



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

Refs: PQ 63681/22 – 63687/22

01<sup>st</sup> February 2023

**Deputy Réada Cronin**  
**Dáil Eireann**  
**Dublin 2**

Dear Deputy Cronin

I refer to your PQ's listed below which have been forwarded to me for attention. Please see set out here-under the information which you require.

**PQ 63681/22 - To ask the Minister for Health the reason that the current neurofibromatosis clinic has been left understaffed and underfunded, that it is now closed to new patients, and with an inability to access treatment of serious import to children, their health and families; and if he will make a statement on the matter.**

**PQ 63682/22 - To ask the Minister for Health if he will confirm that there will be a designated neurofibromatosis clinic at the new children's hospital; if he will ensure that this designated neurofibromatosis clinic will have the full complement of specialisms to include consultant dermatology, neuropsychiatry, psychology and associated teams; and if he will make a statement on the matter.**

**PQ 63683/22 - To ask the Minister for Health the date on which access to the current neurofibromatosis clinic will be restored for all children in Ireland living with neurofibromatosis and therefore requiring its care; and if he will make a statement on the matter.**

**PQ 63684/22 - To ask the Minister for Health the reason that the condition of neurofibromatosis and medical centres to treat children with the condition do not receive the State's attention and funding of other neurological conditions; and if he will make a statement on the matter.**

**PQ 63685/22 - To ask the Minister for Health if his Department will supply a date by which the lack of appropriate staff and diagnostic equipment at the neurofibromatosis clinic at CHI Tallaght will be resolved; and if he will make a statement on the matter.**

**PQ 63686/22 – To ask the Minister for Health the reason that the current neurofibromatosis clinic is without a resident specialist dermatologist, neuro-psychiatrist and psychologist given that these specialisms are deemed integral to the need and treatment of children with the condition; and if he will make a statement on the matter.**



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**PQ 63687/22 - To ask the Minister for Health if his Department will allow the current neurofibromatosis clinic to accept an OCT machine privately-funded and fundraised by an organisation (NF Ireland); and if he will make a statement on the matter.**

### **Children's Health Ireland Response:**

Children's Health Ireland (CHI) can advise that the Neurofibromatosis (NF1) service in CHI at Tallaght is under the care of a general paediatrician and provides a service for over 130 patients with NF1 from all over the country. The service is not a funded national service and children with a diagnosis of NF1 also avail of services closer to home at their nearest hospital.

The volume of referrals to the NF1 service at CHI at Tallaght has increased considerably as the unique one stop clinic provides valued patient and family experience. The increase in demand coupled with challenges in accessing the multi-specialty clinical teams and associated diagnostics, has resulted in a situation where the acceptance of new patients had been temporarily paused.

Notwithstanding the capacity challenges in accessing diagnostics and specialist services, CHI at Tallaght are committed to scheduling new referrals while looking for more creative ways to manage the older, low risk patients. This work is underway and we are optimising existing capacity to schedule a volume of new referrals currently.

CHI are committed to reviewing the needs of this patient group and are working together to enhance the quality and equity of care provided to this vulnerable cohort of children, across all CHI sites and as we plan to move to the New Children's Hospital.

CHI are also exploring an integrated approach with some community based services and working with the regional and general paediatric hospitals to support continued access to services closer to the patient's home. This option is consistent with the strategic objectives of the Sláintecare model of healthcare delivery.

There is currently a group working to design a multi-disciplinary service for children with NF1 in the new children's hospital. We are proposing that the service will be able to provide dermatology, psychology, ophthalmology, general paediatrics, oncology, genetics counselling and radiology on the single site.

There is still a significant amount of work and extra resources required to be able to develop this world class service.

CHI at Tallaght have a resource of 0.5 WTE Clinical Nurse Specialist allocated solely to NF1. This resource was funded initially by the Children's Health Foundation (charitable) funding and was then converted into more substantive funding.

Every other service being provided to children with NF1 was not specifically funded.



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It is important to note that this service was not designed to be a national service and therefore was not funded specifically.

There are several children with NF1 attending CHI and seeing different clinicians across our multiple sites. If the query is specific to the clinic at CHI at Tallaght, I can advise that there is currently a recruitment campaign for a paediatric dermatologist to resolve this issue.

Please be advised that there were never specific psychiatry or psychology resources allocated to the NF1 clinic at CHI at Tallaght. However, CHI at Tallaght has child psychiatry and psychologists on-site that will review children who are referred to them. Children with NF1 will be managed the same as other children referred to these services at CHI at Tallaght and demand for these services can be considerable.

CHI are working in partnership with representatives of the NF1 patient advocacy group (NF Ireland) on all aspects of service delivery and service development as summarised above.

Finally, please note that the OCT machine is under the remit of Tallaght University Hospital (TUH). The ophthalmology service is provided by TUH and has traditionally been a small service operated out of the Eye and Ear Hospital, Dublin.

CHI are not in a position to advise on the willingness of TUH to accept a privately donated OCT machine.

Yours sincerely

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