TAKE A TRIP TO THE **Biobank**

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Understanding human genetics is an important part of the standards-based science curriculum. In our experience, however, the topic is a difficult one for many students. In this lesson, students examine issues, both pro and con, surrounding genetic databanks and population genetics studies. They then investigate methods of collecting human genome information and evaluate Web sites of various biobanks. Next, they work in groups to create a biobank of their own, which they write about and illustrate. We use this activity with high school general biology students. It would also be appropriate for AP biology and freshman college biology courses.

The suggested time for this activity is three 50-minute laboratory periods. Alternatively, the Web searches may be assigned as homework. Creation and presentation of student biobanks can then be completed in two subsequent 50-minute periods. The purpose of the activity is to promote both content mastery and critical thinking through self-discovery. In the process, students will:

- improve their reasoning and communication skills
- learn about the history of biobank databases
- examine issues raised by genetic databanks
- draw conclusions and communicate their reasoning.

We use this activity to promote three National Science Education Standards: Content Standard C (Molecular Basis of Heredity, Science and Technology), Content Standard E (Abilities of Technological Design and Science in Personal and Social Perspectives), and Content Standard F (Personal and Community Health).

Biobanks & Biobanking

A biobank is a collection of biological specimens along with the information used to identify and analyze them. Worldwide, the number of biobanks continues to grow rapidly. They vary widely in their size and focus. There are biobanks specializing in diverse plant, animal, and microbial species (http://www.biobankcentral.org/importance/what.php). Human biobanks may be organized as disease specific collections to investigate conditions such as Alzheimer's disease, colon cancer, diabetes or multiple sclerosis (http://biobanktalk.ca). Others act as repositories targeting groups of people or entire populations. An excellent example is the Dor Yeshorim program. Founded by a rabbi who had four children die from Tay-Sachs disease, the program tests participants for a panel of genetic disorders known to be more common among Ashkenazi Jews. This information is a valuable guide for couples contemplating marriage. The data is collected and stored confidentially. If a dating couple finds both of them are carriers of the same recessive trait, they may choose not to have children or even marry. The program has been highly successful. Today, Tay-Sachs disease is nearly non-existent in this community (Lewis, 2007).

Our activity focuses specifically on human population biobanks. The goal of population biobanking is to find new drugs or treatments by better understanding the complex relationship between genes, environment, and disease. The potential benefits from this research are considered so important that many countries have established national biobank programs. Iceland, Estonia, Sweden, Canada, and the UK have national biobanks that seek to collect samples and complete health records from large populations of people. The UK Biobank, for example, aims for 500,000 patient participants (http://www.ukbiobank.ac.uk/). Other biobanking initiatives are being conducted by non-profit or for-profit companies, such as pharmaceutical and biotechnology companies.

Commercialization, along with privacy concerns over who has a right to access sensitive medical and lifestyle information, makes biobanking controversial (Lewis, 2007). Privacy advocates point to recent highly-publicized cases involving loss or theft of medical and credit card data as evidence that no database is completely secure. Maintaining confidentiality while providing researchers access to samples and data remains an important issue. If the medical information stored in a biobank is considered a public resource, how will that information be made available to research facilities within the community? If the genetic discoveries are patented or copyrighted, who will profit from them? Will participating communities be given access to new treatments or receive royalties? What about genetic discrimination? What can be done to guarantee that participants will not be fired or denied insurance based on their genetic profile revealing a potential disorder? Civil rights groups express concern over loss of civil liberties if samples collected during routine medical care or for research purposes are accessed by law enforcement. Others wonder if the potential benefits justify the cost. To date, few treatments are directly attributable to biobanks (http://www.genewatch.org/).

Preparation

You will need access to the Internet, software such as PowerPoint, HyperStudio, or Microsoft Word for presentations and copies of the student guide (Table 1.). Alternatively, handouts of biobank Web pages and chart paper or poster board may be used if the Internet and computer programs are not available. This activity is considered non-hazardous. However, regular safety procedures should be followed during any classroom activity. Before beginning this

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lesson, students should be familiar with gene structure and function. While some of the details of genetic testing may be more complex than required for a general biology course, students will benefit from exploring the process at a basic level. Some important terms that might be presented in your discussion are listed in the Teaching Tips section below.

Procedure

We have students work in groups of three or four depending on class size. We ask them to use various search engines and databases such as Google, Internet Explorer, Safari, PubMedCentral and Google Scholar to investigate biobanks of interest. The students should be sure to research both pro-biobank and anti-biobank sites. After reviewing each site, they describe the function of these existing biobanks and explain the services they offer. Do the biobanks focus on a particular population group, age range, or type of disease? We ask students to describe how a person volunteers and whether there is a charge for participation.

