

Teacher Guide: Genetic Screening of Newborn Infants: What Should We Test and Why?

ACTIVITY OVERVIEW

Abstract:

Students form Task Forces to research genetic disorders and then develop a public health policy on screening newborn infants for those disorders. Each Task Force then prepares a presentation to the class. Students choose and assume a role to play on their Task Force, approaching the assignment from the perspective of that role. Information about 12 genetic disorders, tests for those disorders, and other applicable data are available in the Activity Resources Packet for this module.

Module:

Genetic Screening of Newborn Infants

Prior Knowledge Needed:

Basic inheritance, dominant and recessive traits, chromosomes, structure of DNA, genes, mutations, protein production

Key Concepts:

Genetic disorders; public policy; ethics; technology; demographics; genetic screening

Materials:

Activity Resources Packet, Binders or file folders optional

Appropriate For:

Ages: 12 - 20
USA grades: 7 - 14

Prep Time:

3 hours to review, plan and copy (if necessary)

Class Time:

2 hours to 2 weeks depending on the depth and breadth of student research on genetic disorders

Activity Overview Web Address:

<http://gslc.genetics.utah.edu/teachers/tindex/overview.cfm?id=newborn>

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I. PEDAGOGY

A. Learning Objectives

- Students will learn about the causes, symptoms and treatment of various genetic disorders.
- Students will think critically about how genetic technologies influence decisions made by individuals and society.
- Students will examine a problem from the perspective of various stakeholders.
- Students will use quantitative data and research to support a position.
- Students will work in groups to achieve consensus and communicate the result.

B. Background Information

Technological advances and extensive research in recent years have greatly advanced our knowledge of human genes and our understanding of genetic disorders. The Human Genome Project and sequencing the genomes of model organisms such as yeast, roundworm, fruit fly and mouse have contributed greatly to this understanding and promise to reveal more through continued research. Identifying and understanding the role of particular genes is a much larger task, but rapid progress is being made in this area.

One outgrowth of the technological advances associated with the Human Genome Project is an improved ability to test for genetic disorders. As genes are identified, new genetic tests can be developed. Once a cost-effective and reliable test is available, several questions arise:

- Who should be tested?
- When should they be tested?
- Who should pay for it?
- What should be done with the results?

If a genetic disorder is identified early, parents can be better prepared to deal with symptoms if and when they occur. Early diagnosis also means early treatment, where treatment is available. As a result, many people support the idea of broad genetic screening of newborns.

Newborn screening has some disadvantages, too. One is the cost, for parents and for the government. Another is the danger of prejudice based on knowledge of having a gene associated with a disorder, whether or not the genetic disorder actually develops.

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The Human Genome Project is unusual in providing funds to consider the ethical, legal and social implications of the work (a subprogram called ELSI). This program provides support for studying patient's rights, societal rights, privacy, and health policy related to genetic research and issues.

Although scientific findings are based on a rigorous discipline instead of public opinion, societal and personal values shape how scientific knowledge is applied. Ethical discussions require good skills for decision-making. A person needs to research the topic and consider the effects of any choices. Personal values help place a worth on a particular course of action. Once a preference is understood, the individual (or group) should be able to discuss it using well-reasoned statements based on evidence. Finally, each person must see the consequences of choices and accept responsibility for them.

Each government develops its own public policy for genetic screening. In the United States these decisions are currently made at the state level, although a national policy is being considered. In other countries, newborn screening policies are decided on a regional or national level. Given demographic considerations, certain tests may be more appropriate in one country or U.S. State than another, even if they share similar general policies about newborn screening.

As set forth by the American Academy of Pediatrics (AAP) Newborn Screening Task Force, the U.S. national agenda should:

- Better define federal and state public health responsibilities
- Develop and distribute model state regulations, including criteria for disorder test selection
- Develop innovative testing technologies
- Apply minimum national standards for screening activities such as laboratory quality, sample collection and storage, and access to patient information
- Develop and distribute patient follow-up, diagnosis and treatment guidelines
- Design a system of care for diagnosed individuals from infancy to adulthood
- Develop strategies to better inform families and the public about genetic screening issues.

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A U.S. national policy is being advocated, in part, by parents who live in states that do not offer particular newborn screening tests that are offered in other states' programs. These parents indicate that, as a consequence of testing variability, some children with genetic disorders are going undiagnosed until it is too late to begin the most effective treatments. However, the national agenda proposed by the AAP does not recommend that all newborns in the United States be screened for the same disorders, only that the test selection criteria are the same.

Regarding the possible development of an international policy, the Council of Europe Recommendations (1994) state that "because there are differences in health needs and health services, as well as in ethical values and in legal norms and rules between countries, the decision to implement a screening programme should be taken in cooperation with the medical profession by each country".

The European Society of Human Genetics Public and Professional Policy Committee takes another view: "Some issues can be regulated at a national level, but international regulations seem to be preferred for several reasons: the development in genetics is an international one, affecting individuals in all countries, which creates a common responsibility concerning possible harmful consequences. Fundamental divergence of national legislation may have adverse effects on international scientific cooperation and the mobility of health professionals and patients across frontiers. For others, international regulation may enlarge the protection and provide further equality".

