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	Aonad 4A, Áras Dargan, An Ceantar Theas, An Bóthar Míleata, Cill Mhaighneann, Baile Átha Cliath 8, D08 NN9V	Unit 4a, the Dargan Building, Heuston South Quarter, Military Road, Kilmainham, Dublin 8, D08 NN9V	t 01 795 9972 e acutehospitals@hse.ie

Deputy Patrick Costello
Dáil Éireann
Leinster House
Dublin 2

11th May 2023

PQ 16738/23 - To ask the Minister for Health the average waiting time for people with a rare disease to access genetic testing and then to receive a subsequent diagnosis after a referral; and if he will make a statement on the matter.

Dear Deputy Costello,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary question, which you submitted to the Minister for Health for response.

Children's Health Ireland (CHI) have advised that the waiting time for a routine appointment at the Department of Clinical Genetics (DCG) in CHI at Crumlin is currently 24 months, with some referrals having a shorter waiting time depending on the clinical urgency.

CHI advised that it may take a significant amount of time for a patient who may potentially have a rare disease to be seen by other specialists before being referred to DCG, even to get on to the 2 year waiting list.

In addition, CHI advise that most test results take approximately 3 months to come back unless they are urgent. Despite use of the best available testing, not all patients will receive a diagnosis and may require re-investigation later when testing technology has moved on.

It is of importance to note that a significant amount of rare disease genetic testing takes place independent of the DCG in Children's Health Ireland (CHI) at Crumlin in other institutions, for example testing takes place in the Mater and Beaumont yet have been advised that data is not available.

I trust this is of assistance,

Yours sincerely,

Nessa Lynch
General Manager
Acute Operations