

DECISIONS, DECISIONS!

By Sharon Nelson

Students will:

- use research/study skills to investigate a particular human genetic disorder;
- assume role(s) of doctor, genetic counselor, parents, sibling(s), affected individual (as the case requires);
- work cooperatively with other students;
- make informed decision(s) based on consideration of the bioethical issues involved;
- generate a written report summarizing the information gathered;
- give an oral presentation to the class, explaining their particular circumstance, the bioethical issues involved, and the decisions that were made by their group.

PROCEDURE

Students will be assigned to work in groups. Students will then choose a scenario for role playing. Their job is to research any and all information pertinent to their situation. Students will divide the roles in any way they see fit (one may choose to assume the role of parent, another the role of doctor, etc.) Once they have the necessary information, they must make some decisions regarding their situation, based on the bioethical issues involved. In addition to a 5 minute presentation, students must, with their group members, turn in one written report.

ROLE PLAY SCENARIOS

1. Your 16-yr-old daughter is 6' tall. After some discussion about her health and some probing by the family physician into your family's history, you are referred to a genetic counselor. The physician suspects the possibility of Marfan's Syndrome. Your daughter is currently on the varsity basketball team, and the season has just gotten underway.
Your joint income: \$75,000 Insurance: HMO, 80% coverage.
2. You and your wife have just lost a child to Tay-Sachs disease. You were referred to a genetic counselor before deciding to have more children.
Your joint income: \$95,000 Insurance: none
3. You and your husband are in your early forties and have decided you would like to have another child. Your physician refers you to a genetic counselor to discuss concerns regarding Down Syndrome.
Your joint income: \$150,000 Insurance: 80% coverage
4. You and your partner are both African American. You have two children: the second child, a girl, is an albino; the first child, also a girl, is visually impaired. You would like another child and seek the advice of a genetic counselor.
Your joint income: \$120,000 Insurance: full coverage.
5. You have one child, age 3, that has cystic fibrosis. You are three months pregnant with your second child; you and your husband separated a month ago. You have been referred to a genetic counselor.
Your income: \$45,000 Insurance: coverage through spouse's employer.
6. You have just married. You and your spouse are healthy but your husband's brother has two children with sickle cell anemia and your sister has the same disease. You are thinking of having children and have sought the advice of a genetic counselor.
Your joint income: \$81,000 Insurance: none

7. Your oldest child has PKU that was diagnosed at birth. You are unexpectedly pregnant with a second child and have been referred to a genetic counselor.

Your joint income: \$92,000 Insurance: through your employer jointly; your husband has just been laid off from his job.

8. You have hemophilia; you and your spouse would like to have children. You are referred to a genetic counselor.

Income: You just lost your job due to missing so many days of work for hospital stays. Wife's income as teacher's aide: \$23,000.

Insurance: none

9. You and your wife both have achondroplasia. You have just built a house to suit your needs. You would like to have a family and have been referred to a genetic counselor.

Joint Income: \$150,000. Insurance: HMO, 90% coverage

10. Gloria, 19, is married to Robert, 21, and they wish to start a family. Both of Gloria's parents are healthy (Sonia, 39, and Todd, 40). However, Gloria's grandfather died at the age of 43 after being diagnosed with Huntington's Disease. Gloria and Robert have many questions and seek out a genetic counselor for information.

Joint Income: \$92,000. Insurance: both, through employers

11. Jim, 32, and Tammy, 28, have had two healthy children: Twila, age 3 and Terry, age 5. They have, however, recently discovered some background news about Tammy's family that concerns them. They have just found out that a brother of Tammy's, who was confined to a wheelchair by age 10, has Muscular Dystrophy. They would love to have a family of four children. Genetic counseling is available.

Joint Income: \$120,000 Insurance: 50% coverage

12. As a result of information learned in his high school biology class, Jim thinks he may have Klinefelter's Syndrome. His parents have never heard of this disorder and they seek out a genetic counselor.

Joint Family income: \$92,000 Insurance: full major medical coverage.

13. Cindy, 38, is expecting her third child. She has two healthy children. Due to her age, her doctor suggests that amniocentesis be done at sixteen weeks post-conception. The karyotype reveals that the child has Turner's Syndrome. Cindy and her husband Stan are referred to a genetic counselor with this information in hand.

Joint Income: \$135,000 Insurance: self-insured