



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

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

30<sup>th</sup> January 2023

Deputy Réada Cronin  
Dáil Eireann,  
Leinster House  
Kildare Street  
Dublin 2

**PQ 63688/22 - To ask the Minister for Health the reason that there is no current pathway from paediatric to adult care for persons aged 16 years and above with neurofibromatosis; the date on which such a pathway will be established; and if he will make a statement on the matter.**

Dear Deputy Cronin,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted for response. I have examined the matter and the following outlines the position.

Neurofibromatosis Type 1 is one of the more common rare diseases with an estimated European prevalence of 1-5/10,000 individuals. It is probable that there are several hundred individuals in Ireland with Neurofibromatosis Type 1 who are now age over 16 who require transition from paediatric to adult services for the complex highly specialised multidisciplinary care required in an adult centre.

In 2018, the National Clinical Programme for Rare Diseases published the HSE 'Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases'. There were a number of paediatric and adult rare disease specialists involved in the drafting of this 'Model of Care', in addition to patient representatives and national stakeholder involvement. The document provides recommendations and guiding principles for healthcare providers to ensure a smooth, safe and effective transition of young people with a rare disease from paediatric to adult health services including that the paediatric provider site should work in anticipation with a selected adult provider for transition planning and that the appropriate resources should be considered by the agreed adult provider service with budget planning.

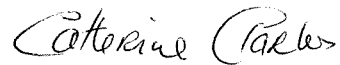
In 2022, the HSE National Clinical Advisor and Group Lead (NCAGL) for Children and Young People established a Transition of Care to Adult Services working group with multispecialty and multidisciplinary representation from adult and paediatric services. A key outcome of the work of this group is to develop a national framework to guide transition of care of young people to adult health services including those with rare diseases. It will build on the work of the Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases.

The National Rare Disease Office (NRDO) under the governance of HSE Acute Operations is currently leading out on the development of a number of the more common rare diseases which are included in the European Reference Networks.

Included in this is the development of a best practice care pathway for Neurofibromatosis type 1 (NF1) (Paediatric focused with transition recommendations) in collaboration with the relevant clinical lead, patient organisation and a wider stakeholder group. Once this pathway is approved, it is envisaged that this document will also support financial planning for transition of young adults to the appropriate adult site.

I trust this information is of assistance to you but should you have any further queries please contact me.

Yours sincerely,

A handwritten signature in cursive script that reads "Catherine Clarke".

---

Catherine Clarke  
Assistant National Director, Acute Operations