



15<sup>th</sup> November, 2024

Deputy Gary Gannon, TD  
Dáil Éireann  
Leinster House  
Kildare Street  
Dublin 2

**PQ 44245/24**

**To ask the Minister for Health what initiatives are being considered to raise awareness and provide information about amyloidosis in Ireland, especially given the challenges faced by patients too advanced in their illness to travel to the UK for a SAP scan; and if he will make a statement on the matter.**

Dear Deputy Gannon,

The Health Service Executive has been requested to reply directly to you in relation to the above representation, which you submitted to the HSE for response. I have consulted with the National Clinical Programme for Neurology (NCPN) and the National Rare Diseases Office (NRDO) on your question and have been informed that the following outlines the position.

The HSE National Rare Diseases Office (NRDO) aims to support, inform and empower people living with rare diseases (PLWRDs), their families and caregivers. The NRDO information line service signposts rare disease families, patient organisations, health care professionals, researchers, and policy-makers to current validated information, national and European clinical expertise and patient organisations, social care supports, research and clinical trials.

The NRDO engages in rare disease education and training initiatives for healthcare professionals, advocates for rare disease patients within the Irish healthcare system and raises awareness of the needs of PLWRD and their families.

The HSE acknowledges the need to improve awareness of amyloidosis in the medical and non-medical communities. A HSE Amyloidosis Model of Care was approved in 2022 and a number of Irish clinicians with expertise in amyloidosis continue to raise awareness in the medical community through educational training days.

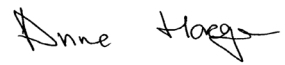
The HSE's Amyloidosis Model of Care is based on the premise of the creation of a national amyloidosis service to implement a proposed new Model of Care for patients with amyloidosis. When a model of care is approved it is then progressed to implementation operationally. There are a number of areas identified in the model of care that require funding in order to progress to implementation.

There has been progress with the approval of pharmacological treatments included in this model of care, where relevant, through the HSE's medicines management approvals process.

Currently, after being diagnosed with amyloidosis, in the absence of a dedicated specialist centre, many patients are referred to the UK National Amyloidosis Centre via the Treatment Abroad Scheme (TAS) to confirm diagnosis and guide treatment. Unfortunately due to the nature of the disease, some patients may be too unwell to travel.

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely

A handwritten signature in black ink that reads "Anne Horgan". The signature is written in a cursive style with a long horizontal flourish at the end.

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**Anne Horgan**  
**General Manager**