



Ref: PQ 21611/23

25th May 2023

Deputy Michael McNamara
Dáil Eireann
Dublin 2

Dear Deputy McNamara

I refer to your below parliamentary question which has been forwarded to me for attention. Firstly, please accept my apologies for the delay in issuing a response.

PQ 21611/23: To ask the Minister for Health the actions being taken by his Department and the HSE to reduce waiting times for genetic testing at Our Lady's Children's Hospital, Crumlin; the investment that is being made in diagnostic services for the estimated 300,000 people living with a rare disease in Ireland at present; and if he will make a statement on the matter.

Children's Health Ireland (CHI) Response:

The Department of Clinical Genetics at Children's Health Ireland (CHI) at Crumlin provides a clinical and laboratory genetic service for children and adults affected by, or at risk of, a genomic condition. It has expertise in rare genetic conditions and can arrange appropriate genetic or genomic testing.

The Department of Clinical Genetics at CHI at Crumlin currently has 4.2 whole time equivalent (WTE) Consultants and 5.84 WTE Genetic Counsellors. Just over 6,000 patients were seen at 4,226 appointments by the clinical service in 2022.

Patients referred to the clinical service are triaged according to priority, and the type of clinical case. There are currently 1,709 patients on the waiting list to be seen in the department, 1,134 of whom are waiting to see a Consultant Geneticist, and 575 of whom are waiting to see a Genetic Counsellor on 25th May 2023.

The waiting time for a routine Consultant appointment is now 24 months. Waiting times for those prioritized as urgent cases are significantly shorter. The waiting list is actively managed on a daily basis by the Clinical Service.

There has been a significant amount of work done to successfully reduce the waiting time for patients, which had been at 36 months in 2021. Additional funds were provided from the HSE

Sláinte Leanaí Éireann



Children's Health Ireland

Sláinte Leanaí Éireann (SLÉ), Herberton, Siúlán San Séamas, Rialto, D08 HP97, Éire
Children's Health Ireland (CHI), Herberton, St James's Walk, Rialto, D08 HP97 Ireland

waiting list initiative for Locum Consultant clinics and additional Genetic Counsellor clinics and this continues to have an impact.

Further staffing appointments are expected reduce the clinic waiting times further. An additional Consultant Geneticist has commenced their post in the Department of Clinical Genetics at CHI at Crumlin in May 2023, and a currently vacant Consultant Geneticist post will be re-advertised as soon as possible. Additional specialist training posts in clinical genetics have been funded by the National Doctors Training Programme (NDTP). Additional Genetic Counsellors are being recruited to fill a total of 3.25 WTE equivalent Genetic Counsellor posts which are currently vacant.

The recent 'The National Strategy for Accelerating Genetic and Genomic Medicine in Ireland' has identified the continuing need for expansion of the genomic workforce to improve access to timely and equitable genomic care.

Yours sincerely

PROF. SEAN WALSH
CLINICAL DIRECTOR/ SITE LEAD
Children's Health Ireland (CHI) at Crumlin
Crumlin, D12 N512, Ireland
E ceo.admin@olchc.ie www.olchc.ie

Our **Mission** is to: Promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence. We will do this in partnership with each other, with children, young people and their families through a network of children's services in Ireland.

CRA Registered Charity Number (RCN): 20202295 Revenue Charitable Status CHY: 22235

Board Members: Prof James Browne (Chairman), Mr Con Cronin, Ms Mary Cryan, Prof Martin Elliott, Ms Catherine Guy, Dr Anne Kilgallen, Dr Gavin Lavery, Ms Brigid McManus, Ms Eleanor O'Neill, Mr Turlough O'Sullivan, Mr Sean Sheehan