



BY EMAIL ONLY

Deputy Emer Higgins
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

2nd February 2024

PQ1741/24- Deputy Emer Higgins- To ask the Minister for Health to provide information on the current state of genetic services in Ireland, including the waiting times for genetic testing and the resources available to people living with a rare disease; and if he will make a statement on the matter.

Dear Deputy Higgins,

Thank you for your representation.

The Health Service Executive has been requested to reply directly to you in the context of the above parliamentary question (PQ 1741/24), which you submitted to the Minister for Health.

The below table provides waiting list figures as of 28th December 2023 for adults and children who have either a date for their first outpatient appointment or are waiting for an outpatient appointment date.

Clinical (Medical) Genetics Waiting List Figures for Adults as of 28/12/23					
No. of months waiting	Total	0-6	6-12	12-18	18+
No. of patients	2,977	701	721	633	922
Clinical (Medical) Genetics Waiting List Figures for Children as of 28/12/23					
No. of months waiting	Total	0-6	6-12	12-18	18+
No. of patients	704	158	377	157	12

Source: National Treatment Purchase Fund

In 2023, the National Genetics and Genomics Office was established and is responsible for the delivery of the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland. The strategy highlighted the need for a fit-for-purpose and agile workforce to meet current and future demands in genetic and genomic healthcare. A priority for 2024 is the development of a robust workforce plan to support the recruitment, retention, education and career development of specialised roles. In Q1 2024, a piece of work will commence to establish the as is for the existing specialised workforce and to help determine where additional resources may be required. The 2024 National Service Plan will also identify where additional resources



will be allocated to provide services to patients and their families living with a rare or inherited disease.

The National Rare Diseases Offices manages the National Rare Disease Information Service which supports people and families affected by rare diseases through the provision of current evidence-based information on rare conditions, access to clinical expertise and services. The Information Service can help navigate and signpost to the relevant health and social care supports and services available to people affected by rare diseases.

I hope this provides you with some assistance.

Yours sincerely

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

Sharon Hayden
General Manager
Office of the Chief Clinical Officer