



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: 11th July 2022

Deputy Bernard J Durkan
Dáil Éireann
Leinster House
Dublin 2.

PQ 36353/22 * To ask the Minister for Health the number of person who have rare diseases awaiting a decision in respect of reimbursement for medication; the number of cases still awaiting a diagnosis and access to treatment and reimbursement 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 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.

HSE decisions on which medicines are reimbursed by the taxpayer are made on objective, scientific and economic grounds. There are formal processes which govern applications for the pricing and reimbursement of medicines, and new uses of existing medicines, to be funded and/or reimbursed.

There are various medicines for which the HSE has received applications for pricing and reimbursement and for which assessments are ongoing. Some will be for rare diseases and some will be for non rare diseases. When a decision is taken to approve a medicine (add it to reimbursement list or fund through hospitals) all qualifying patients gain access it. It is not a patient by patient decision process.

There is no data collected on patients who are awaiting a diagnosis for a a rare disease or who may be prescribed a medicine once it is approved.

I trust that 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 large, looped initial "B".

Brian Dunne
General Manager
Acute Operations