The Genetic Screening of Newborn Infants module provides students the opportunity to learn about 12 representative genetic disorders, investigate issues related to genetic testing and technologies, explore these issues from the viewpoint of diverse stakeholders, and work as a committee to develop a newborn genetic screening policy for their state, region or nation.

See Page 10 of the Activity Resources Packet for a list of the 12 disorders covered in this module.

C. Teaching Strategies

1. Timeline

- Before the activity:
 - Read through the Activity Resources Packet (available from the Online Activity Overview) and decide if you will have each group research and make decisions about all 12 genetic disorders, or if you will divide the genetic disorders among the groups (such as 3-4 per group, or one disorder for all groups to research and work with).

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- Schedule use of a computer lab if you want students to do additional online research.
- Print the Activity Resources Packet and make the appropriate copies. As there is a large amount of material in the Activity Resources Packet, you may want to prepare a 3-ring binder or set of file folders for each team (see Materials Preparation Guide, page 8).
 - Order copies of any articles listed in *General References* that are not available online and that you want available for students to use in their research. Articles can usually be ordered through Inter-Library Loan at your local library, often free of charge.
- Decide the state or country for which each Task Force will develop its policy.

Note: The demographics of a country or state may affect the need for certain genetic tests. You may choose to assign a different state or country to each group.
- If needed, send parents a letter informing them of the upcoming activity. A sample letter is available on Teacher References page 28.
- Day of activity:
 - Divide students into groups and assign, or have them choose, Task Force roles.
 - Assign each group the genetic disorders you would like them to research and create policy on.
 - Distribute copies of the Activity Resources Packet.
 - Provide computer time for students to begin research.
 - Continue work for the amount of time you have chosen (2 days - 2 weeks, see Activity Timelines on Teacher References pages 13 - 14).

2. Classroom Implementation

- Begin class by asking: "If you had a newborn child, would you want it to be tested for genetic disorders? Explain." You may want to have students record their answers for reference after the activity.
- Inform the class that they will be serving on task forces to research genetic disorders, to create a policy on testing newborns for these disorders, and finally to prepare a written report and/or presentation to justify their policy to the class. (See *Your Challenge* in the Activity Resources Packet for guidance.)
- Divide the class into Task Forces and assign, or have them choose, a role within the group. (See *Task Force Roles* in the Activity Resources Packet. Copymasters for the roles are also available on Teacher References pages 15 - 18)
- Assign each Task Force the genetic disorder(s) you would like them to research and develop a policy about. You may have students work with all disorders, a selected few, or all students work with the same disorder(s) Also, assign the

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country or state for which you would like the groups to develop a policy. Again, you may chose to vary the state or country assignment among groups.

- Provide a printed Activity Resources Packet to each group.
- Give each Task Force time to research, discuss and create a policy. You may want to give students the Procedure Summary (Teacher References page 19) to help them stay focused.
- Suggestions for guiding group work time. You may want to do some or all of the following:

- Have students meet with members of other Task Forces who have the same role to discuss the issues from that role's viewpoint.

A meeting among all the “doctors” or all the “legislators” is helpful for students to discuss and solidify their roles. This might include a discussion of the concerns of a person in their role and how a newborn screening policy might address those concerns. If time permits, have these groups of students meet again after they have conducted research on the issues and before they meet for their Task Force discussions, to share information and opinions related to their role. You might also have them meet at the end of the activity to discuss compromises they had to make as their Task Force developed a consensus policy and how successful they were in convincing their Task Force to address their concerns.

- Have each group make a research plan as a committee that addresses the following:
 - What criteria or issues should your Task Force consider?
 - Make a chart or list of issues to guide your research.
 - Decide what material each member will review.
- Begin or end each class with a question and answer session.
- Remind students to approach the assignment in character with their role.
- Assign group process roles within each Task Force.

Suggestions:

- Chair Lead - Leads the discussion.
- Focus Lead - Takes the lead in insuring that the team stays focused on the policy development task.
- Participation Lead - Takes the lead in ensuring that everyone participates equally on the team and has opportunities to speak during team discussions.
- Recorder Lead - Takes the lead in keeping notes on the discussion.
- Resources Lead - Takes the lead in finding and gathering resources to answer the teams' questions.
- Librarian Lead - Takes the lead in keeping track of resources and materials the team gathers.

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- Give struggling groups an example Procedure Summary (Teacher References page 19).
- Use the Ethical Decision Making Framework (Teacher References page 20) to guide the groups' discussion. The Values Discussion Questions (Teacher References page 21) may also be helpful.

