

ISCC-PEG Annual Meeting Agenda

- **8:30 a.m. – 9:00 a.m. (Room D/E) "Ask Eric Anything" Moderated Q&A with Eric Green, M.D., Ph.D., NHGRI Director**
- **9:00 a.m. – 9:20 a.m. (Rooms F/G - Main Room) Open Networking Time**
- **9:20 a.m. – 10:25 p.m. Class #3 ISCC-PEG Scholar Presentations**
 - **Ava Willoughby, M.S., CGC, Research Genetic Counselor, Nationwide Children's Hospital**
Provider Practices and Perceived Barriers towards Counseling on Reproductive Options for High-Risk Individuals
 - **Molly Felix, B.S., M.S. Candidate in Genetic Counseling, Virginia Commonwealth University School of Medicine**
Genetic Counselor's Adaptations and Perceptions in Language Discordant Patient Encounters
- **10:30 a.m. – 10:55 a.m. Welcome & Introductions, ISCC-PEG Co-Chairs**
Rich Haspel, M.D., Ph.D., Beth Israel Deaconess Medical Center and Harvard Medical School
Donna Messersmith, Ph.D., Education and Community Involvement Branch, NHGRI
- **10:55 a.m. – 11:15 a.m. NHGRI Welcome, Ben Solomon, M.D., NHGRI Clinical Director**
- **11:15 a.m. – 12:00 p.m. ISCC-PEG Strategic Planning, Beth Tuck, M.A., NHGRI Education and Community Involvement Branch Chief, and ISCC-PEG Co-Chairs**

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-Post-It board: Please put suggestions

- **12:00 p.m. - 1:00 p.m. Lunch Break**
- **1:00 p.m. – 1:45 p.m. (Rooms F/G) Keynote Lecture, Teri Manolio, M.D., Ph.D., NHGRI Division of Genomic Medicine Director**
- **1:45 p.m. – 2:00 p.m. Framing Project Group Breakouts and Move to Rooms**
 - **(Room C) DTC-GT** - <https://bit.ly/ISCC-PEG-DTC-GT>
 - **(Room D) LGBTQI+** - <https://bit.ly/ISCC-PEG-LGBTQI>
 - **(Room E) Nursing Genomics** - <https://bit.ly/ISCC-PEG-Nursing>
 - **(4B31 Conference Room) PGx** - <https://bit.ly/ISCC-PEG-PGx>
 - **(4B39S) Physician Assistant** - <https://bit.ly/ISCC-PEG-PA>
 - **(4B39B) OB/GYN** - <https://bit.ly/ISCC-PEG-OB-GYN>
 - **(4B39C) Rare Diseases** - <https://bit.ly/ISCC-PEG-Rare>
 - **(4th Floor Franklin Conference Room) Health Equity/Community Engagement** - <https://bit.ly/ISCC-PEG-HealthEquity>
- **2:00 p.m. – 3:30 p.m. (Breakout Rooms, 6th and 4th Floors) Working Sessions**
- **3:40 p.m. – 4:45 p.m. (Rooms F/G) Project Group Summaries**
- **4:45 p.m. – 5 p.m. Wrap up/Future Directions**

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

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

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ISCC-PEG: Annual Meeting 2024 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

April 5, 2024



National Human Genome
Research Institute



Thanks to our members and NHGRI for your support!!

Beth Tuck, Rosann Wise, and
Larry Brody, Nancy Reid, Jesus
Aguilar Pinzon, Faye Brown,
Jerryl Somani, Jacob Jaffa,
Alvaro Encinas, Mukul Nerurkar



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- Slides will be available


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~ 10th anniversary!!

