Social Implications for the Minority Communities** **Panel Presentation** *Mark Rothstein, Esq.* Health Law and Policy Institute University of Houston Law Center, Houston, Texas *Keith T. Hill, Esq.*, Regional Attorney New Orleans District Office U.S. Equal Employment Opportunity Commission

Mr. Valerie Setlow, Deputy Director
Tulane/Xavier Center for Bioenvironmental Research
Tulane School of Public Health and Tropical Medicine

11:45 a.m. **Group Session:** Open dialogue-Identifying Issues and Concerns of Minority Communities

Questions and Answers

Moderator:
Dr. Rosalind Pijeaux Hale
Chair, Division of Education, Xavier University
Vice-Chair, Zeta Phi Beta Sorority National Education Foundation

12:15 p.m. **Lunch** (*Student Center - Gold Rush Room*)

Greetings
Mrs. Vondell Smith-Sloan
State Director
Zeta Phi Beta Sorority, Inc.

Eugene Green, Executive Assistant to the Mayor of New Orleans
Economic Develop.m.ent Office

The Honorable Cynthia Willard-Lewis, State Representative
100th District, Louisiana

Keynote Speaker
Jeanette Wolfley, Esq., Member, Shoshone-Bannock Tribes
Adjunct Associate Professor, Idaho State University

1:45 p.m. **Workshops:** Further Presentations And Discussion In Smaller Group Sessions. IDEAS AND RECOMMENDATIONS FOR POLICYMAKERS AND RESEARCHERS

Workshop I: THE BIOTECHNOLOGY INDUSTRY AND ECONOMIC AND CAREER OPPORTUNITIES FOR MINORITIES

Workshop Leader & Presenter
Dr. William Whalen, Assistant Professor
Biology, Xavier University

Dr. Karen Nelson, Assistant Investigator
The Institute of Genomic Research, Rockville, Maryland

Dr. Margaret Werner-Washburne
National Science Foundation, Arlington, Virginia

Workshop II: ISSUES IN GENETIC SCREENING (EXPLORATION OF ETHICAL ISSUES AND SOCIAL CONFLICT, ADVANTAGES, AND BARRIERS FOR MINORITIES)

Workshop Leader and Presenter
Dr. Todd Stanislav, Associate Professor
Biology, Xavier University

Mark Rothstein, Esq.
University of Houston Law Center
Health law and Policy Institute

Workshop III: PUBLIC POLICY ISSUES (MINORITY ACCESS TO MEDICAL GENETIC SERVICES; TRUST IN PUBLIC INSTITUTIONS, THE MEDICAL SCIENCE PROFESSION; ACCESS TO GENETIC INFORMATION, AND MISUSE OF SUCH DATA; EQUAL REPRESENTATION OF MINORITY SEQUENCE DATA IN GENETIC RESEARCH)

Workshop Leader and Presenter
Dr. Michelle B. Boissiere, Assistant Professor
Biology, Xavier University

Keith T. Hill, Esq., Regional Attorney
New Orleans District Office
Equal Employment Opportunity Commission

Dr. Valerie Setlow, Deputy Director
Tulane/Xavier Center for Bioenvironmental Research

3:15 p.m. **Workshop Summaries/Recommendations**
KEEPING THE MINORITY COMMUNITIES INFORMED

4:00 p.m. **Conference Evaluation**

4:30 p.m. **Conference Closure**

ABSTRACTS

OF

PRESENTERS

The Arc

a national organization on mental retardation

Q&A

Genetic Causes of Mental Retardation

What is genetics?

Genetics is "the science that studies the principles and mechanics of heredity, or the means by which traits are passed from parents to offspring" (Glanze, 1996). Through genetics a number of specific disorders have been identified as being genetically caused. One example is fragile X syndrome, a common genetic cause of mental retardation, which is caused by the presence of a single non-working gene (called the FMR-1 gene) on a child's X chromosome.

Genetics originated in the mid-19th century when Gregor Mendel discovered over a ten year period of experimenting with pea plants that certain traits are inherited. His discoveries provided the foundation for the science of genetics. Mendel's findings continue to spur the work and hopes of scientists to uncover the mystery behind how our genes work and what they can reveal to us about the possibility of having certain diseases and conditions. The scientific field of genetics can help families affected by genetic disorders to have a better understanding about heredity, what causes various genetic disorders to occur, and what possible prevention strategies can be used to decrease the incidence of genetic disorders.

Can a person's genes cause mental retardation?

Some genetic disorders are associated with mental retardation, chronic health problems and developmental delay. Because of the complexity of the human body, there are no easy answers to the question of what causes mental retardation. Mental retardation is attributable to any condition that impairs development of the brain before birth, during birth or in the childhood years (The Arc, 1993). As many as 50 percent of people with mental retardation have been found to possess more than one causal factor (AAMR, 1992). Some research has determined that in 75 percent of children with mild mental retardation the cause is unknown (Kozma & Stock, 1993).

The field of genetics has important implications for people with mental retardation. Over 350 inborn errors of metabolism have been identified, most of which lead to mental retardation (Scriver, 1995). Yet, the possibility of being born with mental retardation or developing the condition later in life can be caused by multiple factors unrelated to our genetic make-up. It is caused not only by the genotype (or genetic make-up) of the individual, but also by the possible influences of environmental factors. Those factors can range from drug use or nutritional deficiencies to poverty and cultural deprivation.

How often is mental retardation inherited?

Since the brain is such a complex organ, there are a number of genes involved in its development. Consequently, there are a number of genetic causes of mental retardation. Most identifiable causes of severe mental retardation (defined as an IQ of 50 or less) originate from genetic disorders. Up to 60 percent of severe mental retardation can be attributed to genetic causes making it the most common cause in cases of severe mental retardation (Moser, 1995). People with mild mental retardation (defined as an IQ between 50 and 70-75) are not as likely to inherit mental retardation due to their genetic make-up as are people with severe mental retardation. People with mild mental retardation are more likely to have the condition due to environmental factors, such as nutritional state, personal health habits, socioeconomic level, access to health care and exposure to pollutants and chemicals, rather than acquiring the condition genetically (Nelson-Anderson & Waters, 1995). Two of the most common genetically transmitted forms of mental retardation include Down syndrome (a chromosomal disorder) and fragile X syndrome (a single-gene disorder).

What causes genetic disorders?

Over 7,000 genetic disorders have been identified and catalogued, with up to five new disorders being discovered every year (McKusick, 1994). Genetic disorders are typically broken down into three types: Chromosomal, single-gene and multifactorial.

Chromosomal disorders affect approximately 7 out of every 1,000 infants. The disorder results when a person has too many or too few chromosomes, or when there is a change in the structure of a chromosome. Half of all first-trimester miscarriages or spontaneous abortions occur as a result of a chromosome abnormality. If the child is born, he or she usually has multiple birth defects and mental retardation.

Most chromosomal disorders happen sporadically. They are not necessarily inherited (even though they are considered to be genetic disorders). In order for a genetic condition to be inherited, the disease-causing gene must be present within one of the parent's genetic code. In most chromosomal disorders, each of the parent's genes are normal. However, during cell division an error in separation, recombination or distribution of chromosomes occurs. Examples of chromosomal disorders include Down syndrome, Trisomy 13, Trisomy 18 and Cri du chat.

Single-gene disorders (sometimes called inborn errors of metabolism or Mendelian disorders) are caused by non-working genes. Disorders of metabolism occur when cells are unable to produce proteins or enzymes needed to change certain chemicals into others, or to carry substances from one place to another. The cell's inability to carry out these vital internal functions often results in mental retardation. Approximately 1 in 5,000 children are born with defective enzymes resulting in inborn errors of metabolism (Batshaw, 1992). Although many conditions are generally referred to as "genetic disorders," single-gene disorders are the most easy to identify as true genetic disorders since they are caused by a mutation (or a change) within a single gene or gene pair.

Combinations of multiple gene and environmental factors leading to mental retardation are called **multifactorial disorders**. They are inherited but do not share the same inheritance patterns typically found in single-gene disorders. It is unclear exactly why they occur. Their

inheritance patterns are usually much more complex than those of single gene disorders because their existence depends on the simultaneous presence of heredity and environmental factors. For example, weight and intelligence are traits inherited in this way (Batshaw, 1992). Other common disorders, including cancer and hypertension, are examples of health problems caused by the environment and heredity. Multifactorial disorders are very common and cause a majority of birth defects. Examples of multifactorial disorders include heart disease, diabetes, spina bifida, anencephaly, cleft lip and cleft palate, clubfoot and congenital heart defects.

How are genetic disorders inherited?

Genetic disorders can be inherited in much the same way a person can inherit other characteristics such as eye and hair color, height and intelligence. Children inherit genetic or hereditary information by obtaining genes from each parent. There are three common types or modes of inheritance: dominant, recessive and X-linked (or sex-linked).

Dominant inheritance occurs when one parent has a dominant, disease-causing gene which causes abnormalities even if coupled with a healthy gene from the other parent. Dominant inheritance means that each child has a 50 percent chance of inheriting the disease-causing gene. An example of dominant inheritance associated with mental retardation is tuberous sclerosis.

Recessive inheritance occurs when both parents carry a disease-causing gene but outwardly show no signs of disease. Parents of children with recessive conditions are called "carriers" since each parent carries one copy of a disease gene. They show no symptoms of having a disease gene and remain unaware of having the gene until having an affected child. When parents who are carriers give birth, each child has a 25 percent chance of inheriting both disease genes and being affected. Each child also has a 25 percent chance of inheriting two healthy genes and not being affected, and a 50 percent chance of being a carrier of the disorder, like their parents. Examples of disorders which are inherited recessively and are also associated with mental retardation include phenylketonuria (PKU) and galactosemia.

X-linked or sex-linked inheritance affects those genes located on the X chromosome and can be either X-linked recessive or X-linked dominant. The X-linked recessive disorder, which is much more common compared to X-linked dominant inheritance, is referred to as a sex-linked disorder since it involves genes located on the X chromosome. It occurs when an unaffected mother carries a disease-causing gene on at least one of her X chromosomes. Since females have two X chromosomes, they are usually unaffected carriers because the X chromosome that does not have the disease-causing gene compensates for the X chromosome that does. Therefore, they are less likely than males to show any symptoms of the disorder unless both X chromosomes have the disease-causing gene.

If a mother has a female child, the child has a 50 percent chance to inherit the disease gene and be a carrier and pass the disease gene on to her sons (March of Dimes, 1995). On the other hand, if a mother has a male child, he has a 50 percent chance of inheriting the disease-causing gene since he has only one X chromosome. Consequently, males cannot be carriers of X-linked recessive disorders. If a male inherits an X-linked recessive disorder, he is affected. Some examples of X-linked inheritance associated with mental retardation include fragile X syndrome, Hunter syndrome, Lesch Nyhan syndrome and Duchenne muscular dystrophy.

Can genetic disorders which cause mental retardation be fixed?

In the past, only a few genetic disorders could be detected and treated early enough to prevent disease. However, the Human Genome Project, an international project among scientists to identify all the 60,000 to 100,000 genes within the human body, is significantly increasing our ability to discover more effective therapies and prevent inherited disease (National Center for Human Genome Research, 1995). As more disease-causing genes are identified, scientists can begin developing genetic therapies to alter or replace a defective gene. However, the development of gene therapies is still in the infancy stage.

Gene therapy (also called somatic-cell gene therapy) is a procedure in which "healthy genes" are inserted into individuals to cure or treat an inherited disease or illness. Although there is a role for gene therapy in the prevention of mental retardation, it will most likely benefit only those people who have single-gene disorders, such as Lesch-Nyhan disease, Gaucher disease and phenylketonuria (PKU) that cause severe mental retardation (Moser, 1995). Gene therapy is far less likely to provide treatment of mild mental retardation which accounts for 87 percent of all cases of mental retardation (The Arc, 1993).

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The Arc would like to thank Stacie R. Rosenthal, M.S., Mary Simmons, M.S. and Gail Brookshire, M.S., genetic counselors with Children's Medical Center of Dallas, for reviewing this publication.

This Q&A was funded, in part, by the U. S. Department of Energy ELSI Program under Grant No. DE-FG03-96ER62162 and produced by The Arc's Human Genome Education Project, Sharon Davis, Ph.D., Principal Investigator and Leigh Ann Reynolds, Project Associate. Support from DOE does not constitute an endorsement of the views expressed in this publication.

#101-50 December 1996

The Arc® Genetic Issues In Mental Retardation

A Report on The Arc's Human Genome Education Project Vol. 1, No. 1

The Arc's Human Genome Education Project is part of the U.S. Human Genome Project, which is an international effort to identify all the genes within the human body. The goal of The Arc's project is to promote education and discussion of the ethical, legal and social concerns resulting from innovative genetic research. It is funded through the U.S. Department of Energy's ELSI (Ethical, Legal and Social Implications) program.

An Introduction to Genetics and Mental Retardation

The Human Genome Project

The Human Genome Project (HGP) is an international effort involving hundreds of scientists who are attempting to map all 60,000 -- 100,000 human genes. Doing so would be the first step to unlock the nature of human life, shining light on its secrets and mysteries. The project, which is being directed by the National Institutes of Health (NIH) and the Department of Energy (DOE), began in 1990. Its ambitious goal is to identify all genes within the human body by the year 2005. Aside from gene identification, the project is also attempting to identify and answer specific ethical questions related to the consequences of new genetic findings within society. The hope is to begin developing policy options which can address the ethical questions sparked by the project.

