



**Oifig an Stiúirthóra Náisiúnta
Géaroibríochtaí**

Aonad 4A, Áras Dargan, An Ceantar Theas,
An Bóthar Míleata, Cill Mhaighneann, Baile
Átha Cliath 8, D08 NN9V

**Office of the National Director
Acute Operations**

Unit 4a, the Dargan Building,
Heuston South Quarter, Military
Road, Kilmainham, Dublin 8, D08
NN9V

www.hse.ie
[@hselive](https://twitter.com/hselive)

† 01 7959972

acutehospitals@hse.ie

14th July 2022

Deputy Bernard Durkan

Dáil Éireann,

Leinster House

Kildare Street

Dublin 2

PQ 36104/22 - To ask the Minister for Health to indicate the incidents of rare diseases reported/diagnosed in this country in the past five years; the extent to which it has been found possible to offer appropriate medication within a short time; and if he will make a statement on the matter.

Dear Deputy Durkin,

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.

Currently there is no central mechanism in place for rare disease surveillance and reporting. The development of rare disease registries is key to monitoring national prevalence and incidence of rare diseases. This is a key function of the European Reference Networks (ERNs) and since January, Ireland is now a member of 18 ERNs. The European Commission Cross Border Care Directive 2011/24/EU requires that ERNs and healthcare providers wishing to join ERNs should have the capacity to develop rare disease registries. Currently, all the approved ERNs have declared that the development of registries is a priority.

The HSE is committed to providing access to as many medicines as possible, in as timely a fashion as possible, from the resources available (provided) to it. The HSE robustly assesses applications for pricing and reimbursement to make sure that it can stretch available resources as far as possible and to deliver the best value in relation to each medicine and ultimately more medicines to Irish citizens and patients. When a decision is taken to approve a medicine (add it to reimbursement list or fund through hospitals) all qualifying patients gain access to it. It is not a patient by patient decision process.

I trust this answers your question to your satisfaction.



Yours sincerely,

A handwritten signature in black ink that reads "Brian Dunne". The signature is written in a cursive style with a long horizontal line extending to the right.

Brian Dunne

General Manager, Acute Operations