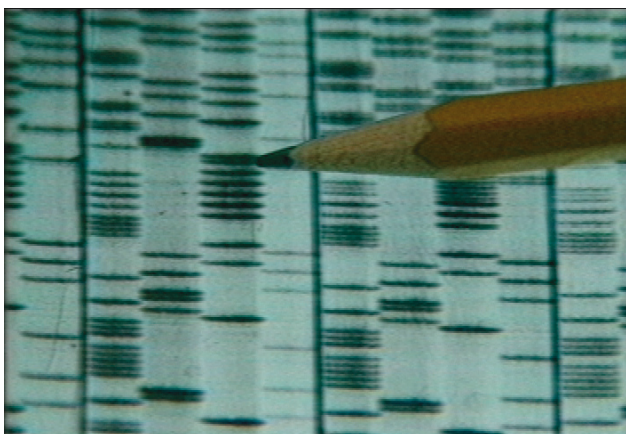


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GENE BLUES



Dilemmas of DNA Testing

Discussion Guide

by
Melissa Young and Mark Dworkin

**GENE BLUES:
DILEMMAS OF DNA TESTING**

a 30 minute video

Grades 9-12, College, Adult

Produced by

Mark Dworkin and Melissa Young,

Moving Images

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Written by Melissa Young and Mark Dworkin
Thanks to Phil Bereano, Bill Aal, Jane Rissler,
Margaret Mellon, Ruth Hubbard

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INTRODUCTION

Recent advances in genetic technology promise to help analyze and understand human medical conditions, but what are the risks in pursuing this type of research? “**Gene Blues: Dilemmas of DNA Testing**” [30 minutes] takes a look at the ethical and social implications of research and testing of human DNA. The video presents the potential benefits of the new genetic research, and takes a critical look at a number of issues which are beginning to arise with genetic testing, including privacy, genetic discrimination, and what it means to be a human being.

Topics addressed include:

1. **Genetic Discrimination.** Few laws protect the privacy of genetic information, and there is already discrimination in jobs, health care, and reproductive rights with the application of new genetic technologies, with and without the person's knowledge.

2. **DNA Data Banks.** The Department of Defense and various state governments, with FBI help, are establishing data banks of DNA information. The military wants DNA samples on file to help identify remains of personnel killed in action. Police and the FBI use DNA data in criminal investigations. But just as credit information needs to be safeguarded from abuse, so does the even more personal information on file in DNA data banks.

A. **Privacy.** Many are concerned about what this data will be used for, and who will have access to it. Misuse could lead to genetic discrimination, or to public knowledge of highly personal information, like parentage, or susceptibility to a disease.

B. **DNA and Crime.** The O.J. Simpson case is the best known example, but DNA testing is used for forensic purposes on a routine basis, and in some cases has exonerated people accused of certain crimes. Yet there's a danger of depending too heavily on DNA information, because this DNA "fingerprinting" is scientifically less accurate than many people think, and the process is subject to error and abuse.

3. **Pre-Natal Genetic Testing and the New Eugenics.** The increasing availability of genetic tests for various health conditions and the growing reliance on genetic explanations for health and social problems fuels an increasing stigmatization of those deemed "genetically flawed", including some calls to restrict reproductive rights

or coerce selective abortions for genetic disorders. As Marsha Saxton, a leading disability rights activist and bio-ethicist put it, “I’m pro-choice! But when they talk about eliminating spina bifida, that means eliminating people with spina bifida. They’re talking about people like me!”

4. Genetics and Health Care. Some researchers are attempting to use the new genetic information to develop gene therapies, but thus far they have been unsuccessful. In the meantime, genetic tests are becoming more common, and they bring with them difficult decisions on the part of individuals. Would you, for example wish to know that you had the gene for a debilitating condition before it became evident?

