

Genetic Testing

Genes are passed down from parent to offspring. Scientists have discovered that changes in genes can cause cells to stop functioning properly. When this happens, there is a chance of developing a genetic, or hereditary, disease. Many provinces, including Ontario, have public health programs that conduct newborn genetic testing to identify changes in genes. In Canada, millions of babies are tested each year for genetic abnormalities that cause genetic diseases, such as cystic fibrosis (Figure 1).



Figure 1 Cystic fibrosis affects 1 in 3600 babies born in Ontario each year. Newborn testing can diagnose this genetic disease before a baby turns one month old to ensure early treatment.

Cystic fibrosis (CF), a hereditary disease caused by a defective gene, was recently added to Ontario's genetic screening program. Babies born with CF produce excess mucus, clogging the lungs and other vital organs. Early diagnosis and treatment of CF can prevent lung damage and increase life expectancy. 🌐

Genetic tests done later in life can also be useful. If a family member has developed a genetic disease, the rest of the family may want to be tested for the disease to find out if they carry the same genetic information. Genetic diseases include some cancers, celiac disease, and Alzheimer's disease.

The quality of life, and sometimes life expectancy, for individuals with genetic diseases is often improved by early testing and treatment. Doctors can suggest treatments that delay, or even stop, the disease. However, genetic testing is not always accurate. It might indicate that disease-causing genetic material is present when, in fact, it is not. Similarly, testing can sometimes fail to identify a genetic problem. Also, not everyone who has a genetic problem develops the disease. Often, diet, exercise, or medicines can reduce the chance of a disease occurring.

SKILLS MENU

- Defining the Issue
- Researching
- Identifying Alternatives
- Analyzing the Issue
- Defending a Decision
- Communicating
- Evaluating

To learn more about cystic fibrosis,

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LINKING TO LITERACY

Questioning

Critical literacy explores alternative perspectives through questioning. Throughout this role-playing activity, ask yourself, “What do the authors/speakers want me to think? What are their biases? How does knowing this help me fully understand this issue?”

The Issue

There are growing concerns about genetic testing of newborns. Genetic tests are quite expensive. Also, most people do not inherit disease-causing genes, so it would not be efficient to test everyone.

Some important questions need to be addressed:

- Should genetic testing in newborns be more widespread?
- Who should pay for the tests—the government or families?

A public meeting will be held to gather responses to these questions. A government representative will be there to receive recommendations. A variety of people will attend—members of the public, doctors, genetic testing lab technicians, government policy makers, religious leaders, and so on. You will take on one of these roles and participate in the public meeting. Your teacher will take on the role of the government representative.

Goal

To prepare recommendations for the Ontario government on the issue of genetic testing.

Gather Information



To prepare for the meeting, research the topic in small groups. Find out what tests for genetic diseases (in newborns and adults) are currently available in Ontario. Who pays for these tests?

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Identify Solutions

Develop answers to the Issue questions. Be sure to support your position with evidence.

Make a Decision

In your group, decide what recommendations you will make to the government representative. How will you present your recommendations to ensure that they are implemented?

Communicate



After all members of your group have presented their positions, discuss any disagreements. Agree on one person to summarize the recommendations in a brief speech at the public meeting.