3. Extensions

- Invite guest speakers who are in some way involved in genetic testing to speak to the class.
Some suggestions:
 - A nurse who collects newborn screening samples
 - A representative from the laboratory that processes samples
 - A pediatrician
 - A genetic counselor
- Invite guest speakers from task force roles such as:
 - Doctor
 - Lawyer
 - Legislator
 - Lobbyist
 - Officer from a health insurance company
 - Parent of a newborn infant
 - Parent of a child with a genetic disorder
- Daily Journaling
Ask students to reflect on their learning each day. You may want to use the Discussion Questions (Teacher References page 22) to guide the writing assignment.
- Math Activity (see Teacher References Pages 23 - 25)
Use this activity to sharpen students' math skills and their ability to use quantitative data.
- Provide or ask students to locate genetic screening policies in your area and/or materials about testing given to parents of newborns.

4. Adaptations

- This activity can be adapted in numerous ways to fit your time frame and needs.
 - If you have only one day, do one of the following:
 - Have all groups work with the same disorder
 - Have all groups do the same disorder but for various regions
 - Assign one disorder per group, each group with a different disorder

Time saving tip: If all groups work with the same disorder, the background information for that disorder can be presented to the whole group at once.

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- If you have 2 or more days, do one of the following:
 - Assign two or more different disorders to each group
 - Assign all disorders to each group
- See Activity Timelines (Teacher References pages 13 - 14) for suggestions.
- If you would like to create smaller groups, eliminate certain Task Force roles.
- You may want to create additional Task Force roles such as: representatives of the religious community, a genetic counselor, or a bioethicist.

5. Assessment Suggestions

- Written policy. Task Force teams prepare a formal committee report that includes their recommendations for all genetic disorders they considered as well as the rationale for their decision on each disorder.
- Presentations. Use one of these formats or another creative idea for group presentation of the policy. Presentations should be about 5-15 minutes.
 - Formal Presentation of the Task Force policy
 - Interview for a TV or radio news broadcast, talk show or program
 - Legislator making a presentation to the legislature
 - Public service announcement
 - Couple visiting a genetic counselor
 - Other skit or roleplay
- Statement of pre- and post- activity views on genetic screening. You and the students can use this for comparing any change in their views between the beginning and end of the activity. Use the question: "If you had a newborn child, would you want it to be tested for genetic disorders? Explain." posed at the beginning of the activity for this purpose.
- Daily journaling. Student journals can be part of your formative assessment during the module. You may have students write about how their views on genetic testing are changing, questions that are being raised for them during the activity, any problems with group dynamics, or responses to specific questions you pose.
- Ethical decision-making framework. Task Force teams can document their decision-making process using this outline. See Teacher References page 20.
- Task Force portfolio. Task Force teams can submit a portfolio of their work. This might include interviews with community members, research outlines, charts of daily accomplishments, data analysis and the final written report.
- Short essay questions. See Teacher References pages 26 - 27. Ask students to respond to one or more of the essay questions following the activity.

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- Discussion Questions. See Teacher References page 22. Have students prepare written or oral responses to one or more of the questions. Students may work individually or in groups.

II. ADDITIONAL RESOURCES

A. Activity Resources linked from the online Activity Overview:

<http://gslc.genetics.utah.edu/teachers/tindex/overview.cfm?id=newborn>

- Activity Resources Packet: Genetic Screening of Newborn Infants: What Should We Test And Why?
- Additional Resources: an extensive listing of additional resources on topics covered in this module.

III. MATERIALS

A. Detailed Materials List

- Activity Resources Packet for Genetic Screening of Newborn Infants: What Should We Test And Why?
- 3-ring binder or file folders for each Task Force (optional)

B. Material Preparation Guide

As there is a large amount of material in the Activity Resources Packet, you may want to prepare a 3-ring binder or set of file folders for each team. Suggested tab labels for the materials are:

- (Before 1st tab, if using binders with 8-tab dividers)
 - Front page
 - Table of contents
- Introduction
 - Your Challenge
 - What is a Task Force?
 - Key Issues for the Task Force to Consider
 - What is Newborn Genetic Screening?
 - Table 1: Disorders Tested for in Newborn Screening Programs
- Medical Info.
- Demographics
- Legislation
- Sample collection
- Cost
- References
- Glossary

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IV. STANDARDS

A. U.S. National Science Education Standards

Grades 5-8:

- Content Standard C: Life Science - Reproduction and Heredity; hereditary information is contained in the genes, located in the chromosome of each cell
- Content Standard C: Life Science - Reproduction and Heredity; the characteristics of an organism can be defined in terms of a combination of traits.
- Content Standard E: Science and Technology - Understandings about science and technology; perfectly designed solutions do not exist. All technological solutions have trade-offs, such as safety, cost, efficiency and appearance.

Grades 9-12:

- Content Standard C: Life Science - Molecular Basis of Heredity; in all organisms, the instructions for specifying the characteristics of an organism are carried in DNA.
- Content Standard C: Life Science - Molecular Basis of Heredity; changes in DNA (mutations) occur spontaneously at low rates. Some of these changes make no difference to organisms, while others can change cells and organisms.
- Content Standard F: Science in Personal and Social Perspectives - Science and Technology in Local, National and Global Challenges; science and technology are essential social enterprises, but alone they can only indicate what can happen, not what should happen. The latter involves human decisions about the use of knowledge.
- Content Standard F: Science in Personal and Social Perspectives - Science and Technology in Local, National and Global Challenges; understanding basic concepts and principles of science and technology should precede active debate about the economics, policies, politics and ethics of various science - and technology-related challenges.
- Content Standard F: Science in Personal and Social Perspectives - Science and Technology in Local, National and Global Challenges; individuals and society must decide on proposals involving new research and the introduction of new technologies into society. Decisions involve assessment of alternatives, risks, costs, and benefits and consideration of who benefits and who suffers, who pays and gains, and what the risks are and who bears them.

