

## actionbioscience.org lesson

To accompany the peer-reviewed article by Carol Isaacson Barash, Ph.D.

“Ethical Issues in Pharmacogenetics” (Feb. 2001)

<http://www.actionbioscience.org/genomic/barash.html>

## Who Owns Rights to Pharmacogenetic Information? (Feb. 2003)

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Student handout 1: <i>p. 4</i>
Student handout 2: <i>p. 5</i>

### Grades & Levels:

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

### Time Recommendations:

- 1-2 days for article review and discussion
- 1-3 days for projects

### NSES (USA) Content Standards, grades 9-12:

- NSES 1.3. Unifying Concepts & Processes: change, constancy & measurement
- NSES 2.2. Science as Inquiry: understanding about scientific inquiry
- NSES 4.2. Life Science: molecular basis of heredity
- NSES 6.2. Science & Technology: understanding about science & technology
- NSES 7.1. Science in Personal & Social Perspectives: personal & community health
- NSES 7.6. Science in Personal & Social Perspectives: 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...

- develop an understanding of the rationale of ownership over scientific information
- research the commercial applications of DNA sequences
- formulate an opinion about sharing scientific information
- analyze how to evaluate medical ethics issues
- understand the implications of public access to personal DNA information

### Key Words Include:

anemic, conflict of interest, deleterious, DNA, drug reaction, drug receptor sites, enzyme, gene, gene profiling, genetic discrimination, genome, human genome project, metabolism, mutations, polymorphism, predisposed, single nucleotide polymorphisms (SNPs)

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## Preparation

### Article Discussion:

- Distribute or ask students to download and read the article by Dr. Barash at: <http://www.actionbioscience.org/genomic/barash.html>
- Follow the reading with questions about the article. Suggested questions are listed on page 3. Students can answer questions orally in class, brainstorm answers in groups, or complete questions as a written assignment. *Note:* Some extension questions may require research.

**Student Handout 1:** Follow article discussion with project assignments suggested in the handout. These can be assigned as a class or team activity.

**Student Handout 2:** It consists of a single class activity that requires research and preparation, as discussed below. *Note:* Some projects listed in Student Handout 1 may be added to Handout 2 or used as alternative activities.

### Student Handout 2: “Ownership of DNA”

#### Background:

The Human Genome Project created unprecedented debates about the ownership and sharing of genetic sequences. Genetic information at one time was published freely in scientific journals or was provided on-line for no cost. The arrival of pharmacogenetics has driven people to gain rights to genetic sequences in an attempt to control use of the information. This activity explores the issues associated with the ownership of DNA sequences.

#### Instructions:

##### *1. Research and summary composition*

- Hand out or have students download Student Handout 2: “Ownership of DNA.”
- Explain to the students that they will be representing the views of various groups having concerns about the ownership of DNA sequence information. Tell them that they must have a brief, compelling argument that can be presented in 5 minutes.
- Ask students to choose one of the groups on the Handout. Have no more than three students represent each group. Assign most of the students to represent the indigenous people of Africa group.
- Give the students homework time to research information and compose summaries of their justifications for favoring or opposing the ownership of DNA sequence information.

##### *2. Presentation and evaluation*

- Explain that groups are to present their views to the indigenous people of Africa. They will have 5 minutes to present their argument.
- Instruct each group to meet as needed to prepare for their presentation.
- After each group presents its arguments, have the indigenous people of Africa meet to discuss a unifying opinion. Then have them vote and present their decision to favor or oppose the ownership of DNA sequences unique to them.

##### *3. Assessment*

The projects and presentations can be graded on accuracy, completeness, and quality of work. This activity can be assessed using multiple-choice questions asking facts about genomics and pharmacogenetics. A short essay inquiring about the activity’s learning objectives would be a way to test higher-order learning.

#### Internet Searches:

Tell students that their Internet searches can begin with the links that follow the article they have just read and discussed. They are listed in the sections *Learn More*, *Get Involved*, and *Educator Resources*. The “useful links for student research” in *Educator Resources* are selected links that help students with activities in the handouts.

