

I-DSD/I-CAH NEWSLETTER



December 2019

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

The 8th I-DSD Symposium 2021

The next biennial symposium will take place in Bern, Switzerland on 8th-10th July 2021. **SAVE THE DATE!**

I-DSD school is also running: 6-7th July 2021 Bern, for 20-26 trainees.



For more information on the 2021 Symposium or the I-DSD school, please follow these links:

home.i-dsd.org/the-8th-i-dsd-symposium-2021/

home.i-dsd.org/i-dsd-school/

The I-DSD/I-CAH Platform

A new platform is currently being developed for the I-DSD & I-CAH registries. The new platform will have greater functionality and improved access for patients, parents and professionals. During Data migration in mid-December 2019, access to the registry will be suspended. Users will be informed of the exact duration of this planned down time.

Centre Membership

For full details regarding membership of I-DSD and I-CAH, home.i-dsd.org/create-an-account/

Ethics Renewal

On 9th September 2019, the I-DSD and I-CAH registries received approval from the Research Ethics Service to continue collecting data for a further 5-year period. Check the website for the new [Data Access Policy](#) (replacing the SOP), Conditions of Approval and new [patient information sheets and consent forms](#) available to download.

Call for Start-Up Grants for New Rare Registries

The call for start-up grants for developing new registries will be launched at the Rare Registries Workshop taking place in Glasgow on 12th-13th December 2019. The deadline for submission of 28th February 2020. For further information and to download an application form visit eurreca.net/call-for-applications-to-develop-disease-registries/



The Scientific Panel

The Scientific Panel advise the Steering Committee on studies that request to use data from the Registry. Membership of the panel and details of the application and review process are available at home.i-dsd.org/scientific-panel/

The Steering Committee

The Steering Committee invites applications for new members. Patients and active users of I-DSD are encouraged to apply. The committee will also expand with representatives of Societies around the world that have a DSD/CAH working group.

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

Registry Related Outputs Since December 2019

Visit the website for a full [list of publications](#)

- Flück C, Nordenström A, Ahmed SF, Ali SR, Berra M, Hall J, Köhler B, Pasterski V, Robeva R, Schweizer K, Springer A, Westerveld P, Hiort O, Cools M, [Standardised data collection for clinical follow-up and assessment of outcomes in differences of sex development \(DSD\): recommendations from the COST action DSDnet](#). *Eur J Endocrinol*. 2019;181:545-564.
- Hiort O Cools M, Springer A, McElreavey K, Greenfield A, Wudy SA, Kulle A, Ahmed SF, Dessens A, Balsamo A, Maghnie M, Bonomi M, Dattani M, Persani L, Audi L, [Addressing gaps in care of people with conditions affecting sex development and maturation](#). *Nat Rev Endocrinol*. 2019;15(10):615-622.
- Van der Straaten S, Springer A, Zecic A, Hebenstreit D, Tonnhofer U, Gawlik A, Baumert M, Szeliga K, Debulpaep S, Desloovere A, Tack L, Smets K, Wasniewska M, Corica D, Calafiore M, Ljubicic ML, Busch AS, Juul A, Nordenström A, Sigurdsson J, Flück CE, Haamberg T, Graf S, Hannema SE, Wolffenbuttel KP, Hiort O, Ahmed SF, Cools M, [The External Genitalia Score \(EGS\): A European multicenter validation study](#). *J Clin Endocrinol Metab*. 2019 Oct 29.
- Ljubicic M, Jørgensen A, Acerini C, Andrade J, Balsamo A, Bertelloni S, Cools M, Cuccaro RT, Darendeliler F, Flück CE, Grinspon RP, Maciel-Guerra A, Guran T, Hannema SE, Lucas-Herald AK, Hiort O, Holterhus PM, Lichiardopol C, Looijenga LHJ, Ortolano R, Riedl S, Ahmed SF, Juul A, [Clinical but Not Histological Outcomes in Males With 45,X/46,XY Mosaicism Vary Depending on Reason for Diagnosis](#), *J Clin Endocrinol Metab*. 2019;104(10):4366-4381.
- Pofi R, Prete A, Thornton-Jones V, Bryce J, Ali SR, Faisal Ahmed S, Balsamo A, Baronio F, Cannuccia A, Guven A, Guran T, Darendeliler F, Higham C, Bonfig W, de Vries L, Bachega TASS, Miranda MC, Mendonca BB, Iotova V, Korbonits M, Krone NP, Krone R, Lenzi A, Arlt W, Ross RJ, Isidori AM, Tomlinson JW, [Plasma renin measurements are unrelated to mineralocorticoid dose in patients with primary adrenal insufficiency](#), *J Clin Endocrinol Metab*, 2019
- Ali S, Lucas-Herald A, Bryce J and Ahmed F S. [The Role of International Databases in Understanding the Aetiology and Consequences of Differences/Disorders of Sex Development](#). *Int. J. Mol. Sci*. 2019; 20(18), 4405.
- Tack L, Maris E · Looijenga L.H.J · Hannema S.E. · Audi L. · Köhler B. · Holterhus P.-M · Riedl S. · Wisniewski A · Flück C · Davies J.H. · T'Sjoen G · Lucas-Herald A.K· Evliyaoglu O · Krone N · Iotova V · Marginean O · Balsamo A· Verkauskas G · Weintrob N · Ellaithi M· Nordenström A · Verrijn Stuart A· Kluivers K.B · Wolffenbuttel K.P · Ahmed S.F, Cools M, [Management of gonads in adults with androgen insensitivity: an international survey](#). *Horm Res Paediatrics* 2018; 90:236–

The I-DSD & I-CAH Registries would like to thank its users for continuing to help with past and currently active studies. For a list of currently active studies, please visit home.i-dsd.org/ongoing-studies If you have an idea for a new study please feel free to [contact us](#).

Season's Greetings and Happy New Year!

On behalf of the whole I-DSD/I-CAH team, thank you for your continuous support and contributions.



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