

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

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

Teleconference

**Agenda**

|  |  |  |  |
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|  | **Item** |  | **Papers (to be precirculated)** |
| 1. | Welcome | Chair (AN) |  |
| 2. | Approval of Minutes of 7th SC | Chair (AN) | Minutes |
| 3. | Action List – update | FA | Action List  (see Minutes) |
| 4. | Current Tasks   * Ongoing revisions   + Modules     - PRO-CAH     - Phenotyping (DSDnet)   + Users     - Data access     - View Records     - Patient Access     - Centre Details * Metrics * Research Activities * I-DSD/CAH Research Support fund | FA  FA  JB | Patient view with  Centre details  Metrics  List of Studies |
| 5. | Ethics | SB |  |
| 6. | EndoERN & DSDnet | OH |  |
| 7. | EUROCAT | FA |  |
| 8. | I-DSD Symposium   * Programme | FA | Programme |
| 9. | AOB - Staffing   * Portuguese version of registry | FA |  |
|  |  |  |  |
|  | Date for next meeting |  |  |

Invited Participants:

|  |  |  |  |
| --- | --- | --- | --- |
| Name | Role | Affiliation |  |
| Anna Nordenstrom | Chair | Karolinska Institute |  |
| S. Faisal Ahmed | Project Lead | University of Glasgow | Y |
| Olaf Hiort | EU | University of Lübeck | N |
| Rodolfo Rey | SA | Centro de Investigaciones Endocrinológicas, Buenos Aires |  |
| Anu Bashamboo | EU | Institut Pasteur | N |
| Stephanie Bernstein | Ethics Adviser | Universität Göttingen |  |
| Amy Wisniewski | USA | University of Oklahoma |  |
| Richard Ross | UK | University of Sheffield | N |
| Jillian Bryce | Project Manager | University of Glasgow | Y |
| Martina Rodie | Co-Investigator | University of Glasgow | N |
| Jipu Jiang | I-DSD developer | University of Glasgow |  |
| John Watt | GRID engineer | University of Glasgow |  |
| Tom Muir | MVLS IT | University of Glasgow | N |
| Marian Kourime | Visiting Fellow | University of Glasgow |  |
| Martin McMillan | Lab Manager | University of Glasgow | Y |

I-DSD Steering Committee teleconference

1-2.30 pm UK time

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Please join the conference call by using the passcode and dial-in numbers below (toll-free numbers recommended, but if there is an issue please use the direct dial in number for your country or if none, the international dial in number for the USA:

Participant Passcode: **13136257#**

Dial-in Numbers:

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Argentina toll free: 08002661505 Recommended Number

France international direct dial-in: +33 (0)157323696

France international direct dial-in: +33 (0)157323978 French

France toll free: 0805540429

France toll free: 0805540460 French

Germany international direct dial-in: +49 (0)69945192108

Germany international direct dial-in: +49 (0)69380789058 German

Germany toll free: 08005030014

Germany toll free: 08005030015 German

Netherlands international direct dial-in: +31 (0)202061752

Netherlands international direct dial-in: +31 (0)202035074 Dutch

Netherlands toll free: 08000202539

Netherlands toll free: 08007777703 Dutch

Sweden international direct dial-in: +46 (0)851761750

Sweden toll free: 0201605868

United Kingdom toll free: 08000328069

United States international direct dial-in: +1 (1)2124440616 East Coast

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| |  |  | | --- | --- | | Name: | **Jillian Bryce** | | UK Freefone: | **0800 032 8069** | | Chairperson passcode: | **97383381 then #** | | Participant passcode: | **13136257 then #** | |
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