

**Details of Study ID 202305_MEB**

<p>Name of the Principal Investigator:</p> <p>Gil Guerra-Junior/ Mayra El Beck</p>
<p>Contact details including institution:</p> <p>Department of Paediatrics – School of Medical Sciences – State University of Campinas (UNICAMP) 80, Vita Brasil Street– Brazil – Zip Code 13083-888</p> <p>E-mail: gilguer@unicamp.br or gileandrea@uol.com.br</p> <p>Mayra: maelbeck@gmail.com</p>
<p>Coinvestigators:</p> <p>Mayra de Souza El Beck, Brazil; Angela Lucas-Herald, UK; Guilherme Guaragna-Filho, Brazil; Zofia Kolesinska, Poland.</p>
<p>Date of Approval:</p> <p>May 2023</p>
<p>Name of study:</p> <p>Gender identity and gender contentedness in individuals with XY DSD raised as girls</p>
<p>Summary of the proposed work to be performed with the registry data:</p> <p>Assigning sex in DSD can be a challenging issue in many cases. Over the last few decades, we have been changing the way we assign sex for some conditions, placing greater emphasis on the known genetic and prenatal influences of hormonal exposure in the central nervous system rather than the external genital appearance. In fact, previous data collected in the I-DSD Registry suggest that more infants with a Y chromosome complement are raised as boys. However, we do not have sufficiently large cohorts to understand the gender-related outcomes in those who were raised as girls and we do not clearly understand the timing of any gender distress. The aim of this study is to gather data from centres all around the world on gender identity and contentedness in XY DSD adolescents who have been raised as girls and study any association to diagnosis, physical features and the psychosocial support that may be available.</p>
<p>Lay summary for the public (for the I-DSD/CAH websites and other publicity materials) (maximum 50 words)</p> <p>Assigning sex in complex forms of DSD can often be challenging issue. This study will use the I-DSD Registry to understand gender contentedness in adolescents with XY DSD who were raised as girls.</p>
<p>Inclusion criteria</p> <p>XY DSD cases raised as girls at birth and who are between the ages of 12 years and 21years old at the time of study launch.</p>



Exclusion criteria

Non-Specific XY DSD (ie individuals without a specific DSD diagnosis).

Data to be collected for all participating cases:

Centre, Country, Register ID, Consent for registry, Country of usual residence, Patient follow-up status, First contact with centre, Date of Birth, Sex at birth, Country at birth, Current gender, Karyotype, Disorder type Age for definition of sex of rearing, Actual diagnosis, Date of condition onset, Date of diagnosis, How was diagnosis reached? Age, Original sex assigned, Current gender, Child raised as, External phenotype, Spontaneous Puberty, Puberty Induction, Psychosocial, Gender identity.

Centres with eligible patients will be asked to complete a baseline I-DSD assessment to confirm the diagnosis and collecting physical and biochemical features at initial presentation and an annual DSD assessment (if available) from age 12 up to the age of 21 years (focussing specifically on the data above). In those cases where there is evidence of any gender distress, the centres shall be invited to complete an annual assessment from the age of 8 years. In those cases where there is evidence of any gender distress at 8 years, the centres shall be invited to complete an annual assessment from the age of 4 years.

We may have to contact you for further clarifications.

Expected outputs

We expect that this project will generate more conclusive data on gender identity and gender contentedness in some DSD conditions.

We expect to disseminate our findings through a publication in a high impact international scientific journal and through presentations in national and international conferences.

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

The authors involved in study design, data extraction and analysis and writing the paper will be listed first. Clinical contributors would be listed next according to the alphabetical order The senior authors involved in initial design of the study, data analysis and continuous supervision will be listed last.