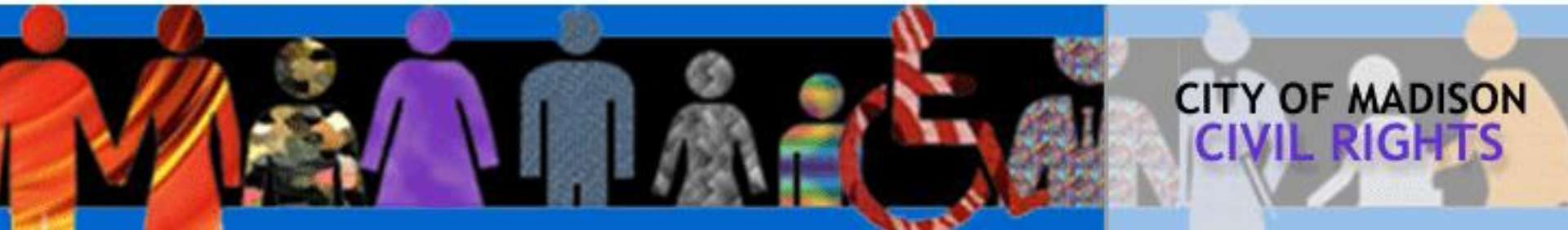




G.I.N.A


Genetic Information Non-Discrimination Act
Federal Proposed Legislation

August, 2010



City of Madison
Department of Civil Rights
Equal Opportunities Division

Developed by:
Melissa Gombar
and
Cathyanna Johnson



CITY OF MADISON
CIVIL RIGHTS

Title I

CITY OF MADISON
CIVIL RIGHTS

- Covers Health Insurance
- Departments of Labor, Treasury and Health and Human Services



Title II

CITY OF MADISON
CIVIL RIGHTS

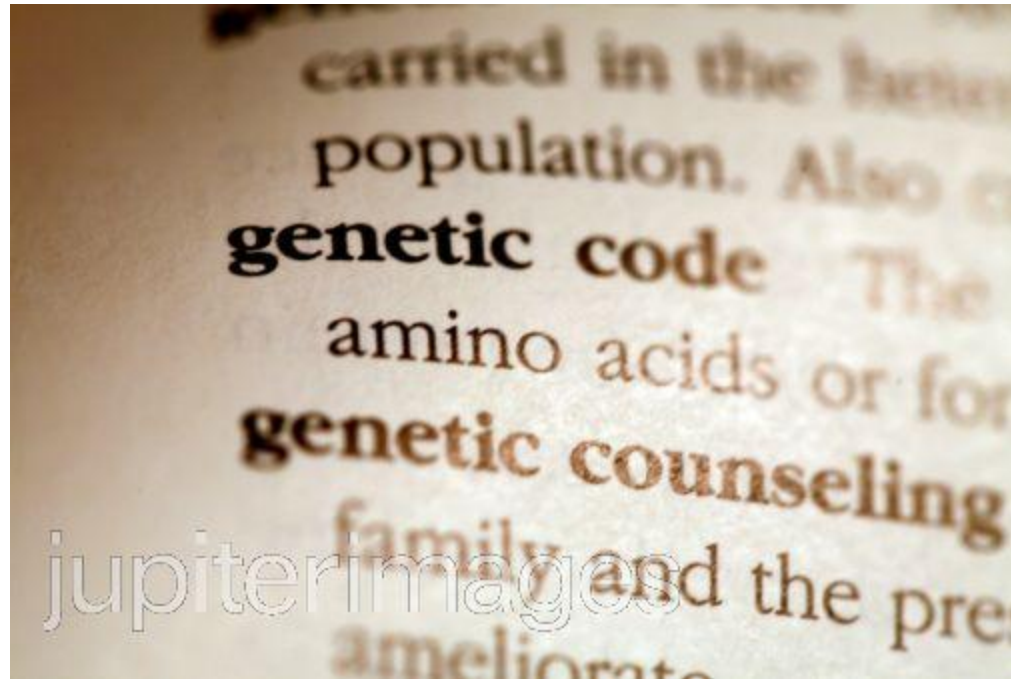
- Covers Employment
- Equal Employment Opportunity Commission (EEOC)



A banner at the top of the slide features a row of stylized human figures in various colors (orange, purple, blue, green, red) and a wheelchair icon. To the right, the text "CITY OF MADISON CIVIL RIGHTS" is displayed in a light purple font.

