



# Genetic Discrimination

Cheryl Erwin, JD, PhD

University of Texas

Medical School - Houston

June 2009 HDSA: Phoenix



**Huntington's Disease Society of  
America**

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2006 HDSA convention program is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

# 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 21<sup>st</sup> 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

- Internal / self coping mechanisms
  - Meditation
  - Spirituality
  - Psychotherapy
  
- External / social coping
  - Participate in HDSA
  - Educate others
  - Complain / seek legal redress

Coping with discrimination and stigma

# 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?