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B. AAAS Benchmarks for Science Literacy

Grades 9-12:

- The Living Environment: Heredity - some new gene combinations make little difference, some can produce organisms with new and perhaps enhanced capabilities, and some can be deleterious.
- The Living Environment: Heredity - the information passed from parents to offspring is coded in DNA molecules.
- The Living Environment: Heredity - genes are segments of DNA molecules. Inserting, deleting, or substituting DNA segments can alter genes. An altered gene may help, harm, or have little or no effect in the offspring's success in its environment.
- The Living Environment: Cells - the genetic information encoded in DNA molecules provides instructions for assembling protein molecules.
- The Human Organism: Human Development - the development and use of technologies to maintain, prolong, sustain or terminate life raise social, moral, ethical and legal issues.
- The Human Organism: Physical Health - faulty genes can cause body parts or systems to work poorly. Some genetic diseases appear only when an individual has inherited a certain faulty gene from both parents.

C. Utah Secondary Science Core Curriculum

Intended Learning Outcomes for the Utah Secondary Core Curriculum in Science

4. Demonstrate Awareness of the Social and Historical Aspects of Science
 - g. Accept responsibility for actively helping to resolve social, ethical and ecological problems related to science and technology.
 - h. Respect the contributions scientists make to informing public policy debates, but acknowledge that policy issues cannot be resolved by science alone because value issues must also be considered.

7th Grade

Standard 4: Students will understand reproduction and heredity of organisms

Objective 3: Analyze issues related to genetics

- Cite advantages and disadvantages of genetic technologies

Biology (9-12)

Standard 4: Students will evaluate the significance and impact of genetic alteration on living organisms

Objective 2: Describe how mutations affect genes and genetic expression

- Research and report on various genetic disorders

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Human Biology (9-12)

Standard 3: Students will analyze the how genetic information is passed from one cell to another

Objective 3: Describe the significance and impact of genetic alteration on living things

- Identify and discuss factors that may alter genes or chromosomes and consider the effects
- Describe applications of genetic technologies
- Evaluate a publicized position concerning a genetic technology

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V. CREDITS

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Acknowledgements:

The values discussion questions were presented by Lola Szobota, Hanover Park High School, East Hanover, NJ at a workshop at the 2000 Annual Meeting of the National Association of Biology Teachers.

The Activity Timeline for 10 days was developed by Andee Bouwhuis, Science Teacher, South Hills Middle School, Riverton, UT for use with her classes.

The Ethical Decision-Making Framework is from: Campbell C, Donnelly S, Jennings B, and Nolan K. *New Choices, New Responsibilities: Ethical Issues in the Life Sciences*. Briarcliff Manor, N.Y.: Hastings Center, 1990.

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A. Activity Timelines

The flexible nature of this activity allows it to be adjusted for various amounts of time. Below are several suggested timelines.

TIMELINE 1 : 2 days	
Day 1: 50 minutes	<ul style="list-style-type: none"> Brief introduction to newborn screening Students write a paragraph about their pre-activity views Assign Task Force teams, roles and one genetic disorder/ team Students sharing the same roles meet Task Force teams meet and divide background material readings as homework
Day 2: 50 minutes	<ul style="list-style-type: none"> Task Force teams meet and discuss a policy for one genetic disorder Teams present their policy to the class Class discussion of the policies Students write a paragraph about their post-activity views

TIMELINE 2 : 4 days	
Day 1: 50 minutes	<ul style="list-style-type: none"> Introduction to newborn screening Students write a paragraph about their pre-activity views Assign Task Force teams, roles and two genetic disorders/team Assign background readings appropriate for each role
Day 2: 50 minutes	<ul style="list-style-type: none"> Students sharing the same roles meet Task Force teams meet to discuss policies for two genetic disorders
Day 3: 50 minutes	<ul style="list-style-type: none"> Task Force teams complete their discussion, write their policy plan and plan a presentation
Day 4: 50 minutes	<ul style="list-style-type: none"> Task Force team presentations Class discussion Students write a paragraph about their post-activity views

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A. Activity Timelines *continued*