The Arc's Human Genome Education Project

Imagine being able to pinpoint the source of every genetic disorder affecting mankind. For The Arc, the secrets of genetic disorders related to mental retardation could be uncovered. The Human Genome Project could provide a possible future of treatments and cures of some forms of mental retardation.

The Arc received funding from DOE to educate its members and leaders about the ethical, legal and social implications of genetic knowledge and use. As a result, issues can then be evaluated and discussed, and positions developed, based on adequate understanding.

The Arc's involvement stems from the fact that many mental retardation disorders have a genetic cause. As genes causing mental retardation are discovered, the possibility of treatments, cures and genetic testing for inherited conditions raise ethical dilemmas regarding such areas as privacy, fairness and discrimination.

To address these issues, three percent of DOE's overall Human Genome budget is devoted specifically to funding research focusing on the impact of Ethical, Legal and Social Implications (ELSI) of new genetic findings within society. The ELSI program seeks to involve concerned individuals and groups -- like The Arc -- who are directly affected by genetic research. Specific ELSI issues addressed by The Arc's project include:

- Discrimination in insurance and employment
- Genetic testing, screening and counseling
- Genetic therapies to "cure" mental retardation

The Arc's mission is to carry out the following objectives:

- Develop and disseminate educational material for members and leaders of The Arc to inform them about the HGP and mental retardation.
- Conduct training for The Arc's leaders on the scientific, ethical, legal and social aspects of the HGP and mental retardation who can, in turn, provide training to their state and local chapter's membership.
- Disseminate educational material to other disability organizations and the general public as appropriate.

Ethical, Legal and Social Concerns Arising from New Genetic Findings

Why should The Arc become involved in ethical discussions about genetics? Many mental retardation disorders have genetic causes, with Down syndrome and fragile X syndrome being the most common. (See "Genetic Causes of Mental Retardation" for other mental retardation disorders with genetic causes.) More than 350 inborn errors of metabolism have been identified, most of which lead to mental retardation. Specific genes have already been discovered for a number of single gene conditions, including fragile X syndrome, for which a treatment may be a possibility in the future.

There is a long history of discrimination against people with mental retardation, ranging from the eugenics movement resulting in involuntary sterilization, to the practice of allowing infants born with Down syndrome to die from lack of medical treatment, to the current call to harvest organs of babies born with anencephaly for transplant purposes, even though the infant has not been declared dead.

With this history of discrimination, it is imperative that the scientific and medical community hear the views of consumers and families regarding ethical issues involving new genetic findings. We will prepare educational materials and offer training and opportunities for our association to consider such questions as:

- Must a physician offer prenatal genetics screening to all pregnant women (or risk medical malpractice liability if he or she doesn't)? Does a woman have a right to refuse prenatal screening?
- Should genetic testing be offered when there is no treatment? What about access to testing for poor people?
- What rights does a child have to agree to or refuse testing? Who has rights to the test results? Are parents endangering their child's future employability and insurability? What about psychological harm to the child? (Your young teenage daughter learns she's a carrier for fragile X syndrome, for example.)

- How can the confidentiality of test results be maintained to prevent insurers from discrimination? Can employers discriminate on the basis of a person's genes?
- Should therapies for genetic conditions causing mental retardation even be considered? Is there positive value in diversity? How can we avoid stigmatizing those living with a genetic condition while trying to eliminate the condition in others? Are some conditions so destructive to the individual that if a therapy is possible it should be undertaken?
- Should you include your newborn child in experimental gene therapy research? Do any guidelines exist to help you make this difficult decision?

These are some examples of the challenging issues The Arc will be addressing throughout the two-year project. With the scientific community often basing their decisions on their beliefs about quality of life of a person with mental retardation, The Arc must participate in the discussions on the ethical, legal and social issues regarding use of genetic knowledge.

Genetic Disorders Associated with Mental Retardation with an Estimated Incidence in Excess of 1:100,000

Diagnosis	Type of disorder	Genetics	Incid./1,000
Down syndrome	Chromosomal		1.30
Fragile X	Single gene	Triplet repeat*	0.60
Duchenne muscular dystrophy	Single gene	X-linked recessive	0.15
Trisomy 13	Chromosomal		0.125
Tuberous sclerosis	Single gene	Autosomal dominant	0.1
Phenylketonuria (PKU)	Single gene	Autosomal recessive	0.067
Cri du chat	Chromosomal		0.05
Galactosemia	Single gene	Autosomal recessive	0.017
Hunter syndrome	Single gene	X-linked recessive	0.01

*Triplet repeat diseases are inherited in a unique way. The genetic defect can worsen as the gene is passed from one generation to the next. Triplet repeat is named by the three-letter sequences of DNA code which are repeated too many times in the genes causing disorders.

SOURCE: Moser, H.W. (1995),"A Role for Gene Therapy in Mental Retardation,"*Mental Retardation and Developmental Disability Research Reviews.* Reprinted by permission of Wiley-Liss, Inc., a subsidiary of John Wiley & Sons, Inc.

Genetics: An Introduction

Children resemble their parents and relatives, and these traits are passed on for generations. In other words, a child may have his father's nose, her mother's eyes, and those traits might be passed along to that child's child and so on for generations. Biologically this is called inheritance, and genetics is the biology of inheritance. Geneticists study the mechanisms of hereditary transmission -- and sometimes the variations -- of human characteristics.

The characteristics we inherit and pass on are contained within the nucleus of our cells, and the human body is composed of 100 trillion cells. The cell's nucleus carries a blueprint for life composed of contributions of the ancestors who preceded us. That blueprint is in our chromosomes -- our genetic code. The genes on our chromosomes determine our physical and biochemical properties; in effect, our genetic inheritance.

The tens of thousands of genes carried on our chromosomes determine everything from what an individual cell's job is -- whether the cell is a skin cell, a heart muscle cell or a brain cell -- to our physical and developmental characteristics. This complete set of 46 chromosomes is called the cell's genome.

Genetic Causes of Mental Retardation

With up to 100,000 genes encoded in each cell and 100 trillion cells making up the human body, people are a mind boggingly complex organism. Add to that the constant division and replication of those cells as part of their natural life spans and it is amazing that more things don't go wrong.

Because of this complexity, there are no easy answers to the question of what causes mental retardation. It is attributable to any condition that impairs development of the brain before birth, during birth or in the childhood years. It is caused not only by the genotype or genetic make-up of the individual, but also by the possible influences of environmental factors. Those factors can range from drug use or nutritional deficiencies to poverty and cultural deprivation. As many as 50 percent of people with mental retardation have been found to possess more than one causal factor.

In 30 percent of people with severe mental retardation, the cause of mental retardation remains unknown. When compared to those severely affected, identifying the cause of mental retardation in children mildly affected is much more difficult. Roughly 90 percent of all cases of mental retardation fall within the mild range. Some research has determined that in 75 percent of children with mild mental retardation the cause is unknown.

Most identifiable causes of severe mental retardation originate from genetic disorders. Since the brain is such a complex organ, there are many genes involved in its development. Therefore, there are many different genetic causes of mental retardation. Up to 60 percent of severe mental retardation can be attributed to genetic causes making it the most common cause. (See table for an overview of the more common genetic disorders associated with mental retardation.)

Genetic disorders are generally associated with mental retardation, chronic health problems and developmental delay. In order to have a better understanding as to how genetic disorders occur, they are typically broken down into three types: Chromosomal, single-gene and multifactorial. Two of the most common genetically transmitted forms of mental retardation include Down syndrome (chromosomal disorder) and fragile X syndrome (single-gene disorder).

Chromosomal disorders affect approximately 7 out of every 1,000

infants. The disorder is caused by a person having too many or too few chromosomes, or when there is a change in the structure of a chromosome. Half of all first-trimester miscarriages or spontaneous abortions occur as a result of a chromosome abnormality. If the child is born, he or she usually has multiple birth defects and mental retardation.

Most chromosomal disorders happen sporadically. They are not necessarily inherited (even though they are considered genetic disorders). Only a few specific types are inherited in the same way single-gene disorders are inherited. In order for a genetic condition to be inherited, the disease-causing gene must be present within one of the parent's genetic code. In chromosomal disorders, each of the parent's genes is normal. However, during cell division an error in separation, recombination or distribution of chromosomes occurs. Examples of chromosomal disorders include Down syndrome, Trisomy 13, Trisomy 18 and Cri du chat.

Single-gene disorders (sometimes called inborn errors of metabolism or Mendelian disorders) are caused by non-working genes. These disorders of metabolism occur when cells are unable to produce proteins or enzymes needed to change certain chemicals into others, or to carry substances from one place to another. The cell's inability to carry out these vital internal functions often results in mental retardation.

Although many conditions are generally referred to as "genetic disorders," single-gene disorders are the most easy to identify as true genetic disorders since they are caused by a mutation or change within a single gene. Single-gene disorders are considered to be potentially the most responsive to gene therapy since they are caused by a mutation within a single gene, as opposed to being caused by mutations within several different genes.

Approximately 1 in 1,500 children are born with defective enzymes resulting in inborn errors of metabolism. Over 7,000 genetic disorders have been identified and catalogued, with up to five new disorders being discovered every year. Though rare, there is a one in 500 chance for a child inheriting this type of disorder.

Single-gene disorders are inherited in one of three ways:

1) Dominant Inheritance. This occurs when a person has a dominant, disease-causing gene which causes abnormalities even if coupled with a "normal" gene. An example associated with mental retardation is tuberous sclerosis.

2) Recessive Inheritance. This occurs when there are two copies of a non-working gene. Parents of children with autosomal recessive conditions are called "carriers" since each parent carries one copy of a disease gene. They show no symptoms of having a disease gene and remain unaware of this until having an affected child. Single-gene disorders are usually classified as autosomal recessive disorders and can be discovered prenatally if the mother is at risk for this genetic condition. Examples associated with mental retardation include phenylketonuria (PKU) and galactosemia.

3) X-linked disorders. These affect those genes located on the X chromosome and can be either X-linked recessive or X-linked dominant. Because there are so few X-linked dominant disorders, more attention is generally paid to X-linked recessive disorders.

The X-linked recessive disorder is also referred to as a sex-linked disorder since it involves genes located on the X, or female, sex chromosome. Since females have two X chromosomes, they are usually unaffected carriers and are less likely than males to show any symptoms of the disorder. On the other hand, males have only one X chromosome and, therefore, cannot be carriers of X-linked recessive disorders. If a male inherits an X-linked recessive disorder, he is affected. Some examples associated with mental retardation include fragile X syndrome, Hunter syndrome, Lesch Nyhan syndrome and Duchenne muscular dystrophy.

Combinations of multiple gene and environmental factors leading to mental retardation are called *multifactorial disorders*. They do not follow a normal inheritance pattern and no one knows exactly why they occur. They are inherited (passed on throughout family generations) but do not share the same characteristic inheritance patterns of single-gene disorders.

Their inheritance patterns are usually much more complex than those of single-gene disorders because their presence of several heredity and environmental factors. For example, weight and intelligence are inherited in this way. These disorders are very common and cause a majority of birth defects. Examples of multifactorial disorders include heart disease, diabetes, some cancers, spina bifida, anencephaly, cleft lip and cleft palate, clubfoot and congenital heart defects.

Becoming familiar with the genetic causes of mental retardation paves the way for more thorough discussions of ethical issues involving genetic research. For example, how will the discovery of new genes associated with mental retardation impact those individuals who have mental retardation? How will individuals who carry a gene for mental retardation, but who show no symptoms of a disorder, be affected?

Knowing how mental retardation is genetically inherited opens the door for a clearer understanding and more educated discussions about the ethical issues involved with genetic research. Upcoming reports will address these issues in greater depth by highlighting some of the more common genetic disorders associated with mental retardation.

By focusing on these specific disorders, those ethical questions most applicable to The Arc's membership can be defined and discussed. Ultimately, these discussions prepare The Arc to confidently tackle genetic and ethical issues by developing carefully thought out positions related to the use of innovative genetic research.

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The following resources can be helpful for those seeking additional information on the Human Genome Project and other topics related to genetic research.

Alliance of Genetic Support Groups
35 Wisconsin Circle, Suite 440
Chevy Chase, MD 20815
301-652-5553
1-800-336-4363 (1-800-336-GENE)
Contact: Mary Davidson, Executive Director

Provides information for individuals affected by genetic conditions and their families, as well as the public or media and professionals. They provide peer support, professional counseling, crisis intervention, referrals for non-medical services and genetic counseling. Technical assistance is offered to those interested in forming a group or chapter and in fundraising. They maintain a database of support groups on specific genetic disorders and publish a *Directory of National Genetic Voluntary Organizations*.

National Organization for Rare Disorders (NORD)
P.O. Box 8923
New Fairfield, CT 06812
203-746-6518
1-800-999-6673 or 1-800-999-NORD
Contact: Abbey S. Meyers, President
http://www.w2.com

Provides information about symptoms, causes, treatments for those affected by a genetic disorder and research on more than 5,000 rare disorders. Also provides assistance in forming support groups or chapter bylaws and fundraising, and referrals to appropriate organizations. Maintains a registry of affected individuals and research grants (linking researchers with families).

