EMPAG
EUROPEAN MEETING ON PSYCHOSOCIAL ASPECTS OF GENETICS

EMPAG Scientific Programme

The programme is subject to change.

Saturday, May 21, 2016

10:30 - 12:00 **EMPAG/ESHG Educational Session E2: Genetic Privacy and Data Sharing**
Room 155+116

E02.1 Identifying Personal Genomes by Surname Inference
***Yaniv Erlich**, US*

E02.2 The role of policy in navigating the privacy landscape and promoting responsible genomic data sharing
***Edward Dove**, UK*

14:00 - 14:30 **Opening: joint with ESHG Welcome addresses**

14:30 - 16:00 **EMPAG Plenary Session 1: The evolution of Genetic Counseling**
Room 112+123

EPL1.1 Data sharing to support UK clinical genetics and genomics services
***Sobia Raza**, A. Hall, C. Rands, S. Deans, D. McMullan, M. Kroese;*
Cambridge, United Kingdom

EPL1.2 Landscape of genetic tests worldwide: a report from the NIH Genetic Testing Registry (GTR)
***Adriana J. Malheiro**, B.L. Kattman, B. Gu, V. Hem, K.S. Katz, M. Ovetsky, R. Villamarin-Salomon, G. Song, C. Wallin, D.R. Maglott, J.M. Lee, W.S. Rubinstein;*
Bethesda, United States

EPL1.3 Informing clinical implementation of genomics by "doing" - Practitioner perspectives on integrating genomics in their practice

Melissa Martyn, *E. Forbes, A. Kanga-Parabia, I. Macciocca, S. Metcalfe, L. Keogh, E. Lynch, the Melbourne Genomics Health Alliance, C. Gaff;*
Parkville, VIC, Australia

EPL1.4 Genetic Counsellor training in the Genomics Era: The development of a new training scheme in England

Michelle Bishop, *C. Benjamin, L. Boyes, G. Hall, R. Macleod, M. McAllister, A. Middleton, C. Patch, N. Latham, A. Seller, V. Davison, S. Hill;*
Birmingham, United Kingdom

EPL1.5 Ensuring patient centred care in genomics - patients' experiences of the Melbourne Genomic Health Alliance demonstration project

Elly L. Lynch, *M. Martyn, I. Macciocca, S. Metcalfe, N. Mupfeki, E. Forbes, E. Creed, G. Brett, E. Wilkins, D. Bradford, A. Sexton, L. Keogh, L. di Pietro, Melbourne Genomics Community Advisory Group, Melbourne Genomics Health Alliance, C. Gaff;*
Parkville, Melbourne, Australia

EPL1.6 Evolving genetic counselling practice in bicultural New Zealand, a case study of CDH1 testing in a large Maori whanau (family)

Kimberley K. Gamet;
Auckland, New Zealand

16:00 - 16:30 Coffee break

16.30 - 18:00 **EMPAG Symposium ESY1: "Diversity"**
Room 122+123

ESY1.1 Introductions to speakers & objective of the session

Nadeem Qureshi
Nottingham, United Kingdom

ESY1.2 Reducing inequalities in the USA: implementation of NHGRI's genomics research programs in clinical medicine

Vence Bonham
Bethesda, MD, United States

ESY1.3 Experience from Melbourne Genomics Health Alliance to improve access for underserved population

Elly Lynch; Sylvia Metcalfe
Melbourne, Australia

ESY1.4 How is Genomics England talking inequalities?

Michael Parker; Julian Barwell
Leicester, United Kingdom

Round table discussion with Q&A session

18:00 - 18:30 Coffee break

18.30 - 20:00 **EMPAG/ESHG Joint Concurrent Session C06: Carrier and Newborn Screening**
Room 111

C06.1 Responsible implementation of expanded carrier screening - Recommendations of the European Society of Human Genetics

L. Henneman, P. Borry, D. Chokoshvili, M.C. Cornel, C.G. Van El, F. Forzano, A. Hall, H.C. Howard, S. Janssens, H. Kayserili, P. Lakeman, A. Lucassen, S.A. Metcalfe, L. Vidmar, G. De Wert, W.J. Dondorp, ***Borut Peterlin****;*
Ljubljana, Slovenia

C06.2 Setting the scope of screening: ethical reflections on the offer of reproductive choice

Greg Stapleton*;*
Maastricht, Netherlands

C06.3 Factors for successful implementation of population-based expanded carrier screening: what can we learn from existing initiatives?

