ISCC-PEG: In-Person Meeting 2020

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

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!
  • 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

- Determine Needs/Create Useful Resources
- Disseminate/Learn About Best Practices

Collaboration
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

![Universal Genomics Workshop Instructor Handbook](image1)

![Project Inclusive](image2)

![G3C Global Genetics and Genomics Community](image3)

**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**


**Table: PATIENT TREATMENT BASED ON GENOMIC RESULTS**

<table>
<thead>
<tr>
<th>Patient care</th>
<th>Systems-based practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPA: Use genomic information to make treatment decisions.</td>
<td>&quot;Treat the patient who has the disease,&quot; i.e., be aware of the patient's needs as an individual who also has a genetic disease or pharmacogenomic variation.</td>
</tr>
<tr>
<td>Identify medical conditions and drug responses that have a strong genetic component.</td>
<td>Interprofessional collaboration</td>
</tr>
<tr>
<td>Recognize that variants affecting drug responses found in a patient may also have implications for other family members; and</td>
<td>Recognize potential involvement of multiple organ systems in genetic disorders and therefore appreciate the need to seek appropriate consultation with experts in the field; and</td>
</tr>
<tr>
<td>Discern the potential clinical impact of genetic variation on risk stratification and individualized treatment.</td>
<td>Make medical and genetic information available to other health-care professionals, upon obtaining proper consent, while keeping the patient's interests as the primary priority.</td>
</tr>
</tbody>
</table>
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 G2G2 (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)

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

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