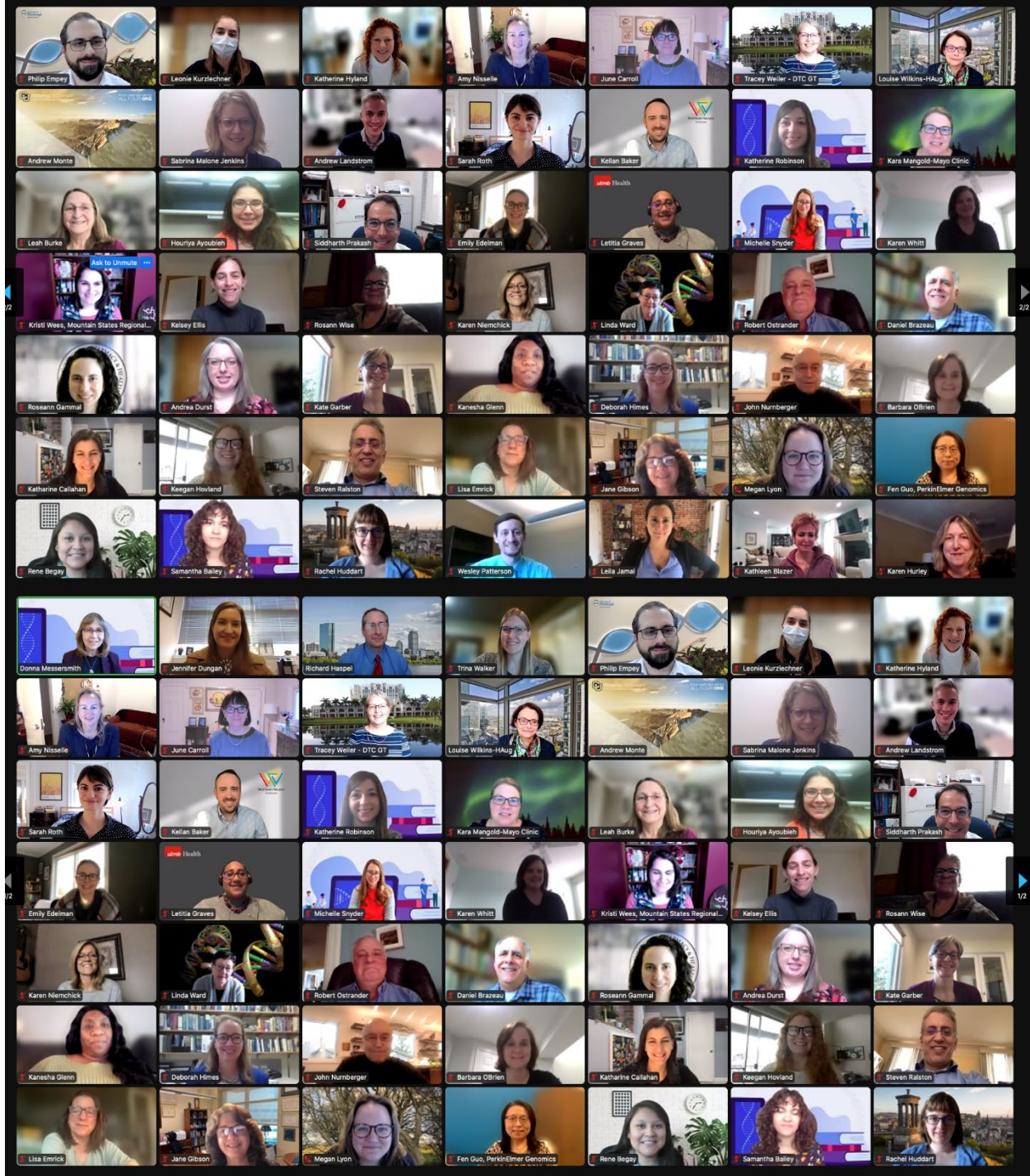


Inter-Society Coordinating Committee for
Practitioner Education in Genomics (ISCC-PEG) Meeting Minutes
Eleventh Annual Meeting, Virtual, (Eastern Time Zone), Minutes
February 16, 2022

<https://genome.gov/iscc>



147 registrants (116 external; 17 from NHGRI; 14 from other NIH institutes)
119 attendees (99 external; 11 from NHGRI; 9 from other NIH institutes)

Welcome and Introductions

Rich Haspel, MD, PhD, welcomed the ISCC members to the 11th Annual Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG).

As part of the welcome, Larry Brody, PhD, Director of the Division of Genomics and Society, Acting Branch Chief of the Education and Community Involvement Branch (ECIB), National Human Genome Research Institute (NHGRI), announced that NHGRI is hiring for the position of Branch Chief of the ECIB. The ISCC-PEG was encouraged to share this open position with their networks. More information about this position can be found at

<https://www.genome.gov/careers-training/NHGRI-Jobs/chief-education-and-community-involvement-branch>

ISCC-PEG: Annual Meeting 2022 Roadmap

Rich Haspel, MD, PhD, Co-Chair, Inter-Society Coordinating Committee for Practitioner Education in Genomics

Donna Messersmith, PhD, Co-Chair, Inter-Society Coordinating Committee for Practitioner Education in Genomics

The meeting began with Dr. Haspel introducing the roadmap for the day. The ISCC-PEG was informed that all [slides](#) presented during the meeting would be made available and the program was being recorded.