Kim C.A. Holtkamp, *I.B. Mathijssen, P. Lakeman, M.C. Van Maarle, W.J. Dondorp, L. Henneman, M.C. Cornel;*
Amsterdam, Netherlands

C06.4 Advantages of expanded universal carrier screening: What is at stake?

Sanne van der Hout, *K. Holtkamp, L. Henneman, G. De Wert, W. Dondorp;*
Maastricht, Netherlands

C06.5 Clinical utility of expanded carrier screening: reproductive behaviors of at-risk couples

C. Ghiossi, K. Ready, C. Lieber, J.D. Goldberg, I.S. Haque, ***Gabriel A. Lazarin****, K.K. Wong;*
South San Francisco, United States

C06.6 Genetic counseling in an oocyte donation program: knowledge, satisfaction and psychological

impact of the expanded carrier screening.
***Josep Pla**, E. Clua, M. Boada, B. Coroleu, P.N. Barri, A. Veiga, X. Estivill, G. Lasheras, A. Abulí;*
Barcelona, Spain

20:00 - 21:30 **Networking Mixer at the CCIB (conference venue)**

Sunday, May 22, 2016

08:30 - 10:00 **EMPAG/ESHG joint Symposium S01: The future lies in uncertainty**
Plenary Hall

S01.1 Public understanding of risk/ how to interpret big data
***Anneke Lucassen**, United Kingdom*

S01.2 Receiving personal genomic services: consumer's perspective
***Scott Roberts**, United States*

S01.3 The blessings of uncertainty in the genomics era
***Aad Tibben**, The Netherlands*

10:00 - 10:15 Coffee Break, Free Poster Viewing, Exhibition

10:15 - 11:15 **Poster Viewing with Authors (Group A)**

11:15 - 12:45 **EMPAG Educational Session EE1: DTC genetic testing revisited: empowering patients – caring for consumers?**
Room 122+123

EES.1 Shifting roles and relationships: the impact of direct-to-consumer genetic testing on healthcare delivery
***E. Gordon**;*
Mountain View, CA, United States.

EES.2 The "activated patient": A fresh look at empowerment
***B. Prainsack**;*
London, United Kingdom.

EES.3 Closing the Gap?
***Heidi Howard**;*
Uppsala, Sweden.

12:15 - 13:00 Break

13:00 - 14:30 **EMPAG/ESHG Joint Concurrent Session C09: Prenatal Decision Making**
Room 117

C09.1 Introduction of non-invasive prenatal testing as a first-tier screening test: A survey among Dutch midwives about their role as counselors
*L. Martin, J. Gitsels-van der Wal, **Lidewij Henneman**;*
Amsterdam, Netherlands

C09.2 Should we be worried about children born after PGD for Huntington's Disease?
***Mariska den Heijer**, A. Tibben, G. de Wert, W. Dondorp, M. van der Sangen, C. de Die;*
Rotterdam, Netherlands

C09.3 Informed choice in prenatal genetic testing: the choice between non-invasive and invasive prenatal testing
***Sanne L. van der Steen**, K.E.M. Diderich, I.M. Bakkeren, M.M.F.C. Knapen, A.T.J.I. Go, A. Tibben, M.I. Srebniak, D. Van Opstal, M.G. Polak, R.J.H. Galjaard, S.R. Riedijk;*
Rotterdam, Netherlands

C09.4 Attitudes, decision-making and experiences of preimplantation genetic diagnosis (PGD) users
***Shachar Zuckerman**, S. Gooldin, G. Altarescu;*
Jerusalem, Israel

C09.5 What do pregnant women think of prenatal whole-exome sequencing? A cross-cultural comparison
***Camilla Richards**, S. Dheensa, A. Newson, Z. Deans, S. Shkedi-Rafid, J. Hyett, Z. Richmond, A. Fenwick;*
Southampton, United Kingdom

C09.6 Why do pregnant women accept or decline prenatal diagnosis for Down syndrome?
Charlotta Ingvoldstad, *E. Ternby, O. Axelsson, G. Annerén, P. Lindgren;*
Stockholm, Sweden

14:30 - 15:00 Vitamin Break

15:00 - 16:30 **EMPAG Workshop: Getting personal: Beyond the genetic test result**
Room 122+123

Speakers: Gerrit van Putten and Lara Ras

Sequencing techniques are generating huge amounts of data. Each significant result has an impact on a person, a family and perhaps even a generation. Lara was confronted with a tough decision about her pregnancy at 23 weeks gestation. Gerrit was told all his life that he did not need to worry about the Huntington's disease in his family, but he chose to engage in predictive testing. In this session Lara and Gerrit are willing to share their experience with genetic testing and be interviewed by the audience. This session is intended as a bridge between those who develop and use ever more advanced techniques and those receiving the results.

