

19 March 2026

Patients with Diagnosis of Neurofibromatosis Type 1 (NF1) – Children & Adults

Could you kindly advise in the previous 3 years, how many children under 10 years old have received a positive diagnosis of Neurofibromatosis Type 1 (NF1)?

How many patients (both adults and children) in total in Northern Ireland have been diagnosis of NF1 in the past 3 years?

Could you also break this down per year?

Paediatric Service:

The total figures for children diagnosed with NF1 are:

2023: 17
2024: 21
2025: 5

Please note that the numbers in 2025 may be lower because it is possible that there are still outstanding results from 2025, as the testing can take up to 6 months to come back.

Adult Service

2023: Clinical diagnosis	7
Molecular diagnosis	10
2024: Clinical diagnosis	5
Molecular diagnosis	16
2025: Clinical diagnosis	<5
Molecular diagnosis	<5

Use of <5 (less than five): We are unable to provide an exact figure - exempt from release under Section 40(2) of the Freedom of Information Act - Personal Information relating to a third party, as the small numbers involved could make patients personally identifiable. Disclosure would constitute a breach of the principles of the General Data Protection Regulation 2018.