Dr. Haspel shared some ISCC-PEG insights:

- Overall, there are 268 ISCC-PEG members
- Member represent 79 organizations, 45 government/institutes, 14 companies, and 130 individual members including 26 students/scholars
- 50 new members have joined since the February 2021 meeting

The ISCC-Peg Scholars Program has entered its second year. The program pairs a scholar with an ISCC-PEG mentor who provides guidance on a scholar led project. When the meeting is in-person, scholars receive travel funds to attend. There are four new scholars this year, for a total of eight over the two years. The scholars introduced themselves and their research interests. ISCC-PEG members were encouraged to reach out with ideas to help the scholars move forward in their experience.

The 2021-2023 class of scholars includes:

- Abimbola Muinat Oladayo, BDS, MPH (ISCC-PEG Mentor: Louise Wilkins-Haug, MD, PhD)
- Sarah Roth, BA, MFA, MA (ISCC-PEG Mentors: Audrey Squire, MS, CGC, and Danielle McKenna, MS, LCGC)
- Katharine Press Callahan, AB, MD (ISCC-PEG Mentor: Sabrina Malone Jenkins, MD)
- Lisa Ferrand, BS, MS (ISCC-PEG Mentor: Kathleen Blazer, EdD, MS, CGC)

The goal of the ISCC-PEG is to improve genomic literacy. There are two components to achieving this goal: (a) determine the needs and create useful resources, and (b) disseminate and learn about best practices. These are all done under the umbrella of collaboration.

The ISCC-PEG creates resources by collaborating in Project Groups. Dr. Messersmith presented various resources and dissemination practices of Project Groups. Examples of Project Group activities include:

- Inclusion in the Practice of Genomic Medicine: Exploring the Impact of Biases Towards Disability (Shoumita Dasgupta and Maya Sabatello)
 - [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](#)
- 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 Applications.
 - Speakers: Robert J. Ostrander, MD, AAFP Liaison to ISCC-PEG and Roseann S. Gammal, PharmD, BCPS
- Direct-to-Consumer Genetic Testing (DTC-GT) (Tracey Weiler, Houriya Ayoubieh):
 - The [Direct-to-Consumer Genetic Testing FAQ for Healthcare Professionals](#)
 - [ASHG 2021 Poster: “Addressing the Direct-to-Consumer Genetic Testing Knowledge Gap for Non-Genetics Healthcare Professionals”](#)
- Rare Diseases (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
- Recently Formed Project Groups:
 - Obstetrics and Gynecology (OB/GYN) Genetics Curriculum (Barbara O’Brien, Louise Wilkins-Haug)
 - LGBTQI+ Issues in Genomics (Kellan Baker, Leila Jamal)
 - Nursing Genomics (Trina Walker, Anne Ersig)

More information about the Project Groups and their activities can be found on the [ISCC-PEG webpage](#).

New Project Groups are always welcome. Reach out to Dr. Haspel and Dr. Messersmith to discuss your ideas. Mention was made of the ISCC-PEG conflicts of interest and material review and dissemination policies which are available on the ISCC-PEG website.

Suggestions were offered on opportunities for Project Groups:

- Dissemination of resources
 - Where will the resource live?
 - Make use of organization listservs
- Apply to present at annual meetings
- Consider funding/salary support (*The ISCC-PEG does not provide funding*)
 - R25 grants from NHGRI and NCI and other Institutes and sources
- Evaluations/Publications
- Recognize value of connections with professional societies

NHGRI funding opportunities were presented. Opportunities include:

- Curriculum development
- Training and career development for practitioners
- Training and career development for future researchers

More information about funding opportunities can be found on the [Funding for Research Training webpage](#).

Examples of grant-funded courses were presented for courses that are either in progress or coming soon.

- [Genomic Competencies for Nurses from Theory to Application: An Online Course](#)
- [An Immersive Experience in Medical Genomics](#)
- [Translation and Integration of Genomics is Essential to Doctoral Nursing](#)

NHGRI updates can be found on the [ISCC-PEG website](#). New FAQs, policy webpages including informed consent, and the “Method for Introducing a New Competency: Genomics” [MINC website](#) can all be accessed on the webpage. NHGRI plans to host a social media event in June 2022; planning will involve ISCC-PEG and is ongoing at this time. The Compendium describes ISCC-PEG member interests and genomic education projects; updates are in progress.

A [slide](#) is available for download on the ISCC-PEG website for members to use in presentations to highlight ISCC-PEG projects and goals, and encourage additional healthcare providers to join.

During the meeting Dr. Haspel encouraged participants to visit the [Padlet](#) page to leave ideas/comments on the page. It is a tool used in medical education and can inspire discussion.

