



Ref: PQ 15591/24

29th April 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 15591/24 – To ask the Minister for Health the number of people who have attended cancer genetics counselling services in Children's Health Ireland at Crumlin for each of the years 2019, 2020, 2021, 2022 and 2023, 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.

Department of Clinical Genetics at CHI at Crumlin

An active triage system using a Family History Questionnaire ensures that only patients at a high risk of a cancer predisposition syndrome are seen in the cancer genetic clinic, keeping the waiting list appropriate with correct referrals. In 2023 the service received 1129 cancer referrals (24% of total referrals) and sent out 383 family history questionnaires. 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.

The introduction, in May 2022, of a dedicated paediatric cancer genetics multidisciplinary monthly meeting is proving successful in streamlining the diagnostic process for these children. Where appropriate appointments are offered by video or telephone, as well as face to face.

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, Mr Bernard McLoughlin, Ms Brigid McManus, Ms Eleanor O'Neill, Mr Sean Sheehan



Together these measures ensure that patients are dealt with in the most appropriate and timely way. Patients potentially have the choice of video, telephone or face to face appointments ensuring equity of access and service.

The demand for the service continues to grow year on year and this impacts on the waiting list.

The table below reflects this with a 46.37% increase in appointments attended in the 5 year period

Department of Clinical Genetics, CHI at Crumlin: Cancer Genetic Appointments Attended 2019-2023

Year	Diagnostic (affected by cancer)	Predictive (cascade screening)	Total
2019	250	425	675
2020	314	343	657
2021	366	404	770
2022	474	453	927
2023	465	523	988

Please note: >1 patient may attend the appointment for counselling and testing

Yours sincerely

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