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

Friday 30th June 2017, 08:00-09:00am

Meeting Room 93, Rigshospitalet, Copenhagen

**Agenda**

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|  | **Item** |  | **Papers (to be precirculated)** |
| 1. | Welcome | Chair (AN) |  |
| 2. | Approval of Minutes of 8th SC | Chair (AN) | Minutes |
| 3. | Action List – update | FA | Action List  (see Minutes) |
| 4. | Current Tasks   * Ongoing revisions   + Modules     - PRO-CAH     - Phenotyping (DSDnet)     - Portuguese Registry   + Users     - 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. | EndoERN & DSDnet | OH |  |
| 6. | Future Directions   * Governance, * Sustainability * Charitable status | FA |  |
| 7. | I-DSD Symposium 2019 | FA |  |
| 8. | AOB - Staffing (Sam, Mariam) |  |  |
|  |  |  |  |
|  | Date for next meeting |  |  |

Invited Participants:

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| Name | Role | Affiliation |  |
| Anna Nordenstrom | Chair | Karolinska Institute |  |
| Faisal Ahmed | Project Lead | University of Glasgow |  |
| Olaf Hiort | Member | University of Lübeck |  |
| Rodolfo Rey | Member | Centro de Investigaciones Endocrinológicas, Buenos Aires |  |
| Anu Bashamboo | Member | Institut Pasteur |  |
| Stephanie Bernstein | Member | Universität Göttingen |  |
| Amy Wisniewski | Member | University of Oklahoma |  |
| Richard Ross | Member | University of Sheffield |  |
| Jillian Bryce | Project Manager | University of Glasgow |  |
| Martina Rodie | Co-Investigator | University of Glasgow |  |
| Sam Okure | Database developer | University of Glasgow |  |
| Hannah van Hove | Admin Support (Minutes) | University of Glasgow |  |

Map showing location of Meeting Room 93