ISCC-PEG Scholar Presentations

The 2020-2022 scholars led presentations about the research they are conducting with their mentors. The ISCC-PEG is encouraged to share project feedback with the scholars. All scholar presentation slides can be accessed on the [ISCC-PEG 11th Annual Meeting webpage](#).

Samantha Bailey, University of Pittsburgh School of Pharmacy; Mentor: Phil Empey, PharmD, PhD

Presentation Title: *Disseminating Pharmacogenomic Education: Understanding the Needs of the ISCC-PEG Partner Organizations.*

A survey will be developed to inform the creation of an educational toolkit that can be disseminated to the ISCC-PEG and other healthcare providers.

Rene Begay, Johns Hopkins School of Public Health; Mentors: Christina Daulton, MA, and Yi Liu, MS, GC.

Presentation Title: *G3C Case Study: Providing Healthcare for Indigenous Patients with Inherited Cardiomyopathy.*

The project will create a module for the [Global Genetics and Genomics Community \(G3C\) learning portal](#). The module will focus on a patient with hypertrophic cardiomyopathy (HCM) to inform healthcare providers about the intersection of this disease and indigenous people.

Kelsey Ellis, The University of North Carolina at Greensboro, Genetic Counseling; Mentor: Michelle Snyder, MS, GC

Presentation Title: *Developing an App for Non-Genetics Providers Working with Rare Disease Patients*

The project is based on an app that could be utilized by non-genetics healthcare providers as a point-of-care resource throughout the genetic testing process.

Kathleen Robinson, St. Jude Children's Research Hospital, Doctor of Pharmacy; Mentor: Kristine Crews, PharmD

Presentation Title: *Optimizing Oncology Care with Germline Pharmacogenomics: Case-Based Education for Oncology Practitioners.*

The project will create an online, interactive module that will be case-based and focused on pharmacogenomics in oncology.

ISCC-PEG Meeting Evaluation Survey Reminder

ISCC-PEG members are encouraged to take the meeting evaluation survey at <https://www.surveymonkey.com/r/ISCC22>.

Project Group Summaries and “Asks” of ISCC-PEG Members

The ISCC-PEG Project Groups provided updates and “Asks” for the entire group.

Obstetrics and Gynecology (OB/GYN) Project Group, Presenter: Louise Wilkins-Haug.

The OB/GYN group is focused on curricular development and a case-based series for education of women’s healthcare providers. Abimbola Muinat Oladayo, a 2021-2023 ISCC-PEG scholar, will be working with the OB/GYN Project Group contributing to how the genetic information is disseminated and the delivery of information to patients by providers.

OB/GYN “Asks” include:

- The group is interested in having the ISCC-PEG’s involvement in a survey on curriculum items for women’s health care providers
- The group encourages ISCC-PEG suggestions regarding platforms that can booster remote engagement

- The group is seeking ISCC-PEG members interested in working on any of the cases for the curriculum, in particular, fetal anomaly genetic evaluation and teratogenicity

Adult Cardiovascular Genetics Project Group, Presenters: Alana Cecchi and Siddarth Prakash

The Adult Cardiovascular Genetics Project Group reviewed the adult cardiovascular genomics curriculum Siddarth Prakash and collaborators developed. The group discussed the clinical/variant interpretation app that providers can use to decipher the clinical implications of variants related to adult cardiovascular genetic diseases.

Adult Cardiovascular Genetics Group “Asks”:

- ISCC-PEG members: try the Genetic Variant Interpretation Tool app and provide feedback. App link: https://redcap.uth.tmc.edu/plugins/HTAD_app/index825.php
- ISCC-PEG is asked to share and test adult cardiovascular genomics modules with the target audience at their institutions: internal medicine, family medicine, cardiovascular surgery, CV nurses. How to Access the UTHealth Cardiovascular Genomics Certificate Program Course:
 - Step 1: Find the course on the UTHealth Canvas course catalog page: <https://uthealth.catalog.instructure.com/browse/ms>
 - Step 2: Enroll in the course. If you have a Canvas Catalog account, enter your credentials. Otherwise, create a free account by following the page prompts.
 - Step 3: Access the course and navigate the modules.

LGBTQIA+ Project Group, Presenters: Kellan Baker and Leila Jamal

Sarah Roth was introduced as a 2021-2023 ISCC-PEG scholar with this Project Group and is working on a study exploring the experiences of trans and non-binary populations navigating hereditary cancer care. The LGBTQIA+ Project Group is new to the ISCC-PEG and some of the themes the group hopes to pursue include: raise awareness of issues affecting LGBTQIA+, which refers to lesbian, gay, bisexual, transgender, queer, intersex, asexual as well as other sexual and gender diverse populations, or as NIH uses the terminology, sexual and gender minorities. Some deliverables for the next year include an academic publication, a curriculum toolkit for genetic counselors and a public communication strategy. This will dovetail with the soon-to-be-released consensus study from the National Academy of Sciences that collected sex and gender identity and sexual orientation data and was commissioned by the NIH with funding from 19 Institutes and Centers.

