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ISCC-PEG: Annual Meeting 2023 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 15, 2023



Thanks to our members and NHGRI for your support!!

Rosann Wise, 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



- 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
Genetics Education Center - Knowledge Organization
Genetic Education for professional healthcare - Knowledge Organization

 National Society of Genetic Counselors

 ZIBODY 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®

 NIH
National Human Genome Research Institute

 Australian Genomics
Health Alliance

 NIH
U.S. National Library of Medicine

 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

 ISONG

 Cincinnati Children's

 ACMG
American College of Medical Genetics and Genomics

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

 American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

 ATM

 PHARMGBK

 ASCP
STRONGERTOGETHER

 aphmg
Association of Professors of Human and Medical Genetics

 NIH
National Heart, Lung, and Blood Institute

 The Jackson Laboratory

 AAMC
Association of American Medical Colleges

 PerkinElmer
For the Better

 Genome British Columbia
Leading • Investing • Connecting

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

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

 NIH
National Institute on Alcohol Abuse and Alcoholism

 23andMe®

 Nursing at the NIH Clinical Center

 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 NEUROLOGY®

 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

286 members!

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

- Representation from: 58 organizations, 11 government/institute, 7 companies, and 138 individuals
- Welcome to 31 new members since last in-person meeting!
 - Individual (16): Abtin, Aryana; Ashfaq, Myla; Colville, Molly; Felix, Molly; Haidar, Cyrine; Huser Blum, Nicole; Kudron, Elizabeth; Luu, Michael; Palaniappan, Latha; Rajani, Bansari; San Miguel, Sandra; Snyder, Cindy; Ssebunnya, Gerald-Michael; Willoughby, Ava; Yoon, Robin; Zoran, Sara
 - Government and Institutes (11):
 - NHGRI: Jackson, Amber; McCague, Allison; McGregor, Imani; Nerukar, Mukul; Pittman, Mauresa; Rider, Renee; Sey, Nancy; Volpi, Simoa; Willis, Valerie
 - NCBI: Kane, Megan
 - HRSA: Swanson, Loraine
 - Organizations (4): Church, Alana (AMP); DeBruin, Erin (Genome British Columbia); Terrill, Bronwyn (Australian Genomics Health Alliance); Tracy, Morgan (Cincinnati Children's)

Sorry if we missed anyone/something incorrect (let us know)



PROFESSIONAL DEVELOPMENT PROGRAMS

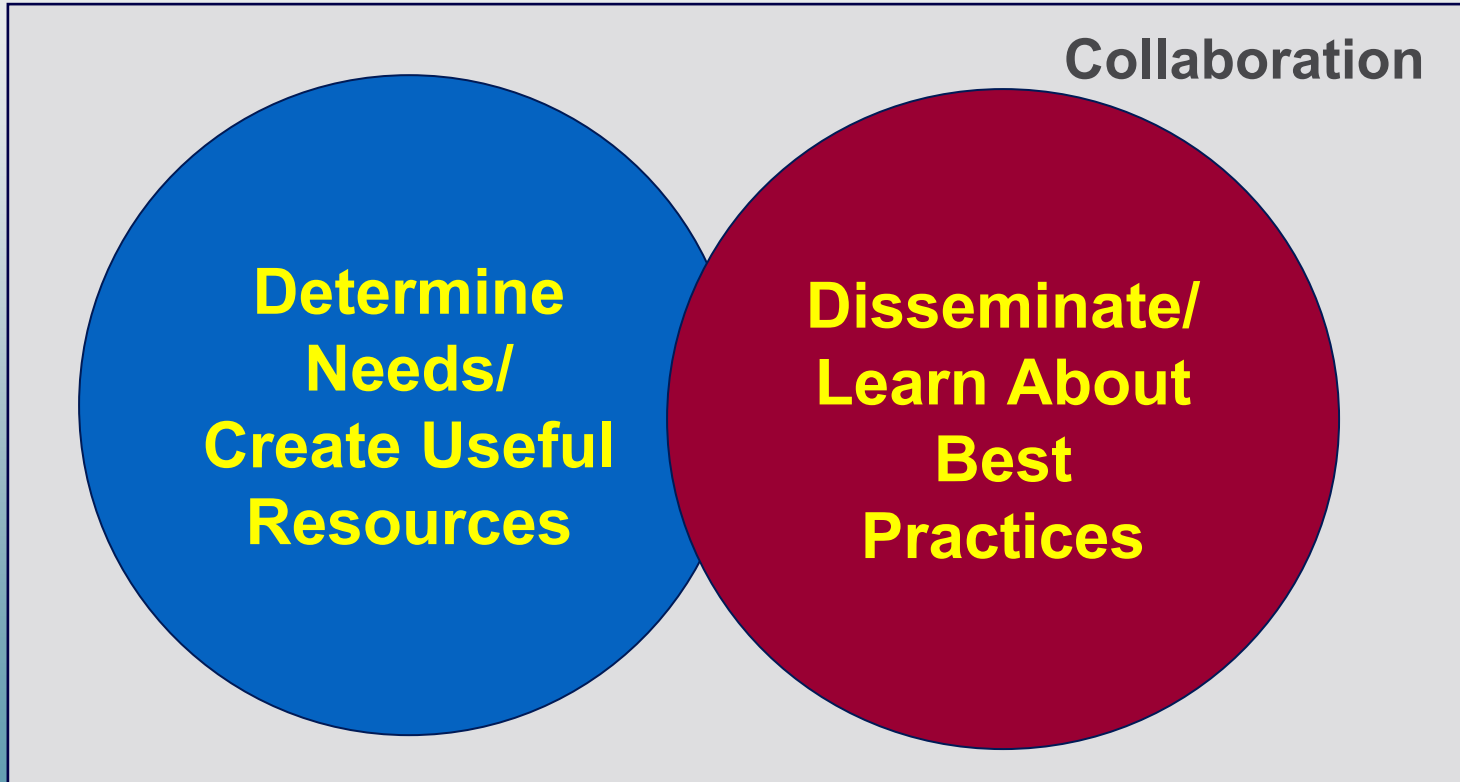
ISCC-PEG Scholars Program: A Genomics Education Opportunity >

