



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

## COMPENDIUM

Genomic Education Activities of Member Organizations

January 2018



National Human Genome  
Research Institute

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*Dear ISCC Members,*

*We hope you find this first edition of the ISCC 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 continued updates posted on the ISCC 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.*

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

*Thanks,*

*Rich Haspel  
ISCC Co-Chair*

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## Accreditation Council for Continuing Medical Education (ACCME)

- 1) *Name of Individual(s) Submitting Entry:* **Steve Singer, PhD, Vice President of Education and Outreach**
- 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/>).*

ACCME sets the standard for high-quality continuing medical education (CME) as the accreditor of the national educational system that serves the needs of physicians in practice. Nearly 2,000 healthcare organizations—include a large percentage of ISCC members—are accredited within the ACCME system. In 2016, the CME system delivered more than 158,000 educational activities, comprising more than 1 million hours of instruction through 27 million interactions with physicians and other health professionals.

Resources to support ISCC members include:

- **ACCME Website ([www.accme.org](http://www.accme.org))**  
*Resources to maximize the value of accredited CME for your institution and its educational community including pedagogy best-practices, interviews, and how-to tutorials.*
  - **ACCME Annual Meeting ([www.accme2018.org](http://www.accme2018.org))**  
Held annually in April, the ACCME Meeting brings together education and healthcare leaders, government representatives, and other healthcare stakeholders to share best-practice approaches to advance CME within our shared system during a 4-day conference.
  - **ACCME Accreditation Workshop ([www.accme.org/events](http://www.accme.org/events))**  
Held annually in August, the ACCME Accreditation Workshop is an intensive 2-day meeting that prepares CME professionals for planning and delivering CME that meets ACCME requirements.
  - **Find a CME Provider ([www.accme.org/find-cme-provider](http://www.accme.org/find-cme-provider))**  
Web-based resource to look up organizations accredited in the ACCME system.
- 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 have already offered to lead a session on “Addressing Practice Gaps”. I am hoping that sharing some novel approaches for this exercise may model some opportunities for collaboration for the group at large.**

- 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.*

**Given that ACCME is an accreditor, and not a content-expert in genomics. I don't think it would be appropriate for us to lead a 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.*

**Yes... in reference to our discussions, we would like to foster some engagement to focus future collaboration (for ISCC) on addressing current gaps in clinician practice with CME/CE. We also recognize that the efforts to address gaps in practice could be accelerated significantly through interprofessional continuing education that recognizes the need to bring multiple professions—reflective of the practice environment—together.**

- 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).*

## African Genomic Medicine Training Initiative

- 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 <http://genomicseducation.net/>).*

### 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 H3 Africa 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)

- 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 <http://genomicseducation.net/>).*

**Periodic articles on aspects of genetics the journal American Family Physician.**  
<http://www.aafp.org/afp/topicModules/viewTopicModule.htm?topicModuleId=56>

- 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 Association for Clinical Chemistry (AACC)

- 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 <http://genomicseducation.net/>).*
  - **Many of the resources below are already linked to G2C2, but all can be linked**
  - **Webinars on many genomics-related topics:** <https://www.aacc.org/store/all-webinars/on-demand-webinars>
  - **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/clinical-chemistry-trainee-council/trainee-council-in-english/pearls-of-laboratory-medicine>
    - **A Question Bank:** <https://www.aacc.org/clinical-chemistry-trainee-council/trainee-council-in-english/question-bank>
    - **Webcasts:** <https://www.aacc.org/clinical-chemistry-trainee-council/trainee-council-in-english/webcasts>
    - **Clinical Case Studies:** <https://www.aacc.org/publications/clinical-chemistry/clinical-case-studies>
    - **Journal Club:** <https://www.aacc.org/publications/clinical-chemistry/journal-club>
    - **Brief Question and Answer articles:** <https://www.aacc.org/publications/clinical-chemistry/q-and-a>
  - **Online Certificate Program (paid content) in Molecular Pathology:** <https://www.aacc.org/education-and-career/online-certificate-programs/laboratory-testing>
  - **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)

- 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 <http://genomicseducation.net/>).*

**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)

- 1) *Name of Individual(s) Submitting Entry:*  
**Christina Aquilante**
- 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/>).*

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 and research. ACCP is the professional home for more than 16,000 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** ([http://www.accp.com/bookstore/th\\_03pg.aspx](http://www.accp.com/bookstore/th_03pg.aspx)), 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 will be offering a **Clinical Pharmacogenomics Certificate Program** starting in October 2018. The program is designed to enable participants to apply pharmacogenomic information to clinical practice and select the most appropriate therapeutic interventions. Topics that will be 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 will consist of required and elective course work and will be delivered via live and online teaching modalities.

- 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 organization's Clinical Pharmacogenomics Certificate Program at the ISCC 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.*

**Not at this time. However, we would be interested in collaborating on the universal pharmacogenomics module that is being developed by ISCC.**

- 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).*

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

- 1) *Name of Individual(s) Submitting Entry:* **David Flannery**
- 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/>)*

**\*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:**

<http://www.acmg.net/ACMG/Education/ACMG/Education/Home.aspx?hkey=b43f18f0-61b9-485c-a87c-b3b2c547f255>

**Additionally, we have educational videos on our YouTube channel:**

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

**Another long-term educational program has been our Summer Scholars program, through the ACMG Foundation for Genetic and Genomic Medicine:**

[http://www.acmgfoundation.org/ACMGFound/ACMGF\\_Programs/Summer\\_Scholars/ACMGFound/ACMGF\\_Programs/Summer\\_Scholars\\_Program.aspx?hkey=e235b4f9-2775-4de3-a042-ca4c2f58b1c7](http://www.acmgfoundation.org/ACMGFound/ACMGF_Programs/Summer_Scholars/ACMGFound/ACMGF_Programs/Summer_Scholars_Program.aspx?hkey=e235b4f9-2775-4de3-a042-ca4c2f58b1c7)

- 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. David Flannery or our Associate Director of Education, Jane Radford**
- 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 sure what project you have in mind.**
- 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, as education is not what I do in my current position, but ACMG is recruiting a person who will have a role in content development for education and this may be something that person would be able to do.**
- 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 College of Obstetricians and Gynecologists (ACOG)

- 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 <http://genomicseducation.net/>).