Rare Disease Project Group, Presenter: Sabrina Malone Jenkins

The Rare Disease Project Group has a curriculum developed for providers that focuses on the ethical considerations of consenting for a test, how to choose the correct test, interpret the test results, and integrate genomic testing results into clinical care. It also addresses how to provide families with information about rare diseases. The curriculum is adaptable to different cases and has been presented previously at the Pediatric Academic Societies meeting. The Project Group has submitted a workshop to the American Academy of Family Practitioners. Katherine

Callahan is the 2021-2023 ISCC-PEG Scholar with the Rare Disease Project Group and will explore developing educational tools that help neonatologists avoid misunderstandings and biases in interpreting test results and help them manage the uncertainty inherent in many results.

Rare Disease Project Group “Ask”:

- Does the ISCC-PEG include any specialties or conferences or trainees that would benefit from this case-based curriculum that the Rare Disease Project Group can work with?

Direct-to-Consumer Project Group, Presenter: Houriya Ayoubieh

Lisa Ferrand was introduced as a 2021-2023 ISCC-PEG Scholar. The scholar is mentored by Kathy Blazer, a founder of the Direct-to-Consumer (DTC) Project Group. The scholar may develop a perioperative direct-to-consumer educational tool that healthcare providers could use to understand direct-to-consumer results, and use the information to evaluate whether a procedure should proceed or not.

The Direct-to-Consumer Frequently Asked Questions (FAQ) for Healthcare Professionals is available on the [genome.gov website](https://www.genome.gov). The Project Group will be hosting a plenary session at American College of Medical Genetics (ACMG) Annual Meeting in March, focused on developing recommendations for the application of direct-to-consumer genetic testing in clinical care. They will also be hosting a workshop with the American Academy of Physician Assistants in May. In addition, the group is working on a point-of-care tool for healthcare professionals for direct-to-consumer genetic testing.

Direct-to-Consumer Project Group “Asks”:

- ISCC-PEG members share the [Direct-to-Consumer Frequently Asked Questions \(FAQ\) for Healthcare Professionals](#) with their institutions and share ideas for additional dissemination.
- ISCC-PEG members respond to the email the Project Group will send seeking input on each of the recommendations for the application of direct-to-consumer genetic testing
- ISCC-PEG members share input and/or advice about how the Project Group can proceed with creating a responsive point-of-care website or application
- ISCC-PEG members share suggestions about direct-to-consumer genetic testing resources that can be created and made freely available
- ISCC-PEG members share conferences that may be interested in a direct-to-consumer genetic testing workshop. The Project Group will then create a proposal.

Pharmacogenomics Project Group, Presenter: Phil Empey and Andrew Monte

The Pharmacogenomics (PGx) Project Group has nearly completed nine expert-developed and peer-reviewed PGx education modules that will be made available for dissemination on genome.gov, with a path for broad continuing education. ISCC-PEG PGx education will be

highlighted by Bob Ostrander in a presentation in September at the American Academy of Family Physicians (AAFP) “FMX” meeting.

PGx Project Group “Asks”:

- ISCC-PEG members participate in peer review of final products
- ISCC-PEG members support the PGx Scholars and respond to their asks
- ISCC-PEG members participate in the dissemination of PGx work products to be made available on genome.gov

Nursing Genomics Project Group, Presenter: Trina Walker

The Nursing Genomics Project Group’s mission is to support the integration of genetics and genomics into nursing education and practice at all levels. The Project Group is doing a landscape analysis pulling together resources for nursing faculty and practicing nurses to create a nursing repository for the NHGRI website. The group is exploring the [G2C2](#) platform and the resources on the NHGRI website that have been identified for nursing. Working groups will work on resource updating, identifying gaps for needed resources, updating the G2C2 platform resources, and developing webinars and flyers to educate nurses on how to find and use resources. Future plans include creating and updating a blueprint for each level of nursing followed by a strategic plan for implementation. The group is open to new members and meets on the second Tuesday of every month at 11 a.m. EST.

Nursing Genomics Project Group “Asks”:

- NHGRI provide support for advertising
- The formation of a multidisciplinary group to improve the G2C2 platform for full integration when it is available

Rich Haspel encouraged ISCC-PEG members to share information about any potential grants or funding opportunities for the Project Groups.

Keynote Presentation: Advancing the Equitable Implementation of Genomics into Clinical Care

[Vence Bonham Jr, JD](#), Acting Deputy Director, NHGRI, and Associate Investigator, Social and Behavioral Research Branch, NHGRI

