

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

# **COMPENDIUM**

Genomic Education Activities of Members

April 2020



#### Dear ISCC-PEG Members,

We hope you find this edition of the ISCC-PEG Compendium useful. By promoting sharing of resources and interests, we believe this document will foster collaboration and communication. Thanks to all those who have completed an entry for your organization. To those who haven't, we consider the Compendium a living document with plans for annual updates and posting on the ISCC-PEG webpage. As such, it is never too late to send in a form (a blank one is at the end of the Compendium). Updates to existing forms are also welcome. We have also entered Compendium resources into the Genetics/Genomics Competency Center (G2C2: <a href="https://genomicseducation.net/">https://genomicseducation.net/</a>). Any resource entered into G2C2 is listed at the top of the Compendium entry including the type of resource, whether CME/CE credit is available, and if it is a free or paid resource.

Please feel free to contact me if you have any suggestions for this Compendium or other ideas for ISCC-PEG.

Thanks,

Rich Haspel ISCC-PEG Co-Chair

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# **Organizations/Institutes**

### **African Genomic Medicine Training Initiative**

Compendium: African Genomic Medicine Training Initiative: Introduction to Genomic Medicine Training Course for Nurses in Africa

https://training.h3abionet.org/AGMC 2016/course-description/

Course / No / Free

Compendium: African Genomic Medicine Training Initiative: The eGenomics catalogue <a href="https://egenomics.h3abionet.org/">https://egenomics.h3abionet.org/</a>

Website / No / Free

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Dr. Vicky Nembaware
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).
  - a) African Genomic Medicine Training Initiative

The African Genomic Medicine Training Initiative is a working group that aims to facilitate the translation of genetics and genomics research into clinical practice through training of healthcare professionals, researchers and the public. The African Genomic Medicine Training Initiative was launched in Dakar, Senegal by a group of experts and stakeholders from across the continent who were interested in promoting and addressing a combined H3Africa and African Society of Human Genetics Meeting.

We have two key educational activities which are supported by H3Africa, the African Society of Human Genetics and the H3ABioNet.

b) The Introduction to Genomic Medicine Training Course for Nurses in Africa:

The AGMT developed a professional development course, Introduction to Genomic Medicine Training for Nurses in Africa, and ran a pilot in 2017. The course sought to support improved Genetics & Genomics knowledge, attitudes and skills for:

- research nurses in the biomedical field or those aspiring to be research nurses.
- specialist nurses working in the genomics/genetics field, and
- general nurse practitioners in their day to day duties, or recent graduates.

The course emphasized the practical application of content into learners' current settings and roles. In addition, skills in Genetic Counseling, Community Engagement/Ethical Conduct in research and patient care and development of health promotion material were reinforced. This pilot aimed to

- Develop and implement a plan of care for patients' that incorporates genetic and genomics information and is sensitive to individual and cultural preferences and norms,
- Offer basic genetic counselling to patients and families, and
- Conduct genomics research that is ethical and appropriate to their context.

The course was delivered via a distributed virtual classroom approach, similar in structure to the STARS Career development course which was developed through the Association of Commonwealth Universities and was recently adopted and adapted by the H3ABioNet Introduction to Bioinformatics Training course. Lecturers delivered the courses online via pre-recorded videos and a virtual room and learners, together with their facilitators, accessed the lessons in physical classrooms distributed across Africa. 19 classrooms from 11 countries signed up for the course. We plan on running the course again in 2018 and expanding to other healthcare professionals.

#### c) The eGenomics catalogue

The eGenomics catalogue was initiated by H3ABioNet and is maintained by volunteers from across the globe, in particular H3Africa Fellows. This catalogue maintains free online Genomics educational material and community based reviews/evaluations. The material aggregated via this website includes: Books; Journals, Courses, MOOCs, Opencourseware Databases. The material is categorized based on topics proposed by the H3Africa Education and Coordinated Training Working Group, in addition the EDAM ontology has been used to categorize Bioinformatics relevant courses. In the near future we plan on including organizations focusing on diagnostic services and support services relevant to patients and families with genetic diseases.

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.

Dr Vicky Nembaware could present on behalf of the working group. Possible topics:

"Impact of the Introduction to Genomic Medicine for Nurses Course in Africa" "eGenomics – aggregator of online free genomics and genetics material and resources"

- 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.

Will send once we have some ideas.

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).

Will send once we have some ideas.

## American Academy of Family Physicians (AAFP)

Compendium: American Academy of Family Physicians (AAFP): Periodic articles on aspects of genetics in the journal American Family Physician. <a href="http://www.aafp.org/afp/topicModules/viewTopicModule.htm?topicModuleld=56">http://www.aafp.org/afp/topicModules/viewTopicModule.htm?topicModuleld=56</a>
Article / Yes / Paid

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Robert J. Ostrander, M.D.
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

Periodic articles on aspects of genetics in the journal American Family Physician. <a href="http://www.aafp.org/afp/topicModules/viewTopicModule.htm?topicModuled=56">http://www.aafp.org/afp/topicModules/viewTopicModule.htm?topicModuled=56</a>

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.

I am not prepared to do this at this time. I think we can learn about best practices from others with a narrower focus.

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.

At this time most of my other genetics work is with ACHDNC and there are constraints on fostering collaboration.

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.

#### Not at this time.

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).

Creating a compendium of resources applicable to primary care physicians in all the primary care disciplines; creating an avenue for sharing resources among pediatric, FP, IM, Med-Peds and Ob-Gyn organizations.

## **American Academy of Ophthalmology (AAO)**

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Veeral Shah, PhD and J. Timothy Stout, MD, PhD, MBA
- 2) List and briefly describe your organization's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links. Dr. Shah and Dr. Stout present a two hour workshop at the annual American Academy of Ophthalmology meeting. This course is well attended and has been presented for the past three years.
- 3) Would you or someone affiliated with your group be interested in presenting your 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.
  Not at this time.
- 4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.
  Not at this time.
- 5) Would you or someone in your group 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.

  Not at this time.
- 6) Can your organization/society/institute disseminate ISCC genomics education resources of otential interest to your group's members? If yes, how? Course material is distributed both electronically and in hard copy form to all students that attend the course.
- 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).
   None.

## American Academy of Pediatrics (AAP)

Compendium: American Academy of Pediatrics (AAP) Council on Genetics: Clinical guidelines for genetic conditions for primary care providers:

https://pediatrics.aappublications.org/committee on genetics

Guideline / No / Free

Compendium: American Academy of Pediatrics (AAP): manual from the Genetics in Primary Care Institute (GPCI): Medical Genetics in Pediatric Practice [Paperback] <a href="https://shop.aap.org/medical-genetics-in-pediatric-practice-paperback/">https://shop.aap.org/medical-genetics-in-pediatric-practice-paperback/</a>
Book / No / Paid

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Leah W. Burke, MD
- 2) List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

The AAP has developed a number of educational resources over the years. The AAP provides education and instruction to primary care providers through their clinical guidelines for genetic conditions that are produced by the former Committee on Genetics, now the American Academy of Pediatrics Council on Genetics. These can be found at:

https://pediatrics.aappublications.org/committee\_on\_genetics

The AAP also supported a genetics education initiative called the Genetics in Primary Care Institute (GPCI) that was quite an in depth undertaking and had a number of presentations and products. Unfortunately, many of those resources are no longer available on line through the AAP. However, out of that, the AAP has produced a manual: Medical Genetics in Pediatric Practice [Paperback] <a href="https://shop.aap.org/medical-genetics-in-pediatric-practice-paperback/">https://shop.aap.org/medical-genetics-in-pediatric-practice-paperback/</a>

The Council on Genetics of the AAP submits and provides educational sessions every year at the annual AAP National Conference on Education. IN addition, we provide an in depth annual story as well as late-breaking stories for the AAP News.

3) Would you or someone affiliated with your group be interested in presenting your 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.

I would be happy to approach the Council Executive committee to ask about any other resources and I would be happy to present these at a future meeting.

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

I am currently working with the Rare Diseases Group, and feel that this is the best place to spend my time. I am not sure I know of another person in our organization who would like to lead a project.

5) Would you or someone in your group 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.

I would be happy to lead a discussion and also could involve others on the Council.

6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Yes, I can disseminate directly to the members of the Council as well as to my local chapter. TO disseminate anything officially through the AAP, you have to have it validated and approved at several different levels.

7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

I would recommend including Residency Program Directors from pediatrics, family medicine, pathology and obstetrics and gynecology.

## American Association for Clinical Chemistry (AACC)

Compendium: American Association for Clinical Chemistry (AACC): Lab Tests Online: <a href="https://labtestsonline.org/">https://labtestsonline.org/</a>
Website / No / Free

Compendium: American Association for Clinical Chemistry (AACC): Online Certificate Program (paid content) in Molecular Pathology: <a href="https://www.aacc.org/education-and-career/online-certificate-programs/laboratory-testing">https://www.aacc.org/education-and-career/online-certificate-programs/laboratory-testing</a>
Course / Yes / Paid

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Christina Lockwood
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).
  - Many of the resources below are already linked to G2C2, but all can be linked
  - Webinars on many genomics-related topics: <a href="https://www.aacc.org/store/all-webinars/on-demand-webinars">https://www.aacc.org/store/all-webinars/on-demand-webinars</a>
  - Clinical chemistry trainee council is a freely available repository of many educational resources that cover genetics and genomics, including:
    - "Pearls" that are audio + slide podcasts: https://www.aacc.org/clinicalchemistry-trainee-council/trainee-council-in-english/pearls-oflaboratory-medicine
    - A Question Bank: <a href="https://www.aacc.org/clinical-chemistry-trainee-council/trainee-council-in-english/question-bank">https://www.aacc.org/clinical-chemistry-trainee-council/trainee-council-in-english/question-bank</a>
    - Webcasts: <a href="https://www.aacc.org/clinical-chemistry-trainee-council/trainee-council-in-english/webcasts">https://www.aacc.org/clinical-chemistry-trainee-council-in-english/webcasts</a>
    - Clinical Case Studies: <a href="https://www.aacc.org/publications/clinical-chemistry/clinical-case-studies">https://www.aacc.org/publications/clinical-chemistry/clinical-case-studies</a>
    - Journal Club: <a href="https://www.aacc.org/publications/clinical-chemistry/journal-club">https://www.aacc.org/publications/clinical-chemistry/journal-club</a>
    - Brief Question and Answer articles: https://www.aacc.org/publications/clinical-chemistry/q-and-a
  - Online Certificate Program (paid content) in Molecular Pathology: <a href="https://www.aacc.org/education-and-career/online-certificate-programs/laboratory-testing">https://www.aacc.org/education-and-career/online-certificate-programs/laboratory-testing</a>
  - Numerous Books and Multimedia published by AACC Press: https://www.aacc.org/publications/books-and-multimedia
- 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.

- Dr. Nguyen Nguyen from AACC presented at the 2016 in-person meeting. AACC would be happy to present again if there is sufficient space available.
- 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.
  - AACC members would be interested in joining projects related to genomic testing.
- 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.
  - Discussion related to genomic testing (methodology, limitations, reimbursement, utilization management, etc) would be of interest to AACC members.
- 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).

## **American Board of Medical Specialties (ABMS)**

2019 02 04:

- 1) Name of Individual(s) Submitting Entry: Susie Flynn, Director of Academic Services
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

As part of the ongoing efforts to improve and advance the Member Boards Continuing Certification Programs, the ABMS developed the MOC Directory, a repository of MOC activities (also accredited for CME) that have been approved by one or more ABMS Member Boards. Initially developed in partnership with the AAMC, the MOC Directory was transitioned to the ABMS Website (see link below) and will be relaunched onto a new robust platform (and transitioned to the Continuing Certification Director) effective January, 2018. As part of this MOC Initiative, accredited CME activities can be submitted through a common submission form and ABMS facilitates the MOC approvals on behalf of the CME Providers. Once one or more MOC approvals are achieved, the activity is indexed in the MOC Directory. The CME providers receive an MOC approval statement that they share with their attendees upon completion of the activity. The accredited CME activities that are currently indexed in the G2C2 repository could also be submitted to the MOC Directory to further advance the dissemination of genetics education.

http://www.abms.org/initiatives/abms-moc-directory/

- 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.
  - If I was able to attend the meeting, I would be happy to present on the Continuing Certification Directory and identify opportunities to disseminate accredited CME activities that are currently indexed in the G2C2 repository, facilitate MOC approvals through the Boards Community and to additionally index them in the MOC Directory to expand their reach and uptake in participation across multiple specialties.
- 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.
  - I currently serve as the project lead for the MOC Directory and engage with many external stakeholders in regards to their participation and outreach efforts to the MOC Directory.
- 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.

# Again, I would be interested in sharing the MOC Directory with members of the ISCC.

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).

Not at this time.

## **American College of Clinical Pharmacy (ACCP)**

Compendium: American College of Clinical Pharmacy (ACCP):

www.accp.com Website / Yes / Free

Compendium: American College of Clinical Pharmacy (ACCP): Precision Medicine: Applied

Pharmacogenomics Certificate:

https://newimis.accp.com/Applied PGx/ContentAreas/Applied PGx.aspx

Course / Yes / Paid

Compendium: American College of Clinical Pharmacy (ACCP): Pharmacogenomics:

Applications to Patient Care

https://www.accp.com/store/product.aspx?pc=TH\_03PGG

Book / No / Paid

#### 2020 02 25:

1) Name of Individual(s) Submitting Entry:

### Christina Aquilante (Christina.aquilante@cuanschutz.edu)

2) List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

The American College of Clinical Pharmacy (ACCP) is a professional and scientific society that provides leadership, education, advocacy, and resources enabling clinical pharmacists to achieve excellence in practice, research, and education. ACCP is the professional home for more than 17,000 clinical pharmacy practitioners, scientists, educators, administrators, students, residents, and fellows from more than 60 countries committed to excellence in clinical pharmacy and patient pharmacotherapy.

Pharmacists and health care practitioners, educators, and trainees providing patient care services are affected by the ever-advancing science of pharmacogenomics. In response, ACCP's third edition of Pharmacogenomics: Applications to Patient Care (<a href="https://www.accp.com/store/product.aspx?pc=TH\_03PGG">https://www.accp.com/store/product.aspx?pc=TH\_03PGG</a>), developed by expert clinicians and researchers in the field, provides a state-of-the-art resource that distills the overwhelming body of scientific and clinical evidence and suggests practical actions for the translation and clinical application of pharmacogenomics to everyday practice. Edited by Julie A. Johnson, Vicki L. Ellingrod, Deanna L. Kroetz, and Grace M. Kuo, the third edition of this book provides up-to-date contributions from the groundbreaking efforts of pharmacogenomics research.

Through its Academy, ACCP offers a <u>Precision Medicine: Applied</u> Pharmacogenomics Certificate Program. This program is designed to

enable participants to apply pharmacogenomic information to clinical practice and select the most appropriate therapeutic interventions. Topics that are covered include: fundamentals of pharmacogenomics; interpretation of pharmacogenomic test results, literature evaluation and use of evidence-based guidelines; case-based scenarios; and a heavy focus on how to implement clinical pharmacogenomics in different health care settings. The program consists of required and elective course work and is delivered via live and online teaching modalities.

ACCP members have also published a White Paper and an Opinion Paper related to clinical pharmacogenomics:

- White Paper: "Precision pharmacotherapy: Integrating pharmacogenomics into clinical pharmacy practice." J Am Coll Clin Pharm. 2019 Jun; 2:303-313. https://doi.org/10.1002/jac5.1118
- Opinion Paper: "Application of precision medicine across pharmacy specialty areas." J Am Coll Clin Pharm. 2019 Jun; 2: 288-302. https://doi.org/10.1002/jac5.1107
- 3. Would you or someone affiliated with your group be interested in presenting your 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.

Yes, we would be interested in presenting our organization's Applied Pharmacogenomics Certificate Program during an ISCC plenary call or face-to-face meeting.

4. Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

Not at this time. However, we would be interested in collaborating on pharmacogenomics materials that are developed by ISCC.

5. Would you or someone in your group 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.

#### Not at this time.

6. Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Potentially, depending on the type of resource. Possibly via our website or dissemination of the information via email to leaders and members of our Pharmacogenomics Practice and Research Network.

7. 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).

## American College of Medical Genetics and Genomics (ACMG)

Compendium: American College of Medical Genetics and Genomics (ACMG) education page:

www.acmgeducation.net

Website / Yes / Free

Compendium: American College of Medical Genetics and Genomics (ACMG) educational videos:

https://www.youtube.com/user/TheACMGChannel

Multimedia / No / Free

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Jane Radford, MHA, CHCP
- 2) List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.
  - \*Our most active education activities are monthly Genomic Case Conferences, which can be accessed on our Education page.

Most of our educational materials are hosted at our Education page: <a href="https://www.acmgeducation.net">www.acmgeducation.net</a>

Additionally, we have educational videos on our YouTube channel: https://www.youtube.com/user/TheACMGChannel

3) Would you or someone affiliated with your group be interested in presenting your 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.

#### Yes. Director of Education, Jane Radford

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

#### Possibly, depends on project

5) Would you or someone in your group 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.