16:30 - 16:45 Coffee Break, Free Poster Viewing, Exhibition

16:45 - 17:45 **Poster Viewing with Authors (Group B)**

17:45 - 19:15 **EMPAG Plenary Session 2: The Implication for Families of Various Genetic Diseases**
Room 122+123

EPL2.1 Feedback on professional experiences on the disclosure of genetic information to family members in France
Sandrine de Montgolfier, *E. Rial-Sebbag, D. d'Audiffret, C. Farnos, B. Derbez, A. de Pauw, F. Galacteros, D. Stoppa-Lyonnet;*
Paris cedex 13, France

EPL2.2 Co-designing an intervention to facilitate family communication about inherited genetic conditions (IGC).
Alison Metcalfe, *E. Rowland, I. Eisler, M. Ellison, F. Flinter, J. Grey, S. Hutchison, C. Jackson, L. Longworth, R. MacLeod, M. McAllister, T. Murrells, C. Patch, G. Robert, F. Ulph;*
London, United Kingdom

EPL2.3 CANCELLED
Holly Etchegary, *K.A. Hodgkinson;*
St. John's, Canada

EPL2.4 Twenty years' experience conducting presymptomatic testing for late-onset neurological diseases: what have we learned?
M. Paneque, J. Félix, Á. Méndes, C. Lemos, S. Lêdo, J. Silva, ***Jorge Sequeiros****;*
Porto, Portugal

EPL2.5 Predictive testing for Huntington's disease under the age of 18 years in the UK 1993-2014.
Oliver W.J. Oliver, *R.C. Cann, A. Clarke, C. Compton, A. Fryer, S. Jenkins, N. Lahiri, R. MacLeod, Z. Miedzybrodzka, P.J. Morrison, H. Musgrave, M. O'Driscoll;*
Sheffield, United Kingdom

EPL2.6 'I've had to fight for everything': a qualitative study exploring the experiences of support of young people with juvenile Huntington's Disease, and their parents, in England.
Penny Curtis, *O. Quarrell, R. Cann, H. Santini;*
Sheffield, United Kingdom

Monday, May 23, 2016

08:30 - 10:00 **EMPAG/ESHG/ASHG Symposium S09. Debating germline genome editing**
Plenary Hall

S09.1 Technical opportunities of genome editing
Robin Lovell-Badge, *UK*

S09.2 Clinical aspects of germline gene editing
Kiran Musunuru, *US*

S09.3 Ethical aspect of germline gene editing
Annelien Bredenoord, *NL*

S09.4 ASHG statement on germline genome editing
***Kelly Ormond**, US*

10:00 - 10:15 Coffee break

10:15 - 11:15 **Poster Viewing with Authors (Group C)**

11:15 - 12:45 **EMPAG Plenary Session 3: Incidental Findings and Consent**
Room 122+123

EPL3.1 Development of a shared clinical exome sequencing consent form across multiple organisations
***Ivan Macciocca**, Z. Stark, D. Bruno, J. Taylor, S.M. White, T.Y. Tan, G.R. Brett, E. Creed, E. Lynch, C. Community Advisory Group, A. Januszewicz, C. Gaff;*
Melbourne, Australia

EPL3.2 Genomic investigations and incidental findings:the time for broad consent
***Gillian Crawford**, A. Fenwick, A. Lucassen;*
Southampton, United Kingdom

EPL3.3 Outcomes of a Randomized Controlled Trial of Consent Models for Genome Sequencing
***Barbara B. Biesecker**, P. Chrysostomou, H. Peay, L. Nelson;*
Bethesda, United States

EPL3.4 The UK 100,000 genomes project: views, expectations, and experiences of the first patients recruited
***Sandi Dheensa**, A. Lucassen, A. Fenwick, G. Crawford;*
Southampton, United Kingdom

EPL3.5 Diagnostic whole exome sequencing in pediatrics: Comparing parents' pre- and post-disclosure attitudes toward return of results
Candice Cornelis, A. Tibben, W. Dondorp, M. van Haelst, A. Bredenoord, N. Knoers, M. Düwell, I. Bolt, M. van Summeren;*
Utrecht, Netherlands

