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# ISCC-PEG: Annual Meeting 2022 Roadmap

**Rich Haspel, MD, PhD**

Beth Israel Deaconess Medical Center  
Harvard Medical School  
Co-Chair ISCC-PEG

**Donna Messersmith, PhD**

NHGRI, Education and Community Involvement Branch  
Provider Education Specialist  
Co-Chair ISCC-PEG

February 16, 2022



# Thanks to our members and NHGRI for your support!!

Carla Easter, Christina Daulton, Rosann Wise, Belen Hurle, Sherese Teixeira, Tasha Stewart, and Larry Brody

Google Drive with useful info (e.g., minutes, presentations):

[https://drive.google.com/drive/folders/1D-zKzTvNXILTHsA\\_UgoabkQ3sphy6AKk?usp=sharing](https://drive.google.com/drive/folders/1D-zKzTvNXILTHsA_UgoabkQ3sphy6AKk?usp=sharing)



- Everything recorded (except Working Sessions)
- Slides will be available



 American Heart Association

 ACOG  
The American College of Obstetricians and Gynecologists

 Association for Molecular Pathology

 ABMGG  
American Board of Medical Genetics and Genomics

 HUDSONALPHA  
INSTITUTE FOR BIOTECHNOLOGY

 cap

 AACC  
Better health through laboratory medicine.

 APHA  
AMERICAN PUBLIC HEALTH ASSOCIATION  
For science. For action. For health.

 ASCO  
AMERICAN SOCIETY OF CLINICAL ONCOLOGY

 NIH  
NATIONAL CANCER INSTITUTE

 AAFP

 Pennsylvania MEDICAL SOCIETY  
ADVOCATE. EDUCATE. NAVIGATE.

 GEC+KO  
Genetic Education Center - Knowledge Empowers

 National Society of Genetic Counselors

 ZIBDY HEALTH

 NCBI  
National Center for Biotechnology Information

 dVINCI  
INTERACTIVE  
POWERED BY Learning

 NIH  
Eunice Kennedy Shriver National Institute of Child Health and Human Development  
Health research throughout the lifespan

 ISPG  
INTERNATIONAL SOCIETY OF PSYCHIATRIC GENETICS

 ACNN  
ASSOCIATION OF CHILD NEUROLOGY NURSES

 Mountain States  
REGIONAL GENETICS NETWORK

 AMERICAN SOCIETY OF HEMATOLOGY

 NCEMNA

 Rady Children's Institute  
Genomic Medicine

 HRSA  
Health Resources & Services Administration

 illumina

 AMA

 AMWA  
The Vision and Voice of Women in Medicine since 1915  
American Medical Women's Association

 ONS  
Oncology Nursing Society

 ACCP  
American College of Clinical Pharmacy

 Global Genomic Medicine Collaborative

 american physiological society



 NIH  
National Heart, Lung, and Blood Institute

 ACMG  
American College of Medical Genetics and Genomics

 American Board of Medical Specialties  
Higher standards. Better care.®

 youScript

 STRONGERTOGETHER

 PHARMGKB

 UNITEDHEALTH GROUP®

 The Jackson Laboratory

 AAMC  
Association of American Medical Colleges

 PerkinElmer  
For the Better

 aphmg  
Association of Professors of Human and Medical Genetics

 APhA  
AMERICAN PHARMACISTS ASSOCIATION  
Improving medication use. Advancing patient care.

 ACP  
American College of Physicians  
Leading Internal Medicine. Improving Lives.

 American Society of Pharmacovigilance

 NIH  
National Institute on Alcohol Abuse and Alcoholism

 23andMe®

 Nursing at the NIH Clinical Center

 AMERICAN ACADEMY OF NEUROLOGY®

 THE COLLEGE OF FAMILY PHYSICIANS OF CANADA  
 LE COLLÈGE DES MÉDECINS DE FAMILLE DU CANADA

 NIH  
National Center for Advancing Translational Sciences

 SGIM  
Society of General Internal Medicine  
Creating Value for Patients

 ADEA

 ICF

 AMERICAN ACADEMY OF OPHTHALMOLOGY®

 AGMT  
AFRICAN GENOMIC MEDICINE TRAINING INITIATIVE

 NIH  
National Eye Institute  
Research Today...Vision Tomorrow

 NAHN  
National Association of Hispanic Nurses

 CPIC  
Clinical Pharmacogenetics Implementation Consortium

 IGNITE  
Implementing GeNomics In practice

 CDC

 Greenwood Genetic Center

 INVITAE

 NSW GOVERNMENT

 Health Centre for Genetics Education

# 268 members!

New members always welcome...free and easy to join!

