International DSD Registry Newsletter

Autumn 2012

www.i-dsd.org

Aim of the Newsletter

- Provide an update of I-DSD registry and network activity
- Disseminate relevant news and research in the field of DSD
- Promote links between health care personnel, researchers and the wider public

Brief History of the I-DSD Registry

2006	Chicago Consensus states the need for clinical and research networks
2007	ESPE Research Unit funds a working group to develop a DSD core dataset
2008	As part of the EuroDSD project, EUFP7 funds the development of a DSD Registry.
2011	End of the EuroDSD project
2011	MRC UK funds further development of the DSD Registry and its conversion into an international DSD Registry.

How Can The Registry Help Improve DSD Care

- The Registry consists of brief non-identifiable details of over 1000 affected people with a range of rare conditions leading to a DSD.
- The Registry contains contact details of the specialists who are involved in the care of people with DSD
- Registered users can use this information to design new studies and recruit to studies
- Doctors involved in the care of a person with a rare DSD can find details of other specialists with experience of the same condition
- The I-DSD Registry acts as a secure clinical and research network

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I-DSD Symposium

The 4th International-DSD Symposium will take place on 7th-9th June 2013 at the University of Glasgow.
Invited speakers consist of experts in the field of DSD from UK, Europe and the rest of the world. Abstracts are also invited for oral and poster sessions.

Registration opens on 1st October 2012
Further details are available from the I-DSD website www.gla.ac.uk/idsd

Websites of interest

I-DSD website :	www.gla.ac.uk/idsd
Accord Alliance :	www.accordalliance.org
CAH support group:	www.livingwithcah.com
DSDFamilies:	www.dsdfamilies.org
Endocrine Society :	www.endo-society.org
ESPE:	www.espe.org
EuroDSD :	www.eurodsd.eu
Succeed Clinic:	www.succeedclinic.org

Research Publications by Registered Users

- Sarafoglou K & Ahmed SF. Disorders of sex development: challenges for the future. J Clin Endocrinol Metab 2012
- Jürgensen M et al; the DSD Network Working Group. Psychosexual development in adolescents and adults with disorders of sex development. Results from the German Clinical Evaluation Study. J Sex Med. 2012
- Wu JY et al. A novel NR5A1 variant in an infant with elevated testosterone from an Australasian cohort of 46,XY patients with disorders of sex development. Clin Endocrinol 2012
- Kogan BA et al Challenges of disorders of sex development: Diverse perceptions across stakeholders. Horm Res Pædiatr 2012
- Hullmann SE et al. Transition from pediatric to adult care for adolescents and young adults with a disorder of sex development. J Pediatr Adolesc Gynecol 2012

Contact Us If You Are Interested In Using the I-DSD Registry For Research Or Clinical Networking

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Sponsors
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University of Glasgow

MRC Medical Research Council

Please submit items for the Spring newsletter to the Project Manager by 15th February 2013