#### We strive to provide excellent educational offerings.

6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

7)	Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

## American College of Obstetricians and Gynecologists (ACOG)

Compendium: American College of Obstetricians and Gynecologists (ACOG): Education in Women's Genomics Counseling

https://www.acog.org/education-and-events/courses/genomics

Course / Yes / Free

Compendium: American College of Obstetricians and Gynecologists (ACOG): Genetic Screening and Testing

https://www.acog.org/topics/genetic-screening-and-testing

Guideline / Yes / Paid

#### 2019 02 04:

- 1) Name of Individual(s) Submitting Entry: Megan McReynolds, Director, Genetics
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).
  - a. ACOG Education in Women's Genomics Counseling\*
    (<a href="https://www.acog.org/Education-and-Events/ACOG-Womens-Genomics-Counseling">https://www.acog.org/Education-and-Events/ACOG-Womens-Genomics-Counseling</a>)
  - b. ACOG Genetics Resource Page\* (<a href="https://www.acog.org/About-ACOG/ACOG-Departments/Genetics">https://www.acog.org/About-ACOG/ACOG-Departments/Genetics</a>)
- 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.
  - a. No, unfortunately we cannot attend.
- 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.
  - a. Not at this time. Please consider ACOG future projects, we are interested.
- 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.
  - a. Not at this time.
- 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).

## **American Heart Association (AHA)**

Compendium: American Heart Association (AHA): Basic Concepts and Potential Applications of Genetics and Genomics for Cardiovascular and Stroke Clinicians <a href="http://youtu.be/gxsYk7oPX-I">http://youtu.be/gxsYk7oPX-I</a>

Multimedia / No / Free

Compendium: American Heart Association (AHA): Improving Genomic Literacy Among Cardiovascular Practitioners via a Flipped-Classroom Workshop at a National Meeting <a href="http://circgenetics.ahajournals.org/content/9/3/287">http://circgenetics.ahajournals.org/content/9/3/287</a>

Article / No / Free

Compendium: American Heart Association (AHA): Basic Concepts and Potential Applications of Genetics and Genomics for Cardiovascular and Stroke Clinicians, A Scientific Statement From the American Heart Association

http://circgenetics.ahajournals.org/content/8/1/216

Article / No / Free

Compendium: American Heart Association (AHA): Enhancing Literacy in Cardiovascular Genetics: A Scientific Statement From the American Heart Association <a href="http://circgenetics.ahajournals.org/content/9/5/448">http://circgenetics.ahajournals.org/content/9/5/448</a>
Article / No / Free

#### 2020\_02\_25:

- 1) Name of Individual(s) Submitting Entry: Kiran Musunuru, Andrew Landstrom
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

Genetics videos available via YouTube (<a href="http://youtu.be/gxsYk7oPX-I">http://youtu.be/gxsYk7oPX-I</a>); flipped-classroom workshops at national meetings (<a href="http://circgenetics.ahajournals.org/content/9/3/287">http://circgenetics.ahajournals.org/content/9/3/287</a>); published Scientific Statements on genomics literacy (<a href="http://circgenetics.ahajournals.org/content/8/1/216">http://circgenetics.ahajournals.org/content/8/1/216</a>, <a href="http://circgenetics.ahajournals.org/content/9/5/448">http://circgenetics.ahajournals.org/content/9/5/448</a>)

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.

Yes; although we have presented about our educational activities in cardiovascular genomics at face-to-face meetings in the past, we would welcome the opportunity to do so in the future.

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.

The American Heart Association has launched an effort to create a cardiovascular genetics/genomics certificate program geared towards cardiovascular practitioners. Andrew Landstrom is leading the effort. We would be open to collaborating with other groups, with the caveat that our effort is focused solely on cardiovascular disease.

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.

#### Nothing to propose at this time.

 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).

We would be interested in developing a means to measure long-term outcomes of efforts to improve genomic literacy.

7) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Yes. We have more than 1,000 members of the American Heart Association who are affiliated specifically with the AHA's Council on Genomic and Precision Medicine, and it would be feasible to distribute links to resources to them via email. We also have a journal focused on cardiovascular genomics (*Circulation: Genomic and Precision Medicine*) that has a broader international reach via its website and social media.

## American Medical Association (AMA)

Compendium: American Medical Association (AMA) Ed Hub: Precision Medicine and Genomics <a href="https://edhub.ama-assn.org/pages/genomics-cme-course">https://edhub.ama-assn.org/pages/genomics-cme-course</a>
Course / Yes / Paid

Compendium: American Medical Association (AMA) and JAMA Network<sup>TM</sup>: Genomics and Precision Health <a href="https://sites.jamanetwork.com/genetics/">https://sites.jamanetwork.com/genetics/</a> Course / Yes / Paid

Compendium: American Medical Association (AMA) Journal of Ethics: Human Genome Editing (<a href="https://journalofethics.ama-assn.org/issue/governing-human-genome-editing">https://journalofethics.ama-assn.org/issue/governing-human-genome-editing</a> Course / Yes / Paid

Compendium: American Medical Association (AMA) Journal of Ethics: Precision Health <a href="https://journalofethics.ama-assn.org/issue/ethics-precision-health">https://journalofethics.ama-assn.org/issue/ethics-precision-health</a>)
Course / Yes / Paid

Compendium: American Medical Association (AMA): Precision Medicine Resources for Physicians https://www.ama-assn.org/delivering-care/precision-medicine

Course / Yes / Paid

Course / Tes / Tale

#### 2020\_02\_25:

- 1) Name of Individual(s) Submitting Entry: Sean C. McConnell, PhD
- List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

Resources to support ISCC members include:

- AMA Ed Hub™ provides trusted, high-quality CME/MOC and education to
  physicians and other health care professionals who seek to stay current and
  continuously improve the care they provide. Accessible on any device and at
  any time, courses are available in a variety of formats, so that learners can
  listen, watch, read or interact in ways that best suit their needs. Physicians can
  claim CME credit for all applicable activities. (<a href="https://edhub.ama-assn.org/">https://edhub.ama-assn.org/</a>)
- AMA Ed Hub features a collection of education on Precision Medicine and Genomics: \*(https://edhub.ama-assn.org/pages/genomics-cme-course)
- Extensive and relevant content on Genomics and Precision Health is also available from the JAMA Network<sup>TM</sup> \*(https://sites.jamanetwork.com/genetics/)
- The AMA Journal of Ethics includes CME, with recent issues focused on human genome editing and precision health. (<a href="https://journalofethics.ama-assn.org/issue/governing-human-genome-editing">https://journalofethics.ama-assn.org/issue/ethics-precision-health</a>)

- Precision Medicine For Your Practice is a series of modules developed from a collaboration among the AMA, The Jackson Laboratories, and Scripps Translational Research Institute. (https://www.
- <u>.org/education-and-learning/clinical-and-continuing-education/precision-medicine-for-your-practice</u>) A new CME module on PGx is scheduled to be published in 2020.
- The AMA offers additional **precision medicine resources** for physicians. (https://www.ama-assn.org/delivering-care/precision-medicine)
- 3) Would you or someone affiliated with your group be interested in presenting your 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.

Yes, we would welcome the opportunity to present best practices and case studies on how educational/CME content can reach a broad audience and engage learners when the right, relevant content is timely delivered through an innovative platform such as the AMA Ed Hub™.

We would prefer a face-to-face meeting, but also welcome conference calls if easier for participants to attend.

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

Perhaps, if an opportunity arises with adequate alignment.

5) Would you or someone in your group 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.

Open to discussion.

6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Yes, education may be disseminated via AMA Ed Hub™, AMA's education delivery platform.

7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

Additional resources may need to be developed to advance clinical decision support for precision medicine.

## **American Medical Women's Association (AMWA)**

#### 2019 02 04:

- 1) Name of Individual(s) Submitting Entry: Eliza Lo Chin, MD, MPH
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).
  - AMWA has been involved with outreach for the All of Us initiative of the NIH. As the oldest U.S. association of women physician providers representing all medical specialties, our members are often asked to address the utility and interpretation of direct to consumer genetic test results, cardiac genetic testing, and more recently Alzheimer's disease genetic testing.
- 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.
  - At this point in time, we realize the need to develop more formal educational programs and resources to share.
- 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.
  - We would be interested in leading a project to better understand potential biases that may occur when delivering genetic results to men and women. AMWA has helped launch a highly successful Sex and Gender Health Education Summit <a href="https://www.sghesummit2018.com">https://www.sghesummit2018.com</a> to address sex and gender specific health education across five major health professions (medicine, nursing, dentistry, pharmacy, and allied health). We would like to incorporate genetics into this discussion. Some programming can be around implicit bias as it relates to physician disclosure practices of genetics information between men and women.
- 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.
  - Neelum Aggarwal, MD, AMWA's Chief Diversity and Inclusion Officer (CDIO), currently Co-Chairs a Genetic and Biomarker Disclosure Work Group regarding Alzheimer's Disease Genetic and Biomarker test result disclosure. This Workgroup encompasses researchers, clinicians, patient advocacy group and patients who are concerned about how genetic disclosure processes are

occurring at present. The Workgroup has particular focus on disclosure practices to minority and under-served populations and for women.

AMWA and its CDIO would be interested in giving updates on the progress of this Workgroup in a face to face meeting or call

The work of this Workgroup can also be showcased in upcoming conferences and information presented discussed as to how it relates to other associations noted in this compendium.

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).

We are very interested in collaborating on potential projects particularly any that focus on sex and gender issues in genomics education.

## **American Society of Pharmacovigilance (ASP)**

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Benjamin Brown, Executive Director, Sara Rogers, PharmD, BCPS, Director, Clinical Affairs
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

ASP is in the process of applying for ACCME accreditation and securing ACPE accreditation to broaden its reach and impact from internal efforts relating to improving genomics literacy for both pharmacists and physicians. We are developing a new content series relating to various aspects of pharmacogenomics, including: (a) navigating DTC PGX testing, (b) interpreting and understanding confirmatory pharmacogenetics test reports and results, (c) analyzing and assessing the implications of social determinants of health relating to pharmacogenetics testing and (c) other educational initiatives relating to removing barriers to pharmacogenomics access and reimbursement. We continue to offer free live webinars targeted to healthcare professionals in areas related to pharmacovigilance, including pharmacogenomics. Examples below:

- Pharmacogenomics unveiled An inside look at PGx testing (live webinar)
- Developing Deprescribing Practices to Help Manage Polypharmacy
- 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.
  - Sara Rogers would be glad to give an overview of ASP's content development strategy, and overview of our process for collaborative education development and outreach. We are also interested in exploring opportunities to co-develop educational activities with ISCC member organizations on relevant topics and work together to identify best methods of dissemination of content.
- 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.
  - Yes. Benjamin Brown is currently coordinating and facilitating educational module development projects by and between both DTC and PGX working groups. There are a lot of opportunities to expand content and module development to include and collaborate with other working groups inside of ISCC. Always open to new ideas and new ways of thinking about advancing genomics literacy.

- 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.
  - Yes, Sara Rogers would be glad to discuss opportunities to integrate genomics education in pharmacy school curricula at a future meeting. Benjamin Brown is open to leading a discussion relating to DTC PGX testing and its implications for primary care physicians. This could be conducted on the phone.
- 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).
  - a. Exploring pharmacogenomics as a tool to prevent adverse drug events
  - b. Identifying barriers to the widespread implementation of pharmacogenomics, especially specific educational pieces
    - i. Create a framework, workflow and/or process for patient and provider education and re-education
  - c. Integrating educational resources within the EMR, from the prospective of all users (physicians, pharmacists, nurses, genetic counselors, etc)

## **American Thoracic Society (ATS)**

Compendium: American Thoracic Society (ATS) Section of Genetics and Genomics: <a href="https://www.thoracic.org/members/assemblies/sections/gg/index.php">www.thoracic.org/members/assemblies/sections/gg/index.php</a>
Website / No / Free

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Benjamin Raby
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

The Section of Genetics and Genomics (SGG), of the Allergy, Immunology and Inflammation Assembly of the American Thoracic Society has responsibility for organizing educational activities and resources for the membership of the American Thoracic Society. To date, initiatives related to genomic education include:

- i) Post-graduate courses: The SGG offers yearly post-graduate courses at the annual meeting of the ATS (each May). On alternate years, we hold either clinical-or research-oriented courses. The clinical course, "Clinical Pulmonary Genetics" is a daylong course that reviews the spectrum of genetic disorders of the respiratory system, with a focus on recognition of presenting manifestations, a review of the diagnostic approaches (including the use of genetic testing), and current management guidelines. Additional topics covered include interpretation of genetic test reports, the ACMG guidelines for variant classification, and a review of the importance of pre- and post-test genetic counseling. The research-based course reviews the science of high-throughput omic approaches to studying lung disease. Topics included in this course change yearly, but have included reviews of genetic (GWAS, NGS), epigenetic (CpG profiling, ChIP-based profiling), and genomic (transcriptomics, scRNA-Seq, eQTL mapping) approaches.
- ii) Symposia: Each year, the SGG proposes at least 2 symposia for planning considerations by the ATS Programming Committee. Most recent topics of these 3 hours sessions include the role of genetics in clinical practice, advances in integrative genomics of lung disease, and results of the TOPMed pulmonary projects.
- iii) Featured Speaker at SGG meeting: Each year, we hold a keynote address at the SGG annual meeting. The speaker is asked to speak on a new technology or genomic approach that can be applied to pulmonary disease.
- iv) Webpage: The SGG maintains a webpage (<a href="www.thoracic.org/members/assemblies/sections/gg/index.php">www.thoracic.org/members/assemblies/sections/gg/index.php</a>) with access to compiled resources for advancing genetics and genomics, including a directory of

online genetics and genomics courses, a list of relevant online podcasts and journal clubs, and a list of available funding opportunities.

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.

Yes, I could give an overview of our initiatives, with a focus on the courses. Happy to do in person or by phone.

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.

I would need more information about this to answer - what types of projects?

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.

I would be happy to participate in such an endeavor, but I am not sure I would be best suited leading the discussion.

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).

It might be interesting to think about setting up an ISCC educational display in exhibit halls of each of the societies' annual meetings. The display could focus on raising awareness for one or two key issues (how to take a family history, recognizing genetic disease, a gene quiz). Could include a participation raffle for some prize, etc. This would raise profile of ISCC at each meeting, and get people thinking about genetic disease.

## Association for Molecular Pathology (AMP)

Compendium: AMP-Education Online or AMPED™ online

http://educate.amp.org Website / Yes / Free

Compendium: Molecular-in-My-Pocket<sup>TM</sup> cards

https://www.amp.org/education/education-resources/molecular-in-my-pocket-guides/

Other / No / Free

Compendium: AMP Outreach Course

https://amp19.amp.org/program/molecular-pathology-outreach-course/

Course / Yes / Paid

#### 2020\_02\_25:

1) Name of Individual(s) Submitting Entry: Eriko G. Clements, PhD, AMP Content Manager and Lucia P. Barker, PhD, AMP Director, Education Programs

2) List and briefly describe your organization's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

AMP-Education Online or AMPED<sup>™</sup> online: Found at <a href="http://educate.amp.org">http://educate.amp.org</a>,\* this learning management system (LMS) contains a growing collection of online content provided by AMP experts in molecular pathology.



#### The AMP Training and Education (T&E)

Committee works with the AMP Education team to design, implement, and review an array of educational offerings. This includes one of AMP's most popular resources, the Molecular-in-My-Pocket<sup>TM</sup> cards\* created by subject matter experts in Molecular Pathology. The T&E Committee is also involved in planning and facilitating our popular AMP Outreach Course, an interactive workshop which includes a case-based immersive NGS component, designed to bring pathologists up to speed in molecular pathology.

3) Would you or someone affiliated with your group be interested in presenting your 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.

Yes, if there is interest (in the fall)
Launching a learning management system – lessons learned. AMP could speak to
the process of selecting and launching a new LMS

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.

#### Not now

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.

#### Not now

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).

#### N/A

## **Association of American Medical Colleges**

Compendium: Association of American Medical Colleges (AAMC): MedEdPORTAL https://www.mededportal.org/

Website / Yes / Free

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Lisa Howley, PhD, MEd, Sr Director of Strategic Initiatives and Partnerships
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

The AAMC serves and leads the academic medicine community to improve the health of all. Founded in 1876 and based in Washington, D.C., the AAMC is a not-for-profit association dedicated to transforming health care through innovative medical education, cutting-edge patient care, and groundbreaking medical research. The AAMC has 171 medical school members (154 in the U.S., 17 in Canada), nearly 400 member teaching hospitals and health systems, 85 academic societies, approx. 50 VA medical centers, 173,000+ full time faculty, 129,000 resident physicians, 89,000 medical students.

- The AAMC provides many services to lead and serve the academic medicine community, including:
  - Medical College Admissions Test (MCAT)
  - American Medical College Application Service (AMCAS)
  - Electronic Residency Application Service (ERAS)
  - Curriculum Inventory (CI)
  - MedEdPORTAL and Academic Medicine Journals

#### Resources to support ISCC members include:

- AAMC Website www.aamc.org
- AAMC Annual Meeting <a href="https://www.aamc.org/professional-development/events/learn-serve-lead">https://www.aamc.org/professional-development/events/learn-serve-lead</a>
- MedEdPORTAL https://www.mededportal.org/
- Curriculum Inventory <a href="https://www.aamc.org/what-we-do/mission-areas/medical-education/curriculum-inventory">https://www.aamc.org/what-we-do/mission-areas/medical-education/curriculum-inventory</a>
- AAMC Affinity Groups <a href="https://www.aamc.org/professional-development/affinity-groups">https://www.aamc.org/professional-development/affinity-groups</a>

- o AAMC Data and Reports <a href="https://www.aamc.org/data-reports">https://www.aamc.org/data-reports</a>
- 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.

Possibly if interest in better understanding medical education, curriculum development, practices across continuum of physician education

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.

