

From: Simpson, Gayle [mailto:gsimpson@sfcaustin.com]
Sent: Wednesday, June 02, 2010 2:22 PM
To: Genetic Testing Registry (NIH/OD/OSP)
Subject: NIH GTR RFI Comments

To Whom It May Concern:

As a genetic counselor I regularly use GeneTests. This website provides not only information on laboratories providing genetic testing, but I also use the website for the comprehensive Reviews of disorders, list of research opportunities, and list of resources.

While I am excited about the potential of the GTR to be a comprehensive resource for genetic testing, I worry that there is no plan for the GTR to include additional information such as disorder reviews, research labs, and resources. The current GeneTests website is a fabulous tool because it is truly comprehensive for the clinician. You can access clinical summaries, and then learn where to order the test and direct families to resources. I hope that the new GTR will also be a comprehensive resource like GeneTests and include additional information beyond just a list of labs doing genetic testing.

I strongly feel that without a resource like GeneTests I would not be able to do my job as efficiently and effectively as I currently do. Please consider that the genetics community would be strongly impacted by the dissolution of GeneTests if the new GTR does not include all the resources GeneTests currently provides.

Thank you,

Gayle Patel

Gayle Simpson Patel, MS, CGC
Genetic Counselor
'Specially for Children
1301 Barbara Jordan Blvd. Ste 200
Austin, TX 78723
512-628-1952 (phone)
512-628-1841 (fax)
gsimpson@sfcaustin.com
www.speciallyforchildren.com

Clients and parents: Please be advised that e-mail messages you send to and receive from healthcare providers constitutes medical communication and is considered part of the medical record. This e-mail may contain Protected Health Information (PHI) as defined under the Health Insurance Portability and Accountability Act of 1996. If you prefer not to receive email communication from this provider, please inform the sender by reply email.

This email message is for the sole use of the intended recipient(s) and may contain confidential and privileged information. Any unauthorized review, use, disclosure or distribution is prohibited. If you are not the intended recipient, please contact the sender by reply email and destroy all copies of the original message.