actionbioscience.org lesson

To accompany the peer-reviewed article by Philip Bereano, Ph.D., J.D.
"Does Genetic Research Threaten Our Civil Liberties?" (Aug. 2000)
http://www.actionbioscience.org/genomic/bereano.html

Genetic Research and Civil Liberties (Apr. 2002)

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Educator's section: *p. 1-2*
Student handout 1: *p. 3-4*
Student handout 2: *p. 5-6*

Grades & Levels:

- **Handout 1:** high school (general)
- **Handout 2:** high school (advanced/AP) – undergraduate (year 1)

Time Recommendations: at least 2 class periods for either handout, with research time between classes

NSES (USA) Content Standards, 9-12:

- NSES 2.2. Science as Inquiry: understanding about scientific inquiry
- NSES 7.1. Science in Personal & Social Perspectives: personal & community health
- NSES 7.6. Science in Personal & Social Perspectives: sc. & tech. as local/national/global challenges

Note: View the NSES content standards on this site to choose other curricular applications for additional activities at:
http://www.actionbioscience.org/educators/correlationcharts.html

Learning Objectives: Students will …

- examine civil liberties issues in relation to genetic research
- understand that genes are not the sole cause of disease
- discuss how genetic medical information may be used
- present personal viewpoints about genetic research as it relates to civil liberties

Key Words Include:
civil liberties, genetic research, genome, genetic profile, altruistic, database, discrimination, genetic enhancement, eugenics/perfectionism, PKU, predisposition, ramification, recidivism, conflict of interest, medical privacy, commodity

Preparation

Article Discussion:

- Students should print out "Does Genetic Research Threaten Our Civil Liberties?" at http://www.actionbioscience.org/genomic/bereano.html.
- It is suggested that students read the article on their own for the next class period.
- Point out that this article has been written by the co-founder of the Council for Responsible Genetics and therefore carries bias. (In other words, there may be viewpoints unrepresented by this article.)
- *Note to non-U.S. educators*: Explain that the article examines civil liberties in the U.S. only. You may want students to research examples of genetic research issues in their own country and compare them to the examples in the Bereano article.
- The vocabulary in this article is elevated, so it is recommended that students research definitions of key words and other unfamiliar words. Clarify any ambiguity.
- After the students have read the article, use the Article Discussion questions on page 2.

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Student Handout 1 or 2:

- Have students print out the appropriate handout or distribute copies to students.
- Have students work in pairs or small groups on activities listed in the handout.
- Explain that students need to research their organizations (as outlined in their handout) and to
  - come prepared with a presentation supporting or refuting genetic research (Handout 1)
  - write a report, as well as present summary of organization's stand to class (Handout 2)

  Note to non-U.S. educators: You may want to substitute some of the American organizations with similar organizations in your country. The activities will work for any country.
- After student presentations and discussion, conduct a class vote on whether or not genetic research threatens our civil liberties. Discuss the results.
- It is suggested that you create a web or concept map on the board of the main issues that students will tackle in their activities:
  a) perfectionism (eugenics)
  b) protection of privacy
  c) control of information
  d) unwilling submission of data
  e) genetic discrimination

For Educators: Article Discussion

About the article by Philip Bereano, Ph.D., J.D.:
"Does Genetic Research Threaten Our Civil Liberties?"
http://www.actionbioscience.org/genomic/bereano.html

Note: Before posing questions on the article, ask individual students to summarize each section of the article in their own words. You may want to ask for class reactions to each summation.

Introduction (before the sub-title "Our technological society")

- What reasons does former President Clinton give for supporting the Human Genome Project?
- What are genetic diagnostics?
- What do people believe is the connection between genes and disease?
- How is genetic research big business?

Our technological society

- How are technologies not value neutral?
- The author claims that only the rich will benefit from genetic research. Why?
- How can genetic research lead to perfectionism (or eugenics)?

Loss of privacy

- What does genetic privacy mean?
- Give an example of the lack of genetic privacy policies and your reaction to it.
- What stand has the American Civil Liberties Union taken on genetic screening and third parties?

Genetic discrimination

- Why is discrimination the major infringement of civil liberties in genetic research?
- Give an example of genetic discrimination and your reaction to it.
- Has the US government enacted sufficient laws to guarantee that health insurance companies will not discriminate?

Conclusion

- Is it accurate to think that people who carry a defective gene will become ill?
- Why is medical help only part of the solution to illness?
- Do you agree or disagree with the author's conclusions. Why or why not?

Genetic Research and Civil Liberties
Student Handout 1

Instructions:

1. Your organization has been requested to join a government task force on genetic research. Your mandate is to determine whether or not genetic research threatens civil liberties.
2. Choose one of the following organizations: Council for Responsible Genetics (a real organization), FBI (a real organization), Parents of Terminally-Ill Children (a fictional organization).
3. Research your organization and find out its stance on five issues: a) perfectionism (eugenics), b) protection of privacy, c) control of information, d) unwilling submission of data, and e) genetic discrimination. *Note:* Some organizations may not take a position on all issues. Special instructions are provided below for fictional organizations.
4. Create a presentation that adheres to the following format:

   We are here as representatives of [name of your organization]. When it comes to genetic research, our organization's goal is to [summarize goal in one paragraph]. As representatives of the organization, we believe genetic research is [valuable/dangerous] because [four statements defending your view]. In conclusion, we believe the answer is [yes/no]: genetic research [does/does not] threaten our civil liberties. Thank you.

   Your presentation should reflect the views of the organization you have chosen, not your own. Document all quotes and sources.
5. Following the presentations, there will be a discussion where others may challenge your comments.