Vence Bonham Jr, JD provided the keynote presentation to the ISCC-PEG members. In [NHGRI’s Strategic Vision](#), one of the nine principles and values is to maximize the usability of genomics for all members of the public, including the ability to access genomics and healthcare. This is key to the work of healthcare professionals and researchers, the next generation of the workforce, and ensuring how everyone can benefit. Barriers, particularly for diverse communities, exist impacting access, services, and participation in clinical research. Inequities in research participation have resulted in a lack of diversity in human genetics studies. To address this issue, NHGRI has a number of initiatives targeting certain percentages of participants that must be from under-represented ancestral backgrounds. Educating the next generation is essential to the question of equity and how we make genomic medicine beneficial for everyone. One aspect of this education involves conversations about the appropriateness of the use of race in clinical care and if it is time to move beyond the use of race algorithms. In the

field of genomics and genetics, the use of ancestry, ethnicity and race is fluid and ever changing. NHGRI argues that the time is now to stop using population descriptors based on historical social constructs such as race. Genomics education can think about this issue focusing on how an environment can be created for clinicians to move beyond thinking about race and genetics as one. A new consensus study has begun from the National Academies of Science, Engineering and Medicine (NASEM) and co-led by NHGRI which will be reviewing existing methodologies, benefits and challenges in the use of race and ethnicity and other population descriptors in genomics research. Finally, the promise of genomics cannot be fully achieved without attracting, developing, and retaining a diverse workforce. NHGRI has proposed an [action agenda](#) for building a diverse workforce within the institute. To that end, NHGRI has created the [Training, Diversity and Health Equity \(TiDHE\) Office](#) to champion a diverse genomics workforce, address health disparities and reach a more equitable and healthy society. The NIH aims to end structural racism and inequities in biomedical research through its [UNITE](#) initiative. The NIH and NHGRI are thinking about these issues and sharing with the broader scientific and genomics community.

Keynote Presentation References:

<https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-456>

<https://pubmed.ncbi.nlm.nih.gov/34861173/>

<https://www.sciencedirect.com/science/article/pii/S2666247721000336>

https://www.genome.gov/sites/default/files/media/files/2021-01/NHGRI_DiversityActionAgenda.pdf

[https://www.cell.com/ajhg/fulltext/S0002-9297\(20\)30449-3](https://www.cell.com/ajhg/fulltext/S0002-9297(20)30449-3)

ISCC-PEG Annual Meeting Zoom Chat

Chat – Meeting Opening by Larry Brody, NHGRI

11:32:53 From Larry Brody to Everyone:

ECIB Branch Chief job information: <https://www.genome.gov/careers-training/NHGRI-Jobs/chief-education-and-community-involvement-branch>

Chat – Introduction and Roadmap by Rich Haspel and Donna Messersmith

11:44:38 From Tracey Weiler to Everyone:

<https://www.genome.gov/For-Health-Professionals/Provider-Genomics-Education-Resources/Healthcare-Provider-Direct-to-Consumer-Genetic-Testing-FAQ>

11:56:47 From Tracey Weiler to Everyone:

Padlet: bit.ly/isccpeg2022

Chat – Samantha Bailey, ISCC-PEG Scholar

11:57:32 From Larry Brody to Everyone:

NHGRI's Policy Branch has also collected several FDA applications and correspondence related to requesting approval to carry "investigational" genetic/testing in research.

<https://www.genome.gov/about-genomics/policy-issues/Regulation-of-Genetic-Tests/IDE-Greenhouse>

12:06:21 From Tracey Weiler to Everyone:

I would suggest that an additional barrier has to do with the lack of curricular real estate that is dedicated to genetics and precision medicine in undergraduate medical education

12:10:59 From Emily Edelman to Everyone:

Samantha, this is a great project. Are you all coordinating with the IGNITE network? I know their PGx toolkits include educational resources and projects.

12:11:55 From Erin Dickman to Everyone:

Great work, Samantha! Was there a validated tool you found in the literature that you will be using for the survey?

12:12:23 From Katherine Hyland to Everyone:

@Tracey completely agree, there still seems to be a lack of appreciation among non-geneticist clinical educators around the need to train UME AND clinical educators!

12:12:44 From June Carroll to Everyone:

the Nisselle et al article is excellent *Frontiers in Genetics* 2019 - for a logic model if planning an educational intervention: Nisselle A et al. Ensuring Best Practice in Genomic Education and Evaluation: A Program Logic Approach

12:17:39 From Samantha Bailey to Everyone:

Thank you for the great questions! If you'd like to get in touch with me my email is slb162@pitt.edu

12:20:45 From Linda Ward to Everyone:

Agree re value of Niselle model to inform development, evaluation and dissemination of genetic-genomic educational interventions

Chat – Rene Begay, ISCC-PEG Scholar

12:23:26 From Kristine Crews to Everyone:

This is fantastic and important work, Rene.

12:24:03 From Rebecca Kronk to Everyone:

I agree - this is a really impressive and needed project

12:25:13 From Emily Edelman to Everyone:

Thank you for sharing! This is a great addition to G3C

12:25:40 From Vinaya Murthy to Everyone:

Really excited that you working on this, Rene! I will be following up with you.

12:25:49 From Tracey Weiler to Everyone:

Are the goals more about genetics and HCM, or genetics and culturally responsive engagement with patients?

12:26:10 From Louise Wilkins-HAug to Everyone:

Wonderful format - I will also follow up with you

12:26:26 From Kristi Wees, Mountain States Regional Genetics Network to Everyone:

Great Work Rene! Looking forward to learning more about this project!

