Genetic Discrimination
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What is Genetic Discrimination?

• Unfair treatment
• Loss of opportunities
• Any different treatment that adversely affects the person at risk
  – Example: the denial, limitation or increased price of insurance
• Based solely on genetic susceptibility, not manifest disease
• Genetic discrimination is defined as the denial of rights, privileges or opportunities or other adverse treatment based solely on genetic information, including family history of HD.

• In the questions that follow the term “treated unfairly” refers to the experience of genetic discrimination.

  – From the RESPOND-HD survey, 2007
How is genetic information used?
How does your employer see you?
Four areas of concern

• Privacy (the right to control *collection* of genetic data): Others can collect information about your genetic status without knowledge or consent
  – Example: Companies may require a genetic test as a condition of getting health insurance

• Confidentiality (the right to control *disclosure* of information): Having genetic information discovered by commercial entities searching health records for genetic information
  – Example: Commercial entities search through medical records for genetic information
Four areas of concern

• Use of genetic information based on *false* beliefs about the significance of genetic traits
  – Example: Being excluded from a job opportunity because the employer thinks a genetic test predicts higher insurance costs – the BNSF case

• Use of genetic information to make a decision about something of importance
  – Example: Someone at-risk for HD is denied custody of children in a divorce because of the risk of developing genetic disease in mid-life
Genetic Information Non-disclosure Act of 2008

• First civil rights legislation of the 21st century
• Protects individuals from genetic discrimination in health insurance and employment contexts
• At least 15 years lobbying and awareness efforts by many groups
What is Genetic Information?

• Genetic information is defined as information about
  • an individual’s genetic tests;
  • the genetic tests of family members of an individual; or
  • the occurrence of a disease or disorder in family members of an individual
GINA: Health insurance provisions

• Prohibits specific types of access to genetic information
  – cannot require a genetic test (except for payment)
  – cannot request, require or purchase access to genetic information (but may acquire incidentally)
GINA: Health insurance provisions

• Prohibits use of genetic information for certain activities:
  – cannot determine eligibility or premium rating
  – pre-existing condition clause cannot be triggered unless symptomatic
Health insurance limitations

• Liability limited to $500,000 per violation

• Asymptomatic individuals only: it is not unlawful to discriminate against individuals based on manifest disease

• No protection for life, disability or long-term care insurance
GINA: employment provisions

- Apply to employers, employment agencies, labor organizations and training programs
  - Makes it illegal to request, require or purchase genetic information
  - May not refuse to hire or discharge any applicant or employee due to genetic information
  - May not discriminate with regard to terms, conditions of employment, compensation or privileges based on genetic information
GINA: employment provisions

- Employers may possess genetic information without penalty if voluntarily disclosed
- Incidental disclosures of genetic information are not protected
  - Includes Family Medical Leave Act absences, wellness programs
- GINA provides a prohibition against retaliation for bringing a complaint
Employment limitations

• Coercion: Employers may obtain genetic information after a conditional offer of employment and require an authorization for the release of their medical records
  – ADA § 102(d)(3)
What GINA does not protect

- Other types of genetic discrimination outside the realms of employment and health insurance
  - Obtaining a mortgage

  Legal disputes:
  - adoption,
  - custody,
  - contributory negligence

  Stigmatization of individuals who are at risk for genetic disease
Discrimination
- the denial of rights, privileges or opportunities or other adverse treatment based solely on genetic information
- Overt: forthright acknowledgment of reasons - we cannot afford to keep you on payroll
- Covert: stonewalling, pretext, covering up the real reasons for adverse treatment

Stigma
- Variable causes – disease, social status - leading to a social interpretation of the meaning of a condition
- “Negative stereotypes and isolation” (Sankar, 2005)
- “an attribute that conveys a devalued social identity within a particular context” (Crocker, Miller 2001)
- Subtle actions including exclusion, daily hassles
- Includes major events such as denial of job, insurance
Coping with discrimination and stigma

- **Internal / self coping mechanisms**
  - Meditation
  - Spirituality
  - Psychotherapy

- **External / social coping**
  - Participate in HDSA
  - Educate others
  - Complain / seek legal redress
What will GINA mean?

Will it make a difference in how people make health care decisions?

What are the trade-offs you make if you decide to/not to get a genetic test?

Will it make a difference to whom you feel safe to reveal genetic information?

Will you “stand out” *more* if the awareness of genetic discrimination is now raised?