Genes and Justice
Privacy Laws

- Lines of Privacy
  - Constitutional – 4th, 5th, & 14th Amendments
  - Common Law – invasion of privacy
  - Statutory Privacy – State & Federal statues aimed at specific medical practices

Bottom Line: No area of privacy is specifically designed to deal with medical matters
An employee sued her employer for the public disclosure of private facts.
Worker in a nuclear power plant
Previously had a hysterectomy
Fainted on the job and had to disclose medical history to a single co-worker for the purpose of company records.
Other co-workers thought she fainted from radiation
In order to stop rumors, her history was disclosed
Invasion of Privacy
Discussion Questions #1

- Who is right in this case, the defendant or the employee?

- Under what circumstance do employees have a right not to disclose their medical records?

- Under what situations do employers have the right to know an employees medical history?
Doctors & Privacy

- “Genes transcend individuals” (Green, 1999, p. 64).

- Justice – “The fair apportioning of the benefits and harms of research or clinical care as well as efforts to combat discrimination and prejudice” (p. 64)
Discussion Questions #2

- Do doctors have an obligation to their patient or to society? Individual vs. common good

- Should genetic information be treated in the same way as medical records? i.e. should genetic testing procedures and results be accessible to insurance companies?
Genes & Schooling

- Reasons for genetic information in schools
  - Educational: improve school performance, behavior management, cope with health impairments
  - Non-educational: public health screening
- Privacy and confidentiality
  - Genetic information is unlike other medical information—extremely sensitive, stigmatizing
  - Affects not only the individual, but also the family
Problems with Current Policies

- How genetic information is handled
  - Results of genetic tests may not be accurate
  - Difficult to understand even accurate genetic information

- Informed Consent
  - Paperwork leaves room for error
  - Parents may not understand risks involved
  - What role should children play in giving consent?
Discussion Questions #3

- Should genetic testing in schools be mandatory, optional, or outlawed?

- Many genetic disorders, while having negative aspects, also have several benefits (e.g., ADHD—creativity, sensitivity to environment). How do you think this should influence genetic testing?

- Should schools test for “advanced” genes in children as well as disabilities? What would the consequences be of such testing?
Genetic Discrimination

- Being denied or refused something (such as employment) on account of testing positive for a gene that raises the risk of developing a potential fatal or debilitating disease.
...In the Workplace

- Economic incentives - minimize labor costs (training employees, paying benefits, paying medical leave, etc) by minimizing people susceptible to disease

- Council on Ethical and Judicial Affairs of the American Medical Association (1991)-

  "genetic tests are poor at predicting diseases and even poorer at predicting whether a specific health problem will interfere with an individual’s work performance" (Hubbard & Wald, 1999, p. 133)
Discussion Questions #4

- Would this lead to a decrease in safety standards since all employees would be the top choices from the applicant pool?

- Should employers be allowed to screen for “hyper-susceptible” individuals if the environment calls for exposure to chemicals and toxins?

- If the results of genetic testing were released, would this effect interpersonal work relations (i.e., a predisposition to violence, or a superior ability to your own?)
MAOA & XYY Defenses

- MAOA – monamine oxidase A – a deficiency of this was found by Brunner et al., (1993) to be related to aggression (Andrews, 1999).
- The XYY defense has been around since the 70’s stating individuals with the XYY karyotype are more prone to antisocial behavior
- Antisocial acts, therefore, are not crimes but manifestations of an illness
- Responsibility (insanity?)
Predicting Violence

- Not all violence will be a result of a genetic deformity
- Historically, clinicians have been poor at predicting violence for patients that have a history of violence
- Implications of a violence gene-surveilliane, preventative education, medical intervention, & preventative detention.
Discussion Questions #5

- Will having a relative who has been violent in the past, stigmatize future relatives if an antisocial gene is discovered?
- Will genetic defenses be available to all defendants? (because genetic research is not at the same pace for all disorders)
- Will having someone with a certain disease stigmatize all other people with that disease?
- Will having a gene cause an individual to be victim to self-fulfilling prophecy?