## Possibly depending on topic, need and scope

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.

#### Possibly depending on topic, need and scope

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).

Would like to see increase in scholarship related to genomics education: What are current practices, where are opportunities to build exemplary practices, and collaborative research?

## Association of Professors of Human and Medical Genetics (APHMG)

Compendium: Association of Professors of Human and Medical Genetics (APHMG): Genetics Education Resource Exchange (GERE)

https://www.aphmg.org/ Website / No / Paid

Compendium: Association of Professors of Human and Medical Genetics (APHMG): Medical School Core Curriculum in Genetics

https://adebf24d-d0c7-4842-b28b-

a002a216f521.usrfiles.com/ugd/8707df\_d23bbc19ede2400b9d6c578ee91f8028.pdf

Other / No / Free

Compendium: Association of Professors of Human and Medical Genetics (APHMG): Project Inclusive Genetics:

https://www.bucme.org/activity/8001

Course / Yes / Free

2020\_02\_25:



- 1) Name of Individual(s) Submitting Entry: **Shoumita Dasgupta, Tracey Weiler, Kate Garber, Kathy Hyland**
- List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

\*Genetics Education Resource Exchange (GERE)
Available to APHMG members, aphmg.org

This Genetics Education Resource Exchange (GERE) is a project of the APHMG Curriculum Directors Special Interest Group (CD SIG). The goal is to provide an easy way to share teaching materials and resources related to medical and human genetics. The posted materials include:

- multiple choice question bank
- small group sessions
- flipped classroom materials
- summaries of available teaching videos
- sample clinical genetic test results
- materials from previous workshops
- USMLE Step Review materials
- · articles for teaching

<sup>\*\*</sup>Website is undergoing reorganization so as to be compatible with Donna's expressed design preferences (e.g. more descriptive material up front), in order to link to G2C2.

Medical School Core Curriculum in Genetics – available on the <u>APHMG home</u> page

- This document outlines Genetics and Genomics content considered essential to include in Medical School curricula. It contains high-level learning objectives mapped to the ACGME competency domains, and is constructed around a broad set of competencies that the APHMG membership agree that all graduating medical students should achieve. To maintain currency, North American medical schools were surveyed to identify topics of emerging importance and topics of declining importance.
- 3) Would you or someone affiliated with your group be interested in presenting your 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.

Yes – Shoumita Dasgupta (or any of us) would be happy to present on APHMG and its initiatives and resources.

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

#### **Project Inclusive Genetics:**

Shoumita Dasgupta is the project group leader for Project Inclusive Genetics that seeks to understand the connection between unconscious bias, disability, and genetic counseling practices. The educational module was developed with input of expert members of the ISCC, and was accredited for free CME/CEU credit. The module is available here: <a href="https://www.bucme.org/activity/8001">https://www.bucme.org/activity/8001</a>.

The project group is interested in partnering with professional societies to encourage participation by their members.

#### <u>Direct-to-consumer genetic testing:</u>

APHMG member Tracey Weiler co-chairs the DTC working group, and Kate Garber and Kathy Hyland are also members. This group is drafting frequently asked questions and hopes to develop a point-of-care tool for use by providers who are asked about DTC testing.

5) Would you or someone in your group 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.

Yes – we can speak about active learning methodologies, including active classroom (or workshop) pedagogical design, small group discussions, interactive online learning, and other distance/digital learning methods.

### Best done in person, but video-conference call would also work.

6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Yes – we can send them to our listservs and present them at our annual meeting.

7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

## Centers for Disease Control and Prevention (CDC), Office of Genomics and Precision Public Health (OGPPH)

Compendium: Centers for Disease Control and Prevention (CDC), Office of Genomics and Precision Public Health (OGPPH):

Public Health Genomics and Precision Health Knowledge Base (PHGKB)

https://phgkb.cdc.gov/PHGKB/phgHome.action?action=home

Website / No / Free

Compendium: Centers for Disease Control and Prevention (CDC), Office of Genomics and Precision Public Health (OGPPH): My Family Health Portrait – the Surgeon General's family health history collection tool, formerly hosted by NHGRI

https://phgkb.cdc.gov/FHH/html/index.html

Website / No / Free

Compendium: Centers for Disease Control and Prevention (CDC), Office of Genomics and Precision Public Health (OGPPH): Genomics and Health Impact Blog <a href="https://www.cdc.gov/genomics/blog/index.htm">https://www.cdc.gov/genomics/blog/index.htm</a>

Website / No / Free

Compendium: Centers for Disease Control and Prevention (CDC), Office of Genomics and Precision Public Health (OGPPH): Genomics and Precision Health Weekly Update <a href="https://www.cdc.gov/genomics/update/current.htm">https://www.cdc.gov/genomics/update/current.htm</a>
Other / No / Free

Offici / No / Free

Compendium: Centers for Disease Control and Prevention (CDC), Office of Genomics and Precision Public Health (OGPPH): Tier 1 Toolkit – Information for patients and providers on Hereditary breast and ovarian cancer

https://www.cdc.gov/genomics/implementation/toolkit/hboc 4.htm

Other / No / Free

Compendium: Centers for Disease Control and Prevention (CDC), Office of Genomics and Precision Public Health (OGPPH): Tier 1 Toolkit – Information for patients and providers on Lynch syndrome

https://www.cdc.gov/genomics/implementation/toolkit/lynch\_4.htm

Other / No / Free

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Dave Dotson and Ridgely Fisk Green
- List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

Public Health Genomics and Precision Health Knowledge Base (PHGKB) – integrated knowledge base that includes published scientific literature, CDC resources, and other materials that address the translation of genomic

discoveries into improved health care and disease prevention <a href="https://phgkb.cdc.gov/PHGKB/phgHome.action?action=home">https://phgkb.cdc.gov/PHGKB/phgHome.action?action=home</a>

MyPHGKB – user interface for PHGKB that allows customizable search results based on user preferred information sources, along with email alerts on user defined topics of interest <a href="https://phgkb.cdc.gov/PHGKB/myPHGKB.action">https://phgkb.cdc.gov/PHGKB/myPHGKB.action</a>

Cancer PHGKB – specialized subset database of PHGKB aggregating content on translation and implementation of cancer genomic science <a href="https://phgkb.cdc.gov/PHGKB/specificPHGKB.action?topic=cancer&query=home">https://phgkb.cdc.gov/PHGKB/specificPHGKB.action?topic=cancer&query=home</a>

Infectious Diseases PHGKB - specialized subset database of PHGKB aggregating content on pathogen genomics, host interactions, and the human microbiome

https://phgkb.cdc.gov/PHGKB/specificPHGKB.action?topic=Infectious diseases&query=home

HLBS-PopOmics (Heart PHGKB) – subset of PHGKB aggregating content on heart, lung, blood, and sleep disorders

 $\frac{\text{https://phgkb.cdc.gov/PHGKB/specificPHGKB.action?topic=HLBS&query=hom}}{\underline{e}}$ 

Rare Diseases PHGKB – subset of PHGKB aggregating content on rare diseases

https://phgkb.cdc.gov/PHGKB/specificPHGKB.action?topic=rare&query=home

My Family Health Portrait – the Surgeon General's family health history collection tool, formerly hosted by NHGRI <a href="https://phgkb.cdc.gov/FHH/html/index.html">https://phgkb.cdc.gov/FHH/html/index.html</a>

Tier-Classified Guidelines Database – genomic guidelines sorted according to highest applicable evidence tier level <a href="https://phqkb.cdc.gov/PHGKB/tierStartPage.action">https://phqkb.cdc.gov/PHGKB/tierStartPage.action</a>

Genomics and Precision Health Weekly Update – subscribe to the update to get the latest information and publications on genomics and precision health <a href="https://www.cdc.gov/genomics/update/current.htm">https://www.cdc.gov/genomics/update/current.htm</a>

Genomics and Health Impact Blog - CDC experts and invited bloggers share information on topics in genomics and family history that are important to health care providers, public health professionals, policy makers and the public <a href="https://www.cdc.gov/genomics/blog/index.htm">https://www.cdc.gov/genomics/blog/index.htm</a>

Events and Multimedia - CDC experts and invited speakers provide information on topics in genomics and family history that are important to health care providers, policy makers and the public

https://www.cdc.gov/genomics/videos/index.htm

OGPPH Publications - a list of publications by year from the CDC Office of Genomics and Precision Public Health

https://www.cdc.gov/genomics/publications/index.htm

Tier 1 Toolkit – customizable materials including factsheets for patients and providers, guideline summaries, and letters to relatives for hereditary breast and ovarian cancer

https://www.cdc.gov/genomics/implementation/toolkit/hboc 4.htm and Lynch syndrome https://www.cdc.gov/genomics/implementation/toolkit/lynch\_4.htm

State Genomics Implementation Map – clickable map providing information on public health genomics activities in states and territories <a href="https://phgkb.cdc.gov/PHGKB/stateMapStartPage.action">https://phgkb.cdc.gov/PHGKB/stateMapStartPage.action</a>

Web pages written for the general public

Family Health History – a rich source of information on learning about, and acting on, family history, geared towards a wide variety of stakeholders, includes links to tools and resources

https://www.cdc.gov/genomics/famhistory/index.htm

Genomics and Health – web pages on family history and genetics for different health conditions

https://www.cdc.gov/genomics/disease/genomic\_diseases.htm including hereditary breast and ovarian cancer

https://www.cdc.gov/genomics/disease/breast\_ovarian\_cancer/index.htm and hereditary colorectal cancer

https://www.cdc.gov/genomics/disease/colorectal\_cancer/index.htm

Genetic Counseling and Testing – basic information explaining what genetic counseling and testing are

https://www.cdc.gov/genomics/gtesting/genetic counseling testing.htm

3) Would you or someone affiliated with your group be interested in presenting your 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.

Yes. Ridgely Fisk Green would be interested in presenting information on OPHG's resources for state health departments and other partners. Dave Dotson could present an overview of the Public Health Genomics and Precision Health Knowledge Base (PHGKB). Call-in presentations likely preferred for budgetary reasons.

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

Yes. Ridgely Fisk Green would be interested in leading development of an online course in genomics and precision health.

5) Would you or someone in your group 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.

Muin Khoury might be interested in leading a talk on OPHG initiatives, including possible genomics and precision public health course, and future development strategies and how these could better support genomics education. Face-to-face meeting or call-in discussion would both be possibilities.

6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Yes, OGPPH could potentially add links to some materials on our website and include information about them on Twitter (@CDC\_Genomics)

7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

OGPPH is interested in exploring how to support cascade screening for hereditary breast and ovarian cancer, Lynch syndrome, and familial hypercholesterolemia. OGPPH is also interested in genomics education for the public.

## **Centre for Genetics Education NSW Health (Sydney, Australia)**

Compendium: Centre for Genetics Education NSW Health (Sydney, Australia): <a href="https://www.genetics.edu.au">www.genetics.edu.au</a>
Website / No / Free

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Kate Dunlop (Director)
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).
  - a. \*Website (<u>www.genetics.edu.au</u>) with fact sheets (eg <a href="http://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-15-genetic-and-genomic-testing">http://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-15-genetic-and-genomic-testing</a>)
  - b. \*Clinical Genomics Research Resource- to include when completed March 2018
- 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.

#### Yes - Kate Dunlop when resources completed Mid 2018

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.

#### I would like to think about this one!

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.

#### Yes- Kate Dunlop around engagement of health professionals

 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).

Evaluation framework: Australian Genomics Program 4 is planning to develop a framework (to commence February 2018) to enable evaluation of genomic resources. We have invited Teri Manolio to work with us on this project – it would be good to discuss later next year as this develops and in terms of evaluation of resources generally

# Clinical Pharmacogenetics Implementation Consortium (CPIC®) and The Pharmacogenomics Knowledgebase (PharmGKB®)

Compendium: Clinical Pharmacogenetics Implementation Consortium (CPIC®)

https://cpicpgx.org/ Website / No / Free

Compendium: The Pharmacogenomics Knowledgebase (PharmGKB®)

www.pharmgkb.org Website / No / Free

Compendium: The Pharmacogenomics Knowledgebase (PharmGKB®): What is

Pharmacogenomics?

https://www.pharmgkb.org/whatIsPharmacogenomics

Website / No / Free

Compendium: The Pharmacogenomics Knowledgebase (PharmGKB®): Pharmacogenomics for

clinicians

https://www.pharmgkb.org/page/clinicianFAQ

Website / No / Free

Compendium: The Pharmacogenomics Knowledgebase (PharmGKB®): CPIC Guideline

**Summary Videos** 

https://www.youtube.com/playlist?list=PLbP5DJELA1WM1mqVf0OHfhxRoQtyb-QJh

Multimedia / No / Free

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Mary Relling, PharmD; Teri Klein, PhD; Kelly Caudle, PharmD, PhD; Roseann Gammal, PharmD; Michelle Whirl-Carrillo, PhD; Rachel Huddart, PhD
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).
- 1. The Clinical Pharmacogenetics Implementation Consortium (CPIC) (<a href="https://cpicpqx.org/">https://cpicpqx.org/</a>) is an international collaboration that addresses what has been one of the major barriers to clinical implementation of pharmacogenetic tests: the lack of freely available, peer-reviewed, updatable, and detailed gene/drug clinical practice guidelines. CPIC was formed in 2009 as a shared project between the Pharmacogenomics Knowledgebase (PharmGKB) and the Pharmacogenomics Research Network (PGRN). CPIC guidelines enable the translation of genetic laboratory test results into actionable prescribing decisions for specific drugs. Following peer-review, CPIC guidelines are published in Clinical Pharmacology and Therapeutics and posted to the CPIC and PharmGKB websites. A key assumption underlying CPIC guidelines is that as clinical genomic testing expands, clinicians are faced with uncertainty about how to use genetic test results, even if they have not explicity ordered a test for a specific

drug. Thus, CPIC guidelines help clinicians understand *how* to use available genetic test results to guide prescribing and do not focus on *whether* to order genetic tests. Each CPIC guideline adheres to a standard format that includes which variants define alleles, assignment of function to alleles, translation of diplotypes into phenotypes, prescribing recommendations (graded according to strength), graded evidence to support prescribing recommendations, allele frequencies for major ancestral groups, and algorithms and example language for clinical decision support. CPIC is funded by the National Human Genome Research Institute of the National Institutes of Health.

- a. \*CPIC guidelines: <a href="https://cpicpgx.org/guidelines/">https://cpicpgx.org/guidelines/</a> (already integrated in G2C2 at <a href="http://genomicseducation.net/search/advanced/CPIC">https://genomicseducation.net/search/advanced/CPIC</a>)
- b. <u>CPIC resources including information on current implementers and details of CPIC standardization projects: https://cpicpgx.org/resources/</u>
- c. Information about the CPIC informatics group: https://cpicpgx.org/informatics/
- 2. The Pharmacogenomics Knowledgebase (PharmGKB) (www.pharmgkb.org) is a comprehensive online resource that collects, curates, and disseminates knowledge about the impact of human genetic variation on drug responses. Since its founding in 2000, PharmGKB has become the premier repository for this information, serving as a valuable tool for clinicians, researchers, and the public. Some of the highlights include annotations of genetic variants and gene-drug relationships; illustrations of drug-centered pathways; summaries of very important pharmacogenes, and annotations of pharmacogenomics in drug labels and pharmacogenomic-based dosing guidelines. PharmGKB is funded by the National Institutes of Health, including the National Human Genome Research Institute.
  - a. The 'What is Pharmacogenomics?' page offers a general introduction to pharmacogenomics: <a href="https://www.pharmgkb.org/whatlsPharmacogenomics">https://www.pharmgkb.org/whatlsPharmacogenomics</a>
  - b. The 'What is PharmGKB?' page provides an introduction to the different types of information found on the PharmGKB website: <a href="https://www.pharmgkb.org/whatlsPharmgkb">https://www.pharmgkb.org/whatlsPharmgkb</a>
  - c. Clinicians with questions about pharmacogenomics can visit our 'Pharmacogenomics for clinicians' page: https://www.pharmgkb.org/page/clinicianFAQ
  - d. PharmGKB pathways: <a href="https://www.pharmgkb.org/pathways">https://www.pharmgkb.org/pathways</a>
  - e. Very Important Pharmacogenes: https://www.pharmgkb.org/vips
  - f. Guideline annotations: https://www.pharmgkb.org/guidelines
  - g. Drug label annotations: https://www.pharmgkb.org/labels
  - h. PharmGKB training exercises can be downloaded from: <a href="https://www.pharmgkb.org/downloads">https://www.pharmgkb.org/downloads</a>
  - i. Video summaries of CPIC guidelines: <a href="https://www.youtube.com/playlist?list=PLbP5DJELA1WM1mgVf0OHfhxRoQ">https://www.youtube.com/playlist?list=PLbP5DJELA1WM1mgVf0OHfhxRoQ</a> tyb-QJh
- 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.

Yes; we have already done so and would like to keep updating ISCC.

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.

Andrew Monte, a CPIC member, is currently the Co-Chair of the ISCC Pharmacogenomics Project Group, which is tasked with creating pharmacogenomics educational materials for physicians, other healthcare providers, and the public. The Pharmacogenomics Project Group is comprised of several representatives from CPIC (Mary Relling, Roseann Gammal) and PharmGKB (Teri Klein, Rachel Huddart, Michelle Whirl-Carrillo).

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.

Yes; we would be interested in discussing how to use existing resources in educational materials for clinical pharmacogenomic testing.

