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 Description and Objectives

Advances in genetics and genomics have initiated a new era in medical practice and led to a major paradigm shift in how health care will be approached. Not only did this technological advance lead to routine use of genetic testing in standard patient care in most areas of medicine, but also to the recent (and unusual) emergence of several companies in the US and around the world, offering direct-to-consumer (DTC) genetic testing for ancestry determination, and potentially for predictive markers of traits and diseases, ranging from medically insignificant traits to serious diseases such as cancer and heart diseases. The emergence of these companies continues to generate significant debates and controversies among geneticists, medical professionals, ethicists, and in the public. Consequently, many moral challenges arise that are complex, ambiguous, and might jeopardize the future of that industry.

DTC genetic testing is increasingly allowing general public access to testing outside of the boundaries of the traditional clinic and conventional patient-doctor relationship. However, the information that consumers obtain can be overwhelming, particularly

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addressed while the field is still in its infancy.

The objective of the workshop is to bring to light ethical issues surrounding DTC genetic testing and to examine business strategies that account for those. We aim to engage all stakeholders in a conversation that will help to get this business "morally right".

## To view the Agenda, click here

#### Registration

There are no registration fees, but registration is required.

# To register, please fill out the online form here.

Google sign-in required. Don't have a Google account? Contact Dr. Bassem Haddad at haddadb1@georgetown.edu for registration.

### Workshop Dates and Location:

The workshop will be held at Georgetown University on Thursday September 12 and Friday September 13, 2019, in the Rafik B. Hariri building (37th and O St., N.W., Washington, DC).

Day one will be held in the Fisher Colloquium and Day 2 in Room 415.

#### Workshop Organizers

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Bassem R. Haddad, MD (Georgetown University)

Father Kevin T. FitzGerald, SJ, PhD, PhD (Creighton University)

Luc Wathieu, PhD (Georgetown University)

#### Workshop Speakers

Catherine Ball, PhD (AncestryDNA)

Lawrence Brody, PhD (NIH/NHGRI/Division of Genomics and Society)

Megan T. Cho, ScM, CGC [C] (NIH/NHGRI)

Sarah Elson, PhD (23andMe)

Eden V. Haverfield, DPhil, FACMG (Invitae)

Lorens A. Helmchen, PhD (The George Washington University)

Manuel Hermosilla, PhD (The Johns Hopkins University)

Diane Hoffmann, J.D., M.S

Sara Mahmoud-Davis, J.D., LL.M. (Attorney-at-Law)

John W. Mayo, PhD (Georgetown University)

Dianalee Mcknight, PhD, FACMG

Beth N. Peshkin, MS, LCGC (VA) (Georgetown University)

Andelka Phillips, PhD, BA/LLB, LLM (University of Waikato, New Zealand, and

University of Oxford, England)

Christopher Slobogin, J.D., LL.M (Vanderbilt University)

Jennifer K. Wagner, J.D., PhD (Geisinger)

## **Contact Information**

For questions, please contact Dr. Bassem Haddad

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# Transportation and Dining Options

Getting to Georgetown University

Dining Options