

*ISCC Direct to Consumer (DTC)  
Genetic Testing Project Group*

Project Update

*Thursday, February 7th, 2019*



# Purpose

- 1) Collecting and documenting existing DTC information resources (including educational, position statements and peer-reviewed literature and news media);
- 2) Assessing need, generating ideas and facilitating development for additional DTC educational resources for healthcare professionals and educators; and
- 3) Identifying venues to partner in disseminating DTC educational resources appropriate to the needs of organizations needing DTC education (ISCC member organizations and others).

# ISCC DTC Project Group (Est July 2018)

NAME	Organization
Blazer, Kathleen (Co-Chair)	City of Hope Medical Center, Cancer Genomics Education Program
Weiler, Tracey (Co-Chair)	Florida International University
Carroll, June	College of Family Physicians of Canada/U Toronto and Genetics Education Canada – Knowledge Organization (GEC-KO)
Christopher, Dyanna	National Human Genome Research Institute (NIH/NHGRI)
Dreike, Sandra	National Society of Genetic Counselors (NSGC)
Easter, Carla	National Human Genome Research Institute (NIH/NHGRI)
Filipski, Kelly	National Cancer Institute (NCI)
Flowers, Elena	International Society of Nurses in Genetics (ISONG)
Garber, Kate	Emory University
Hanson, Karen	NCATS, ICF (and Genetic and Rare Diseases Information Center (GARD))
Hyland, Kathy	University of California San Francisco
Kapustij, Cristina	National Human Genome Research Institute (NHGRI)
Kuo, Grace	University of California San Diego, PharmGenEd Program
Lewis, Janine	ICF International (and Genetic and Rare Diseases Information Center (GARD))
Massart, Mylynda	University of Pittsburgh
Messersmith, Donna	National Human Genome Research Institute (NIH/NHGRI)
Mills, Rachel	National Society of Genetic Counselors (NSGC)
Yusuf, Safa	Genetics Education Canada – Knowledge Organization (GEC-KO)

# Needs Assessment Survey

Determine the educational and resource needs of **healthcare practitioners and genetics educators** with respect to DTC genetic testing\*. Goal to assess:

**who** is most interested in DTC genetic testing information, how **frequently** DTC genetic testing issues are coming up in clinical practice, **confidence** with navigating patient needs related to DTC information, what educational **resources and tools** are of interest and importance.

Based on this needs-assessment, the DTC Genetic Testing Working Group hopes to curate and develop effective tools and resources related to DTC genetic testing, patient care and education.

\* Direct to consumer (DTC) genetic testing refers to genetic tests that are marketed directly to consumers, providing people access to their genetic information without **necessarily** involving the patient's own healthcare provider.

# DTC Genetic Testing Education Needs Assessment

Currently revising based on initial feedback

Target to BOTH both healthcare providers and educators

ISCC Feedback

Willingness to take the survey and distribute to their members

Ideas about other organizations/groups to survey

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