

The Genetic Information Nondiscrimination Act of 2008

“GINA”

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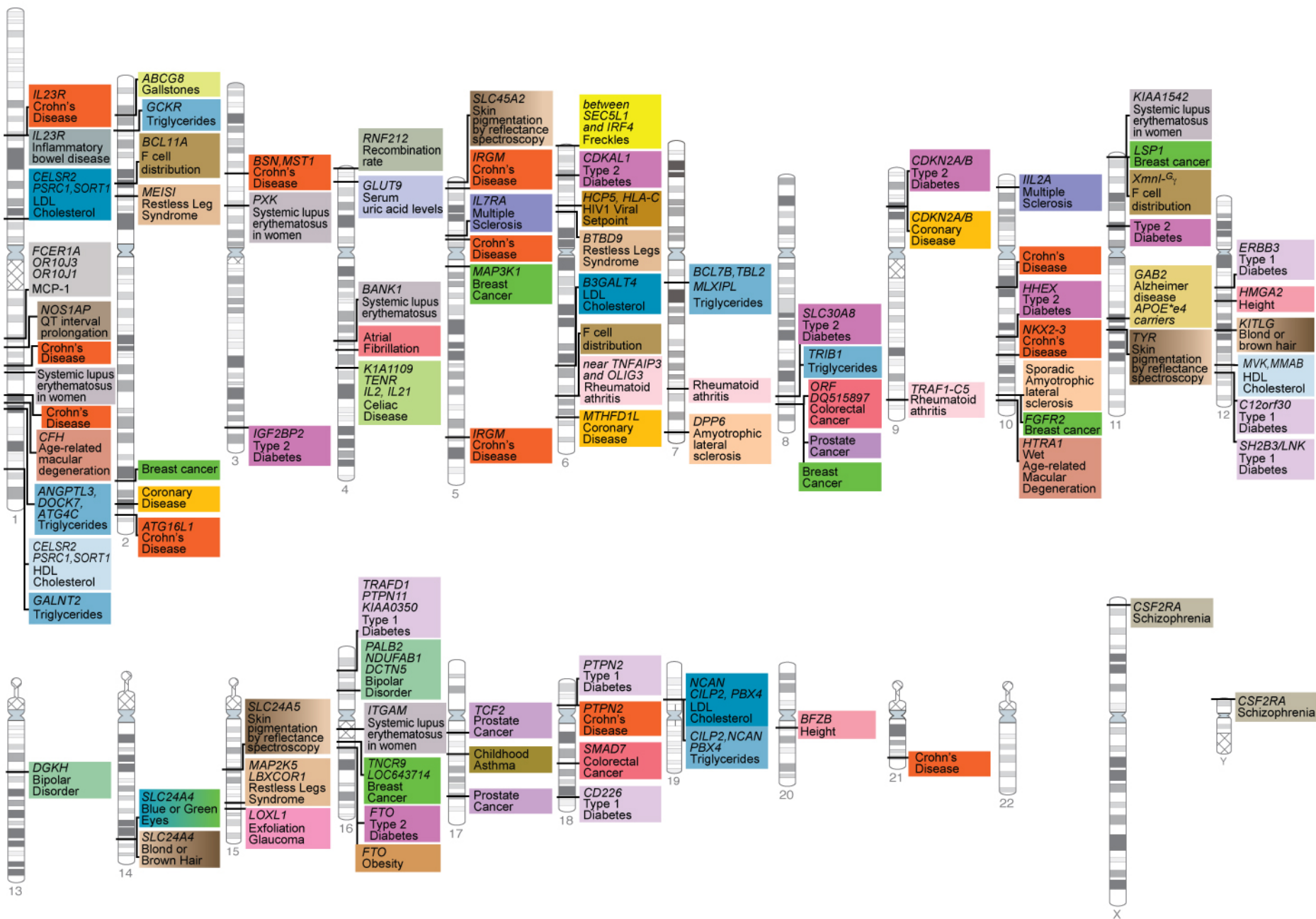
Science

BREAKTHROUGH OF THE YEAR

Human Genetic Variation

<http://www.sciencemag.org/cgi/content/full/318/5858/1842>

AAAS



Major advances – but we cannot realize potential applications to health unless...

