

# Wellness Program Group Seeks Moratorium on GINA Rules

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Byline: Matt Jones

NEW YORK (GenomeWeb News) – An alliance consisting of health insurance and pharmaceutical companies, hospitals, union interests, and biomedical firms focused on providing wellness programs, has asked the Obama Administration to put a hold on the final regulations of the Genetic Information Non-discrimination Act of 2008 (GINA), claiming that part of the rules will cause the use of such programs to "decline precipitously."

The Disease Management Association of America's Care Continuum Alliance in a letter last week asked the administration to stop implementation of the regulations and to create a panel that would review how they will impact wellness and chronic disease management programs.

DMAA argued that GINA's Title I, which prohibits health insurance companies from requesting, requiring, or buying genetic information and related family history information from individuals for underwriting purposes, will make it difficult for wellness programs to collect health risk assessments (HRAs), because it will not allow them to offer incentives such as reduced premiums.

The group claim that the definition of "underwriting" in the rules is too broad, and that it includes incentives for completing HRAs, such as changing deductibles or other cost-sharing tools, discounts, rebates, payments in kind, or other cost-sharing programs.

In the letter to the secretaries of the Departments of Labor, Health and Human Services, Treasury, and to the White House, DMAA President and CEO Tracey Moorhead called the HRA "an essential, proven tool to identify individuals who are at-risk for or currently managing chronic illness.

"This isn't about getting rid of wellness programs, this is about them changing the way they use HRAs," Jeremy Gruber, who is president of the Council of Responsible Genetics, and founder and executive committee member of the Coalition for Genetic Fairness, told *GenomeWeb Daily News* today.

Gruber said that he wants to make sure that "wellness is not being used as a back door for obtaining crucial health information," and that the request for a moratorium on GINA and rule changes to incentives could be just that.

"The worry and the concern is that they will use HRAs to acquire personal health information and then use it to discriminate," he said.

Gruber also said that incentive-based HRAs can be used as a kind of financial pressure to entice people to offer up genetic or family history information, which could be used to set premiums or to make coverage decisions.

"That's exactly the type of question that GINA was supposed to prohibit... Title I says that you cannot use genetic information for underwriting, period," he said, pointing out that Title II of the legislation, which deals with employers, provides an exception for wellness programs that are voluntary.

"Once that information is collected it is more likely that it will be used," said Gruber. "The reason why it was so crucial to include those rules for both employment and insurance is that it is very difficult to identify discrimination when it happens."

Gruber, who has been active in the development of the legislation for years, said that wellness programs had their opportunity to be at the table while the law and the regulations were discussed, but he characterized them as largely absent from the discussion over HRAs, and said they may have been "caught off guard" by how the rules will affect them.

Moorhead described the interim final rule as leaving health plans and employers "with two equally unattractive options: end incentives for completing an HRA that elicits genetic information (including family medical history) or remove questions about genetic information from the HRA.

"In the former case, participation in wellness and disease management programs will decline precipitously... [and] in the latter, the effectiveness of the HRA will be severely diluted, as family history and other genetic information are strong indicators of predisposition to a chronic illness," Moorhead wrote in the letter.