

30 September 2026

Neuromuscular Healthcare Provision

We are writing to seek access to the following information:

- 1 Please provide the total annual funding provided for adult and paediatric neurology for the financial year 2022-23, 2023-24, 2024-25, and 2025-26.**

"The total allocation for Adult Neurology Services within Belfast Health and Social Care Trust was £28.8m in 2022/23, £31.5m in 2023/24, £29.1m in 2024/25 and £22.7m in 2025/26. These figures comprise both pay and non-pay allocations for Neurology Services."

Financial Year	Staff Costs (£)	Non-Pay/Goods (£)	Total Allocation (£)
2022/23	7,972,055	20,802,861	28,774,916
2023/24	8,348,289	23,180,066	31,528,355
2024/25	9,270,216	19,834,956	29,105,172
2025/26	10,144,442	12,537,589	22,682,031

Please see attached Pay and Non-Pay budget for Paediatric Neurology Service information for the previous 4 financial years.

- 2 Please provide the total annual funding allocated for neuromuscular care for the financial year 2022-23, 2023-24, 2024-25, and 2025-26. If exact figures are not available, please provide an approximation based on the records you hold.**

For Adult Neurology Services

This needs to be redirected to the South Eastern Trust as they currently have a neuromuscular service.

[Freedom Of Information - South Eastern Health & Social Care Trust](#)

For Paediatric Neurology Service

Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.

The Belfast Health and Social Care Trust does not hold a separately identified annual budget for paediatric neuromuscular services. Funding information is not recorded in a format which allows a discrete neuromuscular allocation to be extracted for the years requested it is included in the paediatric neurology information.

30 September 2026

3 Within the past three years (2023-24, 2024-25, 2025-26), have you reviewed improvement in care and pathways for neuromuscular conditions?

a. If yes, what did this review find? Please provide any relevant reports or discussion papers.

For Paediatric Neurology Service

The regional paediatric neuromuscular service was reviewed during 2023-24 and has continued to be reviewed annually thereafter. These reviews considered service capacity, patient demand, workforce requirements and the impact of emerging therapies on service delivery.

The reviews identified the need for stabilisation within the consultant workforce in the service. Recruitment to a replacement consultant post was identified as a priority; however, appointment was delayed due to difficulties recruiting suitably qualified applicants. A replacement consultant neurologist was appointed in 2026.

The reviews also identified a number of workforce and service development requirements, including:

- Additional occupational therapy support.
- Additional specialist neuromuscular nursing capacity.
- Dedicated psychology support.
- Dedicated dietetic support.

The reviews further highlighted the increasing complexity of care resulting from the introduction of new therapies including Ataluren, Nusinersen, Risdiplam, Zolgensma gene therapy, participation in exon-skipping drug trials, Givinostat and Vamorolone. The Belfast Trust also acts as a regional infusion centre for gene therapy treatments.

The reviews concluded that additional multidisciplinary workforce investment would be required to improve service resilience and support current and future treatment developments.

b. If no, please confirm whether and when your organisation has plans to review this.

For Adult Neurology Services

This needs to be redirected to the South Eastern Trust as they currently have a neuromuscular service.

[Freedom Of Information - South Eastern Health & Social Care Trust](#)

30 September 2026

- 4 Over the same time period, have you reviewed the care and support needs of people living with a neuromuscular condition within your local population, and planned services to meet these needs?**
- a. If yes, what did this review find? Please provide any relevant reports or discussion papers.**
 - b. If not, are there plans to do so?**

For Adult Neurology Services

This needs to be redirected to the South Eastern Trust as they currently have a neuromuscular service.

[Freedom Of Information - South Eastern Health & Social Care Trust](#)

For Paediatric Neurology Service

The annual service reviews considered current and future care requirements for the regional paediatric neuromuscular population and identified the need to strengthen service resilience in response to increasing patient demand and the continuing introduction of new therapies.

The service identified that emerging therapies place significant additional demands on clinical teams. For example, Zolgensma gene therapy requires intensive monitoring for potential complications, including prolonged follow-up for up to six months following treatment. Givinostat has also introduced a new and resource-intensive monitoring pathway requiring regular clinical review and laboratory surveillance.

In response to these increasing demands, a business case was developed to strengthen the neuromuscular service and improve resilience. This included proposals for additional workforce support, including a neuromuscular clinical fellow role to assist with treatment monitoring requirements. The Trust subsequently provided the clinical fellow post on an at-risk basis in an effort to help manage growing demand and support the team.

The regional paediatric neuromuscular service has experienced a significant increase in workload over recent years as a result of advances in treatment and the introduction of new therapies for spinal muscular atrophy and muscular dystrophy. While the Trust has provided a number of interim mitigations to support service delivery, annual reviews have consistently identified the need for additional multidisciplinary workforce investment to ensure long-term service resilience and support future treatment developments.

- 5 Does your Trust provide community-based neurology services?**
- a. If yes, can you confirm whether the community-based neurology services treats people with neuromuscular conditions? Please provide the referral criteria used by each team, including a list of conditions which are accepted/covered by the team.**

30 September 2026

For Adult and Paediatric Neurology Services

We do not currently have any community-based neurology services in the Belfast trust.

6 Please confirm whether your Trust includes people with lived experience of neurological conditions in decision-making about the commissioning of neurological services. If yes, please provide further details. If not, please outlines the barriers.

For Adult Neurology Services

The NI neurological charities alliance was consulted on the Regional Review of Neurology Services which was commissioned by the Department of Health.

For Paediatric Neurology Service

The Trust is aware that the Northern Ireland Neurological Charities Alliance was consulted as part of the Regional Review of Neurology Services commissioned by the Department of Health.

In relation to the regional paediatric neuromuscular service, no specific barriers to patient and family engagement have been identified. The service previously benefited from patient advocacy arrangements between approximately 2010 and 2020; however, these arrangements ceased during the COVID-19 pandemic.

7 Please confirm whether your Trust offer a resident neurology provision for people living with neurological conditions. If yes, please provide further details. If not, please outlines the barriers.

For Adult Neurology Services

Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that this information is not held in a centrally recorded format.

For Paediatric Neurology Service

The Belfast Health and Social Care Trust provides inpatient paediatric neurology services, including care for children and young people with neuromuscular conditions, through the Royal Belfast Hospital for Sick Children and associated paediatric neurology services.