- Representation from: 79 organizations, 45 government/institute, 14 companies, and 130 individuals (26 of whom are students/Scholars)
- Welcome to 50 new members since last in-person meeting!
  - Individual (44): Abraham, Veronica Alexandra; Antonacci-Fulton, Lucinda; Baker, Kellan; Berro, Tala; Bohnert, Kelsey; Brazeau, Dan; Clowes Candadai, Sarah; Dewell, Sarah; Dungan, Jennifer R.; Emrick, Lisa; Ferrand, Lisa; Gillentine, Madelyn; Glenn, Kanasha; Graves, Letitia; Gropman, Andrea; Haga, Susanne; Himes, Deborah; Holm, Nichole; Jamal, Leila; Keddis, Mira; Lucas, Ruth; Malone Jenkins, Sabrina; Mangold, Kara; Mann, Sylvia; Mathis, Holly; McKenna, Danielle; Murthy, Vinaya ; Ojukwu, Kenechukwu; Oladayo, Abimbola Muinat; Pagliuso, Delaney; Palmquist, Rachel; Press Callahan, Katharine; Quinteros Espinoza, Badí Israel; Roth, Sarah; Squire, Audrey; Tamraz, Bani; Terry, Alissa; Walker, Trina; Wand, Hannah; Ward, Linda; Whitt, Karen; Wilder, Jennifer; Williams, Kaylee; Zayhowski, Kim
  - Government and Organizations (5): Barfield, Whitney (National Cancer Institute (NCI/NIH)); Cowan, Brenda (Association of Child Neurology Nurses (ACNN)); Hobbs, Charlotte (Rady Children's Institute for Genomic Medicine); Patterson, Wesley (Greenwood Genetics Center (GGC)); Wees, Kristi (Mountain States Regional Genetics Network (MSRGN))
  - Industry (1) : Ashcraft, Kristine (Invitae)



PROFESSIONAL DEVELOPMENT PROGRAMS

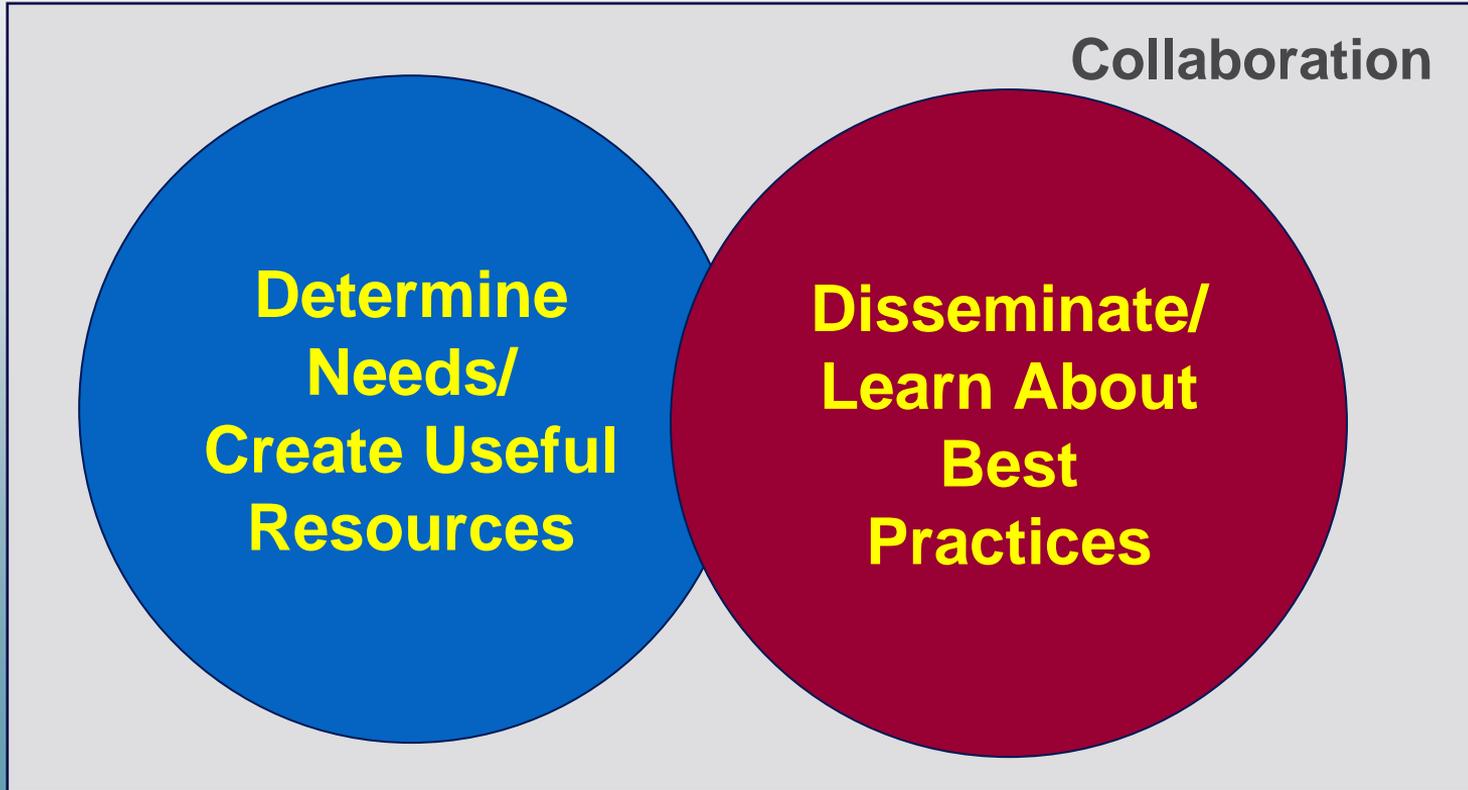
**ISCC-PEG Scholars Program: A Genomics Education Opportunity >**