TIMELINE 3 : 10 days	
Day 1: 90 minutes	<ul style="list-style-type: none"> • Values discussion • Introduction to newborn screening • Students write a paragraph about their pre-activity views • Familiarize students with the available materials and resources • Assign Task Force teams; students choose roles • Students meet as role groups
Day 2: 90 minutes	<ul style="list-style-type: none"> • Brief question-and-answer session • Guest speaker on newborn screening • Math activity using demographic data
Day 3: 90 minutes	<ul style="list-style-type: none"> • Brief question-and-answer session • Role groups conduct interviews (phone or in person) with adult representatives of their role
Day 4: 90 minutes	<ul style="list-style-type: none"> • Brief question-and-answer session • Discuss plan of action for Task Forces • Task Force teams meet to decide on key issues to research, divide activity materials and read them
Day 5: 90 minutes	<ul style="list-style-type: none"> • Brief question-and-answer session • Task Force teams conduct Internet research
Day 6: 90 minutes	<ul style="list-style-type: none"> • Brief question-and-answer session • Role groups meet to share issues and information from their research • Task Force teams meet to discuss and debate policy for 12 genetic disorders using the ethical decision making framework and key issues
Day 7: 90 minutes	<ul style="list-style-type: none"> • Brief question-and-answer session • Task Force teams continue to meet
Day 8: 90 minutes	<ul style="list-style-type: none"> • Brief question-and-answer session • Task Force teams prepare a written policy plan and a presentation based on it
Day 9: 90 minutes	<ul style="list-style-type: none"> • Brief question-and-answer session • Students videotape their presentations
Day 10: 90 minutes	<ul style="list-style-type: none"> • Students view a videotape of their presentations and those of other classes • Class discussion • Role groups meet to discuss compromises and successes • Students write a paragraph about their post-activity views

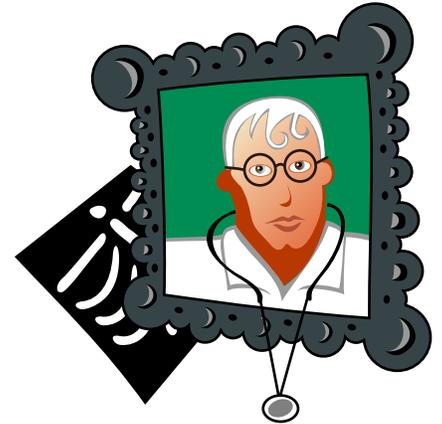
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B. Task Force Roles

Task Force _____

Doctor:

You are a specialist in genetic disorders, concerned about childrens' health and well-being. You believe that genetic testing will assist doctors in providing better medical care. Not only do you know a lot about genetic disorders, you also realize how important it is to teach the public and the parents of newborns about these disorders.



Some of your questions are:

- What treatments are available for each disorder, and at what age does treatment begin?
- How sensitive and reliable is each test?
- How should health care workers counsel parents and families?
- What laws are needed to protect doctors?



Task Force _____

Lawyer:

You are concerned about protecting the rights of the individual and the rights of health care institutions. You know many legal issues will arise with an expanded screening program.

Some of your questions are:

- Who keeps the screening results? Who has access to them? What are the confidentiality issues?
- Will hospital administrators be sued over testing errors or if tests are not given?
- Should parents have the right to refuse screening?
- Are laws needed to protect citizens' or doctors' rights?



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B. Task Force Roles *continued*

Task Force _____

Legislator:

Your major concern is that any screening program must be cost-effective. But you also see the importance of a comprehensive screening program for public health and disease prevention. With a limited budget, you know that an expanded genetic screening program for newborns could sacrifice some other health program. As an elected official, you also pay attention to public opinion.



Some of your questions are:

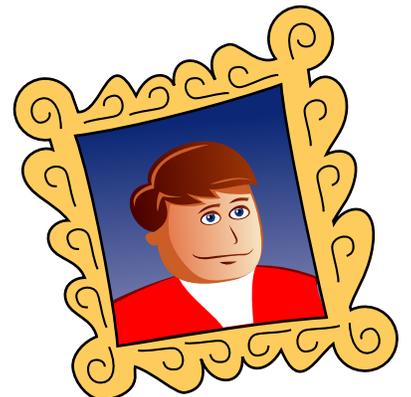
- How much will the proposed genetic screening program cost and who will pay for it?
- Based on demographics, how many people in my constituency are likely to be affected by each genetic disorder?
- How will constituents who do not have children react to their tax money being used for newborn screening as opposed to something else that would benefit them personally?
- What policies have other governments enacted?



Task Force _____

Lobbyist for a genetic disorder interest group:

You speak for those affected by genetic disorders. The efforts of your forerunners led to the initiation of newborn genetic screening in the 1960's. You support genetic screening when early identification and treatment of a disorder will make a difference to that person.



Some of your questions are:

- Are the proposed tests the most sensitive and reliable ones available?
- Who will have access to the screening results?
- Will test information result in prejudice against individuals with genetic disorders?
- Will test information make it difficult for an individual to obtain health insurance? Will a predisposition to a genetic disorder be considered a "pre-existing condition"?

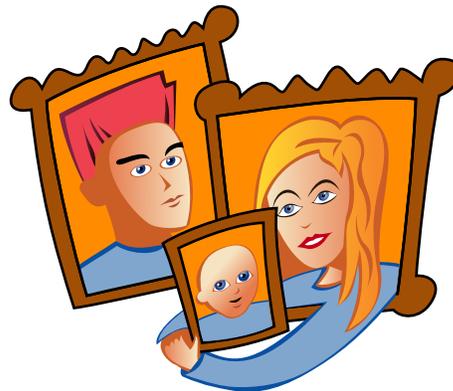
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B. Task Force Roles *continued*

Task Force _____

Parent of a newborn infant:

You are concerned about the health of your newborn, both now and as the child grows up. Your child was screened for several genetic disorders soon after birth. You have heard that tests for other genetic disorders are available and wonder if your child should have been screened for those as well. Your concerns extend to the parents of other newborns as well.



