

# ISCC-PEG: Promoting Collaboration in Genomics Education

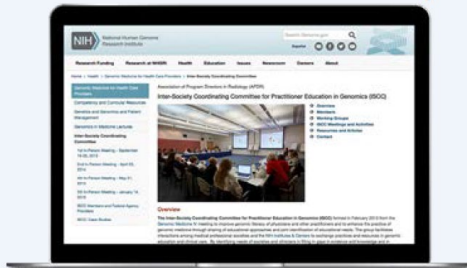
Rich Haspel, MD, PhD

Beth Israel Deaconess Medical Center

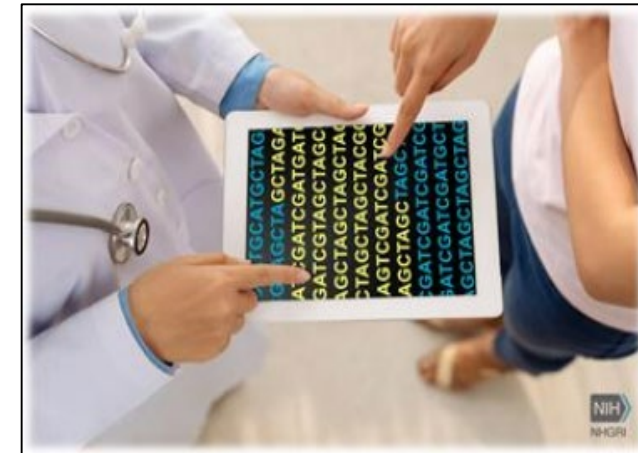
Harvard Medical School

Co-Chair ISCC-PEG

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



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



# What is the ISCC-PEG?

- The Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG)
  - Formed in February 2013 from the Genomic Medicine IV meeting.
  - Supported by the NHGRI Division of Policy, Communications, and Education
    - Education and Community Involvement Branch (ECIB)
- Membership
  - >160 members
    - Representatives from >80 organizations
    - 24 Individual
    - 10 Industry
  - Looking for new members!
  - International!



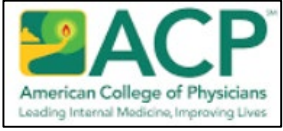
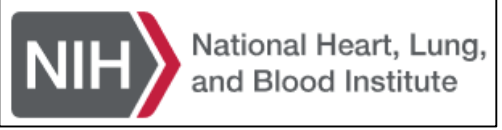
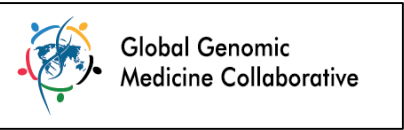
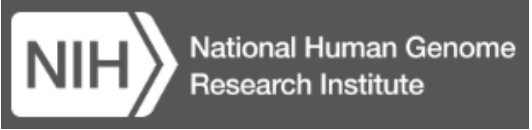
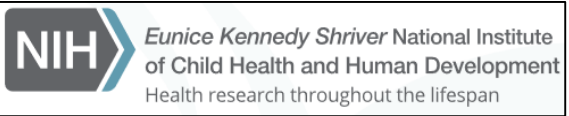
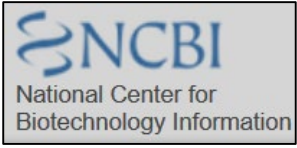
Donna Messersmith, PhD  
Provider Education Specialist



