



Dearadh agus Nuálaíocht Chliniciúil; Oifig an Príohifigeach Cliniciúil
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Deputy Sorca Clarke, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: PQ 24038/22

To ask the Minister for Health the number of persons under 18 years of age who have diagnosis of ataxia telangiectasia; and the treatment that is available to them in Ireland.

Dear Deputy Clarke,

The Health Service Executive has been requested to reply directly to you in relation to the above parliamentary question, which you submitted to the Minister for Health for response. I have consulted with the National Clinical Programme for Children on your question and have been informed that the following outlines the position.

Ataxia telangiectasia is extremely rare amongst children in Ireland. There are less than 5 children affected by ataxia telangiectasia known to the National Paediatric Immunology service at CHI. Children with ataxia telangiectasia will be under the care of a paediatric neurologist. They receive holistic care from the multidisciplinary paediatric neurology team and they will also be seen by the paediatric immunology team due to the increased risk of infection. Care is provided in the community by primary care services and/or Children's Disability Network Teams, if needed.

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely

Anne Horgan
General Manager