### **ACOG Education in Women's Genomics Counseling\***

**(<https://www.acog.org/Education-and-Events/ACOG-Womens-Genomics-Counseling>)**

**ACOG Genetics Resource Page\* (<https://www.acog.org/About-ACOG/ACOG-Departments/Genetics>)**

- 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, 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.

**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.

**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)

- 1) *Name of Individual(s) Submitting Entry: Kiran Musunuru*
- 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/>).*

**Genetics videos available via YouTube and in a format that confers CME/CE credit (<http://youtu.be/gxsYk7oPX-I>, <https://learn.heart.org/activity/3517565/detail.aspx>); flipped-classroom workshops at national meetings (<http://circgenetics.ahajournals.org/content/9/3/287>); published Scientific Statements on genomics literacy (<http://circgenetics.ahajournals.org/content/8/1/216>, <http://circgenetics.ahajournals.org/content/9/5/448>)**

- 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.*

**Nothing to propose at this time, but we are always interested in helping with projects that are at all relevant to cardiology practitioners.**

- 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.**

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

## American Society of Human Genetics (ASHG)

- 1) *Name of Individual(s) Submitting Entry:* **Karen Hanson**
- 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/>).*

**ASHG's health professional education initiative aims to develop and implement educational programs for non-genetics health professionals that improve the practice of medicine and patient health outcomes. Our programs are found at: <https://www.pathlms.com/ashg/courses>**

**Pediatric Genetic Testing (<https://www.pathlms.com/ashg/courses/3497>) is a three-part webinar series covering testing technology, result interpretation and ethical and communication issues and is CME eligible.**

**Prenatal cfDNA screening (<https://www.pathlms.com/ashg/courses/4595>) is a multi-media program consisting of 3 pre-recorded webinars, 3 video presentations and point-of-care materials on various topics around prenatal cell-DNA testing and is CME eligible.**

**Both of these courses have been submitted to G2C2.**

- 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, and we presented at last year's face-to-face meeting. We'd be happy to share our progress and any up-dates.**
- 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, 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, we could talk about our educational 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).*  
**One topic for discussion would be ideas for disseminating educational programs to health care professionals.  
ASHG is open to collaboration and has a variety of content experts within its membership.**

## American Thoracic Society (ATS)

- 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 <http://genomicseducation.net/>).*

**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 ([www.thoracic.org/members/assemblies/sections/gg/index.php](http://www.thoracic.org/members/assemblies/sections/gg/index.php)) 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)

- 1) *Name of Individual(s) Submitting Entry:*  
**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. Place an asterisk next to any resources you would consider for inclusion in G2C2 (the genomics educational repository at <http://genomicseducation.net/>).*



**AMP-Education Online or AMPED online:** Found at <http://educate.amp.org>,\* this learning management system contains a growing collection of online content provided by AMP experts in molecular pathology. The [AMP Training and Education Committee](#) works with the AMP Education team to design, implement, and review an array of educational offerings listed on the AMP website under [Education Resources](#).

One of the most popular resources is pocket reference cards, called “Molecular in My Pocket” created by different subject matter experts. These can be found under [Education Resources](#)\*.

- 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, but not immediately – and preferably in a face-to-face setting. The topic would be TBD but could cover the generation of molecular pathology content, reference materials, and courses as well as mechanisms for standardizing best practices in sample ordering, collection, processing, and/or results reporting.**
- 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).*

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

- 1) *Name of Individual(s) Submitting Entry: Shoumita Dasgupta*
- 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/>).*

**\*Genetics Education Resource Exchange (GERE)**  
**Available to APHMG members, [aphmg.org](http://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**

**\*\*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.**

**\*\*We are also looking into editing the multiple choice questions and developing a new platform for sharing the questions in an interactive way. It is currently stored as an Excel database.**

- 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'm happy to, if people would like to hear from APHMG; either is 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.*

**I'm very excited to learn that the topic of unconscious bias will be included in our next ISCC meeting. As you know, I had proposed developing an instructional module focused on nondirective counseling and how it might be impacted if people harbor unconscious biases towards the disability community. I'd be happy to work on this with other committee members and think it is an important topic not just for medical students, but also for providers. I would also be able to**

**facilitate working on such a project during the APHMG meeting, if members were able to attend. It would be key to have access to a web developer to move this forward, either through one of the committee members or perhaps through the NIH.**

- 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 can do something along these lines in terms of active learning methodologies favored in the medical school curriculum. I am most knowledgeable about active classroom (or workshop) pedagogical design, but it would also be great to have a focus on distance/digital learning methods. This type of thing is probably best done as an in-person discussion, I'm guessing.**

- 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).*

**Please see above for idea to develop resource to highlight principles of nondirective counseling and to compare with potential implicit biases of providers or trainees.**



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

- 1) *Name of Individual(s) Submitting Entry:* **Dave Dotson**
- 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/>).*

**\*Public Health Genomics Knowledge Base (PHGKB)** – integrated knowledge base, cosponsored by the Division of Cancer Control and Population Sciences at the National Cancer Institute, including published scientific literature, CDC resources, and other materials that address the translation of genomic discoveries into improved health care and disease prevention

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

**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 <https://phgkb.cdc.gov/PHGKB/myPHGKB.action>

**Cancer PHGKB** – specialized subset database of PHGKB aggregating content on translation and implementation of cancer genomic science

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

**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](https://phgkb.cdc.gov/PHGKB/specificPHGKB.action?topic=Infectious_diseases&query=home)

**\*State Genomics Implementation Map** – clickable map providing information on public health genomics activities in states and territories

<https://phgkb.cdc.gov/PHGKB/stateMapStartPage.action>

**\*Public Health Genomics Podcasts and Videocasts** - 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>

**\*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

<https://www.cdc.gov/genomics/blog/index.htm>

**\*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>

**\*Tier 1 Toolkit** – catalog of resources focused on the activities that public health can do right now in human genomics to save lives and improve health

<https://www.cdc.gov/genomics/implementation/toolkit/index.htm>; Tier 1 genomic applications are listed in the Genomic Tests and Family History by Levels of Evidence Table which includes a growing number of genomics tests and family health history applications <https://phgkb.cdc.gov/PHGKB/topicStartPage.action>

**\*Genomics and Diseases -**

[https://www.cdc.gov/genomics/disease/genomic\\_diseases.htm](https://www.cdc.gov/genomics/disease/genomic_diseases.htm)

