



Ref: PQ 15592/24

25th June 2024

Deputy Duncan Smith
Dáil Eireann
Dublin 2

Dear Deputy Smith

I refer to your below parliamentary question which has been forwarded to me for attention.

PQ 15592/24 – To ask the Minister for Health the number of people currently waiting to attend cancer genetics services in CHI at Crumlin Hospital by waiting time period 0-6 months, 6-12 months, 12-18 months, 18+ months, in tabular form.

Children's Health Ireland (CHI) Response:

The Department of Clinical Genetics (DCG) at Children's Health Ireland (CHI) at Crumlin provides a comprehensive genetic and genomic medicine service for all Rare Disease including assessing those for inherited cancer predisposition syndromes (diagnostic and predictive). The service is offered to all patients throughout their life time (including prenatal testing and reproductive choices).

Specialist cancer genetics services are also provided at St James's Hospital (SJH) Cancer Genetics Service. Cancer genetic testing also occurs in selected affected individuals via mainstreaming when specific criteria are met. Predictive genetic testing is within the remit of specialist cancer genetics services only.

There are currently 440 patients (adult and children) on the cancer genetics waiting list in CHI at Crumlin.

Department of Clinical Genetics at CHI at Crumlin

An active triage system using a Family History Questionnaire ensures that only high risk patients are seen in the cancer genetic clinic. Those not requiring an appointment receive appropriate advice by letter. Predictive (cascade screening) is available to members of families already known to our service, by completion of a Cascade Referral Form which allows direct access to our waiting list.

Referrals are also triaged based on clinical need (urgent, semi-urgent, and routine). Where appropriate, appointments are offered by video or telephone, as well as in person.

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, Ms Mary Donovan, Prof Martin Elliott, Ms Catherine Guy, Dr Gavin Lavery, Mr Bernard McLoughlin, Ms Brigid McManus, Ms Eleanor O'Neill



The introduction, in May 2022, of a dedicated paediatric cancer genetics multidisciplinary monthly meeting is proving successful in streamlining the diagnostic pathway for these children.

Children Health Ireland has recruited an additional Genetic Consultant, who commenced post in May 2023 and a further Genetic Consultant is due to commence later this year, which will bring the departmental complement of Consultant Geneticists to six (5.8 WTE). The current HSE embargo on recruitment has impacted the service's ability to recruit both Genomic Resource Associates and Genetic Counsellors or to backfill maternity leave, therefore limiting opportunities to improve waiting times further.

Currently almost 96% of patients have been waiting < 12 months

Department of Clinical Genetics at CHI at Crumlin: Cancer Genetics Waiting List as of 18th of April 2024

Waiting time in months	Number of patients (% of total)
0-6 months	271 (61.59%)
6-12 months	154 (35%)
12-18 months	14 (3.18%)
>18 months	1 (0.23%)
	13 (2.95%) [all already offered appointment, but rescheduled at patient request]
Total	440

There are 182 patients on the cancer genetics diagnostic waiting list, and 258 on the cancer genetics predictive waiting list.

Average waiting times

Non-urgent cancer genetics diagnostic clinic = ~13 months.

Non-urgent cancer genetics predictive clinic = ~15 months.

Semi-urgent patients < 3 months.

Urgent patients < 1 month.

Referrals

We received 1129 cancer genetic referrals in 2023 (24% of total DCG referrals) and sent out 383 family history questionnaires.

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

Activity

There was a total of 987 cancer genetic appointments (please note >1 patient may attend the appointment for counselling and testing) attended in 2023 (47% diagnostic, 53% predictive). This is 23% of all DCG appointments attended. The failure to attend rate was 8.6%.

Yours sincerely

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