Title II

- Employers may not discriminate against employees or applicants because of genetic information
- Restricts acquiring genetic information
- Limits disclosure of genetic information



USEFUL TERMS



Non-Genetic Tests

- There are tests that are non-genetic
 - Fitness tests
 - Drug tests
 - HIV tests
 - H1N1 tests



Genetic Services

CITY OF MADISON
CIVIL RIGHTS

- Genetic Test
- Genetic Counseling
- Genetic Education
- Participation in Research Study



Genetic Tests

- Chromosomes
- DNA
- RNA
- Proteins
- Metabolites



Genetic Test Examples

Chromosomes, DNA, RNA, proteins and metabolites detect:

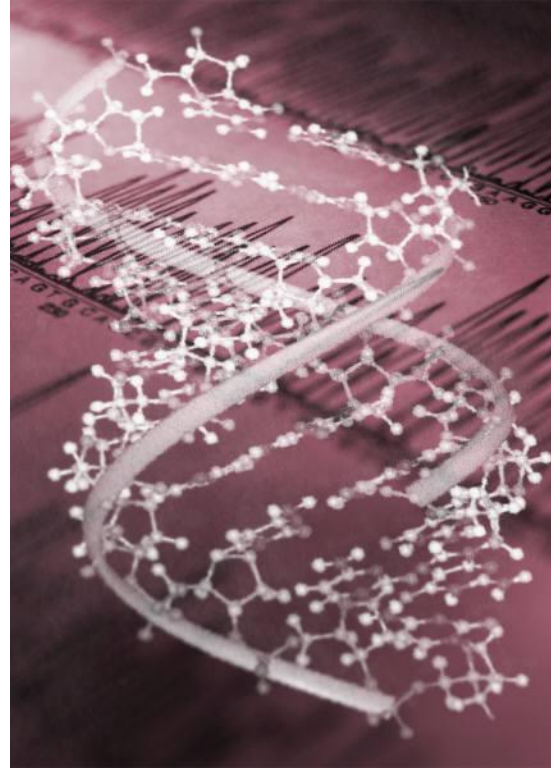
- Genotypes
 - Paternity Test
- Mutations
 - Sickle Cell Anemia
- Chromosomal Changes
 - Down Syndrome





Genetic Information

- Information about an individual's genetic tests
- Information about genetic tests of family members
- Recognized symptoms of disease or disorder of family members (family medical history)
- Request for or receipt of genetic services



GENETIC DISCRIMINATION



Discrimination

CITY OF MADISON
CIVIL RIGHTS

- Employers may not use genetic information to discriminate against employees in any aspect of employment:
 - Hiring
 - Firing
 - Layoff
 - Job Assignment



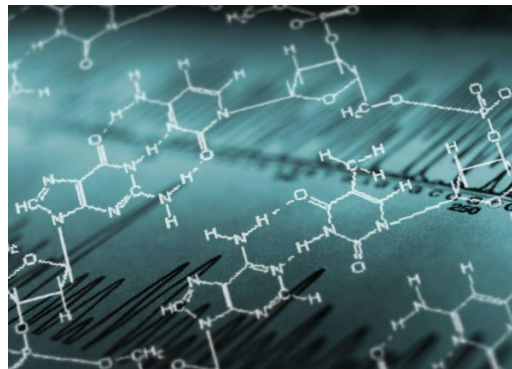


Harassment

- Employers may not permit harassment in the workplace based on genetic information
- Pervasive/Severe – Creates hostile work environment