- 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. Ridgely Fisk Green might be interested in presenting information on OPHG's Tier 1 Toolkit and other resources. Dave Dotson could present an overview of the Public Health Genomics Knowledge Base (PHGKB). Call-in presentations likely preferred for budgetary reasons.**

- 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.*

**Interest in discussing potential opportunities here, through collaboration with Genomics and Population Health Action Collaborative.**

- 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.*

**Muin Khoury might be interested in leading a talk on OPHG initiatives 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) *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.**

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

- 1) *Name of Individual(s) Submitting Entry:* **Kate Dunlop (Director)**
- 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/>).*
  - a. **\*Website ([www.genetics.edu.au](http://www.genetics.edu.au)) with fact sheets (eg <http://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-15-genetic-and-genomic-testing>)**
  - 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**
- 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).*

**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®)

- 1) *Name of Individual(s) Submitting Entry:* **Kristin Weitzel, Mary Relling and Teri Klein**
- 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/>).*

- a. <http://genomicseducation.net/search/advanced/CPIC> \* already included on G2C2
- b. <https://cpicpgx.org/resources/>
- c. <https://cpicpgx.org/guidelines/>
- d. <https://www.pharmgkb.org/>
- e. <https://www.pharmgkb.org/whatIsPharmacogenomics>
- f. <https://www.pharmgkb.org/whatIsPharmgkb>
- g. <https://www.pharmgkb.org/page/overview>

- 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.*

**Yes, Kristin Weitzel is leading a pharmacogenomics project that will utilize both CPIC and PharmGKB resources.**

- 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.*

**Main topic is how to use existing resources in educational materials for clinical pharmacogenomic testing. Yes, Kristin is the right contact.**

- 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).*

## College of Family Physicians of Canada

- 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 <http://genomicseducation.net/>).*

**Active educational programs are through GECKO Genetics Education Canada – Knowledge Organization [www.geneticseducation.ca](http://www.geneticseducation.ca)  
Presentations at Continuing Education events across Canada are posted on the GECKO website**

- 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).*

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

- 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 <http://genomicseducation.net/>).*

Active educational programs are through GEC-KO Genetics Education Canada – Knowledge Organization [www.geneticseducation.ca](http://www.geneticseducation.ca)

### 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](http://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](http://www.geneticseducation.ca) > Education Modules > \_\_\_\_\_

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

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

Pediatric Genetics: <http://geneticseducation.ca/education-modules/pediatric-genetics/>

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

### 1. Non-Invasive Prenatal Testing (NIPT) with microdeletions (Nov 2017)

Following this session the learner will be able to:

- a. Appropriately refer to their local genetics centre and/or order non-invasive prenatal testing (NIPT)

- b. Discuss and address patient concerns regarding NIPT
  - c. Facilitate patient informed decision making regarding prenatal screening options
  - d. Find high quality genomics educational resources appropriate for primary care
2. **Direct-to-Consumer Genetic Testing (Nov 2017)**  
Following this session the learner will be able to:
- a. Discuss and address patient concerns regarding direct-to-consumer genetic testing (DTC-GT)
  - b. Find high quality genomics educational resources appropriate for primary care
3. **Hereditary Breast and Ovarian Cancer (HBOC) syndrome (BRCA1/BRCA2) (Nov 2017)**  
Following this session the learner will be able to:
- a. Refer to their local genetics centre and/or order genetic testing appropriately regarding hereditary breast and ovarian cancer
  - b. Discuss and address patient concerns regarding family history of hereditary breast and ovarian cancer syndrome
  - c. Find high quality genomics educational resources appropriate for primary care
4. **Expanded carrier screening (June 2017)**  
Following this session the learner will be able to:
- a. Refer to their local genetics centre and/or order genetic testing appropriately regarding reproductive genetic carrier screening
  - b. Discuss with patients expanded carrier screening, beyond family history and ethnicity
  - c. Find high quality genomics educational resources appropriate for primary care
5. **Autism Spectrum Disorder and Genetics (June 2017)**  
Following this session the learner will be able to:
- a. Refer to their local genetics centre and/or order genetic testing appropriately for autism spectrum disorder
  - b. Understand the features that distinguish non-syndromic from syndromic ASD (ASD plus)
  - c. Find high quality genomics educational resources appropriate for primary care
6. **Familial hypercholesterolemia (Oct 2016)**  
Following this session the learner will be able to:
- a. Identify and appropriately refer individuals who may benefit from consultation with lipid specialist and/or genetic consultation
  - b. Discuss and address patient concerns regarding family history of familial hypercholesterolemia
  - c. Find high quality genomics educational resources appropriate for primary care
7. **Long QT Syndrome (Oct 2016)**  
Following this session the learner will be able to:
- a. Appropriately refer to their local genetics centre and/or arrhythmia specialist for long QT syndrome
  - b. Discuss and address patient concerns regarding family history of long QT syndrome
  - c. Find high quality genomics educational resources appropriate for primary care
8. **Consanguinity (Nov 2015)**

Following this session the learner will be able to:

- a. Refer to their local genetics centre and/or order genetic testing appropriately regarding consanguinity
- b. Discuss and address patient concerns regarding consanguinity
- c. Find high quality genomics educational resources appropriate for primary care

**9. Prenatal Chromosomal Microarray (Nov 2015)**

Following this session the learner will be able to:

- a. Appropriately refer to their local genetics centre and/or order prenatal chromosomal microarray
- b. Discuss and address patient concerns regarding prenatal chromosomal microarray
- c. Find high quality genomics educational resources appropriate for primary care

**10. Alzheimer Disease (March 2015)**

Following this session the learner will be able to:

- a. Refer appropriately to their local genetics centre for Alzheimer disease
- b. Discuss and address patient concerns regarding family history of Alzheimer disease
- c. Find high quality genomics educational resources appropriate for primary care

**11. Multiple Sclerosis (March 2015)**

Following this session the learner will be able to:

- a. Appropriately refer to their local genetics centre for multiple sclerosis
- b. Discuss and address patient concerns regarding family history of multiple sclerosis
- c. Find high quality genomics educational resources appropriate for primary care

**12. Hypertrophic Cardiomyopathy (Jan 2015)**

Following this session the learner will be able to:

- a. Appropriately refer to their local genetics centre and/or cardiologist for hypertrophic cardiomyopathy
- b. Discuss and address patient concerns regarding family history of hypertrophic cardiomyopathy
- c. Find high quality genomics educational resources appropriate for primary care