Carla Easter, PhD  
Chief, ECIB

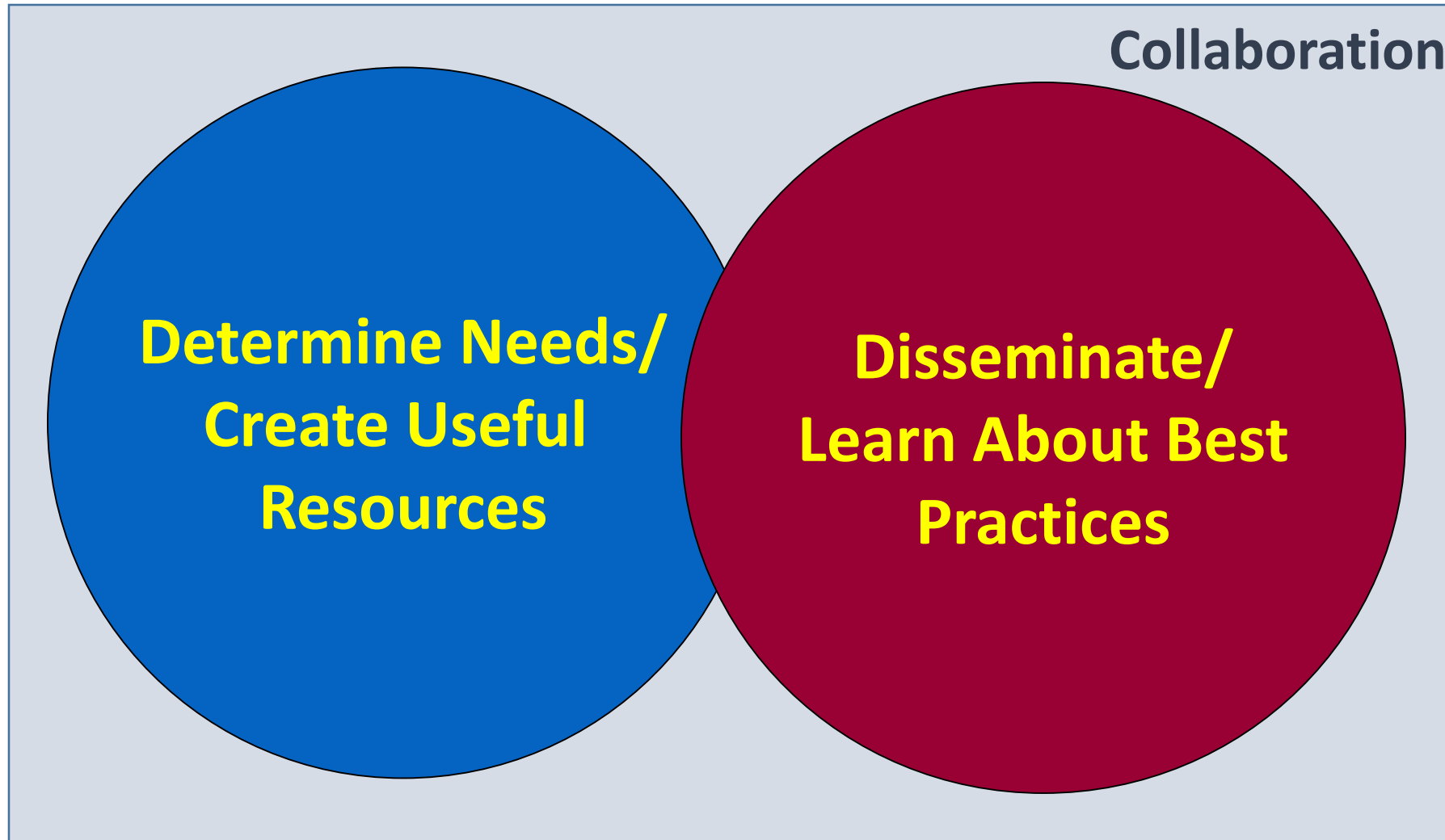
Thanks to NHGRI  
for your support!!





