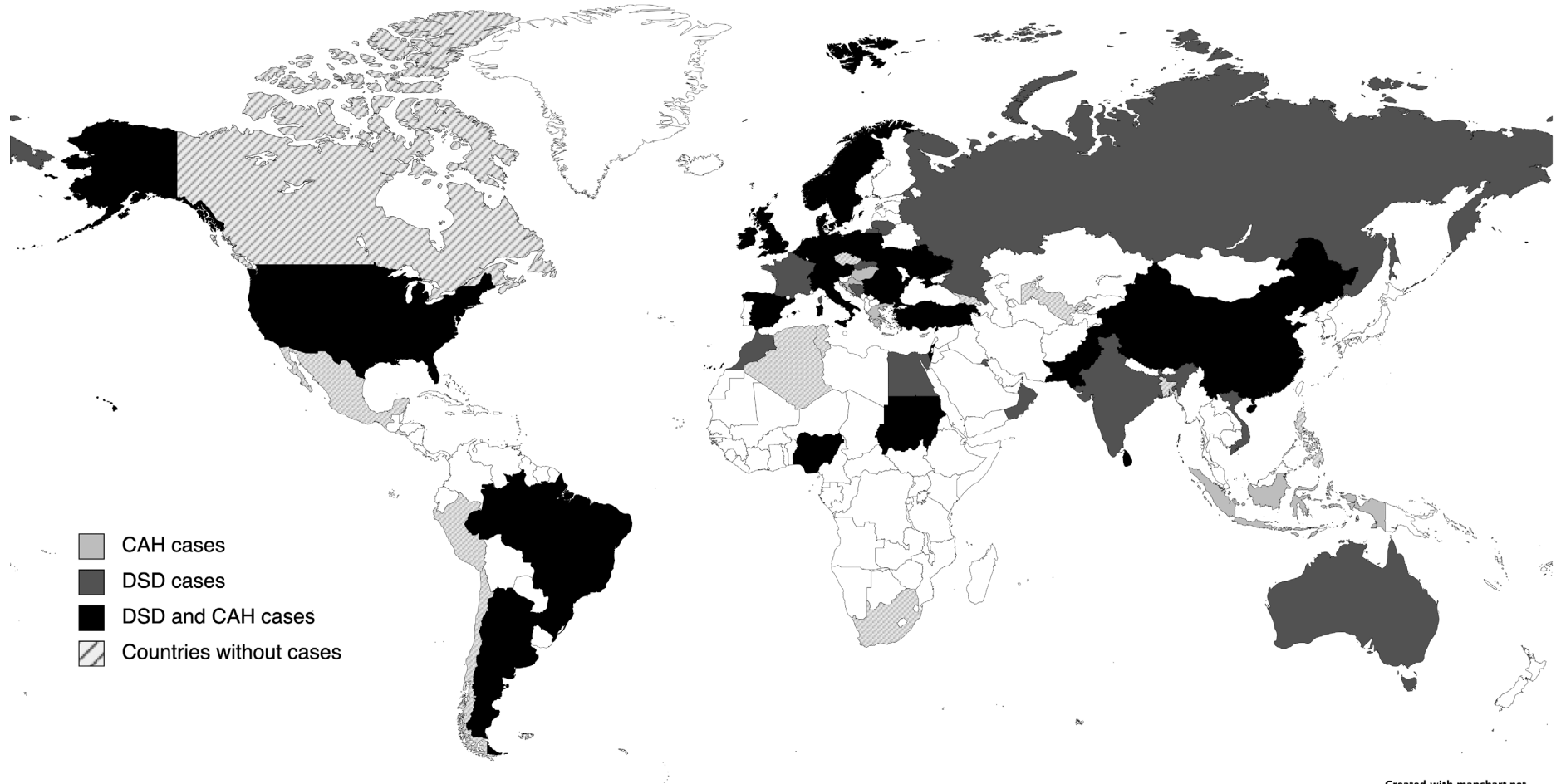




Activity Report June 2023



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

