

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 50398/25

08th October 2025

Deputy Pádraig Rice Dáil Eireann Dublin 2

Dear Deputy Rice

I refer to your parliamentary question below. Firstly, please accept my apologies for the delay in issuing a response.

PQ 50398/25 – To ask the Minister for Health the information provided to parents of intersex infants; the involvement, that intersex people have in informing and monitoring this information; if parents with intersex infants are being referred to an organisation (Intersex Ireland); and if she will make a statement on the matter.

Children's Health Ireland (CHI) Response:

To start, please note that there is no universally agreed term and we acknowledge that *some* but *not all* choose to use the term "intersex". The term "differences/disorders of sex development (DSD)" was devised as a classification system (by international medical consensus) to allow further understanding of this heterogenous group of conditions and ensure appropriate treatment options. We have therefore referred to this terminology below.

Children's Health Ireland (CHI) can advise that parents of children with differences of sex development (DSD) are given information on an individual basis from the outcome of the multi-disciplinary team meetings (MDT). The information given is dependent on the age of presentation, the underlying diagnosis and complexities, and proposed MDT informed management plan. Parents are also provided with leaflets relevant to the patient's condition and age (e.g. The Story of Sex Development by DSD families About:DSD Families) and are also referred to relevant websites.

In some cases, with more commonly seen conditions, CHI healthcare professionals may reach out to parents of other patients with the same condition to ask if they can speak to families with newly diagnosed conditions, but this is very much case by case approach. We are now working more with families and patient advocacy groups on future information provided to families as part of the National Rare Disease Strategy.

CHI's priority is to ensure that patients' families are aware of the many support resources available to them in this field such as DSD Families, CAH UK, Turner syndrome societies,

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CRA Registered Charity Number (RCN): 20202295 Revenue Charitable Status CHY: 22235

Board Members: Ms Mary Donovan, Ms Eleanor O'Neill, Ms Orla O'Brien, Dr Ruben Diaz, Mr Jim Frawley, Mr Joe Quinn, Dr Yvonne Traynor, Ms Anne Carrigy, Mr Tim Hynes, Mr Alan Seabourne



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and they are invited to participate in the international sex development and maturation (SDM) registries.

CHI does not endorse one resource available over another given the complexities of individual conditions, and the most suitable resource is determined on a case-by-case basis.

Yours sincerely

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Chief Medical Officer

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