- Formed in February 2013 from the Genomic Medicine IV meeting
- Progress
 - Members: 149 (2017) → 333 (2024)
 - Since 2020: Helped develop 19 resources (see “accomplishments”)
- Keynote speaker: Teri Manolio, MD
 - NHGRI Director of the Division of Genomic Medicine
 - A Founder of ISCC-PEG
 - Former Co-Chair





 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

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 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 Epidemiology Canada - Knowledge Organization

 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

 ISONG

 Cincinnati Children's

 ACMG
American College of Medical Genetics and Genomics

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 usp

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

 American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN.™

 ATM

 PHARMGBK

 STRONGERTOGETHER

 aphmg
Association of Professors of Human and Medical Genetics

 G2NA
GLOBAL GENOMICS NURSING ALLIANCE

 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.


 ASP
American Society of Pharmacovigilance

 NIH
National Institute on Alcohol Abuse and Alcoholism

 23andMe

 Nursing at the NIH Clinical Center

 THE COLLEGE OF FAMILY PHYSICIANS OF CANADA
 LE COLLEGE DES MEDICINS 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

333 members!

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

- Representation from: 61 organizations, 11 government/institute, 8 companies, and 182 individuals
- Welcome to 54 new members since last in-person meeting!
 - Individual (44): Kim Skellington; Jessica Chong; Rachel Burnside; Helen Anderson; Carolyn Oxencis; Jennifer Woo; Fatemeh Choupani; Briana O'Leary; Helen Burns; Tomas Herrero; Swathi Balaji; Sarai Barrios; Chase Beeman; Seda Byurat; Natasha Casas; Ana Castro Castillo, Kelly Caudle; Anwar Chahal; Jessica Chong; Atanu Dutta; Lauren Edgar; Naama Elefant; Danielle Fournier; Rachel Joseph, Rachel; Apolline Jungels; Becky Ma; Fatima Mraiche; Kathleen Muglia; Frank Munoz; Nick Nguyen; Alberto Partida; Alice Popejoy; Nandana Rao; Ellen Romesburg; Laura Roselli; Steven Silverman; Anne Slavotinek; Vanessa Smith; Claire Spahn; Alexia Story; Radha Sukhu; Allison Werner-Lin; Zachary Woodward; Setareh Zandihaghighi
 - Industry (1): Brianne Kirkpatrick (23andme and Watershed DNA)
 - Organizations (9): Blaine Groat (United States Pharmacopeia (USP))*; Marjorie David (Association for Molecular Pathology (AMP)); Madhu Ouseph (College of American Pathologists (CAP))*; Wylie Burke (American College of Physicians (ACP)); Andrew Dwyer (Global Genomics Nursing Alliance (G2NA))*; Kalisi Logan (The Jackson Laboratory); Kelly Rose (American Society of Hematology (ASH)); Pamela Trapane (American Academy of Pediatrics (AAP)); Brett Fogel (American Academy of Neurology (AAN))

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



PROFESSIONAL DEVELOPMENT PROGRAMS

ISCC-PEG Scholars Program: A Genomics Education Opportunity >

Now in fourth year!

- Graduated 2nd class of 4 scholars in 2023!
 - [Wrap-up presentations](#) available
- Currently 6 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!

