



G.I.N.A

Genetic Information Non-Discrimination Act Final Regulations

November 2010





City of Madison
Department of Civil Rights
Equal Opportunities Division

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Overview

- History and Background
- Genetic Discrimination
- Terms defined in GINA
- ADA vs. GINA
- Acquiring Genetic Information
- Madison General Ordinance
- Case Examples



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

Why do we need GINA?

Kelly wears her breast cancer awareness pin and bracelet every day.

Her supervisor notices the pin and bracelet, and inquires about why she wears them.

Kelly explains her mother passed away from breast cancer recently.

The week after she reveals this information, her employment is terminated.



Why do we need GINA?

Tom and Sally, newlyweds, are thinking about having a baby.

They both have a family history of Huntington's Disease, so they have heard that their baby may have a high chance of getting it.

However, Tom heard his boss say last week that the company can't have any liabilities, and if someone is getting a genetic test, something must be wrong with them.

It is rumored Tom's boss fired someone else because they went in for a genetic test.

A banner at the top of the slide features silhouettes of diverse people in various colors (orange, purple, blue, green, red) holding hands. On the right side of the banner, the text "CITY OF MADISON CIVIL RIGHTS" is written in a light blue, sans-serif font.

Why do we need GINA?

John participates in an employee wellness program, and finds out he is predisposed to Fragile X Syndrome.

Although he does not show symptoms, if it is passed on to his children, it could cause learning disabilities and developmental problems.

John mentions this to a coworker he trusts, and later overhears his supervisor calling him “retard.”

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Why do we need GINA?

Alex is a supervisor hiring a clerk typist for the front desk.

He has heard that African Americans are more likely to have sickle cell disease.

Although he interviews a few African Americans, he ends up hiring a Caucasian.

He believes this way the company will save on insurance costs and sick leave pay.



GINA

- GINA provides protections against genetic discrimination in both the health insurance and employment settings
- Puts limitations on the access to and disclosure of genetic information

Legislative History

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- Enacted in response to developments in field of genetics
- Congress was concerned that people were not taking advantage of genetic tests





Legislative History

- First introduced in 1995 by United States Representative Louise Slaughter (D-NY)
- Rejected several times since 1995
- Signed into law by President Bush in 2008
- Title II went into effect on November 21, 2009
- Final regulations on November 9, 2010
- Effective date of final regulations January 10, 2011

Title I

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





Title I

- Health Insurers may not use genetic information to make decisions regarding eligibility or premiums
- Health Insurers may not require individuals to provide genetic information
- This does not include diseases or disorders that are already present

Title II

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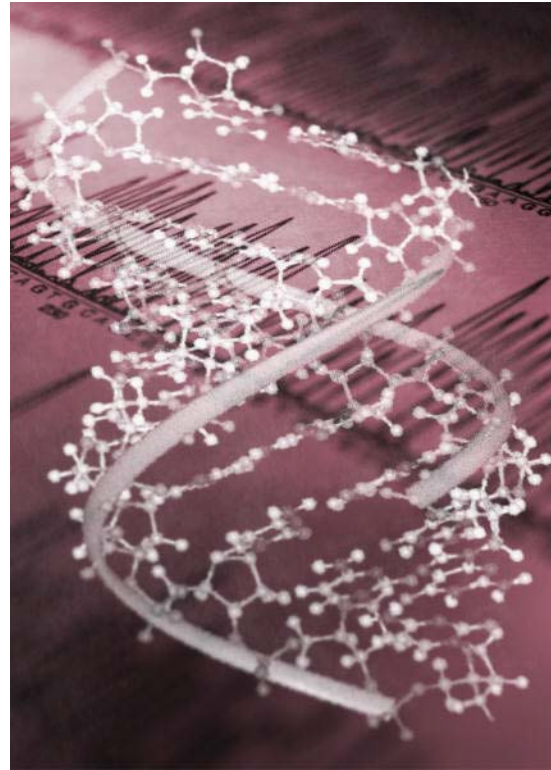
- Covers Employment
- Equal Employment Opportunity Commission (EEOC)





Title II

- Employers may not discriminate against employees, former employees or applicants because of genetic information
- Restricts acquiring genetic information
- Limits disclosure of genetic information
- Provides remedies for individuals who have been discriminated against



GENETIC DISCRIMINATION



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Discrimination

- Covered entities may not use genetic information to discriminate against employees in any of the following areas:
 - Hiring
 - Terms, conditions, privileges of employment
 - Job assignment
 - Compensation
 - Firing
 - Layoff





Discrimination Example

Joan asks her supervisor Sam permission to take off work on Friday. When asked the reason, Joan reveals that her mother has been recently diagnosed with breast cancer, and she is having surgery on Friday.