- 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).
- 7) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Yes; we are able to disseminate ISCC genomics education resources to CPIC members and PharmGKB users through PharmGKB's blog, CPIC's announcement email list, and the Twitter accounts for PharmGKB and CPIC.

## **College of Family Physicians of Canada**

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: June Carroll
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

Active educational programs are through GECKO Genetics Education Canada – Knowledge Organization <a href="www.geneticseducation.ca">www.geneticseducation.ca</a>
<a href="Presentations at Continuing Education events across Canada are posted on the GECKO website">www.geneticseducation.ca</a>
<a href="Presentations at Continuing Education events across Canada are posted on the GECKO website">www.geneticseducation.ca</a>

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.

We have presented GECKO materials in the past – at the in-person meeting and on a call – the International Working Group – however always happy to present them

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.

#### Not at this time

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.

#### Uncertain on this one – depends on objectives

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).

# Genetic and Rare Diseases Information Center (GARD), National Center for Advancing Translational Sciences (NCATS)

Compendium: Genetic and Rare Diseases Information Center (GARD)

https://rarediseases.info.nih.gov/

Website / No / Free

Compendium: Genetic and Rare Diseases Information Center (GARD): Frequently Asked

Questions: Patients

https://rarediseases.info.nih.gov/guides/pages/96/patients-families-and-friends

Website / No / Free

Compendium: Genetic and Rare Diseases Information Center (GARD): Frequently Asked

Questions: Healthcare Professionals

https://rarediseases.info.nih.gov/guides/pages/97/healthcare-professionals

Website / No / Free

Compendium: Genetic and Rare Diseases Information Center (GARD): Frequently Asked

**Questions: Researchers** 

https://rarediseases.info.nih.gov/quides/pages/98/researchers

Website / No / Free

Compendium: Genetic and Rare Diseases Information Center (GARD): Frequently Asked

**Questions: Educators** 

https://rarediseases.info.nih.gov/guides/pages/99/teachers-and-students

Website / No / Free

#### 2020 02 25:

**Genetic and Rare Diseases Information Center (GARD):** 

https://rarediseases.info.nih.gov/

1) Name of Individual(s) Submitting Entry:

Michelle Snyder, MS, CGC Karen Hanson, MS

- List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.
- GARD provides a website and contact center that offers vetted information and resources about genetic and rare diseases for the public. GARD Information Specialists have advanced degrees in genetics and have experience working with people who have rare conditions.
- The <u>GARD website</u> contains data on more than 6,500 rare and/or genetic diseases. You can also find guides with tips on general topics, important resources, and answers to frequently asked questions from <u>patients</u>, <u>healthcare professionals</u>, <u>researchers</u>, and <u>educators</u>.
- 3) Would you or someone affiliated with your group be interested in presenting your 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.

Yes – we would be willing to talk about GARD's initiatives and programs.

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

Michelle Snyder currently leads the Rare Disease Project Group.

- 5) Would you or someone in your group 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.
- We would be willing to lead a discussion related to plain language writing or resource identification/evaluation.
- 6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?
- Yes, we can include educational resources on the GARD website or through NCATS social media accounts.
- 7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

## **Genetics Education Canada – Knowledge Organization (GEC-KO)**

Compendium: Genetics Education Canada – Knowledge Organization (GEC-KO):

https://geneticseducation.ca/

Genetics Education Canada - Knowledge Organization

Website / No / Free 🗼

Compendium: Genetics Education Canada – Knowledge Organization (GEC-KO): Prenatal and preconception genetics

http://geneticseducation.ca/education-modules/prenatal-genetics/

Website / No / Free

Compendium: Genetics Education Canada – Knowledge Organization (GEC-KO): Adult genetics

http://geneticseducation.ca/education-modules/adult-genetics-2/

Website / No / Free

Compendium: Genetics Education Canada – Knowledge Organization (GEC-KO): Pediatric Genetics

http://geneticseducation.ca/education-modules/pedatric-genetics/

Website / No / Free

Compendium: Genetics Education Canada – Knowledge Organization (GEC-KO):

Cardiogenetics

http://geneticseducation.ca/education-modules/cardiogenetics/

Website / No / Free

#### 2019 02 04:

- 1) Name of Individual(s) Submitting Entry: Shawna Morrison
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

Active educational programs are through GEC-KO Genetics Education Canada – Knowledge Organization <a href="https://www.geneticseducation.ca">www.geneticseducation.ca</a>

#### **Best Practices:**

- Be evidence-based and brief, get to the point quickly
- Keep resources up-to-date and relevant (e.g. provincially or nationally applicable)
- Limit barriers to information access e.g. no sign in to access resources
- Provide resources for point of care
- Integrate into existing education venues
- Workshop format with interactive component
- Engage and listen to stakeholders
  - Be flexible, responsive, continuously evolve
  - Meet clinical needs and questions of stakeholders
- Use Program Logic Model

- Provides clear and purposeful direction, and justification for activities
- · Evaluate improvement in skills when possible

#### RESOURCES AND LINKS:

All of GEC-KO's resources are evidence-based with expert input. GEC-KO is a non-profit organization and supports use of its content by all (e.g. health care practitioners, self-directed learners, educators). All resources are freely available. Permission is hereby granted to reproduce, distribute, and translate copies of content materials provided that (i) credit for source (www.geneticseducation.ca) is acknowledged; and (ii) a link to the original material is provided whenever the material is published elsewhere on the Web.

\*EDUCATION MODULES: Self-directed primary care case-based education modules that can be used by educators or motivated learners, to discuss new advances in genomics and their impact on practice. www.geneticseducation.ca > Education Modules > \_\_\_\_\_

Prenatal and preconception genetics: <a href="http://geneticseducation.ca/education-modules/prenatal-genetics/">http://geneticseducation.ca/education-modules/prenatal-genetics/</a>

Adult genetics: <a href="http://geneticseducation.ca/education-modules/adult-genetics-2/">http://geneticseducation.ca/education-modules/adult-genetics-2/</a>
Pediatric Genetics: <a href="http://geneticseducation.ca/education-modules/pedatric-genetics/">http://geneticseducation.ca/education-modules/pedatric-genetics/</a>

Cardiogenetics: http://geneticseducation.ca/education-modules/cardiogenetics/

- 1. Prenatal Screening Non-Invasive Prenatal Testing (NIPT) and Enhanced First Trimester Screening (eFTS) (Updated June 2018)
- 2. Prenatal Genetic Screening: Common misconceptions and practice tips (Updated Nov 2019)
- 3. Genetics of Autism Spectrum Disorder (Updated June 2018)
- 4. Lynch Syndrome: Hereditary Nonpolyposis Colorectal Cancer Syndrome (Updated June 2018)
- 5. Expanded carrier screening (June 2017)
- 6. Familial hypercholesterolemia (Oct 2016)
- 7. Family history (Nov 2019)
- 8. Long QT Syndrome (Oct 2016)
- 9. Hereditary Breast and Ovarian Cancer syndrome (May 2016)
- 10. Direct-to-Consumer Genetic Testing (May 2016)
- 11. Prenatal Chromosomal Microarray (Nov 2015)
- 12. Consanguinity (Nov 2015)
- 13. Multiple sclerosis (March 2015)
- 14. Alzheimer disease (March 2015)
- 15. Hypertrophic Cardiomyopathy (Jan 2015)
- 16. Factor V Leiden (Dec 2014)
- 17. Hereditary Hemochromatosis (April 2014)

#### \*EDUCATIONAL RESOURCES:

<u>www.geneticseducation.ca</u> >Educational Resources > GEC-KO *on the run* or GEC-KO *Messengers* or Other GEC-KO Resources

http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/

http://geneticseducation.ca/educational-resources/gec-ko-messengers/

http://geneticseducation.ca/educational-resources/gec-ko-resources/

GEC-KO Messengers are comprehensive summaries for healthcare providers on genetic disorders, technologies or topics. Each GEC-KO *on the run* is a concise summary for healthcare providers on a genetic disorder, technology or topic. GEC-KO Messengers and GEC-KO on the run are written by a team that includes genetic counsellors, geneticists, genetic researchers, family physicians and content specialists. All are reviewed by a family physician to be primary care relevant. They are evidence-based and referenced, and feature a 'Bottom line' with recommendations. They were developed as a 'spin-off' of the successful Gene Messengers which were part of the GenetiKit project. Findings from this study were published and can be found in Carroll JC, Wilson BJ, Allanson J, Grimshaw J, Blaine SM, Meschino WS, Permaul JA, Graham ID. GenetiKit: a randomized controlled trial to enhance delivery of genetics services by family physicians. *Fam Pract* 2011; 28(6): 615-23. Other GEC-KO resources include resources that act as a supplement to the core GEC-KO tools including GECKO Messenger, GEC-KO *on the run*, and GEC-KO point of care tools.

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\*POINT OF CARE TOOLS: <a href="www.geneticseducation.ca">www.geneticseducation.ca</a> > Point of care tools > \_select topic\_
Tools on a variety of genomic topics ready to use at the point of care. Intended to facilitate integration of genomic medicine into practice, to help identify and appropriately refer patients who may benefit from genetic services and reassure those at population risk.

- Genetics of autism spectrum disorder: point of care tool includes a road map of possible genetic tests and consultations for the individual with autism spectrum disorder (2017)
- 2. Expanded carrier screening: (2017)
  - a. Point of Care tool #1: Tips to for providers BEFORE ordering expanded carrier screening.
  - b. Point of Care tool #2: Tips to for providers AFTER ordering expanded carrier screening
- 3. Reproductive genetic carrier screening in Canada: (2016)
  - a. Ashkenazi Jewish (AJ) reproductive genetic carrier screening.
  - b. French Canadian reproductive genetic carrier screening
  - c. Reproductive carrier genetic screening for hemoglobinopathies
  - d. Reproductive carrier genetic screening for specific disorders(cystic fibrosis (CF), fragile X syndrome and *FMR1*-related disorders, spinal muscular atrophy(SMA))
- 4. Long QT syndrome: red flags for how to identify LQTS and the individuals who would most likely to benefit from referral to genetics and a cardiac arrhythmia specialist (2016)
- 5. Familial hypercholesterolemia: (2016; updated 2018 Oct)
  - Part I: How to identify Familial Hypercholesterolemia and individuals most likely to benefit from referral to a lipid specialist
  - Part II: Diagnosis of Familial Hypercholesterolemia
- 6. Hypertrophic Cardiomyopathy: Evaluation and Management Tool (2014)
- 7. <u>General Hereditary Cancer Syndrome</u> Triage Tool: Red Flags to identify those with risk of a Hereditary Cancer Syndrome most likely to benefit from a referral to genetics.(2014)
- 8. <u>Hereditary Breast and Ovarian Cancer Syndrome</u> (BRCA1/BRCA2): Hereditary breast and ovarian cancer referral screening tool to identify patients most likely to benefit from referral to genetics. (2014; updated 2019 July)
  - a. This point of care tool has two parts. Part I of this tool is used to predict which individuals should be referred for genetic counselling due to increased risk for a hereditary breast cancer syndrome including but not limited to hereditary breast and ovarian cancer (HBOC) syndrome caused by mutations in BRCA1 and BRCA2 genes. Part II of this tool is used to identify individuals who are at high risk to carry a mutation in BRCA1 or BRCA2 genes.

- 9. <u>Lynch Syndrome</u>: Red Flags to identify those at high risk of Lynch Syndrome most likely to benefit from a referral to genetics. (2014)
  - This point of care tool has two parts. The first part contains three questions
    for your patient that will better help you stratify his/her risk for hereditary
    colorectal cancer and to identify those that would benefit from a referral for
    genetics consultation. Part II contains further personal and family history Red
    Flags to identify those at high risk of LS most likely to benefit from a referral to
    genetics.
- 10. <u>Hereditary Renal Cell Cancers</u>: Triage point of care tool: Practical guide to identify those patients most likely to benefit from referral to genetics (2014)
- 11. <u>Hereditary Hemochromatosis:</u> Triage and Surveillance point of care tool (2014; updated Jan 2019)
- 12. Factor V Leiden: Genetic Testing and Management Tool (2014)
- 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.

We have presented on GEC-KO and materials we've developed in the past – at the in-person meeting and on a call – the International Working Group – however always happy to present them

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.

#### Not at this time

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.

#### Not at this time

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).

#### Depends on objectives

7) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Yes. Upon approval of the resource by the GEC-KO team, a link can be posted on our website, www.geneticseducation.ca. Also, we can include the relevant resource when we present at various continuing education meetings (local, provincial, national and international venues).

## GenomePlus Pty Ltd, Australia

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Nicholette Conway
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

GenomePlus partner and collaborate with a network of education specialists, genomic research and disease specialists from Australia and internationally to provide clients with the education and insights appropriate for their work practice. We recognise that genomic literacy is critical for the integration of genomics into healthcare practice, not only for healthcare practitioners but those in the pharmaceutical and medical device industries, allied health and ancillary business such as life insurance, banking, insurance.

- 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: **No**
- 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.

Not in 2018, potentially in 2019. We are still in a start up phase, so at the moment we have limited resources. We hope as we grow we can give back to the group.

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.

#### Not in 2018, potentially in 2019.

 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).

## **Genomics Forum, American Public Health Association (APHA)**

Compendium: Genomics Forum, American Public Health Association (APHA) <a href="https://www.apha.org/apha-communities/forums/genomics-forum">https://www.apha.org/apha-communities/forums/genomics-forum</a> Website / No / Free

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Tung-Sung Tseng, DrPH, MS, CHES/MCHES
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

Genomics is increasingly relevant to assuring the public's health. Developments in biomedical science and technology are shedding new light on how the "conditions" or environments in which people live, work, and play — be they physical, chemical, ancestral, psychological, or social — affect our genomes, the expression of genes, and ultimately our health individually and collectively.

The Genomics Forum will engage the public health community to promote workforce competency in genomics, including an improved understanding of the relevance and impact of genomics on public health. We will engage public health and health care communities and others in projects and activities that increase the awareness, knowledge, and skills of genetic services as these services relate to:

- The ethical, legal, and social issues surrounding genetics/ genomics/ epigenetics;
- The relationships and relevance of genomics to public health, health care, and health disparities;
- Professional and public education; and
- Other areas as generated by Forum members

We are continuing to increase our visibility and activities through the APHA trough awards, call for abstracts, forum meetings, policy statements, newsletters, and website:

- <a href="https://www.apha.org/apha-communities/forums/genomics-forum">https://www.apha.org/apha-communities/forums/genomics-forum</a>
- https://aphagenomicsforum.wixsite.com/apha
- 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.

Yes, we would be interested in presenting our forum activities in the conference meeting. We'd be happy to share our website, newsletters and any updates.

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.

#### Tentatively.

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.

Yes, we are looking forward to further collaborations, and would prefer a 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).
  - Develop an educational guideline for health professions.
  - Built an collaboration through social media integrating educational resource, funding opportunity, research and services projects information
- 7) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Yes. We have more than 200 Genomic Forum members of the American Public Health Association (APHA). it would be feasible to distribute links to resources to them via email. We also can disseminate some policy document through APHA website.

## **Global Genomic Medicine Collaborative (G2MC)**

2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Bruce R. Korf, MD, PhD
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).
  - Our main effort so far has been the G2MC grand rounds, which is done using Webex and targets an international audience. This has been on hiatus the past 6 months but is restarting early this new year. We are also creating a survey of genetics professional education in the various countries represented in G2MC.
- 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.
  - Dr. Korf has already done so, and can provide updates in the future.
- 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.
  - We would be glad to collaborate on an ISCC 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.
  - We are glad to do so with regard to global issues in education on genomic medicine.
- 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).

## **Health Education England Genomics Education Programme**

Compendium: Health Education England Genomics Education Programme

www.genomicseducation.hee.nhs.uk

Website / No / Free

Compendium: Health Education England Genomics Education Programme: Genomics Courses <a href="https://www.genomicseducation.hee.nhs.uk/education/?swoof=1&product\_cat=online-courses">https://www.genomicseducation.hee.nhs.uk/education/?swoof=1&product\_cat=online-courses</a> Course / Yes / Free

Compendium: Health Education England Genomics Education Programme: Condition Factsheets

https://www.genomicseducation.hee.nhs.uk/doc-type/genetic-conditions/

Website / No / Free

Compendium: Health Education England Genomics Education Programme: Cinical Tools <a href="https://www.genomicseducation.hee.nhs.uk/genomics-in-healthcare/">https://www.genomicseducation.hee.nhs.uk/genomics-in-healthcare/</a>
Website / No / Free

Compendium: Health Education England Genomics Education Programme: Multimedia Genomics Education

https://www.genomicseducation.hee.nhs.uk/education/?swoof=1&product\_cat=videos Multimedia / No / Free

### 2020\_02\_25:

- 1) Name of Individual(s) Submitting Entry: Dr. Michelle Bishop
- List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.
  - Master's framework in Genomic Medicine
  - Online courses\* topics range from fundamentals in genomics to specific resources for different clinical areas such as tumor assessment for genomic testing
  - Condition factsheets \*
  - Clinical tools (e.g. family history tool)\*
  - Multimedia assets available on Vimeo and Flickr education and training purposes\*
  - Board Games\*

For more information and links please see www.genomicseducation.hee.nhs.uk

3) Would you or someone affiliated with your group be interested in presenting your 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.

We would be interested in presenting our entire programme of work. As we are based in the UK, this would most likely be via a plenary call. This could be

## presented by Dr. Anneke Seller (Scientific Director) or Dr. Michelle Bishop (Education Lead).

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

Not at this moment, although we would be interested to hear of any possible collaborations.

