**9th International-DSD Registry Steering Committee Meeting**

Friday 30th June 2017, 08:00-9:00

Rigshospitalet, Copenhagen, Denmark

**Minutes**

**Attending:** Faisal Ahmed, Anu Bashamboo, Stephanie Bernstein, Jillian Bryce, Olaf Hiort, Anna Nordenstrom, Rodolfo Rey, Martina Rodie, Richard Ross, Hannah Van Hove, Amy Wisniewski.

**Apologies**: Sam Okure.

1. **Welcome**

The Chair welcomed everyone to the meeting.

1. **Approval of Minutes of 8th I-DSD SC meeting**

Approved.

1. **Action List - update**

Action points have mostly been covered. Developing a new structure for governance of I-DSD and I-CAH, piloting local language patient views in a few countries and developing the Longitudinal Phenotyping module are action points which are priorities for the next year.

1. **Current Tasks**
   1. **Ongoing revisions**

MRC funding is coming to an end (4/10/17). Other sources of funding being secured/sought.

**4.1.1 Modules**

* PRO-CAH: A longitudinal module has already been developed for I-CAH which can be used as a reminder of procedures to carry out in the clinic. For PRO-CAH, a questionnaire is being developed which collects information on patient experiences. Over the next two years, a web-based reporting system will be developed which will allow patients and parents to enter data themselves including patient/parent reported outcome. Ethics approval is already in place for the collection of routine clinical data, and will need to be revised for PRO-CAH.
* Phenotyping (DSDnet): Identified as a priority for the next year. DSDnet has provided the information which will be added to the pipeline.
* Portuguese Registry: Portuguese version is in development. A desire for Mandarin has also been expressed. It was agreed the translating of the patient view was a priority for the Registry. **[Action: JB to contact clinicians in different countries to provide translation of the fields]**

**4.1.2 Users**

Patient Access & Centre Details (Appendix 1)

JB demonstrated patient view and centre lead view. The aim is to tailor the page to the patients’ condition and have it in their local language. **[ACTION: JB to upload centre details for patients view and invite other centre leads to complete on-line]**

* 1. **Metrics (Appendix 2)**

There are currently 75 centres with cases and 165 centres registered around the world. All 6 continents are now contributing to the registry.

**[Action: JB to contact the centre in the US (Houston) for a copy of the approvals in place to distribute to other US centres]**

* 1. **Research Activities (Appendix 3)**

There are currently 20 active research projects. Outputs of studies are available on the I-DSD website. **[Action: JB to update Research Studies list on website and link to outputs]**

* 1. **I-DSD/CAH Research Support Fund:**

The fund supports any activity that involves the use of or promotion of the registry. This was previously limited to a travel fund, but has recently been widened to include research support in general. The registry has recently started to collect a fee for accessing data in the registry and this fund can cover those fees for early career researchers etc.

**5. EndoERN & DSDnet**

OH reported on the development of ERNs currently in process in the EU. DSDnet will end in April 2018 (workshop in February) and the question now is how to get sex development as part of the larger ERN programme. It was noted that registries play a major part in the ERN as the basis of clinical research. From a scientific point of view, the ERNs are eager to stretch beyond the EU.

**6. Future Directions: (Appendix 4)**

**6.1 Governance**

**6.2 Sustainability**

**6.3 Charitable Status**

The MRC funding will come to an end in October. The Registry could become a charitable society with a structure similar to that of ENSAT. Affiliation with other societies such as ESPE and ESE was also suggested but it would be useful to have a wider range of specialisms, representing all of the constituents of the current group. It was agreed that a teleconference will be arrange for the Committee to discuss the long-term sustainability of I-DSD/I-CAH. The steering committee agreed to continue beyond the end of current funding until the new structure is in place. **[ACTION: JB to set up doodle to identify date for SC teleconference on governance and long-term sustainability: FA to propose a membership structure]**

**7. I-DSD Symposium 2019**

The next I-DSD Symposium will take place in Sao Paulo, Brazil in July 2019.

*Since the meeting, feedback has been collated on the I-DSD 2017 symposium in Copenhagen (Appendix 5)*

**8. AOB – Staffing (Sam, Mariam)**

Sam Okure has started as the new database developer and Mariam Kourime will be starting later this year as a research assistant on PRO-CAH.

**Date for next meeting: tbc**

**ACTION LIST**

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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** | Sept-17 |
| 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 |
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