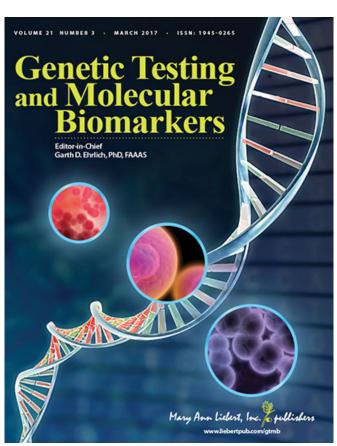


The benefits and dangers when genetic testing companies partner with orphan drug developers

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Credit: Mary Ann Liebert, Inc., publishers

Pharmaceutical companies developing Orphan Drugs are increasingly partnering with direct-toconsumer (DTC) genetic testing firms to identify individuals with rare diseases, in a trend that is raising concerns related to privacy, drug costs, and rising healthcare-related financial burden for consumers. An in-depth look at the enormous positive potential and concomitant dangers of these evolving corporate relationships and their impact on consumers and the healthcare system is published in *Genetic Testing and Molecular*

Biomarkers.

In the article "Direct-to-Consumer Genetic Testing and Orphan Drug Development," coauthors Matthew Mason, James Levenson, MD, and John Quillin, PhD, Virginia Commonwealth University School of Medicine, Richmond, discuss the dynamics and key factors that affect these two sectors of the healthcare industry. The authors examine the science behind DTC genetic testing and the industry's market growth, how drugs for rare diseases are regulated, the potential for innovation and applying genetic testing results to orphan drug development, and suggested oversight and safeguards needed to protect patients from threats to their privacy and possible price-gouging.

"This paper provides an excellent overview as well as a thoughtful perspective of the interactions between the commercial developers of <u>orphan</u> <u>drugs</u> and the patients and families that they aim to serve who are afflicted with <u>rare genetic diseases</u>," says <u>Genetic Testing and Molecular Biomarkers</u> Editor-in-Chief Garth D. Ehrlich, PhD, FAAAS, Professor of Microbiology and Immunology, Executive Director, Center for Genomic Sciences and Center for Advanced Microbial Processing, Institute for Molecular Medicine and Infectious Disease, Drexel College of Medicine (Philadelphia, PA).

More information: Matthew Mason et al, Direct-to-Consumer Genetic Testing and Orphan Drug Development, *Genetic Testing and Molecular Biomarkers* (2017). DOI: 10.1089/gtmb.2017.0087

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