



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: 19th March 2021

Deputy Thomas Pringle
Dáil Éireann
Leinster House
Dublin 2.

PQ 12334/21 To ask the Minister for Health the supports in place for persons with rare diseases in Ireland; and if he will make a statement on the matter.

Dear Deputy Pringle,

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:

Persons with rare diseases access a range of services including acute services, appropriate GP and community services during their diagnosis and treatment. How patients interact with these services varies depending on assessment and diagnosis, and the treatment plan which usually involves a number of health care professionals across a broad spectrum of service areas.

Frequently the care of individuals with rare diseases is provided in the context of services for common diseases in the specialty with shared general resources.

The HSE Rare Diseases Office (RDO) is a HSE facility that provides information for persons with rare diseases, their families and the healthcare workers who support them, to support their care. with an information service and an information portal- website, www.rarediseases.ie .The 2020 'Easy Guide to Rare Diseases 'developed by the Rare Diseases Taskforce is accessible on this site

The Rare Diseases Office supports the Orphanet Ireland site. This provides information regarding national rare disease expert resources (expert centres for multidisciplinary care, patient organisations, diagnostics, research and registries) and also information about these resources in European countries for virtual or physical cross border care (www.orpha.net).

Community care services; The relevant community care services may include public health nurse, home help, personal assistance, psychological services, speech and language therapy, occupational therapy, social work services, physiotherapy, daycare and respite.

Benefits and Schemes, such as the Long term Illness Scheme and the Treatment Abroad Scheme.

Patient Support Groups and Advocacy Services.

Counselling and information as to how to access services.

Information about European Reference Networks

I trust that this answers your question to your satisfaction.

A handwritten signature in black ink, appearing to read "Brian Dunne". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Brian Dunne
General Manager
Acute Operations