Retaliation

- Employers may not retaliate against an applicant or employee for:
 - Filing a charge of discrimination
 - Participating in a discrimination proceeding
 - Opposing discrimination





**AMERICANS WITH DISABILITIES ACT (ADA)
AND
GENETIC INFORMATION NON-DISCRIMINATION ACT (GINA)**





ADA vs. GINA

- Americans with Disabilities Act (ADA) covers discrimination for disabilities, which are conditions and symptoms that have already appeared, or conditions that a person **actually has**

A banner at the top of the slide features a row of stylized human figures in various colors (orange, purple, blue, green, red) and patterns. On the right side of the banner, the text "CITY OF MADISON CIVIL RIGHTS" is written in a light purple font.

ADA vs. GINA

- Genetic Information Non-Discrimination Act (GINA) covers discrimination for only **genetic information**

A banner at the top of the slide features silhouettes of diverse people in various colors (orange, purple, blue, green) and the text "CITY OF MADISON CIVIL RIGHTS" in a light blue font on the right side.

ADA vs. GINA Example

- Robert has taken a genetic test and it shows that he has the genetic predisposition for Huntington's disease.
- Until he shows symptoms of Huntington's Disease, GINA will protect him from discrimination.
- When he has Huntington's Disease, ADA will protect him from discrimination.



ACQUIRING GENETIC INFORMATION



Acquiring Genetic Information

- Employers can not request, require or purchase genetic information of an applicant or employee
- There are exceptions



Acquiring Genetic Information

Exception #1:

- When information is inadvertently given
- Example:
 - You ask “how are you” and someone reveals genetic information





Acquiring Genetic Information

Exception #2:

- Family & Medical Leave Act (FMLA)
Application
- Example:
 - Individual applying for FMLA may provide genetic information or family medical history

Acquiring Genetic Information

Exception #3:

- Purchase of documents commercially and publically available
- Example:
 - Newspaper obituary





Acquiring Genetic Information

- Even though the employer can obtain genetic information under the exceptions, if they use it to make any employment decision, that is considered discrimination
- An employer may not obtain genetic information in any other way than described in the exceptions



