

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

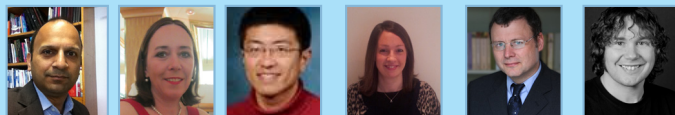
Brief History of the I-DSD Registry

- 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

The Project Management Group



Faisal Ahmed Jillian Bryce Jipu Jiang Martina Rodie Richard Sinnott John Watt

The Steering Committee



Ian Ford John Achermann Feyza Darendeliler Olaf Hiort Ieuan Hughes Berenice Mendonca



Ellie Magritte David Sandberg Claudia Wiesemann

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 Paediatr 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

Jillian Bryce
I-DSD Project Manager
Child Health, Royal Hospital for Sick Children
Yorkhill, Glasgow, G3 8SJ, UK
Jillian.Bryce@glasgow.ac.uk

Sponsors

The I-DSD Registry was originally developed with funding from ESPE and ECFP7 and is currently supported by MRC and hosted at the University of Glasgow



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