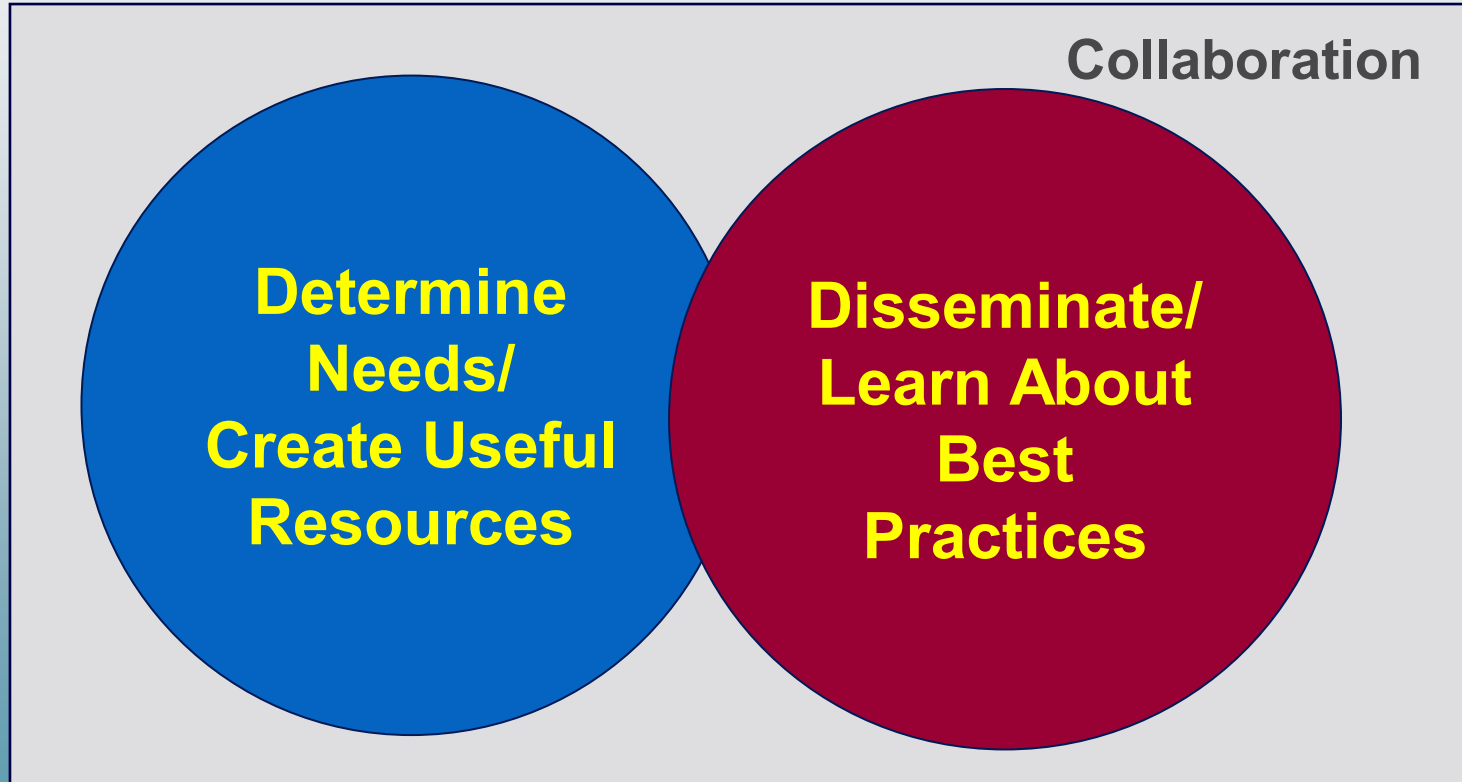
Scholar	Affiliation, Degree in Progress	Mentor(s)	Affiliation
2023-2025 Class of Scholars			
Chase Beeman, BS	Ohio State University College of Medicine, Genetic Counseling Graduate Program, Columbus, OH	Richard L. Haspel, M.D., Ph.D.	Beth Israel Deaconess Medical Center
Vanessa Smith, BS	Master of Science, Genetic Counseling, Vanderbilt University, Nashville, TN	Amber Jackson, BS Donna Messersmith, Ph.D.	Amber: Training, Diversity and Health Equity Office; Donna: Education and Community Involvement Branch National Human Genome Research Institute
Swathi Balaji, BA	Master of Science, Genetic Counselor/Counseling, Master of Public Health, Medical/Human Genetics, Department of Human Genetics, University of Pittsburgh	Kathleen Blazer, Ed.D., M.S., CGC	Director Cancer Genomics Education Program, Division of Clinical Cancer Genomics, City of Hope National Medical Center, Duarte, California
Setareh Zandihaghighi, BS	Master of Science in Genetic Counseling, The University of Michigan Master's in Genetic Counseling program - Michigan	Houriya Ayoubieh, M.D. FACMG	Internal Medicine/ Clinical Genetics, Texas Tech University Health Sciences Center- El Paso, Texas

ISCC-PEG Mission Statement

- ISCC-PEG Mission: To improve genomic literacy of healthcare providers and enhance the effective practice of clinical genomic medicine by facilitating interactions among key stakeholders in genomics education. Through ISCC-PEG, members can collaborate to identify educational needs and potential solutions, share best practices in educational approaches and develop educational resources.



