

actionbioscience.org lesson

To accompany the peer-reviewed article by Oksana Hlodan:

“For Sale: Iceland’s Genetic History” (June 2000)

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

Iceland’s Genetic Database: Good or Bad Idea? (Apr. 2002)

Lesson by Oksana Hlodan, educational writer/consultant
and Project Director, www.actionbioscience.org
North Port, FL (USA) & Caledon, Ontario (CAN)

Educator’s section: *p. 1-2*

Student handout 1: *p. 3*

Student handout 2: *p. 4*

Grades & Levels:

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

Time Recommendations:

- 1-2 class periods for article review and discussion
- Up to 1 week for students to complete project assignment
- 1 class period for project presentations

NSES (USA) Content Standards, 9-12:

- NSES 1.3. Unifying Concepts & Processes: change, constancy & measurement
- NSES 4.2. Life Science: molecular basis of heredity
- NSES 6.1. Science & Technology: abilities of technological design
- NSES 7.1. Science in Personal & Social Perspectives: personal & community health

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 ...

- be introduced to population genetics
- become aware that the predisposition to disease can be inherited
- learn about the history of Iceland’s medical database
- examine issues raised by genetic databanks

Key Words Include:

DNA, database/databank, genetic information, legislation, parliament, opposition, genealogy, exclusive/sole rights, genetic predisposition, homogeneity, population, eugenics, heredity, stereotyping, pharmaceutical, health insurance, stipulation, patents, copyright, discrimination, monopoly (business); *note: a select glossary of terms is provided at the end of the article*

Preparation

Article Discussion:

- Have students download or distribute copies of the article “For Sale: Iceland’s Genetic History” at <http://www.actionbioscience.org/genomic/hlodan.html>
- Review the key words with students or assign their definitions as individual research.
- Questions on the article are provided on page 2. You may wish to ask the questions in class for a verbal response or ask students to form teams and write their answers.

Student Handouts:

- Handout 1 is for high school, general courses and Handout 2 is suitable to high school, advanced/AP courses – year 1, undergraduate level.
- Both handouts contain several activities that require research, mainly on the Internet, and visual or oral presentations.
- It is suggested that students choose only one activity to perform as a take-home assignment.
- Activities can be conducted in whole or in part individually, in pairs, or in small groups.

For Educators: Article Discussion

About the article by Oksana Hlodan: “For Sale: Iceland’s Genetic History”

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

Article Content Questions

1. Why did the government decide to add genetic information to its medical database?
2. What kind of contract did the government give deCode?
3. How did deCode explain its agreement with Hoffman-LaRoche?
4. What is the Book of Icelanders?
5. Why were people concerned that a private company got the database contract?
6. What makes Iceland an ideal place to study genetic diseases?
7. Why is homogeneity important in the study of genetic diseases?
8. What is population genetics?
9. How can population genetics data be manipulated to support dangerous ideas?
10. Did Icelanders get the right of consent in the database project?
11. Could the project lead to stereotyping of Icelanders?
12. What special benefits did deCode obtain in its contract?
13. Can other scientific organizations access the deCode data?
14. Do citizens who participate in the database receive any benefits?

Personal Viewpoint Questions

1. Do you think deCode’s agreement with Hoffman-LaRoche was based on insider information about the government database project?
2. Do you think any database is hacker-proof?
3. Do you think other nations should follow the Iceland example? Why or why not?

Extension Questions

Give students 10-15 minutes to think about and answer the 8 questions listed at the end of the Hlodan article. Students can work in pairs or groups and should use their best judgment in their answers. Point out that these questions relate to genetic information in general, not just the Icelandic database. These 8 questions are:

1. Who has the right to access and use our personal genetic information?
2. Who controls the information?
3. If medical records are used as a community resource, should they not be available to all research facilities within the community?
4. Will the medication for a disease discovered through population genetics studies be freely available to the participants?
5. Can anybody own parts of our genome through patents, copyright, and the like?
6. Should genetic testing be done and how scientifically reliable is it?
7. How will others perceive an individual whose genetic tests reveal a potential disorder?
8. Will the information lead to discrimination by business or institutions?

Iceland's Genetic Database: Good or Bad Idea?

Student Handout 1

Choose from the projects shown below for your assignment. Be prepared to answer questions about your presentation in class.

Population Genetics

Describe the study of population genetics in outline form. Your description should be divided into two sections:

- the basic principles of population genetics
- the tools used by population geneticists in their research

deCode Genetics

Go to the deCode Genetics web site and write a one-page report about their business. Include a section on the Icelandic database. You can choose to create a business brochure rather than a report.

Mannvernd

Go to the web site of the database's official opposition, Mannvernd. Click on "doctors' stand" on their home page. Read the doctors' statements and write a summary of at least two doctors' views. Write a brief statement whether you agree or disagree with their views.

Iceland

Research the history of Iceland's population. Create a genealogy tree that shows which immigrant populations contributed to the making of the modern Icelandic.

Human Genome

Find out how the human genome can be sequenced. Create a chart or other graphic to explain the methods.

Iceland's Genetic Database: Good or Bad Idea?

Student Handout 2

Choose from the projects shown below for your assignment. Be prepared to answer questions about your research and presentation in class.

U.K. Database

The United Kingdom is planning to create a genetic databank, with goals similar to the Icelandic medical database. The genetic information will be collected by Biobank UK, in collaboration with the Wellcome Trust, the Medical Research Council, and the Department of Health. Research the databank project and its opposition. Write a one or two-page report describing the project and three major concerns of the opposition.

Hereditary Diseases

There are a number of hereditary diseases mentioned in the article you read about Iceland's database. Find out how much of the population in your country suffers from these diseases. Use a chart and illustrate your research in percentages. The diseases to research are: emphysema, Alzheimer's, multiple sclerosis, osteoarthritis, and schizophrenia.

deCode vs Mannvernd

Go to the web sites of deCode Genetics and Mannvernd. Compare their views on the Icelandic database. Present the comparison in a chart or other presentation.

Genomic Mapping Careers

What kinds of careers are possible for people interested in sequencing and understanding the human genome? Research three careers in the field and write a short job description, including educational requirements.

Pharmaceutical Patents

Research at least three patents held by pharmaceutical companies that will give them a monopoly on medications related to genetic diseases. Write a short summary, describing the DNA patent and the cure the companies are hoping to discover.