



Rannán na nOspidéal Ghéarmhíochaine
Aonad 4A, Áras Dargan
An Ceantar Theas
An Bóthar Míleata
Cill Mhaighneann
Baile Átha Cliath 8

Acute Operations
Health Service Executive
Unit 4A, The Dargan Building
Heuston South Quarter
Military Road
Kilmainham
Dublin 8

25th April 2022

Deputy Denis Naughten,
Dáil Eireann,
Leinster House
Kildare Street
Dublin 2

PQ 19024/22* “To ask the Minister for Health the process for patients with rare diseases to obtain accurate and timely diagnoses via European Union cross border genetic testing (details supplied); the number and the cost for the provision of this service in each of the past five years; and if he will make a statement on the matter”

Dear Deputy Naughten,

I refer to your recent parliamentary question in relation to cross border genetic testing which was forwarded to the HSE by the Department of Health for direct reply.

Broadly speaking the process for patients with rare diseases to obtain accurate and timely diagnoses via European Union cross border genetic testing is as follows;

- o Requesting consultant and patient must sign the consent section of the request form before the request can be activated
- o A sample of the patients DNA is forwarded to the cross border testing laboratory with details of the test requested
- o Results of the genetic test are sent from the laboratory directly to the requesting consultant who provides these results to patients

The table below indicates the number and cost of patients who have availed of the EU cross border genetic testing under Treatment Abroad Scheme from 2017 to 2021. The total number of patients who availed of genetic testing under this scheme during this 5 year period is 11.

Year	No of Patients	Costs
2021	Cannot be disclosed*	€6,962.21
2020	Cannot be disclosed	€585.58
2019	Cannot be disclosed	€3,515.05
2018	Cannot be disclosed	€2,243.65
2017	Cannot be disclosed	€226.63
Total		€13,533.12

*any data which relates to five or less patients in compliance with FOI/GDPR cannot be disclosed

I trust this answers your question to your satisfaction.

Yours sincerely,

Brian Dunne
General Manager, Acute Operations