Council of Regional Networks for Genetic Services (CORN)
Emory University
Pediatrics/Medical Genetics
2040 Ridgewood Drive
Atlanta, GA 30322
404-727-1475
Contact: Cynthia Hinton, M.S., M.P.H., CORN's Project Coordinator

CORN is a consortium of genetic service providers whose goal is to improve access to genetic services and enhance the quality of these services. There are ten regional networks nationwide which provide opportunities for consumers and professionals to communicate and become active in shaping genetic services in their region and nationally.

National Center for Human Genome Research
Building 31, Room B1C35
9000 Rockville Pike
Bethesda, MD 20892
301-402-4570
Contact: Leslie Fink
http://www.nchgr.nih.gov

Provides timely information about the progress of the Human Genome Project, as well as numerous written materials and other resources.

Human Genome Management Information System (HGMIS)
Oak Ridge National Laboratory
1060 Commerce Park, MS 6480
Oak Ridge, TN 37830
423-576-6669
http://www.ornl.gov/hgmis/

Facilitates genetic research and education for the U.S. Department of Energy (DOE) Human Genome Program Task Force. Staff answer questions about the genome project and provide general information through an information clearinghouse. Produces numerous publications on the project, including a newsletter and the Primer on Molecular Genetics.

Primer on Molecular Genetics
by Denise Casey
1991-1992 DOE Human Genome Report
Contact: HGMIS (above)
http://www.gdb.org/Dan/DOE.intro.html

A good overview of genetics, including the basics of DNA, genes and chromosomes, is clearly explained in this document, especially as this information relates to genetic research being conducted by the Human Genome Project. It is a popular resource for teachers, genetic counselors and educational organizations.

Additional Genetic Information Available on the Internet

DOE Office of Health and Environmental Research (OHER) Home Page for the DOE Human Genome Program
http://www.er.doe.gov/production/oher/oher-top.html

Provides information on DOE's Human Genome Project and other OHER projects and links to other program-related sites.

National Center for Genome Resources (NCGR)
http://www.ncgr.org

NCGR's Genetics and Public Issues program covers a wide array of genetic information.

For more information, contact:

The Arc of the United States
500 E. Border St., S-300
Arlington, Texas 76010
(817) 261-6003
TDD (817) 277-0553
Http://TheArc.org/welcome.html.

Produced by The Arc's Human Genome Education Project, Sharon Davis, Ph.D., Principal Investigator and Leigh Ann Reynolds, Project Associate. Funded by the U. S. Department of Energy ELSI Program under Grant No. DE-FG03-96ER62162. Support from DOE does not constitute an endorsement of the views expressed in this publication. October 1996 - Rev. Dec. 1996

The Science Behind the Human Genome Project

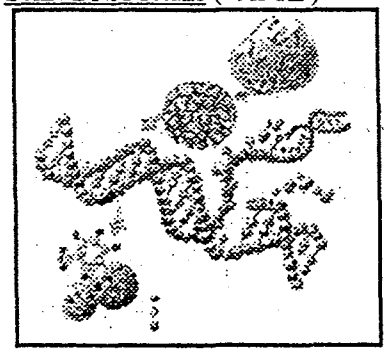
Understanding the Basics and How the HGP is Implemented

Quick Index:

The Basics

The complete set of instructions for making an organism is called its **genome**. It contains the master blueprint for all cellular structures and activities for the lifetime of the cell or organism. Found in every nucleus of a persons many trillions of cells, the human genome consists of tightly coiled threads of deoxyribonucleic acid (**DNA**) and associated protein molecules, organized into structures called **chromosomes**.

Some DNA details (49k GIF)



If unwound and tied together, the strands of DNA would stretch more than 5 feet but would be only 50 trillionths of an inch wide. For each organism, the components of these slender threads encode all the information necessary for building and maintaining life, from simple bacteria to remarkably complex human beings. Understanding how DNA performs this function requires some knowledge of its structure and organization.

DNA

In humans, as in other higher organisms, a DNA molecule consists of two strands that wrap around each other to resemble a twisted ladder whose sides, made of sugar and phosphate molecules, are connected by rungs of nitrogen-containing chemicals called bases. Each strand is a linear arrangement of repeating similar units called **nucleotides**, which are each composed of one sugar, one phosphate, and a nitrogenous base. Four different bases are present in DNA: adenine (A), thymine (T), cytosine (C), and guanine (G). The particular order of the bases arranged along the sugar-phosphate backbone is called the DNA sequence; the sequence specifies the exact genetic instructions required to create a particular organism with its own unique traits.

The two DNA strands ar 'd together by weak bonds between ti ases on each strand, forming **base pairs** (bp). Genome size is usually stated as the total number of base pairs; the human genome contains roughly 3 billion bp.

Each time a cell divides into two daughter cells, its full genome is duplicated; for humans and other complex organisms, this duplication occurs in the nucleus. During **cell division** the DNA molecule unwinds and the weak bonds between the base pairs break, allowing the strands to separate. Each strand directs the synthesis of a complementary new strand, with free nucleotides matching up with their complementary bases on each of the separated strands. Strict base-pairing rules are adhered to; adenine will pair only with thymine (an A-T pair) and cytosine with guanine (a C-G pair). Each daughter cell receives one old and one new DNA strand. The cells adherence to these base-pairing rules ensures that the new strand is an exact copy of the old one. This minimizes the incidence of errors (mutations) that may greatly affect the resulting organism or its offspring.

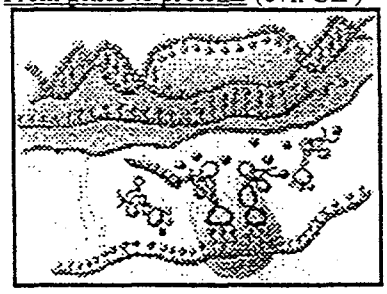
Genes

Each DNA molecule contains many genes--the basic physical and functional units of heredity. A **gene** is a specific sequence of nucleotide bases, whose sequences carry the information required for constructing proteins, which provide the structural components of cells and tissues as well as enzymes for essential biochemical reactions. The human genome is estimated to comprise approximately 80,000 genes.

Human genes vary widely in length, often extending over thousands of bases, but only about 10% of the genome is known to include the protein-coding sequences (exons) of genes. Interspersed within many genes are intron sequences, which have no coding function. The balance of the genome is thought to consist of other noncoding regions (such as control sequences and intergenic regions), whose functions are obscure.

All living organisms are composed largely of proteins; humans can synthesize about 80,000 different kinds. **Proteins** are large, complex molecules made up of long chains of subunits called **amino acids**. Twenty different kinds of amino acids are usually found in proteins. Within the gene, each specific sequence of three DNA bases (codons) directs the cells protein-synthesizing machinery to add specific amino acids. For example, the base sequence ATG codes for the amino acid methionine. Since 3 bases code for 1 amino acid, the protein coded by an average-sized gene (3000 bp) will contain 1000 amino acids. The genetic code is thus a series of codons that specify which amino acids are required to make up specific proteins.

From genes to proteins (67k GIF)



The protein-coding instructions from the genes are transmitted indirectly through **messenger ribonucleic acid** (mRNA), a transient intermediary molecule similar to a single strand of DNA. For the information within a gene to be expressed, a complementary RNA strand is produced (a process called **transcription**) from the DNA template in the nucleus. This mRNA is moved from the nucleus to the cellular cytoplasm, where it serves as the template for protein synthesis. The cells protein-synthesizing machinery then translates the codons into a string of amino acids that will constitute the protein molecule for which it codes. In the laboratory, the mRNA molecule can be isolated and used as a template to synthesize a

complementary DNA (cDNA) strand, which can then be used to locate the corresponding genes on a chromosome map.

Chromosomes

The 3 billion bp in the human genome are organized into 24 distinct, physically separate microscopic units called chromosomes. All genes are arranged linearly along the chromosomes. The nucleus of most human cells contains 2 sets of chromosomes, 1 set given by each parent. Each set has 23 single chromosomes--22 autosomes and an X or Y sex chromosome. (A normal female will have a pair of X chromosomes; a male will have an X and Y pair.) Chromosomes contain roughly equal parts of protein and DNA; chromosomal DNA contains an average of 150 million bases. DNA molecules are among the largest molecules now known.

Chromosomes can be seen under a light microscope and, when stained with certain dyes, reveal a pattern of light and dark bands reflecting regional variations in the amounts of A and T vs G and C. Differences in size and banding pattern allow the 24 chromosomes to be distinguished from each other, an analysis called a karyotype. A few types of major chromosomal abnormalities, including missing or extra copies of a chromosome or gross breaks and rejoinings (translocations), can be detected by microscopic examination; Downs syndrome, in which an individual's cells contain a third copy of chromosome 21, is diagnosed by karyotype analysis.

Most changes in DNA, however, are too subtle to be detected by this technique and require molecular analysis. These subtle DNA abnormalities (**mutations**) are responsible for many inherited diseases such as cystic fibrosis and sickle cell anemia or may predispose an individual to cancer, major psychiatric illnesses, and other complex diseases.

Implementing the HGP: Goals 1998-2003

In September 1998, advisory committees at DOE and NIH approved new 5-year goals aimed at completing the Human Genome Project (HGP) 2 years earlier than originally planned in 1990. The target date of 2003 also will mark the 50th anniversary of Watson and Crick's description of DNA's fundamental structure.

The new plan was published in the October 23, 1998, issue of *Science*, which also cited the contributions of international partners. These partners include the Sanger Centre in the United Kingdom and research centers in Germany, Japan, and France.

The U.S. HGP began officially in 1990 as a $3-billion, 15-year program to find the estimated 80,000 human genes and determine the sequence of the 3 billion DNA building blocks that underlie all of human biology and its diversity. The early phase of the HGP was characterized by efforts to create the biological, instrumentation, and computing resources necessary for efficient production-scale DNA sequencing. The first 5-year plan was revised in 1993 due to remarkable technological progress, and the second plan projected goals through FY 1998. The latest plan was developed during a series of individual and joint DOE and NIH workshops held over the past 2 years.

Observers have predicted that the 21th century will be the "biology century." The analytical power arising from the reference DNA sequences of several entire genomes and other genomic resources is anticipated to help jump start the new millennium.

Human DNA Sequencing

The HGP's continued emphasis is on obtaining a complete and highly accurate reference sequence (1 error in 10,000 bases) that is largely continuous across each human chromosome. Scientists believe that knowing this sequence is critically important for understanding human biology and for applications to other fields.

A March 1999 update of the October 1998 plan calls for generating a "working draft" of the human genome DNA sequence by the spring of 2000 --accelerating the efforts of the 1998 plan which called for a draft by December 2001. The working draft will comprise shotgun sequence data from mapped clones, with gaps and ambiguities unresolved. If these data sets can be merged with those from the private sector, they may increase the depth of the mapped draft, which scientists expect will contain about half the genes. Draft sequence will provide a foundation for obtaining the high-quality finished sequence and also will be a valuable tool for researchers hunting disease genes.

According to Ari Patrinos, DOE Associate Director for Biological and Environmental Research, "Although we have as our primary goal the finished Book of Life' by the end of 2003, we also want the working draft to be as useful as possible."

NIH and DOE sequencing centers expect their facilities to generate about 60% to 70% of the human DNA sequence, which will be made available broadly and rapidly via the Web to stimulate further research.

Sequencing Technology

Although current sequencing capacity is far greater than at the inception of the HGP, achieving the new sequencing goals will require a two- to threefold improvement. Further incremental advances in sequencing technologies, efficiency, and cost will be needed. For future sequencing applications, planners emphasize the importance of supporting novel technologies that may be 5 to 10 years in development.

Sequence Variation

A new goal focuses on identifying individual variations in the human genome. Although more than 99% of human DNA sequences are the same across the population, variations in DNA sequence can have a major impact on how humans respond to disease; environmental insults such as bacteria, viruses, toxins, and chemicals; and drugs and other therapies.

Methods are being developed to detect different types of variation, particularly the most common type called single-nucleotide polymorphisms (SNPs), which occur about once every 100 to 300 bases. Scientists believe SNP maps will help them identify the multiple genes associated with such complex diseases as cancer, diabetes, vascular disease, and some forms of mental illness. These associations are difficult to establish with conventional gene-hunting methods because a single altered gene may make only a small contribution to disease risk.

Functional Genomics

Efficient interpretation of the functions of human genes and other DNA sequences requires that resources and strategies be developed to enable large-scale investigations across whole genomes. A technically challenging first priority is to generate complete sets of full-length cDNA clones and sequences for human and model-organism genes. Other functional-genomics goals include studies into gene expression and control, creation of mutations that cause loss or alteration of function in nonhuman organisms, and development

of experimental and com. ational methods for protein analyses.

Comparative Genomics
The functions of human genes and other DNA regions often are revealed by studying their parallels in nonhumans. To enable such comparisons, HGP researchers have obtained complete genomic sequences for the bacterium *Escherichia coli*, the yeast *Saccharomyces cerevisiae*, and the roundworm *Caenorhabditis elegans*. Sequencing continues on *Drosophila melanogaster* and the laboratory mouse. The availability of complete genome sequences generated both inside and outside the HGP is driving a major breakthrough in fundamental biology as scientists compare entire genomes to gain new insights into evolutionary, biochemical, genetic, metabolic, and physiological pathways. HGP planners stress the need for a sustainable sequencing capacity to facilitate future comparisons.

Ethical, Legal, and Social Implications (ELSI)
Rapid advances in the science of genetics and its applications present new and complex ethical and policy issues for individuals and society. ELSI programs that identify and address these implications have been an integral part of the U.S. HGP since its inception. These programs have resulted in a body of work that promotes education and helps guide the conduct of genetic research and the development of related medical and public policies.