5) Would you or someone in your group 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.

We are more than happy to do this and could provide a perspective from the UK. This could be presented by Dr. Michelle Bishop (Education Lead) or Dr. Anneke Seller (Scientific Director).

6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

We don't have a system in which to promote resources that have been developed outside of the UK – however we are looking at ways in which we can do this in the future.

 Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

None at this time

## Implementing Genomics in Practice (IGNITE) Network

Compendium: Implementing Genomics in Practice (IGNITE) Network: IGNITE Toolbox: Implementation of genomics in healthcare: Genomic medicine resources for clinicians and researchers

https://dcricollab.dcri.duke.edu/sites/NIHKR/Pages/IGNITEToolbox.aspx Website / No / Paid

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Geoffrey Ginsburg and Tejinder Rakhra-Burris
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

IGNITE is an NIH-funded network dedicated to supporting the implementation of genomics in healthcare. The first iteration of the IGNITE Network established the Provider Adoption, Barriers, and Education working group to promote the adoption of genomic medicine in practice by identifying and addressing implementation barriers experienced by healthcare providers and share and disseminate educational resources, strategies and related data from IGNITE Network sites to facilitate collaboration and information sharing within the Network. The Network also contributed to the evidence base of patient, provider, and student/trainee education supporting clinical implementation of genomic medicine and pharmacogenomics.

The IGNITE Toolbox (located on the IGNITE Website at <a href="https://ignite-genomics.org">https://ignite-genomics.org</a>) was created to disseminate methods and best practices developed by the IGNITE Network in order to advance the implementation of genomics in healthcare and provides genomic medicine resources for clinicians and researchers. The IGNITE Toolbox houses both unique implementation resources that were created by the first iteration of the IGNITE Network members and affiliate sites and also links to other helpful resources available on the web.

To continue research that will provide evidence that genomic medicine will improve patient outcomes, the second iteration of the IGNITE Network is focused on developing and conducting a few large network-wide genomic medicine pragmatic clinical trials, which will allow for bigger, more efficient clinical trials and help researchers and clinicians understand what to expect in real-world clinical settings.

In addition to the tools developed and aggregated within the first iteration of IGNITE, the IGNITE Toolbox is linked to the NIH Collaboratory Knowledge Repository, a searchable collection of resources related to pragmatic clinical trials compiled by the NIH Collaboratory Coordinating Center (https://rethinkingclinicaltrials.org)

- 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? Yes. 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? Yes. 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).

None at this time.

## International Society of Nurses in Genetics (ISONG)

Compendium: International Society of Nurses in Genetics (ISONG)

https://www.isong.org/ Website / No / Free

Compendium: International Society of Nurses in Genetics (ISONG): Genomics Education

Webinars

https://www.isong.org/page-1325047

Website / Yes / Paid

#### 2019 02 04:

1) Name of Individual(s) Submitting Entry: Elena Flowers

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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

We offer webinars available to the public: <a href="http://www.isong.org/ISONG\_webinars.php">http://www.isong.org/ISONG\_webinars.php</a>

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.

Yes – I can present or can ask the Chair of the Education Committee.

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.

Yes – through my faculty appointment, I teach a series of courses on genomics to advanced practice students. Much of this content is delivered in an online format. I'd be interested in scaling up the course across other institutions.

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.

Yes, and prefer face to face. Happy to be a facilitator.

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).

## International Society of Psychiatric Genetics (ISPG)

Compendium: International Society of Psychiatric Genetics (ISPG)

www.ispg.net Website / No / Free

Compendium: International Society of Psychiatric Genetics (ISPG): Training Module for Residents on Psychopharmacogenomics

http://www.nncionline.org/course/progressive-case-conference-psychopharmacogenomics/ Website / No / Free

Compendium: International Society of Psychiatric Genetics (ISPG): Training Module for Residents on Autism Genetics

http://www.nncionline.org/course/autism-spectrum-disorder/

Website / No / Free

Compendium: International Society of Psychiatric Genetics (ISPG): What Should a Psychiatrist Know About Genetics? Review and Recommendations From the Residency Education Committee of the International Society of Psychiatric Genetics.

https://www.ncbi.nlm.nih.gov/pubmed/30549495

Article / No / Free

#### 2020\_02\_25:

- 1) Name of Individual(s) Submitting Entry: John Nurnberger
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

We have a Residency Education Committee (current Chair Gwyneth Zai, U. of Toronto). We have developed an outline of the genetics knowledge we believe every psychiatrist should have, and this is summarized in two publications (Nurnberger et al, J. Clin. Psychiat., October 2019 and Besterman et al, JAMA Psychiat, January, 2020). We also have links on thour website (<a href="www.ispg.net">www.ispg.net</a>) to two learning modules that are particularly pertinent (one on genetic testing for neurodevelopmental disorders and one on pharmacogenetic testing). These modules were designed in conjunction with the National Neuroscience Curriculum Initiative (funded by NIMH) and are available at <a href="mailto:nncionline.org">nncionline.org</a>. There is also a brief article on polygenic risk scores available on that website.

We have presented these ideas at several meetings, including the American College of Neuropsychopharmacology (ACNP) meeting, Orlando, December 2019 and the Psych Congress, San Diego, October 2019. Reception has generally been very positive.

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.

## I would be happy to present our program during a call.

- 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).

We are presently undertaking a survey of our membership to assess the level of genetic education in residency training programs in the US and in other countries to which our members belong. I would be happy to report the results when we have them.

## **National Cancer Institute (NCI)**

Compendium: National Cancer Institute (NCI): PDQ Cancer Genetic Summaries <a href="http://www.cancer.gov/publications/pdq/information-summaries/genetics">http://www.cancer.gov/publications/pdq/information-summaries/genetics</a>
Website / No / Free

Compendium: National Cancer Institute (NCI): NCI Dictionary of Genetic Terms <a href="https://www.cancer.gov/publications/dictionaries/genetics-dictionary">https://www.cancer.gov/publications/dictionaries/genetics-dictionary</a> Website / No / Free

### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Kathleen Calzone, PhD, RN, AGN-BC, FAAN, Research Geneticist, NCI, Center for Cancer Research, Genetics Branch
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

**Programs:** 

Title	Website	Description
NCI Summer	cpfp.cancer.gov/summer-	Includes two courses:
Curriculum in Cancer	<u>curriculum</u>	<ul> <li>Principles and Practice of</li> </ul>
Prevention		Cancer Prevention
		Control and Molecular
		Prevention

#### **Resources:**

Title	Website	Description
National Cancer Institute	https://www.cancer.gov/	Main website for all information and resources from the National Cancer Institute. Includes information on cancer for health professional and lay public as well as information on research, grants, training, news and events inclusive of scholarly meeting.

PDQ Cancer Genetic	http://www.cancer.gov/publications	The PDQ cancer genetic
Summaries	/pdq/information-	summaries are an online
	summaries/genetics	evidence based cancer genetic
		summaries developed and
		maintained by an
		interprofessional editorial board.
		These include the follow topics:
		Cancer Genetics Overview
		<ul> <li>Cancer Genetics Risk</li> </ul>
		Assessment and Counseling
		<ul> <li>Genetics of Breast and</li> </ul>
		Gynecologic Cancers
		<ul> <li>Genetics of Colorectal</li> </ul>
		Cancer
		Genetics of Endocrine and
		Neuroendocrine Neoplasias
		Genetics of Kidney Cancer
		(Renal Cell Cancer)
		<ul> <li>Genetics of Prostate</li> </ul>
		Cancer
		<ul> <li>Genetics of Skin Cancer</li> </ul>
NCI Dictionary of	https://www.cancer.gov/publications/di	The NCI Dictionary of Genetics
Genetic Terms	ctionaries/genetics-dictionary	Terms contains technical definitions
Geneue Terms	Chonanes/genetics-dictionary	for more than 200 terms related to
		genetics.
		yourus.

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.

The Cancer Genetics PDQ summaries are worth reviewing for the ISCC constituency. Robin Juthe the Editorial Board Manager and Mary Daly, MD, PhD the Board Editor-In-Chief would likely both be willing to present.

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.

NCI already co-leads G3C and the Short Course

- 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.
  - Happy to describe the MINC project and MINC website-not clear that this is best practice and is nursing specific but is driven by the evidence and could be part of a broader discussion.
- 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).

Consider ISCC sponsored presentation at each of the organizations national meetings who are members of ISCC.

# National Center for Advancing Translational Sciences (NCATS), Office of Rare Diseases Research (ORDR)

2019 02 04:

- 1) Name of Individual(s) Submitting Entry: Eric Sid
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

The Office of Rare Diseases Research (ORDR) NCATS' programs and initiatives support the translation of rare diseases research across basic, translational and, clinical sciences, to accelerate and advance diagnosis and new therapeutics for the treatment of rare diseases. Many of these initiatives are for rare genetic diseases, some of which are particularly focused on on education for patients, patient organizations and the general public.

#### NCATS programs/events directly involving genomic education:

\*Genetic And Rare Disease (GARD) Information Center\* <a href="https://rarediseases.info.nih.gov">https://rarediseases.info.nih.gov</a>

GARD is a publicly accessible web-based educational resource that currently includes plain-language information on ~6,500 rare diseases and contact center staffed by information specialists trained in directing and informing public members about resources for patients with rare diseases.

# \*NCATS Toolkit for Patient-Focused Therapy Development <a href="https://rarediseases.info.nih.gov/toolkit">https://rarediseases.info.nih.gov/toolkit</a>

The Toolkit is a living website that shares best practices and resources identified by and targeted towards patient organizations working to support research and therapy development.

# \*Rare Disease Registry (RaDaR) Program <a href="https://ncats.nih.gov/radar">https://ncats.nih.gov/radar</a>

RaDaR is an educational platform that will provide stepwise instructions as well as tools, templates, and links to external resources that aims to help instruct patient organizations on how to promote research through organizing their community via registries and connecting to potential researchers.

#### \*Rare Disease Day at NIH – Annual Event – Feb. 28, 2019 https://ncats.nih.gov/rdd

This public event brings together patients, advocates, researchers, clinicians, industry members, regulators, and legislators together that are impacted by or work on rare diseases. This event is free and held in-person on the NIH campus, or can be viewed online.

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.

Yes; Patient engagement and partnerships with patient organizations; NCATS/Office of Rare Diseases Research; No preference.

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.

Unfortunately, we currently do not have staff available to take on new projects but may be able to collaborate on programs overlapping with our existing initiatives.

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.

Given that we are new to the ISCC, not at this time.

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).

The diagnostic odyssey in receiving timely diagnosis for patients with a genetic or rare disease, gene therapies and genome editing, the building of plain language resources for consumer-level health information for a patient audience, and informatics-data science innovations that can enable operationalizing genomics information.

## **National Center for Biotechnology Information (NCBI)**

#### 2019 02 04:

- 1) Name of Individual(s) Submitting Entry: Brandi Kattman & Rana Morris
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

We have and currently are offering an in-person workshop for Clinicians and genetic-disease interested folks – a real-world, case-based, student focused active learning exercise to help people find resources for clinical decision support and disease/disorder molecular etiology.

We are also offering a couple of in-person workshops targeted for translational science researchers and helping them learn how to use NCBI resources in their genetic/genomic discovery.

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.

Not sure we have "best practices", so no....not at this point – but maybe in the future.

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.

Unfortunately we do not have the time to do this at this point.

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.

Not sure we have discrete "best practices", so no....not at this point.

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).

We'd love to chat with participants at this in-person meeting and come up with some ideas that may be useful.

# **National Eye Institute (NEI)**

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Santa Tumminia
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

The NEI supports a variety of grants, cooperative agreements, clinical trials and contracts related to genetics and genomics of both rare and complex inherited eye diseases, but we do not currently support education-based projects.

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.

We don't have anything to present in this arena at this time.

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.

Unfortunately, we do not have staffing to support this activity.

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.

Not at this time.

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).

None at this time.

### National Human Genome Research Institute (NHGRI)

Compendium: National Human Genome Research Institute (NHGRI): Global Genetics and Genomics Community (G3C) Interactive Genomics Cases

http://genomicscases.net

Multimedia / No / Free

Compendium: National Human Genome Research Institute (NHGRI): Method for Introducing a New Competency: Genomics (MINC): Ways to Integrate Genomics into Practice <a href="http://genomicsintegration.net/">http://genomicsintegration.net/</a>

Multimedia / No / Free

Compendium: National Human Genome Research Institute (NHGRI): Webinars for Health Insurers and Payers: Understanding Genetic Testing <a href="http://www.genome.gov/insurersgenetictesting/">http://www.genome.gov/insurersgenetictesting/</a>

Website / No / Free

Compendium: National Human Genome Research Institute (NHGRI): Frequently Asked Questions About Genetic and Genomic Science <a href="https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics">https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics</a> Website / No / Free

Compendium: National Human Genome Research Institute (NHGRI): Polygenic Risk Scores <a href="https://www.genome.gov/Health/Genomics-and-Medicine/Polygenic-risk-scores">https://www.genome.gov/Health/Genomics-and-Medicine/Polygenic-risk-scores</a> Website / No / Free

Compendium: National Human Genome Research Institute (NHGRI): The Talking Glossary of Genetic Terms

https://www.genome.gov/genetics-glossary

Website / No / Free

Compendium: National Human Genome Research Institute (NHGRI): 15 Ways Genomics Influences Our World

https://www.genome.gov/dna-day/15-ways

Website / No / Free

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Donna Messersmith, PhD, Provider Education Specialist, Education and Community Involvement Branch, Division of Genomics and Society, NHGRI
- List and briefly describe your organization's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

### "Global Genetics and Genomics Community "(G3C) genomics cases

(<a href="http://genomicscases.net">http://genomicscases.net</a>): Unfolding interactive simulated cases that demonstrate how genetics and genomics link to health and illness. Students and practicing healthcare providers address the multi-dimensional needs of patients through self-guided, videotaped "patient-

provider" interview simulations. Supplemental educational activities expand upon genetic/genomic learning concepts. Videotaped expert commentaries by specialists are provided for many cases.

"Genetics/Genomics Competency Center" (G2C2) genomics education repository (http://genomicseducation.net/): Searchable collection of general and discipline-specific genomics information and educational resources for genomic healthcare educators and providers. Resources are searchable by terms, topics, disciplines, or genomic competencies (http://genomicseducation.net/competency).

Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC) (http://www.genome.gov/ISCC): Medical and clinical educators from professional societies and related organizations, representing multiple professional disciplines, share their approaches and resources for genomic education. Project groups address genomic educational gaps in resources, methods, and target audiences. The Education and Community Involvement Branch of NHGRI provides staff support. The current ISCC Co-Chairs are Richard Haspel, M.D., Ph.D., Beth Israel Deaconess Medical Center and Carla Easter, Ph.D., Branch Chief, Education and Community Involvement Branch, NHGRI. Donna Messersmith, PhD, Education and Community Involvement Branch, NHGRI, is the Project Group Coordinator.

#### Method for Introducing a New Competency: Genomics (MINC)

(<a href="http://genomicsintegration.net/">http://genomicsintegration.net/</a>):Toolkit based on the efforts of Magnet® hospital nurses that provides resources for nurses integrating genomics into practice. Includes video testimonials from health administrators and educators describing how they overcame barriers as they developed the necessary genomics knowledge to offer personalized care to their patients.

Webinars for Health Insurers and Payers: Understanding Genetic Testing (ISCC Insurer Education Working Group) (http://www.genome.gov/insurersgenetictesting/): A webinar series to prepare insurers/payers for understanding genetic testing strategies, interpretations, outcomes and patient care, to prepare insurers to make sound decisions regarding the healthcare activities of their insured. Produced by ISCC and BCBSA collaboration.

#### **NHGRI Short Course in Genomics for Healthcare Professionals**

(https://www.genome.gov/shortcourse/healthprofessionals/): This multi-day course offered participants the opportunity to learn best practices from leaders in genomics education and practice for health professionals. In past years, the course has been targeted to nurses, nurse practitioners, physician assistants and the faculty who educate these health professionals. The course has focused on integrating genomics into existing curricula and successful models in which genetics/genomics have been integrated into practice.

My Family Health Portrait Tool (https://phgkb.cdc.gov/FHH): This web-based tool helps users organize family health history information into a family tree and chart which can then be printed out for their health care provider and family members. Risk assessment tools for diabetes and colon cancer are also available.

#### Frequently Asked Questions About Genetic and Genomic Science

(<a href="https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics">https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics</a>): Explanations of complex genetic concepts and research techniques for a non-scientific audience. Includes information about Genetic Counseling, Genetic Disorders, Genetic Testing, Pharmacogenomics, and related topics.

Fact Sheets on Science, Research, Ethics and the Institute (https://www.genome.gov/about-genomics/fact-sheets): An overview of NHGRI, an exploration of the social implications of genetic research, and explanations of complex genetic concepts and research techniques intended for a non-scientific audience.

Polygenic Risk Scores (https://www.genome.gov/Health/Genomics-and-Medicine/Polygenic-risk-scores): Explanations through illustrations and videos of polygenic risk scores, which are one way by which people can learn about their risk of developing a disease, based on the total number of changes related to the disease.

<u>GenomeTV</u> (<u>https://www.genome.gov/video</u>): Videos that include lectures, news documentaries, and full video collections of meetings that tackle the research, issues and clinical applications of genomic research.