12:26:45 From Barbara OBrien to Everyone:

Excellent project.. also willing to help!

12:27:55 From June Carroll to Everyone:

Great way to also include cultural safety awareness and understanding alongside the case

12:28:00 From Christina Daulton to Everyone:

If interested in contributing to Rene's project:

https://docs.google.com/forms/d/e/1FAIpQLSdpiZchqgYWqLq4ILMh5_9Mbp4iS2kMXX4PwyLRc4dlqF9vJQ/viewform?usp=pp_url

12:27:27 From Christina Daulton to Everyone:

Even if you have a comment! We are interested in hearing from you.

12:28:01 From Tracey Weiler to Everyone:

Culturally responsive engagement is a huge problem, and goes beyond the indigenous community too.

12:29:05 From Rene Begay, MS (she/her/hers) to Everyone:

Email for me: rene.begay@cuanschultz.edu

12:29:25 From Tracey Weiler to Everyone:

Have you reached out to any other geneticists that are working well with indigenous communities?

12:33:37 From Karen Hurley to Everyone:

Really great work! Part of my journey in cultivating humility was learning about the Havasupai case - several good resources out there, including articles and a video "Blood Journey" that explore issues in-depth.

Chat – Kelsey Ellis, ISCC-PEG Scholar

12:34:20 From John Nurnberger to Everyone:

Can you put the link for the genetic testing app in the chat?

12:37:58 From June Carroll to Everyone:

This is amazing work - can you let the ISCC members know when we are able to disseminate it? Great resource for practice and teaching

12:38:17 From Kristi Wees, Mountain States Regional Genetics Network to Everyone:

I am really excited about this app! Is it ready for "prime time" or sharing or if not, is there a projected LIVE date?

12:38:23 From John Nurnberger to Everyone:

Very nice indeed!

12:38:23 From Katherine Hyland to Everyone:

This app looks great! very comprehensive. do you cover all the standard genetic/genomic tests? e.g. CMA, gene panel, gene sequencing vs. targeted sequencing, exome sequencing?

12:38:38 From Tracey Weiler to Everyone:

Excellent work!

12:38:48 From Michelle Snyder to Everyone:

App Link: tinyurl.com/genetestapp

Feedback Link: tinyurl.com/genetestfeedback

12:39:03 From Katherine Hyland to Everyone:

Agreed, very exciting! Would be great for this to be on the smart phone of every clinician!

12:39:49 From Katherine Hyland to Everyone:

It would be great to disseminate very broadly, e.g. AAMC

12:39:57 From Rachel Mills to Everyone:

Great work Kelsey 🍌

12:40:07 From Lisa Ferrand to Everyone:

This is wonderful, much needed...are you considering this app as only available to licensed providers for download?

12:40:12 From Leonie Kurzlechner to Everyone:

Awesome app Kelsey!

12:40:13 From Trina Walker to Everyone:

This is fantastic!

12:40:46 From Nguyen Park to Everyone:

This is wonderful!

12:41:00 From Tracey Weiler to Everyone:

It seems like many of us are suggesting that clinicians should "phone a genetics friend" if they don't know what to do next. It would be very helpful if there were a link that is consistent and updated frequently

12:41:55 From June Carroll to Everyone:

Genetics Education Canada www.geneticseducation.ca — we would be interested - we provide educational materials for non-genetics HCP - contact me
June.carroll@sinaihealth.ca

12:42:44 From Rachel Mills to Everyone:

NSGC might also be interested in helping to disseminate! I can share with the Board of Directors for their feedback.

12:42:59 From Leah Burke to Everyone:

Great work. Kelsey and I have spoken about having the Executive Committee of the Council on Genetics of the American Academy of Pediatrics to make sure that it is in a useful format for pediatricians.

12:43:13 From Soohyun Kim to Everyone:

HRSA can help dissemination through our Genetics Programs - both providers and families - and potential recruitment for usability testing - feel free to reach out -
skim@hrsa.gov

12:43:24 From Katherine Hyland to Everyone:

Not too much to go through all the standard tests - think differentiating between types of tests would be very helpful for clinicians, since they are ordering genetic tests more and more and it's important for them to learn what test is appropriate. Very exciting tool!

12:43:42 From Megan Lyon to Everyone:

The National Coordinating Center for the Regional Genetics Networks (NCC) (<https://nccrcg.org>) would be interested in disseminating. Please feel free to reach out to me (mlyon@nccrcg.org).

12:43:59 From Katherine Hyland to Everyone:

Agree - present at meetings like AAMC as well as specialty-specific

12:44:03 From Vinaya Murthy to Everyone:
Kelsey - I would be interested in talking with you about this as part of my PhD research study.

12:44:10 From Claudia Mikail, MD, MPH to Everyone:
Great presentations! @Kelsey I'd be happy to serve as a resource in clinical genetics for the app.

12:45:57 From John Nurnberger to Everyone:
I would like to help disseminate to psychiatric clinicians.

12:46:00 From Katherine Hyland to Everyone:
@Kelsey I'd like to use your tool for clinicians at my own institution for faculty development, and for them to have your app as a 'go to' resource. can't wait for it to be available for general use!