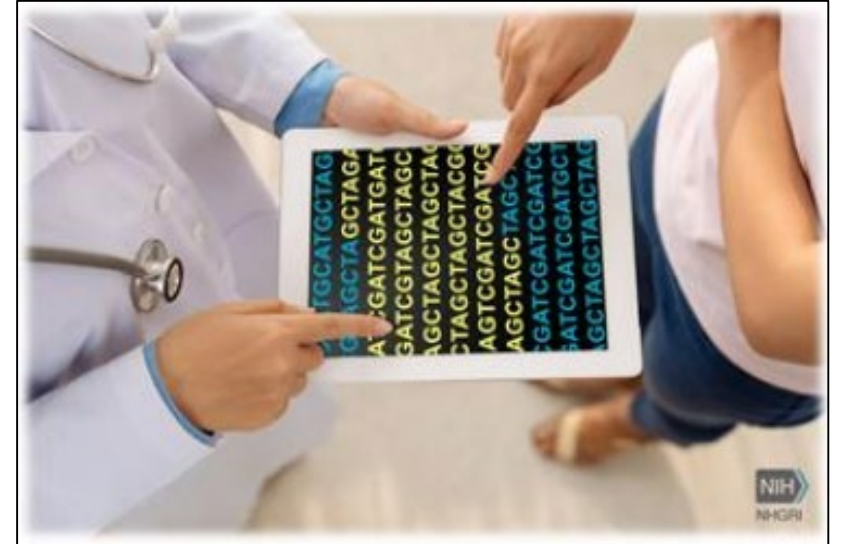


# Goal of ISCC: Improve Genomic Literacy



# ISCC-PEG: How it works

- One NHGRI and one outside co-chair
  - Carla Easter and me
- Membership
  - Organizational/Institute
  - Individual
  - Industry
  - “Policy for Ensuring Independence in ISCC Activities”
- No dues
- Conference calls every other month
  - Members provide intros/updates
  - Project group updates
- In-person meeting once a year
  - At NIH
  - Can call in
- Website
- Project groups have conference calls
- Compendium updates twice a year



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# COMMITTEES

JUST LIKE TEAMWORK. ONLY WITHOUT THE WORK.

# ISCC has created useful resources

- Developed competencies
- Educational resources
  - Webinars
  - Educational 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

- 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; and
- Discern the potential clinical impact of genetic variation on risk stratification and individualized treatment.

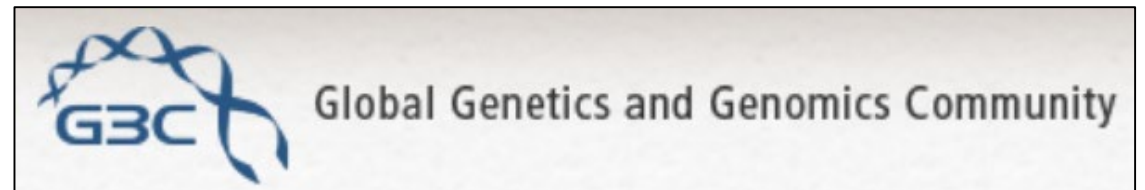
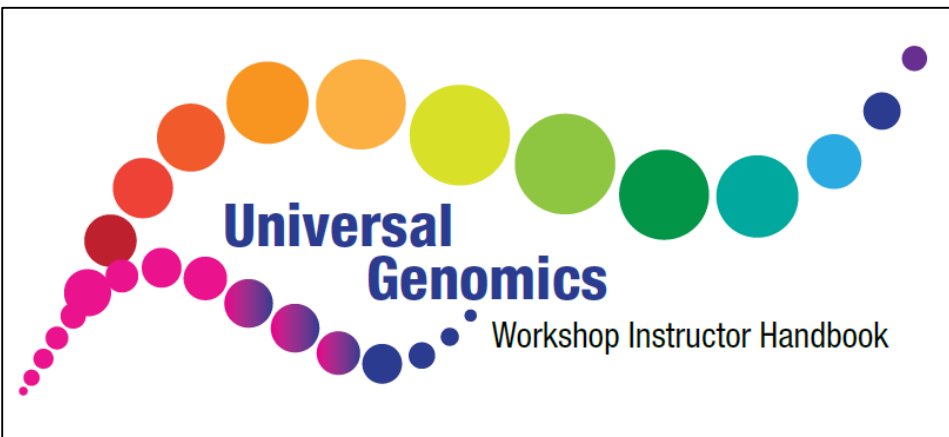
### Knowledge for practice

### Systems-based practice

- “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.

