Minutes of the Ethics of the Laboratory Techniques SIG

Wednesday, 12 July 2016
Berlin, Germany

SIG Chair: Vincenzo Cirigliano
Number in attendance: 23

Hot Topics for Position statements/opinions:
- Position statement on data sharing of variants
- Guideline on data storage and retrieval/review mechanisms, length of storage, level of security, what is stored, etc.

Topics and presenters for potential webinars:
NB A number of these topics were covered either in precongress courses or by invited speakers at ISPD and so could the recordings be used or those speakers asked to do to webinar as preparation has already been done.
- Counselling issues in NIPT? – with examples discussed at end of pre-congress course added in
- Issues in PGD/PGS at day 3 and at day 5
- Issues around mosaicism – Francesca Grati
- Experience of aCGH in the general population – Francesca Grati
- EQA for NIPT screening for aneuploidy – Sandi Deans
- Delivering fetal fraction – Eric Sistermans
- Lessons to be learnt when implementing NIPT in a public sector laboratory – Eric Sistermans and/or Lucy Jenkins

What topics does this SIG want to consider?
Would like to contribute to the pre-conception education of women regarding prenatal screening and diagnosis

What gaps are there in this area of special interest?
We lack an interactive area on the website to post difficult/interesting cases and get feedback.

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Suggestions for courses:
There were three suggestions, with two being discussed in detail.

1. **Bio-informatics – Vincenzo Cirigliano**
   Initially this was considered as a hands on course using laptops, but later discussion revolved around a more introductory course around the principles of bio-informatics for a broader and less specialist audience.
   - Introduction to bioinformatics to include interpretation of genomic data – Rossa Chiu
   - Research design
   - Data storage – how long, what data, what level of security, what is reported and what is stored in the patient record etc
   - Reclassification – when should this happen, should data be regularly reviewed if so how often, implications etc
   - Are there different standards required when offering this pre- as opposed to post-natally.
   - Implications for the commercial sector
   - Ethical and legal aspects – Rosario Slomas (recent review in Nature Genetics)

2. **PGD/PGS – Francesca Grati**
   This was discussed but several members felt that this is a topic better covered at ESHRE or other similar meetings. However, there was also a view that whilst this might apply in Europe, for an ISPD meeting in the US this might attract more interest. Topics of importance to include were mosaicism and timing of testing.

3. **Prenatal Diagnosis of monogenic disorders – Lyn Chitty**
   This wasn't discussed in detail but would include NIPD for monogenic disorders, prenatal WES and WGS, ethical and counselling issues, the future – WGS using NIPD, prenatal screening for monogenic disorders, etc.

**Attendees (from hand-written list)**
Javier Fernandez-Martinez
Wendy Rodenburg
Shagun Aggarwal
Martina Cornel
Meredith Miller
Boris Wang
Isabel Filges
Binbin Lu
Rossa Chiu
Catarina Silveira
Martijn Dollé

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Else Marie Vestergaard  
Angela Barrett  
Suzie Drury  
Stephanie Allen  
Sarah Mitchell  
Peter Johansen  
Angelique Kooper  
Francesca Romana Grati  
Sandi Deans  
Katrien Janssens  
Lyn Chitty  
Vincenzo Cirigliano

**Members not in attendance**

Erik Sistermans  
Lucy Jenkins  
Simon Patton  
Jane Hayward