



Ethical, Legal, and Social Issues

Discussion Vignettes
National DNA Day
April 25, 2008

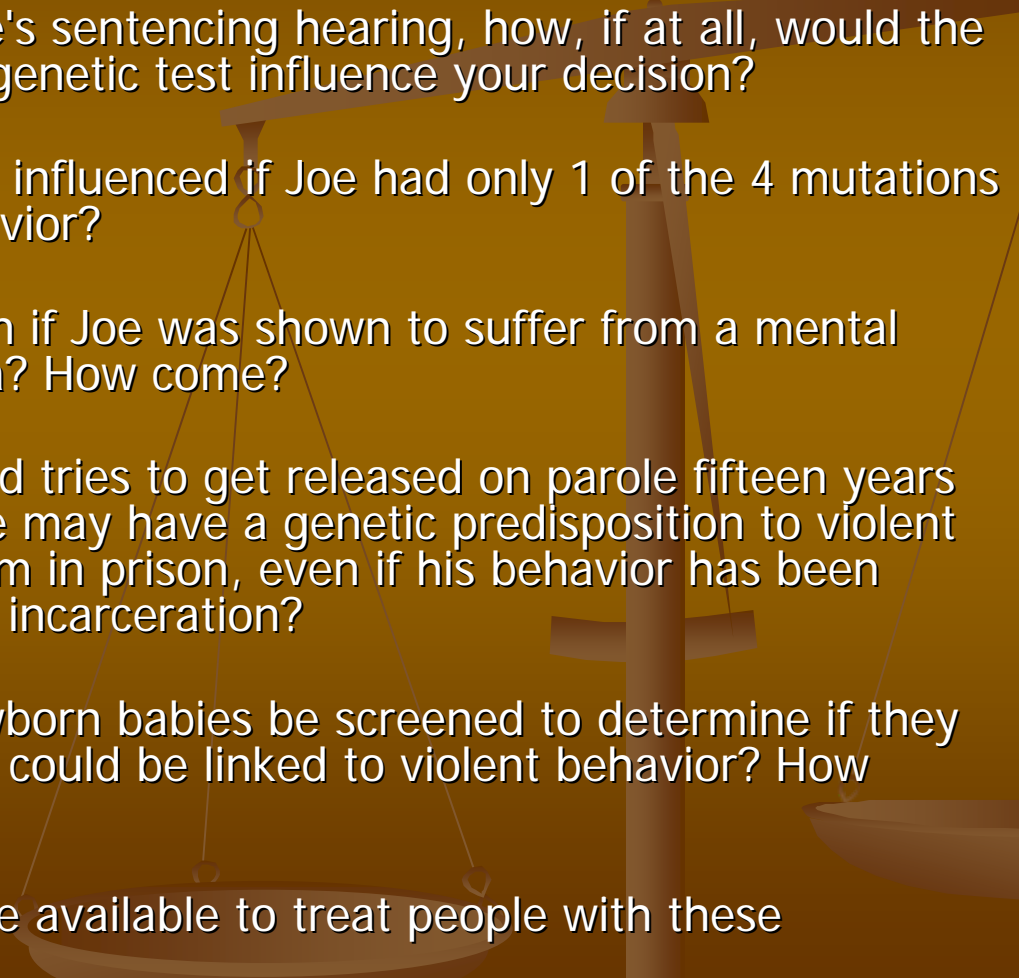
Ethical, Legal, and Social Issues

- Genetics is a complex field both scientifically and socially
- How will society respond to the implications of genetic information?
- What sort of issues should we be considering when new advances are made in the field?
- Who is capable of making decisions?
- The following vignettes are from the Online Education Kit: Understanding the Human Genome Project, produced by the National Human Genome Research Institute

Vignette 1:

- It is 2010, and Joe Schmoe has been charged with assault. The physical evidence supporting his guilt is overwhelming and he pleads guilty. In preparation for his sentencing hearing, Joe's lawyer asks him to undergo a series of genetic tests to determine whether he carries any of four genetic mutations that have been associated in research literature with violent behavior. The tests, while controversial, show that Joe's DNA does, in fact, contain all four mutations. Based on these results, Joe's lawyer will argue that Joe should be sent to a psychiatric facility rather than to state prison. He claims that because Joe's genetic status predisposed him to this violent act, it would be unfair to sentence him as a criminal for behavior over which he had essentially no control.