5. Geneticization. It is widely agreed that the causes of cancer are largely environmental, while genetic tests may indicate which individuals are more susceptible to those environmental factors. But now these genetic indicators are becoming the focus, and we tend to forget or ignore the non-genetic factors. Rather than clean a risky workplace, for instance, a company can refuse to assign susceptible workers to jobs that involve exposure to dangerous substances.

DISCUSSION QUESTIONS BEFORE VIEWING

1. Do you or someone you know have a genetic condition? How does the condition affect your quality of life?
2. What do you think about cloning yourself?
3. There have been many newspaper stories in recent years claiming a gene has been found for this or that behavior, including alcoholism, criminality, or even shopping. What do you think about those reports?

DISCUSSION QUESTIONS AFTER VIEWING

General

1. What are some of the areas where the new genetics holds promise?
2. What are some of the risks?
3. Why, as Troy Duster says in the video, should these issues not just be left to scientists?

Discrimination and Normalcy

4. How tall is a normal human being? Is it normal to be right-handed, or left? Do you wear glasses? Do your parents? Do your children? What other characteristics vary widely from person to person? Why are some conditions considered “abnormal” and others not? What is a normal human being?
5. According to research by the life insurance industry, most people think it is fair for the industry to consider whether someone smokes or not, when setting policy rates. However, while people from different racial groups may be more or less susceptible to certain diseases, it is illegal to discriminate in insurance based on race, and most people agree with that. What about a person’s genetic profile? Where do you draw the line?
6. Should a worker be tested to see if his/her genes protect him/her from exposure to toxins in a work place, or should the company be required to make the work site safer for everybody?
7. Should an employer have the right to test employees without their knowledge or consent, like at the Lawrence Berkeley Laboratory?
8. Recently under the Americans with Disabilities Act, a genetic predisposition [*e.g., a genetic marker for a*

genetic condition, even though the condition may not be apparent] was ruled to be unacceptable as a basis for discrimination. Do you agree?

9. Research and debate is increasing about whether genes play a role in conditions like alcoholism [*or violence or shopping or homosexuality*]. If a predisposition for alcoholism could be identified, do you think everyone should be tested for this gene before being issued a driver's license?

Privacy

10. What information about you should be kept private? Medical? Genetic? Psychological? Financial? Legal?

11. Donald Power, who appears in *Gene Blues*, refused to cooperate when the Navy wanted to give him a DNA test. However, most people over the course of their lives have given blood samples for medical tests or blood donation. Should anyone have access to these samples without your consent? What about the police, employers, researchers, other family members?

12. Some of the data collected about Tay-Sachs disease – a painful genetic condition that leads to early death – was re-analyzed for genetic information on breast cancer. Do you think DNA information collected for one purpose should be used for another?

Prenatal testing

13. If you were a pregnant woman over 35, would you test for a Down's Syndrome fetus? Would you abort if the genetic anomaly was present? Why?

14. According to population geneticists, eliminating a recessive genetic condition such as cystic fibrosis from the human gene pool would take thousands of years of coercive programs. Why?

15. Genetic testing sometimes turns up unexpected information. In prenatal testing, genetic counselors find that in one of twenty fetuses tested, the male spouse is not the biological father. Do you think the parents should be informed? Why?

Human Health

16. Thus far gene therapy to treat the genetic condition cystic fibrosis has not been very successful. Why is it so difficult?

17. What has the genetic research on breast cancer revealed?

18. What are some of the misconceptions about the tests for BRCA 1 and BRCA 2 [*so-called breast cancer genes*]?

Priorities of the biomedical industry

19. If U.S. medical research concentrated on developing a cure for malaria it could improve the health of millions of people affected by this disease. Why do you think the focus is on genetic research, sometimes for relatively obscure conditions, rather than on diseases that affect many more people around the world?

Patents

20. Does patenting a human being conflict with the 13th Amendment to the United States constitution which prohibits slavery?

21. Industry argues that patenting cell lines or genes is necessary to recoup the high costs of genetic research. However, the Salk polio vaccine was not patented. It is in the public domain and used universally. Why is it now necessary to have patent protection before drug companies will develop new medicines and procedures?