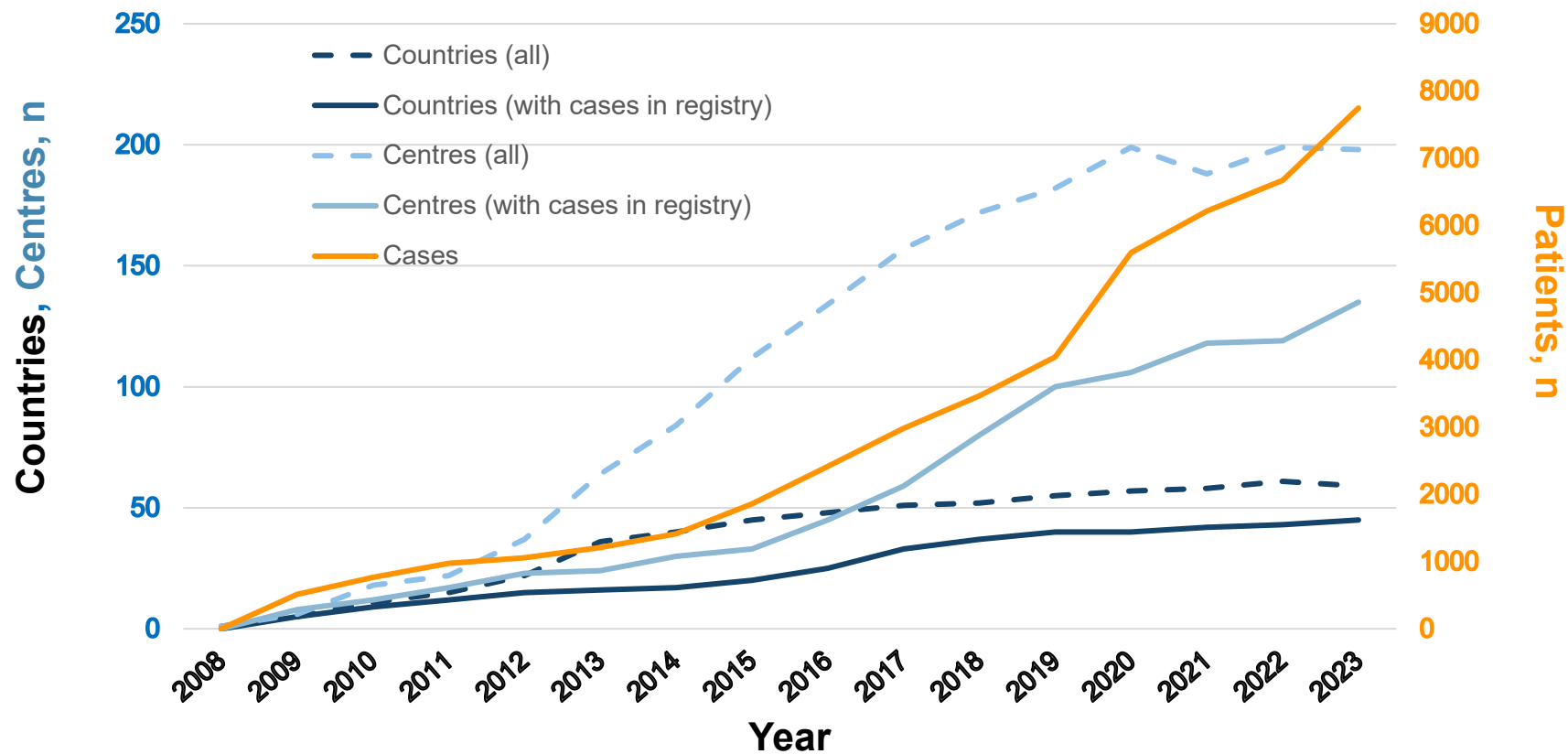
Newborn to 96 yrs
Median Age – 18 yrs

Approved by ethics to store routinely collected clinical data following informed consent