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...

- Direct-to-Consumer Genetic Testing (DTC-GT), Co-Chairs: Tracey Weiler; Houriya Ayoubieh
 - Create educational information for healthcare professionals to integrate DTC-GT into clinical practice. ([FAQ](#))
- LGBTQI+ Issues in Genomics, Co-Chairs: Kelsey Bohnert; Lee Willams
 - Highlight and amplify awareness of LGBTQI+ identities, populations, and needs in genomic education
- Nursing Genomics, Co-Chairs: Trina Walker; Anne Ersig
 - Support the integration of genetics and genomics into nursing education and practice at all levels. ([FAQ](#))
- OB/GYN Genetics Curriculum, Co-Chairs: Barbara O'Brien; Louise Wilkins-Haug
 - Develop a national Obstetrics and Gynecology (OB/GYN) genetics/genomics curriculum.
- Pharmacogenomics (PGx), Co-Chairs: Phil Empey; Roseann S. Donnelly (Gammal)
 - Multidisciplinary group develops educational content for clinicians of all specialties. ([Learning Series](#))
- Physician Associates/Assistants. Chair: Nguyen Park (our newest group)
- Rare Diseases, Chair: Sabrina Malone Jenkins
 - Develop resources to educate healthcare professionals on available resources for rare genetic diseases.
- Adult Cardiovascular Genomics, Co-Chairs: Siddharth Prakash; Bansari Rajani ([Certificate Program](#))
- Inclusion in the Practice of Genomic Medicine: Exploring the Impact of Implicit Biases Towards Disability, Co-Chairs: Shoumita Dasgupta; Maya Sabatello ([Project Inclusive](#))

2023 accomplishments: Not just talk!

Type	Venue	Title	Project Group
Presentation	SGIM Regional Meeting Workshop	Cases in Direct-to-Consumer Genetic Testing	DTC
Presentation	ACMG Annual Meeting	Perspectives of Genetics Healthcare Professionals on Direct-to-Consumer Genetic Testing Practice Recommendations	DTC
Resource	G3C	Autism Spectrum Disorder and Vaccines: Ethan and his mother, Dai	G3C
Resource	Genome.gov	Genomics Education Resource Center (GenomeEd)	ISCC-PEG
Resource	NHGRI Listserv	HCPGenomicsEd	ISCC-PEG
Resource	Genome.gov	Healthcare Professionals' Genomics Education Week	ISCC-PEG
Resource	Genome.gov	Genomics FAQ for Entry-Level Nurses	Nursing Genomics
Resource	Genome.gov	Genomics FAQ for Advanced-Practice Nurses: Nurse Practitioners	Nursing Genomics
Resource	Genome.gov	Genomics FAQ for Advanced-Practice Nurses: Nurse Educators	Nursing Genomics
Presentation	APGO Annual Meeting	Developing Genetics Competencies for Trainees in Women's Health Care: A Structured and Interdisciplinary Approach	OB/Gyn
Presentation	WPA Regional Conference	Using Pharmacogenomics in Practice	PGx
Resource	University of Pittsburgh School of Pharmacy	ISCC-PEG Pharmacogenomics Learning Series	PGx
Resource	University of Pittsburgh School of Pharmacy	Pharmacogenomics Nomenclature	PGx
Resource	University of Pittsburgh School of Pharmacy	Pharmacogenomics (PGx) Resources	PGx
Presentation	AAPA Annual Meeting	Training PAs in Genomics: A Case-Study Approach	Rare Diseases

Project Groups: Some thoughts...