## For Educators: Article Discussion

About the article by Carol Isaacson Barash, Ph.D.:

“Ethical Issues in Pharmacogenetics”

<http://www.actionbioscience.org/genomic/barash.html>

### Content Questions:

1. What is the difference between pharmacogenetics and pharmacogenomics?
2. Describe how a person’s DNA plays a role in the way his/her body responds to drug treatments.
3. Describe a way in which pharmacogenetic differences can affect the way a drug works in the body.
4. Describe a situation in which a person diagnosed with a genetic disorder could find it more difficult to get medication or treatment.
5. How can pharmacogenetic information improve a physician’s ability to treat disease?
6. What problems can arise from “one-size-fits-all” medications?
7. How do environmental factors play a role in drug response?
8. Why are “pre-disposition” tests important?
9. What are some of the dangers of gene profiling by health insurance companies?
10. What is the possible impact of medical privacy laws on the use of pharmacogenetic information?
11. In what ways can pharmacogenetic information profit companies that identified the information?

### Extension Questions:

1. What is the Hippocratic oath? How could this oath support or come into conflict with medical information used in research?
2. How can medical researchers come into a conflict of interest when they discover a new drug? Do you think medical researchers should be able to profit from their discoveries?
3. Describe two ways that pharmacogenetic information about a person can be misused.

# Who Owns Rights to Pharmacogenetic Information?

## Student Handout 1

### 1. Flow Chart

You've been asked to be a teacher's aide in a middle school class. Your task is to help the teacher explain the process of medical research, using an example in graphic form.

- Create a diagram, chart, or other visual presentation to illustrate the path of discovery in pinpointing the cause of why some African-American soldiers became ill after ingesting an anti-malarial drug. Refer to the information presented by Dr. Barash in the article's introduction.
- Write a short paragraph of how this example illustrates the field of pharmacogenetics, so that it would be understood by a student in middle school.

### 2. Designer Drugs for Animals

You and your partners have created a company that specializes in designer drugs for animals. You are preparing for your first exhibit at an agricultural fair.

- a) Create an information brochure about the potential of pharmacogenetics on domesticated animals. Include examples of current research in this area, e.g., any animals that have been evaluated for pharmacogenetic differences.
- b) Produce a flyer or poster that advertises one of your company's products.

### 3. On Trial

Reread *Ethical Issue # 4: Whose Right Predominates* in the article by Dr. Barash. Plan a court case in which the son asks the court to release his father's medical information after the father objected to the unauthorized disclosure of his medical information. The verdict should focus on the question "*Whose right predominates in this case - the father's or the child's?*" Students should choose a role from the following:

- the son
- the father
- the judge
- the lawyer for each side (2)
- a doctor involved in the genetic research study
- the father's doctor
- a representative from the Office for Human Research Protections (OHRP)
- the jury (the rest of the class)

### 4. Pro or Con?

Support or dispute one of the following viewpoints:

- a) Bioinformatic companies that identify pharmacogenetic information have a right to patent the information and make a profit from it. After all, other corporations exercise the right to make an income from life-saving technologies.
- b) The mandatory testing of children for pharmacogenetic conditions must be done for the betterment of individual health and the improvement of medical care.

Use the Internet to get background information on one of the above topics before presenting your position or debating it.

# Who Owns Rights to Pharmacogenetic Information?

## Student Handout 2

### OWNERSHIP OF DNA

#### Introduction

In this activity, several groups will present their views about the ownership of human DNA sequences that have value in pharmacogenetics in order to persuade a group of indigenous people from Africa to favor or oppose the ownership of DNA information.

#### Instructions

Choose one of the following groups. Research and discuss your group's position and motivations behind the position with other members of your group. Circle the number of the group you will be investigating:

1. Group of research geneticists who *oppose* the ownership of DNA sequence information
2. Group of corporate geneticists who *favor* the ownership of DNA sequence information
3. Consortium of small pharmaceutical companies who *oppose* the ownership of DNA sequence information
4. Native Americans who *oppose* the ownership of DNA information
5. Native Americans who *favor* the ownership of DNA information
6. Indigenous people of Africa who will make a decision based on the testimonies of the other groups

Each group, except the indigenous people of Africa, will have 5 minutes to present its view. The indigenous people of Africa will then have to evaluate the arguments of the groups and meet to vote on a decision.

#### Gathering Background

Begin your research with the “issues in DNA sequence research” web sites listed under “useful links for student research” found in the *Educator Resources* section at the end of the article by Dr. Barash.