

Case Studies

NOVA Activity | **Cracking the Code of Life**

Patenting of Genes

Dr. Lydia Mendoza and her company, Genmania, have spent years working to identify how the gene for albinism works. The mutation in this gene causes no pigment to be produced in the hair, skin or eyes. Identifying the gene would open the door to curing the condition. Finally, her team succeeds.

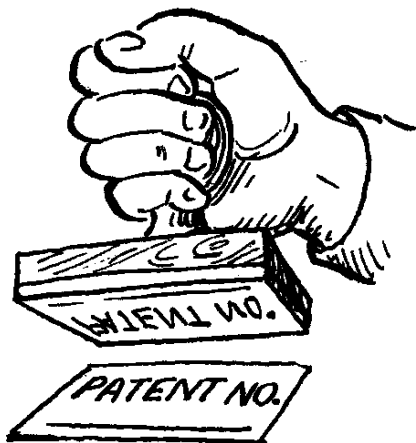
But the years spent on research were expensive. One way to make back that money is to patent the gene that team members just identified. Then, anyone who wanted to develop either treatments or tests would have to pay a fee to use the gene.

When a patent is submitted to the government, the company must prove that the item to be patented is original and patentable.

Questions

Write your answers on a separate sheet of paper.

- ① What do you think about patenting a gene that already exists in the human body?
- ② Should the government allow this gene to be patented? Why or why not?
- ③ Some think that genes should not be patented because they are a medical discovery and not an invention, and everyone should be allowed to use the information without paying. What do you think?
- ④ If, in the future, Genmania develops a test for this gene, should they be allowed to patent the test? Why or why not?



Therapy vs. Enhancement

Scientists in New Jersey have recently inserted a gene to create a mouse with increased capacity for learning and memory—basically, a gene that increased the animal's intelligence quotient (IQ).

Normal, average human IQ is about 100. Sometimes IQ can go way up to 130s, 140s, 150s, etc. An IQ of about 70 or below is considered to indicate mental disability.

Although currently highly theoretical and perhaps impossible, it might in the far future become possible to insert a human gene identified through the Human Genome Project to increase human IQ by 30 points. Consider these two scenarios:

- A couple has a 5-year-old son with Downs syndrome with an IQ of 70. They want to use gene therapy to insert a gene to increase the IQ of their son from 70 to 100 in order for him to function normally. This is considered gene therapy, where technology is used to help a person function better.
- A second couple has a 5-year-old son with an IQ of 120. They want to use the technology to bring their son's IQ up to 150. They feel he would then have a better chance to get accepted to a more prestigious university. This is called gene enhancement, where technology is used to help a person who is already at or above functioning levels to enhance a particular characteristic even more.

Questions

Write your answers on a separate sheet of paper.

- ① Should gene technology be used for gene therapy? Why or why not?
- ② Should gene technology be used for gene enhancement? Why or why not?
- ③ Who should decide? Parents? Doctors? Government? Society? Someone else?

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Newborn Screening

The Johnsons are married and their first child is just born. Marsha had a perfectly normal pregnancy and continued working until one week before the baby's birth. Al and Marsha's son appears, at birth, to be perfectly normal.

It is quite a surprise when the doctor calls them a few days after they take the baby home and asks them to bring him in for more tests. The doctor asks that both the mother and father come along because he wants to talk to them.

In his office the doctor says that a blood test was done while the baby was in the hospital as required by law. The test shows that the baby might have a genetic disease called phenylketonuria (PKU). However, more tests are needed to be sure. The Johnsons were told not to worry because there was a treatment for the condition. But neither Marsha nor Al has ever heard of the disease nor has anyone in their family.

Questions

Write your answers on a separate sheet of paper.

- ① If all newborns are going to be screened, should parents have a chance to refuse? Why or why not?
- ② If you were the Johnsons, what would you do next?
- ③ Should screening for diseases or defects be allowed when there is no cure or treatment? Why or why not?
- ④ Why might someone not want their child screened?
- ⑤ In the future, many more tests for genetic conditions will be available. Should we test all newborns for these, too? Why or why not?



Genetic Discrimination

Jonathon Jackson is 30 years old when his father dies of complications of Huntington's disease, a genetic condition that usually does not show up until a person is 35–40 years of age. Huntington's is characterized by a slow progression of physical and mental deterioration leading to death.

There is now a test available for the status of the Huntington's gene and Jonathon opts to be tested. Jonathon discovers he has the Huntington's mutation and faces a situation similar to his father's. This is called presymptomatic testing—checking for the presence of a harmful gene before any symptoms appear.

Somehow, Jonathon's health and life insurance companies learn about the results of his test and both cancel his protection. Then he is released from his job where he had worked faithfully for more than eight years. Company officials are afraid the medical costs of caring for his future medical complications will increase the group insurance rate.

Questions

Write your answers on a separate sheet of paper.

- ① What would you do if you were Jonathon?
- ② Should the company be allowed to make decisions based on medical information from Jonathon's DNA? Why or why not?
- ③ Should the company be able to make Jonathon's information available to other companies Jonathon is interviewing with? Why or why not?