

**From:** Pradyumna Tummala [mailto:petummala@yahoo.com]  
**Sent:** Thursday, July 01, 2010 8:02 PM  
**To:** Genetic Testing Registry (NIH/OD/OSP)  
**Cc:** Wendy Book  
**Subject:** GTR Suggestions from the American Partnership for Eosinophilic Disorders (APFED)

Sir/Madam:

On behalf of the American Partnership for Eosinophilic Disorders (APFED), I would like to stress the importance of establishing the Genetic Testing Registry. APFED supports patients, families and communities affected by eosinophilic disorders and in particular eosinophilic gastrointestinal disorders, which are rare, but increasing in incidence, and cause serious nutritional deficiencies, growth retardation in children, and disabling gastrointestinal symptoms of nausea, vomiting, abdominal pain, diarrhea, and others. Although there are the beginnings of advances in identifying alleles and other genetic markers of these diseases, establishment of the GTR would greatly facilitate the development of not only testing for disease conditions, but also in identifying markers of disease activity via databases that may include microarray expression profiles in specific disease states. We fully support the formation of a registry that is as comprehensive as possible with regard to genetic testing, including:

1. identification of genes related to diseases
2. identification of microarray expression profiles
3. identification of unique protein expression in tissues affected by disease states
4. reporting of genetic markers and gene expression profiles in animal models of disease
5. reporting data on sensitivity, specificity, positive and negative predictive values with regard to specific gene expression profiles/biomarker expression and severity/extent/presence of disease.
6. opening up access to this database to international researchers, physicians, and patients.

Thank you for considering our comments. Sincerely,

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