



09 July, 2025

Deputy Colm Burke, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: 34702/25

To ask the Minister for Health if she will support the establishment of a national clinical programme for pulmonary arterial hypertension, along with rare heart diseases; and if she will make a statement on the matter

Dear Deputy Burke,

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

There is currently no plan to establish a national clinical programme for pulmonary arterial hypertension, along with rare heart diseases.

The National Rare Diseases Office (NRDO)¹ was established by the HSE in 2015. The NRDO is the national rare disease coordination hub and the HSE's main contact and driver of rare disease initiatives and projects, to support national rare diseases centres of expertise, aligned with the standards of care set by the European Reference Networks (ERNs) and the 2019 HSE Model of Care for Rare Diseases.

In accordance with the National Rare Disease Plan for Ireland (2014-2018) and the HSE Model of Care for Rare Diseases (2019), the aim of NRDO is to support people with rare conditions and their families by improving accessibility and quality of services

Pulmonary arterial hypertension (PAH) is a group of diseases characterised by increased resistance in the pulmonary arteries, which can lead to right heart failure.

According to Orphanet [the international portal for rare diseases] there are several Irish expert centres that care for people with rare respiratory diseases, such as pulmonary arterial hypertension and rare heart diseases. These expert centres for PAH in Ireland include:

- National Pulmonary Hypertension Unit, Mater University Hospital (Adult service)
- National Pulmonary Fibrosis Centre, Tallaght, which incorporates the Rare Lung Disease Clinic at Tallaght University Hospital (Adult service)
- Rare Paediatric Respiratory Conditions Clinic, CHI Crumlin (Paediatric service).

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

Anne Horgan
General Manager

References:

1. <https://www.hse.ie/eng/services/list/5/rarediseases/>