**13. Factor V Leiden (Dec 2014)**

Following this session the learner will be able to:

- a. Refer to their local genetics centre and/or order genetic testing appropriately for factor V Leiden
- b. Discuss and address patient concerns regarding family history of factor V Leiden
- c. Find high quality genomics educational resources appropriate for primary care

**14. Hereditary Hemochromatosis (April 2014)**

Following this session the learner will be able to:

- a. Refer to their local genetics centre and/or order genetic testing for hereditary hemochromatosis
- b. Discuss and address patient concerns regarding family history of hereditary hemochromatosis
- c. Find high quality genomics educational resources appropriate for primary care



15. **Lynch Syndrome: Hereditary Colorectal Cancer Syndrome (April 2014)**  
Following this session the learner will be able to:
  - a. Refer to their local genetics centre and/or order genetic testing appropriately for Lynch syndrome (LS)
  - b. Discuss and address patient concerns regarding family history of LS
  - c. Find high quality genomics educational resources appropriate for primary care
  
16. **Autism/ Developmental Delay and Chromosomal Microarray (Nov 2014)**  
Following this session the learner will be able to:
  - a. Refer to their local genetics centre and/or order genetic testing appropriately for autism/developmental delay (ASD/DD)
  - b. Set appropriate expectations for a family referred for genetic consultation regarding a child with ASD/DD
  - c. Discuss the pros and cons of first tier genetic testing for ASD/DD

**\*EDUCATIONAL RESOURCES:**

[www.geneticseducation.ca](http://www.geneticseducation.ca) >Educational Resources > GEC-KO *on the run* or GEC-KO

**Messengers**

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

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

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.

1. Morrison S, Allanson JE, Carroll JC. Direct-to-consumer genetic testing. 2017 Oct. In: GEC-KO *Messengers* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-messengers/direct-to-consumer-genetic-testing/>
2. Morrison S, Carroll JC, Carter MC, Allanson JE. Genetics of autism spectrum disorder. 2017 Oct. In: GEC-KO *Messengers* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-messengers/autismspectrumdisorder/>
3. Morrison S, Carroll JC, Carter MC, Allanson JE. Genetics of autism spectrum disorder. 2017 Oct. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/autismspectrumdisorder/>
4. [not credited] A guide to understanding prenatal screening tests. 2017 June. In: Public Resources. Ottawa (ON): Genetics Education Canada – Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/public->

[resources/prenatal-and-preconception-genetics/guide-to-understanding-prenatal-screening-tests/](#)

5. Morrison S, Allanson JE, Hegele RA, Hadjiyannakis S, Carroll JC. Familial hypercholesterolemia. 2016 Oct. In: GEC-KO *Messengers* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-messengers/familial-hypercholesterolemia/>
6. Morrison S, Allanson JE, Hegele RA, Hadjiyannakis S, Carroll JC. Familial hypercholesterolemia. 2016 Oct. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/familial-hypercholesterolemia/>
7. Morrison S, Cremin C, Tomiak E, Allanson JE, Carroll JC. Hereditary breast and ovarian cancer syndrome(*BRCA1/BRCA2*). 2016 April. In: GEC-KO *Messengers* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-messengers/hereditary-breast-and-ovarian-cancer-brca1brca2/>
8. Morrison S, Cremin C, Tomiak E, Allanson JE, Carroll JC. Hereditary breast and ovarian cancer syndrome (*BRCA1/BRCA2*). 2016 April. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/hereditary-breast-and-ovarian-cancer-brca1brca2/>
9. Honeywell C, Rutberg, J, Gow R, Green M, Carroll JC, Allanson JE, Morrison S. Long QT syndrome. 2016 Oct. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/long-qt-syndrome/>
10. Morrison S, Sroka H, Allanson JE, Carroll JC. Chromosomal microarray, Prenatal. 2015 Sept. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/prenatal-chromosomal-microarray/>
11. Morrison S, Allanson JE, Carroll JC. Direct-to-consumer genetic testing. 2015 April. [Updated 2017 Oct] In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/direct-to-consumer-genetic-testing/>
12. Morrison S, Armour CM, Allanson JE, Carroll JC. Non-invasive prenatal testing. 2015 April. [Reviewed 2017 Oct]. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/non-invasive-prenatal-testing/>
13. Dorman H, Carroll JC, Morrison S, Allanson JE, Meschino WS. Alzheimer disease. 2014 Jan. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/alzheimer-disease/>
14. Morrison S, Carroll JC, Allanson JE. Consanguinity. 2014 May. [Reviewed 2017 Oct]. In: GEC-KO *Messengers* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-messengers/consanguinity/>

15. Morrison S, Carroll JC, Allanson JE. Consanguinity. 2014 May. [Reviewed 2017 Oct]. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/consanguinity/>
16. Morrison S, Carroll JC, Allanson JE. Factor V Leiden. 2014 Oct. In: GEC-KO *Messengers* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-messengers/factor-v-leiden-inherited-thrombophilia/>
17. Morrison S, Carroll JC, Allanson JE. Factor V Leiden. 2014 Oct. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/factor-v-leiden-inherited-thrombophilia/>
18. Dorman H, Carroll JC, Morrison S, Allanson JE. Huntington disease. 2014 Jan. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/huntington-disease/>
19. Honeywell C, Carroll JC, Morrison S, Allanson JE. Hypertrophic cardiomyopathy. 2014 June. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/hypertrophic-cardiomyopathy/>
20. Morrison S, Allanson JE, Tomiak E, Semotiuk K, Carroll JC. Lynch syndrome. 2014 April. In: GEC-KO *Messengers* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-messengers/lynch-syndrome/>
21. Morrison S, Allanson JE, Tomiak E, Semotiuk K, Carroll JC. Lynch syndrome. 2014 April. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/colorectal-cancer-lynch-syndrome/>
22. Guimond C, Sadovnick D, Dymont D. Multiple sclerosis. 2014 Sept. In: Carroll, JC, Allanson, JE, Morrison S, editors. GEC-KO *Messengers* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-messengers/multiple-sclerosis/>
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25. Rideout AL, Allanson JE, Morrison S, Carroll JC. Schizophrenia. 2014 Jan. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from: <http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/schizophrenia/>
26. Dorman H, Carroll JC, Morrison S, Allanson JE, Meschino WS. Type 2 diabetes. 2014