A continuing challenge is to safeguard the privacy of individuals and groups who contribute DNA samples for large-scale sequence-variation studies. Other concerns are to anticipate how the resulting data may affect concepts of race and ethnicity; identify potential uses (or misuses) of genetic data in workplaces, schools, and courts; identify commercial uses; and foresee impacts of genetic advances on the concepts of humanity and personal responsibility.

Bioinformatics and Computational Biology
Continued investment in current and new databases and analytical tools is critical to the success of the HGP and to the future usefulness of the data it produces. Databases must adapt to the evolving needs of the scientific community and must allow queries to be answered easily. Planners suggest developing a human genome database, analogous to model organism databases, that will link to phenotypic information. Also needed are databases and analytical tools for studying the expanding body of gene-expression and functional data, for modeling complex biological networks and interactions, and for collecting and analyzing sequence-variation data.

Training
Planners note that future genomic scientists will require training in interdisciplinary areas that include biology, computer science, engineering, mathematics, physics, and chemistry. Additionally, scientists with management skills will be needed for leading large data-production efforts.

The HGP already has revolutionized biology by providing tools and resources for basic research and has catalyzed the growth of the life sciences industry. Current and potential applications of genome research address national needs in molecular medicine, waste control and environmental cleanup, agriculture and animal husbandry, biotechnology, energy sources, and risk assessment.

To learn more about the Genome Project and Its Underlying Science and Applications, visit the following pages on the Human Genome Project Information Website http://www.ornl.gov/hgmis

- See the following short publications:
  - DOE *Primer on Molecular Genetics*
    http://www.ornl.gov/hgmis/publicat/primer/intro.html
  - *To Know Ourselves*
    http://www.ornl.gov/hgmis/publicat/tko/index.htm
    a review of the role, history, and achievements of DOE in the HGP and an introduction to the science and other aspects of the project.
  - *Your Genes, Your Choices*
    http://www.ornl.gov/hgmis/publicat/genechoice/index.html
    a book describing the Human Genome Project, the science behind it, and the ethical, legal, and social issues that are raised by the project.

- Check Genome Frequently Asked Questions (FAQs):
  http://www.ornl.gov/hgmis/faq/faqs1.html
  to find answers to a number of questions including
  - What's a genome? And why is it important?
  - How big is the human genome?
  - Whose genome is being used for study in the HGP?
  - Where can I find maps of genes that have been found on different chromosomes?

- Browse the newsletter and other publications
  - *Human Genome News* newsletter
    http://www.ornl.gov/hgmis/publicat/hgn/hgn.html
  - Other Publications
    http://www.ornl.gov/hgmis/publicat/publications.html#publications
    Department of Energy Human Genome Program Reports and other miscellaneous documents which outline the research being funded by the DOE HGP

- Visit the Human Genome Project Research site for more technical information
  http://www.ornl.gov/hgmis/research.html

Modified: March 25, 1999

Submitted By:
Betty Mansfield, Managing Editor
Human Genome News

The Genetics of Behavior and IQ:
Scientific and Folk Ideas about Heredity

Modern anthropology refutes three commonsense folk ideas about heredity, which nevertheless endure in the popular consciousness. The first, popular since the turn of the century, runs:

Genes code for the Brain;
the Brain is the seat of the Mind;
the Mind contains Thoughts;
therefore, bad thoughts are caused by bad genes.

The second is that the observation of consistent differences between groups of people implies a constitutional basis for those differences. In fact, while consistent differences may be due to heredity, differences in any specific feature may be due to other factors. An inference of genetic difference, therefore, requires genetic data.

The third is that human abilities are measurable and their limits knowable. In fact, however, ability is a metaphysical concept, observable only in retrospect and in the context of a particular lived life.

These inferences lie in the realm of "folk heredity", not in modern genetics.

"Folk heredity" comprises the ideologies of heredity which are culturally commonsensical, but not valid scientifically. All cultures have non-scientific theories of heredity, including our own, and their unscientific nature may be difficult even for scientists to recognize. The four major theories of folk heredity in modern society are *taxonomism* (that our species is naturally divisible into a small number of groups equivalent to zoological subspecies), *racism* (that individuals can be judged by properties attributed to the group to which they are assigned), *hereditarianism* (that particular differences between people are innate), and *essentialism* (that there is an unseen basic constitution shared by people, in spite of their apparent differences).

Submitted By:
Dr. Johnathan Marks
Department of Anthropology

THE HUMAN GENOME PROJECT, HEREDITARY DISEASES AND GENE THERAPY

THE HUMAN GENOME PROJECT

The Human Genome Project (HGP) is the international research program that began in 1990 with the goal to determine the complete nucleotide sequence and the functions of the entire complement of genes that make up the human genome. This sequencing work, being conducted at more than 17 collaborative centers worldwide, is expected to be completed by the year 2003. It is anticipated that the knowledge gained from sequencing the human genome will contribute a complete understanding of the estimated 60,000 to 100,000 human genes and their functions.

THE CELL, GENETICS AND GENETIC DISORDERS

The genetic information that determines the makeup of the human body is present in the cell nucleus in the form of 46 chromosomes. The functional units of heredity (genes) found on the chromosomes are composed of DNA. A consistent pairing of complementary bases allows DNA to replicate itself accurately when cells divide. The strict base pairing ensures that the new strands that form are an exact copy of the old strand, thus reducing chance of mutations in the DNA that may affect the organism or its offspring.

The genetic material within a typical human cell carries an estimated 3 billion pairs of nucleotides. Each individual, except for identical twins, has a unique nucleotide sequence. However, approximately 99.9% of the every human genome is identical with an estimated less than 1 difference per 1000 nucleotides. This high level of similarity allows for the comparison of genetic material between individuals, making a search for differences or mutations possible.

Mutations result from a variety of factors. Although some disorders are due to the combined effects of multiple gene mutations (multigenic disorders), or to the combined effects of genes and the environment (multifactoral disorders), the most commonly described type of genetic disorder are those which result from a single defective gene (Mendellian disorders). Over 3,000 single gene disorders are known, ranging from mild conditions such as red-green color blindness to life threatening diseases such as cystic fibrosis.

The identification of a disease causing gene allows for the characterization and study of the molecular alterations that resulted in the disease as well as the mechanisms that underlie the disease. In addition, an indication can be made as to whether the mutated gene, or the protein that is normally produced by this gene, can be replaced or fixed to correct the disorder. Among the more prominent genetic disorders for which genes have been identified are Alzheimers' disease, breast cancer Type 1 and 2, cystic fibrosis, Fragile - X syndrome, Huntington's disease, Duchenne muscular dystrophy (DMD), neurofibromatosis, sickle cell anemia and primary congenital glaucoma (homozygous). Extensive research is currently being conducted to characterize the genes associated with the age-related disorders osteoporosis, atherscleresis and certain cancers. Active work also continues in the areas of genetic screening for genes associated with diabetes, prostate cancer, obesity, asthma, lupus and schizophrenia.

FROM THE HUMAN GENOME PROJECT TO GENE THERAPY

One of the most significant aspects of the availability of the complete sequence of the human genome will be the potential for the increased understanding of human disease. An understanding of the underlying causes of diseases will allow for the applications of many new technologies designed to treat these diseases. For example, human somatic gene therapy is a new technology whose initial successes suggest it may eventually be a practical strategy for treating genetically linked diseases.

Most gene therapy trials conducted so far have employed modified viruses to introduce a therapeutic gene to cure the patient's disease. Many basic problems remain with this technology, some relate to size limitations for the viral packaging unit and the transfer method for getting the gene into the necessary site on the chromosome. In addition, a high efficiency of transmission and expression stability are required for successful gene transfer. There are also issues which relate to the risks associated with the possibility of random integration of genes and their vectors, and the insertion of foreign genes into chromosomes, the overexpression of transferred genes, and the inactivation of critical genes by gene or vector insertion within a coding region. Questions remain with respect to the long-term safety of patients who undergo gene therapy, the economics of the technology when compared to conventional methods of disease therapy, and the ethical aspects of this technique.

Evidently more basic and applied research is required before gene therapy becomes an effective standard option for treating genetic diseases. In the future, gene therapy might also be used to alter germ cells in attempts to prevent genetic defects from being transmitted to future generations. Gene therapy employing germ-line cells is likely to be associated with difficult social and ethical questions. This is because germ-line gene therapy would change the genetic makeup of an individual's offspring forever, thus permanently altering the human gene pool.

DISEASE AND MINORITY POPULATIONS

Among the genetically linked diseases, hypertension, hypertensive heart disease, stroke, prostate cancer, and diabetes have been shown to have a higher incidence in various minority populations. For example, American black males have been shown to have the highest incidence of prostate cancer in the world coupled with the highest mortality rates. Prostate cancer survival rates in American males suggest an interaction of genetics with the environment, access to medical care, and cultural and social differences including diet. Hypertension is another example of a disease that exemplifies the interactions of genetics and the environment. In studies carried out in the USA, African Americans have been shown to have a higher incidence of hypertension and hypertensive renal disease than white Americans do.

Evidently, there is a need to describe the diversity of disease expression in humans and to target groups at risk for disease prevention and early intervention. Although many disease expression studies have focused on white or black Americans, Hispanics are the second largest minority in the United States, and are expected to be the largest minority group by the year 2020. These demographics will need to be considered when formulating health care studies that have to be applied to such a diverse population. Even within races, there is a great

degree of variation, a variation that could appear to be greater than the variation between races of people.

CONCLUSION

The sequence of the human genome, and gene identification will revolutionize how we address human disease. Among the early benefits of the HGP are a better understanding of how DNA influences our growth, development, and health, as well as the development of tools that can be used in molecular biology and genetics. Sequencing the human genome will aid in the rapid identification and diagnosis of inherited disorders, and will lead to early intervention, prevention or therapeutic methods for addressing these disorders, as well as the development of new drug targets. As an added major benefit, gene therapy may eventually become an effective method for addressing hereditary diseases.

Considering that all diseases are thought to have a genetic component, it is without doubt that the information gained from the HGP will accelerate the pace with which progress is made in prevention, diagnosis, treatment and drug development for many diseases. This is already evident by progress made in delaying the onset of heart disease, cancer and stroke in some populations.

Submitted By:
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Genetics Research in Louisiana

Research in human and medical genetics has been the focus of active inquiry in Louisiana for the past four decades. Early investigations into hereditary health problems were conducted by the late Dr. H. Warner Kloepfer of Tulane University School of Medicine. Numerous investigators have followed in Dr. Kloepfer's footsteps, both in delineating new clinical syndromes and in documenting the genetics of the populations of Louisiana. The distribution of genetic traits and hereditary diseases across the state reflects the immigration patterns of past centuries as well as the unique geographic features that have served to isolate and distinguish various subpopulations. An appreciation of relevant historical developments related to genetic problems in Louisiana is fundamental to an understanding of current research programs and clinical services that are ongoing throughout the state.

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THE USE OF GENETIC INFORMATION FOR NONMEDICAL PURPOSES

MARK A. ROTHSTEIN[1]

I. INTRODUCTION

We have recently entered a great new age of genetics. The Human Genome Project, officially begun in 1990, is a fifteen-year, international research effort to map and sequence all of the human genome, including the estimated 100,000 human genes. As a result of this research, our knowledge of human genetics will expand exponentially, thereby promising to improve the quality of life and giving hope that even some of the most dreaded diseases can be cured. Nevertheless, as we accumulate vast amounts of genetic information on an individual and aggregate basis, there are legitimate concerns that this information could be misused.

My goal is to provide a broad overview of some of the ways in which genetic information may be used for nonmedical purposes. Before I get to this specific topic, however, I want to briefly note, for definitional reasons, the various medical uses of genetic information. These include diagnosis, reproductive planning, disease prevention, treatment, and research. These uses, of course, raise numerous legal and ethical issues, including informed consent, privacy,

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confidentiality, duty to warn, public health screening, and medical malpractice. These topics, however, are beyond the scope of this lecture.

When one thinks about the use of genetic information by third parties for nonmedical purposes, one of the first things that comes to mind is the question of how the third party can gain access to the information. There are three main ways. First, and most importantly, the third party may obtain records developed in the clinical setting. In other words, if someone wants a job or insurance, that person may be required to sign a release authorizing the third party to access those records. Second, the genetic records might be obtained through a genetic data bank. Third, the third party may actually perform genetic testing itself or ask questions that elicit genetic information indirectly through family histories.

I will address the following eight nonmedical uses of genetic information: (1) identification, (2) employment, (3) insurance, (4) commercial transactions, (5) domestic relations, (6) education, (7) criminal justice, and (8) tort litigation.

II. Specific Areas of Possible Use of Genetic Information

A. Identification

Although I am primarily concerned with the identification of specific human beings, I should note that DNA identification techniques may be useful in other areas as well. For example, recently in Japan DNA tests were performed on whale meat. The tests indicated that some of the whale meat being sold was from humpback whales, which are on the endangered species list. The authorities used the information to track down the individuals who were trafficking in illegal whale meat.

One of the most common uses of human genetic information is in criminal forensics (although I will have more to say about the nonforensic application of DNA technologies later). Essentially, criminal investigators use DNA evidence to determine whether samples from criminal suspects match biological evidence, such as blood on walkways outside condominiums, found at the scene of a crime. Seventeen states already mandate DNA profiling (loosely referred to as DNA fingerprinting) of all convicted felons. The FBI also has a growing DNA data bank. The proliferation of criminal databases raises concerns about privacy and confidentiality and whether in criminal investigations the police literally will "round up the usual suspects."

