**11th International-DSD/CAH Registry Steering Committee Meeting**

Tuesday 31st October 2017, 13:00-14:30 GMT

Webex Conference

**Minutes**

**Attending:** Faisal Ahmed, Stephanie Bernstein, Jillian Bryce, Anna Nordenstrom, Sam Okure Richard Ross.

**Apologies**: Anu Bashamboo, Olaf Hiort, Hannah Van Hove, Rodolfo Rey, Martina Rodie, Amy Wisniewski.

1. **Welcome**
2. **Apologies**
3. **Approval of Minutes of 10th SC**

No comments

1. **Proposed plan for membership (Appendix 1)**

The proposed plan for membership was tabled by FA . It was agreed that a fee was a good idea and although it would not allow the registries to become completely self sustainable, it would encourage commitment whilst providing a level of independence. There was a need for clearer definition of who would pay for each centre. FA proposed that it would be the centre. The fee structure would be created in Euros. FA proposed that the membership would be managed by the Office for Rare Conditions within the University of Glasgow which is itself a charity. The registry would be positioned within the structure of this Office which has its own cost centre and is audited by GU. The registry would, therefore, continue to rely on GU to provide support and governance. It was agreed that we should rely on these existing structures and not consider setting up a new charity.

**ACTION:**

**JB to check with GU about receiving payment in Euros.**

**FA & JB to revise membership definition**

**JB to circulate final draft**

1. **Collaboration with Diurnal**

FA proposed that another model for sustainability was collaboration with pharma. The current SOP states that data can be shared with commercial as well as non-commercial partners. However, there is a need to explore whether the registry meets the standards required by pharma. Diurnal is currently exploring whether the data meets their needs for assessing natural history and perhaps pharmacovigilance in the future. Of the 26 centres contacted, 19 were happy to share data with pharma and for some centres the response was awaited (update- 23 centres said yes, 2 said no, 1 awaited). The two centres that did not allow sharing stated that their consent forms did not allow this. The question of a financial compensation was also discussed in detail and this may become a more important issue if there are concerns about the quality of the data and the datasets are extensive.

**ACTION: JB to revise info-sheets for I-DSD/CAH and obtain ethics approval and then send to all centres.**

1. **I-DSD/CAH workshop Athens 2018**

To be held adjacent to the ESPE 2018, probably an evening meeting on the night before the start. To invite all I-DSD/CAH users who are actively entering data in the registry. Given the extent of work going on with the Registry, an hours meeting in the main meeting will not be very effective. Diurnal willing to support with an unrestricted education grant. It was agreed that Nils Krone would be approached to lead the ‘POC’

**ACTION: Anna to contact NK about organising the workshop.**

**JB to arrange a TC between AN, NK and FA.**

1. **I-DSD/CAH Symposium Sao Paulo 2019**

Dates: 4-6th July 2019

Aim to have the programme by summer 2018

Funding. BM identified local sources. Sponsored lectures was suggested by AW. Societies will be approached to sponsor lectures and asked to identify a person to invite. The meeting will rely on local and regional speakers as much as possible.

**ACTION: List of sponsors to be devised (societies/ERNs/COST actions/ Companies)**

**JB to arrange another meeting with BM to discuss costs and develop a plan for funding.**

1. **European Registries for Rare Endocrine Conditions (EuRRECa) (Appendix 2)**

This is currently in negotiation with CHAFEA and the funding almost secured. There were only 5 projects approved out of 22 ERNs. In summary, the project will consist of an e-reporting system for the conditions covered by Endo-ERN, this will be followed by a core registry which will also contain core outcome measures and this registry will signpost users to detailed disease registries which are approved by Endo-ERN as being of high quality. The EuRRECa funding will support the development of the e-reporting system, the core registry and the development of the framework for having a high quality network of registries. It is anticipated that the e-reporting system will be operational in early 2018 and the core registry will be operational in early 2019. The project will also be open for participation by those who are not members of Endo-ERN.

1. **AOB. Ideas for further funding**

FA highlighted the recent call for EC funding that will attempt to link ERNs

**Date for next meeting: March 2018 (webex)**

**ACTION: JB to create doodle poll to identify a date**

**ACTION LIST (including c/f)**

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| **WHO** | **ACTIONS** | **DUE** |
| JB | Arrange another meeting with BM to discuss costs and develop a plan for funding. | Nov-17 (done) |
| JB | Check with GU about receiving payment in Euros. | Nov-17 |
| FA/JB | Revise membership definition | Dec-17 |
| JB | Circulate final draft of revised membership structure | Dec-17 |
| JB | Contact clinicians in different countries to provide translation of the fields | Dec-17 |
| JB | Upload centre details for patients view and invite other centre leads to complete on-line | Dec-17 |
| JB | Update Research Studies list on website and link to outputs | Dec-17 |
| JB/ALL | Develop a list of sponsors for I-DSD 2019 (societies/ERNs/COST actions/companies etc) | Dec-17 |
| RR | Approach Diurnal to provide funds for I-DSD 2019 | Dec-17 |
| JB | Invite Nils Krone to join SC to plan I-CAH research meeting at ESPE in Athens 2018 | Dec-17 |
| AN | Contact NK about organising the workshop. | Dec-17 |
| JB | Arrange a TC between AN, NK, FA | Dec-17 |
| JB | Revise info-sheets for I-DSD/CAH and obtain ethics approval and then send to all centres | Jan-18 |
| BM/FA | Develop a POC for I-DSD 2019 | Jan-18 |