EPL3.6 Who is my family's keeper? Professional and family ethics in the era of unsolicited findings
***Roel H.P. Wouters**, E.E. Voest, R.M. Bijlsma, M.G.E.M. Ausems, J.J.M. van Delden, A.L. Bredenoord;*
Utrecht, Netherlands

12:55 - 13:00 Break

13:00 - 14:30 **EMPAG Plenary Session 4: Reporting the Results: Clinical and Ethical Considerations**
Room 122+123

EPL4.1 When children become adults: should biobanks re-contact?
Noor A.A. Giesbertz, A.L. Bredenoord, J.J.M. van Delden;*
Utrecht, Netherlands

EPL4.2 Re-contact in clinical practice: investigating the perspectives of healthcare professionals in the United Kingdom
***Daniele Carrieri**, S. Dheensa, S. Doheny, P.D. Turnpenny, A.J. Clarke, A.M. Lucassen, S.E. Kelly;*
Exeter, United Kingdom

EPL4.3 Incidental findings derived from Next-Generation sequencing: what does actionable in childhood really mean?
*A. Laberge, **Julie Richer**;*
Ottawa, Canada

EPL4.4 Autonomy in the genomics era
***Ainsley J. Newson**;*
Sydney, Australia

EPL4.5 An exploration of reporting practices for next generation sequencing technologies with laboratory personnel
Danya F. Vears, K. Sénécal, P. Borry;*
Leuven, Belgium

EPL4.6 Informing preparation for personal genomic screening
***Jane Fleming**, B. Terrill, M. Dziadek, E. Kirk, A. Roscioli, K. Barlow-Stewart;*
Sydney, Australia

14:30 - 15:00 Vitamin break

15:00 - 16:30 **EMPAG Plenary Session 5: From Public Understanding to Educating Professionals**
Room 122+123

EPL5.1 Socialising the Genome
Anna Middleton, *J. Borra, K. Nevin-Ridley, V. Parry, A. Sanders, J. Rayner;*
Cambridge, United Kingdom

EPL5.2 General public's attitudes towards genetics and genetic testing
Davit Chokoshvili*, *C. Belmans, R. Poncelet, S. Sanders, D. Vaes, I. Huys, P. Borry;*
Leuven, Belgium

EPL5.3 Exploring Australian public knowledge and understanding of genetic concepts and terminology in the era of personal genomics
Sylvia A. Metcalfe, *B. Terrill, C. Hickerton, J. Savard, E. Turbitt, A. Newson, C. Gaff, K. Gray, A. Middleton, B. Wilson;*
Parkville, Vic, Australia

EPL5.4 Development of Test Ordering Recommendations for Clinicians with Minimal Genetics Background from the ClinGen Consortium Consent and Disclosure Recommendations (CADRe) Committee
Kelly E. Ormond, *M. Hallquist, A. Buchanan, M. Cho, K. Brothers, C.R. Coughlin II, L. Hercher, L. Hudgins, S. Jamal, H. Levy, H. Peay, M. Roche, M. Stosic, M. Smith, W. Uhlmann, K. Wain, W.A. Faucett;*
Stanford, United States

EPL5.5 E-learning to improve communication about cancer family history and knowledge on hereditary colorectal cancer by non-genetic health professionals
Kirsten F.L. Douma, *E.M.A. Smets, E. Dekker, P.J. Tanis, C.M. Aalfs;*
Amsterdam, Netherlands

EPL5.6 Onco-equip: Preparing healthcare professionals in cancer care for routine genetic testing.
Leigh M. Jackson*, *H. Skirton;*
Plymouth, United Kingdom

16:30 - 16:45 Coffee Break

16:45 - 17:45 **Poster Viewing with Authors (Group D)**

17:45 - 19:15 **EMPAG Plenary Session 6: Helicopter View On Cancer Genetics**
Room 122+123

EPL6.1 Genetic Counselling Preferences and Psychological Impact of the Analysis by Next-Generation-Sequencing in Clinical Oncology (PIANO study)
Irene Esteban, *F. Balaguer, E. Adrover, E. Carrasco, N. Gadea, M. Vilaró, G. Llort, R. Jovert, M. Herráiz, S. Kohrrami, A. Herreros de Tejada, R. Morales, J. Cano, R. Serrano, B. Graña, C. Guillén, J. Alés, J. Brunet, J. Balmaña;*
Barcelona, Spain

