I-DSD Activity Report
June 2022

Prepared 09 July 2022
Wide reach for DSD, CAH & TS events, education & newsletters

2022 – 6671 cases
120 centres from 43 countries with cases
199 centres from 59 countries in total

Newborn to 84 yrs
Median Age – 15 yrs

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

Countries with cases
Countries without cases
Median lag between study launch and publication = 2 yrs (1, 5)
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.

<table>
<thead>
<tr>
<th>Uta Neumann, Berlin</th>
<th>Tulay Guran, Istanbul</th>
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<tbody>
<tr>
<td>Ruth Krone, Birmingham</td>
<td>Feyza Darendeliler, Istanbul</td>
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<td>Federico Baronio, Bologna</td>
<td>Olaf Hiort, Lübeck</td>
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<td>Inas Mazen, Cairo</td>
<td>Hedi Claahsen, Nijmegen</td>
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<td>Ajay Thankamony, Cambridge</td>
<td>Jeremy Tomlinson, Oxford</td>
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<td>Martine Cools, Ghent</td>
<td>Silvano Bertelloni, Pisa</td>
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<td>Faisal Ahmed, Glasgow</td>
<td>Erica van den Akker, Rotterdam</td>
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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

1st Postgraduate Course in DSD 2022
Bern
Being repeated and will be combined with an assessment of research quality
I-CAH Acute Adrenal Insufficiency Project

Publication of the ‘Real World Estimates of Adrenal Insufficiency Related Adverse Events In Children with CAH’ showed the potential of the I-CAH Registry to act as a tool to create clinical benchmarks in CAH care.

All I-CAH centres that participated in this project are provided with a biennial, individualized report which provides information on the quality of the data in the I-CAH Registry and the quality of care, as reflected by sick day episodes and adrenal crises (benchmarking report example). Participating centres are encouraged to update the I-CAH Adverse Events dataset on patients at 6-monthly intervals so that we can continue providing these biennial reports.
Collaboration With Industry

Feasibility & Site Identification
- Diurnal
- Spruce Biosciences
- Neurocrine Biosciences
- Acerus Pharmaceuticals

Unrestricted Education Grants
- Diurnal
- Neurocrine Biosciences

Biennial I-DSD/I-CAH Symposium
- Diurnal
- Sandoz
- Merck-Serono
- Karger
- Spruce
- EffRx
- Pfizer
- Novo Nordisk

Research Participation Awards
- Neurocrine Biosciences