FDC BEAT

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The Genetic Information Nondiscrimination Act (GINA): Federal Law Adds New Protections Against Discrimination

The Genetic Information Nondiscrimination Act (GINA) is a new law that was passed by Congress and officially signed by President Bush on May 21, 2008. GINA prohibits health insurance and work-place discrimination based on genetic information. This law aims to prevent health insurers from denying coverage or increasing premiums based on a person's genetic predisposition to a particular disease and to prevent employers from discriminating based on predictive genetic information. This law will help alleviate fear and concerns about genetic discrimination, therefore enabling and encouraging individuals to take advantage of genetic screening, counseling, testing, research and new medical therapies that will result from advances in the field of genetics. The health insurance related provisions of GINA will go into effect in May 2009, and the employment provisions in November 2009.

What is genetic discrimination?

Genetic discrimination is unfair treatment or consideration based on genetic status rather than an actual medical condition. In reality, there have been few, if any, cases of genetic discrimination reported in the US in employment, health insurance or life insurance. However, genetic discrimination has been a fear shared by many Americans since genetic testing was first made available more than 3 decades ago.

Some people fear they will be charged higher premiums or denied health insurance due to genetic information while others fear they may find it more difficult to obtain a job or promotions if their employer learns they have a genetic disorder or genetic predisposition to a disease.

Genetic information protected by GINA includes the results of a person's or family member's genetic tests, manifestations of a disease or disorder in a family member, and participation of a person or family member in genetic research. Some people view genetic information differently than other medical information because it can be used to predict disease that may not actually exist in the present time (or may never even occur), and also because it can affect an entire family.

What protections against genetic discrimination already exist?

There are already some existing protections that prohibit genetic discrimination provided by some federal laws including the Health Insurance Portability

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FDC Project Receives NIH Refunding!

We are pleased to announce that our FDC grant was refunded for four more years by the National Heart, Lung, and Blood Institute (NHLBI), a section of the National Institutes of Health (NIH). This is especially gratifying because NIH funding has been extremely competitive due to tight budgets, and our success attests to the scientific significance of this project. Your participation is essential to our success and we thank you very much for your participation.

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and Accountability Act (HIPAA) and the Americans with Disabilities Act (ADA). In addition, over 34 states have passed laws addressing genetic discrimination; however, these laws are not consistent across states.

HIPAA, originally passed in 1996, is a law that protects the portability of an individual's health insurance when they change jobs and makes the health care system more accountable for costs of healthcare. In addition, HIPAA provides standards for the privacy and security of health information, therefore providing protections on a federal level against health insurance discrimination. HIPAA prohibits group health insurers from denying someone coverage or increasing premiums on a health plan due to a genetic susceptibility.

The ADA, originally passed in 1990, provides some protections against employment discrimination. However, the extent of the protections outlined by the ADA is unclear, particularly in regards to individuals who have a genetic risk for a disease but do not have symptoms. This law also does not address the privacy of genetic information or prohibit an employer from collecting genetic information.

Why is GINA important?

GINA is a necessary law because it provides basic legal protections against genetic discrimination in health insurance and in the workplace for *all* Americans. With less fear about genetic discrimination, this will allow medical communities to more readily use genetic information in medical decision making, which will open doors for more advancements in the treatment of genetic conditions. Therefore, GINA may also have a positive effect on the number of individuals and families who participate in genetic research. The involvement of as many individuals and families as possible who are affected by FDC is critical to advancing genetic knowledge about this condition.

GINA: Hope for the future of genetics in medicine

GINA provides an added level of protection against health insurance and employment discrimination based on clinical genetic information for the American public. Hopefully, individuals who previously were deterred from genetic testing on a clinical level will now feel more comfortable.

For further reading about GINA, useful websites include:
http://geneticalliance.org/
http://www.workrights.org/issue_genetic/gd_fact_sheet.html
http://www.genome.gov/PolicyEthics/

Quick Guide to GINA

What GINA DOES:
GINA includes protections against the following:
- o Prohibits group and individual health insurers from using a person's genetic information in determining eligibility or premiums
- o Prohibits employers from requesting or requiring that a person undergo a genetic test
- o 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
- o Prohibits employers from requesting, requiring, or purchasing genetic information about persons or their family members

In addition, GINA will:
- o Be enforced by the Dept. of Health and Human Services, the Department of Labor, and the Department of Treasury, along with the Equal Opportunity Employment Commission; remedies for violations include corrective action and monetary penalties

What GINA DOES NOT DO:
- o Prevent health care providers from recommending genetic tests to their patients
- o Mandate coverage for any particular test or treatment
- o Prohibit medical underwriting based on current health status
- o Cover life, disability, or long-term-care insurance
- o Apply to members of the military

New Research Papers by the FDC Project Group

The FDC team has published new papers. This work was made possible with the help and dedication of you and your family. Please encourage your physicians to take a look at these papers!

Parks SB, Kushner JD, Nauman D, Burgess D, Ludwigsen S, Peterson A, Li D, Jakobs P, Litt M, Porter C, Rahko P, Hershberger RE. Lamin A/C mutation analysis in a cohort of 324 unrelated patients with idiopathic or familial dilated cardiomyopathy. Am Heart J 2008;156:161-9.

