



## Details of Study ID 202212\_EW

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<p><b>Date of Approval:</b></p> <p>January 2023</p>
<p><b>Name of study:</b></p> <p>Trends in glucocorticoid prescribing practice in CAH over the last 5 years (2017-2022)</p>
<p><b>Summary of the proposed work to be performed with the registry data:</b></p> <p>Persons affected by CAH need glucocorticoid replacement for their entire life. It can be very challenging to replace this correctly since both too high and too low doses can affect their wellbeing. Most people with CAH receive multiple daily doses of hydrocortisone, usually as a tablet. We know from research that most available hydrocortisone tablets are often not ideal since the body needs more hydrocortisone in the second half of the night/ early morning, i.e. during sleep. In addition, very young children often have their tablets broken or crushed which leads to the dose they receive being inaccurate.</p> <p>Researchers have therefore developed new versions of hydrocortisone to address these problems. These include; slow-release or modified hydrocortisone and low dose hydrocortisone granules.</p> <p>With this project we want to find out how many people with CAH looked after by I-CAH centres are receiving the new hydrocortisone medications.</p>
<p><b>Lay summary for the public (for the I-DSD/CAH websites and other publicity materials) (maximum 50 words)</b></p> <p>Over the last few years multiple new treatment options have become available for managing steroid hormone replacement in congenital adrenal hyperplasia. This project aims to look at the availability of these new medications across all I-CAH centres.</p>
<p><b>Expected outputs</b></p> <p>The phase one data will be analysed over a 6 month period (October-April 2023) with the data submitted as an abstract to an International conference in 2023. The study group and participating I-CAH centres will work with the PI to prepare the analysed data for publication with the aim for the paper to be published by October 2024</p>



**Publication Plan for authorship in outputs (refer to [guidance](#))**

All members of the study group and PIs of participating centres will be authors on all planned publications.

All authors will be required to meet all criteria listed below:

- Contributions to the conception, design, acquisition, analysis or interpretation of the work
- Drafting and revising the work
- Approving the final version of the work prior to dissemination
- Accountability for all aspects of the work

**Inclusion criteria**

Cases of 21 hydroxylase deficiency, CAH requiring glucocorticoid replacement

Visits between 2017-2022

**Exclusion criteria**

Cases of 21 hydroxylase deficiency not requiring glucocorticoid replacement

No Visits since 2016

Data to be collected for all participating cases:

*Core:*

Consent (Y), Can be contacted for research purposes, Data can be shared for research purposes (Y), DOB, Actual diagnosis (CAH 21-OHD), Date of diagnosis, Diagnostic genetics

*CAH visits:*

*Anthropometry:* Age at 1st presentation, age at date of visit, Height, weight, BMI, BSA,

*Medication:* Adherence, has Tx changed, why Tx changed, GCs, GCs medicine, how take GCs, GCs dose, GCs unit, GCs time FC, total daily FC dose, FC freq, current GC replacement