- Jan. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from:  
<http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/type-2-diabetes/>
27. Morrison S, Carroll JC, Allanson JE. Chromosomal microarray (pediatric/adult). 2013 Sept [Updated 2015 Nov]. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from:  
<http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/chromosomal-microarray/>
  28. Morrison S, Carroll JC, Graham GE, Allanson JE. Hereditary hemochromatosis. 2013 Sept. In: GEC-KO *Messengers* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from:  
<http://geneticseducation.ca/educational-resources/gec-ko-messengers/hereditary-hemochromatosis/>
  29. Morrison S, Carroll JC, Graham GE, Allanson JE. Hereditary hemochromatosis. 2013 Sept. In: GEC-KO *on the run* [Internet]. Ottawa (ON): Genetics Education Canada - Knowledge Organization. 2011-2017. Available from:  
<http://geneticseducation.ca/educational-resources/gec-ko-on-the-run/hereditary-hemochromatosis/>

\*POINT OF CARE TOOLS: [www.geneticseducation.ca](http://www.geneticseducation.ca) > 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.

1. [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)
6. Part I: How to identify Familial Hypercholesterolemia and individuals most likely to benefit from referral to a lipid specialist
7. Part II: Diagnosis of Familial Hypercholesterolemia
8. [Hypertrophic Cardiomyopathy](#): Evaluation and Management Tool (2014)
9. [General Hereditary Cancer Syndrome](#) Triage Tool: Red Flags to identify those with risk of a Hereditary Cancer Syndrome most likely to benefit from a referral to genetics.(2014)

10. [Hereditary Breast and Ovarian Cancer Syndrome \(BRCA1/BRCA2\)](#): Hereditary breast and ovarian cancer referral screening tool to identify patients most likely to benefit from referral to genetics. (2014)
11. 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.
12. [Lynch Syndrome](#): Red Flags to identify those at high risk of Lynch Syndrome most likely to benefit from a referral to genetics. (2014)
13. 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.
14. [Hereditary Renal Cell Cancers](#): Triage point of care tool: Practical guide to identify those patients most likely to benefit from referral to genetics (2014)
15. [Hereditary Hemochromatosis](#): Triage and Surveillance point of care tool (2014)
16. [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.*

**Uncertain – 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).*

**Standardized and meaningful evaluation of educational resources and sessions**

## GenomePlus Pty Ltd, Australia

- 1) *Name of Individual(s) Submitting Entry:* **Nichollette 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 <http://genomicseducation.net/>).*

**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.**

- 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).*

## Global Genomic Medicine Collaborative (G2MC)

- 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 <http://genomicseducation.net/>).*

**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

- 1) *Name of Individual(s) Submitting Entry:* **Dr. Anneke Seller and Dr. Michelle Bishop**
- 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/>).*

- **Master's framework in Genomic Medicine**
- **Online courses (from introductory courses to specific resources aimed at those delivering the 100,000 Genomes Project)\***
- **Condition factsheets \***
- **Clinical tools (e.g. family history tool and 100,000 Genomes Project eligibility wheels)\***
- **Board Games\***
- **For further information please see [www.genomicseducation.hee.nhs.uk](http://www.genomicseducation.hee.nhs.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 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).**

- 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 moment, although we would be interested to hear of any possible collaborations.**

- 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 moment.**

- 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).*



## Implementing Genomics in Practice (IGNITE) Network

- 1) *Name of Individual(s) Submitting Entry: Vicky Pratt and Kristin Weitzel*
- 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/>).*

IGNITE is an NIH-funded network dedicated to supporting the implementation of genomics in healthcare. 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 and strategies and related data from IGNITE Network sites to facilitate collaboration and information sharing within the Network; and contribute to the evidence base of patient, provider, and student/trainee education supporting clinical implementation of genomic medicine and pharmacogenomics.

The Network disseminates the methods and best practices its members develop in order to advance the implementation of genomics in healthcare through the [SPARK Toolbox \(https://ignite-genomics.org/spark-toolbox\)](https://ignite-genomics.org/spark-toolbox), which provides genomic medicine resources for clinicians and researchers. The SPARK Toolbox houses both unique implementation resources that are created by IGNITE study and affiliate sites and also links to other helpful resources available on the web. Below is a list of some examples/types of unique educational resources that can be found in the toolbox. I would recommend linking to the toolbox itself (vs. individual resources) since the website is updated frequently to maintain current copies of the resources and/or newly available resources.

### SPARK Tool – Researchers

#### Study Recruitment and Education Materials

CYP2C19 – PPI Study Provider Education Sheet Source: University of Florida Health Personalized Medicine Program CYP2C19 – PPI Study Patient Education Sheet Source: University of Florida Health Personalized Medicine Program CYP2D6 – Pain Medicine Study Patient Education Sheet Source: University of Florida Health Personalized Medicine Program CYP2D6 – Pain Medicine Study Patient Education Sheet (OneFlorida  
...

### SPARK Tool - Clinicians

#### Resources for Patients and Providers: CYP2D6 – Opioids

CYP2D6 Summary for Patients and Their Families Source: St. Jude Children's Research Hospital CYP2D6-Codeine Pharmacogenomic Lab Test Summary Source: Mayo Clinic Center for Individualized Medicine CYP2D6 Information Page Source: St. Jude Children's Research Hospital Medical Genetics Summary: Codeine Therapy and CYP2D6 Genotype Source: NIH National Center for Biotechnology Information Medical Genetics Summary: Tramadol Therapy and ...