Now in third
year!

- Graduated 1st class of 4 scholars in 2022!
 - [Wrap-up presentations](#) in 10/2022
- Currently 6 Scholars
 - 2 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
2022-2024 Class of Scholars			
Ava Willoughby	The Ohio State University Genetic Counseling Graduate Program	Barbara O'Brien, M.D.	Beth Israel Deaconess Medical Center
Molly Felix	Master of Science in Genetic Counseling Virginia Commonwealth University	Vinaya Murthy, MPH, M.S., LCGC Ebony Madden, M.S., Ph.D.	Vinaya Murthy: Indiana University School of Medicine Ebony Madden: Training, Diversity and Health Equity Office, NHGRI

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):

- **Presentation:** The Society of Teachers of Family Medicine Conference
- **Publications:**
 - American Journal of Human Genetics (submitted)
 - “Irreducible Subjects: Disability and Genomics in the Past, Present and Future” NHGRI Symposium (in progress)
- **Resource:** [Clinical Decision-Making in the Prenatal Setting](#) on the BU/CME website.

Project groups: Not just talk

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Pharmacogenomics (Andrew Monte, Phil Empey):

- **Presentation:** American Academy of Family Physician's 2022 Family Medicine Experience ("FMX"), September 20 - 24, 2022: "[Using Pharmacogenomics in Practice: A Step-By-Step Guide](#)" (PDF), Robert J. Ostrander, MD , AAFP Liaison to ISCC-PEG (posted on genome.gov)
- **Collaboration:** CMEs provided through the University of Pittsburgh
- **Resource:** PGx educational modules for primary care practitioners

Project groups: Not just talk

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

Presentations:

- 2022 ACMG Plenary Session: “Developing Recommendations for the Application of Direct-to-Consumer Genetic Testing in Clinical Care”
- 2022 American Academy of Physician Assistants: "Direct-to-Consumer Genetic Testing: What Every PA Needs to Know"
- Posters: ASHG 2021 and 2022, AGBT 2022

Publication: "Cases in Precision Medicine: When Patients Present with Direct-to-Consumer Pharmacogenomic Test Results" (submitted)

Resource: genome.gov: [Direct-to-Consumer Genetic Testing FAQ for Healthcare Professionals](#)

Project groups: Not just talk



Rare Diseases (Sabrina Malone Jenkins):

- **Presentations:**

- International Society of Nurses in Genetics, November 20, 2022: “Teaching Genomic Medicine: A Train-the-Trainer Workshop”
 - Faculty : Sabrina Malone Jenkins, MD; Rich Haspel, MD, PhD, Rebecca Kronk, PhD; Rachel Palmquist, MSC,CGC; Deborah Himes, PhD; Rachel Mills, MS, CGC; Wesley Patterson, PhD, Karen Whitt, PhD
 - “Well organized and executed,” “Really excellent and engaging, thanks so much!”
- American Academy of Physician Assistants, May 23, 2023: “Training PAs in Genomics: A Case-Study Approach”

- **Publication:**

- Callahan KP, Radack J, Wojcik MH, Jenkins SM, Nye RT, et al. Hospital-level variation in genetic testing in children's hospitals' neonatal intensive care units from 2016 to 2021. Genet Med. 2022 . Epub ahead of print.