Sam grants her permission, but the next week Joan finds out that her position is being switched to part-time.

Joan overhears Sam speaking to Jane, the Department Manager, about how the company will now be able to save money on health benefits since part-time workers do not get health insurance, and Joan is more likely to get breast cancer because her mother has it.



Harassment

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



Harassment Example

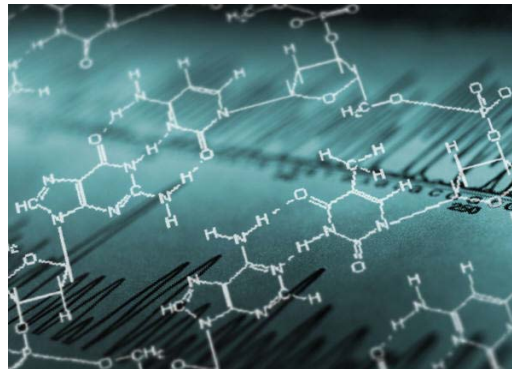
Some of Joan's co-workers have known for awhile that her mother was diagnosed with breast cancer.

One of the other supervisors in another department, Dale, has been making negative comments to her about breast cancer. He says that people with breast cancer are a waste and are weak, and they should not be allowed to work.

Everyday he makes a comment to this effect, and it is making Joan unable to concentrate on her work. This behavior has gone on for about a month.

Retaliation

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





Retaliation Example

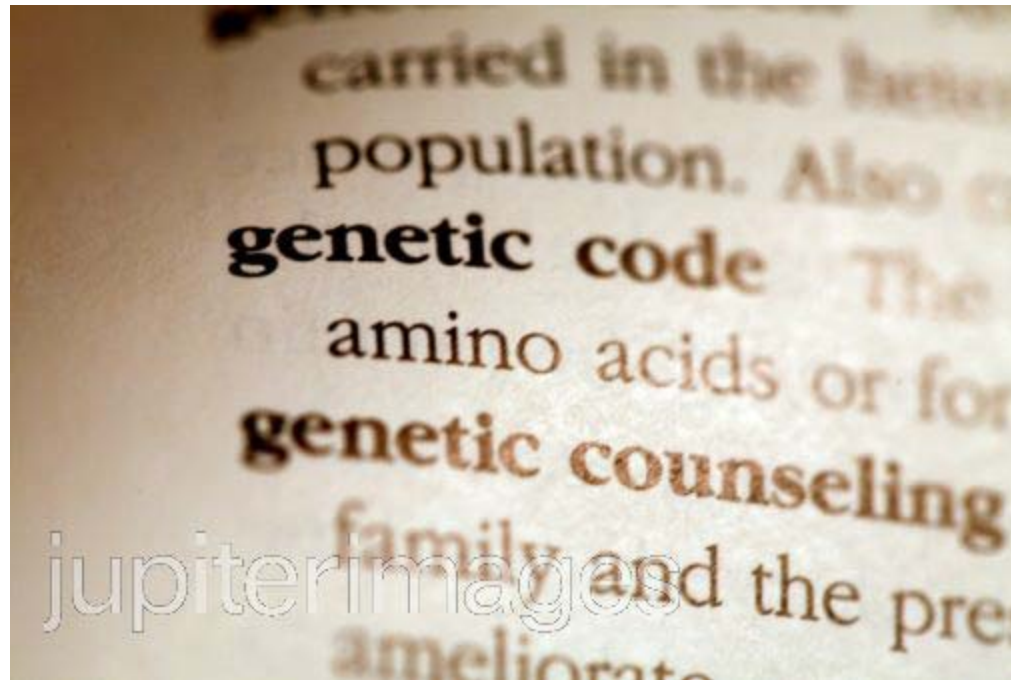
Joan complains to the CEO, Angela, that she feels that she has been discriminated against by her supervisor, Sam, and harassed by Dale.

The next day, Joan is told that she is being terminated instead of being switched to part-time. Her position is being “eliminated for budget reasons.”