CASE EXAMPLES



CITY OF MADISON
CIVIL RIGHTS



Case Example

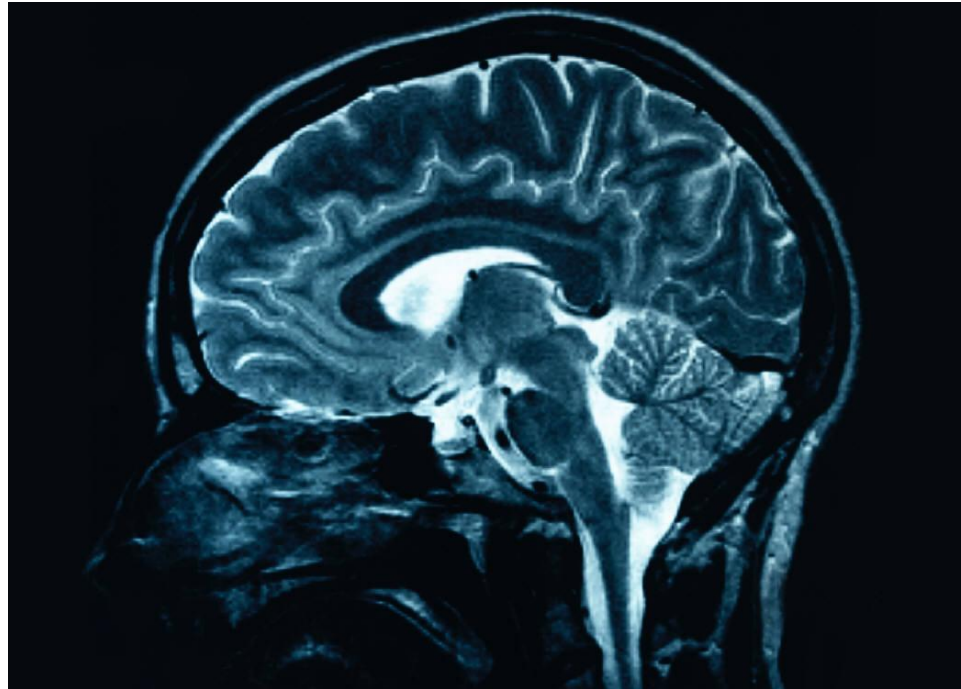
CITY OF MADISON
CIVIL RIGHTS

- Burlington Northern Santa Fe Railroad
- Secretly tested employees for rare genetic condition (hereditary neuropathy with liability to pressure palsies – HNPP) causes carpal tunnel as one of its many symptoms
- One employee who refused testing was threatened with possible termination
- Information used as a defense to Workers Compensation claims



Case Example

- Lawrence-Berkeley Labs
- Between 1968-1993 Lawrence-Berkeley Laboratories gave annual medical exams
- Included sickle cell genetic markers
- Did not get employee consent



FINAL THOUGHTS





Contact Information:

City of Madison
Equal Opportunities Division
266-4910
www.cityofmadison.com/dcr

Equal Employment Opportunity Commission
1-800-669-1400
www.eeoc.gov





Resources

CITY OF MADISON
CIVIL RIGHTS

Cases of Genetic Discrimination. (n.d.). Retrieved from National Human Genome Research Institute: <http://www.genome.gov/12513976>

Congresswoman Louise Slaughter. (n.d.). Retrieved from http://www.louise.house.gov/index.php?option=com_content&view=article&id=39&Itemid=61

Equal Employment Opportunity Commission. (n.d.). Retrieved from www.eeoc.gov

Faces of Genetic Discrimination: How Genetic Discrimination Effects Real People. (n.d.). Retrieved from Fairness, National Partnership for Women & Families on Behalf of the Coalition for Genetic: http://www.geneticalliance.org/ksc_assets/documents/facesofgeneticdiscrimination.pdf

Fergus, K. a. (2000, August 23). *Breast and Ovarian Cancer in the Ashkenazi Jewish Population.* Retrieved from Genetic Health: http://www.genetichealth.com/BROV_GEN_of_BROV_In_ASHJ.shtml

Genetic Discrimination: Position Paper. (2001). Retrieved from Council for Responsible Genetics: <http://www.councilforresponsiblegenetics.org/pageDocuments/2RSW5M2HJ2.pdf>



Resources

Genetic Testing, Privacy and Discrimination. (n.d.). Retrieved from Council for Responsible Genetics:

<http://www.councilforresponsiblegenetics.org/Projects/PastProject.aspx?projectId=1>

Gruber, J. (n.d.). *The New Genetic Information Nondiscrimination Act*. Retrieved from Council for Responsible Genetics Genewatch:

<http://www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pageId=185&archive=yes>

History of Gina. (n.d.). Retrieved from Coalition for Genetic Fairness:

http://www.geneticfairness.org/ginaresource_history.html#2

Leibig, K. (2009, June 3). Genetic Information Nondiscrimination Act of 2008 and EEOC's Notice of Proposed Rulemaking. Baltimore, Maryland, US.

Markel, H. (n.d.). *Scientific Advances and Social Risks: Historical Perspectives of Genetic Screening Programs for Sickle Cell Disease, Tay-Sachs Disease, Neural Tube*. Retrieved from National Human Genome Research Institute. Promoting Safe and Effective Genetic Testing in the United States, Appendix 6: <http://www.genome.gov/10002401>

Press Release 2-9-01 EEOC Petitions Court to ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing Under Americans with Disabilities Act. (n.d.).

Retrieved from Equal Employment Opportunity Commission:

<http://www.eeoc.gov/eeoc/newsroom/release/2-9-01-c.cfm>

Public Law 110-233 Genetic Information Non-Discrimination Act of 2008. (n.d.). Retrieved from

http://www.ornl.gov/sci/techresources/Human_Genome/publicat/GINAMay2008.pdf