Some of your questions are:

- What are the effects of the genetic disorders to be tested, and how can they be treated?
- What genetic tests are available?
- Will parents be able to choose or refuse tests?
- Will testing (or lack of testing) be a source of distress for newborns or their parents?



Task Force _____

Parent of a child with a genetic disorder:

Your 1-year-old child was not tested for this disorder at birth, but only later after symptoms appeared. You wonder if newborn screening would have led to earlier and perhaps more effective treatment for your child. You oppose providing genetic screening only to those who can be identified as belonging to particular racial and ethnic groups, since some infants who have the disorder but who do not belong to those groups may be missed. You voice the concerns of other parents whose children have genetic disorders.



Some of your questions are:

- What are the effects of each genetic disorder to be tested, and how can it be treated?
- What tests are available, and how sensitive and reliable are they?
- Who will have access to the test results?
- Will test information result in prejudice against individuals with genetic disorders?

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B. Task Force Roles *continued*

Task Force _____

Officer from a health insurance company:

You know that genetic screening will add to the cost of health care. However, you also know that early identification of some genetic disorders can lead to improved treatment and decreased health care cost in the long term. You would like access to test results to help predict insurance costs.



Some of your questions are:

- What is the cost per test and the total for screening?
- Who will pay for the screening program?
- Are the benefits of an expanded testing program worth the cost?
- Will early identification of persons with genetic disorders lead to cost savings in treatment or care?



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C. Procedure Summary

1. Write your thoughts about this question: "If you had a newborn child, would you want it to be tested for genetic disorders? Explain."
2. Accept a challenge: read the governor's letter inviting you to join the Task Force.
3. Form a Task Force: the biographies will help you select members.
4. Optional: meet with members of other Task Forces who have the same role to discuss the issues from your role's viewpoint.
5. Make a research plan as a committee: What criteria or issues should your Task Force consider? Hint: make a chart or list of issues to guide your research. Decide what material each member will review.
6. Review available information: use the resources at this website and/or consult outside material.
7. Meet as a Task Force committee: discuss what you have learned and decide what policy you will recommend.
8. Write a public policy: prepare a written statement of your Task Force's recommendations.
9. Present your Task Force recommendations to the class: be prepared to discuss your policy and others in a constructive way.
10. Compare your current ideas with those you originally wrote down in Step 1: Have you changed or extended any of your views?

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D. Ethical Decision Making Framework

This framework provides a guide for Task Force discussion and decision making, or for assessment. This decision-making framework can be used for any bioethics case study discussion. The six steps are listed below with sample answers.

State the ethical question(s) that is raised in this situation.

This question usually begins with “should”. For example: “Should a test for alpha-1 antitrypsin be included in newborn screening?”

List all of the relevant facts.

These might include symptoms, treatments, age of onset, incidence, demographics, available test(s), cost, and current laws.

Identify the stakeholders (those who will be affected by the decision being made) and their primary concerns.

These include the individuals, organizations and/or entities that will be affected by the decision. Any of the Task Force roles might be listed along with their primary concerns.

Identify the values that play a role in this issue.

Answers will vary.

List several possible solutions.

These might include: test all newborns for the disorder; test only those populations most at risk; do not include a test.

Choose the solution you think is best and justify your choice.

Answers will vary. The solution should be consistent with the facts and values identified while meeting the concerns of the stakeholders.

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E. Values Discussion Questions

Bioethical decision-making is based not only on facts but also on values. Students participating in the Task Forces are asked to respect each others' viewpoints while working to reach a consensus policy. To assist students in this aspect of the activity, we suggest beginning this module with a discussion of values. Record students' responses on the board as you discuss each of the following questions. You may find it helpful to have students discuss each question in small groups of 2-3 before the group discussion.

1. Where do values come from?

Responses may include parents, family, church/religion, friends, self, teachers, the media, and society.

2. How are values taught?

Responses may include through example, "being told", observation, experience, and religious texts such as the Bible, Koran, and Torah.

3. Can we give names to values?

Responses may include honesty, being fair, loyalty, keeping your word, being trustworthy, providing for your husband/wife/child, empathy, caring for your elders, not shaming your family, not harming others, money, love, personal health, physical appearance, having fun, being in charge (power), being well-known (prestige), recognition, skill at ____, and being respected.

4. How can we categorize these values?

Responses may include individual, family, religious, and societal.

5. Are there universal values that many people agree on? Which values listed in response to question 3 are universal values and which are more individual values?

This discussion can be used to model respectful discussion and reaching consensus.

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F. Discussion Questions

These questions may be used in addition to the list of key issues that help guide student research, or as an assessment.