Questions for Discussion:

- If you were the judge at Joe's sentencing hearing, how, if at all, would the results of this controversial genetic test influence your decision?
 - How would your decision be influenced if Joe had only 1 of the 4 mutations associated with violent behavior?
 - What would be your decision if Joe was shown to suffer from a mental illness such as schizophrenia? How come?
 - If Joe gets sent to prison and tries to get released on parole fifteen years later, should the fact that he may have a genetic predisposition to violent behavior be used to keep him in prison, even if his behavior has been consistently good during his incarceration?
 - In the future, should all newborn babies be screened to determine if they have genetic mutations that could be linked to violent behavior? How come?
 - What if a medication became available to treat people with these mutations?
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Vignette 2:

- Alice Smith is a 75-year old woman with four adult daughters. Two years ago, she was treated for medullary thyroid cancer, a disease known to run in families. Alice dies. Now, Lucy, Alice's eldest daughter, has been diagnosed with medullary thyroid cancer. Lucy's physician tells her that she likely inherited the genetic alteration and encourages her to warn her siblings and her children. Lucy is very angry with her mother's physician for not warning her. She feels that her cancer could have been detected much earlier if she had known she was at increased risk. Lucy considers filing a lawsuit against the physician.

Questions for Discussion:

- Did Alice's physician have a duty to warn Alice that medullary thyroid cancer runs in families and she might wish to notify her family of their increased risk?
- Did Alice's physician have a duty to warn Lucy and her sisters that they were at increased risk for a genetically transferable disease?
- If Alice's physician had warned Alice, but she asked him not to say anything about this to her children, did the physician have a duty to keep silent or to warn the children?
- Would any of your answers change if you knew that an affordable test was available to detect early signs of medullary thyroid cancer?
- Would any of your answers change if an effective treatment was available to prevent the onset of this disease?



Vignette 3:

- Lisa and Tonya are college roommates. They agree on almost everything, but react very differently to an advertisement they saw in the local newspaper. A company was offering a blood test to screen for mutations in the BRCA1 and BRCA2 genes.
- Tonya's 44-year old mom was recently diagnosed with breast cancer. Fortunately, the disease was diagnosed early and successfully treated by removing the small lump from her breast. Tonya's mom is now feeling great and has fully recovered from the surgery. Lisa, on the other hand, has had a very different experience with the disease. When her mom was diagnosed with breast cancer at age 45, the cancer had already spread to other parts of her body. After two agonizing years of chemo- and radiation therapy, Lisa's mom died. It was a month before Lisa's high school graduation.

Vignette 3:

- Lisa desperately wants the genetic test. At this time, she feels convinced it will be just a matter of time before she will get breast cancer and die from it. She also says, that although she wants to have children some day, she won't if she is found to have one of the mutations in BRCA1 or BRCA2. She says she would rather adopt children than risk passing it on to her children.
- Tonya thinks the test is unnecessary. She says it costs too much and has heard how hard it is to get health insurance if you don't 'pass' a genetic test. Tonya believes that having a genetic test is just not worth the risks involved. She decides she will do self breast-exams regularly, since that is how her mom initially found her lump. She will also start having regular mammograms sometime in her 20s. She feels that while she may one day get breast cancer, she will catch it early and do as well as her mother did.

Questions for Discussion:

- Why do you suppose Tonya and Lisa have had very different reactions to the availability of the genetic test for breast cancer?
- How important do you think knowing this information is to Tonya? To Lisa?
- What scientific, medical and societal information should each consider before deciding whether or not to take the gene test?
- What are the potential benefits of the test? For Tonya? For Lisa?
- What risks are associated with genetic testing? Do you think there are risks to family members of Tonya or Lisa?
- Do you think the identification of a BRCA1 or BRCA2 mutation would have an impact on how people monitor themselves for breast cancer? How would the identification of a genetic mutation change your surveillance?
- If Tonya or Lisa decide to go ahead and have a genetic test, but no mutations are found, can they safely assume that there is NO chance that they will ever develop breast cancer?

Vignette 4:

James Sr. was a class valedictorian for Central High School in 1975 and earned an aerospace degree from Georgia Institute of Technology. He became an accomplished pilot for Skyway Airlines, but his dream of flying ended when his employer restricted him from being a pilot even though he had outstanding scores on all his physical tests, because a blood test revealed the sickle cell trait.

James Jr. has his father's ambition to become a pilot. He has just graduated from college with an aerospace engineering degree and was looking for a job as a pilot. His father has read recent newspaper stories about how most employees are not protected from genetic discrimination in the workplace. He is very worried that his son might also have sickle cell trait and be denied a job. James Jr. thinks his dad is overreacting and does not want to discuss these issues with his dad. He dismisses his father's concerns and is ready to interview with a number of airlines and willing to give a blood sample if necessary.

Questions for Discussion:

- **Are James Sr.'s concerns justified? How come?**
- **What lessons can be learned from the sickle cell screening programs of the 1970's?**
- **Is it reasonable for any employer to collect a blood sample from prospective employees and screen them for genetic variations?**
- **What additional concerns are there when a genetic test is available for disease with a higher prevalence in specific populations?**



Vignette 5:

John Jones has been working in a nuclear power plant for 15 years and has applied for a medical discharge because of the emergence of tumors in different parts of his body, all of which are attributed to a genetic condition called Von Hippel Lindau syndrome. In spite of these cancers, John has been an exemplary employee, having earned numerous awards throughout his career.