### SPARK Tool - Clinicians

#### Reimbursement and Coding for Genetic Testing

**Guidance on the Use of Current Procedural Terminology Coding for Molecular Pathology Source: IGNITE Clinical Validity, Utility, and Economics Working Group Webinars for Health Insurers and Payers: Understanding Genetic Testing Source: NHGRI Insurer Education Working Group of the Inter-Society Coordinating Committee for Practitioner Education Resources for Coverage and Reimbursement of Genetic Tests Source: National Human ...**

#### **SPARK Tool - Clinicians**

##### **Resources for Patients and Providers**

**Monogenic Diabetes Intake Questionnaire – MODY Source: University of Maryland  
Algorithm for Monogenic Diabetes Genetic Testing – MODY Source: University of Maryland  
Maryland Guide for Discussing APOL1 Genetic Risk with Patients – APOL1 Source: Icahn School of Medicine at Mount Sinai  
Understanding the Risks of Your APOL1 Genetic Test Result – APOL1 Source: Icahn School of Medicine at Mount Sinai ...**

#### **SPARK Tool - Researchers**

##### **Resources for Patients and Providers**

**Quick Facts on the Correlation of APOL1 with Chronic Kidney Disease Source: Icahn School of Medicine at Mount Sinai  
Preventing Kidney Disease through Genetic Testing Source: Icahn School of Medicine at Mount Sinai ...**

#### **SPARK Tool - Clinicians**

##### **Resources for Patients and Providers: CYP2D6 and CYP2C19-SSRIs**

**Drug-Gene Testing Information (including CYP2D6 and CYP2C19-SSRIs) Source: Mayo Clinic Center for Individualized Medicine  
Patient Education Handouts Source: Cincinnati Children’s Hospital  
Article: UF PharmaNote – CYP2D6 and CYP2C19 for SSRIs Source: University of Florida Health  
Personalized Medicine Program  
Pediatric SSRI PGx Cheat Sheet – Educator Source: University of Florida Health Personalized Medicine Program  
Pediatric SSRI ...**

#### **SPARK Tool - Clinicians**

##### **Resources for Patients and Providers: TPMT – Thiopurines**

**TPMT Summary for Patients and Their Families Source: St. Jude Children’s Research Hospital  
TPMT-Thiopurines Pharmacogenomic Lab Test Summary Source: Mayo Clinic Center for Individualized Medicine  
TPMT Information Source: St. Jude Children’s Research Hospital  
NCBI Medical Genetics Summary: Azathioprine Therapy and TPMT Genotype Source: NIH National Center for Biotechnology Information  
NCBI Medical Genetics Summary: Mercaptopurine Therapy and TPMT ...**

#### **SPARK Tool - Clinicians**

##### **Resources for Patients: Family History**

**My Family Health Portrait Tool Source: Department of Health and Human Services  
Family History Resources for Patients Source: Duke Center for Applied Genomics and Precision Medicine  
Genomics and Diseases Information Page Source: Centers for Disease Control and Prevention  
Presentation – How Family History Can Affect Your Health Source: IGNITE Educational Working Group  
Brochure – Information ...**

#### **SPARK Tool - Clinicians**

##### **Resources for Patients and Providers: CYP2C19 – Clopidogrel**

**Brochure on Genetic Testing for Clopidogrel (Plavix) Source: University of Florida Health Personalized Medicine Program  
Video: CYP2C19 and Clopidogrel (Plavix) Response**

Source: Coriell Personalized Medicine Collaborative Patient Education Brochure for Clopidogrel Source: Icahn School of Medicine at Mount Sinai CYP2C19 Summary for Patients and Their Families Source: St. Jude Children's Research Hospital CYP2C19-Clopidogrel Pharmacogenomic Lab Test ...

### Publications

To date, IGNITE Network grants have supported 0 publications Multisite Investigation of Outcomes With Implementation of CYP2C19 Genotype-Guided Antiplatelet Therapy After Percutaneous Coronary Intervention Authors: Cavallari LH, Lee CR, Beitelshes AL, Cooper-DeHoff RM, Duarte JD, Voora D, Kimmel SE, McDonough CW, Gong Y, Dave CV, Pratt VM, Alestock TD, Anderson RD, Alsip J, Ardati AK, Brott [...]

### Working Groups

The IGNITE working groups support the mission of the Network through the creation of guidelines and methods for the adoption of genomics into clinical practice, evaluating implementation efforts and assessing outcomes. They help to encourage collaboration and networking among researchers, clinicians, providers and other stakeholders. Common Measures Working Group (CMG) Mission statement: The mission of [...]

### Genomic Medicine Implementation: The Personalized Medicine Program (PMP)

As part of the UF Clinical and Translational Science Institute, the UF Health Personalized Medicine Program partners with health professionals and patients at UF Health and across the state to develop, implement, study and refine methods that allow genetic information to be used as a routine part of patient care. Our initial focus is on [...]

### Genetic Risk and Primary Care

People of African ancestry (Blacks) have increased risk of kidney failure due to numerous socioeconomic, environmental, and clinical factors. Two variants in the APOL1 gene are now thought to account for much of the racial disparity associated with hypertensive kidney failure in Blacks. However, this knowledge has not been translated into clinical care to help ...

### Implementation, Adoption, and Utility of Family History in Diverse Care Settings

The study will take place in 35 clinics across 6 states in 5 U.S. health systems: Duke University, Essentia Health, Medical College of Wisconsin, University of North Texas, and Travis Air Force base. These settings represent a diversity of populations (underserved, rural, migrant, and white collar), a diversity of clinics (academic, indigent health, and community [...])

- 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..*

We are currently developing Implementation "How-To" guides for clinical practice to be available in the SPARK toolbox in Jan 2018. We are submitting an abstract that summarizes the process used to develop these guides, literature findings, and final structure. It may be helpful for ISCC to present the IGNITE SPARK toolbox as an implementation/education resource and also include data from the implementation guide development process, which has been very interesting.

- 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.*

**Kristin Weitzel is currently leading....**

- 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.*

**Resources and needs for education on genomic medicine implementation?**

**Presenter: Kristin Weitzel?**

- 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)

- 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 <http://genomicseducation.net/>).*

**We offer webinars available to the public:**  
[http://www.isong.org/ISONG\\_webinars.php](http://www.isong.org/ISONG_webinars.php)

- 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)

- 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 <http://genomicseducation.net/>).*

**We have a Residency Education Committee (which I currently chair). We have developed an outline of the genetics knowledge we believe every psychiatrist should have, and this is posted on the website [www.ispg.net](http://www.ispg.net) . We also have links on this website to two learning modules that we believe are particularly pertinent (one on genetic testing for neurodevelopmental disorders and one on pharmacogenetics testing). These modules were designed in conjunction with the National Neuroscience Curriculum Initiative (funded by NIMH).**

- 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. The problem that I have is that I have clinical responsibilities on Wednesdays and it is usually difficult for me to participate on that day.**

- 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)

- 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 <http://genomicseducation.net/>).*

### Programs:

Title	Website	Description
NCI Summer Curriculum in Cancer Prevention	<a href="http://cftp.cancer.gov/summer-curriculum">cftp.cancer.gov/summer-curriculum</a>	Includes two courses: <ul style="list-style-type: none"> <li>• Principles and Practice of Cancer Prevention</li> <li>• Control and Molecular Prevention</li> </ul>

### Resources:

Title	Website	Description
National Cancer Institute	<a href="https://www.cancer.gov/">https://www.cancer.gov/</a>	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.
Cancer Genetics Services Directory	<a href="https://www.cancer.gov/about-cancer/causes-prevention/genetics/directory">https://www.cancer.gov/about-cancer/causes-prevention/genetics/directory</a>	List of professionals who provide services related to cancer genetics (cancer risk assessment, genetic counseling, genetic susceptibility testing, and others). Professionals must apply to be listed in this directory and must meet certain criteria.