EPL6.2 The impact of predictive genetic testing for cancer on young adults
Lea Godino, *D. Turchetti, L. Jackson, C. Hennessy, H. Skirton;*
Plymouth, United Kingdom

EPL6.3 How to approach all high risk members in known Lynch Syndrome families? Experiences of different contact methods and perceived challenges in passing the information to family members in Finland
Katja I. Aktan-Collan, *A. Haukkala, E. Kolttola, J. Mecklin, K. Pylvanainen, H. Kääriäinen;*
Helsinki, Finland

EPL6.4 Increasing awareness of lifestyle recommendations for cancer prevention among Lynch syndrome mutation carriers: results of a randomized controlled trial
A. Visser, A. Vrieling, M. Hoedjes, E. Kampman, ***Nicoline Hoogerbrugge****;*
Nijmegen, Netherlands

EPL6.5 Group-based patient education (GPE) courses for hereditary breast and ovarian cancer
Wenche Listøl, *H. Høberg-Vetti, G. Eide, C. Bjorvatn;*
Bergen, Norway

~~**EPL6.6 International Attitudes of General Practitioners and Breast Surgeons towards Breast/Ovarian Cancer Genetic Testing**~~
~~**Claire Julian Reinier**~~
This presentation had to be cancelled

20:00 Networking party

Tuesday, May 24, 2016

09:00 - 10:30 **EMPAG Plenary Session 7: Breaking News**
Room 111

EPL7.1 Development of new resources to improve communication in genetic counselling practice
Marina Álvarez Estapé, *I. Cuscó, L. Pérez-Jurado, C. Serra-Juhé;*
Bellaterra, Spain

EPL7.2 What determines decision making in preconception carrier screening and can it be influenced with message framing and narrative information?
Jan S. Voorwinden, *A.H. Buitenhuis, E. Birnie, A.M. Lucassen, M.A. Verkerk, I.M. van Langen, M. Plantinga, A.V. Ranchor;*
Groningen, Netherlands

EPL7.3 Transparency in the marketing of direct-to-consumer genetic tests
Jacqueline A. Hall, *J.E. Amato, C. Pagliari;*
Bellingdon, United Kingdom

EPL7.4 Genomic Newborn Screening: Public Health Policy Considerations and Recommendations
Martina C. Cornel, *J.M. Friedman, A.J. Goldenberg, K.J. Lister, K. Sénécal, D.F. Vears, the Global Alliance for Genomics and Health Regulatory and Ethics Working Group Paediatric Task Team;*
Amsterdam, Netherlands

EPL7.5 Cancer genetic counselling based on electronic mega-pedigrees incorporating Cancer Registry information
Vigdís Stefansdottir, *O.T. Johannsson, H. Skirton, L. Tryggvadottir, J.J. Jonsson;*
Reykjavik, Iceland

EPL7.6 Genetic testing for osteogenesis imperfecta on children suspected of abuse: does testing put parents at greater risk?
Emily Youngblom*, *D.J. Bowen, P.H. Byers, P. Pecora, L. Kelly;*
Seattle, United States

10:30 - 11:00 Coffee Break

11:00 - 12:30 **EMPAG/ESHG Joint Concurrent Session C20: Gene Editing: To Fear or to Cheer?**
Room 112

C20.1 Introduction by the Chair

C20.2 Regulating Genome Editing Technologies: Loopholes, rabbit wholes and the search for consistency
Rosario Isasi;
Miami, United States

C20.3 Are biomedical research fundamental principles appropriate for using genome editing in humans?
Emmanuelle Rial-Sebbag, *A. Cambon-Thomsen;*
Toulouse, France

C20.4 One small edit for man, one large edit for mankind? Points to consider for a responsible way forward with gene editing
Heidi C. Howard, *G. de Wert, C.G. van El, F. Forzano, D. Radojkovic, E. Rial-Sebbag, M.C. Cornel, on behalf of the Public and Professional Policy Committee of the European Society of Human Genetics;*
Uppsala, Sweden

C20.5 Ethical issues of gene editing: what does popular media report?
Emilia Niemiec*, *B.M. Zimmermann, H.C. Howard;*
Bologna, Italy

C20.6 Optimising CRISPR genome editing using machine learning
Riley Doyle;
London, United Kingdom

12:30 End of EMPAG meeting