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**BY EMAIL ONLY**

Deputy Darren O'Rourke  
Dáil Éireann  
Leinster House  
Kildare Street  
Dublin 2

29<sup>th</sup> May 2024

**PQ20153/24- Deputy Darren O'Rourke- To ask the Minister for Health the average waiting times for genetic testing services for rare diseases in Ireland; and the measures the HSE is taking to improve access and speed of results for patients in need of genetic testing services.**

Dear Deputy O'Rourke,

Thank you for your representation.

There are a number of genetic and genomic tests and techniques used in the diagnosis of Rare Diseases and depending on the complexity and urgency of the test the turnaround times are different. In addition, there is variation across laboratories used outside of Ireland.

The Strategy for Accelerating Genetic and Genomic Medicine in Ireland focuses on a number of areas of improvement including ensuring the mainstream clinical workforce has the appropriate knowledge and skills to offer testing at an earlier time in the patient diagnostic pathway and this will be guided by the completion and publication of a National Test Directory. In addition, the Strategy recommends an increase in the specialist genetic workforce.

The HSE's National Genetics and Genomics Office is working on delivering on these areas.

I hope this provides you with some assistance.

Yours sincerely

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Sharon Hayden  
General Manager  
Office of the Chief Clinical Officer