- “Project Group” vs. “Working Group”
- Consider:
 - Needs assessment
 - Dissemination
 - Where will the resource “live”?
 - Organization/institute listservs/websites
 - 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 or institute. Examples: AAFP; AAPA; ISONG

Healthcare Professionals' Genomics Education Week

- **September 2024!**
- **Since 2021!**
- **All ISCC-PEG Members and organizations can participate!**
- **Opportunity for you and/or your organization to disseminate genomics resources to share with other healthcare professionals and the interested general public!**
- **More info to follow**



NHGRI

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

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- **4:45 p.m. – 5 p.m. Wrap up/Future Directions**

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

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

Strategic planning

- ISCC-PEG Mission: To improve genomic literacy of healthcare providers and enhance the effective practice of clinical genomic medicine by facilitating interactions among key stakeholders in genomics education. Through ISCC-PEG, members can collaborate to identify educational needs and potential solutions, share best practices in educational approaches and develop educational resources.
- With the mission in mind, what would you want to see for the future of ISCC-PEG?
- How could ISCC-PEG better help you in your education role?

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- Consider:
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Project Group Breakout Rooms

- **(Room C) DTC-GT** - <https://bit.ly/ISCC-PEG-DTC-GT>
- **(Room D) LGBTQI+** - <https://bit.ly/ISCC-PEG-LGBTQI>
- **(Room E) Nursing Genomics** - <https://bit.ly/ISCC-PEG-NursingGenomics>
- **(4B31 Conference Room) PGx** - <https://bit.ly/ISCC-PEG-PGx>
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Google drive

- https://drive.google.com/drive/folders/1D-zKzTvNXILTHsA_UgoabkQ3sphy6AKk?usp=sharing

The Compendium: Sharing ideas and resources????remove

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).

2024 Agenda (up to now)



7:30am Arrival at NIH Gateway Center, to Building 31 C Wing, (purchase food in cafeteria)

8:30am – 9:00am (Room D/E): Breakfast + “Ask Eric Anything” Q&A with Drs. Eric Green and Rich Haspel

8:50am – 9:00am Group Photo (Move from D/E breakfast to F/G Main Room)

9:00am – 9:20am Open Networking

9:20am-9:25am Introduce Scholars (F/G Main Room)

9:25am – 9:55am ISCC-PEG Scholar Ava Willoughby presentation for project feedback

9:55am – 10:25am ISCC-PEG Scholar Molly Felix presentation for project feedback

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

2024 Agenda



10:30am – 10:55am Virtual Meeting Starts + Introductions, ISCC-PEG Co-Chairs (F/G Main Room)

10:55am – 11:15am (F/G Main Room): NHGRI Welcome – Dr. Ben Solomon, NHGRI Clinical Director

11:15am – 12:00pm (F/G Main Room): ISCC-PEG Strategic Planning – Beth, Donna, Rich

12:00pm – 1:00pm Lunch Break – Bldg 31, (purchase food in cafeteria)

1:00pm – 1:45pm (F/G Main Room): Keynote: Dr. Teri Manolio, NHGRI Director of the Division of Genomic Medicine

1:45pm – 1:50 pm (F/G Main Room): Framing Project Working Groups – ISCC-PEG Co-Chairs

1:50pm – 2:00pm: BREAK, move from F/G Main Room to Breakout Rooms

2:00pm – 3:30pm Project Team Working Group Sessions (Teams will take notes): DTC-GT (C); LGBTQIA+ (D); Nursing Genomics (E); PGx (4B31); (4B39S) Physician Assistant (4B39S); (4B39B) OB/GYN (4B39B); (4B39C) Rare Diseases (4B39C); Health Equity/Community Engagement (4B09A)

3:30pm – 3:40pm Break/Reconvene into (F/G Main Room)

3:40pm – 4:45pm (F/G Main Room): Project Working Group Summaries

4:45pm – 5:00pm (F/G Main Room): Recap of meeting; Closing

**-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)**

-Post-It board: Please put suggestions