

Meeting of February 25, 2009 - on Notice of Proposed Rulemaking Implementation of Title II of the Genetic Information Non-Discrimination Act of 2008

Statement of Jeremy Gruber, J.D. President and Executive Director Council for Responsible Genetics

Good morning and thank you for inviting me to speak with you today. My name is Jeremy Gruber and I am the President and Executive Director of the Council for Responsible Genetics and the former legal director of the National Workrights Institute. I am also a member of the Pew working group on GINA and a founder and executive committee member of the Coalition for Genetic Fairness.

When we founded the Coalition for Genetic Fairness almost 12 years ago, it was with the hope that we could organize the myriad organizations that were working independently on genetic non-discrimination legislation into a single organization to represent our combined interest and the hope that such an organization could help advance this legislation through the Congress. Little did we imagine the roller coaster journey we would be undertaking, but little did we also imagine the strong new law that would eventually emerge through the combined efforts of so many.

I am particularly excited to be here today, for as many of you remember there was once a question as to whether employment would even be covered under a Federal genetic non-discrimination law and as an employee rights' advocate it has been particularly exhilarating to have watched the Congress pass, and President sign, a new genetic non-discrimination law with such strong protections for employees.

Indeed, with GINA this is really the first time that the Congress has passed such legislation before the covered discrimination has become completely ingrained in the social fabric and in that respect, I think we should all be proud.

Title II of GINA is a relatively commonsense law; my hope and expectation is that the regulations under Title II of GINA reflect the intent of Congress that employees enjoy strong protections under the law not just to protect them from discrimination but from access to and disclosure of their personal genetic information as well. Under the best of circumstances discrimination cases are difficult to prove. Employers are often the only party with access to information supporting a discrimination claim; indeed employees are often unaware, let alone able to prove that discrimination has occurred. Preventing access to information that can lead to discrimination is the best way to ensure discrimination never happens.

It is with these thoughts in mind that we hope the regulations address the following:

In terms of acquisition of genetic information generally:

GINA prohibits employers from requesting genetic information even in the rare case where it is arguably job related (though examples to date of such have been extremely difficult to demonstrate). Nevertheless in terms of the Americans with Disabilities Act, for example, this

poses a change to the authorized collection of medical information relevant to meeting a reasonable accommodation request. Employers will need to modify their requests for medical information under these circumstances to remain in compliance with GINA. Similarly under the ADA there is virtually no limit to the scope of post conditional offer of employment medical evaluations. Given that most individuals' medical files include such things as family history and may even have genetic test information, an employer that requires access to a large amount of information may run afoul of GINA. Employers will have to modify their medical release forms to minimize this risk. Our hope is that the regulations will provide some guidance in these areas.

In terms of the exceptions to the rule prohibiting acquisition of genetic information, it is our belief that such exceptions should be interpreted in the strictest sense possible to ensure employee privacy and Congressional intent.

With regards to the inadvertent acquisition or so called water-cooler exception:

It is clear that it protects the employer when an employee spontaneously volunteers their family history. It isn't clear, however, how this exception applies when an employer begins asking probing questions that may or may not be innocent. Nor does it specifically address situations where an employer acquires information more broadly where they should know that family history would likely be included. We hope that some guidance can be provided to protect both employers and employees in this situation.

With regards to the exception allowing for acquisition of genetic information where health or genetic services are provided by the employer:

Under GINA employers can ask for genetic information as part of a wellness program as long as it is voluntary (along with other requirements.). It is unclear, however, at what point the voluntary requirement is met. Can an employer condition participation in a voluntary wellness program on completing an often standard health risk assessment including questions regarding family history or must the employer allow participation in the program for an employee who refuses to complete elements of the questionnaire dealing with potential genetic information?

Additionally there has been much discussion regarding the HIPAA nondiscrimination rules which currently permit a great deal of discrimination based on health status. It is our hope that the EEOC will consider whether such wellness programs currently authorized under HIPAA qualify as "voluntary" wellness programs under federal employment law and how this rule intersects with this exception. Furthermore it is our hope that the regulations provide guidance as to when such programs are governed by Title I as opposed to Title II.

With regards to the exception related to monitoring for toxic exposure:

Some employers have programs which conduct genetic tests of workers in specific hazardous environments to determine if they need to be reassigned before symptoms of adverse affects even appear. Such genetic monitoring programs are allowed under GINA. However, GINA makes an important change in the law on this subject. Currently, employers can require employees to be tested. Under GINA, participation in such programs must be voluntary. If the employee wants to keep working in the hazardous area (perhaps because of a pay differential), the employer cannot force him to submit to testing, no matter how benevolent their intentions. Under such situations can an employer transfer the employee to another part of the facility and if so under what conditions?

In terms of disclosure:

GINA permits disclosure of genetic information in response to a court order (as long as additional requirements are met). A general reading of this language would prohibit disclosure for related procedures such as subpoenas and discovery requests. Will the regulations make this distinction clear?

And finally in terms of construction, what if any steps will the regulations take to further refine the firewall between Titles I and II of GINA?

Thank you again and I welcome any questions you may have.