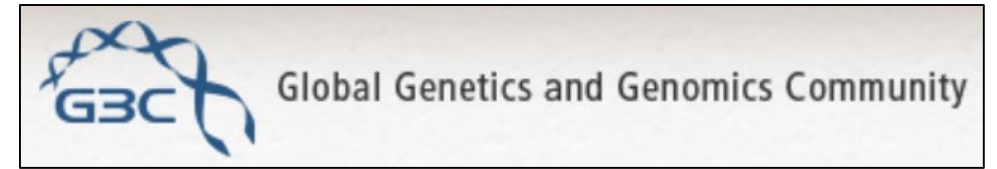
### Interprofessional collaboration

- 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
- 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.





# ISCC G3C Case Development



Larissa

View Patient Info

Name: Larissa

Age: 35

Height: 5' 5"

Weight: 130 lbs.

BP: 115/78

Pulse: 79

Temp: 98.2


Background

Larissa is a 35-year-old elementary Spanish teacher who recently had blood work done at a health fair. The result showed that her cholesterol levels were high. She followed up with her gynecologist who...

Read More

Health Record

Case Notes

A video frame showing a woman with dark hair tied back, wearing a purple long-sleeved shirt. She is standing in a clinical or laboratory setting with a window with blinds behind her and some equipment on a counter to her right.

Click here to begin

- Contributing to the existing/successful G3C educational platform
- ISCC-PEG Hypercholesterolemia case: Cardiologist and Genetic Counselor input

[https://genomicscases.net/en/user\\_home](https://genomicscases.net/en/user_home)

# Universal exercises are “plug-and-play”

- 4 team-based learning exercises
  - Single gene testing
  - Use of multigene assays
  - Whole-exome sequencing
  - Polygenic testing/ pharmacogenomics
- Handbook and Toolkit
  - Detailed instructions
  - Adaptation examples
    - PowerPoint slides
    - Handouts
- Funded through an NHGRI supplement to an NCI R25

## Case Presentation

Given the results from the first exercise, you would like to explore other possible genetic causes of the patient's *(diagnosis)*. You begin to look into commercially available gene panels.

1. List 2 criteria to guide the selection of variants that should be on the gene panel for this patient. (REVEAL)
2. You notice that two different reference laboratories offer gene testing for this patient.
  - a. List the genes tested for using *(laboratory 1)* (search online)
  - b. List the genes tested for using *(laboratory 2)* (search online)
  - c. The *(geneA)* is tested for in both laboratories but *(geneB)* is only tested for at laboratory 1 but not laboratory 2. Using OMIM (<http://www.ncbi.nlm.nih.gov/omim>), for each gene:
    - i. List the first 3 studies cited in the OMIM entry for this gene.
    - ii. Determine how many participants in these studies, carried your patient's diagnosis?

 American Heart Association



Improving Genomic Literacy Among  
Cardiovascular Practitioners via a Flipped-  
Classroom Workshop at a National Meeting

