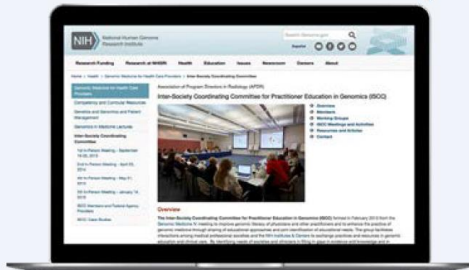


ISCC-PEG: In-Person Meeting 2020

Rich Haspel, MD, PhD
Beth Israel Deaconess Medical Center
Harvard Medical School
Co-Chair ISCC-PEG

Inter-Society Coordinating Committee for
Practitioner Education in Genomics (ISCC)



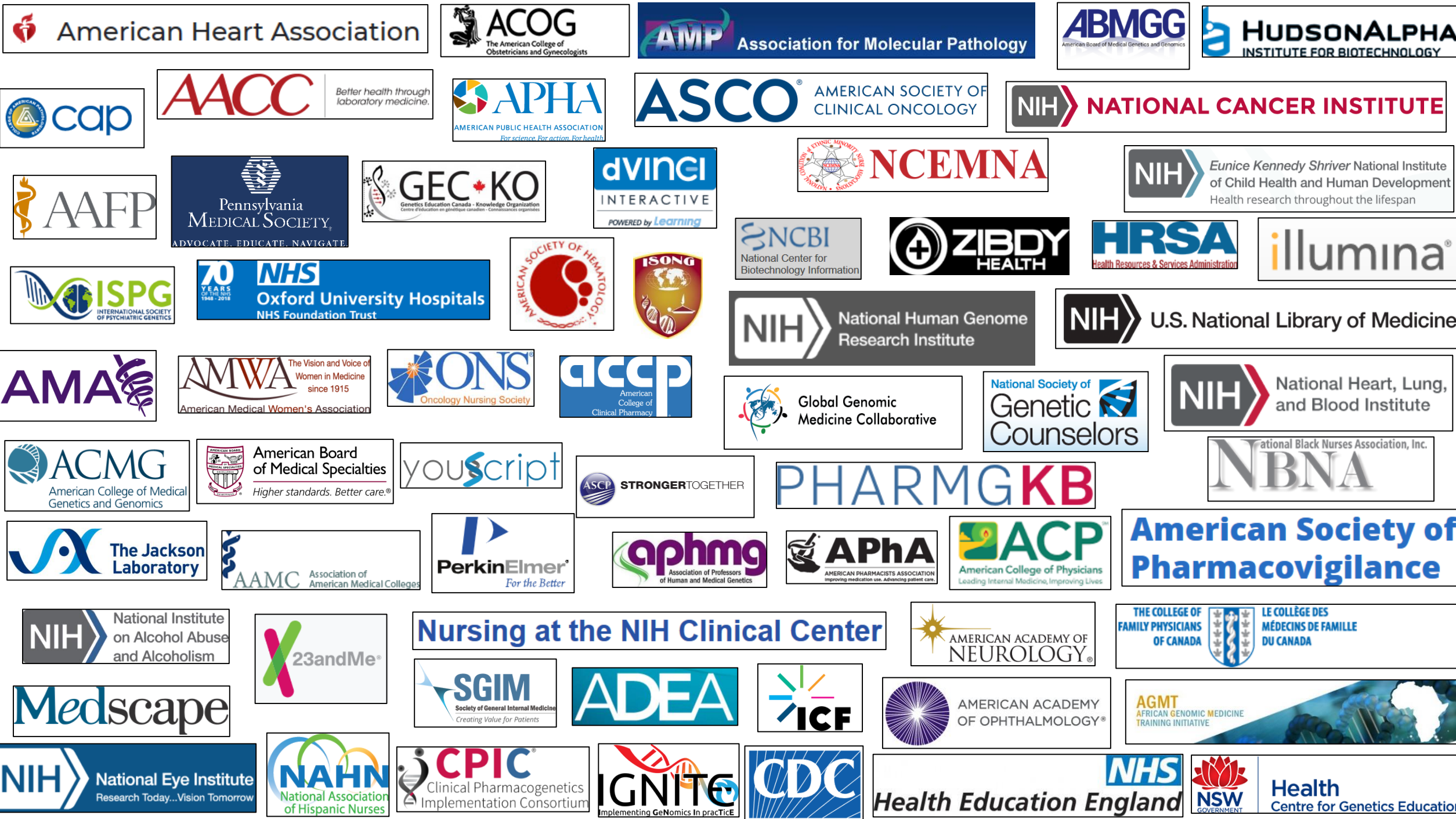
<https://www.genome.gov/ISCC>



Thanks to our
members and NHGRI
for your support!!

Carla Easter, Donna Messersmith, Christina
Daulton, Sherese Teixeira, Laura Rodriguez,
Larry Brody and Teri Manolio

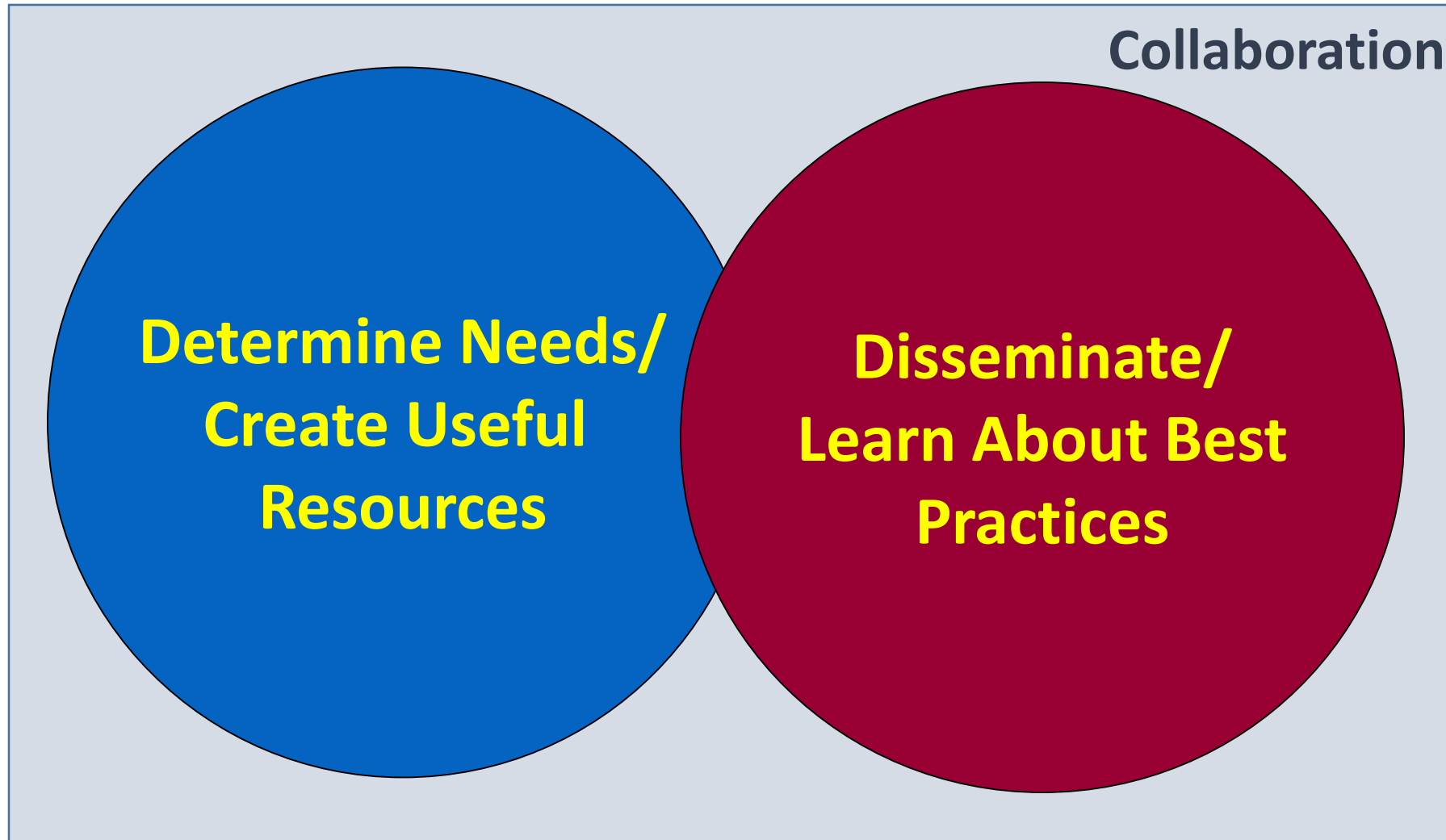




Over 150 members!

- 10 Industry, 21 Institute (NIH-non-NHGRI), 85 Organization, 38 Individual
- Welcome to new members since last in-person meeting!
 - Individual: Houriya Ayoubieh, Megan Doerr, Andrea Durst, Christine Formea, Julia Gerow, Karen Hurley, Anastasia Jacko, Vivian Jiang, Rebecca Kronk, Emili Leary, Heewon Lee, Ming Li, Ed Michaud, Melissa Murfin, Karen Niemchick, Aniwaa Owusu-obeng, Prital Patel, Orlando Rafael Serrano-Barrera, Angela Trepanier, Markos Tesfaye Woldeyohannes
 - Institutes and Organizations: Michelle Snyder (ICF/GARD), Yassmine Akkari (AMP), Jehannie Austin (ISPG), Kelly East (HudsonAlpha), Andrew Landstrom (AHA), Jane Radford (ACMG), Steven Ralston (ACOG), Gabriella Ryan (ASH), Tung Sung “Sam” Tseng (APHA)
 - Industry: Valerie Baron (YouScript), Madhuri Hegde (PerkinElmer), Sally Reidy (D’Vinci Interactive)

Goal of ISCC: Improve Genomic Literacy



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COMMITTEES

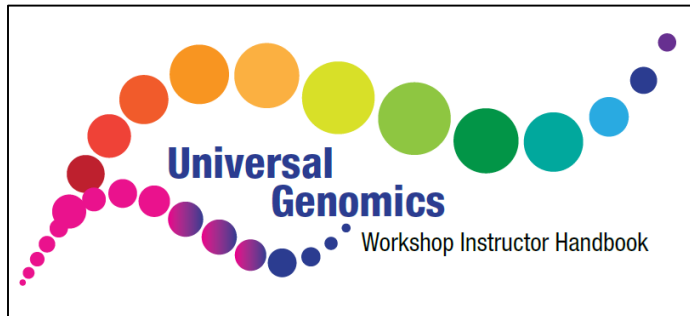
JUST LIKE TEAMWORK. ONLY WITHOUT THE WORK.

ISCC has created useful resources

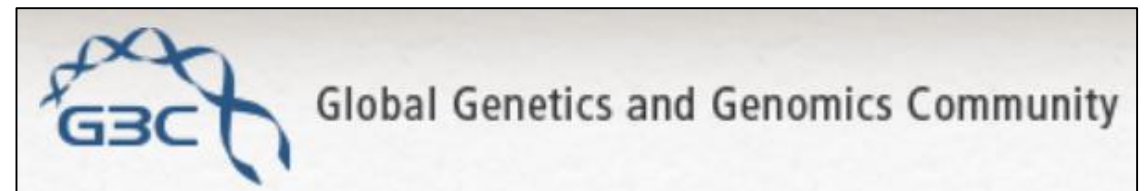
- Developed competencies
- Educational resources
 - Webinars
 - Educational tools/cases
 - Universal exercises
 - Contributing to existing projects

Framework for development of physician competencies in genomic medicine: report of the Competencies Working Group of the Inter-Society Coordinating Committee for Physician Education in Genomics

Genet Med. 2014 Nov;16(11):804-9.