- The public is willing to participate in research and genetic testing as part of their medical care
- Genetic information is protected from discriminatory uses

People are Afraid

- NIH research with families at risk for hereditary colorectal cancer has shown that the number one concern regarding genetic testing is the fear of losing health insurance.
- Even health care providers are vulnerable to these fears. A survey of the personal attitudes of cancer genetics specialists showed that 68% of respondents would not bill their own insurance companies for cancer-related genetic testing due to fears of discrimination, and 26% said they would use an alias when being tested.

- In a January 2008 survey of 4,659 Americans about their attitudes regarding genetic testing, 74% reported that it would be “very important” to them that it would be illegal for insurers and employers to have access to their genetic information.
- Fear of being tested or of sharing genetic information with health care providers can have tragic consequences, as detailed in the NY Times article “The DNA Age; Fear of Insurance Trouble Leads Many to Shun or Hide DNA Tests,” by Amy Harmon, Feb. 24, 2008.



Katherine Anderson,
Factor V

Victoria Grove, Alpha-1

Anonymous, BRCA





Genetic Information Non-Discrimination Legislation: A 13 Year Effort

- Efforts to pass federal legislation protecting all Americans from discrimination based on their genetic information began in 1995, with 14 different bills introduced over the years
- Entrenched opposition by employers, lesser difficulty with the insurance industry

Legislative Process

1. Bill introduced by sponsor in House or Senate
2. Referred to committees of jurisdiction
3. Hearings, markup, vote (hopefully!)
4. Sent to other chamber / repeat steps 2 - 4
5. Negotiate differences between House & Senate's versions ("conference")
6. Vote again
7. Send to the President

Opposition Arguments

- Frivolous litigation
- Burden of compliance for employers
- Other laws provide adequate protection
- No evidence that discrimination is occurring

May 8, 2002

Illegal genetic testing of 36
employees by Burlington Northern
results in enforcement action by the
Equal Employment Opportunity
Commission (EEOC)

Subsequent \$2.2 million settlement

What is GINA?

- A federal law that prevents health insurers and employers from discriminating based on an individual's genetic information
- The bill is intended to allow Americans to take advantage of the benefit of genetic testing without fear of losing their health insurance or their jobs

What will GINA do?

- Prohibit health insurers from requiring genetic information or using it in decisions regarding coverage, rates, or preexisting conditions
- Prohibit employers from requiring genetic information or using it for decisions regarding hiring, firing, or any terms of employment

Specifics

- Prohibits group and individual health insurers from using a person's genetic information in determining eligibility or premiums
- Prohibits an insurer from requesting or requiring that a person undergo a genetic test
- Prohibits employers from using a person's genetic information in making employment decisions such as hiring, firing, job assignments, or any other terms of employment
- Prohibits employers from requesting, requiring, or purchasing genetic information about a person or his or her family members

What GINA does not do

Does not prevent health care providers from recommending genetic tests to their patients

Does not mandate coverage for any particular test or treatment

Does not prohibit medical underwriting based on current health status

Does not cover life, disability, or long-term care insurance

Does not apply to members of the military

Does not preempt state law

- *Genetic information* includes information about:
- a person's genetic tests
- genetic tests of his or her family members (up to and including fourth-degree relatives)
- any manifestation of a disease or disorder in a family member
- participation of a person or family member in research that includes genetic testing, counseling, or education

**GINA will enable the American people to
take advantage of the promise of genomic
medicine without fear of insurance and
employment discrimination**

GINA

- “The first major new civil rights bill of the new century”

Senator Edward Kennedy

April 24, 2008

110th

108TH
108TH CONGRESS
1ST SESSION

~~S. 1053~~

~~S. 306
H.R. 1227~~

S. 358

H.R. 493

AN ACT

To prohibit discrimination on the basis of genetic information with respect to health insurance and employment.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Genetic Information Nondiscrimination Act of 2003”.

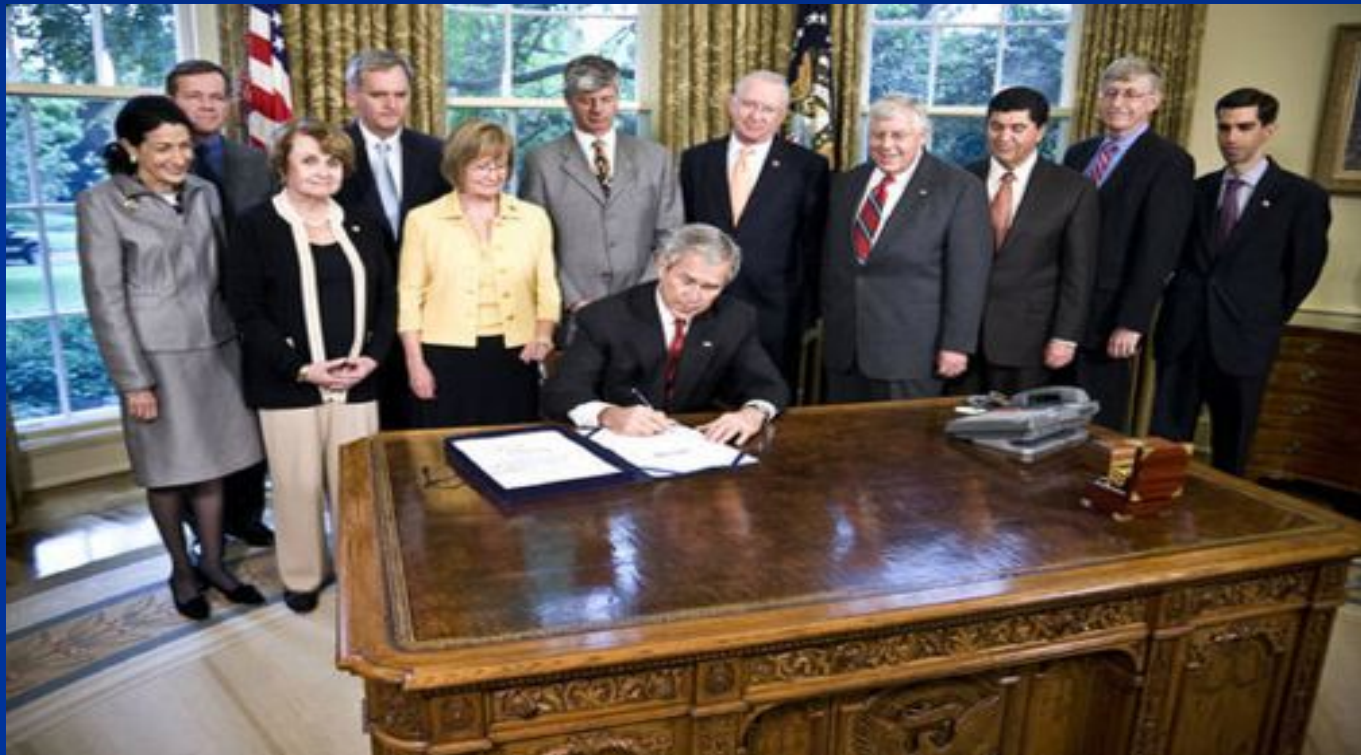
“GINA”

- GINA passes the House April 25, 2007, 420-3
 - Blocked in the Senate for a full year
- GINA passes the Senate April 24, 2008, 95-0
 - Finally!
- GINA gets final passage by the House May 1, 2008, 414-1





GINA Becomes Law!



May 21, 2008

Now what?

- Regulations being drafted to implement GINA
- Insurance protections go into effect May 09
- Employment protections go into effect
November 2009

NHGRI GINA Team Past & Present



Next challenges

- Regulation of genetic tests
- Reimbursement
- Incorporation of genomics into healthcare
- Educational efforts