Direct-to-Consumer Marketing of Genetic and Genomic Tests

irect-to-consumer (DTC) marketing of personal genetic and genomic (PG) tests has increased the availability of these products before the evidence of benefit in routine clinical practice has been established (Feero, Guttmacher, & Collins, 2008; Hudson, Javitt, Burke, & Byers, 2007; Manolio, Brooks, & Collins, 2008). PG tests are designed to provide either a comprehensive genetic risk profile for many diseases or specific genetic risk information for diagnostic or predictive purposes (Khoury et al., 2009). DTC marketing may include marketing of PG tests or products via print advertisements, television, or the Internet, and the sale of PG test kits directly to the consumer. Healthcare professionals may or may not be involved in ordering or interpreting testing results (Genetics and Public Policy Center, 2008a; Genetics Home Reference, 2010). DTC marketing of PG tests may encourage consumers and healthcare providers to become more proactive in health promotion, documentation of individual and family health history, and early detection of disease and disease management (Hunter, Khoury, & Drazen, 2008).

DTC marketing of PG tests may lead to (a) unnecessary diagnostic, pharmacologic, and surgical interventions (McGuire & Burke, 2008; Robson, Storm, Weitzel, Wollins, & Offit, 2010); (b) consumer preference for pharmaceuticals and genetic/genomic services of questionable benefit (Manolio et al., 2008); (c) false sense of reassurance based on negative test results; (d) children being subjected to inappropriate PG testing (Genetics and Public Policy Center, 2008b); and (e) privacy risks (e.g., if company goes out of business) (Genetics and Public Policy Center, 2008b).

It Is the Position of ONS That Oncology Nurses

- Integrate new evidence-based genetic and genomic information into oncology nursing practice.
- Educate patients and the public about the potential benefits and limitations of PG testing.
- Advocate for the development of culturally sensitive PG patient information.
- Integrate genetic competencies into oncology nursing education.
- Access evidence-based PG continuing education.
- Advocate for the ethical and legal use of genetic and genomic information.
- Advocate for patients to receive pretest education, counseling, and informed consent, with post-test disclosure and follow-up.
- Join with other healthcare professionals and professional organizations to define the appropriate use of genetic and genomic technologies.
- Access credible resources to evaluate PG tests.
- Conduct nursing research that contributes to the understanding of nursing-sensitive, patient-specific genetic and genomics outcomes.

Approved by the ONS Board of Directors, 3/2010.



References

Feero, W.G., Guttmacher, A.E., & Collins, F.S. (2008). The genome gets personal—almost. *JAMA*, 299, 1351–1352. doi: 10.1001/jama.299.11.1351

Genetics and Public Policy Center. (2008a). Direct-to-consumer genetic testing: Empowering or endangering the public? Retrieved

- from http://www.dnapolicy.org/policy.issue.php?action=detail &issuebrief id=32
- Genetics and Public Policy Center. (2008b). GPPC reveals the molecular full Monty: Personal genomes, personal health. Retrieved from http://www.dnapolicy.org/news.enews.article.nocategory.php?action=detail&newsletter_id=34&article_id=148
- Genetics Home Reference. (2010). What is direct-to-consumer genetic testing? Retrieved from http://ghr.nlm.nih.gov/handbook/testing/directtoconsumer
- Hudson, K., Javitt, G., Burke, W., & Byers, P. (2007). ASHG statement on direct-to-consumer genetic testing in the United States. Obstetrics and Gynecology, 110, 1392–1395. doi: 10.1097/01.AOG .0000292086.98514.8b
- Hunter, D.J., Khoury, M.J., & Drazen, J.M. (2008). Letting the genome out of the bottle—Will we get our wish? *New England Journal of Medicine*, 358, 105–107. doi: 10.1056/NEJMp0708162
- Khoury, M.J., McBride, C., Schully, S.D., Ioannidis, J.P., Feero, W.G., Janssens, A.C., . . . Xu, J. (2009). The Scientific Foundation for personal genomics: Recommendations from a National Institutes of Health–Centers for Disease Control and Prevention multidisciplinary workshop. *Genetics in Medicine*, 11, 559–567. doi: 10.1097/GIM.0b013e3181b13a6c
- Manolio, T.A., Brooks, L.D., & Collins, F.S. (2008). A hapmap harvest of insights into the genetics of common diseases. *Journal of Clinical Investigation*, 118, 1590–1605. doi: 10.1172/JCI34772
- McGuire, A.L., & Burke, W. (2008). An unwelcome side effect of direct-to-consumer personal genome testing: Raiding the medical commons. *JAMA*, 300, 2669–2671. doi: 10.1001/jama.2008.803
- Robson, M.E., Storm, C.D., Weitzel, J., Wollins, D.S., & Offit, K. (2010). American Society of Clinical Oncology policy statement update: Genetic and genomic testing for cancer susceptibility. *Journal of Clinical Oncology*, 28, 893–901. doi: 10.1200/JCO.2009.27.0660

Digital Object Identifier: 10.1188/10.ONF.385