Now in second year!

- Currently 8 Scholars
  - 4 new this year
- Paired with ISCC-PEG member mentor to work on project
  - 2 years
- Travel to ISCC-PEG Annual Meeting
- Many thanks to all our mentors!

Scholar	Affiliation, Degree in Progress	Mentor(s)	Affiliation	ISCC-PEG Project Group
<b>2021-2023 Class of Scholars</b>				
Abimbola Muinat Oladayo, BDS, MPH	Department of Preventive and Community Dentistry, College of Dentistry, University of Iowa, MS in Dental Public Health	Louise Wilkins-Haug, MD, PhD	Brigham and Women's Hospital Division Director of Maternal Fetal Medicine and Reproductive Genetics at Brigham and Women's Hospital	OB/GYN Genomics Curriculum Development
Sarah Roth, BA, MFA, MA	JHU/NIH Genetic Counseling Training Program, Baltimore, MD, ScM in Genetic Counseling, PhD in Anthropology	Audrey Squire, MS, CGC Danielle McKenna, MS, LCGC	Audrey Squire: Seattle Children's Hospital; Danielle McKenna: Penn Medicine	LGBTQI+ Issues in Genomics
Katharine Press Callahan, AB, MD	The Children's Hospital of Philadelphia and the University of Pennsylvania, Philadelphia, PA, MS in Medical Ethics	Sabrina Malone Jenkins, MD	Assistant Professor of Pediatrics at the University of Utah in the Division of Neonatology	Rare Diseases
Lisa Ferrand, BS, MS	Barry University, PhD in Nursing	Kathleen Blazer, EdD, MS, CGC	Director Cancer Genomics Education Program Division of Clinical Cancer Genomics City of Hope National Medical Center	DTC-GT

# Goal of ISCC: Improve Genomic Literacy



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# COMMITTEES

JUST LIKE TEAMWORK. ONLY WITHOUT THE WORK.

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# Project groups: Not just talk

## Inclusion in the Practice of Genomic Medicine: Exploring the Impact of Implicit Biases Towards Disability (Shoumita Dasgupta, Maya Sabatello):

See the [free Patient-Centered Prenatal Genetic Counseling resource](#) on the BU/CME website.

- Published in [PLoS One](#): “Exploring the impact of patient centered counseling training on physical disability bias in the prenatal setting.”
- Featured in inaugural [ACMG DEI/health disparities symposium](#).