- 1. What is a genetic screening program? What is its purpose?**
- 2. Should genetic testing of newborns be required by the government or be done at the option of parents or doctors?**
- 3. Suppose you are a genetic research scientist or a genetic counselor working on human genetic disorders. Would widespread genetic screening of newborns help you? Should you have access to that information?**
- 4. Who should be consulted when laws regarding testing policy and privacy of genetic data are written?**
- 5. Suppose you work for a large medical supply company or commercial medical laboratory involved in genetic testing. In what ways is your view of the question of newborn testing valuable? In what ways might you be biased?**
- 6. How does testing for a genetic disorder differ from other medical tests, such as one for the presence of HIV (the AIDS virus) or for a bacterial infection?**
(Hint: keep in mind that HIV is infectious through bodily fluid contact, is treatable but incurable and can cause a fatal illness. Bacterial infections are easily infectious, range from mild to deadly, and are generally curable through antibiotic treatment.)
- 7. What additional information would you like to have had in order to make good recommendations in your policy report? Would your Task Force recommend additional funding to support new research or extended medical services related to this topic?**
- 8. In the U.S. should newborn screening policies continue to be determined by individual states or should there be federal guidelines or laws?**

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G. Math Activity

The online resources provided in the Newborn Testing Module can be used in a variety of ways, including quantitative analysis of census data.

This mini-activity is a quick way to sharpen students' math skills and use of quantitative data. Done as an informal, quick question and answer challenge in class, this extension activity can be effective in 15 - 20 minutes. Use these questions to prompt students to read data charts carefully, do simple math, and reason with quantitative data using the information in the Demographics section of the student Activity Resources Packet. Although these questions are recommended as a quick oral drill, you may prefer to print them for distribution to students.

The following challenge questions are based on the census data. You may want to adjust them to reflect specific interests of your class. You may substitute the country or U.S. state of your choice in questions 3-8.

1. What is the ethnic population breakdown by percentage for your country or U.S. state?
Referring to Tables 2-6 record the data listed in the third column. Notice that based on the way the census is taken, the sum may not be 100.
2. What do the figures in the second column represent in Tables 2-6?
Total population for the ethnic group in a particular state or country, based on 2000 or 2001 estimates.
3. A. Using the data for the Asian population, what would you estimate the total population of California to be? *Estimate total population as follows: Population size of this ethnic group divided by the percentage for the group. For California: $3,697,513 / 0.109 = 33,922,138$.*
 B. How does this estimate compare to the total population number for California shown in Table 1?
Total California population from Table 1 is 33,871,648. The population estimate based on the Asian population is high by 50,490 people. ($33,922,138 - 33,871,648 = 50,490$).
 C. Estimate the total population of California using data for the black population and compare to Table 1.
For California: $2,263,882 / 0.067 = 33,789,284$. This estimate is low by 82,364 people. ($33,871,648 - 33,789,284 = 82,364$).
 D. Estimate the total population of California using data for the Caucasian population and compare to Table 1.
For California: $20,170,059 / 0.595 = 33,899,259$. This estimate is high by 27,611 people. ($33,899,259 - 33,871,648 = 27,611$).

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G. Math Activity *continued*

4. A. Do the same calculations of total population for Utah.
Total population for Utah is 2,233,169.
Based on the Asian population the estimated total population is $37,108 / 0.017 = 2,182,824$.
The difference between the estimated and real numbers is $2,233,169 - 2,182,824 = 50,345$ low.
Based on the black population, the estimated total population is $17,657/0.008 = 2,207,125$.
The difference between the estimated and real numbers is $2,233,169 - 2,207,125 = 26,044$ low.
Based on the Caucasian population, the estimated total population is $1,992,975 / 0.892 = 2,234,277$. The difference between the real and estimated numbers is $2,234,277 - 2,233,169 = 1,108$ high.

B. Do the figures agree when you compare results based on the different ethnic data?
No. The estimates range from 1,108 high to 50,345 low.

C. Try this calculation for your state or country.
Responses will vary.
5. Calculate the percent change from 1990 to 2000 in the Hispanic population of California. In 1990 the Hispanic population of California was 7,704,348.
Referring to Table 5, the total Hispanic population of California in 1999 was 10,966,556.
Subtract the 1990 population total from this number to get the numeric change. Divide this number by the 1990 population total to calculate percent change. $(10,966,556 - 7,704,348) / 7,704,348 = 42.3\%$ increase.
6. If 912,000 Caucasians and 50,200 blacks moved to Rhode Island next year, how would this alter the percentage of blacks and Caucasians in the state?
The Rhode Island black population is 4.5% black and 85% Caucasian. Students should be able to estimate that these new arrivals would approximately double each ethnic group, keeping the percentages almost unchanged. i.e. 92.93% Caucasian and 5% black.
7. In how many U.S. states is the Native American population equal to or more than 5%?
Look for the percentage figures of 5% or more in the third column of Table 3.
Number of states = 6.

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G. Math Activity *continued*

8. What percent of the total U.S. population lives in the state of A. California? B. Florida? C. Arkansas?

Referring to Table 1, divide the total population of the state by the total population of the United States. Total population of the U.S. is 281,421,906.

