



Rannán na nOspidéal Ghéarmhíochaine
Aonad 4A, Áras Dargan
An Ceantar Theas
An Bóthar Míleata
Cill Mhaighneann
Baile Átha Cliath 8

Acute Operations
Unit 4A, The Dargan Building
Heuston South Quarter
Military Road
Kilmainham
Dublin 8

4th July 2022

Deputy David Cullinane,
Dáil Eireann,
Leinster House
Kildare Street
Dublin 2

PQ 29486/22 - To ask the Minister for Health if there is a registry of individuals with Addison's disease; if not, if he plans to develop one; and if he will make a statement on the matter. -David Cullinane

Dear Deputy Cullinane,

I refer to your recent parliamentary question in relation to a registry of individuals with Addison Disease which was forwarded to the HSE by the Department of Health for direct reply.

Currently there is no registry of individuals with Addison Disease. However, since January 2022, three centres of expertise have joined the European Reference Network (ERN) for Rare Endocrine disorders (ERN-Endo). Every ERN is engaged in the triple obligation of highly specialised healthcare, research, and education. This includes a number of key work packages such as the creation and maintenance of registries, databases and biobanks. The development of registries will be a key objective for our ERN Clinical Leads across the five ERN participating hospitals. The National Rare Diseases Office is assisting the five hospitals to co-ordinate their requirements for ERN integration.

The implementation of Orphacodes (rare disease coding system) is an essential part of ERN integration and the operationalisation of key work packages such as the development of registries for rare diseases. The National Rare Diseases Office is working with the OCIO to co-ordinate the implementation of Orphacodes into the routine coding systems across the five hospitals.

I trust this answers your question to your satisfaction.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Brian Dunne', written over a horizontal line.

Brian Dunne
General Manager, Acute Operations