SUGGESTED ESSAY TOPICS

1. Patenting Human Beings

Can anyone “own” the rights to the genetic makeup of another living being? Should a government be allowed to “own” the DNA of its citizens? The government of Iceland just granted a private company exclusive access to genealogical and genetic information of its citizens. The U.S. Dept. of Commerce tried to secure a patent on the DNA of Guaymi Indians in Panama, until stopped by public interest groups, including the Rural Advancement Foundation International and the Council for Responsible Genetics. A doctor in California patented disease fighting elements from the spleen of John Moore, a Seattle man who sought treatment for hairy leukemia. The doctor cultured Mr. Moore’s tissue in an ‘immortal cell line’ from which he can profit indefinitely. Moore sued, but the Supreme Court upheld the doctor’s right to profit from his patient’s genetic material, and Moore has lost all right to control or profit from its sale.

2. Prospecting for Indigenous Genes

“Indigenous peoples are facing a new wave of colonization, this time at the molecular level. Advances in molecular biology have enabled scientists to identify unique genetic data in human DNA. Since indigenous populations represent a significant percentage of the world’s human diversity, we are also priority subjects for scientific curiosity.”

“Worldwide efforts such as the Human Genome Diversity Project (HGDP), and numerous independent research projects, are interested in collecting human DNA samples from indigenous peoples.”

“Genetic research raises a complex range of legal, ethical and social issues for indigenous peoples. Current legal protocols which govern the conduct of research on human subjects fail to recognize the rights of groups, like tribes, to control genetic material and information shared

collectively by the group. While we have recognized rights and jurisdiction over our territories and membership, recognition of our rights to our collective intellectual and cultural knowledge, and genetic resources are battles yet to be waged and written into law and policy.”

Indigenous Peoples Coalition Against Biopiracy

As the race to identify genetic material heats up, a number of projects are collecting human DNA. They include: the Human Genome Diversity Project, a worldwide project to collect DNA from disappearing indigenous groups; the National Institutes of Health Environmental Genome Project with a priority to collect from Native American and Asian populations; and pilot projects for the Human Genome Diversity Project funded through the National Science Foundation. Stated purposes of the efforts include tracing the historic relationships between different cultural groups, and discovering variations in the human genome between different groups or locations. The collection of genetic material from blood, cheek scrapings, hair roots, etc. has at times been done without clear understanding and consent on the part of the indigenous donors. Numerous groups who were the subjects of collections in Colombia, for example, understood that the purpose of the study was to help cure diabetes.

Human genetic material is preserved in gene banks in various parts of the world, and with the new technologies it can be reproduced without limit and sent out for various research purposes. While advocates think it is important to examine genetic material from a diversity of human groups, critics ask why these expensive research projects to collect and immortalize certain cell lines can get funded but programs that might help the cultural survival of these groups do not. For more information, Indigenous Peoples Coalition Against Biopiracy, articles in the RAFI Communiqué [*see Additional Resources below*]

3. Prenatal Testing and Disabilities

“The array of prenatal testing available to pregnant women has expanded exponentially over the 25 years since amniocentesis was first made available to high-risk pregnant women. Currently, no bright light guides individuals who use prenatal testing to attempt to select for any specific disability, medical condition, tendency or trait. Routinized prenatal testing opens the door to potential testing and termination for a broad range of characteristics. The important variability in the human population is due, at least partially, to genetic variation, but genetic make-up is surely only one ingredient in the recipe for personhood. Our life experiences, environment, development, and even chance, all play a significant role in determining who we are. In addition, individual characteristics such as height, gender, complexion, personality, physical and mental disabilities, and the characteristics of the people around us, all impact our own life experiences. Such variations could become much less vibrant in a generation or two if we selectively target some characteristics for elimination.”

