

From: Sarah.Klemm@spectrum-health.org [mailto:Sarah.Klemm@spectrum-health.org]
Sent: Wednesday, June 02, 2010 1:13 PM
To: Genetic Testing Registry (NIH/OD/OSP)
Subject: Request for information on the NIH Plan to Develop the genetic testing registry

Hello,

I am a certified genetic counselor who is responding to the request for input regarding the plan to have the NIH develop a genetic testing registry. I am writing to STRONGLY urge you to consider developing a website similar to the current website known as genetests (or gene clinics or gene reviews...) As a practicing genetic counselor I access the genetests website at least once daily. The well written and peer reviewed gene reviews are an essential part of my practice (and the practice of my genetic counseling colleagues) Where else are we going to find free, easily accessible, up-to-date information on the many single gene disorders without this resource? Many of us have limited journal access at our institutions. Not to mention that by using gene reviews we are giving consistent information and care recommendations to our patients NATIONWIDE. I cannot be sure that the counselors at any other institution have found the same journal article I did and have counseled about it, what if we missed something and are giving varying recommendations based on centers? In my opinion by removing the Gene Reviews would cause a detriment to medical genetics nationwide.

As to testing listed by this new program. I feel that the current gene tests model works well where a test can be searched for by gene or condition. I believe that it is critical to have contact information listed for these laboratories including a website if it is available. I also believe that there should be some effort made to distinguish between those tests which are for "carrier testing" and those which are diagnostic. In the group that are determined to be "carrier testing" I think that there should be some clearly visible notice regarding the many professional organizations that do not endorse carrier testing of minors as this does not impact their medical care. Also-could you have something that indicates for ALL tests that most laboratories and medical organizations recommend that patients give informed consent for genetic testing.

Thank you for your time!

Sarah

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