PATIENT TREATMENT BASED ON GENOMIC RESULTS	
EPA: Use genomic information to make treatment decisions.	
Patient care	Systems-based practice
<ul style="list-style-type: none">Identify medical conditions and drug responses that have a strong genetic component;Recognize that variants affecting drug responses found in a patient may also have implications for other family members; andDiscern the potential clinical impact of genetic variation on risk stratification and individualized treatment.	<ul style="list-style-type: none">"Treat the patient who has the disease," i.e., be aware of the patient's needs as an individual who also has a genetic disease or pharmacogenomic variation.
Knowledge for practice	Interprofessional collaboration
	<ul style="list-style-type: none">Recognize potential involvement of multiple organ systems in genetic disorders and therefore appreciate the need to seek appropriate consultation with experts in the field; andMake medical and genetic information available to other health-care professionals, upon obtaining proper consent, while keeping the patient's interests as the primary priority.



ISCC Project Groups: Not just talk

- **Inclusion in the Practice of Genomic Medicine** (Shoumita Dasgupta, PhD)
- **Pharmacogenomics** (Andrew Monte, MD and Phil Empey, PharmD, PhD)
- **Direct-to-Consumer Genetic Testing** (Tracey Weiler, PhD and Heewon Lee, MS, LGC)
- **Rare Diseases** (Michelle Snyder, MS, CGC)

New project group members and ideas welcome!

Inclusion in the Practice of Genomic Medicine

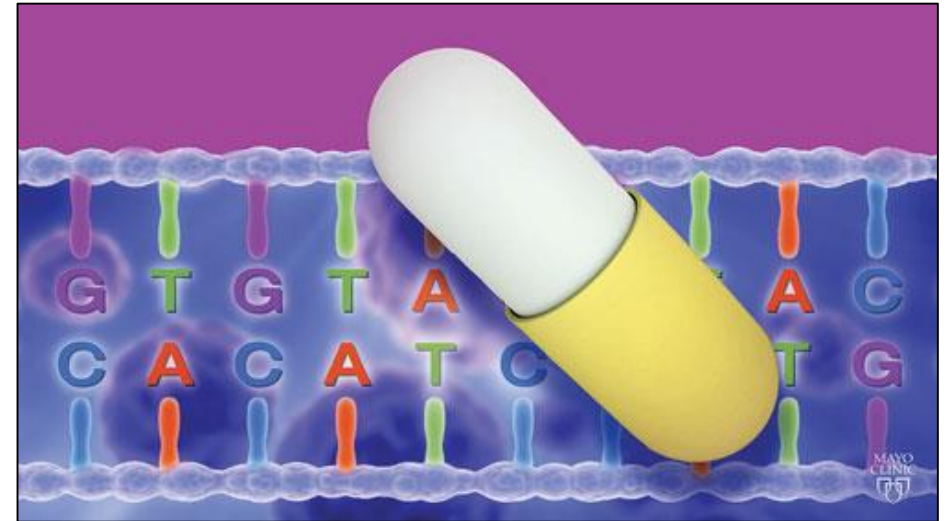
- Chair: Shoumita Dasgupta
- Goals
 - Identify implicit and/or explicit bias held by medical students and clinicians towards individuals with physical and/or intellectual disability.
 - Determine whether these biases impact genetic counseling recommendations in a prenatal setting.
 - Assess whether training in patient-centered counseling can positively impact subjects' ability to appropriately make unbiased prenatal recommendations.
- Progress to date
 - Developed and released CME module and hope to disseminate through ISCC
 - Plans to test module efficacy



