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Reproductive Endocrinology

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Pilot Data Collection From The New I-HH Registry For Surveillance Of Hypogonadotropic Hypogonadism, Implementation Of Best Practice Management And International Standardisation

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Introduction: Hypogonadotropic hypogonadism (HH) is a rare, male predominant condition, due to mutations in over 60 known genes, which can have profound consequences for fertility. Significant advances are required in the diagnosis and treatment of HH to improve health, fertility and psychological outcomes. Diagnosis is often delayed and management can also be variable, particularly with the recent introduction of gonadotropin use. The I-HH registry, within the SDMregistries platform, is an international electronic registry for HH, that can collect standardised natural history data as well as enable comparison of the different treatment regimens that are often employed. **Methods:** The first full data collection from the I-HH registry occurred in April 2025, capturing data on 96 patients (37 female, 59 male) from 15 centres across 13 countries. Ages ranged from 10 to 34.5 years. Thirteen were born at 34-37 weeks gestation; the remainder at term (≥37 weeks).Pubertal induction was commenced in 49 patients (34 male, 15 female), at median age 14 years (IQR 12–17; range 11–19). One additional female received treatment to complete puberty. Among males, 13 (22%) reported impaired smell—8 with anosmia, 5 with hyposmia. Three females (9%) had anosmia. Micropenis was noted in 15 males (25%), undescended testes in 17 (29%), and 14 (24%) had both.Genetic data were available for 32 patients (23 male, 9 female), revealing known HH-associated variants in genes such as *ANOS1*, *FGFR1*, *PROKR2*, *CHD7*, *SOX10*, *GNRHR*, and *PROP1* (linked to pituitary hormone deficiency).Medication details were recorded for 34 males; 16 received gonadotropins. These patients came from 4 centres in 3 countries.Seven females and no males underwent fertility treatment. Spermatogenesis data were available for 4 males—3 post-gonadotropin therapy. Sperm concentrations were 14.4–59.9×10^6/ml in those post gonadotropin pubertal induction (WHO 2021 reference range ≥16 x10^6/ml, 95% CI 15-18 x10^6/ml). **Summary:** This inaugural data collection from the I-HH registry demonstrates that prospective longitudinal data collection is feasible for this rare condition, connecting worldwide centres to assess treatment modalities and long-term outcomes. The registry is currently in its infancy, and while current data are mainly cross-sectional, the registry lays a foundation for assessing treatment and long-term outcomes, including interpretation of growth and pubertal progression. Future work will prioritise analyses using peak height velocity as a surrogate for puberty via SITAR growth curve modelling. Centres will be encouraged to include detailed pubertal induction and growth data, focussing on peri-pubertal testicular volume and fertility outcomes to enhance granularity of future analyses.

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