



Géaroibríochtaí  
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Míleata Cill Mhaighneann, Baile Átha Cliath 8

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Date: 20/11/2019

Deputy Louise O'Reilly TD

Dáil Éireann

Leinster House

Dublin 2

PQ No. 46139/19, 46140/19

To ask the Minister for Health if his attention has been drawn to Ehlers-Danlos syndrome; if his Department or the HSE keep a register of persons with the condition; if so, the age, location and number of persons with the condition; and if he will make a statement on the matter.

To ask the Minister for Health his plans to compile a register of persons with Ehler-Danlos syndrome; and if he will make a statement on the matter.

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 National Clinical Programme for Rheumatology (NCPR) is an advocate for the use of registries to improve patient care. Currently no register exists however the NCPR has proposed an Arthritis Registry in the NCPR model of care to support the future development of services for patients with bone and joint diseases in Ireland and which would ultimately include Ehler-Danlos syndrome.

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**