Project groups: Not just talk

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Obstetrics and Gynecology (OB/GYN) Genetics Curriculum (Barbara O'Brien, Louise Wilkins-Haug)

- **Presentation:**
 - Abstract accepted to 2023 Association of Professors of Gynecology and Obstetrics Annual Meeting: “Developing Genetics Competencies for Trainees in Women's Health Care: A Structured and Interdisciplinary Approach”

Project groups: Not just talk

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Adult Cardiovascular Genomics (Siddharth Prakash)

- **Resource:** [UTHealth Cardiovascular Genomics Certificate](#)
 - Online educational modules about the genetics and genomics of adult-onset cardiovascular diseases.
 - For healthcare providers who do not have specialized training in genetics.
 - May be taken individually for continuing education credit or completed entirely for the stand-alone Cardiovascular Genomics certificate.
 - Supported by NHGRI: [Training Modules in Genomic Medicine for Healthcare Professionals](#)

Project groups: Not just talk

LGBTQI+ Issues in Genomics (Outgoing Co-Chairs: Kellan Baker, Leila Jamal; New Co-Chairs: Kelsey Bohnert and Lee Williams)

- **Plans:**
 - Developing an information page for the NHGRI website to provide appropriate terminology and other additional useful information on LGBTQIA+ Issues in Genomics
 - Collaborating with the Community Engagement in Genomics Working Group

Project groups: Not just talk

Nursing Genomics (Trina Walker, Anne Ersig)

- **Product Development:** "Frequently Asked Questions about Nursing Genomics" text and expert commentaries for:
 - 1) Entry-level nurses and the general public
 - 2) Advanced Practice Nurses – Academic Nurse Educators
 - 3) Advanced Practice Nurses – Nurse Practitioners

Project groups: Not just talk

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GenomeEd (Donna Messersmith)

- **Plans:** Reviews in progress for first set of submissions to GenomeEd, built on the foundation of G2C2
 - **GenomeEd Review Committee:** Myla Ashfaq, Sarah Clowes Candadai, Philip Empey, Anne Ersig, Elizabeth Kudron, Megan Lyon, Claudia Mikail, Vinaya Murthy, Aniwaa Owusu Obeng, Nguyen Park, Wesley Patterson, Matthew R. G. Taylor, Karen Whitt
- **Resource:** Repository of genomics educational resources for healthcare professionals

Project groups: Not just talk

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G3C (Kathy Calzone, Yi Liu)

- **Product Development:**
 - “Autism Spectrum Disorder and Vaccines”
 - “Cardiac Conditions in Indigenous Populations”
- **Resource:** Global Genetics and Genomics Community (G3C)
 - [17 Cases](#) posted
 - [G3C Flyer](#)

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
 - Opportunities for scholarship: Presentations; Grants; Evaluation/Publication
- 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. Examples: AAFP; AAPA; ISONG

Healthcare Professionals' Genomics Education Week

Jun 5-9 | #MedGeneEd23

- **All ISCC-PEG Members and organizations can participate!**
- **Via social media, you and/or your organization can:**
 - **Tweet and retweet other participant tweets using the hashtag #MedGeneEd23**
 - **Create graphics for the week or host a quiz**
 - **Disseminate genomics resources to share with other healthcare professionals and the interested general public**
- **You and/or your organization can host a webinar/panel discussing a topic related to genomics**



NHGRI

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

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

2023 Agenda

8:30 a.m. – 9:00 a.m. (Room C) Networking breakfast (food and drink purchased on your own)

9:00 a.m. – 9:30 a.m. (Rooms A/B) Introductions, ISCC-PEG Co-Chairs

Rich Haspel, M.D., Ph.D., Beth Israel Deaconess Medical Ctr and Harvard Medical School

Donna Messersmith, Ph.D., Education and Community Involvement Branch, NHGRI

9:30 a.m. – 10:00 a.m. Welcome, Eric Green, M.D., Ph.D., NHGRI Director

10:00 a.m. – 11:00 a.m. *Delivering on Our Promise: DNA Results for All of Us Participants and What It Means for Healthcare Providers*, Josh Denny, M.D., M.S., CEO of All of Us

11:00 a.m. – 11:15 a.m. Break (food and drink purchased on your own)

11:15 a.m. – 12:15 p.m. ISCC-PEG Scholar Presentations

Abimbola Oladayo, University of Iowa: *Reviewing Genetics and Genomics Resources for OB-GYN Professionals*

Katharine Press Callahan, University of Pennsylvania: *Hospital-Level Variation in Genetic Testing in Children's Hospitals Neonatal Intensive Care Units from 2016 to 2021*

Sarah Roth, JHU/NIH Genetic Counseling Training Program, *'Multiple weights off my chest': Exploring Gender Diverse Experiences of Hereditary Cancer Care*

12:15 p.m. – 12:45 p.m. NHGRI Extramural Grant Opportunities, Dave Kaufman, Ph.D. and Simona Volpi, Ph.D.

12:45 p.m. – 1:15 p.m. Lunch (Rms A/B or break-out rooms; food/drink purchased on your own)

1:15 p.m. – 1:30 p.m. Move to break-out rooms (6th and 4th floors)

1:30 p.m. – 3:30 p.m. Working Sessions (break-out rooms)

3:30 p.m. – 3:45 p.m. Re-convene in Rooms A/B

3:45 p.m. – 4:45 p.m. Project Group Summaries and "Asks" of ISCC Membership

4:45 p.m. – 5 p.m. Wrap up/future directions



-Everything recorded (except Working Sessions)

-Slides will be available

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