

Genetics and Public Policy Center

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**Testimony of Susannah Baruch, J.D.
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Before the Equal Employment Opportunity Commission
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Good morning and thank you for the opportunity to testify today. I am Susannah Baruch, the Director of Law and Policy at the Genetics and Public Policy Center, supported by The Pew Charitable Trusts at Johns Hopkins University. Our mission is to help policy makers and the public better understand and respond to the challenges and opportunities arising from rapid advances in human genetics and its application to healthcare. Previously, I was involved with GINA as Director of Health Law Policy at the National Partnership for Women and Families and in 2000, I had the opportunity to provide testimony to the United States Senate on the topic of genetic testing in the workplace.

Scientists and genetic researchers increasingly have the ability to uncover genetic factors that contribute to health and disease. But for too long, patients' fear of genetic discrimination has interfered with our ability to maximize the benefits of genetic medicine. We know that in the past, patients have passed up genetic testing that could benefit their health, and have gone to great lengths to keep genetic information secret – even from their own doctors. With the passage of

GINA and its implementation, we welcome a new era. There are many factors an individual may consider in deciding whether to take a genetic test, but the fear of discrimination must not be one of them.

EEOC has played a critical leadership role in establishing that genetic information could not be used to discriminate in the workplace. Your interpretation of the ADA as it relates to genetic information and your involvement in cases such as Burlington Northern provided robust analysis of many of the issues that underlie GINA. Since GINA's passage, we have led a collaborative effort with the National Workrights Institute and the Georgetown Health Policy Institute to help federal policymakers implement and enforce GINA. "Project GINA" as we call it, has followed closely the progress on GINA regulations related to Title I and we eagerly await the opportunity to see the NPRM you have released today.

I have four main points to make.

1. GINA need not and should not create a burden for employers. Employers who are already following good employment and HR practices in complying with existing laws such as Title VII, the American with Disabilities Act, and the FMLA should find that GINA's prohibitions are consistent with those laws in terms of procedures and enforcement. We expect the regulations will provide assurance that this is the case.
2. Definitions matter. For concepts like genetic test, genetic information, and manifest disease, we hope that the EEOC, in coordination with DOL, HHS, and Treasury, will provide clear examples and remain flexible as science changes.

3. Employers are prohibited from requesting, requiring, or purchasing genetic information. This protection is critical, and we will be looking particularly closely at the way the exceptions to this rule are handled. In particular,
 - a. We recognize that employers need clarity on what constitutes inadvertent acquisition of information.
 - b. The NPRM should handle the issue of “wellness programs” carefully. We hope that EEOC will provide guidance on issues overlapping Title I and Title II --particularly as these issues relate to wellness programs that impose substantial financial penalties and higher deductibles on participants. We would welcome EEOC’s discussion of whether wellness programs currently authorized under HIPAA qualify as “voluntary” wellness programs under federal employment law.

4. In considering the section of GINA known as the “firewall” between Title I and Title II, please consider the reality. A majority of Americans receive their healthcare benefits through their employer. Although federal law makes a distinction between the employer and the “employer-sponsored health plan”, often, especially in smaller offices, the same person controls hiring and firing as controls ADA or FMLA claims that may reveal medical and genetic information as controls administration of health care benefits. That person – as well as other employees -- must know how to handle that reality. Genetic information, medical information, and health benefits information must be handled carefully and appropriately. We believe that because GINA’s rules are internally consistent between the Titles, protections should be consistent and enforcement should be seamless to the individual. Thus, although the technicalities of what is the employer vs. what is the employer sponsored health plan

may be of legal interest, the important fact is that neither may request or require genetic information nor use it to discriminate, and both must have rules and procedures in place that ensure compliance.

Thank you very much for the opportunity to speak today and I look forward to continued discussions.