# Project groups: Not just talk

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## Pharmacogenomics (Andrew Monte, Phil Empey):

**EVENT:** American Academy of Family Physician's 2021 Family Medicine Experience ("FMX"), Oct. 2, 2021

- TITLE: "Pharmacogenetics: Basic Concepts and Practical Application"
- SPEAKERS: Robert J. Ostrander, MD , AAFP Liaison to ISCC PEG and Roseann S. Gammal, PharmD, BCPS

**EVENT:** American Academy of Family Physician's 2022 Family Medicine Experience ("FMX"), Fall, 2022

# Project groups: Not just talk

## Direct-to-Consumer Genetic Testing (DTC-GT) (Tracey Weiler, Houriya Ayoubieh):

Published on Genome.gov: [See the Direct-to-Consumer Genetic Testing FAQ for Healthcare Professionals](#)

- Published ASHG 2021 Poster: “Addressing the Direct-to-Consumer Genetic Testing Knowledge Gap for Non-Genetics Healthcare Professionals”

**EVENT:** Panel presentation scheduled for 2022 ACMG Plenary Session: “Developing Recommendations for the Application of Direct-to Consumer Genetic Testing in Clinical Care”

# Project groups: Not just talk

## Rare Diseases (Michelle Snyder and Sabrina Malone Jenkins):

**EVENT:** Pediatric Academic Societies Meeting, Sept. 21, 2021

- **TITLE:** “Training Next Generation Pediatricians in Genomics: A Case Study Approach”
- **PRESENTERS:** Michelle Snyder, MS, CGC, Luca Brunelli, MD, PhD, John Carey, MD, MPH, Kristen Fishler, MS, CGC, Rich Haspel, MD, PhD, Sabrina Malone Jenkins, MD, Rachel Palmquist, MS,CGC

# 2021 New Project groups:

- **Obstetrics and Gynecology (OB/GYN) Genetics Curriculum** (Barbara O'Brien, Louise Wilkins-Haug)
- **Adult Cardiovascular Genomics** (Siddharth Prakash)
- **LGBTQI+ Issues in Genomics** (Kellan Baker, Leila Jamal)
- **Nursing Genomics** (Trina Walker, Anne Ersig)

# Project Groups: Some thoughts...

- “Project Group” vs. “Working Group”
- Consider:
  - Dissemination
    - Where will the resource “live”?
    - Organization listservs
    - Apply to present at an organization’s annual meeting
      - Example: Rare Disease Project Group and Pediatric Academic Societies Meeting
  - Funding/Salary Support
    - R25 grants from NHGRI and NCI
  - Evaluation/Publication
    - Example: Inclusion in the Practice of Genomic Medicine study
- Keep in mind COI, Material Review and Dissemination Policies (on website)
- Note the value of participation in Project Group by a member of professional organization. Example: Bob Ostrander from AAFP.

# NHGRI funding opportunities for training and career development

## Curriculum development



- **Genomic Curriculum Development for Medical Students (R25)**
  - Target Audience: Medical Students
- **NHGRI Short Courses for Genomics-Related Research Education (R25)**
  - Target Audience: Clinicians

## Training/career development for practitioners



- **Mentored Research Experiences for Genetic Counselors (R25)**
  - Target Audience: MS-level Genetic Counselors
- **Short Term Mentored research Career Enhancement Award to Promote Diversity (K18)**
  - Target Audience: faculty members

## Training/career development for future clinical researchers



- **Predocutorial to Postdoctoral Transition Award to Promote Diversity (F99/K00)**
  - Target Audience: Ph.D. students
- **Predocutorial to Postdoctoral Transition Award to Promote Diversity (F99/K00)**
  - Target Audience: Ph.D. students
- **Research Experience in Genomic Research for Data Scientists (R25)**
  - Target Audience: MS Data Scientists
- **Genome Research Experiences to Attract Talented Undergraduates into the Genomic Field to Promote Diversity (GREAT) program (R25)**
  - Target Audience: Undergraduates

# Examples of funded grants

- **Genomic Competencies for Nurses from Theory to Application: An Online Long Course (R25)**

<https://www.duq.edu/academics/schools/nursing/faculty/grants/genomic-competencies-for-nurses-from-theory-to-application-an-online-course>

- **An Immersive Experience in Medical Genomics (R25)**

<https://www.childrensmercy.org/childrens-mercy-research-institute/research-areas/genomic-medicine-center/genomic-medicine-short-course/>

- **Translation and Integration of Genomics is Essential to Doctoral Nursing: "TIGER" (R25)**