“There will always be people with disabilities because most disability is not genetic in origin. However, the basic presumption that disability is a condition to be cured or prevented, devalues people living with disabilities. There is a delicate tension here between the respect for the rights, desires, and life experiences of affected families and the collective impact individual, personal decisions to test prenatally could have on our society. Therefore, we need a systematic process to curb the encroachment of prenatal testing.”

“Women must be able to make a free and informed choice regarding prenatal diagnosis, meaning they must receive non-directive and non-discriminatory genetic counseling before they are approached about prenatal diagnosis, as well as after any tests. This counseling must be provided

without undue pressure from medical professionals or insurance providers, and without undue influence from public policy. For example, the established gestational time limits to terminate a pregnancy should be the same whether the reason for termination is based on inconvenience, specific traits, gender or disability. In addition, counseling should not be based on a negative value judgment about the lives of people with disabilities. Finally, our society must continue to remove systematic barriers faced by people with disabilities to help families feel less anxious about carrying to term a fetus predicted to have a disability.” Ruth Ricker, former President of Little People of America. Reprinted from GeneWatch, April 1999.

DEFINITIONS OF TERMS

Chromosome: Microscopic structures in the nucleus of cells composed of DNA and proteins. They duplicate themselves each time a cell divides.

Clone: To make identical copies of a particular piece of DNA or of an entire organism. “Dolly” is a sheep created from and containing the exact same DNA as the adult sheep that was the source of the DNA. During normal mammalian reproduction, the offspring would have DNA from two parents and thus would not be identical to either parent.

Cystic fibrosis: A recessive genetic condition, experienced only by those who receive particular genes from both their father and mother, that causes excessive production of mucus in the lungs, increased susceptibility to infectious diseases, and usually premature death.

DNA [Deoxyribonucleic acid]: The molecule in the chromosomes that specifies the composition of proteins, and thus certain characteristics of the organism.

DNA databank: Center where DNA information is stored. In the U.S., the F.B.I. and the Department of Defense are among the sponsors of DNA databanks.

Down Syndrome or Down's Syndrome: A form of mental retardation of variable extent that is usually not hereditary and is associated with an extra copy of a normal chromosome in the nucleus of a person's cells.

Eugenics: A social theory that proposes to improve the genetic makeup of human beings by encouraging those with "good genes" to reproduce, and those with "bad genes" to not.

Gene: Functional unit of heredity usually carried on the chromosome and made up of DNA.

Gene therapy: The effort to repair or replace damaged genes, e.g. those responsible for inherited diseases or conditions.

Genetic discrimination: To show partiality for or prejudice against a person [*for insurance or employment, etc.*] based on the results of genetic testing of the person or family member.

Huntington's disease: A severe disorder of the nervous system, caused by inheriting one defective gene from either parent, with adult onset, that gradually affects the brain and nervous system and causes early death.

Prenatal genetic testing: Testing blood or amniotic fluid for abnormalities during pregnancy.

Sickle cell disease: A genetic disease that produces sickle shaped rather than round blood cells. Leads to painful episodes of anemia, transfusions and usually premature death. A person must inherit genes from both parents to have the disease.

ADDITIONAL RESOURCES

Organizations

Accion Ecologica: Quito, Ecuador

<http://www.accionecologica.org/>

Environmental organization influential in discussions of genetics and policy making in South America.

Alliance of Genetic Support Groups: 4301 Connecticut

AV, NW, #404, Washington, DC 20008-2304, 202-966-5557,

<http://www.geneticalliance.org>

Information and support groups for people and families with genetic conditions.

American Academy of Actuaries: 1100 - 17th St. NW,

7th Floor, Washington, DC 20036, 202-223-8196

<http://www.actuary.org/>

Insurance industry organization.

American Civil Liberties Union: 125 Broad Street, New

York, NY 10004-2400, 212-549-2565 <http://www.aclu.org/>

Australian Gen-Ethics Network: Australian Conserva-

tion Fndn., 340 Gore Street, Fitzroy 3065, Australia,

Non-governmental organization that takes a leading role in debates on genetic policy. They have developed excellent teaching resources on ethical/social/ environmental issues of biotechnology.

Biotechnology Industry Organization: 1625 K Street,

N.W., Suite 1100, Washington, D.C. 20006-1604, 202-

857-0244, <http://www.bio.org/>

Leading organization of companies in the field of biotechnology. Publishes BIO News bimonthly.

Council for Responsible Genetics: 5 Upland Rd., Suite

3, Cambridge, MA 02140, <http://www.gene-watch.org/>

National nonprofit organization of scientists, public health

advocates and others which promotes a comprehensive public interest agenda for biotechnology. Position papers on Genetic Discrimination, Germ Line Genetic Manipulation, No Patents on Life, etc. Subscribe to GENE-WATCH quarterly.

Edmonds Institute: 20319 - 92nd AV W, Edmonds, WA 98020, 206-775-5383

<http://www.edmonds-institute.org/>

Research, publication of papers on issues of biotechnology.

Foundation for Economic Trends: 1660 L St NW, Washington, DC 20036-5603, 202-775-1132

Organization headed by Jeremy Rifkin who has been very outspoken about the dangers of genetic technology.

Human Cloning Foundation

<http://www.humancloning.org>

Proponents of cloning. Check links to other websites for wide range of cloning applications.

Indigenous People's Coalition Against Biopiracy:

<http://www.ipcb.org/>

Perspectives from indigenous people on human and plant and animal genetic prospecting.

National Breast Cancer Coalition: 1707 L St. NW, Suite 1060, WA DC 20036, 202-296-7477

<http://www.edmonds-institute.org/>

National Institute for Human Genome Research:

<http://www.ncgr.org/>

Genetics and Public Issues section will refer you to many more websites addressing issues of public education on biotechnology. This is a useful site to see what the proponents of biotech are arguing.

Rural Advancement Foundation International: 110 Osborne St, Suite 202, Winnipeg MB, R3L 1Y5 CANADA 204-453-5259, <http://www.etcgroup.org/en/>

Group that first publicized the attempt to gather and patent genetic material from indigenous people. Subscribe to Rafi Communiqué. Articles about bioprospecting, patents, impacts on farmers. Information in English, French, Spanish.

Stanford University Center for Biomedical Ethics: 701 Welch Road, Suite 1105, Palo Alto, CA 94304, 650-723-5760, <http://bioethics.stanford.edu/>

Third World Network: 228 Macalister Rd., Penang, Malaysia, +60-4-2266-159, <http://www.twinside.org.sg/>
An organization of people from many countries of Asia, Africa and Latin America that promotes third world perspectives on biotechnology.

World Institute on Disability: 510 Sixteenth Street, Suite 100, Oakland, CA 94612-1502, 510-763-4100 <http://www.wid.org/>
Research and publication on issues affecting people with disabilities.

Books for future research

The Biotech Century Jeremy Rifkin, Putnam, New York, 1998

Altered Fates: The Genetic Re-engineering of Human Life Jeff Lyon & Peter Gorner, W. W. Norton & Co., New York, 1994

Biotechnics and Society: The Rise of Industrial Genetics Sheldon Krimsky, Praeger, 1991

The Clone Age: 20 Years at the Forefront of Reproductive Technology Lori B. Andrews, Henry Holt, 1999

The Code of Codes Daniel J. Kevles & Leroy Hood, eds., Harvard University Press, 1992

Dangerous Diagnostics: The Social Power of Biological Information Dorothy Nelkin & Laurence Tancredi, Basic Books, Inc., Publishers, New York, 1989

The DNA Mystique: The Gene as a Cultural Icon Dorothy Nelkin & M. Susan Lindee, W. H. Freeman & Co., New York, 1995

The DNA Story: A Documentary History of Gene Cloning James D. Watson & John Tooze, W.H. Freeman & Co., San Francisco, 1981