Circulation: Cardiovascular Genetics. 2016;9:287–290

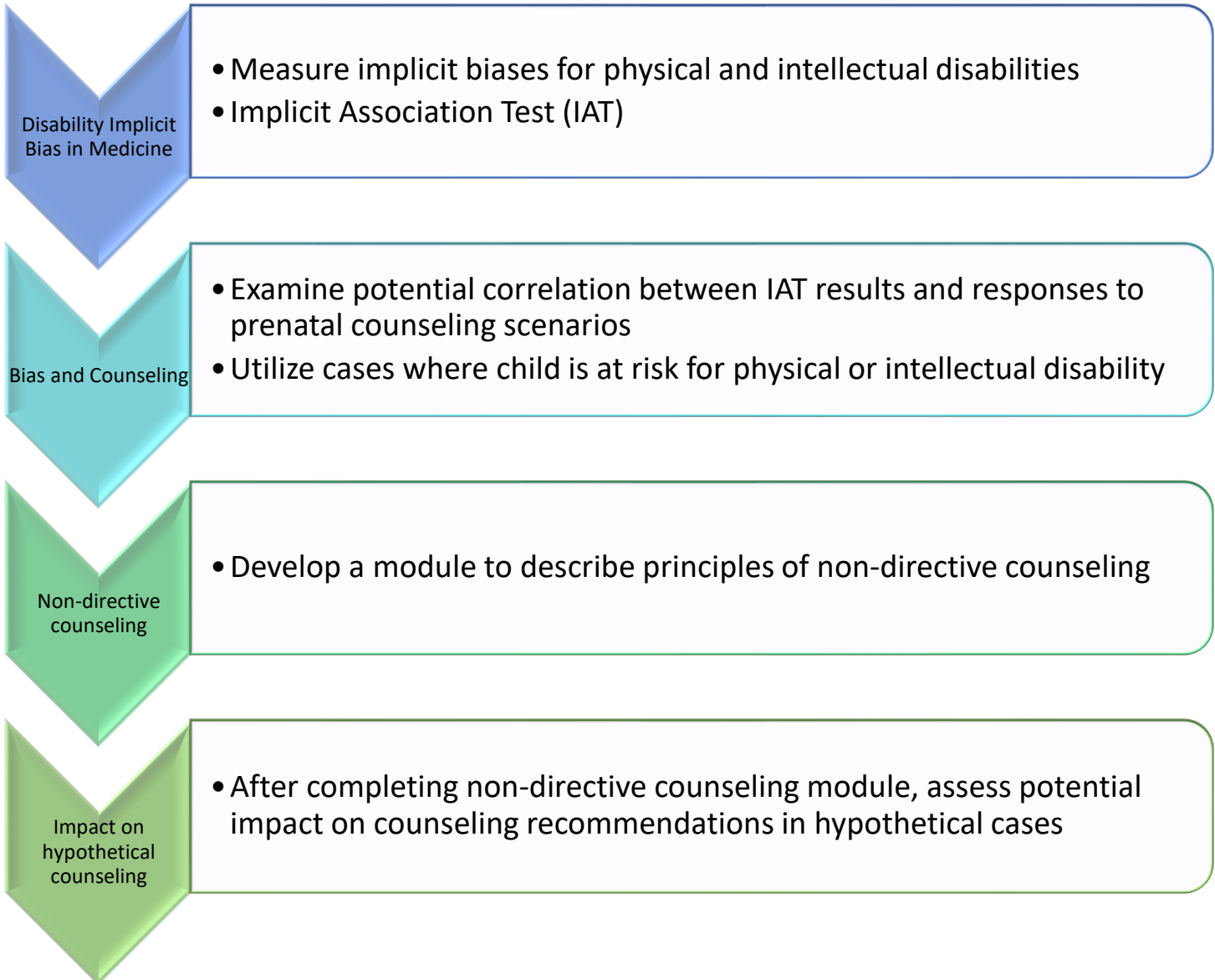
# ISCC Project Groups: Not just talk

- **Project Inclusive Genetics** (Shoumita Dasgupta, PhD)
- **Pharmacogenomics** (Andrew Monte, MD and Donna Messersmith, PhD)
- **Direct-to-Consumer Genetic Testing** (Kathy Blazer, EdD and Tracey Weiler, PhD)
- **Promoting and Supporting Diverse Health Care Professionals (Patients & Caregivers) through Inclusive Outreach and Engagement** (Carla Easter, PhD)
  - Potential collaboration with Education and Community Involvement Branch (ECIB) and Community Engagement in Genomics Working Group
- **Rare Diseases** (Michelle Snyder, MS, CGC)
  - Potential collaboration with Genetic and Rare Disease Information Center (GARD)

**New project group ideas welcome!**

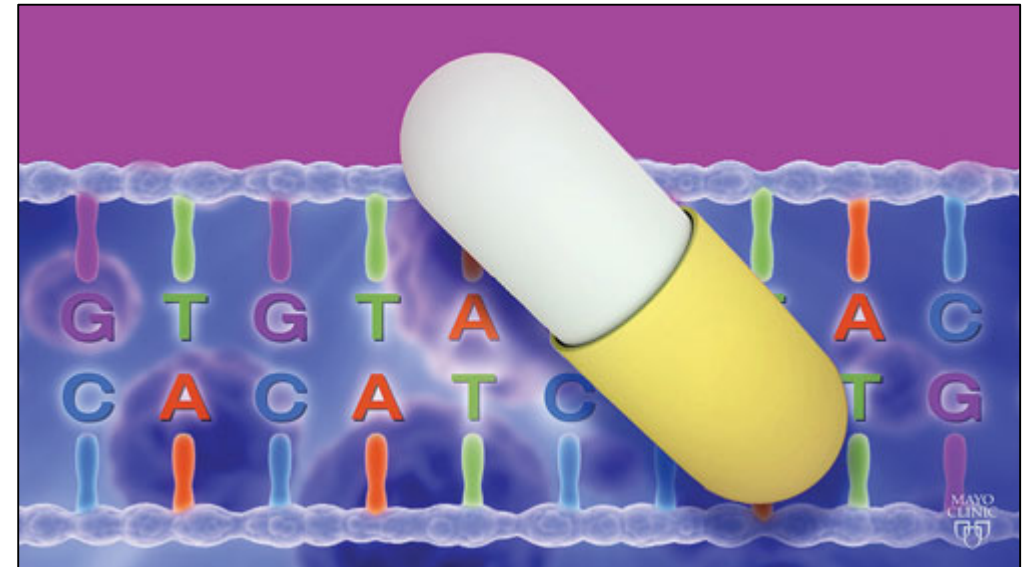
# Project Inclusive Genetics

- 5 members, Chair: Shoumita Dasgupta, PhD
- Developing educational resources related to studying unconscious bias for individuals with disabilities during prenatal screening.
- Progress to date
  - Developed implicit bias test related to individuals with disabilities and incorporated into teaching module
  - Almost ready for release! Hope to circulate through ISCC membership



# Pharmacogenomics

- *21 members, Co-chairs: Andrew Monte, MD, Donna Messersmith, PhD*
- *Goals:*
  - *Create and/or re-purpose pharmacogenomics educational content and resources targeted to primary care providers (PCPs). Prepare for presentations at professional meetings of PCPs.*
  - *Tailor pharmacogenomics educational content for Nurses, Pharmacists, Physician Assistants, Genomic Counselors, and other healthcare professionals.*
  - *Educate the public in pharmacogenomics for improved healthcare.*
- *Progress to date*
  - *Have developed first teaching educational activity related to pharmacogenomics of clopidogrel*
  - *Underwent outside review*
  - *Almost ready for release! Plans for AAFP to distribute, possibly AMA*





# Direct-to-Consumer (DTC) Genetic Testing

- 20 members, Co-chairs: Kathy Blazer, Ed.D and Tracey Weiler, PhD
- Goals:
  - Collect and document existing DTC information resources (including educational, position statements and peer-reviewed literature and news media)
  - Assess need, generate ideas and facilitate development for additional DTC educational resources for healthcare professionals and trainees.
  - Identify venues to partner in disseminating DTC educational resources appropriate to the needs of organizations needing DTC education (ISCC member organizations and others).
- Progress to date
  - Have developed needs assessment survey questions to be incorporated into “Healthcare Providers and Educators Genomic Literacy Survey”
  - Based on results plan to develop resources

Home / About Genomics / 15 Ways Genomics Influences Our World / 15 for 15: Direct-to-Consumer Genomic Testing

## 15 for 15: Direct-to-Consumer Genomic Testing



# The Compendium: Sharing ideas and resources

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## 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 Doc)

X

ISCC Members\_Meetings.xlsx

+

Open with Google Sheets

▼

A+

+

|   | 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      | <a href="http://www.ashg.org/2019meeting/">http://www.ashg.org/2019meeting/</a> | 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 | <a href="https://www.aphmg.org/schedule">https://www.aphmg.org/schedule</a>     | Shoumita Dasgupta | dasgupta@bu.edu, info@aphmg.org |
| 6 |   |  |                        |                  |   |                   |                                 |

- Considering additional tools (through Google Drive)
  - Ideas/Suggestions doc
  - Meeting minutes
  - PowerPoint presentations

