Oifig an Stiúrthóra Náisiúnta
Géaroibríochtaí

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Deputy Alan Kelly
Dáil Éireann
Leinster House
Dublin 2

23rd June 2023

PQ 28436/23- To ask the Minister for Health the services currently available for people who have multiple sulfatase deficiency

Dear Deputy Kelly,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary question, which you submitted to the Minister for Health for response.

Multiple sulfatase deficiency (MSD) is a very rare and life-limiting lysosomal storage disease. It can present in neonates (most severe), infants (most common) or juveniles (rare). Its manifestations include hypotonia, coarse facial features, mild deafness, skeletal anomalies, ichthyosis (skin disorders), hepatomegaly, developmental delay, progressive neurologic deterioration and hydrocephalus. Multiple sulfatase deficiency can affect many of the bodies systems and patients often require input from multiple disciplines.

Services for multiple sulfatase deficiency are currently available in the following expert centres in Ireland:

1. The National Centre for Inherited Metabolic Disorders, CHI @ Temple Street
2. The National Centre for Inherited Metabolic Disorders – Adult Services, Mater Misericordiae University Hospital

These services are part of an Expert Centre Network: The National Centre for Inherited Metabolic Disorders at CHI and National Centre for Inherited Metabolic Disorders at MMUH and are members of the European Reference Network: MetabERN.

I trust this information is of assistance to you but should you have any further queries please contact me.

Yours sincerely,

Brian Dunne

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Brian Dunne
General Manager, Acute Operations