<p>PDQ Cancer Genetic Summaries</p>	<p><a href="http://www.cancer.gov/publications/pdq/information-summaries/genetics">http://www.cancer.gov/publications/pdq/information-summaries/genetics</a></p>	<p>The PDQ cancer genetic summaries are an online evidence based cancer genetic summaries developed and maintained by an interprofessional editorial board. These include the follow topics:</p> <ul style="list-style-type: none"> <li>• Cancer Genetics Overview</li> <li>• Cancer Genetics Risk Assessment and Counseling</li> <li>• Genetics of Breast and Gynecologic Cancers</li> <li>• Genetics of Colorectal Cancer</li> <li>• Genetics of Endocrine and Neuroendocrine Neoplasias</li> <li>• Genetics of Kidney Cancer (Renal Cell Cancer)</li> <li>• Genetics of Prostate Cancer</li> <li>• Genetics of Skin Cancer</li> </ul>
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- 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.**

- 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).*

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



## National Center for Biotechnology Information (NCBI)

- 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 <http://genomicseducation.net/>).*

**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)

- 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 <http://genomicseducation.net/>).*

**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)

- 1) *Name of Individual(s) Submitting Entry:* **Donna Messersmith, PhD, Health Policy Analyst, Genomic Healthcare Branch, Division of Policy, Communications and Education, NHGRI**
- 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/>).*

### **“Global Genetics and Genomics Community “(G3C) genomics cases**

(<http://genomicscases.net>): 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. All resources are vetted by the G2C2 Editorial Board consisting of genomics education specialists including genetic counselors, nurses, pharmacists, physicians, and physician assistants. 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, sharing their approaches and resources for genomic education. Project groups address genomic educational gaps in resources, methods, and target audiences. The Genomic Healthcare Branch of NHGRI provides staff support. The current ISCC Co-Chairs are Richard Haspel, M.D., Ph.D., Beth Israel Deaconess Medical Center and Teri Manolio, M.D., Ph.D., Director, Division of Genomic Medicine, NHGRI.

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

(<http://genomicsintegration.net/>): 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 offers 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://familyhistory.hhs.gov/>): 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.

**Family Health History Tool Conference** (<https://www.genome.gov/27565264/the-nih-family-health-history-tool-conference-2016/>): The goal was to prepare the Family Health History Tool field to improve personal health by responding effectively to rapid changes in Family Health History data uses, Health Information Technology capabilities, and research opportunities.

**The Genomics in Medicine Lecture Series (NHGRI and Suburban Hospital)**

(<http://www.genome.gov/27555276>): Videos of hour-long lectures for healthcare professionals; aimed to enhance understanding of the intersection between genomics and medicine. Includes some disease- and specialty-specific topics. 2011-2014, 24 lectures.

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

(<https://www.genome.gov/19016904/faq-about-genetic-and-genomic-science/faq-about-genetic-and-genomic-science/>): 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/10000202/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.

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

**International Genomics Education Meeting** (<https://www.genome.gov/27567039/nhgri-international-genomics-education-meeting/>): Presentations from this meeting include an overview of primary care oriented education programs and best practices for genomics education implementation. International institutions participated. 2016.

**A Proposed Genomic Literacy, Education, and Engagement (GLEE) Initiative**

(<https://www.genome.gov/27568855/june-6-2017-a-proposed-genomic-literacy-education-and-engagement-gee-initiative/#1>), March 2017: Strategic visioning meeting to create a national campaign to enhance genomic awareness and understanding.

**National DNA Day** (<https://www.genome.gov/10506367/national-dna-day/>): 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/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/27550079/division-of-genomic-medicine/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.

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

(<http://rarediseases.info.nih.gov/gard>): Information about genetic and other rare diseases provided in lay-language. The GARD Information Center responds to requests for information from patients, family members, and providers by phone, email, and via a web form.

**Genome: Unlocking Life's Code** (<https://unlockinglifescode.org/>): 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/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.

- 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 Division of Policy, Communications and Education 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.

**Donna Messersmith and Kathy Calzone are leading the creation of a new module on familial hypercholesterolemia (FH) for the G3C resource, with collaboration from members of ISCC who are serving on the FH Module Advisory Board. Depending upon future funding, collaboration with ISCC members on future G3C modules is open to discussion.**

- 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 Division of Policy, Communications and Education 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).

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

- 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 <http://genomicseducation.net/>).*

**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 Society of Genetic Counselors (NSGC)

- 1) *Name of Individual(s) Submitting Entry:* **Colleen Caleshu**
- 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/>).*

Online Course Name	Link	Number of Contact Hours Available	Contact Hours Available Until
Exome 101	<a href="#">Learn more</a>	3.82 Category 1 Contact Hours	10/17/2019
NextGen Sequencing A to Z	<a href="#">Learn more</a>	4.51 Category 1 Contact Hours	05/12/2019
Psychiatric Genetics across Genetic Counseling Practice Settings	<a href="#">Learn more</a>	3.45 Category 1 Contact Hours	04/27/2018
Rare Diseases: Genetic Counselor and Patient Experiences	<a href="#">Learn more</a>	<i>This event has been submitted to the National Society of Genetic Counselors (NSGC) for approval of Category 1 CEUs. The American Board of Genetic Counseling (ABGC) accepts CEUs approved by NSGC for purposes of recertification. Approval for the requested CEUs and Contact Hours is currently pending.</i>	
A Psychosocial Approach to Genetic Counseling: Translation from Theory to Skills	<a href="#">Learn more</a>	4.33 Category 1 Contact Hours	11/1/2018



