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**Sent:** Friday, June 11, 2010 10:47 AM  
**To:** Genetic Testing Registry (NIH/OD/OSP)  
**Cc:** Wen-Hann.Tan@childrens.harvard.edu  
**Subject:** RFI

To whom it may concern:

My main difficulty with the proposed GTR is that there is no plan to have the information reviewed and vetted by professionals in the field. Because it is being established by the NIH, it will have de facto credibility, but I am gravely concerned that since "Submitters will be solely responsible for the content and quality of the data they provide to the GTR"

<http://www.ncbi.nlm.nih.gov/gtr/qa/>, there is opportunity to market testing directly to consumers without oversight by a neutral party that assures submitter's claims of clinical utility are valid. "The GTR will incorporate quality assurance safeguards and checks against inadvertent submitter error, but these will not substitute for the submitters' obligation to assure that the information they contribute is correct." Though information submitted may be factually correct, it may be slanted by the submitter (who has an obvious incentive to portray the testing as more useful than it may really be) and opportunities to mislead the public seem rife. I would hate to see such a registry replace the existing GeneTests.org, which provides valuable information to geneticists and non-geneticist physicians and health care providers, who rely upon it heavily as a source of peer-reviewed credible information. Is it not possible to add to the existing GeneTests.org such that there can be a new section aimed at consumers, while still maintaining professional review of the information?

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