

# Ethical Consequences of Genomics

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# Video

[Video](#)

[http://www.youtube.com/results?search\\_query=genomic+ethic&search=Search](http://www.youtube.com/results?search_query=genomic+ethic&search=Search)

# History of Technology in Genomics

- ◆ 1970's- Restriction enzymes discovered, methods to determine the sequence of DNA
- ◆ 1975- Conference in Asilomar, CA to set guidelines for genetic engineering
- ◆ 1983- PCR developed
- ◆ 1995- H. influenza 1st organism to have its entire genome sequenced
- ◆ 1996- "Dolly" the sheep becomes first mammal to be cloned by nuclear transfer
- ◆ 1998- Mice and cows cloned
- ◆ 1999- Monkeys cloned, Jesse Gelsinger becomes 1st death attributed to gene therapy
- ◆ 2003- The human genome sequenced; Dolly dies at an early age

# Changes From the Days of Biotechnology

- ◆ General biotechnology has a slow pace of change in comparison to genetic engineering
- ◆ Traditional biotechnology has been applied on a relatively small number of species, such as crop plants, farm animals and yeast. Genetic engineering is more ambitious in scope and seeks to change these organisms such as those involved in sewage disposal, pollution control and drug production.

# Genetic Testing

- ◆ Life Insurance
- ◆ Universal Screening
- ◆ Genomic Diversity Banks
- ◆ Who Will Benefit the Most?
- ◆ ELSI was formed to study Ethical Legal and Social Issues of genomics in 1990

# What does ELSI Do?

- ◆ ELSI Privacy and Fairness in the Use and Interpretation of Genetic Information
- ◆ Clinical Integration of New Genetic Technologies (examines impact of genetic testing on individuals, families, and society)
- ◆ Issues Surrounding Genetics Research (the design, conduct, participation in, and reporting of genetics research)
- ◆ Public and Professional Education

# Ethical Issues Surrounding Genetic Testing

- ◆ When a new disease-associated gene is discovered, a genetic test for this gene may soon follow.
- ◆ Is genetic testing a new form of eugenics?
- ◆ Who has the right to know the results of your test?
- ◆ Who has the right to obtain your DNA for genetic testing?

# Life Insurance in England

- ◆ British life insurance companies can use data from 8 genetic tests, including breast cancer, colon cancer, Alzheimer's, and (as of 2000) Huntington's Disease
- ◆ People who test positive for Alzheimer's can be denied further insurance.
- ◆ Should those who are free of a disease pay lower rates than those who test positive?
- ◆ Will this decrease the likelihood of people taking the tests?



# Life Insurance in the United States

- ◆ Some have recommended legislation be passed that would prevent insurance companies from discriminating on the basis of genetic information.
- ◆ Some of the main stipulations of this proposal are:
  - 1) Insurance Providers should be prohibited from using genetic information to deny or limit any coverage
  - 2) Insurance Providers should be prohibited from establishing differential rates or premium payments based on genetic information
  - 3) Insurance Providers should be prohibited from requesting or requiring collection or disclosure of genetic information
  - 4) Insurance Providers and other holders of genetic information should be prohibited from releasing genetic information without prior consent of the individual

# Increased Universal Screenings

- ◆ Every pregnant woman in America is informed of the availability of a test for Cystic Fibrosis
- ◆ This is the 1st of nearly 400 genetic tests to be implemented nationally
- ◆ Cystic Fibrosis is the most common genetic disease for Caucasians
- ◆ Cystic Fibrosis occurs in 1 out of 2,500 Caucasian births
- ◆ Moreover, the efficiency of detection is 85% in Caucasians

# Effects of Universal Screenings

- ◆ Most experts agree that a universal test for CF does not make sense
- ◆ But, HMO Kaiser Permanente conducted a pilot test They offered the test to all Caucasian patients
- ◆ About 18,000 women have been screened to date
- ◆ 90% of these women have terminated their pregnancy if the fetus was homozygous for CF.
- ◆ What are the implications of this?

# Genomic Diversity Banks

- ◆ In 1996, Kari Stefansson started a company called deCODE
- ◆ The company's goal is to create genomic fingerprints for the entire population of Iceland - 275,000 people.
- ◆ Iceland is ideal for this because the majority of the population is descended from a few European explorers and its people have kept detailed family trees.
- ◆ Differences which lead to medical conditions should be easier to find in such a population.

# Privacy Rights in Diversity Banks

- ◆ Iceland has a single medical provider and all records are kept in the same database
- ◆ deCODE purchased the medical records and has correlated family relationships with medical records
- ◆ Every citizen will give blood to determine a genetic fingerprint unless they opt out
- ◆ Some physicians worry that patient-physician trust has been broken and that patients may be less forth-coming with medical information
- ◆ Estonia has expressed interest in forming similar program

# Implications from the Media

- ◆ News media outlets tend to over-simplify findings, but most Americans do not understand the scientific literature
- ◆ The media has recently reported on the discovery of a: gay gene, smart gene, fat gene, worry gene, Alzheimer's gene, cancer gene, and fountain-of-youth gene.
- ◆ Most of the time, the fact that these are just one of many genes affecting a given condition or that environmental factors exist is buried in the story or left out completely
- ◆ This can create harmful thoughts about the genes of those with particular traits.

# Sources Consulted

- ◆ Magill, Gerard - Genetics and Ethics: An Interdisciplinary Study
- ◆ Bauer, Martin - Genomics and Society: Legal, Ethical & Social Dimensions
- ◆ Pilnick, Alison - Genetics and Society: An Introduction