



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  
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Kilmainham  
Dublin 8

28<sup>th</sup> November 2022

Deputy Peadar Tóibín  
Dáil Eireann,  
Leinster House  
Kildare Street  
Dublin 2

**PQ 56156/22- To ask the Minister for Health the number of persons with rare disease in Ireland as of 2022, by county and by rare disease type in tabular form.**

Dear Deputy Tóibín,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted for response. I have examined the matter and the following outlines the position.

In accordance with the HSE Model of Care for Rare Diseases (2019) an estimated 300,000 people live with rare diseases in Ireland (1 in 17; 6% of population). As a result of inadequate rare disease coding systems and the lack of development of registries for rare diseases, the total dimension and extent of the disease burden for these conditions is not currently quantified.

The implementation of Orphacodes (rare disease coding system) and the development of registries for rare diseases are essential to the successful integration and operationalisation of the 18 European Reference Networks (ERNs) into the Irish health care system. Both initiatives are critical to addressing the current significant gaps and challenges in the accurate codification of rare diseases and monitoring and reporting of the national prevalence and incidence of rare diseases. The development of registries for rare diseases is a key recommendation in the National Rare Disease Plan for Ireland 2014-2018 which the HSE are committed to implementing.

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

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Brian Dunne'.

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**Brian Dunne**  
General Manager, Acute Operations