**8th International-DSD Registry Steering Committee Meeting**

Monday 21st November 2016, 13:00-14:30 GMT (UK time)

Teleconference

**Minutes**

**Attending:** Faisal Ahmed, Jillian Bryce, Martin McMillan, Anna Nordenstrom, Rodolfo Rey, Amy Wisniewski.

**Apologies**: Anu Bashamboo, Stephanie Bernstein, Olaf Hiort, Tom Muir, Martina Rodie, Richard Ross.

1. **Welcome**

The Chair welcomed everyone to the meeting

1. **Approval of Minutes of 7th I-DSD SC meeting**

Approved

1. **Action List**

Action points are mostly covered. Some actions will be discussed in this meeting.

Invited speakers for I-DSD 2017 are in the programme on the website.

The I-CAH/I-DSD user group meeting took place at **ESPE [ACTION: JB to upload the I-CAH review to the SC area]**

The Autumn newsletter was distributed at ESPE.

Centre details to be added manually from questionnaires for patient view **[ACTION: JB]**

I-DSD/I-CAH Research Fund now used for anything related to the registry (e.g. support data access fees)

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**

Main focus on CAH but also non-CAH DSD

* Diurnal Ltd is supporting development of modules via an industry partnership award from NIHR RD TRC (CAH-UK) and Patient Reported Outcome (PRO-CAH). This links to D Sandberg published work on PRO who are looking at tools. Actively recruiting for research assistant and DB developer posts.
* Phenotyping: DSDnet WG1 (M Cools, A. Springer) – waiting for info for registry.
* QoL questionnaires – brief and patient friendly. **[ACTION: Consider a pilot before next SC meeting]**
* Language in registry. Portuguese version is in development. Guilherme Guaragna is the local support in Brazil. RR would support a Spanish version, esp for patient view. A desire for Mandarin has also been expressed. The research support fund could support this in pilot form.

**4.1.2 Users**

**Data access**

Data can be accessed in 2 ways. Advance search in registry, or completion of a data search form submitted to JB. Access to the data is provided unless there is a potential clash. AN suggested the SC could be involved in this process. A study advisory group could be formed to provide advice on study design and improve quality. Comprised of members of SC and co-authors on previous publications**. [ACTION: Consider setting up Study Advisory Group within a revised governance structure for I-DSD]**

**View records**

Members of each centre can now edit any record in their centre.

**Patient Access & Centre details (Appendix 1)**

Improved view with other languages possible. Centre leads can edit their centre details to their own language. Could also explore local language for the patient record data. **[ACTION: Pilot in a few countries]**

**4.2 Metrics (Appendix 2)**

In November 2016 there were 2434 cases in the registry – a third of which are CAH.

There are 63 centres with cases in 30 countries. Median age is 16, which is good for outcome studies.

**4.4 Research Studies (Appendix 3)**

Current studies on the website are hyperlinked to outputs. MK recently submitted a manuscript on quality of the registries to Orphanet**. [ACTION: JB to make list into excel template with outcomes]**

**4.5 Research Support Fund**

The fund can now be used for any purpose that promotes use of the registries. Grants of up to £500 available for I-DSD meeting presentations, visits and support research (data search fees).

1. **Ethics**

SB on maternity leave **[ACTION: JB to check with SB on any ethics issues]**

1. **Endo-ERN & DSDnet**

Endo-ERN was approved by EU and awaiting news of funding. A registries workshop will be held in Glasgow in December. Need to develop a registry for all conditions.

DSDnet held a workshop in October in Bologna for patients and parents to explore gaps in DSD care. The workshop was run by a parent (Joanne Hall) and Caroline Sanders. Documents are in preparation. A workshop within the workshop about registries demonstrated that patients/parents want to know more about what happens with their data. Development of outputs such as reports, newsletters are planned. Personalised patient view will develop to become tailored to the condition and links to relevant active studies. It was noted that CAH patients in US will not participate in DSD studies, so would require a CAH interface.

1. **EUROCAT**

This is European network of population-based registries for the epidemiologic surveillance of congenital anomalies. I-DSD should link to this. E.g. EUROCAT notified by HCP about a hypospadias patient. They notify I-DSD and I-DSD contacts the clinician to ask if they want to take part in I-DSD. This model could be effective for EndoERN registry.

1. **I-DSD symposium**

All invited speakers are confirmed. There is a dsdLIFE parallel session. Patients and parents are invited to register. Need to publicise more actively. Include former symposium participants in mailing. Activists can be disruptive, although were fine in Ghent. **[ACTION: JB More active publicity] [ACTION: AJ to invite local support groups]**

Use of pictures has been an issue. There is a need to develop a policy on images. Either advertise ‘sensitive’ material or not allow. **[ACTION: JB to provide guidance on original communications]**

1. **AOB**

Jipu is leaving and we will recruit a new DB developer.

Date of next meeting: Friday 30th June, 8-9ampm Rigshospitalet, Copenhagen. **ALL TO NOTE**

**ACTION LIST**

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| --- | --- | --- |
| **WHO** | **ACTIONS** | **DUE** |
| ALL | SC to feedback on developing modules in the registry | ongoing |
| JB | More active publicity for symposium | Jan 17 |
| AJ | AJ to invite local support groups | Apr 17 |
| JB | Upload I-CAH review to Steering Committee area | May 17 |
| JB | Complete manual upload of centre details into registry for patient view | May 17 |
| JB | Convert studies list into excel template with outcomes | May 17 |
| JB | Check with SB on any ethics issues | May 17 |
| JB | Provide guidance on original communications | May 17 |
| JB | Develop a new structure for governance of I-DSD and I-CAH | June 17 |
| JB | Pilot local language patient view in a few countries | June 17 |
| JB | Longitudinal Phenotyping module | June 17 |