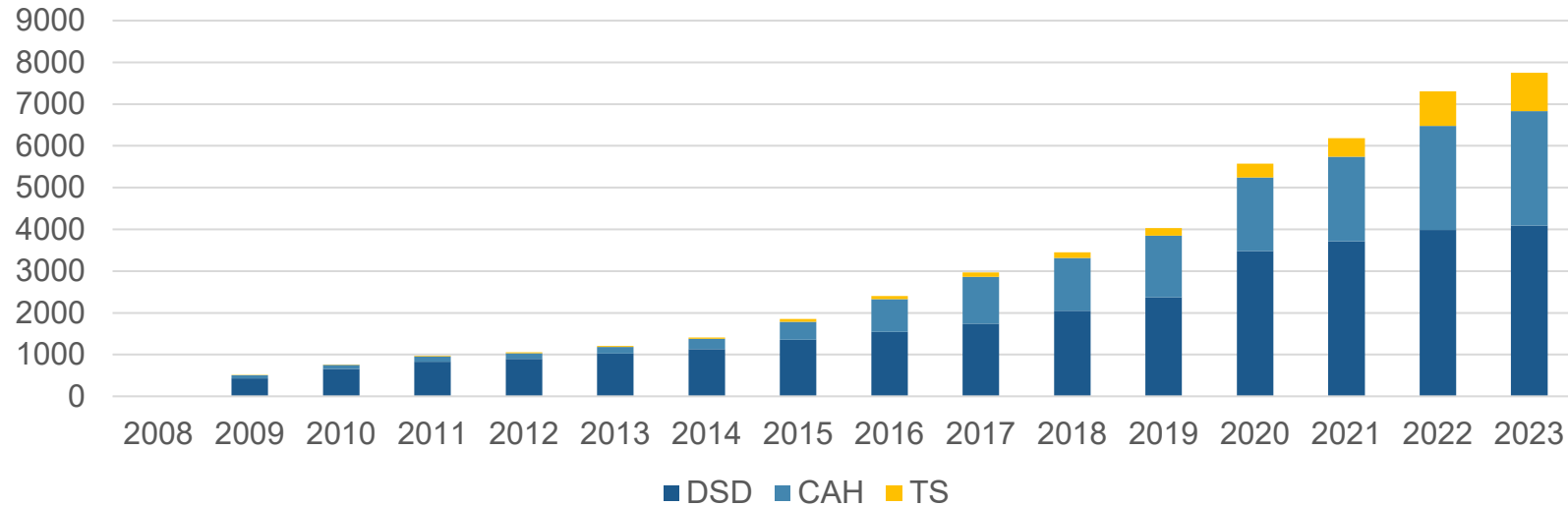


The I-DSD/I-CAH/I-TS Network - Trends

Countries, Centres & Patients

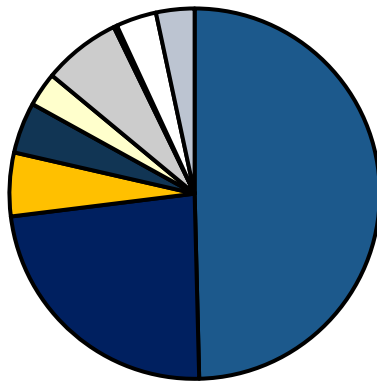


Cumulative Broad Groups of Conditions

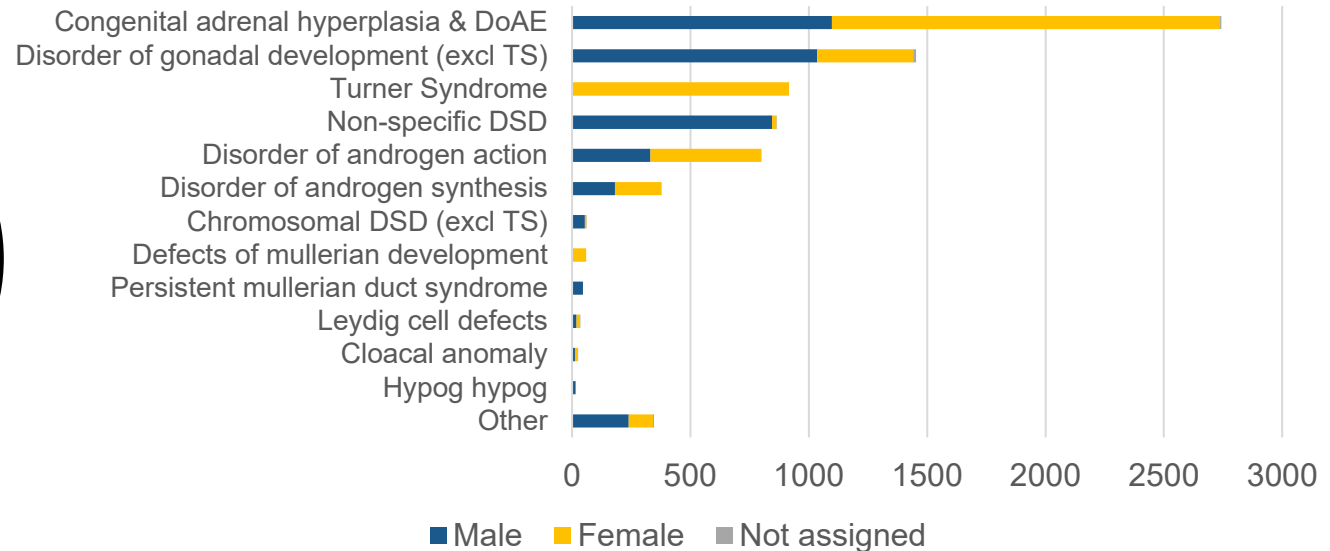


Karyotype

- 46,XY
- 46,XX
- 45,X
- 45,X/46,XY
- Other TS Karyotypes
- 47,XXY
- 46,XX/46,XY
- Other
