Activity Report
June 2023

I-DSD  I-CAH  I-TS

Prepared 20 June 2023
Wide reach for DSD, CAH & TS events, education & newsletters

June 2023 – 7749 cases
135 centres from 45 countries with cases
Additional 63 centres from 15 countries in dissemination list

Newborn to 96 yrs
Median Age – 18 yrs

Approved by ethics to store routinely collected clinical data following informed consent
The I-DSD/I-CAH/I-TS Network - Trends

Countries, Centres & Patients

- Countries (all)
- Countries (with cases in registry)
- Centres (all)
- Centres (with cases in registry)
- Cases

Year

Countries, Centres, n

Patients, n


0 50 100 150 200 250 300 350 400 450 500 550 600 650 700 750 800 850 900

0 1000 2000 3000 4000 5000 6000 7000 8000 9000
Outputs & Research 2012-2023

https://sdmregistries.org/research-output/

Project approved n,65
- No activity & no patient data supplied
- Patient level data supplied
- Quality assessment
- Surveys of practice

Funding of projects that were activated n,57
- Industry (feasibility)
- Public/University
- Public/University/Industry

Cumulative outputs – original data publications

Outcome of activated research projects

Destination of original data publications

Extent of Partnership

Median lag between study launch and publication = 2 yrs (1, 9)
In 2022 Research Participation Awards were conferred on centres in the top quintile for participating in the highest number of studies that led to a publication until the end of 2021 and for contributing the largest number of cases into these studies. These awards will next be presented in 2024.

The 2022 awards were kindly supported by Neurocrine Biosciences