I-DSD/I-CAH newsletter - April 2019

Welcome to the April newsletter

This is the 4 monthly update on current activities in the I-DSD and I-CAH registries. If you have an item you would like to include in future newsletters, please contact registry@i-dsd.org

I-DSD Symposium 2019

The 7th I-DSD Symposium will take place in Sao Paulo, Brazil from 4-6th July 2019.

The programme which is available on the I-DSD and the I-CAH websites follows the format of previous symposia. As always the meeting will be preceded by the I-DSD training workshop and will kick off with a short lecture providing a patient perspective. A total of 100 abstracts were submitted and the meeting has been approved for 13 hours of CME by UEMS-EACCME. Approximately 10% of the abstracts have used data from the I-DSD or I-CAH Registries!

Registration is open at idsd2019.eventbrite.co.uk. Early bird registration closes on 30th April 2019

We would like to extend our thanks to Diurnal Ltd, the ESPE DSD Working Group, FAPESP, Karger, Merck Serono, Sandoz and SLEP for their generous support.

Centre Membership

For full details regarding membership of I-DSD and I-CAH please visit here.

Registry-Related Outputs Since April 2018

Visit the website for a full list of publications

- Tack L et al. Management of gonads in adults with androgen insensitivity: an international survey. Horm Res Paediatrics 2018 doi.org/10.1159/000493645
- Ali S et al. The current landscape of European registries for rare endocrine conditions. Eur J Endocrinol. 2018 Nov 1. doi.org/10.1530/EJE-18-0861.
- Sanders C et al. Involving individuals with disorders of sex development and their parents in exploring new models of shared learning: Proceedings from a DSDnet COST action workshop. Sex Dev 2018 Jun 23. doi.org/10.1159/000490081.
- Kodra Y, et al. Recommendations for improving the quality of rare disease registries. Int J Environ Res Public Health. 2018;15. doi.org/10.3390/ijerph15081644.

Active Studies

- Marianna Stancampiano (Milan) - Testosterone replacement therapy in boys and young men in the I-DSD Registry
- Alessandra Boncompagni (Modena) - Long term outcome of 46, XY Leydig Cell Hypoplasia (LCH) cases
- Irina Bacila (Sheffield) - Rare forms of Congenital Adrenal Hyperplasia
- Grit Sommer (Bern) - SF1 next
- Salma Ali (Glasgow) - Adverse Events in Congenital Adrenal Hyperplasia
- Jeremy Tomlinson (Oxford) - Optimizing mineralocorticoid replacement in patients with CAH
- Katya DeGroote (Ghent) - Cardiovascular pathology in patients with 45,X/46,XY (or variant) karyotypes
- Lloyd Tack (Ghent) - Growth and pubertal course in 46,XY SGA boys born with atypical genitalia of unknown origin
- Angela Lucas-Herald (Glasgow) - Trends in gonadectomy in DSD
- Nils Krone (Sheffield) - Defining the dose, type and timing of glucocorticoid treatment in children with Congenital Adrenal Hyperplasia in the UK (CAH-UK)

New I-DSD Website

The I-DSD website has been migrated to www.i-dsd.org and the Registry login can now be found at registry.i-dsd.org. There is a redirect in place

from the old site's homepage.

The I-DSD/I-CAH Platform

The original platform used by the Registry is now becoming outdated and will undergo a revision in the near future. It is anticipated that the new platform will have greater functionality and improved access for patients, parents and professionals.

The Steering Committee

The Steering Committee would like to welcome Ken Scott as a patient/parent representative. We also welcome new members who will represent PES (Yee-Ming Chan, Courtney Finlayson) and APEG (Michelle O'Connell, Shubha Srinivasan). We are extending membership of the Steering Committee to other regional professional societies that have a dedicated working group in DSD.

If you are interested in joining the committee, please contact Jillian.Bryce@glasgow.ac.uk

Job Opportunity

A predoctoral researcher in Paediatric Endocrinology at Ghent University & Ghent University Hospital. **Title of the research project:** "Alteration of the sexually dimorphic phenotype by early puberty suppression and cross-sex hormone therapy". Please contact martine.cools@ugent.be for further details. – Deadline 20/4/19

University of Glasgow
Office for Rare Conditions
Royal Hospital for Children & Queen Elizabeth University Hospital
Glasgow
Tel: +44 141 451 5843
www.i-dsd.org
www.i-cah.org