- NK

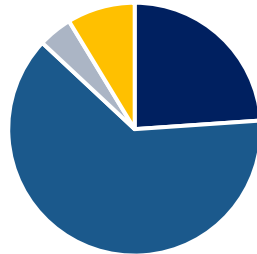


Diagnoses & Sex



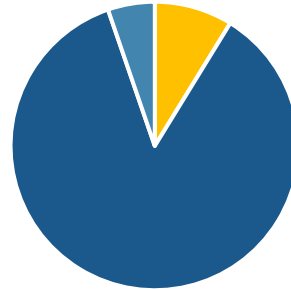
<https://sdmregistries.org/research-output/>

Projects approved n,65



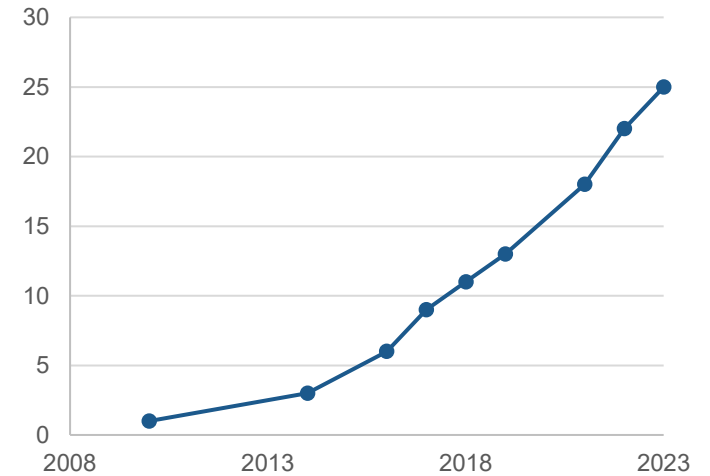
- No activity & no patient data supplied
- Patient level data supplied
- Quality assessment
- Surveys of practice