12:47:40 From Katherine Hyland to Everyone:
@Donna - can we have access to all these powerpoints? really great projects and presentations!!

Chat – Katherine Robinson, ISCC-PEG Scholar

12:55:37 From Tracey Weiler to Everyone:
@Katherine, and all other fellows - I look forward to seeing these cases fleshed out so that they can be incorporated into medical student education.

12:57:28 From Tracey Weiler to Everyone:
@Katherine - you might be able to engage medical student oncology interest groups in the process. I think they would really love to be involved!

12:58:06 From Jennifer Dungan to Everyone:
Katherine, did providers express lack of confidence with insurance coverage/payment for genetic testing? This is a common barrier of providers, even when they are in an academic medical center. Also, will you address disparities in genetic testing for underserved populations? Many don't know that genetic counseling and genetic testing subsidies can be available to patients going through Federally Qualified Health Care centers. An NP colleague of mine found that her patients could get counseling and testing for \$1 a piece, with counseling center located on the free bus line 1 mile away from their FQHC center.

12:58:35 From Kristine Ashcraft to Everyone:
GCs order many oncology genomic tests and may be worthy of adding as educational targets.

12:58:56 From Donna Messersmith to Everyone:
Agenda is posted at bottom of this page; slides will be posted with the agenda

12:58:59 From Donna Messersmith to Everyone:
<https://www.genome.gov/event-calendar/iscc-11th-annual-meeting-virtual-february-2022>

13:00:53 From Dave Kaufman, NHGRI to Everyone:
Very strong projects, very impressive work

13:01:14 From Chris Gunter to Everyone:

Great to see these — well done, everyone!

13:02:07 From Katherine Hyland to Everyone:

@Donna - can we have access to your background? Its great! would be great for teaching virtually! 😊

13:02:21 From Rosann Wise to Everyone:

ISCC Meeting Evaluation Survey link: <https://www.surveymonkey.com/r/ISCC22>

13:02:51 From Richard Haspel to Everyone:

bit.ly/isccpeg2022

13:04:49 From Katherine Robinson to Everyone:

@Jennifer Dungan, yes, reimbursement is always cited as a barrier to pharmacogenomic testing. There has been improvements to the reimbursement landscape so might be worth addressing that in the modules as well. And I think that's a great idea to incorporate disparities in underserved populations. Thank you for sharing that resource

13:05:02 From Katherine Robinson to Everyone:

This is the pubmed link for the article discussed
<https://pubmed.ncbi.nlm.nih.gov/34996412/>

13:05:31 From Katherine Robinson to Everyone:

Great ideas everyone! Thank you for the feedback. my email is kmr180@pitt.edu if you have further ideas

Chat – OB/GYN Project Group

15:50:23 From Tracey Weiler - DTC GT to Everyone:

I think we need to be set up to do hybrid teaching so that people can be remote if sick, but present if healthy.

15:52:50 From Tracey Weiler - DTC GT to Everyone:

@Louise - regarding cases... does fertility fit into this curriculum?

15:53:42 From Barbara OBrien to Everyone:

This is Barbara.. We have an IVF case that involves ethical issues

15:54:35 From Tracey Weiler - DTC GT to Everyone:



Chat – Adult Cardiovascular Genetics Project Group

16:04:37 From Siddharth Prakash to Everyone:

Link to our Adult CV Genomics Variant Interpretation Tool:

https://redcap.uth.tmc.edu/plugins/HTAD_app/index825.php Please try and feedback to us! Siddharth.K.Prakash@uth.tmc.edu

16:05:36 From Siddharth Prakash to Everyone:

How to Access the UTHealth Cardiovascular Genomics Certificate Program Course:

Step 1: find the course on the UTHealth Canvas course catalog page:

<https://uthealth.catalog.instructure.com/browse/ms>

Step 2: enroll in the course

If you have a Canvas Catalog account, enter your credentials. Otherwise, create a free account by following the page prompts;

Step 3: access the course and navigate the modules

Chat – LGBTQIA+ Project Group

16:08:11 From Tracey Weiler - DTC GT to Everyone:

@Kellan - in addition to words, are you going to incorporate information about how to address these individuals with respect to pedigrees?

16:08:59 From Leila Jamal to Everyone:

We will, but we are hoping to move to a broader and more thorough focus on the issue since so much of the work that has gone on so far has focused rather specifically on pedigrees

16:09:21 From Tracey Weiler - DTC GT to Everyone:

OK!

16:09:27 From Sarah Roth to Everyone:

Thanks, Kellan!!

16:09:52 From Katherine Hyland to Everyone:

@tracey - NSGC is coming out with new more inclusive pedigree guidelines.

16:12:34 From Sarah Roth to Everyone:

“Unanswered Questions: Hereditary breast and gynecological cancer risk assessment in transgender adolescents and young adults”:

<https://onlinelibrary.wiley.com/doi/abs/10.1002/jgc4.1278>”<https://onlinelibrary.wiley.com/doi/abs/10.1002/jgc4.1278>

16:12:54 From Tracey Weiler - DTC GT to Everyone:

@Rich - I love the idea of presenting to the bigger group!

