I-DSD / I-CAH Registry Newsletter

Spring 2016

How can the Registry help improve care?

- *The Registry consists of non-identifiable details of affected people in a secure clinical and research environment*
- *The Registry contains contact details of clinical experts and active researchers in the field of DSD/CAH*
- *Users can use this information to perform studies and discuss rare conditions with other experts*
- *Patients can access a space that provides details of their condition and their centre*

I-DSD Symposium 2017

Planning is underway for the 6th I-DSD symposium which will take place in June 2017.

I-DSD/I-CAH Registry User Audit

Research accounts will be revised in April 2016. Clinical and Networking accounts can be requested via the registry (www.i-dsd.org). All users should log in at least every 6 months and keep their profile up to date.

Changes To Access Of Data In Registry

From April 2016, searching the Registry for data at centres other than the user's own centre will only be possible by the project management team. Depending on the amount of work involved these searches will incur a small fee and researchers are advised to contact Jillian Bryce for further information.

I-DSD Support Grants

Grants to support travel between centres and research requiring access to the Registry are available to I-DSD registry users. See the I-DSD website or contact Jillian Bryce for more information.

Steering Committee & Project Management Group

The I-DSD Steering Committee thanks members Alex Springer and Miriam Muscarella for their valuable contribution. The Project Management Group welcomes new members; Andy Jenkins, Martin Macmillan and Mariam Kourime. Applications for new members of the Steering Committee are invited from current I-DSD users.

Personalised Participant View

Access for participants can be personalised with information about the clinical centre in which the participant is registered. 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 including DSD

The application call for European Reference Network for rare conditions has just been launched and I-DSD/CAH users who are interested should contact Olaf Hiort

CAH-UK

The Registry has recently received funding through a UK based project funded by NIHR Rare Diseases Translational Research Collaboration, the Chief Scientist of Scotland & Diurnal to further enhance the CAH module. Contact Nils Krone for further information.

I-CAH Visits module

A longitudinal module to capture data in CAH has been launched. Clinical users entering CAH data met at the ESPE meeting in Barcelona to develop a study group which will work together to develop and support collaborative studies. Abstracts have been submitted to ESE & ESPE. Further details of the studies are available at Research Studies

Bulk Upload

A process of bulk upload of core data has been developed and is available under Records after login to the Registry. For details contact Jillian Bryce

Research Studies

Active research studies are listed on the I-DSD website

- 29 users from 15 countries are currently developing or performing studies using the Registry

- Participation in research studies requires approval by the I-DSD/I-CAH Project Management Group.

Ethics Update

Ethics approvals and patient information leaflets and consent forms in several languages are available on the I-DSD website

Research Highlights

Data on long-term outcome in young men with PAIS will be presented as an oral communication at ENDO 2016 in Boston and they have also been submitted for publication.
Further details on research outputs can be accessed at Publications & Dissemination

Registry Statistics (March 2016)

- *2062 cases, uploaded by 53 centres in 24 countries*
- *265 registered users, 163 users have used the Registry in the last 12 months*
- *Highest number of new cases added over the last 6 months was from Berlin!*

Contact us if you are interested in the I-DSD Registry

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Articles for the next newsletter should be submitted by August 28th 2016