

# I-DSD & I-CAH Registries Newsletter

## Spring 2017



### How can the Registries help improve care?

#### The Registry

- contains non-identifiable details of affected people in a secure environment
- contains contact details of experts in the field of DSD/CAH
- allows users to perform studies
- allows patients to access details of their condition and centre

### International DSD Symposium 2017



EAC-CME has approved the 6<sup>th</sup> I-DSD symposium for 15 credits. We have received 115 abstracts for the symposium which will take place from 29<sup>th</sup> June–1<sup>st</sup> July 2017 in Copenhagen, Denmark. Early bird registration closes on 15<sup>th</sup> April. [I-DSD symposium 2017](#)

### Changes To Access Of Data In Registries

Searching the Registries for data at centres other than the user's own centre is now performed by the project management team. Please contact Jillian Bryce for further information if you would like to perform any searches.

### Research Support Grants

Small grants are available now to support travel related to Registry-based research. Visit the [I-DSD website](#) or contact [Jillian Bryce](#) for more information.

### Steering Committee & Project Management Group

The [I-DSD & I-CAH Registries Steering Committee](#) welcomes applications for new members from current registry users.

### Personalised Patient & Parent Participant View

Access for patient and parent participants can be personalised with information about the participant's clinical centre. Centre leads are encouraged to maintain up to date information on their centre for the participant. To provide access to patients and parents see step-by-step instructions at [Participant Access](#)

### ERN for rare endocrine conditions incl DSD & CAH

European Reference Network for rare endocrine conditions (EndoERN) was approved by the EC on 15<sup>th</sup> December 2016, coinciding with a workshop on registries in the ERN. I-DSD & I-CAH users who would like more information should contact [Olaf Hiort](#)

### News From The I-CAH Registry

Well done to the CAH User Group for continuing to enter CAH cases. 35% of the cases in the two registries have a diagnosis of CAH. Data from the registries reveals a temporal shift in diagnostic practice of CAH towards the use of molecular genetics. Abstracts have been submitted to ESE & ESPE. Funding has been secured to develop the Registries further including a new study exploring patient reported outcomes in CAH (PRO-CAH). Further details of active studies are available at [Research Studies](#)

### Recent Publications From The I-DSD & I-CAH Registries

- M. Kourime, J. Bryce, J. Jiang, R. Nixon, M. Rodie and S.F. Ahmed. *An assessment of the quality of the I-DSD and the I-CAH registries - international registries for rare conditions affecting sex development*. Orphanet Journal of Rare Diseases 2017 12:56
- S Poyrazoglu, F Darendeliler, S. F Ahmed, I Hughes, J Bryce, J Jiang, M Rodie, O Hiort, S E. Hannema, S Bertelloni, L Lisa, T Guran, M Cools, A Desloovere, H Claahsen-van der Grinten, A Nordenstrom, P-M Holterhus, B Kohler, M Niedziela, N Krone. *Birth Weight in Different Etiologies of Disorders of Sex Development*. J Clin Endocrinol Metab 102: 1044–1050, 2017
- A Kyriakou, A Dessens, J Bryce, V Iotova, A Juul, M Krawczynski, A Nordenskjöld, M Rozas, C Sanders, O Hiort and S. F Ahmed. *Current models of care for disorders of sex development – results from an International survey of specialist centres*. Orphanet Journal of Rare Diseases 2016 11:155.

### Other Research Highlights

- Active research studies are listed on the [I-DSD website](#)
- 33 users from 12 countries are currently developing or performing studies using the Registry
  - Further details on research outputs can be accessed at [Publications & Dissemination](#)

### Registry Statistics (February 2017)

- 2614 cases, uploaded by 67 centres in 31 countries over 5 continents
- Highest number of new cases added over the last 6 months was from Nijmegen (41 new patients)

#### To find out more contact

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