<https://www.aacnnursing.org/Faculty/Faculty-News/View/ArticleId/25038/Application-TIGER-Translation-and-Integration-of-Genomics-is-Essential-Doctoral-NuRsing>

# NHGRI Updates

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- Updated ISCC-PEG homepage: <https://www.genome.gov/iscc>
- New on genome.gov:
  - DTC-GT FAQ: <https://www.genome.gov/For-Health-Professionals/Provider-Genomics-Education-Resources/Healthcare-Provider-Direct-to-Consumer-Genetic-Testing-FAQ>
  - Policy Branch: <https://www.genome.gov/about-genomics/policy-issues> , including new webpages on Informed Consent
  - MINC: <https://www.genome.gov/minc>
- Healthcare Professionals Genomics Education Week: June 2022
- Sharing announcements related to genomics education:  
<https://docs.google.com/spreadsheets/d/1ixiPLiCK-5P8ip-kAOY-K6HuoKXf-uNQ/edit#gid=1705622299>

# The Compendium: Sharing ideas and resources

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American Heart Association (AHA).....	21
American Medical Association (AMA) .....	23
American Medical Women's Association (AMWA) .....	25

## 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).

# Interested in genomics education? Join ISCC-PEG!

- Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG)
  - Over 200 Members: Open to individuals, organizations, and industry interested in healthcare provider genomics education
  - Supported by NHGRI
  - Free to join!
  - Collaborate to:
    - Identify educational needs and potential solutions
    - Share best practices in educational approaches
    - Develop educational resources.
  - Scholars program:
    - Student opportunity: Work on a genetics/genomics-related education project under the mentorship of an ISCC-PEG member.
    - Two year appointment
    - Travel funded for the annual ISCC-PEG in-person meeting



Please visit:

[genome.gov/iscc](https://genome.gov/iscc)

# Using Padlet

- Go to link: [bit.ly/isccpeg2022](https://bit.ly/isccpeg2022)
- Just double click on the screen to add a new post
  - Can add pictures and links
- Can click “add comment” to comment on a previous post
- We’d like to know:
  - What do you like about ISCC-PEG?
  - What ideas and suggestions to you have for ISCC-PEG?
  - To discuss during wrap-up and in future
- Note: Use chat for in-session comments

# Agenda



**11:30 a.m. – 12:00 p.m. Welcome and Introductions**, ISCC-PEG Co-Chairs  
**Rich Haspel**, M.D., Ph.D., Beth Israel Deaconess Medical Center and  
**Donna Messersmith**, Ph.D., Education and Community Involvement Branch, NHGRI

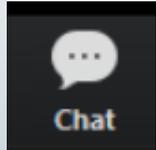
## **12:00 p.m. – 1:00 p.m. ISCC-PEG Scholar Presentations**

**Samantha Bailey**, University of Pittsburgh School of Pharmacy: *Disseminating pharmacogenomic education: understanding the needs of ISCC-PEG partner organizations*

**Rene Begay**, Johns Hopkins School of Public Health: *G3C Case Study: Providing Healthcare for Indigenous Patients with Inherited Cardiomyopathy*

**Kelsey Ellis**, The University of North Carolina at Greensboro, Genetic Counseling: *Developing an App for Non-Genetics Providers Working with Rare Disease Patients*

**Katherine Robinson**, St. Jude Children's Research Hospital: *Optimizing Oncology Care With Germline Pharmacogenomics: Case-Based Education for Oncology Practitioners*



**:Padlet**

[bit.ly/isccpeg2022](https://bit.ly/isccpeg2022)

**1:00 p.m. – 1:45 p.m. Break; 1:00 p.m. – 1:30 p.m. Optional break-out room to network**

**1:45 p.m. – 3:45 p.m. Working Sessions (break-out rooms)**

**3:45 p.m. – 4:30 p.m. Project Group Summaries and “Asks” of ISCC Membership**

**4:30 p.m. – 5:30 p.m. Keynote Presentation:** “*Advancing the Equitable Implementation of Genomics into Clinical Care*”, [Mr. Vence Bonham](#), acting deputy director for NHGRI and an associate investigator in NHGRI's Social and Behavioral Research Branch

-Everything recorded (except Working Sessions)  
-Slides will be available

**5:30 p.m. – 6 p.m. Wrap up/future directions**

**Working sessions: Feel free to join even if not a Project Group member (industry members can also attend)**