Other rules

- Limiting, segregating and classifying
- Causing a covered entity to discriminate



TERMS DEFINED IN GINA



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General Definitions

- Many definitions come from Title VII of the Civil Rights Act of 1964



Employee

- Individual employed by a covered entity
- Applicant for employment
- Former employee



Covered Entity

- Employer
- Employing Office
- Employment Agency
- Labor Organization
- Joint Labor-Management Committee



Employer

- Any person that employs an employee
- Any agent of such person
- Does not include an Indian tribe, or a bona fide private club that is exempt from taxation under section 501(c) of the IRS Code of 1986

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Employing Office

- Personal office headed by a person with the final authority to:
 - Appoint, hire, discharge, set terms, conditions or privileges
 - In Federal Government offices



Employment Agency

- Any person regularly undertaking with or without compensation to secure employees for an employer or to secure for employees opportunities to work for an employer.



Labor Organization

- An organization with fifteen or more members engaged in an industry affecting commerce, and any agent of such an organization in which employees participate and which exists for the purpose of dealing with employers concerning grievances, labor disputes, wages, rates of pay, hours or other terms and conditions of employment.



Joint Labor-Management Committee

- An entity that controls apprenticeship or other training or retraining programs, including on-the-job training programs.

Family Member

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- Dependent
 - Through marriage, birth, adoption or placement for adoption
- Any other individual that is a first, second, third or fourth degree relative



Family Medical History

- Phrase often used by medical professionals when examining patients
- Information about diseases or disorders that family members have had



Non-Genetic Tests

- There are tests that are non-genetic:
 - Complete blood counts
 - Cholesterol tests
 - Liver-function tests
 - Alcohol tests*
 - Drug tests
 - Fitness tests
 - HIV tests
 - H1N1 tests



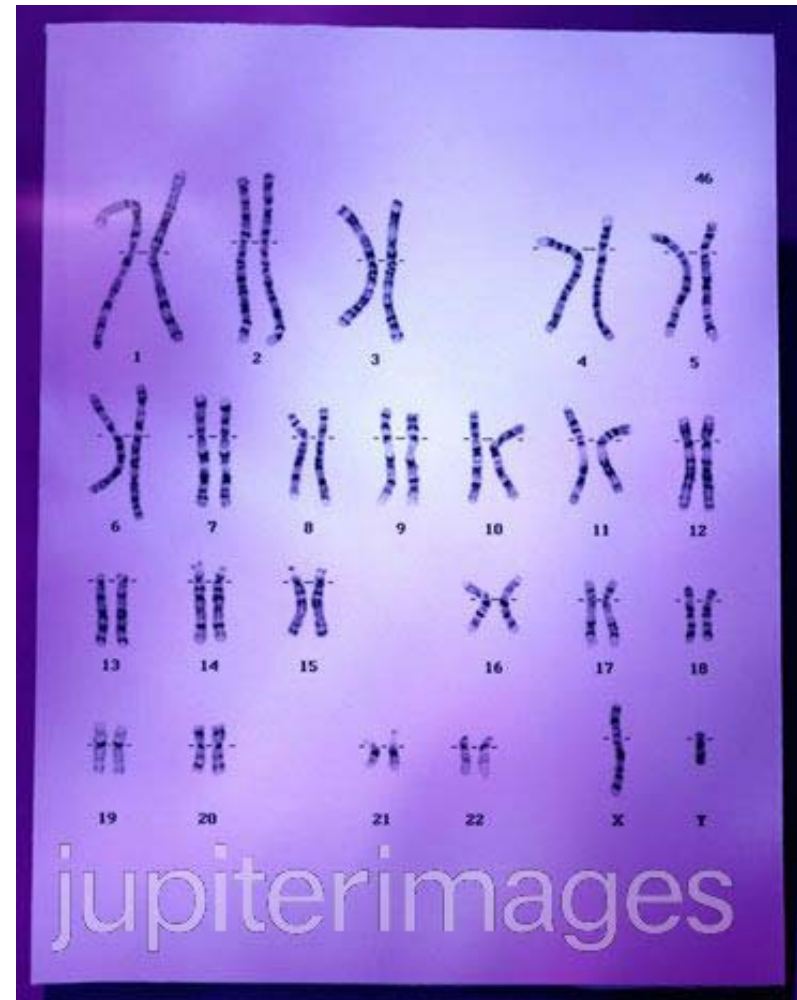
Genetic Test

Analysis of human:

- Chromosomes



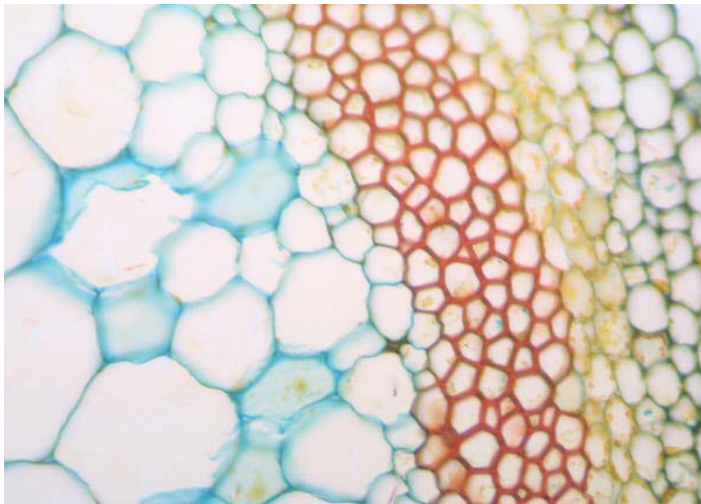
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Genetic Test

Analysis of human:

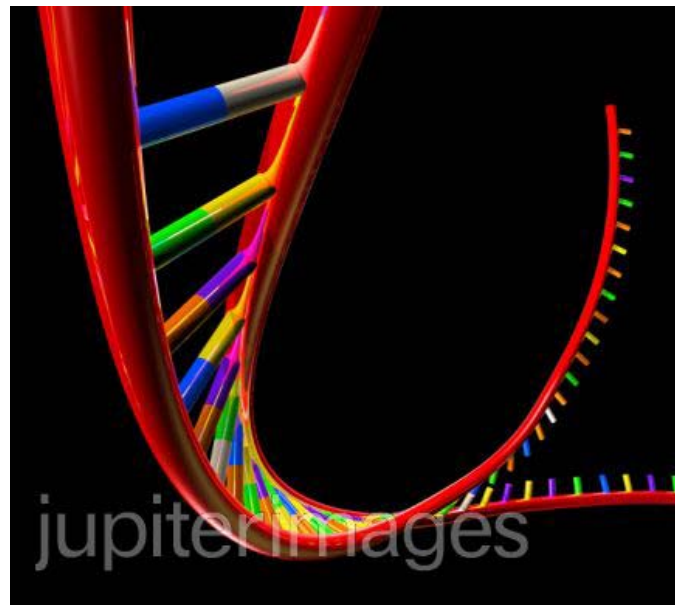
- DNA



Genetic Test

Analysis of human:

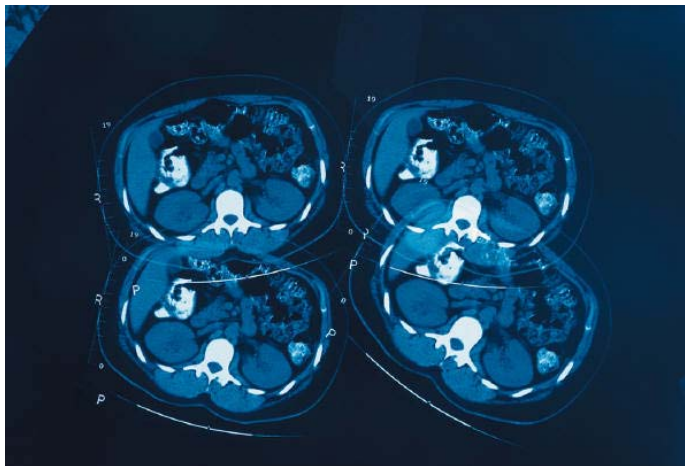
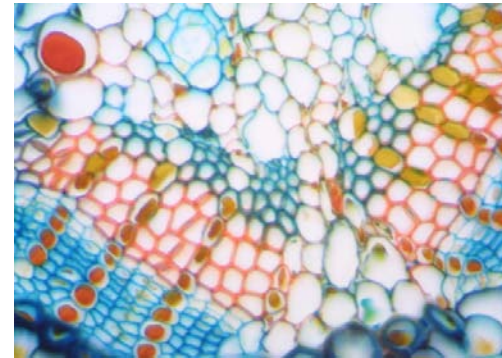
- RNA