Exploding the Gene Myth [especially recommended] Ruth Hubbard & Elijah Wald, Beacon Press, Boston, 1997

Genetic Engineering: Dreams or Nightmares, Brave New World of Bad Science & Big Business Mae-Wan Ho, Third World Network, 1997

The Human Body Shop: The Engineering and Marketing of Life Andrew Kimbrell, Harper, San Francisco, 1993

The Mismeasure of Man Stephen Jay Gould, W. W. Norton & Co., Inc., New York, 1981

In the Name of Eugenics Daniel J. Kevles, University of California Press, 1985

Not In Our Genes: Biology, Ideology, and Human Nature R.C. Lewontin, Steven Rose & Leon J. Kamin, Pantheon Books, New York, 1984

Quest for Perfection: The Drive to Breed Better Human Beings Gina Maranto, Scribner, New York, 1996

Refiguring Life: Metaphors of 20th Century Biology
Evelyn Fox Keller, Columbia University Press, New York, 1995

Remaking Eden: Cloning and Beyond in a Brave New World Lee Silver, Avon Books, New York, 1997

Journals

Cultural Survival Quarterly, issue on Genes, People and Property, Volume 20, Issue 2, Summer, 1996. 46 Brattle St., Cambridge MA 02138

The Disability Rag & ReSource The Avocado Press, P.O. Box 145, Louisville, KY 40201

Genewatch, quarterly bulletin of the Council for Responsible Genetics [see resources above]..

Journal of Genetic Counseling, National Society of Genetic Counselors, Inc.

Nature, international weekly journal of science, 968 National Press, Bldg, 529 - 14th St. NW, Washington, D.C. 20045.

Science, weekly magazine published by American Association for the Advancement of Science, 1200 New York Avenue NW, Washington, D.C. 20005

Scientific American, monthly magazine of physical, life and social sciences and their application to industry, professions and public policy, 415 Madison Ave, New York, NY 10017.

Videos from Bullfrog on Related Topics

RISKY BUSINESS: BIOTECHNOLOGY AND AGRICULTURE

<http://www.bullfrogfilms.com/catalog/risky.html>

*24 minutes/Grades 9-12, College, Adult/with Study Guide
Produced by Mark Dworkin and Melissa Young, Moving Images.*

A companion film to GENE BLUES by the same producers, this documentary raises questions about the impact of genetically engineered foods, plants, and animals on farmers, our food supply, public health and the environment.

FIELD OF GENES

44 minutes Grades 7-12, College, Adult

<http://www.bullfrogfilms.com/catalog/fog.html>

Produced by Janet Thomson for CBC's "The National", FIELD OF GENES looks at both sides of the issue of genetically modified crops, with particular emphasis on the practical decisions being made by farmers.

SOWING FOR NEED OR SOWING FOR GREED?

56 minutes/Grades 9-12, College, Adult

Produced by Judith Bourque and Peter Gunnarson

<http://www.bullfrogfilms.com/catalog/sow.html>

Looks at the connection between multinational chemical companies and the food they want us to eat. Questions whether the biotechnology revolution will be a re-run of the failed Green Revolution.

What they say about GENE BLUES...

“A brilliant look at the social implications of genetic knowledge.”
Sheldon Krinsky, Ph.D.,
Professor of Urban and Environmental Policy, Tufts University

“A n informative, useful teaching tool...a great basis for discussion.”
Ruth Hubbard, Ph.D.,
Professor of Biology, Harvard University

“This is a great video for high school biology, general science, or even social studies classes. It is also suitable for college-level courses... The information is accurate, current, and relevant...an excellent video and I highly recommend it.”
The Science Teacher

“This well-produced overview...serves as a good discussion starter for high-school classes or public-library social-issues forums.”
Booklist

“The key is that genetic testing should be debated by the public, not merely by a few ‘experts.’”
GeneWatch

Bullfrog Films
PO Box 149, Oley PA 19547
(610) 779-8226
<http://www.bullfrogfilms.com>