<u>National DNA Day</u> (<a href="https://www.genome.gov/dna-day">https://www.genome.gov/dna-day</a>): National DNA Day is a unique day when students, teachers and the public can learn more about genetics and genomics! The day commemorates the completion of the Human Genome Project in April 2003, and the discovery of DNA's double helix in 1953.

Issues in Genetics (https://www.genome.gov/about-genomics/policy-issues): Topics from the Policy Branch of the Division of Policy, Communications and Education include Coverage and Reimbursement of Genetic Tests, Genetic Discrimination, Regulation of Genetic Tests, Privacy in Genomics, Informed Consent, Genomics and Health Disparities, and Gene Editing.

Division of Genomic Medicine (https://www.genome.gov/about-nhgri/Division-of-Genomic-Medicine): Plans, directs and facilitates multi-disciplinary research to identify genetic contributions to human health and to advance approaches for the use of genomic data to improve diagnosis, treatment and prevention of disease; through research grants, research training grants, and contracts.

**Genome: Unlocking Life's Code** (<a href="https://unlockinglifescode.org/">https://unlockinglifescode.org/</a>): Companion website to the Smithsonian/NHGRI science museum exhibit; several modes to explore online, including a virtual visit; learning resources for teachers and students; topics on genomic medicine, cancer genomics, and much more.

The Talking Glossary of Genetic Terms (https://www.genome.gov/genetics-glossary): Website providing definitions of terms and concepts used in genetic research. In addition to definitions, specialists in the field of genetics share their descriptions of terms, and many terms include images, animation and links to related terms.

"15 Ways Genomics Influences Our World" (https://www.genome.gov/dna-day/15-ways): Website providing fifteen ways in which genomics influences different areas of science and health, including Rare Genetic Disease, Noninvasive Prenatal Genetic testing, Human Origins and Ancestry, and Pharmacogenomics.

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.

Staff from NHGRI's Education and Community Involvement Branch can present the resources described above.

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.

Yes.

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.

Yes, staff from NHGRI's Education and Community Involvement Branch can lead discussions on a range of genomic education topics.

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).

### National Institute on Alcohol Abuse and Alcoholism (NIAAA)

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Hemin Chin
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

The NIAAA supports a variety of grants, cooperative agreements, clinical trials and contracts related to genetics, genomics, and epigenomics of alcohol use disorders, but we do not currently support education-based projects.

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.

We don't have anything to present in this arena at this time.

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.

We do not have staffing to support this activity.

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.

Not at this time.

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).

None at this time

# **Eunice Kennedy Shriver** National Institute of Child Health and Human Development (NICHD)

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Melissa Parisi
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

We fund a variety of grants, cooperative agreements, and contracts related to genomics in our child health and related arenas, but we don't have any explicitly education-based projects.

We do fund a face-to-face and distance learning project (R25) for fellows interested in rare diseases research, which includes some modules on study design for such populations, but genomics is not a focus of the program. We also fund the David W. Smith Workshop on Malformations and Morphogenesis via an R13 mechanism, which annually convenes a group of genetics providers and trainees to present findings on genetic syndromes. Neither of these activities has any web-based materials to share more broadly.

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.

We don't have anything in this arena to present.

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.

Melissa Parisi is interested in the possibility of adding more pediatric-focused genomics cases to G3C, in particular given her role as serving as the NICHD liaison to the American Academy of Pediatrics Council on Genetics, (AAP COG) where this resource was discussed. (The AAP has a project known as "Think Genetics" which grew out of a resource that is already on g2c2.) She also encouraged her colleagues on the AAP COG to submit their compendium entry for the ISCC (Leah Burke and Emily Chen).

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.

No, not as relevant to NICHD.

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).

We at NICHD would be very interested in encouraging more modules and educational activities around the use of pharmacogenomics in the pediatric setting. Both NICHD and NHGRI have identified this as a gap in knowledge/education, so we would welcome ideas on how to partner with groups such as PharmGKB and CPIC in this arena.

# National Institutes of Health, Clinical Center Nursing Department (NIH/CC Nursing)

2019 02 04:

- Name of Individual(s) Submitting Entry: Dr. Gwenyth R. Wallen, Chief Nurse Officer, Sharon Flynn, Nurse Practitioner, Nursing Research and Translational Science, Georgie Cusack, Director of Education and Patient Safety at NHLBI and Adjunct Nurse Leader, Nursing Research and Translational Science
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

Tiered genetic/genomic nursing competency required for all bedside nurses in the Clinical Center Nursing Department\*

Course: Introduction to Genetics and Genomics in Health Care (in-person course only, open to anyone interested in attending with a focus on RNs, nurse practitioners, and physician's assistants)

Course: Intermediate Genetics and Genomic in Health Care (in-person course only, open to anyone interested in attending with a focus on RNs, nurse practitioners, and physician's assistants)

Facilitator's Guide to Genetic & Genomic Competency Validation\*

Participant's Guide to Genetic & Genomic Competency Validation\*

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.

If there is an interest in our genomic nursing competency work, we would be interested in presenting

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.

#### Maybe, if it pertained to clinical research nursing

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.

### Developing genetic/genomic nursing competencies

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).

Electronic pedigree best practices, especially interested when the RN is collecting the pedigree versus another health care team member

# **National Society of Genetic Counselors (NSGC)**

Compendium: National Society of Genetic Counselors (NSGC): The Formation of Implicit Biases and Practical Strategies to Address Them <a href="https://www.nsgc.org/p/bl/et/blogid=59&blogaid=1150">https://www.nsgc.org/p/bl/et/blogid=59&blogaid=1150</a>
Course / Yes / Free

#### 2020\_02\_25:

- 1) Name of Individual(s) Submitting Entry: Rachel Mills
- 2) List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

Course Name	Link	Number of Contact Hours Available	Contact Hours Available Until
The Formation of Implicit Biases and Practical Strategies to Address Them	Learn more	3.91 Category 1 Contact Hours	11/23/2021
Integrating Pharmacogenomic Testing into Clinical Practice	Learn more	3.51 Category 1 Contact Hours	10/1/2021
Update on Common Conditions: Epilepsy, Diabetes, Autism, Alzheimer's Disease	Learn more	3.98 Category 1 Contact Hours	7/23/2021
Ethical, Legal and Social Challenges with Genetic Testing	Learn more	3.61 Category 1 Contact Hours	5/31/2021
Direct-to-Consumer Genetic Testing 201: Technology, Complex Cases and Resources	Learn more	5.11 Category 1 Contact Hours	12/16/2020
Evidence-based Practice: What It Is and Why It Matters	Learn more	3.88 Category 1 Contact Hours	10/12/2020
New Frontiers in Genetic Technology	Learn more	5.06 Category 1 Contact Hours	5/15/2020
Genetic Counseling Specialties Review: Cancer, Prenatal, Personalized and Precision Medicine	Learn more	4.98 Category 1 Contact Hours	5/15/2020

NextGen Sequencing A to Z	Learn more	4.51 Category 1 Contact Hours	05/13/2021
Psychiatric Genetics across Genetic Counseling Practice Settings	Learn more	3.45 Category 1 Contact Hours	05/29/2021
A Psychosocial Approach to Genetic Counseling: Translation from Theory to Skills	Learn more	4.33 Category 1 Contact Hours	11/5/2020
Revisiting Research: Improving Your Skills to Integrate Research into Your Role	Learn more	3.57 Category 1 Contact Hours	10/11/2020
What the Specialized Genetic Counselor Needs to Know about Other Areas of Genomic Medicine	Learn more	4.63 Category 1 Contact Hours	05/01/2020
Variant Interpretation in the Era of WES/WGS	Learn more	3.60 Category 1 Contact Hours	05/01/2020
Career Advancement and Professional Development	Learn more	9.63 Category 1 Contact Hours	05/18/2021
Medical Ethics: Mitigating Genetic Counselor Conflict of Interest and Legal Compliance	Learn more	1.0 Category 1 Contact Hours	05/01/2020
2018 Annual Conference Recordings	Learn More	Up to 62.39 Category 1 Contact Hours	2/1/2021

3) Would you or someone affiliated with your group be interested in presenting your 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.

Yes; we have multiple members, myself included, who would be happy to present on a variety of topics if there is interest from ISCC members.

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

Not at this time

5) Would you or someone in your group 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.

Not at this time

6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Yes; we have various email listservs for the membership as well as Special Interest Groups for members of certain specialties.

7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

## **Oncology Nursing Society (ONS)**

Compendium: Oncology Nursing Society:

https://www.ons.org/ https://www.ons.org/learning-libraries/precision-oncology

Website / No / Free

Compendium: Oncology Nursing Society: Genomic Testing in Cancer Care <a href="https://www.ons.org/webinars/genomic-testing-cancer-care-recorded-webinar">https://www.ons.org/webinars/genomic-testing-cancer-care-recorded-webinar</a> Website / Yes / Free

Compendium: Oncology Nursing Society: It's In the Genes: Understanding Genetics and Genomics in Oncology

https://www.ons.org/webinars/its-genes-understanding-genetics-and-genomics-oncology-

recorded-webinar Website / Yes / Free

Compendium: Oncology Nursing Society: Hereditary Cancer Genetics – ONS Congress <a href="https://www.ons.org/podcasts/episode-56-hereditary-cancer-genetics-ons-congress">https://www.ons.org/podcasts/episode-56-hereditary-cancer-genetics-ons-congress</a> Multimedia / Yes / Free

Compendium: Oncology Nursing Society: Understanding Genomics in Oncology Nursing <a href="https://www.ons.org/podcasts/episode-39-understanding-genomics-oncology-nursing">https://www.ons.org/podcasts/episode-39-understanding-genomics-oncology-nursing</a> Multimedia / No / Free

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Erin Dickman and Lisa Kennedy Sheldon
- 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/).
  - It's in the Genes: Understanding Genetics and Genomics Webinar
  - Genomic Testing in Cancer Care Webinar
  - Podcasts: What You Need to Know About At-Home Genetic Testing
  - Masny, A., Jenkins, J., Calzone, Kathleen (2010) Genetics and Genomics in Oncology Practice Publication. Pittsburgh, PA: Oncology Nursing Society.
  - Clinical Journal of Oncology Nursing articles written on genetics and genomics
  - Genomics Advisory Board initiated in May 2019
  - Precision Oncology Learning Library
  - ONS Voice articles: <u>Testing in the Era of Precision Oncology</u> and additional articles on genetics and genomics
- 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.

We would be happy to present our current resources and plans for our genetics/genomics work on a call.

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.

We are very interested in contributing to a project team, but not leading one at this time.

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.

We have assembled a panel of nursing experts to help us determine priority education topics but have not yet established their interest in speaking. Once we have flushed out our plan, we may be interested in starting a discussion around these priority areas. We will keep the committee updated.

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).

Create an oncology focused point of care tool to assist HCPs interpret test results, educate their patients, and choose the most appropriate treatment options based on findings.

# The Jackson Laboratory

Compendium: The Jackson Laboratory: Hereditary cancer syndromes: Are your patients at risk? https://learn.education.jax.org/browse/hpe/cme/courses/hcop

Course / Yes / Free

Compendium: The Jackson Laboratory: Genomics Education and Learning

https://www.jax.org/education-and-learning

Website / No / Free

Compendium: The Jackson Laboratory: Direct-To-Consumer Genetic Testing for Breast Cancer Risk. <a href="https://www.jax.org/education-and-learning/clinical-and-continuing-education/cancer-resources/breast-cancer-direct-to-consumer-genetic-testing">https://www.jax.org/education-and-learning/clinical-and-continuing-education/cancer-resources/breast-cancer-direct-to-consumer-genetic-testing</a>
Website / No / Free

Compendium: The Jackson Laboratory: Shared Decision Making about Tumor Testing. <a href="https://www.jax.org/education-and-learning/clinical-and-continuing-education/tumor-testing/sdm">https://www.jax.org/education-and-learning/clinical-and-continuing-education/tumor-testing/sdm</a> Website / No / Free

Compendium: The Jackson Laboratory: Immune Checkpoint Inhibition Biomarkers. <a href="https://www.jax.org/education-and-learning/clinical-and-continuing-education/tumortesting/immunotherapy-biomarkers">https://www.jax.org/education-and-learning/clinical-and-continuing-education/tumortesting/immunotherapy-biomarkers</a>

Website / No / Free

Compendium: The Jackson Laboratory: Cascade Screening Infographic. <a href="https://www.jax.org/education-and-learning/clinical-and-continuing-education/cancer-resources/cascade-screening-infographic">https://www.jax.org/education-and-learning/clinical-and-continuing-education/cancer-resources/cascade-screening-infographic</a>
Website / No / Free

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Kate Reed and Emily Edelman
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

#### **Online Courses**

Free, self-directed programs for continuing education credit.

#### **Hereditary Cancer Syndromes: Are Your Patients at Risk?**

Practice identifying patients most appropriate for cancer genetic testing, choosing the right test, and using the results to develop a management plan.

<sup>\*</sup>All are appropriate for inclusion in G2C2 and many already are

#### **Collecting Family History**

Practice asking the right questions to elicit enough information to assess family history disease risk and get tools to implement your skills.

Access CME Module | Access CNE Module

#### **Identifying Red Flags and Patterns That Increase Risk**

Practice identifying risk factors in case scenarios and receive tools to help make this task easy to implement in your practice.

Access CME Module | Access CNE Module

#### **Categorizing Cancer Risk**

Analyze family histories and classify patients' risk into average, increased (moderate), or high risk for cancer.

Access CME Module | Access CNE Module

#### **Using Family History to Inform Management**

Practice determining appropriate management based on family history risk stratification.

Access CME Module | Access CNE Module

#### **Pretest Decisions and Counseling**

Practice deciding when and if genetic testing is appropriate given a patient's clinical and personal context.

**Access CME Module | Access CNE Module** 

#### **Genetic Testing Technology**

Practice weighing the benefits, risks, and limitations of different tests within specific patient contexts.

**Access CME Module | Access CNE Module** 

#### **Genetic Testing for Breast Cancer Risk**

Practice evaluating how well a particular genetic test assesses breast cancer risk and the potential impact of testing on patient outcomes.

Access CME Module | Access CNE Module

#### **Genetic Testing for Colorectal Cancer Risk**

Practice evaluating the fit between a patient's history and a particular genetic test for hereditary colorectal cancer syndromes.

Access CME Module | Access CNE Module

#### **Genetic Testing Process**

Familiarize yourself with the steps involved in ordering genetic testing for hereditary cancer risk.

Access CME Module | Access CNE Module

#### **Interpreting Genetic Testing Results**

Practice interpreting genetic testing results within a patient's specific context.

Access CME Module | Access CNE Module

**Precision Medicine for Your Practice: Expanded Carrier Screening** 

Practice facilitating shared decision making and interpreting results for expanded carrier screening with case based scenarios.

**Access CME Module | Access CNE Module** 

Precision Medicine for Your Practice: Prenatal Cell-Free DNA Screening Learn about the benefits and limitations of cell-free DNA screening in prenatal care. Access CME Module | Access CNE Module

Precision Medicine for Your Practice: Exploring Somatic Cancer Panel Testing Learn how to determine when somatic cancer panel testing is appropriate for your patients and how to interpret results of such testing.

Access CME Module | Access CNE Module

Precision Medicine for Your Practice: Interpreting Results from Somatic Cancer Panels Learn how to identify important test characteristics, compare and contrast offerings from different labs, find actionable information on the test report, and interpret results in the context of the individual patient.

Access CME Module | Access CNE Module

#### **Genomic Testing for the Healthy Individual**

Learn how to elicit patient motivations for genomic testing and to assess if a particular genomic test is a good fit for their concerns.

Access CME Module | Access CNE Module

#### **Exome Testing for Diagnosis**

Learn how to identify patients who may benefit from exome testing, communicate with patients and families about testing, recognize clinically significant exome test results, and collaborate with genetic experts.

**Access CME Module | Access CNE Module** 

#### **Genetic Testing in Pediatric Neurology**

Learn about the benefits and limitations of genetic tesitng for pediatric neurological conditions.

**Access CME Module | Access CNE Module** 

#### **In-person Courses**

**Cancer Genetic Management in the Primary Care Setting.** 

A highly interactive, in-person workshop for primary care providers that focuses on skill building in cancer risk assessment, genetic testing, and management. This six-hour program can be implemented at local sites in collaboration with JAX and the American Society of Human Genetics.

#### **Select Other Educational Resources**

<u>Direct-To-Consumer Genetic Testing for Breast Cancer Risk</u>. Provides tips for understanding and using DTC BRCA1/2 results in patient care.

<u>Shared Decision Making about Tumor Testing.</u> Provides a communication guide for discussing the risks, benefits, and limitations of tumor genomic testing with patients.

<u>Immune Checkpoint Inhibition Biomarkers</u>. Provides an overview of the benefits and limitations of commonly used immune checkpoint inhibition biomarkers in tumor testing, including PD-L1, tumor mutation burden and MSI.

<u>The ABCs of Chromosomal Microarray.</u> Explains features of chromosomal microarray, including how the test works, what it detects, common indications, and considerations in results interpretation.

<u>Cascade Screening Infographic</u>. Presents an overview of cascade screening, the systematic testing in a family with a hereditary syndrome to identify unaffected individuals also with the condition.

<u>Genetic Testing Methods eBook.</u> Provides information about different genetic testing methods currently used in testing for hereditary cancer syndromes (enhanced e-book available for download).

<u>Genomic Technologies for Oncologists eBook.</u> Provides an overview of genomic technologies used in cancer research and clinical care (enhanced e-book available for download).