# 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,

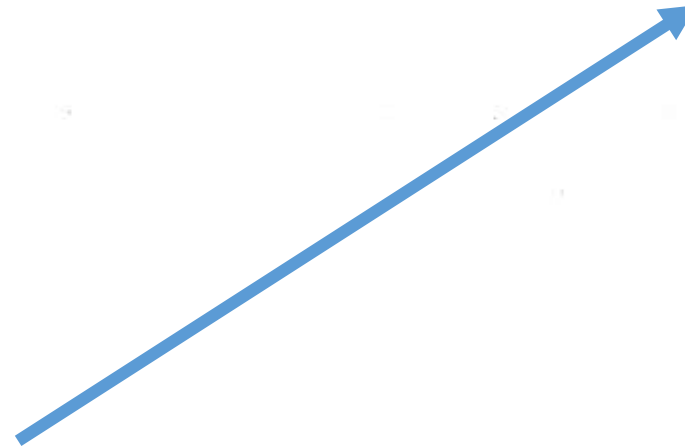
In 2011, you wrote that “it is time to get serious about genomics education for all health care professionals.”<sup>1</sup> Since then, NHGRI has taken major steps towards improving genomics education including, over the last 6 years, supporting the work of the Intersociety Coordinating Committee for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

## Genomics Education for Health Care Professionals in the 21st Century

W. Gregory Feero, MD, PhD

Eric D. Green, MD, PhD

JAMA, September 7, 2011—Vol 306, No. 9 **989**



# Medical Education Theme Issue 2009

Call for Papers

Robert M. Golub, MD

JAMA, March 4, 2009—Vol 301, No. 9

“As with the practice of medicine, the best hope for understanding the quality of current educational techniques and for evaluating proposed new approaches is by conducting and disseminating research based on sound principles.”



# Main message: Pathways to funding

- NCI R25s as a Model
- Potential ISCC projects
  - Universal exercises
  - Project Inclusive Genomics
  - Pharmacogenomics
  - Direct-to-Consumer
  - Rare Diseases
- Adapt “Research Experiences”
  - NCI R25 to encourage research careers
  - Critical shortage in genetics professionals
  - Adapt program
    - To attract interest in genetics careers
    - Provide immersive experiences for health professionals to better integrate genetics into their practice

|  | PAR-15-150<br>(Curriculum or Methods Development) | PAR-15-151<br>(Courses for Skills Development)  | PAR-15-152<br>(Research Experiences)   |
|--|---|---|--|
| Award project period                           | Up to 3 years                                     | Up to 5 years   | Up to 5 years  |
| Award budget <sup>a</sup>                      | Up to \$100,000                                   | Up to \$300,000   | Up to \$300,000  |
| Personnel (salary/fringe) and consultant costs | As appropriate                                    | Up to \$150,000   | \$3500 per participant   |
| Participants                                   | Not applicable                                    | Researchers, healthcare providers, graduate and health professional students, certain lay community members | Undergraduate, graduate, and health professional students  |
| Per participant costs                          | Not applicable                                    | Subsistence: none   | Subsistence: Up to \$6000 (undergraduates); up to \$7200 (graduate/health professional students) |
|  |   | Materials: \$500<br>Housing/per diem: \$1000<br>Travel costs <sup>b</sup>                                   | Research costs: \$1000<br>Housing: \$1000<br>Travel costs  |
| Competing renewals                             | No  | Yes   | Yes  |

Progress already being made: Initiative to Maximize Research Education in Genomics: Courses (PAR-19-185: \$150,000 per year over 5 years)

# Success of NCI R25s

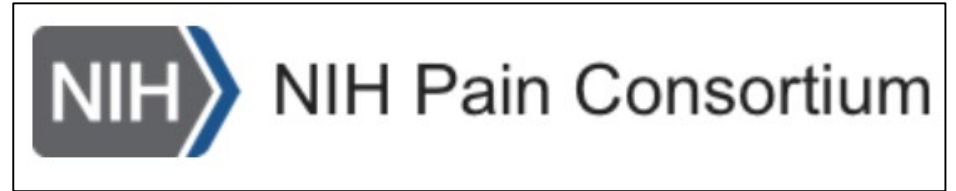
## **The National Cancer Institute R25 Cancer Education Grants Program: A Workshop Report**

