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Sent: Friday, July 09, 2010 8:16 AM

To: Genetic Testing Registry (NIH/OD/OSP)

Subject: Request for Information (RFI) on the NIH Plan to Develop the Genetic Testing Registry

14. Are there any other issues that NIH should consider in the development of the GTR?

One of the issues that should be considered is the security of the testing agency. The public is very concerned about security of the personal information when it's stored by the government but they will submit samples for testing with no knowledge or understanding of what private companies do or don't do to protect them. There needs to be a standard for security which any company participating in the registry should adhere to and the public should have access to the information on the security policies. There also needs to be information which allows or disallows patients to share information with researchers and other medical personnel.

I know this is a tall order but to set up a registry of tests without giving the public this type of information could not only be detrimental to patients but could potentially lead to a lack of confidence in the registry.

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