<u>Family History Core Principles Slide Set.</u> Teaches about inheritance patterns, genetic red flags, and risk assessment using didactic presentation and case studies to demonstrate concepts.

<u>GINA Discussion Guide.</u> Provides talking points and key information about genetic discrimination and the Genetic Information Nondiscrimination Act (GINA), which protects individuals from the misuse of genetic information in health insurance and employment.

- 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.
  - Yes, if such a presentation would be helpful to the ISCC membership. We have presented in the past, including a presentation by Kate Reed in January 2016 at the in-person meeting about the JAX-AMA-Scripps project Precision Medicine for Your Practice. In May 2016, Emily Edelman presented about JAX's educational approach and portfolio for non-genetics providers on a monthly call. We would be happy to provide updates about either of these projects and topics again, or present on a new topic.
- 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.
  - Not at this time, but possibly in the future. We are interested to develop a validated evaluation instrument to assess knowledge and skills around family history collection, risk assessment, and genetic testing, and see this as a beneficial collaboration within ISCC, but do not have the bandwidth to lead this effort right now.

- 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.
  - Maybe. A major focus of Clinical Education at JAX is dissemination of educational products and messages, and sustaining engagement among practicing clinicians over time. We could be interested to facilitating a discussion around activities and best practices in the marketing and dissemination of genetics education to the healthcare workforce. This would likely be most effective discussed face-to-face but could also be done over the phone.
- 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).

# Training Residents in Genomics (TRIG) and Undergraduate Training in Genomics (UTRIG) Working Groups

Compendium: Training Residents in Genomics (TRIG) and Undergraduate Training in

Genomics (UTRIG) Website <a href="http://pathologylearning.org/trig">http://pathologylearning.org/trig</a>

Website / No / Free

Compendium: Training Residents in Genomics (TRIG): Genomic Pathology Workshop Instructor Materials

http://www.pathologylearning.org/trig/resources

Website / No / Free

Compendium: Training Residents in Genomics (TRIG): Universal Genomics Instructor Handbook and Toolkit

http://www.pathologylearning.org/trig/resources

Website / No / Free

Compendium: Training Residents in Genomics (TRIG): Genomic Pathology/Oncology Workshop Instructor Handbook and Toolkit

http://www.pathologylearning.org/trig/resources

Website / No / Free

Compendium: Training Residents in Genomics (TRIG): Online Genomic Pathology/Oncology Modules

http://www.pathologylearning.org/trig/resources

Website / No / Free

#### 2020\_02\_25:

- 1) Name of Individual(s) Submitting Entry: Rich Haspel, MD, PhD; Chair, TRIG Working Group; Co-Chair, UTRIG Working Group
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).
- 1. In 2010, the Training Residents in Genomics (TRIG) Working Group was formed through the Pathology Residency Directors Section (PRODS) of the Association of Pathology Chairs (APC). The goals of this group, made up of experts in medical education, molecular pathology, and clinical genetics, are to develop teaching tools, and promote genomic pathology education. The TRIG Working Group represents a unique collaborative effort in pathology education with members from many major pathology organizations and representatives from the National Society of Genetic Counselors (NSGC) and American College of Medical Genetics and Genomics (ACMG). Through grant support from the National Cancer Institute, the TRIG Working Group has held genomic pathology workshops and courses at the annual meetings of major pathology and oncology organizations. Using teambased learning and flipped classroom methods, these workshops have been

recognized as an "educational innovation" for the unique approach to teaching at national meetings. An Instructor Handbook and Toolkit - as well as Online Modules are available to enable residency programs and other groups to locally implement similar training. There have also been train-the-trainer sessions at the national meetings of the NSGC, ACMG and American Society for Human Genetics. TRIG-resources include:

- a. The TRIG Working Group Resident Genomic Pathology Workshop Instructor Handbook and Toolkit provides the materials and guidance needed to implement a structured and field-tested introductory genomic pathology/oncology curriculum. The curriculum consists of approximately seven hours of instruction and uses a team-based learning approach. The instructor leading this workshop does not need to be an expert in genomics; however some background in molecular pathology/oncology is recommended. The first version of these materials was released in 2014. The current version, released in 2019, has significant updates including new cases, variants, websites and actual genomic testing reports. Links to Google forms are also provided that allow learners to more easily access exercise questions, online resources and record their answers and notes.
- b. A series of Online Genomic Pathology Modules have been created to simulate the team-based learning (TBL) experience offered at the in-person workshops. Released in 2016, the four core areas of the TRIG Working Group curriculum are covered: single gene testing; prognostic gene panel testing; design of a multigene assay and whole exome sequencing. Following introductory information providing the curricular framework, each of the four core modules consist of the following components:
  - An instructor-delivered 15-30 minute interactive PowerPoint lecture that allows the participant to answer preparation questions and review content needed to undertake the TBL activity.
  - A 30-45 minute activity simulating the TBL environment. The participant answers questions with their "team" and learns, through guided simulation, the use of online genomics tools.
  - An instructor-delivered 15-30 minute PowerPoint lecture presenting answers to the activity questions. At the end of the final module there is also a summary of the key concepts and a short review of non-oncology genomic testing.

These modules were highly reviewed during the piloting process as an enjoyable educational experience that successfully translates the in-person workshop to the virtual environment.

2. Through grant support from the National Human Genome Research Institute and working with the ISCC Innovative Approaches Working Group, a <u>Universal Genomics Instructor Handbook and Toolkit</u> are available to allow educators to develop specialty-specific TRIG-based exercises. The materials, released in 2017, are designed as a template to allow the user extensive customization to meet the unique needs of their specialty. It consists of a Universal Genomics Instructor

Handbook containing four "universal exercises," adaptable for use in almost any specialty, in the areas of single gene testing, use of multigene assays, whole-exome sequencing, and polygenic testing/pharmacogenomics. Of note, this last exercise (recognizing additional needs beyond that of the TRIG curriculum) includes pharmacogenomics data and genome-wide association studies (GWAS). The exercises are in a "plug-and-play" format in which diseases and genes can be added to allow specialty-specific customization. There is also a Universal Genomics Toolkit contains examples of how the curriculum has been adapted to cardiology, neurology, and ophthalmology audiences.

All resources listed above are available for free, after a brief registration process, on the TRIG website (<a href="http://pathologylearning.org/trig">http://pathologylearning.org/trig</a>). Upcoming workshops are also listed on the website.

#### References:

- 1. Haspel RL, Ali AM, Huang GC. Using a Team-Based Learning Approach at National Meetings to Teach Residents Genomic Pathology. J Grad Med Educ. 2016 Feb;8(1):80-4.
- 2. Musunuru K, Haspel RL; Innovative Approaches to Education Working Group of the Inter-Society Coordinating Committee for Practitioner Education in Genomics. Improving Genomic Literacy Among Cardiovascular Practitioners via a Flipped-Classroom Workshop at a National Meeting. Circ Cardiovasc Genet. 2016 Jun;9(3):287-90.
- 3. Haspel RL, Ali AM, Huang GC, et al. Teaching Genomic Pathology: Translating Team-Based Learning to a Virtual Environment Using Computer-Based Simulation. Arch Pathol Lab Med. 2019;143(4):513–517.
- 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.

We have presented information about TRIG and the Universal Exercises on calls and live meetings. UTRIG is a new initiative and, if there is interest, we could describe this working group and plans to adapt TRIG to medical students.

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.

While the ISCC Innovative Approaches Working Group is "retired." We would be very interested in helping others translate the Universal Exercises to their specialty.

I would also be interested in a project related to designing a validated exam to test health practitioner genomics knowledge. We have used a structured process to create a transfusion medicine exam and administer to over 500 internal medicine and hematology trainees worldwide. A similar approach may work for developing a genomics exam.

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.

#### Not at this time.

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).

The R25 grant supporting TRIG and UTRIG was renewed in 2017 for another 5 years. Both the UTRIG and TRIG Working Groups are looking for representatives from other organizations to help in the revision of the existing cancer genomics curriculum and developing a genomics curriculum for medical students. Please contact Rich Haspel if interested.

## University of South Wales, UK, Genomics Policy Unit

Compendium: University of South Wales, UK, Genomics Policy Unit: Telling Stories: Understanding Real Life Genetics

www.tellingstories.nhs.uk

Website / No / Free

Compendium: University of South Wales, UK, Genomics Policy Unit: Genomics Nursing Alliance (G2NA)

www.g2na.org Website / No / Free

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Emma Tonkin \*Please note that Maggie is retiring next month.
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

Set up in 1996 to study the 'new genetics', the Genomics Policy Unit (GPU), at the University of South Wales, is one of the longest established research groups in this field in the UK. We have been conducting a range of innovative research programmes that relate to the impact of genomic technologies on health and social care, particularly in relation to the implications for healtprofessionals and the public. The GPU has made a significant contribution to the development of policy and practice in genetics/genomics at national and international level with particularly pioneering work in the fields of public engagement with genetics and genetics/genomics competence of health professionals. Our key focus has been on nursing and midwifery education and practice. One major initiative has been the development of a free-to-access, web-based education tool Telling Stories Understanding Real Life Genetics <a href="https://www.tellingstories.nhs.uk">www.tellingstories.nhs.uk</a>. [It is already on the repository.]

Between 2004-2012, Prof. Maggie Kirk (Emeritus) and myself led the nursing education programme at the NHS National Genetics Education & Development Centre (now subsumed with the Health Education England, Genomics Education Programme). We have continued our interest in promoting genomics within nursing and midwifery practice at national and international levels.

A key focus of our current work has been the establishment of the Global Genomics Nursing Alliance (G2NA) <a href="www.g2na.org">www.g2na.org</a> in collaboration with Dr Calzone and other colleagues from the US and UK.

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. We did present during an ISCC Education products working group call in April 2017, on the G2NA programme and would be happy to update on this, with Dr Calzone G2NA, eg our tool developed to benchmark progress in integrating genomics into nursing practice and our global minimum competencies work I would also be happy to talk about Telling Stories and our work generally in developing competencies, delivering education programmes and research around the challenges of integrating genomics into general nursing and midwifery practice.

Face to face meetings present us with a difficulty because of the funding and travel time constraints

- 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.
  - During 2019, I will be leading an initiative for G2NA in establishing global minimum competencies in genomics for nurses. There may be scope for collaboration as we develop our advisory panel and participant lists
- 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.

Yes, please see response above.

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).

# **Industry:**

#### **ICF**

#### 2020 02 25:

 Name of Individual(s) Submitting Entry: Karen Hanson, MS Michelle Snyder, MS Janine Lewis, MS

 List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

ICF is a global consulting services company with over 7,000 full and part time employees. At ICF, business analysts and policy specialists work together with digital strategists, data scientists, subject matter experts and creatives to help organizations solve complex challenges.

Our Bioinformatics line of business focuses on development, implementation, and ongoing support of services that help advance the management and exchange of biomedical and health information to drive the improvement of overall health.

Our subject matter expertise includes cancer, HIV/AIDS, genomics, dietary supplements, complementary and integrated health, rare and orphan diseases, and common data elements. Our team is comprised of data analysts, certified project managers, science writers and editors, certified translation specialists, data scientists and certified meeting planners

#### **Examples of our work include:**

- GARD Genetic and Rare Disease Information Center under the leadership of the National Center for Advancing Translational Sciences (NCATS), at the NIH. GARD provides the public with access to current, reliable and easy-to-understand information about rare and genetic diseases in English and Spanish. GARD also provided resources to help support the rare disease community.
- The Physician's Data Query (PDQ) on the National Cancer Institute (NCI)Website. PDQ content includes cancer information summaries, written in health professional and patient language and translated into Spanish, Drug Information Summaries, the NCI Drug Dictionary, the NCI Dictionary of Cancer Terms, and the NCI Dictionary of Genetic Terms
- Genetics Home Reference (GHR) website under the National Library of Medicine. ICF staff provides genetics expertise and scientific writing to create accurate, high-quality content for GHR.

3) Would you or someone affiliated with your group be interested in presenting your 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.

Yes – our staff would be willing to talk about GARD's initiatives and programs. Michelle Snyder has already presented during an ISCC plenary call.

Janine Lewis is willing to talk about the NCI cancer information work that we do. We can coordinate a speaker to discuss other work ICF does in the area of genomics.

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

Michelle Snyder leads the Rare Genetic Disease project group and Janine Lewis and Karen Hanson are both members

5) Would you or someone in your group 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.

#### No

6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

It may be possible through GARD's website, but would require approval through NCATS.

We can help facilitate cancer genomics educational dissemination needs with NCI or other relevant programs.

7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

#### **PerkinElmer**

#### 2020\_02\_25:

- 1) Name of Individual(s) Submitting Entry: Akanchha Kesari/ Madhuri Hegde
- 2) List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

College of American Pathologists ClinGen ACMG

3) Would you or someone affiliated with your group be interested in presenting your 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.

Not at this time. We have just become members. We need to understand the activities better.

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

Yes- Akanchha Kesari. We will submit a proposal

- 5) Would you or someone in your group 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) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Through our website and global genomics network-

www. Perkinelmergenomics.com

7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

#### WebMD

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Steve Murphy, Director of Public Health Solutions, WebMD/Medscape Tel 202-489-6669 <a href="mailto:smurphy@webmd.net">smurphy@webmd.net</a>
- 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/).

WebMD develops educational programs for Federal agencies and the private sector and can help organizations develop engaging and cutting-edge content using tools such as virtual reality and simulation. As the largest provider of online CME WebMD's sister platform Medscape has a rich set of tools, adult learning expertise and a wide range of learning formats as well as outcomes tools. Medscape both develops CME activities and can host already accredited activities.

WebMD carries news articles and develops features on genomic, genetic testing and precision medicine such as:

https://www.webmd.com/baby/genetic-testing

https://doctor.webmd.com/find-a-doctor/specialty/medical-genetics

https://www.webmd.com/baby/pregnant-genetic-testing#1

https://www.webmd.com/a-to-z-guides/what-is-genetic-counseling#1

https://www.webmd.com/diabetes/diabetes-type-1-genetics

https://www.webmd.com/cancer/features/precision-medicine-future#1 https://www.webmd.com/cancer/features/precision-medicine-doctor-visit#1

Medscape has resources on genomics such as:Cme Learning Center Genomics - <a href="https://www.medscape.org/resource/genomic-medicine/cme">https://www.medscape.org/resource/genomic-medicine/cme</a>, Genomic Testing and Precision Medicine in Cancer Care, Genomic Medicine Articles

A Primer on Genomic and Personalized Medicine: How Will It Affect Your Practice?

Medscape has education such as:

<sup>\*</sup>https://emedicine.medscape.com/indexpages/genomics

<sup>\*</sup>https://www.medscape.com/resource/genomic-medicine \*\*

<sup>\*</sup>How Routine Genomic Medicine 'Will Change People's Lives'

<sup>\*</sup>A New Day? Fast, Cheap Human Genome Sequencing Will Open Doors

<sup>\*100,000</sup> Genomes' Project: Linking Genome Sequencing to Outcomes

<sup>\*</sup>How Many Patients Benefit From Genome-Driven Cancer Therapy? CME / ABIM MOC / CE

<sup>\*</sup>Clinical and Public Health Genomics: Informing Prevention and Population Medicine

<sup>\*</sup>The Genomics of Cancer and Molecular Testing: What You Need to Know

#### \*Are Patients With Breast Cancer Receiving Genetic Counseling? CME / ABIM MOC / CE

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.

Steve Murphy, Director of Public Health, is available to speak during an ISCC call or face to face meeting about WebMD and Medscape's educational capabilities. We can also discuss how to generate greater awareness and acceptance, myths and facts, and the best ways to present genomics education so it is relevant to clinicians, patients and consumers.

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.

We will collaborate with any organizations interested in leveraging WebMD & Medscape platforms.

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.

Yes, we can update our 2017 ISCC presentation that provided a series of educational formats from teaching foundational basics to peer discussions, case-based learning, medical simulation to advanced learning using augmented and virtual reality.

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).

## **YouScript**

2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Valerie Baron, PharmD, Director of Clinical Product Management
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

YouScript is a clinical decision support tool that synthesizes all evidence impacting drug response, including pharmacogenomic testing, to support doctors and pharmacists in making faster, more proactive decisions when prescribing and managing medications. YouScript is also the only clinically validated system that shows improved outcomes, reduced costs, and high patient and provider satisfaction.

In pursuit of our mission, YouScript aims to be a trusted partner to value-based healthcare organizations, providers, and payers who want to bend the healthcare cost curve with the power of precision medicine. Successfully integrated into the clinical workflows of Epic, Cerner and Allscripts, YouScript provides embedded pharmacogenomic education through clinical decision support at the point of care. Additionally, the YouScript team takes a personalized, hands-on approach to facilitating the rollout of a comprehensive pharmacogenomics program utilizing YouScript, customized to the unique needs of each healthcare partner through the use of robust internal clinical and technical workshops.

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.

Yes, via call/webinar. Ideal topics would be: 1) Best practices for implementation of a new pharmacogenomics program in your healthcare system and 2) Best practices for integrating pharmacogenomic clinical decision support into your workflow. Open to other topics that relate to pharmacogenomics, clinical decision support, electronic health record integration and/or implementation processes. Speaker would likely be one of our clinical pharmacists and/or implementation team members.

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.

Not at this time.

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.

Not at this time.

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).