DNA identification techniques are also used in the identification of dead bodies. DNA samples of all military personnel are now taken for identification purposes. Indeed, the military DNA data banks were first used to identify human remains in the Gulf War. Privacy concerns, similar to those of law enforcement data banks, are raised in connection with these data banks primarily limiting who has access to the information. DNA testing is also utilized for identifying the victims of plane crashes.

Furthermore, DNA information determines parentage with much greater certainty than information from prior technology does. This information is important not only to paternity testing but to testing that already is used to reunite children with their parents or grandparents after being separated by war or political oppression.

Fourth, genetic identification methods may be used to determine heirship. Unlike blood-based tests, DNA testing may be performed on any available tissue. Therefore, DNA testing can be done posthumously, which raises interesting issues about heirship.

B. Employment

There are two main ways in which genetic information is useful to employers. Some genetic traits make individuals more susceptible to occupational diseases. For example, alpha-1-antitrypsin deficiency, the lack of a protective serum protein, greatly increases the risk of emphysema and other lung disorders. Employers might consider this risk factor in deciding which individuals to assign to work in dusty environments.

The more likely use of genetic information by employers, however, involves diseases unrelated to workplace exposures. Employers concerned with controlling escalating health care costs may be interested in knowing whether an individual is likely to contract a nonoccupational illness in the future. In any given year, five percent of health care claimants represent fifty percent of health care costs; ten percent of health care claimants represent seventy percent of health care costs. Consequently, if an employer could identify beforehand the people who were likely to become seriously ill and exclude these people (or their dependents), the employer could save a tremendous amount of money on health benefits.

The exclusion of current or potential employees because of concerns about future health costs raises serious legal questions. Nine states have enacted laws that specifically prohibit genetic discrimination in employment. Some of the laws are limited to particular genetic traits, while others define "genetic" more broadly. In my view, the enactment of specific genetic discrimination legislation is not the best way to proceed. Such legislation often fails to resolve fundamental problems, including the core issue of how to define "genetic." The most promising approach is to apply more general disability discrimination laws.

At the federal level, the Americans with Disabilities Act (ADA) applies to all employers with fifteen or more employees in the private as well as the public sector. Federal government employees, however, are excluded from coverage under the ADA, but they are protected under section 501 of the Rehabilitation Act. Under the ADA there is a three-part definition of an individual with a disability: 1) an individual with a physical or mental impairment that substantially limits one or more of the individual's major life activities; 2) an individual who has a record of such an impairment (e.g., someone who had cancer and is now in remission); or 3) an individual who is regarded as having such an impairment (e.g., an individual who has no impairment but who is perceived as having an impairment).

Individuals with expressed genetic illnesses are clearly covered under the ADA. The difficult questions are whether the ADA covers someone who is presymptomatic for a late onset genetic disease, someone who has a genetically increased risk of a multifactorial disorder such as cancer or heart disease, or someone who is the unaffected carrier of a recessive or X-linked disorder. In the latter situation, the individual will not be affected, but his or her offspring

may be and, as covered dependents under a health benefits plan, might have substantial future claims.

The ADA is silent on the issue of genetic conditions, and there is little authoritative discussion in the legislative history. It was not until March 1995 that the Equal Employment Opportunity Commission (EEOC) stated that individuals who are subject to discrimination in employment because of a genetic predisposition to disease are "regarded" as having a disability and therefore are covered under the third part of the definition of "individual with a disability."

Closely related to the permissible use of genetic information by employers is the issue of how employers gain access to genetic information. Aside from performing the tests themselves (currently not done for financial and other reasons and an unlikely prospect for the near term), there are two main ways. At the preemployment stage, before an offer of employment has been extended, employers are not permitted to make any inquiries about whether the individual has a disability or the nature and extent of any disabilities. At the "preplacement stage," however, after an employer makes an offer of employment conditioned on the individual undergoing a medical examination, the employer may require a medical examination of unlimited scope. These medical examinations need not be limited to assessing job-related physical or mental capacities.

At the same time, the conditional offerees also can be required to sign a release, authorizing their personal health care providers to disclose all of their medical records. These medical records, of course, could contain the results of genetic tests or other genetic information. The ADA provides that a conditional offer of employment may not be withdrawn based on medical information unless the medical information is job related and bears directly on whether the individual is able to perform essential job functions. Nevertheless, simply permitting access to the information will often make it extremely difficult to ensure that the information is not used.

The second way in which employers may obtain genetic information is through health insurance claims. Employer-provided health insurance is either purchased through a commercial insurer or Blue Cross/Blue Shield or through self-insurance. If an employer is self-insured, then the employer itself acts as the insurer, bearing the risks and paying the claims directly. When employees submit health insurance claims, the health care providers indicate a diagnosis or check a diagnostic code. In this way, the employer can learn the nature of the medical conditions for which the employee and any covered dependents are receiving treatment.

There are a variety of ways in which the employer may act on the basis of the health insurance claims data aside from the most drastic (and unlawful) step of discharging the employee. In fact, the employer does not even need to have the information in personally identifiable form to take action adverse to the employee's interests. For example, the employer's benefits department may determine that it is paying for a few very high cost diseases or procedures that, if eliminated from the employer's benefits package, would save thousands of dollars each year. Or the benefits department might determine that dependent coverage is costing a tremendous amount of money and should be discontinued.

Although state insurance laws frequently mandate that all policies written in the state cover certain medical conditions and limit the situations in which policies may be cancelled, self-insured employers are not subject to these laws. The federal Employee Retirement Income Security Act (ERISA) preempts these state insurance laws as to self-insured employers. Under ERISA, self-insured health benefit plans may be amended or discontinued altogether at any time, so long as the employer is not doing so as a subterfuge for disability discrimination (in violation of the ADA) and so long as the employer complies with the necessary notice provisions in the particular plan agreement it has drafted.

The impact of ERISA is important to consider. Most major employers in the United States are self-insured, including ninety percent of employers with 20,000 or more employees, eighty-two percent of employers with 5,000 or more employees, and over half of all employees. The problems raised by using health insurance claims data are not unique to genetic information. What is unique is the ability of employers to use genetic information to predict future health costs before claims are even filed.

C. Insurance

About eighty-five percent of Americans under age sixty-five are covered by health insurance of some kind. Of those who are covered, eighty-five to ninety percent are covered by group insurance. Of those people who have group insurance, about seventy percent obtain their group insurance through employment, either as the employee or as the dependent of an employee. That means that only ten to fifteen percent of insured individuals are covered under individual health insurance policies.

The central role of employers in our health insurance system arose by happenstance. During World War II, to prevent runaway wage inflation caused by labor shortages, wage and price controls were established. Because employees could not get wage increases, employers (frequently as a result of collective bargaining) provided employees with additional fringe benefits. The first fringe benefit at many companies was hospitalization coverage. Since World War II, the coverages have become increasingly comprehensive, increasingly generous (extending to dependents and retirees and covering physician visits, allied health services, eyeglasses, hearing aids, and other devices), and increasingly expensive.

Traditionally, medical underwriting was only used by insurance companies for individual insurance policies, the rationale being that, on the average, employees and their dependents were at least as healthy as the general population. Because the same can not be said of applicants for individual health insurance coverage, medical assessments of risk were used. This practice of medical underwriting, however, has recently spread into the small group insurance market. Many small employers with a high claims history or in perceived high risk industries or locations are unable to obtain health insurance at standard rates, if at all.

Medical underwriting for individual health insurance is driven by the principle of adverse selection. Individuals who know they are likely to need health insurance are the most likely ones to seek it. To prevent individuals from seeking health insurance based on medical information known only to the

applicant, insurance companies seek to have access to the same medical information as the individual. And this medical information includes genetic information. To prevent genetic-based discrimination in health insurance, twelve states have enacted legislation that specifically prohibits health insurance companies from using genetic information to exclude individuals from coverage.

Similar issues of adverse selection are raised in the context of life insurance. If someone knows that he is going to die in a year, one of the first things he might do is try to take out $10 million of life insurance at standard rates. If everyone could do this, life insurance companies would either go out of business or they would raise their rates so high that life insurance would be prohibitively expensive. Thus, avoiding adverse selection is considered key to the viability of life insurance.

Morally, is there a difference between health insurance and life insurance? I think few people would consider life insurance to be a necessity today, whereas I think most people would say that health insurance is. Yet, allowing any insurance company to obtain access to increasingly sophisticated genetic information could have extremely deleterious consequences to public health. Individuals at risk of genetic illnesses might forego genetic testing for fear of being denied insurance coverage.

In the Netherlands, life insurance companies have started a five-year experiment in which individuals are considered for life insurance policies up to 200,000 guilders (about $100,000) without *any* medical inquiries. One advantage of treating genetic risks the same as other medical risks is that it avoids the difficult problem of defining exactly what a genetic test or condition is. For example, is a simple blood test that reveals inherited hypercholesterolemia a genetic test? Although American insurance companies are vehemently opposed to issuing policies without medical underwriting, individual life insurance policies in very small amounts (typically $5,000) already are available without medical underwriting. Nevertheless, I am not aware of any studies which attempt to measure empirically the monetary level at which adverse selection pressures become unacceptably high.

D. Commercial Transactions

Forensics, employment, and insurance are the three areas that quickly come to mind in the use of genetic information for nonmedical purposes. The other five areas I am going to discuss are less commonly considered, but all of them could be significant.

If you think about it, any third party with an economic interest in the future health of an individual automatically has an interest in the individual's future health—and consequently his or her genetic profile. For example, if a person applies for a thirty-year mortgage, the mortgage company would certainly want to know if that person is going to be alive in thirty years. The same can be said of any commercial loan or various business ventures.

It seems to me that it may only be a matter of time before commercial entities demand access to genetic information. Currently, there are no legal limitations on the ability of lenders or other commercial entities to require or use medical, including genetic, information. Even though this is not common practice today, there is little basis for assuming that it will not take place in the future.

E. Domestic Relations

There are three ways in which genetic information could be used in domestic relations. The first involves premarital genetic assessment of the partners, especially with regard to recessive disorders. Although this directly relates to reproductive planning, which I said at the outset would be beyond the scope of this talk, I would like to mention just one example. In New York City, Orthodox Jews have established a program called Dor Yeshorim. Each unmarried young person undergoes genetic testing for Tay Sachs disease, Canavan disease, and Gaucher's disease, but they are not told of the result. They are merely given a code number. When a couple is proposed to marry (often through arranged marriages), the central registry is called and told the two numbers. The registry then indicates whether the proposed match would be a "good" one or not. The number of rich ethical issues raised by screening programs such as this one are evident.

A second area of domestic relations that could be affected by genetic information is child custody disputes. The following example was related to me by my colleague, Professor Lori B. Andrews of the Chicago-Kent College of Law. In April 1994, a South Carolina divorce lawyer was approached by a client with a troubling request. There was a custody battle over the client's daughter, and the client wanted his ex-wife to be tested for the Huntington's disease gene. Because the ex-wife's mother had died of Huntington's disease, the ex-wife was at a fifty percent risk of developing this invariably fatal, late-onset, dominant neurological disorder. If she tested positive for the Huntington's gene, then the ex-husband was going to argue that his ex-wife should not be granted custody of their child because she would be unable to care for the child after she developed symptoms.

Interestingly, the ex-husband's lawyer was a former genetic counselor, and she realized that getting a court order requiring genetic testing was not necessarily the best thing to do. She knew that most people who are at risk for Huntington's disease do not elect to be tested for both economic (fear of losing employment and insurance) and psychological reasons. The lawyer also was concerned about her own potential liability if, on her motion, the ex-wife were tested, found out she had the Huntington's gene, and then jumped off a bridge. To make a long story short, the motion to compel testing was filed, and it was granted by the court. But the mother fled the jurisdiction with the child before the testing took place.

In other cases, it may be that a parent will come into court after voluntarily being tested. He or she might argue that, having gotten a "clean" bill of genetic health, this fact should be considered by the court. Courts consider various factors in determining what is in the best interest of the child, including the health of the parents and whether one parent smokes. It is quite possible that genetic information also might be considered.

Genetic information also could be of great interest in adoption proceedings. Each of the interested parties in an adoption—the biological parents, the child, and the adoptive parents—might be subject to genetic testing. Twenty-two states already require genetic and other available medical information from biological parents to predict the health risks of the child. As direct DNA testing becomes available for more genetic conditions, parental testing will be

unnecessary because the child can be tested directly. Eight states currently require genetic information about an adoptive child, and forty-nine out of the fifty states (Nevada being the exception) require more general health and medical information about the child without specifically mentioning genetic information.

What happens when the child being placed for adoption tests positive for a genetic disorder? Is it moral or should it be legal for adopting parents to say, in effect, we are no longer interested in adopting this child because the child is going to develop a certain disease in the future? Is there some minimum standard of genetic merchantability for adoptive children, or is this making children into commodities? Although there is a natural inclination to say that children are adopted on an "as is" basis, I suggest that the issue is more complicated than it might appear.

Suppose that a couple is about to adopt a child and the adoption agency says that the child to be adopted has the gene for Tay Sachs disease and is going to die around age two after a very terrible, painful, miserable existence. Does the couple have to go through with the adoption? Suppose the reason the couple was adopting a child is that they already had a child die of Tay Sachs disease? Is it unreasonable or morally repugnant for the couple to say that they could not handle adopting this child?

On the other hand, suppose that the child carried the gene for a late-onset disorder, such as Huntington's disease, which is fatal, but has a median age of onset of forty, or Alzheimer's disease, which would not manifest until even later in life? Suppose it is a treatable disorder, such as hemochromatosis? Or suppose the child merely has a genetic predisposition to cancer or heart disease? It seems to me that it may be very difficult to draw the lines for legal regulation of genetic testing in adoption.

The theory of testing adoptive parents, which is also a possibility, is similar to the one I raised earlier with regard to child custody. That is, a late-onset disorder would interfere with the ability to be a good parent. The courts have upheld considering the adoptive parent's age, and they have upheld considering the health status of adoptive parents. Why not also consider the likely future health of adoptive parents by looking into their genetic profile.

F. Education

Genetic information could be used at every stage of education, from preschool to graduate school. As to younger children, genetic testing may be used to identify children with a genetic trait or predisposition to learning disabilities, such as dyslexia. Based on genotype alone, children might be placed in certain educational tracks before they have had a chance to demonstrate their ability or their motivation, making those tracks self-fulfilling prophecies for the child.

Fragile X syndrome is named for the unusual constriction of the X chromosome. It is one of the most common monogenic forms of mental retardation. It is an X-linked disorder with a prevalence of one in 2,000 males and a carrier prevalence of one in 1,000 females. About one-third of carrier females show some milder form of mental retardation even though they will not be affected severely. Despite great concerns in the genetics community,

fragile X screening programs supported by commercial interests are already under way in schools in Colorado and Georgia.

Genetic information also may be used at higher levels in the educational process. Dr. Nancy Wexler, a well-known clinical psychologist and genetics researcher, tells the story of a mother who brought her two at-risk teenage children to a medical center to be tested for the Huntington's disease gene. It is unusual to perform genetic testing on minor children for late-onset disorders. Because Huntington's disease is a dominant disorder, each child had a fifty percent risk, although of these two children neither or both of them could have been affected. The mother said she wanted her children tested because she could only afford to send one of them to college.

These same sort of difficult dilemmas also could arise in professional schools. For example, medical schools make major investments in their students. As a society, we do not begin to recoup the cost of paying for medical education until the individual has completed training and has been practicing for a number of years. Would it be legal or ethical for a medical school to refuse to admit a student who already had amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig's disease), where the mean survival after diagnosis is only two to five years? If denying admission to such an individual would not be unreasonable, what about denying admission to an individual who was presymptomatic for ALS and was likely to develop the disease within ten years? What about other late-onset disorders, such as myotonic dystrophy? When, if at all, would it be acceptable to use genetic information as a basis for admissions, internships, residency placements, or other aspects of medical education?

G. Criminal Justice

I have already discussed the forensic use of DNA evidence for identification. There are two other, less well-analyzed, areas of criminal justice in which genetic information also may be relevant. The first is the use of a defendant's genotype as a defense. The attempt to use the XYY defense, which began in the 1960's, presents an historical precedent. The theory that men with an extra Y chromosome are predisposed to violent or criminal behavior has now been thoroughly discredited. More recently, however, other types of genetic information have been proffered to bolster an insanity defense in much the same way that evidence of organic brain disease is used today.

The second possible application of genetic information is in parole hearings. Suppose that, at some point, geneticists are able to identify genetic factors that predispose an individual to violent behavior. Would it be permissible for a parole board to consider this information in assessing the individual's likelihood of recidivism? Thus, the use of genetic information in this context would raise a number of constitutional issues.

H. Tort Litigation

With new genetic discoveries being introduced into the clinical setting, the standard of care in medicine will continue to change. Consequently, there are likely to be a greater number of medical malpractice, wrongful life, wrongful

birth, and other causes of action based on genetic medicine. There are other ways, however, in which genetic information may affect tort law.

The first involves the proof of causation. For example, a case was filed in California in 1990 on behalf of a child who was born with microcephaly, an abnormally small head. He also had severe mental retardation and an IQ of 40. The child's mother alleged that the child's birth defects were caused by her prenatal workplace exposure to chemicals at the defendant's plant. Consequently, a products liability action was brought seeking $5.6 million in damages against the mother's employer as well as several manufacturers of the chemicals to which she was exposed.

The defendants' experts asserted that the child's symptoms seemed to be remarkably similar to those of a child with fragile X syndrome, and they filed a motion to require the child to undergo genetic testing. The court ordered the genetic testing over the objection of the plaintiff. This example illustrates how genetic information could be relevant to the issue of causation in personal injury cases.

Another possible use of genetic information involves damages. Suppose, as a result of the defendant's negligence, a thirty year-old man with a $100,000 a year income is run over while crossing the street and rendered totally disabled. The starting point in assessing compensatory damages is lost income. In this case, if the plaintiff had a work-life expectancy of forty years, then the damages for lost income would be $4 million, exclusive of possible salary increases and inflation. Now suppose that, because of some genetic trait, the defendant could show that the plaintiff would not live to age seventy but could only be expected to live to age forty. From the defendant's standpoint, this is a bonanza and results in savings of at least $3 million. The potential magnitude of these savings raises the issue of whether defendants might be tempted to engage in genetic "fishing expeditions" in all personal injury actions where the damages include future lost earnings or medical expenses. It is an open question, however, whether genetic testing could be ordered during discovery or whether certain genetic evidence, such as an increased risk of a multifactorial disorder, would be admissible.

III. Ethical and Policy Considerations

It is evident that the use of genetic information for nonmedical purposes raises a variety of fascinating legal issues. In trying to resolve these issues it may be valuable to formulate a series of broad ethical and policy principles for guidance.

First, I would strongly suggest that we should not adopt any policies that discourage at-risk people who want to undergo genetic testing from doing so for fear of the nonmedical use of the information. It is already commonplace for some people to forego genetic testing that they would prefer to have because they are afraid that their employer or their insurance company will gain access to the results. Other people pay in cash for genetic services or try to be tested anonymously or without medical records being kept.

Second, we do not want to adopt policies that coerce people who do not want to be tested into being tested. Genetic testing often creates great psychological, personal, and social turmoil. People vary widely in whether they want to know

about their likely future health. We should adopt policies that respect this important aspect of individual autonomy.

Third, I think there is a great danger in misinterpretation of genetic information by lay people. This concern applies to both single gene and multifactorial disorders. Modern genetic concepts such as variable penetrance, variable expressivity, latency, imprinting, and allelic expansion are difficult to understand. Lay people should not be put in the position of making important decisions affecting individuals based on genetic concepts that they do not fully comprehend.

Fourth, there is a paramount individual privacy interest in genetic information. There must be compelling reasons to require individuals to share such innately personal information, and in the nonmedical context this may be a difficult burden to meet.

Fifth, the confidentiality of genetic information must be maintained. Before any genetic information is acquired, it should be clear as to whom the information may be redisclosed. It has yet to be determined what rights individuals have to keep genetic information confidential.

Sixth, we should act to preserve the quality of genetic testing and counseling. Third parties using genetic information in the nonmedical setting do not have the same interest in quality assurance as the individual being tested. By applying less rigorous standards of genetic testing, or failing to provide appropriate genetic counseling, there is a risk of both laboratory error and great psychological harm.

Seventh, we should act to conserve medical resources. There are a finite number of geneticists, genetic counselors, and genetic laboratories. There is also a limited amount of money that reasonably should be spent on genetic testing. Genetic resources should be allocated with the primary goal of improving health rather than for various nonmedical purposes.

Eighth, we should be careful not to waste human resources. For example, society loses when an individual currently in good health is rendered unemployable because a genetic test indicates a risk of future health problems. It is also unjust to base decisions allocating essential societal opportunities on immutable biological characteristics. Merely drawing lines based on genes creates a danger of stigmatization -- both on an intrafamilial and a societal basis. Similarly, genetic discrimination would often be multigenerational and would often fall along racial or ethnic lines.

Finally, the use of genetic information in nonmedical settings creates great risks of unintended societal consequences. These include reductionism and determinism, loss of equality of opportunity, and altered conceptions of normality. Reductionism and determinism, as well as the other concepts, relate to the question of what kind of society we are going to have when this tidal wave of genetic information washes over us. Will we become a society of risk takers who figure that we might as well start sky diving and alligator wrestling? Or will we become a society of the paranoid, "worried well," who think that every cough is the first sign of lung cancer?

IV. CONCLUSION

As I mentioned at the outset, the use of genetic information for *medical* purposes raises enough profoundly difficult moral and legal issues. I think we should be very careful before sanctioning the use of genetic information for nonmedical purposes for the reasons I suggested and, perhaps more importantly, for the numerous other reasons that we have yet to realize.

Submitted By:
Mark Rothstein, Esq, Director
Health Law and Policy Institute
University of Houston Law Center

The Human Genome Project: Implications for Indian Tribes

The Human Genome Project (Project), an international undertaking to find the location of every one of the 100,000 or so genes in human chromosomes, will have an impact on the indigenous peoples or Indian tribes of the United States. Many native people, however, consider the blood and tissue sampling which will be a prominent part of the project, a tinkering with life and a direct threat to tribal peoples, tribal sovereignty and life itself.

The Project raises many ethical, legal, social, scientific, and international policy questions, many of which are unanswered. For example, some basic questions are: Can anyone "own" the human genome? If yes, who precisely is the owner? Can scientists and companies have property claims to particular genes or certain sequences of genes? Is the human genome the property of humankind or a community with similar genetic makeup? Or is the human genome a gift? If one "owns" their genetic material and genetic information, can the person transfer, barter, and sell that material? What controls are there in the area of genetic research and wholesale use of genetic materials? These questions and others are before us as we move into the next century.

Many people are enthused by the recent advances in molecular genetics and biomedical research, which could have enormous benefits to humankind. At the same time, many people are deeply concerned by the ethical and religious problems raised by the new medical possibilities. Critics worldwide have pointed out that it is totally inappropriate and unacceptable to take out any patents on and in some sense "own" the basic genetic materials of someone else's life. Even if the Project does not seek to patent any genetic material, there still remains the very basic conflict between indigenous peoples' and the Project's world views of the origins of life and humanity, and the role and responsibility of sacredness. The heart of the differences relates to defining a human gene, its purpose, and who might be considered the "owner". In short, the Project is based upon a societal world view that is not representative not includes tribal communities.

The Project has many implications for tribal communities in the United States, including issues relating to tribal sovereignty, intellectual property rights and patenting, and access to databases. In many ways, Tribal communities view the appropriation of tribal genetic samples through the Project as no different than the appropriation of tribal lands, resources, and culture which took place over the past five hundred years on this hemisphere. Gene prospecting is simply one of the "last frontiers" in Indian communities in which western science is again seeking answers to its questions and theories.

Submitted By:
Jeannette Wolfley, Esq
Law Offices of Jeanette Wolfley

The Biological Revolution: Genomics and its Challenge for Minority Education.

Abstract. It never occurred to me as a graduate student that I would live through a real scientific revolution. But in the past 10 years, a profound change in the level of scientific inquiry has led to a revolution in biology. As technology development allowed scientists to begin to know the entire DNA sequence or organisms, a completely new level of organization has become available for research. Instead of thinking about one gene or one protein, scientists can now begin to understand how the entire cell responds to its environment at the level of gene expression. Instead of imagining the different organisms in any square foot of soil or water, we can identify completely unknown organisms and begin to understand ho they live.

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 sociologist, educators, and political scientists. The potential financial value of discoveries in this area has led to more interactions with industry and the law. Thus, genomics can be viewed as a thread - a revolutionary thread that is connecting the patches of our academic quilt more firmly tan 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 an be counted 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 as changes it will take to enable a student form a predominantly minority or rural school to be able to choose 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 in 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 our world, to protect and enhance it, ourselves, and our cultures, and to bring 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 form your community and all of our communities can take advantage of the moment for us, themselves, and their children?

Submitted By:
Dr. Margaret C. Werner-Washburne, Program Director
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Michelle B. Boissiere, Ph.D. is a lifelong resident of New Orleans. After graduating from St. Mary's Academy High School, she entered Xavier University of Louisiana, where she received the Bachelor of Science degree in Biology in 1986. Her graduate studies were pursued in the Department of Biology at Tulane University. She received the Master of Science in 1989, and the Doctor of Philosophy in May 1994. Her dissertation research focused on the role of membrane character in human sperm function. The research was conducted in association with the Department of Urology at Tulane University School of Medicine.

Dr. Boissiere has been a a full time faculty member at her undergraduate alma mater, Xavier University, since January of 1994. Her primary teaching responsibilities include Genetics Lecture and Laboratory, and Embryology Laboratory. Additionally, she serves a s a student research mentor, she is the advisor to many student organizations, and she serves on several university committees. During the summer, she serves as the Director of BIOSTAR, a summer program for high school students who are preparing to take their first biology course.

Dr. Boissiere's research has been presented at national and international meetings, and published in referred journals. One of her papers, "Effect of sodium nitroprusside on human sperm lipid peroxidation and functional parameters," was a finalist in the 1993 Prize Paper in Male Reproduction Competition from the American Fertility Society.

Presently, Dr. Boissiere is a member of a multidisciplinary research community which is examining the interface of science and theology in alternative medicine practices. Additionally, a reproductive biology research collaboration with Tulane University School of Medicine is currently being planned.