Revisiting Research: Improving Your Skills to Integrate Research into Your Role	<a href="#">Learn more</a>	3.57 contact hours	08/23/2018
What the Specialized Genetic Counselor Needs to Know about Other Areas of Genomic Medicine	<a href="#">Learn more</a>	4.63 contact hours	05/02/2018
Variant Interpretation in the Era of WES/WGS	<a href="#">Learn more</a>	3.60 contact hours	05/02/2018
Personalized and Precision Medicine	<a href="#">Learn more</a>	10.32 contact hours	06/09/2019
Incorporating Technology Into Genetic Counseling Practice	<a href="#">Learn more</a>	10.17 contact hours	05/31/2018
Career Advancement and Professional Development	<a href="#">Learn more</a>	10.60 contact hours	05/18/2019
Medical Ethics: Mitigating Genetic Counselor Conflict of Interest and Legal Compliance	<a href="#">Learn more</a>	1.0 contact hours	05/17/2018
2016 NSGC Conference Recordings	<a href="#">Learn more</a>	Up to 56.38 contact hours	01/31/2019
2015 NSGC Conference Recordings	<a href="#">Learn more</a>	Up to 61.3 contact hours	03/17/2018

- 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.*

**Not 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 don't have any specific projects in mind 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).*

**Information regarding what healthcare providers of different types need to know to provide baseline genetic services in their area of practice and when/where to refer when additional services are needed.**

## The Jackson Laboratory

- 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 <http://genomicseducation.net/>).*

**\*All are appropriate for inclusion in G2C2 and many already are**

### **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. Learn more about the program at [www.jaxge.org/cancergenomics](http://www.jaxge.org/cancergenomics).

### **Online Courses**

Free, self-directed programs for continuing education credit.

#### **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](#)

### **Hereditary Breast and Ovarian Cancer (HBOC)**

Learn how to identify, evaluate, and manage patients at increased risk of HBOC.

[Access CME 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](#)

### **Select Other Educational Resources**

[The ABCs of Chromosomal Microarray](#). Explains features of chromosomal microarray, including how the test works, what it detects, common indications, and considerations in results interpretation.

[Cascade Screening Infographic](#). Presents an overview of cascade screening, the systematic testing in a family with a hereditary syndrome to identify unaffected individuals also with the condition.

[Genetic Testing Methods eBook](#). Provides information about different genetic testing methods currently used in testing for hereditary cancer syndromes (enhanced e-book available for download).

[Genomic Technologies for Oncologists eBook](#). Provides an overview of genomic technologies used in cancer research and clinical care (enhanced e-book available for download).

[Family History Core Principles Slide Set](#). Teaches about inheritance patterns, genetic red flags, and risk assessment using didactic presentation and case studies to demonstrate concepts.

[GINA Discussion Guide](#). 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. Additionally, Kate Reed, June Carroll and Teri Manolio will be attending an invited meeting in Australia which is aimed at developing an evaluation framework for assessing efforts to integrate genetics into the clinical workforce in February 2018. This program may inform ISCC's approach to evaluation, and we suggest revisiting this project of creating an evaluation instrument after February.**

- 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

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 <http://genomicseducation.net/>).*

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 organizations. Using team-based 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 resident genomic pathology curriculum. Released in 2014, the curriculum consists of approximately seven hours of instruction and uses a flipped classroom and team-based learning approach. The instructor leading this workshop does not need to be an expert in genomic pathology, however; a strong background in molecular pathology is recommended.
- 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 Universal Genomics Instructor Handbook and Toolkit 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 (<http://pathologylearning.org/trig>). 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) *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.**

**References:**

1. Haspel RL, Lin Y, Fisher P, Ali A, Parks E; Biomedical Excellence for Safer Transfusion (BEST) Collaborative. Development of a validated exam to assess physician transfusion medicine knowledge. *Transfusion*. 2014 May;54(5):1225-30.
2. Haspel RL, Lin Y, Mallick R, Tinmouth A, Cid J, Eichler H, Lozano M, van de Watering L, Fisher PB, Ali A, Parks E; BEST-TEST Investigators. Internal medicine resident knowledge of transfusion medicine: results from the BEST-TEST international education needs assessment. *Transfusion*. 2015 Jun;55(6):1355-61.

- 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

- 1) *Name of Individual(s) Submitting Entry: Maggie Kirk\* and 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 <http://genomicseducation.net/>).*

**The Genomics Policy Unit (GPU), University of South Wales, is one of the longest established research groups studying the 'new genetics' in existence in the UK. Since 1996 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 professionals 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 in relation to this has been the development of the Telling Stories Understanding Real Life Genetics web-based education tool. It is already on the repository.**

**From 2004-2012, Dr Tonkin 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 (we are both members of the International Society of Nurses in Genetics).**

**A key focus of our current work is in establishing the Global Genomics Nursing Alliance (G2NA), 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. We would also be happy to talk about Telling Stories and our work 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.*

**Dr Emma Tonkin will be leading an initiative with G2NA in establishing global minimum competencies in genomics for nurses.**

- 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).*

**Through our work within the G2NA, we are also planning to disseminate and apply a benchmarking tool we have developed in relation to progress in integrating genomics into nursing practice globally. We shall shortly be seeking funding for this major initiative.**

## Compendium Entry (Blank form for new entries or updates)

Name of Organization:

- 1) Name of Individual(s) Submitting Entry:
- 2) List and briefly describe your organization's active educational programs/best practices/initiatives/resources related to genomics education. Please include any relevant links. Place an asterisk next to any resources you would consider for inclusion in G2C2 (the genomics educational repository at <http://genomicseducation.net/>).
- 3) Would someone be interested in presenting your organization's educational programs/best practices/initiatives/resources during an ISCC plenary call or face-to-face meeting? If yes, please indicate topic, who might present, and whether there is a preference for a call or face-to-face meeting.
- 4) Would someone in your organization be interested in leading a project? If yes, please describe project including deliverable(s), opportunities for collaboration and who might lead the project.
- 5) Would someone in your organization be interested in leading a discussion related to issues/best practices in genomics education during an ISCC plenary call or face-to-face meeting? If yes, please describe topic, who might lead a discussion, and whether there is a preference for a call or face-to-face meeting.
- 6) Other ideas for ISCC: please include additional potential projects, discussions and opportunities for collaboration (even if someone in your organization would not be interested in leading).