**10th International-DSD/CAH Registry Steering Committee Meeting**

Sunday September 2017, 08:00-9:00

ESPE Washington, USA

**Minutes**

**Attending:** Faisal Ahmed, Anu Bashamboo, Olaf Hiort, Anna Nordenstrom, Rodolfo Rey, Richard Ross, Amy Wisniewski.

**Apologies**: Stephanie Bernstein, Jillian Bryce, Hannah Van Hove, Sam Okure, Martina Rodie

It was good to meet up collectively and individually in Washington and discuss a few I-DSD/I-CAH related issues. We did not have enough time to discuss all the issues together when we met on Sunday morning but let me quickly summarise some of the points. Jillian will arrange a TC in the near future for 2 hrs.

Main points discussed were:-

1. The future of I-DSD and I-CAH

People agreed that a gradual move towards a sustainable independent structure is best. There was also general agreement that this should have a worldwide reach. The first step would be the paid membership model although it was recognised this may result in a fall in users. The membership model will be managed by the Office for Rare Conditions in Glasgow. Please have a look at the terms in the document Jillian sent before.

2. I-DSD 4-6th July 2019 Sao Paulo

Prior to the meeting on Sunday, I had also met Berenice and discussed a few issues.

i. Funding - This will be the first time this will be held without anchor funding from the MRC. Everybody agreed that the ethos has to remain as ‘spartan’ as possible without compromising the quality. Possible sources of support:-

- sponsored lectures e.g. the PES offer of a Claude Migeon lecture raised by Amy; we should develop a list of potential sources (societies/ERNs/COST actions, etc and identify members of SC who will approach them)

- pharma support - Richard has kindly offered to approach Diurnal, we should include potential sources of pharma support in the above list

- Jillian and I are working with Berenice to estimate costs

ii. Programme - need a POC which represents the wide interests within the broadest umbrella possible of DSD (incl CAH). In addition, the POC needs good representation from Latin America. We should try to make sure there are ample speakers from the region - maximises the local profile of DSD, reduces speakers costs and increases local participation. Berenice is keen to keep the overall theme around age and condition specific outcomes.

3. I-CAH Sep 2018 Athens

Richard and I were discussing a satellite workshop which would be held adjacent to ESPE 2018 in Athens funded by Diurnal. Either the day before or the day after ESPE. It will be only open to those attendees who are already attending ESPE and are currently using I-CAH. I was looking at asking Hedi Claahsen to lead on getting a programme together for the I-CAH users workshop. She is very active with using the I-CAH Registry. If its okay, with others then it would be good to ask her if she could be in the SC for this year just the way Berenice is there for 2 yrs until I-DSD/CAH 2019.

4. Database development

This has slowed down as the new database engineer is coming up to speed with the structure and content of the database. Priorities remain modifications to the patient specific module, addition of the longitudinal module and data extraction tools.

5. Profile

Activities include revision of the website with a move away from the university of Glasgow banner and a new data sharing agreement and clearer information on data governance.

6. EuRRECa

The outcome is due on the 20th Sep!

**Date for next meeting: Tuesday 31st October, 2017, 1-2.30pm (webex)**

**ACTION LIST (From 9th SC meeting)**

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| **WHO** | **ACTIONS** | **DUE** |
| JB | **Contact the centre in the US (Houston) for a copy of the approvals in place to distribute to other US centres** | done |
| JB | **Set up doodle to identify date for SC teleconference on governance and long-term sustainability** | done |
| JB | **Contact clinicians in different countries to provide translation of the fields** | Oct-17 |
| JB | **Upload centre details for patients view and invite other centre leads to complete on-line** | Nov-17 |
| JB | **Update Research Studies list on website and link to outputs** | Nov-17 |
| FA | **Membership structure** | Nov-17 |
| JB/ALL | Develop a list of potential sources of funds for I-DSD 2019 (societies/ERNs/COST actions, etc) and identify members of SC who will approach them) | Dec-17 |
| RR | Approach Diurnal to provide funds for I-DSD 2019 | Dec-17 |
| BM | Develop a POC for I-DSD 2019 | Jan-18 |
| JB | Invite Hedi Claahsen to join SC to plan I-CAH research meeting at ESPE in Athens 2018 | Nov-17 |