



Géaroibríochtaí  
Aonad 4A, Áras Dargan, An Ceantar Theas, An Bóthar  
Míleata Cill Mhaighneann, Baile Átha Cliath 8

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**Date: 15/10/2020**

Deputy Louise O'Reilly TD  
Dáil Éireann  
Leinster House  
Dublin 2

**PQ No. 29685/20 To ask the Minister for Health if decompression, fusion and re-tethering, treatments will be made available for patients with ehlers-danlos syndrome.**

Dear Deputy O'Reilly,

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. I have examined the matter and the following outlines the position.

**Response:**

The most common form of Ehlers-Danlos Syndrome (EDS) is hypermobility of the joints and requires management by physiotherapy and primary care but does not usually need specialist input. The most severe and very specialist cases are rare (1 per 100,000 live births) and are usually managed by paediatric rheumatologists based at Our Lady's Children's Hospital Crumlin (OLCHC). Based on these figures the total number of patients with severe EDS is likely to be in the order of 20-40 patients nationally.

Paediatric and Adult rheumatologists are trained in the diagnosis and management of EDS. They are supported by a multidisciplinary team and have access to other relevant consultant specialists needed for the care of EDS sufferers. Any treatments deemed necessary for any patient are made available on referral by their treating consultant.

I trust this answers your question to your satisfaction.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Emma Benton'.

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**Emma Benton**

**General Manager**

**Acute Operations**