Organization #1: Council for Responsible Genetics

Read the following excerpt taken from Philip Bereano's article, discussed in class, to help you with your research and presentation:

> Genetic discrimination is the other major civil liberty threatened by genetics research. Scientists working with the Council for Responsible Genetics have documented hundreds of cases where healthy people have been denied insurance or employment based on genetic "predictions."[7] Of course, relatively few genetic diseases are deterministic; most tests (which have inherent limits themselves) cannot tell us if a genetic mutation will become manifest; if it does do so, it cannot tell us when in life this will occur; and if it happens, how severe the condition will be. In addition, many genetic conditions can be controlled or treated by interventions and environmental changes; that is why governments mandate testing newborns for PKU.

Organization #2: Parents of Terminally-Ill Children

You are each a parent of a child with cancer. You know that genetic research is close to finding a cure for the type of cancer your child has, but the government has halted all research until this task force makes its decision. Meanwhile, your child is very ill and time is running out. Research your situation to find similar true stories to help you with your research and presentation.

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Organization #3: Federal Bureau of Investigation (FBI)
Read the following excerpts taken from Philip Bereano's article, discussed in class, to help you with your research and presentation:

The FBI has been promoting the genetic screening of criminals to establish state DNA identification data banks to be used in criminal investigations; indeed, Federal legislation penalizes states fiscally if they don't participate, and now all do. Yet the data includes samples from those whose crimes have low recidivism rates or don't leave tissue samples; in some states people merely accused are forced into the program, and in others there are politicians calling for an expansion along these lines, despite the Constitutional presumption of innocence.

The American Civil Liberties Union advocates that "the decision to undergo genetic screening is purely personal" and it should not be "subject to control or compulsion by third parties" or the government.

Genetic Research and Civil Liberties
Student Handout 2

Instructions:
1. Your organization has been requested to join a government task force on genetic research. Your mandate is to determine whether or not genetic research threatens civil liberties.
2. Choose one of the organizations: Human Genome Project (real organization), DNA Justice Citizen's Group (fictional organization), and Against Insurance Discrimination (fictional group).
3. Research your organization and find out its position on five issues: a) perfectionism (eugenics), b) protection of privacy, c) control of information, d) unwilling submission of data, and e) genetic discrimination. *Note:* Some organizations may not take a position on all issues. Special instructions are provided below for fictional organizations.
4. Write a report about your organization:
   - Describe your organization and it's goals.
   - Summarize your organization's stand on the five issues mentioned above in #3.

Your report should reflect the views of the organization you have chosen, not your own. Document all quotes and sources.
5. Be prepared to discuss your organization's summary and reply to classmates who challenge your stand.

Organization #1: Human Genome Project

Read the following excerpt taken from Philip Bereano's article, discussed in class, to help you with your research and presentation (***Note:*** the article is dated August 2000 and you should research the latest HGP's breakthroughs):

> The science of genetics is a flourishing new industry, nourished in large part by the federally funded Human Genome Project. The goal of this ambitious research endeavor is to identify every gene found in the human body, perhaps 100,000 in all. Several months ago, the US government and a private corporation announced that they had "completed" the "map" of the genome, although actually there are still many gaps. Much related research focuses on genetic diagnostics – tests designed to identify genes thought to be associated with various medical conditions. More than 50 new genetic tests have been identified in the past five years alone.

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Genetic Research and Civil Liberties
Student Handout 2 *(cont.)*

Organization #2: DNA Justice Citizen's Group

1. A classmate has been charged with non-violent theft. It is your friend's first offense. The police intend to take a sample of your classmate's DNA and put it on their criminal database. You have joined the DNA Justice Citizen's Group to take a stand on the DNA database issue (you can choose whether your group is for or against its use). Research your situation to find similar true stories and legislation on the issue.
2. Read the following excerpt from Philip Bereano's article, discussed in class, to help you with your research and presentation:

> … genetic screening of criminals to establish state DNA identification data banks to be used in criminal investigations; indeed, Federal legislation penalizes states fiscally if they don't participate, and now all do. Yet the data includes samples from those whose crimes have low recidivism rates or don't leave tissue samples; in some states people merely accused are forced into the program, and in others there are politicians calling for an expansion along these lines, despite the Constitutional presumption of innocence.

Organization #3: Against Insurance Discrimination Group

1. You have recently started a family and are trying to get life and disability insurance. Unfortunately, both of your parents died of a terminal genetic illness. Genetic research has just revealed that you too are a carrier of the disease, though there is only a 10% chance you will develop symptoms. Because the laws regarding genetic research and genetic databases are new and evolving, your insurance company is aggressively trying to attain the records of your recent genetic testing.
2. Research how life or disability insurance works. Also research new insurance legislation that may modify some of the author's information on health policies.
3. Read the following excerpt from Philip Bereano's article, discussed in class, to help you with your research and presentation:

> Federal legislation, the Health Insurance Portability and Accountability Act (HIPPA, 1996), limits genetic discrimination as a basis for denying certain insurance medical insurance policies, but it does not prohibit charging higher premiums, nor does it cover life, disability, or automobile insurance or to employment -- all areas of documented discrimination. Slowly, state by state, the CRG, ACLU, and patients' rights groups are trying to get legislation passed to reduce or eliminate genetic discrimination; about 40 states have enacted some type of protections, but many are very weak and/or partial. Federal rules for medical privacy (including genetic information) under HIPPA were announced in August 2000, after weaker proposals by the Clinton Administration received a great deal of criticism. While providing standards for the disclosure of bio-information, the rules require that the patient only receive notice, not give consent; thus, there still would not be full patient control over sensitive information. The President has also announced his support of a Federal bill which would prohibit health insurance providers from using any type of genetic information for making decisions about whether to cover a person or what premium to charge. This legislation would address some of the discrimination problems which have been occurring. And he has issued an Executive Order barring genetic discrimination in Federal employment.

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