

# **Experiencing Technological Difficulties: How the Genetic Information Nondiscrimination Acts Fails to Adequately Protect**

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In an attempt to alleviate the public's growing concerns regarding the potential misuse of genetic information, legislation was first introduced in Congress almost two decades ago. Nonetheless, the Genetic Information Nondiscrimination Act ("GINA") was not signed into law until May of 2009 and did not become fully effective until May of 2010. Unfortunately, although this long-awaited Act did provide some protection, it also appeared to have a number of major shortcomings. Partially in an attempt to alleviate some of the associated deficiencies, the U.S. Department of Health and Human Services proposed and then implemented regulations approximately one year ago.

While at first glance the new regulations may appear to resolve these issues, in light of recent technological advancements, it is clear that GINA fails to provide the necessary protection and is clearly inadequate. This is due to the fact that the manner in which data is now gathered and stored, as well as the increasing ease with which seemingly anonymized data can be linked to a particular individual, exposes the seriously deficient privacy safeguards. This is especially problematic as evidence shows that countless patients have refused genetic testing due to fears of how this type of information would be handled and ultimately utilized if the results were positive. However, the data obtained from such tests is often exceptionally helpful in making treatment decisions and taking preventative measures to minimize the likelihood of the occurrence or severity of many diseases.

This paper and presentation will identify and examine the various problems with GINA that can only fully be appreciated by including a technology overlay to the evaluation. Additionally, model language will be proposed to eliminate the current gaps in protection. Without such necessary changes, the goal of dispelling patients' fears over how their genetic information might be used is unlikely to come to fruition in the near future.