This paper examined the frequency of mutations in a gene called *LMNA* in 324 FDC Project participants with

idiopathic dilated cardiomyopathy (IDC) or (familial dilated cardiomyopathy) FDC. The study shows that mutations in *LMNA* occur in about 8% (8 out of 100) of individuals with familial dilated cardiomyopathy and in approximately 4% of individuals with idiopathic dilated cardiomyopathy who do not have a family history of the disease. These results suggest that regardless of family history, it may be reasonable to consider *LMNA* testing in evaluating the cause of IDC.

We also found that in 6 of 19 families (32%) with a *LMNA* mutation, at least one affected family member did not have the mutation detected in other members of the family. This suggests that individuals who do not have the *LMNA* mutation that was detected in another relative may have other genetic or non-genetic factors that explain their heart problems.

Hershberger RE, Parks SD, Kushner JD, Li D, Ludwigsen S, Jakobs PM, Nauman D, Burgess D, Partain J, Litt M. Coding sequence mutations identified in *MYH7, TNNT2, SCN5A, CSRP3, LBD3,* and *TCAP* from 313 patients with familial or idiopathic dilated cardiomyopathy. Clin Trans Scie 2008;1:21-26.

This paper examined the frequency of mutations in six genes (*MYH7, TNNT2, SCN5A, CSRP3, LBD3*, and *TCAP*) in 313 FDC Project participants with IDC or FDC. This study shows that mutations in these genes account for a small proportion of familial (FDC) and non-familial (IDC) cases. We also found that participants with IDC and FDC had similar mutation frequencies (11%; 11 out of 100); therefore, mutations may be present even in the absence of a family history.

In addition to two original research articles, our group has also published a series of review articles (examinations of current literature on specific topics related to FDC). The references and a brief summary are provided below:

Cowan J, Morales A, Dagua J, Hershberger, RE. Genetic testing and genetic counseling in cardiovascular genetic medicine: Overview and preliminary recommendations. Cong Heart Fail 2008;14(2):97-105.

This article reviews the genetic tests currently available to cardiologists and the issues raised by the genetic testing process, including those for patients with IDC. We also provide our preliminary recommendations for genetic testing in cardiovascular genetic medicine clinics.

Nauman D, Morales A, Cowan J, Dagua J, Hershberger RE. The family history as a tool to identify patients at risk for dilated cardiomyopathy. Prog Cardiovasc Nurs 2008;23(1):41-44.

This article reviews FDC with emphasis on the family history evaluation of IDC in cardiovascular nursing practice.

Morales A, Cowan J, Dagua J, Hershberger RE. Family history: An essential tool for cardiovascular genetic medicine. Cong Heart Fail 2008;14(1): 37-45.

This article reviews how to obtain information, ask questions and analyze pedigrees of individuals and families with cardiomyopathies and arrhythmias.

The FDC Project Welcomes A New Team Member!

A genetic counselor, Jill Siegfried, RN, MS, CGC, has been recruited to the FDC Program. She will assume the role and responsibilities of Jason Cowan, MS.

A Brief Message From Jill Siegfried

After obtaining a Bachelor's degree from the University of Delaware, my passion for the field of genetics led me to obtain a Master's degree in Medical Genetics from the University of Cincinnati. After completing my degree I moved to Philadelphia, where I spent the last four 4 years working full-time as a cancer genetic counselor at Pennsylvania Hospital. While in Philadelphia, I also attended night school and obtained a Bachelors of Science in Nursing from LaSalle University.

While working as a cancer genetic counselor, I played a large role in the enrollment of patients in familial breast cancer studies at the University of Pennsylvania. This experience piqued my interest in genetic research, particularly in the genetics of adult onset hereditary diseases. As I was relocating to Miami in July 2008, joining the FDC project presented me with a perfect opportunity. I'm so delighted to join the FDC team and I look forward to working with you and your family in the years to come!

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MEDICAL FOLLOW-UP

If anyone in your family is newly diagnosed with heart problems, please let us know. Also, if you or anyone in your family has had heart tests performed, either for follow-up or for the first time, regardless of results, we would be interested in receiving copies. Please contact us and we will send you a medical record release form. If we have sent you medical record release form(s), please send us the completed form(s) as soon as possible.

EMAIL US THROUGH THE "Contact Us" PAGE ON OUR WEBSITE: WWW.FDC.TO

ADD ME TO THE MAILING LIST

If you are not currently a participant in our study, but would like to receive our newsletter, please contact us with your name and address, and we will be pleased to add you to our mailing list.

CONTACT INFORMATION UPDATES

If you have moved and/or have an email address we can contact you at, please call or email us so we can get in touch with you for any follow-up and continue to send you our newsletter.

FDC BEAT Newsletter

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The FDC Project Group
Cardiovascular Division
P.O. Box 019132, C-205
Miami, FL, 33101

303706

ADDRESS SERVICE REQUESTED

TO: