



Rannan na nOspideil Ghearmhfochaine  
Aonad 4A, Aras Dargan,  
An Ceantar Theas,  
An B6thar Mfleata  
Cill Mhaighneann,  
Baile Atha Cliath 8

Acute Operations  
Health Service Executive  
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Deputy Padraig Mac Lochlainn,  
Dail Eireann,  
Leinster House,  
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Dublin 2

**October 6th 2020**

PQ 25384/20\* To ask the Minister for Health if his attention has been drawn to calls by persons living with amyloidosis to take actions (details supplied) with reference to the HSE amyloidosis working group; and if he will make a statement on the matter.\*

**Response:**

Dear Deputy Mac Lochlainn,

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

A working group commissioned by the Office of the National Clinical Advisor and Group Lead in the HSE Acute Hospitals Operations Division has recently finalised its report on developing a Model of Care for amyloidosis which when implemented will improve the diagnosis and treatment of patients on the island of Ireland.

The current amyloidosis care pathway is heavily reliant on the referral of patients to the UK. Due to Brexit and the current pandemic this reliance poses a risk to the service and to patients.

The Model of Care proposed by the Working Group which was produced after wide consultation with healthcare professionals, patients, family members and patient groups centres around a number of recommendations which when implemented will:


- Result in speedier diagnosis through the employment of a gate system which will allow for amyloidosis to be diagnosed in instances where it may not be under consideration, allowing for a timelier diagnosis.
- Early diagnoses will allow for more effective referral pathways resulting in reduced referrals to complex care centres and more care in community settings closer to the patient.
- This new model, which is grounded in research and international best practice, will allow for improved links with the European Rare Disease Networks through the national links in the respective networks.
- It will allow Ireland to contribute to and benefit from the growing body of amyloidosis research at a global level.

The HSE Rare Diseases Medicinal Products Technology Review Committee meets in response to requests for assessment of new products for rare diseases or expanded indications for existing products for rare diseases. I can confirm that it met recently and is currently reviewing 'Patisiran' a new medication for Amyloidosis .

In addition to work related to new treatments the Technology Review Committee is currently carrying out a review of its existing terms of reference in order to more effectively encompass the re-imbursement process into it's reviews.

I trust this answers your question to your satisfaction.

Yours sincerely,



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