

**6th International-DSD Registry Steering Committee Meeting**

Wednesday 27th January 2016, 12:00-14:00 GMT (UK time)

Teleconference

**Agenda**

|  |  |  |  |
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|  | **Item** |  | **Papers (to be precirculated)** |
| 1. | Welcome | Chair (AN) |  |
| 2. | Approval of Minutes of 5th SC | Chair | Minutes |
| 3. | Action List – update | FA | Action List  (see Minutes) |
| 4. | DSDnet | OH | 10 mins |
| 5. | Current Tasks   * Ongoing revisions   + Modules     - I-CAH     - Surgery boys/girls     - Phenotyping (DSDnet)   + Users     - View My Records     - Centre Details   + Patient Access   + Bulk Upload   + Fees for access * Ethics Update * Metrics * Research Activities * Travel Awards | JJ  FA  FA  JJ  FA  JJ  JJ  FA  JB  JB  JB  JB | Patient view  Metrics  List of Studies |
| 6. | I-CAH | RR |  |
| 7. | I-DSD Symposium   * 2015 feedback * 2017 location * Invited speakers/theme suggestions | FA | feedback |
| 8. | Term of Office   * New chair * New members * MRC extension to 4/10/17 | JB |  |
| 9. | AOB |  |  |
|  |  |  |  |
|  | Date for next meeting |  |  |

Invited Participants:

|  |  |  |  |
| --- | --- | --- | --- |
| Name | Role | Affiliation |  |
| Anna Nordenstrom | Chair | Karolinska Institute | ✓ |
| S. Faisal Ahmed | Project Lead | University of Glasgow | ✓ |
| Olaf Hiort | EU | University of Lübeck | ✓ |
| Rodolfo Rey | SA | Centro de Investigaciones Endocrinológicas, Buenos Aires | ✓ |
| Leendert Looijenga | EU | ErasmusMC, Rotterdam | X |
| Alex Springer | EU | University of Vienna | ✓ |
| Anu Bashamboo | EU | Institut Pasteur | ✓ |
| Stephanie Bernstein | Ethics Adviser | Universität Göttingen | ✓ |
| Miriam Muscarella | Patient Support Representative | Dsdteens.org |  |
| Carol Proctor | Patient Support Representative | UK |  |
| Amy Wisniewski | USA | University of Oklahoma | ✓ |
| Richard Ross | UK | University of Sheffield | ✓ |
| Jillian Bryce | Project Manager | University of Glasgow | ✓ |
| Martina Rodie | Co-Investigator | University of Glasgow | ✓ |
| Richard Sinnott | Co-Investigator | University of Melbourne | X |
| Jipu Jiang | I-DSD developer | University of Glasgow | ✓ |
| John Watt | GRID engineer | University of Glasgow | ✓ |
| John Achermann | UK | University College London | X |

I-DSD Steering Committee teleconference

12-2pm 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

Australia international direct dial-in: +61 (0)280238301

Australia toll free: 1800051469

Austria international direct dial-in: +43 (0)1206091266

Austria international direct dial-in: +43 (0)1206091409 German

Austria toll free: 0800203653

Austria toll free: 0800202370 German

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

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