



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

Rannan na nOspideil Ghearmhíochaine  
Aonad 4A – Áras Dargan  
An Ceantar Theas  
An Bothar Mileata  
Cill Mhaighneann  
BÁC 8

Acute Operations  
Health Service Executive  
Unit 4A - The Dargan Building  
Heuston South Quarter  
Military Road  
Kilmainham  
Dublin 8.

Date: 11<sup>th</sup> July 2022

Deputy Bernard J. Durkan  
Dáil Éireann  
Leinster House  
Dublin 2.

***PQ 36352/22 \* To ask the Minister for Health if adequate funding support is available to identify and treat rare diseases; if such diagnoses can trigger a rapid response particularly in respect of the lesser known rare diseases; if such a provision will be made at an early date and if he will make a statement on the matter.\****

Dear Deputy Durkan,

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.

### **Response:**

The HSE has in place a comprehensive system by which Hospital Groups submit plans to the HSE for new service developments and, where there the demand on existing services is increasing, work with stakeholders to develop plans to apply for additional funding where it is required.

The infrastructure and resources required for the effective treatment of rare diseases is embedded within the acute hospital system and has been developed and put in place over many years. While those suffering from or seeking a diagnosis of rare diseases require a high level of clinical input and care, in the context of the overall acute hospital system the resources devoted to rare diseases are relatively small.

In order to support the HSE and the Dept of Health in ensuring resources are allocated effectively upto date data and research is required. In this regard the work of the National Office for Rare Diseases (NRDO) is essential. The following projects which are being overseen by the NRDO and the acute hospitals are aimed at ensuring this information is available to policy makers and service providers:

**Orphacodes** – the integration of the rare disease nomenclature into the health service systems will significantly address the current gaps and challenges in the collection and reporting of rare diseases therefore increasing visibility of people with rare diseases and timely access to diagnosis.

**European Reference Networks (ERN)** – these are networks of healthcare professionals working in rare, low prevalence and complex diseases across Europe. They have been established to pool together the scarce and scattered medical expertise on rare and complex diseases throughout the European Union (EU) with the objective to share knowledge and research in order to support the timely, accurate diagnosis and follow-up treatment for the patients affected by a rare disease. Ireland is now a member of 18 ERNs and is in the process of integration across the five participating hospitals.

Individual diagnoses do not normally trigger the allocation of resources. However the system of funding allocation does respond flexibly where a service comes under particular pressure.

I trust that this answers your question to your satisfaction.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Brian Dunne". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

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**Brian Dunne**  
**General Manager**  
**Acute Operations**