Sláinte Leanaí Éireann (SLÉ), Herberton, Siúlán San Séamas, Rialto, D08 HP97, Éire
Children's Health Ireland (CHI), Herberton, St James's Walk, Rialto, D08 HP97 Ireland

Ref: PQ 19667/24

02nd July 2024

Deputy Leo Varadkar
Dáil Eireann
Dublin 2

Dear Deputy Varadkar

I refer to your below parliamentary question which has been forwarded to me for attention. Firstly, please accept my apologies for the delay in issuing a response.

PQ 19667/24 – To ask the Minister for Health If the Government has any policy or guidelines on surgery carried out on intersex infants; and if he will make a statement on the matter.

Children's Health Ireland (CHI) Response:

Thank you for your PQ 19667/24 asking the Minister for Health and Children's Health Ireland (CHI) if the Government has any policy or guidelines on surgery carried out on "intersex" infants.

To start, please note that use of the term "*intersex*" together with *pseudo-hermaphroditism, hermaphroditism, sex reversal*, and gender based diagnostic labels is particularly controversial. These terms are perceived as potentially pejorative by patients, and many prefer not to be referred to as people with "*intersex*" or "*intersex people/infants*". The Council of Europe has called for a review of medical classifications that unnecessarily medicalise intersex traits.

The term "*Disorders of Sex Development"* (DSD) has been proposed in 2006 by a Consensus Statement on Management of Intersex Disorder, and since then is used in clinical practice worldwide, similar to classification systems used to describe congenital conditions affecting other organs or systems of the body. Another accepted broad term is *Disorders of Sex Maturation (DSM)*. "Disorders" or "differences" of sex development (DSD) are a heterogeneous group of congenital conditions affecting human sex determination and differentiation (1). DSD are mainly caused by genetic defects of fetal sexual differentiation presenting as atypical genitalia (3) and can be associated with gonadal dysfunction and germ cell cancers (2).

In the past two years, CHI has joined the International DSD Registry (https://sdmregistries.org/) and as part of this CHI is participating in an international surveillance study of gonadectomy. The team at CHI already has institutional experience in understanding the prevalence of

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Gonadoblastoma in children with Turner mosaic syndrome with Y chromosome material, and the team at CHI have recently been awarded an Irish Research Council/Government of Ireland stipend to look at data on Gonadoblastoma in all DSD conditions. This research will inform optimal management of gonads in different DSD conditions, specifically in relation to indications and timing of gonadectomy and surveillance measures to monitor for malignant change in retained gonads (e.g risk at different stages of life including childhood and puberty). This is extremely important research the results of which will help parents make informed decisions regarding surgical options for their child going forward.

Safe and well-accepted national guidelines are currently being developed by CHI to standardise the management of any child presenting with atypical genitalia in the neonatal period (the draft guidelines have recently been reviewed by the National DSD MDT, and are being submitted to the CHI Clinical Guidelines Committee). Furthermore, CHI is member of ENDO-ERN (European Reference Network), which incorporates the Main Thematic Group (MTG7) Sex Development & Maturation looking at research and guideline development for DSDs across the lifespan of the patient (https://endo-ern.eu/rare-sex-development-maturation-conditions/expert-centres/). Endo-ERN's mission is to reduce and ultimately abolish inequalities in care for patients with rare endocrine conditions in Europe through facilitating knowledge sharing and related healthcare and research. Endo-ERN provides equality between paediatric and adult patients. Membership of this ERN ensures that Irish patients have access to expertise across the EU if required.

The management of these patients requires a multidisciplinary approach involving specialists from paediatric endocrinology, paediatric urology, clinical genetics, clinical psychology, gynaecology, and clinical nurses specialists. In CHI there are 3-4 multidisciplinary DSD clinics per year where cases from across the country can be discussed.

In light of recent changes in clinical recommendations as well as active ethical issues, the decision to proceed with any surgical intervention involves detailed robust multi-disciplinary discussion on an individual basis to fully inform and involve the patient and/or family in the decision-making process. The role of surgical intervention in DSD patients is mostly conservative and is confined to obtain information on the complex anatomy of DSD patients, to take biopsies/remove anatomical structures that might be at risk of malignant transformation or to reconstruct complex congenital genital anomaly such as hypospadias, in line with current international best practice.

Please do not hesitate to contact us if you have any further queries.

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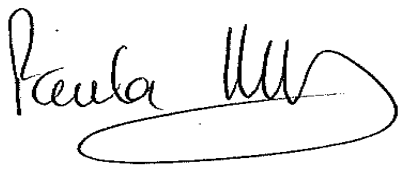
3. Abacı A, Çatlı G, Berberoğlu M. Gonadal malignancy risk and prophylactic gonadectomy in disorders of sexual development. J Pediatr Endocrinol Metab. 2015;28(9-10):1019-27.

Yours sincerely



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