J Canc Educ (2017) 32:3–10

- “The impact of the program is far reaching as these awards support educational activities in a broad range of cancer research fields benefiting more than 3200 Cancer Education Grants Program participants at various career stages every year.”
- The Universal Exercises ISCC project was funded through an NHGRI supplement to an existing NCI R25
  - NCI grant: Training pathology residents/pathologists/medical students in cancer genomics
  - NCI would not allow funding of non-cancer genetics education with existing R25 grant
  - Supplement would no longer be allowed by NCI

# Inter-institute collaboration?

- “The NIH Pain Consortium was established to enhance pain research and promote collaboration among researchers across the many NIH Institutes and Centers that have programs and activities addressing pain.”
- Issuing joint RFAs (“HEAL initiative”)
- Model for genomics education?
- Are supplements an option?



**Common Fund's Acute to  
Chronic Pain Signatures Program  
- New Funding Opportunity**

# Another good NCI idea?

- NCI Awardee Skills Development Consortium: Research Education Short Courses (RFA-CA-19-010)
  - Part of the National Cancer Institute (NCI) initiative to establish the "NCI Awardee Skills Development Consortium (NASDC)."
  - "Provide opportunities for current NCI grantees...to enhance their skills in areas that are critical for...successful independent academic cancer research careers."
- Could specific education RFAs be issued that are linked to existing grant awards
  - K, R, Consortia



# Other funding ideas...

- Small grant awards (\$1,000-\$20,000)/in-kind support
  - Review but more rapid turnaround
  - Project Inclusive Genomics
  - Only invoice method available
- ELSI?
- Continued funding of NHGRI Education and Community Involvement Branch (and ISCC-PEG)





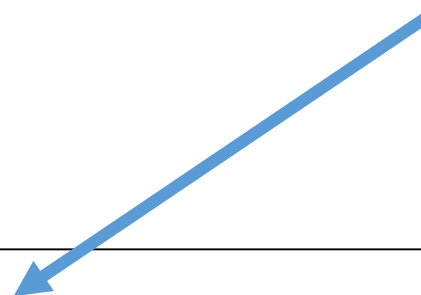
RE: ISCC strategic planning letter



Green, Eric (NIH/NHGRI) [E] <egreen@nhgri.nih.gov>

Tue 7/2/2019 8:57 AM

ISCC-PEG wants to help!



Rich:

Thanks for your email (below) and the accompanying letter, all on behalf of the Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG). I want to thank you and the ISCC-PEG for contributing to National Human Genome Research Institute's (NHGRI's) strategic planning process.

Practitioner education/training has been and continues to be an important focus of NHGRI, and I appreciate hearing from the members of the ISCC-PEG about ways in which we can move forward in the coming years. The implementation of genomic medicine will require practitioner engagement, and the ISCC-PEG will assuredly play a major role in facilitating this engagement.

We will continue to update you as our 2020 strategic plan gets developed and will certainly look to the ISCC-PEG membership for continued guidance. In the coming months, NHGRI will solicit additional input from its partners regarding specific elements of the strategic plan, and I anticipate that we will enlist members of the ISCC-PEG in future discussions and meetings that will help to finalize that plan. Our strategic plan will be strengthened by the inclusion of ideas from our stakeholders.

Thank you, again, for providing such a thoughtful and constructive response to NHGRI's request for ideas.

All the best,

Eric

# Future plans

- Logistics
  - Disclaimer/Central review of resources
  - Logo
  - Tweak website
  - 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 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.*



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

# ISCC-PEG: To sum up

- Diverse membership
  - Organizations
  - Institutes
  - Industry
  - Individuals
- A forum for discussion
- Developing collaborative resources
- New members/project groups welcome!
- Want to help with strategic planning—especially education funding
- Thanks
  - NHGRI
  - Carla Easter, Donna Messersmith, Christina Daulton, Sherese Teixeira, Laura Rodriguez and Teri Manolio
  - All ISCC-PEG members

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



Email: [ISCC-NHGRI@nih.gov](mailto:ISCC-NHGRI@nih.gov)

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