## ZibdyHealth, San Diego, USA

#### 2019 02 04:

- 1) Name of Individual(s) Submitting Entry: Hirdey Bhathal, Sanjay Mehta, MD <a href="mailto:support@zibdy.com">support@zibdy.com</a> (https://www.zibdy.com)
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

One of ZibdyHealth's major goals is to make genomics simple to understand, easy to use, and useful for everyone. To facilitate the success of the genomic revolution- i.e. leading to real impact among large numbers of people, we need to make genomic data understandable and clinically useful. At ZibdyHealth, we do not produce genomic data but we help the public consume it.

We noticed that the DTC genomic industry reports are far too complicated for an average person to understand, and most resources developed are aimed at healthcare professionals, not an average person. We have created YouTube videos and written blogs to help make pharmacogenomics simple to understand and useful. Our application turns these complicated reports into digestible information that lay people can understand.

https://youtu.be/t-e4R6MF43s \*

https://www.zibdy.com/pharmacogenomics-and-the-future-of-medicine/ \*

In addition to our pharmacogenomics work, we have also built a novel tool to build more accurate and detailed family medical histories. This tool uses a completely new approach, different from the one used by CDC, US Surgeon General and NIH. The educational material prepared for family medical history is found here:

https://www.zibdy.com/family-health-on-zibdyhealth/ \*
https://www.genome.gov/pages/health/healthcareprovidersinfo/fhht\_bhathal.pdf \*

We are in the process of creating more educational material on the integration of genomics, family medical history and clinical data for people to take advantage of using our upcoming features. We will be releasing translation of all material in Spanish and Portuguese as soon as we can.

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: Yes, we can present our integration of pharmacogenomics with clinical data. It may look and sound too simple for genomics experts, but that was our goal - to make it simple and easy to

understand for an average person. We can include our approach to family medical history with it.

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.

We would be happy to collaborate on projects looking at how the integration of pharmacogenomics data with clinical data influences choice of medications for a condition (e.g. hypertension). However, at this time we do not have the bandwith to take the lead on a project. We are also open to a project to integrate genomics with clinical data for other conditions, and family medical history, to look for "unknown unknowns".

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.

Yes, we strongly feel that most of the material is produced for highly educated persons, or an expert in healthcare or genomics. The primary persons who will most benefit from pharmacogenomics data are the elderly, chronically ill or economically vulnerable - and none of them are experts in interpreting genomic information. We need to demystify genomics for an average person.

We would prefer a call to start.

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).

We would like to explore ways to collaborate with anyone who is interested in the integration of genomic and clinical data.

## 23andMe, Inc.

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Anne Greb, MS, CGC
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

23andMe is a consumer genetics, therapeutics and research company founded in 2006 with the mission to help people access, understand and benefit from the human genome. The 23andMe Personal Genetic Service provides information and tools for individuals to learn more about their DNA. 23andMe is the first and only company authorized by the FDA to provide direct-to-consumer (DTC) personal genetic health risk, cancer predisposition, carrier status, and pharmacogenetic reports.

Currently more than 150 reports on health, ancestry and traits are available to 23andMe Health + Ancestry Service customers through a secure online account. In addition to opting-in to receive health reports, 23andMe customers are given the option to participate in research. Approximately 80% of customers consent to participate in research, which, to date, has generated more than 2 billion phenotypic data points and 130 publications in peer-reviewed journals.

23andMe's medical education mission is to optimize the potential of consumer-driven genetics/genomics in patient care by closing the gap in genomic medicine preparedness among healthcare professionals. Currently our education initiatives are focused on 1) preparing healthcare professionals for meaningful conversations with their patients who want to discuss 23andMe, and 2) equipping the clinical community to integrate consumer-driven genetics/genomics in health promotion, disease prevention and management.

#### **Resources:**

- 1. Healthcare professional's website: 23andMe for Healthcare Professionals
  - a. 23andMe overview
  - b. Professional resources
    - i. Sample reports
    - ii. Educational videos
    - iii. Medical team
- 2. Continuing Medical Education: The following CME activities are freely accessible on Medscape Education and were supported by an independent educational grant from 23andMe. Activities are enduring and valid for CME credit for one year following their release date.
  - a. Direct-to-Consumer Genetic Testing: What Clinicians Need to Know
  - b. <u>Direct-to-Consumer Genetic Testing: Successfully Navigating Patient Encounters</u>

- c. The DTC Genetics Talk Show: Finding the Advantage for Patients
- 3. Personal genetic testing in education has been studied and reported as an effective method to enhance student learning, motivation and engagement in genomic and personalized medicine.
  - a. The 23andMe Health + Ancestry Service is available at a discount for healthcare providers and trainees interested in learning genetics firsthand. Contact Anne Greb, MS, CGC for additional information (anneg@23andme.com).
- 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.

## An overview was provided at the November 2018 meeting. Anne Greb can present again in the future.

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.

#### Not at this time.

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.

#### Perhaps in the future.

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).

Patient/HCP discussion guides, case studies, participatory/experiential and other innovative approaches for HCP education.

# <u>Individuals:</u>

## Ersig, Anne

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Anne Ersig, PhD, RN
- List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.
  - I am a faculty member at the University of Wisconsin-Madison School of Nursing. I am in the process of implementing education on genetics and genomics across the 3 levels of education (BSN, DNP, PhD). My current focus is on the BSN and DNP programs, and I anticipate adding the PhD program in the next academic year.
- 3) Would you or someone affiliated with your group be interested in presenting your 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 you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.
  - I would appreciate the opportunity to connect with other faculty members in schools of nursing, medicine, public health, etc., to learn more about how they are implementing genetics education in their institutions. I don't know that my practices are "best" but I do rely on resources indexed on <a href="http://www.genomicseducation.net">http://www.genomicseducation.net</a> (I am a former editorial board member of G2C2).
- 5) Would you or someone in your group 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) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?
  - I'd be happy to share my ideas and resources with others in a group. I would prefer not to make them widely available, however.

7)	Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

## **Eugene, Andy**

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Andy R. Eugene, MD, PhD
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).
- 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.
  - Yes. I would share the most practical online resources for medical practice that physicians may use when prescribing medications.
- 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.
  - Currently, I would be happy to assist in making existing projects a success to benefit the public, educators, and practicing healthcare professionals to generally advance the field.
- 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.
  - Absolutely. I would be interested in sharing teaching points to enhance physicians, pharmacist, nurses, physician assistant, and the public to understand the underlying concepts of drug pharmacokinetics which form the basis for gene-drug interactions (pharmacogenomics) that result in an increase in the area-under-the-concentration-time curve (AUC) and maximum plasma concentration (Cmax) as detailed within the FDA drug package inserts. These teaching modules would be informative and last really only 7- to 10-minutes.
- 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).

It is important to increase awareness and encourage medical students to enter training in (1) Laboratory Genetics and Genomics or (2) NIGMS-funded Clinical Pharmacology Training programs and the ISCC to work with state medical licensing boards to begin licensing these trainees directly to advance genomic medicine. This will facilitate having physicians trained as experts in pharmacogenomics and to support and interpret pharmacogenomic results that will apply broadly across medical specialties.

## Kolesar, Jill

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Jill Kolesar, University of Kentucky, Markey Cancer Center
- 2) List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.
- Bimonthly Molecular Tumor Board targeted to health professionals. One hour Zoom conference on first and third Tuesdays where interprofessional team discusses NGS reports with treating physicians. CME provided.
- 2) Annual Precision Medicine Conference (4<sup>th</sup> is Feb 21, 2020). One day conference with 2 national speakers and a mix or regional and local speakers.
- 3) Patient education initiatives in genomics. Developed and are evaluating educational materials geared towards patients cancer receiving NGS as well as patients with cancer and a mutation in a cancer predisposition gene to help the cancer patient discuss hereditary testing with their family members. These are being used in a population genomic sequencing project in family medicine and cancer.
  - 3) Would you or someone affiliated with your group be interested in presenting your 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.

Yes, both or molecular tumor board and our patient education initiatives. Jill Kolesar would present and no preference for in person versus call

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

Yes, we would like to implement precision medicine in community oncology practices (NGS and germline sequencing). We have done this is Kentucky and are interested in scaling the program.

5) Would you or someone in your group 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.

Not at this time

- 6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?
- 1) Our MTB is available as a Zoom call and is free of charge
- 2) Our educational materials are available
  - 7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

## Leary, Emili

#### 2020\_02\_25:

- 1) Name of Individual(s) Submitting Entry: Emili Leary, PharmD
- List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

I am the Program Director for the Marshfield Clinic Research Institute's Pharmacogenomics Certificate Program

(https://www.marshfieldresearch.org/News/research-institute-pilots-pharmacogenomics-certificate-program)

I also serve as the Lead Pharmacist for Pharmacogenetics Education and Resources/Interpretation at Marshfield Clinic.

(https://www.marshfieldresearch.org/profiles/9419)

I lead a group who is currently working on internal CME/CPE/CEU computerbased training (CBT) modules for pharmacogenetic education at Marshfield Clinic.

- 3) Would you or someone affiliated with your group be interested in presenting your 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.
  - Yes, I would be willing to present at a plenary call (Topic: Overview of Marshfield Clinic Pharmacogenomics Certificate Program; Presenter: Emili Leary, PharmD; Preference: Call).
  - I am unable to attend the in-person meeting.
- 4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.
  - No, I do not have the resources at this time to lead a project, however I am happy to help with education as related to pharmacogenomics.
- 5) Would you or someone in your group 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.
  Unsure at this time.

6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?

Yes and No.

Yes in the context that we could integrate ISCC genomics education into our Certificate Program, which our learners could carry forward and help introduce other healthcare professionals to this education.

No in the broader context of dissemination at Marshfield Clinic.

7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

I am happy to help contribute to pharmacogenomics education as requested.

## Murfin, Melissa

#### 2019\_02\_04:

- Name of Individual(s) Submitting Entry: Melissa Murfin, PharmD, BCACP, PA-C
- 2) List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links. Working toward education of PAs and PA students in genomics and best practices
- 3) Would you or someone affiliated with your group be interested in presenting your 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.

for ordering and interpreting genetic testing. Specific interest in pharmacogenomics.

- Not at this time but maybe in the future.
- 4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.
  - I have an interest in democratizing pharmacogenomics to reach all patients who may benefit. This would involve reaching out to free and underserved clinics to insure patients have access to PGx testing. Happy to collaborate with anyone!
- 5) Would you or someone in your group be interested in leading a discussion related to issues/best practices in genomics education during an ISCC plenary call or face-toface 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. Not at this time
- 6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how? Yes, I work with the PA genetics special interest group that is sponsored by AAPA as well as the genetics education providers in PAEA (Physician Assistant Education Association).
- 7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).
  - I am happy to collaborate on just about anything!

## Niemchick, Karen

#### 2020\_02\_25:

- 1) Name of Individual(s) Submitting Entry: Karen Niemchick (Individual Member)
- 2) List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

I teach Public Health Genetics in our MPH program at Grand Valley State University. I am also involved in APHA's Genomics Forum Policy committee where we are beginning a genomics education working group for the collaboration and exchange of ideas in genomics higher education.

3) Would you or someone affiliated with your group be interested in presenting your 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.

Perhaps in the future.

4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

Perhaps in the future. I would like to address genomics in higher education, especially in public health. I need to think more on this.

- 5) Would you or someone in your group 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. Perhaps in the future. Same as Question 4.
- 6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how? Yes, in my classes and to my collaborative partners from a local health system.
- 7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

## Sabatello, Maya

#### 2020\_02\_25:

- 1) Name of Individual(s) Submitting Entry: Maya Sabatello, LLB, PhD
- 2) List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.

Our institutions includes various seminars about precision medicine to increase the genomic literacy and understanding of ethical, legal, and social implications of genetics among healthcare providers and the lay public. I also co-direct (with Prof. Gil Eyal) the Precision Medicine: Ethics, Politics, and Culture Project which engages scholars from the humanities, law, political science and medicine in discussions about precision medicine.

My own work focuses on teenagers in the genomic era and on people with disabilities in the context of precision medicine research. With regards to the latter, we conducted a national study and are currently working on manuscripts that include an education component to increase knowledge about disability inclusive practices among translational genomic researchers. For one such publication that focuses on the blind community and accessibility, pls see:

Sabatello, M., Blake LA., Chao A., Zhang, Y., Chen, Y., Silverman, A., Appelbaum, P. (2019). Including the Blind Community in Precision Medicine Research: Findings from a National Survey and Recommendations. *Genetics in Medicine*, 2019 Nov;21(11):2631-2638

For a broader conversation about the need in "disability culture competency" among precision medicine researchers and IRB members, see:

Sabatello, M. Cultivating Inclusivity in Precision Medicine Research: Disability, Diversity, and Cultural Competence. *J Comm. Genetics*, 2019; 10(3):363-373

In addition, I have collaborated in the past year with Dr. Dasgupta's team on the project, "Inclusion in the practice of genomic medicine: Exploring the impact of implicit biases towards disability."

3) Would you or someone affiliated with your group be interested in presenting your 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 you or someone in your group 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 you or someone in your group 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) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?
- 7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).

## Serrano-Barrera, Orlando Rafael

#### 2020 02 25:

- 1) Name of Individual(s) Submitting Entry: Orlando Rafael Serrano-Barrera, MD, MSc
- 2) List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.
- We have created a Multidisciplinary Study Group on Genomic Medicine in The University of Medical Sciences of Las Tunas, Cuba, in order to coordinate our efforts to integrate genomics and personalized medicine into medical curricula. We have designed an optional course for undergraduate medical education, Introduction to omics technologies. We are also working with an undergraduate student's research group, as an extracurricular strategy to promote learning on genomics and personalized medicine through research activities (on microbiome effects on health and disease, pharmacogenetics, assessment of the opinions about the ethical dilemmas, and the design of educational materials). We are elaborating a number of online resources in Spanish, including supercourses (the first about bioinformatics) and a digital bulletin (GenoMed, downloadable at https://blogs.sld.cu/oserranob/otrosrecursos/). Twice a year, we update and offer, free of charge, a Digital Library on Genomic and Personalized Medicine, a collection of digital resources on the subject (scientific papers, books, chapters, regulations, presentations, other documents and videos) that can be copied by health students and professionals at our activities.
- 3) Would you or someone affiliated with your group be interested in presenting your 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.
- Yes. I would be interested in discussing the current treatment of omics technologies and personalized medicine as contents in Medicine syllabus, and the alternatives for an effective integration, as an individual module, whether residential or online, within the existing subjects, or as extracurricular activities. As I live and work in Cuba, it would be more practical to do it by a call.
- 4) Would you or someone in your group be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.

- It would be great to be part of a project and/or collaborate on any area related to the promotion of omics technologies and personalized medicine in undergraduate medical education.
- 5) Would you or someone in your group 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.
- It would be great to be part of a discussion related to the promotion of omics technologies and personalized medicine in undergraduate medical education. It would be practical to do it by phone.
- 6) Can your organization/society/institute disseminate ISCC genomics education resources of potential interest to your group's members? If yes, how?
- We manage a website, Genomic Medicine (<a href="https://blogs.sld.cu/oserranob/">https://blogs.sld.cu/oserranob/</a>), to disseminate information about present and potential applications of omics technologies in the clinical practice. It includes a page on resources (<a href="https://blogs.sld.cu/oserranob/otros-recursos/">https://blogs.sld.cu/oserranob/otros-recursos/</a>) and another related to papers about published educational initiatives (<a href="https://blogs.sld.cu/oserranob/formacion/">https://blogs.sld.cu/oserranob/formacion/</a>). We celebrate a number of workshops of our Multidisciplinary Study Group on Genomic Medicine during each year, with participants being mainly medical students, residents and health professionals, where we always present resources, initiatives and breakthroughs about genomic and personalized medicine.
- 7) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).
- It would be valuable to collaborate in a number of areas: assessment of syllabi in terms of the inclusion of contents related to genomic medicine, evaluation of perceptions and opinions of health educators, professional and students about this area, through standardized tools. Also, to work on an open repository of resources, and the creation of a fund to cover exchanges and residential courses.

## Weiler, Tracey

#### 2019\_02\_04:

- 1) Name of Individual(s) Submitting Entry: Tracey Weiler, Ph.D.
- 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 <a href="http://genomicseducation.net/">http://genomicseducation.net/</a>).

I am a faculty member teaching genetics throughout the undergraduate medical curriculum at FIU. I have coordinated a set of active learning case-based discussion sessions in the second year organ systems courses that address genetic and genomics competencies relevant for primary care practitioners. I have also developed a module in the third year internal medicine clerkship that integrates both genetics and clinical knowledge into a single assessment and illustrates how genetics can be incorporated into primary care.

I am also very interested in using sample direct to consumer genetic testing data in medical education so that students can engage with the data, compare and contrast their findings and learn what DTC data can deliver, what it can't and how to interpret the findings for their patients.

- 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.
  - Yes Tracey could present either second year active learning curriculum or third year internal medicine clerkship module. Face to face or call are both fine.
- 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).

## **Compendium Entry (Blank form for new entries)**

Name of Company/Organization/Society/Institute (or write "Individual Member"):

- 1) Name of Individual(s) Submitting Entry:
- List and briefly describe you or your group's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links.
- 3) Would you or someone affiliated with your group be interested in presenting your educational programs/best practices/initiatives/resources during an ISCC-PEG 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 you or someone in your group 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 you or someone in your group be interested in leading a discussion related to issues/best practices in genomics education during an ISCC-PEG 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) Can your organization/society/institute disseminate ISCC-PEG genomics education resources of potential interest to your group's members? If yes, how?
- Other ideas for ISCC-PEG: please include additional potential projects, discussions and opportunities for collaboration (even if you or someone in your organization would not be interested in leading).