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30<sup>th</sup> July 2020

**Deputy David Cullinane,  
Dáil Eireann,  
Leinster House,  
Kildare Street,  
Dublin 2**

*PQ 17340/20 - To ask the Minister for Health the status of the work of the Rare Diseases Technology Review Committee; the sittings it has had since its inception; if it will conduct a review of the terms of reference of the committee in tabular form; and if he will make a statement on the matter.*

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Dear Deputy Cullinane,

The Health Service Executive (HSE) has been requested to reply directly to you in the context of the above Parliamentary Questions, which you submitted to the Minister for response.

A Technology Review Committee for Rare Diseases (as recommended by the National Rare Disease Plan for Ireland) was appointed in late 2018 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.

Since the Committee was established, there have been five meetings held following requests to review new or existing medicinal products for rare diseases. Between meetings, a significant volume of work is carried out by members including the production of prescribing guidelines, outlining how managed access programmes would work, identifying starting and stopping criteria for drugs etc. Due to COVID-19 pressures, the Committee has not met in recent months, however meetings are scheduled for quarter 3 of 2020 at which time the terms of reference will be reviewed. Refresh of the membership is currently underway which includes the filling of the currently vacant Pharmacist and Administration posts funded to support the Committee.

I trust the above addresses your query but please do not hesitate to contact me if you require any further details.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Helen Shortt', written in a cursive style.

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**Helen Shortt**  
**A/National Director**  
**Acute Strategy & Planning**