Dr. Boissiere has given presentations on Xavier University's Pre-Medical Programs at several other institutions and national meetings, including the American Association of Colleges and Universities Symposium on Undergraduate Science Education. She regularly speaks at Career Day Activities and serves as a science contest judge for local high schools. She is an active member of her church, and is presently the vice-president of the parish pastoral council.

Sharon Davis, Ph.D. is the Director of the Department of Research and Program Services for the Arc, a national organization on mental retardation. She directs and supervises department staff in the oepration of projects and conducts other activities to implement The Arc's strategic plan activities related to inclusion and choice and prevention of mental retardation. Prior to joining The Arc in 1984, Dr. Davis worked for several agencies in the Washington, D.C. area, including the American Coalition of Citizens with Disabilities, The Council for Exceptional Children and Rehab Group, Inc. where she directed federally funded projects focusing on concerns of people with disabilities. She also served a 14 month internship in the Bureau of Education for the Handicapped, U.S. Office of Education. Dr. Davis received her Ph.D. in Education from Cornell University. She recently completed work as principal investigator on The Arc's Human Genome Education Project funded by the Department of Energy.

Rosalind Pijeaux Hale, New Orleans, Louisiana: Chair and Associate Professor, Division of Education, Xavier University of Louisiana. Current research interests include urban m;iddle school education and women in education in educational leadership. Nearly twenty-nine years in education. Former middle school principal, high school assistant principal, instructional specialist, computer trainer and mathematics and science teacher. In higher education for the last eight years focusing on educational leadership issues and multicultural education. Has made presentations and served as a consultant on issues related to educating disadvantaged youth, school leadership and effective teaching. Ed. D. in educational leadership, Auburn University.

Keith T. Hill, Esq. is Regional Attorney for the Equal Employment Opportunity commission, New Orleans District Office. He received his B.A. in 1975 from Xavier University of Louisiana, and a Juris Doctorate Degree in 1981 from Antioch School of Law in Washington, D.C.
Prior to attending law school, he was employed as the Director of Housing Improvement Services for Refugee Assistance Programs for the Associated Catholic Charities of the Archdiocese of New Orleans.

During law school, he served as a law clerk for the Executive Office of President Jimmy Carter's Council on Wage and price Stability, and for the United States Department of Housing and Urban Development in Washington, D.C.

After graduating from law school, He served as a staff attorney for the Lawyers' Committee for Civil Rights Under Law. In 1982, he began working for Equal Employment Opportunity Commission Office of Review and Appeals in Washington, D.C. He joined the New Orleans District Office of the Equal Employment Opportunity Commission in 1983 as a trial attorney. Mr. Hill was appointed Supervisory Trial Attorney in 1986, and has served as Regional Attorney since 1988. He is a member of the District of Columbia Bar Association.

Issie L. Shelton Jenkins, Esq. is an attorney and a partner in the Shelton Group, a consulting firm located in the Washington, D.C. area. She is also a member of Zeta Phi Beta Sorority, Inc., and the Chairperson of the Zeta Phi Beta Sorority National Educational Foundation, sponsors of this conference. She is a native of Louisiana.

Ms. Jenkins has been active in the community and in civil rights issues involving minorities. She has served in a number of legal and management positions at the United States Equal Employment Opportunity Commission, including Deputy General Counsel of the Equal Employment Opportunity commission, and as the Commission's Executive Director. In those positions she had responsiblity for the legal enformcement of Title VII of the Civil Rights Act of 1964, prohibiting employment discrimination, and the Americans With Disabilities Act. She served as Chairperson of the Federal Bar Association's Council on Community Affairs. She has chaired a number of Foundation community education programs.

Ms. Jenkins received an A.B. Degree fom Indiana University, a Juris Doctorate Degree from Boston University School of law, and a LL.M. Degree from George Washington University.

Her research has included papers on age discrimination in employment against older women. She is the author of several articles on Employment discrimination and civil trial practice, including "*Effective Discovery Techniques Under the Federal Rules of Civil Procedure: Depositions*" PBI Institute, 1986; and "*Employment Discrimination Cases: Trial Strategy for Claimants*" ALI-ABA, 1984.

Betty Mansfield, M.S. In 1989, Ms. Mansfield became founding editor of the Department of Energy sponsored newsletter Human Genome News and Task Leader of the Human Genome Management Information System (HGMIS) at ORNL.HGMIS is dedicated to communication about the Human Genome Project. Ms. Mansfield was the 1997 recipient of the Exceptional Service Award from the DOE Biological and Environmental Re search Program for her work "for Exploring Genomes.

Johnathan Marks is currently Visiting Associate Professor of Anthropology at the University of California at Berkeley. Before that, he taught at Yale University, and held appointments in both the anthropology and biology departments there.

Professor Marks has spent his adult life vacillating between the natural and social sciences: After taking an undergraduate degree in science at Johns Hopkins and a Master's in genetics at the University of Arizona, he took a Master's and doctorate in anthropology at Arizona, then carried out post-doctoral work in genetics at California-Davis, before coming back to anthropology at Yale. His primary area of research is molecular anthropology – the application of genetic date to illuminate our place in the natural order—or more broadly, the area of overlap between (scientific) genetic data and (humanistic) self-comprehension. Nevertheless, his interests are wide-ranging across evolutionary theory, history, human genetics, and sociology and philosophy of science. His research has been published in scientific and scholarly journals ranging from *Nature* through the *Journal of Human Evolution to History and Philosophy of the Life Sciences*. He is the co-author of *Evolutionary Anthropology* (Harcourt, Brace, Jovanovich, 1993), and author of *Human Biodiversity* (Aldine de Gruy, 1995).

He is President-elect of the General Anthropology Division of the American Anthropological Association.

Karen E. Nelson is an Assistant Investigator in The Department of Prokaryotic Genomics at the Institute for Genomic Research in Rockville, Maryland. She is the Project Leader on the Whole Genome Sequencing Project on Thermotoga maritima, and Pseuidomonas putida which are environmental organisms being used as models for understanding genomic information.

Dr. Nelson received her Ph.D. in Animal Science and Microbiology from Cornell University in 1996, and her Master of Science Degree from the University of Florida. She has a Bachelor of Science Degree from the University of the West Indies in Trinidad and Tobago.

Mary Z. Pelias joined the faculty of the L.S.U. Medical Center in 1976 and is now Professor of Genetics in the Department of Biometry and Genetics. She is certified as a Ph.D. Medical Geneticist by the American Board of Medical Genetics and is a Founding Fellow of the American College of Medical Genetics. She is also a recent recipient of a Congressional Science and Engineering Fellowship, sponsored by the American Association for the Advancement of Science, the American Society of Human Genetics, and the United Stated Department of Energy.

Since 1980 Dr. Pelias has pusued the search for the gene that causes a severe form of deaf-blindness in many families in southwestern Louisiana, and she has documented the hereditary nature of several other clinal syndromes. In addition to a continuing interest in clinical genetics, here more recent research interests focus on legal and ethical issues related tot he new genetic technologies, particularly questions of personl autonomy and privacy of genetic information.

Dr. Pelias is a native of New Orleans and has a long interest in the history and culture of southern Louisiana. She has studied at Germany and has traveled extensively.

Mark A. Rothstein, Esq. is the Hugh Roy and Lillie Cranz Cullen Distinguished Professor of law and Director of the Health Law and Policy Institute at the University of Houston. He received his undergraduate degree from the University of Pittsburgh and his law degree from Georgetown University. Under his direction since 1986, the Health Law and Policy Institute has become the nation's premiere program for the study of health law, policy, and ethics.

Professor Rothstein is a leading authority on the ethical, legal, and social implications of genetic information. He has served as an advisor to the NIH, CDC, DOE, U..S. Congress, Institute of Medicine, National Conference of State Legislatures, and numerous other public entities.

He is the author or editor of 12 books and over 100 articles. His most recent book, "Behavioral Genetics: The Clash of Culture and Biology," co-edited with Ronald Carson, will be published by Johns Hopkins University Press in the spring of 1999. In 1999 he received the Public Health Hero Award from the University of California-Berkeley School of Public Health.

Dr. Todd Stanislav is an Associate Professor of Biology and the Director of the Center for the Advancement of Teaching at Xavier University of Louisiana. He received his Ph.D. in Cytogenetics in 1992 from the University of Kansas; he joined Xavier's faculty that same year. His research interest are in speciation and evolution, especially the evolutionary consequences of hybridization and introgression. Additionally, Dr. Stanislav investigated aspects of chromosome evolution, and chromosome synapsis and genetic recombination. As a member of Xavier's Biology Department, he principally teaches Genetics, Human Cytogenetics, and Botany.

As Director of Xavier's Center for the Advancement of Teaching, He is responsible for the day-to-day activities in the Center, as well as the management of two faculty development grants—one from the Bush Foundation and one from the Andrew W. Mellon Foundation.

Maggie Werner-Washburne spent her first 18 years in southeast Iowa in a town on the Mississippi River. Her mother, Marta Lucia Brown y Morales, was born in Mexico, moved to Iowa with her family during the Mexican Revolution, and was a social activist all her life. Dr. Warner-Washburne did her undergraduate work at Stanford, graduating with a B.A. in English. In the five years prior to entering graduate school, she lived in Mexico, Central and south America, Alaska, and Minnesota. During this time she became interested in ethnobotany- or the traditional use of plants for food, clothing, and medicine. She completed an M.S. in botany at the University of Wisconsin- Madison in 1984. After Completing her post doctoral work in yeast molecular genetics, she and her family (husband Bruce and two sons) moved to Albuquerque, NM, where she is now an associate professor of Biology.

Over the past 11 years, she has mentored 33 undergraduates, 4 Ph.D. student, two masters students, and 4 postdoctoral students. Of these, 28 have been minorities, including 9 Native Americans and 3 African Americans. She has served on committees for several national science organizations, including the board of directors of SACNAS (The Society for the Advancement of Chicanos/Latinos and Native Americans in the Sciences). She has always taken a rainbow coalition of students to SACNAS meetings, because she believes that it is critical for students to know how to interact with and lead us all. Last year, with the support of NSF, PBS, and Los Alamos National Laboratories, a video about her research entitled "The Mystery of an Ancient Gene" was completed and broadcast nationally.

Over the past 11 years, Dr. Werner-Washburne has been associated with the *Neurospora* Genome Project, an undergraduate training program funded by NSF to introduce students to the area of genomics. Her laboratory works on understanding stationary phase in the yeast *Sacchromyces cerevisiae* and she is moving into the area on genomic technology development. She is currently a visiting program director in Microbial Genetics at the National Science Foundation in Arlington, VA.

Jeanette Wolfley is an enrolled member of the Shoshone-Bannock Tribes of the Fort Hall Reservation, Idaho. Since 1996, she has been in private law practice involving federal litigation, federal Indian law, natural and cultural resources protection and preservation, and environmental matters on behalf of tribal governments, tribal corporation and individual Indians.

Ms. Wolfley served as General Counsel for the shoshone-Bannock Tribes for eight years. Prior to her general counsel work she worked with the Native American Rights Fund in Boulder, Colorado where she served as Staff Attorney and Deputy Director for six years.

Ms. Wolfley has a wealth of experience in the field of Indian law. She has published many law articles relating to tribal juridiction, gaming, taxation, voting, nuclear waste and air quality, and presented practiced before numerous administrative, tribal, federal and state courts. In addition to her legal work, Ms. Wolfley is an Adjunct Associate Professor at Idaho State University teaching upper division courses in the Indian Studies Program including Tribal Government, Federal Indian Law, Current Issues in Indian Country, and a Senior Seminar.

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Xavier University of Louisiana is Catholic and historically Black. The ultimate purpose of the University is the promotion of a more just and humane society. To this end, Xavier prepares its students to assume roles of leadership and service in society. This preparation takes place in a pluralistic teaching and learning environment that incorporates all relevant educational means, including research and community service.

The Division of Education received accreditation by the national Council for Accreditation of Teacher Education (NCATE) in March 1998 which signifies that the graduate will have been prepared according to accepted national standards of excellence and that the programs meet high standards in areas including program design, delivery, and quality of faculty. The accreditation standards are performance oriented and are compatible with new, more rigorous emerging state licensing expectations in many states. Xavier is the first private college in Louisiana to receive this prestigious rating.