John learns that some workers who developed cancer were eligible for a substantial compensation from the employer. The company regulations governing qualification for the compensation package exempt diseases that are "hereditary and/or genetic" on the assumption that these diseases were incurred prior to employment with the company. Without this additional compensation, John's medical benefits do not cover a majority of his medical expenses and he is very concerned about how he will support his family.



Questions for Discussion:

- Is it fair for employers to differentiate between employees who have a condition with a known genetic basis and those with a medical condition not identified as genetic?
- Should employers hire individuals with a known medical condition? Should they be required to cover their medical benefits?
- Is it fair for employers to use genetic information? Under what circumstances? As more and more diseases are discovered to have a genetic component, what will this mean for employees and their medical benefits?
- Would your answers be different if John knew he was at risk for developing these cancers and sought employment in a potentially hazardous work environment?



Vignette 6:

✦ In 1999, scientists reported that a particular variant of the angiotensin–converting enzyme (ACE) gene was associated with superior physical endurance. The variant, known as the ACE insertion polymorphism, was found to be present in a higher proportion of elite endurance athletes, especially long distance runners, than in the general population.

✦ Marathon University (MU) is offering full–tuition scholarships and a guaranteed spot on the varsity track team to high school sophomores who "pass" a genetic test. If the parents sign a consent form, University doctors will screen them for the ACE insertion polymorphism.

Questions for Discussion:

- ✦ Is it likely that a single gene determines physical endurance?
- ✦ Are other genes likely to be important?
- ✦ What other factors determine whether a child will grow up to be an elite endurance athlete?
- ✦ Should parents be allowed to use genetic information to make decisions that will limit their children's choices in adulthood?
- ✦ What else should MU do if it is concerned about the well being of the future student-athlete?

Vignette 7

Kyle is a gifted athlete who led his college football team to the national championship and achieved his life's ambition of playing professional football. When he went pro, he signed a long term contract worth \$50 million over eight years. Throughout his first three seasons, his performance has not lived up to his coach's high expectations, and there has been talk that the team would like to trade him.

During a recent routine physical, team doctors offer the option for all players to take a series of genetic tests that would determine whether any players had a likelihood of developing heart disease. The doctors tell the players that the tests could inform them of potential increased risks for heart disease, but will not actually tell them if they have the disease. Though Kyle's team is not requiring any player to take the tests, they tell players that if a test gives a positive result, they won't be able to play football because football players are put through strenuous amounts of exercise that may put too much stress on their hearts. The team argues that learning such information could be extremely valuable and potentially life-saving to its players.

Vignette 7

After hearing all of the information and weighing the potential consequences, Kyle chooses to take the genetic tests. Based on the results of the tests, doctors learn that Kyle has a 25 percent chance of developing a specific heart disease that causes the heart muscle to thicken and work less efficiently. Because Kyle's football team does not want to take any chances, the front office decides to release Kyle from his \$50 million contract on medical grounds, even though Kyle may not ever develop any sort of heart disease.

Questions for Discussion:

- **Advances in technology are making it easier and less expensive to screen for genetic contributions to diseases. Should employers or insurance companies be allowed to require these types of genetic testing for diseases that might be related to the possible future health (or illnesses) of their employees, even when a person is not sick and/or has no family history of genetic disease?**
- **What are the positive and negative implications for employers and employees if employers (not just this football team) required these types of tests?**
- **Employers want to hire healthy people. Besides protecting employees from harm on the job, if they fail to provide a safe work environment, employers may be held legally responsible for any harm that comes to their employees. If work related activities (exercise in Kyle's case) involve a higher risk for disease or injury, should employers have the right to require genetic testing to exclude specific people from working in that environment? Why or why not?**

Vignette 8:



Anna and Carlos' first child Vincent suffers from a rare form of cancer. Doctors explain to Anna and Carlos that chemotherapy could potentially cure Vincent's type of cancer, but there is no guarantee this mode of treatment would work in his particular case. Another option is a bone marrow transplant, which involves killing Vincent's cells that do not work correctly and replacing them with healthy cells from someone else. If successful, the bone marrow transplant could cure Vincent of the cancer. However, for this treatment to work, the donor's tissue type would have to be a very close match to Vincent's, which is very rare.

