

Direct-To-Consumer (DTC) Genetic Testing: What needs to be done to get this Business "Morally Right"?

A workshop at Georgetown University

September 12 and 13, 2019

Workshop Agenda

Thursday September 12, 2019- Hariri Building, Fisher Colloquium

8:00-8:15

Opening Remarks

Edward B. Heaton, M.D., M.P.H.
Executive Vice President for Health Sciences
and Executive Dean
Georgetown University Medical Center

Dennis P. Quinn, PhD
Vice Dean and Powers Term Professor in International Business
Georgetown University McDonough School of Business

8:15-8:45

A Personal Account of Ancestry Testing with Unexpected Results

A Conversation with Dianalee Mcknight, PhD, FACMG
Moderator: Bassem R. Haddad, MD (Georgetown University)

8:45-10:00

Scientific Session

Lawrence Brody, PhD (NIH/NHGRI): *The Science Behind Direct-to-Consumer Genetic Testing*

Megan Cho, ScM, CGC [C] (NIH/NHGRI): *The Science of Risk Communication: What We Tell Them and What They Hear*

10:00-10:30

Break

10:30-12:00

Industry Session

Cathy Ball, PhD (AncestryDNA): *Consumer-Centered Privacy for DTC Genomics Data*

Sarah Elson, PhD (23andme): *Informed Consent, Transparency, and Privacy in Consumer-Driven Genetics Research*

Eden V. Haverfield, DPhil, FACMG (Invitae): *Patient-Initiated Ordering: A Medically Responsible Hybrid Approach to Increasing Accessibility in Genetic Testing*

- 12:00-1:30 Lunch Break
- 1:30-2:45 Business Session:
- Marketing of Genetic Testing to Consumers: A Panel Discussion*
 Luc Wathieu, PhD (Georgetown University)
 Lorens Helmchen, PhD (The George Washington University)
 Manuel Hermosilla, PhD (The Johns Hopkins University)
- 2:45-4:00 Privacy and Counseling Session
- Christopher Slobogin, J.D., L.L.M. (Vanderbilt University): *What DTC Privacy Policies Don't Tell You*
- Beth N. Peshkin, MS, LCGC (VA) (Georgetown University): *Clinical Issues in Consumer Genomic Testing: The Good, The Bad and The Ugly*
- 4:00-4:30 Break
- 4:30-6:30 Public Policy and Regulatory Session
- John Mayo, PhD (Georgetown University): *Markets and the Regulation of New Technologies: Traditional Lessons and Emerging Dilemmas*
- Diane Hoffmann, J.D., M.S (University of Maryland): *Regulation of Genetic and Microbiome-Based Diagnostic Tests: What's the Appropriate Regulatory Framework?*
- Jennifer Wagner, J.D., PhD (Geisinger): *Shams, Scams, and Flimflams: Consumer Protections for the Personal Genomics Industry*

Friday September 13, 2019- Hariri Building, Room 415

- 8:00-8:15 Recap
- 8:15-9:30 International Experience with DTC
- Andelka Phillips, PhD, BA/LLB, LLM (University of Waikato, New Zealand and Oxford, UK): *Regulating Personal Genomics - Contracts and Privacy*
- Sara Mahmoud-Davis, J.D., LL.M. (Attorney-at-Law): *European Laws on Informed Consent and Recommendations for Empowering and Protecting EU Consumers*
- 9:30-10:00 Break
- 10:00-11:00 *Ethical Issues Surrounding Direct-to-Consumer Genetic Testing*
- Kevin Fitzgerald, SJ, PhD, PhD (Creighton University and Georgetown University)
- 11:00-12:15 *Discuss/propose best business practices (Group Discussion)*