<https://storystreetconsulting.com/project-inclusive/>

Pharmacogenomics

- Co-chairs: Andrew Monte and Phil Empey
- Goals:
 - Create and/or re-purpose pharmacogenomics educational content and resources targeted to clinicians.
 - Prepare for presentations at clinician professional meetings.
 - Tailor pharmacogenomics educational content for nurses, pharmacists, physician assistants, genetic counselors, physicians, researchers, and other healthcare professionals.
 - Educate the public in pharmacogenomics to improve healthcare.
- Progress to date
 - Have developed first teaching educational activity related to pharmacogenomics of clopidogrel
 - Underwent outside review
 - Working with AAFP to help distribute
 - Looking into collaboration with other project groups
 - Possible Psychiatry PGx Project Group (Daniel Mueller)



Direct-to-Consumer (DTC) Genetic Testing

- Co-chairs: Tracey Weiler and Heewon Lee
- Goals:
 - Assessing need, generating ideas and facilitating development for additional DTC-GT educational resources for healthcare professionals and trainees.
 - Identifying venues to partner with to develop and distribute DTC-GT educational resources appropriate to the needs of organizations needing DTC-GT education (ISCC member organizations and others).
 - Collecting and documenting existing DTC-GT information resources (including educational, position statements and peer-reviewed literature and news media).
- Progress to date
 - Have developed needs assessment survey questions to be incorporated into “Healthcare Providers and Educators Genomic Literacy Survey”
 - Working on DTC FAQ for health care providers



Rare Diseases

- Chair: Michelle Snyder
- Goals:
 - Educate healthcare professionals on available resources for rare genetic diseases.
 - Develop resources to address the challenges of rare diseases, such as diagnostic delays, lack of available treatment guidelines, and limited referral pathways.
 - Identify effective dissemination methods for information about rare diseases by specialty or practice area.
- Progress to date
 - Added question to “Healthcare Providers and Educators Genomic Literacy Survey”
 - Discussing developing resources



The Compendium: Sharing ideas and resources

African Genomic Medicine Training Initiative	9
American Academy of Family Physicians (AAFP).....	11
American Academy of Ophthalmology (AAO)	12
American Association for Clinical Chemistry (AACC)	13
American Board of Medical Specialties (ABMS).....	15
American College of Clinical Pharmacy (ACCP).....	17
American College of Medical Genetics and Genomics (ACMG).....	19
American College of Obstetricians and Gynecologists (ACOG).....	20
American Heart Association (AHA).....	21
American Medical Association (AMA)	23
American Medical Women's Association (AMWA)	25

28 updates!!

Draft sent:

-Please review

-New/modified entries still welcome

-Plan to finalize in 2 weeks

Compendium Entry (Blank form for new entries or updates)

Name of Organization:

- 1) Name of Individual(s) Submitting Entry:
- 2) List and briefly describe your organization's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links. Place an asterisk next to any resources you would consider for inclusion in G2C2 (the genomics educational repository at <http://genomicseducation.net/>).
- 3) Would someone be interested in presenting your organization's educational programs/best practices/initiatives/resources during an ISCC plenary call or face-to-face meeting? If yes, please indicate topic, who might present, and whether there is a preference for a call or face-to-face meeting.
- 4) Would someone in your organization be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.
- 5) Would someone in your organization be interested in leading a discussion related to issues/best practices in genomics education during an ISCC plenary call or face-to-face meeting? If yes, please describe topic, who might lead a discussion, and whether there is a preference for a call or face-to-face meeting.
- 6) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if someone in your organization would not be interested in leading).

Tools to promote interaction (Google Drive)

Folders

Name ↑

2019_ISCC-PEG Plen... 2019_Sept_NHGRI Ad... 2020 ISCC-PEG In-Per... Compendium

Strategic Planning

Files

ISCC Members_Meeti...