California = $33,871,648 / 281,421,906 = 12.0\%$.

Florida = $15,982,378 / 281,421,906 = 5.7\%$.

Arkansas = $2,673,400 / 281,421,906 = 0.9\%$.

9. Consider the issue of making a genetic screening program cost effective. If a particular disorder occurs mainly in a particular minority population, is the total population size or the percentage population for that minority of more importance in deciding if the test should be included in screening in a particular country or U.S. state?

There is no "correct" answer. Students should realize that a larger total population for a particular group targeted by the test means a larger cost for screening. However, this cost may be partially offset by the larger overall tax base. Percentage of population for a particular group indicates the likelihood of positive results for a particular test.

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H. Short Essay Questions

- 1. In your own words, write a short description of the public policy recommended by your Task Force.**
Responses will vary among individual students.
- 2. In your own words, write a short description of your views through the role of the particular Task Force member you played.**
Responses will vary among individual students.
- 3. Consider the question, “If you or your family had a newborn infant, would you want the child to be tested for genetic disorders? Explain.” How do your views now compare with those you recorded before you carried out this activity?**
Responses will vary among individual students.
- 4. What is “public policy”? Who determines it?**
Public policy is a general plan of action or intent that is decided by a group of citizens or a government body. It should be well-reasoned and supported by evidence. It takes into account factual information and values. It should consider the impact of any actions that are recommended.
- 5. What does genetic screening reveal?**
Genetic screening reveals whether or not an individual has inherited the genetic make-up underlying a particular disorder. It does not mean that the individual has or may ever develop symptoms for the disorder.
- 6. Why might newborn screening for genetic disorders be helpful?**
To determine inherited disorders early so that they can be treated or so that preparations can be made for possible future health problems; to acquire data to help with research and medical decisions relative to the entire population; to inform parents about potential genetic issues if they plan to have more children.
- 7. Why might newborn genetic screening be harmful?**
Anxiety for parents; invasion of privacy; cost to individual or to state for the tests; potential for prejudice.
- 8. What factors did your Task Force consider in making its recommendations?**
Responses will vary with individual students. Answers may include cost of screening, cost of treatment, cost to society of the illness, effectiveness of early treatment, severity of disorder, how widespread the disorder is, inconvenience to medical staff or parents, invasion of privacy, importance of collecting medical data for future research, importance of information regarding future reproductive decisions, anxiety or relief in response to test results.

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H. Short Essay Questions *continued*

- 9. What is the connection between demographics and incidence of a genetic disorder in planning a public policy?**

Disorders vary in incidence, that is, some occur more frequently than others. The incidence also may differ among different ethnic subgroups of the overall population. Population distribution in different regions makes some disorders more common in one area than another. Since screening policies are set by each country or U.S. state, these differences may influence policy.

- 10. What did your Task Force recommend should be done with genetic data from screening procedures? To whom is it of value?**

Responses will vary with individual students. The data are of value not only to the parents or newborn and their physicians but also to genetic researchers and possibly to insurance companies.

- 11. Name three genetic disorders for which screening is available and give a brief description of each one.**

Students may draw on information from the medical information sheets for this question.

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I. Sample Letter to Parents

Dear Parent:

Next week our class will begin an activity on “Genetic Screening of Newborn Infants”.

As you may know, blood samples are collected from all newborns by means of a heel stick soon after birth. These samples are used to screen for several genetic disorders. Discovery of the genes responsible for many genetic disorders as well as technological advances have made it possible to test for more disorders than are currently included in this screen. Despite the fact that we could test for these disorders, should we?

Students in our class will participate in simulated government Task Forces charged with making these public health policy decisions. Each student will be assigned the role of a person on the Task Force (such as doctor, lawyer, legislator, or parent of a child with a genetic disorder) and will approach the discussion from that point of view.

This activity will enable students to integrate and apply what they have been learning about genetics to a real-life situation. Students will be learning about genetic disorders, newborn screening programs and current laws as well as decision-making, teamwork and careers.

I encourage you to discuss the issues raised by this activity with your student as they work with their Task Force team to formulate a policy. If you have questions, please contact me at:

Sincerely,

Assessment Rubric: Genetic Screening of Newborn Infants: What Should We Test and Why?

Written Policies or Presentations should include:

- A clear focus and objective
- The state or country for which your screening program was developed
- The newborn screening tests you recommend and why
- Supporting data - demographic, medical, etc.
- Recommended policies for at least 2 issues in addition to specific disorder tests
- Everyone on your Task Force

GRADING RUBRIC FOR WRITTEN POLICIES OR PRESENTATIONS		
Presentation component	Possible points	Points earned
Includes Task Force recommendations for genetic disorders to be tested	20	
Data and demographics used to support recommendations	25	
Presents policies for at least two issues in addition to specific disorder tests	20	
State or country for which policy was developed is clear	5	
Clear focus and objective	10	
Creativity of presentation*	10	
All members of team participate in presentation*	10	
Total	100	

* presentation only