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ACKNOWLEDGEMENTS

The organizers of the conference are grateful for the assistance of the following persons:

Pat Arnould, Louisiana Governor's Office of Indian Affairs

Patricia Bivens, District Director, EEOC

Sharlena Black, Xavier University of Louisiana

Dr. Barbara Carpenter, Southern Unviersity

Joanne Cochran, U.S. Department of Energy

Dr. Daniel Drell, U.S. Department of Energy

Dr. Martha Krebs, U. S. Department of Energy

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Mary Sayles, Xavier University of Louisiana

Dr. Margaret Werner-Washburne, National Science Foundation

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Zeta Phi Beta Sorority National Educational Foundation

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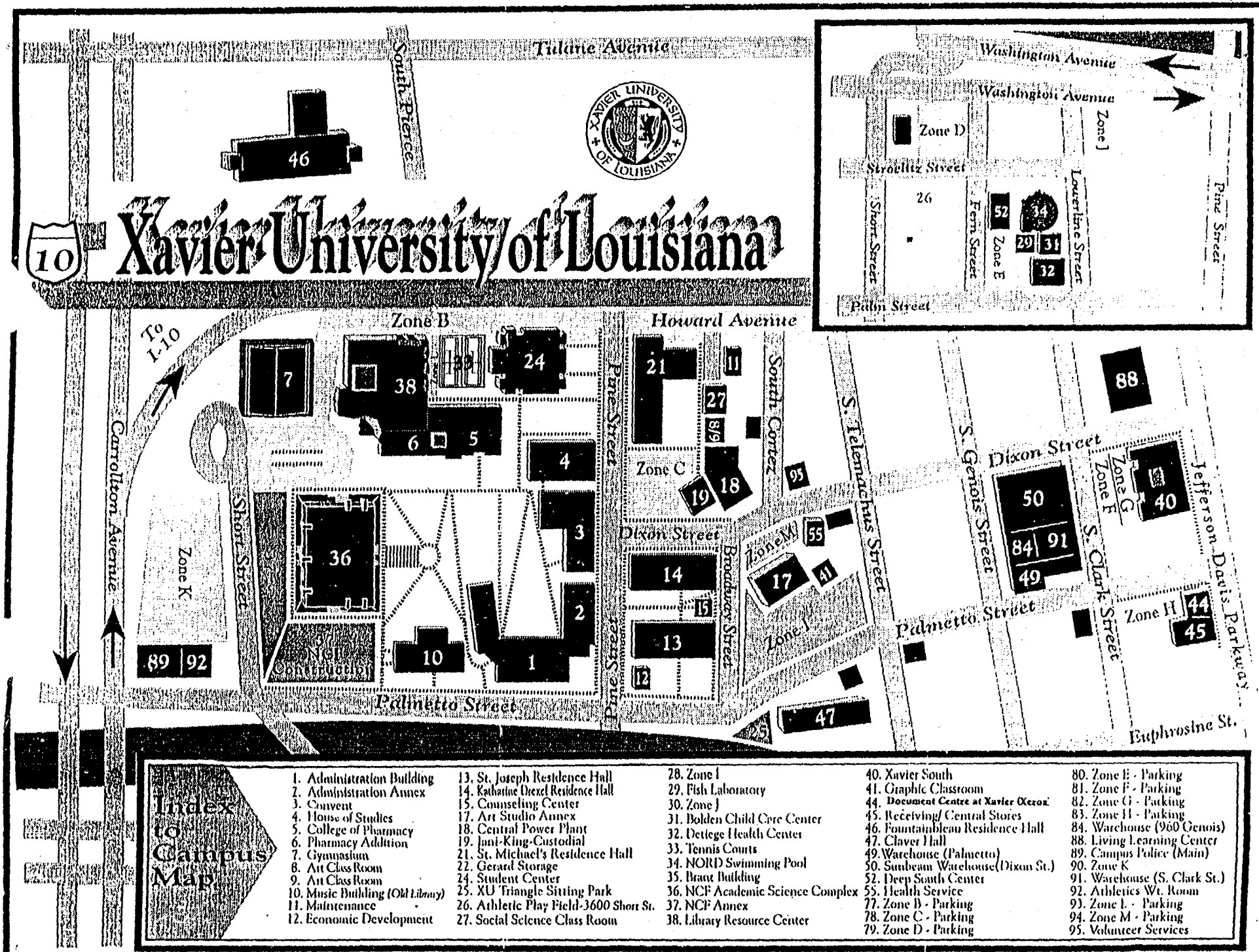
Conference supported by grant from:

The U. S. Department of Energy



Index to Campus Map

1. Administration Building
2. Administration Annex
3. Convent
4. House of Studies
5. College of Pharmacy
6. Pharmacy Addition
7. Gymnasium
8. Art Class Room
9. Art Class Room
10. Music Building *(Old Library)*
11. Maintenance
12. Economic Development
13. St. Joseph Residence Hall
14. Katharine Drexel Residence Hall
15. Counseling Center
17. Art Studio Annex
18. Central Power Plant
19. Jani-King-Custodial
21. St. Michael's Residence Hall
22. Gerard Storage
24. Student Center
25. XU Triangle Sitting Park
26. Athletic Play Field-3600 Short St.
27. Social Science Class Room
28. Zone I
29. Fish Laboratory
30. Zone J
31. Bolden Child Care Center
32. Dettlege Health Center
33. Tennis Courts
34. NORD Swimming Pool
35. Brant Building
36. NCF Academic Science Complex
37. NCF Annex
38. Library Resource Center
40. Xavier South
41. Graphic Classroom
44. **Document Centre at Xavier (Xerox)**
45. Receiving/ Central Stores
46. Fountainbleau Residence Hall
47. Claver Hall
49. Warehouse (Palmetto)
50. Sunbeam Warehouse(Dixon St.)
52. Deep South Center
55. Health Service
77. Zone D - Parking
78. Zone C - Parking
79. Zone D - Parking
80. Zone E - Parking
81. Zone F - Parking
82. Zone G - Parking
83. Zone H - Parking
84. Warehouse (960 Genois)
88. Living Learning Center
89. Campus Police (Main)
90. Zone K
91. Warehouse (S. Clark St.)
92. Athletics Wt. Room
93. Zone L - Parking
94. Zone M - Parking
95. Volunteer Services

HUMAN GENOME PROJECT CONFERENCE

Sponsored by

Zeta Phi Beta Sorority, Inc./
National Educational Foundation
U.S. Department of Energy
Xavier University
New Orleans, Louisiana

APRIL 16-17, 1999

CONFERENCE EVALUATION SUMMARY

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17 Evaluation Forms Returned
17 participants responded as follows:

1. How successful do you think the conference was in imparting useful information to members of your group?

   76%-Very Successful 24%-Somewhat Successful

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   71%-Very Relevant 29%-Somewhat Relevant

3. How much did you learn about the following aspects of the Human Genome Project?

   1=A Great Deal 2=A Little 3=Not Very Much
   4=Nothing At All 5=Don't Know

   a. The science being done in the HGP

      47%-Great Deal 47%-A Little
      6%-Not Very Much

   b. Legal inplications of the HGP

      41%-Great Deal 47%-A Little
      6%-No Answer

   c. Ethical implications of the HGP

      59%-Great Deal 35%-A Little
      6%-Not Very Much

   d. Social implications of the HGP

      53%-Great Deal 41%-A Little
      6%-Not Very Much

   e. Potential benefits of the HGP for minority groups or communities

      59%-Great Deal 35%-A Little
      6%-Not Very Much

   f. Potential harmful efforts of the HGP for minority groups or communities

      76%-Great Deal 12%-A Little
      12%-Not Very Much

   g. Others

      (1) Opportunities in HGP for minorities Great Deal

(2) Careers	Great Deal
(3) Job/Educational Opportunities	Great Deal

4. Based on what you learned about the HGP at this conference, do you think that the benefits of the HGP will be greater than its harmful effects, or that the harmful effects of the HGP will be greater than its benefits for members of your racial/ethnic community or group?

Benefits will be greater	53.0%
Harmful effects will be greater	23.5%
Don't Know	23.5%

5. If members of your racial/ethnic community or group had the same information about the HGP as you have gained from this conference, do you think they would believe that the benefits of the HGP will be greater than its harmful effects, or that the harmful effects of the HGP will be greater than its benefits?

Benefits will be greater	47%
Harmful effects will be greater	35%
Don't Know	18%

6. Based on what you learned about the HGP and its implications at this conference, how much do you think members of your racial/ethnic community or group should be concerned about each of the following?

1=Very Concerned 2=Somewhat Concerned
3=Not Very Concerned 4=Not At All Concerned
5=Don't Know

(1) Availability of genetic information to insurance.
Very Concerned-82% Somewhat Concerned-18%

(2) Availability of genetic information to employers.
Very Concerned-88% Somewhat Concerned-12%

(3) Use of genetic information to justify ethnic stereotypes.
Very Concerned-88% Somewhat Concerned-12%

(4) Use of genetic information in family planning decisions.
Very Concerned-53% Somewhat Concerned-47%

(5) Availability of the benefits of genetic research only to privileged groups of people.
Very Concerned-88% Somewhat Concerned-6% Not Very Concerned-6%

(6) Use of genetic information to help design programs for alleviating crime, alcoholism or poverty.
Very Concerned-88% Somewhat Concerned-6% Not Very Concerned-6%

(7) Diverting resources from basic medical care to genetic research.
Very Concerned-59% Somewhat Concerned-35% Not Very Concerned-6%

(8) Other,please specify. No Response

7. In your opinion, what was the most useful feature of this conference?

   (a) The wealth of information given, and the diversity and availability of the speakers/ panelists! 6 Responses

   (b) Genetic research in the State of Louisiana. 1 Response

   (c) All Topics. 1 Response

   (d) Career workshop was most beneficial to students. 3 Responses

   (e) Demonstration showing how traits/disorders occuring in minorities aren't spoken about from minorities. (i.e. sickle cell anemia) 1 Response

   (f) Lack of minority community knowledge regarding genomics makes minorities perfect targets (guinea pigs) for studies and exploitation. 1 Response

   (g) To meet people who are actually involved in genetics and the HGP. 1 Response

   (h) People would not otherwise have discussed these issues with each other had the opportunity to meet and share ideas. 1 Response

   (i) Potential harmful effects of the HGP. 1 Response

   (j) No Response to question 7. 1

8. What was the least useful feature?

   (a) Discussion regarding how many jobs there are in the field. (Not any jobs as yet) 1 Response

   (b) Some of the information was repetitive, and for scientists and science students some of it was like a review from classroom lectures. 1 Response

   (c) All of the information was useful and important. 12 Responses

   (d) Too many overhead films. 1 Response

   (e) The event was not publicized enough to maximize the number of people who could and would have attended. 1 Response

   (f) No response ro question 8. 1

9. What knowledge was attained/clarified for you at this conference?

   (a) The basis/progress of the HGP. 1 Response

   (b) Career opportunities in this field. 1 Response

   (c) That there are many possibilities both positive and negative for the information that can

be attained from HGP genomics in general. 2 Responses

(d) Genes and their overall functions. 1 Response

(e) The information about genetic studies and findings in Louisiana population. 1 Response

(f.) Highly informative/valid information. 1 Response

(g) Much learned about the specifics of the HGP. 2 Responses

(h) The process and concerns for HGP involving minorities. (The lack of knowledge and the few opportunities/jobs currently held by minorities in the HGP.) 1 Response

(i.) The actual use of other disciplines in the HGP.

(j) The concept of the HGP. 1Response

(k) The HGP is of huge importance and minorities should be on the forefront of project planning. 1 Response

(l) More money should be given to community representatives to sell this kind of conference better with more aggressive propaganda so that more representation from various communities could attend. Radio and television ads and speakers should be invited to promote this educational conference. Thanks for All of the Knowledge!
1 Response

(m)No Response to question 9. 3

FINI

HUMAN GENOME PROJECT CONFERENCE WORKSHOP EVALUATION SUMMARY

WORKSHOP ONE

5 Evaluation Forms Returned
5 Participants responded as follows:

1. Workshop Content

   The majority of the respondents found the Workshop Content to be excellent.

71%-Excellent	.036%-No response	.018%-Average
20%-Very Good	0%-Poor	.036%-Fair

2. Presenters

   The majority of the respondents found the Presenters to be excellent.

93%-Excellent		0%-average
7%-Very Good	0%-Poor	0%-Fair

3. The overall workshop was rated excellent.

   100%-Excellent

4. Respondents listed the following topics to be considered for another workshop.

   a. More of the same
   b. How to set goals leading to fields and careers in HGP. (What courses to take? What are good prepatory programs to consider?)

5. What General Knowledge was attained or Clarified?

   a. Future career goals.
   b. The many career opportunities available for minorities in the medical, genome field.
   c. Job opportunities, research advice, how to get started.

6. There were no listed concerns.

7. Other Comments:

   a. Workshops were great.
   b. Due to the amount of information, would like workshops to be longer.
   c. This was a very informative workshop dealing with human genomes and bio-technology I enjoyed it thoroughly.
   d. This was very informative for my career goals.

FINI

HUMAN GENOME PROJECT CONFERENCE WORKSHOP EVALUATION SUMMARY

WORKSHOP TWO

4 Evaluation Forms Returned
4 Participants responded as follows:

1. Workshop Content

   45%-Excellent
   32%-Very Goodd
   9%-Average
   5%-Fair
   9% of particular items- no response

2. Presenters

   The majority of the respondents found the presenters to be excellent.

   71%-Excellent
   17%-Very Good
   12%-No Response

3. The overall workshop rating was:

   a. 1-Excellent
   b. 2-Very Good
   c. 1-Average

4. Topics to be considered for another workshop.

   No Response

5. What General Knowledge was Attained or Clarified?

   No Response

6. There were no listed concerns.

7. Comments:

   Workshop too short.

FINI

OPEN DIALOGUE DURING HUMAN GENOME PROJECT CONFERENCE WORKSHOPS

1. CAREER GROUP

   (1) Careers that are available for students and faculty.

   (2) Diversity in backgrounds (computers, physics and mathematics) Learn how to learn.

   (3) Graduate school paths (how to pick your programs) "Post graduate experience for the alternative student)

2. (Dr. Bell)

   (1) New scientific ethics are needed.

   (2) Under-representation in the realm of new genetics.

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   (4) Who owns the information of genome tests? (Insurance, doctors or individual?)

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3. (Issie Jenkins) Genetic Testing

   (1) Consent forms that hold no real protection for individual information.

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   (1) Continue the dialogue further.

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