Students then identify similarities and differences among the biobanks they have investigated and create a chart or graphic organizer comparing and contrasting what they find. Next, we have them create Web-based, multimedia, or text-based summaries of their search findings for presentation to the class. You may wish to use the board or a wall chart to help students keep track of the information presented. Feel free to add any points that you feel have been overlooked.

Based on the research they have conducted and this classroom discussion, we have students create a biobank of their own. They should develop a name, rules for collection of samples, privacy safeguards, and other defining characteristics. Questions used at this stage are important. Research and experience have shown that content mastery and critical thinking are best facilitated when the teacher asks divergent rather than convergent questions. Divergent questions are open-ended and allow students to generate their own ideas. Some key opening questions might include the following: How will you keep the data in your biobank confidential and secure? How will you decide who can access and use the information? How will you keep the information in your biobank from leading to discrimination?

Teachers should encourage students to evaluate their ideas in the context of prior knowledge and resolve inconsisten-

Table 1. Student Guide

GENETIC BIOBANKS PROJECT

Name_____ Date _____

Objectives

1. To improve your reasoning and communication skills
2. To learn about the history of biobank databases
3. To examine issues raised by genetic databanks
4. To draw conclusions and communicate your reasoning

Materials

Access to the Internet or biobank Web pages

Software such as PowerPoint, HyperStudio or Microsoft Word

Copy of the student guide

Procedure:

1. Work with your lab partners. Use your Internet search engine to select and investigate biobanks of interest to you. Be sure to include both pro-biobank and anti-biobank sites.
2. Next, create a Web-based, multimedia, or text-based summary of your search findings for presentation to the class.
3. Based on the research you have conducted, be prepared to participate in a group discussion. Identify similarities and differences among the biobanks you have investigated. Your teacher may use the board or wall chart to help you keep track of the information discussed. You will want to copy this into your notebook to refer to as you complete the rest of the activity.
4. Based on the search you conducted and the classroom discussion, work with your group to create a biobank of your own. Refer to questions posed by your teacher to guide the development of your biobank.
5. Write about and illustrate your newly-created biobank. For example, you may wish to create a brochure or flyer, write a newspaper article, create a poster, Web page or multimedia presentation describing your biobank. Be creative! Act as if you are advertising or marketing your biobank to the class!!
6. After you have finished your writing and illustrations, be prepared to share your ideas with the class.

Application Questions

1. In order to create a valuable biobank, you need to have a working definition of the following terms:
   a. biobank
   b. DNA
   c. genetic discrimination
   d. genetic predisposition
   e. heredity
   f. patent
   g. population
2. What privacy issues are involved with biobanks?
3. What security issues are involved?
4. How do privacy and ethical issues differ between the U.S. and other countries?
5. What kind of an example is the UK Biobank for others to follow?
6. Should private medical records be used as a public resource?
7. Who can own genetic information through patents or copyrights?
8. What concerns are there about genetic discrimination with biobanks?

cies for themselves. Avoid the temptation of suggesting a "correct" answer as this often discourages critical thinking and self-discovery. The purpose here is not to arrive at a single "correct" description of a biobank, but to introduce your students to the process of gathering and reporting scientific information.

Teaching Tips

Students should write about and illustrate their newly-created biobanks. For example, you may wish to have them create a brochure or flyer, a newspaper article, poster, Web page or multimedia presentation describing their biobank. Students may choose from software choices available to them for presenting their finished products (PowerPoint, HyperStudio, Microsoft Word, Internet, etc.). After creating their biobanks, have them share their ideas with their classmates. To facilitate a good discussion, devise a method to ensure that the students know the meaning of key vocabulary. Examples might be DNA, database, population, predisposition, heredity, patent, copyright, and discrimination. Have students add these to a word wall or their notebook word list.

Evaluation & Extension

Ideally, evaluation should include both formative and summative assessments of content and process skills. For example, while the class is engaged in the activity, we observe each student's performance to check for progress and understanding. We use laboratory notebooks to collect products of individual student and group work such as first drafts, drawings, self-evaluations, and answers to assigned questions. We also assign open-ended questions such as the Application Questions included in the student guide (Table 1.). Students are given an assessment rubric along with the PowerPoint assignment so they know their performance expectations. We observe students as they make presentations to the class and assess them using this rubric. During the classroom discussion, we always ask what other questions the presentations have brought to mind and have students respond using reflective journal entries. Their responses are then discussed with their lab partners and as a class.

Conclusion

Research indicates that the effectiveness of instruction is enhanced when it incorporates materials that actively engage students in the generation of scientific explanations. To this end, the present exercise allows students to examine issues surrounding genetic databanks and population genetics studies using readily-available resources. As one student responded when asked on a survey to comment about this laboratory exercise, "This activity helped me understand what a biobank is and how it might be useful. It also made me aware of privacy issues and genetic discrimination–something I had never considered before."

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