ISCC Members_Meetings.xlsx

Open with Google Sheets

	A	B	C	D	E	F	G
1	This spreadsheet is for ISCC-PEG members to enter information about upcoming events (e.g., annual meetings) of potential interest to ISCC-PEG membership.						
2							
3	Professional Society	Meeting name	Meeting date	Meeting location	Meeting link	Entered by:	Contact email (optional)
4	American Society of Human Genetics (ASHG)	ASHG 2019 Annual Meeting	October 15-19, 2019	Houston, TX	http://www.ashg.org/2019meeting/	Donna Messersmith	donna.messersmith@nih.gov
5	Association of Professors of Human and Medical Genetics	APHMG 2020 Annual Workshop (Focus on educators, providers, program directors, etc)	April 29 - May 1, 2020	Palm Springs, CA	https://www.aphmg.org/schedule	Shoumita Dasgupta	dasgupta@bu.edu, info@aphmg.org
6							

- Minutes, compendium
- Meeting list (please add)
- Considering additional tools
 - Suggestions doc?
 - Ideas welcome

https://drive.google.com/drive/folders/1D-zKzTvNXILTHsA_UgoabkQ3sphy6AKk

Letter for strategic planning

June 26, 2019

Dr. Eric Green

Director, National Human Genome Research Institute

National Institutes of Health

BG 31 RM 4B09

31 Center Drive

Bethesda, MD 20892

Dear Dr. Green,

In 2011, you wrote that “it is time to get serious about genomics education for all health care professionals.”¹ Since then, NHGRI has taken major steps towards improving genomics education including, over the last 6 years, supporting the work of the Intersociety Coordinating Committee for Practitioner Education in Genomics (ISCC). In turn, the ISCC has

Future plans

- Logistics
 - New Dissemination/Review Policy
 - Logo
 - Google Drive
- Expand membership
- Spread the word
 - “Tag-on” slides for members
 - Presence at health professional/genetics meetings
- Working groups
 - Support existing
 - Encourage new
 - Develop and disseminate resources
- Strategic planning/Funding?
 - Encourage applications for NHGRI PAR-19-185

This [explain activity] was prepared or accomplished by [insert author's name] in his personal capacity. The opinions expressed in this article are the author's own and do not reflect the view of the National Institutes of Health, the Department of Health and Human Services, or the United States government.

 **NATIONAL CANCER INSTITUTE**
Division of Cancer Control & Population Sciences



[Home](#) / Implementation Science Consortium in Cancer

Agenda

- **8:00 a.m. - 8:30 a.m. Set-up and Breakfast**
- **8:30 a.m. - 9:00 a.m. Welcome and Introductions**
- **9:00 a.m. - 10:00 a.m. Keynote: Tools for Public Education about Research Ethics**
Jeffrey Botkin, M.D., M.P.H.
Professor of Pediatrics and an Adjunct Professor of Human Genetics and Internal Medicine at the University of Utah
- **10:00 a.m. - 10:30 a.m. Extramural Training Opportunities/News**
Heather A. Colley, M.S.
Program Director, Division of Genomic Medicine, NHGRI
- **10:30 a.m. - 11:00 a.m. Ethical, Legal and Social Implications Research Program**
Dave Kaufman, Ph.D.
Program Director, Division of Genomics and Society, NHGRI
- **11:00 a.m. - 11:30 a.m. Organization Members and ISCC Collaboration**
Robert Ostrander, M.D.
SUNY Upstate Medical University,
Representative from American Academy of Family Physicians
- **11:30 a.m. - 12:00 p.m. ISCC Business: Discussion of ISCC Description and Draft "Policy on Review of Materials and Dissemination" document**
- **12:00 p.m. - 12:45 p.m. - Lunch (on your own) / Networking**
- **12:45 p.m. - 2:45 p.m. - Project Group Meetings**
- **2:45 p.m. - 3:45 p.m. - Project Group Meetings Updates and "Asks" of ISCC Membership**
- **3:45 p.m. - 4:30 p.m. - General discussions and suggestions for ISCC**



Please post suggestions!