16:13:11 From June Carroll to Everyone:

Great idea to present to the group

Chat – Rare Disease Project Group

16:17:37 From Sabrina Malone Jenkins to Everyone:

Sabrina.malonejenkins@hsc.utah.edu

16:18:59 From Katharine Callahan to Everyone:

Would anyone be willing to “pilot” the interview questions? Particularly hoping to recruit neonatologists but open to others’ perspectives too

16:19:33 From Amy Nisselle to Everyone:

Sabrina - we developed and ran a national online program in 2021 (modules + virtual workshops) for acute care genomics which was targeted at the whole team who work in BICU/PICU - neonatologists/intensivists, nurses, geneticists and GCs. The materials are not publicly available (yet) but happy to chat. All aspects of the program were evaluated (clinical utility, education, GC issues, economics, etc.) - loads of papers out already, education one in prep. Maybe something there for you guys?

16:20:36 From Sabrina Malone Jenkins to Everyone:

Amy, that would be fantastic. Do you mind emailing me your contact info:

Sabrina.malonejenkins@hsc.utah.edu

Chat – Direct-to-Consumer Project Group

16:20:42 From Tracey Weiler - DTC GT to Everyone:
@Lisa - No hopefully about it... You are a member of our DTC-GT group. We claim you!

16:21:03 From Amy Nisselle to Everyone:
No probs - amy.nisselle@mcri.edu.au - happy to follow up!

16:22:28 From Lisa Ferrand to Everyone:
Thanks tracey

16:23:34 From Tracey Weiler - DTC GT to Everyone:
The hard work also includes Donna's hard work to get it published on genome.gov.
Thanks to Donna!

16:24:05 From Deborah Himes to Everyone:
I'm so excited this resource exists. I'm going to use it in my teaching!

16:25:29 From Tracey Weiler - DTC GT to Everyone:
<https://www.genome.gov/For-Health-Professionals/Provider-Genomics-Education-Resources/Healthcare-Provider-Direct-to-Consumer-Genetic-Testing-FAQ>

16:27:03 From Amy Nisselle to Everyone:
we have some resources developed from a national study of Australian's use of/opinions about DTC - <https://www.genioz.net.au/page/community-resources/> - evidence-based, freely available to share. I can connect you with the researchers/authors if helpful

16:28:39 From Tracey Weiler - DTC GT to Everyone:
@Amy - yes please! tweiler@fiu.edu

16:30:58 From Kellan Baker to Everyone:
I have to run - thank you all for your support of the LGBTQI+ Project Group and for our scholar Sarah Roth in particular!

16:35:04 From Amy Nisselle to Everyone:
Re publishing evaluation papers, Australian Genomics published reporting standards to help people write up education programs for publication if helpful:
<https://www.equator-network.org/reporting-guidelines/ensuring-best-practice-in-genomics-education-and-evaluation-reporting-item-standards-for-education-and-its-evaluation-in-genomics-rise2-genomics/>

Chat – Vence Bonham Jr, Keynote Presentation

16:37:01 From Larry Brody to Everyone:
https://en.wikipedia.org/wiki/Vence_L._Bonham_Jr.

17:19:59 From Larry Brody to Everyone:
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8756537/>

17:20:48 From Amy Nisselle to Everyone:
What an amazing image of the tapestry on the second last slide! It conveys so much. Is it publicly available by any chance?

17:21:22 From Amy Nisselle to Everyone:
Sorry, and firstly, thank you for a wonderful talk. That was really super. Thank you!

17:23:22 From Tracey Weiler - DTC GT to Everyone:

Thanks for the great talk. NHGRI is very focused on genomics careers and research. ISCC-PEG is more focused on training and genetics literacy of non-genetics professionals. Is there a way to propagate these ideas beyond the genetics community?

17:25:29 From Houriya Ayoubieh to Everyone:

Great talk! What resources would you recommend to teach medical students about this?

17:31:32 From Rene Begay to Everyone:

With regard to Indigenous communities, are there additional or unique factors that people working in genomics should be aware of? thank you for the great talk.

17:34:50 From Jennifer Dungan to Everyone:

Thank you Dr. Bonham. Amazing insights and research. Hope your mother is well!

17:35:51 From Rosann Wise to Everyone:

Take a moment to do the ISCC Survey: <https://www.surveymonkey.com/r/ISCC22>

17:38:10 From Letitia Graves to Everyone:

This has been an excellent meeting! Thank Dr. Bonham and the co-chairs. There has been a lot of rich discussions here today. Excited about all the working being done in this group and from the ISCC-PEG scholars.

17:40:02 From Richard Haspel to Everyone:

bit.ly/isccpeg2022

17:40:03 From Tracey Weiler - DTC GT to Everyone:

Us old folks need a social media tutorial so we know how to make it work!

17:40:47 From Tracey Weiler - DTC GT to Everyone:

Are you our new "Kim"?