Genetic Test

Analysis of human:

- Proteins
- Metabolites

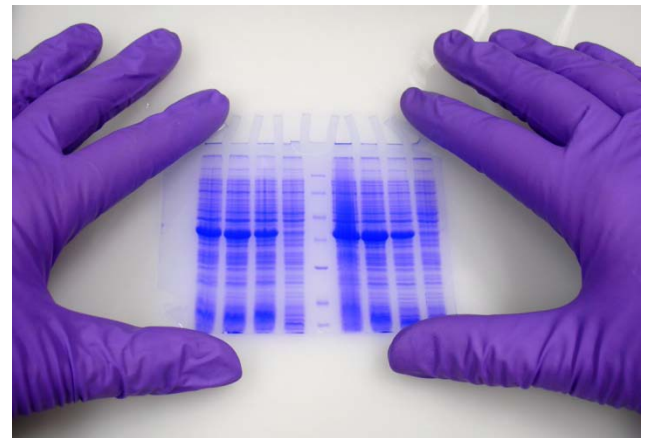


Genetic Test

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Chromosomes, DNA, RNA, proteins and metabolites detect:

- Genotypes
- Mutations
- Chromosomal Changes



Genetic Test Examples

- 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 information of a fetus



Genetic Information

- Does NOT include information about age or sex
 - Age: Age Discrimination in Employment Act
 - Sex: Title VII of the Civil Rights Act of 1964
- Does NOT include information about current disorders
 - Disability: Americans with Disabilities Act

Genetic Services

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- Genetic Test
- Genetic Counseling
 - Obtaining, interpreting or assessing genetic information
- Genetic Education





Manifestation/Manifested

- Disease, disorder or pathological condition that an individual has been or could reasonably be diagnosed as having by a health care professional with appropriate training and expertise in the field of medicine involved.
- A disease, disorder or pathological condition is **not** manifested if the diagnosis is based principally on genetic information.



**AMERICANS WITH DISABILITIES ACT (ADA)
VS.**

GENETIC INFORMATION NON-DISCRIMINATION ACT (GINA)





ADA vs. GINA

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

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ADA vs. GINA

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

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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 individual or family member of the individual
- There are exceptions



Exception #1

- When information is inadvertently requested or required
- Example:
 - Requesting information for legally allowed purpose (FMLA, disability accommodation, etc.)
 - Overhearing conversation
 - Casual conversation
 - Unsolicited conversation or e-mail
 - Social media platform



Exception #2

- Health or genetic services as part of wellness program
- Example:
 - Workplace wellness program
 - Voluntary participation
 - Participant provides written voluntary authorization
 - Specific information goes only to individual and healthcare provider
 - Employer only gets summary of results of entire workplace without detailed information
 - May not provide financial incentive for individuals to provide genetic information





Exception #3

- Family & Medical Leave Act (FMLA) Application
- Information must be kept in separate file
- Example:
 - FMLA or other Federal, State, or local leave request applications require employees to provide information about health condition of the family member to prove need for the leave

Exception #4

- Documents commercially and publically available for review or purchase
- Example:
 - Newspaper obituary
 - Magazine story
 - Electronic media
 - Television
 - Internet



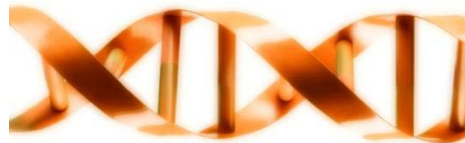
Exception #5

- Genetic Monitoring
- Workplaces with toxic substances
- Written Authorization Required
- Example:
 - You work with hazardous chemicals and federal law dictates your employer must test you to assure workplace safety



Exception #6

- Forensic Lab/Human Remains Identification
- Example:
 - You work in a forensic lab testing DNA found at crime scenes. Your employer needs your DNA code on file to assure that the samples you test are not contaminated with your DNA.





Acquiring Genetic Information

- Even though the employer can obtain genetic information under the above six exceptions, it would be discrimination if that information were used to make any employment decisions.

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Acquiring Genetic Information

- An employer may not obtain genetic information in any other way than described in the six exceptions above

Confidentiality

If an employer has genetic information:

- It must be kept confidential
- Maintained in a separate file
- Disclosure rarely permitted
 - Court order
 - FMLA compliance
 - Health researcher in compliance with law
 - The employee or family request information in writing





Racial and Ethnic Discrimination

- Some genetic markers are more common in individuals of certain races or ethnic backgrounds
- African Americans more likely to carry gene for sickle-cell disease
- Ashkenazi Jewish Population women more likely to carry BRCA-1 mutation that indicates a predisposition towards breast cancer



Madison

MADISON GENERAL ORDINANCE

39.03



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Genetic Identity

Genetic identity means the genetic information unique to the individual, including information regarding:

1. such individual's genetic tests,
2. the genetic tests of family members of such individual,
3. the manifestation of a disease or disorder in family members of such individual, and
4. any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual.
5. The term 'genetic identity' shall not include information about the sex or age of any individual.



Genetic Test

Genetic test means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes. The term `genetic test' does **not** mean:

1. an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or
2. an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved; or
3. any genetic testing, to include DNA testing, conducted specifically for law enforcement agencies investigative purposes or for the purpose of determining paternity.



CASE EXAMPLES





Case Example

Kim is a social worker with a large human services agency. During a staff workshop on caring for people with chronic illnesses, Kim mentions that she was the primary caretaker for her mother who died of Huntington's disease.

Kim herself has a 50% chance of developing this fatal genetic condition.

One week after she reveals her risk status, Kim is fired from her job, even though she has received outstanding performance reviews in the months prior to the firing.



Case Example

Mary has a family history of breast cancer, both her mother and her aunt have been diagnosed with it.

She worries about her future, and is considering getting tested for BRCA-1, a gene associated with some forms of hereditary breast cancer.

Ultimately, she decides not to take advantage of the test, because she fears a positive result will jeopardize her chances for promotion in her law firm.



Case Example

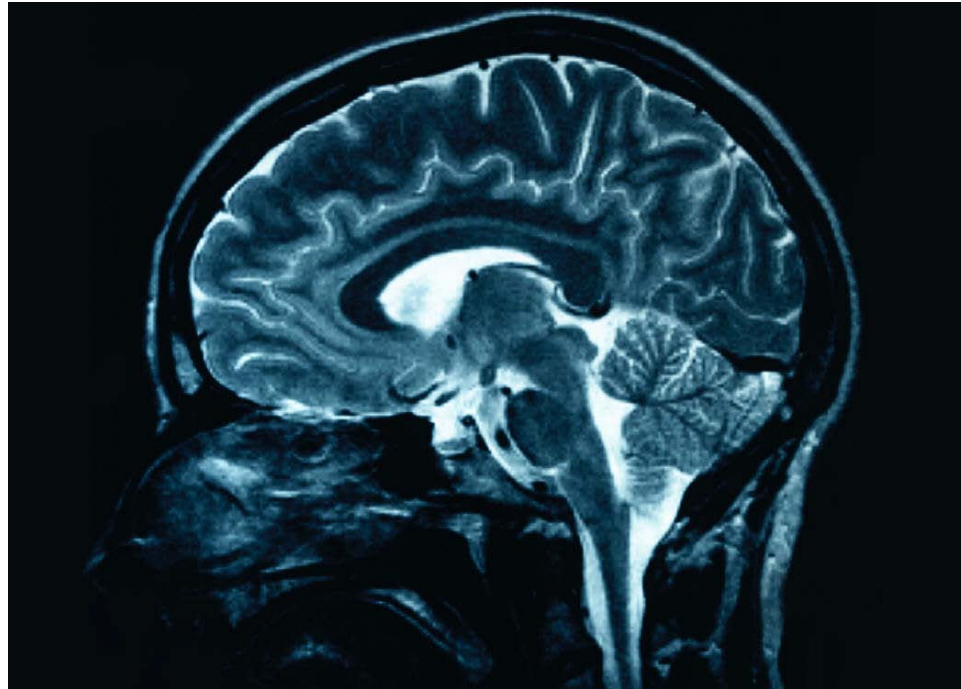
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- Burlington Northern Santa Fe Railroad
- Secretly tested employees for rare genetic condition (hereditary neuropathy with liability to pressure palsies – HNPP)
- Causes carpal tunnel as one of its many symptoms
- Company utilized test results in defense of workers compensation claims



Case Example

- Berkley Labs
- Between 1968-1993 Lawrence-Berkley Laboratories gave annual medical exams
- Included sickle cell genetic markers
- Did not get employee consent
- Made it possible for genetic information to be considered confidential like other medical information



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

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