Funding of projects that were activated n,57

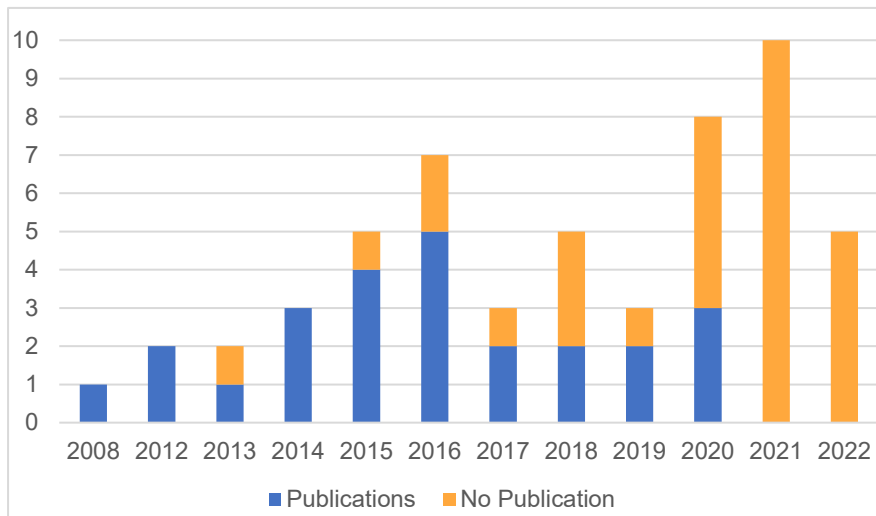


- Industry (feasibility)
- Public/University
- Public/University/Industry

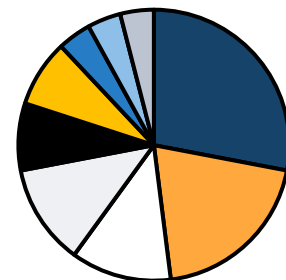
Cumulative outputs – original data publications



Outcome of activated research projects

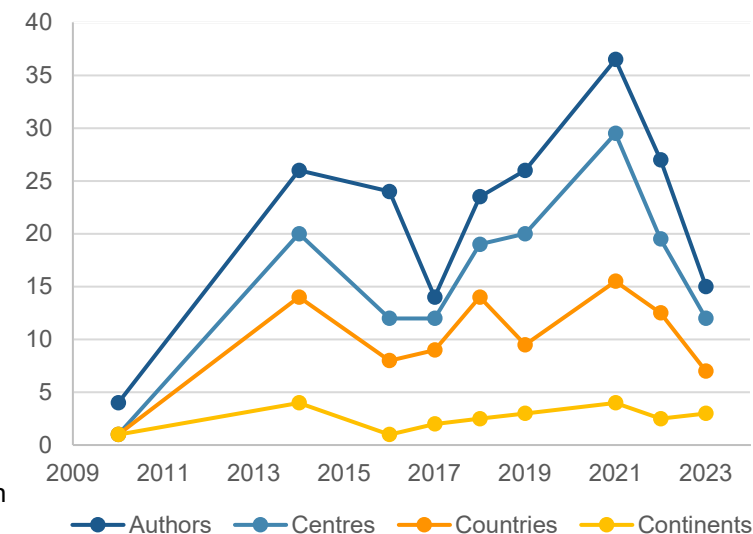


Destination of original data publications



- JCEM
- EJE
- OJRD
- Pediatr
- Endocrine
- Sex Dev
- HRP
- Clin Endo
- BMJ Open

Extent of Partnership



Median lag between study launch and publication = 2 yrs (1, 9)



Research Participation Awards 2022

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.



Uta Neumann, Berlin



Tulay Guran, Istanbul



Ruth Krone, Birmingham



Feyza Darendeliler, Istanbul



Federico Baronio, Bologna



Olaf Hiort, Lübeck



Inas Mazen, Cairo



Hedi Claahsen, Nijmegen



Ajay Thankamony,
Cambridge



Jeremy Tomlinson, Oxford



Martine Cools, Ghent



Silvano Bertelloni, Pisa



Faisal Ahmed, Glasgow



Erica van den Akker,
Rotterdam

The 2022 awards were kindly supported by Neurocrine Biosciences





**4th I-DSD 2013
Glasgow**



**5th I-DSD 2015
Ghent**



**6th I-DSD 2017
Copenhagen**



**7th I-DSD 2019
Sao Paulo**



**8th I-DSD 2021
Webinar**



**9th I-DSD 2022
Bern**



**10th I-DSD 2023
Webinar**



**11th I-DSD 2024
Stockholm**



**1st PG Course 2022
Bern**



**2nd PG Course 2024
Stockholm**

