



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: 23rd February 2021

Deputy Burke,
Dáil Éireann
Leinster House
Dublin 2.

PQ 7590/21 * To ask the Minister for Health if a list of the Rare Disease Technology Review Committee recommendations in 2020 will be made available in tabular form; and if he will make a statement on the matter.

Dear Deputy Burke,

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 Technology Review Committee for Rare Diseases (as recommended by the National Rare Disease Plan for Ireland) was established in 2017 with responsibility for:

1. Reviewing proposals received from industry or expert groups in Ireland for funding of new products for rare diseases, or expanded indications for existing products for rare diseases and making recommendations as to the implementation of the relevant recommendations from the National Rare Diseases Plan 2011-2018; and
2. Providing contributions to the development of clinical guidelines for relevant Orphan Medicinal Products (OMPs) and supporting the implementation of guidelines in conjunction with the National Drugs Management Programme Office where applicable.

During 2020 the Rare Disease Technology Review Committee, reviewed two drugs at the request of the HSE Drugs Group. These were:

Drug	For treatment of
Patisiran	hereditary transthyretin-mediated amyloidosis
Burosumab	X-linked hypophosphataemia (XLH)

The Technology Review Committee issued a statement to the Drugs Group on 26th November recommending their use for the conditions cited.

I trust that this answers your question to your satisfaction.

Yours sincerely,



Brian Dunne
General Manager
Acute Operations