Vignette 8:



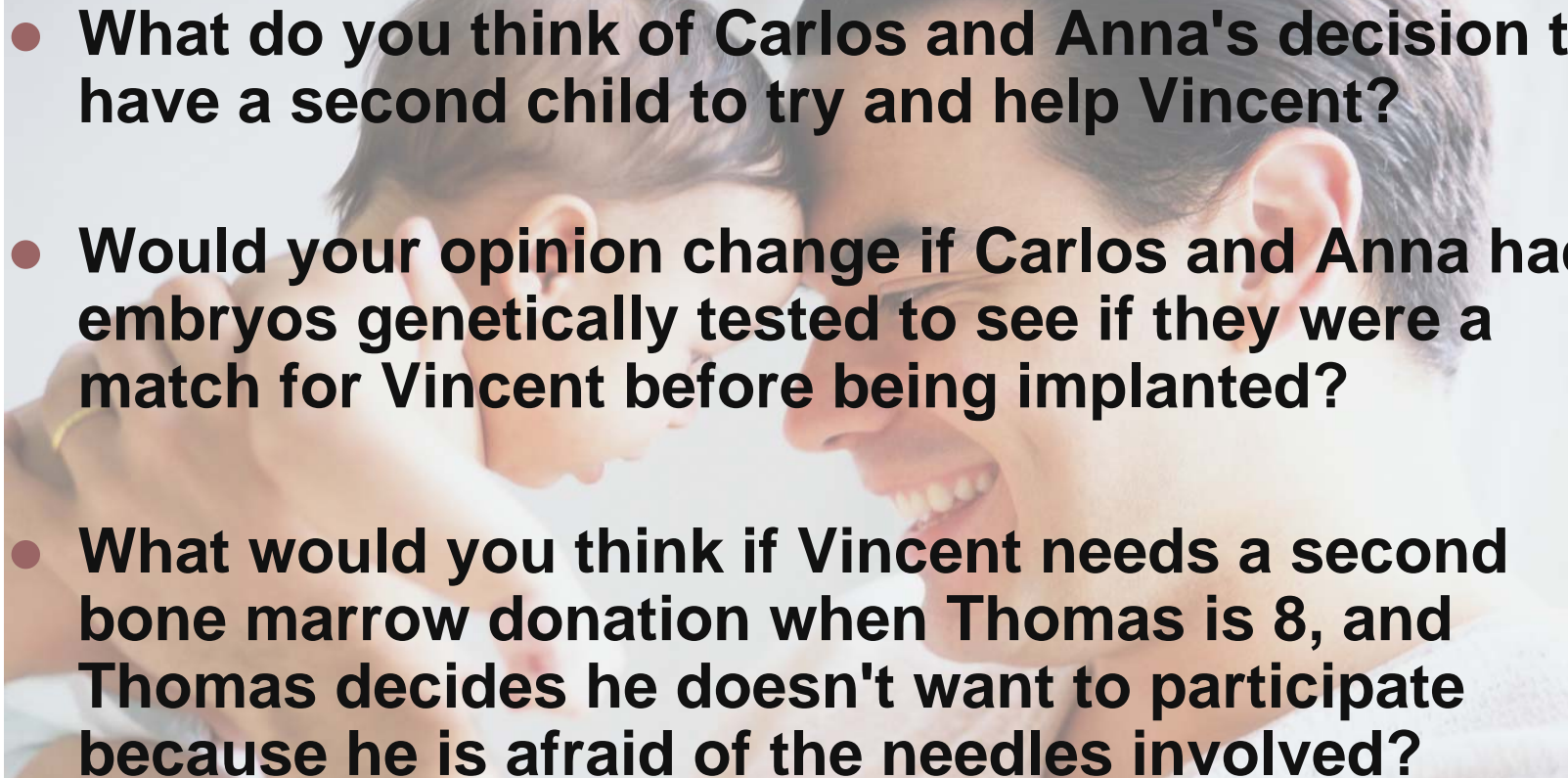
Anna and Carlos desperately want Vincent to have a bone marrow transplant, but neither of their tissue types are close enough to Vincent's to work. The doctor tells them they could have a second child, and, if this child's cells match Vincent's, the new baby could donate cells from its umbilical cord blood to complete a bone marrow transplant.

Vignette 8:



Anna and Carlos decide to go ahead and have a second child, whom they name Thomas. At the time of Thomas' birth, doctors collect the blood from his umbilical cord for possible use in Vincent's bone marrow transplant. The parents are overjoyed to learn that the baby's tissue is indeed a good match for Vincent's, but doctors caution that this treatment, while more successful than chemotherapy, still does not guarantee a cure. They caution that Vincent may need further tissue donations from Thomas later in life that require more invasive procedures, such as removal of bone marrow or organ donations, such as a kidney transplant.

Questions for Discussion:

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- **What do you think of Carlos and Anna's decision to have a second child to try and help Vincent?**
 - **Would your opinion change if Carlos and Anna had embryos genetically tested to see if they were a match for Vincent before being implanted?**
 - **What would you think if Vincent needs a second bone marrow donation when Thomas is 8, and Thomas decides he doesn't want to participate because he is afraid of the needles involved?**